



OUR VALUES, FAMILY LIFE & CARE

OUR VISION



OUR MISSION



CONTENTS

OUR CHARTER

- 1 Every child* and family member will be treated with respect and dignity.
- 2 The child and family will be offered an individual care and support package that is built around their unique needs.
- **3** Supported by a multi-disciplinary team we will work and communicate with the child and familu in an open and honest manner.
- 4 Children and families will always be listened to and encouraged to talk through their wishes and care choices.
- **5** At all stages of care, from diagnosis to death through bereavement, families will provided with accurate and relevant information in a language they understand.
- **6** Where possible, children will be cared for in the familu's place of choice—at home, a hospice or in hospital.
- **7** Emotional, psychological and spiritual support will be offered the child and family.
- 8 Children and young people will be given the opportunity to access appropriate education, therapies and stimulation.
- **9** The child and family's wishes concerning end of life care will be discussed and planned for well in advance.
- **10** Support and care will extend to all family members.
- When the term 'child' is used, it refers to any baby, child or young person with a life-limiting or condition.



CEO & CHAIRMAN STRATEGIC OVERVIEW

Dear Friends,

Welcome to the 2013 Annual Report of LauraLynn – Ireland's Children's Hospice. As Ireland's only children's hospice we provide care and advocate for children, young people and families who need our unique services at a time of their greatest need.

As we reflect on another successful year for LauraLynn, we acknowledge the contributions from our supporters and staff, who made it all possible. However, we also recognise there are huge challenges ahead for us to achieve our vision to provide care and support to children and their families in their choice of location, when they need it.

By working with companies and organising community events, we raised €3.3 million which will provide children's palliative care for another year at LauraLynn. This will enable us to continue to expand our family support programmes which include sibling and family camps, bereavement support and therapies. Our need to continue to increase income is vital to sustain our existing care and commence our LauraLynn@Home hospice care pilot programme in the summer of 2014, which will bring hands-on palliative care and respite into the comfort of a child's family home.

We will be challenged in the year ahead to continue to improve the quality of our care despite the impact of the health service reforms and public sector funding cuts. We constantly strive for excellence in all we do. We will monitor, review and amend policies and procedures in keeping with HSE, DOH and HIQA statutory policies and standards to ensure we deliver excellent care. We welcome the commencement of inspection by HIQA in 2014.

Like many other voluntary organisations, our fundraising been impacted by the negative media coverage which has resulted in a huge lack of trust within the charitable sector. We have endeavoured in this report to provide clear and transparent information on our governance and funding. We wish to acknowledge the many hundreds of people who support us in other ways – regular donations, hours spent volunteering and running fantastic events. Their support enables us to assist the children and families we work with and in return we hope they will have trust in us that their contributions are used in the provision of that care.

We wish to acknowledge the leadership and invaluable support and expertise from our voluntary Board and Trustees who give of their time freely. Our heartfelt gratitude to all the families, staff, volunteers, donors and partners whose enthusiasm, commitment and support has brought LauraLynn to new levels of achievement.

We look forward to 2014 and onwards, extending our respite, end-of-life and hospice home care support care to more children and families across Ireland so that "all children who need us can access us". We look forward to you continuing on this remarkable journey with us and thank you for your support.

Dello Philogae Due

David Andrews Chairman

Philomena Dunne CEO





Board of Directors:

David Andrews (Chairman)

Joan Banks (retired December 2013)

George Balmer (retiring June 2014)

Frances Fletcher

Niall McHugh (appointed 3/9/2013)

Moira McQuaid

Hugh Monaghan

Eugene Mitchel

Michael O'Donoghue

Andrew Paul

Nicholas Quigley (appointed 3/9/2013)

Martin Wall (retired 25/6/2013)

OUR CARE & SUPPORT

We provide specialist care and supports not only to the child but also to the whole family during their child's illness and support them after their child dies. Our holistic approach to care ensures that we are supporting the whole family, allowing parents to have time to be a 'Mum and Dad' rather than full-time carers.

- We offer support for children from birth to their 18th birthdau
- All of our care is free for families
- Children can be referred to LauraLynn from anywhere in Ireland

Our Multidisciplinary Team work in partnership with the child's Consultant and other Care Providers, with a shared goal of ensuring high quality Respite, Crisis, Transitional and End-of-life Care.

