



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

www.pscpartners.org

PSC Partners Seeking a Cure Newsletter

Vol. 4, Issue 1, February 2008

Edited by David Rhodes and Ricky Safer

PSC Partners Seeking a Cure Board Members:

Dike Ajiri, Lee Bria, Elissa Deitch, Dr. Gregory Everson, Joanne Grieme, Chris Klug, Scott Malat, David Rhodes, Ricky Safer, and Deb Wente

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This issue of the newsletter is focused on the upcoming 2008 Conference

2008 Conference

The 2008 PSC Partners Seeking a Cure Conference will be held May 2-4, 2008 at the Mayo Clinic in Jacksonville, Florida.

Please consider arriving in Jacksonville on Thursday, May 1, so that you can attend either the St. John's River boat ride, or the golf tournament on Friday May 2.

It's That Time Again!

I can't believe that we will be holding our fourth annual conference for PSCers and caregivers in less than three months. This weekend is always a highlight of my year...the chance to reconnect with our wonderful "PSC family" and to learn about the newest developments in PSC genetics, treatment options and coping mechanisms.

Don and I have just returned from another trip to Jacksonville, where we worked out many details of the May 2-4 weekend. All of you who are able to attend the conference this year will greatly benefit from the information packed presentations from the knowledgeable Mayo physicians. In addition, you will enjoy the beauty and serenity of the Mayo campus. The warm sunny Florida weather will be a real plus for those of us in the midst of a cold winter.

When you look at the agenda, you will see that we have made some changes to the conference

weekend, based on the evaluations that we received at the end of the 2007 conference. Since many attendees suggested the addition of some pre-conference activities, we have arranged two exciting activities for Friday morning May 2. Attendees have a choice of a golf tournament or a boat trip on the St. John's River. Please think about joining us!

On Saturday, we have made some new additions to our program:

- During Saturday lunch, we will have "Lunch With a Physician" breakout groups. These are the same groups that we split into on Sunday morning.
- We have added three new breakout groups (PSCers on the transplant list, Post-transplant PSCers, and PSCers in their 20s and 30s) to our basic breakout groups (Male PSCers, Female PSCers, Spouses of PSCers and Parents of PSCers). Each of these groups has specific concerns to discuss.
- We have a session giving an update on PSC research, including speaker Dr. Tom Karlsen from Norway, who will be discussing his work on PSC genetics.
- Since there are always many questions about facing a liver transplant, we have put together a panel of PSC patients and caregivers who will participate in a Transplant Experience question and answer session.
- To lighten up the day, our own Shelley Hussey will talk about The Power of Humor.
- At the end of the day Saturday, there is an optional hospital tour. Mayo Clinic's new hospital facility will be completed a few weeks before our conference, and they have offered to show us around.

If you are planning to attend the conference, please be sure to make your hotel and plane reservations soon. Remember to send in your registration form before April 4, the start of late registration. The conference agenda and the registration form are posted on our home page at www.pscpartners.org.

If you have any questions or concerns about attending the conference, please feel free to write to me at contactus@pscpartners.org.

Ricky Safer



The Road to Jacksonville

Traveling from the site of our 2007 conference (Denver, CO), to the site of our 2008 conference (Jacksonville, FL), we have 2,000 miles to cover. Each mile is covered by raising \$50. Our progress is indicated by painting the road **red**.

<http://www.pscpartners.org/RtJ.htm>

**Distance Traveled = 702.7 Miles = \$35,136
Raised for Research, as of 02/08/08**

% of Goal Attained = 35.14%, as of 02/08/08

Thank you to all those who have contributed!

4TH ANNUAL
PSC PARTNERS SEEKING A CURE CONFERENCE
FOR PSC PATIENTS AND CAREGIVERS



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

MAY 2-4, 2008

MAYO CLINIC
JACKSONVILLE, FLORIDA

REGISTER NOW

For conference agenda
and registration form,
visit our website at:
www.pscpartners.org

OR CONTACT:

Ricky Safer, Conference Chair

contactus@pscpartners.org

The fourth annual PSC Partners Seeking a Cure conference will be held in Jacksonville, Florida on May 2-4, 2008 to educate and support PSC patients and caregivers. Healthcare providers will give presentations to assist attendees in understanding and coping with Primary Sclerosing Cholangitis. Speakers will have time to answer questions and network with attendees. There will also be ample time to meet other PSCers and caregivers and share concerns.

