Action for
Pulmonary Fibrosis

Hello, I'm Jo, and as a specialist nurse at Action for Pulmonary Fibrosis, I'm privileged to speak to many of you on our Support Line every day. Today, I'm asking if you would consider making a donation to ensure that we can continue to answer calls from everyone affected by pulmonary fibrosis.

Our Support Line is open all year, including throughout the festive period, to answer questions and provide emotional support during what can be an isolating time of year for people living with pulmonary fibrosis. As the nights grow longer and getting outside feels tougher than ever, our nurse-led support can offer a lifeline for many. Just one call could make someone's journey with this difficult condition a little more comfortable.

Demand for our Support Line has increased by over 30% this year. This means we have answered the phone to over 3,000 people who turned to Action for Pulmonary Fibrosis following their diagnosis. Enquiries vary in topic, from how to manage symptoms like breathlessness and coughing, to information on medication, oxygen and benefits. Our Support Line is open to everyone - whether you are living with pulmonary fibrosis or you have a family member or friend with the condition.

> “I can't begin to express how grateful my family and I are for the incredible support we've received from APF's nurses on the Support Line. At a time when my father's pulmonary fibrosis diagnosis left us feeling overwhelmed and uncertain, they stepped in with not only vast knowledge but also with compassion and kindness. Thank you for your support and practical recommendations that provided my father with the necessary comfort and care. We are forever grateful.”
>
> **Sam, daughter of person living with pulmonary fibrosis**

I know that many people are struggling to get the care and specialist support they need. Our 2025 survey highlighted that one in three people wait more than a year for their diagnosis. Our Support Line has become a place to turn to for answers, comfort and understanding. Each call is vital, and the team and I need to be able to respond quickly to everyone.

Can you help ensure someone is always at the end of the phone for anyone who needs support this winter? Donate today by:

- Calling **01733 839642**
- **Visiting our website**

Wherever you are on your journey with pulmonary fibrosis or if you're supporting us in memory of a loved one, thank you for considering making a donation. Your support means that no one needs to face this journey alone.

Remember, if you ever need us, we're here for you – our Support Line number is **01223 785725**.

Best wishes,

Jo

Registered office:
Action for Pulmonary Fibrosis, Stuart House,
East Wing, St John's Street, Peterborough PE1 5DD

England & Wales Charity Registration Number: 1152399
Scotland Charity Registration Number: SC050992

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A message from our CEO

It's been a busy and inspiring few months at Action for Pulmonary Fibrosis (APF), and we're so pleased to bring you another packed issue of Insider magazine.

From powerful personal stories to exciting research developments and community-led events, there's so much to share with you since our last edition.

We begin with one of the highlights of our year, Pulmonary Fibrosis Awareness Month. You may have received our Every Breath Counts campaign mailing at the start of September; the response was truly incredible. Whether you shared your story, donated or helped spread the word in your local community, thank you. We were genuinely moved by the generosity and enthusiasm shown across the country. Your support not only raises awareness but creates real change for people living with pulmonary fibrosis (PF). You can read more about the campaign and the remarkable efforts of the PF community on **page 3**.

In our last issue, we invited you to complete our State of the Nation survey, our biggest consultation asking people affected by PF to share their experiences of care. Over 1,200 people responded, giving us an extraordinary insight into what's working, what isn't, and where the most urgent improvements are needed. On **page 9**, Peter shares how getting involved in creating the survey felt like a step towards real, lasting change.

We know that research is close to many of your hearts, so we're thrilled to include not one, but two research-focused features in this edition. On **pages 4 and 15**, you'll find updates on some of the exciting work taking place in the UK, made possible by our incredible supporters.

This issue also brings you closer to the people behind the headlines. On **page 10**, meet Sarah, who opens up about her diagnosis and the constant learning curve she is navigating.

Then, on **page 16**, Eileen shares her personal journey of finding strength in community after her husband died of PF. We're incredibly grateful to both for their honesty, courage and generosity in telling their stories.

If you haven't yet joined one of our Talking PF webinars, now is a great time to catch up on the recordings. These online sessions have become a lifeline for many, offering expert information, peer support and practical tips for everyday life with PF. On **page 12**, we recap one of our most popular topics, managing fatigue, and share how you can access the full library of recorded sessions.

As we approach the final months of 2025, I want to thank you again for being part of the APF community. For those celebrating the festive season, I wish you peace, joy, and precious time with loved ones. And to everyone, I hope you enjoy reading this latest edition of Insider.

