

---

# The Duct

Bringing you news on PSC



PSC PARTNERS  
SEEKING A CURE

research, education, and support

**PSC Partners Seeking a Cure Foundation Winter 2013**

---

## Join Us in Pittsburgh!



We are pleased to announce the details of the *PSC Partners Seeking a Cure Ninth Annual Conference* for PSC patients and caregivers, to be held in association with Dr. Kapil Chopra and his colleagues at UPMC (University of Pittsburgh Medical Center) the weekend of April 26-28, 2013. Pre-conference activities begin on Thursday night and continue all day Friday before the official conference starts at Friday's reception dinner at 6:30 p.m. in the DoubleTree Ballroom. We hope that you will consider joining us for an educational and inspiring weekend.

I'd like to thank Dr. Kapil Chopra, Dr. Adam Slivka and Dr. Christopher Hughes, our UPMC co-hosts, who have put together a fascinating agenda of superb speakers and topics. I'd also like to thank Joanne Grieme, my conference co-chair, for coordinating every detail with us and for providing leadership for this event.

We are particularly excited about this year's agenda, which is jam-packed with sessions that will appeal to conference newcomers as well as repeat attendees. Some new topics that will be covered this year include Management of Pruritus; Metabolic Bone Disease in PSCers; MELD Issues/The Unknowns About How UNOS Works; New Techniques in ERCP; How to Keep Your Liver Healthy: Myths and Reality; European Research Updates from Dr. Annika Bergquist of Sweden; Improving Quality of Life: Targeting Pain, Sleep and Fatigue and many others. We have included special breakout sessions

targeted towards parents of pediatric PSCers and for teen PSCers as well. Each session will provide ample time for attendee questions. As always, there are many opportunities built into the weekend schedule for attendees to get to know other PSCers and caregivers.

If you are arriving early, please join us for our pre-conference activities on Thursday evening and Friday.

At the conference, we also hope to be rolling out our new patient registry. We have been working hard with the National Institutes of Health (NIH) to develop our registry and to standardize our survey so as to become compatible with the NIH Global Rare Disease Registry and Data Repository (GRDR) <http://www.grdr.info> . If you are an adult PSCer or a caregiver of a PSCer younger than eighteen, please consider joining our patient registry. We will need each one of you to help researchers understand PSC better, develop clinical trials, and find effective treatments for PSC.

If you have any questions about the conference, feel free to write to me at [contactus@pscpartners.org](mailto:contactus@pscpartners.org).

I'm counting down the days until the conference, when I'll be able to catch up with my old PSC friends and caregivers, meet the new attendees, and welcome our entire PSC family. As always, this will be an unforgettable weekend, filled with valuable medical education and the warmth of being together with people who share a common bond and a strong desire to make a difference for all of us.

Thanks to the unique spirit of the PSC Partners group and the positive power created by all of us being together, I always return home with renewed energy, hope and optimism. Please join us in 2013 in Pittsburgh to experience this enriching and empowering weekend yourself!

Together in the fight, whatever it takes!

Ricky Safer, CEO

## Could you be a 2013 Conference Sponsor?

We love our sponsors and recognize their gifts to help support the conference.

Diamond Level (\$15,000)  
Platinum Level Sponsorship (\$10,000)  
Gold Level (\$5000)  
Silver Level (\$2500)  
Bronze Level (\$1000)

Consider pooling donations with friends to have a greater impact. It's all tax deductible. For sponsorship opportunities, [click here](#).

# 2013 PSC Partners Seeking a Cure Conference



We are pleased to announce PSC Partners Seeking a Cure's ninth annual conference for PSCers and caregivers which will take place in Pittsburgh, Pennsylvania the weekend of April 26-28, 2013. The 2013 conference has been organized in association with Drs. Kapil Chopra, Adam Slivka, Christopher Hughes and their colleagues at UPMC (University of Pittsburgh Medical Center).

## CONFERENCE AGENDA

Please check out the 2013 conference agenda for details of the entire weekend. Please see page 13 or [click here](#) to see the full agenda.

### NOTES:

**TEEN PROGRAM:** We have organized some special activities for the teen PSCers attending the conference. Once the teens register for the conference, we will send them an update.

**ATTENDEES:** The nature of all conference activities is **exclusively** directed towards PSC patients and caregivers 13 years of age and older. We do not have the resources to provide activities, childcare or meals for children under 13 years old.

**GO GREEN!** With the exception of the Friday morning brunch on The Gateway Clipper (within easy walking distance), all weekend activities will take place in the DoubleTree Hotel, so you will NOT need a car.

## EARLY CONFERENCE CHECK-IN

There will be a PSC Partners table in the DoubleTree Hotel from Thursday morning (4/25/13) through Friday evening at 6 p.m. so that conference attendees can sign-in early and pick up their information packets as soon as they arrive.

We hope that you'll consider arriving in Pittsburgh by Thursday evening April 25th to participate in our pre-conference activities on Thursday and Friday. Last year, more than half of the conference attendees attended these events. We received very positive feedback from attendees who greatly appreciated the chance to get acquainted with other participants.

