

19th Annual
**PATIENT & CAREGIVER
CONFERENCE**

Sept 8-10, 2023

Just 10 min from the Las Vegas airport!

TIME	SESSION	LOCATION
8:00 AM - 12:00 PM	TEEN LOUNGE (OPEN FROM 5:00 PM THURSDAY, 9/7 - 12:00 AM SUNDAY, 9/10)	La Luna
8:00 AM - 4:30 PM	ON-GOING CHECK-IN/CONFERENCE REGISTRATION/PSC PARTNERS AWARENESS SHOP	Registration Desk
9:30 AM - 4:30 PM	DROP-IN C-VENT TRAINING	PSC Welcome Room
9:30 AM - 10:00 AM	MENTOR & MENTEE MEET UP	Del Sol
10:00 AM - 11:00 AM	NEWCOMER ORIENTATION	Grand Ballroom I
11:30 AM - 1:00 PM	LUNCH (ON YOUR OWN)	
1:00 PM - 2:00 PM	<u>GENERAL SESSION #1</u>	Ballroom II-IV
	<p>Moderator: Ricky Safer</p> <p>Welcome - Ricky Safer</p> <p>Welcome - Joshua Korzenik, MD, Brigham and Women's Hospital & Christopher Bowlus, MD, UC Davis School of Medicine</p> <p>Personal PSC Experience - Mahesh Krishna, Medical Student, The Johns Hopkins University School of Medicine</p> <p>The State of PSC Research in 2023 - Gideon Hirschfield, FRCP, PhD, University of Toronto</p> <p>Driving Progress through Collaboration: CZI Rare As One and Collaborative Research Networks - Stephen Rossi, PharmD</p>	
2:00 PM - 2:15 PM	PASSING PERIOD TO BREAKOUT SESSION #1	
2:15 PM - 3:15 PM	<u>BREAKOUT SESSION #1</u>	
	<p>PSC 101 (The Basics Track) - Sponsored by The Kenneth S. Hollander Charitable Foundation</p> <p>David Assis, MD, Yale University</p> <p><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></p>	La Sirena II
	<p>Pediatric PSC: Everything You Want to Know (The Pediatric Track): Sponsored by The Chris & John Browner Family</p> <p>Cara Mack, MD, ChiLDReN Network, Medical College of Wisconsin</p> <p>Andrew Wehrman, MD, Boston Children's Hospital</p> <p><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></p>	La Cascada 1
	<p>Liver Transplantation: The Why, How, and When (The Transplant Track)</p> <p>Richard Green, MD, Northwestern University Feinberg School of Medicine</p> <p>Espen Melum, MD, PhD, Oslo University Hospital</p>	Grand Ballroom 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.

Mindfulness: Chair Yoga and Thoughtful Meditation (The Caring For You Track)

La Estrella

Elizabeth Szewczyk, RYT200, MS

Chair yoga uses the support of the chair to arrive in yoga poses, move, and breathe. This session will include an accessible chair flow, including breathing and moments of meditation, followed by discussion on how to personalize your specific needs for mindfulness.

Benefits of chair yoga include increased mobility, increased strength, stretching of the body, reducing stress, reducing pain & clearing the mind.

Symptom Management in PSC

La Sirena IV

Olumuyiwa Awoniyi, MD, Cleveland Clinic

Jennifer Lai, MD, MBA, University of California San Francisco

This talk will focus on the comprehensive management of common symptoms associated.

with Primary Sclerosing Cholangitis (PSC). We will explore evidence-based strategies to address symptoms such as fatigue, pruritus, and abdominal discomfort. The talk aims to equip healthcare providers and patients. with practical insights for improving patients' quality of life through symptom management in PSC.

Caregivers: Challenges and Rewards Psychological and Social Stresses in PSC

La Sirena III

Jerome Schofferman, MD, Post-Transplant PSC Patient

Sally Holland, PhD, PSC Caregiver

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.

Unique Research Approaches

La Cascada II

Olivier Barbier, PhD, Université Laval

Heather Francis, PhD, Indiana University School of Medicine

Theo Heller, MD, National Institutes of Health

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.

