

**PSC PARTNERS  
SEEKING A CURE**

# THE DUCT

A Monthly Newsletter for the PSC Community

**May 2020**

[Patient Registry](#)

[2021 Conference](#)

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Have you celebrated a birthday, anniversary, or other special occasion during this time of isolation? We know it's likely not how you wanted to celebrate, but the staff at PSC Partners Seeking a Cure hopes you found some joy & happiness.

**PSC Partners Funds Seven  
New Research Projects**  
*Total Grant Funds To Date Tops \$4 Million*



In an ongoing effort to find effective treatments and a cure for primary sclerosing cholangitis (PSC), PSC Partners Seeking a Cure is excited to announce the funding of seven new, promising,

international research investigations. Three additional investigations are being funded through PSC Partners Canada. Those projects will be announced soon.

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- **Defining the Interactome of Bile Duct Inflammation in PSC**, Espen Melum, MD, PhD: Norwegian Research Center, Oslo, Norway
  - **The Beneficial Effects of Endothelial Progenitor Cells in Primary Sclerosing Cholangitis**, Fanyin Meng, PhD: Indiana Center for Liver Research, Indianapolis, IN, USA
  - **Integrative Analysis of Intraductal Papillary Neoplasia of the Bile Duct in Patients with Primary Sclerosing Cholangitis**, Stephanie Roessler, PhD & Benjamin Goepfert, MD: Institute of Pathology, University of Heidelberg, Germany
  - **Micro-RNA Based Therapy for Primary Sclerosing Cholangitis**, Pasquale Piccolo, PhD: Telethon Institute of Genetics and Medicine, Pozzuoli, Italy
  - **The Role of Activating Transcription Factor 4 in Primary Sclerosing Cholangitis**, Xiaoying Liu, PhD: Northwestern University Feinberg School of Medicine, Chicago, IL, USA
  - **Treating PSC with Idefenone**, Joy Xiaosong Jiang: UC Davis, California, USA
  - **Human Disease Model of PSC for Discovery of Effective PSC Therapy** Yoon-Young Jang, MD, PhD: Johns Hopkins University School of Medicine, Baltimore, MD, USA

To see a complete list of PSC Partners-funded research, including progress reports, [click here](#).

Thank you to the members of our [Scientific Medical Advisory Committee \(SMAC\)](#) for all of your efforts and commitment to our mission.

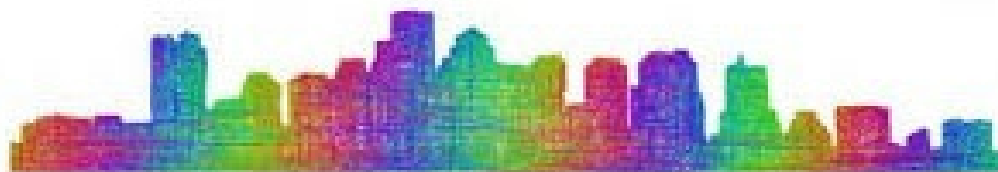
**Take a Tour of**

# OUR NEW WEBSITE



PSC Partners is excited to offer a newly designed website. We hope the freshly organized information, edited material, and new sections will be useful to our community, newly diagnosed folks, pediatric PSCer parents, caregivers, and others interested in primary sclerosing cholangitis (PSC).

[Click Here To Take A Look](#)



## BOSTON 2021

Start making your plans to attend the next  
**PSC Partners Conference, June 11-13, 2021, Boston, MA.**

We are excited to collaborate with Dr. Josh Korzenik, Brigham and Women's Hospital, and Dr. Dan Pratt, Massachusetts General Hospital, for this event.

[CLICK HERE FOR MORE INFORMATION.](#)

[Click here](#) to see a slide show from the 2019 PSC Partners @ Mayo Clinic.



## *Virtual Get-Together for PARENTS OF PEDIATRIC PSCers*



Because our recent Teen ZoomRoom was such a success, we'd like to offer a ZoomRoom for the parents/guardians of PSCers ages 0-20-years-old.

Date: Wednesday, May 27  
6 p.m. MDT  
(5 p.m. PDT, 7 p.m. CDT, 8 p.m. EDT)

Space is limited. Pre-Registration Required: [Click Here](#)  
After registering, you will receive a confirmation email containing information about joining the meeting.

## **October PFDD Meeting NOW VIRTUAL**



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**Please plan to virtually attend the Patient-Focused Drug**



## Development (PFDD) meeting on Friday, October 23, 2020.

Although we are no longer able to hold this meeting in person, your participation is still vital, because it is a one-time opportunity for our PSC patient voices to be heard by the FDA, pharmaceutical leaders, researchers, and clinicians.

We are hoping for participation by as many PSC patients and caregivers as possible, because we want the FDA to experience the commitment of our patient community in order to understand the urgent need for treatments and an eventual cure for PSC.

### How You Can Participate:

- We are looking for PSCers who have had cholangiocarcinoma and would be willing to talk about their journey.
- We need PSCers to complete the soon-to-be released PFDD PSC survey. Watch social media and your inbox for more information.
- Attendees can submit comments to the FDA during the open comment period of the event.
- Even if you don't want to speak, being a part of the virtual audience is important to show the strength of our community.
- We hope all attendees will participate in audience polling during the event.

**For more information, email [joanne@pscpartners.org](mailto:joanne@pscpartners.org)**

## PSC Partner Registry Gets an Upgrade



A new and improved PSC Partners Patient Registry is now in beta testing and coming soon. The upgrades will enhance this vital tool that collects de-identified patient information about diagnosis, family history, quality of life, medications, surgeries, other diseases, and patient demographics to facilitate and speed up PSC

research towards a cure for primary sclerosing cholangitis (PSC).

[Click here for more information about the PSC Partners Patient Registry.](#)

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REGISTRY PARTICIPANTS...  
**Check Junk Mailbox for Message  
From PSC Partners Registry Team**

Earlier this week, we sent a message to everyone who is already in the PSC Partners Registry asking that you participate in a very important survey about PSC and COVID-19. We understand that numerous messages landed in junkmail. Please check, and make sure that you include [registrycoordinator@pscpartners.org](mailto:registrycoordinator@pscpartners.org) in your contact list, so all PSC Partners Registry mailings arrive in your inbox.

If you have PSC and also have/had/suspect having COVID-19, please complete the following survey.

[PSC and COVID-19 Survey](#)

Thank You!

***Living with PSC  
Podcasts:***

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](#) to listen to the last 18 episodes hosted by Niall McKay.



**COVID-19 WEBINARS AND  
LINKS TO MORE INFORMATION**

Did you catch the last two PSC Partners webinars? If you

missed them, no worries. We've got you covered. See links below.



First Webinar in the PSC Partners 2020 Annual Conference Series: [COPING WITH PSC FOR PATIENTS &](#)

[CAREGIVERS AND EPIDEMIC PSYCHOLOGY](#)

## [PSC/IBD AND COVID-19 \(CORONAVIRUS\): WHAT YOU WANT TO KNOW](#)

(A 2nd COVID-19 webinar with new and updated information will be offered in June.)

We continue to collect links to vital COVID-19 information for our community.

[Click here for links.](#)

## Join us in the **YOU'RE NOT ALONE ZONE** (#YNAZone)

In an effort to ensure that our community feels connected even during this time of social distancing, we have created the You're Not Alone Zone (#YNAZone) on social media. Make sure you follow us on [Facebook](#), [Instagram](#), and [Twitter](#) (plus our Facebook group pages), and participate in our #YNAZone activities.



**Let's support each other and show that,  
while we may be separated, we're not alone!**

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*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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