A Community in Bloom

Flower Power as CFI records the most successful 65 Roses Day to date!
CEO’s Message

CFI acknowledges that the COVID-19 crisis has been a very challenging time for our members. Normal CF services have been disrupted, for very understandable reasons and we very much hope they can return as soon as possible as part of the Government’s Roadmap to exit this crisis.

CFI wish to acknowledge and give a huge thanks to all those in the Government, Department of Health and HSE that have provided policy leadership and frontline services during the COVID-19 crisis.

Many of our CF hospital teams have been working long hours on COVID-19 as well as CF. Their dedication is much appreciated- we thank you for your dedication at a very difficult time.

CFI has sought to respond to the crisis by offering a range of additional supports, some of which are outlined in this issue of Spectrum. Again, many thanks to the Board of CFI and the dedicated staff of CFI who have ‘gone the extra mile’ to provide these services.

This issue of Spectrum gives an update on Trikafta and other key developments including Beaumont Hospital which shows that progress continues. We have also been active in our advocacy work, including the need to sustain the COVID-19 payments to ensure employees with CF are not pressurised into returning back to the workplace while cocooning is still in place.

Since March of this year all our fundraising has been ‘virtual/digital’ as all of our community fundraisers were cancelled. This issue of Spectrum particularly seeks to highlight all the support we have received- we could not have done it without you. Special thanks to those who supported 65 Roses Day/ Awareness week, we raised over €450,000 which is fantastic and will help sustain our work going forward.

Finally many thanks to the significant contribution of Patricia Duffy-Barber our chairperson who steps down in September and who reflects on the progress during her term of office in this issue of Spectrum.

Philip Watt, CEO, CFI

Nuala McAuley & Samantha Byrne, Editors
The Social Protection Needs of Employees who are High-Risk to COVID-19

CFI have been part of a joint submission to Government that seeks to highlight the social protection policy anomalies which are emerging during the COVID-19 crisis, in the context of people in Ireland who are designated High-Risk. A number of these individuals and their families are being caught between public health advice to ‘Cocoon’ and the economic need to earn money to support their family. Now a number of high risk individuals in employment face very significant problems and dilemmas as they are about to lose their enhanced COVID-19 payments.

The submission has been prepared by Disability Federation of Ireland, Muscular Dystrophy Ireland and Cystic Fibrosis Ireland. However we are aware that this is also an issue of concern for a number of other groups who are similarly affected.

Summary of Key Concerns and Recommendations

Many employees, who also happen to be high or very high risk from COVID-19 have been in receipt of the Pandemic Unemployment Payment (PUP) while their workplace was closed due to the lockdown. As the country begins to reopen their workplaces may also reopen. Current advice from the Department of Employment and Social Protection (DEASP), that high risk individuals will no longer receive the PUP once their workplace reopens, seems at odds with public health advice.

CFI contends that there needs to be a joint approach between public health advice and social protection provision in this regard. Many high risk individuals, and their family members, cannot currently return to their workplace due to the severity of the risk. Economic supports must be put in place to support high risk individuals to continue to follow public health advice and Cocoon/stay at home until that official advice changes.

The 3 organisations are asking the Government to:

• Consider the significant economic and health risks to high risk individuals in the context of the ongoing move towards reopening the country and the return to work.

• Issue advice and guidance to the government that it must economically support high risk individuals and family members who live with them, to enable them to protect their health and lives by continuing to stay home.

• Recommend that the PUP/enhanced illness benefit continue to be paid, and/or be extended to all high-risk people with disabilities and the family members who share a household with them, who cannot return to work due to their health status and the need to follow public health guidance.
Summary of CFI Response to COVID-19

In response to COVID-19 CFI has brought in a number of additional measures and initiatives. These include:

- Online exercise supports and mentoring (licenses paid by CFI)
- Anti-bacterial hand gel circulated to branches/members
- Frequent updates on a wide range of issues through our website and social media
- Advocacy on the Leaving Certificate
- Provision of online counselling to members
- Advocacy on the continuation of COVID-19 enhanced payments for employees at high or very high risk from COVID-19
- Support phone calls to members and parents
- Supporting 5 Hospital CF units to develop virtual clinics through funding
- Seeking earlier approval of Trikafta through a submission to the EMA
- Monitoring continued access to other CF medications
- Bringing forward the second round of the exercise grants
- Working with other respiratory NGO’s to produce educational webinars
- Developing a new digital fundraising strategy
- Developing well-being initiatives.

Beaumont Hospital Update

CFI continues to liaise closely with the management and design team in Beaumont hospital and our colleagues in CF Hopesource on the promised 20 room CF in patient unit in Beaumont Hospital.

Easyguide to Rare Diseases Launched by Minister Simon Harris to mark International Rare Disease Day

CFI played a key role in the research and publication of the Easyguide to Rare Diseases. The publication was edited and mostly written by Philip Watt, CEO CFI and financially supported by CFI in partnership with other rare disease groups, many of whom are much smaller and less resources than CFI. As well as providing profiles on people living with a rare disease, the publication includes consensus actions for Government, including the Programme for Government.

The Easyguide is the second edition of this publication and is published by the Rare Disease TaskForce (HRCI, IPPOSI an RDI) and is available on all their websites.
Keelin Shanley

Keelin Shanley was a true friend to Cystic Fibrosis Ireland. She supported our awareness campaigns for many years in her role as an honorary ambassador for our association.

Keelin was of course best known as a very fine journalist with RTE News and current affairs. She died of cancer in February 2020 aged 51 years.

In memory of Keelin CFI included a tribute to her in the recent joint publication to mark Rare Disease Day. At the same occasion we presented a memento to her husband Conor Ferguson to acknowledge Keelin’s wonderful contribution and support (Mansion House, Dublin on 27th February 2020).

‘And soon my friend we shall have no time for dances’ (Louis MacNeice)

Irish CF patients play a key role in extension of Kalydeco to children aged 6 months and over

Parent Seamus Conlon with support from other parents and CFI have played a key role in successfully advocating for the extension of Kalydeco to children who are 6 months and over who have the R117H gene mutation. This will enable about 50 additional children in Ireland to access Kalydeco (which has been available for other individuals in Ireland with the relevant genotypes since 2013, but was not previously available for those with R117H younger than 18 years of age).

The CHMP, a sub group of the EMA adopted a change to the indication for Kalydeco tablets as follows:

Kalydeco tablets are indicated for the treatment of adults, adolescents, and children aged 6 years and older and weighing 25 kg or more with cystic fibrosis (CF) who have an R117H CFTR mutation or one of the following gating (class III) mutations in the CFTR gene: G551D, G1244E, G1349D, G178R, G551S, S1251N, S1255P, S549N or S549R.

Kalydeco tablets are also indicated for the treatment of adults, adolescents, and children aged 18 years and older and weighing 25 kg or more with cystic fibrosis (CF) who have an R117H mutation in the CFTR gene.

Kalydeco tablets are also indicated in a combination regimen with tezacaftor 100 mg/ivacaftor 150 mg tablets for the treatment of adults and adolescents aged 12 years and older with cystic fibrosis (CF) who are homozygous for the F508del mutation or who are heterozygous for the F508del mutation and have one of the following mutations in the CFTR gene: P67L, R117C, L206W, R352Q, A455E, D579G, 711+3A→G, S945L, S977F, R1070W, D1152H, 2789+5G→A, 3272 26A→G, and 3849+10kbC→T.

The CHMP also adopted a change to the indication for Kalydeco granules as follows:

Kalydeco granules are indicated for the treatment of infants aged at least 6 months, toddlers and children weighing 5 kg to less than 25 kg with cystic fibrosis (CF) who have an R117H CFTR mutation or one of the following gating (class III) mutations in the CFTR gene: G551D, G1244E, G1349D, G178R, G551S, S1251N, S1255P, S549N or S549R (see sections 4.4 and 5.1).

Breaking news - at the time of going to print the European Commission has approved the use of Kalydeco for patients between 6 months and 18 years. Well done to everybody involved in getting this extension over the line.
Update on Trikafta

The new and innovative drug, ‘Trikafta’ otherwise known as the ‘triple combination therapy’, is due to be made available in Ireland as soon as it is approved by the European Medicines Agency (EMA). This is likely to be in the Autumn of 2020 but could possibly be earlier if ‘fast-tracked’ by the EMA.

This is a direct result of the progressive and welcome deal between the HSE and Vertex Pharmaceuticals in 2017 which not only provided the important bridging drug Orkambi, but also provided subsequent age and genotype extensions of CFTR drugs Kalydeco, Orkambi and Symkevi as soon as EMA approval was given- hence it has become known as the ‘pipeline (or portfolio) agreement’.

The most important outcome of the 2017 deal was the emerging knowledge that an even better drug was in the pipeline, a drug that had the potential to cover 90 per cent of the CF population worldwide. In effect this agreement means that along with Germany and Denmark, Ireland will be the first country in Europe to have Trikafta once approved by the EMA.

When approved in the United States of America, ‘Trikafta’ inspired the Director of the National Institutes of Health, Dr Francis Collins, to state in October 2019:

‘With the approval of Trikafta, most people with CF have, for the first time ever, a real chance at managing this genetic disease as a chronic condition over the course of their lives. That’s a tremendous accomplishment considering that few with CF lived beyond their teens as recently as the 1980s.’

The data from two studies provides the rationale for this excitement. Trikafta is a breakthrough treatment for people with CF aged 12 and over, that treats the underlying cause of CF and not just the symptoms. The first study was for those with the F508del gene mutation plus another gene mutation. The following is a summary of the results:

- Lung function increased by an average of 13.8 per cent compared with those on the placebo
- Pulmonary exacerbations decreased by 63 per cent on average
- Increase of body mass of 1kg/M squared on average

The second study was for those with two copies of the F508del gene and it was compared against Symdeco/Smykevi – a similar drug to Orkambi that was made available in 2018 in Ireland. This study showed that on average the lung function of those taking Trikafta was 10 per cent better than those on Symdeco/Smykevi.

While this is very welcome news for 90 per cent of people with CF worldwide – depending of course on national access approval, which is not a certainty in many other countries – there is an estimated 10 per cent who may not have any benefit from a CFTR drug because of their particular rare gene mutation. It is heartening, however, that there is considerable investment in other innovative therapies such as gene editing.

Cystic Fibrosis Ireland has made representations to the EMA to seek to ensure that the license for Trikafta covers as many gene combinations as possible and that it is approved as soon as possible. Early approval would also be advantageous in the context of COVID-19 as a generally healthier CF population in Ireland should mean that individuals are able to cope better with other infections.

It is too early to be conclusive about the long-term impact of Trikafta but the future appears bright. As with all drug therapies there will be side effects and it is important that these are discussed with your clinician, once the drug is approved. Trikafta will not, of course, undo damage that has already been done by CF. Next steps following approval in coming months and years will be to extend Trikafta to those under 12, and perhaps as early as six months, as we have seen with its sister drug Kalydeco.

CFI will update you further as information becomes available.
Chairperson's Chapter

Patricia Duffy-Barber is stepping down after her term as chairperson of CFI in September 2020. Trisha made a very important contribution to the work of CFI over the past 3 years and on behalf of all of us at CFI we know you will join us in thanking her for all her work.

Philip Watt, CEO.

