

## 2017 Conference, Cleveland, OH


SCHEDULE	SESSION	LOCATION
<b>THURSDAY, June 22, 2017</b>		
11:00 AM - 9:00 PM	Early Check-in for Attendees PSC Partners Conference Registration	3 <sup>rd</sup> Floor InterContinental Hotel (ICH)
11:00 AM - Midnight	Teen/Young Adult Lounge	2 <sup>nd</sup> Floor Six Continents Room
<b>Thursday – Sunday</b> (Please visit shop to see daily hours of operation)	PSC Partners' Shop	2 <sup>nd</sup> Floor Phillips Break Area
6:00 PM - 8:30 PM	Pre-Conference Event: Casual Get Together/Dinner Note: Tickets need to have been purchased IN ADVANCE	2 <sup>nd</sup> Floor Ballroom C
<b>FRIDAY, June 23, 2017</b>		
7:30 AM - 5:00 PM	Check-in/PSC Partners Registration	3 <sup>rd</sup> Floor ICH
8:00 AM – Midnight Friday - Sunday	Teen/Young Adult Lounge	1 <sup>st</sup> Floor Falcon Room & Study
8:00 AM	Buses load at InterContinental Hotel to travel to Brunch Walking Option allow 15-20 minutes	1 <sup>st</sup> Floor LOBBY ICH
8:30 AM - 11:30 AM Track Sponsor: Chris and Nicole Carlos and The McMurtry Family	Cleveland Botanical Garden (CBG) Brunch Event Mentor/Mentee Meet and Greet/Seating by Peer Group	CBG
11:15 AM	Buses load to return to InterContinental Hotel Walking Option allow 15-20 minutes	Entrance CBG
12:00 - 12:30 PM	Newcomer Orientation Moderators: Wes Hendrix and Jennifer Sims Board Members, PSC Partners Seeking a Cure	3 <sup>rd</sup> Floor AMPHITHEATER A&B
12:45 - 1:15 PM	<b>Friday Afternoon General Session for All Attendees</b>	
12:45 - 1:15 PM	<u>Preventive Medicine and PSC</u> Michael Roizen, MD Department of Preventive Medicine and Wellness Institute	3 <sup>rd</sup> Floor AMPHITHEATER A&B
1:15 - 1:30PM	Break and Transition to Afternoon Breakout Sessions	3 <sup>rd</sup> Floor Amphitheater Foyer
1:30 - 2:30 PM	<b>Friday Afternoon Breakout Session #1</b>	
The Basics of PSC (The Basics Track)	Carlos Romero-Marrero, MD, Chief of Hepatology, Department of Gastroenterology and Hepatology, Digestive Disease and Surgery Institute, Cleveland Clinic	2 <sup>nd</sup> Floor Six Continents Room
Track Sponsor:  DURECT		
Comparing Options: Cadaveric and Living Donor Liver Transplant (Transplant Track)	Moderator: Koji Hashimoto, MD, PhD, Transplantation Center, Department of General Surgery, Cleveland Clinic Panelists: Mahwish Ahmad, MD, MPH, Transplant Ethics Fellow, Center for Ethics, Humanities and Spiritual Care, Annette Humberson, LISW-S, CCTSW, Liver Transplant Team Social Worker, Donna Ferchill, RN, BSN, LDLT Transplant Coordinator	Room 207
Track Sponsor: Hatchett Family		

