

JOIN THE REGISTRY

The PSC Partners Patient Registry is an online platform to amplify your voice in PSC research. By participating, you share health information that helps accelerate research in PSC and potentially find new treatments and a cure.

By joining, you can:

- Share your PSC experience through confidential surveys
- Track symptoms, treatments, and medical history over time
- Stay informed about research studies and clinical trials

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

Your identity is protected. Names, contact details, and other identifying information stay securely in the Registry and are never shared with researchers.

Join today and be part of a community driving progress toward better treatments.

→ pscpartnersregistry.org

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.

**RESEARCH.
SUPPORT.
HOPE.**



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LIVING WITH PSC

Primary Sclerosing Cholangitis



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THE PSC BASICS

Primary sclerosing cholangitis, or PSC, is a rare liver disease that causes inflammation and scarring of the bile ducts inside and outside the liver. Over time, these ducts can form strictures (narrowing or blockages), which can damage the liver by slowing bile flow.

PSC can lead to cirrhosis and sometimes a liver transplant. In some cases, PSC can return after transplant. More than 75% of people with PSC also have inflammatory bowel disease (IBD), most often ulcerative colitis.

PSC at a Glance

- Affects about 1 in 10,000 people
- Often diagnosed between ages of 30 and 40, but can affect all ages
- More common in men, but can affect women and children
- Often linked with IBD
- Not caused by alcohol
- No known cause and not contagious

YOU ARE NOT ALONE

PSC Partners is here to connect you with the resources, guidance, and encouragement you need.

HOW PSC IS DIAGNOSED

PSC is often suspected in people with IBD who have abnormal liver blood tests.

Commonly elevated labs include:

- Alkaline phosphatase (ALP)
- Gamma-glutamyl transferase (GGT)
- Sometimes ALT and AST

To confirm PSC, doctors usually use MRCP (specialized MRI) imaging to look closely at the bile ducts. In some cases, an ERCP is used. A liver biopsy is rarely needed.

Additional blood tests may help rule out similar conditions.

PROGRESSION

PSC progression is tracked by monitoring blood tests, bile duct strictures, and liver stiffness. Complications of advanced disease (cirrhosis) include:

- Fluid buildup in the belly (ascites)
- Swollen veins in the esophagus or stomach (varices)
- Confusion (hepatic encephalopathy)
- Enlarged spleen

Progression varies widely. Less than half of people with PSC need a liver transplant, and for those who do, the average time from diagnosis to transplant is 15 to 20 years.

SYMPTOMS & RISKS

Some people have no symptoms, while others experience a range of symptoms at any stage of disease, including:

- Itching (pruritus)
- Fatigue and/or brain fog
- Abdominal discomfort or pain
- Jaundice (yellowing skin or eyes)
- Depression, anxiety, and insomnia

Some experience cholangitis attacks, a serious infection often requiring intravenous antibiotics. Signs include fever or chills and worsening abdominal pain or jaundice.

PSC increases the risk of bile duct and colon cancer. Other risks include vitamin deficiencies and osteoporosis. Regular monitoring and ongoing care are vital.

TREATMENT

There is currently no FDA-approved cure for PSC. Treatments focus on managing symptoms and complications.

- Medications can help relieve itching
- ERCP may temporarily open blocked bile ducts
- Liver transplant may be needed for advanced disease
- Discuss medications, treatments and clinical trials with your provider