



# THE DUCT

A Monthly Newsletter for the PSC Community

May 2019

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*Our CEO Ricky is ALL SMILES, because she can't wait to see you at the 15th Annual PSC Partners Conference!*

**June 21-23, 2019**

**Rochester, MN**

**[Click here](#) for 2019 Conference information.**

**Regular Registration Deadline  
Approaching for  
for the 2019 Conference**



We are excited to see you at the 15th Annual PSC Partners Patient and Caregiver Conference, in conjunction with Mayo Clinic Rochester. Make sure your registration is received on or before May 27 to ensure you are not assessed a late fee. The registration schedule is below:

**Regular Registration: Deadline 5/27/19:**

\$240 per person

**Late Registration: Deadline 6/9/19:**

\$270 per person

**Corporate/Professional & Medical Provider Registration:**

**Deadline 6/9/19:**

\$330 per person

ALL fees must be received by  
**6/9/2019.**

[Click here](#) for more information and to register.

***Remember: No one under the age of 13 may attend any part of the conference, including meals.***

## Hotel Filling Up Reserve NOW



If you're planning to come to the conference, but have not, yet, reserved your room, NOW IS THE TIME! The discounted block of rooms is almost full. So, please reserve ASAP before this rate is no longer available.

[Click here](#) to visit the hotel reservation page.

## Important Shuttle Reminder



The Rochester Shuttle Service can transport you to and from the Minneapolis-St.

Paul or Rochester airports, and has offered a discounted rate for PSC Partners conference attendees. If you need roundtrip transportation, you must make a reservation. RESERVE YOUR SHUTTLE BOTH WAYS NOW.

To make a reservation, [click here](#). Enter the code **MAYO1** (all caps, no spaces - *It's MAYO with a 1 after it, as in MAYO Clinic.*) at checkout after the times and dates of shuttle service have been selected. The discounted rate from Minneapolis-St. Paul is \$27 one way, \$54 round trip.

**Be sure to make a round trip reservation.** The Rochester Shuttle Service has a representative at the Kahler Grand Hotel, if you need assistance on site. You do not need a car during the conference.

## **Mentor/Mentee Program Adds Depth to Conference**

***Don't Miss Your Chance to Connect***



The well-loved, valuable mentor/mentee program helps conference newcomers feel immediately welcome while enabling conference veterans to help out in a meaningful way. Additionally, there is an on-going program that ensures that the PSC Partners community receives the information and support needed to live their best lives.

### **Conference Mentor/Mentee Program**

This is a program for first-time attendees of the conference. It enables those new to the conference to touch base with conference veterans, allowing them to learn what to expect, while also ensuring they immediately have a friendly face in the crowd when they arrive at the conference. This program is successful, because of all the previous attendees who volunteer each year to be mentors. Keep in mind that not everyone who volunteers to be a conference mentor gets a mentee. The mix is totally dependent on the type of attendee (PSCer, Spouse, Parent, etc) asking for a mentor.

*If you are new to the conference, please consider signing up for a mentor. If you have been before, even just once, your experience is valuable. You can sign up when you register for the conference or contact Trish at the email listed below.*

### **Year-Round Mentor/Mentee Program**

PSC Partners is contacted routinely by newly diagnosed families asking for guidance. Although no medical advice can be given, it is helpful to be able to put

these individuals in touch with someone who has been in their shoes. Coordinators do their best to make matches based on the relationship to the patient as well as geographical location. Mentor/mentee pairs often meet for coffee or lunch, and stay in touch by phone or email. Talking to someone who is in a similar circumstance and understands our concerns is very cathartic.

We are in the process of making this a year-round program. Look for more information in the coming months, including a new registration process to become a mentor.

*The mentor/mentee program is coordinated by volunteer Trish Stoltzfus, in conjunction with PSC Partners staff, and was conceived by Sandi Perlman, both fierce advocates of the PSC community.*

***To participate in either program, contact [Trish@pscpartners.org](mailto:Trish@pscpartners.org).***

## Say Hello to Raquel Valerio



We are pleased to welcome Raquel Valerio as the new Program Administrator at PSC Partners.

Raquel is a Colorado native and has spent the last 20 years assisting her husband with his successful general contracting business while also working as an independent contractor. She has helped small businesses with their account management, billing, and sales support. For many years, she served on different non-profit boards and enjoys community involvement. Most recently, Raquel worked in the medical billing field. She says this was a turning point for her. She realized she wanted to be a part of a solution to a cure. Raquel says she is excited to be a part of the PSC Partners team and to serve its community. She loves spending time with her husband Andrew, their four children, and her very large extended family. She enjoys walking, reading, music, playing with her two dogs, and, most of all, impromptu trips to the mountains with her family!



