



Action for  
Pulmonary  
Fibrosis



# Five-year strategy

2026

For Every Breath, For Every Journey, For Every Future

[actionpf.org](https://actionpf.org)

Charity Commission England & Wales Registered Charity Number: 1152399  
Scottish Charity Regulator Number: SC050992

## 1 Foreword

Pulmonary fibrosis is a devastating condition and for far too long it has been under recognised, underfunded and misunderstood. Action for Pulmonary Fibrosis is determined to change that and our new five year strategy is part of that change.

Over the next five years, Action for Pulmonary Fibrosis will work to ensure that no one faces pulmonary fibrosis alone and that fewer lives are lost to this disease.

We will continue to do what we do best, providing trusted, compassionate support to people affected by pulmonary fibrosis, informed by their lived experience. However, we will also go further by providing significant investment into research that brings us closer to a cure; campaigning for faster diagnosis and fairer access to care; and working across the UK to improve care and inclusion for everyone affected by pulmonary fibrosis.

Our strategy is ambitious but so are the people we support. People living with pulmonary fibrosis face uncertainty and isolation with extraordinary courage. Their determination inspires us every day and it will drive this strategy forward.

We're proud of what Action for Pulmonary Fibrosis has become, a respected national charity, rooted in community and evidence, with a clear voice and a growing impact. We are proud too of the people behind this strategy – our staff, trustees, volunteers, fundraisers, partners, supporters and especially the people with lived experience who have helped shape it.

Together, we are building something that lasts. Not just services, partnerships or campaigns but a movement. One that brings hope, challenges injustice and works every day to improve lives.

Thank you for being part of it.



**Daniel Saxton**  
Chief Executive Officer



**Mike Stubbins**  
Chair

January 2026

## 2 About Action for Pulmonary Fibrosis

Action for Pulmonary Fibrosis (APF) is the UK's leading charity dedicated to supporting people affected by pulmonary fibrosis, driving research and shaping policy. We are rooted in the lived experiences of patients, families, carers and clinicians and united by a shared belief that **people with pulmonary fibrosis deserve better.**

### Our Mission

We work together to stop lives being lost to pulmonary fibrosis.

### Our Purpose

We bring people together to drive change so that everyone affected by pulmonary fibrosis can live well for longer.

### Our Vision

A future where everyone with pulmonary fibrosis has access to effective, evidence-based care and ultimately, a cure.

Our work spans four interconnected areas:

- ✔ **Support:** Providing trusted, compassionate support for people affected by pulmonary fibrosis.
- ✔ **Awareness:** Raising the profile of pulmonary fibrosis and tackling stigma and misinformation.
- ✔ **Advocacy:** Campaigning for faster diagnosis, better care and health equality.
- ✔ **Research:** Funding and influencing science to improve lives and bring hope.

We are a values-led organisation. In everything we do, we strive to be:



### Compassionate

Listening to and acting on the voices of people affected by pulmonary fibrosis.



### Expert

Combining lived experience with scientific and clinical evidence to inform everything we do.



### Bold

Challenging inequality and striving for lasting change in diagnosis and care.



### Collaborative

Working across sectors and communities to achieve greater impact together.

### 3 The journey so far: our growth and impact

Since Action for Pulmonary Fibrosis was founded in 2013, it has grown from a grassroots initiative into the UK's leading charity for people affected by pulmonary fibrosis and a world-leader in patient advocacy.

Born from the vision of patients and clinicians who knew that people deserved better, Action for Pulmonary Fibrosis has become a driving force for support, awareness, research and policy change.

Over the last decade, we have reached tens of thousands of people through our support line, online education, printed resources and digital tools, as well as supporting over 80 local support groups across the UK.

We have advocated for increased access to life-extending treatments, launched a pathway for pulmonary fibrosis treatment within the NHS, invested in pioneering pulmonary fibrosis research and built one of the UK's largest lived experience involvement networks.

Our impact has grown, but so too has the need. More people are being diagnosed with pulmonary fibrosis each year, yet still too often diagnosis takes too long and access to care remains unequal. Research funding continues to fall behind other conditions and persistent health inequalities shape lives in unjust ways.

