

ANNUAL REPORT 2017

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CONTENTS MENU



Niall McHugh Chairman



Rachel Nolan Interm CEO

WELCOME MESSAGE FROM THE CHAIRMAN AND INTERIM CEO

We are delighted to introduce you to our 2017 Annual Report and Financial Statements. As you will read in these pages, it was another fantastic year for LauraLynn, that saw continued growth, recognition and change as well as many special moments and achievements to reflect on. Our Hospice and Disability Services increased their reach and range of services this year meaning that, in addition to our adult residents, we cared for more children and supported more families than ever before. Service expansion included the introduction of our Autumn Leaves Program for parents and pre-schoolers and in hospital visits for hospice service users; plus a volunteer 'Buddy Programme', Scents of Reference' communication programme and social activities programme for our disability service users.

LauraLynn is committed to extending hospice and palliative care services to more children who need them. Children as young as one-week old are now accessing the service, whilst our cohort of pre-teens and teenagers has led us to begin development of a Transition Care Pathway to ensure delivery of palliative care extends seamlessly from our children's service into adult services when a child reaches 18 years of age.

2017 was a year of recognition of LauraLynn and the work we do. Our disability services received a very positive appraisal from our first unannounced HIQA inspection, with particular recognition of our team's knowledge of the residents' needs and the level of comfort that residents displayed towards staff. We were honoured to receive special recognition in the Charity Impact Awards (Community Impact and Trustee categories), Irish Healthcare Awards (Excellence in Healthcare Management category) and to pick up a winning Repak Pakman Award for our battery recycling partnership with WEEE Ireland. Our representation at national and international healthcare meetings was strong too with 7 LauraLynn poster presentations at the 3rd International Children's Palliative Care conference in Farmleigh in November.

Our hospice is hugely dependent on fundraised income to cover operational costs and despite the economic lift, this year was very challenging as we strived to reach our target of €3.5m. Trust in the charity sector has been damaged in recent years and we would like to pay tribute to our generous supporters and reassure them of our commitment to being open and transparent about how we raise and spend our money.

Following three years of exceptional leadership we bid a fond farewell to CEO Sharon Morrow this year and to Head of Finance Mike Higgins, who also stepped down as Company Secretary. Board Member Mary Ainscough resigned her position and was replaced by Kevin Keating. We would like to thank them all for their dedication and service and at the same time welcome Kevin and our incoming CEO, Orla O'Brien, who will be assuming her post in April 2018.

2018 will be another busy year for LauraLynn as we develop our next Strategic Plan. More children and families require our services and this increased demand will bring additional challenges for funding and recruiting expert staff. A concerted and collaborative effort will be required to progress the children's palliative care agenda and we are looking forward to playing a leading role in this work.

Lastly, we would like to thank and pay tribute to our donors, funders, supporters, volunteers, management team and staff who work so hard to change lives every day. We feel sure that with your continued assistance, LauraLynn is well placed to meet the challenges ahead and deliver more and better services to the children and families who need us...helping us to achieve our vision, that 'all children who need us can access us'.

Niall McHugh Chairperson

Rachel Nolan Interim CEO



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WHAT WE DO

LauraLynn, Ireland's Children's Hospice was formed in 2011 following the merging of the long standing Children's Sunshine Home and the LauraLynn Foundation, and now comprises LauraLynn Hospice Service and LauraLynn Disability Services. All services are run from our main campus in Leopardstown, Dublin 18





Our Hospice Service provides specialised palliative care to children with life-limiting conditions and support to their whole family. We also offers a range of bereavement care, supports and events.

Our Disability Services comprises **Willow View** – a residential care service that is home to seven adults with complex disabilities - and **Hazel House** - a residential and respite care service for children with complex disabilities. While our Disability Services are funded by the Health Services Executive (HSE) through a Section 38 Provider Grant, our Hospice Service is mainly funded through fundraised income and private donations, supplemented with some statutory funding.

LauraLynn is a learning organisation with a volunteer ethos, with highly trained volunteers supporting staff in all aspects of the organisation's work.

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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 Life Care

SOME PEOPLE WHO HELP MAKE IT ALL POSSIBLE

TRUSTEES

DIRECTORS

David Andrews Niall McHugh Michael O'Donoghue Nicholas Quigley Niall McHugh (Chairman) David Andrews Frances Fletcher Kevin Keating Angie Kinane Denise McDonald Michael O'Donoghue Ann O'Driscoll Tony McPoland Nicholas Quigley Rachel Nolan COMPANY SECRETARY

INTERIM CEO

Kerry McLaverty



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, step-down, 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.

OUR JOURNEY SO FAR





WHAT WE DO

Caring for a child with a life-limiting condition, impacts the whole household, so it is vital that there is individualised care and support on hand for the whole family unit. Our Hospice Service 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; supporting them through the course of the condition, from the point of diagnosis to crisis and end-of-life care and through bereavement.



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We offer a range of nursing, medical, emotional and practical care in the optimum location for each child and family – in the family home, in our hospice or in the community. All our care is provided free to families. These include:

SHORT BREAKS

Planned short breaks for the child and family can range from a couple of hours in the family home to several nights stay at LauraLynn House. Unplanned short break stays provide immediate placement for children in the event of an emergency within a family.