We also continue to provide Residential Care (formerly Children's Sunshine Home) for our young adults with profound intellectual and physical disabilities who have been in our care since childhood. In line with national policy we no longer accept new referrals for this service.

Children's Palliative Care services are provided for children with life-limiting conditions through Respite, Transitional, Crisis and End-of-Life Care, 24-hour 7 days a week, 52 weeks of the year.

Residential services are provided to 10 adults and 4 children with disabilities. 24-hour 7 days a week, 52 weeks of the year.

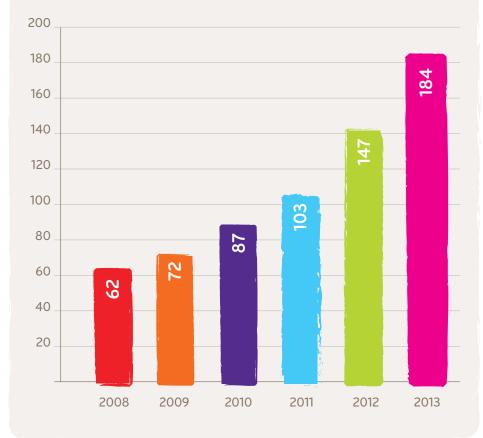
Respite and Crisis Care and support is provided to children with disabilities and complex health care needs in Hazel House our respite unit, with a maximum of 5 children at any time, 24-hour 7 day week, 50 weeks of the year.

In the entire service 184 children and young adults have availed of our services, 101 of these are new referrals to LauraLynn House since opening in September, 2011.

Our admissions process ensures that those children who need our services most receive priority. We do not operate a waiting list, or intend to have one, as often children and their families cannot wait for services. We have experienced an increase of approximately 60% in referrals to our hospice service since opening LauraLynn House in 2011. (25 in 2010 compared to average of 40 in 2013)



Number of children using LauraLynn services 2008-2013





In 2013 we began:

Parent & Child Support Programme

Children's palliative care differs from that of adults in that it continues throughout the trajectory of the child's illness, which may be required for a few days, months or over many years. There is also a notable overlap between the needs of children requiring palliative care and those with disabilities. With this in mind our Health and Social Care Professionals work together as part of a multidisciplinary team to provide a holistic approach to care.

LauraLynn@Home

When a child has a life-limiting condition, the majority of families take on the role of primary carer for their child. Studies have shown that where possible parents prefer to care for their child in their family home. During 2013, a project plan was developed to pilot an exciting new initiative LauraLynn@Home. It aims to provide hospice care in the family home by a team of experienced nurses and healthcare assistants. LauraLynn@Home aims to deliver Respite, Palliative and End-of-life care to children and their families. This pilot project will run for one year from June 2014 in two (of the four) areas of the Health Service Executive: Dublin-Mid-Leinster and Dublin/ North-East regions.

Technology-dependent Children

At LauraLynn we have the skills, experience and facilities to provide transitional care for children with technology-dependence. During 2013, exploratory work began with the HSE to establish how LauraLunn could support families to transition their child from the acute hospital to home, through the provision of high quality transitional care.

In 2014 we will provide:

- · LauraLynn@Home
- · Transitional Care
- Family Camps
- · Early Start Programme "Roadshow"
- Bereavement Group
- Quality of Life Group monitoring and ensuring a high QOL for all adults in residence and children in the service, ensuring there are positive outcomes for each adult and child in line with Regulations and National Standards.
- Clinical Services Research Joint music therapy and physiotherapy research project which will investigate the use of music therapy to influence physiological and behavioural responses in children with life-limiting conditions
- Play Therapy Programme
- · Multisensory Room Development across three units.

Family

- Early Start Parent & Toddler Programme
- Sibling Days
- Shooting Stars Halloween Camp with Sibling Day
- Family Day at Barretstown
- Massage Therapy for Parents

Bereavement

- Memorial Services
- Bereavement Days
- Psychosocial Support





OUR FAMILIES

Children and their families are at the heart of everything we do.

Each family is unique and everyone's journey will be different

We estimate that there are 3,840 children and young people across Ireland with life limiting conditions who are unlikely to reach adulthood. Families caring for these children often 24 hours a day, seven days a week – are under enormous emotional, physical and financial strain. These are ordinary people leading extraordinary lives.

Our journey with Ellie's illness is a rollercoaster - you are our seat belts to mind, care and protect us in every possible."

