



Cheers to Chester! 75th Support Group launches

"It is a magnificent achievement but there is still much to do to reach patients who don't have a support group near them. We're on the case and will continue until everyone affected by pulmonary fibrosis has the support they need."

After only six years Action for Pulmonary Fibrosis is pleased to announce the launch of the 75th Support Group. Find out more about the **Chester Support Group** inside this issue, as APF Ambassador Wendy Dickinson pays them a visit and looks back on the beginnings of the charity.

Research offers new hope

Nintedanib and pirfenidone, anti-fibrotic drugs used to slow down progression of idiopathic pulmonary fibrosis, have been shown to work on many other types of progressive pulmonary fibrosis.

APF Chair Steve Jones attended the European Respiratory Society Congress in Madrid to hear the results of two international clinical trials.

Read the full story, as well as other research news, on pages 12 and 13 inside.

Pulmonary Fibrosis Month – a huge thank you to everyone who took part

This September, during PF Month and IPF World Week, Action for Pulmonary Fibrosis asked you to pull together to do something very special. We launched our Listen To Our Lungs campaign and asked support groups and individuals to write to GPs across the UK to raise awareness.

You rose to the challenge magnificently and also held amazing events to raise awareness and funds in your own community. Thank you from all of us at APF. See inside for stories and pictures from an amazing month of PF awareness.

Chair's Report from Steve Jones



These are exciting times for Action for Pulmonary Fibrosis. Our CEO Louise Wright and team are strengthening the capacity of the charity so that we can support more patients and their families better and further invest in research.

"These are exciting times for Action for Pulmonary Fibrosis."

But these are also sad times for the charity. This month we say goodbye to Lorna McLauchlan in her role as National Support Groups Coordinator, after three years with the charity. She has done an amazing job in driving the development of the support group network from under 30 when she joined to 75 today.

Lorna has been a great member of our team and has always been there when support groups have needed advice or assistance. She will remain involved in APF in different ways, but I know that you will want to join us in thanking her for all she has done and warmly wish her the best for the future.

I am pleased to say that we have appointed Debra Chand to take over as National Support Manager and develop our work with support groups. Debra joined us in mid-October, bringing 25 years' experience of successful work in the charity sector. Debra will assume responsibility for developing and helping support groups to increase their reach and impact around the country. She will introduce herself in the next newsletter though I expect many of you will hear from her before then!

Cheers to Chester!

75th Pulmonary Fibrosis Support Group Launch



"As I drove up the M6 to the launch in Chester of the 75th UK support group for pulmonary fibrosis patients and their families, my thoughts turned to how Action for Pulmonary Fibrosis began in 2013.

A handful of patients, family members and consultants set up the charity and became founding trustees. We all knew, from personal experience, how isolated, scared and alone many patients and families felt after receiving a diagnosis of PF. We also knew that our top priority was to give those people the support they deserved and needed. At the time there were only a handful of groups in the UK.

Our first chair, IPF patient Mike Bray (pictured left), was very passionate about their value and, with his wife trustee Elizabeth Bray, travelled the country helping to start new groups. We soon appointed Lorna McLauchlan as Support Group Co-ordinator and she and Mike did a magnificent job driving the development of the network. After Mike's death two years ago our current chair, IPF patient and lung transplantee Steve Jones, took up the baton with equal passion. It is thanks to them, and to the patients, carers, nurses, physios and consultants who shared our determination to make life better for patients, that there are now 75 groups in the UK.

At Chester there was a wonderful turnout of twenty-two patients and partners. The first meeting of a new group is always fascinating. People often enter the room with a look of trepidation on their faces, probably thinking, "Is this going to be all about being ill and dying?" Chester was no different. Everyone was quiet and a bit nervous. Patient Caroline Dillon, who inspired and drove the setting up of the group, did the introductions and Respiratory Nurse Specialist Sam Roberts, Lorna and I had our say. (Lorna, Caroline and Sam are pictured right). Then the chat began and the noise level rose. Suddenly everyone was talking to their neighbour, exchanging stories, asking questions and making new friends.



A quick straw poll revealed that the two subjects most people want to learn more about were handling the side effects of anti-fibrotic drugs and oxygen therapy. Everyone shared their story and plans were made for future talks, tea and cake.



I felt very privileged to be there and very proud of the part that APF has played in growing the number of groups to 75 in just six years. It is a magnificent achievement but there is still much to do to reach patients who don't have a support group near them. We're on the case and will continue until everyone affected by pulmonary fibrosis has the support they need."

