



News Update

**Cystic Fibrosis
Association of Ireland**

Summer
August 2008

Introduction

There has been a lot of activity in the Association since our last News Update in May and we are starting to see more results of our campaign to improve CF services across the country. We have succeeded in making CF a national issue. CF awareness across the country is at its highest level ever. Last April we were a finalist in the Irish Hospital Innovation Awards. In June we were awarded the Public Relations Institute of Ireland Award for Excellence in PR in the Charity / Voluntary Sector. CF coverage in the media continues at a high level. At the European and CF Worldwide meeting in Prague we were recognised by other countries for the huge progress that, they

see as outsiders looking in, has been made in Ireland over the last number of years. Substantial capital and revenue funding has been committed to cystic fibrosis in Ireland. The release of this funding into the system has been frustratingly slow for us. The funding has not been withdrawn and we will continue to work proactively with all stakeholders to ensure that this hard won money is put to good use. At the time of writing this News Update the first eight single ensuite rooms are being commissioned at St Vincent's University Hospital. These interim rooms were built to an impressive high standard and we look forward to the continuation of the development plan with the provision of further interim beds in the short term

and culminating with our final goal of a properly resourced world class CF centre for Adult patients. Our campaign is not a single centre or a single region campaign, we are national and our campaign is making progress nationally in both adult and paediatric services. The Association has made commitments to raise and spend considerable funds to develop both the National Paediatric CF Referral Centre and the National CF Microbiology Reference Laboratory. This is in addition to regional commitments that are already in place in Cork and Galway for example.

We have the foundations in place, now we must build a strong house that will weather the storms of the future.

European CF Meetings—Prague June 2008

The 31st European Cystic Fibrosis Society (ECFS) Conference was held in Prague, Czech Republic between 11th – 14th of June 2008. CF Patient Associations arrange their annual meetings to coincide with this major international symposium. This resulted in a full week of intensive meetings. CFAI were requested to make a presentation at the 2nd European Cystic Fibrosis Network Building Conference. This day long conference reviewed CF care in participating countries, looked at what constitutes a strong CF Association, looked at various fundraising initiatives, and discussed how best to campaign for access to care. CFAI presented a case study on Ireland that was well received. The second day consisted of the Annual Meetings of CF Worldwide and CF Europe which both CFAI are members of both. This includes the presentation and passing of the Financial Report and updates on various programmes undertaken by both affiliated groups. CFW have been in protracted discussions with the World Health Organization

(WHO) since 2003. One of their main priorities is to get pancreatic enzymes listed on the WHO Model List of Essential Medicines. In 2007 CFW have completed the very tedious task of completing the application to put pancreatic enzymes on the WHO Necessary Drug List and now work towards submitting this application in 2008. Both CFW and CFE do a considerable amount of work in promoting CF Education, CF Clinical Care and the development of CF Associations in emerging countries. One success story was Macedonia where for the first time CF has been recognized by the government and drugs who's availability we take for granted such as Pulmozyme, Colistin, Tobramycin and Creon are now being made available to all CF patients. There is a huge amount of work still to be done in newly developing European countries. One of the most important aspects of this week was the opportunity to network and learn from other national associations and to interface with the top scientific minds in CF. The following summaries have been prepared by those who attended the conference and we would like

to thank, Louise Harty, Thomas Thompson, Vinnie O'Malley and Helen Whitty for their contributions.

How can I improve my life with Cystic Fibrosis?

For the majority of CF adults we have been through phases where we are not as compliant with our treatment as perhaps we need to be. For the past few years I have realised the importance of good health and the value of a good physiotherapy regime .

This was highlighted at the European Medical Conference for Cystic Fibrosis, where I was able to see the positive results of the clinical trials done to minimize secretions and keep airways open.

I was very interested in the lecture on "Physiology of Airway Clearance" which was given by Dr Mark Elkins about enhancing mucous clearance. In his talk he explained about the CFTR which controls the sodium and chloride levels in the lungs and plays a vital role in controlling the viscosity of the mucus in the lungs needed to remove the

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bacteria. With CF we get a very thick and sticky mucus. This slows mucous clearance and pathogens and all the nasty bacteria are left in the lungs causing inflammation and long term infections. In order to increase the viscosity of the mucus Mucoactives are needed.

What are Mucoactives?

Hyper Tonic Saline is available in concentrations of 3%, 7%, and 12% Saline. Of these 7% is best tolerated and appears to get the best results. This clearance is done during inhalation and is proven to have a more sustained effect than regular inhalations. By reducing sputum viscosity it restores the surface liquid in the lungs, inhibits and disrupts bio films and reduces motility of pseudomonas by stimulating coughing. Studies show it improves lung function, reduces exacerbations, and improves the quality of life with no long term effects.

