

SPECTRUM

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Association of Ireland



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Dear Friends,

Despite all the challenges facing our country at present, it is great to report on some good news. A new adult in-patient and out-patient facility is being developed in Limerick and a new day care facility also recently opened in Beaumont Hospital in Dublin. CFAI wishes to acknowledge the fantastic work of our three Branches in Tipperary, Limerick and Clare (TLC4CF) for their tremendous work and commitment to improving CF services in the Mid-West.

While these developments are welcome, they should be seen as part of the start rather than an end of a process to improve CF services in Ireland.

January also saw the Budget 2011 being implemented. To help you get to grips with how it has affected you and your family, please refer to the 'Budget 2011' section inside. We also remind you about Round 1 of the Exercise Grant Scheme 2011, as well as the Transplant Grant, which is available to members all year round.

In effort to reduce costs, we will now be producing *Spectrum* on a bimonthly basis, but we will endeavour to update members via E-news bulletins with important information throughout the month, where necessary.

We hope you enjoy this month's issue – until next time.

Warm wishes,

Philip Watt (CEO)

Alica May (Editor)

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CHAIRPERSON STEPS DOWN

Acknowledgement to Paul Higgins

Following the recent announcement that Paul Higgins has stepped down as Chairperson of CFAI, we wish to acknowledge the contribution that Paul has made to the work of the Association.

Paul served for 18 months as Chairperson of our Association during a time of change, challenge and progress in CF services. We take this opportunity to acknowledge the significant contribution and commitment that Paul has made to improving CF services at both a national and regional level in his home city of Cork, and to wish him the very best in his future work.



Paul Higgins, who recently stepped down as Chairperson of CFAI

BUDGET CUTS WILL HIT PEOPLE WITH CF

The overall cut of 5% to the health budget on top of previous cut-backs is already impacting on CF services, despite Government assurances that frontline services would be protected. Philip Watt, CEO of CFAI noted "the non-replacement of key CF healthcare staff on maternity or sick leave in some CF centres is cutting nursing, physiotherapy and social work supports down to unacceptably low levels." Much remains to be done to ensure the full implementation of the Pollock report, which was largely endorsed by the HSE in 2009. Gaps and weaknesses in both paediatric and adult care remain in many CF centres around the country. As a result of cut-backs, improvements in CF centres will be much more dependent on charitable donations in future.

The €8 per week cut in income supports, as announced in the Budget, is a "serious blow to disabled people and their families" according to John Dolan of the Disability Federation of Ireland. Government has long acknowledged that people with disabilities have extra costs in relation to their ordinary day-to-day living on items such as food, heating, clothing, and transport. DFI is very concerned that more and more people with disabilities are receding into poverty and away from inclusion.

This additional cut comes on top of the 6% cut last year, and is again being made on means-tested income. It must be remembered that disabled people are subject to cuts in general, and to the extra demands being made on their income. There is no evidence in this Budget of overall protection of this vulnerable group, and the consequence of this is that more disabled people will experience poverty.

BEAUMONT HOSPITAL, DUBLIN

New Unit Opens

The Pollock Report published by the CFAI in 2005 and subsequently largely endorsed by the HSE in 2009, identified Beaumont as one of the key CF centres in Ireland. As part of this strategy, an ambulatory day care facility has opened that will provide a significantly enhanced service to adult CF patients attending Beaumont

The new 2,500 square foot unit has been built, at a cost of €3.5 million, with funds provided under a capital allocation from the HSE. This new centre, which is specifically for people with CF, will facilitate the delivery of a comprehensive range of services by multidisciplinary teams and allow more patients to be seen during each day. These services including consultations with doctors and nurses, provision of treatments which might otherwise have required hospitalisation, assessment of pulmonary function, physiotherapy, dietetics and psychology.

The building includes consultation and therapy rooms with air filtration units which allow for 12 air changes per hour, approximately three times the average rate in a normal room. This has significant benefit in reducing the time needed between patients for infection control purposes, which is particularly important for people with CF.

Dr Cedric Gunaratnam, a Respiratory Consultant at Beaumont with a special interest in Cystic Fibrosis, says that there are significant benefits for patients in having all services provided in a CF facility as it should be.

Along with priority access to a number of en-suite inpatient rooms, it means that CF patient's admission as an inpatient via the Emergency Department is now a rare occurrence.

Philip Watt, CEO of the CFAI, said that "This is a very welcome development. There have been significant gaps and weaknesses in CF services in Ireland both to children and more especially to adults. Improved services are needed because of historic under-funding of CF services in Ireland and because in recent years the number of people with CF over 18 years of age has been steadily increasing. We wish to take this opportunity to acknowledge the key role that the CF Hopesource Foundation, including Paul Dempsey and Maeve Mullins, played in lobbying for the Beaumont development."

CF STAFF DEVELOPMENTS

University College Hospital Galway

Dr Michael O'Mahoney will shortly be taking up post as the Adult CF physician in University College Hospital Galway.

