

Spectrum

Spring / 2017



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Cystic
Fibrosis
Ireland

Foreword



Thanks to all who participated in our annual conference in Killarney the weekend of 1 April 2017. We had a particularly stellar line up of speakers this year including Professor Stuart Elborn, Professor Barry Plant and Professor Charlie Gallagher. The videos of proceedings will be available on our website for those unable to join us on the day.

The Cork and Kerry branches who hosted the conference did us proud - thanks in particular to their chairpersons Marion Barrett and John Healy who made everyone feel so welcome in the beautiful Brehon hotel. We are investigating the possibility of the conference being hosted in the north east in 2018 and we will be consulting with the branches in that region before a decision is made.

On the eve of the conference CFI received an email from John Hennessey, a senior official in the HSE to let us know that HSE negotiators will be clearing their diaries for negotiations with Vertex the week following the Conference.

While we have given this a cautious welcome, we have also reminded the HSE of the very high levels of anxiety in the CF community as we await fulfilment of previous repeated promises that an agreement is imminent on these very important drug therapies. CFI will seek to keep up the pressure for a decision that is so badly needed by our community.

There appears to be consensus at this point from the HSE, Vertex and CFI that the deal on Orkambi and Kalydeco should be inclusive of pipeline medications from the same company. In this context the recent results of two phase 3 trials on a combination drug therapy called Tezacaftor (tezacaftor and ivafator) have shown statistically significant improvements in lung function for 12 year olds (and other important improvements) for those with one or two copies of the F508del gene alteration. A license from this new therapy will likely be sought from European Medicines Agency in 2018.

CFI are preparing a paper on the 'soft opt out' organ donation consent system in Ireland. An extract of the submission can be found in this edition of Spectrum. Thank you to Celeste de Peize for all her work on this project.

Philip Watt (CEO)
Samantha Byrne (Editor)

Front Cover: Keelin Shanley with Tom & Jessica Cassidy at the launch of 65 Roses Day.

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Latest News

Tezacaftor/Ivacaftor: Promising Results from Phase 3 Clinical Trials

Results released from the first of the large Phase 3 clinical trials of the drug combination Tezacaftor/ivacaftor demonstrated that people with CF 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.

Tezacaftor/ivacaftor was well tolerated, with an overall incidence of side effects similar to that seen in the placebo treated group. Additionally, respiratory complications were similar between placebo and treatment groups.

The 24-week study was conducted at over 90 clinical trial sites in North America and Europe. In total, more than 500 people with two copies of the F508del mutation, ages 12 and older participated in the study.

The second of the Phase 3 clinical trials tested the safety and effectiveness of tezacaftor in combination with ivacaftor for people with one F508del mutation and a second CFTR mutation that results in residual function.

The eight-week study showed that, compared with those on placebo, participants with one F508del and one residual function mutation who took the combination treatment improved lung function by 6.8 percentage points. The study also tested ivacaftor without tezacaftor. Participants who only received ivacaftor had a 4.7 percent improvement in lung function compared to placebo.

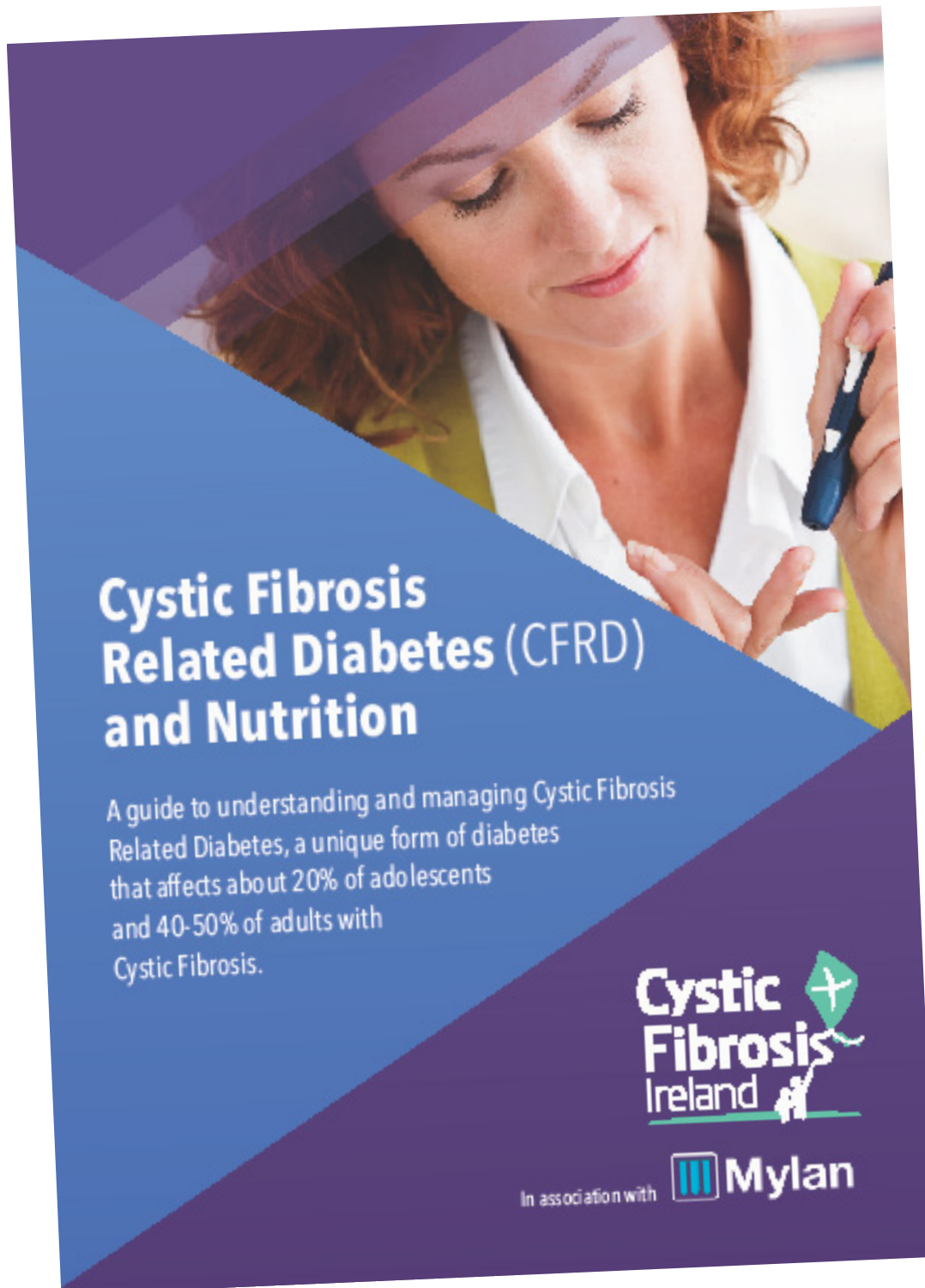
The residual function mutations eligible for inclusion in the residual function trial were chosen using pre-clinical analysis that identified them as likely to respond to ivacaftor. The list of residual function mutations eligible for inclusion in the trial are 2789+5G->A, D110E, R352Q, 3849+10kbC->T, D110H, A455E, 3272-26A->G, R117C, D579G, R1070W, 711+3A->G, E193K, S945L, F1074L, E56K, L206W, S977F, D1152H, P67L, F1052V, D1270N, R74W, R347H, K1060T, E831X.

