MP Briefing on the Rare Cancers Bill: Second Reading

Context

The Rare Cancers Bill has been brought forward by Dr Scott Arthur MP as a **Private Member's Bill**. Dr Scott put forward the Bill after his father-in-law died of glioblastoma, a type of brain tumour.

The Bill presents a unique opportunity to address the chronic underfunding and lack of research into rare cancers, including pancreatic cancer, which have long been overlooked by policymakers. The Bill defines a rare cancer as one that affects fewer than 1 in 2000 people in the UK.

Despite accounting for 47% of UK cancer diagnoses and 55% of cancer-related deaths in the UK, rare cancers like pancreatic cancer do not receive the same level of focus or research investment as more common cancers. For pancreatic cancer specifically, this has meant survival rates have remained stagnant, with less than 7% of patients surviving five years after diagnosis. This hasn't changed substantially in decades.

Dr Scott's Bill could change this by driving desperately needed research into cancers like pancreatic, which will be crucial in improving survival for this deadly disease.

About the Bill

Dr Scott Arthur MP's Rare Cancers Bill was introduced as a Private Members' Bill. **The Bill has since progressed to its second reading, which is due to take place on 14th March.**

This new legislative proposal presents a unique opportunity to incentivise research and innovation in the treatment of rare cancers. The Bill has the strong support of leading charities in the cancer sector, including the Less Survivable Cancers Taskforce.

As one of the rare cancers that would benefit from this Bill, pancreatic cancer demonstrates why this legislation is so urgently needed. It has a shockingly low survival rate – with half of people dying within 3 months of diagnosis.

Despite its devastating impact on families throughout the UK, pancreatic cancer (like many other cancers covered by this Bill) has not attracted the same focus and research investment as other cancers have in recent years.

There has been a chronic underfunding of research, which has resulted in fewer diagnostic and treatment breakthroughs. Furthermore, pharmaceutical companies lack incentives to invest due to poor survival rates and limited clinical trial options.

What the new law would do

The Bill draws inspiration from the US legislation that has resulted in a stepchange in investment and drive on these cancers, including the Recalcitrant Cancer Research Act and the Orphan Drugs Act. If put into law, it has the potential to transform survival for rare cancers, including pancreatic cancer, by:

- Ensuring there's a named lead in government with a responsibility to support research and innovation for rare cancers. For pancreatic cancer patients, this could mean a strategic focus on improving chronically low survival rates through coordinated research efforts.
- Ensuring patients can get better access to and find relevant research and clinical trials. Currently, many pancreatic cancer patients miss out on potentially life-extending clinical trials simply because they don't know about them.
- Placing a duty on the Government to review (and potentially strengthen) "Orphan Drug Regulations" to incentivise research into rare cancers like pancreatic cancer, where current incentives for pharmaceutical companies aren't strong enough.

Action you can take: Attend second reading on Friday 14th March

- The Bill is now at a crucial stage and it is vital that as many MPs as possible attend the second reading on 14th March and vote in favour to ensure its progression.
- The Private Members Bill is first on the order paper on 14th March.
- The passing of this Bill would mean a significant milestone towards incentivising research into rare cancers, including pancreatic cancer, and drive forward much-needed advancements in treatment and survival outcomes.
- If you are planning on attending second reading, please get in touch with Emily Waller, Senior Public Affairs Manager (Emily.waller@pancreaticcancer.org.uk).

Find out more about Dr Scott's story.