

SPECTRUM

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Issue 24: Nov/Dec 2011

www.cfireland.ie

Dear All,

All of us in CFAI hope it goes well for you over the next few weeks in the run up to Christmas and, as this is the final issue of 2011, we wish you season's greetings and the very best for 2012.

This issue of *Spectrum* features the opening of the new CF unit at Crumlin hospital and the ongoing work around the country, including the fantastic work of our Branches – there is certainly a stronger sense of our Association working together to achieve our goals even in an increasingly more difficult environment.

This stronger sense of purpose is reflected in the progress we have made in CF Centres around the country. It is also evident in the well-attended Board meetings, chaired by John Coleman, and the advice and expertise provided by our Medical and Scientific Council, chaired by Dr Barry Plant.

We hope that this renewed sense of purpose is also reflected in your area, but we commit ourselves to redoubling our efforts in 2012, and we realise we still have much to do to improve services for people with CF in Ireland. Our Annual Report, which will be published in January, will provide you with a full report of our work this year.

To assist in the work of our Branches, a new Regional Worker (1 year post) will be commencing after Christmas, funded by CFAI and TLC4CF. This post will help with the immense efforts of the Branches in the Tipperary, Limerick and Clare area, which are well down the route of building a new CF centre for adults in the Mid-Western Hospital in Limerick.

We will of course be watching what happens in the next Budget to see what impact it will have on people with CF and their families. We welcome that the Government have recently promised that people on the long-term illness scheme will be able to avail of free GP visits from March 2012.

On a festive note, De Dannan including renowned musician Frankie Gavin will be playing two major fundraising concerts for CFAI in Tuam, Co. Galway (19th December) and Ashbourne, Co. Meath (20th December). The band will be performing songs and ballads, including favourite Christmas hymns and carols. Check out our website for further details on what will prove to be a really special night.

With best wishes to you and your family this Christmas,

Philip Watt (CEO)

Alica May (Editor)

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

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LATEST NEWS



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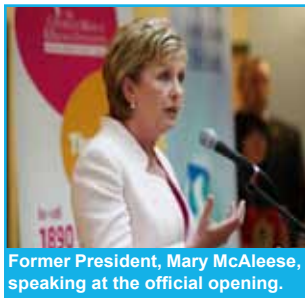


NEW CF WARD OPENS IN CRUMLIN HOSPITAL

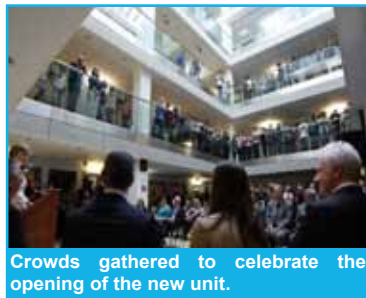
Former President Mary McAleese at Official Opening

The new four bed in-patient ward at Our Lady's Children's Hospital Crumlin was officially opened by former President, Mary McAleese, on 4th October 2011. The event was very well attended by friends of the Association as well as family members, past and present. Members of the CF multi-disciplinary team also came along to celebrate the official opening of the new unit.

In the former President's speech, the opening was described as a watershed moment for the hospital management and staff and, most especially, for children with cystic fibrosis and their families.



Former President, Mary McAleese, speaking at the official opening.



Crowds gathered to celebrate the opening of the new unit.



'A huge thank you from the bottom of my heart', Bevin Murphy (PWCF).

The CFAI provided €750,000 towards the development of the four bed ward, which came from three main sources – the Shane Kinsella Foundation, the '1 in 1,000' mini-marathon initiative in 2010, and other fundraising from the CFAI. CFAI would again like to extend sincere gratitude to the Shane Kinsella Foundation and the '1 in 1,000' team for their huge fundraising efforts.

'This entire project has come to fruition because of dogged determination and an ambition to improve life for those with CF. The journey is far from over but this is a very good point at which to stop just for a moment and draw breath in celebration of a milestone reached and a new more optimistic era that will follow because of it. That same drive and capacity for hard work, for struggling against the odds, is the energy that will change the future for CF patients. I hope this new unit will have even more stories of achievement reached in the years ahead.'

'We owe a massive debt of thanks to The Cystic Fibrosis Association of Ireland for providing funding for the development of this unit and for all the work of overcoming that has been done on behalf of people with CF in terms of treatment, facilities, information, advice and the all-important research, which it is hoped will in the end comprehensively overcome CF.'

Former President Mary McAleese



The origin of this project came from the 'Pollock Report', an independent review of cystic fibrosis services in Ireland that was commissioned by the CFAI. Our Lady's Children's Hospital in Crumlin was identified as a crucial part of the framework to improve CF facilities for children in Ireland.

CFAI also paid tribute to Dr Gerard Canny by presenting him with an award to thank him for all his work with children and young people with CF over many years, and to wish him a happy retirement.

The CFAI would again like to fully acknowledge and thank the Board of Crumlin Hospital, its CEO, to the project manager, Michael Kearns, the CF multi-disciplinary team led by Dr McNally and formerly by Dr Gerard Canny and Dr Barry Linnane. The team includes consultants, CF nurses, dietitians, physiotherapists and social workers. The CFAI would also like to thank the Children's Medical and Research Foundation who funded refurbishment of the existing ward.

To read the full speech by former president Mary McAleese, please go to the following link:
www.president.ie/index.php?section=5&speech=1011&lang=eng

With thanks to Our Lady's Children's Hospital Crumlin for permission to reproduce photos.



WHY WE NEED SPECIALIST CF STAFF

Focus on Physiotherapy

Cystic fibrosis is a complex disease requiring a holistic approach to treatment. Centre care by a team of trained and experienced health professionals is essential to ensure the best outcomes for patients.

Specialist care in dedicated CF centres is associated with improved survival and quality of life. Such care involves frequent clinical evaluations and monitoring for complications by a physician led multi-disciplinary team for the management of CF and early treatment interventions. This approach to CF care is accepted by the HSE and is based on the recommendations of the CFAI's Pollock Report and the standards set out by the European Cystic Fibrosis Society (ECFS).

Unfortunately there have been instances in recent months where members of multi-disciplinary teams who are on extended leave due to maternity or illness, or who have moved jobs, have not been replaced by experienced CF specialised staff. This appears to be as a result of a combination of cutbacks, inadequate planning within hospitals and a worryingly lack of understanding by decision makers on the need for specialised CF staff, despite accepted government policy.

After significant lobbying in recent weeks, one of these decisions has since been reversed. However, there remains problems. For example, one CF centre has been without a specialised CF nurse since August 2011.