It should be noted that there are no pre-existing drug therapies presently available for those with one F508del gene alteration and one residual function alteration.

The Cystic Fibrosis Foundation in the United States believes these triple combinations will allow us to eventually increase the number benefitting from these modulator therapies to over 90 percent of people with CF.



Information



CFI have produced a booklet on CF related diabetes in conjunction with the CF Nutrition Interest Group which includes Hilary Colgan (Chair), Marianne O'Reilly, Ruth Hannon and Jessica O'Driscoll. This booklet explains what CFRD is, and gives information on how to manage the condition. Please contact the office if you would like a copy of the booklet. It will also be available to download from our website.

The need to Move to a 'soft opt out' Organ Donation consent system in Ireland

By Celeste de Peiza



The following is an extract from a forthcoming submission from CFI to the Irish Government urging fulfilment of their stated promise in the Programme for Government to change the form of organ donor consent from the present 'opt in' to a proposed 'opt out' system.

Despite significant improvements in aspects of transplant services in Ireland in recent years, organ donation in Ireland is not on par with countries such as Spain and Croatia. Although 280 organ transplants were successfully undertaken in 2016, it is approximated that a sizable 650 patients are still on the waiting list for lung, heart, liver, kidney or pancreas transplant.

Analysis of the factors that influence organ donor and transplant services on a global scale by CFI leads us to urge government to implement a meaningful public awareness program as part of their commitment to implement a soft opt-out system. This should include the active participation of patient groups concerned with transplantation in Ireland.

Public awareness and educational initiatives should be ongoing and continue after the legislation to change consent on organ donation is introduced. CFI support the government's continued investment in transplant infrastructure and the work of the Office for Organ Donation and Transplantation in Ireland (ODTI).

In review of the newly implemented donation system in Wales, CFI also advocates for the establishment of a National Organ Donor Registry, which is automatically accessible to organ procurement services and managed by the Department of Health. CFI suggests that the registry provide potential donors the opportunity to indicate if they wish to opt-out of all or some forms of organ donation. This development would contribute to the consent process as it would show the next of kin proof of decision by the deceased.

Background

In the Republic of Ireland, an 'opt-in' organ and tissue donation system is currently in place. It requires living donors to provide informed consent. Likewise, people who wish to become donors after they suffer from cardiac or brainstem death are expected to carry an organ donor card.

Alternatively, they can note their intent to donate on the Organ Donor Ecard smartphone app and/ or on their driver's license. Willing donors are also asked to inform their family of their decision, as it is the next of kin whose consent is currently required to authorise the donation of the deceased's organs. (If no next of kin is available or if they are indecisive, no consent is provided and organ donation does not proceed.)

With the exception of the living donor programme for kidneys, organs are transplanted after the death of the donor. After consent is provided, post-mortem organ donation only proceeds once a compatible, hospitalised donor is confirmed to have lost brain or heart activity. Donors who die of unnatural causes and/ or outside of a hospital setting also require that a Coroner approve the organ donation.

Ireland has forty donating hospitals and three transplant centres. The Health Service Executive (HSE) governed Organ Donation and Transplant Ireland (ODTI) coordinates the country's organ donation and transplantation services. ODTI is informed by the National Organ Donation and Transplant Advisory Group which contains one patient group representative.

The National Organ Procurement Service at ODTI coordinate organ donation between the donating hospitals and transplant centres. Organ Donation

Personnel, working in each of the seven hospital groups, ensure that ICU and other relevant staff are employing good practices when meeting with donor families.

While organ procurement services have been enhanced and new regulations for quality and safety have been implemented in healthcare environments, there is still a shortage in organs donated in Ireland. Additional reform is needed because many people are still dying on the waiting list. A 'soft opt-out' system has been proposed over the years because countries with an opt-out have high donation rates. The Programme for Government published in 2011 states:

"We will legislate to change the organ donation to an opt-out system for organ transplantation, rather than an opt-in system so as to improve the availability of organs for patients in desperate need."

Unfortunately in 2017, no legislative framework in Ireland governing the use or withholding of consent in regard to the donation of body organs has been implemented. However, Simon Harris, T.D. and current Minister of Health, has recently contended that he "plans to bring the proposals [for a soft opt-out policy] to the Oireachtas Health Committee in 2017." This is to be welcomed.

Analysis

The impact - Why implement a soft opt-out system?

A soft opt-out system has the potential to raise organ donor rates by increasing public participation. A soft opt-out system will close the gap between intent and action because individuals who want to donate their organs, who never get around to opting-in, will automatically be considered donors. According to public surveys, approximately 67% of the Irish population are willing to donate their organs, yet only 29% of respondents carry a donor card. Therefore, if this survey is representative of the public's opinion, the introduction of an opt-out system will increase the number of donors.