This strategy builds on a strong foundation while looking firmly to the future. A future where fewer lives are lost to pulmonary fibrosis and everyone affected gets the support, care and hope they deserve.

### 4 Why now: the case for change

The next five years represents a pivotal window for progress on pulmonary fibrosis care and research. Despite its severity, pulmonary fibrosis remains under recognised and underfunded.

The number of people affected is growing, NHS services are overstretched and research breakthroughs are urgently needed. Action for Pulmonary Fibrosis is uniquely positioned to lead and support this shift.

We are trusted by people with pulmonary fibrosis, respected by clinicians and increasingly recognised as a national and international voice in health and research policy.

This strategy outlines how we will use that position to bring about lasting change for individuals, families and the wider pulmonary fibrosis community.

Our strategy is built around three bold priorities, each designed to drive meaningful change for people affected by pulmonary fibrosis. They are rooted in the real needs, ambitions and voices of our community.

Each priority sets out a significant focus area where Action for Pulmonary Fibrosis will concentrate energy, investment and leadership over the next five years. They form a framework for change: improving support and care today; transforming diagnosis and pathways tomorrow; and driving the discovery of new treatments and ultimately, a cure for the future.

Our strategic priorities are ambitious. They reflect who we are – a charity rooted in compassion, driven by lived experience and determined to create lasting change. They form the driving force that will define the next chapter for Action for Pulmonary Fibrosis and most importantly, for the thousands of families we support.

### Our three strategic priorities:



#### For Every Breath

Expanding trusted support, information and services so that no one faces pulmonary fibrosis alone.



#### For Every Journey

Championing faster diagnosis, fairer care and a world-leading model of pulmonary fibrosis healthcare.



#### For Every Future

Investing in bold, inclusive research that improves lives now and brings us closer to a cure.



## Strategic priority

# For Every Breath

### **Expanding trusted support, information and services so that no one faces pulmonary fibrosis alone.**

Living with pulmonary fibrosis often means navigating complex physical, emotional and practical challenges, yet too many people face gaps in their care and delays in accessing support. While the NHS provides essential clinical treatment, Action for Pulmonary Fibrosis is uniquely placed to complement this with a nationally accessible support, information and education service that is shaped by lived experience.

Over the next five years, we will invest in developing Action for Pulmonary Fibrosis as a trusted provider of clinically informed support services. Alongside this we will work with local support groups and partners to reach people earlier in their journey, help them live well with pulmonary fibrosis and ensure no one is left to cope alone.

Strategic project	What we will do
<b>Specialist support line and clinical hub</b>	Develop our support line into a nationally accredited, clinically informed service that offers holistic, person-centred support and guidance.
<b>Volunteer led support network</b>	Build a national network of volunteers to increase our reach, amplify our voice and deliver real impact. Volunteers will act as ambassadors, helping to extend our services, build community connections, raise awareness and drive fundraising across the UK.
<b>Trusted information and education hub</b>	Become the leading provider of trusted, accurate and accessible information and education for everyone affected by pulmonary fibrosis.
<b>Psychological and bereavement support</b>	Ensure that people with pulmonary fibrosis, and people who care or grieve for them, have access to compassionate emotional and psychological support.
<b>Tackling inequity in care</b>	Everyone affected by pulmonary fibrosis deserves access to high-quality support. We will take a bold, proactive approach to equity, designing services that not only remove barriers, but actively restore imbalances in access and outcomes.
<b>Empowering inclusive, sustainable support groups</b>	We will strengthen our relationships with local support groups through an affiliation offer, providing clarity, connection and practical support for groups that choose to partner more closely with us. We will continue to collaborate respectfully with all groups that support people affected by pulmonary fibrosis.
<b>Strengthening prevention through awareness and education</b>	We will use our national communications and education platforms to lead the way on prevention messaging. Better understanding of risk factors, earlier identification of symptoms and improved workplace awareness can help reduce harm, support timely diagnosis and improve outcomes.





