

Briefing for the Public Petitions Committee

Petition Number: [PE1783](#)

Main Petitioner: Fiona Govan

Subject: Public Awareness and funding for childhood cancers with low survival rates

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

Background

The petitioner is concerned about the lack of focus on research on, and treatment for, childhood cancers in Scotland.

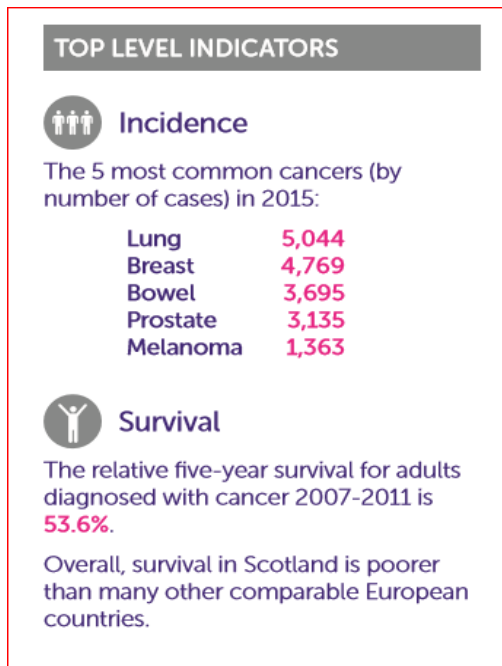
According to [NHS Inform](#):

“Cancer diagnoses in children and young people are rare. In Scotland, about 150 new cases are recorded each year for children aged up to 16 years and 180 new cases are recorded for young people aged 16 – 24 years.”

[Cancer research also publish data on the incidence of childhood cancers across the UK](#) which is broken down in various ways, including by age, sex and UK country. They state that childhood cancer incidence represents less than 1% of the total cancer incidence across the population.

Teenagers and younger adults can develop cancers most commonly seen in children, although sometimes they develop cancers that are more common in adults.

By way of comparison with the figures given above for childhood cancer incidence in Scotland, the incidence of adult cancers (the five most common) in Scotland was cited by [Cancer Research in March 2018](#) as follows:



Diffuse Intrinsic Pontine Glioma (DIPG)

The petitioner specifically refers to this childhood cancer, for which there is no cure and for which treatment is, therefore, always only palliative.

According to the website of a US organisation, DIPG.org, dedicated to this particular cancer, DIPG:

“is a type of brain tumor found in an area of the brainstem known as the pons. The name ‘diffuse intrinsic pontine glioma’ describes how the tumor grows, where it is found, and what kinds of cells give rise to the tumor.

- **Diffuse** means that the tumor is not well-contained – it grows out into other tissue so that cancer cells mix with healthy cells. For this reason, it is impossible to surgically remove DIPG tumors without damaging healthy tissue, making it very hard to treat.
- **Pontine** indicates that the tumor is found in a part of the brainstem called the pons. The pons is responsible for a number of important bodily functions, like breathing, sleeping, bladder control, and balance. Because these functions are vital to survival, the pressure from the growing tumor is very dangerous.
- **Glioma** is a general term for tumors originating from glial cells. Glial cells are found throughout the brain. They make up the white matter of the brain that surrounds and supports the neurons (neurons are cells that carry messages in the brain). Gliomas can form in different areas of the brain. DIPG occurs in glial cells in the pons.”

DIPG.org is closely linked to a charity called [‘The Cure Starts Now®’](http://TheCureStartsNow.org), also US based, but which supports research worldwide into DIPG and other childhood cancers.

[Macmillan Cancer Support provides information](#) on a number of childhood cancers.

