



# Spectrum



## e-Bulletin from Cystic Fibrosis Association of Ireland

*Issue 15, September 2010*

Dear All,

Welcome to the 15<sup>th</sup> issue of our monthly e-Bulletin '*Spectrum*'.

It's that time of year again when we ask ourselves where the summer has gone! Around the country, students are getting ready to go back to school or are beginning college for the first time. This issue of *Spectrum* brings you an update of schemes and scholarships available to PWCF undertaking full-time higher-education courses to make them aware of the options and benefits available to them.

We also bring you the very latest news on building work at St Vincent's University Hospital, and will endeavour to update our members with further developments as soon as they arise.

September is set to be another busy month on the fundraising front, with the CF Lugathon and the Lakes 10k running over the next few weeks; details of these events, and many more, can be found inside this issue.

If you would like to see anything in particular included in the next issue of *Spectrum*, please email your ideas to [amay@cfireland.ie](mailto:amay@cfireland.ie).

Until next month!

Kind Regards,

Philip Watt (CEO)  
Alica May (Editor)



## • Latest News •

### Update: Work on St Vincent's University Hospital to commence shortly

Further to our previous *Spectrum* reports on progress – The CEO of St Vincent's University Hospital (as of 7<sup>th</sup> September 2010) is confident that work on the new ward block in the hospital will commence in the next few weeks, possibly before the end of September. This vital facility will provide single en-suite patient accommodation (100 rooms) and a dedicated day unit for people with Cystic Fibrosis.

The CFAI has publicly expressed disappointment that the completion date has now been signalled as 'early 2012' instead of the end of 2011, and will continue to insist on the earliest possible completion date. The CFAI has highlighted the continuing inadequacies of existing CF facilities in St Vincent's for both staff and patients. **Note:** Construction was delayed in June 2010 as a consequence of the need for a new construction company to be appointed to undertake construction when the preferred tenderer went into financial difficulties. The preliminary work on clearing the site and decanting and removing the prefabs on the site was reported in previous issues of *Spectrum*.

The Irish Times (8<sup>th</sup> September 2010) reported that the Minister for Health and Children, Mary Harney TD has again reiterated the government's commitment to build the CF Unit in St Vincent's University Hospital. This commitment was also given in a written reply to a question from independent TD, Finian McGrath and in recent meetings with the Minister with the CFAI.

### Staff Shortages Causing Increasing Concern for the CFAI

The HSE's inflexible policy of not replacing key staff that are on maternity or sickness leave is causing ongoing concern for the CFAI. A very worrying example of this policy in practice was recently illustrated in the Mid-Western Regional Hospital in Limerick where a senior physiotherapist went on maternity leave and was not replaced by the hospital. This resulted in no out-patient physiotherapy service for some 75 children with CF in Limerick between the period of May–August 2010. Following robust representations made to the hospital and the HSE by the CF Head Office in partnership with local CF Branches in Tipperary, Limerick and Clare (through TLC4CF), an interim physiotherapist from existing staff was appointed in August 2010. The CFAI is fully aware of the current cutbacks in health services but it is completely unacceptable that a crude application of mechanism, such as a staff embargo, could be placing children's lives in danger.

### Audit of Staff Vacancies

The CFAI will be undertaking an audit of CF specialist staff vacancies over the next few weeks to identify gaps in the multidisciplinary teams in CF Centres around the country. It is hoped that this audit will allow us to establish a benchmark by which we can measure fluctuations in CF services.

### CFAI Internship

The CFAI welcomes Kristin Francis as a research intern in the Association until the end of October 2010. Kristen is originally from Chicago and has completed a Masters in Public Health in UCD where the focus of her Masters was on CF services.

### RCSI Researchers make Breakthrough in Understanding Gender Gap in Cystic Fibrosis

The CFAI welcomes results from a recent study, published in the *American Journal of Respiratory and Critical Care Medicine*, which found that oestrogen limits the lung's ability to respond to infection. The research was carried out by scientists at the Royal College of Surgeons in Ireland (RCSI) and Beaumont Hospital. Oestrogen was found to prevent the release of a chemical signal (IL-8) that triggers the influx of white blood cells (neutrophils) into the lungs to fight the infection when cells are attacked by bacteria.



