



Cliona's Foundation

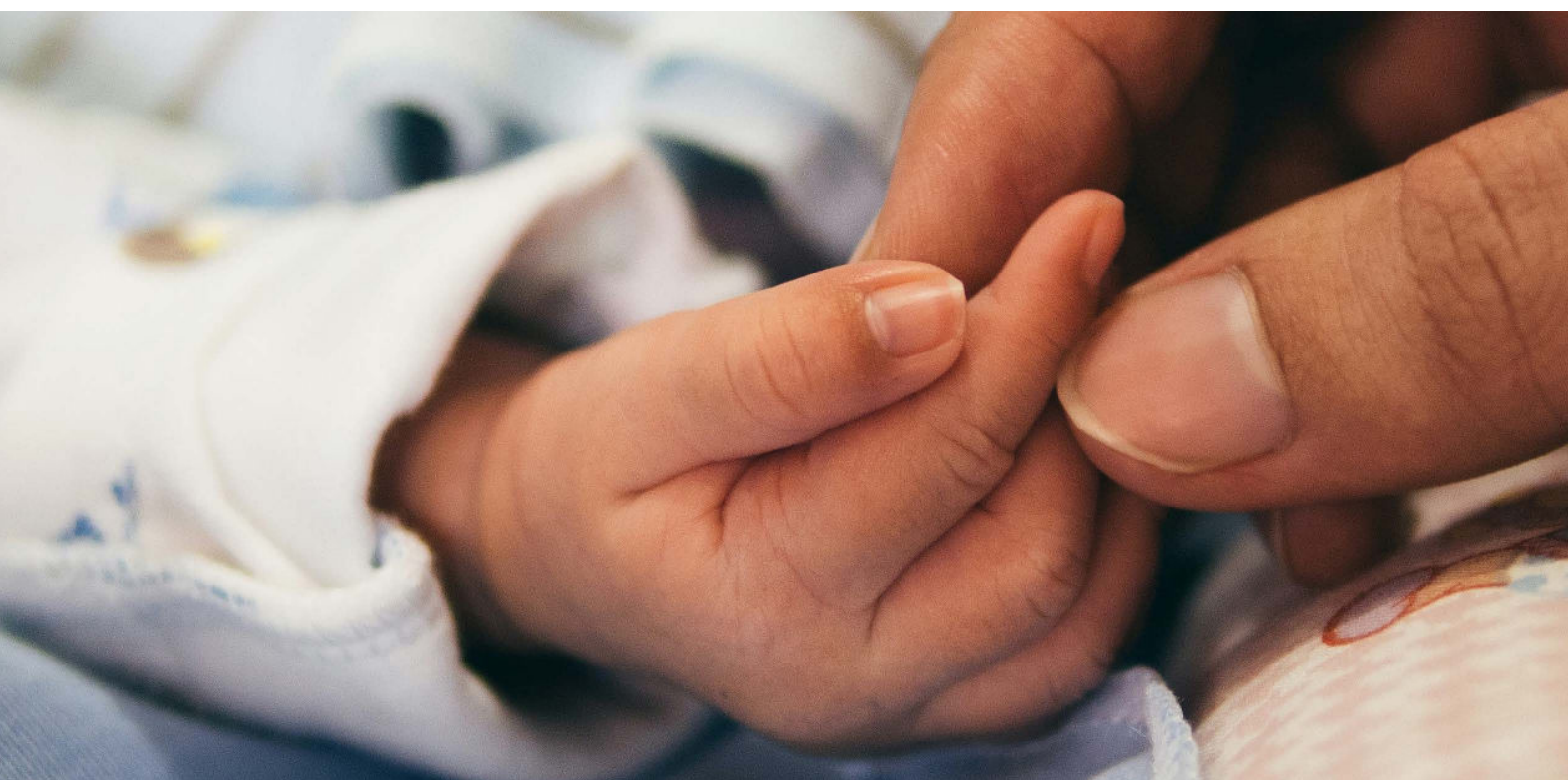
**Pre-Budget Submission to Health
Service Executive / Department
of Health**

