

YOUNG LIVES
vs CANCER

A YOUNG CANCER PATIENT TRAVEL FUND

Improving equitable access to treatment for young cancer patients: The case for a Young Cancer Patient Travel Fund

February 2024



YOUNG LIVES vs CANCER

ABOUT YOUNG LIVES vs CANCER

Young Lives vs Cancer is the leading UK charity for children and young people (0-25) with cancer. We work tirelessly to make sure that young cancer patients and their families get the support they need, and that their voices and experiences are heard. We do this by:

- Providing day-to-day support through our social workers based in all main children and young people's cancer hospitals, and who are experts in helping families handle the challenges that come with a cancer diagnosis. They work closely with NHS professionals, as an integral part of the care team, to make sure families get the support they need throughout treatment.
- Providing financial grants to support with the huge financial costs of cancer.
- Offering free places for young cancer patients and their families to stay, close to their treatment centre, through our 11 Homes from Home across the UK.
- Working in partnership with the NHS, other third sector organisations and partners to make sure that families get the best care and support possible.
- Standing alongside young cancer patients and their families to make sure their voices are heard.

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INTRODUCTION

Each year, around 4,200 children and young people (aged 0 to 24) in the UK are diagnosed with cancer.^{1,2}

Given its specialist nature, unlike many other major conditions and forms of treatment, cancer treatment for children and young people largely takes place in a small number of specialist hospitals and centres, known as Principal Treatment Centres (PTCs). As a result, many children and young people have to travel beyond their local hospital and area to get the cancer treatment they vitally need. Young cancer patients and their families report living an average of 40 miles away from their main specialist cancer treatment centre.³

Not only do many young cancer patients and their families have to travel significant distances to their main treatment centres, the intensity of their treatment also means travel back and forth is often very frequent. Half (50%) report having to travel more than once a week across the duration of their cancer treatment,³ with treatment lasting around 12 months on average.

The distance and regularity with which many young cancer patients and their families are required to go back and forth for treatment add up to an average of 350 miles a month. Not only can this be physically and emotionally exhausting, it can also come at a significant financial cost. Travel to and from specialist treatment costs children and young people with cancer and their families an average of £250 every month. For seven in 10 young cancer patients and their families (71%), these unforeseen additional costs are also coupled with losses in their income.³

As a result, at a time when they should be focused entirely on getting through their treatment, children and young people with cancer and their families are often also dealing with the costs of travel.

To change the current system, so it better supports all children and young people with cancer and their families, Young Lives vs Cancer is calling for better financial support for travel costs for young cancer patients and their families. This report sets out how this support can be delivered through a **Young Cancer Patient Travel Fund**; how such a fund would operate, the costs, and the potential impact of the fund. It also sets out how travel costs support can be approached in each UK nation.



CURRENT SUPPORT AVAILABLE

Despite the significant costs faced by children and young people with cancer and their families, just one in 10 (12%) are currently receiving support that covers their costs of travelling for treatment³.

Healthcare Travel Costs Schemes

Healthcare Travel Cost Schemes exist across the UK to refund the costs of travelling to and from treatment. However, a range of barriers to receiving this support mean the vast majority of children and young people with cancer miss out on this much needed assistance. These barriers include strict income-based eligibility requirements, low awareness, and significant delays processing applications and being awarded.

Non-Emergency Patient Transport Services

In addition to these refund schemes, Non-Emergency Patient Transport services are available across the UK. However, even when young cancer patients and their families are aware of and eligible for direct transport support it is often not appropriate or safe for many children and young people with cancer, for example, because they are immunocompromised following treatment.

Young Patients Family Fund

For those living in Scotland, reclaiming their travel costs is also a possibility for some young cancer patients and their families through the Young Patients Family Fund. The Scottish Government introduced the Fund in 2021, offering reimbursement for travel and food costs for families of inpatients under 18 in Scotland. The introduction of this support was due to successful campaigning of organisations and campaigners, including Young Lives vs Cancer and other charities, making the case for the impact a fund would have on young cancer patients and families experiences.

Whilst providing a positive impact on families struggling with travel and related costs, there is room for improvement in this model of travel support, for example the administrative process involves submission by post or to an in-person hospital finance desk. The budget of £4 million for 2022-23 was underspent in this period suggesting the utilisation of the Fund is not being maximised. Detailed evaluation on spend categories, uptake and experience are awaited from Scottish Government at the time of writing.