**PRE-CONFERENCE SCHEDULE OF EVENTS**  
**FOR THURSDAY, APRIL 25 AND FRIDAY, APRIL 26**

**THURSDAY EVENING:** Please stop in and join us at Villa Reale Pizzeria for an informal get together from 6-9 p.m., Thursday, April 25th. Villa Reale Pizzeria ([www.villarealepizza.com](http://www.villarealepizza.com)) is located at 628 Smithfield St. in downtown Pittsburgh, just a few minute walk from the DoubleTree Hotel. Villa Reale offers a number of options including pizza, pasta, and salad. Most menu items are under \$10.

**GET ACQUAINTED BRUNCH CRUISE: FRIDAY**  
**FROM 10:00 a.m.-12:30 p.m. (fee \$20 per person)**

Please join us for an informal brunch and sightseeing cruise on the Gateway Clipper ship ([www.gatewayclipper.com](http://www.gatewayclipper.com)). This is an opportunity to get to know one another while enjoying a brunch buffet as we cruise along the unique Three Rivers of Pittsburgh on a boat that is reserved exclusively for PSC Partners.

The walk from the DoubleTree Hotel to the Convention Center, where our boat will depart, takes 10-20 minutes. Please let us know in advance if this walk will be difficult for you and we will try to accommodate your needs. The boat will be boarding from 10-10:30 a.m. and will depart at 10:30 a.m. We will disembark at 12:30-12:45 from the Convention Center.

You must register and pay for the brunch/cruise at the same time you complete your conference registration.

**THE REMAINING CONFERENCE**  
**ACTIVITIES WILL TAKE PLACE AT THE**  
**DOUBLETREE HOTEL**

**FRIDAY AFTERNOON INTERACTIVE**  
**SESSION FROM 1:45 - 3:00 p.m.:** We will offer a choice of two sessions:

- 1. Affordable Care Act and its Impact on People with Serious Chronic Diseases.** The Affordable Care Act offers new protections and rights for people with chronic diseases. What are those protections? And what do those protections mean in terms of affordability of coverage and access to providers, both in the short term and long term? The expansion and the limits of protections under the ACA and how to ensure your rights are protected are the subjects of this presentation.

**Consider**  
**volunteering at the**  
**conference!**

*It takes a lot to keep the conference moving each day, and we could use your help.*

*Check the box on the registration form to let us know that you will be available behind the scenes to make it a success!*

**Thank you!**



**2. Interactive Tai Chi Session.** Tai chi is an ancient Chinese martial art involving deep breathing and graceful dance-like movements which create physical and emotional balance and instill a sense of spiritual and physical well-being. This session is meant for both PSCers and caregivers as a chance to try a new low impact exercise.

**NEWCOMER ORIENTATION FOR FIRST TIME ATTENDEES FROM 4:00 -**

**4:30:** The goal of this short session is to give first-time attendees a head start in understanding what to expect during the weekend and how to get the most out of the conference. To prepare for Saturday's sessions, we'll hand out a packet of reference materials with medical terms, abbreviations and acronyms that will provide the necessary background to better understand the medical presentations. We will also provide a background on PSC Partners Seeking a Cure foundation, our family-style culture, whom to ask for help, what to expect in each session and how to successfully navigate the jam-packed weekend.

**MENTOR/MENTEE CASUAL MEET AND GREET FROM 4:30 - 5:00:** If you are a first-time attendee (either a PSCer or a caregiver), we suggest that you request a mentor when you fill out your registration form. We will match you with a mentor who will be in your same peer group during the weekend. You will have the opportunity to communicate with your mentor before the conference and ask any questions you may have. This session is your chance to be introduced in person to the mentor who has been helping you, and who will continue to be your special contact.

**CONFERENCE FEES**

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

<b>Early Bird Fee:</b>	<b>From the opening of online registration until 2/07/13</b>	<b>\$160 per person</b>
<b>Standard Registration Fee:</b>	<b>2/08/13 to 3/28/13</b>	<b>\$170 per person</b>
<b>Late Registration Fee:</b>	<b>3/29/13 to 4/12/13</b>	<b>\$190 per person</b>

**ALL FEES MUST BE RECEIVED BY APRIL 12, 2013.**

**Friday pre-conference brunch and cruise: \$20 per person\***

\*The brunch fee is NOT included in the conference fee and will be added to your conference fees when you register online.



Note: We try to keep our registration fees as low as possible, in the hope that more people will be able to attend the conference. PSC Partners and our 2013 conference sponsors subsidize a significant portion of your conference costs. (In 2012, the registration fee per person covered less than half the cost for each attendee; the rest was covered by our generous conference sponsors).

**REGISTRATION INFORMATION**

To register online, [click here](#).

