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# HOUSE OF COMMONS
## OFFICIAL REPORT

# PARLIAMENTARY DEBATES

## (HANSARD)

**Friday 14 March 2025**

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# House of Commons

*Friday 14 March 2025*

*The House met at half-past Nine o'clock*

**PRAYERS**

*The Second Deputy Chairman of Ways and Means took the Chair as Deputy Speaker (Standing Order No. 3).*

**Shaun Davies** (Telford) (Lab): I beg to move, That the House sit in private.

*Question put forthwith (Standing Order No. 163) and negatived.*

## Rare Cancers Bill

*Second Reading*

9.34 am

**Dr Scott Arthur** (Edinburgh South West) (Lab): I beg to move, That the Bill be now read a Second time.

We all know someone who has suffered from a rare cancer—a brain tumour, childhood cancer, pancreatic cancer, liver cancer, or one of the other cancers on a long list that are unfortunately all too familiar. Each of them may statistically be considered rare, but collectively they are anything but rare. Blood Cancer UK states that rare and less common cancers account for 47% of all UK cancer diagnoses—a staggering 180,000 a year. The irony of the Bill's title is that so-called rare cancers are not rare. Common cancers deserve attention, but so too do rare cancers.

I want to share an example of a family in my constituency who were confronted with a rare cancer. Tilly's first symptoms were leg pains and loss of appetite. This was in September 2021, when face-to-face GP consultations were not possible. On visiting A&E, she was given ibuprofen. It was thought that she might have a virus. Six weeks later, she returned to A&E and was transferred to the cancer ward, where she was diagnosed with stage 4 neuroblastoma. On diagnosis, she was given a 50% chance of survival. Despite undergoing over a dozen rounds of chemotherapy and an operation, she sadly passed away about a year after her first symptoms appeared. Tilly was just four years old. Her father Jonathan, a headteacher in my constituency, is in the Gallery. He reached out to me after reading about the Bill. He explained his frustration that the development of new treatments for neuroblastoma has been moving at a glacial pace for too long. The same is true for many other rare cancers. This slow pace of change is not respected by these cancers, and it meant that Tilly missed her seventh birthday yesterday.

I thank Jonathan for sharing Tilly's story, and wish him all the best as he moves to Northern Ireland with Tilly's mum and big sister Emily to start a new job. I thank Livingston's Team Jak for their ongoing support for Tilly's family and many others. Neither Jonathan nor I want to suggest that the Bill would have saved Tilly, but we hope that it will improve survival rates for others, and take them beyond the 50% rate given to Tilly. That is why Jonathan is here today, and why I am here today.

Nobody told me that the most amazing thing about being an MP would be the people we meet almost daily, who want to make their community, our country or even the world a better place. That is particularly true of the people I have been humbled to meet on my journey to speaking about the Bill today, including cancer patients, survivors, the bereaved and campaigners, all of whom want just one thing: justice. Although the healthcare system in the UK is founded on the notion of equality, fairness and justice, they believe that rare cancer patients are being overlooked. Their demand for justice covers three points.

The first is that beating a rare cancer should not be less likely than beating other cancers. I have said that 47% of all UK cancer diagnoses each year are of rare and less common types. These patients already have the cards stacked against them, as they are 17% less likely to survive—an injustice caused by the relative lack of research and development in this field over many years.

Secondly, having a rare cancer should not mean being less likely to benefit from a medical breakthrough. According to Cancer52, in 2024, an astonishing 82% of patients with rare and less common cancers were not offered a clinical trial, and so were denied access to potentially lifesaving treatments. Often that is because such trials do not even exist, because there has been so little progress, and when they do exist, they are not always easy for patients to access.

Let me give an example: there is a remarkable young woman in my constituency known as Kira the Machine. Kira has been living with neuroblastoma since she was 10. She has been through it all: a prognosis of inoperability, 26 rounds of chemotherapy and eight relapses. Her and her mum, Aud, are fundraising legends locally. I do not know a school or workplace in Edinburgh that did not help when they were given just three weeks to raise £500,000 for lifesaving specialist treatment in the USA. Now 21 and fundraising for other cancer sufferers, Kira is an example to us all. She owes her life to a lung cancer drug not typically provided to treat neuroblastoma and not yet generally available in the UK for that purpose, although I understand that Solving Kids' Cancer is working on that.

Kira appears on my social media so much, and is really well known in Edinburgh because of the fantastic campaign that she and her mum ran. She is a bit of a celebrity, if I can use that word. She came into my office recently to talk about the Bill. It was really humbling to meet her, and because she has that celebrity status, in my mind, I was also quite starstruck; I told her that it was like Taylor Swift entering my office. I resisted the temptation to exchange friendship bracelets with her, but she gave me a Solving Kids' Cancer badge, which I am proud to wear today.

Kira's story is important because it reminds us that repurposing existing drugs can unlock great benefits, but those benefits can be delivered at scale only through additional medical research efforts and clinical trials.

**Dame Siobhain McDonagh** (Mitcham and Morden) (Lab): The NHS has a drug repurposing office. To date, it has repurposed one drug, and that was for breast cancer. Does my hon. Friend think that is good enough?

**Dr Arthur:** I welcome that intervention; I think that was a leading question. Of course it is not good enough. I do not think that anybody here thinks that it is good enough, including the Minister. Unfortunately, at present there are very few clinical trials in this country for rare cancer treatments. Families such as Kira's should not need to crowdfund for treatment overseas; we should be building the capacity here in the UK.

Thirdly, having a rare cancer should not mean that a diagnosis is delayed when compared with diagnoses of other cancers. Rare cancer sufferers tell me that their symptoms are often less likely to be recognised, as doctors are less familiar with them.

**Mrs Emma Lewell-Buck** (South Shields) (Lab): I thank my hon. Friend for the powerful way he is introducing his Bill. My constituent Steph is just 29 years old and is a mam to two little girls. She was diagnosed with grade 4 glioblastoma, known as astrocytoma, on her birthday last year. For months prior to her diagnosis, she was treated for migraines by her GP. Steph knew that she was not suffering from migraines, yet she was rudely dismissed by an A&E doctor, and felt nobody was listening to her. Steph has since had brain surgery, radiotherapy and chemotherapy. My hon. Friend knows that early diagnosis and treatment is vital. Can he assure Steph and her family, and me, that the Bill will help to raise awareness across the medical profession of rare brain cancers?

**Dr Arthur:** Absolutely. Last week, I attended a reception for the Eve Appeal. I was really struck by the fact that early diagnosis was a big feature of what the charity was talking about, and I will come on to that in just a second.

As a consequence of the lack of recognition of the symptoms of rare cancers, too many people are diagnosed too late. Last week, at an event hosted by the Brain Tumour Charity, I met Gabrielle and her wife and children. Gabrielle told me how the neurologist to whom she was initially referred did not recognise her brain tumour symptoms, and told her instead to go home, breathe into a paper bag and get some counselling. If only curing brain tumours was so easy. Reflecting on the comment made by my hon. Friend the Member for South Shields (Mrs Lewell-Buck), an observation that I have made on this journey is that so many of the people who have talked about late diagnosis have been women. That is purely anecdotal, but it seems to be the case. When I was at the Eve Appeal reception, the point was made that so many women are turned away; the GP tells them that they are hormonal, premenstrual or premenopausal.

**Jenny Riddell-Carpenter** (Suffolk Coastal) (Lab): My hon. Friend is making an incredibly important point, with which many across the Chamber will agree. The statistics are particularly stark for women from black, Asian and minority ethnic backgrounds; they are even more likely to be dismissed.

**Dr Arthur:** I thank my hon. Friend and office neighbour for making that point, which was also made by Eve Appeal. I cannot remember the statistics, but there is a stark difference. I talked about this issue when I met the Minister yesterday and she gently pointed out to me that it is not just in healthcare where women are dismissed as hormonal, premenstrual and so on. I thanked her for reminding me of that in the gentlest possible way.

It is a cruel irony that rare cancers such as Gabrielle's tumour are typically less survivable, making early diagnosis even more important. Rare cancer patients require early, not later, diagnosis. I have spoken about poor outcomes, lack of progress in developing treatments and late diagnosis. My Bill focuses on the first two points, but I want to acknowledge the need to improve diagnosis, because of comments that have already been made. I am sure that will feature in the cancer plan.

I am the first to admit that, when I was successful in the private Member's Bill ballot, I found it daunting as a new MP. I thought I had some really good ideas for a Bill, but as soon as my ping-pong ball was picked from the goldfish bowl, I was inundated with calls from constituents, charities and lobbyists, each telling me that their cause was better than any I could think of. I considered many worthwhile causes over the following days, but while having a coffee in Colinton Mains Tesco in Edinburgh South West, I received emails from members of the public who support the campaign of my hon. Friend the Member for Mitcham and Morden (Dame Siobhain McDonagh). Just last week I met Oriana, one of the people who emailed me. It was incredibly moving to meet her; it took me right back to the start of this journey. I posted on my Facebook page about meeting her, and straight away somebody said that they knew her and that she had helped them when their family had been faced with glioblastoma. That is a reminder that so many people affected by these conditions turn their loss into something really positive and help other people.

My hon. Friend's campaign relates to glioblastoma, a type of tumour that took my father-in-law. I felt that the stars had aligned for me. I really do mean that; I really did get that feeling. I want to pay tribute to my hon. Friend. [Hon. Members: "Hear, hear."] More, more! I know her to be a formidable woman who in this context is driven by glioblastoma taking her sister, Margaret. I did not know her sister at all, which is my loss, but I do know that she shaped my party and she helped change our country for the better, and I know above all that she was loved by her sister.

Glioblastoma is typical of so many rare cancers, and it started me on this journey so I want to talk about it further. My father-in-law, Ivor Hutchison, was a dignified man but glioblastoma did not respect that. He was a technical teacher at Bell Baxter high school in Fife. He was married to Sylvia and they have four daughters, Denise, Iona, my lovely wife Audrey who is in the Gallery —I have just embarrassed her—and Sarah. In time, Ivor and Sylvia had grandchildren: Andrew, our daughter Ruth, Hannah, Matthew, our son Ben, Rory and Sophie. Ivor was not a passive grandfather; he worked hard to ensure his grandchildren flourished.

In September 2017, Ivor began having problems with his speech. My wife Audrey, an NHS nurse, was concerned that it might be a sign of dementia. We all hoped that that was not the case. Following an MRI scan in the November, we received the devastating news that Ivor had glioblastoma. At Christmas he was still very much himself and enjoyed the festivities. Ivor never had a pound of fat on him, but when it came to Christmas time he really did hoover up the food and enjoyed the Christmas meal. It was great to see him that Christmas, but we did feel that it would be his last. Once we entered the new year, he began to lose his mobility, and eventually

he was admitted to Adamson hospital in Cupar. In 2018, surrounded by his wife and daughters, Ivor died peacefully, eight months after his first symptoms. He had a good life and his daughters are a fantastic legacy to him, as well as all the pupils he taught at school.

However, as a physically fit man, Ivor should have lived longer: he should have lived to see his birthday last weekend, and if he had done so, he would not have missed two of his grandchildren getting married and his first great-grandchild, Fraya, being born in December last year. I assumed that he had been unlucky with glioblastoma. It was not until I met my hon. Friend the Member for Mitcham and Morden that I learned that only 25% of glioblastoma patients live beyond 12 months after diagnosis, and only one in 20 survive beyond five years. Despite that awful prognosis, as for other rare cancers, the drugs to treat glioblastoma have not changed in decades. That is why I knew in my heart that I needed to introduce a Bill that would help equip those working hard to fight against glioblastoma, and all rare cancers, with the tools they need to further their efforts and, ultimately, save lives.

Over the past 15 years, thanks to the dedicated work of charities, survivors and researchers, we have seen a 10% rise in survival rates for those diagnosed with cancer. Globally, new treatments are being developed and rolled out to patients, improving outcomes and saving lives in our NHS every single day. However, rare cancer patients are being left behind, and I need to explain why. It is not due to a lack of effort by charities or those affected by the disease. In fact, in the Gallery today are members of some incredible charities who are fighting against rare cancers in what is often an uphill battle. I thank them for their hard work in helping me to develop the Bill—they really have helped me—which aims to address the injustices faced by rare cancer patients and their families. For all the people I have met from the charities, their work is much more than a job for them; it is about making a difference to people's lives, improving survivability and supporting families.

The reason for the uphill battle is that research into rare cancer is much less appealing to pharmaceutical companies when compared with more common conditions. With smaller patient populations, there is an increased logistical challenge in bringing patients together. Currently, we are lacking a sufficient development strategy and there is no single source of patient data, meaning companies must undertake the costly endeavour of finding patients and verifying eligibility. Even if they succeed in running a clinical trial and a drug proves to be an effective treatment, companies face the challenge of selling a drug developed at great expense to a small market. Ultimately, these companies exist to return a profit for their shareholders. Given a choice between investment in potential treatment for a rare cancer or a more a common one, too often rare cancer patients lose out.

Having set out the challenges faced by those diagnosed with rare cancers, let me now address what the Bill aims to accomplish. I will list four key measures and explain their impact: appointing a named responsible lead for the delivery of rare cancer research; creating a single registry of rare cancer trials; creating a single registry of rare cancer patients available for trials; and defining an evidence base for repurposing new cancer treatments. Let me explain in turn why these are important.

First, the Bill would place a duty on the Secretary of State to facilitate and promote research related to rare cancer patients. The appointment of a national specialty lead for rare cancers in the National Institute of Health and Care Research would provide the Secretary of State with advice on the design and planning of research to facilitate collaboration between relevant parties. That will ensure co-ordination and accountability for the delivery of new cancer research in the UK.

Secondly, the Bill would increase access to clinical trials via a service tailored to rare cancer patients. Through the Secretary of State's new duties, that would be accomplished as part of the existing "Be Part of Research" registry, ensuring that all trials are registered in a single place.

Thirdly, charities and clinicians tell me that more trials would be attracted to the UK if we had easier access to patient cohorts. Establishing a single database of willing patients would remove a significant burden on researchers in finding and verifying eligible people for clinical trials.

**Sir Christopher Chope** (Christchurch) (Con): I congratulate the hon. Gentleman on introducing a Bill on this important subject. He mentions research. Can he explain why the extent of clauses 2 and 3 is limited to England and Wales? What is happening in Scotland in relation to the research issues?

**Dr Arthur:** The challenge is devolution. I am a huge fan of devolution, but often the UK is at its best when it works together, particularly on healthcare. I hope that in time we will see progress and the nations will work together. I do not want to overstate this, but there have been discussions across the UK about how we could work together on the issue, so perhaps the answer is, "Watch this space."

The Bill's fourth measure is to trigger a review by the Government of the orphan drug regulations, to examine how they can be reformed to better incentivise pharmaceutical companies to invest in clinical trials for rare cancers. Specifically, it will consider how incentives could be provided to pharmaceutical companies to trial the repurposing of new cancer treatments. We often hear about how drug development for one cancer can be used to defeat another; that is what Kira relies on right now. My Bill aims to build a foundation for industrialising that approach via incentives. The EU has a similar system for incentivising the testing of drugs for paediatric use that have already been approved for adult use, so the approach has been tried and tested.

Together, these measures will ensure that we have leadership in Government and will remove the barriers to running new clinical trials that researchers and pharmaceutical companies face.

**Joe Powell** (Kensington and Bayswater) (Lab): I thank my hon. Friend for the powerful way in which he is introducing the Bill. Will he recognise the work of pioneering teams such as the one at Charing Cross hospital, under Imperial College healthcare NHS trust, where Professor Michael Seckl is leading the way in groundbreaking treatment for and research on gestational trophoblastic disease and germ cell tumours? Does he agree that those centres need support to expand and share their research findings with the rest of the NHS?

**Dr Arthur:** Absolutely. There is fantastic expertise in our universities across the UK; as I say that, I have to refer hon. Members to my registered interests because of my connections with the university sector. There is much more that we can do to attract the best researchers to the UK and build capacity in UK universities.

The Bill will provide greater accountability for the delivery of new research, but please do not just take my word for it. Brain Tumour Research has described it as

"essential for a brain tumour cure".

I did not feel any pressure at all when I read that quote! No, it was quite daunting, to be honest. The Less Survivable Cancers Taskforce says that the Bill

"could be a truly transformative moment in the UK's approach to research for rare and less common cancers."

My friends at the Brain Tumour Charity say that the Bill

"is a framework for tangible, impactful change."

At this point, I have to mention my daughter's connection with the Brain Tumour Charity. She is running a marathon in May to raise funding for it, and I wish her well. [Hon. Members: "Hear, hear."] Thank you.

Let me list some of the other groups that support the Bill. They include Pancreatic Cancer UK, which has been absolutely fantastic in its support for what we are doing; Cancer52, an organisation that represents more than 100 groups; the Angel Mums; the Grace Kelly Childhood Cancer Trust; and the Inflammatory Breast Cancer Network UK. Inflammatory breast cancer accounts for 2% of breast cancer diagnoses in the UK each year, but 10% of the deaths.

The Bill is also supported by Target Ovarian Cancer, Brainstrust, AMMF—the Cholangiocarcinoma Charity, the Urology Foundation, the Tessa Jowell Brain Cancer Mission, Action Kidney Cancer and Sarcoma UK, which I met this week. I have a friend with that cancer, and it is a fantastic organisation that I hope to work more with in the future.

It is supported by Maggie's, Shine Cancer Support, Solving Kids' Cancer, the British Liver Trust, Blood Cancer UK, Radiotherapy UK, Leukaemia UK, CCLG—the Children and Young People's Cancer Association, CLL Support, Neuroblastoma UK, Salivary Gland Cancer UK, Neuroendocrine Cancer UK, Melanoma Focus, Myeloma UK, Hope For Tomorrow, Alike, Yorkshire Cancer Research, Young Lives vs Cancer, the Tessa Jowell Foundation, the UK Mastocytosis Support Group, the Bone Cancer Research Trust, the Neurosciences Foundation and the Eve Appeal.

The Eve Appeal had a fantastic reception last week, and when I went along to it, having its support felt like a real tipping point in the progress we are making in building support for the Bill. It was great to see the Minister as well, and I have to say—this is not a trivial point—that the cake there was absolutely fantastic. I do not doubt that when I get back to my office and check my emails, more organisations will have got in touch to say that they want to support what we are doing today.

I know that many Members in the Chamber today will have deeply personal stories to tell, on their own behalf and on behalf of their constituents. I look forward to hearing those testimonies as we debate this Bill, because it is so important to give those people a voice. I will conclude by saying that the Bill we are debating today has a real chance of making a difference. For too long, rare cancer patients have been left on the sidelines without significant advancement—this cannot go on. Tilly and Ivor deserved a better chance of beating the cancer inside them, and those who are yet to be diagnosed deserve a better chance of a full life. Let us pass this Bill today and work across the UK to take the fight to rare cancers and save lives. I commend this Bill to the House.

**Several hon. Members** *rose—*

**Madam Deputy Speaker (Judith Cummins):** Before I call the first speaker, I am aware that this is a very personal debate for some Members, so please feel free to leave the Chamber if you need to. Let's look after each other today.

10.1 am

**Mike Wood** (Kingswinford and South Staffordshire) (Con): I congratulate the hon. Member for Edinburgh South West (Dr Arthur), both on his good fortune in being drawn in the private Member's Bill ballot and on his wisdom in picking this very important issue to take forward. Having been similarly lucky in being drawn in that ballot a few weeks after I was first elected, nearly a decade ago, I know the barrage of calls and emails that suddenly come your way—the very sudden and slightly fleeting popularity that comes from coming towards the top of the private Member's Bill ballot—and the very many, very worthy causes and campaigns that come your way for you to choose between. The hon. Gentleman could not have picked a better cause than the one represented by this Bill, and if he is never again quite as popular as he was in the few hours after the publication of the ballot results, I know that he would willingly exchange all of that popularity in an instant for the difference that this legislation can make to so many lives across the country, if and when it is passed and implemented—as we hope it will be.

I stand today not just as a Member of this House but as a friend who is deeply moved by the pain of seeing someone I care about—someone who has become like family—struggle against an insidious disease. This Bill is not just another piece of legislation; it is a cry for help. It is a plea for those who are fighting for their lives—a lifeline for families who are watching their loved ones slip away, bit by bit and day after day. Too often, those diagnosed with rare cancers are left stranded in a system that does not have the answers they need.

We know the wonders that pharmaceutical companies can do in drug development, but the horrible truth is that few people are able or willing to invest the enormous amount of money needed to take forward drug development—knowing that about one in 25,000 drug candidates make it to market—for conditions that will require that drug 1,000 or 2,000 times a year, at most.

**Dame Siobhain McDonagh:** Does the hon. Gentleman agree that there is a whole range of new modern immunotherapy drugs that could be used on these cancers? They already exist, they are used to treat other people, but they are simply not tried. The cost of those trials is not overwhelming and we can do them, and the NHS repurposing project should be doing them.

**Mike Wood:** The hon. Lady is obviously right, and I know that she approaches this subject with, tragically, a huge amount of personal experience. We have already seen drugs—in some cases, long-marketed drugs—being applied for new purposes and new conditions. Without those costly clinical trials, they will not be licensed or approved for prescription, and that is why the Bill is so important. Clinical trials are sadly a distant hope for far too many currently, and many patients are left with the crushing, gut-wrenching words, "There is nothing more we can do." Those words can be a death sentence, but they do not have to be—not if we act.

Many Members and House staff will know my senior parliamentary assistant and dear friend Dan Horrocks. He is best known as the owner of Bella, his therapy shih tzu who he had while he was being treated for his third brain tumour and who is often seen roaming around the Palace and 1 Parliament Street. Dan has worked for me since I was first elected in 2015, but he is not just my senior parliamentary assistant; he has become like family. He is a father, a husband and a four-time cancer survivor. For 14 years, he has fought this monster, each time feeling the ground slip more from under him as his options narrow, leaving him and his family with ever-reducing hope. We have seen him face unimaginable pain. I have watched him endure brain surgeries and radiotherapy, and seen the fear in his eyes each time the disease comes back and he hears his doctors tell him that they do not know how much more his body can take, and whether he can be put through that next course of radiotherapy.

Dan's journey started with something as simple as headaches, as the hon. Member for Edinburgh South West referred to in another case, that no one thought were serious at the time. As a teenager, three GPs all misdiagnosed that tumour and for unknown reasons, the GPs did not want to send Dan for a scan. A simple scan to check that there were no malign causes would have identified those tumours months earlier. It was a free voucher for an eye test that saved Dan's life, because it was not until, by sheer luck, an optician noticed something wrong in his eyes that anyone realised the nightmare he was living. That optician saved his life.

What followed has been nothing short of a nightmare: brain tumours, surgeries, radiotherapy and the heart-wrenching hope that every treatment might be the last, only for the disease to rear its ugly head again. Now the cancer has spread to his spine. His doctors and consultants have no answers. His options are dwindling, yet Dan's fight is far from over, because Dan is not just fighting for himself, but for his two-year-old son, Elijah, who deserves to grow up with his father by his side, cheering him on at his first football match and guiding him through life's milestones.

Dan dreams of walking his son to school every day and of being there for every moment that really matters, whether it is his graduation or his wedding—the moments that every parent should have the chance to see. He is fighting with his wife, Sonia, who has been his rock through all of this. Sonia has stayed by his side through every hospital visit, through every sleepless night, and through every moment of doubt and fear. Together they have dreamed of a life growing old together, of watching their child grow up, and of building memories that will last forever, but that future is slipping away. That is why we are here today—to ensure that no parent, no family, no child has to face the horror of rare cancer without hope. This Bill is not just about changing laws or regulations; it is about giving families like Dan's a fighting chance. It mandates a review of the orphan drug regulations to ensure that rare cancers get the investment they so desperately need, creates the national specialty lead to drive research and innovation, and establishes a registry service to help to connect patients to the clinical trials that really could save their lives.

This Bill gives hope—a real chance for families who are facing the unimaginable. I stand here today with a heart full of hope, but also with a heavy heart, because I know that time is not on their side. Dan does not have the luxury of waiting. His family do not have the luxury of waiting. No one diagnosed with rare cancer has that luxury. That is why this Bill is so very urgent. We spend a lot of time in this Chamber talking about politics, but this is not about politics: it is about real people like Dan who desperately need our help.

Cancer does not care about politics. It does not care what background we come from, our age or gender or what party we belong to. It strikes indiscriminately. It takes what it wants, and it leaves devastation in its wake. That is why we must respond with urgency, with compassion and, most importantly, with action. I strongly support this Bill and I urge all hon. Members here today to stand with us, to stand with the families clinging to the hope that there is something more we can do and to stand with those, like Dan, who are fighting for more time, for more moments, for more chances to hold their loved ones close. The cost of inaction is measured not just in money, but in precious lives lost. Let us pass this Bill. Let us give people like Dan and his family the hope they so desperately need. Let us give them a future—a future that is still within reach.

10.12 am

**Josh Fenton-Glynn** (Calder Valley) (Lab): I rise to speak about a Bill that will increase research funding focused on more effective treatments for rarer forms of cancer. I thank my hon. Friend the Member for Edinburgh South West (Dr Arthur) for introducing the Bill.

Like many in this House, I rise today because I have lost a family member to a rare cancer, and I also rise as a member of the Health and Social Care Committee. In the last Parliament, the Committee conducted a Future Cancer inquiry, which recommended that

"the UK should be leading on driving up international action to tackle the poor outcomes for the least survivable and least common cancers. "

This Bill will do that—but, as I say, my reason for speaking in this debate is much more personal. On 20 January this year, my brother Alex English passed away from high-grade acinic cell carcinoma, a form of salivary gland cancer. I tell his story to highlight what we can win, because this Bill can give families the gift of more time with the special people they love.

