



THE DUCT

A Monthly Newsletter for the PSC Community

April 2019

[Patient Registry](#)

[2019 Conference](#)

[Donate Now](#)

In this issue: [Conference Registration and Info.](#), [Conference Newcomers](#), [Employee Farewell](#), [Podcast: PSC and Motherhood](#), [Grant Review](#), [Mayo Appointments](#), [Biobank Help](#), [Conference Sponsors](#), [PSC Partners Swag](#)



Support and Understanding Guaranteed at PSC Partners 15th Annual Conference!
June 21-23, 2019
Rochester, MN

[Click here](#) for 2019 Conference information.

Registration
NOW OPEN
for the 2019 Conference
Held in Conjunction w/ Mayo Clinic



It's time to register for the 2019 PSC Partners Conference in Rochester, MN, June 21-23, 2019. [Click here](#) to register and see important information about the 15th annual conference. To see the full agenda, [click here](#).

Don't Forget To:

- Make your hotel reservation before the discounted block of rooms fills up. Once they are filled, the discount will no longer be available. [Click here](#) to be directed to the PSC Partners Kahler Grand Hotel reservation page.
- Reserve your shuttle to and from the airport, whether you are flying into Rochester or Minneapolis-St. Paul (which may be more affordable). [Click here](#) to receive a discount with Rochester Shuttle Services. Enter **MAYO1** to receive the discount.
- Plan to come a day early to enjoy the pre-conference Thursday night dinner at the Rochester Art Museum the night before the conference. Reservations can be made directly on the conference registration form.
- Register soon to receive early bird pricing. The deadlines are:

Early Bird Registration: Deadline 4/29/19

\$220 per person

Regular Registration: Deadline 5/27/19:

\$240 per person

Late Registration: Deadline 6/9/19:

\$270 per person

Corporate/Professional & Medical Provider Registration:

Deadline 6/9/19:

\$330 per person

ALL fees must be received by

6/9/2019.

- Bring a fun, crazy, tacky, or funny camping outfit for the Saturday night camping-themed shindig. Anything goes, and creativity is encouraged.



Remember: No one under the age of 13 may attend any part of the conference, including meals.

Conference Newcomers Receive Special Attention

If this will be your first time attending a PSC Partners Conference, we understand if you are a little nervous. We've all been there. Conference veterans will be on hand to welcome you with open arms, and, soon, you will feel like part of the family.

There are a few easy ways to ensure you hit the ground running and make the most of your time at the conference.

Request a Mentor: When you fill out your registration form, ask for a mentor. You will be matched with someone from your peer group. During Friday's lunch, you will meet your mentor in person, if you haven't connected previously.

Attend the Conference Orientation Session: On Friday, June 21, 9-9:30 a.m., PSC Partners board members will present an introduction to the conference and provide tips for making the most of your time. This session is not to be missed by newcomers and those who would like a refresher.

Take Advantage of Peer Group Sessions: You will be assigned to a peer group that meets at various times throughout the weekend. These groups convene to offer invaluable support, share knowledge, and discuss personal experiences. Be sure not to miss the Sunday peer sessions.

Take it from a past first-timer:

*"We learned so much and met such wonderful people.
Now we don't feel so alone and isolated.
In fact, we feel encouraged and supported. Thank you all!"*

Fond Farewell to Katie Randall



We are sad to say goodbye to PSC Partners Associate Director Katie Randall (*standing between Founder & CEO Ricky Safer and Executive Director Meegan Carey*). For close to four years, Katie has been an integral part of the PSC Partners team. Her amazing efforts have propelled the organization forward, and she will be missed. We wish Katie well as she moves on to other endeavors.



Living with PSC Episode #11: PSC and Motherhood

In this episode of Living with PSC, Niall McKay discusses motherhood and PSC with Monika Aldarondo, a PSCer juggling parenthood and her rare disease. [Check it out here.](#)

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.

SMAC REVIEWING GRANT APPLICATIONS

The Scientific/Medical Advisory Committee (SMAC) is a group that directs the path of the PSC Partners research program in order to find new treatments, and,

eventually, a cure for PSC. These dedicated medical experts are in the process of reviewing the grant applications submitted this year. Grants are offered to researchers conducting studies that address an important and novel, basic, or clinical research question related to PSC and closely associated diseases (such as inflammatory bowel diseases (IBD) and cholangiocarcinoma). The program seeks to encourage investigators to conduct research in promising new areas, with the goal that data generated will lead to federal (NIH) or external international funding.

