

SPECTRUM

Published by
Cystic Fibrosis Ireland



IN THIS ISSUE:

- Update on Building Developments at CF Centres
- New Dublin West Branch
- Spotlight on Neil McCarthy from Ballyshannon Co Donegal
- Dealing with Diagnosis, a Fathers Perception
- The Circle of Life is Complete and Life is Good, Helen Ryan-Lawless
- Volunteers Needed for National Awareness Week 2015



The Circle of Life

'The circle of life is complete and life is good' are the concluding words in the remarkable article by Helen Ryan-Lawless in this issue of *Spectrum*. We are not certain, but we think that Helen is the first person with CF in Ireland to become a grandmother. Helen's daughter Elizabeth was born 30 years ago this month and we also think she may have been the first baby born to a person with CF in Ireland. Many congratulations on a possible 'double first' to Helen, David, Elizabeth and baby Ryan!

We also hear from surf enthusiast Neil McCarthy, PWCF age 13 from Ballyshannon Co Donegal, who appears on the cover this issue. Neil is an inspiring young man whose resilience and accomplishments will be motivating and encouraging for other young PWCF. Ronan Whitmarsh also gives a moving account about how he dealt his son Finns' diagnosis of CF earlier this year — this is a must read for all new dads.

Many congratulations also to the Dundalk, Drogheda and Meath Branches and to Manfredi Anello (architect) as the Drogheda CF Paediatric outpatient unit won a silver award in the Royal Institute of the Architects of Ireland. Congratulations to CFI Galway Branch which won a commendation for 'Patient Organisation Project of the Year' in the recent Irish Healthcare Awards.

Once again it's great to report on all the progress around the country, not least the fact that there have been 17 CF double lung transplants undertaken this year to date by the Mater Hospital, almost double the figure for last year (9). It is a truly remarkable record and demonstrates that our community's support and confidence in the Mater programme was the right one.

Many thanks also to the record breaking 60 people who took part in Dublin City Marathon this year for Cystic Fibrosis Ireland, you are an inspiration to us all.

Wishing you seasonal best wishes and merry Christmas from the staff and the Board of Cystic Fibrosis Ireland and thanks to all the clinicians and their teams for their hard work and care for CF during 2014.



Philip Watt (CEO)
Alica May (Editor)

Front Cover: Neil McCarthy from Ballyshannon Co Donegal, see Spotlight page 19.

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

Section 01:

LATEST NEWS:

Page 2—5

Update on Building Developments at CF Centres

Northern Ireland Rare Disease Plan Launch

CF Foundation Announces Unprecedented Acceleration and Expansion of CF Research, Care and Patient Programs

Transplant News

Survey on Fertility Treatment Supports and CF

Meet Niamh, Our New Office Administrator!

New Look Website

CFI Christmas Cards

CFI Annual Conference 2015 — Save the Date!

--

Section 02:

RESEARCH: Page 6—7

Focussing on Patient Participation; from Drug Development to Patient Access

Channel 4 Report on New Potential Treatment Option for PWCF

--

Section 03:

INFORMATION/ SUPPORTS: Page 8—11

State Supports for People with CF

Diabetic RetinaScreen — The National Diabetic Retinal Screening Programme

Medical Card Review Process — Recent Announcement

Long-Term Illness Book Update

7th Annual National Conference of the Irish Research Nurse Network

--

Section 04:

BRANCH FOCUS:

Page 12—13

New Dublin West Branch, By Marie Duffy, Chairperson, Dublin West Branch

--

Section 05:

DAD'S CORNER: Page 14—16

Dealing with Diagnosis, a Fathers Perception, By Ronan Whitmarsh

--

Section 06:

SPOTLIGHT: Page 17—20

The Circle of Life is Complete and Life is Good, By Helen Ryan-Lawless

SURFING — Natural Therapy! By Claire and Brian McCarthy on behalf of their son Neil, PWCF, age 13 from Ballyshannon, Co Donegal

--

Section 07:

FUNDRAISING:

Page 21—29

Challenges and Events

McCabes Pharmacy Charity Gift Wrapping Service

Thank You

Volunteers Needed for National Awareness Week 2015

CF Ireland Fundraising Notice!

--



Update on Building Developments at CF Centres

There continues to be good progress on buildings for better CF services in Ireland. The table below highlights these projects, including input from local CF charities.

Building Project	Status	Partners involved
Drogheda <i>Paediatric Outpatient Centre</i>	Opened and fully operating. The HSE have recently confirmed that it meets all its standards and it will be transferred to the hospital shortly. There has been an increase in three children attending since the new building opened earlier this year.	CFI/LM ₄ CF/Hospital/HSE/Lottery
Mayo General Hospital <i>Outpatient Unit</i>	Work commenced January 2014. Due to be completed in early 2015 and progressing well	CFI/Mayo West/HSE/Hospital/Lottery
University Hospital Limerick <i>Outpatient and InPatient Unit (adult)</i>	Core of building nearing completion. Clarification being sought re HSE support for fit-out and running costs	CFI/TLC ₄ CF/Hospital/Leben
University Hospital Waterford <i>4 room Inpatient unit (paediatric)</i>	4 room unit in UHW is substantially complete and is being equipped out at present and should be ready for operational use after Christmas	CFI/CFI Waterford Branch/Hospital
Cavan General Hospital <i>(paediatric)</i>	Outpatient suite completed April 2014. Proposal to upgrade two paediatric rooms under discussion	CFI/CFI Cavan Branch/Hospital
Beaumont Hospital <i>(adult)</i>	Three additional rooms provided following lobbying by CFI and CF Hopesource (separate charity) in July 2014. Plans for 20 room inpatient unit being developed (see below)	CFI/CF Hopesource/Hospital
Cork University Hospital <i>(adult)</i>	Adult inpatient ward nearing completion	Build ₄ Life (separate charity)
Cork University Hospital	Support for CF research	CFI Southern Branch

Beaumont University Hospital

A five storey building including one floor with 20 dedicated rooms for PWCF has been identified as a priority by Beaumont Hospital. This is the first firm commitment for a CF inpatient facility by the hospital.

It will be part of a project that will include high dependency rooms for other patients. The timescale, providing everything goes to plan, is commencement in 2016 and completion 2017. Considerable work still needs to be undertaken to ensure this project is fully realised. Following lobbying by CFI and CF Hopesource, there are now 7 inpatient rooms – an improvement on the 4 rooms that used to exist, but inadequate to meet the demand for the 150 patients now attending Beaumont Hospital.

Cork University Hospital

The new CF adult inpatient facility funded by separate charity, Build4life, is now nearing completion. CFI (Philip Watt CEO and Cathy Carlton, Southern Branch) recently met with management and clinicians in Cork. They thanked CUH for recent progress, but highlighted ongoing staff shortages and the need for urgent action to develop a new CF paediatric inpatient and outpatient unit. We understand that a new paediatric tower (forthcoming development) will improve overall paediatric services in CUH, including for PWCF and their families. *Spectrum* will update you further on this in future issues.

Hospital management in CUH and clinicians highlighted the importance of the €130,000 provided by the CFI Southern Branch towards CF dedicated over the past 2 years.

University Hospital Limerick

The building work continues in University Hospital Limerick (UHL). Further clarification is being sought on the resources for fit-out and equipment — resources which had been expected from UHL/HSE. To date, CFI/TLC4CF have raised €5.2 million for this project, including fantastic support from JP McManus Pro Am Tournament. Further updates in the next issue of *Spectrum*.

Northern Ireland Rare Disease Plan Launch

CF is recognised as rare disease worldwide and there is significant untapped potential for improving cross-border co-operation in Ireland on CF care and research (and other rarer diseases). The recent Northern Ireland Rare Disease Plan Launch in Stormont was a good opportunity to raise these issues for all rare diseases.



NI Minister for Health Jim Wells, MLA, Christine Collins NI Rare Disease Partnership and Philip Watt representing the Rare Disease Task Force (Ireland) and Alistair Kent UK Rare Diseases.

