



## Action for Pulmonary Fibrosis invests £580,000 in research

### Scientists welcome "incredible opportunity" of Mike Bray Fellowships

Action for Pulmonary Fibrosis has made a major investment of £580,000 in two research projects into the causes and treatments of Idiopathic Pulmonary Fibrosis (IPF). The awards have been funded entirely from the generous donations and funds raised by supporters of APF.

The charity invited applications for the first APF Mike Bray Fellowship in IPF last year. The Fellowship – named after the charity's late founder - was originally for £300,000 over three years. However, the quality of applications was so impressive that trustees decided to fund two research projects over three years.

Each year around 6,000 people die from IPF and the average life expectancy from diagnosis is only three years. Compared with diseases of similar prognosis, IPF receives little attention and limited research funding. Action for Pulmonary Fibrosis is now a leading funder of research into this life shattering disease.

The Fellowships have been awarded to Dr Richard Allen of the University of Leicester and Dr Philip Molyneaux of Imperial College, London.

**You can read more about their planned research on page 3**

See inside for...

APF's new Chief Executive ... advice on going on holiday ... Is pulmonary fibrosis hereditary? ... fundraising ideas for 2019 ... and more



APF founder Mike Bray

## Record increase in Support Groups!



The number of support groups has made a giant leap from 48 to 67 in 2018. This is fantastic news for everyone involved.

APF Chairman Steve Jones commented, "This is great news for APF and all of the families and health professionals who support us, and I'm very proud of our role in this success story. We're getting ever closer to our goal of a support group in easy reach for all those living with pulmonary fibrosis."

The rapidly expanding Tameside Group is pictured here. See inside for more news about them and the other support groups across the country.

Details of all support groups are on our website - [www.actionpulmonaryfibrosis.org](http://www.actionpulmonaryfibrosis.org)



## welcome

Welcome to the Spring 2019 edition of your newsletter from Action for Pulmonary Fibrosis.

2018 was a very exciting year for support groups as we watched them grow from 48 groups at the beginning of the year to a staggering 67 groups by the end of the year. This demonstrates the need for this type of support. Listening to the feedback from individual members, it's clear how groups not only provide support locally but also network nationally. It is amazing how many groups are finding ways to raise awareness of PF in their local communities. We have seen many group members take to live radio, television and YouTube, involve local councillors and MPs at their meetings and utilise Facebook and Twitter to share ideas and support others nationally.

I was privileged to meet many group members, families and carers at two of the APF big events last year - the Voice of the Patient Council meeting in Sutton Coldfield and the Doncaster Patient Information Day. Hearing patient stories and talking to those affected by pulmonary fibrosis reminds me of why we do what we do. We carried out 91 visits to existing support groups across the UK last year and we intend to keep reaching out to meet and talk about what matters most to you. I hope you enjoy this edition and please keep sending your events, stories and ideas so that we can share them with the support group community.

Lorna McLauchlan  
National Support Group Co-ordinator

## APF appoints first Chief Executive

Following five years of rapid growth and impressive achievements, Action for Pulmonary Fibrosis has appointed its first Chief Executive – Louise Wright – to work with charity trustees to build on this strong foundation.

“From my 20 years working in the charity sector, my own battles with pneumonia and having a family connection to pulmonary fibrosis I understand the frustration and fear caused by this diagnosis,” says Louise.

“I have been privileged to see many support groups in action, providing much needed help, happiness and information at a critical time for people living with the disease and their family members. I have been uplifted and inspired by the unveiling of the Mike Bray Fellowship, leading the way for APF in funding research that will get us closer to effective treatments. And of course, seeing the outpouring of support via social media with families and professionals running, cycling and shaking tins to raise much needed funds so that we can reach more people across the country. A huge thank you from me.



**“It’s my absolute pleasure to join the remarkable team at Action for Pulmonary Fibrosis in the fight against this terrible disease.”**



“As I start to understand the workings of the charity, I am struck by the ambition, not just of the trustees, but of our supporters who want to make sure no one is left alone, feeling isolated or fearful. There is a lot to do to grow our reach from around 3,000 people who attend support groups around the UK to over 30,000 people. I am passionate about helping people living with the disease, or family members, to use their first hand experience to help others feel more positive about the future. Watch this space!

