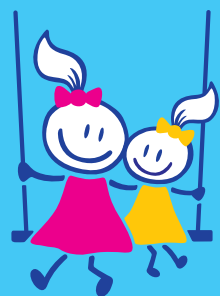


# ANNUAL REPORT 2016



**LauraLynn**  
IRELAND'S CHILDREN'S HOSPICE

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**Niall McHugh**  
Chairman



**Sharon Morrow**  
CEO

Looking back on 2016, we reflect on a year of great progress in the delivery of our unique service by an incredibly committed team, working tirelessly on behalf of our children, adults and their families.

This year was even busier than last; with more children and families than ever before using our growing range of hospice services. We've seen a significant increase in the number of referrals we're getting, and we have implemented a new holistic needs assessment so we can build a tailored care plan to meet each family's specific requirements. We continued with the implementation of our new model of care, and have added expert members to our Family Support and Symptom Management teams.

We constantly strive to improve our facilities. Under the guidance and support of our Family Engagement Committee, our new Family Suite and décor changes have brought a more 'homely' atmosphere to LauraLynn House which has been warmly received by children, families, volunteers and staff alike.

The children and adults in our disability services enjoyed a broader range of community engagement activities this year, both individually and collectively. Whether it was trips away on holiday or days out swimming or horse riding, these outings were a source of fun and fulfilment and we'll be planning more in the future.

Our registered volunteer numbers continue to grow, now exceeding the number of staff and enabling us to deliver care to many more children and their families.

# WELCOME MESSAGE FROM THE CHAIRMAN AND CEO

In keeping with our rotation of Directors, David Andrews stepped down as Chairman of our Board and Dr Hugh Monaghan and Prof. Philip Larkin announced their retirement as Directors. We would like to thank them all for their dedication and service. At the same time, we welcomed the arrival of Dr Denise McDonald to strengthen the Board.

We would like to express our heartfelt gratitude to Jane and Brendan McKenna, who this year stepped back from their public role with LauraLynn. On behalf of all of us here and the many children and families needing hospice care, we say a humble and sincere thank you for their energy, inspiration and achievements.

The year ahead will bring many challenges – none the least the continued challenge of funding our services in the face of a growing demand for care. We are humbled by the tireless efforts of our many supporters, partners and donors who give so generously. Your continued trust in us will be met with openness and transparency about how we raise and spend our much needed funds.

Finally, our deep appreciation to our volunteers, management team and staff who work so hard to change lives every day. As we review our strategy and mission for the next three years, we hope that you will continue with your support and journey with us as we work to develop and improve our care services. We feel sure that, with your help, 2017 will be another exciting year for LauraLynn and the children, adults and families we care for.



Niall McHugh



Sharon Morrow







## A COMING OF AGE



**This year LauraLynn, Ireland's Children's Hospice marked its fifth birthday, a significant milestone for Ireland's only dedicated children's hospice. It's also a time for reflection and gratitude, for the pioneers of the hospice movement in Ireland, people like Jane and Brendan McKenna and our dedicated staff; and for the many volunteers and supporters who have so far helped raise vital funds to ensure that Irish children who require hospice care, can receive it.**

Over the last five years, LauraLynn has helped hundreds of terminally ill and life-limited children and their families through the toughest days of their lives. Since opening in September 2011, more than 350 children and their families have availed of LauraLynn's services. We have provided more than 265,000 hours of short break stays, and 442 family members have attended bereavement events.

As leaders in the field of children's hospice care, we have grown in knowledge and skill to provide support and high quality care to children and young people with life-limiting conditions. Our experience in providing high quality care and support to children and adults with complex disabilities extends to more than 50 years and was evidenced this year with the granting of our HIQA registration status following our first official inspection.

# A COMING OF AGE FOR LAURALYNN

In 2016, LauraLynn continued to keep hospice care firmly on the political agenda. In November we met with the Minister for Health, Simon Harris TD in Leinster House and December saw him return that visit to LauraLynn.

These meetings provided an opportunity to brief the Minister on our tireless work and to address how the Government might best support the delivery of hospice care. We intend to continue highlighting core issues; including the urgent need for a national approach to children's hospice care in Ireland. We see the next phase of our journey about being the driver of the change that is so urgently needed.

Through our experience of delivering hospice care, it has become increasingly evident that children's hospice care is much more than just a hospice building – it is a specialised, compassionate approach to providing tailored, holistic care in the location of choice of the family according to the needs of the child and family.

As a result our service and our facility have evolved to respond more flexibly to their needs. In 2014 LauraLynn launched a hospice-at-home service which enabled us to expand our services to reach more families. Throughout 2016 our LauraLynn@HOME nursing team made 1,443 home visits, providing targeted direct care, symptom management and end-of-life care within the child's own home.

We also understand that the respite care needs of children and families are dynamic and change over time, so service plans and delivery needs to be flexible and responsive. This year we have begun to focus on transitional care as young people transition out of the paediatric care system into the adult care system. Where service gaps appear, we will work to see them closed.

LauraLynn Children's Hospice focuses on making the most of short and precious lives and creating memories to last a lifetime. That's why this year we embarked on a year full of fun activities, from the Hollywood glamour of our first ever Oscar's Ceremony to our 'one time only' performance of LauraLynn's 'The Magical Cake Making Machine' production in The Abbey

Theatre. The programmes we create not only benefit the children we care for, but also the families who love and care for them.

All of this would not be possible without the support of our volunteers, donors, the local community and partners who ensure that we can be there for more children and their families, every day of the year. Over the last five years, supporters of LauraLynn have run 50,150,000 steps in the Women's Mini Marathon and skydived 540,000ft – equivalent of the distance from Dublin to Waterford – and much much more.





# A COMING OF AGE

In 2016, we were delighted to be chosen by Rory McIlroy's charitable trust, The Rory Foundation, as recipients of funds raised from the Irish Open. We were also delighted to continue our partnership with TV3 for Children's Hospice Week which raised close to €110k.

There will be many challenges in the years ahead. The shadows cast on the charity sector have made fundraising more difficult. To actively demonstrate our openness, transparency and integrity we have achieved the Standard of Recommended Practice (SORP) for financial management which means that we operate to the triple lock standard of transparent reporting, good fundraising and good governance.

For the last five years, LauraLynn has provided exceptional, innovative, hospice and disability care for Ireland's most vulnerable children and adults, and the families who love them. We are committed to providing the very best children's palliative and disability care we can through a culture of compassion. We want to continue to be there for the children, adults and families we serve with the very best care and support we can provide.





# FAMILY HIGHLIGHTS



We increased the range of in-house activities and community engagements for the residents of our Adult and Children's Disability Services to include: horse riding and swimming lessons, and social outings to the cinema, bowling and concerts etc.



We expanded our play therapy-led programme to include a film project involving six families who went on to participate in our inaugural LauraLynn Oscars Ceremony; and a LauraLynn/Abbey Theatre original production – “The Magical Cake Making Machine” – in collaboration with the National Concert Hall and National Gallery of Ireland, and starring seven LauraLynn superstars.



Our Music Therapist began visiting children and families in their homes in addition to on-site in our hospice. Frequently these visits are done in collaboration with our Occupational Therapist to maximise the benefit.



Attendance at our annual Family Fun Day and Christmas Party has now grown so large that we've moved venue, to our neighbour Leopardstown Racecourse. In total, 251 attended our 'Day at the Races' themed summer fun day while more than 143 children had the thrill of meeting Santa and Mrs Claus in our purpose-built grotto.





# FAMILY HIGHLIGHTS



Our Memory Making supports, particularly at end-of-life, have become increasingly important to families availing of our service. As a result, we have increased our focus and resources in 2016 and see the need for further expansion in the future.



Our dedicated Family Engagement Committee representing families, carers and guardians met six times this year. This committee offers a forum to engage management and offer valuable insights to inform environmental, practical and process improvements.



Our newly opened Family Suite extension has made a huge difference to families at very difficult but different junctures with their child – their first ever stay in LauraLynn or alternatively during end-of-life care. The purpose-build suite has adjoining rooms, allowing parents to sleep together during their stay.



The LauraLynn Choir, which comprises service users, families, volunteers and staff from our services, performed at our major events including Light Up LauraLynn, family events and our memorial services.





# FUNDRAISING HIGHLIGHTS

Without the support of individuals, groups, schools, companies and trusts, our hospice would not be able to provide our vital care to the children and families who depend on us. Here's a snapshot of fundraising highlights from throughout the year.



In May we partnered with TV3 again to celebrate Children's Hospice Week and raise awareness and funds for our hospice care. Stars of TV3's daytime programming – Alan Hughes, Elaine Crowley, Cassie Stokes, Tommy Martin and Ray Foley - donned their superhero attire for a competitive obstacle race, raising a whopping **€109k** between them. We're delighted that TV3 have agreed to partner with us again next year.



Following a very successful Face to Face donor recruitment campaign we have gained **771 new monthly direct debit donors**, establishing a base of sustainable annual funding, which we plan to grow into the future.



We were delighted to be selected by the Rory Foundation to be one of three recipients of their Dubai Irish Open initiative. The super generous Rory McIlroy went on to win the Irish Open Title, donating his full winnings to the initiative. LauraLynn was thrilled to receive an incredible **€317k** as a result!



# FUNDRAISING HIGHLIGHTS



Our first LauraLynn Heroes Ball took place raising **€67,500**. Hosted by our patron Miriam O'Callaghan, the superhero extravaganza was attended by 424 guests including supporters Alan Hughes, Norah Casey, Rory Cowen and Lisa Fitzpatrick. We are hugely grateful to our ball sponsors Arup, Marks & Spencer, RR Donnelley and ModernGreen.



Community Fundraisers (schools, third party events, challenges & marathons) continue to be a large part of our overall income generation, raising **€1,103,756** up €70k from 2015. In total, 240 3rd party events were run for us in 2016 (296 in 2015) with one in three organised outside Dublin.



The business community were amazingly supportive again this year. In total, 529 businesses donated **€1,343,657** (up from €1,052,682 in 2015), with 18 new companies choosing us as their Charity Partner. In addition to raising funds for LauraLynn, 181 corporate volunteers took part in on-site and event volunteering opportunities.





# MEET HARRY

## CHILDREN HELPING CHILDREN FOR LAURALYNN

There's nothing quite as touching as the help we receive from children. One of our long term supporters is Harry, age seven years, who's been giving to LauraLynn since he was three. Harry's mum explains why...

Harry is now seven years old; he will be eight in December.

For his 3rd birthday, his first real birthday party with little pals back in 2012, we decided on donations to LauraLynn in lieu of birthday presents.

LauraLynn has always been close to our hearts, since I learned from my mum about Brendan & Jane McKenna's beautiful daughters and their phenomenal fundraising efforts for Ireland's first children's hospice. Then becoming LauraLynn, a charity we have always supported and have now passed down this ethos to Harry.