Young Lives vs Cancer suggests a number of improvements to increase the utility and impact of the Fund; the expansion of Fund eligibility to cover all children and young people with cancer, including those receiving outpatient care, aged up to 25, and undergoing treatment outside Scotland. These are set out in more detail in the next section of this document.

Other welfare support

There are a number of welfare support and benefits that young cancer patients may be entitled to such as Personal Independence Payment (PIP) for those over 16 years of age, and Disability Living Allowance (DLA) for those under 16 years. Some families may be claiming Universal Credit, Carers allowance or a combination of these. In Scotland Child Disability Payment (CDP) is available but waiting times are currently proving a barrier with accessing this support.

Government support for young cancer patients and their families is crucial. However, our research and feedback from social care teams highlight challenges in accessing benefits, including prolonged delays (often 12-20 weeks) for DLA and PIP, affecting decision and payment timelines. These delays also impact access to other benefits like Carer's Allowance and Blue Badges. Parents and young patients face difficulties as they can only apply three months after experiencing symptoms, despite cancer's immediate, and lasting impact. Applying for DLA and PIP is stressful - 58% of parents and 73% of young patients note assessors often lack the necessary understanding and knowledge.⁴

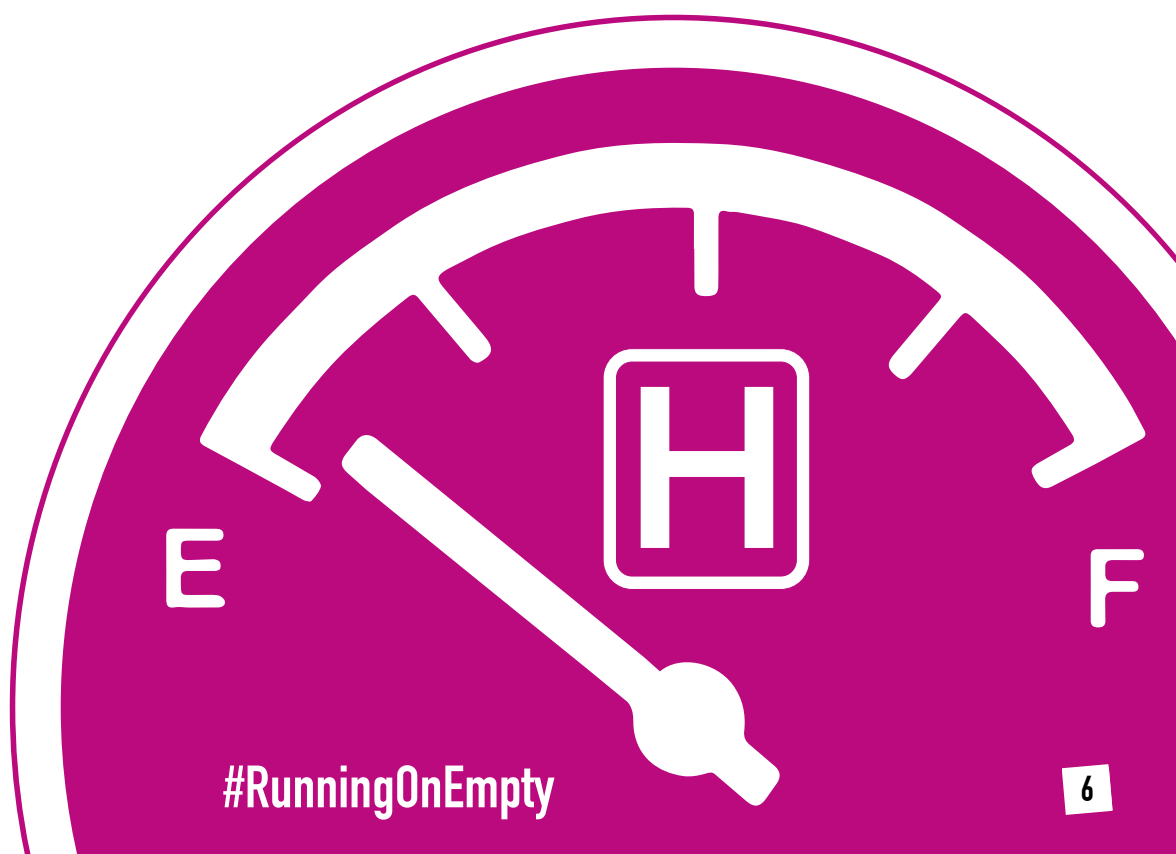
Ultimately, the purpose of these financial supports is not to enable patients to access NHS treatment. Even with improvements in the above, the need for travel costs support is great.

