PF Together

News, support and stories for everyone affected by pulmonary fibrosis

Summer 2026

Live well
Practical ways to manage breathlessness

A new treatment milestone
What nerandomilast approval means

PF Awareness Month 2026

Big or small, every action helps people affected by PF

TAKE ACTION FOR PF

Action for Pulmonary Fibrosis

Welcome

WELCOME TO PF TOGETHER, THE NEW NAME AND LOOK FOR THE MAGAZINE YOU PREVIOUSLY KNEW AS INSIDER.

The design has changed, but its purpose remains the same: to bring people affected by PF together through trusted information, shared experiences and clear ways to find support and take action.

Every September is Pulmonary Fibrosis Awareness Month. This year, our campaign is Take Action for PF, asking everyone to choose one practical action to carry out during September. You can register and prepare now, and Action for Pulmonary Fibrosis (APF) will provide materials and support to help you take part.

Pulmonary fibrosis can leave people feeling unheard, unsupported or unsure where to turn. Yet we see every day how much can change when people share trusted information, tell their story, speak up, bring a community together or take on a personal challenge.

That is why this edition is built around a simple idea: big or small, every action helps people affected by PF. On pages 6 to 11, you will find six ways to take part, along with practical support to help you get started.

Elsewhere, we share techniques for managing breathlessness, explain an important new treatment milestone and look at what the latest evidence tells us about inequalities in PF care. We also meet people whose determination, generosity and personal experiences are helping to build a better future.

Whatever your connection to PF, and whatever feels possible for you, you are part of this community. Thank you for being with us.

Best wishes,

Daniel Saxton
Chief Executive Officer
Action for Pulmonary Fibrosis

In this edition

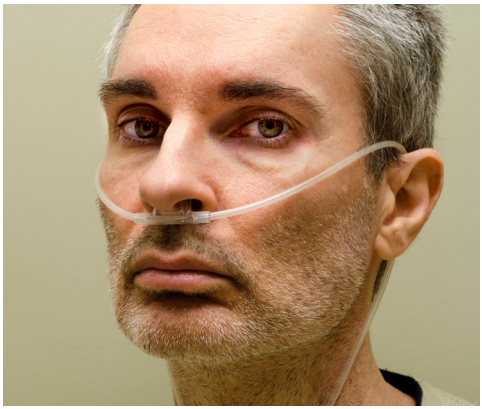
PF Together

Live Well

Our Stories

Research and Change

Get Involved



Pauline
APF Support Manager

Support for you

The first thing we do is listen

Living with pulmonary fibrosis can bring questions, uncertainty and difficult emotions. Pauline, one of APF's Support Managers, explains what to expect when you contact the Support Line.

Who is the Support Line for?

Anyone affected by PF can contact us, including people living with the condition, carers, family members, friends and healthcare professionals. We can also arrange a translation service.

What can I ask about?

Anything connected with PF or how it is affecting you. Recent enquiries have included medication, benefits, oxygen, travel, support groups and mental health. We cannot give individual medical advice, but we can help identify the right source of support.

What happens when I contact you?

We start by listening. We can guide you towards APF information and services, direct you to other help and, where useful, arrange a follow-up call.

Do I need to be in crisis?

No. You might need help understanding information or simply want to talk to someone who understands PF. As I say:

"If it matters to you, it matters enough to call."

PF Together

Call: 01223 785725
Monday to Friday,
9am to 5pm

supportline@actionpf.org

actionpf.org/support

> I'm so glad I picked up the phone, I feel less alone with this and have ideas on what to do next, thank you.

