



A Monthly Newsletter for the PSC Community

January 2019

Patient Registry

2019 Conference

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Don't miss the laughter, fun, learning, support, and special moments at the upcoming conference in conjuction with Mayo Clinic, June 21-23, 2019. <u>Click here</u> for important information.

Research Grant Proposals Now Accepted Deadline: March 23, 2019

We are now accepting applications for the 2019 cycle of our research grant program. PSC Partners Seeking a Cure and

affiliate PSC Partners Canada offer these grants to researchers conducting scientific investigations addressing an important and novel, basic, or clinical research question related to primary sclerosing cholangitis (PSC) and closely associated diseases, such as inflammatory bowel disease (IBD) and cholangiocarcinoma. For a list of past grant recipients, click <u>here</u>.

Our research grants program seeks to encourage investigators to conduct studies in promising new areas, with the goal that initial research will lead to federal (NIH) or external international funding.

Click here for more information and to apply for a grant.

Applications are due on or before March 23, 2019. Grant applications are reviewed by the PSC Partners Scientific/Medical Advisory Committee (<u>SMAC</u>). Ad hoc reviewers will be used when appropriate. Funding decisions will be sent approximately three months after submission.





We do everything in our power to make our annual conference as affordable as possible without sacrificing the quality of our educational offerings. PSC Partners subsidizes approximately half of the conference costs for each attendee. Our generous conference sponsors help us cover these costs, support our mission, and provide a special experience for everyone who attends. Interested in sponsorship? <u>Community</u> and <u>Corporate</u> conference sponsorships are available now.

Click <u>here</u> for more information about the annual conference in Rochester, MN.

Living with PSC Episode 8 Dr. Heather Francis, PhD: Influence of Ursodiol on PSC

In the eighth episode of Living with PSC, Niall McKay



Click <u>here</u> to listen to the discussion.

discusses the influence of the medication Ursodiol (aka URSO and UDCA) on PSC, including the impact of combining it with antihistamines, with Dr. Heather Francis, PhD, associate professor at the Texas A & M College of Medicine and recipient of a PSC Partners research grant.

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 <u>here</u> for a list of past episodes.



PSC Partners and You Putting the Pieces Together

Highlights of 2018

Thanks to the generous support of our donors and the invaluable

engagement of everyone in the PSC community, PSC Partners Seeking a Cure had a productive and impactful year!

- Passed the \$3 million mark for PSC research funded to date (Check out our complete list of grants <u>here</u>.)
- Increased PSC patient registry participants to almost 1,300 and growing! (Click <u>here</u> to join the registry.)
- Secured the new ICD-10-CM code for PSC K83.01
- Hosted conference for patients & caregivers in Sacramento. (Click <u>here</u> to revisit last year's presentations, including full videos and other presentation materials.)
- Awarded two Young Investigator research grants for the first time

- Launched PSC podcast series (Check it out here.)
- Nurtured international collaborations

We have lots of big plans for 2019. Over the next 12 months, PSC Partners will:

- Continue awarding grants to support the most promising international PSC research
- Host a conference in conjunction with the Mayo Clinic in Rochester, MN, June 21-23, 2019
- Augment outreach for the new PSC ICD-10-CM code (K83.01), leading to patient registry growth and high-quality research
- Expand international collaborations
- Launch a new website to elevate education and amplify support for our PSC community, and
- Continue to represent the PSC patient voice in our quest to find better treatments and a cure for primary sclerosing cholangitis.

Get Social with PSC Partners



PSC Partners is active on social media, and we'd love to get social with you!

- Connect with us on <u>Facebook</u> at our main page, or on our open and closed PSC community pages
- Check us out on Twitter
- Follow us on Instagram, and
- Link with us on our newest platform, LinkedIn

By following us, sharing our posts, linking to information on our <u>website</u>, and tagging us, you are not only helping us spread important news, but you also are increasing awareness about primary sclerosing cholangitis and PSC Partners. It's a *win-win*, and we *thank you*!

New Options Available at PSC Partners ONLINE STORE

From water bottles to baby items to comfy tshirts and sweatshirts, there are even more items

available for purchase on the PSC Partners <u>online shop</u>. This is an awareness-raiser, not a fundraiser, and additional items will be available, as usual, at the 2019 conference store.





PSC Partners Wins Make a Difference Community Partner Grant

PSC Partners was one of five nonprofits to win a *Make A Difference* grant from <u>Mytech Partners</u>. (Close to 50 nonprofits entered.) We are excited to receive a grant to create a strategic IT plan from Mytech and a consulting engagement to customize Salesforce (customer relationship management software tool) from their

partner Apoorva!

Fundraise Via Facebook

Did you know that you can create personal fundraisers directly on Facebook? Whether you're celebrating a birthday, honoring a loved one, or just looking for a simple yet impactful way to show your support, creating a Facebook fundraiser is an easy way to give back, and 100% of the funds you raise are sent to PSC Partners Seeking a Cure. Visit our <u>Facebook</u> page, scroll down to *fundraisers*, and click *create*. It's that easy!

Big thank you to everyone who has raised funds for PSC Partners viaFacebook. We truly appreciate your support!

Don't forget that another unique way to raise funds is via a <u>car donation</u>. Even if it doesn't run, we'll take it! Click <u>here</u> to check out other ways to give.



As Heard at 2018 Conference Point/Counterpoint: Oral Vancoymicin Therapy for PSC

At the 2018 Conference, Dr. Yinka Davies and Dr. James Tabibian discussed the reasons for and against treating PSC patients with oral vancomycin. Watch the full video here, and visit the conference recap to download additional presentation material, and to revisit other lectures from last year's conference.



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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