WHERE CAN I FIND INFORMATION & SUPPORT?

MISSION

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.

WEBSITE

The PSC Partners website serves as a hub for the PSC patient and caregiver community. Visit **PSCPartners.org**.

MONTHLY NEWSLETTER

Join our mailing list to receive news about new research findings, clinical trial information, our annual conference, and more.

CONFERENCE

We welcome you to our annual conferences held in collaboration with top U.S. medical centers.

MENTORS

Via our mentor program, we connect our community for one-to-one support for PSC patients, caregivers, and family members.

REGISTRY

Join the PSC Partners Patient Registry. By adding vital information, PSC patients have the power to help researchers move closer to finding a cure. Learn more, including clinical trial information, at **PSCPartnersRegistry.org**.

SOCIAL MEDIA

Our Facebook patient pages offer a safe place to ask questions, share concerns, stay up to date on events and information, and connect with PSC patients, caregivers, and others in the community. You can also connect and stay informed by following us on:

Facebook @PSCPartnersSeekingACure
Twitter @PSCPartners
Instagram @psc.partners
LinkedIn @PSC Partners Seeking a Cure
YouTube @PartnersSeekingaCure

OTHER SITES TO VISIT

American Association for the Study of Liver Diseases:
aasld.org
European Association for the Study of the Liver:
easl.eu
For information on IBD:
CrohnsColitisFoundation.org

PSC PARTNERS SEEKING A CURE

Founded in 2005, PSC Partners Seeking a Cure is a 501(c)(3) nonprofit organization. The various programs give support to patients, caregivers, families, and friends, educate patients and the medical community about PSC, and drive ground-breaking research in the search for a cure.

FOR MORE INFORMATION

Visit our website at
PSCPARTNERS.ORG

or e-mail
contactus@pscpartners.org

TO CONTRIBUTE

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 pscpartners.ca

Photo Credit: Kelly J. Shepherd Photography

PSC PARTNERS SEEKING A CURE
PSCPARTNERS.ORG

PSC PARTNERS SEEKING A CURE CANADA
PSCPARTNERS.CA

living with PSC

primary sclerosing cholangitis

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living with PSC

primary sclerosing cholangitis

Together, we are creating a world where a PSC diagnosis comes with a cure.

PSC PARTNERS SEEKING A CURE

A Publication of PSC Partners Seeking a Cure

PRIMARY SCLEROSING CHOLANGITIS

Primary sclerosing cholangitis (PSC) is a rare disease that causes the bile ducts inside and outside of the liver to become scarred, narrowed, and eventually blocked. As more and more ducts are blocked, bile becomes trapped and damages the liver. This damage causes liver cell injury, which can ultimately lead to cirrhosis and require a liver transplant. PSC returns in about 30% of transplanted livers. This is referred to as recurrent PSC. Over 75% of PSC patients also have inflammatory bowel disease (IBD), usually ulcerative colitis (UC).

PSC DIAGNOSIS

PSC should be suspected primarily in patients with IBD who have elevated liver enzymes. Liver chemistry tests include:

- alkaline phosphatase (ALP)
- alanine aminotransferase (ALT)
- aspartate aminotransferase (AST)
- gamma-glutamyltranspeptidase (GGT)

Elevated ALP and GGT usually indicate an injury to the bile ducts and are almost always elevated in PSC. The ALT and AST may also be elevated in PSC. The diagnosis of PSC requires an image of the bile ducts called a cholangiogram. This is usually done by a special MRI called an MRCP (magnetic cholangiopancreatography). Sometimes, a procedure called ERCP (endoscopic retrograde cholangiopancreatography) is performed instead. Rarely, a liver biopsy is also needed for diagnosis. Additional blood tests may be performed to exclude other diseases, which can look like, or mimic, PSC.

