

THE DUCT

A Monthly Newsletter for the PSC Community

July 2017

Patient Registry 2018 Conference Donate Now

We are always looking for interesting people, research and stories to feature in our newsletter. Please <u>contact us</u> 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



Thank you for Attending our Annual Conference for PSC Patients and Caregivers!

Each year, we are amazed by the strength of this community, and by the resilience, bravery, and hope that attendees share with us and each other. We are extremely grateful that you decided to join us this year in Cleveland, and hope that you can join us in Sacramento in 2018.

SAVE THE DATE:

The <u>Sacramento conference</u> will be held in partnership with the University of California, Davis Medical Center and take place from **June 22-24th**, **2018** at the downtown Sheraton Grand Hotel. We will share details as they evolve.

Right now, we are in the process of pulling together the videotaped sessions and speaker presentations in addition to some thoughtful videos of both physicians and members of the PSC community that we took during the conference. These individuals offered to share some of the key take-aways with those who couldn't make it and we can't wait to share their thoughts with you! You will see these in the next couple of weeks on our blog and in our upcoming newsletters.

Finally, a big thank you to everyone who completed a postconference evaluation. We received some excellent feedback that will help us make next year's conference even better!

Education / Research / News



Congratulations to our 2017 Grantees!

Every year, on the recommendation of the Scientific/Medical Advisory Committee and the decision of Board of Directors, PSC

Partners Seeking a Cure chooses the most promising research projects to support. This year PSC Partners will fund six research projects and our affiliate, PSC Partners, Canada will fund one project.

In 2017, PSC Partners received 29 grant applications, from leading PSC institutions worldwide. The projects that have been selected for funding are listed below. In the coming weeks, additional information and lay summaries will be shared for each project.

PSC Partners US Awards

The Role of Hepatic XBP1 in Cholestatic Liver Injury Richard M. Green, MD, Northwestern University

A Multicenter Collaboration to Study PSC in Children, Pediatric PSC Consortium

Mark Deneau, MD, MS, University of Utah, Primary Children's Hospital

Apical and Basolateral Exosome Signaling in Normal and

PSC Cholangiocytes

David J. Katzmann, Ph.D, Mayo Clinic

A Gut-liver Cross-disease Map to Identify Concrete Gene Targets for Therapeutic Intervention by Characterizing Expressional Changes in PSC and UC

David Ellinghaus, Prof., PhD, Kiel University, Germany

Dissecting the Genomic Variants of PSC Outcomes

Konstantinos N. Lazaridis, MD, Mayo Clinic College of Medicine

Professor Tom Hemming Karlsen, MD, Oslo University Hospital Rikshospitalet

Exploring The PSC Matrisome: Discovery Of Serum
Biomarkers For The Stratification And Classification Of
Patients With Primary Sclerosing Cholangitis
Massimo Pinzani, MD, PhD, FRCP, University College London
(UCL) Institute of Liver and Digestive Health (ILDH)

PSC Partners Canada Award

Integrin AVB6 Aa A Therapeutic Target For Primary Sclerosing Cholangitis-Associated Cholangiocarcinoma Yury V. Popov, M.D, Ph.D, Harvard Medical School

We thank all of our donors throughout the years who have supported our mission of raising funds to research causes, treatments and cures for primary sclerosing cholangitis. Your contributions have made these awards possible! We look forward to sharing more about this research with you on our blog in the upcoming weeks.



Clinical Trials

Are you interested in information about current clinical trials for PSC? If so, please visit our website to learn more. You will find information about current trials that are going on now as

well as guidelines regarding important questions you may want to consider before enrolling in a clinical trial.

How You Can Support Us

Last Chance for the \$10K Match - Pedal for PSC is Almost Here!

If you enjoy the great outdoors and want to spend some quality time with family and friends, please consider joining us on **July 29th i**n glorious Woodstock, VT.



Help fight PSC as we ride on the Road to a Cure! <u>Pedal for PSC</u> is open to anyone who wants to bike to make a difference in the lives of PSCers everywhere. (This group ride is not a race, and participants can go at their own pace.)

The food will be awesome and feature Vermont grown foods. You will enjoy Cobb Hill cheese, an award winning artisanal cheese that is made at Cobb Hill Farm. This cohousing farm is the first rest stop and focuses on community, farming and sustainability and, best of all, one of the bike guides lives there, so you will get the inside scoop. Finally, we can't forget the Deep River Chips. Deep River "gives a chip" about PSC Partners' mission and will be providing plenty of chips to keep you energized!

If you can't make the event, you can still help us receive this match by visiting our <u>fundraising page</u> and scrolling to the bottom and donating to "ducted out for a spin". With your help, better treatments and a cure are within our reach!

Learn More and Register

Know others who may be interested? Share this flyer in local bike shops, bars, or wherever you think it might attract bikers interested in supporting our cause.

A big "thank you!" to <u>Great Freedom Adventures</u> for organizing 2017 Walk or Pedal for PSC and to our event sponsor, <u>Deep River Snacks</u>.





PSC Awareness Week is September 10th - 16th

PSC Awareness Week is a great way for us to get the word out about PSC. We are beginning to plan for 2017 PSC Awareness



Week and welcome any ideas you may have for getting the word out. We are also looking for volunteers who can help us build awareness. If you have expertise in PR, nursing, pharma or some other area and can help us get the word out about PSC, we welcome your assistance. Send us an <a href="mailto:email

Organizational News



PSC Forum Update

This week, Ricky Safer attended a steering committee meeting for the <u>PSC Forum</u> to represent the patient voice. We are very

excited about this collaborative initiative and look forward to sharing updates / reports as they become available.

Upcoming Conferences!

Following is a list of conferences PSC Partners' staff and board members will be attending this fall.



July 13 - 14th- Mayo Endowment

Meeting - Ricky Safer will attend a Mayo Endowment Meeting to learn the latest from Mayo and to share information about

PSC Partners' work and opportunities for collaboration.

October 6-8th- Cincinnati Children's Pediatric Autoimmune Liver Disease Symposium and Family Day, Cincinnati, OH

October 15th - 17th- NORD, Washington DC

October 20th - 23rd- AASLD, Washington DC

November 1st - 4th- NASPGHAN, Las Vegas, NV

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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