I look forward to writing to you again in 2026, with even more to share, celebrate, and work towards together.

Best wishes,

Daniel Saxton
Chief Executive Officer
Action for Pulmonary Fibrosis

Scan QR codes to visit web pages

Open the camera on your smart phone or tablet. Point the camera at the QR code. Make sure you can see the whole QR code on your screen. When a link appears on your screen, tap to visit the web page.

You can also call us on 01733 839642 about anything in this magazine.

Every breath counts: **Pulmonary Fibrosis Awareness Month 2025**

This September, we set out to show that people affected by pulmonary fibrosis (PF) are not just a number. Behind every diagnosis is a story of courage, resilience and hope.

Our Every Breath Counts campaign ensured those stories took centre stage, with Lorraine and Allan, Dave, Meg and Milan leading the way. They bravely shared their unique experiences of PF, inspiring others to see the people, not just the condition, behind PF.

Making a difference together

Thanks to you, our campaign was spread far and wide. You shared our posts, told your stories and took action. **Together, we shone a national spotlight on pulmonary fibrosis**.

Our social media posts generated more than **1,500 shares**, an incredible **385,000 views**, and they brought more than **6,500 people** to our campaign website.

Across the country, communities got involved by dressing up in purple, holding fundraisers, and creating awareness of PF. From bake sales to sponsored walks, every action helped show that every breath truly counts.

Your support didn't stop at raising awareness. You also helped raise vital funds to support more people living with PF.

Pulmonary Fibrosis Awareness Month SEPT 2025

Thank you for standing with us, sharing your stories and making this PF Awareness Month one to remember.

Support from the PF community

The Grampian PF Support Group held an awareness day supporting our Every Breath Counts campaign.

Fundraising in PF month

Mary, a retired nurse living with PF, and her daughter, **Jenn**, teamed up to raise vital funds and awareness. Mary committed to daily walks with her dogs and loved ones, and Jenn Created a Stir by hosting a raffle. She also turned her nail salon into a purple haven for the month.

Thanks to our pharmaceutical sponsors for supporting our PF Month campaign this year, with a total of **£39,500!**

avalyn pharma | Boehringer Ingelheim | ENDEAVOR BioMedicines | trevi THERAPEUTICS | gossamerbio | Chiesi

APF researcher spotlight: **Dr Jennifer Dickens**

Action for Pulmonary Fibrosis are determined to back the brightest minds who share our mission: finding better treatments and improving the lives of people affected by pulmonary fibrosis (PF). One of those minds is Dr Jennifer (Jenny) Dickens, an APF-funded researcher. Jenny's groundbreaking work has led to her role as Principal Investigator at the Cambridge Institute for Medical Research, where she now has her own research lab.

From the clinic to the labs

Jenny is in a unique position to drive change in research. As a respiratory doctor at Royal Papworth Hospital, she sees first-hand how PF affects patients and families. In the lab, she studies **the molecular causes of disease**. She focuses on familial (inherited) PF and looking at surfactant proteins. Surfactant proteins are essential for keeping our lungs working properly.

By working both in the lab and clinic, Jenny ensures her research is never just about cells in a dish, but about people in real life.

Why this research matters for people affected by pulmonary fibrosis

PF remains a devastating condition with limited treatment options. Jenny's research is helping us to understand the biology behind the disease. Understanding the role of surfactant proteins may be an important part of this. By understanding their role, treatments could be developed in the future to target these proteins and stop the disease developing. These treatments could one day slow, stop or even prevent PF.

> “Supporting researchers like Jenny means every pound raised for research is pushing science closer to answers for people living with PF today.”
>
> **Bradley Price, Director of Policy, Research and Involvement**


Jenny putting cell samples on microscope slides


Jenny's lab in Cambridge

APF at the heart of her work

Jenny's route to Principal Investigator has been fuelled, in part, by **funding from APF supporters**. Alongside other funders, our investment has allowed her to:

- Develop new organoid models that mimic the lung's air sacs. This helps scientists study how disease begins at the molecular level.
- Investigate how surfactant proteins sometimes misfold or get 'lost' inside cells – problems that can trigger lung damage and fibrosis.
- Lay the foundations for future therapies that could correct these errors and protect lung function.
- Attract additional funding to contribute to her future work.

