



PSC PARTNERS
SEEKING A CURE

THE DUCT

A Monthly Newsletter for the PSC Community

January 2018

[Patient Registry](#)

[2018 Conference](#)

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Education / Research / News

SAVE THE DATE FOR PSC PARTNERS 2018 ANNUAL CONFERENCE

June 22nd-24th, 2018, in collaboration with **UC Davis Medical Center**, Sheraton Grand Hotel, Sacramento, CA. Stay tuned for more details on our [conference page](#) this February.



RARE DISEASE DAY®

February 28th is RARE DISEASE DAY! Help us get the word out about PSC and other rare diseases.

In the upcoming weeks, we will be asking for your support to help us spread the word about PSC this Rare Disease Day.

What is Rare Disease Day?

Rare Disease Day takes place on the last day of February each year and aims to raise awareness about rare diseases and their impact on patients' lives among the general public, researchers, policy makers, and industry representatives. It's a rare day to put rare diseases in the spotlight.

Rare Disease Day reaches hundreds of thousands of people around the world. The campaign started in 2008 as a European event and is a world-wide initiative, with participation in [94 countries](#) in 2017. Hundreds of cities continue to take part in Rare Disease Day and it's likely that even more will join in 2018.

Why is it important?

Building awareness of rare diseases is critical because 1 in 20 people will live with a rare disease at some point in their life. Despite this, there is no cure for the majority of rare diseases and many go undiagnosed. Rare Disease Day improves knowledge of rare diseases among the general public while encouraging researchers and decision makers to address the needs of these patients.

Visit the [website](#) to learn more about Rare Disease Day and stay tuned for more information about how you can help us spread the word. If you are interested in attending a local event, visit the [Rare Action Network's site](#) and click on the state map to find one near you.



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ATTENTION RESEARCHERS
2018 Grant Applications are Due by
March 25th!

We've Funded Over \$2.6 Million in Research and
Won't Stop Until a Cure is Found!

Attention Researchers: Research Grant Application Deadline is March 25th!

Each year, PSC Partners awards grants for research that addresses a novel, basic or clinical research question related to Primary Sclerosing Cholangitis (PSC) and associated diseases (such as

IBD or cholangiocarcinoma). If you are a researcher or know of a researcher who is interested in conducting PSC research, please [visit our website](#) to learn more about our 2018 PSC research grant opportunities.

Attention Young Investigators

This year we are funding a new grant of up to \$80K for a young investigator. [Visit our website](#) to learn more about this new grant opportunity.



Couldn't make it to Salt Lake?

The patient/caregivers sessions during the first day of the conference will be a live streamed and you will be able to view the sessions and ask questions via your computer, tablet or mobile device.

Patient/Caregiver Sessions

Wednesday, January 31st 12:00pm until 8pm (Eastern Standard Time)

Cholangiocarcinoma Foundation Live Streaming Sessions TOMORROW, January 31st.

If you are a PSC patient or caregiver living with or concerned about Cholangiocarcinoma, The Cholangiocarcinoma Foundation will be live streaming the patient / caregiver sessions during the first day of their annual

conference **TOMORROW.**

You can view the sessions and ask questions via your computer, tablet or mobile device. The patient/caregiver sessions will be held tomorrow, January 31st from 12:00pm until 8:00pm Eastern Standard Time.

See the Cholangiocarcinoma Foundation's website to [learn more about the conference](#) to [participate in the live streaming](#), and to see the [agenda](#).

Policy Alert: President Signs RAISE Family Caregivers Act



Policy Alert: President Signs RAISE Family Caregivers Act

The President recently signed the [RAISE \(Recognize, Assist, Include, Support and Engage\) Family Caregivers Act](#) into law.

The bill directs the Department of Health and Human Services (HHS) to develop, maintain, and periodically update a National Family Care-giving Strategy and to create a Family Care-giving Advisory Council to advise the department on ways to recognize and support family caregivers. The Council will include: federal agency representatives, family caregivers, older adults with long-term services and support needs, health care providers, and others in the care-giving community.

We thank the President and congressional co-sponsors of this legislation and the advocates who worked so hard to get this bill passed. The RAISE Family Caregivers Act is a significant step in bolstering family caregivers on the national level. If you'd like to learn more about this act or issues affecting caregivers, please visit the [National Alliance for](#)

[Caregiving's website](#). The National Alliance will continue to follow this law into implementation.

Community Spotlight

New Blog Post on Important PSC Research: "Mahesh Notes"

We recently announced [Mahesh Krishna](#) who will be guest blogging for us from time to time. Mahesh is a college student and PSCer who is very interested in the latest science and research related to PSC. This month he summarized the following study.



Title: "Primary sclerosing cholangitis - a comprehensive review"

Authors: Tom Karlsen, Trine Folseraas, Douglas Thorburn, and Mette Vesterhus

Visit [our blog](#) to see [Mahesh's summary](#) of this important review.

WHAT WOULD YOU LIKE US TO BLOG ABOUT?

Contact us at contactus@pscpartners.org to share your ideas for our blog. We always welcome new ideas and guest bloggers. While we all share some of the same challenges that a PSC diagnosis brings, each patient and caregiver has a unique experience that the entire community benefits from. We are happy to keep your blogs anonymous - so don't be shy!



Listen Up: PSC Podcasts Are Here!

