

# Spectrum

Autumn / 2015

A young child with curly hair is jumping over a large pile of autumn leaves in a grassy park. The child is wearing a purple long-sleeved shirt and blue jeans. In the background, another child is visible, and there is a white fence and trees.

## *Inside this issue:*

- » Hospital Development Update
- » Information Evenings
- » Research Update
- » Living with CF; Julie Forster
- » Fundraising Updates

# Foreword



Welcome to the autumn issue of Spectrum. Once again it's going to be a very busy period for Cystic Fibrosis Ireland over the next few months with the opening of new centres; new and innovative therapies 'on the horizon' and nationwide information meetings, to name but a few of the key priorities.

## Information evenings

We are organising a series of information evenings nationwide, the first will be held on the 21st of October in the Hermitage Hotel in Portlaoise town centre in partnership with the Midlands Branch and the second will be held in the Ashling Hotel in Dublin on the 4th of November. The Portlaoise meeting will be 'live streamed' for those not able to attend. There will be more information meetings that will be announced shortly, including in Limerick and Cork and Galway. The main focus of the first two meetings is on new drugs for CF and we will also be giving you a general update on progress in CF care.

## Opening of new centres

It is great to report that that 3 and possibly 4 new CF building projects will be opening soon. The biggest of these is the new CF adult unit in University Hospital Limerick which will be opening on a phased basis between now and Christmas. Following significant lobbying, the HSE has agreed to cover the additional staffing needs required to run the new Leben building in Limerick, which includes 2 floors for CF care. We will also shortly see the official openings of the new outpatient unit in Mayo General Hospital and the 4 room paediatric development in Waterford Hospital and hopefully their new 'gym' and outpatient development. We remain optimistic that there will be good news about the adult CF inpatient rooms in Cork University Hospital in the near future. This latter project is supported by a local CF charity.

## Don't forget your 'flu vaccination

As always at this time of year we remind our members about the importance of the influenza vaccine as people with CF are one of the 'at risk groups' that need an annual vaccination. There may be other members of your family in a 'at risk' group that should also consider such a vaccination. As the strains of 'flu change every year, it is crucial that this vaccine is undertaken every year.

**Philip Watt (CEO)**  
**Samantha Byrne (Editor)**

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DISCLAIMER: The views of contributors, when expressed in this publication, do not necessarily reflect the position or policy of Cystic Fibrosis Ireland.

# Latest News

## Hospital Developments

### New CF Unit in Limerick (UHL) to open before Xmas on a phased basis

There has been great progress in relation to the forthcoming CF unit in University Hospital Limerick. The new building will have state of the art facilities for adults with CF; patients with who have endured a stroke; those needing particular oncology (cancer) services and those with Parkinsons Disease. In short, the whole Leben project will have an impact for many patients in the greater Limerick/Clare/Tipperary region.

Construction work is now complete and the Leben building, as it is unofficially known, at present includes 2 CF floors has been formally handed over to UHL by the construction company. 'Leben' is an ancient word that translates into 'Life'.

It was the name of the company that was jointly established by CFI/ TLC<sub>4</sub>CF, The UHL Hospital Foundation and the Parkinsons Association.

Following extensive lobbying by CFI/TLC<sub>4</sub>CF the hospital have agreed to provide sufficient staff cover to open 5 of the 9 in-patient rooms. Target period for opening of the 5 rooms and the outpatient centres is before Xmas, perhaps as soon as November, but this is dependent on the arrival or equipment and the successful deep cleaning programmes.

In addition to all those who provided funding for this new unit including the JP McManus group and all the public support gained by TLC<sub>4</sub>CF, CFI wishes to acknowledge the support of the Hospital Manager in UHL, local public representatives, the HSE and the Ministers' for Health (Minister Varadkar) and Finance (Minister Noonan) who have recently sanctioned the additional staff costs associated with this project.

CFI pays tribute to the Tipperary, Limerick and Clare branches (TLC<sub>4</sub>CF) who have done much of the 'heavy lifting' on this project with support from the national and regional office and the Board of the association. In particular it is important to acknowledge the TLC<sub>4</sub>CF committee of Owen Kirby, Liam O' Kelly, Caitriona Hayes, Marcella Clancy and Linda Drennan and regional officer Erin Sugrue. We also thank the support of the hospital CEO Colette Cowan.





## Cavan

€100,000 has recently been received from the Minister of Health national lottery fund for this project (July 2015). This will allow the 2 room paediatric in-patient and paediatric unit reconfiguration required to proceed, with the main funding raised by the CFI Cavan Branch and with support from the Hospital. Particular thanks to all closely involved in this project from the Cavan branch.



## Cork

The 8 room CF inpatient unit funded by a local CF charity in Cork with considerable support from CFI members, will open shortly. There was a delay to its operational opening due to staff shortages during the summer months. The paediatric out-patient unit is currently decanted to allow for badly needed remedial work in the children's section of CUH.



## Beaumont

There have been several meetings over the summer to progress the appointment of a dedicated CF Registrar and a CF specialised nurse and to advance the building of a new 20 room CF adult in-patient centre. A new CF nurse will be appointed shortly and it is expected that the vacant registrar hours will also be resolved within the next few weeks.

## Mayo

The new CF clinic in Mayo General Hospital opened for patients in early September 2015

The formal opening will be arranged shortly and will be a great day for families reliant on the CF services in Mayo and the clinical team led by Dr M O'Neill

Just to acknowledge once again the work of Tomas Thompson, Caroline Heffernan and of course Martina Jennings and the whole of the Mayo branch/CF West team and all our supporters on this project. It's been a great partnership project.

## New Rare Disease Office

CFI has been very closely involved in the National Rare Disease Plan for Ireland. Philip Watt (CEO) spoke on behalf of all patient groups at the opening of the Rare Disease Office on 4 June 2015 in the Mater Hospital. It is important to note that CF is a borderline rare disease in Ireland, but is a rare disease in the rest of the world. A copy of his speech is available on the MRCC website [www.mrcg.ie](http://www.mrcg.ie)

## National Clinical Programme for CF

The first reconvened meeting of the NCP for CF took place on the 2nd of October. NCPs will draw up national clinical standards and pathways for the care of a particular disease.

## Waterford University Hospital

The Four room paediatric in patient project has been completed and is already been used by both children with CF and other children needing high spec rooms.

Following a meeting between CFI and the hospital management it was identified that there is no dedicated space for paediatric out-patient assessment on the Paediatric Ward. They are accommodated in any available clinical space on the ward which already has a high volume throughput. There is also no dedicated physiotherapy area for the children with CF and this is currently undertaken in the common hospital physiotherapy department.

To address these pressing issues, a further \$73,000 was committed by CFI for this project on top of the \$200,000 that had been raised for the 4 room unit. Many thanks to all those who were involved in this fundraising at a local level including patients, their families, nurses, and the general public, it has been a great effort.

