



STRATEGIC PLAN 2024-30

Foreword

It gives us great pleasure to present PSC Support's new five-year strategic plan. This document has been shaped by the lived experience of those affected by Primary Sclerosing Cholangitis (PSC), the knowledge we have gained through our work and our vision to see a world without PSC.

PSC is a rare and complex disease affecting thousands of individuals and their loved ones in the UK. Those affected by PSC are often faced with uncertainty, anxiety, and frustration as they navigate a healthcare system that is still catching up with their needs. We continue to be inspired by the enormous strength and resilience of those living with PSC, despite all the challenges they face.

Through collaboration with patients, researchers, healthcare professionals, and other partners, we've come a long way, but there is still much to do.

We have laid out our roadmap for the next five years of our work, building on three pillars: empowering our community, progressing research and demanding better care. We are committed to providing first-class information and support, driving critical research and advocating for improved care and treatments for PSC. We believe that by focusing our efforts on these important areas, we can make significant inroads towards improving lives now, while also working towards a future where no one suffers from PSC.

On behalf of the trustees, staff and volunteers at PSC Support, thank you for helping us to achieve our vision.

#LetsBeatPSC



Tim Waterson
Chair



Paula Hanford
CEO, PSC Support

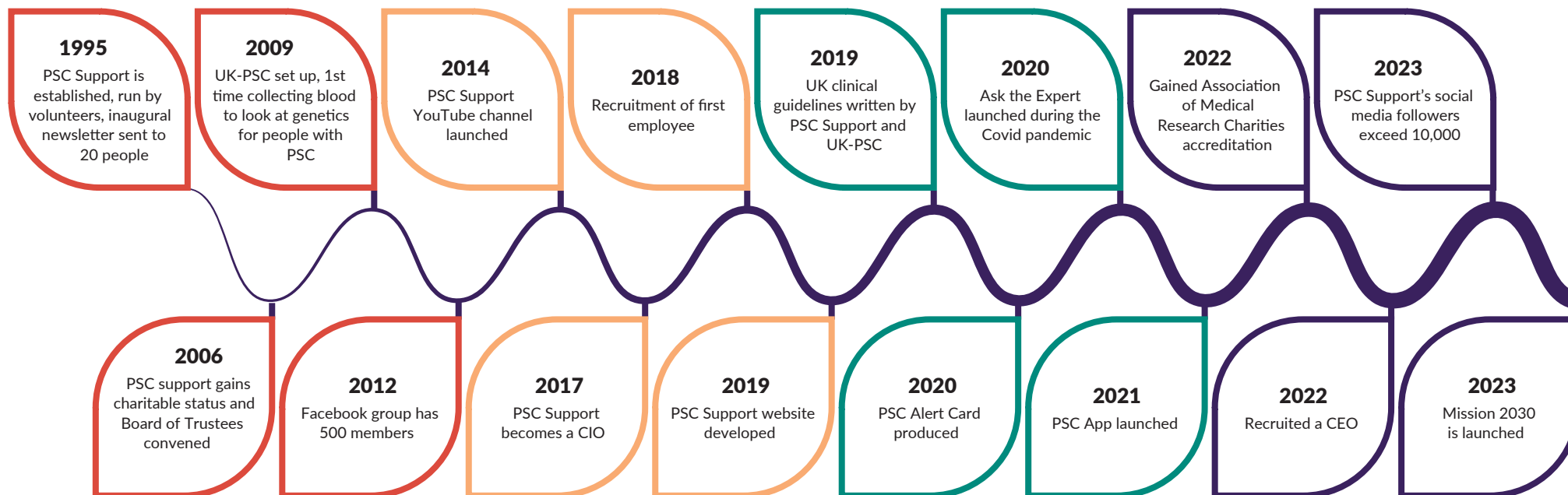
Why are we needed?

In the UK, between 5,000 to 10,000 individuals live with PSC making it a rare disease but one with a profound and far reaching impact on those affected by it. It is an unmet clinical need and a disease which is under-resourced and under-researched.

PSC is an incurable condition that significantly impairs the lives of those affected. It is often invisible, leading to widespread misunderstanding and inadequate support for individuals with the disease. Many medical professionals lack comprehensive knowledge of PSC, exacerbating the challenges faced by patients. The insufficient research into PSC further highlights the urgency of our involvement.

PSC Support is the only UK charity solely focused on PSC aimed at improving the lives of people living with PSC and promoting and funding research into the disease. We are working hard to change the futures of those affected by PSC and help them lead happy and healthy lives.

PSC Support Timeline



Introduction

Having been run for many years by extremely dedicated volunteers, PSC Support recruited its first part time member of staff in 2018. Since then the staff base, although still small, has expanded to allow us to address the ambitions of the charity.

2023 saw the launch of **Mission 2030: Help us Find an Effective Treatment for PSC**. As part of this campaign the charity has committed at least £1 million to PSC research by 2030, allocated through peer reviewed funding including the funding of a dedicated three-year research fellowship. There is an urgent need to develop effective treatments for everyone with PSC with Mission 2030 remaining a focal point for the charity for the foreseeable future.

None of these accomplishments would be possible without the unwavering support of fundraisers and donors and we would like to take this opportunity to thank all those involved in achieving our goals.

Our team

PSC Support is governed by nine trustees each with their own unique skill set including finance, legal, HR, digital, communications, data protection, medical and governance. Our board represents a diverse team of talented individuals.

