



THE DUCT

A Monthly Newsletter for the PSC Community

February 2020

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*Find the support and information you need at the PSC Partners Annual Conference
April 24-26, 2020
Check out registration and more conference details below.*

***Register Today for PSC Partners
Patient and Caregiver Conference
April 24-26, 2020
Denver, Colorado***



**Registration is now open for the Annual PSC Partners Conference.
Click the button below.**

Register Now

*Early Bird Registration

Through 02/29/2020: \$250 per person

* Regular Registration

From 03/01/2020 Through 03/29/2020: \$270 per person

* Late Registration

From 03/30/2020 Through 04/10/2020: \$300 per person

* Corporate/Professional & Medical Provider Registration

Through 04/10/2020: \$375 per person

ALL fees must be received by 04/10/2020.

Conference fee includes:

- The Friday brunch at Red Rocks Amphitheater (Transportation Included). Seats are limited. This is a first-come, first-served event.
- Afternoon snack and dinner on Friday
- Breakfast, lunch, snacks, and banquet dinner on Saturday
- Breakfast and snack on Sunday
- Evening entertainment, presentations, breakouts, open forums, and all conference attendee materials

Conference fee applies to ALL those who attend ANY PART of our conference and cannot be pro-rated.

Nobody under the age of 13 is allowed to attend any part of the conference, including meals. This applies to babies, as well. There are no exceptions.

Conference fee receipts and confirmations will be sent to your e-mail address once the registration form is completed.

Please note: If you do not receive your confirmation letter, please

check your spam folder. While we've made every effort to ensure all of our correspondence hits in-boxes, we don't want you to miss a bit of news. If your letter is marked as spam, click the "not spam" option, so you will be sure to receive updates about the conference and other PSC Partners news.

We're still looking for Conference Sponsors. Take a look.

[2020 Community Sponsorship Opportunities](#)

[2020 Corporate Sponsorship Opportunities](#)

Conference Agenda Packed with **AMAZING SESSIONS** From Engaging Presenters



The 16th Annual PSC Partners Seeking a Cure Patient and Caregiver Conference offers an abundance of interesting and informative sessions for PSC patients, caregivers, family members, and friends. Here is a sampling of the learning opportunities available in Denver, April 24-26.

PSC 101

Lisa M. Forman, MD, MSCE, Professor of Medicine, Program Director, Gastroenterology/Hepatology, Director of the Autoimmune Research Unit, University of Colorado Anschutz

What's New in Pediatric PSC?

Cara Mack, MD, Professor of Pediatrics, Hewit/Andrews Chair in Pediatric Liver Disease, Medical Director of the Pediatric Liver Center, Children's Hospital Colorado

The Gut Microbiota in IBD with PSC: An Update

Tom Hemming Karlsen, MD, PhD, Leader of Norwegian Research Center, Department of Transplantation Medicine, Division of Surgery, Inflammatory Medicine and Transplantation, Oslo University Hospital Rikshospitalet

Teens Q&A: Every Question is Fair Game

(exclusively for teens & college-age attendees)

Julia Boster, MD, Pediatric Fellow in Gastroenterology, Hepatology & Nutrition, Children's Hospital Colorado, and Keith Hazelton, MD, PhD, Pediatric Transplant Hepatology Fellow, Children's Hospital

What's New in PSC/IBD: Pathophysiology, Staging and Treatment - Panel Discussion

Moderator: Cara Mack, MD, Children's Hospital Colorado

Risk Stratification Tools - What Does It Mean for Me?

Gideon Hirschfield, MB, BChir, FRCP, PhD, Hepatologist, Toronto Centre for Liver Disease, Professor of Medicine, University of Toronto

Patients: The Everyday Stresses of Living with PSC

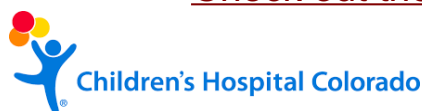
Jerome Schofferman, MD, PostTransplant PSC Patient

3-D Virtual Reality of the Liver Presentation

Albert Fung, MScBMC, Team Lead, The Toronto Video Atlas of Surgery, Toronto General Hospital

[Check out the Agenda Here](#)

[Check out the Speaker Biographies Here](#)



[uhealth](#)

Need a Mentor? We're On It!



