

## FOR MORE INFORMATION & TO REGISTER

[PSCPartnersRegistry.org](http://PSCPartnersRegistry.org)

or contact

[RegistryCoordinator@PSCPartners.org](mailto:RegistryCoordinator@PSCPartners.org)

## YOUR VOICE IS IMPORTANT

PSC is a rare disease. Every PSC patient's participation is important to push research forward. Join the PSC Partners Patient Registry to help make PSC a well-understood disease with treatments and a cure.



### CLINICAL TRIALS

For information and news on clinical trials and PSC research, check out the newsletters and Clinical Trials page at [PSCPartnersRegistry.org](http://PSCPartnersRegistry.org)



### COMMUNITY EDUCATION & SUPPORT

For news on our PSC community, PSC Partners conferences, and webinars, please join the mailing list at [PSCPartners.org](http://PSCPartners.org)



### CONNECT WITH US

Search for PSC Partners Seeking a Cure on Facebook, Twitter, Instagram, LinkedIn, and YouTube.



### DONATE TO HELP FUND THE CURE

[PSCPartners.org](http://PSCPartners.org) (US) or  
[PSCPartners.ca](http://PSCPartners.ca) (Canada)



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PSC Partners Seeking A Cure is a 501(c)(3) nonprofit organization with a mission 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.

**PSC Partners Seeking A Cure**  
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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*



## INVITING PSC PATIENTS WORLDWIDE

**You are an important piece of the PSC puzzle!**

Join the patient-driven PSC Partners Patient Registry to move research forward and facilitate clinical trials.

[PSCPartnersRegistry.org](http://PSCPartnersRegistry.org)



## WHAT IS THE PSC PARTNERS PATIENT REGISTRY?

- A secure online database of health information entered by patients or their caregivers
- An international registry that assists, accelerates, and supports research to better understand PSC and develop effective therapies and an eventual cure

## WHY IS IT IMPORTANT TO HAVE A PATIENT-DRIVEN REGISTRY?

- PSC is a rare disease, making it difficult for researchers to gather sufficient PSC data. This patient-reported Registry collects data from any patient anywhere.
- Any authorized medical professional/ researcher can study the de-identified data in the Registry.
- The Registry builds a PSC community that powers research and clinical trials.

## WHAT IS THE FUNCTION OF THE REGISTRY?

- The Registry aims to capture changes in PSC symptoms and records how a patient feels and functions over time.
- The Registry assists in connecting PSC patients with clinical trial or study opportunities for which they may be eligible.
- The Registry collects patient-reported real-world evidence that is valuable for research.

## WHERE IS YOUR DATA?

- Patient information is stored in a medically secure environment that protects your privacy and meets the U.S. HIPAA and FISMA government standards.
- No information that could identify you or your family members ever leaves the Registry.
- You can withdraw from the Registry at any time and ask for your data to be deleted.

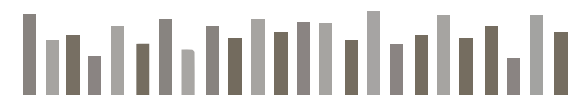
## WHAT ARE SOME BENEFITS OF JOINING THE REGISTRY?

- Knowing that you are part of the solution to the PSC puzzle
- Learning how you can participate in research and clinical trials
- Accessing an interactive tool to explore de-identified, collective Registry data
- Reading about drug development news at the Registry site and through The Viaduct Registry newsletters



## WHAT CAN YOU DO?

- Sign up to join the Registry yourself or for your loved one.
- Provide information about your medical history, symptoms, and quality of life by filling out Registry surveys and updating them annually.



**“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