**Strategic priority**

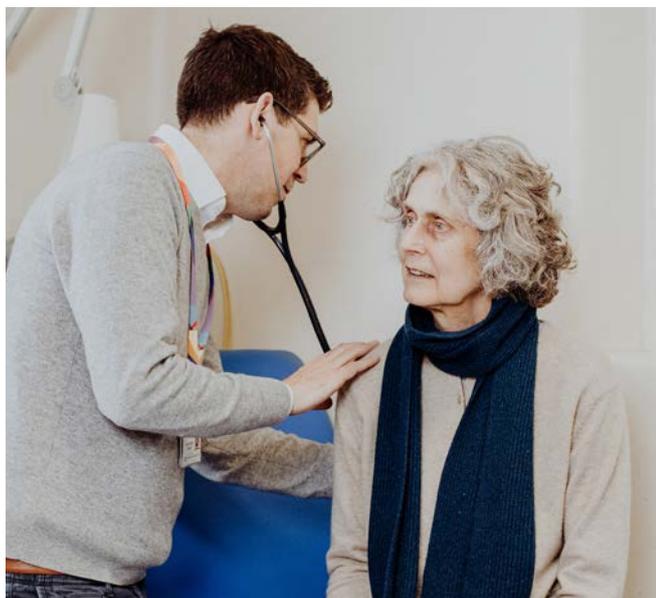
# For Every Journey

**Championing faster diagnosis, fairer care and a world-leading pulmonary fibrosis pathway.**

Pulmonary fibrosis care remains unequal and under resourced. We believe everyone affected by pulmonary fibrosis should receive the same high standard of care, no matter who they are or where they live.

Over the next five years, we will champion and support the delivery of a world leading model of pulmonary fibrosis care – equitable, evidence based and shaped by lived experience, bringing together all stakeholders with an interest in improving interstitial lung disease care.

Strategic project	What we will do
<b>OneVoiceILD UK wide implementation</b>	Lead and support the national rollout of a tiered, standardised pulmonary fibrosis care model for each of the four nations.
<b>National policy influence</b>	Strengthen our position in the UK policy landscape as the leading advocate for people affected by pulmonary fibrosis.
<b>Pulmonary fibrosis data infrastructure and leadership</b>	Position Action for Pulmonary Fibrosis as the UK's leading voice on pulmonary fibrosis data, championing transparency, accountability and action.
<b>National standards and centre accreditation</b>	Explore the development and implementation of a framework for pulmonary fibrosis centres of excellence that set out what world-class care looks like and supports services to achieve it.
<b>Building professional knowledge to improve patient care</b>	Equip healthcare professionals with the knowledge, skills and support to deliver faster diagnosis, better care pathways and improved outcomes for people with pulmonary fibrosis.
<b>International collaboration and leadership</b>	Strengthen our global connections to accelerate progress for people affected by pulmonary fibrosis, by driving innovation, improving standards of care and promoting global equity in access to treatment and support.
<b>Clinical engagement and influence network</b>	Establish a national clinical engagement function to build strong, two-way relationships with interstitial lung disease clinicians, nurses and professional networks to amplify the voice of the patient and support best practice.



