

A world without PSC



PSC Support Trustee

Recruitment Pack



Trustee Vacancies

Digital, Communications, HR and Young Trustee

How to Apply

- To find out more about our charity, please see www.pscsupport.org.uk
- To apply, please email your CV and cover letter to paula@pscsupport.org.uk.
- Deadline for applications: 18th November 2022
- Interviews (via Zoom): tbc

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Introduction from Tim Waterson, Chair of Trustees

Thank you for your interest in volunteering as a Trustee with PSC Support.

PSC Support is a small charity that improves the lives of people affected by the rare, autoimmune liver disease, primary sclerosing cholangitis (PSC).



PSC affects people of all ages and can lead to advanced liver disease, requiring life-saving liver transplant. Despite being rare, PSC is one of the leading indications for liver transplant in Europe. PSC has no cure and confers an increased risk of aggressive cancers such as bile duct cancer and bowel cancer. On top of that, people with PSC live with daily debilitating symptoms, which are often invisible, like itch, pain and fatigue. People with PSC urgently need an effective treatment and PSC Support funds high quality research towards that goal. We also work closely with researchers whose mission is to better understand PSC and how it develops.

PSC is complex and unpredictable. PSC Support provides vital information for both patients and healthcare professionals. We recognise that, in the absence of effective treatment, people with PSC live with uncertainty about what will happen to them and when. PSC Support provides much needed information and emotional support for patients and their families, and advocates for better liver healthcare services for patients.

We are lucky enough to have close working relationships with many of the UK and world PSC experts and we value their commitment to our charity. Although we are based in the UK, our reach is international. We are determined to continually evaluate and improve our work. We want to create a sustainable organisation, so that we can continue to meet the considerable needs of people affected by PSC. As a patient-led charity, we know a great deal about PSC and very much value the professional skills and experience our Trustees bring.

You would be joining a small, dedicated team, passionate about making a difference to those affected by PSC, and ultimately, seeking a world without PSC. If you believe you have the experience, skills and passion to work with us to help us widen our reach and achieve our goals, we would love to hear from you.

Yours faithfully

A handwritten signature in black ink that reads "T. Waterson". The signature is written in a cursive style and is positioned above a horizontal line.

Tim Waterson (PSC Support Chair of Trustees)

What PSC Support Does

PSC Support is the only UK charity solely focused on improving the lives of people affected by PSC and funding PSC research.

Charitable incorporated organisation

PSC Support was registered with the Charity Commission on 27th October 2017 as a [Charitable Incorporated Organisation \(number 1175427\)](#). Previously, PSC Support was registered as an Unincorporated Association (number 1115615) and was removed as a charity on 17th February 2018. Details are listed on the Charity Commission [Register of Merged Charities](#).

Vision and Mission

Our vision is to see a world without PSC.

Our mission is to improve the lives of people with primary sclerosing cholangitis in the following ways:

- **Research** - we will establish a pathway towards finding a cure or effective treatment for PSC.
- **Information and Support** - we will provide support and information to improve the quality of life and wellbeing of people affected by PSC.
- **Improving Care** - we will advocate for the highest standards of care for people living with PSC.

Values

At the heart of our work in PSC Support is a set of core values which inform every aspect of our services, policies and practices.

We believe the people with PSC and their families need:

- easily accessible, up to date and free information about PSC.
- their clinical care delivered by health professionals who understand PSC.
- effective monitoring of disease progression and cancer risk.
- effective symptom management options.
- their psychological and emotional needs are recognised and supported.
- effective, curative treatment.

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 Value

Patients are involved and contribute to all aspects of our work.

Tenacity

- We will never give up hope.
- We will never give up our search for a cure.

Our History

PSC Support began in 1995

PSC Support was set up in 1995 by Deborah Martin, whose husband tragically passed away from PSC. Because there was no support available for PSC patients at that time, she set up the support group with help from world PSC expert, Dr Roger Chapman, with the key purpose of finding 'help in each other'. The very first issue of 'PSC News' was issued in April 1995. The tradition of finding out what patients wanted began there and then with the very first PSC Support survey - all paper based!

