



THURSDAY, JUNE 2, 2022

Times listed are Mountain Daylight Time

5:00-6:00 PM Social Gathering, TBD

6:00-7:00 PM Peer Groups

FRIDAY, JUNE 3, 2022

Times listed are Mountain Daylight Time

DAY 1

8:00-8:15 AM
GENERAL SESSION

WELCOME

Ricky Safer, CEO, PSC Partners Seeking a Cure
Joshua Korzenik, MD, Brigham and Women's Hospital
Daniel Pratt, MD, Massachusetts General Hospital

8:15-9:05 AM
KEYNOTE ADDRESS

The International Collaborative Research Model: Turning Hope into Action

David Fajgenbaum, MD, MBA, MSc, FCPP, Castleman Disease Collaborative Network

During this Keynote, Dr. David Fajgenbaum, co-founder and CEO of the Castleman Disease Collaborative Network, will share his journey with Castleman disease and the incredible efforts he undertook to identify a treatment and save his own life. Living in "overtime," Dr. Fajgenbaum developed a "Collaborative Network Approach," paving the way for rare disease organizations, like PSC Partners, to turn hope into action for their own communities.

9:05-9:30 AM
RESEARCHERS & CLINICIANS

Identifying and Solving Health Inequities in PSC: Discussion among Researchers and Clinicians

Presenters TBD
Description TBD

9:05-9:30 AM PATIENTS & CAREGIVERS	Caring for You Session 1: Activities for Patients and Caregivers (Patients and caregivers can attend one of the three activities listed below.) <i>Mindfulness: Michael Dunn</i> <i>Restorative Stretching: Julianne Vasichuk</i> <i>T'ai Chi Chih: Cindy Dunn</i> <p>Patients, caregivers, family, and friends can enjoy our “Caring for You” activities during this time. You also may choose to join a Networking Lounge, contact an attendee for a direct conversation, or visit the exhibitor booths.</p>
9:30-9:40 AM	BREAK
9:40-10:40 AM GENERAL SESSION	Launch of the International Collaborative Research Network (ICRNetwork) and the PSC Partners Research Agenda <i>Christopher L. Bowlus, MD, UC Davis School of Medicine</i> <i>Ruth-Anne Pai, PhD, PSC Partners Seeking a Cure</i> <i>Christoph Schramm, MD, University Medical Center Hamburg-Eppendorf</i> <i>Michael Trauner, MD, Medical University of Vienna</i> <i>Moderator: Jesse Kirkpatrick, PhD, MIT/ Harvard Medical School, Member PSC Partners Board of Directors</i> <p>During this groundbreaking session, Ruth-Anne Pai, PhD, will introduce the draft PSC Partners Research Agenda. Everyone is encouraged to attend this exciting session to learn and prepare for a group discussion later in the day. Through this work together, we can accelerate the pace of PSC research and drug development and center the PSC patient voice through the International Collaborative Research Network (ICRNetwork).</p>
10:40-11:10 AM RESEARCHERS & CLINICIANS	Live Poster Session for Researchers and Clinicians <p>During this time, we encourage all researchers and clinicians to visit the posters. Poster presenters will be present, and the chat function will be live. This is a great opportunity to ask your questions and engage with the many talented poster presenters!</p>
<i>Patients and caregivers can choose to attend an activity or a Meet the Professor session.</i>	
10:40-11:10 AM PATIENTS & CAREGIVERS	Caring for You Session 2: Activities for Patients and Caregivers (Patient and caregivers may attend one of the sessions listed below.) <i>Restorative Stretching: Julianne Vasichuk</i> <i>T'ai Chi Chih: Cindy Dunn</i> <p>Patients, caregivers, family, and friends can enjoy our “Caring for You” activities during this time. You also may choose to join a Networking Lounge, contact an attendee for a direct conversation, or visit the exhibitor booths.</p>