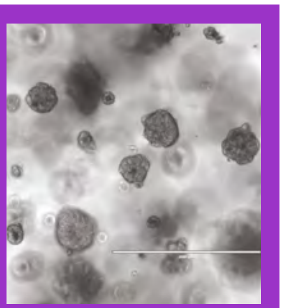
This is a powerful example of how donations to APF are directly helping to advance world-leading science.

Looking Ahead

Jenny's appointment as Principal Investigator marks the start of an exciting new chapter. With APF's continued support, she will:

- Expand her lab team at Cambridge, meaning more scientists are working on finding out more about PF.
- Push forward her organoid-based discoveries, which would help with targeted treatments in the future.
- Keep the needs of people affected by PF at the centre of her science.

Organoids



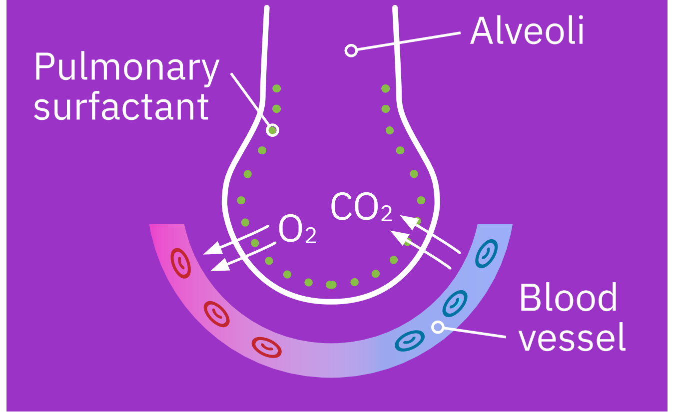
Organoids are tiny, lab-grown models of human organs. Scientists make them from a specific type of cell. They grow them in 3D layers so they behave more like real tissue.

In Jenny's research, organoids are used to mimic the air sacs of the lung. This allows her team to study how diseases like PF start at the molecular level. This could help to test new treatments in a safe and controlled way, before moving to clinical trials involving people.

Surfactant proteins

Your lungs are full of tiny air sacs (alveoli) where oxygen enters your blood. The alveoli are lined with a slippery substance called pulmonary surfactant. This is produced by lung cells. Surfactant stops the air sacs from collapsing when you breathe out. This helps to keep your lungs healthy and working properly.

A key ingredient in pulmonary surfactant is surfactant proteins. They help the pulmonary surfactant work efficiently. When something goes wrong with these proteins, e.g. they are folded the wrong way or stuck inside cells, the lungs can become damaged and scarred. How and why this happens is one of the puzzles Jenny is working to solve.



Be part of the story

Jenny's success shows what's possible when the pulmonary fibrosis community, researchers, and charities work together. But research like this only happens with continued support.

Help us fund groundbreaking researchers like Jenny and bring hope to people affected by pulmonary fibrosis.

bit.ly/apf-donate ✉ fundraising@actionpf.org ☎ 01733 839642

Money matters: **benefits for people affected by pulmonary fibrosis**

If you’re affected by pulmonary fibrosis (PF), there are benefits and financial support designed to help you manage the financial impact of the disease. From extra help with daily life, to schemes that make travel easier, knowing what’s available means you can focus on what matters most.

Extra help for daily life

If PF affects your ability to manage everyday tasks or get around, you may be able to claim:

- Personal independence payment (PIP) in England, Wales and Northern Ireland.
- Adult disability payment in Scotland.
- Attendance allowance (in England, Wales and Northern Ireland) or pension age disability payment (in Scotland) if you are also over pension age.

These benefits aren’t means-tested, so your income or savings don’t matter. If someone cares for you regularly, they may be able to claim carer’s allowance (or carer support payment in Scotland).

If work becomes difficult

PF can make working life more challenging. Depending on your situation, you could be entitled to:

- Statutory sick pay if you’re employed and need time off.
- Employment and support allowance if your condition limits your ability to work.
- Universal credit if you’re on a low income, unable to work, or caring for someone.

Support in later life

Once you reach pension age, you may qualify for:

- State pension, based on your national insurance record.
- Pension credit if your income is low, which can also unlock extra help with rent or council tax.

If your PF is related to work

For some people, their PF may be linked to working in certain environments. In this case, you may be able to claim industrial injuries disablement benefit (IIDB), and sometimes a government lump sum payment.