Dr O'Mahoney is currently Attending Physician in the Department of Pulmonary and Critical Care Medicine Weill Cornell Medical College, New York Presbyterian Hospital in the United States.

65 ROSES WEEK

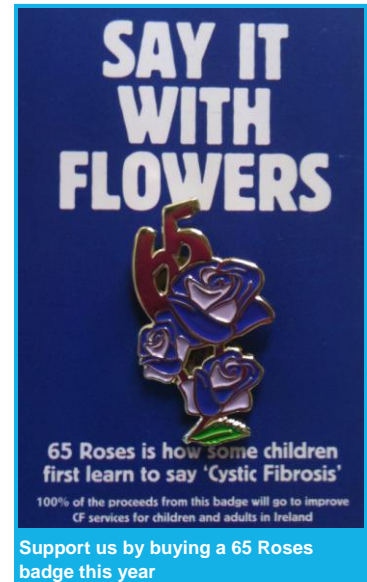
April 8th-15th 2011; Volunteers needed

The Cystic Fibrosis National Awareness week will run from April 8th-15th this year. We will have our 65 Roses badges once again this year, but with a different card backing. Proceeds of the badges will be shared between the National Office and the Local Branches and we have been approaching shopping centres for permission to collect.

We need volunteers to co-ordinate and undertake fundraising for us during this week. If you want to help, please contact Eufemia (Tel: 01-496 2433 or Email: esolinas@cfireland.ie).

A Gardai permit is not necessary to sell the badges. We are suggesting some shopping centres but please feel free to order badges and sell them during the week in other ways, for example, transition year students in schools might be one way.

The badges will be available from the beginning of March 2011, but please order now by completing the form enclosed with this month's *Spectrum*.



CFAI ANNUAL CONFERENCE

April 8th-10th 2011

The Annual Conference and AGM will be held in the Knockranny House Hotel in Westport, County Mayo between Friday 8th-Sunday 10th of April. Around 230 people attended last year's conference in Kilkenny. As usual, there will be a wide range of topics covered and plenty of opportunity for everyone to contribute to the discussion.

The social side of the conference is also very important. It's a chance to meet up with old friends but it's also an opportunity for people new to the Association to find out more about CF.

The main conference is on the Saturday which will include a range of experts on CF. On the Friday evening there will be an important Keynote Speaker. It will be an opportunity to highlight the ongoing needs of CF patients in Ireland to the new Government. The AGM of the CFAI is on the Sunday morning.

The Knockranny House Hotel was recently voted the best 4 star hotel in Ireland and includes a leisure centre for those who wish to make a weekend of the conference. For those only attending the conference on the Saturday, the conference will be free. For those staying overnight on the Friday and Saturday and participating in the Gala Dinner we hope to keep costs down to last year's level, depending on the level of sponsorship we secure. A brochure and booking form will be circulated within the next 2 weeks.

EUROPLAN CONFERENCE

Stay Informed

What is EUROPLAN?

EUROPLAN is a three year project funded by the European Union which began in April 2008. Its main goal is to develop recommendations to establish A **National Strategy for Rare Diseases** in each member state including Ireland by 2013.

EUROPLAN proposes to review and analyse existing initiatives in the following areas of intervention: institutional frameworks, provision of care, surveillance systems and support to patient organisations. The idea is to identify best practices based on these evaluations.

A National conference to present EUROPLAN recommendations was held in Dublin on 20th January in Farnleigh House to address these issues, which was well attended by key stakeholders including national authorities and healthcare planners, healthcare professionals, researchers and patients. Caroline Heffernan, CF Advocate, and Alica May, Services and Information Officer, represented CFAI at this event.

The main reports from this conference are now being collated and will soon be made available to the wider public.

BELFAST STUDY INTO CYSTIC FIBROSIS

Hopes to Improve the Quality of Life of PWCF

A major cystic fibrosis study is being carried out at Queen's University in Belfast to help improve the quality of life of people with CF.

The £1.7m grant is the largest awarded in the UK to study the microbiology of the lung disease.

The study is a collaborative US-Ireland international study with researchers in the Royal College of Surgeons Ireland, Dublin, the University of North Carolina at Chapel Hill, USA and the School of Pharmacy and the Centre for Infection and Immunity at Queen's University, Belfast.

Leading the study, Professor Stuart Elborn, Director of the Centre for Infection and Immunity in the School of Medicine, Dentistry and Biomedical Sciences at Queen's said "The results of the study will be of important clinical relevance to people with cystic fibrosis because, if we show that these anaerobes are contributing to infection and inflammation in the lungs of cystic fibrosis patients, in the future patients could potentially be given more appropriate and effective antibiotics which should improve their clinical outcome and quality of life," he said.

The research project has been funded for five years with an aim of recruiting a total of 450 Cystic Fibrosis patients across the three sites.

SPECTRUM

Now Bimonthly

We would like to inform readers that *Spectrum* will now be produced on a bimonthly basis in an effort to reduce costs at National Office. We will however endeavour to stay in touch with members on a regular basis through e-news bulletins, where necessary.