CONFERENCE HIGHLIGHTS

Keynote Speaker-Dr. Greg Gores, Mayo Clinic in Rochester, MN, Cholangiocarcinoma and PSC

Overview of PSC-Dr. Denise M. Harnois, Mayo Clinic

The Surgical Consult-Dr. Winston Hewitt, Mayo Clinic

Lipids and Bone Disease/Nutrition for PSC-Dr. Jaime Aranda-Michel, Mayo Clinic

IBD "Double Trouble"-Dr. Michael Picco, Mayo Clinic

Endoscopic Therapy-Dr. Stephen Lange, Mayo Clinic

Coping with PSC-Dr. Adriana Vasquez, Mayo Clinic

What Can Genetic Studies Do for PSC?-Dr. Tom Karlsen, Norwegian PSC Center, Oslo, Norway

CO-SPONSORED BY:

PSC Partners Seeking a Cure
Mayo Clinic-Jacksonville

Directions to Mayo Clinic

From the Airport: Signs at the airport will lead you to I-95. Follow the signs to I-95 South and take State Road 9A South (Exit 362A) toward Blount Island. Follow 9A South to J. Turner Butler Boulevard. Go east on J. Turner Butler Boulevard to San Pablo Road exit. You'll see a sign, "Mayo Clinic, next right" on the right just before the exit. Take the exit and at the light, turn left onto San Pablo Road. Mayo is one-quarter mile ahead on the left.

From I-95 south of Jacksonville: Take Butler Boulevard, exit No. 344, and go east (toward the beach). You'll pass St. Luke's Hospital on the left. Stay on Butler Boulevard until you exit at San Pablo Road. You'll see a sign, "Mayo Clinic, next right" on the right just before the exit. At the light, turn left on San Pablo Road. Mayo is one-quarter mile ahead on the left.

Mayo Clinic Campus

When you arrive at Mayo Clinic, follow the main road and go straight onto the campus. Free parking is available in Patient Parking Lots A, B and C. If your vehicle has a state disabled-person sticker, decal or license plate, parking in the garage is free. Otherwise, the 600-space facility is available for a fee. The parking garage is located next to the Davis Building.