“Like the families we support, I am also passionate about funding research that will provide hope for the thousands of people yet to be diagnosed. We are united in our ambition to improve access to early diagnosis, ensure there is a support group nearby and ultimately find a cure.

“I hope to meet many of you over the coming months. If you have any questions you can reach me directly on Twitter @louisewright1 or [louise@actionpulmonaryfibrosis.org](mailto:louise@actionpulmonaryfibrosis.org)

Louise Wright  
Chief Executive

## APF invests £580,000 in research

(cont'd from front page)

The APF Mike Bray Fellowship in IPF will enable Dr Richard Allen to investigate the genetic causes of IPF and Dr Philip Molyneaux to research the impact of lung bacteria on the disease and the potential use of antibiotics. The studies are expected to lead to the development of new treatments.

APF Chair, Steve Jones said: "IPF is a devastating and incurable disease. The two projects seek to understand different aspects of the disease and we hope they will each open up new avenues for treatment. This research would not have been possible without the commitment and generosity of individual fundraisers and those who have donated in memory of a loved one, often at a very difficult time in their own lives. We are immensely grateful to everyone."



Dr Philip Molyneaux

**"I look forward to the next few years of exciting research ahead."**

In IPF there are changes in the number and types of bacteria in the lungs, but we don't understand why they are there or what they are doing. Dr Molyneaux's research will aim to answer these questions, looking at how bacteria interact with cells in the lungs and what changes happen following antibiotics. Understanding this may allow us to identify new treatments or specific groups of patients with IPF who will benefit from existing therapies.

Dr Molyneaux, said, "It's fantastic to be able to undertake research supported by Action for Pulmonary Fibrosis, a patient-driven charity. I look forward to the next few years of exciting research ahead."

Dr Allen's project will compare the DNA of individuals with IPF to identify the genes that explain why some people experience very severe disease while others have milder symptoms.

This will improve our understanding of IPF and hopefully lead to the development of new treatments which are better targeted to the individuals who are most likely to benefit from them.



Dr Richard Allen

**"I would like to thank Action for Pulmonary Fibrosis for giving me this incredible opportunity."**

Dr Allen, commented, "I am so excited to be given this chance to extend my work on the genetics of IPF, which will help guide the development of new treatments for this devastating disease. I would like to thank Action for Pulmonary Fibrosis for giving me this incredible opportunity."

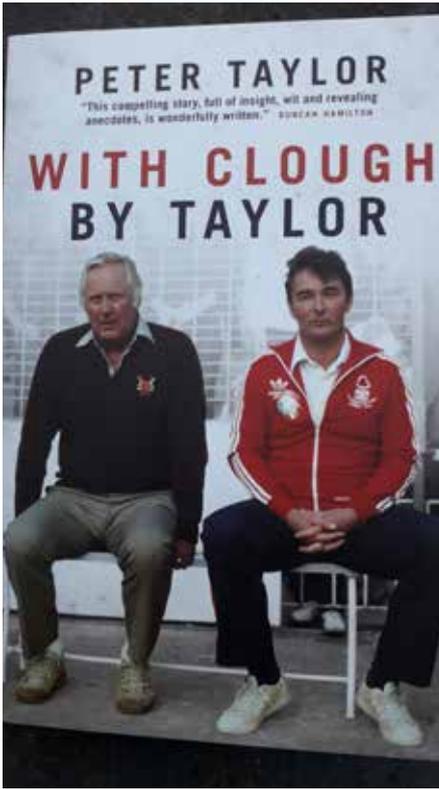
### Make your voice heard!

If you're a patient with pulmonary fibrosis then APF wants to hear from you. Everything we do is guided by patients and carers. To make that bold claim we need to listen. You and your family can have a real influence on our work by joining our Voice of the Patient Council, which helps us make crucial decisions.

Council members get together once a year for a day-long conference but we also contact them during the year by email. In the past we have asked Council members to review our Support Group Guide which helps new groups get started. We also asked them to look at our website content and give us feedback and we even asked for their input into this new newsletter.

To join just visit our website [www.actionpulmonaryfibrosis.org](http://www.actionpulmonaryfibrosis.org) and you will see the sign-up section on our Homepage. We'd love to hear your voice. Join us.

