

Help Us Discover A Cure for Primary Sclerosing Cholangitis



What is Primary Sclerosing Cholangitis (PSC)?

PSC is a rare, incurable disease that is thought to be autoimmune in nature. It causes the bile ducts both inside and outside the liver to become scarred, narrowed and eventually blocked. As more and more ducts are blocked, bile becomes trapped and damages the liver. The damage causes liver cell death, which leads to cirrhosis and may eventually require a liver transplant.

PSC can strike in anyone, man, woman, or child. Many PSCers also have other autoimmune or inflammatory bowel diseases, the most common ones being ulcerative colitis or Crohn's disease. All PSCers, whether age 6 or 60, are desperately hoping and searching for better treatments and a cure.

No one knows what causes PSC. There may be genetic, autoimmune, and environmental origins. We do know that it isn't contagious. You can't get PSC from kissing, hugging, touching, sexual activity, or blood transfusion/contact.

There are medications and procedures that can help relieve some aspects of the disease and symptoms, but the only definitive treatment is a liver transplant and even then sometimes PSC recurs. As we all know, organs are all too often not readily available even if transplant is an option. Many PSCers take multiple daily medications in an attempt to help relieve some of their symptoms and allow them to live as normal a life as possible.

What is PSC Partners Seeking a Cure?

PSC Partners Seeking a Cure is a 501(c)3 nonprofit foundation, started by PSCers and their caregivers in 2005, dedicated to educating and supporting PSC patients and their families, raising funds to find treatments and a cure for PSC, and promoting awareness of PSC and organ donation.

Today, this liver disease lacks any definitive treatments. PSC can be scary. PSC can affect anybody and doesn't seem to follow a set course. But with your help, we are NOT alone.

So, join us in the fight. Help us hold fundraisers, educate yourself, your family and your friends and together we can prove that PSC stands for Power, Strength, Courage.

What's life like for a PSCer?

While it can be different for every PSCer, most report at least some of the following symptoms and many have all on this list plus other, more rare, symptoms:

- **Pruritus (intense itching)** can occur anywhere including eyes and mouth, although it's most common on hands and feet. Many PSCers describe this as if somebody has poured itching powder into their bloodstream. Lotions and topical remedies offer little or no help.
- **Fatigue** is a pervasive exhaustion that sleep and rest can't fix. It is physical, emotional and mental in nature. For many PSCers, the exhaustion interferes with daily life activities. Something as simple as playing on a playground, having a conversation, taking a shower, or going out to dinner with friends is often too exhausting for PSCers to accomplish.
- **Depression** is a common symptom with feelings of despair or hopelessness.

- **Pain** in the Right Upper Quadrant is the most common. This generally occurs on the right side or middle of the abdomen (under/around the rib cage) and can extend to the back or shoulder blade. Pain can be of any intensity.
- **Jaundice** is yellowing of eyes and skin caused by excess bilirubin. Yellowing of skin and eye color can be shocking and drastic.
- **Chills and fever** are signs of bacterial infections in bile ducts requiring immediate medical attention including administration of antibiotics.

Why should I get involved and why with PSC Partners?

You probably never heard of PSC. It's a frightening diagnosis. The medical system is intimidating. The diagnostic tests can be daunting; the future may look uncertain. Together, we can change all of that.

PSC Partners uses only a small percentage of all funds donated to keep our organization running. Every other penny earned goes directly to research and education, towards finding better treatments and a cure for PSC. Our organization is almost completely run by volunteers as we have only one paid employee. All of the positions on the Board of Directors and our Scientific/Medical Advisory Committee are unpaid. Here's some of what PSC Partners has accomplished to date:

- **Education, support, and research grants** that greatly improve the quality of life for PSCers and caregivers. Now, when PSCers are diagnosed, they have a place to go for help.
- **Yearly conferences** to update PSCers, caregivers and physicians on the latest developments on the disease and provide connections for PSCers. The conference is often the only place a PSC-stricken family can meet another PSCer, which can literally be life-altering in the best of all possible ways.
- **Research grant funding** (made possible by your donations!). In our first seven years, we have been able to fund over a half million dollars in research grants to help find new treatments and a cure for PSC. To see the grants that we are funding, go to: www.pscpartners.org/grants
- **Free literature** to PSCers, caregivers, and physicians. Some of our most popular offerings include brochures and our PSC Literature site.
- **A website, newsletters, support groups** (online and in selected locations) that are powerful and informative.

How can I help?

PSC can make you feel as though your life is over. That isn't the case.

Please, join us today and help us take control of the future. Help us spread awareness and information. Help us get much-needed funds into the hands of leading researchers. Help us to save lives and make a real difference in the lives of those who so desperately need it.

For more information or to make a tax deductible donation of any amount, send a check to

PSC Partners Seeking a Cure

5237 So. Kenton Way

Englewood, CO 80111 or go to www.pscpartners.org/waystodonate

Contact Us

Please feel free to contact us with any additional inquiries. The office of PSC Partners Seeking a Cure can be reached at the following:

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