It is anticipated this second project will be complete by Xmas 2015 and we would then aim for a formal opening of both the areas in partnership with the Hospital management.



# Research

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## Calling all young researchers!!

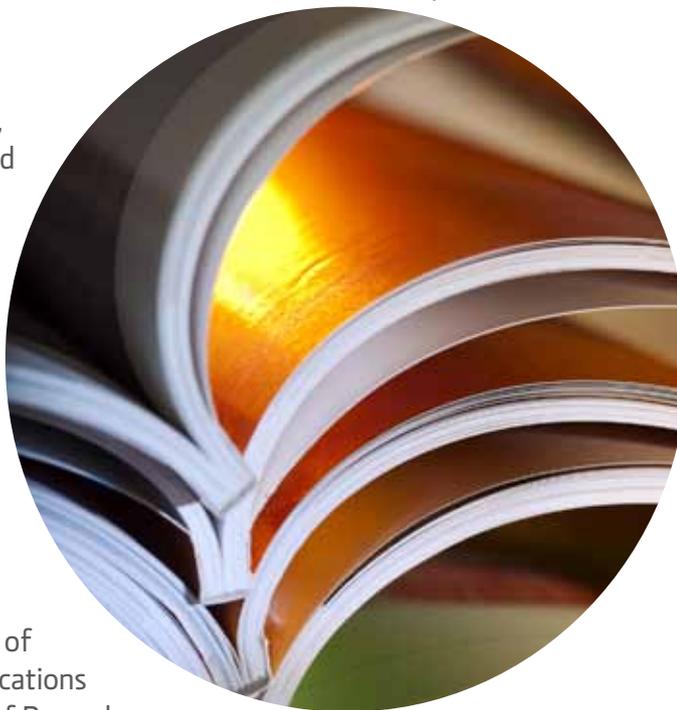
The 10th European Cystic Fibrosis Investigators' Meeting will take place in the Institut Pasteur in Paris from the 10th to 12th of February 2016. This scientific meeting is organised by the European Cystic Fibrosis Patients' organisations, in partnership with the European Cystic Fibrosis Society.

The overall aim of this event is to foster interactions between young scientists, in order to create a long-term collaborative European network of CF Investigators. The meeting will cover all CF research fields, considering basic research and clinical research.

A total of forty young investigators (under 35 years old) will be selected by an international scientific committee to present their work on CF. Successful applicants will be asked to give a 10 scussion, where there will be an award for the best presentation. This meeting provides a unique opportunity for young scientists to share experiences and learn from their peers and experts in the field of CF.

Participation is free! There is no registration fee. Travelling costs, housing and meals will be covered by Cystic Fibrosis Ireland for any successful applicants from the Republic of Ireland.

If you meet the criteria outlined and would like to apply for this wonderful opportunity get in touch with us here at CFI, by emailing [kmurphy@cfireland.ie](mailto:kmurphy@cfireland.ie) and we will forward an abstract form which must be completed and returned to organisers by the 1st of November 2015. Successful applications will be contacted from the 15th of December, where additional information will be made available.



## CFRI Registry Patient Portal

Earlier this month, CFI, in partnership with the Cystic Fibrosis Registry of Ireland, disseminated a survey which aimed to capture your views and thoughts on the development of a Registry Patient Portal, which is a secure website and App that enables individual registry patients to view their own CFRI health record.

In Ireland, the CFRI collects clinical information from hospital records for patients who agree to this, by signing a registry consent form (93% of the CF population in Ireland to date). The Irish CF registry is one of the most detailed CF registries, capturing over 400 pieces of information per patient per year.

With a Registry Patient Portal, the idea is that a patient would be able to view relevant registry information such as hospitalisation, medication, lung function, growth, microbiology, etc. The study investigators will be monitoring whether patients with access to their registry health record are better able to manage their condition, and in particular, will look at changes in clinical measures and patient reports of wellbeing.

The online survey is now closed, but if you would like to participate or share your views please contact [kmurphy@cfireland.ie](mailto:kmurphy@cfireland.ie) and we will send you a hard copy of the survey.

We would like to thank everyone who took the time to complete this survey – it is a wonderful way for us to gather the views of our members.



## EUPATI

The European Patients' Academy (EUPATI) is a European Innovative Medicines Initiative project, led by the European Patients' Forum, with partners from patient organisations, universities and not-for-profit organisations, along with a number of European pharmaceutical companies.

The overall aim of EUPATI is to help patients learn, and become more involved in the research & development process of new medicines by offering reliable, objective, comprehensive lay-friendly information and training on the research and development process of medicines.

One of the major strands of work in EUPATI is the 'EUPATI Expert Training Course', which is an exciting and unique opportunity offering patients and patient advocates expert-level training in medicines research and development.

The course aims to increase the capacity of patients to be effective advocates, with meaningful involvement in areas like drug discovery and non-clinical testing, planning and conduct of clinical trials, regulatory affairs, assessment of safety of medicines, benefit-risk assessment, as well as principles of health technology assessment.

Cystic Fibrosis Ireland are delighted that Katie Murphy (PWCF, and Research & Development officer at CFI) has been offered a place on this course and will use the knowledge gained through her studies to ensure CFI are fully informed and involved in the development process for new CF medicines.

## EMA recommends licenses for Orkambi and Kalydeco (ivacaftor).

Cystic Fibrosis Ireland welcomed the news that the European Medicines Agency's (EMA) Committee for Medicinal Products for Human Use (CHMP), which is responsible for preparing the EMA's opinions on all questions concerning medicines for human use, has made the following recommendations regarding two genotype-specific cystic fibrosis treatments;

- Orkambi, the combination therapy of ivacaftor and lumacaftor, should be licensed for use in people aged 12 and over with two copies of the F508del genotype (the most common form of cystic fibrosis).
- Kalydeco (ivacaftor) is licensed for use for those, aged 18 years and above, with one copy of the R117H mutation,
- Kalydeco's current licence for nine gating mutations, including G551D, is extended to cover children aged two and above. The drug is currently only available for those aged six years and over.

**Please note** that these recommendations from the CHMP on both these drugs must now go forward to the European Commission for final approval at EU level before they will be considered for reimbursement by the Irish Government, where they may be subject to a full Health Technology Assessment (HTA) by the relevant bodies in Ireland, which are the NCPE and the HSE CPU Unit. This process usually takes a matter of months.

CFI will continue to monitor this process closely and will keep everyone up-to-date.

### Patient Experience on Orkambi

CF Ireland are looking to hear from anyone who has taken part in the clinical trial for Orkambi. The increased need to capture additional Quality of Life (QoL) and patient-reported outcomes have been recognised both in Ireland and across Europe, but we cannot represent your collective views without your input. So if you were part of the clinical trials for Orkambi and are willing to share your experiences please get in touch with us by emailing:

kmurphy@cfireland.ie or call us on 01 496 2433.



