



LauraLynn

IRELAND'S CHILDREN'S HOSPICE

# ANNUAL REPORT 2012



Caring for children with life limiting conditions and their families

• TRANSITIONAL CARE • HOME SUPPORT  
• RESPITE • CRISIS & END OF LIFE CARE

## OUR VISION

All children who need us, can access us.



### OUR VALUES

#### Family

Children's palliative care is a roller-coaster journey for families. Learning that your child has a condition with no cure is devastating. It's a time when families need care, support and information so that they don't feel isolated. We aim to keep families together and allow them to be "Mum & Dad"

#### Life

We believe in putting life into a child's day not days into child's life. Making the most of short & precious lives, celebrating and creating memories to last a lifetime.



#### Care

We are deeply committed to each child and family as a whole. As their needs change, we provide tailored expert care in a home from home setting or in their family home.

### 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 A multi-disciplinary team will work together to support the family, and communicate with the child and family in an open and honest manner.
- 4 Children and families should always be listened to, and be encouraged to talk through their wishes and care choices.
- 5 At all stages of care, from diagnosis to death and bereavement, families should be provided with accurate and relevant information in a language they understand.
- 6 Where possible, children should be cared for in the family's place of choice— at home, a hospice or in hospital.
- 7 Emotional, psychological and spiritual support should be offered to 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 should be discussed and planned for well in advance.
- 10 Support and care will extend to all family members.

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# CHAIRMAN & CEO STRATEGIC OVERVIEW



David Andrews  
Chairman



Philomena Dunne  
CEO

Dear Friends,

## Welcome to our 2012 Annual Report.

In 2012, despite a challenging year in difficult economic times, we have stayed on track to further develop our care to children and their families. To this end, we reviewed our strategy to shape our **next phase of development**, to deliver more services to children in the way families want. We know that families want to care for their child at home. They need the supports in place to manage that very difficult time when their child is diagnosed.

In order to develop the care that families wish to have for their sick child, we have invested hugely in attracting **excellent professionals** onto our team and we continue to develop our internal capacity through the provision of Education and Research opportunities.

Our first Birthday celebrations took place for LauraLynn House in September 2012 when we were joined by our dear friends Jane and Brendan McKenna and many of the children and families who availed of LauraLynn over its first year.

As part of our journey, we have been acutely aware of our need to address our **branding**. Having two brands – The Children's Sunshine Home and LauraLynn has proved to be confusing for all of our stakeholders. Following a full review, the conclusion was that LauraLynn had the greater potential to be the 'lead brand' and so it was agreed that our new brand going forward is 'LauraLynn, Ireland's Children's Hospice'. This has been favourably received by all audiences.

We continue to face the challenge of increased costs, cuts in statutory **funding** and having to sustain increased fundraising for LauraLynn. Our heartfelt thanks to all our donors and supporters for their wonderful support through these difficult times. We continue to lobby our government to assist us in supporting children with life limiting conditions and their families through LauraLynn.

In 2013, we will be subject to audit from **HIQA** and embrace this as an opportunity to ensure our quality service.

We were delighted with the progress that has been made at the level of the **National Development Committee on Children's Palliative Care** and we urge the HSE to continue on this path of development. Hospice at Home is a critical development that is needed and we intend at LauraLynn to pilot a programme of **Hospice at Home** for children and their families. We are also aware that there is a need for increased Respite Care – both in-home and out-of-home from the publication of the recent National Needs Assessment – *Respite Services for Children with Life-Limiting Conditions and their Families in Ireland – 2013*.

Despite the competition for scarce resources, we also ensure that our care is keeping with **National Policy** and best practice. Ultimately we deliver services that families need. With the new direction of our Health Service where money follows the patient we will need to ensure efficiency, effectiveness and value for money.

We embrace the need for **learning** and are delighted that in 2013, we will be partnering with other key stakeholders in hosting a conference on children's palliative care in Dublin, which will have an international dimension.

Regularly we review how we work – our structures, systems and practices to best position LauraLynn as a leading provider of children's palliative care in Ireland. We are forging strong links with other international providers so that we can ultimately measure our success and benchmark our progress.

We wish to acknowledge the **leadership** and invaluable support from the Board and Trustees (both old and new). Our heartfelt thanks to all the families, staff and volunteers whose enthusiasm and commitment have brought LauraLynn, formerly the Children's Sunshine Home to new levels of achievement.