Dr Sanjay Chotirmall, joint lead author of the study commented, "Our research may contribute towards narrowing the gender gap in CF by identifying new potential targets for treatment, such as stabilisation of oestrogen levels, or more aggressively employing preventative strategies against infection during the one week of the four week menstrual cycle where oestrogen levels are at their highest. Our ultimate aim would be improving the quality of life and survival rate for female sufferers of CF."

"The reduced response to infection combined with a greater likelihood of acquiring an infection in the first place, both caused by high oestrogen levels, goes a long way towards explaining how females with CF have more aggressive disease, particularly with the onset of puberty," Dr Chotirmall continued.

It is hoped that the findings from this research study will lead to new treatments for the disease. The study was funded by the Higher Education Authority PRTL Cycle 4, through a Molecular Medicine Ireland Clinician-Scientist Fellowship Programme.

### Sisters with CF Audition in America's Got Talent

Ali (20) and Christina (13) Christensen are sisters from Idaho who have made it to the semi-finals on the latest show of America's Got Talent, which is currently running in the states. Along with their other two siblings, Christina and Ali were diagnosed with CF at an early age. In spite of their illness, their dream is to inspire people who face challenges, or who have lost hope.



"I want the judges to look beyond everything", says Ali, "and just see us for who we are. Cystic fibrosis does not define us. We define ourselves," continued Ali.

Christina and Ali will be performing again in the semi-finals of America's Got Talent on Tuesday Sept 7<sup>th</sup> at 9pm – we wish them the very best of luck!

*L-R: Ali and Christina Christensen, sisters with CF.*

### National Children of Courage Awards 2010

Once again this year the **Share a Dream Foundation** will host its 'National Children of Courage Awards' & Dream Ball on 27<sup>th</sup> November in The Radisson Blu, Limerick and as always it promises to be a magical event where dreams actually will come true on the night.

**Eight very special children** will be selected from nominations from all over Ireland, who have shown courage and determination to get as much out of life as possible in spite of their life-threatening illness or disability, will be honoured. In addition to being guests of honour at the Dream Ball and receiving their awards, they will also have their fondest wish come true on the night.

So if you can think of any deserving candidates with CF who have demonstrated such courage and bravery, despite their suffering, perhaps you will consider sending in a nomination! As part of their overall prize, all eight award-winning children and their parents will go on a Magical VIP Trip.

To enter, simply detail (in 200 words or less) why you think he or she is a child of courage and send it to: Share a Dream Foundation, Roselawn House, Castletroy, Limerick. For more information please contact the Share a Dream Foundation by calling 061 633 777, email [dreams@shareadream.ie](mailto:dreams@shareadream.ie) or log on to [www.shareadream.ie](http://www.shareadream.ie).



## Message from PWCF Adult Group

As most of you know, the PWCF Adult Group meet once a month via a teleconference line to discuss issues relative to living with CF; it was through this group that the Exercise Grant Scheme was born. Two members of this group are elected on to the NEC on an annual basis and actively participate on the Board as the voice of PWCF.

On a few occasions the CF Advocates have been asked if there could be a similar service for parents and/or younger teens to talk to their respective peers. If you think you might be interested in such communications please let Caroline know on 087 9323933 or email [cheffernan@cfireland.ie](mailto:cheffernan@cfireland.ie), and we will try to facilitate conference calls if people are genuinely interested.

## Anam Cara Parental and Sibling Bereavement Support

Anam Cara have extended an invitation to any CFAI members interested in attending a talk being held in Dublin on 15<sup>th</sup> Sept (details below). This event is offered at no cost to parents, Anam Cara's only brief being to offer people the appropriate support services after the passing of a child. If you need any other information about this event or about Anam Cara, please call Sharon Vard at 01 4045378 or email [s.vard@anamcara.ie](mailto:s.vard@anamcara.ie).

