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# The Duct

Bringing you news on PSC



PSC PARTNERS  
SEEKING A CURE

research, education, and Support

PSC Partners Seeking a Cure Foundation Winter 2009

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## Announcing: The 2009 Conference in Chicago, May 1-3

*by Becky Long and Ricky Safer, Conference Co-Chairs*

It's hard to believe that 2009 has arrived already! We hope that everyone had a wonderful holiday season and that you're enjoying good health. We are thrilled to send out information for our 2009 conference, which will be held in Chicago May 1-3, in conjunction with Northwestern University Feinberg School of Medicine.

If you have already attended one of our conferences, you know what an amazing experience it is to learn about the latest advances in the PSC world and to spend a few days bonding with other PSCers and caregivers who understand your concerns, questions, and hopes. *(Continued on page 2.)*

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## Yes, That's a New Logo

*by Scott Malat, PSC Partners Board Member*

We are excited to announce a new look for PSC Partners: an updated logo. We believe the new logo will help us to better represent our message and the organization.

We wanted a logo that showed our support for patients and symbolized our work towards finding a cure. After input from many designers and literally hundreds of revisions we are proud to introduce our updated look.

Our logo of puzzle pieces represents bringing together the pieces to find a cure. The cure is the missing piece on the right side, which *we will* find. At the same time, the puzzle pieces stand shoulder to shoulder, working together to provide research, education, and support. *(Continued on page 2.)*

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In addition, we thought it was important to keep our original maroon color in the logo, as the first puzzle piece. We believe this will help tie the new with the old, and keep our sense of pride in what our growing organization has already been able to accomplish.

Ricky Safer is now working with a professional web designer plus a team of writers and editors from our group to create an updated website. The website redesign team will create a site that is easier to use and provides vital information for PSC patients, caregivers, and medical professionals. The goal is to include member-developed tips and observations on managing PSC in a user-friendly format.

Website development has been funded by a grant from the Cordis Corporation, a subsidiary of Johnson and Johnson.

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If you haven't attended one of our conferences, please try to join us this year, as we can promise you that it will make a huge difference in the way you cope with life with PSC. We both wait all year to reconnect with all of our PSC family!

Our 2009 conference will be held at the Wyndham Chicago (633 North St. Clair), a luxury hotel which is just off Chicago's Magnificent Mile--a wonderful location! We have been able to secure an extremely reasonable room rate for the group.

Because we know that these are difficult economic times for everyone and because we were able to secure an extra sponsorship, we are pleased to announce that we are able to slightly lower the registration fee this year. Please refer to the registration form on pages 11-13 for all this information.

We have been working closely with the physicians at Northwestern to put together an excellent agenda of presentations for Saturday May 2.

We will be using the same format as in past conferences: several speakers will give their presentations, which will then be followed by a lively question and answer session. We have put together a group of very knowledgeable and compassionate physicians from Northwestern who will give us presentations on a variety of topics.

We are pleased to welcome the Division Chiefs in Hepatology and Gastroenterology, Transplant and Surgery, among others.

In addition, we have three guest speakers whom you will enjoy: Dr. Jennifer Heathcote from the University of Toronto, Canada,

Dr. Konstantinos Lazaridis from the Mayo Clinic/Rochester, and Jennifer Jaff who is an attorney/Crohn's patient who advocates for patients with chronic illness. (Please check her website at [www.advocacyforpatients.org](http://www.advocacyforpatients.org)).

In the afternoon, you have a choice of breakout sessions. At lunchtime on Saturday, we will repeat the Lunch With a Physician sessions that we tried last year, which were extremely well received.

During the weekend, you will also get a taste of the city of Chicago. If you can join us for pre-conference activities on Friday May 1, we will start with a complimentary brunch at Lake Point Tower, which is right on Lake Michigan. Thank you to Deb Wente's family, who has offered the use of their beautiful condo as the venue for our brunch!

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After the brunch, there are two great options: an architectural boat tour or the Cubs game. Feel free also to stroll along Michigan Avenue at your leisure. At our Friday night reception and Saturday night's banquet, you will also be introduced to the flavor of the city.

If you have questions about the conference weekend, feel free to write to us:

Ricky at [contactus@pscpartners.org](mailto:contactus@pscpartners.org)

Becky at [beckylong98@aol.com](mailto:beckylong98@aol.com)

The agenda and conference registration form are on the web at these sites:

<http://www.pscpartners.org/2009ConfAgenda.pdf>  
and

<http://www.pscpartners.org/2009ConfRegForm.pdf>

Whether or not you can attend the conference, please think about helping us with our Itching for a Cure/Road to Chicago fundraiser. This year, we have a phenomenal opportunity to raise money for research. We have an anonymous donor who will match dollar for dollar all donations that we receive up to the amount of \$45,000! Make your donations double magically!

