All I Want for Christmas is You!

Baby's First Christmas
CEO’s Message

Welcome to the Winter edition of Spectrum.

It was really fantastic news for the HSE and Minister Simon Harris TD to announce on the 13th of December that the triple combination drug (Trikafta as it is known in the United States) will be available in Ireland for all eligible aged 12 years and over as soon as it is approved by the European Medicines Agency (EMA).

Trikafta (whose name will be changed by the time it is available in Ireland) is likely to be available before the summer of 2020 all being well. It could even be available sooner if the EMA decides to fast track.

This issue of Spectrum has a lovely spotlight on fertility, pregnancy and parenthood. The most beautiful 'thank you' cards CFI often receives are those of our members we have supported through our fertility grant.

Even in women without CF, pregnancy carries a risk for some this risk can be very significant. Ideally, pregnancy and CF should be planned and that includes talking with the CF team about the implications of becoming pregnant.

We hope you enjoy the Christmas break and we look forward to more positive developments in CF care in 2020.

A huge thanks to our board led by Patricia Duffy Barber, our staff, our branches and all who supported us in 2019, including the wonderful support from SPAR.

Philip Watt, CEO, CFI

Nuala McAuley & Samantha Byrne, Editors
Hospital Updates

Beaumont:
Cystic Fibrosis Ireland will have a meeting of the capital (building) sub group of Beaumont which includes CF Ireland, CF Hopesource, BH buildings office, clinicians and the CEO of Beaumont Hospital on January 20th 2020. We should be able to update you further on the promised 20 bed after that date.

Temple Street Hospital
The CEO of CF Ireland and Bernie Martin, volunteer patient advocate, had a meeting with Mona Baker, CEO of Temple Street Hospital and senior staff on 10th December where we raised key issues such as access to in-patient rooms; avoiding ED; staff training; the new children’s hospital and shared care with other centres.

University Hospital Limerick
Cystic Fibrosis Ireland and TLC4CF have a meeting scheduled with the CEO and senior hospital staff in January to discuss clinical staff shortages including Clinical Nurse Specialists.

Post Transplant CF Care
Have you had a double lung transplant as a person with CF?
Do you feel you are getting adequate access to post transplant CF care for ENT, GI and cancer screening for example? Is there someone available to give you expert CF advice on diet for example.
If you have any issues email Philip Watt CEO of CFI pwatt@cfireland.ie

Rare diseases guide
CFI is coordinating a second issue of the Easy Guide to Rare Diseases in Ireland.

CFI Conference
The CFI conference is in the Ardilaun Hotel Galway on the weekend of April 3rd - 5th 2020.
With a great line up to be published soon, registration for the conference will open in January.
Trikafta to be available in Ireland in 2020 when EMA grants approval.
Ireland likely to be the first EU country to reimburse Trikafta.

People with Cystic Fibrosis in Ireland have been contacting CFI to clarify and share the excitement of the news that the ground-breaking drug Trikafta will be available in Ireland once approved by the European Medicines Agency.

A decision to fast-track Trikafta will be considered by the EMA in January 2020. This could mean that Trikafta, the new triple combination CFTR drug from Vertex, should be available for people with CF in Ireland for all eligible patients aged 12 and over before the summer of 2020.

Once approved, it is likely that Trikafta will be extended to younger ages as in the case of other CFTR drugs such as Orkambi and Kalydeco. CFI warmly welcomes the support of the HSE and Minister for Health, Simon Harris TD in securing prompt access to Trikafta in Ireland.

The origins of the Trikafta deal for Ireland was contained in the 2017 pipeline/portfolio deal agreed between Vertex and the HSE. In summary this 2017 deal meant that anyone who was then eligible for an existing CFTR drug such as Kalydeco, Symdeco/Symkevi and Orkambi would be given extensions of the drug, once the eligible age was lowered. They would also get access to a better drug if developed within a set timeframe.

The deal agreed on December 13th between Vertex and the HSE significantly extends the 2017 pipeline agreement (see statements for the HSE and Vertex below).

No-one left behind
CFI knows that this good news will not apply to everyone with CF in Ireland and there is a small percentage of patients that will not benefit form a CFTR drug. We welcome the news that the CF Foundation in the US are investing more than $500m in potential therapies for these and indeed all CF patients.

HSE Statement
The Health Service Executive in Ireland would like to confirm that after recent collaborative discussions with Vertex, we have expanded our existing reimbursement agreement with Vertex so that all cystic fibrosis patients eligible to be prescribed VX-455 (Elexacaftor), Tezacaftor and Ivacaftor Triple Combination treatment i.e. patients 12 years or older, will have access subject to receipt of EMA approval.

VX-445 (elexacaftor/tezacaftor/ivacaftor and ivacaftor) is not currently licenced or approved for use in Ireland - Vertex submitted a Marketing Authorisation Application (MAA) to the European Medicines Agency (EMA) on October 31st 2019.

Issued by HSE National Press Office
Vertex Statement

Vertex Pharmaceuticals Incorporated (Nasdaq: VRTX) today confirmed that, following recent collaborative discussions, it has negotiated an agreement with the Health Service Executive (HSE) in the Republic of Ireland to expand the existing long-term cystic fibrosis (CF) reimbursement agreement to include the triple combination regimen (elexacaftor, tezacaftor and ivacaftor), which is under review and pending approval by the European Medicines Agency, for all eligible patients ages 12 and older in line with the potential future licensed indication.

This expands the existing agreement which had already included access to current and future Vertex medicines for people in Ireland with CF of any age who:

Have one of the specified mutations as included in the KALYDECO® marketing authorization (G551D, G551S, S549R, G1244E, S1251N, G1349D, S1255P, G178R or S549N) or

Are homozygous for the F508del mutation or

Are heterozygous for the F508del mutation and have a specified mutation (P67L, D579G, D1152H, R117C, 711+3A→G, 2789+5G→A, L206W, S945L, 3272-26A→G, R352Q, S977F, 3849+10kbC→T, A455E or R1070W) and people ages 18 and older and have an R117H mutation.

This innovative long-term agreement also enabled rapid access for people with these mutations if the labels of the existing medicines were expanded to cover additional age groups and if new Vertex medicines were approved for these populations.

Ludovic Fenaux, Senior Vice President, Vertex International, said, “With this expanded agreement, even more patients in the Republic of Ireland will be among the first in Europe to benefit from the triple combination treatment once the medicine is licensed.”


Public Service Credit Union

We were delighted to attend a reception hosted by the Public Service Credit Union (PCSU) at the National Concert Hall, Dublin on November 22nd.

The PCSU had selected Cystic Fibrosis Ireland as their charity partner for 2019.

Pictured right are members of several CFI Branches accepting a generous donation to CF branches from PSCU.

www.cfireland.ie
Until recent years in Ireland and worldwide, pregnancy for mothers with cystic fibrosis was generally discouraged. However, as CF services and outcomes have improved and there is more understanding of the risks, there is an increasing recognition that pregnancies can result in favourable foetal and maternal outcomes.

According to data from the 2017 Cystic Fibrosis Ireland Independent Living Survey, 26% of respondents with CF, 21 years or older, are parents. This would have been virtually unheard of in 1998 because of the combination of health issues, the prevailing medical advice at the time and the absence of availability of in vitro fertilisation (IVF).

The following accounts from fathers and mothers, both PWCF and partners, take us through their fertility journeys. If you are considering fertility treatment and wish to talk to a member who has been through a similar experience, please contact Samantha in CF House on sbyrne@cfireland.ie.

Ideally, when a woman with CF is planning to become pregnant, the first thing they should do is talk to their partner and CF team about the implications of becoming pregnant and having a child.

Becoming a Father

I grew up on a farm where new life coming into the world was a normal part of life. Myself and my two older sisters were always very excited at the birth of a new foal or the arrival of a calf, puppy or kitten. Growing up on the farm, I really enjoyed looking after the animals.

