

# Spectrum

Summer / 2017



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# Foreword



This issue of Spectrum covers a very exciting period for CF care in Ireland.

The HSE and Vertex have signed off on the final agreement in the provision of Orkambi and the extension of Kalydeco. Assessments are now underway in specialised CF centres to provide the new medications and the drug therapies are now available.

This does not mean everyone who has the appropriate genotype will be on the drug therapies straight away. There is a process in place to assess everyone, and those who need it most from a health perspective, will be given priority. In short, we ask for everyone's continued patience while these processes are completed. It's vitally important that all patients attend their 3 month assessments and continue to manage and adhere to existing medications, treatments, diet and exercise. To do otherwise may lessen the benefit of these new therapies.

CFI participated in the European CF conference and this issue includes a report from our Chairperson, Patricia Duffy Barber. A report from Erin Sugrue, our Regional Officer will be available on our website.

In recent weeks CFI have been visited by the CEOs of both the Australian and New Zealand CF associations. The visits were an opportunity to exchange news and good practice and to hear of their excellent work. There was also a strong interest in the fact that Orkambi is available in Ireland and not in NZ or Australia.

It was fantastic to see Katie Murphy take to the stage in the Gaiety as part of the opening night of Riverdance in their summer season. She was a star and we thank Riverdance for making us a charity partner.

Likewise a huge thanks to the GAA and SPAR for making us one of their 'Charities of the Year'. We know you will support them both at a regional and local level.

Have a great summer.

**Philip Watt (CEO)**  
**Samantha Byrne (Editor)**

*Front Cover: Jessica Cassidy PWCF with the cast at the launch of Riverdance's Summer run at The Gaiety Theatre in Dublin*

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# Latest News

## Overview of agreement between HSE and Vertex on Orkambi and Kalydeco (June 2017)

The agreement has the following elements (note Ireland previously approved Kalydeco for 6 years old and upwards in 2013)

- Orkambi will be made available for all CF patients 12 and older who have two copies of the F508del mutation
- Expanded access to Kalydeco for children ages 2 to 5 with any approved gating mutation (G551D, G178R, S549N, S549R, G551S, G1244E, S1251N, S1255P and G1349D)
- Access to Kalydeco for people ages 18 and older who have an R117H mutation



### The pipeline aspect of the agreement

A unique feature of the agreement between Vertex and the HSE is the 'pipeline' dimension.

In a nutshell, this means rapid access for people with all the above mutations (ie: two copies of the F508del mutation, G551D, G178R, S549N, S549R, G551S, G1244E, S1251N, S1255P and G1349D, R117H) if the labels of the existing medicines are expanded to cover additional age groups and if new Vertex medicines are approved for these populations.

It should be noted that if a medicine is developed for the mutations not listed above there would have to be further reimbursement discussions between the Irish health authorities and Vertex.

### Conclusion

As a result of this agreement and the 2013 agreement on Kalydeco, CFI estimates that around 70% of the CF population in Ireland will have access to some form of CFTR drug (either Orkambi or Kalydeco). Further, this existing group will benefit from new Vertex drug therapies that are currently being developed. This is important as recent trials of Tezacaftor/Ivacaftor have been promising. People with two copies of the F508del mutation ages 12 and older who received the treatment had significant improvements in lung function (4 percentage points compared to placebo) and in other key measures of the disease, including exacerbations (sudden worsening of symptoms) and quality of life.

CFI notes that in time some of the remaining 30% of patients may benefit from an existing or pipeline drug, but for others there is still the hope that





further drug therapy breakthroughs will follow. The most encouraging aspect of this statement is the amount of resources going into further research and clinical trials.

### Next Steps: When will I get Orkambi or Kalydeco?

Orkambi and Kalydeco will only be dispensed from specialised CF centres and not shared care centres. Whether you will be prescribed Orkambi or Kalydeco (and when) will be dependent on a number of factors. Everyone eligible will need to be assessed and then further assessed on a three month basis. It is vital that patients keep up their full treatment regime and attend their regular assessments. Please note that it is planned that those whose health is worse will be at the top of the queue for the new drugs. In short, there may be some continued delays but these delays are for good reason.

As with all drugs there is always the possibility of side effects. CFI urges patients to be aware of side effects when making informed decisions about taking a new drug.



### Orkambi and Northern Ireland

Last year the National Institute for Health and Care Excellence (Nice), which helps decide which new treatments should be available on the NHS in England and Wales, rejected the drug Orkambi, which has been shown in clinical trials to improve lung function and respiratory symptoms in people with the genetic condition.

The charity the Cystic Fibrosis Trust said that since Nice undertook its appraisal, new data had been published that suggested Orkambi almost halved the rate of decline in lung function in people with the disease.

We fully support PWCFs and our colleagues in the North of Ireland in their efforts to have Orkambi made available and trust our CF community will support and share any social media campaign launched by CF Trust.

# ECFS, Seville

**Patricia Duffy Barber, Chairperson of CFI gives an insight into the European CF Society Conference. The conference was held in Seville, Spain 7-10 June 2017.**

I attended on behalf of the CFI accompanying Philip our CEO and Erin Sugrue, Regional officer in Limerick. We were blessed with fabulous weather, and were able to do some quick sightseeing at the beautiful Alcazar, which is a UNESCO world Heritage site and home of Spanish royalty over many centuries in Seville. The Conference opened on Wednesday evening. The programme included a retrospective on 40 years of ECFS conferences and award presentations to notable researchers. We were treated to some traditional Spanish flamenco dancing on stage. Dr Patrick Harrison from UCC had the honour of being one of the speakers at the opening ceremony his focus was on progress in gene editing which may lead to future CF therapies.

The Conference Centre in Seville - Fibes conference centre was host to 2,300 participants mainly CF clinicians, researchers and allied health professionals. Ireland and the UK were well represented by both clinicians and scientific researchers. There was a packed schedule of presentations from 8.30am to 6.30pm Thursday and Friday.

Our CFI delegation also made time to meet with delegates from the Canadian, Australian and New Zealand patient associations who were keen to hear



about our success in advocating for government funding of Orkambi and the extension of Kalydeco.

ECFS kindly prepared an electronic copy of all of the Abstracts submitted for the Conference; this is available from CF House should anyone wish to peruse the range of abstracts. Further details of the Programme can be found online via the [www.ecfs.eu](http://www.ecfs.eu) or via the ECFS app.

## Highlights from the Presentation:

It is difficult to capture the range of research and clinical presentations attended across the 2 days.

