

Action for Pulmonary Fibrosis Strategy 2019 -2024

Introduction

Pulmonary fibrosis refers to a specific group of lung diseases thought to be affecting around 70,000 people in the UK. The nature of these diseases all cause stiffening or scarring of the lungs, preventing the transfer of oxygen into the bloodstream. It has a devastating impact on both the quality of life and is invariably fatal.

Idiopathic Pulmonary Fibrosis is one of the most aggressive and commonest form of the disease. It has no known cause, limited treatments and no cure. Life expectancy can be between three to five years following diagnosis and around 6,000 people die from it every year in the UK.

The debilitating nature of the disease means as people become increasingly breathless their need for physical and emotional support become greater. Patients and their families can experience a profound sense of loss as the disease progresses. Pulmonary fibrosis affects every area of family life. Yet there is very little dedicated support available to patients and families affected.

After six years of growth APF is well placed to expand its work to meet the growing needs of patients and their families.

Whilst improving the lives of people living with pulmonary fibrosis, we will partner with others to create a world in which people no longer die from pulmonary fibrosis.

APF was set up as a charity in 2013 by a group of patients, family members and healthcare professionals to support patients and families, raise awareness, educate healthcare professionals and fund research. We are now the largest dedicated charity in Europe supporting families and funding research into the causes and treatments of pulmonary fibrosis.

In developing this strategy, we have reflected on what we have achieved so far and assessed how we can best bring about the biggest possible improvements to the lives of people affected by pulmonary fibrosis.

This strategy has been built on the views and experiences of patients, their carers and families. We have also engaged with healthcare professionals and other supporters. We have assessed external factors that are likely to affect our work now and over the next five years.

This resulting strategy is ambitious. During the period of our strategy, 2023 marks APF's 10th birthday and we want families to have something life-changing to celebrate. The increasing pace of research means our understanding of pulmonary fibrosis is growing, but until a cure is found we will continue to better meet the ever-changing needs of pulmonary fibrosis patients and families right now.

This strategy is underpinned by annual plans and budgets that will be reviewed and monitored to track our progress, successes and everything that we have learned along the way.

Every year, in our Annual Reports, we will share our progress and the impact APF is making to the lives of people affected by pulmonary fibrosis.

Our vision, mission and values – drives everything we do

APF's vision is to find a cure for pulmonary fibrosis

so that everyone affected by the disease has a better future. We provide support to families, raise awareness, campaign and educate to improve access to the highest standard of care for everyone affected. We are committed to finding a cure through funding research.

Our values drive everything we do:

- **Patient led:** We empower patients, who are at the heart of everything we do.
- **Caring and compassionate:** We respect and understand the needs of patients and carers, and help them to get the support they need
- **Striving for excellence:** We work with integrity and professionalism in all that we do
- **Open and approachable:** We ensure people affected by pulmonary fibrosis feel able to turn to us for advice and support in their time of need
- **Ambitious:** We will improve the lives of people affected by pulmonary fibrosis and **bold** in the ways we do this.

Starting points for this strategy

Our history

In 2013, APF was formed when two of the leading Interstitial Lung Disease (ILD) doctors met with a small and ambitious group of patients and carers. The result? Action for Pulmonary Fibrosis, the charity, which puts patients and their families at the heart of everything it does. This remains true today. This unique connection of APF to patients and families drives everything the *charity has* achieved.

Ten years ago, knowledge of the disease amongst many healthcare professionals was patchy; a lack of doctors with in-depth knowledge of the disease; there were few specialist respiratory doctors and nurses; little access for patients to pulmonary rehabilitation and very little research into causes or treatments. There were few specialist centres to treat patients and no effective drug therapies. There were very few support groups around the country and little information, either printed or online, for families to access.

Since APF was formed we have:

- Helped nearly **70 support groups** to establish and operate across the UK with more planned in the future so that patients and families do not feel alone
- Set up a **telephone support line and website** to provide growing numbers of patients and their families access to the information they need
- Educated 500 GPs and nurses about pulmonary fibrosis over the past two years through on-going expert-led study sessions across the UK
- **Campaigned for improvements in NHS care** for patients by collecting evidence and lobbying NHS management and politicians. In recent months we have published our 2018 Patient Survey: [Giving Patients a Voice](#) which has featured in three national papers reaching over 7 million readers across the UK
- **Collaborated with specialist organisations** dedicated to improving the care and life expectancy of people with pulmonary fibrosis, including the British Lung Foundation, the British Thoracic Society, and the Interstitial Lung Disease – Integrated Nurse Network (ILD-INN).
- **Helped found the EU-IPFF** (the European IPF & Related Disorders Federation), a group of 17 patient organisations across Europe, improving the quality of life and prognosis for IPF patients
- Funded **research**, including two major fellowships investigating the causes and treatments for IPF with the ultimate aim to **find a cure for the disease**.

