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### CEO’s Message

Welcome to the Spring issue of Spectrum in which we look towards 65 Roses Day and our annual conference.

We hope that you will be able to join us at our annual conference in the lovely Mount Wolseley Hotel in Tullow, County Carlow on the last weekend in March 2019. Remember you can still participate for free by attending the Saturday of the conference 9am-4.30pm or join us by live stream on www.cfireland.ie or if you are busy that weekend we will have the podcasts on our website within three weeks of the conference.

CFI continues to battle for funding for the CF unit in Beaumont Hospital. We are joined in this process by local charity CF Hopesource and we are making some progress, but we need government sanction for funding before the general election which many forecast will be within six months.

It has been a very busy period for CFI in recent weeks as we gear up for 65 Roses Day on the 12th of April. We would be grateful for your support on 65 Roses Day. There are four ways to get involved: Buy a purple rose, take on a 65 Roses Challenge, volunteer on the day or donate online. Go to page 22 for more information.

Our annual report for 2018 is now available on our website and we hope you will take time to read it. Thanks again to all the fantastic work of our board led by Patricia Duffy Barber (Chairperson).

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**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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Philip Watt, CEO, CFI

Samantha Byrne & Nuala McAuley, Editors
Advocacy Activities

It has been a busy time with preparations for the Annual Conference and 65 Roses Day. In addition to this, CFI continues our advocacy work for funding for the CF unit in Beaumont Hospital that was promised in the Programme for Government in 2016. We are also urging the Government to fulfil their promise about changing organ donor consent in Ireland, again promised in the Programme for Government. We recently met with 53 TDs and Senators on these two issues.

UK Government and Vertex, still no agreement

Unlike people with CF in Ireland, those living in Northern Ireland and in England, Scotland and Wales still have virtually no access to the ground breaking precision drugs Orkambi and Symkevi.

This is really unfair, particularly to patients and their families in Northern Ireland who can see patients south of the border benefitting from Orkambi and Smykevi. There is some speculation that the delay in approving these drugs is related to reluctance by the NHS to commit the needed additional funding in the wake of the uncertainty on Brexit, but this remains speculation.

Orkambi

Orkambi is the second precision drug to be licensed in the UK for use in people with cystic fibrosis, the first was Kalydeco which impacts on potentially 10% of the CF population in the UK (13% in Ireland)

- Orkambi treats the double F508del gene alteration, which impacts on around 50% of people with CF in the UK (as compared with 57% in Ireland)

- Orkambi is a combination medicine, made up of ivacaftor and lumacaftor. Lumacaftor helps get more proteins to the surface of cells in the body, and ivacaftor helps the chloride channels in the cells to operate more effectively. The combination of these two things helps to keep a healthy balance of salt and water in the organs – particularly the lungs. Orkambi is manufactured by Vertex Pharmaceuticals.
**Orkambi only available in the UK on very limited compassionate grounds**

- According to the 2014 CF Registry Report in the UK, there are 2,834 people with CF in England, 243 people in Scotland, 118 people in Wales and 101 people in Northern Ireland who could benefit from Orkambi.

- Orkambi has been licensed for use in the UK for people with CF over the age of two who have two copies of the F508del mutation. Despite this, the National Institute for Health and Care Excellence (NICE) the equivalent of the NCPE in Ireland has rejected its use.

- In June 2016, NICE recognised Orkambi as an important treatment.

- NICE were unable to recommend Orkambi for general use within the NHS (including NI) on grounds of cost-effectiveness and a lack of long-term data.

- Orkambi is currently only prescribed to people on compassionate grounds. Compassionate use means that Vertex Pharmaceuticals provide the drug to people who fulfil a number of criteria. Contact your clinician for more information on compassionate use.

- Orkambi was extended for use for 6-11 year olds by the European Medicines Agency in Europe in January 2018, and was again licensed for 2-5 year olds in January 2019 - these extensions are available in Ireland.

- Symkevi, which in many ways is an alternative drug for those that are eligible but do not benefit form Orkambi, is also not available in the UK except on very limited compassionate use grounds.

- The absence of the NI administration in Stormont is a major drawback for people with CF as the Civil Service in NI have delayed meeting with patients.

We know all CFI members in Ireland will be concerned with the lack of availability of Orkambi and Smykevi in the UK.

The absence of Orkambi and Symkevi in the UK may dissuade PWCF and their families from moving to the UK, and may limit their employment opportunities otherwise available outside of Ireland.

**Patient families in Northern Ireland refused a meeting on Orkambi by Stormont Health Official**

According to the Belfast Newsletter (11 March 2019), Stormont’s top health official has refused to meet families who are demanding access to Orkambi. The paper reports that ‘Northern Ireland patients are caught in the middle’. They give the example of Liam McHugh from Tyrone who told the Newsletter that his 26 year old daughter Rachel whose life had been transformed by Orkambi and another family who said they will be forced to move home to the Republic of Ireland if Orkambi was not made available. The Cystic Fibrosis Trust in the UK continues to campaign for Orkambi and Smykevi in England, Wales and Northern Ireland. The Permanent Secretary for Health in Stormont contended that a meeting with parents should be deferred until they have had a chance of exploring the potential of introducing the same arrangements that were available in Scotland.

**Vertex CEO Remuneration Package Criticised**

The Guardian newspaper (6 March) reported that Vertex Inc has been criticised for a $78.5m remuneration package (pay and stocks and shares) for its CEO in 2017 making him the third highest remunerated healthcare CEO in the United States.
Positive developments in Scotland and other countries

In contrast to Northern Ireland, England and Wales in December 2018 the Scottish Government confirmed that a deal has been reached with Vertex pending the submission of Orkambi and Symkevi to the Scottish Medicines Consortium (SMC). In the meantime, interim access will be possible through a system they have which is called the PACS Tier 2 system. PACS 2 can be used by senior clinicians to request access to licensed medicines on an individual patient basis that are either not recommended for use in NHS Scotland following evaluation by the SMC or where SMC advice is awaited. Cystic Fibrosis Today (3 January 2019) reported that Vertex will submit an application to the SMC on Orkambi, Symkevi and Kalydeco reimbursement in the near future.

Orkambi is fully reimbursed in nine countries including Australia, Austria, Denmark, Germany, Ireland, Israel, Italy, Sweden, the Netherlands and the United States.

Five Feet Apart

‘Five Feet Apart’, a film about two teenagers with cystic fibrosis is due to be released in Ireland in April.

The film is the story of two teenagers with cystic fibrosis who fall in love, despite the challenges posed by their condition and by cross-infection. As their connection intensifies, so does the temptation to throw the rules out the window and embrace that attraction.

‘Five Feet Apart’ seeks to cover a lot of real life challenges facing the CF Community including adherence to treatment, cross infection, isolation, clinical trials and the impact a diagnosis can have on a family.

These are challenging subjects so we must commend the film makers in producing such a film, which is very different to a factual documentary.

Just to stress, no one in Cystic Fibrosis Ireland has seen the film, nor have we been part of the film’s production, but we are hopeful that the movie will be a positive opportunity to increase awareness of CF and the challenges people with cystic fibrosis face living with their condition.

The film has been classified as 12A, deeming it appropriate for viewers aged 12 and over or for those under the age of 12 provided they are accompanied by an adult. The film may contain scenes which some viewers may find upsetting and as with all films there are likely to be some scenes filmed for dramatic effect rather than strict reality, so viewer discretion is advised.

As with all films there is likely to be different views, we would really welcome your feedback on the film!

If you would like to discuss any issues raised following viewing you can contact a member of the CF Ireland Member Services Team as follows:

Samantha Byrne – 01 496 2433 / sbyrne@cfireland.ie

Caroline Heffernan – 087 932 3933 / cheffernan@cfireland.ie

Rory Tallon – 087 932 3930 / rtallon@cfireland.ie
SPOTLIGHT: Hobby Horses

The media regularly reports on how we are leading busier lives and have less free time and there is no doubt that the stress of everyday life impacts on our mental health.