I didn’t think about what it might be like to have a family of my own until both my sisters went away to boarding school. I was very lonesome at home by myself. It made me realise how nice it is to have a family and to have that company. It made me realise I wanted a family of my own and a house full of life and vitality.

My brother Andrew, who had Cystic Fibrosis, tragically died when he was five and I was just a baby. Growing up I didn’t know other people with Cystic Fibrosis. I didn’t realise it could put limits on what I could do and, in general, it didn’t hold me back. I played a lot of sport, especially hurling, and I enjoyed school. In fact I got an award for never missing a day in school throughout my entire time in secondary school. Although when I was growing up, everyone in the family made a fuss of me, I assumed that was because I was the baby of the family and the only boy.

When I finished school and went away to study horticulture at third level, my health started to deteriorate. I began the first of a series of stays in hospital where I was given intravenous antibiotics to tackle lingering lung infections. I was very unwell and everyone in the family was very worried.
The CF Ward in Vincent’s was the first place I ever had the opportunity to talk to other people with Cystic Fibrosis. I was also given literature on the illness for the first time – I didn’t know a whole lot about it before that. That’s when I read that CF can mean infertility.

Reading those words left me feeling very down. The life I had imagined for myself – marriage and children – seemed to melt away. I didn’t talk to anyone about it. I was just 18 and I didn’t know where to turn. At the time, some of the other patients that I got to know had a very negative outlook on life. They assumed the future would be very bleak. I became very withdrawn. My family were very worried about me but I didn’t know how to communicate what was wrong to them.

Eventually I confided in one of the specialist nurses on the CF Ward. She was brilliant. She explained that the infertility issues that arise with CF are easily resolved and that IVF success rates were very good for people with CF. That changed everything and helped me relax and feel better. I knew a family was possible.

I met my wife Mary at Macra in Kilkenny – members are generally from farming backgrounds and Macra is a great social outlet with lots of team activities. We got to know each other over about two years before we started going out.

Mary is a pharmacist so she had a great understanding of Cystic Fibrosis already. Once we started going out, we knew from very early on that we were going to be together for the rest of our lives.

We began discussing having a family before we got married. Every three months I have a check up and on one of those visits, Mary and I sat down with one of the CF nurses to go through the process. The nurse was brilliant and talked us through the different steps involved. We made arrangements for the first step: a trip to Holles Street for fertility tests.

I took the tests twice and it was confirmed that although I could become father, I couldn’t do so without IVF. The specialist nurse in St. Vincent’s Hospital referred us to the Rotunda Hospital and we met with some members of the team.

I had to have a procedure to obtain healthy sperm. That was nerve wracking because of the nature of the procedure and because I was told I couldn’t run or do any strenuous exercise for four weeks after it. Running is an essential part of my health regime and I was concerned that I’d pick up an infection if I wasn’t able to run to loosen mucus to get rid of it and prevent infections. I tried to figure out what might be a good alternative, then bought a boxing kit and started boxing every morning. This did the trick.

My wife had to do some tests also. These included tests to see if she carries the CF gene – she doesn’t. She then had to begin a process of hormone treatment, which is part and parcel of IVF.

My wife loves children and she is fantastic with them. I felt very bad that she had to go through the complicated IVF process to become a mother. Daily injections followed by egg harvesting took place. At every stage, I felt nervous but I was always optimistic and I always believed we’d have success – I always remembered the reassurances I was given by the medics.

The hospital then fertilised a number of eggs of which one survived. That obviously reduced our chances of conceiving on this round of IVF treatment and it was upsetting and a little stressful. We hadn’t told anyone what we were doing so we dealt with the highs and lows by ourselves.

After a few days we went to Dublin for the implantation. We were excited, nervous and anxious at the same time. It was such an important day after many months of build up. The implantation was a success. We then hoped and prayed that the pregnancy would work out. Ten days later, a pregnancy test confirmed the good news. It seemed too good to be true. Finally, after she produced three positive tests, I accepted that Mary was pregnant and the thing that we wanted most in the world would happen: we were having a baby. We were absolutely over the moon!
There was a little bit of morning sickness but generally Mary was well. We waited the customary three months before telling anyone. Telling our families was very emotional. Because we hadn’t told anyone we were taking steps to start a family nobody suspected our news and there were lots of happy tears when we shared it.

During the pregnancy, I felt nervous. There was a lot in the news about things going wrong with pregnancies and births and these horror stories swirled around in the back of my mind. But Mary had a good pregnancy. She was positive and serene. All the scans went well. We were reassured the baby was healthy. My sister was pregnant at the same time which was very special.

Mary was due in on 12 March. The month began with heavy snow, cutting off access to our house. I was terrified that Mary would go into labour in our isolated farmhouse. The Council cleared part of the road so we could at least get out if we needed to reach the hospital at short notice. During the first week of March, Mary went into early labour – a process that went on for a few days. Eventually, we headed to the hospital and then two days later, our son Edward was born.

The enormity of his birth is hard to describe. It was the greatest feeling in the world. It felt like magic. I couldn’t believe I had a baby son and we were now a family of three. Everyone in our families was delighted and excited and so happy.

I was so relieved that Edward was healthy and his high pitched, loud cries confirmed healthy lungs.

I couldn’t wait to bring Mary and Edward home.

Once Edward came home, we adjusted to major changes. Mary’s mother – a very experienced grandmother - came to stay for a few days. Mary was amazing – she understands the routines I have to undertake to stay well – exercising, nebulisers and the rest. That meant I wasn’t always able to do what needed to be done at the moment it needed to be done - and I was very conscious of that. But we worked out a good model. I became an expert at nappy changing – individually and as a team member when two were needed. Even though no one in my family can sing, babies don’t seem to mind, and I developed a repertoire of lullabies in an effort to persuade Edward to sleep. My own mother helped out a huge amount with babysitting.

Mary grew up on a farm too and she is a great believer in the positive impact of fresh air so we had Edward outside in his pram all the time when we were working near the house. Anytime I was away from him, I missed him. I’ve only been away from Mary and Edward for two nights since his birth in March 2018 and, on those nights, I found it hard to sleep without them.

These days when I run, Edward joins me for the last part. It is a tremendous feeling to be running alongside him with Mary waiting for us – the highlight of my day!

Mary is expecting our second child in May 2020. We are nervous and excited – but it’s all much easier the second time around.

Becoming a father is the best thing I’ve ever done – I’d recommend it to anyone.

Brian Kavanagh
The Journey to Motherhood

My baby boy Milo is 7 months old now, I still can’t believe how lucky I am to be his mum, and it’s something I’ll never take for granted. I’m 33 years old and was diagnosed with Cystic Fibrosis at 6 months of age. Noel and I are together almost 11 years now. We always talked about kids, and hoped we would be lucky enough to have some of our own. I’m very maternal and babysat for almost everyone in my town! When I turned 30 I decided to concentrate extra hard on my health and try prepare myself for getting pregnant, fingers crossed.

I have been lucky with my lung function for the last 10 years, I work very hard on keeping it in the late 90s. But my bowel gives me a lot of trouble, I attend clinics with the surgical team in Beaumont regarding it. I’m trying to avoid getting a stoma for as long as possible. I was nervous at the thought of pregnancy and getting unwell but it definitely wasn’t going to stop me! I took all the extra vitamins and kept up my fitness to try my best at staying healthy and strong.

Noel and I were so excited to find out I was pregnant during the summer of 2018, but sadly we found out it was an unhealthy pregnancy that ended in a miscarriage. We were devastated. But it really made me think of people who go through fertility issues, how heart breaking it all must be. Miscarriage isn’t really spoken about much but for me I had to acknowledge the fact that it happened, so that meant talking about it.

Luckily we got pregnant again and this time things worked out.

