



Together, we are creating a world where a
 PSC diagnosis comes with a cure!

2022 Annual PSC Partners Conference and Inaugural Meeting of the PSC Partners International Collaborative Research Network

AGENDA

THURSDAY JUNE 2, 2022

Times listed are Mountain Daylight Time

**PRE-EVENT
 EVENING**

5:00-6:00 PM

**PATIENTS &
 CAREGIVERS**

Kick-off Social Event for Patients & Caregivers

Join other PSC patients and caregivers for this fun kick-off social event of the Annual PSC Partners Conference. Be matched with other attendees for casual, serendipitous conversations. Mingle virtually with old friends while welcoming those who are new to the PSC Partners community.

6:00-7:00 PM

**PATIENTS &
 CAREGIVERS**

Peer Groups

Peer Group sessions provide a time to connect with others and get to know your PSC peers. Everyone is welcome, including those new to the conference, as well as those who have attended a prior conference or *ZoomRoom*. Join others who truly understand and care. Please join the peer group you selected when you registered for this session.

6:00-7:00 PM

TEENS+

Teen and Young Adult Social Event

If you are 21 years or younger, spend an hour with Lisa LaCroix, a multi-talented friend of PSC Partners. Lisa is an actress, podcaster, and TikTok influencer. Join this casual and fun session to become involved with your peers. Get to know one another in a casual setting while learning fun, useful communications skills.

FRIDAY JUNE 3, 2022

Times listed are Mountain Daylight Time

DAY 1

7:00-8:00 AM

Exhibit Booths Open

Our exhibitors and sponsors look forward to talking with you. Please connect with them through the chat.

8:00-8:15 AM

GENERAL SESSION

WELCOME

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

8:15-9:05 AM

GENERAL SESSION: KEYNOTE ADDRESS

Keynote: The International Collaborative Network Approach: Turning Hope into Action

David Fajgenbaum, MD, MBA, MSc, FCPP, Castleman Disease Collaborative Network
Moderator: Daniel S. Pratt, MD, Massachusetts General Hospital

During his Keynote, Dr. David Fajgenbaum, co-founder and president of the Castleman Disease Collaborative Network and national bestselling author of Chasing My Cure, will share his journey and lessons learned as a physician, researcher, and patient with Castleman disease and the incredible efforts he undertook to identify a treatment to save his own life and others. 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 Mitigating Health Inequalities in PSC

Celeste, PSC patient, and Francis, PSC caregiver
Christopher L. Bowlus, MD, UC Davis School of Medicine
Cynthia Levy, MD, University of Miami Miller School of Medicine
Joanne Hatchett, Medical Science Liaison, PSC Partners Seeking a Cure
Moderator: Kidist K. Yimam, MD, California Pacific Medical Center

This session is for researchers and clinicians. The goal of this discussion is to identify barriers to healthcare affecting underrepresented and disadvantaged patients with PSC and propose steps we all can start taking to mitigate these factors and help improve the healthcare provided.

9:05-9:30 AM

PATIENTS & CAREGIVERS

Caring for You Session 1: Activities for Patients and Caregivers

(Patients, caregivers, family, and friends can attend one of these activities.)
T'ai Chi Chih: Cindy Dunn, Accredited T'ai Chi Chih Instructor
Mindfulness – "A Life Saver Now and Later": Michael J. Dunn, O.D.
Restorative Stretching: Julianne Vasichuk, Hockey Coach & PSC Patient

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.

FRIDAY JUNE 3, 2022

9:30 – 11:20 AM

DAY 1 CONTINUED

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***Christopher L. Bowlus, MD, UC Davis School of Medicine**Ruth-Anne Pai, PhD, Director of Research Strategy, PSC Partners Seeking a Cure**Christoph Schramm, MD, University Medical Center Hamburg-Eppendorf**Michael Trauner, MD, Medical University of Vienna**Moderator: Jesse Kirkpatrick, PhD, MIT/ Harvard Medical School, Member PSC Partners Board of Directors*

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).

**10:40-11:10 AM
RESEARCHERS &
CLINICIANS****Live Poster Session for Researchers and Clinicians**

We encourage all researchers and clinicians to visit the poster area and support those who submitted posters for this first-ever PSC Partners poster presentation. 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!