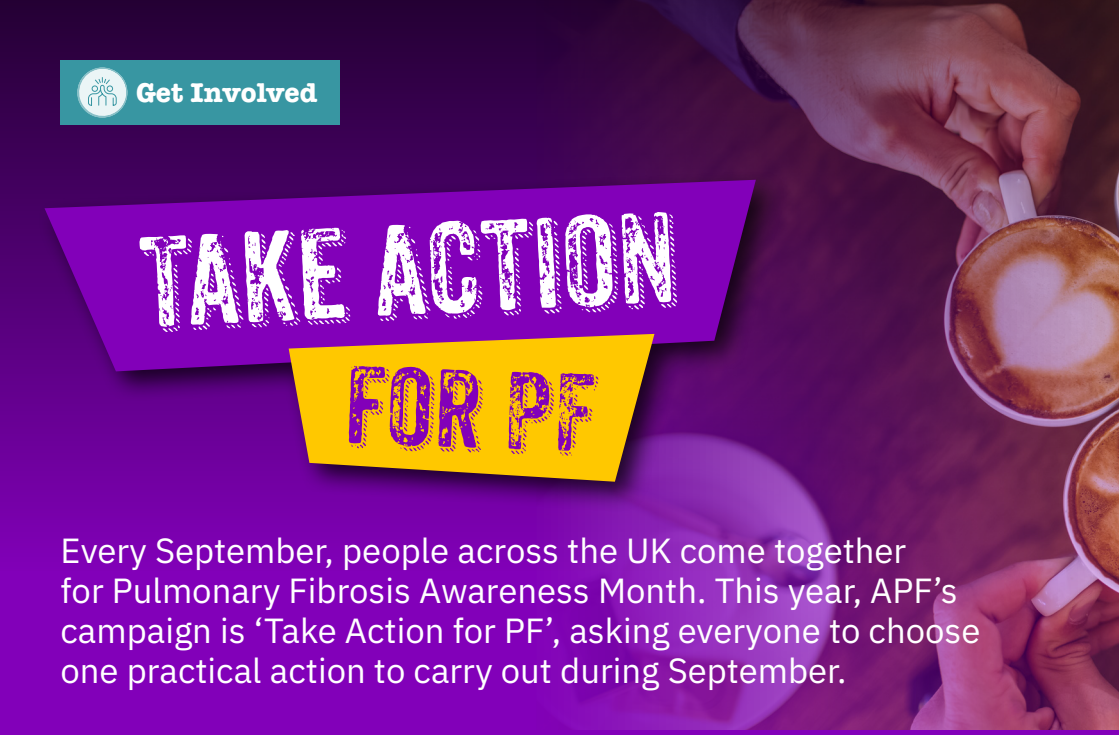
New: Navigating Pulmonary Fibrosis

Being told that you or someone close to you has pulmonary fibrosis can feel overwhelming. Our new Navigating Pulmonary Fibrosis booklet explains what PF is, suggests questions to ask your healthcare team and explores coming to terms with a diagnosis, talking to family and friends and finding support.

Download it or order a printed copy:
actionpf.org/navigating-pf

Once support reaches one person, sharing it can help someone else find help sooner.

TAKE ACTION FOR PF



Every September, people across the UK come together for Pulmonary Fibrosis Awareness Month. This year, APF's campaign is 'Take Action for PF', asking everyone to choose one practical action to carry out during September.

You can register and prepare now. APF will provide digital or printed materials to help you get ready, then we will take action together throughout September.

Big or small, every action helps people affected by PF.

Whatever you choose, your action helps people affected by pulmonary fibrosis find support, access better care and live well for longer.

Why action is needed

Too many people still receive a PF diagnosis without the information or support they need. Friends and family can suddenly find themselves providing care while trying to understand a condition they may never have heard of.

Marie cared for her husband Mark after he was diagnosed with PF. She only found APF after Mark died and, looking back, could see how much difference earlier information might have made.

> "THE LACK OF INFORMATION FROM THE POINT OF DIAGNOSIS WAS A HUGE SETBACK."

Nicholas found APF while looking for help after his father's diagnosis. Information from our website and conversations with our Support Line helped him understand that every PF journey is different, what support may be available and how to face challenges one step at a time.

Their experiences show why awareness matters. A shared post might help someone recognise the signs of PF. A poster could lead a newly diagnosed family to APF.