For details on this fundraiser and how you can help, please go to (<http://www.pscpartners.org/RtC.htm> ). All contributions raised from this fundraiser will go directly to support research to find that elusive cure for PSC.

Our first individual grant proposal program has been a huge success. We have received thirteen submissions for research grant proposals from topnotch PSC researchers throughout the United States and internationally.

Our Medical Advisory Board, headed by Dave Rhodes, is busy reviewing submissions. We will make the exciting announcement of our research winners at the May conference! These research proposals will be funded by our Itching for a Cure/Road to Chicago fundraiser, so please help us by asking friends and family to donate to our important cause.

You probably noticed our new logo on this newsletter. We hope that the new logo better illustrates who we are and where we are headed as a foundation.

Here's hoping to see as many of you as possible at our 2009 conference!

### ***Help Sponsor the Conference***

As many of you know, our annual conference is the premiere meeting for PSC patients in the United States. Please see the information on page 14 for sponsorship opportunities. Consider asking your employer, friends, and relatives with businesses to help sponsor this important event.

We expect 150 or more attendees from all over the U.S., and also from Canada, the UK, Sweden, and Israel. Our affiliated internet support group boasts over 2,000 members. Since this highly motivated and educated group participates actively in their health care decisions, product and sponsor information will be distributed to medical professional and caregivers world-wide. Sponsors of this meeting are eligible to attend all talks and breakout sessions.

We will acknowledge the support on the PSC Partners Seeking a Cure website and newsletter edition, all conference materials, conference gifts, etc. Thank you for your support.

# PSC Partners 2009 Conference Agenda

All conference events will take place at the Wyndham Chicago 633 N. St. Clair in conjunction with Northwestern Feinberg School of Medicine

## Friday, May 1, 2009

10:30AM-12:30PM	Pre-Conference Event: Complimentary Brunch at Private Residence in Lake Point Tower 505 N. Lake Shore Drive Optional Afternoon Activities: Architectural boat tour from Navy Pier (1PM) or Cubs game at Wrigley Field
5:30-7:30PM	Registration and Welcome Reception

## Saturday, May 2, 2009

7:30-8:30AM	Buffet Breakfast
8:30-10:15AM	<p>Opening Remarks – (8:30-8:40) <b>Don &amp; Ricky Safer</b>, PSC Partners Seeking a Cure Foundation</p> <p>Presentation 1 (8:40-9:00) "The Bile Ducts and the Liver in Health and Disease" <b>Dr. Richard Green</b>: Chief, Division of Hepatology, Northwestern Memorial Hospital</p> <p>Presentation 2 (9:00-9:20) Keynote Address: "Looking Ten Years Ahead: Potential Therapies for PSC" <b>Dr. Jenny Heathcote</b>: University of Toronto, Canada, Head of the Patient Based Clinical Research Division at Toronto Western Research Institute</p> <p>Presentation 3 (9:20-9:40) "Live Donor Transplantation for PSC" <b>Dr. Michael Abecassis</b>: Chief, Division of Organ Transplantation Surgery, Northwestern Memorial Hospital</p> <p>Question &amp; Answer Panel (9:40-10:15) Panel: <b>Drs. Green, Heathcote, Abecassis, Baker</b></p>
10:15-10:35AM	Break/Snacks
10:35-12:10PM	<p>Presentation 4: (10:35-10:55) "New Frontiers in Imaging Techniques and Tissue Acquisition in PSC" <b>Dr. John Martin</b>: Endoscopy Lab Director, Northwestern Memorial Hospital</p> <p>Presentation 5: (10:55-11:15) "IBD and PSC" <b>Dr. Terry Barrett</b>: Chief, Division of Gastroenterology, Northwestern Memorial Hospital</p> <p>Presentation 6: (11:15-11:35) "Behavioral Strategies for Coping with PSC/IBD" <b>Dr. Laurie Keefer</b>: Director of the Center for Psychosocial Research in Gastroenterology, Northwestern Memorial Hospital</p> <p>Question and Answer Panel (11:35am-12:10 pm) Panel: <b>Drs. Martin, Barrett, Keefer</b></p>
12:10-1:25PM	Lunch with a Physician Seating in break-out groups: Male PSCers/Female PSCers/Spouses of PSCers/Parents of pediatric PSCers/Parents of adult PSCers/Post-transplant PSCers/PSCers in their 20s & 30s
1:25-1:55PM	Update on "PROGRESS: PSC Resource of Genetic, Risk, and Synergy Studies" <b>Dr. Konstantinos Lazaridis</b> : Assistant Professor of Medicine, Mayo Clinic College of Medicine, Department of Gastroenterology, Rochester, MN

