

2019 Conference, Rochester, MN All breakout and general sessions will take place at the Mayo Civic Center

	Thursday, June 20, 2019	
TIME/SESSION	DESCRIPTION/SPEAKER	LOCATION
11:00 AM - 9:00 PM	Early Check-in for Attendees PSC Partners Conference Registration	Mayo Civic Cente Grand Lobby
12:00 PM - 6:00 PM Sponsor: Kimberly Brosamer	Conference Information Desk (Thursday PM Only) Teen/Young Adult Lounge (Thursday through Sunday Evenings)	Kahler Grand Hote Centennial Roon
Thursday – Sunday	PSC Partners' Shop (Please visit shop to see daily hours of operation)	Mayo Civic Cente Suite 10
6:00 PM - 8:30 PM Sponsor: The Gomel Family	Pre-Conference Event: Casual Get Together/Dinner NOTE: Tickets are not included in the conference registration fee and must have been pre-purchased	Rochester Art Cente 40 Civic Center Dr, St Rochester, MN
	Friday, June 21, 2019	
TIME/SESSION	DESCRIPTION/SPEAKER	LOCATION
7:30 AM - 5:00 PM	Check-in/Conference Registration	Mayo Civic Cente Grand Lobb
7:30 AM - 8:30 AM Sponsor: Kenneth S. Hollander Charitable Foundation	Breakfast at the Kahler Grand Hotel	Kahler Grand Hote Heritage Hall II & I
8:30 AM - 9:00 AM	Walk to Mayo Civic Center 30 Civic Center Dr., SE Rochester, MN 55904	
9:00 AM - 9:30 AM	Newcomer Orientation Moderators: Travis Stoltzfus and Jennifer Sims Board Members, PSC Partners Seeking a Cure	Mayo Civic Cente Auditoriun
9:30 AM - 9:45 AM	Conference Welcome and Introductory Remarks	Mayo Civic Cente Auditoriur
9:45 AM - 10:00 AM	Transition to Breakout Session I	
10:00 AM - 11:00 AM	Friday Morning Breakout Session I	
TIME/SESSION	DESCRIPTION/SPEAKER	LOCATIO
The Basics of PSC (The Basics Track) Track Sponsor: The Hatchett Family	Robert C. Huebert, M.D., Mayo Clinic	Mayo Civic Cente Suite 10
Liver Transplantation for PSC in 2019 (Transplant Track) Track Sponsor: The Sabernick Family	Julie K. Heimbach, M.D., Mayo Clinic	Mayo Civic Cente Suite 10
Raising Kids with PSC: The Medical Side of Pediatric PSC and Transitioning from Pediatric to Adult Care (Pediatric Track) Track Sponsor: John & Chris Browner	Mounif El-Youssef, M.D., Mayo Clinic Dilshad Kassam-Lallani, BSN, MN, NP-PHC, Nurse Practitioner, Holland-Bloorview Kids Rehabilitation Hospital/University of Toronto, Parent of Post-Transition PSCer Afsana Lallani, Post-Transition PSCer	Mayo Civic Cente Riverview /
T'ai Chi Chih for PSC Patients and Caregivers (Caring for You Track) Track Sponsor: Grover & Wente Families 6/11/2019	Cindy Dunn, FNAO, Certified T'ai Chi Chih Instructor	Mayo Civic Cente Riverview D

