

SPECTRUM

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www.cfireland.ie

Dear All,

In the run up to Christmas it's really heartening to see the progress on lung transplantation in Ireland in 2013. The lung transplant rate in the Mater, both for all lung transplants and CF transplants, has more than doubled over the last 11 months compared with 2012, which was the previous best year for lung transplants in Ireland. Many congratulations to the Mater lung transplant team, co-ordinated by Professor Jim Egan. Lung transplantation is a complex and challenging intervention and will not be suitable for many CF patients but it remains an important aspect of CF care. For the most part adult CF transplants will now be undertaken in Ireland. This is to be welcomed from a wide range of perspectives. CFI will continue to work closely with the key stakeholders to ensure that this progress is sustained and perhaps in the not too distant future, the small number of paediatric CF transplants may also be undertaken in Ireland.

Spectrum readers will know that CFI has also been active in supporting the move to the soft opt-out form of donor consent over the past 12 months to increase the number of lungs (and other solid organs) available for transplantation. CFI has been campaigning for organ donor co-ordinators to be appointed to our major A&E hospitals to support this change, in partnership with our colleagues in the Irish Donor Network. If you have not seen it already, catch the documentary 'A Perfect Match' on the RTÉ Player (available for the next two weeks) which tracks the inspirational story of Joe Brolly and his support for soft opt-out in Ireland North and South. It is a very moving story that is worth watching.

Many congratulations to the Cavan Branch of CFI for their 50th Remembrance and Thanksgiving ceremony in Cavan town on the 9th of November. This important event was a credit to the Cavan Branch and a way of thanking all who have been involved over many years, see Latest News in this issue of *Spectrum*.

Finally, to wish you season's greetings. Christmas is a period of hope and looking forward and despite all the challenges, we are in a period of hope for Cystic Fibrosis. We look forward to the exciting new CF building projects in 2014, many directly supported by CFI, and hope that research and clinical trials will lead to more new and innovative therapies over the next few years.

Kind regards,



Philip Watt (CEO)

Alica May (Editor)

Front Cover: Michael Cullen (CEO Investec Ireland), Orla Ni Cholmain, Philip Ahearne and Katie Murphy (CF Ireland). See Corporate Focus section for more information.

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100% Increase in Lung Transplantation in the Mater

There rate of lung transplantation in the Mater University Hospital has more than doubled since last year. As of November 29th, the total number of CF double lung transplants is 9 compared with 4 in 2012. The total number of all lung transplants undertaken in the Mater this year is 30 to date, compared with 14 for the whole of 2012. 2013 is by far the best year for lung transplantation in Ireland. With many thanks to the transplant team in the Mater, including Ms Karen Redmond, Ms Donna Eaton, Mr Lars Nolke and Professor Jim Egan and all the members of the multi-disciplinary team.

The HSE has indicated that going forward, almost all adult CF lung transplantation will now be undertaken in the Mater University Hospital but the small number of paediatric transplants needed will continue to be undertaken in the UK. The CFI is currently seeking further clarification of the details of arrangements going forward and will continue to monitor progress and keep our members informed. In this context we would also like to acknowledge and thank the Freeman Hospital in Newcastle.

Soft Opt-Out Organ Donor Consent, the Irish Donor Network and Joe Brolly

CFI has taken a very active role in advocating for a change in organ donor consent from opt-in (present system) to opt-out. In this context we have worked very closely with many of our colleagues in the Irish Donor Network (IDN). The position of CFI is that the change in organ donor consent is welcome but needs to be accompanied by resources, especially there is a need for organ donor co-ordinators to be appointed to our accident and emergency hospitals. These are dedicated staff who can take the time to link in with next of kin and who can discuss the organ donation option. Under the new system, next of kin will continue to be able to veto a transplant and it is envisaged that those not wishing to donate organs can 'opt out' through an online registry. The IDN has met with the Minister for Health on these issues in February, we also made a written and oral submission to the Dáil committee on Health and made a further submission to a Seanad debate in August.

Public awareness on this issue has been given a significant boost by the fantastic work of Joe Brolly. The recent RTÉ programme 'A Perfect Match' highlighted the outstanding personal commitment of Joe on this issue at both a personal and policy level. Joe has also been very active in supporting fundraising for CFI.

Thanks should be given to Dr James Reilly TD, Minister for Health, who included soft opt-out in the programme for Government in a good example of government leadership on an important health issue. The outcome of the public consultation process is now available on our website www.cfireland.ie. This report of the consultation shows that the vast majority of patient groups, clinician and medical organisations and other key stakeholders are in favour of the move to soft opt, provided it is resourced. The HSE service plan will indicate the level of resources that will be made available for the introduction of soft opt-out — we are hoping for €3 million.

Follow up on Cork University Hospital CF Paediatric Needs

In the last issue of *Spectrum* CFI highlighted the gap in CF specialist nurse cover in the CF paediatric unit at Cork University Hospital (CUH). The CEO of CFI met with the CEO of CUH along with the consultants and the nurse manager. Parents using the service will be aware that there are a wider range of challenges for the unit, for example, the absence of a psychology service for children and young people with CF and the on-going challenges of working in a building that is not of an adequate standard for CF care. CFI is currently finalising a report summarising the issues raised and we will update you on further progress.

Launch of 'Stepping Up' – Transition Information Website

'Stepping Up' is a new website that will provide information for children and young people (aged 13-18 years approx.) who are preparing to make the move from child to adult healthcare services. The site is the first of its kind in Ireland, and aims to provide young people with a useful resource that will support them in preparing for and making the move. It was developed by researchers at the School of Nursing and Midwifery, Trinity College Dublin, with assistance from young people with long-term illness.

CF Ireland have been working with the researchers in an advisory capacity during the development of the website and two people with CF, Daniel O'Carroll and Bevin Murphy, feature in the video blogs that can be viewed on the website (see the Spotlight section of this issue of *Spectrum* where Daniel speaks more about transition).

SteppingUP.ie was launched by Alan Sothorn, Irish International Hockey Player and Ambassador for Diabetes Ireland, on Tuesday 3rd Dec 2013 at The Digital Hub, Crane St., Dublin 8.



So what are you waiting for – log on to www.steppingup.ie now to find out all you need to know about transition to adult healthcare services!

High Calorie Recipe Booklet for People with CF

This recipe booklet was compiled by the CF Dietitian Specialist Interest Group and produced by CF Ireland with the assistance of an unrestricted educational grant by Abbott Laboratories Ireland Limited.

The booklet contains recipes that are high in both energy and fat and are thus designed to promote weight gain in individuals with Cystic Fibrosis (CF). If you currently have an ideal body weight through your current dietary intake it may not be necessary for you to consume these recipes as it may result in excess weight gain.

The booklets, once printed, will be sent to each of the CF centres around the country and the pdf will also be made available on our website.

Alternatively please call us in the National Office and we would be delighted to send you out a copy.

With thanks to the CF Dietitian Specialist Interest Group for taking the time to compile this booklet, in particular to Ciara Howlett, Senior Clinical Nutritionist, CUH, and Marie Roddy, CF Dietitian, AMNCH, Tallaght.



Cork Physiotherapy Workshop

CF Ireland held the first regional physiotherapy workshop on Tuesday 5th November in Ballincollig, Co Cork. Claire Hickey and Pat Shanahan from the adult and paediatric physiotherapy teams in Cork University Hospital facilitated the seminar and covered a range of issues from the different physiotherapy techniques that can be used to the various types of equipment available. The benefits and importance of incorporating exercise into the whole family routine was also emphasised.

The feedback we received from members who attended this workshop was positive, but we will take any suggestions or comments into consideration before holding the next workshop in Galway in March 2014 (details below). This workshop will be streamed live so those who cannot attend will be able to tune in from the comfort of their home or watch the seminar online at a later date. The third physiotherapy workshop will probably be held in Dublin in May/June 2014.

Many thanks again to Claire and Pat for offering their personal time to host this very informative seminar.



Claire and Pat, CF Physiotherapists from Cork University Hospital who kindly hosted the workshop for us.



CF Ireland Annual Conference 2014 – Date for your Diaries!

The 2014 CF Ireland Annual Conference will be taking place on the 28th-30th March in Galway.

As with previous years we are planning on having informative and interesting seminars that will be beneficial to all of our members as well as a sociable weekend for members to have a break and to catch up with friends.

All CFI members attending the conference can avail of a special hotel rate that will help make the weekend not only enjoyable but affordable too! More information will be released early next year; in the meantime, if you have any more queries please contact Suzie directly on 01 4962433 or info@cfireland.ie

The staff of CF Ireland look forward to seeing you at the conference!

Cavan Thanksgiving & Remembrance Service

By Karen Keogan, Hon. Secretary Cavan Branch, CFI

The Cavan Branch of CF Ireland, which has been active in Cavan for well over three decades, recently marked the 50th anniversary of the founding of the Association in Ireland with a thanksgiving and remembrance ceremony in the Hotel Kilmore.

Present at the ceremony to commemorate the founding of Association in 1963 was founder Anne O'Dwyer and first CEO Bridie Maguire, and they were joined by branch members, healthcare professionals from Cavan General Hospital and families in the area who had lost PWCF.

Patsy Galligan, the first Chairperson of the Cavan Branch, said he was delighted to welcome so many distinguished guests to the event including National Chairperson John Coleman, Vice Chairperson Cyril Gillen, Brendan and Anna Hughes from Monaghan, Peter Hughes, Michael and Agnes Lannion from Drogheda and families from neighbouring counties.