Donor consent rates should also increase following the increase in organ donation awareness associated with the introduction of the soft opt-out system. Initially, more people may communicate their views about organ donation by opting-out and/ or by talking to their fami-

lies. Over time, these actions should become the norm, as the personal risk associated with failing to opt-out (unwillingly donating your organs) is high. This increase in public participation is desired because it decreases the level of uncertainty present when doctors and the next of kin are discussing organ donation. This is important because the deceased's wishes are highly valued. "According to the UK Transplant Potential Donor Audit Summary Report ... 90% of families consent to donation if the deceased was registered on the [organ donation registry] compared to a general consent rate of 61% ." Increase in awareness also facilitates the initiation of the organ donation conversation that must be had to confirm donors and increase donor rates.

Why not implement a soft opt-out system?

There are no legal barriers to implementing a soft opt-out organ donor system, so long as certain standards are met. After the legislation is introduced, there needs to be enough time allocated to ensure that the public understands the change and can express their views - opt-out if they don't want to donate. This would require considerable investment in a public awareness programme, targeted to reach every citizen. Funds for the development, establishment and maintenance of a secure database, to be used to show the next-of kin the proof of decision by the deceased, would also need to be provided. Finding the money for these initiatives may be an obstacle.

The soft opt-out system should also protect vulnerable individuals from abuse and have systems in place to allow people to change their decision over-time. An audit, performed by a Legal Working Group within the UK's Organ Donation Taskforce, noted the importance of involving the family in the decision to donate. Family counsel is key to confirming that the deceased's wishes and beliefs are being represented. For example, if the deceased didn't want to donate their organs but failed to opt-out because they had an incomplete understanding of the system, due to a language barrier or their lack of connection to basic services, their family would be able to communicate this to the doctors. Therefore, family involvement is required to protect the authority of the deceased's consent. Additionally, the family can also provide helpful clinical information by informing the doctors of the deceased's medical and behavioural history. This would enhance transplant success.

There are also no ethical issues that challenge the introduction of soft opt-out legislature. The system does not manipulate the "moral principles that govern a person's behaviour" because donation is not compulsory. The policy does not undermine the principles of organ donation as a gift because donation is still a choice - people can still express their unwillingness to donate. If, for some reason, someone fails to opt-out and doesn't want their organs donated, safeguards are in place to prevent the removal of their organs.

A soft opt-out system in isolation does not enhance organ donation. "In Spain presumed consent had been part of statute for 10 years prior to the organisational changes without any effect on rates of donation. The US does not have presumed consent legislation. Both have impressive rates of organ donation and both have seen a rapid increase in a relatively short period of time. Sweden switched to a presumed consent system in 1996 but continues to have inadequate rates of organ donation (10 PMP)". Therefore, additional factors are involved. Those responsible for low donor rates are outlined below.

- a) Failure to identify potential donors
- b) Lack of awareness about organ donation
- c) Poor transplant infrastructure
- d) Misinformed public

Concomitantly, there are several interdependent elements that contribute to a successful donation program. Initiatives taken to raise donor rates which include:

- a) Increase donor availability
- b) Increase consent rates
- c) Invest in transplant infrastructure and services
- d) Introduce public incentives
- e) Educate the public
- f) Monitor the system

How a soft opt-out organ donation system would operate in practice

Any transition to a soft opt-out system must be supported by increased investment in physical and personnel infrastructure. In respect of the lung transplant programme in Ireland, these facilities include the opening of 7 presently 'mothballed' rooms in MMUH and key clinical staff posts.

These services and personnel are already needed to compensate for existing services never mind the likely increase in organ procurement arising from soft opt out. Additional organ donor personnel were recruited into the major hospital groups in Ireland in 2014 thanks in part to lobbying by patient organisations, such as

CFI as part of the Irish Donor Network, and Joe Brolly. "They provide training, education, support and advice to ICU staff. They ensure [that] good practices are in place and that relevant staff have the skills and training when meeting with a donor family". The ODTI annual report states that their introduction assisted with the increase in organ donation from 63 deceased donors (in 2014) to 81 deceased donors (in 2015). However, more transplant surgeons must be appointed. The shortage of kidney transplant surgeons and the fact that there is only one hospital that provides kidney transplant services is taking its toll in Ireland. "If the European Working Time Directive was strictly adhered to in transplantation, [Ireland] would probably need twenty transplant surgeons to run our current service. Presently, we have four whole-time equivalents, i.e. funding for four transplant surgeons in our service." This needs to be addressed.

In Wales, which implemented the soft opt-out policy alongside their previous opt-in policy in December 2015, a bilingual information website and a two year, multiphase public information campaign (supported by public relations and social media) were launched on December 2013. The first phase aimed to inform the public of when the law would change and to explain the rationale behind the new legislation. The second phase explained why organ donation was important. The third phase provided more detail about the choices available under the new law. The final two phases encouraged people to register a clear decision. To opt-out in Wales, people over the age of 18 who have lived there for at least a year, can add their name to a register by phone or online. Those who wish to register a positive decision to opt-in can still do so.

CFI is indebted to Celeste de Peiza for researching CFI's submission. The full version of this submission, including full references in this article, will be available shortly on our website www.cfireland.ie

Celeste de Peiza is a University of Ottawa graduate with a BSc. in Biomedical Science. She has performed community outreach, administrative and clinical duties to aid in the development of a database of healthy medical test values in children at the Hospital for Sick Children in Toronto, Canada. She has instructed interactive science school programs through Mad Science Toronto in Toronto, Canada. Celeste currently conducts health policy research at Cystic Fibrosis Ireland in Dublin, Ireland

Competitive Swimming

By Ella Burns, PWCF

My name is Ella Burns. I'm eighteen years old and I'm from Westport in County Mayo. I have one younger sister Martha who is eleven. I'm currently studying for my Leaving Cert in the Sacred Heart School here in Westport and I hope to study science in UCD from next September. Obviously, that all depends on how I get on in June but I'm optimistic enough! I've always enjoyed school, especially the academic side as I love learning and I would definitely say that my school experience has been a positive one.