10:40-11:10 AM PATIENT & CAREGIVERS	<p>Meet the Professor Session 1: A Time for Patients and Caregivers to Connect with the Experts</p> <p><i>Canada: Aliya Gulamhusein, MD, Mayo Clinic</i> <i>Europe: Espen Melum, MD, Norwegian PSC Research Center</i> <i>USA: John Eaton, MD, Mayo Clinic</i> <i>Pediatric: Dennis Black, MD, University of Tennessee Health Science Center</i></p> <p>During these fun, informal conversations, patients and caregivers have the opportunity to get to know a leading PSC researcher and clinician. Bring your questions!</p>
11:10-11:20 AM GENERAL SESSION	<p>Introducing the ICRNetwork Think Tank: Your Chance to Discuss the Future of PSC Research</p> <p><i>Joanne Hatchett, RN, MS, FNP (retired), PSC Partners Seeking a Cure</i></p> <p>Join to hear an overview and learn what to expect during the first ever International Collaborative Research Network Think Tank.</p>
11:20-12:30 PM	<p>ICRNetwork Think Tank: Discussion of the PSC Partners Research Agenda (Calling all PSC patients, caregivers, researchers, and clinicians.)</p> <p>During this interactive session, we welcome all patients, caregivers, researchers, and clinicians to join together during the very first International Collaborative Research Network Think Tank. In small groups, we will discuss the draft research agenda and ensure that we address the most important questions as a collective ICRNetwork. This is where YOUR voice is so important! While no one is required to speak, your feedback today or following the conference is vital to the success of the development of the Research Agenda. We hope to see you there!</p>
12:30-12:40 PM	BREAK
12:40-1:00 PM GENERAL SESSION	<p>Envisioning a Brighter Future: Uniting Efforts through the ICRNetwork</p> <p><i>Ricky Safer, CEO, PSC Partners Seeking a Cure</i> <i>Joshua R. Korzenik, MD, Brigham and Women's Hospital</i> <i>Moderator: Daniel Pratt, MD, Massachusetts General Hospital</i></p> <p>Join to hear Dr. Josh Korzenik and Dr. Dan Pratt, conference Co-Chairs, and Ricky Safer, PSC Partners CEO, discuss the Bright Future of PSC Research through the new International Collaborative Research Network. Oh, the places we can go with the ICRNetwork!</p>
1:00-2:00 PM GENERAL SESSION	<p>Poster Session Oral Presentations</p> <p><i>Moderator: TBD</i></p> <p>Stay with us at the end of Day 1 for the FIRST EVER PSC Partners poster session! We are very excited to offer this session, during which we will hear four presentations from authors receiving the PSC Partners Outstanding Abstract Award.</p>
2:00 – 3:00 PM	<p>Meet-up for Canadian Attendees</p> <p>Moderator, Mary Vyas</p>

SATURDAY, JUNE 4, 2022

Times listed are Mountain Daylight Time

DAY 2

8:00-8:10 AM

GENERAL SESSION

WELCOME

*Ricky Safer, CEO, PSC Partners Seeking a Cure
Joshua R. Korzenik, MD, Brigham and Women's Hospital
Daniel Pratt, MD, Massachusetts General Hospital*

8:10-8:40 AM

GENERAL SESSION

Sharing Patient Perspectives

*Britt, Joe, Mónica, and Niall
Moderator: Mary Vyas, PSC Partners Seeking a Cure Canada*

The voice of the patient is the driving force of all activities: research, education, and support. A discussion session with PSC patients will offer an understanding of what it means to live with PSC and reinforce the need to advance research and intensify our search for treatments.

8:40-10:10 AM

GENERAL SESSION

International PSC Research: Updates Across the Spectrum – From IBD and Fibrosis to Genetics and the Environment

*Richard Green, MD, Northwestern University Feinberg School of Medicine
Tom Hemming Karlsen, MD, PhD, Norwegian PSC Research Center
Joshua R. Korzenik, MD, Brigham and Women's Hospital
Moderator: Joel Pekow, MD, University of Chicago Medicine*

Join to hear three PSC experts discuss the most exciting updates from the past year of PSC research. This is a can't miss session and a crowd favorite at every PSC Partners Conference!

10:10-10:20 AM

BREAK

10:20-10:45 AM

RESEARCHERS & CLINICIANS

The PSC Partners Grant Program: Overview and Call for Abstracts from PSC Researchers

*Richard Green, MD, Northwestern University Feinberg School of Medicine
Ruth-Anne Pai, PhD, PSC Partners Seeking a Cure*

PSC Partners has dedicated more than \$5.5 million towards PSC research! Join to learn more about the PSC Partners Grant Program, and bring your questions. PSC Partners also wants to hear from you on ways to improve the program and better meet your needs. *Session is open to researchers and clinicians.*

DRAFT 4/14/2022

Patients and caregivers can choose to attend an activity or a Meet the Professor session.

