

Spectrum

Spring / 2015



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Foreword



It was great to see a huge turn-out for the formal opening of the Nutley Wing in St Vincent's University Hospital on 23rd of March. Although it has been up and running for over two years, the Nutley wing was officially opened by Minister for Health Leo Varadkar with speeches also from Professor Charles Gallagher, lead CF clinician, and Philip Watt CEO, CFI. David Fitzgerald, Chairperson of CFI, also represented the association.

At the launch, CFI asked the Minister to consider SVUH as a benchmark for other adult and paediatric CF services across the country and pointed to the remaining work that needs to be undertaken in Beaumont (adult); Cork (paediatric); Limerick (adult), in particular, and in other CF centres around the country. The Minister acknowledged the huge fundraising efforts of CFI, local branches and supporters for improving CF services in Crumlin; Drogheda; Galway; Waterford; Limerick; Cavan and Mayo hospitals.

We would also like to take this opportunity to acknowledge the dedicated support of so many people with CF, many of whom are sadly no longer with us, who spoke out and advocated for improvements in CF services over the years.

This issue of *Spectrum* also includes a focus on our '65 Roses' National Awareness Week which runs from April 20th to April 26th. There are many ways you can support us throughout this week including buying one of our Purple Silk Roses which will be on sale in shopping centres around the country, or take up the 65 Roses challenge!

We also highlight new information videos for members which are underway — the first of these will focus on supporting new parents following a diagnosis, and will be launched at our forthcoming conference in Limerick. We look forward to meeting everyone there shortly.

Until the next issue,

Philip Watt (CEO)

Alica May (Editor)

Front Cover: Joe Brolly (CFI Ambassador) and Keelin Shanley (broadcaster and journalist) taking part in the photoshoot for our 65 Roses National Awareness Week .

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Latest News

Hospital Developments

Beaumont Hospital

Cystic Fibrosis Ireland (CFI) and our colleagues in CF Hopesource (a local North Dublin based CF charity) met with Beaumont hospital management and clinicians on Tuesday 17th of February 2015 to lobby for urgent action to resolve issues raised by patients related to access to CF inpatient and outpatient services for adults in the hospital.

The following actions were agreed by the Beaumont Hospital management to address short-term and long-term problems:

1. A Registrar (experienced non-consultant doctor) will be appointed as soon as possible to the CF outpatient service. This post will be funded for one year by Cystic Fibrosis Ireland and CF Hopesource (circa 100k). This appointment will result in a significant expansion of the opening hours of the CF inpatient-service. The hospital will also consider our urgent request for the appointment of an additional specialised CF nurse.
2. Beaumont Hospital had promised that as an interim measure the number of inpatient rooms would be increased from 4 to 7 in 2014. Patient groups pointed out that only 6 (i.e., an additional 2 rooms) had been delivered to date. The hospital management explained that this was due to the recent Accident and Emergency crisis. We can confirm that the 7th room is now open.
3. There has been progress on developing the new CF 20 bed ward block required for CF inpatients in Beaumont since our last meeting in November. The Beaumont hospital board has approved this new ward block as part of a broader ambulatory care campus development.

Work has now commenced to draw up architectural plans that will be ready for June/July 2015. The board is seeking government funding for this project, including a meeting with the Minister. It is envisaged that most of the funding for this project will come from government but CFI and CF Hopesource will meet shortly to determine if we can also contribute some funding for this project. If this project goes to plan the hospital estimate it will take 2.5 years to complete.



University Hospital Limerick

An assurance has been given that the new adult CF inpatient and outpatient unit in University Hospital Limerick (UHL) will be opened in the last quarter of 2015. This is not before time as the existing facilities are not fit for purpose.

Representatives from CFI/TLC4CF met with hospital management and Ministers' Noonan and Varadkar in January 2015 to ensure that Hospital/HSE commitments for equipment and running costs are fully honoured. Since that meeting the hospital management have agreed to publish a detailed plan and timescale for opening the new unit in the last quarter of 2015. We hope to have a final date shortly. To date, all the funding for this €5.2m project has come from CFI/TLC4CF and philanthropic funding (JC McManus Pro Am).

CYSTIC FIBROSIS LEBEN UNITS PRE-OPENING PROGRAMME PROJECT DRAFT 1 PLAN-																	
	WEEK 1	WEEK 2	WEEK 3	WEEK 4	WEEK 5	WEEK 6	WEEK 7	WEEK 8	WEEK 9	WEEK 10	WEEK 12	WEEK 13	WEEK 14	WEEK 15	WEEK 16	WEEK 17	WEEK 18
CLEANING TENDER FOR THE BUILDING	Yellow																
VENTILATION TESTING	Red																
DEEP CLEANING BUILDING		Blue	Blue	Blue										Blue			
POST CLEANING CHECK					Blue										Blue		
CLEANING ENVIRONMENT SAMPLING/TESTING															Red	Red	Red
ORDERING OF EQUIPMENT	Green	Green	Green	Green													
RECEIPT OF OPENING REQUIRED EQUIPMENT						Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green
COMMISSIONING & ASSOCIATED TRAINING OF EQUIPMENT															Green	Green	Green
RECEIPT/COMMISSIONING NON-OPENING REQUIRED EQUIPMENT											Green						
STAFFING RECRUITMENT																	Dark Purple

While it is anticipated that the builders will hand over the new multifunctional ward block at the end of March 2015, much remains to be done before the new CF unit in University Hospital Limerick can open to patients with CF later this year. The Gantt chart above shows the tasks including: a 'deep clean' of the centre; the recruitment of staff and the ordering and commissioning of equipment. If everything goes to plan the new CF centre will be open in the autumn of 2015 on a phased basis, beginning with five inpatient rooms which will increase to nine. The new centre will make a huge difference to the care of adults with CF in UHL.



University Hospital Waterford

The four room paediatric CF inpatient unit in University Hospital Waterford is now open and has already had children with CF using the rooms. CFI and in particular through the fundraising efforts of the Waterford Branch of CFI, contributed €200,000 for this partnership project with the hospital. The official opening has been promised in the next few months.



Mater University Hospital and Transplants

It is great to see the continuing progress in the Mater transplant programme. In 2014 there were a record 20 CF double lung transplants undertaken. To date in 2015 there have been 5 CF double lung transplants undertaken in the Mater. Many thanks to all the team led by Professor Jim Egan. The new Whitty wing in the Mater Hospital will be formally opened shortly.



Mayo General Hospital

The new CF outpatient unit in Castlebar is almost complete and will cost in the region of €1.3m, which has been raised by a mix of local and national fundraising by CFI/CF West, including the Mayo Branch of CFI.

Many congratulations to all those involved in the project.

Brussels Recognises the Role of CFI in the Approval of Kalydeco

Philip Watt, CEO of Cystic Fibrosis Ireland was invited to give a speech in Brussels recently in the presence of the EU Commissioner for Health. The focus of the conference was the role of patient groups in ensuring the reimbursement of new and innovative drugs for rarer diseases. Philip highlighted the crucial role of clinicians in Ireland in the Health Technology Assessment process and the support of Minister James Reilly, TD, Minister of Health.

Martina Jennings Award

Many congratulations to Martina Jennings who was named 'Mayo's Most Inspirational Woman' at an awards ceremony in the TF Royal Hotel in Castlebar on January 6th 2015. Martina is Chair of the Mayo Branch of CFI. She played a key role in the fundraising for the new outpatient unit in Mayo General Hospital through her involvement in the Branch and local CF fundraising initiative 'Mayo West'. We are delighted for Martina for this thoroughly deserved award.

See page 16 for an article written by Martina in this issue of *Spectrum*.

CFI Annual Conference 2015

Final preparations are underway for our Annual Conference, which is just around the corner on 10th-12th April in the Limerick Strand Hotel.

For those that cannot make it this year, be sure to check our website for live streaming of talks in the main conference room. The agenda and speaker profiles are attached on the following pages so you have plenty of time to decide which seminars most interest you.

Getting there

The Limerick Strand Hotel is accessible from all major driving routes including the N7 and N69. With the new M7 route, Dublin is just a 90 minute drive from the Limerick Strand Hotel.