As a family we are very into sport. Soccer would have definitely been the sport of choice for my family. We are Westport United and Chelsea fanatics and we never miss a United game. We all enjoy going to games and watching the Blues, especially at the moment! However, no one would have predicted that I would become a competitive swimmer. I learnt to swim at a very young age. Initially just to be water safe, but my parents realised early on that I really enjoyed it and I haven't had an extended period out of the pool since my very first lessons at the age of two.

When I was ten I was very eager to join the local swimming club. The summer before I had seen the competitive swimmers in the pool and I was intrigued - I wanted to be as good as them! So in September 2009 I joined Westport Swimming Club and I've been hooked since. I progressed fairly quickly and I loved training for the first couple of years. It was very enjoyable and I became great friends

with everyone. Every couple of weeks we'd head off to galas around Connacht. Swimming has also enabled me to become a fully qualified beach and pool lifeguard and that has given me options for employment during the summer months when I'm at college.

My new found passion at ten probably dismayed my parents a little bit. They had an idea of how crazy the sport of swimming was but they truly realised it when I started competing. I improved progressively and by the time I was in first year I was going to the University of Limerick and training with the High Performance Centre's development squad. The training was very tough but extremely beneficial. My swimming improved quite a bit over the period of eighteen months that I trained there. There were camps during the school holidays and thirteen year old me would get up at 4:30 am for training until 7:00am every morning and I would come back in the evening for another two hours. Looking back I can't believe I even survived those weeks, but I did. Even though the training was hard I obviously enjoyed it because I kept going back!

I established quite quickly that I was a breaststroker. When I was fourteen I qualified for the Irish Open Long Course Championships in Dublin in the 50m breaststroke. This is the biggest senior competition in the country. In that particular year multi Olympic gold medallist Katinka Hosszu and our own Olympian Fiona Doyle were both there. It wasn't easy to achieve that qualifying standard considering I was on IVs a month before, however I somehow pulled it out of the bag.



During my Junior cert year I probably let my swimming slip towards the end and I started to get slightly fed up. I think every swimmer goes through that period. It took until I was on IVs in December 2014 for me



to finally decide that I needed to get back swimming properly. After Christmas I really went for it and started gym sessions. They helped immensely especially with muscle gain. I set a target to get near the qualifying time for The Irish Open long course championships that year. I finally swam the qualifying time in March at the Leinster championships in the national aquatic centre and I was so relieved.

In the last couple of years I've swam in multiple Irish Championships. In June 2015 I went to the BEST swim centre in Mallorca for three weeks training. It is an amazing facility and I loved training outside - I even got a tan. While I was there the Balearic Islands swim championships happened to be on. I managed to swim big PBs in all my events and I was over the moon. I also picked up a couple of medals in the 50m breast and the relays. The BEST centre was a great discovery.

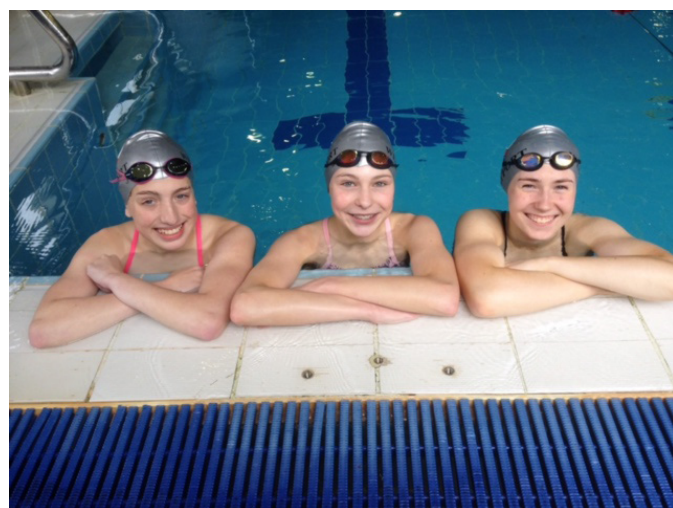
Last year was my probably my best season yet. I trained five days in the pool and three days in the gym doing strength work. I've been fortunate to have had access to great trainers like Phil Keegan (brother of Lee the Mayo gaelic footballer) and Ray Moylette (professional boxer) and they have been brilliant to me. I nearly started to like the gym more than the pool! I qualified for the Irish short course championships in December. I made finals at the Dave McCullagh Swim Ulster meet in the 50m breast and had a big PB in my 100m breast. I also went to Bournemouth for a week during mid term

to train with Bournemouth Collegiate School.

It was a brilliant experience and I learned a lot there. The coach there is Zoe Baker, a former world record holder and Olympian and the contact was made through a family member who works in the school. While I was in Bournemouth I met a superb swimmer by the name of Alice Tai. Alice is also eighteen and last year she won two medals at the Rio Paralympics. It would be great if I was eligible for the paralympic swimming but I do however realise that it would be impossible to classify me under the current system.

I returned to Mallorca for another three weeks during June. I once again attended the Balearic championships and won silver in the 50m breast and bronze with the relay.

I came home and one week later travelled back to the centre with Bournemouth collegiate school for another weeks training. I felt well prepped for the Irish Summer Open. However, my preparation was hampered as I had picked up a bad virus after doing two weeks elective IVs in March. This seriously impacted on my training. I was pleased enough then with my performance at the summer championships, however I was a slightly off my best.



This year with the Leaving Cert I'm training a lot less, about three times a week. However I'd say I'd be doing more if not for a virus I picked up in November. Up until then I was training five times a week. I now train with Castlebar club as the early morning training times suit better with all the study during the evenings. I really hope to go to UCD as they have a great sprint swimming programme there. Hopefully, I'll get back to competing all the time once this Leaving Cert is 'dust'. I'm planning to go to Zagreb and Slovenia in July for a training camp

with Bournemouth Collegiate School. I'm really looking forward to that.