10:20-10:45 AM

**PATIENTS &
CAREGIVERS**

Caring for You Session 3: Activities for Patients and Caregivers

Mindfulness: Michael Dunn

Restorative Stretching: Julianne Vasichuk

Patients, caregivers, family, and friends can enjoy our “Caring for You” activities during this time. You also may choose to join a Networking Lounge, contact an attendee for a direct conversation, or visit the exhibitor booths.

10:20-10:45 AM

**PATIENTS &
CAREGIVERS**

Meet the Professor Session 2: A Time for Patients and Caregivers to Connect

Canada: Amanda Ricciuto, MD, PhD, FRCPC, The Hospital for Sick Children

France: Chantal Housset, MD, PhD, Sorbonne Université

USA: Mario Strazzabosco, MD, PhD, Yale School of Medicine

Pediatric: Mercedes Martinez, MD, Columbia University

During these fun, informal conversations, patients and caregivers have the opportunity to get to know a leading PSC researcher and clinician. Bring your questions!

10:45-11:45 AM

GENERAL SESSION

The PSC Partners Worldwide Integration of Natural History Databases Initiative (WIND): The Power of Natural History Data to Support Drug Development for PSC

Gideon Hirschfield, MA (Oxcon), MB, BChir (Cantab), FRCP, PhD, University of Toronto

Cynthia Levy, MD, University of Miami Health System

Cyriel Ponsioen, MD, Amsterdam UMC

Moderators: Ruth-Anne Pai, PhD, PSC Partners Seeking a Cure

Mary Vyas, PSC Partners Canada

During this session you’ll hear updates from international researchers supporting the development of the Worldwide Integration of Natural History Databases Initiative (WIND) and learn more about ongoing international initiatives aimed at understanding the natural history of PSC and supporting our quest for treatments and a cure.

11:45-12:35 PM

GENERAL SESSION

WIND Think Tank: Discussion of PSC Partners Worldwide Integration of Natural History Databases (WIND)

Christopher L. Bowlus, MD, UC Davis School of Medicine

Gideon Hirschfield, MA(Oxcon), MB, BChir (Cantab), FRCP, PhD, University of Toronto

Cynthia Levy, MD, University of Miami

Moderators: Ruth-Anne Pai, PhD, PSC Partners Seeking a Cure

Mary Vyas, PSC Partners Seeking a Cure Canada

During this interactive session, we welcome all patients, caregivers, researchers, and clinicians to join together for an open discussion of the PSC Partners Worldwide Integration of Natural History Databases Initiative (WIND). Here we will discuss our goals for the prospective cohort and request your feedback. While no one is required to speak, your feedback today or following the conference is vital to the success of the development of the WIND Initiative. We hope to see you there.

12:35-12:45 PM BREAK

12:45-1:35 PM
GENERAL SESSION

**The PSC Partners Patient-Reported Outcomes Measure (PROM) Project:
Updates from the Research Leads**

Donna Evon, PhD, University of North Carolina at Chapel Hill

Bryce Reeve, PhD, Center for Health Measurement

Moderator: Joanne Hatchett, RN, MS, FNP (retired), PSC Partners Seeking a Cure

As a community, we strive for treatment options that reduce symptom burden and improve the daily function of PSC patients. In clinical trials, we can measure these changes through a patient-reported outcomes measure (PROM). Join this session to hear more from the research leads guiding the development of a PROM for PSC.

1:35-2:00 PM
GENERAL SESSION

Envisioning a Brighter Future: Progress Toward a Cure for PSC

Ricky Safer, CEO, PSC Partners Seeking a Cure

Joshua R. Korzenik, MD, Brigham and Women's Hospital

Daniel Pratt, MD, Massachusetts General Hospital

Where are we, and where are we going? What are the next steps? What do we hope for as we move forward? How can you continue to be involved and provide support as the PSC initiatives move forward? You won't want to miss this session.

2:00-4:00 PM

Social Gathering TBD

Sunday, June 5, 2022

Times listed are Mountain Daylight Time

DAY 3

9:00-9:15 AM

GENERAL SESSION

WELCOME

Ricky and Don Safer, Co-Founders, PSC Partners Seeking a Cure

9:15-11:00 AM

PEER GROUPS

Peer Group Sessions: Connecting and Bonding in our Shared Experiences

11:00 AM - Noon

GENERAL SESSION

Brief Insights from Peer Group Discussions & Closing Thoughts

Ricky and Don Safer

Reports from Peer Group Volunteers

DRAFT 4/14/2022