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

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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</table>
| **5:00-6:00 PM** | **Kick-off Social Event for Patients & Caregivers**  
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** | **Peer Groups**  
PATIENTS & CAREGIVERS: 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. |
### FRIDAY JUNE 3, 2022

**Times listed are Mountain Daylight Time**

#### DAY 1

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>7:00-8:00 AM</td>
<td><strong>Exhibit Booths Open</strong></td>
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<tr>
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<td>Our exhibitors and sponsors look forward to talking with you. Please connect with them through the chat.</td>
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<tr>
<td>8:00-8:15 AM</td>
<td><strong>WELCOME</strong></td>
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<tr>
<td></td>
<td><strong>Ricky Safer, CEO, PSC Partners Seeking a Cure</strong></td>
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<td></td>
<td><strong>Joshua R. Korzenik, MD, Brigham and Women’s Hospital</strong></td>
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<td></td>
<td><strong>Daniel S. Pratt, MD, Massachusetts General Hospital</strong></td>
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<td>8:15-9:00 AM</td>
<td><strong>GENERAL SESSION: KEYNOTE ADDRESS</strong></td>
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<td><strong>Keynote: The International Collaborative Network Approach: Turning Hope into Action</strong></td>
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<td></td>
<td><strong>David Fajgenbaum, MD, MBA, MSc, FCPP, Castleman Disease Collaborative Network</strong></td>
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<td><strong>Moderator: Daniel S. Pratt, MD, Massachusetts General Hospital</strong></td>
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<td>During his Keynote, Dr. David Fajgenbaum, co-founder and president of the Castleman Disease Collaborative Network and national bestselling author of <em>Chasing My Cure</em>, 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.</td>
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<tr>
<td>9:00-9:30 AM</td>
<td><strong>RESEARCHERS &amp; CLINICIANS</strong></td>
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<td></td>
<td><strong>Identifying and Mitigating Health Inequalities in PSC</strong></td>
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<td></td>
<td><strong>Celeste, PSC patient, and Francis, PSC caregiver</strong></td>
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<td><strong>Christopher L. Bowlus, MD, UC Davis School of Medicine</strong></td>
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<td><strong>Cynthia Levy, MD, University of Miami Miller School of Medicine</strong></td>
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<td><strong>Joanne Hatchett, Medical Science Liaison, PSC Partners Seeking a Cure</strong></td>
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<td><strong>Moderator: Kidist K. Yimam, MD, California Pacific Medical Center</strong></td>
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<td>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.</td>
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<tr>
<td>9:00-9:30 AM</td>
<td><strong>PATIENTS &amp; CAREGIVERS</strong></td>
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<td><strong>Caring for You Session 1: Activities for Patients and Caregivers</strong></td>
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<td><em>(Patients, caregivers, family, and friends can attend one of these activities.)</em></td>
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<td></td>
<td><strong>T’ai Chi Chih: Cindy Dunn, Accredited T’ai Chi Chih Instructor</strong></td>
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<td><strong>Mindfulness – “A Life Saver Now and Later”: Michael J. Dunn, O.D.</strong></td>
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<td><strong>Restorative Stretching: Juliane Vasichek, Hockey Coach &amp; PSC Patient</strong></td>
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<td>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.</td>
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## FRIDAY JUNE 3, 2022

**9:30 – 11:20 AM**

### 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

**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!

### 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 Vasichek, 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**
<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
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| 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 | **Join and/or Create a Network Lounge**  
  Network lounges are a great way for one-on-one or group chats. |
### DAY 2