I would certainly say that swimming has kept me very well. Swimming undoubtedly ticks a lot of boxes for me. It's a brilliant form of physiotherapy. Club swimming is also a great social outlet, everyone is in it together. Despite burning around one thousand calories each training session it happens to help me gain weight. I have a massive appetite and great energy because of swimming. Food is one of my favourite things in the world; I'd live at an 'all you can eat' buffet if I could.

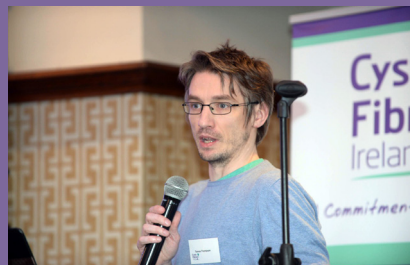
My parents have always been brilliant with the nutrition part of it so that benefits me greatly. I consume a lot of calories but I also have taken a 'Calshake' every day of my life since the age of six. It's the only supplement I can force myself to take - I think it's the fresh milk! However, to save on luggage space when we go abroad I replace my 'calshake' with about two litres of ice-cream a day. I don't know how I'm going to cope cooking three and a half thousand calories a day next year in college - I could do with a food sponsor so if there is anyone out there!

I'm so grateful that I found something that I love and also keeps me in shape. I think that swimming has been my incentive to always get back

and stay well if I have to do IVs. I miss it a lot even if it's only for two weeks. I launch back into it straight away with a new found energy every time. Obviously I've had my set backs with swimming but everyone does in sport CF or no CF. Whether it is illness, injury or the dreaded plateau no one has it easy in this sport. It's very individual but also, I could never do it without the brilliant people along the way. Your teammates are so important and I'm really lucky to have had the best friends swim with me over the last few years. I mightn't swim at this level forever but I'll certainly look back with fondness on it. If you're still swimming competitively at eighteen I think you'll be a swimmer for life!











Annual Conference 2017 The Brehon Hotel Killarney

Hosted by the Cork and Kerry branches

The Present

By Eddie Murphy

There is a most wonderful man who comes into my therapy room. He has an amazing sense of humour, and a wonderful smile. He is very connected with nature and teaches me something every time he comes. He has incredible integrity and has a great genuineness. He says it as it is, and some F's get expressed and that's okay because that is how it is at times.

On a little aside there are a lot of 'effing and blinding' in therapy rooms all over Ireland. When it first pops out the client apologies, I say it's okay many people use this language and it's ok, then it flows! Emotions are very powerful forces.

Like many people in the world you might pass by him, ignore him, but hey that's your loss. He arrived in my office seeking help with insomnia. I think about him often. We are getting the insomnia sorted. I can't resist pushing for more. I think if his world got bigger then his insomnia would shift even more. To me he is too caught up in a small world. Working every day and doing the books for his business. He hasn't had a holiday in 3 years. He is not in a relationship and apart from looking after someone else's pets, he has no children. I wonder what is it all about?

Are you stuck in a life, where you wonder what it is all about? Whether you have adult children who ignore you apart from seeking financial assistance, or in a relationship that is perfunctory, with little fun, love or spark. Are you just going through the motions for others; your partner, friends, parents, or children? Is there more? I think so, much more, loads.

What present can you give yourself?

Could you contemplate a year where you are your Real Self; authentic and contented.

I invite you to break the mode. Develop your BHAG your Big Hairy Audacious Goal!. Imagine. Your dream, what would that look like. Could you give yourself that present?

Do something extraordinary talk to your love interest, climb Carrauntoohil, run 5k, write a poem, learn how to surf the web, book a ticket online, get more involved in your community, learn mindfulness!

I am honoured to be Ambassador for the 2017 Paddy Kierans International Walk and am looking forward to visiting Croatia, learning more about CF and making new friends - this is my present. Taking place from September 22nd to 29th, the Walk will cater for various levels of fitness, so that each walker can take part at a pace they are comfortable with. This will be an unforgettable experience. The 2017 walk, which starts in Dubrovnik and finishes in Orebic, sees participants walking an average of 10km each day and taking in such sights as Medjugorje, Korcula Island and the historical town of Ston with its great walls. Walking creates a great opportunity for lifelong wellness and friendships. Come and join us, with Cystic Fibrosis Ireland, you will never walk alone!

Imagine a Present to yourself this Easter where nothing is holding you back. This is the moment to say stop to your life going small. It's time to Carpe Diem - seize the day or more forcefully to Seize Your Life now! Carpe is a tame way of putting this, it's like grasping a flower, so for your life it needs to be more energetic and forceful so Capesse Vitam - Seize your life. Take control. Believe in yourself and go for it!

Where would this take you? I hope somewhere magical where there is no horizon as you keep pushing, wanting, dreaming and achieving.

So ask yourself are you living a life of pleasure, meaning and engagement?

You were born to be the greatest you that has every lived - go be the greatest you.

For some, faith and spirituality play an important role, after all without meaning and source you are drifting.

Change starts with you. Don't wait. Don't think you can't change. What's next for you? And what are you going to do about it?

Life is not a dress rehearsal it's a performance. Go for it full throttle. You have the power to do it.

Going back to my patient in the office this is the Present I wish he could give himself, allowing himself to go there and think, feel and be. I may signpost, support, cheer and encourage but fundamentally it goes back to Choice.

Choose this Easter to give yourself the greatest gift of all; 'The Present' is 'the present' and that living in the present is where your dream begins.

Happy Easter.

Dr. Eddie.

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) 4962433 or email fundraising@cfireland.ie

April 13th: 65 Roses Day - National Fundraising Day for Cystic Fibrosis Ireland

Cystic Fibrosis National Awareness Week takes place from Monday 10th April to Sunday 16th April 2017. We are looking for support to help raise funds and increase awareness of Cystic Fibrosis throughout the country. There are 3 ways you can help support PWCF during CFI National Awareness Week.

