Nicola Blackwood

Childhood Cancers

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

7.16 pm

Nicola Blackwood (Oxford West and Abingdon) (Con): Skye was born on 5 November 2008. He was a happy, healthy young boy with a wonderful sense of humour who loved his younger brother, Jesse. In July 2013, he became unwell with nausea and vomiting and after many visits to the GP and the failure of medication to help, he was referred to the John Radcliffe in Oxford where he had a CT scan and was diagnosed with a brain tumour. That was 27 August 2013. Skye was operated on less than a week later and tissue analysis identified the tumour as a grade IV metastatic medulloblastoma, the most commonly occurring paediatric brain tumour. It is an aggressive form of primitive neuroectodermal tumour, which originates in the cerebellum, the part of the brain which controls movement and co-ordination. Although Skye's tumour had been caught early, it had already metastasised throughout the brain and spinal cord. Surgery was quickly followed by what is known as the Milan protocol: four cycles of chemotherapy over 11 weeks, and a further five weeks of hyper-fractionated radiotherapy. After a four-week period of recovery, Skye had high-dose chemotherapy that confined him to hospital for seven and a half weeks.

He then had four weeks rest at home, and was due to head back to hospital on 14 May 2014 for another round of high-dose thiotepa, but a urinary tract infection delayed the treatment until 28 May, which in hindsight was fortunate. Instead of getting stronger, it became apparent that Skye was getting weaker and an emergency MRI scan on 20 May revealed widespread white matter lesions within his brain and spinal cord, which caused a flurry of correspondence between consultants across the UK and abroad. He was quickly started on high-dose steroids to combat the inflammation.

It was initially diagnosed as radionecrosis, which had been brought on by the combination of therapies that he had had to endure. It was later confirmed as radio-chemo neurotoxicity. His parents were told that that was highly unusual and very rare. We now know that a number of other children have also developed severe neurological side effects and the Milan protocol was quickly withdrawn from use in the UK. He was in a state of paraplegia, with double incontinence, and very poor use of his upper limbs and hands. Skye sadly died at home on 29 August 2014.

I did not meet Skye and I only met his parents some time after his death. They are in the Gallery tonight and have demonstrated to me the most extraordinary bravery in the face of losing their child in this most distressing of ways. They have set up Blue Skye Thinking, a charity that supports research so that all children diagnosed with brain tumours will have a better chance of survival and a better quality of life post-treatment. They continue to support many other parents whose children are suffering from cancer today.

I have taken some time to explain Skye's story in detail this evening because it illustrates only too well some of the things that are working in childhood cancer treatment at the moment and some of the things that

need improvement. The overall story of childhood cancer treatment over the past 30 years is a positive one. Eight in 10 children with cancer survive five years or more, compared with just three in 10 in the 1960s. Short-term survival is also high: fewer than 10% of children die within a year of diagnosis and only 2% die within 30 days.

I congratulate the Government on that. Ministers have demonstrated a clear commitment to fighting cancer and the work and money that has been put into the system to improve cancer survival rates are bearing fruit and proving that the money is being well spent. However, we should not allow these headline statistics, encouraging though they are, to blind us to the fact that, rare though childhood cancer is, it remains the leading cause of death in children and teenagers in the United Kingdom. Childhood cancers account for just 1% of cancer diagnoses in the UK. For research purposes that is a small cohort, but 700 children and young people are diagnosed with a brain tumour every year.

Jim Shannon (Strangford) (DUP): I thank the hon. Lady for bringing this matter to the House today, and for allowing me to intervene. Cancer Research UK has given me some figures today showing that 60 people are diagnosed with cancer each day in Northern Ireland. When Josh Martin, a young boy at secondary school, went into hospital to have his appendix removed, he was found to have progressive cancer. His family started the Pray for Josh campaign, which is being supported by his family and by the Churches. It has not only given great comfort to the family but helped to highlight the scourge of cancer and the fact that funding for drugs and help for families are very important. One of the organisations that can help is Macmillan Cancer Support. Does the hon. Lady agree that the support of such organisations can be important for families at times like these?

Nicola Blackwood: The hon. Gentleman is absolutely right to say that this is about not just Government funding but the way in which funds are given, and charities in particular play an important part. The fundraising that they do through individuals is vital.

As I was saying, 700 children and young people are diagnosed with a brain tumour every year, and that makes it the most common form of cancer affecting children and young people. It is also the most lethal. Brain tumours kill more children and young people than any other cancer—around 160 children a year—but despite being responsible for more than a third of childhood cancer deaths, brain tumours receive only 6% of childhood cancer funding. That funding matters because children's cancers are biologically very different from adult cancers and treating them effectively requires specifically tailored research and targeted treatment regimes. At the moment, only about 50% of childhood cancers are part of a clinical trial; the remainder are treated using standard treatment guidelines. As Sally and Andrew Hall discovered, that can have serious consequences. Cancer treatment is harsh at the best of times, and recent studies show that while many survivors of children's cancers go on to live healthy lives, others face long-term disability and reduced immunity. Radiotherapy, the gold standard in terms of its efficacy in treating cancer, can also have damaging long-term consequences for the developing child. This is particularly true of childhood brain tumour survivors, 60% of whom are left with a

life-altering disability. In a few cases, the side effects can be so severe as to be fatal. That is what happened in Skye's case.