Date	Location	Speaker	Topic	Venue
7.30–9.30 15th Sept 2010	Dublin	Nuala Harmey	Supporting Siblings after a death of a brother or sister	Carlton Dublin Airport Hotel, Santry, Dublin

## Volunteer Reminder – PWCF still needed for Research Project

Lois McCrea, Chartered Physiotherapist, is still looking for volunteers for a study entitled “*The Prevalence of Musculoskeletal Pain in Irish adults with Cystic Fibrosis.*” Musculoskeletal pain is any pain that affects the bones, muscles, ligaments and tendons. It can include pain, discomfort, aches, or symptoms associated with pain, for example, stiffness.

The research is likely to be carried out via an **anonymous postal questionnaire**. In order to be eligible to take part in this study you must:

- Have cystic fibrosis
- Be 18 years of age or over
- Be resident in the Republic of Ireland

In this study, Lois proposes to examine the area of musculoskeletal pain in CF to determine both its **prevalence** and its effect on **quality of life**. It is hoped that the results from this study will help with the future management of CF, especially as the prevalence of musculoskeletal pain is likely to increase in view of the ageing population. If you would be interested in volunteering for this study please contact CF house or email [amay@cfireland.ie](mailto:amay@cfireland.ie).

## Fertility Grant Scheme 2010 still open – Reminder!

We are still accepting applications to the Fertility Grant Scheme 2010. The purpose of this grant is to provide financial support to PWCF and their respective partners who wish to undergo fertility assessment/treatment in the hope of becoming pregnant.

This grant is limited to one cycle of fertility treatment per couple; members who applied in 2009 may not apply again. The maximum value of the Fertility Grant in 2010 is €2,500; this is inclusive of initial fertility assessment costs. Please be advised that each Applicant and their respective Partner must undergo an **initial fertility assessment** at the Fertility Clinic *before* applying to the CFAI for a Fertility Grant.



The Application Form and Grant Policy and Conditions documents are now available for download from the CFAI website at [http://www.cfireland.ie/articles.php/fertility\\_grant](http://www.cfireland.ie/articles.php/fertility_grant), or you can request copies be posted directly to you by contacting the National Head Office.

The **deadline** for submission of Applications and Supporting Documentation is **Friday 10th December 2010**. If you have any queries about this scheme, please contact Alica May at CF house t: 01 496 2433; e:[amay@cfireland.ie](mailto:amay@cfireland.ie).

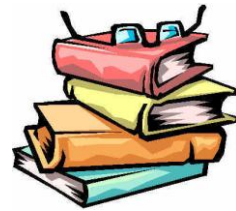
### Discussion paper on End-of-Life Care for People with Cystic Fibrosis

In 2009, the CFAI decided to prepare a discussion document considering the area of end of life care for PWCF. This discussion paper, which was prepared in conjunction with the Irish Hospice Foundation, summarises the responses of questionnaires issued to the CF teams and the views of PWCF, as well as setting out international perspectives in this area. This document has been prepared in order to create more awareness of the issues that are present in this area, to promote discussion within the community, and to seek consensus regarding the potential mechanisms that would enhance service responses in supporting and addressing the end of life needs of PWCF and their families. It concludes with a summary of the general issues raised and a number of recommendations relative to PWCF, their families and the CF teams, as well as the role of specialist palliative care teams in this area.

The paper is now available for consultation (until 1st October), and has been distributed to CF teams and those involved in Specialist Palliative Care across the country. If you would like to request a copy of this discussion paper, please contact Alica May at CF House t: 01 496 2433; e:[amay@cfireland.ie](mailto:amay@cfireland.ie).



### Update on Third-Level Education Supports for PWCF



#### The Back to Education Allowance

If you are going to college or are taking part in a full-time education course in 2010/11 you may qualify for financial assistance. The Back to Education Allowance (BTEA) is a scheme available to people with disabilities (including PWCF) who are receiving the Disability Allowance. The BTEA can be paid to people who wish to undertake approved second or third-level courses of education. BTEA is **not** an unemployment payment. Participants get a standard rate of payment which is not means tested.