1:30 - 2:30 PM		Friday Afternoon Breakout Session #1
<b>Pediatric PSC and AIH/IBD: Navigating Social and Academic Relationships (Pediatric Track)</b> <b>Track Sponsor:</b> <b>John &amp; Chris Browner Family</b>	<b>Katherine Lamparyk, PsyD</b> Center for Pediatric Behavioral Health Cleveland Clinic	<b>Room 202</b>
<b>Interactive Session: T'ai Chi Chih (Caring for You Track)</b>  	<b>Cindy Dunn, FNAO</b> , Certified T'ai Chi Chih Instructor	<b>2<sup>nd</sup> Floor Ballroom B</b>
<b>Track Sponsor:</b>		
<b>Issues for Female PSCers in their 20s/30s</b>	<b>Moderator: Uma Perni, MD</b> , Department of Obstetrics and Gynecology, Division of Maternal-Fetal Medicine <b>Panelists: Elaine Bishop, MSN, CNM</b> , Fetal Care Coordinator, Department of Obstetrics and Gynecology, <b>Monika Aldarondo and Jennifer Sparks</b> , PSC Patients	<b>Room 205</b>
<b>IBD and PSC: Pre- and Post-Transplant Issues</b>	<b>Moderator: Kareem Abu-Elmagd, MD, PhD</b> , Director Cleveland Clinic Transplant Center <b>Panelists: Bo Shen, MD</b> , Department of Gastroenterology and Hepatology, <b>Tracy Hull, MD</b> , Surgical Section Chief, Section Chief, Inflammatory Bowel Disease, <b>Megan Costedio, MD, FACS</b> , Department of Colorectal Surgery, <b>Anthony DeRoss, MD, FACS, FAAP</b> , Department of Pediatric Surgery	<b>2<sup>nd</sup> Floor Ballroom C</b>
<b>PSC and Cholangiocarcinoma: Multidisciplinary Approach to Treatment (ERCP, Radiology Options, Surgery)</b>	<b>Moderator: K. V. Narayanan Menon, MD</b> , Medical Director of Liver Transplantation, Department of Gastroenterology and Hepatology, Cleveland Clinic <b>Panelists: Madhu Sanaka, MD</b> , Medical Director, Center for Advanced Endoscopy, Department of Gastroenterology and Hepatology, <b>Federico Aucejo, MD</b> Surgical Director, Liver Tumor Clinic, Liver Transplantation, Department of General Surgery, <b>Dustin Thompson, MD</b> , Department of Diagnostic Radiology	<b>2<sup>nd</sup> Floor Ballroom A</b>
<b>PSC Caregivers: Coping with the Stress of Living with PSC</b>	<b>Moderator: Wes Hendrix</b> , Caregiver <b>Panelists: Scott Bea, PsyD</b> , Department of Psychiatry and Psychology, <b>Sharon Nanz, Jennifer Sims, Caroline Vanneste</b> , Caregivers	<b>Room 204</b>
<b>Disability Benefits: What to Expect When You Can No Longer Work</b>	<b>Jeremy Burke, D.Mus., ALHC</b> , Senior Learning Consultant, Aetna Group Insurance	<b>Room 206</b>
<b>Is a Clinical Trial Right for Me?</b>	<b>Lisa Pedicone, PhD</b> , Executive Vice President, Clinical Affairs, Focus Medical Communications, Parent of a PSCer <b>Carol Burke, MD, FACP, FAGC, FASGE, AGAF</b> , Vice Chair, Department of Gastroenterology and Hepatology	<b>Room 201</b>
<b>Social Media Workshop</b>	<b>Clare McMillan</b> , PSC Partners, Director of Communications	<b>Room 203</b>
<b>2:30 - 3:00 PM</b>  <b>Snack Sponsor:</b> <b>The Sabernick Family</b>	<b>Break with Snacks</b> <b>Transition to Breakout Session #2</b>	<b>3<sup>rd</sup> Floor Amphitheater Foyer A &amp; B</b>