We look forward to 2013 and onwards, extending our respite, end-of-life and home and family support services to more children and families across Ireland so that *"all children who need us can access us"*.

David Andrews  
Chairman

Philomena Dunne  
CEO



# HIGHLIGHTS & ACHIEVEMENTS

## THE STRATEGIC OBJECTIVES COMMENCED IN 2012:

### 1 CHILD CENTRED CARE

Ensure seamless access to and provision of integrated care for the child.

In 2012 LauraLynn cared for over 160 children and their families, sadly 22 children died during this period.

### Family Support Services

Families were interviewed between April and June 2012 to determine what kind of inter-disciplinary supports they need. The results identified the following:

- day respite
- out-patient clinics
- in-home respite
- out-of-home respite.
- hospice at home

### Development of Hospice at Home

In keeping with National Policy and providing services close to home, planning for bringing services outside of Dublin mid-Leinster commenced in 2012. A pilot will be planned during 2013 to address gaps in services which may include a second location outside of Dublin

The aim of Hospice-at-Home is to ensure that children are supported and cared for at home. The development of In-Home Respite as well as out-of-Home Respite care would complement this service.

### 2 QUALITY AND STANDARDS

Achieve external accreditation across all of our services to validate and embed standards of highest quality in all aspects of care. Policy work began in 2012 in preparation for a HIQA audit in 2013.

### 3 EDUCATION AND RESEARCH

A Clinical Education and Research department was established in September 2012. This will lead to enhanced care for the child and develop capacity of our teams to position LauraLynn as centre of excellence for paediatric palliative care.

### 4 ORGANISATIONAL CAPACITY

- Attract, empower and retain experienced palliative care medical professionals and staff committed to achieving our vision.
- Enhance the regional and national profile of LauraLynn across all media
- Secure the necessary financial resources to ensure the long-term sustainability of LauraLynn
- Demonstrate cost effectiveness and value for money across all of our services

## NEXT PHASE OF DEVELOPMENT

### We will provide:

- Day Respite
- Out-patient clinics
- Second Hospice Location Identified
- Hospice at Home
- Respite at Home





# HIGHLIGHTS & ACHIEVEMENTS



## HAPPY BIRTHDAY LAURALYNN!

In September 2012 we celebrated LauraLynn House's 1st birthday, what a special year!

Hard to believe it was a year ago, that glorious sunny day with President McAleese, our patron Miriam O'Callaghan, shared by lots of families and specials guests.



## FIRST EUROPEAN CONGRESS OF PAEDIATRIC PALLIATIVE CARE

A huge honour that our clinical team were invited to present at the 1st European Congress of Paediatric Palliative Care in Rome in November. By sharing a 'snap shot' of the experiences of parents and children alongside the number of referrals during this first year, LauraLynn Hospice will validate it's aspirations to collaborate and partner existing national service provision for Irish children's palliative care.



## LAURALYNN BRANDING

After extensive research we redeveloped the Children's Sunshine Home & LauraLynn brand. Launching in September 2012 as **LauraLynn – Ireland's Children's Hospice**

# FINANCIAL REVIEW & HIGHLIGHTS

## GOVERNANCE

During 2012, LauraLynn continued to ensure that strong internal controls were embedded in the organisation. The regular meetings of the Trustees, Board of Directors and Sub-Committees ensured that the organisation adhered to the standards required in relation to the management of budgets, recognition of income and expenditure and compliance with the processing of donated funds.