AUGUST 2023

www.clionas.ie

Summary of Key Points

- ▶ Demand for the service provided by Cliona's Foundation is growing year on year. Sustainable, additional funding will allow the Foundation to continue to provide core support to families, while expanding their reach to additional families.
- ▶ We are proposing a one-year pilot initiative between Cliona's and the HSE/Dept of Health with the objective of demonstrating the feasibility of a long-term, co-funded support scheme for parents of children with a terminal illness.
- ▶ It cost **€660,000** to fund Cliona's Foundation in 2022 - our prediction based on current applications in 2023 is that it will cost **€768,000** to fund the organisation including operational costs.
- ▶ We are seeking **€250,000** to create a sustainable, collaborative funding model, with Cliona's committing to match HSE funding with a contribution of €250,000. €50,000 required to administer and measure the impact of the fund.
- ▶ The aim of the scheme will be to provide one-off crises payments to parents, within agreed eligibility criteria, to cover non-medical costs.
- ▶ The proposed funding model will create a hybrid scheme drawing on the expertise and assets of the non-profit sector - through Cliona's - and the state sector - through the HSE/ Dept of Health. Cliona's will work in partnership with the HSE/Dept of Health to ensure the scheme is underpinned by appropriate administrative, governance and financial processes.
- ▶ At the end of the one-year demonstration phase, Cliona's will undertake a project review to capture the impact and efficacy of the scheme with a view to entering into a long-term co-funding arrangement with the HSE/Dept of Health.



1. Introduction

Every year, 400 children in Ireland are diagnosed with a terminal illness and 400 children die with a terminal illness. At any one point, there are 4,000 critically ill children in the country.

Cliona's Foundation is the leading Irish organisation providing financial support for non-medical costs to these families¹. Since its establishment as a charity in 2008, Cliona's Foundation has assisted more than 1,200 families across the island of Ireland (Fig.1), through the provision of one-off grants of €2,500 to qualifying families. Specifically, the foundation supports families with the hidden costs of caring, including, accommodation, food, travel costs, parking and other miscellaneous expenses. However, requests for support to Cliona's Foundation continue to grow year on year. By June 2023, 135 families had either been approved or had received support across 25 counties, compared to 69 families at the same time in 2022. However, the total amount required each year to help all the families that need assistance across Ireland is significant and beyond the capacity of any one charity.

This document seeks to make the case therefore for the establishment of a care-support model for families of children with life-limiting conditions that combines new public funding with complementary support services from charities such as Cliona's Foundation.

It also calls for the urgent establishment of a "looking after a child with a life-threatening illness" grant, with a straightforward application process which could be run collaboratively between the HSE and Cliona's Foundation on a pilot basis.

Fig.1 Location of families assisted across Ireland



¹ Little Blue Heroes and the Irish Cancer Society both provide support to children with life limiting conditions. Little Blue Heroes, is a volunteer-led initiative of retired Garda personnel, with similar objectives but currently operating on a considerably smaller scale compared to Cliona's Foundation. The Irish Cancer Society only provides support to children with cancer.

2. Needs Description

It is estimated² to cost an additional €10k to €15k to care for a seriously sick child in Ireland, having enormous, financial, mental and emotional impact on families already struggling to cope with the trauma of a seriously ill child.

The impacts include:

- Loss of employment and/or reduction in household income due to one parent taking time out to care for their child
- Homelessness due to the consequent inability to meet mortgage or rental payments.
- Financial stress of meeting ongoing non-medical expenses, including accommodation, transportation and funeral expenses
- Mental health impacts on parents and siblings
- Marriage/family breakdown due to stress and exhaustion
- Parental and/or sibling addiction issues due to some/all of the above

Research carried out by Children in Hospital Ireland in 2020³ provides evidence of the range of non-medical financial costs incurred by parents whose child requires prolonged and/or repeated hospital care. In most cases, parents are required to be constantly present with their child in hospital which restricts their ability to participate in paid employment.

