Action for Pulmonary Fibrosis

May 2021

APF Insider

Support — Research — Educate — Campaign

Ron and Myles – enjoying a pre-lockdown ride

Spring forward!

Papworth Support Group members Myles Greensmith and Ron Fish have long been keen cyclists and advocates of exercise. “On retiring and being diagnosed with IPF we’ve aimed to keep up cycling as a gentle form of exercise,” Myles told us.

Exercise releases endorphins which stimulate feelings of wellbeing, helping to combat stress and pain. It doesn’t have to be strenuous – even a gentle walk can be a good thing.

“The benefits of exercise are indisputable. We would recommend everyone to exercise as much as they can. Just do as much or as little as you are comfortable with – every little helps!”

Here’s to some sunny days as lockdown eases and we can start to enjoy the outdoors again. ●

Who we are/what we do

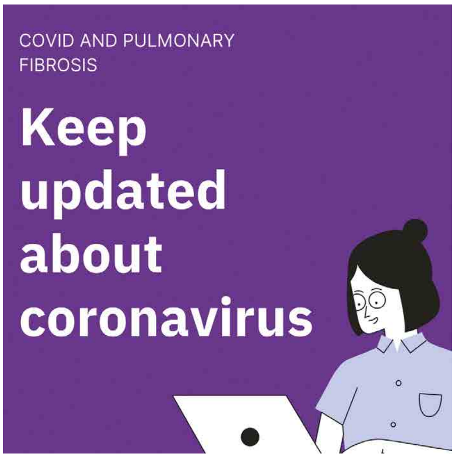
Action for Pulmonary Fibrosis: Who we are and what we do

Louise Wright, CEO

"Action for Pulmonary Fibrosis is Europe's leading charity supporting people with all forms of PF. We provide expert information and support to improve people's understanding of PF and increase people's confidence in their ability to cope with this life changing disease. We do this through a growing network of support groups, telephone support and information that is widely available on and offline. We fund ground-breaking research. We raise awareness of the disease and educate health care professionals to ensure patients receive the highest quality of care. We also campaign to improve equitability and access to the very best healthcare. Patients, carers and families are at the heart of everything we do and our work is led by them. Our vision is to find a cure and for everyone affected by pulmonary fibrosis to have a better future." ●

Information and support

Visit our website and Coronavirus Hub
www.actionpf.org



For all support group enquiries please email or call our National Support Group Manager
debra@actionpf.org – 07931 270801

Call our Support Line for access to a specialist nurse who can advise on health aspects, or to speak to a befriender.

☎ **01223 785725**

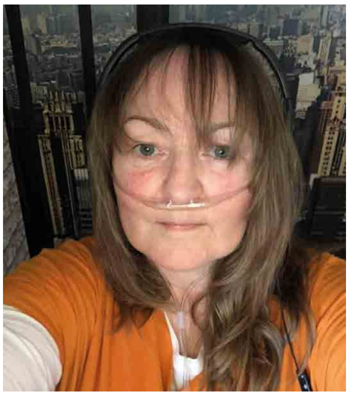
Volunteer Befrienders

Our 18 volunteer befrienders all have a personal connection with pulmonary fibrosis. They are fully-trained and provide a listening ear and support when you need it most.

Dawn explains how this support service has helped her:

> "I really can't overestimate the impact volunteer Susan has had on me. She inspires me so much. I think what makes it so impactful is that Susan is a similar age to me and totally understands the specific challenges of living with PF."

Susan



Dawn

Donate

If you would like to help us continue to be there for everyone affected by PF join our Giving Circle by setting up a regular gift to APF. See Page 14 for more details.

Follow us on social media

facebook.com/actionpulmonaryfibrosis

twitter.com/ActionPFcharity

A warm welcome from the Chair

“Hello everyone. I hope you are keeping well. It’s crazy to think we’ve been locked down for nearly 15 months! I found the winter pretty hard – I know many of you did too. Even though I had lots to do with APF and the European Pulmonary Fibrosis Federation (EU-IPFF), time did drag. No matter how positive you are, you can’t help getting the blues some days.”

“It’s wonderful now that the days are longer and warmer. My wife Hilary and I are seeing our grandchildren in the garden again and having friends over for socially distanced tea outside. But I have yet to step inside a shop, pub or café.”