I attend Beaumont CF Unit, so I was given the option to have my prenatal care in Dublin, but I opted for my local hospital in Mayo. I couldn’t imagine travelling for all the extra clinics, especially the bigger I got! I already attended clinics in Dublin for CF, ENT, Gastro Surgical and Rheumatology – I didn’t want to add another one if it wasn’t necessary. I attended prenatal clinics more frequently than others due to my CF, I saw my obstetrician every 2 to 4 weeks at Mayo University Hospital. And I also had an ultrasound of the baby every 4 weeks. The care I received was brilliant, everyone looked after me so well. I was referred to see a doctor at the Coombe Maternity Hospital in Dublin, who deals in high risk pregnancies. She was lovely, after my check up with her she was happy for my care to continue in Castlebar. She mentioned that due to my fitness (having run marathons, etc.), it would all stand to me during the pregnancy.

My obstetrician was worried about my bowel issues – thinking the bigger the baby got the more likely I’d run into trouble. After discussing it with my surgical team in Beaumont they decided a planned caesarean section would be best for me. They made this decision early on in my pregnancy so at least I had plenty of time to get my head around it. I didn’t mind really, I just kept thinking whatever will get my baby out safely. Luckily I was able to continue all bowel treatments and medications while pregnant. But I had a thought that kept creeping in, a worry that I may be unwell with bowel issues at the end of my pregnancy. I so badly wanted to be well enough to mind my baby once they arrived.

I’m a self employed visual artist, I work mainly on commissions or bursaries. I had finished up a year long project where I was awarded the New Work Award with Arts and Disability Ireland, and I had also just graduated from my Masters course. I decided to stop working in February, my baby was due in May. The plan was to rest as much as possible, to make sure I would be fit for the baby’s arrival! I had sinus issues while pregnant and had to take antibiotics. I had a lot of joint pain as well, this is something I get anyway – I attend the rheumatology department in Beaumont.

Noel, my fiancé, got tested around 5 years previous to see if he was a carrier of the CF gene and he isn’t. So we knew the baby wouldn’t have CF, but they may be a carrier of the CF gene.
As I was a public patient I wasn’t entitled to a private room while in hospital having my baby. This was something that caused me to worry because of my CF and cross infection. The thought of being in a ward and being open to infection, I knew I would be full of anxiety. So I had pre arranged with infection control and the maternity ward that I would be given a private room. They were so nice and helpful.

We were told that the baby was big from day one! I’m 5 foot 9 and Noel is 6 foot 2 so they said it was genetics. I went in for a prenatal clinic on a Monday and they said they would keep me in and I’d have the baby that Wednesday! 10 days early! I was nervous about the section, and the spinal tap. I’ve had previous allergic reactions to medications. I also have urticaria and angioedema, so I was worried about them flaring up. But I felt better after I spoke to the anaesthetist, and I was so happy that the consultant was doing the caesarean section herself. They had extra doctors in theatre in case there were any issues regarding my bowel, but thankfully they weren’t needed. All went really well.

Baby Milo arrived on the 1st of May, weighing 10lbs 1oz! My heart was so full.

The few days I was in hospital after having Milo I found it all so overwhelming – I felt so full of love I could have burst! Milo had to go to the special care unit for 48 hours due to his blood sugar levels. I hated being away from him but I could visit him. And of course it made me think of people who had very sick babies, I can’t imagine the worry. Milo’s doctor was also my CF doctor Prof O’Neill. It was so strange for my CF doctor at Mayo University Hospital to now be my baby’s doctor. It was so emotional. I suddenly thought of all the friends I had with Cystic Fibrosis who sadly passed away throughout the years, and how lucky I was. I was the first CF mum to have a baby at Mayo University Hospital in 16 years.

I love being a mum and still can’t believe how lucky I am to be one. My days are filled with play time, feeds, nappy changes and walks! We go to a Little Swimmers class once a week. I’m breastfeeding Milo, so I have to make sure I get lots of calories in. I also have to make sure I take the time for my medications and to do my treatments. I recovered well from my caesarean section. We went on Milo’s first holiday when he was 5 months old, we visited my brother and his family in Korea. We had the best time. Milo was great with all the travelling, he’s a very calm, happy baby. I have been sick a few times since Milo arrived but just needed some oral antibiotics – plus I can nap when he naps if needed. Once he turned 6 months I started back at the gym, I go to classes 4 mornings a week. I need to continue on keeping my lung function in the late 90s. Fitness definitely helps with my health. My mum only lives 5 houses away from us so we’re very lucky to have a babysitter on hand!

Milo isn’t a carrier of the CF gene. So that means right now for my immediate family the CF gene ends with me, so strange to think about. During my pregnancy I kept thinking all I want is a healthy happy baby. Now that I have this gorgeous happy healthy baby I keep thinking please let me live long enough to watch him grow – I don’t think this is to do with my CF, it’s probably more of a crazy mom thought!

I look at Milo now and continue to thank him for letting me be his mum while he just smiles at me and chews on everything.

Katie Moore
Our Story

We had been in Kiev over a week, getting ready for another day of sightseeing, when all of a sudden a text message appears on our new phone with a photo of the most adorable little newborn baby boy and a message saying ‘your baby has been born’. We had been there for over a week following a false alarm the previous Tuesday and had spent the week getting to know our surrogate mother better. The last thing we expected was this news as she had looked so comfortable the previous night. John was born by emergency C section following a prolapse of the umbilical cord. After a bucket load of tears I managed to pull myself together and my husband and I raced to the maternity hospital to meet our newborn son. It was love at first sight and he took our breath away.

What a day, what a year!!

I grew up with CF and battled from a young age in and out of hospitals with all the associated CF problems. Back in those days we were usually admitted to St Paul’s Ward sharing a 6 bed room with other CF’s. Not ideal for cross infection, but it was an amazing therapy in itself, sharing stories and laughs with other CF’s forging friendships for a lifetime.

In 2010 I got married and life moved on again for me. Naturally, I had always dreamt of a family but knowing the issues pregnancy and raising a baby could bring, it was more of a dream than a reality.

Following a heartbreaking meeting with my CF consultant, we knew it was off the table.

Life moved on and marriage was amazing, however my health continued to deteriorate and lung function was steadily falling.

In August 2016, together with CF specialists I made the decision to go on the transplant list.

What a scary decision it was but what were my alternatives?

I had known several post transplant CF patients and to see their quality of life transform I knew it was the way to go.

Following a few conversations, of what to expect post recovery and what to look forward to, it was a ‘no brainer’. I wanted a transplant. I am happy to say they were right and they have become the best of friends and an amazing support in life.

The transplant list was an unknown, but I had been told I was a good candidate for donor lungs and had a chance of a call but with no guarantees.

After just 14 weeks my phone started hopping one night and before I knew it I was sitting in the back of an ambulance on my way to the Mater Hospital.

12 hours later we were on our way home deflated and disappointed, but knowing someone else was better suited and on the table eased the pain.

Four weeks later in the early hours of Christmas Eve I got my next call and again with more tests and timing resulted in a mismatch.

Four days later, after my third and final call, I was on the table getting my new lungs and beginning my new life. On the 29th December 2016, I got the gift of life.
The next 6 months post transplant were extremely tough but I had turned a corner and started to experience a newfound health.

Energy levels were better than ever and being able to breathe effortlessly suddenly a whole new life opened up to me.

Throughout all those years struggling with health, my longing for a baby never left me and all of a sudden I found myself dreaming again and thinking of the possibilities.

Surrogacy had never been a consideration as before lung transplant energy levels were never good and my consultants advised caring for a child would be just as damaging to my health.

Now with a bundle of energy and feeling so well things had changed and I started to dream.

We never really considered surrogacy or researched it too much, but 9 months after transplant while an inpatient of the mater hospital I attended my first surrogate meeting with my post transplant friend in portlaoise.

It was exciting and we both came away with ideas, however we were both very aware of the costs.