The Milan protocol, under which Skye was treated, was a standard treatment guideline, because as with about 50% of other childhood cancers there is no clinical trial available. It has become clear that there is currently no formal infrastructure in place to collect, record and share data, particularly on adverse effects of treatment, about standard treatment guidelines. I understand that before 2008 the responsibility for collecting and sharing data for clinical trials and for standard treatments fell under the remit of the Children's Cancer and Leukaemia Group. Subsequently, clinical trials monitoring was tightened, and the CCLG's "Guide to Clinical Trials" states:

"Clinical trials are very closely monitored by a number of different individuals and organisations. This will include the Chief Investigator…the working group…and

relevant staff within the clinical trials unit. An Independent Data Monitoring Committee may also be established to oversee the conduct of the trial. At a national level, there will be an ethics committee and the national regulatory body. If there are any concerns about the conduct of the trial or the results, a trial may be stopped early."

By contrast, in a letter responding to my concerns about the issue, the National Cancer Intelligence Network, told me that
"all of us in the field accept that (adverse effects in Standard Treatments) is something that should, under ideal circumstances, be a part of the data that we routinely collect. Such data are, however very much more difficult to collect than might be imagined and adverse effects were never part of what the CCRG (Childhood Cancer Research Group) or the CCLG themselves collected outside of a clinical trial. There are no nationally agreed datasets relating to adverse effects and few clinicians systematically collect and collate data of this sort...but it is clearly something that we in the NCIN should be considering."

I am grateful that the NCIN has recognized that these data should be collected and collated, but I do not think that considering doing it is a sufficiently robust or urgent response to the problem, given the gravity of the consequences if a standard treatment goes wrong.
Clearly, in an ideal world all childhood cancers would be the subject of a full clinical trial and new targeted therapies being developed to reduce the long-term risks, but all of us know the challenges associated with research into childhood cancers, where cohorts of rarer cancers can be incredibly small and the ethical issues are more complex, making recruiting participants more difficult. Obviously, I am going to urge the Government to do whatever they can to fund and encourage more research into childhood cancers. I am going to ask the Minister to consider whether having only 6% of childhood cancer funding going to the biggest killer in childhood cancer represents getting the balance right, and I am going to ask her to maintain investment in the Health Research Authority programme to streamline the regulation and governance processes for clinical research in the NHS.
Mr Brian Binley (Northampton South) (Con): May I say that, as a cancer sufferer, I welcome my hon. Friend's courage in bringing this debate? May I pay tribute and offer my sorrow to these parents? May I also say that our Front-Bench team need to take on board the problems? I have seen parents, week in, week out in Northampton general hospital, and I know the case she is making is a real and heartfelt one. I hope that we will get good words from the Minister.
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Nicola Blackwood: I thank my hon. Friend for his intervention and his support. I wish to emphasise the need for investment in the HRA streamlining programme, because I believe it will have a significant impact on reducing the resource and time required to set up trials across multiple sites in the UK, and that can only be good for research into childhood cancers, as it will be for research into all cancers.
I particularly want to focus today on the complete absence of data collection, recording and sharing on standard treatments of childhood cancers in the UK. I am very disappointed that having written to the life sciences Minister about this issue in early December I have yet to receive a substantive response. This issue could not be more serious for the treatment and long-term outcomes of children with cancers, especially brain tumours. Consultants around the country who work with incredible dedication to save the lives of their young patients struggle with their inability to quickly access information about the potential adverse effects of very tough treatment regimes, and it is a problem that we must try to fix. The architecture for collecting the information—the NCIN and the CCRG—is in place, but the lack of a formal data collection requirement and of a single responsible body can have devastating consequences for families.

When Skye's consultant noticed there was an unexpected problem with Skye—the severe white matter damage shown on the MRI scan—she immediately tried to see whether any other clinicians had experienced similar issues. This was important in order to ascertain what other symptoms to look out for, what other treatments could be tried and what other outcomes they had had. Despite the fact that we now know that other children had been suffering in a similar way and that different treatments had been tried, she could not easily obtain this information; it was a matter of phoning around individual colleagues in an ad-hoc way to ask them one by one, and all this took place while Skye deteriorated. Time in such situations is of the essence so this is an unacceptable situation and it cannot be allowed to continue. Had there been a system in place to monitor adverse effects, things might have been different.

In so many ways, we are making tremendous strides in tackling cancer in the UK, including childhood cancer, but the complete absence of monitoring for adverse effects of standard treatments of childhood cancers can lead to life-long disability and death. I hope the Minister will take this away and take urgent action to rectify the situation. I also hope she will arrange for myself and Sally and Andrew Hall to meet the appropriate representatives from her Department to address this issue, once and for all. If details of those adverse effects are properly collected, recorded and shared, we might be able to avoid those consequences in more cases, increase childhood cancer survival rates and improve the quality of life for survivors even more.