PSC SYMPTOMS

Although some patients report few symptoms, if any, PSC symptoms can include:

- Fatigue: Feeling run down, unable to get enough sleep, flu-like exhaustion
- Pruritus (intense itching): Particularly on the palms of the hands or soles of the feet, though it can occur anywhere, including in the eyes and mouth
- Pain: On the right side or middle of the abdomen towards the rib cage; may be of any intensity, and may last for an indefinite period of time
- Jaundice: Yellowing of the eyes and skin caused by a blockage of bile flow in the bile ducts or excess bilirubin, which cannot be processed by the liver
- Chills and Fever: Signs of bacterial infections in the bile ducts requiring immediate medical attention
- Additional symptoms may include depression, anxiety, uncertainty, insomnia, and more.

Signs that PSC has progressed to cirrhosis, evidence that liver transplantation may be indicated, include:

- Ascites: Buildup of fluids in the abdomen
- Encephalopathy: Personality changes, confusion, and sleep disturbances caused by a buildup of toxins, such as ammonia, in the blood
- Varices: Swollen veins prone to bleeding, usually in the esophagus. When bleeding occurs, it can cause vomiting of blood or passage of black, tarry stool. Medical attention should be sought immediately when this happens
- Splenomegaly: An enlarged spleen
- Abnormal Blood Tests: Several blood tests, including bilirubin, creatinine, and International Normalized Ratio (INR), may become abnormal and may indicate whether a liver transplant is needed

Although the average time from diagnosis to liver transplantation is 15-20 years, some patients need transplants sooner, and some never need a transplant.

PSC PARTNERS SEEKING A CURE

FREQUENTLY ASKED QUESTIONS

HOW DID I GET IT? IS IT CONTAGIOUS?

Currently, no one knows what causes PSC. There appears to be a complex interaction of many genetic and environmental factors at work. Although there is a genetic predisposition to PSC, very rarely are family members, including children of patients, affected with PSC. PSC is not contagious, and it is not caused by alcohol consumption. PSC Partners supports research to discover causes, treatments, and a cure for PSC.

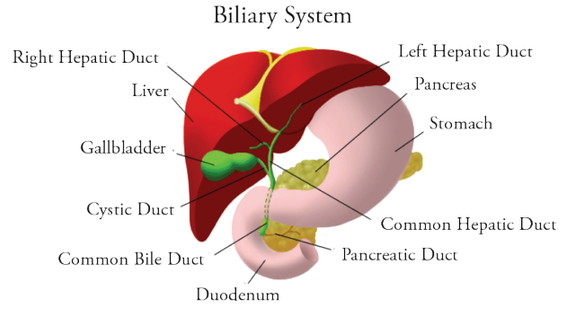
WHAT IS THE TREATMENT?

At this time, there are no FDA-approved medications for the treatment and cure of PSC. Some medications can help control PSC symptoms like pruritus (itching). ERCP can sometimes be used to open bile duct strictures and temporarily restore bile flow. More information on PSC medications and treatments can be found on our website. There are an increasing number of ongoing PSC clinical trials. PSC Partners encourages everyone to research and discuss all potential medications and treatments, including participation in clinical trials, with their healthcare professionals.

To learn more about PSC clinical trials, visit PSCPartnersRegistry.org. Information about PSC Partners-funded research projects can be found at PSCPartners.org/Research.

THE LIVER AND BILIARY SYSTEM:

From: The Ohio State Medical Center, The Liver: Anatomy And Functions



PSC is a disease of the bile ducts that transport the bile produced by the liver cells to the gallbladder and duodenum (the first part of the small intestine).

WHO GETS PSC?

PSC is a rare bile duct disease affecting about one in every 10,000 people. Although PSC can occur at any age in both males and females, it is more common in men, and is typically diagnosed between the ages of 30-40. PSC is often accompanied by inflammatory bowel disease (IBD), usually ulcerative colitis (UC). More than 75% of PSC patients have UC, while only 2-5% of patients with UC have PSC. PSC can sometimes be associated with other autoimmune diseases.

WHAT OTHER RISKS ARE INVOLVED WITH PSC?

There are two types of cancer that occur with increased frequency in PSC patients: colon cancer and bile duct cancer (cholangiocarcinoma). The increased risk of colon cancer is mainly in PSC patients who also have underlying IBD (UC or Crohn's Disease). For information on colon cancer, visit ccalliance.org. For information on cholangiocarcinoma, visit cholangiocarcinoma.org.

living with PSC