Harry knows LauraLynn hospice is a place for very sick children and by donating money to LauraLynn he says ***"it gives me a really good feeling to give money towards helping sick children and making them happy, maybe LauraLynn can give them medicine or maybe buy them lots of balloons. It is nice to help sick children"***.

He loves when LauraLynn texts to say how much he has raised (and it doesn't matter how much is raised, in Harry's eyes it's millions !!)

Harry has always said ***"I don't mind not getting birthday presents because Santa Claus comes every year and Santa Claus always brings me a present!"***



# WHAT WE DO

**LauraLynn, Ireland's Children's Hospice is the only children's hospice in Ireland, however it's much more than that too. Formed following the merger of the long standing Children's Sunshine Home and the LauraLynn Foundation, in 2012, the organisation comprises both a Hospice Service and Disability Service.**

LauraLynn's Hospice Service provides specialised care to children with life-limiting conditions as well as supports for their families. All services are tailored to meet the unique needs of each family unit, from the point of diagnosis to end of life and throughout bereavement, and are focussed on enhancing the quality of life of the child and all the family.

It costs €5.1 million every year to provide this wide ranging specialist care, free of charge, to families from across Ireland. The majority of this - €3.5 million - is funded by voluntary donations from individuals, groups, organisations and businesses. To continue providing these services, we must raise this amount each year.

In addition to our Hospice Service, we also provide residential and respite care through our Disability Service, formerly known as The Children's Sunshine Home. These services are fully funded by the Health Services Executive (HSE) through a Section 38 Provider Grant.



## SOME PEOPLE WHO HELP MAKE IT ALL POSSIBLE

### TRUSTEES

David Andrews  
Niall McHugh  
Michael O'Donoghue  
Nicholas Quigley

### DIRECTORS

Niall McHugh (Chairman)  
David Andrews  
Mary Ainscough  
Frances Fletcher  
Angie Kinane  
Michael O'Donoghue  
Dr. Denise McDonald  
Ann O'Driscoll  
Tony McPoland  
Nicholas Quigley

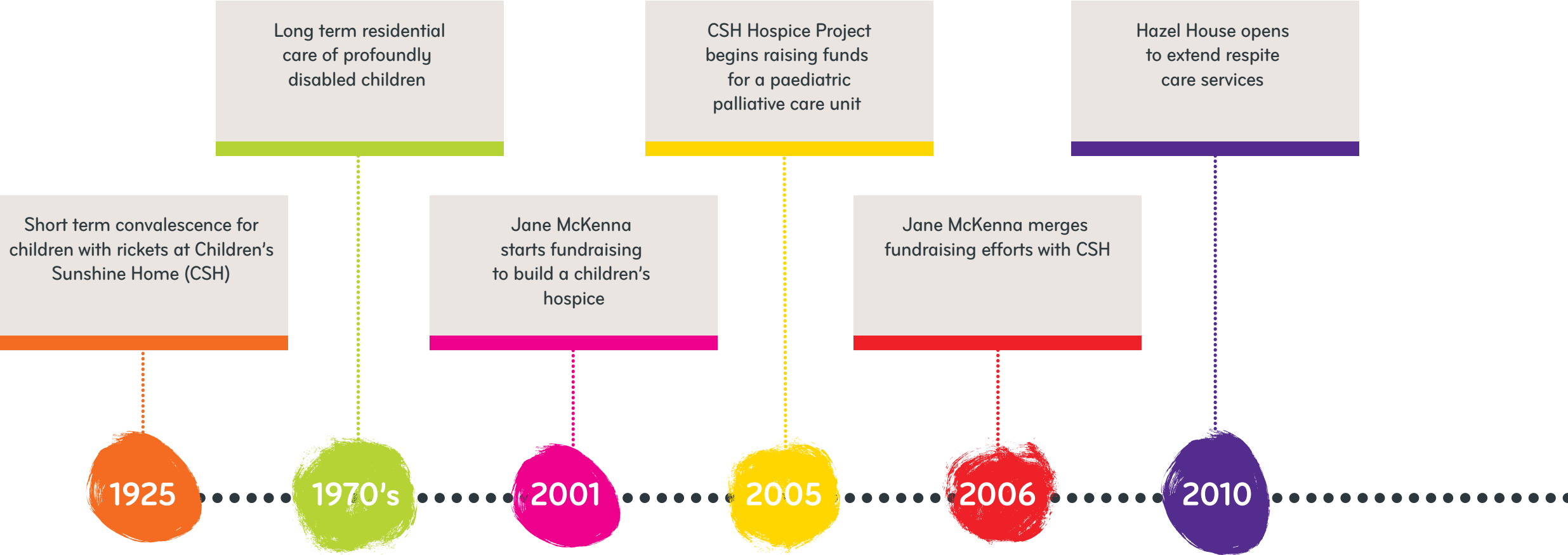
### CEO

Sharon Morrow

### COMPANY SECRETARY

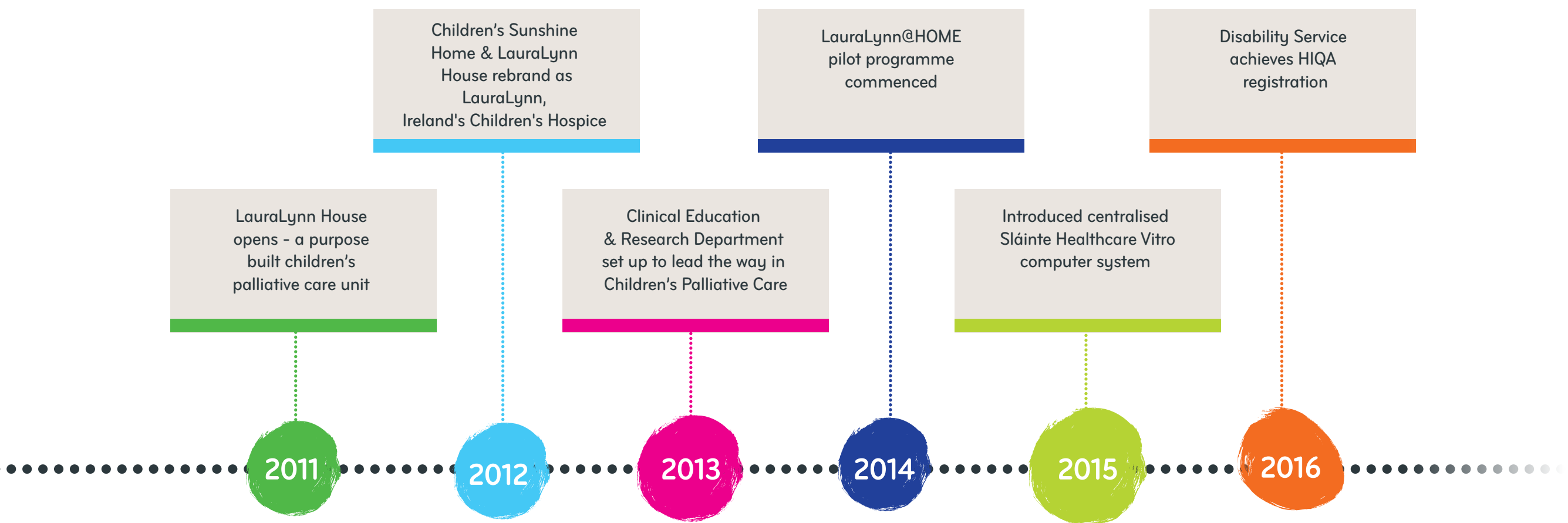
Michael Higgins

# OUR JOURNEY SO FAR





# OUR JOURNEY SO FAR





## OUR VALUES

Family Life Care

## OUR VISION

All children who need  
us can access us

## OUR MISSION

To provide the highest  
level of children's  
palliative and disability  
residential and respite  
service to the children  
and adults in our care

# OUR VALUES

## FAMILY

- Children's palliative care is a rollercoaster 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 "Mums and Dads" (not nurse, doctor, carer).



## LIFE

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

## CARE



- Children and families are in safe hands.
- We care for children with life-limiting conditions by providing planned short break stays, transitional, crisis, home support and end-of-life 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.



# HOSPICE SERVICE

**LauraLynn Hospice Service, provides palliative care to children (aged 0-18 years old) with life-limiting conditions and their families. Our exclusive service embraces all the family and all faiths, beliefs and cultures and is provided free of charge.**

Care focusses on enhancing quality of life, which includes physical comfort and wellbeing, as well as the emotional, social and spiritual aspects of care of the family; and involves supporting families from the point of diagnosis to end of life, and throughout bereavement, with a range of nursing, practical, emotional and medical services.

Our care is delivered by a team of healthcare professionals and volunteers in our purpose-built hospice, in hospital, in the community, or in the family home, depending on the child and family's preference and the medical requirements of the child.

Given the complexity and high level of care needs of children who are life-limited, we ensure each child receives one to one clinical care when they're with us, supplemented by our family support team and activities volunteers.

Our holistic approach ensures we support the whole family, allowing patients to be children and parents to be Mums and Dads rather than full-time carers. Each child and family has a tailored care plan to meet their specific and changing needs.



# HOSPICE CARE & SUPPORT

At LauraLynn we understand that the whole family is affected when there is a life-limited child within the household, and so the whole family needs care and support. Each child and family is given unique care plan which outlines the particular services and supports that are most pertinent to their needs. Depending on the care needs of the child, LauraLynn offers families a choice regarding the location they avail of our services – in hospice, at home or in hospital.

We offer families a range of supports that best meet their needs, including:

- Planned Short Breaks\*
- Unplanned Short Breaks\*  
(step-down or emergency care)
- End-of-Life Care\*
- Symptom Management
- Bereavement Support
- Music and Play Therapy
- Therapeutic Family Work
- Clinical Psychology
- Chaplaincy
- Social Work
- Physiotherapy
- Occupational Therapy
- Family Camp

\* These supports are provided in our hospice, at home or in hospital.



# DID YOU KNOW?



There are about

**3,840**

children in Ireland  
living with a life  
limiting condition<sup>1</sup>



We estimate more than

**30,000**

parents, carers, brothers,  
sisters, relatives and friends  
are affected.

UP TO



children with  
a life-limiting  
condition  
require  
hospice care<sup>2</sup>

LauraLynn  
is the only  
children's  
hospice  
in Ireland.



**LauraLynn**  
IRELAND'S CHILDREN'S HOSPICE

Approximately

**350**

children die each  
year because of  
their life-limiting  
illness, most in their  
first year of life<sup>1</sup>

## A life-limiting condition

is an illness that a  
child may be born  
with or acquire during  
childhood, for which  
there is no reasonable  
hope of cure and from  
which the young person's  
life is limited in scope.



<sup>1</sup> (National Development Committee for Children's Palliative Care, 2016).

