

# APF Insider

Support — Research — Educate — Campaign

How to get  
the most out  
of remote  
consultations  
See page 9



## We'll meet again

Derby PF Support Group were thrilled to finally meet face to face in September. Our picture shows Group member Margaret Johnson with her APF tote bag.

**See page 4 for more support group news.**

**Head to page 3** for great news from Chair Steve Jones about NICE: "It's a proud moment for us at APF who have campaigned actively for the past five years..."



[www.actionpf.org](http://www.actionpf.org)



Support line  
**01223 785725**

# Who we are and what we do

## A message from our CEO



**At APF, we understand more than anyone the mix of feelings we have as we approach our third Christmas shadowed by Covid-19. But in this issue we wanted to focus on the opportunities and possibilities that will change people's lives for the better.**

Steve covers our important work with NICE, so that more people have access to anti-fibrotics. We focus on research and show how taking part in a trial can lead to improved health for people with IPF. We lift the lid on the unseen burden of living with PF; sharing experiences on cough and showcasing how a specialist pharmacist can help manage debilitating symptoms. Mostly, we wanted to show a glimpse of what your amazing fundraising and support through our toughest year yet has helped deliver. Thank you.

**Louise Wright**  
Chief Executive

## Could you be our one in 20 million?

Volunteering in the UK has a long and inspiring history. 20 million adults volunteer every year and APF wants to invite you to be part of this very special group.

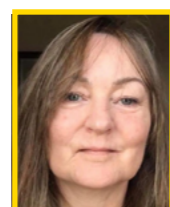
Could you join our growing team of APF Befrienders? They are people who have lived experience of pulmonary fibrosis - either as patients, carers or family members. You will support others affected by PF via telephone and will receive on-going training and support which will include guidance on the boundaries of the role, how to conduct calls and safeguarding. You will be supported by the APF team and matched with a peer buddy.

**Your support could be life-changing for a patient or carer: your volunteering could be life-changing for you as you learn new skills and take immense satisfaction from helping someone.**

If you could commit to volunteering with us for one to four hours a week for a minimum of three to four months, please get in touch to find out more. We'd love to hear from you!

Contact [Annabel@actionpf.org](mailto:Annabel@actionpf.org) or call **07949 454351**

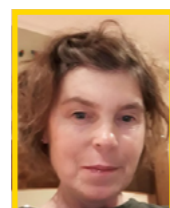
**Dawn** currently has Susan as her befriender and says:



**"She is still a link for me between my world and everything going on outside as I still have limited access to my circle of friends and family.**

**She is a fantastic listener. She is very empathetic to the struggles I face daily."**

**Susan**, who has PF became an APF Volunteer Befriender and was matched with Dawn:



**"Dawn is around my age and, like me, she is a potential future lung transplant candidate. She lives alone, is dependent on oxygen and**

**looks forward to our Tuesday calls. She tells me her worries and her plans for the future. I enjoy our calls."**

# Message from our Chair



**It's a proud moment for us at APF who have campaigned actively for the past five years so that UK doctors will soon be able to prescribe the antifibrotic drug, Nintedanib for people living with non-IPF pulmonary fibrosis.**

**The Scottish Medicines Consortium (SMC) approved the new treatment in July and we are delighted that NICE has now followed suit. This will make possible a real step-change in treatment for the 15,000 people living with pulmonary fibrosis associated with rheumatoid arthritis and sarcoidosis; and those with chronic sensitivity pneumonitis (for example, farmer's lung, bird keeper's lung), asbestosis and other conditions.**

Currently, patients with non-IPF pulmonary fibrosis are given a range of treatments including steroids and immune suppression. While these drugs help some patients, the side effects can be serious and many patients choose to give up treatment. Nintedanib has been proved in a clinical trial and offers doctors another treatment they can use to slow down disease progression and hopefully extend life. We are delighted this will now be available to patients.

