



# PSC PARTNERS SEEKING A CURE

## 2012 PSC Partners Conference Registration Form

### Please fill out a separate registration form for EACH attendee.

If you plan to register for the 2012 conference by mail instead of submitting your registration online, simply print out and complete this registration form and send it with your payment to PSC Partners Seeking a Cure at:

PSC Partners Seeking a Cure  
5237 So. Kenton Way  
Englewood CO 80111

**All required \* fields must be completed in order to register. Thank you.**

#### Attendee Information

First Name \* \_\_\_\_\_

Last Name \* \_\_\_\_\_

Specify the name as you would like it to appear on conference name tag.

Name Tag \* \_\_\_\_\_

Attendee Category \* Please check the **ONE** category that applies to Attendee:

- PSC Patient
- Transplant Recipient
- Spouse/Partner
- Parent
- Other Relative
- Friend
- Other (Please specify) \_\_\_\_\_

Specify your relationship to the PSC patient \_\_\_\_\_

Address \* \_\_\_\_\_

City \* \_\_\_\_\_ State \* \_\_\_\_\_

Postal Code \* \_\_\_\_\_ Country \* \_\_\_\_\_

Email \* \_\_\_\_\_

Home Phone \* \_\_\_\_\_ Mobile Phone \_\_\_\_\_

Are you attending the conference with someone? \* Yes \_\_\_\_\_ No \_\_\_\_\_

Please list the other people attending with you\* \_\_\_\_\_ (We ask for this information so that we can assign each attendee to the appropriate group).

What is your relationship to the people you are attending with? (example: parent, fiancé, sibling, partner...) \* \_\_\_\_\_

Is this your first time at a PSC Partners conference? \* Yes \_\_\_\_\_ No \_\_\_\_\_

Please answer the following if this your **FIRST** PSC Partners Conference:

Would you like to be introduced to a mentor? (Mentors can be either PSCers or Caregivers) Yes \_\_\_\_\_ No \_\_\_\_\_

Confirm if you will attend the Mentor/Mentee Meet and Greet on Friday at 6-6:30 PM Yes \_\_\_\_\_ No \_\_\_\_\_

We highly recommend that you join us for the Newcomer Orientation on Friday 5:30 –6:00PM As a first time attendee, confirm that you will attend the Newcomer Orientation if you are interested. Yes \_\_\_\_\_ No \_\_\_\_\_

Please answer the following if this is **NOT** your first PSC Partners Conference:

Would you like to volunteer to be a mentor for a first time attendee? Yes \_\_\_\_\_ No \_\_\_\_\_

(Mentors can be either PSCers or caregivers)

All attendees please answer the following: Would you like to be included in the 2012 conference attendee booklet to be handed out to the conference attendees? \* Yes \_\_\_\_\_ No \_\_\_\_\_

If Yes, I would like the following information to be included: (check all that apply)

- Name
- Address
- Email

How did you hear about the PSC Partners Seeking a Cure conference? (Check all that apply) \*

- Attended a past conference
- Facebook Support Group
- Web Search
- Physician
- Yahoo Support Group
- Other (please specify) \_\_\_\_\_

Where will you be staying? Please select one: \_\_\_\_\_ DoubleTree Hotel \_\_\_\_\_ Hilton Garden Inn \_\_\_\_\_ Other

If other please specify where: \_\_\_\_\_

Name on the hotel reservation: \_\_\_\_\_

Please make your reservations as soon as possible. The number of rooms available for the PSC Conference is limited!

Will you join us for the Friday activities? \* Yes \_\_\_\_\_ No \_\_\_\_\_

If attending activities on Friday, please check all that apply.

- Get Acquainted Brunch at 10:30AM -12:30PM (Additional Fee of \$10 for the Brunch)
- Interactive Session: Stress Management and Resiliency Training for PSCers and Caregivers 1:30 – 4:00PM

Will you join us for the Friday night Registration and Welcome Dinner from 6:30-9 p.m.? \* Yes \_\_\_\_\_ No \_\_\_\_\_

Will you join us for the Saturday night banquet? \* Yes \_\_\_\_\_ No \_\_\_\_\_

Do you have special dietary needs? \* Yes \_\_\_\_\_ No \_\_\_\_\_

The DoubleTree Hotel will only provide special gluten free and vegetarian meals.

