



THE DUCT

A Monthly Newsletter for the PSC Community

September 2019

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"You're a very inspiring group! Although I know nobody can promise me that my mother will be okay, it is so refreshing to see people with PSC banding together and living it up!"

2019 Conference Presentations NOW ONLINE



From a discussion about PSC and Healthy Bones to The Social Side of Raising Kids with PSC to Organ Allocation in 2019, slides and/or video from the presentations at the recent PSC Partners conference are available on our website. [Click here](#) for the list. To view the slide presentations in video format, visit the PSC Partners [YouTube channel](#).

2020 Conference -- April 24-26 DENVER, COLORADO



Mark your calendars for the 16th Annual PSC Partners Conference, in collaboration with University of Colorado Health and Children's Hospital Colorado, taking place in Denver, April 24-26, 2020. Presenters will include

medical professionals with the most up-to-date information about primary sclerosing cholangitis. Additionally, the conference is an opportunity for folks to spend time with others who understand this disease.

The conference draws patients and caregivers (spouses, partners, parents, siblings, and friends) who want to learn about the latest research on treatments, medications, procedures, and the disease outlook.

DON'T MISS IT!

Registration information will be available soon.

uhealth



Host the 2021 Conference Deadline to Apply: Oct. 15



Do you want to bring the 2021 PSC Partners Conference to your city? We're accepting host proposals now. To be considered, complete the [Conference Host Proposal](#) by October 15, 2019. The PSC Board of Directors will choose a venue and announce the host city

at the 2020 conference. If you have any questions, email us at contactus@pscpartners.org.



Living with PSC Episode #14: VANCOMYCIN

In this [episode](#) of Living with PSC, Niall McKay has a conversation with Dr. James Tabibian, a gastroenterologist and director of endoscopy and resident research director at Olive View-UCLA Medical Center, about the possible use of

Vancomycin as a treatment for PSC.

[Click here to listen to the podcast.](#)

The Living With PSC podcast series is moderated by Media Producer 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 complete list of episodes as well as past PSC Partners blog posts.

Improved Outcomes in Pediatric Transplants the Goal of New Starzl Network

The Starzl Network for Excellence in Pediatric Transplantation (SNEPT) unites top pediatric transplant centers in North America with the goal of improving outcomes for transplant children and families. As stated in the Starzl Network brochure:



Pediatric transplantation is a lifelong journey filled with challenges and opportunities. The Starzl Network is committed to identifying and implementing transplant best practices so that children have access to the highest quality of transplantation care no matter where they live. Through candid collaboration, transparency, and a commitment to patient and family input and feedback, the Starzl Network aims to create successful long-term practice changes.

"As transplant families, we were invited to give feedback on the initiatives already in place, and they are encouraging us to continue to be involved as this program evolves," says PSC Partners Assistant Registry Coordinator and PSC Caregiver Sharon Nanz.

Nanz says that Dr. George Mazariegos, director of Pediatric Transplantation at the Thomas E. Starzl Transplantation Institute, indicated that the group is starting with a core of some of the best programs and will soon engage others, saying that there are 65 in the U.S.

[Click here](#) for more information.

PFDD MEETING in Wash., D.C. OCT. 16, 2021

PSC Partners is excited to announce that



we have been accepted to conduct an externally-led Patient-Focused Drug Development (PFDD) meeting through the FDA's Center for Drug Evaluation and Research (CDER) Office. The letter of acceptance states, "We have determined that an externally-led PFDD meeting on Primary Sclerosing Cholangitis (PSC) will be of great value and interest to the patient community, patient advocates, researchers, drug developers and FDA."

PSC patient and caregiver participation is vital to the success of the meeting. Please mark your calendars, and watch our newsletter, social media, and website for more information about how to get involved.

PSC Awareness Day ***October 29, 2019***



Mark your calendars for PSC Awareness Day, Oct. 29, 2019. It is a chance for PSC Partners, our supporters, and others in the PSC community, both in the U.S. and internationally, to educate friends, family, and the community about primary sclerosing cholangitis (PSC). There are a few ways you can get involved:

- Record a short video (20-30 seconds) highlighting *one* thing you want people to know about PSC. Videos should be uploaded to your personal social media pages on Oct. 29 with the hashtag #PSCAware. Remember to tag PSC Partners in your post.
- On Awareness Day, PSC Partners will be debuting an exciting new video, which can be shared.
- Add a PSC Awareness Day frame to your social media profile photos. The frame will be available soon.
- Wear PSC Partners (or other PSC gear) on Awareness Day. If you need PSC Partners swag, check out the [online shop](#).



PSC
SUPPORT
AUSTRALIA

A patient voice of hope and healing

PSC Patient Forum

Sunday 22nd Sept (12:30-3:30)

Monash Medical Centre, Clayton

Lecture Theatre 2, Level 2

Light lunch provided

Please RSVP to info@pscsupport.org.au

Hear from health professionals on:

- **PSC and You (subtypes, progression and medications)**
- **Understanding test results**
- **Diet and Nutrition**
- **Liver Transplant in Australia**

*With thanks to our presenters Dr Alex Hodge (Monash Medical Centre),
A/Prof Paul Gow (Austin Hospital) and Stephanie Cowan (Dietician)*

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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