

## PSC Partners Seeking a Cure

# 19th Annual PATIENT & CAREGIVER CONFERENCE

Henderson, Nevada  
Sept 8-10, 2023

Just 10 min from the Las Vegas airport!



Friday, September 08, 2023

TIME	SESSION	LOCATION
8:00 AM - 4:30 PM	ON-GOING CHECK-IN/CONFERENCE REGISTRATION	Registration Desk
9:30 AM - 11:30 AM	DROP-IN C-VENT TRAINING	Room:TBD
9:30 AM - 10:00 AM	MENTOR & MENTEE MEET UP	Room:TBD
10:00 AM - 11:00 AM	NEWCOMER ORIENTATION	Room:TBD
11:30 AM - 1:00 PM	LUNCH (ON YOUR OWN)	
1:00 PM - 2:00 PM	<b><u>GENERAL SESSION #1</u></b> Moderator: Ricky Safer Welcome - Ricky Safer Welcome - Joshua Korzenik, MD, Brigham and Women's Hospital & Christopher Bowlus, MD, UC Davis School of Medicine Personal PSC Experience The State of PSC Research in 2023 - Gideon Hirschfield, MB, BChir, PhD, University of Toronto Driving Progress through Collaboration: CZI Rare As One and Collaborative Research Networks - Stephen Rossi, PharmD	Grand Ballroom
2:00 PM - 2:15 PM	PASSING PERIOD TO BREAKOUT SESSION #1	
2:15 PM - 3:15 PM	<b><u>BREAKOUT SESSION #1</u></b> <b>PSC 101 (The Basics Track)</b> David Assis, MD, Yale University <i>Newly diagnosed with PSC? Learn what PSC is, what it means for you, and what you should discuss with your doctor. This session will cover an introduction to primary sclerosing cholangitis (PSC), including how the diagnosis is made, how it is evaluated, and the initial steps to manage medical care with PSC.</i> <b>Pediatric PSC: Everything You Want to Know (The Pediatric Track): Sponsored by The Chris &amp; John Browner Family</b> Cara Mack, MD, ChiLDReN Network, Medical College of Wisconsin Andrew Wehrman, MD, Boston Children's Hospital <i>This session will review new society guidelines for the diagnosis and management of PSC, current and future therapies of PSC, and updates on current research studies of pediatric PSC.</i> <b>Liver Transplantation: The Why, How, and When (The Transplant Track)</b> Richard Green, MD, Northwestern University Feinberg School of Medicine Espen Melum, MD, PhD, Oslo University Hospital <i>In this session, we'll review the indications for liver transplantation. We'll focus on the US national organ allocation system, the unique opportunity a living donor may provide, as well as exciting new developments in the field of liver transplantation. Finally, we'll discuss post transplantation outcomes and some of the center-specific qualities to consider when choosing care.</i>	Room:TBD Room:TBD Room:TBD