After a few more meetings and some financial planning with my husband, we began to research the complex world of surrogacy and decided to go for it.

We had a financial plan and knew it would be tough but it was a journey we wanted to finance on our own.

The decision to go for surrogacy was also a confusing one as I had felt for previous years all I wanted was to be transplanted and healthy and here I was looking for more. Was I being greedy? It was such a massive decision to make and one that we didn’t make lightly or quickly.

We flew to Ukraine in October 2018 to meet with surrogacy clinics and begin our journey! We spent a week going from clinic to clinic and finally made a decision and signed a contract.

It was then the excitement started to grow!! We were matched with a gestational surrogate which meant she would have no biological connection with the baby.

On the 2nd January 2019 the clinic did a single embryo transfer. We would know if we were successful in just 14 days and they told us they would send us an email. That morning Shane went off to work and we both agreed we would open the email that evening together!

Of course Shane couldn’t wait and phoned me that morning to ask if I opened the email!!! Needless to say I knew by his tone of voice it was good news!!!

We were going to have a baby in September...... 2019 was going to be our year.

The months that followed were so exciting and nerve racking! I had started to make contact with our surrogate Anastasia and build up a relationship with her. She was 25 years old, was married and had a 5 year old daughter of her own. She lived 9 hours on a train from Kiev and every 2 weeks made the journey to the clinic for an Ultrasound until she was 5 months pregnant. After that she and her daughter had to move to apartment accommodation near our clinic for the remainder 5 months.
I had known previously about the fertility grant CF Ireland had given to people with CF requiring IVF, but wasn’t aware of anyone that had gone down the road of surrogacy.

I spoke with Sam in the office and explained that we were taking on the adventure! So we applied for the fertility grant when we knew our surrogate Anastasia was almost 12 weeks pregnant and amazingly they approved our application.

What a generous gift, what a difference it made. We couldn’t believe the generosity.

The months that followed were full of preparation for our baby’s arrival and our grand trip to Kiev. We had and still have a solicitor in Ireland looking after all the legalities at home and a Ukrainian solicitor looking after that side of things in Kiev. We had to organize DNA tests here in Dublin for when the baby was born and also look into an apartment that we were going to live in the Ukraine for approximately one month. I bought and packed bottles, formula, clothes along with a list of baby paraphernalia that would be needed for John’s first weeks in Kiev. I packed the bag at 30 weeks and then next to pack was two months medications in the event that we were delayed for some reason or some of them were to go missing.

When Anastasia was approximately 20 weeks pregnant I explained to her that I had a condition called cystic fibrosis and why I needed a surrogate. I explained that I had gotten donor lungs and that this was my second chance at life and having a baby was just the icing on a most wonderful cake.

Her response to me was “I am very happy to be able to give life to your life”. It really moved me and that is exactly what she did for us.

On 13th September 2019 our son John Paul was born. Our lives changed in an instant and we fell head over heels in love with him. Our amazing journey to finally become parents came to an end, and now our journey as parents is just beginning.

Surrogacy is such an amazing gift, and although the journey is long and emotional, together with our prayers it was as perfect as perfect could be. There are not enough words to thank Anastasia for her gift.

John was our little miracle, I firmly believe it.

Joy Byrne
A Partner’s Perspective

When my husband and I were first married we assumed life would take the usual course – making a home together, having a family, growing old together with presumably a few bumps along the way. Ironically, we waited a year before starting a family not realising any issues lay ahead. After nine months of trying and with a growing sense of fear that something was wrong, we took action and we visited our GP. Blood tests were done to check different hormone levels which were all normal. My husband then attended for sperm analysis and we were shocked when the results showed no sperm in the sample. We could not understand it – except for some minor medical issues such as asthma my husband was fit, active and lead a healthy lifestyle. We longed to be parents, so to that end, we were referred to a fertility clinic as well as a urologist. During our consultation with the urologist he suggested my husband’s lack of sperm could be due to several reasons, including that he could have a condition known as CBAVD (congenital bilateral absence of the vas deferens) if he was a carrier for cystic fibrosis.

The fertility clinic did further detailed blood tests as well testing my husband for a CF gene, at the recommendation of the urologist. My world fell apart when the results showed that my husband was not a CF carrier – he had tested positive for two CF genes and he had cystic fibrosis. We knew nothing about cystic fibrosis only that it was a serious medical condition. Our fertility journey hadn’t even really started, and we were dealt with this blow that perhaps my husband wasn’t as fit and healthy as he appeared to be. In all my life I had never felt so lonely, afraid, isolated and hopeless.

My husband was referred to a cystic fibrosis specialist unit and we continued to visit the fertility clinic. They explained our difficulty in conceiving a child was due to my husband having CF and CBAVD but that he could undergo a procedure called TESE to determine if he had any viable sperm and if so, it could be extracted and frozen for later use. It was also explained that if I was a carrier for CF, that any potential children we may have would have a 50% chance of having CF too. But also, if I was a carrier, there was a new technique available at the time in Belgium called PGS (Preimplantation Genetic Screening), where any potential embryos we might have could be sent there and checked for CF before implantation. I was tested for the CF gene and we were referred for genetic counselling to Our Lady’s Children Hospital in Dublin. I tested negative for the 10 most common genes and was given <0.1 chance of having a child with CF. The consultant also spoke about fertility treatment and the risks of birth defects associated with the procedure, but he was still happy for us to continue. After the appointment I felt daunted about potentially more problems in the future but when I asked my husband what he thought he said, ‘I think we should go as far as we can with this’ and that’s what we did.

With this news, the fertility clinic was able to offer us fertility treatment and PGS no longer concerned us. The next step was to determine if my husband had any viable sperm. This is a short procedure carried out at the clinic and that day we received the wonderful news that they had retrieved lots of healthy sperm. For the first time in a long time I felt a small glimmer of hope that our chances of becoming parents may come true.

Some weeks later, we embarked on our first IVF cycle, namely ICSI, which is a type of IVF where the egg is fertilised by injecting the sperm into it. It is used in cases of male infertility and carried out in the laboratory. We were quoted a 40% chance of having a successful pregnancy. I found the cycle challenging as I had never had any real medical issues before. The first couple of weeks involved taking lots of medication and having to get up in the middle of the night to do so. I had to inject myself in the tummy which was difficult. There were frequent visits to the clinic for scans and blood tests. It was a busy time, but I took it all in my stride as for the first time in ages I felt that I was doing something about our situation and that felt good. Eventually I was scheduled for the egg collection which
is a procedure done under sedation and over ten healthy eggs were harvested. I was sent home. I was very sore and was only allowed take paracetamol but felt much better soon after. The following day the clinic called with the wonderful news that some of the eggs had fertilised. We received regular updates from the clinic over the coming days and finally five days after the egg collection we were left with four embryos still going strong. I had one transferred, which was a simple procedure, and the remaining three embryos were frozen.

The next step was emotionally the hardest as we had to wait two weeks before I could test to see if I was pregnant. I hoped and prayed that we would have success and tried to keep busy. Unfortunately, it wasn’t to be. Eleven days after our little embryo had been transferred, I had a heavy bleed. I was in work and had to smile and pretend everything was normal. I rang the clinic and they confirmed what I already knew – the cycle had failed, and I wasn’t pregnant.

We were absolutely devastated. All our hard work for nothing. Another year had passed, and we still had no baby. We allowed ourselves to grieve and a few months later we embarked on our second cycle. This was a frozen cycle and involved more medication, scans and blood tests but I found it physically much easier to do. The clinic also put me on a different type of progesterone medication as they thought that what I had been prescribed on the first cycle had not been enough to sustain the pregnancy. One embryo was thawed, transferred and two weeks later I got a positive pregnancy test! I will never forget that day and how happy and free and light-hearted I felt. I was referred to the maternity hospital and my pregnancy was treated like any other. I was never made to feel like I was different because my baby was conceived via IVF, in fact, it was never really mentioned.