I hope this finds you all well. It is a strange time for all our families still, isn’t it? Many of our PWCF have written in the press about how living in lockdown is similar to living with CF. It struck me how everyone described their own new found ways of coping. The conversation about supporting mental health in CF is always important and needs to continue over the coming months and years. I hope that we will all keep patient during the return to our pre-lockdown lives - it will be a marathon rather than a sprint.

Between working from home (myself and my husband) and my son’s ever increasing school work, keeping a work/life balance has been a complete challenge in itself. I’ve started committing to yoga (almost daily!) and find it is fantastic, in many ways, mentally and physically. I would recommend everyone to try and find some kind of healthy outlet for themselves as a parent/person with CF that is your one thing you do for you, it really helps.

Since our last AGM in Carlow so much has happened, it feels like a lifetime ago.

I am mindful of other CF friends and family we have lost since Carlow. Of note there was an all too brief spell between October 2019 and May 2020, when there were no deaths of PWCF. That is a ‘first’ in my recollection of over 20 years involvement with CF Ireland. Sadly in January this year, Seamus Bohan former Chairperson passed away. Seamus was Chair when I first took my seat at NEC representing the CF adult branch. Seamus’ tenure was at a time when the standard of services and supports were minimal. As a chairperson now, I recognise Seamus demonstrated a gentlemanly master class in maintaining order amidst very impassioned discussions about how to improve standards nationally. Ar Dheis De go raibh a anam dhilis.

Our AGM this year would have marked the conclusion of my term in the role of Chairperson. It is impossible to revisit all of the highs and lows since 2017 when I took over from David Fitzgerald as outgoing Chair. Both David and Philip expressed unwavering confidence in my ability to take on the role and I am grateful to PWCF advocate Caroline Heffernan who encouraged me out of my comfort zone into taking the role. I have learned a lot, and will be grateful for this chapter in my life. You will have to indulge me in some retrospection as I look back over my term.

This term of office coincided with the culmination of some life changing landmark projects achieved by CFI and its Branches; TLC4CF Limerick build at University Hospital Limerick, the paediatric in-patient rooms at Cavan, the out-patient unit in Drogheda and the four in-patient rooms in Waterford. I was often fortunate to represent CFI at the opening of these facilities. I witnessed the joy and relief felt by hard working branch members at seeing better facilities up and running.

It feels like a long time ago - in 2017 Kalydeco and Orkambi were a reality but we were still hoping for the other CFTR drugs to come down the pipeline; Symkevi and Trikafta were a long way off.

www.cfireland.ie
My term also coincided with increased financial stability in CFI & notably our partnership with Spar. I was astounded at how their support made a phenomenal contribution to our awareness raising across the country, and how they supported our community events like Malin2Mizen and Head2Head for Beaumont. In fundraising terms, Spar enabled us to raise our game. In terms of the supports CFI could offer families, it has been a partnership like no other.

It would be remiss of me not to mention National Awareness Week 2020. This year 65 Roses Day was shaping up to be a shadow of previous years, when suddenly a sleeping giant awoke. I was literally blown away to see the enthusiasm of people (many typically quiet about their CF) as they took to social media explaining about the virtual 65 Roses Day and generating fundraising challenges in their own home or community like never before. I was so proud to see the overwhelming enthusiasm and ownership of fundraising by people with CF and their families, you made it your national awareness week this year. Go raibh mile mile maith agaibh.

I was truly honoured to meet our President Michael D Higgins and Sabina at the Aras. To follow his address, being asked to speak on behalf of you all was a moment of fear and pride that will always stay with me. My dad keeps a photo capturing that moment to hand, and proudly showed each visitor to the house for months after.

I’ve had the pleasure of attending a number of interesting events, the recording and premiere of the Fight to Breathe Cinema campaign, the launch of the beautiful ‘Our Baby has 65 Roses’, the inaugural Christmas Jumper Day for CFI, our ambassador Michael Carruth’s Boxing event in the National Stadium and the launch of a number of National Awareness week campaigns. I was so proud to accompany / trail behind my husband Kieran on his second completion of the Malin2Mizen cycle! To see it first hand, Malin2Mizen is the embodiment of commitment and the CF family coming together to fundraise at its very best. I am constantly struck by the care and attention to detail by all of the staff (past and present) of CFI when at these events. Their consummate professionalism is a pleasure to witness; they always go above and beyond when representing CFI.

I have been honoured to represent the organisation and CF Community at a range of events and activities including (L to R) The launch of the Christmas Jumper Day Campaign, The Fight to Breathe Cinema Awareness Campaign and Launch of "Our Baby has Sixty Five Roses"
As the first person with CF to take the role of Chair, I am particularly proud that the Independent Living Report was designed and launched during my term. It made such an inspiring read when the findings from 2017 were compared to the circumstances in 1998. The measurable improvement in health services, opportunities and education was evident. It will be a repository for future research I’m sure. Several subsequent projects have been developed from this Report.

It is my only regret during my term that despite engagement from PWCF and a very dedicated subcommittee we didn’t get further with the issue of cross infection measures to facilitate PWCF to attend CFI functions. I’ve been aware when representing you at events that many PWCF would love to have participated, but due to risk of cross infection, could not be present.

Ironically, risk of infection with COVID has made us more creative about how we can get to grips with technology to connect and participate remotely. The staff at CFI including the PWCF advocates are now completely working from home and we’ve also held our first virtual Board NEC meeting. I hope it will be a lasting legacy of this year that we will finally use technology to engage directly with more PWCF than ever before. I am also hopeful about the potential for technology to change the nature of our outpatient clinic experiences.

Attending the launch of the National Clinical Programme for Cystic Fibrosis in 2019 with members of the CFI Board and Staff.

Leading the first zoom meeting of the CFI National Executive Meeting in May 2020.

It is traditional at the end of term to thank fellow Board members and Executive Officers of the NEC, and I am delighted to have the opportunity to do so. A harmonious mix of gracious experience and new enthusiasm, they have brought strong voices and passion to the table, representing their loved ones with CF and the families in their local Branches with commitment. They have also been patient and kept faith with the vision of the Association which necessitates a Director to be able to take account of the broader landscape involved in our decision making, including the agencies who deliver our services, the prevailing political landscape, our financial limitations and the needs of the CF community as a whole, not just the needs of their own loved ones.

I’d also like to mention Philip Watt who has been both an anchor and a visionary for CFI for many years. In his term of office, the lives of people with CF have been extended in quantity and improved in quality. He has been both a source of wisdom and a willing counterpart in debating the finer points of issues.

The new chairperson will be elected in September. I want to welcome the nomination of Christine Drummond, our current vice chairperson, who has been proposed as Chairperson by the Staff & Finance Committee. Christine as a parent of an adult with CF has seen the evolution of our Association over a number of years and we are lucky to have her to guide us forward. I didn’t assume this role to be a role model (to anyone other than my son) but now I am struck by the realisation that if other people with CF want to fully engage with CFI or any other organisation at the highest levels, my tenure at CFI should at least demonstrate that having CF shouldn’t be a barrier to their ambition.

Slán go fóill.

Trisha

www.cfireland.ie
As some members of the CF Community move into their fourteenth week of cocooning, PWCF Greg Foley recounts his experience so far. As a lecturer working online, he is embracing new technology and enjoying a break from the traffic. In this spotlight, Greg writes about the importance of treating and recognising mental health as well as physical.

As the country begins to reopen and restrictions are lifted, people with cystic fibrosis and those who are medically vulnerable are advised to stay home as much as possible and urged to use judgement on how best to apply the public health guidance.

While this remains a challenging time, Cystic Fibrosis Ireland would like to remind members that we are here to support you. CFI issue regular updates to members on our website, www.cfireland.ie

Details of supports available to members can be found on page 13

I’ve been in lock-down for over two months now and while there is a feeling of Groundhog Day about my current existence, I’m doing fine. It helps that I’m an introvert at heart and while I enjoy being with people I’m also happy enough to spend long periods on my own. It does help, of course, that we can all stay in contact with our friends and loved ones through WhatsApp and social media. Being locked-down in the 1970s would have been a much different proposition.

I’ll be 57 in June having somehow survived pretty much everything CF can throw at a person, including multiple infections, collapsed lungs, blocked bowels, years on home oxygen, and ultimately a double lung transplant (in 2002) and a kidney transplant (in 2011). Except for about nine months in 2003, I have worked without any major interruption since I was 23. I’ve been incredibly lucky and can’t claim any credit for my survival.

I’ve been a lecturer in DCU since 1986 and while the job has provided me with a lot of flexibility, it has been demanding. In a curious way, work, not CF, has dominated my life and if anything defines me, it’s my work. It has consumed me.

Anyway, by the middle of 2019, I was feeling very tired, both emotionally and physically. I think I was suffering from burnout and this was not helped by the fact that my transplanted kidney is not working very well. I had developed a sort of depression/anxiety for which I decided to take medication, medication that seemed to put me back on an even keel. I think we all need to be prepared to admit that we are suffering mentally and not try to battle through. We take bucketloads of medication for our malfunctioning bodies, so why not for our malfunctioning ‘souls’.
Nonetheless, the lock down period has been a welcome break for me. I’ve had to work, of course, because we had to move all our teaching online and that was a bit of a learning curve for us all. But I enjoyed the whole process - it was something new.

But now as things are quieter for me, I can pause and reflect, take it easy, read more, write a bit, and generally do the things that my work schedule didn’t allow. I go for a walk every day, usually before 9am, and I always wear a mask. I don’t miss the early starts, the sitting in traffic and the useless meetings that seem to be a feature of all workplaces. But I miss my friends and colleagues, and even my students. Students keep me young!

My only real worry in all of this is that my wife, Julie, who lives separately with my son, Leo, might catch Covid-19 and I’ll be left to bring up Leo on my own. Given my health and limited life expectancy, that is a terrifying prospect. But as I’ve done throughout my CF life, I try to park those fears and just focus on the here and now. That tactic has worked for me so far.

I’m not sure when, and if, things will go back to normal for me. My employer is understanding and knows that I may have to teach online for a lot longer than my colleagues but one thing I know for sure is that I’m not going to risk Leo’s future by being reckless and trying to be a hero.

So for now, I’m happy to live a day-by-day existence but I have to admit that I miss going down to Wicklow and walking in Glendalough and generally being close to nature. For now though I’m just glad to be able to hear the dawn chorus, louder than ever because of the reduced traffic levels. Life could be a lot worse.

Greg Foley
As we anxiously await the approval of Trikafta here in Ireland, we are delighted to share with you one member’s experience on this groundbreaking new therapy. This person with CF, who has chosen to remain anonymous, gives us a sneak preview of the encouraging results they have seen over the past six months. A member of CF Ireland, this PWCF is currently living in America.

Further information on Trikafta is available on page 4.

It is too early to be conclusive about the long-term impact of Trikafta but the future appears bright.

At the heart of this piece, I want to show you what Trikafta has meant for me. Because I want anyone reading this who will be eligible once it is approved, to feel hope. Trikafta is a game changer.

On the morning of the 3rd of December I sat at my work desk and took my first dose of Trikafta. I was on the phone to my mom talking about how nervous I was to take it. I had made myself a breakfast with the requisite level of fat—a bagel and cream cheese if you’re asking—and was just peering down at these two, small, light orange tablets. I had read so much about this drug. My work is in science and I have been avidly following Vertex’s developments, clinical trials, announcements and even stocks for years. I never bought stocks though, shame on me. My friend, however, on my advice, did buy some, and he is now forever indebted to me. I watched over the past five years but my gene combination was such that neither Kalydeko nor Orkambi/ Symdeko/ Symkevi were for me. So I was one of the ones who had to wait, but here I was, my day had come. I popped those pills and laughed with my mom at my dramatics.

