

Insider

Living well with pulmonary fibrosis

- Celebrating our 10th anniversary
- Social connection for wellbeing
- Caring for someone with pulmonary fibrosis
- Campaigning for better care

Spring/Summer 2023



Action for
Pulmonary
Fibrosis

10

2013-2023

www.actionpf.org

What's inside...

Welcome to our **10th anniversary edition** of Insider. In this Spring/Summer edition, we're celebrating 10 years of Action for Pulmonary Fibrosis and talking about the benefits of social connection for wellbeing.

Meet our contributors:



Maxine, 62, cares for husband Ron, also 62, who was diagnosed with idiopathic pulmonary fibrosis in 2014. They love to travel and have visited a staggering 78 countries in five years after Ron's diagnosis. Just before this issue was printed, Ron had a lung transplant.



Judit is a psychologist and researcher who is also involved with the Wessex Interstitial Lung Disease support group. Judit loves to connect with others through dancing, a fun way to keep your mind and body active, no matter your age or how fit you are.



We need your voice

Please fill in our survey enclosed in this issue of Insider to help us make things better for people affected by pulmonary fibrosis.

We believe no-one should have to face pulmonary fibrosis alone, and that everyone affected should be able to get the support and care they need, when they need it. By filling in this survey you will help us develop the evidence we need to help services be better organised and more accessible to all.

To complete the survey online please visit:
www.actionpf.org/news/survey2023



← Scan this QR code to view the online version of this survey.

2023
Survey

10

2013 – 2023

Message from our Chair



Over the last 10 years, huge strides have been made in pulmonary fibrosis (PF) research and we have seen significant advances in care and treatment. While this is a cause for celebration, we have a long way to go to reduce suffering, improve the lives of people living with the disease and find a cure.

What was the PF world like in 2013? Well, when Action for Pulmonary Fibrosis (APF) started, there were no antifibrotic medications, only a few pulmonary rehabilitation courses and a handful of local support groups.

My story with idiopathic pulmonary fibrosis started in 2008. It was a difficult and isolating time to be a patient with nowhere to turn for help. I found the Papworth Hospital Support Group in 2013 and things started to change. I remember how amazing it felt to be in a room with 50 other people, all of whom were affected by PF. I no longer felt alone – I felt connected.

Community is at the heart of APF. Everything we do is guided by patients and their families. This is so important and makes us what we are.

I'm so proud of what we have achieved over the last 10 years. Highlights for me include:

- Our successful campaign to make antifibrotic medicines available more widely for PF patients.
- Building a network of over 75 independent support groups across the UK.
- The way we responded to support patients and their families during the COVID-19 pandemic.

There's no stopping now, though. We need more specialist nurses, faster and more accurate diagnoses, more patients taking part in research, much better care throughout the patient journey and better data on how many people live with the disease. We've already started working with healthcare professionals across the four

nations on the groundbreaking #OneVoiceILD initiative to improve access to care and treatments. We won't stop until we've improved the lives of everyone affected by PF.

What will happen in the next 10 years? Well, I feel confident that by working together we will make the world a much better and more hopeful place for people affected by PF.

Happy birthday, APF!



Steve pre-transplant in 2015

“None of this could not have happened without everyone in the PF community – patients, carers, clinicians, researchers and industry. Thank you all for your help.”

Steve Jones

Wellbeing

Why social connection matters

Judit, a psychologist working in Southampton General Hospital, talks about how social connection affects our health and wellbeing, and why she loves to bring people together.



“Writing this feature made me realise that not only do I love to connect with my friends, family and even strangers, but I also love to help other people connect.”

Judit Varkonyi-Sepp

What counts as social connection?

Any interaction with other people that gives you positive emotions and makes you feel good. It doesn't matter what type of connection it is or how many you have, as long as you feel connected on the inside. This could be spending the evening on the sofa with your friend or chatting to a stranger in the Post Office queue.

Online connections can be just as important as those in-person.

Why does it matter?

Early humans had to be social to survive. We needed friends and family to protect us from predators and help us find food. Whilst we live differently now, our brains and bodies haven't changed much. Our biology still needs social connection and sends us warning signs if we don't have it. These warning signs can be changes in our physical and mental health that are very real.

How does social connection affect physical and mental health?