# Information

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## Big Thank you to Helen

A big Thankyou to Helen Whitty who has left Cystic Fibrosis Ireland to pursue new professional and personal goals after more than 13 years of service.

Helen worked with Cystic Fibrosis Ireland since 2002, first as Office Manager and subsequently as Operations Manager.

The management of CFI operations throughout that period required considerable skill, diplomacy and the deployment of a wide range of skills, particularly at a time of change. Helen demonstrated these skills consistently and contributed in no small way to the effectiveness of our work over the period she was with CFI.

During her time in CFI Helen also demonstrated a determination to develop her personal development and professional skills. For example, through the undertaking of a MSc in Health in TCD and the achievement of first class placing, while continuing to work on a full time basis. This was a considerable achievement.

Helen will be fondly remembered by many of our members and clinicians who got to know her. The operational work in which she was involved with required a dedication and attention to detail. Her contribution was particularly important when conditions in many CF Hospitals failed to meet accepted international standards on issues such as single ensuite room occupancy and infrastructure that militated against adequate cross infection procedures. Helen was great at championing the needs of individual patients and their families.

Thanks Helen !



## Presentation to Brendan McLoughlin

Brendan McLoughlin is now 23 years post-transplant. In August 1992 Brendan underwent a 9 hour transplant in the Freeman Hospital in Newcastle - more than a decade before the Irish lung transplant programme was established in the Mater Hospital. Brendan spoke shortly after the operation and said 'before the operation I was gasping, struggling for health. I couldn't lie flat - there had to be six pillows supporting me. Afterwards everything had changed. It was like a new life'.

His operation was unusual. Because of Brendan's small frame, he only received a single lung. But he has lived a very full life since 1992. Brendan is very well known in his home town of Ballybofey in County Donegal and has been on Highland radio many times campaigning on CF and other local issues. In 2000 Brendan also received a kidney transplant.

Philip Watt CEO of CFI said: 'Brendan is a very caring person and keeps a watchful eye over his elderly mother, Frances and sister also called Frances who live in Ballybofey. We wish Brendan and his mother Frances a quick recovery from their recent illnesses and congratulate Brendan on his 23 years post-transplant.



*Philip Watt, CEO of CFI presents Brendan McLoughlin with a framed page from the Irish Times that reports his lung transplant in 1992 to celebrate his 23 years post-transplant in the Mater Hospital.*

## Flu Vaccination

### Vaccination season is here!

#### Who is most at risk from flu?

Anyone can get the flu but it is more severe in people aged 65 years and over and anyone with a chronic medical condition such as Cystic Fibrosis. Pregnant women have also been found to be at increased risk of the complications of flu. These groups of people are targeted for influenza vaccination.

#### How can flu be prevented?

Flu can be prevented by vaccination. Flu vaccine is a safe, effective way to help prevent flu infection, avoiding hospitalisation, reducing flu related deaths and illnesses.

#### What is the seasonal (annual) flu vaccine?

Each year the seasonal (annual) flu vaccine contains three common influenza virus strains. The flu virus changes each year, this is why a new flu vaccine has to be given each year.

Remember, if you have a long term medical condition, you should also ask your doctor about the **pneumococcal vaccine** which protects against pneumonia, if you have not previously received it. A once only booster vaccination is recommended 5 years after the first vaccination.



# Cystic Fibrosis Ireland Information Evenings

Cystic Fibrosis Ireland are delighted to announce that we are hosting two information evenings for our members, which will primarily focus on new treatments in the pipeline for people with Cystic Fibrosis (PWCF), taking place in Portlaoise & Dublin.

Dr Ed McKone, CF Consultant at St Vincent's University Hospital, Dublin, has kindly agreed to be our keynote speaker at each event – where he will share his expert insight and knowledge regarding the treatment pipeline for people with CF in Ireland.

## Agenda

*The Heritage Hotel, Portlaoise, Co. Laois*

*21st October*

**7.00pm** Registration Refreshments served

**7.15pm** Welcome from the CFI Midlands Branch  
David Fitzgerald, Chirperson of CFI

**7.25pm** **Progress Update from CFI**  
Philip Watt, CEO, CFI

**7.45pm** **New Therapies in Cystic Fibrosis**  
Dr Ed McKone, Cystic Fibrosis Consultant,  
St Vincent's University Hospital, Dublin

**8.15pm** **The Approval Process for New Therapies**  
Katie Murphy, Research & Development Officer, CFI

**8.30pm** **Questions & Answers**

\* Please Note that due to cross infection people with CF are not permitted to attend. However, we will be providing a live streaming service of this evening so that everyone can tune in online!

Live streaming will be available at [www.cfireland.ie](http://www.cfireland.ie) from 7.15pm



**Address:** Portlaoise Heritage Hotel, Jessop Street,  
Portlaoise, Co. Laois

**Website:** <http://www.theheritagehotel.com/>

Parking available adjacent to hotel

Register your attendance by emailing

[kmurphy@cfireland.ie](mailto:kmurphy@cfireland.ie) or call CFI on 01 496 2433

**7.00pm** Registration Refreshments served

**7.15pm** **Welcome Address**  
David Fitzgerald, Chairperson of CFI

**7.25pm** **Progress Update from CFI**  
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Dr Ed McKone, Cystic Fibrosis Consultant,  
St Vincent's University Hospital, Dublin

**8.15pm** **The Approval Process for New Therapies**  
Katie Murphy, Research & Development Officer, CFI

**8.30pm** **Questions & Answers**



**Address:** Ashling Hotel, Parkgate Street, Dublin 8

**Website:** <http://www.ashlinghotel.ie/>

Parking available adjacent to the hotel and Heuston Station is a 2 minute walk from the hotel.

\* Please Note that due to cross infection people with CF are not permitted to attend. Information videos covering all topics will be made available.

# REELING IN THE YEARS

## CHRISTMAS '83

As part of a new series, we will be revisiting some older publications to look at the association as it was a few decades past.

The first example, from Christmas 1983 shows just



...ion — anyone ready for some cake?



Olwen & John — just a word in your ear.

EVENT OF THE YEAR

how far CF care in Ireland has come in the past 30 years. In the issue, Chairman Alan Patrick stated that the provision of physiotherapy was the largest single item of expenditure for the organisation. Thankfully services for PWCF have improved and physiotherapy



### CONGRATULATIONS

Race Night:  
Our thanks to Shay Duffy for a most enjoyable and profitable Race Night in Mollee Barracks.

Left to Right:

Mr Holland — Manager Cork Greyhound Race Track, Mr Ross Anderson — Marketing Manager  
Mr Jim O'Shea — Managing Director of Multi Channel, Margaret Kingston — Assistant Treasurer  
Mrs Hallinan — Treasurer S.B. at the greyhound races on behalf of C.F.

is a standard part of care. However, CFI continue to support PWCF in this area by providing Exercise Grants.

