

THE DUCT

A Monthly Newsletter for the PSC Community

#### March 2018

#### Patient Registry

2018 Conference

**Donate Now** 



#### SPRING IS JUST AROUND THE CORNER Which only means one thing...it's almost PSC Partners conference time!

#### Only 108 Days to Go!

The 2018 conference for PSC patients and caregivers officially begins on the morning of Friday, June 22, and continues through mid-day Sunday, June 24. We hope that you will consider



arriving in Sacramento on Thursday, June 21 to join us for an informal pre-conference meet and greet dinner. All 2018 conference events will take place at the Sheraton Grand Sacramento Hotel. <u>Click here</u> for everything you need to know about the 2018 conference.

Conference registration will open soon. We will let you know as soon as registration is available.

#### The Discounted PSC Partners Conference Hotel Rate is Now Available. Book Today!

The Sheraton Grand Sacramento Hotel has set up a personalized group page for conference attendees to reserve their hotel rooms at a discounted rate. <u>Click here</u> to book your room and take advantage of our special room rate and subsidy.



We are pleased to offer a discounted group rate for conference attendees. This year, for the nights of Thursday, Friday and Saturday (June 21-23) only, PSC Partners Seeking a Cure will subsidize \$20.00 per room per night for conference attendees staying at the

Sheraton Grand Sacramento Hotel. When you reserve online for these dates, the group room rate of \$139.00 per night, plus taxes and fees, will appear on your confirmation email. This group rate does NOT reflect the additional \$20.00 subsidy provided by PSC Partners - you will see the subsidy on your final room bill after your stay, but you will not see the \$20.00 subsidy when you make your reservation. For these three nights, if you book before the room block is filled or May 25 (whichever happens first), the cost of your room will be \$119.00 per night, plus taxes and fees.

For all information about the discounted room rate and the room subsidy, please <u>click here</u>.

## But seriously...you should try to book your hotel soon.

Believe it or not, the PSC Partners conference will not be the only event taking place in Sacramento on the weekend of June 22-24, 2018. In fact, a <u>comic convention</u> will be happening just down the block at the Sacramento Convention Center, so be sure to <u>book a</u> <u>room in the PSC Partners reserved block</u> while rooms are available!





Rumor has it that Super Liver will be signing autographs and posing for photo ops. More info soon.

Hot Off the Press: The 2018

**Conference Agenda Is Here!** 

agenda for this year's conference. In past years our speakers have come almost exclusively from the host medical center. This year, the scope of our conference has been widened to include speakers from

We are so excited to share the

#### PSC PARTNERS SEEKING A CURE

TIME/SESSION	DESCRIPTION/SPEAKER	LOCATION
	THURSDAY, June 21, 2018	
11:00 AM - 9:00 PM	Early Check-in for Attendees	Sheraton Fover
	PSC Partners Conference Registration	
11:00 AM - Midnight	Teen/Young Adult Lounge	
Thursday - Sunday	PSC Partners' Shop	
	(Please visit shop to see daily hours of operation)	
6:00 PM - 8:30 PM	Pre-Conference Event: Casual Get Together/Dinner	Masonic Temple
	Location: Sacramento Masonic Temple	
	1123 J Street, Sacramento, CA 95814	
	NOTE: Tickets are not included in the conference registration	
	fee and need to be purchased IN ADVANCE	
	FRIDAY, June 22, 2018	
7:30 AM - 5:00 PM	Check-in/Conference Registration	
1.50 Aut - 5.00 F III		
8:00 - 9:00 AM	Continental Breakfast	Ballroom
9:00 - 9:30 AM	Newcomer Orientation	Ballroom
	Moderators: Wes Hendrix and Jennifer Sims	
	Board Members, PSC Partners Seeking a Cure	
9:30 - 9:45 AM	Transition to General Session	
9:45 - 11:45 AM	Misha Ruth Cohen, OMD, LAc., Doctor of Oriental Medicine.	Ballroom
Friday General Session	Licensed Acupuncturist, Clinic Director Chicken Soup	
	Chinese Medicine, Executive Director MRCE Foundation,	
Integrated Chinese Medicine and	Faculty American College of Traditional Chinese Medicine at	
PSC: Accessing the Best of East and West	California Institute of Integral Studies	
11:45AM - 12:00 PM	Break and Transition to Lunch with Peers and Mentors	
12:00 PM - 1:45 PM	Lunch with Peers and Mentors	Ballroom
1:45 - 2:00PM	Break and Transition to Afternoon Breakout Sessions	
2:00 - 3:00 PM	Friday Afternoon Breakout Session I	
Basics of PSC	Christopher Bowlus, MD, Lena Valente Professor and Chief,	
(The Basics Track)	Division of Gastroenterology, UC Davis School of Medicine,	
	Co-Chair of PSC Partners Scientific Medical Advisory	
	Committee	
Track Sponsor: Pre-Transplant Considerations:		
Pre-Transplant Considerations: When and Where to Consider Liver	Kidist K. Yimam, MD, Medical Director, Department of Hepatology and Liver Transplantation, California Pacific	
Transplant Evaluation for PSC	Medical Center	
(Transplant Track)	incontai contai	
Track Sponsor:		
PSC in Kids: The Medical Side of	Sunpreet Kaur, MD, Assistant Professor, Pediatric	
Pediatric PSC	Gastroenterology and Nutrition, UC Davis Children's Hospital	
Transitioning from Pediatric to	Dilshad Kassam-Laliani, BSN, MN, NP-PHC, Nurse	
Adult Care (Pediatric Track)	Practitioner, Holland-Bloorview Kids Rehabilitation	
Hardin Care (Feanadic Track)	Hospita/University of Toronto, Parent of Post-Transition	
Track Sponsor:	PSCer and Afsana Lallani. Post-Transition PSCer	

