

SPECTRUM

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Cystic
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Issue 41 Sept/Oct 2014

www.cfireland.ie

Dear All,

Flu Vaccine Reminder

As winter will soon be here (in spite of our glorious autumn) we take this opportunity to remind our readers to get the Flu vaccine, particularly if you have CF.

Each year the seasonal (annual) flu vaccine contains three common influenza virus strains. The flu virus changes each year and this is why a new flu vaccine has to be given each year. Some CF centres will provide the vaccine, in other cases you can go to your GP or your local pharmacy.

CF Building Projects

CFI is delighted to confirm that the building of new inpatient and outpatient facilities in Limerick, Castlebar and Waterford continues and that the new CF inpatient unit in Cork University Hospital is underway.

We also welcome the decision of Beaumont Hospital to provide an additional 3 rooms to increase the number of adult CF rooms from 4 to 7. This still falls short of the 13 rooms needed in Beaumont to meet present demand.

Staff Shortages

At a recent meeting, the CEO of CFI called on the new Minister for Health to lift the recruitment embargo that means that key clinical staff (such as nurses) are not being replaced while on sick leave or maternity leave. We also call on vacant CF nursing posts in hospitals such as Limerick and Beaumont to be filled as soon as possible.

Business for CF Initiative

We need you help to ensure CFI becomes the charity of the year for more businesses/workplaces. We have a fantastic arrangement for 2014 with the Dublin Airport Authority (DAA), along with the Jack and Jill Foundation and Special Olympics. As always, a huge thanks to all those who took part in fundraisers for CF in the last few weeks including Joe Brolly and Pat Divilly who are both ambassadors for CFI.



Philip Watt (CEO)
Alica May (Editor)

Front Cover: Declan Houlihan. PWCF Age 32, from Co Kildare who contributes to Spotlight this issue.

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

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National Lung Health Awareness Week

Launched by Minister for Health, Leo Varadkar TD, National Lung Health Awareness Week took place from 22-29th September. Cystic Fibrosis Ireland is a member of the Irish Lung Health Alliance that co-ordinated the event, which is a group of Irish charities that have joined forces to promote healthy lungs for people in Ireland. The Irish Lung Health Alliance are calling on the Government to develop a National Programme for Healthy Lungs.

To coincide with the awareness week, a national roadshow visited Dublin, Cork, Galway and Portlaoise to offer free lung testing and showcase an education exhibition to highlight the importance of healthy lungs for life.

Lung disease incorporates asthma, lung cancer, cystic fibrosis, tuberculosis, sleep apnoea, lung fibrosis, sarcoidosis, alpha one antitrypsin deficiency, and chronic obstructive pulmonary disease, also known as COPD, bronchitis or emphysema. Lung disease is the most common reason to visit a GP and the third most common reason for acute hospital admission.



Minister for Health, Leo Varadkar TD, with members of the Irish Lung Health Alliance at the launch of National Lung Health Awareness Week.



At the launch of National Lung Health Awareness week.

Taking part in the launch of National Lung Awareness Week, Lar Brennan (PWCF from Co Wexford) represented CFI and was interviewed on The Last Word with Matt Cooper on Today FM and on the Journal.ie to promote the importance of keeping fit and healthy and getting a lung test done.

Lar, who underwent a double lung transplant in November 2013, is a big advocate of exercise and keeping fit, and is now training to be a fitness instructor. "People are walking around with lung disease without realising it, because they're not working the body enough," Lar said. "It's also important that parents get their children as active as possible."

To listen to Lar speaking with Matt Cooper: www.todayfm.com/player/podcasts/The_Last_Word_with_Matt_Cooper/The_Last_Word_with_Matt_Cooper/2024/1/lung_health_awareness_week/cp_2

To read the article in the Journal.ie: www.thejournal.ie/lung-disease-health-awareness-week-lar-brennan-1679341-Sep2014/

To read a Spotlight article Lar previously contributed to *Spectrum*: www.lunghealth.ie/

One Republic – Raising International Awareness of Cystic Fibrosis

The awarding winning American pop rock band One Republic are creating international awareness of Cystic Fibrosis. They have released a new video for their single 'I Lived' which is a touching tribute to Bryan Warnecke, a 15 year old person with CF and a huge fan of the band!

The music video shows viewers the rigorous daily routine that comes with having CF, but also shows how Bryan doesn't let CF stop him from achieving his goals and ambitions in life. He is a very active teenager, who is shown cycling, skateboarding, running and playing hockey – pushing his limits and always striving to achieve more. The song and video carry a very powerful message for everyone – not only people with CF – and that is to live life to the fullest, no matter what difficulties you may face on a daily basis.

Be sure to watch this inspiring video by visiting www.youtube.com/watch?v=zorxydSolwU



Bryan Warnecke, a 15 year old person with CF features in the new One Republic video.

25 Years Since the Discovery of the CF Gene

2014 marks the 25th year since the first discovery of the CF gene. The year was 1989, and Dr. Lap-Chee Tsui and his colleagues at the Hospital for Sick Children in Toronto, Canada, made the breakthrough discovery that would change the lives of people with CF forever.

CFTR was the first disease-causing gene to be identified and at the time was regarded as 'one of the most significant discoveries in the history of human genetics.'

Tsui also set up a mutation database that would house the collection of mutations in the CF gene so researchers around the world could benefit from the most up-to-date genetic information about the disease. This database remains a major resource for clinical and basic research and serves as a model for other genetic disease databases.

Life expectancies for people with CF have changed dramatically since the first discovery of the CF gene, with better treatments becoming available and CF facilities improving. With the arrival of new mutation-specific drugs (Kalydeco) that target the underlying cause of CF, there is much to be hopeful for in the next 25 years.

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*.