Take the role of the CF physiotherapist as an example. The physiotherapist should be involved in the evaluation of patients, providing advice on airway clearance techniques, quality control, and professional development. This role cannot be left to a physiotherapist with little or no experience in CF as this it could lead to a significant risk in patient care. Yet there have been instances in recent months where the HSE have attempted to employ inexperienced physiotherapists to manage the care of both children and adults with CF.

According to European guidelines (ECFS), the CF centre physiotherapist should assess patients every 1–3 months or at every out-patient clinic visit by:

1. Carrying out and interpreting the results of pulmonary function tests and respiratory symptoms and signs and exercise capacity
2. Monitoring sputum volume and characteristics, and the degree of dyspnea
3. Assessing posture, chest mobility, muscle strength and endurance
4. Evaluating treatment quality and adherence

Education and treatment compliance are further important dimensions to the role of the physiotherapist.

The CFAI, working with multi-disciplinary teams and HSE staff, will continue to monitor the impact of cutbacks on CF care and will continue to intervene where HSE decisions impact on patient care and standards.



CF AND GENETIC SCREENING

In the Papers Recently

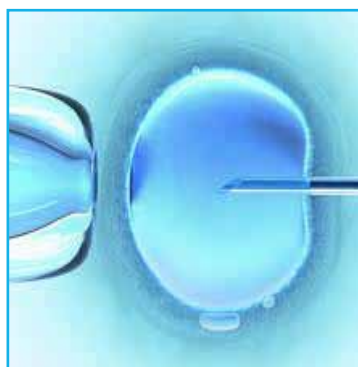
According to the Irish Times (22 November 2011) and the Irish Daily Mail (23rd November 2011) several clinics in Ireland are planning to offer genetic screening of embryos next year. The Irish Times reports:

'The move is likely to spark controversy among ethical campaigners who fear it could eventually lead to embryos being screened for minor deficiencies or even sex selection. However, many health professionals say the screening of embryos could play a vital role in preventing miscarriages and the inheritance of debilitating genetic conditions.'

At least three clinics, two in Dublin and one in Cork, are planning to obtain permission from the Irish Medicines Board to begin offering the procedure from 2012 onwards.

Pre-implantation genetic diagnosis, which involves testing embryos for conditions such as Huntington's disease, haemophilia and cystic fibrosis, is increasingly being used across Europe.

It involves taking a single cell from a three-day-old embryo and testing it for disease, while allowing the remaining cells to grow before being placed for implantation in the womb. The clinics in the Republic plan to send these cell samples to specialist facilities in Britain for testing.



While there are no laws which govern assisted human reproduction in Ireland, there is an EU directive over the use and storage of tissue used in in-vitro fertilisation (IVF) and other procedures.

The Irish Medicines Board is obliged to approve any procedures in line with this. A spokeswoman for the board was unable to comment yesterday on the likelihood of approval being given for pre-implantation genetic diagnosis screening.

However, many health professionals are confident they will obtain permission given that the practice is widespread across Europe.'

Comment from CFAI

At present, the CFAI has no policy position on pre-implantation genetic diagnosis. We would get the sense from calls received in the National Office that some of our members appear to be in favour of such developments and others against. We would be concerned about the lack of legislation in this area in Ireland to guide the standards of centres offering such procedures. We would call on the government to develop legislation in consultation with patient groups.

Furthermore, there is an immediate need to ensure that adequate resources are provided to enable families to access independent genetic counselling on all issues related to CF, including to the National Centre for Medical Genetics in Crumlin.

The CFAI will be drawing up a discussion paper over the next few months on this and related issues and we would welcome everyone's views on the sensitive and complex issues that are of interest to our members.



EUROPEAN CF CONFERENCE IN DUBLIN

Call For Volunteers!

35th EUROPEAN CYSTIC FIBROSIS CONFERENCE
6 - 9 JUNE 2012 | DUBLIN, IRELAND



Volunteers are needed for the European CF Society Conference in Dublin, June 6th-9th 2012 and for some of the the days leading up to the Conference. The 2012 ECFS conference coincides with the 50th anniversary of the CFAI and the 20th anniversary of the last time the conference was held in Dublin.

As readers of *Spectrum* will know, the convention centre in Dublin will be the venue for the ECFS Conference next year. The conference attracts around 2,000 participants and there is a huge amount of work in staging such an event. CFAI is committed to helping out as much as possible. We will need at least 60 volunteers to help out over the three days of the conference and in the days leading up to the conference. Some of the tasks include helping with:

1. Conference Bags Packing
2. Self-Printing Terminals
3. Conference Material
4. Poster Helpdesk
5. Entrance Control
6. ePosters
7. ePoster Corner
8. Social Events
9. Speaker Preview Room
10. Internet Café
11. Helping to dismantle the conference
12. General assistance to participants



The ECFS conference will take place at the Convention Centre in Dublin.

In return for helping out, volunteers will be able to access some of the conference free of charge. T-shirts and meals will be provided and for particular tasks there will be training and support as necessary. The CFAI will be working with the conference organisers to co-ordinate volunteers and we need your help. An application form and guidance will be available on our website. We would particularly encourage volunteers who have an interest in the medical and scientific dimensions of CF.

CFAI ANNUAL CONFERENCE

13th-15th April 2012 in Whites Hotel, Wexford

We are pleased to announce that the CFAI Annual Conference 2012 will be taking place in Wexford on the 13th-15th April 2012 in Whites Hotel, Wexford town. Booking rates are not yet available but we will be sending out further information in due course.

If you have any questions please contact Suzanne in the office on 01-4962433 or email info@cfireland.ie.



ZOE WOODWARD RECOGNISED AS 'MUM OF THE YEAR'

SMA Nutrition Maternity and Infant Awards 2011

Zoe Woodward, mum of two little girls with Cystic Fibrosis and member of the CFAI, was given special recognition last week at the annual SMA Nutrition maternity and infant awards.

Zoe was honoured for her outstanding fundraising campaign which resulted in raising €200,000 to help the Cystic Fibrosis Association of Ireland fund a new children's in-patient CF unit at Our Lady's Hospital for Sick Children Crumlin (see first news article in this issue). Zoe picked up the Mum of the Year accolade at the awards which took place in the Shelbourne Hotel, Dublin on November 18th.



'Mum of the Year' Award 2011 went to Zoe Woodward, who has two little girls with CF.

With the help from her friends, Zoe launched the 1 in 1,000 mini-marathon initiative in 2009, which was a call for 1,000 women to take part in the Flora Women's Mini-Marathon and help raise vitally needed funds to go towards the new unit at Crumlin. What is even more outstanding is that Zoe launched and co-ordinated the campaign while pregnant with her third child and actually ran the marathon three weeks after giving birth!