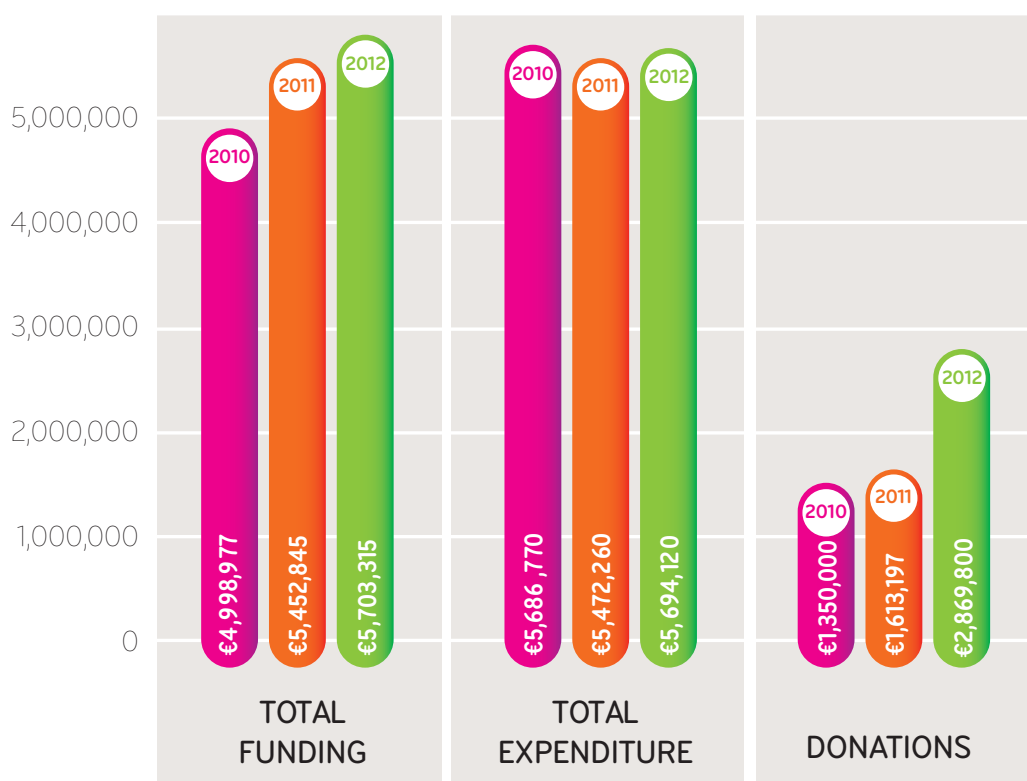
The company has controls in place to limit potential exposures and management and the directors regularly review, reassess and proactively limit any associated risks. In addition the Directors are committed to The Governance Code for Community, Voluntary and Charitable Organisations in 2013.

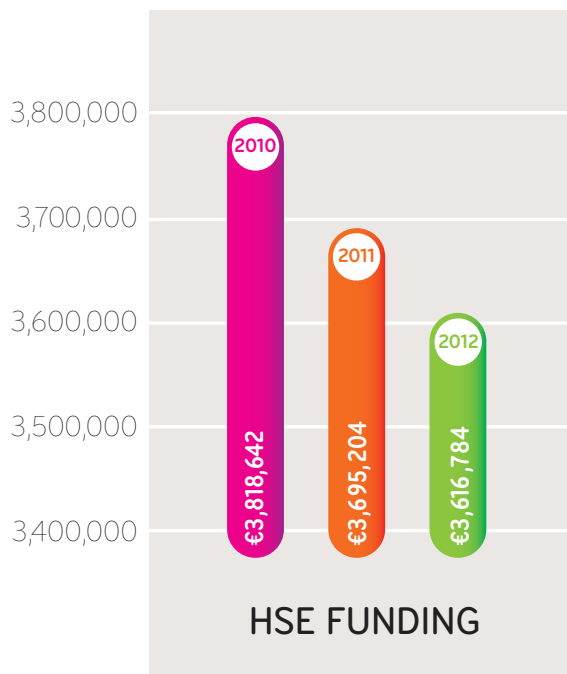
## FINANCIAL RESULTS

For 2012 LauraLynn generated a small surplus of €8,640. This compares to a loss of (€915) for the previous year. A summary financial overview of the organisation for the last three years is illustrated in the table below:

Our HSE funding for Children's Sunshine Home was reduced again in 2012. The nature of our services is such that approximately 85% of our costs are people-related. We regularly review our working practices and continue to negotiate with our suppliers to ensure quality and value for money in all our purchasing.

There is no doubt that we will have to rely more and more on fundraising to continue to provide services. In this regard we are fortunate that our Trustees continue to support us financially.





## INCOME

This downturn in the economy resulted in another reduction in our CSH/HSE funding for 2012 of 2.1% that equates to €78,420.

## EXPENDITURE

Total expenditure increased by €221,860 year on year from €5,472,260 to €5,694,120. This is accounted for mainly by an increase in staff numbers and to some extent some increases and decreases in Non-Pay costs. LauraLynn continues to review all expenditure to ensure savings can be achieved where possible and that value for money exists.