CFI Submission on Water Charges

CFI recently (August 2014) made a submission to the Commission on Energy Regulation on the Economic Regulation of the Public Water Service Sector. The purpose of the submission was to highlight the additional strain which will be placed on people with Cystic Fibrosis (PWCF) and the households in which they reside when the impending water charges are introduced next year.

This submission is based on the concerns of our members, highlighting the additional water needs of this patient population and also the need to ensure the provision and affordability of basic services to the most vulnerable populations in society.



Summary of key points in the submission

- Water is a basic human right and therefore mechanisms ensuring affordability and access for Ireland's vulnerable households, including those with a medical condition, must be established and implemented before charges are introduced. This can be achieved through the allocation of free water allowances and medical allowances.
- A large proportion of PWCF are now managing their illness in their home. This requires a rigorous daily routine of treatments, such as taking numerous nebulisers, airway clearance (including exercise) and often over 30 tablets per day. The need for water for equipment cleaning, adopting correct hygiene procedures, personal hygiene after exercise and large volumes of drinking water are essential to the management of this illness.
- The majority of PWCF are pancreatic insufficient, which is generally managed through pancreatic enzyme replacement therapy. However, this complication often causes an increased volume of protein and fat in the bowls, resulting in diarrheal symptoms and increased use of the toilet.
- Cystic fibrosis can cause a person to become easily dehydrated or to have very low salt levels. This makes it very important for people with cystic fibrosis to drink high volumes of water on a daily basis.
- Households with a medical condition, such as Cystic Fibrosis, are identifiable through medically assessed payments, such as the Long-Term Illness scheme & the medical card scheme or through social supports, such as domiciliary care allowance, carers allowance, disability allowances, etc

To read the full submission, please go to www.cfireland.ie

Update 29th Sept 2014

Charges will be capped at the assessed rate for people whose medical condition requires extra water usage. Customers can request this facility from Irish Water but a list of specific medical conditions has not been drafted.

Read more about the process involved here:

www.cer.ie/docs/000979/CER14756%20Water%20Charges%20and%20Medical%20Conditions%20requiring%20Higher%20Water%20Usage.pdf

We will keep members updated with any further developments on the issue.

National Children's Hospital Update

Cystic Fibrosis Ireland representatives took part in the most recent Parent Reference Group in relation to the new development of the National Children's Hospital on St James' site, Dublin. This meeting was attended by patient/parent representatives, National Clinical leads in Paediatrics; Professor Alf Nicholson and Professor John Murphy, and the CEO of children's hospital group Eilish Hardiman, which made for a productive and worthwhile meeting.

The plans for the new children's hospital have been questioned and criticised in recent times, with primary issues arising around access to services and parking within the new site. It was felt by parent representatives that hospital management were not addressing these issues effectively, with very little information being disseminated publicly. HSE representatives acknowledged this shortfall on their part and have committed to providing more transparency and information on all stages of the national children's hospital development, which has been evident in media coverage during the past week.

It is estimated that the new development will open its' doors in spring 2019, but it is important to note that this is dependent on obtaining planning permission from An Bord Pleanala. The design team has been appointed to this project and is expected to finish its work "in a matter of months" according to Minister for Health Leo Varadkar — with a view to securing planning permission and beginning site clearance and enabling works next year. It was also highlighted that traffic specialists (Arup) have been appointed to the design team to deal with access and parking issues.

The new hospital will include 384 inpatient beds including 62 critical care beds, all single and ensuite. It is expected to deal with over 28,000 inpatients a year and 223,000 outpatient attendances.

CF Ireland will continue to engage with the hospital development board and the parent's reference group on a bimonthly basis, evaluating the progress of the project and representing the views of our membership. If you have views which you would like us to bring up at the next meeting please submit your thoughts in writing and email kmurphy@cfireland.ie.

A Tribute to Dr Brendan Watson

Cystic Fibrosis Ireland wishes to pay tribute to Dr Brendan Watson, former CF paediatric consultant in Cork University Hospital.

Dr Watson made a very significant contribution to the development of CF services in the Southern region from the time of his appointed in 1979 until his retirement. Dr Watson died on 22 August 2014. Our thoughts are with his wife Bernie, his children and grandchildren and his former colleagues in CUH.

Flu Vaccine 2014/5 — Reminder

What is seasonal flu (influenza)?

Seasonal Flu is a highly infectious viral illness of the respiratory tract that can be life threatening. Flu is a serious illness which can cause complications in people with long term medical conditions, those aged 65 years and over and pregnant women.

Is it cold or flu?

Flu symptoms come on suddenly with a fever, muscle aches, headache and fatigue. A cold is a much less severe illness than flu. A cold usually starts gradually with a sore throat and a blocked or runny nose. Symptoms of a cold are generally mild compared to flu.

What is the seasonal (annual) flu vaccine?

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

How does seasonal flu vaccine work?

Seasonal flu vaccine helps the person's immune system to produce antibodies to the flu virus. When someone who has been vaccinated comes into contact with the virus these antibodies attack the virus.

How safe is flu vaccine?

Seasonal flu vaccines have been given for more than 60 years to millions of people worldwide. Reactions are generally mild and serious side effects are very rare. The seasonal flu vaccines cannot give you the flu.

Who should get seasonal flu vaccine?

Vaccination is strongly recommended for:

- Persons aged 65 and over
- Those with a long-term medical condition such as diabetes, heart, kidney, liver, lung (including **Cystic Fibrosis**) or neurological disease
- People whose immune system is impaired due to disease or treatment
- Persons with a body mass index (BMI) over 40
- Pregnant women (at any stage of pregnancy)
- Residents of nursing homes and other long stay institutions, healthcare workers and carers
- People with regular close contact with poultry, water fowl or pigs.



Who should NOT get seasonal flu vaccine?

The vaccine should not be given to those with a history of severe allergic (anaphylaxis) reaction to a previous dose of the vaccine or any of its constituents.