This was an enormous achievement by any standards but what makes Zoe exceptional, according to her friend Jaime who nominated her for the award, is how she manages to achieve all this and still raise three young children.

From the outset Zoe and her husband Dave ensured that they researched the disease thoroughly and they continue to keep up to date with the latest research.

As part of their daily routine, Zoe and Dave must carefully plan the girls diet to try and maximise the nutrients they get from their foods. As well as this the girls must take enzymes when they eat, which they do without complaint. Physiotherapy and exercises is also a key part of their daily routine to avoid a build-up of mucus in their lungs. Due to Zoe and Dave's positive and encouraging attitude for both Emily and Lana, their daily treatment and exercises are part of 'normal' life.

The judges deemed Zoe truly worthy of the title of 'Mum of the Year' as they felt she was a true inspiration to other mums, showing just what love for your children and a drive to ensure the best future possible for them can achieve.

Now in their fourth year, the 2011 maternity & infant awards were sponsored by SMA Nutrition, a wholly Irish brand that has played a major part in the lives of many Irish mums and kids around the country for decades. The awards will be broadcast on TV3 on December 5th.

For more information visit www.maternityandinfant.ie



TOBI® PODHALER® FOR PWCF

Launched by Novartis on 22nd July

TOBI Podhaler is a new dry powder form of tobramycin for treating chronic *Pseudomonas aeruginosa* lung infection in CF patients over six. Data shows that the new formulation reduces administration time by 72% compared with TOBI, with same efficacy¹ and using a more convenient, patient-friendly device.

The TOBI® Podhaler® was approved for use in the European Union on 22nd July 2011. EU approval was based on data showing that TOBI Podhaler provides the same efficacy² as TOBI® (tobramycin solution) with a comparable safety profile². TOBI is the most widely used inhaled antibiotic for chronic *Pseudomonas aeruginosa* infections in CF³. TOBI Podhaler has a unique dry powder formulation, developed using novel PulmoSphere® technology to produce particles that are light and porous for deep delivery into the lung. This means treatment can be given with a portable, patient-friendly device, in contrast to TOBI which is administered with a nebulizer.

Data show that patients using TOBI Podhaler completed their tobramycin treatment in 5-6 minutes instead of 20 minutes with TOBI, a reduction of 72%¹. Nebulized treatments require additional time for assembly and disinfection, unlike TOBI Podhaler, which also does away with the need for refrigeration of the active compound and a power source for the delivery device. A study found that patients treated with TOBI Podhaler had significantly higher treatment satisfaction than those treated with TOBI¹.

Due to the complexity of existing anti-*Pseudomonas aeruginosa* treatment, most patients do not fully adhere to their therapy^{3,4,5}. In addition, many patients do not clean their nebulizers properly and these are often contaminated^{6,7,8,9}. With TOBI Podhaler, the inhaler device is disposable and the dry formulation potentially reduces the risk of bacterial contamination.

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(Extract from Novartis Press Release: www.novartis.com)



FREE GP VISITS FOR LTI CARD HOLDERS

Announcement from the Minister for Primary Care

Minister for Primary Care Roisin Shortall has announced that people registered under the long-term illness scheme will be able to avail of free GP visits from March of next year – they already receive free drugs under this scheme.

Following this, from March 2013, patients on the high-dependency drugs scheme will also no longer pay GP fees. These changes will give free GP care to an additional 100,000 people. The move is in line with the Programme for Government, which promised to introduce free GP care on phased basis, with free GP care for the whole population set to be introduced by around 2015

UPDATE ON NEW VERTEX DRUG

Application submitted to the US Food and Drug Administration for Priority Review

Vertex Pharmaceuticals, Inc., announced in October that it has submitted an application to the U.S. Food and Drug Administration (FDA) for a potential new CF therapy, VX-770 – under its new proposed trade name, KALYDECO™. If approved, it will be the first drug on the market that targets the underlying cause of CF. Therapies available to people with CF to date only treat symptoms of the disease.

Vertex has asked the FDA for priority review of the potential drug, which, if granted, could shorten the review from 10 to 6 months. The FDA grants priority review status for several reasons, including in situations where a potential drug is considered a major treatment advance.

The company is seeking approval for the drug in people with cystic fibrosis age 6 and older who carry at least one copy of the G551D mutation of cystic fibrosis. Results released earlier this year from Phase 3 clinical trials of KALYDECO in people with the G551D mutation of CF showed that those receiving the drug had remarkable and sustained improvements in lung function and other key symptoms of the disease, compared with those on placebo.

As FDA review of the potential drug gets underway, Vertex has set up a program to provide KALYDECO to people age 6 and older with the G551D mutation who are in critical medical need and could benefit from the treatment prior to potential approval.

KALYDECO (kuh-LYE-deh-koh) was discovered in a collaboration between Vertex and the Cystic Fibrosis Foundation, which provided substantial scientific, financial and clinical support throughout the development process.

For the latest information on this topic, please log on to: <http://investors.vrtx.com/press.cfm> or check the Cystic Fibrosis Foundation website at: www.cff.org/research/ClinicalResearch/FAQs/VX-770/



LOVE YOUR LUNGS CAMPAIGN

New Public Awareness Programme

Healthcare professionals and medical/patient advocacy groups are coming together as the 'Lung Health Network' to organise a public awareness campaign to focus on the importance of lung health in Ireland in a campaign called 'Love Your Lungs'.

The campaign will kick off on St Valentine's Day, 14th February 2012 and will highlight a new awareness week 'Love Your Lungs' 25th-29th June 2012, which includes 'World Spirometry Day', 27th June 2012. It is hoped that this campaign will emphasise the early signs of lung disease and encourage individuals to be aware and proactive in relation to their lung health.

The campaign will be co-ordinated by the Lung Health Network which brings together bodies concerned with lung health in general, but with a particular interest in the following list of conditions:

- Asthma
- COPD
- Lung cancer
- Pneumonia
- Tuberculosis
- Cystic fibrosis
- Sleep apnoea
- Interstitial lung diseases
- Influenza
- Alpha-1 Antitrypsin Deficiency

'Communicating information about maintaining lung health is often difficult due to the complexity of factors that influence lung health. The aim of our campaign is to send out a simple clear message on the importance of looking after your lungs to promote overall health and well being.'

The most powerful way to do this is by bringing together the broad spectrum of organisations involved in promoting lung health, to speak with one voice.'

*Dr Edward McKone,
Incoming President of the Irish Thoracic Society*



UNDERSTANDING THE VIRULENCE OF CF PATHOGENS

EU COST Action

BM1003 is a research project supported by COST (European Cooperation in Science and Technology).