It can reduce our risk of depression and anxiety, and positively affect many biological processes. For example, recent research suggested that feeling lonely or socially isolated might increase the risk of inflammation in the body and reduce our ability to fight off viral infections. On the other hand, feeling connected with others might help to reduce inflammation and improve our body's immune response to viral infections.

I spend time around people but I don't count it as socialising. Does that have an effect?

Research tells us that we still get lots of health benefits even if we don't have close emotional ties with the people we're connecting with, so people who aren't friends or family. Things like caring for another person or doing something for someone can also be beneficial to us. These things can be small acts of kindness such as checking in on someone, teaching something to children or contributing to a group, maybe a church or community group.

Over to you...

Use the questions below to think about how social connection can help you live well. Jot down some answers on a piece of paper or talk to someone about your thoughts.

- What interactions do I enjoy the most?
- What opportunities are there for social connection during my week?
- What do I need to do make sure I'm connecting with others?
- If I need help to connect with others, who can I ask?

Talk to our friendly team about social connection or living well with PF. Call our support line on **01223 785725** or email supportline@actionpf.org

Life with PF

Life with pulmonary fibrosis (PF) looks different for everyone. We asked people living with PF about their experiences and they shared some of their thoughts and insights.

How do you talk to others about your experiences with PF?

“With young children, I think it’s important they understand you are still the same person but need oxygen to help you get around better.”

Geraldine

“I think it’s best to be honest from the start. In my experience, I feel my family have coped with my diagnosis by being informed of how the fibrosis worsens over time.”

Susan

“Keep things clear in simple language and relatable to everyday experiences. Such as how it affects activities and behaviours everybody does like walking, talking, gardening, cooking, showering, dressing.”

Dawn

“I am honest but take notice of other people’s reactions so I don’t give out information they might not be ready for or understand.”

JD

How do you live well with PF?



“Work as a team with your partner or family and friends. Involve them, find out as much as you can and share it with them. It’s a roller coaster journey but made easier with the support of those that love you.”

Maggie

“Being able to stay connected and do usual activities differently is so important for psychological wellbeing. One day at a time.” Margaret



If you’d like to share your story, get in touch with us at **01733 839642** or email info@actionpf.org



“I have a Border Collie and he needs plenty of exercise. I walk two to three miles a day with him, we cycle on disused railway lines and he runs between us. I have bought an electric bike, that certainly helps with the hills around here!”

Jeff

Our Life with PF: Maxine & Ron

Changing relationships and life as a carer



Ron’s diagnosis of idiopathic pulmonary fibrosis in 2014 changed their lives but brought with it some unexpected positives. Maxine tells us about the shifts in their relationships, both with each other and people around them, since Ron’s diagnosis.

For Maxine and Ron, it’s been important to spend time with people who are also living with pulmonary fibrosis (PF).

“We made new connections and some special friendships from joining PF support groups. We’ve been on a cruise with a couple we met at our very first meeting. Ron and Terry text every week to swap football scores which is lovely as it’s not all about PF. We also had a whole table of friends from the PF community at our wedding.”

“It’s ok to feel overwhelmed by it all, we haven’t been trained to cope with this.”

Maxine wears two hats in their relationship, wife and carer. *“It’s since Ron’s PF has progressed that I have become the carer. It’s about keeping Ron as healthy as possible and that’s the main goal for both of us.”* Maxine explains that whilst they sometimes disagree on the best way to do this, the experience has brought them closer together.

If you care for someone with PF, we’re here for you. Call our support line on **01223 785725** or visit www.actionpf.org/information-and-support/carer-family-friends.



“We sit and talk about how Ron sees a situation and how I see it. This means that when I tell him to turn his oxygen up or rest, he understands that it’s because I care and I’m not just nagging!”

At the beginning of their journey, Ron seemed to want to protect Maxine from what was happening *“I explained that the less I know about what’s really happening the more I imagine and that’s probably worse. It’s hard when you feel shut out.”* Since then, they discuss everything together as they agreed that PF affects both of their lives.

Ron’s diagnosis also affects their family, and special occasions have become more significant in the Flewett household since then. *“We enjoy life in a different way now”* Maxine says, explaining that everything is appreciated, even a simple meal with family.

“We got together with all the family for the first time at Christmas. This included our son, Connor, and grandson, Mika, from Germany which was very special as it was Mika’s first Christmas.”

Maxine and Ron’s tips for living well with PF

- Plan ahead. Will there be hills where you’re going? Do you have enough oxygen and the right mobility aid?
- You can find a way around most things, you might just have to do things in a slightly different way.