What about people with egg allergy?

People with egg allergy can get seasonal flu vaccine. This may be given by your GP or you may need referral to a hospital specialist.

Why do pregnant women need to get seasonal flu vaccine?

Pregnant women are at higher risk of severe complications from flu. Flu vaccine protects pregnant women during pregnancy and provides ongoing protection to their newborn baby.

When should you get the flu vaccine?

Vaccination should take place in Sept and Oct.

How long does it take the vaccine to work?

The vaccine starts to work within 2 weeks.

What can I expect after vaccination?

The most common side effects will be mild and may include soreness, redness or swelling where the injection was given. Headache, fever, aches

and tiredness may occur. Some people may have mild sweating and shivering as their immune system responds to the vaccine.

How do I get vaccinated?

People aged 18 years or older may attend either their GP or Pharmacist. People under 18 years of age should attend their GP for vaccination. If you have a Medical Card or GP Visit Card the vaccine and consultation are free. If you do not have either of these you will be charged a consultation fee for seasonal flu vaccine. Please make an appointment with your GP or Pharmacist NOW.

Pneumococcal vaccine

If you are 65 or over or have a long term medical condition you should also ask your doctor about the pneumococcal vaccine which protects against pneumonia if you have not previously received it.

For more information visit www.immunisation.ie

McCabes Pharmacy Special Offer – Free Flu Vaccination!

McCabes Pharmacy are once again this year offering people with Cystic Fibrosis and their immediate families a FREE Flu vaccination in any of their branches!

This service is available to anybody over the age of 18 years. If you wish to avail of this service, please visit www.mccabespharmacy.com to find your nearest branch.

How do I avail of this offer?

You must make an appointment with the pharmacist in advance of going to the pharmacy.

You must tell the pharmacist that you are a person with Cystic Fibrosis or are an immediate family member. This is to ensure no other person with Cystic Fibrosis will be in the pharmacy at the same time.

Arm Yourself with a flu vaccine

Getting a flu vaccination is the single best way to avoid getting the flu.

Plus, it can help you avoid serious complications, especially if you're at higher risk.

High Risk

- Persons aged 65 and over
- Those with a long-term medical condition such as diabetes, heart or lung disease
- People whose immune system is impaired due to disease or treatment
- Persons with a body mass index (BMI) over 40
- Pregnant women (can be given at any stage of pregnancy)
- Residents of nursing homes and other long stay institutions
- Healthcare workers
- Carers
- People with regular close contact with poultry, water fowl or pigs

For more information log on to www.mccabespharmacy.com

McCabes are offering a FREE flu vaccine for PWCF this year!

MCCABES PHARMACY
ADVISE YOU CAN TRUST

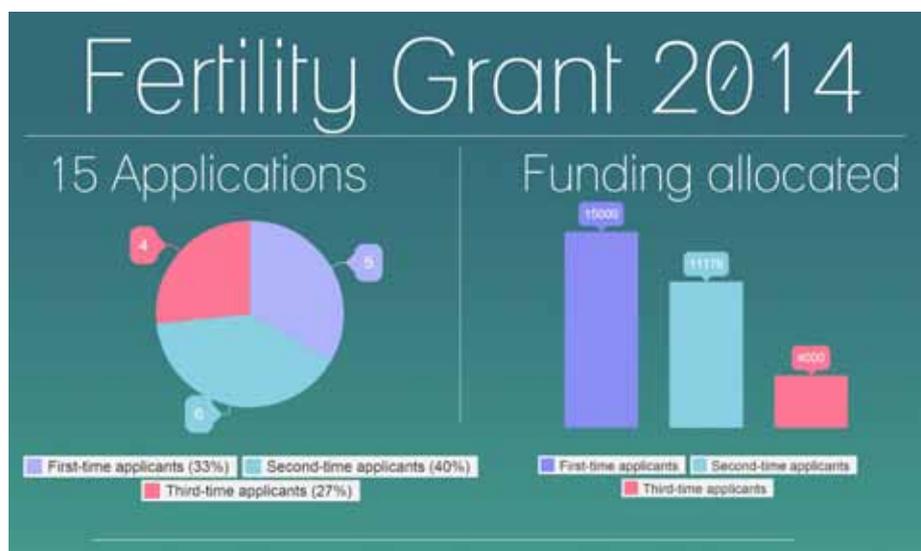
McCabes pharmacy will endeavour to space out appointments for PWCF half an hour apart. The vaccination will be conducted in a well ventilated area and our hygiene standards are impeccable. Fully trained pharmacists will administer the vaccination. The procedure will take approx. 10 minutes and you must allow enough time to remain in the pharmacy for 15 minutes after the vaccination.

Please ensure that you bring your Long-term Illness book or medical card with you. If it is a family member getting the vaccination, please bring the same with you and a source of ID.

For more information on McCabes Flu vaccination service please log onto: www.mccabespharmacy.com/health-checks/flu-vaccine-vaccinations-ireland

Fertility Grant Scheme 2014 — Now Closed!

The fertility grant scheme 2014 is now closed. We received a total of 15 applications to the round this year, all of which were approved.



Overview of Fertility Grant Scheme 2014			
	First-time applicants	Second-time applicants	Third-time applicants
Number of fertility grants awarded	5	6	4
Funding awarded	€15,000	€11,176	€4,000
TOTAL	€30,176		

Wishing all applicants the very best over the next few weeks and months. Please do stay in touch and let us know how you get on.

Exercise Grant Scheme 2014 — Round 2 Update

Round 2 of the exercise grant scheme 2014 is also now closed. We are still busy processing the last rush of applications that came in but will make contact with everyone shortly to let you know whether your applications have been successful.