The overall aim of the project is to increase our understanding of the mechanisms of infection caused by opportunistic pathogens and the immune response in patients with CF in order to translate this knowledge into new therapies to prevent lung infections. It is hoped that this group will also help inform research policy makers in the EU regarding the challenges in terms of treating CF infections, and the need for future research funding in this area.

It is estimated that the cost of activities carried out under the Action will be in the region of €44 million over a period of 4 years.

Reasons for the Action

The major reasons for launching this Action are to rapidly develop novel therapies for CF and non-CF patient groups at risk for lung infections with opportunistic Gram-positive and Gram-negative bacterial pathogens. This aim will be achieved by the co-ordination of researchers into a European network of the already funded national research. Networking will also avoid repetition or duplication of scientific work and thus spare valuable resources of prior isolated research groups in Europe. A defined panel of clinically relevant bacterial pathogens will also be created as an open user resource.

This COST Action will enable researchers to develop novel inhibitors of bacterial cell wall synthesis with the aim to reduce lung inflammation in CF airways and to eradicate the pathogens with novel treatment strategies. This will increase the life expectancy of the CF patients. The pathogens that will be studied are also known to affect other patient groups including patients with immunodeficiencies, such as burns patients and ventilated patients in critical care units.

Improvement in knowledge of bacterial pathogenesis would have important implications for these patient groups, the quality of life of affected individuals, and with the potential to reduce the inappropriate use of currently administered antibiotics, which increase the number of resistant pathogens in the European community.

Who is involved?

Researchers across 16 countries of the European Union are involved in this study. Dr Siobhan McClean (Institute of Technology Tallaght), Prof. Brian Harvey (Royal College of Surgeons in Ireland) and Dr Maire Callaghan (Institute of Technology, Tallaght) are the Irish partners involved in the Action.

For further details on the Action, please log on to: <http://cost-bm1003.info/scientific.html>.



GRANTS & PUBLICATIONS

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SECTION 03

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EXERCISE GRANT SCHEME 2012

Details to be Announced in January

The Exercise Grant Scheme was once again a huge success in 2011, with over 230 grants being awarded to adults and children with CF. CFAI committed a total of €60,000 to the scheme this year with grants being awarded for a range of activities including swimming, horse-riding and gymnastics lessons, trampolines, gym memberships, weights and rowing machines to name but a few!

Details on application procedures and deadline dates for the Exercise Grant Scheme in 2012 will be announced in the next edition of *Spectrum*.



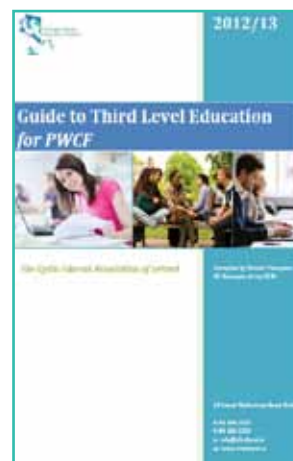
GUIDE TO THIRD LEVEL EDUCATION FOR PWCF

Now Available!

The 'Guide to Third Level Education for PWCF' is now available on the CFAI website.

It contains up to date information on application procedures for students with disabilities considering entering third level, and outlines financial supports available through, for example, the student grant scheme, back to education allowance and other bursaries, funds and scholarships.

The Guide also has tips for finding accommodation if you are moving away from home for the first time, and some PWCF have also provided accounts of their experiences in college. Please contact the National Office if you would like a copy posted to you.





HANNAH KETT

Child with CF, Age 8, from Co Clare

The following article was written with the help of Hannah's Mum, Deborah Kett.

Hi. My name is Hannah Kett and I have CF. I am 8 years old and I live in Co. Clare with my Mammy, Daddy, my brother Mikey and our dog Sammy. I'll be 9 in January – I can't wait to get birthday presents and birthday cake!

I have my letter to Santa written and posted. I have asked for a "Hello Kitty" camera with a case and Monster High Shopping Mall dolls. Mammy said I've been good this year so hopefully I'll get those things. Mikey wants Lego City Harbour from Santa but I don't know if he was good – I'm not sure! I think he should get them as long as he's nice to me!



Hannah at her First Holy Communion.

Mammy says I was diagnosed with CF when I was 14 months old. It came as a big shock to my parents as they didn't know anything about CF, how serious it was and as my mammy says "there was no history of it in either side of the family!" I know a lot about my illness and how it effects me. When I get sick or have to have some tests done in the hospital, everything is explained to me so that I understand what is happening to me and why I feel so bad. My parents also tell me why I have to take all my medicines.

Freddie is my implantofix so that means I don't have to stay in hospital for i.vs anymore because Mammy does them all at home, which is cool! I've been to Crumlin a few times to have my lungs cleaned out (bronchoscope), but my doctor is in Limerick hospital and that's where I go for my check-ups and if I have to stay for a few days if I'm really, really sick.

We went on holidays to Disneyland, Florida last year. I had to stay in hospital for a while because I got quite sick. But we saw a cool lightning storm, a spaceship fly off into space and we became good friends with Nurse Karen.

I'm in 3rd class now in the Gaelscoil and Angela is my teacher's name. She is lovely and all the teachers are really nice to me, as well as Donál the Principal and Lorraine the Secretary. I am the only person in my school with CF. I get home tutoring to help me keep up with my friends when I miss shcool. This year I am getting 3 hours of home tutoring a week (the amount of hours you get depends on how many days of school you miss). I've been doing tutoring since I was in Junior Infants and I think it really helps me to understand what is going on in class so I don't get confused or left behind in my lessons.



Before my First Holy Communion I also learned how to use a Bi-Pap machine by sticking my head out of the car window while Mammy was driving – that was funny! So when I went to hospital to properly learn how to use it, it was SO easy. I also had to lie in a ‘doughnut’ machine and have warm ink put into my vein and then have a special picture of my lungs taken (CT scan). I get a lot x-rays taken every year and once a year I have an ultrasound which involves a freezing cream being put on my tummy and then funny pictures are taken through a special wand.

My best friends in the whole wide world are Seoda, Sarah and Jamila. They are in 3rd class with me and I love them! Mikey is in 1st class and his best friends are Piaras, Jack, Noah, Odhrán and Darragh. I live beside my cousins, my aunt and uncle and my grandad. They are all my Daddy’s family and my Nana and my Mammy’s family live in Dundalk, Dublin and Belfast, so I don’t see them too much as it’s far away. Sadhbh is my youngest cousin and she’s in 1st class too, but in a different school. We play loads of games together but the best game we play is dolls. I have my doll and her name is Baby and Sadhbh’s doll is called Isabella.