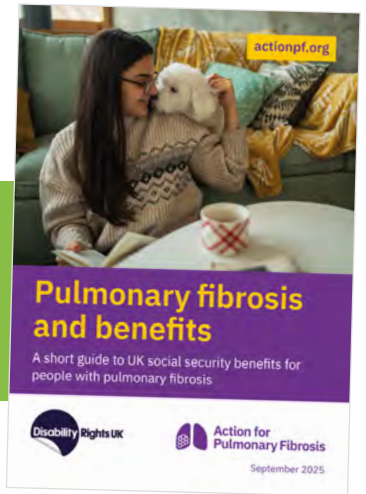
Other support

You may also qualify for schemes such as the Motability Scheme, the Blue Badge for parking, the Disabled Person’s Railcard, and help with NHS costs like prescriptions or dental treatment.

Please note: this is a summary of some UK benefits and does not include all details or eligibility criteria. Please refer to our booklet for further information.

For more information, see our free digital or printed booklet, co-created with Disability Rights UK. It explains how each benefit works, who may be eligible and how to apply.

↗ bit.ly/apfbenefits ☎ 01733 839642



actionpf.org

Pulmonary fibrosis and benefits

A short guide to UK social security benefits for people with pulmonary fibrosis

Disability Rights UK

Action for Pulmonary Fibrosis

September 2025

Help us be there for more people this winter

Thanks to your incredible generosity, in the last year we’ve been able to take **30% more calls on the Support Line.**

Without supporters like you, we wouldn’t be there for people like Sally.

> “I cannot thank Pauline [Support Line Manager] enough because she helped me last year. I was on the phone for half an hour to Pauline to calm me down enough to go and see my husband. And it was probably the worst day of my life. Pauline has been superb. She’s amazing.”

Sally*, affected by PF

Can you donate to help us continue this vital work?

We need your help to keep our Support Line open this Winter. Donate to our appeal today.

☎ **01733 839642**

↗ **bit.ly/apfwinter**

Complete the donation form enclosed in this magazine

*Name anonymised for confidentiality

Evidence for change

We know that pulmonary fibrosis (PF) care needs to change, but we have to prove it. Change doesn't happen without evidence, and that's the purpose of our 2025 State of the Nation survey. It shows what needs to change and why it can't wait. We're putting all this evidence into a report that could shape the future of PF care.

What is the State of the Nation Survey?

In June 2025, we launched the State of the Nation survey to learn about people's experiences with PF health services. We asked about:

- Where you first reported your symptoms.
- If you were misdiagnosed.
- How long it took until you received a diagnosis.

> “The response to the survey was incredible – more than 1,200 people took part. Thank you to everyone who took the time to complete the survey. Every response matters.”
>
> **Lisa Murray, Policy & Public Affairs Officer**

By understanding what's working, and what isn't, we can start to work on changing things for the better. This survey builds on our 2023 survey, which explored the individual impact of being affected by PF. You can read the results of the 2023 survey in our I Wish It Was Cancer report.

Read the I Wish It Was Cancer 2023 report here

bit.ly/surveyreport2023

What will the survey do?

Every answer helps to build a picture of PF care. This helps to prove that these issues are real, and many people are affected by them. We've worked with expert analysts to dig deeper into the responses and find patterns that might go unnoticed. For example, we're asking:

- Are people more likely to be misdiagnosed if they seek help from A&E than their GP?
- Do people with a certain type of PF wait longer to be referred to a specialist?

Your experiences become powerful evidence. They help us to understand how people affected by PF navigate the healthcare system. These insights help NHS decision-makers and clinical teams to make better-informed decisions about PF care. These decisions could directly improve someone's journey through diagnosis, treatment and ongoing care.

What happens next?

Once this analysis is complete, we'll publish a full report that sets out the key insights. This will give us the facts and figures we need to back up what we often hear – that things need to change. We'll use this evidence to guide our work with NHS decision-makers and clinical teams across the UK. We will:

- Show where services aren't working well, so no one misses out on the care and support they need.
- Start informed discussions with those in charge about what needs to change.
- Support clinicians and service planners who want to improve ILD services across their region.

A vital piece of the puzzle

Peter, aged 71 from Devon, cared for his wife who had PF. He helped to decide what should be in this year's survey to ensure we truly understand the experiences of people affected by PF.

'Decision makers need more than stories,' Peter explains. **'They also need evidence – hard numbers - before they will act. It's tough to win support for PF in today's world, with so many other causes competing for attention. Surveys like this give funders and politicians proof they can't ignore – whether it's the 'soft' evidence of personal stories, or the 'hard' facts.'**

> “Being a part of the group that helped design the survey made me feel like I am contributing something. Maybe small, but hopefully it's a valuable piece of the puzzle.”
>
> **Peter, living with PF**

Whether you share your experiences, shape research, or take part in campaigns, you're helping to shape our work.