Here is some feedback with received we recently received from members about the exercise grant:

"I really benefitted from the exercise grant. It was great to be able to go to the gym and use everything such as the treadmill, bike, cross-trainer and then I could go for a swim. I could really feel my chest clearing from exercising and I could do a lot more things during the day as well. Thanking you so much for the chance to join the gym and enjoy life — it really changed my life."

"I was granted an exercise grant last year and to say it has changed my life would be an understatement. I joined the gym and started training and since then I have had a massive increase in my physical health as well as my mental health."

Better Options 2014 – College Fair for Students with Disabilities

This year's Better Options college fair for students with disabilities and specific learning difficulties will take place in the National College of Ireland in the IFSC in Dublin on Nov 24th 2014 and will run from 10:00 to 13:00. This is an ideal fair for students looking to find out about courses and support services provided by colleges as well as garner key information on the access routes (for example the Disability Access Route to Education) for those with disabilities.



If you are in 5th or 6th year in school, this would be a great event to go along to if you are thinking of going to college.

Most of the major colleges will be represented in the Exhibition hall and seminars will run concurrently on the following topics:

- Getting the most from your Disability Service
- Looking after your mental health in college
- College 101: surviving freshman year

Registration is not required for this event, you simply need to turn up on the day. To find out more, logon to www.ahead.ie/betteroptions

From the Domiciliary Care Allowance to the Disability Allowance

Most parents of children with CF get the domiciliary care allowance (DCA). This monthly payment is not means tested and is made available to parents of a child under 16 with a severe disability and who requires ongoing care and attention, substantially over and above the care and attention usually required by a child of the same age.

However, the DCA payment will cease once a person turns 16. Notification should be sent to you a few months before the DCA ceases to inform you of this, and to recommend you to consider applying for the Disability Allowance (DA). **Transition to the DA is not automatic – you must apply for it!**

The DA is a weekly allowance paid to people with a disability from 16 years of age. This is the natural progression for most people with CF. Unlike the DCA, the DA is means tested (income from a spouse, civil partner or cohabitant is also taken into consideration). You are required to have your own doctor complete a medical report, which is part of the application form. We also recommend you provide a letter from the CF Consultant to support the application.

In the unlikely event the application is refused on medical grounds, please contact CFI and we can help support you through the appeals process.

The application form for the DA is available here: www.welfare.ie/en/pdf/da1.pdf

Tax Reliefs and Credits for Parents and People with CF – New Information Sheet

There are a variety of tax reliefs and tax credits that people with Cystic Fibrosis and parents of children with Cystic Fibrosis may be able to avail of. A new information sheet has been developed by CFI to highlight these various supports.

These include:

- Claiming Tax Relief on Medical Expenses through the MED1 form
- Incapacitated Child Tax Credit
- Tax Relief on Deposit Interest Retention Tax



So log on, get the facts and see if you are eligible for claiming some tax back! www.cfireland.ie/pdf/Tax_Relief_Credits.pdf

Respiratory Bugs Common in People with CF

We've been getting a few queries in the office recently about the different bugs people with CF are particularly susceptible to picking up.

People with cystic fibrosis are vulnerable to germs that can cause serious infections. These infections are often difficult to treat with antibiotics so it is important to keep these bugs from spreading.

We just wanted to remind everyone about our 'Respiratory Bugs Common in People with CF' information sheet which addresses some of the most frequently asked questions in relation to these bugs (Where do you get it? How do we treat it?).

You can view it online at www.cfireland.ie. Alternatively please contact the National Office and we can send you out a copy, or email amay@cfireland.ie.

SENSE-ational Mealtimes for families with fussy/picky eating and feeding difficulties

Does your child struggle at mealtimes? Are they picky eaters? Dr Denise Stapleton completed her PhD in nutrition education in CF in 2002 and edited the Australasian CF nutrition guidelines published in 2006. She has recently published a book in association with Gillian Griffiths on children who struggle at mealtimes, the causes and what you can do to overcome these issues.

The book has been very well received by parents of children with CF in Australia so we are sharing it with members in the hope it will also be of some benefit to you. Below is more information about the book:

Do you know a child who struggles to enjoy eating?

- He won't eat fruit
- She overstuffs her mouth or will only eat food in packets
- She turns food over and over before putting it in her mouth
- He has to have the same food in his lunch box every day, all separate and gets upset if one thing touches another
- She gets distressed when food sticks to his fingers
- He'll do cooking activities, but never tastes the food

Problems with feeding and mealtimes can make it extremely difficult for parents to make sure their children eat enough fruits, vegetables and foods high in iron.

How common are mealtime problems?

One in two infants and toddlers are reported by their parents to have feeding problems. Fussy or picky eating usually passes after a few months. However, mealtimes for some families with young children are fraught with ongoing grimacing, gagging, distress, anxiety, worry, frustration and anger.

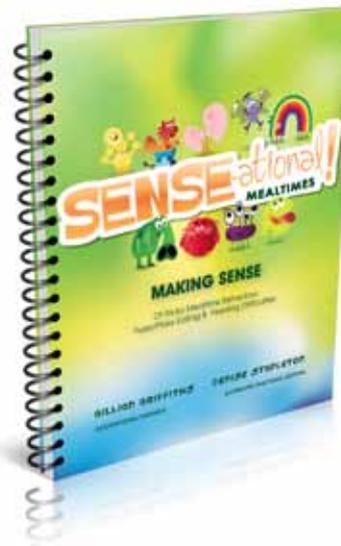
What causes mealtime difficulties?

Premature or complicated birth, early hospitalisation, medical or developmental conditions, pain, trauma, excessive stress, reflux, vomiting, ear, throat or chest infections, allergies, intolerances, and constipation can contribute to complex mealtimes. Post-natal depression, anxiety and stress can also make mealtimes tricky for some families.

What can families and caregivers do to help their fussy/picky eater or food refuser?