**New Therapies:** There was a heavy focus on the new therapies and emerging understanding of how they will impact on different genetic mutations/alterations and on variations within the same genetic mutation. It seems we are beginning to understand more about how medications such as Kalydeco and Orkambi are impacting on all aspects of our illness from the lungs to digestion and exercise tolerance.



It was heartening to see that the scientific search for useful correctors for other mutations continues. An interesting development for those still waiting for CFTR correctors / potentiators is a process involving the patient's own cells (taken from the patient) and used to facilitate laboratory testing myriad different CFTR- changing drugs. It really seems to be the start of individually tailored medicine.

A variety of Poster Presentations from the Conference focussing on New Therapies will be available to view on the CFI website.

**Physiotherapy:** There was a number of different sessions with multiple presentations in each, focussing on research and clinical approaches to airway clearance,

clearance, and the role of exercise in physio. There was a definite message that exercise is key irrespective of your lung capacity. Finding an exercise that you enjoy and can regularly challenge your fitness level to a moderate level of discomfort will reap rewards over time.

A common theme was that physiotherapists are moving toward using a variety of measures of respiratory strength and vitality including 6 minute walk test, leg muscle strength and quality of life measures; rather than focusing solely on traditional measures of lung function and volume of oxygen.

One presentation of note was Carsten Schwarz 'Antimicrobial Stewardship in Cf- a juggling act?'

Research is continuing to understand more about our existing antibiotic 'weapons' and their impact on old 'enemies' such as pseudomonas (*P. aeruginosa*). Our antibiotic options for (*P. aeruginosa* and *Klebsiella pneumonia*) include colistin (colomycin), aztreonam (cayston), tobramycin and levofloxacin. *Stenotrophomonas maltophilia* is tackled with colistin (colomycin), tobramycin and levofloxacin. *E. coli*, staph aureus and MRSA is treated with levofloxacin. He noted the anti-inflammatory benefits from azithromycin, but cautioned that long term monotherapy use is linked with resistance.

When tackling an exacerbation with iv antibiotics, there have been various studies examining the benefits of monotherapy or combined antibiotics and Schwarz noted : *In a Cochrane review of 45 research studies, 'didn't demonstrate any significant differences between monotherapy, and combination therapy in terms of lung function; symptom scores; adverse effects; and bacteriological outcome measures'.* However in follow up 2-8 weeks after treatment there was a trend for more resistancy with monotherapy. *Juggling the benefits of antibiotic action with the possibility of resistance remains a key clinical challenge.*

**Microbiology** is often a challenging area for the lay person to get to grips with! Of note microbiologists were reporting about different types of bacteria that have been identified such as *Pandorea* and sub species of the *B Cepacia* complex. They are trying understand

more about the relative impact of these on the CF lung and assessing our current range of antibiotic and antifungal treatments against these. The interaction between bacteria in the lung (the microbiome of the lung) is also a vast area of research. Fungi including *Aspergillus* and Non tuberculosis mycobacterium abcessus (NTM) are continuing to evolve in their level of sophistication. There is a greater level of understanding about the factors playing a role in inflammation at a cell level.





# David Gilmore Award

## Award honours legacy of gifted engineer

A prestigious award has been set up in memory of a former engineering student of NUI Galway, who has been described as an 'extraordinary graduate'.

The David Gilmore award for best student in Electronic & Computer Engineering at NUI Galway was officially launched at the university recently to honour the past pupil who passed away in 2011.

David studied Electronic & Computer Engineering at NUI Galway, graduating in 2007 - he was notable because he had Cystic Fibrosis and struggled with his health while studying on the programme. It was here, at NUI Galway, that he met Paul Killoran - the steering force behind setting up the prestigious award.

The duo went on to become lifelong friends and then business partners. "A friendship ensued," Paul explained and in 2008 they decided to go into business together. "We went into Galway Technology Centre, we knocked on the door, it would have been January 2008, looking for a desk. The two of us like Batman and Robin!"

Paul had started a company called Starlight the previous year and he asked David to join him in helping to build the business. David agreed and the pair set about building web applications for universities across Ireland.

Two years later they decided to rebrand the company and, after securing a grant from the Local Enterprise Office and a bank loan, Ex Ordo was born.

Sadly, David passed away before the company was incorporated. Following his passing in April 2011, Paul made a promise to his parents that his legacy would be remembered.

"Despite the fact that David had an illness, which was Cystic Fibrosis, he was an incredibly gifted individual. He was very, very smart. He was a great engineer - one of the best engineers I've ever worked with and so what I wanted to do when he passed away was, I said to his parents, I want his legacy remembered in such a

way that it was bound with excellence and academic achievement because that's what he would have wanted to be known for."

Paul credits David with 'laying the foundation' for his company Ex Ordo which has gone on to achieve global success. "The world will never fully know necessarily how smart or gifted he was as an engineer so I intend to make that live on through this award and through his association with the company that is Ex Ordo."

Today Ex Ordo powers conferences in nearly 60 countries worldwide and has been used by nearly 150,000 researchers. It is used by 11 of the top 20 universities in the world and their customers include; Stanford, Harvard, Columbia, Oxford, Cambridge and the European Space Agency.

"David was a great friend of mine and without him I wouldn't be able to do what I did today. There's lots of things that have happened in the company over the last 12 months; I've just bought a house and I signed the papers for that house the morning that we unveiled the plaque so, irrespective of your religious beliefs, for me there is a guiding force there and he has certainly been helping me a lot," said Paul.

### TRIBUTES

Tributes paid to David at the launch of the award recalled a 'vibrant, intelligent and determined individual.'

The Registrar and Deputy President of NUI Galway, Prof. Pol O'Dochartaigh, Programme Director for the BE and ME in Electronic & Computer Engineering, Dr. Martin Glavin, The Dean of Engineering and Informatics, Prof. Peter McHugh, David's parents, Tommy and Mary Gilmore and CF Galway representatives Mary Lane Heneghan and Jarlath Feeney attended the ceremony.

The first recipient of the David Gilmore award, Barry McDermott also attended the launch.



*At the unveiling of the plaque at the Engineering Department of NUI Galway recently were: L-R: Tom and Mary Gilmore (David's Parents); Programme Director for the BE and ME in Electronic & Computer Engineering, Dr. Martin Glavin; Paul Killoran CEO of Ex Ordo; and Mary Lane Heneghan, Chair Cystic Fibrosis Galway. Photo: Boyd Challenger.*

## AGM Announcement

Eastern branch A.G.M will be held in C.F house, Lower Rathmines Rd, Dublin 6 on Monday the 28 August at 8pm.