To give some background, I’ll tell you the top notes about me and my journey. I was born in Dublin thirty five years ago. At six weeks old I was diagnosed due to the fact I was growing in length but losing weight and crying around the clock. My poor parents! Once I got started on pancreatic enzymes it was pretty much plain sailing. All the way through school I had no infections and was blessed to never need IV treatments. I was extremely active through ballet and tap dancing, playing lots of sport – mainly hockey and basketball, and having a mom who was aware of cross infection before that was even a thing. I had a great start in life and am forever grateful for that. I went to UCD for third level and it’s safe to say I probably enjoyed the social side of college life a little too much! It was around that time I started to need IV antibiotics. At first this was once a year but when that frequency started increasing I realized that if I didn’t take action, it was going to get really serious.
Thankfully, I matured and was able to regain control of my health. Throughout that time I never really gave up the exercise and maybe that is what stood to me. After my degree I completed a PhD and started working in the field of nutrition science. In general my health was very good. There were ups and downs but all in all I was in good shape.

I cannot express enough the importance of fitness and eating well. After the sports-focused environment that school-life offers, I spent a few years just going to a normal gym. I ran three half marathons as well as many 10k runs. Then, in my late twenties I found CrossFit. This form of high intensity workout combined with weight training brought an important new aspect to my training. I realized I did better in a group setting as I would push farther than I would on my own in a gym. My doctor advocated for me doing this and it showed great results. I found that eating “clean” was helpful too. By this I simply mean eating plenty of calories from whole foods and avoiding fast-food and high-sugar foods as much as possible.

I have always been a very private person in all aspects of my personal life. I have never made my CF public. This is just what works for me. However, I very much admire those who choose to make their lives public and advocate or inspire others. In that respect I would like to mention two individuals because I believe the work they are doing to promote fitness for people with CF is ground breaking and so important. Both men have CF but have reached high levels of fitness and athleticism themselves. Ben Mudge is a fitness model and personal trainer based in Belfast. He regularly poses dressed up as the super-hero “Thor” while taking his nebulizer in an effort to offer a role model for children with CF. He has also created a training program specifically for people with CF. Find him and his inspiring stories on Instagram at @benmudge_. Then there is Josh Llewellyn-Jones OBE...yes he recently received an OBE in recognition of his work! Josh completes extreme physical challenges and encourages other “CF Warriors”. Follow him at @joshlj24.

About five years ago I was lucky enough to move to the US to take up a new role. This was made possible by my very supportive parents, siblings and a granddad who encouraged me to go for it! To explore new waters you have to be ok with leaving the shore behind. I think that is sage advice for many parts of life. My job in the US provides excellent health insurance. However, the system here was really alien to me. It is just so different to home. My clinic here was wonderful in helping me figure it out. I will spare the details but suffice to say, if anyone is considering a move to the US please ask Philip for my details. I would be so happy to help anyone navigate it.

I still do CrossFit, run and am recently getting into hiking. I still make a conscious effort to eat well: high calorie, high fat, high protein and as low sugar as possible – with treats here and there of course. I am the only person at my clinic practicing AD (autogenic drainage). It is not commonly practiced in this region but my doctor is a big fan of it. I met my fiancée three years ago and life here is very good to me. We are getting married this year! Trikafta could not have come at a better time.
About six months ago, before starting Trikafta, I spoke to my doctor about an issue that was bugging me. I exercised daily and was really good at my AD, doing a few clearance sessions throughout the day. However, it had become the norm that in the middle of each night I would wake up and need to do a massive clearance. It felt like soup in my chest. I would sometimes stay up for half an hour doing this...it was seriously taking its toll. What was worse was in the morning I would wake up and feel like it was all back: more coughing, more clearing, it felt like a never ending cycle. This was really, really difficult when staying in other people's houses and would cause me a lot of stress. Arriving to a hotel with friends or to my in-laws house I would quietly investigate the bathroom set-up: would I wake people up in the middle of the night with my coughing? It was just so annoying! So I found myself thinking, if only I could wake up in the morning and not need to clear, or not need to cough.

Since starting Trikafta I can say this: I wake up every morning now with no secretions...NOTHING. No cough. I still take all my nebs (Trikafta is not replacing them) and do AD sessions but some days there is simply nothing to clear. I can now laugh loudly and deeply without it becoming a coughing fit. I can complete a workout without turning heads with the sound of my hacking; more and more I am seeing how radical a change this has been.

Back to the 3rd of December, I hung up the phone from chatting with my mom and went about my work. I took my two orange pills around 9am and I think around 2pm I felt the gurgling. For the next 48 hours there was a heavy stream of secretions flowing up. Yes, flowing is a good word here- it was thin, watery mucous and there was a lot. I could do the easiest, most effortless huffs and out it came. On many online forums people have nick-named this “the purge” – I think that is apt! This subsided around day 3 and I felt just...clear. It was such a beautiful feeling.

I was very fortunate to not experience any of the negative side effects the pharmacist had warned me about: headache, rash, pain and thankfully no increase in liver enzymes. All was fine. About two weeks in I travelled home for Christmas, taking the long trans-Atlantic flight that I am now so familiar with. While at home I felt amazing. There was one day I had pretty bad pain in my abdomen. I figured out that I was able to start cutting back on Creon. Some trial and error has revealed I can take about 1/3 fewer capsules- a really nice bonus!

I had my first clinic appointment at day 12. Some interesting figures to give context to my story. Despite having great fitness levels my PFTs have never been stellar numbers: but always stable. I hovered around 50% for the last 10-12 years. I would say in the year leading up to Trikafta I was around 48% most of the time. I never got big jumps but, then again, I never got big falls. So I was steady. The last PFT I did before starting Trikafta was low for me at 1.45L: 46%. Then, on day 12 after starting it, I blew 1.66L: 52% - an 8% increase! My SATs were 100% (having usually been about 96%). I had gained a kilogram! I had been around 51-52kg for so long and despite doing weight lifting and trying hard to eat more – that scales was not budging...until Trikafta. I am now just finishing week 8 and last week at a clinic appointment I weighed in at 54.8Kg (personal best!) I blew 1.71L – 56% - a 10% increase! And I feel that is still climbing.

So if you come away from reading this article with anything let it be this: there is hope.

Thirty years after the discovery of the CFTR gene the advances in medicine are finally translating. And if Trikafta is not for you please do not despair – the gates are just opening. There are other companies working on more modifiers, gene therapy is coming and there are some promising anti-inflammatories in the works. Every day you get out of bed make a decision to do all you can to help yourself. Do the exercise, do the treatments and, most importantly, be your own cheerleader. Your thoughts are the voice you have to listen to twenty-four seven; let it be a kind one. And above all, keep on fighting because help is on the way.
The Member Services team have been supporting members by phone and email during the Covid pandemic and while the nature of queries have changed since cocooning measures began on 18th March, the themes remain consistent.

Emergency financial support was provided to some members who were waiting for a regular Covid Illness Benefit payment to be established. Many PWCFs and their families were cocooning before this action was advised. The members services staff have received and made several hundred calls since March, many of which resulted in a letter of support being sent for employers to request working from home arrangements or where this was not possible, staying at home to cocoon their family member with CF. Members also requested letters to access businesses at times reserved for high risk individuals. Other queries included access to hand sanitiser, masks, protective equipment.

We are attempting to contact all PWCFs by phone to check-in and identify any difficulties they may be experiencing. This is not possible for all members if we do not have accurate details – if you need to update your contact details please contact us.

Teaching support was offered to leaving certificate students before the announcement that they could opt for calculated grades.

An arrangement has been made where members can access up to eight counselling sessions online.

It became apparent over the last few months that some members were understandably experiencing anxiety and issues with coping with cocooning. As a response to this, we are currently offering an online Wellness Workshop, facilitated by Niamh Connolly, a qualified CBT therapist who runs The Mind Gym. The uptake has been excellent by PWCF and parents alike and topics include Covid mindset management, resilience and communication.

The opportunity for PWCF to exercise has been hampered by cocooning and the closure of gyms. CFi bought 50 licences from Beam – an online resource for PWCF which has exercise programmes designed by CF physiotherapist and our members are now using these sessions to reach their daily exercise goals. You can read more about BEAM on page 15.

To access any of the supports mentioned above or to speak to someone on the Member Services team for support / advice on any issues you are experiencing, whether they relate to CF, Covid-19 or not, details are below:

Samantha Byrne
Member Services Senior Coordinator
sbyrne@cfireland.ie
087 135 5228

Caroline Heffernan
CF Advocate
cheffernan@cfireland.ie
087 932 3933

Rory Tallon
CF Advocate
rtallon@cfireland.ie
087 932 3930

Liz Jacques
Regional Development Officer, TLC4CF
TLC4CF@cfireland.ie
087 195 4213
Exercise Grant Round 2

Opening Monday, June 29th

Exercise Grant Round 2 – opening 29th June 2020

Round 2 of the Exercise Grant has been brought forward at the request of members, to facilitate the purchase of items which may be used to exercise at home.

This round will be managed exclusively online and grants will be paid electronically though the bank.

Applications cannot be accepted until June 29th.

Please check our website and social media later this month for the link on how to apply. Grants will be processed on a first come, first served basis.

Handmade Soap Company

Cystic Fibrosis Ireland would like to say a big thank you to the Handmade Soap company for their amazing support during the COVID-19 pandemic. The Handmade Soap company made a donation of over 280 litres of hand sanitiser which has been distributed to the CF Community nationwide through the support of our branches.

The cost of this donation is over €15,000, but the impact of this donation is immeasurable. During a very anxious time for the CF Community, this supply of hand sanitiser was a vital support.

The Handmade Soap Company are an Irish brand whose mission is to make the world a better place, by not only lifting spirits and tickling the senses and raising the bar- They have certainly raised the bar in their support of the CF Community in Ireland.

A huge thank you to Donagh Quigley and everyone in the Handmade Soap Company. Your support has helped so many people

If you can, please share the love and like the Handmade Soap Company on IG, Facebook and Twitter.

Cystic Fibrosis Ireland gives much thanks to Zoe Woodward for organising this support, Karen O’Neill in Beekon Batches for facilitating this introduction, the branches of CF Ireland for arranging distribution to the CF Community, Dave Stears who supported the PWCF branch with deliveries in the greater Dublin area and all other community volunteers who helped distribute the hand sanitiser. We couldn’t have done it without you!
During the COVID-19 pandemic we know that it’s been tough to stay active. Staying healthy and keeping active aren’t straightforward at the best of times. But as people with CF are cocooning, it can be harder than ever to get moving and to feel good.

CF Ireland are delighted to announce our partnership with online fitness service Beam. Beam helps people with cystic fibrosis to get more active, with on-demand and live classes, group support and handy resources. Beam is all about helping people with cystic fibrosis (ages 16+) to get more active in a way that feels good, no matter where they are along their health journey.

Beam classes are led by specialist physiotherapists and trainers who are trained in, or live with, cystic fibrosis, so you can feel confident that they understand you.