Applications were submitted at the end of March, and awards will be announced in May.

To see past awards, [click here](#).



HOW TO SECURE AN APPOINTMENT AT MAYO CLINIC

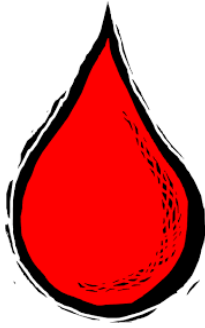
Many people have expressed an interest in scheduling appointments with Mayo Clinic before or after the conference. Please understand that PSC Partners is unable to help facilitate scheduling. However, we are happy to share a few tips with you regarding booking an appointment:

- Contact the Central Appointment Office at 1 (507) 284-2111 for new patient appointments in the Mayo PSC Clinic.
- The PSC Clinic calendar opened 12 weeks prior to the conference weekend (end of March).

PSC patients will likely first be seen by Andrea Gossard, APRN, C.N.P. Numerous PSCers have met with her. She is extremely knowledgeable about PSC, and she will be presenting at the 2019 Conference.

***Participation in
Blood Specimen Collection***

Encouraged at the Conference



A PSC research effort is currently underway at Mayo Clinic, and PSC patients attending the 2019 PSC Partners Conference are encouraged to participate. Researchers are creating a biobank of specimens and collecting clinical data for use in current and future research to better understand primary sclerosing cholangitis (PSC). Mayo Clinic researchers will be collecting blood specimens from PSC patients on Friday and Saturday during the conference weekend. The hope is to develop better testing for early detection and a greater understanding of disease complications and progression.

Research Coordinators for Mayo Clinic will be on hand Thursday afternoon during check-in to answer questions. The blood draws will be held on Friday and Saturday at the Mayo Civic Center from 9 a.m.- 5 p.m. Mayo Clinic representatives will assist with the consent process during this time. All participants must have the consent form signed prior to specimen collection. Please contact Erik Schlicht (schlicht.erik@mayo.edu), 507-284-4312, or Jacki Bianchi (Bianchi.jackie@mayo.edu), 507-266-0346, to get a copy of the consent form in advance of the conference, if you have any questions about the study, or if you would like to meet with someone to discuss the study.

Mayo Clinic is encouraging all PSC patients to provide blood samples regardless of past participation in Mayo studies. PSC patients who may be at Mayo Clinic earlier in the week are welcome to meet with a Research Coordinator and have their blood drawn at that time. Please contact Erik or Jacki for more information about how to schedule this visit.

THANK YOU TO OUR 2019 CONFERENCE SPONSORS!

PLATINUM PARTNERS



The Kenneth S. Hollander Charitable Foundation
The Parry Family

GOLD PARTNERS

The McMurtry Family

SILVER PARTNERS

William Bandy & Mary Jo Jordan

John & Chris Browner Family

Grover & Wente Families

The Hatchett Family



The Litton Family

The Sabernick Family

The Safer Family

The Shepherd Family



BRONZE PARTNERS

Albireo Pharmaceuticals

Randall and Catherine Oates

Frank and Barbara Resnek

COPPER PARTNERS

Anonymous

The Belmont Family

The Kerdman Family

COMMUNITY PARTNERS

The McKinney Family

There is still time to support PSC Partners by becoming a [corporate](#) or [community](#) sponsor. For more information, email info@pscpartners.org or call 303-771-5227.

**For sponsorship recognition to be included in printed event materials,
all funds must be received by May 15, 2019.**

Amazing PSC Partners Swag Available @ Conference!



As usual, the PSC Partners Conference Shop will have great clothes and other fun products available during the conference. The items are priced affordably, so everyone can proudly wear their PSC Partners attire.

If you'd like to purchase PSC Partners clothing before the conference, items are available at our [online shop](#). There's a little something for everyone, and we thank you for raising awareness for PSC and PSC Partners.

The apparel and swag available at the conference and online will not be the same.

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