Wendy Dickinson
APF Ambassador

Welcome

Welcome to the Autumn 2019 edition of the newsletter. I write this message at the start of Pulmonary Fibrosis month. This year in September we marked the event with our campaign Listen to our Lungs. It's a powerful message reaching out to raise awareness of the early signs of pulmonary fibrosis and aiming to speed up the time it takes for patients to receive a diagnosis.

The issue of late diagnosis was clear from our recent patient survey and the information provided has informed this campaign. Many groups joined in, and I would like to take this opportunity to thank you for all the hard work you have done arranging events to make our collective voice heard. Find out what our supporters did to raise awareness on page 8.

Since the last newsletter the APF team have visited many groups, both established and new, and we have now reached 75, again demonstrating the hard work and commitment of the PF community.

By the time you read this I will have stepped down from my role as Support Group Co-ordinator for APF and we welcome Debra Chand, an experienced charity and support group worker to the team. Whilst I hope to continue doing some work for the charity, I would like to take this opportunity to thank all the groups and their members for the warm welcomes I have received on my visits and to wish you all the best for the future.

Lorna McLauchlan
Support Group Co-ordinator

Support Group roundup



Coffee and Cake in Sandringham

The Sandringham Estate in Norfolk is the setting for a regular get-together for cake, coffee and a chat for PF patients and families in the area. Some members also attend the **Norfolk and Norwich Support Group** but Mick Donoghue, who helps organise the Coffee Group says: "Our regular support group in Norwich is excellent and meets every three months, but for many in Norfolk and Cambridgeshire it's just too far to travel. It's therefore great for those people to have the support of others through the Coffee Group. It's

quite informal and we don't have speakers, but everyone is welcome." If you'd like to join the group please contact Mick on 01945 880576 or 07857 717768.

Spotlight on Wales

Wales is definitely on the APF map, with a brand new group launched over the summer. **Denbighshire Support Group** in the village of Trefnant south of Prestatyn, launched in June and was joined by Lorna, support group co-ordinator who said, "It was amazing to see so many people attending the group in such a small rural village. People had travelled from a wide area demonstrating the great need for this type of support in North Wales."

Jaime Ashton (pictured right with nurses Maria Jones and Debbie Jones) set up the group in memory of her dad, Ian, and is also carrying on his fundraising legacy. Her local triathlon club in Llandudno, GOG Triathlon, have picked APF as one of their nominated charities for 2019.

Despite the blustery cold weather, APF CEO Louise Wright was extended a very warm welcome to Wales by Maggie Crawford, who runs the vibrant and active **Swansea Support Group**. Around 30 people shared their positive experiences of using oxygen when out and about and running fundraisers for APF, and group member Fran George shared a copy of her article in South Wales Evening Post raising awareness of IPF. The group donated £500 for APF which was gratefully received.



Also in Wales, APF Ambassador Wendy Dickinson met patients and carers at the **Princess of Wales Support Group** in Bridgend, to update them about the charity's work and to hear their exciting plans for raising funds and awareness. "The group are very inspiring and full of great ideas," said Wendy.

Led by ILD Nurse Specialist, Natalie Murray, the group incorporate Tai Chi into their meetings and have a busy programme of educational and social events.

Anyone interested in attending can contact Natalie at Natalie.Murray@wales.nhs.uk or on 01656 752482 or 07812 672366.



Music – and human table football!

The Hallows Golf Club in Dronfield have been a fantastic support for the **Sheffield Support Group** over the summer, hosting two amazing events. The first – a music quiz – attracted over 100 people who put their musical knowledge to the test. HSBC Bank generously pledged to match the funds, producing a magnificent total of £974. It was certainly a cause for 'Celebration!' (Kool & the Gang 1980 in case you're wondering!!) They then got extremely creative, taking a Table Football table and enlarging it ten times to 40ft x 20ft. Plastic figures were replaced with people. Throw in a full size football, blow the whistle and stand back...this is Human Table Football!

"It was the hardest day's work I've done since I retired but I can't remember a day when I laughed so much."

I can't remember a day when I laughed so much. Thanks to Hallows Golf Club and all who came along and helped to raise over £1,000."

