



THE DUCT

A Monthly Newsletter for the PSC Community

October 2017

[Patient Registry](#) [2018 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.

Education / Research / News

PSC Partners Patient REGISTRY
Give 1/2 an hour of your time...
Participate in PSC research!
Be a voice in our tiny but SO mighty PSC army!
Join at www.pscpartnersregistry.org

TODAY:
1070 participants

OUR GOAL for
SEPTEMBER:
1100

For international, paediatric and adult, and transplanted PSCers.
For more information, contact registrycoordinator@pscpartners.org

WE DID IT! We Reached Our Goal of 1,100 in the Patient Registry.

A sincere thank you to all who joined our registry last month. We are excited to announce that we met our goal and now have 1,103 PSCers in our registry. What a

phenomenal community we have!

If any of you are interested in joining, but haven't gotten to it yet, the timing is still great to register. PSC Partners will be attending The Liver Meeting in Washington DC from October 20th - 23rd. We will have a booth and will be visible to 10,000+ hepatologists (it is likely yours will be there). The more people we have in the registry, the more attention we will get from these medical professionals. Let's show them how passionate we are for better treatments and a cure. IF YOU HAVEN'T JOINED, PLEASE DO SO TODAY! Help ensure that we don't lose one more person to this insidious disease. [Register today!](#)

We are deeply grateful to Rachel Gomel for her tireless work

not only to get the registry up and running, but also to get PSCers registered. Thank you Rachel!!!



Interested in Learning More About the 2017 Research Grant Awardees?

Visit our [research page](#) to read the lay summaries for our most recent grant awardees.

If you prefer to get your information in tidbits, research updates will also be posted on our blog every couple of weeks. Below are two recent research posts.

[Dissecting the Genomic Variants of PSC Outcomes](#)

Principal Investigators:

- **Konstantinos Lazaridis**, MD, Consultant Gastroenterology and Hepatology, Professor of Medicine, Mayo Clinic College of Medicine
- **Professor Tom Hemming Karlsen**, MD, Department of Transplantation Medicine, Division of Surgery, Inflammatory Medicine and Transplantation, Oslo University Hospital, Rikshospitalet

2017 AASLD Award Funded by PSC Partners Annually

An award presented to the investigator presenting the most promising PSC research at The Liver Meeting.

[Improvement in GGT predicts event-free survival in primary sclerosing cholangitis regardless of ursodeoxycholic acid treatment: data from the Pediatric PSC Consortium](#)

Principal Investigator:

- Dr. Mark Deneau, MD, MS University of Utah, Salt Lake City, UT

Researchers, we always welcome updates and additional thoughts about your work and are happy to share them via our blog and newsletter.

Do You Know How to Interpret Your Blood Test Results?

Newly diagnosed patients often ask us questions related to



interpreting their blood test results. We believe well informed patients are better able to participate in their treatment process. If you are interested in learning more about what ALT, AST, ASP, bilirubin and other blood test terms actually mean, please visit some of the presentations given on this topic

at our previous annual conferences. [This chart](#) which was created by Dr. Christopher L. Bowlus at the University of California Davis, was presented at our 2011 conference and is especially helpful! You can find other informative presentations from our previous conferences [here](#). Finally, if you thought this was useful, you may also like this [presentation on liver enzyme test results](#).

Community Spotlight



Show Your Smiling Face on this Year's Holiday Card

We are currently pulling together pictures for our annual holiday card and would love to include yours. We need approximately 7-9 pictures that show the diversity and strong spirit of our community. Help us bring peace and hope to PSC patients and their caregivers by sharing a picture that will make us smile. Send your pictures

to contactus@pscpartners.org by **Friday, October 20th** and include the following:

- First name, state and a short statement about yourself - what you enjoy, are you symptom free, pre-or-post transplant?

Below are a few examples:

- John, Virginia - 20 month post-transplant. John's daughter Molly amplifies his appreciation for life and

health. John owns his own security business and is pursuing a career in specialized law enforcement.

- Nathan, Wisconsin - Is enjoying his third year clinical clerkship as a medical student at the University of Wisconsin, and was lucky to marry his wife Ann this fall.
- Britt, Minnesota - Appreciates every day of health, happiness and laughter.

Please note that all pictures will be greatly appreciated, but not all will be chosen for the card. We look forward to seeing your smiling faces!