CF Foundation Announces Unprecedented Acceleration and Expansion of CF Research, Care and Patient Programs

On Wednesday the 19th of November the Cystic Fibrosis Foundation (CFF) announced what they consider to be a 'transformational moment in the journey to cure Cystic Fibrosis'. The CFF is to receive US\$3.3 billion through the sale of its royalty rights to CF treatments developed by Vertex Pharmaceuticals Inc. to Royalty Pharma.

The CF Foundation have taken a unique approach to speeding up medicines development by providing upfront funding to research and develop therapies to tackle CF. In the 1990s, the CFF took an unprecedented risk by investing US\$150 million into a small biotech company called Aurora Biosciences, which was later acquired by Vertex Pharmaceuticals — responsible for the development of Kalydeco.

The CFF Chief Executive, Robert Beall has said that the Foundation will use the US\$3.3 billion to support further research into a cure for Cystic Fibrosis; "These new resources will allow us to supercharge our efforts to help all people with CF live long, healthy and fulfilling lives today and work to find a cure".

Transplant News

There have been 17 CF double lung transplants undertaken in Ireland this year in the Mater Hospital.

This is by far the greatest number of transplants undertaken since the transplant programme was established. This represents an almost doubling of the number of CF double lung transplants undertaken in Ireland in 2013.

A key issue for all forms of organ transplantation in Ireland remains the need for more organs, so we would encourage everyone to indicate to their next of kin their wish to donate and to carry an organ donor card.

Reminder If your loved one receives a transplant, be sure to contact us here in Cystic Fibrosis Ireland to avail of the transplant grant.

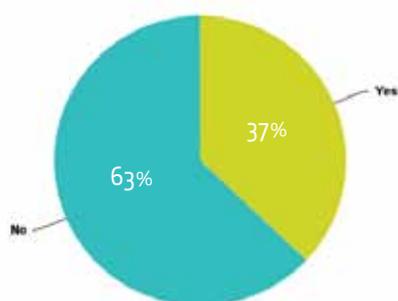
Survey on Fertility Treatment Supports and Cystic Fibrosis



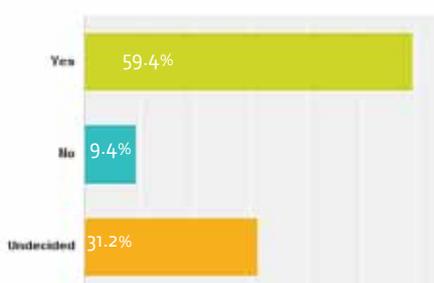
Cystic Fibrosis Ireland circulated a survey to all people with CF over the age of 21 in November on 'Fertility Treatment Supports and Cystic Fibrosis'. Thank you to all 112 of you who responded!

With the outlook constantly improving for people with CF, parenthood is becoming a realistic option for many. The survey was circulated to gain an insight into the experiences of people with Cystic Fibrosis who have pursued fertility treatment, and from those who may consider starting a family at some point in the future. We hope that this piece of research will help us identify the barriers or challenges of those who have already gone down this road yet also to determine any supports received along the way. We also asked people to respond who have not yet embarked on this journey.

Do you feel well informed about fertility options available to PWCF?



Would you consider PGD as an option if pursuing fertility treatment?



Preliminary results

Preliminary findings reveal that most people with CF (63% of survey respondents) do not feel well informed about fertility treatment options. About a quarter of respondents have pursued some form of fertility treatment (IVF, ICSI).

When asked about the barriers or challenges of those who pursued fertility treatments, most respondents alluded to the financial and emotional toil of the process. Several members also reported that the fertility clinics did not have a good understanding of CF, and its impact on fertility.

According to one respondent, "Having CF and having to undergo IVF which when it does result in failure makes one often feel guilty that you are depriving your wife of children. The cost adds to this as well as the huge emotional stress which can test a relationship significantly. If the cost burden was reduced it would help as one could go again without crippling oneself financially."

Approximately 95% members agreed that the state should make fertility treatments available to people with CF who experience unique reproductive challenges as a result of their medical condition.

It is hoped that the information gathered from this survey will be used to inform an advocacy document, which will be communicated to the Department of Health outlining the case for why fertility treatment should be made accessible to people with CF who may require assistance. It will also enable us to identify information gaps, and help us to respond accordingly to the needs of our members.

We will convey further result to you in the next issue of *Spectrum* and will make the final document available once completed in 2015.

Meet Niamh, Our New Office Administrator!



I am delighted to have begun working with Cystic Fibrosis Ireland in September 2014 as Office Administrator.

My role includes ensuring the efficient running of the Cystic Fibrosis Ireland national office, including secretarial duties, financial and general administrative support. I am also responsible for supporting and co-ordinating special events and providing assistance to the management team. I have 5 years' previous experience in the non-profit sector including working as a carer for children with tracheostomy which I found very tough, but at the same time I feel passionate about working in this area and understand the challenges that come with it.

I enjoy supporting new and existing members both in and out of the office and since starting with CFI, I have been overwhelmed as to the amount of support that members have shown throughout all the branches.

The team here at CFI are a lovely group to work with. I am looking forward to getting to know everyone a little more in 2015.

New Look Website

Our website is undergoing a bit of a facelift this month! Sections will be easier to access from the homepage and new information has been added.

The new website will also be mobile friendly, which is how most people access information online these days. These changes should be implemented by the middle of the month so log on, check it out, and let us know what you think!

Nov/Dec 2014

CFI Christmas Cards!

Our annual CF Ireland Christmas Cards are now on sale! There are 6 different packs of Christmas cards available — each pack contains 8 cards of the same design and cost €6.99 each (not including postage).

Buy them on our website (www.cfireland.ie) now or alternatively call our office on 01 496 2433 to order them.

All proceeds will be going direct to vital CF services and support.



CFI Annual Conference 2015 — Save the Date!

The CFI 2015 Annual Conference will take place from 10th-12th April 2015 in the Limerick Strand Hotel.

As with previous years we plan to have informative and topical seminars that will be beneficial to all of our members as well as a sociable weekend for members to have a break and catch up with friends.

Booking forms and additional details for the Conference will be open in January 2015. Additional information for bookings and conference programme will be provided in the next issue of *Spectrum*.



Focussing on Patient Participation; from Drug Development to Patient Access

By Katie Murphy, Research and Development Officer at CFI

November was certainly a busy month, perhaps it is an unofficial 'conference month', as there were numerous exciting meetings and conferences happening throughout Europe, two of which primarily focused on access to new therapies. First up on the agenda was the European Congress for the International Society for Pharmacoeconomics and Outcomes Research (ISPOR), which was held in Amsterdam. Last year Dublin played host to this impressive event which sees over 4,000 delegates gathering from across the globe to discuss the latest in health research, drugs/therapy development, health economic assessments, etc. In 2013 the breakthrough CF drug Kalydeco was certainly a hot topic throughout the event, which was reflected in the programme of events. The opening plenary session in 2013 was 'The Patient and Health Technology Assessment: Challenges and Opportunities', using Kalydeco as an example. It was remarkable how surprised the delegates were to hear a patient speaking about this topic and even more startling how few patient representatives were in attendance. Of the 4,000 delegates in attendance, an expert-patient round table discussion of about 20 people was established to promote the patient perspective in all aspects of medicines development. One year later and the 2014 agenda certainly had a greater focus on the need to capture more 'real-life', 'patient-centric' evidence and to have it included in Health Technology Assessment (HTA) when assessing the effectiveness of new therapies. It is reassuring to hear the discussion about patient involvement is happening from the top down, with senior members of organisations like the European Medicines Agency (EMA), the FDA and other regulatory bodies advocating for greater involvement of patients in all aspects of medicines development.