### AGENDA

1. Welcome and Introduction
2. Minutes of last A.G.M
3. Matters Arising
4. Chairpersons Address
5. Secretary's Report
6. Treasurers Report
7. A.O.B

Mary McCarroll  
Secretary Eastern Branch

# My Malin2Mizen Journey

By Brian McCarroll PWCF

Hello. My name is Brian McCarroll  
I am a 28 year old PWCF.

On the 11th May this year I took part in the Malin2Mizen CycleforCf. This was a cycle from the most northerly point of Ireland to the most southerly point. In total it was 630Km over a four day period. This cycle was set up in memory of Triona Priestley who passed away in April 2014. The first cycle was held in 2015.

Since August 2013 I have been on the drug Orkambi. It has improved my health so much that I have only had two admissions to St Vincent's Hospital since June 2013. Over the last year I wanted to do something to show the CF community how well I have been doing and to give them hope that better days are to come for all of us. I had previously spoken on radio shows about my health before and after Orkambi became available. I had heard about the cycle in 2016 and always said to myself that I would love to do it. After a post on facebook in January this year I decided to sign up. I didn't even own bike but signed up anyway. In total I had 13 weeks to train for something most people train for years for. I applied for the exercise grant and thanks for CF Ireland, I used it to get a bike. A great friend of mine owns The Penny Farthing bike shop in Dublin City

Centre. He gave me a great deal on the bike and also sponsored all the gear that I needed.

The weather in February and March wasn't great so I wasn't able to train as much as I needed. I asked my local gym West Park if they could help me with sponsorship to train for the time I needed. They were so helpful that they gave me a full free year membership and shared my story on their facebook page. It was one of their most popular posts they had ever put on facebook. It helped spread awareness for CF and so many people gave donations to my gofundme page. My first 'big cycle' was up to View Point in the Dublin/Wicklow mountains. It was probably the hardest thing I had done in my life. While cycling I remember saying to myself "Are you mad? Turn back now, this isn't worth it". I just kept going and when I arrived at the top I just stopped at the car park and had a look down at Dublin City and from that moment I was hooked! After a couple weeks I had built up my fitness and was able to cycle all the way up to Sally Gap. After that it was day trips to Greystones or Baltinglass. Some days I would be doing over 70km. I knew I would have to build up to over a 100km in one day so I signed up to a Cycle4CF that was 65km loop from Blanchardstown to Dunboyne. I decided to cycle over and after I would cycle home bringing the total up to exactly 100km. When I arrived home my km tracker said I had only done 99.99km. Not to be disheartened, I got back on the bike for the final metre. Job done!

On the 10th May I travelled to Buncrana and had an overnight stay in The Harbour Inn Hotel. It was great to meet everyone involved. It's funny that you can meet 50 strangers and over the next few days have friends for life. The first day was approximately 147km. At 9am, we left Malin Head and travelled to Drumkeen for our first food stop. The sun came out and it was a glorious for the remainder of the day. We then headed towards Letterkenny and on to Donegal Town. We had been split into two groups because there were so many doing the cycle. The more experienced cyclists went first and beginners went second. While cycling, we would drop on and off and get to know each other, cycling two abreast. Everyone was eager to speak to me once they heard I had CF. Some people doing the cycle had kids with CF so they were so pleased to see someone





like myself taking part. We finished up in Bundoran and stayed in The Great Northern Hotel. The scenery in Donegal was amazing. That night we all sat down to a meal and got to know each other a bit more.

Day 2 was the longest day, 172km in total from



Bundoran to Oranmore. We left Bundoran at 8.30am and travelled down through Sligo town then onto Charlestown for some well-deserved food in the local Supermacs. After that we headed towards Tuam. Some other cyclists including Caroline Heffernan (who also has CF) were from Tuam so when we arrived we were greeted by the whole town. It was an amazing experience. We all felt like we were taking part in the Tour de France. From Tuam to Oranmore we had a Garda escort. Thankfully we did because the weather began to turn and we all just had to put our heads down and push on. When we arrived at the hotel, we were already checked in thanks to the many helpers we had so all our bags were ready to collect. After a beautiful steak sandwich I sat down to a three course meal. Everyone with CF knows the struggle of not eating enough calories and after burning 5000 and cycling for 8 hours I think it was well deserved. After two full days of cycling I felt fantastic and not tired at all. I barely had a cough and was full of energy.

### Day 3

It was a cold start to the day and by lunchtime it was raining. I couldn't feel my legs or feet after a couple of hours but I knew they were still working because the bike kept moving. It was the shortest of the 4 days but was definitely the toughest. On our way into Limerick City myself and another guy led everyone in for about 15km. It was a long journey with many roundabouts and obstacles but the Gardai were there to help again. During the final 20km of that day I began to feel a slight pain in my left knee but I didn't think it would be anything serious. At the hotel there was 4

physiotherapists to help with any niggles and also to give massages. I got my leg checked out and put some ice on it that night. Unfortunately the next morning I was in lots of pain and walking with a limp. My knee had swollen up pretty badly.

### Day 4

After getting up at the crack of dawn ready for the day I was feeling a bit emotional. I don't think I had taken time to think about what I was about to achieve. The pain in my leg didn't ease up and I felt every stroke of the pedal. It was very hard to get going that morning so I just stayed at the back until I felt better. After lunch the pain hadn't gone so I just put it to the back of my mind. There was no way in hell that it would have stopped me completing the cycle. I would have chopped my leg off and cycled with one leg. During the last few hours I think everyone was beginning to feel some sort of pain but we all kept going. We kept seeing signs for Mizen Head but it didn't seem to get any closer. One sign had said Mizen 8km then the next one said Mizen 12km. Not to be disheartened we all pushed along. With 4km to go we regrouped and planned to all head in together. I was in the middle of the group before we started moving again and I could hear people up the



front call my name. They wanted myself and Caroline to lead everyone in. It was a beautiful and kind gesture.

The final stretch was very hilly and because I was up the front I couldn't stop. When we hit a big hill or when the legs started to burn, I kept saying to myself "just keep going Brian, you're nearly there, keep going!" I also thought of my many friends that have CF and are unwell at the moment. I was doing this for them. Arriving at Mizen Head, we were all greeted by our families and it was an amazing feeling. I was on a high. After all the photographs, hugs and kisses a gang of us headed back to the Schull Harbour Hotel for the evening. I have never enjoyed a pint as much in all my life as I did that night. Later, there was a sing song in the bar thanks to John Sweeney who brought his guitar. It was a great end to a fantastic few days. Memories and friends that I won't forget.