Studies have proven that having a pastime is good for your physical and mental health as it helps to relieve stress, reduces depression, gives social support and challenges you which in turn can lead to better sleep, increased energy and an increase in confidence.

A hobby is defined as an activity done regularly in one’s leisure time for pleasure. A hobby can be creative, physical, relaxing, outdoors, indoors, individual or part of a team or club.

In this Spotlight we hear from members of the CF Community about their hobbies and the impact they have on their lives. Hopefully their stories will inspire you to pursue a pastime that ignites a passion for you.

GAME FOR ADVENTURE

Growing up in my family, we usually played a lot of board games especially draughts, chess, ‘Guess what it was’, ‘Play the game’ and monopoly etc.

I carried on playing chess during secondary school, but only in the last few years have I started to play chess more with my friends. I love it so much, we even played chess on the morning of my wedding, and it did calm my nerves.

You can get a great feeling when you plan out your next move and try predicting your opponent’s next move, but after playing too much against one particular friend we kind of know what our next move was going to be unfortunately.

I also played cards growing up like 45, 110 or Poker (for Poker we used match sticks instead of money). The whole family played together which of course resulted in some bickering, but this soon changed to laughter…..well most of the time :)

After secondary school, I played poker with friends or sometimes at Casinos, and I loved it. I played it for a few years which kept my mind fresh and occupied while my health was declining. It also helped me to have that quality time with family and friends when I couldn’t go out or do more physical activities. Then I just stopped just before I had the transplant. I’m hoping to go back one day.

Around 2007 a friend of mine invited me to go-karting for his birthday, I had never driven one before, but I loved watching rally races, so I thought I would give it a go. I was terrified that I would be bad at it and would have others overlapping me, but once I started to build up my confidence I started to drive better. I would go travelling to different go-kart centres all over in Ireland where we would race for fun and where I met new people and made a lot of new friends.
The go-karting was a great way to forget you have CF as the adrenaline rush was so great. I just love the feeling of racing fast, trying to predict your next manoeuvre or sometimes even a near crash is still fun.

I joined the Irish Deaf Go-Karting which is at amateur level. We travelled to different places such as Northern Ireland and England. The Euro-Nations competition, which is where each country competes against each other, was also fun.

Unfortunately, my lungs started to decline and I went on the transplant list in 2011. I had refused to go on the list a previous time, but in 2011 I stopped racing. I got transplanted in late 2014, which was very successful.

In 2016 I was asked if I wanted to go go-kart racing for fun, so I went to the go-karting centre, but as I went around, what you would call the warm up lap, I hit the barrier on my side and I felt a pop. I thought I had broken my rib or something as I was in so much pain that I couldn’t move or drive home. I actually had to get my friend to drive me home. I went to the doctor and it turned out it was just a bruise, so the pain went away a few days later. I kind of avoided going back to go-karting as I was frightened when I had hurt myself.

After a long break, in 2018 I went back and raced in county Louth with friends where I finished every lap without any problems which I was delighted with.

I hope that one day I will race for Irish Deaf Go-Karting.

**Nick**

“It’s as natural as breathing to want to be in the theatre”

Actor Kenneth Branagh was the one to utter these words and they have resonated with me ever since I heard them. Believe me when I say I am not ignorant to the subtle irony hidden amongst this statement. For the last 12 years, performance has played a bigger role in my life than I would have ever imagined. From primary school productions to dancing ballet in the National Concert Hall, the allure of being onstage has long been irresistible.

Having been raised in a home where music was commonplace, beginning ballet at the age of 6 seemed so organic. There was no sense of my mam shoving me into a pair of ballet slippers just so I had something to keep me occupied on a Saturday. I truly loved what I was doing. Prancing around that room, most likely making a complete fool out of myself, I unearthed a passion within me that has led me to so much more.
Living with cystic fibrosis, I have never once felt incapable. I firmly believe this is due to the undying love and dedication I have towards a craft I continuously aim to hone. Whilst I cannot hold a candle to the stars of Golden Age Musicals, (here’s looking at you Julie Andrews), I am proud of how far I have come throughout the years. No performance can summarise this more than Nenagh Choral Society’s 2018 production of “My Fair Lady”. Taking on the lead role of Eliza Doolittle truly encompassed every ounce of hard work I had put in to develop my abilities. Having been a member of Nenagh Choral since 2008, auditioning for this role took ten years of confidence building. Recognising that not only did I have the talent to pull it off, but that I had earned it. After five spectacular nights of staging, the show came to a close, and my levels of pride and satisfaction were astronomical, practically bordering on conceited. I can honestly say that few other experiences in my life can compare to the feeling of elation I felt when I took my final bow.

Behind all this however, was a much deeper sense of delight in myself. A feeling, that believe it or not, came solely from the existence of CF in my life. With two months to go until the show I was admitted to St Vincent’s Hospital for the very first time. Having never been hospitalised due to my CF, this first admittance for IV’s really devastated me. Both my parents and I had worked so hard for the previous 18 years to prevent this very scenario. But alas here I was. And do not get me wrong, I am eternally grateful for my standard of health. I recognise that I am blessed to have had 18 hospital free years, but none the less it was a tough pill to swallow. However, as the saying goes, “the show must go on”, and so I did. I learned lines as antibiotics fed into my line and rehearsed lyrics as I rebuilt my strength. I came out the other side raring to go. In a strange way the experience bettered me. I do not think the role would have meant as much to me had I not wanted so badly to prove I could do it.

Reflecting on this a whole year later, whilst once again I sit in a hospital bed, it’s clear to me I would not be the person I am today without theatre in my life. Since finishing up on “My Fair Lady” I have taken up vocal coaching and joined UL Drama Society, taking part in one of their two autumn semester productions. I can say without a doubt that this is one of the best decisions I have ever made. Not only has it allowed me to explore an entirely different aspect of performance, but it gifted me with an entirely new family. One who can both appreciate my passion for drama and allow me to feel something greater than myself. Performing has filled me with a confidence I never believed I could have and led me to friends I treasure more than anything.

As far as CF is related, yeah it does impact me on occasion. Sometimes singing is overtaken by coughing. Dancing can be just that little bit too strenuous. Or worst of all, an unplanned hospital stay means you pull out of your upcoming play (my apologies to the Drama Society). But at the end of the day I like to think of Kenneth Branagh’s words. For me, theatre really is just as natural as breathing. As long as my love for theatre exists, I’ll give it lung function of 110%.

Alannah
Don't Worry, BEE Happy!

My name is Oliver O’Brien. I come from Kilbrittain, a small village in West Cork. I am 43 years old. I was diagnosed with CF when I was 5. I was not thriving and coughed a lot and as my older brother had CF, a sweat test confirmed that I had CF also. Sadly my brother passed away in 1983 aged 9. I am fortunate to be on the milder end of the CF spectrum and have lived a relatively normal life. My parents always encouraged a sporty, outdoor lifestyle and as a result, I keep relatively fit and have never spent a night in hospital as a result of CF. I am taking Kalydeco for a few years which has helped me maintain my level of fitness and quality of life.

I’m a beekeeper!

I was introduced to beekeeping a few years ago through a guy at work. Having never really expressed an interest in bees up to then, I can say now that I’m fascinated by the whole world of beekeeping. Bees are fascinating creatures, essential for pollination throughout the world. Most of the food we eat has had to be pollinated at some point and bees play a huge role in this process. The ancient art of beekeeping is a very interesting hobby. The job of the beekeeper essentially is to help the colony or hive of honeybees to survive. In the modern world, honeybees in particular are under huge pressures from climate change, over use of pesticides, predators such as the Asian Hornet, disease and pests such as the Varroa Mite. All these issues make it a challenging time for the bees and the beekeeper. However, with improvements in disease control and treatments, and changing attitudes towards climate change and pesticides, there may be a positive future for our honeybees.