A personal story can help another person feel understood. A message to an MP can show why faster diagnosis and fairer care cannot wait.

No single person has to do everything. Choose one action that feels right for you, or combine several if you wish.

> "BIG OR SMALL, EVERY ACTION HELPS PEOPLE AFFECTED BY PF"

SIX WAYS TO TAKE ACTION

TAKE ACTION FOR PF

SHARE ONLINE

Help more people understand PF by sharing information about its signs and symptoms, APF support and the need for better care. You could use social media, WhatsApp, email, a workplace newsletter or a community group's online page.

APF will provide ready-to-use graphics and suggested wording, so you do not have to create everything yourself.

Every share helps more people understand PF.

TELL YOUR STORY

If you live with PF, care for someone, support a family member or remain connected after a bereavement, your experience can help others understand what PF really means.

You can submit a full story, a short reflection, a photograph or a quotation through APF's story platform. Share only what feels right for you. We will explain how your contribution may be used and ask for your consent.

Every story helps someone feel less alone.

BRING PEOPLE TOGETHER

Make PF more visible where you live, work or spend time. Display a signs and symptoms poster, share Support Line cards, hold an awareness stand, organise a coffee morning or arrange a collection where permission has been given.

APF can provide printed information, campaign materials and practical guidance to help you plan safely and confidently.

Every local action helps make sure no one faces PF alone.

GO YOUR DISTANCE

Choose a challenge that works for you. Walk, run, swim, cycle, climb or create a personal goal of your own. Your distance and pace are yours to decide.

You can take part on your own or with family, friends, colleagues or a local group. APF can help you set up a fundraising page and provide guidance and campaign materials.

Every challenge helps bring us closer to better treatments and, one day, a cure.

SPEAK UP FOR BETTER CARE

Ask decision-makers to listen to why PF care must improve. APF's campaign materials will help you contact your MP and ask one clear question:

"Will you take action for people affected by pulmonary fibrosis?"

Your experience can help MPs understand why people need faster diagnosis, better support and fairer access to specialist care, wherever they live.

Every voice adds to the call for better PF care.

DONATE TODAY

HELP US BE THERE FOR MORE FAMILIES

Donations make APF's work possible. They fund practical support and trusted information, help us campaign for better diagnosis, treatment and care, and enable research into the causes of PF, better treatments and, one day, a cure.

If giving is the action right for you, please use the enclosed donation form or donate at: takeactionforpf.co.uk/donate

REGISTER AND GET YOUR MATERIALS

1

Register now at **takeactionforpf.co.uk/action** or scan the QR code below and tell us how you would like to take action.

2

Download digital materials or order a printed campaign pack, then make your plans.

3

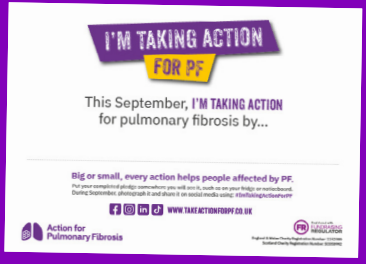
Carry out and share your action during September.

Prefer not to register online?

Use the details on the enclosed Take Action for PF card to email or call us.

MAKE YOUR PLEDGE FOR SEPTEMBER

We have included a Take Action for PF pledge card with this magazine. Write down what you plan to do, put it somewhere you will see it, or photograph it and share it on social media during PF Awareness Month using **#ImTakingActionForPF**.



REGISTER AND PREPARE NOW

Take action during September

Share a post. Tell your story. Plan something locally. Set your challenge. Speak up. Donate. Whatever you choose, APF is here to help.

WHY TAKING ACTION MATTERS

TAKE ACTION FOR PF

When many people take even one action, pulmonary fibrosis becomes harder to overlook. Sharing information and personal stories can help people recognise PF and find support sooner.

Community activity and speaking up can strengthen the case for faster diagnosis, fairer access to treatment and better NHS care.