Increasingly, more common cancers are treatable or are illnesses that people can live with, but on rare cancers we still have a way to go, and without focus we will not get any further. There are more than 700 diagnoses of various forms of salivary gland cancer each year, but my search for related terms in *Hansard* finds only two mentions in this Chamber in the past 30 years—my hon.

*[Josh Fenton-Glynn]*

Friend has just made the third. One of those mentions was from me, following my brother's death. That is why we need more focus.

In evidence to that Select Committee inquiry, Cancer52 noted that, while they represent 47% of diagnoses of less common cancers, rare cancers account for 55% of deaths. Members across this House have our own cancer journeys—ourselves, our friends or our loved ones—and I want to talk about my brother's journey. Not all cancer journeys have the outcome that we want, and even with this Bill we will still lose some people, but more investment into research for rare cancers can give us something crucial: time. I would do anything for more time with my brother.

If you will indulge me, Madam Deputy Speaker, I would like to talk for a minute about the person who Alex was. The most important thing about Alex was not how he died; it was how he lived and the mark he left on the world. He fit a lot into 53 years. A lot of us think that our elder siblings are rock stars, but in my brother's case that was literally true. The band he joined at university, called Pure, toured with bands like Soundgarden and reached the top 10 in Japan.

I have always been tremendously proud to call him my brother. I was proud of the horse-drawn narrowboat company he ran in Hebden Bridge, which forms part of many people's happy childhood memories, and of his subsequent time at the National Trust, where he helped properties to become profitable, worked to restore nature and worked with local authorities. His last major project was creating woodlands near Lunt, in Liverpool. But most of all, I was proud of the person he was. He was always funny—he had a surreal wit. He was unfailingly kind and the sort of non-toxic model of masculinity that the world needs more of. I remember the humour and love in the best man's speech he gave for me, and I will never not be sorry that I have written eulogies for my brother but never a best man's speech.

While preparing for Christmas in 2023, I got a call from Alex and he asked if I had a minute to talk, which was unlike him, because he would not generally be over-serious. He said he had a lump on the side of his face that was, in his words, unsightly but not overly concerning. It might have been cancer, but there are a number of other things that it could have been, and if it was cancer, it was likely to be a very treatable form. He instructed me to be aware of it but not make a big deal of it, because, typically, he did not want to worry our mum. Later, it transpired that it was acinic cell carcinoma, but the prognosis was good and they were going to operate. The cancer continued to grow. His operation took 14 hours. The thing about Alex's tumour is that the version of the illness he had was high grade, which meant that it mutated faster. It is something that has only been identified in about 100 cases, and which no doubt could have been identified earlier had we known more about cancers like his.

Last spring, in my mum's garden, during a hushed conversation with a different family member to the side, they told me that Alex might only have 18 months to live. I hugged my two-year-old son, who was playing in the garden unaware, because I was trying not to make a big deal of it—but sometimes you need to hug someone. Every update got worse, until I took a day off during the election campaign to visit him at the Christie hospital because his lung had collapsed.

Then, because it is never a straight line, his health improved. He got to sit up there in the Gallery to watch my maiden speech in Parliament. We went to a Pixies concert together at the Piece Hall in Halifax. Then he got worse, Madam Deputy Speaker, and on Christmas Eve last year he was hospitalised again. When he returned home, we knew he was coming home to die. I cannot say enough about his wonderful friends, particularly Matt and Sarah, and my incredible family, who cared for him at the end. All of us would have spent more time at his bedside if we could, because time with people you love is a privilege.

That is what this Bill is about: giving people more time with those they love, perhaps even a full lifetime together. In cases where the cancer is worse and it cannot be treated or cured, it is about giving people more time, better health and an understanding of the journey that they are on. It is about giving people more special moments, be it a Pixies concert or reading a story to a child—Alex read the best stories—and time to organise what you leave behind. People who develop cancers that are rare still matter, and they still deserve more time. The work to help people like Alex in the future must start today.

The Government have a renewed emphasis on tackling rare cancers, in memory of the sister of my hon. Friend the Member for Mitcham and Morden (Dame Siobhain McDonagh) and of Tessa Jowell, and for countless other campaigners, including those in the Gallery. What we need is focus and determination to respond quickly. I thank the House for indulging me today. Let us be that world leader that is so desperately needed in tackling rare cancers. Let us give families special time with those they love the most. Let us pass this Bill.

10.20 am

**Monica Harding** (Esher and Walton) (LD): I thank the hon. Member for Edinburgh South West (Dr Arthur) for bringing the Bill before the House, and pay tribute to him and to the hon. Members who have already spoken so movingly on this subject, including the hon. Member for Calder Valley (Josh Fenton-Glynn). I also pay tribute to the hon. Member for Mitcham and Morden (Dame Siobhain McDonagh) for her tireless advocacy.

The many forms of cancer categorised as rare according to the Bill might each strike a small number of people, but taken together rare cancers make up almost one in five of all cancer diagnoses. Each incident, each diagnosis, each prognosis has the same devastating impact on families throughout the country, my own being no exception. My brother-in-law, Group Captain Pip Harding, who was 53, was diagnosed with stage 4 glioblastoma this time last year. At the time, he was serving in the Royal Air Force with the US Indo-Pacific command, one of his many tours, including in Afghanistan and Iraq. He was given nine to 12 months to live. For his wife Claire and his five children, the news changed everything.

In September, I joined Pip, his family and over 400 other loved ones at RAF Benson in Oxfordshire for what was called a "dining out" or farewell ceremony, an event to allow everyone to be together with Pip, potentially for one last time. You can imagine how difficult, yet how

moving, that was. A few weeks later, Pip was lucky enough to come across the pioneering brain surgeon Dr Paul Mulholland, who has been trialling a treatment called oncothermia. This employs radio frequencies to target and heat malignant cancer tumour cells while avoiding healthy cells. Oncothermia is not currently available on the NHS and each one-hour treatment costs £1,000. A tumour like Pip's requires 36 sessions.

For most people, indeed for almost all of us, that kind of money and, consequently, that course of care, is out of reach, but the 400 friends and family who attended Pip's farewell dinner set up a GoFundMe page, which is now covering the cost of the treatment. We love Pip, which is why we all put in as much as we could to fund it. Cancers like this, with a brutal and bleak prognosis, bring people together to fight it. I want the Government to share that resolve. Since starting the monthly oncothermia sessions in December, the first MRI scan showed that Pip's brain tumour had reduced in size from 7 cm to 1.7 cm. Pip is, thank God, still alive and watching today. European studies now suggest that oncothermia can extend life for four to five years. For Pip's five children, that time is everything.

But that is not the whole of my experience with glioblastoma. In 2021, my husband John's best friend Ian died from the disease. His widow Nicola is in the Gallery. Almost unbelievably, Nicola's sister Karen, who had done so much to help Nicola through the loss of Ian, was herself diagnosed with a stage 4 glioblastoma last year and died a few months later.

I know that others in the Chamber and in the Gallery have had their lives touched by glioblastoma, too. I am sure they will agree that in the past three decades there has been an unacceptable lack of progress made on this disease: a lack of progress in developing new treatments, making them widely accessible and keeping those diagnosed with glioblastoma here with their loved ones. In the past 50 years, cancer survival rates in the UK have doubled. Whereas in the 1970s only 25% of those diagnosed were expected to live 10 years, today over half do. That is a record of staggering success and represents countless lives extended, made richer and fuller, and even saved. When it comes to glioblastoma, however, there is far less to celebrate. The chances of living a decade with the disease are one in 100. The gains in life expectancy over recent decades can be measured in months—precious, yes, but not nearly enough.

Glioblastoma is a rare cancer, but also an exceptionally lethal one. Brain tumours are the biggest cancer killer of children and of adults under the age of 40, yet in recent years, glioblastoma has been apportioned only around 1% to 2% of UK cancer funding. In 2018, to honour Dame Tessa Jowell, the Government announced a doubling of funding for research into brain tumours, but six years later, it was widely reported that less than half of the pledged £40 million had actually been spent. During each of those years, as funding was being delayed and sluggishly deployed, more than 3,000 people in the UK were diagnosed with glioblastomas. Will the Government update the House on how the remaining funds have been and are being spent? Will the Minister assure me that as the national cancer plan is developed alongside the NHS 10-year plan, deliberate and specific consideration will be given to glioblastomas?

The Medicines and Healthcare products Regulatory Agency incentivises research on orphan drugs, granting exclusivity for manufacturers and making it cheaper to bring drugs to market once they are developed, but clearly, when it comes to glioblastomas, it has not had adequate success.

**Dame Siobhain McDonagh:** I have been to see the MHRA numerous times and have asked about repurposed drugs. Many pharmaceutical companies are worried about repurposing drugs; the fear is that if glioblastoma research were to affect the main cause for having the drug, that might make the drug less successful. We have beseeched the MHRA to treat glioblastoma separately. Would the hon. Lady support such a move?

**Monica Harding:** I would of course support such a move, and I urge the Government to listen and take action.

Getting it right on glioblastoma is vital. Despite minor breakthroughs, exciting innovations and apparently promising research leads, for this disease, there has simply not been the improvement in survival rates that most cancers have had. To put it bluntly, glioblastoma remains a death sentence—an increasingly common one. In the UK, cancer diagnoses have increased, but although there are some worrying sub-themes, this trend is largely due to increased life expectancy. However, that is not the case with glioblastoma. In the past 30 years, rates in the UK have more than doubled. There has been far more of an uptick than is attributable to us all living longer. More people are developing this disease, yet we have failed to make meaningful strides on treatment and cures, or even on giving those with glioblastoma a little more time with those dearest to them. Now is the moment to do something about that.

I welcome the Bill. I welcome its emphasis on improving research—I have already touched on drug development—and the provisions to facilitate clinical trials, because the grim reality is that for glioblastoma, those trials are hard to conduct. There are too few patients, and frequently their life expectancy is too limited. Anything that can be done to connect eligible patients with researchers faster and with less friction is valuable.

I emphasise that there are great opportunities in front of us for accelerating research and making broad advances in the battle against rare cancers. Along with almost half my parliamentary colleagues, I am proud to have pledged my support for the Lobular Moon Shot project, which advocates a boost of around £20 million over five years for research on the basic biology of invasive lobular breast cancer, with a view to developing new treatments. Despite being the second most common form of breast cancer, lobular breast cancer is in many ways treated like a rare cancer. It is under-researched, difficult to diagnose through the standard screening mammogram, and often presents fewer symptoms than invasive ductal carcinoma, which makes up the overwhelming majority of breast cancer incidents.

**Sam Rushworth** (Bishop Auckland) (Lab): As the hon. Lady is explaining very well, invasive lobular breast cancer is not classed as a rare cancer. I am concerned that it would not come within the scope of this Bill, so I

*[Sam Rushworth]*

gently ask if it could be widened at the next stage. As she says, lobular breast cancer has many characteristics of a rare cancer.

**Monica Harding:** I thank the hon. Gentleman for that intervention. Yes, lobular breast cancer is treated in many ways like a rare disease.

I recently met my constituent Kate, who was diagnosed with lobular breast cancer in 2023. She explained to me that because almost all breast cancer research is based on the ductal variant, women like her are diagnosed later and often receive treatment oriented towards a cancer with a different biology from lobular cancer. Those two factors result in higher recurrence and lower survival rates. Kate has been in remission for more than a year, and has become an advocate for research. On her behalf, I ask the Minister whether she has met with the Lobular Moon Shot campaigners. What steps are the Government taking to increase research into the cancer? What consideration has she given to updating guidelines for the National Institute for Health and Care Excellence to encourage the use of MRIs to diagnose lobular breast cancer earlier?

The moon shot idea is the right one. In fighting cancer we should set ambitious goals, and we should innovate until we meet them. Moreover, as the Apollo project shows, research into seemingly narrow things often has spillover effects, producing vast, unanticipated benefits. That is often true when it comes to orphan drugs. To take just one example, Gleevec has changed the game, and not just for one rare form of leukaemia; it is now used to treat a range of other cancers and conditions.

The British pharmaceutical development sector is exceptionally strong, and now is a moment of potential. On genome mapping, artificial intelligence, biotech, immunotherapy and cancer vaccines, the UK is in a position to transform and save lives. I recognise the limited scope of the Bill, but I believe it to be vital. This House must take a keen interest in accelerating and incentivising research into rare cancers, including glioblastoma. This legislation meaningfully advances that goal.

I will speak briefly about young people and children, and specifically a lovely girl called Maddie Cowey. At the age of 18, Maddie was diagnosed with an alveolar soft part sarcoma. Sarcoma is an uncommon cancer that can occur anywhere in the body. All cancers in someone of Maddie's age are considered rare, but in her case, the classification was ultra-rare. Partly in consequence, it took five months for her to receive a diagnosis. Maddie had just started university. She recalled that at the time it

"felt like my life was falling apart. In many ways it was and it did. It was a very lonely place."

Maddie was diagnosed almost 10 years ago now. There are no approved treatments for Maddie's type of rare cancer, and she is undergoing a clinical trial. It is likely that she will remain on treatment for life. Maddie is amazing; she is brave and she will not let cancer define her. I bring up her story because cancer in young people is so uncommon that often it is diagnosed later. Neither medical professionals nor young people expect it, but the later a diagnosis comes, the more likely the cancer is to be lethal. What steps are the Government taking to ensure that the rare cancers afflicting young people are caught earlier?

Finally, I am reminded of something that Emily Dickinson once wrote about hope:

"I've heard it in the chillest land, and on the strangest sea".

We must get this right. We must give sufferers hope. We owe that to Pip's family—his wife Claire and his five children—and to Nicola in the Gallery, and her and Ian's sons Adam and Oliver, and to so many others who have suffered and who are here with us. I believe that we can.

10.33 am

**Dame Siobhain McDonagh** (Mitcham and Morden) (Lab): Through you, Madam Deputy Speaker, I want to apologise to the young black man on the Northern line tube from Colliers Wood this morning for having to spend his journey looking at me sobbing my heart out. It must have been a very odd experience. I wanted to say to him, "I am not just sad; I am angry." I am angry at the NHS. I am angry at the MHRA. I am angry beyond belief at the National Institute for Health Research. It should be renamed the national institute for something that does not do very much at great public expense.

All these institutions are bedevilled by the desire to carry on doing what they have always done. It does not get them sacked. As the former Home Secretary John Reid—Lord Reid—constantly tells me, "Siobhan, nobody ever got sacked for continuing to do the same thing. You are only sacked if you do something different." My God, has this morning not told us that we need to do something different? We have the tools to do something different, but the people in positions of power and responsibility choose not to. We have the best health system in the world for potential drug trials—a uniform system with well-trained doctors, great scientists, great universities and great hospitals—but do we do them? No. Do we fail people every single day? Yes. Do we threaten those doctors who try to do something different? Let me tell the House, groundbreaking oncologists are looking over their shoulder, waiting for the regulator to come and get them when one of their colleagues grasses them up. That is the atmosphere in our intellectual and health service institutions.

I could feel sorry for myself and for my loss, but I do not want that; I want things to change. All of us, from all parties, need to run fast and break things, and provide a challenge to the people running our systems. We have a drug repurposing project in the most universal health system in the world, so why are we not repurposing drugs for people with rare cancers? Why is that not being done for glioblastoma? Why is it that in May, we will open a drug trial at University College London and University College London Hospitals trust in Margaret's memory to trial one such drug that has been in the system for years? We organised a dinner with former Prime Minister Tony Blair; some ran marathons; and others sold cakes and scones in beautiful Cornwall villages. Doing those things gave us a great deal, but why, under our system, do we have to do them?

Why is it that the trial in May, under the amazing Paul Mulholland, will be based in only one trust? It is because if we had negotiated with all the other hospital trusts that are experts in this field, it would have taken

us two years to get started. Why are we outstripped by Israel, Spain, America and any number of countries? It is because we cannot get our act together to start a trial, as each hospital trust is arguing about and seeking to renegotiate every trial and every plan.

This is not new. The issue was raised by Lord O'Shaughnessy in his great report on clinical trials. That report is two years old, but we have made no progress. We made no progress under the former Conservative Government, and we have made no progress under our Government. The £40 million given to the National Institute for Health and Care Research in 2017 for glioblastoma and brain cancer drug trials has not been spent. Can any Member of the House explain to me how that is humanly possible? Do we not have drugs that we could trial? Yes, of course we do. Trials are not that complicated; we can do them if we choose to. We have the doctors to do them. We need to want to change.

I apologise to the Under-Secretary of State for Health and Social Care, my hon. Friend the Member for West Lancashire (Ashley Dalton), because when she came to talk to me in the Tea Room this morning, she got this at a very fast pace. I have now met four wonderful cancer Ministers, two Conservative and two Labour. They have all been dedicated, and all wanted to sort this out, but we cannot do this by edict, or by hoping and wishing. Unless we change things and unless, I dare say, some people are removed, it will never happen. All the institutions I mentioned continue to exist because they do not do things differently.

Someone diagnosed with a glioblastoma will get the same treatment that they would have got 25 years ago. They will have their tumour removed. They will be delighted that it is gone, but it is not gone; it is coming back. They will be given eight weeks' radiotherapy. It is brutal. It will help them for a while, but the tumour will come back. Then they get given chemotherapy— the drug is temozolomide, which was approved at the beginning of the 2000s. It will help, but the tumour will come back. They have to be able to withstand that drug themselves.

Margaret could not do that. By March, five months on from her diagnosis, she could not take it; her kidneys collapsed. What happens then? We had money and good friends. At this point, I would like publicly to thank Lord Waheed Alli for the kindness and friendship he showed us through Margaret's journey. The treatment that he has experienced from the press is absolutely appalling. He helped us on our way. But what about somebody with no money who cannot fundraise? Their life ends at the chemotherapy. There is nothing on the NHS, but those lucky enough to have the money can find a way.

I am really grateful that the brother-in-law of the hon. Member for Esher and Walton (Monica Harding) is on the oncotherapy machine. My sister fundraised for that machine, because we had to go to Dusseldorf to have it, so we brought it here. It is great that he is receiving much benefit from it. I know that many other people are, too.

Why is the NHS, which is so risk-averse that it will not allow slightly alternative therapies for cancer, happy for people who are really ill to get on a plane and go to a different country? Is it because it does not see what happens in another country, so that is okay? I have told the stories of holding my sister's head as she was sick in a bucket in terminal 5 at Heathrow airport, of carrying her on to a plane in the hope that the air stewardess would not see how she was, of lying next to her overnight hoping that she would be alive in the morning, because what was I going to do in a hotel in Germany, where I could not speak that language? That is my experience, but I am only one of thousands and thousands of people who do this every year, including children, because our system will not allow the use of novel treatments.

Why? Why can't we change things? Why don't we get up every single day and want to cure something? I do not know about other hon. Members, but since I joined the Labour party, and since I became an MP in 1997, I have got up every day and hoped that we could make things better in some way. I do not understand why our systems do not want to do the same thing. I want to understand, but it is beyond me. If there are drugs that could cure or give longer life to people with glioblastoma, why don't we trial them? That is not beyond our ability. We have the money to do it. If we do not have the money, we will raise it. We just need the opportunity.

I do not know why we do not have that wish to achieve. I was given some hope yesterday by the proposed abolition of NHS England, because something needs to change. I do not know whether that is the right or wrong thing to do, but we need to liberate people to do things. Let us face it: in the end, only people who are well motivated and willing to take a risk can change things. Beyond that, people will continue to die, will continue having to go to other countries, will continue having to spend large amounts of money. People not lucky enough to be in that position will just die prematurely.

I thank my hon. Friend the Member for Edinburgh South West (Dr Arthur) for introducing the Bill and for the courtesy he has always shown me, which must have been difficult at times as I sat shouting at him in Portcullis House about how everything was useless and hopeless. In my calmer moments, I understand that progress begins with small steps. I am frustrated that those steps are too small. I am delighted that there will be one database for trials, but if there are no trials, the database does not get us very far.

We will have a report on the orphan drug Act in 18 months' time. In that period, over 3,500 people will have been diagnosed with a glioblastoma, and many of them will have died. Why is it going to take us 18 months? Why can't we change things now? Why, in spite of the huge support we have had for the Bill from the Secretary of State for Health, could we not get something much more fierce in it? It is not a criticism; it is an observation. I know progress begins slowly, and I am grateful for my hon. Friend the Member for Edinburgh South West taking up the Bill and for having the calm demeanour that I lack, because I do not think the Whips would have accepted anything that I would have come up with as a private Member's Bill.

We need a revolutionary attitude. We either see and harness progress, or we come back next year, the year after and the year after that to ask why there has been no progress. All of us, individually and communally, need to dedicate ourselves to that progress and to keep asking the questions, being angry and simply refusing to accept that nothing can be done.

10.46 am

**Charlie Maynard** (Witney) (LD): I thank the hon. Members for Edinburgh South West (Dr Arthur), for Mitcham and Morden (Dame Siobhain McDonagh) and for Birmingham Erdington (Paulette Hamilton), because I have enjoyed working with them on the Bill. We all have our own stories. I should state my personal interest. My sister Georgie is sitting in the Gallery. She was diagnosed with a GBM—glioblastoma multiforme—nearly two years ago. I would like to say that she is alive and well, but let me just say that she is alive and she is doing well. She has been brave, determined and an inspiration to us all. It is particularly painful as she is a mother of three, a wife, a daughter and a sister. We have a lot to focus on, and it is on us collectively.

I will not rehash too much, and I will try to resist having a cry-fest, but it might be difficult. Our actions, and what we do as a team, are what we will be judged on. I am going to throw it over to the Labour side a little, because they are in government now and they have more power than we do in opposition. When we leave the Chamber today, I ask each Government MP to ask, "Okay, what are we actually going to do?" The talk in this Chamber is nice, but it is the actions that count.

I will pick up on two points. The first is the trial register. We have first-hand experience with Georgie of trying to find what trials are out there. Obviously, there are not enough trials; we know that, and that is something we need to fix. Also, matching patients with trials is not rocket science—that is a basic thing. I would also encourage the Government, rather than just starting from scratch and taking months to reinvent the wheel, to find out what is going on in the private sector and what trials and registers of people seeking trials are already out there, and to build on that. If there is a partnership with some company, that is fine, but let us move quickly, because speed really counts.

The second point is about orphan drug regulations. A key trigger for me getting into politics was Brexit. I thought it was a disastrous idea, and I still do. I struggle to find any possible gains from Brexit, but there is one thing that we could do. The EU has regulations on orphan drugs; ours could be more generous. We could pull research into the UK by giving patents for a few extra years, which would encourage people to dig into the research in these critical areas. I live in hope of that one potential gain.

Even if products are obtained, reimbursement has to be accessible on the NHS, which is far from certain. Ensuring that there is a robust, timely and accessible route to making these drugs available on the NHS for patients really counts. It is critical that that does not fall off the radar. Also, we are really falling behind in the number of clinical researchers active in the UK today. If we want to get this research moving, we must think about what we are doing to get clinical researchers working hard in this space and in others, because we are not doing a good enough job on that.

That is all I will say. Let me just return to my first point: we need action. It is good to have those in the Gallery here today.

10.50 am

**Sam Rushworth** (Bishop Auckland) (Lab): I thank my hon. Friend the Member for Edinburgh South West (Dr Arthur) for bringing the Bill to the House, and join him in paying tribute to our hon. Friend the Member for Mitcham and Morden (Dame Siobhain McDonagh) for her campaigning, and for her powerful speech calling for a revolution in attitudes. I also thank my hon. Friend the Member for Calder Valley (Josh Fenton-Glynn) for his very moving speech. As somebody who lost a brother much too young, I was deeply moved by his words.

I have come here today to speak on behalf of my constituent, Katie Swinburne. She is a much-loved school teacher—in fact, she was the school teacher of one of my staff—and a mother of three who was diagnosed with invasive lobular breast cancer. As was mentioned a moment ago, lobular breast cancer is not classed as a rare cancer—in fact, it is the second most common type of breast cancer in the world, with 8,500 diagnoses annually in the UK alone—but it shares many characteristics of rare cancers in the sense that it is very difficult to detect. In Katie's case, as in many others, it did not initially form as a lump in the breast, for example. It has distinct genetics, so is not detectable in genetic tests, and it is very easily missed in mammograms and ultrasounds.

As a consequence, many of the women who get this form of cancer will not be diagnosed until long after it has already spread. I am also told—thankfully, Katie is watching today; I received a WhatsApp message from her a moment before speaking—that a key point that I should make to the Minister is that, because lobular breast cancer presents differently from other forms of breast cancer and is not separated out in clinical trials, there is very little trial data on it. I met recently on Zoom with Katie and others who have been campaigning for the moonshot. This is not a lot of money; it is simply £20 million of funding that the University of Manchester could use to better understand the biological architecture of this type of cancer. That would lead to the possibility of developing the right treatments, because it currently has no specific treatment. This is a gentle request, really, that in the next stage of the Bill lobular breast cancer be considered alongside the rare cancers for which it already provides.

I finish by paying tribute to Katie and all the many brave individuals I have met. I cannot imagine what it is like to be young and have parenting responsibilities and be diagnosed with an advanced stage of cancer. Many of those campaigning know that they might not live to see the day when the better drugs and treatments are available, but they are bravely taking up this cause on behalf of those who come after them.

Katie was bravely doing a mile a day sponsored walks. My predecessor in this place joined her on one of those miles, and although we disagree about many things politically, we have already seen today that this is a cause that unites, because there is little—in fact, there is nothing—more precious in life for any of us than time spent with the people we love. Money cannot buy that—nothing can buy that—and, as my hon. Friend the Member for Mitcham and Morden made clear, the decisions we make in this place can have a real impact in the lives of others.