Again, we would encourage readers to let us know what it is you would like to see included in future issues. Your input is invaluable to shaping *Spectrums'* content and your feedback is most welcomed. Please contact Alica May at amay@cfireland.ie with any ideas or topics you would like to see covered in future issues.

INVITATIONS TO MEMBERS

Students Looking for Volunteers – Can You Help?

Photography Project – Stephanie McDonnell (Masters Student)

Stephanie is currently studying for a Masters in Design, specialising in photography and for her project she would like to document through photography a number of different people with Cystic Fibrosis.

The project would aim to provide an insight into the lives of those with Cystic Fibrosis and would hopefully demonstrate their experiences in a realistic but positive manner. The project aims to deal with people from different age groups to give different perspectives, and she is looking for people who would be interested in taking part in this project.

If there are any readers who would be interested themselves, or may know of someone who the project would appeal to, Stephanie would love to hear from you. Please email her at smacd18@hotmail.com for more details.

Occupational Therapy – Michelle Lowry (Undergraduate Student)

Michelle, a 4th year undergraduate student, would like to invite you to participate in a research project entitled 'What can Occupational Therapy (O.T)* offer Adults with Cystic Fibrosis in Ireland?'

Why?

The aim of the project is to explore the current level of engagement of adults with CF in daily activities including work, self-care and leisure. The study also aims to gain insight into potential activity limitations that Occupational Therapists may be able to assist with or advise on.

What's involved?

If you are interested in being involved in the study, you will be invited to participate in a semi-structured interview that will adopt a conversational style format with the principal researcher.

Who to contact?

Michelle Lowry (O.T student); e-mail: m.lowry1@nuigalway.ie

*For those unfamiliar with the O.T profession, it is a discipline concerned with enabling individuals to participate in those daily activities which are meaningful to them. One of the principal aims is maximising the fit between what a person wants and needs to do with his/her ability to achieve this.

TLC4CF AND DEVELOPMENT OF SERVICES IN LIMERICK

Completion Date of 2012

TLC4CF delighted with the announcement of €10.5 million Development of Specialist Health Services, at the Mid-Western Regional Hospital, Limerick.

TLC4CF, the group formed by the Tipperary, Limerick and Clare Branches of the Cystic Fibrosis Association has announced that planning permission has been granted for the new CF adult day care centre and in-patient unit at the Mid-Western Regional Hospital (MWRH) in Limerick. The six-storey unit that will consist of two floors for CF patients will provide a specialised CF out-patients unit with five treatment rooms and a dedicated in-patient unit with nine en-suite rooms. It is hoped that building work will commence in the first half of 2011 and that the building will be completed by the end of 2012.

Details of the new purpose-built six-storey building at the MWRH, which aims to fill significant gaps in the provision of specialist services in the Mid-West, was announced at a joint Press Conference between the Parkinson's Association of Ireland, Dermatology, Breast Cancer and TLC4CF. The new building will be funded by the Mid-Western Hospitals Development Trust and the various charities involved.

Owen Kirby, Chairperson for TLC4CF said "This is a very positive move and a critical next step in TLC4CF's goal of achieving a world class facility for CF Adults in the MWRH. TLC4CF would also like to acknowledge the other very positive fact that the staff complement at MWRH dedicated to CF patients has increased as part of our over drive."

"The number of adult CF patients attending MWRH is increasing all the time as people living with CF are surviving longer. There is a dedicated Paediatric CF Team at this hospital, but at present the facilities in the Mid-West for adults with CF are very basic, which is why this announcement is so important." he said.



The TLC4CF Committee, who have worked so hard over the last 2 years, are delighted to finally arrive at this point in their quest for better facilities for all PWCF attending the MWRH. L-R: Liam O'Kelly, Caitriona Hayes, Linda Drennan, Marcella Clancy & Owen Kirby.



Dr. Brian Casserly, Dr. Barry Linnane, Dr. Michael O'Mahony, Linda Drennan, Katie Drennan, Marcella Clancy, Liam O'Kelly, Owen Kirby & Caitriona Hayes.

Also speaking at the recent press conference was 20-year old cystic fibrosis patient Katie Drennan from Ennis, Co. Clare. The 20-year-old, second-year business studies student at the University of Limerick, was diagnosed with the disease when she was nearly three years of age. Her 19-year-old brother, Jordan, also has CF.

Katie said that the difference the new development will make to her quality of life and for many other Cystic Fibrosis patients was “difficult to summarise”.

“Over the past 20 years I’ve had a lot of experience of the Irish health system, some of it good and some quite inadequate. I’ve spent a lot of time as an in-patient in the Mid-Western Regional Hospital, in Our Lady’s Hospital for Sick Children in Crumlin and in St Vincent’s Hospital. This wonderful new facility will improve the lives for all Cystic Fibrosis patients in the Mid-West Region.” she said.