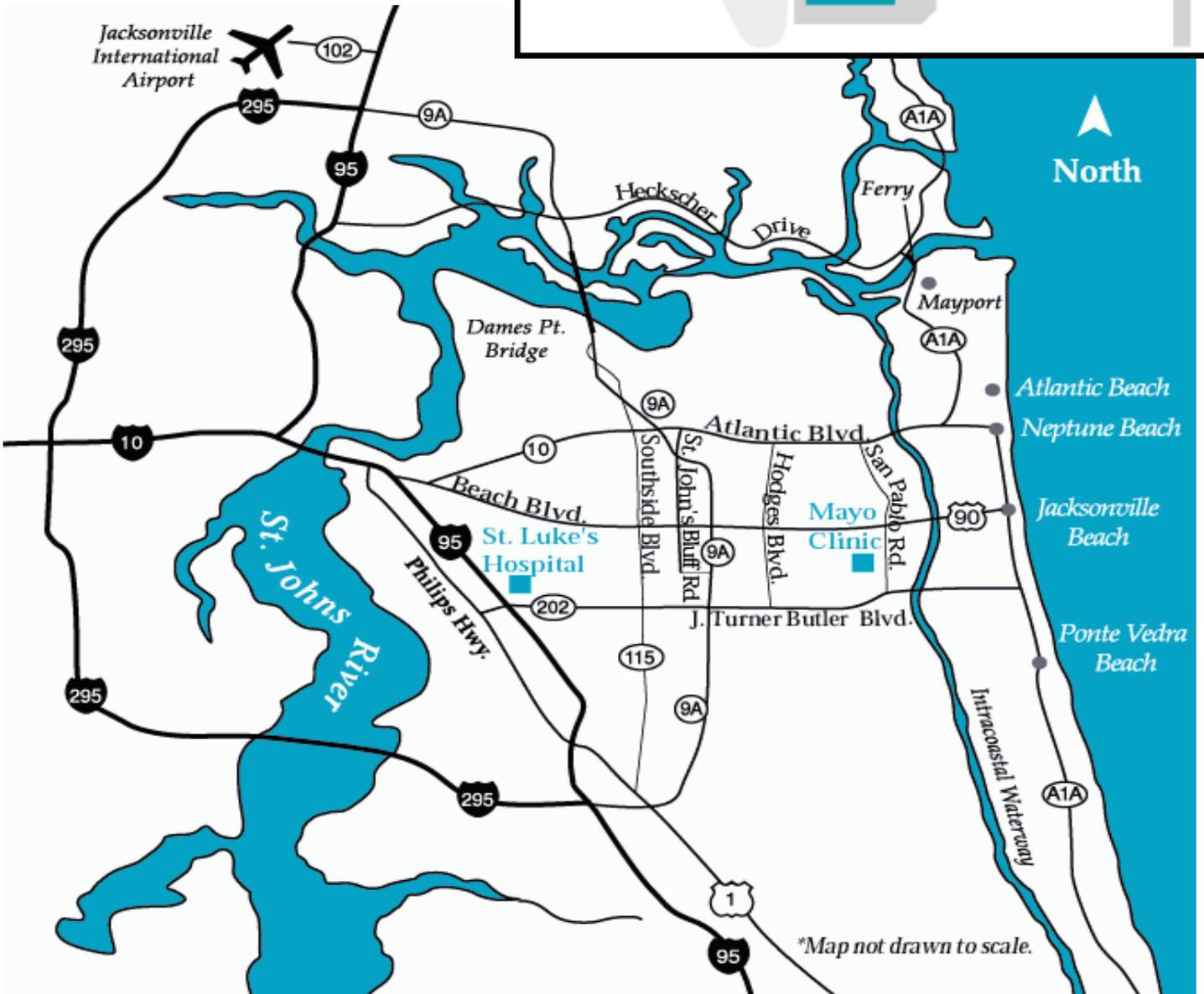
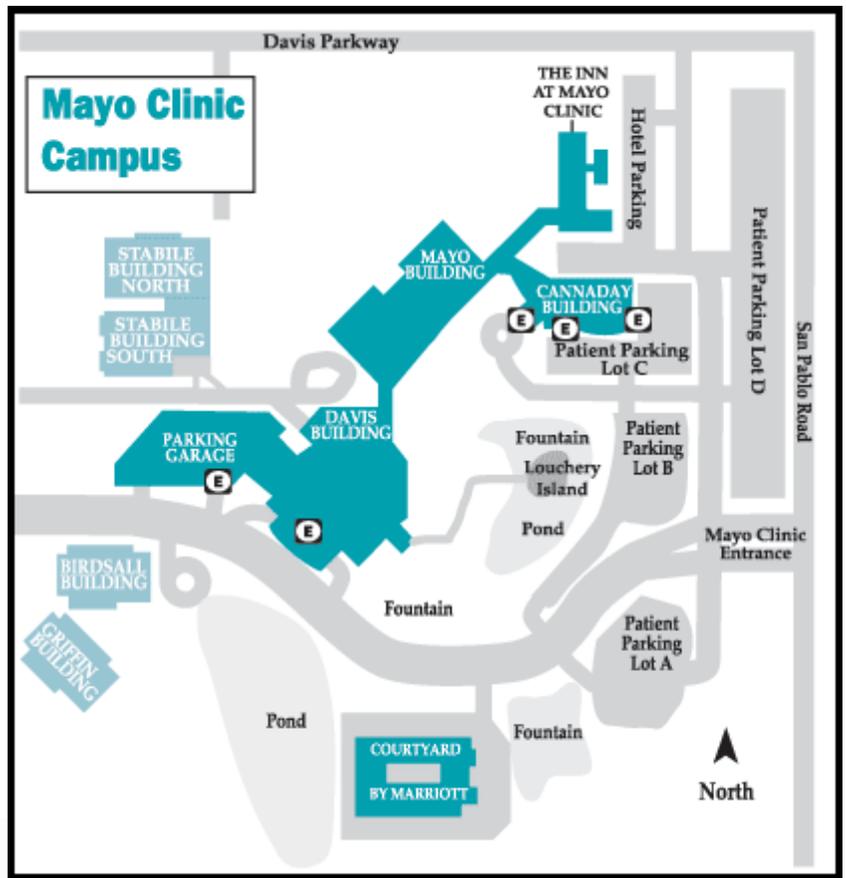
Pay special attention to the building where your appointment is located since it will help you determine the most convenient parking spot. Wheelchairs are available at main entrances to the Davis, Mayo and Cannaday buildings.

