

## Support Line? – Lifeline!



This summer saw the launch of the much-needed APF Telephone Support Line for patients, carers and families. Everyone living with pulmonary fibrosis knows just how difficult it can be coping with the diagnosis, treatment and management of the disease. Sometimes, in addition to your dedicated health care professionals, you just need someone

sympathetic, well-informed and experienced to talk to.

The Support Line 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. If you have an urgent or emergency medical need please call 111 or 999.

Interstitial Lung Disease (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. They have experience and knowledge from both the professional and patient viewpoint. As the number of calls grows they hope to bring more nurses and expert patients on board so that everyone continues to get a timely response.

**“Call us on 01223 785725”**

Lucy, who previously worked in intensive care before becoming an ILD Nurse Specialist at the Royal Brompton Hospital says, “Calls can vary from questions about oxygen, going on holiday and local

support groups, to help with understanding an IPF diagnosis and treatment options. Some of the calls can be quite heart-breaking as people struggle to get the care they need for themselves or a member of their family. But we are here to help if they don't feel they can talk to their doctor or just need some signposting. We are not here to replace your health care team and we cannot give specific medical advice but we are here to support you.”

Lucy also makes follow up calls if people seem vulnerable and sends out lots of emails with additional information and advice.

**“We are here to listen and help in any way we can”**

APF Chair Steve Jones commented, “We decided to launch the Support Line because we know that having pulmonary fibrosis can be very isolating and it can be difficult to get information. We are here to listen and help in any way we can. We hope that as the service develops it will be expanded and improved to respond to the needs of patients and families.”



## 64 and counting!

We are delighted to announce that there are now 64 PF Support Groups across the country! New for 2018 are:

Bolton, Gloucester, Northwich Park, Tameside, Middlesbrough (pictured above), Bradford, Hywel Dda, West Kent, Boston, East Surrey, Luton, West Bromwich, East Berkshire, Cornwall, Wyre Forest and Chesterfield.

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

See inside for lots of Support Group news!

## Inside this issue...

Great Manchester Run... Support Group news... Coping with the Cold... Survey response... IPF World Week... IPF in the workplace

## Welcome



Welcome to the second edition of your patient support group newsletter. A lot has happened since we launched the newsletter in April. Since then we've helped health care professionals, patients and families to set up ten new support groups across the country bringing the current number of groups to 64 as we go to press...with more in the pipeline. This not only strengthens the support for PF patients but also increases awareness of the condition amongst local communities and health professionals.

However, we have a lot more work to do if we are to achieve our vision of having a support group for every patient in the country within an acceptable distance of their home. APF continues to develop its support for the PF community in other ways - by introducing a new Telephone Support Line for patients and families, holding Patient Information Days, carrying out a major survey looking at patient care and bringing together members of our Voice of the Patient Council.

Support Groups are always thinking of new ways to improve awareness and fundraise, and this edition includes some of the amazing journeys patients have taken in achieving this. IPF World Week in September was another great opportunity for increasing awareness and you can read about some of the groups' events later in this newsletter. We hope you enjoy it. Please get in touch with any ideas you may have for future editions or if you would like your group to feature in the next time.

Lorna McLauchlan, SG Co-ordinator

## Clap Along with Fife and Tayside



The Fife and Tayside PF Support Group has turned to song to raise awareness and funds for Action for Pulmonary Fibrosis.

It was the idea of group member Alan Noble (seated centre above) who was diagnosed with IPF almost five years ago. Alan and his wife Marna have raised money for charity throughout their working lives and wanted to help others with this devastating condition.

**"I didn't want it to be all doom and gloom...but also not flippant or frivolous. Getting the right balance was very important."**

Alan decided to write a poem about IPF. "I didn't want it to be all doom and gloom...but also not flippant or frivolous. Getting the right balance was very important. The poem had to contain three basic elements: What is IPF? What needs to be done? How can we help? Anyone with a lung condition will tell you that, as the condition progresses, we become increasingly restricted in the physical things we can do. However, most people are able to clap their hands so I set my poem to music, so everyone can clap along."

The group has now recorded a video of them singing the song, with the support of the Lundin Links Choir from Fife. It is introduced by Alan and APF Chair Steve Jones and there is also information about how to donate to support research into IPF.

Take a look at the video at [www.actionpulmonaryfibrosis.org](http://www.actionpulmonaryfibrosis.org)...and clap along!