Katie Drennan, 20-year old CF patient from Ennis, Co Clare who spoke at the recent TLC4CF press conference.



The new unit at MWRH, Limerick, including one floor dedicated to a CF adult day care centre and another to the CF in-patient unit. Remainder floors for the Parkinson's Association, Neurology/Dermatitis and breast cancer.

“The benefits of such a unit are many. It means we will not have to travel to other cystic fibrosis centres in Dublin to receive our treatment. We will not have to endure long hospital stays away from home. We will no longer fear the risk of cross-infection when we attend the hospital for treatments. Such a unit will also benefit our families as well, as long-term absence from home due to frequent hospital stays can sometimes be very difficult, and the absence from our friends can sometimes be the hardest of all to deal with.”

Katie said the importance of an isolation facility could not be emphasised enough, and she described the recent appointment of Dr Brian Casserly as the first adult cystic fibrosis specialist consultant in Limerick as “a major step forward”.

“TLC4CF hopes that the development of this new unit will also mean that CF Patients attending the Mid-West Regional Hospital will not have to go through A+E to be admitted to hospital, which can increase the risk of cross-infection to the CF patients. With the development of this new unit, all CF patients in the Mid-West region won’t have to endure the dangerous and inadequate services that previously existed” said Katie, and added, “we all look forward to enjoying better facilities and a higher standard of care which will play a major role in improving the lives of so many people with Cystic Fibrosis.”



BORN TO RUN

By Evan Scully

When asked why or how I started running, I reply with 'I'm not 100% sure'. However, I am told that when I was about 4 or 5 years old I entered into a "Run Til You Drop" themed race. I was the youngest in the race by a few years. People in their teens toed the line beside me. After a while I was asked to stop by the people that set the race up because they wanted to go home – so I think I was just born to run!

I was always an active kid. Playing "Tip the Can" and "Manhunt" was high on my list of what to do after school. I also played football well into the dark of the night. This led me to play football for St. Patricks Athletic where we won the Dublin Schoolboys League when I was 11. I stopped playing football because I moved from Dublin to Meath, and to be honest the local team didn't compare to Pats. I then started to swim, and came 2nd in the National Community Games (but was subsequently disqualified for not touching the wall with two hands).

My first race was during school; I didn't know there was a race on until the last minute so I had to run it in my uniform and my school shoes. Only in 5th class, I was put into a 6th class race whereupon I won the race and qualified for the next round against other schools. I came 3rd in that, which qualified me to run in the Meath schools. I wasn't sure what I was doing but I went eyeballs out from the start and won that too.

I joined Tara A.C and won a few Meath Championships. Nothing too big. I then joined Dundrum South Dublin A.C (D.S.D A.C). Within a few months I was into the All Ireland and finished 21st. The next year I finished 3rd in the same race – this enabled me to run for Ireland. There were several international races but the best one was probably the Schools International which was England, Ireland, Scotland and Wales. I finished 5th in that race out of around 60 athletes, and we won the team medal.

A few times a year, I travel to Portugal for warm weather training. This entails training twice (sometimes even three times) every day. I've also trained at 3,200m altitude with who, in my opinion, the greatest athlete the world has ever seen – Haile Gebrselassie. He has 26 world records, two Olympic gold medals, and a countless amount of World Championship gold medals. I was able to stay in his house and train with him every day – something I will never forget.

A Typical Weeks Training

Mon: morning 10 miles, evening 5 miles
Tues: morning 10 miles fast, evening 5 miles
Wed: morning 10 mile speed session, evening 5 miles
Thurs: 16 mile mountain run (The Hell Fire)
Fri: morning 7 miles, evening 5 miles
Sat: 12 mile speed session
Sun: 20 to 22 mile. I run up two different mountains.
 Three Rock & Hell Fire



Evan Scully; Athlete, Sports Therapist and student in Traditional Chinese Medicine.

Roughly 5 years ago I injured myself during training but ignored it and kept on running. I came 2nd in Ireland Track & Field with twisted ligaments in my hip. This injury led to 6 months off of any sort of activity and it took longer for me to get back to full fitness than it should have. After several years of trying to get back to where I was, I started to get places. I came 2nd in the Intervarsities Track and Field 10,000m. However, what I didn't know is that I had a huge iron deficiency. I felt constantly tired and even trying to walk became a problem. I thought it was the amount of training I was doing. Weeks upon weeks of 115 miles a week of running, and weight training should make anyone feel tired! That's all in the past now and it's onwards and upwards from here. I have my eyes set on a marathon in the next few years and hopefully get the qualifying time to run in the 2016 Olympics in Brazil.

I am a fully qualified Sports Therapist, and am also studying Traditional Chinese Medicine. I have personally found acupuncture very helpful for my digestive system and sinusitis. I run my own clinic and treat several top athletes including the u23 Cross Country European Champions. My Grandad never missed a day's work due to his Diabetes; I think I get a lot of my strength from him, and the stubbornness of my Dad. Brilliant combination for me to not let CF run my life. If I could bottle that idea I'd be a rich man.