## CONFERENCE SPONSORS

We sincerely thank our 2013 conference sponsors:

Diamond Sponsors:	ITW 
Platinum Sponsors:	UPMC 
Gold Level Sponsors:	Steve and Joanne Grieme Don and Ricky Safer Anonymous
Silver Level Sponsors:	Steve and Joanne Hatchett
Bronze Level Sponsors:	Aubrey Goldstein and Caroline Vanneste

**How to Become a Conference Sponsor:** We are still in the process of looking for individual and corporate conference sponsors, so if you are interested in becoming a sponsor or if you know someone whom we should contact, please email us at [contactus@pscpartners.org](mailto:contactus@pscpartners.org).

## IMPORTANT HOTEL INFORMATION

All conference events (starting Friday afternoon April 26th) will take place at the DoubleTree Hotel and Suites Downtown (One Bigelow Square). See the map below. The hotel's website is: [www.PittsburghDowntownDoubleTree.com](http://www.PittsburghDowntownDoubleTree.com)

We are pleased to offer a discounted group rate for conference attendees. The DoubleTree has set up a personalized group page for conference attendees to reserve their hotel rooms. To take advantage of our special group rate of \$119 per room per night plus taxes, please click [here](#).

These rates are available to our conference attendees from April 22-28, in the event that you would like to extend your stay before or after the conference. The special room rate will be available until **April 1st** or until the group block is sold out, whichever comes first. After April 1st, the discounted group rate will only be offered depending on availability and prevailing rates, so it is **strongly advised that you make reservations as soon as possible to take advantage of the group rate.**



## TRANSPORTATION INFORMATION

### How to Get to the DoubleTree Hotel & Suites, Downtown

Pittsburgh International Airport – Distance from Hotel is 18 miles, approximate drive time is 25 minutes.

The typical one-way minimum charge:

Super Shuttle	24.00 USD
Rental Car	Rates Vary
Taxi	45.00 USD
Limousine	60.00 USD
Bus Service	3.75 USD

### *Early Bird Conference Rates Will Expire on These Dates*

**February 7, 2013:** End of early bird rates

Register for the conference before the late fees apply!

**March 28, 2013:** Register for the conference at the standard rate on or before March 28th, when late registration starts.

### **If you will be driving:**

**From the North via Pennsylvania Turnpike,** take exit 28 Rt. 19/I-79 South approximately 3 miles to I-279 South (Pittsburgh). Follow I-279 South for approximately 11 miles. Follow signs for Veterans Bridge I-579 South (Exit 2A). Follow sign for Downtown Exits; Sixth Avenue and Seventh Avenue. Once on the exit ramp, follow sign for Consol Energy Center. Once at the end of the Consol Energy Center exit ramp, the hotel will be in front of you. Continue straight through first traffic light onto Chatham Square (the EXIT to the parking garage of the hotel will be on your right) continue to the stop sign and make a right onto Centre Ave. If you would like to park your car in the DoubleTree garage, make a right into the garage ENTRANCE on Centre Avenue. If you would prefer to check in prior to parking your car, follow Centre Avenue to the first traffic light and make a right onto 6th Avenue, then make your next right onto Bigelow Blvd. The main entrance to the hotel will be on your right.

**From the East via PA Turnpike:** Take Exit 57 Pittsburgh from the PA Turnpike. Follow signs for downtown Pittsburgh and take I-376 West. Follow I-376 to the Grant St. Exit., a left hand exit, and follow Grant St. approximately 4 blocks and make a right turn onto 6th Avenue. Turn left at the first traffic light onto Bigelow Blvd. and the main entrance is on the right. If you would like to park prior to check-in, continue past the hotel's main entrance and make your next right onto Chatham Square; pass the parking garage EXIT on your right and follow Chatham Square to the stop sign (Centre Ave.). Make a right onto Centre Avenue; the ENTRANCE to the Doubletree garage will be on the right hand side.

**From Pittsburgh Int'l Airport:** Follow Airport Exit signs to I-376E/US-22 E/US 30 E. Stay on I-376E/US-22 E/US 30 E for approximately 6 miles to the Fort Pitt Tunnel. Go through the Fort Pitt tunnel and over the Fort Pitt Bridge and stay in the far right lane and take the first right exit which is I-376 E for a short distance to the Grant St. Exit which is a left lane exit. Follow Grant St. approximately 4 blocks and make a right turn onto 6<sup>th</sup> St.

**Parking at the DoubleTree:** There is no self parking at the hotel. Valet parking is 22.00 USD per day.

**Shuttle Service:** We have obtained a \$4 round trip discount with SuperShuttle for shuttle service between the Pittsburgh airport and the DoubleTree Hotel, Downtown. This group discount applies to reservations made online, only, in advance, using Group Discount Code **PSC13**. To make your reservation, please click [here](#).



We come from all over the U.S. and different corners of the world. Join us at the conference, wherever you are!