Charity grants

A number of charities including Young Lives vs Cancer provide financial grants to families to cover a range of costs associated with being a young cancer patient. These costs are set out in our Cancer Costs research.⁵ This support is increasingly vital in the current economic climate and provides for families to cover the heavy burden of cancer costs such as increasing energy bills, food or clothing. Every penny that they have to spend on travel, means a choice between other essential costs.

Inconsistent and inadequate support

All of the above leave young cancer patients with a patchwork of inconsistent financial support to help them access vital cancer treatment. This lack of adequate support is leaving many struggling financially. Far from being uncommon or just affecting those in the lowest incomes, seven in 10 of all young cancer patients and their families (71%) report struggling to pay for the costs of travelling to and from cancer treatment. These struggles include half (49%) going into their savings and three in 10 (31%) having to borrow or take on additional debt as a direct result of the costs of travelling to treatment. When no further cutbacks or sacrifices are possible, to meet the costs of travelling to and from treatment, one in 10 young cancer patients and their families (10%) are faced with no alternative but to delay or miss their treatment and care.³



ADDRESSING THE NEEDS OF EACH UK NATION

To address the problem, Young Lives vs Cancer calls on governments across the UK to ensure that adequate travel costs support is available for all children and young people with cancer and their families in all parts of the UK.

Due to the specialist nature of cancer treatment and care for children and young people, it largely takes place in a small number of specialist hospitals and centres. As a result, many children and young people have to travel beyond their local hospital and area, including travelling across national borders. For those in Scotland, Wales and Northern Ireland, 2 in 5 report travelling to a different country for some of their treatment and care.³ In some cases, certain types of treatment, or care for certain cancer types, are only provided in a small proportion of these specialist centres on behalf of the whole UK. For example, proton beam radiotherapy is only available at centres in Manchester and London for young cancer patients from all areas and nations of the UK.

To address all travel needs for all young cancer patients, Young Lives vs Cancer is **asking the UK Government to implement a Young Cancer Patient Travel Fund** that is sufficiently resourced to meet the needs of all young cancer patients and families across the UK. More details on this are outlined in the next section of this document.

It is recognised that there are different landscapes in each nation, regarding existing provision, population, devolved health funding, and geographical spread, which mean that a bespoke approach may be necessary and pragmatic. Any solution, devolved or UK-wide, must support those who need to travel across national borders. The following sections outline recommendations for each UK nation.

Scotland

Young Lives vs Cancer is asking the Scottish Government to **expand the Young Patients Family Fund eligibility criteria** within its current available resourcing so it is open to all children and young people with cancer in Scotland and their families.

The Young Patients Family Fund received £4 million in resource (2022-23) from the Directorate for Health and Social Care, of which just over £2.5 million was spent.^{6,7} Based on the modelling set out in this document, the expansion of the Fund's eligibility criteria to the below groups is achievable within its current resourcing.

This Fund should be expanded to those:

Receiving day or outpatient care:

Currently the Fund is only available to inpatients (staying overnight in hospital), and whilst some children and young people with cancer will need to stay overnight in some cases, the majority of cancer treatment is delivered on a day-patient basis, therefore the majority of patients are currently excluded from accessing the Fund.

Aged up to 25:

Currently the upper age limit of the Fund is 18 years of age. Young people age 18-25 with cancer undergo the same treatment for the same types of cancers as those under 18, and are treated in the same specialist PTCs, therefore undertake the same journeys and experience the same costs as under 18s.

Receiving treatment outwith Scotland:

Currently, the Fund only supports travel to treatment within Scotland. Whilst there are some mechanisms in place for travel outwith Scotland to be reimbursed by Health Boards, these processes are not working effectively for children and young people with cancer and their families. They experience delays after incurring significant costs upfront and in some cases only receive reimbursement because of the efforts they put in to chasing their claims. Subsuming this process within the Fund would streamline this and ensure families receive more timely reimbursement through one process.