The Human Table Football Tournament attracted 12 teams, who battled it out for four hours to determine the winners - the Hallows Juniors Team 1. Gordon Harrison, Vice Chair of the Sheffield Support Group, who helped to organise the Tournament as well as playing in it said, "It was the hardest day's work I've done since I retired but

Rotherham are our new video stars

Our thanks to Christine and Stephen of the **Rotherham Support Group**, who allowed their arms to be twisted to take part in videos to support our communications work. They were filmed along with one of our Mike Bray Research Fellows, Dr Richard Allen, from the University of Leicester. Becca Thomas, APF's Digital Communications Specialist filmed our volunteers and said: "We wanted to capture people's stories and provide practical tips and advice for others living with pulmonary fibrosis. Richard talked with the two patients and told them about his exciting research into the genetics of the disease.

"It was a wonderful afternoon and I admired Stephen and Christine's bravery and honesty in coming forward to talk about their very difficult journeys. We talked about pacing yourself, adjusting tasks and the things you love so that you control PF and don't have it control you, and the importance of talking to friends and family. A huge thank you to everyone - look out for the videos on social media."



Bracing walk for Brighton

The **Brighton Support Group** launched in June and have had a number of speakers already, including Bernadette O'Donoghue from Brighton and Hove Council who talked about benefits. September also saw the group's first fundraising event - a walk along Brighton seafront to raise awareness as well as funds for APF, pictured left.

Small but friendly in Derry

Trustee Elizabeth Bray was very pleased to attend the June meeting of the **Western Support Group** in Derry, Northern Ireland, to talk about APF and

how the charity helps support groups and patients. The small but growing group is one of only two support groups in Northern Ireland and is organised by Ann Box, the respiratory nurse at Altnagelvin Area Hospital.

Living with Pulmonary Fibrosis: delayed diagnosis and the psychological impact of IPF on patient and family



Keith and Marian Maw have been married for 50 years and live in Porthcawl in Wales. Thanks to both for sharing their experience of living with pulmonary fibrosis and the psychological impact on patient and family of delayed diagnosis.

Marian: a carer's perspective

"Keith had been finding activities more difficult and although it was in part due to normal ageing, there seemed to be more to it than simply slowing down. Each year he would suffer a persistent cough and become increasingly breathless when doing normal activities. Eventually he would visit the GP, who prescribed antibiotics which seemed to have a temporary effect. His symptoms were often dismissed as getting older or simply 'one of those things you have to live with'.

Over the years I have learned to recognise how Keith is and how he changes. We had planned a cruise to celebrate our 50th anniversary but didn't go ahead as he was feeling unwell. After considerable 'nagging' from me – I believe women are more honest about health issues – he eventually capitulated and made an appointment with his GP for a proper discussion.

"A common story is that diagnosis at GP level is spasmodic, haphazard even."



He was referred to a consultant cardiologist with suspected Atrial Fibrillation (irregular heartbeat). The consultant wasn't too happy with the chest sounds – Velcro Lung was mentioned – and referred Keith to his colleague. Eventually, a diagnosis of Idiopathic Pulmonary Fibrosis (IPF) was given. Speaking to others affected by the condition, a common story is that

diagnosis at GP level is spasmodic, haphazard even, and this itself has made the situation worse for the sufferer and their families.

Since diagnosis and subsequent anti-fibrotic medication, we have had a great deal of support from the specialist team which we very much appreciate, but I am still frustrated by the fact that for so long no-one suspected that there may be a serious problem. It is apparent that many health professionals are unaware of the condition and prognosis and whilst I acknowledge that treatment is only provided under strict NICE guidelines, the fact that we struggled for a long time not knowing is still a source of great frustration."

Keith: a patient's perspective

"Following extensive tests and procedures my diagnosis was finally confirmed in October 2018. Marian had surfed the Internet and we had a pretty good idea about it, and the inevitable prognosis.

"We are determined to make the best of what we have and continue to live our lives as normally as possible."



While I have to live with the disease alongside me, my family also suffer and I am fully aware, as we all are, that there is no happy ending to IPF. However, we are determined to make the best of what we have and continue to live our lives as normally as possible within the inevitable limitations.

Currently there is no cure and the onset is insidious with many symptoms creeping up on me. However, we know that we can improve the quality of everyday life and make the most of what we can still do. Here in the Bridgend area we are fortunate to have a dedicated and hard-working support framework in the form of the IPF team. The Princess of Wales IPF Support Group in Bridgend and a recent Pulmonary Rehabilitation course have helped me learn a great deal more about my condition and how I may best manage it with the help of the professionals and my family.

