



News Update

**Cystic Fibrosis
Association of Ireland**

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Introduction

Welcome back after the summer. We hope that you have all had a healthy and happy holiday period. The time has flown by here at CF House. We have been fully occupied all summer long between meetings with the HSE as a follow up to the Pollock Report; preparing for our TD and Senator Presentation and Briefing Session in June; to attending the European

CF Congress in June; culminating with our address to the Joint Oireachtas Committee on Health. We are fighting very hard to improve services for People With Cystic Fibrosis (PWCF) and we will be putting our case very strongly to the Minister of Health when we meet with her later this month. We cannot allow the current unacceptable level of CF ser-

vices to continue. We must all voice our objections to our public representatives. We cannot afford to let the CF issue disappear off the political radar.

Let us all work together so that we see a considerable improvement in CF services during 2006.

Mater Hospital – Keen to progress to first CF Lung Transplant

As of the 23rd September 2005 the team at the Mater Hospital have successfully completed three lung transplants. On speaking with Dr Egan recently he and the other members of

the transplant team are keen to progress to their first CF lung transplant. The key factor holding up the first CF lung transplant is in finding the right tissue, blood and size match.

This is very positive news as the Association has been campaigning for some years to have an operational lung transplant unit in Ireland.

First World Day for Organ Donation & Transplantation

The First World Day for Organ Donation and Transplantation has been set for October -14th, 2005 under the patronage of the Council of Europe and in association with the European

Society for Organ Transplantation (ESOT) & the European Transplant Co-ordinators Organisation (ETCO) and the World Health Organisation. Please use this day to promote

awareness of the importance of organ donation.

Drive For Life Campaign Raised €412,600 for CF Research & CF Patient Facilities at Crumlin

Recently, a cheque was handed over to the Cystic Fibrosis Association for a fantastic €412,660 from which expenses have to be deducted. The final figure will be €366,162 that includes a reserve of €10,000 on the "Mount Everest Hurley" still to be auctioned.

Drive for Life was a four-month, 22,000-mile overland

journey by Land Cruiser from Melbourne to Dublin by three Crowley brothers, one of whom has Cystic Fibrosis. Drive for Life aimed to raise awareness and funds for the Cystic Fibrosis Association of Ireland so that people would realise the significance of the disease and carry organ donor cards.

A special Drive for Life Fund account has been set up where the funds collected will go towards specific CF research projects and a selected Crumlin Hospital project. The Associations' sincere thanks goes to the Crowley family, friends and all those who contributed to this enormous project.

Inside this issue:

Fundraising Issues 2

Infection Control 2

Pollock Report Follow-on 3

Joint Oireachtas Committee on Health 3

CF Registry 3

CF Adult Christmas Party Notification 3

NEC Members 4

Hospital Visits 4

Adult CF Group 4

Annual Conference 4





Wristband Campaign A Huge Success

We have had a very successful CF awareness wristband campaign and would like to sincerely thank everyone who contributed. The SPAR campaign in itself raised €90,400 from the green bands with Cork, Kerry, Kilkenny, Tipperary and Dublin colours raising an additional €70,000. It was really inspiring to see the

drive and enthusiasm from our members particularly those who arranged specific publicity events and photo shoots with the various GAA teams. Building public awareness is just as important as fund raising. The awareness campaign continues and now Eirjet (an Irish charter airline) has nominated CFAI as their charity of the year and

they will be promoting our wristbands on their flights. It is hoped that another campaign with a petrol station chain will be announced shortly.

A very special word of appreciation needs to go to Joe Brown for everything he has put into this project. Without him this project would never have taken off.

All Ireland Football Tickets

Two All Ireland Football Final tickets were auctioned successfully in aid of the Association on eBay for the fantastic sum of €1,605. The people who bought the tickets where from the North so they got value for their money! A big thank you to the parent (wishes to be anonymous) who donated the tickets.

Sign up For Cape Town

The Cape Town fundraising walk takes place between 10th – 21st February 2006. Please inform your friends and work colleagues about this event as we always welcome new friends to participate in our events. Information on the walk is available on our website and is also available through CF House from Martin Cahill

Boston Walk

The Association hopes that all those who participated in the recent Boston / Cape Cod walk had a really enjoyable time and we thank them for their contribution.

Health Squad

Paulina Masterson, a CF adult recently featured on the RTE 1 Health Squad Programme.

PDFORRA Charity for 2006

The Permanent Defence Force Other Ranks Representatives Association has chosen CFAI as their Charity of the Year commencing March 2006. We look forward to developing a strong relationship with the Defence Force.