The group has only been going for a year and at first struggled to attract new members. They eventually spread their wings to cover a wider geographical area and now attract patients from three different hospitals.

Chairperson Maureen Ward says, "Keeping in contact and arranging meetings that members have a chance of getting to can be challenging, so we meet one month in the Dundee area and the following month in Kirkcaldy. The meetings are as informal as possible and we have regular guest speakers. We are also in contact with each other online sharing any topics relating to IPF that we find."

## Support Group round-up



The **Princess of Wales IPF Support Group** in Bridgend continues to meet monthly and has now begun Thai Chi at the start of each meeting which helps with breathing control. They also completed their second round of IPF specific pulmonary rehab and finished off with some Nordic walking. The respiratory team participated in the Barry Island 10k at the start of August and were able to promote the group and IPF awareness in the local press which was really helpful. They even found a few new members who were not aware of the support group.

The **Chorley and Preston Lung Fibrosis and Carer Support Group** had a stall and raised awareness at the NHS Lancashire Health Mela, which is held every year to encourage the local community to take an active and enjoyable part in securing its own health and wellbeing. Its origins date back to Preston in 2001, when healthcare professionals and members of the Preston Gujarat Hindu Society held an event to improve health education amongst the local south Asian community. Over the years the scope of the Health Mela expanded to become a multi-ethnic event taking in all sections of the community.



The **Luton and Dunstable PF Support Group**, above, launched in July supported both by APF and the Pulmonary Fibrosis Trust. All affected by pulmonary fibrosis – patients, carers, relatives and friends – are welcome. The group meets in Luton and contact details for future meeting dates can be found here [www.actionpulmonaryfibrosis.org/support](http://www.actionpulmonaryfibrosis.org/support)

The **Leicestershire and Rutland PF Support Group** raised awareness of the disease and the support and friendship the group offers at a Wellness Event

at Ulverscroft Manor in Markfield this summer. APF Ambassador Wendy Dickinson helped on the stall and said, "The group is thriving but members are keen to let everyone who might need support know that they are there. They all work hard to spread the word and raise funds and welcome everyone affected by pulmonary fibrosis to their meetings."

The **Nottingham PF Support Group** were thrilled when the local ASDA chose them as one of three charities to take part in their 'green coin' charity scheme. Customers are given a plastic coin and drop it into one of three charity bins. The one with the most coins at the end of the month wins. Nottingham 'beat off' competition from a local pet rescue group and a foodbank and were presented with a £500 cheque by the supermarket.



### Clive is live on Tameside Radio

In our last newsletter we reported on the new **Tameside PF Support Group** launched by Clive Green, a retired firefighter and patient. It was standing room only at the very first meeting!

Clive and his wife Sue work tirelessly to promote the group and this soon came to the attention of local Tameside Radio. Clive was invited to go on the Joshua Littlehales programme to talk about the new group and what it means to live with IPF. Lorna McLaughlan, Support Group Co-ordinator, also joined Clive for his first broadcast.

Clive was obviously a natural. He made such an impression that he's been given a regular monthly slot on Joshua's programme, Tameside Today, and broadcasts just before every meeting. As well as covering the group's activities and how it is developing, he also adds humour and appeals to listeners to support the group by donating items that can be used as raffle or quiz prizes.

The group meets every month at the local Fire Station, with different speakers and the chance to share experiences and advice. More details here [www.actionpulmonaryfibrosis.org/support](http://www.actionpulmonaryfibrosis.org/support)



## Hull PF Support Group - four years on and still going strong

"I have worked with patients with pulmonary fibrosis for about nine years. As Hull and East Yorkshire Hospital became a growing referral centre many people said they would like to meet others to share experiences and learn more about this rare disease.

"We first met early in 2014 with around 60 people. We now meet every three months and have talks on a wide range of subjects from pulmonary rehab and yoga to first aid and oxygen therapy. Our Clinical Trials Unit are ever present and give updates on national and local research trials.

"Four years on the group continues to be well

attended and we have raised over £17,000, some of which has been donated for research. Funds are raised through events, sales of T-shirts etc. and donations from relatives who have lost loved ones to IPF.

"One of our transplant patients has recently completed a coast to coast bike ride and raised over £2,000. He is now planning to travel the length and breadth of Britain visiting many of the support group locations.