I have a few hives that keep me busy especially during the summer months. There is great satisfaction to inspect a beehive and see it doing well, a large colony of healthy bees, a strong Queen and plenty of brood (young bee larvae). The Queen is the most important bee in the colony. A Queen-less hive is doomed to failure. She is the organiser of the colony and determines everything that happens within the hive. To spot the Queen in a colony of thousands of bees takes a trained eye and there is a great feeling of relief when you do see her on a frame. She is a master at hide and seek! The rest of the bee population is made up of female workers and male drones. The workers do all the work from nursing the young larvae, feeding & cleaning the Queen, ‘housekeeping’, and when mature, foraging for pollen and nectar. The drones have one job. That is to mate with a new Queen!

There are many local beekeeping associations around the country and I would encourage anyone to try beekeeping. It is a hugely rewarding hobby especially at the end of a season and you can taste your own local natural honey. There is simply nothing better!

Oliver

www.cfireland.ie
MY JOURNEY THROUGH DANCE AND CF

My name is Georgia Duncan, I am 12 years old, I have cystic fibrosis and I love to dance.

I was diagnosed with Cystic Fibrosis at the age of 15 months. I started my journey in Our Lady’s Hospital in Drogheda. Since then, I have been working my way through Cystic Fibrosis. At the age of 4 I had to get a peg in my stomach as I was unable to keep weight on.

Cystic Fibrinous affects the lungs, pancreas, liver and many more organs in your body. Ireland has the highest incidence of cystic fibrosis in the World, there are over 1300 people in Ireland living with this condition.

CF patients have a lot mucus in their lungs which sticks to their organs which makes you unwell. It is vital that you have a good exercise regimen.

Dancing is how I achieve my exercise.

I started freestyle disco dancing at the age of 8 years old. In the beginning we weren’t sure if I would be able to keep up or compete, but with hard work and dedication and belief I competed in my first competition and at the age of 9 and I came 1st and I became under 10 beginner world champion. This was start of my dancing journey.

I train three hours a day, five nights a week in my dance studio with my dance family. This has been keeping me so well that I haven’t had a hospital admission in 4 years! The doctors and nurses keep saying how well I have been. My PFTs are up to 109 per cent at my clinic. I do cartwheels for the nurses at every clinic.

For those who don’t know freestyle dancing is an intense sport where people get costumes with diamonds, get their hair done and wear makeup and tan when they’re competing. Freestyle dance is a great exercise for me because I move around and keep the mucus moving around my lungs. There are lots of competitions that I do around the World.

I would love to keep dancing in my older years and become a dance teacher. I am now one level away from the highest level in the dance world. I have been made ambassador for Invictus a dance competition that has raised money and awareness for cystic fibrosis.

I wouldn’t be here if it wasn’t for my Mam and Dad and Temple Street so thanks for listening to my story. I hope people that are suffering really badly can be like me and one day be able to do some exercise.

Georgia
LINE UP, LINE UP!

Hi my name is Sharon and I am 44. My life can be divided into two. The first 22 years were great! Although I was diagnosed with CF as a baby, I spent my youth playing every sport going and my summers swimming in Youghal beach. I played camogie with Midleton and got an All-Ireland Secondary School camogie medal. The only time I saw indoors was food time and bed time. I cycled, skated (four wheels) and went clubbing. I worked weekends in Roches Stores while at college, I then worked my way up to full time in Roches Stores – life was going well, working and socialising and living on my own in Cork city.

Then BANG, I got epilepsy in my early 20’s and had to give up swimming, cycling to work, and eventually I had to give up work and my flat and move home. I sank into depression and didn’t want to go anywhere outside my safe place on the couch. My family, close friends and my GP were very good to me.

A few years later I went to my local library for books one day and saw a bunch of women having a laugh and talking away while knitting and crocheting, and for the first time in a long time I felt a reaction to something, I got hooked – pardon the pun! I used to love crochet when at school. Those ladies welcomed me into their group and there were no questions asked - just turn up when you feel up to it and come for coffee after. Four years later I go every Tuesday. I have made baby blankets, hats, ponchos for kids, a ring cushion for my sister’s wedding and my proudest thing I made was the christening shawls for the twins.

Then I decided I needed something else to do that was exercise, but would not feel like exercise. Around 3 years ago I saw a flyer for line dancing classes starting up and a few of the Tuesday ladies and I went and I have never looked back. I go to class once a week and there is always a social night on and weekends away. I have increased my lung function and speed test has upped, but even better I am exercising without knowing I am doing it.

Sharon

Music is the spice of Life

My name is Sara. I’m 32 years old and was diagnosed with CF when I was two. I was very fortunate to get a double lung transplant nearly 13 years ago in the Freeman Hospital in Newcastle.

For as long as I can remember, music has always been a huge part of my life. My parents always had music on around the house and my Dad has been playing guitar and performing in bands since he was a teenager.

I began to learn how to play piano when I was six and took part in choirs and dance groups from an early age too. I was really lucky to have a hugely influential music teacher, Mary Amond O’Brien. Her passion for music was
hugely inspiring and influential in developing my own love of music. I was never great when it came to getting involved in sports growing up. Less due to CF and more due to my inability to catch a ball! But I did make it to Mosney for Community Games a couple of times growing up...albeit as part of a choir...!

With music, I found it helped me to make friends and connect with people. This was really helpful, particularly when many of my school friends would spend their weekends cycling around the country roads and meeting up. This wasn’t always possible for me if I was having a chest exacerbation but I could connect with my peers at a dance class or a choir practice. For this reason, CF never really impacted my involvement in music, instead it enabled me to continue to get on with my childhood and adolescence and continue to feel “normal” even if I was unwell.

I continued to join music groups and choirs as I progressed through secondary school. Whenever I was hospitalised for the usual two week stay of IV antibiotics, this was often when I would discover a new album or music artist. There are albums that I now listen to that bring me right back to sitting on my bed in St. Michael’s Ward in Crumlin as a frustrated teenager. They remind me of a difficult time but a time that, in hindsight, I would never change. Indeed, it was during the hazy initial few days after the transplant I couldn’t get one song out of my head. Sheryl Crow’s “All I Wanna Do is Have Some Fun”. Telling of my intentions, once I got home from Newcastle!

When I was able to begin my Primary Teaching degree in St. Patrick’s College, a few months after transplant. I studied music as my additional subject. I was part of the choir in the college and started to learn classical flute alongside piano. Again, I found that it was the other students in my music class that I had the most in common with. Indeed, it was over a love of Kanye West that myself and one of my classmates and now best friends bonded, driving up and down to college at the weekend...!!

Now as a Primary teacher, I am able to bring my love of music into the classroom and have continued to take part in different music groups, most recently with the Carlow Gospel Choir. I love being able to help out with anything music related in school and this year, my new project is to learn the trumpet, just to keep these new lungs on their toes!

I feel very lucky not only to have gotten the transplant and to have been able to lead a relatively normal adult life but also to have had a passion that has brought me such joy in the good times and in the tough times.

Sara

Sister Act the Musical!

My name is Shauna. I’m seventeen years old. I’m in fifth year in Coláiste Bríde in Enniscorthy.

I have loved singing and listening to music for as long as I can remember. I grew up with a musical family and as a child, I had an MP3 player that I would listen to wherever I went, singing along without even realising. I was raised listening to whatever my family played in the house, and I have been able to sing the guitar solos from Bohemian Rhapsody and Don’t Stop Me Now since I was in junior infants.

I got a guitar for my eleventh birthday, but I didn’t put my mind to learning how to play until I was about to start secondary school. I fell in love with
playing and started to play ukulele, bass and a very limited amount of piano. I never had much confidence in playing in front of anybody until second year, when we got a new music teacher who was very helpful and supportive to me. She said that I had talent but that I lacked confidence, and while I didn’t realise it at the time, she helped me to build the confidence that I have now. She let me play guitar in the senior choir and started to give me solos and put me into group singing in the hope that I would overcome my nerves and share my music with others. I achieved a lot in the two years that she taught me - I started my YouTube channel, played my own small gigs, recorded in a studio for the first time and I sang in front of the whole school at the annual Christmas Quiz. Without her help I wouldn’t have had the confidence to do many of those things.