I can safely say that without running, I would be in some awful state, health wise. I firmly believe that doing all these sports has been instrumental in my never having to be hospitalised for more than two days.

I hear a lot of doom and gloom in the media these days about CF (and about the economy). I've been told it's not only recently, but maybe I'm just more aware of it now. I don't know if I've had an easy ride with the CF. Like many, I've had MRSA and Pseudomonas, but we act on it and don't stop until it's gone. That's the stubbornness again. When I say 'we', I mean my family, and more recently my girlfriend, Yas. The questions like "do you need enzymes with that??" will never get old. I get 100% support from them day in day out. If it wasn't for the resilient persistence of my Mam and Dad, I would probably be lying on my bed with IVs in my arm, and not getting ready to go out for a run like I am doing at the moment.

I hope I give some reader a little bit of hope because in my eyes CF is beatable, and I'm kicking it in the arse. Like we say every birthday I have...."we're winning!!!"

DOUBLE LUNG TRANSPLANT RECIPIENT

By Mary Mallon, PWCF

Wednesday November 11th 2009, was check-up day in Beaumont, usual feelings HOPING that the PFT's would be up even a % but nope, it went down again. The word "Transplant" was shortly mentioned. How could this be? I thought I knew it was coming, it was always in the background, but now here it was facing me. I asked my questions and thought long and hard about it. I never intended on going for a transplant, but now the time had come, and I wasn't ready, I now had priorities in life.

I went home and spoke about it with my family (Mam, two sisters and brother) and my future husband. We were getting married on June 18th 2010, now questions were running through my head like "Will Ciaran still want to get married?", "Will he even want to stay with me?" – after all marriage was for life not a couple of months. He chose to stay.

I had till February 2010 to give my decision, I decided to go ahead with the transplant and I would stay at home in the Mater for it, that way the one doctor will be there from the beginning, it would be easier for family and friends to visit, and that even though more are done in Newcastle, there are also more people on the list. My thinking was that I'd give it 5 years waiting time, and if it was to happen, then it would happen, "What's for you, won't pass you". After all, my Daddy was up there looking out for me. So I kept busy planning the wedding of my dreams. After all, if time was up I was going to go with a big party. June 18th came and it was the best day of my life. I managed to have my first dance without the oxygen – it was tough seeing everyone else up dancing while I sat unable to be no more the "Dancing Queen". We went to St. Lucia for a week on Honeymoon and it was paradise. I spent a lot of time in our room on the oxygen, and was unable to partake in all the activities available, but we battled through none the less.

We were home only 7 weeks when I got taken into Beaumont; things were tough and the Pfts were down to 17%. I had to stay in for 2 weeks and arrived home on the 25th August not feeling much better, and spending a lot of the days on the coach asleep unable to do much else. I was exhausted all the time. Then on the 28th August at 7.50pm and only 3 weeks on the waiting list the phone call came. Barbara, the transplant nurse, told me that there was a possible set of lungs suitable for me and that she was sending an ambulance to pick me up and go to the Mater. It was here and it came so quickly. There was no more time for thinking and myself and my new husband headed off for the Mater, while my Mum, two sisters, brother, eldest niece and sister-in-law followed.

We arrived and got the routine X-rays and blood done while I waited for word of approval. Then at 12.50am, the nurse came and told me it was going ahead and the trolley for theatre was outside. It all happened so fast. Everything went well and it wasn't until the first week that we realised something was wrong; I couldn't talk. It seems whilst I was on the by-pass machine my left vocal cord became paralysed.

This meant that I couldn't talk and when I was allowed to eat ice-cream went down the wrong way and into my lovely new lungs, causing me to be unable to breath. I had to be incubated again and the next morning the tube was removed and a trachea was put in. This meant no food, no drink and no talking. This was very frustrating as nobody could understand what I was trying to say, and it continued for 6 weeks, while Prof Egan did everything in his power to mend the problem. What he didn't know about he got the experts in for their advice.

Three months on and I'm home 5 weeks and loving my new lungs. I'm back out walking in the snow, running up and down the stairs, and simply being able to Hoover the house without oxygen wires getting caught up and pulling the ears of me; life's pretty good. Obviously I have to be extra careful of infection. I attend Prof. Egan every 2 weeks for check-ups but at least I'm able to attend. Currently, I'm on 2 weeks of home IVs. My routine biopsy last Tuesday showed that my lungs are brilliant at taking in Oxygen 98%, but have to work better on clearing themselves.

So there it is, that's what 2010 had to offer me, I don't think anyone could complain with a year like that. If 2011 is half as good, I'll be doing well!

WHAT DOES IT MEAN FOR PWCF?*By Tomás Thompson, CF Advocate, CFAI***Budget 2011 changes**

This month will see for many the impact of the Budget 2011 firsthand. The budget changes that came into effect in January will impact on almost every household with the hardest hit being lower income households with children. The government is set to save €4 billion in 2011; €1 billion is to be raised in taxation measures with €2.2 billion to be saved on expenditure measures. The Departments of Social Welfare, Education and Health are to cut severely; the remaining amount is set to be saved on capital Expenditure such as infrastructure.