### ***Living with PSC Episode #12: PSC and Living Donor Donations***

In this episode of Living with PSC, Niall McKay discusses living donor liver donations with John Crowley, a PSCer who received a life-saving donation from his brother. Check it out [here](#).

The Living With PSC podcast series is moderated by Niall McKay. Each month, this podcast explores the latest research and knowledge about PSC. From patient stories to the latest research updates from PSC experts to collaborations that are necessary to find better treatments and a cure, this podcast has it all! Click [here](#) for a complete list of episodes.



## **Blog Spot**

### **Conversation with Winning Athlete & PSC Patient YVETTE MATTHEWS**



For this month's blog, we would like to introduce you to Yvette Matthews. Yvette was diagnosed with PSC in 2001, and received a liver transplant in 2013. Prior to her diagnosis, Yvette was a college athlete and a semi-pro beach volleyball player. So, understandably, her PSC diagnosis came as a complete shock, like it does for many in our community. Yvette's health eventually began to decline,

and, after many years of living with the complications of PSC, she received a transplant. Within a year after her surgery, Yvette was slowly able to regain the strength and spirit to train once more for competition. She successfully competed in her first Transplant Games in 2014. She has been to several Transplant Games since, and is now competing in the National Senior Games as well, which will take place the same weekend of the PSC Partners Conference. *(We'll miss you, Yvette, but we'll be cheering you on!)* Yvette has been an active volunteer for PSC Partners and has attended many PSC Partners conferences over the years, always bringing her vivacious spirit and energy to the event.

We were excited to talk with Yvette about her journey. [Click here](#) to read the full blog post.

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## **International Collaboration Brings Us Closer to a Cure**



A recent article in Mayo Connect highlighted a valuable collaboration that started a decade ago between Tom Hemming Karlsen, M.D., Ph.D. (top left), who leads the Norwegian PSC Research Center (NoPSC), and Mayo Clinic's Konstantinos Lazaridis, M.D. (bottom left), to uncover the factors driving PSC.

"We realized that, to have robust and significantly valuable findings, we had to come together," says Dr. Karlsen.



In 2009, in an effort to address the numerous unanswered questions about PSC, Drs. Lazaridis and Karlsen collaborated to build the PSC Resource Of Genetic Risk, Environment, and Synergy Studies, termed PROGRESS, a comprehensive collection of clinical data and research biospecimens from over 1,300 PSC U.S. patients. Additionally, in 2010, Dr. Karlsen co-founded the International PSC study group.

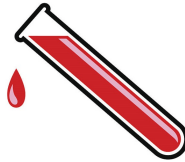
At the time, neither could have foreseen the transformative power of their collaborative genetic study on the global PSC research landscape. The shift was possible, Dr. Karlsen says, thanks to a unique spirit of community.

The two ushered in a new era of research between the largest PSC referral centers in the U.S. and Norway that did away with the old customs of secrecy and competing laboratories not sharing research findings.

[Click here](#) to read the full article in Mayo Connect.

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## **Reminder: WE NEED YOU For Blood Specimen Collection**



We want to remind everyone that researchers from Mayo Clinic will be collecting blood samples from PSC patients during the conference. We encourage all PSC patients to contribute to this important biobank which will be used in future studies to find a cure for PSC. Blood draws will be done Friday and Saturday at The Mayo Civic Center from 9 a.m.-5 p.m. No appointment needed! [Click here](#) for more information, and scroll down to the paragraph titled *MAYO CLINIC BLOOD SPECIMEN COLLECTION*.

*Mayo Clinic is encouraging all PSC patients to provide blood samples regardless of past participation in Mayo studies.* PSC patients who may be at Mayo Clinic earlier in the week are welcome to meet with a Research Coordinator and have their blood drawn at that time. Please contact Erik ([schlicht.erik@mayo.edu](mailto:schlicht.erik@mayo.edu), 507-284-4312) or Jacki ([Bianchi.jackie@mayo.edu](mailto:Bianchi.jackie@mayo.edu), 507-266-0346) for more information about how to schedule this visit.

**THANK YOU TO OUR 2019 CONFERENCE SPONSORS!**

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For more information, email [contactus@pscpartners.org](mailto:contactus@pscpartners.org), or call 303-771-5227.

## GLOSSARY OF COMMONLY USED MEDICAL TERMS

We have prepared a [Glossary of Terms](#) related to PSC. We hope this is helpful for everyone in the PSC community. If you are attending the 2019 Conference, we suggest you print out this page, and keep it with you during the event.

## We'll Take That Ol' Car Off Your Hands and Turn it Into a Cure



Let's face it...That old car you parked in your front lawn and turned into a flower bed was quaint for awhile, but now it's an eyesore. Your neighbors are going to start complaining, and who needs that? PSC Partners can take that car off your hands, and put the money to good use in the search for a cure.

[Click here](#) for more information. Your neighbors (and PSC Partners) will THANK YOU!



*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  
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