Strategic priority

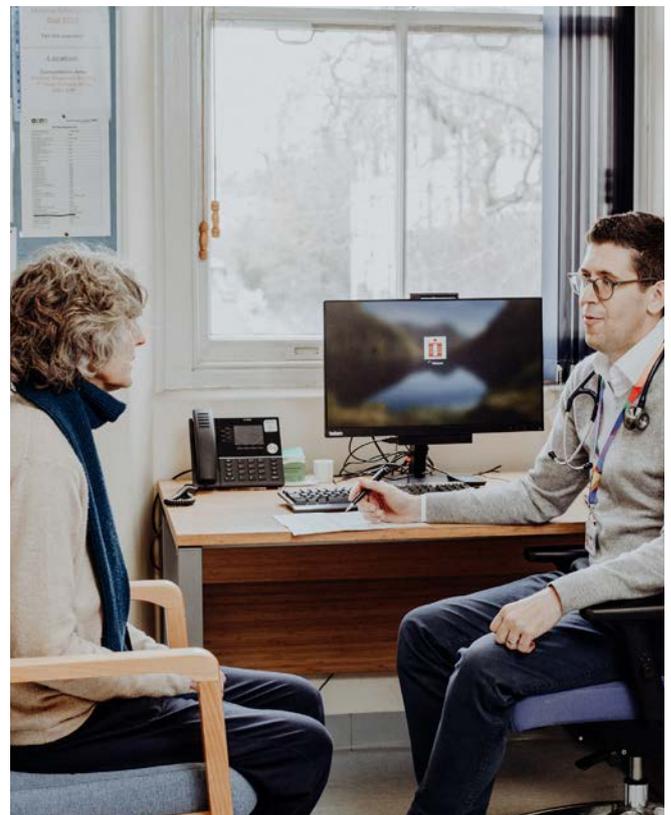
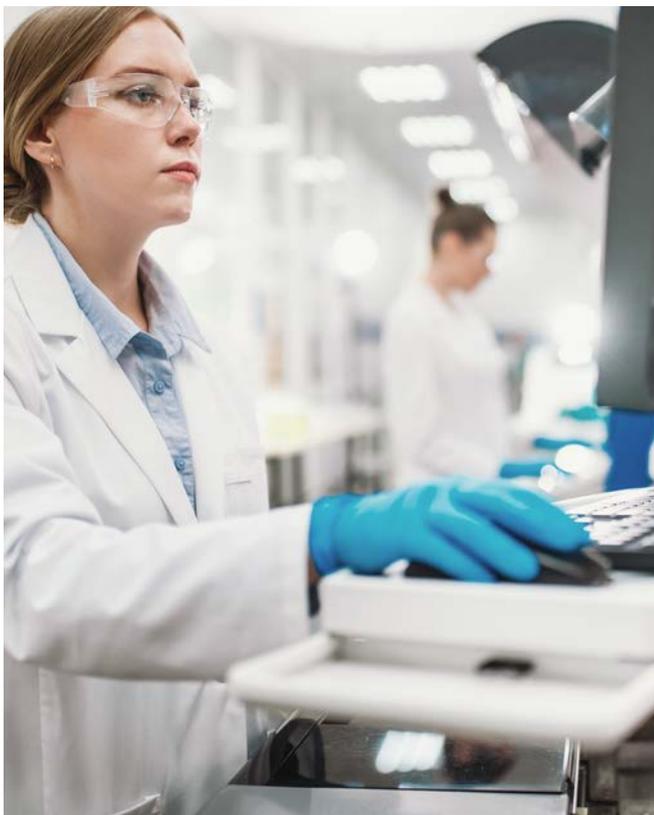
# For Every Future

**Drive bold, inclusive research to improve lives now and bring us closer to a cure for pulmonary fibrosis.**

There is currently no cure for pulmonary fibrosis but we are working towards one. Through bold, collaborative research and patient driven innovation, we aim to accelerate the development of new treatments, improve care and build hope.

Over the next five years, we will invest in inclusive, impactful research shaped by lived experience. We will strengthen our role as the UK's leading pulmonary fibrosis research charity, grow our patient involvement network and influence national and global research agendas in partnership with the pharmaceutical sector.

Strategic project	What we will do
<b>Inclusive, patient-led funded research and participation</b>	Strengthen our role as the leading patient-led research funder in the UK. Drive research that reflects the priorities, experiences and hopes of people with pulmonary fibrosis, investing in impactful studies and ensuring people living with pulmonary fibrosis have opportunities to participate and shape research.
<b>Global leadership on patient involvement</b>	Build a world-leading involvement network that will grow into a patient advocacy programme, ensuring the voices of people affected by pulmonary fibrosis drive innovation and influence global change.
<b>Collaboration with industry and academia</b>	Strengthen partnerships with the pharmaceutical and research sectors, promoting ethical collaboration that advances patient-led progress.
<b>Research advocacy, communications and sector influence</b>	We will position Action for Pulmonary Fibrosis as the leading advocate and communicator for pulmonary fibrosis research - informing, inspiring and influencing change.