10.56 am

**Clive Jones** (Wokingham) (LD): I have to say, Madam Deputy Speaker, that as I was waiting to speak, I was very pleased that you did not call me after the hon. Member for Calder Valley (Josh Fenton-Glynn) because

I do not think I would have been able to get through parts of my speech so shortly after listening to his story; he did really well.

I was diagnosed with breast cancer in 2008, which is relatively unusual for a man, and the hardest thing I ever had to do was tell my two daughters, who were 13 and 14 at the time, about my diagnosis. It was an experience that left me wondering if our family of four was about to become a family of three. I had to explain to all of them that I would have an operation to remove a tumour and I might need another one. As things turned out, my cancer had spread and I did need to have another operation. I also had to say that I would need chemotherapy and radiotherapy, and that that was going to take nine months out of our lives—not just mine, but the lives of my immediate family, my wider family and our friends.

I consider myself very lucky that my treatment pathway was relatively clear, but that is not the case for many rare cancers. The reach of cancer is an evil that is growing across our society with nearly one in two of us projected to get cancer in our lifetime, meaning we all know someone close to us, whether family or friend, who will begin what can be a very traumatic journey. It is a fight that causes your life to be taken completely out of your hands, and that leaves families forced to hear rarely used terms like "malignant" or "metastasised" as if they were common expressions, clouding the horror of medical jargon.

It is with these words that I am proud to associate myself with the hon. Member for Edinburgh South West (Dr Arthur), and I congratulate him on his campaign that demands better for cancer patients and especially on bringing forward the Rare Cancers Bill, because it is a powerful and necessary step forward to end the experience that I described at the beginning of my speech.

Rare cancers are often under-researched and the regulatory environment simply fails to cope with them. They have smaller patient populations which makes research and investment less appealing and an evidence base harder to achieve. Where clinical trials are taking place, patients often do not know very much about them. A Cancer52 survey of rare cancer patients found that 65% cited not knowing about trials as the main barrier to accessing the trial in the first place. The Bill seeks to rectify those flaws in our system, and I would like to highlight the powers it contains to ensure that patients can get better access and find relevant clinical trials. As was highlighted in the Teenage Cancer Trust's "Improving Young People's Access to Cancer Clinical Trials" report, it is also difficult for the clinical trial leads themselves to find the necessary patients, meaning that they struggle to recruit. Both patients and researchers want to be in those clinical trials, but the system does not allow for that common-sense joining up.

I hope that as a result of the changes made by the Bill, people in my constituency of Wokingham and across England will begin to see a shift towards prioritising rare cancers, because such a shift is long overdue. Last week, I met a constituent to discuss his wife's cancer. She had leiomyosarcoma, which has an incidence rate of six cases per 1 million people annually in the UK. He explained to me that one of the potential treatment options for his wife is exploiting faults in the BRCA2 genes through PARP inhibitors. However, with an estimated 30 new cases of leiomyosarcoma every year and only three with the BRCA2 mutation, there are too few patients to allow for a sufficient clinical trial, and therefore NICE does not license those drugs for that particular cancer.

What are the Minister's views on efforts within the European Union's life science industry to develop clear guidance to make cross-border clinical trials easier? If that were to happen, it would address one of the major problems with rarer cancers such as leiomyosarcoma. Individual nations may not have a sufficient pool of patients to conduct a clinical trial, but multiple nations working together could. Does the Minister see cross-nation trials as having great potential for developments in oncology? If the EU were to advance easier cross-border co-operation, would that be something that the United Kingdom could potentially negotiate its way into? This is no time for a Government to be isolationist.

My constituent also highlighted that PARP inhibitors are available in the United States. What efforts is the Minister making to ask that if drugs are approved by the United States Food and Drug Administration, NICE has the opportunity to take the US evidence into account when considering whether to approve licences for drugs in the UK?

Sarcomas are just one tumour type that has poor survival outcomes and limited treatment options. Despite the investment by charities such as Sarcoma UK to fund research into new treatments, we do not know enough about the disease, because so few people are affected. Other constituents have written in to share their experience of losing loved ones to brain tumours such as glioblastomas and to blood cancers. All have expressed hope that this Bill will create a world in which we can better encourage pharmaceutical companies to run trials on rarer cancers in order to create innovative new treatments, so that the pain they went through will not be a fate that others must endure in future.

Before I conclude, it would be a missed opportunity if I did not ask the Minister about the national cancer strategy, which will be so important in ensuring that a long-term plan is in place to deliver better services for patients with rare and less common cancers. The NHS needs to be prepared for the innovations of the future by preparing for an increase in demand for companion diagnostics. The turnaround times for existing tests are already causing delays in optimal treatments. What steps is the Minister taking to ensure that there is enough capacity for the ever-increasing demand for diagnostic tests?

The national cancer strategy needs to be thoroughly scrutinised before its final draft is published, to ensure that the measures demanded by cancer charities and patient groups, and ideas from by the life sciences sector, are properly covered. NHS performance must be measured regularly over the lifetime of the strategy to see if improvements are actually being made. Will the Minister explain what accountability mechanisms are being considered for the national cancer strategy?

I thank the hon. Member for Edinburgh South West once again for bringing the Bill to the House.

11.5 am

**Peter Dowd** (Bootle) (Lab): I rise to support my hon. Friend the Member for Edinburgh South West (Dr Arthur). I know he has put a huge amount of effort into bringing

*[Peter Dowd]*

the Bill before the House, in collaboration with many others, including patients, families, professionals and charities. I send my condolences to him, his wife and family on the death of his father-in-law, and to Tilly's family. To lose a child is unbearable and against the natural order of things.

The Bill is much needed and I welcome the opportunity to make some observations about it. Before I do so, I refer to my hon. Friend the Member for Calder Valley (Josh Fenton-Glynn) and his brother. I live in the area of Lunt that he referred to, where there is going to be a remarkable legacy for his brother: the area has been rewilded and there will be a forest there in due course, which is absolutely fantastic. I invite him and his family to come down—I will show them around and they can see the legacy that his brother has left us.

I also want to refer to comments made by the chief executive officer of the Brain Tumour Charity, Dr Michele Afif, about the context of the Bill and why it is before the House. In an online article last month, she wrote:

"During my clinical career I was frequently moved by the courage and determination of my patients and their families."

It behoves all of us to support the endeavours of my hon. Friend the Member for Edinburgh South West to help those people who "don't have a voice", as Dr Afif says, by giving our unambiguous backing to what she calls "a Bill of hope."

We must ensure that that hope is turned into reality: that is the job of every Member in the Chamber. We owe it to those affected by rare cancers to champion their needs, treatment and lives. The proposed legislation would be a starting point—a first base. It will enable and facilitate the promotion of research into rare cancers and better access to clinical trials, as has been said, and initiate a review of marketing authorisations for so-called orphan products, which I will explore in more detail.

It is devastating to have a cancer diagnosis. We all know family members who have been diagnosed with one form or another. The shock and trauma that comes with such news is hard to take in, as the hon. Member for Wokingham (Clive Jones) said. But then to find out subsequently that the spectrum of intervention with medicines or other allied interventions is limited because of the rare nature of a particular cancer surely adds to that distress and worry. As the hon. Member for Esher and Walton (Monica Harding) and my hon. Friend the Member for Mitcham and Morden (Dame Siobhain McDonagh) said, with glioblastoma, questions inevitably sweep through the minds of those affected as to whether an appropriate medicinal intervention is available or even on the horizon.

Orphan products are those drugs that are used to treat not only rare cancers but other rare diseases. The pharmaceutical industry is reluctant to develop the drugs because of the cost, time and effort when they will not be commercially productive, given the number of people who will use them. The fact that these potentially lifesaving, or life-changing, drugs are not produced leaves a significant lacuna in the treatment options for those with rare cancers. Although there is a public health need—of that there is absolutely no doubt—there is no resource to enable that lacuna to be filled. That resource should be made available.

I am therefore pleased that clause 1 of the Bill will place a duty on the Secretary of State for Health and Social Care to undertake a review of the law relating to marketing authorisations for potential orphan medicines. I note that the Bill will require an assessment of regulatory approaches in other countries, which is also welcome. That is an excellent and much-needed step in the right direction, linked in with the other requirements in the Bill relating to research programmes and initiatives. It sends a clear and unambiguous message to those affected and those who will be affected—that could be anybody in this Chamber and, as we have heard, it is some people in this Chamber—that the Government have heard what they have said and are not only listening to that message and that plea, but are taking practical action to put it into effect, which is more than welcome.

Other countries have introduced similar legislation in this respect. The provision in clause 1(2) will help to form a more progressive, informed approach and its requirements will enable information, practices and protocols from other jurisdictions to be harvested. For example, Genetic Alliance UK points out that there are as many as 7,000 rare diseases—possibly more—affecting one in 17 people, with approved treatments available for only one in 20 rare diseases more generally. Although those are not significant cohorts of people per se in a particular disease category, collectively millions of people are affected in one fashion or another by a rare disease, including rare cancers—and it is no less the case for rare cancers: a disease is a disease, and those affected by it, whether it is rare or not, are entitled to equity of care and intervention.

In this case, such potential interventions cannot simply be left to market arrangements. That is why it is important to facilitate a more comprehensive approach to the development of orphan medicines, which must be set against the context of, for example, a 2022 survey of 61 orphan medicines that received EU approvals between 2018 and 2021. Of those, 36 orphan medicines were made available in England, compared with 55 in Germany, 50 in Italy, 48 in France and 31 in Spain. While those medicines do not specifically relate to cancer, that helps to contextualise the difference in numbers for orphan medicines.

A research programme between 2020 and 2025 at the University of Sheffield, funded by the Wellcome Trust, indicated:

"Furthermore, only a third of EU authorised orphan drugs are recommended by NICE… Thus, the medical needs of UK rare disease patients are potentially underserved compared to both the USA and EU."

Indeed, the programme is called the Orphanisation project. Clearly, as the university puts it, there is a

"major international debate…currently ongoing about how we might improve patients' access to orphan drugs, raising important questions about how to value these medicines, and the ethics of resource allocation".

The project sets out a path for being creative in progressing the relatively new concept of orphanisation,

"as a way of understanding contemporary changes in the biopharmaceutical sector. Specifically, the project examines the extent to which orphanisation occurring in the EU, UK, and USA",

and seeks to understand how it is informed by

"different technologies, institutions, and actors, addressing the implications for industry, health policy and patients".

I look forward to the progress that it will make. I believe that the proposals in the Bill will help. They follow through systemically and consistently to change that scenario for the better. International explorations and comparisons are one method to inform decision makers about how they can be more proactive in facilitating access to medicines for those most in need of them, especially when the size and extent of the available medicinal range is limited. That is often the case with the rare cancers we are talking about, and rare diseases more generally.

Once again, I thank my hon. Friend the Member for Edinburgh South West for enabling the House to debate this issue and for the opportunity to tease out many of the issues affecting our constituents and, as I referred to earlier, to discuss crucial lifesaving and life-enhancing treatments for diseases more generally.

I again pay tribute to all those colleagues who have brought their stories and their experiences to us today, including my hon. Friends the Members for Calder Valley and for Mitcham and Morden, the hon. Members for Wokingham and for Witney (Charlie Maynard) and others. They deserve our admiration and thanks, but more importantly, they need our support to get the job done. That point has been made by so many. Such expositions, however painful for the Members concerned, bring home the real need for this House to act on this issue, which is literally a matter of life and death. Finally, I look forward to seeing the Bill progress through the House in the coming weeks, as no doubt do many others. I thank you, Madam Deputy Speaker, for your indulgence.

11.16 am

**Dr Lauren Sullivan** (Gravesham) (Lab): I am here today to support the Rare Cancers Bill, a vital piece of legislation introduced by our hon. Friend the Member for Edinburgh South West (Dr Arthur). I begin by paying tribute to his father-in-law and all those who have shared their stories here today.

My hon. Friend's story, like so many, is a stark reminder of how aggressive and under-researched cancers can be, leaving patients with little or no hope. It is assumed that rare cancers, as has been mentioned today, affect a low number of people, but that is not the case. Cancer Research UK says that rare and less common cancers account for 47% of all UK cancer diagnoses and 55% of all cancer-related deaths. Some 82% of rare cancer patients are never even consulted about joining a clinical trial. That means that while each individual rare cancer may affect relatively few people, together they make up almost half of cancer cases, yet the funding and research remain disproportionately low.

I will briefly mention Charlie Shrager, one of my constituents in Gravesham. Like so many, she is fighting cholangiocarcinoma, or bile duct cancer. It is a supposedly rare but devastating form of liver cancer, and there is rising incidence. In 2001, 2.9 out of 100,000 people were diagnosed with it. In 2018, it was 4.6. Some 79% of these patients are diagnosed at stage 3 or stage 4, meaning that their likelihood of survival is limited. Histotripsy is a non-invasive treatment that uses sonic beam therapy. It is incredible. The problem is that we do not have a machine in the UK. They cost £10 million, and let us get one here, because for people facing this disease or pancreatic cancer, it is a lifesaver, and they desperately need it. As Charlie put it:

> "I was lucky enough to afford treatment abroad, but I know many who aren't. They don't have that option. Why should their chances depend on their bank balance?"

We must recognise that "rare" does not mean "insignificant". People across the UK are battling cancers that remain underfunded, under-researched and underserved by clinical trials, which is criminal. It is a pattern that is repeated again and again with bile duct cancer, glioblastoma, leiomyosarcoma—a rare soft tissue cancer that demands personalised medicine—pancreatic cancer and blood cancers. Each of these cancers devastates lives. We have discussed what the Bill can do: appoint a national specialty lead for rare cancers, review and improve the UK's orphan drug regulations, and improve data sharing.

As a research scientist in biochemistry, I worked on neglected infectious diseases and came across the Drugs for Neglected Diseases initiative. It was launched 25 years ago to co-ordinate research outcomes, negotiate with big pharma and test drugs that have been developed for other neglected diseases, and it is now eliminating diseases across the globe. It can be done—we have the blueprint—so I urge the Minister to reach out to that initiative to see what we can learn and implement here.

For too long, rare and neglected cancers have meant a rare chance of survival, and that must change. Given the strength of feeling among everybody here, there is the will to bring about change. I look forward to seeing the Bill go forward, and to seeing that people are not left behind and that we find a cure for everybody.

11.21 am

**Martin Rhodes** (Glasgow North) (Lab): We have already heard so much moving and powerful testimony in this debate, but despite the tragic impact that rare cancers have on people across the UK, they garner too little attention, are under-researched and lack investment in their treatment. Though cancer survival rates rose by nearly 10% between 2005 and 2020, rare cancers still have some of the lowest survival rates, leaving too many people without hope.

I thank the hon. Member for Edinburgh South West (Dr Arthur) for introducing this Bill. I will argue in favour of it today, using three examples: first, the story of a constituent suffering from a rare cancer; secondly, the importance of this Bill for extremely rare cancers; and, lastly, its importance for future research.

There are many rare forms of cancer that individuals suffer, often without specialised treatments or public awareness, but every rare cancer patient has a name and a story. Take that of a constituent I recently met in Parliament at an event for World Cancer Day, who suffers from T-cell large granular lymphocytic leukaemia. Although the five-year survival rate for leukaemia currently stands at 55%, the figure for acute myeloid leukaemia, a rare and aggressive form, is one of the lowest of all cancers. It has a 22% survival rate beyond five years after diagnosis. This means that, sadly, nearly 80% of those diagnosed with AML today will not survive until the end of this Parliament. Surgery is not a viable treatment option for those diagnosed with leukaemia, so such patients often depend on the discovery of new and innovative treatments to survive the disease.

*[Martin Rhodes]*

Though every cancer has a name and a story, some are so rare that there is little representation of them, even in debates like this. That brings me to my second example: composite hemangioendothelioma, or CHE. It was first medically identified in only 2006, and by 2022 had fewer than 60 cases reported in English-language literature. Because of its rarity, it is hard to treat and garners little attention from companies that could develop treatments. However, those affected by CHE have names, families and stories. Hopefully, my mentioning CHE in this debate may, in a small way, help raise awareness of its existence. This Bill will assist us in this matter, as it will result in the appointment of a named person who is responsible for overseeing the delivery of research into rare cancer treatments. That will facilitate some political accountability for rare cancer research and encourage an ecosystem that can hopefully lead to future treatments for, or at least more attention to, even some of the rarest cancers, such as CHE.

Talking of treatments, earlier this week, I met a constituent who is a researcher at the University of Glasgow. She was in Parliament for the STEM for Britain exhibition. We discussed her research on a novel approach to treating osteosarcoma. Although it is the most common primary bone cancer, only 160 people are diagnosed with osteosarcoma each year in the UK—fewer than three people in every 1 million of the population—making it a rare cancer under the Bill. Current treatments lack specificity in targeting the tumour and often have unwanted side effects. My constituent's research looked at the potential use of small molecules to create a more effective and non-invasive treatment for osteosarcoma. The Bill's support for information sharing in the research registry system will help researchers like my constituent. It will help with research and clinical trials by giving researchers greater access to the patient population with rare cancers like osteosarcoma. A patient survey in 2024 found that 82% of those with a rare or less common cancer were not offered a clinical trial. That is why the Bill is important.

The Bill will help to foster an environment in which there can be more research and clinical trials on rare cancers such as osteosarcoma. For patients like my constituent suffering from t-cell large granular lymphocytic leukaemia, for those diagnosed with the least-understood cancers, and for the researchers trying to find new treatments, the Bill represents a commitment to the fight against rare cancers. I therefore urge the House to support my hon. Friend the Member for Edinburgh South West and the Bill today.

11.26 am

**Chris McDonald** (Stockton North) (Lab): Those of us who have lost a friend or a family member to cancer will no doubt have heard them described—often, I think, somewhat unhelpfully—as courageous, but this morning we witnessed the most courageous exposition I have ever heard in my life from my hon. Friend the Member for Calder Valley (Josh Fenton-Glynn). I thank him for the privilege of allowing us to listen to his loving tribute to his brother. We also heard from a number of Members, including the hon. Members for Kingswinford and South Staffordshire (Mike Wood), and for Witney (Charlie Maynard), and, most forcefully, my hon. Friend the Member for Mitcham and Morden (Dame Siobhain McDonagh), about the pressure of time, and the urgent need to do something to find a cure or treatment for rare cancers. We have heard a number of moving speeches this morning, but I will allow hon. Members to relax and recharge their emotional batteries a little bit, because I will address the issue of time, and the practical considerations of how we can turn drug discovery into treatment as speedily as possible. To do that, I will lift the lid on our drug supply chain and set out the vital role that the NHS can play in it.

There are lessons we can learn from the covid pandemic when it comes to the drug supply chain. We very quickly developed a vaccine in the UK, in Oxford, but we saw quite quickly that the vaccine was worth nothing until it was in the arms of the population. Getting that done required a big effort, including in industry. As we heard from my hon. Friend the Member for Gravesham (Dr Sullivan), industry is also important. The Fujifilm factory in Billingham in my constituency manufactured one of the covid vaccines, and it will shortly turn Billingham into the largest biopharmaceutical manufacturing centre in the UK. When it was making the vaccine, it found that it had a big problem. This brings into play another town, just up the River Tees from Billingham, in the constituency of my hon. Friend the Member for Bishop Auckland (Sam Rushworth). Members may have heard of it—it became famous for a particular reason during the pandemic—but they may not be sighted on the reason why I will talk about it, which has more to do with glass than glasses. Barnard Castle is home to GlaxoSmithKline, which bottled the vaccines. There was, at the time, a global shortage of bottles for vaccines, and in the UK we have only one glass manufacturer capable of doing that job, although soon there will be another in St Helens.

Hopefully, after that little overview, Members can sense that there is a big industrial supply chain issue that we need to address before we can get treatments to the people who need them most. In fact, there are a number of researchers working on this area. I am sure that when we think of research into rare cancers, we think of people in white coats and laboratories in places like Oxford, Cambridge and Imperial, but I urge us to also think about the process operators in Billingham, the bottle fillers in Barnard Castle and the furnace operators in places like Glass Futures in St Helens, who are also working hard on research projects to deliver those treatments.

The second issue that I would like us to consider is the role that the NHS can and must play. I want to see a transformatively different approach from the NHS in this area. A month ago in Parliament, I met representatives of Pancreatic Cancer UK, which I know supports the Bill. They talked to me about pancreatic enzyme replacement therapy, which is a treatment for pancreatic cancer, and about the difficulties in sourcing sufficient quantities of treatment. We all know from our constituency surgeries that there is the same issue with common drugs; people suffering with other conditions and people who have children with attention deficit hyperactivity disorder and so on are struggling to get the drugs that they need.

Part of the issue is that we rely so much on imports. We could be manufacturing these products in the UK. The NHS is the single biggest purchaser of drugs in the world; it has the market power to demand that production

be centred in the UK. That would bring clear economic benefits to the UK, but it would also shorten cycle times for innovation, because the researchers and the manufacturers would be close to one another, and it would ensure security of supply in the UK. It would mean that we could be proud of manufacturing drugs that help to treat people around the world. It would also fit in with our industrial strategy. My right hon. Friend the Secretary of State for Health and Social Care was talking only yesterday about the importance of life sciences to our industrial strategy, and about their creating British jobs in research and in factories.

I very much thank my hon. Friend the Member for Edinburgh South West (Dr Arthur) for introducing the Bill. He described his father-in-law as a dignified man; my hon. Friend gave an incredibly dignified speech, and I am sure that his father-in-law will be very proud. We look forward to the days when people who suffer from rare cancers are not offered such treatments as breathing into a brown paper bag, as my hon. Friend described, or taking a paracetamol, as my hon. Friend the Member for South Shields (Mrs Lewell-Buck) described. Instead, we should use the power of our NHS and the efficiency of our UK supply chains to turn discoveries into drugs, and trials into lifesaving treatments.

11.32 am

**Lorraine Beavers** (Blackpool North and Fleetwood) (Lab): I thank my hon. Friend the Member for Edinburgh South West (Dr Arthur) for introducing the Bill.

I remember the day my dad was diagnosed with terminal cancer. I remember my mum and dad picking me up off the floor. I was supposed to be supporting them, but that did not happen that day. Dr Lau at Blackpool Victoria hospital explained that my dad's cancer was terminal. My dad was initially given chemotherapy to try to shrink the tumours and give us more time. Later, he was asked to take part in a trial using immunotherapy. It was explained that the immune system does not recognise cancer as alien and as a threat. Immunotherapy teaches the immune system to recognise cancer, and enables the body's immune system to fight back.

My dad was a fighter and he was willing to try anything. His body struggled with chemotherapy, and after we nearly lost him twice in 12 months it was stopped, but the immunotherapy continued. He finished the course without any complications. Once my dad started the treatment, the cancers—there were many—never moved. To this day, we do not know whether the treatment cured him and he was left with just scar tissue, or whether the cancers lay dormant. What I can tell the House is that my dad did not die of cancer; it was something else that took him from us.

My family believe that we were given an extra three years of loving and being loved by my lovely dad because of immunotherapy. We will always be grateful for the Christmas days, the birthdays, the celebrations and sometimes the tears that we were all able to share with my wonderful, caring dad.

People with rare cancers deserve the funding and research trials that the Bill will initiate. They should have the chance of life that my dad was given. That starts with ensuring that patients can get better access to clinical trials. Many people miss out on potentially life-extending trials because there is just not as much information out there as there needs to be. Recent research has found that 82% of respondents with a less common or rare cancer were not offered an opportunity to be part of a clinical trial. That has to change, and the Bill would achieve that.

I support the Bill, because everyone diagnosed with cancer should be given every chance of survival. Without the Bill, people with rare cancers will die sooner than other cancer patients, not having been given the chance to fight this terrible disease. I speak for them, so that they can have the chances that were awarded to my dad. I thank Dr Lau, my dad's consultant, for giving an 81-year-old man the precious gift of life for a few years longer.

11.35 am

**Euan Stainbank** (Falkirk) (Lab): I thank my hon. Friend the Member for Edinburgh South West (Dr Arthur) for introducing the Bill. It may be the most repeated phrase in the Chamber, but politics is about choices and he, having ranked so highly in the private Member's Bill ballot—an early accolade in this Parliament—chose a Bill that would put patients suffering from a rare cancer and their families higher up on the list of priorities. As my hon. Friend the Member for Calder Valley (Josh Fenton-Glynn) so movingly put it, I hope that, in time, the Bill will mean that in some instances, my constituents in Falkirk and families across the United Kingdom will get precious extra hours, days, weeks and years to spend with our loved ones.

Every Member of the House and every constituent I have spoken to about this has a story of a loved one who has suffered through the heartbreaking cruelty of a cancer diagnosis. I lost two of my grandparents in their early 60s. I still remember the seven years of my life that I spent with my grandad Robin. We found plenty of time to exchange robust views on football, and I am sure that if he had more time with us, we would today be exchanging views on life and politics, too. He was lucky, though, to meet all four of his grandchildren, thanks to the immense care he received from his doctors and the support he got from his family.

I remember my granny Janet, who passed away in 2012 after a 10-month battle with a brain tumour. I remember most fondly her fussing over everyone in the house to make sure they had absolutely everything they needed at all times. I remember holding her hand in Strathcarron hospice, where she had volunteered for a number of years, and where she received care in her final days. One thing I have drawn from those experiences is the value of our NHS and hospice staff to those who have cancer and their families. Those staff, day in, day out, take the worst parts of life and allow us to endure them. We should arm them with the best possible tools for treating illness and disease.

Statistically, half of us in the Chamber will have to comprehend our own diagnosis of some type of cancer. The definition of "rare cancer" is, for the purposes of the Bill, one that affects fewer than one in 2,000 people. We must acknowledge that active intervention is required to ensure that research, treatment and clinical pathways for those cancers have parity with other cancer research. As has been mentioned, rare cancers account for about 47% of all cancer diagnoses.

