

# April 2004 Newsletter

## **Important message from your chairperson:**

The FGS Report makes clear that not only must we get all delegates to attend the NEC meetings but that those people must rotate so that we have fresh blood and fresh ideas coming through all the time. The election of officers usually takes place around the end of May or early June and I would urge you to find people with energy and ideas who are prepared to come to Dublin to the NEC meetings. You may know of a CF parent who does not normally attend the Branch meetings but who you feel would be a good person to have on board. Go and approach him/her, cajole them, twist their arm and don't give up until they agree! If you have someone and they just need a final push, let me or one of the Officers know and we will give them a call and reassure them that they will be very welcome at the table. After Easter I will be contacting all Branches to discuss this matter so in the meantime please put on your 'thinking caps' for suitable people.

Carl Rainey, Chairperson

## **National Medical Conference & AGM:**

The Annual National Medical Conference and AGM for the Association was held in Sligo on the weekend of the 26th - 28th March 2004. The weekend was very successful and well received by speakers and members. Lectures covered nutrition, psychology to lung transplantation. The Officers and members of CF House would like to pay special thanks to the Sligo Branch especially Iris Murphy and Andy Leggit for all their hard work behind the scenes and dedication to the Conference over the past 6 months. Presentations of different speakers will be available for circulation shortly, please contact CF House for further information.

## **Annual National Raffle:**

Due to the An Post strike in March many people were unable to return raffle tickets for the annual national draw in time for the Conference. As a result of this strike, the date for the raffle has been extended to the next NEC meeting on Sunday May 16th. For those who still have raffle tickets outstanding please return them to CF House before May 12th. There are tickets still available through CF House for people who wish to sell more. Please contact Kay for more raffle tickets.

## **Fundraiser Updates:**

- **Women's Mini Marathon :** The Annual Women's Mini Marathon is to take place on June Bank Holiday Monday (7th June). The 10k race is in its 22 year and is the biggest all female event of its kind in the world. Nearly all participants run for a chosen charity. Applications forms for the event can be got from the Evening Herald newspaper every Thursday and Saturday until the end of April. For those interested in fundraising for charity while competing in the mini marathon, sponsorship cards and t-shirts can be obtained from CF House.

- Cuba Walk 2004 : This year's walk destination welcomes you to the tropical Caribbean Island, Cuba! This Jewel Island is the largest in the Caribbean and extends 750 miles (roughly the size of Pennsylvania) and is a beautiful mix of mountain ranges and plains. There are over 200 bays and 289 sun drenched beaches to explore. It is a vibrant mix of Latin American and West Indian culture intermingling with the communist way of life, which makes it a fascination to visit. So start planning today and tell others about this wonderful opportunity - there are limited places available so book now to avoid disappointment.  
Total Cost Per Person: ?3,200 (single supplement applies)  
Departure Date: Friday 24th September 2004  
Return Date: Sunday 03rd October 2004  
Booking Deposit: ?250  
For further details and registration/booking from(s), please contact Helen @ 01 4962433 OR download from our website [www.cfireland.ie](http://www.cfireland.ie)
- People in Need- Telethon Funding: The People in Need telethon is a great way to raise money for charity and all monies raised in each county stay in each county. If you would like to do some fundraising this May for People in Need and apply for funding for your branch please contact People in Need ? 01 6792944 or log on to [www.telethon.ie](http://www.telethon.ie)

#### **Launch of the Lung Transplant Unit:**

The new and long awaited lung transplant unit was officially opened in the Mater Hospital on Monday March 29th. The new unit signals the beginning of a new era for Cystic Fibrosis patients who await lung transplants. It is hoped that the first transplant will take place this summer and a further 3 transplants will take place by the end of 2004. Once the third theatre is built, all transplants will take place in the Mater Hospital for Irish patients. At present both pre and post operative care is carried out in the Mater hospital.

#### **Have you signed a consent form yet?**

The CF Registry is proceeding very well indeed. We now have 337 (31%) Consent Forms on file; 237 PWCF are entered on the Registry and there are approximately seventy forms in hand to be entered. There are individual medical reports on each person registered and summary reports available to Consultants. Our goal is to have at least three quarters (800+) of our CF population entered with at least one Annual Assessment by the end of 2004. If we achieve that we will have a very good basis for the next Annual Report. In order to improve the Registration process, members could help by asking their CF nurse for a Consent Form when they visit their clinic. If anyone needs more information regarding the CF Registry, please visit the website, [www.cfairegistry.org](http://www.cfairegistry.org) or phone Linda Foley at 01 491 2722. Information Booklets are available from either the Registry office or the CFAI and may be downloaded from the website.

Linda Foley

#### **Christmas Card Orders:**

For Branches who would like to place orders for Christmas Cards 2004, please contact

CF House by the end of April. Same delivery and pay system applies as for 2003 i.e. direct dealings with All Print & Design.

**CF House Database:**

Are you receiving more than one copy of any of our literature?

Are we sending literature to the correct address?

Contact CF house so we can update your details

**NEC Meeting:**

Please note that the next NEC meeting is to be held in CF House on Sunday 16th May at 1.30pm. All delegates are kindly asked to attend.