## 6 Strategic pillars: building the foundations for delivery

Delivering bold change takes more than a vision. To achieve lasting impact for people affected by pulmonary fibrosis, Action for Pulmonary Fibrosis must be strong, agile, inclusive and financially stable. An organisation that is ready to deliver at scale and with confidence.

Alongside our three strategic priorities, we will invest in three strategic pillars, the internal foundations that enable delivery, growth and resilience. Together, these pillars ensure that Action for Pulmonary Fibrosis has the structure, culture and resources required to deliver this strategy, not just ambitiously, but sustainably.



### **Shaped by Experience**

Embed the insight and lived experience of people affected by pulmonary fibrosis across all areas of our work.



### **Stronger Foundations**

Build the governance, infrastructure and processes that allow Action for Pulmonary Fibrosis to operate efficiently, transparently and with confidence at scale.



### **Funding the Future**

Grow diverse, ethical and sustainable income streams and embed a fundraising culture that empowers Action for Pulmonary Fibrosis to deliver independent, high-impact action.



## Strategic pillar

# Shaped by Experience

### **Embed lived experience and inclusivity at the heart of everything we do.**

People affected by pulmonary fibrosis and those who work alongside them, are central to everything Action for Pulmonary Fibrosis delivers.

Over the next five years, we will establish a national volunteer network, grow a thriving, inclusive workforce and make sure lived experience directly shapes our strategy, services and culture.

By building confidence, contributions and opportunity across the Action for Pulmonary Fibrosis community, we will become stronger, smarter and more connected, ensuring we can deliver greater impact for the people we support.

Strategic project	What we will do
<b>Volunteer development and leadership</b>	Establish a national volunteer network that reflects our community, delivers impact and grows with purpose.
<b>Embed lived experience across Action for Pulmonary Fibrosis</b>	Ensure people affected by pulmonary fibrosis are central to our decision making, design and delivery.
<b>Workforce development and inclusive culture</b>	Create a workplace where people thrive, contribute meaningfully and are supported to grow.
<b>Build excellence in people management</b>	Embed the tools, standards and values that enable consistent, people-centred leadership.
<b>Data and insight to strengthen supporter relationships</b>	Use insight to build stronger, more personal and effective relationships with supporters.



## Strategic pillar

# Stronger Foundations

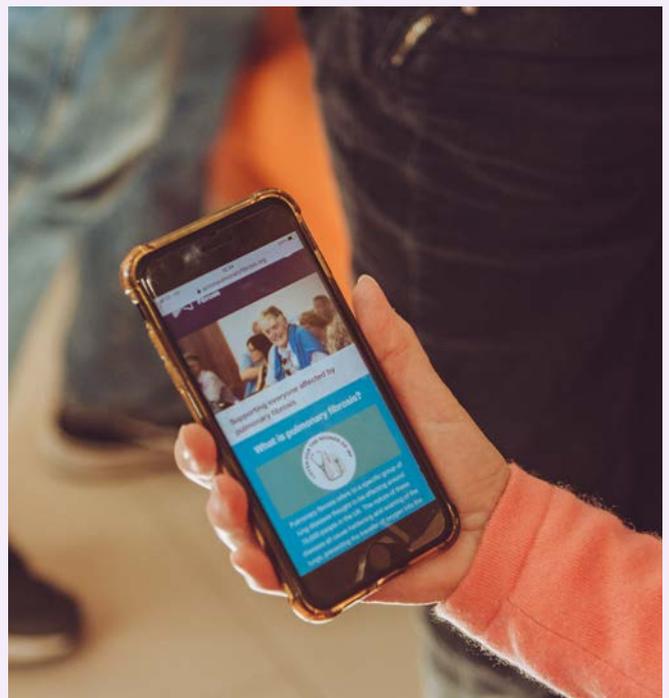
### **Build the governance and infrastructure to support sustainable, high impact delivery.**

Action for Pulmonary Fibrosis's ability to deliver this strategy depends on strong internal foundations – our platforms, people and processes. These enable us to grow responsibly, act decisively and respond with confidence.