"My advice to anyone thinking of starting a group would be:

1. Don't hold meetings too frequently as people will lose interest and you may run out of topics and speakers.
2. Get your specialist consultant involved and participating in meetings whenever possible.
3. Include the specialist nurse in organising meetings as they may have more contacts in the field of IPF. They will also be aware of local patients and be able to send out invites.
4. Try to be self-sufficient and raise money as you go. We provide refreshments at meetings, but make money on the raffles etc. to support that.
5. Don't make the meetings too long as some people don't like being out for too long and it may exclude patients on high flow oxygen!
6. Don't be afraid to repeat sessions. New patients and family come through all the time and may have missed previous talks. Allow plenty of time for people to talk and interact during the meetings. Don't make it all educational!"

Mark Major, Specialist Respiratory Nurse (pictured with colleague Mandy Bell)



## Join our voice of the Patient Council...and your voice will be heard

APF's third successful Voice of the Patient Council Conference was held at The Belfry Hotel in Warwickshire during IPF World Week in September when patients, carers and APF staff and trustees came together to share information and ideas. The Voice of the Patient Council is crucial to the work the charity does and, if you are a patient, we would welcome you as a member.

As well as our once-a-year conference, members are consulted throughout the year by email and asked for their views on various aspects of our work - from website content and this newsletter to our support group guide and the care they are receiving. It's your opportunity to get your voice heard.

To join, 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 from you.



## Health Tips

### Coping with the Cold

Just as people living with fibrosis may have found the hot weather challenging, so the cold weather brings its own problems. It's estimated that the winter months bring up to 80% more hospital admissions for people with lung disease compared to March to May.

**Here are some tips to help you cope with the cold from Respiratory Nurse Specialist Nancy Howard.**

#### Plan ahead

Work out a management plan with your GP or nurse in case you get a chest infection. Don't assume it will get better on its own. Know who to call and when to act. If your plan involves medications, make sure you have enough, that they have been reviewed, and are still in date. You may be offered a prescription in advance to get medication quickly if you get chest infection symptoms.

- Flu can be very serious for people with a lung condition so ask your GP practice about the flu jab as well as inoculations against pneumonia and shingles.
- Try to organise appointments/engagements outside of the more severe winter months.
- Get advice on whether you qualify for Fuel Allowance and apply as soon as you can.
- Prevention is better than cure, but it is important to act if you do pick up an infection and your symptoms get worse despite home treatment or worse than you have experienced before. If you are struggling to breathe and you are unable to get a GP to see you the same day, call 111 for advice or, if necessary, call 999. Calls won't always result in a hospital admission, unless this is the best place for you.

#### Once winter arrives

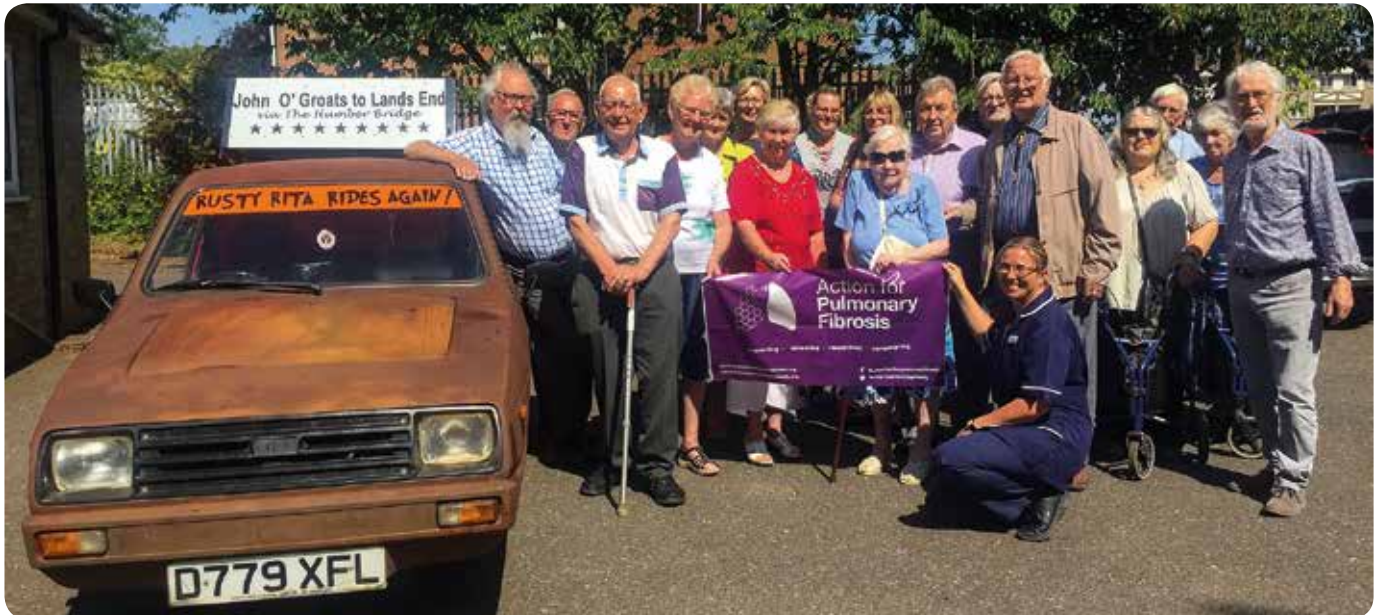
The best idea is to try to avoid picking up colds and flu from others. Not easy but you can take reasonable precautions. Children are notorious for spreading infections so be sensible when you are with family and friends. It may seem anti-social but you must put yourself first. Some practical tips:

