

Mr Richard Case
*Address omitted
from online version*

29th February 2016

Mr. Huw Irranca-Davies MP
House of Commons
Westminster
LONDON
SW1A 0AA

Dear Mr. Irranca-Davies,

RE: Cian Case and Childhood Cancer

I am writing to you on [Rare Disease Day 2016](#) as a concerned constituent and father.

At the end of November 2015 my 4 year old son Cian was admitted into the Royal Glamorgan Hospital with acute stomach pain.

Urine tests, blood tests and organ scans could not identify the cause of the problem, and it was not until he started to develop a loss of sensation and mobility issues affecting his lower limbs, did the doctors realise that the issue was more serious and complex than they anticipated.

An MRI scan identified a tumour growing on Cian's spine.

He was rushed to the University Hospital of Wales, Cardiff, where an immediate operation was performed to safely remove as much of the tumour as was possible, and he was admitted to Noah's Ark Children's Hospital.

The trauma of that operation left Cian completely paralysed from the waist down with the neurologists sceptical about how much mobility he could ever recover.

We received the devastating diagnosis on 7th December 2015 that the tumour was cancerous, and classified as [Atypical Teratoid Rhabdoid Tumour \(AT/RT\)](#).

AT/RT is an extremely rare and aggressive cancer that affects the Central Nervous System, and is mainly diagnosed in very young children. As such, the survival outcomes are not very favourable.

In addition to the tumour on the spine it was also established that 'seeds' of the cancer had also spread to Cian's brain.

Cian's health rapidly deteriorated shortly after diagnosis and a decision was made to administer emergency chemotherapy in an attempt to improve his condition to a point where he could receive further life saving treatment.

Fortunately, Cian did respond positively to that initial dose of chemo and is now following the EU Treatment Protocol which was published in 2009.

This protocol consists of 9 courses of intensive chemotherapy and 6 weeks of daily radiotherapy to the affected areas (in Cian's case his entire brain and full length of his spine).

As I write this letter I can inform you that Cian has received 3 courses of the chemotherapy and has also completed the entire radiotherapy regime.

On top of this Cian receives daily physiotherapy to try to improve his mobility.

Cian has been hospitalised ever since he was first admitted to hospital in November, with occasional home visits only recently being possible. This meant that during this time he has had an unconventional Christmas, New Year and 5th Birthday (on Valentine's Day).

I am pleased to report that Cian is continuing to make very good progress, which is exceeding the expectations of his consultants; and his mobility is improving weekly, which is defying his original prognosis.

Although I am able to provide this positive update, there are many challenges that lay ahead for Cian, and us as a family (Cian has a 9 year-old brother Dylan, and a six year old sister Bethany):

- As stated, the survival outcomes for this form of cancer are low, and the fear of a downturn in his health, or future recurrence is very real.
- **When Cian recovers from the cancer** he will still have to overcome his mobility issues. It is still unknown if he can ever regain full movement in his lower limbs.
- The long-term side effects of his chemotherapy and radiotherapy are frightening:
 - Cian's growth will be affected and he will never reach the height that he would have otherwise achieved. He will require long-term steroid treatment for this.
 - He will not attain as high an IQ and may require special educational assistance.
 - Cian may develop behavioural problems.
 - He is likely to have issues relating to puberty and fertility, which may require hormone therapy.
 - There is an increased risk that Cian will develop other cancers in the future.
 - Treatments are likely to affect future function of other vital organs.

As a Member of Parliament of a rural constituency, you will be aware that this diagnosis and situation not only affects Cian and his family, but also the wider community.

Primary schoolchildren who should be experiencing the joy and innocence of childhood, are now exposed to the horror of cancer as one of their classmates battles this terrible disease; and the rest of the community becomes a little more fearful for their loved ones, as a rare disease to which people often think could never happen to us, becomes more a reality when it appears on your doorstep.

You are also in a unique position as a Member of Parliament who can influence issues relating to research funding at a UK level; and also a candidate to become a Welsh Assembly Member, who has devolved control of the NHS in Wales.

[I have recently signed a Parliament e-petition](#), asking for more funding into the causes, diagnosis and treatment of brain tumours.

It is my perception, that as cancers such as Cian's are rare, there is less effort and resource being expended on them by Governments, Pharmaceutical Companies, Research Agencies and Charities, than on some more notable cancers. This may be because the amount of time and money spent in these areas may not yield the same level of results and recognition that they crave.

Looking at cancer research in this statistic based approach, would be unethical and short-sighted, as an impact assessment approach would demonstrate that research into cancers that affect children and the young would have longer term benefits. For example, a child who survives cancer could have a long life with expensive and complex medical needs as a result of their treatment, for which the state would have to meet. If new treatments were more targeted and 'kinder', then the outcomes for the patient, the community and the country would be much better.

I am not saying that funds should be diverted from other cancer research or treatment. [As a family we have already successfully campaigned for improved genetic testing for Welsh breast cancer patients, following my wife's diagnosis and treatment in 2012/2013.](#)

As the Brain Tumour e-petition collected in excess of 120,000 signatures I respectfully ask you to support the need for a Parliamentary Debate, and to champion the cause.

As today is also Rare Disease Day, I would ask that you also ensure that rare diseases are not forgotten in terms of research for better diagnosis, improved treatments and potential cures.

[I noticed a tweet from you earlier today to "support Cancer Research UK's policy for early diagnosis calls in Wales"](#), so I hope that you will be sympathetic to my request.

You can follow Cian's progress through his treatment via [his blog](#) or [Facebook Page](#); and I invite you to visit the Rainbow Ward at Noah's Ark Children's Hospital to see Cian and the other inspirational children there who are courageously fighting their battles with cancer.

I want to conclude this letter by bringing to your attention the following:

- The exceptional care that Cian has received from the staff and volunteers from the Royal Glamorgan Hospital, Noah's Ark Children's Hospital for Wales and Velindre Cancer Centre.
- The amazing response by Rhondda Cynon Taf Council and Llanharan Primary School to ensure Cian's longer term community needs are considered.
- The overwhelming support we have received from the community of Llanharan (and surrounding communities).

Yours sincerely,

R. M. Case

Richard M. Case