END-OF-LIFE CARE

Is offered in the final days and weeks of a child's life to provide maximum physical comfort through pain and symptom management. Additionally, we offer psychological, social, spiritual and bereavement support for the entire family during and after the child's death.



FAMILY SUPPORT

We offer family support programmes that allow families to be together as a family unit, to have fun together, to meet other families in similar circumstances, and support them along their journey.

> Supports available to families include: Clinical Psychology; Chaplaincy; Social Work; Physiotherapy; Occupational Therapy; Music Therapy & Play Therapy; Therapeutic Family Work and Family Camps.

SYMPTOM MANAGEMENT

Families may need support to manage changing symptoms, improving the quality of life for the child and family.

BEREAVEMENT SUPPORT

We assist families in their experience of loss during a child's life; beginning at the point of acceptance to LauraLynn's service, throughout the course of their condition, around the time of the child's death, and in the weeks, months, and years that follow. There are services to support the entire family.

Demand for our Hospice Service this year was the highest it's ever been, with more children and families from across the Republic of Ireland availing of our expanded range of specialised care options...

ATTEND HOSPICE	0
RECEIVE LL@HOME	٥
2017 REFERRALS	¢







LauraLynn is the rainbow in our clo

rainbow in our cloud. A place full of magic, a place that helps us make dreams come true.⁷⁷

Sam, Isabella's Mum



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THE IMPACT OF LIFE-LIMITING CONDITIONS

Children in Ireland living with a life-limiting condition

Approximately 350

children with a life-limiting condition die each year

720 Up to 1 in 5 in need of specialised hospice care

50%

have palliative

care needs

30,000+

Parents, brothers, sisters, relatives and friends are impacted.





DISABILITY SERVICES

WHAT WE DO

LauraLynn's Disability Services are registered with HIQA as a Designated Centre for Persons (Children and Adults) with Disabilities and are funded by the HSE under a Section 38 Provider Service Level Arrangement.

Comprising **Willow View**, an adult residential service, and **Hazel House**, a residential and respite service for children and adolescents, we strive to provide a homely setting that promotes the privacy, dignity and safety of each child and adult. While we are no longer accepting admissions to our residential care programmes, we are committed to supporting the children and adults in our care.



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DISABILITY SERVICES

This year we appointed an Activities & Recreation Co-ordinator, whose role is to work with the adults, children, families and staff in our Disability Services. The aim is to provide a comprehensive programme of activities that support each child/ adult to fulfil their social, cultural, and recreational needs, develop and maintain personal relationships and links with the wider community. As a result of the new resource, we have a schedule of activities planned each week and increased engagement with our volunteer programme to support the children and adults in accessing a variety of occasions/events including concerts, swimming, horse riding and outings to places like the Japanese Gardens, beach and stud farm in Kildare. We have developed an Activities Room equipped with a variety of resources for the children and adults to use with staff, volunteers and families.



GUIDING PRINCIPLES

Our disability care is based on HIQA's 9 Key Principles which guide us on how best to provide a safe and effective care to children and young people with disabilities.



CHILDREN'S DISABILITY SERVICE

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

Our respite service grew this year to 31 children and families, up from 27 families in 2016. Families received an allocation of, on average, 24 nights respite (no change since 2016). On average the children attending Hazel House have been receiving our service for 9 years and 4 months. Each respite stay is planned to ensure the child has a positive, enjoyable experience packed with fun activities and excursions. Examples of these were: horse riding, meeting Bosco, Easter Camp, going bowling, visiting Imaginosity, excursions to Dundrum and St. Stephen's Green on the Luas, walks in Dun Laoghaire, Bray, and Powerscourt.

17 trained volunteers support the team in Hazel House in delivering a fun and interactive programme of activities such as sensory storytelling and play.





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BRIAN NOLAN DAD TO ETHAN, AGE 11

Ethan was born in 2007 through an emergency c-section and like every new parent, the first two months with Ethan were bliss, filled with giggles and cuddles, wrapped up in a baby bubble. However it was shortly after the two-month mark that we began to see a change. Ethan was having trouble feeding and became easily irritated. After visiting our GP to try find the cause of Ethan's problems, he was diagnosed with colic, yet we felt this diagnosis didn't fit Ethan and we continued searching for answers. Our doctor sent us to Crumlin where a multitude of tests were completed. It was here that we discovered the truth about Ethan's condition and how his life would change from what we currently knew. While pregnant, Ethan's mum had contracted the CMV virus, which led to the calcification of Ethan's brain. This meant that Ethan was born with cerebral palsy, is deaf in one ear and has further complications. We spent two and a half months in Crumlin with Ethan, coming to terms with what this meant.

Following our time in Crumlin, we tried to focus on the present and do the best we could for Ethan. We had never heard of LauraLynn or were aware of the work that they do until we were recommended through a connection in the Jack & Jill Foundation. This is where things changed. We visited Hazel House in LauraLynn with Ethan to view the facilities and meet the staff and from that initial encounter we knew LauraLynn was a very special place.