3:00 - 4:00 PM Friday Afternoon Breakout Session #2		
<b>Interpreting Your Test Results (The Basics Track)</b>  <b>Track Sponsor: DURECT</b>	<b>William Carey, MD, MACG</b> , Department of Gastroenterology and Hepatology, Cleveland Clinic	<b>Room 201</b>
<b>Post-Transplant Issues (Transplant Track)</b>  <b>Track Sponsor: Hatchett Family</b>	<b>Moderator: Bijan Eghtesad, MD, Liver Transplantation, Department of General Surgery</b> <b>Panelists: K. V. Narayanan Menon, MD</b> , Medical Director of Liver Transplantation, Department of Gastroenterology and Hepatology, Cleveland Clinic, <b>Jessica Bollinger, PharmD</b> , Liver Transplant Clinical Pharmacy Specialist, <b>April Waby, PA-C, Karen Kerepesi, PA-C</b> Liver Transplantation, Department of General Surgery, <b>Fred Sabernick, John Crowley, Jeanne Heys</b> , Post-Transplant PSC Patients	<b>Room 207</b>
<b>Pre-Transplant Considerations (Transplant Track)</b>  <b>Track Sponsor: Hatchett Family</b>	<b>Moderators: Annette Humberson LISW-S, CCTSW</b> , Liver Transplant Team Social Worker, and <b>Donna Ferchill, RN, BSN</b> , Liver Transplant Coordinator, <b>Panelists: Joanne Grieme</b> , Caregiver, <b>Tom Davenport</b> , and <b>Tawny Blum</b> , PSC Post-Transplant Patients	<b>2<sup>nd</sup> Floor Six Continents</b>
<b>Medical Issues for Pediatric PSCers, Including Transition to Adult Care (Pediatric Track)</b>  <b>Track Sponsor: John &amp; Chris Browner Family</b>	<b>Moderator: Barbara Kaplan, MD</b> , Pediatric Gastroenterology <b>Panelists: Vera Hupertz, MD</b> , Pediatric Medical Director of Hepatology and Liver Transplantation and <b>Kadakkal Radhakrishnan, MD, MRCP, MRCPCH, FAP</b> , Pediatric Hepatology and Gastroenterology, <b>Bette Klein, MS, RD, CSP, LD</b> , Advanced Practice Pediatric Nutrition Support Dietitian	<b>Room 206</b>
<b>Mindfulness and Meditation (Caring for You Track)</b>  <b>Track Sponsor:</b>	<b>Ashley Neuman, PCC-S</b> , Wellness Enterprises Account Executive	<b>Room 203</b>
<b>Current State of Liver Stem Cells/ Regenerative Medicine Research: An Update and Implications</b>	<b>Natesh Parashurama, MD, PhD</b> Assistant Professor, University at Buffalo, Schools of Engineering and Medicine, Department of Chemical and Biological Engineering and Department of Medicine	<b>2<sup>nd</sup> Floor Ballroom A</b>
<b>Financial Planning for PSC Families</b>	<b>Stu Barnett, AAMS</b> , Charles Schwab and Co., Inc., PSC Patient, <b>Joe Iannucci</b> , Finance Manager, Digestive Disease Institute, Cleveland Clinic	<b>Room 202</b>
<b>PSC Patients: Coping with the Stress of Living with PSC</b>	<b>Moderator: Tim Wholey</b> , PSC Patient <b>Panelists: Scott Bea, PsyD</b> Department of Psychiatry and Psychology, <b>Travis Stoltzfus, Linda Waters</b> , PSC Patients	<b>Room 204</b>
<b>Traditional and Complementary Drug Therapies for PSC and IBD</b>	<b>Bo Shen, MD</b> , and <b>Anne Feldman, CNP</b> , Department of Gastroenterology and Hepatology	<b>2<sup>nd</sup> Floor Ballroom B</b>
<b>Teens: Every Question Is Fair Game – PSC Patient Q&amp;A (Session for Teen PSCers Only)</b>	<b>Lori Mahajan, MD</b> , Department of Pediatric Gastroenterology and <b>Jessica Philpott, MD, PhD</b> , Department of Gastroenterology and Hepatology	<b>2<sup>nd</sup> Floor Ballroom C</b>
<b>4:00 - 5:30 PM Afternoon Sessions End – Time to Relax</b>		
<b>5:30 - 8:30 PM</b>	<b>Welcome Dinner</b> <b>Dinner Sponsor: Gomel, Safer and Shepherd Families</b>	<b>2nd Floor Ballroom C</b>
<b>8:30 - 9:30 PM</b>	<b>PSC Partners Canada Group Meeting</b> All Canadians Welcome	<b>Six Continents Room</b>