Hannah, Sadhbh and Mikey.

A few months ago in August my Mammy’s brother, our Uncle Philip, got married to Patrice and I was flower girl and Mikey was pageboy. We had a great time at the wedding and I became friends with the other flower girl Abbey. I had a lovely dress, shoes and flowers and I had to get my hair put up in the hairdressers. We took loads of pictures and Philip and Patrice gave us toys to say thank you for helping them with their special day.



Hannah with her brother Mikey.

I love collecting handbags and I have *loads* and *loads* of them – I even have more than Mammy! They are loads of different colours but my favourite ones are my pink ones, then my red ones, then my blue and then my brown ones. Pink and red are my favourite colours ever and my room is painted pink and it has pink curtains too. I even have a pink bike. I love drawing pictures and I make cards and pictures for my Mammy and Daddy and my friends all the time. My favourite programmes on TV are Phineas and Ferb, Spongebob Squarepants and Peppa Pig. They are so funny and I love watching the Big Big Movie on Saturday night after dinner as well.

When I am sick I don’t really like to eat so I have my chocolate milk instead. It’s a Calshake and I have it hot with marshmallows or I have it cold out of the fridge – it’s just yummy! My favourite food is Chinese and prawn crackers and I even use chop sticks to eat it! I have Coco pops for my breakfast and then I do all my masks and physiotherapy before I go to school.

It is hard having CF and being sick all the time. There’s a lot of the stuff that goes with CF like the needles, the x-rays, all the yucky medicines and the physio. I did get to meet the REAL Santa though because I’m sick, and I’m hoping to meet Jedward with my ‘Make a Wish’. I’ve also been on TV a few times and the camera man even came to my school and met my friends! I even have my own website (www.hannahsbags.com), which was made for us as a present. You should take a look at it – we tell the story of a typical day in my life, and there are also tips that Mammy has included for parents and schools where a child with CF attends.

I have to go now because I have to do my “bits” before I go to bed and it’s a school night so it’s bed early – Bye!



DECLAN O'DOHERTY

Double Lung Transplant Recipient, Co Galway

Hi, my name is Declan and I am 37 years of age. Originally from Tullamore Co Offaly, but currently living in Loughrea, Co Galway, I moved to Galway about 5 years ago and am living here with my partner and her two children.

I was diagnosed with CF back in the 70's when I was 3 months old. CF was a disease not many people knew about back then. My life expectancy at that time was 14 years of age, but with medical advances that have taken place since, I far out-lived that prediction!

All my friends knew I had CF growing up and although they didn't really know what it was, they knew I was sick. I was always the smallest in the group, but was very well looked after by all my friends. My health stayed very well up to my teens and I suffered from very few chest infections, although I did have a lot of operations on my nose due to severe infection and inflammation.

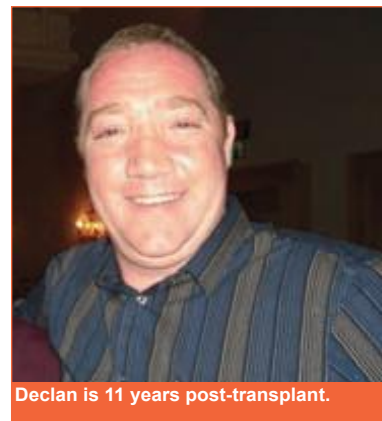
In my late teens I began to get really sick. In my early twenties I began to get chest infection after chest infection, and when I was 23 I was told about the transplant.

I was on the transplant list for about two and a half years. When I was initially called for the transplant assessment I felt that I was in quite good health, but was told I needed time on my side because 'you don't know when you will get the call'. As time went by, my health deteriorated and I got more ill. In 1999, and literally overnight, I went downhill – my oxygen levels dropped and I was put on the bipap machine (to help patients breathe). In January 2000 I finally got the lung transplant I had been waiting and hoping for – I weighed only six stone, was on 8 litres of oxygen and on the bipap machine 24 hours a day.

During the time I was on the transplant list there were a lot of thoughts going through my head – will it work, how different will my life be when it is over, and so on. I went through feelings of fear, anxiety and depression, but these emotions are only natural in preparation for such a big operation. I tried to maintain a good outlook on life and trusted the doctors because they were the experts and they knew what they were doing. My positive mental attitude kept me going and my motto during this time was 'every day that goes by is a day closer to the transplant'. Anyone who is going for a transplant should also try and stay positive about it because even though it is hard at times, being positive gets you through it.

The support I received from the staff in St Vincent's was second to none; they were kind, friendly and, most of all, supportive. I was also lucky enough to have great support from my family and friends. There were a lot of people to thank after my transplant!

It was 6pm when I woke from the operation. My mam and a few nurses and doctors were around me and I hadn't a clue what was going on or where I was. A nurse explained what happened and I tried to talk but I was incubated (a tube down my throat). After a few hours when all the checks were done and everything was ok, they told me they were going to take out the tube. I was a little nervous at first, but when they did the first thing I felt was a fresh cold blast going



Declan is 11 years post-transplant.

'The first thing I felt was a fresh cold blast going into my lungs. It was the most amazing feeling I ever had'



into my lungs. It was the most amazing feeling I have ever had – just to be able to take a deep breath and feel the rush of air go into my lungs – this is the moment that will stay with me for the rest of my life.

I know is that my donor was a 28-year old Irish man. The lungs travelled over with me on the plane to Newcastle (I didn't know this until after the operation). I sent a letter to the donor family through the Transplant Co-ordinator because I wasn't allowed contact the family directly, but unfortunately got no reply. This made me a little sad because I wanted to thank the donor family directly.

My life has changed so much since the transplant. I have done things I wouldn't have ever dreamed of doing. I bought my first car 4 months after the operation, I have travelled all over the world, I have represented Ireland in the European and the World Transplant Games in Japan in 2001, France in 2003 and Dublin in 2010, and I have been to America twice.

I have been interviewed on television and radio, as well as for newspaper articles, always trying to promote organ donation, and working closely with the CFAI and the Irish Kidney Association. Right now, I am making a life for myself in Galway. I have a great outlook on life and I see a bright future for myself.

