

**PSC PARTNERS
SEEKING A CURE**

THE DUCT

A Monthly Newsletter for the PSC Community

September 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.

Community Spotlight

Thank You for Participating in PSC Awareness Week!

Thank you to all who participated in PSC Awareness Week. This community never ceases to amaze us. Our collective voice boomed globally and ensured that we were heard all around the world last week! Over 24 thousand impressions were made on Twitter and we reached around 15 thousand on Facebook.



#PSCaware

Additionally, many organizations partnered with us to share our message with their stakeholders and expand our reach even further. Finally, our very own Super Liver put on more miles than the Cassini probe as he toured around the globe. This hearty soldier lit up the skies and reached over 185 supporters in the US, Canada, Australia, the UK, Israel, Sweden, Scotland and Germany in less than 7 days!



If you missed out and want to see the many videos and resources available please visit our [Awareness Page](#) to listen in on ["behind the scenes" conversations](#) with experts, [read fascinating patient stories](#) and [watch new educational videos](#) about PSC. There are even some [PSC puzzles](#) (courtesy of Mike Pearlman) to solve with your family and friends.

We sincerely thank all of you who joined us in the fight by participating in this most important week; the strength and resilience of our collective voice is what motivates others to support our mission!



Current Healthcare Legislation Alert

The Senate is currently considering the "Graham-Cassidy" bill in another effort to replace the Affordable Care Act (ACA). This proposed bill could

have serious implications for patients with chronic illnesses like PSC. We strongly encourage you to do your homework, and to [contact your Senators](#) today to share your unique perspective and experiences. A decision is expected before the end of the month, so help us make the voices of the PSC community heard now!

Post-Conference Reflections and Takeaways

The Cleveland Clinic conference speaker presentations and



resources have been posted. If you weren't able to make it this year, please check out our [conference recap page](#) to see what you missed. Many of the sessions were videotaped and you can watch them to gain valuable insights.

You can also check out our recent blog article: [Reflections on the Power of PSC Partners Annual Conference](#) to listen to first-time [attendee reactions](#) to the experience. If you've been on the fence about attending a conference, we hope that these attendees will inspire you to join us in Sacramento this year!

Education / Research / News



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.

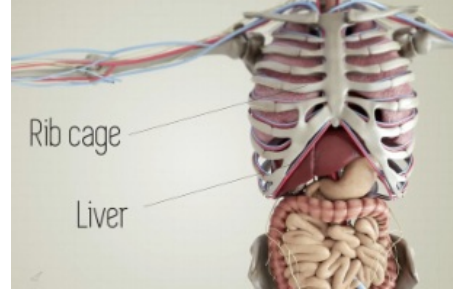
- [THE ROLE OF HEPATIC XBP1 IN CHOLESTATIC LIVER INJURY](#)
Richard M. Green, MD, Professor of Medicine, Division of Gastroenterology and Hepatology, Northwestern University Feinberg School of Medicine, Chicago, IL
- [APICAL AND BASOLATERAL EXOSOME SIGNALING IN NORMAL AND PSC CHOLANGIOCYTES](#)
David J. Katzmann, PhD, Biochemistry and Molecular Biology, Mayo Clinic, Rochester, MN

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

New Animation Explains PSC!

In 2016 PSC Partners funded an educational project proposed by

Dr. Cyriel Ponsioen and his team in the Netherlands. This project aimed to develop a 3D animation to help patients and caregivers understand the basic principles of Primary Sclerosing Cholangitis. Ponsioen noted that



