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Sunflower Days 6th & 7th June 2014

Angels In Pyjamas

Children across Ireland wore their pyjamas to school and raised over €200,000 for the Hospice Home Care for Children Programme

€200,000 and Counting

On March 7th a record 55,000 children wore their pyjamas into school to raise vital funds for Ireland's National Pyjama Day! The money raised for the Irish Hospice Foundation (IHF) will be donated to our Hospice Home Care for Children programme. The proceeds are still being counted as crèches and preschools from around the country send their returns into Early Childhood Ireland but we are

delighted to let you know that we have already reached our target of €200,000 this year! A huge thank you.

This year was the fourth year the Irish Hospice Foundation cooperated with Early Childhood Ireland for Pyjama Day and to date, over €700,000 has been raised for Hospice Home Care for Children.



National Pyjama Day at Learning for Life Childcare, Lucan – Natalia Wójcik and Faye Haynes, both aged 3.

Children helping Children

CEO of the IHF Sharon Foley commented: "I would like to sincerely thank all the childcare staff, the children and their parents for such fantastic support. In Ireland, 1,400 children are living with a life-limiting illness and 350 of these children die each year – most in the first year of life. Every donation is vital as the IHF is funding 85% of the National Paediatric Palliative Care Programme."

DESIGNER LOUISE KENNEDY OPENS A NEW HOME FROM HOME

Acclaimed designer Louise Kennedy returned to her native Tipperary in March to open a marvellous new Family Room in Nenagh Hospital.

Families need private space in hospitals

This wonderful new facility is especially designed for relatives of patients who are seriously ill or near the end of life – and for bereaved families – so they can have the privacy and comfort they need.

As Ann Doherty, CEO of UL Hospitals, said: “Families need a private dignified space during this most critical time. Now they can stay day and night while their loved one is coming to the end of their lives. We aim to ensure that patients and families who are with us during their final journey will have a peaceful and dignified experience.”

The room was funded under the Design & Dignity Grants Fund which is operated and co-funded by the IHF and the Health Service Executive. The new facility cost approximately €35,000 and joins the ten other projects in acute hospitals countrywide which the Fund has been supporting since 2010.

Located near the main entrance to the hospital, the new family room was innovatively created by combining two small rooms. The clever use of space has allowed the hospital to have a tea and coffee making facility, a couch, armchairs and a pull-out bed should relatives wish to stay overnight near their loved one as they face life’s end.

Grieving Properly

Louise Kennedy warmly welcomed the new facility: “Our father Jimmy Kennedy spent time in Nenagh Hospital. He received amazing care from the very dedicated nursing team who also gave my family the support we needed at a very vulnerable and anxious time. It is such a welcome facility that Nenagh Hospital now has a family room for loved ones to grieve privately and to be in a calm and peaceful environment.”

Nenagh Hospital's Specialist Palliative Care Nurse, Carmel Sheehy, who was instrumental in the development of this room, explained: “This family room was

both a practical and a profound project. It involved a lot of skilled people working collaboratively on every aspect of this facility: design, interior colours, lighting, artwork, acoustics, fabrics and furnishings. We are proud of what has been created and hope this small but dignified space will demonstrate our compassionate care for families.”

So congratulations to Carmel and all involved – Nenagh hospital management, Nenagh’s End-of-Life Care Committee, the staff at Nenagh Hospital, HSE Estates, Julian O’Mahony of Collins Building & Civil Engineering Ltd and architect Magdalena Kubat on doing such a wonderful job. We know that this family room has inspired similar projects in other hospitals in the region.

We have also developed Design & Dignity Guidelines which the HSE have adopted for all new building and refurbishment projects.

Other Design & Dignity Projects

Mater Hospital	Family room on an acute medical ward
St James’s Hospital	Bereavement suites in the emergency department
Mercy University Hospital, Cork	Mortuary renovation
Sligo General Hospital	New mortuary
Beaumont Hospital	Mortuary renovation
Our Lady’s Hospital, Navan	Family room with kitchenette, ensuite & garden
Mayo General Hospital	Family room & ward reception area
Connolly Hospital	Family room & garden
Mid-western Regional Hospital, Limerick	Mortuary renovation
St Luke’s Hospital, Kilkenny	Bereavement room/infant viewing room



DEALING WITH BEREAVEMENT IN THE WORKPLACE

The Irish Hospice Foundation launches a new bereavement training scheme for workers.

Over 190,000 workers are affected by bereavement each year.