Do you need gluten free meals? \* Yes \_\_\_\_\_ No \_\_\_\_\_

Do you need vegetarian meals? \*      Yes \_\_\_\_\_      No \_\_\_\_\_

Please choose the **ONE** group for Saturday's lunch that best describes **YOU**: \*

- Teen PSCers (include age of child) Age: \_\_\_\_\_
- Female PSCers in their 20s/30s (For group assignments) Age: \_\_\_\_\_
- Male PSCers in their 20s/30s (For group assignments) Age: \_\_\_\_\_
- Female PSCers
- Male PSCers
- Post-transplant PSCers
- Spouses/Partners/Caregivers of PSCers
- Parents of Pediatric PSCers (include age of child) Age: \_\_\_\_\_
- Parents of Adult PSCers (include age of child) Age: \_\_\_\_\_
- Siblings/Other Caregivers of PSCers

**Choose ONE speaker for EACH Saturday Breakout Session.**

**Session I 1:30 – 2:15PM \***

Please select only **one** of the following to attend in Session I:

- Cancer Surveillance: Risks and Outcomes / Gregory J. Gores, MD (Repeated in Session II)**

Discussion of the risks of colorectal cancer, cholangiocarcinoma and gall bladder cancer in PSC patients, focusing on screening and treatments for these cancers.

- Inflammatory Bowel Disease and PSC / Sunanda V. Kane, MD (Repeated in Session II)**

In the context of PSC, we discuss the management of bowel issues, which are independent of liver issues. Most patients with PSC have underlying inflammatory bowel disease, and some may not even know it.

- Role of MRI and Advanced Endoscopic Techniques in PSC / Jayant A. Talwalkar, MD, MPH**

Discussion of the indications and performance of MRI/MRCP, EUS and ERCP in the diagnosis and management of PSC.

- Living Donor Liver Transplantation: A Guide / Julie K. Heimbach, MD**

Discussion of issues surrounding living donor liver transplant, including patient selection and anticipated outcomes for donors and recipients.

- Proactive Planning for Transplant / Lynn Pearson, RN, CCTC, Jayne Kleist, LSW, and Marilyn Salley, Patient Financial Services**

Common fears surrounding transplant include wait times and recovery statistics, as well as what life might look like after transplant. This session addresses these issues and how your transplant team will help you every step of the way.

- Pediatric Parents: Letting Your Kid Be a Kid / Saul J. Karpen, MD, PhD**

Discussion of daily practicalities and expectations for your child and how to help with medications, sports, IBD issues, and the future. We will also discuss opportunities for clinical trials involving children.

- **Special Topics for 20s/30s Female PSCers / Nataliya Razumilava, MD and Andrea A. Gossard, RN, CNP**

Gather with your PSC peers in a social setting to discuss social and medical issues relevant to your age group.

- **Special Topics for 20s/30s Male PSCers / Craig S. Lammert, MD**

Gather with your PSC peers in a social setting to discuss social and medical issues relevant to your age group.

- **Caregivers: Helping Us Help Others / Panel of PSC Caregivers / Moderator Mike Pearlman, JD**

This panel of experienced PSC caregivers provides an interactive forum supporting and addressing the challenges that caregivers may face on a daily basis.

- **NONE**

### **Session II 2:35 – 3:20PM\***

Please select only **one** of the following to attend in Session II:

- **Cancer Surveillance: Risks and Outcomes / Gregory J. Gores, MD (Repeated in Session I)**

Discussion of the risks of colorectal cancer, cholangiocarcinoma and gall bladder cancer in PSC patients, focusing on screening and treatments for these cancers.

- **Inflammatory Bowel Disease and PSC / Sunanda V. Kane, MD (Repeated in Session I)**

In the context of PSC, we discuss the management of bowel issues, which are independent of liver issues. Most patients with PSC have underlying inflammatory bowel disease, and some may not even know it.