Mannitol is another Mucoactive. I had never heard of this one but the President of CF World-Wide, (who also suffers from CF) has been on it for years although he says he finds it great, he says it tastes awful.

This is a dry powder which is used with an inhaler twice daily. It draws water into the airways it improves airway clearance and results in increased lungs function, physical health and vitality.

I personally find the Hyper Tonic Saline very effective and would recommend anyone to discuss this further with their CF consultant.

Neonatal Screening

The purpose of Neonatal Screening for CF is to limit morbidity and mortality. The benefit of an early diagnosis must outweigh potential disadvantages from screening to both the affected and unaffected. With Neonatal Screening Programmes in place for CF for more than 30 years, there is now consistent evidence emphasising the benefits of such a programme. The benefits of an early diagnosis have been well documented with the screening process varying from country to country. Some countries just search for the three most common mutations, delta F508, G551 and R553x while other countries do a more in depth search for many different mutations. This is able to diagnose both those with CF and carriers of these mutations.

The positive aspects for Neonatal Screening are that early treatment may improve survival and early intervention improves nutrition and growth. As yet there is no clear evidence on whether it can improve or maintain lung function.

The negative aspects of Neonatal Screening can be that with mild mutations many CF's would be non productive of mucus and pancreatic sufficient. This would mean that parents of a CF child could live with the diagnosis for years without symptoms and it has been proven that it can interfere with the

normal interaction and bonding process between parents and child due to anxiety and stress of a diagnosis for which there is no cure.

It is important also that a good standard of care and support to back up a diagnosis be in place. Multi-disciplinary training sessions should be established to assist the health workers deliver the results as in some countries it has become apparent that some do not have the skills and knowledge with which to undertake this task.

Today there are more than 1550 mutations of the CF gene, many of these can go undetected even with screening though the majority of those have been characterised.

Anxiety and depression

Cystic fibrosis is a complex multi-system disease. Patients often face a number of physical and psychological problems. It is acknowledged that psychological morbidity has adverse effects on the outcome of medical illnesses, and therefore addressing the psychological needs is important. The UK National Consensus Standards for the Nursing Management of Cystic Fibrosis states that patients should be supported by specialist nurses who have knowledge and experience of cystic fibrosis, the disease process and the clinical and psychological outcomes.

80 patients attending the Adult Clinic were asked to complete the Hospital Anxiety and Depression Questionnaire when attending Clinic, with an explanation regarding the purpose of the assessment. Results were then collated. Scores between 8–10 indicate mild symptoms; 11–14 moderate symptoms; 15–21 severe symptoms.

80 CF patients (41 males; age range 18–57) completed questionnaires. 33 patients (41%) reported significant scores for either anxiety or depression. 26 patients (33%) recorded clinically significant scores for anxiety (17 mild; 6 moderate; 3 severe); 17 were female (65%). 7 (9%) reported clinically significant scores for depression (3 mild; 3 moderate; 1 severe); 5 were male (71%). Those with depression also had high scores for anxiety; 4 were male (57%).

The Results showed that anxiety was more prevalent than depression and anxiety was more common in women. These results indicate the need for the cystic fibrosis team to develop treatment strategies such as cognitive behavioural therapy for the management of anxiety and depression in adult patients with CF.

Disability—Access and Attitudes

The Association participated in a Disability Forum hosted by President Mary McAleese at Arus an Uachtarain as part of a DFI delegation. We presented a report that was compiled by our patient advocates to the President outlining disability issues that they felt were important for PWCF's and how they could play a more active role in society.

Swedish Consensus Policies

Birgitta Strandvik is a Cystic Fibrosis specialist and founder of two of the four centres in Sweden. Her care is based on monthly visits and a holistic view regarding treatment. Her treatment policy has resulted in good clinical status and good quality of life with normal median growth and pulmonary function at all ages despite low costs:

Standards of care

Her care is centralised with only one doctor seeing the same patient each visit as they are better able to assess their well being.

Treat early with antibiotics, even a viral infection as any infection causes scarring in the lung. Treat at the mild stage of infection i.e. loss of appetite, more frequent stools, lethargic.

Only Anti-Staphylococcus drugs should be considered for long term activity. They are recommending Prophylactic Treatment for any young child that has ever grown staph because sputum samples can be difficult to obtain in small children. Some do not agree with this due to the fear it can speed up colonisation of other bacteria's, though resistance to Flucloxacillin is extremely rare and in countries such as Sweden it is very rare that they isolate M.R.S.A.

(Methicillin Resistant Staphylococcus Aureus)

The use of Bromhexine orally is (1mg/kg/day divided into 3-4 doses.) This supports the body's own mechanism for cleaning mucus from the respiratory tract. It increases production of serous mucus making the phlegm thinner and less sticky. This also helps the cilia transport the phlegm from the lung.