TIME/SESSION	DESCRIPTION/SPEAKER	LOCATION
Complementary Medicine for PSC	Matthew A. Bartlett, M.B., B.Ch., B.A.O., Mayo Clinic	Mayo Civic Center Suite 104
Navigating Medical Insurance	Randy Oates, Chief Operating Office, IronHealth (Retired), PSC Patient	Mayo Civic Center Riverview C1
Liver Cirrhosis in PSC: Diagnosis and Management	Douglas A. Simonetto, M.D., Mayo Clinic	Mayo Civic Center Riverview B
PSC Caregivers: The Stresses and Rewards of Being a Caregiver	Jerome Schofferman, M.D., Post-Transplant PSC Patient Sally Holland, PhD, PSC Caregiver	Mayo Civic Center Suite 101
Clinical Trials in PSC: A to Z	John E. Eaton, M.D., Mayo Clinic Lisa Pedicone, PhD, Executive Vice President, Clinical Affairs, Focus Medical Communications, Parent of a PSCer	Mayo Civic Center Auditorium
IBD: A Comorbidity of PSC	Laura E. Raffals, M.D., Mayo Clinic	Mayo Civic Center Suite 105
Learning About PSC in the Era of Social Media	Konstantinos N. Lazaridis, M.D., Mayo Clinic Sumera H. Rizvi, M.B.B.S., Mayo Clinic	Mayo Civic Center Edith Graham Mayo Board Room
PSC and Healthy Bones	Angela Cheung, M.D., Mayo Clinic	Mayo Civic Center Suite 106
11:00 AM - 11:15 AM	Break with Mentor/Mentee Introductions Before Lunch	
11:15 AM - 12:45 PM Sponsor: William Bandy & Mary Jo Jordan	Lunch with Peers and Mentors	Mayo Civic Center Auditorium
12:45 PM - 1:00 PM	Break and Transition to Breakout Session II	
1:00 PM - 2:00 PM	Friday Afternoon Breakout Session II	
TIME/SESSION	DESCRIPTION/SPEAKER	LOCATION
Understanding Your Test Results (The Basics Track) Track Sponsor: The Hatchett Family	Andrea A. Gossard, APRN, C.N.P., Mayo Clinic	Mayo Civic Center Suite 103
Care After Liver Transplant (Transplant Track) Track Sponsor: The Sabernick Family	Tammy M. Kremers, APRN, C.N.P., Mayo Clinic	Mayo Civic Center Suite 105
Raising Kids with PSC: The Social Side (Pediatric Track) Track Sponsor: John & Chris Browner	Mounif El-Youssef, M.D., Mayo Clinic	Mayo Civic Center Riverview A
Mindfulness, the Path to Now (Caring for You Track) Track Sponsor: Stuart and Debra Barnett	Michael Dunn, OD, Optometrist	Mayo Civic Center Riverview D1
Teens Q&A: Every Question is Fair Game (For Teens Only)	Angela Cheung, M.D., Mayo Clinic	Mayo Civic Center Suite 106
Why Everyone Needs an Estate Plan	Stu Barnett, AAMS®, CFP®, VP-Sr., CERTIFIED FINANCIAL PLANNER™, Charles Schwab and Co., Inc., PSC Patient	Mayo Civic Center Suite 108
PSC Patients: Coping with the Stress of Living with PSC	Jerome Schofferman, M.D., Post-Transplant PSC Patient	Mayo Civic Center Suite 101

TIME/SESSION	DESCRIPTION/SPEAKER	LOCATION
PSC and IBD: Women's Health Issues	Laura E. Raffals, M.D., Mayo Clinic (IBD) Alina M. Allen, M.D., Mayo Clinic (PSC)	Mayo Civic Center Suite 109
Everything You Want to Know About Cholangiocarcinoma in PSC	Gregory J. Gores, M.D., Mayo Clinic	Mayo Civic Center Suite 102
ERCP for the Diagnosis and Management of PSC	Vinay Chandrasekhara, M.D., Mayo Clinic	Mayo Civic Center Suite 104
Couples Coping with PSC	Moderators: Richard and Jeanne Heys <u>Panelists</u> : Drew and Cari Buckley	Mayo Civic Center Suite 110
Doctor, What's Gonna Happen to Me? History of PSC Care	Nicholas F. LaRusso, M.D., Mayo Clinic	Mayo Civic Center Auditorium
2:00 PM - 2:15 PM	Break and Transition to General Session	
2:15 - 3:45 PM GENERAL SESSION Stress Management and Resiliency Training (SMART)	Amit Sood, M.D. Mayo Clinic	Mayo Civic Center Auditorium
3:45 PM - 6:00 PM	Afternoon Sessions End – Time to Relax	
6:00 PM - 8:30 PM Sponsor: The McMurtry Family	Welcome Dinner	Mayo Civic Center Auditorium
8:30 PM - 9:30 PM	PSC Partners Canada Group Meeting All Canadians Welcome	Mayo Civic Center Suite 104