Medically there is nothing other than an ameliorative process available and the monitoring and support is much appreciated. However, I believe it is equally important that there is more social and psychological support. It is clear that many sufferers and families are struggling to come to terms with the illness and the inevitable outcome. Some of the support group are inspirational and show us what can be achieved with commitment and support, but there are others who clearly are finding it difficult to come to terms with their own feelings and those of their family and close friends."

If you need extra support, or just someone to talk to, call the APF Support Line on 01223 785725. Leave a message and we'll get back to you as soon as we can.

Charity Cards for Christmas



APF is delighted to be able to offer some very special Christmas Cards again this year. Camilla Inglis, whose son Wilf designed last year's Chilly Robin, is once again offering to process all orders on behalf of the charity. Will has also added a lovely penguin image and an impressive owl, as illustrated, and these will all be available in handy packs.

For more information on prices and how to order - and to cross one thing off your Christmas to do list - please email fundraising@actionpulmonaryfibrosis.org.

PF Month - Listen To Our Lungs

"Raising awareness of IPF and PF with GPs was a priority for us over PF month in September this year. We asked for your help and encouraged you to use #ListenToOurLungs as a call to action. You didn't disappoint.

From a GP awareness event in Middlesbrough, to healthcare professional activity in Devon and Exeter to fabulous videos by nine-year-old twins, Max and Pheobe, our community spoke with one voice across the UK. You can read about these and other stories here.

Thank you from all of us at APF."

Louise Wright, CEO



Study day for GPs

Tees Support Group held a GP Study Day in Middlesbrough. Patient frustration at the lack of knowledge of PF amongst GPs has been a key issue from the early days of the support group.

Oxygen Nurses Francheska Sarkodie and Debbie Hagan worked with fellow group founder Angela Charlesworth to set up the study day for GPs, practice nurses and nurse practitioners. It was

chaired by local consultants, with input from specialists from the Royal Victoria Infirmary in Newcastle. The programme included information about treatments and palliative care, as well as an introduction to APF from Chair Steve Jones. Any groups wishing to organise a similar event are welcome to contact franchiseska.sarkodie-gyan@nhs.net or d.hagan@nhs.net for advice.

Birthday gift for APF

When Lou Tristram realised her birthday fell in Pulmonary Fibrosis Awareness Month she only wanted one thing – for her friends and family to raise awareness and funds for APF to help find a cure. Lou's mum, Jayne Mee, was diagnosed with IPF three years ago aged 59.

As Lou says, the diagnosis 'rocked our world'. "As a nurse myself and my mum a health care worker at the time, we had heard the words flitted about but never really understood what it entailed. I was heartbroken, scared, angry, lost and the one person I always turned to for answers and support was mum, but this time I couldn't. As a family we've pulled together and mum has been amazing." As well as asking for donations in lieu of gifts, Lou and her nine-year-old twins Max and Phoebe made videos which we shared across social media. A huge thank you to Lou, Jayne and all the family for their magnificent support. Lou is pictured with her mum, the twins and elder daughter Ruby.



Stepping out in Norfolk

Mick Donoghue, who runs the **Sandringham PF Coffee Group**, is pictured in Hunstanton setting out on the first day of IPF Week to walk part of the famous Norfolk Coastal Path. Mick was diagnosed with IPF three years ago and is a passionate walker. "I find I can do less and less as my breathlessness increases and my muscles don't get enough oxygen," says Mick, "But when I get out of breath I stop and admire the view. The beautiful Norfolk scenery seemed the best way of setting a motivating challenge for myself while also raising much needed funds for APF." Hats off to Mick who completed the 38 kilometres from Hunstanton to Wells next the Sea.



Raising awareness in Blackburn

The **East Lancashire Support Group** attracted a lot of interest from staff, patients and relatives at their PF Month stall in the Royal Blackburn Hospital on.

Our thanks to everyone who gave their time to organise this. Pictured left to right are Collette Baiamonte, Janine Hood and Dr Saumitra Baksi from the Respiratory Service East Lancashire.

All hands on deck in Devon and Exeter

Representatives from the research and clinical teams at the Royal Devon and Exeter Hospital also joined with their local support group on a stand during IPF Week in September. From left to right our picture shows Chris Scotton (lead researcher), Owen Tomlinson (research technician), Dr Michael Gibbons, Angela Thurgood (ILD co-ordinator), Sarah Lines (ILD specialist nurse), Jessica Mandizha (research nurse), Stephanie Prince (research nurse), Howard Almond (patient), Anne McGahey (research nurse) and Bruce Robinson (patient).



