SPECTRUM

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IN THIS ISSUE:

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- Education Supports for PWCF
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- Fundraising Events this Autumn

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Dear All,

Preparations are underway at Our Lady's Children's Hospital Crumlin where President of Ireland, Ms Mary McAleese will open the new CF in-patient ward on 4th October 2011. The new four bed ward, which was funded by the Cystic Fibrosis Association of Ireland, will have a significant impact on children and young people who are attending Crumlin Hospital.

September also saw representatives from the CFAI meet with the Minster of Health and Children, Dr James Reilly, to express our concerns over many issues facing our members, including staff shortages at CF centres, the need for improvements in out-patient, day care and in-patient facilities for people with CF around the country, and the requirement to increase the rate of double lung transplantation in Ireland. We are currently expecting a letter from the Minister in response to these issues and will keep you informed of further outcomes.

Information on education supports available for PWCF at primary, secondary and third level is included in this issue, so make sure you have a read through this section if it's applicable to you or your family. Nutrition tips from Ruth Hannon, Senior Dietitian at Beaumont Hospital, should also help answer some of the common questions PWCF have in relation to their diets and enzyme supplements.

Our PWCF Spotlight series turns to Co Cork this issue – Debbie McCarthy tells us what it was like growing up at a time when not a lot was known about CF, how her parents encouraged and supported her and her siblings growing up, and how becoming a mum has completed her family unit. Our Parent Profile hears from Mark Duggan, father of a son with CF. Mark tells us about his role with the Irish Air Ambulance Service and how it ensures that patients have 24hr access to a first-class medical transport service. This is welcome news and is sure to have a positive impact on many of our members.

It is heartening to see so many fundraising initiatives taking place around the country in support of CF – this committment is essential to maintain the flow of income to CFAI in order to sustain our planned programmes, and prepare for new developments in the quest for better treatments and facilities for PWCF in Ireland.

We hope you enjoy reading this issue and we look forward to updating you on all subsequent developments in CF in the next edition.

Kind Regards,

Philip Watt (CEO)
Alica May (Editor)

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LATEST NEWS

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PRESIDENT TO OPEN NEW CF WARD IN CRUMLIN FUNDED BY CFAI

4th October

The President of Ireland, Ms Mary McAleese will open the new CF in-patient ward in Our Lady's Children's Hospital Crumlin on 4th October 2011. The ward was funded through a grant of €750,000 from the Cystic Fibrosis Association of Ireland.

President Mary McAleese will open the new CF in-patient ward in Our Lady's Children's Hospital Crumlin on 4th October.

Parents are already telling us that the new 'state of the art' four bed ward has made a fantastic difference to the children and young people who are attending Crumlin Hospital.

The CFAI has worked in partnership with the Board of the Hospital and the Children's Medical and Research Foundation (CMRF), which funded the refurbishment of the existing ward.

The origin of this project came from the 'Pollock Report', an independent review of cystic fibrosis services in Ireland that was commissioned by the CFAI, carried out by Dr. Ronnie Pollock and was published in February 2005. Our Lady's Children's Hospital in Crumlin was identified as a crucial part of the framework to improve CF facilities for children in Ireland.

In 2007/8, the major deficit identified in the hospital was the in-patient facility for children and adolescents. It was clear that the existing ward did not meet the standards set out in the Pollock Report. This put patients at potential risk of early acquisition of life-threatening infections.

In addition, from 2005 to 2007 there had been a 60% increase in the number of in-patients attending Crumlin Hospital, which put additional demands on the existing CF services.

While the HSE funded additional staff, despite requests, a capital investment for a new ward was not forthcoming. As a consequence, CFAI and the hospital entered into a partnership to fundraise and build a new state of the art four bed in-patient ward.

The CFAI has provided €750,000 towards the four bed ward. This was given in the knowledge that such facilities were needed immediately by our parents and their children and adequate facilities could not wait for a promised new National Children's Hospital (see article on continued delays in this edition of *Spectrum*).

The funding for the CFAI's Crumlin Building Fund came from two main sources, the Shane Kinsella Foundation and '1 in 1000'.

The Shane Kinsella Foundation (SKF) was founded following the premature accidental death of Shane who died in the United Sates following a fall in a national park. Shane was only 21 years old.

The following year his family and friends decided to set up SKF in his memory to help young people in need and through meeting Cystic Fibrosis (CF) pioneer, Jim Somers, the first cause chosen was CF. The funding was granted to the CFAI for the Crumlin project. Many thanks to Jim and Terry, Edelle, Hilary, Nicola and Tom and Michael and all their supporters for this funding.

The second key source of funding was provided by '1 in 1000' and centred around the extended family and friends of the Woodward/Scanlan/Soden families. This group of women organised a huge effort to get over 1000 women to fundraise for Crumlin through the Flora Women's Marathon in 2010. Many thanks to Zoe, Natasha, Gillian, Lou and Carol and all the '1 in 1000' team for this funding.

The CFAI also wishes to fully acknowledge and thank the Board of Crumlin Hospital, its CEO, to the project manager, Michael Kearns, the CMRF and the CF multi-disciplinary team led by Dr McNally and formerly by Dr Gerard Canny and Dr Barry Linnane. The team includes consultants, CF nurses, dietitians, physiotherapists and social workers. We also wish to acknowledge the important role of the National Centre for Medical Genetics in Crumlin, particulary its role in newborn screening.

On a final note, we wish Dr Gerard Canny all the best in his retirement this year and thank him for all his work with children and young people with CF over many years.

CFAI CONCERNED OVER DELAYS IN BUILDING THE NEW NATIONAL CHILDRENS' HOSPITAL

No Commencement/Completion Dates

It is now almost 7 years since the McKinsey report recommended a single world-class tertiary paediatric centre that would bring together the three existing children's hospitals in the capital, which are Crumlin, Tallaght and Temple Street Hospital. The report recommended that the new hospital should be located in Dublin adjacent to an adult hospital.

In 2007, an HSE taskforce selected the Mater campus as the development site and this was endorsed by the government. The chosen location has proven to be controversial and has contributed to significant delays in the commencement of building.

Artists view of the new National Children's Hospital.

In 2009 the Taoiseach Brian Cowen promised that the hospital would open by the end of 2014, however, the Chairman of the Board that was developing the hospital resigned after the Minister for Health, Mary Harney, learnt that he questioned the site's suitability for the project.

In March 2011 the Board's second Chairman, John Gallagher, resigned saying he is at "risk of incurring further material ongoing costs in the project without full government support". In May 2011 Minister for Health James Reilly announced an independent team to review site decision and by July he affirmed that the correct site was chosen and planning application for the new hospital is submitted to An Bord Pleanála.