Sat Nav Co-ordinates: 52.665979 N -8.631391 W

Drive Time:

Dublin: 90 mins	Tipperary: 30 mins	Cork: 70 mins
Shannon: 15 mins	Galway: 55 mins	Kerry: 80 mins

There is an on-site car park at the hotel with over 200 spaces. The car park is located on level -2 and there is direct access to the hotel lobby from the car park. A reduced rate of €6 per 24 hours applies to residents.

We are looking forward to meeting everyone there shortly and to place faces to people we're regularly chatting to on the phone.

If you have any queries about this conference, please contact Niamh in the National Office on 01 4962433 or email info@cfireland.ie

With thanks again to our 2015 Sponsors:



Annual Conference

Evening Reception, Conference Opening Address | Friday 10th April

5.00pm: Conference Registration

6.30pm: Drinks Reception

7.00pm: **Conference Opening** David Fitzgerald, Chairperson, CFI, and Philip Watt, CEO, CFI

Special Guests **TBC**

Presentation of CFI Special Recognition Awards for 2015

8.00pm: Buffet and Drinks Reception

Conference Agenda | Saturday 11th April

8.30am: Conference Registration

9.00am: Tea/Coffee

Conference Chair (Morning Sessions)

9.30am: **CFI Progress Report** Philip Watt

9.50am: **CFI Information Video Project Launch**

10.00am: **Healthy Nutrition in CF – the Good, the Bad, the Ugly** Marie Roddy, CF Dietitian, AMNCH

10.30am: **My Independent Life – Finding and Achieving Balance** Rosie Fitzgerald, PWCF

11.00am: Tea/Coffee & Poster Presentations

11.30am: **New Therapies for Cystic Fibrosis – What is Going to Change?**

Keynote Speaker: Professor Peadar Noone, University of North Carolina

12.00pm: **The Role of the Health Technology Assessment in Accessing New Therapies**

Eibhlin Mulroe, IPPOSI

12.30pm: **Panel Discussion/Q&A session**

1.00pm: Lunch

Conference Chair (Afternoon Sessions)

2.00pm: **Family Matters – Find the Balance with CF**

Dr. Mandy Bryon, Clinical Psychologist, Great Ormond Street Hospital, London

2.30pm: **Workshops**

1. Dr. Mandy Bryon & Sorcha Connellan,
Senior Psychologist, University Hospital, Limerick

2. **Physiotherapy** (Title **TBC**) Irene Maguire, CF Physiotherapist, University Hospital Galway

3. **Nutrition (Practical Advice to Achieving Nutritional Goals in CF)** Marie Roddy, CF Dietitian, AMNCH & Zoe Woodward, CF Parent

4.00pm: Conference ends

7.30pm: Gala Dinner & Dance

AGM & Conference Closing | Sunday 12th April

11.15am: Tea/Coffee and Scones

11.30am: Annual General Meeting (everyone invited)

12.30pm: Light Lunch

Speaker Profiles

Marie Roddy, CF Dietitian, AMNCH

Marie Roddy is a Senior Paediatric Cystic Fibrosis Dietitian currently working at The National Children's Hospital, Dublin. She has almost 15 years working as a Dietitian with the last 10 working in the area of CF. She has carried out numerous research projects in the area of CF and has presented these at both national and international CF conferences.

Rosie Fitzgerald (PWCF)

Rosie Fitzgerald is from Dublin and was diagnosed with Cystic Fibrosis at six months old in 1987. Following a lung transplant in 2006, she studied Applied Psychology at college, before moving to Manchester in 2011 to do a Masters in Cognitive Brain Imaging. For the past three years Rosie has been working full-time as a web design researcher at the BBC.

Dr Peadar G. Noone MD, CF Consultant, University of North Carolina Hospital

Dr. Peadar Noone is a pulmonologist in Chapel Hill, North Carolina and is affiliated with the University of North Carolina Hospitals. He received his medical degree from National University of Ireland, Galway and has been in practice for 31 years. He has specialised in the area of Cystic Fibrosis with a particular interest in gene therapy, novel therapies for CF, lung transplantation, drug delivery to the lung and genetics of airway diseases.

Eibhlin Mulroe, Chief Executive, IPPOSI

Ms Eibhlin Mulroe has a BSSc Hons in Politics from Queens University Belfast and is an MBA graduate from the Smurfit Business School, University College Dublin. In her early career she worked in Irish Politics and then the NGO sector where she worked as CEO of the Asthma Society of Ireland.

In July 2007, she became the first CEO of the Irish Platform for Patients' Organisations, Science and Industry (IPPOSI). In 2014 she spoke at the ISPOR Patient Roundtable on patient involvement in HTAs and the World Orphan Drugs Conference. IPPOSI areas of expertise are patient access to, and development of, innovative therapies.

Dr Mandy Bryon, Clinical Psychologist, Great Ormond Street Hospital, London

Dr Mandy Bryon is a Consultant Clinical Psychologist and Joint Head of the Paediatric Psychology and Play Services at Great Ormond Street Hospital for Children, London, UK. Mandy has worked as the psychologist for the cystic fibrosis team since February 1990. She lectures extensively within the UK on psychosocial aspects of childhood illness, particularly cystic fibrosis, to professional and parent audiences. Mandy co-founded the UK Psychosocial Professionals in Cystic Fibrosis Group and currently organises the International Psychosocial Special Interest Group for the European Cystic Fibrosis Society.

Irene Maguire, CF Physiotherapist, University Hospital Galway

Irene Maguire is the CF Specialist Senior Physiotherapist in Paediatric and Adult CF at University Hospital Galway since 2002. Prior to this, Irene worked with children with CF in both Our Lady's Children's Hospital, Crumlin and The Children's University Hospital, Temple Street and with adults with CF in St Vincent's Hospital. Irene is an active member of the Irish Physiotherapists in CF group and the International Physiotherapy Group in CF.

Zoe Woodward

Zoe is a mum of three children, two girls ages 9 & 7 with CF and a 5 year old boy without CF. In 2010 she established the 1in1000 running for Cystic Fibrosis campaign, which was awarded the inaugural Outstanding Contribution Award. Following a long term interest on the effects of food on the body she studied as a Nutrition Therapist and has a diploma from the Health Sciences Academy. Over the past three years she has moved her family from the traditional CF diet to a more whole-foods lifestyle. Her interest areas include Epigenetics, anti-inflammatory foods, anti-bacterial foods, and natural foods to support the respiratory, digestive and immune systems.

Research

Cystic Fibrosis Ireland — Irish Thoracic Society — Gilead Research Fellowship

The Irish Thoracic Society (ITS) in partnership with Cystic Fibrosis Ireland (CFI) is pleased to invite applications for a Research Fellowship kindly supported by Gilead UK and Ireland through an unrestricted educational grant

The objective of this fellowship is to support a clinician with a keen interest in working in the area of Cystic Fibrosis, who is in the early stages of his or her career, to carry out basic or clinical research projects and to develop, acquire



and apply advanced research procedures and techniques in the area of cystic fibrosis medicine and healthcare. Priority would be given to candidates who are members of Specialist Registrar programmes in Respiratory Medicine or Paediatric Medicine and who intend to register with a University for an MD (or equivalent) degree. Research projects must be carried out in the Republic of Ireland.

Selection of recipients will be made on the basis of scientific and expert evaluation of the application and the proposed work as set out by the candidates in the project description. Independent reviewers will be selected by the Committee of the Irish Thoracic Society and Cystic Fibrosis Ireland to carry out this task and the final decision will be made by the ITS and CFI, with the assistance of the reviewers assessments.

For a detailed description of this Fellowship and the terms and conditions please visit www.cfireland.ie or <http://irishthoracicsociety.com/> or contact kmurphy@cfireland.ie.

Conference and Education Grant

We are delighted to have secured funding from Vertex Pharmaceuticals to provide financial assistance to CF healthcare professionals, researchers and patient representatives to attend and participate in Cystic Fibrosis specific conferences and training courses.

In order to provide support to as many people as possible, we will be providing funding to cover/partially cover the cost of registration for the event/course.