Some of the main changes affecting CF families are set out below. If you are unsure of how any of the cuts or Tax changes will impact your family, you can contact the CFAI or the Citizen's Information Office in your area directly. If you also feel that there are unforeseen cut-backs that are happening, particularly in the area of health, please contact the office and let us know.

Taxation Measures:

- Income/health levies to be replaced by single universal social charge (USC). Rates on the charge will be 0% below €4,004 a year, 2% up to €10,036, 4% from €10,036 to €16,016, and 7% above this level. The new service charge replaces the income levy that PWCF who hold Medical cards could claim back. Previously Medical Card holders did not have to pay Health Levy or Income Levy – they will have to pay the USC. This change will have a major impact on your take home pay if you have a Medical Card.
- Value of tax bands and credits to be reduced by 10% – families who pay large amounts of income tax will see their tax credits reduced by 10%, resulting in a reduction in income. See the table below for details of some of the reductions in tax credits.

Tax Credits from January 2011		
	2010	2011
One Parent Family Tax Credit	€1,830	€1,650
Home Carer Tax Credit	€900	€ 810
Dependent Relative Tax Credit	€80	€70
Incapacitated Child Tax Credit	€3,660	€3,300

Expenditure Measures

- €10 reduction in **Child Benefit** rates. Child Benefit will be reduced by €10 per month from January 2011 on both the lower and higher rate with an additional €10 per month decrease for the third child. The new rates will be €140 per month (first and second child), €167 (third child), €177 (fourth and subsequent children).
- **Carer's Allowance** for those under 66 to be cut by €8 to €212 a week
- **Disability Allowance** being cut by €8 to €186 a week
- €8 cut for **Social Welfare**, jobseekers payments
- €40 increase payment for **Fuel Allowance** recipients. This will be paid directly to families who are currently in receipt of this allowance.
- The **Rent Supplement Scheme** will include an additional €2 per week contribution by certain welfare recipients towards the cost of rent.
- Third-level **student charges** are to rise by €500 to €2,000. There is also going to be a €200 charge for PLC students. The higher Student Service charge will only apply to one child in a family at any one time.
- **Student maintenance grants** are to be cut by 4%. The qualifying distance for full maintenance grants from the collage is to increase from 24km to 45km.
- **School transport** – Increase post-primary charge to €350 and introduce €50 fee at primary level (exc. Medical card holders), subject to maximum family charge of €650.

The Budget of 2011 and the upcoming budget of 2012/13 are going to be difficult. Many of the cuts are only going to be seen over the coming months and years, leading to longer waiting times, cut-backs in health, education and social welfare services for families with CF. The CFAI is here to lobby such cuts and would like you to inform us as to how the cuts are impacting on your family and how CF services are being affected in your area, so we can lobby government to improve CF care.



EXERCISE GRANT SCHEME 2011

Submission deadline Friday 4th March

Need some inspiration for your New Year's resolutions? Why not apply to our Exercise Grant Scheme and be in with a chance of getting a grant towards your annual gym membership, swimming lessons, or try something new like yoga or Pilates! The value of the Exercise Grant is €300 for members over 16 years of age and €250 for those under 16.

How do I apply?

In order to avail of this grant, all you need to do is send in an application form and either a receipt or quotation that records what is it that you have bought, or what you intend to buy with this grant. An application form can be downloaded from the 'Grants' section of our website or you can contact National Office directly and a copy will be posted to you (Tel: 01 496 2433 or Email: amay@cfireland.ie).

The deadline for submission of applications to the first round is **Friday 4th March**. A limited number of grants are available, so please send in your application forms as soon as possible in order to be in with the best chance of securing a grant in this round.

Note: *Members are advised to read the Grant Guidelines and Policy document carefully before applying for this grant.*

TRANSPLANT GRANT

Ongoing support to members

The CFAI provides financial assistance towards incidental expenses (accommodation, meals and transport) incurred to members and their families who must travel for transplant assessment, transplant and follow-up phases both to Dublin and the UK.

The transplant assessment/review grant is €300 and the transplant grant is €850. Get in touch with Alica May in the National Office by emailing amay@cfireland.ie or call 01 496 2433 to find out more information about how you can avail of this grant.

IRELAND TO EVEREST – 32 STEPS FOR CF

Local Participation Welcome

As previously reported, Cian O’Brolchain and Lorna Murphy have chosen to undertake a climb to the summit of Mount Everest in 2012. Under the training and supervision of Ian Taylor, the youngest Irishman to reach the summit (2008), they are undertaking a challenge to climb the highest peak in every county in Ireland over a period of months in 2011 to raise funds for CF.

Due to the recent run of bad weather conditions, this initiative has been postponed twice and finally commenced on Sunday 9th January at Mullaghmeen, which was well supported and attended locally.