PSC Support in 2001

Ivor Sweigler and Susan Sutton took over the running of the group in February 2001 when Deborah retired. Two years later, Susan Sutton retired, leaving Ivor to take the helm with a number of other volunteers. The newsletter was issued 2-3 times a year and the charity ran an annual meeting in Oxford, with continued support from Dr Chapman.

PSC Support in 2006

2006 saw PSC Support become a registered charity (1115615) with 300 members. In 2009, the UK-PSC Study was born, thanks to the hard work of Dr Roger Chapman, Dr Simon Rushbrook and Dr Graeme Alexander, and funding from PSC Support. PSC patients embraced this initiative and began to provide blood samples to help us better understand PSC.

PSC Support in 2011

The charity underwent some major changes in 2011 when Ivor passed away and three of the five Board members stepped down after many years of dedicated volunteering with the charity. Martine Walmsley, who had been volunteering with the newsletter production since 2007, was elected as Chair of Trustees, along with two new Trustees (including Professor David Adams) and a new Treasurer.

The new board of Trustees recognised that the time was right for the vision of PSC Support to be widened and relationships strengthened within the hepatology community. Work began to take greater advantage of the opportunities offered by new technologies, and fresh operational policies were introduced to comply with charity legislation, ensure medical information was correct and that fundraising income was allocated in accordance with the charity's objectives and priorities.

PSC Support has continued to grow and now has a reach spanning over 150 countries throughout the world. Although our work is primarily focused in the UK, we recognise that global collaboration is key to improving services and clinical care for everyone, and speeding up important PSC research. To that end, PSC Support has strong connections to patient groups throughout Europe, America, Australia and New Zealand, and continues to work with other organisations that share our vision and values. Within the UK, we are active in a strong network of liver patient groups, liver transplant groups and the rare disease community.

PSC patients encounter many quality of life related issues, and it is important to develop treatments for PSC that improve quality of life (as well as working to find an effective treatment for PSC itself). In 2015 we embarked on an exciting project in partnership with the British Liver Trust to create the first Quality of Life Measure for PSC. There is no single tool that effectively measures quality of life in PSC patients. It's important that there is one, because if a treatment is found for PSC, and it is to be licensed and made available to patients, we need to be able to demonstrate to the regulatory authorities that the drug actually helps patients. Furthermore, if we're to improve services for people with PSC, then we need to be able to evidence what life is like with the condition. Asking the right questions, at the right time, will enable that.

Clinically meaningful change in PSC: the patient perspective. In March 2016, PSC Support was delighted to be asked to be one of only two patient organisations in the world to present PSC patients' perspectives on their unmet needs and clinically meaningful change to an international PSC audience which included researchers, international regulatory authorities and pharmaceutical companies. This was a huge honour and responsibility

that we took seriously. The wealth of important patient opinions, descriptions and views on living with PSC and research priorities we'd gathered from our own patient surveys allowed us to successfully deliver our message: we are serious about progressing PSC research, PSC patients are highly motivated to progress research and there is no doubt that the unmet needs of PSC patients are wide-reaching and significant.

In late 2016, work began within the charity to evaluate the constitution and move to a CIO in order to modernise the charity and provide sustainability and capacity for future work. The Trustees took professional advice on transforming PSC Support into a new legal entity termed a charitable incorporated organisation (CIO) and achieved CIO status on 27th October 2017. The beginning of 2018 saw progress towards ensuring that the assets of the original charity were transferred to the CIO to continue to be used for the same charitable activities. Our operational goal to employ someone to help Martine Walmsley with our support, advocacy, education and research programme came to fruition in December 2018 when our first employee, Maxine Tapp, started work with us as our Programme Development Officer.