This change has allowed the Association to provide other vital grants for PWCF including Fertility Grants and Transplant Grants to name but a few.

One thing that was evident from the issue was the sense of community. From wedding notices to bonny baby victories it was great to see personal achievements of PWCF celebrated throughout the issue.

Although the media channel may have moved from print to social, thankfully the CF community is still going strong today, if not in fact stronger.

The issue highlighted the huge improvements that have been made in CF care in Ireland, but was a stark reminder that there is still more to do.

We cannot share the entire issue with you, but please enjoy these snapshots from the 1983 Christmas edition of the CFI Newsletter.

### PAINTING COMPETITION RESULTS

With such a big response to the competition, the judges with a lot of deliberation finally named the following:

The winners of the Painting Competition are:

- 1st Prize: Ambrose O'Malley,  
Carrowkeel,  
Brickens,  
Claremorris,  
Co. Mayo. Aged 5 years.
- 2nd Place: Gillian McNulty,  
Glack,  
Longford. Aged 7 years.
- Runners Up: Bernadette and Jennifer Maguire,  
11 Glenmore Drive,  
Drogheda,  
Co. Louth.  
Bernadette is Aged 8 years.  
Jennifer is Aged 10 years.
- Anne O'Sullivan,  
Hilltop,  
Killorglin,  
Co. Kerry. Aged 5 years.

## Key events in 1983:

- The kidnapping of Shergar
- Eamonn Coghlan won Gold in the 5,000 metres at the World Championships in Helsinki
- Dublin won the All Ireland (some things never change)
- Kilkenny won the All Ireland Hurling Championship (some things stay the same)

## RUNNING FOR CYSTIC FIBROSIS

A big number of Shannon marathon enthusiasts will go to the starting line for the Dublin City Marathon at the end of next month. For many of them the knowledge that local charities stand to benefit considerably will be an added encouragement to get around the gruelling 26 miles 385 yards course.

Among the Shannon runners who are fund-raising are six members of Shannon senior athletic club, including their chairman, secretary and treasurer. They will be wearing the singlets of the Cystic Fibrosis Assoc.

Cystic Fibrosis is an inherited disease which seriously affects the lungs and digestive system. It seriously threatens the lives of hundreds of Irish children from birth.

The athletes include from left: P.J. Considine, Aidan Bennis, Tom Twomey, Margaret Phelan, Hughie McParland, James Neville and Greg Duff. Also in the photograph Greg's son Earl.



## SOUTH-EASTERN / TIPPERARY

Michael and Bridie Hickey are very grateful to the Clonmel Citizen Band Radio Club who presented them with a cheque for £1,225.27.

To the Clonmel Athletic Club for a cheque for £800.00 and to Brendan Dunne of Davis Road, Clonmel, who presented them with a cheque for £65.00 they would also like to thank Brendan for the use of his Lounge free of charge for meetings and functions. The people of Clonmel are to be congratulated for their generosity in subscribing £1,098.08 to the Church Gate collection this year.

Members of Clonmel Citizen Band Radio Club who presented Michael and Bridie Hickey with a cheque for £1,225.27 as a result of a pram push from Thurles to Clonmel. The presentation took place at Brendans Lounge, Davis Road, Clonmel.

Members of the Clonmel Athletic Club who presented Michael and Bridie Hickey with a cheque for £800 proceeds from the Dublin City Marathon. The presentation took place at Brendans Lounge, Davis Road, Clonmel.



Robert Byles, Thomas Meade, Eoin Walsh, Edmund Walsh presenting Brian Walsh with money, which they raised during their school holidays selling second hand books.

## SOUTHERN

Our Fisherman Group again excelled this year and our thanks to them and worthy of mention is Mr Coleman Flaherty, who ran a total of 97 miles in 3 days.

The Cork and Kerry Branches united in a Kerry Mountain Climb and we extend a sincere thanks to them for all their help and hospitality.

In June Cork and Kerry Children joined forces for an enjoyable day out at the Zoo.

Our thanks to the Irish Wool Secretariat, when we hosted the Irish Fashion Road Show. Our thanks to Ed Shanahan, Producer and Director of the show.

To Cathy Carlton, our very hard working liaison officer we extend a sincere vote of thanks to her from all the parents. This appointment has been an outstanding success.

### Notes for your Diary:

5th Annual Christmas Dinner Dance – 2nd December '83. Metropole Hotel, Cork, 8 p.m. – 2 a.m. Tickets £10.00.

Ken French



Kelly twins Thomas and David of Ballincollig, Co. Cork.

# Living with CF

By Julie Forster

My name is Julie Forster (nee Mullally). I am married to Karl and we have three kids, Shauna 13, Tom 3, and Ruth 23 months. We live in Enniscorthy in Co. Wexford.

My story really starts with my youngest daughter Ruth. Ruth was born on October 29th 2013 in Wexford General Hospital. She was born with M.I. (Meconium Ileus) which became apparent at about 24 hours old as she wasn't able to sustain her feeds and had a very swollen tummy, she was moved into the special care unit in Wexford General at that point, to be transferred to Crumlin three days later at the request of the paediatric team there. They ran several tests and scans on her to discover a blockage of the bowel. Cystic Fibrosis was mentioned then, we were asked about family history but neither of us knew of anything. Thankfully the bowel cleared itself without surgery and after a week we were allowed home with her as she seemed to be doing a lot better.

We were home about a week with her when we had an appointment in Crumlin with the Orthopaedic Department as she had been born with a dislocated hip. We had just arrived home that evening when I got a call to be back up first thing the next morning to have her weight checked. We made it up by lunch time to be brought to a side ward and met by the C.F. team and told she had Cystic Fibrosis. Even though she hadn't been gaining weight we had thought that once the bowel had cleared CF was off the table. We knew nothing whatsoever about CF at that point, the CF Team in Crumlin gave us a brief outline that day. We came back up again the next day to be admitted for a week to learn how to deal with Ruth's condition. After that week Ruth's care was moved to the CF Team of The National Children's Hospital in Tallaght as we live in Wexford.

Ruth is pancreas insufficient and is on very high dosage

of Creon, thankfully her lungs are good. She's on Tobi nebs as she grew Pseudomonas on two occasions but other than that she's on her preventative antibiotic and her vitamins.

As part of Ruth's diagnosis we were offered genetic testing. At the time we didn't really understand what this was, we accepted in the fog of the early days of the diagnosis. The appointment came out for December of last year. In the meantime we had gained a better understanding of CF and how our little girl came to have it. She's Double DF508 so we knew we'd both

passed on the DF508 gene to her. We intended cancelling the genetic testing as we figured it was cut and dried and we had nothing to learn from it.