“What can you say?”. So many times that is people’s reaction to a bereavement. In the workplace it can be difficult to know how to respond to someone who has been bereaved. In Ireland, for many, it’s still a taboo subject which is best avoided or dealt with in private.

So in March of this year The IHF launched an innovative resource pack aimed at helping managers and workers to support their colleagues affected by bereavement. The free resource pack

gives clear, concise guidelines on how workers and managers can respond in informed and compassionate ways to help co-workers who are bereaved.

The helpful resource pack is made up of six information sheets which are simple, easy to use guides and deal with topics such as “How to Deliver Bad News” and “What to Say”. The pack can be downloaded free of charge from: www.griefatwork.ie

Doing It Right

Welcoming the announcement, the Minister for Jobs, Enterprise & Innovation, Richard Bruton said: “Supporting workers during times of difficulty such as the death of someone close, is not only the right thing to do, it also makes good business sense.”



The IHF’s Training and Development Officer, Breffni McGuinness notes one worker’s response to the great support she received in her workplace when her father died – ‘Do this well and you’ll never be forgotten. Do this badly and you’ll always be remembered’.

This is the kind of model project that our inspiring donors’ gifts make happen. For further information contact Breffni McGuinness on 01 679 3188 or email breffni.mcguinness@hospicefoundation.ie

PRIMARY PALLIATIVE CARE CONFERENCE

One of the UK’s leading GPs has encouraged the development of a national palliative care, end-of-life and bereavement strategy in Ireland and said the care of the dying needs a higher profile at all levels of healthcare worldwide.

Professor Mayur Lakhani, the Chairman of the British-based National Council for Palliative Care, addressed 150 delegates at the IHF’s Primary Palliative Care Conference ‘*Living and Dying Well in the Community: The Future of Primary Palliative Care in Ireland*’ which was opened by Minister for State for Primary Care, Alex White TD on May 15th.

Every year about 26% of Irish people die at home. Each GP in Ireland could expect between 10 and 20 deaths annually in their practice. The conference was organised by the Collaborative Primary Palliative Care Programme which is an initiative of the IHF. Presentations from the day are available on www.hospicefoundation.ie For more information, please contact Marie Lynch, Programme Manager on 01 679 3188 or email marie.lynch@hospicefoundation.ie

What Irish People Think

In May The Irish Hospice Foundation conducted an important survey on public attitudes to dying, death and bereavement and results will be published shortly. The survey will update the research conducted by the IHF in 2004 on public attitudes. It’s vital that people’s ideas and feelings feed into policy and services.



SAY HELLO TO OUR NEW CHILDREN'S OUTREACH NURSES

The Hospice Home Care for Children Programme is one of the most important and rewarding of all our activities. Run in partnership with the Health Service Executive we fund five Children's Outreach Nurses to provide support to families caring for their seriously ill child in the privacy and comfort of their own home.

We are now delighted to tell you that all eight Children's Outreach Nurses positions have been filled! The IHF, through the kind support of our amazing donors, is funding five of these positions.

We would like to welcome them to the Irish Hospice Foundation family.

They are:

Irene O'Brien – Our Lady of Lourdes Hospital, Drogheda

Liane Murphy – Waterford Regional Hospital

Hilary Noonan – Regional Hospital (Dooradoyle) Limerick

Laura Flaherty – Our Lady's Children's Hospital, Crumlin

Deirdre Murphy – Midlands Regional Hospital, Mullingar

The Hospice Home Care For Children Programme is also funding Ireland's first Consultant Paediatrician with a special interest in Paediatric Palliative Care, Dr Mary Devins, who is based in Our Lady's Children's Hospital Crumlin.



We would like to thank all those who have supported us, made donations, or contributed in any way to our crucial work. Your support is vital as the Irish Hospice Foundation currently funds 85% of the National Paediatric Palliative Programme

YOUR LEGACY CAN MAKE A LASTING IMPACT



Making a gift to the Irish Hospice Foundation in your Will leaves your lasting mark and makes a real difference.

When making your Will, it's important to take care of your family and friends first. But if you wish to make a gift to charity in your Will – please consider the Irish Hospice Foundation?

Legacies (gifts in Wills) are a vital source of funding for the Irish Hospice Foundation. We know that making a Will is not something most of us like to think about. But, you can make or easily amend your Will at any stage of your life.

There are a number of ways you can leave a gift in your Will to the Irish Hospice Foundation:

- **A gift of the remainder or part of the remainder of your estate**
- **A gift of a specific sum of money from your estate**
- **A specific gift of property: e.g. jewellery, a building or shares**

Your solicitor will be able to provide you with advice on which option best suits your wishes and circumstances.