## SUGGESTIONS FOR THURSDAY, APRIL 25

**DAY ACTIVITIES:** If you plan to arrive in Pittsburgh early, please check out the Greater Pittsburgh Convention and Visitors Bureau ([www.visitpittsburgh.com](http://www.visitpittsburgh.com)) for visitor information and printable maps. Here are some sightseeing suggestions:

### FUN THINGS TO DO IN AND AROUND PITTSBURGH

According to National Geographic Traveler, the following Pittsburgh must-see spots offer something for everyone to enjoy:

- 1) **Ride the Duquesne or Monongahela Incline** - Also known as funiculars, these "inclined planes" were built in the late 1800's to transport immigrant workers from work at plants along Pittsburgh's rivers to their homes atop Mt. Washington. While they still serve as transportation for area residents, they are also a great way to enjoy the beautiful panoramic Pittsburgh skyline, a view ranked as the second most beautiful place in America by USA Today. The Duquesne Incline, still utilizing the two original 1877 wooden cable cars, is also a working museum.
- 2) **Have Lunch at Primanti's** - Primanti's offers a wide variety of delicious sandwiches, with the cheese-steak being their most popular. Several locations exist around the city, but the original 1933 location in the heart of Pittsburgh's historic Strip district, open 24/7, is the best.
- 3) **The Strip** - Join locals in Pittsburgh's popular warehouse district. Grab a great cup of coffee and a fresh biscotti, before taking a stroll through this combination farmer's market/street fair. Vendors, shops and exotic grocery stores offer everything from kitchenware to costumes or Steelers merchandise to fresh flowers and fish.
- 4) **Can't Miss Point State Park** - At this tiny state park in downtown Pittsburgh, on land once coveted by three empires, the Monongahela and Allegheny Rivers meet to form the Ohio. The 'glass castle' PPG building dominates the skyline. And one of the tallest fountains in the nation (a 275-foot geyser that blasts 6,000 gallons of water per minute) is fed by an aquifer found 53 feet underground (sometimes referred to as Pittsburgh's fourth river). While there, explore the Fort Pitt Block House & Museum located among the remains of the famous British fort or just sit and watch the boats go by.
- 5) **Spend an Afternoon at One of the Carnegie Museums** - Visit the [Museum of Natural History](#), with one of the best dinosaur collections of anywhere in the world, or enjoy more than 250 exciting, hands-on science and technology exhibits at the [Carnegie Science Center](#). Treat yourself to a day of browsing the renowned architecture collection at the [Carnegie Museum of Art](#), or Heinz ketchup boxes at the [Andy Warhol Museum](#), the most comprehensive single-artist museum in the world.

- 6) Visit the [Cathedral of Learning](#) - A 42-story neo-Gothic structure at the center of the University of Pittsburgh campus, the Cathedral contains 26 Nationality Rooms designed by the different ethnic groups that resided in Allegheny County. On the grounds of the Cathedral you'll also find the beautiful Heinz Memorial Chapel which, with its 23 enormous stained-glass windows, is a favorite Pittsburgh wedding location.
- 7) [Senator John Heinz Pittsburgh Regional History Center](#) - This former ice house has been reborn as a seven-story museum, with interactive exhibits that bring more than 250 years of Western Pennsylvania history to life. Discover how immigrants shaped the region, uncover the myths of the Underground Railroad or climb aboard a 1940's Pittsburgh trolley. Two floors are dedicated to the [Western Pennsylvania Sports Museum](#). After all, what's the history of Pittsburgh without Franco Harris, Mario Lemieux, Roberto Clemente, Arnold Palmer and the gang?
- 8) [The National Aviary](#) - Just across the Allegheny River from the History Center is the National Aviary, where over 600 of the world's most incredible birds are displayed in naturalistic exhibits and walk-through habitats. Marvel at hummingbirds the size of a thumb or Andean Condors with giant 10-foot wingspans at the nation's premiere bird zoo!
- 9) [Phipps Conservatory & Botanical Gardens](#) - Stroll through one of the largest Victorian "glass houses" in the country to see towering tropical plants that were the original seedlings at the 1890 Exposition, indoor and outdoor gardens, and a fabulous bonsai collection. Children will revel in the Discovery Garden, where they are invited to exercise their green thumbs and explore the world of plants and flowers, worms and all. Seasonal exhibits include a butterfly garden, flower shows, and a miniature railroad display.
- 10) [Just Ducky Tours](#) - Just Ducky Tours takes riders on Pittsburgh's only adventure through the city on land and water. Each excursion begins at historic Station Square before waddling downtown for the ride of your life.

### OTHER PERTINENT INFORMATION

**HELP US FIND A CURE FOR PSC:** Please consider donating to or holding a fundraiser for our Road to a Cure annual campaign, as all donations go directly to support the mission of PSC Partners Seeking a Cure. For information, click on <http://www.pscpartners.org/fundraisers>.



**PSC PARTNERS MAILING LIST:** If you aren't already on our mailing list, please sign up now by clicking [here](#) to receive e-mail updates about the conference and other programs.

**CONFERENCE FAQs:** If this will be your first PSC Partners conference, be sure to visit the [FAQ section](#) on our website.

**PHOTOS AT THE CONFERENCE:** Informal photographs and videos will be taken throughout the conference weekend. If you object to the use of your likeness in these images for our website or promotional materials, please contact Meegan Carey at [Meegan@pscpartners.org](mailto:Meegan@pscpartners.org) at any time.