PSC Support employs a small team, comprised of CEO, Head of Research Strategy, Administration Manager, Fundraising and Events Officer, and Helpline Nurse Manager. We are gratefully supported by a freelance marketer and several dedicated volunteers who are responsible for fundraising, merchandise and Facebook moderation on a daily basis. PSC Support also recognises the pivotal contribution from medical experts and patients who provide vital insight and perspectives to ensure we continue to provide accurate and relevant information for the PSC community.

Our Approach



Our Vision is to see a world without PSC.



Our Mission is to improve the lives of people affected by PSC through research, information and support, and improved patient care.



Our Values are at the heart of PSC Support guiding our work and how we operate:

- **Transparency** We are transparent and accountable to all our stakeholders.
- **Together We're Better** We work collaboratively with all our stakeholders to deliver the best outcomes for PSC patients.
- **Patient Voice** Patient involvement and contribution enables patients' voices to be heard in all aspects of our work.
- **Tenacity** We will never give up hope. We will never give up our search for a cure.

Our strategic plan has been updated to guide the next phase of PSC Support by improving on our three key pillars of focus, in line with our unwavering commitment to improve the lives of those affected by PSC. As an organisation, it is important to regularly step back, review the unmet needs of the PSC community, and assess the evolving challenges and opportunities in diagnosis and treatment. We aim to maximise the impact of our work and improve outcomes for people living with PSC by refreshing our focus and exploring new ideas.

PSC Support's Strategic Objectives

Research

Our goal is to improve understanding of the biology behind PSC and turn new discoveries into tools and treatments that can quickly diagnose PSC, identify those most at risk, and manage symptoms and complications. We work closely with patients and experts in science and industry to support and fund new research.

With our Mission 2030 campaign, we're working with research partners around the world who share our vision for the PSC community. We're determined to gather more evidence on PSC and explore every option. We're improving our research efforts to ensure transparency, thoroughness, and effective global collaboration.

We believe our research will make a real difference and improve outcomes for everyone affected by PSC.

Accelerate PSC research through powerful partnerships

- Invest in top-quality research from the best teams.
- Build strong partnerships with industry, universities, other funders, regulators, and other patient organisations, while encouraging new ideas.
- Elevate the voices of people with PSC to guide and shape research.
- Support participation in clinical trials and studies.

Information and Support

We understand that knowledge is power for many people living with a disease. That's why providing information and support is central to what we do.

We offer timely, accurate information, evidence-based educational resources, and support services created with input from people with PSC. Their insights help us deliver relevant materials to various groups, including patients, families, employers, and medical professionals.

By raising awareness of PSC-related diseases like IBD and partnering with other patient organisations, we aim to help more people through their PSC diagnosis and treatment.

Engage and inform a wider PSC community with quality information

- Continue being a trusted source of clear, up-to-date PSC education and trial information for doctors and patients.
- Make information easier for patients to access.
- Increase PSC knowledge among healthcare providers, especially those working with related conditions.
- Use new technology early to connect better with new and existing audiences

Improving Patient Care

PSC is a rare, complex, and unpredictable disease. People with PSC need to feel confident in their care no matter where they live. They also need hope for the future and the chance to reach their full potential at work, in school, and in other parts of life.

We aim to support everyone in the PSC community and give a voice to those who feel unheard or have unmet needs, whether those needs are medical, emotional, or social.

As an organisation, we use our experience and knowledge of PSC to help develop new technologies and medicines. We work to ensure these advances are reviewed quickly by regulators so that people with PSC can benefit from them as soon as possible.

Improve outcomes for people living with PSC

- Expand our reach and engagement of the PSC patient community.
- Advocate for the needs and priorities of PSC patients in clinical guidelines.
- Build stronger partnerships with regulators and policymakers to speed up approval, access, and coverage for new tests and treatments.
- Work with our partners to influence government and medical bodies to raise awareness of PSC and address the unmet need.

These strategic objectives are underpinned by the following functional areas:



Fundraising

We raise income to deliver our ambitions for all of our services, including our commitment to invest £1 million into research by 2030, by:

- Ensuring our fundraisers and donors have the best possible experience in raising money for the charity by increasing fundraising capacity
- Developing new fundraising products to keep our fundraisers interested and to give them easy fundraising options. This includes our new annual 20K Your Way Challenge and the 750 running events we have on our website.
- Exploring new income streams including trust and foundation fundraising for the first time with a target of funding our nurse-led helpline and other initiatives.



Governance

We govern the charity to maximise the benefit for those affected by PSC by:

- Regularly reviewing our strategy and by conducting an annual strategy day to bring together staff, trustees and other stakeholders
- Following the Charity Governance Code and other charity legal and best practice guidelines
- Ensuring our trustee board always has the skills to support the work of the charity
- Implementing robust monitoring and evaluation mechanisms to assess the effectiveness of our services



Staff and Volunteers

Skilled and dedicated staff and volunteers drive our research and services, we are committed to:

- Reviewing our staff needs at the end of 2024
- Expanding our volunteer base in 2025 to help develop our services

Our Partners

We will continue to work collaboratively with partners and other stakeholders to share information, expedite research and care for those affected by PSC. Our partners include:

- PSC Partners Seeking a Cure
- Other PSC patient groups across Europe and in Australia
- European Liver Patients Association
- European Reference Network for Rare Liver Diseases
- The British Liver Trust
- The AMMF –the cholangiocarcinoma charity
- The National Liver Alliance
- The UK-PSC
- The National Bowel Alliance

PSC Support remains committed to our mission of creating a lasting positive impact for those affected by PSC. With this strategic plan, we will continue to work collaboratively and relentlessly towards achieving meaningful change for our community.

To get in touch please email the CEO,
Paula Hanford paula@pscsupport.org.uk.