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Bringing you news on PSC



PSC PARTNERS
SEEKING A CURE

research, education, and Support

PSC Partners Seeking a Cure Foundation Winter 2011

Hoping to See You in Sacramento!

It's that time of year again when our annual conference is fast approaching. This is a special newsletter edition dedicated to providing all the available information about our 2011 conference.

Our seventh conference for PSCers and caregivers will be held the weekend of April 29-May 1, 2011 at the Sheraton Grand in Sacramento, California, in conjunction with Dr. Chris Bowlus and his colleagues at the University of California Davis. We are expecting well over 200 attendees from throughout the United States and Canada, as well as from Australia, the UK, Sweden and Israel.

It is shaping up to be an exciting weekend with a lineup of impressive PSC experts from the University of California Davis, University of California San Francisco, California Pacific Medical Center, University of Toronto Canada, and the Norwegian PSC Research Center.

Add to that the positive, compassionate spirit of our PSC Partners family, and I can promise you an educational, uplifting and inspirational weekend, which is often life changing.

If you have not attended a previous conference, read carefully all the information in this newsletter edition, and feel free to write to us at contactus@pscpartners.org with any questions that may arise.

You will have many opportunities during the weekend to visit with other PSCers and caregivers to ask questions, share PSC concerns and experiences and to learn from each other.

By the end of the weekend, you will no longer feel alone in your fight against PSC. You will return home armed with updated medical knowledge and new friends who will continue to understand and support you.

Based on suggestions that we received in the 2010 post-conference evaluations, we have made some additions to our weekend agenda.

Starting Thursday morning (April 28) and continuing through Friday evening, attendees will be able to register early and receive their information packet. We will have a PSC Partners Seeking a Cure table in the lobby of the Sheraton

Grand where attendees can sign in as soon as they arrive.

We have also added two new sessions for first time attendees:

Newcomer Orientation and the Mentor/Mentee Meet and Greet. You can find details in the Conference Information sheet on page 8.

Starting Thursday and lasting through Sunday, we will have a dedicated lounge set up for the PSCers in their 20s/30s.

For PSCers who would like to volunteer for PSC research being done at UC Davis, there will be a blood draw done at various times during the weekend. To learn more about this program and/or to sign up, check the conference information section.

We hope that you'll be able to arrive in Sacramento early so that you can join us in Friday's pre-conference activities: brunch at the State Capitol Building followed by an interactive session on Nutrition, Exercise and Alternative Therapies for PSCers and caregivers alike (page 8).

If you can extend your stay before or after the conference, take the time to visit some of

California's special places nearby (San Francisco, Berkeley, Lake Tahoe, Napa and Sonoma Valleys). For more details, click here: <http://www.pscpartners.org/sites/default/files/files/pdfs/Things-to-Do-In-and-Around-Sacramento.pdf>.

I'd like to thank my team in California for helping plan details and logistics of the conference: Dr. Chris Bowlus of the University of California Davis and Joanne Hatchett and Jennifer Soloway, my conference co-chairs.

I'm counting the days until I can reconnect with my old PSC friends and meet the newcomers in Sacramento. Together, we'll learn the latest information about PSC and PSC research, share our personal concerns and suggestions, and enlarge our unique PSC family.

We'll laugh and we'll cry while we all experience the positive energy that emerges when we are together. Hoping to see you in Sacramento!

Together in the fight, whatever it takes! Wishing everyone a healthy, happy 2011!

Ricky Safer
President

Could you be a 2011 Conference Sponsor?

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

Several levels of donation are available: Premier Platinum Level Sponsorship (\$10,000), Gold Level (\$5,000) Silver Level (\$2500), and Bronze Level (\$1,000) are available.

Consider pooling donations with friends to have a greater impact. It's all tax deductible.