“I hope you are getting vaccinated – it’s so important that we all do. I’ve had my jabs and am starting to be a little bit more adventurous. But, since they don’t know if the vaccine works well for people with transplants, I am still being careful.”

“It makes me really proud to see how APF has supported people living with pulmonary fibrosis through the pandemic. The team has done a brilliant job in continuing to provide services while developing new initiatives, especially for isolated people living alone or in difficult circumstances. Thanks to all our volunteers and supporters who have also done so much to help.”

“Thanks are also due to Katie Price and her mum Amy, a member of our Transplant Patients Group, for their support.”

“For me the last few months seems to have been a non-stop series of webinars and ‘summits’ (the new word for conferences!). Meetings like these are important in raising awareness of PF and building our relationships with health care professionals, pharmaceutical firms and NHS policy makers.”

“A good example was the joint webinar we organised in April with the Royal Society of Medicine on Medicine and Me: Living with pulmonary fibrosis, looking to the future. Dr Helen Parfrey, one of our trustees, and Dr Phil Molyneaux, an APF Mike Bray Research Fellow, talked about living with the disease and potential new therapies. Both presentations were excellent, and over 200 people viewed the event.”

“APF also played a major role in the first ever European Pulmonary Fibrosis Patients Summit, organised by EU-IPFF. APF staff and trustees made presentations, including Professor Gisli Jenkins who gave the closing keynote address on ‘Covid-19 and curing the incurable’. Gisli held out the hope that one day we will find the ‘holy grail’ – a cure for pulmonary fibrosis! All the sessions were recorded and are available on **www.eu-ipff.org**.”

“Bye for now. I am looking forward to the time when we can all meet again face-to-face. In the meantime, I hope you can all get out more and enjoy the weather.”

Steve Jones
APF Chair

Living with pulmonary fibrosis, looking to the future

Extend your learning beyond this lecture:
RSM members have access to e-resources on the go.
Join today quoting **ACD15** and receive **15% off RSM membership.**
Become a member – **www.rsm.ac.uk/join**
Visit **www.rsm.ac.uk/resources** to learn more

A Growing Network of Support

It's been a long winter and chilly spring but summer is almost here at last. The support groups have been as busy as ever offering a lifeline for patients, carers and families living with pulmonary fibrosis, whether meeting online, taking part in training or looking forward to the day we can meet face-to-face again. Along with the groups, a growing network of support includes the volunteer telephone befrienders, wellbeing initiatives and new information, as we all work to ensure that no-one has to face PF alone.

Debra Chand, National Support Manager

Wellbeing sessions for Volunteers and Carers

More than 50 people took part in the zoom 'Spotlight on' sessions this Spring. The wellbeing sessions aimed to boost mood while having fun learning about new hobbies and interests, including the benefits of 'singing for breathing', 'hobbies for health' and 'pets for wellbeing'. The sessions went so well we plan to run more during Volunteers Week and Carers Week in June. Sign up via our website or email us at **support@actionpf.org** for the links to join.

Support Group Leaders Chi Me

When UK PF Support Group Leaders met recently to discuss developments in health, support, and research, they also enjoyed a taster Chi Me exercise session led by Mark Millar from Northern Ireland. Chi Me is influenced by Tai-Chi exercises and theory. You can contact Mark on Facebook **@mmfitandrecover**

Peer Learning Events

In March, Steve Milward (pictured below), lead for Bolton PF Support Group, hosted his second peer learning session for group leaders in the South, following a successful session for the North region.

Steve shared practical advice and tips on what has worked well since the Bolton support group started in 2018. From choice of venue and different formats for meetings, to promoting the group more widely and working in partnership with other agencies and organisations to strengthen the group and increase awareness of pulmonary fibrosis in their region. A big thank you to Steve and congratulations to all the Bolton PF members who celebrated their third support group anniversary recently.

10 Year Celebration for Andrew and Ivy

Andrew and Ivy Learmonth recently celebrated 10 years since Andrew's initial diagnosis of IPF. Ivy writes:

"Ten and a half years ago my husband was diagnosed with IPF. He was told that his life expectancy was about two years, but was asked if he would be willing to go on a Nintedanib drugs trial. At that point there were no drugs for IPF and we felt that Andrew had nothing to lose – if it didn't help him, it may help others.