**SATURDAY JUNE 4, 2022**

**Times listed are Mountain Daylight Time**

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<tr>
<td>8:00-8:10 AM</td>
<td>WELCOME</td>
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<td></td>
<td><em>Ricky Safer, CEO, PSC Partners Seeking a Cure</em></td>
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<td></td>
<td><em>Joshua R. Korzenik, MD, Brigham and Women’s Hospital</em></td>
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<td><em>Daniel S. Pratt, MD, Massachusetts General Hospital</em></td>
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<td>8:10-8:40 AM</td>
<td>GENERAL SESSION</td>
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<td><strong>Sharing PSC Patient Perspectives</strong></td>
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<td><em>PSC Patients: Britt, John, Mónika, and Niall</em></td>
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<td><em>Moderator: Mary Vyas, President, PSC Partners Seeking a Cure Canada</em></td>
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<td>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.</td>
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<tr>
<td>8:40-10:10 AM</td>
<td>INTERNATIONAL PSC RESEARCH: UPDATES ACROSS THE SPECTRUM – FROM IBD AND FIBROSIS TO GENETICS AND THE ENVIRONMENT</td>
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<td><em>Richard Green, MD, Northwestern University Feinberg School of Medicine</em></td>
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<td><em>Tom Hemming Karlsen, MD, PhD, Norwegian PSC Research Center</em></td>
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<td><em>Joshua R. Korzenik, MD, Brigham and Women’s Hospital</em></td>
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<td><em>Kirsten Muri Boberg, MD, PhD, Norwegian PSC Research Center (Q&amp;A)</em></td>
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<td><em>Moderator: Joel Pekow, MD, University of Chicago Medicine</em></td>
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<td>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!</td>
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<td>10:10-10:20 AM</td>
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<td>10:20-10:45 AM</td>
<td>RESEARCHERS &amp; CLINICIANS</td>
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<td><strong>The PSC Partners Grants Program: Overview and Call for Abstracts from PSC Researchers</strong></td>
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<td><em>Richard Green, MD, Northwestern University Feinberg School of Medicine</em></td>
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<td><em>Ruth-Anne Pai, PhD, PSC Partners Seeking a Cure</em></td>
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<td><em>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.</em></td>
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</table>
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 Vasichek, 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/Chair: Mary Vyas, President, PSC Partners Seeking a Cure
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
Mary Vyas, President, PSC Partners Seeking a Cure Canada
Moderator/Chair: Veronica Miller, PhD, Berkeley Public Health
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

2022 PSC Partners Seeking a Cure
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, check out the information uploaded to their booths, and get your questions answered.
### SUNDAY JUNE 5, 2022

**Times listed are Mountain Daylight Time**

#### DAY 3

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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| 9:00-9:20 AM | **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 Mónika Aldarondo, PSC Caregiver and Member of PSC Partners Board of Directors Kathy Halloran, and PSC Partners Seeking a Cure Executive Director Meegan Carey |
| 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 | **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.

<table>
<thead>
<tr>
<th>Date</th>
<th>Title</th>
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<tbody>
<tr>
<td>Jul 11</td>
<td>PSC and IBD: What Everyone Wants to Know About Diet and Nutrition</td>
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<tr>
<td>Sep 21</td>
<td>The Clinical Trial Landscape in PSC: Current and New Opportunities for Patients</td>
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<tr>
<td>Jul 27</td>
<td>Living with PSC: Psycho-Social Stresses and Strains: Coping Strategies for Patients</td>
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<tr>
<td>Oct 12</td>
<td>The Future of PSC Diagnosis and Management: With a Focus on Symptoms, Complications, and Cancer Prevention and Surveillance</td>
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<td>Aug 10</td>
<td>The PSC-IBD Connection</td>
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<td>Nov 10</td>
<td>Liver Transplant: Everything You Want to Know Both Pre- and Post-Transplant</td>
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<tr>
<td>Sep 7</td>
<td>PSC: The Stresses and Strains of Being a Caregiver: Coping Strategies for Caregivers</td>
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<tr>
<td>Dec 1</td>
<td>What Can We Learn from International Perspectives on PSC Care?</td>
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Thank you to our Corporate and Community Sponsors. We couldn’t do it without you!

Thank You to Our 2022 Annual Conference Corporate Sponsors!

Signature Sponsor: GILEAD

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Mass General Brigham
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The Gomel Family

The Barnett Family
The Gregory Family

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

pascpartners.org