Amy Ellie's Mum



" Changed our lives, it's such a happy place, Alicia comes out equally good if not better and that for us is a huge plus"

Gervin Alicia's Dad

Jack's Story

The first day we left Jack at LauraLynn, I cried. I stayed at the Dundrum Centre for a couple of hours in case they called. Needless to say that didn't happen. He absolutely loved it.

Jack is 8. He has chronic renal failure which means he is on dialysis 6 nights a week, 11 hours a night. He is on a special renal feed as well as NG fed (via a tube in his nose) 3 times a day, on meds 4 times a day. He is in a wheelchair and profoundly deaf. Now with the aid of a cochlear implant he can hear but has no speech. He vomits periodically during the day and is still in nappies. Jack needs a kidney transplant but there is a high probability that he will die on the operating table and when his kidneys do fail, he will need palliative care.

My husband and I work part-time so we are there to care for Jack. Having the day respite from LauraLynn has been life changing for us as a family. We are now able to relax and are better prepared to care for Jack.

One of the first Sundays we dropped him in, my husband and I had a coffee and then headed home to read the papers. We looked at each other and couldn't quite believe how relaxed we were. We never realised how high our stress levels are when having to constantly care for Jack and Jack too needs a break from his parents!

The staff are wonderful. You can see the care and love they have for the children.



" Having the day respite from LauraLynn has been life changing for us as a family"

Jacks Mum



OUR PEOPLE

Our People

It is the commitment and resilience of all the people who work in LauraLynn that underpins the organisation's achievements and never more so than in these difficult times.

We are indebted to our staff, who continue to show dedication and loving care to vulnerable children and their families, despite huge challenges. Like many organisations, our staff have been negatively impacted by salary cuts and staff embargoes, which have impacted on all health care professionals and we thank them for their commitment.

All LauraLynn staff undergo training in line with all HSE, Dept. of Health and HIQA requirements. Our HR department supports the strategic objectives of the organisation in the selection, recruitment, induction and training of our staff and volunteers. We have a staff of 120 in our palliative care and intellectual disability service supported by 60 volunteers, we provide training initiatives. Vigorous vetting procedures are in place for the recruitment of staff and volunteers to ensure the safety of children in our care.

We would like to thank Ms Shirley Devitt our Clinical Services Manager who retired in December 2013 after 12 years of service leaving a notable legacy in the transition of our services from a disability provider for children to one which meets the needs of families of children with life-limiting conditions.

Our Volunteers

We are dependent on a wonderful network of volunteers for so many of our fundraising and developmental activities. We acknowledge with gratitude the work and commitment of all our volunteers, without whom we could not operate. From Corporate Volunteers at events like Light Up LauraLynn and our Family Fun Days to our dedicated volunteers who visit us every week to help out by reading or singing to the children or simply taking them out for a walk. Thank you all, it means so much.

In 2013

We were delighted to welcome Dr Julie Ling as Head of Strategic Development, bringing a wealth of knowledge in children's palliative care. Additional key roles to support our strategic objectives included a Senior Clinical Psychologist Dr. Aiden McKiernan who provides a variety of psychotherapeutic services to help families cope with the demands of life-limiting childhood illness. Other new staff appointed included Nurse Managers. Volunteer Co-ordinator, Nurse Tutor and Researchers. We welcome the increasing numbers of staff who have embarked on third level and further education in the area of children's palliative care.

In 2014 we will

- · Begin our recruitment campaign for LauraLynn@Home.
- Review our Induction Process for new staff.

Our Clinical Education and Research

A busy and exciting year for this brand new department! We embraced the challenge of creating Ireland's first dedicated national centre of excellence in relation to Clinical Education and Research in children's palliative care (CPC) with gusto.

We now have a dedicated team in place, with expert knowledge around the specialties of Children's Palliative Care and Intellectual Disability, workforce training and empirical research. Having investigated the educational needs and skill requirements of staff who care for children and families with life-limiting and palliative conditions, a programme of courses for 2013 was put in place tailored to meet their needs. All programmes for the period 2013-2015 are free for all staff working at LauraLynn. All programmes are accredited by the Nursing and Midwifery Board of Ireland and are peer reviewed.