Northern Ireland

We believe there should be Travel Costs support in each Nation. In addition to calling for a **Young Cancer Patient Travel Fund** that supports all children and young people with cancer in Northern Ireland, we are also supporting the **Northern Ireland Children's Health Coalition on the call for a Young Patients Fund**. This would follow a similar approach to the Scottish Young Patients Family Fund, and take learnings from the approach in Scotland so far.

A Young Patient Fund could significantly reduce the burden on young patients, including those with cancer, in Northern Ireland.

England and Wales

In England and Wales we are calling for a **Young Cancer Patient Travel Fund** which could operate as set out in the next section of this document. A fund which supports all families experiencing this massive and unavoidable cost of accessing cancer care for a young patient, which is designed to be administered with the least possible burden on families and professionals, collects and provides data for evaluation and impact measurement, and which is easily accessed by those who need it.

The next section explores how this Fund could operate in practice, the costs and potential impact.



YOUNG CANCER PATIENT TRAVEL FUND MODEL

The proposals for the Fund set out in this section are based on research undertaken by Young Lives vs Cancer.

The research comprised an online survey and follow-up interviews with a total of 259 people between February and April 2023. This consisted of young people (aged 18 to 26) and parents / caregivers of young people (aged under 27) from across the UK who have experience of cancer treatment and care in the past two years. In addition, a series of focus groups were conducted with young cancer patients and their families, front-line workers, and charities between August and October 2023.

Principles

To best meet the needs of children and young people with cancer and their families, we believe the Fund should be based around the following three principles.

Be available to all young cancer patients and their families:

Far from being a challenge affecting only the lowest income households, the scale of costs involved in travelling to treatment mean that most young cancer patients and their families struggle to afford their travel costs. These substantial costs are often compounded by significant losses in income due to having to take time away from paid work. Since the struggles in meeting the costs of travelling to cancer treatment don't discriminate, neither should any Fund that is developed. It is important therefore that the Fund be available to all young cancer patients and their families.

Be available from the point of diagnosis:

The travel to and from treatment, and its associated costs, begin immediately upon a child or young person's cancer diagnosis. Wider financial challenges are also experienced during this period. These often include having to leave or take time away from employment to attend treatment and being ineligible for or not yet receiving any financial support through the social security system and from other organisations. The urgency of these combined challenges means it is important that any Fund developed is available from the point of diagnosis.

Be available quickly following their travel:

The frequency of a child or young person's treatment and the associated travel, along with the significant distances often involved with making these journeys, mean the travel costs young cancer patients and their families are paying out can quickly add up. As a result, unless the Fund is paid promptly following their travel, they can find themselves having to use savings and/or take on debt to be able to pay up-front for the journeys to and from treatment. It is therefore important that for any Fund developed, payments are made quickly following their travel.

Grants model

To deliver on these principles, we believe the Fund should operate two grant modes.

Upfront grants:

A one-off grant provided to all new children and young people with cancer upon registration to the Fund immediately following diagnosis. This grant would be aimed at addressing the significant travel young cancer patients and their families face in the immediate period following their diagnosis, often occurring before being able to access wider information, advice and support. This grant would also help to address the immediate financial challenges faced by many resulting from associated losses in income and delays in accessing support from the social security system. The value of this grant should be based on an evidence-based estimate of the average monthly cost faced by young cancer patients and their families travelling to and from treatment.

Reclaim grants:

An ongoing grant available to all children and young people with cancer and their families to cover their travel costs to and from treatment. This grant would be aimed at addressing the ongoing travel costs of young cancer patients and their families throughout the duration of the treatment. All transport modes should be covered by this grant. For non-ticketed forms of transport (for example: car), this should be paid based on a mileage rate. For ticketed forms of transport (for example: train, bus), this should be paid based on the direct costs and receipts produced. In exceptional cases where young cancer patients and their families did not have the money to travel to treatment, the reclaim grants should be paid in advance.

By adopting this grants-based model, the Fund should not impact the benefits received by young cancer patients and their families.

Delivery model

To deliver on the principles and grants, we believe the Fund should operate as follows.

Be referrer led:

The Fund should be referrer led, whereby referrers would apply for the grants on behalf of the young cancer patients and their families. This would better ensure access, overcome barriers to Fund awareness, and reduce the administrative burden placed on young cancer patients and their families during a challenging time. A referrer led Fund would better enable children and young people with cancer and their families to focus on getting through their treatment.