Our beautiful baby son was born a few days before Christmas, perfectly healthy, and we fell in love with him instantly. It was two years since the initial CF diagnosis, but we had persevered and never lost hope and he was finally here. As with any new baby, our lives were thrown into chaos, but he was so worth it and eventually we settled down into family life.

One year later we were keen to have another child. We did two further cycles with our remaining frozen embryos but sadly neither were successful. We took the failures very badly, me in particular. Even though I now had a baby and the fear I had felt in the past that I might never become a mother was gone, it was now replaced by a different fear that I would not be able to give my son a sibling. However, any plans we had to try for another baby had to be put on hold because I was diagnosed with gallstones and had my gallbladder removed. Doctors told me that I was unlucky in that the fertility medication had probably caused the gallstones, and this was difficult news to bear.

Sometime after, we decided to try another fresh cycle which resulted in three embryos and two weeks later I was pregnant again. This time I developed gestational diabetes - my age and family history had increased my chances of this happening, but IVF was also another contributing factor.

I worried during the pregnancy that I may not love the second baby as much as the first, but all my worries disappeared when our beautiful baby daughter was born and I realised that love does not divide, it only multiplies. I could not believe we now had two healthy children and a sense of contentment washed over me that I had never felt before.

Even though we were thrilled with our little boy and little girl we were determined to see the story to the end and so we embarked on another two frozen cycles. My husband and I felt that we had been given an amazing chance to become parents and the remaining embryos deserved that same chance. For us it was the right thing to do.

The first cycle resulted in our second beautiful, healthy baby son, born 18 months after our daughter and he is such a fantastic addition to the family.
Unfortunately, our final cycle was unsuccessful, and we found this to be the hardest of all the failed pregnancies. Maybe it was because it was our last embryo and due to our age, we weren’t going to try any more. Suddenly, our IVF journey that had taken the best part of ten years had ended abruptly and it was like hitting a brick wall. It took some time to get over these feelings but when we emerged from this period of sadness, we were ready to embrace this new chapter where we could now just enjoy life with our wonderful children.

Our IVF experience is one we will never forget. It was a time of extreme highs and lows. Often it was physically, mentally and emotionally very difficult, not to mention the expense or the strain it put on our relationship at times. It would be easy to focus on all the negatives but on reflection there were many positive aspects too. The staff in the fertility clinic were wonderful and even though our journey was sometimes very challenging, we always felt that we were in good hands. We were able to avail of the grant awarded by CF Ireland for fertility treatment and that coupled with the Drug Payment Scheme card for the medication was a huge help financially. Confiding in family and close friends was also so helpful and they supported us endlessly. I also did acupuncture on my second and third successful cycles and I felt they played a crucial role in helping me remain calm, focussed.

But the overwhelming positive of our experience has been the children. Being a parent is such a pleasure and privilege and we are truly thankful for them and all the joy and happiness they have brought into our lives.

Glamorous Granny!

When Jamie walked into the sitting room in Jan 2019 I just knew from his face that he had something important to tell me, what came next was a definite surprise and if I’m honest I had a few choice words, in relation to his genetics and the fact that he was only 20. However within seconds, all thoughts went to life with a new baby in our family.

As a family we had a month of worry as we waited on Caitlin’s genetics, the fear of both of them being carriers and passing the genes onto their baby was heart wrenchingly tough.

Being a grandmother (nanny) was something I was always afraid to hope and dream about as I firmly believe in taking one year at a time and not looking too far into the future, I made a point of enjoying each stage of my children’s lives as a positive step forward in my fight against CF.

Milo Jay arrived on Fran’s (Grandad’s) birthday 14th Sept 2019 weighing in at a healthy bouncy 7’13 baby. However he gave us a few shocks, he was in NICU within 24hrs and had two more hospital admissions before he was 6 weeks (not related to CF). Thankfully all is fine now and nothing showed up on his heel prick test and he is thriving.

Being a Nan is the most wonderful joyous experience, I could just eat him. Milo is at the stage of recognising our voices and following us around with his eyes and when he jiggles my heart just melts with uncontrollable love. I now have another reason to fight the fight that is life with CF.

Caroline Heffernan
Fertility Grant

Cystic Fibrosis Ireland (CFI) Fertility Grant Scheme provides financial support to people with cystic fibrosis (PWCF) and their respective partners who wish to undergo fertility assessment/treatment in the hope of becoming pregnant. Since this scheme was first rolled out in 2010, a total of 130 fertility grants have been awarded to members.

The value of the grant for first-time applicants is €3,000. The value of the grant for second-time applicants is €2,000 and €1,000 for third-time applicants. In recent times, CFI contribute an additional €1,000 to the cost of PGD where a partner of a PWCF has been identified as a carrier of the CF gene.

How to Apply

The Application Form must be fully completed, signed and returned to CFI for further consideration. The Fertility Grant Policy and Guidelines should be thoroughly read before completing the Application Form.

The Process

If the Applicant and their partner have been deemed suitable for fertility treatment (after initial fertility assessments), two letters (one from the Applicant’s CF Consultant and the other from the attending Physician in the Fertility Clinic) must accompany each Application Form. All such documentation must be authentic and legitimate, i.e., be on letter headed paper.

The Application Form must be submitted with the Supporting Documentation to the CFI National Office. Applicants will be informed by letter whether their applications have been successful within 2-3 weeks of submission.

Pregnancy and CF – The Challenges

Even in women without CF, pregnancy carries an element of risk for mother and child and requires lifestyle changes such as carefully managed nutrition and improved fitness. This is especially true for the woman with CF, as there are simply more things to consider if she plans to become pregnant.

Notwithstanding this, all women and all pregnancies are unique and ultimately having a child is a very personal decision for the partners concerned however as with all pregnancies, it will also not always be possible for a couple to plan the pregnancy in advance.

Ideally, however, when a woman with CF is planning to become pregnant, the first thing they should do is talk to their partner and CF team about the implications of becoming pregnant and having a child. This provides the opportunity discuss the medical facts, the probable course of the condition, the effect of CF on their pregnancy, the effect of pregnancy on CF and the impact of caring for an active toddler on treatment and care.
Christmas is a fun time, with visits from energetic elves, writing letters to Santa, time off school, playing games with family and friends and presents! However, it is no fun when you are sick, especially when you are sick at Christmas!

Here are some top tips to help stay fit and healthy and make sure you don’t miss out on all the fun!

1) **Get plenty of sleep** - it can be tough to sleep with the excitement of knowing Santa is coming, but if we don’t get enough sleep our body gets tired and it can be hard to fight off infection!

2) **Wash your hands** - when you come in from playing, before you eat your meals, after going to the bathroom and after rubbing your pets. Bugs love the cold weather so make sure to wash your hands with warm water and get rid of any germs!

3) **Cover your mouth** - when you cough or sneeze, this way if you have any bugs or colds you will stop them spreading to other people!

4) **Wrap up warm** - the weather outside is frightful! Make sure to keep warm, this will help you stay healthy over the holidays.

5) **Stay Active** - with lots of new toys to play with and yummy food to eat, make sure you don’t forget to exercise. Keeping active will help clear the mucus from your lungs and stop any infections before they make you sick.

Happy Christmas!

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**PUZZLE SOLUTION**

Autumn 2019

Can you find the six Christmas crackers in the wordsearch below?

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CAROL  CHRISTMAS  HOLLY
MERRY  PRESENTS  SANTA
STAR  WREATH  TREE
YOUTH REACH

CHRISTMAS CROSSWORD PUZZLE

USE THE CLUES TO COMPLETE THE CROSSWORD PUZZLE.

Across
1. One of Santa’s Reindeer
3. Santa’s Helpers
5. December 25th is ________.
7. Christmas Drink
10. The name of a popular snowman.

