

PSC Support - Charity Update

New Strategy

- 5 year till 2030
- Accelerate research, patient care and information & support
- Three strategic pillars or areas of work

Research



Improving patient care



Information and support



Research

accelerate research through powerful partnerships

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



Improving Patient Care

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.



Information and Support

Engage & 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.



Research - our plans include:

- Support promising diagnostic tools and endpoints - eg acute cholangitis measure, QoL measure
- Annual funding rounds - already funded over £757,660 research funding as part of Mission 2030.
- Advocate for PSC research and care priorities to medicine regulators and other stakeholders
- Implemented a new grant management system - to manage the large volume of grants
- New volunteer to build capacity in this area of work



Improving patient care - our plans include:

- Approaching all hospitals to make sure all HCP's know about PSC Support and can signpost their patients to us
- Expand our reach by making sure we are reaching younger audience - TikTok eg
- Advocating for the needs of the community - helping deliver new guidelines for PSC
- Through work of the BLT - lobby government better liver care



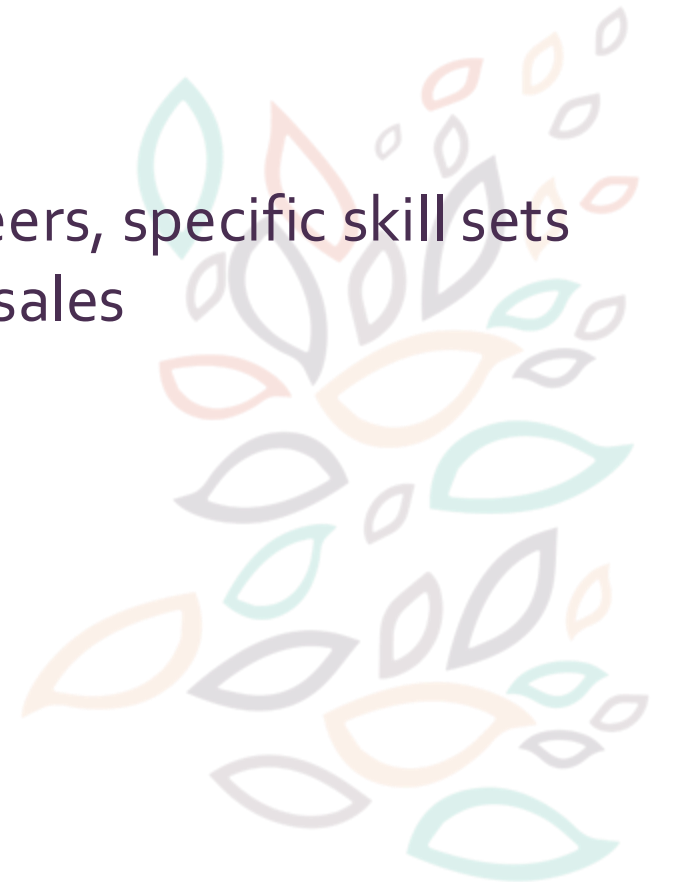
Information and Support - our plans include:

- Produce a patient focused podcast - peer learning
- Audit and update our website - infographic journey
- Want to make sure our information is accessible by all - audit and changes
- Create packs of information (newly diagnosed, awaiting transplant etc) for patients
- Scoping out the possibility of online networking groups and other ways to build relationships amongst you- all important peer support



How can you help?

- Volunteer - patient panels, research administration volunteers, specific skill sets
- Fundraise - lots of runs, London marathon, zip wires, bake sales
- Donate - monthly donation or one off donation



Thank you!

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