For me and my family Hazel House is a lifeline. Ultimately without Hazel House, we as a family would receive no respite care for Ethan. Having the support of the disability services at Hazel House in LauraLynn allows us to function as a normal family and it is not only a godsend for the children who stay there but also for the other siblings. While Ethan is in Hazel House we are safe in the knowledge he is having fun and has his every need cared for which gives us, as parents, the chance to relax and spend some time with the other children, taking part in everyday activities we can't regularly do. It also allows us to devote our time to our two other children and allow them the time to be children themselves without distraction. The most important thing for me as a parent is to see my children happy. At LauraLynn the staff are exceptional and I know Ethan has a ball. Everyone gets involved in having fun with the children and I know from the moment I drop Ethan off to when I see him when I collect him, that he's happy and that's all that matters to me!





ADULT DISABILITY SERVICE

Willow View is home to seven adults – three men and four women - with severe to profound intellectual and physical disabilities, providing the high level of support they need when they need it. The average length of residency in Willow View is 24 years, with three residents living here for over 34 years.

We strive to ensure that Willow View provides all the security, stimulation, comfort and choice that one expects to have at home, whilst also offering communal activities and events for our residents and their families to enjoy. 12 trained volunteers support the team in Willow View with our activities programme, including companionship visits, reading and music sessions. And this year saw the successful introduction of a Volunteer 'Buddy Programme', matching volunteers with a resident of the service with the goal of increasing engagement and socialisation. This year we introduced 'Scents of Reference' as a communication aid for use by our adults with visual impairments who respond better to sensory stimulus. The initiative has been successful in promoting greater autonomy by assisting the residents in navigating their home environment by creating different smell associations with each room.

As all our adults attend a day service during the week, most 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.







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FAMILY HIGHLIGHTS

Some very special visitors popped in this year, making many picture-perfect moments for our families. These included regular favourites like Bosco, The Speks, Santa and the cast of 'Once', as well as Her Royal Highness Princess Takamado of Japan, Taoiseach Enda Kenny, Ireland Football Manager Martin O'Neill, Miss Ireland and 'Joshua Tree: New Roots' artists Fangclub, Kodaline with Tracy Clifford and the 2FM Roadcaster





Families enjoyed even more opportunities to enjoy precious time together at new **family support services**. Highlights included the introduction of a five-week Autumn Leaves Programme for pre-school children (aged 0-4yrs) to help parents adapt music and sensory play to suit their child.

The adults and children using our Disability Services and their families enjoyed a range of celebrations, activities and excursions organised by our new Activities & Recreation Coordinator. Highlights this year included: Spring Week, scouts bonfire night, Sports Day, summer camp and Halloween Party. **Children's Hospice Week** – more than 30 Families participated in our awareness raising and outside broadcast event, with many more enjoying events and activities during the week. In addition to meeting our TV3 Champions Alan Hughes, Elaine Crowley, Anna Daly, Karen Koster, Deric O'hArtagain and Muireann O'Connell, our families were delighted to receive the support of some special friends including Jenny McCarthy, Norah Casey, Shane Byrne, Isaac Boss, Fiona Coughlan, Baz Ashmawy, Deirdre O'Kane, Dustin, Bosco, Catherine Leydon, Ali Canavan, Rory Cowan, Lucy Kennedy, Darren Kennedy, Glen & Ronan, Neil Lennon, Martin King, Twink, Jennifer Zamperelli and I Heart Disney All Stars.







For the second year, we held our annual **Family Fun Day** and **Christmas Party** off site in The Pavilion, Leopardstown Racecourse. In total, 228 attended our 'Under the Sea' themed summer fun day while, more than 200 children attended our Family Christmas party to visit Santa and Mrs Claus in our purpose-built grotto; receiving the welcome news that they were present on his 'Good' list. The adults celebrated their summer party with a country and western themed extravaganza and hosted their Christmas party in Willow View for their families and friends. Our dedicated Family Engagement Committee representing families, carers and guardians of LauraLynn continued their invaluable work this year meeting six times and providing feedback and insight to the Board and Management to inform service innovation, process improvements and design changes.

Light Up LauraLynn was a spectacular occasion with families and guests catching up with our great supporter Ray Darcy and enjoying festive treats, carolling, firework display and a special surprise performance from Hozier. Ray was joined by members of the Kielt family to perform the tree lighting ceremony. Our **First Annual Memorial Walk** was held in the Phoenix Park in September with 56 people attending - including parents, siblings, grandparents, aunts, uncles and cousins from 13 families – in memory of their deceased child. After the beautiful 2.5k walk, the families enjoyed a picnic and ice creams together.







CHRISTMAS AT LAURALYNN







OUR PEOPLE

During 2017 the team in LauraLynn grew to 276 people (269 in 2016), comprising 128 members of staff (122 in 2016) and 148 volunteers (144 in 2016). There continues to be a national shortage of children's nurses and staffing in LauraLynn, like all other healthcare organisations, has fluctuated this year.

Despite our new recruitment/retention initiatives in 2016–values based recruitment and parent representatives on interview panels–our staff turnover this year was 19%, a slight increase from 18% in 2016. This compares to 12.82% turnover of companies in the Dublin region who are similar in company size and financial turnover.

Innovation, learning and development continue to be a pillar for driving excellence in care and service development. In addition to providing traditional formal courses to staff and volunteers, this year we enabled individuals and teams to learn from their work through our new Schwartz Rounds, Share and Learn sessions, and attending workshops, seminars and conferences.