The funding is primarily in place to facilitate participation in;

1. The European Cystic Fibrosis Conference
» www.ecfs.eu/brussels201w5
2. The North American Cystic Fibrosis Conference
» www.nacfconference.org
3. Managing the Care of Children and Adults with CF, Multidisciplinary course
» www.cfcourse.co.uk

Completed application forms, available at www.cfireland.ie should be sent to Katie Murphy, CF House, 24 Rathmines Road Lower, Dublin 6. Please enclose a copy of your registration receipt or invoice which indicates the exact amount of support you are requesting.

For any queries regarding this grant please call 01 496 2433 or email kmurphy@cfireland.ie

Vertex Announces Data from 12-Week Phase 2 Safety Study of VX-661 in Combination with Ivacaftor in People with Cystic Fibrosis Who Have Two Copies of the F508del Mutation

The primary objective of this Phase IIb trial was to assess and ensure patient safety when taking the combination of VX-661 and Ivacaftor. The study evaluated two doses of VX-661 (100 mg once daily or 50 mg every 12 hours) in combination with Ivacaftor (Kalydeco) (150 mg every 12 hours). The study showed that the combination regimen was generally well tolerated, and all patients completed 12 weeks of treatment. The most common adverse events were pulmonary exacerbation, and cough.

Secondary endpoints evaluated the effect of the combination on lung function. The patient group who received the 100 mg dose of VX-661 plus Kalydeco, patients reported a 4.4% improvement in lung function at 4 weeks, and a 3% improvement at 12 weeks. Consistent with prior Phase 2 studies that evaluated 4 weeks of treatment with VX-661 in combination with Ivacaftor, this study showed a rapid improvement in lung function within four weeks of treatment, and after patients completed treatment, lung function returned to baseline.

Keeping up with the Clinical Trials!

There has been a very welcome surge in the number of clinical trials being conducted globally over the past decade — and Cystic Fibrosis is very much a part of this growth. Due to increasing awareness and interest in new therapies and clinical trials we have seen an increase in the number of queries around these studies. We are always delighted to provide support and information but another great way to keep up-to-date and to read about on-going clinical trials is to visit <https://clinicaltrials.gov>. ClinicalTrials.gov is a registry and results database of publicly and privately supported clinical studies of human participants conducted around the world.

If you log on to the above website and search 'Cystic Fibrosis', you will see detailed descriptions of status of trials, which phase they are in, where they are taking place, results (if any), etc. It is a great tool for interested people to stay informed and up-to-date.



These safety and efficacy data, together with other data from multiple previously completed Phase 2 studies of VX-661, support Vertex's ongoing Phase 3 program of VX-661 in combination with Ivacaftor. The Phase 3 program is evaluating VX-661 (100 mg once daily) in combination with Ivacaftor (150 mg every 12 hours) and consists of four Phase 3 studies, including a study in people with two copies of the F508del mutation that began enrolment in February. The other three studies will enroll people with CF who have one copy of the F508del mutation and a second mutation that is either a gating mutation, residual function mutation or a mutation that results in minimal CFTR function.

To read the full release visit <http://investors.vrtx.com/releasedetail.cfm?ReleaseID=902790>

Challenges Parents Experience in Caring for a Child with CF

Are you interested in helping researchers at the University of Ulster understand more about the challenges parents' experience in caring for a child with cystic fibrosis?

Are you:

- Over 18 years of age and under 65?
- The parent of a child who has received a diagnosis of Cystic Fibrosis?
- Living in Ireland?
- Interested in giving up 30 minutes of your time to answer a confidential survey?

Your assistance will help the team to understand more about parental levels of distress, coping strategies, supports, and quality of life which will help in identifying support requirements for parents caring for children with cystic fibrosis. If you would like to take part, the following options are available:

Take the survey online here: https://ulsterhealth.eu.qualtrics.com/SE/?SID=SV_bw1jfkH2SO4iXCR

or

You can contact Greg Stynes on stynes-g@email.ulster.ac.uk to have a paper version of the questionnaire posted to you for completion.

An information sheet is included in the survey outlining:

- The purpose of the study
- Potential benefits and risks in taking part
- What you will be asked to do if you take part
- What will happen the results of the study
- Who is being invited to take part funding and payment in relation to the study
- Your rights regarding taking part and withdrawing from the study
- Who has reviewed the study
- Confidentiality of your answers — they will be anonymous!
- What to do if you have a comment, question or complaint about the study

The closing date for this survey is April 10th.



Information

Information Videos in Progress

Supporting New Parents

Cystic Fibrosis Ireland (CFI) is in the process of producing several different information videos for members, courtesy of grant support provided by Novartis Pharmaceuticals, Abbott and LinkedIn.

The first video will act as a support to new parents following the diagnosis of their child through the newborn screening programme. Two families kindly agreed to participate in the short video for us (thank you!), and there will also be input from the multidisciplinary team.

We wish to demonstrate to new parents how others have coped, how CF will form part of their daily routine, and to provide them with hope for the future. The short video, one finalised, will be available on our website but we will be launching it at our forthcoming conference.

Other videos in the pipeline include one promoting exercise and adherence, third level education, employment, and highlighting PWCF who have families of their own so watch this space!

Fertility Grant Scheme

Now Accepting Applications

The CFI Fertility Grant Scheme is now accepting applications.

In contrast to previous years, the call will be open for the majority of the year until 6th November. Since this scheme was first rolled out in 2010, a total of 70 fertility grants have been awarded to members.

We are delighted to let everyone know that we are aware of 4 success stories from PWCF who received the grant in 2014.

As for previous years, the value of the grant for first-time applicants is €3,000, the value of the grant for second-time applicants is €2,000 and the value of the grant for third-time applicants is €1,000.

A Fertility Grant application form and supporting documentation from your CF Consultant and the fertility clinic you plan on attending must be sent to the CFI National Office. Members are advised to read the fertility grant guidelines in advance of applying for this grant.

Go to www.cfireland.ie for more information or contact Alica on **t:** 01 496 2433 **e:** amay@cfireland.ie

Hotel Discount for Transplant Assessment / Transplant in the Mater

Cystic Fibrosis Ireland have secured a hotel discount for people with CF attending the Mater hospital in Dublin for transplant assessment/transplant. This offer also extends to immediate and extended family members.

The minimum discount agreed is 10%, however this may be greater if booked in advance (may be the case for assessments) and depending on demand. Car parking spaces will also be prioritised for members where possible.

Please contact us in the National Office for more information on how to avail of this discount rate.

"These treatments can be a huge, emotional and physical burden. The fertility grant we received from CFI aided us in ways it would be impossible to estimate. We are now expecting twins in March 2015!"

One Couple's Journey through Fertility Treatment

Damien (PWCF) and Stacey Saul

Myself and Damien would first of all like to thank Cystic Fibrosis Ireland for their help to make it possible for us to have fertility treatment. The costs are high and can be very stressful on a relationship.

We were trying to have a baby for a long time and were unsuccessful in becoming pregnant. We went to St. Vincent's University Hospital and the team told us our options. I had a blood test to see if I was a carrier of the CF gene so that we would know the chances of having a child with CF. The test revealed I wasn't a carrier so we went ahead with the next step and made an appointment with the HARI clinic. We met Dr Edgar Mocanu there and he really gave us a lot of hope and said that our age would stand to us.

I was 23 at the time and had already had a son when I was 17. I took to being a mother so effortlessly, I loved kids and all I ever wanted was a family. Damien bonded with my son as soon as they met, but I knew if this treatment didn't work that both of us would have been broken hearted.

Our families were very supportive of our decision to go for fertility treatment. Damien had to undergo an operation to extract the sperm, which was a painful procedure. We had to wait a whole day to find out whether this was successful. This was difficult as I didn't want to see him go through any more pain.

We were already engaged at this stage and I thought we could just book our wedding to take our minds off kids for a while. I wanted to be with Damien, kids or no kids.

The next day things were looking up as we were told that enough sperm was extracted from the procedure so we could go ahead with the treatment. Unfortunately soon after, I had terrible pains in my stomach and went straight to the clinic. I had a large cyst on my ovaries that was about to burst and I wouldn't be able to continue with fertility treatment until it was removed.