#### *What courses qualify for BTEA?*

A third level course at any university, third level college or institution as long as it is:

- A full-time day course
- Approved by the Department of Education and Skills for the
  - Higher Education Grant Scheme,
  - Vocational Education Committee's Scholarship Scheme, **or**
  - Third Level Maintenance Grant Scheme for Trainees, **or**
- Recognised by the Higher Education and Training Awards Council (HETAC)

#### **Note:**

The postgraduate option of the BTEA scheme is only for people who wish to take:

- A postgraduate course of study that leads to any Higher Diploma (H. Dip.) qualification in any discipline, **or**
- A postgraduate Diploma in Education (Primary or Secondary teaching).



Other postgraduate qualifications including a Master's degree are not recognised for BTEA purposes; however, you can continue to receive your Disability Allowance on such courses.

#### *How do I qualify for BTEA?*

You can qualify for BTEA if you are aged 18 or over, have CF and are receiving the Disability Allowance.

#### *How do I apply?*

Once you have been offered a place on a course, notify the BTEA office (details below) and fill in the form [BTE1 Application form](#).

Applications for BTEA must be made prior to commencement of an approved course but late applications will be accepted if received within 30 days of the commencement date of the course, provided there are reasonable grounds for doing so.

Return the completed [BTE1 Application form](#) to the following address: Department of Social Protection, Social Welfare Services, Ballinalee Road, Longford. LoCall: 1890 927 770

#### *How is the BTEA paid?*

The BTEA is paid at the same rate as your Disability Allowance. The rate of payment is affected only by changes in the Budget each year and changes in qualified adult or qualified child status.

The allowance is paid **instead** of the social welfare payment that entitled you to take part in the BTEA scheme. You can get the BTEA paid directly into your account in a financial institution. This account must be a current or deposit savings account (**not** a mortgage account).

#### *What is the 'Cost of Education Allowance'?*

If you qualify for the BTEA you may also be entitled to the 'Cost of Education Allowance' (also known as a book grant) towards the cost of your studies. This allowance, currently €500, is paid once written confirmation is received from your school or college that you have registered on your course at the start of each academic year.

#### *Secondary benefits*

You may keep any secondary benefits you already have such as Fuel Allowance, Diet Supplement, Rent Supplement or Mortgage Interest Supplement (any increase in income may affect your Rent or Mortgage Interest Supplement), under the Supplementary Welfare Allowance Scheme.

Earnings from part-time employment do not affect the basic BTEA payment. However, any income which you or your spouse or partner gets **is** assessable for Rent or Mortgage Interest Supplement.

### **Other Grants**

#### *Grants and Scholarships Specifically for Students with PWCF*

The National University of Ireland-Disabled Persons' Award Scheme provides awards of €500 for a small number of new entrant undergraduate students registering for the first year of a primary degree course of studies in one of its constituent Universities or recognised Colleges.

Students who propose to pursue a University Primary Degree course in the National University of Ireland may apply. Awards will be made at the end of the first term. Should recipients not complete their first year course they may be liable for repayment of all or part of the award. Applicants are required to submit evidence of their disability with their completed application forms which are available from: The Registrar, National University of Ireland, 49 Merrion Square, Dublin 2. Closing Date is **November 1st** of each year.



### *Department of Education Special Fund for Students with Disabilities*

This fund is specifically designed to financially assist third-level students with special needs. It is administered by the Higher Education Grants Section, Department of Education and Science, Tullamore.

You should apply to this fund through your third level institution in September/October of each year. Contact the Disability Officer, Student Services or the Registrar's office of the relevant institution for more information.

### *Other Scholarships*

Individual institutions have in the past offered first year students with CF a small scholarship or grant. Also, some companies sponsor students with disabilities. You should enquire with the Disability Officer or the Registrar's office for details, if any, of these initiatives.