In May 2022, the PSC Support's second employee, Paula Hanford joined the charity as Chief Executive, bringing the skills and experience to take us from a 'kitchen table charity' to the next level.

PSC Support today

Over the past 25 years, our small support group has grown into a national charity working at the highest level to influence policy and research. PSC itself has gone from a disease that was considered a mystery to one that has several promising strands of research in progress and an international PSC research community. There is still so much we need to do to achieve our ultimate goal of finding an effective treatment for PSC: we are committed to achieving it so that no one has to ever face a diagnosis of an untreatable disease called PSC.

PSC Support runs regular, national Information Days, and introduced a web-based format of live 'Ask the Expert Q&A' sessions during the COVID-19 pandemic. We also operate a Helpline and support email service, and moderate a Facebook group of over 3,000 people.

PSC Support continues to provide a voice for PSC patients as a lead patient representative on a number of key national and international research and healthcare improvement initiatives.

PSC Support runs a dedicated research grant programme, accredited by the Association of Medical Research Charities, offering grant funding to high quality PSC research studies.

PSC Support developed and launched the first app in the world to help PSC patients access the right healthcare, information and support when they need it.

PSC Support offers the most comprehensive evidence-based PSC information in the world for patients on our freely accessible website.

PSC Support Structure

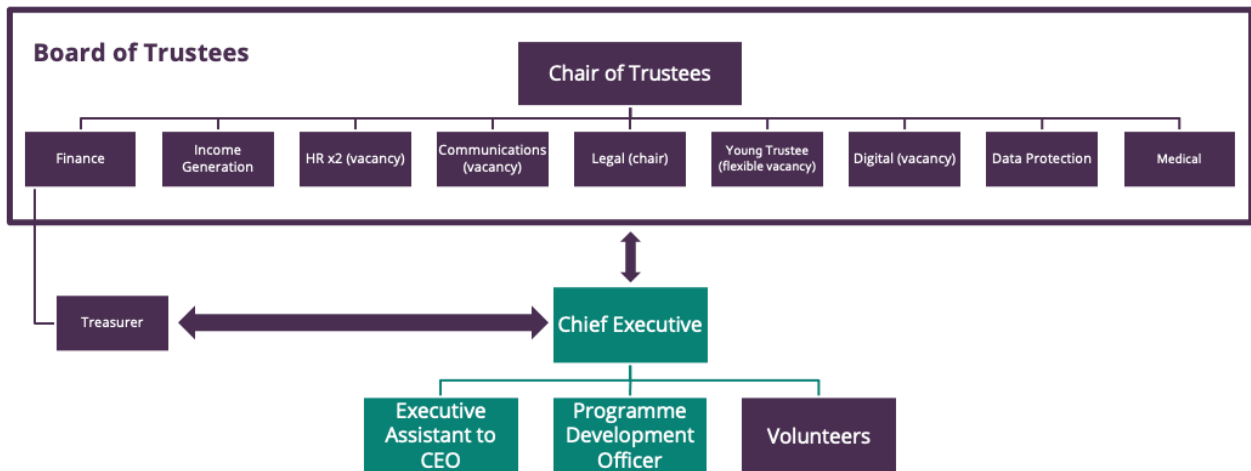
PSC Support Board of Trustees

- Prof David Adams (Medical)
- James Brown (Income Generation)
- Rick Dallaway (Data Protection)
- Dr Roger Chapman (Medical)
- Nick Kane (Finance)
- Shelley Spence (HR)
- Tim Waterson (Legal)

Operations

- Paula Hanford – Chief Executive
- Maxine Tapp - Programme Development Officer (part-time)
- Martine Walmsley – Executive Assistant to the Chief Executive
- Keith Anderson - Treasurer
- Regular volunteers for all activities

Structure



Finance

An overview of our income and expenditure can be found on [our website](#).

Applications

We welcome and encourage applications from everyone regardless of age, disability, sex, gender reassignment, sexual orientation, pregnancy and maternity, race, religion or belief and marriage and civil partnerships.