I’ve come very far since she left my school, too. I started to write my own songs during the months after I did my Junior Cert and played at busker festivals, pub gigs and even weddings. During Transition Year, I had the opportunity to do work experience in a local recording studio where I learned about how equipment is set up in the studio and how songs are put together from scratch, and I even got to record one of my original songs, 23:47, which is available on Spotify, Apple Music, Google Play and most other music platforms.

From the time I first started playing music, I worked very hard at it because it has always meant a lot to me. I love the feeling of accomplishment when I finally finish learning a new song and get to perform it to people. Writing songs has helped me to express my emotions during both good times and bad times and listening to music helps me to concentrate on school work.

In 2012, my little brother, Tom, was born. We have an age gap of ten years and I loved him from the day he was born. I always sang to him and danced with him to the radio in the kitchen. In 2013, our little sister, Ruth, was born. At one day old she was moved to the special care unit of Wexford General Hospital as she couldn’t sustain her feeds and three days later, she was moved to Crumlin. When she was around two weeks old she was diagnosed with DDF508 CF. She is pancreatically insufficient, but we are very lucky that apart from that, she is very well. She is on a high dosage of Creon and she’s on Tobi nebs.

When Ruth was diagnosed, everybody in my family was routinely genetically tested, and this is when we discovered that my mam has two mutations, DF508 and R117H, meaning she also has CF. This was a big surprise to us because she had been a smoker for years and her lungs were still more than good for someone suffering from CF. She had digestive issues when she was younger but she put that down to the fact that she had her gallbladder removed when she was twenty.

My mam and Ruth being diagnosed with CF brought a lot of change into my life. I feel like I did a lot of growing up very quickly in the months that followed, but I was surrounded by helpful and supportive people. My music also really helped me through this time. It helped me to forget the things that were going on around me and to focus on taking songs and making them my own. I have since played music at fundraisers for CF and plan to do so again in the future. Tom and Ruth both really enjoy singing with me - Tom, now six years old, is learning to play the ukulele and Ruth, who is now five, has an incredible ear for harmony.

To this day, Mammy and Ruth are both doing very well - Ruth is starting Orkambi this month, which we are so thankful for as it will help her to keep well and have the best quality of life that she can. I’m still working on my music and writing songs. You can find me on YouTube (Shauna Hever), Instagram (@shaunahevermusic) of Facebook (Shauna Hever Music).

Shauna
**Designer Life**

In April 2008 our first child Harry arrived into this world, the first grandchild on both sides. There were battles at the maternity ward door to get in to see him! Within hours we had a feeling something was not right as he was vomiting bile and soon after he was whisked off to Crumlin Hospital with a Meconium ileus and so began our CF journey.

Being a graphic designer and working in one of Ireland’s largest design companies, I hummed and hawed about what to do in regards going back to work. The thought of leaving my fragile child in the hands of a minder or crèche was not something I could fathom and I made the huge decision to leave work and become a full time carer. Lots of friends and family at the time were having babies and as each baby was born I made them a little card or picture to welcome them and then one day I had the brainwave... I loved doing this... why not open my own little part time business, and so Duckblue.ie was born. This was 10 years ago this month.

My company has gone from strength to strength over the last 10 years. Having the freedom to be a carer for my two children, to be there for them at home as well as being available for hospital clinics, pharmacy collections, surgeries and admissions, yet work part time each morning at something I love, when they are at school, has given me so much joy. I create bespoke cards and pictures and my ethos is simple, I create cards you want to keep...

My cards and pictures are mostly bespoke. What makes them different to shop bought cards is that almost all of them are hand drawn. It’s coming into Communion season which is a big part of my business. People love to order personalised cards of the child in their outfit in front of the church. It’s a lovely keepsake for a special occasion, and I think with CF in our lives we learn all the more to cherish these very special days. Wedding and Engagement cards are also very popular but my favourite to make is probably new baby cards. I illustrate the babies name and I just know the minute a family opens this card they are usually new customers for life as that feeling of love when you open a card and you know someone special got this made for you or your child is very emotional.

Every Christmas I make a Christmas Card range and I give 10% from the sales of these cards to CF Ireland. My customers love to support such a wonderful charity and I love giving this donation as a gesture of thanks for all CF Ireland do for me and my family.

In 2018 I was accepted to do an expansion course with Kildare LEO and the Design Council of Ireland. I learned so much from this course. In a way I couldn’t believe my little business was picked out as one of the best of Kildare and the confidence boost it gave me has really changed my life. I would never have taken the step to open my own business if my child was not born with CF. He and my daughter have taught me to follow my dreams, take chances and live. Life is short and the fact I can be at home, care 100% for my family and run a small business is just wonderful. I really feel blessed.

**Ruth**
Ireland’s 2nd Annual Cystic Fibrosis Art Exhibition

Welcome everyone to our second art exhibition! Last year we made an impression. One that told people who we are as a community and the achievements we can reach together. Now let’s show people what we can really do.

This year’s theme is “Expression of Experience”. This can be any experience that made an impact on your life and the world around you. Let this be a chance to branch out and make a statement on where you are going. Tell the world a story of you.

All artists must be PWCF. The piece can be as large as 30” x 30”. One piece per person is allowed. The medium can be drawing, painting, computer art, fabric craft or ceramics. Your piece can be mixed media. Please ensure you have a way to hang or display your piece. All art must be submitted to CB1 Gallery, O’Connell Street, Limerick (for the attention of Sara Cross) by the first week of May including personal information you would like included in the brochure. The photo of artist, photo of piece, short bio, age, location, name of piece and price, should be emailed to sara@centralbuildings.ie by Friday 26th April 2019.

The event is to take place from May 20th – June 2nd and will have an opening launch. Full exhibition is to take place at Central Buildings (CB1) Gallery in Limerick City, open weekdays to the public. Entrance is free. Cross infection guidelines apply, but private viewings of the event can be scheduled in advance.

Thank you for participating and please feel free to contact me at anytime. You can reach me by phone on 0851533968 or email sara@centralbuildings.ie.

Sara Cross

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Heading away in 2019? Got Questions?

Travel Insurance
Taking medications abroad
Traveling with Oxygen
CF Clinics abroad
Talking to your CF team

Call Rory Tallon on 087 9323933 or
Caroline Heffernan on 087 9323930

Enjoy your holiday!
Cystic fibrosis affects our lungs, but what do we know about our lungs? Let’s learn!

Our lungs are one of the biggest organs in the body, they help us to breathe - inhaling fresh air and exhaling stale air, help us to talk and sing, swallow, laugh and cry!

We have two lungs, but they aren’t the same size!

Can you name other parts of the body that come in pairs? Are these identical?

The lungs are located in the chest and protected by the rib cage. You can’t see your lungs, but you can feel them! Put your hands on your chest and breathe in deep, when you inhale your lungs will grow and your chest will get bigger. When you breathe out your chest will become smaller as your lungs release the air!

As we breathe and the air moves around our body it gets warmer. Which is why in cold weather we can often see our breathe when we exhale, as it is warmer!

When we have colds and flus it means bugs have gotten into our lungs, these bugs can irritate the lungs which make us cough more. A good way to keep our lungs healthy and free from bugs is exercise! When we exercise we breathe more deeply so our lungs need more air and work harder, this means we give the bugs less chance to settle!

Like air moving through our body when we breathe, can you navigate your way through the maze?

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Wordsearch Solution

Winter 2018

What Am I?

You can hold me without using your hands, but not for very long!
Living with CF can be unpredictable. Sometimes plans have to change due to feeling unwell or requiring a hospital stay. It doesn’t matter how far in advance you made the plans or how well you have been adhering to your exercise and treatment regimes, sometimes things are out of your control. This can be hard to accept, especially when it is something that you have been looking forward to. Often people use an event as a motivator to improve their health - wanting to make sure you are in the best shape possible for the class trip or a family holiday or making sure your lungs are in top condition to sing along to your favourite artist at a concert or festival. When this is the case, if you become unwell and can’t attend the event it can be even more frustrating. The frustration makes way for a wave of emotions - anger, disappointment, jealousy, annoyance, stress. Having these feelings is natural, but how do you react in these situations? Managing what we say and do when experiencing a range of negative emotions is called Emotional Intelligence. While controlling what we say, how we say it and what we do is something we can all do, it isn't always easy. Below are some tips on how to better manage emotional reactions:

RECOGNITION
Say what you feel - say it to yourself, say it to your parents, say it to a friend or write it down, but acknowledge what the feeling is.