The first 32 Steps to Everest climb held on Sunday 9th January in Mullaghmeen, Co Westmeath.



32 Steps to Everest; check out the website at www.irelandtoeverest.com

They welcome local participation in these events, particularly with sponsorship cards, collections and actual climbing if you so desire.

The challenge will see them climbing shortly:

- Slieve Beagh, Co, Monaghan (6th February),
- Cupidstown Hill, Co. Kildare (13th February);
- Seltannasaggart, Co. Roscommon (20th February);
- Brandon Hill, Co. Kilkenny (27th February)

Funding will go to the National Lung Transplant Fund, which was recently established by the Cystic Fibrosis Association of Ireland.

For further information on the Ireland to Everest 32 Steps for CF challenge see: <http://irelandtoeverest.com/32-steps-for-cf> or www.cfireland.ie.

FESTIVE FILLIES DRAW

Winners announced

Another casualty of the bad weather, the draw and gala evening eventually took place in The Rising Sun, Mullinavat, on Saturday 8th January.

Many thanks to those of you who bought raffle tickets online or by post. Given that there are 10 charities involved in this event, CF did extremely well in the prize draw. Ms. Catherine Moore, CF parent from Wicklow, won the top prize of a €10,000 fitted kitchen sponsored by Tom Frisby of Frisby Furniture, Mullinavat, and Ms. Brid Nee, PWCF from Galway, was also in the top ten prize winners. Congratulations to you both!

Many thanks particularly to Susan Walsh and the Festive Fillies committee, and particularly to Maria Phelan, CF parent and chartered member of the Festive Fillies who was instrumental in selling a huge amount of tickets on behalf of CFAI.

We are proud to be associated with this event over the last three years and look forward to future support of, and collaboration with, the Fillies. Well done, ladies!

GENERAL ELECTION DAY

This might be an ideal day to have a bucket collection in your area in the proximity of the election booth venue. At time of writing, we do not know the exact date though it is likely to be 25th February.

It is important to remember that the local Chief Superintendent is the granting authority, so if you choose to do so, please go to your local garda station to make an application. We understand there is no legal bar on such collections and permission is at the discretion of the local Chief Supt.

GALA VALENTINE'S BALL

11th February 2011

Georgina Cavey (Aunt of Matthew Thornton, PWCF) and her colleagues from the Project Management Class at Smurfit Business School are organising a Gala Ball on behalf of CF. The Ball is going to be held on Friday 11th February 2011 in the Royal Marine Hotel Dun Laoghaire, Dublin.

The Carnival Ball will be a Black Tie event, with a Champagne Reception, a three course-evening meal and entertainment. There will be a raffle and a silent auction on the night and the ticket price is €55. Further details can be obtained from Head Office or by calling Georgina on 086 374 6348.

ROSE OF TRALEE FESTIVAL

Regional Heats Commence Soon

CFAI are one of the official charities of the Rose of Tralee Festival this year. The regional heats commence in March and there is one in every county in Ireland.

We are proposing that Branches may wish to enter a contestant (PWCF, perhaps) in their local county heat. We have full details of all contacts in the various locations but these are too numerous to list here. Noelle Clerkin, Monaghan Rose 2010 and Radiographer at St Vincent's University Hospital, has agreed to coach and advise any PWCF interested in entering the regional heats. Please contact Martin/Eufemia at national office for further details.

There may be fundraising opportunities around the heats so if you have any ideas or would like to get involved, please get in touch.

IPPA HAPPY FACES 2011

12th March 2011

As already notified we are once again chosen as the charity of choice for Irish Professional Photographers Association (IPPA) Happy Faces in 2011; tentatively, the 12th March is the main day, and full details will be on our website shortly.

Last year IPPA members raised €55,000 for CFAI and with your participation we can do even better this year! You can have your picture taken at your local qualified IPPA photographer's studio or event location for just a €25 donation.

All proceeds will benefit The Cystic Fibrosis Association of Ireland.

Let us jointly build on the success of last year's event!



Pictured at the launch of IPPA Happy Faces 2011: (L-R) RTE Weather presenter Nuala Carey; Martin Cahill of CFAI; IPPA President Gareth Byrne; Jonathan Sultan of Canon Ireland; Tiarnán Ahearne (9) & Saoirse Ahearne (6)



PARIS MARATHON

10th April 2011

We have 11 participants signed up for this event, seven of whom also recently completed the New York Marathon. There are a few places left but spots are selling out quickly. Each participant is obliged to raise a minimum of €2,500 to take part. There is also a package for spouses/non-runners to travel.

Contact Martin of Eufemia at Head Office for more information on this event.

65 ROSES CYSTIC FIBROSIS NATIONAL AWARENESS WEEK 2011

8th-15th April 2011

The Cystic Fibrosis National Awareness Week will be taking place from 8th-15th April 2011, with the Annual Conference being held in the Knockranny House Hotel in Westport on the weekend of the 8th. Awareness Day will be on Friday 15th.