**CONFERENCE FLYER:** Click here for our [conference flyer](#) (also see p.12 of this newsletter). Please print copies and deliver the flyers to your gastroenterologist or hepatologist to display in his/her office.

**COMMENTS FROM PAST ATTENDEES:** If this will be your first PSC Partners conference, please take the time to read [comments](#) from some of our past attendees.

To read “I Refuse to Miss One of These Gatherings,” [click here](#) and scroll down.

To read “The Top Ten Reasons to Attend a PSC Partners Conference”, [click here](#).

Thank you for your interest in attending the ninth annual PSC Partners Seeking a Cure conference. It will be an informative and fun weekend filled with new insights, caring friends and a sense of hope!

If you need further information or have any questions, please write to Ricky or Meegan at [contactus@pscpartners.org](mailto:contactus@pscpartners.org)

If you are a first-timer at the conference, make sure to sign up for a mentor when you register. We can promise you a warm welcome!



See Conference Flyer Below. Many PSCers do not know about our weekend event. You can help spread the word by leaving copies of the flyer at your doctors' offices. Please [click here](#) if you would like to print copies of the flyer.





## NINTH ANNUAL CONFERENCE

APRIL 26 – 28, 2013

# REGISTER NOW

PITTSBURGH, PA

The purpose of this conference is to provide a forum on the latest medical advances in the search for better treatments and a cure for primary sclerosing cholangitis and to offer PSC patients and caregivers the chance to network with speakers and fellow PSCers in an informal setting.

### SOME TOPIC HIGHLIGHTS INCLUDE:

- Natural History of PSC - **Kapil Chopra, MD**
- Current Concepts and Management of the Pruritus of Cholestasis - **Nora Bergasa, MD**
- New Advances in the Evaluation of Biliary Strictures - **Adam Slivka, MD**
- European perspective on Urso treatment and Genetics in PSC / UC - **Annika Bergquist, MD, PhD**
- PSC in Children - The Same Disease? - **Benjamin Shneider, MD**
- Improving Quality of Life in PSC: Targeting Pain, Sleep and Fatigue - **Eva Szigethy, MD, PhD**
- Living Donor Liver Transplant - **Abhinav Humar, MD**

***To register and for more conference information, visit [pscpartners.org/nextannual](http://pscpartners.org/nextannual)  
or write to us at [contactus@pscpartners.org](mailto:contactus@pscpartners.org)***



UPMC LIFE  
CHANGING  
MEDICINE

TIME	SESSION	LOCATION
<b>THURSDAY, APRIL 25, 2013</b>		
6:00 PM - 9:00 PM	<b>Pre-Conference Event: Casual Get Together</b> (Please note that there are no specific gluten free options on this menu.)	VILLA REALE PIZZERIA
<b>FRIDAY, APRIL 26, 2013</b>		
9:00 AM - 8:00 PM	<b>Check-in/PSC Partners Registration</b>	DOUBLETREE
10:00 AM - 12:45 PM	<b>Pre-Conference Event: Brunch Cruise (Pre-registration required)</b>	GATEWAY CLIPPER SHIP
1:45 - 3:00 PM	<b>Affordable Care Act and Its Impact on People with Serious Chronic Diseases</b> <b>Victoria Veltri, JD, LLM, State Healthcare Advocate</b> Office of the Healthcare Advocate, Hartford, CT <b>Interactive Tai Chi Session</b> <b>Instructor TBD</b>	DOUBLETREE HOTEL
4:00 - 4:30 PM	<b>Newcomer Orientation</b>	DOUBLETREE BALLROOM
4:30 - 5:00 PM	<b>Mentor/Mentee Casual Meet &amp; Greet</b>	DOUBLETREE BALLROOM
6:30 - 8:30 PM	<b>Welcome Dinner</b>	DOUBLETREE BALLROOM
<b>SATURDAY, APRIL 27, 2013</b>		
7:30 - 8:30 AM	<b>Buffet Breakfast</b>	DOUBLETREE BALLROOM
8:30 - 8:40 AM	<b>General Session Opening Remarks:</b> Don and Ricky Safer PSC Partners Seeking a Cure	DOUBLETREE BALLROOM
	<b>GENERAL SESSION I</b> <b>Adam Slivka, MD, PhD, Moderator</b> Professor of Medicine, University of Pittsburgh Medical Center	
8:40 - 9:00 AM	<b>Presentation 1: Natural History of PSC</b> <b>Kapil Chopra, MD,</b> Director of Hepatology, Associate Professor of Medicine, UPMC	
9:00 - 9:20 AM	<b>Presentation 2: Current Concepts and Management of the Pruritus of Cholestasis</b> <b>Nora Bergasa, MD</b> Chief, Department of Medicine, Metropolitan Hospital Center, New York, NY Professor of Medicine, NY Medical College, Valhalla, NY	
9:20 - 9:40 AM	<b>Presentation 3: MELD Issues/The Unknowns about How UNOS Works</b> <b>Christopher Hughes, MD</b> Associate Professor of Surgery, Surgical Director, Liver Transplantation Starzl Transplant Institute, University of Pittsburgh Medical Center	
9:40 - 10:15 AM	<b>Questions and Answers</b> Panel: Drs. Chopra, Bergasa, Hughes	
10:15 - 10:35 AM	<b>BREAK WITH SNACKS DoubleTree Ballroom Foyer</b>	
	<b>GENERAL SESSION II</b> <b>Kapil Chopra, MD, Moderator</b> Director of Hepatology, Associate Professor of Medicine, UPMC	DOUBLETREE BALLROOM
10:35 - 10:55 AM	<b>Presentation 4: New Advances in the Evaluation of Biliary Strictures</b> <b>Adam Slivka, MD, PhD</b> Professor of Medicine, University of Pittsburgh Medical Center	
10:55 - 11:15 AM	<b>Presentation 5: Metabolic Bone Disease in PSC Patients</b> <b>Mara Horwitz, MD</b> Associate Professor of Medicine, Division of Endocrinology University of Pittsburgh School of Medicine	