Pictured from left to right – Dr. Julie Ling, Clare Quinn, Dr. Aidan McKiernan and Dr. Joanne Balfe.



to be the best we had to LEARN to be the very best

OUR TRAINING & RESEARCH

Facilitating, pioneering and coordinating high quality research and service evaluation is of utmost importance to LauraLynn, particularly in the areas of children's palliative care, life-limiting conditions and intellectual disability

We are committed to investing in evidence based research to underpin the clinical training and education that we offer to all health professionals.

We work closely with several universities including National University of Ireland Galway, University College Dublin and Trinity College Dublin, as well as partnering with national children's hospitals, The Irish Association of Palliative Care (IAPC), The All Ireland Institute of Hospice & Palliative Care (AllHPC) and The Disability Federation of Ireland.

Our Activities 2013

Research Projects - Currently underway

- Establishing the role and potential impact of the first children's hospice in the Republic of Ireland: Health and social care professionals' perspectives - Post Doctoral work - UCD/UCD
- Fathers' experiences of caring for a child with complex need - Doctoral Study - UCD
- · Parental decisions around end-of-life care locations for their child – a Grounded Theory Study - Doctoral study - End of Life Observatory, Lancaster University, UK

Collaborative Research

LauraLunn is collaborating with various research projects through several universities including TCD, UCD, RCPI DCU and Lancaster University, UK.

Ireland's first collaborative Children's Palliative Care Conference

Working with other organisations to improve the quality of children's palliative care, we recently collaborated in the hosting of Ireland's first Conference on Children's Palliative Care, www.irishcpcconf.ie. This conference reflected a range of expertise and international approaches to caring for children and families, recognising that all organisations working together is the best way of achieving excellence in Children's Palliative Care in Ireland.

In 2014 we will

- Conduct competency Based Workshops
- Manage statutory training for LauraLynn
- · Host Master Classes facilitated by eminent CPC speakers
- Develop knowledge and understanding around the key issues inherent in children's palliative care



Respite services for children with life-limiting conditions and their families in Ireland - A National Needs Assessment (2013) -LauraLynn, Ireland's Children's Hospice and The Irish Hospice Foundation

Research

Developed and co-authored with Irish Hospice Foundation on Respite Services for Children with Life-Limiting Conditions and their Families in Ireland.

Key Findings

- 1 While respite services are provided in all four Health Service Executive (HSE) regions, access was often dependent on the geographical location of the child and their diagnosis.
- 2 The report estimated that up to €7.6m was currently needed to provide respite care for about 812 children and €8.62m would be required to care for 925 children by 2021.
- 3 This works out as an average of less than €10,000 per child being invested in respite services.





ADVOCACY & RAISING AWARENESS

In 2013 we:

- Presented to the Joint Oireachtas Committee on Health & Children about end-of-life care for children.
- Support, Understanding and Commitment was secured from a number of Senators and TDs to advocate on our behalf statutory funding for children's palliative care in the future.
- No Time to Die Documentary aired on RTE1 on 29 March and looked at paediatric palliative care through the eyes of four families, three of whom attended LauraLynn and offered a rare insight into the realities of life for parents caring for a dying child.
- New Website Work commenced on the development of a new responsive website, enabling it to be accessed and navigated using mobile and digital media. With content designed to serve 3 distinct audiences: 1 Families 2 Health Professionals 3 Supporters
- Social Media the number of supporters grew by 42% across Facebook and Twitter.

In 2014 we will:

- Influence the development of future policy and funding mechanisms of the government, and lobby to enable children's hospices to access fair and appropriate statutory funding
- Advocate on behalf of children and families to ensure a national voice
- Work collaboratively with care providers to ensure excellence in Children's Palliative Care
- · Launch an information hub website on children's palliative care.
- Rise to the challenge ensuring that policy-makers continue to put the needs of life-limited children, young people and their families first."





793

The number of press cuttings to create awareness and support

114

The number of media broadcasts raising awareness for children's palliative care

2013 AT A GLANCE





Light Up LauraLynn

On the first Sunday of December, we hosted our first "light up" ceremony. Up to 500 people came to share in a very special evening where carols were sung and loved ones remembered.