*[Euan Stainbank]*

I will go through the Bill and each of its clauses to show why I support it. Clause 1 and the statutory requirement for a review relating to orphan medicines will be an essential step to gaining a comprehensive understanding of the availability of medicines and how they can best be calibrated towards new treatments and new research. The comparative approach that the Bill puts forward for the review acknowledges that while we have a proud history of world-class research, other countries have been able to make substantial strides in this area in recent years when we have not. In the last six years, the UK has dropped from being ranked second for the availability of orphan medicines—behind only Germany—to England being 10th and Scotland being 13th among European countries. That does not necessarily look like regression, but it potentially exposes stagnation in advancing research that would benefit those suffering from a rare cancer. The British pharmaceutical industry has stated that it is increasingly challenging to develop medicine for rare diseases in this country, citing, among other things, the low prospect of NHS reimbursement for rare disease medicines.

Clause 2 gives the Secretary of State a duty to promote research on rare cancers, ensure that patients can be easily contacted about such research, and ensure appropriate oversight of rare cancers. That is a progressive move, as the duty to promote research will write into law that any Health Secretary must take a proactive approach to maintaining and promoting rare cancer research. It embeds in the Government's job description a duty to ensure that ease of contact is properly facilitated, and that there is appropriate oversight. The Bill is not overreaching when it says that strategic co-ordination is key. The appointment of a national speciality lead for rare cancers will put into law the requirement for a champion who can cut through any silos that exist, or that start to develop as the Bill takes effect.

Clause 3 is a critical part of the framework. It will aid the building of a robust evidential basis for clinical trials by making a bespoke register for those with a rare cancer. The sharing of information from the national disease registration service by the NHS with the NIHR's "Be Part of Research" registry, so that patients can be identified and contacted, will improve an issue that has come up several times when I have spoken to organisations in this space: there are not enough people available for clinical trials for rare cancers. Correspondingly, as has been mentioned by other Members, clearly there is a substantial barrier at the patient end. Cancer52 found that 82% of those with a rare cancer had not been offered a clinical trial. That evidences the clear case for the change proposed in the Bill.

With rapid advances in cancer treatment, there is a massive opportunity to take steps forward in increasing survivability after diagnosis. For all these new treatments to be effective, there needs to be corresponding clinical trials. Currently, connecting those with a rare cancer to clinical researchers involves an amount of luck that the information about the trial will make its way to the patient or that they will be aware of a clinical trial. Organising the register so that clinical trials can get in touch with patients will simplify and improve the efficiency and efficacy of the system, saving time and increasing the chance of successful trials. I give the Bill my full support.

11.40 am

**David Pinto-Duschinsky** (Hendon) (Lab): I start by thanking my hon. Friend the Member for Edinburgh South West (Dr Arthur) for raising this deeply important issue. I know that I speak for everyone here in finding his words about his father-in-law, and the story of Kira, very moving. I join him in welcoming Kira's family. I pay tribute to my hon. Friend the Member for Mitcham and Morden (Dame Siobhain McDonagh) for her campaigning on this issue—her sister would be very proud of her. I also pay tribute to everyone who has spoken, for both their bravery and the immense bravery of their constituents and their family members.

I particularly want to recognise the hon. Member for Kingswinford and South Staffordshire (Mike Wood) and the story of Dan, the hon. Member for Esher and Walton (Monica Harding), my hon. Friend the Member for Blackpool North and Fleetwood (Lorraine Beavers) for her powerful speech about her father, and my hon. Friend the Member for Falkirk (Euan Stainbank) for his speech about his grandparents. I give a special mention to my hon. Friend the Member for Calder Valley (Josh Fenton-Glynn); I am so sorry that I did not get a chance to meet his brother Alex. He sounds like a phenomenal human being. I am so sorry for my hon. Friend's loss, but I know that his brother would be very proud of him.

My heart goes out to those who have shared their stories. I thank them for their bravery. As so many stories show, the term "rare cancers" is misleading. The cancers we class as rare in total account for almost half of all cancer diagnoses each year, and as has been mentioned, tragically they account for over half—55%—of all cancer deaths. Given that, on average, one in two of us develops some form of cancer in our lifetimes, the chances of experiencing one of these so-called rare or less common cancers, or seeing them diagnosed in a loved one, are far higher than the term suggests. In the coming year, 182,000 people will be diagnosed with these types of cancers—equivalent to the population of a city the size of Swindon. Sadly, 92,000 people will lose their lives as a result—the population of a city the size of Chester.

Behind each one of those tragic statistics lies a story of families bereaved; of mothers, fathers, sisters, brothers and children lost, and of lives torn apart. That was brought home to me when I visited Chai Cancer Care in my constituency to hear the stories of many people battling to live with cancer. Their bravery is inspiring and they need our help now. I commend the Government's work to improve cancer outcomes for all. Last month they launched the call for evidence to inform the development of a national cancer plan, and I hope that we can pass the Bill to support those efforts.

Illnesses classified as rare or less common are among some of the very cruellest. The Bill seeks to address some of the fundamental reasons why diagnosis of a comparatively rare form of cancer can leave patients with a disproportionately lower chance of making a full recovery. For a start, rare cancers are harder to diagnose. There are many reasons for that. Some of the more common cancers have screening programmes, which means that many people are diagnosed before they have symptoms. Sadly, that is much less common in the case of rare cancers. Additionally, doctors see the symptoms of common cancers more frequently, and so are more

likely to spot them. Also, currently, 82% of patients with a rare or less common form of cancer are not offered a clinical trial.

The Bill will seek to reduce the knowledge gap on rare cancers, proposing a national specialty lead for rare cancers to advise on research design and facilitate collaboration in rare cancer research, and a specific rare cancer registry to share information to improve the recruitment of participants for rare cancer clinical trials. However, although we need to incentivise research, it is not the only barrier that we face to improving rare cancer outcomes. The comparatively lower occurrence of many rare cancers mean that, although drugs to combat them often exist, for economic reasons they are not developed by the pharma industry, despite the pressing and urgent need for them. These orphan drugs have the potential not only to save thousands of lives but to provide hundreds and thousands of families with that most valuable thing, to which my hon. Friend the Member for Calder Valley referred: more time with their loved ones.

Under normal market conditions, pharma companies may be unwilling to invest in the research and development of new treatments for diseases that affect fewer people than the most common forms of cancer. The figures are stark: five of the six less survivable cancers received only 17% of the research funding for more survivable cancers. By proposing that the Secretary of State will be required to review the current laws on marketing authorisations for these orphan drugs, and by placing a duty on Government to support research and innovation further, the Bill would go a long way to achieving something that many of us would view as common sense: incentivising the production of these medical products and putting them to use where they are so badly needed in the diagnosis, prevention and treatment of cancer.

I also pay tribute to my hon. Friend the Member for Edinburgh South West and his team for the work they have done to improve the power of collaboration among Members of Parliament, the charity sector and patient advocates. Drawing on medical expertise and lived experience, their diligence in bringing about the Bill is borne out by the widespread support it has gathered across the House. According to Pancreatic Cancer UK, the Bill has the potential to transform survival for rare cancers by encouraging a greater focus and drive to research, and the Brain Tumour Charity has also praised it.

I know from my own experience, talking to constituents in Hendon and visiting hospitals such as the Royal Free, just how crucial one word can be: hope. Cancer is one of the defining health issues of our time, causing the death of 460 people in this country every single day. We know there is no silver bullet. We must fight cancer on all fronts, from research to prevention to diagnosis to treatment, and I know the Government are wholly committed to doing that. Thanks to huge oncological steps forward in recent years, outlooks for cancer patients have improved dramatically. We have reached the milestone of more than 50% of people diagnosed with cancer in England and Wales now surviving their disease for 10 years or more, yet this number falls sharply for many of the rarer cancers we have talked about today. We must recognise—as this Bill does—where the shortfalls are in our shared knowledge and the resources we put into the rarer forms of this disease. We have a duty to put this right. We must ensure that those suffering from rare and less common forms of cancer, and those yet to be diagnosed, have as much cause for hope as possible. I support this Bill.

11.48 am

**Jenny Riddell-Carpenter** (Suffolk Coastal) (Lab): I start by thanking my hon. Friend the Member for Edinburgh South West (Dr Arthur) for bringing forward this important Bill. I thank the many other Members from across the House who have contributed so movingly today, and my constituents who reached out to me to share their views. I will try to keep my contribution brief, because I know others will want to speak.

In particular, I would like to thank Maria and her daughter Lauren, who told me about Maria's journey and her fight against leiomyosarcoma—I am the second person today to struggle to pronounce that word—and how that diagnosis, during the covid lockdowns, turned her life upside down. Navigating the pandemic was hard enough; navigating it while one of the people you love most in the world is suffering with cancer must have been nearly impossible.

Maria is still living with leiomyosarcoma and has chemotherapy once a month. As she and her daughter told me, living with cancer is tough enough; when it is a rare cancer, patients live with the fear that the disease will act quicker than the research makes progress. That is why this Bill is so important. We need to close the gap in the treatment so that more people diagnosed with rare cancers have the same chance of survival as those with other cancers.

Another constituent of mine knows the cost of that all too well. He has asked me not to share his or his wife's name, but instead to tell her story. She passed away last year after being diagnosed with leiomyosarcoma. Despite the best efforts of the oncology unit, the rarity of the cancer meant that it took too long to identify her condition. A year of chemotherapy followed, sadly to no avail.

Although I have two examples of leiomyosarcoma in my constituency, it is incredibly rare. One challenge of that cancer is its genetic variability and the fact that it has many different subtypes. Personalised medicine is particularly important for rare cancers with different subtypes, but because of the small number of patients with leiomyosarcoma, it is extremely difficult, if not impossible, to run robust clinical trials. Research is possible, however, and great strides are being made in the US, showing that better treatment and outcomes are possible. It is vital that we incentivise research of and investment into the treatment of rare cancers and begin to close that gap.

I thank my hon. Friend again for introducing this important debate and the Bill.

11.50 am

**Shaun Davies** (Telford) (Lab): I thank my hon. Friend the Member for Edinburgh South West (Dr Arthur) for introducing the Bill. He has channelled his personal experience, and that of his family, to produce a vital piece of legislation. I hope that he succeeds in driving change on this issue. He certainly has my support and that of all Members of the House. It is on days like this

*[Shaun Davies]*

that I call Members of Parliament from across the House my hon. Friends rather than hon. Members. This cause certainly unites us.

I know from reading emails from my Telford constituents that they are fully behind the Bill. I join my hon. Friends in paying tribute to the many people who have told the stories of loved ones in their families and communities—they are far braver than I. Next Thursday, I will be a bearer at the funeral of a woman who is very special in my life. I am not quite brave enough to tell her story today, but maybe one day I will.

I have heard about devastating impacts from a number of constituents who have contacted me to share their stories. I heard from one constituent about the mother of his three teenage children. She is in her 40s and battling terminal pancreatic cancer after a late diagnosis. Among those stories, a familiar theme arises: conditions such as pancreatic cancer are being diagnosed too late and there is no available treatment. My constituents' loved ones are given just months to live.

I focus on pancreatic cancer because it is an example of the scandal of rare cancer treatment. It is classed as a rare cancer by the Bill because it affects fewer than one person in every 2,000. Every year, one in every 6,000 people are diagnosed with pancreatic cancer, and half of them die within three months. There are roughly 107,000 people in Telford, which means that 18 of my constituents will be diagnosed with that awful cancer each and every year, and nine of them will die within three months of diagnosis. That is absolutely shocking. I owe it to those 18 people in my constituency to speak up in the Chamber and demand drastic change.

It is easy to see how this problem can arise, although that does not make it any less galling. In a healthcare system under strain that is failing cancer patients in particular—last year, UK cancer survival rates were 25 years behind some other European countries—decision-makers might be faced with a Sophie's choice: the unenviable task of prioritising cancer treatments. When resources are scarce, the treatments that will save the most people are prioritised, but that is no consolation to the 47% of patients in the UK whose cancers are rare and less common.

An even more damning statistic is that sufferers of rare and less common cancers make up the majority of cancer deaths, as we have heard—55%. Clearly, that is not sustainable, fair or just. We cannot let a single cancer patient slip through the cracks in our healthcare service, let alone 90,000 people each and every year. All too often, people in my constituency and across the country will, as we have heard, rally around to raise money for their loved ones—their children—to receive treatment. On one level, that is amazing to see, but on another, it is depressing that that has to be done in order for people to access lifesaving treatment.

The Bill is about acknowledging that we can do better. The treatment of rare cancer patients is a scandal—not in the sense that any one individual is liable or culpable, but because the system as a whole has let tens of thousands of cancer patients down. To the healthcare and research sectors, we say, "You must do better, we want you to do better, and we will work alongside you to do better." The Bill is a welcome first step in doing that. I urge the Government to be bold. This cohort of Members of Parliament and Ministers can do a lot on this agenda. We talk a lot in this place about hope and change. Well, goodness me—what better example is there than this Bill of providing hope and change to millions of people across our country? Let's make cancer history.

11.56 am

**Katrina Murray** (Cumbernauld and Kirkintilloch) (Lab): There is hardly a family in the UK who have not been touched by cancer in some way—this morning's debate has shown how much we reflect the population—and the feeling of fear, anxiety and heartbreak that comes with it. But for those diagnosed with a rare cancer, the challenges are even greater: delayed diagnosis, fewer treatment options and the shocking lack of research, which means that these patients and their families are often left in the dark. I am glad that we are united in saying that that has to change. I am so proud to support the Bill introduced by my hon. Friend the Member for Edinburgh South West (Dr Arthur)—I think I possibly worked with his father-in-law at Bell Baxter many years ago—because we now have the chance to turn the tide and focus on people with rare cancers.

We have talked a lot about the statistics. Rare cancers still do not get the same investment in research or access to clinical trials as common cancers. As a result, survival rates for some of the least survivable cancers, like pancreatic cancer, brain cancer and stomach cancer, are stuck at just 16%, which is not good enough.

Seven weeks ago, I lost my dad. More time has now passed since his death than the time we had between his diagnosis and his passing. The grief is still exceptionally raw.

**Johanna Baxter** (Paisley and Renfrewshire South) (Lab): I pay tribute to my hon. Friend's dad. He would be extremely proud of her, and of the speech that she is making.

**Katrina Murray:** I thank my hon. Friend for that intervention.

The Brain Tumour Charity and Brain Tumour Research have highlighted time and again that just 1% of national cancer research funding goes towards brain tumours, despite their being the biggest cancer killer of children and adults under 40. That is totally unacceptable. People who are dealing with these devastating diagnoses need more than words; they need real investment in clinical trials and better pathways to diagnosis. The Bill is about fairness—it is about tackling the lack of funding, the difficulty in getting patients into research, and the absence of clear Government leadership in this area.

People miss out on life-changing trials because they simply do not know that they exist. My hon. Friend the Member for Mitcham and Morden (Dame Siobhain McDonagh) talked about having a universal system in this country. We also have one of the most siloed systems. People in one part of the system often do not know what is going on in other parts, and we need that to stop. We have talked a lot about the approaches in places like the United States, where targeted policies have led to surges in new treatments for rare cancers. But we also need to recognise what else is going on in

the United States: a raft of Executive orders from the White House is putting higher education and current clinical trials into a tailspin.

I want to pay tribute to the people who have helped me a lot over the last few weeks, in particular my hon. Friend the Member for Mitcham and Morden. She talks about being angry. I just remember that anger is a natural stage of grief, but it is also a massive driver for change and for getting things done. I am not at the angry stage just yet, but I will be at some point, and when I get there I will certainly be joining my hon. Friend; it is something we all get.

Somebody said to me many years ago that the greatest gift that any of us can give is the gift of time. No matter our political differences on other things, we have a chance today to give others the gift of time and to make sure no other families have to experience what we have had to go through. Please pass this Bill. Thank you.

12.1 pm

**Paulette Hamilton** (Birmingham Erdington) (Lab): I thank my hon. Friend the Member for Edinburgh South West (Dr Arthur) for bringing forward this important Bill and for his tireless work in championing the need for a greater focus on research into rarer cancers. Having worked as a district nurse for over 25 years, I have seen time and again the devastation cancer brings, not just to those diagnosed but to their families, friends and communities. The harsh reality is that one in two of us will face cancer at some point in our lives; it is an issue that touches all of us in some way.

While we have made significant strides in cancer treatment and survival rates, progress has not been equal. Some cancers, like the rarer, less survivable cancers, have been unjustly left behind. Cancers such as pancreatic, oesophageal, liver, brain and stomach still face staggeringly low survival rates. Currently, the least survivable cancers have a five-year survival rate of just 16%, compared with 55% for all other cancers. This disparity is not just a statistic; it is a failure in our services and the way these cancers are researched, which has cost lives, shattered families and left too many of us without hope.

A key driver of this has been the chronic underfunding and lack of focus on research into these cancers, which has meant that we lack tests and the tools and treatments needed to give people a fighting chance. The consequences of this neglect are devastating.

This issue is deeply personal to me. I have lost loved ones to pancreatic cancer, a disease that steals lives with ruthless efficiency. I lost my best friend, a woman full of life and love, to this cruel illness. She endured months of uncertainty before finally receiving a diagnosis in August, only to pass away shortly after. Her story is of delayed diagnosis, missed opportunities and a system that failed her. Sadly, her story is not unique. I find it truly shocking that in 2025, more than half of those diagnosed with pancreatic cancer will die within three months and only 7% will survive.

Pancreatic cancer is the fifth biggest cancer killer in the UK but receives only 3% of the UK cancer research budget. This lack of investment has meant we are not seeing the treatment breakthroughs that have transformed outcomes for other types of cancer. It does not have to be this way. We know that sustained research funding and strategic focus from the Government can dramatically improve survival rates—we have seen it work for other cancers. I particularly welcome the Bill's proposal to nominate a named lead to focus on these rarer cancers, ensuring that they are no longer overlooked, as well as its provisions to give people a better opportunity to take part in innovative, cutting-edge trials. That is why I support the Bill.

The Rare Cancers Bill offers a road map to bring real-life, lifesaving changes to those diagnosed with life-threatening diseases. It is not just about policy, but about people; it is about giving hope to those who have been left behind. As chair of the all-party parliamentary group on the less survivable cancers and vice-chair of the Health and Social Care Committee, I firmly believe that through the provisions of this Bill, we can start—I say start—to bring forward access to innovative treatments that could turn the tide. I say to Members of this House, "Let us be bold. Let us make a difference. Let us ensure that future generations have a better chance of survival than those who came before them. Let us send a clear message to patients and their families that they are not forgotten. This is our moment to make a lasting impact—let us make it count. Let us support this Bill."

12.6 pm

**Daniel Francis** (Bexleyheath and Crayford) (Lab): I pay tribute to my hon. Friend the Member for Edinburgh South West (Dr Arthur) for introducing the Bill and for his work in bringing about this necessary debate on rare cancers. I also pay tribute to all Members who have spoken today, but particularly to my hon. Friend the Member for Calder Valley (Josh Fenton-Glynn) for his heartbreaking tribute to his brother.

Like too many across this House and throughout the United Kingdom, I have been on the receiving end of the devastating news that a loved one has been diagnosed with cancer, but when that cancer is defined as rare, it is infinitely more terrifying, when confronted with the reality that there is a lack of funding and research dedicated to those cancers. I therefore welcome the three steps in the Bill to encourage further research into rare cancers. I welcome the fact that it will place a duty on the Secretary of State for Health and Social Care to facilitate or otherwise promote research into rare cancers. The Bill will ensure that appropriate arrangements are in place for patients to be easily contacted about research opportunities and clinical trials, and will also ensure that there is adequate oversight of research delivery for rare cancers.

I also pay tribute to my hon. Friend the Member for Mitcham and Morden (Dame Siobhain McDonagh) for her dedication in bringing glioblastoma and other types of brain cancer to the forefront of the political debate. I would like to mention the all-party parliamentary group on brain tumours and its work to raise awareness of the issues facing the brain tumour community. I have seen at first hand how devastating glioblastoma can be: my dear friends and constituents, Ann and Richard Lucas, lost their son Fionn in 2022. Fionn was diagnosed with glioblastoma aged 58 in June 2022, and his cancer left him with a very short time to live—he died two months later. The Lucas family has supported the work of the Brain Tumour Charity to help find new treatments, offer the highest level of support and drive urgent change, given the charity's aims of saving and improving lives and carrying out research into brain tumours globally.

*[Daniel Francis]*

Glioblastomas are fast-growing brain tumours. They are the most common type of cancerous malignant brain tumour in adults, yet as has been said, there is still a lack of funding. Of the 54% of research that is specifically about rare cancers, only 16% is focused on brain and nervous system cancers. I therefore welcome this Bill, thank my hon. Friends the Members for Edinburgh South West and for Mitcham and Morden, and place on record my support for the aims of the Bill—to support research, and to support those impacted by rare cancers.

12.9 pm

**Sarah Smith** (Hyndburn) (Lab): I will try to keep my remarks brief as I am keen that other colleagues get to speak in this important debate. As we have heard, rare cancers are defined as those that affect fewer than one in 2,000 individuals; in Hyndburn, that equates to an estimated 1,500 people being impacted. Behind every number is a story, as we have heard, of a patient and those who love them, of lives cut short that could have been saved or prolonged had the right diagnosis and treatment been available.

I want to spend a few minutes speaking about constituents in Hyndburn who have reached out to me and about some of my personal experience. I am grateful to Carol who reached out on behalf of herself and her daughter Emma, who is battling a rare cancer and is the mum of two girls. Every day, and every advancement, could be transformational for that family. I thank Janet, who lost her granddaughter Elizabeth, for also reaching out. Elizabeth was a real fighter; she raised over £100,000 before she died, and she left her body to research, demonstrating what individuals are doing in this fight. It is now the Government's turn to step in and meet what has already been put in by families and communities.

I want to thank Sheila, who sadly lost her sister Margaret and her father-in-law to pancreatic cancer. I also want to mention Milly, the incredible young girl who died of leukaemia when she was just 11 years old, not 18 months after being diagnosed. Her mother Lorraine always reminds me to talk about Milly's life and what she brought while she was with us. She should have turned 16 last year, but she was the girl with the brightest smile who took on life and everything it threw at her and who was brave to the last. We owe it to the memory of Milly and her mum's incredible work with their charity Milly's Smiles, to do all we can to tackle this in future and to take action today.

When I was in my late 20s, one of my best friends lost both her mother and her sister within a year, one to melanoma and the other to ovarian cancer. The reality is that if they had been living in America, for at least one of them, if not both, we would have had more time. That is not good enough; I refuse to accept that, and today we can take steps to ensure that people like my friend do not have to be left literally with none of their family and can have that precious time, however long that might be, because every day, week and birthday really counts.

The Rare Cancers Bill represents a comprehensive approach to addressing the disparities faced by individuals with rare cancers. By revising the regulatory frameworks, promoting dedicated research and facilitating patient participation in clinical trials, this legislation has the potential to transform the landscape of rare cancer treatment in the UK. I am glad that this Labour Government are supporting the Bill as part of the development of the desperately needed national cancer plan, recognising that the provisions of the Bill are a crucial step towards equity and excellence in cancer care for all patients, regardless of the rarity of their diagnosis.

12.12 pm

**John Slinger** (Rugby) (Lab): I commend my hon. Friend the Member for Edinburgh South West (Dr Arthur) on bringing forward his important Bill. I also commend hon. Members across this House for their powerful and moving speeches, particularly those of my hon. Friends the Members for Calder Valley (Josh Fenton-Glynn), for Mitcham and Morden (Dame Siobhain McDonagh) and for Cumbernauld and Kirkintilloch (Katrina Murray), who showed that the love for a sibling or child persists forever and can be harnessed to bring about change.

I am speaking today because my constituent Mr Peter Realf contacted me about his son Stephen, who was training to be an RAF pilot when he was diagnosed with astrocytoma. He was just 19. Tragically, despite his cancer being described as "low-grade" and despite receiving treatment that prolonged his life, he died six years later, aged just 26. I cannot imagine the pain and sense of loss felt by Stephen's family and friends, and my heart goes out to them and all those who have faced the consequences of this cruel disease.

Mr Realf and his family have campaigned tirelessly since Stephen's death to address the baffling paradox that despite brain tumours killing more children and adults under 40 than any other cancer, and despite them robbing patients of more years of their life than any other cancer, only a fraction of the Government's research funding into cancer is used for brain tumours at just 1.37% of national spend, according to the charity Brain Tumour Research.

Stephen Realf's case is stark: a talented, hard-working and clearly impressive young man who died young, losing perhaps 50 years of life and 50 years of potential. A huge public petition and an article written by Stephen's sister Maria led in 2015 to the then-new Petitions Committee of this House conducting its first inquiry. I challenge any right hon. and hon. Member to read the report's conclusions from 2016—nine years ago—and not to conclude that, in general, little has improved since then.

We should be deeply concerned—though perhaps, as my hon. Friend the Member for Mitcham and Morden has indicated, the appropriate emotion is a stronger one. We hear of the additional £40 million pledged by the last Government and how, according to reports, £28 million of it is yet to be released to scientists. After one of the relevant authorities, the National Institute for Health and Care Research, came to see us at the all-party parliamentary group on brain tumours recently, my colleagues and the campaigners, patients and families present still could not fathom just why the money had not been spent in all those years.

I am relatively new to this place, but I have been observing politics for a long time, and something about this issue does not fit. It does not feel right. Something is profoundly wrong. Where there should be outrage,

there appears to be relative indifference—not to death and suffering, of course, but to the need for radical changes to get money flowing. Where there should be urgency among the authorities—for, after all, people are dying, often young—there appears to be a degree of inertia, and where there should be action, we often get lost in the chilling snowstorm of bureaucracy.