TIME	SESSION	LOCATION
11:15 - 11:35 AM	<b>Presentation 6:</b> Treatment with UDCA in PSC: What Do We Learn from the Scandinavian Urso Study? <b>Annika Bergquist, MD, PhD</b> Associate Professor, Karolinska University Hospital Karolinska Institutet, Stockholm Sweden	
11:35 - 12:10 PM	<b>Questions and Answers</b> Panel: Drs. Slivka, Horwitz and Bergquist	

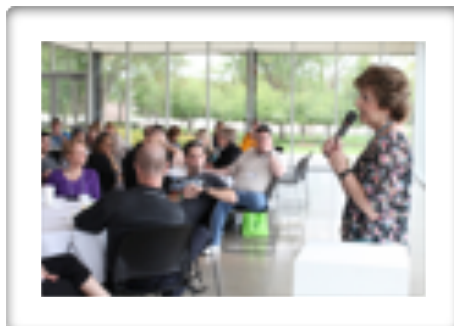
12:10 - 1:20 PM	<b>LUNCH</b> Box Lunches Available to Take to Group Lunch in Breakout Rooms	DOUBLETREE BALLROOM FOYER
12:10 - 1:20 PM	<b>Group Lunches in Breakout Rooms</b> Teen PSCers Female PSCers in their 20s/30s Male PSCers in their 20s/30s Female PSCers Male PSCers Post-Transplant PSCers Parents of Pediatric PSCers Parents of Adult PSCers Spouses/Caregivers of PSCers Siblings & Other Caregivers of PSCers	<b>GROUP BREAKOUT ROOMS:</b> Saturday only Field Trip for Teens

## BREAKOUT SESSIONS

1:30 - 2:15 PM		
SESSION I		
<b>PSC and Your Liver: How to Keep Your Liver Healthy: Myths &amp; Reality</b> (Repeated in Session II)	<b>Kapil Chopra, MD,</b> Director of Hepatology Associate Professor of Medicine, UPMC	DOUBLETREE
<b>Medical and Nutritional Management of IBD</b> (Repeated in Session II)	<b>David Binion, MD</b> Director, Nutrition Support Service Co-Director, Inflammatory Bowel Disease Center Director, Translational IBD Research Division of Gastroenterology, Hepatology and Nutrition, UPMC Presbyterian Hospital Professor of Medicine Professor of Clinical and Translational Science University of Pittsburgh School of Medicine	DOUBLETREE
<b>PSC in Children-The Same Disease? (For Pediatric PSCer Parents &amp; Caregivers)</b>	<b>Benjamin Shneider, MD</b> Professor of Pediatrics University of Pittsburgh School of Medicine Director of Pediatric Hepatology Children's Hospital of Pittsburgh of UPMC	DOUBLETREE
<b>Transplant Surgical Considerations in PSC</b>	<b>Christopher Hughes, MD</b> Associate Professor of Surgery, Surgical Director Liver Transplantation, Starzl Transplant Institute, University of Pittsburgh Medical Center	DOUBLETREE
<b>How to Navigate the Healthcare System and Maximize the Patient-Physician Relationship</b>	<b>Alison Jazwinski, MD, MHS</b> Assistant Professor, Division of Gastroenterology, Hepatology and Nutrition, UPMC	DOUBLETREE
<b>Interpreting Your Test Results</b>	<b>Shahid Malik, MD</b> Clinical Assistant Professor of Medicine Associate Program Director Transplant Hepatology Fellowship Division of Gastroenterology, Hepatology and Nutrition UPMC	DOUBLETREE
<b>Long Term Disability: Understanding Your Options and Benefits</b>	<b>Jeremy Burke, DM, ALHC</b> Learning Consultant Aetna Disability Benefits	DOUBLETREE

