

THE DUCT

A Monthly Newsletter for the PSC Community

April 2017

Patient Registry 2017 Conference Donate Now

*Note: In an effort to streamline our email communications to you, we will be consolidating the majority of our news into one monthly newsletter.

We are always looking for interesting people, research and stories to feature in our newsletter. Please <u>contact us</u> if you'd like to see your story or research featured in a future issue or if you are interested in being a guest-blogger for us.

Community Spotlight



Register Now for our 2017 Patient and Caregiver Conference

Our annual conference is the highlight of our year; we look forward to seeing new and familiar faces, sharing the latest research impacting PSCers and, most of all, connecting with each

of you. This year is no different! We encourage you to learn a little more about this year's conference as follows:

- 1. Check out <u>the agenda</u> to see the wide variety of topics of interest to PSCers.
- Plan to join us for a pre-conference dinner on Thursday evening!
 Conference attendees, particularly first time attendees, appreciate the opportunity to get acquainted with other PSCers and caregivers before our more formal educational schedule starts on Friday.
- 3. At Saturday night's gala, we will unveil where the 2018 conference will be held. And, if you're lucky, we might even surprise you with a board member or two wearing a kilt. No wait! That was last year, but we can't wait to see what they'll be rockin' in this year.
- 4. Check out what our <u>prior conference attendees have to say</u> about our conference. Here's a glimpse...

"Best decision I ever made."

"The most exciting thing to learn about was the future of PSC research and the journey toward a cure. It was impossible not to feel the sense of hope in the room as we heard from the brilliant minds working on a breakthrough."

"Spending time with my peer group of 20-30 year-old male PSC patients was the highlight of my weekend. For the first time, I met other young men who were living with my disease. I finally found people who could relate to some of the things I hate the most about PSC and the things that make me worry most about the future."

Are you looking for opportunities to get involved with finding a cure for PSC?

Our annual conference is a great place to start!

Over 100 volunteers support this event each year, and we couldn't do it without them. This year, we have a variety of opportunities available with some commitments taking as little as 20 minutes. To learn more about volunteer opportunities, please contact Joanne Hatchett

at <u>contactus@pscpartners.org</u> or select specific options that align with your interests when you register for the conference. Also, as a patient or caregiver, if you've been to a conference before, you may want to consider being a mentor for a first-time attendee.

REGISTER HERE FOR THE CONFERENCE

Education / Research / News



A Whopping 29 PSC Research Grant Applications Received!

Funding PSC-focused research is one of the most important things we do. This year, PSC Partners received a whopping 29 grant applications from around the globe. Applications poured in from notable institutions all over the world

including The Netherlands, Germany, Finland, Norway, Canada, Switzerland, UK, Israel and the US. We were delighted to see a broad array of topics ranging from gene targets to recurrent PSC, to the links between PSC/IBD, to diagnosing and treating cholangiocarcinoma, and finally, to the microbiome. We were also happy to see collaborations between institutions both nationally and internationally and pediatric-focused proposals. It's exciting to see new ideas and insights for research focused on PSC; this research is critical for PSC patients and gives us a reason to be optimistic knowing that there are great people and institutions working toward better treatments and a cure.

Over the next three months, our <u>Scientific Medical Advisory Committee</u> (<u>SMAC</u>) will review the applications and select the most promising proposals to recommend to the Board of Directors for funding, based on scientific merit.

Awardees will provide a 1- to 2-page annual summary of results to PSC Partners. We look forward to sharing those results with you. Click here to learn more about the research PSC Partners has funded to date and stay tuned to see which new projects get selected.

How You Can Support Us

\$20,000 Match Challenge!

Our <u>2017 Road to a Cure</u> campaign is underway! Are you ready to be "Together in the fight - whatever it takes"? PSC Partners is proud to support the worldwide PSC community through education, support, patient advocacy, maintaining a patient registry that drives clinical trials and funding research that will bring us closer to a world without PSC. But we can't do all of this without <u>your</u> support.

We're excited to announce that a generous donor has challenged us to raise \$20,000 by June 25th with a \$500 match for every \$500 raised through personal fundraising campaigns!

How can you join us on the Road? Here are three easy steps:

- 1. Write a short personal introduction or make a short video about YOUR journey with PSC as a patient, family member, caregiver or friend.
- 2. <u>Set up your fundraising page</u> on our website and add your story. <u>Check out this</u> toolkit with tips, ideas and sample messages.
- 3. Spread the word! We need our community of supporters to grow so we can be a loud voice for PSC patients and their families. Share your story, invite friends and family to donate and ask a loved one to fundraise with you.

If you don't want to do a personal fundraiser, you can join us on the Road with a gift today. Every \$500 donation will be doubled with a \$500 match from our challenge donor!

Together, we're stronger on the Road to a Cure.

Start a Campaign

Donate Now

2017 Walk or Pedal for PSC

July 28-30, 2017

Woodstock, Vermont

Hurry, <u>register now</u> to book your room before they run out!

2017 Luxury Home Tour

April 22 & 23, 2017 Fairfield County, Connecticut Learn more and purchase tickets here. A portion of proceeds benefits PSC Partners

Thanks to our supporters for giving us hope for a smoother road ahead.

Organizational News



PSC Partners to Attend ILC Conference in Amsterdam

We're heading to Amsterdam next week for the International Liver Congress (ILC) conference. The ILC is the annual meeting of the European Association for the Study of the Liver (EASL) and is attended by over 14,000 people in the liver community. Ricky Safer will be attending sessions relevant to the PSC community and will be meeting with clinicians, researchers and industry representatives to build new relationships and promote broader global awareness of the work PSC Partners is doing. Visit us on Twitter or Facebook for updates!





The mission of PSC Partners 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.

> PSC Partners Seeking a Cure (303) 771-5227 | contactus@pscpartners.org | pscpartners.org 6900 E Belleview Ave Ste 202, Greenwood Village CO 80111