It's hard to describe how I felt or still feel after completing this cycle. All I wanted to do was to prove that Cystic Fibrosis cannot stop somebody from doing something once they set their mind to it. I'm just so grateful that my health is so good the last few years. I hope people reading this get some encouragement from it and are looking to the future with great hope.

Brian.



# Fundraising

## Challenges and Events

For further details on any of our fundraising events, visit our website [www.cfireland.ie](http://www.cfireland.ie), contact the CFI Fundraising Team on (01) 4962433 or email [fundraising@cfireland.ie](mailto:fundraising@cfireland.ie)

### July 15th: Spar Fit Live

Cystic Fibrosis Ireland are delighted to have been selected as the Official Charity Partner of Spar and would like to thank Gerard Farrelly, Aisling & Barry Jones and everybody else who helped us secure the nomination and Spar Store votes to secure this partnership. We are looking forward to a close working relationship with Spar over the next two years and the first event being held by Spar is the Spar Fit Live run which takes place in the Phoenix Park on July 15th

You can register now to take part at [www.Fitlive.ie](http://www.Fitlive.ie) and don't forget to contact Cystic Fibrosis Ireland for your fundraising pack.



### Sept 22nd to 29th: Paddy Kieran's International Walk

There is still time to register to take part in the Paddy Kieran's International Walk for Cystic Fibrosis Ireland which will take in the Charms of Croatia from September 22nd to September 29th.

Join Dr. Eddie Murphy, well known TV psychologist, in this overseas trek where you will experience a different culture, make new friends, and create magnificent memories all whilst raising money to support Cystic Fibrosis Ireland.

Croatia offers a breath-taking landscape, from spectacular mountains, to lush woodlands, to shimmering lakes - there really is something for everyone. With the help of trusted guides, this walk offers a great opportunity for people to explore one of Europe's most beautiful countries, taking in such sights as Medjugorje, Korcula Island, and the historical town of Ston. The Walk will cater to all levels of fitness.

The fundraising target for the Walk is €2,980 and this will cover all costs including flights, accommodation and meals.

The journey of a lifetime starts with a single step! Make that first step now, contact Nuala in CFI for more information on 01 496 2433 or email [nmcauley@cfireland.ie](mailto:nmcauley@cfireland.ie)





## Sept 24th: Head2Head Walk - Howth Head to Bray Head

The annual Head2Head Walk will take place this year on Sunday 24th September with all proceeds going to help Cystic Fibrosis Ireland continue provide support and services for people with cystic fibrosis. Over €17,000 was raised from the event in 2016 and we hope to make 2017 even bigger and better.



It will be a 24 mile walk beginning at Howth Dart Station and finishing in Bray. For those who feel the full distance is a bit too strenuous there will be the option of starting at Howth and finishing in Sandymount or join the walk at Sandymount and finish in Bray. Enjoy a scenic walk along the coast, while helping a greater cause. Invite friends to sign up with you and make a day of it.

Registration is now open at [www.cfireland.ie](http://www.cfireland.ie). All walkers will also receive a Head2Head T-Shirt upon registration and a medal for taking part.

We encourage everyone to play their part by taking a sponsorship card and raising whatever you can to help make this event a success. All those who fundraise €100 or more and have their funds lodged by 31st October will be entered into a free draw for a laptop.

For further information please contact Peter on 01 496 2433 or email [fundraising@cfireland.ie](mailto:fundraising@cfireland.ie)

## Oct 29th: SSE Airtricity Dublin City Marathon

The 2017 SSE Airtricity Dublin Marathon takes place on Sunday October 29th.

Are you up for the Marathon Challenge? Put your lungs to good use and Run for CF!

The 26.2 mile route is a mostly flat, single lap which starts and finishes near Dublin city centre. The route is open for 8 hours so you can run, jog or walk to your own ability! The SSE Airtricity Series includes a number of racing challenges to help you prepare for the Marathon. There are also top tips on training, nutrition and pacing available for beginners, novices and regular runners on [www.sseairtricitydublinmarathon.ie](http://www.sseairtricitydublinmarathon.ie)

Registration costs €90 and race entry is guaranteed upon payment.

Don't forget to contact Cystic Fibrosis Ireland once you register for your Fundraising Pack, so that you can help people with CF as well as taking on this momentous challenge!

The Dublin Marathon is the 4th Largest Marathon in Europe and is known as the 'Friendly Marathon' due to the number of supporters who line out the streets to cheer on participants. You are guaranteed to have plenty of support to encourage you along your journey.

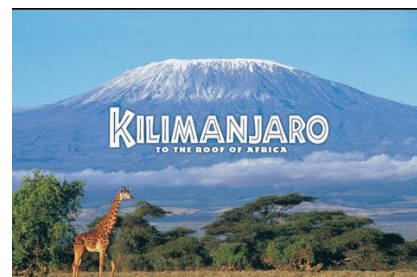
For information on to sign up to receive your fundraising pack, contact Nuala in CF House on 01 496 2433 or email [nmcauley@cfireland.ie](mailto:nmcauley@cfireland.ie).



## All Year: Kilimanjaro

CFI facilitate treks to Kilimanjaro each year and there will be a number of treks during 2017. Spaces on these treks fill up quickly, so if you are thinking of taking part, we advise that you book your place early.

For more details and a full list of tour dates please see our website [www.cfireland.ie](http://www.cfireland.ie) or contact Peter at [pminchin@cfireland.ie](mailto:pminchin@cfireland.ie)



## Skydives

A skydive has to be one of the most exciting things you will ever do in your life. Now is the chance to tick this off your bucket list, while raising much needed funds for CFI. Jump from 10,000 feet, free fall for 30 seconds before the parachute opens and take in the views like you've never seen them before.

To get started, visit our website, [www.cfireland.ie](http://www.cfireland.ie) which contains all the details you need to make this dream become a reality. For more details, contact Peter at [pminchin@cfireland.ie](mailto:pminchin@cfireland.ie)



# Thank You

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

## 65 Roses Day - National Fundraising Day for Cystic Fibrosis Ireland

CFI would like to say a big thank you to all our supporters who supported our national fundraising day '65 Roses Day' 2017 on Thursday 13th April. Once again 65 Roses Day proved to be a great success with over €100,000 raised so far from this year's campaign. Well done to all our volunteers who sold our purple roses in shopping centres, schools and workplaces throughout the country. Special thanks also to our CF Branches around the country who get behind the day each year. It is the tremendous support of our volunteers and branches which helps us to continue to make '65 Roses Day' bigger and better each year.