"Ten years on Andrew still receives the medication free of charge as he was on the trial. We felt that this 10-year milestone was something we wanted to share and celebrate with our friends at Leeds PF Support Group, which we did at our recent Zoom meeting."

Name change for Antrim

The Antrim Area PF Support Group has changed its name to Northern Trust. A competition to design a new logo came up with the winner, selected by a panel of consultants and nursing staff. Tom McMillan in NI writes: "The trees inside the lungs represent the tree names of many of the Northern Trust hospital buildings; trees are also good for the environment. The hands represent the support group members and medical staff all working together to support people with PF."

A boost for Scotland

We have received wonderful news of funding to develop more support groups and initiatives in Scotland, including the potential to appoint a Scotland Coordinator. This is great news and at the time of writing we await the outcome of our application for registration with the Scottish Charity Regulator, OSCR. Watch this space!

Keep up the good work, Tameside!

Huge thanks to our friends in the Tameside PF Support Group who continue to campaign on behalf of patients and raise awareness. During lockdown they lobbied their three local MPs to get them to petition supermarkets to suspend delivery charges for people who were shielding. The reaction from the major supermarkets was mixed but the Tameside group are certainly raising the profile of PF. Looking forward to your next campaign, Tameside!

Nottingham reaches out

The Nottingham PF Support Group – recognising that getting people to come back to face-to-face meeting post-pandemic could be difficult – is turning creative to reach out to those affected by PF in the East Midlands. They have produced a two-sided flyer which the respiratory team at Nottingham University's NHS Trust are giving out to patients and sending out in clinic letters. They include an open invite to Zoom meetings and contact details for new support group leader, Robert Hay. Robert said, "We also have plans to set up our own website in the next few months. We've been inspired by other groups who say many people are self-referring to their groups after finding their websites"

Nottingham Pulmonary Fibrosis Support Group

Pulmonary Fibrosis

Don't face it alone

We offer help, advice and support for patients, carers and family members.

We meet monthly to:

- **support** each other
- **share** ideas and experiences
- **learn** more about how to live well with pulmonary fibrosis

Media Training

Support group leaders and members met for a media training workshop recently. Media specialist and APF team member, Emma Pelling, guided participants on how to engage the media, such as writing letters to the editor or sharing your story to raise awareness about pulmonary fibrosis. This taster session proved popular and we hope to run more events soon. ●

From Pauline Millar to Everyone

Oops brilliant....

Content training - We're on Zoom

A Singing for Breathing Zoom in full swing!

Health Tips: Support Groups are good for your health!

...Says Wai Lam-Richardson, Nurse Specialist for the Long Covid Rehab Service in West Hertfordshire. She set up a PF Patient Support Group at Guy's & St Thomas' Hospital in London when she was an ILD nurse there.

"I really enjoyed meeting families and patients in an informal setting. The clinic is more formal and there is very little time to get to know someone. But in the support group we can talk like real people. Initially they saw me as 'the nurse' – now we're friends.

"Living with the huge burden of symptoms such as breathlessness and cough affects quality of life. You are unable to do the things you used to. This causes stress and can lead to depression, affecting the whole family. Patients feel most upset when their role changes: watching their partner take the wheelie bin out, or not being able to care for their children in the way they used to. They feel they're losing their identity."

> "At one time we had lost several members and many of the group felt very down. Then a new member joined who was very motivated. It's amazing the difference that made. He told us how much better he felt and needed less oxygen when he started going to the gym every day. That boosted morale!"

"When members see another patient doing well, that speaks to them far more than anything I can say in clinic.

"We also take part in singing for lung health. Members love it and there are so many benefits. Patients learn breath control and it takes their mind off their symptoms.

The coach gives a gentle voice warm up and gentle body movements to loosen joints. This is great for anyone who is too frail to have full pulmonary rehabilitation.

"For the future, I'd like to see much more psychological support. Patients can feel stressed by symptoms, sad that they can't do what they used to and uncertain about their future. Meditation and mindfulness, even for ten minutes at the start or end of the meeting, is calming and they can use the technique at home.