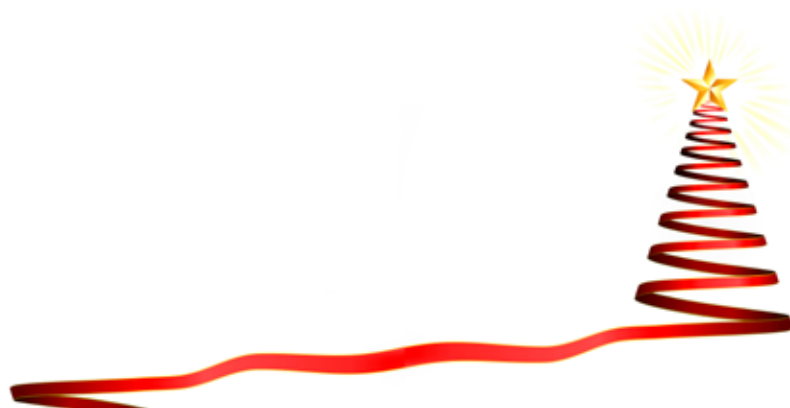
I would encourage people who are considering going for transplantation to please think about it very seriously. Talk to your family and to your doctors about it because I am living proof that it can work – I am almost 12 years post-transplant now and still going strong!

If anybody ever wants to talk to me about going for transplant, be it a patient, parent, family member or even boyfriend/girlfriend of someone waiting on the list, please do not hesitate to contact me – you can get my details from the CFAI National Office.



I urge everyone to carry an Organ Donor card because some day you could get the chance to save the life of someone else. It is only down to the fact that my donor carried an organ donor card that night that I have the privilege of contributing to this today.

And finally, always discuss your wishes about organ donation with your family.





CHRISTMAS IDEAS



SECTION 05

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CFAI CHRISTMAS CARDS 2011

Call Now to Order!

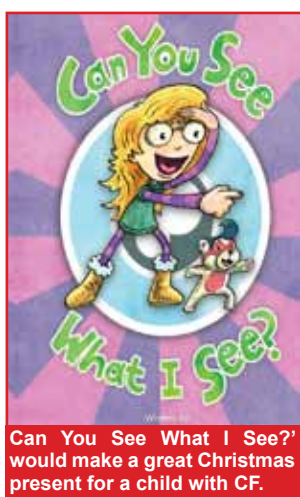
Christmas is fast approaching so why not place your order now for our 'limited' edition "65 Roses" Christmas Cards. This pack contains ten different designs wherein the artwork was prepared by CF children (this pack is from our 2010 stock). The pack costs €5 plus postage. Alternatively, purchase our Traditional Christmas card pack, which also contains ten different traditional designs, at a cost of €5 per pack plus postage.



For small orders, you can place your order online via our online shop; for large orders you can call our office at 01 496 2433 and ask for Catherine or email ccronogue@cfireland.ie. Payment can be made at our online shop, by cheque, or through direct lodgement into the CFAI fundraising account (details can be provided, where necessary).

CAN YOU SEE WHAT I SEE?

A Beautifully Illustrated Book for Children with CF



Louise Byrne, parent of a little girl with CF, has written a book called 'Can You See What I See?' to support children with CF and their parents. It tells an engaging story of a little girl with CF who has a superhero style approach to health challenges. It is a heart-warming and fun story for all kids with practical and positive tips for parents.

'Can You See What I See?' is now available for purchase through our online shop at www.cfireland.ie at a cost of €15.

'Louise Byrne has written an engaging, informative and beautifully illustrated storybook for younger children with Cystic Fibrosis - with lots of practical tips for their parents as well!'

Philip Watt, CEO, CFAI



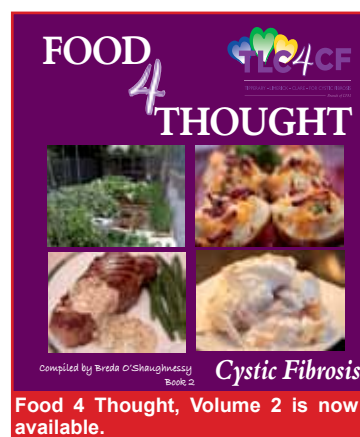
TLC4CF COOKERY BOOK

Food4Thought, Volume 2 – Now on Sale

After the great success of their Cookery Book, Food4Thought, which raised over €110,000 for building the adult in-patient and out-patient unit for people with CF at the MWRH in Limerick, TLC4CF have now launched a second volume of the book!

Volume 2 is again compiled by Breda O'Shaughnessy and she is confident that having learned the basics in Volume 1, everyone is now ready to expand their knowledge and skills. Volume 2 offers just that with recipes that are a little more complex, but not Masterchef level!

ALL proceeds from book sales go directly to TLC4CF 'equipment fund' to equip the new CF unit with beds, respirators, monitors etc. The book is now available through the CFAI online shop at www.cfireland.ie at a cost of €12.50 (inclusive of packaging and postage). Alternativley, please contact TLC4CF directly.



IRISH COUNTRY HOUSE GARDEN DIARY AND JOURNAL

All Proceeds Going to TLC4CF



The Irish Country House Garden Diary and Journal is now available.

The Irish Country House Garden Diary and Journal would make an ideal Christmas gift this year. The 80 page month-by-month guide is packed with amazing photography and useful information and helpful tips for any gardener.

The journal is produced locally, printed locally, photographed locally and 100% of funds go to TLC4CF.

The book is now available through the CFAI online shop at www.cfireland.ie at a cost of €12.50 (inclusive of packaging and postage). Alternativley, please contact TLC4CF directly.

'NUDE' POSES FOR CYSTIC FIBROSIS

Charity Calendar for CF West

Charity calendar 2012/13 "Nude Poses for Cystic Fibrosis" features 41 people including four people with CF and 1 double lung transplant recipient, who took off their clothes and posed naked (with strategically placed props) for this calendar. All money raised through sales of the calendar will go towards the €1,000,000 cost of building a new CF respiratory out-patient unit on the grounds of Mayo General Hospital (MGH).

The calendar can be purchased on the CFAI online shop at www.cfireland.ie for a cost of €13 (inclusive of postage and packaging).



FUNDRAISING

SECTION 06

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THUNDERBOLT FIGHT NIGHT

4th December, Burlington Hotel, Dublin

A fight night will take place on 4th December in the Burlington Hotel, Dublin in aid of Cystic Fibrosis. The event is being organised by Joe Dunne, father of a daughter with CF, and his cousin Johner O'Brien of Thunderbolt Boxing. There will be a total of ten fights and it is set to be a great night for all.

Tickets are €30 each or a table of ten costs €300. Tickets are available from Joe Dunne by emailing him at jwdunne@eircom.net. Anyone wishing to donate to the night can do so on the following link www.mycharity.ie/event/joe_dunne_thunderbolt_fight_night/

A big thank you to Johner O'Brien and Peter Murphy for training all the lads for the fight at Thunderbolt Boxing.

