



The Scottish Parliament
Pàrlamaid na h-Alba

PUBLIC PETITION NO.

PE01783

Name of petitioner

Fiona Govan

Petition title

Public Awareness and funding for childhood cancers with low survival rates

Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to raise public awareness of harder to treat childhood cancers and to provide additional funding to finding cures.

Action taken to resolve issues of concern before submitting the petition

I have contacted Kenneth Gibson MSP.

Petition background information

My grandson was diagnosed with Diffuse Intrinsic Pontine Glioma (DIPG) in November 2016, shortly before his 3rd birthday. DIPG currently has 0% survival rate.

My grandson had 6 weeks of palliative radiotherapy at the Beatson Institute in 2016/17. After diagnosis, we made wonderful memories with him for 11 months before he died age 3 on 17 October 2017.

When childhood cancer entered our family's life we became aware of the lack of progress not just for DIPG but also for some other childhood cancers, especially on relapse (relapsed neuroblastoma has just a 20% survival rate), and the woeful lack of funding for childhood cancer research. Cancer Research UK allocate less than 2% of their funding to all the childhood cancer combined.

While such cancers are relatively rare that does not matter when it is your child or grandchild. We need more awareness and research and, more than anything, a cure.

The average age for diagnosis of childhood cancers is 6, the average age for most is in the 50s or 60s therefore years lost (when fatal) is almost 70 versus 20-30 years. This does not impact upon funding decisions. In the last 6 years 77 new drugs have been developed for adult cancers: in the last 77 years only 3 cancer medications have been specifically developed for children.

My grandson, just like your child or grandchild, deserved to grow up. He was

my grandson, just like your child or grandchild, deserved to grow up. He was diagnosed with a fatal brain tumour in relation to which no meaningful progress has been made towards a cure in decades. Treatment for DIPG has not advanced meaningfully in over 50 years. My grandson received the same palliative treatment in 2016 that Neil Armstrong (the astronaut's) daughter received in 1962.

On 14 June 2017 Kenneth Gibson MPS tabled business motion, S5M-06094 asking MSPs to raise awareness of DIPG.

I have also previously lodged two petitions with the UK Parliament. My DIPG petition (239638) had 41,675 signatures after 6 months. My other petition (269637) had 37,664 signatures after 2 months but was closed due to the General Election. The UK Government's response at 10,000 signatures to both my petitions was utterly woeful.

Unique web address

<https://www.parliament.scot/GettingInvolved/Petitions/curechildhoodcancer>

Related information for petition

Do you wish your petition to be hosted on the Parliament's website to collect signatures online?

YES

How many signatures have you collected so far?

0

Closing date for collecting signatures online

19 / 02 / 2020

Comments to stimulate online discussion

Should the Scottish Government provide direct funding for research into cures for harder to treat childhood cancers?

Should the Scottish Government raise public awareness of harder to treat childhood cancers?