But, while this is good news, the fight is not over. APF is working hard to persuade NICE to change its rules so that ALL IPF patients can receive antifibrotic treatment (Pirfenidone or Nintedanib) when they need it. Currently roughly half of IPF patients (those newly diagnosed with a lung function over 80% and those under 50%) are denied treatment. This must stop.

Why should a newly diagnosed patient have to wait until their lung function deteriorates to 80%, before being given antifibrotics? You wouldn't tell a cancer patient their tumour is too small and they should come back for treatment after they've got worse! So why are IPF patients treated this way?

APF thinks the current rules are grossly unfair. Doctors should be able to give antifibrotic medicines to IPF patients as soon as they are diagnosed, as in every other Western country.

Following APF's energetic 2020 campaign in which over 50 MPs sent letters to NICE and the government, NICE finally announced in May 2021 that it would review its rules which deny thousands of IPF patients access to antifibrotics they need.

Although NICE still has to give a start date for the review, we think the case is strong. We are hopeful that these restrictions on IPF patients will soon be a thing of the past and ALL pulmonary fibrosis patients in the UK will have access to antifibrotic medicines when they need them.

## Here to help

Visit our website and Coronavirus Hub:

[www.actionpf.org](http://www.actionpf.org)

Speak to our Support Team:

[support@actionpf.org](mailto:support@actionpf.org)

Call our Support Line: **01223 785725**

Call our Support Line Volunteer

Befrienders: **01223 785725**

 [www.actionpf.org](http://www.actionpf.org)



**Steve Jones**

# Support Group round up

## Launches, relaunches and first face-to-face meetings have all been happening over the summer.

**Northamptonshire PF Support Group** members enjoyed their first face-to-face meeting in 11 months on 27 July.

The group moved to a different part of their venue at the Centre in Mawsley for their meeting. This was self-contained from the rest of the building, with its own entrance and fire exit which could be left open, and more space to enable adequate social distancing.

Members had a long awaited catch up with each other and Jo Ruck, Regional Support Coordinator (North) attended the meeting to give an update from APF for the members.

Richard Hanna, one of the support group members presented her with a donation cheque for a fantastic £625. Richard is a member of the Catenian Association Circle No 35. Northampton, and the Association picked APF as one of their chosen charities during lockdown to raise funds for. Many thanks to Richard and the Catenian Association for their kind and generous donation.



Richard presents the donation cheque to Jo Ruck

The first meeting of the **Forth Valley Patient Support Group** took place in June 2021, thanks to the hard work of local Specialist Respiratory Nurses and APF Chair Steve Jones. Steve talked to the group about the work of APF, and they agreed to meet on the last Monday of each month. So far, they have had meetings with specialist speakers on 'Managing Breathlessness' and 'Managing Medications'. Future meetings include Managing Symptoms, Understanding Lung Function Tests, and Developments in Treatments. They also hold mutual support meetings. Members say the Group is a great way to connect with healthcare professionals outside of the normal clinical setting, and to talk with others going through the same illness.

As one member said,

*"I love it. We have good discussions, discover things we didn't know, and find new friends who understand what we're all going through."*

Support group members in the Southampton and Portsmouth areas met by Zoom for the **Wessex ILD Group** (WILD) relaunch. Facilitated by Research Fellow Tim Wallis, and Health Psychologist Judit Varkonyi-Sepp, the group had plenty to discuss in their breakout rooms, and appreciated Dr Sophie Fletcher's clinical overview of ILD, Tim's overview of Wessex ILD research, and APF Research Champion Jeff Taylor-Jackson's hopes for more people to get involved and work together in clinical trials:

*"Without patients, trials can't go ahead and without the trials, we won't get new treatments and progress."*

Discover more about the group at [www.wildsupport.co.uk](http://www.wildsupport.co.uk) or contact [ILDclinical@uhs.nhs.uk](mailto:ILDclinical@uhs.nhs.uk)



The **Derby PF Support Group** have met monthly online throughout the pandemic to help keep members in touch and feeling supported. In June, members were thrilled to learn the news of the first ILD Specialist Nurse appointment for University Hospitals of Derby and Burton NHS Foundation Trust – a warm welcome to Lise-Anne Grundy who has joined Dr Srividya Narayan, Dr Rob Berg (ILD Consultants) and Emma Toplis (Advanced Clinical Practitioner Respiratory) in the ILD team.