PSC Partners Seeking a Cure Conference Agenda: April 29-May 1, 2011

FRIDAY, APRIL 29, 2011

- 9:00 AM-5:00 PM Check in at PSC Partners registration table in Sheraton Grand Lobby
- 10:00 AM-
12:30 PM **Pre-Conference Event:** Brunch at State Capitol Building
- 12:50-3:35 PM **Healthy Living Perspectives: Nutrition, Exercise and Alternative Therapies**
Introduction: Integrated Chinese Medicine and PSC: Accessing the Best of East and West
Misha Ruth Cohen, DOM, Doctor of Oriental Medicine, Licensed Acupuncturist, Research Specialist, University of California San Francisco
- 4:30-5:00 PM **Newcomer Orientation**
- 5:00-5:30 PM **Mentor/Mentee Casual Meet and Greet**
- 5:30-8:00 PM **Registration and Welcome Dinner**

SATURDAY, April 30, 2011

- 7:30-8:30 AM **Buffet Breakfast**
- 8:30-8:40 AM **Opening Remarks:** Don and Ricky Safer, PSC Partners Seeking a Cure

SESSION I **Carlo Selmi, MD, Ph.D., Moderator**

Department of Translational Medicine, University of Milan, Assistant Professor of Medicine, Division of Rheumatology, Allergy and Clinical Immunology, University of California Davis

8:40-9:00 AM **Presentation 1: Introduction to PSC**
Christopher L. Bowlus, MD, Associate Professor, Division of Gastroenterology and Hepatology, University of California Davis

9:00-9:20 AM **Presentation 2: Urso: Pro vs. Con**
Gideon Hirschfield, MD, PhD, Clinician Investigator, Liver Center, Toronto Western Hospital, Toronto, Canada and Christopher L. Bowlus, MD, University of California Davis

9:20-9:40 AM **Presentation 3: Managing PSC Symptoms**
Natalie Torok, MD, Associate Professor, Division of Gastroenterology and Hepatology, University of California Davis

9:40-10:15 AM **Questions and Answers Panel:** Drs. Bowlus, Hirschfield and Torok

10:15-10:35 AM **BREAK WITH SNACKS**

SESSION II **Chrisopher L. Bowlus, MD, Moderator**

10:35-10:45 AM **Presentation 4: PSC Partners Research Grants Overview**
David Rhodes, PhD, Purdue University, Chair, PSC Partners Scientific/Medical Advisory Committee and Steven Miller, MD, PSC Partners Scientific/Medical Advisory Committee

10:45-11:05 AM **Presentation 5: PSC Immunology: Lessons to be Learned from PBC**
M. Eric Gershwin, MD, Distinguished Professor of Medicine, The Jack and Donald Chia Professor of Medicine, Division of Rheumatology, Allergy and Clinical Immunology, University of California Davis

11:05-11:25 AM **Presentation 6: New PSC Genes – What Should We Do With Them?**
Tom Hemming Karlsen, MD, PhD, Chief Executive Manager, Norwegian PSC Research Center, Clinic for Specialized Medicine & Surgery, Oslo University Hospital Rikshospitalet

11:25-Noon **Questions and Answers Panel:**
Drs. Gershwin, Karlsen, Rhodes, and Miller

12:05-1:15 PM **LUNCH**

BREAKOUT SESSIONS

1:15-2:00 PM **SESSION I**

IBD Management in PSC

Sooraj Tejaswi, MD, Division of Gastroenterology and Hepatology, University of California Davis

Pre-Transplantation and the MELD Score

Maurizio Bonacini, MD, Department of Liver Disease Management and Transplant, California Pacific Medical Center, Associate Professor of Clinical Medicine, University of California San Francisco

Interpreting Your Blood Tests

Christopher L. Bowlus, MD, University of California Davis

The Role of ERCP in PSC

James Ostroff, MD, FAGA, Lynne and Marc Benioff Endowed Chair, Kenneth Rainin Distinguished Professor, Professor of Medicine, Pediatrics and Radiology Director, Endoscopy Unit and GI Consultation Service, University of California San Francisco

Special Topics for Post-Transplant PSCers

Aubrey Goldstein, MD, PSC Post-Transplant Patient, and PSC Partners Scientific/Medical Advisory Committee

Ask a Chef: Natural Cuisine for Healthy Cooking

Russell Michel, Executive Chef Sheraton Grand Hotel, Celebrity Chef Winner 2010-Sacramento, Fox 40 Live "Ask a Chef"

Liver Transplantation and PSC

John McVicar, MD, Professor, Department of Transplant Surgery, University of California Davis

2:00-2:20 PM **BREAK**

2:20-3:05 PM **SESSION II**

IBD Management in PSC

Sooraj Tejaswi, MD, Division of Gastroenterology and Hepatology, University of California Davis

Coping for PSCers: Making Your Life More than PSC

Philip Burke, PhD, PSC Patient, Clinical Psychologist, Assistant Professor, Department of Psychology, Southern Illinois University at Carbondale