Saturday, June 22, 2019 All Saturday Events at Mayo Civic Center Auditorium, Unless Indicated		
TIME/SESSION	DESCRIPTION/SPEAKER	LOCATION
7:15 AM – 3:00 PM	Check-in for Speakers / Registration	Mayo Civic Center Grand Lobby
7:15 AM - 8:15 AM Sponsor: The Litton Family	Buffet Breakfast	Mayo Civic Center Auditorium
8:15 AM - 8:30 AM Welcome and Opening Remarks	Don and Ricky Safer PSC Partners Seeking a Cure	
	Konstantinos N. Lazaridis, M.D., Mayo Clinic General Session I	
8:30 AM – 10:00 AM	Genes, Environment, and Animal Models in the I PSC	Pathogenesis of
8:30 AM – 10:00 AM	Moderator: Robert C. Huebert, M.D., Mayo Clinic	
8:30 AM – 8:50 AM Genes and Environment in PSC	Presentation 1 Konstantinos N. Lazaridis, M.D., Mayo Clinic	
8:50 AM – 9:10 AM Animal Models in PSC	Presentation 2 Gregory J. Gores, M.D., Mayo Clinic	
9:10 AM - 9:30 AM Nutrition for PSC/IBD Patients	Presentation 3 Nickie M. Francisco Ziller, R.D.N., L.D., Mayo Clinic	
9:30 AM – 10:00 AM Question and Answer Panel from Session I	Moderator: Robert C. Huebert, M.D., Mayo Clinic <u>Panelists</u> : Speakers from presentations in General S	Session I
10:00 AM - 10:30 AM Snack Sponsor: The Belmont Family	Break with Snacks	
10:15 AM	Teens and College-Aged Participants Leave for Outing	