Similarly, the World Orphan Drug Congress 2014 took place last month which starkly reminds us of the difficulties facing rare and ultra-rare diseases with regards to drug development, pricing and patient access. Speaking with patient representatives from ultra-rare disease groups is a reminder just how far we have come in the treatment and management of CF. Many illnesses have no treatment options available for patients, with little or no funding available or being invested in research/drug development. The Cystic Fibrosis Foundation's model of venture philanthropy model, through which the organisation provides upfront funding for pharmaceutical companies to help reduce the financial risk of developing drugs to treat CF, is a great example of patient groups leading the way in medicines development – but for some patient groups, representing as few as 20 patients in a country, this is not a feasible model to adopt. So although there has been a growing focus on cost-effectiveness accessing new therapies for patients, for many rare disease groups, accessing new therapies is not currently on their agenda.

Growth in the number of new therapies in the pipeline for CF means it is more important than ever to keep up-to-date on current practices in health assessments and also ensure that patient views are constantly represented with all stakeholders; industry, regulators, and payers.



For more information:

Health Technology Assessment (HTA) guidelines:
www.ncpe.ie/submission-process/hta-guidelines/

Channel 4 Report on New Potential Treatment Option for PWCF

On the 11th of November, Channel 4's Jon Snow reported about recent Phase 1 trial results of potential treatment option for people with CF. The research project, which is being undertaken by Dr Anil Mehta from the University of Dundee, was described as a 'Eureka moment' that offered the hope of a 'cystic fibrosis cure'. Understandably there was a stir of excitement amongst the CF community after the report was released. However, we have been having a closer look at this promising research and would like to take this opportunity to highlight some important points about this research news.

According to the University of Dundee's press statement this research is an early stage clinical study being undertaken in Italy, which has trialled the combined use of two drugs already licensed for use in other conditions – Cysteamine, and epigallocatechin gallate (EGCG) – involving 10 people with CF, with two copies of the DF508 gene. This statement from the university says that the study found that the combination of the two aforementioned drugs reduced inflammation in 9 out of 10 patients' airways and also reduced sweat chloride levels – these promising results certainly warrant further investigation but it is important to remember this is an early stage trial with a very small sample.

The CF Trust, who provided funding to the earlier stages of this research, have also spoken out around the report and have said "talk of a potential cure was misplaced", to which Dr Mehta (lead researcher) also agreed.

What happens next?

Dr Mehta is now hoping to bring this work to a larger Phase 2 research study involving 120 patients. The CF Trust have also told us that Dr Mehta is planning to submit a funding application to the UK Government's Medical Research Council for support, however, there are a great number of regulatory hurdles the work will have to overcome first.

Although this initial research indicates positive results, it is important to remember that drug development is an incredibly slow and expensive endeavour and positive results at the early stages of development does not guarantee success in clinical terms further down the line.

In summary, the potential outcomes from this project are exciting, however it is clear that the media's portrayal of this research project as a possible cure for Cystic Fibrosis is premature and misleading.

For more information:

To read the CF Trust statement about this research news visit this link: <http://cftrust.blogspot.ie/2014/11/a-cystic-fibrosis-cure-understanding.html>

To read University of Dundee's official press release visit this link: www.dundee.ac.uk/news/2014/new-strategy-to-treat-cystic-fibrosis.php

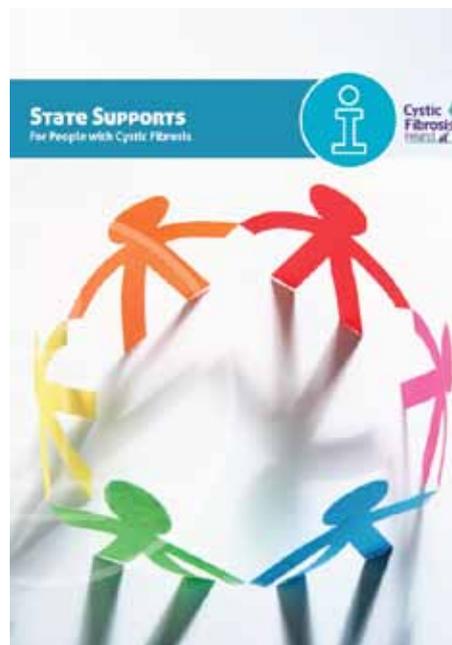
State Supports for People with CF

A new information booklet on 'State Supports for People with Cystic Fibrosis' is now available. This booklet was produced by Cystic Fibrosis Ireland in partnership with the Dublin 2,4,6 Citizen's Information Service, who are also kindly providing us with a grant to print the publication.

The booklet outlines social welfare and health service supports as well as avenues for tax relief for people with CF. Information on rent supplement, the housing adaptation grant for people with a disability and the better energy home scheme is also included.

We hope that this booklet will prove to be a useful resource for people with CF, parents of people with CF and anyone working in a support role in this area.

You can view this booklet through our website now or call us in the National Office to order a hardcopy, which we are expecting in from the printers shortly.



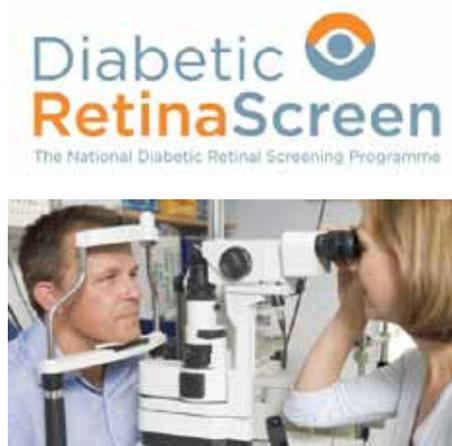
Diabetic RetinaScreen — The National Diabetic Retinal Screening Programme

Do you have CF-related diabetes and require insulin? Have you availed of the retinal screening programme yet?

Diabetic RetinaScreen — the National Diabetic Retinal Screening Programme is a free programme that offers regular diabetic retinopathy screening to people with diabetes aged 12 years and older. Retinopathy is a complication of diabetes which affects the small blood vessels in the lining at the back of the eye and can lead to deterioration in vision.

Diabetic retinopathy may not affect sight in the early stages which is why it's so important to get tested as if it is caught early, treatment is effective at reducing or preventing damage to sight.

If you or a loved one has CF-related diabetes, you should have received a letter informing you about this screen but you are still required to arrange your own appointment. You must call freephone 1800 45 45 55 to follow up on making the consent to give the programme permission to receive, hold and share your personal details within the programme. You will then be sent an appointment letter to attend for free diabetic retinopathy screening at a local screening centre.



For more information:

www.diabeticretinascreen.ie

Medical Card Review Process — Recent Announcement

CF Ireland made a submission in June 2014 to advocate for medical card eligibility on the basis of medical need, and for people with CF to be included in this cohort based on their lifelong progressive illness. Further to this submission, we were invited to attend focus groups with other patient organisations and provide more input on the issue.

At the end of November, Minister for Health Leo Varadkar and Minister for Primary and Social Care Kathleen Lynch announced the following changes to improve the operation of the medical card system, particularly for people with significant medical needs. The ten point actions include:

1. An enhanced assessment process which takes into account the burden of an illness or a condition
2. The greater exchange of information between the medical card central assessment office and the local health offices
3. People with a serious illness who hold a discretionary card can also be reassured that they will retain their card pending implementation of the actions to improve the operation of the scheme
4. The power of GPs to extend medical cards in difficult circumstances will be strengthened
5. A clinical advisory group is being established by the HSE to develop guidance on assessing applications involving significant medical conditions
6. The default position for medical cards given to people with terminal illnesses is that they will no longer be reviewed
7. The HSE will be empowered to provide people with therapies or appliances if that's what they need, even in the absence of a medical card
8. The HSE will develop a single, integrated process for people to apply for a medical card, a GP visit card, the Long-Term Illness scheme, and the Drugs Payment Scheme
9. Access points will be established around the country in health offices to support and assist people to make applications
10. The Department and the HSE will consider the best way to make medical aids and appliances available to persons who do not hold a medical card, the provision of services to children with severe disabilities, and to enable people with particular needs to have these met on an individual basis rather than awarding a medical card to all family members

"From now on, wider discretion and greater humanity will be exercised as part of an enhanced process that takes into account the burden of an illness or condition," Mr Varadkar said.