We ran 3 focused awareness weeks, Medication, Safeguarding and Bereavement. These all included formal and informal learning sessions with presentations from invited speakers and staff about key aspects of the topic. Employees at LauraLynn receive training from a range of providers. All are complementary to each other and give employees the skills they need to provide high quality care. Our employees are really engaged with our training programmes and see the value in continuing training. Mandatory training is absolutely essential for our employees and the services we provide We ran 72 mandatory classroom based training sessions in 2017. We also introduced E-learning programmes for Food Handling and Child Protection training. Our commitment to training and education is ongoing. In 2018 we hope to introduce Performance Achievement training workshops.



SARAH BRADFORD CARE COORDINATOR

Sarah Bradford is a Care Coordinator / CNM1 in LauraLynn House and has been working here for four and a half years. Sarah chose to work at LauraLynn as she has a strong interest in and passion for children's palliative care. Sarah says: *"The most rewarding aspect of my role is feeling like I am making a difference to the lives of children with palliative care needs and their families. Soon after starting, I had my first experience of providing 1:1 end-of-life care. This is where I felt I had really made a difference, by ensuring the child was comfortable and also that the family were cared for, comfortable and had all their questions answered".*

Sarah believes that LauraLynn is a special place and she is proud of the role she can play in supporting families and children, "LauraLynn is special as it is the only children's hospice in Ireland. Unlike what people would normally think, LauraLynn is filled with colour, fun, and lots of laughter. The staff, the children and families make LauraLynn the magical place that it is". At LauraLynn, families can access a range of supports and services within the hospice in Dublin, in the home* or hospital, depending on the child's medical needs and family's preference



While working in children's palliative care may not be for everyone, knowing you are helping bring happiness, fun and comfort to those most in need make it all worthwhile. To see a child smile makes this job the most rewarding job out there and I love working at LauraLynn and with each of the children."

Sarah Bradford, Care Coordinator

*Available for families living within a two-hour journey from the LauraLynn hospice in Dublin 18.

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67

VOLUNTEER PROGRAMME

2017 was another successful year for the LauraLynn Volunteer Programme which continues to grow and develop. Volunteer training was a priority for 2017 with 420 hours training completed by volunteers. Volunteers provide support to every department in LauraLynn across 12 identified roles, including a new 'Volunteer Buddy' role which was introduced this year. In recognition of their considerable contribution to our work this year, volunteers Colm Quinn, Monica Byrne, Paula Falcao, Robin Keane and Kevin Murphy were named LauraLynn Volunteers of the Year and nominated in the national Volunteer of the Year competition.

THE PLAN FOR 2018

- Continue recruitment drive
- New Wellness at Work Programme
- New Performance Management Process and Training
- Learning & Development Showcase Week

148 NUMBER OF REGISTERED VOLUNTEERS.

> 12 NUMBER OF VOLUNTEER ROLES

256

Corporate Volunteers who further assisted with fundraising, events & activities ;;;o;

Corporate Volunteering events in 2017 (e.g. window decorating and cleaning, gardening and working at events)

23

BRIAN LENNOX VOLUNTEER

Brian Lennox has been volunteering at LauraLynn for over three years where he has helped across a variety of roles. As a retired man, Brian wanted to get involved with something that would give him a focus, however he was initially hesitant to volunteer at LauraLynn due to his perception of what a children's hospice would be, as he was concerned he wouldn't be able to manage the environment. However as Brian says "The slogan changed things for me - 'At LauraLynn we make the most of short and precious lives' - that's what did it for me. Ever since I walked through those doors on that first day, I realised my perception of a children's hospice was all wrong. I couldn't have been more surprised to see the joy, fun, care and respect that is shown to each of the children and families"

As a LauraLynn volunteer, Brian has helped out in a number of ways over the last three years. As Activity Assistant Brian has helped each child in our hospice to take part in daily activities, whether that is arts and crafts, music classes or theatre performances. Brian also helps out with weekly vehicle checks, ambulance driving and most recently, he is undergoing training to use LifeLites, a tech-savvy interactive project that will engage the children in a number of different ways. Brian hopes to pass this knowledge onto other volunteers at LauraLynn.



I am one of 140 volunteers at LauraLynn and we all play our part. It's very humbling to be part of such a positive community and help the children and families in any way we can."

Brian Lennox

OUR PERFORMANCE

2017 marks the final year 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 of delivering care.





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. It 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.
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 is registered with the Charities Regulatory Authority and supports the implementation of the Charities Act 2009. We are compliant with our HSE Annual Compliance Statement and The Governance Code for Community, Voluntary and Charitable Organisations. We are signed up to all ICTR fundraising regulations 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.

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. Our policy is to welcome and encourage feedback so that we can learn and inform continuous improvements in our services. We have robust systems in place to record and investigate critical feedback of the service that requires a response. LauraLynn is committed to insuring that children, adults, their families and members of the public are aware of their rights throughout the feedback process. In 2017, 5 formal complaints were received across our disability and hospice services. All were dealt with in line with our policy and closed within the recommended timeframe. Any actions/improvements arising from these complaints were implemented and no appeals against the outcomes was received.

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.



OUR BOARD

Both the Children's Sunshine Home and CSH Childcare Services are governed by the same non-executive Board of Directors, who are drawn from diverse backgrounds and possess 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 Committee, Finance & Operations Committee, Financial Audit Committee, Nominations, Corporate Governance & Remunerations 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 with includes our Conflict of Interest Policy. Every Board Meeting commences with a request for expression of conflict of interest. The Board delegates the day-to-day management of the organisation to the Executive Management Team, which comprises of 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 approximately €104k, 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.

