



## General Trustee Role Description

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

### 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 through support, education, research and advocacy:

- we provide up to date and accurate information for anyone affected by PSC
- we help PSCers connect with others sharing similar experiences
- we provide support to patients and their families
- we fund vital medical research
- we organise meetings including questions and answers sessions, with hospital consultants with a special interest in PSC
- we promote awareness and education about PSC to the medical community
- we advocate for PSC patients for improved clinical care
- we advocate for PSC patients regarding liver transplant policy and services
- we promote organ donation

Our goals are to:

- support and fund research to find a cure or effective treatment
- ensure PSC patients receive consistent standards of care wherever they live in UK
- be the definitive source of information about PSC for patients and healthcare professionals
- provide online and face to face support for people affected by PSC
- improve quality of life for people affected by PSC

### Responsibilities of all Trustees

- Ensure that PSC Support complies with its constitution, charity law, company law and any other relevant legislation or regulations
- Ensure that PSC Support pursues its objects as defined in its Constitution
- Ensure PSC Support applies its resources exclusively in pursuance of its objects

- Contribute actively to the Board of Trustees' role in giving firm strategic direction to PSC Support, setting overall policy, defining goals and setting targets and evaluating performance against agreed targets
- Safeguard the good name and values of PSC Support
- Ensure the financial stability of PSC Support
- Protect and manage the property of PSC Support and to ensure that proper investment of PSC Support's funds
- Follow proper and formal arrangements for the appointment, supervision, support, appraisal and remuneration of the chief executive (if PSC Support employs one)

## Specific Duties

In addition to the above statutory duties, each Trustee should use any specific skills, knowledge or experience they have to help the Board of Trustees reach sound decisions. This may involve leading discussions, focusing on key issues, providing advice and guidance on new initiatives, evaluation or other issues in which the Trustee has special expertise.

## Qualities of all Trustees

- Willingness and ability to understand and accept their responsibilities and liabilities as trustees and to act in the best interests of the organisation.
- Ability to think creatively and strategically, exercise good, independent judgement and work effectively as a board member.
- Ability to work at a strategic level whilst understanding the detail and complexities of delivery, and the influencing skills needed to bring staff and stakeholders along with plans.
- Effective communication skills and willingness to participate actively in discussion.
- A strong personal commitment to equity, diversity and inclusion.
- Ability to analyse risks and opportunities, and take a balanced approach to both.
- Enthusiasm for our vision and mission.
- Long term commitment to PSC Support.
- Willingness to lead according to our values:
  - 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' voice 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.
- Commitment to Nolan's seven principles of public life: selflessness, integrity, objectivity, accountability, openness, honesty and leadership.

## Time Commitment and Location

- The Board meets once a quarter (4 times a year) using virtual conferencing (1-2hours)
- The Board occasionally makes more urgent decisions by email
- Occasional emails from employees for Board for advice or to update on ongoing matters
- Meetings for strategic planning
- Some *ad hoc* committee work
- Papers are distributed one week in advance of meetings
- Trustees can claim out of pocket expenses incurred in travelling to meetings
- The term for a Trustee role is three years