How wrong we were and how lucky I forgot to cancel the appointment. We attended the appointment with Dr Alana Ward in Crumlin, we had the bloods drawn and never thought of it again. About three months

later I got a call from Dr Ward with our results, Karl is a carrier of DF508 (as expected), however

I have two mutations DF508 & R117H (7t variant). Having a better understanding of CF at this point I asked would that not mean I have CF rather than being a carrier to which I was told yes... She did explain to me that the 7t variant generally tends to be a very mild mutation but that she was referring me to the CF Team in St. Vincent's.

I called Ruth's team in Tallaght the next morning to try and get more information from them as I'd come up with a lots of questions overnight. They were absolutely brilliant and brought me up for a sweat test. The really frightening part of all this was that they told me the R117h mutation isn't on the heel prick so my son Tom who we'd taken to be clear as he was born in 2012 and would



have been caught on the heel prick needed to be tested. His sweat test came back slightly elevated so genetic testing was recommended. Dr. Ward got me the results very quickly and he was clear. We knew Shauna was ok as she'd been sweat tested after Ruth's diagnosis as CF wasn't on the heel prick when she was born.



I still found all this very hard to take in. I was the complete opposite to almost everything we'd learned about CF since Ruth's diagnosis. I've been overweight since my teens, I've never had chest issues despite being a 20-30 a day smoker up to about 4 years ago. I have digestion/bowel issues but had never looked for any sort of diagnosis, I'd had my gallbladder removed and suffered pancreatitis when I was 20 and always accepted that the issues were a result of that.

My appointment in St. Vincent's came up quite quickly, to be honest I found it all very surreal as I was told the implications of this condition and things that could arise from it, I couldn't believe it was me they were talking about. I'd learned so much about CF from Ruth's team and a fantastic group of CF Mammies here



in Ireland, (many of whom I've met at this stage) that I was familiar with most of what they were telling me, it was like sitting in Ruth's appointments in the early days.

I've since had my full annual assessment with the CF Team in Vincent's, my lung function is excellent, my CT scan and ultrasound came back clear. I have some sinus congestion, and I need to use a Ventolin inhaler when I exercise, and I've been put on a low dosage of Creon and medication for reflux. All very minor issues, easily manageable at the moment. Hopefully if I look after myself I'll stay this well as I don't want to put Ruth at any risk of cross infection if it can be avoided at all.

My main reason for agreeing to write this piece is to encourage parents to take up the offer of genetic testing no matter how predicable or straightforward you think it will turn out. We were so lucky that Tom is ok, and that I've been caught before there are any issues rather than maybe being misdiagnosed with something else further down the line, which gives us the advantage of knowledge and being better armed to look after our family's future.

The last two years have been tough at times, but we've come through the other side, I have three fantastic



children, I married my best friend this year, and the one good thing to come from all this is I've seen who my friends are and made some fantastic new ones through the CF network in Ireland.

# Spotlight

By Rick Kelly, Artist

I've been told that I was very sick as a baby but growing up I wasn't too bad apart from the couple of weeks here and there where I would have to miss school. I was always very active as a child and out playing with friends and playing football for hours every day. I moved to Manchester in 1994 and over there the facilities and care were way better than here and they even had their own CF Unit way back then so it goes to show how far Ireland were behind. I made new friends over there and continued to play football and the years went by without any trouble. I had lots of nights out and more or less had a normal life.

I moved back to Ireland in 2001 and continued on as normal. I had a couple hospital admissions for chest infections. I was going to the gym regularly and I got a part time job in Dunnes Stores which allowed me to earn some money, but more importantly gave me time to look after myself and stay healthy. I got myself in great shape but around 4 years ago I noticed I was losing a lot of weight. I lost a stone and a half in 3 weeks so went to get checked out and I was diagnosed with CF-related Diabetes. It really set me back and I find it impossible to get the weight back up. I then had 3 hospital admissions with chest infections and my lung function dropped. I had to have an operation to get my sinuses sorted out and then suffered from bowel blockages which made me lose even more weight. I lost all my gains from the gym which really set me back. I was looking after myself better than I ever have done and kept getting all these problems. I was feeling really down and was probably suffering from depression but I carried on and tried to get back to normal which I did, except I was getting a few more chest

infections each year. Dunnes Stores were great and I can't thank everyone there enough especially my boss who gave me days off, etc. whenever I needed them.

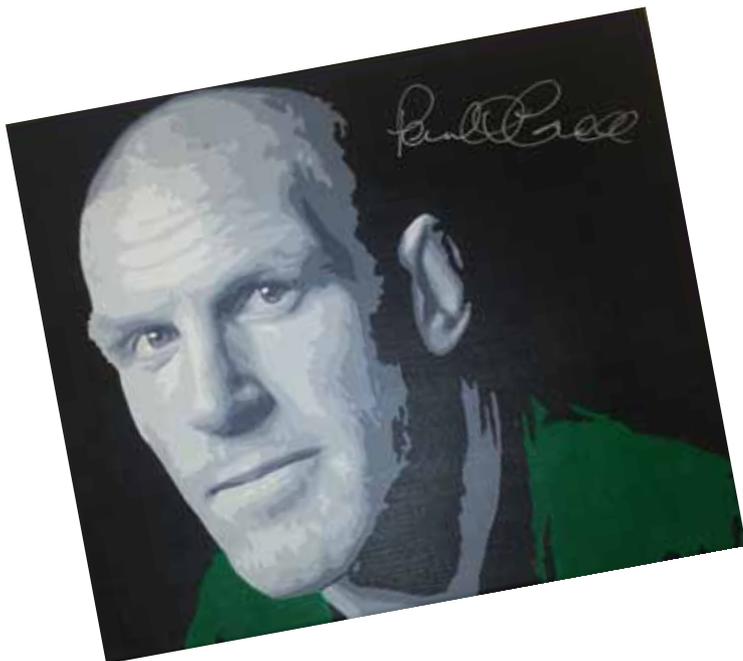
I then started getting pains in my back and this was going on for months, which had me worried. Tests were done and doctors said my veins were widening going into my liver from the flow of blood and they suspected I might have CF related Liver Disease which set me back once again. I now couldn't lift heavy in the gym. Once again I felt really down. I really wasn't in the mood to go into work every day because my back was sore and I started to pick up more and more infections. If one

person got a cold everyone would get it and when I got it I would end up in hospital, so I was really thinking of leaving work. My mind was made up to leave work. There was something I wanted to do as a hobby because I always have to be doing something and I didn't want to be at home doing nothing. When I was a kid I was always drawing but I just gave it up as I got older. I always had an interest in art though and a friend of mine in Manchester had his own art page and he used to paint footballers etc. and I loved his work. He inspired me to start drawing again which I did but I was only sketching and started drawing caricatures.