"And raising the profile of ILD would really help. Not many people know what 'ILD' means or what an ILD nurse does. I'm a member of the ILD-IN (Interstitial Lung Disease Interdisciplinary Network) committee. The network is helping to raise the profile of PF, and we meet other specialists – occupational and physiotherapists, pharmacists, community nurses etc – and share expertise. We also run a mentorship scheme. We are so much stronger together!" ●

APF Giving Circle – Together we are stronger

“Being part of a support group means you know you’re not on your own.”

Over the past year, APF has increased support for people and families affected by pulmonary fibrosis, helping our community to stay connected and feel supported during the most difficult of times.

APF is needed now more than ever and we plan to continue our fight against PF and grow support further so nobody needs to face this devastating illness alone. If you would like to help us continue to be there for everyone affected by PF, join our Giving Circle by setting up a regular gift to APF. With your help we can:

- ✔ **Increase access to vital information about pulmonary fibrosis, treatments and support**
- ✔ **Grow our services so we can support more people and ensure nobody needs to face this disease alone**
- ✔ **Fund ground-breaking research that we hope will help people live well for longer and find new treatments that could one day lead to a cure**
- ✔ **Campaign for a better tomorrow, making the voices of the pulmonary fibrosis community heard.**

Be a part of our future, and help us create a better tomorrow for everyone affected by pulmonary fibrosis by setting up a regular gift to APF today.

As little as £5 per month will make a huge difference, and we will provide regular updates on how your gifts are making a difference within our community. **https://www.actionpf.org/get-involved/donate**

Sign up and receive your free fundraising pack

Create a Stir this summer for APF!

As restrictions hopefully begin to ease across the country, why not make the most of the warmer weather by Creating a Stir for APF this summer! You could host a garden party with family and friends, or have a socially distanced coffee morning with some friends from your local Support Group, collecting donations from your guests to help support APF’s services, research and campaigns.

Your garden party could be the perfect opportunity to reunite with loved ones and raise money for APF. We’ll make sure you have everything you need to host the perfect party, from balloons, banners, collection boxes and coasters, to straws and drink stirrers! We will also help you keep up to date with government guidance on social distancing so you can host your party safely.

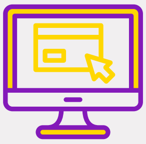
If you are interested in Creating a Stir for APF, please visit www.actionpf.org for your free party pack today. ●

2020 A look back at a challenging year

At the start of 2020 we had amazing plans at APF – developing the thriving support group network, funding patients and carers to attend the first ever Europe-wide IPF Patient Summit in Warsaw and Team APF were limbering up for the Great Manchester Run. Then Covid hit and we were totally focussed on giving our patients, carers and

MARCH 2020

The Coronavirus Hub on our website is regularly updated with useful resources, videos and advice on everything from managing anxiety to keeping physically fit. As government advice and guidelines change the APF Hub is the place to go for all the latest information.



13K

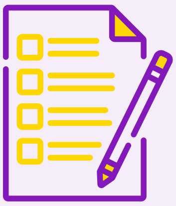
Page views to date, since we set up The Coronavirus Hub on our website

68%

Increase in demand for the APF Support Line in the first three months of lockdown

APRIL 2020

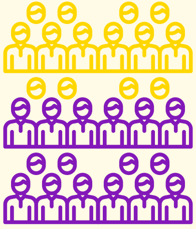
Who can forget when PF patients were missed off the **Shielded Patient List** which gave people with serious conditions specific advice and – amongst other things – access to priority shopping? APF campaigned hard against this injustice and our patients were finally included on the list.



APF campaigned hard with the NHS and government to ensure our patients were finally included on the Shielded Patient List

MAY 2020

Our telephone support volunteers – all with personal experience of PF – provide a listening ear to anyone feeling isolated or anxious.



14+ volunteers have supported over **30+** patients and carers

JUNE 2020

We supported 30 groups as they switched to meeting via Zoom and established two national groups – for carers and those who have had or are waiting for, a lung transplant. The groups helped us develop our shielding lanyards and we helped 50+ support group leaders to network and learn from each other.