We would like to say a special thanks to our 65 Roses Ambassadors, Keelin Shanley, Jenny Dixon, Chef Adrian, Rosanna Davison and Joe Brolly who helped us to promote the day. We would also like to thank the families who took part in the photoshoots for 65 Roses Day. There was great media coverage across TV, newspapers and radio which helped to make the day the success that it was. We would also like to say a special thank you to Malone Group who sponsored our 65 Roses Day radio advert.

## 65 Roses Challenges

Thank you to all the individuals, schools and workplaces who organised events as part of our 65 Roses Challenge. It would be impossible to list all the challenge events but they included 65 Roses Fun Runs / Walks, 65 Exercises in 65 minutes, a Comedy Show, a Waxathon, 65km Cycle, our 65 Roses Skydive and 65 Roses Bake Sales to name but a few.

If anyone still has outstanding funds to lodge from either 65 Roses Day or from a 65 Roses Challenge we would ask that you lodge the funds to the below fundraising account as soon as you can:

Fundraising Account: IBAN IE59 AIBK 931071 08578593 BIC: AIBKIE2D

## 65 Roses Skydive

CFI would like to say a big thank you to all those who signed up to take part in the 65 Roses Skydive on Friday 14th April. Over €16,000 was raised from the event with 17 brave jumpers taking part. Well done to all involved.







## Ballyouskill Horse Ride

Well done to the members of the North Kilkenny Hunt who organised the Ballyouskill Sponsored Horse Ride which raised €4,300 for Cystic Fibrosis Ireland. PIC - Front L-R John McGuinness T.D., Sean Doheny (Master North Kilkenny Hunt), Frances Palmer, Nicki O'Neill (Cystic Fibrosis Ireland), Frank Brennan, Cllr. Maurice Shortall. Back Row L-R Pat Mooney, Paul Palmer, Philip Doheny, John Kennedy, Kieran Mooney, Jimmy O'Neill.



## AIB Kanturk Coffee Day

Thank you to Emer Crowley and all the staff of AIB in Kanturk who organised a 65 Roses Coffee & Cake Day in their branch. A total of €469 was raised. The bank also invited along 30 preschool children to sing songs which the customers were delighted with. Well done to all who supported the day.



## McLaughlin's Bandon Medical Hall Pharmacy

Thank you to Sarah Jennings and all the staff of McLaughlin's Bandon Medical Hall in Bandon who supported 65 Roses Day. They decorated the store in purple for the day and sold CF purple roses along with 65 Roses cupcakes. Well done to all for getting involved.



## St. Nicholas Primary School Sleepathon

Big thanks to the Junior Infants of St. Nicholas Primary School in Longwood, Co. Meath who held a Sleepathon in aid of CFI and raised €800. The children put on a concert for their parents at 7.00pm and afterwards relaxed in the classroom until 9.30pm with pizza and chips before heading to bed at 10.00pm. Thanks to Aideen Djennadi, Sheila Connaughton and Sharon Magee and the principal Mr. John Smyth for looking after the children and making this a successful event.



## Laughter Lines 65 Roses Comedy Night

Well done to Declan McFadden and friends in Laughter Lines Dublin who organised a charity comedy night in aid of CFI for 65 Roses Day. A great night was had by all.



## Santa Sabina Secondary School TY Ball

Cystic Fibrosis Ireland would like to thank Santa Sabina Secondary School Sutton for their support during the school year.

The Transition Year class, led by students Hannah Cosgrave, Olwyn Hughes, Nicole Kennedy and Ruth Nolan held a number of fundraising and awareness events for CFI including a TY Ball, a bag pack and volunteering on 65 Roses Day. The students recently presented CFI with a cheque for an amazing €10,216.

## Malone Group 65 Roses Cycle

Well done and a big thank you to Malone Group who organised a 65km cycle as part of the 65 Roses Challenge. The cycle started outside their head office in Blanchardstown and went in a loop around north Dublin before finishing again outside their head office. All cyclists thoroughly enjoyed the event which was very well organised and supported and a fantastic total of €3,105.36 was raised on the day.



## Michael Collins Walking Tour

Following the success of the 1916 Walking Tour in 2016, a Michael Collins Walking Tour took place in Dublin on Good Friday, April 14th.

The tour, led by Dr. Eoin Walsh took in numerous sites associated with Michael Collins including No. 10 Exchequer Street where the offices of the Irish National Aid Fund were situated, the GPO and Vaughan's Hotel, Parnell Square which was used by Collins as a safe meeting point. Lasting just over 2 hours, the tour was extremely enjoyable and informative.



Thank you to Lorcan Collins and Eoin Walsh for supporting Cystic Fibrosis Ireland. If you missed out, don't worry, the Michael Collins Walking Tour runs daily, beginning at 3pm from the International Bar on Exchequer Street. If you can, check it out, you won't be disappointed!

## Dunnes Stores Fundraising Day

Well done to Jacqueline Redmond and all at Dunnes Stores Head Office who held a fundraising day and raised €4,155 for Cystic Fibrosis Ireland. The day included a raffle and casual day. Special thanks to Janette Nangle who supplied a themed cake for the event. Jacqueline will take part in the Paddy Kierans International Walk in September in aid of CFI and her colleague Joe Mc Dermott recently completed the Milan Marathon.



## Malin2Mizen Cycle4CF

The Malin2Mizen Cycle4CF 2017 turned out to be a fantastic success with 42 cyclists signing up to make this event even bigger and better than the previous year. Each cyclist was asked to raise a total of €2k, with most cyclists raising more than this, ensuring the overall income for the event, including sponsorship is expected to reach €150,000. Similar to the previous year, the event consisted of a 4 day cycle beginning in Malin Head, County Donegal and finishing in Mizen Head, County Cork. The distance covered over the 4 days was approximately 640km so it was a massive achievement for all the cyclists involved.

A special mention should go to Brian McCarroll (PWCF) from Dublin and our own Caroline Heffernan (PWCF) who both cycled the 4 days, with Caroline completing the cycle on a tandem bicycle.





