



**PSC PARTNERS
SEEKING A CURE**

THE DUCT

A Monthly Newsletter for the PSC Community

April 2018

[Patient Registry](#)

[2018 Conference](#)

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EARLY BIRD REGISTRATION ENDS APRIL 8
Register today to take advantage of early bird prices!

Conference Registration Deadlines

If you haven't registered for the 2018 annual conference but are still planning to attend, please pay attention to the following important deadlines and prices. The final registration cutoff is June 9, 2018. If you have already registered but need to cancel, the deadline to do so and receive a refund is June 9th. After that date, all registrations are non-refundable.



- Early Bird Registration through 4/08/2018: \$200/person

- Regular Registration 4/09/2018 - 5/28/2018: \$220/person
- Late Registration 5/29/2018 - 6/09/2018: \$250/person
- Corporate/Professional & Medical Provider Registration Through 6/09/2018: \$310 per person

[Click here](#) for everything you need to know about the 2018 conference. We can't wait to see everyone in Sacramento!

Hotel Rooms are Filling Up! Book Today!



PSC Partners is happy to provide a discounted group rate for conference attendees. This discount is available through May 25, or until the room block is filled, **whichever happens first**. The room block is filling up quickly, so we highly encourage attendees to book

rooms as soon as possible. [Click here](#) to book a room and take advantage of our special room rate and subsidy. For more details about the hotel and our discounted rates, please [click here](#).

Calling All Mentors

If you have previously attended a PSC Partners conference, please consider volunteering to be a mentor this year for our new attendees. We try very hard to match our mentees with a similar mentor, so the mix of patient and caregiver mentors needed each year depends on the mix of new attendees. If you didn't sign up to be a mentor when you registered, it isn't too late! Just [send us an email](#) and let us know you are interested in participating. Thank you!



Help Us Spread the Word

Our goal is to ensure that no PSC patient or caregiver feels isolated and alone. We constantly seek to spread the word about our annual conferences to people who haven't heard about us before. You can help! Please share our [2018 Conference Flyer](#) with your medical providers, and ask them to tell their PSC patients and caregivers about our conference. Feel free to download, print, and share online!



PSC PARTNERS
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**14th ANNUAL
CONFERENCE**

For Patients and Caregivers

June 22-24, 2018, Sacramento, CA



Location:
Sheraton Grand
Hotel

**Education and Support for the Primary
Sclerosing Cholangitis (PSC) Community**

Register by June 9 to join PSC Partners and UC Davis Medical Center for a weekend of educational presentations and opportunities to connect with other PSC patients and caregivers.

Conference Highlights

- ❖ *Managing PSC Symptoms, Nutrition, Pre-and Post-Transplant Issues, IBD, Microbiome, Cholangiocarcinoma, Clinical Trials and Promising Drugs*
- ❖ *Point-Counterpoint: Ursodiol & Vancomycin*
- ❖ *Coping with the Stress of Living with PSC*
- ❖ *Liver Stem Cell Research*
- ❖ *PSC Sponsored International Research*
- ❖ *Mentor Support*
- ❖ *Peer Group Discussions*

Special Tracks:

- Pediatric PSC
- Transplant
- PSC Basics
- Caring for you

To learn more or to register online:
<http://pscpartners.org/upcoming-conference/>

Questions? Email us at: contactus@pscpartners.org or call 303-771-5227

Consider Becoming a 2018 Conference Sponsor

Every year, the cost of attending our annual conference is cut in HALF by the generous support of conference sponsors. Every sponsorship helps - no matter how big or small. PSC Partners offers different levels of sponsorship for [community members](#) and for interested [corporate sponsors](#). We are so grateful for the support of sponsors who help ensure that the annual conferences are as affordable as possible. Consider becoming a conference sponsor today!

Conference Photographer Needed

We are still looking for an experienced photographer who is willing to take photos throughout the 2018 conference. If you are interested, please [email us](#) so we



can learn more about you. For a sample of past conference photos, please [click here](#).

Education / Research / News

PSC Partners Has a Podcast!



We are thrilled to announce the launch of *Living With PSC*, a podcast moderated by Niall McKay. Each month, this podcast will explore the latest research and knowledge about PSC. From patient stories, to the latest research updates from PSC experts, to collaborations that are necessary to find better treatments and a cure, this podcast has it all!