CFI will be keeping a close eye on the implementation of this ten point plan, and will keep members updated on all subsequent developments in the area.

For more information:

Submission from CFI on 'Medical Card Eligibility and CF': www.cfireland.ie/pdf/CFIMedicalCard_Submission_2014.pdf

Report of the Expert Panel on Medical Need for Medical Card Eligibility:
www.hse.ie/eng/services/publications/corporate/expertpanelmedicalneed.pdf

External review of the Medical Card Process, undertaken by Prospectus and Deloitte.
www.hse.ie/eng/services/publications/corporate/medicalcardprocessreview.pdf

Long-Term Illness Book Update

CFI made a submission on 'CF and the Long-Term Illness scheme' in April 2014. The purpose of this submission was to highlight the difficulties some members were experiencing in accessing certain items and medications through the LTI scheme. Clarification from the HSE on what drugs are currently available to PWCF through the LTI scheme was sought to reduce confusion amongst both community pharmacists and PWCF.

From June 2014, an updated Core List was published by the HSE that lists all the medications automatically approved for all new people with CF. We are happy to reveal that many of the items listed in our submission are now included on this list.

For people joining the LTI Scheme from September 2014, medicines on this Core List are now **automatically approved** for people with CF. It is hoped that this Core List will make it much clearer for people with CF and health professionals on what types of medicines are included in the LTI scheme, and will reduce the amount of administration for patients and healthcare professionals in adding medication to a patients LTI book.

Where a PWCF is prescribed an item on the Core List for CF, it will no longer be necessary to get approval on each occasion that a medicine is changed.

My GP has prescribed a new medication and my pharmacist informs me that it is on the Core List. Do I need to send my LTI Book to the local office for updating?

No. It is not necessary for you or your GP to send in your LTI Book for updating where the medicine prescribed for you is on the Core List for your LTI condition.

I have a medical card and I have a LTI book. I can't / My pharmacist won't give me all my medicines on my LTI book.

Your pharmacist is aware that not all of your medicines are available to you under the LTI scheme. The HSE is satisfied that all medicines that should be necessary for the treatment of your primary LTI condition are provided on the Core List. Those that are not on the Core List can be provided to you under the Medical Card scheme for which you will have to pay a prescription charge.

How can I register an appeal with the HSE to have a medicine approved that is not listed on the Core List of the LTI?

If the medicine has been prescribed or recommended by a hospital, you can register an appeal with your HSE Local Health Office to get the item added to your LTI book. You may be asked to get your hospital clinician to complete an individual reimbursement form.

You can access the full core list of medications for PWCF through the LTI scheme here: www.hse.ie/eng/services/list/1/schemes/lti/aprovmed/



7th Annual National Conference of the Irish Research Nurse Network

By Caroline Heffernan, CF Advocate, CF Ireland

The 7th Annual National Conference of the Irish Research Nurse Network (IRNN) was held at the Royal College of Surgeons in Dublin on Wednesday the 12th November. The topic for this conference was 'The Power of Data'. The IRNN invited CFI to attend to give a presentation on Patient Engagement in the Clinical Research Agenda. Caroline Heffernan, CFI Patient Advocate, pictured right with members of the IRNN organising committee and other guest speakers Dr Fionnuala Keane, Tracy O'Carroll and Eibhlin Mulroe of IPPOSI who chaired the morning session.



I briefly explained how CF affects people with cystic fibrosis (PWCF) on a daily basis, treatments involved, and the impact of living with a long-term illness for the PWCF and their family. I also touched on CF genetics as later in my presentation I discussed the effect Kalydeco has had on PWCF. As you are all aware Kalydeco treats the defect in the CF gene not the symptoms of CF, so it was important for all in attendance to understand the workings of the faulty CF gene.

The graph to the right shows the impact of all the research trials and improvements in CF care from Pancreatic Enzymes through to Kalydeco.



My genetics are not a match for Kalydeco, so I asked PWCF who were on the Kalydeco trial for their opinions and thoughts of the trial. It is very clear to see that the initial excitement encouraged suitable candidates with G551d to take part in the trial. The initial trial took 4 years and during that time there were lots of long hospital visits (approx. 14hrs), tests on each visit included bloods, x-rays, ECGs, head to toe physical examinations, long questionnaires about quality of life, fitness and mental health. Restrictions were placed on certain foods and medications, for example, if you took a pain killer it had to be documented etc — I was quite shocked at all that was entailed in the trial — it wasn't as clear cut and easy as I had thought. However if you were one of the people who enjoyed a huge boost in lung function and energy levels, increased weight etc the difficulties were soon forgotten about but unfortunately not everyone received the same level of increase. For those who didn't improve it was a long 4yrs.

As PWCF we realise how important clinical trials are, however, I think as a patient group we need to be more involved from the outset. We are after all the experts in the day-to-day care of our CF, we know what we will take and how we well it works for us either as a tablet/nebuliser/inhaler/IV.

If anyone would like to share their experiences of clinical trials or have suggestions on how to improve same, please get in contact with me by emailing cheffernan@cfireland.ie or call 087 9323 933.

New Dublin West Branch

By Marie Duffy, Chairperson, Dublin West Branch

I am pleased to announce that the new Dublin West Branch of Cystic Fibrosis Ireland is now up and running since June 2014.

After seeing a gap for a new branch in the Dublin area in order to cover its large population, I decided to set about opening a new branch for CF Ireland in the Dublin West area. I got two other parents to come on board and I am hoping to recruit new members.

The following areas will be covered by the Dublin west branch: Blanchardstown, Clonsilla, Castleknock, Clonee, Lucan, Ashtown, Cabra, Finglas, Tyrellstown, Whitestown, Mulhuddart, Huntstown, Hartstown, Ballymun, Glasnevin, Phibsboro, Whitehall and Santry.

We are dedicated to helping and supporting people with Cystic Fibrosis and their families in the Dublin West area. We plan to hold information nights for members with topical issues, we will also arrange parent support evenings where parents can get together for an informal social chat, share experiences and learn from one another and we will be holding fundraising events.

From a parents perspective I feel it is important for people to have support services nearby. The struggles that parents and families can go through are often eased by someone that has walked that road and can offer the reassurance which we are hoping to do.

At present, we only have three committee members which includes me, Marie Duffy (Chairperson) and I have a daughter with CF aged 3, Bernie Priestley (Vice Chairperson) who has a son aged 27 with CF and Triona aged 15 who sadly passed away last April, and finally Rebecca Horgan (Secretary) who has a daughter aged 4 with CF.

Your help is needed – we are looking for anyone who is interested in joining us to please get in contact. We are looking for a Treasurer and other committee members (everyone is welcome). We are also looking for people to fundraise for our Branch and want to reassure people that the money raised will go back into your local area.

Since June 2014 we have already raised over €40,000

The Castleknock 5km was held with all proceeds going to the Dublin West Branch as our first instalment. The day was a massive success. The event raised a massive €37,500.

Almost 1,300 people took part in the inaugural Castleknock 5km which was officially started by Dublin footballer Alan Brogan and saw Irish greats Catherina McKiernan and Eamon Coughlan line-out along with Minister for Health Leo Varadkar. The event was run in memory of Castleknock

"The struggles that parents and families can go through are often eased by someone that has walked that road and can offer the reassurance which we are hoping to do."



More supporters of the 5km event.



Marie Duffy, Chairperson of the new Dublin West Branch, at the cheque presentation with Philip Watt, CEO, CFI.

man Rory Doherty who passed away last June after a tragic work accident at just 33 years of age. As a result of Rory's organ donations, four lives were saved in Ireland through kidney, pancreas, liver and lung transplants. Rory was a close friend of Maries.

Other events were also held in memory of Triona Priestly such as 'Song for Tri', which was a concert held in An Draiocht, Blanchardstown. This event was also a massive success and a beautiful memorial of Triona for her family and friends.

