

THE DUCT

A Monthly Newsletter for the PSC Community

March 2019

Patient Registry 2019 Conference Donate Now

In this issue: 2019 Conference Agenda, Transportation and Lodging Info., Conference Fees, Living with PSC Podcast, New SMAC Members, New Staff, Expert Q & A, Doc. Appointment Tips, Car Donation, PSC Partners Shop



Attendees of the PSC Partners annual conferences always give the event a thumbs up. In fact, one attendee described the PSC Partners Conference as, "One of the best weekends of mv life."

Don't miss it!

June 21-23, 2019 Rochester, MN Click here for 2019 Conference information.

What's on the 2019 Conference Agenda? Take a Peek!

PSC Partners is busy preparing for the 2019 Annual Conference



in conjunction with Mayo Clinic, in Rochester, MN, June 21-23, 2019. While we're still tweaking the agenda, it's almost complete. From vital presentations on medical topics to peer-to-peer mentoring to fabulous social events, there's a little something for everyone, and you won't want to miss this event. Check out the draft agenda here.

For more information about the annual conference click here.

Help us spread the word. Ask your healthcare provider to post this <u>flyer</u> in their office.



Travel, Lodging, & Meetings... We've got the 2019 Conference DEETS!

This year's PSC Partners Conference, June 21-23, is in Rochester, MN. Check out important information below:

TRANSPORTATION: While flying directly into Rochester is an option, it may be less expensive to fly into Minneapolis-St. Paul, which is 79 miles from Rochester (about a 2 hour shuttle ride/drive). The Rochester Shuttle Service can take you from either airport, and, as a PSC Partners conference attendee, you will receive a discount. Click here to make a reservation. Enter the code MAYO1 (all caps, no spaces) at checkout after the times and dates of shuttle service have been selected. The discounted rate from Minneapolis-St. Paul is \$27 one way, \$54 round trip. Be sure to make a roundtrip reservation. The Rochester Shuttle Service has a representative at the Kahler Grand Hotel, if you need assistance on site. You do not need a car during the conference.

MAJOR AIRPORTS:

 Rochester International Airport is about 8 miles from the Kahler Grand Hotel, 20 2nd Ave. SW, Rochester, MN 55902. See the information about shuttle transportation above. Minneapolis-St. Paul International Airport is 79 miles from Rochester. Airfares may be more affordable in and out of this airport. Use the information in the Transportation section above to book a shuttle.

HOTEL: The Kahler Grand Hotel is the designated conference lodging, 20 2nd Ave., SW, Rochester, MN. In order to take advantage of the *PSC Partners Conference discount*, click here to book your room now. The discounted rate is available from Sun., June 16-Wed., June 26, 2019. Once all blocked rooms are reserved, the discount rate will no longer apply. So, it is strongly advised that you make reservations as soon as possible to take advantage of the group rate.

MAYO CIVIC CENTER: Conference meetings and meals will take place at the Mayo Civic Center, 20 Civic Center Dr., SE, Rochester, MN, which is just four blocks from the hotel and easily accessible via a convenient skywalk.

More details will be posted on the website, as they become available.

Conference Registration Fees

The registration for the 2019 PSC Partners Annual Conference will be live soon. For planning purposes, please see the registration fee info. below:

Early Bird Registration: \$220 per person Regular Registration: \$240 per person Late Registration: \$270 per person

Corporate/Professional & Medical Provider Registration: \$330 per person

ALL fees must be received by 6/07/2019. Registration will be open soon.

Conference registration fees include: Friday: breakfast, lunch, and dinner

Saturday: breakfast, lunch, snacks, and banquet dinner

Sunday: breakfast, snacks

Fees also cover: evening entertainment, presentations, breakout sessions, open

forums, and all conference materials.

The Thursday evening dinner at the Rochester Art Center costs an additional \$23, if you elect to join us for this pre-conference event.

Conference fee applies to ALL those who attend ANY PART of the PSC Partners 2019 Annual Conference. Fees cannot be pro-rated.

Living with PSC Episode #10: Nutrition and PSC

In the tenth episode of Living with PSC, Niall McKay discusses nutritional guidance for PSC patients with Dr. Valentina Medici, Associate Professor, University of California Davis. Click here to listen to the podcast.



The Living With PSC podcast series is moderated by Niall McKay. Each month, this podcast explores 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! Click here for a list of past episodes.

Five Doctors Join SMAC

The Scientific/Medical Advisory Committee (SMAC) directs the path of the PSC Partners research program in order to find new treatments, and, eventually, a cure for PSC. We are excited to introduce you to the five new members of SMAC.



Dr. Annika Bergquist is an adjunct professor and researcher at Karolinska Institutet Stockholm, Sweden.

Dr. Heather Francis, PhD, is a Professor of Medicine, VA Research Scientist, and Scientific Director, Indiana Center for Liver Research, Richard L. Roudebush VA Medical Center, and Indiana University.





Dr. David Goldberg is an Assistant Professor of Medicine and Epidemiology at Penn and Medical Director for Living Donor Liver Transplantation at the Hospital of the University of Pennsylvania (HUP).

Dr. Cynthia Levy is an Associate Professor of Medicine at the University of Miami and the Program Director for the Transplant Hepatology Fellowship program.



Dr. Cara Mack is a Professor of Pediatrics at Children's Hospital Colorado, Medical Director of the Pediatric Liver Center, and



Director of the Pediatric GI, Hepatology and Nutrition Training Program.

For more information on our newest SMAC members as well as the

other valuable members of this 18-person team, click here.

Meet New Team Member BLAIR OCONNOR



We are excited to introduce you to the newest member of the PSC Partners staff Blair OConnor, business and program coordinator. Blair is a registered nurse who has a strong interest in patient education and advocacy.

Welcome aboard, Blair!

As Heard @ 2018 Conference PSC Q & A with the Experts

At the 2018 PSC Partners Conference, a team of experts answered a variety of questions about PSC, including inquiries about gene editing, use of stem cells, the PSC Forum, and more. View the entire presentation here.

Check out information and presentations from past conferences here.



PSC Partners Blog Spot Tips To Make the Most of Your Next Doctor's Appointment

PSC can be difficult. In addition to battling symptoms, there's a lot of

confusing medical considerations and swirling emotions. With proper preparation before, during, and after your doctor's appointment, however, you can make the most of your resources, so you can feel confident in your care plan. Husband and wife team Tyler and Nicola Tessier share tricks of the trade to help patients, caregivers, and family members make the most of the next visit to the doctor. Check out their blog post here.



Your Neighbor Called... They Want You To Get Rid of the Rusty Car in Your Driveway WE CAN HELP!

Hey, can we talk? That old car in your driveway that barely runs isn't doing anybody any good just sitting around. By donating your car to PSC Partners, you will ensure that your old, trusty automobile makes a real difference. It's an easy process. Click here to learn more about it.



Another simple and impactful way to support PSC Partners is by making a recurring donation. Whether it's \$10 a month or \$1,000 a month, your consistent donation will go a long way to helping PSC Partners achieve its mission. Click here for more information. Thank you!

Looking for Snazzy Gear to Wear @ Conference? We've Got You Covered (literally)



Whether you're in the market for a sweatshirt, a tshirt, or fancy jammies, the PSC Partners online shop has what you want to make sure you are looking your best at the conference. Click <u>here</u> to check out the shop. (This is not a fundraiser.)

Remember: There will be lots of fun swag available at the conference store, as well.

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.

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