### **Post-Graduate Grants**

Higher Education Grants (HEG's): If you received a HEG for undergraduate study, you may apply for a further education grant if you wish to continue at post-graduate level.

If you did not receive a HEG but meet the following conditions you may be considered:

- Commencing an approved post-graduate course
- Entering an approved third-level course for the first time

Apply to your local county council/corporation. You may seek 1-2 years funding, depending on the length of the course.

### *Advanced Technical Skills (A.T.S.) Programme*

Some post-graduate courses receive financial assistance from the European Social Fund under the A.T.S. Programme which caters for persons who, through experience, have found that they require advanced qualifications in order to secure acceptable employment. There is no upper age limit for admission to this programme.

If a course is A.T.S. approved, there are no tuition fees payable. Although there is no maintenance grant available under the programme, students who qualify for such an allowance under the HEG Scheme of the Vocational Committee's Scholarship Scheme may continue to receive it in respect of their attendance on the courses, where the A.T.S. course is the student's first post-graduate course.

### *The Dr. Ciaran Barry Research Scholarship: Central Remedial Clinic*

This scholarship is reserved for post-graduate students with a disability and is open to any academic discipline. Applicants must be graduates of a recognised University or third level institution. Candidates sitting their final examinations may also apply.

A proposal must be submitted on a special application form, outlining the research topic, proposed methodology, timescale, expected outcomes and funding requirements. All proposals must have a significant research component.

All grants will, in general, cover one academic year. A longer period may be agreed if the study is deemed to warrant an extension. The continuation and termination of the scholarship will be at the discretion of the Trustees of the Central Remedial Clinic Research Trust.

On completion of a research project/thesis, the recipient of the scholarship must submit a copy of the research project to the Trustees. All publications or papers arising from the research will acknowledge funding from the Trust. Recipients may be expected to participate in general publicity relating to the award of a grant.

The scholarship is advertised in the public press in late February or early March, with a closing date for completed applications in mid May. Application forms are available from The Central Remedial Clinic, Vernon Avenue, Clontarf, Dublin 3.



### *National Disability Authority*

The National Disability Authority (NDA) offers some post-graduate research scholarships to promote research on disability, rehabilitation and related matters. These scholarships are open to both non-disabled and disabled applicants. The primary consideration in awarding the scholarships will be the extent to which the research will be of benefit to PWCF.

Applicants should be graduates of recognised third level institutions, and be nominated by a Professor or Head of Department who is familiar with the candidate's undergraduate work. Candidates sitting their final examinations may also apply, and experience in areas related to the proposed research would be an advantage. Awards are normally paid from the start of the academic year, in three instalments.

Closing date for applications is usually 1st May of the relevant year. Applications are available from The Manager, Planning, Development and Independent Living Services, NDA, 25 Clyde Road, Dublin 4. See the following link for more information:

<http://www.nda.ie/website/nda/cntmgmtnew.nsf/0/F903B182313DCFD802570660054EC0B?OpenDocument>

### *Fulbright Scholarships*

Awards a number of scholarships to graduates with disabilities, with two scholarships in particular targeted at such candidates. See <http://www.fulbright.ie> for more details.

The Fulbright American Ireland Fund Scholarship is awarded to a graduate wishing to undertake research at Gallaudet University for the Deaf.

The scholarships are usually advertised annually in the National Press in the autumn. For further information contact Hainault House, St. Stephen's Green, Dublin 2.

## **Other Sources of Financial Assistance**

### *Individual College Hardship Funds*

Most colleges have a fund for all students experiencing financial difficulties. All applications are considered very carefully, as funds are strictly limited. These funds are normally allocated as loans, repayable by an agreed date before the student finishes college. Applications are usually made through Student Services.

### *Student Union Hardship Funds*

Most student unions administer very modest hardship funds, to which all students may apply. Contact the Student Union Office of the respective college or university for further information.