Pediatric PSC and Potential Therapies

Philip Rosenthal, MD, Professor of Pediatrics and Surgery, Medical Director, Pediatric Liver Transplant Program, Director, Pediatric Hepatology, University of California San Francisco

An Overview of Disability Law

Becky Long, PSC Partners Board Member and Legal Counsel

Screening and Treatments for Cholangiocarcinoma

Carlo Selmi, MD, University of Milan and University of California Davis

Practical Considerations Before Transplant

Panel of Post-Transplant PSC Patients and Caregivers

3:05-3:30 PM **BREAK WITH SNACKS**

3:30-4:15 PM **SESSION III**

Caregivers: Helping Us Help Others

Panel of PSC Caregivers

Medical Therapies on the Horizon

Drs. Bowlus, Selmi, Hirschfield and Karlsen

The Effects of Diet on Inflammation

Charles Stephensen, PhD, Adjunct Professor, Department of Nutrition, University of California Davis, USDA ARS Western Human Nutrition Research Center Scientist

Special Topics for 20s/30s PSCers

Valentina Medici, MD, Division of Gastroenterology and Hepatology, University of California Davis and Drew Ingram, MD, Fellow, Division of Gastroenterology and Hepatology, University of California Davis

Financial and Insurance Considerations for Transplant

Christina Allman, Financial Coordinator Supervisor, Transplant Program, University of California Davis

Ninth Inning Stretch: Relaxing Yoga

Amanda Gill and Billy Gill, Registered Yoga Instructors

6:00-9:00 PM **BANQUET DINNER**

SUNDAY, MAY 1, 2011

- 7:30-8:30 AM **Buffet Breakfast**
- 8:30-9:10 AM **Open Forum**
PSC Partners Foundation Report
Announcements and Foundation Updates
- 9:15-11:20 AM **Group Sessions in Breakout Rooms** (10:15-10:25: Break/Snacks)
College Age PSCers and Teenaged 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
- 11:30-12:20 AM **Open Forum Reconvenes: Feedback from Group Sessions**
- 12:20-12:30 PM **Closing**
Don and Ricky Safer, PSC Partners Seeking a Cure Foundation

2011 Conference Information

PSC Partners Seeking a Cure's seventh annual conference for PSCers and caregivers will take place April 29-May 1, 2011 at the Sheraton Grand Hotel in Sacramento, California in conjunction with Dr. Christopher L. Bowlus and his colleagues at the University of California Davis.

We hope that you'll consider arriving in Sacramento by Thursday evening to participate in our pre-conference activities. Last year, more than half of the conference attendees came early. They greatly appreciated the chance to get acquainted with the other participants and gain healthy living tips before the official start of the conference.

PRE-CONFERENCE ACTIVITIES FOR FRIDAY, APRIL 29

GET ACQUAINTED BRUNCH: 10:00 a.m.-12:30 p.m. (fee \$10 per person): Please join us for an informal brunch at the State Capitol Building (10th and L Streets) to meet fellow PSCers and caregivers.

If you're up early, take time to visit this beautiful historical building, which has been the heart of California state government since 1869. There is an interesting museum and a self-guided tour. Also, take a stroll through surrounding Capitol Park, designed as a Victorian garden with forty acres of trees and plants from around the world as well as cultural and historic monuments. The State Capitol Building is a five to eight minute walk from the Sheraton Grand.

HEALTHY PERSPECTIVES: NUTRITION, EXERCISE AND ALTERNATIVE THERAPIES from 12:50 to 3:35 p.m. (Held at the Sheraton Grand). This session is targeted for both PSCers and caregivers. Come in casual or workout clothes and be ready for some new experiences. Our introductory speaker Dr. Misha Ruth Cohen (Doctor of Oriental Medicine, Licensed Acupuncturist and Research Specialist at the University of California San Francisco) will speak about Integrated Chinese Medicine and PSC: Accessing the Best of East and West.

After Dr. Cohen's presentation, attendees will be able to choose two interactive breakout sessions from a variety of choices such as Exercise for PSCers by PSCers Julianne Vasichek and Cameron Wohl, Organic Cooking Demonstration by Patrick Mulvaney of award-winning Sacramento Mulvaney's S & L Restaurant, The Value of Eating Organically by Shawn Harrison, Executive Director of Soil Born Farms and UC patient, Interactive Yoga by Amanda and Billy Gill, Hints for Gluten Free Eating by a representative from the Gluten Free Specialty Store, and others.