TONI AND GUY, DUNDRUM

5th December

On Monday 5th December, Toni and Guy Dundrum Town Centre (Level 4, Unit 3) are hosting an evening of 'cut & colour' to raise funds for CF. Enjoy 5 star service in a relaxed yet invigorating atmosphere!

Toni and Guy has a catwalk-to-client philosophy, adapting and enhancing fashion inspired looks to capture your style and compliment your lifestyle. All staff will be giving their time free of charge; it will be a fun Christmas evening with added extras, goody bags etc. donated by L'Oreal and Redken.

All proceeds of the evening will be donated to CF.



Toni and Guy are hosting a 'cut & colour' evening for CF.

GALA DINNER DANCE

Dunboyne Castle Hotel and Spa, 27th January

This event takes place on 27th January 2012 and is being organised by Ms. Nicole Parker (CF parent) for the benefit of both CFAI and CF Hopesource as a gesture of appreciation for the assistance both organisations have afforded her and her children in recent years. Tickets at €45 are available from Nicole – phone 087 7622632 for more details.



‘FRANKIE GAVIN & DE DANNAN’

‘Joy of Christmas’ Tour in Support of CFAI

Irish traditional supergroup ‘Frankie Gavin & De Dannan’, along with some very special guests, will be performing in a select number of venues as part of ‘The Joy of Christmas’ tour in support of the Cystic Fibrosis Association of Ireland on the lead up to Christmas. The tour will see the band performing many musical and vocal numbers associated with Christmas in addition to other inspirational pieces.



Frankie Gavin & De Dannan will be performing a series of concerts for CF in December.

‘Frankie Gavin & De Dannan’ comprises Frankie Gavin on fiddle, viola, whistle, flute and piano; Michelle Lally on vocals; Eric Cunningham on percussion, flutes, whistles and piano; Barry Brady on accordion, and Mike Galvin on guitar and keyboards. Frankie Gavin is also the ‘Guinness World Record’ fastest fiddle player. The current band has performed everywhere from ‘The White House’ & ‘US Capitol Building’ to ‘Beijing Opera House’.

An album entitled ‘The Joy of Christmas’ will be available for purchase at all concerts, and a contribution from the album sales will also go to CFAI.

The two dates that have been confirmed to date are **19th December** at the Cathedral in Tuam Co Galway, and **Tuesday 20th December** at the GAA Club in Ashbourne Co Meath.

The group will also be performing on other dates in various locations around the country as part of their ‘Joy of Christmas’ tour.

For further information on the remaining concerts, please check the De Dannan website at www.dedannan.com or the CFAI website at www.cfireland.ie.

CHARITY SANTA IN GALWAY

Volunteers Required!

A free charity santa event will take place in the Eyre Square Centre in Galway city soon. There are three charities involved, so the month of December is divided between them.

The Cystic Fibrosis Galway Hospital Fund are collecting in December from 12pm-6pm on the following days:

- Friday 9th
- Saturday 10th
- Sunday 11th
- Sunday 18th
- Monday 19th
- Tuesday 20th
- Friday 23rd

If there is anyone available to volunteer a couple of hours on any of these days, please contact Simone Corbett of the Galway Branch by calling 087 299 4736.





ROME MARATHON 2012

Everyone's a Winner – Team CF

We have decided to bring our Team CF to run the marathon in one of the most beautiful cities of the world: Rome.

The beauties of Rome are world-renowned from the Colosseum to the Trevi Fountain not to mention the Vatican. Opportunities of this kind don't happen every day.

The Marathon takes place on March 18th 2012 and will bring you across some of the most amazing monuments of all time including the Colosseum, St. Peter's Basilica, Trevi Fountain, just to name a few!

The fundraising target is €2,500, which includes return flight, four nights' accommodation in a twin room in a centrally located hotel (single room available with supplement), and race entry.

Availability is limited, so places will be allocated on a first come first served basis. Further details are available in the enclosed brochure.



If you would like to take part, contact us as soon as possible as participation in this event has already raised a lot of interest.

THREE LEGGED RACE WORLD RECORD ATTEMPT

Navan Racecourse, April 2012



Rebecca Keating, a young lady from Navan who is a 'Friend of the Association', is in the process of organising an attempt on the world record for the number of participants in a '3-legged race'.

The event is scheduled to take place at Navan Racecourse in April 2012. Rebecca says that she needs at least 1,000 teams of two (obviously). Full details will be published on our Facebook page and website as soon as they are to hand.

So get in training now for what promises to be a great fun day while generating lots of publicity and income for Cystic Fibrosis!



GREAT STRIDES WALKS CAMPAIGN 2012

Sponsored Walks in aid of CF

'Great Strides' is a concept developed in the USA and now licensed to us and many other CF organisations around the world. Discussions with CF Canada and CF Foundation USA indicate that this has become a very successful fundraising campaign annually.

Essentially it involves a series of CF dedicated sponsored walks in various locations throughout Ireland. We intend to roll out this campaign in 2012 by choosing five Branch areas as a pilot and, in discussions with the chosen Branches, plan how best this can be done.

The aim is to create further awareness of CF and maximise income to the Branch, and also to increase National Office income for the provision of services to the CF community in general.

DONEDEAL.IE

€26,603 Rasied for CFAI

DoneDeal.ie, Ireland's premier buying and selling website, chose CFAI as their charity for the month in October 2011. Essentially, 30 cent of the cost of every advert placed in October was donated to CFAI, resulting in a fantastic donation of €26,603.70.

We are extremely appreciative of the CSR ethos of DoneDeal.ie who have donated upwards of €150,000 to charities in recent times. This bodes well for our sector in straitened economic times, when corporate income has come under significant pressure.

To Donna, Shane and Mel, thank you for your warm welcome, kind hospitality and pleasant disposition when Fiona and Martin visited your offices.



Shane Fox presenting cheque to Ms. Fiona Bodels, (CF parent) and Chairperson of Wexford Branch with Martin Cahill, CFAI.

CARLOW FUNDRAISING

In memory of Paul Minchin R.I.P.

John Candy and colleagues recently raised a total of €25,000 for charity by organising a dance night in the Seven Oaks Hotel, Carlow. The idea was to raise funds and distribute among charities represented in the county area.

As Paul, Ireland's first double-lung transplantee, was well known to the organisers they decided to donate a sum of €3,000 to CFAI in his memory.



PADDY KIERANS MEMORIAL ISTANBUL & CAPPADOCIA WALK 2011

Thanks to All Involved!

CFAI and the Walk Committee would like to take this opportunity to thank each and every walker who took part in the Walk in Istanbul and Cappadocia this year.