HSE Launches Guidelines for Hand Hygiene & on the control of MRSA

Two documents, which give hospitals clear policy and practical guidance on the control of healthcare associated infection (HAI) were launched by An Tánaiste and Minister of Health & Children, Ms Mary Harney T.D. on September 19th 2005. Speaking at the launch the Acting Director of the National Hospitals Office, Dr Mary Hynes stated that the HSE was determined to tackle the issue

of health care associated infections and the spread of MRSA. She emphasised that 'maintaining good hand hygiene is one of the simplest and most effective measures that can be used to stop the spread of MRSA and other infections'. Copies of these 2 reports are available for download from the web at the following address:

<http://www.hpsc.ie/>

Infection Control Guidelines

The Association's Infection Control Guidelines have been updated by the Infection Control Sub Committee of the Medical & Scientific Committee. These will be put before the next meeting of the MSC and NEC for approval. Once this

takes place copies will be made available for distribution. The Association would like to thank those members of the Committee you have given considerable personal time into putting this document together.

Gala Charity Ball 2006

A committee has just been set up to organise a CF Charity Ball at the Four Seasons Hotel, Ballsbridge on February 4th 2006. The Chairperson of this committee is Jim Somers. This event will be very much focused at the corporate market with the aim of raising signifi-

cant funds for CF projects. Current committee members are Jim Somers, Nicola Somers, Edelle Collins, Louise McCann, Martin Cahill and Godfrey Fletcher. Anyone interested in assisting with this event please contact Martin Cahill at CF House.

Corporate Sponsorship Required for CF Athlete

In our next Annual Newsletter we will be running a feature on Evan Scully a CF adult who has taken on the best of his class in athletics. He has a full competitive race schedule planned out through to August of next year culminating in the goal to qualify for the final of the European

Under 23 Finals of the Mazda Track & Field Leagues. Training, materials, gym fees, dietary supplements, physio/massage etc all run up huge expenses so if any member has contacts in the corporate sponsorship world please get in contact with his father, Eamon Scully through CF House.

Have You Ordered Your CF Christmas Cards?

Christmas Cards can now be ordered through your branch or through CF House. For

further details contact Kay Cannon at CF House.



Pollock Report Follow-on

The multi disciplinary working group established by the Hospital Services Executive (HSE) is still meeting and preparing a recommendation on how Cystic Fibrosis services in Ireland will be structured and funded into the future. It is expected that the Group will be publishing its recommendations by the end of October.

As a direct result of the findings of the Pollock Report the HSE

did issue €300,000 in recurring emergency funding to immediately address the under resourcing of St Vincent's CF services. The position for a second CF Consultant has now been approved and was advertised along with a CF Clinical Nurse Manager. It is anticipated that certain refurbishment of existing CF facilities will take place before the year end.

Minister of Health Agrees to meet with CFAI

The Association has been requesting a meeting with the current and the previous Minister of Health. An Tánaiste, Mary Harney T.D. has agreed to meet with a delegation from the CFAI on October 27th. This will be the culmination of a series of events that began with the launch of the Pollock Re-

port in February, followed by a successful briefing morning for T.D's and Senators on June 15th, that led to our presentation to the Joint Oireachtas Committee on Health. The Association looks forward to this meeting and the opportunity to put our case forward to the Minister.

Are you signed up to the CF Registry?

The CF Registry enrolled its first PWCF in the summer of 2002. Since that time, the Registry has entered over 500 more PWCF. The total number of patients registered is now 528, with a further 70 PWCF to be entered. This represents approximately 50% of the population. If you are not already signed up please take some time to read the enclosed notification, information leaflet and consent form from Linda

Foley, Director of the CF Registry of Ireland.

The Registry has now moved to its new home and its new address is as follows:

CF Registry of Ireland
Woodview House
UCD – Belfield
Dublin 4
01-7163177

linda.foley.1@ucd.ie

lindamfoley@eircom.net

Christmas Party for CF Adults

Anthony Dempsey and Carl Brady, the organisers of this year's CF Adult Christmas Party are pleased to announce that this year's function will be taking place on December 10th at the Abbey Court Hotel,

Nenagh, Co Tipperary. Information on this event and booking details is enclosed with this mailing. Please note that cross infection guidelines will be strictly enforced by the Association.

Oireachtas Committee

On September 29th the Association made a presentation to the Joint Oireachtas Committee on Health. The delegation was made up of Mary Lane Heneghan (Chairperson), Carl Rainey (Vice Chairperson), Dr C Gallagher (Chairperson Medical & Scientific Committee), Rory Tallon (CF Adult NEC Representative) and Godfrey Fletcher (CEO). Godfrey Fletcher made a seven minute

presentation and this was followed by an extended question and answer session. A strong case was put forward for increased funding for CF services that would include additional staffing and improved facilities. Our presentation received considerable support from all members of the Committee.

Photo ID's Available

Credit Card size Photo ID cards are now available from CF House for any person with CF who requires proof of ID and illness. These could be used to prove illness when requesting special treatment from a service provider e.g. early boarding on an airline, use of disability friendly facilities etc. This initiative came about as a direct result of positive input from our adult members. Anybody interested in having a CF ID Card please contact Helen Whitty or Orla Moore.