Antrim activity

The **Northern Ireland Support Group** in Antrim held a number of events during September and October, including a coffee morning, a lunch with live music at Ballycastle, a quiz night and a 70s/80s theme night, as well as two members running in the September Half Marathon in Belfast and a grand raffle throughout the month. One member's Australia-based son is even doing a charity run in Melbourne!

Information about the group can be found on Facebook: just search for Antrim Area IPF Support Group.

Media highlights

The Listen To Our Lungs campaign received a huge boost with the support of Janice Long, who talked openly to the media about the impact IPF had on her brother Keith Chegwin and their family. Action for Pulmonary Fibrosis worked alongside Janice on national news stories and the Sunday Express kicked off IPF Week with a double-page feature on her story.

This was followed by a Channel 5 News feature on the Monday of IPF Week with Janice Long and Helen Parfrey, Consultant Physician and Founding Trustee of APF (pictured right with presenter Claudia-Liza Armah).

Media coverage continued with articles in the Mirror, the online Saga Magazine and the Belfast Telegraph. Steve Jones, Chair of APF, said, "Listen To Our Lungs is about empowering lung fibrosis patients to connect with their local GP and medical professionals. We are incredibly grateful to all the patients, carers and their families who have supported this initiative for Pulmonary Fibrosis Awareness Month."



Health Tips – Your questions answered

Earlier this year Dr Ajay Kamath, Consultant Physician from the Norfolk and Norwich University Hospitals' ILD service, gave a talk to the local support group. We thought it would be a good idea to share a summary of some of the interesting questions and answers from the event. Readers should bear in mind these answers were in response to specific questions from the members of the Norwich Support Group and based on expert opinion and clinical experience.

Why is it that on some days I feel fine and on other days I feel I can't do anything without getting out of breath?

"Think about what is happening with your mental outlook. Increasingly we recognise that our physical health affects our mental health, but the reverse is true too."



With all long-term conditions it is normal to have good and bad days. There are all sorts of reasons for feeling less well – a sudden, marked worsening of symptoms may suggest an infection but an odd 'off day' might reflect symptoms that are not just to do with the fibrosis. Think about what is happening with your mental outlook. Increasingly we recognise that our physical health affects our mental health, but the reverse is true too. Everyone's ability to cope is different but if you feel persistently anxious or depressed, do talk to your doctor or nurse about it.

Managing anxiety by developing techniques for relaxation and mindfulness can be very helpful, shouldn't these be taught more?

Thank you for raising this – as doctors we are conscious that we can become a bit focused on the lungs rather than the whole patient. We know that a change in the lung function tests doesn't mean very much day to day if you are living with lung disease. What matters is how you feel and most people just want to feel a bit better. Breathlessness clinics, pulmonary rehabilitation and advice from specialists in palliative care are all available – do ask if you would like to be referred. Also think about other support groups such as Breathe Easy or Singing for Breathing groups.

We know there is a strong prevalence of acid reflux in PF. Is any more known about this yet?

A study over 10 years ago showed that a significant proportion of people with PF had what is termed 'silent reflux', when there is reflux but no obvious symptoms. We think reflux worsens cough by irritating the back of the throat, but we don't yet have concrete evidence that taking medicines to reduce the production of acid have any effect on the lung scarring, although they may improve symptoms.

Could my fibrosis be linked to my psoriasis, polymyalgia (PMR) or recent heart attack?

There is no known link between these conditions and fibrosis but sometimes drugs used to treat them can cause lung problems, e.g. Amiodarone in some heart diseases. Muscle weakness, such as you get in PMR, can worsen symptoms of breathlessness and fatigue so these things all need to be taken into account.

Does PF break down the immune system? And if other conditions like rheumatoid arthritis (RA) are treated with biologics, does that have an impact on fibrosis?

There is not a break down in the immune system as such, more an abnormality in the way the immune system works, so that the body attacks its own cells. In RA this causes symptoms of joint pain and in some patients, the lungs are also affected, with the development of fibrosis. The biologic treatments transform the joint effects of the condition but we don't know if they have an impact in the lungs. There is no evidence yet that they do, so it seems likely that there is different, complex process going on in the lungs.

Are there family links between IPF and RA in different generations?