<sup>2</sup> (Fraser et al.... & 2016 Census figures)



# WHAT IS CHILDREN'S HOSPICE CARE?

Children's hospice services provide interdisciplinary care for children with life-limiting conditions and their families. The aim of these services is to meet the physical, emotional, social, and spiritual needs of the child and family through a variety of services, including but not limited to:

- Support for the entire family (including parents, siblings, grandparents and extended family)
- Provision of information, support, education and training to carers
- Specialist short break care
- Bereavement support
- Practical help, advice and information
- 24-hour telephone support
- Provision of specialist therapies, including physiotherapy, play and music therapy
- 24-hour access to emergency care
- 24-hour end-of-life care



# THE PEOPLE WE SUPPORT

In 2016 a total 214 families from all across Ireland availed of our Hospice Services, an increase from 152 families in 2015.

We actively provided direct care and/or indirect support to 153 children and their families during the year. A further 61 families availed of our tailored bereavement supports. We processed 62 (nine outstanding from 2015) new referrals and accepted 48 new children.

During the year we provided 38,808 short break stay hours of care and our LauraLynn@HOME nursing team supported 47 children in their home or in hospital. Our multi-disciplinary team was busier than ever, with a marked increase in collaborative therapeutic interventions.

201 Play Therapy Programme activities were supported in the hospice.

Our Play Therapist provided Bereavement Support to 32 children from 25 families, following the death of their sibling.

Sadly 26 children availing of LauraLynn services died during 2016. Half of those were supported to die at home.



	Children	Parents	Siblings
Our Occupational Therapist saw	100	48	37
Our Music Therapist & Occupational Therapist jointly saw	27	40	26

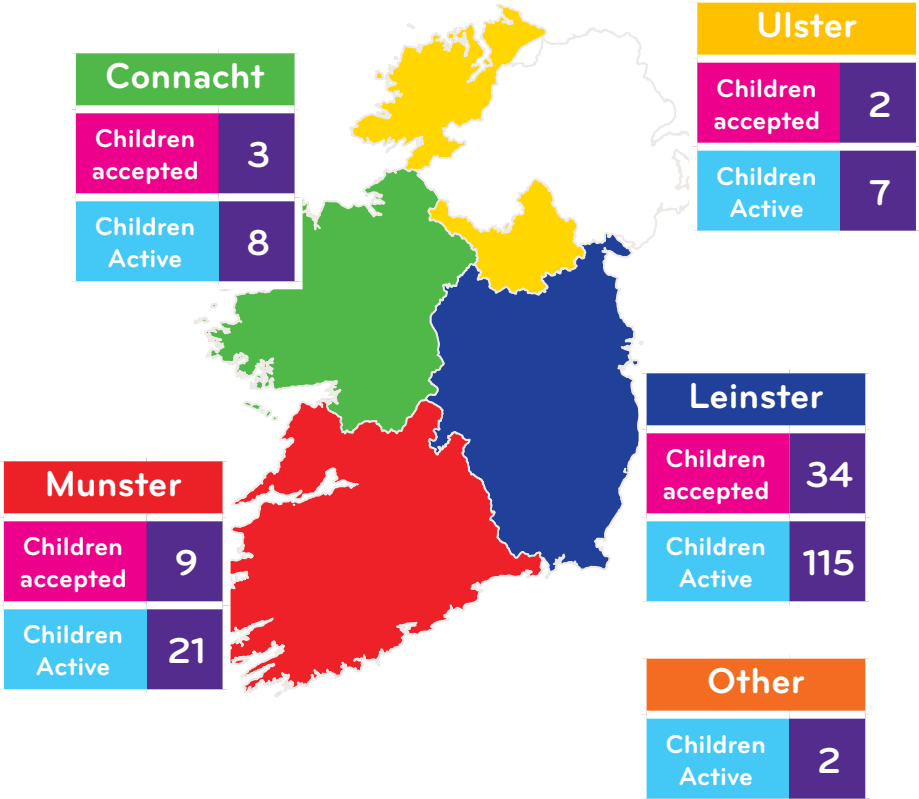
# WHO ATTENDS LAURALYNN?

Children of all ages attended LauraLynn’s Hospice Service in 2016.

Age	Children accepted in 2016	Children active in 2016
0-1 years	12	17
2-5 years	11	42
6-10 years	14	52
10+ years	11	42
Total	48	153

Although predominantly Dublin-based (44%), children and families came from 22 counties to avail of the services of LauraLynn in 2016. The exceptions were Counties Sligo, Kerry, Wexford and Carlow.

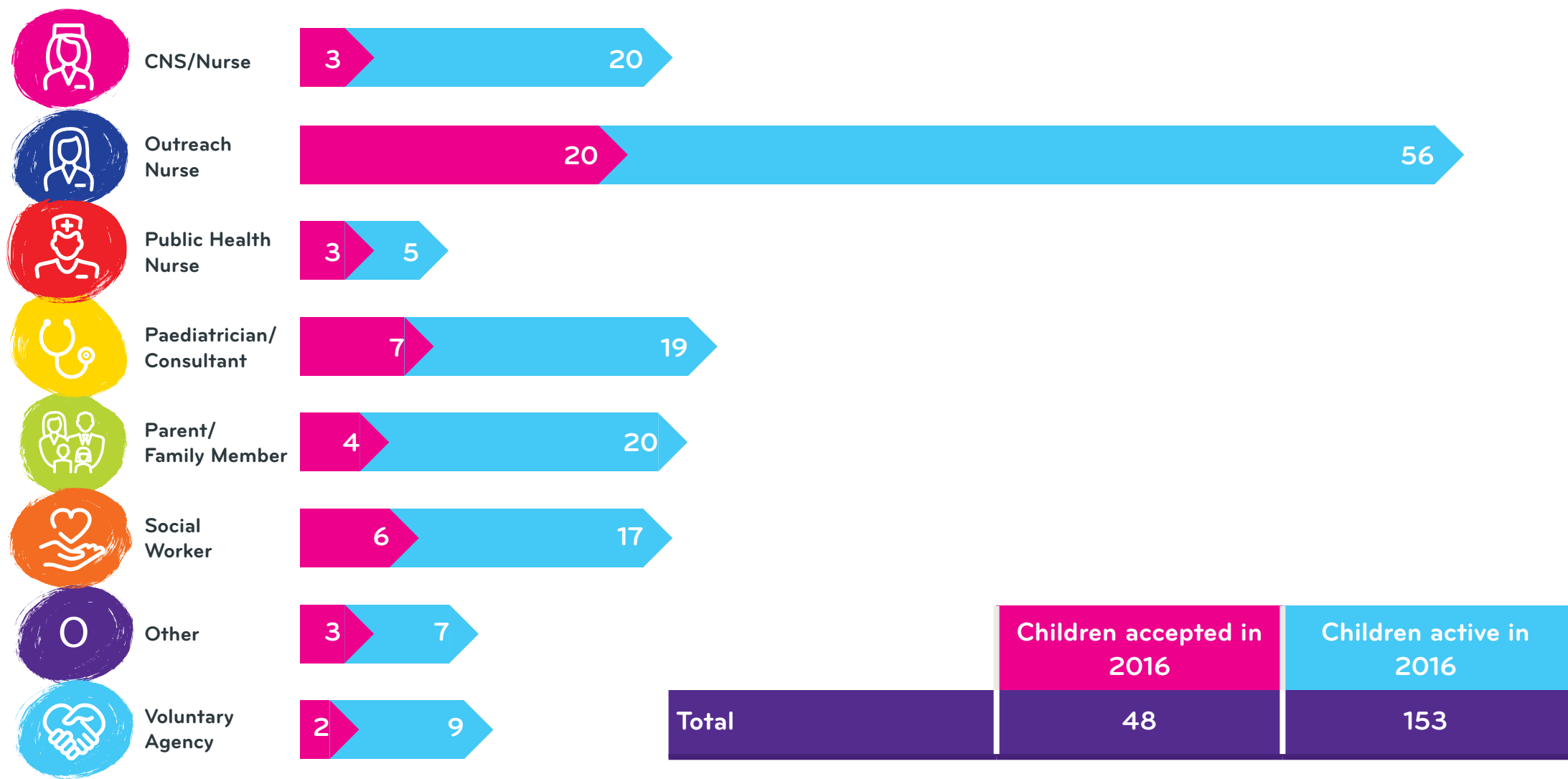
	Children accepted in 2016	Children active in 2016
Total	48	153





# WHO REFERS TO LAURALYNN HOSPICE SERVICE?

In 2016 referrals were predominantly from Children's Outreach Nurses (45%), up from 13% in 2015. Paediatrician referrals also showed strong growth this year accounting for one in five referrals.



# WHY ARE CHILDREN REFERRED TO LAURALYNN HOSPICE SERVICE?

## Diagnostic Conditions

There was a increase in referrals of children with a diagnosis of a neurological condition in 2016, up to 38% compared with 29% in 2015.

Diagnostic Categories	Children accepted in 2016	Children active in 2016
Circulatory	0	1
Congenital	5	39
Metabolic	8	20
Neurology	19	55
Oncology	5	6
Perinatal	6	23
Respiratory	0	2
Other	5	6
Unknown	0	1
Total	48	153

ACT Categories	Children accepted in 2016	Children active in 2016
Category 1	5	11
Category 2	6	22
Category 3	9	23
Category 4	28	97
Total	48	153

# ACT CATEGORIES OF REFERRAL EXPLAINED

## Categories of Referral – ACT 4

### CATEGORY 1

- Life-threatening conditions for which curative treatment may be feasible but can fail. Where access to palliative care services may be necessary when treatment fails.

### CATEGORY 2

- Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.

### CATEGORY 3

- Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years.

### CATEGORY 4

- Irreversible but non–progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death.



# DISABILITY SERVICE

Our Disability Service provides a residential setting that is homely and promotes the privacy, dignity and safety of each child and adult. We have a Children's Residential & Respite service (Hazel House) and an Adult Residential Home (Willow View).

Using a social model of care approach, our residential care programme supports children and adults in a variety of ways including:

- A person-centred approach to care
- Care and support that promotes individuality
- Safety and protection
- A care programme that listens to and promotes equal rights
- Enabling health and development
- Promoting and encouraging friendship and social activities

While we no longer accept admissions to our residential care programmes, we are committed to supporting our resident children and adults in a person-centred environment.

LauraLynn's Disability Service is registered with HIQA as a designated centre for persons (Children and Adults) with Disabilities and is fully funded by the HSE under a Section 38 Provider Service Level Arrangement.



# DISABILITY SERVICE

## HAZEL HOUSE

Hazel House provides residential care to three children and respite care/crisis care to children with profound learning difficulties, accompanying physical disabilities, complex medical and healthcare needs and who may have additional sensory impairments, with a maximum occupancy of seven children at any time.