If you are staying at The Inn at Mayo Clinic, take the first right after entering the Mayo campus and follow the signs. If you are staying at the Courtyard by Marriott, turn left at the first stop sign after entering the Mayo campus.

(please see maps on p. 4)



Cannaday Building and Atrium



PSC Partners Seeking a Cure Golf Tournament, Jacksonville, FL, May 2, 2008

With just three months to go before that road ends in Jacksonville, PSC Partners Seeking a Cure is getting ready to hold its very first golf tournament at Windsor Parke Golf Club. After golfers have had their coffee and pastries, they will take to the golf course. At approximately 8:30 AM on the morning of May 2nd, we will kick off with a shotgun start. For those unfamiliar with the shotgun start, groups of 4 golfers will be stationed at different holes around the golf course and a horn will go off signaling the start of play. After 9 holes have been played, a small snack will be provided and golf resumed. After completion, we will have a luncheon with awards and prizes handed out. (Since they play every Wednesday, the doctors will win them all.) Joanne Grieme has secured wonderful prizes from companies supporting our cause. With closest to the hole and longest drive competitions, it would be nice to see if we can raise additional dollars. There will be opportunities for companies to sponsor holes, carts or the refreshment station. So please start thinking about employers or family friends that would be interested in this great opportunity. These are all details that will be worked as the time goes on. We have been able to negotiate a very reasonable fee of \$60 per golfer, which includes continental breakfast, a snack, luncheon, and golf. For those of you interested, please let your family and friends know that they are welcome to join us.

We are expecting to get additional non-conference attendees to participate. We will be able to offer those golfers not coming to the conference the same hotel rate as the attendees. So please encourage your golf buddies to take a vacation in Jacksonville and come support PSC Partners Seeking a Cure by playing along with us. Finally, I would ask anyone who is considering playing to let me know as soon as possible. We would like to get an approximate number of participants. My email address is timwholey@carolina.rr.com

My wife and I look forward to seeing many of you on the course. If we don't see you there, we will see you on Friday night as our road from Denver to Jacksonville is finally realized.

Tim Wholey (Tarheel Tim)

Conference Agenda

All conference events will take place in the Kinne Auditorium in the Cannaday Building on the Mayo Campus in Jacksonville, Florida.

FRIDAY MAY 2, 2008

- Morning to early aft. Pre-conference activities:
Golf tournament at Windsor Parke Golf Course-7:30 am to 2 pm
Boat trip on St. John's River-9 am to 1 pm
- 6:00 pm to 9:00 pm Registration/Reception and Casual Dinner

SATURDAY MAY 3, 2008

- 7:00 am to 8:00 am Continental Breakfast
- 8:00 am to 9:50 am Opening Remarks (8:00-8:10) **Don and Ricky Safer**, PSC Partners Seeking a Cure Foundation
Presentation 1 (8:10-8:30) Introduction and Overview-**Dr. Denise M. Harnois**, Mayo Clinic
Presentation 2 (8:30-8:55) Cholangiocarcinoma-**Keynote Speaker-Dr. Greg Gores**, Mayo Clinic, Rochester MN
Presentation 3 (8:55-9:15) The Surgical Consult-**Dr. Winston Hewitt**, Mayo Clinic
Question and Answer Panel (9:15-9:50) Moderator: **Dr. Denise M. Harnois**
- 9:50 am to 10:10 am Break/Snacks
- 10:10 am to 12:10 pm Presentation 4 (10:10-10:35) Lipids and Bone Disease/Nutrition for PSC-**Dr. Jaime Aranda-Michel**, Mayo Clinic
Presentation 5 (10:35-10:55) IBD "Double Trouble"-**Dr. Michael Picco**, Mayo Clinic

SATURDAY MAY 3, 2008 (contd.)

