



Instructions to PSC Partners Patient Registry Participants:

Why participate?

We invite you to join the PSC Partners Patient Registry at www.pscpartnersregistry.org. Each of you joining the registry has the power to make PSC a less obscure disease and to push research forward. You may be a primary sclerosing cholangitis (PSC) patient, a parent or guardian, or the caregiver of a deceased PSCer. You may have had a liver transplant. You may be living in Denver, Johannesburg, or Oslo. We are together in the fight . . . whatever it takes!

It has been clearly shown that where well-implemented patient-driven registries and active patient organizations exist, there is an increased likelihood for developing a treatment for the disease (Gliklich RE, Dreyer NA, eds, "Registries for Evaluating Patient Outcomes," 2010).

The goal is to increase and accelerate research by using your anonymous data; to enable clinical and drug trials; and contribute to the search for PSC treatments. Our patient-driven registry can be a tool to turn us into powerful advocates for finding treatments and for getting closer to that elusive cure. For that, we need every one of you to take an active part in the registry.

We will send you news about new clinical trials and studies, directly from the registry. When you meet the requirements for joining a clinical trial, we will let you know, and you will have the choice to contact the researcher and decide whether you would want to participate in that study.

Explore the feature that is exclusive for registry participants! You will be able to see the anonymous data on how others have responded to each question by clicking on the Registry Data tab.

You can make the registry your own private space for keeping your test results by clicking on the Attachment tab and uploading test results as you receive them. Several participants are already using the attachment space to store all their test results. You can update any change in your health status at any time, or you can wait for our annual reminders.

For your data to be accepted, you will need to attach a proof of diagnosis, by uploading ANY test result (MRCP, ERCP) stating that you have PSC, or had PSC before transplant. This is truly simple. We have made it very easy for those of you who don't have online test results or scanning possibilities. Please see FAQ #7.

Make sure to add registrycoordinator@pscpartners.org to your contacts, so our communications do not get lost in your spam box.

Frequently Asked Questions:

1. How long will it take me to complete the survey?

It will take you about twenty minutes to read the section, "Understanding Your Participation" and complete the registration and consent forms. The survey itself takes about 15-30 minutes to complete. You do not have to finish the survey in one sitting. To have your data in the registry, you will need to upload a proof of diagnosis. Please see Question #7 for instructions on attachments.

2. Where will my data be kept?

The registry is a secure online site that is managed by Patient Crossroads which was selected by the NIH and manages many patient registries. Our registry adheres to U.S. governmental and NIH security requirements. The registry was created in collaboration with the NIH Office of Rare Diseases

Research (ORDR) after PSC Partners was selected to join their registry pilot program. Our registry has been approved by an Institutional Review Board (IRB) and abides by HIPAA regulations. It will undergo annual IRB review. Your data is made anonymous (a number), and researchers can see only your medical information without any of your identifying information. Your identifying data does not leave the registry.

For those who would like more specific information about the registry: PSC Partners owns the de-identified registry data. This registry will be managed by Patient Crossroads that manages other rare disease registries like ours <https://www.patientcrossroads.com/advocacy-research-clients.html> . Patient Crossroads does not have access to your personal information. Patient Crossroads is hosted in a SAS 70 Type II HIPAA and FISMA compliant infrastructure with dedicated firewalls and advanced intrusion detection to secure the participant's data. All registry network transmissions are encrypted for an added level of protection. All transmissions are sent via encrypted SSL (Secure Sockets Layer, i.e. a system of codes that provide communication security over the internet), and personal health information will be encrypted in the database.

3. **What are the steps to join the PSC Partners Patient Registry?** At the registry site www.pscpartnersregistry.org, click on the blue box that says “Join the Registry.” This will take you to a document entitled “Understanding Your Participation.” After reading this document, you can click on the “Next” button and create an account and complete the Consent Form. After completing the Consent Form, you will be ready to answer the survey questions. Remember your login password and ID to be able to return to your survey to correct, complete, or update your data.
4. **What are the questions with red asterisks?**
They are required questions that you need to answer before moving to the next section. They also identify “skip questions” which means that if you respond “No” to that question, you will be skipping a set of questions that are not relevant to you.
5. **How do I go back a page or two if I haven’t completed a section?**
The back arrows on your computer **should not** be used at all.
The “Next” button moves you to the next section and also saves your responses.
After you get to the end of the survey, you can return to your survey and will see a list of all the registry sections. You can click on each one and go through the survey from beginning to end, or you can just click on the section you would like to complete. To change answers, please click on the small edit icon that is located on the left of each question. This will let you change your answer. Take the survey again **ONLY** if you are updating your data (not correcting) to record a change in health status. All updates will be kept in the registry for comparison.
6. **What does the word “participant” mean in this registry?**
Whenever you see the word “participant” in the registry, the word means the “patient.”
7. **How do I attach the mandatory proof of PSC diagnosis file to the survey?**



The screenshot shows the PSC Partners Seeking a Cure website. At the top, there is a navigation bar with links for Home, Register, Glossary, Registry Data, and My Profile. Below the navigation bar, there is a section for adding a family member, with a dropdown menu showing 'apple apple' and a button 'Add a Family Member'. Below that, there is a 'Registered By:' field with a blue box. A message states: 'Use the tabs below to complete your registration. Each time you login to the registry, you will as health status, medications, treatments or testing change. You can log back into the Regist update your profile.' Below this message, there is a tabbed interface with tabs for Survey, Health Care Providers, Measures, Account Info, and Attachments. The 'Survey' tab is selected. Below the tabs, there is a message: 'To complete a survey, select the survey name below. Please re-take your surveys information you share, the more the community can learn!' At the bottom, there is a link for 'Clinical Questionnaire' and a warning icon with the text 'Please complete this survey and ensu'.

By clicking on the “My Profile” tab (see above screen shot), you will see the “Attachment” tab. This is where you can upload your proof of having PSC or having had PSC before transplant. *This does not have to be the original diagnosis!* It can be a current or old MRCP, ERCP or blood test result or a doctor’s report, stating that you have PSC or had PSC before transplant. If your records are online, you can either upload the document by clicking on the registry “attachment” tab or can send us a screen shot of your test result, so we can see that you have, or had PSC. If you have your test results on paper, then you can take a picture of the results and upload the picture. Please note that apostrophes are not accepted in the document name (ex: ’14) and should be re-saved without the apostrophe before uploading. If this process is difficult for you, please contact us at registrycoordinator@pscpartners.org, and we will find the easiest way for you to complete this step. Without such a test result, your data cannot be considered complete, and your data cannot be added to the registry.

Please add your physicians by clicking on the “Health Care Providers” tab. And click on “Measures” to add your height and weight.

8. How do I take a screen shot of my files?

Easy instructions for Mac and Windows users are found in these links:

<http://www.wikihow.com/Take-a-Screenshot-in-Mac-OS-X>

<http://www.wikihow.com/Take-a-Screenshot-in-Microsoft-Windows>

9. A tip on the registry password

Your PSC patient registry password has specific requirements to increase password security: Your password should have no spaces, should have at least 8 characters and contain lower and upper-case letters, numbers and special signs (ex: ABCdef&55).

If you have any questions, please do not hesitate to write to us at registrycoordinator@pscpartners.org.

We are together in this fight . . . whatever it takes!