# Royalties from Clough and Taylor book to go to research



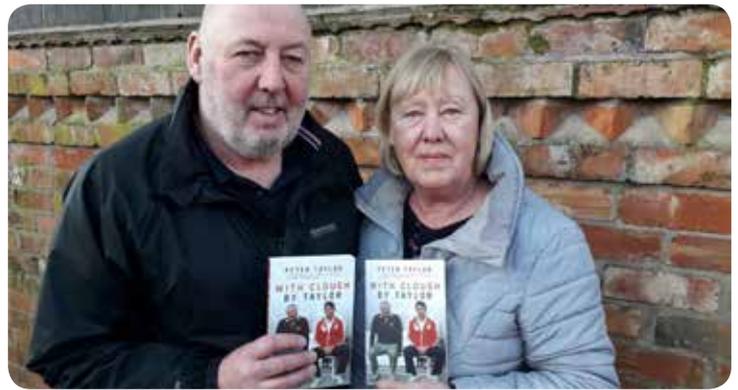
Action for Pulmonary Fibrosis founding trustee Wendy Dickinson and her brother, Philip Taylor, are donating the royalties from the publication of a book written by their father, Peter, to APF for research.

Peter died from Idiopathic Pulmonary Fibrosis in 1990 at the age of 62. He was a football manager who had a spectacular career with his partner, Brian Clough, managing Derby County and Nottingham Forest. They won countless league titles and trophies including two European Cups with Forest. Their style of management was revolutionary at the time and Clough became one of the most outspoken and memorable figures in world football.

Wendy said, “We were approached last year by a publisher who wanted to reprint dad’s 1980 book - With Clough, By Taylor. It charts their lives from meeting as players to their great successes as managers. We are passionate supporters of Action for Pulmonary Fibrosis and felt it was appropriate for any royalties to go to this great charity. Dad died just three years after diagnosis and, as a family, we felt very alone. I am so proud of the work that APF is doing both in research and in supporting patients and Phil and I are delighted to make this donation.”

With Clough, By Taylor can be purchased at books shops or direct from the publisher <https://www.bitebackpublishing.com/books/with-clough-by-taylor>.

“We are passionate supporters of Action for Pulmonary Fibrosis and felt it was appropriate for any royalties to go to this great charity.”



Wendy Dickinson and her brother, Philip Taylor

## APF Chair speaks at European Parliament



APF plays an active part in the European IPF Federation (EU-IPFF) which seeks to improve care and treatment for people living with pulmonary fibrosis across Europe.

APF Chair Steve Jones commented:

“APF is a founding member of the European Federation. Being part of the organisation helps us to learn about pulmonary fibrosis treatment across Europe which we can, in turn, use in campaigning for better care in the NHS. As a leader in developing support groups across the UK, we too can share our experiences for the benefit of people living with pulmonary fibrosis across Europe. Membership also strengthens our voice in discussions with pharmaceutical companies developing anti-fibrotic drugs.”

Our photo shows APF Chair Steve Jones (right), at the European Parliament after presenting a major EU-IPFF policy study on IPF care. Also in the picture are John Proctor, MEP for Yorkshire and Humberside (2nd right) and Carlos Lines Millán EU-IPFF President (centre).

## Is Idiopathic Pulmonary Fibrosis hereditary?

Is IPF hereditary? It is a question that people living with the disease and families often ask when Action for Pulmonary Fibrosis trustees and ambassadors travel around the UK meeting patients and families. We've asked Dr Helen Parfrey (below), APF trustee and consultant respiratory physician at Royal Papworth Hospital, to give us some answers.



"Although most cases of IPF occur sporadically, it can cluster in families. Studies suggest that about 20% of patients with IPF have a family history of pulmonary fibrosis. This means that two or more members of the same family (either a parent, sibling, child, cousin or aunt/uncle) have been diagnosed with IPF. One copy of an altered gene in each cell is sufficient to cause the disorder, but some people who inherit the altered gene never develop pulmonary fibrosis. Therefore, if one or more family members have IPF it doesn't necessarily mean anyone else in the family will be affected.

"Importantly, studying families with pulmonary fibrosis has led to the identification of mutations in specific genes that increase the risk of developing IPF. However, it remains to be determined how these genetic risks interact with other factors such as smoking, occupational exposures or viral infections, to cause pulmonary fibrosis."

Research continues to improve our understanding of the mechanisms involved in the development and progression of IPF, in the hope that this may lead to the development of more effective treatments for pulmonary fibrosis.