If you would like to fundraise or become part of the Dublin West Branch committee then please contact Marie Duffy on 086 237 1184 or email mariedelaneyoo@yahoo.com and we would be delighted to welcome you.



Gordon D'Arcy, Irish Rugby star, at the Castleknock 5km event.

Dealing with Diagnosis, a Fathers Perception

By Ronan Whitmarsh, Father to Finn, PWCF age 11 months

My name is Ronan Whitmarsh. My wife Linda and I have been married five years now. On 29/02/2012, the leap year day, our oldest boy Liam was born. Since before we got married we both agreed that we would like to have a good sized family and that we would try and have them close together in age so that they would be friends growing up. When we found out that we were going to have another child, we were delighted and decided not to find out the sex of the child. We would keep it as a surprise, especially as I had missed the birth of Liam by five minutes due to a very speedy labour on Linda's behalf.

Our second boy Finn was born on the 04/01/2014 and we were over the moon. Liam would now have a little brother to play with. Linda did brilliantly during the labour and thankfully I was there for the delivery this time. Men don't often speak about their emotions, but to be honest I found it to be a very emotional event. After some time in hospital we took Finn home. We were on cloud nine and kept commenting to each other about how easy Finn was sliding into our family.

The little boy didn't have a great suck so we bottle fed him. The same thing happened with Liam so we tried not to beat ourselves up about it and just got on with things. Unfortunately our new found bliss slowly transformed into worry over the next two weeks. Both I and my wife Linda are registered general nurses, and although we are still fairly young we have over fifteen years of combined experience, so when Finn started to lose weight, despite taking a more than adequate amount of formula, we were very concerned.

At two weeks old Finn's lips turned blue for a few seconds and along with a slight failure to thrive, we decided to take him into hospital. We were admitted to the paediatric ward and Finn's intake was strictly measured. Linda was like a rock when we were in hospital. She stayed with Finn twenty four seven. I spent my time either with her or downstairs in work on my unit. The first week that we spent in hospital with our boy was very hard on all of us, luckily we had the help of my mother and Linda's sister to mind Liam. We were into our fourth day when I called up to see Linda and Finn during my break. I spent my time on the ward with them instead of getting something to eat and when my break was nearly over, I prepared to say goodbye and go back to work. Before I could leave one of the paediatric nurses stopped me and said I couldn't go back yet as the consultant was on his way round and we were next to be seen. I told the nurse that Linda could represent us and that I had to get back to work as our department was very short staffed.

I thought it was a little weird that the nurse insisted and then left the room only to return a moment later and tell us that she would stay with Finn and the consultant was waiting for us in the office. When we left Finns room we were met by another nurse and ushered gently towards the privacy of the room at the top of the hall. It was at this moment that I realised I was being handled. Compassionately, yet still being handled. Upon seeing the office door I remembered that I had taken so many patients and family members

"Keep the faith, support each other, promote awareness, do not let cystic fibrosis define you, talk to somebody and together we will all get through this and beat CF"

into rooms just like this one over the years to give bad news. Looking back I think that the door opened in slow motion and waiting inside for us was one of the consultants.

The next couple of minutes consisted of tears, shock, anger and an uncontrollable feeling of loss for both of us. As a husband I had always been able to comfort Linda no matter what the crisis, but nothing I could do helped and I had never felt more crushed in my life. As a man I had never been faced with something I couldn't either work towards completing or even brutally overcome from determination. However nothing I could do would or will change the fact that our beautiful, innocent, sweet little baby boy had ddf505 cystic fibrosis.

We knew there were distant cousins on my father's side that passed away some time ago due to cystic fibrosis when I was a child, but we never knew of any relatives on Linda's side that had experience with this. As a nurse that has worked in a variety of settings I did what is expected of all nurses. Once we had seen the multidisciplinary team, I focused my attention on what was required to care for Finns needs. After all, that's what nurses do. Not long after that we were discharged home. The weeks that followed were full of percussions, enzymes, weights and swabs. It was like Finn had been born to us a second time. The child that I had witnessed being born was now gone and we took home a new baby Finn.

My role changed from being a father to being a 24 hour nurse and I can honestly say I felt less like a dad. This feeling continued and despite helping the best that I could I found myself not connecting to my boy like I did with Liam. Following a bad pneumonia Finn was transferred to Temple Street. While I was in the tiny room with Finn, I noticed after I had fed him that he was watching me. Really watching me. I had placed him in his cot in a considerably upright position and as I moved around the room his eyes followed me. On seeing this I stopped and looked at him. I then moved in the opposite direction and his little blue eyes stayed with me. This made me smile as on this admission Finn had suffered a collapsed lobe and had been very ill. What I didn't expect was



The 3rd week, this is the following day after Finn really smiled and acknowledged me.

"Finn returned my smile with the brightest, most joyful looking grin I had ever experienced. It was at this instinct I felt like a father and not just his nurse"



Attending Temple St 3 weeks ago.

that Finn returned my smile with the brightest, most joyful looking grin I had ever experienced. It was at this instant I felt like a father and not just his nurse. On thinking now about how I felt back then I realise that during the weeks I spent looking after Finn I was obviously very effected by the diagnosis. As a man I found it hard to deal with these emotions, my heart was broken and it took the smile of my little boy to start putting it back together again.

The point of this story is simple, its ok to be affected by the diagnosis of cystic fibrosis as it will affect your child's life along with yours and your families. Fathers by definition are expected to be a pillar of strength but nothing is unbreakable and

it is important to talk to someone, be it a family member or friend. Any help you get through this particular difficult time can make you stronger when you need it and remember to keep the faith – advances in medicine these days are very exciting. Breakthroughs occur when we least expect them and always have.

There was a time when diabetic children were kept in large units where 50 or more patients would be packed into a ward mostly comatosed. Grieving family members were often in attendance awaiting an inevitable grim ending. In 1922, in one of medicines breath taking moments, James Collip, Frederick Banting and Charles Best, went from bed to bed injecting the comatose inhabitants of an entire ward with the new purified extract called insulin. Before they had reached the last dying child, the first few children had already woke from their comas to the uncontrollable cheers of their families.

Keep the faith, support each other, promote awareness, do not let cystic fibrosis define you, talk to somebody and together we will all get through this and beat CF. As fathers we too will play our part. At one of Finns outpatient appointments I asked one of the physiotherapists which sport would benefit our boy when he was older. She told me that martial arts is great for breathing and posture. So I joined a Tae kwon do club to learn the skills required to help Finn down the line. Since that I have become National Champion in the beginner level. I also raised funds for CF Ireland by running Dublin city marathon and have come third in a local 5k run. These sporting activities have helped as it provides me with an outlet for my anger and gives me a sense of accomplishment.

Astronaut Walter M. Schirra Sr said that fathers don't raise heroes, you raise sons. And if you treat them like sons, they will turn out to be heroes.



My happy little boy.



Finn's christening.



Finn on Halloween night!

The Circle of Life is Complete and Life is Good

By Helen Ryan-Lawless, PWCF, Dublin

Thirty years ago this month I introduced my beautiful daughter Elizabeth Ryan-Lawless to the CF community.

The previous September, I was diagnosed with having Cystic Fibrosis and admitted to St Paul's ward in St Vincent's University Hospital (SVUH) under the care of Prof Muiris X Fitzgerald. I was also told I was pregnant. David, my husband, and I were in shock.

I had been treated for bronchiectasis, had my gallbladder removed and was told I couldn't have children by my doctor. So here I was, the first CF patient to be pregnant, unable to take any medications or keep down food. What to do? We just took one day at a time...

I spent 6 months in SVUH and 6 weeks in Holles Street before my daughter Elizabeth was born. We had to wait for 6 weeks to have her sweat test, which was clear. We decided she would be our one and only.

Being an inpatient on St Paul's was made easier by Sr Patricia Hennessey who talked to you each morning to see how you were doing, she looked after us all like family. Physiotherapy was a communal event and involved being tilted in the bed on the ward while Deirdre Concannon went from one to another clapping away. At times it felt like boarding school with the late night chats, games and high jinx. The camaraderie was felt all the more when one of our friends lost their fight with CF. Later through fundraising we got our own TV room with a kitchen to help us escape from the ward. So different from today's cross infection protocol.