Down
2. Christmas Month
4. He hates Christmas!
6. You hang them by the chimney.
8. On Christmas morning we unwrap our ________.
9. ___ to the world!
Welcome Sarah!

Sarah Tecklenborg joined CFI in December 2019 as Senior Research and Policy Coordinator.

She previously worked in the HSE Sexual Health and Crisis Pregnancy Programme and the Health Research Board. Sarah is passionate about improving people’s health through evidence-informed policy and practice. She brings extensive research experience having undertaken three post-doctoral research positions in the Royal College of Surgeons in the areas of Epidemiology, Sexual Health and Pharmacoeconomics. Sarah graduated from Trinity College Dublin with a BA in Microbiology, a MSc in Global Health and a PhD in Molecular Epidemiology.
In November, we were delighted to launch our revamped website, www.cfireland.ie. The new website is mobile enabled, which will allow members to browse the site on the go. Easier navigation makes it more accessible allowing for a user friendly browsing experience!

The redevelopment of the website is the first step in a new approach to member engagement and communication, in line with our strategic plan.

With new content includes content for all audiences both within and outside the CF Community, we hope the website will be the first point of contact for members of the CF Community on a range of issues including travel, insurance and fertility and serve as an information resource for fundraisers, medical professional and media.

**Webinar - Save the Date!**

The second session of our Superbugs Webinar Series will take place on Tuesday January 21st at 7pm. The webinars are run by Cystic Fibrosis Ireland in conjunction with Professor John Moore and Cherrie Millar.

Details on how to get involved will be announced in January on our website and social media channels.
AGM Notice

The Galway Branch of C.F.I. cordially invite you to attend

the 2020 Cystic Fibrosis Ireland Annual Conference & AGM

The Ardilaun Hotel

April 3rd - 5th 2020

Join us in the European City of Culture for an educational, informative and fun weekend.

Programme will be available in January 2020

Visit www.cfireland.ie for details on how to register

Pic left to right: Maria Kelly, Business Development Manager Ardilaun Hotel; Liz Gantly; Geraldine Lohan; Mary Lane Heneghan; John Ryan Proprietor The Ardilaun Hotel & Fergus Mannion.
Encourage your employer to select Cystic Fibrosis Ireland as their Charity of The Year?

As companies look at who they are going to select as their Charity of The Year for 2020, why not ask your employer or ask your friends and family to ask their employer to nominate Cystic Fibrosis Ireland. We can provide you with support information about CFI and our work as required or visit your employer to outline to them how their support will help provide key supports and services for people with cystic fibrosis in Ireland.

Triple Locked

Cystic Fibrosis Ireland were delighted to be confirmed as a Triple Locked member of Charities Institute Ireland during 2019. This demonstrates to our beneficiaries and donors that CFI operates with openness, transparency and integrity by adhering to the Triple Lock Standards - transparent reporting, good fundraising and governance.

Ways your company and work colleagues can support Cystic Fibrosis Ireland ...

Charity of the Year (COTY)

The easiest and most recognised way your company can provide support to CFI whilst meeting their own Corporate Social Responsibility expectations would be to select Cystic Fibrosis Ireland as their COTY. Many companies allow their employees to select the COTY. If you get the opportunity please nominate CFI as your chosen charity and encourage your colleagues to vote for us! If you need any support from CFI with the process, please give the Fundraising Team a call on 01 4962433 and we will be happy to help you with supporting materials, application forms, advice, presentations etc.

If your workplace does not have a COTY scheme in place, it may be something they are willing to consider and again we would be happy to support you if your employer would like more information about CFI and the work we do.

The following activities would normally form part of the COTY partnership, but they can also be something you do within your workplace during the year as stand-alone activities to raise funds and awareness to help people with cystic fibrosis in Ireland.

Corporate Sporting and Social Activities

Many companies host a variety of sports and social activities during the year which could range from coffee morning and bake sales, to sports days, quiz nights or golf days, all of which can be occasions to raise money to support the work done by CFI.

These type of activities are encouraged within business as a fun way to break down barriers and to build teamwork between employees, while providing a great opportunity to raise funds and awareness to support charities.
Spar

Cystic Fibrosis Ireland was chosen as the Charity of the Year by Spar in May 2017. This has proven to me the most successful Charity Partner for Cystic Fibrosis Ireland ever with over €600,000 raised to date to help people with Cystic Fibrosis by Spar. The final amount raised will be confirmed as the partnership comes to an end in 2019! The funds have been raised through collection boxes in 400 SPAR stores nationwide, a donation on selected SPAR Own Brand products and through public fundraising for a number of key events.

It has been an excellent partnership with Spar participating and supporting Cystic Fibrosis Ireland with all our key campaigns including 65 Roses Day, Malin2Mizen Cycle4CF, Head2Head Walk and Christmas Jumper Day 4 CF.

Grafton Merchanting ROI

Cystic Fibrosis Ireland were delighted to be selected as the Charity of the Year by Grafton Merchanting ROI for 2019. Grafton Merchanting ROI selected Cystic Fibrosis Ireland as one of four charities to raise funds for as part of their Four Peaks Challenge with €17,114.03 raised to help people with Cystic Fibrosis.

The Four Peaks Challenge involved all 22 Grafton Merchanting ROI participants climbing the highest mountain in each of the four provinces over four days.

PWCF in Ireland need your support!

Cystic Fibrosis Ireland – Sporting Events

You can support CFI with your colleagues by participating in a range of Sporting Events in 2020 either as part of a COTY programme where you work or by simply putting a team together and participating in our events with your colleagues. Full details of all events will be available on our website at www.cfireland.ie and once your enter, contact the CFI Fundraising Team and we will organise your Fundraising Pack. 2020 events will include;

- 6.5k Remembrance Walks / Duleek 10k / Virgin Money London Marathon - (April), Malin2Mizen Cycle4CF / One in 1000 VHI Women’s Mini Marathon (May), Paris2Nice Cycle / Head2Head Walk / Paddy Kieran’s International Walk (Sept), KBC Dublin City Marathon (Oct), TCS New York City Marathon (Nov), Christmas Jumper Day 4 CF (Dec), Skydives / Kilimanjaro / Overseas Challenges (All Year).

You can have great fun with your work colleagues while raising much needed funds to help support provision of services to help PWCF in Ireland. Why not check also if your employer is willing to provide match funding for monies raised by their employers to support CFI.
65 Roses Day – Friday 10th April

65 Roses Day (Our National Flag Day) takes place on Friday 10th April. This is the National Fundraising Day for Cystic Fibrosis in Ireland and we will have volunteers selling our emblem, the purple rose in Shopping Centres and on the streets across Ireland. If your company is looking for volunteering opportunities and perhaps allows for volunteer days to support charities, then why not ask your colleagues if they would like to volunteer to help CFI on 65 Roses Day.

If you and your colleagues can help us on the day, please call the CFI Fundraising Team on 01 4962433 and we will organise to get you involved in your local or most suitable collection on the day.

Corporate Sponsorship

Another way your employer could help support people with CF in 2020 would be to sponsor one of the major events hosted by CFI. This could include our National Conference which takes place in Galway in April, 65 Roses Day also in April, the Malin2Mizen Cycle4CF in May, One in 1000 VHI Women’s Mini Marathon also in May or the Head2Head Walk in September.

By sponsoring our events, we can cover the costs involved in organising events, recruit additional participants allowing us to generate more funds to support the provision of support and services for PWCF in Ireland.

For more information....