There is no evidence that there is any connection between IPF and RA but we do know that lung fibrosis can develop up to five years before joint symptoms appear. The blood tests we do when we first see you try to rule out auto-immune diseases but sometimes we have to revisit the diagnosis later if new symptoms appear.

Can you tell us about cough in pulmonary fibrosis and what can be done about it?

This is one of the commonest symptoms and often the first abnormal thing people notice. It is also one of the most difficult to treat effectively. We try to rule out known aggravators like reflux, then we can try cough suppressants like codeine linctus but it commonly causes constipation.

There is no clinical evidence that plant-based remedies or inhalations help. The physiotherapists advise cough suppression techniques which can be very helpful, as can the input of the palliative/supportive care teams.

For more about coping with cough see the article in the APF Spring 2018 newsletter at www.actionpulmonaryfibrosis.org/support/support-group-newsletters

Generous gift boosts APF

It's not every day APF receives a cheque for £35,000, but back in June Lorna McLauchlan, Support Group Co-ordinator, was presented with the generous gift by Jacqui Bramhall on behalf of her aunt Elizabeth Burnside, pictured right, who sadly passed away from IPF.

Elizabeth was an active member of the Manchester Pulmonary Fibrosis Support Group held at Wythenshawe hospital. She was passionate about raising awareness of the condition and keen to improve care and treatments for IPF patients.

Jacqui told us, "Our aunt was so passionate about your charity and was determined to help. The only way she could do this was after her death in her legacy. She wanted other sufferers to benefit from this money by the way of research."

Elizabeth's family have also helped fundraise for the charity and in August her nieces Kerry Jane Sargeant and Nadine Burton organised a fantastic afternoon tea and fun day to raise money and awareness for IPF. The girls managed to raise an amazing £488 for APF too.

These donations will help more families affected by the disease. Thank you so much to Elizabeth's family and the **Manchester Support Group** for all your support.



Sunday 29th March 2020



Want to be a part of the only half marathon to go through both the City of London and the City of Westminster?

NOW is the time to apply for one of 25 charity places and raise funds for
Action for Pulmonary Fibrosis

*Please register your interest with APF by emailing fundraising@actionpulmonaryfibrosis.org
You will be guided through the application process and asked to tell us why you'd like to take part, how you plan to fundraise and how APF can best support you to achieve your goals.*

RESEARCH: Finding a cure for pulmonary fibrosis



Steve Jones, APF Chair, looks at current research projects in the UK and beyond.

"APF's vision is to find a cure for pulmonary fibrosis so that everyone affected by the disease has a better future.

When I was diagnosed with idiopathic pulmonary fibrosis (IPF) in 2008, there was little known about the causes of the disease and no available treatments. Since then, there has been a rapid growth in research by universities, research institutes and pharmaceutical companies ('pharma') into the different types of the disease. Most effort has gone into IPF, which is the most common and aggressive form of the disease, but other conditions are also being investigated.

Two anti-fibrotic drugs for IPF - pirfenidone and nintedanib - have been released and more are in the pipeline. If on-going trials of these new therapies prove successful, they could become available to patients in the next two to five years. The two existing drugs have recently been tested on other progressive forms of pulmonary fibrosis, such as hypersensitivity pneumonitis. First indications are positive (see opposite), bringing hope to many more pulmonary fibrosis sufferers. Nintedanib has also recently been shown to be effective against pulmonary fibrosis caused by an auto-immune disease, scleroderma.

The precise cause of IPF is not known but it is believed to be triggered in people with a genetic predisposition by exposure to cigarette smoke, dust and pollution. Acid reflux from the stomach may also play a role.

So far, IPF has been shown to be associated with almost 20 genetic variations in patients. Over the next three years, we expect to identify many more IPF-associated genetic variations as a result of research by Dr Richard Allen at the University of Leicester, recipient of the Mike Bray Research Fellowship. This will hopefully lead on to the identification of different chemical and biological pathways involved in the process of fibrosis and to new treatments.

These new genetic insights into the disease are encouraging because they raise the future prospect of precision medicine, making it possible to target treatments to patients with specific genetic or molecular abnormalities.

Another important avenue for research is the role played by bacteria in causing IPF and progress of the disease. This is being investigated by another Mike Bray Research Fellowship research project being undertaken by Dr Phil Molyneaux of Brompton Hospital and Imperial College. He is examining the role bacteria play in disease progression and whether taking prophylactic antibiotics can slow down disease progression.