1:55-2:35PM	"Know Your Rights- An Overview of Health Insurance and Federal Disability Law" <b>Jennifer Jaff, Esq.</b> Advocacy for Patients with Chronic Illness, Inc. Farmington, CT ( <a href="http://www.advocacyforpatients.org">www.advocacyforpatients.org</a> ) and Crohn's Patient
2:45-3:45PM	Breakout Sessions-Choose ONE of the following sessions (Snacks provided in breakout rooms):  <p>Session I: <u>Question and Answer Panel on Pediatric PSC</u>  Panelist: <b>Dr. Jeff Brown:</b> Children's Memorial Hospital, Division of Gastroenterology, Hepatology, and Nutrition, Assistant Professor of Pediatrics, Northwestern Feinberg</p> <p>Session II: <u>Pre-Transplant: Planning and Preparation</u>  Panelists: <b>Dr. Alfred Baker:</b> Professor Emeritus, Division of Hepatology, Northwestern Feinberg School of Medicine  <b>Katie Turpin, MSN, NP-C:</b> Transplant Coordinator, Northwestern Memorial Hospital</p> <p>Session III: <u>The Post-Transplant Experience</u>  Panelists: <b>Dr. Jennifer Trainor:</b> Assistant Professor of Pediatrics at Northwestern and living donor recipient  <b>Dr. Aubrey Goldstein:</b> PSC Partners Member and transplant recipient, Ottawa, Canada</p> <p>Session IV: <u>Nutrition and Healthy Living for PSC</u>  Panelists: <b>Beth Doerfler, MS, RD:</b> Northwestern Feinberg School of Medicine  <b>Dr. Laurie Keefer:</b> Director, Center for Psychosocial Research in Gastroenterology, Northwestern Memorial Hospital</p> <p>Session V: <u>Question and Answer on Advocacy for Patients with Chronic Illness</u>  Panelist: <b>Jennifer Jaff, Esq.</b></p> <p>Session VI: <u>Learn About PROGRESS: How to Get Involved</u>  Panelist: <b>Dr. Konstantinos Lazaridis</b></p>
3:45-3:55PM	Video Presentation: Update on Norwegian Research, <b>Dr. Tom Karlsen:</b> Norwegian PSC Center, Medical Department, Rikshospitalet, Oslo, Norway
3:55-4:00PM	Wrap-up, <b>Don and Ricky Safer</b>
6:30-8:30PM	Banquet Dinner

## Sunday, May 3, 2009

7:30-8:30AM	Buffet Breakfast
8:30-8:40AM	Presentation: Update on Dr. Chapman's Research, <b>Ivor Sweigler:</b> PSC UK Support Group
8:40-10:40AM	Open Forum/Support Group in Breakout Rooms-(Male PSCers/Female PSCers/Parents of pediatric PSCers/Parents of adult PSCers/Spouses and other caregivers of PSCers/Post-transplant PSCers/PSCers in their 20's & 30's)
10:40-11:00AM	Break/Snacks
11:00-11:40AM	Open Forum reconvenes in Main Ballroom for Breakout session summation
11:40-11:50AM	PSC Partners – Foundation Progress Report ( <b>Deborah Wente,</b> Treasurer – foundation financial report)
11:50-12:00PM	Closing Remarks – <b>Don &amp; Ricky Safer</b> PSC Partners Seeking a Cure Foundation
12:00-12:20PM	Committee Sign Up (Optional): Media/PR, Organ Donation, Legislative, Database, Newsletter, Corporate Fundraising



Working together to provide research, education, and support for people affected by Primary Sclerosing Cholangitis

**2009 Conference Information and Registration Form**  
**Wyndham 633 N. St. Clair CHICAGO, ILLINOIS**  
**In conjunction with Northwestern University Feinberg School of Medicine**  
**Friday May 1 (5:30 pm) – Sunday May 3 (Noon)**

Pre-Conference Activities for Friday, May 1, 2009:

**BRUNCH 10:30AM:** Please join us for a complimentary brunch to mingle and enjoy stunning city views from a private residence on the 55<sup>th</sup> floor of Lake Pointe Tower at 505 N. Lakeshore Drive. Lake Point Tower is a 1/2 mile from the Wyndham Chicago—an approximately 10 minute walk or \$5 cab fare.