We've sent out over 1,600 'APF I'm Shielding' lanyards

AUG 2020

While all this was going on **research** funded through the Mike Bray Fellowship Award continued and resulted in a breakthrough. Changes in three genes that had not been known to be involved with the disease were shown to put some people at higher risk of IPF. APF Research Fellow Dr Richard Allen, said: "These are really exciting discoveries. Hopefully this research will help in the development of treatments which are desperately needed for this devastating disease."

140 webinar attendees

95% who rated the talk, rated it as excellent

families the support they needed. The staff and trustee team shut the office doors and started working from home. Here's a snapshot of what we have been able to achieve during the most challenging year we have ever faced. We – literally – couldn't have done any of this without your continued support – Thank you!

SEPT
2020

Pulmonary Fibrosis Month
We launched a training module for GPs, developed in partnership with the Royal College of General Practitioners, to highlight the clinical signs and symptoms of PF, how to refer for investigations and anti-fibrotic therapies.

We **campaigned for anti-fibrotic drugs** to be prescribed to all IPF patients and over 50 of you wrote to your MP or equivalent government representative across the UK. NICE prioritised a review and we are awaiting their decision.

200+

GPs have completed the state-of-the-art eLearning course

Your fundraising efforts have been inspiring and we supported you with raffles, crafting ideas, Jog on January and a host of virtual challenges.

Patient interviews on ITV and BBC News reached over 15M viewers; Janice Long spoke on eight radio stations about losing her brother Keith Chegwin to IPF and many of you got stories in the press across the UK.

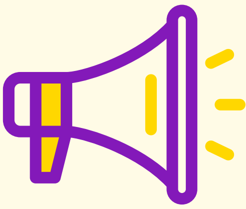
You helped us raise over

£20k

throughout #PFmonth

FEB
2021

We launched the **James Lind Alliance Priority Setting Partnership** and asked patients, carers and health care professionals what questions about PF they want answered by research. The survey will help us identify the Top Ten priorities for researchers.



400+

people have completed the initial survey so far, supported by 8 partners

#EveryVoiceMatters

APRIL
2021

APF Chair Steve Jones is President of the EU-IPFF. The first European Pulmonary Fibrosis Patient Summit was finally held virtually in April and included news on cutting-edge research and new developments in antifibrotic therapies as well as sessions on person-centred care and advocacy.

APF has continued to be at the forefront of PF activity around the world and is one of the founding members of the European Pulmonary Fibrosis Federation

APF Steppers – Where are they now?

During the month of March our community came together to do something amazing. They pledged their steps in a bid to jointly walk the distance of the UK coastline. In total, our steppers covered 3,899 miles and raised an incredible £12,500.

APF Stepper Philip Hart set himself the challenge of walking 60 miles over 28 days and raised a fantastic £3,645.

Philip's PF diagnosis was picked up by a scan when undergoing investigation for a different illness. He recalls, "No one was more surprised than me with the diagnosis. After a period of numbness my wife and I decided to get on with our lives and make the most of it.

> "Through doing the Step Up Challenge, not only have I been able to raise money for a cause that directly supports PF patients, but it's also given me the chance to challenge myself."

With the support of Philip's wife, family and friends, he surpassed his target of 60 miles!

A very big thank you to everyone that took part in Step Up this year. Every step and every penny raised will help us create a better future for people affected by pulmonary fibrosis.

Do it for APF

APF receives no government funding, and we rely solely on the support of our fundraisers, people donating, corporate supporters, and gifts in wills to continue our vital work. We are blown away by the support, dedication, and determination of our supporters. We are so fortunate to have such a committed community with us.

Back in 2019, APF supporter Lesley Culley ran the London Marathon and raised over £3,000 that will help more people feel better informed about their condition and more supported through our services such as the APF Support Line.

"I am incredibly proud and honoured to have raised this in memory of my mum. I know the money will be invaluable in the APF cause and I hope you continue to receive vital support."

If you would like to take part in a challenge for APF, we'd love to hear from you. From local runs, triathlons, Three Peaks hikes or marathons, your fundraising will go a long way in helping us continue our work. ●

Coming up next time

Sukh lost her beloved dad to PF last year. See our next issue to find out how she is supporting APF in his memory through her business.