- 10:10 am to 12:10 pm Presentation 6 (10:55-11:15) Endoscopic Therapy-**Dr. Stephen Lange**, Mayo Clinic
Presentation 7 (11:15-11:35) Coping with PSC-**Dr. Adriana Vasquez**, Mayo Clinic
Question and Answer Panel (11:35-12:10) Moderator: **Dr. Denise M. Harnois**
- 12:10 pm to 1:25 pm Lunch with a Physician:
Seating in breakout groups: Male PSCers/ Female PSCers/ Spouses of PSCers/ Parents of PSCers/ PSCers on transplant list/ Post-transplant PSCers/ PSCers in their 20s and 30s
- 1:25 pm to 2:15 pm Presentation 8 (1:25-1:50) The Transplant Experience Question and Answer Panel
Patients/caregivers: **Dr. Aubrey Goldstein, Pat Bandy, Joanne Grieme, Ali Lingerfelt-Tait**
Moderator: **Dr. Andrew Keaveny**
Presentation 9 (1:50-2:15) Financial Issues (Health Insurance/ Medicare/Disability/Pharmacy options) Question and Answer Panel
Panelists: **Christopher M. Toby**-Transplant Financial Co-ordinator
Ann T. Few- Transplant Financial Co-ordinator
Jason DuBois-Pharmacist/Solid Organ Transplant Clinical Specialist
Elaine Gustetic-Case Manager/Social Worker
Tiffany A. Norman-Pre-transplant nurse
Kelly A. Norman-Post-transplant nurse
Moderator: **Dr. Andrew Keaveny**
- 2:15 pm to 2:35 pm Break/snacks
- 2:35 pm to 4:00 pm Presentation 10 (2:35-2:55) What Can Genetic Studies Do for PSC?-**Dr. Tom Karlsen**, AASLD prize winner, Norwegian PSC Center, Medical Department, Rikshospitalet, Oslo, Norway
Presentation 11 (2:55-3:15) Thoughts on Vitamin A, IBD and PSC-**David Rhodes**, PhD. Purdue University, PSC Partners Seeking a Cure Board Member
Presentation 12 (3:15-3:35) STOPSC Genetic Database-**Dr. Dennis Black**, University of Tennessee, Memphis
Question and Answer Panel (3:35-4:00) Present and Future PSC Research
Moderator: **Dr. Barry G. Rosser**, Mayo Clinic
- 4:00 pm Hospital Tour
- 6:30 pm to 9 pm Evening Banquet : The Power of Humor-**Shelley Hussey**, PSC Caregiver/Author

SUNDAY MAY 4, 2008

- 7:00 am to 8:00 am Continental Breakfast
- 8:00 am to 8:15 am Presentation: Update on Dr. Chapman's Research-**Ivor Sweigler**, PhD., PSC UK Support Group
- 8:15 am to 8:45 am PSC Partners Seeking a Cure Progress Report (**David Rhodes**-Update on PSC Partners' supported research and **Deborah Wente**-foundation financial report)
- 8:45 am to 10:15 am Open Forum/Support Groups
Male PSCers/ Female PSCers/Spouses of PSCers/ Parents of PSCers/ PSCers on transplant list/ Post-transplant PSCers/PSCers in their 20s and 30s
- 10:15 am to 10:35 am Break/snacks
- 10:35 am to 11:50 am Open Forum Continuation
- 11:50 am to noon Closing Remarks-**Don and Ricky Safer**, PSC Partners Seeking a Cure



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

2008 Conference Registration Form

JACKSONVILLE, FLORIDA

Mayo Clinic

Friday May 2 (6:00 pm) – Sunday May 4 (Noon)

*****New addition this year*****

Last year's conference attendees asked for more social time in 2008, so we have put together two pre-conference activities which we think you will enjoy. Please think about joining us on Friday May 2 for:

GOLF TOURNAMENT at Windsor Parke Golf Course (5 minutes from Mayo)

7:30 Continental breakfast and warm up

8:30 Shotgun tournament starts, followed by lunch and awards ceremony

All level players are welcome, so please join us!

Cost \$60 per person (includes breakfast, lunch, golf, and range balls)

OR

BOAT TRIP ON THE ST. JOHN'S RIVER

Discover the beautiful St. John's River and the area's natural history and beauty by joining us on a two hour ecotour given by the St. John's Riverkeeper. A Riverkeeper staff member will escort us and provide commentary plus plenty of time to socialize. We have rented the boat specifically for our group. It is very comfortable and has a covered area. We have also rented a bus which will pick us up at the Courtyard by Marriott on the Mayo Campus at 9 a.m. The boat trip will last from 10 a.m.-noon, when the bus will pick us up and bring us back to the Courtyard by around 1 p.m. Cost is \$35 per person, which includes roundtrip bus transportation, the boat ride, and snacks with cold drinks. Hope to see you there!

Conference Fees:

- Standard (on or before April 4) \$170 per person, \$320 per couple
- Late (after April 4): \$190 per person, \$360 per couple

Registration Deadline: All fees must be received by April 18, 2008

Please print the next two pages and include this form with your check or money order made payable to: PSC Partners Seeking a Cure. We cannot accept credit cards.