Patients and caregivers can choose to attend a Meet the Professor or Caring for You session**10:40-11:10 AM
PATIENT &
CAREGIVERS****Meet the Professor Session 1: A Time for Patients and Caregivers to Connect with the Experts***Canada: Aliya Gulamhusein, MD, University of Toronto**Europe: Espen Melum, MD, PhD, Norwegian PSC Research Center**USA: John Eaton, MD, Mayo Clinic, Rochester, MN**Pediatric: Dennis Black, MD, University of Tennessee Health Science Center*

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

**10:40-11:10 AM
PATIENTS &
CAREGIVERS****Caring for You Session 2: Activities for Patients and Caregivers***(Patients, caregivers, family, and friends can attend one of these activities.)**T'ai Chi Chih: Cindy Dunn, Accredited T'ai Chi Chih Instructor**Restorative Stretching: Julianne Vasichuk, Hockey Coach and PSC Patient*

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.

11:10-11:20 AM

BREAK

11:20-11:30 AM
GENERAL SESSION

Introducing the ICRNetwork Think Tank: Your Chance to Discuss the Future of PSC Research

Joanne Hatchett, RN, MS, FNP-retired, Medical Science Liaison, PSC Partners

Join to hear an overview and learn what to expect during the first ever International Collaborative Research Network Think Tank.

11:30-12:30 PM

ICRNetwork Think Tank: Discuss the Future of PSC Partners Research Agenda

Calling all PSC patients, caregivers, researchers, and clinicians! During this interactive session, we encourage patients, caregivers, researchers, and clinicians to join together for 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 and following the conference is vital to the success of the development of the Research Agenda. See you there!

12:30-12:40 PM

BREAK

12:40-1:00 PM
GENERAL SESSION

Envisioning a Brighter Future: Uniting Efforts Through the ICRNetwork

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

Daniel S. Pratt, MD, Massachusetts General Hospital

Ricky Safer, CEO, PSC Partners Seeking a Cure

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 (ICRNetwork). Oh, the places we can go with the ICRNetwork!

1:00-2:00 PM
GENERAL SESSION

Outstanding Poster Abstracts: Live Presentations

Moderator: Heather Francis, PhD, Indiana University

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.

2:00–3:00 PM

Meetup for Canadian Attendees

Moderator: Mary Vyas, President, PSC Partners Seeking a Cure Canada

Calling all Canadians! Please join Canadian PSC community members for an update on the Canadian affiliate activities, new board member introductions, volunteer recognition, and a general opportunity to meet and greet in this smaller group setting.

2:00-3:00 PM

Exhibit Booths Open

Our exhibitors and sponsors look forward to talking with you. Please connect with them through the chat.

2:00-3:00 PM

Teen PSC Social Event

TEENS+

Join your peers to play fun games with others. Ages 13-21.

SATURDAY JUNE 4, 2022

Times listed are Mountain Daylight Time

DAY 2

7:00-8:00 AM

Exhibit Booths Open

Our exhibitors and sponsors look forward to talking with you. Please connect with them through the chat.

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 S. Pratt, MD, Massachusetts General Hospital

8:10-8:40 AM

GENERAL SESSION

Sharing PSC Patient Perspectives

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

Mary Vyas will lead a discussion session with PSC patients who will offer an understanding of what it means to live with PSC. Patients will reinforce the need to advance research and intensify our search for treatments and a cure.

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
Kirsten Muri Boberg, MD, PhD, Norwegian PSC Research Center (Q&A)
Moderator: Joel Pekow, MD, University of Chicago Medicine

Join to hear 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 Grants 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

This session is open to researchers and clinicians. PSC Partners has dedicated more than \$5.5 million towards PSC research! Join to learn more about the PSC Partners Grants Program, and bring your questions. PSC Partners also wants to hear from you on ways to improve the program and better meet your needs. You also may choose to join a Networking Lounge, contact an attendee for a direct conversation, or visit the exhibitor booths.

Patients and caregivers can choose to attend a Meet the Professor or Caring for You session

10:20-10:45 AM
**PATIENTS &
CAREGIVERS**

Meet the Professor Session 2: A Time for Patients and Caregivers to Connect*Canada, Pediatrics: Amanda Ricciuto, MD, PhD, University of Toronto**France: Chantal Housset, MD, PhD, Sorbonne Université**USA: Mario Strazzabosco, MD, PhD, Yale School of Medicine**Pediatric: Mercedes Martinez, MD, Columbia University*

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

10:20-10:45 AM
**PATIENTS &
CAREGIVERS**

Caring for You Session 3: Activities for Patients and Caregivers*Mindfulness – “How to Keep it With You at All Times”: Michael J. Dunn, O.D.**Restorative Stretching: Julianne Vasichuk, Hockey Coach and PSC Patient*

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.