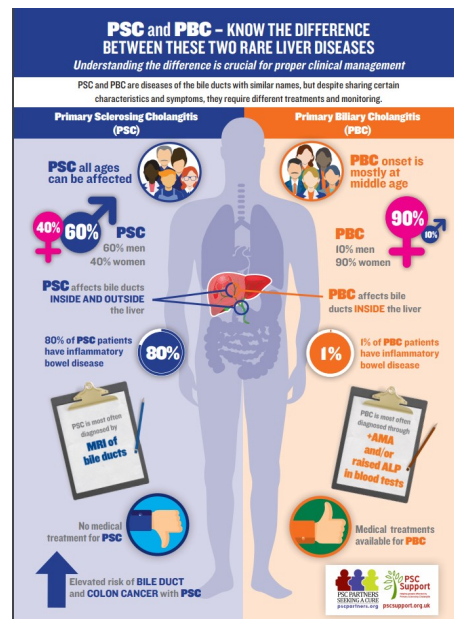
"knowing more will empower patients to participate more in their treatment process" and "well educated patients have been shown to have better clinical outcomes." Another benefit of this animation is to provide a reliable source of information for patients as the internet can often mis-inform them. We are excited about the outcome of this project and hope you find [the animation](#) useful for helping others understand what it means to have PSC.

New Infographic Clarifies the Differences Between PSC and PBC

The international community of the bile duct disease PBC (formerly known as primary biliary cirrhosis) recently changed the name of its disease to primary biliary cholangitis. PSC Partners Seeking a Cure and [PSC Support](#) in the UK saw this name change as an opportunity to

educate our global PSC community about these two diseases with similar names.

Although PSC and PBC share certain symptoms and characteristics, they require different treatment and monitoring to ensure excellent patient care. We aimed to highlight the differences between the two conditions, so that PSC and PBC patients alike may avoid the dangerous and detrimental effects of an inaccurate diagnosis. Please take a moment to view the [new infographic](#) and share it with your doctors.



Help Us Reach Our Goal of



1100 People in the Registry by the End of September!

Thank you to those who joined the registry this month. We are getting closer to reaching our goal of 1,100 PSC patients by the end of September, but we can't do it without you! Only 14

more people need to join to reach our goal for September!

Given that PSC is a rare disease, it is a challenge for researchers to find a large enough number of patients to conduct a PSC study. Imagine researchers giving up on a PSC study because they are not sure they can enlist enough patients. Imagine researchers spending months identifying and recruiting PSC patients for their studies. Now, imagine the difference we can make with our data in expediting research towards treatments and a cure!

The PSC Partners Patient Registry has no geographical boundaries and reaches the far corners of the earth. Many of the registry participants are not connected to hepatologists or to major medical centers. Researchers can tap into this unique dataset that comprises of a community eager to participate in PSC studies. In one instance, overnight, we had a waiting list of candidates ready to take part in a study.

Our patient-driven registry is a powerful tool, and this is why we ask PSC patients to join the registry. Let's show the world that, while we may be tiny, we are a very mighty community. Help ensure that we don't lose one more person to this insidious disease! [Register today!](#)

How You Can Support Us

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 Emmys: A Shout-Out to Our Incredible Volunteers

A heartfelt thank you to the many people in our community who work tirelessly to support us.

While we can't name names for privacy reasons, we wanted to take a moment to say thank you to the many dedicated volunteers who move mountains for the PSC community.



We are grateful to those who supported us with video creation and editing work, and to the mission-focused team who initiated, created and are managing a local support group program. Thank you to the coder-genius for her brilliant work on an advocacy initiative we will be sharing soon! Thank you to the "wizards behind the IT, conference planning, social media and partnership-building curtains" - your work on a daily basis is so appreciated; the wheels would come off without you.

Finally, thank you to all of you who have offered to help, but we haven't quite found your niche yet - we haven't forgotten you.

Without all of you, about 1/10th of what happens around here would happen. You are the gas that fuels our engine and we truly appreciate your tireless efforts to keep us humming!

Upcoming Conferences

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



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
November 18th- **California Pacific Medical Center** - Patient and Caregiver Conference (for PSC, AIH and PBC patients).

SAVE THE DATE FOR NEXT YEAR'S PSC PARTNERS' CONFERENCE:

June 22nd-24th, 2018, **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](mailto:pscpartners@pscpartners.org).

*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
6900 E Bellevue Ave Ste 202, Greenwood Village CO 80111