**OPTIONAL AFTERNOON GROUP ACTIVITIES**

<p>Architectural Boat Tour on the Chicago River 1:00PM-2:00PM</p> <p>This tour is a wonderful way to view the sights of the city. Shoreline Sightseeing’s tour leaves from Ogden Slip on Navy Pier, just steps from Lake Point Tower. For more information visit <a href="http://www.shorelinesightseeing.com">www.shorelinesightseeing.com</a>.</p> <p>Fee: \$17 per person</p> <p>Please include payment with this form by <b>April 3</b>, to reserve tickets.</p>	<p>Cubs v. Florida Marlins TBA (typically 1:20 start)</p> <p>If enough interest is expressed, we will try to coordinate a group outing when the game time is announced. Please send an e-mail with the number of tickets requested to <a href="mailto:beckylong98@aol.com">beckylong98@aol.com</a> by <b>February 1</b>. We will send updates via e-mail. If a group sale is not possible, please visit <a href="http://www.cubs.com">www.cubs.com</a> for tickets or <a href="http://www.stubhub.com">www.stubhub.com</a> for the official fan-to-fan ticket market place. Day-of tickets are often available from the box office at 1060 West Addison. You must enter Wrigley Field directly from this box office. Cubs also play 5/3/09.</p>
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**Additional Suggested Individual Activities**

- **Attractions accessible from Navy Pier:** Millennium Park, Art Institute of Chicago, Adler Planetarium, Field Museum, and Shedd Aquarium.
- **Attractions steps away from the Wyndham:** Water Tower, John Hancock Observatory, Museum of Contemporary Art, and premium shopping on Michigan Ave.

**Conference Fees**

- Standard (**on or before April 3**) \$150 per person, \$280 per couple, \$140 for each additional family member or caregiver
- Late (**after April 3**): \$170 per person, \$320 per couple, \$160 for each additional family member or caregiver

**Registration Deadline:** Fees & Registration Form (p.11-13) must be received by **April 17, 2009**

## **Important Hotel Information**

We are pleased to offer a room block at the Wyndham Chicago at 633 N. St. Clair just one block off the Magnificent Mile in Chicago's Gold Coast. The very special PSC Partners rate for Thursday night through Saturday night (April 30 – May 2) is \$99 plus tax for a double room. The rate for three nights before and after the conference (April 27-29 and May 3-5) is also deeply discounted to \$119 plus tax for a double room.

Attendees can reserve rooms at [http://www.wyndham.com/groupeventsnew/orddt\\_pscpartners/main.wnt](http://www.wyndham.com/groupeventsnew/orddt_pscpartners/main.wnt) or at [www.wyndham.com](http://www.wyndham.com) with Group Code 0501600PSC. To make reservations by phone, call the hotel directly at (312)573-0300 or at 1-800-996-3426. Be sure to ask for the special rate for PSC Partners Seeking a Cure.

The room block reserved will be allocated on a first-come, first-served basis. The special group rate will expire when all allotted rooms have been reserved or on **April 15, 2009**, whichever comes first. It is strongly advised that you make reservations as soon as possible since it will be difficult to find comparable lodging in this location for a similar rate. Guest cancellation will be accepted up to 72 hours prior to arrival.

Be sure to take a moment to customize your stay by listing your travel preferences on-line with Wyndham ByRequest to receive free internet access, free local and long distance calling, and a complimentary snack or amenity during your Chicago visit.

## **Transportation from O'Hare Airport to Wyndham Chicago**

**Public Transit:** Chicago Transit Authority's Blue Line elevated train/subway is the only "el" train leaving from O'Hare. Follow the signs from baggage claim to CTA/Blue Line. Be prepared for a 10 minute walk with movable walkways. Fare is currently \$2.25 per person and you will need to purchase a CTA pass from the vending machine or in advance from [www.chicago-card.com](http://www.chicago-card.com). Travel time to downtown is approx 35 minutes once on the train.