at Buffalo, SUNY.

#### UCSF, UCLA, UC Berkeley, California Pacific Medical Control California Pacific Medical Co

California Pacific Medical Center, Stanford University and University

Topics on this year's agenda include:

- Point/counter-point session on the risks and benefits of Ursodeoxycholic Acid and Vancomycin for PSC patients
- Understanding the clinical trial process and how to maximize the patient's role
- Current PSC research on the microbiome and future research possibilities
- Recent changes made by UNOS to the MELD score and how it may affect PSC patients
- How to navigate and optimize the new insurance landscape
- Transitioning from pediatric to adult care
- Pre- and post-transplant considerations
- Current research and future outlook of liver stem cell research

To view the full agenda for the 2018 conference, click here.

#### First Time Attending a PSC Partners Conference? Visit our Conference FAQ Page for More Information

It is perfectly normal to have lots of questions before your first PSC Partners conference. It is also very common for first-time attendees to be anxious about attending a conference about PSC. Fear not! You are about to meet the PSC Partners family: a community of caring, understanding, supportive, and at times downright silly people who completely understand what it means to live with primary sclerosing cholangitis. If you have any questions before the conference, do not hesitate to <u>email us</u>. We are here to help. Many of the most common questions are covered on our



<u>Conference FAQ Page</u>. We can't wait to meet you in Sacramento!

### **Consider Becoming a 2018 Conference Sponsor**

Every year, the cost of attending our annual conference is cut in HALF by the generous support of conference sponsors. Every sponsorship helps - no matter how big or small. PSC Partners offers different levels of sponsorship for <u>community members</u> and for interested <u>corporate sponsors</u>. We are so grateful for the support of sponsors who help ensure that the annual conferences are as affordable as possible. Consider becoming a conference sponsor today!

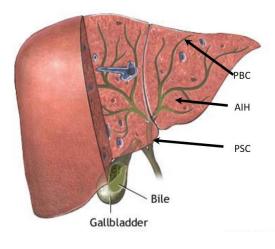
#### **Conference Photographer Needed!**

We are looking for an experienced photographer who is willing to take photos throughout the 2018 conference. If you are interested, please <u>email us</u> so we can learn more about you. For a sample of past conference photos, please <u>click here</u>.



#### **Education / Research / News**

Recent Presentation at UC Davis Provides Research and Treatment Updates for



#### **PSC and PBC Patients**

At the end of January, Dr. Chris Bowlus at the University of California Davis hosted a meeting for patients affected by primary sclerosing cholangitis (PSC), and primary biliary cholangitis (PBC). Although PSC and PBC share certain symptoms and characteristics, they

require different treatment and monitoring to ensure patient safety. The presentation at UC Davis shed light on the basics about PSC and PBC, as well as current treatment recommendations and research study results for both conditions. The slides from the presentation are available <u>here</u>.

PSC Partners Seeking a Cure has conducted an awareness campaign to help educate patients and medical professionals about the critical differences between PSC and PBC. <u>Click here</u> to learn more.

## How You Can Support Us

#### AmazonSmile is Tripling Its Donation Amount March 12-31



# Now your support goes 3 times as far

From Mar 12 – 31, Amazon will triple the donation rate to 1.5% on your first eligible purchase at smile.amazon.com.

### amazon smile

Have you <u>selected PSC Partners to receive donations</u> when you shop on Amazon? It's an easy way to turn your online shopping habit into a philanthropic activity! From March 12-31, Amazon will TRIPLE its donation amount to 1.5% of your first eligible purchase, and then 0.5% for additional purchases. So wait until March 12, and then go ahead and buy that new flat screen you've had your eyes on. Or stock up on shampoo. You do you.



# Support PSC Partners with a Donor Advised Fund (DAF)

A donor advised fund (DAF) provides you with the flexibility and most favorable tax benefits to support your favorite charities. DAFs 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. Read our <u>blog post</u> to learn more about the benefits and how DAFs work.

#### **Organizational News**



#### **Local Support Groups**

Interested in starting or joining a local PSC Support Group? <u>Click</u> <u>here</u> to learn more, or <u>send us an</u> <u>email</u>.

\*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 Seeking a Cure 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 | <u>contactus@pscpartners.org</u> | pscpartners.org 6900 E Belleview Ave Ste 202, Greenwood Village CO 80111