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.



PUBLIC BENEFIT

LauraLynn is Ireland's only Children's Hospice. We provide palliative care to children with life-limiting conditions and their families. With a 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 child and family needs – physical, emotional, social and spiritual.

Additionally, there is a commitment to provide a 'home' for children and young adults with profound intellectual disabilities. We no longer accept new referrals for our adult residential care service, but we are committed to caring for those in our care and supporting them to realise their ambitions and have dignity in their lives.



				BOARD SUB-COMMITTEES					
COMMITTEE ID	А	В	с	D	E	F	G	н	1
COMMITTEE	Board	Trustees	Family Engagement	Finance & Operations	Financial Audit	Fundraising	Nominations, Remuneration & Corporate Governance	Quality, Risk & Safety	Research & Ethics
NUMBER OF MEETINGS	6	4	5	8	2	4	3	6	meets depending on receipt of applications
Niall McHugh (Chairman) A, B, G	6	4					3		
David Andrews <mark>A, B, D, F</mark>	6	3		8		4			
Mary Ainscough Resigned 31st January 2017	0								
Frances Fletcher A, C	6		5						
Angie Kinane <mark>A, F, G</mark>	5					4	3		
Michael O'Donoghue <mark>A, B, I</mark>	5	4							о
Ann O'Driscoll <mark>A, H</mark>	5							6	
Denise McDonald <mark>A,</mark> H	5							3	
Tony McPoland <mark>A, E, G</mark>	6				2		3		
Nicholas Quigley A, B, C, D	6	4	3	8					
Kevin Keating Appointed 31st January 2017 A	1/1								• • • • • • • • • • • • • • • • • • • •
COMPANY SECRETARY									
Michael Higgins Resigned 21st November 2017	2/5								
Kerry McLaverty Appointed 21st November 2017	1/1								



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BOARD SUB-COMMITTEES

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 agree and action key elements of the organisation's fundraising & marketing strategy and meets at least three times a year. In 2017 the Fundraising Sub-Committee met four times.
Chairperson: David Andrews

2 FINANCE AND 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 2017 the Fundraising Sub-Committee met eight times.

Chairperson: Nicholas 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. The Research & Ethics Sub-Committee meets as required on receipt of applications. **Chairperson: Michael O'Donoghue**

4 QUALITY, RISK AND 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. In 2017 the Quality, Risk and Safety Sub-Committee met six times. Chairperson: Ann O'Driscoll

5 FINANCIAL AUDIT Sub-Committee 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 the internal and external audit process; and ensuring that the organisation maintains effective risk management processes relating to the organisation's management of financial risks, prevention of corruption and waste and the system of internal control. In 2017 the Financial Audit Sub-Committee met twice.

NOMINATIONS, REMUNERATION & CORPORATE GOVERNANCE

Sub-Committee monitors and reviews the structure and composition of the Board. It deals with matters of Board succession, disciplinary issues at a senior executive level of the organisation, 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

FAMILY ENGAGEMENT Sub-Committee was established to provide an effective representative body for families, guardians and carers to communicate effectively with the Board of Directors and our Staff. Having regard to the best interests of children, young adults and families in each strand of the organisation, this Sub-Committee develops communications from the Board of Directors and Staff to 'Families' It aims to develop and foster communication within the 'Family Groups' and to articulate and put forward suggestions, issues, concerns etc. for the improvement of the service in an open and constructive forum. In 2017 the Family Engagement Sub-Committee met five times. Chairperson: Frances Fletcher



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 a little funding for the hospice. In 2017 our combined services (Hospice and Disability) had an income of €8,041,831, this was €205,140 down from 2016. €4,112,867 of our funding came from the state, including €3,681,161 under a Service Level Arrangement (SLA) with the HSE for the provision of disability services. In 2016 the state funding was €4,619,454.

The Grant from the Trustees in 2017 to support the Children's Hospice increased by €333,598 to €3,612,885. Fundraising from the public generated €3,509,173—up 4% on 2016. In total, it cost €8,685,762 to operate LauraLynn, this was an increase of €204,184 on 2016 costs, largely as a result of our increased investment this year in sustainable income generation. The cost of the disability service was €3,884,010 and €4,801,752 was spent on the Hospice Service.

In addition to this, donors kindly gave us €235,586 in gifts and services free of charge.

LauraLynn is grateful to the HSE for funding the Disability Service and making a contribution to the Hospice Service. However, we are still very dependent on fundraised income for the day-to-day operations of the Hospice Service.





OUR FINANCIALS AT A GLANCE



2016 2017

OUR FINANCIALS

HOW WE SPENT OUR MONEY



EXCLUDES: Gifts-in-kind, depreciation and amortisation.

OUR FINANCIALS

HOW WE SPENT OUR MONEY

83c	SERVICE PROVISION
11c	GENERATING FUNDS
4c	SUSTAINABLE INCOME GENERATION
2c	GOVERNANCE



EXCLUDES: Gifts-in-kind, depreciation and amortisation.



HOW WE SPENT OUR MONEY: A DETAILED LOOK



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EXCLUDES: Gifts-in-kind, depreciation and amortisation.