The cyclists came from all parts of Ireland and we even had a few cyclists from Scotland. Everyone gathered in Buncrana on Wednesday 10th May before beginning the cycle the following morning from Malin Head. Day 1 saw the cyclists cover a distance of 160km with the cyclists arriving into The Great Northern Hotel that evening. Weather conditions were good with the cyclists enjoying a well-earned break along the way at Kernan's Diner in Drumkeen, thanks to the hospitality of the owners. Day 2 saw the cyclists leave Bundoran and make their way to Oranmore in Co. Galway. The first food stop was in Sligo at Mullins SPAR service station where there was plenty of food and drinks available, again kindly supplied by the proprietors. The next main food stop was in Charlestown where the Mayo Branch kindly looked after the needs of our cyclists and crew by sponsoring the food and drinks. Later in the day the cyclists made their way in to the town of Tuam, the home town of our tandem cyclists, including Caroline Heffernan, and a massive reception was awaiting us all there, with the town coming to a standstill to welcome the cyclists. The finishing point on Day 2 was The Maldron Hotel, Oranmore where after a Champagne Reception courtesy of the Galway Branch, everyone got a well-earned rest for the night.



Day 3 saw the cyclists make their way from Oranmore to Charleville. The weather was quite nice early in the day with the cyclists stopping in Maxol Clarecastle before making their way to Maxol Dooradoyle. Members of both the Clare and Limerick branches were out to show their support in both locations which was fantastic to see. After leaving Dooradoyle, the cyclists made their way to The Charleville Park Hotel and with the rain now coming down quite heavy the cyclists were glad to finish here for the day. Day 4, the final day, saw the cyclists make their way from Charleville to the final destination of Mizen Head. The first stop was Coleman's Maxol in Millstreet with the second stop in Macroom. The cyclists were now getting excited at the prospect of reaching the finish in Mizen and kept pushing on strongly towards the finish. Drimoleague was the last main stop before regrouping close to Mizen Head with all the cyclists wheeling into Mizen Head together to a fantastic reception from family and friends. There were great scenes of emotion and a great sense of achievement felt by all involved in the cycle.

This event takes a lot of planning and organising and could not happen without the generous support of so many people. CFI would like to thank our sponsors for the event who included TLC Nursing Homes, Maxol Ireland, Dunnes Stores, Bradley Motors (Tuam), Frank Keenan (Cycling Ireland) and Dunleavy Bespoke Furniture.



We would also like to extend a huge thank you to Bernie, Sean & the Priestley family, Brendan Quigley, John Sweeney (Clare Sports Partnership), Phelim Macken (Limerick Sports Partnership), Myles Sweeney (Donegal Sports Partnerships), Caroline Heffernan, Claire Dunleavy, Anne McCarthy, An Garda Síochána, the bike marshals, the physios, all the Local Sports Partnerships and our ambassadors Sean Kelly, Alan Brogan and Eoghan Clifford. We would also like to thank those who came along this year to provide extra support and who helped along the way with the luggage, food, driving lead



and who helped along the way with the luggage, food, driving lead cars, taking photographs, etc. They were Mary Kennedy, Anette Hanlon, Marguerite O' Flaherty, Tony McHugh, Henry Cahill Snr, Jim Furlong, John Crowley and Virginia Diskin. Also special thanks to our bike mechanic, Phelim McCallion for all his tremendous work.

Thank you to all the CF branches who provided cyclists and helped support the cyclists fundraising efforts and to the CF branches along the route who supported the event. Special mention should also go to all 42 cyclists who took part and who did a huge amount of fundraising, we really appreciate it.

We are looking forward to and planning for Malin2Mizen Cycle4CF 2018 which will take place from May 10th to May 13th, 2018.

## One in 1000 - VHI Women's Mini Marathon

There was rain on Bank Holiday Monday, June 5th 2017, but it did not dampen the spirits of the 700 women and men who took part in the 2017 VHI Women's Mini Marathon as part of the One in 1,000 Campaign for CFI.

One in 1,000 is a national fundraising event for CFI and that was evident from the participants this year, from Dublin to Donegal, Kildare to Kerry! A huge thank you to the branches for their support in supplying teams and promoting the event locally.

Following a turbulent year which saw CF patients battle for access to new therapies, it was fantastic to see the CF Community come together again, this time for a fun event. This year saw 12 people with cystic fibrosis take on the 10km route, a record number! This only heightened the sense of hope for the future for all those taking part and spirits were high on the day!

A huge thank you to everyone who took part in the One in 1,000 Campaign and fundraised for Cystic Fibrosis Ireland. Just a reminder that anyone who raises over €100 will be entered into the 'Lucky One in 1,000' Raffle which will take place on September 8th. Income must be returned to CF House by August 31st to be included in the raffle. There are lots of great prizes to be won including a Sunway Holiday Voucher, €50 Dunnes Stores Voucher, two €50 Penney's vouchers, a Lindt Chocolate Hamper and much more.

Thank you to our One in 1,000 Ambassadors Roisin O'Donovan, Evanne Ní Chuillín and Anne Skelly for their support of the campaign. Thanks also to Mylan who sponsored the T-shirts for the day, which ensured our participants were kitted out to perfection and Carey London Ltd. who sponsored our One in 1,000 Radio Advertisement, allowing us to promote the event to a new and wider audience.



Since the One in 1,000 Campaign began, it has helped to raise over €900,000 for CFI. This year, we hope to reach the One Million milestone. To everyone who took part this year and who has taken part in the past, on behalf of CFI and the CF Community we support, Thank You! You are proof that One person CAN make a difference.

We hope everyone who took part enjoyed the day. It was great to see so many of you in DTwo Harcourt Hotel before and after the Mini Marathon.

Remember, to the world you may be ONE person, but to ONE person you are the world!

## Riverdance



CFI are delighted to have been chosen as the Charity Partner for Riverdance 2017 which is running in The Gaiety Theatre from June 21st to September 3rd. A launch of the Charity Partnership took place in June where it was announced PWCF Katie Murphy would join the Riverdance troupe on stage on the Opening Night of June 22nd. The purple carpet was rolled out and the stars were out in force for the opening night, when Katie made her stage debut. Huge congratulations to Katie on this amazing achievement.



On June 29th a Riverdanceathon took place outside The Gaiety Theatre in aid of Cystic Fibrosis Ireland. The event ran for 12 hours, from 10am to 10pm and featured over 20 dance schools, members of the Riverdance troupe and two PWCFs; Katie Murphy and Jessica Cassidy, aged 7.

A huge thank you to Riverdance for selecting Cystic Fibrosis Ireland as their Charity Partner for 2017. Collection boxes are in place for the duration of the show's run in The Gaiety so if you are attending, please support this charity partnership.

## Cork Marathon



Sunday June 4th was a marathon day for Cork with the Cork Marathon, Half Marathon, Team Relay and Youth Challenges all taking place. CFI were delighted to have the support of Fianna Fail Cork North West and the Paddy Healy Cumann Ballincollig on the day, who entered teams in the Team Relay and participants for the Marathon.