Cholangiocarcinoma Basics and Treatment Horizon

Del Fuego

Jesus Banales, PhD, Biodonostia Health Research Institute – Donostia University Hospital

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.

Patients Driving Research: PSC Partners PROM and WIND-PSC Initiatives

La Sirena I

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

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.

PSC-IBD Research: A Key to Understanding PSC

Ballroom II-IV

Joel Pekow, MD, University of Chicago

Joshua Korzenik, MD, Brigham and Women's Hospital

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.

Teens Question and Answer: Every Question is Fair Game

La Cascada III

Alexander Miethke, MD, Cincinnati Children's Hospital

Amanda Ricciuto, MD, PhD, SickKids Hospital, Toronto

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!

3:15 PM - 3:45 PM SNACK AND PASSING PERIOD TO BREAKOUT SESSION #2

3:45 PM - 4:45 PM **BREAKOUT SESSION #2**

How to Interpret Your PSC Test Results: Imaging and Labs (The Basics Track) : Sponsored by The Kenneth S. Hollander Charitable Foundation **La Sirena IV**

Sayed Obaidullah Aseem, MD, PhD, Virginia Commonwealth University

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&A session with a discussion in more detail about how to incorporate these skills into care collaboration.

Special Topics in Pediatrics: Mental Health and A-LiNK (The Pediatric Track): Sponsored by The Chris & John Browner Family **La Cascada II**

Mercedes Martinez, MD, Columbia University

Amy Taylor, MD, Cincinnati Children's Hospital

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.

Post Liver Transplantation: What to Expect (The Transplant Track) **La Cascada I**

Michael Li, MD, MPH, University of California San Francisco

Gentle Movement: An Invitation to Move Your Mind and Body (The Caring For You Track) **La Estrella**

Julianne Vasichek

3-D Virtual Reality of the Liver Presentation **El Viento II**

Albert Fung, MScBMC, The Toronto Video Atlas of Surgery, Toronto General Hospital

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.

Patients: The Everyday Stresses of Living with PSC **La Sirena III**

Jerome Schofferman, MD, Post-Transplant PSC Patient

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.

Critical Patient Involvement For a Successful Clinical Trial **La Sirena I**

David Goldberg, MD, MSCE, University of Miami School of Medicine

Gideon Hirschfield, FRCP, PhD, University of Toronto

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.

The Gut Microbiome: What We Know and Where We're Going **Ballroom II-IV**

Johannes Hov, MD, PhD, Oslo University Hospital

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.

Uncovering the Cellular Drivers of PSC: Discovery and Innovation through Collaboration **Grand Ballroom I**

Sonya MacParland, PhD, University of Toronto

Mary Pressley Vyas, President, PSC Partners Canada

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.

Specific Issues in Women's Health: PSC & IBD **La Sirena II**

Lisa Forman, MD, University of Colorado

Jana Al Hashash, MD, MS, Mayo Clinic

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&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.

4:45 PM - 5:00 PM PASSING PERIOD TO SPONSOR PRESENTATIONS AND CLINICAL TRIALS

5:00 PM - 6:00 PM	THE CLINICAL TRIAL LANDSCAPE IN PSC: UPDATES AND OPPORTUNITIES Moderator: Joanne Hatchett, RN, MS, FNP-retired, Medical Science Liaison, PSC Partners Seeking a Cure Matt Frankel, MD, MBA: Chemomab Therapeutics - Chief Medical Officer, Vice President of Drug Development Escient Anthony Loizides, MD: Ipsen Biopharmaceuticals - Medical Director of Clinical Development Ikenna Okechukwu, MD: Ipsen Biopharmaceuticals - Medical Development Director Chris Peetz: Mirum Pharmaceuticals, Inc. - President & Chief Executive Officer Richard Pencek, PhD: Pliant Pharmaceuticals - Senior Director, Clinical Development <i>We are extremely excited to be able to gather five clinical-trial leaders who will be presenting their company's on-going PSC study. Conference attendees will have the opportunity to ask questions in person at some of the booths which will be open through Saturday.</i>	Ballroom II-IV
6:00 PM - 7:00 PM	BREAK AND REFRESH	
7:00 PM - 9:00 PM	DINNER AND SOCIAL TIME	Opium Terrace
9:00 PM - 9:30 PM	CANADIAN MEET-UP	Del Sol