Over the next five years, we will invest in modern digital infrastructure, including secure and scalable data systems and communication channels, to strengthen our reach, reliability and resilience. We will embed best practice governance and financial oversight, ensuring our Board of Trustees, committees and reporting systems are robust, inclusive and accountable.

We will protect our long-term sustainability through clear financial planning, reserve management and ethical investment. We will create a modern, flexible working environment that enables staff and volunteers to work productively, collaboratively and with purpose. Through improved internal systems, we will ensure that every interaction with Action for Pulmonary Fibrosis, whether digital, personal or public, reflects the trust and professionalism we work hard to earn.

Strategic project	What we will do
<b>Smarter systems and secure data</b>	Invest in digital infrastructure that enables us to grow, adapt and support with excellence.
<b>Governance, compliance and Board assurance</b>	Embed high standards of governance to protect our mission, people and long-term success.
<b>Financial strategy and performance management</b>	Build financial resilience to fuel growth, deliver impact and protect our future.
<b>Modern, flexible working environment</b>	Create the conditions for people to do their best work, wherever they are.
<b>Patient-centred design and user experience</b>	Make every interaction with Action for Pulmonary Fibrosis work for the people we support.
<b>Communications development and digital engagement</b>	Strengthen our communications infrastructure to provide trusted, accessible information and deepen our engagement with people affected by pulmonary fibrosis, healthcare professionals and supporters.
<b>External accreditation and quality standards</b>	Pursue recognised accreditations that reflect our values and ensure we are operating to the highest standards across all areas of our work, demonstrating our commitment to excellence, transparency and best practice.





## Strategic pillar

# Funding the Future

**Secure diverse, ethical and sustainable income to deliver long-term impact, independence and growth for people affected by pulmonary fibrosis.**

Growing sustainable income is vital to deliver on ambitious plans to transform the lives of people affected by pulmonary fibrosis.

We have a responsibility to secure the resources needed to expand support, drive research and influence real change, not just today, but for the future.

We will strengthen every aspect of our fundraising, building deeper relationships with supporters and positioning Action for Pulmonary Fibrosis at the forefront of ethical, sector-leading income generation for pulmonary fibrosis.

Strategic project	What we will do
Diversify and grow sources of income	Expand and strengthen income streams to support long-term delivery and reduce financial risk.
Reinvigorate fundraising among communities and support groups	Strengthen grassroots fundraising to empower local communities and increase regional reach.
Embed a donor-centric approach	Build meaningful, long-term relationships with supporters by putting their experience first.
Build an organisational fundraising culture	Create a shared mindset across Action for Pulmonary Fibrosis that values and supports fundraising as part of our mission.
Strengthen strategic and ethical partnerships	Ensure Action for Pulmonary Fibrosis’s collaborations generate impact while upholding our values and independence.
Drive excellence and sector leadership	Optimise operations and showcase Action for Pulmonary Fibrosis’s leadership in ethical, high-impact fundraising.



## 7 Making it real: planning oversight and adaption

This strategic plan sets out a bold vision for change. Its success will depend on how we implement, monitor and adapt in response to learning, insight and changing needs. We will embed strong planning, governance and review structures that ensure the strategy remains a living, evolving commitment to the people we support.

### **Annual planning and oversight**

Each year, the Senior Leadership Team will produce a detailed delivery and financial plan aligned to this strategy. We will define clear operational objectives and KPIs, detailed income and expenditure plans, precise organisational priorities and highlight the key risks and mitigation strategies.

### **Governance and review**

Strategic delivery will be overseen by the Board of Trustees, supported by quarterly progress reviews, subcommittees and consistent collaboration and engagement with the CEO and Senior Leadership Team.

### **Mid-strategy review (2028)**

A formal mid-strategy review will be undertaken in 2028. This will assess the progress against intended outcomes, the financial and operational assumptions and external changes in policy, workforce or the wider environment.



## 8 Measuring our impact

To deliver real impact, we must be clear about the long-term outcomes this strategy is designed to achieve and define what success will look like by 2030.

Measuring our impact is essential to understanding whether our work is improving lives, informing change and delivering value for the people we support.