I then decided to go to art college for a year and continued working in Dunnes part-time. Within three months of being at college I learned to paint and started to have a go at painting footballers and famous people just like my friend (Mark Stenson Illustration & Painting



on facebook). I was texting Mark almost daily and he helped me and gave me tips and I can't thank him enough. Mark had a brother himself who passed away from CF before he was born. I started to get better and better at the painting and decided to leave Dunnes. I was selling the odd painting and I finally found my passion. As the weeks went on I got better and better. My art teacher wanted me to stay on and do the next level but during that college year I was in hospital twice with chest infections and I realised I can't be around people too much especially when they have colds, etc. and I got what I wanted from that year in college. So here I am still painting and getting better and selling some of my work and working from home, which is perfect. I set up my own art page Art by Rick Kelly and my plan is to keep improving and go as far as I can with it. I am aiming high!. I have also realised life is short, so do whatever you want to do and follow your dreams. I don't have CF-related Liver Disease by the way so they don't know why my veins are widening, so tests are ongoing, but I'm very happy with my life right now and it's only going to get better. At 38 years old, I have found my passion and I'm going to keep moving forward.



# Fundraising

## Challenges and Events

### Dublin Marathon: 26th October

The 2015 SSE Airtricity Dublin Marathon takes place on Monday, October 26th. Once again we have a strong contingent running for CF and this year we are particularly delighted to have some international runners join Team CFI.

The 26.2 mile route is a single lap which starts / finishes near Dublin City Centre. If you live along the route why not come out on the day and cheer on the runners and show your support for Team CFI!

Good luck to all taking part.

Missed the registration deadline to take part in this Marathon Challenge? Don't worry, there are numerous marathons you can take part in – International and National. Be sure to check out the website [www.cfireland.ie](http://www.cfireland.ie) for information on marathons and other fundraising events!



### Raise the Bar for CF

There have been numerous reports of people with “Stars in Their Eyes” thanks to CFI’s latest fundraising campaign – Raise the Bar for CF. The campaign is a novel fundraising event where Bar Owners sing a song behind the bar to entertain the customers, have a whip around for CF, post the song and amount raised on Facebook and nominate the next Pub to participate. Several pubs have already taken part in the Campaign; from the music man in Athy to duets in Wexford including Meatloaf & Cher and Sonny & Cher!

We are looking for Pubs across Ireland to participate, so get your local to sign up now and become a star in their bar! Nominate them directly or #tagyourlocal on Facebook

<https://www.facebook.com/RaisetheBarforCF>

To take part they just need to follow 6 simple steps;

**Step 1:** The nominee accepts the “Raise the Bar for CF” challenge.



**Step 2:** The nominee becomes a star for the night and must sing a song (of their own choosing) for their customers. The performance must be recorded.

**Step 3:** A collection will take place, with all proceeds going to Cystic Fibrosis Ireland.

**Step 4:** All monies collected by the bar are donated to the 'Raise the Bar for CF' My Charity Page naming the bar, the singer and the amount collected.

<http://www.mycharity.ie/event/raisethebarforcysticfibrosis/>

**Step 5:** The recording is then posted to the 'Raise The Bar for CF' Facebook Page naming the bar, the singer and the amount collected.

<https://www.facebook.com/RaisetheBarforCF>

**Step 6:** Nomination time! The bar nominates the next bar to participate and the owner / bartender they want to take on the challenge.

Once the bar has accepted the challenge, CFI will supply them with a pack with everything they need to help Raise the Bar!



## London Marathon: Event Date

We are pleased to announce details of the 2016 Virgin Money London Marathon 2016, one of the world's greatest sporting events.

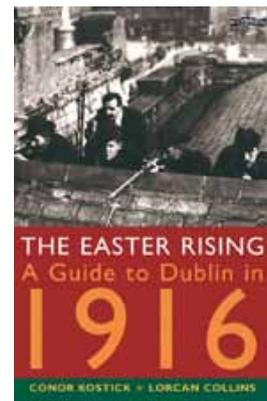
The marathon starts at 9.30am on Sunday, April 24th from Blackheath, near Greenwich, and runs through many famous London districts and past many landmarks, including the Tower of London, the Houses of Parliament, Big Ben and Buckingham Palace. Through our partnership with Sports Travel International we can GUARANTEE your place in the marathon of a lifetime, regardless of your previous marathon times (if any). All entries are sold as part of a full tour package only.

**If you are interested in taking part in this event, please call Peter on 01 496 2433 or email [pminchin@cfireland.ie](mailto:pminchin@cfireland.ie) for a full information pack and booking form.**



## 1916 Walk: 25th March 2016

“Irish historians Lorcan Collins and Conor Kostick founded the 1916 Rebellion walking tour in 1996. As well as running the tours, the pair co-wrote *The Easter Rising - A Guide to Dublin in 1916*. Like the tour, the book goes through the main places of interest and details the events of the rising. A fascinating read, and brilliantly illustrated, the book is the perfect complement to the tour. The 1916 Rebellion walking tour is a true gem. Fascinating, intriguing and eye opening, even for those that have visited the capital before, or who have lived here all their lives” – Irish Times.



Lorcan has kindly agreed to conduct an exclusive 1916 Walking Tour for Cystic Fibrosis Ireland on Good Friday – 25th March 2016. The tour will be limited to 70 participants and details of the walk will be posted on our website with booking details. The cost of the walk will be €50 including a copy of Lorcan’s book, with all proceeds from the walk going towards helping provide services for people with Cystic Fibrosis. Places are limited and will be allocated on a first come first served basis.

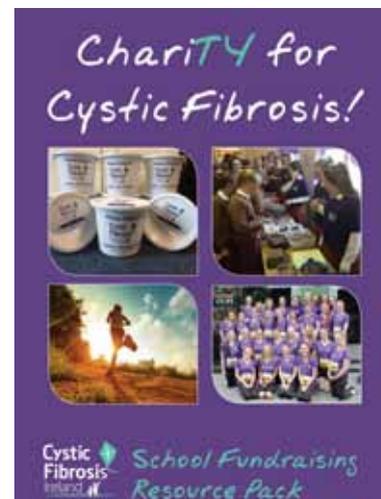
Photo: *The Easter Rising – A Guide to Dublin in 1916*

## Schools' Transition Year Fundraising

CF Ireland are seeking your school's support as part of our ChariTY School Programme. The aim of the programme is to educate Transition Year students on Cystic Fibrosis and to encourage them to undertake a fundraising event/activity on behalf of CF Ireland.

We now have a TY School Fundraising Pack available, which will provide students with some helpful information and guidance on organising a school fundraising event. The pack will help explain to students how to get started with fundraising, it will contain some fundraising ideas, how to get publicity for your event and how to manage the money. The pack is available to download from our website [www.cfireland.ie](http://www.cfireland.ie) or just give our office a call on 01 496 2433 and we will send out a pack to you.