Challenges, fundraising and donations raise money for APF's support services, campaigning and research into the causes of PF, better treatments and, one day, a cure.

Each action is different, but together they build awareness, influence change and fund hope for the future.

Six ways to manage breathlessness

Important: Breathlessness can have several causes. Ask your healthcare team to assess any new or changing breathlessness. If it becomes suddenly or severely worse, seek urgent medical help.

Why PF can make breathing feel difficult

When we breathe in, air travels into millions of tiny air sacs in the lungs called alveoli. Oxygen passes from these air sacs into the blood and carbon dioxide moves out.

With interstitial lung disease, including PF, inflammation and scarring can make the lungs stiff and less able to stretch.

Oxygen does not move into the blood as easily and breathing takes more effort.

The brain senses that more air is needed, which we experience as breathlessness.

Feeling breathless can trigger the body's alarm response. Breathing and heart rate may increase, muscles in the chest and neck can tighten and anxiety can make the sensation feel stronger.

Natalie Waterman
Respiratory
Physiotherapist
BSc (Hons)

Breathlessness is a common and sometimes frightening part of living with pulmonary fibrosis. Respiratory physiotherapist Natalie Waterman, from Medway NHS Foundation Trust, shares practical techniques that may help you feel more in control.

The following techniques are intended to help interrupt that cycle.

1. Try cool air on your face

A small handheld fan can reduce the sensation of stable, long-term breathlessness for some people.

Hold it around 15cm (six inches), from your face. Aim the cool air towards your cheeks, nose and mouth for several minutes.

Keep the fan somewhere easy to reach and use it alongside any breathing or positioning techniques recommended by your respiratory team.

2. Regain control of your breathing

Find a supported, comfortable position. Relax your jaw, neck and shoulders.

- Breathe in gently through your nose.
- Let the breath out gently, allowing the out-breath to last a little longer.
- Notice your tummy rise and fall without forcing the movement.
- Focus on making each breath as calm and comfortable as possible.

You may find it helpful to close your eyes or focus on one object while your breathing settles.

3. Pace yourself and save energy

Pacing is not about giving up activity. It is about using your energy in a way that reduces breathlessness and recovery time.

- Break larger activities into smaller stages.
- Sit down for tasks when possible.
- Keep frequently used items within easy reach.
- Slide objects rather than lifting them.
- Consider a wheeled walking frame or kitchen trolley if recommended for you.
- Try “blow as you go”: breathe out during the challenging part of an activity, such as standing up or lifting something light.

Plan short rests before you become exhausted rather than waiting until you have to stop.

4. Release physical tension

Check what your body is doing when you become breathless. Gently lower your shoulders, loosen your hands and soften your jaw and lips. Let your arms rest or shake them gently to release tension.

A supported forward-leaning position may help some people, but ask a physiotherapist or your healthcare team to show you positions that are safe and suitable for you.

5. Calm the alarm response

Distraction and relaxation can help reduce the fear that sometimes comes with breathlessness.

Try a puzzle, music, reading or focusing on something you enjoy. Some people find visualisation helpful: picture a familiar place and notice its colours, sounds and details.

Positive self-talk can also help: "I have felt this before. I know what to do. I can give my breathing time to settle."

Light clothing, a cool drink and a comfortably cool room may also help you feel more at ease.

6. Keep active

Although you may experience some breathlessness when you move about, it is still important to keep your muscles strong so that you can continue to do the activities you enjoy. It's about balance and learning how much it is safe to push yourself and what techniques you can use to help you recover.

Your physiotherapist can help guide you with this.

The information in this article is general and is not a substitute for advice from your healthcare team.

Find more support

actionpf.org/breathlessness

Contact the APF Support Line on **01223 785 725**.

A new treatment milestone

In July 2026, the Medicines and Healthcare products Regulatory Agency (MHRA) approved **nerandomilast** in the UK, also known by the brand name **Jascayd**, for adults with idiopathic pulmonary fibrosis (IPF) and progressive pulmonary fibrosis (PPF).

