



# THE DUCT

A Monthly Newsletter for the PSC Community

June 2017

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[2017 Conference](#)

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*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

**Exciting News! PSC Partners is Partnering With the Forum for Collaborative Research to Support Finding Effective Treatments for PSC.**



PSC Partners is thrilled to announce a new partnership with the [Forum for Collaborative Research](#) called the [PSC Forum](#). The forum is the same group that was instrumental in finding effective treatments for both Hep C and HIV and we are tremendously excited that they have now chosen to focus their efforts on PSC.

Founded in 1997, as a public/private partnership, the Forum for Collaborative Research operates under the auspices of the University of California, Berkeley to address regulatory hurdles and advance safe and efficient drug development. It provides an independent and neutral venue for ongoing multi-stakeholder dialogue between experts from academia, industry, patient community and regulatory agencies in a non-competitive environment that breaks down inefficiencies, increases clarity and decreases uncertainty.

We are eager to represent the priorities and voices of PSC patients and their families as part of this partnership and to help move this important work forward! Visit [our blog](#) to learn more about this vital collaboration and link to the [project launch announcement](#).

**Whoop. Hoo! The 2017**

## Conference Begins This Thursday.

PSC Partners 2017 Conference is finally here. We are looking forward to seeing you in Cleveland this week!

This year's conference promises to be very informative and fun and we are excited to share the latest news with you about our our 2017 research grant awardees, new partnerships and the latest from the experts at Cleveland Clinic.



Two final reminders for those attending:

1. Please note that we are at the InterContinental Hotel on Carnegie Street (not the InterContinental Suites on Euclid) These hotels are only a quarter of a mile from each other and we want to make sure you get to the right one.
2. It's quite cold in the rooms, so bring a sweater or light jacket, so you can be comfortable. Also, rain is in the forecast, so don't forget your rain gear.

Stay tuned for highlights from the conference in our next newsletter!

## Education / Research / News



### PSC Partners to Fund Seven (7) Grants in 2017!

The SMAC committee met to review their evaluations and choose the most promising proposals for rewarding grants. A total of 7 grants were awarded and one of them will be funded by our affiliate, PSC Partners

Canada! The award-winning proposals covered topics ranging from multi-center collaborative work around Pediatric PSC, to exosome signaling, to gene targets for therapeutic intervention, to genomic variants, to the PSC matrisome, stratification and classification of PSC patients, and finally, to therapeutic targets for CCA. We will officially announce the winners at our annual conference next week and will share more details about the names, institutions and goals for each grant once they have all been accepted! Stay tuned.

**Join the Patient Registry to Help Find a Cure for PSC.**

## What is the Patient Registry?

The PSC Partners patient registry was launched in April 2014 with the goal of expediting and facilitating PSC research. Our patient-driven registry was created in collaboration with the NIH Office of Rare Disease Research (ORDR), is IRB approved and HIPAA compliant and partly interfaces with the IPSCSG and NIH Global Registry by sharing common data elements.



Since PSC is rare and poorly understood, it can be difficult to locate PSC patients, gather information and develop treatments. In addition, the rarity of the disease makes it difficult to conduct large clinical trials. The purpose of the registry is to track disease progression, to assist clinical trial recruitment, to facilitate drug safety monitoring for new drugs and to allow patient participation at each level of research.

To date, **over 1,000** PSC patients have joined the registry and **5 studies** have resulted from registry data.

## Why Join the Registry?

The patient-driven registry is a critical component of our efforts to find treatments and a cure for primary sclerosing cholangitis. It is an efficient tool for conducting searches based upon inclusion and exclusion criteria for recruiting patients for clinical trials. Help researchers worldwide unlock the mysteries of primary sclerosing cholangitis (PSC) by joining our patient registry. We are actively working with pharmaceutical companies to speed up their search for treatments for PSC.

## How Do I Join the Patient Registry?

It's simple to join the registry and only takes about a half an hour.