Laura Bradbury Wins the PSC Story Contest

A heartfelt thank you to all who shared their stories. We loved reading the entries and learning more about the incredible people who make up our PSC community. If you missed out on these stories, you can read them [here](#).



A hearty congratulations to Laura Bradbury for winning the PSC Awareness Week story contest sponsored by Deep River Snacks. As the winner, Laura gets to choose a case of the Deep River Chips of her choice. Thank you Deep River Snacks for "giving a chip" and sponsoring this contest.

We HIGHLY recommend reading Laura's beautiful story - it will touch your heart and inspire you to reflect on what really matters in life. You can read it [here](#). We hope you enjoy it as much as we do! Also, if you like Laura's writing and want to read more of her work, check out her [blog](#).

We sincerely thank all of you who joined us in the fight by participating in this contest; your stories are a powerful resource for helping others know what it means to live with PSC and why they should get involved in helping us find a cure!



PSC Partners Has Two New Guest Bloggers!

We are excited to announce two new guest bloggers who will be sharing their stories and insights about nutrition and other topics with our community. Visit [our blog](#) to meet [Brittany](#) and [Mahesh](#) and learn more about the topics they will be blogging about. If you have something you'd like to share with our community feel free to contact us at contactus@pscpartners.org to share your ideas.



How You Can Support Us

Tis the Season for Workplace Giving and the Combined Federal Campaign (CFC)



Workplace giving allows each of us to be a philanthropist. This unique donation opportunity allows employees to donate over the course of a year in small, manageable amounts or to make a one-time donation. It also allows employers to make a direct impact in their community.

How can designating PSC Partners for your workplace giving make a difference? We just funded six new, PSC-focused research grants. With your help, there's more to come!

Check with your HR department to see if your organization has a workplace giving program and designate PSC Partners Seeking a Cure as recipient of your workplace giving campaign. Make the following designations, depending on the campaign offered in your company:

[United Way](#) or other campaigns: Write in "PSC Partners Seeking a Cure" and our address: 6900 E. Belleview Ave. Suite 202, Greenwood Village, CO 80111.

[Combined Federal Campaign](#) #79370

Are you a federal employee who wants to join PSC Partners in fighting this terrible disease? CFC is the world's largest and most successful annual workplace charity campaign, with almost 200 CFC campaigns throughout the country and overseas raising millions of dollars each year. Pledges made by Federal civilian, postal and military donors during the campaign season (October 2nd to January 12th) support eligible non-profit organizations that provide health and human service benefits throughout the world. <https://www.opm.gov/combined-federal-campaign/>

Please note that we can only acknowledge your donation if your employer shares your name with us. We encourage you to select PSC Partners Seeking a Cure as your charity of choice! As 2017 begins to draw to a close, please remember PSC Partners during your workplace giving campaign. Together, we will continue to make strides towards better treatments and a cure for PSC.



Support PSC Partners with a Donor Advised Fund (DAF)

DAF DIRECTSM

[What is this?](#)

Donate now from:
-- Please select --

Designation:

Amount:
\$

A donor advised fund (DAF) is a type of giving program administered by a third party that provides you with the flexibility and most favorable tax benefits to easily support your favorite charities. DAFs are designed to manage charitable donations on behalf of an organization, family or individual and are becoming increasingly popular. They are an excellent way to simplify your charitable giving and facilitate your strategic philanthropic goals.

You will receive a tax deduction when you make a contribution of cash, stock and other assets and, at a later time, you can grant specified amounts to the

charities of your choice. Read our recent [blog post](#) to learn more about the benefits and how they work.



FINAL REMINDER: Know a Great Facility to Host our 2019 Conference?

We are seeking a facility with expertise in PSC to host our 2019 conference. PSC Partners counts on its supporters to co-chair its annual conferences because we are a mostly volunteer group. If

you'd like to step up and co-chair the annual event, we'd like to hear from you. If you are interested in hosting the conference, please [see our guidelines and complete the Conference Host Proposal Form](#).

Hosting forms are due **by November 15, 2017**, so our board can choose the venue for 2019 and announce it at our 2018 conference. If you have any questions, please [email us](#).