Mail form & fees to:

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

Conference fee applies to ALL those who attend ANY PART of our conference.

Fees include: Presentations, breakout sessions, open forums, conference materials, and group meals/breaks/Friday night reception. Conference fees cannot be pro-rated. Pre-conference activities are a separate fee.

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

1. _____

PSC patient____ Transplant recipient____ Friend, relative and/or caregiver____

2. _____

PSC patient____ Transplant recipient____ Friend, relative and/or caregiver____

Address: _____

City/State/Zip/Country _____

E-mail: _____

Phone: _____ Cell: _____

Online name: _____

I would like my ___name ___address ___e-mail to be included in the 2008 conference attendee 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 join the hospital tour on Saturday at 4:20? Yes____No____Number of people _____

Will you be staying at the Courtyard by Marriott San Pablo? Yes___ No____

Will you be staying at The Inn at Mayo Clinic? Yes ___ No ___

• If yes, name on hotel reservation: _____

Will you be participating in The Road to Jacksonville fundraiser? Yes ___ No ___

• For more information, please visit <http://www.pscpartners.org/RtJ.htm>

Breakout Sessions for Saturday lunch: Please choose ONE for each registered attendee.

Male PSCers: Name_____

Female PSCers: Name_____

Spouses of PSCers: Name_____

Parents of PSCers: Name (s)_____

PSCers on transplant list: Name (s) _____

Post-transplant PSCers: Name_____

PSCers in their 20s and 30s: Name_____

Amount enclosed: US funds only, check or money order

Total: _____ \$170 per person, \$320 per couple - **On or before April 4**

Total: _____ \$190 per person, \$360 per couple - **After April 4**

Golf tournament _____\$60 per person Name(s) _____

Boat trip _____\$35 per person Name(s) _____

If you would like to be put on a mailing list or otherwise receive email messages from PSC Partners Seeking a Cure, please check one or more of the following boxes below:

- Information on annual conferences
- Online newsletters
- Fundraising updates/opportunities
- Volunteer opportunities
- Research updates
- None of the above

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 stamped self-addressed envelope with your registration form and check. Payment receipts will not be sent without a valid e-mail address or stamped self-addressed envelope enclosed.

Important Hotel Information:

The two hotels on the Mayo Campus are pleased to provide specially priced rooms for PSC Partners Seeking a Cure (\$85 per room per night plus tax at the Courtyard and \$89 per room per night plus tax at The Inn. A two bedroom unit at The Inn is \$219 per night.)

Attendees can reserve rooms at the Courtyard by Marriott San Pablo by phone or online. To make reservations by phone, call the hotel directly at 904 223-1700 or at their 800 number: 800 321-2211. Be sure to ask for the special rate for PSC Partners Seeking a Cure.

Attendees can reserve rooms at The Inn at Mayo Clinic by calling 904 992-9992 and asking for the special rate for the PSC Partners block.

A block of rooms has been reserved at this special rate at both hotels and will be allocated on a **first-come, first-served basis. Please make your reservations as soon as possible. The special group rate will expire when all allotted rooms have been reserved or on April 20, 2008, whichever comes first. Reservations after the cut off date will be accepted on a space available basis at the current rate that the hotel has available.** Cancellations will be accepted no later than six p.m. the day of arrival.

Both hotels are on the Mayo Campus, within short walking distance to the Cannaday Building, where the conference will be held. There is also a free shuttle service available on campus. The Courtyard has a fitness center, pool, complimentary high speed Internet, and a small restaurant. The Inn is a long term residence, and all rooms are suites with kitchens included. There is an exercise room and complimentary high speed Internet. Continental breakfast is included in the rate. The Inn is directly attached to the Cannaday Building.

Transportation from Jacksonville Airport to Mayo Clinic:

In Jacksonville, there is no shuttle that covers the roundtrip airport-Mayo route (35 miles each way) on a regular circulating basis, but after extensive research, here are the most reasonable and reliable options:

1. There are several reliable **private shuttle services**, but you must reserve **in advance!**

***George Goodwin at Errands and More 904 608-9866..\$48 one way for 1-2 passengers...After that, each additional passenger is \$15 per person...Vans available for larger groups.