The group had planned an outdoor picnic as their first face to face meet up in August but sadly this had to be cancelled due to the weather. However, on 2 September the group managed a long awaited first meeting back at the Mickleover Golf Club, which lifted everyone's spirits and was enjoyed by all.

There was a special presentation for Doreen Goodes as retiring Chair – a thank you for all her hard work and support as group Chair over the last few years.

Members enjoyed catching up in person, sharing stories and experiences, and discussing plans for the group going forward. A small patient consortium group was elected by members, who will support the day to day running of the group, facilitated by the hospital ILD team going forward. There were lots of exciting ideas discussed for future topics, speakers and social activities and the group is hoping for less challenging times ahead to be able to explore these plans further and put them into action.



Doreen Goodes being presented with a 'Thank You' bouquet, as retiring Chair of Derby PF Support Group, from Margaret Beasley

## New Carers Support Group

What started as an APF focus group has now developed into a full PF Carers Support Group! Run by and for carers, the group meet online monthly to support each other and share experience on ways to make life better for you and the person you are supporting. Former carer Wendy Jones, whose mum had PF, is helping to facilitate the group and said:

*"Carers have a vital role but caring can feel a lonely place. This group is open to all PF carers – you are not alone, we are there for you."*



Wendy pictured with her mother Diana and son Ben

For further information and the meeting link contact [support@actionpf.org](mailto:support@actionpf.org) or phone **01223 785 725**.

# Research update

Every minute of every day there are people around the world carrying out pulmonary fibrosis research. And this research is changing lives.

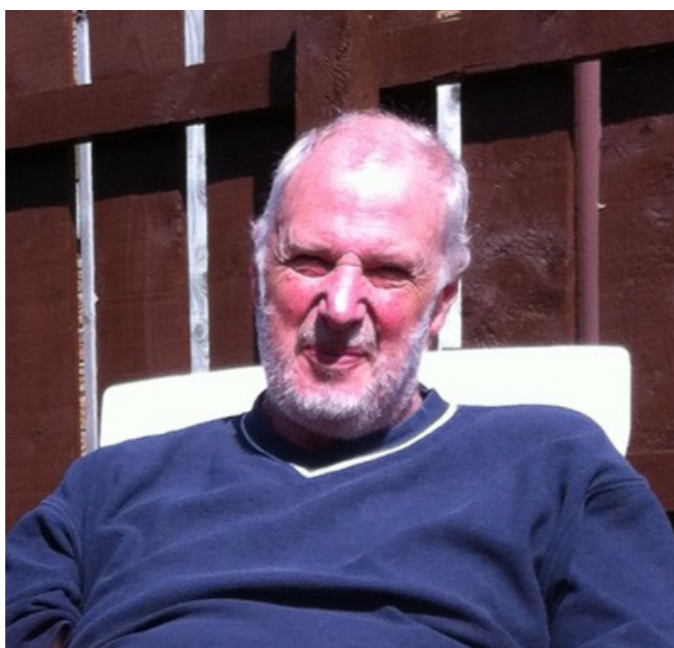
**When Andrew Learmonth was diagnosed with idiopathic pulmonary fibrosis, he was given a two-year life expectancy.** In 2010, the opportunity arose for him to take part in a clinical trial testing whether a new drug could help slow the progression of the disease. That drug turned out to be Nintedanib, one of only two antifibrotic medications now available to be prescribed to eligible patients with idiopathic pulmonary fibrosis.

This fantastic outcome was the result of years of work and millions of pounds of investment. But the question remained, could this drug also help people with other forms of pulmonary fibrosis? Scientists, clinicians and patients began investing time in answering this question. And the evidence shows that it does.

