

SCHEDULE	SESSION	LOCATION			
THURSDAY, JUNE 23, 2016					
11:00 AM - 9:00 PM	Early Check-in for Attendees PSC Partners Conference Registration	Omni Hotel Mezzanine Level			
6:00 PM - 9:00 PM	Pre-Conference Event: Casual Get Together/Dinner NOTE: Tickets need to have been purchased in	Fornarelli's Ristorante			
	Advance. Walk-in registration is not available	99 Orange Street			
	FRIDAY, JUNE 24, 2016				
7:30 AM - 8:00 PM	Check-in/PSC Partners Registration	Omni Hotel Mezzanine Level			
8:00 AM	Buses load at hotel entry to travel to brunch	Omni - Lobby Level			
8:30 AM - 11:15 AM	Brunch in New Haven at Anthony's Ocean View Mentor/Mentee Meet and Greet/Seating by Peer Group	450 Lighthouse Rd.			
11:15 AM	Buses load to return to Omni Hotel	Front Entrance			
12:00 PM – 12:30 PM	Newcomer Orientation Moderators: Wes Hendrix and Jennifer Sims	Ballroom C			
1:00 - 2:00 PM	Friday Afternoon Breakout Session #1				
Intro to PSC A to Z (The Basics Track)	David Assis, MD, Assistant Professor of Medicine Yale University School of Medicine Section of Digestive Diseases and Yale Liver Center	Temple Room			
The Use of Liver Transplantation in PSC: What to Know and Recent Updates (Transplant Track)	Brett Fortune, MD, Assistant Professor of Medicine Digestive Diseases and Transplant Surgery, Yale University School of Medicine	Ballroom B			
Pediatric PSC Medical Issues (Pediatric Track)	Udeme Ekong, MD, MPH, Associate Professor of Pediatrics, Yale University School of Medicine, Medical Director, Pediatric Hepatology and Pediatric Liver Transplantation, Yale-New Haven Transplantation Center	Chapel A Room			
Interactive Session: T'ai Chi Chih (Caring for You Track)	Cindy Dunn, FNAO, Certified T'ai Chi Chih Instructor	Ballroom A			
Intervention in PSC: Perspectives from Radiology and ERCP Providers	Jeffrey Weinreb, MD, FACR, FISMRM, FSCBT/MR Professor of Radiology and Biomedical Sciences, Yale University School of Medicine Director of MRI Service, Yale-New Haven Hospital Veeral Oza, MD, Clinical Instructor, Advanced Endoscopy Fellow, Section of Gastroenterology and Hepatology, Yale University School of Medicine	George A & B			
How to Find a Doctor and an Advocate and Navigate the Healthcare System	Sylvia Lempit, MSN, APRN, Clinical Transplant Coordinator, Department of Surgery, Yale-New Haven Transplantation Center	College B Room			
IBD and PSC	Myron Brand, MD, Clinical Professor of Medicine, Division of Internal Medicine, Yale University School of Medicine	York Room			
PSC Patients: Coping with the Stress of Living with PSC	 Dwain Fehon, PsyD, Director, Behavioral Medicine, Yale- New Haven Hospital, Assistant Professor, Psychiatry, Yale University School of Medicine Panel of PSC Patients: Fred Sabernick, Nate Baggett, Ruth Blatt and Nicklas Holmgren 	Ballroom C			
Disability Benefits: What to Expect When You Can No Longer Work	Jeremy Burke, D.Mus., ALHC, Senior Learning Consultant, Aetna Group Insurance	Whitney Room			
2:00 PM – 2:30 PM	Break with Snacks	Ballroom Foyer			

2:30 - 3:30 PM	Friday Afternoon Breakout Session #2	
Interpreting Your Test Results	James Boyer, MD, Ensign Professor of Medicine,	York Room
(Basic Track)	Emeritus Director of the Liver Center, Yale University School of Medicine	
Medical Management Following Liver Transplant (Transplant Track)	Cary A. Caldwell, MD, Clinical Associate Professor of Medicine, Yale University School of Medicine	George A & B