One of Helen's patients, Ron Fish, is contributing to this research through the Addenbrookes Genetics Service and the 100,000 Genome Project, both of which are ongoing. Ron was diagnosed with IPF in 2015, but it wasn't until then that the possibility of a family trait came to light.

Ron had three older sisters, two of whom were diagnosed with IPF and one of whom it was suspected also had the condition.

"To be honest I didn't know anything about IPF, certainly not that there was a familial type," said Ron, "so I thought Brenda and Jean suffering from the same lung complaint was nothing more than a coincidence. Also, when Jean had been diagnosed it was suggested that her siblings might like to be tested, and a chest x-ray indicated my lungs to be clear.

"When I started to get breathless with exercise a couple of years ago, alarm bells should have sounded, but my first thoughts were of my previous heart problem or the fact I was just getting older."

Finally, as Ron's symptoms got worse he went to see his GP, was referred to a specialist and eventually transferred to Helen's care so that he could be treated as part of a clinical trial testing the drug Nintedanib. At the same time, his family history led to his involvement with the two research programmes.

Although the outcomes are long term, clinicians like Helen and patients like Ron are helping to improve support for those with IPF. You can read about one of the studies Helen has contributed to at [www.thelancet.com](http://www.thelancet.com). Just search for Helen Parfrey on the site to find the article on genetic variants and IPF.



Ron and Sylvia Fish

**"Although most cases of IPF occur sporadically, it can cluster in families. Studies suggest that about 20% of patients with IPF have a family history of pulmonary fibrosis."**

## Support Group round-up

The number of pulmonary fibrosis support groups continues to grow apace – in January there were 67 live groups! Here's a round-up of some of the groups' activities.



Nancy Howard and the respiratory team at Worcestershire Acute Hospitals hosted a wonderful first anniversary meeting of **Worcester Support Group** at St Matthias Church Hall, Malvern in November, pictured above. APF trustee Howard Almond attended and talked about the progress made by the charity over the last 12 months.

Congratulations to Specialist Respiratory Nurses Rebecca Bunn and Helen Gremo from the Kent Community Health Foundation Trust on the launch of the **East Kent Support Group**. They worked with APF Support Group Co-ordinator Lorna McLauchlan to set up the group, which meets in Canterbury.

The **Wyre Forest Support Group** launched in October, when group organiser Elaine Ball was joined by APF National Support Group Co-ordinator Lorna McLauchlan, Respiratory Nurse Specialist Nancy Howard, local councillor David Rees and Respiratory Lead at Worcestershire Royal Hospital Jane Nolan. Elaine appeared on BBC Radio Hereford and Worcestershire prior to the meeting to improve awareness and advertise the group. Nancy and Lorna gave presentations, and David said he had not been aware of the condition prior to this meeting and was amazed at the work being done by the charity to help people living with the condition.

People affected by IPF in **Northamptonshire** have been waiting a long time for a support group and they certainly made up for lost time at the launch in January. The chat, coffee and cake went down well and more than 30 people attended. The group exists because of the passion and determination of Penny Tremayne who lost her mum to the disease. She was ably supported by Brenda Coe and Alan Tratt from the Leicestershire group and our own Lorna McLauchlan.

Following a course organised by the British Lung Foundation, local choir enthusiast Carol Shepherd talked to the **Swansea Support Group** about the benefits of singing for lung health. Weekly meetings have been organised for 2019. Each session starts

with gentle relaxing body movements whilst sitting and is therefore manageable for all people with breathing difficulties, and we finish by all being able to sing simple rounds. Making such a happy noise is good for the soul and a welcome distraction to all!

**Tameside Support Group** was launched in April 2018 by Clive and Sue Green. Lorna McLauchlan and Stephen Morgan-Hyland from APF went to the launch and, seeing that it was standing room only, Stephen quoted from the film Jaws - "You're going to need a bigger boat!" Who would have thought that, after only eight meetings, Stephen's words would ring true, and the group has had to move to a bigger venue in Ashton-under-Lyne.

Morrisons supermarket hosted the **Mid Essex Support Group** for IPF World Week last year, pictured below.



Many groups had special events for Christmas, including the **Princess of Wales SG**, **Boston SG**, **Tees SG** who held a Christmas wreath making session and **Tameside SG** who celebrated their first Christmas in their new venue as reported above. **Sheffield SG** started their Christmas celebrations early this year with a trip up the Sheffield/Tinsley Canal on Tuesday 11th December - see below. Amongst other destinations, their cruise took in the sights of The Wicker, Attercliffe and Tinsley, with lunch followed by a fiendishly tricky Christmas quiz and a sing-song which would have challenged Gareth Malone's Choir!