**In October this year, NICE agreed that Nintedanib could be prescribed to all patients with progressive fibrosing ILD.**

Andrew, who was in the original clinical trial, said **“I feel everyone who is diagnosed with pulmonary fibrosis should be offered Nintedanib. It has prolonged my life and quality of life.”**

APF are proud to have been part of the campaign to make this change happen and we're so grateful to everyone who was part of this process. However, we know this news has not come soon enough for many. There is much more to be done. Slowing the progression of the disease is not enough, we want to stop it in its tracks.



Andrew Learmonth

## What do we do at APF to champion research?

At APF we're passionate about research. Through research we generate new knowledge, ideas and understanding that will improve the way we diagnose, monitor and treat PF.

- We directly fund cutting-edge pulmonary fibrosis research
- We enable researchers to raise awareness of pulmonary fibrosis and develop their careers by sharing their research around the world
- We work alongside researchers to bring the patient voice to research
- We support researchers to share opportunities to take part in research with you.



## So how can you get involved in research?

- You can share your views and lived experience of PF with researchers to help them to develop better quality research that is important and relevant to the PF community. This patient and public involvement is a hugely valuable part of the research process.
- Taking part in research doesn't just mean testing a new drug. You could be a participant in a study that may involve completing a survey. Our partnership with the James Lind Alliance is moving into its next stage and we'd love to have input from everyone in the PF community in our next survey in early 2022.
- Getting involved could be as simple as spending a few minutes reading about research or taking part in a webinar.
- If you'd like to get involved you can speak to your clinical team about opportunities that might be available or contact APF for more information.

## What does the future look like?

- The COVID pandemic has led to some novel ways of working that have sped up the research process.
- In the past year patients have had access to technologies and treatments far more quickly than ever before, and this innovation will benefit the PF community.
- The number of clinical trials in the last 10 years has increased, and this trend looks set to continue with more potential treatments in the pipeline.
- Alongside you, APF is dedicated to accelerating change. There is more work to be done, but together, we will create a better future for everyone affected by PF.

**Pepe Gonzalez is one of many people who champion PF research. Here he talks about his motivations for getting involved.**

## What made you get involved in research?

I think the key moment was when I found out there's no cure for my diagnosis. When I was diagnosed with IPF it was a huge shock for me and my family. I felt compelled to do something to make the situation better, not just for me, but for other patients so nobody has to go through this situation in the future.

## What motivates you to get involved in research?

I am a strong believer that research is key to finding a cure and better medications to improve the quality of life and care of patients. Being involved in research has also helped me to improve my understanding of my condition and how to live my life in a way that helps me to deal with better with the symptoms of IPF.

## What have you done to get involved in research?

I have volunteered to take part in various study projects and new drug trials to help research into IPF. Some of these are simple procedures involving completing research questionnaires while others required physical exercises and/or taking medication, always under the guidance of medical staff. I feel that most patients could and should take part and support research.

## How does it make you feel being involved?

It makes me feel that, although no cure has been found so far, through research there has been progress and doctors have gained a huge amount of knowledge. Being involved in research makes me feel that I am helping, not just myself, but also others in the fight against this awful disease.

I am full of admiration for patients taking part and medical staff working in research and I am looking forward to the day when IPF is no longer a terminal disease.



Pepe Gonzalez

## Be a part of the change – donate towards research today.

We have already made great strides in pulmonary fibrosis research, but it will cost over £1 million to fund our ambitious plans to help find new research and strengthen our chances of finding a cure.

If you would like to take action and help us in our mission to find a cure to pulmonary fibrosis, please donate towards our Hope for All Research Appeal today.

To make a donation please visit [www.actionpf.org/get-involved/donate/hope-for-all](https://www.actionpf.org/get-involved/donate/hope-for-all) or complete the form below and return with your cheque made out to Action for Pulmonary Fibrosis, to 'freepost ACTION FOR PULMONARY FIBROSIS'.

Name:

Address:

Postcode:

Email:

Phone:

**Boost your donation by 25p of Gift Aid for every £1 you donate.** Gift Aid is reclaimed by APF from the tax you pay for the current tax year.