Before they can apply on behalf of young cancer patients and their families, referrers should be pre-approved by the organisation operating the Fund. Recruited referrers should be professional health, social care and/or charity workers, directly supporting children and young people with cancer and their families, as well as other staff and volunteers operating in the PTCs. Having the professionals working with the young cancer patients acting as gatekeepers to the Fund would both support promotion, reduce the need for additional layers of eligibility checks, and result in improved processing speeds for young cancer patients and their families.

Be digital first:

The referrers should make applications to the Fund via an online portal. As part of registering and making applications, referrers would be expected to provide relevant information about the young cancer patients and their families, and supply details of the trip being claimed for (including relevant evidence). Young cancer patients and their families should also be asked to consent to be contacted, so this information and data can be used to regularly and effectively monitor and evaluate the Fund.

Use of a dedicated online portal would mean the Fund would not need access to other established systems to operate (for example: health systems, social security systems), and therefore could be simpler to design or purchase, and easily administered by a range of organisations. The Fund should pay the grants primarily via a bank transfer. In exceptional cases where young cancer patients and their families do not have access to a bank account, alternative payment arrangements should be made to ensure inclusivity. This could include issuing relevant vouchers (for example: fuel cards). The online application process and primary bank transfer system would help ensure quick processing of applications and payments.

Be available for all young cancer patients and their costs:

The Fund should be available for all children and young people with cancer aged under 25, and be available throughout the duration of their treatment, from the point of diagnosis to the end of their treatment. The Fund should pay for travel to both inpatient and outpatient appointments within the UK, and pay for travel to these appointments of both young cancer patients and their travel companions.

The Fund should pay for the direct costs of travelling to these appointments, including:

- Vehicle fuel / charging
- Train / Tram tickets
- Bus tickets
- Plane tickets
- Boat / Ferry tickets
- Taxi fares
- Tolls and congestion charges

It is not proposed that the Fund cover wider costs associated with travelling, such as accommodation and food.

Funding

Based on the modelling, we estimate the Fund could cost £10 million per year to deliver and operate across the UK. The breakdown of the estimated costs are set out below:

	UK	England	Scotland	Wales	Northern Ireland
Total children and young people diagnosed with cancer (per year)	4,212	3,568	329	179	135
Total grant cost per young cancer patient	£2,135	£2,135	£2,135	£2,135	£2,135
Total grant cost (per year)	£8,993,000	£7,618,000	£703,000	£383,000	£289,000
Total admin cost (per year)	£900,000	£726,000	£71,000	£39,000	£29,000
Total costs (per year)	£9,893,000	£8,380,000	£774,000	£422,000	£318,000

The modelling for the Fund is based on the following assumptions:

Number of young cancer patients:

The modelling is based on cancer incidence rates among children and young people. This is informed by an analysis of health service data undertaken by Cancer Research UK.^{1,2} To ensure that the funding allocated continues to reflect need over time, it is important that the allocation should be tied to diagnosis levels.

Treatment length for young cancer patients:

Treatment length for young cancer patients can vary due to a range of factors. The modelling estimates an average treatment length of 12 months, based on incidence rates by cancer type among children and young people and the average treatment lengths for these.^{1,2}

Distance travelled by young cancer patients:

The distance travelled each month by young cancer patients and their families can vary due to a range of factors. The modelling for the reclaim element of the Fund is based on an average monthly travel distance of 349 miles.³

Upfront grant cost:

The monthly travel costs of young cancer patients and their families vary significantly. The modelling for the upfront element of the Fund is based on the average monthly travel costs of £250.³

Mileage reclaim cost:

It is recognised that young cancer patients and their families use a range of different modes to get to and from treatment. However, based on 2023 research by Young Lives vs Cancer, it is recognised that most journeys are undertaken by car (93%).³ The modelling for reclaim element of the Fund is therefore based on HMRC mileage rate (45p per mile).⁸ It is recognised that other forms of transport will be more expensive per mile (for example: taxi, train), but others will be cheaper (for example: bus) or free to the young cancer patient and their families (for example: non-emergency patient transport). To ensure the funding allocated continues to reflect need over time, it is important that the allocation should be tied to HMRC mileage rates and data collected through ongoing monitoring and evaluation on the costs of other forms of travel.

Uptake rates:

The modelling assumes 100% uptake by young cancer patients and their families.

Administration cost:

The modelling factors in a 10% management and administrative costs.