- **Step 1:** Go to the [registry page](#) and take a brief survey on your diagnosis symptoms, medications, surgeries, quality of life and family history. The collected data is used for research. No identifying information will ever leave the registry.
- **Step 2:** If you are a good match for a study or a clinical trial, our Registry Coordinator will contact you and you will contact the researcher from there. For more information, go to our [website](#) or contact the registry coordinator at: [registrycoordinator@pscpartners.org](mailto:registrycoordinator@pscpartners.org)

The more patients we have, the more powerful of a tool the registry will be!

## How You Can Support Us

**It's Not Too Late to Help us  
Receive a \$10,000 Match**

## Join us for Pedal for PSC!

Grab your friends and family and spend a day outdoors biking or walking to support PSC Partners. Learn more [here](#).

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.



## Organizational News



### A Warm Welcome to Our New Board Members!

PSC Partners is excited to introduce 4 new board members. Please join us in giving Stuart Barnett, Britt Moore, Travis Stoltzfus and Bill Wise a warm welcome!

**Stuart Barnett** was diagnosed with PSC in 2013. After his wife Debra quickly and easily found PSC Partners on Facebook he was amazed at the abundance of information and support that helped him cope with this mysterious disease. He attended his first conference in New Haven in 2016 and found the welcome amazing and comforting. That welcome never died down the entire conference and he and Debra left knowing that there was more to be done to help this cause and wanted to be involved immediately.

Stu graduated the University of Albany in NY in 1998 with a degree in Economics and is a CERTIFIED FINANCIAL PLANNER(TM) and VP- Sr. Financial Consultant for Charles Schwab & Co., Inc. He has 20 years of experience in the financial industry. When he is not helping people with their finances he is spending time with his 3 kids Jadon, Kaila and Emma (aka Little Red), and his wife Debra on Long Island where they live.

**Britt Moore** is a Board Certified Behavior Analyst and works with families of children diagnosed with developmental disabilities. She completed her

undergraduate degree at Luther College in Day Decorah, Iowa and her Master's Degree at Western Michigan University, both in Psychology. Britt currently works with families and caregivers teaching them to use behavior analytic principles to enhance their children's appropriate behavior and learn new skills in their home environment.

Britt was diagnosed with PSC in the fall of 2011 and was able to attend her first conference in the spring of 2012 in her very own Minnesota. She was blown away by the friendships and knowledge she gained while at the conference and has been involved ever since. She lives in Saint Paul with her husband and two children where they love to get out when the weather allows it; gardening, golfing, skiing, camping, and listening to music.

**Travis Stoltzfus** was diagnosed with PSC in 2010, shortly after his 16th birthday. He attended his first PSC Partners conference in 2013 and was immediately welcomed into 'the family.' In PSC Partners, Travis has found support, encouragement, hope and friendship. He is committed to doing his part in finding a cure. Out-going and positive, he has worked in the service industry since graduating high school. Travis is the restaurant manager at a local country club where he enjoys meeting and interacting with all types of people. As a young man living with PSC, he offers valuable perspective and insight to the Board.

**Bill Wise** - More information coming soon!



## Update from AIHA Conference

A big thank you to Mary Vyas (PSC Partners Canada) and Chris Browner for attending the AIH Conference in Indianapolis from June 10th - 11th to help create broader awareness of PSC and share information about PSC

Partners' mission and programs. Chris and Mary shared the following feedback about the conference.

- The mission of the Autoimmune Hepatitis Association (AIHA) is to provide support and hope to patients and families affected by autoimmune hepatitis through disease education and provision of research opportunities. Dr. Craig Lammert is the Executive Director of the organization.
- The conference was held at Indiana University and people from all over the US attended.
- Dr. Lammert shared that AIH is just getting started as a patient organization and credited both the PSC and PBC organizations for being a valuable voice for their patients.
- There were only a handful of PSC Patients at the conference, but it was valuable in terms of getting answers to questions about AIH.

- In the future, we'd love to see AIHA have an information table at a PSC Partners conference to share information with people in our community who are impacted by AIH as well.
- Free Fibroscans and a quality of life survey were available to anyone who was interested. Results were shared the second day of the conference.
- Patients with AIH could enroll in the GRACE study if they were interested, (Genetic Repository for the Study of Autoimmune Liver Disease and Contributing Exposures). Click [here](#) to learn more about this study.

***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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