Retail therapy for a good cause

We know that our supporters are passionate about raising awareness and funds, and now they can do both when buying goods from the APF Store!

We have a range of branded items that you can buy for yourself, or as a gift for a loved one. From t-shirts, tote bags, wristbands, and pin badges, whenever you buy something from our shop you will be helping us make a real difference to the lives of people affected by pulmonary fibrosis. Simply complete the order form below and return it to APF. Happy shopping!” ●

APF Store Order Form

Title First Name Surname

Address

Postcode

Phone Number Email

Please choose from the items listed below:

PIN BADGE £2.50	**TOTE BAG £5**	**WRISTBAND £2.50**
Quantity	Quantity	Quantity

T- SHIRT £10 each: Please circle the size you would like and add the quantity

Small – Quantity Medium – Quantity Large – Quantity X Large – Quantity

TOTAL AMOUNT £

You can pay by either cheque or **bank transfer**. If you would like to pay by BACS, please send payment to:
Account name: Action for Pulmonary Fibrosis
Account Number: 00023412 Sort Code: 40-52-40
Please reference APF Store when making the payment.

If you would like to pay by **cheque** please make paymrents to **Action for Pulmonary Fibrosis**.

Please return this form to: Action for Pulmonary Fibrosis, Stuart House, East Wing, St John’s Street, Peterborough, PE1 5DD. Orders will be sent out between 5-10 working days.

Living with pulmonary fibrosis – Robert's story

Coping with a diagnosis of IPF is bad enough at any time. But to get that news during the year of Covid must have been impossibly difficult. Robert Hay had been having symptoms since late 2018 but only received a confirmed diagnosis in Spring 2020. He describes it as an 'epic trek to diagnosis...not epic good but epic dreadful'.

"Isn't the Internet a wonderful thing? From it I had been able to prepare a whole raft of questions to ask my respiratory consultant who had suspected that I had PF. It was time wasted because when he confirmed the suspicion, I was suddenly in denial. My wife and I had talked about this and I thought I was prepared to hear what I was being told but that wasn't the case, I was stunned into shock. I declined into a fog of disbelief, hoping a coat of the stoic, stiff-upper lip, happy-go-lucky attitude would disguise this. Finally, 'the letter' arrived, confirming the diagnosis in black and white.

"The two pieces of information I found so difficult to come to terms with – no cure and a life expectancy of three to five years – still kept me awake at night. In one of my 'black dog' moments, I found a leaflet about Action for Pulmonary Fibrosis. I decided to contact the APF Support Line and spoke with respiratory nurse Lucy. The conversation with Lucy managed to lift me out of the doldrums. There actually was light at the end of the tunnel! Admittedly, the light was probably the Grim Reaper's lamp but, hey, with some support and self-help, that tunnel could be as long as I chose to make it. And there was plenty of living evidence out there to back up that theory. My tunnel extension is now a continuing 'work-in-progress.'

"As an ex-military man, I understand the benefits of regular exercise. With that in mind and cribbing some exercises online I began to include them in my daily routine. Episodes of breathlessness and the chronic coughing increased and made it hard work. However, a quotation from my basic military training in 1966, reinforced my determination.

"In the words of Norwegian explorer, Fridtjof Nansen: 'Never give up because you're scared; you are never more likely to be wrong. The difficult takes a little time; the impossible is what takes a little longer.'

"With that, I continued exercising and slowly began to get fit. I even did the APF Go the Distance challenge in September 2020 exceeding my target of 180 miles by 40 miles.

"In January this year I started an online pulmonary rehabilitation class, some 18 months after being referred and told that there was a very long waiting list. I've now completed the course and continue with my exercise regime.

"Whilst I get fitter, episodes of breathlessness have declined but the incessant cough still plagues me. I am passionate about exercise, though, and really believe that it is having a positive impact on my health.

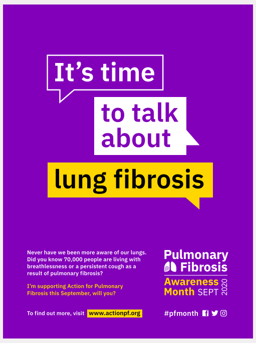
"Another key moment during my first year of diagnosis was being offered anti-fibrotic drugs. After looking on the Internet and chatting to people, I chose Nintedanib. The first month's supply arrived in October 2020 and six months later I have as yet suffered no ill-effects. Whether or not they're working I shan't find out until my consultant reviews the results of my next lung function test.