UNDERSTANDING
Once you know what you’re feeling, you can understand why you feel that way. If you’re unwell and can’t attend a concert that you’ve been looking forward to, of course you are going to be angry and upset.

ACCEPTANCE
Knowing what you are feeling and why you are feeling it will allow you to process the feeling. Being annoyed at missing something you were looking forward to is a normal reaction. You are entitled to feel what you feel.

DON’T COMPARE
Never compare yourself to anyone else. Maybe someone else you know missed out on the event too and while it may seem they are dealing with it better there are no comparisons between you. The reasons they are missing out are different to yours, they may have had more time to deal with it, they may not have been looking forward to the event as much as you. Comparing yourself to someone else can make your feelings worse, so try not to do it.

COUNT IT OUT
In the moment, when feeling negative emotions we can say things we don’t mean that can be hurtful to others. This can than lead to us feeling guilt on top of our other negative emotions and add to our burden. Counting to 10 is always a good way to help us think before we speak!

CHANNEL THE ENERGY
Use the energy, the anger, the frustration and channel it into your exercise or a hobby, check out the Spotlight section on page 4 for some interesting hobbies.

TIME’S UP
While it is important to let yourself feel your emotions, it is important not to dwell so give yourself time and then try to move on. Set your own time, don’t rush it, but allow yourself to see an end point.

Learning to react will take practice, but practice means progress.
It’s been roughly 65 months since I last contributed to Spectrum. On the 27th of September 2013, I am writing about my experience as a participant in a film week run by Helium, a children’s charity here in Ireland who work to transform the healthcare experience of children and teens through the arts. I took part predominantly via Skype, and in the article, I chronicle the highs and lows of that experience as an online participant, from my official acting debut to the odd dropped call. Let’s call this article ‘The Original Piece’. On the 20th of February 2019, I’m reading The Original Piece again, delving into the mind of a 16-year-old who thinks the Junior Cert is the be-all and end-all, and who has yet to join Facebook. She’s not a half-bad writer, though she makes a point of bringing her cat into a story that, really, he needn’t have been in at all (for those interested, however, he is now a waddling mass of tabby fur and laziness who remains at the centre of my universe in both my mind and his). In that way, so much has changed in the last 65 months but also, so much hasn’t.

For a start, writing is as much a part of my life today as it was six years ago, though not in the way I would have expected. In 2013, I was gripped with writing fantastical tales: teenagers with the ability to control the elements, and shape-shifting dragons who attended secondary school. My dream was to write the next Harry Potter, and I don’t think I’d given any thought to writing about ‘The Real Stuff’. Funnily enough, The Original Piece is my first ever attempt at something quasi-journalistic, and in many ways could be called ‘the place where it all began’. In the second year of my undergraduate degree – the year I joined my university’s student magazine as a section editor – I don’t know if I looked back on that article and recognised it as the milestone that it was. I do now.

Another chasm of difference between 2013 and now? In 2013, my Achilles heel was a fear of admitting that I not only liked to write, but that I actually did. My face burned every time a relative or friend declared my endeavours to a group: ‘She likes to write! She’s writing a book!’ (I still cringe a little now and can’t quite bring myself to re-read those early drafts). This embarrassment was far from something I was in denial about – there’s a line in The Original Piece that makes me glow whenever I read it: “I said that I wanted to be a writer when I was older [...]. To be able to say that in front of a group of people with no hesitation was a whole new experience for me because it’s not something I normally do. Looking back on it, I can see how the project really boosted my confidence in that way.” I could not have anticipated fully the formative power of my involvement with Helium at that early stage, but in the span of a few short months I had come to recognise that a switch – some switch – had already been flicked in my brain: more confidence? More pride? I think I realised that being a writer was not something reserved for those with a surname like ‘King’ or ‘Rowling’. I also realised that wanting to be a creator was far from unique, and that that was an enormously good thing. The more, the merrier, the messier, the more creative. In 2019, you are living under a rock if you know me well enough but don’t know that I write. We are one and the same thing, my writing and me. It helps that I post about it a lot on Facebook, which I did eventually join.
Something else The Original Piece draws attention to which I hadn’t expected to see: the issue of disclosure. I don’t refer to it in those words, but it’s there from the very beginning in my whistle-stop tour of my childhood as a PWCF: in how I laugh at my ‘uniqueness’ in taking tablets before I eat, and at the weirdness of having an illness that no one knows about unless they play detective (or just ask). If Helium normalised my love of writing, it also set the seed for normalising my disability. In these last four years especially – in the mind-stretching experience that is a university education – I have come to recognise that the daily popping of prescription pills is far from extraordinary. That doesn’t diminish from the gravity of the reason for taking them, but it’s been a humbling lesson: I can be as ordinary or extraordinary as I want – CF does not set the standard because that power rests with me. (Permit me to indulge, nonetheless, for a moment, in the abnormality of my situation. To those lovely people I still haven’t had this conversation with: Hey. How are you. If I’ve offended you, then I apologise; I don’t like drawing attention to things, least of all myself. Let’s grab a coffee and a slice of chocolate cake and we can try to guess the fat count. And if you’re unconcerned, wonderful. Let’s have cake anyway).

The end of The Original Piece is probably my favourite part. “I don’t intend to let CF stop me trying any of it,” I say, referring to my wild, literary aspirations for the future. It’s a line that would make for a stern act of defiance if I knew what I was really saying – if I had a morsel of an idea what it means to fight in the face of someone’s assertion that you can’t, shouldn’t, couldn’t. I didn’t know that feeling then and I certainly don’t know it now. CF has never figured in my life as an obstacle – even putting those two concepts in the same sentence makes me feel uncomfortable, disingenuous, like I’m aspiring for a tragedy without the hamartia – though I don’t doubt that that experience, like any, is subjective at best. I can only speak for myself – boldly, this one time, with an eye to both past and present – that CF has been a site for change, for growth, for opportunity all throughout my life. I wouldn’t have the piece from September 27th without it, nor would I have the one that you just took the time to read (thank you). I wouldn’t have spent that wonderful week in November writing scripts and thwarting fears, and who knows where my writing would be without that singular time? Better still: who knows where I would be without my writing?
Vertex Plans to Ask for Extended Approval of Symkevi in Europe for Children with CF Ages 6-11

Results from a Phase III trial demonstrated that Symkevi (tezacaftor and ivacaftor combo) is safe and can effectively improve lung clearance in children with CF aged 6 to 11 years. Based on these results, Vertex Pharmaceuticals is planning to submit a request to the European Medicines Agency (EMA) in the second half of 2019 to expand Symkevi’s label to include this patient population – children who have CF due to two copies of the F508del mutation in the cystic fibrosis transmembrane conductance regulator (CFTR) gene or one copy of the F508del mutation plus one residual function mutation.

This comes on the heels of a supplementary new drug application that Vertex submitted in 2018, with the US Food and Drug Administration, seeking an extension of approval of Symdeko (the name of Symkevi in the US) for the same indication.

The Phase III clinical study (NCT03559062) enrolled 67 CF children, from 6 to 11 years old across 23 sites in Europe and four in Australia. All participants had CF caused by either two copies of the F508del mutation or one copy of the F508del mutation and one residual function mutation.

The children were randomised to receive Symkevi, ivacaftor alone or a placebo for a total of eight weeks. The main goal of the study was to evaluate changes to the lung clearance index (LCI), which is a measure of lung ventilation capacity, during the period of treatment. LCI is considered a more sensitive measure to detect early lung disease than forced expiratory volume in one second (FEV1). Higher LCI scores indicate poorer lung function.