I am not impugning the decency, compassion or professionalism of officials, researchers or clinicians; they are of course committed to helping to cure, treat and prevent cancer. However, as with other examples of institutional failure, it does not take overt malice, just the absence of grip and tenacity in the face of injustice, or of challenging the status quo, for good things not to happen, or even for bad and preventable outcomes to occur.

I do not know why progress does not seem to be happening. What reasons could there possibly be for the continuing paradox of the underfunding of rare cancer research? We must find out the reasons and overcome those forces, or perhaps even vested interests, because the stakes could not be higher. Little has changed in terms of treatment and survivability since the 1960s. Patients with brain tumours do not have time on their side, as many hon. Members have said; sadly, most of those diagnosed die within five years.

The following statistics from Brain Tumour Research are stark, but, before I read them, I should say that I am glad of the progress on more common cancers, which have affected my family as they have every family. Brain Tumour Research states:

> "Brain tumours kill more children than leukaemia. Brain tumours kill more men under 70 than prostate cancer and more women under 35 than breast cancer. Incidences of and deaths from brain tumours are increasing… At the current rate of spending, it could take 100 years for brain cancer to catch up with developments in other diseases and find a cure."

That is why the Bill introduced by my hon. Friend the Member for Edinburgh South West is so needed. It offers practical steps to get more funding into research to take on and defeat those cancers.

Finally, I know my ministerial colleagues want only the best for patients, so I gently encourage them, if they have not already done so, to ask this question of officials: "Why is it that research into these cancers, which cause so much death and suffering among the young and rob so many people of so many years of life, are receiving so little funding?" Ministers should keep asking until they get a satisfactory answer. MPs should keep asking until we get a satisfactory answer. We should work together, cross-party if possible, to overcome obstacles and we should certainly pass this Bill. The pain, loss, concern and even anger must be channelled into urgent, substantive action. We owe it to the past, current and future victims of rare cancers and to their families.

12.19 pm

**Patricia Ferguson** (Glasgow West) (Lab): I thank my hon. Friend the Member for Edinburgh South West (Dr Arthur) for bringing forward this Bill. If, as we always say, politics is the language of priorities, then my hon. Friend has got his absolutely correct. I thank all Members who have shared their experiences and their stories, some incredibly moving. They should be what inspires us to take forward all the action we are proposing today.

I was struck by the fact that the hon. Member for Wokingham (Clive Jones) and I have something in common, which we probably would not want to have in common, in that we were both diagnosed with breast cancer in 2008. I have to say, my breast cancer was a strange breast cancer, and it always feels slightly strange talking about it, because no one's ever heard of it. It is not a rare cancer as such, because it is a breast cancer, although there are some who argue it is actually a soft tissue sarcoma—whatever, it was treated as a breast cancer. It is called a phyllodes tumour.

Unlike other breast tumours, phyllodes tumours do not go into the ducts, but into the connective tissue. It presents differently from other cancers of the breast, and the treatment is also different, in that the only treatment that works is excision. Excision can be anything from a lumpectomy to a mastectomy. The hope is that there are clear margins, which mean the patient will be okay, but—and it is a big "but"—when a malignant phyllodes tumour is present, it can spread, and it can be difficult or impossible to treat. That is when it becomes a very different outcome.

I mention it today not because it is a rare cancer, but because it can be difficult to diagnose. It does not show up in a mammogram, for example, and there is no definitive explanation why such tumours occur. Some research is going on just now, but it is not conclusive as yet. A lot more work needs to happen, and because incidence is so low, it is difficult to research. The things we know about it for certain seem random to me. They tend to occur more often in the left breast. Why? I have no idea. They usually occur when a patient is in their 40s. As I have said, they do not seem to respond to chemo or radiotherapy, and they are not thought to be genetic or hormonal.

The reason I mention my case is that it can be a lonely thing to have an unusual cancer. When trying to explain it to family and friends, you say, "No, it did not show up in a mammogram. No, I am not getting chemotherapy or radiotherapy. No, I do not know why it happened. No, I had not heard of it either." You begin to doubt yourself a little, and you begin to question what is actually going on. For someone with a very rare cancer, it must be incredibly difficult when there is not a background of research, not anything that they can read, and no one can give them a pamphlet about it and tell them what is happening.

It seems to me that we should know more about cancer full stop. We have got to 2025, and we know some things about cancer. We know how to treat some cancers, but there are so many others that we do not have the answer for. We need people to be diagnosed more quickly, which means that we have to have the research. We need people to have the best possible treatment, which means we have to look at the drugs and find out what works and what does not work, and where a drug can be transferred from one thing to another successfully. Crucially, we have to know why it is that some people get cancer and others do not.

This Bill will make a huge difference to the lives of some of the people we have heard about today. For some, as we know, it will not be soon enough. It is the responsibility of every single one of us to make change happen, and we have an opportunity today to take that step forward. My hon. Friend the Member for Mitcham and Morden (Dame Siobhain McDonagh) spoke about

*[Patricia Ferguson]*

her sister, Margaret, who I worked with for a time in the Labour party. While I was listening to the other speeches, I was reflecting on what my hon. Friend said. I think we all need to be angry. We need to say—to shout it from the rooftops—that change begins today.

**Madam Deputy Speaker (Ms Nusrat Ghani):** That was very powerful. I call Leigh Ingham.

12.25 pm

**Leigh Ingham** (Stafford) (Lab): I am proud to share the Benches with all the hon. Members here. The advocacy that we have heard has been incredibly moving. My constituents Rosalind, Rob, Mark and Michelle asked me to speak today; they support the Bill, as do I.

Patients with rare cancers face incredible challenges, including delayed diagnoses, limited treatment options and a lack of research investment that often leaves them feeling forgotten. This Bill will change that narrative. It is a call to action for greater investment, better access to clinical trials and a stronger commitment to research that will ultimately save lives. Barriers and bureaucracy must not stand in the way of innovation. That is why I support the measures in the Bill that call for a comprehensive review of how we approve treatment for rare cancers. My hon. Friend the Member for Mitcham and Morden (Dame Siobhain McDonagh) said that more powerfully than I ever will.

The Bill is about fairness, dignity and hope. It has significant support from hon. Members across the House, not just as politicians but as people who understand the value of every life. I hope that we all get to vote for it today.

12.26 pm

**Tracy Gilbert** (Edinburgh North and Leith) (Lab): I thank all hon. Members for their moving, passionate and powerful speeches. I congratulate my hon. Friend the Member for Edinburgh South West (Dr Arthur) on bringing forward the Bill and on the work he has done with so many stakeholders. I commend him on sharing the story of his father-in-law, who will be sadly missed by him and his family.

The story of my hon. Friend's father-in-law has prompted a significant number of my constituents in Edinburgh North and Leith who are advocates for the Bill to share their stories. A constituent told me about their friend, who passed away aged 45 in November 2023. They were diagnosed with two rare cancers. On each occasion, they were informed by their doctor that it was a cancer that they did not know how to treat. My constituent's friend tragically died unable to understand why more was not known about those rare cancers, despite the large amount of money that has been put into research and the wins achieved in cancer care and treatment by scientists and medics over the past few decades.

In Edinburgh, many cancer patients are treated at the Edinburgh Cancer Research Centre at the Western general hospital, which borders my Edinburgh North and Leith constituency. Established in 2022, the Cancer Research UK Scotland centre brings together the very best in cancer research from Edinburgh and Glasgow, working with over 80 teams. The centre has established processes, and has access to two of the largest cancer treatment centres in Scotland, making trials and research more efficient. One of the centre's six research themes is mesothelioma, a rare cancer that affects the lining of the lungs, abdomen or heart. I am keen to hear from my hon. Friend the Member for Edinburgh South West about his engagement with the University of Edinburgh and the Edinburgh Cancer Research Centre on the Bill.

The Bill crosses devolved and reserved areas. I believe in pooling and sharing resources. Just as profit should not be a barrier to research, neither should the border at Gretna. I am keen to hear from my hon. Friend or the Minister about any discussions that have taken place with the Scottish Government and other devolved Administrations to ensure that we work across the UK, and use the research talent of the University of Edinburgh and others across the UK. We need a joined-up approach to make breakthroughs on the treatment and care of those with rare cancers. Has there been dialogue with Ministers in Scotland and other devolved Ministers on clauses 2 and 3? Have devolved Ministers given any undertakings to replicate the proposals?

In conclusion, the Bill will make a difference to our constituents, and I am delighted to speak in support of it. My mum Violet died two decades ago within six weeks of her cancer being diagnosed. I hope that the Bill will give hope and time to every family impacted by a cancer diagnosis.

12.29 pm

**Juliet Campbell** (Broxtowe) (Lab): I thank my hon. Friend the Member for Edinburgh South West (Dr Arthur) for introducing the Bill. Many of my constituents have shared with me their experiences of rare cancer, and the experiences of their families and friends. Rare cancers make up almost half of cancer diagnoses, so the Bill is very much welcome.

A constituent wrote to me recently about their seven-year-old son, who was diagnosed with medulloblastoma, a rare form of brain cancer. Sadly, their son did not survive, despite that cancer having a 75% survival rate. Medulloblastoma is on a spectrum of high to low risk, which further complicates ability to predict the outcome of treatment. I am here to represent that child, their family and other families affected by rare cancers. I welcome the increase in research, funding and support for early detection and diagnosis. I welcome the introduction of the Bill and wholeheartedly support it.

12.30 pm

**Johanna Baxter** (Paisley and Renfrewshire South) (Lab): I will be brief, because I understand that we are at the end of the debate, but I rise to support the Bill and pay tribute to my hon. Friend the Member for Edinburgh South West (Dr Arthur) for bringing it forward, and for the dignified, collegiate manner in which he has gone about things. Up to 95 people in Paisley and Renfrewshire South will be facing a less survivable cancer. That is 95 people who will wait longer for a diagnosis, will face a postcode lottery to access specialist treatment, and will be left asking why there are so few treatment options available.

The truth is that rare cancers do not receive the research attention or funding that they need. The Bill would take decisive action to change that. It would

introduce measures to break down systemic barriers preventing research and innovation in rare cancers. These are not abstract policy changes but lifesaving reforms that would give patients with rare cancers greater access to clinical trials. Researchers would have better tools to study the diseases, and pharmaceutical companies would be given stronger incentives to invest in treatments that could transform lives.

Behind every rare cancer diagnosis is a person fighting for their future, a family searching for answers and healthcare professionals looking for better treatment options. We cannot allow those individuals to be left behind simply because their condition is considered rare. We have the opportunity to change that. By supporting the Bill, we send a clear message that no cancer is too rare to matter, and that no patient should be forgotten. I am proud to support the Bill and thank my hon. Friend for bringing it forward.

**Madam Deputy Speaker (Ms Nusrat Ghani):** I call the shadow Secretary of State.

12.32 pm

**Edward Argar** (Melton and Syston) (Con): May I start by extending to the hon. Member for Cumbernauld and Kirkintilloch (Katrina Murray) and her family my sincere condolences on the passing of her father?

This is an important Bill. I often say to constituents, "If you wish to see the House of Commons at its best, tune in and watch on a Friday." I say that again today, having heard the debate. It is it is rare for a shadow Secretary of State to take to the Front Bench on a Friday to respond on a private Member's Bill, but the debate has reinforced my determination to be here.

As the hon. Member for Bootle (Peter Dowd) said—I like to call him my hon. Friend—this is a Bill of hope. I pay tribute to the hon. Member for Edinburgh South West (Dr Arthur) for his clear and compelling articulation of the case for the Bill, and for being willing to share something as personal as the loss of his father-in-law and his family's circumstances. He spoke about that with great dignity.

With a debate of such quality, it is always invidious to pick out contributions, but I cannot resist doing so. I have to pick up the contribution of the hon. Member for Mitcham and Morden (Dame Siobhain McDonagh). When I was a Minister, we often worked with each other and spoke on matters relating to health, although not this subject. Her passion, determination and energy for change and for something better comes across in everything she does, and that builds on the fact that this is a Bill for hope. I pay tribute to her for her work and her dedication.

I have been a Member of this House for 10 years, and before the election I was a Minister for six. Two and a half of those years were spent as a Minister in the Department of Health and Social Care during the pandemic, in times that were challenging for everyone, but I have to say that I have rarely heard a speech as powerful and moving, or that held the House so completely, as that of the hon. Member for Calder Valley (Josh Fenton-Glynn). Although I did not know his brother, I suspect that he would have been deeply proud of the hon. Member today.

"Rare" in this context is often a misnomer, because although individually these cancers are rare, collectively they are sadly all too prevalent. As we have heard from hon. Members, approximately 55% of all cancer deaths are down to so-called rare cancers. The breadth of those rare cancers is huge: they include blood cancers, cancers of the female reproductive organs, head and neck cancers, pancreatic cancer, brain cancer—the hon. Member for Mitcham and Morden spoke about glioblastomas—and, importantly, children and young people's cancers, which the hon. Member for Esher and Walton (Monica Harding) spoke about.

We have all seen the amazing work by powerful campaigners on these issues and by the huge array of charities campaigning in this space: Cancer52, the Brain Tumour Charity, the Tessa Jowell Brain Cancer Mission, Leukaemia UK, Pancreatic Cancer UK and a whole range of other dedicated and amazing institutions. They do a fantastic job. Like other hon. Members, I recently met Pancreatic Cancer UK to hear about its work; the hon. Member for Birmingham Erdington (Paulette Hamilton) may well have done the same. Initially, it was to discuss pancreatic enzyme replacement therapy drug shortages and the urgent need for some sort of solution, but we also had the opportunity to talk more broadly about pancreatic cancer and rare cancers.

Pancreatic Cancer UK highlighted issues that are specific to pancreatic cancer but that I suspect are reflective of many rare cancers: the challenge of diagnosis, the challenges posed by late diagnosis, the reliance on a single therapeutic or a small number of therapeutics with complex supply chains, and the challenges of clinical trials. Sadly, so few people with pancreatic cancer, even when they are able to enlist on such trials, survive long enough to provide the data that will make a real difference. The Bill will help to address that.

Because each rare cancer is different, each rare cancer needs focused research and treatment. The hon. Member for Bootle set out clearly the orphan drugs regime for rare cancers. Yes, there are incentives; under the 2021 regulations it is possible to incentivise pharmaceutical companies that may not be inclined to invest in research in areas that may benefit only a few, in comparison with the large numbers affected by other cancers. The regime seeks to give market exclusivity rights for 10 years, helping to reduce the costs of market authorisation, but we have to ask the question that the Bill asks: is it actually doing the job it needs to do to genuinely incentivise companies to invest in research in this space?

The hon. Member for Mitcham and Morden mentioned the NHS repurposing project. If we make it work effectively, it will be a very practical way in which, while we wait for specialist research to come through, we can still do something. I believe that the Bill goes a long way towards addressing the issues. The review of the orphan drugs regime, particularly the international angle, is hugely important. I welcome all the provisions in the Bill, especially those on the specialist registry and on the sharing of information to get more people into trials. As with any Bill, there are some things that I believe would benefit from further explanation, but that is what Committee is for. As shadow Secretary of State, I am happy to confirm that the hon. Member for Edinburgh South West has our support for the passage of his Bill through Second Reading and into Committee.

*[Edward Argar]*

In this place and in life, there is a time to act. I believe that this is it. We have huge potential and huge talent in this country. Let us help focus that on saving more lives and giving more precious time to more people. I am pleased and proud to offer my support to the hon. Gentleman for the passage of his Bill.

12.41 pm

**The Parliamentary Under-Secretary of State for Health and Social Care (Ashley Dalton):** First, let me say how sorry I was to hear that my hon. Friend the Member for Edinburgh South West (Dr Arthur) recently lost his father-in-law to glioblastoma. I congratulate him on introducing this legislation less than a year after his election. His wife and children will be immensely proud to see him in the Chamber today. He has the full support of many charities, such as Pancreatic Cancer UK, the Brain Tumour Charity and Cancer Research UK, as well as people up and down the country who have written to their MP urging them to join this debate and vote for the Bill.

I also pay tribute to all those right hon. and hon. Members who have lost loved ones and remembered them so powerfully today. I thank them for the courage that they have shown in sharing their stories. Particularly, I do not think that anyone in this Chamber or watching from the Gallery or beyond could have failed to be moved by the powerful stories from my hon. Friends the Members for Calder Valley (Josh Fenton-Glynn), for Cumbernauld and Kirkintilloch (Katrina Murray) and for Mitcham and Morden (Dame Siobhain McDonagh), to whom I give particular thanks for her tireless campaigning on glioblastoma following the untimely loss of her sister Margaret.

I also pay tribute to those who remembered their constituents. I am delighted that very soon I will be meeting my hon. Friend the Member for Hyndburn (Sarah Smith) and Lorraine to discuss Milly's Smiles. Let me take the opportunity to add my memories of Joe Chilcott, the son of my friends Tim and Verity and sister to Ellie, who was diagnosed with a brain tumour at the age of 10. It was heartbreaking to lose him when he was just 18.

I thank all the hon. Members who have spoken today. I will seek to address as many of the issues raised as possible. There were so many stories. I recognise the people who were remembered in those stories, those in the Gallery, and the many more watching at home. They are willing the Bill to succeed. On behalf of the Government, it is my great pleasure to pledge our support for the Bill. We are undertaking fundamental reform of the NHS. People living with rare cancers must be at the heart of that change. Rare cancer patients deserve better, and the Bill gives them something that has been spoken about across the House today: new hope.

Let me begin my remarks on what the Bill will do, why we support it and our policy on rare cancers more generally. Clinical research is one of the most important ways in which we can improve healthcare, by identifying the best way to prevent, diagnose and treat cancer. The Bill will encourage the placement of clinical trials for rare cancer in England, by ensuring that the patient population can easily be contacted by researchers, streamlining the recruitment process. It will also ensure a Government review of regulations relevant to orphan drug designation, to ensure that they continue to deliver for patients. Innovations in the Bill will complement the radical actions that we are developing through the 10-year health plan and the national cancer plan to fix the NHS, on which I will expand later.

Research is a key part of this effort, which is why the Department of Health and Social Care, through the National Institute for Health and Care Research, invests more than £1.6 billion a year in health research. In 2023-24, the NIHR invested £133 million in cancer research. As we have heard, rare brain cancers such as glioblastoma have a devastating impact on people and their loved ones. That is why the NIHR announced in September 2024 a new package of funding opportunities for brain cancer research, and established in December a new national brain tumour research consortium, bringing together researchers from a wide range of different disciplines. That is in parallel with a dedicated funding call for research into wraparound care and the rehabilitation and quality of life of patients with brain tumours. We remain committed to accelerating new breakthroughs in high-quality research to drive improvement in the diagnosis, management and treatment of brain and other rare cancers, for better survival rates and patient outcomes.

The hon. Member for Esher and Walton (Monica Harding), my hon. Friend the Member for Mitcham and Morden and others asked how the £40 million promised for brain tumours has been spent. In the five years since 2018-19, the NIHR has invested £11.3 million directly in brain cancer, with a further £31.5 million to enable brain tumour research in 227 studies involving 8,500 people. The commitment remains in place. I can confirm that there is no upper limit on that funding. We are exploring additional research policy options to encourage more clinical trials in early phase research and the development of medical devices and diagnostics.

We have also talked a lot about other rare cancers, including lobular breast cancer, for which we are supporting research through the research infrastructure, including biomedical research centres. We welcome further funding applications for research on all conditions, including lobular breast cancer. We continue to consider whether abbreviated forms of breast magnetic resonance imagining —fast MRI—can detect breast cancers that are missed by screening through mammography, such as lobular and the other types of breast cancers that have been mentioned. We are also supporting the opening of 171 studies on blood cancer, providing an online registry called "Be Part of Research", which allows users to search for and participate in studies relevant to them.

Clinical trials are a crucial part of cancer research. They provide patients with early access to groundbreaking and possibly lifesaving treatments. The measures in the Bill align strongly with our commitment to that, and aim to streamline clinical trial recruitment processes. My hon. Friend the Member for Mitcham and Morden spoke passionately about how long it takes trusts to negotiate contracts. We recognise that issue and are beginning to make progress. NHS commercial contracting has been standardised, and the national contract value review has reduced study set-up times by 36%, from 305 days to 194 days in the first 12 months' analysis. We continue in that work.

The hon. Member for Wokingham (Clive Jones) and my hon. Friend the Member for Bootle (Peter Dowd) asked how we are working across borders. We are taking forward the most significant reform of UK clinical trial regulations in over 20 years, while maintaining robust protections and safeguarding for clinical trial participants. The MHRA already authorises cross-border clinical trials, including those conducted in the EU and on UK-based trial sites. The "Be Part of Research" programme uses information from national and international sources.

My hon. Friend the Member for Mitcham and Morden spoke so passionately—we have all commented on her passion and anger. I appreciate her frustration and share her desire for radical action. I think we can all agree that the Government's announcement yesterday on scrapping NHS England demonstrates our willingness to be bold, take risks and do things differently.

Members raised several other matters. I will come back to them all with more detailed information on those issues, but I do not have the time to do so today. I will address the national cancer plan, however, which was raised a number of times. It is really important to fulfil our goal of transforming cancer care, and we will not just cherry-pick the most common cancers; we need a rising tide that will lift all ships. As a person who is living with an incurable cancer myself, I cannot overstate how deeply I feel the honour and responsibility of being asked to drive forward our work in creating the national cancer plan—it is my absolute honour. But while we take strides to fix cancer services, I am under no illusion that the Government or I hold all the answers, so my plea is for hon. Members to work with us and share their expertise. I ask them please to visit "Shaping the national cancer plan" on the Department's website and to contribute evidence.

The Government are committed to making a real difference for patients with rare cancers. For those affected by this devastating disease, every discovery, every treatment and every moment matters. We will do all we can to facilitate the passage of this Bill here and in the other place.

12.50 pm

**Dr Arthur:** With the leave of the House, I would like to thank a few people. First and foremost, I thank the Minister for her speech. I met her yesterday, and she was filled with genuine passion, energy and excitement for this subject. It is great to see her come here today and use her power to support this Bill, and let us hope that it passes.

I thank the shadow Secretary of State, the right hon. Member for Melton and Syston (Edward Argar). Before this debate, people told me that he was respected across the House, and he has shown why. I must also thank my hon. Friend the Member for Crawley (Peter Lamb). People in the Gallery will not know this, but he has worked really effectively, right throughout the debate, to ensure that all the people who wanted to speak could do so. I thank him for that.

I thank the Whips and the Speaker's Office for managing the debate sensitively, because this is quite a difficult subject, and I thank you, Madam Deputy Speaker, because it was you who pulled my ping-pong ball from the goldfish bowl. It was very skilfully done.

I wish I had time to thank everybody who spoke in the debate. Sadly, I do not, but they have my thanks and respect. They have done a great job of thanking each other as the debate has proceeded, so I thank them all. I will watch the debate again over the weekend, because it has been quite incredible and quite moving.

I thank our colleagues from the Department of Health and Social Care, who are in the officials' box. They have been fantastic. Without them, this Bill would not have happened. Privately, there have been a few Sir Humphrey moments, but those from the Department have been absolutely fantastic, and that was very clear yesterday when I met the Minister.

I thank the charities that backed the Bill. They did not just back it; they helped get it to where it is. They were not just backing a finished product; they influenced and shaped it. I think that is why so many people are here to support it.

I thank the staff in the Public Bill Office for their patience and so much more, and I thank the staff in my office. I think Noel and Solomon are here today, but it is a team effort. Back in Edinburgh are Lucie, Salim, Xavier, Evie and Hannah. [Hon. Members: "Hear, hear."] They deserve that.

In all the contributions today, we have heard evidence that people with a rare cancer diagnosis face great injustice, because their chances are so much slimmer and they face so much uncertainty. We have shown that we want change. We are not just being angry; we are using that anger to get even, which is really important. We talk in this Chamber, but often there is no action. Today we have talked and agreed, and hopefully there is going to be action.

**Madam Deputy Speaker (Ms Nusrat Ghani):** That was most definitely Parliament at its best.

*Question put and agreed to.*

*Bill accordingly read a Second time; to stand committed to a Public Bill Committee (Standing Order No. 63).*

# Free School Meals (Automatic Registration of Eligible Children) Bill

*Second Reading*

12.54 pm

**Peter Lamb** (Crawley) (Lab): I beg to move, That the Bill be now read a Second time.

I am very grateful for my good fortune in having the chance to introduce a Bill in my first year as a Member of this House and to seek to address, in part, one of my greatest policy concerns: childhood poverty. The previous Labour Government made reducing child poverty one of their most significant missions in office, and research by the Institute for Fiscal Studies has demonstrated that without the changes they made to benefits, child poverty would have increased by more than a quarter by 2010—instead, it fell by more than a quarter. It was a remarkable achievement under the circumstances.

Unfortunately, the actions of the Conservatives in the years since have reversed much of that good work. Today, in one of the wealthiest countries in the world, almost a third of our children—innocents who have no control whatsoever over their personal circumstances—are living in poverty. Harold Wilson famously said that the Labour party is

"a moral crusade or it is nothing."

If this Government are to be judged on anything over the next five years, let it be how they treat the most vulnerable members of our society.

Like many Members of my party, I have found the decision not to immediately lift the two-child benefit cap extremely painful. We do not need further reports on how this policy was one of the most significant drivers of child poverty under the previous Government; at this point, I do not believe the bookshelves of the House of Commons Library could support any more evidence, were it to be submitted. However, I do accept that £3.2 billion cannot simply be found overnight. If we are serious about ending childhood poverty, we need to consider all the issues in the round, and the child poverty taskforce is a vital part of ensuring that limited public money is used most effectively to address this crisis.