Navigating Pediatric PSC: A Surgeon's Perspective (Pediatric Track)	 Manuel Rodriguez-Davalos, MD, FACS, Associate Professor of Surgery and Pediatrics, Director, Pediatric Transplant Program, Yale University School of Medicine Karan Emerick, MD, MSCI, Director of the Liver Service, Connecticut Children's Medical Center, Associate Professor of Pediatrics, University of Connecticut School of Medicine 	Chapel C Room
Interactive Session: Mindfulness (Caring for You Track)	Carol Eggers, MSN, APRN, Yale Digestive Diseases, Yale University School of Medicine	Ballroom A
Maintaining Bone Health in PSC	John Wysolmerski, MD, Professor of Medicine, Section of Endocrinology and Metabolism, Department of Internal Medicine, Yale University School of Medicine	Chapel A Room
PSC and Cholangiocarcinoma: Certainties, Uncertainties, and Future Directions	Tamar Taddei, MD, Associate Professor, Section of Digestive Diseases, Yale University School of Medicine	Temple Room
How to Decide if a Clinical Trial is Right for Me?	David Assis, MD, Assistant Professor of Medicine, Yale University School of Medicine, Section of Digestive Diseases and Yale Liver Center	College B
The Importance of Good Nutrition and Exercise in PSC	Anne Marie Rivard, MPH, RD, CSR, CD-N, and Lyle Hawes, Physical Therapist, Yale New Haven Hospital	Ballroom B
PSC Caregivers: Coping with the Stress of Living with PSC	 Dwain Fehon, PsyD, Director, Behavioral Medicine, Yale- New Haven Hospital, Assistant Professor, Psychiatry, Yale University School of Medicine Panel of PSC Caregivers: Joanne Grieme, Tyler Tessier and Jennifer Sims, Carla Schwartz 	Ballroom C
FMLA: Understanding your rights under the Family Medical Leave Act	Jeremy Burke, D.Mus., ALHC, Senior Learning Consultant, Aetna Group Insurance	Whitney Room
3:30 PM – 5:30 PM	Afternoon Sessions End – Time to Relax	
5:30 PM – 8:30 PM	Welcome Dinner with Improv by The Reunion Boys	Omni Ballroom
	SATURDAY, JUNE 25, 2016	
7:15 - 8:15 AM	Buffet Breakfast	Omni Ballroom
8:15 - 8:30 AM	Welcome and Opening Remarks for General Session	Omni Ballroom
8:30 - 10:00 AM	General Session 1: Understanding PSC Moderators: Tom Karlsen, MD, PhD Professor of Internal Medicine, Oslo University Hospital Rikshospitalet, Norway Keith Lindor, MD Dean, College of Health Solutions, Arizona State University, Professor of Medicine, Mayo Clinic, PSC Partners Scientific/Medical Advisory Committee	
8:30 AM – 8:50 AM	General Session 1 - Presentation 1: <u>New Insights into the Natural History of PSC</u> Cyriel Y. Ponsioen, MD, PhD, Academic Medical Center, Amsterdam, Department of Gastroenterology and Hepatology, PSC Partners Scientific/Medical Advisory Committee	

8:50 AM – 9:10 AM	General Session 1 – Presentation 2: <u>Environmental Risk Factors and Primary Sclerosing</u> <u>Cholangitis</u> John Eaton, MD, Assistant Professor of Medicine, Gastroenterology and Hepatology, Mayo Clinic Rochester
9:10 AM – 9:30 AM	General Session 1 – Presentation 3: <u>PSC and Genetic Factors</u> Tom Karlsen, MD, PhD, Professor of Internal Medicine, Oslo University Hospital Rikshospitalet
9:30 AM – 10:00 AM	Question and Answer Panel: Dr. Ponsioen, Dr. Eaton, Dr. Karlsen
10:00 AM – 10:30 AM	Break with Snacks Ballroom Foyer
10:30 AM – 12:00 PM	General Session 2: Managing PSC Moderators: Christoph Schramm, MD Professor, University Medical Center Hamburg-Eppendorf Kidist Yimam, MD, Director, Autoimmune Liver Disease Program California Pacific Medical Center, San Francisco, CA
