

PE1783/E

Petitioner Submission of 19 May 2020

I am grateful for the opportunity to respond and for the responses which Children with Cancer UK (hereinafter CWCUK), Abbie's Army (AA), Cancer Research UK (CRUK) and the Scottish Government (ScotGov). I am also so grateful that the Scottish Parliament petitions committee does not put the insurmountable hurdles before petitioners that the UK Government petitions committee does (where I am currently on the 3rd petition started and unlikely to make the 100,000 signatures required for them to even to consider a debate).

I am not going to use up the limited space available to me for this submission rehearsing at any length my own, or rather my grandson's experience, other than to say that when he was diagnosed we had never heard of DIPG (Diffuse Intrinsic Pontine Glioma) and I never imagined that there were still childhood cancers that are terminal on diagnosis. I would also flag up that what I have learned focuses almost exclusively on DIPG albeit the petition is directed towards all of the childhood cancers with depressingly awful survival rates.

I would, in the interests of disclosure, say too that I am a committed supporter of CWCUK and AA but far less so of CRUK. When my grandson was diagnosed I was appalled to learn that CRUK allocate less than 2% of their research funding to all childrens' cancers, that they use children with cancer in around 40% of their fundraising materials and it is only if you specifically ask for your donation to go to their "kids and teens" fund that children will specifically benefit from that donation (if you do not do so 98% will go to research into adult cancers predominantly breast cancer (with a 90%+ survival rate), lung and colo-rectal cancers).

I fully appreciate the wonderful work CWCUK, CRUK and other cancer specific charities have done to massively improve the five-year survival rates for many of the common childhood cancers through research and raising awareness. With DIPG the earlier the diagnosis, the sooner you learn your child will die, but for so many others raised awareness leads to earlier diagnosis and better outcomes (I would pay particular tribute in this regard to Headsmart (for brain tumours) and the Grace Kelly Ladybird Trust (more generally) and to my MSP Kenneth Gibson for asking NHS Ayrshire to ensure that these awareness materials were to be found in local GP surgeries etc – **for what it's worth I think this should happen across Scotland and in National initiatives such as the red book and maybe even the baby box – depressing and alarming as this is, it may save lives**). I would also strongly support initiatives to raise awareness amongst GPs and A&E staff (my grandson was taken to the GP and A&E outpatient clinic on several occasions before an MRI was ordered and he was diagnosed).

I can only echo all that Amanda Mifsud of AA says. She, like us, lost her child to DIPG (and did not have, as we do, the comfort of a sibling to thereafter keep her going) and all her maternal love and limitless intellectual capacity is now directed towards finding the cure in memory of Abbie, my grandson and so many others and for every family to come (for DIPG c 30 -40 children every year). She, like I, is angry that there have been no improvement in survival rates for DIPG in decades. What she has not written is that this family inspired charity has funding over £1 million of research into DIPG

which, I suspect, is £1 million more than Government and mainstream charities have done.

Whilst batting my own head against the brick wall that is the Westminster Government and petitions committee I have been constantly fobbed off with responses that refer to national funding initiatives such as the Tessa Jowell Brain Cancer Mission but the UK Government is UNABLE to advise how much of the £40 million funding has been allocated to either DIPG specifically or childhood cancers more generally (decision notice: FS50851572). The way in which the UK National Institute for Health Research (“NIHR”) record their data makes it IMPOSSIBLE to determine what percentage is allocated to adult versus paediatric cancers. I do not know if the Scottish equivalent does any better.

I am certainly not oblivious to the fact that the incidence of say breast cancer is around 1 in 10 and childhood cancer is 1 in c280 but the way in which Governments and pharmaceutical companies prioritise research DOES NOT take account of the facts (a) of survival rates – i.e. 90+% versus for DIPG 0% AND (b) years lost – average age of adult cancers c 66 years (17 years lost), children 6 years (71 years). In these respects Members may wish to refer to Dr David Walker’s 2016 piece in The Telegraph: <https://www.telegraph.co.uk/news/health/children/12140533/We-need-to-think-about-how-we-fund-childrens-cancer.html> .