What can we do here today, while we await the findings of the taskforce, to try to improve the conditions of children living in poverty? Members will be aware that private Member's Bills cannot authorise new expenditure, and I do not seek to challenge that. This Bill seeks simply to ensure that the children whom this House has already stated should receive free school meals receive them automatically, unless their parents actively opt out of the system. It will not require a penny more in expenditure than is necessary to fulfil the social contract that generations of Parliaments have sustained with our poorest children.

The requirement to qualify for free school meals is a combined household income of £7,400 or less—an income of roughly half the average rent in my constituency. I find it hard to believe that it is possible to sustain a household on such a low income. It is these children the Bill seeks to support. The stories we hear of child poverty are heartbreaking, not only because of the hunger and the impact on children's performance at school, but because of the stigma, with stories of children pretending to bring food out of their bags so that they can fit in with their friends at school, even when there is nothing available.

**Shaun Davies** (Telford) (Lab): Us former council leaders have to stick together. I pay tribute to my hon. Friend for bringing forward this Bill. As I mentioned in my maiden speech, I was a recipient of free school meals myself. I remember that stigma; I remember getting a blue ticket when I went to get lunch with my friends, while they got a yellow one. The stigma is still with me today. It runs very deep in me. Does he agree that the Government's child poverty taskforce has to consider everything in the round? We should welcome the Government's announcements on free breakfast clubs and the roll-out of the trial of those clubs. Does he also agree that we need to see urgency from the Government and the Minister, as I am sure we will, to address this issue and to take a systematic look at families and children in poverty?

**Peter Lamb:** I absolutely agree. I am very grateful to my hon. Friend for his intervention. The Government are doing a lot to try to address this issue, but that is not to say that we cannot do more. We hear those stories of stigma, with children pretending to bring food out of their bags so that they do not miss out or so that they fit in, even if they do not have the actual food. We should be glad that over the years since, the system of free school meals has changed, so that people cannot tell which children are in receipt of free school meals. I will come back to that point, but it hopefully has encouraged parents to make use of the option.

Free school meals are estimated to save roughly £500 a child. Against such a low income, that amount makes a huge difference. For a family affected by the child benefit cap, it would increase their income by a fifth or more. Why, given the difference that it could make to their household, is every eligible family not claiming? There is a range of reasons. In some cases, there is a belief that their children might be bullied due to being in receipt of a free school meal, as my hon. Friend the Member for Telford (Shaun Davies) mentioned. If there is one immediate outcome of this debate, I hope it is to reinforce the message to parents that no one can now identify which child is on a free school meal. There is no stigma in claiming—please make the application.

We know also that the same barriers exist as with any other form of state support, where barriers of language, agency, awareness and ability ensure that those facing the greatest disadvantages in our society are the least likely to access the support available. These are the families who would benefit most from this legislation.

**Leigh Ingham** (Stafford) (Lab): This Bill is so important exactly because of what my hon. Friend has just said. It removes administrative barriers that get in the way, but that can frequently be overcome sensibly. Importantly, it still provides an opt-out for parents, which is important, because not everybody would want to take this up for their child. Does he agree that this Government should do everything they can to remove any administrative barriers?

**Peter Lamb:** It has been a while since I looked at the numbers, but my understanding when I last looked was that the level of unclaimed benefits in our system is at least 10 times greater than the total value of benefit

fraud. People are choosing not to access the support available by and large because of stigma or a lack of awareness, but the impact within our society is real, and we should be doing everything we can to reduce that stigma.

We all pay in so that there is a safety net for us when we need it and to ensure that other members of our community, our neighbours and the people we care about do not have to go without when they fall on difficult times. We should do everything possible to avoid the vilification that is disgustingly often put upon people simply because they are poor.

Beyond the moral argument, this measure is about the future of our country. Education is an investment in the future prosperity of our country and of our citizens. It is the bedrock of economic growth and of enabling people to live independent and successful lives. Auto-enrolment stands to improve educational outcomes in three ways. The most obvious is by reducing hunger, the impact of which upon concentration and educational performance is well known. School meals were introduced 120 years ago next year to ensure that children received at least one nutritious meal a day, so that they could function effectively.

Secondly, auto-enrolment would improve household incomes, and household income is positively correlated with educational outcomes. In fact, there is a double-digit improvement in performance at GCSE level between children in the lowest and second-lowest income deciles, and that improvement continues all the way up in decreasing amounts until we hit the third-highest decile, where for all the money spent on private schools, educational outcomes plateau across the top 30% of incomes.

**Sam Rushworth** (Bishop Auckland) (Lab): I thank my hon. Friend for the speech he is making and for putting child poverty at its heart. On educational outcomes, does he agree that auto-enrolling children would mean that schools could take advantage of many of the gateway supports that are premised on how many children at a school are on free school meals? I am sure that, like me, he will have spoken to schools carrying a heavy level of debt that is school dinner debt, because they are having to provide meals for hungry children.

**Peter Lamb:** I agree with my hon. Friend. I am well aware of the amount of effort that local schools are having to make directly to deal with the consequences of financial deprivation. It is important that we try to ensure that the statistics on free school meals are accurate, because it is a gateway to support. It is also how we measure any number of indicators of poverty in our society. If there is a statistical link between some groups under-reporting compared with other groups, we will have inaccurate figures on where deprivation is in our society and how best to try to address that problem.

The last benefit of auto-enrolment relates to the pupil premium of £1,455 a pupil, which is designed to counter the impact of deprivation on educational outcomes. It is a payment that schools receive on the basis of the number of pupils in receipt of free school meals. Low uptake of free school meals is now directly limiting the funding available to those schools where it would make the most difference to educational outcomes.

As a Government who are ambitious for the education of our children and committed to securing high levels of economic growth, the failure to address these matters of deprivation is a hurdle that we have to clear if we are going to succeed. This is well recognised. The Education Committee recently reported:

> "We consider that the arguments for auto-enrolment in free school meals for those children currently eligible are conclusive. In the interests of alleviating hunger in schools and improving health and educational outcomes for the poorest children, auto-enrolment must be brought in without delay."

Pilots run by local authorities, which quite heavily bend the rules set by current legislation to try to get as many of their children registered as possible, have repeatedly shown over recent years the scale of under-registration and the impact that auto-enrolment could have, both for those families benefiting and for school funding in deprived communities. The Government's own figures suggest that under-registration stands at a minimum of 11%, which is equivalent to a quarter of a million children, although research nationally and in my own constituency suggests that the overall figure could well be significantly higher.

It is worth noting that the £7,400 income threshold cuts off the overwhelming majority of children who are living in poverty in this country, who still do not qualify for free school meals. That should certainly be corrected in due course, but for now, this Bill would make the most amount of difference to the very poorest children, benefiting them, their families, their schools and—through improvements in educational outcomes—society at large.

I accept that the mess the new Government have inherited from the last Government and the economic uncertainty created by decisions currently being taken in Washington mean that it may be too much to expect a wholesale adoption of the policy today. However, I hope that the Minister—who has been generous with his time with me on this matter, and has demonstrated his commitment to increasing the uptake of free school meals—will be able to give a commitment that auto-enrolment will be given serious consideration as part of the work now being undertaken to bring an end to childhood poverty in the United Kingdom. I also hope that today's debate will underline the support among Members of this House for bringing about this change on behalf of our most vulnerable constituents. Surely, the very least that our country has a right to expect of its Parliament is that we will ensure that the nation's children are fed.

1.7 pm

**Mrs Sharon Hodgson** (Washington and Gateshead South) (Lab): It is a privilege to follow my hon. Friend the Member for Crawley (Peter Lamb). I am so happy that his name was drawn in the private Member's Bill ballot, and that he has chosen this excellent subject and most important topic for his Bill.

As my hon. Friend said, school food has been available for almost 120 years. That is thanks to an MP for Bradford—little known by most—called Fred Jowett, who introduced the concept in his private Member's Bill in 1906. My hon. Friend follows in the footsteps of a great man, and I thank him for that. Free school meals have existed in one form or another for the best part of 80 years, meaning that countless generations of children have received a hot, nutritious meal at lunch time. They are

*[Mrs Sharon Hodgson]*

life-changing for pupils—no one knows that better than I do. Growing up as a recipient of free school meals, from almost the day I started school to the day I left school, the knowledge that there would be food at lunch time gave my mam, me and my brothers the security that I would not be hungry going into the rest of the school day.

I echo the feelings of stigma that my hon. Friends the Members for Crawley and for Telford (Shaun Davies) have spoken about. I also recall having a different dinner ticket and, even worse, having a different meal queue to stand in. Our queue was served after the paid-for children were served; it is horrifying, I know. I am glad to say that that does not happen any more—children are not separated in such an abhorrent way—but the stigma is still very real and alive today, no matter how hard schools try to alleviate it through cashless systems and so on. Ask any child in school, "Who are the children on free school meals?", and they will look to them straightaway. They all know. I have been to many schools over 20 years; I always ask them, and they always nod sheepishly that they know—sometimes because they are that very child, but sometimes because they know who those other children are. That stigma never leaves you; it stays with you, and in the sixth richest economy in the world, we should not be subjecting our children in school to that stigma any longer.

We are all aware of the countless, cross-cutting benefits of free school meals, so I will not waste the House's time by relisting them all; I will only say that, from increased attendance to attainment and more, free school meals are a multifaceted policy with widespread benefits across society. I am proud to be the founder and current chair of the all-party parliamentary group on school food since 2010. The group was instrumental in shaping the universal infant free school meals scheme, along with the authors of the school food plan, Henry Dimbleby and John Vincent, and we are still in discussion on the best delivery of the universal primary breakfast club programme. We—I, the MPs involved and all the stakeholders, who I think number 300 now—all want the early adopter to be a huge success.

The all-party parliamentary group met only yesterday, and the Wilson Room was packed. The group is always well attended by school food stakeholders: we had around 50 in attendance yesterday, but I have known us to fill Committee Room 14 with 80 to 100 attendees, and I hope the Minister knows he has an open invitation to attend when his diary allows.

The early adopter scheme, due to roll out to the first 750 schools this April, will show us where lessons can be learned for a smooth introduction to all primary schools next year—but, as my hon. Friend the Member for Crawley has already said, this Government can and should go further. We can make marginal, low-cost improvement to the statutory free school meals scheme that we already have by introducing an opt-out system, as outlined in the Bill. We will capture around 200,000 children who are eligible for this crucial support but are not currently receiving it. Admin barriers should not mean that one in 10 students whose household income is already below the £7,400 threshold before benefits, miss out on free school meals support when they need it most.

This auto-enrolment Bill cannot be seen as extra spending. Government funding already exists for the children who are not claiming this statutory support, so it is the lowest of low-hanging fruit. Moreover, increased free school meals uptake unlocks, as we have heard, a whole host of other benefits, including vital pupil premium funding of up to £1,455 extra per child. If this House wants to talk about better education funding, surely unlocking funding that already exists is the most logical and economically efficient way of doing that?

In closing, extending free school meals by automatic registration to these most needy 200,000 children should be a no-brainer for any Government and a moral imperative for this Labour Government. I hope to see this Government and this Minister rectify that at their earliest opportunity.

1.13 pm

**Mike Wood** (Kingswinford and South Staffordshire) (Con): I congratulate the hon. Member for Crawley (Peter Lamb) on promoting this Bill so ably. The last Conservative Government massively expanded eligibility for free school meals, meaning that the proportion of children and young people eligible is much higher than was the case under any previous Government. The evidence here proves that the inheritance we left behind in this area last July was much kinder than that which the last Labour Government left us in 2010, with one in three children able to get a free school meal—as opposed to one in six when the previous Labour Government was last in office—despite a large fall in the number of workless households.

**Sam Rushworth:** We see in the bodies of children increased stunting, with the average 10-year-old 1 cm shorter than they were in 2010. How does that square with what the Minister is saying? We see a malnutrition crisis.

**Mike Wood:** When we look at dietary habits in recent decades, we see that that is not confined to parts of the income spectrum. There has been a deterioration in the quality of diets going back over several decades that is quite separate from issues of poverty.

As of January 2024, more than 2.1 million pupils were eligible for benefits-related free school meals, which amounted to 24.6% of all pupils. In addition, more than 90,000 disadvantaged students in further education received a free school meal at lunch time. Collectively, this supported the children and young people who needed it most to ensure that they could make the most of their world-class education, boost their health and save their parents considerable amounts that they could not afford.

**David Pinto-Duschinsky** (Hendon) (Lab): Will the hon. Gentleman give way?

**Mike Wood:** I really must continue. The Government have promised to move on to the next Bill at quarter to two, so I need to keep interventions to a minimum.

We also introduced extensive protections which have been in effect since 2018. They ensure that while universal credit is being fully rolled out, any child eligible for free school meals would retain their entitlement and keep getting free school meals until the end of the phase; in other words, until they complete either primary or

secondary school if their family's income rises above the income threshold such that that would otherwise have stopped.

On breakfast clubs, we all know that breakfast is the most important meal of the day, setting people up with the fuel they need to make the most of the day ahead, and the evidence supports that. At this point, Madam Deputy Speaker, I ought to declare an interest. My wife is in teaching, although she is providing one-to-one special needs teaching rather than in a classroom at the moment. We know that those children who do not have breakfast are more likely to have issues with behaviour, wellbeing and learning. That is why the previous Government expanded the provision of breakfast, investing up to £35 million in the national school breakfast programme. That funding supported 2,700 schools in disadvantaged areas, providing thousands of children from low-income families with a free nutritious breakfast at school to support their attainment, wellbeing and readiness to learn. Moreover, we trusted school leaders to deliver, building a breakfast provision that fitted the needs of their pupils. That involved five different models, ranging from a traditional breakfast club to a healthy grab and go. The programme has had great success in supporting those who needed it most and I welcome the Minister's confirmation that his party will continue to support it until at least next March. I hope the support extends past that date.

Nutrition does not cease to be an issue outside of term time, which is why the previous Government rolled out the holiday, activities and food programme to support during holiday periods disadvantaged and low-income families in receipt of free school meals. Since 2018, the programme has delivered enriching activities and nutritious food to the children and young people who need it most, with more than £200 million each year delivering 15.6 million half days to children and young people across every single one of the 153 local authorities in England.

The Bill requires local authorities in England to identify each child of school age resident in its area who is eligible for free school meals. It also requires state-funded schools that identify a child who is eligible to provide those meals. We support the desire to ensure that all those eligible for free school meals have an opportunity to receive them, so do not wish to prevent the Bill from proceeding. However, I have a couple of questions about how the Bill will achieve that, which I hope that the Bill's promoter can address in his closing remarks so that Members can consider that as the Bill proceeds.

I know that the hon. Member for Crawley has extensive experience in local government, and I think that 20 local authorities have now piloted their own auto-enrolment schemes at some point. In drafting the Bill, what consideration did he give to the burden that will be added to local authorities? Does he have any assessment or measure of the cost for local council tax payers and how that relates to both the savings for local families and the additional income for schools through pupil premiums?

The Bill would also give powers to the Secretary of State to make regulations to make provision for the definition of the term "state-funded school". In what circumstances does the hon. Member believe that a change in definition will be necessary?

I will be clear, as we were in government, that we believe in targeting support to where it is most needed. We believe that the state should do less but do it well—but that does include delivering sufficient support to those who need it most, and particularly to children and young people.

1.21 pm

**The Parliamentary Under-Secretary of State for Education (Stephen Morgan):** I thank my hon. Friend the Member for Crawley (Peter Lamb) for his Bill and for providing the opportunity to consider the importance that free, nutritious meals have in breaking the link between background and achievement. He is a true champion for his constituents and for children and families across the country. I was delighted to meet him to discuss the Bill and hear how passionate he is about our opportunity mission. I also thank my hon. Friend the Member for Washington and Gateshead South (Mrs Hodgson), who has been a champion for free school meal provision in this place for a considerable time. I also thank her for her leadership on the APPG.

I am proud to serve under this mission-driven Government who are breaking down the barriers to opportunity for every child in every part of our country. We currently spend about £1.5 billion annually on free lunches for 2.1 million school pupils under benefits-based free school meals alongside over 90,000 disadvantaged students in further education and about 1.3 million infants under universal infant free school meals.

We consider the aim of those measures at their core to be to ensure that those who need it get the support that they are entitled to, which is a goal that we are supportive of. Free lunch programmes provide pupils with essential nutrition, support attendance and ultimately ensure that pupils can concentrate, learn and get the most out of their education. They are essential to breaking down barriers to opportunity and tackling child poverty: a task that is more important than ever as a result of the legacy of rising child poverty left behind by the previous Government. Shamefully, there are 700,000 more children in poverty than in 2010, and over 4 million children are now growing up in a low-income family. That is why I am proud of a new ministerial taskforce that is working urgently to develop a child poverty strategy to address that.

The child poverty taskforce is considering a range of levers to tackle child poverty, including key cost drivers for households such as food, to develop a comprehensive strategy that will be published later this year. That is in addition to action that we are already taking to deliver on our mission to break down barriers to opportunity by rolling out free breakfast clubs in every state-funded primary school, providing food and childcare to children and to socialise them before the school day as well as put more money back into parents' pockets—on average £450 a year. Further, the holiday activities and food programme, which is established in every local authority area in England and delivers vital support to children and families during school holidays, will again receive more than £200 million in 2025-26.

We facilitate the claiming of free meals by providing the eligibility checking system, a digital portal available to local authorities that makes verifying eligibility for free lunches quick and simple. I can tell the House that

*[Stephen Morgan]*

the checking system has been redesigned to allow parents and schools to check eligibility independently from their local authorities. This system will make it quicker and easier to check eligibility for school meals, and has the potential to further boost take-up by families meeting the eligibility criteria.

Further to that, my Department is aware of a range of measures that are being implemented by local authorities to boost the take-up of free lunches. We welcome locally led approaches and I am personally keen to learn from them. By working directly with their communities, local authorities can overcome the barriers to registering and take action to ensure that families have access to the support for which they are eligible, subject to those activities meeting legal requirements, including those on data protection.

To support those local efforts, my Department is working with the Department for Science, Innovation and Technology on exploring legal gateways that can enable better data sharing. In the meantime, we will continue to engage with a range of stakeholders, including families and young people, as I have done personally, to understand the barriers for households that meet the criteria for a free lunch but are not claiming them, including through working closely with local authorities to understand the approaches that they have taken.

In conclusion, I thank my hon. Friend the Member for Crawley for bringing forward this Bill. We all agree that it addresses a matter of great importance. I hope it is apparent from my remarks that the Government are supportive of the aims of the Bill. We are working with the Department for Science, Innovation and Technology to explore legal gateways that could enable better data sharing, and there is further consideration of improving free school meal enrolment through the work of the child poverty taskforce. This Government are determined to break down the barriers to opportunity for every child. Our work to simplify enrolment is important to achieving that aim. We are confident that the actions I have outlined will improve take-up of free meals, alongside the local work being trialled by many local authorities across the country. For that reason, I hope that my hon. Friend can be encouraged to withdraw his Bill while we continue to explore enrolment and keep free school meals under review.

1.27 pm

**Bambos Charalambous** (Southgate and Wood Green) (Lab): I congratulate my hon. Friend the Member for Crawley (Peter Lamb) on his private Member's Bill on this very important topic, and on his excellent speech.

It is a well-established fact that good nutrition is essential for children's brain development and learning. When children go to school without eating a nutritious meal, or eating at all, it has a detrimental effect on their behaviour and educational performance. Barnardo's latest research, "Nourishing the Future", found that

"1 in 3 schools said hunger and food insecurity was impacting on children's ability to learn, including poor concentration, tiredness and behavioural problems."

As a school governor, I know the challenges that schools face in dealing with challenging behaviour and getting children to learn, so anything that helps improve behaviour and learning is to be welcomed.

Free school meals are meant to be a lifeline for low-income families. They are meant to ensure that the most disadvantaged children in society get a free nutritious meal every day that they are in school, to help them concentrate, learn and achieve. However, according to the Child Poverty Action Group, over 900,000 children across the UK do not qualify for free school meals because of restrictive qualifying criteria. According to the Food Foundation, a further 250,000 eligible children are missing out on free school meals for a variety of reasons, including lack of awareness, stigma or embarrassment, the complexity of the forms—the Minister referred to the previous checking system—or language barriers.

The fact that obtaining free school meals is an opt-in process, requiring parents or carers to apply, is itself a barrier. If we want our children to flourish, thrive and get the best start in life, that needs to change. As the Minister mentioned, one of the Labour party's five missions is to break down barriers to opportunity, and I believe this is one of those barriers. The solution is auto-enrolment for free school meals, as set out in the speech by my hon. Friend the Member for Crawley. However, he is not the only person to call for such a change; that call has come from many quarters. In 2021, the Conservative Government commissioned Henry Dimbleby, co-founder of the restaurant chain Leon, to produce a food strategy for the Department for Environment, Food and Rural Affairs. Recommendation 4 of the strategy was to extend eligibility for free school meals, and one of the three ways to achieve that recommendation was to:

"Enrol eligible children for free school meals automatically."

The rationale for that recommendation was that

"even eligible children are often missing out. Currently, FSMs are 'opt-in': parents have to know about the scheme and apply for it. The effect of this is that, according to a 2013 estimate by the DfE, 11% of children entitled to FSMs do not receive them."

In the benefits section of recommendation 4, it was noted that:

"This would have benefits for those children's health, but also for their educational achievement. Following one pilot of universal free school meals in 2009–11, primary school pupils made between four and eight weeks' more progress than expected. Pupils from poorer families and those who had previously done less well at school showed the most improvement."

It was stated that there were clear education and health benefits in children having a nutritious free school meal—and that came from the Conservative Government's food strategy. Sadly, as with many of the recommendations, auto-enrolment was not implemented.

More recently, the Education Committee's "Scrutiny of the Children's Wellbeing and Schools Bill" report of 28 February states at paragraph 35

"that the arguments for auto-enrolment in free school meals for those children currently eligible are conclusive. In the interests of alleviating hunger in schools and improving health and educational outcomes for the poorest children, auto-enrolment must be brought in without delay."

We are lucky in London that the Mayor of London, Sir Sadiq Khan, has agreed to fund free lunches for all London's children in state primary schools, which is already making a difference to children's educational outcomes. It is a shame that this policy does not apply to secondary schools too, but in the absence of such a policy, auto-enrolment is the best way to ensure all

eligible children get the free school meals that they are entitled to and deserve. If we are to ensure that children get the best start in life, learn and thrive at school and achieve to their full potential, auto-enrolling of eligible children on to free school meals is the best way forward. We need to remove that barrier to opportunity, and this would, at a stroke, make a huge difference to those children's lives.

The Government are already doing many good things in education, and the announcement of the breakfast club early adopters was warmly welcomed by me and, I am sure, colleagues on both sides of the House. I hope that the Government will adopt this policy, because it helps alleviate child poverty, is good for children, and is the right thing to do.

I hear what the Minister said about the child poverty taskforce strategy, and look forward to it reporting later in the year on what it would do to challenge child poverty. Data sharing is obviously to be welcomed, and I know that the Government will do all they can to ensure that all eligible children get the free school meals that they deserve, to help them learn and thrive.

1.33 pm

**Shaun Davies** (Telford) (Lab): I pay tribute to my hon. Friend the Member for Crawley (Peter Lamb) for bringing forward this private Member's Bill on a process that, as a former council leader, I saw as a bureaucratic, red-tape nightmare. Children eligible for free school meals were not accessing them simply because a form was not filled in. Even though local authorities, schools and communities knew exactly who those children were, bureaucracy was getting in the way. I was pleased to hear the Minister say at the Dispatch Box that he is working with the Department for Science, Innovation and Technology to look at ways in which data sharing and passported benefit checks could be used to ensure that more children get food.

However, this must be looked at in the round. I heard from a constituent this week who has just taken their child out of a breakfast club because the cost of the club has gone up by £15 a week. Sadly, that school is not one of the 750 early adopters of breakfast clubs, but it will benefit from that policy initiative as it is rolled out. It is an excellent initiative and we should be proud of it. We should call on the Government to go harder, faster, in implementing the policy.

Some 900,000 more children in working households were living in poverty in 2023 than in 2010. That means that 1,350 children entered poverty every single week for the first 13 years the Conservatives were in power. In my area, Telford, absolute poverty rose from 14.9% to 18.4% between 2014 and 2023, and we know that a huge number of families who are not included in the poverty figures were also struggling to make ends meet.

Ultimately, we need an economy that is growing and getting people into work so that the poverty trap can be removed. Like the shadow Minister, I declare an interest: my wife is a primary school teacher in Telford. She tells me about the direct contrast between the children she teaches now and the cohort that she taught when she started 20 years ago. Children are coming in with major social issues, and those social issues have to be addressed as a whole.

The Government also need to consider the huge regional inequality in deprivation. Child poverty in some parts of the country went down under the last Conservative Government, but in my region it soared. We need to engage with councils and, where applicable, with combined authorities and mayors to ensure a systematic approach.

**Claire Hughes** (Bangor Aberconwy) (Lab): My hon. Friend mentions working with regions. May I add a point about nations? In Wales, all primary school children have been eligible for free school meals since September last year. Does my hon. Friend agree that in designing the roll-out of free school meals in England, the UK Government could learn from the experience in Wales?

**Shaun Davies:** I absolutely agree. My county borders Wales, so I know Wales very well indeed. The Westminster Government should absolutely learn from the Welsh Labour Government's approach to child poverty, and to inequality more generally. We should congratulate and acknowledge the work of Welsh Labour in that space.