For support with any discussions with your employer or a potential Corporate Sponsor, please do not hesitate to contact the CFI Fundraising Team (01) 4962433 or email fundraising@cfireland.ie

Meet the fundraising team

Fergal Smyth
Fundraising Manager

Rachel Byrne
Digital Marketing & Community Events Coordinator

Brendán O’Regan
Community Events & Branch Coordinator

Christina Trieu
Community & Individual Giving Fundraising Coordinator
FUNDRAISING:

Challenges and Events

For further details on any of our fundraising events, visit our website www.cfireland.ie, contact the CFI Fundraising Team on (01) 496 2433 or email fundraising@cfireland.ie

Apr 10th: 65 Roses Day

Cystic Fibrosis Ireland’s 65 Roses Day will take place on Friday 10th April. We are looking for your support to help raise funds and increase awareness of Cystic Fibrosis across the country. There are 3 ways you can help support Cystic Fibrosis Ireland on 65 Roses Day.

1) 65 Roses Day – Friday 10th April

65 Roses Day is our National Flag Day and our emblem, the CF Purple Rose will be on sale across the country for €2. We will be looking for volunteers to help sell our purple roses in every county across Ireland. This year we will be looking for even more volunteers as Dunnes Stores has granted us access to every store nationwide on 65 Roses Day. If you feel you can help us then we would love to hear from you. Please contact our office on 01 496 2433 or email fundraising@cfireland.ie. We will also be working closely with our CF branches to ensure that everyone will be able to buy a purple rose on the day. Keep an eye out for the campaign on TV, Radio, Press and Social Media in the coming weeks.

2) 65 Roses Challenge

As part of the 65 Roses Challenge, we are asking our supporters to organise a ‘65’ themed fundraising event as part of the 65 Roses campaign. Previous examples of challenges include a 65 Roses Tea Party, a gym doing 65 exercises in 65 minutes and schools holding a ‘No Uniforms Purple Day’. We also have the 65 Round challenge organised by Michael Carruth for any people willing to leap into the ring, keep an eye on our social media and website for further details. The challenge can be as simple or as challenging as you wish, so get your thinking caps on. For more ideas, check out our 65 Roses Challenge FB Page.

3) 65 Roses Text Donate

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

Text costs €2. Cystic Fibrosis Ireland will receive a minimum of €1.80. Service Provider: LIKECHARITY. Helpline: 076 6805278.
Cystic Fibrosis Ireland
6.5k Remembrance Walk

Apr 11th: 6.5k Remembrance Walks

Cystic Fibrosis Ireland, with the support of our branches across the country, are holding 6.5k Remembrance Walks on Saturday, April 11th. The day will see people nationwide walking 6.5k in our purple t-shirts at 2pm to remember and celebrate the lives of those we have sadly lost to Cystic Fibrosis.

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

You can register now to participate in a 6.5k Remembrance Walk in your area or contact us if you would like to organise a walk locally. Help us turn Ireland purple on Saturday 11th April in memory of our CF Angels. Contact fundraising@Cfireland.ie for more information.

Apr 26th: Duleek 10k

We are delighted to announce that we will be running this event in collaboration with Ann Noone and all the team at the Duleek 10k this year for its 8th year in succession. CFI will be sending out the packs to your address so that you do not have to worry about picking them up on the day.

This Duleek is aimed at people of all fitness levels and is suitable for runners and walkers alike.

The event is to remember and celebrate the lives of cousins Cathy O’Brien and Kelley Noone and all friends and families touched by Cystic Fibrosis.

The aim of the event is to increase public awareness about CF and to raise funds for Cystic Fibrosis Ireland. Over the past 7 years the Duleek 10k has raised more than €138,000 to help support people with CF in Ireland.

You can register now online at www.cfireland.ie or contact us on the details below:

**Email:**
duleekcf10@gmail.com  brendan@cfireland.ie

**Phone:**
Ann - 086 2852642  Sarah - 087 6465457
Brendán - 01 496 2433

Apr 26th: Virgin Media London Marathon

Thank you to everyone who has registered for the Virgin Money London Marathon.

This event is now SOLD OUT and we wish all participants on behalf of Cystic Fibrosis Ireland the very best of luck on Sunday 26th April in London.

Best of luck to our 3 runners Michael Kelly, Maireadh Kiely and Kieron Bracken.
May 7th to 10th: Malin2Mizen Cycle4CF

The Malin2Mizen Cycle4CF will take place from Thursday 7th to Sunday 10th May. The 2020 cycle was launched at the Athlone Springs Hotel on 5th October. We would like to thank the South Roscommon Cycling Club for facilitating the 50km at the start of the day and all the past cyclists and members of the support team including the Ted and the Bike Marshals who joined us for the presentations.

Malin2Mizen Cycle4CF 2020 will begin at Malin Head in Co. Donegal on Thursday 7th May and will finish in Mizen Head in Co. Cork on Sunday 10th May, having covered the following route;

Thursday 7th May: Malin Head – Bundoran 155km
Friday 8th May: Bundoran – Oranmore 173km
Saturday 9th May: Oranmore – Mallow 163km
Sunday 10th May: Mallow – Mizen Head 155km

Registration for the cycle is now open at www.cfireland.ie. All participants are asked to raise €2,000 to take part. This will also cover your food and accommodation for the 4 days of the cycle. All funds raised will go to CFI to help us continue to support people living with Cystic Fibrosis. Places are limited with registration closing on January 31st so please register NOW to ensure you secure your place in this life changing event!

May 31st: Vhi Women’s Mini Marathon / One in 1000

Cystic Fibrosis Ireland are delighted to be celebrating 10 Years of One in 1,000!

2020 is the 10th year of One in 1,000, and we would like to thank each and every one of you who has supported us over the past decade! We are hoping that our 10th year is our biggest and best yet, so we are calling on all our past participants, as well as new faces, to take part in the Vhi Women’s Mini Marathon for Cystic Fibrosis Ireland on Bank Holiday Sunday 31st May.

Why not get your girls together and get exercising for CFI? A great day out, with a base provided at the D2 Harcourt Hotel - food and entertainment provided, as well as a venue to relax in before and after the event, leave your stuff and meet your friends. It is a unique day out while raising vital funds for people living with cystic fibrosis in Ireland!

Keep an eye on our website and our social media channels for announcement of sign up details for One in 1,000 – 2020. Contact Rachel at rbyrne@cfireland.ie / 01 496 2433 for more details.
Sept 11th to 17th: Paris2Nice Cycle
CFI are currently recruiting cyclists for the Paris2Nice Cycle. This is a really well organised and extremely rewarding event. Cyclists will fly to Paris on Friday 11th September and begin cycling on Saturday 12th. The cycle makes its way along beautiful country roads with plenty of food stops in the scenic villages and towns along the route. The cycle will finish on the Promenades Des Anglais on Thursday 17th where you will be greeted by the welcoming team followed by a celebration dinner that night. Cyclists are free to fly home the following day or some choose to make a weekend of it in the beautiful city of Nice.

We would encourage anyone thinking of taking part to let us know here in the CFI office by calling us on 01 4962433 or email fundraising@cfireland.ie. We also suggest you sign up for Paris2Nice mailing list on the website www.paris2nice.com where you can find details of the upcoming information evenings. The first information evening will take place on January 15th in the Boat Bar & Grill, Dundrum.

Sept 25th to Oct 3rd: Paddy Kierans’ Memorial Walk
The CFI Walk Committee are delighted to announce that the 2020 Cystic Fibrosis Ireland International Walk will be visiting ‘Beautiful Bulgaria’ from Friday September 25th – Sunday October 3rd.

2020 marks the 26th year of Cystic Fibrosis Ireland's International Walk and promises to be another unforgettable experience for all walkers.

The Walk, which starts in Burgas and finishes in Sofia, will see participants walking an average of 10km each day, taking in sights such as the old town of Nessebar Beach with ruins of Byzantine era fortifications and baths, the fairy-tale style Ravadinovo Castle and its stunning landscaped gardens, the medieval Asen’s Fortress and Bachkovo Monastery, and the impressive structure of the Roman Amphitheatre in Plovdiv.

Does this sound good to you? Why not dust off those walking shoes and join the fun! See the world and make friends for life, all the while raising much needed funds for people living with CF in Ireland.

