WHERE CAN I FIND INFORMATION & SUPPORT?

PSCPARTNERS.ORG

For over a decade, PSC Partners Seeking a Cure, a 501(c)(3) nonprofit organization, has provided education and support to PSC patients, families and caregivers and has raised funds to research causes, treatments and potential cures for primary sclerosing cholangitis.

The PSC Partners website serves as a hub for the PSC patient and caregiver community. We welcome you to visit us at www.pscpartners.org and join our mailing list to receive news about new research findings, clinical trials, our newsletter and our annual PSC Partners conferences.

We welcome you to our annual patient and caregiver conferences held in collaboration with top medical centers in the U.S. Join us for our next conference.

Since 2004, we have maintained a collection of literature on PSC that is regularly updated to provide PSC patients and caregivers easy access to a vast body of information concerning PSC and connected illnesses.

By joining the PSC Partners Patient Registry, PSC patients have the power to help researchers move closer to finding a cure. We encourage you to learn more about our PSC Partners Patient Registry and participate online.

Our Facebook page offers a place to ask questions, share concerns and connect with other PSC Partners members. The community is always welcoming and helpful to new members.
Find us on Facebook at PSC Partners

We're also on Twitter @PSCPartners

Read about PSC Partners' independent national and international support groups on our website.

For information on inflammatory bowel disease, visit the Crohn's and Colitis Foundation of America (CCFA) website at www.ccfa.org

PSC PARTNERS SEEKING A CURE

PSC Partners Seeking a Cure is a 501(c)(3) nonprofit organization that was formed to give PSC patients a collective voice in healthcare issues. The mission of PSC Partners Seeking a Cure is to provide education and support to PSC patients, families and caregivers and to raise funds to research causes, treatments and potential cures for primary sclerosing cholangitis.

FOR MORE INFORMATION

Visit our website at
PSCPARTNERS.ORG

or send an e-mail to
contactus@pscpartners.org

TO HELP FUND THE CURE

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 www.pscpartners.ca

PSC PARTNERS SEEKING A CURE
PSCPARTNERS.ORG

PSC PARTNERS SEEKING A CURE CANADA
PSCPARTNERS.CA

living with
PSC
primary sclerosing cholangitis

PSC PARTNERS SEEKING A CURE

This brochure was written by persons without formal medical training. The information in this brochure is not intended nor implied to be a substitute for professional medical advice, diagnosis, or treatment. Please consult with your doctor before using any information presented here. The views and opinions expressed herein are not intended to endorse any product or procedure.

living with
PSC
primary sclerosing cholangitis

PSC PARTNERS SEEKING A CURE

Chris Klug, snowboarder, Olympic medal winner, author, PSC patient and liver transplant recipient.

Chris was diagnosed with PSC in the early 1990s. He received a liver transplant in July 2000. Just 18 months later, Chris achieved a lifetime ambition, winning the Bronze Medal at the Olympic Games. He is an inspiration to all those diagnosed with PSC.

"PSC can be beat. After my transplant, I'm healthier and stronger than ever before."

– Chris Klug

A Publication of PSC Partners Seeking a Cure

PRIMARY SCLEROSING CHOLANGITIS

Primary sclerosing cholangitis (PSC) is a 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 DIAGNOSIS

Patients diagnosed with PSC often do not have symptoms, but on routine blood tests are found to have elevated liver function numbers. PSC should be suspected in patients with inflammatory bowel disease (IBD) and elevated liver tests because over 75% of PSC patients also have IBD, usually ulcerative colitis. Diagnostic liver tests called liver function tests or LFTs 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, but usually not as much. The diagnosis of PSC requires an image of the bile ducts called a cholangiogram. This can be done by a special MRI called an MRCP (magnetic cholangiopancreatography) or sometimes a procedure called an ERCP (endoscopic retrograde cholangiopancreatography). Sometimes a liver biopsy is needed. Other blood tests may be performed to exclude other diseases which can look similar to PSC.

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

PSC SYMPTOMS

Although many patients report few symptoms, if any, some of the symptoms of PSC include the following:

- Fatigue: Feeling run down, unable to get enough sleep, flu-like exhaustion
- Pruritus or intense itching: Particularly on the soles of hands or 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
- Jaundice: Yellowing of the eyes and skin caused by a blockage of bile flow in the bile ducts or by excess bilirubin which cannot be processed by the liver
- Chills and fever: Signs of bacterial infections in the bile ducts requiring immediate medical attention

Additionally, signs that PSC has progressed to cirrhosis, and 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 in these cases.
- Splenomegaly: An enlarged spleen
- Abnormal blood tests: Several blood tests including bilirubin, creatinine and INR (International Normalized Ratio) may become abnormal and are used to determine if liver transplant is indicated.

FREQUENTLY ASKED QUESTIONS

HOW DID I GET IT? IS IT CONTAGIOUS?

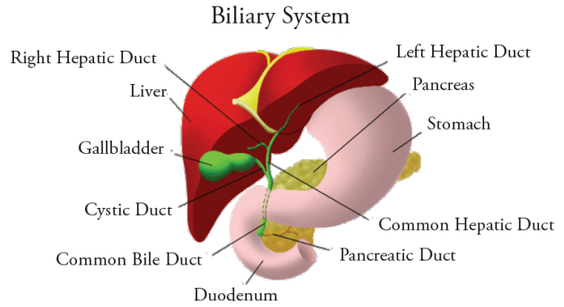
Currently, no one knows what causes PSC. Although PSC is a liver disease, it is not caused by alcohol consumption. There appears to be a complex interaction of many genetic and environmental factors at work. Although there is a genetic predisposition to PSC, very rarely are family members, including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

WHAT IS THE TREATMENT?

At present, there are no medical therapies proven to slow the progression of PSC, although there is an increasing number of clinical trials ongoing in PSC. Studies of new treatments can be found at www.pscpartners.org/clinical-trials/.Notably, the progression of PSC varies between patients. Urso ® (ursodeoxycholic acid, Ursodiol) has been the most studied medication for the treatment of PSC. Urso has not been shown to slow progression of PSC and might be dangerous at high doses. However, it appears to improve liver tests in some people. Presently, there is no definitive answer, so your physician and you should make a decision based on your individual case. ERCP can sometimes be used to open up bile duct strictures and temporarily restore bile flow. Treatments for pruritus (itching) associated with PSC include cholestyramine, rifampin and naltrexone.

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 liver disease affecting about 1 in every 10,000 people. Although PSC can occur at any age in both men and women, PSC is more common in men and is typically diagnosed between the ages of 30 and 40 years. PSC is often accompanied by inflammatory bowel disease (IBD), most often ulcerative colitis (UC), and sometimes Crohn's disease. Over 75% of PSC patients have ulcerative colitis, while only 2-5% of patients with ulcerative colitis have PSC. PSC can sometimes be associated with other auto-immune diseases.

WHAT OTHER RISKS ARE INVOLVED WITH PSC?

There are mainly 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 inflammatory bowel disease (ulcerative colitis or Crohn's).