

## **Action for Pulmonary Fibrosis Strategy 2019 -2024**

### **Introduction**

Pulmonary fibrosis is an umbrella term for a range of progressive, terminal lung diseases which affects around 70,000 people in the UK. The nature of these diseases all cause stiffening and scarring of the lungs, preventing the transfer of oxygen into the bloodstream. It has a devastating impact on quality and quantity of life and on breathing, with many patients having to use supplementary oxygen 24/7 towards the end of their lives.

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

The debilitating nature of these diseases means as people become increasingly breathless their need for physical and emotional support becomes greater. Patients and their families experience a profound sense of loss as the disease progresses – from independence, both financially and physically to increased levels of anxiety and depression. Pulmonary fibrosis affects every area of family life. Yet there is very little dedicated support available to patients and families affected.

This is why Action for Pulmonary Fibrosis (APF) exists.

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 for patients and families and raise money for research. We are now the largest dedicated charity in Europe supporting families and funding research into the causes and treatment 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 10<sup>th</sup> 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 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 help find a cure for pulmonary fibrosis and for everyone affected by the disease to have a better future.** We provide support to families, raise awareness of the disease, campaign and educate to improve access to the highest standard of care for people living with all forms of pulmonary fibrosis. We are also one of the largest funders of pulmonary fibrosis research and are committed to driving the search to find a cure.

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 PF feel able to turn to us for advice and support in their time of need
- **Ambitious:** To improve the lives of people affected by PF 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 health care professionals was patchy; a rarity of doctors and nurses with in-depth knowledge of the disease; there were few specialist respiratory nurses in PF; little access for patients to pulmonary rehabilitation and very little research into causes or treatments. There were no 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 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 of and treatments for IPF with the ultimate aim of **finding a cure for the disease.**

The progress of care and treatments over the past six years has been fast, but we have had a lot to catch up on especially compared to cancer care.

## **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 PF.
- ✓ Technological change will continue to contribute to improved quality of life and improved communications for families with PF. Families, healthcare professionals and APF staff and volunteers should benefit from greater engagement and communication.
- ✓ There are increasingly more connections of climate change and the effects of pollution on our lungs
- ✓ The potential for an economic downturn, combined with increasing regulation affecting communication and fundraising, APF remains committed to ethical 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:

- ✓ More researchers will collaborate and share their breakthroughs
- ✓ More people with PF will have the opportunity to participate in research than ever before
- ✓ Increased funding of research on IPF making APF the leading funder in Europe
- ✓ New technologies improving the diagnosis and treatment of PF

### **2. Faster and more accurate diagnosis and care**

A third of patients told us it took six months or more to get a diagnosis. 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 PF or IPF.

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 palliative care services

### **3. Families who are better informed and supported to live well with pulmonary fibrosis**

Being diagnosed with pulmonary fibrosis is frightening and confusing. Families need information that is easy to access, understand and tailored to them at every stage in their journey. Support from others going through the same thing at the same time is invaluable and helps practically and emotionally.

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

- ✓ More tailored information from APF online, via email and phone
- ✓ Easier access to 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. APF is 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 low 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 PF, 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 continue to focus on efficiency and effectiveness; investing in systems and processes to improve our capacity
- ✓ We have a greater knowledge of our impact and the difference we make to people's lives everyday
- ✓ We look after 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.