1) 65 Roses Day - Thursday 13th April

65 Roses Day is our National Flag Day and our emblem, the CF Purple Rose will be on sale across the country for just €2. We are looking for volunteers to help sell our purple roses in every county. If you can help us, please get in touch by e-mailing fundraising@cfireland.ie. We will be working closely with our CF branches to ensure everyone can buy a rose on 65 Roses Day, with the campaign supported on TV, Radio, Press and Social Media.

2) 65 Roses Challenge

You can organise your own fundraising challenge to help raise funds and support PWCF during National Awareness Week. The challenge can be any kind of fundraising event with a 65 theme. Previous examples include a 65 Roses Tea Party, 65 exercises in 65 minutes, staff walking 65 laps of the office or even schools holding a 'Purple Day' in school. It can be as simple or as challenging as you wish. If you need any help or support with your fundraising event then please email our fundraising team at fundraising@cfireland.ie. Further details available on www.cfireland.ie

3) 65 Roses Text Donate

Support our 65 Roses Text Donate campaign and Text 65 Roses to 50300 to donate €2 to Cystic Fibrosis Ireland or donate online at www.cfireland.ie. Please SHARE with your friends and work colleagues.

100% of your donation goes to CFI across most network operators. Some operators apply VAT which means that a minimum of €1.63 will go to CFI. Service provider: LIKECHARITY. Helpline 0766805278.





April 14th: 65 Roses Skydive Challenge

CFI are delighted to announce that we will be holding our 65 Roses Skydive Challenge on Friday 14th April in The Irish Parachute Club, Clonbullogue, Co. Offaly. Our aim is to get 65 people to take to the sky and jump for CF as part of this 65 Roses Challenge.

The cost of registration is €20 with a fundraising target of €500. Registration forms can be downloaded from our website www.cfireland.ie or contact our office on 01 496 2433 or e-mail Peter at pminchin@cfireland.ie

Family and friends are encouraged to come along on the day to show their support.

April 14th: The Michael Collins Walking Tour

The second 65 Roses Challenge taking place on Good Friday, April 14th is the Michael Collins Walking Tour.



Led by historian Lorcan Collins, the tour will begin at Trinity College and visit numerous sites associated with Michael Collins, taking approximately two hours at a gentle to moderate pace.

To secure your place on the walk register online at www.65RosesDay.ie or by phone on 01 496 2433. Registration is €25 and places are limited to 65 participants.

May 11th to 14th: Malin2Mizen Cycle4CF

Preparations for the 2017 Malin2Mizen Cycle4CF, a national fundraising event for CFI, are now well underway for the cycle which will take place from Thursday May 11th to Sunday May 14th.



Thank you to the cyclists from across the country who have registered for the event. The fundraising target to take part in the cycle is €2,000, which covers your entry in the cycle, accommodation and food over the four days. We will be providing a full information pack to all cyclists over the coming weeks.

Further details of the event are available at www.cfireland.ie or alternatively call our office on 01 496 2433 or email Peter at pminchin@cfireland.ie.

June 5th: One in 1000 - VHI Women's Mini Marathon

The One in 1,000 Campaign to recruit 1000 participants for Cystic Fibrosis Ireland for the VHI Women's Mini Marathon which takes place on Bank Holiday Monday, June 5th is now well underway.

This largest annual fundraising event for Cystic Fibrosis Ireland, the One in 1,000 campaign is built on the ethos that one person can make a difference. The one person could be you!

One in 1,000 is much more than a fundraising event, it is a day that brings together supporters of PWCF from across the country. As past participants will tell you, the atmosphere on the day is fantastic and with a great team surrounding you, you don't feel the kilometres go by. CFI provide the best of facilities for participants on the day including a cloakroom, refreshments and a base to come to before and after the 10km to soak up the atmosphere and celebrate your achievement.

The Mini Marathon is a 10km route suited to all levels of fitness so you can walk, jog, run or skip. Open to females aged 14 and over, the event attracts over 40,000 participants annually.

Individuals are always welcome to the One in 1,000, but it is always great to have some familiar faces with you so why not round up your friends, family or colleagues and ensure you bring a Team of 10 people with you? In 2016 we saw an increase in the number of branch, corporate, family and memorial teams taking part.

If you are interested in registering a team or would like more information on how to start a team, please contact Nuala on (01) 496 2433 or email nmcauley@cfireland.ie

So, the question is - Will you be One in 1,000 for CFI in 2017?

To register for the Mini Marathon log on to www.vhiwomensminimarathon.ie and then contact Nuala in CF House to receive your One in 1,000 fundraising pack.

Remember One person can make a difference, you can be that One for cystic fibrosis.

For further information on the VHI Women's Mini Marathon and the One in 1,000 Campaign visit www.cfireland.ie, contact Nuala by email at nmcauley@cfireland.ie or phone our office (01) 4962433



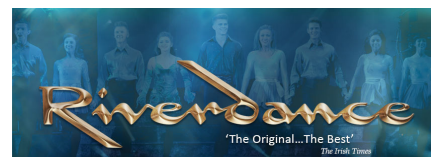
June 29th: Riverdance Dance A Thon

CFI are delighted to have been chosen as the Charity Partner for Riverdance 2017.

The 2017 Riverdance show will run at the Gaiety Theatre from June 21st to September 3rd 2017.

As part of the Charity Partnership we are delighted to announce a Dance-a-thon will take place with the Riverdance Team on Thursday June 29th on South King Street, Dublin.

If you are part of a dance school and would be interested in taking part in the dance-a-thon or if you would like to volunteer at the event, we would love to hear from you - (01) 496 2433 or email Nuala on nmcauley@cfireland.ie



Sept 16th to 21st: Paris2Nice Cycle

CFI are currently finalising recruitment of cyclists for the Paris2Nice Cycle 2017. This event always proves to be an incredibly enjoyable and rewarding challenge.

Cyclists will fly to Paris on Friday September 15th and begin cycling on Saturday 16th September. You will pass through many beautiful villages and towns on quiet country roads as you make your way southwards towards Nice. The cycle will finish on the Promenade Des Anglais on Thursday 21st September where you will be greeted by the welcoming team followed by a celebration dinner that night.

