

September 2003 Newsletter

Cross Infection:

The Officers of the Association realise there is disquite among some members regarding the cross infection policy adapted by the Association as a result of the letter from our Medical and Scientific Committee. As a result of this we have written to Dr. Philip Murphy, consultant in Medical Microbiology and Chairperson of the Cross Infection Sub-committee asking him to clarify certain issues regarding the suitability or otherwise of the CFWW cross infection guidelines in various situations. Dr. Murphy has responded but we require further clarification which we are awaiting. We have emphasised the urgency of the situation and hope to hear from him in the near future. We also published with the kind permission of the CF Trust an article from their Autumn magazine regarding this very issue and I strongly recommend that everyone should read it. Carl Rainey, Chairperson.

New CF Website & Community Forum:

Over the summer, our new website was developed courtesy of Gordon Lucas. The new CF website is both bright, colourful and informative. It contains general medical information, cyber campus page and links to other relevant websites. A community forum has also been introduced and has several different categories which people can post questions, comments or information. Log on to www.cfireland.ie and have a look!

Tribute to Robbie Peters:

The Officers of CFAI and staff at CF House would like to pay tribute to the late Robert (Robbie) Peters who passed away in August. Robbie generously helped the Association by working and tutoring students online on different phases of the Cyber Campus course. Robbie worked to better and further people's education through the modular based distance learning course and showed that distance e-learning was an effective educational tool for gaining qualifications. Robbie was a cornerstone of the project and will be greatly missed in CF House and by all tutors and students who knew and worked with him.

Fundraiser Updates:

*Drive For Life Homecoming Ball The Drive for Life consisted of a 22,000 mile drive, by the three Crowley brothers - Darragh, Cian and Shane, overland from Melbourne, Australia via 19 countries through to Dublin. The Drive for Life Ball took place on Saturday 27th Sept and was attended by 8 members of the Association. It was a hugely successful night with over 550 people in attendance at the The Pavillion, Leopardstown. During the night there was a raffle and an auction and they were able to announce that they had exceeded their initial fundraising target of ?250,000. We congratulate Darragh, Cian and Shane and everyone involved, on a fantastic adventure and on achieving their very ambitious fundraising target.

- Spiddal - Cooley Tractor Drive. Special thanks to Eoin Monaghan for his Tractor Drive between Spiddal and Cooley which raised ?13,000 for Cystic Fibrosis.
- South Africa Walk 2003. The South African walkers took off to Table Mountain and the other fascinating sites in South Africa on Sept. 23rd for 10 days. Many thanks to all participants and the Walk Committee for their hard work in organising the walk this year. The walk details for 2004 are already underway and will be announced in the coming months. It is hoped that a large crowd will participate in next years walk again.
- Dublin City Marathon. The Dublin City Marathon enters its 24th year and proves to be a popular race through the Georgian streets of the capital for both national and international runners. The race starts at 9am on Bank Holiday Monday, October 27th. For those interested in fundraising for charity while competing in the marathon, sponsorship cards can be obtained from CF House.
- Annual National Conference. A note for your diaries - the Annual National Conference will take place in March 2004. The Conference will be held on 26th - 28th March at the Sligo Park Hotel. More details will be available about the Conference in coming months.
- Annual National Raffle. Tickets for the National raffle will be available as of December 2003 - donation of prizes are welcome.

James Cannon:

James Cannon (an IT student) worked in CF House over the summer period. James was of great help in the office covering general IT, parts of the website and the database. All the staff at CF would like to thank James for all his hard work over the summer period and wish him all the best at college this year.

Annual Newsletter 2004:

For those of you who have any articles they wish to have published in the Annual newsletter 2004 please send them into CF House or email info@cfireland.ie in the coming weeks. Please include contact details so photographs may be returned.

CF Registry Information:

Work on the Registry is progressing well. Informed consent forms are coming in and there are now nearly 100 PWCF entered on the database. At the same time work has begun on producing individual reports for each person, which the doctors and nurses will have to hand when they view someone's medical chart. These reports summarise all medical care and infections from the previous twelve months. This can be very useful when a person's previous history has been archived in medical records and is not readily available when the person attends a clinic or is admitted to hospital. Work is about to begin on a PWCF census for 2003 and a submission for future funding from the Department of Health & Children. It is hoped that the Department will see its way to funding the Registry on a permanent basis.

Linda Foley.

News from the CF Adult Group:

Just to keep you up to date - the next issue of Future Force is underway and should be delivered in November. Please contact the Magazine Group at CF House or by email at the address below, if there's anything you'd like to contribute (pictures, questions articles) for the next issue, we'd be delighted to hear from you! The Adult Group are currently negotiating with the Medical and Scientific Council (MSC) to the Association regarding the development of Guidelines to reduce the risks of cross infection. These guidelines will seek to examine various aspects of daily life- not just socialising with other CF Adults. Social events (including our Christmas Party Weekend) will be postponed until the relevant guidelines and procedures are in place- please write to us at the Head Office address, or email us at futureforcemag@hotmail.com if you would like to learn more on this issue. The new guidelines will be adopted by the Adult Group in organising any future events- so be prepared for some changes in the year to come!

Patricia Duffy, Chairperson Adult Group.

FGS Report:

The final draft of the FGS Report on the internal review of services and operations of the Cystic Fibrosis Association will be available in Mid October 2003.

External Review:

A draft copy of Dr. Pollack's external review - 'Provision for the treatment of Cystic Fibrosis in Ireland' has been completed and is being considered by the Medical and Scientific Council. As soon as a final report is complete, it will be circulated to all members.

Note on Flu Vaccine:

Those with low suppressed immune systems are advised to see their GP at this time to avail of the Flu vaccine.

If you have any news stories or event information that you would like added to our News Update Page, please contact us with the details...