CF Ireland recently gifted 12-month Beam memberships to 50 of our PWCF members, via an online promotion. The free memberships were so popular they were gone within a number of days. One member who applied for the free Beam membership offer was 21 year old Rachel O’Rourke:

“I’m 21 years old and I have been using Beam since cocooning started. I’m finding it a great benefit because I usually run to keep the lungs well, but I couldn’t do that for the last few weeks. I’ve started yoga classes on it and I’m loving them!”

We can’t wait to hear how other members are progressing with Beam.

You can find more information about Beam’s online exercise programmes, live classes and community by visiting their website – www.beamfeelgood.com  Every movement matters and it’s never too late to get more active.

CORK BRANCH PROVIDES FREE MEMBERSHIPS
The Cork CF Branch have generously offered to fund free 12-month Beam memberships for PWCF who regularly attending Cork University Hospital. This generous donation comes from local fundraising efforts and will benefit any eligible PWCF aged 18+. The kind donation is in response to the COVID-19 crisis and recognition that some PWCF are finding it increasingly difficult to maintain exercise regimens at home.

If you attend Cork University Hospital and would like to receive a free 12-month membership to Beam, contact your CF physiotherapist. Offer is available during the month of June only.

"When we have CF, we shouldn’t work out like everyone else. We’re different. The problem is – no one wants to treat us like we’re different. But we need better strategies if we’re going to fight this monster we call Cystic Fibrosis. We have to train smarter. We have to train with purpose. It’s about time – we owe it to ourselves. At least, that’s my feeling as a person and personal trainer with CF and transplant survivor. Having faced the battle, I’ve learned a thing or two about how we need to work out and want to share my experiences."

Tim Sweeney, PWCF & Personal Trainer with BEAM
20\textsuperscript{th} National Cystic Fibrosis Clinical Meeting

The 20\textsuperscript{th} National Cystic Fibrosis Clinical Meeting took place on Thursday the 30th and Friday the 31\textsuperscript{st} of January 2020 in Killarney, County Kerry. The Clinical Meeting highlighted the remarkable improvements in health outcomes for people living with Cystic Fibrosis over the last two decades and how the changing spectrum of CF has led to new challenges emerging.

Infections in CF

The management of infections in people living with CF was a strong theme in this year’s conference. Professor Jon Koff, Associate professor and Director of the CF programme, Yale School of Medicine discussed three novel approaches to multidrug resistant CF pathogens: Gallium, Nitric Oxide and Bacteriophage (phage) therapy. Phage therapy is the therapeutic use of bacteriophage (viruses that infect bacteria) to treat bacterial infections. Prof. Koff described his team’s experiences of using phage therapy to treat patients with multidrug resistant Pseudomonas infections. A personalised therapy approach with phage is preferable, where libraries of phages are screened to identify an effective phage against a patient’s pathogenic bacteria. Personalised therapy is difficult to commercialise however and phage therapy requires work to optimise the safety, delivery, treatment strategy and to investigate phage resistance.

Professor Claire Wainwright, Respiratory physician and head of CF services in University of Queensland & Queensland Children’s Hospital, Australia, provided both sides of the argument on whether to wait or eradicate a Mycobacterium abscessus infection. Young children, two to five years old are at increased risk for M. abscessus infections. The treatment can be long and toxic with a 50% success rate. While the best treatment strategy is unknown, the clearance of the pathogen is associated with better outcomes.

The lung and gut microbiome in PWCF was the focus of a presentation by Professor Michael Tunney, Queen’s University Belfast. The microbiome is the community of microbes and their genes in a given area of the body. In end stage lung disease the diversity of organisms in the lungs declines massively becoming dominated by specific pathogens, e.g. Pseudomonas, Stenotrophomonas. The question was asked if altering gut microbiota could improve long term respiratory health.

Benefits of real time digital data

Dr Martin Wildman, University of Sheffield, UK outlined a systems approach to sustaining self-care in PWCF. Most days we do what we did yesterday, tomorrow we will do what we did today, so how do we do something different tomorrow and then how do we keep doing it next week? He explored complex system optimisation using real time digital data to improve adherence among patients. For example, a patient presents with a new exacerbation of disease, if their self-reported data on medication adherence is good, the doctor will search for an alternative cause for the exacerbation. However, patients tend to overstate their adherence, in reality they may only be adhering to 30% of their therapy. Quality metrics allow us to make the invisible visible, identifying problems so solutions can be sought.
**Optimising care strategies**

Ms Jacqui Cowlard, Clinical Nurse Specialist, Royal London Children’s Hospital, UK., discussed the differing international guidelines for the management of CFSPID (Cystic Fibrosis screen positive inconclusive diagnosis). An ongoing challenge with newborn screening programmes is finding the right balance between sufficient sensitivity of the programmes to not miss affected individuals, while minimising the detection of infants with CFSPID. The management of CFSPID is a complex and challenging situation, consensus is required on the frequency of repeat testing and long-term management strategies. Remote monitoring may be a useful, less burdensome measure for people with CFSPID.

Professor Ala K. Shaikhkhalil, Ohio State University College of Medicine, USA, explored optimising nutrition and the management of pancreatic insufficiency. Prof Shaikhkhalil discussed different treatment approaches to the failure of nutrition therapy including RELiZORB, an in-line digestive enzyme cartridge containing Lipase covalently bound to polymer beads designed to hydrolyse available fats before ingestion of enteral tube feeding formula. In RCTs RELiZORB increased fat absorption.

Michael Twomey, a final year PhD student in UCC discussed memory recall in CF patients during medical appointments. Cognitive abilities are reduced during medical appointments because of stress, this affects a patient’s abilities to recall their medical history and also to remember what has been discussed during the appointment. Mr Twomey outlined how he was developing a digital version of a patient checklist booklet to aid patients through their clinic appointments.

**Update on the CF Clinical Programme**

Professor Charles Gallagher, Clinical Lead with the National Clinical Programme for Cystic Fibrosis provided an update on the significant work that has been done by the Clinical Programme to get CF services in Ireland up to National and European standards. A national model of care alignment strategy is currently under development.

A working group has been established to develop a separate model of care dedicated to the care of PWCF post-transplant. Professor Gallagher also outlined the need for mental health research to reduce the sense of isolation among PWCF as they are kept apart during clinical care to minimise risks of cross infection.

**Cystic Fibrosis in 2040**

Professor Stuart Elborn, Queen’s University of Belfast, UK., provided the Keynote address of the conference. He looked not back over the last 20 years of progress but forward to envision the future for people living with CF. With continued progress many people living with CF will maintain a good level of health well into adulthood. As early mortality becomes less common, the care of ageing patients with CF will require a new generation of healthcare providers with the skills to manage emerging complications of CF in later life. Multidisciplinary teams will be able to monitor the wellbeing of patients remotely with new technologies providing real time data. These are exciting times for cystic fibrosis, with advances in health outcomes new opportunities and challenges will emerge.

*Note: This is not an exhaustive account of all of the presentations given at the clinical meeting.*
In many ways people living with Cystic Fibrosis and their families have been better prepared than most for life with this new coronavirus. A heightened awareness of infectious pathogens and the ways to prevent contracting and spreading them is the norm for people with respiratory disease. Here we discuss some of the most frequently asked questions about this new virus and what we know so far about pandemics.

**What is a virus and how are they different from bacteria?**

A virus is a very tiny particle of DNA or RNA genetic code packaged in a protein wrapper. They do not contain any sophisticated cellular machinery of their own and can only replicate, or make more virus particles, by hijacking the energy and protein processing mechanisms of a cell they invade. These new viruses then burst out of the infected cells and go on to infect another host cell.

Bacteria on the other hand are much larger and carry all of the cellular machinery required for replication by themselves. Bacteria can also be motile, capable of moving around, where viruses are essentially inert particles which go wherever they are carried, or coughed and sneezed in the case of coronavirus.

To put the size of a virus in perspective, we could fit approximately 100 million virus particles on the head of a pin. Because they are so small, billions of virus particles can be spread in the air by just one cough.

**What is a Pandemic?**

A pandemic is a disease outbreak that spreads across countries and continents. The world has been through many pandemics - Black Death in the 14th century swept northwards through Europe and killed up to two thirds of Europe’s population. The Spanish Flu pandemic, which it is believed originated not in Spain but in the US, killed between 50 and 100 million people worldwide over three waves in two years 1918 and 1919. HIV has infected over 75 million people since the early 1980’s. More recently we have seen the Swine Flu pandemic in 2009, and SARS a novel coronavirus variant which emerged in southern China in late 2002 before spreading to Hong Kong in 2003 and on to 17 countries. 8098 cases of SARS were identified before the virus was contained in July 2003.

**Is the risk of new pandemic diseases growing?**

Yes, the risk of new pandemic diseases is growing for a number of reasons:

1. Increasing proximity between humans and animals increases the chances of an animal virus making the move into humans. Zoonosis is the word used to describe a disease which can be transmitted from animals to humans. Many recent emerging viruses have come from an animal origin. Swine Flu and Bird Flu as the names suggest originated in pigs and birds. SARS it is believed jumped to humans from civet cats. MERS, the middle eastern respiratory syndrome, also a coronavirus, is transmitted through camels. The new coronavirus causing COVID-19 is thought to have originated in bats.

2. Increasing population density, mega cities, urbanisation and poverty all provide the opportunity for viruses to spread much faster than before.

3. Global transport. In earlier pandemics the virus could only spread internationally as fast as the mode of transport of the time. A virus travelling across Europe by foot or on horseback would take much longer than one who caught the next flight three-hour flight to Rome.

4. Ecological change. Population increases are driving people to intrude into temperate rainforest areas, where billions of viruses and bacteria reside which have never before been part of human populations. Additionally climate change is introducing animal vectors such as mosquitos to countries they never existed in before.

This is not all bad news however, because just as the possibility of pandemics is growing, so to is our knowledge, preparedness, ability to respond, surveillance mechanisms and development of therapeutics and vaccines.
What is SARS-CoV-2? What is COVID-19?
Severe Acute Respiratory Syndrome Coronavirus-2 (SARS-CoV-2) is the name given to the 2019 novel coronavirus. SARS-CoV-2 is a new strain of coronavirus that has not previously been identified in humans. COVID-19 is the name given to the disease associated with the virus (Coronavirus Disease and 2019 being the year it was first identified).

What is the mode of transmission?
The virus seems to be transmitted via small respiratory droplets which are spread when an infected person coughs or sneezes or when people interact with each other for some time in close proximity. These small droplets can then be inhaled or they can land on surfaces. The virus can survive on different surfaces from several hours (cardboard, copper) up to a few days (stainless steel and plastic). The amount of viable virus on surfaces declines over time. A person may become infected if they touch a surface which harbours the virus and then touch their nose, mouth or eyes.

The virus can be spread from an infected person two days before symptoms begin and people may remain infectious for up to 2 weeks.

How can I protect myself from SARS-CoV-2?
Coronavirus consists of a piece of genetic code, a protein coat and an outer layer of fat. This fat coating is what makes hand hygiene so important with SARS-CoV-2. Twenty seconds of thorough hand washing with soap and warm water can destroy the fat layer protecting the virus, the same way washing-up liquid helps clean a greasy frying pan.

The virus enters the body through the eyes, nose and mouth, it is important to avoid touching your face with unwashed hands. The use of alcohol-based hand gel is recommended in all settings where hand washing is not possible.

Social distancing (keeping 2 metres away from other people) reduces the chance of infection through respiratory droplets.