For further information please contact Peter on 01 496 2433 or email pminchin@cfireland.ie



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

The journey of a lifetime starts with a single step!

Join the Paddy Kieran's International Walk for Cystic Fibrosis Ireland and take in the Charms of Croatia, September 22nd - 29th.

Visit a new country, make new friends and create magnificent memories all while raising funds to support people with cystic fibrosis in Ireland.

This year, we are delighted to have Dr. Eddie Murphy, well known TV psychologist as Ambassador for the International Walk.

"Walking creates a great opportunity for lifelong wellness and friendships. Most importantly, of course, they will be helping to raise much-needed funds for supports for people with Cystic Fibrosis and their families. We know how challenging life can be for people with Cystic Fibrosis. This is your chance to do something really special to show your solidarity to the CF Community."





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, accommodations and meals.

For more information on the 2017 International Walk 2017 or to request a brochure contact Nuala McAuley on 01 496 2433 or email nmcauley@cfireland.ie

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



The Head2Head Walk 2016 was once again a great success and we hope you are already looking forward to next year's event. The Head2Head Walk 2017 will take place on Sunday 24th September. Make sure to join us on what always proves to be a fantastic day out.

For further information please contact Peter on 01 496 2433 or email pminchin@cfireland.ie

Oct 29th: SSE Airtricity Dublin City Marathon

Are you up for the Marathon Challenge?

Put your lungs to good use and run for Cystic Fibrosis Ireland in the 2017 SSE Airtricity Dublin Marathon on Sunday October 29th! Registration costs €70 and race entry is guaranteed upon payment. The 26.2 mile route is mostly flat and is a single lap which starts and finishes near Dublin city centre.



The SSE Airtricity Dublin Marathon is now the 4th Largest Marathon in Europe and is known as the 'Friendly Marathon' due to the number of supporters lining out the streets of Dublin to cheer on the participants. The SSE Airtricity Series includes a number of racing challenges to help you prepare for the Marathon. For further information on the Race Series, the Marathon or for top tips on training and nutrition visit www.sseairtricitydublinmarathon.ie



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

Nov 5th: TCS New York City Marathon

Registration is now open for the TCS New York City Marathon 2017 which will take place on Sunday 5th November. This is the most popular marathon in the world and very difficult to secure a place for, so we are delighted to announce we have GUARANTEED PLACES for this event. We have a lot of interest in this event, so we encourage anyone who is thinking of taking part to let us know as soon as you can and we will provide you with full details of the Marathon package.

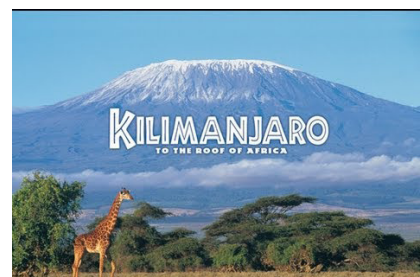


Please email Peter at pminchin@cfireland.ie or call us on 01 496 2433 for more information and to secure your place.

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 in a trek, we advise that you book your place early.

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

Microsoft European Development Centre



As part of their Christmas Charity Week, Microsoft European Development Centre raised €3,047.40 in aid of Cystic Fibrosis Ireland on behalf of Team Mason.

The charity week, which took place from December 5th to 9th 2016 saw numerous events take place onsite including poker, table tennis, a table quiz, darts, snooker and a bake sale!

In addition to the amount raised by the employees, Microsoft then matched this donation with another €3,000. The total raised for the event was €6,047.40.

A huge thank you to all the employees in Microsoft EDC for their support.

Mykidstime



Cystic Fibrosis Ireland are delighted to announce we have been selected as Mykidstime's Charity of the Year 2017.

A huge thank you to all who supported CFI over the past few weeks by voting and sharing our posts to give us a total of 38% of the vote. Your interaction not only helped us secure our place as My Kids Time's Charity of the Year, but also helped raise awareness of cystic fibrosis, CFI and the services we provide.

We look forward to working with My Kids Time throughout the year.

Q Cafe



As long standing corporate partners and supporters of CF Ireland, Q Cafe Company, have taken part in numerous fundraising events over the past two years including the One in 1,000 Campaign and 65 Roses Day.

Q Cafe recently presented CFI with a cheque for €3,096 raised during their Q Bake Off. which was held in their stores nationwide and saw customers entering their tasty treats in a bid to win top prize!

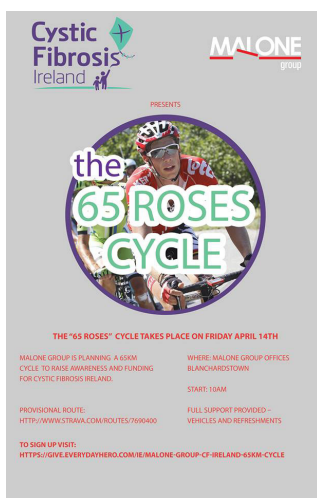
A huge thank you to the staff and customers of Q Cafe for their fundraising efforts and continued support of Cystic Fibrosis Ireland.



San Francisco - Rose of Tralee

Cystic Fibrosis Ireland would like to congratulate Amanda Donohoe on being selected as the San Francisco Rose of Tralee. Amanda will travel to Tralee in August where she will represent Cystic Fibrosis Ireland as one of the 65 Roses in the Rose of Tralee Festival.

Amanda and her family are great supporters of Cystic Fibrosis Ireland. We are delighted that Amanda has chosen to represent Cystic Fibrosis Ireland as her charity of choice and we wish her the very best of luck in the Rose of Tralee finals.



Malone Group

Cystic Fibrosis Ireland would like to extend a huge thank you to the Malone Group for sponsoring the three week Radio Advert running from 20th March on RTE Radio One for 65 Roses Week with our ambassador Keelin Shanley. The advert has helped us establish 65 Roses Day on Thursday 13th April as our National Fundraising Day and ensures we get a great response from the public when volunteers go out to sell our Purple Rose and collect across the country.