Maxine’s tips for carers

- Don’t be afraid to ask questions at appointments. PF affects your life too.
- Make sure to do something for yourself, even if it’s just taking a bath or reading a book.

Our Journey

10 groundbreaking years



Action for Pulmonary Fibrosis



2013



FOUNDED AND OUR FIRST DONATIONS

Action for Pulmonary Fibrosis (APF) is founded. Donations flood in from supporters affected by PF. Income in Year 1 exceeds expectations at £50K.

FIRST SUPPORT GROUPS

Founding Chair Mike Bray and other trustees criss-cross the country meeting health care practitioners and encouraging new support groups. Over 25 support groups formed in first three years, with sponsorship from pharmaceutical companies.

APF INFLUENCES NICE

APF influences NICE on quality standards for IPF treatment and on new antifibrotic drugs.



2015



APF INTERNATIONAL

APF is a founder member of the European Pulmonary Fibrosis Federation and establishes links with PF organisations in North America.

FUTURE PROOFING CARE FOR IPF PATIENTS

APF's report on its first survey used to campaign in parliament for better care.



2017

ON THE UP

Our yearly income was £360k, reaching new levels.



2018

A GROWING TEAM

Board of trustees decides to appoint full-time staff to drive development of the charity. Steve Jones becomes Chair of Trustees.

CAMPAIGN ON ACCESS TO ANTIFIBROTICS

APF launches campaign to persuade NICE and the Scottish Medicines Consortium to make antifibrotics more widely available for people with PF.

NEW WAYS TO HELP

Support Line launches, reaching 200 people in its first year.

In support.
In research.
In progress.

In real, life-changing action.

As we mark this special milestone, I want to take the chance to thank every single one of you for being here. For believing in all that we strive for. Whether that's as part of our incredible team, raising money, researching, campaigning, running support groups or looking after the people you love. We all want the same thing; to help people affected by PF to have a better future. This is something we can all believe in. Here's to the next 10!

"I still remember the meeting where we first considered the possibility of forming a charity. It didn't seem possible that Action for Pulmonary Fibrosis would grow into something this amazing 10 years later."

Professor Gisli Jenkins
APF President and founding member



2023

CAMPAIGNING FOR CHANGE

The launch of #OneVoiceILD with health care professionals across the UK to improve treatment and care for people with PF.

ON THE UP

APF is on track to raise over £1m in 2023 which will help us reach more people than ever and fund vital new research.



2022

PRIORITISING RESEARCH

1400 people help to produce our top 10 research priorities for pulmonary fibrosis in the UK.

CELEBRITY SUPPORT

Our first celebrity appeal goes live, with Julie Hesmondhalgh as the face of the campaign.



2021

FUNDING WIN

We're awarded a £489k grant from the National Lottery Community Fund to extend our services for people living with PF now.

FIRST VIRTUAL EDUCATION DAY

During the pandemic, our first virtual education day sees more than 800 people registering to join.

ANTIFIBROTIC CAMPAIGN SUCCESS

Following APF's campaign, NICE and the SMC authorises the antifibrotic drug nintedanib for use by almost all PF patients in UK.

2020

ONLINE ONLY

We help 30 support groups meet online throughout the pandemic and implement a buddying system for people feeling isolated.

COVID HUB HITS

13,000 people visit our new online Covid Hub in one month.



2019

HERE FOR ALL TYPES OF PF

APF broadens its aims so it serves everyone affected by PF, not just IPF.

RESEARCH PROJECTS LAUNCHED

Our first two research fellowships, costing £600K, are funded helping to make life-changing progress possible.



SCAN ME

We've helped change thousands of lives, but there's so much more we need to do. We want to STOP pulmonary fibrosis. Help us change lives. Text INSIDER to 70450 to donate £10 or scan the QR code.

Ten years. One goal. #StopPF

60 seconds with...

Founding Trustee, Wendy Dickinson

10

2013 – 2023

APF Founding Trustee Wendy Dickinson is a journalist and communications professional and runs the Nottingham Pulmonary Fibrosis (PF) Support Group. Her dad was the Nottingham Forest & Derby County assistant manager, Peter Taylor, who died from idiopathic PF in 1990.

Wendy shares her reflections on starting APF in 2013 alongside the other founding trustees, and how things have changed since then.



Wendy and her brother, Phil, with their Dad's book. It was reprinted last year with royalties going to APF.