<b>Exciting Research at UPMC:</b>		DOUBLETREE
<b>-IGg4-related Cholangiopathy and Pancreatitis</b>	<b>Dhiraj Yadav, MD, MPH</b> Associate Professor, Division of Gastroenterology, Hepatology and Nutrition, UPMC	
<b>-Novel Optical Approaches for Screening and Diagnosing Cholangiocarcinoma</b>	<b>Randall E. Brand, MD</b> Professor of Medicine, Division of Gastroenterology, Hepatology and Nutrition, UPMC	
<b>2:15 - 2:35 PM</b>	<b>BREAK</b>	
<b>2:35 - 3:20 PM</b>	<b>SESSION II</b>	
<b>PSC and Your Liver: How to Keep Your Liver Healthy: Myths &amp; Reality</b> (Repeated in Session I)	<b>Kapil Chopra, MD</b> Director of Hepatology Associate Professor of Medicine, UPMC	DOUBLETREE
<b>Medical and Nutritional Management of IBD</b> (Repeated in Session I)	<b>David Binion, MD</b> Director, Nutrition Support Service Co-Director, Inflammatory Bowel Disease Center Director, Translational IBD Research Division of Gastroenterology, Hepatology and Nutrition UPMC Presbyterian Hospital Professor of Medicine Professor of Clinical and Translational Science University of Pittsburgh School of Medicine	DOUBLETREE
<b>Training Your Brain to Help Your Body Cope with GI Problems</b> (For PSC Teens Only)	<b>Eva Szigethy, MD, PhD</b> Associate Professor of Psychiatry, Pediatrics and Medicine Medical Director of Visceral Inflammation and Pain Center Division of Gastroenterology, University of Pittsburgh Director, Medical Coping Clinic Department of Pediatric Gastroenterology Pittsburgh Children's Hospital	DOUBLETREE
<b>I Was Referred for Liver Transplant: Now What?</b>	<b>Stacey Walsh, RN, CCTC</b> Clinical Transplant Coordinator Thomas E. Starzl Transplantation Institute, UPMC <b>Jennifer Hollenberger, MSW, LSW</b> Clinical Social Worker, UPMC	DOUBLETREE
<b>Living Donor Liver Transplant as an Option</b>	<b>Abhinav Humar, MD</b> Thomas E. Starzl Professor in Transplantation Surgery Clinical Director of Starzl Transplant Institute	DOUBLETREE
<b>Transplant in Pediatric Patients: Long Term Outcomes-What You Need to Know</b> (For Pediatric PSCer Parents & Caregivers)	<b>George Mazariegos, MD, FAC</b> Director of Pediatric Transplantation Jamie Lee Curtis Professor of Surgery and Critical Care Medicine, Hillman Center for Pediatric Transplantation Children's Hospital of Pittsburgh of UPMC	DOUBLETREE
<b>Genetics in PSC and UC: A European Perspective</b>	<b>Annika Bergquist, MD, PhD</b> Associate Professor, Karolinska University Hospital Karolinska Institutet, Stockholm, Sweden	DOUBLETREE
<b>FMLA: Finding Your Way Through The Family And Medical Leave Act And Other Employment Related Issues</b>	<b>Tiffany Rotondo, PHR</b> Corporate Human Resources Generalist The Jel Sert Company	DOUBLETREE

<b>Emotional Wellbeing Amidst Disease: Psychological Progression of PSC</b>	<b>Philip Burke, PhD</b> Clinical Psychologist, Assistant Professor of Clinical Psychology, Southern Illinois University CEO, MoreThanIllness.org, PSC Patient	DOUBLETREE
<b>3:20 - 3:45 PM</b>	<b>BREAK WITH SNACKS</b>	DoubleTree Ballroom Foyer
<b>3:45 - 4:30 PM</b>	<b>SESSION III</b>	
<b>Emotional Wellbeing Amidst Disease: Psychological Progression of PSC</b>	<b>Philip Burke, PhD</b> Clinical Psychologist, Assistant Professor of Clinical Psychology, Southern Illinois University CEO, MoreThanIllness.org, PSC Patient	DOUBLETREE
<b>Improving Quality of Life in PSC: Targeting Pain, Sleep and Fatigue</b>	<b>Eva Szigethy, MD, PhD</b> Associate Professor of Psychiatry, Pediatrics and Medicine, Medical Director of Visceral Inflammation and Pain Center, Division of Gastroenterology University of Pittsburgh, Director, Medical Coping Clinic Department of Pediatric Gastroenterology Pittsburgh Children's Hospital	DOUBLETREE
<b>Growing Up with a Chronic Illness: Challenges and Strategies for Successful Transition to Adult Care (For Pediatric and Teen Parents and Caregivers)</b>	<b>Beverly Kosmach-Park, DNP</b> Clinical Nurse Specialist Department of Transplant Surgery Children's Hospital of Pittsburgh	DOUBLETREE
<b>Life After Liver Transplant</b>	<b>Mimi Funovits, RN, BS, CCTC</b> <b>Panel Moderator</b> Clinical Transplant Coordinator II Thomas E. Starzl Transplantation Institute UPMC Montefiore Hospital Panelists: Todd Clouser, Fred Sabernick, Alison Collins	DOUBLETREE
<b>Caregivers: Helping Us Help Others</b>	<b>Mike Pearlman, JD, PSC Parent</b> <b>Panel Moderator</b>	DOUBLETREE
<b>Panel of PSCers: Interactive Question and Answer Session</b>	<b>Sandi Pearlman, Community Relations Chair</b> <b>PSC Partners Seeking a Cure, PSC Patient</b> <b>Panel Moderator</b> Panelists: Corrine Perrett, Matt Ayuen, Arne Myrabo	DOUBLETREE
<b>Make a Difference: Effective Fundraising Made Easy</b>	<b>Ken Shepherd</b> <b>Managing Partner, Miller Toyota &amp; Warrenton Toyota,</b> <b>PSC Partners Board Member, PSC Parent</b>	DOUBLETREE