For students that feel this might be of interest to your school, why not speak to your Transition Year co-ordinator and get in touch with us. For more details please e-mail Peter at [pminchin@cfireland.ie](mailto:pminchin@cfireland.ie)



## Dates for your diary:

Cystic Fibrosis National Awareness Week – W/C 11th April 2016: Start planning your 65 Roses Challenge now!

65 Roses Day – Friday, 15th April 2016: Sell Purple Roses to help raise funds to support PWCF

One in 1,000 Campaign – Monday, 6th June 2016: VHI Women’s Mini Marathon

## Thank You

It is not possible to list all of the Fundraising Events that have been organised since our last edition of Spectrum, but we would like to take this opportunity to thank everyone that has volunteered and raised money on behalf of people with Cystic Fibrosis. Every cent raised helps provide a better quality of life for people with CF and please keep up the great work. Here is a short summary of some of the remarkable efforts of our Volunteers.

### Row A Round Ireland:

The 2015 summer may have featured more rain than sunshine, but the changeable weather didn't dampen the spirits or determination of the Row A Round Ireland Crew. Having set off from Bray on May 31st, the crew of 20 rowers battled through rain, sun, hail and wind to complete their arduous adventure – arriving back to shore in Bray on September 26th.

Congratulations to the team – both the rowers and the land crew for all their hard work. To date the Row A Round Ireland has raised over €75,000.

On behalf of CFI and Row A Round Ireland, thank you to everyone who supported the crew on their journey through donations, warm welcomes and encouragement.

A special note of thanks to the sponsors which include Lyons Tea, Cullen Communications, Frank Keane BMW, Topaz, Adlantic.ie & Olive Media.

A homecoming ball for Row A Round Ireland takes place on Friday, October 16th.



### Paris2Nice: September 18th to 24th

We would like to offer a huge Thank You to Samantha O'Neill and the Paris2Nice Team who departed from Paris on September 18th and arrived in Nice on September 24th. Further details of this great 720km cycle and funds raised will be available in the next issue of Spectrum. We would also like to thank the sponsors of this team which included Allcare Pharmacy, Universal Products and Label Craft.

For anyone considering taking part in this life changing event, recruitment for Paris2Nice 2016 will start soon, please email Peter at [pminchin@cfireland.ie](mailto:pminchin@cfireland.ie) for more information.





### Rome2Nice: August 29th to September 5th

A huge Thank You to Dr Barry Jones and his team who cycled from Rome, departing on August 29th and arriving in Nice on September 5th. A cheque presentation for the funds raised by the Rome2Nice Team this year will take place over the coming weeks and we look forward to confirmation of the amount raised from this fantastic team effort. In the meantime, here are a couple of photos from the cycle. We would also like to thank everyone who helped the team in their fundraising drive including the Jefferson Smurfit Foundation for their generous donation and Michael Fetherston who organised a Golf Classic at Luttrellstown Golf Club.



### Montenegro Walk: September 27th to October 4th

The participants for the 21st International Walk for Cystic Fibrosis departed on September 27th. It was an early start for our walkers who met up in Dublin Airport at 5am ready to leave the dull skies behind for the magnificent sights of Montenegro. We were delighted to have Walk Ambassador Mary Duff take part for the second year in a row, fresh from the launch of her charity single for CFI, Breathe With Me – which is available for download from <http://www.maryduffmusic.com/shop/>



32 walkers travelled to Montenegro and took part in the walk in fabulous locations such as Budva National Park and Tara Canyon.

Congratulations to everyone who took part in the 2015 Paddy Kierans Memorial Walk, we hope to see you all again next year. If you are interested in joining the 2016 Walk, contact Nuala at [nmcauley@cfireland.ie](mailto:nmcauley@cfireland.ie) or keep an eye on the website for dates and details!

### Skydives:



On 19th September, 73 year old Terence Dardis from Dublin, took part in a skydive for CFI, making him one of the oldest people in Ireland to undertake a skydive for charity. Terence was inspired to take the jump as his grandson Alfie is a PWCF. Although not a great fan of heights, Terence wanted to do something to help contribute to the work of CFI who continue to support people living with Cystic Fibrosis, so he chose a skydive and in his own words “this was one small step for grandad Dardis, but one giant leap for Cystic Fibrosis”. So far Terence has raised over €4,000 with more to come in. Well Done Terence!

Photo: Terence Dardis and members of Alfie’s Army

Video link:

<http://www.independent.ie/life/health-wellbeing/health-features/watch-brave-granddad-faces-fear-of-heights-by-skydiving-for-grandson-with-cystic-fibrosis-31558404.html>

Our own Fundraising Manager here in CFI, Fergal Smyth, also took to the skies to take part in a skydive for CFI. Fergal was accompanied by his wife Patricia and the brave couple completed their jump on 29th August. Well done guys!

If you would like to do a skydive for CFI, please follow the link below for all the details.

<https://www.cfireland.ie/get-involved/skydive-for-cf>



### White Collar Boxing:

Staff from the National Ambulance Service and Dublin Fire Brigade lined out for Cystic Fibrosis in a White Collar Boxing event dubbed The Battle of the Blues and Twos, which took place in TEK Football Club, Dublin on Saturday, August 15th. The event was organised in the name of Mason Merrigan, a young PWCF from Wexford.

Ten fights took place on the night, with the final tally, a draw between the two teams. Congratulations to all the fighters who took part and a huge thank you to the organisers and fighters for their support and to all who attended.



### One in 1000:

A huge thank you to everyone who took part in the VHI Women's Mini Marathon on Monday, June 1st and raised funds for Cystic Fibrosis Ireland. We are delighted to announce that the One in 1,000 Campaign has reached the income target of €100,000. Since the One in 1,000 Campaign began in 2010, it has raised over €800,000. Funds raised through the campaign are used to improve services for children and adults with CF in Ireland.

If you have not already done so, please return your sponsorship money to CFI. For account information or details on how to return your money contact CFI on 01 496 2433.

The 2015 Women's Mini Marathon may be over, but it is never too early to put the date in your diary for next year – Monday, June 6th.





### Rock The GAA For Cystic Fibrosis:

For the second year in a row, Edenderry Rocked the GAA for Cystic Fibrosis. On August 5th, crowds gathered in Edenderry GAA Club for a night of music, entertainment and fundraising. A mammoth raffle took place on the night with over 60 prizes up for grabs.

Over €800 was raised for CFI. A huge thank you to all who attended, participated and supported Rock the GAA for Cystic Fibrosis.



### Ladies Night:

It certainly was Ladies Night in The Purty Kitchen as crowds gathered to help raise funds for CFI. Team Hayden organised a fantastic night and raised over €1,400. Congratulations to all involved!