What is the impact of COVID-19 in people living with Cystic Fibrosis?
Viral respiratory tract infections are more severe in patients with CF than in the general population. There is an increased risk of complication and potential negative impact on lung function. While the outcomes of some early case reports of COVID-19 in PWCF have been better than initially predicted based on previous pandemics, the data is too limited to conclude what the impact of COVID-19 in PWCF may be. The small number of reported cases of COVID-19 to date in PWCF may reflect the efforts of cocooning PWCF and their families to protect them from this infection. The medium and long-term impact of SARS-CoV-2 in PWCF is still unknown.

Have we learnt anything from previous pandemics - How will this end?
Almost all previous pandemics have ended. The widespread application of social distancing was first tested during the Spanish Flu. The earlier an authority enacted social distancing, the slower the spread and lower the mortality rates. The Spanish Flu pandemic came to an end as those who recovered from infection became immune and herd immunity was established. The initial SARS pandemic was also halted by aggressive public health measures of isolating those with symptoms, tracing and quarantining all contacts and social controls. The Swine flu outbreak in 2009 was brought under control as a vaccine was developed within 6 months. Researchers believe the ending of this pandemic will be based 50% on the social and political responses and 50% from science, with a vaccine or effective therapy.

“It is not the strongest of the species that survives, nor the most intelligent that survives. It is the one that is most adaptable to change.”
Charles Darwin

As one of our members recently stated, PWCF have been in training for this their whole lives. The CF community has the skills, resilience and determination to get through this pandemic and to thrive in our new way of life that lies ahead.

www.cfireland.ie
Cystic Fibrosis Ireland’s Survey of the Impact of the Covid-19 pandemic on the CF Community in Ireland

“It’s like walking on top of (a) wall all the time having CF, without the storm of Coronavirus to push you off”

( Parent of child with CF)

Cystic Fibrosis Ireland undertook a survey of people living with CF in Ireland and their families to identify their concerns around Covid-19 and the daily challenges they are facing in light of the outbreak. The survey saw 300 responses in total (105 people with CF; 195 parents/relatives) and was undertaken in late March/early April 2020, the same week that cocooning guidance was introduced.

Almost one in two (45%) people with CF fear contracting the virus and the potential health implications this may cause.

Most concern is for those who already have severe respiratory problems and those with CF who are post-transplant.

These fears were compounded by the lack of international data on the effects of COVID-19 in people with CF.

“I fear not having enough lung function to survive it”

“I have a low lung function and fear any respiratory virus”

(PWCF)

Over a quarter (27%) of people with CF are concerned about how long self-isolation will last and the implications on their physical and mental health.

“One in Three (33%) people with CF are concerned about their ability to safely access hospital care, particularly if the coronavirus emergency is prolonged.

“Isolation is already an issue for the CF community and now it is even harder…. Exercise, getting out, socialising help to make the illness a part of me but not all of me. Without that, the illness can take over”

(PWCF)
For two in five people (39%) with cystic fibrosis, the most common practical challenge is the ability, or otherwise, to maintain regular exercise while in isolation.

Exercise is a crucial part of CF health management and reduced opportunities to exercise could result in a negative impact on a person’s health in the longer-term.

Resilience being tested
People with CF and their families are a resilient community, but their resilience is being severely tested by the coronavirus pandemic. The fears arising from the uncertainty of the Covid-19 outbreak is a recurring theme which underpinned many of the responses to the questions in this survey. While the wait for a vaccine or treatment goes on, the reality that the threat of Covid-19 will be a part of daily life going forward is causing concern. There is strong support for ‘cocooning’ within the CF community and many cocooned before they were advised to do so, but there is concern about it’s impact on mental health and wellbeing especially if the Covid-19 crisis becomes very extended.

Cystic Fibrosis Ireland plan to undertake a second survey of the CF community in Ireland to identify any emergent issues related to Covid-19 and to explore the impact of cocooning on our members thus far.

“What affects me the most right now is not being able to be with my family and friends and the uncertainty of how long this will go on for. Isolation is exactly that. Isolating. I’ve spent so much time appreciating inclusion, taking care of myself so that I can stay out of the hospital isolation rooms and be with my family and friends. I understand we’re all in this together to a certain extent.

It’s just difficult to come to terms with. The unknown.”

PWCF
65 Roses Day
Thank you to everyone who supported 65 Roses Day!
Goes Virtual!

supported 65 Roses Day!
June -September - Virtual: Vhi Women’s Mini Marathon / One in 1000 Campaign
As you will be aware the Vhi Women’s Mini Marathon is going virtual, with details to be announced............

We are encouraging ladies (and men – why not!) to participate by completing a 10k walk or run in aid of Cystic Fibrosis Ireland. To take part for Cystic Fibrosis Ireland, all you need to do is sign up for our Virtual One in 1000 campaign. To sign up, just fill out the registration form on our website www.cfireland.ie/onein1000.

We will send a FREE SPECIAL EDITION race shirt for this momentus year – our 10th One in 1000 campaign, to the first 500 participants who sign up on our website.

Once you’ve clicked ‘Submit’, your digital fundraising page on iDonate.ie will be automatically set up for you – don’t forget to share it on your social channels and with your friends and family! We will then send a SPECIAL EDITION MEDAL again to commemorate our 10th year of the One in 1000 campaign to anyone that raises €20 or above for Cystic Fibrosis Ireland.

The good news is you can complete your 10k walk or run anything that suits you over the Summer. Just be sure to take a selfie and share it to your social channels tagging @cf_ireland!

We can’t wait to see all your amazing pictures and fundraising results.

If you have any questions regarding Virtual One in 1000, please email Rachel at rbyrne@cfireland.ie.

September 12th to 17th – Cancelled: Paris2Nice Cycle
We regret to inform you that the Paris2Nice Cycle for 2020 has been cancelled. Thank you to everyone that had registered to take part and we look forward to bringing you details of the 2021 cycle once announced.

If you have any questions, please contact fundraising@cfireland.ie.
Sept 20th – Under Review: Head2Head Walk

Our Head2Head walk is scheduled to take place from Howth Head to Bray Head on Sunday 20th September. We will continue to monitor the guidelines issued by the relevant authorities to confirm if we can proceed with the walk, with the health and safety of everyone involved the determining factor in this decision.

We will confirm arrangements for the Head2Head Walk as soon as the guidelines for events in September are available. If you have any questions, please contact fundraising@cfireland.ie.

September 24th - 27th - Malin2Mizen Cycle4CF (Under Review)

At this stage for anyone involved in the Malin2Mizen Cycle4CF, you will be aware that we have postponed the event until September. We will continue to monitor the guidelines issued by the relevant authorities to confirm if we can proceed with the cycle, with the health and safety of everyone involved the determining factor in this decision.

A huge thank you to all of our cyclists who have continued to fundraise and train - including indoor group training sessions on Zoom, kindly organised by Caroline Heffernan, PWCF and a Cycle Leader for Malin2Mizen Cycle4CF 2020.

We will confirm arrangements for Malin2Mizen Cycle4CF 2020 as soon as the guidelines for events in September are available.

Sept 25th to Oct 3rd - Postponed: Paddy Kierans’ Memorial Walk

Unfortunately we have had to make the difficult decision to postpone the Cystic Fibrosis Ireland International Walk to Bulgaria planned for September until 2021. The wellbeing and safety of our Walkers is of utmost importance to us at this time. If you have registered for Bulgaria 2020, you should have already received a communication from Rachel in this regard and we will issue further details about our walk in 2021 as these are finalised!

If you have any questions in relation to the International Walk, please email rbyrne@cfireland.ie.

www.cfireland.ie
October 25th - Cancelled: KBC Dublin Marathon
We regret to confirm that the KBC Dublin Marathon planned for October has been cancelled.

If you were planning to participate this year, perhaps you would consider completing the Marathon within the relevant travel and social distancing restrictions and forwarding your pictures to Rachel at rbyrne@cfireland.ie.

We can provide you with further details on setting up a fundraising page and provide you with one of our fabulous purple Cystic Fibrosis running singlets so you look great when completing your own Marathon for CFI!

November 1st – Under Review: TCS New York City Marathon
At this stage the TCS New York City Marathon is under review and we will issue an update in relation to the event as soon as this is announced. In the interim, please contact brendan@cfireland.ie if you have any queries.

December 11th: Christmas Jumper Day 4 CF
On Friday 11th 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...

Ask your staff or colleagues to support Christmas Jumper Day 4CF on Friday 11th December. Encourage everyone to wear their most Seasonal looking Christmas Jumper to work in return for a €5 donation to support people with Cystic Fibrosis in Ireland!
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:

**65 Roses Day Goes Virtual**

Cystic Fibrosis Ireland would like to say a HUGE THANK YOU to everybody who donated or fundraised for our Virtual 65 Roses Day on Friday 10th April.

To those of you who donated online and via text, set up fundraising pages, took part in challenges, sent us in testimonials for us to share, encouraged your family and friends to donate and get involved... Thank You. We are totally overwhelmed by the support we received. Over €450,000 was raised from our 65 Roses Day campaign this year which is absolutely amazing and so important as all of our other fundraising events have been cancelled or postponed for the remainder of the year.

Without you, we would not be able to continue to carry out the work that we do to help people living with Cystic Fibrosis in Ireland which is needed now more than ever during the COVID-19 pandemic. All our supporters including everyone within the CF community are incredible. Thank you again from everyone at Cystic Fibrosis Ireland.
65 Roses Challenges

A massive Thank You to everyone who organised a 65 Roses Challenge either online or within the travel and social distancing guidelines. We had an incredible response and it would not be possible to include all of the events organised. However we appreciate every single event and euro raised which helps Cystic Fibrosis Ireland continue to support people with CF in Ireland.

Here is a sample of some of the events organised with further details and videos available on our website www.cfireland.ie

Ratoath GAA

Ratoath GAA Senior Ladies Camogie team and Senior Men’s Football teams spent a bank holiday weekend running and walking over 4,000km (smashing their original target of 1,500km!) in aid of CFI and Dublin Rape Crisis Centre

An absolutely incredible €32,495 was raised, what an amazing feat!

Please join us in saying a huge thank you to Ratoath GAA club and Shane Duffy who led the way with the organisation.

Bishopstown GAA

Bishopstown GAA club organised a massive run for their 65 Roses Challenge, equivalent to the distance of running from Malin Head at the top of Ireland to Mizen Head at the bottom of Ireland. This mammoth 65 Roses Challenge has raised over €22,000 to date!

What an amazing contribution from everyone involved! Thank you!

Alex O’Herlihy

PWCF Alex O’Herlihy (8) had great fun completing lots of 65 and 6.5 related sports challenges, raising over €2,500! Well done Alex!

Check out our website www.cfireland.ie for some fantastic video footage captured of Alex as he completed his various sporting challenges.
Gary Bailey
PWCF Gary Bailey completed 65 days of intense training in the run up to 65 Roses Day and raised just under €6,000!
Congrats Gary on this fantastic 65 Roses Challenge and thank you for your support!

Bevin Murphy
Following on from the success of her 65 Roses Challenge in 2019, PWCF Bevin Murphy decided to challenge herself again this year, but got her friends & family involved! Bevin and her friends each ran 65km over the month of April as part of their 65 Roses Challenge. This was all completed within their 2km radius and by Bevin on the treadmill as she is cocooning. This fantastic 65 Roses Challenge raised over €7,000!
Thank you to Bevin for spearheading this challenge and congratulations to all those who took part.