It is the first new medicine licensed for PF in more than a decade. This is an important and hopeful step, but it does not mean that the treatment is immediately available through the NHS.

What does MHRA approval mean?

The MHRA assesses the quality, safety and effectiveness of medicines. Its decision means nerandomilast can be supplied within the terms of its licence. Decisions about routine NHS availability involve a further assessment.

New medicines matter, but treatment is only one part of good PF care.

The latest State of the Nation evidence shows why the whole system must improve.

What happens next?

The National Institute for Health and Care Excellence (NICE) is assessing the clinical and cost effectiveness of nerandomilast for IPF and PPF. At the time of writing, NICE expects to publish its guidance later this year.

APF is contributing evidence so the experiences, needs and priorities of people affected by PF are part of the discussion about NHS access.

What should I do now?

Continue taking any prescribed treatment and do not make changes without speaking to your healthcare team. They may not yet be able to say whether nerandomilast will be suitable or available for you.

Questions or concerns?

Call the APF Support Line on **01223 785 725**.

Stage 1

MHRA LICENCE

Complete

Licensed for use in the UK.

Stage 2

NICE APPRAISAL

Underway

Clinical benefit and value for the NHS are assessed.

Stage 3

NHS ACCESS

Decision to follow

Availability depends on final guidance and implementation.

Access routes and timings differ across the four UK nations. Visit actionpf.org/news for the current position.

The evidence is clear: **PF care must change**

More than 1,200 people contributed to APF's 2026 State of the Nation report, revealing serious delays, misdiagnosis and unequal access to specialist care and support.

What people told us

- One in three respondents had initially been misdiagnosed.
- Around half waited more than six months for a confirmed diagnosis, with more than a third waiting over a year.
- One in five attended more than five medical appointments before being referred.

Almost half of respondents living more than 100 miles from a specialist centre waited up to two years for a diagnosis. Access to rehabilitation, physiotherapy, psychological support and coordinated care also varied depending on location.

Where someone lives should not determine how quickly they are diagnosed or the care they receive.

Turning evidence into change

APF is calling for care closer to home, more regional specialist expertise and consistent treatment and support. Through OneVoiceILD, people affected by PF and healthcare professionals have developed an Integrated Care Pathway setting out what good care should look like.

Taking your voices to Europe

At the European PF Patient Summit in Brussels, APF's Senior Policy and Public Affairs Officer Lisa Murray shared the report's findings and the OneVoiceILD Integrated Care Pathway. Taking this evidence to patient organisations, clinicians, researchers and policymakers strengthens the case for better care.

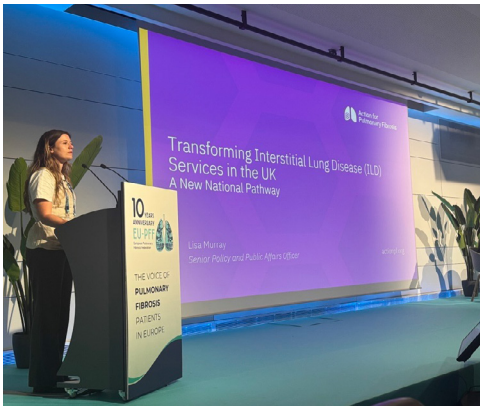
> There is a great deal we can learn from each other and so much we can achieve together.
>
> **Lisa Murray**

Speak up for better care

As part of Take Action for PF, you can ask your MP to support faster diagnosis, better support and fairer access to specialist care.

Visit **takeactionforpf.co.uk** or use the contact details on the enclosed Take Action for PF card.

Read the State of the Nation report: **actionpf.org/state-nation**



Lisa Murray presenting "Transforming Interstitial Lung Disease Services in the UK: A New National Pathway" at the European PF Patient Summit, Brussels, April 2026.

Could my work have contributed to my PF?