We will track delivery through a strategic outcomes' framework, publish annual impact reports and involve people with pulmonary fibrosis in defining, measuring and reviewing progress.

### Outcomes frameworks: what success looks like

#### Strategic priorities – intended outcomes

Strategic Priority	What success looks like
<b>For Every Breath</b>	People affected by pulmonary fibrosis have timely access to trusted support, information and services, wherever they live in the UK.
<b>For Every Journey</b>	Diagnosis is faster, care is more equitable and people experience a joined up healthcare journey informed by national standards.
<b>For Every Future</b>	Pulmonary fibrosis research is more inclusive, better resourced and shaped by the priorities of people living with the condition.

#### Strategic pillars – intended outcomes

Enabler	What success looks like
<b>Stronger Foundations</b>	Action for Pulmonary Fibrosis operates with excellence, transparency and resilience, enabling sustainable growth and delivery at scale.
<b>Shaped by Experience</b>	People affected by pulmonary fibrosis, and our workforce, help shape our strategy, services and culture at every level.
<b>Funding the Future</b>	Action for Pulmonary Fibrosis secures diverse, ethical and sustainable income to deliver long-term independence and greater impact.

## 9 Our financial approach

We will grow our income from an estimated £1.7 million to £3.5 million over the strategy period, enabling strategic investment in services, research, infrastructure and a new programme of charitable grant-giving.

Our financial approach is phased:

### Long-Term Financial Ambition (2025–2030)

Year	Income	Expenditure	Position	Strategic Phase
2025/26	2,000,000	£2,000,000	Break-even	Reset and stabilise
2026/27	£2,200,000	£2,100,000	+£100,000	Reserve growth
2027/28	£2,600,000	£2,400,000	+£200,000	Reserve growth
2028/29	£3,000,000	£3,100,000	-£100,000	Strategic investment
2029/30	£3,500,000	£3,600,000	-£100,000	Strategic investment

These figures are illustrative and intended to provide a directional model. All forecasts are subject to annual review and adjustment based on organisational performance and external context.

This roadmap is designed to balance ambition with stability and will be reviewed annually to respond to organisational priorities and external conditions.

## 10 Our commitment

We believe that change is possible because we see it every day in the courage, strength and determination of the people we support.

This strategy is more than a plan. It is a commitment to stand with everyone affected by pulmonary fibrosis, to drive faster progress and to build a future where no one faces this disease alone.

We know the road ahead will not always be easy. But we move forward with clarity, with purpose and with the extraordinary power of community at our side.

Every project we deliver, every partnership we build, every voice we raise, are all steps towards the world we believe is possible.

# 5 Year Strategy – 2026

Pulmonary fibrosis is a devastating condition that is under recognised and misunderstood. Action for Pulmonary Fibrosis is determined to change that and we will work to ensure that no one faces pulmonary fibrosis alone and that fewer lives are lost to this disease.

## Our Mission

We work together to stop lives being lost to pulmonary fibrosis.

## Our Purpose

We bring people together to drive change so that everyone affected by pulmonary fibrosis can live well for longer.

## Our Vision

A future where everyone with pulmonary fibrosis has access to effective, evidence-based care and ultimately, a cure.

## Strategic priorities

Our strategy is built around three bold priorities, each designed to drive meaningful change for people affected by pulmonary fibrosis.



### For Every Breath

Expanding trusted support, information and services.



### For Every Journey

Championing faster diagnosis, fairer care and a world leading healthcare model.



### For Every Future

Investing in bold inclusive research that brings us closer to a cure.

## Strategic Pillars

Alongside our three strategic priorities, we will invest in three strategic pillars, the internal foundations that enable delivery, growth and resilience:



### Shaped by Experience

Embed the insight and lived experience of people with pulmonary fibrosis.



### Stronger Foundations

Building the governance and infrastructure that allow APF to operate efficiently.



### Funding the Future

Growing diverse and sustainable income streams to deliver independent, high impact action.

## Values

We are a values-led organisation. In everything we do, we strive to be:



Compassionate



Expert



Bold



Collaborative

Together, we will make the difference.



For Every  
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For Every  
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