"I always walk out of a support group meeting with a spring in my step and an unbreakable belief in the human spirit."

Wendy

Which achievement stands out the most for you as we celebrate 10 years of APF?

There are so many! In the early days it was about getting our website and social media up and running so that people could find us; connecting with the NHS and parliamentary decision-makers; building the support group network as quickly as possible and raising funds.

How is the PF world different now compared to when your dad was diagnosed in 1987?

Everything is different. In those days our family felt abandoned. No one knew about the condition - we didn't meet anyone else who had it; no drugs; no oxygen therapy; no pulmonary rehab. Just me, my mum and my brother watching my dad die within three years of diagnosis. We just couldn't help him.

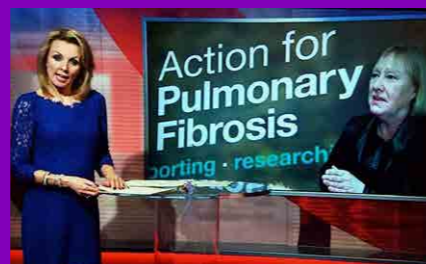
Is there anything that has surprised you about the PF world?

Ten years ago, I was amazed how people affected by PF welcomed the charity. It was as if they had found a home. Fundraisers flocked to hold events, take on challenges and donate. It really showed how patients and families had felt alone but now had a charity that truly represented them. This enthusiasm continues to this day and can be seen in the growing numbers of fantastic volunteers, fundraisers and supporters.

What has been the most important thing you have learned from your involvement with the PF community?

That people affected by PF have amazing resilience and spirit. The Nottingham PF Support Group is a

wonderful bunch of people coping with an awful disease who come together to support each other in the most difficult of times. It doesn't matter what troubles I have or what mood I'm in, I always walk out of a meeting with a spring in my step and an unbreakable belief in the human spirit.



Wendy on BBC Midlands when launching the Nottingham support group.

Research: it's for everyone

Our involvement in research has grown over the last 10 years and we're more committed than ever. We want to make it easier for people to be involved in research and to keep up to date with what's going on.

Al Hinde, 79, living in Lancashire, tells us how his commitment to finding solutions led to him being involved in research.

How did you hear about research opportunities?

I was guided towards research opportunities by the late Geoff Carter, who was the research champion at Tameside Pulmonary Fibrosis (PF) Support Group. Since then, I've taken part in three drug trials and several consultation projects about my experiences of idiopathic PF.

What made you sign up to those trials?

I get interested in investigating things and then I'm like a dog with a rat. I keep going. My main motivation for getting involved is to help find a treatment that stops and reverses PF. That's what I get from being involved in research.

What made the experience positive?

It wasn't just a tick box exercise, you felt valued. One trial, I didn't pass the initial tests to be a participant. Even



Al and Anne Hinde

though I wasn't successful, they took the time to tell me why. I was kept fully involved in what was happening and felt valued.

What was it like to be involved in consultation projects?

There was a group of us and we all added our three pennies worth. It was open and there seemed to be some kind of trust and support for you to say what you wanted to say. If you feel like you're in a relationship where you're trusted, supported and people are open with you, things are usually better. I got that feeling from day one with this group in the consultation project.

Is there anything else you'd like to say?

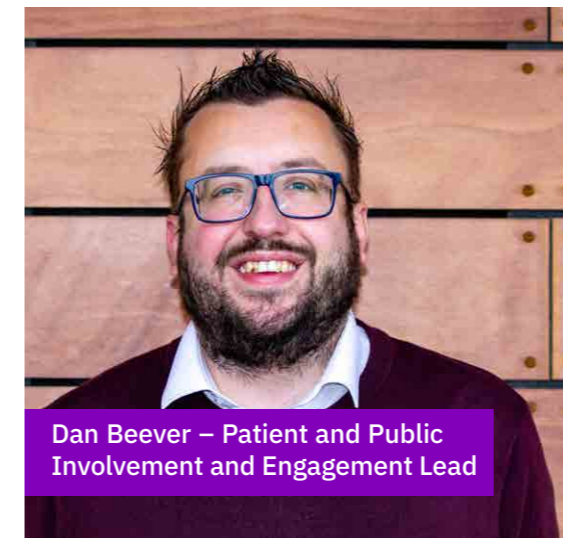
When I take my antifibrotic medication, I'm reminded that this drug was only made possible because of the sacrifices made by people living with PF at the time. This motivates me to commit to research and I believe it's my duty to be committed for as long I am able.