10:45-11:45 AM
GENERAL SESSION

The Power of Natural History Data to Support Drug Development for PSC*Gideon Hirschfield, MB, BChir, PhD, University of Toronto**Cynthia Levy, MD, University of Miami Miller School of Medicine**Cyriel Ponsioen, MD, Amsterdam UMC**Moderator: Mary Vyas, President, PSC Partners Seeking a Cure Canada**Moderator: Ruth-Anne Pai, PhD, Director of Research Strategy, PSC Partners*

During this session, you’ll hear updates from international researchers supporting the development of the WIND Initiative (Worldwide Integration of Natural History Databases) 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, MB, BChir, PhD, University of Toronto**Cynthia Levy, MD, University of Miami Miller School of Medicine**Moderator: Ruth-Anne Pai, PhD, PSC Partners Seeking a Cure**Moderator: 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 WIND Initiative (Worldwide Integration of Natural History Databases). We will discuss our goals for the prospective cohort and request your feedback. While no one is required to speak, your feedback today and 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

**12:45-1:40 PM
GENERAL SESSION**

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

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

Bryce B. Reeve, PhD, Duke University School of Medicine

Moderator: Joanne Hatchett, RN, MS, FNP-retired, Medical Science Liaison, 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.

**1:40-2:00 PM
GENERAL SESSION**

Envisioning a Brighter Future: Progress Toward a Cure for PSC

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

Daniel S. Pratt, MD, Massachusetts General Hospital

Ricky Safer, CEO, PSC Partners Seeking a Cure

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.

2:00-3:00 PM

Time to Celebrate!

Let's get together to kick off our shoes and unwind at the end of two days full of new and exciting information! There will be more serendipitous networking, providing chances to connect with PSC friends new and old.

2:00-3:00 PM

Exhibit Booths Open

Our exhibitors and sponsors look forward to talking with you. Please connect with them through the chat.

2:45-4:00 PM

TEENS+

Teen & Young Adult Social Event (must sign-up at registration)

Graffiti Workshop: This dynamic experience is an online graffiti history lesson and a hands-on graffiti masterclass with a renowned street artist and educator! There will be moments of interaction throughout, using breakouts, time for Q&A with the artist, and a general informal, fun tone throughout.



SUNDAY JUNE 5, 2022

Times listed are Mountain Daylight Time

DAY 3

9:00-9:20 AM
GENERAL SESSION

WELCOME

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

Sunday begins with a welcome from Ricky and Don Safer, followed by additional updates from PSC Patient Mónica Aldarondo, PSC Partners Seeking a Cure Executive Director Meegan Carey, and PSC Caregiver and Member of PSC Partners Board of Directors Kathy Halloran.

9:20-11:00 AM

Peer Group Sessions: Connecting and Bonding in our Shared Experiences

**PATIENTS &
CAREGIVERS**

The Sunday Peer Group sessions provide a time to connect with others and get to know your PSC peers. Everyone is welcome, including those new to the conference, as well as those who have attended a prior conference or ZoomRoom. Join others who truly understand and care. Please join the peer group you selected when you registered for this session.

11:00 AM-Noon

Teen Peer Group Gathering

TEENS

11:00 AM - Noon
GENERAL SESSION

Brief Insights from Peer Group Discussions & Closing Thoughts

*Ricky and Don Safer, PSC Partners Seeking a Cure
Reports from Peer Group Volunteers*

For many PSC patients and caregivers, the insights and closing remarks are one of the most meaningful experiences during the conference. We welcome the peer group attendees to stay for this session.

JULY - DECEMBER 2022

Times, information, and registration link on the events page at pscpartners.org.

POST-EVENT WEBINARS

Jul 11: PSC and IBD: What Everyone Wants to Know About Diet and Nutrition

Sep 21: The Clinical Trial Landscape in PSC: Current and New Opportunities for Patients

Jul 27: Living with PSC: Psycho-Social Stresses and Strains: Coping Strategies for Patients

Oct 12: The Future of PSC Diagnosis and Management: With a Focus on Symptoms, Complications, and Cancer Prevention and Surveillance

Aug 10: The PSC-IBD Connection

Nov 10: Liver Transplant: Everything You Want to Know Both Pre- and Post-Transplant

Sep 7: PSC: The Stresses and Strains of Being a Caregiver: Coping Strategies for Caregivers

Dec 1: What Can We Learn from International Perspectives on PSC Care?