YOUR VOICE IN RESEARCH

By joining the PSC Partners Registry, you can share your PSC journey and your priorities to advance patient-centered research.

In a rare and variable disease like PSC, each story is vital to uncover the underlying patterns in patient journeys.

- **13 years** of patient-driven research with 25+ studies to-date
- **2,800+ participants** contributing their stories
- **55 countries** represented across the global PSC community

> *I participate in the Registry because I want* ***my unique PSC experience*** *to be accurately reflected in the research.*
>
> *- L.N., Post-transplant Patient*

Join the global effort to advance PSC research and new treatments.

→ **pscpartnersregistry.org**

SHARE YOUR STORY

pscpartnersregistry.org

✉ contactus@pscpartners.org

☎ 303-771-5227

PSC PARTNERS SEEKING A CURE

6900 E Belleview Ave Ste 202
Greenwood Village, CO 80111

Founded in 2005, PSC Partners Seeking a Cure is a 501(c)(3) nonprofit organization.

The mission of PSC Partners Seeking a Cure is to drive research to identify treatments and a cure for primary sclerosing cholangitis (PSC) while providing education and support for those impacted by this rare disease.

The Registry is the exclusive property of PSC Partners.

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PSC PARTNERS
PATIENT REGISTRY

JOIN THE PSC PATIENT REGISTRY

Help advance research and bring us closer to a cure for primary sclerosing cholangitis.

→ **pscpartnersregistry.org**

WHAT IS THE REGISTRY?

The PSC Partners Patient Registry is a secure online program that amplifies your voice in PSC research. By participating, you share health information, including changes over time, that helps researchers better understand PSC and develop new treatments and a cure.

Your data is shared with researchers in a way that protects your privacy. The Registry can also connect you with new clinical trials and research studies.

WHY IS IT IMPORTANT?

PSC is a rare disease that varies widely from person to person, which makes it challenging to gather enough information to fully understand it.

Some aspects of PSC, like cases in children or related cancers, are even harder to study because they are less common. These may require thousands of patients to conduct effective research.

Everyone has a unique PSC story. Your participation in the Patient Registry can help lead to new discoveries.

WHO CAN JOIN?

The Registry is open to anyone diagnosed with PSC, including post-transplant, wherever you are in the world. Parents and caregivers can enroll a child, or manage an adult account with permission.

> “*I am hopeful that every detail I provide, every survey I fill out will spark a little something that gets us* ***closer to a cure.***
>
> *- Registry Participant*

WHAT CAN YOU DO?

- ▶ Sign up for the Registry for yourself or a loved one.
- ▶ Share your story by completing surveys about medical history, symptoms, and quality of life, and update them each year.

JOIN TODAY

HOW WILL YOU BENEFIT?

The Registry offers simple tools to share your experience and engage in research.

Research made possible by the Registry improves care and helps develop new treatments for PSC.

Manage your care with optional medication reminders, symptom trackers, and journals.

Stay informed about new clinical trials and studies.

HOW IS PRIVACY PROTECTED?

No identifying information ever leaves the Registry.

Names, contact details, and other identifying information are never shared from the Registry. All data is stored in a secure, encrypted server that meets U.S. HIPAA privacy standards.

- Only data that has had identifying info removed is shared with researchers.
- You can withdraw at any time and request that your data be deleted.