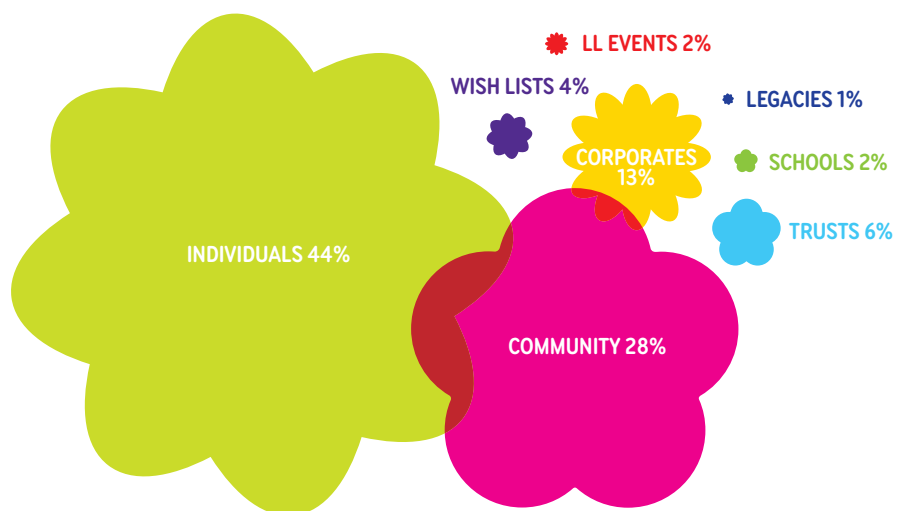
## FUNDRAISING

LauraLynn has not been exempt from the downturn in the economy. The total fundraised income for 2012 was €2,869,800 and is analysed below.

## VOLUNTEERS

We are overwhelmed by our wonderful volunteers who constantly give generously of their time to LauraLynn. Volunteers are crucial to the LauraLynn team in every aspect from gardening, reading, driving families to appointments, fundraising and maintenance. In 2012, volunteers gave 16,800 hours, and we could not provide the care we do without them.

## 2012 FUNDRAISING INCOME





# OUR CARE

We care for children with life limiting conditions and their families by providing – respite, transitional, crisis home support and end-of-life care.



"LauraLynn is the haven for butterflies who need protection, cradling them and all who love them. It gives them room and a safe place to learn to fly."

LauraLynn helped our baby Victoria to be become a great colourful butterfly at peace, that will never die. All fragile butterflies that need LauraLynn are protected and safe there, till their wings are strong enough and they are ready to fly, fly higher than us all."

Sharon, Victoria's mum

"She gets all kind of stimulation & care here, a haven for little Katie. We all feel revived after our stays in LauraLynn"

Olive, Katie's mum



"LauraLynn was our back-up, our other home. It was a night away for Lucas with 24-7 care. It was a home away from home for him."

June, Lucas' mum



"We can hold him and he looks up at me and smiles, he looks up at Catherine and he smiles. He gets into the cot with his sister and they both have a little play around. It is the most wonderful thing."

John, Leo's dad

## KEY ADMISSION CRITERION

CATEGORY	DESCRIPTION	SERVICES OFFERED
<b>Medically complex newborn babies</b>	<ul style="list-style-type: none"> <li>Babies with less than one year life expectancy</li> </ul>	<ul style="list-style-type: none"> <li>Planned transitional care with a defined discharge date</li> <li>Respite (home support)</li> <li>Crisis Care</li> <li>End-of-life care</li> </ul>
<b>Medical trauma cases</b>	<ul style="list-style-type: none"> <li>Traumatic Brain Injury</li> <li>Critical cardiac conditions</li> <li>Progressive Neurological Conditions</li> </ul>	<ul style="list-style-type: none"> <li>Transitional Care (0-12)</li> <li>Respite (birth to 17 years)</li> <li>Crisis Care (birth to 17 years)</li> <li>End-of-life care (birth to 17 years)</li> </ul>
<b>End-of-life care</b>	<ul style="list-style-type: none"> <li>Progressive Neurological Conditions</li> <li>Cystic Fibrosis</li> <li>Oncology</li> <li>Heart Defects</li> </ul>	<ul style="list-style-type: none"> <li>Home Support</li> <li>Centre based terminal care</li> </ul>

New admissions to service are accepted from birth to 16 years