Brand names are: Bisolvon, Vasican, Paxirasol.

Home treatments are recommended in order to make patients independent, to lower cross infection and to reduce costs.

Fatty acids should be increased in the diet to improve bone density. Many CF patients as they grow older experience reduced bone density.

Linoleic Acid supplementations are an essential part of the diet.

Physiotherapy and physical activity are very much part of the standards of care. Many of her patients use Hypertonic Saline.

It must be noted that this is just the treatment regime that is followed by one centre and is not stating that treatment regimes used by other centres are not as effective.

2009 European CF Conference

The 32nd European Cystic Fibrosis Conference will be taking place in Brest in Brittany in 2009. CF Worldwide will not be meeting in Europe in 2009 and have requested that we support Southern Hemisphere patient associations by attending the CF Worldwide meeting in Australia. The European CF Patient Associations intend to meet in Paris prior to the main ECFS meeting.



What's New For 2008

By Tomas Thompson

In the past number of years huge technological advancements in the treatment of CF have been made in the areas of nebulizer / compressors. The reports on these technologies have been very mixed, so I spent some time at the conference investigating this.

In relation to nebs on display in Prague the two which looked most promising are the e-Flow Rapid and the I-neb. The e-Flow is made by Pari and is the model sold in the USA. The e-Flow Rapid is the new and improved model sold in Europe. The I-neb is made by Respiroics and can only be obtained by those on the medication Promixin (Colistimethate), which is the same as Colomycin.

The e-Flow Rapid is lightweight, silent, can run on batteries and is faster than older nebs and it can cut treatment time in half. The e-Flow uses VMT (vibrating mesh technology) which is silent and can deliver the medications much faster than older nebs. There is currently no direct supplier in Ireland so it must be bought directly from the UK.

The biggest issue with the e-Flow is the high initial cost and the fact that parts must be replaced a number of times each year, an additional cost to the purchaser! The e-Flow costs roughly €800 and the membrane needs replacing every 6 months at a cost of €75 each time. This is a Pari recommendation, but the experience is that this could be as low as every 2 months. Maintaining an e-Flow could cost up to €200 - €300 a year on top of the cost price.

I would say that the e-Flow would play a role for PWCF who travel a lot but it does not seem to be the solution for every day use, just yet. There are advantages, such as its silent use and its faster inhalation times, but it also takes much longer to clean 10-15 minutes and must be cleaned very well to prolong the life of the membrane.

The I-neb is also third generation nebulizer using AAD (Adaptive Aerosol Delivery) system. It is a small, battery powered, lightweight and virtually silent drug delivery device designed to replace the conventional nebulizer/compressor. The I-neb works by delivering a precise, reproducible dose of drug. The aerosol is created through VMT (vibrating mesh technology) just like the e-Flow, and the dosage of drug is controlled through an AAD Disc and specific metering chambers. I have used the I-neb and it is a huge advance in nebulizer technology. Not as much medication is required as little or none of the drug escapes into the environment. This removes the need for filters and pipes out the window. Inbuilt software monitors the number of times it is used! The down side to the I-neb is that it can't be bought and if it could it would cost over €2,000.

It can only be obtained by those using the medication called Promixin (Colistimethate) as the company which makes the I-neb also owns the company that makes the Promixin.

The question of what medications can be taken

in the e-Flow is conflicting. Pari have carried out their own research (see <http://pari.de/>) on the use of medications such as Tobramycin and say that it can be used in the e-Flow. The manufactures of Tobramycin on the other hand are saying that Tobramycin can't be used in the e-Flow or the I-neb, as it has not been approved and they are not convinced that it works correctly 100% of the time. Medications such as Pulmozyme and other antibiotics also have question marks over them but not to the same degree as Tobi. Respiroics have carried out some research on the use of Tobi and the I -neb and also say that the I-neb can be used for Tobi. The main reason that the manufactures of Tobi will not approve any new nebulizer is that they would have to re-do medical trials for each one, at a huge cost of time and money. On the other hand Tobi are working on their own new delivery device, which is currently on trial and will work just like an inhaler. This should be available in the next 2 years which is very welcome news.

As it currently stands and for the foreseeable future if you want an e-Flow Rapid you will have to invest in one yourself, as they are not approved for use in meds such as Tobramycin so clinics can't prescribe them. In turn the HSE won't pay for them. If you want an I-neb you can only get one if you are on Promixin, which the HSE also won't pay for! If you would like more information on the range of new nebs they will be reviewed in the next issue of Future Force.

High Frequency Chest Wall Oscillation The Vest

The use of The Vest has increased in Ireland in the last year, with the pros and cons been debated up and down the county. The Vest is widely used in the U.S. but is only now being used more in Europe.