In Episode 1, Niall speaks with Ricky Safer, Founder and CEO of PSC Partners Seeking a Cure. [Click here](#) to listen.

PSC Partners to Attend the International Liver Congress in Paris, April 11-15

Each April, the European Association for the Study of the Liver (EASL) hosts the [International Liver Congress](#) at a different location in Europe. The ILC is attended by over 10,000 scientific and medical experts who gather from around the globe to discuss the latest updates in liver research.

PSC Partners Seeking a Cure will host a booth at the 2018 ILC to raise awareness of the many unmet needs of primary sclerosing

cholangitis patients. We will also attend PSC-related sessions and meet with clinicians, researchers, and industry representatives to foster new collaborations and promote international awareness of the work that we do. Keep an eye on Twitter and Facebook next week for updates throughout the event!

4 Tips to Follow a Low-Sodium Diet Like a Pro

There is no specific PSC diet, and many PSC patients do not have to make any dietary changes, except to continue to eat in a healthy, sensible way.

That said, a low sodium diet might be recommended for individuals with ascites, which can occur in people with liver failure. Our guest blogger and licensed dietitian Brittany Roman-Green shares some practical advice for lowering sodium intake. [Click here](#) to read Brittany's latest post. To learn more about nutrition and PSC, [visit our website](#). Bon appétit!



Ricky Safer Presents Recent Registry Survey Data at Cholangiopathies Symposium

On March 16-17, the American Association for the Study of Liver Diseases (AASLD) sponsored a symposium entitled Emerging Trends Conference on Cholangiopathies: The Dawn of Curative Treatments. The objective of the two day symposium was to provide a review of the most updated research in genetics, pathogenesis and treatment opportunities, and ultimately to facilitate continuing international collaborations on future therapies and clinical trials for adults and children with these diseases of the biliary tree.

In their introduction to the conference, Drs. Chris Bowlus and Mario Strazzabosco expressed their belief that we are currently at an exciting time to be studying PSC and other cholangiopathies, as there is greater understanding of these diseases, some



promising research being shared and a variety of clinical trials taking place.

Ricky Safer was the last speaker, and she presented the patient perspective on enrolling in clinical trials. Thanks to the 402 registry participants who kindly responded to our survey, Ricky was able to share interesting trends and data, especially regarding patient concerns about enrolling in clinical trials. We continue to receive feedback from researchers who are listening to our concerns, and seeking to address them in future clinical trial design. Our patient voice is being heard!

The 2018 Research Grant Application Review Process is Underway!

A critical component of our mission is to raise funds to research causes, treatments and cures for primary sclerosing cholangitis in both adult and pediatric patients. March 25th was the deadline for submission of 2018 grant proposals, and we were thrilled to receive many innovative applications from leading research institutions worldwide. In the next three months, our [Scientific Medical Advisory Committee \(SMAC\)](#) will review the applications and select the most promising proposals to recommend to the Board of Directors for funding, based on scientific merit.

[Click here](#) to learn more about the research PSC Partners has funded in the past. Stay tuned to see which new projects are selected this year!

Registry Update: Recent Surveys, Presentations, and Research Efforts

The PSC Partners Patient Registry entered the hepatology community at precisely the right time. We were right there with the NIH in 2010 when discussions focused on patient-driven



registries as being the most effective way of giving the silent rare-disease patients a voice. The NIH worked with us to... [Read Full Article](#)

Support Resources



Caregiver Corner

Being a caregiver can be stressful and demanding at times, particularly with a disease that is as unpredictable as PSC. [Click here](#) for some practical

advice and personal stories from PSC caregivers who know what you're going through and have learned some lessons along the way.

Local Support Groups

Do you think you might want to start a support group, but aren't quite sure where to start? [This article](#) provides a great overview of what is involved and what you can expect. We also have some [pointers on our website](#), and are [always available](#) if you have any lingering questions.



*Note: local support groups are not endorsed by PSC Partners and are fully independent of PSC Partners. PSC Partners accepts no responsibility for any information, activities, or costs associated with local support groups.

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.

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