To take advantage of Sacramento's location in an agricultural valley, we will also be holding a Mini Farmer's Market where booths will be staffed by farmers selling their local products. There will also be a bookstore with a display of healthy eating cookbooks, etc.

Please join us for an exciting start to our weekend.

NEWCOMER ORIENTATION FOR FIRST TIME ATTENDEES from 4:30-5 p.m. The goal of this short session is to give first time attendees a head start in understanding what you'll experience during the weekend and how to get the most out of the three days. 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'll give you 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 5-5:30 p.m. If you are a first time attendee (either a PSCer or a caregiver), when you fill out your registration form, we suggest that you request a mentor. We will match you with a mentor who will be in your same group during the weekend. You will have the opportunity to communicate with your mentor before the conference and have your questions answered. 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 AGENDA

Please check out the conference agenda for details of the rest of the weekend on page 3.

NOTE: With the exception of the Friday morning brunch at the State Capitol Building, all weekend activities will take place in the Sheraton Grand, so you will NOT need a car.

For the first time this year, we will have a PSC Partners Seeking a Cure table in the Sheraton lobby from Thursday morning through Friday evening, so that attendees can complete early registration and pick up their information packets as soon as they arrive at the Sheraton Grand.

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 applies to ALL those who attend ANY PART of our conference and cannot be pro-rated.

We have made two changes in our registration process this year:

Each attendee must register separately.

The registration fee depends on when you register.

Early Registration: \$150/person until 2/28/11

Regular Registration: \$160 per person 3/1-3/30/11

Late Registration: \$180 per person 3/31 to 4/15/11

Friday pre-conference brunch: \$10 per person*

*The brunch fee is NOT included in the conference fee and should be added to your conference fees if you are planning to attend the Get Acquainted Brunch on Friday.

All fees must be received by April 15, 2011.

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 2011 conference sponsors subsidize a significant portion of your conference costs. (In 2010, the registration fee per person covered less than half the cost for each attendee; the rest was covered by our generous conference sponsors).

Thank you to our 2011 conference sponsors so far:

Early Bird Conference Rates Will Expire on These Dates

Do your budget a favor and register for the conference before the late fees apply.

March 30, 2011: Register for the conference at the standard rate on or before March 30, when a late registration fee starts. (Our online registration will be available soon, and will be announced on our website.)

April 8, 2011: Reserve your room at our \$99 special group rate at the Sheraton Grand before the April 8 cutoff date. The special group rate will expire when all allotted rooms have been reserved or on April 8, whichever comes first.

You can still register after those dates, but not at the lower rate.

Sharing: Another Way to Save at the Conference

If you're interested in sharing a ride to the hotel from the airport or in sharing a room, let us know. We can't make any guarantees, but we may be able to match you with another conference-goer. To make a connection contact Sandi at: sandi@pscpartners.org

Premier Platinum Level Sponsors: Anonymous

Gold Level Sponsors: Don and Ricky Safer

Silver Level Sponsors: Ken and Patty Shepherd and Stephen and Joanne Hatchett

We are still in the process of looking for individual or corporate conference sponsors, so if you are interested in becoming a conference sponsor or if you know someone whom we should contact, please write to us at contactus@pscpartners.org.

TO REGISTER: Registration for the 2011 conference will be available soon. We are finalizing a new and improved online registration system. As soon as online registration is available, we will post a message on our website and send a notice to everyone on our mailing list. We appreciate your patience.

Please consider helping with our **Itching for a Cure/ Road to Sacramento** fundraiser to raise money for PSC research (www.pscpartners.org/fundraisers). Join us on the real or virtual road to Sacramento and help us all get closer to finding a cure for PSC.

MISCELLANEOUS INFORMATION

PARTICIPATE IN PSC RESEARCH WHILE YOU

ARE IN SACRAMENTO: Dr. Bowlus and his research team will be enrolling patients into the UC

Davis PSC Patient Registry during the PSC Partners annual conference. Participation requires providing some of your medical records related to PSC and a blood draw. If you are interested, contact Mia Minoletti at mia.minoletti@ucdmc.ucdavis.edu or 916 703-5501 for details.

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 at any time.

Click here for our conference flyer:

http://pscpartners.org/sites/default/files/files/pdfs/2011_conference_flyer.pdf. Please print copies and deliver the flyers to your gastroenterologist or hepatologist to display in his/her office.