OUR FUNDRAISING





A MESSAGE TO OUR SUPPORTERS

Thank you for understanding that in supporting LauraLynn, you are helping the families of some of Ireland's sickest children, when they need it most. With you by our side, we have been able to continue providing families with home support, family and sibling support, end-of-life care, planned and unplanned breaks and crucially more time together as a family. Thanks to the continued generosity and goodwill of our Ladies Appeals Committee, the public and business community, in 2017, we raised a total of €3,509,173 an increase of 4% on 2016. As a result, we were able to invest in the future of LauraLynn. During the year, almost 2,000 new supporters joined our Community of Monthly Donors. This regular, monthly income—which now accounts for 7% of funds raised—allows us to plan our service provision and is crucial to LauraLynn attaining our 2018 fundraising target of €4.2m, helping us fulfil our vision that 'all children who need us can access us'.

We also continued to grow the number of supporters we reached this year through our newsletters and fundraising appeals, sharing the incredible impact their support is having. Our tax refunds from Revenue under the Charity Tax Refund increased, reflecting the growing number of donors who are aware of the value of donating a minimum of €250 annually where they can.

Legacy fundraising is a small but growing fundraising area for LauraLynn. The new Online Will Making service offered to our supporters has already generated pledges and it is hoped that with greater awareness of Legacy fundraising, more supporters will consider leaving a bequest to a charity in their Will.

Corporate support is critical to our sustainability. In total, 765 companies supported LauraLynn, with over €1.5 million donated and raised by companies and their staff. This was a marked increase from 529 companies, donating €1,343,657 in 2016.

Community fundraisers (schools, external events, challenges & marathons) continue to be a very important part of our overall income generation, and though they declined in number a little this year they still raised close to €1 million for us! In total, 226 external events were run for us in 2017 (240 in 2016) with one in three organised outside Dublin.

Throughout 2018 and beyond, we hope to continue to grow our supporterbase, making sure that the children and families who use the services of LauraLynn aren't alone on their journey.

GOVERNANCE/TRANSPARENCY

As the new charity legislation and data protection requirements become clearer, we will continue to review and update our policies and procedures to maintain our triple lock status and uphold the highest standards of fundraising practice. We are committed to adhering to our Donor Charter to ensure the best possible supporter experience.







FUNDRAISING INCOME

7%	Challenges & Marathons	€251,217
18%	Community Fundraising	€644,551
43%	Corporate Support	€1,521,112
24%	Individual Donations	€844,525
1%	Legacies	€16,313
2%	Schools	€63,068
3%	Trusts & Foundations	€117,747
1%	Major Gift	€29,500
1%	Courts	€21,140
TOTAL		€3,509,173





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. In 2017, we raised an extraordinary €3,509,173, an increase of 4% on 2016, thanks to all those who went the extra mile to support our special hospice. Here's a snapshot of fundraising highlights from throughout the year. In January our fundraising team took time out to celebrate International **Thank You** by making phone calls, sending cards, writing emails, posting videos and even delivering homemade scones to thank some of our wonderful fundraisers, supporters and volunteers.

For **Children's Hospice Week** in May, the stars of TV3's daytime programming – Alan Hughes, Elaine Crowley, Anna Daly, Karen Koster and Muireann O'Connell – along with more than 30 of our families, raised huge awareness of and funds for our special hospice. The showcase event of the week was the first Children's Hospice Telethon and a whopping €117,500 was raised in total. We are hugely grateful to our media partners TV3 for their ongoing commitment and support and are looking forward to working together again next year. Our **Face to Face donor recruitment** campaign continued, gaining us almost 2,000 new monthly direct debit donors, growing our base of sustainable annual funding to €241k in 2017.

Our Heroes Ball in the Intercontinental Hotel was kindly hosted by our patron Miriam O'Callaghan and attended by 420 friends and families of LauraLynn including, Alan Hughes, Norah Casey and our special band Perfect Day. An incredible €76,000 was raised on the night (€67k in 2016) to support our little heroes and their families. Special thanks to our ball sponsors DCC plc., Marks & Spencer and Verve Live Agency, our event management sponsor.







OUR FUNDRAISING

Our long-standing partnership with WEEE Ireland and brand ambassador Bosco, reached new heights this year. In addition to WEEE Ireland's cumulative donation since 2011 reaching a staggering €285,000, we were delighted to be recognised with a PAKMAN Award for Excellence in Waste Management & Recycling for our battery recycling initiative. As Bosco always tells the boys and girls "Every Moment Matters, Every Battery Counts!"



In October we partnered with Universal Music Ireland and 2FM to launch **"The Joshua Tree: New Roots"** album, featuring the pick of Irish music talent, in aid of LauraLynn. The album shot to No 1 in the Irish Charts gaining recognition by originators U2 and the public at large. Funds for the project will be received in 2018. Community Fundraisers (schools, external events, challenges & marathons) continue to be a very important part of our overall income generation, and though they declined in number a little this year they still raised close to €1 million! In total, 226 external events were run for us in 2017 with one in three organised outside Dublin.



In addition to the business community donating €1.5 million to LauraLynn this year, 256 **Corporate Volunteers** gave their time in support of 23 separate volunteering opportunities both on-site and at our events; with even more companies providing professional skills.