10:30 AM – 10:50 AM	General Session 2 - Presentation 1: <u>Looking After Patients with PSC: The Big Picture</u> <u>Approach</u> Gideon Hirschfield, MD, Senior Lecturer/Consultant Transplant Hepatologist, University of Birmingham, PSC Partners Scientific/Medical Advisory Committee
10:50 AM – 11:10 AM	General Session 2 – Presentation 2: <u>Non-Invasive Assessment of PSC Progression</u> Olivier Chazouilleres, MD, Head of Hepatology Unit, Hospital Saint Antoine, Paris, France Coordinator of the Rare Liver Diseases French Network
11:10 AM – 11:30 AM	General Session 2 - Presentation 3: Endoscopic Management of PSC: Is ERCP Helpful? Mark Topazian, MD, Professor of Medicine, Mayo Clinic Rochester
11:30 AM – 12:00 PM	Question and Answer Panel: Dr. Hirschfield, Dr. Chazouilleres, Dr. Topazian
12:00 PM – 1:20 PM	Peer Group Sessions in Breakout RoomsPeer Groups:Teens/College Aged PSCers (Registered Attendees Depart for Outing. Take Box lunch.Meet in Lower Lobby)Female PSCers in their 20s/30s (George A Room)Male PSCers in their 20s/30 (George B Room)Female PSCers Group A (Chapel C Room)Female PSCers Group B (Chapel B Room)Male PSCers Group B (Chapel B Room)Male PSCers Group A (Ballroom C)Male PSCers Group B (Temple Room)Post-Transplant PSCers Group A & B (Ballroom A)Parents of Pediatric PSCers (17 and under) (Whalley Room)Parents of Young Adult PSCers (18-25 years old) Group A (Whitney Room)Parents of Young Adult PSCers (18-25 years old) Group B (Davenport Room on 19 th Floor)Parents of Adult PSCers (26 and up) Group A (Goffe Room)Parents of Adult PSCers (26 and up) Group B (Chapel A Room)Spouses/Partners/Caregivers of PSCers Group A & B (Ballroom B)Spouses/Partners/Caregivers of PSCers Group A & B (Ballroom B)Spouses/Partners/Caregivers of PSCers Group A (College A Room)Siblings and Other Caregivers of PSCers Group B (College B Room)Caregivers Coping with Loss & Carrying on the Spirit (Crown Room)
1:20 – 1:30 PM	Transition to General Session

1:30 PM – 4:15 PM	General Session 3: PSC and the Future Moderators: David Goldberg, MD, MSCE, Assistant Professor of	Omni Ballroom
	Medicine, Assistant Professor of Epidemiology, Medical Director of Living Donor Liver Transplantation, University of Pennsylvania	
	Cynthia Levy, MD , Associate Professor of Medicine, Division of Hepatology, University of Miami	
1:30 PM – 1:50 PM	General Session 3 – Presentation 1: Concepts and Key Issues Specific to PSC Transplant	
	Assessment and Planning Bertus Eksteen, MD, PhD, Clinical Associate Professor of	
	Medicine, University of Calgary, PSC Partners Scientific/Medical Advisory Committee	
1:50 PM – 2:10 PM	General Session 3 – Presentation 2:	
	New Paradigms for Transplant Surgery in PSC: MELD	
	and Living Donor Considerations David Mulligan, MD, Professor and Chief, Transplantation	
	and Immunology, Yale University and Yale-New Haven Hospital	
2:10 PM – 2:55 PM	Break with Snacks	Ballroom Foyer
2:45 PM	Teen/College Aged Outing Participants Return to Hotel	
2:55 PM – 3:15 PM	General Session 3 – Presentation 3:	Omni Ballroom
	<u>Seeking Treatments for PSC – Out of the Desert and</u> into the Woods	
	Christopher Bowlus, MD, Professor and Chief, Division	
	of Gastroenterology and Hepatology, University of	
	California Davis School of Medicine, PSC Partners	
2.45 DM 2.25 DM	Scientific/Medical Advisory Committee General Session 3 – Presentation 4:	
3:15 PM – 3:35 PM	Future Directions in PSC Research	
	Ulrich Beuers, MD, Professor of Gastroenterology and	
	Hepatology, Academic Medical Center, University of	