In addition to ongoing costs, there would likely be one-off set-up costs to establish the Fund, which could include purchasing or developing the online portal and recruiting referrers.

IMPACTS

In delivering the proposals set out, we believe the Fund would have the potential to achieve a range of positive short-term and long-term impacts for the around 4,200 children and young people diagnosed with cancer each year, their families, charities supporting them, and the health service.

In addition, the Fund would capture data and evidence of the outputs delivered, including the referrers registered, young cancer patients and journeys supported, and processing of grants.

Increasing access and uptake to support

As our research demonstrates, just one in 10 young cancer patients and their families (12%) are currently receiving support covering the costs of their travel.³ A combination of restrictive eligible criteria and the design of existing support schemes, mean many young cancer patients miss out. The creation of the Fund, based on the principles, grants and delivery model set out, would help remove and reduce the barriers that are resulting in the vast majority of children and young people with cancer missing out on much needed assistance in their time of need.

Reducing financial difficulties

One of the key principles of the NHS is that it is free at the point of use. However, as our research sets out, young cancer patients and their families are having to spend £250 per month on average just to get to their treatment. As a result, seven in 10 (71%) report struggling to pay the costs of travelling. To try and meet these costs, many are cutting back, spiralling into debt, and making difficult decisions between travelling to hospital, or paying for day-to-day essentials.³ The creation of the Fund would mean that a cancer diagnosis does not automatically result in financial difficulties for the vast majority of young cancer patients and their families.

Improving health outcomes

As a result of the costs of travel, in addition to leading to financial difficulties, our research found one in 10 young cancer patients are delaying or missing appointments.³ Any delayed or missed treatment can have adverse consequences on young cancer patient's outcomes. The creation of the Fund would mean the cost of travel should no longer be a barrier to attending treatment, reducing delayed or missed appointments, and improving the long-term health and wellbeing of young cancer patients. In addition, the Fund would help reduce the worry, stress, strain, panic, and fear associated with these financial difficulties and improve the mental and emotional wellbeing of both young cancer patients and their families.

Generating cost savings to the health service

Every delayed or missed appointment comes at a cost to the health service, estimated to be £120 per outpatient appointment.⁹ If the one in 10 young cancer patients reporting delaying or missing appointments due to the costs of travel, only did this once during their treatment, this is currently costing the health service a minimum of £50,000 per year. However, for many, the costs of travelling will lead to them delaying or missing more than one appointment. If this group delayed or missed one appointment per month during their treatment, this will be costing the health service in excess of £600,000 per year.¹⁰ The creation of the Fund would mean a reduction in the numbers of young cancer patients not attending planned appointments due to the costs of travelling, saving the health service resources, releasing capacity, reducing unnecessary follow up appointments and reducing waiting times.

Optimising charity support

Recognising the difficulties facing young cancer patients and their families, our research found several charities are currently stepping in to try and fill the gap. Almost half of young cancer patients and families (47%) report receiving some support from charities to help with the costs of travelling to and from treatment.³ However, in most cases these were one-off grant payments, rather than ongoing financial support throughout treatment. As a result, this often only provides a temporary reprieve from the financial difficulties created by travelling for treatment. The creation of the Fund would mean charities could redirect the funding currently offered around travel to other forms of support for young cancer patients and their families.

CONCLUSION

Young cancer patients face a financial uphill struggle to access cancer treatment, because of the unavoidable travel costs to get to specialist treatment centres. Current support doesn't adequately cover these costs.

There has been some encouraging progress such as the Young Patients Family Fund in Scotland, but too many children and young people with cancer and their families across the UK are facing this financial burden without adequate support.

Improving the current provision in Scotland, and introducing similar provision in each UK nation has the potential to alleviate one of the biggest non-medical expenses associated with cancer, providing value for money to the NHS through potential savings elsewhere in the system and improving the patient experience of those undergoing cancer treatment as a child or young person.

Young Lives vs Cancer is calling for a Young Cancer Patient Travel Fund. So far over 12 thousand people have shown their support for this.

More information about the #RunningOnEmpty campaign can be found at younglivesvs cancer.org.uk/travelcosts

For more information contact Campaigns@younglivesvs cancer.org.uk



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#RunningOnEmpty

younglivesvscancer.org.uk/travelcosts

Young Lives vs Cancer is an operating name of CLIC Sargent Cancer Care for Children.
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