## Spotlight on... Bolton Pulmonary Fibrosis Support Group

It's been a busy first year for the Bolton Support Group – and now they are set to make an impression for many more years to come. Here's the story of their first year supporting people affected by pulmonary fibrosis and their families in the north-west.



Group organisers John Latham and Steve Milward with Support Group Co-ordinator Lorna McLauchlan

The group was launched in February 2018 following the first idiopathic pulmonary fibrosis rehabilitation programme held at the Royal Bolton Hospital. The local Bolton Community and Voluntary Services Hub was chosen as the group's venue as it has a disabled-friendly environment with ample parking and

**"I thought the oak tree would be the perfect representation for our group... both the group and the tree were germinated and established in 2018."**

is a natural meeting place for many local groups. It was through the CVS that Steve Milward learned about the opportunity to apply for a Health and Wellbeing grant. After a free seminar and guidance on how to make a successful bid, the group was finally successful in September 2018. They were granted a fantastic £4,195 for two years as part of the Greater Manchester Health and Social Care Partnership.



**Top Tip:** Check out what grants are available in your area to support local voluntary groups. You can do this by contacting your local council.

The support group then took to the airways in November. Steve, John Latham and Lorna McLauchlan, APF's National Support Group Co-ordinator, were interviewed on Bolton 96.5 FM community radio station. They promoted the group and talked about pulmonary fibrosis, how it affects day-to-day life and how support groups can help both patients and their families.

However, the most exciting development for the group was when they were chosen as one of only 80 recipients to receive a commemorative oak tree and time capsule as part of Manchester Airport's 80th birthday celebrations. As chair Steve explains, "I thought the oak tree would be the perfect representation for our group in a number of ways. Both the group and the tree were germinated and established in 2018, both support life and provide resources for the benefit and future of others, and the branches of the lungs echo the trunk and branches of an oak tree as represented in our logo."



The time capsule has been planted alongside the tree and includes an item from Manchester Airport and others chosen by the group including information about present day knowledge of the disease, the names of the members of the Bolton Support Group, along with the consultants who are treating and supporting them. With the usual lifespan of an oak tree being around 300 years, and some living over 1,000 years, the time capsule is a fantastic opportunity to leave a lasting legacy for future generations.

Pictured left at the planting are members of the Bolton Support Group with – far right – APF National Support Group Co-ordinator Lorna McLauchlan and APF Trustee Stephen Morgan-Hyland.

# Living with Pulmonary Fibrosis

## Going on holiday

Everyone likes a holiday, but if you're living with pulmonary fibrosis it can take more planning than usual.

In this issue, Nurse Consultant Sandra Olive, below, from Norfolk and Norwich University Hospitals provides the advice, and we learn about one couple's experience of a holiday cruise.



Holidays in the UK don't usually present too many issues, while travelling abroad takes a bit more thought. But wherever you plan to go, consider how long a journey you can manage, whether you need to move around, how you will manage connections and whether you get assistance with luggage and transfers.

Think about your destination - will the climate and weather affect your breathing? Local terrain and altitude may be a factor. Find out as much as you can about the accommodation and facilities, accessibility and how flexible they can be to meet your particular needs.

## Oxygen

If you need oxygen at home when at rest, including overnight, you will need to arrange a supply at your destination. In the UK, you can contact your home oxygen supplier to arrange for your usual equipment to be provided. Contact your supplier several weeks before you plan to travel.

If you need different equipment from usual, you will need to contact whoever has prescribed oxygen for you.

Provision of oxygen abroad varies but usually needs to be hired. Your local oxygen supplier or oxygen service can advise.

There is helpful information about holidaying in Spain on [www.healthcareinspain.eu/visiting-spain](http://www.healthcareinspain.eu/visiting-spain). Private suppliers such as [www.oxygenworldwide.com](http://www.oxygenworldwide.com) and [www.omegaoxygen.com](http://www.omegaoxygen.com) can also help. Don't leave it to the last minute to arrange oxygen. It can take several weeks to get everything in place.