I welcome the previous Government's household support fund and its extension by this Government. As a council leader and as chair of the Local Government Association, I worked with Conservative Ministers on the fund. The approach and ideals were absolutely right, but the one-year duration means that the money is not being used to the best possible extent. That goes back to the point about the importance of a cross-ministerial taskforce looking at the issue in the round.

We have heard a lot this week, from the Prime Minister downwards, about the need for delivery, about urgent action and about the ability to make a difference and demonstrate change. As a Labour Government, we cannot be in a position where, in four or five years' time, we point to bureaucracy and red tape as the reason why we have not made a huge impact on the lives of the poorest children in our country.

1.38 pm

**Sam Rushworth** (Bishop Auckland) (Lab): I am grateful for the opportunity that the Bill provides to put on record the importance of discussing the scourge of child poverty in our country, particularly as it relates to children's nutrition. It is a simple fact that the height of an average five-year-old increased progressively until 2013 but has since reversed; children aged five are shorter today than in the past. We face a dual burden: not only stunting, but obesity. We have seen a 30% increase in obesity since 2006 and a 22% increase in teenagers with type 2 diabetes since 2017.

All of this points to the poverty of children's diets in this country. When we have this conversation, for me it is never a matter of what we can afford to do; we cannot afford not to do something about it, because the knock-on in the NHS is immense, and the knock-on in future work days missed by the next generation will be immense. It is a sad reality that, as my hon. Friend the Member for Crawley (Peter Lamb) said, in a typical UK classroom one third of children will be living in relative poverty. Children are also the group most likely to be living in cold homes in this country.

Probably the most startling statistic from my county of Durham, which really shows what austerity has done to our children over the last decade and a half, is the 250% increase in the number of children in the care

*[Sam Rushworth]*

system. The cost of that for the local taxpayer is immense, as is the human and social cost for those children. But somewhere between being in the care system and being a happy child with a healthy life are many children who live in conditions of neglect. That is why it is so important that the state and schools sometimes do the work to provide what children are not getting in the home.

I hope that the child poverty taskforce will report soon, and we will see some positive change. I welcome the breakfast clubs introduced by the Government, which will make a difference not only to ensuring that children start the day well fed and having settled, but to the cost of living. I met a constituent a few months ago who shared with me that it cost her £400 a month just to pay for her children to be looked after from 7.30 till the start of the school day. That was having a massive impact on her, so for her, that breakfast club is an extra £400 a month, and I am grateful for that.

What is being proposed today is a modest and sensible tweak that addresses the challenge of children not being enrolled. I am grateful to the Minister for saying that the Government will look at this issue, because we cannot afford to allow a generation of children to grow up as they are right now.

1.42 pm

**Leigh Ingham** (Stafford) (Lab): The Bill aims to make a meaningful and lasting difference to the lives of children across our country. We must come together to focus on the future of our young people, understanding that the way we invest in them today is how we shape our society of tomorrow. The Government have been clear in their commitment to address child poverty—I welcome that—and the work already being done through the ministerial taskforce, which is shaping a long-term strategy to bring about change. That commitment was also evident in the King's Speech, which announced further investment in children's wellbeing through the introduction of breakfast clubs, which I also welcome.

Financial support for the least well-off is another key element of our approach. As a former councillor, I know that the additional £1 billion allocated in the most recent Budget to the household support fund will allow local authorities to provide targeted help to those who need it most. We must always ensure that support for families is not just well intentioned but well delivered. That is why the Bill is so important. It removes unnecessary barriers, streamlining the process so that every eligible child is automatically registered for the help to which they are entitled. No family should have to navigate unnecessary bureaucracy or miss out due to a lack of awareness. At the same time, the Bill respects parental choice, which is incredibly important.

It is essential to recognise that the most effective way to reduce poverty and improve life chances is by focusing on long-term, sustainable economic growth. By fostering a strong economy we can boost household incomes and ensure that public services remain well funded and effective. The long-term vision must always be to create an environment where families can thrive, children can reach their full potential, and the cycle of poverty can be broken for good.

While we work towards that vision, it is important to continue implementing practical, well targeted measures, such as those in the Bill, that can bring about immediate improvements. The decisions we make today will shape the society we live in tomorrow.

**Josh Fenton-Glynn** (Calder Valley) (Lab): Before I entered this place, I worked on poverty for the Child Poverty Action Group, Oxfam and Church Action on Poverty. Back in 2010, there was cross-party consensus that we should end child poverty. Gordon Brown referred to it as his guiding mission. Should we return to that time?

**Leigh Ingham:** I completely agree. Gordon Brown was a wonderful Prime Minister.

To conclude, the Bill represents a crucial step in our ongoing commitment to tackling child poverty.

*Ordered*, That the debate be now adjourned.—*(Christian Wakeford.)*

*Debate to be resumed on Friday 11 July.*

## Arm's-Length Bodies (Review) Bill

*Second Reading*

1.45 pm

**Sir Christopher Chope** (Christchurch) (Con): I beg to move, That the Bill be now read a Second time.

As you will know, Madam Deputy Speaker, timing is important in politics. When, last autumn, I chose today for the Second Reading of the Bill, how could I have predicted that arm's length bodies, which I will abbreviate to ALBs, would have been mentioned four times in *The Times* leader this very morning? Nor could I have predicted the generosity of the Government Whips in allowing—indeed, facilitating—debate on this important Bill.

I first introduced the Bill in the 2023-24 Session, but Dissolution prevented it from being debated. I have to say, I do not think the Government who were in office at that time would have been very responsive to the contents of the Bill. It is therefore beyond my wildest dreams that a Labour Government seem to understand, at least in part, the problem that arm's length bodies present to Parliament, particularly to the House of Commons, and the Ministers, through their unaccountable structures.

As *The Times* leader this morning puts it:

"Arm's-length bodies…have often been favoured by ministers as a way of distancing themselves from contentious issues. But the result is often a duplication of effort, resulting in turf wars between Whitehall ministries and ALBs over policy. Free of the need to answer to voters, ALBs can go rogue, as Highways England did over its promotion, in the face of public opposition, of so-called smart motorways."

For another current, topical example of that problem, one need look no further than the Sentencing Council. Earlier this month, on 5 March, that independent arm's length body issued new guidelines for the sentencing of offenders from minority groups. That issue was taken up by the shadow Secretary of State for Justice, my right hon. Friend the Member for Newark (Robert Jenrick), during the questions that followed a statement by the Justice Secretary.

My right hon. Friend challenged the Justice Secretary by pointing out that the new sentencing guidelines would make a custodial sentence less likely for those from

"an ethnic minority, cultural minority, and/or faith minority community."

In her response, the Justice Secretary said:

"As somebody from an ethnic minority background, I do not stand for any differential treatment before the law for anyone. There will never be a two-tier sentencing approach under my watch".—[*Official Report*, 5 March 2025; Vol. 763, c. 287.]

Within hours, however, it became apparent that the Justice Secretary did not have the control that she thought she had over the activities of the Sentencing Council. The new guidelines, due to be implemented from 1 April, remain unaltered and unaffected by what both the Secretary of State for Justice and her shadow have said to this House.

I understand from today's newspapers that yesterday there was a meeting between the Justice Secretary and the chairman of the Sentencing Council, Lord Justice William Davis. I would have expected to have seen in the same press release that Lord Justice William Davis had now conceded to the Justice Secretary, who I think spoke for everybody in this House by saying that we should not have a two-tier justice system. I would have thought that he would have accepted that he got it wrong, and the new guidelines would be withdrawn before 1 April. However, that does not seem to have happened yet.

We now know that the guidelines were the subject of quite critical comments when they went out to consultation, including from the Magistrates Association, which described them as a get-out-of-jail-free card. Why have we set up a system whereby the Sentencing Council is able to dictate this type of policy, overriding the will of Ministers and elected Members of Parliament?

**Deirdre Costigan** (Ealing Southall) (Lab): I respect the points that the hon. Member is making about the Sentencing Council, but given that this issue has been around for the past few years—he said that the guidelines were out for consultation—why does he think the previous Government were unable to take any action on it?

**Sir Christopher Chope:** I cannot speak for the previous Government because I was not a member, although obviously I was in the House. My understanding is that this has become a live issue only within recent weeks and months, and that the present Government have been involved in discussions behind the scenes. I am not blaming the Justice Secretary, because I think that perhaps her officials misread what she said or perhaps did not understand the need to consult her. They seem to have been to meetings with the Sentencing Council. It is my understanding that the consultation process came to a conclusion after the present Government came into office.

We should all agree that we need to try to find a way through. A Bill promoted by my right hon. Friend the Member for Newark, which is on the Order Paper today—the Sentencing Council (Powers of Secretary of State) Bill—would enable the House and the Minister to take back control from the Sentencing Council over issues relating to a sentencing policy and guidance. I would find it amazing if the Government sought to block progress on that Bill today. There is everything to be said for it going through all stages in the House in one day, because it is essentially an emergency measure in response to the fact that, so far, the Sentencing Council does not seem to have responded positively to the representations of the Justice Secretary.

The Sentencing Council is not unique in being able to ignore the wishes of Ministers and Parliament. Most arm's length bodies have a similar status to the Sentencing Council. They are in three different categories: executive agencies, non-departmental public bodies and non-ministerial departments. They have slightly varying relationships with the House and with Government, but there are far too many of them. How many arm's length bodies are there? I was told by a Cabinet Office Minister in response to my question that on 4 July last year, there were 307 arm's length bodies, and 135 of those had an annual operating expenditure in excess of £5 million in 2023-24. Although the Minister ducked my other question of how many there are now, we know that since coming into office, the Government have removed one quango

*[Sir Christopher Chope]*

and created 27 new ones. Although the Prime Minister has taken some decisive action on one quango, there are a heck of a lot of others that I hope will come under his scrutiny. My Bill seeks to ensure that the most significant quangos are accountable to Parliament.

**Leigh Ingham** (Stafford) (Lab): Given the Prime Minister's announcement yesterday, does the hon. Member welcome the announcement that the largest of those organisations is to be moved within ministerial and departmental oversight?

**Sir Christopher Chope:** I am just coming to that—I have to say that I am absolutely delighted. I am not ambivalent about it; it is really good news, and I will give some examples of how frustrating it has been in my constituency to try to engage with the organisation called NHS Dorset—it used to be called the integrated care board—and how difficult it has been to get any timely responses. I am delighted that the Prime Minister obviously agrees with the objective of the Bill. Whereas this Bill inevitably had to tread carefully around the subject matter, the best way of getting parliamentary accountability of the activities of arm's length bodies is to abolish those bodies completely, which is what the Prime Minister announced yesterday.

**Patricia Ferguson** (Glasgow West) (Lab): I am very much aware that the hon. Member has been a Member of this Chamber for much longer than I and many of my colleagues have, given that many of us were elected for the first time last July, but does he recall that between 1997 and 2010, the Labour Government cut the number of quangos in this country by 39.8%? That shows what Labour does in government. Wait until the end of the five years and see how many we have cut by then—I am sure he will be delighted by the number.

**Sir Christopher Chope:** I am more interested, actually, in looking at the number of people in the civil service. There was a low point during the Blair years, but I am sorry to report that under the last Conservative Government and in the time that this Government have been in office, the number of civil servants has continued to increase exponentially. We are talking about between 100,000 and 200,000 more civil servants since the Brexit referendum. The size of the state, the Government and the civil service are important issues, and they are fundamental to this, but my Bill focuses on trying to ensure that the officials who are paid handsomely by the taxpayer are more accountable than they have been to this House and the Government.

The Prime Minister said yesterday that these quangos and regulators end up blocking what the Government want to do, and that is obviously unsatisfactory. In a democracy, we elect a Government, and we expect them to take action on our behalf.

**David Pinto-Duschinsky** (Hendon) (Lab): Could the hon. Gentleman enlighten me on a slight confusion I have with the wording of his Bill? The Government are talking about bringing more of these agencies back under Executive control so that the Executive, elected by the British people, can drive their performance. His Bill would provide direct parliamentary control, which in many cases—such as with the Prison Service, which is overseen by the Ministry of Justice—would move control and oversight from the Executive to Parliament. I may be confused, but would the Bill not make some of that harder not easier?

**Sir Christopher Chope:** I do not think my Bill would make any of that harder. What I am saying is that if the Government wish to abolish these arm's length bodies, or some of them, and to create a more direct relationship between the activities of those bodies when they are under direct Government control and this House, I welcome that. I have already made that clear. However, the Government have already shown that they are intent on increasing the number of arm's length bodies. Later, I was going to come on to what I regard as an egregious example of giving substantial new powers to an arm's length body—namely the powers for Natural England set out in the Planning and Infrastructure Bill that was published earlier this week. I will come on to that in due course.

What is important is that these arm's length bodies are not able to go on a frolic of their own and ignore the wishes of the people's representatives. As such, my Bill attempts to remedy that accountability gap. As has been said, the most direct way of doing that is to abolish the arm's length bodies altogether. Currently, the Government are indeed legislating to abolish one arm's length body through the Institute for Apprenticeships and Technical Education (Transfer of Functions etc) Bill. I was chairing that Bill's Committee stage yesterday, so I will not comment on its merits or otherwise, but its proposals are dwarfed by the announcement of the abolition of NHS England. I welcome that decision; as I said earlier, I have a constituency concern about the way in which NHS England's outpost in Dorset, NHS Dorset, lacks responsiveness to Members of Parliament.

To give the House a topical example from this week—indeed, it is still going on—the continuing healthcare department at NHS Dorset has failed over many months to sort out an issue relating to a quadriplegic who is one of my constituents. He has now moved into a different residential care home, and his social worker is from the NHS continuing healthcare team. As we speak, he is threatened with losing his mobility vehicle this very weekend because of the NHS's inability to deal with the Department for Work and Pensions and sort the matter out.

This very week, my constituent's mother wrote to me, and I immediately tried to contact NHS Dorset. I have sent an email and left phone messages with both the social worker and the organisation, and my secretary is busy phoning today to try to get a response. No response is forthcoming from NHS Dorset, and in my view, that is unacceptable. That is just a small example of the problem, which I hope will be properly addressed by bringing NHS England back under direct control of the Government. It would mean, for example, that I would be able to put down questions about this matter—I could try to table an urgent question for the Minister.

That direct accountability is, I think, what Lord Lansley was trying to avoid when he was Secretary of State. It was an embarrassment to the Conservative Government—the coalition Government—that they could be asked questions by MPs on the sort of subject I have just raised, yet

what more important role is there for an MP than trying to drive through these bureaucratic blocks and deliver what our constituents are expecting?

**Josh Fenton-Glynn** (Calder Valley) (Lab): The case of the hon. Member's constituent is a really interesting one, although I do not know the full details. However, sometimes when we get rid of a quango, it is a case of, "Be careful what you wish for." One of the jobs I had before coming to this place was parliamentary officer for the Public and Commercial Services Union. One much lamented former body from the bonfire of the quangos was the Independent Living Fund, which provided support for some of the most complex cases—potentially like the hon. Gentleman's constituent—and was able to work much more easily. In a cost-saving measure, that support was transferred into local government, and local government is much less efficient at administering it, so I would say, "Be careful what you wish for when you close quangos just because they are quangos."

**Sir Christopher Chope:** I hear the hon. Gentleman's cautionary tale, and I am not suggesting that anything will be a panacea. My Bill is just a tentative step to try to introduce a little more accountability.

**Martin Vickers** (Brigg and Immingham) (Con): My hon. Friend is making a powerful speech and I agree entirely with the points he is making. As I recall from the coalition days, one of the reasons for the Lansley reforms was to make the NHS more independent of Government, which clearly failed. My personal view is that all these arm's length bodies, quangos and so on should be within the Departments. Then, as he says, we would be able to question Ministers on the issues. The idea that we should make them independent of their political masters is something we need to overturn.

**Sir Christopher Chope:** Absolutely; that is why, although the term "independent" sounds seductive to people outside, it quite often means a lack of control by elected representatives over the body in question.

I am not going to spend all my time talking about NHS Dorset, but I must offer one other illustration of my concerns. I have a letter here from the chief executive of NHS Dorset, who I think receives a lot more remuneration than even the Prime Minister. I wrote to her in November, and she wrote back at the end of January about an issue relating to dermatology services in Dorset. I wrote back to her saying, "What is being done to address this issue? You haven't answered that in your letter." It took until 5 March, with further queries following up on it, for me to receive an answer. The letter cites my question, which I first raised back in November, as:

"Concern over the 'unacceptably long waiting list for dermatology services. What is being done to address this issue by the Integrated Care Board?'"

The answer given is:

"As part of a Commissioning for Sustainability programme, Dermatology is one of the services that is being focussed on. The aim of the programme is to recover services to the 18-week standard target, whilst maintaining sustainability. As part of this we are currently reviewing how the commissioning and delivery of services can best achieve this."

That is after more than four months. There is no suggestion of when the review started, when it is likely to end or what will happen. I take that as an example of the Member of Parliament being fobbed off by officialdom for having the temerity to raise an important issue on behalf of his constituents.

I could go on with many other examples from NHS, but I will not do that. Instead, I will see whether, through this debate, I can encourage the Government to go further than just abolishing NHS England. I have had many dealings with the NHS Business Services Authority, another arm's length body, apparently controlled by the Department of Health and Social Care, but essentially a law unto itself.

I have been in dealings with the NHSBSA on a number of different subjects, but particularly on the subject of the access and treatment of people who suffered vaccine damage and have applied for vaccine damage payments. The NHSBSA is responsible for organising and running that scheme, yet progress in dealing with applications is desperately slow. As at last November, it had more than 17,000 claims relating to covid-19 vaccines, but of those, more than 7,000 were awaiting resolution, and some had been waiting more than 18 months to be resolved.

Once a claim has been rejected, as it often is, the claimant has an opportunity to go for a mandatory reversal application before they can get access to a tribunal. Dissatisfied claimants can go for the mandatory reversal, but the NHSBSA can hold up that process. As at 27 February this year, 1,657 rejected claims had been subject to mandatory reversal. Some 600 of those are outstanding, and 81 have been outstanding for more than a year. That is intolerable, because it can take more than a year for someone to have their claim dismissed. They then get a mandatory reversal and need to go to tribunal. After three years, someone's right to litigate on this subject is taken away by the limitation period. That is an example of what happens when Departments and arm's length bodies start taking over and being thoroughly incompetent.

**Peter Dowd** (Bootle) (Lab): If the hon. Gentleman was so concerned about that, why did he vote for the Health and Social Care Bill, which included the setting up of NHS England, on 13 March 2012?

**Sir Christopher Chope:** I was probably in one of my less rebellious periods at that stage, but the hon. Gentleman is right to chide me, because I think it was a big mistake.

**Peter Dowd:** This is such a fundamental issue for the hon. Member, so why should we pay any attention whatever to what he is saying to us today?

**Sir Christopher Chope:** I am not insisting that anybody should pay attention to what I am saying. All I am putting forward is a proposition that these arm's length bodies, of which there are far too many, should be brought to account more than they are at the moment.

I have just given an example of the NHS Business Services Authority. Another example is Natural England. One of the means by which arm's length bodies are meant to be accountable to Parliament is through the publication of annual reports, with accounts. If one looks at the situation with Natural England, it has not produced an annual report and accounts for the year ending 31 March 2024. The last accounts it produced were in December 2023 for the financial year ending

*[Sir Christopher Chope]*

31 March 2023. That is unacceptable. The Government guidance is that these arm's length bodies should produce their report and accounts within three months of the end of the financial year.

**Deirdre Costigan:** In light of what the hon. Member is saying, will he support Labour's Planning and Infrastructure Bill, which takes away Natural England's power to delay or stop the building of vital infrastructure, including energy and rail infrastructure and the 1.5 million homes that we need in this country?

**Sir Christopher Chope:** The hon. Lady tempts me to move on to the Planning and Infrastructure Bill.

**Sarah Smith** (Hyndburn) (Lab): Before the hon. Gentleman moves on from Natural England, in my constituency we have got a huge problem with the Whinney Hill tip, which Natural England and the Environment Agency are both heavily involved in. My residents face horrendous issues with gulls, the stink and many other challenges from that tip, but we have been limited in finding an alternative because elected officials need to plan for an alternative waste station. If the Environment Agency had greater teeth, it might have been able to push the issue and find a better solution. Is it not sometimes about having the right powers in place rather than removing quangos altogether?

**Madam Deputy Speaker (Ms Nusrat Ghani):** That intervention was slightly broad in scope, but it returned at the end.

**Sir Christopher Chope:** The Environment Agency as an arm's length body is found wanting in many respects, not least that it argues that it has a lack of resource to introduce the necessary prosecutions and enforcement of the regulations that it is meant to be in charge of. Just to illustrate that point—this also relates to Natural England, actually—towards the end of the last Parliament, I arranged with the then Minister at the Department for Environment, Food and Rural Affairs to have a meeting in his office with officials from Natural England and the Environment Agency to discuss the state of the Avon valley: the river, the nitrates and phosphates problems, and the break in the Avon valley footpath, which crosses the River Avon in my constituency but, as a result of neglect, is no longer viable.

The Minister set up the meeting in his Department. The first time I went along to the Department with him, he was sitting there with his private secretary and we were meant to have officials from Natural England and the Environment Agency with us online on Zoom—I do not know whether they were working from home—but nothing happened. At the last minute, there was a message saying that they could not attend. I said to the Minister that he should get heavy with them, because this was intolerable. It was another month or six weeks before we had an in-person meeting with them. I wish that I could say to the hon. Member for Hyndburn (Sarah Smith) that, as a result of all that, the issues have been resolved, but they have not. I have got a meeting with Natural England on site on 1 April in the Avon valley in my constituency.

All is not well with these arm's length bodies. There are probably different solutions for resolving that, depending on their specific nature.

**Peter Dowd:** The former Paymaster General, the right hon. Member for Salisbury (John Glen), said in guidance that

"ALBs are closely aligned, but distinct from their sponsor departments"

and so on. It continued that ALBs

"are each responsible to Parliament for their use of public funds."

Is that not contrary to what the hon. Gentleman seems to be telling us? Who is right—him or the former Paymaster General?

**Sir Christopher Chope:** That is the difference between the words and the reality. Strictly speaking—I was coming on to this—they have to produce annual reports and accounts, which go to what are described as their sponsoring Departments. In most cases, the sponsoring Department lays those accounts before the House. With Natural England, for example, we do not know what has been going on since 31 March 2023, so it is accountable, but not in what I would describe as a meaningful sense such that we can ask specific questions.

**Joy Morrissey** (Beaconsfield) (Con): On the point about arm's length bodies and their accountability to Parliament, does my hon. Friend agree that it would be useful to have a mechanism to bring them to Parliament to hold them to account, not just through their annual accounts? If there is gross negligence in a Department or an arm's length body, particularly those that deal in medical or other delicate matters, or if there is some issue that needs to be brought to the fore, we could have a mechanism for them to come to Parliament so that there could be direct parliamentary accountability. Although it is said in theory that those bodies are accountable to us, there is no evidence to show that that is the case.

**Sir Christopher Chope:** My hon. Friend takes me back to the content of my Bill, which seeks to achieve exactly what she requests. Clause 1 states:

"House of Commons approval of relevant documents

(1) Within a period of forty days starting on the day on which a relevant document is laid before the House of Commons by, or on behalf of, a qualifying body, a Minister of the Crown must move a motion that the House of Commons approves the relevant document."

That means that we, in the House, would be able to decide whether we approved that document.

The Bill goes on to say:

"If the House of Commons does not approve a motion under subsection (1), the relevant document shall stand referred to the Committee of Public Accounts."

It seems to me that the best body that we have in the House to deal with this sort of situation would be the Public Accounts Committee, so there would be an automatic referral to that Committee if the Members of this House decided that they were dissatisfied with the performance of the relevant arm's length body.

**Peter Dowd:** Has the hon. Gentleman had any discussions with the Chair of the Public Accounts Committee, the hon. Member for North Cotswolds (Sir Geoffrey Clifton-Brown), to assess how much of the Committee's time

would be taken up with going through the accounts of, potentially, 150 quangos, which would be directly responsible to Parliament?

**Sir Christopher Chope:** Quangos are not directly responsible to Parliament, which is why I have brought forward the Bill.

**Peter Dowd** *rose—*

**Sir Christopher Chope:** I am not going to give way any more, but I will just make this comment: the hon. Gentleman seems to be intent on finding a reason for not taking action in this area and to block progress. May I suggest that he pursue an alternative career in the civil service, because that is exactly the sort of role that he would be well suited to?

The Planning and Infrastructure Bill was published this week. It gives extensive and revised powers to Natural England, which has not even produced its annual report for last year. Instead of abolishing Natural England, which might have been the right approach following the Prime Minister's abolition of NHS England, so that the relevant responsibilities could be taken on by the Department for Environment, Food and Rural Affairs directly, clauses 48 to 78 of the Planning and Infrastructure Bill give Natural England, an unelected, arm's length body, responsibility for environmental delivery plans, the administration and control of the nature restoration levy, and a whole lot of other responsibilities, which would be better suited to the Government so that there is more direct accountability.

I can see why the Government are frustrated at the delays by Natural England. I have experienced that in my own constituency, where there was a ridiculous attempt by somebody to try to build a new open-air surfing lake. Although the site was only three miles from the coast, they wanted to build that new infrastructure, but Natural England sat on the responsibility of advising on the project and refused to take action. I kept asking the planning inspector what we could do about that, and the answer was nothing. We had to wait until Natural England got round to deciding what it was going to do, if anything, which added months.

There is a development site in the middle of Christchurch, a former police station. As a result of Natural England's faffing about over phosphates, the cost of developing the site has increased by over £3 million, and there is a significant delay of probably two years or more. The Government need to take these powers back into the Department, rather than, as set out in the Planning and Infrastructure Bill, give even more power to Natural England, which is an unelected and scarcely accountable quango.