In the meantime, everywhere we looked friends and family seemed to be having babies. We were so envious of them — we would be having a good day and then we would hear someone was having a baby and it was like going from 100% to 0. We got through it after many chats and about 100 cups of tea with Damien's mother — without her support we wouldn't have been able for it, she was our backbone and our rock.

10 healthy eggs were finally injected with sperm and 3 of these made it. I had a choice — they could choose one of these eggs not knowing at this stage which was the strongest or wait for 2 more days to know which one was best. I had 15 mins to make this discussion, biggest one of our lives, it was so hard. I looked at my duvet and it had a flower with 5 petals — I chose the fifth day and left it to chance, if it was meant to be it would be. As it turns out there was one egg left after the 5 days and this was the one they inserted.

After 15 days I did a pregnancy test at 6am in the morning. I was pregnant! We couldn't take it in, I think I took 5 tests for it to sink in, we were over the moon. I had a normal healthy pregnancy and so much to look forward to.

Then 3 weeks before my due date we had the worst news — Damien's mother had died. We were absolutely torn apart. We would not have been able to go through what we did without her and she would not get to meet her grandchild. It was bitter sweet as we were getting everything we ever wanted yet were going through such a big loss. Only 3 weeks later and Demi Eve was born, 9lbs 1 ounce. She was so like her nanny we couldn't believe it! She was sent at a time to bring back some joy to the family's life and that's just what she did.



» Demi Eve was born, 9lbs 1 ounce

Mum's Corner

By Gemma Dardis, Mum to Alfie, Age 2 ½



» Alfie was diagnosed with CF at 5 weeks.

"Our hopes and dreams for him remain the same, I still want him to do all the things I hoped for him."



» Alfie with his mum and big sister

Our son Alfie was diagnosed with Cystic Fibrosis 2 ½ years ago, aged 5 weeks, following urgent emergency surgery and a month of anti-natal treatment for meconium ileus (MI) at Our Lady's Children's Hospital, Crumlin. I often think back to that time following our diagnosis, wishing I had just a small bit of insight into what the next few years would bring, offering a small glimmer of hope as we entered into a world of unknown.

The past two and a half years have not been easy ones, and have had ups and downs. I never thought it possible in the early days, but now CF is just a daily part of our lives and this is our story...

Our Diagnosis

On the 3rd August 2012, we were due to attend a scheduled follow up at Holles Street for our 5 week old baby following his recent MI surgery, when we received a call that would change Alfie's, and our family's lives, forever.

My husband informed me that a Dr Paul McNally had called from Crumlin Children's Hospital to ask that we make our way, that morning, as quick as we could to meet with him following Alfie's post birth admission, and surgery in Crumlin. My need for research got the better of me, and I turned to Google, and entered his name into the search, the top hit informed me that he was 'Paediatric Cystic Fibrosis Consultant/Respiratory Medicine' Our Lady's Children's Hospital Crumlin.

I remember little of the short drive to the hospital, other than the fear and waves of sickness rising inside me, in fear of what lay ahead. We arrived at the designated department in Crumlin and were asked to wait for him to come and meet us, as the Consultant (that we know so well now) walked down the corridor towards us, it was clear by the look on his face he was not delivering good news. As he approached us, and we sat there with our beautiful baby boy in his new buggy, recovering from surgery and the trauma of his first month, Dr Paul McNally introduced himself with a gentle look as we were directed to a door which read 'Reserved — Two Hours, Respiratory Medicine'...it was clear, our beautiful son of one month was about to be diagnosed with Cystic Fibrosis.

Any parent of a child with CF will have their own story of diagnosis, and none of them are good as one minute you are looking at your baby/child exactly as you see them, and the next you are faced with a life changing diagnosis.

As we sat in that room surrounded by a team of medical professionals who tried their best to explain the complexities of a CF diagnosis and what our life was now going to entail, I sat there somewhere in a parallel universe asking myself 'Will he go to a regular school like all his friends?', 'Will he be able to run around the field and play football, like a regular young boy?',

"How will I go back to work with a sick child?' and 'Will my son ever lead a normal life?'...amongst some other darker questions my mind was asking, but I was too scared to ask out loud.

Having just welcomed home our baby who had spent one month undergoing major MI surgery and a lengthy stay in Crumlin, the Consultants questions turned to our other child, Alfie's 4 year old big sister. How was her health? Did she have any issues with recurring chest infections or digestion problems? I realised slowly where they were going with their questioning, having just told me one of my children was being diagnosed with a life limiting genetic condition, they had to ask the obvious question, to them...'Did she also have CF?' At that point my world fell apart, that morning I had woken up with two beautiful healthy children...within hours Alfie had been diagnosed with CF, and a question was being raised over my only other child. Could life really be that cruel?

a strong willed 2 ½ year old into that mix who requires twice daily medications, physio/nebuliser routines... especially after long days in crèche and it can be more than a challenge!

In the early days his diagnosis was all consuming, and it was hard to see anything past his cystic fibrosis and the perceived limitations that it brought him, and us. Following a long rollercoaster ride of emotions in those days including tears, anger and sadness amongst many others, I was determined that I would educate myself and immerse myself into finding out as much as possible about the condition that previously I hardly knew existed. For me, research and reading up on others people's experiences helped hugely.

I returned to work when Alfie was 9 months old and looked for a crèche that I was happy could manage his care as required. After a brief stint with one crèche which didn't work out, I found a place that was warm,



A tense, sickening blur of a 48 hour period followed as our eldest underwent a sweat test which would let us know if her life would also change forever. I still have no idea how we made it through that. Two days later we were called back into Crumlin to be told that she did not have CF, and we were unable to know if she was a carrier until she turned 16 and that information was passed over to her.

So, from there we tried to come to terms with the fact that our newborn baby, and our families life — had changed forever.

Daily Life, with a Job a 6 year old and a 2 ½ year old with CF

I am happy to report that almost 2 ½ years later, things are better than they were following our diagnosis. As a family we have learnt to incorporate Alfie's CF care into our daily routine, which at times can be more than a little hectic! Sometimes that is easier than others, add

caring, and appeared to be able to provide Alfie with everything he would need. I am not going to proclaim that it was an easy choice, leaving your child and returning to work isn't easy for anyone, but it was a decision that thankfully has worked out wonderfully.

Alfie spends three full days a week often from 8am-5pm in crèche, to accommodate my job in Dublin. His carers are incredible with him, their attention to his condition and quest to find out more about its intricacies still impresses me and (like me) they now dose him with Creon without batting an eyelid.

They are able to administer his Creon as per my direction following consultations with the crèche Chef on forthcoming menu selections, and are perfectly capable of dealing with adhoc food such as birthday parties and seasonal celebrations that arise, and medicating him correctly. He is happy, and cared for, which is all I want for him. Two and a half years ago, I never thought this would be possible. To the girls in 'The Park Academy' I thank you from the bottom of my heart!

Sometimes when I arrive to collect my highly charged two year old from crèche, who has spent his days painting, gardening, playing, baking amongst many other activities...I have to remind myself that this is the 'sick' child, that a few years ago, I never felt I would be able to let out of my sight, whose life would be dominated by hospital admissions/visits and who would never be like all other children his age.

Sibling Challenges

Alfie has a big sister who dotes on him and loves him dearly, but it can be very difficult for other children in the family. How do you explain to them about their siblings condition, do you explain it to them? How do you deal with the questions that arise, and how honest should you be?

Our daughter was 4 when Alfie was diagnosed, so she accepted that he had to spend lots of time in hospital. Although this has led to her having a distinct fear of Doctors, as his arrival into the world was not the one that she eagerly awaited for the long months of pregnancy. One mistake we made early on was doing treatments (physio and nebulisers) on her small baby brother behind closed doors in an attempt to 'protect her' which only did the opposite...and made her worry what we were doing to him "that made him cry in that room". Once we brought everything out into the open, a short period of inquisitiveness was forgotten and it was quickly accepted as the 'norm'.