	Amsterdam	
3:35 PM – 4:15 PM	Question and Answer Panel: Dr. Eksteen, Dr. Mulligan, Dr. Bowlus, Dr. Beuers	
4:15 PM – 6:00 PM	Afternoon Sessions End – Time to Relax	
6:00 PM – 9:00 PM	International Dinner	Omni Ballroom
	Keynote Speech: Seeking Partnership Between PSC	
	Research and Patient Organizations Tom Karlsen, MD, PhD, Professor of Internal Medicine,	
	Oslo University Hospital Rikshospitalet	
9:00 PM – Midnight	Karaoke	
	SUNDAY, JUNE 26, 2016	
7:30 AM – 8:30 AM	Buffet Breakfast for PSC Partners Seeking a Cure and the International PSC Study Group Attendees	Omni Ballroom
8:30 AM – 10:00 AM	General Joint Session for PSC Partners Seeking a Cure and the International PSC Study Group Attendees	Omni Ballroom
8:30 AM	Welcome: Dr. James Boyer, Ensign Professor of Medicine, Emeritus Director of the Liver Center, Yale University School of Medicine	
8:35 AM – 10:00 AM	Joint Plenary Session:	Omni Ballroom
	Surrogate and Patient Reported Outcomes in PSC	
	Moderators Erik Schrumpf, MD, PhD Professor Emeritus, Oslo	
	University Hospital Rikshospitalet	
	Roger Chapman BSc, MBBS, MD, FRCP, MA	
	Consultant Emeritus, Oxford University Hospital	

8:35 AM – 8:50 AM	Joint Plenary Session – Presentation 1: <u>Patient Registries – Collaboration, Competition, or</u> <u>Confusion?</u> Christopher Bowlus, MD, Professor and Chief, Division of Gastroenterology and Hepatology, University of California Davis School of Medicine, PSC Partners Scientific/Medical Advisory Committee	
8:50 AM – 9:05 AM	Joint Plenary Session – Presentation 2: <u>Defining Surrogate Outcomes for PSC</u> Cyriel Y. Ponsioen, MD, PhD, Academic Medical Center, Amsterdam, Department of Gastroenterology and Hepatology, PSC Partners Scientific/Medical Advisory Committee	
9:05 AM – 9:20 AM	Joint Plenary Session – Presentation 3: Defining Value Based and Patient-Reported Outcomes in PSC David Assis, MD, Assistant Professor of Medicine Yale University School of Medicine, Section of Digestive Diseases and Yale Liver Center	
9:20 AM – 10:00 AM	Question and Answer Panel: Dr. Bowlus, Dr. Ponsioen, Dr. Assis	
10:00 AM – 10:30 AM	Informal coffee/snack discussion time: Physicians, Patients, Caregivers	Ballroom Foyer
10:30 AM	PSC Partners and IPSCSG split to continue individual programs	
10:30 AM – 11:50 AM	Peer Group Sessions in Breakout Rooms Peer Groups: Teens/College Aged PSCers (Wooster Room) Female PSCers in their 20s/30s (George A Room) Male PSCers in their 20s/30 (George B Room) Female PSCers Group A (Chapel C Room) Female PSCers Group B (Chapel B Room) Male PSCers Group B (Chapel B Room) Male PSCers Group A (Temple Room) Post-Transplant PSCers Group A & B (Ballroom A) Parents of Pediatric PSCers (17 and under) (Whalley Room) Parents of Pediatric PSCers (18-25 years old) Group A (Whitney Roo Parents of Young Adult PSCers (18-25 years old) Group B (Davenport Re Parents of Adult PSCers (26 and up) Group A (Goffe Room) Parents of Adult PSCers (26 and up) Group B (Chapel A Room) Spouses/Partners/Caregivers of PSCers Group A & B (Ballroom B) Spouses/Partners/Caregivers of PSCers Group A (College A Room) Siblings and Other Caregivers of PSCers Group B (College B Room) Caregivers Coping with Loss & Carrying on the Spirit (Crown Room)	oom on 19 th Floor)
11:50 AM – 12:00 PM	Break and move back to General Session	Omni Ballrooms A & B
12:00 PM – 1:00 PM	Feedback from Peer Sessions and Closing Remarks	Omni Ballrooms A & B

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