The two main companies which manufacture vests were on show at the exhibition. They were Smartvest (www.electromed-usa.com) e-mail bhsen@electromed-usa.com and Hill-Rom (www.thevest.com) or e-mail willie_annette@hill-rom.com. Each of the companies promotes and sells the use of The Vest with Hill-Rom having a distributor in Ireland for around €12,000 inc VAT. Smartvest do not yet have a distributor in Ireland however Vests can be shipped directly to Ireland for around \$10,000. Import taxes apply on top of that and the vest may have to be returned to the US for servicing or repair.

It must be noted that the use of both of these products have to be prescribed by a specialist medical practitioner.

Vertex shows positive Results targeting the G551D mutation

At the European Conference Vertex presented very encouraging results of their phase 2a clinical trials. Analysis of their results so far show that as an oral agent their VX-770 improved lung function and improved the function of the CF Transmembrane Conductance Regulator (CFTR) protein as measured by changes in sweat chloride levels and changes in nasal potential difference. Vertex stated that it is unprecedented for an investigational compound for the treatment of CF to have such a marked effect on multiple measures of CF disease activity. The next phase of the clinical trials is now being planned and we could see part of these trials taking place in Europe and possibly Ireland.

Fourth Lung Transplant Takes Place

Freeman Hospital in Newcastle have now carried out their 4th double lung transplant on an Irish CF patient this year. This is wonderful news and we wish the recipient a speedy recovery.

The Association is very concerned with the limited number of organs coming available for transplant particularly lungs. We have been unsuccessful in securing a meeting of the main stakeholders involved in lung procurement and transplantation. This was scheduled for May but had to be cancelled due the unavailability of key stakeholders. We have proposed that this meeting now takes place in September. In the meantime CF Europe asked us to represent them at the Council of Europe's European Directorate for Quality of Medicines & Healthcare Working Group for the Guide to safety and quality assurance for organs, tissues and cells. The main benefit to us in participating in this group is that it exposes us to the key people involved in organ recovery and transplantation across Europe—people who we call upon for advise in the future.

We continue to engage with all the key stakeholders on a daily basis to try and find possible solutions to this very serious issue.

Heart & Lung Transplant Games

The European Heart and Lung Transplant Games took place in Vichy, France between 21st and 26th June. Rosemary Fitzgerald and Mikey Dwyer participated and came away with 4 medals between them in swimming and badminton.

Congratulations to both.



Waterford Regional Hospital

The friends of Waterford Hospital wish to raise funds for two isolation rooms for the use of Oncology and CF patients. We hope to meet with the hospital and with representatives of the friends to get further information on this project.

CF Paediatric Facilities

In our May News Update we outlined the importance that paediatric CF services continue to develop on a national basis. Dr Canny from Our Lady's Hospital for Sick Children (the National Paediatric CF Referral Centre) in a letter to the Irish Times outlined the importance of the availability of isolation rooms for children with CF and the importance of handing over patients in the best possible health at transition time to adult services. The Board of CFAI have now approved that we fund the construction of 4 isolation suites for Crumlin Hospital. The terms of the project has been approved by both parties and a project team is now being established. A site has been identified that is in close proximity to the existing St Michael's Ward. Our target would be to get this facility up and running within 18 months.

Cork Project Moves To Next Level

The Statement of Need (SON) for the adult in patient CF unit and day centre at Cork University Hospital has now been accepted by the Executive Management Board of the hospital. The Next phase is to have our requirements (11 en-suite rooms) included in the hospital's project plan.

The Second CF adult nurse specialist has been appointed and is due to take up her position shortly. The CFAI Clinical Registrar's post has proved very beneficial and our board has agreed to fund this position for a second year. A new registrar took up his post from 1st July. The previous registrar has taken up a new post as CF Research Registrar which has been sponsored by an Irish Thoracic Society grant. The medical team are dedicated to developing CUH into a CF Research Centre. Already they have four poster presentations accepted for the American CF conference in October. CFAI have awarded the CF research team a consumables grant of €35,000 per annum for the next three years.

National Microbiology Referral Centre at Tallaght Hospital

A plan for the development of a National Microbiology Reference Laboratory was presented by Prof. Philip Murphy to hospital management and to the CFAI. The Association has been supporting the "CFAI National Reference Laboratory" for the last number of years by supplying funding for a specialist CF microbiology technologist. The board of CFAI recognises the importance of this Laboratory at a National level and has agreed to fundraise approximately €700,000 for the development of a Reference Laboratory. The terms of this project are currently being negotiated.