Dr Chris Barber
Consultant Respiratory Physician

Dr Chris Barber is a consultant respiratory physician with specialist expertise in occupational lung disease. Here he explains how workplace exposure can contribute to some forms of pulmonary fibrosis and what to do if you are concerned.

How can work contribute to PF?

Some forms of PF can develop after breathing in harmful airborne substances over months or years. These may include asbestos or silica dust, mists from metalworking fluids, and fumes or vapours from some paints and industrial processes.

The health effects may only become apparent many years after the exposure happened, so jobs from earlier in life can still be relevant.

How is a workplace cause investigated?

Your healthcare team will usually ask about previous employers, job titles, tasks and substances you worked with.

Assessment may also include scans, blood and lung-function tests, a bronchoalveolar lavage – sometimes called a lung wash – or a biopsy. Not everyone needs every test.

Why does knowing the cause matter?

Identifying a current exposure may help prevent further harm. It can affect how your condition is managed and whether financial support or compensation may be available.

Do not stop work or make major employment decisions without advice. Your medical team, an occupational lung disease service or occupational health professional can help.

What should I do if I am concerned?

If you are concerned about a current exposure, discuss this as soon as possible with your respiratory team (or GP) and ask whether specialist referral to an occupational lung disease service is appropriate.

For historic exposure, write down the jobs you have done, the dates and any dusts, fumes, vapours or chemicals you remember and share this with your respiratory team (or GP if appropriate).

You may also wish to seek advice about Industrial Injuries Disablement Benefit or speak to an appropriately qualified solicitor.

Free initial legal check

APF works with Irwin Mitchell to raise awareness of work-related PF and interstitial lung disease. If you are concerned that workplace exposure may have caused or worsened your condition, APF's Support Line can direct you to Irwin Mitchell's specialist occupational-disease team for a free initial legal check.

There is no obligation to take matters further, and the team will explain whether they may be able to help. APF does not provide legal advice and cannot comment on whether a claim is likely to succeed.

irwinmitchell

APF Support Line

Call: 01223 785725
Monday to Friday,
9am to 5pm

supportline@actionpf.org

Get Involved

What's on

Online

Talking PF: Planning for End of Life

Wednesday 16 September, 3pm to 4pm

Our panel will discuss Advance Care Plans, palliative care, Wills and funeral plans in a sensitive and supportive environment.

Online

Talking PF: Benefit Entitlement

Wednesday 18 November, 3pm to 4pm

Find out what financial support may be available to people affected by PF, where to start and where to get specialist advice.

Find out more and register

actionpf.org/webinars

education@actionpf.org

Need help registering?
Call the APF Support Line on **01223 785 725**.

Webinars provide general information and cannot offer individual medical advice, treatment or prescriptions.

Please discuss questions about your own care with your healthcare team.

Breath of Hope
Podcast series

Listen at any time

Breath of Hope: Pulmonary Fibrosis Stories is APF's podcast featuring people affected by PF and members of the APF team.

Episodes share experiences, practical insight and conversations about life with PF.

Listen at:
actionpf.podbean.com

Talking **PF**
Webinar series

Join us for Talking PF

Our free online Talking PF webinars bring together healthcare professionals, people affected by PF and members of the APF team to share expert information and answer questions.

Our Stories

Peter's way of taking action

When Peter was diagnosed with pulmonary fibrosis, he quickly realised how little he and many people around him knew about the condition. Finding reliable information helped him feel better equipped to manage life with PF. It also prompted him to support progress for others.

Peter's first contact with APF followed a frightening period of uncertainty. A lifelong non-smoker, he had initially been told that his symptoms might be lung cancer. Later, a consultant at the Royal Brompton Hospital suggested APF as a source of information and practical help.

Peter began reading APF's magazine and online information and joined webinars, including a session about oxygen. While he had access to exercise support in London, APF's information helped him understand the wider picture and prepare questions about his care.