**Option #1:** Take the Blue Line to Grand Avenue Exit (escalator up only). Take a cab from Grand Avenue heading east to the Wyndham for approx. \$8 (add one dollar for each additional person). Depending on the time of your arrival, you may also take the #65 Grand bus east (Direction: Navy Pier) to Grand and St. Clair (walk two blocks north to the Wyndham) or the #33 Magnificent Mile Express bus east to Michigan and Ontario (walk one block east).

**Option #2:** Take the Blue Line to Lake Street Exit (escalator and elevator access). Take a cab from Lake (heading east) or LaSalle (heading north) to the Wyndham for approx \$7.

**Option #3:** Google Maps lists several other routes using exclusively CTA, such as the Blue Line to Washington Exit (stairs only). Walk one block north and one block east to State and Randolph. Take #145 Wilson/Michigan Express bus going north (Direction: Lawrence) to Michigan and Ontario. Walk one block east to the Wyndham. Or take the #2 Hyde Park Express bus (Direction: Navy Pier) to Ohio

and St. Clair. Walk two blocks north to the Wyndham. You can take whichever bus comes first. Bus travel may add significantly to your travel time.

**Airport Shuttle:** Airport Express operates a multi-passenger van service to and from the Wyndham. Prices per person are: single \$27 one way & \$49 round trip; pair \$19 one way & \$35 round trip; groups of 3 or more \$14 one way & \$27 round trip.

Book on-line at [www.airportexpress.com](http://www.airportexpress.com) for \$2 off round trip fare. Shuttles depart from O'Hare airport every 10-15 minutes for downtown service to Chicago hotels. Loading zones for boarding the Airport Express van are at Door 1E, Door 2D, and Door 3E across from baggage claim on the Baggage Claim level. The last van leaves O'Hare at 11:30PM. AE Ticket Counters for purchasing tickets are located at Door 1E, Door 2D, and Door 3F lower level across from baggage claim on the Baggage Claim level. Reservations are NOT required to Downtown Chicago.

**Cab:** Cabs are plentiful from the cab line. You may encounter a slight wait depending on your time of arrival. With light traffic, travel time is approx 30 minutes (18 miles), and \$40 one way (add one dollar for each additional person.) At rush hours travel time is significantly longer and the Blue Line is an efficient option.

Shared-ride service is available from the taxi starter booth for \$22 to downtown with a 3 rider max, though this option is really only a discount for passengers traveling alone (metered rate will be more economical for parties of 2 or more at approx \$40). Tell the starter that you want to share a cab and they will designate the next one as a "share-ride" cab. From the time you enter the cab, the driver is obligated to wait ten minutes for two other passengers. Once they enter the cab, you go. If after ten minutes there is only one other passenger, the driver must take you at the shared-ride rate. If no other passengers show up in ten minutes, you pay the full metered rate.

### **Transportation from Midway Airport to Wyndham Chicago**

**Public Transit:** Chicago Transit Authority's Orange Line elevated train is the only "el" train leaving from Midway. Follow the signs from baggage claim to CTA/Orange Line. Be prepared for a 10 minute walk to the Orange Line station from baggage claim. At the station, an elevator is located to the right of the stairs (train is one floor down). Fare is currently \$2.25 per person and you will need to purchase a CTA pass from the vending machine or in advance at [www.chicago-card.com](http://www.chicago-card.com). Travel time to downtown is approx 25 minutes once on the train.

**Option #1:** (CTA plus short cab ride) Take the Orange Line to Lake Street exit (escalator and elevator). Take a cab from Lake (heading east) or LaSalle (heading north) to the Wyndham for approx \$7 (add one dollar for each additional person). The Orange Line runs on a continuous circle through the Loop so when you return to Midway, be sure to enter the Lake station on the south side of the street (the side with Dunkin Donuts) to head directly to the airport.

**Option #2:** (All CTA) Take the Orange Line to Roosevelt. Transfer to Red Line at Roosevelt (stairs and elevator). Take the Red Line to Grand Avenue exit (stairs only). Walk 3 blocks east and 3 blocks



north to the Wyndham. For elevator and escalator access (recommended with luggage), exit at the next stop which is Chicago Avenue and walk the same distance to the Wyndham (3 blocks east and 3 blocks south).

**Airport Shuttle:** Airport Express operates a multi-passenger van service to and from the Wyndham. Prices per person are: single \$22 one way & \$39 round trip; pair \$15 one way & \$27 round trip; groups of 3 or more \$12 one way & \$22 round trip.

Book on-line at [www.airportexpress.com](http://www.airportexpress.com) for \$2 off round trip fare. Shuttles depart from Midway airport every 15 minutes for downtown service to Chicago hotels. The Airport Express ticket counter and loading zone is located at Door 3, lower level across from baggage claim. The last van leaves Midway at 10:30PM. Reservations are NOT required to Downtown Chicago.