CF was all new to me — being diagnosed late I was eager to learn as much as I could. I became the Chairperson of the adult association, Vice President of the National Association, and was on the Board of IACFA — the international adults group. It became all consuming — my friends were all PWCF, we socialised and went on holiday together. I had become too involved. I had become CF not a PWCF.

Anyway I took a step back from the world of CF to get a healthier perspective on life for my family. When Elizabeth was in primary school I picked up every cough or cold going. In secondary things settled down. I managed on home IVs with the help of David my husband, friend and carer.

"I have the pure joy of introducing my precious grandson Ryan, who was christened recently. David and I are thrilled with our new status as grandparents"





Helen today.



David and Helen with their grandson Ryan.



Elizabeth and Ryan at Halloween.

My health stabilised for a few years. I worked part time. Taking delight in every milestone and special occasion in our lives.

When Elizabeth announced her engagement, the issue of genetic testing was mentioned. I found it very emotional, the quilt, the questions, as it was something I had not had to deal with myself. All I could do was get the information.

I was privileged to be one of the first occupants of our new state of the art unit St Christopher's. Unfortunately, I was in for four months. Getting out on special occasions like picking out my daughter's wedding dress. I got home for a few months then landed back in SVUH. Thanks to the care of Prof Gallagher, Dr McKone and the staff of St Christopher's Ward, I got out three days before the wedding. A day I honestly thought I'd never see. One of the best days of my life.



Helen's grandson Ryan.

Now a year later I have the pure joy of introducing my precious grandson Ryan, who was christened last week. David and I are thrilled with our new status as grandparents.

The circle of life is complete and life is good.

SURFING — Natural Therapy!

By Claire and Brian McCarthy on behalf of their son Neil, PWCF, Age 13 from Ballyshannon, Co Donegal

We would like to tell you about a very inspiring young surfer, our son Neil who turned 13 in November. His diagnosis of CF was when he was 10 years old. As a younger child he was always chesty, and doctors were quick to diagnose 'hidden asthma', even though he did not have a wheeze or asthmatic symptoms. He did not absorb fats, but again, the doctors measured his height and weighed him and said he was thriving. This was in part due to him avoiding fats in his diet, using multivitamins, and having a fussy mother who made sure his diet was balanced. His distended tummy was "something he would grow out of as he got older". However, it became more pronounced. As parents, we were always concerned but were reassured by the various GPs who treated him, however, we were not convinced.

When he was 10 years of age, an internet search of his usual symptoms, brought up a result that it may be undiagnosed CF. Immediately, we knew, this was what Neil had. A meeting with a Paediatric Consultant, resulted in him being admitted to hospitals for a series of tests, mainly due to his enlarged spleen, ruling out Leukaemia, Gaucher's disease, and eventually giving us a confirmed CF diagnosis, on 14 December 2011 in Crumlin Hospital.

His Cystic Fibrosis-related Liver Disease diagnosis came immediately after this with an oesophageal bleed and further tests in the New Year. This was the cause of his enlarged spleen. He had to give up all contact sports with immediate effect, to prevent injury to his spleen. At the time, he was a member of his local Gaelic, soccer and rugby teams, and his dream was to be a premiership footballer or an international rugby player. He had been an integral member of each team in the position of defence. For him, this was the hardest thing to accept. His childhood was turned on its head, as his sports defined him.

He also had to accept the CF regime of medicines, physiotherapy and nebulisers overnight. He had several hospital admissions with pneumonia, chest infections and routine scopes under anaesthetic in the years that followed. He was also in hospitals for 3 months last year when he was unlucky to have an undiagnosed rumbling appendix which finally burst. At this time, he was very ill and lost a lot of weight. However, Neil bounced back to full fitness within a few months.

As parents, what has kept us strong has been his resilience. He has taken everything in his stride. We know that an early diagnosis is best; however, at 10 years of age, it was not possible to wrap him up in cotton wool. The person he had already become had to be acknowledged and consulted and brought on board. In the midst of all of this, Neil kept up swimming with the local swimming club, winning medals in relay team events and individual events in the South-West Minor League, and County and All Ireland Community Games medals. He hauled in 5 medals at the National Indoor Irish Water Safety Nippers Championships in early 2012.

Nov/Dec 2014



Neil with his 13th birthday present.

"We would encourage parents of CF babies and toddlers to allow their children to participate in sports from an early age, so they develop the self-motivation and fitness required to manage their health"



Today he loves all water sports, continuing with Nippers, both indoors and outdoors in the sea, and qualifies for the nationals each year. He completes Irish Water Safety classes in Rescue, Endurance and Safety and is working his way through the levels.

His love of all things water-related has taken over since he had to give up contact sports. He has his own kayak, and takes it out in the rivers, lakes and sea. Where he lives in Ballyshannon, Co Donegal is a haven for water sports. His main passion is for surfing. The last few years has him checking weather charts and surf websites to predict when and where the next swell will hit. Birthdays, Christmas and confirmation gifts all revolve around new boards, wet suit, board bags, booties, and other surf paraphernalia. His latest acquisition is a custom designed surfboard, shaped and made to his specification with a custom designed logo design with his initials.

Some years ago, Australian researchers found that CF children that surfed had significantly healthier lungs. Doctors determined that inhaling saltwater mist has a powerful effect on rehydrating the lining of the lungs, which allows CF patients to more easily eliminate bacteria-contaminated mucus. This discovery led researchers to develop a hypertonic saline solution, which CF patients around the world now inhale every day. In essence, CF patients now mimic a "surf session" on a daily basis. For anyone with CF, we cannot recommend surfing more as a natural way to get clean saline air into your lungs, at the same time keeping physically active. In our house we call it 'Natural Nebs'.

Neil has been lucky in that he was introduced to surfing by his dad, Brian who has surfed since he was a teenager. Coming into winter, the sea is getting colder, and winter wet suits, gloves, helmets and booties are required to stay warm. We travelled to Portugal during mid-term in October to get some more surfing, as the sea in Ireland is too cold in the winter months. In Spring, we hope to travel back to Biarritz in the South of France to start off the 2015 surfing year.

In the meantime, Neil is very grateful to Cystic Fibrosis Ireland for granting his application for the Exercise Grant. He has purchased an exercise bike which he is using to stay fit during the winter months, when the sea is off limits. He will couple this with swimming in the local swimming pool to keep up his fitness level.

We know it has been said time and time again that exercise is a key element of a PWCFs regime. Neil's late diagnosis is in part due to his fitness and love of exercise from an early age. It is keeping him well now also, with good growth gain due to a healthy appetite, positive attitude and self-motivation. We would encourage parents of CF babies and toddlers to allow their children to participate in sports from an early age, so they develop the self-motivation and fitness required to manage their health. Swimming has been especially beneficial as the rhythmic breathing out exercises all the airways. Neil is also a keen cyclist and skateboarder, he plays the drums and walks his dog regularly. At the moment Neil surfs for the pure pleasure of it. Who knows, next year he may plan to surf on the national competitive scene.

Watch this space...

Challenges and Events

Montenegro Walk 2015

The 2015 Paddy Kierans Memorial Walk will take on the sights and landscapes of Montenegro and some stop overs in Croatia. This should be a memorable trip with 4 days of walking amongst beautiful scenery and towns.

The Paddy Kierans Memorial Walk has been raising much needed funds for CF Ireland for over 15 years now. Join them today and help raise much needed funds for people with CF and their families.

For more information on this please contact the fundraising department on 01 496 2433 or email fundraising@cfireland.ie.



To reserve your place on this trip please download and complete the Montenegro Walk 2015 application form and return it to CF Ireland with a deposit of €350. The total target to be raised for this walk is €2,900.

