



**THE FORUM**  
For Collaborative Research<sup>SM</sup>

# PSC Patient Databases Working Group

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PSC Partners Seeking a Cure

# PSC Patient Databases Working Group

## ■ Goals:

- create a list of current PSC databases (including patient registries, industry registries and cohort studies)
- define the purpose of each
- identify the information being collected
- determine any gaps in information
- suggest other fields that can be included

# Current PSC Databases

- Consortium for Autoimmune Liver Disease (CALID) Registry
- IPSCSG Registry
- Netherlands Trial Register for PSC & PBC
- Pediatric PSC Registry
- PSC Partners Patient Registry
- PSC Registry Canada
- PSC Resource of Genetic Risk, Environment & Synergy Studies (PROGRESS)
- Registry of the European Reference Network (ERN)
- STOPSC
- UK-PSC Database and Biobank

# PSC Databases & Registries

- The Forum for Collaborative Research created a webpage to highlight the PSC databases

## Goals

- To sensitize and inform PSC patients about registries available to them
- To encourage researchers to engage in collaborative data-sharing

**Registries currently on the PSC Forum database webpage:**

**PSC Partners Patient Registry, CALID Registry, Registry of the European Reference Network, UK-PSC Database & Biobank**

# Working Group Databases Webpage

Information about PSC databases and registries include:

- Requirements to join the registry
- Age of participants
- Geographic area
- Other pertinent information
- Contact information

## PSC Forum Webpage: PSC Partners Patient Registry

- Created in 2014 in collaboration with the NIH ORDR
- Opt-in, patient-provided health & QoL data
- International; includes patients treated in non-specialized centers
- Only de-identified data leaves the registry



**Goals:** To speed up and facilitate PSC studies by providing the patient voice, serving as recruiting tool, disseminating academic surveys, and assisting in future PSC Partners-initiated research

# PSC Forum Webpage:

## PSC Partners Patient Registry



<b>Requirements to join the registry</b>	Anyone with PSC (with or without liver transplant) is invited to join the PSC Partners Patient Registry. <a href="https://pscpartners.patientcrossroads.org/">https://pscpartners.patientcrossroads.org/</a>
<b>Age of participants</b>	All ages
<b>Geographic area the registry covers</b>	Worldwide
<b>Other pertinent information about the registry</b>	A priority of the PSC Partners Patient Registry is to ensure the protection of the PSC patient’s privacy. The registry and the data belong to PSC Partners Seeking a Cure. To protect our participants, our registry has been reviewed and approved by an Institutional Review Board (IRB). All registry network transmissions are encrypted for protection.
<b>Contact and email</b>	Rachel Gomel <a href="mailto:registrycoordinator@pscpartners.org">registrycoordinator@pscpartners.org</a>



# Working Group Members

- David Assis
- Pol Boudes
- Chris Bowlus
- Mark Deneau
- Lara Dimick-Santos
- Rachel Gomel
- Claudia Filozof
- Gideon Hirschfield
- Sandy Lehrman
- Rich Pencek
- Ricky Safer
- David Shapiro
- Johannes Taminiau
- Martine Walmsley



# Next step? Towards a global registry of PSC registries?

Thank you!