Being diagnosed with PSC can be scary. Watching as a loved one deals with this disease can be equally as overwhelming. We have a mentor program available for folks in our community. Interested? When you register for the conference, request a mentor.

Whether you're a PSCer, caregiver, parent, or fit another category, we will take great care to match you with a mentor who is just right for you. Please be patient. The matching process may take awhile, but it's worth it!

Do you want to be a mentor? You can let us know that on your registration form, as well. Big thank you to volunteer Trish Stoltzfus for coordinating this important program.

Questions? Reach out to us at contactus@pscpartners.org.

Volunteer: We also need volunteers to help at the conference. When you register, let us know how you'd like to help. Thanks!

Conference Hotel Offers Discount to Conference Go-ers

Discounted Rooms Available on a First-Come, First-Served Basis



Most attendees choose to stay at the conference hotel, Hyatt Regency Denver Tech Center, 7800 E. Tufts Ave., Denver, CO. This is also the location of most conference activities.

PSC Partners conference attendees receive a special group rate that is available until the block of rooms is sold out. [Click here](#) to visit the hotel PSC Partners page and reserve your room. In order to ensure your spot at the hotel, make your reservation as soon as possible.

Attention: *There is a Hyatt Regency downtown, as well. The conference hotel is in the Denver Tech Center (DTC).*

Field Trip to Red Rocks Included in Conference Registration Fee



We are excited to offer a field trip to the iconic Red Rocks Amphitheater, just 40 minutes from the conference hotel. Transportation and a fabulous brunch are provided. Pre-registration is required. **Seating is limited. First come, first-served.**

Be sure to register and bring your ticket. We will load the buses at 7:45 a.m. on Friday morning, and return to the conference hotel at 1 p.m. Spring weather in Colorado can be unpredictable. To make the most of this outing, layer your clothing, bring a warm coat, wear comfortable

The PSC Partners Conference Offers Something for Everyone

Click on the photos below to find out what brings folks to the PSC Partners Conference.



Help Us Spread the Word About PSC Partners Conference



Please help us get the word out about the PSC Partners 16th Annual Patient and Caregivers Conference, April 24-26, in Denver, CO.

- Print [this flyer](#) and ask your medical provider to post it in their office.
- Put a [link to conference information](#) on your social media. Use #PSCPartners2020.
- Share [this link](#) to let folks know that registration is open.

Thanks!

PSC Partners Selected for CZI Rare As One Project Grant



Rare As One

The Chan Zuckerberg Initiative (CZI) announced funding to 30 patient-led organizations, including PSC Partners Seeking a Cure, that are working to find treatments and cures for rare diseases. These grants are part of CZI's Rare As One Project aimed at supporting and lifting up the work that patient communities are doing to accelerate research and drive progress in the fight against rare diseases.

"We were so excited to have the opportunity to apply for this important grant, and we're thrilled to be part of the group selected. The grant will enable us to take a significant step forward in our search for treatments and a cure for primary sclerosing cholangitis (PSC)," says PSC Partners CEO Ricky Safer. "Thank you to everyone in the PSC community who has contributed to our success. We couldn't do it without you."

The funds, which are designated for one particular research initiative, will be distributed over a two-year period.

[Check out the full list of Grantees](#)
[Visit the PSC Partners CZI Rare As One Project Page](#)
[Read the CZI Rare As One News Release](#)

What is the PFDD Meeting, Why Should You Be There, and How Can You Help?



When is the PFDD Meeting? The PSC Partners Externally-Led Patient Focused Drug Development (PFDD) meeting, hosted by PSC Partners, is on Friday, October 23, 2020, in the Washington, D.C., area.

What is the PFDD Meeting? This is a one-time opportunity for our patient voices to be heard by attendees who will include the FDA, pharmaceutical leaders, researchers, and clinicians.

Who should be involved? We are hoping for participation by as many PSC patients and caregivers as possible, so please save the date and plan to attend in person or via webcam. Facilitated discussions will

happen, so patients and caregivers in the audience can share their stories, thoughts, perspectives.



How can you become a panelist? To prepare for the PFDD meeting, we will be choosing two panels of adult PSCers and one panel of pediatric PSCers and/or their parent to tell the story of their PSC journey.

If you would like to be considered as a panelist, please capture your story on one page (approx. 500 words), and send it to us. You have a choice of one of two topics to cover that have been designated by the FDA.