Philip Watt, current CEO of CF Ireland, said that the Association had much to celebrate and be thankful for over the last 50 years, at both branch and national level, and he congratulated the Cavan branch on organising such an inspiring, moving and magnificent ceremony.

The ceremony included a Service of Light when families who had lost a family member to CF were called by Karen Keogan, Branch Secretary, to light a special candle of remembrance from the anniversary candle.

In the main address Felix Gormley sketched the evolution of the many changes over the last 50 years, particularly in the awareness levels, management and treatment of the disease. He was very happy with the completion of the first phase of the development of a shared care centre in Cavan General Hospital and looked forward to Cavan General Hospital having a critical role in the forthcoming National Clinical Programme for CF.

Ray Dunne, Chair of the Cavan Branch, thanked all who donated both their time and money over the years and in particular he said the branch was grateful to three groups who had each organised fundraising functions for over 30 years. He cited Ballinagh Concert Committee, Mountnugent Friends of CF and Co. Cavan Motor Club for special mention, acknowledging their exceptionally long and loyal commitment to the branch.



Front row (L-R) Karen Keogan, Hon. sec of Cavan Branch, Anne O'Dwyer Founder CF Ireland, Bridie Maguire, First CEO CF Ireland, Ray Dunne Chair Cavan branch. Back row (L-R) Lorraine O'Neill, Philip Watt CEO CF Ireland, John Coleman National Chairperson, Felix Gormley former Chair Cavan Branch, Patsy Galligan first Chair Cavan Branch, and Eileen Galligan.

"Congratulations to the Cavan Branch on organising such an inspiring, moving and magnificent ceremony."

Philip Watt, CEO, CF Ireland



A huge array of people turned out for the Thanksgiving & Remembrance Service in Cavan recently.

CF Ireland Christmas Cards 2013

Our annual CF Ireland Christmas Cards are now on sale!

This year CFI will be offering 6 different packs of Christmas cards. Each pack will have one design per-pack, containing 8 cards. Each pack costs €6.99 (not inc. postage).

They will be available to buy on our website www.cfireland.ie or alternatively pop into the office to buy them directly.

If you wish to sell some as part of a fundraiser or have a space to sell them somewhere please contact us on 01 4962433 or email info@cfireland.ie.

All proceeds will be going direct to vital CF services and support!



Children of Courage Award for Beth Byrne

The National Children of Courage Awards 2013 will take place in the magnificent setting of Clontarf Castle in Dublin on Saturday the 30th of November. The event will be hosted by Ray D'Arcy and Noel Cunningham.

Eight children who have shown extraordinary courage will be honoured at the event and will receive their National Children of Courage Award. Our very own Beth Byrne, a little girl with Cystic Fibrosis, is one of these children who will be honoured on the night. John Coleman, Chairperson of CF Ireland, will be attending the event in support of Beth.

Wishing Beth and her proud mum Rachel all the very best on the night from everyone at CF Ireland!



Martin Cahill: An Appreciation

By Philip Watt and Helen Whitty on behalf of all of us in CFI

Martin Cahill died on 10th of November 2013 after a brief illness borne with much courage. His Funeral Mass took place on Tuesday 12th of November in Ratoath, County Meath in the Holy Trinity Church on a beautiful sunny day. The service was attended by many family, friends and colleagues. Members of the Army Signal Corps carried Martin to the church and to his final resting place. His grandson, Seán played a favourite tune at his graveside. Martin was due to be conferred with a doctorate on 6th of December 2013, shortly before what would have been his 62nd birthday. His beloved daughter Audrey, who did so much to manage his caring when Martin became ill along with many other members of his close family, will be accepting the thesis in his place at a later date in the new Year.



Martin was Fundraising Manager with Cystic Fibrosis Ireland (CFI) for almost a decade and during a period of huge demands on our association. Martin contributed enormously to the work of CFI in this role, both in relation to fundraising and as a member of the senior management team in CFI along with his friends and colleagues. He travelled the length and breadth of Ireland in the cause of CF. CFI was represented at the funeral by all the officers, CEO and staff of CFI and many representatives from Branches across Ireland.

Martin previously worked for the Children's Medical and Research Foundation in Crumlin and in the insurance industry. For 21 years he served in the Irish army, rising to the rank of Company Sergeant he served in the Signal Corps in Ireland, London (attached to the Irish Embassy) and the Lebanon.

Martin had a very spiritual side to him which became apparent once you got to know him over a period of time. He loved music and poetry and sang and played guitar in a folk group for many years. Education was very important to Martin. He undertook a degree, masters and doctorate over a period of many years after leaving the army. His PhD thesis was on the topic of governance in the voluntary sector. Martin was very sociable and readily made many friends wherever he lived in Killcullen, in Ratoath and around Rathmines where he worked.

Martin was diagnosed with cancer in June 2013. He was given very supportive and expert care in St Vincent's University Hospital and Blanchardstown Hospital. One of his last wishes was to be able to die at home. This wish was granted by his doctors and the Meath Hospice Association were very supportive during this difficult time for Martin and his family.

We deeply miss our colleague and friend Dr Martin Cahill and we extend our deepest sympathies to his family, friends and colleagues at this very difficult time.

Exercise and Your Child

By Fiona Kennedy, CF Physiotherapist, National Children's Hospital Tallaght

Physical activity is considered by many physiotherapists to be as important as airway clearance in managing the symptoms of CF. It's something that we get asked about regularly at clinics as more families become interested in finding creative ways to encourage their children to get active and stay healthy. In this article, I hope I have compiled a useful list of the most common questions I get asked at the National Children's Hospital in Tallaght.

My child is only a toddler, what kind of exercise can he/she do?

At different ages some activities may be more appropriate than others for your child. This is because with normal human development we acquire new skills and abilities as our bodies and brains mature. These are known as developmental milestones. Your physiotherapist may check your child within the first year to make sure he/she is reaching these milestones. Here are some examples of what are considered age appropriate skills for normally developing children:

Within the first year:

- By 6 months many babies can roll, reach for objects and have good head control
- From 7-9 months many babies can sit independently or with minimal support, begin to crawl and some may begin to pull themselves up to stand
- From 10-12 months many babies can walk short distances supported by furniture or on their own

Most 2 year olds can:

- Walk
- Run slowly
- Throw a ball overhead
- Kick a football by running into it

Most 3 year olds can:

- Pedal a tricycle
- Kick a stationary football
- Jump with 2 feet together from the bottom step of stairs
- Catch a football and chase after it

Most 4 year olds can:

- Cycle & steer a tricycle
- Kick a moving football
- Use a racquet to hit a ball
- Stand on 1 leg for 5 seconds
- Hop a few times on their preferred foot
- Jump forwards and backwards

Most 5 year olds can:

- Cycle a bike
- Play a variety of ball games
- Stop a moving ball with his/her foot
- Skip without using a rope
- Hop on either foot

Most 6 year olds can:

- Bounce and catch a tennis ball
- Skip with a rope

(Courtesy of Eat Smart, Move More Campaign, Irish Nutrition and Dietetic Institute & Irish Society of Chartered Physiotherapists)

Every child is individual and some children develop slightly faster or slower than the timelines given here. If your child has difficulty achieving some of these milestones your physiotherapist may advise you about how you can help him/her with this.



What is the best type of exercise for my child?

The best type of exercise is the activity that your child enjoys doing. Fun is an important part of childhood and a major factor in keeping your child physically fit and healthy. Each child's interests and abilities may be different. If possible, try to expose your child to a variety of activities — this can include informal play such as chasing games, skipping, ball games or family walks or more formal activity such as sports clubs and teams. A good variety helps to reduce boredom and encourages children to keep fit.

Your child may have particular goals he/she wants to achieve and based on this, might need more aerobic, anaerobic or flexibility type training. It's a good idea to discuss these goals with your physiotherapist who will advise you on the right type of training to do. Weight bearing activities such as running, dancing and jumping can help stimulate the development of strong bones, while non-weight bearing activities like swimming may be excellent cardiovascular exercise. If your child has problems with their bone density you may need to discuss with your physiotherapist and dietician what the most suitable type of exercise is for him/her and they may need supplements such as calcium and vitamin D in their diet to help build strong bones.



What happens if my child becomes short of breath when they are exercising?

When we exercise, the body needs to get more oxygen to the muscles and tissues that are working hard. We tend to do this by breathing deeper and faster. Breathing faster is a normal response to exercise, however, if your child becomes wheezy, unable to catch their breath, reports chest pain or tightness or the shortness of breath does not resolve with rest or bronchodilators (inhalers) then you should consult your CF team or GP. If your child has been prescribed bronchodilators by the CF team it may be appropriate to take these before their match/activity to minimise wheeze. Ask your physiotherapist what type of Rating of Perceived Exertion (RPE) tool they can teach your child to help monitor breathlessness during activity.

My child coughs a lot during exercise — is this ok?

Breathing deeper and faster as a result of exercise can cause secretions which are sitting in the lungs to dislodge, move and be coughed up. Many children report that PE or playing chasing games can really help to clear their lungs. Although this can be common in CF, some children do not like coughing a lot in front of their teammates or friends. If your child is conscious of their cough it may be a good idea to do an extra session of airway clearance before their activity commences. Even performing huffs and coughs during breaks from activity may also help to reduce the build-up of mucus in the lungs while playing.