Ella Burns
Ella Burns, a keen swimmer from Westport was another PWCF who took on a 65 Roses Challenge! Ella cycled 65k each day of 65 Roses Week on a stationary bike and raised an astonishing total of over €13,000.
Congrats Ella and another fantastic 65 Roses Challenge!
65 Roses Day Live Stream
On 65 Roses Day, artists Paddy Casey, Isaac Butler, Katherine Lynch and the Celtic Tenors gave outstanding performances to help raise money for Cystic Fibrosis Ireland. If you missed these wonderful live streams, they are well worth checking out under our Facebook Posts on 65 Roses Day!

A huge thank you to all the artists for their contribution.

Ballinteer St. John’s GAA Club
Ballinteer St John’s GAA Club Senior Footballers took on a mammoth 65 Roses Challenge as they ran or cycled the equivalent distance to every county ground in Ireland over 14 days to raise funds for CFI. They kicked off their challenge on Friday 1st May and to date have raised €13,725.

What an amazing 65 Roses Challenge! Thank you to everyone in Balinteer St. John’s GAA Club for their support.

5k Rock Run
Blackrock College students and faculty held their 5k Rock Run on Saturday 23rd of May for Cystic Fibrosis Ireland and Aidlink Ireland.

A special thank you to Christian Coleman, PWCF who is a student in Blackrock College and his family. Christian posted an inspirational video calling on people to donate to this event and it certainly worked. The college have raised an amazing €28,845 and counting.

Thank you to everyone at Blackrock College for their incredible support.

Central Bank
A huge Well Done to the Central Bank of Ireland’s HR Operations team who organised a 65 Roses Day Challenge raising almost €2,000! Each team member either walked 65 times around their estates or gardens, or cycled indoors for 6.5km!
Malone Group Cycle

Cystic Fibrosis Ireland would like to say a huge thank you to Malone Group and everyone who participated in the Malone Virtual 65km Cycle.

A massive €12,155 has been raised so far from this amazing event!

Zwift 500 Mile Cycle

Friends Neil Campbell (Ireland), Niall McLeod and Stuart Howie (Scotland) were training for an Ironman 70.3 Triathlon which was cancelled due to the Coronavirus. They thought rather than waste all that training they would put it towards a good cause to help in the current crisis. This turned out to be a Zwift 500 mile in aid of CFI – a 24 hour indoor cycle with an amazing €1760 raised. A huge thank you to Neil, Niall and Stuart for their support.

Joe Delaney

Garda Sergeant Joe Delaney raised €3,350 by running 65km on a treadmill as part of the Malone Group Virtual Cycle.

Thank you Joe!

Chris O’Grady

Mayo Man Chris O’Grady decided he would walk 267 km, equivalent to the distance from his home in Dublin to his native Louisburgh, Co Mayo, all in his back garden.

Chris has raised an amazing €8,525. Thank you Chris!

6.5k Remembrance Walks

Many thanks to everyone who took part in the Virtual 6.5k Remembrance Walks this year.

Over €6,000 was raised to help support people with CF!

This is a special day for everyone as we remember those lost to Cystic Fibrosis and we look forward to the opportunity to meet up and celebrate this day again in 2021!
Cystic Fibrosis Ireland would like to say a huge thank you to everyone who took part in this year's Virtual Duleek 10k!

An incredible €21,240 was raised and counting.

A special thank you to Ann Noone and all in the Duleek 10k committee who pulled out all the stops to switch the event to a Virtual Duleek 10k this year. They look forward to welcoming everyone back to Duleek again in 2021!

David Cousins
Huge congratulations to David Cousins for running 42km within the travel and social distancing guideline in aid of CFI in honour of his goddaughter Aoibhe Moriarty (PWCF, 19 months).

Dave had never run a marathon before and started training in December. An amazing achievement with €7,855.74 raised for Cystic Fibrosis Ireland!

Lucan Sarsfields GAA
Thank you to the Lucan Sarsfields Senior Football Team who ran from Sunrise on May 2nd to Sunrise on May 3rd. They raised a huge €7,769.

Tomas De Faoite
CFI would like to say a huge thank you to Tomas De Faoite who ran 65 miles (2096 laps of his house) and raised an absolutely amazing €13,790 for CFI!

The Kennedy Family
The Kennedy family completed multiple 65 Roses Challenges raising an unbelievable total of €8,000 to help support people with Cystic Fibrosis in Ireland.

Thank you for your continued support!
Pass The Sliotar Not The Virus

Clare hurler Cian Galvin started the hugely popular #PassTheSliotharNotTheVirus campaign on Twitter during the 65 Roses Day Campaign. The campaign caught on like wildfire with a huge reaction across Social Media. Cystic Fibrosis Ireland received €37,935 from text donations during the 65 Roses Day campaign with many of these generated by this wonderful challenge initiated by Cian!

Thank you Cian for organising the campaign and thanks also to everyone who took part.

Shane Collins

Cystic Fibrosis Ireland would like to say a huge thanks to Shane Collins who is running two marathons in May within the travel and social distancing guidelines, to raise funds for Cystic Fibrosis Ireland! Shane has raised €3,000 and counting! He has already completed one and is now training for the other. Well done Shane!

Kilimanjaro

Congratulations to John Moran and Shane who climbed Mount Kilimanjaro over Christmas and raised an incredible €6,200 and counting for Cystic Fibrosis Ireland!

What a fantastic achievement.

Enjoy your well-deserved rest, guys and thank you for supporting Cystic Fibrosis Ireland!

Corofin GAA Club

A huge thank you to Corofin GAA Club (County Clare) for organising the Everest Climb fundraiser for TLC4CF. 50 members of the Corofin GAA club organised to summit Mullaghmore while simultaneously soloing with a football or hurley & sliothar. Together, these 50 ascents equaled the worlds highest peak, Mount Everest. At time of print, this unique challenge has raised over €15,000!

Castle Park School, Dalkey

Thank you to the pupils in Castle Park School, Dalkey who organised a fundraiser which involved setting up fundraising stalls and raised €1,387 to help people with Cystic Fibrosis in Ireland.

Pictured at the cheque presentation to our Fundraising Manager – Fergal Smyth are the pupils who organised the fundraising stalls and Kathy Johnson who helped co-ordinate the fundraising event in her role with the ‘Friends of Castle Park School’.
St. Brigid’s National School, Greystones

Cystic Fibrosis Ireland would like to say a HUGE thank you to the students, student council, teachers, parents and the parents association of St. Brigid’s National School Greystones who organised their Christmas Jumper Day 4 CF in the school in December.

Pictured handing over the cheque to Fundraising Manager Fergal Smyth, is Principal Máire Costello and students including Senan McCabe (PWCF) and members of the student council. They raised an amazing €1,210 from their Christmas Jumper Day 4 CF to help people with Cystic Fibrosis.

Hospital Saturday Fund

Cystic Fibrosis Ireland would like to say a huge thank you to The Hospital Saturday Fund who presented Fergal Smyth, Fundraising Manager for Cystic Ireland with a cheque for €4,000 at a special reception hosted at the Mansion House in Dublin on Thursday, 20 February by Paul Jackson, Chief Executive of the HSF and Deputy Lord Mayor, Councillor Tom Brabazon

Charity Soccer Match

Pictured above is PWCF Cody Nolan from Carlow receiving a cheque for €2,600 from (l-r) John Farrell David Kelly and Shay Farrell.

The money was raised from a charity soccer match last year in memory of Paul ‘Rasher’ Farrell (PWCF, RIP) who died suddenly in 2015.

We’d like to thank everyone involved who fundraised such an incredible amount! Well done all.

Siemens

Cystic Fibrosis Ireland would like to say a huge thank you to the staff and management at Siemens Gamesa who gave a corporate donation of €1,000 towards services and support for people with CF recently.

Pictured above is Luke Evans of Siemens Gamesa presenting the cheque to CFI’s Rachel Byrne.
Naas Oil
Cystic Fibrosis Ireland would like to say a huge thank you to King’s Gala Group and Naas Oil, who raised a fantastic €1,760 in their stores on Christmas Jumper Day 4 CF in December 2019.

Pictured here are the managers of the two organisations, presenting the cheque to Fergal Smyth, Fundraising Manager of CFI.

Head2Head Walk
The Head2Head Walk committee presenting a cheque to Cystic Fibrosis Ireland for an amazing €59,923.11 raised at the Head2Head Walk 2019.

A huge thank you for the fantastic fundraising from all the walkers and all the work from the Committee organising the walk!

Spar
Cystic Fibrosis Ireland would like to say a huge thank you to Spar at the end of our two and a half year partnership which has raised an amazing €732,309.

Pictured presenting the final cheque to our Fundraising Manager, Fergal Smyth are Colin Donnelly, Sales Director, Spar and Helen Somerville, Marketing Manager, Spar with Store Managers from the National Council of Spar Retailers.

Christmas Jumper Day 4 CF
We extend a huge thank you to everyone who signed up and participated in Christmas Jumper Day 4 CF 2019. Thank you for making our second Christmas Jumper Day 4 CF year such a huge success with an amazing €43,865.35 raised.

We look forward to seeing all your Christmas Jumpers again this Christmas.
The cystic fibrosis teams nationwide have been working tirelessly throughout the Covid-19 pandemic to ensure that CF patients continue to receive the highest standard of care while following cocooning guidance set out by the HSE.

We would like to thank all the CF Clinicians, Nurses, Multidisciplinary teams and support staff for their continuing hard work and dedicated support.

This hospital hub provides updates for some of the CF Centres nationwide. At the time of going to print (June 2020) this information is valid and correct. Members should continue to check in directly with their CF team.

University Hospital Limerick - Caitriona McGrath, CF CNS
The Adult Cystic Fibrosis Team in U.H.L have been working diligently in ensuring all our patients are coping through this difficult period and uncertain time during this crisis. We have been assisting our patients by the following:

- Daily and Weekly Telephone calls, Check in sessions along with follow up calls.
- Invited patients to partake in Virtual Clinics with the multidisciplinary team Tuesday/Wednesday / Friday.
- Invited to partake in Virtual Physio and Psychology sessions.
- Regular Texts to remind all our patients to follow HSE Covid 19 Guidelines & most importantly to ensure they are aware to contact us if support or advice is required.
- We are hoping to commence using additional equipment for our clinics in the coming months once approved.

All management and guidance is provided by Consultant Dr Brian Caserlly, CF /C.N.S Caitriona Mc Grath, Physios Louise Collins, Lauren Kennedy, Dietician Dearbhla O Sullivan, Psychologist Sorcha Connellan. We would like to thank our cohort of patients for their endurance, resilience, and compliance in working with the team during this time. We urge patients to continue to follow the current HSE guidelines and wish everyone to stay safe.

University Hospital Limerick, CF Paeds Unit – Noelle Power, CNS
Your CF team are still at work at the moment, we are managing the CF service in a different way at present.

Our clinics for children with cystic fibrosis are running as video or telephone clinics until further notice. Dates and times of your appointments remain unchanged but there may be slight delays. The consultant will call you on the day of your appointment and have a discussion in relation to your child. As always we are available for advice and ‘drop in reviews’ when necessary are taking place by contacting the CNS on 061-482220. Annual reviews have been suspended until further notice.