He also took part in an APF-funded research study at the Royal Brompton exploring new approaches to diagnosis. Alongside the study, he received dietary advice to help address the weight loss that can accompany PF.

"I have benefited from APF's help in a number of ways," says Peter. "The magazine, online information and webinars have all given me useful background and practical support. I was also able to participate in research funded by APF."

Learning from another field

Peter's experience of cancer, through his own life and his family, showed him what greater awareness and sustained research can achieve. He was struck by the difference between public understanding of cancer and the limited recognition of pulmonary fibrosis.

That comparison strengthened his determination to help. Over several years, he has supported APF's work financially and by taking part in research. More recently, as his breathing difficulties have increased, he has also included a gift to APF in his Will.

For Peter, that decision is one more part of a much longer relationship. It sits alongside the information he has used, the research he joined and the regular support he has given.

> "I wanted to help ensure APF's work continues after my lifetime."

Creating hope beyond one lifetime

Gifts in Wills help APF plan for the long term. They support trusted information and services, research into the causes and treatment of PF, and work to improve diagnosis and care.

Leaving a gift is a personal choice. Family and friends come first, and there is no expectation or obligation. Peter hopes that sharing his decision will simply encourage other people to think about the kind of future they would like to help create.

His story also captures the spirit of Take Action for PF. Action does not have to be one large gesture. It can mean learning more, sharing information, taking part in research, giving what you can or making plans for the future. Each choice can help progress continue.

Peter is one of many people turning personal experience into action. On **page 26**, we celebrate challenges, collections and community activity from across the UK.

Our community in action

52 climbs for Dennis

After her husband Dennis died from IPF in 2024, Tara Roche Schiavon set herself the challenge of climbing 52 mountains and big hills in one year.

Through her challenge, 'To Help Them Breathe', she has raised over **£5,000**, despite health challenges of her own. Each summit is helping more people hear about PF.

Tough Mudder Triumph

Competing in memory of his dad, Jonathan took on the challenge only 2 years after surgery had left him unable to walk, raising over **£3,000** for APF.

Stay Connected

info@actionpf.org

01733 839642

Support Line: 01223 785725

actionpf.org

Across the UK, people are turning their experiences of PF into action. From mountain climbs to collections, every effort raises funds, builds awareness and brings our community together.

Walking for Dad

Laura and her family and friends held their annual walk in memory of Laura's dad, Les, raising over **£6,100** after walking 21 miles to Les's memorial bench.

Taking action in Cardiff

Marianne and her daughter Kayla were among 31 volunteers who joined APF's bucket collection at Cardiff City Stadium in memory of Brent Davies.

Marianne wanted to give something back for the support she had received. Kayla took part after seeing first-hand the challenges PF can bring for her mum.

Company challenge champions

The team at Converta took on the Yorkshire Three Peaks and raised more than **£3,000** in memory of their colleague Stuart's mum, Angela. Each summit is helping more people hear about PF.

Thank you to everyone who takes action for people affected by PF.

Invest in hope for generations to come

Because every breath matters.

After taking care of family and friends, a gift in your Will to Action for Pulmonary Fibrosis can help future generations find support, access better care and benefit from research into new treatments and, one day, a cure.

Thinking about writing or updating your Will?

APF will pay the cost of writing or updating a simple Will through our trusted Will-writing partners, Octopus Legacy and the National Free Wills Network. The service is provided at no cost to you, and there is no obligation to include a gift to APF.

Request your Gifts in Wills Guide.
actionpf.org/wills

There is no pressure or obligation. We are here whenever you feel ready.

APF covers the cost of a simple Will. If your needs are more complex, your provider will explain any additional charges before you proceed.

For Every Breath. For Every Journey. For Every Future.

Action for Pulmonary Fibrosis, Studio 8, Stuart House, St John's Street, Peterborough PE1 5DD
fundraising@actionpf.org 01733 839642

octopus legacy

NATIONAL FREE WILLS NETWORK

Registered with FUNDRAISING REGULATOR

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