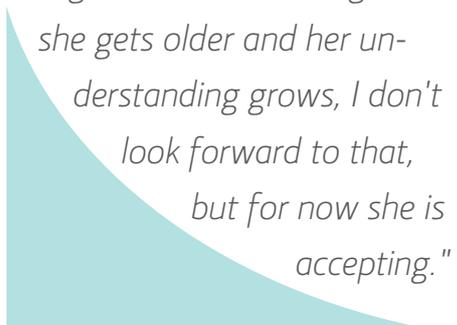
Now, at 6 ½ her questions are smarter. She is aware that his medicines and physio are not what every kid does, and they are unique to him. Whilst we don't go into his condition in depth, she is aware that his coughs can be worse than other kids, he needs medicine to help him and he needs to do physio to get rid of his coughs. We have had some periods of jealousy, and even when you believe you don't treat one any different to the other it can be hard to be asked by a 6 ½ year old "Why don't you care as much about me when I cough, as you do when he does?". I know the questions from her will get smarter and tougher as she gets older and her understanding grows, I don't look forward to that, but for now she is accepting.

On days that Alfie isn't in crèche, we try and incorporate additional physical exercise that doubles up as supplementary physio without him realising. He attends a gymnastics class one day a week, and in addition to that we spent lots of time outdoors running, scooting, swimming and doing anything else we can think of!

Outside Help

In the early months post diagnosis I wish I had spoken to people with young children who had been where we were, and were managing CF as part of their lives as I found it hard to think ahead, and spent most of my maternity leave worrying and dreading the forthcoming years and what they would bring. I was too scared to talk to anyone for fear of what they were going through, and acknowledging we might be just at the start of a long and painful road.

I now belong to a wonderful online network of Irish CF mothers who are an incredible wealth of knowledge and support, no matter how large or small the problem is. Just the simple act of seeing other children with CF under-



"I know the questions from her will get smarter and tougher as she gets older and her understanding grows, I don't look forward to that, but for now she is accepting."



taking 'normal' childhood activities with gusto, managing the independence of school, taking holidays abroad etc helped me picture a future for my son that was not dictated by CF.

Unfortunately, the cruel nature of CF means that direct interaction with other CF parents and their children, is not an option, but it's here that the internet can come into its own. There are good discussion forums, and Facebook groups, twitter and YouTube can all offer informative and inspirational information from across the world. Certainly as a new parent I think picking sites that can offer constructive and accurate advice is essential, as the internet can be your best friend and your worst enemy.

Personally I take great comfort in researching CF, reading updates on drug trials and trying to educate myself as much as possible in the disease and what it can entail. Sometimes I marvel at how my bed time reading matter has changed over the past two years!

I can remember being told several times in the early months post diagnosis by our consultant, "Don't let CF stop you living the life you wanted for your child before diagnosis" and it was great advice (however hard it was to adhere to early on). I am now a firm believer in that, and aim to do just that for our son. Our hopes and dreams for him remain the same, I still want him to do all the things I hoped for him and aim to do everything I can within my power to ensure that he stays as healthy and happy as he is today!

We do, and always will, owe a debt of gratitude to Our Lady's Children's Hospital Crumlin for his emergency care after birth, and for his fantastic ongoing treatment from Dr Paul McNally and his CF team. It is not the path that I had thought we would be walking with one of our children, but I know that in the past 2 ½ years the care he has received here has been outstanding, and has helped him stay as healthy as he is...and for that I thank them.

Mayo's Most Inspirational Woman

By Martina Jennings, Mayo 'Person of The Year'

"Cystic Fibrosis had always been a part of our house, and nothing about the illness was ever hidden from us."

My Dad, Tony O'Toole was a founding member of CFI, and my mother Maureen O'Toole was the first Liaison Officer in the west for Cystic Fibrosis. Having lost their first son to CF, they saw a need to improve services for people with cystic fibrosis (PWCF), and instead of complaining about it, they both got up and did something about it.

This was years ago, and in a time when there was NO awareness about this illness, or support for families. Dad, along with the Mayo CF Consultant at the time, Dr. David O'Kane (RIP), fought for and secured two private rooms in the Paediatric ward in Mayo General hospital for all CF patients. To this day, these rooms are still available to PWCF in Castlebar. Mam saw a real need for parents of newly diagnosed babies to have someone to talk to. We spent our Sundays as children being packed into a car and driven to many a house, to meet these families. She provided a kind ear and valuable advice to these families. I know this, because so many of them came to us after she died at the early age of 48, and told us that she was their lifeline.

She left behind my Dad, my two sisters Caroline and Maria, and our two younger brothers Anthony and Billy aged 12 and 7. Billy, as well as being the baby of the family, also had Cystic Fibrosis.

Like most families who go through a loss like this, we pulled together as a team, and our instinct always was to look out for each other and mind each other as best we could. Caroline, Maria and I became mothers overnight to our two younger brothers. We had no experience of motherhood, but we had learnt from the best, and each of us brought a piece of Mam to An-



» Martina with her sisters Caroline and Maria, her brothers Anthony and Billy, and father Tony.

thony and Billy, supported by our Dad. We knew from our parents that all any child really needs is love and security, and that's what we tried to give the lads.

Cystic Fibrosis had always been a part of our house, and nothing about the illness was ever hidden from us. Also, Billy had been quite a 'good' CF.

I distinctly remember the first time that CF really reared its ugly head after Mam had died. Billy was about 9, and caught a really bad infection. He was admitted to Mayo General Hospital, and as he was too young to stay on his own, I stayed with him. I will never forget how much he shook with fear. Instead of sleeping on the floor mattress that was kindly provided, I opted to sleep beside him, hugging him tightly, until he fell asleep. This was just the first of many hospital stays that Billy had, and we all took our turns staying with him, until he got older, and it was no longer 'cool' to have us stay.

Billy is now 28, and in October 2010 he received a double lung transplant in the Freeman hospital, Newcastle. The transplant was a huge success. Unfortunately, 3 months later he contracted swine flu. He spent 9 days on life support, and we were given very little hope of him pulling through. But he did, and fought back to full health. In May of last year he had a massive brain haemorrhage. Yet again we were given very little hope, but after 2 weeks in a coma, he pulled through. Like all PWCF, he has an incredible, positive attitude. Also, his fighting spirit is unbelievable, and inspirational. I would urge everyone to go onto his website www.billycf.ie, and read his battles in his own words. You will be inspired, and humbled, and you are also guaranteed a laugh, as he has a wicked sense of humour.

Seven years ago, in 2008, my sister Caroline and I decided we really needed to do something for Cystic Fibrosis, and keep our parents legacy alive. We set up 'Friends of CF', and our aim was to provide support to PWCF and their families. We underestimated the support we would receive. It was incredible. We provided financial assistance and grants to PWCF. We met with the wonderful Dr. Michael O'Neill, CF Consultant in Castlebar, and asked him to tell us his wish for PWCF in the West. He very quickly told us that his wish would be to have a specialised clinic in Castlebar for PWCF. When he explained to us the difference that this would make to the patients, their families, and the amazing medical team, we promised him that we would grant his wish.

Very quickly afterwards we met with Tony Canavan, who was at that time, General Manager of Mayo General Hospital. We told him that we would build this clinic, if he would give us a site on the ground of Mayo Gen-



» Martina (right) with her daughter Rachel (left). Photo courtesy of Patricia Forde.

eral Hospital. He went away and thought about it, and came back to us with an amazing site to build our clinic. We then applied for planning permission, which was granted to us. At this stage we thought the cost would be €600,000, but to build a state of the art clinic, it was going to cost much more. We realised that we could not achieve this on our own. So we approached Philip Watt, CEO of CFI, who came to Mayo to meet with us. He recognised our passion and belief in the clinic, and the absolute need for it in Mayo. After that meeting, CF West was formed. The clinic is now built at a cost of €1.3m, and our dream is about to become a reality.

Although we started it, this would not have been possible without incredible teamwork and partnership between CF West, CFI, the HSE and Mayo General Hospital. The CF West committee consists of myself as Chairperson, Edel Fahey (Secretary), Tina Tuohy (Treasurer), Caroline Heffernan (CF Advocate and Fundraiser Extraordinaire), Tomas Thompson (CF Advocate and Project manager/Co-ordinator).



» The new outpatient unit in Mayo General Hospital is set to open shortly.



» Martina on receiving her 'Mayo's Most Inspirational Woman' Award. Photo courtesy of Patricia Forde.