There is, at present, no clear indication of when the new hospital will be commenced or completed. The CFAI has made a submission and met with representatives of the Children's Hospital Development Board to seek to ensure that wherever the Hospital is developed it has world class in-patient, out-patient and day care facilities for children and young people with Cystic Fibrosis.

Whatever site is chosen in the final analysis, it is vitally important that the Hospital is actually built, even if there are problems with the chosen Mater site. Further delays may jeopardise the whole project. While much of the discussion around an alternative site has focussed on Newland's Cross, it is also worth noting that because of the economic crisis and the role of NAMA, other sites owned by the Government are now available. It is perhaps too late, but the massive amount of property around the north quays adjacent to the HQ of Anglo Irish Bank might have also offered an alternative that was worth considering?

In the meantime, the CFAI will continue to campaign to ensure there are adequate facilities in existing children's hospitals in both Dublin and around the country, because young people need these services now rather than an indeterminate time in the future.

CFAI MEETS MINISTER OF HEALTH AND CHILDREN, DR JAMES REILLY

Key Issues Raised

A delegation form the CFAI met with Minster of Health and Children, Dr James Reilly TD, on 16th September in Hawkins House in Dublin. The following article summarises some of the key issues raised at that meeting.

Staff shortages in CF centres

Each CF centre in Ireland should be staffed with a multi-disciplinary team that includes specialist consultant paediatricians or adult physicians, clinical nurse specialists, physiotherapists, dietitians, social workers, psychologists, pharmacists, co-ordinators, clerks and/or secretarial support.

Gaps are increasingly evident in these multi-disciplinary teams in recent months because of the moratoriums on recruitment and other HSE restrictions aimed at saving money. These gaps are emerging at a time when there is already additional pressure on both adult and paediatric CF services due to the growth of the CF population in Ireland, steadily increasing survival ages and the recent introduction of newborn screening.

The continuing need to develop and improve out-patient, day care and in-patient facilities

The CFAI and local CF charities are playing their part in fundraising to improve CF centres around the country. We are engaging in massive fundraising efforts in Limerick, Cork, Castlebar, Crumlin, Drogheda, Galway and Cavan Hospitals to ensure that in-patient, out-patient and day-care facilities are adequate, including cross-infection standards.

There is a need for formal HSE/Philanthropic partnerships to complete these projects in a timely and very cost effective manner. We believe that Government grant-aid of 25-30% of the capital costs and support for fit-out would achieve this.

Idleness of vital equipment needed for CF care

There is a range of equipment that is vital in the treatment of Cystic Fibrosis including, for example, bronchoscopes (for diagnostic and therapeutic purposes), other lung function equipment and dexa-scanners (for measuring bone density).

Some of this equipment is lying idle or underused because of the lack of staff availability or access to theatre time. This problem poses a threat to the health of our patients in some centres, as well as being a waste of resources.

National clinical standards

The development and resourcing of national clinical standards for CF must be given priority by Government.

Transplantation

We welcome the fact that the first dedicated lung transplant surgeon commenced in the Mater Hospital in September 2011. We urge the government to ensure there will be an increase in the rate of double lung transplantation undertaken in Ireland. The government needs to do more, for example, to appoint donation co-ordinators in ICU hospitals, to develop a national register of donors, to implement the EU Directive and to adequately resource the new National Office on Organ Donation and Transplantation.

Medical cards

There has been discussion for many years that Medical cards should to be issued on the basis of a lifelong medical condition. The Government should give revised consideration to issuing all people with CF with a medical card. The CFAI will be making a further submission on continuing problems of accessing medications and social welfare.

The Cystic Fibrosis Registry of Ireland

The CFAI is very concerned about the level of funding being provided by the Government to the Cystic Fibrosis Registry of Ireland (CFRI). This issue was flagged in the last issue of *Spectrum*.

A copy of the full submission will be made available on our website shortly.

ST VINCENT'S BUILDING UPDATE

Programme of Progress

Construction of the new ward block in St Vincent's University Hospital commenced in November 2010. With currently 90 workers on site, building work is well underway and, importantly, on schedule with the original programme of work. The project completion date is April 2012.

The new building will have the potential to accommodate 34 in-patient beds for people with cystic fibrosis (PWCF). When beds are not required for PWCF, they will be used for other in-patients with a clearly agreed protocol that there will always beds available for PWCF who require admission.

Photographs to the right show progress of the building work to date (taken on 16th August).

35TH EUROPEAN CYSTIC FIBROSIS CONFERENCE, DUBLIN 2012

By Prof Stuart Elborn, ECFS President & Professor of Respiratory Medicine, QUB

It is a great privilege and honour for the European Cystic Fibrosis Society to bring its annual European Conference to Dublin in 2012. The Conference attracts around 2000 participants each year to share exciting new research and advances in clinical care for patients with cystic fibrosis in Europe and further afield.

The ECFS Annual Conference will be held in Dublin in 2012.

The European Cystic Fibrosis Society was founded in 1969 as a European Working Group and became a fully fledged medical and scientific society in 1997. The Society's two key aims are to encourage and support top quality research in cystic fibrosis, which will impact our understanding of the disease and lead to new therapies, and secondly to support the optimal care for people with CF by providing education to cystic fibrosis teams throughout Europe.

The Society undertakes these two areas through a series of activities. The centre point for fulfilling these functions is our annual conference where there is an opportunity to hear of important developments but also to network with scientists, physicians, nurses and allied health professionals with expertise across the many important fields of cystic fibrosis, research and care. We also have an annual basic science meeting that is attended by 150 dedicated basic scientists who, with their teams, discuss issues around cell biology, infection and new therapies which provide the foundation for the development of new treatments. The Society also publishes the *Journal of Cystic Fibrosis*, which is the only International Journal solely focused on cystic fibrosis research and clinical care. The Journal has developed an increasingly high profile over the past number of years and attracts papers from around the World.

The ECFS also supports two major infrastructure projects in Europe, again aimed at promoting better research and better care. The first is the European Clinical Trials Network (CTN), which brings together 30 sites across Europe representing 13,500 patients. This network has been in place for 3 years and recently expanded its number of centres. The aim of the CTN is to ensure that clinical trials are undertaken to a high quality and in good time to make sure that new therapies are available as quickly as possible for people with cystic fibrosis. The second major infrastructure programme is the European CF Society Patient Registry. This Registry collects data from over 80% of patients in Europe, either via their national registry or by individual clinic or country using our online software. An important initiative is currently underway to include as many countries in Europe who do not have their own registries, particularly countries in the eastern part of Europe. This is critically important to ensure quality of care of patients across Europe and allow direct comparison of outcomes. Ireland contributes to the European Registry by providing its data each year.