Ireland has reference laboratories for other diseases but no formal body for CF. Tallaght have been providing this service for the past 10 years and prior to this all samples had to be sent outside the country. The Pollock Report and the HSE CF Working Group have both spoken highly of the work undertaken by Tallaght. This new facility will benefit CF patients nationally of all ages and will contribute in the end to better outcomes for these

St Vincent's University Hospital

The reconfiguration of St Mark's Ward has now been completed on time. The new reconfigured ward contains 8 single en suite rooms that have been developed to a very high standard. The design has taken into consideration the latest in infection control recommendations and patient comfort. The new ward has been renamed St Christopher's Ward. Patients will be moved into this ward over the August Bank Holiday weekend.

The hospital and the HSE needs to be recognised for successfully delivering this project on time under severe logistical constraints. We look forward to the development of the remaining interim beds as was promised by the HSE.

Tender bids have been received for the 120 bed replacement block. The hospital projects that the site for this new building will be cleared by December 2008 and that building will commence early in 2009. This is an enormous step forward for CF care in Ireland.

Mid-Western Regional Hospital

A meeting was held with the management and medical staff at the hospital. The main issues at this centre are related to staffing numbers. And approval for the recruitment of specialist consultant respiratory physicians and CF nurse specialists. The hospital are chasing the HSE on this issue and the association continues to lobby for this both at the hospital and at the Nation Hospital's Office.

Psychologist Post at Tallaght Hospital

Meetings were held with the management and representatives from the Psychology Department at the hospital. The main issue being the inability to appoint a Psychologist for CF Services that had been approved as part of the 2005 Budget award. Every effort is being made by the hospital to get this position put in place as soon as possible. The hospital is receiving full support from CF House and we continue to push for a resolution to this issue with the HSE's National Hospital's Office.

CF Registry Research accepted for NACF

Dr. Abi Jackson, the HRB Research Fellow has a research poster accepted for the NACFC in October.

This data again shows that those children with respiratory symptoms are at a disadvantage to early diagnosis; with the females most disadvantaged (although we did not find a statistical difference between the sexes). This again reinforces the importance of neonatal screening.

Dr. Jackson is also working diligently on the survival analysis and aims to have this ready before Christmas. CFRI are gathering missing data from many patients (such as genotype, date of diagnosis and symptoms at diagnosis) both current and deceased, which should enhance the analysis. This work will give us statistically relevant information that we can use in supporting our lobby campaigns as we will be better able to profile our population and project where future services will be required.

Anne Goggin CF Nurse at Waterford Regional Hospital Retires

The Cystic Fibrosis Association would like to express a sincere "Thank You" to Anne Goggin for her years of support and commitment to CF care and treatment in the South East Area. Anne Goggin held the post of CF Nurse Specialist at Waterford Regional Hospital since 1999 and has been a dedicated nurse since 1983. Anne will be sadly missed by CF patients, parents and friends. We wish Anne every happiness and good fortune in her retirement and understand that she is currently en-route for a well deserved holiday in Australia.



Fundraising

Fundraising income to date in 2008 has been considerably buoyed by the greater awareness generated by the unprecedented publicity in January through the RTE Liveline programme, and followed up by the publicity surrounding CFAI National Awareness week. CFAI in general is faring well to date in 2008 despite the economic downturn.

CF National Awareness Week

CF National Awareness Week produced significantly greater returns than 2007 due to a larger number of volunteers being onboard and overall greater participation from the branches participating in on-going street sales of dolls, trolley coins and lapel badges. Once again, however, there is a pressing need for the establishment of a network of volunteers throughout the country to make this annual event the success it can be. Consideration is being given to moving the dates forward to March/April to allow for brighter evenings and possibly even better weather. Suggestions from members would be welcome to put this annual event firmly on the national charity calendar, keeping CF awareness to the fore.

Branch Activity

It is heartening to note greater activity in many branch areas in recent times, Media reports indicate a much higher profile for CF in areas such as Cork, Kerry, Tipperary, Wexford, Clare, Galway, Sligo, Mayo, Drogheda and greater Dublin area. Hopefully this will spread to all branch areas making CFAI a leader in local community fundraising and political awareness. Branches are always looking for new talent and volunteers to join and welcome any new members who want to get involved.

Tesco Charity of the Year 2009

We have been invited once again to submit an application for Tesco Charity of the Year 2009. The proposed refurbishment of the National Microbiology Lab at AMNCH Tallaght is our chosen project for this initiative. We have been unsuccessful in our efforts to secure this selection in previous years but we were shortlisted for 2008. We understand final selection from the shortlist is by staff vote. If we are shortlisted for 2009, we will inform all members immediately and ask you to lobby your local Tesco staff (Charity Manager in each store) to vote for CF.

New Projects

The NEC has approved two major projects to be funded by CFAI. These projects are positive steps forward in improving treatments and facilities for PWCF, both paediatric and adult, in Ireland.