CLICK ON THE LINKS BELOW TO BE BROUGHT TO OUR FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 DECEMBER 2017



DEMAND FOR OUR HOSPICE SERVICES

We provided care to 15% more families in 2017 from last year with increases in both children and families availing of hospice and palliative care supports (176) and in families availing of bereavement care and events (70).

We accepted 48 new children to the service this year. Consultants (13%) and Nurses Outreach Nurses (43%) continue to be most likely referrers to LauraLynn but this year was saw a significant increase in referrals from Hospital Nurses (16%).

Families have an annual allocation of 15 nights stay in our hospice as part of their individualised care plan. This year we saw an increase in demand for additional nights from families requiring crisis care and step-down support following hospitalisation. A total of 1,286 short stay nights were used by families, with 354 nights from outside families' annual allocation. Four families have more than one child availing of LauraLynn hospice care and 32 children have been attending the service for more than four years. LauraLynn currently has 43 children in our service between the ages of 10 and 17 years old, up from 42 in 2016. One child celebrated their 18th Birthday this year and transitioned to adult palliative care services.

Sadly, in 2017 there were 33 bereavements. 24 of the children who passed away were aged 1 year or under and 19 were referred in the same year. Approximately 50% (16) families were supported for end-of-life care in the family home, with 25 families availing of memory making at this time.

In total 28 brothers and sisters received formal interventions to help them to adjust to the diagnosis or loss of their sibling. In recognition of the growing number of children in our service now in their late teens, LauraLynn has identified the need to develop a Transition Care Pathway and Programme to be initiated with each child and family once they reach 12 years of age. Completion and implementation of the pathway as part of our model of care will continue in 2018.

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)
- → Specialist short break care
- → Practical help, advice and information
- → Provision of specialist therapies, including physiotherapy, play and music therapy

- → Provision of information, support, education and training to carers
- → Bereavement support
- → 24-hour telephone support
- → 24-hour access to emergency care
- → 24-hour end-of-life care

AGE PROFILE OF HOSPICE SERVICE USERS



	20	17	2016		
	Children accepted	Children active	Children accepted	Children active	
Total	48	176	48	153	

SOURCES OF ACCEPTED REFERRALS



DIAGNOSTIC PROFILE OF HOSPICE SERVICE USERS

	20	017	2016		
Diagnostic Categories	Children accepted Children active		Children accepted	Children active	
Circulatory	0	1	0	1	
Congenital	9	41	5	39	
Metabolic	5	17	8	20	
Neurology	25	76	19	55	
Oncology	6	13	5	6	
Perinatal	2	12	6	23	
Respiratory	0	2	0	2	
Other	0	2	5	6	
Unknown	1	3	0	1	
Total	48	176	48	153	

LENGTH OF TIME USING HOSPICE SERVICE

Length Using Service	Children Active in 2017	Prior to Child's Death in 2017
0-1 month	15	15
1-6 months	20	6
6 months–1 year	21	3
1-2 years	32	1
2-4 years	56	6
4-6 years	18	2
6+ years	14	0
Total	176	33

6 COMMON MISCONCEPTIONS ABOUT CHILDREN'S HOSPICES

1 CHILDREN'S HOSPICES ARE WHERE CHILDREN GO TO DIE

Although some children come to LauraLynn in their final days or weeks, there are many more who are known to us over many years as their life-limiting condition progresses. Children with a life-limiting condition and palliative care needs can be referred to LauraLynn at any stage from their diagnosis.

2 THEY ARE SAD, DEPRESSING PLACES TO WORK

On walking into LauraLynn, people frequently say it's not at all how they imagined it would be. In fact, it's a bright and fun place, filled with laughter, magical experiences and activities going on. There can be very sad and difficult times but a large part of what we do is helping families make the most of every moment together, and creating lasting memories.

3 MOST CHILDREN IN HOSPICES HAVE CANCER

On average, about 7% of the children who attend LauraLynn have cancer. Other life-limiting or threatening illnesses include heart conditions, neurological degenerative illnesses such as muscular dystrophy, all sorts of unusual genetic diseases and metabolic problems. The range of problems is much wider than those encountered in the adult hospice world.

4 SUPPORT FROM CHILDREN'S HOSPICES DOES NOT EXTEND TO THE FAMILY

At LauraLynn we understand that the whole family is affected when a child has a life-limiting condition and that the whole family needs care and support. We provide a range of support services to help them throughout the course of the child's condition and in bereavement. These supports are offered to the entire family, giving extra consideration to parents, siblings and close extended family members like grandparents.

5 WORKING IN A HOSPICE IS NOT REWARDING

It's a privilege to meet the amazing children who need our care—we call them superheroes—and get to know them and their families. They are going through the most difficult experiences you can imagine and being able to help them through those times is hugely rewarding for staff throughout the organisation.

WHERE HOSPICE SERVICE USERS COME FROM



SCHWARTZ ROUNDS

Throughout the year, there were 9 Schwartz Rounds facilitated, with 27 staff sharing their stories and the themes included 'All's Well that ends well' and 'Putting Compassion to the Test'. This style of learning supports social learning where staff learn through narrative storytelling and reflection. Also, two of our Schwartz Team are mentors for other HSE sites that have adopted the Schwartz Rounds.