The Society also has a number of working groups on neonatal screening, the diagnosis of CF, lung infection, non-tuberculous mycobacteria and exercise. We also publish a series of consensus statements to assist clinicians in their treatment of CF.

ECFS is supported by a great team based in our office in Denmark. Christine Dubois has been our CEO for the past 10 years and with help from Sarah Young and Therese Chalayer, ensures the Society is run in an effective and efficient manner.

The Society is very much looking forward to coming to Dublin.

EASTERN BRANCH PARENTS NIGHT

Thursday 6th October, Harcourt Hotel

The Eastern Branch of the CFAI are hosting a Parent's Night on Thursday 6th October in The Harourt Hotel, Harcourt St in Dublin.

This event has been organised to allow new members the opportunity to meet other parents of children with CF and to get more information about the Association and the support networks existing in the Eastern region.

All are welcome so please come along whether you are a new member or have been involved in the Association for quite some time. For further details and RSVP, please phone Mary McCarrroll of the Eastern Branch at 087 411 9812.

Please note that cross-infection guidelines will apply.

The Eastern Branch Parents Night.

CONFERENCE CALL

Topic Suggestions Welcome

If there are any teenagers, young adults or parents who wish to have a teleconference organised on any given topic, please let us know and we will try to facilitate your request.

Contact Caroline on 087 9323933 or cheffernan@cfireland.ie

INFORMATION FOR NEW FAMILIES

Can You Offer Any Advice?

All newborn babies have the heel prick test within the first 72 hours of birth. Since July of this year, CF has been included in the test. Here at CFAI, we are in the process of updating our information booklets and leaflets, especially our information packs for new families. We would welcome any suggestions our CF community would like to share with us in relation to what should be included in the information.

Many new parents worry that they are not fully complying with treatments, physiotherapy etc. As you know, it can be difficult to come to terms with your child's CF diagnosis. With this in mind, we are asking you to think about things that made life easier so that we cab share any tips you may have for new members. For example, do you have tips on getting high calorie food into your children (favourite recipes) or tips for physiotherapy – all information is greatly appreciated!

Get in touch if you have any tips for new members!

Contact our CF Advocate Caroline on 087 9323933 or cheffernan@cfireland.ie.

’SALTY BABY’, A MEMOIR

By Orla Tinsley

Orla Tinsely, who you will all know, is a 24-year-old journalist and campaigner for CF. Orla has recently published a book called ‘Salty Baby’.

‘Salty Baby’, a memoir by Orla Tinsley.

In her memoir, she takes us on a journey into the inner world of a child whose home from home was hospital, yet who from an early age refused to allow her illness to define her. It is also a story about coming of age in today’s Ireland, as Orla takes us through school, college and the pursuit of her ambition to become a writer.

‘Salty Baby’ reveals the path of a young woman known for her fighting spirit: deeply personal, at times shocking, always honest, and ultimately hopeful.

‘Salty Baby’ is currently the number 4 in the bestseller list in Ireland, which is testament to how well the book has been received.

The book is now available in all major bookstores and can also be purchased online through Hachette publishers:
https://www.hachette.ie/BookDetail.aspx?Id=190891&AuthorId=0

SPECTRUM MAILOUT

Reducing Printing Costs

To further economise and reduce our outgoing costs we are making ongoing changes to our mailing list. At present we are working towards sending only one copy of *Spectrum* to each household. If you wish to receive more than one copy, change to the email version of *Spectrum* or want to make changes to your contact details, please email us at info@cfireland.ie or call the office directly on 01 4962433.

Thank you for your patience and understanding.

HEALTH INEQUALITIES AND CF

British Medical Journal Publication

A study recently published in the *British Medical Journal* has reported that despite improvements in survival for PWCF over the last 50 years, females and individuals from socioeconomically disadvantaged backgrounds continue to die younger than males and people from higher income brackets in society.

The study was carried out by a team of researchers at the University of Nottingham, UK. Their objective was to determine the trend in the association between socioeconomic status and sex and median age at death from cystic fibrosis in England and Wales, over the past 50 years. They analysed all registered deaths from cystic fibrosis in England and Wales from 1959 to 2008.

The past 20 years have seen considerable improvements in healthcare provision, including improvements in antibiotic and nutrition treatment, and the use of multidisciplinary approaches to management with the formation of specialist treatment centres.

However, results from this research reveal that socioeconomic status and sex remain strong determinants of survival from cystic fibrosis in England and Wales, and the magnitude of these effects does not appear to have substantially reduced over time.

Between 1959 and 2008, the median age at death increased from age band 0-4 years to age band 25-29 years, and from the mid 1970s onwards tended to be higher in males than females.

After adjusting for socioeconomic status, males were more likely to die above the median age than females in the 1970s and 1980s. Median age at death was also significantly higher in males compared with females between 2000 and 2008.

“Healthcare workers should be aware that females and low socioeconomic status are associated with poorer outcomes than males and high socioeconomic status,” conclude the authors. Early appearance and persistence of inequalities support the need for early interventions, for example, newborn screening. They suggest that environmental factors or varying access to healthcare might account for some of these differences.

This research has important implications for the treatment of CF in the UK and the CFAI will be encouraging policy makers to take on board its potential implications for Ireland.

To access the full article online, please click on the following link: http://www.bmj.com/content/343/bmj.d4662.full

EDUCATION SUPPORT

SECTION 03 PAGE 10—12

DISABILITY ACCESS ROUTE TO EDUCATION

Information and Advice for PWCF Considering 3rd level

What is DARE?

The Disability Access Route to Education (DARE) is a supplementary admissions scheme which offers college and university places on a reduced points basis to school leavers with disabilities.

DARE has been set up by a number of colleges and universities as evidence shows that disability can have a negative impact on how well a student does at school and whether they go on to college.

A list of the colleges/universities that take part in DARE are listed here: http://www.accesscollege.ie/dare/participate.php

The DARE scheme offers college places to students with disabilities on a reduced points basis.

Who is it for?

DARE is for school leavers who have the ability to benefit from and succeed in higher education but who may not be able to meet the points for their preferred course due to the impact of their disability. PWCF are eligible to apply through DARE under the 'Significant Ongoing Illnesses' category.

Why should I apply to DARE?

You should complete a DARE application if you wish to compete for one of the reduced points places on offer in the participating colleges. Each college that takes part in DARE has a reserved number of places to offer eligible DARE students at lower Leaving Cert points. This is what is meant by reduced points places. Details of places available and minimun course entry requirements can be found at accesscollege.ie.