The event was a resounding success and the feedback received was extremely positive. Istanbul & Cappadocia with its long history at the centre of empires was a different and exciting experience for our group. Walking in this mysterious location, the group had the chance to visit historical beauties like Hagia Sophia, Topkapı Palace, Blue Mosque and At Meydani, before being transferred to the hidden gem of Cappadocia.



Pictured above are the Paddy Kierans Memorial Walkers 2011 who travelled to Istanbul & Cappadocia to raise funds for CF.

Work is already under way to organise the International Walk 2012. The location chosen is Poland and it is expected it will be another amazing trip. Further details will be made available shortly. The walk raises each year vital funds towards research and support services for people with Cystic Fibrosis and their families.

AROUND THE WORLD WITH STARKIDS

€2,198 Raised for CFAI

Children from Starkids performed in their Show stopping show 'Around the world with Starkids'. The children aged 3-18 years performed for four nights (May 16th, 17th, 23rd and 24th) at the Draíocht Theatre, Blanchardstown for a great cause. All proceeds after costs went to CFAI.

The children performed Musical sections from Hercules, Chitty, Chitty Bang Bang and Toystory. They also brought their audience on a trip around the world as they performed songs and dances from Russia, Spain, America, Ireland and India



After an exhausting but exhilarating 2 weeks the children raised €2,198 for a great charity.

The students have already started work on their next productions: 'One Night Only' to be held at the Helix in November and 'Viva Las Vegas' to be held in the Draíocht in May 2012.

Starkids is located in Scoil Oilibhéir Coolmine. For full details contact Brenda Redmond 087 9922402 or 8213659.



LUGATHON 2011

Thanks to All Involved!

Our annual CF Lugathon took place on Saturday 1st October. The event, which involved a hill-walk up Lugnaquilla Mountain, Co. Wicklow, was a success despite the bad weather conditions.

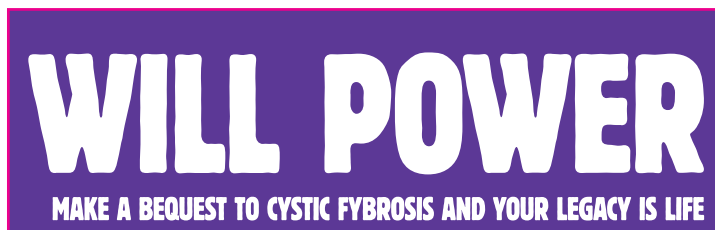
We wish to thank all those who took part in battling the rain and raising funds for Cystic Fibrosis. Particular thanks go to Rory Tallon, Philip Pearson and Tim Clifford, who provided voluntary assistance with this event both this year and last year. Such voluntary assistance is important to CFAI in ensuring the continuity of the event and it is indeed very much appreciated.



LEGACY FUNDRAISING

Will Power Campaign to Commence Soon

Our legacy fundraising campaign, scheduled to start in February 2011 was postponed due to lack of resources. We are, however, in the process of commencing this campaign, which is designed to encourage donors to leave a legacy to CFAI in their will. The title of the campaign, 'WILL POWER', has been displayed on advertising billboards in recent months.



To enhance this campaign, we have become members of 'mylegacy.ie' – a group of charities in Ireland seeking to establish this concept in greater focus in Ireland, and full details will be on our website and at www.mylegacy.ie shortly.

Great sensitivity in seeking this type of donation is important, and we would hope to offer training to Branches and association members where desired in 2012.



Calendar of Key Events

- Love your Lungs' Day / 14th February 2012
/ www.irishthoracicsociety.com/
- Rare Diseases Day (RDDay) on 29th February 2012
- Concert for CF Children's Centre in Drogheda Hospital on 3rd March 2012 at Drogheda Arts Centre
- Rome Marathon 18th March 2012
- CFAI Annual Conference, White's Hotel Wexford, 13-15th April 2012
- Cystic Fibrosis National Awareness Week 13th-20th April 2012
- **65 Roses Day** on 20th April 2012
CFAI National Collection Day
- '1 in 1000'/Flora Women's Mini Marathon on 4th June 2012
/ www.florawomensminimarathon.ie
- European Cystic Fibrosis Society Conference, Convention Centre Dublin on 6-9th June 2012 / www.ecfs.eu
- CFWW/CFE/CFAI European CF Patient Advocacy Conference on 6th June 2012, Convention Centre Dublin
- Dublin City Marathon on 29th October 2012 / www.dublinmarathon.ie

Visit the events calendar on www.cfireland.ie for more information or locall 1890 311211.

Local Branch Contacts

Carlow

Leigh Bolger
059 913 0009

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Karen Keoghan
049 437 1988

Clare

Kenneth Flanagan
086 222 2290

Southern (Cork)

Cathy Carlton
086 893 4335

Denise Taylor
086 050 0803

Donegal

Brendan McLaughlin
074 913 2208

Eastern (inc Dublin)

Mary McCarroll
087 411 9812

Dundalk

Adrian O'Hagan
042 933 5994

Galway

Marie Brennan
086 817 8552

Kildare

Oliver Delaney
087 238 1208

Kilkenny

Carmel Delaney
086 313 6029

Limerick

Owen Kirby
087 967 9176

Louth

Peter Hughes
087 312 4589

Mayo

Pádraig Burns
087 686 7560

Meath

Loretta Allen Byrne
087 205 8778

Midlands

Gerry Johnson
0902 75 704

Esther L'Estrange
087 616 0399

Sligo

Iris Murphy
086 825 8525

Tipperary

Mandy Quigley
052 32 096

Waterford

Bernadette Power
051 64 1913

Wexford

Fiona Bodels
086 603 7470

- TLC4CF: Contact: Marcella Clancy (086 8390942) and Linda Drennan (087 2255650)
- CF West: Contact: Pádraig Burns 087 6867560
- Life Matters 4CF: Contact: Loretta Allen Byrne on 087 2058778

About the Cystic Fibrosis Association of Ireland (CFAI)

The CFAI is a registered charity CHY 6350 that was set up by parents in 1963 to improve the treatment and facilities for people with CF in Ireland. It is a national organisation with many Branches around the country and our members are mostly parents and people with CF.

The CFAI is committed to working to improve CF services in Ireland and our recent progress includes:

- Lobbying to ensure that the new national adult CF centre in St Vincent's University Hospital will be completed
- Providing funding towards new CF Units around the country including Crumlin, Drogheda, Galway, Mayo and Limerick Hospitals
- Funding research
- Campaigning to improve the rate of double lung transplantation in Ireland
- Providing advice and expertise

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