Congratulations to all participants across all four events! If you have caught the Marathon bug, don't delay in registering for the Dublin Marathon which takes place on Sunday October 29th!

## Eureka Secondary School



CFI Would like to say a big thank you to Eureka Secondary School in Kells, Co. Meath who recently raised €600 for through events such as a quiz, a bake sale, a game area during sports day, and selling lollipops etc. throughout the school. It was a joint effort from students and teachers. Well done to all involved.

## Conference Sponsors

Cystic Fibrosis Ireland would like to thank our sponsors for the Annual Conference which took place in Killarney in April and without which our Conference would not be possible.

This year's sponsors were Vertex Pharmaceuticals, Horizon Pharma and Concert Pharmaceuticals.



## CFI Grand Raffle

Thank you to all those who supported the 2017 CFI Grand Raffle which took place at the CFI Annual Conference in Killarney on Saturday April 1st.

We are delighted to confirm the winners were as follows:

1st Prize:	32GB Asus Transformer Book Flip	Ravan Wallace
2nd Prize:	32GB iPad Mini	Carolyn Thornton
3rd Prize:	€200 Sunway Holiday Voucher	Kim Ryan
4th Prize:	Two tickets for Ireland v Austria, World Cup Qualifier	Jack Healy
5th Prize:	2 Night Midweek Stay in The Brehon Hotel, Killarney	Rita Sisk
6th Prize:	16GB 7" Amazon Fire Tablet	Claire Fleming
7th Prize	8GB 7" Samsung Galaxy Tab A6	Ken Pollard
8th Prize	Autographed Cycle Jersey by Sean Kelly & Alan Brogan	Mairead Delaney

Cystic Fibrosis Ireland would like to thank everyone who supported the raffle by selling and purchasing tickets. In particular thanks to our sponsors for donating the fabulous prizes including; Adlantic.ie, Sunway Holidays, The Brehon Hotel, The FAI, PC Peripherals.





## Duleek 10k 2017

CFI would like to take this opportunity to sincerely thank everyone involved in the Duleek Cystic Fibrosis 10K 2017 but obviously cannot name all who so generously gave up their time to make the event so special and successful.

Thank you to The Duleek Court House committee for the use of the Court House. The many stewards who worked so hard on the day. The order of Malta team who thankfully had no incidents. Aileen, Orla & Shane for warm-up and music. Wendy and all her helpers for cooking the burgers. Everyone who made cakes and sandwiches and helpers with teas, registration etc. All the sponsors and donations, very sincerely appreciated. Also Andrea O Grady from Body First. Of course all the participants who travelled from near and far to take part. The local supporters including the local clubs and everyone who cheered the runners/walkers on and to Kerrie & Shauna for the great photos, a big thank you!

And the good news - it is looking like the event is set to reach the €100,000 barrier in income with this year being the 5th running of this event



## Liffey Swim

CFI would like to say a big thank you to everyone in Byrne Casey & Associates in Tullamore, Co. Offaly who recently organised a charity race night which took place in The Townhouse, Tullamore. The night was a great success with the proceeds from the night split between CF Ireland and Dochas Offaly. CFI were delighted to receive a cheque for €6,376.60 from the staff which was recently presented to Sadie Kerrigan on behalf of CFI. Well done to all involved and thank you for your generous support.



## Virgin Money London Marathon 2017

Thank you to Paul Lanigan from Waterford who took part in the Virgin Money London Marathon 2017 in aid of CFI. Paul completed the marathon in a time of 3 hours and 51 minutes. Well done on a great achievement and thanks for your support Paul.

If anyone would like to take part in the Virgin Money London Marathon 2018 then please do get in contact with our office for more details. You can contact us on 01 496 2433 or e-mail [fundraising@cfireland.ie](mailto:fundraising@cfireland.ie)



## Night at the Dogs

A fundraising night took place in Youghal Greyhound Stadium on June 9th, organised by PWCF Ben Mc Carthy. Although the night was wet and windy a large crowd showed up to support Cystic Fibrosis Ireland. The feature race of the night was the Cystic Fibrosis Ireland race, which was won by the Michael Leahy and Patrick Casey owned and trained She Brae.

Pictured at the presentation to owner and trainer Michael Leahy and connections are Marcella Kiely (Grandmother to a PWCF) with other CFI members, Ross Power and Ben McCarthy (both PWCF) Leanne Power, Bríd Uí Chadhlá and Liam McCarthy (parent members). Also pictured is John Mc Grath (Track Manager). Photo by Paidi Walsh.





## Top Oil

Cystic Fibrosis Ireland were delighted to be chosen as the nominated charity for Top Oil in the North East Region. Fundraising will commence at Top Oil Filling Stations across the region in July, with local fundraising initiatives by staff as well as staff participating in upcoming Cystic Fibrosis Ireland fundraising events.

*Photo: Gerard Boylan, Chief Executive of Top Oil and Fergal Smyth, Fundraising Manager, CFI at the launch of the new Charity Partnership*



## Central Bank

Cystic Fibrosis Ireland would like to say a big thank you to The Central Bank who provided a €26,000 donation to CFI to help us continue to support people with cystic fibrosis as one of their charities of the year for 2016 / 2017.



## O'Brien's Wine Tasting

CF Ireland were delighted to be chosen as the Charity Partner for O'Brien's Wines; Wine Fair which took place in The Printworks, Dublin Castle on May 5th & 6th. The two day event which saw three Wine tasting sessions take place, attracted nearly 2,000 visitors. The high incidence of cystic fibrosis in Ireland was evident at the event, as numerous people came to the CFI stand to talk about their own connection to CF through their family, friends, colleagues or neighbours.



In addition to collections held at the event, CFI will receive a percentage of ticket sales from the event.

## UCD Agricultural Science Society

Cystic Fibrosis Ireland would like to express their sincere appreciation to The UCD Agricultural Science Society for choosing CFI as their charity partner for 2016/2017.

The Ag Soc held numerous fundraising campaigns throughout the year including a White Collar Boxing Night, Debate, Society Ball, Collection Day and a Heifer Raffle. Culminating in a total of €50,000 with €40,000 raised for CFI and €10,000 raised for Embrace Farm.

In addition to the fundraising efforts the society members and UCD students supported the CF Community by volunteering for 65 Roses Day and attending the protests for access to Orkambi and Kalydeco in December and February.



A huge thank you to the Agricultural Society Committee for selecting Cystic Fibrosis Ireland as a charity partner and to everyone involved in the Society for their outstanding support and contribution. Thanks also to the students and staff of UCD and everyone who supported the Ag Soc in their fundraising efforts.