Make sure any medical, developmental and relationship issues that may be affecting mealtimes are assessed and well-managed. It is also important that parents and caregivers learn about their own and the child's sensory preferences for mealtimes.

The book costs AUD\$40 (€27.77) excluding postage and is available at: www.sense-ationalmealtimes.com.au



For more information:

www.facebook.com/pages/SENSE-ATIONAL-MEALTIMES/435323863214140

CFI recommend you speak with your CF Dietitian first and foremost should you have any concerns about your child's eating habits.

Get your workplace involved

Cystic Fibrosis Ireland has been fortunate to have a number of close partnerships with businesses and corporate organisations over the years. It's a vital area of income for CF Ireland and one that we need to maintain and grow as we continue our work to support and advocate for people with Cystic Fibrosis in Ireland. You can help CF Ireland build these successful partnerships.

Ways your company & workplace can support CF Ireland...

Charity Of The Year

The easiest and most identifiable way your company or business can provide support to CFI whilst also raising their own profile is by engaging in a Charity of the Year (COTY) partnership. A charity of the year is often chosen by employees! So you can nominate CF Ireland as the chosen charity and encourage your colleagues to vote for us!

If your business or workplace does not currently have a COTY partnership scheme in place, but you think they would be open to it, approach your employer. CF Ireland will be more than happy to provide you with additional information on CFI and the work we do.

Often most of the activities listed below would form part of the overall COTY partnership, but they are very simple ways to increase awareness of CF and to raise funds as stand-alone activities.

Sports & social events

Many companies host a variety of sports and social events throughout the year from coffee mornings & bake sales, to sports days, to quiz nights to golf tournaments in aid of CF Ireland. For us, these activities are crucial, not just in terms of raising funds, but also for raising awareness.

But, more importantly for the business it's a fun way for organisations to break down barriers and encourage team building between management, staff and different departments.

Dublin Airport Authority

Cystic Fibrosis Ireland was chosen as one of three partner charities for the Dublin Airport Authority for 2014. Along with Special Olympics Ireland and Jack & Jill Children's Foundation, CF Ireland will be the beneficiaries of this very valuable partnership. DAA staff voted for the charities involved. Over the course of 2014, DAA staff, and often their families and friends, are hosting creative and innovative fundraising challenges and events such as a crew of rowers who rowed across the Irish Sea, running, biking and hiking challenges, family fun days, a 'Phone-Free Friday' and a Hair-a-thon. Within the airports (Dublin & Cork) the branding of the 3 charities is present, and the 'loose change' towers are located in each terminal.



Investec

Investec held an enormously successful Charity day in 2013 when staff raised €160,000 for four different charities, one of which was CFI.

Cake sales, book and DVD sales, table tennis tournaments, playstation events, giant jenga games, cycling and twister competitions were just some of the events that took place.



We need your support!

Team for challenge events

Every year CF Ireland is fortunate to have hundreds of people participating in different sporting challenges in Ireland and overseas.

Events like the Women's Mini-Marathon, the Dublin Marathon, the Hell & Back, and Tough Mudder provide a perfect opportunity for workplace colleagues to come together as a group, raise funds, train, and participate. This year (2014) we had 5 workplace teams participate in the Women's Mini Marathon and one team of 30 in the Hell and Back challenge!

Our CF Ireland sports-style tech T-shirts are suitable for overprinting so you can print your team name/business name on the t-shirt we would provide. For more information on this, or if you have a team you would like to enter in an upcoming event, please let us know.

Give as you earn schemes

Give As Your Earn or Payroll Giving is an easy way for you and your colleagues to contribute to CF Ireland on a regular basis through payroll deductions.

Increasing research shows that employees want to work for companies that care, that social responsibility is a consideration in employees' decisions to join, stay with or leave companies, and that there is a link between social responsibility and engaged, productive employees.

It works very simply. By donating a fixed amount from your monthly salary – in addition to donations from your colleagues using this scheme – you can help make a big difference to the work of CF Ireland. If you choose to donate more than €250 a year (or €21 a month) through your payroll, your donations can have a double impact as CF Ireland can claim the tax back on the donations.

When Payroll Giving is included as part of a company's CSR initiative, such as Charity of the Year, Payroll Giving can provide a legacy of giving which continues long after the original partnership has ended. Contact us for more information.

65 Roses National Awareness Week

Every year, usually in April, CF Ireland launches National Awareness Week. This is a key period of activity for CF Ireland. All over Ireland our volunteers host a variety of events and activities, raising awareness and much needed funds for CF Ireland. One of the key ways this happens is through the sale of our '65 Roses' emblems. Every year, many of our volunteers sell these emblems at their workplace, often combining it with a coffee morning or bake sale. If you think your workplace would like to be involved in this way, please arrange it with your employer, and we can provide you with the appropriate fundraising pack.



For more information...

We would love to have the opportunity to discuss any of these ideas with you and support you in your workplace fundraising, and in getting your workplace involved.

Please contact Maria at businessforcf@cfireland.ie if you have any questions.



Chasing Continents and Creon (My life travelling with CF)

By Declan Houlihan, PWCF Age 32, from Co Kildare

It's the summer of 1999 and as a Manchester United fanatic I am celebrating one of the greatest seasons in our history, winning the league, FA Cup and the coveted Champions League. I walk around school with my head held high and all is good with the world. I am also excited as I am completing 5th year in secondary school so one more year until freedom! It is June and I am on my summer holidays, the persistent cough that I have had for more years than I care to remember is causing sleepless nights – not only for me, but for my family. Then, one morning my Mother raises me from my bed and says "Declan, I'm taking you to our GP for a check up". Nothing for me to worry about, after all I am a normal teenager doing normal teenage stuff, a bit skinny and constantly coughing with painful stomach cramps but otherwise fine.

"One thing you realise with CF is that life is short, so live for now"



In Bogota, Colombia



Declan arranged a 6 month supply of medications which fitted in a sports bag.