Our respite service supported 27 families in 2016, with an allocation of, on average, 24 nights respite per family. For some, this was taken as two nights respite per month, while others chose longer respite stays so that they could go on holidays. Each respite stay is planned to ensure the child has a positive, enjoyable experience packed with fun activities and excursions. Examples of things children want to do while in on respite are: trips out on the Luas, enjoyable walks, sensory baths and fun activities with peers.

## WILLOW VIEW

Willow View provides high support residential care to seven adults with severe to profound intellectual and physical disabilities. All of our adults attend a day service during the week. We strive to make Willow View a homely environment for them coming home from their busy day, by offering relaxing, multi-sensory activities or creative story time with some of our many volunteers.

As our adults have busy schedules during the week, a lot of our activities and outings are planned for the weekend. These include; shopping outings, day trips to the seaside, eating lunch/dinner out, walks in the park and the sensory garden, cinema, bowling, getting takeaways, attending gigs and concerts and many more fun-filled activities.





# MEET PAUL CIARAN

“

Paul Ciaran is 15 and has been going to Hazel House in LauraLynn since he was nine. He loves respite sleepovers as it gives him a small bit of independence and an enjoyable break away, spending time with friends as any teenager would.

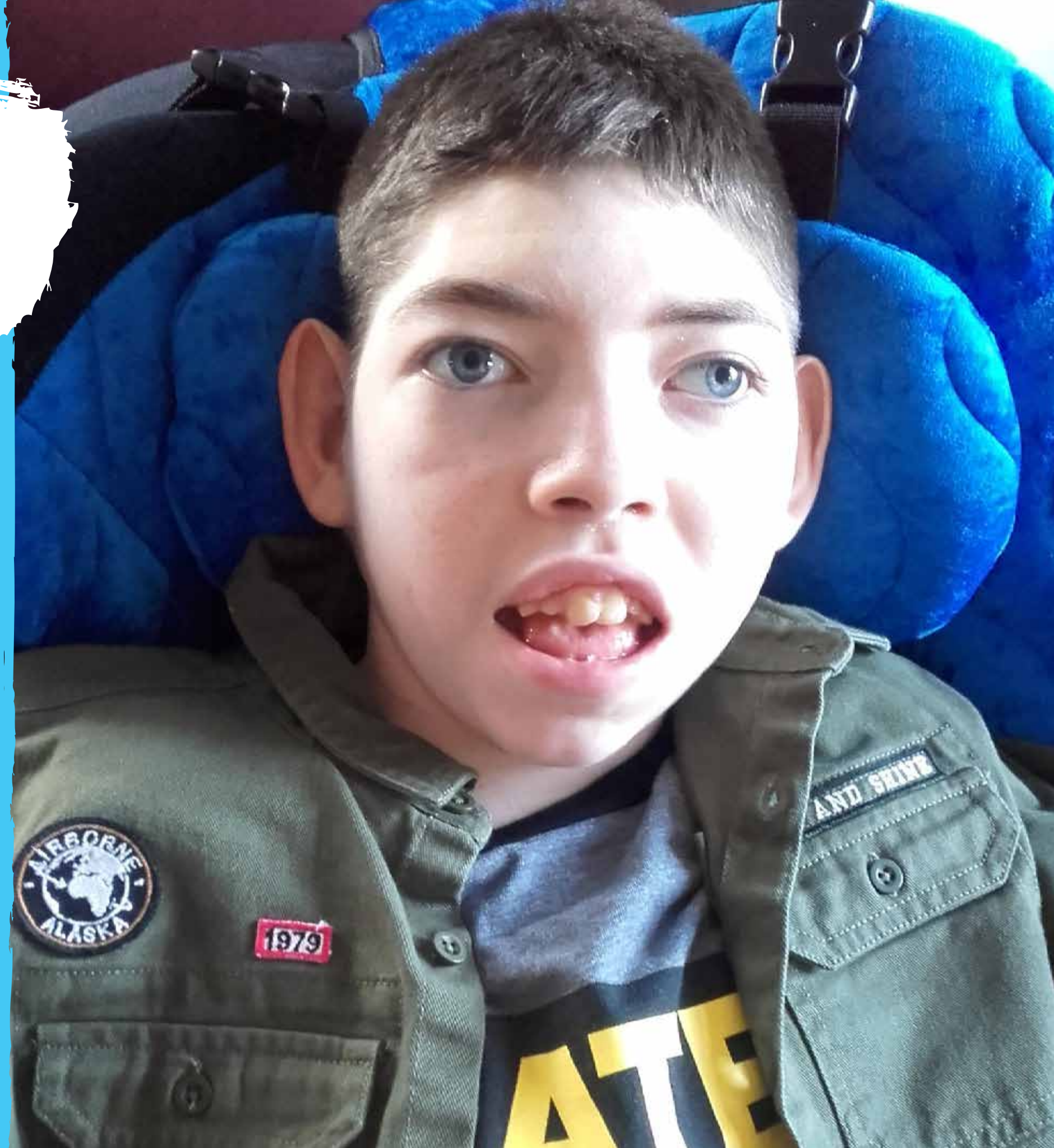
As his mam, when he's in Hazel House it gives me a chance to rest as looking after Paul Ciaran is 24/7. It gives us time to do other things with his little brother and sister.

For us Hazel House is a home away from home, a life line, a place you trust.

”

**Michelle**

(Paul Ciaran's Mum)



# OUR PERFORMANCE

2016 marks the mid-point of our current strategic plan (2015-2017). Our work this year has driven us considerably further in achieving our four stated goals, helping to raise the bar in both the quality of care we provide and the breadth of our reach in delivering that care.

## STRATEGIC GOAL 1

To Pursue Excellence in Care Provision & Service Delivery for our Children's Palliative Care (Hospice) and Disability Services

## STRATEGIC GOAL 2

To Agree & Secure an Appropriate Future Funding Stream for Children's Palliative Care (Hospice Service)

## STRATEGIC GOAL 3

To Ensure an Organisation-wide Programme is in Place to Build & Develop the LauraLynn Team

## STRATEGIC GOAL 4

To Assist in the Development of a National Model of Children's Palliative Care in Collaboration with our Stakeholders



# STRATEGIC GOAL 1

## To Pursue Excellence in Care Provision & Service Delivery for our Children's Palliative Care (Hospice) and Disability Services

### IN 2016:

- In line with international practice in children's hospice care, we remodelled our Hospice Service which included: revising our Referrals and Acceptance process; restructuring our short stay allocations; assigning a key worker team for each service user; implementing a refined Holistic Needs Assessment; and rolling out individualised care plans for children and families.
- We further developed our social model of care approach in our Disability Service in line with the needs of our service users and HIQA requirements. This saw the expansion of our activities programme and personal supports programme for our Disability service users.
- Our family-led facilities improvement programme continued to enhance inclusion and promote a more family-friendly atmosphere in our Hospice and Disability Services, including; construction of new Family Suite as an extension to LauraLynn House, supported by corporate partners Arup/SMBC.
- As part of our commitment to Quality, Safety and Risk Management, we implemented a comprehensive Quality & Safety programme under the guidance of the Quality & Safety Committee, a sub-committee of the Board of Directors.

# STRATEGIC GOAL 2

## To Agree & Secure an Appropriate Future Funding Stream for our Children's Palliative Care (Hospice Service)

### IN 2016:

- In total we generated €3,370,791 through voluntary donations from the public, corporate supporters, trusts and foundations. This year we piloted a Face2Face campaign that successfully recruited 771 regular, direct debit donors and greater diversification of our donor base.
- We successfully secured a significant donation from The Rory Foundation for the development of two new Clinical Nurse Specialist roles.
- As part of our Section 38 Provider Service Level Arrangements, 100% Funding for Disability Services was secured from the HSE
- Significant progress was made with the Department of Health on policy and funding for our Hospice Service.

# STRATEGIC GOAL 3

## To Ensure an Organisation-wide Programme is in Place to Build & Develop the LauraLynn Team

### IN 2016:

- To meet the needs of our growing number of families, we reviewed and restructured staffing in our Hospice Service, including establishing: Consultant Paediatrician, Head of Care, Head of Operations, Care Co-Ordinator and Family Support Team roles.
- We continued to promote learning and development opportunities for both clinical and non-clinical staff. This included rolling out our Clinical Competency Foundation Programme, which provides bespoke in-house training to clinical staff, including our 26 newly recruited nurses.
- We introduced several new service improvement systems, including: piloting a new Quality Initiative – ‘Learning from Excellence’ – in our Hospice Service, to recognise good practice and improve quality of care for service users; beginning ‘Schwartz Rounds’ for all staff to examine the emotional impact of caring on service delivery; and rolling out our ‘#hello, my name is’ campaign to promote open communication across all staff.
- To continue to reduce staff turnover, we successfully introduced new recruitment and retention focused practices including using Value-Based recruitment and having service user representatives on interview panels.



# STRATEGIC GOAL 4

## To Assist in the Development of a National Model of Children's Palliative Care in Collaboration with our Stakeholders

### IN 2016:

- Our CEO continued to Co-Chair the National Development Committee for Children's Palliative Care, which undertook an evaluation of the Children's Palliative Care Programme, which was presented to the Minister for Health, Simon Harris T.D.
- We were an organising partner of the 2nd Collaborative Children's Palliative Care Conference in April, when we had the opportunity to showcase our work through five podium presentations and five poster presentations.
- As part of our ongoing service development, we conducted site visits to Robin House and Richard House children's hospices in Scotland and Forget-Me-Not children's hospice in England, where we had the opportunity to share best practice with these long established providers.
- We continue to be active leaders in key hospice and palliative care networks including: All Ireland Institute of Hospice and Palliative Care (AIIPC); Irish Association of Palliative Care (IAPC); and Together for Short Lives.

# OUR FOCUS FOR 2017

The year ahead will be the final of our current Strategic Plan (2015-2017) and there is still much to do to improve our financial sustainability and progress our vision that all children who need our care can access it.

Our priorities for 2017 will be:



To provide excellent care to the children and adults that use our services.



To grow and develop our people so they have the knowledge, experience and skills to do the complex work required.



To build the financial sustainability of the organisation in order to achieve our key objectives.



To increase the public and political priority regarding children's hospice care in Ireland.

# OUR FINANCIALS

**LauraLynn Ireland's Children's Hospice is financed by our Trustees and the Health Service Executive (HSE). The Trustees, through general public donations, support the funding of our Hospice Service, while the HSE continues to fund our Disability Service and provide some funding for the hospice.**

We are grateful to the HSE for their continuing support of our Disability Service. Since 2009 our funding allocation from the HSE has reduced by €440,740 (10.4%) in keeping with a reduction in the number of service users.

In 2016 our combined service (Hospice and Disability) had an income of €8,246,971, of which €4,619,454 came from the state, including €3,785,028 from HSE under a Service Level Arrangement for the provision of disability services. The Trustees provided €3,279,287 from the fundraised income.