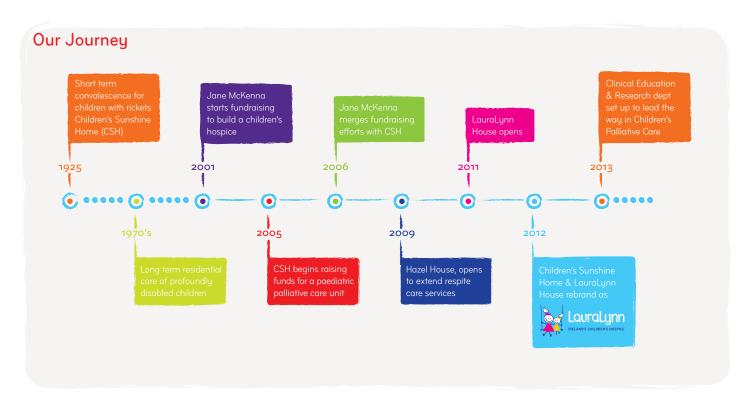
Awards

- * Lama Best Healthcare Building 2013 award and the overall Grand Prix Award with special acknowledgment to David Gilligan, Architects and to Glenbeigh who built LauraLynn House.
- * Women Mean Business Lifetime Achievement Award 2013 – Jane McKenna
- * PRCA Award Flora Mini Marathon 2013
- * Biomnis healthcare Innovation Award 2013

Visit of All-Blacks

Four members of the All Blacks took a

break from training and visited us just prior to their test match against Ireland.



FUNDRAISING

Raising funds to provide more care and services to children with life limiting conditions and families in Ireland

In 2013 we:

- · Achieved a significant increase on last year's income and raised €3.3 million for children's hospice care across Ireland thanks to our ever generous supporters thank you all for your continued support and friendship.
- Secured beneficial new partnerships with a range of companies including Certus, Investec, Microsoft, Google and Bord Gais
- · Strengthened and enhanced our established partnerships including WEEE Ireland, P&G, Millward Brown, Superquinn (SuperValu)
- · Organised our first trek to the Grand Canyon in Sept - with 20 participants who raised over €130K for us.
- · Recruited a team for the famous Paris2Nice cycle in September. We had a team of 16 cyclists who raised over €105,000 for us.
- Held our first ever "Light Up LauraLynn" spectacular light ceremony in December to celebrate life and remember loved ones with our families, friends and neighbours.

- Developed a range of new campaigns to encourage greater support across a range of audiences, these included Green Friday, Hospice Coffee Morning, Xmas Jumper Day
- We are so fortunate to have so many supporters run community events (many repeat) for us comprising over 20% of our revenue achieved.
- Made a significant effort to raise the profile of LauraLynn through print, broadcast and social media. This has no doubt impacted in the high level of funds raised in 2013.

In 2014 we will:

- Continue to raise awareness of the need for funding to sustain our hospice services
- · Work with more companies to raise additional funding for children's hospice care and services with special focus on LauraLynn@Home, bringing hospice care into the comfort of a child's home

- Plan, co-ordinate and implement Children's Hospice Week 2014, strengthening it as the flagship event of the children's hospice sector
- · Establish a calendar of creative fundraising events including Green Friday, Ray D'Arcy's Half Million Half Marathon, #SuperHero selfie, Hospice Coffee Mornings, build on Light Up LauraLynn and Christmas Jumper Day to ensure we can sustain and deliver even more hospice services to families.
- Increase sustainable revenue through increased Direct Debits, Legacies and "In Memory Giving"
- The challenge of increasing our sustainable and regular income.

We are greatly indebted to all our donors for their continued generosity and support.

For every €1 LauraLynn spends: 8.3c 91.7c is spent on is spent on generating delivering care funds and support to children and their families 0

Making Donations Count

Every year there are approximately 320 child deaths and more than 3,840 children living with a life-limiting conditions in Ireland. The monies required to build LauraLynn House were 100% generated through fundraising. It cost €5.5 million to build and fit-out the hospice and it has annual operational costs of €2.1 million.

Our fundraising income goes towards 24:7, 52 weeks a year hospice service for children and their families.

Our mission is to enable children to access high quality care whenever and wherever they need it.

Allocating sufficient administration expenditure is essential to ensure that all resources, including donations, are used to greatest effect for public benefit and that the highest standards are maintained at all times. Of every Euro we receive, 91.7 cent goes directly to caring for children with life limiting conditions and their families. The remaining 8.3 cent is used for fundraising, administration, research, and governance.

Our "Appeals Committee"

Did you know that the Appeals Committee at LauraLynn has been in operation since the late 1950s with some members still with us after 50 years? We wanted to extend a special recognition to these special women who every year organise a series of fundraising events. In 2013 they raised over €25,000 to support our new family therapy programme and worked tirelessly to raise awareness for us across a variety of audiences.