## Fit to fly?

Air cabins are pressurised to the equivalent of 6,500-8,000ft altitude, which means that the level of available oxygen is reduced, resulting in increased breathing and heart rate to maintain oxygen delivery. Generally, we cope with this without noticing but if you have a lung problem you may experience increased breathlessness, discomfort and a blueness to fingertips and lips.

It is important to understand that there are risks to flying with a lung condition. You should discuss with your clinicians whether it is an option for you. They may suggest a hypoxic challenge test where you breathe a mix of gases which simulates cabin oxygen levels. Oxygen saturations are measured throughout the test to determine whether inflight oxygen is needed. The test only tells you whether you can maintain oxygen levels under flight conditions, not whether you are 'fit' to fly. On the day of travel, if you are unwell or have an unstable medical condition, you should avoid flying.

If inflight oxygen is recommended, check the airline's policy and find out what paperwork they need. Most airlines will be able to advise on what special assistance is available. You can find out more at [www.europeanlung.org](http://www.europeanlung.org) and the European Federation of Allergy and Airways Disease - [www.efanet.org](http://www.efanet.org)

## Insurance

At present, the European Health Insurance Card is free for UK/EU citizens and entitles you to all medically necessary treatment - but if local residents have to pay a fee, so do UK visitors. The EHC is not insurance and will not cover repatriation or private medical care, so you should still take out full insurance for you and your companion. You must declare all relevant medical information. You may also want to consider the level of cancellation cover should you be too ill to travel.

Shop around and you might have more success over the phone than just buying online. APF, the British Lung Foundation and the British Insurance Brokers Association provide useful advice.

## Cruise control



Ian and Dorothy Perry, members of Newcastle PF Support Group, have undertaken a number of cruises, mostly from Southampton. They normally

use a local local travel agent to make the trip as stress free as possible and prefer to travel with the same cruise company.

Cont'd on page 9



“When booking, we would normally ask for a cabin near to a lift in the middle of the ship. On arrival at the departure hall we head to the Medical Assistance area. I require a wheelchair

owing to the fact that you would normally have to use an air bridge to enter the ship, and the staff guide you through the booking-in process and also through security so there is no stress or drama about getting on board.

“Excursions can be very tiring so we have found it is better to have a rest day between excursions, and check the tour brochure to see how strenuous they are.

**“Just remember everything is optional. Try to be flexible and enjoy the experience!”**



“Dining areas are often quite large, so you can request a table near the doors which does not require such a long walk from the lifts and restaurant entrance - this should be mentioned on your booking form.

“Just remember everything is optional. Try to be flexible and enjoy the experience!”

### In conclusion

A holiday should be enjoyable. Focus on the things you can do and try to be realistic about what is manageable.

Be prepared – plan well ahead and find out as much as you can about your trip. Consider travel agents specialising in accessible/disabled travel and seek advice from disability forums such as [www.disabilityholidaysguide.com](http://www.disabilityholidaysguide.com), [www.disabledholidayinfo.org.uk](http://www.disabledholidayinfo.org.uk), [www.ageuk.org.uk](http://www.ageuk.org.uk) and [www.disabledinfo.co.uk](http://www.disabledinfo.co.uk). If you need specific advice, talk to your doctor or nurse well ahead of your planned trip.

Make sure you have copies of any medical information – hospital letters, list of medications, details of your oxygen prescription, your GP details, EHC and insurance details - just in case you need healthcare while you are away. And make sure you take enough medication (and spares!).

We would love to hear your experiences of travelling – either at home or abroad. Please share your stories with us on our FaceBook page.

**And Bon Voyage!**



## We couldn't do it without YOU

The fantastic achievements of APF – from growing the support group network to investing over half a million pounds in research – couldn't have happened without YOU. Every penny raised from bake sales, walks, mountain treks and sky dives have made all this possible. We appreciate all your efforts and if you have family members or friends who would like to fundraise for APF through a big challenge get them check out the opportunities below.

Equally, if you want to fundraise for your own support group or APF – or both – we can help. Speak to Sharon, our fundraising co-ordinator at [fundraising@actionpulmonaryfibrosis.org](mailto:fundraising@actionpulmonaryfibrosis.org) and she can help with advice and resources. We have t-shirts, banners, wristbands and leaflets that will help your event go with a bang.