In addition to directly funding research, APF plays an important role in ensuring that patient views are included in the design and implementation of other major research projects, financed by the National Institute of Health Research (NIHR) and others.

We are involved in this way in two major NIHR studies. The first, at the University of Nottingham, seeks to identify biomarkers in the blood, which would make it possible to assess whether a person has rapidly or slowly progressing disease and to tailor their treatment accordingly. The second, at the University of East Anglia, is investigating the potential benefit for IPF patients of controlling gastric reflux. Both these have the potential to transform treatments for patients.

"APF has committed nearly £600,000 to research on pulmonary fibrosis in the last year, all of which was donated by our amazing supporters and fundraisers."

"We would like to give a big thank you to all of you!"

In the UK, Europe and North America, increasing collaboration between doctors, scientists and patient groups is leading to real improvements in outcomes for patients with this devastating disease. As a charity run by patients and leading clinicians, we are making an important contribution to these efforts. We are also a founder member of the European IPF Federation and keep close contact with its Scientific Advisory Group and developments across Europe.

"I have to fit in any research in between busy clinical work. The Mike Bray Fellowship allows me to spend more time in the lab. I'm looking to unravel the link between infection and IPF."

Dr Phil Molyneaux

APF is now one of the main charities funding research on pulmonary fibrosis in Europe. With your help, we are determined to make the greatest contribution we can to national and global efforts to find a cure for this devastating disease."

Research results offer new hope

Nintedanib and pirfenidone, two anti-fibrotic drugs used to slow progression of idiopathic pulmonary fibrosis, have been shown to work for many other types of progressive pulmonary fibrosis.

The results of a 15 country clinical trial were announced at the end of September at the European Respiratory Society (ERS) Congress in Madrid. Scientists found that lung function for patients who took nintedanib declined more slowly than those who took a placebo. The rate of decline in the FVC (forced vital capacity) was -80.8 ml per year with nintedanib and -187.8 ml per year with placebo: a difference of -107 ml per year. Similar results were found by another research team for pirfenidone.

So far these two anti-fibrotic drugs have only been available to people with IPF – the most aggressive and common form of pulmonary fibrosis which has no known cause. But these results bring new hope to patients whose fibrosis is as a result of known causes. These include patients with hypersensitivity pneumonitis; autoimmune interstitial lung disease such as rheumatoid arthritis-associated ILD; sarcoidosis; systemic sclerosis-associated ILD; mixed connective tissues disease-associated ILD; idiopathic non-specific interstitial pneumonia; unclassified idiopathic interstitial pneumonia and others.

The results will now be appraised by the National Institute for Health and Care Excellence, who will decide whether the drugs can be prescribed to this new group of patients in the UK.

APF Chair, Steve Jones, who was at the ERS Congress said, "This is excellent news. The results give hope to a large number of patients with progressive lung fibrosis who cannot currently be prescribed anti-fibrotic medicines".

The Congress brought together more than 20,000 delegates over five days.



Fantastic fundraisers

Harriet's challenging year

Harriet Lyons lost her stepfather Mark last Autumn. She describes him as an energetic, fit man who, despite a diagnosis of PF in 2013, baffled doctors with his enthusiasm, optimism and strength.

"Coming to terms with knowing a loved one is so ill is very difficult. When it's a man who has been in your life for over 30 years, you just can't imagine him not being there". Harriet decided to channel her own energy into fundraising for APF and set about completing one event a month for a whole year. She has remained true to this pledge, and in August completed her biggest challenge yet, a 50k ultra marathon around Salisbury – despite a knee injury! Well done Harriet, you are an inspiration.



The Brierleys - a fantastic fundraising family

When Sue Brierley was diagnosed with PF, like most families hers was shocked at how little was known about this terminal disease. Sue's devoted husband, Tony, their three grown up children and partners and extended family and friends have since become heavily involved in raising funds and awareness for APF.

Tony believes "Pulmonary fibrosis must have its profile raised to the levels of other life limiting illnesses, both nationally and at local level, so that treatments can be developed and research can progress in order to eventually find a cure."

Pictured left is Tony with Sue after the Leigh Community 10k run in August.

A windy run in Edinburgh

David Charlesworth, pictured right, recently completed a very windy Edinburgh Half Marathon. David's wife Angela not only runs the home oxygen service in the North East but is also involved in the **Tees Support Group**. Together they raised over £500 including Gift Aid and David continues to wear his APF running vest at local races to raise the profile of the charity and PF itself.