How long should my child exercise for and how difficult should it be?

Your physiotherapist may discuss your child's activity levels at clinic. Rather than focus on structured exercise such as sports training, many physiotherapists prefer activity as a broader term which incorporates informal play, household chores, structured training, walking to school and the general balance between activity and sedentary behaviour.

There are certain things to consider about activity:

- **Frequency** — How often your child is active
- **Intensity** — How hard your child is working
- **Time** — How long the period of activity lasts

Think **FIT!**

The National Guidelines on Physical Activity in Ireland recommends 1 hour of moderate to high intensity physical activity daily while older guidelines from the UK CF Trust (2005) recommend 30-40 minutes three to four times per week. In many families, a happy medium can be reached. Based on a variety of measures such as severity of disease, formal exercise tests, lung function trends or the presence of infection, your physiotherapist may advise certain alterations tailored to your child's needs. Teenagers often report during exam years it can be harder to participate in physical activity when there is extra homework or study to be done. Your physiotherapist will be happy to try to help you come up with ideas for keeping active and motivated during times like this as stopping exercise completely can result in reduced fitness levels.

Intensity of exercise can be estimated by using scales known as RPE scales — ratings of perceived exertion. Physiotherapists in different centres may use different scales as there are several available. A guideline for cardiovascular training is to train at 60-80% of maximum capacity — it is best to discuss this with your physiotherapist as this will be unique to each child.

(Incorporating exercise into the routine care of individuals with cystic fibrosis: is the time right?; Moran F, Bradley, J. www.expert-reviews.com 2010; Department of Health and Children, Health Service Executive (2009) The National Guidelines on Physical Activity for Ireland ; Cystic Fibrosis Trust Factsheet Exercise & CF March 2005, www.cysticfibrosis.org.uk)

Is there any exercise my child should not do?

UK CF guidelines suggest that certain types of weight lifting such as powerlifts, bodybuilding and maximal lifts should be avoided until skeletal maturity has been reached. It is advisable that any type of weight training be supervised to ensure correct technique and avoid injury. If your child has advanced liver disease or bone fragility your CF team may suggest that contact sports be avoided. Exercising during hot weather may lead to dehydration so it may be advisable to replenish fluids and salts lost due to increased sweating. If your child has urinary incontinence, they may be advised to reduce high impact activities such as jumping, running, situps until they have completed the necessary muscle training to help alleviate the problem.

With acute medical problems such as Pneumothorax, acute severe haemoptysis (coughing up blood) or joint pains your child may be advised by the CF team to stop exercising for a period of time.

(STANDARDS OF CARE AND GOOD CLINICAL PRACTICE FOR THE PHYSIOTHERAPY MANAGEMENT OF CYSTIC FIBROSIS, UK CF Trust 2013 ; www.cysticfibrosis.org.uk)

Why is it important for my child to exercise & play?

Exercise has many benefits and contributes to both physical and emotional development as well as complementing airway clearance. Physically we know that exercise can improve cardiovascular fitness, bone mineral density, motor skills, balance and co-ordination. Self-esteem and confidence grow with the acquisition of new skills and abilities through practice, while social skills and friendships develop as a result of team participation or completing tasks together. Some studies have shown that exercise tolerance is linked with survival.

Can my child exercise when they have a chest infection?

If your child has a high temperature or fever, exercise is not advisable at that time. It is important that if your child has symptoms of a chest infection that you seek advice/treatment from your CF team or GP. Your child may require antibiotic therapy. Activity levels may need to be modified during the period of infection as your child may be more fatigued than usual. You can discuss this with your physiotherapist as appropriate.

Tips for Getting Active & Staying Healthy

- Find an exercise buddy — someone who will go for walks, kick a football or go cycling
- Walking/cycling to school? Time yourself daily and see if you can beat your best time. If you normally get the bus, get off a couple of stops earlier and walk the rest of the way
- Get out and about as a family — long walks, playing football or cycling are great ways of spending time together as a family
- Use the stairs rather than the lift where possible
- Try getting more involved in housework or helping in the garden — exercise isn't always about playing a sport
- Look at the local paper for exercise classes or try some exercise DVDs
- Bad weather and can't get out? Set up an indoor obstacle course! Skipping, jumping jacks, running up and down the stairs, squats, lunges, burpees...
- Hard to motivate your child? Try making an exercise diary: your child can set weekly / daily targets and can tick these off everyday after achieving them
- Exam year? Maybe you can access an exercise bike — you can do your revision as you pedal
- **Don't forget the CFI exercise grant!! If you wish to purchase some exercise equipment or sign your child up for gym membership, the CFI offers a grant of €250 to PWCF under 16 year olds and €300 to those over 16. Look up the CFI website for more details.**



Sticky But Not So Sweet: The interaction of *Pseudomonas aeruginosa* with mucus from the CF lung

By Dr Marguerite Clyne, University College Dublin

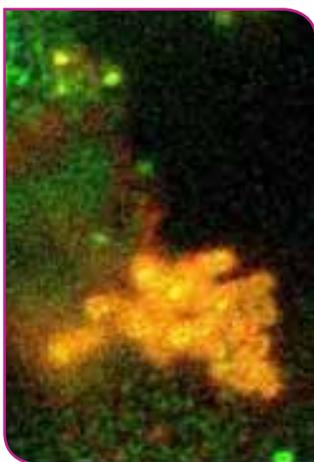
Work funded by Cystic Fibrosis Ireland and the Health Research Board aims to assess the effect of mucus on bacteria and how they interact with host cells in the lung and cause disease.

Bacterial infection of the respiratory tract is a major problem for people who have Cystic Fibrosis. The cells in the lung are covered in a layer of mucus, a wet, sticky and slippery substance that acts to protect the cells and trap foreign particles such as dirt and bacteria. These foreign particles are then removed from the lung by the beating of hairs called cilia on the surface of the cells that move the mucus towards the laryngopharynx, allowing it to be either coughed up or swallowed. However, in individuals with CF the mucus is dehydrated and very heavy, which prevents the cilia from beating and so mucus accumulates in the lung and then bacteria live in this mucus resulting in infection of the lower respiratory tract.



Dr Marguerite Clyne is currently working on a project funded by CFI and the HRB.

Due to the fact that the normal mechanism for removing bacteria is defective in the lungs of CF patients it is very difficult or even impossible to clear infections and so chronic bacterial infection of the airways occurs which is a major problem for people with CF. Dr. Marguerite Clyne and PhD student Mr. Patrick Moore, from the School of Medicine and Medical Science in UCD in collaboration with scientists and clinicians from Our Lady's Children's Hospital in Crumlin are studying how *Pseudomonas aeruginosa*, a bacteria commonly found in the CF lung, behaves when grown in the laboratory with cells that secrete mucus.



Results suggest that *P. aeruginosa* displays a particular predilection for mucin and that mucin alters the behaviour of the organism as when mucus was present the bacteria migrated towards it and aggregated but in the absence of mucus single bacteria are found scattered randomly throughout the cells. When bacteria are in close contact with other bacteria they are able to signal to one another and co-operate in order to establish infection. In addition, larger numbers of bacteria are found on cells with mucus than cells that don't produce mucus indicating that mucus promotes infection. Mucins are large proteins found in mucus that have sugars attached to them. Bacteria are known to bind to these sugars and this is usually how they colonize mucus. We have assessed the interaction of *P. aeruginosa* with mucins purified from the cells and with individual sugars. We are now using cells of CF origin to test the ability of these sugars to prevent the bacteria from colonizing mucus.

As the interaction of the bacteria with mucin is thought to be a key first step in establishing infection in the CF lung, identification of natural compounds, such as sugars, which could inhibit this interaction would be very useful. Sugars could either be used to decrease the incidence of infection and/or administered in combination with antibiotics to increase their effectiveness.

Attended by Katie Murphy, CF Ireland

The International Society for Pharmacoeconomics and Outcomes Research (ISPOR) 16th Annual European Congress took place in Dublin this year, which focused on 'Finding the Right Pieces for the Health Care Decision-Making Puzzle'.

The first plenary session of the event discussed the 'Patient and the Health Technology Assessment (HTA): challenges and opportunities'. The HTA is a systematic evaluation of the clinical effectiveness, cost effectiveness and/or the social and ethical impact of a health technology on the lives of patients and the health care system. The HTA ultimately informs the decisions made by health care policy makers — the HSE in an Irish context.



It is often argued that patients, or patient organisations, should play a more active role in HTA. However, given that reimbursement decisions in most European public health care systems are made from a national population perspective, what is the role of the individual patient viewpoint? The first plenary session of the ISPOR conference aimed to debate the role of the patient in the HTA process. The session consisted of four speakers;

- Dr Ed McKone (CF Consultant, SVUH) — Evidence for supporting reimbursement for a new Cystic Fibrosis drug
- Dr Michael Barry (NCPE) — Health Technology Assessment of the new Cystic Fibrosis drug
- Katie Murphy (PWCF, CFI) — Patient perspective on the new CF drug
- Minister James O'Reilly, TD — 'The Health Care Decision'

It was interesting to hear the wide variety of views of the speakers regarding the reimbursement of this drug. Although the health economists' primary objective is to seek value for money and affordability for new therapies/drugs, it was clear that all stakeholders recognised the need for more formal input from patients and patient organisations in the HTA process. Meaningful patient involvement in the HTA process has the strongest impact in highlighting patients' needs in terms of quality of life and the 'real life' impact of a new therapy. Current investigative tools do not fully assess the impact of a new therapy on a patient's life, and primarily looks at the clinical impact. For example, looking at improvements in lung function tests, and omitting equally informative details which illustrates the impact of a Kalydeco on a patient's life — fewer days missed from school/work, completing exams, socialising with friends, etc.