My GP takes one look at me and seems concerned, he takes some blood, looks at my fingers and sends me to my local hospital. There I am informed that I have a chest infection and a three or four day stay should do the trick. It's my first ever stay in hospital and I am more concerned about missing my upcoming 17th birthday. Day after day passes and test after test, I am becoming more anxious and eager to hang around with my friends. Then one day I am sent to Crumlin for a routine sweat test for an unheard illness – Cystic Fibrosis – I ask "what is that?". But not to worry it would have been diagnosed as a baby I am informed. A few days later and my doctors confirm I have CF. My parents look a bit stunned but I just want to get out of hospital and start taking the tablets – finally I might get rid of this cough! After being referred to St. Vincent's Hospital I begin to understand more and that this illness is a bit more serious than I thought, lung transplants, portable oxygen, enzymes and a life expectancy of about 31 years!!

My final year in school was interrupted by a stay in hospital but I did well in my Leaving Certificate even receiving a Special Contribution award from my school. I suspect they may have felt a bit sorry for me and my condition but I gladly accepted it. I had no interest in going to college as I did not know what I wanted to do. I gained employment with the Health Service as a Clerical Officer and spent my weekends having a few drinks with friends and going to nightclubs. I led a perfectly normal life with no hospital admissions and rarely missing work.

By the time I am 25 I finally get to fulfil a lifelong dream of travelling and living in Australia. Some friends and I booked round the world flights and we were off as I gained a one year career break. I didn't worry about bringing medication, nothing was stopping me. I arranged a 6 month supply which fitted in a sports bag, got some doctor's letters and off to Australia via New York, LA, Fiji and New Zealand. I had no problems at customs until Australia where an official took an interest in my medication bag – I smiled, opened my bag and showed my doctor's letter – after a quick inspection of the boxes I was free to go. Australia was a fantastic experience and not once did I become

ill. I worked long hard hours on a pearling boat for a month and 5 months with an investment bank. Overall I thoroughly enjoyed my time but without a recognised skill and the added complication of my illness the chances of staying permanently were slim. After then spending a month in South East Asia I returned home, glad to see family but missing the good weather and with a burning desire to travel again.

As I approached my late twenties I rented my own apartment, recommenced employment within the Health Service and met an amazing girl who was to become my wife. I continued taking very little medication and going for my three month check ups, aside from my first hospital stay in 11 years in 2010, I was doing great. Life was good as we both travelled Europe extensively but I still wasn't satisfied — my wife also had a desire to travel more so we made it our goal to see the rest of the world. One thing you realise with CF is that life is short, so live for now. I know that my chances of retiring with a pension and seeing grandchildren are slim, so make memories today. My wife and I had our perfect wedding and from there we worked and saved hard, even moving in with my parents! Finally our time had come and our dreams were about to come to fruition; actually second dream come true after I received the breakthrough drug Kalydeco in 2013, one of the few in Ireland to receive it.

Fast forward to today, I am 32 years of age and writing this article from Bogotá, Colombia. I left Ireland on July 23rd with a tear in my eye leaving family, taking my backpack and of course my six months supply of medication bulging from my hand luggage. Our itinerary is Central America, South America, Australia and Asia, after that who knows? My wife and I have twinned our love of travel with an online blog with travel information and up to date stories of our adventure. We hope to turn this into a living some day but if not at least to give hope to sufferers of illnesses, especially Cystic Fibrosis, that it can be achieved. I have been sick on this trip but luckily with some rest have made a full recovery. I have contact details of St. Vincent's and worst case scenario I can fly home if I feel too unwell to continue.

We are now in South America having completed Central America doing such things as volcano boarding, sailing and 24 hour bus journeys!! I understand that many people with CF cannot get the chance to do such things but I hope they can raise a smile or be with us throughout our documented adventures, my bulky medication bag won't slow me down, I just keep on breathing!

If you have any queries about travelling with CF or anything at all you can contact me at the following:

Follow me at: www.continentchasers.com

Facebook: www.facebook.com/continentchasers

Twitter: @ContinentChaser



Che Guevara street art in Cuba.



Declan with his wife in Nicaragua (Cerro Negro Volcano Boarding).

"I understand that many people with CF cannot get the chance to do such things but I hope they can raise a smile or be with us throughout our documented adventures, my bulky medication bag won't slow me down, I just keep on breathing!"



In Guatemala (Pacaya Volcano).



Flanders Peace Walk in Belgium May 2015 in aid of CF

Because 2014 marks the 100th year anniversary of World War One (WW1), there has been much interest in recent weeks about the involvement of Irish soldiers in that terrible conflict. The only part of WW1 where soldiers from Ireland north and south fought together was in the battle of Messines near the town of Ypres in Flanders, Belgium in 1917.

The all-Ireland Peace Park in Messines, with its well-known round tower and monument to the estimated 70,000 Irish casualties of WW1 will be the destination of a 12km walk for Peace in aid of Cystic Fibrosis Ireland's fund for organ donor awareness and transplantation. The walk will take place in May 2015 (dates being confirmed).

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 be given a further few months to fundraise a target of €400.

The Battle of Messines took place on a ridge and involved the detonation of 19 huge mines under the German trenches. We will stop at one of the craters created by a mine as part of the walk — now known as the 'Pool of peace'. These terrible explosions, heard in London, allowed the Irish divisions to capture their objectives with much fewer casualties than expected. However, a significant fatality was Major Willie Redmond, brother of Irish National Party and home rule leader John Redmond, who was killed at the Battle of Messines and is buried beside a nearby convent and war cemetery.