- **Life After Liver Transplant / Jayant A. Talwalkar, MD, MPH**

Discussion of the indications and long term outcomes after liver transplantation for PSC. Specific topics include the risk for recurrent PSC, the natural history of IBD after transplant, long term medication usage and lifestyle issues following liver transplant.

- **Interpreting Your Test Results / Andrea A. Gossard, RN, CNP**

Discussion of blood tests and other tests commonly performed in the management of PSC, including the clinical significance and interpretation of such tests.

- **Teen Session: Letting Yourself Be a Teenager / Saul J. Karpen, MD, PhD**

Discussion of lifestyle and medication issues including, but not limited to, schoolwork, sports, diet, travel, college planning, jobs, dating and social life, parents and siblings, transplant and medication choices and compliance.

- **Gluten Free Diet and Celiac Disease - Joseph A. Murray, MD and Jacalyn A. See, MS, RD**

Learn how to manage the ins and outs of life with a gluten-free diet. Discussion will also highlight celiac disease, an increasingly common and recognized autoimmune disorder characterized by small bowel inflammation leading to malabsorption. It is frequently seen with other autoimmune disorders including autoimmune liver disease.

- **Understanding PSC Medications / Christine M. Formea, Pharm D**

Discussion of drug interactions, drug side effects, alternative medications and potential dangers.

- **NONE**

### **Session III 3:45 – 4:30PM \***

Please select only **one** of the following to attend in Session III:

- **The Future of PSC Research / Moderator: Keith D. Lindor, MD Panelists: Konstantinos N. Lazaridis, MD, Jayant A. Talwalkar, MD, MPH and Saul J. Karpen, MD, PhD**

Discussion of new ideas as far as cause, identifying prognostic markers from genetic studies and future treatment directions.

- **Relationships, Sexuality and Family Planning / Andrea A. Gossard, RN, CNP and Sunanda V. Kane, MD**

This session for PSCers and caregivers provides an overview of commonly asked questions about fertility, relationships and sexuality in the face of chronic illness.

- **How Do I Deal with Life and PSC? / Philip Burke, PhD and Wendi M. Hirsch, PhD**

This open discussion on coping strategies for PSCers and caregivers is led by two psychologists, one a long-time PSC patient who is presently on the transplant list; the other, a sibling caregiver for a PSCer. Session goals include giving patients and caregivers hope and straightforward coping strategies, showing life with PSC has meaning and is “a life worth living.”

- **Be Informed: Disability Benefits and Employment Law Issues / Rebecca Long, JD, Jeremy Burke, ALHC and Tiffany Rotondo, PHR**

Presentations on the basics of FMLA, SSDI and the ADA, followed by a Q and A. Panelists include an educator in private disability insurance, an HR specialist and an attorney/PSC patient. The goal is to help clarify available benefits and guide patients through health-related employment and disability issues.

- **Special Topics for Post-Transplant PSCers / Aubrey Goldstein, MD**

**This session is limited to post-transplant PSCers only.** It is a chance to explore the experiences of other liver recipients, find out how we coped with the issues and the process of recovery from the surgery and from years of ill health to the possibilities of a PSC-free life and beyond.

- **Make a Difference: Effective Person- to- Person Fundraising Made Easy / Ken Shepherd, Sandi Pearlman and Meegan Carey**

The presentation includes a successful, simple fundraising model that provides step-by-step instructions, examples and motivation, empowering you to make a positive difference raising funds for our cause and helping to put an end to PSC. Learn the basics of person-to-person and local fundraising, how easy it is to host a letter writing campaign and ways that you can make your fundraiser a success. Join us and learn how YOU can make a real difference in the fight against PSC and help us earn much-needed research funds.