"To me, it's about people bringing their strengths, or just bringing themselves, because people have different perspectives on research."

The research team at Action for Pulmonary Fibrosis are delighted to welcome Dan to their team. He'll be helping to make research accessible to everyone and supporting people affected by PF to get involved.

"People sometimes think that taking part in research or giving their opinions isn't for them. They aren't sure if their input will be valued or worthwhile. The thing is, it's essential to have perspectives from people other than healthcare professionals and researchers. No one knows a condition like those who are affected by it."

People with PF and carers can be part of any stage of the research process, you don't have to be a participant in the trial. You might want to be involved in identifying areas to research, developing applications for funding or supporting studies that are in progress."



Dan Beever – Patient and Public Involvement and Engagement Lead

Are you interested in being involved in research?
Contact research@actionpf.org or call **01733 839642**.



Celebrate 10 years with us!

This year, we're celebrating 10 years of Action for Pulmonary Fibrosis (APF). What we have achieved over the past decade from funding research into pulmonary fibrosis (PF) to growing our support line would not be possible without the passion and dedication of our supporters and people with PF.

The dedication and generosity of our community has increased hope and support for everyone affected by PF.

We are so thankful for every penny raised towards our work.

Even though we've made great progress in the last 10 years, we've still got a long way to go. There are thousands of people living with PF who need our support and we will be there for them.

Help us fund the next 10 years by celebrating our anniversary. The money you raise now could:

- Fund ground-breaking research that could help us put a stop to PF.
- Provide a lifeline to people living with PF in the future through supporting APF's vital services.

You can help us change lives.

Ways to get involved...

Celebrate with your support group – Throw a 10th anniversary party this summer! We'll send you an APF party pack with banners, balloons, information and collection boxes to help get your party started. If you're planning a 10th anniversary party, get in touch with us.

Take on a challenge – We've teamed up with Action Challenge to offer a range of fantastic events across the UK, like the **Peak District Challenge**. The full 100km challenge takes a route through Derbyshire's finest scenery. Or take on a challenge of your own! Contact us to find out more.

Don't forget PF month! – September is **Pulmonary Fibrosis Awareness Month** and our chance to raise awareness and fundraise across the UK. Could you **Go the Distance** and take part in your very own challenge? Will you **Create a Stir** and host a coffee morning?

Do something incredible this September and help us support more people affected by PF to live well for longer. Drop us an email and we'll send you an information pack.



Have you thought about planning for the future?



Did you know that as many as 3 in 5 adults in the UK don't have a will?

We know it can be a daunting thought, but having a will can assure you that your loved ones are provided for.

There are two main ways of leaving gifts in a will:

1. A percentage of an estate (a residuary gift)
2. A fixed sum of money (a pecuniary gift)

We always recommend speaking to a solicitor when arranging your will to make sure your wishes are fulfilled. After providing for those closest to you, would you consider leaving a gift to Action for Pulmonary Fibrosis? Your gift will help us to

create a better future for everyone affected by pulmonary fibrosis (PF) by helping us to:

- Advance our research into PF to find more effective treatments to help patients live well for longer, which could one day help put a stop to PF.
- Ensure we can be there long into the future to support patients and families affected by PF, so nobody has to face this cruel disease alone.

By leaving a gift in your will, you can help us **change lives** and leave a lasting legacy.

If you'd like to have a chat about leaving a gift in your will:

Meet Sharon, our In Memory and Legacies Coordinator, who is here to support you every step of the way. Please get in touch by calling **07376 321672** or email **sharon@actionpulmonaryfibrosis.org**

Here's all the information you need if you want to remember us in your will:

Action for Pulmonary Fibrosis
 Charity address:
 Stuart House, East Wing, St Johns Street,
 Peterborough PE1 5DD
 Registered charity number: 1152399

Support

Befriending

Sometimes support comes from professionals, sometimes it comes from someone in a similar situation who understands what you're going through.



Margaret



Peter

From listening to our community, we realised how important it is to share experiences and created the APF befriending service. Our fantastic volunteer befrienders offer informal support and companionship on the phone. They all have lived experience of pulmonary fibrosis (PF) so anyone looking for a befriender is matched with someone in a similar situation.

Margaret, 65 from Rishton, and Peter, 84 from Norwich, who became friends through the befriending service, talk to us about their experiences.