It seems to me that UNLESS funds are ringfenced for childhood cancer research funder will continue to prioritise the adult cancers and researchers will do the same – they need the funding. There is an amazing Australian researcher, Matt Dun, who was researching children’s leukaemia’s when his own daughter was diagnosed. He now works on DIPG full time and appears to have successfully brought his funders along with him. My answer to CRUK response is childhood cancer research requires to be ringfenced, highlight notices (discussed in relation to the aforementioned Tessa Jowell Brain Cancer Mission) need to be not just for proposals for brain cancer research but also specifically for paediatric brain cancer research. They refer to 8 in 10 average survival for cancers affecting children and young people and then concede for some types it is “a lot lower” – 0%, 20% is not just a “lot lower”. They talk about this being an important area for them but I do not consider >2% to be eloquent of a priority and I personally believe that their advertising is misleading (when I speak to people about this most, including sensible professional people like our local pharmacist) are staggered that the % allocated is so small. Of course I appreciate the work that CRUK does do for our children but cannot help but wonder whether my grandson might still be here if the same effort (over £40 million per year consistently) that they make for breast cancer had been made for childhood cancers (a total of around £6 million a year). There is so much to be done and this will only happen when Governments, charities and the public focus on these awful cancers.

I wish to highlight a few points from various awareness groups Facebook posts (many from September, childhood cancer awareness months):

- (From 2019): In the last 6 years, 77 new drugs have been developed for adult cancers WHILE in the past 77 years only 3 drugs have been developed for childrens cancers.

- (From 2019) Paediatric cancer mortality rates have dropped more than 50% in the past 40 years while mortality rates for DIPG have remained constant over this period.
- (From 2019) More than 95% of childhood cancer survivors will have significant health related issues by the time they are 45 years old.
- (From 2019) Only 4 cancer medications have been specifically developed and (US) FDA approved for use on children SINCE 1980.
- (From 2019) “7,500 children and young people Worldwide died of cancer in September. It’s not rare.”
- (From 2019) Worldwide: every 2 minutes a child is diagnosed (300,000 per annum); average at diagnosis is 6 years, in 80% of kids with cancer the cancer has ALREADY spread to other areas of the body by the time it is diagnosed; one in 5 children diagnosed will NOT survive.

The truth is no-one wants to believe that it could happen to their child or grandchild so they look away from awareness leaflets/ posts etc, they assume (without checking) that when an advert features a smiling happy bald child when they do donate they will be helping children with cancer, they choose to hear the heartening statistics that five-year survival rates for leukaemia and lymphomas are now around 90%. No-one wants to think about the 0% rate for DIPG, 30% for metastasised osteosarcoma (per CWCUK) and less than 10% for relapsed neuroblastoma (per Solving Kids’ Cancer website: www.Solvingkidscancer.org.uk).

I fully appreciate that the timing of my petition had ended up being disastrous as we face an unprecedented pandemic with huge health and economic consequences. My father-in-law died earlier today (19/05/2020) of Covid-19 in a Scottish care home, and I understand that the vast majority of our focus right now needs to be on finding an effective treatment/ vaccine – the numbers suffering and dying and the fact that every single one of us is potentially exposed to this virus make this so. However, while the numbers are very different, most childhood cancers have no known cause so EVERY single child is at risk. I lost both my parent to cancer, my father in his 80s my mother in her 70s, they both lived their lives, loved, had family, home, careers – there is a peace in knowing they had a “good innings”. Believe me, there is no peace in the death of a 3 year old who will never get the chance for any of those things. Please, this NEEDS to be recognised in the ScotGov’s new Cancer Plan for Children & Young People, in finding incentives to ensure drug companies commit to doing this less profitable research alongside the ones they build their fortunes on and I beg the committee to bring its influence to bear on ensuring that it does.

In summary:

- Please act to improve awareness through Government run schemes and NHS Scotland for earlier diagnosis;
- Please act to ensure ScotGov put real, ringfenced funding into researching these cancers (and ensure that the way such allocations are recorded is transparent);
- Please explore ways in which pharmaceutical companies might be encouraged in Scotland to allocate any/ more of their efforts in finding cures and kinder treatments for childhood cancers;

- Please use your public profile to support smaller charities who do so much – let's see EVERY MSP wearing a yellow ribbon throughout September for Childhood Cancer Awareness Month and encouraging media etc to do the same (as many already do for breast cancer awareness month), let's see (as Mr Gibson has done for DIPG Awareness Day) recognition of some of the other awareness days in Parliament; and
- Please call for transparency in materials issued by charities – if someone wants to give to CRUK they should be aware that less than 2% of their donation will help children with cancer.