- Touching items that other people have touched can spread infection – stair handrails or supermarket trolleys could have been touched by hundreds of people! Always wash your hands after being out and before preparing food.
- Try to keep your home at a minimum of 18°C (64°F) - pick up an easy to read thermometer.
- If you sleep with the windows open don't forget that temperatures can plummet overnight so consider closing windows when very cold. Layer blankets on the bed to trap heat but ensure they're easy to remove in case you get too warm.
- Eat regularly. Hot drinks and hot food are really useful to keep you warm.
- There's no easier or cheaper way to generate body heat than by ensuring that you keep active, from walking round the room at every TV advert break to simple chair exercises or exercises learned at Pulmonary Rehab classes.

#### Going out

- Try to venture out as little as possible in bad weather, but if you do, plan your journey and check the latest weather reports. If appropriate ensure you have extra warm clothes and a thermos flask with a hot drink. Cars that have been standing outside can get very cold. Ask someone to preheat the car before you get in.
- Layer clothing to trap heat, focusing on head, hands and feet. You may want to put a scarf across your nose and mouth to stop the sudden impact of cold, but some can find this confining.
- Try to keep oxygen cannulas tucked inside your clothes to prevent splitting and if possible keep a spare with you.
- If the weather turns bitterly cold or breezy you might have to delay or postpone an outing. Don't feel guilty about making that decision. There will be other days when you can get to appointments or visits.

***"You're living with a serious lung condition, so you need to do what is right and sensible for you, whether that's staying at home or dialling 999."***



## Rusty Rita rides again!

APF Chair Steve Jones visited the Boston Pulmonary Fibrosis Support Group in July to see Shaun Winter (pictured leaning on the car above) who was just back from his John O'Groats to Land's End IPF fundraising trip in 'Rusty Rita'.

Shaun was diagnosed with IPF 11 years ago while working in a forensic hospital, and was diagnosed diabetic at the same time. Despite this, he managed to go to university to train as a mental health nurse, graduating in 2012. When his health deteriorated he had a lung transplant in March 2014. So far all is well apart from the odd side effects of medication.

## New face for fundraising

Hi, I'm Sharon Moon and I have recently taken over the role of Fundraising Support Co-ordinator for APF. I am a keen charity supporter. I did the London to Cambridge Bike Ride in 2014 and again in July this year raising £900 for a local family. I am also a volunteer for Age UK and have previously volunteered for the East Anglian Children's Hospice.



My primary focus with APF is to support the amazing fundraisers who take on all manner of challenges, events and a host of other things to raise money and awareness of pulmonary fibrosis. I had little knowledge of PF but the idea of supporting a small but growing, patient-focused charity was something that really appealed to me.

As a small charity the generosity and support of our fundraisers is invaluable. Elsewhere in the newsletter you can see the creative ways support groups fundraise and the wide range of activities and events held for IPF World Week in September. If you need any support with your fundraising please email me on [fundraising@actionpulmonaryfibrosis.org](mailto:fundraising@actionpulmonaryfibrosis.org)

Shaun told us, "The reason I got into raising awareness of IPF is simple - there is not the information out there. Last year a group of friends and I decided to raise funds for research at Castle Hill Hospital in Yorkshire. We did a coast to coast from Bridlington to Morecambe on small or old motorbikes and raised £,3000. Much fun was had by all!"