I want to Gift Aid all my donations to Action for Pulmonary Fibrosis. I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax in the current tax year than the amount of Gift Aid claimed it is my responsibility to pay any difference.

Please notify APF if you want to cancel this declaration, change your name or address or no longer pay sufficient tax. If you pay income tax at the higher or additional rate and want to receive the additional tax relief due to you, you must include all your Gift Aid donations on your Self-Assessment tax return or ask HMRC to adjust your tax code.

## It's beginning to look a lot like Christmas!

You asked and we listened! Back by popular demand for Christmas 2021, we are selling charity Christmas Cards via our online shop. Pop over to our website and stock up on your stocking fillers. We have a range of fantastic merchandise your friends and family will love unwrapping on Christmas morning. Show your support for APF with our official clothing and gifts. All profits from sales will go directly to our charity's work. <https://www.actionpf.org/get-involved/resources-and-merchandise>

### Light a candle for loved ones

Christmas is a special time of year to spend with loved ones or reflect and remember those who are no longer with us. Action for Pulmonary Fibrosis will continue to be on hand to offer support throughout the festive season so no-one needs to feel alone. We'd love you to join us as we take a moment of reflection to remember our loved ones over the festive period by lighting an APF memorial candle. Our lovely glass snowflake-shaped tealight candle holders will be available to purchase for £7.95 (incl. P&P) on our online shop. Look out for more details coming soon. <https://www.actionpf.org/get-involved/resources-and-merchandise>



### Remember your loved ones through our remembrance event this December

This December we invite you to join us to remember our loved ones through our online remembrance event on Tuesday 14th December. The event will be held on our Facebook page and will be an opportunity to reflect, cherish memories and remember loved ones. We will share readings and invite you to join us in lighting a candle and holding a minute's silence together to remember those we have loved and lost.



## Health Tips



This issue we're putting the focus on how to get the very best out of your remote consultations. We also know that winter can be challenging for people with PF, so Respiratory Nurse Nancy Howard shares her advice on how to stay well.



### Remote consultations

Face to face consultations have become rare during the pandemic, and remote consultations are continuing for many of us. Here are some suggestions to make sure you make the most of your time with your doctor or consultant.

- Find somewhere quiet and private to take the call
- Keep questions short and fact based
- Put down what you want to say in writing before you start so you don't forget anything
- Think about having a friend with you, or preparing your questions with someone beforehand
- As getting an appointment with your GP can be harder these days, you might want to take advantage of tools such as eConsult [www.econsult.net/nhs-patients](https://www.econsult.net/nhs-patients) It's free for NHS patients, and enables you to ask your surgery about health symptoms, conditions or treatment. The GP/health team gets your question in writing, which gives them time to do some research before answering.

For more hints and tips, go to the advice and information section at [www.healthwatch.co.uk](https://www.healthwatch.co.uk) and search for 'virtual'.

### Coping with the cold

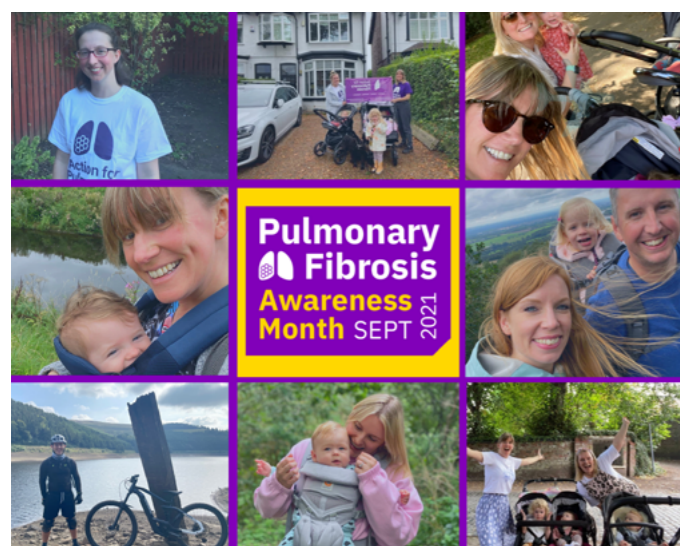
- Eat little and often throughout the day. Missing meals will only contribute to feelings of lethargy and tiredness. Don't wait to feel hungry before you eat, or thirsty before you drink.
- Getting enough exercise is a challenge, so be creative! Use the adverts on television or a particular time on the clock to remind you to stand up and move. Don't allow your partner or carer to prepare all the food and drinks, try to do what you can to keep active.
- Wearing layers of clothing are best for keeping warm as they trap warm air and keep it close to your body. Invest in hot water bottles, blankets, socks or shawls and ideally keep your house and your bedroom above 18°C consistently.
- If you are on oxygen don't leave spare nasal cannulas in the car overnight as the plastic can split with the cold.
- Keep a thermometer at home. If you are feeling unwell with increased breathlessness, cough, high temperature, or flu-like symptoms call your GP immediately. If your lips are tinged blue where they would normally be pink and breathing is harder than normal phone 111. You know your condition better than anyone. If you feel you have deteriorated suddenly, phone 999. That's what they are here for.