<p><b>Seated Yoga (The Caring For You Track)</b> Elizabeth Szewczyk, Development Director - PSC Partners Seeking a Cure <i>Take part in a gentle form of yoga that's done while seated or using a chair for balance.</i></p>	Room:TBD
<p><b>Symptom Management in PSC</b> Olumuyiwa Awoniyi, MD, Cleveland Clinic Jennifer Lai, MD, MBA, FACP, University of California San Francisco</p>	Room:TBD
<p><b>Caregivers: Challenges and Rewards Psychological and Social Stresses in PSC (The Caregiver Track)</b> Jerome Schofferman, MD, Post-Transplant PSC Patient Sally Holland, PhD, PSC Caregiver <i>This highly interactive session will discuss the stresses and benefits of caring for a PSC patient. In addition, we will discuss both positive and negative feelings experienced by caregivers. The session also will examine the interactions between caregivers and patients, including the feelings experienced by patients.</i></p>	Room:TBD
<p><b>Unique Research Approaches</b> Olivier Barbier, PhD, Université Laval Heather Francis, MD, Indiana University School of Medicine Theo Heller, MD, National Institutes of Health <i>This session provides an opportunity to learn about three unique research approaches to better understand the etiology of PSC and the development of future therapies.</i></p>	Room:TBD
<p><b>Cholangiocarcinoma Basics and Treatment Horizon</b> Jesus Banales, PhD, Biodonostia Health Research Institute – Donostia University Hospital <i>This session will review the risk factors, screening recommendations, symptoms, and diagnosis of cholangiocarcinoma. It also will review the latest available treatments, the future of developing diagnosis tools and, the role of liver transplantation for treatment of specific cases of cholangiocarcinoma.</i></p>	Room:TBD
<p><b>Patients Driving Research: PSC Partners PROM and WIND-PSC Initiatives</b> Donna Evon, PhD, University of North Carolina at Chapel Hill Bettina Hansen, PhD, Erasmus University Rotterdam Mary Pressley Vyas, President, PSC Partners Canada Joanne Hatchett, RN, MS, FNP-retired, Medical Science Liaison, PSC Partners Seeking a Cure <i>This session provides updates on two exciting PSC Partners-sponsored research initiatives. The PROM project is developing PSC-specific patient reported outcome measures for symptoms PSC patients experience. WIND-PSC is an international prospective cohort of over 2,000 PSC patients that is launching in 2023 with objectives to accelerate drug development, understand patients quality of life and symptom burden, and provide needed data for biomarker development.</i></p>	Room:TBD
<p><b>PSC-IBD Research: A Key to Understanding PSC</b> Joel Pekow, MD, University of Chicago Joshua Korzenik, MD, Brigham and Women's Hospital <i>Focusing on the fact that a majority of people who have PSC also have IBD may be an important key to understanding PSC. This session brings two PSC-IBD researchers to discuss PSC-IBD research approaches and updates from their ongoing studies.</i></p>	Room:TBD
<p><b>Teens Question and Answer: Every Question is Fair Game</b> Alexander Miethke, MD, Cincinnati Children's Hospital Amanda Ricciuto, MD, PhD, SickKids Hospital, Toronto <i>This session will be geared towards pre-teens and teenagers who have questions related to all aspects of living with PSC. NOTE: This session is for teens and college-age attendees only - No parents allowed!</i></p>	Room:TBD

**3:15 PM - 3:30 PM** PASSING PERIOD TO BREAKOUT SESSION #2

**3:30 PM - 4:30 PM** **BREAKOUT SESSION #2**

<p><b>How to Interpret Your PSC Test Results: Imaging and Labs (The Basics Track)</b> Sayed Obaidullah Aseem, MD, PhD, Virginia Commonwealth University <i>In this session, we'll review the full spectrum of diagnostic tests employed to manage primary sclerosing cholangitis (PSC), including basic blood tests, radiology tests, endoscopic procedures, and biopsy results. We will focus on reviewing how these results are interpreted by hepatologists, so that patients and caregivers can become informed participants in PSC care. The session will be divided into two parts: an initial overview of diagnostic testing and interpretation followed by a Q&amp;A session with a discussion in more detail about how to incorporate these skills into care collaboration.</i></p>	Room:TBD
<p>Special Topics in Pediatrics: Mental Health and A-LiNK (The Pediatric Track): Sponsored by The Chris &amp; John Browner Family</p>	Room:TBD