Shaun and his friends then wanted to do something bigger and came up with Rusty Rita - a plastic Reliant Rialto covered in rust paint. At a meeting of the local branch of the Royal Enfield Owners Club they decided to tackle John O'Groats to Land's End via the Humber Bridge, starting at the home of Hull City FC - and with Rusty Rita being followed by an escort of Royal Enfields.

The team met a lot of people along the way and were supported by many, including at Stoke City FC and Oxford United FC and the old factory sites for Reliant cars and Royal Enfields.

The Boston support group saw Shaun's story on Facebook and got in touch. He was able to join them for their next meeting where the group certainly got a lot out of hearing his story. Unfortunately, on the way home Rusty had a blow out on her front tyre. With help from a couple of farmers and the RAC, four hours later she was back on the road with a broken wheel stud. She did the rest of the journey with a blown head gasket. Not bad for a 30 year old plastic car.

Shaun is determined to get Rusty back on the road next year - but after 2,211 miles she needs some surgery!

## How support groups are supporting APF



APF Chair Steve Jones with John Williams, Derby

2018 has been a year when we have been humbled by the amount of support APF is receiving from support groups and their members. We can't feature you all here...but you know who you are and how grateful we are! We couldn't do the work we do without you.

The **Derby PF Support Group** almost caused a nasty accident when they sent a donation to former trustee Wendy Dickinson. "I opened the letter and inside was a cheque for £3,000. I literally stepped back in shock and fell over," says Wendy. "I immediately rang the Chair, Doreen, to thank her for such fantastic support. The Derby group has a special place in my heart as my dad, Peter Taylor, was a former manager of Derby County and I have visited the group several times." The group has asked for their donation to go to research.

The **Hull PF Support Group**, under the guidance of Specialist Respiratory Nurse Mark Major, continues to give amazing support to the charity. This year they gave us a cheque for £2,300 to add to an earlier donation of £2,000. This vibrant group is brilliant at fundraising and have raised over £17,000 since they began four years ago – see more on page 4.



The **Leeds PF Support Group** made a decision some time ago to raise funds for research and we were delighted to receive a donation for £2,000 this year which is now safely tucked away in the APF Research Fund. Thank you to all in the Leeds area for your generosity.

## Thank You! 775 times over

A huge thank you to the 775 people who responded to our 2018 IPF Patient Survey this summer.

Our first patient survey in 2015 helped us understand how the NICE Quality Standard on Idiopathic Pulmonary Fibrosis - which sets out what treatment and care patients should be receiving - was being implemented across the UK.

The 2018 survey aims to assess if your experience of care has changed since 2015 and identify where greater effort is needed by the NHS. We also want to understand how changes in the NHS have impacted on people living with pulmonary fibrosis and how the needs of the IPF community are evolving.

Check out our website in November when the survey results will be published - [www.actionpulmonaryfibrosis.org](http://www.actionpulmonaryfibrosis.org)

## Patient Information Days - under starter's orders!

APF's first Pulmonary Fibrosis Patient Information Day held at Newmarket Racecourse in July was voted a resounding success by over 100 patients and family members who attended.

Organised jointly with the Papworth Hospital PF Support Group it brought together group members from across East Anglia – Papworth, Bedford, Stevenage, Chelmsford, Norwich and Boston.

Presentations on everything from how pulmonary fibrosis is diagnosed and current research to managing the side effects of drug treatment and the value of pulmonary rehabilitation prompted lively discussions and many questions from the audience. News of APF's Telephone Support Line was particularly welcomed by patients.

APF Ambassador Wendy Dickinson commented, "A day like today is invaluable for patients and carers. It allows them to learn more about all aspects of the disease from leading experts in a relaxed atmosphere. Just as important is the opportunity it gives everyone to share their personal experiences with people who know exactly how they are feeling."

Our Yorkshire Patient Information Day was held on October 22nd at Doncaster, organised by APF Trustee Dr Simon Hart and Specialist Respiratory Nurse Mark Major of Hull and East Yorkshire Hospitals Trust. Look out for news of other events on our website [www.actionpulmonaryfibrosis.org](http://www.actionpulmonaryfibrosis.org).

# Living with Pulmonary Fibrosis

## In the workplace

This issue's Living with Pulmonary Fibrosis feature focuses on the impact of IPF on your working life. We talked to two people who have had very different experiences at work since being diagnosed with IPF.



Clare Beckett is a research scientist and has worked in laboratories for many years. This environment, with its chemicals, gases and elements of manual work, proved increasingly challenging for Clare following her diagnosis with IPF, at the relatively young age of 37.