After the treatment period was completed, children treated with Symkevi showed a mean difference in LCI of -0.51 points, compared with the other groups, which indicates a significant improvement in lung clearance.

Generally, the treatment was well-tolerated, as described in clinical studies previously and no additional safety issues were identified. The most common side effects reported in patients treated with Symkevi were cough, headache and productive cough. No serious adverse events or side effects leading to treatment discontinuation were observed. Currently, Symkevi is approved in the EU for the treatment of CF patients aged 12 or older with specific mutations.

Study shows Interesting associations between Pseudomonas Aeruginosa Infection and Disease Severity

Patients with CF whose lungs have never been colonised by Pseudomonas aeruginosa bacterium have a milder form of the disease, a retrospective study based on registry data indicates. The study, “Clinical and microbiological characteristics of cystic fibrosis adults never colonised by Pseudomonas Aeruginosa: Analysis of the French CF Registry”, was published in the Journal Plos One.

Pseudomonas aeruginosa in the airways can cause inflammation and subsequent pulmonary exacerbations that impair lung function over time. Previous reports from national CF registries in the US, Canada, France, Germany, Ireland and the UK all suggest that Pseudomonas aeruginosa prevalence increases with age up to 20-25 years old and then stabilises at 50-70 percent afterward. This means that 30-50% of CF patients do not have Pseudomonas aeruginosa. These percentages also include patients who have been infected but cleared of the bacterium by antibiotic treatment.

To better understand the predictive features associated with Pseudomonas aeruginosa infection history, a research team in France assessed the difference between patients with reported Pseudomonas colonisation and CF patients with no clinical history of Pseudomonas aeruginosa colonisation.
The study analysed data from 2,130 patients, ages 20 and older, in the French CF patient registry between 2013 and 2014. Of these, 1,872 had been reported positive for Pseudomonas aeruginosa at least once and 303 had no documented history of Pseudomonas colonisation.

Researchers compared clinical features of CF patients, including age, CFTR mutations, pancreas-related implications and lung function. They also analysed associations between Pseudomonas aeruginosa exposure history and the prevalence of other pathogenic bacteria. They found six clinical features that were independently associated with CF patients without documented Pseudomonas aeruginosa infection: older age at diagnosis, absence of diabetes, absence of F508del mutations in the CFTR gene (the main cause of CF) and FEV1 equal or greater than 80%, which is considered a normal value, indicating preserved lung function.

In particular, analysis of CFTR mutation types showed that a lack of F508del, a common mutation in CF, in both alleles (maternal and paternal) was significantly associated with patients with no documented Pseudomonas aeruginosa history. F508del is linked to about 70 percent of defective CFTR alleles and has been shown to predispose CF patients to infections by opportunistic pathogens such as Pseudomonas aeruginosa.

Negative correlations between four preventable or treatable comorbidities, or coexisting conditions, and the absence of Pseudomonas aeruginosa infection were also found. Patients who had never been colonised by Pseudomonas aeruginosa showed an absence of aspergillosis (which is common in CF patients), diabetes and pancreatic insufficiency. Furthermore, compared with CF patients with previous Pseudomonas aeruginosa colonisation, these patients also had preserved lung function.

When researchers further analysed the association between bacterial infections and the two patient groups, they found distinct microbiological profiles related to patients without reported Pseudomonas aeruginosa histories. Specifically, this patient group was significantly associated with the presence of Haemophilus influenzae and absence of Stenotrophomonas maltophilia, Achromobacter xylosoxidans and Aspergillus spp. The researchers note that retrospective studies, although valuable, cannot confirm any causal relationships in CF patients with or without Pseudomonas aeruginosa.

Queens University Belfast breakthrough offers hope to patients with CF

In people with cystic fibrosis (CF), the inflammatory response to infection in the airways is excessive. It is believed that this inflammation causes progressive injury to the airways leading to bronchiectasis (abnormal widening of the bronchi) and loss of lung function.

Up until recently there were limited treatments which looked to specifically deal with inflammation in CF. There were attempts to reduce inflammation by suppression of infection and clearance of airway phlegm but it is only with the recent Queen’s University breakthrough that we are really beginning to see much in the way of promising new potential anti-inflammatory treatments.

Queen’s University researchers have discovered a new treatment which could improve the lives of people suffering from CF through inhibiting the activity of a specific enzyme found in the lungs, cathespin “S”, which has been linked to inflammation. The researchers’ breakthrough builds on a previous study in which they found that high levels of cathespin “S” in the lungs of children with CF were associated with increased inflammation and lung damage.

Cliff Taggart, the lead investigator, from the Wellcome-Wolfson Centre for Experimental Medicine at Queen’s University, said the discovery could make a huge difference. He said that they know that this enzyme plays a key role in provoking symptoms of chronic lung diseases such as CF and COPD. The discovery of a treatment which targets this specific enzyme could significantly reduce inflammation, lung damage and mucus obstruction in patients with CF.

Many drugs are developed as enzyme inhibitors, but they don’t target specific enzymes. The specific targeting of the Cathespin “S” enables the delivery of a more targeted treatment to address symptoms without side effects.
19th National Cystic Fibrosis Clinical Meeting Killarney

The 19th National Cystic Fibrosis Clinical Meeting took place on Thursday 31st January and Friday 1st February 2019 in the Great Southern Hotel in Killarney, County Kerry. The Clinical Meeting demonstrated that CF care has undergone an incredible evolution over the past few decades with many speakers at the meeting outlining how an increasingly complex and time intensive approach to treatment has left us with many questions around what are the best diagnostic tools and tests to inform CF care going forward:

Best Diagnostic Tools and Tests to Inform CF Care

- Owen Tomlinson of the University of Exeter outlined the benefits of cardio pulmonary exercise testing (CPET) over more traditional methods of exercise testing in CF
- Elizabeth Owen, Specialist Dietitian at Greater Ormond Street Hospital for Children, London, explained the significant limitations on using body mass index (BMI) as compared to lean body mass (LBM) and fat mass (FM) which are more sensitive nutritional parameters in CF, with greater association to pulmonary function
- Dr. Felix Ratjen, Division Chief of Paediatric Respiratory Medicine at The Hospital for Sick Children in Toronto, Canada, talked about how the lung clearance index (LCI), measured by multiple-breath washout, is more sensitive that spirometry to detect lung function in children with CF who may have a relatively good FEV1. LCI could be used to develop novel and earlier interventions and improve outcomes for children with CF
- Professor Harm Tiddens, Professor of Paediatric Pulmonology at Erasmus MC-Sophia Children’s Hospital, Rotterdam, Netherlands, explained how computed tomography (CT) imaging was a better diagnostic tool than more traditional imaging techniques in CF such as X-Ray. He further explained that morphological changes seen with CT scanning often precede the functional changes identified with pulmonary function tests and thus should be used as a complement to the information provided by the pulmonary function tests.

Another theme that came up at the clinical meeting was the significant work that has been done in Ireland to get CF services up to recognised European and National standards.

Standardisation of CF Care

Professor Charles Gallagher, Clinical Lead for the National Clinical Programme for CF, gave a presentation on the painstaking work of developing a CF model of care for Ireland. In the past the evolution of different CF models of care or care pathways developed on a local and regional basis. Referral pathways were ad hoc and there was significant variability in the way CF care was delivered in different parts of the country. The publication of the Pollock Report in 2005 (commissioned by CFI) and the HSE Report in 2009 went some way towards shaping and continuing to shape
the model of care for CF in Ireland. The reports highlighted a number of detrimental short-comings in the care being afforded to people with CF in Ireland, particularly the shortages of staff and inadequate facilities and services. Within the last decade, Ireland has established a network of CF centres wherein specialist services have become available. While a lot has been done, there is ongoing and challenging work to standardise CF care in Ireland.

Professor John Moore, Clinical Microbiologist at Belfast City Hospital, talked about the absence of standards in the diagnosis and characterisation of fungal disease in CF. This included a discussion of the lack of standardisation of fungal tests amongst laboratories and the need to update existing microbiology guidelines to reflect both new methodological innovations, as well as better knowledge of fungal disease pathophysiology in CF.