You can find more advice on our website at [www.actionpf.org/information-support/coping-with-cold-weather](https://www.actionpf.org/information-support/coping-with-cold-weather)

# Fundraising in the community

## Pulmonary Fibrosis Awareness Month

During September, we really did live up to our motto **‘Together we are stronger’** as supporters across the UK came together to Go the Distance and Create a Stir to raise funds and awareness for this little-known disease. So far, our supporters and sponsors have **raised an incredible £25,000** and the money is still coming in.



## Thanks to our sponsors

We would like to thank all of our PF Month fundraisers and sponsors. The funds you have raised will help us to create new support groups, train telephone befrienders, continue our support line and fund vital research into this little-known disease.

Special thanks to the sponsors below for their generous contributions to PF Month 2021.

**trevi**  
THERAPEUTICS



## Going the Distance for Graham

**Laura Heslin lost her beloved dad Graham to PF in July 2020. During this difficult time, friends and family came together to donate in memory of Graham and raised an incredible £2,690.**

When Graham was diagnosed, he wanted to help researchers understand his condition better and was involved in clinical research trials. Graham's family continue to fulfil his legacy by raising vital funds for APF. Graham felt frustrated that there was no cure for the disease when he had so much determination to fight for his life, and he wanted to push to help change that for future PF patients.

This September a group of Graham's family, including his two daughters Laura and Sarah, son-in-laws Marcus and Oliver, and nieces Annie and Becky have all taken up a 64 mile challenge each in his memory. A mile to mark each year of his life.

The challenge has been emotional for them all, with each mile for Graham resonating hard, but the family feel passionate about raising awareness and funding for APF. Graham's family wanted to raise awareness of the disease as they don't feel that PF is given the funding that it deserves and needs.

The family also lost Graham's mother, May, to PF and have close friends and relatives touched by this horrible disease, making the campaign even more important to them! They have learnt along the way that although PF touches so many, it is still widely unknown to most people.

They are proud to have raised money for APF and hopefully opened the eyes of many about the devastating disease Pulmonary Fibrosis.

## Never stop talking

Clive and Sue met at Ashton under Lyne Fire Station in 1993 when Sue started work as a cleaner there. He attended many incidents, including fires, road accidents, and some strange rescues involving cows, horses and people - not necessarily at the same time! Some were horrific, some very sad, but some were also quite funny.

He would do it all again if he was capable, but Clive was diagnosed with PF in late 2009. As his health deteriorated he was referred to Wythenshawe Hospital in 2016, and placed under the care of the wonderful Dr Nazia Chaudhuri and her team. They started the **Tameside PF Support Group** in 2018.

**“We decided back in 2017/18 that we would only get through this if we did it together. It was going to affect us both - in different ways - so to go through it together might make it a bit more bearable.**

“If you are lucky to have someone who you live with, or family who understand, then it's important to let them know how difficult things might feel for you. Get the information and support to help you cope with each day.