The Peace Walk

The 12km walk will be 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, Queen's University Belfast, who will be available to answer questions over the weekend. Walkers will be able to stop at important sights on the walk. A visit to the excellent Flanders Fields Museum in Ypres is a poignant and informative 'must' which will help walkers understand the First World War and the battles fought in Flanders. It is hoped to arrange an annual 'Peace Walk' up to the 100th anniversary of the Battle of Messines (1917-2017). The Peace walk is not only to remember all that were killed in the First World War but as a call for peace and justice in our present world.

Visit to Ghent

The weekend on which the walk will take place is planned as both a reflective but also enjoyable and informative experience for groups of friends, couples and individuals. On Saturday 9th May there will be a visit to the beautiful city of Ghent described by Lonely Planet as Belgium's 'best kept secret'. There will be plenty of time to sight-see and take in the lovely restaurants, sample the craft beers and take time to relax before the walk on Sunday.

For Cystic Fibrosis Ireland (organ donor awareness and transplant fund)

The Flanders 'Walk for Peace' is organised by Cystic Fibrosis Ireland. If we can recruit 100 walkers we estimate that we will raise a significant amount.

This funding will be used to support people with CF that are awaiting transplants. CFI provides financial assistance for accommodation, meals and transport incurred to members and their families who must travel for transplant assessment/ transplant. Individuals can be called many times before they are transplanted. We will also use the funding to help highlight and encourage organ donor awareness.

If you are interested, leave a message with Suzie or Peter in the fundraising team fundraising@cfireland.ie marked 'Peace Walk'. Why not get friends involved — it will make a great weekend! Participants must be 18 years or over and the usual cross infection regulations apply.

Blaas For Kids 2014 on WLRfm

What will you be having for your lunch on Friday October 24th? A nice red lead blaa and a cuppa anyone?

It's that time of year again. Blass for Kids on The Big Breakfast Blass on WLRfm is back for the fourth year, helping children in Waterford through our favourite foodstuff — the humble blaa.

The Big Breakfast Blass presenters Timmy Ryan and Karen Tomkins are delighted to announce that this year's chosen charity is the Cystic Fibrosis Project in Waterford. On Friday October 24th WLRfm will be out and about selling blaas to schools, businesses and in shopping centres raising money to for the new Cystic Fibrosis Unit at Unversity Hospital Waterford.

Currently, there are 22 children with CF attending UHW. Spells in hospital are frequent, and are often two weeks at a time as one Waterford Mum, Jenna Barry knows too well.



"My daughter Megan is five and has CF, she's in senior infants now doing what most children her age are doing. However she has to do a lot of physio and exercises every day which make her tired but she's a very happy little girl. When Megan has to go into hospital, it's for two weeks at a time and there's a lot to it. The rooms are very small, you can't have other visitors because of cross-contamination and she can't be near other CF children in the ward."

Already this year, enough funding was raised by the Cystic Fibrosis project to build a dedicated CF Unit in the hospital. However, as committee member Stan Bergin points out, this is just enough to build a structure and it's the fitting-out of this unit that is equally costly in ensuring an easy stay while in hospital for the kids. From beds for parents, armchairs, Tvs and brackets to the added extras, much more funding is needed.

"Even though CF children can go home for a few hours daily during hospital spells, Jenna says hospital can be a tiresome place. "Between IVs and drips they can get bored sitting in a small room. iPads and phones are great and reading books or watching television but it will be great to have the unit built and fitted out for Jenna and lots of kids like her."

So how can you help? WLRfm will be selling blaas in a number of outdoor locations in Waterford city and county. Timmy and Karen and the CF Project members will be delivering blaas to schools across the county that day. Your school or workplace can telephone the Blaa hotline on 051-872248 to pre-order your delivery of freshly made blaas with filling and blaas sponsored by Countrystyle Foods and M&D Bakeries. Give what you can and make a big difference. It's a date for your diary!

The Big Breakfast Blaa on WLRfm 7am-10am Monday – Friday.

For more information contact:

Karen Tomkins

WLRfm

051-872248/ Karen.tomkins@wlrfm.com

Challenges and Events

Dublin Marathon 2014

The 35th SSE Airtricity Dublin Marathon 2014 takes place October Bank Holiday Monday and registration is open: www.dublinmarathon.ie

Get involved...We are looking to get a team of 50 people to take part in the marathon this year. This will be our biggest team yet!

To register to join the CF Ireland Team and to receive a race pack and singlet please e-mail fundraising@cfireland.ie



Remembrance Run 2014

The third annual Remembrance Run 5k will take place in the Phoenix Park on Sunday, November 9th. This year's Remembrance Run, which is open to walkers, joggers and runners, will again have a Special Remembrance Theme of Family or Friends passed, or who may be currently struggling with illness or other life challenges.

This is a truly unique event with a wonderful atmosphere — commentary, music and a special Wall of Remembrance that was filled to capacity last year with signatures and special messages last year.

If you want to take part in the remembrance run in aid of CF Ireland, register at www.remembrancerun.ie and then contact the CFI fundraising department to receive your fundraising pack: fundraising@cfireland.ie

International Marathons

If you would like to set yourself the ultimate running challenge, and raise funds & 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.

Volunteers Needed for 2015

CF Ireland recently attended the DCU Volunteering EXPO held on Thursday 2nd October at DCU (see photo below right). The EXPO took place in the Students Union and there were loads of great causes there looking for volunteers.



The CF Ireland stand was busy with many students enquiring about the work we do on behalf of PWCF and their families and how they could help us through volunteering or fundraising.

We would love to hear from anyone who would be interested in volunteering to help us with our National Awareness Week which will take place next year from 20th-24th April 2015. 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 practices 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 a 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 a permit or not.

Thank you for your continued support!

The CF Ireland Fundraising Team

Thank You

Tough Mudder 2014

Were you Tough Enough...for Tough Mudder?