Have you filled out the Charity Tax Back form we sent you?

Remember the Revenue Commissioners will give the Irish Hospice Foundation an extra tax rebate, of up to 45%, for your kind donation in 2013. And it won't cost you a single cent more. Just remember to complete, sign and return the form we sent you. It's as simple as that. Thank you!



HELPING WHEN THE GRIEF BECOMES TOO MUCH

The Irish Hospice Foundation launches a new programme to deal with the little known but widespread problem of Complicated Grief.

What is Complicated Grief?

About 290,000 people are bereaved in Ireland every year. But it's estimated that between 3,500 and 7,000 of them – for a variety of reasons – are at risk of developing a phenomenon known as Complicated Grief.

For most people, grief becomes more manageable with time and people find their own way through it with the support of family and friends. In Complicated Grief, the natural grieving process is derailed. People can suffer for years – or even decades – after a

death, with feelings of intense yearning, preoccupation with painful memories and with difficulty re-engaging with life.

Complicated Grief is now recognised as a mental health issue and has been included in the American Psychiatric Association's Diagnostic and Statistical Manual.

The journey back to joy

American bereavement expert Dr Kathy Shear has developed a treatment approach which directly deals with the issues that keep grief from being processed and integrated into someone's life. Grief never

goes away entirely, but it can be transformed and integrated so it no longer dominates someone's life and they can again experience joy and satisfaction.

This important new programme was launched by Dr Shear herself. Dr Shear, who is the Marion E. Kenworthy Professor of Psychiatry at Columbia University School of Social Work in New York, also conducted an inspiring and hugely informative workshop for 30 Irish practitioners.

Dr Susan Delaney, who manages the Complicated Grief Programme, explained

"Our Complicated Grief Programme will consist of a small clinical practice but the main thrust of the programme will be capacity-building to ensure that Irish people presenting with Complicated Grief have access to effective treatment."

The programme will maintain a list of professionals trained in the Complicated Grief protocol.

If you want further information on how to access this treatment contact Dr Delaney at 01 679 3188.

THINKING AHEAD



Speak for Yourself

Last month the Irish Medical Journal published a General Practice based study which found a strongly positive response by patients to a request to consider and record their detailed preferences regarding their own end-of-life care.

The scientific paper captures the results of a study by Dr Brendan O'Shea (Lecturer in General Practice at Trinity College) and his Colleagues on the TCD HSE GP Training Scheme. The study involved 100 clinically stable patients in five GP Training Practices attending their GP for routine care. Participants were provided with a "Think Ahead" form and their experience of filling out the form was later explored by telephone survey.

Think Ahead is a citizen-led advance planning tool which has been developed by the National Council of the Forum on End of Life in Ireland – an initiative of the Irish Hospice Foundation. It guides people in looking at and recording all aspects of end of life.

Copies of Think Ahead are available from the Irish Hospice Foundation (01-679 3188) or can be downloaded from www.thinkahead.ie

Making the nation think

We are delighted with the positive response Think Ahead is receiving from the public. We did over 30 presentations in the past year in 14 counties and requests for more presentations continue to come in. Over the past year, nearly 7,000 Think Ahead forms were distributed and we can now say there are forms in 26 counties!

GOING HOME

Demand for Our Nurses For Night Care Service increases

As people near the end of their lives, often, the thing they desire most is simply to be at home. The Irish Hospice Foundation's Nurses for Night Care service makes that possible. This specialist service provides expert and empathetic professional night care so that people with life-limiting illnesses other than cancer can spend that most precious of times in the privacy of their own home surrounded by their loved ones. And the service is provided completely free of charge. Understandably, demand for this wonderful service has grown year on year. And this year alone we will receive requests for over 1,400 separate nights of care which will cost over €450,000.



PEDAL POWER

Cyclists raise over €23,000

Tour de Frank celebrated the lives of Frank and Martin Mimmagh with a mammoth two day cycle of 180 miles/288 kms. All the way from Ferns, County Wexford to Killyclogher, County Tyrone! An incredible feat.

This inspiring family raised over €23,000 for the Irish Hospice Foundation as well as raising funds for Palliative Care Omagh and Marie Curie Cancer Care.

They are just some of the amazing supporters of the Irish Hospice Foundation!

FROM SAN SEBASTIAN TO BARCELONA

We want to give our best wishes to the 49 cyclists of all levels who will be taking on the Kingspan IHF San Sebastian to Barcelona Cycle Challenge from July 20th to 26th this year. They are going to cycle over 600 kms in five short days to raise essential funds for our Nurses for Night Care Service.