What are the application requirements?

You must give evidence confirming that your disability has had a significant impact on your educational performance.You must also meet the minimum entry (matriculation) and subject requirements of the institutions to which you apply (these vary depending on the college or university). You will then compete for one of the quota of places based on your Leaving Certificate results.

A step by step guide on how to apply to the DARE scheme and associated deadlines are available here: http://www.accesscollege.ie/dare/apply.php

Where can I get more Information?

Representatives from Universities, Institutes of Technology and further education colleges will be present at the Better Options Fair, which will be held on 30th November 2011 at the National

College of Art and Design, Dublin 8, 10.30am - 2pm to give you information on application procedures, course details and the various supports that are available for you. They will provide information on courses and will be on hand to discuss supports in third level.

Alternatively, log on to www.accesscollege.ie or AHEAD (Association for Higher Education Access and Disability) http://www.ahead.ie.

SUPPORTS FOR PWCF AT THIRD LEVEL

Reminder for Students

All students with a disability, irrespective of whether they come through DARE or not, are offered a variety of academic, personal and social supports while studying at third level. Individual institutions will determine the nature and delivery of such supports in accordance with their own policies and practices and subject to the availability of resources.

The following are examples of the types of supports available:

- An orientation programme to introduce students to university/college
- Study skills, extra tuition if required and exam support
- Access to student accommodation units (on campus or otherwise) reserved specifically for students with disabilities
- Access to assistive technology and training
- One-to-one meetings with support staff, social gatherings and mentoring

Disability Officers (for universities and some Institutes of Technology) or Access Officers (for most Institutes of Technology and other colleges of higher education) should work collaboratively with students with disabilities in arranging supports that a student with a disability may need while they are in college.

Details of post-entry supports can be found on the Disability Support website of each of the participating institutions: http://www.accesscollege.ie/dare/benefits.php

For More information

Please contact our CF Advocate Tomas Thompson (087 9323 930/tthompson@cfireland.ie) if you would like further information and advice about third level education supports.

Guidelines for PWCF are currently been finalised and will be available very shortly – please contact the National Office if you would like a copy posted to you, call 01 496 2433 or email info@cfireland.ie.

HOME TUITION SCHEME 2011/12

Reminder to Apply

A number of children with cystic fibrosis will, at times, experience unavoidable absenteeism from school due to illness and hospital stays. Even children with CF who are well, will need to attend regular out-patient clinics and annual review assessments. For this reason, they may need additional home tuition in order to catch up with work they have missed at school.

The Home Tuition Scheme is operated through the Special Education Section of the Department of Education & Skills.

Purpose

Home tuition provides a compensatory educational service to children with a significant medical condition which is likely to cause major disruption to their attendance at school on a continuing basis. Therefore home tuition in this category is to be provided for pupils who:
(a) cannot attend school at all.
(b) are absent for a significant proportion of the school year and where the degree of absence is such that without supplementary instruction the pupil is unlikely to be able to perform academically at the level appropriate to his/her level of ability.

Criteria for eligibility under the terms of the scheme

Children with a significant medical condition which is likely to cause major disruption to their attendance at school on a continuing basis are eligible for tuition under the scheme. Eligibility under this provision is assessed with reference to a completed medical report and attendance records supplied by the school in which the pupil is enrolled. The Department may seek updated reports during the course of the year.

Allocation of hours under the terms of the scheme

The maximum allocation of home tuition hours for children with a medical ailment is 10 hours per week, with the allocation reflecting the age of the child and their level of attendance.

Qualifications of tuition providers

As the tuition takes place outside of school supervision there is a need to ensure that the tuition provider is a fully qualified teacher who is registered with the Teaching Council of Ireland. No tuition may commence until the qualifications and identification of the nominated tuition provider have been approved.

Please note applicants for tuition for the 2011/2012 school year are requested to return their application forms to the Department of Education and Skills by 14th October 2011.

Queries in relation to the home tuition scheme can be addressed to:

Home Tuition Unit, Special Education Section, Department of Education & Skills, Athlone, Co. Westmeath - Contact No: 090 6483757, 090 6483926, 090 6483921.

Application Forms

http://www.education.ie/admin/servlet/blobservlet/sp_home_tuition_app_2011_2012_v2.doc

For more information

http://www.into.ie/ROI/InformationforTeachers/DESCirculars/DESCirculars2011/cl0050_2011.pdf

PARENT PROFILE

MARK DUGGAN

By Mark Duggan, Father of PWCF & Member of Irish Air Ambulance service 'AeroMedevac'

I was based in Istanbul, Turkey, working as a pilot when my son Jamie was born. Unfortunately, he was quite ill in the first couple of months of his life. I took a career break to ensure I was at home while he was in hospital and finally in February 2010 he was diagnosed as having cystic fibrosis. This came as a complete shock to my wife and me as there had never been any history of CF in our family. I decided to look for work based in Ireland as I felt that it was unfair on my family for me to be based abroad while they were taking responsibility for Jamie's care. In March this year I heard about Aeromedevac Ireland, the Irish Air Ambulance Service, and immediately knew that this was the type of company I would really enjoy working in.

The Irish Air Ambulance service operated by AeroMedevac Ireland is dedicated to providing the highest standard of rapid response critical care to the ill and injured. Our aircraft is based at Dublin airport and is available to fly 24 hours a day to ensure that patients would have access to a first class medical transport service. We have recently signed a Memorandum Of Understanding with Our Lady's Children's Hospital, Crumlin, to ensure that in the event of the non-availability of an Air Corp jet then AeroMedevac Ireland will transfer their patients to ensure they get the medical care they so desperately need. We are currently in the process of arranging further memoranda with the other Irish hospitals that may require emergency medical transportation.

The mission of AeroMedevac Ireland is to save lives, speed recovery and serve the community.

Up until now, Ireland has been reliant on the Air Corp or companies operating outside of Ireland to provide emergency medical repatriation and evacuation services. As recent events have shown, the Air Corp jet is not always available to carry out emergency medical flights to assist patients trying to avail of transplant opportunities in the UK. However, this service ensures that anyone who needs emergency repatriation back to Ireland or medical transport from Ireland (e.g., patients requiring emergency medical procedures only available in the UK) can be assured that a world class service is available on a 24hr basis. As the father of a child with CF, I feel that it is essential for this service to be available and feel lucky that I can contribute to this organisation.

Inside the air ambulance aircraft.