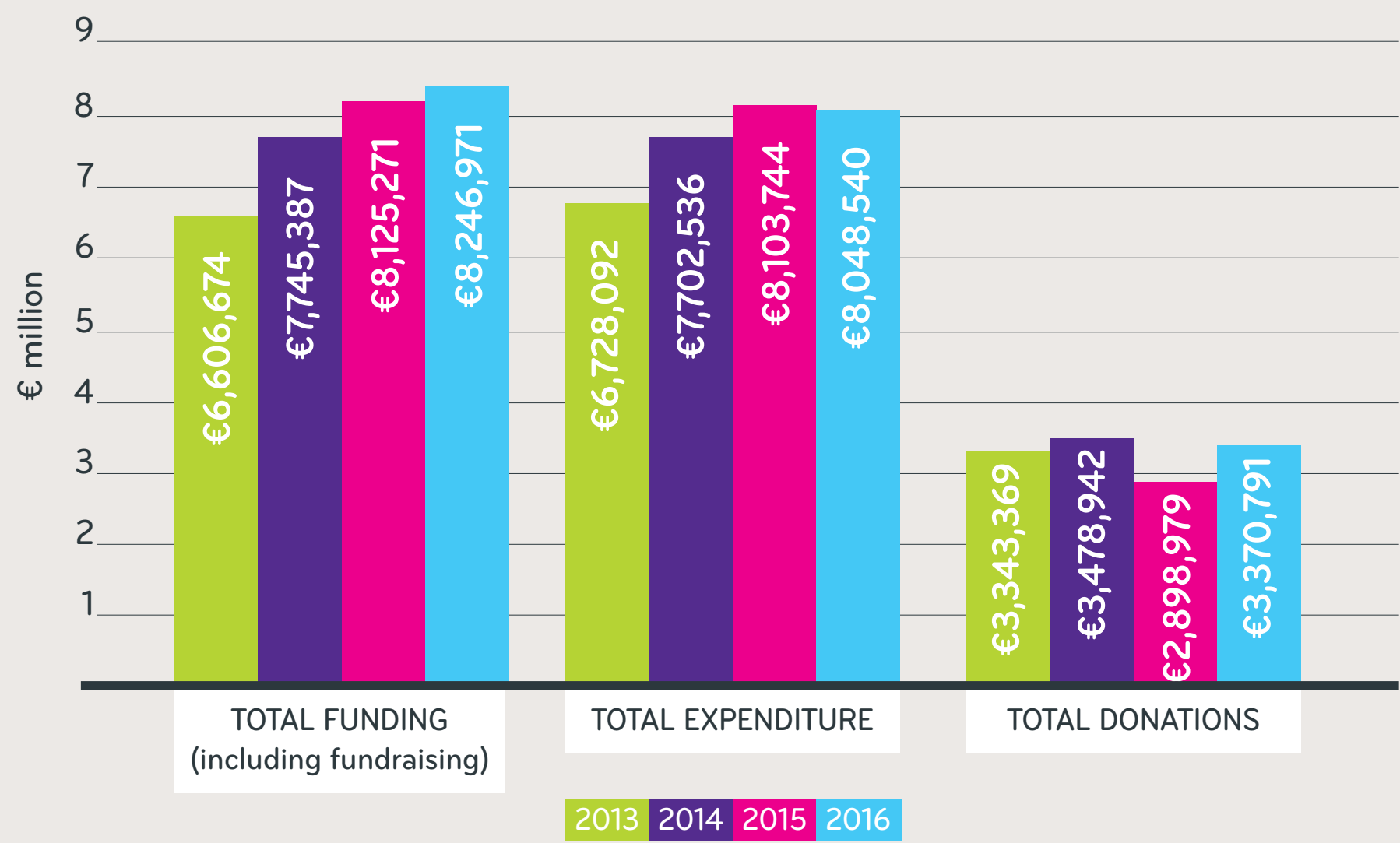
Despite an increase in staffing levels, our expenditure decreased in 2016, as a result of cost saving measures implemented during the year. In total, it cost €8,048,540 to operate LauraLynn in 2016, €4,020,009 for the disability service and €4,028,531 for the hospice service. Our Hospice Service is heavily dependent on voluntary donations (81%).



**LauraLynn takes the commitment and trust of our donors and funders very seriously and we honour it by providing clear and transparent information about how we raise our money, how we account for it and how we spend it. We also welcome donor and supporter visits to see our work first hand.**



# OUR FINANCIALS AT A GLANCE



# WHERE THE FUNDRAISED MONEY CAME FROM

## OUR FUNDRAISING

2016 was a challenging year for fundraising, due to some high profile charity scandals and a fall in public confidence and giving. We were relieved to record an increase of 16.3% in fundraised income, almost returning us to our 2014 level. This was largely due to a significant donation from The Rory Foundation (€317k) and a one off anonymous donation of €111k.

We are hugely grateful for the generosity and goodwill of both the public and business communities, who support the funding of our Hospice Service. Together they donated €3,370,791 and provided €256,120 worth of goods and services free of charge. Due to successful cost saving measures during 2016, of the €3,370,791 raised, the trustees used €3,279,287 for hospice care, with the remaining €91,504 being held for future expansion.

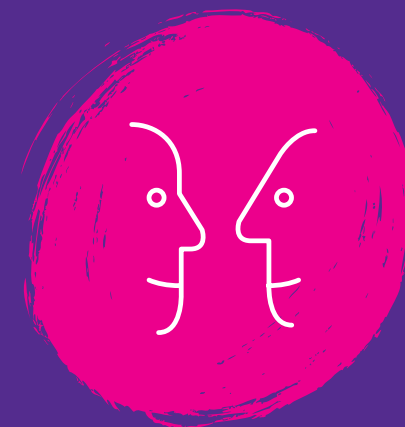
We have an over reliance on the support of corporate and community fundraisers, who together comprise 72% of our total revenue. In 2016, to diversify our funding model the Trustees invested in expanding our regular giving supporters through a pilot 'Face-to-Face' campaign and direct mail activities. As a result, 4% of funds donated during 2016 came from regular givers.

In September we hosted our first Donor Open Day and welcomed more than 120 of our supporters onsite to see first-hand how their donations are making a difference.

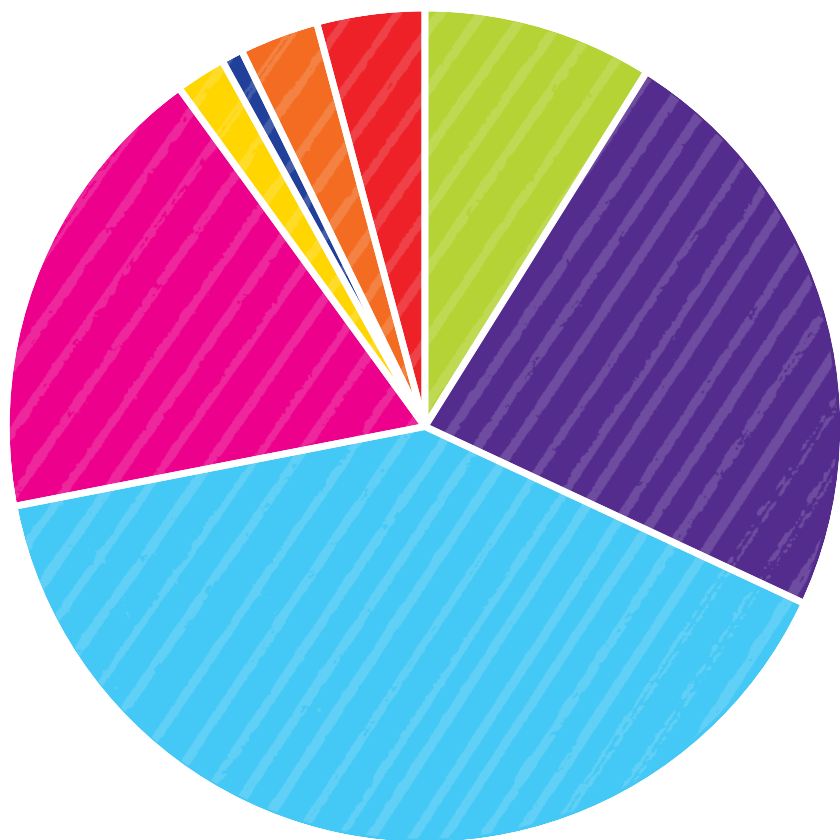
Our goal is to grow our income from individual giving whilst reducing our reliance on ad hoc/once off events. In addition, we look forward to welcoming more of our donors and supporters to our 2nd Open Day and onsite events.

Our **"Face-to-Face"** campaign led to the commitment of 771 new direct debit donors by the 31st December 2016.

We hope that these new donors will remain with us well into the future resulting in an increase of €13k of monthly sustainable income. The net investment in this campaign was a once off cost of €198k.