Professor Billy Bourke, Paediatric Gastroenterologist at our Lady’s Children’s Hospital, rued the lack of standards for the treatment of CF liver disease. For reasons we do not fully understand, in some people with CF the liver becomes damaged over time, resulting in scarring (fibrosis and cirrhosis). There is no specific treatment available for CF liver disease. Ursodeoxycholic acid is a bile fluid that stimulates bile flow. It is widely used to treat CF liver disease and has “limited” side effects. While it may help to prevent and delay the progress of CF liver disease, there is a need for consistent, evidence based standards for the treatment of CF liver disease.

Adherence in CF

Another issue to emerge from the clinical meeting was adherence. Adherence to increasingly complex treatment regimes in CF is time consuming, intrusive and an often overwhelming responsibility. Novel approaches will be required both to improve adherence and decrease the burden of treatment.

Currently, the treatment regimen for CF involves respiratory, antimicrobial and nutritional therapies. It may also include therapies for other CF-related complications such as diabetes, liver disease and chronic pain or depression. As new therapies for CF particularly CFTR modulators are developed, the number and complexity of therapies will continue to increase.

Dr. Alistair Duff, Clinical Psychologist at the Leeds Teaching Hospitals NHS Trusts, addressed some of the psychosocial supports required to overcome the challenges to adherence and self-management of the disease.

Dr. Etna Massip of the Hospital Universitario y Politecnico de La Fe in Valencia Spain, updated the meeting on “MyCFAPP”, an app which uses games to improve nutrition and adherence to treatment in children with CF.

Note: This is not an exhaustive account of all of the presentations given at the clinical meeting. There were also fascinating presentations given on the real world application of CPET exercise testing (Ronan Buckley, Senior Physiotherapist, St Vincent’s University Hospital), on viral infections in CF (Dr Cillian De Gascun, UCD) and on gram negative pathogens in CF (Dr Siobhan McClean, UCD).
For further details on any of our fundraising events, visit our website [www.cfireland.ie](http://www.cfireland.ie), contact the CFI Fundraising Team on (01) 496 2433 or email [fundraising@cfireland.ie](mailto:fundraising@cfireland.ie)

**April 12th: 65 Roses Day**

Cystic Fibrosis Ireland 65 Roses Day will take place on Friday 12th April. We are looking for your support to help raise funds and increase awareness of Cystic Fibrosis across the country. There are 3 ways you can help support Cystic Fibrosis Ireland on 65 Roses Day.

1) **65 Roses Day – Friday 12th April**

65 Roses Day is our National Flag Day and our emblem, the CF Purple Rose will be on sale across the country for €2. Thank you to everyone who has so far offered to get involved by helping to sell purple roses and those who are organising events as part of 65 Roses Day. If you feel you can help out then please get in touch with our office as soon as possible so we can arrange to send you a fundraising pack. You can contact us by calling our office on 01 496 2433 or emailing fundraising@cfireland.ie. Our 65 Roses Day campaign will be featured across TV, Radio, Press and Social Media in the run up to Friday 12th!

2) **65 Roses Challenge**

The 65 Roses Challenge is to organise a ‘65’ themed fundraising event in support of the 65 Roses campaign. Previous examples of challenges include a 65 Roses Tea Party, a gym doing 65 exercises in 65 minutes and schools holding a ‘No Uniforms Purple Day’. The challenge can be as simple or as challenging as you wish, so get your thinking caps on. For more ideas, check out our 65 Roses Challenge Event on our FB Page. If you would like to discuss an idea or need fundraising materials then please call us on 01 496 2433 or email fundraising@cfireland.ie

3) **65 Roses Text Donate**

Support 65 Roses Day by texting 65 Roses to 50300 to donate €2 to Cystic Fibrosis Ireland or donate online at www.65rosesday.ie.

Text costs €2. Cystic Fibrosis Ireland will receive a minimum of €1.80. Service Provider: LIKECHARITY. Helpline: 076 6805278.
April 28th: Virgin Media London Marathon

Cystic Fibrosis Ireland would like to wish our three runners Aisling O’Neill, Olivia Cotter and Mary Gavin the very best of luck in the London Marathon. We would also like to wish the very best to David Crosbie (double lung transplant recipient) and his team who are continuing their quest to complete the Big 6 marathons, having successfully completed the New York City Marathon in 2017, the Berlin Marathon in 2018, they have now moved on to the London Marathon in 2019. The plan is that this will be followed by the Tokyo Marathon in 2020, the Chicago Marathon in 2021 and the Boston Marathon 2022, all the time raising monies to support people with CF.

May 9th to 12th: Malin2Mizen Cycle4CF

We are delighted to confirm that we have already reached our target of 40 cyclists for the Malin2Mizen Cycle4CF for 2019 and registration is now closed. We have a great bunch of enthusiastic cyclists taking part in the cycle this year with the What’s App group buzzing with excitement in anticipation of this life changing challenge. Good luck to everyone with the training and fundraising for the event. We would ask everyone that can to come out and support the cyclists over the 4 days of their 640km cycle which will take them from Malin Head in Donegal (May 9th) through Sligo / Mayo / Galway (May 10th) on to Clare / Limerick (May 11th) and finishing in Mizen Head in Cork (May 12th). They deserve your support so get your Purple T-Shirt on and give them a supportive cheer along the way!

April 13th: 6.5k Remembrance Walk

Cystic Fibrosis Ireland, with the support of our branches across the country, are holding 6.5k Remembrance Walks on Saturday, April 13th. The day will see people nationwide walking 6.5k in our purple t-shirts at 2pm to remember and celebrate the lives of those we have sadly lost to Cystic Fibrosis.

The event will help to continue to increase public awareness of Cystic Fibrosis in Ireland and raise funds for CFI, so we can continue to provide support and services for people living with Cystic Fibrosis in Ireland.

You can register now to participate in a 6.5k Remembrance Walk in your area or contact us if you would like to organise a walk locally. Help us turn Ireland purple on Saturday 13th April in memory of our CF Angels. Contact fundraising@cfireland.ie for more information.

www.cfireland.ie
June 2nd: One in 1000 / Vhi Women’s Mini Marathon

Will you be the One in 1,000 for CFI and take part in the Vhi Women’s Mini Marathon for Cystic Fibrosis Ireland?

The 2019 Vhi Women’s Mini Marathon will take place on Sunday, June 2nd this year. One person can make a difference! You can be that one person for Cystic Fibrosis Ireland by registering to take part in the Mini Marathon as part of our One in 1,000 campaign.

Once you have registered for the race at www.vhiwomensminimarathon.ie, you can sign up with us to be the One in 1,000 for CFI and get your fundraising pack (t-shirt, bandana and sponsorship cards) by filling in our sign up form. Registration for the race is NOW OPEN!

If you have never fundraised for Cystic Fibrosis Ireland for the Vhi Women’s Mini Marathon before, you are in for a treat! We will throw a pre and post-race party for all our fundraisers and provide you with:

- Cloakroom
- Facepainter
- Food (hot food and sandwiches)
- As much water as you could need!
- Goodies (protein bars, bananas, jellies)
- DJ with some great tunes
- Selfie station & professional photographer
- Raffle to win fantastic prizes!

So what are you waiting for? Come and join us and 1,000 other women as we turn the streets of Dublin purple on Sunday June 2nd! Go to www.onein1000.ie or contact Rachel in the office on 01 496 2433 / rbyrne@cfireland.ie.
Sept 14th to Sept 19th: Paris2Nice Cycle

It’s not TOO LATE, there is still a limited window to sign up for Paris2Nice Cycle in 2019. This is always a memorable event for all those who take part so if you are considering it, we would highly recommend signing up for this event sooner rather than later.

Cyclists will fly to Paris on Friday 13th September and begin cycling on Saturday 14th. The cycle makes its way along beautiful country roads with plenty of food stops in the scenic villages and towns along the route. The cycle will finish on the Promenades Des Anglais on Thursday 19th where you will be greeted by the welcoming team followed by a celebration dinner that night. Cyclists are free to fly home the following day or some choose to make a weekend of it in the beautiful city of Nice.

