PSC PARTNERS SEEKING A CURE

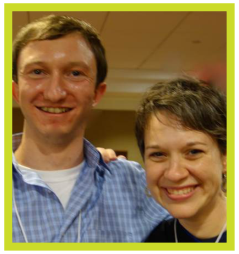
PSC Partners Seeking a Cure is a 501(c)(3) nonprofit organization that was formed to give PSC patients a collective voice in healthcare issues. The mission of PSC Partners Seeking a Cure is to provide education and support to PSC patients, families and caregivers and to raise funds to research causes, treatments and potential cures for primary sclerosing cholangitis.

FOR MORE INFORMATION & TO REGISTER

PSCPARTNERSREGISTRY.ORG
or contact
registrycoordinator@pscpartners.org

WE NEED YOUR VOICE!

We need every PSC patient's participation to push research forward. Join the PSC Partners Patient Registry to help make PSC a well understood disease with treatments and a cure.



For information and news on our PSC community, the latest PSC research and PSC Partners conferences and events, please consider joining our mailing list at PSCPARTNERS.ORG

Find us on Facebook at PSC Partners

We're also on Twitter @PSCPartners

TO HELP FUND THE CURE

Click on the DONATE NOW button at pscpartners.org

or send a tax-deductible donation to
PSC Partners Seeking a Cure
6900 E. Belleview Ave., Suite 202
Greenwood Village, CO 80111

Canadian donors can receive a tax credit by donating directly to www.pscpartners.ca

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PSC partners patient registry

PSC PARTNERS
SEEKING A CURE

Join the PSC Partners Patient Registry in this important step towards finding a cure for primary sclerosing cholangitis (PSC).

NOW ENROLLING PSC PATIENTS!

PSCPARTNERSREGISTRY.ORG

No cost to join • International participation invited

The Registry was created with the collaboration of the National Institutes of Health (NIH) Office of Rare Diseases Research (ORDR) and the National Center for Advancing Translational Sciences (NCATS).
The registry is the property of PSC Partners Seeking a Cure.

A Publication of PSC Partners Seeking a Cure

WHAT IS THE PSC PARTNERS PATIENT REGISTRY?

- The Patient Registry is a secure online database of health information entered by patients or caregivers.

- This international registry will assist, accelerate and support research to better understand PSC and to develop effective therapies and an eventual cure for the disease.

WHY IS IT CRUCIAL TO HAVE A PSC REGISTRY?

- PSC is a rare disease that varies significantly with each patient, making it difficult for researchers to gather sufficient PSC data. The registry will attempt to fill this gap.

- Authorized medical professionals can study the anonymous information in the registry.

- The Patient Registry serves patient, physician and research communities.

WHAT ELSE CAN THE REGISTRY DO FOR PSC RESEARCH?

- PSC Partners developed the registry questions to match those of other registries so that researchers have the ability to compare similarities among diseases.

- The registry may show researchers that effective treatments used for one disease can also benefit PSC patients.

WHERE IS THE DATA COLLECTED?

- All of the patient information will be stored in a HIPAA (U.S. government standards) compliant, secure environment that protects your privacy.

- No information that could identify you and your family members will leave the registry.

- Participants can access and update their own information. They can also withdraw from the registry at any time and ask for their data to be deleted.

WHAT CAN YOU DO?

- Fill out the survey at your own convenience and in the privacy of your home.

- Provide information about your medical history and symptoms, and attach test results that are maintained in a secure environment.

- Elect to receive information about participating in research and clinical trials, and about medical advances and other news from the PSC Partners Patient Registry.

"Where well-implemented registries and active patient organizations exist, the likelihood for developing a treatment for the disease in question is increased." Eurordis-NORD-CORD (Rare Diseases Europe, National Organization for Rare Disorders (US), Canadian Organization for Rare Disorders)

JOIN US NOW

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