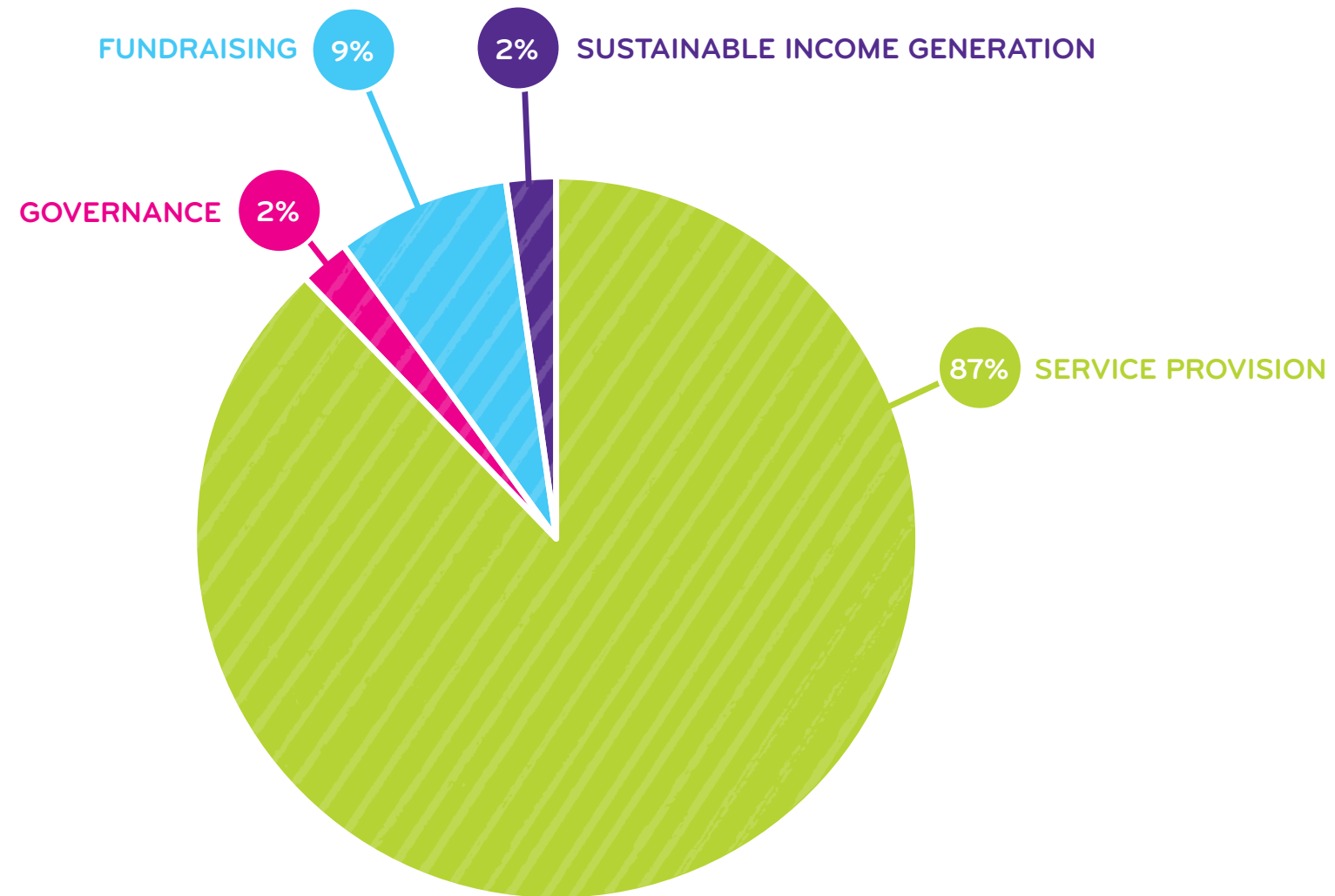
# 2016 FUNDRAISED INCOME



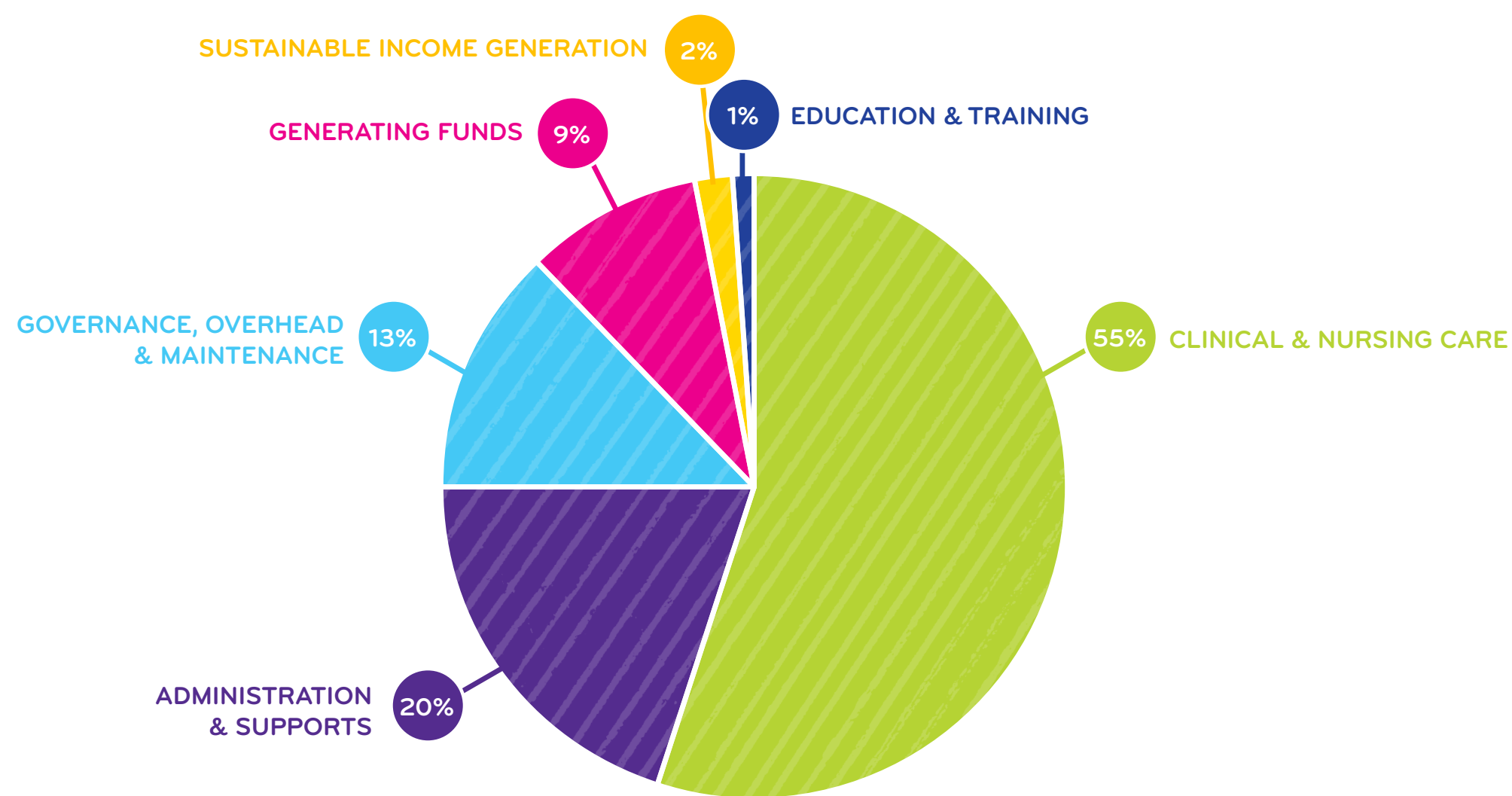
9%	Challenges & Marathons	€284,608
23%	Community Fundraising	€773,709
40%	Corporates	€1,343,657
18%	Individual Donations	€608,709
2%	Legacies	€59,871
1%	Schools	€45,439
3%	Trusts & Foundations	€106,282
4%	Direct Debits	€133,916
<1%	Courts	€14,600
TOTAL		€3,370,791



# AND HOW WE SPENT OUR MONEY



# HOW WE SPENT OUR MONEY – A DETAILED LOOK





## NEW SERVICES

Our funding from supporters was used to provide a number of significant new services for children with life-limiting conditions and their families during 2016. These services included:

- Increase in clinical staff following a successful recruitment campaign in a difficult market.
- Construction of our new Family Suite as an extension to LauraLynn House supported by corporate partners Arup/SMBC.
- Further development of interior of LauraLynn House to enhance the homely environment.
- Development of our Fundraising and Marketing & Communications Teams.
- Development of links with National Maternity Hospital.
- Introduction of the “hello, my name is...” campaign.
- Introduction of Schwartz rounds.

## RESERVES

In accordance with best practice, the Trustees’ policy aims to have sufficient reserves to ensure that we can react and adapt to challenging times. As a dynamic organisation that is committed to continuing to expand its hospice care provision, we also need to hold adequate reserves to develop our services as we work towards giving more families real choice in terms of the location of hospice care for their child.

## INVESTMENT POLICY

LauraLynn places excess funds on deposit with a view to maximising return on a short to medium-term basis, without hindering the capacity of the organisation to operate normally.



# STRUCTURE & GOVERNANCE

## Structure

The Children's Sunshine Home (Disability Service) was founded in 1925 and its principal objective set out in the Memorandum of Association is to provide care for sick children. Following a strategic review in 2002-2004 it was decided to address the needs of children requiring palliative care and the Children's Sunshine Home Hospice Project was established to fundraise for a children's hospice building. In 2006 it joined forces with The LauraLynn Foundation which had been established by Jane and Brendan McKenna, who also saw the need for respite and specialist care for children with life-limiting conditions following their own personal experience with the deaths of their two daughters, Laura and Lynn.

CSH Childcare Services (Hospice Service) was established in 2011 and LauraLynn House was opened in September of that year on the grounds of the Children's Sunshine Home and now provides short breaks, symptom management, end-of-life and crisis care to children with life-limiting conditions and support to their whole family.

Both The Children's Sunshine Home and CSH Childcare Services are limited by guarantee and are registered charities operating under LauraLynn Ireland's Children's Hospice.



# STRUCTURE & GOVERNANCE

## Governance

LauraLynn takes the commitment and trust of our donors, funders and the public very seriously and we honour it by providing clear and transparent information about how we raise our money, how we account for it and how we spend it. We also welcome donor and supporter visits to see our work first hand.

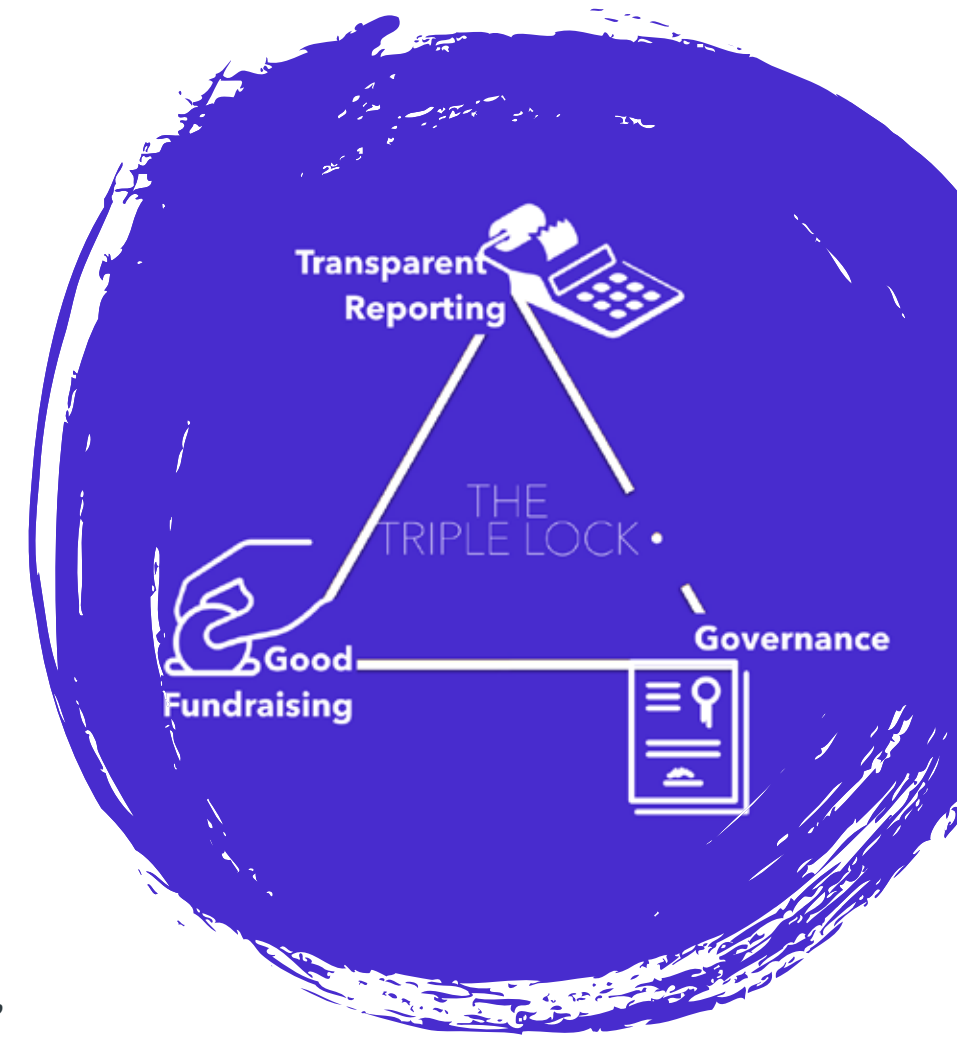
Our voluntary Board of Directors and Trustees are ultimately responsible for our governance, strategic direction, ethos and values.