If you have any questions in relation to third-level education supports you can contact the CF Advocate Tomás Thompson at 087 9323930 or e-mail [tthompson@cfireland.ie](mailto:tthompson@cfireland.ie), or view a Guide to 3<sup>rd</sup> Level Education for PWCF on the CFAI website: [http://www.cfireland.ie/articles.php/publications/information\\_booklets](http://www.cfireland.ie/articles.php/publications/information_booklets)



## • Fundraising •

### CF Lugathon 2010

The CF Lugathon 2010, which is part sponsored by Tipperary Natural Mineral Water and Fyffes Bananas, will take place this **Saturday 11<sup>th</sup> September** and involves a hill-walk up Lugnaquilla Mountain, the highest mountain in Wicklow. A shorter walk on more level ground through wooded scenic area is available for the non-hillwalkers. Soup and sandwiches to sate the appetite will be available afterwards. We currently have circa 70 participants signed up, but for those that are not, you may come along and register on the day.



We are requesting participants to raise a minimum sponsorship of €200. For more info check our website: [http://www.cfireland.ie/articles.php/fundraising/cf\\_lugathon\\_2010](http://www.cfireland.ie/articles.php/fundraising/cf_lugathon_2010). To request a sponsorship pack, please contact Martin or Eufemia at CF House by calling 01 4962433.

CF Lugathon Saturday 11th September 2010 – Schedule		
Time	Item	Action
9:30	Guides/Staff meet at Fentons Pub, Glen Of Imaal, Wicklow	<ul style="list-style-type: none"> <li>• Tim Clifford assisted by Rory Tallon/Martin Cahill leading/marshalling 'Easy' walk</li> <li>• Phillip Pearson and group leading/marshalling 'Lug' Walk</li> <li>• Eufemia/Suzanne registering all participants</li> </ul>
10:00	Participants arrive and register	<ul style="list-style-type: none"> <li>• Participants to indicate which walk they are undertaking</li> </ul>
11:00	Walks commence	
14:00 approx	'Easy' walkers return to Fentons	<ul style="list-style-type: none"> <li>• Check-in and obtain meal voucher</li> </ul>
15:00 approx	'Lug' walkers return to Fentons	<ul style="list-style-type: none"> <li>• Check-in and obtain meal voucher</li> </ul>
16:00	Event finishes with tea and sandwiches	

#### Notes:

- In the event of poor weather conditions on the day, a decision will be made in relation to the feasibility or otherwise of undertaking the 'Lug' walk. The Guides decision is binding on all, and the CFAI will not take responsibility for participants who act contrary to their decision.
- In the event of the cancellation of 'Lug' walk, all will be invited to undertake the 'Easy' walk.
- As safety of all participants is of paramount importance, all participants are requested to adhere to the instructions of the Guides. Please do not wander away from the group, particularly on Lugnaquilla Mountain.
- Whether participants remain on, or leave immediately after their walk is finished, it is necessary to check in with Eufemia or Suzanne to ensure all arrive back safely.
- It is important to dress appropriately for the walk you are undertaking. e.g.
  - > 'Easy' walk: A good standard pair of runners will suffice as this walk is mainly on road surface.
  - > 'Lug' walk: Walking boots are necessary. A change of clothes would be appropriate also.
 In either case, it is advisable to carry rain gear, dress in layers and do not wear jeans.
- CFAI will supply water, bananas and energy bars. However, participants are encouraged to bring their own supplies in any event.



## The Lakes 10K

The Lakeshore Striders are still looking for willing participants for The Lakes 10K 2010. Olympic medallist **Kenny Egan** will lead off the event, and also plans to run it.

The event will take place for the second year in the fast and scenic route around the beautiful Blessington Lakes on **25<sup>th</sup> September** and will raise again much needed funds in aid of the CFAI. Don't miss your chance to join this fantastic group. Entries are limited to only 600 participants. If you would like to receive further details, please contact [thelakes10k@gmail.com](mailto:thelakes10k@gmail.com).

**Note:** All entrants must register online at [www.thelakes10k.ie](http://www.thelakes10k.ie)\*. For further information visit this website or contact Martin or Eufemia at CF House by calling 01 4962433.