**SATURDAY, June 24, 2017**

<b>7:30 AM – 3:00 PM</b>	<b>Check-in / Speakers and Attendees</b>	<b>3<sup>rd</sup> Floor ICH</b>
<b>7:30 - 8:15 AM</b>	<b>Buffet Breakfast</b>	<b>2<sup>nd</sup> Floor Ballroom C</b>
	<b>Breakfast Sponsor:</b> <b>Intercept</b>	
<b>8:30 - 8:45 AM</b>	<b>Welcome and Opening Remarks for General Session</b> Don and Ricky Safer, PSC Partners Seeking a Cure	<b>AMPHITHEATER A&amp;B</b>
<b>8:45 - 10:15 AM</b>	<b>Saturday General Session I</b> <b>Moderator: Bijan Eghtesad, MD</b> , Liver Transplantation, Department of General Surgery	<b>AMPHITHEATER A&amp;B</b>
<b>8:45 - 9:05</b>	<b>General Session 1 - Presentation 1</b> <b><u>Management of PSC Symptoms</u></b> Pruritus/ Dermatology - <b>Alok Viji, MD</b> Insomnia/ Sleep Disorders - <b>Harneet Walia, MD, FAASM</b> Director of Behavioral Medicine, Digestive Disease Institute	
<b>9:05 - 9:25 AM</b>	<b>General Session I - Presentation 2</b> <b><u>Intervention in PSC: Perspectives from ERCP Provider</u></b> <b>Sunguk Jang, MD</b> , Staff Physician in Department of Gastroenterology and Hepatology, Cleveland Clinic	
<b>9:25 - 9:45 AM</b>	<b>General Session I - Presentation 3</b> <b><u>How to Communicate Effectively with your Physician</u></b> <b>Carol Santalucia</b> , Director of Patient Experience	
<b>9:45 - 10:15 AM</b>	<b>Question and Answer Panel from Session I</b> <b>Moderator: Bijan Eghtesad, MD</b> , Liver Transplantation, Department of General Surgery <b>Panelists:</b> Speakers from presentations in General Session I	
<b>10:15 - 10:45 AM</b>	<b>Break with Snacks</b>	<b>3<sup>rd</sup> Floor Amphitheater Foyer A &amp; B</b>
	<b>Snack Sponsor:</b> <b>The Poletto Family</b>	
<b>10:45 - 12:15 PM</b>	<b>Saturday General Session II</b> <b>Moderator: William Carey, MD, MACG</b> , Department of Gastroenterology and Hepatology	<b>AMPHITHEATER A&amp;B</b>
<b>10:45 - 11:05 AM</b>	<b>General Session II - Presentation 1</b> <b><u>Bone Health and Maintaining Fitness</u></b> <b>Mathilde Pioro, MD</b> , Department of Rheumatologic and Immunologic Disease	
<b>11:05 - 11:25 AM</b>	<b>General Session II - Presentation 2</b> <b><u>Nutrition and PSC</u></b> <b>Srinivasan Dasarathy, MD</b> , Department of Gastroenterology and Hepatology	
<b>11:25 - 11:45 AM</b>	<b>General Session II - Presentation 3</b> <b><u>Fecal Microbiota Transplantation for IBD</u></b> <b>Bret Lashner, MD, MPH</b> , Inflammatory Bowel Disease Center Department of Gastroenterology and Hepatology	
<b>11:45 - 12:15 PM</b>	<b>Question and Answer Panel from Session II</b> <b>Moderator: William Carey, MD, MACG</b> , Department of Gastroenterology and Hepatology <b>Panelists:</b> Speakers from presentations in General Session II	