The research found that one-third of parents had given paid employment to care for their child and estimated a median loss in income of €300 per week for families. 58% of parents reported a significant negative financial impact on the household finances and 61% of parents took on debt to meet non-medical costs associated with having a child in hospital care. Research conducted by Cliona's Foundation in July 2023, found that in 73% of families the main earner had to give up their job in order to look after their child, while 71% of families said that their partner had to reduce their working hours.

Research Results at a Glance



58% of parents reported a significant negative financial impact on the household finances.



61% of parents took on debt to meet non-medical costs associated with having a child in hospital care.



In 73% of families the main earner had to give up their job in order to look after their child.



71% of families said that their partner had to reduce their working hours.

² <https://clionas.ie/wp-content/uploads/2020/03/Too-Dear-to-Visit-Academic-Report.pdf> p.24

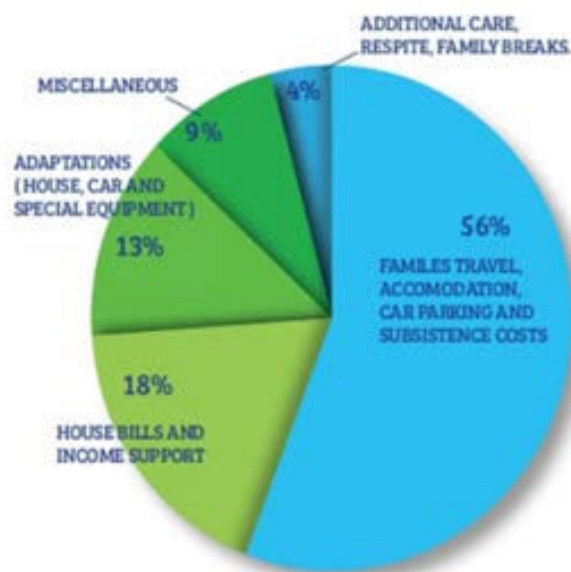
³ https://childreninhospital.ie/wp-content/uploads/2021/09/Children-in-Hospital-Report_1-FINAL.pdf

While the State does provide⁴ a number of entitlements to support families with life limiting conditions, entitlement and access are often dependent on the specific condition the child is suffering from, and where in the country the family may be located.

The bureaucracy involved in the application process can also be stressful and prolonged, with parents in some cases reporting that their child has died before the funds are granted. A survey conducted by the Foundation found that 99% of all families surveyed believed State support to be insufficient to meet the additional costs of caring for a child with a life threatening condition.

Over half of the funds provided by Cliona's Foundation goes on travel, accommodation and subsistence costs (Fig 2) while a further €110,000+ helps families to deal with reduced income and various household bills that arise on top of the costs of caring for their child.

Fig.2 Breakdown of how families spend financial support



Government Policy Imperative

Cliona's is calling on the Government to do more to relieve the significant financial pressure experienced by families caring for a child with a terminal illness.

Better Outcomes, Brighter Futures (BOBF), the national policy framework for children and young people, aligns government commitments to children and young people against five national outcomes. BOBF sets out seven priorities, three of which directly relate to the experiences of families with a terminally ill child. It prioritises the need to:

- I. Better support parents and families
- II. Tackle child poverty
- III. Improve childhood wellbeing

These priorities are supported by Transformational Goal 1, "Support Parents". This highlights that "ensuring all parents are appropriately supported and resourced to care for their children is central to realising the rights of all children and young people" and states that "supporting parents to parent confidently and positively is one of the primary, universal and most effective supports that the State can provide along the continuum of family support."

Crucially, Transformational Goal 1 points out that the UN Convention on the Rights of the Child places a duty on States to respect the rights and responsibilities of parents (Article 5) and to support them with their child-rearing responsibilities (Article 18).