6:00 - 9:00	<b>BANQUET DINNER</b>	DT BALLROOM
9:00 PM	<b>Entertainment</b>	DT BALLROOM
<b>SUNDAY, APRIL 28, 2013</b>		
7:30 - 8:30 AM	<b>Buffet Breakfast</b>	DOUBLETREE BALLROOM
8:30 - 9:15 AM	<b>General Session</b> PSC Partners Foundation Report Announcements Foundation Updates	DOUBLETREE BALLROOM
9:15 - 9:25 AM	<b>BREAK - Move to Group Sessions</b>	
9:25 - 10:15 AM	<b>Group Sessions in Breakout Rooms</b> Teen PSCers Female PSCers in their 20s/30s Male PSCers in their 20s/30s Female PSCers Male PSCers Post-Transplant PSCers Parents of Pediatric PSCers Parents of Adult PSCers Spouses/Caregivers of PSCers Siblings & Other Caregivers of PSCers	<b>GROUP BREAKOUT ROOMS:</b>
10:15 -10:25	<b>BREAK WITH SNACKS</b>	DT BALLROOM FOYER
10:25 - 11:20 AM	<b>Group Sessions Reconvene</b>	GROUP BREAKOUT ROOMS
11:30 - 12:20 PM	<b>General Session Reconvenes</b> Feedback from Group Sessions	DOUBLETREE BALLROOM
12:20 - 12:30 PM	<b>Closing</b> : Don and Ricky Safer PSC Partners Seeking a Cure	DOUBLETREE BALLROOM

## Thank you to our 2013 Conference Sponsors

### Diamond



### Platinum



### Gold

Steve and Joanne Grieme  
Don and Ricky Safer  
Anonymous

### Silver

Steve and Joanne Hatchett  
Bronze  
Aubrey Goldstein and  
Caroline Vanneste



**PSC Partners Seeking a Cure** is a 501(c)3 nonprofit foundation that endeavors to find a cure for Primary Sclerosing Cholangitis.

The three-fold purpose of the **PSC Partners Seeking a Cure** foundation is to: raise funds for research on the causes and cures of PSC, provide education and support to PSC patients and their families, and promote awareness of PSC and organ donation.

Ricky Safer is the principal contact person for the PSC Partners Seeking a Cure Foundation. Reach her at: [contactus@pscpartners.org](mailto:contactus@pscpartners.org)

To make a tax-deductible donation, please click on [www.pscpartners.org/waystodonate](http://www.pscpartners.org/waystodonate).

#### **Website**

[www.pscpartners.org](http://www.pscpartners.org)

#### **PSC Partners Seeking a Cure Board Members**

Joanne Grieme (chair), Ricky Safer (CEO), Dike Ajiri, Monica Walters Crowley, Aubrey Goldstein, Rachel Gomel, Scott Malat, Rosalind Parry, Ken Shepherd, and Deb Wentz

**Advisory Board Member:** David Parry

#### **Honorary Members**

Dr. Gregory Everson, Chris Klug

#### **Medical/Scientific Advisory Committee**

Dr. Christopher Bowlus (co-chair), Dr. Richard Green (co-chair), Dr. Dennis Black, Dr. Steven Deitch, Dr. Aubrey Goldstein, Dr. Denise Harnois, Dr. Gideon Hirshfield, Dr. Johannes Hov, Dr. Keith Lindor, Dr. Stephen Miller, David Rhodes, PhD, Dr. Don Safer

#### **Note to Readers:**

Articles in this newsletter have been written by persons without formal medical training. Therefore, the information in this newsletter is not intended nor implied to be a substitute for professional medical advice.

Please consult with your doctor before using any information presented here for treatment. Nothing contained in this newsletter is intended to be for medical diagnosis or treatment. The views and opinions expressed in the newsletter are not intended to endorse any product or procedure.

#### **The Duct Newsletter**

*Editor:* Rachel Gomel assisted by Ricky Safer

*Webmaster:* Arne Myrabo

*Photographers:* Karen Pearlman & Arne Myrabo

#### **Contributors**

Ricky Safer, Meegan Carey