Your CF team continue to advise families to seek medical care appropriately through the same channels as before (your GP, your emergency department at UHL) and not to avoid or postpone review if concerned.
Every CF service in the country has experienced challenges in caring for people with CF during the current COVID-19 public health crisis. Thankfully our adult CF service in Cork continues to adapt to the situation. A remote access clinic was established to ensure our patients continue to receive the care they require. The new clinic format allows us to review patients by means of a video conferencing platform. In addition, patients have been given a portable spirometer, a fingertip pulse oximeter, a weighing scales and a thermometer to enhance the quality of the multidisciplinary clinic review. Initial feedback has been positive and encouraging towards further use of the new clinic format at this time.

Home visits, with precautions, have continued to be facilitated where possible and this is very reassuring for our patients.

An effective COVID-19 swabbing protocol with a short result turn-around time was also established to ensure our CF day unit remains operational and to date COVID-19 negative. Our patients can continue to receive hospital based care where indicated.

Good communication has always been important to ensure our patients receive the quality of care they need and never has it been more the case than in the current health crisis. We have done our utmost to ensure patients have been kept updated and informed by means of regular informative and motivational text messages and phone calls. Patients have been very appreciative towards these efforts. Most importantly we continue to offer ongoing support to all of our patients and their families. Finally, we thank them for their understanding and flexibility to work with us during this pandemic.

The Covid-19 pandemic has been a challenging time for everyone but most especially those in high risk groups. The Paediatric CF service at CUH continues to strive to keep our children with CF and their family’s health and safety as a priority.

Since the start of the Covid-19 pandemic the clinic review format has changed from hospital visits to phone consults. While this appears to have functioned quite well, we are working hard to set up videoconference clinics in the very near future. Urgent reviews have continued in the CF unit while adhering to HSPC/HSE advice. With the easing of national public health restrictions we hope to be able to review more of our children with CF in our unit, in a controlled manner over the coming months. The phone service remains unchanged.

We would like to thank our children and their families for their understanding and co-operation in these unprecedented times. Stay safe!
Cavan Paediatrics Dept – Dr Anne Leahy, Consultant Paediatrician

During the Covid 19 restrictions all patients are advised to adhere to the NCPCF Guidance Document for people with CF and their families. This is HSE and Dept of Health policy and has been in the public domain for some time.

Currently, patients with CF Clinic appointments will be contacted by telephone. If any of our CF patients are unwell at any time we would like them to contact us on 049-437-6616 or 049-437-6854. We will then arrange to see them promptly and safely. We urge patients NOT to arrive unannounced. “Actual “ outpatient clinics will resume when restrictions allow.

We are extremely grateful to CF Ireland and their Cavan Branch for our 2 dedicated in patient CF rooms which opened in 2017. These rooms have made a tremendous difference to the comfort of children admitted to hospital. CF Ireland were also instrumental in providing us with a CF outpatient suite. I would like to take this opportunity to thank our Paediatric and Respiratory nurses, Physiotherapists and Dieticians who play a huge role in the care of our CF patients.

I would like to welcome Lorraine Smith Clinical Nurse Manager for OPAT who has just joined our team.

We are all very proud of how our patients have complied with regulations for Covid 19 and wish them, and all with CF in Ireland, good health during this worrying time.

Galway University Hospital – Dr Michael O’Mahony

Along with most of our colleagues we are trying to continue with clinics online. We have been using Zoom to see our patients and talk to them.

We are also using new technology to monitor patients remotely using an app developed by an Irish technology company “PatientMpower” which allows patients to monitor their symptoms, lung function and oxygen levels and is currently being trialled in many of the Adult patients at University Hospital Galway. Dr Michael O’Mahony, the Adult CF Consultant at University Hospital Galway said that the video conferencing helps the CF Team interact with patients at home but there is difficulty in making decisions about treatment without objective measurements of lung function, weight and oxygen saturation. He said the use of the app as part of a pilot in the last few weeks had been very helpful and contributes to providing the high-quality care cystic fibrosis patients need while reducing the visits to hospital.

Our Lady of Lourdes Hospital Drogheda – Mary Hanratty-woods, CNS

The past few months have brought many changes to the delivery of care in our CF unit. As CF Teams we are all committed to protecting our patients, providing the highest standard of care, preventing infection and safeguarding our patients. However, we never imagined we would be delivering care in the midst of a global pandemic. Routine clinics at our Shared Care service for now have been postponed. Should our patients become unwell and require assessment, we are doing triage via phone call to determine if they need to be clinically reviewed. Children requiring procedures such as port flushes are facilitated. We want our patients to know we are available for clinical reviews should they be required, and to contact us without delay if they have any concerns.

Our next challenge is to set up virtual clinics, which is a new system we all must become accustomed to in the delivery of care. Psychological and social support is vital at this time, to promote wellbeing and we will be working with our social work department to facilitate necessary supports.

Living with Cystic Fibrosis places huge demands and stresses on everyday life but this time is particularly difficult. Our children are so adaptable and always amaze me with their resilience. As a CF nurse what I miss most is the interaction, stories, fun and most of all inspiration we get from the children. For the moment we must deal with phone assessments, virtual clinics, staying 2meters apart, and providing care and support in a new way. I look forward to when we can get back to seeing our children face to face and sharing a joke. For now to all our families, stay safe, smile and keep in touch.
St Vincent’s University Hospital, Dublin – Jo Doyle, CNS

We hope this message finds you well.

We appreciate this continues to be a worrying time for all of our patients and their families. Hospitals cancelled routine elective work in order to prioritise resources for patients with COVID19 infection and to reduce the risk of transmission to patients. As your safety is important to us, our routine CF clinics in the outpatient department (Suite 3) have been cancelled. We hope to reopen these clinics in the near future. The CF team are still available to you, to offer help and support when required.

We can be contacted by telephone or email.

Contact Details  email: cfnurses@svuh.ie  
Tel:  01 2214684 or 01 2214000

Catherine Carroll:    Bleep 564
Josephine Doyle:     Bleep 565
Suzanne Kearns:      Bleep 514
Paula Farrell:            Bleep 105

Sat/Sun & Out of hours  - St Christopher’s Ward  01 2216282/ 01 2213274

- We are running virtual CF outpatient clinics. If you are due a clinic appointment, we will contact you by telephone to offer you support and advice.
- For patients that need to be reviewed in person, appointments will be arranged by the CF nurses for you to be seen in the CF day-ward. If your symptoms are at baseline we will perform routine checks including PFT’s and physiotherapy review.
- If you are unwell or off your baseline and need to be reviewed please contact the CF nurses in advance of attending the hospital in order to arrange a designated time for review. At this stage you will be swabbed for Covid 19. People positive for Covid 19 will not be nursed on St. Christopher’s ward. If you think you need admission please bring your belongings that you need for your stay in SVUH.
- Presently there is no visitors allowed in St. Vincent’s University Hospital in all areas.
- In addition, our CF Physiotherapist team have drafted a letter with some exercise recommendations for CF patients at home.
- The most important thing that you can do is to prevent the spread of infection to yourself and others by following the advice on the HSE website, https://www2.hse.ie/conditions/coronavirus/coronavirus.html

Other Information
- Take care of yourself.
- It is essential to keep taking your medications and other treatments regularly as prescribed. Stopping or reducing your treatments may increase your risk if you get coronavirus or other infection.
- Keep you prescriptions up to date.
- Please contact the CF nurse in advance of any appointment to discuss your ETA if you are attending an appointment in SVUH
- Please wear a mask while attending the hospital.
- Wash your hands regularly and use hand gel.
- Please continue with physical distancing.
- Avoid close contact with people who are unwell.
Hospital Hub: Spotlight

University Hospital Limerick Physiotherapy

Meet the Team

Louise Collins graduated with a BSc in Physiotherapy from University College Dublin in 2003.

She has worked in University Hospital Limerick since 2004. She has worked in CF for over 10 years, with experience of working with both adults and paediatrics.

She is currently a Clinical Specialist Physiotherapist in Adult CF at the University Hospital Limerick.

She is undertaking a MSc in Sports and Exercise Performance at the University of Limerick.

Máire Curran graduated a BSc in Physiotherapy from the University of Limerick in 2013 and completed her staff grade rotations in the University Hospital Limerick, where she developed a keen interest in Respiratory Physiotherapy.

She is a Senior Physiotherapist in Adult Cystic Fibrosis at University Hospital Limerick.

She is currently undertaking a PhD at the University of Limerick, which aims to optimise physical activity and health in adults with Cystic Fibrosis.

Lauren Kennedy graduated with a BSc in Physiotherapy from the University of Limerick in 2007.

Since qualifying she has had a special interest in Respiratory Physiotherapy. She has extensive clinical experience in both acute and community HSE settings across Galway, Tipperary and Kilkenny.

In 2017 she returned to her native Limerick where she currently works as a Senior Physiotherapist in Adult CF in University Hospital Limerick.

Rebecca White graduated with a BSc in Physiotherapy from the University of Nottingham in 2009.

Since qualifying she has gained specialist interest in Paediatrics and Respiratory Physiotherapy. She has a variety of clinical Physiotherapy experience across the UK, New Zealand and Ireland.

Rebecca has been working for the Paediatric CF team in Limerick since 2017 as a Senior Physiotherapist.
At University Hospital Limerick (UHL), the Physiotherapy Team are broadening physiotherapy treatment horizons to augment patient care. Working in this specialised area of physiotherapy poses unique opportunities to develop new management approaches. As Cystic Fibrosis (CF) physiotherapists we feel our role in this area is rewarding, diverse and fulfilling. Physical activity and exercise are important in the management of CF and one of our key roles is personalising prescription of exercise to suit individual needs. This is being accomplished by incorporating the use of modern technology in the forms of Fitbits and online video sessions into our range of treatment options. This work had commenced prior to the COVID-19 crisis, however COVID-19 has further accelerated our efforts to use technology to improve the physiotherapy service at UHL.

Senior Physiotherapist, Máire Curran, is trailblazing the way with her innovative PhD which is centred around the use of Fitbits for monitoring and increasing physical activity levels. This involves measuring the amount of physical activity a participant carries out on a normal day to day basis. The physiotherapists are investigating the effect a Fitbit with remote monitoring will have on numerous health outcomes such as lung function, fitness levels, body composition, quality of life and sleep. Thus far, there has been very positive feedback from both staff and participants in relation to this study. As a result of this research, the physiotherapy team are exploring possibilities of expanding the use of Fitbits for more PWCF who attend Limerick for their care.

In addition to this, the physiotherapists in Limerick have been collaborating with Microsoft and are now able to offer online video sessions through Microsoft Teams. This evolving service is now enabling the physiotherapists to complete airway clearance and exercise sessions remotely. Delivering remote sessions has become a clear priority for the team during the COVID-19 crisis, in an effort to reduce our patient exposure to the hospital setting. To access this service PWCF are emailed a link and follow the simple online steps to securely access the online session. So far, there has been hugely encouraging feedback from those who have participated. Our goal is to continue to offer this innovative service and we have seen significant growth over the last few months.

UHL Physiotherapy Team

5 Top Tips for Exercise & Physical Activity

1) Make exercise a habit! Schedule your exercise into your routine at a time of day that suits you.

2) Mix it up - add in some weight training to cardio sessions

3) Set yourself short- and long-term goals to help keep you on track and motivated. For example, is your goal to run a local 5k? Do you want to increase your step count?

4) Step it up! Increase your physical activity levels. Take the stairs instead of the lift or parking further away in the car park is a good way to increase steps

5) Hold yourself accountable. If you’ve got a workout Buddy you will be more likely to keep it up. Or perhaps you could ask a friend or family member to check in on your progress regularly.