Contact Rachel at rbyrne@cfireland.ie / 01 496 2433 to receive more information as we would love you to join us in Bulgaria in September!

Sept 20th: Head2Head Walk
Our Head2Head walk takes place on Sunday 20th September. This walk goes from strength to strength as walkers hear about this wonderful event, walking along the sea front in a sea of purple CFI shirts. If you have any questions, please contact christina@cfireland.ie with full details to follow about the event later in the year!
Skydives
If a skydive has always been on your bucket list then now is your chance to tick it off, while supporting a great cause. Details are available on our website www.cfireland.ie or you can contact our office on 01 496 2433 or email fundraising@cfireland.ie for more information.

Kilimanjaro
CFI facilitate treks to Kilimanjaro, so if you are thinking of taking part in a trek, we advise that you book your place now for 2020.

Oct 25th: KBC Dublin Marathon
Did you manage to get your hands on a coveted spot in the KBC Dublin Marathon?

If so, why not run for Cystic Fibrosis Ireland? Funds raised will help us to provide services and support to people living with CF in Ireland.

Contact Rachel for more details, or to receive your marathon pack with sponsorship cards and race singlet. 01 496 2433 / rbyrne@cfireland.ie

Nov 1st: TCS New York Marathon
Registration will open at the end of January for the TCS New York City Marathon. This is a hugely popular event and is one of the world’s greatest participatory events. For anyone who takes part it is always an unforgettable experience. The marathon on Sunday 1st November runs through all 5 city boroughs (Staten Island, Brooklyn, Queens, The Bronx and Manhattan).

You can sign up with CFI to take part and the package includes:
- Direct return flights from either Dublin or Shannon to New York
- 4 or 5 nights’ accommodation
- Return airport transfers
- Private coach from the hotel to race start on Staten Island
- Guaranteed race entry
- Services of Sports Travel guides

If you would like to sign up or find out more then please contact the fundraising team on 01 496 2433 or email fundraising@cfireland.ie.

All Year:

Back To School
CFI have issued our ‘ChariTY for CF’ school fundraising pack to all Secondary Schools, with a focus on Transition Year students.

By getting involved, not only will ChariTY for CF help schools raise awareness of cystic fibrosis and help raise much needed funds to help support people with CF, it will also help students to develop and strengthen their involvement in community and charity work.

To request a pack or to find out more please contact our office on 01 496 2433 or email fundraising@cfireland.ie

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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:

**FUNDRAISING:**

Paddy Kierans’ Memorial Walk in ‘Glorious Greece’

Cystic Fibrosis Ireland would like to say a HUGE thank you to each of the 37 walkers who took part in the 2019 CFI International Walk to Greece. A whopping total of €118,746.08 was raised! Well done to all for the hard work on the fundraising. We look forward to seeing you all in Bulgaria in 2020! CFI would also like to say a MASSIVE thank you to the voluntary Walk Committee: Bernie Murphy, Vinnie O’Malley and Tony Griffith who oversaw the safety and well-being of all of the walkers in Greece and ensured the itinerary and walks kept everyone in good spirits!

Keep an eye on our website and social media channels over the coming weeks for more info on Bulgaria 2020 and if you have any questions drop Rachel an email at rbyrne@cfireland.ie or call 01 496 2433.

L-R: Fergal Smyth (Fundraising Manager, CFI), Vinnie O’Malley, Bernie Murphy (Chairperson, CFI International Walk Committee), Tony Griffith, and Rachel Byrne (Project Manager, CFI).
Darts Night

Cystic Fibrosis Ireland would like to say a huge thank you to Ian Osborne, Ali Kinnear, and Stephen Whelan who organised a darts night in the Clock Inn Pub on Vicar Street on the 8th August and raised a fantastic €2,015!

Huge well done to all involved!

Christmas Jumper Day 4 CF

CFI would like to say a huge thank you to all who participated in Christmas Jumper Day 4 CF, 2019!

It was our second year running the campaign and we were delighted that it was such a great success, thanks to the support of so many work places, schools and individuals who participated around the country.

KBC Dublin Marathon

We would like to say a huge thank you to all of the runners who took part in the KBC Dublin Marathon for Cystic Fibrosis Ireland.

Well done on smashing your goals as well as fundraising some really fantastic amounts. We hope you have recovered well at this stage!

Golf Classic

Cystic Fibrosis Ireland would like to say a huge thank you to the friends and family of Eddie Maher, who organised the Eddie Maher Golf Classic a few weeks ago and raised an incredible €2,800!

Please join us in saying a big thanks to all involved.

Paris2Nice Cycle

CFI would like thank Enda Greehy from Cork for taking part in the 2019 Paris2Nice cycle and for raising funds on behalf of CFI.

The cycle took place from 12th to 17th September and saw a large number of cyclists taking part to raise funds for a number of different charities. Enda raised a huge €5,000 in aid of CFI.

Camino 4 CF

CFI would like to say a massive thank you to Alexandra Sawicka who walked the Camino de Staniago in October this year.

Alexandra walked the Camino after her boyfriend Conan lost his battle with CF this past July and she did it in his memory.

She raised a massive €14,226.04.
Castleknock Community College

We were delighted to attend an awards night at the Castleknock Community College on Wednesday night where Sean Priestley presented Fundraising Manager of CFI, Fergal Smyth, with the Spirit of The Community Award 2019 on behalf of the College in recognition of the work of Cystic Fibrosis Ireland including all of the work in the Castleknock area, led by Bernie & Sean and all the members of the Dublin West Branch of CFI.

Pictured above L-R is John Cronin (Principal), Aisling O’Neill (Student), Fergal Smyth (Fundraising Manager, CFI), Sean Og MacSheoin (Student), Sean Priestley (Fundraiser), and Dr John Walsh (Chairperson of BOM at Castleknock Community College).

Ballyouskill Hill climbers

CFI would like to say a massive thank you to Nicki O’Neill and the Ballyouskill Hill climbers for their amazing fundraising as part of climbing Croagh Patrick, raising a total of €5,624 back in September.

Well done to all involved and we can’t wait for the next challenge.

Nicki was presented the cheque from the climbers on November 22nd in The Wheel Pub, Ballyouskill.

William Fry

Cystic Fibrosis Ireland would like to say a huge thank you to William Fry, who raised a fantastic €895 for CFI during their 6th Annual Funds Bake-Off, which took place in October.

Rachel visited the William Fry offices in November to accept the cheque.

Pictured above L-R is Julieann Byrne who nominated CFI as their chosen charity, Rachel Byrne (CFI), Hope Smith, 2019 Bake-Off Winner, and Karina Caraher.

AIB Kells

Cystic Fibrosis Ireland would like to say a huge thank you to AIB Kells who raised a fantastic €789 from their coffee morning held earlier this month.

Fundraising Manager of CFI, Fergal Smyth, visited the branch on Friday to receive the cheque. Massive well done to all involved!
# CFI Fundraising Calendar of Events 2020

<table>
<thead>
<tr>
<th>Month</th>
<th>Event Details</th>
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| April  | Friday 10th: 65 Roses Day  
Saturday 11th: 6.5k Cystic Fibrosis Remembrance Walk  
Sunday 26th: Duleek 10k  
Sunday 26th: Virgin Media London Marathon |
| May    | Thursday 7th to Sunday 10th: Malin2Mizen Cycle4CF  
Sunday 31st: One in 1,000 / VHI Women's Mini Marathon |
| September | Saturday 12th to Thursday 17th: Paris2Nice Cycle  
Sunday 20th: Head2Head Walk  
Friday 25th to Saturday 3rd October: Paddy Kierans’ Memorial Walk in Bulgaria |
| October | Sunday 25th: KBC Dublin Marathon |
| November | Sunday 1st: TCS New York City Marathon |
| December | Friday 11th: Christmas Jumper Day 4 CF |