Safety equipment such as protective suits and masks assume normal lung function, and working in a lab mean restrictions on drinking due to contamination risks. However, Clare's employers at the University of Cambridge were very supportive. Adjustments were made to enable her to continue in her role, and she was given remote access at home when she needed more time to recover from a cough or cold.

When the emotional impact of the diagnosis eventually hit Clare she was also able to take time off and return to work gradually. However, over time her lung function worsened and it became increasingly difficult to control the risks inherent in a lab environment. Clare reduced her hours to three days a week and the University supported her in looking for an alternative role. She is now working in an administrative post in a different department which encourages flexible working.

While her employer has been supportive, Clare is realistic about the future and wants to be fair to the University too: "It's a two way street – they have been helpful and I've been able to find a new role, but there may come a time when I just can't do the job anymore and I want to be honest about that."

Clare continues to develop new skills and is continually thinking about how she might need to adapt to ensure that she can still work and have time for her family in the future.

Huw Thomas's experience has not been so positive.

"I started working for the bank in 1976, but was dismissed last year for not being fit enough for full-time work in a specialist sedentary role: there were no part-time jobs available. I was certified unfit to work during the dismissal process so, although it was legal, it still felt unfair and frustrating."

Huw had been finding it harder to breathe when sitting upright at a table or working at a desk, and was finally diagnosed with IPF in 2014. He wasn't ill enough for a retirement package, and having no regular income took some getting used to. Even harder to cope with were the feelings of dismissal and isolation, but becoming a trustee of the Pulmonary Fibrosis Trust and having the chance to help other people affected by fibrosis has helped Huw to cope.

"Could more have been done to help me stay in work? Of course, but it would have involved a relaxation of working practices that others might have thought should be offered to them, such as having reclining chairs and laptops. Perhaps there will come a time when all employers understand the anxieties and issues that being short of breath gives us, and become more empathetic and helpful. In the meantime we can all help by putting our points of view carefully and increasing awareness of these concerns."

The Equality Act 2010 applies to people with fibrosis, and places obligations on employers to make reasonable adjustments to the workplace. However, the Equality Act doesn't force employers to provide part time work, and the process can be weighted in favour of the employer on the definition of what is 'reasonable' when there is no obvious physical impairment, such as is often the case with IPF.

You can find out more about your rights under the Equality Act at [citizensadvice.org.uk](http://citizensadvice.org.uk) or [acas.org.uk](http://acas.org.uk)

## Chair takes international role



We are delighted to announce that APF Chair, Steve Jones, has been elected to the Executive Board of the European Idiopathic Pulmonary Fibrosis & Related Disorders Federation (EU-IPFF).

The EU-IPFF is made up of 17 patient organisations from 13 European countries inside and outside the EU and is the first such pan-European organisation. It aims to improve the quality of life and prognosis for IPF patients, and patients suffering from other interstitial lung diseases.

It brings together European national patient associations committed to defending their vision of equal access to treatment and care for all IPF patients, regardless of geography, socio-economic status or age. Action for Pulmonary Fibrosis was a founding member of EU-IPFF.





## Unforgettable day for APF at Great Manchester Run

By Alex Croft

"I have been involved with APF since the charity was founded in 2013 and spent several years as Fundraising and Marketing Co-ordinator until I left in June, 2018. During that time, I have been inspired by many amazing fundraisers. APF always gives fundraisers the utmost support but had never been part of a big, organised event before...until the Great Manchester Run in May this year.



"We put the word out that we were getting a team of runners together and the response was overwhelming. On the day we had 48 amazing runners for APF. It was an incredible weekend for everyone who was there. I can't tell you how proud we were to see our charity name next to wonderful long-established charities such as Dementia UK, Cancer Research, Macmillan, British Heart Foundation and MIND. APF didn't exist five years ago yet there we were at this amazing event! Our tent was packed with runners and their families and had a real family atmosphere. It was wonderful for us to at last meet the people who have supported APF for many years.

**"Thank you to all the runners, the families and friends who supported them and to the APF volunteer team. WE DID IT!!"**

"There were lots of tears from runners (and us!) as many were running for loved ones they had lost – their parents, grandparents, uncles, aunts and

friends. It was very moving and special. It was a blisteringly hot day and they did us proud. The finishers arrived back at the tent to huge cheers and a massage from volunteers Kathleen and Rowan.