Wider context

As part of this review we have been keen to understand the broader changes in society that might impact our focus and how we work.

- ✓ As we are likely to leave the European Union, we will monitor how that will impact the people we work with and support. We will assess and respond to changes as they unfold.
- ✓ Constrained public spending is set to continue over the next five years. Equal and easy access to benefits and statutory services for patients and families is critical to good care.
- ✓ We anticipate increased demands on families affected by pulmonary fibrosis, especially carers, as health and care needs become increasingly complex with age.
- ✓ We want people with pulmonary fibrosis to live longer and have a better quality of life. With an ageing population we anticipate an increase in the number of people living with pulmonary fibrosis.
- ✓ Technological change will continue to contribute to improved quality of life and improved communications for families with pulmonary fibrosis. Patients, families, healthcare professionals, APF staff and volunteers should benefit from greater engagement and communication.
- ✓ There are increasingly more connections between climate change and the effects of pollution and the health of our lungs.
- ✓ The potential for an economic downturn, combined with increasing regulation affecting communication and fundraising, APF remains committed to ethical, cost effective and efficient practices at all times.

What will make the biggest difference to people's lives?

Below are APF's key strategic aims that will drive the focus of our work over the next five years. Our ambitions can only be achieved in collaboration with others.

1. Better treatments and a cure – faster

Families tell us that it's too late for them now, but they want better treatments and a cure so that families in the future don't have to go through what they have.

By 2024, APF will progress its support of research in the following areas:

- ✓ Increased funding of research making APF the leading charitable funder in Europe
- ✓ More people with pulmonary fibrosis will have the opportunity to participate in research than ever before
- ✓ New technologies improving the diagnosis and treatment of pulmonary fibrosis
- ✓ Develop the next generation of researchers

2. Faster and more accurate diagnosis and care

A third of patients told us it took at least six months to be diagnosed with pulmonary fibrosis. Patients and their families really value the help of nurses, physiotherapists and other healthcare professionals but getting access to help is sometimes hard and they don't always understand pulmonary fibrosis.

By 2024, APF will progress the education of healthcare professionals in the following areas:

- ✓ Greater awareness and training to help accurate and timely diagnosis amongst healthcare professionals (especially GP's and Nurses)
- ✓ Greater access to tailored pulmonary rehabilitation
- ✓ Improve timely access to supportive and palliative care services

3. Patients and families who are better informed and supported to live well with pulmonary fibrosis

Being diagnosed with pulmonary fibrosis can be frightening and confusing. Patients and their families need information that is easy to access, understand and is tailored to them at every stage in their journey. Support from who have gone through the same thing is invaluable and helps practically and emotionally.

By 2024, APF will progress providing support and information so that there is:

- ✓ More tailored information from APF online, via email and phone
- ✓ Easier access to emotional and practical help and support; locally and remotely
- ✓ More support for carers and family members

4. Quality public services and a nation more aware of pulmonary fibrosis

Some changes to public services will take longer than the five years of this strategy to achieve. Often we can only influence change but we are committed to ensuring patients' views and experiences influence the nature and quality of public services that are needed to live well. Families tell us how a lack of awareness of the disease affects not just their diagnosis, but also how they are treated. Talking to their own friends and families can be hard. Raising awareness of PF can bring about positive changes, locally and nationally.

By 2024, APF will progress campaigning and raising awareness so that:

- ✓ More people will be aware of pulmonary fibrosis, the symptoms and how-to better support someone with the disease
- ✓ There is greater access to a wider variety of treatments
- ✓ There is greater equality of healthcare
- ✓ PF will be recognised as a disease equal in seriousness to many cancers

5. APF - Here for as long as it takes; sustainable and well run

As the numbers of people living with PF are expected to grow and families tell us about their long road to diagnosis, their battle for care and their hope that one day there will be a cure, APF must invest for the future.

By 2024, APF will continue to develop and invest so that:

- ✓ We have a greater knowledge of our impact and the difference we make to people's lives everyday
- ✓ We continue to focus on cost effectiveness and efficiencies; investing in systems and processes to improve our capacity and ensure money is spent in the right way
- ✓ We support our fundraisers so that we can make a greater difference to more people
- ✓ We grow our dedicated staff and volunteer team who are focussed on impact and rooted in APF's values

Summary

This five-year plan is ambitious, bold and optimistic.

It is built on the needs and experiences of patients and their families. It reflects the experiences and knowledge gained since the charity began in 2013 and has taken into account previous successful achievements. It is rooted in APF's unique position as the voice of patients and families affected by pulmonary fibrosis in the UK.

We thank everyone who has supported our work, past and present. Together we will find a cure and ensure everyone affected by pulmonary fibrosis has a better future.