



PSC PARTNERS
SEEKING A CURE

THE DUCT

A Monthly Newsletter for the PSC Community

October 2018

[Patient Registry](#)

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PSC Awareness Day is October 29th

Had you ever heard of PSC before you or a loved one was diagnosed? I hadn't, despite a steady diet of ER and Gray's Anatomy. Once a PSC diagnosis rears its head in our lives, it is hard not to be nostalgic of a time when we were blissfully ignorant! Nevertheless, public awareness of our disease means more money for research, more interest from doctors and scientists, and increased support for PSCers. We need to holler so loud about PSC that everyone knows what those letters mean and how they can help. October 29th is the official PSC Awareness Day, so stay tuned on Facebook, Twitter, and on the PSC Partners website for ways that you can help to spread our message.

Laura Bradbury, Post-Transplant PSC Patient

Our Registry Team is Expanding!

We now have a [PSC Partners Patient Registry](#) team! We are very happy to welcome Sharon Nanz and Mary Vyas, who have joined registry coordinator and registry founder Rachel Gomel at a time when the registry is preparing to go through a radical overhaul and PSC research activity is rapidly advancing.

Sharon and Mary are both leaders of our PSC Partners community, have extensive experience communicating with patients and medical stakeholders, and are both passionate about finding new ways of making our patient voice louder and more effective. We couldn't be happier!



Living With PSC Episode 6 - Trish Stoltzfus: The New ICD-10-CM Code for PSC

In the sixth episode of Living with PSC, Niall McKay interviews Trish Stoltzfus, professional medical coder and mother of a PSC patient, about the new ICD-10 code for primary sclerosing cholangitis (K83.01). **The new code went into effect in the United States on October 1, 2018**, which will change the world of future PSC research!

[Click here](#) to listen to the latest episode! Past episodes of the Living With PSC Podcast are [available on our website](#).

News from Recent Pediatric PSC Meetings

During the last week of September, Ricky Safer, CEO of PSC Partners, had the opportunity to attend two conferences of great importance to



pediatric PSC patients and their parents and to give presentations to share the mission and programs of PSC Partners.

The Steering Committee of the Childhood Liver Disease Research Network (ChiLDReN) met in Alexandria, VA September 27-28. ChiLDReN is a collaborative team of doctors, scientists, nurses, research coordinators, medical facilities, patient support organizations and the National Institutes of Health. The ChiLDReN Network has clinical sites and research laboratories in the U.S., Canada, and the United Kingdom. Their recent addition of PSC to the other eight liver diseases that they are researching will expand pediatric PSC research. The protocol for PSC research projects is already being developed.

The second annual Pediatric Autoimmune Liver Disease Symposium and Family Day took place September 29-30 at the Center for Autoimmune Liver Disease (CALD) at Cincinnati Children's Hospital Medical Center. The agenda covered a wide variety of topics of interest to PSC and Autoimmune Hepatitis families, including medical therapies, nutrition, coping, and an update on clinical studies to research on the microbiome. A highlight was Dr. Ken Cox's presentation on vancomycin use for PSC.

PSC Partners Featured in Gastroenterology & Endoscopy News

PSC Partners Seeking a Cure was featured in [a recent article in Gastroenterology & Endoscopy News](#). The article explains the results from a recent study conducted among PSC Partners Registry participants regarding participation in clinical trials, and summarizes Registry data about PSC outcomes as presented by researchers at UC Davis at the AASLD's Emerging Trends conference focused on cholangiopathies.

2020 Annual Conference Hosting Proposals

Due November 15, 2018

Plans are well underway for the 2019 annual conference in Rochester, MN, and we're beginning to turn our sights to 2020!

If you are interested in bringing the 2020 conference to your home town, we ask that you collect some information about the venue and host institution so that our Board can select the best fit for a conference host. Proposals are due **no later than November 15, 2018**. To learn more about what information is required and to submit your proposal, [click here](#).



2019 Conference Hotel Reservations Are Open!

The 2019 conference will take place at the Mayo Civic Center and the Kahler Grand Hotel in Rochester, Minnesota. We are pleased to offer a discounted group rate for conference attendees staying at the Kahler. [Click here](#) to access the reservation page for conference attendees to reserve their hotel rooms at the discounted rate.



Looking to Get Rid of an Old Car? Donate it to PSC Partners!

We have recently changed to a new vehicle donation platform. Unwanted vehicles including cars, trucks, motorcycles, RVs, boats, airplanes, heavy equipment, and farm machinery (running or not) are all eligible for donation. The process is very simple, and they'll come pick up the vehicle for you! (Some restrictions apply.)

Donating an unwanted vehicle is an easy way to make a significant donation to support the mission of PSC Partners! For details, [click here](#).



Support PSC Partners with a Charitable IRA Rollover Gift

Did you know that funds can be transferred directly to PSC Partners Seeking a Cure from a traditional or Roth IRA, avoiding the tax implications of an income distribution and having an immediate impact on people living with PSC? Ask your financial advisor how to make a charitable distribution or [contact us](#) to learn more.

How It Works: If you are 70-1/2 or older, you may transfer up to \$100,000 per year directly from your traditional IRA to a qualified charity, like PSC Partners. If your spouse has a separate IRA, he or she is also eligible to make a charitable IRA rollover gift. The amount of the transfer will not be included in your taxable income, and the transferred amount counts toward the IRA's required minimum distribution. Talk to your financial advisor to determine whether a charitable IRA rollover is the right option for you. [Contact us](#) for the information your custodian will need.

Thank you for supporting PSC Partners!

The mission of PSC Partners Seeking a Cure is to provide education and support to PSC patients, families and caregivers and raise funds to research causes, treatments and cures for primary sclerosing cholangitis.