Following the success of APF's first organised challenge event - last year's Great Manchester Run (pictured above) - we are going to do it all again this year! Now is the time to act on those New Year resolutions and grab a place in the 10k or half marathon run on Sunday 19th May. To register for your place please contact [fundraising@actionpulmonaryfibrosis.org](mailto:fundraising@actionpulmonaryfibrosis.org).

Ever thought you'd like to do a Tandem Skydive but haven't quite got round to doing it? Well now's your chance! This is a great challenge and you can increase motivation by committing to raising funds for APF. Visit the APF website for more info at [www.actionpulmonaryfibrosis.org/skydive/](http://www.actionpulmonaryfibrosis.org/skydive/)

Want a challenge of a lifetime? Previous participants in TrekFest have loved these exciting routes involving either a 25k or 50k trek with a mini festival thrown in just for fun! There is an easily achievable fundraising target to help spur you on, so why not have a look here [www.actionpulmonaryfibrosis.org/fundraising/sportsactive-challenges/](http://www.actionpulmonaryfibrosis.org/fundraising/sportsactive-challenges/)

There are many more exciting challenges and events you can get involved in, whatever your level of fitness. For more info contact [fundraising@actionpulmonaryfibrosis.org](mailto:fundraising@actionpulmonaryfibrosis.org)

## Running for loved ones

Fundraising is vital for a small charity like Action for Pulmonary Fibrosis both to enable us to fund vital research and to support those affected by the disease. We appreciate everything that all our fundraisers do to support this work. This issue we're shining a spotlight on just four stories about people running to raise money, but thanks to all who have done their bit around the country.



Katy Gallagher, above, took part in the Great Scottish 10k Run at the end of September with some of her colleagues. Katy's mum was diagnosed with IPF in 2014 and Katy's dad eventually took on the role of full-time carer for the family. Her mum passed away on 1st May last year and Katy says this whole experience has had a devastating effect on the entire family. Her run raised £725 for the charity. Katy commented, "The work APF is doing for individuals and families affected by IPF is great and I would like to help in any way I can."



Martin, Steve and Dave Colclough lost their dad, Alan, to IPF in May. In his memory they decided to take on the challenge of running the Manchester Half Marathon in October and, together with their 122 supporters, have raised a staggering £4,570 plus Gift Aid – smashing their £3,000 target! Martin feels very passionate about Action for Pulmonary Fibrosis.

He says, "It's our absolute pleasure to fundraise for the charity! The work you do is incredible, and a lifeline for those affected by IPF. Running a race and raising money is easy in comparison."

**"I want to help with research into a cure and prevention so that future generations may be given a chance to win the battle that is pulmonary fibrosis."**



Sarah Messer's story started a few years ago when her dad, Dr Denis Morgan, received the diagnosis that he, like his mother and sister, had developed pulmonary fibrosis. He passed away peacefully in June last year at the age of sixty-nine and left a huge hole in the lives of his loving family and those who knew him. Sarah said, "Knowing that there is no cure for this disease and that it has hit our family three times already, I want to help with research into a cure and prevention so that future generations may be given a chance to win the battle that is pulmonary fibrosis." Sarah ran the Cardiff Half Marathon with friends Kay Sellick and Mike Cadden and they raised a fantastic £2,670.



Marilyn Montgomery, above, ran her first ever half marathon, the Kanga-Roo Kanter in Ashdown Forest last year for APF, as her husband, Sam, was diagnosed with pulmonary fibrosis in 2012. Marilyn's company, PRO, matched her fundraising bringing the total raised to £908. Wendy Todd from the company's Charities Committee said, "PRO has decided to match this great effort, and we hope that this donation will help the fantastic work that you do".

## Top award for Sheffield nurse



Dawn Weston, a specialist nurse at Sheffield Teaching Hospitals Trust and one of the founders of the **Sheffield Pulmonary Fibrosis Support Group**, recently received the coveted Patient Experience Award 2018 from her local NHS.

Out of 17,000 staff working for the Trust, 400 were nominated for an award and Interstitial Lung Disease (ILD) nurse Dawn was one of the worthy winners.

An inspiration to all, Dawn has worked tirelessly to improve patient experience, including developing a dedicated patient support group and offering a telephone contact line and an outpatient clinic service. The phone line alone attracts 20 to 30 calls per day! Dawn also trains new ILD nurses and has been involved in the education and training of several regional teams.