Find out more about the APF Involvement Network.

✉ involvement@actionpf.org

☎ 01733 839642

How can I read the report when it's published?

Sign up to our e-newsletter and you'll be notified when we publish the report.

bit.ly/apf-news

Learning as I go

“Hi, I’m Sarah. I’m 48 and live in West Sussex with my two dogs. In 2017, I was diagnosed with a life-changing illness – hypersensitivity pneumonitis. This journey is a constant learning curve, and I’ll keep giving it my best shot.

Finding my way

When I was first diagnosed, I was discharged from hospital with a load of oxygen cylinders. It was chaos – if the dogs got excited, the cylinders would get knocked over and go flying down the hallway.

Six months later, I discovered liquid oxygen. This was much more convenient and gave me so much more time to walk my dogs. As with anything, it has pros and cons. One of the cons is that the liquid oxygen started evaporating, so I researched and came across portable concentrators. This works well in the heat, but carrying it can make my back ache.

And that’s what it’s like to live with PF – this journey is a constant learning curve. You’ve got to experiment with different things until you find what works for you. It’s not easy, but it’s worth trying to find what works for you. This can make your days a little easier and keep doing the things you love.

The spoon theory

In the early days, I was told about the spoon theory. For me, walking my dogs was always the priority, and still today, they come first. We walk as much as we can to keep active. One of the best pieces of advice I was given was ‘use it or lose it’: keep as active as possible so you can continue doing the things you love.

What is the spoon theory?

The spoon theory is a metaphor that can help you manage your energy. A spoon represents a unit of energy. Each day, you have a limited number of spoons to use. Making a drink may use one spoon, whereas going to the shops may use more. Planning how to use your spoons may help you manage your tiredness.

Planning ahead

Once a week, I sit down and plan my week. If I’m going out, I’ll think about how far I’ll need to walk, whether there are places to rest, how much oxygen I’ll need, how busy the rest of my week is... planning can feel like a full-time job! I tend to have a day on followed by a day off, so if I’m seeing a friend on Monday, I’ll rest on Tuesday. I try to keep plans a bit flexible too, because sometimes you just need a break.

Wednesday is always my rest day, and usually reserved for crafting. A hobby is so rewarding and takes your mind off everything else going on.

Support and confidence

I’m single, so I’ve had to navigate all this by myself. I want people to know that if you’re on your own, you can do this.

The APF online support group has been a big help. I recently went on holiday for the first time since being diagnosed, and I only did it because someone in the group gave me confidence. She does it regularly and shares her experiences. Sometimes you do have to put your big girl pants on and say, ‘I am going to do this.’

Shifting relationships

It can be hard to talk to loved ones about pulmonary fibrosis. When you’ve been friends with someone for 30 years, it’s not easy to say you can’t do what you used to. Sometimes it takes time for people to realise you’re struggling but trying your best.

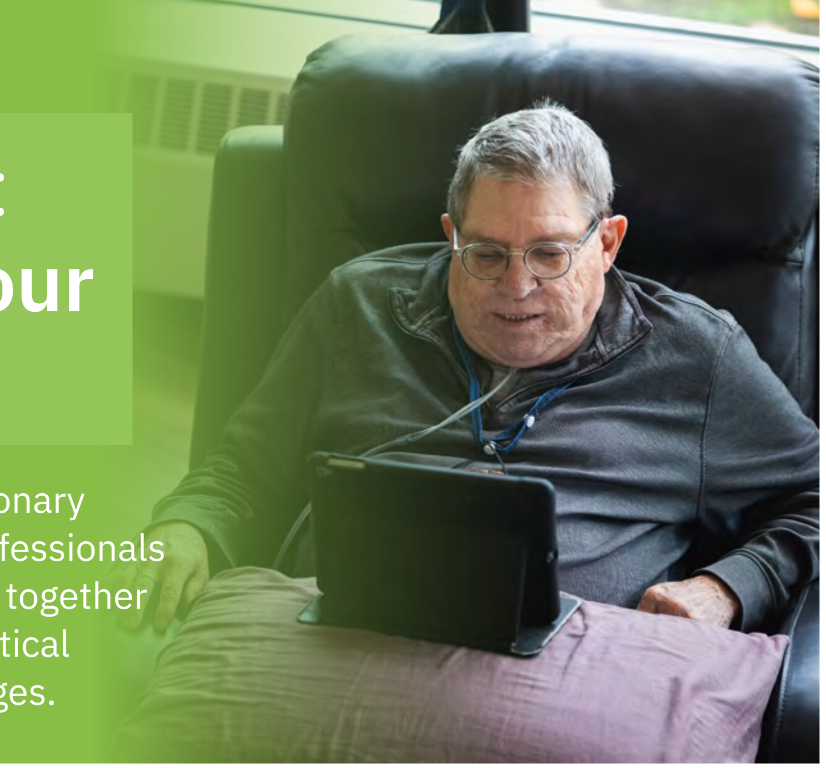
The problem with a lung condition is that you can look okay, so people think you are okay. But your family and friends don’t really know how you feel.