Provision of a dedicated CF Paediatric Unit containing 4 isolated ensuite beds at Our Lady's Children's Hospital, Crumlin at an estimated cost of €750,000. This is a build-on to the main hospital and will benefit a large number of CF children. Funding is available for this project from strategic cash reserves, but as we have obtained agreement from the hospital to fundraise using their branding, we propose to launch a major campaign to raise this money. In any event, we expect to open this unit within 12 months.

Provision of a new National CF Microbiology Reference Laboratory in the grounds of AMNCH, Tallaght. The service currently provided by the existing laboratory to all CF units and teams throughout Ireland has expanded over the years with the discovery of newer strains of bacteria affecting the CF lungs. Due to accommodation pressures, much of this work is being transferred to Trinity College labs, which is unsatisfactory. The Executive of Tallaght Hospital has kindly provided the physical area adjoining the existing lab for the building of the new lab. Again, a major campaign is in the planning stages to raise the necessary €900,000 for this project.

Mycharity.ie

CFAI is now a subscriber to mycharity.ie. This is a fundraising service wherein individual fundraisers can set up their own fundraising page to advertise their particular event/campaign and receive donations online directly. This is open for use by anyone fundraising on behalf of CFAI and branches are encouraged to advise local fundraisers to use this service. See www.mycharity.ie or follow the link from CFAI homepage www.cfireland.ie.

Fundraising Events

A wide variety of community fundraising events have taken place so far in 2008. There are too many to give individual mention in this article but the on-going fundraisers below continue to grow in participation levels on behalf of CFAI.

Flora's Womens Mini-Marathon

Had approx. 600 ladies participating for 2008, our highest number ever.

Fundraising Events Cont.

Dublin City Marathon

Is looking good also and a campaign led by Dublin's Country Mix 106.8FM spearheaded by presenter Alan Corcoran (also of Southeast Radio) will hopefully increase the number of participants in 2008.

We have also been represented in Barcelona marathon (4 O'Connell brothers from Limerick), Boston Marathon (Blayne rockets from Castleblayney), London Marathon (Allie Woodward) and a series of 12 marathons being run over the year by Alan Mullin and Darren O'Connell from Shannon, Co. Clare We have also filled 15 places in New York Marathon including PWCF participants. Particular good wishes to Caroline Heffernan, Luke Murtagh and Noel Lannon in this event. Rory Tallon will be at the finish line to greet you. Best wishes to all participants and thank you for your fundraising.

Golf Classics

So far this year we had a number of golf classics both within the branch network and independently. Events in Donabate, Edmondstown, St. Margaret's Golf Club, East Clare and Castleknock have raised considerable funds and the forthcoming Allergan Golf Classic and Tom Walsh's Artane Golf Classic for which support is currently being sought will add to this fundraising channel.

Ironman Triathlon Challenges

Ray and Timmy Power of the Defences Forces, Curragh Camp completed this gruelling event in Lanzarote while Alan Thorpe and Cathal Murphy completed the same challenge in France.

Getout.ie Lugathon

This tough hill walk up Lugnaquilla Mountain in Wicklow in June saw 50 participants brave the elements to raise funds for CF. Organised by Hugh Redmond of singles website Getout.ie in conjunction with Collette and Helen of ACARA Charity Project management, the event was a resounding success with the bowl of stew on completion being most welcome.

Fundraising Database

Our dedicated Fundraising Database package, Raiser's Edge is expected to be fully up and running in early September and will provide greater efficiencies in data captured and campaign co-ordination. In-house training on this package is required for all staff members. Consequently there will be **skeleton staff operating in-house on the 2nd, 3rd & 4th of September 2008**. Please be patient with your queries over this period as there will be some delays experienced.



Cystic Fibrosis Truck Run 2008

This event organised by Seanie and Collette Bentley was a fantastic success raising €37,000 in the process. Judging by the photos (see photo gallery at www.cfireland.ie) of 120 trucks trundling through North County Dublin on a Sunday afternoon, it was an amazing sight and sounded like an earthquake hitting the area. Jack Bentley, PWCF (aged 13) was master of ceremonies for the cheque presentation.

Grace Barrett was recently appointed Fundraising Co-ordinator at national office with a brief to provide support materials and administration to all who are fundraising on behalf of Cystic Fibrosis. With her professionalism, courteous, efficient and pleasant disposition, Grace has been an inspiration to all who have come in contact with her. Sadly, Grace has decided to move on and will be missed by staff and fundraisers alike. We wish Grace well in her travels and future endeavours.