*“Dawn is typical of the many dedicated respiratory nurses across the UK who make a huge difference to the lives of patients with PF.”*



ILD patients now receive a multidisciplinary, holistic and supported care experience, both within and outside routine clinical practice. Dawn's relationships with palliative care organisations ensure that high standards of care are delivered to patients even when they are no longer able to attend hospital appointments. Her knowledge and deployment of oxygen therapy has been essential to symptom management for patients. The team are regularly congratulated and praised by patients on Dawn's involvement and dedication.

Dawn is typical of the many dedicated respiratory nurses across the UK who make a huge difference to the lives of patients with PF. Action for Pulmonary Fibrosis is proud to work on joint projects with many nurses through the ILD Nurse Network (ILD-INN).

## Travel grant inspirations

International conferences are important ways of keeping up to date with the latest research in respiratory disease. APF funds the costs of travel to these events, helping to keep young researchers on top of developments.

Two researchers were funded to travel to the European Respiratory Society (ERS) congress in 2018. Research Psychologist Suhani Patel presented work on muscle weakness in idiopathic interstitial pneumonias to an international audience.



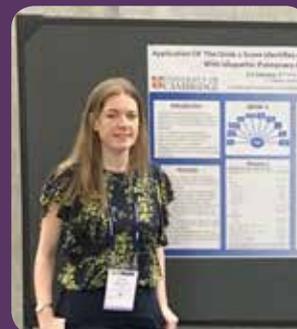
Kasope Wolff, pictured, also attended and commented, “I have come away from the congress not only with a great deal of scientific knowledge but also renewed passion for IPF research. Thank you for giving me this opportunity.”

Another recipient of an APF grant is Amanda Goodwin (pictured right). She attended the International Colloquium on Lung and Airway Fibrosis in California last year. Amanda said, “Each day began with a patient perspective, where a patient with pulmonary fibrosis spoke about their experiences of living with the condition. These sessions were a sobering reminder of why it is essential for us to continue research into pulmonary fibrosis.”



APF also funded two researchers' attendance at the American Thoracic Society conference in San Diego.

Sarah Jones, Doctoral Research Fellow with National Institute for Health Research, is in the first year of her PHD and her attendance meant she could network with specialists in pulmonary rehabilitation.



Emma Denney, pictured, presented work which involved applying a cardiovascular risk prediction algorithm to patients with idiopathic pulmonary fibrosis. This supports early recognition and treatment of cardiovascular disease.

Emma commented, “I am extremely grateful to Action for Pulmonary Fibrosis for their generosity in providing me with this wonderful opportunity.”

## Keep on calling!



The APF Support Line launched in 2018 is going from strength to strength. We provide help for people living with pulmonary fibrosis, carers and family members.

It currently operates as a free 'call back' service – **you call us on 01223 785725**, leave a message and someone will call you back within 24 hours.

ILD specialist nurse Lucy Rodrigues answers most of the calls, with support from APF Chair Steve Jones, himself an IPF patient who has received a lung transplant. This means the Support Line can draw on experience and knowledge from both the professional and patient point of view. Lucy also makes follow up calls if people seem vulnerable and sends out lots of emails with additional information and advice.

We have promoted the Support Line on social media, and 2019 will see more advertising to reach patients who may not use the internet. Please do keep calling. We're here to listen, advise and provide extra help and care when you need it.

## Don't forget IPF World Week 2019!

Although the dates for the global awareness-raising IPF World Week for 2019 aren't pinned down yet, it is usually the third week in September. Don't forget to make a note in your diary.

It's a great opportunity for support groups and health care professionals to raise awareness and funds in their own communities. Keep an eye on Action for Pulmonary Fibrosis website and Facebook page for the date, and for resources to help your event stand out. And let us know about your events and achievements so we can celebrate them in our October newsletter!

IPF World Week has raised tens of thousands of pounds for Action for Pulmonary Fibrosis as well as much needed funds for individual support groups and local hospitals. Events also raised awareness and spread the word about the disease. More families than ever need support through local support groups or by calling the APF Support Line so IPF World Week is a great opportunity for you to focus your efforts.

Contact our Fundraising Co-ordinator Sharon Moon for support at [sharon@actionpulmonaryfibrosis.org](mailto:sharon@actionpulmonaryfibrosis.org).

### Contact us

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If you have a story to share or feedback on this issue, email [debbie@djprm.co.uk](mailto:debbie@djprm.co.uk) or call 07498 056979



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