The last runners returned at 5:30pm and the day was done. But what a day!



## More than a challenge!

Shoppers visiting Exeter's Princesshay Centre on a September weekend were more than a little surprised to find a 24-hour gym session in full swing. What was happening? And what did it have to do with pulmonary fibrosis?

It all started when India Coyle, the current Miss Taunton and a Miss Great Britain contestant, asked her local gym, U7, if they would help her raise awareness of disadvantaged families and those coping with illness.

Not content with just a collection tin on the counter, the U7 More Than A Challenge was born – a 24-hour fitness challenge. The object? To lift as much weight and cover as many metres as possible via a variety of cardio and weight-based exercises.

India's chosen charity was Global's Make Some Noise, which supports disadvantaged children and families. Simon Almond, co-owner of the U7 gym, chose Action for Pulmonary Fibrosis as his father Howard has the disease and is an APF trustee.

Over £2,500 was raised for the charities - £1,000 over the challenge target!

## APF trustee awarded prestigious professorship

APF Trustee, Dr Gisli Jenkins, Professor of Experimental Medicine at Nottingham University Hospitals, has been awarded a prestigious National Institute of Health Research (NIHR) professorship for research into pulmonary fibrosis.

Already one of the leading researchers in the UK, Gisli has been awarded £1.7 million for a five-year project to identify biomarkers of pulmonary fibrosis that can predict the course of the disease and responses to therapy. This biomarker-guided strategy will enable a precision medicine approach to managing patients with pulmonary fibrosis.

He said: "I am so excited about receiving this award because it will enable a step change in translating our understanding of disease biology into better therapeutic strategies for patients with pulmonary fibrosis."



Gisli was a founding trustee of APF back in 2013 and chairs the selection panel for the APF Mike Bray Research Fellowship in IPF.

## Mike Bray Research Fellowship

Earlier this year, APF launched the Mike Bray Research Fellowship in IPF in memory of the charity's founder, who passed away in 2017. Thirteen applications have been received for the £300,000 grant and these were reviewed by independent scientists and clinicians in line with the recommended Medical Research Foundation process. The three applications receiving the highest scores have been invited to submit a full proposal and these are being assessed by a panel in November. The successful applicant will be announced at the end of the year.

The charity is also in the process of developing a research strategy to guide our planned major investments in research in 2019 and 2020. We are also ensuring the patients' voice is heard in other key research programmes on PF funded by national bodies such as the National Institute for Health Research and pharmaceutical companies.

## New trustee Dr Beckie Lang



Welcome to the newest member of the APF Board of Trustees, Dr Beckie Lang, Chief Executive of Parent Infant Partnership (PIP) UK, a small infant mental health charity. Beckie continues APF's commitment to having a board made up of people with personal or professional connections to pulmonary fibrosis.

"My background is in public health," says Beckie. "I trained initially as a nutritionist and entered academic research following my PhD."

"My familiarity with pulmonary fibrosis is through the diagnosis of my maternal uncle, Joe, and then my mum, Trish. More recently, an uncle on my dad's side has also been affected. Sadly, all three have passed away, following different journeys and at different ages. The hardest for me of course was seeing my mum affected, undergo a single lung transplant at the eleventh hour and then three years later pass away from transplant complications."

**"I understand the need for awareness of the disease, support for those affected and their families, and the desperate need for more research and prevention, management and treatment."**

"I have been pleased to see the start of APF and its development over the last few years in order to provide vital support and funds in all of these important areas."

"APF is expanding quickly and I am delighted to be part of its development. Away from work and the APF I'm a married mum of three teenagers and live in Warwickshire. I relax by walking our mad cocker spaniel Oscar, or enjoying a G&T and a laugh with friends."

## IPF world week works wonders!

Over 60 events were held by support groups, health care professionals and APF supporters during IPF World Week. Here are a few of their stories.

Kimberley Jones and family raised an incredible £2,149.42 in memory of her father Tony who passed away last September. The group walked to the peak of Snowdon leaving a painted stone remembering Tony.



Unfortunately Kim couldn't make the climb due to knee surgery the week before but was on hand after the event offering foot massages!

Tina Woodhouse, her mum and sister held a 30 strong Bowling Fundraiser in memory of Tina's dad, Keith Morton. The £800 raised was generously topped up to £1,000 by the Post Office Charity.



Hannah Jukes, aged just 15, completed her triple 10k challenge last weekend raising almost £500 for APF.