Since Jamie's diagnosis I have run marathons in New York and Paris for the CFAI and am running the Berlin marathon at the end of September, with plans to run the Rome marathon on St Patrick's weekend 2012. I really hope that all this exertion won't leave me needing to avail of AMI's services to airlift me home for medical treatment!

DON'T SUFFER FROM CYSTIC FIBROSIS, LIVE WITH IT

Debbie McCarthy, PWCF from Cork

My name is Debbie McCarthy and I live with Cystic Fibrosis. I don't suffer from it and I try not to let it rule my life, but I don't ignore it either. Like I mentioned, I live with it. I am 39, the big 40 in December, so plenty of time yet to sort out the celebrations.

Let's start at the beginning and work from there.

I was born in December 1971, a very different world from today – no mobiles, no internet and knowledge about CF was basic. Back then it was fatal and incurable. End of story. My 6 month old sister Sharon was diagnosed with Cystic Fibrosis and, being a sibling, I was tested too.

My parents found themselves with two small sick children and an illness they knew nothing about. We were put on enzymes and did our physiotherapy etc. Our diets were changed as medical experiments were carried out. First, no fats, then extra fats. Luckily my body can tolerate fats so weight gain was not an issue. Deep fat fried foods were the order of the day! While teenage friends avoided chocolate and crisps, I could eat them away to keep my weight up. I don't take enzymes as I can gain and maintain weight without them. Next to my lungs. I went swimming a lot as a child and have continued to do so as an adult. I also ran track with a local club and have a gold All Ireland under 16 medal. A lot has changed since then; I don't run as much but I like walking, which is good as I am the mother of three children, but that will come later in my short story.

Myself, my sister Sharon and younger sister Ciara – who tends to tell everyone she is adopted since she doesn't have CF and is seriously fit – were treated as normal as possible by my parents Con and Callie. We all went to school, took part in sports and were typical awkward teens. We socialised and had part-time jobs just like everyone else. The reason we were so good as teens (healthwise I mean, for we were troublesome teenage girls) was due to the great groundwork our parents had put down – regular clinic appointments, good healthy diets, sleep, exercise and fun – they didn't treat us any differently.

I finished school, did a few years in college, worked most of my adult life, and then started the hardest job of all – being a mum and wife. In order to be there for your children you need to be there for yourself. I try to take care of myself, I attend the clinic for my annual assessement and keep track of my lung function (currently 126). I keep my weight up, exercise a bit (no point overdoing it) and avoid coughs and colds or getting wet.

I married Tony, my knight in shining armour. I had to go from Midleton to Blarney to find a man with the gift of the gab. Years later we are still hanging in there. It takes time and work but so does life. I have a handsome son Graham who is now a strapping 21 year old that has finished college and is working in the local SuperValu. Unfortunetly fertility can be affected by CF and

so we needed a little help finishing off the rest of our clan. Thanks to Dr Waterstone in the Cork Fertility Clinic we had a boy, Danny, now 6 and a little girl, Leah, 2, to complete our family unit. I was in great health before becoming pregnant thanks to regular check-ups and I got plenty of rest during the pregnancys. Lung function was still high enough for me to chat and roar in the delivery room (only joking about the roaring) – thanks to whoever invented the epidural!

Debbie at home with her family.

Debbie with her daughter Leah.

None of my three kids have Cystic Fibrosis, but they are all carriers of the CF gene so depending on their partners my grandchildren could have CF. This may seem sad but it's actually great progress. When I was diagnosed, Cystic Fibrosis was a childhood disease and most children didn't reach their teens. It has since became a young adults disease and now there are a good few of us in our 30s – we are the rowdy table at the CFAI Annual Conference! As CF adults we have achieved some great milestones including finishing college, marrying, buying homes, having careers and families etc. I am hoping by the time my own daughter has children there will be a cure or a life expentacy of at least 80 for PWCF.

At present, life is good. I am self employed, working from home doing book-keeping accounts, wages, secretariel work etc. I can spend time with my children and work around them. I am not in an unhealthy work place coping with cross infection. I can do work online, when I get off Facebook that is. So my health is not an issue. I hope to build up my client list once we clear the other side of the recession (or if I win the Lotto then its goodbye work and hello villia in the sun!).

Fundraising is very important for the CF community. I have done a number of the Paddy Kierans walks including Italy, South Africa, Thailand, Cuba, Mexico and India. Locally we have the Build4Life initiative and I even stripped for a nude calendar – I'm Miss December. All good clean fun and plenty of money raised.

One of my ambitions was to complete the Cork City Marathon before I turned 40, and I'm happy to say that I achieved this in 6 hours and 56 mins. Tony came with me so that when I was crying at mile 18 he could talk, drag and bully me to the finish line. I'd like to grow old, slowly, live to see my children happy and healthy, and win the lotto of course.

Debbie, after completing the Cork City Marathon.

So thats me in a nutshell. If you want or need any info contact me on debbiemmccarthy@yahoo.ie.

And remember, don't suffer from Cystic Fibrosis, live with it.

NUTRITION FEATURE

SECTION 06 PAGE 16—17

RUTH HANNON

Senior Dietitian, Beaumont Hospital, Dublin

My name is Ruth Hannon and I am the Senior Dietitian in Cystic Fibrosis in the Adult Cystic Fibrosis Centre, Beaumont Hospital. I graduated in 2003 with a BSc in Human Nutrition and Dietetics from DIT and TCD. I have been working in Beaumont Hospital for almost 8 years (apart from six months leave in 2006 to explore the world!). I started working in Cystic Fibrosis in 2007 and quickly realised this was the speciality for me. As a dietitian, working in the area of Cystic Fibrosis keeps me challenged! We are learning more and more about CF on a daily basis and the importance of nutrition in maximising the health of PWCF is paramount.

As healthcare professionals, it is important to keep up to date with the latest international guidelines and best practice. In addition to all the information that I have assimilated from journal articles over the years, many important things I've learned through talking with my patients. After listening to people in clinic or on the wards for a few years, you get a good idea of the challenges that somebody with CF faces on a daily basis.

These are the Top 10 questions I get asked:

1. "I think I'm hungry but I feel full after a few bites; why is that?

Trying to eat when you feel sick is extremely difficult. PWCF can find that having an exacerbation or chest infection impacts on appetite in different ways. Some people find that they can still eat almost the same amounts when they are feeling unwell, however, the vast majority of PWCF find that their appetites start to slip as soon as they feel the symptoms of a chest infection brewing. This feeling of excess fullness after eating small amounts is what we science nerds like to refer to as "early satiety". It can happen when you are unwell because, as part of the inflammatory process that occurs with an infection, a chemical is produced that has an effect on your stomach and makes it feel full even when it isn't. To tackle this problem, choose energy dense foods. This means foods that have a high amount of calories or energy in a small amount. Good snack examples include full fat milk, custard, yoghurts, crackers and cheese, desserts.