Please Pick One of these Angles for Your Story:

1. "How does PSC affect your life, including physical, emotional, and social aspects, and what is important to you?" Tell us what is most bothersome... How it affects you to be fatigued, to itch, to not be able to socialize like you used to, to be unable to think clearly, or whatever is most important to you. Everyone is different, and we need multiple voices to express what PSC does to the individuals suffering from it.
2. "In addition to a cure for PSC, what treatment benefits do you hope for, what are the risks you are willing to tolerate, and/or how could medicine improve your quality of life?"

More about your story submission and being a panelist:

- We are hoping to put together diverse panels representing different disease stages, ages, and a variety of experiences and concerns.
- If you are chosen as a panelist, you will need to be in the Washington, D.C., area on Oct. 22-23, 2020.
- If you are not chosen, it doesn't mean your story isn't important. Please know that we are dedicated to creating a diverse panel representing the many faces of PSC. If you are not chosen to sit on a panel, we hope you will still plan on participating in the meeting. There will be opportunities for audience participation. It is essential that we have a strong community presence, and that includes YOU!
- Once the panelists are chosen, PSC Partners will pay for their travel and hotel costs for the October meeting. Panelists will also participate in a series of training and preparation meetings by phone, and one in-person meeting on Thurs., April 23, prior to the start of the annual patient/caregiver conference in Denver, if possible.

Story Submission Deadline: Feb. 28, 2020

Attach your story to an email and send it to:

joanne@pscpartners.org with subject line, "(PFDD Story - (Your Name))."

If you have any questions, or are having trouble sending your story, please contact Joanne Hatchett at joanne@pscpartners.org, or call 530-304-9458.

Attention Coloradans **Support PSC Partners** **When Completing Taxes**



Donate to a Colorado Nonprofit Fund is a new option for Colorado taxpayers this year. Here's how it works:

- When you have determined that you will get a Colorado refund, use the "Voluntary Contributions" schedule to choose an eligible nonprofit, including PSC Partners.
- Taxpayers should look for the new additional option of "Donate to a Colorado Nonprofit Fund" on that schedule and

insert *all three* of the following:

- A) Nonprofit's name (PSC Partners Seeking a Cure)
- B) Nonprofit's Secretary of State CCSA Registration Number (Our # is 20083006407.)
- C) Amount of Donation

Note: Different tax filing software programs (like TurboTax) will display prompts for tax filers getting refunds in various ways, and donors will have to look for "Donate to a Colorado Fund." If you are using a tax preparer, like H&R Block or a CPA, you will need to inform the tax preparer to include the nonprofit's name, CCSA registration number, and amount.

Thanks for your support!

Get Your Pre-Conference PSC Gear Here!

Fabulous and affordable PSC Partners gear will be available at the 2020 conference store. If you'd like to load up on snazzy gear ahead of time, visit our [online shop](#) and pick some swag, so you can look fantastic at the conference.

(This is an awareness-raiser, not a fundraiser.)



Hatchett New Member of AASLD Committee



We're excited to announce that our own Joanne Hatchett, medical science liaison for PSC Partners, was recently appointed as a community representative on the Communications and Technology Committee for the American Association for the Study of Liver Diseases (AASLD). Joanne is excited to be part of this committee, and we're thrilled to increase our involvement with AASLD.



Important Dates 2020

Feb. 28-March 1: Canadian Liver Meeting CASL, Montreal

Feb. 29: Rare Disease Day ([Click here](#) to see how to get involved.)



March 12: Liver Capitol Hill Day, Wash., D.C.

April 15-19: The International Liver Congress, The European Association for the Study of

Liver (EASL), London

April 24-26: PSC Partners 16th Annual Conference, Denver ([Click here](#) for more information.)

Sept. 27-28: Research Symposium and Family Day, Center for

Autoimmune Liver Disease, Cincinnati Children's Hospital Medical Center

Sept. 21-23: Global Genes, San Diego

Oct. 8-9: National Organization for Rare Diseases (NORD), Wash., D.C.

Oct. 23: PSC PFDD Meeting, Wash., D.C.-area

Oct. 29: PSC Awareness Day

Nov. 13-17: American Association for the Study of Liver Diseases (AASLD), Boston

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
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