As part of our podcast initiative, we are excited to share a new podcast from Monika Aldarondo's PSC Mami series. Monika's podcasts focus on the intersection of PSC and parenthood and feature some fascinating interviews with people in our community who are

grappling with issues related to PSC. Check out her recent [blog post](#) to learn about Monika's motivation to start this blog and read her introduction to PSC Mami. This month we recommend listening to her second podcast featuring [Kiersten](#).

Stay tuned next month for the kickoff of our PSC Partners podcast series, narrated by Niall McKay, a journalist and filmmaker. These monthly podcasts will feature interviews with international PSC industry experts and PSC patients and caregivers. Some upcoming topics are: what is PSC, coping with PSC, live vs. cadaveric transplantation, fecal transplants, genetics and PSC and many more.

ONLINE FACEBOOK SUPPORT GROUPS

Did you know that PSC Partners has two online support groups that are run by some incredibly smart, dedicated and knowledgeable volunteers? If not, you can learn more about them [here](#).



We have both an open and a closed group to support the varying needs of our group members. Following is a little more information about these groups.

Open/ Public Group

The [OPEN GROUP](#), is a public group that provides members of this community an opportunity to share their experiences of living with PSC and bring awareness of the disease to the wider public. Open group posts are visible to outsiders. If you are interested in sharing information to help us spread awareness about what it means to live with PSC with the general public, please join our OPEN GROUP

Closed Group

The [CLOSED GROUP](#) is a private group that provides a place for PSC patients and caregivers to share information they do not want outsiders to see. For many struggling with PSC, sharing questions and concerns brings support, knowledge and empowerment. The information you choose to share with this group is seen only by the members of this group who are screened before joining.

If you, or someone you know could use some extra support, our online support groups provide an excellent opportunity to connect with others who are knowledgeable, empathetic and understand what it means to live with PSC.

How You Can Support Us

Give Your Valentine the Gift of Your Precious Self by Joining the PSC Partners Patient Registry



This Valentines Day, show your loved ones how much you care by joining the PSC Partners Patient Registry. Your participation in the registry motivates PSC research by showing researchers that we are eager to support their work. Your loved ones want a cure just as much (if not MORE) than you do and will be comforted by knowing that you are helping to move PSC research forward. Your participation in the registry is a critical piece of solving this puzzle. Give your valentine something sweet and [join the registry](#) today!



Seeking a Volunteer with PR Expertise

We are looking for a volunteer with PR expertise to donate a couple of hours of their time to help us better navigate engaging the press. Your expertise in best practices for writing press

releases and getting media attention will help us reach and engage a wider audience. Please email us at contactus@pscpartners.org if you can help!

Organizational News

Gearing up for a FANTASTIC 2018: PSC Partners Annual Board Retreat Update



A sincere thank you to the dedicated PSC Partners Board Members who took time out of their busy schedules to meet with the staff and volunteers from the Colorado office to do some critical strategic planning. This committed group of people

braved Chicago weather in January and spent two days helping to refine our existing strategic plan and to develop innovative ways to advance our mission.

Some important takeaways from this year's meeting:

- Discussed opportunities to improve and grow our patient registry
 - the need to add another curator
 - the opportunity to drive more attention to the value of our registry by conducting a patient survey and sharing the results with researchers
- Committed resources to do a website overhaul to better meet the needs of our community and promote better access to the resources on our website
- Resolved to increase staffing and systems to support growth and staff's ability to meet more rigorous goals
- Created a plan to improve and grow our mentorship program
- Committed resources to prioritize expanding physician outreach
- Created a wish list of projects needing funding

We are excited about the promise 2018 holds! A big thank you to the Grover/Wente family for giving us the opportunity to hold the retreat in their beautiful condo in the city.

Update on the PSC Forum

We are looking forward to another PSC Forum meeting and sharing relevant news with you afterwards.



For those who missed the initial PSC Forum meeting held on Thursday, October 19, 2017 in Washington D.C., you can learn more about the progress on the PSC Forum webpage.

Veronica Miller of the PSC Forum kicked off the meeting which had a great turnout of 63 attendees and covered topics including: ICD-10 codes, quality of life measures, PSC inclusion and exclusion criteria, patient databases, pathways and endpoints discussion, EU perspective, and Simtuzumab: lessons learned.

The materials and notes for this meeting are available on the Forum for Collaborative Research's [website](#). You can find an excellent summary of the meeting [here](#).



Upcoming 2018 Conferences

We are excited to be attending and/or presenting at the following conferences this year to ensure that we are getting information about our mission out and reaching as many

stakeholders as possible.

Following is a list of conferences we will be attending this year: March 16th - 18th - AASLD Emerging Trends - DC
April 11- 15th - ILC, Paris France
April 26-27 - World Orphan Drug Symposium, MD
October 3-5 - Global Genes, CA
October 15-16 - NORD, DC
November 9-13 - AASLD, CA
October 25-28th - NASPGHAN, FL



Local Support Groups

Interested in starting or joining a local PSC Support Group? To learn more on this, please visit pscpartners.org/support-groups and/or [e-mail PSC Partners](#).

*Note: local support groups are not endorsed by PSC Partners and are fully independent of PSC Partners. PSC Partners accepts no responsibility for any information, activities, or costs associated with local support groups.

The mission of PSC Partners 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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