320

The number of children who die from a life-limiting



Our wonderful new playground and multi-sensory garden - sponsored by Tour de Picnic & Smurfit Kappa Group

"It's is like an oasis - where you can be with your child, listen to music, watch a DVD or sing or play with your child. I would never have believed I could laugh so much in the midst of it all..."

Oonagh Alec's Mum

You should know that at LauraLynn there are:

- No salary top-ups
- No six figure salaries
- No pension top-ups
- No bonus payments
- No un-vouched travel expenses

1,400

€140,000 for LauraLynn



GOVERNANCE & RISK MANAGEMENT

Governance

The Trustees and Board are committed to maintaining the highest standards of corporate governance. They are determined that LauraLynn should be in compliance with the HSE Annual Compliance Statement and The Governance Code for Community, Voluntary and Charitable Organisations. We have reviewed operations to ensure compliance with Charities Act 2009. In addition the fundraising arm of the Service has signed upto the ICTR's Guiding Principles of Fundraising.

The Board Members and Trustees, all of whom are non-executive volunteers, are drawn from diverse backgrounds and bring with them a wide range of skills and experience. All new Board Members are inducted into the Service and there are clear distinctions between roles of the Board and the Executive Team to which day to day management is delegated.

BOARD OF DIRECTORS 2013

The Board operate from an Annual Work Plan to ensure it has full oversight of its governing responsibilities. Matters such as policy, strategic development, clinical and corporate governance and financial budgets are monitored by the Board. Requests are submitted to the Trustees for consideration for any shortfall in financial budgets that may arise.

The Board has a number of sub-committees reporting directly to it which include:

- Fundraising
- Finance, Remuneration and Operations
- Clinical Governance
- Financial Audit
- Research Ethics
- Nominations & Corporate Governance

All board sub-committees are chaired bu board members or independent non-executives. Members of the executive team attend sub-committee meetings as required and report on their areas of expertise. We thank our board for sharing in their expertise and giving of their time voluntarily.

Financial Responsibilities of Members of the Board

LauraLynn is financed by a mix of statutory and voluntary funding. In 2013 LauraLynn total income was €6,606,674. Income was generated through various channels with 65% cent government funding, primarily allocated through the Health Service Executive for our disability service and the majority of the remainder raised through our fundraising activities. Fundraising activity generated €3,343,469, up €473,578 or 16.5% from 2012. LauraLynn hospice service is funded entirely from fundraised donations

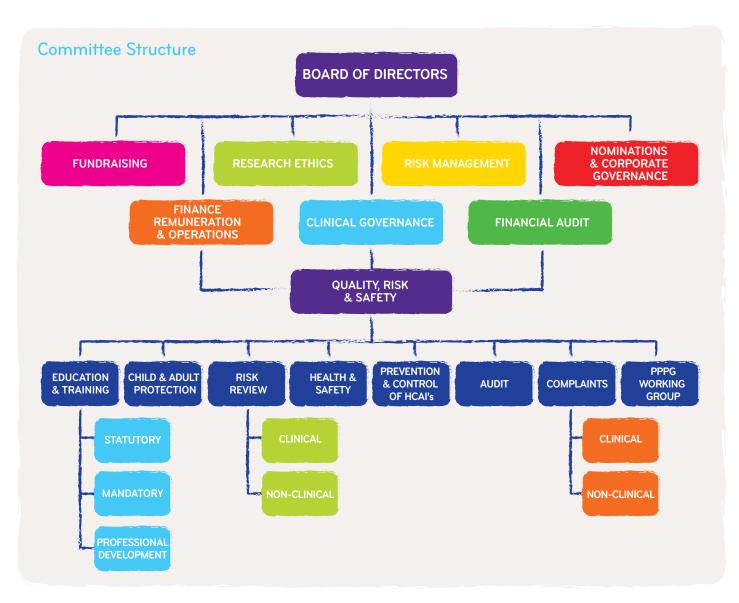
Our investment in supporting children and families in 2013 was made possible through the statutory funding we received through the HSE, government departments and agencies, and the significant support of our voluntary funders. We would like to pay tribute to the generosity of all our donors - ranging from businesses engaged with Corporate Social Responsibility (CSR) programmes to individuals who hosted community events for LauraLynn and made generous donations to us.

