



THE DUCT

A Monthly Newsletter for the PSC Community

May 2017

[Patient Registry](#) [2017 Conference](#) [Donate Now](#)

We are always looking for interesting people, research and stories to feature in our newsletter. Please [contact us](#) if you'd like to see your story or research featured in a future issue or if you are interested in being a guest-blogger for us.

Community Spotlight

Deadline Approaching: Regular Registration for our Annual Conference Ends on Saturday, May 27th.



If you've been putting off registering for our annual conference, now is the time to register and book your hotel. A PSC diagnosis can take you on an insane, unpredictable journey and a PSC Partners conference will help you better prepare to navigate this journey. There is nothing quite like meeting others who truly "get" what it means to have PSC or "get" what it means to be a caregiver for someone who has PSC. In addition to meeting others in your shoes, you will learn from some of the most innovative and respected researchers and clinicians who are working on solving the mysteries of PSC. This year we have special tracks for Pediatric PSC, Transplant and PSC Basics. Below are a few of the topics we'll be covering:

- Liver Stem Cell Research
- Fecal Microbiota Transplantation for IBD
- Live vs. Cadaveric Liver Transplants
- MELD and UNOS
- PSC Sponsored International Research
- Preventative Medicine and PSC with Dr. Michael Roizen

Check out our [complete agenda](#) to see more topics covered. Finally, if you've never been to one of our conferences, check out what [past participants have to say](#). If you have questions or concerns, please email us at: contactus@pscpartners.org or calls us at 303.771.5227

[CLICK HERE TO LEARN MORE AND REGISTER FOR CONFERENCE](#)



CT Luxury Home Tour - A Huge Success!

A big thank you to CEO Gina Calabro and the HBRA of Fairfield County for organizing a successful luxury home tour benefitting PSC Partners. Participants enjoyed an evening cocktail party and had the

opportunity to tour several beautiful homes in Fairfield County, CT, while raising funds to support research and find better treatments and a cure for primary sclerosing cholangitis. A check for \$3,150 will be presented to PSC Partners Seeking a Cure at the association's Annual Dinner on June 9th at the Hyatt Regency in Greenwich. Gina, and team - your hard work and support for the PSC community are deeply appreciated.

Education / Research / News

Update on the EASL ILC Conference in Amsterdam

What is EASL?

EASL is an organization for hepatologists and clinicians focused on liver disease. Each year, they host an annual meeting known as the International Liver Congress (ILC). They also offer a range of liver-related scientific events and initiatives throughout the year. You can learn more about EASL [here](#).



During the 2017 conference, EASL released a clinical practice guideline for PSC entitled: [ROLE OF ENDOSCOPY IN PRIMARY SCLEROSING CHOLANGITIS](#)

ILC's program was organized into six specialties (pictured above).

Ricky Safer (PSC Partners, US) and Martine Walmsley (PSC Support, UK) headed to Amsterdam last month for the International Liver Congress (ILC). The ILC is the annual meeting of the European Association for the Study of the Liver (EASL) and was attended by nearly 10,000 hepatologists and delegates in the liver community. Ricky and Martine attended sessions relevant to the PSC community and met with clinicians, researchers and industry representatives to build new relationships and promote broader global awareness of the work PSC Partners and PSC Support are doing to support the needs of PSC patients and caregivers.

What We Learned at EASL?

We are happy to report some encouraging trends Ricky noted that may positively impact the PSC community:

1. We are excited to see more collaboration around PSC-related research that allows more brilliant minds to work together to make new discoveries that will benefit those with PSC.
2. More PSC-related research is being published.
3. Along with these collaborations, we noticed that awareness of PSC is growing. The climate is changing and the medical community is more open to listening to the patient voice and needs. Essentially what we are seeing is a strong interest in incorporating the patient voice into conversations about PSC.
4. In previous years, the PSC sessions had few participants. This year, the PSC sessions were jam-packed!
5. The strides made for primary biliary cholangitis (PBC) patients in the past few years may have positive implications for the PSC community. Now that the PBC clinical trials for OCA (obeticholic acid) have shown promising results for PBC patients, we hope that the OCA trials for PSCers will get similar results.

We Caught Up With Dr. Douglas Thorburn at EASL

Ricky had an opportunity to meet with Dr. Douglas Thorburn at EASL and get updated on the quality of life tool his team is developing for PSC patients. Dr. Thorburn and his team received a PSC Partners' grant in 2016 to create this validated quality of life tool and the development of this tool is well underway. It involves:

- the identification of relevant issues for patients through scientific literature review and in-depth interviews with patients,
- refining and validating the questionnaire in a large patient survey,
- evaluation in PSC patients to ensure a scientifically sound, valid, reliable and precise tool.

The goal for this tool is to support improving the quality of life of PSC patients and ensure that any new treatments under evaluation are not associated with worsening quality of life for PSC patients. As part of this grant, the UK-PSC research collaboration is working with experienced qualitative researchers and patient groups to develop a disease-specific quality of life measure for PSC and then proceed to validate it internationally via the International PSC Study Group. This international validation is crucial given the rarity of PSC and the need to recruit patients into clinical trials across continents. We are excited about this tool because it will be free to use and it will create greater consistency in how the quality of life in PSC patients is evaluated.

Final Thoughts

There is still a lot of work to be done if we are to find better treatments and a cure for PSC. PSC has been described by hepatologists as the "black box" of liver disease. There are so many factors involved with PSC and, at this point, it is important to try to stratify the disease so we can better pinpoint and eventually treat different forms of it. Many questions still need answers. For example, 70% of PSC patients have IBD. *What is the connection?* Many people with PSC develop cancers. *What is the connection?* After attending EASL, we are optimistic that momentum is building to find better treatments and a cure.