PSC Partners Seeking a Cure

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Saturday, September 09, 2023

TIME	SESSION	LOCATION
8:00 AM - 12:00 AM	TEEN LOUNGE	La Luna
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	GENERAL SESSION #1 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 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	Ballroom II-IV
10:55 AM - 11:30 AM	BREAK WITH SNACK: Snack sponsored by The Don & Ricky Safer Family & Anonymous/Beverages sponsored by The Budjinski Family	Opium Terrace
11:30 AM - 1:00 PM	GENERAL SESSION #2 Moderator: Heather Francis, PhD, Indiana University School of Medicine Current Treatments: AASLD Guidance - Christopher Bowlus, MD, UC Davis School of Medicine What's New and on the Horizon for PSC Treatments - Gideon Hirschfield, FRCP, 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	Ballroom II-IV
1:00 PM	GROUP PHOTO	Grand Staircase
1:00 PM - 2:15 PM	LUNCH WITH PEER GROUPS Teens Living with PSC (13 to 17) Females Living with PSC 20s/30s Males Living with PSC 20s/30s Females Living with PSC Over 40 Group A Females Living with PSC Over 40 Group B Males Living with PSC Over 40: Sponsored by The Kenneth S. Hollander Charitable Foundation Post-Transplant Group A Post-Transplant - Group B Post Transplant - Sub-Group Parents of Pediatric Patients (17 & Under) Parents of Young Adults (Ages 18 to 25) Parents of Adults 26 and Older Group A Parents of Adults 26 and Older Group B Spouses and Caregivers Group A Spouses and Caregivers Group B Siblings, Friends, and Other Relatives and Caregivers	La Luna El Viento 1 Del Sol La Cascada 3 Del Fuego El Viento 3 La Sirena 1 La Sirena 1 La Sirena 2 La Sirena 4 La Sirena 3 La Cascada 1 La Cascada 2 Grand Ballroom 1 Grand Ballroom 1 Del Mar 1

Caregivers Coping with Loss
Industry Guests

La Estrella

2:15 pm - 2:30 PM PASSING PERIOD TO GENERAL SESSION #3

2:30 PM - 4:00 PM **GENERAL SESSION #3**

Ballroom II-IV

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

4:00 PM - 4:30 PM BREAK WITH SNACK: Snack sponsored by The Sabernick Family/Beverages sponsored by The Belmont Family

4:30 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 - 12:00 PM	TEEN LOUNGE	La Luna
8:00 AM - 9:00 AM	BREAKFAST	Opium Terrace
9:00 AM - 9:15 AM	GENERAL SESSION	Ballroom II-IV
9:15 AM - 9:30 AM	PASSING PERIOD TO PEER SESSION ROOMS	
9:30 AM - 11:45 AM	PEER SESSIONS	
	Teens Living with PSC (13 to 17)	La Luna
	Females Living with PSC 20s/30s	El Viento III
	Males Living with PSC 20s/30s	Del Sol
	Females Living with PSC Over 40 Group A	La Cascada III
	Females Living with PSC Over 40 Group B	Del Fuego
	Males Living with PSC Over 40: Sponsored by The Kenneth S. Hollander Charitable Foundation	El Viento III
	Post-Transplant Group A	La Sirena I
	Post-Transplant - Group B	La Sirena II
	Parents of Pediatric Patients (17 & Under)	La Sirena IV
	Parents of Young Adults (Ages 18 to 25)	La Sirena III
	Parents of Adults 26 and Older Group A	La Cascada I
	Parents of Adults 26 and Older Group B	La Cascada III
	Spouses and Caregivers Group A	Grand Ballroom I
	Spouses and Caregivers Group B	Grand Ballroom I
	Siblings, Friends, and Other Relatives and Caregivers	Del Mar
	Caregivers Coping with Loss	La Estrella
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	Ballroom II-IV
1:30 PM	CONFERENCE ADJOURNS	

ENGAGEMENT PARTNERS



CONTRIBUTING PARTNERS



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The Sabernick Family
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PSC PARTNERS ADVOCATES

The Budjinski Family
Stuart & Debra Barnett
The Belmont Family