LauraLynn won special recognition for implementing our Schwartz Rounds initiative in the Excellence in Healthcare Management Category at the Irish Healthcare Awards.

Our LauraLynn Journey So Far... 9 Rounds What 228 Evaluation Sheets **27** Panellists Told us... 69% of staff said the stories were 249Attendees relevant to their daily work 87% of staff agreed/completely agreed that the Rounds help them work better with colleagues 71% have a better understanding of how colleagues feel about their work 93% would recommend Rounds to colleagues Most popular topic... All's Well That Ends Well Lourdum

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ANNUAL STAFF SURVEY

In 2017 we issued our annual staff survey. We believe our staff surveys are crucial because they give employees a venue for open feedback. It is an opportunity to establish two-way communication and involve employees in the development process by giving them a direct voice to the management team. Being actively involved in the planning process demonstrates to employees that we appreciate their involvement in the service and that their opinions are valued. The information obtained from our staff surveys allows us to identify strengths and opportunities for improvement in our service.



VOLUNTEER PROGRAMME 2017



To Pursue Excellence in Care Provision and Service Delivery for the Children's Palliative Care and Disability Services

- As part of the development of our Model of Hospice Care, we launched a new booklet – 'Individualised Children's Hospice Care' – for healthcare professionals. It outlines the elements of our hospice and palliative care services and details our new referral process and holistic needs assessment and individualised outcomes model.
- The appointment of an Activities & Recreation Co-ordinator has further strengthened our Disability Service responding to the needs of our service users and HIQA requirements. It has resulted in further expansion of the community engagement opportunities and personal supports programme of our Disability Service Users.
- In response to the unique needs of a growing number of pre-teens and teenagers availing of LauraLynn, we initiated an interdisciplinary Transition Working Group this year. Their aim is to formulate a Transition Care Pathway based on best international practice that is culturally compatible in the Irish setting. Implementation is set to commence in 2018.
- As part of our commitment to Quality, Safety and Risk Management, a total of 12 Health & Safety Walkabouts took place. All aspects of the service were visited by a senior executive and Board Member to learn about safety issues that are of concern to staff and foster open communication, timely reporting and continuous feedback.

To Agree and Secure an Appropriate Future Funding Stream for Children's Palliative Care

- In total we generated €3,509,173 through voluntary donations from the public, corporate supporters, trusts and foundations.
- Building on the success of 2016, we increased our investment in individual giving including a Face2Face campaign that successfully recruited almost 2,000 regular, direct debit donors; further diversifying of our donor base.
- Our Disability Services continued to be funded by the Health Services Executive under a Section 38 Provider Service Level Arrangement, which also included some funding for our Hospice Service.
- We continued to make progress with the Department of Health on policy and funding for our Hospice Service and welcomed our inclusion in the Slaintecare Report, as well as its acknowledgement of the need for palliative and hospice care for children.

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

- We evaluated how we plan our workforce in order to meet the needs of our growing number of families and adapted a commonly used workforce planning method called the Telfort Model. This has improved our decision making around cost-effective numbers and estimating the size and skills mix of nursing teams. Our strategic workforce planning aims to improve the quality of care delivered to families using our service by ensuring that our future workforce has the right capacity and skills, values and behaviours to meet families' future needs.
- We continued to promote learning and development opportunities for our staff and our professional colleagues We introduced Coaching for High Performance a training programme for all line managers to increase confidence, communication, and employee engagement to lead us to higher performing teams.

- With Volunteers playing an integral role in our care provision, we implemented a comprehensive training programme this year to ensure Volunteers are equipped sufficiently for the various roles and activities they provide. In total 420 hours training was delivered to our Volunteers.
- Many staff received support and sponsorship to complete external university programmes i.e. Postgraduate Certificate & Diploma in Children's Palliative Care and Postgraduate Diploma and M.Sc. in Bereavement.

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

- We significantly strengthened our links with Trinity College, University College Dublin and University College Galway by offering undergraduate and postgraduate clinical nursing placements in LauraLynn. These placements will provide valuable clinical exposure for future nurses.
- LauraLynn became a member of the NMPDU Nursing Practice Development Network (CHO 6 & 7). This will enable the sharing of knowledge and the development of further collaboration with other services within the immediate healthcare area.
- We held two "Working Together Delivering Choices" Workshop and Open Days for Professionals bringing together 50 people from 11 children's services, including staff from the acute paediatric, neonatal and disability services. In addition to learning more about children's hospice care and how it's delivered here, attendees participated in open discussion fora looking at the importance of interagency work and developing links in the community.
- We were an organising partner of the 3rd International Children's Palliative Care Conference again this year, where we had a total of 7 LauraLynn poster presentations on display.

OUR FOCUS FOR 2018

The year ahead will see the launch of our new Strategic Plan (2018-2022) which will chart the direction of the organisation over the next five years as we strive to achieve greater financial sustainability for the service and progress our vision that all children who need our care can access it.

Our focus for 2018 will be:



→ To enhance the dignity and lives of the children, adults and families using our services by providing high-quality, safe and effective family-centred services.



To maintain and develop a happy, motivated and expert workforce comprising staff and volunteers.



→ To maximise awareness and funding to ensure our financial sustainability and be recognised as a model of good governance.



→ To work collaboratively together and with the HSE, local care providers, other charities and like-minded private sector organisations to achieve our vision and mission.