"I am now actively doing what I can to raise awareness and funds and I get involved with APF's campaigns. I am also the new leader of the Nottingham PF Support Group. Wendy Dickinson, APF founding member and trustee – a lovely lady with a very 'persuasive' way – contacted me and during our conversation talked me into taking on the group leader role.

"Fortunately, this month we begin planning our first post lockdown, face-to-face meeting. I am looking forward to finally meeting the members of the group, some of whom I only know from our Facebook group and chats on Zoom. What a year it has been!" ●

If it sounds like Velcro pulling apart... it could be pulmonary fibrosis

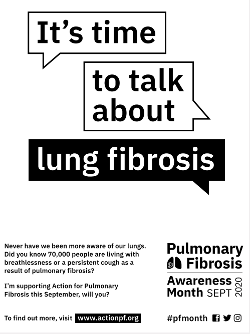
"I wish my GP had known more about my disease," is a regular comment made by patients with pulmonary fibrosis.



Never have we been more aware of our lungs. Did you know 70,000 people are living with breathlessness or a persistent cough as a result of pulmonary fibrosis?

I'm supporting Action for Pulmonary Fibrosis this September, will you?

To find out more, visit www.actionpf.org



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We know that PF can be hard to diagnose, with many GPs confusing the symptoms with asthma or COPD. In fact, our patient survey revealed that more than a third of people are misdiagnosed while almost half are still not diagnosed within six months of visiting their GP.

We want to change this and we need your help.

APF and the Royal College of GPs (RCGP) have developed a free training module to help medical staff in primary care spot the signs and symptoms of progressive lung fibrosis. This e-learning course is particularly relevant given the challenges of seeing patients face-to-face during the pandemic.

As most PF patients know, the distinctive Velcro-like crackles that can be heard when a doctor listens to your chest is one of the signs of the disease. This and other key symptoms of PF that GPs should look out for are on the eye-catching postcard you'll find in this issue. It also pulls apart to make that distinctive Velcro sound.

We're calling on everyone affected by PF to deliver these postcards to their GP surgery. The card encourages GPs to access the RCGP course (which is free to anyone who registers on their website) so they can more easily recognise the early signs of the disease. A poster is also available to download from our website.

Please do contact **info@actionpf.org** if you'd like more postcards delivered to you. We'd also love to hear from you if you've made contact with your GP surgery. Thank you!

Scientists identify gene variation linked to IPF

Knowing more about the genetics of pulmonary fibrosis helps increase our understanding of what causes it, who may be susceptible and how it progresses, meaning better management and treatment of the disease.

AstraZeneca recently led a research project which identified a variant in the SPDL1 gene that increases the risk of IPF. Our APF-funded Mike Bray Fellows, Dr Phil Molyneaux and Dr Richard Allen and APF Trustee Professor Gisli Jenkins were also part of this exciting project.

Prof Gisli Jenkins

Differences or variations within a single gene can lead to changes in the way our bodies work. Some diseases are caused by a single genetic variant. However, the genetics of many diseases, including PF, are far more complex. For example, variations within a gene, how different genes work together and our environment can all affect what actually happens to our bodies.

Dr Richard Allen

We know several genetic variants can increase an individual's risk of IPF, but the cause of the disease remains unknown for most patients. The newly identified variant in SPDL1 is important because we did not know that this gene might have a role to play in IPF. Analysis indicated that the genetic variant is rare, but significantly more common in IPF patients – 2.2% compared to 0.78% in those without this diagnosis. SPDL1 is involved in cell replication and this indicates a possible new pathway to disease, with treatments specifically developed to target its function.

