HOUSE OF COMMONS

Petitions Committee

Oral evidence: Brain tumour and childhood cancer research, HC 242

Thursday 27 May 2021

Ordered by the House of Commons to be published on 27 May 2021.

Watch the meeting

Members present: Catherine McKinnell (Chair); Tonia Antoniazzi; Elliot Colburn.

Questions 1 - 10

Witnesses

Peter Realf, brain tumour awareness campaigner; Fiona Govan, petition creator.

Examination of witnesses

Witnesses: Peter Realf and Fiona Govan.

Q1 **Chair:** Thank you for joining us for today's session on brain tumour and childhood cancer research. The Petitions Committee has a proud history of working with Brain Tumour Research, including a major report in 2016. The Committee last took evidence on this topic in early 2019, so we are holding this session to assess what progress has been made since then, as well as to follow up on more recent petitions, and on funding for research into childhood cancers, which was debated in Westminster Hall in December last year.

We are really pleased that two campaigners whose families have been directly by affected by brain tumours are able to speak to us today, as well as research funders, scientific researchers and the relevant Minister and Government officials. I ask our two panel members to briefly introduce themselves.

Peter Realf: I am Peter Realf. My daughter, Maria, launched the original petition in 2016. It was signed by 120,000 people. She was very surprised at the time to find that just 1.37% of all funding for cancer went into research for brain tumours, particularly when she also discovered that it was the biggest cancer killer of children and under-40s.

Fiona Govan: I am Fiona Govan. I am Logan's grandmother. After my then two-year old grandson was diagnosed and died within the year, at that stage, like Peter I learned that less than 2% of cancer research funding is allocated to children's cancers, and that is all of them combined. I started two petitions, one that did not get to the right mark and one that did. Thank you for having me here, and thank you to all the people who signed.

Q2 **Chair:** Thank you for being here. I was going to ask why this issue means so much to you, but it is fairly obvious from the introductions that you have made why you are campaigning on the issue and why it means so much to you. Do you have anything to add, Peter?

Peter Realf: I am grateful to the Petitions Committee, who addressed this first of all in 2015 and have not let it slide or go on to the back burner. It is a real credit to the Committee that they have continued to follow this through.

Chair: Thank you, I appreciate that. I have to say it is a real credit to the petitioners and the campaigners on this issue as well. Tonia, do you have some questions?

Q3 **Tonia Antoniazzi:** Before I start my questions, I would like to say that I am the chair of the all-party parliamentary group on cancer.

Hello, Fiona, it is nice to see you again. I led on your petition back in 2019. You started two petitions on childhood cancer research, including the one that was debated, led by me in December. Were you satisfied with the response that the Minister gave in the debate?

Fiona Govan: In one word, no. In the debate and in the course of the written response, there were lots of references to things like the Tessa Jowell Brain Cancer Mission, Brain Matrix and the National Institute for Health Research. As far as I am aware, the Tessa Jowell Brain Cancer Mission and Brain Matrix did no work on childhood cancers at that time, and have not to date, so I think it was wrong to refer to that.

The way the National Institute of Health Research classifies its data does not separate adult and childhood cancers. I am sorry, but I do not think there is any evidence to support referring to brain cancer funding as including childhood cancer—DIPG. I am not aware of any direct research into DIPG.

All those issues concerned me. I was wholly moved by many of the speeches by the MPs. There were so many really good ideas, but a significant number of those were not even addressed in the Government's response.

Q4 **Tonia Antoniazzi:** You have spoken about the difference with the research, and that it does not separate between childhood cancer and adult brain tumours. Your petition called for ring-fenced funding for research into DIPG and other childhood cancers. Why do you feel this is so important? I know why it is important to you, and we spoke about it in the debate, but is there anything you want to add?

Fiona Govan: It is an orphan disease. There is no mechanism at present to factor in the years of life lost. These are small people who do not get to grow up. I think the words of my MP, Patricia Gibson, were so on point. She made the point that this is a life unlived. That is not right. It is not the normal order of things.

I lost both my parents to cancer. My dad was in his mid-80s and my mum was in her mid-70s. It is sad, but it is not tragic. Logan was three. He did not get to start school. He did not get to grow up. He did not get to meet a girlfriend or a boyfriend. He did not get to have children. That is because this is ignored. There isn't a mechanism, so the funding goes towards the bigger cancers and the ones with more support in their awareness raising.

You usually see MPs and other public figures on the BBC and all those kinds of places sporting pink ribbons for breast cancer awareness. You almost never, ever, see childhood cancer awareness ribbons in September. Because of that, Logan got the same treatment in 2016 that Neil Armstrong's daughter got in 1962. The dial has absolutely not moved for these children. I just feel it is so important that that changes, and it has to come from Government.

At the moment, we are relying on small charities like Abbie's Army to fund the research. That was behind the petition. I couldn't run marathons, but I could walk them to try to raise funds, but that will never be the same amount of money that a Government are in a position to give if they care about young people's cancers.

Q5 **Tonia Antoniazzi:** Fiona, the Government stated that there are recent initiatives on brain tumour research. Do you think they will benefit DIPG and other childhood brain cancers? Are you hopeful?

Fiona Govan: I have yet to see clear evidence that it will benefit childhood cancers or DIPG specifically. I go back to the issue of transparency. It is simply impossible to tell from the figures. I acquired the National Cancer Research Institute funding analysis for childhood, adolescent and young adult cancer. There is an issue of transparency between adult and child spending. The NCRI report lumps in Government funding with charity funding. You cannot tell whether it is an adult or a childhood cancer, and you equally cannot tell if any of it is coming from Government funding directly.