Moving forward

This is a constant journey of learning, planning and adapting. Planning ahead isn’t always easy, but it’s worth it. And while things don’t always go as expected, you might be surprised by what you can achieve.”

No two experiences of PF are the same. If you’d like to explore ways of managing that work for you, call our friendly Support Line team.

☎ 01233 785725 ✉ support@actionpf.org



Managing fatigue: Highlights from our recent webinar

Fatigue is a common symptom of pulmonary fibrosis (PF). In our recent webinar, professionals and people with lived experience came together to share insights, reassurance and practical ideas. Here are some of the key messages.

Understanding fatigue in PF

Fatigue is more than simply feeling tired after a busy day. Many people describe it as a deep, ongoing exhaustion that rest alone doesn't always improve.

PF causes scarring in the lungs, which makes it harder for oxygen to move into the blood. Imagine your lungs as a sponge – with fibrosis, the sponge becomes stiff and struggles to absorb oxygen.

When less oxygen reaches the blood, the body has to work harder to keep going. The heart beats faster, breathing speeds up, and muscles get tired more easily. This constant extra effort can leave people feeling drained, leading to the lasting fatigue that so many experience.

How occupational therapy can help

Occupational therapists can help people find ways to live well with fatigue. They may be able to help with:

- **Energy conservation techniques** – learning easier ways to do daily tasks.
- **Planning and prioritisation** – focusing energy on what matters most.
- **Pacing** – breaking activities into smaller steps with rests in between.
- **Finding and using adaptive equipment** – tools and aids that reduce effort.
- **Breathing techniques** – strategies to use oxygen more effectively.

The importance of pacing

It can be easy to slip into a 'boom and bust' cycle: pushing hard on a good day, then needing long stretches to recover afterwards. Pacing can help break this cycle, giving you:

- Better management of breathlessness.
- Less fatigue.
- More independence in daily life.
- Energy left for the things you enjoy.
- A greater sense of control and confidence.

Looking ahead

This webinar highlighted just how big an issue fatigue is for people living with PF. We're now working on new information resources to offer further support.

Watch the full webinar – Talking PF: managing fatigue

bit.ly/apfwebinar

You'll also find the full Talking PF series, with webinars on eating well, emotional wellbeing and more.

Powering APF's progress

Pulmonary Paddlers make a splash for APF

The Pulmonary Paddlers, a crew of 17 extraordinary volunteers, braved the baking sunshine at the Bradford Dragonboat festival in June. Solicitors from Irwin Mitchell's Asbestos and Occupational Disease team took to the water and raised £827 for APF.

> "It was a great day out and everybody enjoyed themselves, even if the rowing technique left a lot to be desired! More importantly, we were able to raise vital funds for the wonderful support services that APF provides to people living with pulmonary fibrosis."
>
> **Oliver Collet, Irwin Mitchell Partner**

> "From sports challenges to office competitions, fundraising can be whatever you make it. It's a chance for people to come together, have a laugh, and know it was all for a good cause."
>
> **Becky Williams, Senior Partnerships and Philanthropy Manager**

Who could you get on board?
If you've been inspired by the Pulmonary Paddlers, tell us about a company you know who could support APF.

✉ **fundraising@actionpf.org** ☎ **01733 839642**

The impact of support groups

Support groups are the beating heart of APF's mission - providing friendship, raising awareness, and generating vital funds to support the pulmonary fibrosis (PF) community. Two inspirational groups show how powerful community spirit can be.