## Lucan to Galway Walk in aid of CF

Ciaran Hoey and four of his friends took off on their 132 miles walk from Lucan to Galway on Saturday 4<sup>th</sup> September in order to raise money and awareness for Cystic Fibrosis. The five friends started their challenge in Lucan, Co. Dublin and they are anticipating arrival in Galway the following Friday 10<sup>th</sup> September. Listed below in alphabetical order are towns they will be passing:

Allenwood, Athenry, Ballinagar, Ballinasloe, Ballyfore, Ballyhugh, Blue Ball, Carbury, Celbridge, Clane, Cloghan, Clonony, Clooneymorris, Cloonfad, Daingean, Derrinturn, Edenderry, Esker, Galway, Garbally Demense, Kilconnell, Killoneen, Kiltullagh, Lucan, New Inn, Old Town, Oranmore, Prosperous, Screggan, Shannonbridge, Tullamore, Windmill Cross Road.

So if they will be walking at a location near to you, or if you live in the proximity of any of these areas, please come out and support them. They will need and certainly deserve friendly smiles along the way!!!!!!

## The Paddy Kierans Memorial Walk 'Let's go to San Francisco 2010'

On **September 23<sup>rd</sup>** a dedicated fundraising group will be departing to walk the beautiful San Francisco and its surroundings in aid of Cystic Fibrosis. In only 9 days the walkers will travel on foot from the amazing coast views of Monterrey to the challenging and breathtaking Yosemite National Park. They will finally arrive in San Francisco itself where there will be an opportunity to walk the world famous Golden Gate Bridge, see the unmissable Alcatraz and the lively Fisherman's Wharf, to name just a few of the well known sites. For this amazing experience each walker had to fundraise a total of €3,999.

The CFAI and the Walk Committee wish to take this opportunity to thank each and every walker who has committed to taking on the challenge, and in doing so raise much needed funds in aid of CF. **BEST OF LUCK TO ALL AND KEEP UP THE GOOD WORK!!!!**

## Looking for a Good Christmas Present to give to Family and Friends?

The Irish Professional Photographers Association (IPPA) in partnership with the CFAI is publishing a yearbook. The aim of the yearbook, as well as being an attractive diary, is to provide 12 pen pictures of people with CF and their families to give a sense of both the challenges of living with CF but also the sense of families overcoming these challenges in the best way they can.

The yearbook will also give you the dates of some of our fundraising events that are happening throughout the year. For example, a great way to keep fit and to support people with CF is to run or walk in one of the events flagged in the yearbook.

The yearbook is part of the ongoing successful partnership between the IPPA and CFAI, which includes IPPA 'Happy Faces Day' in April 2011. This is a day when the IPPA photographers take pictures and donate their fee to the CFAI.

Future issues of *Spectrum* will provide details of how to order the yearbook.



### 65 Roses and Christmas Children Art Competition

We have been asking the young CF population to enter our competition with an original and unaided drawing. The winning drawings for each category will be used to produce our national **Christmas Cards** for the year 2010.

We have received quite a number of impressive entries to date and it is looking like the judges are going to have a hard time deciding the winners in each category, given the high standard of entries. Winners will be announced in the October issue of *Spectrum*.

### Association of Irish Floral Artists (AOIFA)

We are delighted to announce that The Association of Irish Floral Artists has chosen the CFAI as their charity of choice for the period 2010–2012. The Association holds a National Flower Festival every two years with members participating at their own expense. This year's event 'Rhapsody in Bloom' is in Castletown House, Celbridge, Co. Kildare, on the 2<sup>nd</sup> and 3<sup>rd</sup> of October. The entire house will be decorated and there will be a large plant sale, floral accessory stands, book stands and a variety of jams and preserves. All proceeds will go to the CFAI.

Member clubs, located in 25 counties around Ireland, will hold fundraising events over the two-year period to raise funds for CF. So please come along and support the event and enjoy what promises to be an amazing experience of floral artistry!