Tough Mudder

In October last year, Sophie Gilligan and the team at the Birmingham office of multinational company Turner Townsend sadly lost a colleague, Peter Gair, to PF. A team of over 20 entered the Tough Mudder Classic in May to raise funds for APF. They also raised additional funds with a raffle, reaching a grand total of just over £1,800.



Northern Soul hits the spot

Brenda Coe, who lost her husband Mick to IPF, is pictured left at the **Leicestershire and Rutland Support Group** presenting APF CEO Louise Wright with £361 raised by the Shoe Town Soul Club in Northampton. All the proceeds from a fantastic night of Northern Soul were donated to the charity. Thanks to club organiser Stephen Clowes, the DJs - Steve C, Tracey Church, Derek Smiley and Glenn Bellamy – and all those who supported the event.

Tea in the rain!

Linda Kirk, also from the **Leicestershire and Rutland Support Group**, didn't let a little thing like torrential rain and wind spoil her garden fundraiser for APF. Afternoon Tea in the rain sounds pretty British doesn't it? And although the heavens opened when Linda and her family held a tea and cake fundraiser it didn't dampen their spirits. They still raised £370!



Sarah's inspiration

Sarah Myers took on a fundraising challenge this September and this is what she has to say about her inspiration.

"My amazing stepdad has unfortunately been diagnosed with PF. He is my rock and inspiration and no matter what pain he's in, he has always gone the extra mile for me. APF aims to improve quality of life for those who suffer from this disease. Without this charity supporting Dave and my mum, the journey they are going through would be a lot more lonely and scary."

Bob's Bikers

Bob's Bikers was formed following the death from IPF of Bob Mason in August 2018 and the team already has a great track record of fundraising. Bob's family wanted to honour his memory and raise as much money as possible for IPF research. Attempting the British Heart Foundation's London to Brighton bike ride seemed ideal.

A matter of days after losing their father, Bob's children Jeremy, Stephen and Jo enrolled on the 2019 ride. As word got out the numbers of riders grew - up to a final total of 16 team members. Most of the funds raised were for APF, with some also going to the BHF.



Jeremy enlisted the help of TV facilities company Hotcam as a kit sponsor to ensure that Bob's Bikers looked the part on the day. And the bright shirt design also raised awareness of APF as the riders made their way along the 54 mile course. Unfortunately the weather was not kind - with biblical amounts of rain - but that didn't dampen the spirits of this very special team. Bob's Bikers raised an astounding £10.5k for APF.

Following the success of the inaugural outing, Bob's Bikers 2.0 is planned for London to Brighton 2020 - with Hotcam again being kit sponsor. Jeremy said, "If you'd like to join our merry band or become a corporate sponsor please get in touch with Sharon at fundraising@actionpulmonaryfibrosis.org. We'll be riding once again in aid of APF, and in memory of a much-loved husband, dad and grandad."



Fundraise for APF - we're here to support you

Fundraising is vital to the work of APF. It has real results in terms of supporting patients and families and funding research. Support groups and individuals across the UK constantly inspire us with their efforts.

If you would like to get involved, Sharon Moon, Fundraising Support Co-ordinator, is on hand with ideas, resources and advice to make your fundraising as successful as possible.

"We have lots of exciting plans to develop our support for fundraisers and are adding a whole range of ideas and resources to our website over the coming months," said Sharon, pictured left.

So, if you'd like to join the many APF fundraisers, keep an eye on our website and social media or contact Sharon on fundraising@actionpulmonaryfibrosis.org

Social scene

These days it seems everyone is on social media – and APF is no exception. Action for Pulmonary Fibrosis can be found on Facebook (@actionpulmonaryfibrosis) and Twitter (@ActionPFcharity).

Social media is a great way to share your stories – whether it's fundraising achievements, meetings or just an experience or observation you think might help others.

Keep your posts short and pithy, and add a picture if you can. Video is even better – it only needs to be very short. Just ten seconds of someone celebrating the end of a charity run is enough to capture the moment. You can post on your own page, or on the APF pages.

If you are mentioning APF, use the relevant tag - @ActionPFcharity on Twitter and @actionpulmonaryfibrosis on Facebook. You should also use hashtags in your message if referring to a particular event or campaign - for example #ListenToOurLungs or #PFMonth. This will help people find your posts.

If you'd like to find out more about social media, take a look at this comprehensive guide – www.moz.com/beginners-guide-to-social-media You'll soon be an expert!

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