



Young Lives vs Cancer  
1 St John's Lane  
London  
EC1M 4AR

The Rt Hon Rishi Sunak MP  
Prime Minister  
10 Downing Street  
London  
SW1A 2AA

12<sup>th</sup> September 2023

Dear Prime Minister,

We are writing to you to submit the enclosed petition to the UK government, calling for the establishment of a **Young Cancer Patient Travel Fund**.

Every year in the UK over 4,000 children and young people under 25 are diagnosed with cancer<sup>1</sup>. That means every day 12 children and young people hear the news they have cancer. Nine children and young people die from cancer every week in the UK, making it the biggest killer of young people by disease.

Having cancer as a child or young person is different to older adults. Whilst there are some commonalities with adult cancer, there are issues and challenges that are specific to children and young people - from the type of cancer they have, to when they're diagnosed, and how and where they're treated, they have unique care and support needs and experience significant, unique emotional and financial impacts.

Earlier this year, Young Lives vs Cancer launched the **#RunningOnEmpty campaign**, focusing on one of these unique needs and challenges - the travel costs incurred by children and young people with cancer and their families in order to receive the specialist treatment they need.

The cost of travelling to treatment and care is one of the most significant costs that young cancer patients and their families face. Cancer in children and young people brings specific travel challenges because most have to travel to a small number of specialist Principal Treatment Centres to get the treatment and care they need – they can't just go to their local hospital. This means that they and their families often undertake regular long-distance travel or need to stay away from home for long periods. This is particularly unique to young cancer patients, who have to travel on average twice as far and spend twice as much as adults with cancer<sup>2</sup>. Due to the nature of their treatment, which can last for a significant period of time, this is often over many months or years.

Our 2023 **#RunningOnEmpty research** has found that young people and their families travel an average of **350 miles a month** for treatment, spending an average of **£250 a month on travel**. As a result, **71% of young people and their families are struggling** to meet these costs and **1 in 10 have missed or delayed treatment** because they could not afford to travel<sup>3</sup>.

In addition, our 2023 **#CancerCosts research** has found that the additional costs that come following a cancer diagnosis as a child or young person have **risen 15%** since 2017, and one of the most significant increases has been in travel costs<sup>4</sup>.

But for some, the impact of travelling for treatment and care is more acute, and this is just the tip of the iceberg, especially for people living in more rural areas, those living in Wales and Scotland, and those

<sup>1</sup> Cancer Research UK, <https://www.cancerresearchuk.org/>

<sup>2</sup> Are We Nearly There Yet? Young Lives vs Cancer (as CLIC Sargent) (2018)

<sup>3</sup> #RunningOnEmpty, Young Lives vs Cancer (2023) [www.younglivesvscancer.org.uk/join-our-fight/get-campaigning/travelcosts](http://www.younglivesvscancer.org.uk/join-our-fight/get-campaigning/travelcosts)

<sup>4</sup> #CancerCosts, Young Lives vs Cancer (2023) [www.younglivesvscancer.org.uk/join-our-fight/get-campaigning/cancer-costs-campaign](http://www.younglivesvscancer.org.uk/join-our-fight/get-campaigning/cancer-costs-campaign)



having to travel to another country for treatment, including those from Northern Ireland. These distances, and therefore the costs, can be much higher for them and others.

To try and meet these costs, young people and families across the UK are cutting back, spiraling into debt, and making difficult decisions between travelling to hospital, or paying for basic, day-to-day essentials<sup>3</sup>;

- 82% are cutting back on recreational and social activities
- 27% are cutting back on buying food
- 20% are falling behind on their bills
- 20% are selling their possessions or assets

While we appreciate there is currently some financial support available, in many instances these schemes are not working for children and young people with cancer and their families. For example, the NHS' Healthcare Travel Costs Scheme and Non-Emergency Patient Transport Services do not meet their needs, and many are not even eligible for the support available. Our research found that **just 12% have received support** which covered their travel costs<sup>3</sup>.

One of the key principles of the NHS is that it is free at the point of use, but with young cancer patients and their families struggling because they are spending hundreds on travel before they even step inside the hospital door, the system is clearly failing them. Tackling the financial impact of cancer and providing support for travel costs is key to improving the experiences and outcomes of young cancer patients and their families.

We believe that all young cancer patients and their families should be focused on is getting through their treatment, not worrying about how they will afford to get there. In order to comprehensively ensure travel costs for young cancer patients are met, we are asking the government to create a **Young Cancer Patient Travel Fund** to help all children and young people with cancer, and their families, afford the cost of travelling for essential treatment.

Our call for a Young Cancer Patient Travel Fund has widespread support as demonstrated by the signatories to tabled [Early Day Motion EDM 1362](#). In 2021, the Scottish Government launched the Young Patients Family Fund, covering expenses for food, travel and overnight accommodation for inpatients under 18. Whilst this provides vital support for some families, Young Lives vs Cancer is calling for this Fund to be expanded so that all young cancer patients can access it. However, a similar fund has not yet been introduced in other nations within the UK for children and young people with cancer and their families, and a lot can be learned from the introduction of this Fund.

We would welcome receiving a response from you to our petition on the establishment of a Young Cancer Patient Travel Fund, and meeting with you to discuss how the government and third sector can work together to ensure the needs of children and young people with cancer and their families are supported.

We look forward to hearing from you soon.

Best wishes,

Rachel Kirby-Rider  
Chief Executive Officer  
Young Lives vs Cancer

*On behalf of Young Lives vs Cancer and the 11,500+ signatories to the #RunningOnEmpty petition.*