NHS treatment and services for children with cancer in Scotland

The [Managed Service Network \(MSN\) for Children and Young People with Cancer](#) is a group of healthcare specialists that work within NHS Scotland Health Boards. The core aims of the network are:

- Cancer services for Children and Young people will be delivered as a single and sustainable service across Scotland, and national multi-disciplinary team working is pivotal to delivering this.
- Every child, teenager and young adult with cancer in Scotland will be enrolled into and treated on a clinical trial where one is available.
- Care pathways will be reviewed to ensure that these deliver consistent, safe and effective care for all patients.
- Outcome measures will be developed against which services can be evaluated.
- There will be an integrated and systematic approach to long term follow-up based on risk.
- The experience of patients, and their parents or carers, will be harnessed to inform the shape of services for children, teenagers and young adults with cancer.
- We will ensure involvement of third sector partners in key decisions about services for children, teenagers and young adults with cancer.
- We will ensure equity of access to the best possible care and will strive to improve outcomes for children, teenagers and young adults with cancer in Scotland.

Initially, most children with cancer are cared for in their local hospital. However, for certain specialised treatments there are different national/network centres in hospitals in Aberdeen, Inverness, Dundee, Edinburgh, Glasgow, Dumfries and Galloway.

There are 'shared care' centres in Dundee, Inverness and Dumfries where care is delivered jointly by the clinicians in those centres in conjunction with another centre such as Aberdeen, Glasgow, or Edinburgh. Some services (e.g. bone marrow transplant) will be carried out in one location only (Glasgow). These pathways of care are designed to give access to the most appropriate and most rapid treatment for all children, teenagers and young people with cancer in Scotland. There are a number of resources and substantial information on the MSN network linked to above.

Research

The main co-ordinating centre for research into childhood conditions appears to be based at the children's hospital in Aberdeen. The [NHS Research Scotland Children's Network](#) is funded by the Scottish Government's Chief Scientist Office (CSO) and aims to increase the safety, efficacy and availability of medicines and health care for children by supporting high-quality clinical trials. Research can be supported by resources at the centre in Aberdeen through the provision of things like recruitment for trials, research nurses, data collection and research governance. There is also a Cancer Clinical Trials Unit in Scotland, [CaCTUS](#), which is a partnership between trials units in Edinburgh and Glasgow, and which is linked in with other units across the UK. The [National Institute for Health Research \(NIHR\)](#), which is UK wide, lists current research projects under a number of headings. The list under the search for 'childhood cancers' brought up [this selection](#) of studies.

Other resources are provided on the NHS Scotland Research website: <http://www.nhsresearchscotland.org.uk/research-areas/cancer/resources>

Scottish Government Action

The [Cancer Plan for Children and Young People in Scotland 2016 - 2019](#), which was launched in February 2016, sets out the priorities for the MSN (see above) over the next three years. The Plan provides priority areas for action, such as data, infrastructure, research, care after treatment and national consistency, and discusses how each will be addressed.

The Scottish Government and the MSN are currently working on the next Children and Young People's Cancer Plan for 2020-25 which will be available in 2020.

Scottish Parliament Action

One of the petitioner's MSPs, Kenneth Gibson, has lodged several motions in support of the campaign about the particular childhood cancer, highlighted by the petitioner, during the current session:

<https://www.parliament.scot/parliamentarybusiness/28877.aspx?SearchType=Simple&Keyword=DIPG&ExactPhrase=False&DateChoice=4&MSPIId=2110&SortBy=DateSubmitted&ResultsPerPage=10>

A number of parliamentary motions and questions have been laid about childhood cancer in the current session of the Scottish Parliament; <https://www.parliament.scot/parliamentarybusiness/28877.aspx?SearchType=Simple&Keyword=childhood%20cancer&ExactPhrase=True&DateChoice=4&SortBy=DateSubmitted&ResultsPerPage=10>.

Also see: <https://beta.parliament.scot/parliamentary-debates-and-questions#evntpdq&query=childhood+cancer&fcts=&dtf=1/1/0001%2012:00:00%20AM&dt=1/1/0001%2012:00:00%20AM&dtset=78db02c79507407a8df319e9d7ac424e&pgch=1&pgcm=1&wap=1&tab=0>

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22 January 2020

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