**Cab:** Cabs are plentiful from the cab line. You may encounter a slight wait depending on your time of arrival. With light traffic, travel time is 25 minutes (14 miles), and \$32 one way (add one dollar for each additional person.) At rush hours travel time is significantly longer and the Orange Line is an efficient option.

Shared-ride service is available from the taxi starter booth for \$16 to downtown with a 3 rider max, though this option is really only a discount for passengers traveling alone. Tell the starter that you want to share a cab and they will designate the next one as a “share-ride” cab. From the time you enter the cab, the driver is obligated to wait ten minutes for two other passengers. Once they enter the cab, you go. If after ten minutes there is only one other passenger, the driver must take you at the shared-ride rate. If no other passengers show up in ten minutes, you pay the full metered rate.

### **A Note on CTA Public Transit**

Bus and rail maps are available at [www.transitchicago.com](http://www.transitchicago.com). The CTA pass works on all CTA trains and buses. (But not METRA rail suburban trains.) Your first transfer within two hours is \$0.25. After that you will receive one additional free transfer within the first two hours. Reloadable CTA passes can be purchased at all elevated train/subways stations but not on buses. One day and three day passes are also available. Cash is accepted on buses only. If you will be sightseeing, consider purchasing a [Chicago Card](http://www.chicago-card.com/cc/) in advance at [www.chicago-card.com/cc/](http://www.chicago-card.com/cc/) (purchase fee waived for first time users). Several buses run up and down Michigan Ave. at a high frequency for your convenience. On Google Maps, select the “By Public Transport” option to get directions between locations on CTA.

### **Alternate Transportation Options**

Amtrak ([www.amtrak.com](http://www.amtrak.com)), Greyhound ([www.greyhound.com](http://www.greyhound.com)), and Megabus ([www.megabus.com](http://www.megabus.com)) may be convenient options for travel by train and bus in the Midwest. From Union Station, cab fare is approximately \$10 or the #151 bus will take you to Michigan and Ontario. From there walk one block east to the Wyndham.

## **Parking**

Overnight parking is available at the Wyndham for \$49 per night with unlimited in and out privileges. Several parking garages are located within 2 blocks such as 233 E. Erie for \$34 (includes a \$5 overnight discount) and 222 E. Huron for \$36 overnight.

Reduced rates are available at parking garages slightly farther away:

247 East Chestnut (312-280-0087) is \$25 for 24 hours (.7 miles)

900 North Lake Shore Drive (312-944-0160) is \$26 for 24 hours (.7 miles)

275 East Chestnut (312-337-2520) is \$27 for 24 hours (.8 miles)

222 East Pearson (312-951-5499) is \$32 for 24 hours (.5 miles)

200 East Delaware (312-266-0365) is \$33 for 24 hours (.6 miles)

Street parking is difficult in this area and not advisable due to various zoning and residential restrictions. Northwestern campus maps are available at [www.nmh.org](http://www.nmh.org).

## **Additional Information**

For general attraction and landmark information, see [www.chicagotraveler.com](http://www.chicagotraveler.com). The website [www.metromix.com](http://www.metromix.com) will let you know what's going on around town during the week of the conference along with event, concert, and restaurant info.

If you would like to see a Sunday matinee performance, consider booking in advance at [www.broadwayinchicago.com](http://www.broadwayinchicago.com), [www.secondcity.com](http://www.secondcity.com), [www.goodmantheatre.org](http://www.goodmantheatre.org), or [www.steppenwolf.org](http://www.steppenwolf.org). Also, the Lookingglass ([www.lookingglasstheatre.org](http://www.lookingglasstheatre.org)) and Drury Lane theaters ([www.drurylanewatertower.com](http://www.drurylanewatertower.com)) are intimate venues located a few blocks from the Wyndham.

*Please note that all conference events will take place at the Wyndham Chicago at 633. N. St. Clair.*

If you have any questions, please send an e-mail to Ricky Safer at [contactus@pscpartners.org](mailto:contactus@pscpartners.org) or Becky Long at [beckylong98@aol.com](mailto:beckylong98@aol.com).

Thank you for attending the 5th Annual PSC Partners Seeking a Cure conference. We know it will be a very informative and exciting weekend filled with fun, hope, and great people. We look forward to seeing you in Chicago!