It is believed that a combination of informed patient involvement and clinical outcome reports would form a much clearer and broader picture of the 'true value' of new therapies like Kalydeco. It has previously been indicated that the NCPE plan to develop HTA training for patient and patient organisations to ensure patients participating in the HTA process are fully informed .

Given the ongoing development of new therapies in the treatment of Cystic Fibrosis — it is important to understand and be involved in the HTA process; something we here at CFI will certainly be working on.

To view a video interview with Katie Murphy at the ISPOR conference visit:
www.youtube.com/watch?v=CxitYELUNZo

Home Adaptation Supports for People with a Disability

Your local authority administers two schemes that provide support for families affected by a disability to carry out adaptations in the home to make it a more suitable environment for the person with the disability to live in.

The two schemes are the **Housing Adaptation Grant for People with a Disability** and the **Mobility Aids Grant Scheme**. You cannot apply for both schemes simultaneously. A brief overview of both grants is provided below but please contact your local authority for further information on application forms as they may not be available online.

NOTE: The budgets for these schemes are generally made available at the beginning of each year and once the budget is exhausted you must wait until the following year to be in with a chance of getting a grant (there may be a waiting list too). There can often be application deadlines depending on the local authority area you live in so we advise you to contact the housing grants department **now** for further information if you are thinking of applying for either of these grants in the New Year.



Housing Adaptation Grant for People with a Disability

You can apply for this grant if you need to make certain adaptations to your home, for example, getting an extension, adding a ground-floor bathroom or toilet, getting a stair-lift.

What is the grant worth?

You may qualify for 95% of the cost of the works (up to the maximum grant amount of €30,000). The proportion of the costs to be grant-aided will be tapered from 95% to 30% which will apply when household income is between €54,001 and €65,000.

NOTE: You cannot apply for this grant retrospectively or if building work has already begun — the grant must be approved before building starts.

How are applications assessed?

Applications are prioritised based on medical need and there are three different priority levels. The local authority might request an occupational therapist's (OT) assessment to support your application.

Is this grant means tested?

Yes — the total household income is assessed to find out if you qualify for the grant and the amount payable.

Mobility Aids Grant Scheme

The scheme provides grants for works designed to address mobility problems in the home. For example, the grant can be used for the purchase and installation of grab-rails, a level access shower, access ramps or a stair-lift.

What is the grant worth?

The maximum grant available is €6,000 and may cover 100% of the cost of the work.

How are applications assessed?

As for the housing adaptation grant, applications are prioritised based on medical need. The local authority might again request an OT assessment to support your application.

Is this grant means tested?

Yes — this grant is available to people with a maximum household income less than €30,000.

Better Energy Home Scheme

The Better Energy Homes Scheme provides grants to homeowners to improve energy efficiency in their homes. This scheme is administered by the Sustainable Energy Authority of Ireland (SEAI).

Grants are available for the following energy-saving work under this scheme:

Measure	Grant
Attic insulation	€200
Cavity wall insulation	€250
Wall insulation – internal dry lining	
- Apartment (any) or mid-terrace house	€900
- Semi-detached or end of terrace house	€1,350
- Detached house	€1,800
Wall insulation – external	
- Apartment (any) or mid-terrace house	€1,800
- Semi-detached or end of terrace house	€2,700
- Detached house	€3,600
High efficiency (more than 90% efficiency) gas or oil fired boiler with heating controls upgrade	€560
Heating controls upgrade	€400
Solar heating	€800
A BER assessment after works are done	€50

Will I qualify for the grant?

To qualify for a grant you must:

- Be the owner of a dwelling built before 2006
- Use a contractor from SEAI's registered list
- Have a BER carried out after the works are done
- Use a BER assessor from SEAI's National Register
- Apply for a minimum amount of €400 with your first application. You can apply for a number of grants under the scheme to reach the €400 minimum application amount but a BER grant cannot form part of this amount.

You must have grant approval before you buy materials or start any grant-funded energy-saving work. If you have already started work, you will not be eligible for a grant.

However, a 'before BER' can be done ahead of grant approval and could prove useful if you are uncertain about your energy-saving options or what to get done first.

How do I apply for this grant?

You can apply online or else download an application form from the SEAI website. Online applications will get a response within 3 working days. Postal applications will get a response within 20 working days.

For more information on the Better Energy Home Scheme:

- Locall: 1850 927 000
- Application Guide is available here: www.seai.ie/Grants/Better_energy_homes/Better_Energy_Homes_Application_Guide.pdf

NOTE: The Government recently concluded the award of the National Lottery Licence for over €400 million. Part of the €200 million to be invested from the sale of the National Lottery licence in 2014 will be allocated to the Better Energy Programme and 5,700 housing adaptation grants for older people and people with a disability will be granted.

Now could be a good time for PWCF to apply for the housing adaptation grant, the budget will be spent over a period of 3-5 years on the 5,700 homes. We encourage as many PWCF families to start who need adaptations to their homes to apply for this grant.

Claiming Tax Relief through the MED₁ form

By Tomás Thompson, CF Advocate and Eimear Higgins (PWCF)

Tax relief can be claimed by a tax paying individual in respect of health expenses paid on their own and any other individual's behalf. Relief is given at the standard rate of tax (20%) and is available on the total amount of qualifying expenditure.

Relief can be claimed for qualifying health expenses for up to 4 years past. Therefore, during 2013, you may claim for 2012, 2011, 2010 and 2009. After 31st December 2013, you lose the right to claim for 2009. **If you have never made a claim through the MED₁ you should try to do so before the 31st of December 2013 to get relief for the last 4 years.**

Relief can be issued in the form of direct bank payment or cheque if the individual does not include bank details with the claim.

The claim can be made either on a MED₁ form or on PAYE Anytime on the Revenue website (www.revenue.ie). The MED₁ form can be found either on the Revenue website or in any local Revenue office. Directions and information required to fill out the form are included on pages 3 and 4 of the application. Information required includes:

- PPS Number
- Bank details
- Income subject to PAYE of claimant (this could be found on a P60 or a P45 or could be obtained from the employer)
- Other income, not subject to PAYE, for example, taxable payments from the Department of Social Protection, investment/foreign income or foreign pensions received
- Receipts (it is not necessary to send these in with the claim, but they must be retained for a period of 6 years in the event of an enquiry)

The MED₁ form must be prepared and submitted separately for each individual tax year.

Additional information required to make a claim on PAYE Anytime:

- Registration and PIN number for PAYE Anytime (this can be requested on the Revenue website after clicking on the PAYE Anytime link)

For taxpayers who complete Form 11 (generally non-PAYE) the amount of the claim should be entered on Panel I on the form.

You cannot claim tax relief for any expenditure which:

- Has been, or will be, reimbursed by another body such as the VHI, Laya Healthcare, Aviva Health, the Health Service Executive or other body or person
- Has been, or will be, the subject of a compensation payment
- Drugs/medications above €132 (from 2012) per calendar month as these amounts are recoverable under the Drugs Payment Scheme



(DPS). Where an individual has been on drugs or medications which are outside the DPS, these should be claimed in addition to the €132 monthly threshold. The amount recoverable for dates prior to 01/01/12 are as follows:

» 01/01/09 – 31/12/09: €100

» 01/01/10 – 31/12/10: €120

» 01/01/11 – 31/12/11: €120

- Relates to routine dental and ophthalmic care (Form MED2 is used for these)

Types of qualifying health expenses

Only health expenses incurred in the provision of 'health care' qualify for tax relief. For the purpose of claiming tax relief 'health care' means prevention, diagnosis, alleviation or treatment of

- An ailment
- An injury
- An infirmity
- A defect
- A disability (PWCF come under this section)

This also includes care received by a woman in respect of a pregnancy as well as routine maternity care.

Qualifying health expenses include:

- Doctors' and consultants' fees
- Diagnostic procedures carried out on the advice of a practitioner
- Drugs or medicines prescribed by a doctor, dentist, or consultant
- Maintenance or treatment in a hospital in connection with the services of a practitioner
- Diagnostic procedures carried out on the advice of a practitioner
- Travel and telephone relating to health issues (see across for further information)
- Diabetic/coeliac foods and products (doctor's letter required)
- Supply, maintenance or repair of any medical, surgical, dental or nursing appliance used on the advice of a practitioner (Appliances can include glucometer, hearing aids, exercise bicycle, orthopaedic bed or wheelchair. Appliances do not include cars for disabled persons, construction work, or telephone installation)

- Laser vision correction surgery
- Physiotherapy treatment
- Orthoptic treatment
- Speech and language therapy carried out by a Speech and Language Therapist for a qualifying person

Note: Speech and Language Therapist means an individual approved by the Minister for Health and Children and the claim must relate to a person under 18 year of age or if over 18 the individual must be receiving full-time instruction at any university, college, school or other educational establishment.

- Educational psychological assessments for a qualifying person as outlined above for Speech and Language Therapist. Note the Educational Psychologist must be entered on a register maintained by the Minister for Education and Skills
- Certain items of expenditure in respect of a child suffering from a serious life threatening illness
- Kidney patients' expenses (up to a maximum amount depending on whether the patient uses hospital dialysis, home dialysis or CAPD).
- Specialised dental treatment
- In vitro fertilisation (IVF)

Travel

Tax relief may be claimed in respect of the cost of transport by ambulance. Where regular continuing treatment or consultation is required and the patient (PWCF) has to travel long distances, tax relief may be claimed in respect of the cost of travelling other than by ambulance. If a private car is used, the cost of travel is determined at a rate as per kidney patients' expenses. This rate is €0.27 per mile or €0.17 per kilometre. No relief is available for the car parking fees. However, relief will not be granted for minor local travelling expenses or occasional travelling (e.g., to undergo an operation {unless by ambulance}).

For example, the following qualifies for relief:

1. The cost incurred in transporting (unlimited journeys) the child and accompanying parents or guardians to and from hospital

2. The cost incurred by the parents or guardians of the child in visiting the hospital when the child is an inpatient where such trips are shown to be essential to the treatment of the child, e.g., overnight accommodation.

A round trip from Mayo to Dublin for treatment is approximately 450km. This would amount to $450\text{km} \times \text{€}0.27 = \text{€}122$ per trip. This would be filled into Section (J) 'Other Qualifying Expenses' in the MED₁ form.



Telephone

Where the child/adult PWCF is being treated at home, a flat rate to include telephone rental and calls may be claimed where the expenses are incurred for purposes directly connected with the treatment of the patient.

The rates are as follows:

- **2009** — €301
- **2010** — €300
- **2011** — €310
- **2012** — €305

If you have any question in relation to the information above please contact CF house at info@cfireland.ie

CF House would like to thank Eimear Higgins (PWCF) for her help in compiling this information, which will also be made available as an standalone information sheet shortly

Reaching Out

By Mary McCarroll, Secretary of the Eastern Branch, CFI

The Eastern Branch of Cystic Fibrosis Ireland was set over 40 years ago, which makes it one of the oldest serving branches of the Association.

The Branch is made up of a committee of people who are dedicated to help and support people with Cystic Fibrosis and their families. We hold information nights for members on topical issues and were involved in hosting the Annual Conference in Dublin this year. We also arrange parent support evenings where parents can chat more informally, share experiences and learn from one another. Fundraising is crucial to sustain the activities of the Branch and the Association as a whole, but it is by no means our sole focus — ultimately we are here to provide support to you, our members.

Four committee members of the Eastern Branch also serve as Directors on the Board of CF Ireland. It is through these four committee members that we can communicate any ongoing concerns or serious matters you are experiencing to Board level. This can range from hospital facilities for people with CF to issues around entitlements. The Branch acts as a very important medium in this respect as it is the channel through which your voices can be heard. This is why it is so important for us to be aware of what is going on in your lives, your needs, how we can help, and what the Association can do as a whole to support you more.

New delegates are elected on an annual basis at our Eastern Branch AGM. We are always looking for new members to get involved — everyone is welcome. If you would like us to hold an information evening on a particular subject next year, come along and let us know. The next AGM will take place in February 2014 (details to follow in the next issue of *Spectrum*).

With all the great developments that happened in St Vincent's in recent years, and the length of time it took to get suitable en-suite rooms in place, the Eastern Branch have recently begun focusing on facilities for people with CF in Beaumont Hospital. Beaumont Hospital is one of three major centres in Ireland for adult Cystic Fibrosis care, yet at present there are only 4 inpatient rooms for CF patients. In June 2011, CF Ireland commissioned a needs assessment for dedicated CF inpatient beds in Beaumont Hospital. The report revealed that 12 CF inpatient rooms are needed as a matter of urgency in the hospital for the 120 adults with CF who attend Beaumont. It is estimated that €2.5 million is needed to complete the project. Although it is unlikely that we will be able to raise this figure alone, the Eastern Branch began to focus on a fundraising campaign to kick start the project.

In December 2012, a meeting was held in the CFI National Office which was attended by myself, James and Lorraine Downes, Tom Bishop and Martin Cahill (RIP) — Brendan Lonergan joined us by teleconference. Brendan coined the term 'Beds for Beaumont' and James came up with the idea of the Head to Head walk from Howth to Bray.

Over the following months, regular meetings were held in preparation for Head to Head. The route was walked, driven and planned in the finest of detail. Safety was of the utmost importance. On Sunday 29th September, the day had finally arrived after many sleepless nights. Groups gathered in Howth and were greeted with perfect weather conditions — the sun was shining and the atmosphere was electric. People with CF, families and friends from all over the Eastern Branch came — the Bentley's from Rush also arrived by minibus! Members from the multidisciplinary team in Beaumont also gathered and everyone set off on the long walk to Sandymount or, for those braver souls, all the way to Bray.

Approximately 200 people took part in Head to Head, which ran without a hitch. The Eastern Branch was overwhelmed by the support received as well as the enthusiasm from everyone who participated.



The event would not have been possible without all the volunteers who dotted the route, many of whom were work colleagues, family members and friends. A special acknowledgement also goes to Tom Bishop who brought great fun to the day. Many thanks also to Phelim O'Neill and colleagues at St John Ambulance, Paul Claffey, Sergeant Bobby Blake and colleague Emma from Crumlin Garda station, all of whom provided essential logistical and safety support on the day. Musgrave and Fyffes also very kindly donated refreshments to participants. Without the expertise and professionalism of Rosie Begley, Fundraising Co-ordinator CF Ireland, this event would not have been possible. Martin Cahill was also with us from the very start of this initiative – we would like to take this opportunity to extend our deepest sympathies to his family, and we will miss him as a friend and a colleague.

Beds for Beaumont has raised over €55,000 so far, with over half of this coming from Head to Head. We hope that Head to Head will become an annual event but this very much depends on volunteers and peoples willingness to get involved. Please do get in touch with me if you are interested in participating or volunteering in this or any other event in aid of Beds for Beaumont. It is so important for us to support one another and the Eastern Branch is committed to providing advice and guidance to the broad spectrum of our membership. In order for us to do this effectively, we must be aware of your needs and what you want from us as a Branch. We would love to see you at our next meeting in February – everyone is welcome.

Finally, I would like to thank and acknowledge Eastern Branch committee members, past and present.

Transition to Adult Clinic — Nothing Has Changed

By Daniel O'Carroll, PWCF aged 24, Dublin

Well hello there, not many of you would know me, my name is Dan O'Carroll and I am a PWCF, and I am just going to give you a brief heads up of the transition clinic and how my life has adapted with CF since I left Tallaght Hospital in 2008, and also how no matter what CF has never held me back from doing anything.

I started discussing the possibility of the transition clinic (from Tallaght Hospital to St Vincent's University Hospital) in about 2005. I was much underwhelmed in what I discovered; no private rooms for in patients, new medical staff, a completely new environment and no designated Cystic Fibrosis clinic for adults. Due to these issues, my family and I decided on making the transition as late as possible, in the small chance of these problems being eradicated in time.

By the time I transitioned, it was early 2008 (yes, I got to annoy the Tallaght staff for another 3 years!) and unfortunately for me, the week of my first appointment in Vincent's, Joe Duffy and Cystic Fibrosis was hitting the news and the issues that I was originally worried about had arisen. This seriously opened my eyes, and made me very nervous as there was no alternative in not taking 'the big step'.

Transition required two different appointments. The first appointment was in the hospital where I was attending, and following this, a final appointment in the hospital where I was getting transferred to. Both sets of staff (nurses and doctors) were present throughout these appointments to help with any difficult or challenging questions.

"My advice would be for anyone who will be transitioning soon — get into the habit of showing more maturity and accountability for your illness"

When I arrived for my transitional clinic in St. Vincent's, I was actually stunned because I had no clue where to go, or what to expect. All that I knew was that I was getting assessed by the doctors and nurses. Eventually (after asking the reception) I found my way to the out-patients department where I was quickly called. I am sure patients will know from paediatric clinics that a family member attends with the patient, I didn't even think of this issue, but was told I had to go in by myself. However, looking back I was a bit stupid to think my Mammy could hold my hand when I was 19 years old!

Thankfully since then, Vincent's has now got fantastic facilities, and the staff as I expected are nothing short of fantastic, helpful and always willing to do their best for you, no matter how big or small. Since my transition, I have been admitted to hospital twice for IVs. The first time was back in 2009, I won't lie when I say it was one of the worst experiences of my life. I was stuck in a ward with geriatrics. I don't think I need to explain more. However, I was admitted about this time last year, and amazingly, I actually enjoyed my week stay! I had my own en-suite room, my own treadmill, an interactive touch screen TV, and to top it off — my own 40 inch plasma HD TV, which of course, like any man with a brain; I hooked my PlayStation 3 up to! All that I was missing was a pint of Guinness (unfortunately I wasn't served that for my dinner). It was more of a hotel than anything, in fact, next time I want a cheap free holiday I may as well pretend I am sick ;). The new facilities are nothing short of incredible, so I beg anyone approaching transition not to worry about the services provided.

Looking back, do I miss Tallaght? Yeah, sure I do, however that is only because I would live closer to Tallaght than Vincent's! If proximity and location is the only drawback about my transition to the CF adult clinic, then I don't think people have much to worry about.

A new website called 'Steppingup' has been set up and will be launched in the coming week (see Latest News section for more information). It will provide information and resources for young people, with long-term illnesses, who are moving to adult health care services. I was asked to help give my thoughts on the transition clinic as I had moved on from the paediatric clinic a long time now and felt that my opinions and advice could help people. I was interviewed and gave every single bit of helpful information as I could. The main aim of this site is to educate and inform the PWCF and parents on how the transition worked, and if there are any tips that someone who has gone through the system can share with younger people.

The video will be uploaded to YouTube and to the site itself. I would advocate any person and parents of PWCF who are about to go through the transition clinic to watch it as it does cover everything. I touch upon how as patients grow older it is up to them to take control of their medication and physiotherapy and any other relevant duties that need to be done. As soon as one reaches the adult clinic, it is advised that these patients have sole responsibility for medication, appointments etc. Thankfully for myself, I adapted to this change way before I had actually transitioned, which gave me a massive advantage and eliminated a lot of the problems that some patients may encounter. My advice for anyone transitioning soon would be to get into the habit of showing more maturity and accountability for your illness.

I would recommend patients to take control of their medicines for a start; be aware of what is needed in the chemist, know when to take certain drugs, and how to properly administer the medications etc. These little steps that I have acquired at a young age has boded well and always stuck by me to this day.



Dan doesn't let CF get in the way of friendships and nights out.



Dan on one of his many trips away with friends.

I have never let Cystic Fibrosis take over my life, nor have I let it get in the way of friendships and relationships etc. I am not vocal about my CF; I don't complain or look for sympathy. For example, if the lads are looking to go to the pub, yes I will kill the myth — I do drink, I go to the pub, and you know what, I bloody well enjoy myself.

I have travelled to many countries by myself since my transition — UK, Belgium, Spain, Portugal, Italy and Germany just to name a few. One of my all time trips away was Munich, for Oktoberfest (6 months after I transitioned) with some of the lads. Every time I go away I bring my big nebuliser, needles and syringes and all my tablets. I just see them as my 'gadgets' or my 'toys', and an extra bag to carry on board. Now it will be even easier for me to travel as they have recently introduced nebulisers in the form of an inhaler and capsules. The little things like that make ones life much easier, however, I have been used to dragging around the big bag of medicines for a long time now.

Throughout all these trips, transitions, and stories, I have graduated from UCD with a degree in Sports & Exercise Management, I am currently coaching a local football team and am working in an IT company. Nothing has stopped me from fulfilling goals, and transition is just something that we have to do.

I hope some of this information has been helpful for fellow PWCF and parents alike — visit the website, listen to opinions and most of all don't be afraid of the change. The transition is just part of the cycle of a PWCF and although a big step there is nothing to worry about, as all that there is now is more responsibility on yourself and a sign that you have control of your life.

Get Your Workplace Involved!!

Most companies and organisations have a social responsibility department which very often can provide support and/or funds for charities and not-for-profit organisations nominated by their employees. It can be quite difficult to become the 'Charity of the Year' for organisations without being nominated internally so we are hoping our members and supporters will investigate their workplace policy and work with CFI to establish new and exciting partnerships.

There have been many members who have nominating CF Ireland in their workplaces through corporate social responsibility programmes over the past year, and we would like to thank them most sincerely for their support and generosity; here are a few examples.

Joe Nangle, Deputy Manager, Schuh

"I wasn't aware that Schuh, the retail company I was working for, had a charity trust fund for which employees could nominate a chosen charity to benefit, until my manager mentioned it to me having noticed my fundraising efforts for Cystic Fibrosis. She then encouraged me to nominate CFI. There was an enormous application form which was slightly off-putting but the staff at CFI carried out the process from start to finish and we were delighted to learn that €5,000 was donated to CFI. It was the easiest fundraising I have ever done – certainly beats climbing Croagh Patrick in my bare feet!! I would definitely encourage everyone to enquire whether their workplace has a charity of the year or possible funding opportunities and get CFI nominated! The staff at CFI were incredibly helpful and professional in the application process and I will certainly be keeping an eye out for any more opportunities!"



Joe has found an easier way to raise money for CF Ireland than climbing Croagh Patrick barefoot!

Marie Duffy, McCabe's Pharmacy

CF Ireland are McCabe's Pharmacy Charity of the Year 2013 and it has been a truly wonderful and rewarding partnership.

"My daughter Grace was diagnosed with Cystic Fibrosis in November 2011 through the newborn screening test. As for any parents, finding out this life changing news was a real rollercoaster for me and my husband Niall. The shock, disbelief, denial, blame and grief were just some of the emotions we endured in the first few months post-diagnosis. Once I got my head together I knew I had to do something to make a difference to people with CF.



Marie with her daughter Grace and Rose of Tralee 2012, Tara Talbot.

I approached the Managing Director of McCabe's Pharmacy who was incredibly supportive and said she would love to help. I then phoned the late Martin Cahill and we got the ball rolling. Within a few days we had a collection box at every single till point in the company. We sold trolley coins during National Awareness Week, we gift wrapped presents for donations at Christmas, staff throughout all stores got involved for awareness week running events such as raffles, cake sales, cyclatons and all day treadmill running, to name but a few! McCabe's are also offering the flu vaccination free of charge to PWCF and their families.

I am delighted that McCabe's Pharmacy has chosen Cystic Fibrosis Ireland as their charity of the year – it means a lot to me and my family". Marie has worked for McCabe's Pharmacy for 14 years.

Philip Ahearne, Investec

The Investec Charity day, which has its origins with NCB Stockbrokers, celebrated its 10th anniversary with an enormously successful day on Thursday the 12th of October. 4 charities had been chosen to be beneficiaries of the day, Pieta House, The Ross Nugent Foundation, Laura Lynn and CF Ireland. The Investec group has a long established Corporate Social Responsibility (CSR) policy and has always been very conscious of its CSR responsibility.

A considerable amount of planning went into the day with the organising committee working diligently behind the scenes to ensure that a full schedule was prepared for the day. A broad range of activities were arranged with something for all tastes and abilities. Cake Sales, Book and DVD Sales, Table Tennis Tournaments, Playstation events, Giant Jenga games, two different cycling competitions, shoe shine (by a Senior Executive) and a Twister competition were just some of the events on the schedule for the day. All staff participated at different stages while continuing to work at their day job so that customers were not adversely impacted.



The office was decked out in balloons and banners and staff wore specially designed t-shirts highlighting the day and the four charities being supported. Local businesses rowed in with donations of coffees, muffins and other treats and customers of the bank made very generous contributions through donations and prizes for both the raffle and auction.

Each floor of the Harcourt building buzzed from 9.00am as the competitive events commenced. The sounds of ping pong balls, foosball tables whirling and an abundance of sausage rolls and cakes certainly set a different tone in the office for the day. From word go you could sense the pride the staff had in being involved in this day. Investec acquired NCB Stockbrokers recently and this event proved to be hugely successful in integrating the two teams. Despite the competitiveness of the various events, it proved to be a great format for people to get to know one another and to meet one another in a slightly different environment. There is nothing like a game of twister to properly introduce people to one another!!

A number of staff from CF Ireland paid a visit to the office on the day. Philip Watt, Rosie Begley and Katie Murphy (PWCF) came along to observe the activities, walk to office and to talk with the participants about what CF Ireland do. Katie had visited the office prior to the day and had presented to the Investec team on CF Ireland. To say she made an impact would be a massive understatement. She spoke eloquently about the challenges faced by people with CF and spoke also of the challenges faced by CF Ireland and the various CF treatment centres particularly in the current climate of cut backs. But, being conscious of sounding too negative, she also spoke about Kalydeco as a positive development. Her words and the manner in which she presented them were very moving and hugely inspirational.

At the end of the day a sum of €160,000 was raised, with each charity to receive €40,000. Investec are delighted to make these donations and the Executive and the staff thoroughly enjoyed the day and the outcome of the efforts and activities undertaken!

The run up to Christmas is always a very busy period for the fundraising team at CF Ireland.

In addition to events running during the festive season, we are glad to report that a lot has already been planned for 2014. Please remember, if you require further information on any event below, or would like to talk about organising your very own event, please get in touch with us by emailing fundraising@cfireland.ie or call 01 4962433.

Community Events

EMS White Collar Boxing Night – 30th November

Two amazing Frontline Emergency Teams came together to create a night not to be forgotten in aid of an amazing cause!

The Paramedic Staff of the National Ambulance Service took on the Fire Fighters of Dublin Fire Brigade in an EMS White Collar Boxing Event in aid of Cystic Fibrosis Ireland. This event took place on Friday 29th November in The Living Room, Cathal Brugha Street, Dublin. The event was opened by Jim 'The Pink Panther' Rock, former IBC World Champion. Twelve fights took place on the night, a mix of both men and women.

If you would like to support the event but couldn't attend you can make a donation to CF Ireland quoting EMS White Collar Boxing (www.cfireland.ie/index.php/donate).

Festive Fillies

The ultimate girls night!

The Festive Fillies 6th Annual Christmas Banquet took place on Saturday 30th November 2013 at the Tower Hotel, Waterford. The event has raised over €110,000 for various charities in the past 5 years. This year proceeds will be given to 10 charities, including Cystic Fibrosis Ireland.



Music was performed by '50 Second Street', a raffle was held with prizes worth €10,000 and much more! Reception was at 7pm, dinner at 8pm, dance till late. Contact Susan on 087 1301059 or Helen on 087 6181847 to find out more!

Ideal for Christmas parties! So get your glitz and glamour ready ladies and enjoy one of the best Christmas nights of the year!

Bag Sale – 1st December

A Bag Sale organised in aid of Cystic Fibrosis took place on December 1st from 1pm to 6pm in the Tolka Rover Sports Campus, Griffith Avenue, Glasnevin, Dublin.

Hundreds of bags of all shapes and sizes were on sale! For information please contact Lorraine at 085 1013543.

Christmas Wax Night – Saturday 7th December @ 9pm

Another exciting and unmissable event coming up is the Christmas Wax Night. The event will take place in The Round O Bar, Navan, Co.Meath [w:www.theroundobar.com/default.html](http://www.theroundobar.com/default.html)

The night will also include a Big Raffle & Auction. Location is The Round O Pub, Navan, Co Meath. Do you want to get involved or receive further info? Please contact Pamela: 087 3911105.

Sponsored Chip Shop Challenge 2013

Support Joseph Doyle (PWCF) in Wexford who will be doing a fast in aid of Cystic Fibrosis.

Joseph has recently undertaken a 2 month challenge to raise funds: his original challenge will see him abstaining of junk food for 2 months.

Challenge started at 1pm on November 3rd and will be ongoing until January 3rd. You can sponsor Joseph online at www.cfireland.ie. Good luck Joe!

Becky's Ball – February 15th

The organisers of Becky's Ball would like to invite you to join them for a Valentine's to remember, in aid of Cystic Fibrosis Ireland.

On the 15th of February, the Castleknock Hotel will be host to a Valentine's Ball, organised in honour of Becky Jones (RIP). The ball bearing her name couldn't be anything but a fun, slightly out of the ordinary, but, above all, a very classy affair.

The evening will begin with a wine reception, followed by a three course meal set against the backdrop of a special guest live band. Guests will be given the opportunity to take part in an auction and a raffle which promises very enviable prizes. All-inclusive tickets for the ball are available for €70, and all proceeds will go to CF Ireland.

It will be an affair not to be missed, get you ticket by contacting Jill at beckysballcf@gmail.com.

Women's Mini-Marathon, 2nd June 2014

Mark it in your diary ladies, the date for the 2014 Flora Women's Mini-Marathon is 2nd June. Keep an eye on our Facebook page and www.cfireland.ie in the New Year with information on how you can be part of it. Here are the banking details for those yet to lodge their funds from 2013:

Bank: AIB

Account Name: One in One Thousand

Sort Code: 93-10-71 (add name to narrative)

Send a cheque to One in 1000, CFI, 24 Lower Rathmines, Dublin 6 (payable to One in 1000)

Make an online donation at www.cfireland.ie (add One in 1000 to narrative)

For any queries, email runningforcf@cfireland.ie or Lo Call 1890 311 211

National Awareness Week 2014

Our 65 Roses National Awareness Week 2014 will take place from March 28th to April 4th.

We would like to invite everyone to organise their very own 65 Roses event during the month of April, and acknowledge those who have already rolled up their sleeves and started thinking and planning some amazing initiatives!

In addition we would like you to let us know if there is a local shop you would like to get involved in the sale of our emblems. Please get in touch, as this is the right time to start booking venues, shops etc to make this year another great one!

Challenges & Events

If you would like to take part in any of the challenges, please register online and contact us for your sponsorship pack.

Santa Skydive for Cystic Fibrosis – 14th & 15th December

Best of luck to all our participants who are braving a Skydive dressed as Santa and raising funds for CF at the Irish Parachute Club Co Offaly.

Skydives are a very popular and fun way to raise funds with friends. Contact us for further info on how to organise a jump.



Hell & Back Titan – Sunday 26th January 2014

Join Team CF Today!

Register at www.hellandback.ie and contact us for a sponsorship pack.

London Marathon 2014 – 13th April

Few places are still available for London Marathon. Package for a fully comprehensive tour including race entry is €2,000. Act fast and book your place before it is too late.

Walk to the Sound of Music in Austria for Cystic Fibrosis

We are delighted to introduce our International Fundraising Walk, which will see a group of willing walkers travelling to Austria in September 2014. The walk which is an annual event will raise much needed funds towards research and support services for people with Cystic Fibrosis and their families.

The walk will take place from September 20th – 27th 2014 and the group will head to the home of the much loved Sound of Music.

Austria will offer not only amazing scenery, but also fantastic company. The Patron of the Walk, singer Mary Duff, will be joining the group in Austria, for what it will be a very exciting and musical experience.

For a taste of what you can expect and for further details, check out the brochure enclosed in this issue of *Spectrum*.

Total cost per person €2,900 (single room supplement available on request).

Kilimanjaro Challenge 2014

One challenge proving to be extremely popular is our Kilimanjaro Trek 2014.

The group is due to depart on October 15th for a fully comprehensive 10 day tour. Once again get in touch to get further details on this challenging event.



50th Anniversary Initiatives

Gerry Walker: 50 Years 50 Peaks Challenge

Well done to Gerry Walker for completing the 50 years, 50 peaks challenge in 6 months and 1 day which began in April 2013. The challenge involved climbing the 50 highest mountains in Ireland within the 50th Anniversary year of CFI.

"It was a challenge well worth doing. It brought us to out-of-the-way peaks we had never been on before and brought me back to many I had scaled up in my thirties before CF really got a hold," said Gerry.

Donations can still be made at: www.mycharity.ie/event/50years50peaks

All funds raised will be used by CF Ireland to fund research and for patient support services. Gerry can be contacted at 087 7686518.

50th Anniversary Appeal: Emergency Call for Cystic Fibrosis Ireland

On behalf of CFI we would like to thank An Garda Síochána & Fire Services who took part in organising events and raising funds for our 50th Anniversary Emergency Call for Cystic Fibrosis this year. Three Garda Stations and one Fire Station were involved (see below) and awards will be presented in December.

- Wicklow Garda Station raised €6,227.51 from S19 Cycle on 20th July
- Bridewell to Bridewell Station raised €7,000 from their Cycle from Dublin to Cork on 5th & 6th Sept
- Kildorrery Garda Station, Co Cork raised €2,255 from their Top to Toe Challenge on 19th October
- Fire Fighter Calendar for Cystic Fibrosis



S19 Cycle participants on 20th July.



Top to Toe Challenge participants.



S19 Cycle cheque presentation.



Top to Toe Challenge.

Fire-fighters in Galway City and County have got together to produce a 2014 Charity Calendar for Cystic Fibrosis Galway Hospital Project. Every year the Galway Fire Service Sports & Social Club undertakes projects to support a number of local Charities. This year the Cystic Fibrosis Galway Hospital Project will be the beneficiary of this event. The Unit based in UCHG cares for 69 adults and children with Cystic Fibrosis, all proceeds from the sale of the calendar will go to the Charity and help upgrade the facility there.

All the Fire-fighters in the calendar are currently serving with the Galway Fire & Rescue Service either in Galway City or County with most of the shots taken in the City Fire Station along with some outside shots incorporating a couple of local Galway landmarks.

The Calendar is available to purchase at www.fireandrescuegalway.com priced at €5.00. Visit Galway Fire-fighters Charity Calendar 2014 on Facebook.

Well done to everyone, great work!



Corporate

Do you work for a large organisation or business and would like to support CFI in your?

If there is anyone who would like to find out more about Corporate Social Responsibility or would like to nominate CF Ireland in their workplace, get in touch now by calling CFI on 01 496 2433 or email kmurphy@cfireland.ie.

Support McCabe's this Christmas!

Please support our friends at McCabe's Pharmacy this Christmas who are fundraising once again for CFI with a gift-wrapping initiative. When any customer buys a gift in McCabe's Pharmacy, staff will gift-wrap it in return for a donation towards Cystic Fibrosis.

CoziDry™

We are delighted to announce CFI was chosen as charity of choice for 2013 – 2014, with which we will receive a donation from each sale of this new brand CoziDry™.

Emily Godson is the brainchild behind the product – "Besides losing a friend/work colleague to CF, I also thought your charity was a perfect choice considering the aim of the product; which is to keep a baby's chest 'dribble dry' when they are drooling and/or teething and positing."

CoziDry™ is a new concept in babywear, specifically designed to help protect baby's skin from the irritation and damp caused by baby drool especially when they are teething using the latest nano-fabric technology.

Share Cozidry info with your friends, on Facebook or follow them on twitter @cozidry.

To find out more about the benefits of Cozidry and support Cystic Fibrosis, please also check out the website on www.cozidry.com



The advertisement features the McCabe's Pharmacy logo at the top right, which includes a red cross and the tagline "ADVICE YOU CAN TRUST". The main heading is "Charity gift wrap service" in white text. Below this, it says "Christmas gifts beautifully wrapped with a bow for a donation to the Cystic Fibrosis Ireland." The central image shows a white gift box with a red ribbon and a red bow, set against a dark red background with sparkling light effects. To the right of the box is a white card with the Cystic Fibrosis Ireland logo, which includes a green leaf-like symbol and the text "Cystic Fibrosis Ireland" and "50". At the bottom of the advertisement, a white text box contains the following text: "When any customer buys a gift in McCabe's Pharmacy this Christmas, staff will gift-wrap it in return for a donation towards Cystic Fibrosis Ireland."

Investec Charity Day

The good folk at Investec decided in early October to donate all trading commissions from its Institutional Equities trading desk for one day 'Charity Day' which also included raffles, games, and more. Cystic Fibrosis Ireland received €40,000, what an amazing achievement!

See Event Focus section for more details.

Thank You

Huge thanks to everyone who contributed by organising and/or supporting our fundraising activities throughout the country.

Lecarrow Run

In September a presentation night was organised following the Run, Walk & Crawl event in Lecarrow held on 30th June. This very enjoyable and successful event was supported by over 700 participants and will be repeated again in 2014.

We congratulate Keith, Lorraine & Claire who organised this major event.

The Branch is also delighted with the fundraising by the Athlone Fire & Rescue Services who held a car wash event in Athlone where they collected €2,700, and which was presented to the Branch.

Lanesboro Triathlon Club swim for CF Ireland

The Lanesboro Triathlon club have raised over €7,500 in aid of Cystic Fibrosis Ireland. Earlier this year, the club organised a 3 kilometre sponsored swim down the river Shannon. Over 50 swimmers from the locality including members of neighbouring Longford Tri Club undertook the swim and helped raise funds for CF Ireland.

The club decided to undertake the swim as a way of contributing to a worthwhile charity. "As a club we rely hugely on the support of volunteers to help stage our annual Two Provinces Triathlon and it was important to us to be able to stage a charity event which benefitted a worthwhile cause and recognised the support which we get from the community throughout the year" said Brendan O'Sullivan, Chairman of the Lanesboro club for 2013. "We chose CF Ireland as the beneficiary of the swim sponsorship as one of our member's children was diagnosed as having CF late last year."

Seán Farrell whose son John was diagnosed with CF said that the support of fellow club members and local people towards the charity was hugely appreciated. "CF Ireland does fantastic work on behalf of people in Ireland with this disease including the provision of dedicated CF facilities in hospitals throughout Ireland. They also provide funding for scientific research aimed at understanding, managing and treating Cystic Fibrosis," he said.



Keith Reynolds, Lorraine Reynolds, Michael Coen, Amy Reynolds, Gerry Johnson and Claire Kelly/Athlone Fire and Rescue Service.



Athlone Fire & Rescue Services collected €2,700 for CF Ireland.



Seán Farrell, Cormac Hoare, Andree Gallagher, Emer Casey, Niall O'Donohue and Seán Mimmagh, all of whom helped to organise the Lanesboro Triathlon Club swim.

The club recently presented the sponsorship proceeds from the swim to Cystic Fibrosis Ireland prior to the club's annual general meeting. Brendan O'Sullivan, 2013 chairman of the Lanesboro club is pictured presenting the sponsorship cheque to Esther L'Estrange, board member of CF Ireland.

Houghton Mifflin Harcourt Cake Sale

CFI was delighted to be joined by Jill Clarke and Teresa Hagan of Houghton Mifflin Harcourt, Dublin 2, for a cheque presentation. HMH organised a very successful cake sale on September 5th in their offices. The event raised €1,000 towards the provision of services and supports to children or families with children with Cystic Fibrosis.

Dublin Marathon

Our heartfelt thanks to all our wonderful runners who pounded the pavement of Dublin City for 26 miles for CF on the 28th of Oct 2013!

Please log onto www.cfireland.ie on how to donate your sponsorship raised. Thank you for your support!

Classical and Irish Favourites Night

Congrats to Darren Mooney Tenor who organised a night of music of Classical and Irish Favourites' and raised €6,600 which was divided between CF Ireland and Wicklow dementia support.

Tipperary Women's Mini-Marathon

Congratulations to 'Catherine Mc Grath and Team' who raised €1,900 after completing the Tipperary Women's Mini-Marathon in Clonmel for their nephew Ciaran who has Cystic Fibrosis.

Hell & Back Titan

Big thank you to all participants who braved the Hell and Back Challenge in November and raised funds for CF.

'Dance For a Cause Zumbathon'

Congratulations to organisers Marta and Alicja from Fittsmile Co Kildare who organised the event 'Dance For a Cause Zumbathon' which raised €1,350 for CFI.

Rummage Vintage Pop-Up Shop

Congratulations to Maria Delaney, Mary and John Daly for organising one of the most successful community events of the year.



Teresa Hagan and Jill Clarke of Houghton Mifflin Harcourt presenting a cheque to Philip Watt, CEO CF Ireland.



Many thanks to Darren Mooney who donated €3,300 to CF Ireland!



'Catherine McGrath and Team' raised €1,900 after completing the Tipperary Women's Mini-Marathon!



Dance For a Cause Zumbathon raised €1,350 for CFI!



Philip Watt, Maria Delaney, Mary and John Daly at the cheque presentation for the Rummage Vintage Pop-Up Shop.

The family with the help of friends set up a pop up show called Rummage for 10 days only, which was stocked with beautiful vintage clothes, shoes and accessories all in aid of CF!

Mary, Maria (PWCF) and John Daly presented Cystic Fibrosis Ireland with a cheque for an amazing €19,000. Thank you!

New York City Marathon 2013

Welcome back to Katie (PWCF), Noel, Stephen and Sarah, who flew over to New York on November 1st to take part in the world famous marathon, which took place on November 3rd.



Noel, Stephen and Katie who took part in the New York marathon for Cystic Fibrosis!

Thank you to all of them for all the hard work in raising the funds as well as undertaking the challenge of running the marathon for CF.

RSCI Cheque Presentation

Thank you to the Royal College of Surgeons who chose us as their Charity of the Year for 2013 and raised €8,510 for CFI.

Racecourse Challenge

Antony Lewis-Crosby, parent, set out on a very unique challenge to visit every one of the 87 racecourses in the UK and Ireland in alphabetical order to raise money for Cystic Fibrosis.



Rosie Begley, CF Ireland at the RCSI cheque presentation to CF Ireland where €8,510 was donated.

The challenge started in 2009 and was split into two parts which will run simultaneously, one in the UK and one in Ireland. The Irish leg of this challenge is now completed and Antony presented CFI funds raised through betting on every race and, where possible, through collections among the crowd, which took place over the last 4 years.

This amazing effort raised an outstanding €16,000 for Cystic Fibrosis Ireland and Philip Watt, CEO of CFI, very proudly received the cheque in the Punchestown Race Course on October 16th.

Antony visited racecourses in Ballinrobe, Bellewstown, Clonmel, Cork, Curragh, Downpatrick, Down Royal, Dundalk, Fairyhouse, Galway, Gowran Park, Kilbeggan, Killarney, Laytown, Leopardstown Limerick, Listowel, Naas, Navan, Punchestown, Roscommon, Sligo, Thurles, Tipperary, Tramore, Wexford and was supported by our members from various regional groups at Clonmel, Curragh, Dundalk, Fairyhouse, Galway, Killarney, Laytown, Navan, Thurles, Tipperary and Wexford.



Antony Lewis-Crosby raised an outstanding €16,000 for Cystic Fibrosis Ireland!

Well done Antony. We look forward to hearing about your new challenge!

Abbott

Another big thank you to Abbott Laboratories Ireland Limited who donated €4,635 to CF Ireland recently.

These funds will be used to print new information and education resources for members. The first of these resources is the High Calorie Recipe booklet for PWCF (see Latest News section).

Coming soon will also be a 'Respiratory Bugs in PWCF' information sheet as well as resources on 'Infection Control and Equipment Care'.

More to follow in future issues of *Spectrum*.



Steven Betts from Abbott Laboratories Ireland with Philip Watt at the recent cheque presentation to CF Ireland.

Hospital Projects

Waterford Hospital Project

A big thank you to all who are involved in fundraising for Waterford Regional Hospital. €152K raised so far with more to come in. For fundraising materials, assistance and advice, call fundraising at 01-4962433 or email: fundraising@cfireland.ie

Beaumont Hospital Project

A big THANK YOU to all who are involved in fundraising for Beaumont Hospital. €50K raised so far with more to come in. You can help us in a number of ways by:

- Organising a fundraiser see list of Fundraising ideas on our website
- Buying a brick at www.cfireland.ie/index.phpdonate for the CF unit for only €10

Benefit Night for Beaumont

A benefit night and raffle will take place on November 30th at 8pm at Ayrfield Club, Dublin 17 in memory of Lisa Kelly (PWCF) who sadly passed away on September 25th 2013.

The family have raised €1600 for the Beds for Beaumont Campaign, and are continuing their amazing fundraising by hosting an event 'A Celebration of Lisa's Life'. You can purchase your tickets on the night priced at €10 or if you would like to make a donation to the Beds for Beaumont Campaign in memory of Lisa please donate at www.cfireland.ie

Head 2 Head Walk — Sunday 29th September 2013 — THANK YOU

On Sunday 29th of September 160+ dedicated fundraisers took on a marathon walk for Cystic Fibrosis. The route covered 26 miles starting at Howth Head and finished in Bray Head to raise much needed funds for the CF Beds for Beaumont Campaign.

On behalf of CFI we would like to thank you all so much for making this day a big success. A fantastic €25k has been raised so far. See Branch Focus section for more information!

About Cystic Fibrosis Ireland (CFI)

CFI 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.

CFI 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 was completed with up to 34 in-patient beds for people with CF
- Providing funding towards new CF Units around the country including Crumlin, Drogheda, Galway, Mayo, Waterford, Beaumont and Limerick Hospitals
- Funding research in Cork University Hospital, St Vincent's University Hospital and University College Dublin
- Campaigning to improve the rate of double lung transplantation in Ireland
- Providing advice and expertise

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