### Mental Bental Challenge:

CF Ireland would like to say a massive THANK YOU to the Irish Defence Forces 48th Infantry Group for organising the 'Mental Bental Challenge' and so far have raised over €2,000 for CFI.

The group are currently on deployment in the Golan Heights and organised a run from their base in Camp Ziouani to the top of Mt. Bental which is a dormant volcano. This was no easy task considering it took place at an altitude of 1171 metres and very high temperatures. Special thanks to Capt. Jack Higgins and Lt. Conor Hurley for organising this.



### Mind-Riot Gig for CF:

Thanks to Liam O'Rourke and Mind-Riot mt. who organised and headlined a fundraising gig in The Yard Bar, Mitchelstown for CFI on August 29th. Special guests on the night were Paradox. Plenty of people rocked up to the event and over €790 was raised on the night.



### Brian Doyle's Truck

CFI would like to say a big Thank You to Brian Doyle from Bagenalstown who works in the haulage industry and recently organised to get a lorry cover printed in support of Cystic Fibrosis. Brian's son Barry is a PWCF and Brian has been a great supporter of CF Ireland for many years now. CFI would also like to thank Dennison Trailers for donating the covers, Cunningham Covers for printing the covers free of charge and Casey Bros. Haulage for the use of their trailer. Keep an eye out for this trailer on the roads of Ireland in the coming months!

## Head2Head Walk: 27th September

Well done to all our walkers who took part in the Head2Head Walk 2015 in aid of the Beds for Beaumont campaign. The day was a great success with a huge turnout and even the weather was on our side. This event could not happen without the help of many volunteers, so thanks to all those who helped on the day to make this both a safe and very enjoyable event. We would like to say a special thanks to the Gardai and St. John Ambulance crew for their support throughout the day. Everyone enjoyed some well-deserved refreshments at the finish point at the Royal Hotel in Bray after completing the walk.



If anyone would like to lodge any fundraising money, you can use the bank details provided below. Please remember to put your name in as a reference. Thank you.



BEAUMONT A/C: IBAN: IE60 AIBK 9310 7111 8352 53 BIC: AIBKIE2D

## D7 Educate Together:

A big Thank You to all the students and staff of D7 Educate Together National School who recently organised the D7 Family Fun Run in the Phoenix Park and handed over a cheque for €830 to CF Ireland.

Pictured below from L to R are: Peter Minchin (CFI), Maisie McMahon, Charlie Dineen, George Fennessy Carey, Tom Brennan



## Waterford I.T.

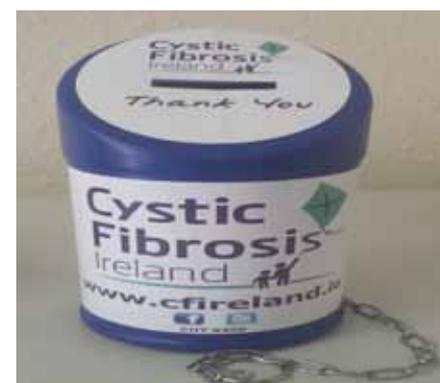
A huge Thank You to the students of Waterford I.T. who organised several fundraising activities and raised €12,000 for charity during their 2015 Raise & Give Week.

CFI were delighted to be one of the chosen charities for the 2015 Raise & Give Week. The W.I.T. Students' Union recently presented a cheque for €3,000 to Fergal Smyth, CFI Fundraising Manager.



## It makes perfect cents!

We would like to thank everyone who has placed or taken Cystic Fibrosis Collection Boxes into their premises or workplace. Collection Boxes provide a regular income which is essential in planning for the provision of services and we are pleased to announce that AdSales and The Sweets for Charity Project are now placing boxes in outlets on our behalf. All boxes placed are our Cystic Fibrosis Ireland boxes as per the image attached and everyone placing boxes for Cystic Fibrosis Ireland has official CFI identification.



## IBM

Thank you to IBM who provided a donation of €900 for the Beds for Beaumont fund.



## Ladbrokes:

CF Ireland would like to say a big Thank You to Ladbrokes of Dun Laoghaire and Ballybrack for their fundraising activities raising a total of €1,950 for CFI. Ladbrokes have been great supporters of CFI over the last number of years and we look forward to their continued support.



## Joe Duffy Motor Group:

Thank you to Joe Duffy Motor Group and all the employees who recently fundraised on behalf of CFI and presented CF Ireland with a cheque for €2,000. A special word of thanks to Colin Kenny from the Joe Duffy Motor Group for organising this.

If you or your company would like to fundraise for CF Ireland please get in touch with our office on 01 496 2433 or e-mail [fundraising@cfireland.ie](mailto:fundraising@cfireland.ie)



## Malone Engineering Group

A big Thank You to Malone Engineering Group who held an All-Ireland Jersey Auction in aid of Cystic Fibrosis Ireland and raised €400.

Congratulations to Richard Garrigan from Doorfix who was successful with his bidding and won the signed Dublin and Kerry Jerseys. Accepting the donation is Fergal Smyth, CFI Fundraising Manager pictured with Richard.



## Permanent TSB Charity Gala Ball

Thank you to Permanent TSB and everyone that supported their Charity Gala Ball on 12th September in the Double Tree Hilton Hotel in Dublin. It was a massive success and raised €50k for their two staff charities, Cystic Fibrosis Ireland and Cork University Hospital, Children's Unit.



## My Legacy

Are you putting off the vital process of making a will?

During Best Will in the World Week, from Monday 2nd - Friday 6th November, you can avail of a will consultation with your local solicitor for just €50. We would also like to encourage you to consider leaving a gift to Cystic Fibrosis Ireland in your will and pass on an ever-lasting gift to PWCF. We have enclosed a leaflet with all Spectrum magazines to provide you with additional information on Legacy Giving.

Further details of Best Will in the World Week will be available in the lead up to this week on our website.



## In Memory Donations for Berkeley Victims

Cystic Fibrosis Ireland wish to thank everyone who provided donations in memory of the Berkeley tragedy victims Ashley Donohoe and her cousin Olivia Burke. The family of Irish American student, Ashley Donohoe, made a statement at the time of her funeral confirming that “Ashley was dedicated to making a difference in this world and would be honoured to raise money for cystic fibrosis on behalf of her younger cousin back home in Ireland. The family ask that in lieu of flowers and other donations to please make a donation to Cystic Fibrosis Ireland at [www.cfireland.ie](http://www.cfireland.ie)”. We are very moved and thankful to the Donohoe and Burke families for thinking of PWCF at such a tragic time in their lives and to everyone who made donations in memory of Ashley and Olivia. May they rest in peace.

# CFI Christmas Cards 2015

Mixed Pack – 4 designs x 2 (8 Cards)



Single Design Packs - 1 design x 8 (8 Cards)



**Branches: Please order via order forms sent to each branch**

**Public: Please order via our website [www.cfireland.ie](http://www.cfireland.ie)**

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