TIME/SESSION	DESCRIPTION/SPEAKER LOCATION
10:30 AM – 12:00 PM	General Session II PSC Management
10:30 AM – 12:00 PM	Moderator: John E. Eaton, M.D., Mayo Clinic
10:30 AM – 10:50 AM Management of PSC and Quality of Life	Presentation 1 David N. Assis, M.D., Yale University
10:50 AM – 11:10 AM Liver Transplantation & Organ Allocation in 2019	Presentation 2 Julie K. Heimbach M.D., Mayo Clinic
11:10 AM - 11:30 AM PSC Myth Busters	Presentation 3 Aliya F. Gulamhusein, M.D., MPH Toronto General Hospital
11:30 AM – 12:00 PM Question and Answer Panel from Session II	Moderator: John E. Eaton, M.D., Mayo Clinic Panelists: Speakers from presentations in General Session II
12:00 PM – 1:30 PM Lunch Sponsors: In Memory of Aubrey Goldstein and The Safer Family	Box Lunch with Peer Groups in Breakout Rooms Box lunches and beverages will be available. Pick up your lunch and proceed to the location of your peer group lunch. Maps and volunteers are available to assist you with finding your room for lunch.
	See the back of your nametag to confirm your peer group assignment.
Peer Groups	Lunch Room
Teen PSCers (On Outing)	
Female PSCers in their 20s/30s	Suite 114
Male PSCers in their 20s/30s	Suite 113
	- • • • • • • • • • • • • • • • • • • •
•	Suite 111
Female PSCers Group B	Suite 112
Female PSCers Group B Male PSCers Group A	Suite 112 Suite 103
Female PSCers Group B Male PSCers Group A Male PSCers Group B	Suite 112 Suite 103 Suite 104
Female PSCers Group B Male PSCers Group A Male PSCers Group B Female Post-Transplant PSCers Group A	Suite 112 Suite 103 Suite 104 Riverview C1
Female PSCers Group B Male PSCers Group A Male PSCers Group B Female Post-Transplant PSCers Group A Male Post-Transplant PSCers Group B	Suite 112 Suite 103 Suite 104 Riverview C1 Riverview C2
Female PSCers Group B Male PSCers Group A Male PSCers Group B Female Post-Transplant PSCers Group A Male Post-Transplant PSCers Group B Parents of Pediatric PSCers (17 and under)	Suite 112 Suite 103 Suite 104 Riverview C1 Riverview C2 Edith Graham Mayo Board Room
Female PSCers Group B Male PSCers Group A Male PSCers Group B Female Post-Transplant PSCers Group A Male Post-Transplant PSCers Group B Parents of Pediatric PSCers (17 and under) Parents of Young Adult PSCers (18-25) Group A	Suite 112 Suite 103 Suite 104 Riverview C1 Riverview C2 Edith Graham Mayo Board Room Riverview A
Female PSCers Group B Male PSCers Group A Male PSCers Group B Female Post-Transplant PSCers Group A Male Post-Transplant PSCers Group B Parents of Pediatric PSCers (17 and under) Parents of Young Adult PSCers (18-25) Group B Parents of Young Adult PSCers (18-25) Group B	Suite 112 Suite 103 Suite 104 Riverview C1 Riverview C2 Edith Graham Mayo Board Room Riverview A Riverview B
Female PSCers Group B Male PSCers Group A Male PSCers Group B Female Post-Transplant PSCers Group A Male Post-Transplant PSCers Group B Parents of Pediatric PSCers (17 and under) Parents of Young Adult PSCers (18-25) Group A Parents of Young Adult PSCers (18-25) Group B Parents of Adult PSCers (26 and up) Group A	Suite 112 Suite 103 Suite 104 Riverview C1 Riverview C2 Edith Graham Mayo Board Room Riverview A Riverview B
Female PSCers Group B Male PSCers Group A Male PSCers Group B Female Post-Transplant PSCers Group A Male Post-Transplant PSCers Group B Parents of Pediatric PSCers (17 and under) Parents of Young Adult PSCers (18-25) Group A Parents of Young Adult PSCers (18-25) Group B Parents of Adult PSCers (26 and up) Group A Parents of Adult PSCers (26 and up) Group B	Suite 112 Suite 103 Suite 104 Riverview C1 Riverview C2 Edith Graham Mayo Board Room Riverview A Riverview B Suite 101 Suite 102
Female PSCers Group B Male PSCers Group A Male PSCers Group B Female Post-Transplant PSCers Group A Male Post-Transplant PSCers Group B Parents of Pediatric PSCers (17 and under) Parents of Young Adult PSCers (18-25) Group A Parents of Young Adult PSCers (18-25) Group B Parents of Adult PSCers (26 and up) Group A Parents of Adult PSCers (26 and up) Group B Spouses/Partners/Caregivers of PSCers Group A	Suite 112 Suite 103 Suite 104 Riverview C1 Riverview C2 Edith Graham Mayo Board Room Riverview A Riverview B Suite 101 Suite 102
Male PSCers Group A Male PSCers Group B Female Post-Transplant PSCers Group A Male Post-Transplant PSCers Group B	Suite 112 Suite 103 Suite 104 Riverview C1 Riverview C2 Edith Graham Mayo Board Room Riverview A Riverview B Suite 101 Suite 102 Suite 105 Suite 106
Female PSCers Group B Male PSCers Group A Male PSCers Group B Female Post-Transplant PSCers Group A Male Post-Transplant PSCers Group B Parents of Pediatric PSCers (17 and under) Parents of Young Adult PSCers (18-25) Group A Parents of Young Adult PSCers (18-25) Group B Parents of Adult PSCers (26 and up) Group A Parents of Adult PSCers (26 and up) Group B Spouses/Partners/Caregivers of PSCers Group B Spouses/Partners/Caregivers of PSCers Group B	Suite 112 Suite 103 Suite 104 Riverview C1 Riverview C2 Edith Graham Mayo Board Room Riverview A Riverview B Suite 101 Suite 102 Suite 105 Suite 106 Suite 108
Female PSCers Group B Male PSCers Group A Male PSCers Group B Female Post-Transplant PSCers Group A Male Post-Transplant PSCers Group B Parents of Pediatric PSCers (17 and under) Parents of Young Adult PSCers (18-25) Group A Parents of Young Adult PSCers (18-25) Group B Parents of Adult PSCers (26 and up) Group A Parents of Adult PSCers (26 and up) Group B Spouses/Partners/Caregivers of PSCers Group E Spouses/Partners/Caregivers of PSCers Group C	Suite 112 Suite 103 Suite 104 Riverview C1 Riverview C2 Edith Graham Mayo Board Room Riverview A Riverview B Suite 101 Suite 102 Suite 105 Suite 106 Suite 108