» Inside the new outpatient unit.

The clinic has cost an incredible €1.3 million to build. We received generous funding from CFI and the National Lotto. However, €850,000 was raised from people in Mayo and beyond. This support has overwhelmed us. Remember we started this in 2008, when the Celtic Tiger decided to leave the country!!!

There have been so many fund-raising events organised, because people believed in us, and the need for the clinic. And we will never be able to thank everyone enough. The only reward and thanks we can give these people is by ensuring them, which because of their generosity of time and money, PWCF in Mayo now have a state of the art clinic to receive their treatment.

In the last 6 years since we started this project, 3 PWCF in Mayo have had double lung transplants, 3 PWCF are currently on the transplant list, and unfortunately 3 PWCF have passed away. We owe it to the memory of these patients that all PWCF get the absolute best treatment and facilities possible.

I want to say a special thanks to the hardworking medical team of Dr. Michael O'Neill, Lorna O'Connor (CF Nurse), and Mary Cunnane (CF Nurse), for the love and care they give our PWCF.

I want to finish by saying that the organisation that my Dad was a founder member of, CFI, has become an incredible support to all PWCF. The work that is being done by Philip and his team is incredible, and sometimes can go unnoticed. The life span of a PWCF has increased over the last few years, mainly due to the work done by CFI. We are now diagnosing patients at birth, fertility grants are being provided to PWCF and they are having their own families, we have CF advocates to provide invaluable help and advice to other patients, new drugs are becoming available thanks to the investment in research. It is for these reasons, that although the clinic in Mayo is now built, I pledge my support to CFI and the Mayo Branch in particular, to help in any way I can. I will continue to build on the foundations set by my parents all those years ago.

Note:

Martina was awarded with 'Mayo's Most Inspirational Woman Award' for her inspirational campaign to raise awareness of CF, as well as the pivotal role she played in developing the new outpatient unit for PWCF in Mayo General Hospital.

More recently, Martina appeared on the 'Today Show' on RTE and received a Local Hero Award. Nominated by her friend Philomena Noyes, who also appeared on the show, and they both spoke about CF and highlighted our upcoming 65 Roses National Awareness Week 20th-27th April. Watch the show here: www.rte.ie/player/ie/show/10385737/

Congratulations again Martina from everyone at CFI!

Spotlight

By Helen O'Sullivan, Age 37, Co Dublin

My name is Helen O'Sullivan (nee Whearity). I am married to Derek and we have one gorgeous daughter Emily. She is 9 years old. We live in Skerries Co. Dublin.

I was diagnosed with Cystic Fibrosis when I was five months old. Recurrent chest infections and little or no weight gain had a path worn to the GP. It was he who suggested a sweat test.

Fast forward 37 years and I can proudly say that I ran the Dublin marathon! It is for this reason that I am writing the article.

2014 was a great year for me. My first run of that year was 'The Great Ireland Run' in the Phoenix Park in April.



» Helen after finishing the half marathon on The Gold Coast.

It had been three years prior since my last run.

In 2011 I spent almost five months in hospital. One infection led to another and then bowel problems kicked off. A cancelled family ski holiday was a particularly low point for us. I spent the following year recovering, going to the gym and gaining strength.

In 2013 I began taking Kalydeco (Ivacaftor). This improved my lung function and general wellbeing to another level. All treatments for me remain the same; including chest clearance twice daily followed by nebulised antibiotics. At the end of 2013 with an air of confidence we booked flights to Australia to visit family the following June.

Feeling good after The Great Ireland Run I decided to train for a half marathon on The Gold Coast while on holidays. I was delighted with my finish time of 1:41:16.

When I returned from Oz I set my sights on the Dublin marathon in October. I followed a training programme. It consisted of three runs midweek with the long run on a Saturday morning and bike on a Sunday. I was very fortunate to have been able to train with friends that are experienced marathon runners.

Derek and Emily will say that I became a little obsessed with my training but it kind of needs that level of commitment. Apart from plantar fasciitis I was lucky to avoid injury. For the last few weeks of training I used the crosstrainer to avoid aggravating the condition of my foot.

On the day of the marathon I did everything as I had been doing for my long run. Chest clearance, sinus rinsing and then breakfast. I was so excited and nervous!

I found my place at the start line and had it in my head to keep the 4 hour time keeper balloons behind me at all times. Running past both Crumlin Children's Hospital and St Vincent's Hospital were particularly joyous for me. I never thought I would be running in the Dublin Marathon.

While keeping the emotions in place and running as fast as I could I crossed the finish line in 3:45:56. Those balloons stayed behind me!

I didn't run for a few months after that in order to recover. I did however start strength and conditioning in the gym and continued on the bike when weather allowed.

It is with great honour to take part in the campaign for the mini marathon in June for CFI. It has given me a goal and I am back running!

Note: Many congratulations again to Helen who won a 'People of the Year 2014' award from Ireland's Adventure Magazine, Outsider. Helen was nominated for the award given her huge determination and achievements in spite of her illness.



» Keelin Shanley with Helen, Ambassador for the 2015 One in 1,000 Campaign.

Fundraising

Challenges and Events

65 Roses National Awareness Week: April 20th to April 26th

Why 65 Roses?

'65 Roses' is how some children first learn how to say 'Cystic Fibrosis'. The symbol in Ireland for '65 Roses Week' is a purple rose.

What can you do to support 65 Roses Week?

1: Text '65Roses' to 50300 to donate €2 to Cystic Fibrosis Ireland

(Note: 100% of the cost goes to charity across most network providers. Some providers apply VAT which means a minimum of €1.63 will go to CFI, Service Provider: Like Charity, Helpline 076 680 5278)

2: Support the '65 Roses Challenge'

Organise a fundraising event in your area using a '65' theme if possible e.g. walk 6.5km, cycle 65km, ask your company to donate €6.50 for every employee who donates to Cystic Fibrosis, have a coffee morning and ask people to donate €6.50 for coffee and cake, remember the sky is the limit, so get creative and set your own challenge.

Share your challenges with us on Facebook @CysticFibrosisIreland

3: Buy a CF Purple Rose

Our CF Ireland volunteers will be out and about in many shopping centres around the country during 65 Roses National Awareness Week from April 20th to 26th and they will be selling the CF Ireland Purple Silk Roses. We encourage everyone to buy a Purple Rose and show their support for Cystic Fibrosis Ireland.

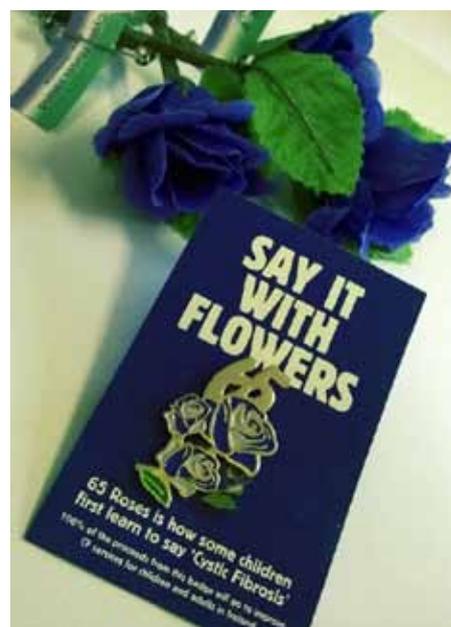
Montenegro Walk: Sept 27th – Oct 4th

2015 marks the 21st year of the International Walk for CFI. What better location for the anniversary walk to take place, but Montenegro. We are delighted to announce that singer Mary Duff will reprise her role as Ambassador and take part in the 2015 Walk. The price of the walk is €2,900 and this covers flights, bed & breakfast accommodation, dinners and guide. The walk is guided all the way so You Will Never Walk Alone.

So, if you fancy a challenge, want to make new friends or simply want to take in the spectacular scenery of Montenegro, the 2015 International Walk could be for you! For more information on last year's Montenegro Walk, see page 27 in this issue or log onto www.cfireland.ie



» 65 Roses Challenge



» CF Ireland Purple Silk Roses

One in 1000: June 1st

Are you One in 1,000?