“If you are not able to talk to a loved one for whatever reason, then find a Support Group or reach out to APF. It is a place where people are going through what you are going through, a place where people understand. You don't have to explain anything, because they already know, and they know how to support and help you.

“It's sometimes hard to think of the upsides of life with PF but one has to be meeting amazing people, and the friends we have made. We try to remain as positive as we can, even though some days can be very difficult. On those days we cry together, we hug, but most importantly, we talk.

**“Our personal hopes are just to get through each day together, and deal with whatever is thrown at us, but above all to enjoy our lives together, and keep talking.”**



Clive & Sue's 20th Wedding Anniversary



Clive & Sue in the early days

## Focus on cough for PF Month

Most pulmonary fibrosis patients suffer from a persistent and uncontrollable cough at some point on their journey. We ran a survey to get your views and received some startling results.

Over half (57%) say their cough affects them every day with 50% worrying they can't breathe. Despite this, 70% say their biggest concern is the reaction and judgement of others, particularly in light of Covid. But we know a PF cough can't be controlled and isn't contagious.

Our live 'Clearing the Air about Cough' webinar, chaired by Steve Jones, took place on the last day of PF Month with leading cough expert and Consultant Respiratory Physician Professor Surinder Biring and patient Liz Robertson. We were overwhelmed with your response. Over 225 took part in the webinar. If you'd like to access it, head over to our YouTube channel.

# Role of pharmacists



**Around a third of patients feel they're not well-informed about their disease and treatment options. Specialist pharmacists are perfectly placed to advise patients, helping to identify the symptoms and management of pulmonary fibrosis.**

**The National Interstitial Lung Disease Pharmacist Network** was set up in 2019 to bring together specialist ILD pharmacists and respiratory pharmacists with a role or interest in managing patients with pulmonary fibrosis. All the specialist ILD centres across the country are represented in the network.



**Marium Naqvi**, Specialist ILD Pharmacist at Guy's and St Thomas' NHS Trust and Chair of the National ILD Pharmacist Network, talks about how pharmacists can help...

## What's the aim of the Pharmacist Network?

The ultimate aim is to share best practice across the UK and improve services for all pulmonary fibrosis patients. It focuses on really strengthening the role of the pharmacist in ILD care. This includes designing pharmacy standards and sharing information among pharmacists on new developments. The pharmacists also support research in ILD – there are a number of projects in the pipeline.

## How can pharmacists support patients?

Pharmacists working in specialist centres can support patients in a variety of ways including; treatment options, advice on preventing and managing potential side effects of medicines, and overseeing the prescribing and supply of medicines.

The pharmacist may also undertake a personalised medicine review to check for interactions, optimise prescribed medicines, and de-prescribe inappropriate medicines.

Although non-specialist pharmacists are not usually directly involved in managing ILD patients, they have a key role to play in referring patients for investigation if they present with breathlessness, dry persistent cough or other symptoms of ILD.

They may also be asked for advice and support on other prescribed medicines, to check for drug interactions with newly prescribed medicines or potential side effects.

The role of the pharmacist has changed since the pandemic. Many now consult patients remotely via video or telephone, with patients using home monitoring devices, such as spirometers and oximeters. In some cases remote monitoring portals, like patientMpower, are used to improve patient care.

Pulmonary fibrosis patients often have complex requirements and pharmacists are well placed to support multidisciplinary teams offering integrated and local care. Sharing care with local teams and including a pharmacist in the patient pathway ensures the most appropriate skills and knowledge are used to provide the best outcomes for patients. Do ask your pharmacist for advice!

Follow us on Twitter **@ILDpharmacy** for updates on our network, pharmacy standards and research.



**Action for  
Pulmonary Fibrosis**

**General enquiries:**

01733 475642

info@actionpf.org

Action for Pulmonary Fibrosis  
Stuart House, St John's Street,  
Peterborough PE1 5DD

[www.actionpf.org](http://www.actionpf.org)



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Registered Charity SC050992 in Scotland



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