- **NONE**

## CONFERENCE VOLUNTEER SIGN-UP

We are looking for volunteers to help us with different aspects of the 2012 conference weekend. We rely upon the support of our volunteers to run the annual conference. Typically, the shifts are short and we will provide complete instructions to help all volunteers! If you would be interested in helping us at the conference, please check the options that appeal to you and we will contact you with more information. Please check ALL that apply:

### **Preparation of Conference Materials**

- For attendees who can arrive early. We will be working together on Tuesday and Wednesday, 5/01/2012 & 5/02/2012.

### **Early Registration**

- Volunteers to man our early registration table in the hotel lobby. We will be assigning shifts beginning Thursday morning 5/3/2012 and running through Friday, 5/4/2012 at 6:00PM.

### **Friday Evening Registration**

- Volunteers to staff our registration table outside the ballroom. The shift will start at 6:00PM on Friday 5/4/2012.

### **Ambassadors and Greeters**

- Various conference greeting and ambassador duties. Shifts will be assigned from Friday morning through Saturday evening.

### **Pre- Conference Activities on Friday**

- Volunteers are needed Friday morning and early evening to help organize and set up for the Friday activities and sessions.

### **Vendor Booth and Attendee Registration Table Coordinators**

- Volunteers are needed Saturday morning/afternoon to help set up, organize and staff the vendor and PSC Partners' tables. In addition, volunteers would help greet and assist our conference vendors.

### **PSC Partners Booths**

- Volunteers are needed to help staff the PSC Partners Seeking a Cure booths at the conference. Shifts will be assigned from Friday afternoon through Sunday morning.

### **Friday and Saturday Dinner Set Up**

- Volunteers are needed to plan and coordinate the set-up of both the Friday evening reception and the Saturday evening banquet. Volunteers will work together both before and during the conference to help plan and staff these events.

**REGISTRATION FEES**

<b>Registration</b>	<b>Postmarked by</b>	<b>Rate</b>
Early Bird Registration	01/01/2012 to 02/10/2012	\$160 per registration
Regular Registration	02/11/2012 to 04/05/2012	\$170 per registration
Late Registration	04/06/2012 to 04/20/2012	\$190 per registration

**Friday pre-conference brunch \$10 per person (not included in registration fee)**

**ALL fees must be received by 4-20-12.**

Conference fee includes: Friday night reception, breakfast, lunch, snack and banquet dinner Saturday, breakfast and snack Sunday, presentations, breakouts, open forums and all conference materials. Conference fee applies to ALL those who attend ANY PART of our conference and cannot be pro-rated.

I would like my conference fee receipts sent to:

Address \_\_\_\_\_ E-mail address \_\_\_\_\_

**PAYMENT INFORMATION**

How will you be paying your registration fees? Check \_\_\_\_\_ Credit Card \_\_\_\_\_

Please remember to include the \$10 brunch fee, if applicable.

Amount to be Paid: \* \$ \_\_\_\_\_

If paying by credit card please complete the following:

Card Type \* \_\_\_\_\_ (Visa, Master Card or American Express)

Card Number \_\_\_\_\_

CVV2 \* (Security code) \_\_\_\_\_

Expiration Month \* \_\_\_\_\_

Expiration Year \* \_\_\_\_\_

**Regardless of the payment method we will need this information:**

All attendees names included in this payment\* \_\_\_\_\_

Amount of conference registration fees included: \*\$ \_\_\_\_\_

Amount of Friday brunch fees included: \*\$ \_\_\_\_\_

Please list all names paid for and attending the Friday Brunch: \_\_\_\_\_

Thank you for completing your 2012 PSC Partners Conference registration.



Please consider participating in The Itching for a Cure/Road to Research fundraiser. All donations go directly to support PSC research. For more information, please visit our website at <http://www.pscpartners.org/fundraisers> or call us at 303-771-5227.

If you aren't already on our mailing list, please sign up now on our website homepage to receive e-mail updates about the conference and other programs.

We're looking forward to seeing you on May 4<sup>th</sup>! If you have any questions, feel free to write to Ricky or Meegan at [contactus@pscpartners.org](mailto:contactus@pscpartners.org) or call PSC Partners at 303-771-5227. The office is located in Denver, Colorado (MST).

Comments? Feel free to send us a message: