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Dear All,

There is much to report in this issue of *Spectrum*. The fine weather is assisting the completion of the many building projects that CFI has been involved in as a partner with our local branches, our network of hospitals and the HSE.

Thanks to the partnership between the branch, in particular the fantastic work of its Chairperson, Mary Lane Heneghan, the hospital, the HSE, and the generous support of the people in Galway and beyond, the new CF paediatric outpatient centre in Galway was opened on July 28th 2014. This is fantastic news for families in the greater Galway region and to the excellent paediatric multidisciplinary team in Galway led by Dr Mary Herzig. Many thanks for the support given by the managers in University Hospital Galway for this project, Mr Bill Maher and Ms Ann Cosgrove and of course to An Taoiseach Enda Kenny TD who formally opened the centre.

With all the progress in Galway, Drogheda, Cavan, Waterford, Limerick and Castlebar, it is disappointing for CF families in the south west that the adult CF inpatient project in Cork University Hospital has not yet commenced. CFI (which is not involved in this project — though many of our members were involved in fundraising) urges local charity Build4Life and the management of the hospital to reassure our members in the Southern and Kerry region that this project will not be further delayed.

The pharmaceutical company Vertex has published the encouraging outcomes from the lumacaftor/ivacaftor trials that will impact on the most common CF gene alteration, DeltaF508. While these results are encouraging, it is still relatively early days and we will continue to watch and report on progress carefully.

The lung transplant programme in the Mater continues to perform very strongly with 14 CF double lung transplants undertaken this year to date compared with 9 in total for 2013.

We hope you enjoy reading this issue of *Spectrum*.

Kind regards,

Philip Watt (CEO)
Alica May (Editor)

Front Cover: An Taoiseach Enda Kenny TD officially opening the new unit in Galway on Monday 28th July. Photo Courtesy of Joe Travers.

DISCLAIMER: The views of contributors, when expressed in this publication, do not necessarily reflect the position or policy of Cystic Fibrosis Ireland.
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THANK YOU

NEW FACE IN FUNDRAISING
New Children’s CF Outpatient Unit Opens in University Hospital Galway

An Taoiseach, Enda Kenny TD officially opened the new outpatient unit for children and young people with Cystic Fibrosis (CF) in University Hospital Galway (UHG) on Monday 28th July.

The unit is a dedicated specialist facility for daycare and outpatient services for approximately 40 children and young people with CF attending UHG, where they can be treated in a physical environment specifically designed to reduce the risk of cross infection.

Chief Executive of the West/North West Hospitals Group, Bill Maher, said “The new unit includes four examination rooms, a treatment room for procedures and a gym for assessment and physiotherapy, along with support services.”

The new centre is a partnership between the hospital, the HSE and Cystic Fibrosis Galway — the Galway Branch of CF Ireland. Philip Watt, CEO CFI, said that “the new centre is a good example of the outcome of partnership between the Galway Branch of CFI and the hospital — I particularly wish to commend the work of the Chairperson of our Galway Branch, Ms Mary Lane Heneghan, and the support of all those in the greater Galway area.”

Mary Lane Heneghan of the Galway Branch of CFI also commented “This is a welcome development for children with CF who now will have a dedicated facility designed specifically to meet their needs for daycare and outpatient activity.”

Echoing the words of Philip Watt, Mary also commented on the partnership approach which facilitated completion of this project, "It is also a very good example of what can be achieved by all parties — CF Galway together with CF Ireland and the West/North West Hospitals group and HSE — working together."

Photos courtesy of Joe Travers.
Recent Building Projects Progress

It is fantastic to see the opening of the new paediatric outpatient centre in Galway University Hospital on the 28th July 2014. The opening by An Taoiseach Enda Kenny received much publicity in the national media. This follows on from the recent completions of build projects in Drogheda and Cavan in partnership with the hospitals concerned.

We also look forward to the completion of the build projects in Limerick and Castlebar in early 2015. CFI is in contact with Cork University Hospital management and we hope to get an update on the reasons for the ongoing delay in the adult inpatient unit. CFI urges the hospital and the local charity, Build4Life, to ensure that this project is started as soon as possible.

CFI Building Developments

<table>
<thead>
<tr>
<th>Building Project</th>
<th>Status</th>
<th>Partners involved and status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Our Lady of Lourdes Hospital, Drogheda</td>
<td>Paediatric Outpatient Centre</td>
<td>Formally launched April 2014 with significant local and national media coverage. To be transferred to the hospital in September 2014. CFI/LM4CF/hospital/lottery Total Cost €700,000 Completed May 2014</td>
</tr>
<tr>
<td>Mayo General Hospital</td>
<td>Outpatient Unit</td>
<td>Work commenced January 2014 Progress satisfactory (see below) CFI/ Mayo West and lottery Total cost €2.1m To be completed by early 2015</td>
</tr>
<tr>
<td>University Hospital Limerick</td>
<td>Outpatient and Inpatient Unit (adult)</td>
<td>Shell and core completed. Building due to be completed early 2015. Staffing issues for the whole building and equipment costs yet to be resolved and could delay opening. CFI/TLC4CF/Hospital/Leben (development company of CFI, Parkinson’s and Hospital Foundation) Total cost €4.1m To be completed by early 2015</td>
</tr>
<tr>
<td>University Hospital Waterford</td>
<td>4 room Inpatient unit (paediatric)</td>
<td>Due to commence CFI/Hospital To commence shortly</td>
</tr>
<tr>
<td>Cavan General Hospital</td>
<td>Outpatient suite of rooms</td>
<td>Completed April 2014 CFI/Hospital Completed April 2014</td>
</tr>
<tr>
<td>University Hospital Galway</td>
<td>Outpatient clinic</td>
<td>Launched 28th July 2014 Hospital/CF Hospital Fund/CFI Completed July 2014</td>
</tr>
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Other (non-CFI) Developments

<table>
<thead>
<tr>
<th>Building Project</th>
<th>Status</th>
<th>Partners involved and status</th>
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| Cork University Hospital  
*Inpatient rooms for adults* | Agreement signed in early 2014 and CF understands that a building contractor is ready to commence when funding is made available. | CFI is currently seeking clarification as to why this project continues to be delayed, which is causing much anxiety in the area. Estimated total cost €2.3m.  
*No commencement or completion date* |

CF Transplant Rates Continue to Rise in Ireland

Since our last issue of *Spectrum*, 8 more CF double lung transplants have taken place in the Mater hospital, bringing the total number in 2014 to 14. This is fantastic news and is indicative of the strides that have been made at the Mater hospital in recent years.

We’d also like to take this opportunity to remind members a transplant grant, valued at €850, is available through the CFI National office. The transplant grant provides financial assistance towards incidental expenses (accommodation, meals and transport) incurred to families as a result of a person with CF (PWCF) undergoing a transplant.

Please contact us directly in National Office to apply for this grant in the event your loved one has undergone a transplant, or alternatively ask your local branch member or member of your CF team to let us know the transplant has taken place. The grant will be issued to the next of kin of the PWCF. For more information on the transplant grant, contact Alicia: amay@cfireland.ie or tel: 01 4962433.

Advocating for Medical Card Eligibility for People with CF

The Government has decided to develop a policy framework for medical card eligibility to take account of medical conditions. An Expert Panel has been established to examine the range of medical conditions that should be considered for inclusion in the policy framework.

The Expert Panel will identify a range of medical conditions, in priority order, that would benefit most from medical card eligibility. Contributions were sought from the public, patient representative groups and professional bodies, to inform the work of the Expert Panel. In addition to encouraging members to provide feedback on this process, CFI also made a submission to the HSE advocating for people with Cystic Fibrosis to be automatically and permanently granted a medical card. The full submission is available on our website at: www.cfireland.ie/pdf/CFIMedicalCard_Submission_2014.pdf

In response to this submission, CFI were invited to send representatives to a key stakeholder meeting on July 24th to convey the challenges faced by people with CF interacting with the medical card application and review process. This provides us with an opportunity to highlight the strengths and weaknesses of the current system and to inform the working group on the necessity for PWCF to be recognised for inclusion in this scheme based on medical need. The Expert Panel has been asked to report to the Director General of the Health Service by September — we will ensure members are kept updated on all subsequent developments relating to the medical card.
Stephen O’Brien Brings Home Two Medals from European Heart and Lung Transplant Games

Congratulations to Stephen O’Brien who won two bronze medals for cycling and badminton as part of an Irish team that travelled to the European Heart and Lung Transplant Games in Vilnius, Lithuania.

Stephen underwent a double lung transplant in the Spring of 2012 and his life has been transformed since. He is now an avid cyclist, recently completing the King of Kerry, and is fitter now than he has ever been.

Family, friends and members of the local Cork branch greeted Stephen on his arrival back at Cork airport recently (see below). Keep an eye out for the next issue of Spectrum where Stephen will contribute an article to Spotlight.

Launch of National Rare Disease Plan for Ireland 2014-2018

The Minister for Health, Dr. James Reilly TD, launched the National Rare Disease Plan for Ireland 2014-2018 on Thursday 3rd July. ”The significance of this plan cannot be overstated because it provides us with a roadmap for the prevention, diagnosis and treatment of rare diseases,” said the Minister.

A rare disease is defined in the EU as a disease or disorder affecting fewer than 5 in 10,000 of the European population. There are an estimated 6-8,000 known rare diseases affecting up to 6% of the total EU population (at least 30 million Europeans), and perhaps up to 300,000 Irish people during their lives. Conditions such as Cystic Fibrosis, Haemophilia and PKU are familiar to many; however, there are many other rare and ultra-rare conditions.

The key recommendations in the National Plan for Rare Diseases are:

- Establishment of a National Clinical Programme for Rare Diseases to include the mapping, development and implementation of care pathways for rare diseases
- Establishment of a National Office for Rare Diseases to facilitate the co-ordination and timely access to Centres of Expertise nationally and internationally, and to provide up-to-
date information regarding new treatments and management options, including clinical trials

- Applications for the use of a fair and transparent means to access orphan medicines and technologies in hospitals through a national budget
- The HSE and NGOs will provide ongoing support for people living with rare diseases and that they cooperate and promote awareness of rare diseases
- Residential respite care be available for children with rare diseases
- Development of a Rare Disease Research Network to enhance the quality and relevance of rare disease research in Ireland
- Patient empowerment and the support of patient organisations the establishment of monitoring and reporting mechanisms on the rare disease plan

To read the full plan for rare diseases and further details of key recommendations, please click on the following link: http://health.gov.ie/blog/publications/national-rare-disease-plan-for-ireland-2014-2018/

David Fitzgerald is elected new Chairperson of CFI

Many congratulations to David Fitzgerald who has been elected by the Board of CFI to serve as Chairperson. Many thanks to the outgoing chairperson John Coleman for his sterling work over an important period for CF services in Ireland. The officers of CFI for 2014/2015 are as follows:

- **Chairperson:** David Fitzgerald
- **Vice Chairperson:** Patricia Duffy-Barber
- **Vice Chairperson:** Cyril Gillen
- **Treasurer:** John Coleman
- **Secretary:** Caitriona Hayes
The European Cystic Fibrosis Society (ECFS) Conference 2014 was held in Gothenberg — Sweden’s second largest city situated by the sea on the west coast.

The ECFS is a massive event on the calendar of CF multidisciplinary teams, patient organisations (CFI included) and pharmaceutical companies throughout Europe and beyond.

Kicking off on Wednesday evening, talks and seminars run from early morning to evening, right through to Saturday. The conference is a great opportunity for networking and culturing relationships with key people and organisations to assist with our work here at CF Ireland.

The choice of lectures is always vast and the difficulty faced is to get to all of the lectures that will assist us in our jobs here at CFI. To give you a flavour of the event, a synopsis of some of the main symposiums and seminars that staff at CFI attended and found interesting will be made available on our website shortly.

**New ECFS Standards of Care**

It has been 10 years since the last ECFS standards of care were written. A lot has changed since then including the proliferation of newborn screening for CF, the rising numbers of the adult CF population and the emergence of new mutation-specific therapies to name but a few.

The 2014 ECFS Standards of Care were published in the latest issue of the *Journal of Cystic Fibrosis* and details were presented at the ECFS conference in Gothenberg.

Some of the main points to report include:

- The 2014 ECFS Standards of Care are now composed of three separate documents: a) best practice guidelines b) framework for the CF Centre and c) quality management in CF care. The new standards were written by 15 experts in CF from 9 different countries. Patients with CF were also consulted in the process. This is an important step in the provision of the best possible care to people with CF.

- The Best Practice document describes the services CF centres should provide including newborn screening and genetic testing for CF, prompt recognition of pulmonary infection and deterioration for required timely intervention, establishment of referral pathways for common CF complications, early recognition, assessment and management of psychological complications, and appropriate management and communication at transplantation referral and end of life.

- The Framework paper outlines the importance of the CF multidisciplinary team (MDT), describes the general structure of paediatric and adult CF centres and highlights the importance of transition. The roles of the MDT members is described and
all disciplines are strongly encouraged to engage with national/international specialist groups and to participate in audit and research.

- The Quality Management document reviews management of quality of care for individuals with CF at several levels: patient, centre, regional, national and international. Improvement issues are examined with particular reference to annual assessment, patient quality management charts, CF team sessions, therapy goals, certification, peer review, public reporting, quality groups, ranking, learning from best practice, interaction with registries, benchmarking, and co-operation with national organisations.

- All European nations should strive to achieve a model of CF care in accordance with the ECFS recommendations.

To access these documents in full, please go to: www.cysticfibrosisjournal.com/issues?issue_key=S1569-1993%2814%29X0004-4

**Strong Irish Presence at ECFS**

Dr. Barry Plant, CF Consultant at Cork University Hospital spoke on many occasions throughout the conference including on novel methods of antibiotic administration in the real world.

Dr Ed McKone, Respiratory Consultant at St Vincent’s University Hospital, spoke on the role and importance of international and European registries (see later). Orla Tinsley, PWCF and Journalist, was also invited to speak about adherence, and her own personal journey in recognising its’ importance.

Dr Kirsten Schaffer, Consultant Microbiologist at St Vincent’s University Hospital, Dublin also presented on ‘Guidance on preventing infection in everyday life’, which involves community guidelines on cross-infection for PWCF. CFI are actively involved in drafting these guidelines which, on completion, will be presented to all CF families as guidance to community awareness of infection.

Dr Abi Jackson, from the CF Registry in Ireland, also presented on perspectives of the Irish CF Registry on how registry data can be used to examine CF health service utilisation.

**ECFS Award**

The 2014 ECFS Award was presented to Prof Eitan Kerem (Israel) to acknowledge his substantial contribution to CF research. His interest in CF spans all aspects, i.e., the association between phenotype and genotype, prognostic factors for disease severity and prediction of mortality, the molecular mechanisms for disease variability, and development of new mutation-specific pharmacological therapies to correct the basic defects in Cystic Fibrosis. He published many papers in this field and is known for his advocacy for children in need. He also has a record of building bridges between Israelis and Palestinians furthering peace through medicine wherever possible.
A Young Researcher’s Perspective of the ECFS Conference

By Christina Kenny

The determination, the courage, the bravery. This is why I studied microbiology and pursued Cystic Fibrosis (CF) research. I spent years watching members of my own family battle the disease, over-come its many challenges and refuse to fall victims to its wrath. They became heroes in my eyes. They inspired me to contribute something.

I started at University College Dublin in 2011 and this year I attended the ECFS conference in Gothenburg, Sweden. I didn’t really know what to expect as I had never attended before. The conference centre was buzzing and the agenda was jam-packed. There were at least four symposiums happening at any one time, posters displaying fascinating and ground-breaking research everywhere, Pharmaceutical companies displaying their CF products and drugs and finally an exciting atmosphere that was undeniable. My own research was completed over a summer spent at the CF & Airways research lab at Queen’s University Belfast. I worked on uncovering how quickly bacteria from both ordinary people and those with CF developed resistance to certain antibiotics. I worked on using bacterial samples isolated from CF patients and subjected them to particular antibiotics over 12 passages — the results were staggering. We uncovered that after only a few passages of the antibiotic some of the bacterial samples were almost totally resistant. After gaining resistance we then stopped passaging with the antibiotic to see how quickly we could lose the resistance. However, in most of our resistant samples, the resistance was stable or took multiple weeks to go away. We were surprised. The resistance was so quickly gained and not so easily lost in some cases. This small amount of research has contributed to our knowledge of how to utilise particular drugs better.

I was amazed by how much I learned from my peers. I learned so many simple yet clever little tips to share with all PWCF. For example, one researcher displayed a poster discussing the bacteria that lives on the toothbrushes of PWCF and how their own toothbrush can re-infect them. So perhaps replacing your toothbrush regularly or after an exacerbation isn’t such a bad idea! I also sat in on a Symposium moderated by the President of the Conference, Prof Stuart Elborn, about the aim and need to unify Europe in terms of treatment plans. Many researchers discussed their use of new, innovative techniques for detection of certain CF pathogens. What was really interesting was the many discussions and research presented on non-pulmonary topics. We are learning that CF is such a multi-faceted disease. I sat in on talks discussing the ageing of CF and how the disease affects other organs and body parts such as kidneys, pancreas and even eyes. It was clear CF has come a long way. We are now learning more about the older generations of PWCF, this is not something we have always had the privilege to talk about. I learned too much at the conference to cram here but one thing I learned that stayed with me was what a difference research makes. If it wasn’t for dedicated researchers we wouldn’t have come as far as we have with CF. There are clearly so many good things to come with CF research and I am excited to be a part of the movement.
### Promising Results from Vertex’s Combination Trial, but how does it work & what does it mean for Irish PWCF?

Vertex Pharmaceuticals Ltd have announced results from a new treatment for people with CF aged 12 and over with two copies of the F508del mutation. This new and innovative ‘combination therapy’ works to tackle the underlying cause of CF for people with CF (PWCF) who have two copies of F508del genetic mutation, which represents approx. 56% of the Irish CF population. This new treatment uses a combination of Ivacaftor (Kalydeco) and Lumacaftor, aiming to tackle the underlying cause of CF.

#### Background information

CF is caused by a faulty gene called the Cystic Fibrosis Transmembrane Conductance Regulator (CFTR) gene. CFTR proteins are found on the surface of some cells in your body, for example, the cells that line the airways in your lungs. Normal CFTR proteins act like channels with ‘gates’ to help keep a balance of salt and water in the lungs. For PWCF, the faulty CFTR gene inhibits the flow of salt and water through the body’s cells, causing a build up of thick, sticky mucus.

#### How does Kalydeco help?

Kalydeco is a CFTR potentiator, helping to open the ‘gates’ in the body’s cells allowing a greater flow of salt and water through the body’s cells, keeping mucus on the inside of the body’s organs thin and watery. Kalydeco has been shown to be effective for ‘Gating’ mutations, aka, G551D mutation.

#### G551D CFTR function BEFORE Kalydeco — we can see very few chloride ions are moving into and out of the cell

![Diagram showing chloride ion movement before Kalydeco](image)

Closed gate

Few chloride ions move in/out of cell, changing the balance of salt and water in the lungs

#### G551D CFTR function AFTER Kalydeco — we can see chloride ions are now moving into and out of the cell

![Diagram showing chloride ion movement after Kalydeco](image)

Kalydeco helps open the gates more often so chloride ions can move in and out of the cell, thereby helping keep a balance of salt and water in the lungs

#### We need your help!

Over the past two years there has been a real focus on the role of the Health Technology Assessment (HTA) in the assessment of ‘cost-effectiveness’ of new therapies. The primary objective of the HTA is to assess the value for money & affordability for new therapies/drugs. More recently, there is a recognised need for a more formal input from patients and patient organisations in the provision of information during these assessments.

CFI are looking to hear from PWCF/parents of PWCF who are currently taking Kalydeco or from PWCF/parents of PWCF taking part in the Lumacaftor/Ivacaftor trial in Ireland. We want to hear about the ‘real-life’ impact of these new therapies, e.g., for education, employment, social life, relationships, things that matter to you, etc. We will be sending out a survey to ask you to share your views and experiences. Information gathered will only be used in the interest of PWCF and aims to gain a greater insight into the patient/parent views of these new therapies.

So keep an eye on emails & our social media pages for the survey & please take the time to participate. For anyone who doesn’t have access to the internet but would like participate, or if you have any questions, please call Katie on t: 1890 311 211 or e: kmurphy@cfireland.ie.
**How does Lumacaftor help?**

For many other genetic mutations in Cystic Fibrosis, including the most common mutation F508del, the CFTR protein is misshapen. As the CFTR protein is misshapen it is unable to transport to the cell surface. This is not the case with the G551D mutation, whose CFTR protein is normally shaped and can reach the cell surface without any help. This is the key difference between these mutations.

Lumacaftor is a drug which targets the misshapen CFTR protein and attempts to facilitate its transport to the cell surface, where Kalydeco can help to 'open the gate' and allow a greater flow of salt and water through the body's cells, keeping mucus on the inside of the body's organs thin and watery.

Therefore, the combination of Ivacaftor (Kalydeco) & Lumacaftor aims:
1) To transport the CFTR protein to the cell surface (Lumacaftor)
2) To open the 'gate' to allow a greater flow of sodium and chloride into and out of the cell (Kalydeco)

**Phase III trial results**

The results of the phase III trial, recently published by Vertex Pharmaceuticals Ltd, demonstrate that the combination of Kalydeco and Lumacaftor could offer PWCF with two copies of the F508del mutation an additional treatment option.

**Summary of the main trial findings:**
- Absolute improvement in lung function (FEV1) of an average of 2.6-4.0%
- Reduction in pulmonary exacerbations of between 30-39%
- Statistically significant improvements in BMI

Vertex Pharmaceuticals Ltd has said they’re planning to submit a New Drug Application (NDA) in the US and Marketing Authorisation Application (MAA) in Europe in the fourth quarter of 2014.
Research into a Vaccine Against *Burkholderia cepacia* complex

*By Dr Siobhán McClean, Institute of Technology Tallaght, Centre of Microbial Host Interactions*

What is *Burkholderia cepacia* complex? It is a group of very multidrug resistant bacteria found in about 5% of people with CF. It is a problem because once a person with CF is colonised with Cepacia, it is very hard to clear because it is so antibiotic resistant. Dr Siobhán McClean and other researchers in the Institute of Technology Tallaght (ITT) Dublin have been looking at other ways to fight this infection.

One of the areas our group study is how Cepacia attaches to lung cells because attachment of these bacteria to lung cells is critical to the infection process. The idea was that if we knew how the bacteria attached to the lung, it might be possible to stop it attaching and as a result, stop Cepacia causing infections.

We discovered that the Cepacia produces a number of molecules at its surface to help it attach to lung cells. We are now focusing on using these molecules to develop a vaccine to prevent Cepacia infections. The idea of developing a vaccine came from previous work done by others researchers in the 80’s on whooping cough. Whooping cough is caused by other bacterium (*B. pertussis*) that attaches to the cells that line the throat. The vaccine now routinely used in children to prevent whooping cough contains five molecules that Pertussis uses to attach to the throat. By immunising children with these five molecules, called 'antigens', it enables the person to produce protective antibodies so that if they come across these molecules again (usually on the surface of the bacteria the next time), their immune system recognises and attacks these molecules and with them, the bacteria.

Once we found out what these antigens were in Cepacia, we produced them in a purified form and tested them in animal models. We discovered that if animals were vaccinated with these antigens, and were then later infected with Cepacia, the infection could be cleared from their lungs within a few days. Control groups that didn’t get the vaccine could not clear the infection and large numbers of Cepacia cells were found in the lungs after the infection. This is very promising as it indicates that the vaccine is having a protective effect.

These are very early stage experiments and it may be two years before trials can be permitted in humans. It is important that the vaccine is safe before testing it in humans. Ultimately, we hope to develop a vaccine that will prevent Cepacia infections in people with CF. We also hope that it can be used therapeutically to help clear existing Cepacia infections.

**Contact details:**
Centre of Microbial Host Interactions  
Dr Siobhán McClean siobhan.mcclean@ittdublin.ie;  
Dr Cindy Collins cassandra.collins@ittdublin.ie
As part of a series, Spectrum will include a focus on some of the pharmaceutical companies based in Ireland that have relevance to the treatment of Cystic Fibrosis, some well-known, others less well known. The first in this series features Astellas Pharma which is involved in the production of immunosuppressant drugs used for transplants. These features are for general information, they are written by a representative from the company but are not sponsored.

Astellas Ireland Co. Ltd

By Martin Coen, Astellas Pharma Inc.

Astellas Ireland Co. Ltd (AICL (KP)) is a subsidiary of the Japanese multinational Astellas Pharma Inc. and was formed in 2005 through the merger of the Fujisawa and Yamanouchi corporations. The plant has been in operation since 1992. The Killorglin plant (KP) is largely involved in the manufacture and packaging of an immunosuppressant pharmaceutical product used in the treatment of patients who have received an organ transplant. Our market is worldwide. We differ from many other pharmaceutical plants in that our relationship with the patient tends to be lifelong. Consequently the need for the sustainability of the company is evident to all.

There is a strong awareness of the dependence our facility has on the Community — without a committed workforce supplying a lifesaving product across the Globe would not be possible. AICL (KP) is a cornerstone of the Killorglin community and economy. The geographic location of the plant also does not go unnoticed. Situated on the Ring of Kerry, the beauty, environmental wealth and sheer power of nature is readily apparent to employees and visitors alike.

From this backdrop a strong environmental conscience developed and a clear commitment to a sustainable relationship with the environment was made. Our commitment to sustainability over the past ten years has not been passive but has always been extremely proactive.

The site has been certified to the International Environmental Management System Standard ISO 14001 for over ten years and is also certified to the Energy Management System Standard ISO 50001. However the proactive approach in Killorglin has never been about getting the certificate. The aim of our Environmental Management System has been about making a difference, environmental protection, and environmental improvements and utilising sustainable resources.

Globally, the Astellas Corporation has a ‘CHANGING TOMORROW’ initiative which has many elements, including Corporate Social Responsibility (CSR) and the environmental projects undertaken over the past number of years in Killorglin are a demonstration of these company values.

Our Renewable Energy Initiatives have resulted in 20% of our electricity needs being provided by our on-site wind turbine. We have also installed a wood chip boiler which supplies 90% of the company’s thermal needs. Initiatives have included proactive involvement with the local community including environmental talks and lectures and a schools calendar competition; the proceeds of which go to the Irish kidney Association. Our waste minimisation and recycling projects have reduced waste sent for disposal to landfill by > 70%.

The company has made a commitment to biodiversity and is actively managing a nature reserve which forms part of the site. In addition, AICL (KP) has provided public walkways and flora and fauna information boards along the nature reserve and off site along the River Laune. Site management have shown their long-term commitment to the community by taking on the responsibility of the clean-up and removal of contaminated material from a landfill operated by a sister plant, despite never having placed waste in the landfill. Astellas’s proactive approach to the environment was recognised in November when the site won the IBEC Environmental Excellence Award.
**CF MedCare — The Cystic Fibrosis Treatment Reminder**

Taking daily medications is really important, but remembering to do so can be a challenge. Many CF patients have a complex and time-consuming regimen, which can lead to non-compliance, due to simple forgetfulness.

CF MedCare is a free App designed by Vertex Pharmaceuticals to help people with Cystic Fibrosis with their therapeutic regime. It sends you an alert when it’s time to take your medications and captures compliance data.

**What does CF MedCare do?**
- Allows you to create your own medication schedule
- Alerts you when it’s time to take your medication and provides you with a reminder of what was taken
- Captures compliance data, so that it is easy to track and remember which doses were taken on time, delayed and which were skipped
- Provides ability to share users’ compliance records via email with their healthcare professional or individual of choice
- Reminds you when it’s time to renew your prescriptions

For more information: www.cfmedcare.eu

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**Fertility Grant Scheme — Still Time to Apply!**

Applications for the fertility grant scheme are steadily coming in. We have already approved 5 grants since the scheme opened this year and we hope to be able to approve many more. With the application deadline on Friday 26th September 2014, there is still plenty of time left to apply.

Unlike previous years, applicants can now apply a third time to this scheme. This decision was made in response to feedback from PWCF. The value of the grant for third-time applicants is €1,000.

If you have any queries about this scheme, please contact Alica May on amay@cfireland.ie or call 01 4962433.
Intreo — National Employment and Income Support Service

The Department of Social Protection has established a new national employment and income support service called Intreo.

What is the Intreo service?
Intreo provides a personalised service, based on your individual needs including advice on education, training and personal development opportunities, job search assistance as well as information on and access to a range of income supports.

What services and supports are provided by Intreo?
- Employment services and income supports
- Expert assistance and advice on employment, training and personal development opportunities
- A focus on your individual needs to assist you enter the workforce
- Self-service facilities to provide you with information and guidance on employment and training opportunities
- Access to information on job vacancies through www.jobsireland.ie
- Information on the full range of income supports provided by the Department of Social Protection, for example, jobseeker’s payments, back to work and back to education payments, one-parent family payments, pensions and others. Also, any queries in relation to your jobseekers or one-parent family payment will continue to be dealt with by the team in your Intreo Centre.

What do I need to bring for my first visit?
Bring your PPS number and proof of your address, such as a utility bill in your name.

Where is my nearest Intreo service?
A list of all local Intreo services is available here: www.welfare.ie/en/Pages/Intreo---Contact-Information.aspx

For more information:
www.intreo.ie

Over the next few issues of Spectrum, we will be providing a few case studies of people with CF who are working, both part-time and full-time, to illustrate the various different employment options out there for people with CF, and to show how other people balance work with managing CF.

First up, we have Keith Murphy, PWCF Age 24 from Co Wexford...
Hi, my name is Keith Murphy. I am 24 years of age and I have Cystic Fibrosis.

I recently finished up college and am now doing an internship as part of my final module to graduate as a software developer. I chose software development after a long list of jobs that I wanted to do from a young age.

Deciding on the right career
First, I wanted to become a carpenter, but I soon realised that it wouldn’t be a good idea due to the amount of saw dust that would be in the air. Then I decided I wanted to become an architect and, again, after a bit of research I realised that would involve spending a lot of time on building sites where there would also be a lot of dust in the air. The next career idea I got excited about was the air corps. I read up everything about it on the Irish air corps website but the excitement ended when I saw the dreaded sentence under people who would be ineligible to enlist — “a person in receipt of disability pension”.

So after much more thought I focused on what the best environment would be for me to work in. An office job came be mind immediately as it’s sheltered from the elements and would have clean air. The ideal situation for me would be to have a job that would allow me to work anywhere in case of hospital stays or home IVs. I always loved computers from a very young age — I remember playing Super Mario on an old Gameboy when I was only 4 and it brought endless fun for me when I was in hospital. So I decided I would become a computer programmer.

Finding the right course and company to work for
I did lots of research and found out that most companies allow their programmers to work flexibly and, most importantly, from home. Next step was finding the right course.

I applied for the computer programming course and got accepted into Carlow IT. I was very excited because I heard they are one of the better places for computer courses since they have ties with Microsoft and other big companies. It was a very tough course for most people and I found the last year (3rd year) extremely tough as the length of time was a third shorter than the others and the workload seemed to be doubled that of previous years. I was very ill then so I decided to split my year into 2; I did 3 of my 7 modules one year and the other 4 the next. The college were very helpful in providing the support I needed to do this.

In 3rd year I chose to do a 6 week placement. After a lot of applications I finally found a suitable company. During the interview I told them about my Cystic Fibrosis and that from time to time I might need time off due to infections and they were perfectly ok with that. I reassured them that I’d still be working if I wasn’t able to come into the office. I explained that this was the reason I chose the course because of the flexibility of that fact — you can work anywhere with a laptop.

I finished up my exams and took 1 week after to relax and unwind from the stress. Then I started fresh on a Monday morning. It felt weird at first working in an office setting. I was introduced to all the employees that I would be working with and shown around the company. It’s a very small company — less than 10 people employed — but I felt at home after a few minutes.
Finding my feet
I was then shown the software that we sell to haulage companies and given a copy of it to play around with to get a feel for what we do. After lunch I was then given a project that would take me around 2 months to complete. It was exciting to start working on something that will actually be used by other companies. I had a sense of achievement knowing that I was writing code on a program that I know hundreds of haulage companies will use one day.

Dealing with setbacks
After about 3 weeks in work the dreaded feeling came to me that my health was starting to decline. You know the feeling, tiredness, coughing more...the usual suspects. I called the hospital and made an appointment. My boss was really good when I rang him after the appointment and told him that I will not be able to make it into the office for the next 2 weeks minimum. I again assured him that even though I wouldn’t be in the office I would still be working on my project. He told me not to work too hard and to take it easy and worry about getting better. I was mainly focusing on getting better, but I made sure to do at least 6 hours of coding a day just to keep up with my project timeline.

After 2 weeks I was back to good health and back in the office. The boss was happy to see me back and looking well. We had a meeting and I told them how far along I was on the project. Everything seemed to be going well. I love working 9 to 5, Monday to Friday. It’s so nice to have my evenings and weekends to myself.

Looking ahead
Work was going grand and about 8 weeks in the lead developer and the boss were having a meeting when I was called in. I immediately thought the worst that I had done something wrong. But that wasn’t the case — instead he asked me when I was to finish up the internship and I told him I still had another 2 and a half months. He turned around and told me that they want to hire me full time!

I was so excited I could barely contain my smile all day. When I went on lunch I told my fiancée and family. My mother actually cried down the phone saying how proud she was and that how hard I had worked to get where I am. It was a brilliant day. I am still finishing up my internship here at the moment with the promise of a full-time job at the end. One project has gone live and I’m now working on another. It’s a very interesting job and can get very stressful at times when things don’t go right but it’s very fulfilling when you finally see the full thing working.

I couldn’t recommend finding a job enough to people with CF even if it’s just a part-time job or volunteering for an hour somewhere — it makes life seem better and gets you out of the house.
EVENT FOCUS

North Clare CF Cycle or Run, Saturday, 6th September 2014, TLC4CF

The TLC4CF North Clare CF Cycle or Run will take place on Saturday 6th September in Kilnaboy, Co Clare in the Burren. Cycle 100km / 70km /40km/10KM, walk/run 6km or run 11km.

There will be four routes covering the scenic Burren, Fr. Teds house, the Cliffs of Moher and Atlantic Coastline, and the Wild Atlantic Way.

This event has something for everyone! Refreshments, goodie bag and backup will be provided. Waterproof, windproof event. Gilets also for sale for the bargain price of €25.

Register online now at: www.tlc4cf.com

- Online registration: €30 for 100km, 70km and 40km
- Online registration: €10 for 10km and 6km, 11km run

This event is supported by Burren C.C and Kilnaboy Athletic Club. For more details on registration and route maps go to www.tlc4cf.com.

Please support TLC4CF and spread the word about this fantastic event!
Challenges and Events

**Marathons — Home & Away**
If you would like to set yourself the ultimate running challenge, and raise funds and awareness for CF Ireland, we are looking for participants for two marathon events — at home & away.

**Dublin Marathon 2014**
The 35th SSE Airtricity Dublin Marathon 2014 takes place on October Bank Holiday Monday and is open for registration right now: www.dublinmarathon.ie

Get involved...We are looking to get a team of 50 people to take part in the marathon this year. This will be our biggest team yet!

To register and join the CF Ireland team, and to receive a race pack and singlet, please e-mail fundraising@cfireland.ie

**NYC Marathon 2014**
There are still places available for people wishing to run the famous NYC Marathon while raising funds for CF Ireland.

If you think you’d like to see New York City from a different perspective and get to run along those famous streets, the NY marathon goes through the 5 Boroughs. It’s sure to be an amazing day and is one of the biggest sporting events of the year.

If you are interested in finding out more and registering for the NY Marathon for 2014, please email us for details: fundraising@cfireland.ie

**Running Down Under for CF Ireland**
Best of luck to Ciara Fagan and her friends who will be taking part in the City2Surf 14km Run on Sunday, August 10th, in Sydney Australia, while raising funds for CF Ireland.

The run is 14km in distance, starting in Sydney’s CBD and finishes on Australia’s famous Bondi Beach.

It’s great to know we have supporters from all over the world. If you know anyone living abroad, but would still like to support CF Ireland, let us know and we will get in touch.

**Tough Mudder 2014**
Are you Tough Enough…for Tough Mudder?

Join Pat Divilly, fitness guru, motivator and CF Ireland Ambassador in a team of 400 at Tough Mudder this October — all with the goal of raising €100,000 for CF Ireland.

Pat has set up a Facebook group for all who are registering, and posts daily tips and inspiration for you to drive your training and motivation — go to his Pat Divilly Fitness Facebook page for more information: www.facebook.com/PatDivillyFit

If you want to know more about Tough Mudder, check out the website: www.toughmudder.co.uk. For more information on how to enter and join Pats inspirational team contact fundraising@cfireland.ie

**Calendar of events to September 2014**
- Dun Laoghaire Bay 10k — 4th August
- RocknRoll Dublin Half Marathon — 4th August
- Oylegate Half Marathon & 10k — 31st August
- Dingle Half, Full & Ultra Marathon — 6th September
- TLC4CF Cycle/Run/Walk — 6th September
- Tough Mudder — 4th & 5th October
- SSE Airtricity Dublin Marathon — 27th October

If you wish to take part in any of the above events please contact the fundraising department and we will organise a fundraising pack for you e: fundraising@cfireland.ie or t: 01 496 2433
Head2Head Walk — Sunday 7th September 2014
Join us on the Head2Head Walk on Sunday 7th September in aid of the Cystic Fibrosis ‘Beds for Beaumont Appeal’. This is the 2nd year of this event and once again the 24 mile route will take place in the beautiful surrounds of Dublin Bay.

Beds for Beaumont Appeal
The campaign aims to raise €2.5 million for 12 inpatient isolation rooms in Beaumont Hospital for people with CF. At present, there are only 4 inpatient rooms, but research and international standards show that 12 CF inpatient rooms are needed as a matter of urgency in Beaumont Hospital.

You can register for this event on our website www.cfireland.ie

For further details please contact Peter on t: 01 4962433 e: pminchin@cfireland.ie or contact one of our committee members below:

Mary McCarroll Mob: 087 4119812
James Downes Mob: 087 9601970

Sharing the History of Kilkenny & Supporting CF
Ray Cleere has written a book on the 150 year history of St. Mary’s Cathedral in Kilkenny. It contains fascinating information about the history of the magnificent building, the people who created that history, from its concept up to the present day, and it recounts many of the events that took place in the Cathedral over a century and a half.

All the profits from the sale of the book are going to Cystic Fibrosis Ireland. Ray is hoping to make €12,000 for CF Ireland by doing so.

If you would like to obtain a copy interesting slice of Kilkenny History — please contact Ray directly: e: raycleere@hotmail.com t: 087 1221976
Thank You

Thank you to all the ‘One in 1000’ CF Ireland’s Flora Women’s Mini-Marathon Team!
The One in 1,000 CF Ireland Team took to the streets on the 2nd June to take part in the Flora Women’s Mini-Marathon. 1,000 women (and some very well dressed men) wore purple and took part in the race representing the CF Ireland Team. We had a fantastic day out and great fun at the race reception afterwards, which was held in the Harcourt Hotel, Dublin.

A huge thank you to everyone who took part! We are close to reaching our target of €100,000, which will go to vital services for people with CF. If you took part and have yet to send in your donation please do as soon as possible. With your help we will get to the €100,000 target!!

Right: Participants from 2014 celebrating outside the Harcourt Hotel, Harcourt St, Dublin.

Triona Priestley Charity Memorial Match
On Sunday 13th July, staff memebrs from the Penney’s stores in both Blanchardstown and Mullingar took part in a charity football match in memory of the late Triona Priestley (RIP). The game took place in St. Mochtas FC and involved Blanchelona taking on Torpedo Mullingar with Blanchelona winning on a score line of 6-0.

The day was a great success with a signed Celtic jersey also raffled on the day and face painting for the kids.

A big Thank You to Trevor Cusack for all the work he put into organising this event and to those who helped out on the day. Imelda Murphy, Sharon Lambert, Maria Stallard, Avril Duffy, Danielle Murphy and Tracy Dugan all who got involved in helping to sell raffle tickets and collecting money on the gate.

Also a special mention to Bobby Ryan, head coach at St. Mochtas, who ensured the pitch was available for the event and for supplying the kit for Blanchelona.

This event was a fitting tribute to the life of a remarkable teenager.
The first inaugural Castleknock 5km took place on Sunday, 13th July. The event, which exceeded expectations, was a massive success with 1,200 people attending the race. It is the first event to be organised by the recently established Dublin West branch of CF Ireland and raised an amazing €38,000!

Congratulations to everyone who organised the event and thank you to everyone who participated! The feedback from the day was fantastic and as well as the race there was tea/coffee, cakes, free fruit, water, popcorn, face painting, Zumba classes and a DJ along with a monster raffle to name but a few!

We will keep you up to date on the new branch fundraising activities, but if you are interested in getting more involved in the CFI West Dublin Branch, please contact us here in CF Ireland and we will link you in with the relevant people who would love to hear from you.

Salesforce Summer Party
A Big Thank You to all the generous staff at Salesforce who held a summer party on Friday 11th July in aid of CF Ireland at the Radisson St. Helen’s Hotel Stillorgan.

The evening kicked off with a number of sports events including Test Your Strength, Tag Rugby, Human Table Football and even a Rodeo Bull which proved very popular.

Later that evening the participants enjoyed a well deserved BBQ and 80’s disco.

Salesforce have pledged to provide matching funds for all donations made by their employees so well done to all involved.

Hollypark Boys National School
CF Ireland paid a lovely visit to meet with and speak to the Hollypark Boys 2nd Class pupils and their teachers.

They very generously donated their communion money to CFI to help fund the exercise grant scheme that will benefit other boys and girls their age who are living with CF.
Presentation of cycle tops to the CF Ireland Team for Paris2Nice Cycle Challenge September 20–25

Philip Watt, CEO, CFI, presents special CF Ireland Paris2Nice Cycle tops to some of the CF Ireland Paris2Nice cycle team. The cyclists wearing their new tops pictured with Philip Watt are Tim Fulcher, Barry Jones and Paul Sheeran.

A big thank you to the cyclists and cycle top sponsors: TLC Group, Jones Investments Ltd, Hermitage Medical Clinic and Tekno Surgical.

M+W Group Fundraising Day

David Denver, General Manager, and Jennie Lytton of M+W Group, Maynooth, Co Kildare, organised a fundraising day in aid of CF Ireland including a bake sale, coffee morning and mini-raffle. They recently presented a cheque of €4,67 to Maria Caldwell, CFI.

123.ie

A huge thank you to all the staff of 123.ie for helping to raise €3,840 through a staff charity football match and a twitter campaign. CF Ireland visited their offices in Sandyford and were delighted to be presented with a cheque by Padraigh O’Neil and Aoife Greene from 123.ie to Suzanne Brock (centre) from CFI.

Castleknock Localise Car Wash raises €680 for Cystic Fibrosis

On a sunny Sunday in May, Castleknock Localise set about raising much needed funds for Cystic Fibrosis, a cause that is very close to many of their hearts. Earlier in April the group decided that they would plan, organise and carry out a fundraising carwash during Sunday masses at Our Lady Mother of the Church in Castleknock. Preparations began in earnest and with a few practice runs the group were ready with buckets, sponges and plenty of enthusiasm for their carwash on the 18th May.

The parishioners of Castleknock brought their cars a-plenty to the church and the Localise members and a few extra volunteers commenced their car washing with vigour. After a busy few hours the Localise group hung up their sponges and counted up their takings, reaching the grand total of €680, a great triumph for the group.

To find out more information about Castleknock Localise or to volunteer as an adult leader please contact Theresa on 085 7082149, or email theresa.oleary@localise.ie.
Whelan’s gig
Pictured backstage at Whelan’s of Wexford Street, are all the wonderful musicians who gave their talents for the ‘Songs I Wish I’d Written’ gig recently. All proceeds from the gig were donated to TLC4CF to help with the fit-out costs for the new adult CF centre in University Hospital Limerick that is due to open in 2015.

The musicians that took to the stage were BellX1, Ham Sandwich, The Walls, Gavin Glass, Superfly, Sarah Lynch and John Sheahan from the Dubliners.

MC for the evening was Fred Cooke from the Republic of Telly, with a little help from Sile Seoige on the backing vocals and raffle duty!

The packed-to-capacity audience heard a soulful version of Raglan Road before all performers came on stage to perform the magical finale. Special thanks to Sarah Lynch and her family and friends for organising such a unique and emotional musical celebration for Cystic Fibrosis.

Fundraising in Foynes raises nearly €10,000 for CF
Two fundraising events during the Foynes Irish Coffee Festival week have raised nearly €10,000 for TLC4CF! The Foynes 5km run and the Knockpatrick Garden ‘open-week’ raised the much needed funds for the new CF unit in University Hospital Limerick.

Knockpatrick Garden, an award winning garden outside Foynes, has been welcoming visitors and raising funds for CF for years. Our thanks to the O’Brien family for their hospitality and for selling so many cookbooks, trolley tokens and raffle tickets! Agnes O’Brien, who organised both fundraisers, was also very pleased by the turnout for the 5km run, which was started by world renowned sports coach Ger Hartmann.

Cards 4 all Occasions
As part of their final push to raise the funds to furnish the fit-out of the new Cystic Fibrosis adult unit in Limerick, TLC4CF have launched a new set of beautiful charity cards that are suitable for every occasion. The cards will be invaluable for anyone who has ever searched for a card for an event at the last moment!

Included in the pack of 8 cards are: a wedding, new baby, congratulations, thank you, sympathy, blank scenery and two birthday cards. Cards are gender neutral, vibrant and a generous size. There are 8 cards in a pack and they are selling for €8. Anyone who is interested in buying the cards should check out the TLC4CF website or Facebook page for more details.
New Face in Fundraising

Introducing Peter Minchin, Community & Branch Fundraising Co-ordinator, CFI

My name is Peter Minchin and I am delighted to be taking on the role of Community & Branch Fundraising Co-ordinator for Cystic Fibrosis Ireland.

I am a native of Co. Carlow. I studied Business Studies in Waterford Institute of Technology where I graduated with a Bachelor of Business Studies in 2005. Following this I spent a number of years working in both the financial services industry and sales support roles before joining Cystic Fibrosis Ireland.

My youngest brother Paul (RIP) had Cystic Fibrosis and sadly passed away in 2011, four years after receiving a Double Lung Transplant in the Mater Hospital in Dublin. As a result I am very much aware of the importance of the work carried out by Cystic Fibrosis Ireland on behalf of people with CF and their families around the country.

My role within Cystic Fibrosis Ireland will involve supporting and co-ordinating fundraising events around the country to help raise much needed funds for the many services provided by CF Ireland. One of the first events that I will be focusing on in the next few months is the Head2Head Walk in aid of the CF Beds for Beaumont Campaign which was a great success in 2013 and with your help and support we hope to make 2014 even better. I will also be involved in supporting the numerous other branch led events around the country over the coming months and any individuals/groups out there who would like to support CF Ireland through fundraising please don’t hesitate to contact me.

I look forward to meeting our members and supporters through the course of my work over the coming months and would love to hear from you if you have a fundraising idea or event that I can be of assistance to.

If anyone wishes to contact me, my details are as follows:

e: pminchin@cfireland.ie

01 496 2433
Help the CFI Ireland LIFE SUPPORT Campaign

Because Ireland has the highest prevalence of Cystic Fibrosis in the world, many people will know someone who is living with Cystic Fibrosis. However, fewer may know how tough it is to stay well when you have CF and the support that Cystic Fibrosis Ireland provides to help people with CF stay well.

There is a constant daily battle for people with CF to maintain their health, often with scores of pills and other medications to take every day and a challenging regime of exercise and physiotherapy that will take at least 2 hours every day, even for those with CF who are comparatively well. For those of our patients who are less well and who may be constantly dependent on oxygen, waiting for a lung transplant or who will spend weeks as an inpatient after a worsening of their condition, the daily treatment regime is much longer and even more of a struggle.

There is a constant battle for funding for CF hospital facilities; for research, for equipment and assisted living. Those with CF and their families contribute daily through determination and perseverance of treatment, but with cutbacks we increasingly need public support to maintain crucial CF services.

With the support of Cystic Fibrosis Ireland and the current advances in medication and our wonderful care teams in CF centres, more people with CF can now hope to be a mum or a dad, perhaps even a grandparent — a dream that was impossible when CFI was set up in 1963 and when children with CF were not expected to reach primary school.

Help us through your donations for CF Life Support.

Donate Details
Text HelpCF to 50300 to donate €2.

100% of text cost goes to charity across most network providers. Some providers apply VAT which means a minimum of €1.63 will go to CF Ireland. Service provided by LikeCharity 01 4433778.