Risk Management

LauraLynn ensures that there is an effective Risk Management System in place to provide a high quality, safe environment for children, adults and their families within an environment and culture that is safe for staff, volunteers and visitors. We also ensure to have in place robust structures, systems and processes to minimise or eliminate so far as is reasonably practicable, risks to children, adults and staff by promoting consistency in practice in clinical and non-clinical areas.

HIQA launched the National Standards for Residential Services for Children and Adults with Disabilities in May 2013. We carried out a Gap Analysis in 2013 on how we were performing against these standards and quality improvement plans were implemented. HIQA monitoring inspections and Registration Inspections are due in 2014 and we will strive to achieve HIQA accreditation.

Meeting Attendance







FINANCIAL REVIEW & HIGHLIGHTS

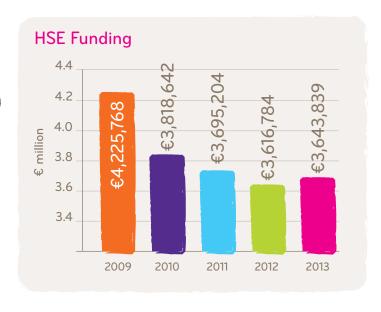
Financial Results

During 2013, LauraLynn continued to recruit staff to further develop our children's hospice care. No HSE funding was received and we continue to lobby for financial assistance for this much needed service. We are grateful to our Trustees for their continued financial support as we strive to meet the ever increasing needs of children with life-limiting conditions and their families.

For the 2013 financial year the Service generated a deficit of €121,418. Although income has increased by 16% year on year it was offset by an increase in expenditure of 18% year on year. A summary of the financial position for the past three years is illustrated here:



For the first time in six years the Service received a small increase in funding from the HSE of €27,055. Although a small increase, it is very welcome in the current economic climate. Our HSE funding used primarily for our disability service (formerly known as the Children's Sunshine Home) as illustrated, shows a reduction of 14% or €581,929 during the last 5 years...

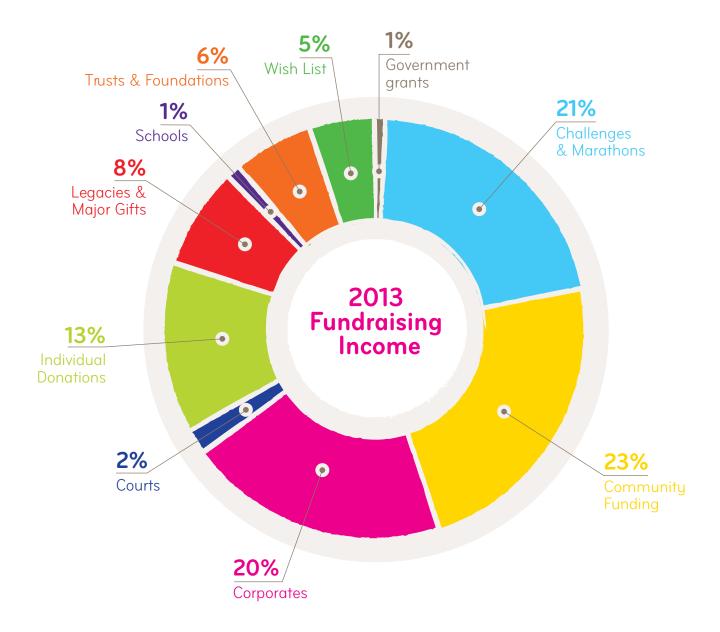


Expenditure

Throughout the year we continued to monitor our cost base to ensure value for money and economies of scale. The reduction in staff costs brought about by the Haddington Road Agreement mid-way through 2013, is not clearly visible as the Service undertook a recruitment drive to fill the vacancies in the palliative care section of our Service. Total costs increased by 18% (€1,033,972) mainly driven by recruitment and staff costs.

Reserves

It is LauraLynn's policy to retain sufficient reserves to safeguard the continuity of its operations, while committing the maximum possible resources to its current services. The objective is that LauraLynn would be able to carry on its work, even if faced with difficult circumstances, and have time to adjust its strategy to meet these changes and secure its future sustainability. The Trustees have designated reserves to ensure the continued operation of our palliative care services into 2016.



Follow Like









GET IN TOUCH

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Charity No. CHY 2633

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