The VHI Women's Mini-Marathon takes place on Monday, June 1st. It is just months away, but we still need participants. So, rally your friends and family and register a team to take part! This year, we are delighted to have three fantastic Ambassadors to motivate and encourage you along the way; Ben Mudge, PWCF and personal trainer, Helen O'Sullivan, mother, PWCF and marathon runner, and Natasha Darcy, a mother, PWCF and double lung transplant recipient.

Follow in their footsteps and register to take part today and raise funds for CFI. Whether you choose to run, jog, walk or crawl the 10km route, it is the taking part that counts. The first step is the hardest, but with a team of 1,000 supporting you we guarantee you will cross the finish line and have fun while doing it!

Register at www.vhiwomensminimarathon.ie to receive your race number and medal.

Register at www.cfireland.ie to receive your sponsorship pack.



» Join Ambassador Helen O'Sullivan on June 1st and be One in 1,000!



Row-A-Round Ireland — We Need YOU!

If you've ever rowed a boat on a lake you'll know it's tough going. Now imagine rowing a boat around Ireland. How long do you think that would take? 2 weeks, maybe a month...actually it's closer to 120 days. So, who and why would you want to do a thing like that, especially in our 'change-able' weather? Well, 20 brave volunteers from across Ireland will be doing so as part of the 'Row a Round Ireland' challenge. And it's all in aid of Cystic Fibrosis Ireland.

The gruelling challenge is the brainchild of Bray man and maritime enthusiast, Ger Crowley. Last year he began the project of building the boat as part of a much larger community programme involving local children and adults. And now, that boat will be rowed around Ireland with the aid of dozens of novice rowers and professional back-up teams. All money raised will be donated directly Cystic Fibrosis Ireland; a charity close to Ger's and the other team members' hearts.

The challenge kicks off from Bray Harbour, Co. Wicklow on May 30th 2015 and will be completed approximately 4 months later. A two-rower crew will have to average 20 miles per day and navigate the some 1,000 miles of rough but beautiful seas off our coast. There will be stopovers in over 60 towns and villages in Ireland, sheltering in tents, jeeps and B&Bs if they're put up for the night.

We need YOUR HELP to make it a success. We want you to participate in any way you can. Ask your business to help out, raise awareness with your friends/family and hopefully donate something to this worthy cause.

More info on the project, the team and how to get involved can be found on the website: www.rowaroundireland.com

Challenge the Greenway

Challenge the Greenway is a joint fundraising event between CF West and CFI. Challenge the Greenway is a 26 mile cycle from Achill Sound to Westport House. The event will take place on Saturday the 25th April leaving Achill at 11am. Light refreshments will be served at the end of the cycle. Register via Eventbrite on www.challengethegreenway.com.



» Take part in the 'Row-A-Round Ireland challenge for CFI!



World War One Walk: May 15th to 17th

Join this unique walk in Flanders, Belgium some 100 years on from World War One, to get a better understanding of 'The Great War' from an Irish perspective. The 14km walk will take place along the Messines ridge where soldiers from Ireland (North and South) fought together in the battle of Messines in 1917. By joining this walk, your fundraising will help the Cystic Fibrosis Transplant Fund and a new post in the Mater Hospital, where lung transplants are undertaken in Ireland.

We will be joined on the walk by Myles Dungan, Historian and Broadcaster for RTE, who will provide us with insightful information about the Irish involvement in World War One.

The cost of registration is €450 which will include return flights, hotel accommodation and breakfast, coach connections, and an afternoon trip to the beautiful city of Ghent. Those who register will also be required to fundraise a target of €450.

If you are interested please email fundraising@cfireland.ie or call our office on 01 496 2433. Registration forms can also be downloaded from our website www.cfireland.ie

Paris2Nice: Sept 18th to 24th

We already have a team of 5 cyclists participating in the Paris2Nice Charity Cycle which takes place from Sept 18th to 24th. Places are now almost all gone for this event so if you are interested, register now at www.paris2nice.com. You do not have to be an accomplished cyclist to take part in this event and it a unique and exceptional experience with over €1.9m raised for various charities by 244 amateur cyclists over the last four years.

TCS New York City Marathon: Nov 1st

Cystic Fibrosis Ireland have pleasure in outlining details of our tour to the TCS New York City Marathon. Walkers as well as runners are welcome to participate. The marathon starts on Sunday November 1st from Staten Island, and runs through all 5 city boroughs (Staten Island, Brooklyn, Queens, The Bronx and Manhattan).

Our travel partners, Sports Travel International, have an allocation of entries and so we can offer you a guaranteed entry as part of our tour package, regardless of your previous times (if you have any). With 2 million spectators and a carnival atmosphere, the TCS New York City Marathon is an unforgettable experience.

We advise immediate booking in order to guarantee your place. Non-running companions are also welcome on the tour. If you would like more details please email Peter at pminchin@cfireland.ie or call our office on 01 496 2433.

One of our supporters, Ciaran Priestley, took part in the NYC Marathon in 2014 in memory of his sister Triona (RIP). You can read his blog by following the link below to hear all about the wonderful experience that he had as a participant in 2014.

www.fairytaleofnewyorkcitymarathon.wordpress.com



» Island of Ireland Peace Park Messines



» Paris2Nice Team 2014



» NYC 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.

PDF4CF

Pat Divilly has spent the past 12 months entirely committed to his role as our charity ambassador, working closely with our fundraising team in setting an ambitious target of €100,000 by entering the world's largest team in Ireland's first ever 'Tough Mudder Challenge'. We call it a 'team' lightly; it was more like an army, an army known to the world as 'PDF4CF' (Pat Divilly Fitness for Cystic Fibrosis). Pat rallied the troops and on the 5th of October 2014 a team of over 540 took on one of the most gruelling and demanding challenges known to man — raising an amazing €165,000 in the process!

Funds raised through this initiative will contribute greatly to two separate projects;

- a) CFI Exercise Grant
- b) Galway Hospital Project

A huge thank you to Pat and everyone from CF Galway who worked on this amazing fundraiser which is shortlisted for the National Awards for Excellence in Fundraising 2015 by Fundraising Ireland for 'Best use of Digital in Fundraising'.

Gary Dillon Valentine's Ball

Organisers of The Gary Dillon Valentine's Ball were thrilled with how well the event went with 300 in attendance on Saturday 14th February. The ball was held to raise funds for Cystic Fibrosis Ireland, in memory of well known Sligo man Gary Dillon, who passed away last year.

Gary died on Valentines Day 2014 aged 31, from Cystic Fibrosis. He was a well known sports man and was also well recognised for his trojan work in campaigning for organ donation. It was through his work in promoting organ donation that Gary befriended GAA pundit Joe Brolly, who was there on the night. Dublin footballer Michael Darragh McAuley, and former Sligo footballer Eamonn O'Hara were also both special guests at the ball in the Radisson.

Well done to everyone involved in organising this fantastic fundraising event.

Duet for One

A huge thank you to Brenda Larby and Mick Shanley who raised over €800 for Cystic Fibrosis Ireland by donating proceeds from the premier of *Duet for One*, a play by Tom Kempinski in which they both starred.



» PDF4CF Shortlisted for National Awards for Excellence in Fundraising 2015



» Fresh RÉ performing at the Gary Dillon Ball in Sligo



» Duet for One



» Cheque presentation from UCD Medical Society

UCD Medical Society

WELL DONE to the UCD Medical Society who held bucket collections all around Dublin in aid of a number of charities and presented a cheque to CF Ireland for €2,500. Pictured above is Aoife McEvoy (UCD), Nuala McAuley (CFI), Samuel Kehoe (UCD) and Peter Minchin (CFI).

VIP Ireland

We are delighted to announce that VIP Ireland have selected us as the 'Chosen Charity' for 2015 and will be supporting us through the year with fundraising events.



» Mark McArdle, Operation Transformation

Intact Software — Mark McArdle

Congratulations to Mark McArdle who finished his Operation Transformation journey with a weight loss of 2st 9.5lbs! Mark was awarded the Silver Axe from the Dublin Fire Brigade on the final show in recognition of his leadership, courage and determination during the series!