Organizational News



PSC Partners Participates in CALD's First Meeting

The weekend of October 7-8 marked the launch of CALD (Center for Autoimmune Liver Disease), an exciting collaboration for the study of pediatric PSC and AIH at Cincinnati Children's Hospital Medical Center. The Pediatric Autoimmune Liver Disease Symposium and Family Day was chaired by Dr. Alex Miethke and generously supported by Chris and John Browner. Mary Vyas of PSC Partners Seeking a Cure Canada was in attendance and Ricky Safer was invited to give two breakout sessions about our organization.

There were two days of presentations by international experts, covering a wide range of topics such as genetics, natural history, bile acid toxicity, endpoints and novel targets in clinical trials, endoscopic therapies, bone disease, vancomycin usage, and more. The general sessions and question and

answer sessions led to ideas for the clinicians and researchers to continue to study. When the powerpoint slides become available, we will post a link. Thank you to Cincinnati Children's for a wonderful weekend.

**PSC Partners is Attending
AASLD Conference October
20th - 24th**



Each year, the American Association for the Study of Liver Diseases (AASLD) holds The Liver Meeting, which attracts nearly 10,000 hepatologists and other health professionals from around the world to discuss the most recent developments in the study and treatment of liver diseases. This year, The Liver Meeting will take place from October 20th - 23rd in Washington DC.

For the 6th year in a row, PSC Partners will staff a booth at The Liver Meeting and meet individually with medical professionals to engage in meaningful conversations about PSC. The value of meeting face-to-face with the world's top hepatologists, physicians, researchers, and industry representatives to discuss our current activities and research projects cannot be understated. Some of our most productive collaborations began through contact at The Liver Meeting, and we value the opportunity to continue to foster these relationships and forge new ones.

We will provide you with an update on AASLD after the meeting.

**PSC Partners Heads to NORD,
October 16th - 17th**



This month, we will be attending the NORD (National Organization For Rare Disorders) conference. NORD is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD has over 260 patient organizations as members and is committed to the

identification, treatment and cure for rare disorders through programs of education, advocacy, research and patient services.

The annual summit is the largest multi-stakeholder event in rare diseases and provides us with the opportunity to attend educational sessions and come together with other rare disease stakeholders to advance the dialogue on emerging issues, policies and strategies that will affect the environment for rare diseases and orphan products.

The summit opportunities include:

- Over 20 roundtable topics each day
- Six breakout tracks
- 96 speakers discussing topics from guidelines to next-generation treatments to advancing global collaboration
- Poster sessions highlighting groundbreaking innovation and emerging research
- Countless networking opportunities to garner new ideas for moving our cause forward

PSC Partners is Exhibiting at NASPGHAN, November 1-4th

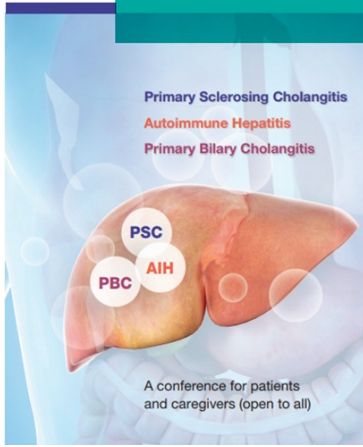
NASPGHAN (the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition) is a professional organization devoted to advancing the knowledge of diseases and function of the gastrointestinal tract, liver and pancreas and nutrition in infants, children and adolescents in North America.

PSC Partners will be exhibiting at the NASPGHAN conference to share information about our research grants and desire to fund pediatric studies and ensure that as many pediatric professionals as possible are aware of how PSC Partners can support their patients and caregivers.



Attention California and Surrounding Area Patients and Caregivers! California Pacific

Living with Autoimmune
Liver Disease
November 18, 2017
8:00 a.m. – 5:00 p.m.



Medical Center is Hosting a Patient and Caregiver Conference on November 18, 2017

The California Pacific Medical Center (CPMC) Patient Support Group has put together a one-day, multidisciplinary conference on Autoimmune Liver Diseases, including Primary Sclerosing Cholangitis, Autoimmune Hepatitis and Primary Biliary Cholangitis for patients and caregivers. Program

topics include: disease overview and complications, current and upcoming therapies, symptom management, role of inflammation and diet, role of integrative medicine and the psychology of chronic illness. Interactive, small group sessions are planned. Invited speakers include: hepatologist, gastroenterologist, interventional endoscopist, radiologist, internist, integrative medicine physicians and clinical nutritionist. Registration is open. For more information please [see brochure](#) or email cpmcAILD@sutterhealth.org

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. More details to come.



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.

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