## 2009 Conference Registration Form

Names (first & last) of persons attending conference (Please print):

1. \_\_\_\_\_  
PSC patient \_\_\_ Transplant recipient \_\_\_ Friend, relative and/or caregiver \_\_\_\_\_  
Please specify relationship \_\_\_\_\_

2. \_\_\_\_\_  
PSC patient \_\_\_ Transplant recipient \_\_\_ Friend, relative and/or caregiver \_\_\_\_\_  
Please specify relationship \_\_\_\_\_

Address: \_\_\_\_\_

City/State/Zip/Country \_\_\_\_\_

E-mail: \_\_\_\_\_

Phone: \_\_\_\_\_ Cell: \_\_\_\_\_

Is this your first time at a PSC Partners conference? \_\_\_\_\_ If yes, would you like to be introduced to a mentor in the group? \_\_\_\_\_

I would like my \_\_\_ name \_\_\_ address \_\_\_ e-mail to be included in the 2009 conference attendee address booklet to be handed out to conference attendees.

How did you hear about the PSC Partners Seeking a Cure conference?

- \_\_\_ Attended a past conference
- \_\_\_ Yahoo support group
- \_\_\_ Web search
- \_\_\_ Physician
- \_\_\_ Other \_\_\_\_\_

Will you be staying at the Wyndham? Yes \_\_\_ No \_\_\_

- If yes, name on hotel reservation: \_\_\_\_\_

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

Will you be participating in The Itching for a Cure/ Road to Chicago fundraiser? Yes \_\_\_ No \_\_\_

- For more information, please visit <http://www.pscpartners.org/RtC.htm>
- An anonymous donor has issued a challenge and will match the first \$45,000 in donations for the Road to Chicago. Help us meet this goal! All donations to Itching for a Cure/Road to Chicago go directly to support PSC research.

Lunch with a Physician Sessions for Saturday: Please choose ONE for each registered attendee:

Male PSCers: Name \_\_\_\_\_

Female PSCers: Name \_\_\_\_\_

Spouses/caregivers of PSCers: Name \_\_\_\_\_

Siblings/caregivers of PSCers: Name \_\_\_\_\_

Parents of Pediatric PSCers: Name (s) \_\_\_\_\_

Parents of Adult PSCers: Name (s) \_\_\_\_\_  
Male PSCers in their 20s/30s: Name \_\_\_\_\_  
Female PSCers in their 20s/30s: Name \_\_\_\_\_  
Post-transplant PSCers: Name \_\_\_\_\_

Please choose ONE breakout session for Saturday afternoon for each attendee:

Session I: Pediatric PSC: Name \_\_\_\_\_  
Session II: Pre-Transplant: Planning and Preparation: Name \_\_\_\_\_  
Session III: The Post-Transplant Experience: Name \_\_\_\_\_  
Session IV: Nutrition and Healthy Living for PSC: Name \_\_\_\_\_  
Session V: Advocacy for Patients with Chronic Illness: Name \_\_\_\_\_  
Session VI: Learn about PROGRESS: Name \_\_\_\_\_

**Please print pages 11, 12, and 13 and include them with your check or money order made payable to: PSC Partners Seeking a Cure. We cannot accept credit cards. Mail form and fees to:**

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

\_\_\_\_\_ \$150 per person, \$280 per couple, \$140 per additional family member or caregiver - **On or before April 3**

\_\_\_\_\_ \$170 per person, \$320 per couple, \$160 per additional family member or caregiver - **After April 3**

\_\_\_\_\_ \$17 per person for Shoreline Boat Tour \_\_\_ one \_\_\_ two \_\_\_ three \_\_\_ four

Total: \_\_\_\_\_ Amount enclosed: US funds only, check or money order

\_\_\_\_\_ I will \_\_\_\_\_ I will not attend the pre-conference brunch on Friday.  
If yes, Number of people attending: \_\_\_\_\_

**Registration Deadline:** All fees must be received by **April 17, 2009**

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

- Conference fee receipts will be sent to your e-mail address. If you DO NOT have an e-mail address and would like a receipt, please include a mailing address.

If you are not already on our mailing list and would like to receive e-mail updates from PSC Partners Seeking a Cure, please check one or more of the following:

- Information on annual conferences
- Online newsletters
- Fundraising updates/opportunities
- Volunteer opportunities
- Research updates
- All PSC Partners communications



## Wyndham Hotel Information from Website:

[http://www.wyndham.com/groupeventsnew/orddt\\_pscpartners/main.wnt](http://www.wyndham.com/groupeventsnew/orddt_pscpartners/main.wnt)



[Book a room](#) [View or cancel a reservation](#)

### PSC Partners



#### Make a Reservation

Welcome to the Wyndham Chicago reservation site for the PSC Partners Block Room Rates. Please use link below to reserve your room.