Mercedes Martinez, MD, Columbia University Amy Taylor, MD, Cincinnati Children's Hospital <i>A-LiNK (Autoimmune Liver Disease Network for Kids) is a network of pediatric centers throughout the nation that engage patients, families, providers, and other stakeholders as partners to improve outcomes in autoimmune liver disease. This session will discuss how A-LiNK strives to facilitate productive, mutually respectful relationships and a shared understanding of key patient-centered outcomes.</i>	
<b>Post Liver Transplantation: What to Expect (The Transplant Track)</b> Michael Li, MD, MPH, University of California San Francisco	Room:TBD
<b>Gentle Movement: An Invitation to Move Your Mind and Body (The Caring For You Track)</b> Julianne Vasichek	Room:TBD
<b>3-D Virtual Reality of the Liver Presentation</b> Albert Fung, MScBMC, The Toronto Video Atlas of Surgery, Toronto General Hospital <i>The Virtual Reality (VR) module will allow participants to examine a 3D model of a liver, complete with the blood vessels and bile ducts, in a virtual space. They will be able to grab, rotate, and re-size the model using their controllers, and highlight specific structures according to their interest. At the same time, an assistant will be present in the virtual space with the participant to guide them through the anatomy of the liver and bring up examples of how PSC may manifest in the liver, bile ducts, and surrounding anatomy. Additional shorter sessions will be available throughout the day on Saturday on a first come, first served basis.</i>	Room:TBD
<b>Patients: The Everyday Stresses of Living with PSC (The Caregiver Track)</b> Jerome Schofferman, MD, Post-Transplant PSC Patient <i>In this interactive session, we will discuss the perspective of being a patient with an invisible illness, and brainstorm coping strategies. The session also will provide an interactive discussion to address the concerns and fears of living with PSC.</i>	Room:TBD
<b>Critical Patient Involvement For a Successful Clinical Trial</b> David Goldberg, MD, MSCE, University of Miami School of Medicine Gideon Hirschfield, MB, BChir, PhD, University of Toronto <i>This session will cover the basics of clinical trial approaches, a description of the different types of clinical trials in PSC, and the challenges and opportunities of clinical trials in PSC, and the importance of patient involvement.</i>	Room:TBD
<b>The Gut Microbiome: What We Know and Where We're Going</b> Johannes Hov, MD, PhD, Oslo University Hospital <i>This talk will focus on enterohepatic circulation, the "gut-liver axis", and the gut microbiota, which form the basis for many hypotheses of PSC etiology. Learn about examples of therapeutic approaches being explored.</i>	Room:TBD
<b>Uncovering the Cellular Drivers of PSC: Discovery and Innovation through Collaboration</b> Sonya MacParland, PhD, University of Toronto Mary Pressley Vyas, President, PSC Partners Canada <i>This session will focus on how scientists are exploring the cellular ecosystem of the healthy liver vs. the PSC liver to better understand PSC and potentially identify therapeutic targets for PSC. Learn about the four-year, CZI-funded, patient-partnered collaboration between PSC Partners and a scientific team in Toronto, led by Dr. MacParland, who are working to uncover the cellular drivers of PSC.</i>	Room:TBD
<b>Specific Issues in Women's Health: PSC &amp; IBD</b> Lisa Forman, MD, University of Colorado Jana Al Hashash, MD, MS, Mayo Clinic <i>This session will include a presentation on issues specifically affecting women with PSC and IBD, including fertility, pregnancy, and pre and post-transplant considerations. During the Q&amp;A section, participants can share their experiences, hear about the journeys of other women with PSC, and learn about resources at the intersection of women's health with PSC and IBD.</i>	Room:TBD

<b>4:30 PM - 4:45 PM</b>	PASSING PERIOD TO SPONSOR PRESENTATIONS AND CLINICAL TRIALS	
<b>4:45 PM - 5:45 PM</b>	The Clinical Trial Landscape in PSC - Updates and Opportunities	
<b>5:45 PM - 6:00 PM</b>	MENTOR AND MENTEE MEET UP (FOR THOSE WHO WERE NOT AVAILABLE IN THE MORNING)	Room:TBD
<b>6:00 PM - 7:00 PM</b>	BREAK AND REFRESH	
<b>7:00 PM - 9:00 PM</b>	DINNER AND SOCIAL TIME	Opium Terrace
<b>9:00 PM - 9:30 PM</b>	CANADIAN MEET-UP	Room:TBD

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Saturday, September 09, 2023