Supported by her Dad, David, she powered through to the last run gaining a personal best time!

Louise Baldwin, her mum and cousin took part in the Peak District 25k Trek Fest following the loss of a very special family member, Barbara, to IPF. They smashed their target of £350 and to date have raised £715 for APF.

Nicola McLean completed the Edinburgh Kilt Walk - 24 miles in all. Nicola lost her mum to IPF and to date has raised over £400 for APF.



## Raising funds and awareness

APF has hundreds of supporters across the UK. You can see their stories on our Facebook page – here are just a few of them - but we love you all!



Congratulations to Tony Brierley and his eldest daughter Hayley who ran the Leigh Community 10K in August. A fantastic achievement raising £1,140 so far for APF. "We are doing this for my beautiful wife Sue who suffers from this terrible disease," said Tony.

Joe Carroll and nine friends completed the Three Peaks Challenge in 23 hours 45 minutes. A fantastic achievement raising £3,015



so far for APF – more than double their target. Joe lost his father to IPF in January 2017 and was keen to do the challenge in his memory to raise awareness.



A huge well done and thank you to Jessica Horn for completing the Cheshire Triathlon for APF and raising a fantastic £335.

A big thank you to the Chair of Breckland District Council Kate Millbank pictured with APF Chair Steve Jones and a cheque for an incredible £4,006.70! Kate chose APF as the district council's charity of the year in memory of a close friend who passed away in 2016.



Thanks to Rachel Hawley and Empingham Dog Training Club who raised £106.50 at their Summer Fun BBQ, with a dog show and mini challenges. Bollie took part in the Junior Handler class - she's very proud of her 2nd place! The group support APF in memory of Rachel's dad who passed away last year.

## Study Days Spread the word



A key commitment of APF is to raise awareness and knowledge of pulmonary fibrosis within the medical profession, to improve early diagnosis and patient care.

We have been offering free nurse study days for two years now - thanks to a grant from the pharmaceutical company, Roche – in partnership with the ILD Interdisciplinary Network of Specialist Nurses. The programme has been a tremendous success with 500 nurses and other health professionals taking part. In 2018, 11 sessions were held, including two in Wales.

At first the programme focused on healthcare professionals in primary care but this year we have been able to expand and tailor the study days to new audiences in community and secondary care.

We learn from every session and feedback has been overwhelmingly positive, as shown by some of the comments we have received:

“A very informative talk. I learnt such a lot about a subject I had only a brief knowledge of.”

“The specialist nurse’s personal experience and enthusiasm was excellent.”

As well as improving health professionals’ knowledge of ILD, the study days encourage them to set up support groups, or raise their awareness of local groups where they already exist.

## Channel 4 News focus on IPF

APF was delighted to be involved in a feature on IPF broadcast on Channel 4 news in the summer. Journalist Victoria Macdonald asked us to find a suitable patient to interview to illustrate the policy of NICE (The National Institute for Health and Care Excellence) on anti-fibrotic drugs for IPF.

The two available drugs – Pirfenidone and Nintedanib – may hold back progression of fibrosis in some patients but are not available to everyone diagnosed. APF supporter Terry Holder from Dunstable was interviewed and explained how he had to wait for his condition to deteriorate before he was eligible for treatment. NICE rules state that antifibrotic drugs can only be prescribed to patients with a lung capacity of 80% or lower. Read the NICE guidance here: [www.nice.org.uk/guidance/cg163](http://www.nice.org.uk/guidance/cg163)

## Raising awareness on radio

The Phoenix Internet Radio held a day of broadcasts dedicated to raising awareness of pulmonary fibrosis in August and raised over £3,000 for APF through listeners’ donations. It was an amazing day with APF Chair Steve Jones and National Support Group Co-ordinator Lorna McLauchlan being interviewed about the disease. The group of friends and volunteers who run the station decided to hold the event following the death of a team member, Tracey Clasper, and the diagnosis of another presenter, Lee Garrett.

“As the music played we reached out to our listeners and the money rolled in - the target was smashed twice. When you take into consideration that most of the listeners are visually impaired and either not working or on relatively low income, it speaks volumes of the support that’s out there. It was a truly memorable day of radio,” said Terry Clasper, Tracey’s husband and co-founder of The Phoenix.

We are extremely grateful and thank everyone involved for their support. If you’d like a change from your favourite radio station try [www.the-phoenix.net](http://www.the-phoenix.net)

## Contact us

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