A huge congratulations and thanks to Pat Divilly and his team for successfully recruiting over 500 participants for the Tough Mudder Competition. Their unbelievable recruitment drive helped them raise an amazing €100,000, with the figure still rising! With the fundraised money going to CF Ireland and the CF Galway Hospital build, we are so delighted with the support, enthusiasm and hard work that Pat has given to us as our official CFI Ambassador.

A huge thank you to everyone who took part on the day and helped Pat and his team reach the €100,000 target! It was great to see so many Tough Mudder's representing people with CF.

For more information on Pat Divilly – fitness guru, motivator, and CF Ireland Ambassador – go to his Pat Divilly Fitness Facebook page: www.facebook.com/PatDivillyFit



Pat Divilly – fitness guru, motivator, and CF Ireland Ambassador.



Tough Mudder Race Day.



Tough Mudder Race Day participants.

Paris2Nice Cycle Challenge

A huge THANK YOU to the CF Ireland Paris2Nice team – who successfully completed a gruelling 700km cycle from Paris to Nice.

Through various fundraising events prior to their departure they have managed to raise an amazing €75,000+. Thank you to everyone on the team and to all the people who took part in fundraising for this great event.



Members of Paris2Nice cycle group after finishing the 700km cycle!

DAA Charity Cycle

Thank you to everyone who took part in the DAA Charities Of The Year fundraising cycle that took place on Saturday 27th September. We were there to see off the cyclists taking part in the 110km route starting from Dublin Airport.

We got pictures at the starting point with DAA staff and members from Jack and Jill Children's Foundation and Special Olympics Ireland.

Special thanks to Joe Broly who came along, as an ambassador for CF Ireland, to lend his support!



DAA staff and members from Jack and Jill Children's Foundation, CF Ireland, Joe Broly and Special Olympics Ireland.



DAA Charity Cyclists at the starting point!

Austria Walk 2014

This year saw the Paddy Kieran's International Memorial Walk 2014 take place in Austria. With 32 walkers on board the event proved to be the 'best walk yet'! Taking in the sites of Zell Am See and Salzburg the walkers got to experience the amazing countryside and scenery during 6 days of walking. This year saw the addition of Mary Duff as our official CF Ireland Ambassador and she brought great entertainment to the event.

Check out some of Mary's great videos of the trip on her official Facebook site — www.facebook.com/pages/Mary-Duff-Official.

Thank you to all the walkers who took part this year. The venue for next year's walk has been decided and Montenegro will be the destination! If you would be interested in joining next year's walk please contact Suzie on sbrock@cfireland.ie or call 01 4962433



The Paddy Kierans Memorial Walk 2014 Group.



Walkers on the mountains in Zell Am See.

Eden Tri Club 5 Mile Challenge

Well Done to everyone who took part in the Eden Tri Club 5 mile Challenge on Sat 27th and Sun 28th September raising much need funds and awareness for CF Ireland.

Pictured are Alan Connolly, Aidan Swords and Michael Collins who took turns in running the infamous Drumcooley 5 mile route over 24 hours and they were joined by many other runners/walkers along the way. A great time was had by all and they are already looking forward to next year.



Alan Connolly, Aidan Swords and Michael Collins at the Eden Tri Club 5 Mile Challenge.

Race Around Ireland Challenge

Congratulations to Barry Gaynor and the Team Celtic Media team who finished 2nd overall in the Race Around Ireland Cycle Challenge. They crossed the finish line after cycling 2150km in 78 hours!!

Well done to all involved.

City to Surf 14km Run in Sydney

A huge thanks and congratulations to Ciara Fagan and all her team who participated in the City to Surf 14km Run in Sydney Australia to raise funds for CF Ireland.

Aisling Maloney – Skydive

A huge thanks to Aisling Maloney who took part in a Skydive in aid of CF Ireland and raised an amazing €1,300!! Well done Aisling and thanks for your support!

If you or anyone you know would like to take part in a Skydive please contact Peter on fundraising@cfireland.ie and we can help take you to 10,000ft.

10th Meath Skryne Scout Group

Many thanks to Brian Leonard and the members of the 10th Meath Skryne Scout Group who presented Philip Watt, CEO CFI, with a cheque for €545 that they raised throughout the year. Philip met with the group and explained about Cystic Fibrosis and the work of CF Ireland.

Thank you to everyone involved for the warm reception. The continued support of the Scout groups around Ireland is greatly appreciated!



Winners of the Race Around Ireland Cycle Challenge.



Ciara Fagan & friends in Sydney, Australia.



Aisling Maloney after her successful skydive.



10th Meath Skryne Scout Group.

HeadzHead Walk for the 'Beds for Beaumont Campaign'

On Sunday 7th September, over 180 walkers took on the challenge of walking from Howth Head to Bray Head in aid of our 'Beds for Beaumont Campaign' and a fantastic day was had by all.

The start point at Howth was a hive of activity from early morning as the walkers prepared to set off on the 24 mile route which took in the beautiful surrounds of Dublin Bay, made all the nicer by the lovely sunshine that we enjoyed.



Walkers in Howth at the start of HeadzHead Walk 2014.



Some of our walkers at the halfway point in Sandymount.



Taking a break in Sandymount.

Most walkers enjoyed a well-earned break at Sandymount Strand and even more walkers joined us here to participate in the second leg of the walk.

There was a great atmosphere at the finish point in The Strand Hotel in Bray where participants received well deserved refreshments after a long days walking. A BIG THANK YOU to all those who took part and to those who helped in the organising and running of this successful event.

Anyone who has sponsorship money to lodge please use the following bank a/c details for our Beaumont A/C and remember to put in a reference so we know who it's from.

Beaumont account:

IBAN: IE60 AIBK 9310 7111 8352 53

BIC: AIBKIE2D



Happy walkers at the finish point in Bray!



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 text cost goes to charity across most network providers. Some providers apply VAT which means a minimum of €1.63 will go to CF Ireland. Service provided by LikeCharity 01 4433778.

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