TIME	SESSION	LOCATION
8:00 AM - 4:30 PM	ON-GOING CHECK-IN/CONFERENCE REGISTRATION	Registration Desk
8:00 AM - 9:00 AM	BREAKFAST	Opium Terrace
9:00 AM - 9:15 AM	PASSING PERIOD TO GENERAL SESSION #1	
9:15 AM - 10:55 AM	<b>GENERAL SESSION #1</b> Moderator: David Goldberg, MD, MSCE, University of Miami School of Medicine Welcome - Don & Ricky Safer; Christopher Bowlus, MD, UC Davis School of Medicine; Joshua Korzenik, MD, Brigham and Women's Hospital Patient Story - Mahesh, Medical Student Johns Hopkins, PSC Partners Board of Directors Blueprint Towards a Cure for PSC - Jesse Kirkpatrick, PhD, Medical Student Harvard University, PSC Partners Board of Directors PSC Partners ICRNetwork Scientific Convening Takeaways - Joshua Korzenik, MD, Brigham and Women's Hospital & Christopher Bowlus, MD, UC Davis School of Medicine PSC Partners Research Programs - Stephen Rossi, PharmD, PSC Partners Seeking a Cure Question & Answer	Grand Ballroom
10:55 AM - 11:30 AM	BREAK WITH SNACK: Snack sponsored by The Don & Ricky Safer Family & Anonymous/Beverages sponsored by The Belmont Family and The Budjinski Family	Opium Terrace
11:30 AM - 1:00 PM	<b>GENERAL SESSION #2</b> Moderator: Heather Francis, PhD, Indiana University School of Medicine Current Treatments: AASLD Guidance - Christopher Bowlus, MD What's New and on the Horizon for PSC Treatments - Gideon Hirschfield, MB, BChir, PhD, University of Toronto PSC Diet and Nutrition: Highlights and Insights - Jennifer Lai, MD, MBA, University of California, San Francisco ChildReN Network: Prospective Observational Study of Primary Sclerosing Cholangitis in Children (PSC) - Cara Mack, MD, Medical College of Wisconsin Question & Answer	Grand Ballroom
1:00 PM - 2:15 PM	LUNCH WITH PEER GROUPS	Opium Terrace
2:15 pm - 2:30 PM	PASSING PERIOD TO GENERAL SESSION #3	
2:30 PM - 4:00 PM	<b>GENERAL SESSION #3</b> Moderator: Christopher Bowlus, MD, UC Davis School of Medicine A Researcher's Story: The Impact of PSC Partners Grants and the Patient Organization - Heather Francis, PhD, Indiana University School of Medicine FDA and the Patient Voice in Drug Development - Frank Anania, MD, Food and Drug Administration A Perspective From the Scientific/Medical Advisory Board: Trends in PSC Research - Richard Green, MD, Northwestern University Feinberg School of Medicine PSC Transplant - Lisa Forman, MD, University of Colorado PSC Partners ICRNetwork: Building Community Involvement - Ricky Safer, Joshua Korzenik, MD, Christopher Bowlus, MD Question & Answer	Grand Ballroom
4:00 PM - 7:00 PM	BREAK AND REFRESH	
7:00 PM - 9:00 PM	DINNER, VISITING AND SOCIAL EVENT	Opium Terrace

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Sunday, September 10, 2023

TIME	SESSION	LOCATION
8:00 AM - 9:00 AM	BREAKFAST	Opium Terrace
9:00 AM - 9:15 AM	GENERAL SESSION	Grand Ballroom
9:15 AM - 9:30 AM	PASSING PERIOD TO PEER SESSION ROOMS	
9:30 AM - 11:45 AM	<b>PEER SESSIONS: Sponsored by The Kenneth S. Hollander Charitable Foundation</b>	
	Teens Living with PSC (13 to 17)	Room TBD
	Females Living with PSC 20s/30s	Room TBD
	Males Living with PSC 20s/30s	Room TBD
	Females Living with PSC Group A/B	Room TBD
	Males Living with PSC Group A/B	Room TBD
	Post-Transplant (Male & Female)	Room TBD
	Parents of Teens (Ages 13 to 17)	Room TBD
	Parents of Young Adults (Ages 18 to 25) A/B	Room TBD
	Parents of Adults 26 and Older A/B	Room TBD
	Spouses and Caregivers A/B	Room TBD
	Siblings, Friends, and Other Relatives and Caregivers	Room TBD
	Caregivers Coping with Loss	Room TBD
11:45 AM - 12:15 PM	BREAK WITH SNACK: Snack sponsored by The Hatchett Family and David Shapiro, MD, FAASLD/Beverages sponsored by Stuart & Debra Barnett	Opium Terrace
12:15 PM - 1:30 PM	FEEDBACK FROM PEER SESSIONS AND CLOSING REMARKS	Grand Ballroom
1:30 PM	CONFERENCE ADJOURNS	

### ENGAGEMENT PARTNER



### CONTRIBUTING PARTNERS



### COMMUNITY PARTNERS

#### SUPPORTING PARTNER



The Kenneth S. Hollander  
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#### FRIENDS OF PSC PARTNERS

David Shapiro, MD FAASLD  
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#### VISION PARTNER

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Anonymous

#### PSC PARTNERS ADVOCATES

The Budjinski Family  
Stuart & Debra Barnett  
The Belmont Family