Why does talking to someone in a similar situation help?

Peter: 'Mostly because we're able to be honest about how we feel. Plus, our personal journeys can be used to help others by sharing information.'

Margaret: 'You don't have to try to explain yourself like you do with family and friends, they already understand how PF affects you both physically and mentally.'

What are the challenges of befriending?

Margaret: 'I felt a bit apprehensive when first becoming a befriender myself in case I wouldn't be able to offer the right support, but most of the time you just need to be a good listener and a sympathetic ear.'

Peter: 'To try and talk to the carer/family about how the befriender is, because, even with the best will in the world, we do try to spin a better picture of how we feel.'

What else has helped you to live with PF?

Peter: 'I have a personal Christian faith which wobbled a bit when I was told I had idiopathic PF and what my life expectancy was. I was able to pray and talk to my pastor – an ex-trauma nurse – about my illness. Being involved with a support group on Zoom was also a breakthrough for me.'

Margaret: 'I recently did a six week course called 'How to still be me' with Minds Matter which had lots of tips and strategies for dealing with long term illness. I'm also going to have some one-to-one counselling as I think your mental health is so important and can really affect your physical health.'

If you're a good listener and have personal experience of PF, as someone with a diagnosis or a carer, you could be our latest befriender!

If you're interested in becoming a befriender or think you would benefit from having a befriender, get in touch with us by calling **01733 839642** or email info@actionpf.org.

Support line
01223 785725

support@actionpf.org

Campaigning: #OneVoiceILD



Not everyone with pulmonary fibrosis (PF) has timely access to the treatments, care and support they need to live well for longer. **We want to change this.**

1 **#OneVoiceILD** is a growing network that is striving to improve treatment, care and support for people affected by PF. We're addressing the issues that people with PF are most concerned about and finding solutions to these problems. Our aim is that everyone affected by PF has a better quality of life and longer life expectancy.



2 **We're coming together with:**

- People affected by PF
- Clinicians across the UK
- Corporate supporters
- Other charities
- Members of Parliament to form **#OneVoiceILD**



3 **Our priorities right now are to:**

- Raise awareness of PF with parliamentarians who can then support our mission.
- Gather data to build an accurate picture of the care received by people living with PF, and the impact on their quality of life.
- **Develop the gold standard in care** that will help clinicians and people living with PF know what to expect from PF care and when to expect it.



4 It's an exciting time for **#OneVoiceILD** as we're in the early stages of our plans.



5 **Want to make a difference?** Over the next few months, there'll be opportunities to get involved with **#OneVoiceILD** to help us bring the changes we all want to see. Help us make a difference by completing our 2023 survey. Your insight will help us develop the evidence we need to improve PF services.



Make sure you don't miss any updates by:

- Following us on social media.
- Signing up for our e-newsletter at: www.actionpf.org/information-and-support/support-groups/newsletter/signup
- Letting us know you're interested in **#OneVoiceILD** by calling **01733 839642**



What does 2033 look like?

10



2013 – 2023

A message from our CEO

As we reach our 10 year milestone, we know there's still so much we need to do. So much more progress we need to see. Because we have to make today better – but we also need to push for brighter tomorrows for everyone with pulmonary fibrosis (PF).



That's why in the next decade, I'm determined that:

Everyone will know what PF is

With more awareness comes the chance for more people to spot the signs and get the support they need. It means people with PF won't have to be isolated and alone. Our voices must be louder and shout further.

We will influence healthcare at a national level

It's the most powerful way we can change the face of patient services in the years to come. We'll expand our team and ensure we are fighting for the gold standard of care that patients and their families need.

Treatments and technology will improve

Let's never stop pushing research forwards. Let's see technology keep up with the patients who need it. And let's see more innovative testing and treatment that will save lives.

One day, we will be able to stop PF

I'm so encouraged by our incredible global network of researchers, scientists, volunteers, patients and experts working together to stop this disease and save lives.

Once again, thank you to everyone who has been part of the past 10 years. Let's stay on this journey together and continue to believe in all that's possible.

Thank you!

Louise Wright CEO

Action for Pulmonary Fibrosis is a patient-driven charity.
Our vision is to stop pulmonary fibrosis so everyone affected has a better future.

Here to help...

Contact our support team:
support@actionpf.org



Support line
01223 785725

General enquiries:

01733 839642
info@actionpf.org

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

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