Please contact your physiotherapists if you have any questions about exercise.
At his 25th anniversary of his heart and lung transplant for Cystic Fibrosis Francis Boylan reflects on his journey......

It’s sort of hard to believe it’s been so long since my life was changed, I still remember it like yesterday.

I feel incredibly privileged to have reached a quarter of a century since my life was saved when I received the incredible gift of a heart and lung transplant.

Even now, every day I am incredibly thankful to the young donor and their family for making the decision to donate and help others at a time that must have been incredibly difficult for them. Without such a selfless gift I would not be here. Through their bravery and kindness I was able to donate my heart to a girl who too was able to benefit from their decision.

For those who are waiting on the transplant list I know it can be a very stressful and anxious time, waiting on that call to come. All you can do is try and keep well, trying to keep as healthy as possible. You’ve got to try and look at the positives as much as possible which I know isn’t always easy.

I would like to thank a few people...

I want to thank my amazing family who without their help and support over the years, things would have been a lot tougher. Being surrounded by great friends and family really makes a huge difference, especially when things are tough and not going right. I have been incredibly fortunate in my life and I know how fragile life can be. I have to thank all the doctors and nurses I have been incredibly fortunate to have met over the years. From the teams on the 5th Floor Toddlers in Drogheda all those years ago to the Brompton and Harefield hospitals in the UK. And lastly the world class team in the Heart & Lung Transplant Department in the Mater hospital, who have saved me on more than a few occasions....

I will forever be grateful to you all for helping me get to today.

Getting a transplant is truly life changing and gives you the opportunity to do so many things that you once, could only dream of.

A few months after my transplant I was able to start secondary school, go to college, get a job and meet some amazing people along the way.

It’s not always an easy road but to get that chance to walk, talk and live without struggling to breathe is something I will always be thankful for.

I once heard a saying “Cherish yesterday, dream of tomorrow, live for today” which I think is a great way to look at life.
A note from the Mater:

Francis is an inspirational person. So positive about life, always happy and it's evident that he and honours the memory of his organ donors though his dedication to self-care and trying to stay as healthy as he can.

We feel very privileged to be working with PWCF like Francis post-transplant at the Mater Hospital. We get to see the enormous positive impact transplant has on them and their friends and family. It’s very special to be part of their journey as they venture into hopefully a happier and healthier life. Life after transplant is a commitment. It’s a completely new lifestyle with new regimens which take time and on-going dedication to get the best outcomes.

The Mater Transplant Programme began in 2005. We now have 260 people attending outpatient clinic. Professor Jim Egan Head of ODTI and Respiratory Transplant Physician sends his well wishes to Francis: “Francis’ case is illustrative of the bravery and resilience of our transplant recipients travelling to the UK 25 years ago to undergo Lung transplantation. Ultimately the generosity of the donating family has translated to enormous benefit to another family. Organ donation saves lives.”

New Research on Newborn Screening

Important new research has been published in the European Journal of Human Genetics on some of the outcomes over 6.5 years of the inclusion of CF in the New-Born Screening Programme. In this research, the observed incidence of CF in the New- Born Sreening Programme is 1 in 2570 (170 cases in 436,940 births) yielding an estimated carrier rate of 1 in 25.3. The authors of the study contend that the likely cause of the overall decrease in incidence of CF in the Republic of Ireland is increased ethnic diversity in Ireland arising from inward migration. The researchers recommend that in the case of counselling for a couple of Irish origin, the carrier rate of 1 in 19 should still be used.

Increased Migrant Diversity in Ireland in Recent Decades

Some statistics to highlight increased migrant diversity in Ireland. According to the most recent Census (April 2016), there were 535,475 non-Irish nationals living in Ireland, representing 11.6 per cent of the total population in 2016 (CSO, 2016). This compares with 420,000 non-Irish nationals recorded in the 2006 census. There was a 143% increase in non-Irish nationals from 2002-2011. The Polish population in Ireland doubled between 2006 and 2011 but then remained static. Migrants are more likely to be of child bearing age than the resident population in Ireland.

The New-born Screening Programme commenced in 2011 after significant advocacy by Cystic Fibrosis Ireland. The Programme means that care for CF can commence from birth. The original Screening Programme commenced in 1966. CF was the 6th condition added to screening (also sometimes called the heel prick test). By 2020 there are now 8 conditions screened in Ireland. Because of the success of the Screening Programme, the Rare Disease Task-Force in Ireland has advocated for further diseases to be added, including for example Sickle Cell Anaemia.
FUN FOR ALL

We know that cocooning during Covid -19 has been tough. Long periods of time spent by yourself can impact your mental health, so it is important to check in with yourself and your family.

With this in mind, we have put together some activities that you can do by yourself or with your friends and family. These activities can help start conversations, but also give you a chance to reflect.

ENJOY!

COVID TIME CAPSULE

While it may be tough now, in the future this will be a time people remember, when Ireland and the world were in lockdown! You are living a part of future history.

Create a time capsule that your future self can look back on. Here are some things to include:

* Information about you - your age, height, shoe size, weight, best friend, favourite tv show etc. *
* Artwork you created *       * Photos taken during lockdown*         * A journal of how you felt *
* What you did to keep busy - books you read, shows / movies you watched, games you played *
* Special occasions that you celebrated *    * People who helped you / who you helped *
* Newspaper Clippings*       * How you stayed connected *
* What you are most looking forward to *  * A letter to your future self *

Spot the difference!

Can you spot the 10 differences in the picture below.

Play this at home: Pick a room, give everyone some time to look around then leave. While they are gone, change 10 things in the room, have everyone come back and see who can guess what’s changed!
SUMMER WORDSEARCH
Can you find the 15 words in the wordsearch below?

ANKSUNGLASSES
PRUADSLIKUACPAMU
SOBLIAEPOPNRDRTNB
FVOONSHITKIBWOOCRPG
ILETLCARCMLEFUNAG
ALYRIZUNGCAMPGING
GUEBKVGIEVCJOGKE
SNDASIECDNHIRAL
AKPRQNNHPAOXKRUPR
NEJBLIEUNSCOFIDF
DADESMABHREYSNTL
CTICECREAMZSUHAE
AHNUBXIDGNINBCSD
SIGEVFMUKTUADLINH
TRYEUIWSMITSITU
LPAANSPYTRNBINMAW
ELISUITECASEGOVEBO
DMACMETAEHULNZNUC
HSSLQHOLIDAYSKR
FUTODJAKBWWUCZIES
PYNCSAREHNEASYRAP
XOILNOCMNBREEWIZ
CATAOZBAUONUBATU
RUEPSHORTSCEOPIN
TSIKUMLEYCNXLMOB

sun sand castle kite picnic ice cream
sea sunglasses beach camping barbecue
pool suitcase shorts holidays swimsuit

WORD LADDER
We all know how important it is to wash our hands, but changing just one letter at a time, can you solve the word ladder puzzle and change wash to hand?

DINGBAT CORNER
Can you work out the four phrases shown in the pictures below?

GIVE GET GIVE GET GIVE GET GIVE
MILONELION
ROADS ROADS
JACK

PUZZLE SOLUTION - Winter 2019
## Cystic Fibrosis Ireland Branch Network

<table>
<thead>
<tr>
<th>Branch</th>
<th>Contact Name</th>
<th>Contact Number</th>
<th>Email Address</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carlow</td>
<td>Leigh Bolger</td>
<td>086 684 3750</td>
<td><a href="mailto:bolgerleigh@yahoo.ie">bolgerleigh@yahoo.ie</a></td>
</tr>
<tr>
<td>Cavan</td>
<td>Lorraine O’Neill</td>
<td>086 829 1561</td>
<td><a href="mailto:lorraineoneill73@gmail.com">lorraineoneill73@gmail.com</a></td>
</tr>
<tr>
<td>Clare</td>
<td>Kieran McCarthy</td>
<td>086 324 4770</td>
<td><a href="mailto:mccarthy.kieran1979@gmail.com">mccarthy.kieran1979@gmail.com</a></td>
</tr>
<tr>
<td>Cork (Southern)</td>
<td>Aisling O’Neill</td>
<td>085 863 8522</td>
<td><a href="mailto:aislingquill@gmail.com">aislingquill@gmail.com</a></td>
</tr>
<tr>
<td>Drogheda</td>
<td>Cyril Gillen</td>
<td>087 694 4922</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Frances McDonagh</td>
<td>086 075 4776</td>
<td></td>
</tr>
<tr>
<td>Dublin West</td>
<td>Marie Duffy</td>
<td>086 237 1184</td>
<td><a href="mailto:cfdublinwest@gmail.com">cfdublinwest@gmail.com</a></td>
</tr>
<tr>
<td>Dundalk</td>
<td>Maire Gallagher</td>
<td>086 825 9656</td>
<td><a href="mailto:mairegallagher@hotmail.com">mairegallagher@hotmail.com</a></td>
</tr>
<tr>
<td>Eastern</td>
<td>Mary McCarroll</td>
<td>087 411 9812</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Christine Drummond</td>
<td>086 874 0338</td>
<td><a href="mailto:christinedrummond3@gmail.com">christinedrummond3@gmail.com</a></td>
</tr>
<tr>
<td>Galway</td>
<td>Liz Gantly</td>
<td>086 173 0180</td>
<td><a href="mailto:gantlyliz@gmail.com">gantlyliz@gmail.com</a></td>
</tr>
<tr>
<td>Limerick</td>
<td>Padraig Gaffrey</td>
<td>087 288 7799</td>
<td><a href="mailto:padraig.gaffrey@analog.com">padraig.gaffrey@analog.com</a></td>
</tr>
<tr>
<td>Mayo</td>
<td>Billy O’Toole</td>
<td>086 059 6255</td>
<td><a href="mailto:billyotoole1@gmail.com">billyotoole1@gmail.com</a></td>
</tr>
<tr>
<td>Meath</td>
<td>Stephen Kennedy</td>
<td>089 488 1371</td>
<td><a href="mailto:bnkennedy2222@gmail.com">bnkennedy2222@gmail.com</a></td>
</tr>
<tr>
<td>Sligo</td>
<td>Iris Murphy</td>
<td>086 825 8525</td>
<td><a href="mailto:carrowcashel@eircom.net">carrowcashel@eircom.net</a></td>
</tr>
<tr>
<td>Tipperary</td>
<td>Mandy Quigley</td>
<td>087 612 0848</td>
<td></td>
</tr>
<tr>
<td>Waterford</td>
<td>Alan Barry</td>
<td>086 336 2229</td>
<td></td>
</tr>
<tr>
<td>Wexford</td>
<td>Claire Merrigan</td>
<td>085 726 2206</td>
<td><a href="mailto:clairewhelan2008@gmail.com">clairewhelan2008@gmail.com</a></td>
</tr>
<tr>
<td></td>
<td>Fiona Bodels</td>
<td>087 167 9279</td>
<td></td>
</tr>
<tr>
<td>TLC4CF</td>
<td>Liz Jacques</td>
<td>087 195 4213</td>
<td><a href="mailto:TLC4CF@cfireland.ie">TLC4CF@cfireland.ie</a></td>
</tr>
<tr>
<td>PWCF Group</td>
<td>Antony Dempsey</td>
<td>086 823 0140</td>
<td></td>
</tr>
</tbody>
</table>