2. Why do I need to have a regular eating pattern? Can't I just eat when I'm hungry?

Some people find it difficult to eat first thing in the morning. If you are feeling unwell and sleeping late or napping during the day, you can easily miss out on valuable eating hours. Try to kick start your appetite by having breakfast every day. An empty stomach tends to exacerbate feelings of nausea and the longer your stomach remains empty, the less hungry you will feel. A glass of orange juice with a bowl of cereal or buttery toast is not too filling but will help get a couple of hundred calories in before 11a.m. When you don't have a regular eating pattern, it can be easy to forget meals or extra snacks. Being at school, work or college helps structure your meals and it is easier to punctuate the day with regular snacks. Try to stick to a routine with your meals and snacks. Weight loss can often occur during Summer holidays or when you move out of home and your usual pattern is disrupted.

3. Why do I need to take my vitamins; I don't feel any different if I forget them?

Fat soluble vitamins are crucial for PWCF and no matter how balanced your diet is, it is impossible to meet your needs for vitamin A, D, E and K without taking the supplements. They can leave a lot to be desired in the olfactory department but they fulfill important roles including helping your body's immune function and bone health.

Vitamins are crucial for PWCF.

4. Why is it impossible to always get it right with my enzymes?

The dosage of enzymes varies hugely between individuals. There are lots of reasons for this, for example, some people may have some residual pancreatic function and everyone's gut is different. Enzymes can sometimes leave the stomach before or after food/drink is consumed (even if you take them at the correct time). This can occur because many different factors affect the way your stomach empties. Enzymes work best in an alkaline environment in the small bowel. If you suffer from reflux or heartburn you may be on a medication to help suppress acid production. This can also improve the efficacy of your pancreatic enzymes.

5. Why do I need to exercise? Doesn't that just burn off all the calories I've just eaten?!

Your physiotherapist is right – exercise is good for you! It improves your appetite and helps you to eat more food without even trying! There is no point having a healthy weight and body mass index unless you have a healthy muscle function to go with it.

6. What do you mean I have to switch to sugar-free drinks?

Managing a new diagnosis of diabetes on top of CF is no mean feat. Getting to grips with insulin and blood sugar levels checks can seem daunting and time consuming. However, saying goodbye to the effervescent sugar-rush of certain carbonated drinks proves to be the toughest part for many people. Unfortunately, drinking large volumes of high sugar fluids cause huge spikes and troughs in your blood sugar levels, making it extremely difficult for you to control your diabetes.

7. Why does my tummy give me problems even if my chest is behaving itself?

Abominable abdominal symptoms plague many PWCF and a discussion on the whys and wherefores could keep me going 'til Christmas. Cramps, bloating, diarrhoea and constipation can all be issues. Having a regular meal pattern, a varied diet, plenty of fluids and taking the correct enzyme doses are important to keep things regular. Discuss your symptoms with your doctor and dietitian if you are having problems.

8. I'm doing everything so why can't I reach my target weight?

Sometimes, even when you follow all the advice and stick to a high calorie diet and take your nutritional drinks, it may not be enough to help you achieve a healthy weight. If you need the extra support, a feeding tube can help deliver additional calories overnight. Getting some information about feeding tubes from your CF dietitian can help dispel some of the concerns that you may have about getting a feeding tube and anything that helps improve your nutritional status can really help your overall wellbeing.

9. Do you have any other PWCF who are overweight?

No two people are the same! Some PWCF are overweight and their focus is more about preventing weight gain which may negatively impact on their breathing.

10. Can you recommend a good takeaway that will deliver to the hospital?

Yes! Talking about food all day gives me a huge appetite and I test out the local eateries from time to time, purely in the name of research of course.

FUNDRAISING

There are many fundraising events taking place around the country at Branch, local and national level over the next few months, not to mention people travelling to New York, Berlin and Rome to run marathons in aid of Cystic Fibrosis. This is heartening to see as we need to maintain and increase the flow of income to CFAI to sustain our planned programmes, and prepare for new developments in the quest for better treatments and facilities for CF in Ireland.

We acknowledge the support and continued dedication of our volunteers and Branch members in this respect.

SOROPTIMISTS INTERNATIONAL IRELAND

€100,000 Raised for CF

As previously reported, Soroptimists International Ireland chose CFAI as their charity for the period 2009-2011.

This initiative comes to a close on Saturday 24th September with their conference in the Old Ground Hotel, Ennis. A total of €100,000 has been raised by these dedicated ladies over the period through local events. Martin Cahill will attend to accept the cheque on behalf of CFAI and to acknowledge the wonderful contribution to CF services that this initiative will make.

CF LUGATHON

Saturday 1st October

Our annual CF Lugathon is scheduled for Sat 1st October. This event involves a hill-walk up Lugnaquilla Mountain, the highest mountain in Wicklow. The view from the summit is amazing.

Previous entrants have been contacted, as well as those living in the surrounding areas. Join us for a great day out, with refreshments afterwards in Fentons, and raise much needed funds for CF. Further details are available on www.cfireland.ie.

ISTANBUL & CAPPADOCIA WALK 2011

October 2011

The departure date is quickly approaching for our group going to Turkey. The 41 strong group will depart from Dublin on October 1st and return on October 9th for what is going to be an incredible adventure. CFAI and the Walk Committee would like to commend and thank all the walkers for the continued support towards the Cystic Fibrosis Association of Ireland and we really hope the Walk 2011 will be the best one yet!!

DUBLIN CITY MARATHON 2011

October 31st

The 31st edition of the Dublin City Marathon will take place on October 31st at 10am. Entries are now closed, but the event is expected to be the biggest one yet.

We have a good number of people taking part in aid of the Cystic Fibrosis Association of Ireland, and if you have registered and/or know somebody who did, come and join our CF Team. Get in touch if you have not done so already and we will provide t-shirts and sponsorship cards for the event.

NEW YORK MARATHON 2011

Sunday 6th November

We have a total of 5 people committed to participating in this year's event, and we wish them all well in their venture in one of the toughest marathons in the world.

We thank you all for your fundraising and good luck!

ROME MARATHON 2012

St. Patricks Weekend

Did you ever wonder what it would be like to run in one of the most historical cities of the world? If you are not interested in the long haul flight to go to New York, but you would like to run a marathon in aid of Cystic Fibrosis while admiring history around you, the Rome Marathon 2012 it is what you are looking for.