1:30 PM – 1:45 PM	Break and Transition to General Session	Mayo Civic Center

Suite 110

1:45 PM Teen and College-Aged Participants Return

Corporate and Medical Professionals

1:45 PM – 4:15 PM	General Session III	
	Future Therapies & Directions	Auditorium

1:45 PM – 4-15 PM	General Session III	
1:45 PM – 4:15 PM	Moderator: Konstantinos N. Lazaridis, M.D.,	Auditorium
General Session III	Mayo Clinic	Auditorium
1:45 PM – 2:05 PM	Presentation 1	
Biomarkers & Imaging	John E. Eaton M.D., Mayo Clinic	
2:05 PM - 2:25 PM	Presentation 2	
Landscape of Clinical Trials	Keith D. Lindor, M.D., Arizona State University	
2:25 PM – 2:45 PM PSC Partners Supported Research	Presentation 3	
•	David N. Assis, M.D., Yale University Presentation 4	
2:45 PM - 3:05 PM	Veronica Miller, Ph.D., UC Berkeley School of Publ	ic Health, UCDC
PSC Forum: Updates and	Campus Professor (Adjunct) Division of Infectious I	
Future Directions	Vaccinology, Executive Director, Forum for Collabo	
3:05 PM - 3:25 PM	Presentation 5	
PSC 10 Year Forecast	Konstantinos N. Lazaridis, M.D. Mayo Clinic	
	Moderator: Konstantinos N. Lazaridis, M.D.,	
3:25 PM - 4:15 PM	Mayo Clinic	
Question and Answer Panel from Session III	Panelists: Speakers from presentations in	
	General Session III	
4:15 PM - 6:00 PM	Afternoon Sessions End – Time to Relax	
6:00 PM - 9:00 PM	Banquet Dinner	Mayo Civic Center
Banquet Sponsor: The Parry Family	Theme: Camping	Auditorium
9:00 PM - Midnight	Karaoke and Photo Booth	Auditorium
Karaoke Sponsor: Jay and Mary Vyas	Naraoke and Frioto Booti	Additorium
	Sunday, June 23, 2019	
	- Canaay, Sanc 20, 2013	
TIME/SESSION	DESCRIPTION/SPEAKER	LOCATION
7:30 AM - 8:30 AM	Buffet Breakfast	Mayo Civic Center
Sponsor: The Shepherd Family	Builet Breaklast	Auditorium
8:30 AM - 8:45 AM	General Session	Mayo Civic Center
General Announcements	Moderators: Don and Ricky Safer	Auditorium
8:45 AM - 9:00 AM	Break - Transition to Peer Group Sessions	
9:00 AM – 11:15 AM	Peer Group Sessions in Breakout Rooms. Peer ses	ssions will be held in
9:00 AW = 11:15 AW	the same rooms and locations as the Saturday lunc	:h.
Peer Groups		Meeting Room
Teen PSCers		Riverview E
Female PSCers in their 20s/30s		Suite 114
Male PSCers in their 20s/30s		Suite 113
Female PSCers Group A		Suite 111
Female PSCers Group B		Suite 112
Male PSCers Group A		Suite 103
Male PSCers Group B		Suite 104
Female Post-Transplant PSCers Group A		Riverview C1
Male Post-Transplant PSCers Group B		Riverview C2
Parents of Pediatric PSCers (17 and under)		nam Mayo Board Room
Parents of Young Adult PSCers (18-25) Group A		Riverview A
Parents of Young Adult PSCers (18-25) Group E	3	Riverview B
Parents of Adult PSCers (26 & up) Group A		Suite 101
Parents of Adult PSCer (26 & up) Group B	Λ	Suite 102
Spouses/Partners/Caregivers of PSCers Group		Suite 105
Spouses/Partners/Caregivers of PSCers Group		Suite 106
Spouses/Partners/Caregivers of PSCers Group		Suite 108
Spouses/Partners/Caregivers of PSCers Group Siblings and Other Caregivers of PSCers	U	Suite 109 Riverview D1
Sibilings and Other Caregivers of PSCers		Kiverview DT

11:15 AM - 11:45 AM

Sponsors: Randall and Catherine Oates

The Kerdman Family

11:45 AM - 1:00 PM

1:00 PM

Feedback from Peer Sessions and Closing Remarks

Conference Adjourns

Mayo Civic Center Auditorium

Thank You To In-Kind Donors!

The Belmont Family
Tim and Monica Campbell
The Halloran Family





PLEASE REMEMBER TO SPREAD THE WORD TO MEDICAL PROVIDERS ABOUT THE NEW ICD-10-CM CODE FOR PSC.

Using this disease-specific code facilitates accurate tracking of PSC statistics, which will advance research into enhanced treatments, and, eventually, lead to the discovery of a cure for PSC.

Thank you!



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