Additionally, the Board are responsible for ensuring that the organisation operates an appropriate system of financial control and complies with relevant laws and regulations.

LauraLynn has a “Safeguarding Protection from Abuse” policy in line with the HSE’s Safeguarding Vulnerable Persons at Risk of Abuse National Policy

We are also fully compliant with the obligations of the Vetting Bureau (Children and Vulnerable Adults) Act 2012 and have child protection policies and practices in place that are in line with Children First 2011.

LauraLynn is registered with the Charities Regulatory Authority and we welcome the progress made to date in implementing the Charities Act 2009. We are compliant with the HSE Annual Compliance Statement and The Governance Code for Community, Voluntary and Charitable Organisations. We are signed up to the ICTR Statement of Guiding Principles for Fundraising and adhere to the data protection laws. We have achieved the Standard of Recommended Practice (SORP) for financial management which means that we operate to the triple lock standards of transparent reporting, good fundraising and good governance.



# ACCOUNTING AND REPORTING BY CHARITIES

In order to provide information relevant to understanding the stewardship of the directors and the performance and financial position of the charity, we have prepared our financial statements in accordance with the formats provided for in the Statement of Recommended Practice (SORP 2015) “Accounting and Reporting by Charities” in accordance with the Financial

Reporting Standards where applicable in the UK (which has been recognised as best practice for financial reporting by charities in Ireland) and Republic of Ireland (FRS102), issued by the Financial Reporting Council, and promulgated for use in Ireland by the Institute of Chartered Accountants Ireland, effective 1 January 2015 and the Companies Act 2014.



# STRUCTURE & GOVERNANCE

## Public benefit

LauraLynn is Ireland's only Children's Hospice. We provide palliative care to children with life-limiting conditions and their families. We focus on enhancing quality of life, providing support from diagnosis, to end of life, and throughout bereavement with a range of practical, emotional and medical care for the whole family.

LauraLynn Hospice takes a holistic approach to palliative care for children and young persons with life-limiting conditions and their families. Care is provided by our interdisciplinary team in partnership with other healthcare providers and specialists. It includes a range of services to meet the needs of the child and their family – physical, emotional, social and spiritual.

Additionally of public benefit, is our commitment to provide a 'home' for children and adults with profound intellectual disabilities. We no longer accept new referrals to our residential programmes but are committed to caring and supporting the adults and children in our Disability Service to enjoy a good quality of life, in a place that feels like home and upholds their personal dignity and respects their privacy



# STRUCTURE & GOVERNANCE

## Our Trustees

Our Trustees act as guardians of the organisation's assets and are entrusted with the land and buildings at Leopardstown Road where LauraLynn operates. The Trustees are responsible for the cash, investments, donations, grants and overall spend and meets three times a year. All Trustees are non-executive.

The Trustees and Board of Directors each have an annual work plan which ensures they have full oversight of their governing responsibilities. Matters such as strategy, policy, quality of care, clinical and corporate governance, finance, investments, facilities and risk are monitored and reviewed at regular meetings throughout the year.

## Our Board

Both the Children's Sunshine Home and CSH Childcare Services are governed by the same Board of Directors. The Board Members are all non-executive and are drawn from diverse backgrounds, possessing a wide range of skills and experience. Each Director is appointed for a period of three years having been recommended by the Nominations Committee and is eligible for re-appointment for two further consecutive three year periods (nine years in total). The Board meets at least six times each year and has responsibility for all the business of the organisation.

The Board is supported by a Board Committee structure which deals effectively with specific aspects of the business of the organisation. The Board committees in place are: the Quality, Risk & Safety Finance & Operations Committee; Financial Audit Committee; Nominations, Remuneration & Corporate Governance Committee; Fundraising Committee; Research & Ethics Committee; and Family Engagement Committee.

All new Board Members and Trustees are inducted into the organisation, receiving a Code of Conduct for Board Members Booklet which includes our Conflict of Interest Policy. Every Board Meeting commences with a request for expressions of conflict of interest.

The Board delegates the day-to-day management of the organisation to the Chief Executive and Executive Management Team.

The Board does not receive any remuneration in respect of their services to the charity and no top up payments are made to LauraLynn employees. Our CEO's salary is less than €100k and this is fully in line with agreed HSE & Department of Health pay scales. None of the CEO's salary is paid from fundraising income; it is provided by the HSE as part of its allocation to LauraLynn as a Section 38 provider. There are no additional benefits, bonus or personal expenses paid to the CEO or other staff.

# COMMITTEES OF THE BOARD

The Trustees and Board are supported by a number of sub-committees, each chaired by a Board Member. Members of the Executive Team attend the sub-committee meetings as required and report on their areas of expertise.

**1 Fundraising** Sub-Committee agrees and actions key elements of the organisation's fundraising & marketing strategy and meets at least three times a year. In 2016 the Fundraising Sub-Committee met six times.

Chairperson: David Andrews

.....

**2 Finance & Operations** Sub-Committee in conjunction with the Board, is responsible for ensuring that the organisation is meeting its operational and financial targets as determined by the Board; developing the overall plans and budgets for the various operational divisions that are represented at committee meetings; and ensuring the successful delivery of services and special projects as allocated to budget holders by the Board.

At least one member of the sub-committee will have relevant accounting or related financial experience and the sub-committee meets at least five times a year. In 2016 the Finance & Operations met six times.

Chairperson: Nick Quigley

**3 Research & Ethics** Sub-Committee ensures that research is conducted according to best practice and maintains ethical standards of practice in research. It protects and preserves the subjects' rights and ensures that the practice of fully informed consent is observed. It provides reassurance to the public and outside bodies that high ethical standards are maintained. It meets twice a year or more depending on receipt of applications.

Chairperson: Michael O'Donoghue

.....

**4 Quality, Risk & Safety** Sub-Committee oversees key aspects of the risk management process to ensure that the organisation: adheres to policies and procedures governing care delivery; has stringent procedures in place for the recruitment of staff and volunteers; audits clinical practice to ensure compliance with our processes; oversees the work of the Child Protection & Vulnerable Adult Team who are dedicated to managing any reported issues and implementation of our policies; and investigates and resolves issues which arise from our Complaints, Compliments & Feedback Team.

Chairperson: Ann O'Driscoll



# COMMITTEES OF THE BOARD

**5 Financial Audit** Sub-Committee whose remit is to assist the Board in discharging its responsibility in: ensuring the organisation adopts, maintains and applies appropriate and accurate accounting and financial reporting processes and procedures; facilitating the independence of the external audit process and addressing issues arising from internal and external audit processes; and ensuring that the organisation maintains effective risk management processes relating to the its management of financial risks, prevention of corruption and waste and system of internal control. It meets three times a year.

**Chairperson:** Tony McPoland

**6 Nominations, Remuneration & Corporate Governance** Sub-Committee monitors and reviews the structure and composition of the Board. It deals with matters of Board succession and disciplinary issues at a senior executive level, ensuring that remuneration for employees is in keeping with the service's Finance Management Policy and the requirements under HSE Compliance and Good Governance and corporate governance on behalf of the Board. It consists of people who are experts in these areas, non-executive directors and employees and meets three times a year.

**Chairperson:** Tony McPoland

**7 Family Communications** Sub-Committee provides a representative body for families, guardians and carers to communicate effectively with the Board of Directors and staff. Having regard to the best interests of children, adults and families in each strand of the organisation, this sub-committee helps cascade communications from the Board and staff to families. It aims to develop and foster communications between families and to articulate in an open forum in order to ststems and service improvements.