Preparations are in hand to target shopping centres, transition year students and volunteer centres nationally to organise sale of CF emblems publicly.

However, we do need your support. Please let us know if there are any local shopping centres or shops in your area that will join us in our National Awareness Week.

We will also have an Awareness fundraising pack for those who wish to organise their own initiative during this important week.

WOMEN'S MINI-MARATHON 2011

Entries open on 2nd March

The first queries are already in!!! Again we will try to make the Women's Mini Marathon event one of the major events for Cystic Fibrosis and certainly one of the most successful for the year. Entries will open at www.florawomensminimarathon.ie on March 2nd and will stay open till April 27th or till maximum number of entries is received.

Watch this space for announcement of the 2011 '1 in 1,000' initiative also.

To request your fundraising pack and start fundraising, please contact Martin or Eufemia at 01 4962433 or email esolinas@cfireland.ie.

TOUR DE FORCE CYCLE

Annual Garda Cycle

This is an Annual Garda Cycle event which in 2011 is taking place in Ireland. CFAI have been chosen as the sole beneficiaries of the proceeds in 2011.

We are delighted to be associated with this prestigious event. The first meeting will take place in Athlone in January involving CF House, Garda Representatives and CFAI Branch personnel from the Midlands, Galway and Mayo Branches.

DUBLIN CITY MARATHON 2011

Register now

The Dublin City Marathon 2011 will take place on October 31st.

It is an event not to be missed by the marathon lovers or by those who love a challenge! We love a challenge too and, with your help, we would like to have a big team taking part and raising awareness for Cystic Fibrosis. Entries are already open at http://dublinmarathon.ie/entry_details.php

Please contact us to request a sponsorship pack and help us reach our goal!

NEW YORK MARATHON 2011

Limited places available

With 10 months to go, the “New York Marathon” fever is already here.

For another year running, this event promises to be a sell-out! However, we as charity have a limited number of places already allocated (entry is otherwise by lottery worldwide!).

The package will be the same as every year: each fundraiser will need to raise €5,000. This includes flights, accommodation, race entry and an unforgettable experience of running/walking/jogging through all five Boroughs of New York. Call Martin or Eufemia at National Office or log on to www.cfireland.ie for further details.

ALL THAT JAZZ PRESENTS “STORMY WEATHER”

In Aid of CFAI, Drogheda Branch

The Drogheda Branch of CFAI has a fabulous event coming up: All that Jazz presents “Stormy Weather”. The event will take place on February 11th on the TLT Concert Hall & Theatre in Drogheda.

Artists contributing to the night include Clare Finegan, Frank McDonagh and instrumentalists Vivienne McKeon on Violin, Gerry Fehily on Drums, Daren Rooney on Double Bass and GoGashka on Piano.

Joining them on stage will be Honor Heffernan and her trio: Phil Ware, Damian Evans and Tommy Gray. Master Of Ceremonies on the night will be Frank McNamara of RTE and International Fame.

Tickets for this amazing night are priced at €20, while price for OAP's and Children under 14 years is €10. Tickets can be purchased online at www.thettl.ie. Alternatively, they can be purchased at the Sound Shop in Drogheda or by contacting Ms Marian Renaudin at 041 9828402 or 087 95722396. For any further information, please visit www.thettl.ie/2010/12/all-that-jazz-presents-stormy-weather/

ISTANBUL & CAPPADOCIA WALK 2011

Paddy Kierans Memorial Walk 2011

CFAI and the International Walk Committee are glad to announce that the Paddy Kierans Memorial Walk 2011 will take place in Istanbul & Cappadocia.

Each walker is requested to fundraise €2,625.00 for an unforgettable trip in the Turkish culture.

The group will depart on October 1st, return on October 9th and will visit amazing places such as the Grand Bazaar and the Spices Market in the mysterious Istanbul. The walkers will then be transferred to the Turkish hidden gem of Cappadocia, unique and miraculous nature wonder. The price is based on p/p sharing and includes flights, accommodation, breakfast and dinner each day and lunches in Cappadocia only. Price includes internal flights and transfers, buses etc.

For information on the walk, please contact Eufemia in CF House at 01 4962433 or one of the Committee members at the following numbers: Bernie 087 2353319; Julia 087 9911331; Frank 086 6060261 or Tony 086 25112731.

Please find enclosed a leaflet with more information on this exciting event.

About the Cystic Fibrosis Association of Ireland (CFAI)

The CFAI is a registered charity CHY 6350 that was set up by parents in 1963 to improve the treatment and facilities for people with CF in Ireland. It is a national organisation with many Branches around the country and our members are mostly parents and people with CF.

The CFAI is committed to working to improve CF services in Ireland and our recent progress includes:

- Lobbying to ensure that the new national adult CF centre in St Vincent's University Hospital will be completed
- Providing funding towards new CF Units around the country including Crumlin, Drogheda, Galway, Cork and Limerick Hospitals
- Funding research
- Campaigning to improve the rate of double lung transplantation in Ireland
- Providing advice and expertise

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