We have already received enquiries and we are in the process of putting details and indeed teams together. Interested parties wishing to take part should call Martin or Eufemia in the National Office for full details, which will go on www.cfireland.ie shortly.

DONEDEAL.IE

CFAI Chosen as Charirty of the Month

DoneDeal.ie have kindly chosen CFAI as their Charirty of the Month for October 2011.

This entails CFAI receiving an agreed precentage of every advertisement placed on the site during the month of October.

The DoneDeal website is a very comprehensive, wide-ranging forum for buying and selling goods of all descriptions. We are delighted to be chosen as beneficiaries in this instance.

See www.donedeal.ie for further information.

THE LAKES 10K

Saturday 10th Sept

The Lakes 10k took place on Saturday 10th September for its third year running. With a sell-out field of 640 runners, the weather didn't deter 500 of these to turn up for one of the most enjoyable road runs in the Irish running calendar. With a blustery wet start, the sunshine came out just in time for the start gun.

While joined by some of Ireland's top athletes, Vinney Mulvey of Raheny Shamrocks and Michelle Cox of Newbridge running club took the win on the day, with Michelle Massey of TV3 The Apprentice, and Paul Plunkett, MD of Ace Autobody both agreeing (with witnesses) to take on the challenge of completing The Lakes 10k in 2012.

Congratulations to all involved in what indeed was a well organised and enjoyable event for such a worthwhile cause, and A huge thank-you to the events main Sponsor Ace Autobody, who have committed to sponsoring the event again in 2012!!!

The run is organised by the Lakeshore Striders running club in Blessington, who have donated in excess of €40,000 in the previous 2 years to the Cystic Fibrosis Association of Ireland. One of the club members has a son living with CF and this is where the fundraising idea started.

L-R: Shane Connolly, Lorna Brennan, Paul Plunkett of Ace Autobody (main sponsor), Michelle Massey and Martin Cahill.

GSK CHARITY OF THE YEAR 2011

Ongoing Fundraising

As previously announced, GSK has chosen CFAI as their Charity of the Year 2011 and all the staff are actively involved in organising events to raise funds for CF.

The Cork office organised a cycle from Cork to Limerick over the weekend of 22nd July. Liam McCarthy and 'little' Ben (PWCF) greeted the cyclists in Fermoy, and Deborah and Patsy Kett with Hannah (PWCF) and Mikey, met the cyclists in Kilkee. By all accounts, this was a tough challenge for the cyclists, but a rewarding one nonetheless and, as Paul Hatton stated "As I sat down that night to think back over the previous two days and the sense of achievement, it dawned on me how much we can take for granted and it really put things into perspective. Being able to get up on a bike and cycle that distance is nothing compared to the battles people with CF all over Ireland have to deal with every day. Meeting those kids and indeed a friend of mine's child who suffers from CF but still go around with a smile on their face made me realise how lucky I am".

Liam McCarthy and 'little' Ben (PWCF) greeted the cyclists in Fermoy.

Deborah and Patsy Kett with Hannah (PWCF) and Mikey, met the cyclists in Kilkee.

GSK staff had a sale of '65 Roses' pins in Grafton on 1st September and raised a sum of €512.93.

GSK's annual Indoor Triathlon took place in Westpark Fitness, Tallaght. The event was well supported and ably organised by Ms. Alison Kane of Westpark, a Trojan supporter of CF.

NATIONAL AWARENESS WEEK 2012

April 13-20th 2012

Plans are already in place for National Awareness Week 2012. CFAI National Awareness Week 2012 will take place from April 13th to April 20th and we have already written to all the major shopping centres in the country requesting permission to hold our Flag Day in their premises on April 20th.

However, we do need your help. If you know your local shop or your local shopping centre, get in touch with them and invite them to support Cystic Fibrosis and raise awareness during that particular week. Each year our Awareness Week is a collective effort and we need support throughout the country to ensure that this important message is delivered!

ROSE OF TRALEE PRESENTATION

CFAI Acknowledge Clare Kambamettu

CFAI made a presentation to Clare Kambamettu, outgoing Rose of Tralee to acknowledge her tireless dedication and work on behalf of CF during her tenure.

Clare took on the cause of CF with great commitment, energy and drive, despite her busy schedule throughout the year, which was much appreciated. Her unassuming attitude endeared her to all who came in contact with her. Thanks again, Clare.

Martin Cahill, Clare Kambamettu, Aishling Spillane and Dave Spillane (both PWCF).

NUDE POSES FOR CYSTIC FIBROSIS

Charity Calendar for CF West

Charity calendar 2012/13 “Nude Poses for Cystic Fibrosis” was launched Friday 2nd Sept in the Brogue Bar Tuam, Co. Galway.

A total of 41 people including four people with cystic fibrosis (PWCF) and 1 double lung transplant recipient took off their clothes and pose naked (with strategically placed props) for this calendar.

All money raised from this calendar will go towards the €1,000,000 cost of building CF respiratory out-patient unit on the grounds of Mayo General Hospital (MGH) for PWCF.

The calendar can be purchased on the CFAI website online shop at www.cfireland.ie

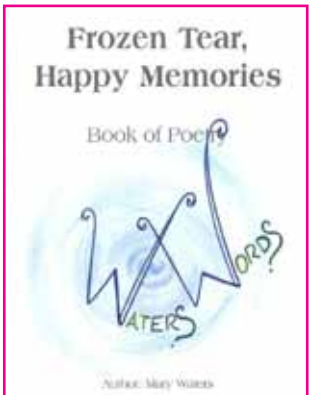
FROZEN TEAR, HAPPY MEMORIES

A Book of Poems by Mary Waters

Co. Kildare VEC sponsors many courses in the Back to Education Initiative (BTEI), giving young people and adults an opportunity to return to education on a part-time basis. Mary, as a participant chose, together with her Project Manager Catherine O’Byrne and the back-up team at Naas VEC, to publish a book of poems describing Mary’s personal experiences in life.

It is a lovely descriptive volume of life situations to which many will relate, and would make an ideal Christmas present.

It is for sale in local bookshops, and shortly in our online shop at www.cfireland.ie at €5. Mary decided in the process, to include information about CF and dedicate all sales proceeds to CFAI.



Frozen Tear, Happy Memories, a book of poems by Mary Waters.

15 TO 1 MOTORBIKE RUN

Took Place on 27th-28th August

The Cystic Fibrosis Association was delighted to be chosen as one of the beneficiaries of the "Fifteen to One Motorbike Run", together with Team Hope.