**Chairperson:** Frances Fletcher

# DIRECTORS AND TRUSTEES

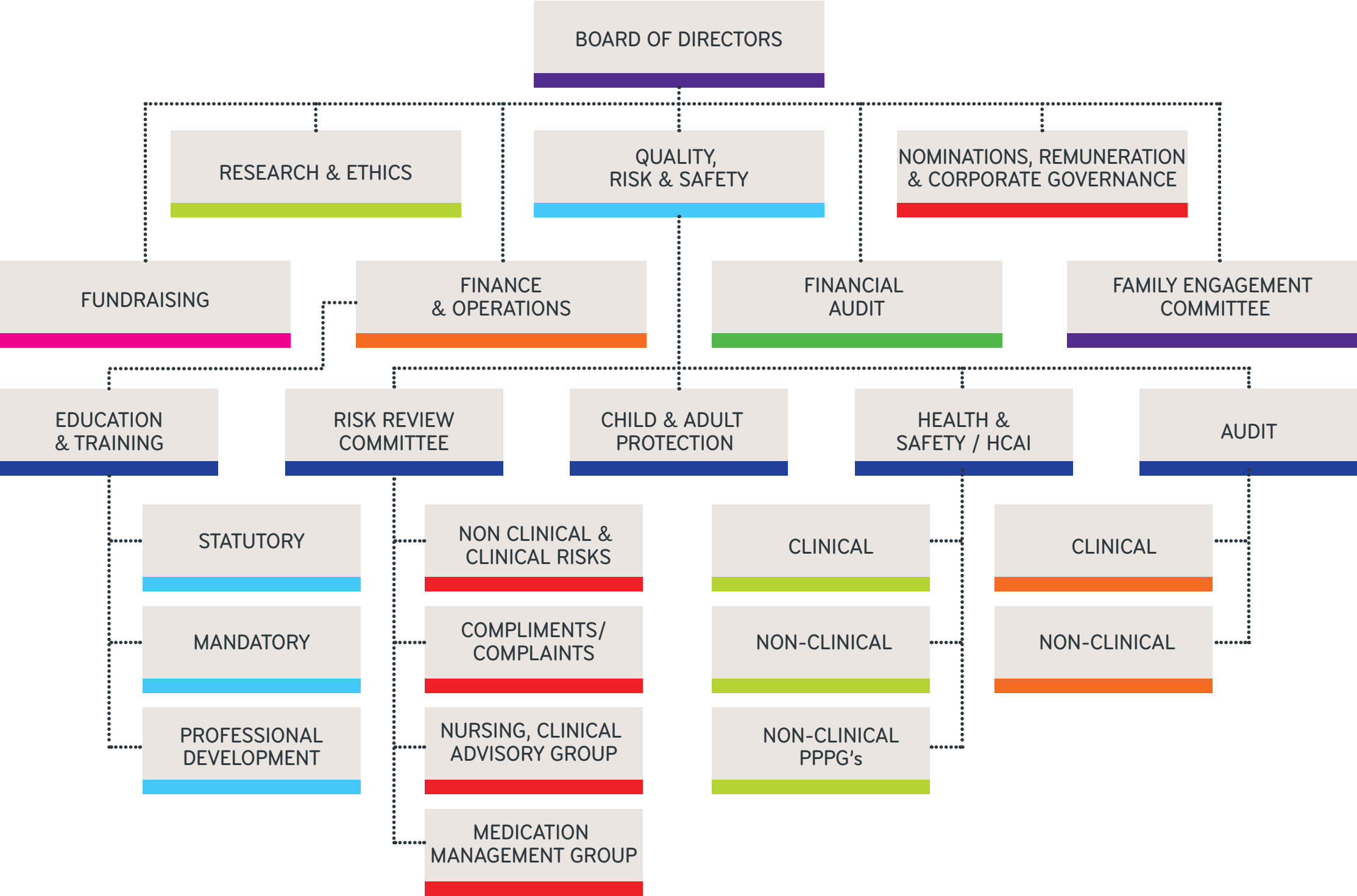
## ATTENDANCE AT MEETINGS

Directors		Attendance
David Andrews	Resigned as Chairman 21st June 2016	5/6
Mary Ainscough	Appointed 23rd June 2015	5/6
Frances Fletcher		6/6
Angie Kinane		6/6
Dr. Hugh Monaghan	Resigned 21st June 2016	0/3
Michael O'Donoghue		5/6
Ann O'Driscoll		5/6
Dr. Denise McDonald	Appointed 21st June 2016	3/4
Niall McHugh	Appointed as Chairman on 21st June 2016	6/6
Tony McPoland		6/6
Philip Larkin	Resigned 21st June 2016	2/3
Nicholas Quigley		5/6

Secretary		Attendance
Michael Higgins		6/6

Trustees		Attendance
David Andrews		5/5
Niall McHugh	Appointed 21st June 2016	3/3
Michael O'Donoghue		4/5
Nicholas Quigley		3/5

# GOVERNANCE STRUCTURE





# OUR PEOPLE

During 2016 the team in LauraLynn grew to 269 people, comprising 125 members of staff (115 in 2015) and 144 volunteers (117 in 2015). By year end, we had recruited 38 new staff, 24 of which were nursing staff.

A number of improvements to our recruitment and retention practices resulted in a continued decrease in staff turnover to 14%, down from 23% in 2014. These improvements included moving to Value Based Recruitment, involving parents on interview panels, launching our '#hello, my name is' campaign and our Learning and Development Programme.

LauraLynn relies on the support of our 144 volunteers, to undertake a wide range of roles from driving our bus to facility maintenance and from musical entertainment to general administration duties. In 2016, 35 new volunteers completed Induction Training and joined the team delivering 6,239 hours of vital assistance.

LauraLynn is also supported by Corporate and Fundraising Volunteers in communities all over the country who have helped to raise more than €3.3 million in 2016.

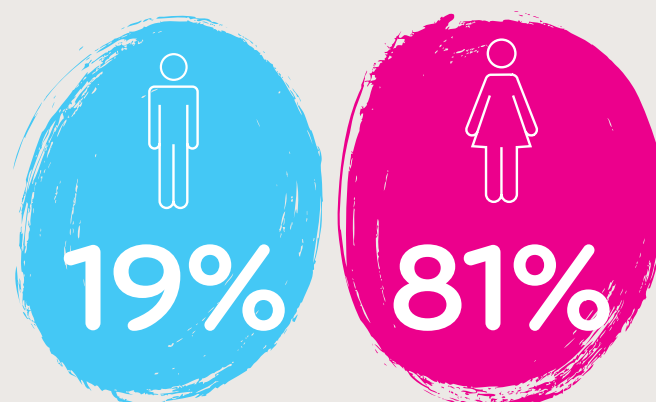


# VOLUNTEER PROGRAMME

Total hours completed



Gender breakdown



Average age

45



New Applications  
In 2016

42

Total Registered

144

Total active in 2016

110

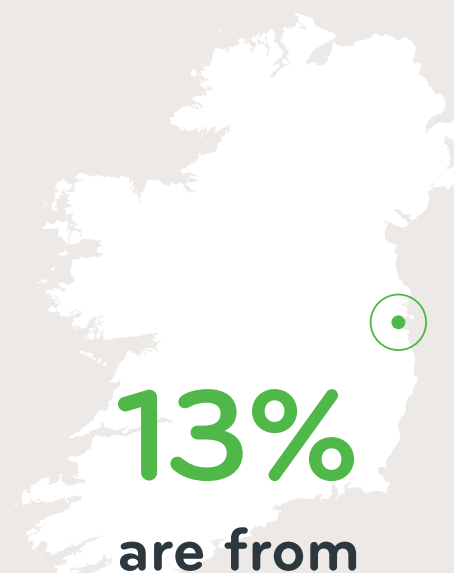
12

Volunteer roles



7,000+

kilometers  
travelled



13%

are from  
outside dublin

# OUR PEOPLE

## NEW TEAM MEMBERS

During 2016, we recruited 38 members of staff, 24 of whom were nursing staff. In particular, recruiting 24 high quality nurses (who will strengthen and develop key areas of our service) was an enormous achievement for us. In late 2016 we were excited to collaborate with The National Maternity Hospital, to recruit a Neonatal Palliative Care Liaison Nurse, plus two Clinical Nurse Specialist positions were approved and funded by the Rory McIlroy Foundation. It is envisaged that these Clinical Nurse Specialists will work between LauraLynn and Temple Street Children's University Hospital.

## VALUES BASED RECRUITMENT

In 2016 we conducted a comprehensive review of all Human Resources activity in order to improve recruitment and selection.

Values Based Recruitment (VBR) is an approach which attracts and selects employees on the basis that their individual values and behaviours. The purpose of VBR is to ensure that the future and current LauraLynn workforce is selected against the values of the organisation so that we have the right people, with the right skills and values, to deliver excellent service user care and experience.

## PARENTS ON INTERVIEW PANELS

We also improved our interview process in 2016 to include people who use our services on our interview panels.

Where possible, parents of a child or adult who uses or has used our service participate on the interview panels for positions at every level. Management and parents work in partnership through the selection and decision making process.



**38 NEW STAFF**  
which included  
**24 NURSES**





# OUR PEOPLE

## LEARNING AND DEVELOPMENT

Throughout the year, staff and volunteers took part in a wide variety of in-house and external learning activities covering professional training needs as well as personal skills development. These activities included formal qualifications, training courses, conferences, seminars, and statutory and mandatory training. We welcome the increasing numbers of staff who have embarked on third level and further education in the area of children's palliative care.

We supported and organised the 2nd International Children's Palliative Care Conference in Farmleigh in April 2016, as one of the partner organisations. This was a successful event with 140 delegates in attendance.

In 2015, we developed a first of its kind nursing learning needs competency assessment tool for children's palliative care. This tool was presented in Rome at the 3rd Congress on Paediatric Palliative Care - a Global Gathering conference. Since then we are in discussions with a children's hospice in Northern Ireland about the possibility of the LauraLynn PaedPal Assessment Tool being used by staff in their hospice.



## '#hello, my name is'

We ran a quality improvement campaign encouraging all staff to share their name with families to create awareness about the importance of introductions.

The aim of the campaign is to help foster a culture of inclusion, compassion and open communication in our service.



# MEET CLODAGH & JESSIE

“

My name is Clodagh. I'm a retired widow and a few years ago I decided I wanted to get involved in some voluntary work. I have 7 wonderful grandsons and decided I would like to do something with children. LauraLynn caught my eye and, as it is not too far from my home, I decided to make enquiries as to how I could contribute.

I'm a violinist and retired from the National Symphony Orchestra some years ago. Since becoming a volunteer, I now get to play for the children in LauraLynn every week. Music is a powerful tool and I enjoy interacting with the children through music. Each week I vary what I play depending on the children and what's going on. Over the years, I've grown to know the favourites of the different children.

I'm also involved with Peata, the pet therapy organisation, so I bring my lovely dog Jessie with me when I play. Jessie, a Cavichon, is a big hit with the children but she also really enjoys the visits.

LauraLynn is such a wonderful organisation! Everyone is so committed to making life as colourful as possible for the children. I cannot praise the nursing staff enough. They not only look after children with demanding medical needs but do it with such love and affection, making each child feel so special.

I'm also impressed by some of the young volunteers who come straight from work and give of their time. LauraLynn is such a rewarding organisation to volunteer for.

”

**Clodagh Vedres and Jessie**



# MEET FRAN & ARTHUR

“

In 2005, my husband, Arthur and I heard Jane McKenna speak on the radio about the tragic events which led to the loss of her and her husband Brendan's only two daughters, Laura and Lynn. She described every nuance of their lives, how Laura had died, aged four, following surgery to repair a heart defect, and that her big sister Lynn had also died less than two years later aged fifteen, having lost her battle against Leukaemia – diagnosed on the day of Laura's surgery.

We were very moved to hear their story and dream of building a children's hospice in memory of their girls. This was the first time we heard of the LauraLynn Foundation and immediately felt that we wanted to do something to help.

I write as a hobby and had a couple of books written which hadn't been published, so that evening Arthur and I decided to invest some money to publish one of my books and hopefully raise some funds. We made contact with Jane and she was enthusiastic about our idea, so Arthur and I established McGuinness Books,

raided our bank account, and published that first novel 'The Married Woman'. Presently I am working on book number eleven. We received help from Cyclone Couriers who very generously stored and delivered the books to the shops for us, and for the last couple of years Southside Storage are equally generous in giving us storage.

The most exciting part was when LauraLynn Foundation merged with The Children's Sunshine Home, and in 2011 LauraLynn Children's Hospice became a reality, and Jane and Brendan's dream came true.

Nowadays we sell the books at larger events mostly in the RDS, as well as LauraLynn merchandise, and at the same time try to raise the profile of LauraLynn.

For us, knowing Jane and Brendan has changed our lives and we will always value their love and friendship. They have worked tirelessly over the years and it has been a wonderful journey. We have every intention of continuing to raise funds for LauraLynn.

”

**Fran O'Brien & Arthur McGuinness**





*Making the most of  
short and precious lives*



LauraLynn

IRELAND'S CHILDREN'S HOSPICE