I am sure that Peter will have words to say on this. From his family's petition came the Tessa Jowell Brain Cancer Mission, and of the £40 million research funding that was committed to that, I understand that less than a quarter has been spent three and a half years later. No, I do not have a huge amount of confidence. I wish I could.

Tonia Antoniazzi: Thank you, Fiona.

Chair: Elliot, do you want to ask some questions? Peter, I know that you might have something to add to what Fiona said, but I am sure that Elliot will ask you something that you will be able to add it to.

Q6 **Elliot Colburn:** Thank you, Chair. Peter, you gave evidence to this Committee in 2016. You were subsequently appointed a member of the Government working group on brain tumours, which reported in 2018. What progress do you feel has been made since that report was handed over in 2018?

Peter Realf: I think there has been some progress made, and that is encouraging. What struck me in reading the document that was produced by the Petitions Committee in 2016 is how much of it largely seems untouched. There were so many recommendations that do not seem to have been addressed at this point.

In terms of the funding, I have made two freedom of information requests. I have also asked a question through my MP as to what funding has been achieved and how much has been spent. I find it very difficult to get an actual answer because all three documents vary, and they vary by quite substantial amounts.

There is something else coming out which is about spend versus allocated funding. There may be funding that is allocated, but has it actually been spent yet on research? In some of the issues that I have looked at, it does not appear that it has. I am disappointed that we are not much further on than we were five years ago.

For brain tumour patients, the one thing they do not have is time; 88% of brain tumour patients die within five years. They do not have time for us to talk about it for a long period. We need to get on with this, and we need to fund some of the research.

Q7 **Elliot Colburn:** Thank you very much, Peter. That is incredibly helpful. You touched on the fact that there are still quite a lot of the report's recommendations that have not really changed over the last few years. Of those conclusions, what do you think are most in need of being addressed today? You mentioned funding. Is there anything else in those recommendations that is most urgent to be addressed?

Peter Realf: Yes. I think there are issues about diagnosis. The Petitions Committee report highlighted quite clearly how often patients go back to their GP time and time again and fail to get a diagnosis. A large proportion of patients—over half, I gather—end up in A&E, having had a seizure, and that is when they are diagnosed.

Having said that, unless we invest in research and come up with some solutions to the issue, and a cure at some point, diagnosing earlier, as my daughter said in her original documents, just means that patients have a longer walk to the grave. It simply is not good enough.

Q8 **Elliot Colburn:** Thank you. Finally, this is to both Fiona and Peter. Ministers on this call will have heard what you have both said. Officials from the Department of Health will have heard as well. When we begin our questioning later in this afternoon's session, what one message or question do you want us to put to them? What is the most important thing you want us to take away from your evidence today?

Peter Realf: I would earnestly ask the Minister to champion the cause of brain tumour patients and to really take this on board. Look at the shocking statistics. Both Fiona and I, I am sure, can give you plenty of those. Basically, look at the statistics and champion this issue in Government.

Maria's original petition in 2015, which was actually launched to mark the first anniversary of my son's death, was to increase funding to give parity of funding with other cancers. At that time, we were calling for £30 million to £35 million. If you look at the £40 million over five years, that is nowhere near what the petition was asking for. It is nowhere near what those 120,000 people were asking for when they signed the petition. We need to get parity of funding, and it needs to happen urgently.

Q9 **Elliot Colburn:** Thank you very much, Peter. Thank you for your evidence. Fiona, I will come to you with the same question. What one message or question do you want us to put to the Minister later on in this session?

Fiona Govan: This comes from another parent, and I think it is spot on. "When will the Government replace numerous words with a viable action plan for funding research into childhood cancers with the lowest survival rate?" That is specific—how much, and how will it be allocated. It is measurable—give us transparent data. It is realistic and properly targeted. Perhaps, in 10 years' time, Logan would not have needed to die.

Elliot Colburn: Thank you very much, Fiona. Thank you both for your evidence.

Q10 **Chair:** Thank you, Elliot, and thank you, Peter and Fiona. Your session with us as a panel has been quite short but incredibly powerful in that short time. Are there any final comments that you want to make before we go to the next panel? We will take evidence on this issue and then, obviously, put the matter to the Government as well.

Peter Realf: In 2008, when my son was diagnosed with a brain tumour, we knew very little about brain tumours, probably like a lot of other parents. His outlook was absolutely hopeless. Research gave him some hope. He hoped that things would change. He hoped that there would be a way to stop the tumour or delay its growth. That was the one thing that was giving him some hope. Sadly, it did not happen, and he died in 2015.

My hope for other families finding themselves in a similar situation lives on through research. We need to do this research. The Petitions Committee said in their report that successive Governments had failed brain tumour patients and their families for decades and that the Government must now put that right. That is very true.

Chair: Thank you, Peter. Fiona, is there something you want to add?

Fiona Govan: I suppose, more than anything, it would be to look to other countries that are doing what we are asking our Government to do. The clear example is the Australian Government's medical research futures fund. They have allocated specific money and are looking to provide grants specifically for childhood cancers.

I understand, "No hope," because so many families who are newly diagnosed make their choice: "Are we going to try and scour the world to find a trial that might give us a few more months or the hope of a cure, or do we do as the hospital tells us and take our children home to make memories because they will die within a year?" That cannot be right in today's society, when you can spend £12 billion on a vaccine for Covid, but you cannot find a fraction of that so that children can grow up.

Chair: Thank you both very much, Fiona and Peter, for the incredibly powerful evidence you have given today.