Upcoming Educational Opportunity for Pacific

Northwestern PSC Community

If you are interested in learning more about novel treatments and management practices for PSC, please join the Liver Care Network for Primary Sclerosing Cholangitis: Updates and Resources on Saturday, **May 20th from 9am- 2pm** at the Swedish Medical Center's Organ Transplant and Liver Center. Dr. Kris Kowdley of the Liver Care Network, Rebecca Lundborg, RD and Deb Cadiente, RN will be speaking. This event welcomes PSC patients, their families and their caregivers. There is no cost for attendance and lunch will be provided. Please call 206-215-2980 to learn more or [fill out this SurveyMonkey to register](#).

Primary Sclerosing Cholangitis: Updates and Resources



Please join the Liver Care Network's Dr. Kris Kowdley in an event that aims to provide primary sclerosing cholangitis (PSC) patients with updates on clinical research and information about the latest treatment and management practices. Other speakers include Rebecca Lundborg, registered dietitian at the Organ Transplant and Liver Center, and Deb Cadiente, nurse navigator for the Digestive Health Network. This event welcomes patients with PSC, their families, and their caregivers.



Saturday, May 20, 9 a.m. to 2 p.m.
Swedish Medical Center
Organ Transplant and Liver Center
1124 Columbia St., Suite 600
Seattle, WA 98104

No cost for attendees. Lunch will be provided.
Please contact 206-215-2980 to register or with any questions.

SWEDISH MEDICAL CENTER AND SWEDISH MEDICAL CENTER ORGAN TRANSPLANT AND LIVER CENTER ARE AFFILIATES OF THE SWEDISH MEDICAL CENTER. SWEDISH MEDICAL CENTER AND SWEDISH MEDICAL CENTER ORGAN TRANSPLANT AND LIVER CENTER ARE AFFILIATES OF THE SWEDISH MEDICAL CENTER. SWEDISH MEDICAL CENTER AND SWEDISH MEDICAL CENTER ORGAN TRANSPLANT AND LIVER CENTER ARE AFFILIATES OF THE SWEDISH MEDICAL CENTER.

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New Grantees Will Be Awarded Soon - Stay Tuned

Our [Scientific Medical Advisory Committee \(SMAC\)](#) is actively reviewing the grant applications we received and will select the most promising proposals to recommend to the Board of Directors for funding. Stay tuned to see which

projects get selected.

How You Can Support Us

\$10,000 Match Challenge for the Pedal for PSC event!

GREAT NEWS: It's happened again! A donor has again stepped up to the plate with an offer to match donations. If we can raise \$10,000 for this event, we will receive an additional \$10,000.

WE NEED YOUR HELP:

We are short on riders/walkers and need your support. If you enjoy the great outdoors and want to spend some time with family and friends, please consider joining us in glorious Woodstock, VT. Show us your **Power**, **Strength** and **Courage** by biking or walking to improve the lives of those with PSC and help us put an end to this devastating liver disease!

Learn more about the one-and-three day options in the links below and click on the details, dates and pricing section of the menu:

- [3 day event - July 28th - 30th](#) - Hurry, register now as rooms must be



booked and meals must be counted by May 28th.

- [1 day event - July 29th](#) - this is perfect for all of you east-coasters who are in driving distance to Woodstock, VT. Grab your friends and family and spend a day outdoors supporting a great cause. For those of you on a budget, this is a great option too!

Know others who may be interested? Share this event! You can post this [flyer](#) in local bike shops, bars, or wherever you think it might attract bikers/walker who support our cause.

Congratulations. We did it!!!

A BIG thank you to those who participated in our \$20,000 MATCH challenge. We are excited to announce that because of your tremendous efforts and generosity we were able to raise enough money to receive the match!



Take that, PSC!!!

As part of this campaign, something amazing happened: one of our fundraising teams was a mere \$3.04 short of reaching their goal and a "goal-oriented" donor decided to help them out with the following message:

"I am not cheap...just goal oriented :) Hugs to you both!"

We encourage you to [visit this page](#) and scroll to the bottom of the campaign page to see if there are other folks (maybe someone you met at a conference) who could use your "goal-oriented" donation to help them reach their personal goal.

Together, we're stronger on the Road to a Cure.



Thank you to all who participated in National Donate Life Month

Thank you to all who participated in Donate Life Month and encouraged people to register as donors and celebrate the lives of those who have saved others through the gift of organ donation. Please continue to educate and promote awareness about the importance of organ donation for our community. We know that many of you

are actively involved in creating awareness and we appreciate your tremendous efforts!

Organizational News

PSC Partners Canada

We want to give a shout-out to PSC Partners, Canada! ("[O Canada!](#)") Established in 2015 by three PSC caregivers living in Canada, our Canadian affiliate shares our mission and exists to support research grants. In 2016, they raised enough money to support a full research grant and funded *The Enterohepatic Metabolome in Primary Sclerosing Cholangitis*, a study by Stephen P. O'Hara, PhD, Assistant Professor of Medicine and Biochemistry/Molecular Biology, Mayo Clinic, Rochester, MN. We are fortunate to partner with them to bring the PSC community closer to a cure and are grateful for their tremendous results!



PSC Partners to Attend AIH Conference

mission and programs.

PSC Partners will be staffing a booth at the AIH Conference in Indianapolis from June 10th - 11th to create broader awareness of PSC and share information about our

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.

PSC Partners Seeking a Cure
(303) 771-5227 | contactus@pscpartners.org | pscpartners.org
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