We are so proud of them!



Last year's Cycle Challenge participants celebrating their incredible achievement



AND THEY'RE OFF

The first ever Irish Hospice Foundation Race day raises nearly €50,000

A Day at The Races

On Sunday March 2nd, over 500 stylish guests arrived at Leopardstown Racecourse for the inaugural Irish Hospice Foundation Race Day. RTE broadcaster Tracey Piggott did a wonderful job as compère for the afternoon and the renowned jockeys, Barry Geraghty & David Casey, gave the crowd some excellent tips for the six races of the day.

After a delicious lunch the guests listened as IHF CEO, Sharon Foley, spoke passionately about the

Foundation and how the money raised will support the crucial work all across Ireland including the Nurses for Night Care Service and the Hospice Home Care for Children Programme.

All agreed it was a fantastic afternoon – a truly memorable and enjoyable day for a worthy cause. People are already looking forward to next year's IHF Race Day, so watch this space.

Also a big thank you to our SSE Airtricity Volunteers who helped make the day go so smoothly!



SUNFLOWER DAYS

The biggest days of the year for the hospice movement are Sunflower Days – national collection for local hospice services.

This year's Sunflower Days took place on Friday, 6th June and Saturday, 7th June.

Over this special weekend you could once again support your local hospice service by buying sunflowers, sunflower pins and sunflower seeds for €2 each from collectors in cities, towns and villages across Ireland.

The Hospice Sunflower Days are a major source of income for hospices and voluntary hospice groups countrywide.

For more information on Sunflower Days visit www.sunflowerdays.ie.

Remember:
All the funds collected on Sunflower Days are spent locally, so thank you for supporting hospice services in your area.

Tracey Piggott



David Casey and Barry Geraghty



GOVERNANCE, FINANCIAL ACCOUNTABILITY AND FUNDING

The Irish Hospice Foundation receives no core state funding. We depend on the generosity of Irish people and caring businesses. We promise to be at all times, transparent, accountable and honest. Our accounts are published in detail every year and are available on our website. We are in the process of signing up to the Governance Code for Community and Voluntary Organisations. We are committed to reporting back regularly to our fantastic donors on how your money is spent to benefit people at the end of life.



DATE FOR YOUR DIARY

The **Irish Childhood Bereavement Network** has a very important date coming up.

On October 4th The Irish Childhood Bereavement Network (ICBN) will host Ireland's first ever National One Day Conference in Dublin Castle on Childhood Bereavement. The ICBN has already held three regional meetings which were a huge success.

Research carried out in 2012 found that 28% of Irish nine year olds have lost a grandparent and 2.2% have lost a parent.

Irish Childhood Bereavement Network:

The ICBN is a hub for those working with bereaved children and those who support

them. Last December we launched our website www.childhoodbereavement.ie

For more information or to become a member please visit our site.

Changing Minds

Seminars on dementia and end of life

This year the Irish Hospice Foundation is organising three special seminars on the palliative care needs of people living with Dementia and the families that care for them. Run as part of the Changing Minds Programme the seminars are designed to promote excellence in end-of-life care for people with dementia. The first of these seminars was held in Limerick on March 26th and was oversubscribed.

Here's what the attendees said:

"Excellent & relevant"

"The whole day was inspiring and thought provoking"

"Very beneficial learning experience. Look forward to future seminars"

Look out for details of the next two seminars which will be held in Dundalk and Waterford this year.

Working for change

Changing the way people perceive end-of-life care and campaigning for better policy to deliver excellent hospice and bereavement services is an essential part of the work the Irish Hospice Foundation. This year we have continued to engage with these important issues, dealing with all ages and sectors of Irish life. Work on this vital topic will expand during 2014. We'll keep you posted.



Marie Lynch, Stephanie Booth and Dr Suzanne Timmins at the Limerick seminar on *Palliative Care Needs of People with Dementia-Building Capacity*.

Way to Go? Death & the Irish

July 1st has been set as the date for broadcast of this documentary for RTE1. Presented by Norah Casey, whose husband Richard died in 2011, the frank and revealing film features first hand experiences of a broad range of people including healthcare professionals and people who are dying speaking openly and honestly about going through what will be the last months of their own lives.

We also hear the thoughts and amusing anecdotes from well-known figures such as actor Gabriel Byrne, broadcasters Marian Finucane and George Hook, and comments from members of the general Irish public.

This project was funded by both the Irish Hospice Foundation and the Think Ahead project as part of its mission to spark a national conversation on end of life in Ireland.

