

Rare Cancers Bill passes second reading

The Rare Cancers Bill had its first formal debate on Friday and passed the second reading. The bill has been introduced by Edinburgh South West MP Dr Scott Arthur. His was one of the Private Member's Bills chosen last year.

His intention is to address the challenges facing people diagnosed with [rare and less common cancers](#), and part of his inspiration was his father-in-law, Ivor.

He explained: "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.”

[Watch the full debate here on Parliament TV.](#)

Dr Arthur also mentioned four year-old Tilly Anderson who died of neuroblastoma, a rare cancer.

Tilly lived in the constituency and her father, Jonathan Anderson, is a head teacher there. Mr Anderson attended the second reading at Westminster, seeing for himself the support for the new law.

He said: ““I am so happy to see MPs choose to back Scott’s Bill. It’s an essential bit of legislation that will do so much to help prevent what happened to my family happening to others.

“People often see parliament as a ‘boo ya’ shouting club. Scott, by dint of his Bill, unified and dignified the House and provided a catalyst for real change.”

One difficulty s faced by those with rare cancers is that there is a small market for trialled drugs to treat them. Drugs companies naturally are more attracted to developing treatment for those who have a more common cancer where there is more need. The lack of investment means that 82% of rare and less common cancer patients were not offered a clinical trial last year according to a Cancer52 survey.

Dr Arthur said “I am overwhelmed by the support for this Bill across the House. We heard many moving testimonies in the debate about why these changes are so important and how urgent action is needed to make sure that rare cancers are left behind no more”.

Cross-party support

During the debate, more than 20 MPs talked of their personal experiences with cancers, and of how their constituents have been impacted.

Katrina Murray (Labour, Cumbernauld and Kirkintilloch) added to the debate, who lost her father to a brain cancer earlier this year added to the debate, “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.

“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.”

Josh Fenton-Glynn MP (Labour, Calder Valley) shared the story of his brother Alex English who died in January from salivary gland cancer. He said of his brother, “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.

“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”.

Rare cancers

A rare cancer is a cancer that affects no more than 1 in 2,000 people. Whilst individually each cancer may be rare, together these cancers make up 47% of all UK cancer diagnoses and 55% of all cancer deaths.

The Bill, backed by over 35 cancer charities, will make changes to the law to provide greater incentives for pharmaceutical companies to invest in researching treatments for rare cancers.

It will do so by:

- Establishing a tailored service that streamlines patient recruitment for clinical trials, removing barriers to both patients and researchers
- Introducing a new responsibility for the Government to delivery rare cancer research and appointing a National Speciality Lead for Rare Cancers
- Triggering a review of the UK’s “Orphan Drug” regulations, that provide

incentives for companies to test new drugs for common cancers against rare cancers too.

[The full debate can be read here.](#)