Special thanks to Pete and Breda O'Donoghue, Richie McKay, Ger and the rest of the team, for such a well organised first event, which was executed safely for all participants. Thanks are also due to the Garda Traffic Corps for their valued assistance.

The event took place over the week end of Sat 27th and Sun 28th of August 2011 and saw motorbikes coming from 15 different starting points around the country and meeting in Kilkenny Castle. The groups met at 11am for entertainment, and an amazing Motorcycle display at the Kilkenny Bike Fest and show with spot prizes on the day and fun for all.

The more adventurous riders then travelled at 3pm sharp from Kilkenny Castle to Cork City for a civic reception and evening entertainment at Silver Springs Hotel. Martin Cahill attended the function and thanked the bikers for their generosity of spirit in raising funds for Cystic Fibrosis.

The Lord Mayor of Cork met the bikers on arrival, along with members from Team Hope and the Cork Branch of CFAI.

On the day, Paul Gaughran of The Green Knights (Defence forces Motorcycle Club) presented a cheque for €2,700 to Martin Cahill, the proceeds of which was from a previous motorcycle run organised in memory of their colleague, Richie Richardson, R.I.P.

Sharon O'Sullivan (PWCF) with fellow biker at the event.

Paul, Ross and Ger presenting a cheque to Martin Cahill.

Civic reception on arrival in Cork for the 15 to 1 Motorbike Run.

CHARITY NIGHT IN AID OF TLC4CF

Held at Sarsfield Barracks

Recently the Privates Mess in Sarsfield Barracks, Limerick held a charity night in aid of TLC4CF.

Pictured are members of the 12 Infantry Batallion, Sarsfield Barracks, along with Lt-Colonel Brendan O'Shea, Officer Commanding the 12 Infantry Batallion presenting Capt Caitriona McDonagh from TLC4CF with the proceeds from the night.

Cheque Presentation to TLC4CF.

AHERLA AND DISTRICT VINTAGE CLUB

Cheque Presentation

Proceeds from the Aherla and District Vintage Run held earlier in the year were recently presented to the Southern Branch of Cystic Fibrosis Association of Ireland.

A cheque to the value of €1,000 was presented to the new Chairman of the Southern Branch, Ger Minihane. Also in picture are Marie O'Donovan (Secretary), Tadg Culhane (Chairman of Club) and club commitee members.

CHARITY BIKE RUN AND RAFFLE IN KERRY

Report by Marisa Reidy, Journalist and Mother of PWCF

The development of the new adult CF unit at Limerick's Mid-Western Regional Hospital is to receive a cash injection of over €6,500 thanks to a hugely successful charity bike run and fund-raising raffle which took place in Kerry in July.

Close to 40 bikers took part in the event, travelling to Limerick and back on July 31, before joining locals and visitors for a great night of entertainment in the north Kerry village of Kilflynn. As well as gathering funds during the bike run itself, organisers also held a fundraising raffle on the night, which – along with some very generous donations – helped generate an impressive total of €6,570 for the project. "It was a fantastic community effort and everyone involved is absolutely delighted with the success of the day," said joint organiser Marisa Reidy, whose 16-month-old daughter Hanna is under the care of the CF team at MWRH.

Presenting a cheque for €6,570 to Owen Kirby of TLC4CF are Declan O'Connell, Marisa Reidy, Aiden Sheehan and Pat Herbert — some of the organisers of the charity bike run and fundraising raffle held in Kilflynn, Co Kerry, on July 31.

"Massive credit is due to the bikers, marshals, those who bought and sold tickets and made donations, as well as all the businesses who provided spot prizes and everyone who helped in any way. We were blown away by people's generosity and how eager everyone was to support this very worthy cause."

Marisa Reidy

The money was presented to Owen Kirby of TLC4CF in Kilflynn on Friday, September 16th.

Photograph courtesy of Paul Tearle.

ENS 5 PEAK CHALLENGE FOR CYSTIC FIBROSIS

Took Place on 30th June

The Directors of Electricity Network Solutions (ENS) in England decided to set a challenge for the employees of ENS Ltd to raise funds for Cystic Fibrosis after an employee suffered the loss of two close family members to the illness. On the 30th June 2011, 35 employees of ENS set off for Scotland to rest for the night before commencing the strenuous task of climbing the five highest peaks in UK & Ireland in 48 hrs.

Ben Nevis - 4409ft: The first challenge was to meet at the base of Ben Nevis, the highest peak in Scotland and start climbing at 6am. The conditions were perfect and all climbers made it up and down in good time. There was only a short amount of time available to allow the climbers a quick bite to eat before the convoy of vehicles set off for Scafell Pike in the Lake District, the highest peak in England.

Scafell Pike - 3,210ft: The drive to Scafell Pike was arduous; drivers had to carefully negotiate the narrow, winding roads of the beautiful Lake District. The weather was perfect, if not a little warm and the view at the top was magnificent. Safely back at base, the climbers enjoyed a Lancashire hot pot kindly provided by ENS staff and family before setting off for the long drive to North Wales.

Mount Snowdon – 3,560ft: Arriving in a dark car park in the very early hours of Saturday morning, the climbers donned head torches ready for a night trek to the top of the highest peak in Wales. Reaching the summit as the sun started to rise was an incredible sight. Our excitement at reaching the top unfortunately woke those unsuspecting campers enjoying a peaceful night sleep scattered along the summit. After the descent, there was just enough time for a quick snack before heading to Holyhead to catch the 8.20am ferry to Dublin. The ferry crossing provided valuable rest and relaxation time for the climbers and drivers.

The 5 Peaks Challenge, in aid of CF West.

Slieve Donard – 2,278ft: Family, friends and fabulous weather greeted us in Northern Ireland. Even though knees and muscles were tired, the climb to the top was pleasant with wonderful views of the coast below. With everyone down safely, we enjoyed some delicious Irish fayre including a wonderful Irish stew served from a horse trailer. At approximately 6pm, the long drive south commenced.

Carrantuohill – 3,406ft: The final challenge commenced at approximately 2am on Sunday morning. With only head torches to guide the way up the mountain, the Devi's Ladder, which is badly eroded, was the biggest challenge of all! Negotiating the right way up was difficult and extremely dangerous. The cross on the top of the mountain was a welcome sight for many. To be greeted at the base by the Carey family, Fr Francis Judge and their neighbours was an emotional end to what had been a tough but rewarding experience.

It was an amazing achievement to complete the challenge within 48 hours but more importantly to know that we had raised valuable funds for Mayo Cystic Fibrosis, Building Fund. A cheque will be presented to the Mayo Branch of the Cystic Fibrosis Association very soon.

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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