12:15 PM - 1:45 PM	Lunch - Box Lunches Available Take to Peer Groups in Breakout Rooms	3rd Floor Amphitheater Foyer A & B
<b>Lunch Sponsor:</b> 		
12:15 PM - 1:45 PM	<b>Peer Lunch Groups</b>	<b>Meeting Room</b>
Teen PSCers		Room 201
Female PSCers in their 20s/30s		Falcon Study - Lobby Level
Male PSCers in their 20s/30s		Falcon Room - Lobby Level
Female PSCers Groups A & B		Carnegie Foyer - 3rd Floor
Male PSCers Group A		Room 202
Male PSCers Group B		Room 203
Post-Transplant PSCers Groups A & B		Ballroom A - 2 <sup>nd</sup> Floor
Parents of Pediatric PSCers (17 and under)		Room 207
Parents of Young Adult PSCers (18-25 years old) Groups A & B		Six Continents Room 2 <sup>nd</sup> Floor
Parents of Adult PSCers (26 and up) Groups A, B & C		Ballroom C - 2 <sup>nd</sup> Floor
Spouses/Partners/Caregivers of PSCers Groups A & B		Ballroom B - 2 <sup>nd</sup> Floor
Spouses/Partners/Caregivers of PSCers Group C		Room 206
Siblings and Other Caregivers of PSCers		Room 204
Caregivers Coping with Loss & Carrying on the Spirit		Room 205
12:15 PM	Teen/College Outing Participants Depart	Meet in lobby
1:45 - 2:00 PM	<b>Break - Transition to General Session III</b>	
2:00 - 2:45 PM	<b>General Session III – Round 1</b> Moderator: Ricky Safer CEO, PSC Partners Seeking a Cure	<b>AMPHITHEATER A&amp;B</b>
2:00 - 2:20 PM	<b>General Session III - Presentation 1</b> <u>PSC Partners - Sponsored International Research</u> Christopher Bowlus, MD, UC Davis, Co-Chair PSC Partners Scientific Medical Advisory Committee, Presenting PSC Partners Seeking a Cure Programs, Research Grants and Patient Registry	
2:20 - 2:30 PM	<b>General Session III - Presentation 2</b> <u>The Forum Collaboration Model: Unique Opportunity in PSC</u> Veronica Miller, PhD, Executive Director, Forum for Collaborative Research, Senior Researcher/Lecturer, UC Berkeley SPH	
2:30 - 2:45 PM	<b>Question and Answer Panel, Round 1 from Session III</b> Moderator: Ricky Safer, CEO, PSC Partners Seeking a Cure Panelists: Speakers from presentations in General Session III	
2:45 - 3:45 PM	<b>General Session III – Round 2</b> Moderator: Narayanan Menon, MD, Medical Director of Liver Transplantation, Department of Gastroenterology and Hepatology Panelists: Speakers from presentations in General Session III	
2:45 - 3:05 PM	<b>General Session III - Presentation 3</b> <u>MELD and UNOS</u> UNOS Perspective - Donna Ferchill, RN, BSN, Transplant Coordinator, Cleveland Clinic, Julie Plescia, RN, Procurement and Preservation Clinical Manager at Lifebanc <b>General Session III (continued)</b>	
2:45 PM	Teen Outing Participants Return to InterContinental Hotel	
3:05 - 3:25 PM	<b>General Session III - Presentation 4</b> <u>Functional Medicine: A Different Perspective for Patients</u> Aunna Herbst, DO, Center for Functional Medicine <b>Saturday General Session III (continued)</b>	