***Express Shuttle 800 394-0116...From the airport to Mayo, this shuttle runs without needing reservations. The cost from the airport to Mayo is \$47.50 for 1-3 passengers...After that, each additional passenger is \$15. To get on the shuttle, go to Baggage Area B, go outdoors, and directly across is the Express Shuttle booth. However, from Mayo to the airport, you must **reserve at least 24-48 hours in advance.** The cost from Mayo to the airport is \$55 for 1-3 passengers...Each additional passenger is \$15...Vans available for larger groups.

***Mark at First Coast Personal Transportation 904 241-1678...\$58 one way for 1-2 passengers...Lesser charge for additional passengers...Vans available... You can call him or go online: www.firstcoastperson.com

***Meho at Celebrity Limo 904 887-7006...\$60 one way for 1-2 passengers...\$30 per person for additional passengers....You can call him or reserve online at www.mycelebritylimo.com

2. Taxi rates are \$65 one way.

3. Check online for car rental rates, as these may be as reasonable/more reasonable than the other options.

If you have any questions, please send an e-mail to Ricky Safer at contactus@pscpartners.org or thesafers@msn.com
Thank you for attending the 4th Annual PSC Partners Seeking a Cure conference in Jacksonville, Florida. We know it will be a very informative and exciting weekend filled with fun, hope and great people. We look forward to meeting you!

UPDATE TO DONATIONS TO PSC PARTNERS SEEKING A CURE

NOVEMBER 2007-FEBRUARY 2008

THE ROAD TO JACKSONVILLE FUNDRAISER

DONOR	IN HONOR OF
Rachel and Abe Gomel Libbie Bailey Penny and Tim Romlein Aubrey Goldstein and Caroline Vanneste	PSC Partners Seeking a Cure
Judy Rhodes' office staff	Steven Rhodes
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Nancy Moyers-Dey

Shelley and Fred Hussey
Ricky and Don Safer
Lee and Bill Bria
Alison and Brian White

Fred Hussey's 60th birthday

DONOR

Susan and Scott Malat
Jennifer Soloway

IN MEMORY OF

Seymour Cherniack
Phil Santens

**DONATIONS TO PSC PARTNERS SEEKING A CURE
NOVEMBER 2007-FEBRUARY 2008**

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Sima and Cliff Malat
Arne Myrabo
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Von Welch
Diane Cvetovich
Harvey Guffey
Keyo and Bruce Ross

IN HONOR OF

Steven Rhodes
Susan Malat
PSC Partners Seeking a Cure

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Julianne Wolf

Bill Wise

Del Leese and all loved ones

Mike Zaloudek

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Mary Ann Long

IN MEMORY OF

Mildred Olszewski

Cathy Dent

Thomas Rogers

Martha Altneu

Lillian Fiorello

A BIG THANK YOU TO OUR NEWEST SPONSORS (since November 2007)!

Platinum level sponsors:	Rachel and Abe Gomel
Gold level sponsors:	Cordis Corporation Goldman Sachs Matching Gift Program Susan and Scott Malat
Bronze level sponsors:	Judy and David Rhodes Lee and Bill Bria Steve Winber Sara and Robert Grover Daniel Stratemeier
Copper level sponsors:	Penny and Tim Romlein Sima and Cliff Malat Price Rosenberg and Bassik

Making Donations to PSC Partners Seeking a Cure

Tax-deductible donations can be sent to:

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

with a check made out to:

PSC Partners Seeking a Cure

Alternatively, donations can be made on-line via PayPal
(<https://www.paypal.com>)
to pscpartners@yahoo.com

Please include a note to indicate whom the donation is in honor
and/or in memory of, and your return address.

We offer several levels of sponsorship

- Platinum level: \$10,000
- Gold level: \$5,000
- Silver level: \$2,500
- Bronze level: \$1,000
- Copper level: \$500

Thank you for your generosity!

One of our foundation goals is to increase organ donor awareness. We encourage U.S.A. readers to visit www.donatelife.net and click on their state. This site gives a state by state guide to the organ donation process. This would be a good place for our members to start thinking about how to help locally, if they are interested....“While donated organs and tissue are shared at the national level, the laws that govern donation vary from state to state. Therefore, it is important for you to know what you can do to ensure your decision to be a donor is carried out.”



GiveLife

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.

Submitting Newsletter Articles

If you would like to contribute an article to a future issue of this Newsletter, please e-mail it to:
newsletter@pscpartners.org

Additional Contact Information

Ricky Safer is the principal contact person for our PSC Partners Seeking a Cure Foundation. She can be reached at:
contactus@pscpartners.org