We would like to thank Mark for picking Cystic Fibrosis Ireland as his Chosen Charity with his employer Intact Software donating €150 for every 1lb lost by Mark during the show up to a maximum of €5,000. As with all his targets, Mark exceeded the target with a total weight loss of 37.5lbs ensuring he raised €5,000 for CF from his employers.



» Cheque presentation from DAA

DAA — Charity of the Year

CF Ireland would like to say a massive THANK YOU & WELL DONE to the DAA and all their staff who over the past year fundraised a total of €210,000 of which CF Ireland received €70,000. The Jack & Jill Foundation & Special Olympics Ireland were the other charities to benefit.

The DAA staff organised many events throughout the year such as cycles, raffles, and even a Strictly Come Dancing Night to mention just a few.

Well done to all involved, your support is greatly appreciated!

The Sweets for Charity Project

We would like to take this opportunity to extend our thanks to Liam Fahy and Maura Ahern for their continued support of Cystic Fibrosis Ireland through The Sweets For Charity Project with a new agreement recently put in place for 2015.

If you would like to organise a fundraising event in aid of CF Ireland either on your own, with your friends, in your workplace or in your school we would love to hear from you. You can call our office on 01 496 2433 or e-mail fundraising@cfireland.ie

Alec Sammon Dublin City Marathon 2014

Cystic Fibrosis Ireland would like to thank Alec Sammon and his daughter Clara for their amazing fundraising efforts for CFI. Alec took part in the Dublin Marathon, raising €579 for CFI to help benefit and support the quality of care PWCF receive in Ireland.

Well done Alec and Clara!



» Alec and Clara Sammon

Kerins Pharmacy Fundraiser

Thanks to Kerins Pharmacy in Blackrock who ran a successful fundraising day before Christmas and raised a fantastic total of €1,000. Pictured to the right is Marie Haughey from Kerins Pharmacy presenting the cheque to Peter Minchin from CF Ireland.

If your workplace would like to hold an event in aid of CFI we would love to hear from you. You can call our office on 01 496 2433 or e-mail fundraising@cfireland.ie



» Kerins Pharmacy cheque presentation

The Hills Were Alive With the Sound of Music

» International Walk Report

Bright Eyed and bushy tailed we all arrived at Dublin Airport by 5am on Saturday September 20th. There was great delight at renewing acquaintances with old friends and greeting very welcomed new walkers. We formally welcomed with great joy Mary Duff, our patron, and Steve Milne her musical partner and then set about grabbing an early morning coffee on our way down to the departure gate for our flight.

We arrived in the middle of the afternoon to a very beautiful hotel embellished in Austrian flavour with its timber facade and its extremely pleasant staff, many of whom were in traditional Austrian attire. Zell am See is the administrative capital of the Zell am See District in the Austrian state of Salzburg. It is a very important and popular tourist destination.

Suitcases quickly to the rooms, a short freshen up and the most enthusiastic among us set about a taster walk to stretch our legs and examine the locality. Immediately it was obvious that we were in a very special place. We took a trail from behind the hotel up to a height that afforded us our first view of the lake.



» Walkers on the trip

The next day we met up with our local guide for a walk around the lake and were introduced to sites where some of 'The Sound of Music' was filmed and learned about not just the Von Trapp Family links with Zell am See, but also that of the Porsche Family. The home of the Porsche family was extremely interesting and I'm sure it was all the more meaningful especially to all the Porsche owners among us, none of whom declared themselves. A heavy shower of rain didn't stop us. It was such a beautiful walk that on

arrival back to hotel some walkers decided to grab bicycles and do it all over again.

Monday was a visit to the city of Salzburg and our walking tour incorporated the experience of more of the sites relating to the Sound of Music film. The main points being The Mirabell Gardens, Hellbrunn Castle and Lake Wolfgang. It was quite noticeable however that Salzburg was much more boastful about being the birth place of Wolfgang Amadeus Mozart.

Tuesday was perhaps one of the most enjoyable days of our journey. We met up with our local guide Burgi who led us to the cable car to bring us to 2000 meters up Schmittner Mountain with its crisp reinvigorating cold fresh air. It was enchanting to experience this snow covered arena. The walk along the mountain track was absolutely exhilarating and some walkers not wanting the day to end opted to walk back down the mountain instead of using the cable car. When we got back down to our hotel in the evening we were in great form for our annual honorary walk award night, which is a presentation night when special recognition is made to a walker that has actively participated in many of our previous walks and thus raising considerable funds for the cause. We also had a moment of solemnity which reminded us why we were on the fundraising walk in the first place. It was with great excitement we all heard that Caroline Dunphy from County Kildare was the winner for 2014. She has along with others done trojan work in fundraising.

After an early start on the Wednesday we moved to our new base which was Bad Vöslau, a spa town located about 40 minutes from Vienna. We stayed in a beautiful fresh old style periodic hotel. Spa water was available to drink from the ornate tap across from our accommodation. Our walking tour on the first day here in the immediate vicinity was very pleasant. Thursday we had a walking tour in the City of Vienna (with an opportunity to visit among many sites the magnificent Schonbrunn palace). Friday the final walking day in the Vienna Woods was tough but magical.

The Austrian welcome was magnificent and the scenery was breath-taking. Perhaps a little mention of the apres walk experience is justified. Foremost we were delighted to experience the beautiful singing of Mary Duff. This was accompanied by a traditional Austrian dance performance, a quiz night organised by Claire Barrett and Catherine Brien and indeed The X Factor night organised by Bernie Murphy. The final evening all walkers were presented with their certificate and tokens to thank them for all their fundraising efforts. We left Austria heavy hearted but took with us beautiful memories and great satisfaction having completed yet another successful walk and raising much needed funds for CF Ireland.

Our 2015 walk is to Montenegro and it promises to be just as special. We have plenty of room and need for more walkers so come with us you can make the difference.

The Walk Reporter

New Faces in Fundraising

Introducing Fergal Smyth, Fundraising Manager, CFI

Fergal was appointed Fundraising Manager for Cystic Fibrosis Ireland in January 2015, having previously worked as Fundraising Manager for The Asthma Society of Ireland. He moved to the Charity Sector following a long successful career in the Grocery Sector, having worked for Valeo Foods, Nielsen Ireland and Unilever UK. He is a graduate of Letterkenny IT (H-Dip in Marketing & Small Business Management) and Sligo IT (Diploma in Business Studies).

Fergal is really looking forward to working with everyone in Cystic Fibrosis Ireland, both in CF House and in the branches around the country. He confirmed that he has been inspired so far by the great work being done by volunteers fundraising across the country to help people with Cystic Fibrosis. "The amount of fundraising work carried out at a local level for Cystic Fibrosis is phenomenal. The CFI fundraising team look forward to working closely with everyone involved and helping continue to drive forward fundraising for CF".

If anyone wishes to contact me, my details are as follows:

e: fsmyth@cfireland.ie

t: 01 496 2433



Introducing Nuala McAuley, Events & Digital Fundraising Co-ordinator, CFI

Nuala joined Cystic Fibrosis Ireland in 2015 as Events & Digital Fundraising Coordinator. In her previous role, within the charity sector, Nuala worked in a number of areas including fundraising, publications, digital media and event management. Nuala graduated from Griffith College in 2007 with a Diploma Sales, Marketing, Public Relations and Advertising and went on to study Digital Marketing and Online Strategy in Dublin Business School.

Nuala will be focusing on the 1 in 1000 mini-marathon campaign here at CFI. If you would like to sign up for this year's event, contact her now!

e: nmcauley@cfireland.ie

t: 01 496 2433



Support the "65 Roses Challenge"

Cystic Fibrosis National Awareness Week
April 20th - 26th 2015



Are you up for the challenge?

Organise a fundraising event in your area - you might even use a 65 theme!

- Take part in a skydive from 6,500 feet
- Create a mini-marathon: swim 65 laps, run 6.5 km, cycle 65 kms
- Ask your company to donate €6.50 for everyone that donates to Cystic Fibrosis
- Gather friends for a mega 65 holes of golf

Remember, the sky is the limit so feel free to get creative and set your own challenge

Share your challenges with us on Facebook @CysticFibrosisIreland

Contact us now!

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