The Nottingham Pulmonary Fibrosis Support Group launched PF Awareness Month in style, when group leader Wendy Dickinson presented a £1,000 donation to APF Trustee Steve Jones. The funds were raised by Sue and Jason Upton, who hosted a fantastic music evening featuring Jason's band, 33 and a Third. Sue and Jason also generously donated £750 to the Nottingham group.

Wendy shared:
'We were amazed by the fantastic amount raised. Our charity and support groups live or die on the generosity and hard work of people like Sue and Jason. We can't thank them enough.'

Meanwhile, the Leicestershire Pulmonary Fibrosis Support Group, led by Alan Tratt, donated an incredible £1,500 to APF.

Alan recalls:
'When I joined in 2017, our meetings rarely reached more than 10 people, but APF's early support was vital. Their information and encouragement kept us going at a time when public knowledge of PF was non-existent. Our group now regularly welcomes over 30 people.'

Our heartfelt thanks go to the Nottingham and Leicestershire Pulmonary Fibrosis Support Groups.

Celebrating milestones: **incredible support groups**

Across the UK, support groups are changing lives every single day. This year, we are delighted to celebrate the 10-year anniversaries of several pulmonary fibrosis (PF) support groups. Together, they remind us just how powerful community can be.

Support group leaders reflect on their groups' achievements over the past decade:

“It's hard to believe it's been 10 years since the formation of the group! Yet, it's not, when I think back to the number of people who attended our meetings and shared their experiences, practical tips and genuine care and support over those years. Supporting not just patients, but carers, their families and friends.”

John Conway, St George's ILD Support Group

“10 years of shared experiences, lessons learnt, information gathered, expert advice, laughter, tears, excellent cakes and sensational raffles. It's an experience no one chooses but easier when not faced alone – a joy and a sadness, and one that we would not have missed.”

Imelda and Ann, Leeds PF Support Group

“Over the last 10 years, our meetings have gone from strength to strength. The generosity from our patients is always overwhelming, from raffle prizes to financial donations. I love to hear all the chatter over coffee, people sharing stories and experiences. Here's to another 10 years!”

Mark Major, Hull and East Yorkshire Support Group

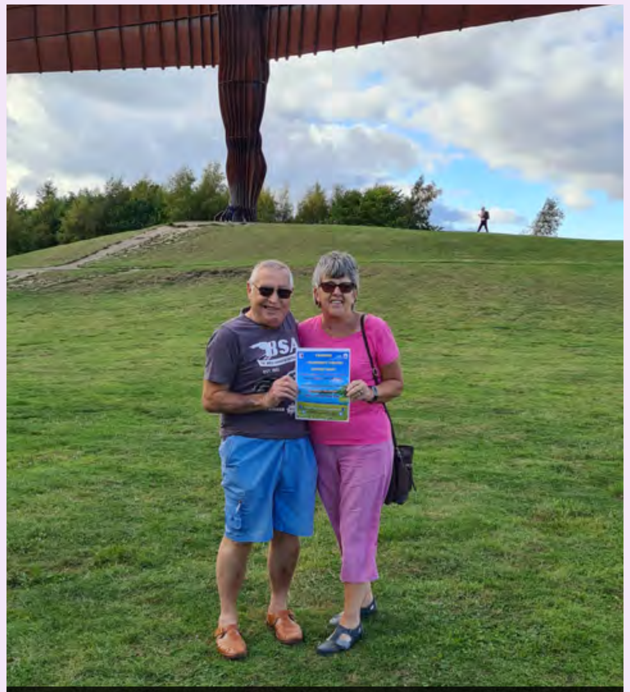
“October 2015 saw the first support group meeting for patients affected by pulmonary fibrosis in East Lancashire, and this month we have celebrated our 10-year anniversary. Thank you to all our supporters, past and present.”

Rugina Choudhury, East Lancashire PF Support Group

Find your local group
bit.ly/pfsupportgroup
01733 839642

Tameside Tribute

Clive and Sue Green have led the Tameside Pulmonary Fibrosis Support Group (TPFSG) from strength to strength since 2018. In March, Clive sadly died from PF. Soon after, his incredible work was honoured at the Greater Manchester Health and Care Awards, where he and Sue won the Community Champion Award.



Clive and Sue taking part in their 'Around the World with TPFSG' challenge

“I was blown away. It was wonderful to be there and amazing to get the award, but bittersweet without Clive.