Grainne Kennedy has taken up the role of Fundraising Co-ordinator and we welcome Grainne to our staff and wish her well in her new appointment. Grainne can be contacted at national office, **Lo-Call:** 1890 311 211 **TEL:** 01-4962433, **E-mail:** gkennedy@cfireland.ie

Paul Brazzill - 200k Run

Paul Brazzill of Barntown in Wexford completed a 200K run through Wexford, Waterford, Kilkenny, Carlow and returning in triumph on Saturday evening 19th July. Paul undertook this challenge to raise awareness and raise funds for Cystic Fibrosis and the Marie Keating Foundation.

Paul's challenge equates with almost 5 marathons run over a 7 day period which is a major physical feat and the oft quoted phrase "the loneliness of long distance runner" certainly applied along parts of the route. Paul states that it was the greatest physical challenge of his life and hopes to be back running within days.

We are grateful to Paul for choosing us as part beneficiaries of his fundraising efforts, to Linda Keating for her co-operation with Garda permits and to the many branch members and friends who helped along the route with the collection. Alan Corcoran and his colleagues at Southeast Radio who kept Paul's morale up during the run and the members of his committee who were present at each major pit stop also deserve a special mention.

It is estimated that a total of €30,000 will have been raised through collections and sponsorship.

The Paddy Kieran's Memorial Walk INDIA 2008

This coming September, 36 willing walkers will take to the streets and hills of India having each raised a considerable amount of funds through the year in aid of Cystic Fibrosis Research.

The walk will begin in Marari, which lies on the South West Coast of India. Walkers will also be given the opportunity to visit Munnar & Cocin. The unique culture of Indian life will be experienced by all it is tipped to be a most unique adventure.

We would like to extend our thanks to all those involved this year and indeed those who have taken part in previous walks to raise funds for CF. In addition, a word of thanks to all those who have fundraised and supported the 36 walkers that will be participating this year.

Fundraiser Co-ordinator at National Office

Other CF Events

Other Events, such as Skerries Rugby Club fundraising, the scaring of the ghosts of Kinnitty Castle by Liz Martin, Maria Hughes & friends, Punchestown Gala Ball, Four Seasons Gala Ball, Lumpers Tain Trek, Malahide Lions Club fundraising, Joe and Sean (PWCF) Kavanagh's forthcoming CF LifeCycle tandem cycle from Bray to Ballyhea, parachute jumps, our selection by Malcomson Law as their Charity of the Year and many other fundraising initiatives, contribute to our ability to carry out our fundamental work in providing services for the Cystic Fibrosis community in Ireland.

We are deeply grateful to all our supporters both past and present and look forward to your continued support in the future.

Thank You!

CFAI wins PR Award for Sick Waiting Campaign (June 2008)

The Cystic Fibrosis Association of Ireland won PRII Award for Excellence in PR for their hugely successful "Sick Waiting" campaign. The Cystic Fibrosis Association of Ireland (CFAI) together with Public Communications Centre (PCC) received a coveted award for Excellence in Communications for the CFAI "Sick Waiting" campaign.

The Public Relations Institute of Ireland (PRII) award ceremony was held in the Round Room in the Mansion House on the 26th June 2008. The PRII awards sets the industry benchmark for excellence across all areas of PR.

The CFAI commissioned PCC to generally raise public awareness of Cystic Fibrosis (CF) and to particularly launch the "Sick Waiting" Campaign for basic internationally acceptable services for people living with CF.

The aim of the "Sick Waiting" campaign by CFAI was to secure international acceptable services for the 1,100 Irish people living with CF. It highlighted that individuals with CF are sick waiting at home for the admission to hospital, for admission to wards, for adequate and safe ward facilities, for the required number of professional staff and, in some regions, for even the most basic facilities.

Following the launch of the "Sick Waiting" campaign in April 2007, PCC & CFAI worked together to meet media demands for information and interviews. CF patients and families themselves played a central role in the campaign and took up opportunities to speak on radio and TV and to write articles on their experiences. **Well Done to all involved.**



A Date for Your Diary Thursday 20th November

**The Cystic Fibrosis Research Trust
Christmas Shopping Spectacular
will be held at the
Pavillion Leopardstown Racecourse
on Thursday 20th November
from 10am-6pm**

This glitzy shopping experience is a great way to support fundraising efforts for CF Research. There are many stalls with unusual presents for all age groups, tombola, raffle and easy parking. We look forward to seeing you. Entrance includes refreshments, €10.

For further information, please contact
Susie Wingfield at 087-2030763.

IKA Annual Service of Remembrance and Thanksgiving

The 2008 Irish Kidney Association (IKA) Annual Service of Remembrance and Thanksgiviing will take place in **Corpus Christi Church, Home Farm Road, Dublin 9 on Saturday, 4th October at 1:00pm.** The Service is open to the families and friends of Organ donors and organ transplant recipients and all are most welcome.

This Occasion is a very important event in the IKA calendar. It is a unique opportunity for donor families and organ transplant recipients to remember and honour the special people who have donated their organs so that others may live. The Book of Remembrance will be available for the benefit of donor families.