Change Process

As part of the implementation of the FGS Report the Association is currently formulating a Strategic Plan that will focus our thought processes on where the Association wants to be in 3-5 years time. This will include a review of our current governance and proposals as to what changes need to be approved to keep the Association in line with the impending changes in charity legislation. Once this plan has been drafted it will be presented to the members for formal approval.

Cyber Campus Continues

Any adult who is interested in obtaining an ECDL (European Computer Driving License) qualification please contact Orla Moore at CF House.

Citizen Information Centre (CIC) weekly information day at St Vincent's Hospital

The Citizen's Information Centre has an information desk available in SVUH every Wednesday from 10am – 4pm. It is located in the main corridor beside the new coffee shop. To find out where your nearest CIC centre is located, visit the following website: www.comhairle.ie or

TEL: 1890 777 121.

Your local CIC provides information, advice and advocacy services, which means you can:

- Get information on all your entitlements.
- Get advice on the best options that are open to you.
- Receive help filling out a form, following up your enquiry or appeal issues if necessary.

It is important to note that this is a free, confidential and independent service that is delivered by trained information providers.



NEC Members Elected

Adult CF Group

After the AGM each year branch and regional meetings are held to appoint branch officers and regional representatives to the Nation Executive Committee (NEC). At the first NEC meeting after the AGM, Officers for the New Year are elected from and by the regional representatives. A list of the current officers and regional NEC representatives are listed below. It is very refreshing to see new blood coming onto committee 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:

Mary Lane Heneghan – Chairperson & Western Region Representative

Carl Rainey – Vice Chairperson & North Western Region Representative

Gerard Fay – Vice Chairperson & North Eastern Representative

John Coleman – Treasurer & Eastern Region Representative
Mairead Delaney – Secretary (ex-officio)

Godfrey Fletcher – CEO

Regional Delegates

Seamus Bohan - Eastern Region Representative

Kathleen Peters – Eastern Region Representative

Marsie Campion – Southern Region Representative

Ann Aston - Southern Region Representative

Esther L'Estrange – Midlands Region Representative

Caroline Higgins – North Eastern Region Representative

Andy Leggett – North Western Region Representative

Majella Kelly – Western Region Representative

Ann O'Rourke – South Eastern Representative

Catherine Murray Smith – South Eastern Representative

Breda Hannon – Mid Western Representative

Diarmuid Meade – Mid Western Representative

Rory Tallon – CF Adult Representative

Jean Byrne – CF Adult Representative

At the last NEC Meeting it was announced that the CF Adult Group was disbanding. The main reasons for this were the legitimate fear of cross infection together with apathy from the Adult CF member base. The Chairperson thanked the Adult Group for their invaluable contribution to the Association. The NEC agreed that the two Adult delegates and sub delegates would remain on the NEC. The contribution by the Adult Group to the Association has been immense particularly in their frank and open comments on key issues relating to cystic fibrosis. The Association

is pleased that the previous members of the Adult Group will continue to produce Future Force, still maintain involvement in the CF Forum website and continue to give valuable contributions to our Annual Conference. The Association would personally like to thank Patricia Duffy, Jean Byrne, Rory Tallon, and Dara McGrath for all the assistance that they have personally given to me and my team at CF House. I know that through their ongoing dedication to the Association that these members will continue to be key contributors on CF issues.

Hospital Visits

Over the past twelve months, our Services Co-ordinator, Ms. Helen Whitty has been making regular visits to the "National Adult Referral Centre" at St. Vincent's Hospital, Dublin. Primarily, these visits were put in place to offer assistance and support to people with cystic fibrosis (PWCF) and their families. Should any member have ongoing concerns or issues that they wish to discuss, please contact Helen Whitty at 01-4962433 or 1890 311 211 (LoCall Number) or E-mail: hwhitty@cfireland.ie.

In the near future, our current Accounts Administrator, Ms. Orla Moore will be taking on the Services Co-ordinator's Role. Orla will be working closely with Helen over the coming months and will initially start liaison work with the Paediatric Hospitals early in the New Year.

Helen now becomes Office Administrator but will retain responsibility for St Vincent's Hospital.

Influenza Vaccination

The Influenza season is on the way again. Don't forget to contact your medical practitio-

ner to arrange for your vaccination.

Annual Conference 2006

31st March to 2nd April

Seamus Bohan and his team from the Eastern Region are already advanced in the planning stages for next year Annual Conference. The chosen venue for the 2006 Annual Conference will be the Portmarnock Hotel, Co Dublin,

home to the famous links golf club. International speakers have already been identified that would make a significant contribution to our learning process in the latest topics relating to CF.

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