In order to reserve your place on the walk, the following payments need to be met:

- Deposit of €350 by 01st February 2015 (non-refundable)
- 1st payment of €1,000 due by 1st May 2015
- Fundraising target of €1,550 to be raised by 20th September 2015

Flanders Peace Walk 2015

As 2014 marks the 100th year anniversary of World War One (WW1), there has been much interest in recent months about the involvement of Irish soldiers in the conflict. Cystic Fibrosis Ireland have decided to organise a 'Peace Walk' to take place in Belgium from 8th-10th May 2015 to raise much needed funds for our organisation.

The walk will be approx. 12km in length and will take place along the low lying and flat Messines Ridge and will include sites of both Irish and general interest along the way. Walkers will be guided by Dr. Tim Watt of Queen's University Belfast, who will be available to answer questions over the weekend. The trip will include a visit to the Flanders Field Museum in Ypres.



The cost of registration is only €450 which will include return flights, hotel accommodation and breakfast, coach connections to Belgium and an afternoon trip to the beautiful city of Ghent. Those who register will also be required to fundraise a target of €400.

If you are interested please e-mail fundraising@cfireland.ie or call our office on 01 496 2433.

Why not get friends involved as well, It promises to be a great weekend.

International Marathons

If you would like to set yourself the ultimate running challenge, and raise funds and awareness for CF Ireland we are looking for participants for two marathon events — please email us for details: fundraising@cfireland.ie

Paris Marathon 2015

We have guaranteed entry places for the 39th Paris Marathon, one of the world's biggest and best marathons, taking place on **Sunday, April 12th**. The marathon route takes in most of the world-famous Paris landmarks, including the Arc de Triomphe, the Bastille, Notre Dame Cathedral and the Eiffel Tower.

London Marathon 2015

We have guaranteed entry places for the London Marathon 2015, taking place on Sunday 26th April. This popular marathon is hard to get entry to but if you choose to fundraise for CF Ireland you will get a guaranteed entry into this 'Marathon of a lifetime'.

The route will see you running through many famous London districts and past many landmarks, including the Tower of London, the Houses of Parliament, Big Ben and Buckingham Palace.

McCabe's Pharmacy Charity Gift Wrapping Service



Support McCabe's this Christmas!

Please support our friends at McCabe's Pharmacy this Christmas who are fundraising once again for CFI with a gift-wrapping initiative. When any customer buys a gift in McCabe's Pharmacy, staff will gift-wrap it in return for a donation towards Cystic Fibrosis.

Thank You

Dublin Marathon 2014

The 35th SSE Airtricity Dublin Marathon took place on Monday 27th October and what a fantastic event it was. Thousands of runners, joggers, and walkers took to the streets to complete the 26 miles around Dublin.

CF Ireland had a team of over 60 people taking part on the day on our behalf, raising vital funds and creating awareness of Cystic Fibrosis. We are all very proud of their efforts, it is hugely appreciated.



If anyone has any fundraised money that they would like to lodge please use the bank details below:

BIC: AIBKIE2D

IBAN: IE59 AIBK 931071 08578593

If you are thinking of taking part in next year's Dublin marathon, registration is already open for next year, 2015. Sign up here: www.dublinmarathon.ie. To register to join the CF Ireland team and to receive a race pack and singlet please e-mail fundraising@cfireland.ie

New York City Marathon 2014

A BIG THANK YOU and well done to Bernie Flynn, Dan Kidd and Ciaran Priestley who all took part in the New York City Marathon on Sunday 2nd November for CF Ireland. They were part of the



50,000 people who pounded the streets of the Big Apple in cold conditions so well done to them all.

It's an amazing achievement and opportunity to run in the most famous marathon in the world so if you or anyone you know would be interested in taking part in this event please contact us at fundraising@cfireland.ie or Lo call 1890 211 311.

Anatomic Fitness Charity Birthday Bash

Well done to all the staff and members of Anatomic Fitness in Castleknock who recently held a Charity Birthday Bash and raised a total of over €20,000. CF Ireland received a cheque for €10,000 while The Bubblegum Club received €5,000 and the CF Unit in Tallaght Hospital also received €5,000.

Anatomic Fitness recently celebrated their first year in business so with the close association of the co-owner Mick Daly, CF Ireland was chosen as the charity of choice. Tickets for the event were sold out within 24 hours and they packed out the Crown Plaza Hotel with over 360 people in attendance. The local community and businesses were very supportive with over 100 spot prizes raffled on the night.

Minister Leo Varadkar kindly attended as a guest speaker on the night along with Jim Gavin, the Dublin Football manager, who also spoke on the night.

A sincere thanks to everyone involved.



Ciaran Priestley, New York City Marathon 2014

I travelled to take part in the New York City marathon on 2nd November and I was joined by my wife, parents, three brothers and their girlfriends. All of us took part in a 5k event on 1 Nov which finished in Central Park, a favourite location of Triona's. We decided to do this in New York as it was Triona's favourite place and one of very happy memories for our family.

The whole trip was emotionally charged for us. I don't know what it was exactly that Triona loved so much about New York. Undoubtedly, it has roots in the family trip we took here in 2004 when she was six. Only our mam had been before and the rest of us were pretty excited about the whole thing. It had a very long build up. I remember driving from JFK with the skyline of Manhattan growing ever closer in the distance. We were pressed up against the windows like stereotypical first-time tourists, trying to name buildings and landmarks we recognised and no doubt getting them all wrong.

Triona took so much pleasure in us all being together and was always concerned that her brothers were happy and doing well. This place ticked all the boxes. It also had Times Square, Central Park and countless other landmarks. New York did not disappoint on the first occasion or any return visits.

As Triona became unwell and a long haul flight was no longer an option, a trip to New York at Christmas took on mythical status. It would have been the first plan to have been made had Triona received the dream transplant that would have given her more time. As this was not to be, we made this trip in her memory.

Although I did not seek sponsorship for my previous marathon, I did wear a CF wrist band which I gave to Triona after it was over. I wore that during my 26.2 mile journey through the five boroughs of New York.

I love her incredibly and always will.



Ciaran after finishing the NYC marathon 2014.



Ciaran and Triona on a previous visit to New York.

DoneDeal Charity of the Month

A big THANK YOU to DoneDeal!

During the month of September DoneDeal donated 10% of the revenue from adverts placed with them to three worthy charities of which CF Ireland was one. A cheque for €11,705 was presented to CF Ireland to go towards the Waterford Hospital Project.

Thanks again DoneDeal for your tremendous support!

Darley Kildangan Stud Sports Day

Well Done to all the staff at Darley Kildangan Stud from Kildare who recently organised a 5km run and 100km cycle and raised a fantastic total of €13,750 for CF Ireland.

All the staff put in a huge effort to make this a successful day and we are all very grateful here in CF Ireland for your support. Pictured below are some of the staff members presenting the cheque to CF Ireland.



Gary Dillon White Collar Boxing Event

Ciaran Coyne and friends recently held a very successful White Collar Boxing Event in memory of their friend Gary Dillon from Sligo. The event was held in The Sligo Park Hotel on Saturday 15th Nov and a great night was had by all.

There was a brilliant atmosphere on the night with the hotel packed out with a large crowd and almost 30 boxers taking part. Well done to all the boxers as they put in a huge amount of training and preparation beforehand.



Boxers for the Gary Dillon White Collar Night.



Karen Sweeney & Eilis Rooney.



Noel O'Donnell & Mark Dillon.

Paris2Nice Cycle Challenge

A BIG THANK YOU to all the Paris2Nice cyclists who raised almost €90,000 for CF Ireland by taking on the challenge of cycling from Paris to Nice. Tim Fulcher, one of the Paris2Nice CF Cycle Challenge team recently presented a cheque to Maria Caldwell, our fundraising manager.

This was a fantastic achievement by everyone involved.

The event always proves to be very popular so if you are interested in taking part next year — register your interest today as spaces are filling up fast. Email info@paris2nice.com to book your place.



Tim Fulcher presenting the cheque to Maria Caldwell, Fundraising Manager, CFI.