⁴ <https://clionas.ie/wp-content/uploads/2020/03/Too-Dear-to-Visit-Academic-Report.pdf> p.11

In relation to children and young people with high health needs, BOBF recognises “the pivotal role of parents and families in providing the additional care and support that children and young people with a disability or chronic illness may require”. It makes a number of statements which recognise the impact of traumatic life experiences, including:

- ◇ “attaining good mental health may be hindered by traumatic life experiences or personal stress” (pg. 49)
- ◇ “children and young people with palliative care needs, and their families, should be supported to maintain the highest attainable quality of life (pg. 52)
- ◇ “the importance of measures that tackle the conditions of parental stress, which may give rise to detrimental experiences for some children” (pg. 65)

Within the context of BOBF policy imperatives, this proposal provides a mechanism for the Government to provide a level of financial support to children and parents impacted by the trauma of childhood terminal illness. It goes some small way to facilitating the State to fulfil its duties under the UN Convention on the Rights of the Child.

3. Project Rationale

Sustainable Funding Base

Since its establishment in 2008, Cliona's has relied entirely on income raised through a range of activities including fundraising, corporate donations, philanthropy, private donations and partnerships with other charities. However, recent events, including the Covid19 crises (which had a severe impact on fundraising income), and the current cost-of-living crises (which is putting significant additional financial pressure on parents with terminally ill children), have highlighted the limitations of this funding model.

The Board of Cliona's recognises that, while being efficacious to the state/taxpayer, the model does not facilitate the organisation to maintain a core support programme, independent of the external fundraising environment. In this context, the Board has identified a critical the need to create a more sustainable, diversified funding base. Its aim is to ensure that Cliona's is positioned to provide core crises supports to the most vulnerable of families on a sustainable basis into the future, while continuing to support parents with ongoing needs through its existing support scheme.

In essence, this new funding model will create a two-tiered financial support programme:

1. A core, ringfenced programme, part-funded by the State, which provides financial assistance to the parents of children who have been recently diagnosed with a terminal illness.
2. A parallel, fully funded through Cliona's fundraising and donation income, which provides financial assistance to support parents with ongoing costs relating to caring for a child with life-limiting or chronic illness.



4. Proposed Administrative Model

Cliona's is proposing the following model for the first year:

- ▶ A joint scheme, co-funded (50% / 50%) by Cliona's and the HSE/Dept of Health
- ▶ Cliona's to administer the scheme on behalf of both parties.
- ▶ The scheme to offer one-off crises payments per family (€2,500 per family)
- ▶ Application criteria to be agreed by Cliona's and HSE/Dept of Health, based on Cliona's current support scheme.
- ▶ A formative evaluation to be undertaken, reviewing the scheme's operational effectiveness and its impact on families. Learning from evaluation will inform discussions between Cliona's and the HSE/Dept of Health on the establishment of a sustainable scheme into the future.

5. Financials

Budget Line	Amount	Cliona's Foundation	HSE Contribution
Core Crisis Support Scheme	€500,000	€250,000	€250,000
Administration (1 f/t staff resource)	€35,000	€0	€35,000
Formative Evaluation (Process and Impact)	€15,000	€0	€15,000
Total	€550,000	€250,000	€300,000

Governance:

Cliona's Foundation is a registered charity. [The Board of Cliona's Foundation](#) has formally adopted the '[Charities Governance Code](#)' as devised by the Charities Regulatory Authority. The Foundation is implementing a [Strategic Plan](#) covering the period 2023-2025, while preparation for a new Strategic Plan will begin in 2024.

Conclusion

As previously noted, the total amount required each year to help all the families that need assistance across Ireland is significant and beyond the capacity of any one charity. The geographical reach of Cliona's Foundation, and its focus on non-medical expenses allows the Foundation to make a unique contribution to addressing a clearly identifiable need.

But as noted also, a more sustainable predictable source of funding is necessary in order to allow Cliona's to continue supporting the core needs of families supporting children with life limiting conditions and to expand its reach to assist the many other families in need of support.

Looking to the future, a care-support model for families of children with life-limiting conditions that combines new public funding with complementary support services from charities such as Cliona's Foundation as detailed above is needed. This could go some way towards ensuring that all the families who require support will receive it in a timely manner.