**Chris Murray** (Edinburgh East and Musselburgh) (Lab): The hon. Gentleman is talking about Natural England and NHS England, which obviously operate only in England. Is he aware that in another part of the UK, Scotland, we have seen an absolute proliferation of quangos under the SNP? We now have more quangos in Scotland than there are Members of the Scottish Parliament. Does he, like me, look forward to the day when the SNP no longer runs the Scottish Government and a Labour Administration promise to crack down on these things?

**Sir Christopher Chope:** Although I was educated at university in Scotland, I will not get drawn into Scottish politics, but there is a lot to be said for having a United Kingdom approach to all these issues. In some respects, we have probably devolved too much power to the Scottish Government for things that should more properly be dealt with by the United Kingdom Parliament. We heard in today's debate on the Rare Cancers Bill that its clauses 2 and 3 are specifically limited to England and Wales. Although it is a very important Bill about research on rare cancers, it would not apply to Scotland. That is a bigger problem, but we will not get into that now, because I am trying to confine my remarks to the several hundred arm's length bodies. I do not have time to go through any more examples, but the Government seem to have undergone a conversion. Suddenly they have seen the light, and realise that they need to take back control.

I will use an anecdote to illustrate my proposition. When I was a Minister in the Department for the Environment, we had 18-storey tower blocks in Marsham Street. I was privileged to be a junior Minister, and Nick Ridley was my Secretary of State. For those who did not know him, he was passionately in favour of the freedom of people to smoke, if they so wished. One day, he arrived in the tower block and there was a big notice in the lift saying, "No smoking in this lift", which caused him to say in a stage whisper, "Can somebody remind me who's in charge of this Department?" Needless to say, the notice was quickly removed. When he was Secretary of State, he gave me the responsibility of dealing with a mega-quango: the Property Services Agency, which was responsible for massive delays and added costs to the building of the British Library, for example. He imbued in me a feeling that Ministers are in charge.

One day, the permanent secretary, who was responsible for the Property Services Agency, went behind my back and basically said to Nick Ridley that I was responsible for a significant decline in the morale of the people working for the Property Services Agency, and he asked whether the Secretary of State could intervene. The Secretary of State said to the gentleman in question, "Sir Gordon, Chris is in charge of the Property Services Agency. If you wish to discuss anything with him, then I am sure his door is always open." He reported that back to me, and from that moment onwards the relationships changed; the Minister was back in charge and the civil servants recognised that they were in a subordinate and accountable role. I hope that is exactly what will happen now with NHS England, and a lot of other arm's length bodies, as a result of the Government's conversion to recognising—

2.30 pm

*The Deputy Speaker interrupted the business (Standing Order No. 11(2)).*

*Bill to be read a Second time on Friday 28 March.*

## Business without Debate

### PUBLIC HEALTH (CONTROL OF DISEASE) ACT 1984 (AMENDMENT) BILL

*Motion made,* That the Bill be now read a Second time.

**Hon. Members:** Object.
*Bill to be read a Second time on Friday 28 March.*

**DEBT RELIEF (DEVELOPING COUNTRIES) BILL**

*Motion made,* That the Bill be now read a Second time.

**Hon. Members:** Object.
*Bill to be read a Second time on Friday 11 July.*

**ARMS TRADE (INQUIRY AND SUSPENSION) BILL**

*Motion made,* That the Bill be now read a Second time.

**Hon. Members:** Object.
*Bill to be read a Second time on Friday 16 May.*

**PENSION (SPECIAL RULES FOR END OF LIFE) BILL**

*Motion made,* That the Bill be now read a Second time.

**Hon. Members:** Object.
*Bill to be read a Second time on Friday 25 April.*

**HERITAGE PUBLIC HOUSES BILL**

*Motion made,* That the Bill be now read a Second time.

**Hon. Members:** Object.
*Bill to be read a Second time on Friday 25 April.*

**STATUTORY INSTRUMENTS ACT 1946 (AMENDMENT) BILL**

*Motion made,* That the Bill be now read a Second time.

**Hon. Members:** Object.
*Bill to be read a Second time on Friday 28 March.*

**DANGEROUS DOGS ACT 1991 (AMENDMENT) BILL**

*Motion made,* That the Bill be now read a Second time.

**Hon. Members:** Object.
*Bill to be read a Second time on Friday 28 March.*

**DOMESTIC ENERGY (VALUE ADDED TAX) BILL**

*Motion made,* That the Bill be now read a Second time.

**Hon. Members:** Object.
*Bill to be read a Second time on Friday 28 March.*

**BBC LICENCE FEE NON-PAYMENT (DECRIMINALISATION FOR OVER-75S) BILL**

*Motion made,* That the Bill be now read a Second time.

**Hon. Members:** Object.
*Bill to be read a Second time on Friday 28 March.*

**QUANTITATIVE EASING (PROHIBITION) BILL**

**Madam Deputy Speaker (Ms Nusrat Ghani):** The Member in charge has given instruction earlier today that he wishes to defer his Bill to Friday 28 March and will not move Second Reading of the Bill today. We will therefore move on to the next Bill set down for today.

**PETS (MICROCHIPS) BILL**

*Motion made,* That the Bill be now read a Second time.

**Hon. Members:** Object.
*Bill to be read a Second time on Friday 28 March.*

**COVID-19 VACCINE DAMAGE PAYMENTS BILL**

*Motion made,* That the Bill be now read a Second time.

**Hon. Members:** Object.
*Bill to be read a Second time on Friday 28 March.*

**ANONYMITY OF SUSPECTS BILL**

*Motion made,* That the Bill be now read a Second time.

**Hon. Members:** Object.
*Bill to be read a Second time on Friday 28 March.*

**CHILDREN'S CLOTHING (VALUE ADDED TAX) BILL**

*Motion made,* That the Bill be now read a Second time.

**Hon. Members:** Object.
*Bill to be read a Second time on Friday 28 March.*

**HIGHWAYS ACT 1980 (AMENDMENT) BILL**

*Motion made,* That the Bill be now read a Second time.

**Hon. Members:** Object.
*Bill to be read a Second time on Friday 28 March.*

**BRITISH BROADCASTING CORPORATION (PRIVATISATION) BILL**

*Motion made,* That the Bill be now read a Second time.

**Hon. Members:** Object.
*Bill to be read a Second time on Friday 28 March.*

**ILLEGAL IMMIGRATION (OFFENCES) BILL**

*Motion made,* That the Bill be now read a Second time.

**Hon. Members:** Object.
*Bill to be read a Second time on Friday 28 March.*

**VACCINE DAMAGE PAYMENTS ACT (REVIEW) BILL**

*Motion made,* That the Bill be now read a Second time.

**Hon. Members:** Object.
*Bill to be read a Second time on Friday 28 March.*

**NHS ENGLAND (ALTERNATIVE TREATMENT) BILL**

*Motion made,* That the Bill be now read a Second time.

**Hon. Members:** Object.

*Bill to be read a Second time on Friday 28 March.*

**TERMINAL ILLNESS (RELIEF OF PAIN) BILL**

*Motion made,* That the Bill be now read a Second time.

**Hon. Members:** Object.

*Bill to be read a Second time on Friday 28 March.*

**COVID-19 VACCINE DAMAGE BILL**

*Motion made,* That the Bill be now read a Second time.

**Hon. Members:** Object.

*Bill to be read a Second time on Friday 28 March.*

**MARRIAGE (PROHIBITED DEGREES OF RELATIONSHIP) BILL**

*Motion made,* That the Bill be now read a Second time.

**Hon. Members:** Object.

*Bill to be read a Second time on Friday 28 March.*

**MOBILE HOMES ACT 1983 (AMENDMENT) BILL**

*Motion made,* That the Bill be now read a Second time.

**Hon. Members:** Object.

*Bill to be read a Second time on Friday 28 March.*

**SENTENCING COUNCIL (POWERS OF SECRETARY OF STATE) BILL**

*Motion made,* That the Bill be now read a Second time.

**Hon. Members:** Object.

*Bill to be read a Second time on Friday 28 March.*

# HS2 Mitigation Projects: Inflation

*Motion made, and Question proposed,* That this House do now adjourn.—*( Christian Wakeford. )*

2.35 pm

**Greg Smith** (Mid Buckinghamshire) (Con): I am grateful for the opportunity to raise this important issue in the House. I want to focus on the impact that inflation has had on the ability of different institutions to deliver the community projects and mitigations that High Speed 2 previously agreed to in Mid Buckinghamshire. The cases are many in number, but I will illustrate the scale of the problem with particular attention to two pressing concerns: noise mitigation measures for St Mary's church in Wendover and the provision of a new ground and facilities for Wendover cricket club.

HS2 has been deeply controversial across my Mid Buckinghamshire constituency and the wider county. I make no bones about my absolute and total opposition to HS2, which is well documented. Many of my constituents have suffered greatly as a result of the disruption that it has caused, from environmental damage to the impact on homes, businesses and local amenities, as well as the damage to our local infrastructure. That is not to mention the hideous cost to the taxpayer.

**Joy Morrissey** (Beaconsfield) (Con): My hon. Friend mentions the cost relating to infrastructure. One of the huge impacts that goes unrecognised is the impact on roads and road surfaces. Not only are many areas of Buckinghamshire on a flood plain, but our roads get a huge amount of use, which is compounded by the HS2 traffic. Does he agree that that is not compensated for by the HS2 fund in any way?

**Greg Smith:** My hon. Friend and fellow Buckinghamshire Member of Parliament is absolutely right. Day in, day out, we see the impact of thousands of heavy goods vehicle movements having churned up our local road infrastructure. These roads originated as cart tracks and do not have deep substructures, so they get churned up very easily. The impact of such big infrastructure projects on our roads is considerable. I have talked about that many times in the House, and had a great deal of correspondence with Ministers on it. No matter what the infrastructure project, we have to get better as a country at understanding the construction impacts before a green light is given, so that they are properly mitigated. It is incumbent on HS2 to fix what it breaks. East West Rail, to be fair to it, has done that. It has resurfaced a number of roads around the Claydons where it has had compounds, and where there have been HGV movements. It is incumbent on HS2 to do the same.

From the outset, affected community organisations have been forced to negotiate their survival with HS2 Ltd, often at great cost to them and ultimately to the taxpayer, but when a town, village, neighbourhood or community is so brutally impacted by big infrastructure, I argue that there is a moral duty on the promoter—in this case, the state—to mitigate, compensate, and treat the places and people affected fairly. The rising cost of inflation since phase 1 was approved in 2017 has meant that commitments made by the state and HS2 Ltd—indeed, by Parliament, through the hybrid Bill process—are at risk of being delayed, watered down or even abandoned altogether. That is simply unacceptable.

*[Greg Smith]*

One of the most egregious examples of such broken commitments is the case of St Mary's church in Wendover. This historical and much loved place of worship has served the community for centuries, not only providing spiritual support but acting as a hub for local activities and events, particularly music concerts. HS2 Ltd had recognised that the noise impact from construction and, in the future, from passing high-speed trains would significantly affect the church, particularly during services and the concerts I have mentioned. As such, it had agreed to provide noise mitigation measures—above all, very sophisticated sound insulation.

Yet due to rising costs and the pressures of inflation since that particular mitigation was agreed in 2016, we are now being told that these measures may not be delivered in full, if at all. After conversations between the church and the project began more than eight years ago, the undertaking and assurance originally given by the Department for Transport have not been honoured, through no fault of the church, despite the project being contractually obliged to do so.

As such, with inflation, the original £250,000 cost referred to in the U&A will now result in less than 50% of the work being affordable, compared with what it would have covered at the time of the U&A. This was confirmed after I intervened to restart discussions, which had effectively stalled because of the fundamental unwillingness on HS2 Ltd's part to engage meaningfully on what is a key community concern—an attitude that, as I have raised many times in this place, is evident across affected Mid Buckinghamshire communities.

This is completely unacceptable. A commitment was made, and the Government must ensure that HS2 Ltd honours it. The congregation of St Mary's church should not have to suffer excessive noise pollution because of a failure to manage costs effectively or the basic fact of construction inflation over so many years. This is a matter of fairness and upholding trust, and ensuring that historic institutions such as St Mary's are protected for future generations.

My second example of a broken promise relates to Wendover cricket club. As I said earlier, I could go much further afield in my constituency, but Wendover town has been particularly affected. This historic local club has been an integral part of the Wendover community for more than a century, offering young people and adults the opportunity to engage in sport, stay active and participate in community life. It is one of the few clubs across Buckinghamshire that offers the wide range of age groups for teams that compete across the whole country. It is part not just of Wendover's identity, but of Buckinghamshire's identity. By evicting the club from its grounds, HS2 is driving a wedge through everyone and everything there.

Due to HS2's construction, the club's existing facilities were rendered completely unusable—indeed, completely severed in two. HS2 Ltd originally pledged to provide new grounds and upgraded facilities to compensate for the disruption, to the tune of £200,000, through another of these undertaking and assurance agreements, signed in 2017. However, the club has now been informed that due to escalating costs, the new facilities may not be delivered to the standard originally agreed upon—or, worse, that they may not be delivered at all because of HS2's reluctance to pay the cost as it is in 2025, or potentially 2026, if it takes that long.

Acting in good faith, the cricket club has already entered into a groundworks contract that includes approximately £90,000-worth of self-funded items. It is also considering a pavilion contract that currently includes approximately £180,000 of items, again self-funded, on the basis of receiving the U&A resource and its own reserves. The U&A states:

> "The Secretary of State for Transport will, subject to Royal Assent, require the nominated undertaker to contribute the sum of up to £200,000 toward the reasonable costs of Wendover Cricket club relocating both its Ellesborough Road and Witchell grounds".

These delays were wholly the result of HS2, so I ask the Minister for an assurance that, at a minimum, the nominated undertaker—in this case HS2 Ltd—honour the spirit of the U&A to Wendover cricket club with an inflation-adjusted figure.

The impact of this situation on local cricket and community engagement cannot be overstated. Wendover cricket club is a volunteer organisation that is trying to provide a service for the local community and encourage youth and adult sport and fitness. Its coaches teach young people discipline and teamwork and contribute to the health and wellbeing of the entire community. The loss of its promised facilities would be a devastating blow to the area and to my constituency.

I understand the significant economic pressures that our country faces. The war in Ukraine, supply chain disruptions and other global economic factors have all contributed to rising costs. However, those factors must not be used as an excuse to renege on commitments that were made to communities directly impacted by HS2. HS2 Ltd and the Government must ensure that funds are allocated properly to deliver on the promises that were made to the people of Wendover and beyond in my Mid Buckinghamshire constituency. If savings in HS2 Ltd need to be found—and let us face it, they do—they should not come at the expense of community projects that were explicitly agreed to as mitigation measures. Instead, we should look at where efficiencies can be made in the wider HS2 project, to ensure that local communities are not short-changed.

I urge the Minister to take the following immediate actions. First, will he confirm HS2 Ltd's commitment to delivering the promised noise mitigation measures for St Mary's church, Wendover, and ensure that no backtracking takes place? Secondly, will he guarantee that Wendover cricket club will receive the new ground and facilities that were pledged, with no reduction in quality of delivery due to cost-cutting measures? Thirdly, will he ensure full transparency from HS2 Ltd regarding how inflationary pressures are impacting community mitigation projects and explore alternative funding mechanisms to safeguard those commitments? Fourthly, will he hold HS2 Ltd accountable for ensuring that agreed mitigation measures are ringfenced and are not subject to arbitrary cost-saving exercises that disproportionately impact communities?

My constituents did not ask for HS2, but they have had to endure years of disruption, environmental damage and upheaval in our communities. The very least that they deserve is for HS2 Ltd to honour the commitments that it has made to mitigate the very worst excesses

of that impact. It is a matter of integrity, fairness and doing the right thing by the people of Wendover and Mid Buckinghamshire. I look forward to the Minister's response and, hopefully, to working together to ensure that these promises are kept.

2.47 pm

**The Parliamentary Under-Secretary of State for Transport (Mike Kane):** I congratulate the hon. Member for Mid Buckinghamshire (Greg Smith) on securing this debate, on standing up so resolutely for civil society institutions in his constituency and on speaking so eloquently about them.

High inflation, the pandemic, protester action, planning appeals, judicial reviews and lower productivity than expected have had a significant impact on the cost of phase 1 of HS2. The Government have been clear that we are committed to getting a grip on the spiralling costs. As part of that work, the Secretary of State for Transport has published the first HS2 report to Parliament under the new Government, setting out some of the immediate actions and interventions that we will take to regain control of HS2's costs and bring the project back on track. For instance, Ministers have tasked the new chief executive officer of HS2 Ltd, Mark Wild, with producing an action plan to reset the programme and deliver the remaining work as cost-effectively as possible. We have also reinstated ministerial oversight of the project through a ministerial taskforce to ensure transparency and accountability. My Department will update Parliament as the important work of resetting the programme and reinstating oversight progresses.

**Joy Morrissey:** May I say, on behalf of two of the Buckinghamshire MPs, that we stand in solidarity in support for scrapping HS2 altogether? It is never too late for a real cost-saving Minister to scrap the whole thing.

**Mike Kane:** Well, it was the former Prime Minister who came to Manchester during the party conference to scrap HS2 from going from Manchester. I have never known quite such a political insult. It was supposed to balance up our country, yet we will have reduced capacity and there is an impact on Northern Powerhouse Rail. The handling of the project over a number of years has had effects both on the constituencies it is going through, as the hon. Member has so passionately extolled, and on those that are not getting it.

Let me get back to the point that the hon. Member for Mid Buckinghamshire is here to talk about. Following discussions with St Mary's in 2016, during the passage of the High Speed Rail (London – West Midlands) Act 2017, the church was given an assurance and commitment that the project would support it in improving its noise insulation. The assurance provided very clearly for a contribution up to a maximum of £250,000, with no provision for inflation. There are many other HS2 assurances on the public register, including commitments to fund particular works or activities. Some of those explicitly provide for index-linking; others do not. The one given to St Mary's does not. It is worth noting that the House of Lords Committee set up to hear from petitioners against the Bill considered the case of St Mary's, and took the unusual step in 2016 of reporting that the £250,000 offer was generous. Furthermore, I am pleased to report that, since the assurances were given, HS2 has made other improvements to its plans for noise mitigation in the locality of the church. That will reduce the amount of noise reaching the church in the first place.

Taking all that into account, it is not considered appropriate to increase the amount of public funding offered to the church or to increase any other financial mitigations that were fixed, not indexed, at the time they were agreed. There is no evidence that the sums are no longer sufficient. We have inherited a difficult situation on HS2, as the hon. Member said, and our priority now is to get a grip of the cost to the Government.

**Greg Smith:** I am grateful to the Minister for his comments, but does he accept, as a point of principle, that that was not an arbitrary amount of money offered to the church as a top-up for church funds, but was very specifically for noise mitigation purposes? If in 2025 the money promised in 2016 simply cannot deliver that, it is not fair on the church or the many other projects in a similar position. I know that it is not a problem of his making, but it is a problem that the Department for Transport, as the sponsoring body, now finds itself with.

**Mike Kane:** The hon. Member is right. HS2 has clearly already put in some noise mitigation, but I hope he will hear me out for a second.

I understand that agreement has not yet been reached on the mitigation works to be undertaken at the church. As a result, according to the terms of the assurance, the funds cannot yet be released. I encourage the hon. Member, and particularly the parties of HS2 and the church, to focus their efforts on agreeing the works that can be carried out and a timeline for them to begin, so that the available funding can be released and stretch as far as humanly possible. I encourage the parties to get together and begin that negotiation.

I am a social member of Wythenshawe cricket club—although my playing days are long behind me—so I know the value that cricket clubs, and other sports and social clubs, provide not just in sporting terms but in the social glue of cohesion and solidarity. The hon. Member spoke eloquently about Wendover in his constituency. The deal that was asked for had an uplift to cover inflation. I understand that the request is currently with HS2, which is looking into the circumstances of the club and will respond in due course. I hope that he will get an answer very shortly; if he does not, he should please contact me. I will then let the Rail Minister know and we will follow it up. HS2 will have heard his impassioned plea that this historic and successful club does not miss out.

The hon. Member for Beaconsfield (Joy Morrissey) raised road conditions. I am aware that HS2 Ltd has been working closely with Buckinghamshire council over the past few years to improve the way that such road repairs are managed. It has already allocated considerable resources to dealing with that problem. Road repairs are measured against the baseline road condition levels agreed at the start of the project. Either payments are made to councils at current prices or the repairs are undertaken by HS2 Ltd contractors, so they are not affected by inflation. I am pleased that the hon. Member for Mid Buckinghamshire has been far more successful with East West Rail on the road repairs in his constituency.

*[Mike Kane]*

I again congratulate the hon. Member on securing this debate. Let me reiterate that transport is an essential part of the Government's mission to rebuild Britain. We will continue to work with hon. Members and local leaders on ensuring that we get the delivery of infrastructure projects right. As I said, I welcome this debate, as it is vital that we continue to discuss our transport projects openly and transparently.

*Question put and agreed to.*

2.55 pm

*House adjourned.*

# Written Statements

*Friday 14 March 2025*

## BUSINESS AND TRADE

### UK Trade Envoy to Brazil: Lord Evans of Sealand

**The Parliamentary Under-Secretary of State for Business and Trade (Gareth Thomas):** The Secretary of State has today appointed Lord Evans of Sealand to the United Kingdom's trade envoy programme as the UK trade envoy to Brazil.

The United Kingdom's trade envoys will play an integral role in the Government's growth mission and delivering our plan for change by helping to create opportunities for UK business to compete abroad, break into new markets and attract greater inward investment from their markets.

Lord Evans of Sealand will play a crucial role in supporting my Department's growth priorities, in particular through helping deliver the industrial and trade strategies and attracting foreign direct investment to every region in the UK.

The role as a United Kingdom trade envoy is unpaid and voluntary with cross-party membership from both Houses.

[HCWS523]

## CABINET OFFICE

### Infected Blood Inquiry: 13 March Announcement

**The Paymaster General and Minister for the Cabinet Office (Nick Thomas-Symonds):** Yesterday, the infected blood inquiry set out its intention to publish an additional report. The inquiry also published a number of witness statements, including ones provided by the Cabinet Office, the Infected Blood Compensation Authority and a number of people directly impacted by the infected blood scandal and their representatives.

The victims of the infected blood scandal have suffered unspeakably and their needs continue to remain at the forefront of our work. The Government will give careful consideration to the statements published by the inquiry. I am committed to continuing to build trust with people who are impacted by this scandal, and to engaging further with representatives of the infected blood community on the Government response. We will continue to co-operate with the inquiry over the coming months.

The Government are determined to deliver justice for people who are infected and affected as a result of the infected blood scandal. That is why, in the autumn Budget, we set aside £11.8 billion to compensate victims of the infected blood scandal. This is one of the biggest compensation schemes in our country's history, and that is entirely right given the scale of this injustice. In line with our commitment, in December last year the Infected Blood Compensation Authority began delivering this compensation. As of Friday 21 February, 204 people have been invited to start their claim, and IBCA is on track to meet its commitment for 250 people to start their claim by the end of March.

Before the end of March, both Houses will have the opportunity to debate the draft regulations for people who are affected including partners, parents, children, siblings and, in some instances, carers. Once in force, the draft Infected Blood Compensation Scheme Regulations 2025 will provide IBCA with the powers it needs to begin making payments to eligible affected people. We have committed that payments to affected people will start by the end of 2025.

The Government also recognise that delivering justice is much more than financial compensation. I am continuing to work with the Department of Health and Social Care, taking forward the inquiry's recommendations to ensure that everything is done to prevent further such tragedies in the future.

My personal commitment to this work, and the people impacted by it, remains steadfast. The Government are acting on the findings of the inquiry. We will continue to work with the Infected Blood Compensation Authority to ensure compensation is delivered as swiftly and compassionately as possible to everyone who so greatly deserves it.

[HCWS525]

### UK-EU Parliamentary Partnership Assembly Membership

**The Paymaster General and Minister for the Cabinet Office (Nick Thomas-Symonds):** Lord Kirkhope of Harrogate has been appointed as a full representative of the Parliamentary Partnership Assembly in the place of Lord Lamont of Lerwick.

[HCWS524]

## DEFENCE

### Single Source Defence Contracts: Baseline Profit Rate 2025-26

**The Minister for Defence Procurement and Industry (Maria Eagle):** I am today announcing on behalf of the Secretary of State for Defence that the baseline profit rate for single source defence contracts will be set at 8.56%, in line with the rate recommended by the Single Source Regulations Office. This an increase of 0.32% from 2024-25. The Secretary of State has accepted the methodology used by the SSRO to calculate these figures. A full explanation of the SSRO methodology is published on their website.

The SSRO's recommendation on the capital servicing allowance to be applied to single source defence contracts has also been accepted and these rates are set out in table 1. These rates have been published in the London Gazette, as required by the Defence Reform Act 2014.

All of these new rates will come into effect from 1 April 2025.

Table 1: Recommended Rates by the Secretary of State for Defence

| Element | 2024-25 rates | 2025-26 rates |
|---|---|---|
| Baseline profit rate (% on contract cost) | 8.24% | 8.56% |
| Baseline profit rate to apply to contracts between the Secretary of State and a company wholly owned by the UK Government, and where both parties agree (% on contract cost) | 0% | 0% |
| Fixed capital servicing rate (% on fixed capital employed) | 3.26% | 3.64% |
| Working capital servicing rate (% on positive working capital employed) | 3.1% | 4.69% |
| Working capital servicing rate (% on negative working capital employed) | 1.61% | 3.21% |

[HCWS522]

# WRITTEN STATEMENTS

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