<b>3:25 - 3:45 PM</b>	<b>Question and Answer Panel, Round 2 from Session III</b> <b>Moderator: Narayanan Menon, MD</b> , Medical Director of Liver Transplantation, Department of Gastroenterology and Hepatology <b>Panelists:</b> Speakers from presentations in General Session III	
<b>3:45 - 6:00 PM</b>	<b>Afternoon Sessions End – Time to Relax</b>	
<b>6:00 - 9:00 PM</b> <b>Banquet Sponsor:</b> 	<b>Banquet Dinner</b> <b>Rock &amp; Roll Theme</b>	<b>2<sup>nd</sup> Floor</b> <b>Ballroom C</b>
<b>9:00 PM - Midnight</b>	<b>Karaoke</b>  <b>Karaoke Community Sponsor:</b> <b>Cleveland Meeting of the Religious Society of Friends</b>	<b>2<sup>nd</sup> Floor</b> <b>Ballroom C</b>
<b>SUNDAY June 25, 2017</b>		
<b>7:30 - 8:30 AM</b>	<b>Buffet Breakfast</b>	<b>2<sup>nd</sup> Floor</b> <b>Ballroom C</b>
<b>8:30 - 8:45 AM</b>	<b>General Session - PSC Partners Organizational Report</b> General Announcements and Updates	<b>2<sup>nd</sup> Floor</b> <b>Ballroom C</b>
<b>8:45 - 9:00 AM</b>	<b>Break - Transition to Peer Group Sessions</b>	
<b>9:00 - 11:15 AM</b>	<b>Peer Group Sessions in Breakout Rooms</b>	
	<b>Peer Groups</b>	<b>Meeting Room</b>
	Teen PSCers	Room 201
	Female PSCers in their 20s/30s	Falcon Study - Lobby Level
	Male PSCers in their 20s/30s	Falcon Room - Lobby Level
	Female PSCers Groups A & B	Carnegie Foyer - 3rd Floor
	Male PSCers Group A	Room 202
	Male PSCers Group B	Room 203
	Post-Transplant PSCers Groups A & B	Ballroom A - 2 <sup>nd</sup> Floor
	Parents of Pediatric PSCers (17 and under)	Room 207
	Parents of Young Adult PSCers (18-25 years old) Groups A & B	Six Continents Room 2 <sup>nd</sup> Floor
	Parents of Adult PSCers (26 and up) Groups A, B & C	Amphitheater Foyer - 3 <sup>rd</sup> Floor
	Spouses/Partners/Caregivers of PSCers Groups A & B	Ballroom B - 2 <sup>nd</sup> Floor
	Spouses/Partners/Caregivers of PSCers Group C	Room 206
	Siblings and Other Caregivers of PSCers	Room 204
	Caregivers Coping with Loss & Carrying on the Spirit	Room 205
<b>11:15 - 11:45 PM</b>	<b>Break with Snacks</b>  <b>Snack Sponsor:</b> <b>Jason and Jennifer Drasner</b>	<b>2<sup>nd</sup> Floor</b> <b>Ballroom Foyer</b>
<b>11:45 - 1:00 PM</b>	<b>Feedback from Peer Sessions and Closing Remarks</b>	<b>Ballroom C</b>
<b>1:00 PM</b>	<b>ADJOURN</b>	

## Long Term Premier Partner



## Patron Partner



## Champion Partner

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## Sustaining Partner

The Blatt Family  
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DURECT

The Gomel Family  
Grover/Wente Families  
The Hatchett Family



The Safer Family  
The Shepherd Family

## Supporting Partner

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The Poletto Family  
The Sabernick Family  
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## Community Partner

The Budjinski Family  
The Belmont Family  
Tim & Monica Campbell  
The Foreman Family  
The Grieme/Clouser Family  
The Holmgren Family  
The Litton Family  
The Pearlman Family  
Mary & Jay Vyas

## Karaoke Partner

Cleveland Meeting of the Religious Society of Friends (Quakers)

## Non-Profit Partner

American Liver Foundation  
Cure for IBD  
Thrivent