Lunch will be served immediately following the service.

The Guide to Third Level For PWCF

Well done! to all PWCF who sat their leaving certificate in 2008 period. It can be a very daunting & anxious time for students waiting for college offers and in many cases re-locating to other towns/cities to be closer to their college of interest. It also can be challenging time financially for both students and parents alike.

Consequently CFAI have compiled a document to help you gain a better understanding of 3rd level education. "The Guide to Third Level for PWCF" is a comprehensive document covering various application processes, grants and financial aids and general information for students. Thanks to Maria Daly, Caroline Heffernan and Tomas Thompson for their valuable work on this publication. The guide is available for download at CFAI's website under the publication section. For any further information, please contact Tomas Thompson at 087-9323930 or E-mail: tthompson@cfireland.ie.

Entitlements for Cystic Fibrosis Families

CFAI in partnership with Dublin 2, 4 & 6 Citizen information Service launched their booklet "Entitlements for Cystic Fibrosis Families" on Thursday the 7th of August 2008 at 12:30pm at the Hilton Hotel, Charlemont Place, Dublin 2.

CFAI and Dublin 2, 4 & 6 have been working in partnership for numerous years and are delighted to work together on this important publication outlining PWCF and their families rights and entitlements. CFAI would like to express sincere thanks and appreciation to the Citizen Information Board (CIB) for their grant funding towards this publication.

The booklet seeks to provided a comprehensive information resource for parents and PWCF. It provides information across the board on social welfare, HSE entitlements, transport, tax, education, housing and supports.

We hope it will provide a useful resource to PWCF, parents of PWCF and anyone working in a support role in this area. (There will be a booklet distributed with this newsletter for all our members).

SOCIAL INCLUSION DFI Pre-Budget Submission 2009

The DFI Pre-Budget Submission 2009 is now available on their website at www.disability-federation.ie. This is part of a long DFI Estimate and Budget campaign where they have sought to resolve underfunding of voluntary disability services, capacity building within disability organization's and the introduction of a cost of disability payment.

In addition to securing the €50 million already committed to for 2009, DFI aim to campaign under these four priority actions:

- To commit €50 million to develop disability services in addition to Multi-Annual Funding for 2009.
- To allocate €20 million to address core funding deficits within voluntary disability organisations.
- To commit €5 million to fund capacity building among voluntary disability organisations.
- To introduce a Cost of Disability Payment of €40 per week to people with disabilities.

CFAI is a member of DFI and are supporting DFI with the above submission.

Cork Branch Host 2009 CFAI Conference

We are delighted to confirm that the 2009 Annual Conference & AGM will be hosted by the Cork Branch and will take place in April 2009.

Exact dates, venue and further information will be announced shortly.

Christmas Cards 2008

Christmas cards will be available from CF House from October 2008. To place your individual orders, please contact Gillian at 01-4962433 or E-mail: info@cfireland.ie

Branch Christmas card orders can be made by contacting Maria at All Print & Design on 01-8786035. Any further queries on the above, please contact CF House directly.



After the AGM each year branch and regional meetings are held to appoint branch officers and regional representatives to the Board of the Association, previously the National Executive Committee (NEC). At the first board meeting after the AGM, Officers for the New Year are elected from and by the regional representatives. A list of the current officers and board members are listed below. It is very refreshing to see new blood coming onto the board and the Association would like to thank all those who currently and who in the past give and gave so much of their personal time to the Association.

Officers:Sean O'Kennedy – **Chairperson**

Mary Lane Heneghan

Vice- Chairperson (out-going)

Joe Browne

Vice-Chairperson (incoming)John Coleman – **Treasurer**Brendan Lonergan – **Secretary****CEO**

Godfrey Fletcher

Regional Board MembersEastern Region:

John Coleman

John Dolan

Ian Duffy

Isobella Higgins

Mid-West Region

Kenneth Flanagan

Catriona Hayes

Midland Region

Esther L'Estrange

Patrick Gallagher

Medical & Scientific

Prof. C. Gallagher

North Eastern Region

Tess Brady

Cyril Gillan

North West Region

Seán O' Kennedy

Tracey O' Kennedy

PWCF

Brendan Lonergan

Nathan Swan

South East Region

Carmel Delaney

Karen Dowling

Southern Region

Paul Higgins

Ann Aston

Joe Brown

Western Region

Louise Harty

The Branch is the building block of the Association and is made up of people who have been directly affected by cystic fibrosis. For newly diagnosed parents of children with CF and for those who just want access to friendly ear our network of branch contacts is a very valuable resource.

An updated list of branch contact names and phone numbers is available on our website www.cfireland.ie under Contact Us.

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