Thank You Tesco Bettystown

Store Manager Stephen Barriscale from Tesco in Bettystown, Co. Meath recently presented a cheque for €529.10 to CF Ireland as part of their Community Fund Programme.

Fundraising in Cavan

PJ Keenan, a native of Shercock, presents a cheque of €900 to Rosaleen Cronin, Honorary Treasurer of the Cavan branch of Cystic Fibrosis Ireland, the proceeds of a raffle organised by PJ in the Glencarn Hotel, Castleblaney on the night of the launch of his new solo CD Faith, Hope & Love (bottom left).

Cynthia Donegan, New Inn, Ballyjamesduff, touches down safely after her recent fundraising skydive in aid of the CFI Cavan Branch project in Cavan General Hospital. In total she raised €2,200 for the project (bottom right).



Store Manager Stephen Barriscale presenting the cheque to Peter Minchin from CF Ireland.



L-R: Robert Dunne, Chairperson of the Cavan branch of CFI and Larry Keenan, father of PJ. Pic: Aidan McCabe.



Cynthia Donegan raised €2,200 for the Cavan Branch!

The B'FEST Festival for TLC4CF

The B'FEST Festival for TLC4CF was a resounding success this year raising €22,800 to fit out the new Adult CF unit in University Hospital Limerick!

The weekend's entertainment included a zorb soccer tournament, fancy dog show, colours run and Fittest Family competition. Live music was provided by Alvin Purple and Zoo 2 on the gig rig. The highlight for many was the hilarious live Pig Racing which brought the village to a standstill, as Miss Piggy battled it out with Ham Sandwich for the top prize! To date the B'FEST has raised over €40,000 for the Limerick Hospital build project. Sincere thanks to the B'FEST committee who work for several months each year to organise this thrilling weekend for CF.



North Clare Cycle /Run /Walk for Cystic Fibrosis

On a sunny September Saturday, over 600 people participated in this year's North Clare Cycle /Run /Walk for Cystic Fibrosis. With 7 distances and over 150km of Burren and Atlantic coast route to choose from, the day was a fantastic success raising over €20,000 for the new CF unit in University Hospital Limerick! Pictured in this photograph is Cycle organiser Marcella Clancy starting the main cycle event. A huge team of volunteers helped out on the day and even Fr. Ted and Mrs Doyle put in an appearance to help serve over 1,500 cups of tea to thirsty competitors!



Charity open-week in the award winning 'Knockpatrick Garden' in Foynes

Pictured are members of the Limerick Cystic Fibrosis branch accepting a cheque for TLC4CF from Agnes O'Brien, Foynes. Agnes and her parents in law, Tim and Helen O'Brien hosted a hugely successful charity open-week in their award winning 'Knockpatrick Garden' in Foynes this summer. Over the past decade, Knockpatrick gardens has donated thousands of Euro to Cystic Fibrosis and the construction of the new adult Cystic Fibrosis unit in Limerick.



Agnes, who has a son with CF and her friends also organised the Foynes 5k run earlier this year. The now annual event was officially started by Ger Hartmann, internationally renowned sports therapist and was sponsored by over 40 local businesses.

Limerick branch members present for the cheque presentation included Liam O'Kelly, Maeve Neville, Agnes O'Brien, Joy Larner, Caitriona Shesgreen, Mairead Moloney, Heather Roche and Breda O'Kelly

6 friends, 2 micras and 10,000km for CF Galway

These 6 friends travelled 10,000km to Mongolia over 5 weeks in 2 Nissan Micras. Great guys with big hearts and all know someone who has CF or bereaved families.

At the cheque presentation (see right) in Galway University hospital were front row: Patrick Curran; Terry Keenan; Adrian O'Malley; George O'Donnell & John Kearney (Mongol Rally team). Back row: Jessica Diskin and Luke O'Malley (CF Galway); Mary Keane representing her son David O'Sullivan who has returned to Australia, Mary Lane Heneghan, Teresa Diskin, Daniel Diskin, John Diskin and Marian (all representing CF Galway).



€28,190.58 was donated to CF Galway from the Mongol Rally team 2014.

Trim Athletic Club

Recently Trim Athletic Club presented a cheque for €1,200 to the Meath Branch of CF Ireland. Pictured is Stephen Kennedy of the Meath Branch accepting the cheque.

Well Done Trim Athletic Club!

Leo-Pharma staff supporting our Beds for Beaumont campaign

CFI would like to say THANK YOU to Leo-Pharma and their staff members who recently presented a cheque for €2,200 towards our Beds for Beaumont campaign.

A number of the staff took part in the Head2Head Walk from Howth to Bray earlier in the year and raised €1,100 which was then matched by the company to give a total of €2,200

Pictured to the right is Austin Kenny from Leo-Pharma along with his colleagues presenting the cheque to Peter Minchin from CF Ireland.



Trim Athletic Club cheque presentation.



Leo-Pharma cheque presentation.

Volunteers Needed for National Awareness Week 2015

Our 65 Roses National Awareness Week 2015 will take place from April 20th-27th.

We would like to invite everyone to organise their own 65 Roses event during the month of April to raise funds to help support people with CF. So get your thinking caps on and start planning for 2015, we are here to help with any ideas you might have.

We would also love to hear from anyone who would be interested in volunteering to help us with the sale of our emblems during National Awareness Week next April 2015. We are currently contacting the many shopping centre's around the country to ask for their help in allowing volunteers to sell our emblems. If you feel you can help us please do get in touch by emailing fundraising@cfireland.ie today.

We look forward to your support!



CF Ireland Fundraising Notice!

Due to a couple of unfortunate incidents in the past few weeks we wish to issue a warning regarding fundraising practises when using sponsorship cards. You cannot under any circumstances use sponsor cards issued by Cystic Fibrosis Ireland to collect money door to door from members of the general public. Collecting cash door-to-door requires garda permit, which you must apply for directly with your local garda station. If you are using traditional sponsor cards PLEASE only use them amongst friends and family, or maybe share with your work colleagues.

We know people fundraise & donate in good faith - and for that we are immensely grateful. Please contact us for more information or if you want to know whether you need to apply for permit or not.

Thank you for your continued support!

The CF Ireland Fundraising Team.



Help the CFI Ireland LIFE SUPPORT Campaign

Because Ireland has the highest prevalence of Cystic Fibrosis in the world, many people will know someone who is living with Cystic Fibrosis. However, fewer may know how tough it is to stay well when you have CF and the support that Cystic Fibrosis Ireland provides to help people with CF stay well.

There is a constant daily battle for people with CF to maintain their health, often with scores of pills and other medications to take every day and a challenging regime of exercise and physiotherapy that will take at least 2 hours every day, even for those with CF who are comparatively well. For those of our patients who are less well and who may be constantly dependent on oxygen; waiting for a lung transplant or who will spend weeks as an inpatient after a worsening of their condition, the daily treatment regime is much longer and even more of a struggle.

There is a constant battle for funding for CF hospital facilities; for research, for equipment and assisted living. Those with CF and their families contribute daily through determination and perseverance of treatment, but with cutbacks we increasingly need public support to maintain crucial CF services.

With the support of Cystic Fibrosis Ireland and the current advances in medication and our wonderful care teams in CF centres, more people with CF can now hope to be a mum or a dad, perhaps even a grandparent — a dream that was impossible when CFI was set up in 1963 and when children with CF were not expected to reach primary school.

Help us through your donations for CF Life Support.

Donate Details

Text **HelpCF** to 50300 to donate €2.

100% of your donation goes to Cystic Fibrosis Ireland across most network operators. Some operators apply VAT which means a minimum of €1.63 will go to Cystic Fibrosis Ireland. Service Provider: LIKECHARITY. Helpline: 0766805278

ISSN 2009-4132

Cystic Fibrosis Ireland
24 Lower Rathmines Road
Dublin 6
Ireland

t: +353 1 496 2433
f: +353 1 496 2201
e: info@cfireland.ie
w: www.cfireland.ie
Company Reg: 449954
Charity: CHY6350