We wouldn't have a group without him – his hard work was relentless. Clive had the idea for our 'Around the World with TPFSG' challenge in 2019. People take a photo in different locations, from their garden to the other side of the world, holding our support group poster. He would give posters to anyone who would listen, right up to a day or two before he passed away.”

Sue Green

Spotlight on rising talent: **APF Conference Award winners shine at ERS Congress 2025**

At this year's European Respiratory Society (ERS) Congress, four early career researchers took centre stage, supported by Action for Pulmonary Fibrosis (APF). They presented research that could transform how we understand, track and treat pulmonary fibrosis (PF).

The APF Conference Award doesn't just give funding. It brings opportunities to share ideas with world-leading experts, get feedback, and bring fresh insights back to people affected by PF and healthcare professionals.

“We are incredibly proud to support these talented researchers. Their work not only pushes forward scientific understanding, but also addresses the real challenges people affected by PF face every day.”

Bradley Price, Director of Policy, Research and Involvement at APF

This work reminds us that every piece of research brings us closer to a brighter future for people affected by PF.

“Not knowing what the future holds can be frightening. Research like this gives me hope.”

Person living with PF

APF Conference Award highlights

Oxygen in daily life – Ellen Jenkins (University of Birmingham) showed that oxygen dips are common during sedentary tasks, not just when someone is physically active. **Her findings could change when and how oxygen therapy is offered.**

Social background and hospital outcomes – Dr Laura White (Lancaster University) found that people living in poorer areas were more likely to be admitted to hospital. **This raises new questions: why are people from poorer areas more likely to be admitted to hospital, and how can we better support them?**

Clues for new treatments – Mathuscha Ratnasingham (University of Leicester) studied a protein called TRPM7. She found that people with idiopathic PF had lower levels of this protein in their lungs. Surprisingly, when scientists blocked the protein in laboratory tests, it slows cell movement and lung tissue repair. This suggests that TRPM7 may play a part in lung scarring. **Understanding how this protein works could help researchers discover new ways to treat PF and slow its progress.**

Predicting disease progression – Dr Giles Dixon (University of Exeter) tested novel tools, including:

- using artificial intelligence to read CT scans,
- special imaging of small blood vessels, and
- scans to measure blood vessel inflammation.

His findings could help to personalise treatments and better understand how PF progresses.

There's a huge variety of research currently happening and you could play a part in it. Turn hope into action, and find research opportunities to take part in through our online Study Finder.

bit.ly/apf-studyfinder **Or ask your healthcare team about research opportunities**

Eileen and Andy

After her husband, Andy, died from pulmonary fibrosis (PF), Eileen found strength in community, fundraising and helping others who are walking the same path.

Eileen and Andy visiting relatives in Canada, 2016

“When Andy was diagnosed with PF in 2017, he took a very stoic approach. He inspired me throughout his illness just as much as he had throughout our more than 50 years together.

Due to Andy’s fitness levels – he played tennis twice a week and golf whenever he could – he was initially able to manage his condition by continuing some of his usual activities. We did daily walks, breathing exercises and meditation. Andy also watched many of the videos on the APF website and found them helpful.

As his condition worsened, he continued to be philosophical about what was happening, and we made the most of our time together.

In September 2023, we attended the first meeting of the Ayrshire PF Support Group. Unfortunately, Andy was too ill to return. He died at the beginning of December 2023, at home, cared for by me and our two sons.

After Andy’s funeral, we collected donations for the support group’s funds, and that’s when I became more involved with the group. It was also what led me to take up the challenge of fundraising for APF.

I know that Andy would want me to keep busy, and since our professional focus was to live with purpose and make a difference, APF seemed like the best place for me to be.

He was also interested in research into the causes of PF and potential cures, so an obvious next step for me was to fundraise for PF research.

The support group was initially a good place for me: being with people who were living with PF and learning how best to deal with the condition. Lately, my focus has turned to one-on-one connections with other carers who are working through grief and loss. This could be meeting for coffee or lunch, listening on the phone, or sending an occasional text.

It has only been 18 months since my wonderful husband died from life-limiting PF, but if he has taught me anything, it was to keep pushing at those limits as long as you can.”

Eileen and Andy at a wedding in Scotland, 2018

The APF Life After Caring Online Support Group welcomes anyone who has been bereaved because of PF. It’s an opportunity to reflect on your journey and explore ways to care for yourself as you move forward. Find out more by getting in touch.

bit.ly/lifeaftercaring ☎ **01733 839642**

Action for Pulmonary Fibrosis

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