Researchers highlight need for wider antifibrotic treatment

In the UK, only patients diagnosed with Idiopathic Pulmonary Fibrosis can be prescribed antifibrotic drugs. However, there are several other scarring lung diseases which behave in an almost identical way to IPF. In 2019, a group of scientists provided evidence that patients with Progressive Fibrotic Interstitial Lung Diseases (PF-ILD) could be effectively treated with Nintedanib. This research has paved the way for NICE to consider whether Nintedanib should be licensed for use for patients diagnosed with other progressive fibrotic ILDs such as those caused by rheumatoid arthritis or chronic hypersensitivity pneumonitis. APF is part of this important process and NICE's final decision is due in September 2021.

Dr Phil Molyneaux

APF Fellow, Dr Philip Molyneaux, has recently published work in the European Respiratory Journal, emphasising the need for increased access to antifibrotic treatment and providing evidence of the number of people who could benefit if NICE changed the licensing guidelines.

"We screened the records of over 2000 patients and established that 14% of all the new referrals seen over the period we studied would have been eligible for antifibrotic therapy. More importantly the survival of patients with PF-ILD was no different to the subjects with IPF highlighting the urgent need for antifibrotics therapy to be more widely accessible." ●

Talking PF: free Zoom sessions about life, lungs and staying strong

If you live with PF as a patient or carer, you might be interested in our free, new online talks. Talking PF meetings are a collaboration between Action for Pulmonary Fibrosis and pharmaceutical company Boehringer Ingelheim Limited. Held on Zoom between May and July, Talking PF will be a series of free live sessions covering key issues, with advice to help you live better with PF.

Each session will cover a different subject, including: strategies to help you live well; advice for carers, from carers; pulmonary rehab; and oxygen therapy. After each talk, there will be a live Q&A session where you can put questions to our speakers – who will include doctors, nurses, carers and patients.

Our next Talking PF session kicks off on 26th May with 'Surviving or thriving: how to live well with PF'. To listen to this, and any of our other talks, simply enter the web addresses of the sessions you'd like to attend into your internet browser and register.

Talking PF

Mini talks and
live Q&As about
lungs, life and
keeping strong

Surviving or thriving: how to live well with PF 26th May, 8pm

To register for this free talk, go to this web address:

Bit.ly/talkingpf-2

Personal experiences of caring for loved ones with PF
9th June, 8pm

To register for this free talk, go to this web address:

Bit.ly/talkingpf-3

Pulmonary Rehab: exercise therapy explained
23rd June, 8pm

To register for this free talk, go to this web address:

Bit.ly/talkingpf-4

Oxygen Therapy: your questions answered 7th July, 8pm

To register for this free talk, go to this web address:

Bit.ly/talkingpf-5

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Talking PF meetings are a collaboration between Action for Pulmonary Fibrosis and Boehringer Ingelheim Limited. Boehringer Ingelheim Limited provided funding and support, with organisation and project management in line with the ABPI Code of Practice.

APF Trustee passionate about improving timely diagnosis

Increasing knowledge and awareness of pulmonary fibrosis within the medical community is a key aim for us at APF. Which is why APF trustee Howard Almond, organiser of the Plymouth PF Support Group, has been getting down with the students in the south-west during the year of lockdown. Howard, and other members of the support group, talked about PF from the patient's point of view to medical students at the Plymouth University Peninsula Medical School. Howard is also involved in education projects at the University of Exeter Medical School where he, a consultant, the lead of the PF research team and a respiratory specialist nurse talk to students about PF from their different perspectives.

"We normally have around 40 first year students taking part in the live sessions on campus. This year, on-line, we had 170, with a lot of good questions for all of us. They were a very engaged group – destined to move on to be scientists, researchers or doctors," explained Howard.

At the University there is also a Nursing Academy, running MSc courses in nursing. Howard was invited to join the patient participation group which gets involved in all aspects of the Academy – including interviewing new staff, student exams and curriculum decisions. He will also be running a class on IPF with one of the lecturers.

"It's been great to fulfil my desire to educate as many medical staff as possible on ILD." ●

Action for Pulmonary Fibrosis

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Staying in touch with Action for Pulmonary Fibrosis

We would like to keep in touch with the information you want to receive, in the way you prefer.
Please tick the boxes to let us know what updates you would like to receive and how:

☐ APF Newsletter including news on the latest research, support for you or a loved one and fundraising

☐ Updates on fundraising events you can get involved with

☐ Campaigning information and how you can get involved

☐ Information on ways to donate to APF

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