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

PSC PARTNERS SEEKING A CURE
pscpartners.org

PSC PARTNERS SEEKING A CURE CANADA
pscpartners.ca

pediatric PSC

primary sclerosing cholangitis

Kyle–Diagnosed at age 8

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.

pediatric PSC

primary sclerosing cholangitis

Chelsea-Diagnosed at age 6

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

WHAT IS PSC?

Primary sclerosing cholangitis (PSC) is a rare, chronic disease that causes inflammation and scarring of the bile ducts outside and/or inside the liver. The liver makes bile that is carried by bile ducts to the small intestine. Bile is important for the absorption of fats and Vitamins A, D, E, and K. With PSC, bile stays in the liver where it damages liver cells, leading to inflammation, fibrosis (scar tissue), and, sometimes, cirrhosis.

WHY DID MY CHILD GET PSC?

Although nobody knows the cause of PSC, there appear to be genetic, environmental, and autoimmune components. As a parent, there is nothing you could have done to prevent PSC in your child.

WHAT ARE COMMON SYMPTOMS?

When diagnosed, most children with PSC are in early stages of the disease process and don't exhibit symptoms. However, initial symptoms that may develop include:

- Fatigue
- Intense, persistent itching (pruritus)
- Pain on right side or middle of abdomen
- Jaundice (yellowing of eyes and/or skin)
- Elevated liver blood tests
- Hepatomegaly (an enlarged liver)
- Splenomegaly (an enlarged spleen)

Most children with PSC have inflammatory bowel disease (IBD), usually ulcerative colitis (UC) or Crohn's disease, which may present with:

- Chronic diarrhea
- Blood in the stool
- Poor growth

PSC PARTNERS SEEKING A CURE

WHEN DO I TAKE MY CHILD TO THE HOSPITAL?

- Fever, chills, and jaundice (signs of bacterial infection in the bile ducts)
- Vomiting blood (sign of burst blood vessel in the esophagus) or dark black blood in the stool (sign of bleeding in the stomach or intestines)

HOW IS PSC DIAGNOSED?

Your child may be diagnosed with PSC after a series of blood and/or imaging tests, or after a liver biopsy.

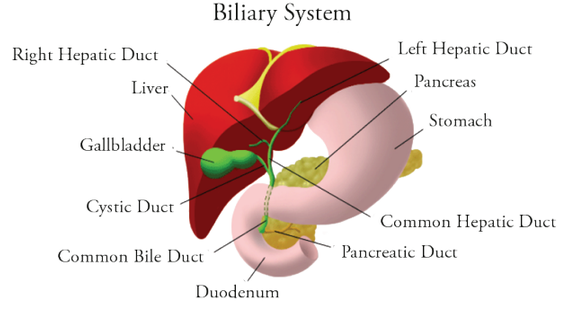
Blood tests: Liver tests, including alkaline phosphatase (ALP); conjugated and unconjugated bilirubin; gamma-glutamyl transpeptidase (GGT); alanine aminotransferase (ALT); aspartate aminotransferase (AST); total protein; albumin; prothrombin time (PT) / international normalized ratio (INR)

Imaging tests:
Magnetic resonance cholangiopancreatography (MRCP): noninvasive, with no radiation exposure, most common diagnostic imaging study; Endoscopic retrograde cholangiopancreatography (ERCP): more invasive, radiation exposure, rarely needed to diagnose PSC; Ultrasound of the liver and bile ducts

Liver biopsy indications:
To test for autoimmune hepatitis (AIH) in the AIH/PSC overlap syndrome; To determine the amount of fibrosis or scarring; To identify small duct PSC

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).

HOW DOES PEDIATRIC PSC DIFFER FROM ADULT PSC?

PSC is less common in children. Overlap of AIH with PSC is more common in children, and children have markers of autoimmune disease more often than adults. Small duct PSC is more common in children. Children rarely have dominant strictures of the common bile duct or cancers of the bile ducts and colon. Experts question whether childhood PSC is a different disease, or an earlier phase of the adult disease.

WHAT IS THE TREATMENT FOR PSC?

At this time, there are no FDA-approved medications for the treatment and cure of PSC. ERCP can sometimes be used to open bile duct strictures and temporarily restore bile flow. Other therapies that children with PSC may need include fat soluble vitamin supplementation (A, D, E, and/or K) and medications to treat itching.

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.

FOR MORE DETAILED INFORMATION ON EACH SECTION, GO TO PSCPARTNERS.ORG/PEDIATRIC-PSC/

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

Researchers' understanding of the efficacy of drugs for PSC is constantly changing. Several promising new drugs for the treatment of PSC are in various stages of development in adults and may be ready for trials in pediatric PSC patients in the near future.

WHO WILL NEED A LIVER TRANSPLANT?

About 15% of children may need a liver transplant for PSC before age 18. There is no reliable way to predict who will have progressive disease leading to the need for liver transplant in childhood.

IS THERE A SPECIAL DIET FOR PSC & WHAT SHOULD BE AVOIDED?

Special considerations must be given to maintain normal nutrition and growth in children with PSC. Although there is no special diet for PSC, patients should eat a balanced diet of protein, carbohydrates, and fat. Fatty foods, processed foods, and preservatives should be avoided. Fat-soluble vitamins (A, D, E, and K), calcium, and phosphorus may require supplementation. Medications that may harm the liver, as well as herbal supplements, alcohol, and recreational drugs, should be avoided. It is important to discuss all medications and supplements with your child's doctor.

HOW WILL PSC AFFECT THE LIFE OF MY CHILD?

The majority of children with PSC have a normal quality of life and do not experience any liver-related symptoms or pain. Children with progressive disease may require more frequent monitoring, clinic visits, hospitalizations, and, in some cases, liver transplantation.