The Malone Group have also gone the extra mile and set of a 65km Cycle to take place on Friday 14th April. This promises to be a great day out and if you are involved in any of our cycles this year, it could prove to be a very helpful training spin. Otherwise, you might be able to just go along on the day and support this 65 Roses Challenge. Full details of the event are available at www.65roses.ie or on our 65 Roses Challenge FB Page.



Carey London Limited

Cystic Fibrosis Ireland would like to extend a huge thank you to Carey London Limited for sponsoring the two week Radio Advert running from 17th April on RTE Radio One / 2FM for our 1 in 1000 Campaign with our ambassador Evanne Nì Chuilinn. The advert will help us in our aim to recruit 1,000 people to participate and fundraise for CFI in the VHI Women's Mini Marathon on Bank Holiday Monday, June 5th.

This is our largest Fundraising Event and this generous sponsorship should ensure we have 1,000 participants on what should be another great day for the CF Community in Ireland.

Mylan



Cystic Fibrosis Ireland would like to extend a huge thank you to Mylan for sponsoring the T-Shirts for the One in 1000 campaign again in 2017. Mylan have been long-term supporters of our One in 1000 campaign and will ensure that our 1,000 participants will be looking great from start to finish in the VHI Women's Mini Marathon on Bank Holiday Monday, June 5th.

We are looking forward to lots of fantastic pictures of our participants and teams from across the country on the day at our base, the D2 Harcourt

Hotel.

Team Mason

Cystic Fibrosis Ireland would like to thank Team Mason for organising the Wedding Dress Ball 2017, which took place in the Ashdown Park Hotel, Gorey on Saturday February 11th.

Over sixty beautiful brides and their significant others enjoyed the event, which raised over €3,500 for CFI. A huge thank you to everyone who supported the event by donating prizes, performing and indeed to everyone who attended the Ball and helped make it such a success.



Raffle Sponsors

A huge thank you to everyone who supported the 2017 CFI Grand Raffle by purchasing and selling tickets.

The raffle draw took place at the Gala Dinner of the CFI Annual Conference in The Brehon Hotel, Killarney on Saturday April 1st. The winners announced on the night will be contacted after the draw and confirmed in the Summer edition of Spectrum.

Cystic Fibrosis Ireland would like to thank everyone who supported the raffle by donating prizes including; PC Peripherals, Adlantic.ie, Sunway Holidays, The FAI, The Brehon Hotel, Killarney.



THE BREHON
KILLARNEY

Rotary Club, Kilkenny

CF Ireland would like to say a big thank you to Rotary Kilkenny who handed over a cheque for €2,500 as proceeds from a charity concert held in the Lyrath Estate Hotel, Kilkenny. CFI were one of three charities to benefit from the concert. Performing on the night was The Army No. 1 Band and The Garda Band.

The night was a musical and instrumental masterpiece with those in attendance treated with big band classics as well as some modern numbers. Club President Brendan Roberts was delighted with the event and Carmel Delaney from Kilkenny accepted the cheque on behalf of CF Ireland.



80s Disco Night

An 80's disco night was held in Kilmallock, Co Limerick in December and over €10,000 was raised for TLC4CF and Dochas Autism Support! A local band was formed especially for the occasion and local businesses sponsored them €50 to learn a particular 80's song to perform on the night. 'Secret Formula' then performed again, by popular demand, at the cheque presentation night in Fitzgeralds Bar. Kate and Adrian were part of the organising committee.





Scout Group, Skyrne

CF Ireland would like to say a big thank you to The 10th Meath Scout Group who recently presented a cheque for €200 to CFI as proceeds from a charity hike. Well done to all who organised this hike and to those who took part and made it a success. Special thanks to Bryan Leonard, scout leader, for all his hard work and on-going support.



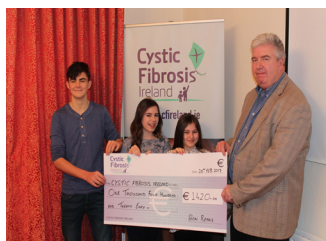
Greenhart Cafe

CFI would like to say a big thank you to Frances Fogarty and everyone in The Greenheart Cafe who presented CFI with a cheque for €1,250 from their launch night in The Dove Hill Design Centre, Carrick on Suir. There were food chats by Frances Fogarty and celebrity Roz Purcell on the night with plenty of food and refreshments. There were also prizes for best dressed. A great night was had by all who attended.

Bon Repas Pop Up Restaurant

Thanks to Ollie Jones and Zoe & Mia Helly who recently set up a pop up restaurant called Bon Repas and cooked a fantastic meal for their adult guests. A very professional job, creating their own menu with a selection of courses including starters, mains and desserts. It was a very enjoyable meal and a fantastic total of €1,420 was raised on the night.

Pictured left are Ollie, Zoe and Mia presenting the cheque to Philip Watt, CEO. Well Done Ollie, Zoe and Mia on doing such a great job and thanks for your support!



Douglas Afternoon Tea

Thanks to Orla Hennessy and her Pilates Class who held an Afternoon Tea fundraiser in aid of Cystic Fibrosis in Cork on January 15th.

A total of €600 was raised by the 30 ladies who enjoyed the afternoon delights and a raffle after their weekly pilates class, a well earned treat!

Wide Eye Media

A huge thank you to Sarah Clohessy and Wide Eye Media who held a raffle for Cystic Fibrosis Ireland at their Film Quiz Night at the Sugar Club on Thursday 23rd March, raising €1,587 to help provide support and services for people with Cystic Fibrosis in Ireland.



Head 2 Head

CF Ireland would like to say a big thank you to James Downes and Mary McCarroll and their team of helpers and volunteers who once again organised a very successful Head2Head Walk in aid of Cystic Fibrosis Ireland. A total of €17,712.12 was raised from the event which took place in September 2016. Well done to all those who fundraised and took part in the walk which was a fantastic day out for all involved. This year's walk will take place on Sunday 24th September 2017 so make sure to keep an eye out for details which will be published at a later date.



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