### Dublin City Marathon 2010

There are only 46 days till the Dublin City Marathon 2010 and we are still looking for willing participants who will take part in the event in aid of CF. We would love to know that CF is well represented in what is one of the biggest Marathon events in Europe. If you are interested joining us in this quest or if you know somebody who has an interest in running, please get in contact with us.

Together, lets raise awareness and funds for CF. For a sponsorship pack, please contact Martin or Eufemia in CF House at 01 4962433. Martin can also be contacted at 087 2627326. Please note that the closing date for entries to the Dublin City Marathon is October 4<sup>th</sup>.

### London Marathon 2010

For every European Marathon lover, the London Marathon is THE unmissable event and that is why places available for the race are filled every year in record time. In fact, ballots for the 2011 entry have already been closed.

But don't despair!!! As a Charity we have the opportunity to offer you a tour package with entry to the race included. You get to take part in this amazing event while raising funds for the cause; however, entries will be allocated on a first-come first-served basis due to the huge amount of requests and those interested will need to act fast as availability is limited!!!

The tour package costs €2,500 and includes:

- Flights from selected airport, including all taxes, fees, charges and checked-in baggage
- 2 nights twin sharing with full buffet breakfast including VAT and service charges
- Guaranteed race entry, including official marathon programme
- Buffet dinner at hotel restaurant on Saturday evening
- Coach transfer to race start from the hotel (runners only)
- Travel insurance (including cover for marathon participation)

Single room supplement of €140 applies, when requested.

If interested, please contact Martin or Eufemia at 01 4962433. We look forward to having a great team running for CF on the other side of the Irish Sea.



## Cycling for CF

Cathal Phelan and Conor Doyle will begin an unsupported bicycle trip around the coastline of Ireland in **October 2010**. The two Dublin friends will cover 2,500km as they trace an outline of our country in an effort to raise funds and awareness for the Cystic Fibrosis.

We are appealing to the CF community in all areas the lads are cycling through to come out, if possible, and cheer them on. Local papers will have details as the cyclists pass through many towns. You can view the cycle route, follow the blog during the trip and donate to the CFAI through the lads' charity homepage: <http://cyclingforcf.blogspot.com/>.



### Attention!

Unfortunately, Cathal, whose birthday fell on 7<sup>th</sup> Sept, had his bike stolen on the day. If you have a spare mountain-type bike in your garage/shed that you could lend to Cathal for the month of October, or if you know of any bikeshop that might sponsor a bike for the event, please let us know at CF House.

### Cycle route Key

- Blue** Icons - Stay the night
- Green** Icons - Passing through
- Red** Icons - Rest day

Date	Location
<b>October</b> 9th	Starting point - Herbert Park
	Arklow
October 10th	Wexford
<b>Passage East</b>	
October 11th	Waterford
	Dungarvan
October 12th	Youghal
October 13th	Cork
	Kinsale
October 15th	Clonakilty
	Baltimore
October 16th	Schull
	Mizen Head
October 17th	Bantry
October 18th	Sneem
	Valentia bridge
October 19th	Knightstown ferry
	Killorglin
October 20th	Tralee
	Shannon Ferry
October 21st	Kilrush
October 22nd	Lahinch
October 23rd	Galway
	Rossaveel
October 25th	Kilkerrin
	Cashel

Date	Location
October 25 <sup>th</sup> contd.	Roundstone
	Ballyconneely
October 26th	Clifden
	Lettereeragh
	Old Head
October 27th	Westport
October 28th	Ballina
October 29th	Sligo
	Bundoran
October 31st	Donegal
<b>November</b> 1st	Letterkenny
November 2nd	Malin Head
November 3rd	Portstewart
	Dunluce Castle
	Giant's Causeway
	Carrick a Rede
	Ballycastle
November 4th	Cushendall
	Larne
November 5th	Belfast
	Portaferry
November 7th	Clough
	Maghereagh
November 8th	Newry
November 9th	Ardee
November 10th	Ashbourne