We would encourage anyone thinking of taking part to let us know here in the CFI office by calling us on 01 4962433 or email fundraising@cfireland.ie. We also suggest you sign up for Paris2Nice mailing list on the website www.paris2nice.com where you can also find details of the upcoming information evenings.

Sept 15th: Head2Head Walk

Our Head2Head walk takes place on Sunday 15th September.

This walk goes from strength to strength as more and more walkers hear about this wonderful event, walking along the sea front in a wave of purple Head2Head Walk shirts. 2018 was our biggest walk to date and we would now like to make 2019 even bigger, are you up for it?

Registration is NOW OPEN at www.cfireland.ie. If you have any questions, please contact christina@cfireland.ie.
Sept 20th to Sept 27th: Paddy Kierans’ Memorial Walk in ‘Glorious Greece’

The CFI International Walk which takes place from September 20th – 27th will explore unique and beautiful Greece. The walk caters for various levels of fitness, so that each walker can take part at a pace they are comfortable with.

The Walk, which starts in Glyfada and finishes in Athens, will see participants walking an average of 10km each day and taking in sights such as the green hills of Sounio National Park, the islands of Aegina, Poros, and Hydra, the National Park of Mt. Parnitha, the Ancient Footpath into Delphi, the Temple of Poseidon, and the UNESCO World Heritage site of the Acropolis.

The fundraising target for the Walk is €3,150 and this will cover all costs including flights, accommodation and meals. For more information on the Cystic Fibrosis International Walk 2019, contact Rachel Byrne at rbyrne@cfireland.ie or call 01 496 2433. Alternatively, you can visit www.cfireland.ie and download the Walk application form.

There are limited places available so we urge you to book as soon as possible to avoid disappointment!

“In 22 years I have completed 20 International Walks. It has been the greatest experience of my life visiting places that I may never have experienced otherwise. I have made lifelong friends and memories to treasure forever” - Bernie Murphy, lifelong Cystic Fibrosis Ireland International Walker

Oct 27th: KBC Dublin Marathon

Were you one of the lucky ones to get a coveted spot in the now SOLD OUT KBC Dublin Marathon? If not, there will be an extra 2,500 places on sale in July... go go go!

For those of you who’ve managed to grab an entry... now that you’ve signed up and started your training, why not consider fundraising for a charity as part of your marathon challenge? We would be delighted if you could fundraise for Cystic Fibrosis Ireland!

Contact Rachel at rbyrne@cfireland.ie / call 01 496 2433, and she will send you out your fundraising pack and let you know how to get started on your fundraising.

Nov 3rd: TCS New York City Marathon

Registration is now open for the TCS New York City Marathon 2019. The marathon starts on Sunday 3rd November and runs through all 5 city boroughs (Staten Island, Brooklyn, Queens, The Bronx and Manhattan). CFI are pleased to say we can offer you a guaranteed entry as part of a tour package which includes:

- Direct return flights from either Dublin or Shannon to New York
- 4 or 5 nights’ accommodation
- Return airport transfers
- Private coach from the hotel to race start on Staten Island
- Guaranteed race entry
- Services of Sports Travel guides

As places are limited we advise anyone thinking of taking part to register as soon as you can. If you would like to sign up or find out more then please contact the fundraising team.

RUN FOR CF!

Bernie Murphy
**Dec 13th: Christmas Jumper Day 4CF**

On Friday 13th December, we are encouraging as many workplaces as possible nationwide to support Christmas Jumper Day 4CF.

Interested in getting involved? All you need to do is...

Email or call the CFI Fundraising Team to register your workplace and we will help you organise everything for the day!

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**All Year:**

**Schools Fundraising Resource Pack**

CFI have written to all Secondary schools as part of our School Outreach Program, which aims to educate pupils on Cystic Fibrosis and introduce pupils, especially in Transition Year, to charity work. We are asking all schools to support our 65 Roses Challenge campaign for 65 Roses Day on Friday 12th April by:

- Organising a 65 themed fundraising event. This could be any event such as 6.5km walk/run to a 65 minute football match
- Holding a Non Uniform Day on 65 Roses Day with CFI wristbands available in exchange for a €2 donation from each pupil on the day
- Selling our Purple Roses for €2 in your school for 65 Roses Day or organise for your school to volunteer to support a fundraising collection organised by CFI in your local area.

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**Skydives**

If you have a skydive on your bucket list then don’t delay, You will never forget the feeling of the aircraft door opening, sliding over and falling out. You will feel the force of the 200km wind blasting on to your body like nothing else. You’ll be glad to know that breathing normally is perfectly fine and easy to do during freefall. You will experience freefall for up to 35 seconds. It’s a great way to raise money and have fun all at the same time.

For anyone who would like more information on it please contact Brendán on brendan@cfireland.ie.

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**Kilimanjaro**

CFI facilitate treks to Kilimanjaro, so if you are thinking of taking part in a trek, we advise that you book your place early.

For more details and a full list of tour dates, please see our website www.cfireland.ie or contact Brendán on email at brendan@cfireland.ie.
FUNDRAISING:

Thank You

It is not possible to list all of the Fundraising Events that have been organised since our last edition of Spectrum, but we would like to take this opportunity to thank everyone that has volunteered and raised money on behalf of people with Cystic Fibrosis. Every cent raised helps provide a better quality of life for people with Cystic Fibrosis and please keep up the great work.

Here is a short summary of some of the remarkable efforts of our volunteers:

Head2Head Walk
We would like to say a massive Thank You to all the participants, helpers and supporters for our Head2Head Walk in 2018, including our amazing committee led by Mary McCarroll and Jem Downes.

A total of €70,296.79 was raised making this our biggest Head2Head walk so far! We look forward to having you all on board again this year for another great year.

Indaver Ireland
Cystic Fibrosis Ireland would like to say a huge thank you to Indaver Ireland Ltd who participated in Christmas Jumper Day 4 CF and raised €3002.49.

Pictured above is (L to R) Fergal Smyth (CFI) Emma Tyrell and Sarah Tyrell (PWCF), Brendán O’Regan (CFI)

Republic of Ireland Soccer Supporters Club
A huge thank you to everyone in the Republic of Ireland Soccer Supporters Club in London who presented Cystic Fibrosis Ireland with a cheque for €3,250 from monies raised at their Charity Quiz Night on Friday 25th January in the Claddagh Ring in Hendon.

Well done to all involved!
Thank you to our Birthday Fundraisers!
You raised an incredible
€10,586.45
In December alone!

Facebook Birthday Fundraisers
A huge big THANK YOU to all of our Facebook birthday fundraisers! Can you believe that you raised a whopping €10,586.45 in December alone?

We really appreciate your small gesture, it creates a BIG impact.

Rita Mc Ginn & Margaret Gannon
CFI would like to say a huge thank you to Rita McGinn and Margaret Gannon who ran the TCS New York City Marathon last November and raised a whopping €31,313.40!

What an absolutely incredible feat. Massive congratulations to these two wonderful ladies!

Robert & Sinead Kennedy
Cystic Fibrosis Ireland would like to say a huge thank you to all in the Black Forge Inn, especially Robert and Sinead Kennedy, who raised an amazing €8,000 in November in aid of Cystic Fibrosis Ireland!

Huge congratulations and well done to all involved.

Christmas Jumper Day 4 CF
We extend a huge thank you to everyone who signed up and participated in Christmas Jumper Day 4 CF. Thank you for making our first year such a success. So far the day has raised an amazing €39,083.35. We look forward to seeing all your Christmas Jumpers again for Christmas 2019.
Will you be One in 1,000 for Cystic Fibrosis Ireland?

Join the One in 1,000 team and take part in the VHI Women's Mini Marathon on Sunday June 2nd for CFI!

Contact rbyrne@cfireland.ie / 01 496 2433 for more information!

Sign up at www.onein1000.ie