**Event Dates:** April 30, 2009 - May 3, 2009

**Stay Dates:** April 27, 2009 - May 6, 2009

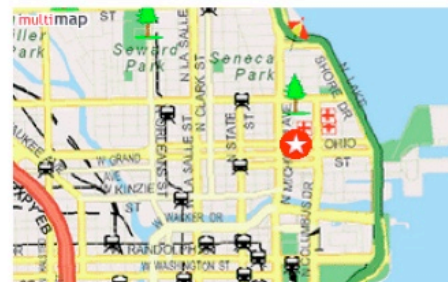
Please note there is a rate change during this time. \$99/night April 30-May 2, 2009 and \$119/night April 27-29 and May 3-5

You can make your room reservation from this site to receive your group's preferred rate. **The correct "group code" will be entered automatically for you on the reservations page.**

72-hour cancellation policy.

[MAKE A RESERVATION FOR THIS EVENT NOW](#)

#### Map to Wyndham Chicago



**Wyndham Chicago**  
633 North St. Clair  
Chicago, Illinois 60611  
United States  
Phone: 1-312-573-0300



## **PSC PARTNERS SEEKING A CURE 2009 CONFERENCE SPONSORSHIP OPPORTUNITIES**

### **PLATINUM SPONSOR LEVEL      \$10,000**

- **Four** complimentary tickets to the conference
- One exhibit table
- Company name listed in local press release as **major sponsor**
- **Table sign at registration signifying major sponsorship**
- Company acknowledged as **major sponsor** by Master of Ceremonies
- Company recognized as **major sponsor** in all pre and post conference publicity
- Company recognition at the conference welcome reception
- Opportunity to distribute company promotional materials in attendee bags
- Company name listed on conference website and foundation online newsletter **with hyperlink**
- Name and logo **prominently** printed on 2009 event brochures and t-shirt

### **GOLD SPONSOR LEVEL              \$5000**

- **Two** complimentary tickets to the conference
- One exhibit table
- **Company name listed in local press release as gold sponsor**
- Company acknowledged by Master of Ceremonies
- Company recognized as **gold** sponsor in all pre and post conference publicity
- Company recognition at the conference welcome reception
- Opportunity to distribute company promotional materials in attendee bags
- Company name listed on conference website and foundation online newsletter **with hyperlink**
- Name and logo printed on 2009 event brochures and t-shirt (**second** tier listing)

### **SILVER SPONSOR LEVEL          \$2500**

- One complimentary ticket to the conference
- One exhibit table
- Company acknowledged by Master of Ceremonies
- Company recognized as **silver** sponsor in all pre and post conference publicity
- Company recognition at the conference welcome reception
- **Opportunity to distribute company promotional materials in attendee bags**
- Company name listed on conference website and foundation online newsletter
- Name **and logo** printed on 2009 event brochures and t-shirt (**third** tier listing)

### **BRONZE SPONSOR LEVEL        \$1000**

- One complimentary ticket to the conference
- One exhibit table
- Company acknowledged by Master of Ceremonies
- Company recognized as bronze sponsor in all pre and post conference publicity
- Company recognition at the conference welcome reception
- Company name listed on conference website and foundation online newsletter
- Name printed on 2009 event brochures and t-shirt (fourth tier listing)

## Our Latest Fund Matching Challenge: We Can Do It!



**Itching  
for a Cure**

**Road to Chicago  
Fundraising Challenge**

PSC Partners Seeking a Cure

### 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.



**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, promote PSC and organ donation awareness, and provide education and support to PSC patients and their families.

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)

Tax-deductible donations can be sent to: PSC Partners Seeking a Cure, 5237 South Kenton Way, Englewood, CO 80111 with a check made out to: PSC Partners Seeking a Cure.

### Website

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

### PSC Partners Seeking a Cure Board Members

Dike Ajiri, Lee Bria, Becky Long, Dr. Gregory Everson, Joanne Grieme, Chris Klug, Scott Malat, David Rhodes, Ricky Safer, and Deb Wentz

### The Duct Newsletter

Editor: Pat Bandy  
[newsletter@pscpartners.org](mailto:newsletter@pscpartners.org))

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