## QuintilesIMS

Cystic Fibrosis Ireland are delighted to have been chosen as Charity of the Year by QuintilesIMS. A huge thank you to the staff of Quintiles IMS who held their first fundraising event for CFI, a fundraising walk in June. Unfortunately the weather was not ideal for the fundraising event, but the staff battled through the outbreaks of rain and scorching sun and raised over €1,000!

As our Charity partner Quintiles IMS have numerous other fundraising and awareness events planned throughout the year including a raffle and a 7-a-side tournament.



## GAA

Cystic Fibrosis Ireland were delighted to be announced as Official Charity Partner for the Official GAA for the year ahead in Croke Park on June 12th.

The GAA will help Cystic Fibrosis Ireland raise awareness about cystic fibrosis and our work as well as champion CFI in our fundraising efforts throughout the coming year. Please take the opportunity to talk to your local GAA Club to confirm Cystic Fibrosis Ireland are an Official Charity Partner for the GAA for the coming year and to see if they can assist you with your fundraising work.

Aogan O Fearghail, Uachtaran CLG confirmed this support at the launch - "I look forward to seeing the Charity Partners benefit and prosper from their link with the GAA over the coming year, and we look forward to helping and supporting them in the extraordinary work they do".

Pictured at the launch yesterday in Croke Park are;

Aogan O Fearghail, Uachtaran CLF, Peter Minchin Branch & Events Co-Ordinator Cystic Fibrosis Ireland, Philip Watt, CEO Cystic Fibrosis Ireland.



## Tayto Park

Cystic Fibrosis Ireland are delighted to have been chosen as the Official Charity Partner for Tayto Park in 2017.

CFI would like to say congratulations and well done to Joe Gaynor (PWCF) aged 7, who on June 15th, helped to officially open the new 'Viking Voyage at the Park' ride at Tayto Park. Joe was invited along with his family to officially open the new Viking themed ride alongside Raymond Coyle, founder of Tayto Park.

With 1.7 million litres of water, a Viking village, 5 replica Viking ships and 20 life size Vikings, families can expect to feel the splash on the latest addition to Ireland's favourite theme park.

Watch out for the Cystic Fibrosis Fundraising Team who are scheduled to hold a Bucket Collection and support other fundraising events in Tayto Park this summer.





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## IAPC Cannes Young Lions Competition 2017

Cystic Fibrosis Ireland are honoured to have been chosen as the Charity of choice for this year's Institute of Advertising Practitioners Ireland Young Lions Competitions for Film, Cyber and Social Media.

Together with IAPC (Institute of Advertising Practitioners in Ireland), Cystic Fibrosis Ireland challenged this year's Young Lions entrants to develop campaigns supporting '65 Roses Day' on April 13th, 2018. Submissions to the Film, Social and Media categories were tasked with increasing public awareness of the challenges faced by people living with Cystic Fibrosis in Ireland. The winning campaigns represented Ireland at the International Cannes Lions Festival in June.



Teams in the Film, Social and Media categories were asked to submit proposals that made an emotional connection with the public, increasing awareness of the challenges faced by and the need for support for people with cystic fibrosis in Ireland.

Conor Hamill and Laura Cahill from Rothco, developed an inspiring and engaging cinema advert which will capture the attention of the cinema audience title 'A Breathing Exercise'. The storyboard invites viewers to take part in a simple breathing exercise to highlight that the average adult breathing at normal pace. The clip will then introduce the audience to the breathing of a person with cystic fibrosis including common symptoms of coughing, shortness of breath, tightness in the chest area and exaggerated inhalation. The film will go into production in the coming months, for release in cinemas nationwide this September

We would like to extend our thanks to Rothco, Pull The Trigger, Wide Eye Media and IAPC who are working diligently on completion of this advert.

## St Lawrence O'Toole Athletic Club

On 12th March St Lawrence O'Toole Athletic Club in Carlow held their annual fit4life 5/10k run. This year they generously chose Cystic Fibrosis Carlow as their charity. A total of €3500 was raised as a result. Many thanks to them and all who organised this event and also to the many volunteers from the Carlow Cystic Fibrosis branch who gave a hand on the day.

# Stories

## Amanda Donohoe San Francisco Rose

My name is Amanda Donohoe, I am 19 years old and grew up in the San Francisco Bay Area. This last March I was crowned the San Francisco Rose.

For several years now I have been working towards a degree in physics, as well as being involved in several extracurricular activities including my sorority, Delta Gamma, intramural sports such as soccer and rugby, and the society of physics students. I stay active in my sorority due to my position, Director of Cultural Interests, which allows me to educate the women of my chapter on to importance of diversity and how it positively affects group mentality. Involvement in my sorority includes social events, but also often revolves around other philanthropic endeavours. The Society of Physics students is a club dedicated to funding students trips to conferences to present their research in the larger physics community. Similarly soccer and rugby have taken up large portions of my day to day life between training, games, and the social aspect that they entail.



Overall despite leading a busy life, I always make sure to find time to volunteer, something I encourage everyone to do.

Since being crowned the San Francisco Rose

I have focused my attention on bringing awareness to Cystic Fibrosis, using the festival as a tool to generate exposure for a highly deserving cause.

A number of things have influenced me to do as much as I can to help as many people as I can. However one of the strongest motivators for my working with Cystic Fibrosis Ireland and choosing it as my charity for the year, is that one of my close family members was diagnosed with CF at a young age. His strength and fighting spirit has been a huge inspiration to not only myself, but many others in our family and has reminded us that that anything is possible through determination

and courage.

Something that has always stood out in my mind when I was younger and didn't quite understand what Cystic Fibrosis was yet, was that my cousin didn't seem like the kind of sick children you see on the TV. He was simply my cousin, trying his best to have a normal childhood. He liked batman, video games, and most of all has always just seemed so full of life. While I now know that my cousin has been blessed enough to have been able to manage his Cystic Fibrosis, something I think a lot of people looking in from the outside forget, is that CF, while a huge part of patient's existence, it is not the only facet to them. This is why CFI is such an important charity to me, because it takes into account the needs of a person suffering from CF, not just the medical treatment of the disease, but also the mental toll it can take being a CF patient.

Amanda Donohoe

2017 San Francisco Rose





# HEAD<sub>2</sub>HEAD WALK

In aid of Cystic Fibrosis Ireland

Sunday 24th September 2017 @ 9.00am

## Walk from Howth to Bray for Cystic Fibrosis Ireland

Sign up at [www.cfireland.ie](http://www.cfireland.ie) or email  
fundraising @cfireland.ie for more details

Official Charity Partner



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