Click here to view information about Sacramento: <http://www.pscpartners.org/sites/default/files/files/pdfs/Slideshow-announcing-2011.pdf>

When planning your trip to Sacramento, please click here for some ideas of what to do in Sacramento <http://www.pscpartners.org/sites/default/files/files/pdfs/Things-to-Do-In-and-Around-Sacramento.pdf>.

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 that you'll be available behind the scenes to make it a success.

Thank you!

If you would like to automatically receive all updates about the conference, our research grants and our foundation projects, please click on www.pscpartners.org to sign up for our online mailing list.

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: www.pscpartners.org/annualconferences

To read “The Top Ten Reasons to Attend a PSC Partners Conference” click here: www.pscpartners.org/patientconferences#personal).

To read FAQs about our conference, click here: http://pscpartners.org/sites/default/files/files/pdfs/2011_Conference_FAQs.pdf .

Thank you for your interest in the seventh 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.

IMPORTANT HOTEL INFORMATION

All conference events (starting Friday afternoon April 29) will take place at the Sheraton Grand Sacramento (1230 J Street) www.sheraton.com/sacramento . The Sheraton Grand is conveniently located in the heart of downtown Sacramento. The beautifully restored building designed by Julia Morgan, who also designed the Hearst Castle, served as the Public Market Building for fifty years. It has a small heated outdoor pool and a fitness center that is open 24 hours a day. The Sheraton Grand will be a great facility for us, since there are many public areas in which to chat informally with other attendees.

We are pleased to offer a room block at the Sheraton Grand Sacramento at the special PSC Partners group rate of \$99 plus state and local taxes for a standard room. This group rate is available to our attendees from April 28 through May 1. If you would like to add dates before or after the conference, the Sheraton Grand will try to provide them.

The reserved room block will be allocated on a first-come, first-served basis. **The cutoff date for the discounted group rate is 5 p.m. California time on APRIL 8.** The special group rate will expire when all allotted rooms have been reserved or on April 8, whichever comes first. After April 8, 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.** Please note that this year, we do not have the flexibility to add rooms to the group block once the reserved block is full.

If you would like to check into the possibility of sharing a hotel room with another conference attendee, please send your arrival dates and information to sandi@pscpartners.org along with any requirements (male/female/non-smoker, etc.) Room-sharing availability cannot be guaranteed.

To reserve your room:

ONLINE: The Sheraton Grand has created a personalized website for PSC Partners Seeking a Cure at <http://www.starwoodmeeting.com/StarGroupsWeb/booking/reservation?id=1006307434&key=9382C>

BY PHONE: Call Sheraton Central Reservations at 1 800 325-3535 and identify yourself as an attendee at the PSC Partners Seeking a Cure conference.

TRANSPORTATION TO SACRAMENTO

Flying into Sacramento International Airport:

You can get comprehensive information about Sacramento International Airport at: <http://www.sacairports.org/int/>

Sacramento International Airport (SMF) is your gateway to Northern California destinations and major cities across the U.S., and the world. Located 12 miles from downtown Sacramento and always open, service is available from 13 major carriers and one commuter airline.

Terminal A Airlines	
Delta Air Lines (Northwest)	(800) 221-1212
Hawaiian Airlines	(800) 367-5320
Southwest Airlines	(800) 435-9792
U.S. Airways	(800) 428-4322

Terminal B Airlines	
Alaska Airlines (B2)	(800) 426-0333
American Airlines (B1) Check in at counter in B1; arrivals in B2.	(800) 433-7300
Continental Airlines (B2)	(800) 523-3273
Frontier Airlines (B1)	(800) 265-5505
Horizon Air (B2)	(800) 547-9308
JetBlue (B2)	(800) 538-2583
United Airlines/United Express (B1)	(800) 241-6522

Sacramento International Airport (SMF) has over 140 nonstop and over 170 direct flights daily.

Ground Transportation to Sheraton Grand from the Sacramento Airport

Comprehensive information about ground transportation to downtown Sacramento is found at:

http://www.sacairports.org/int/parking/ground_transporation.html

SuperShuttle:

This is a shared van service. There is no need for a reservation for transportation from the airport to downtown.

Arriving at SMF Terminal A:

Proceed to the baggage claim area and claim your luggage. The SuperShuttle counter is located inside the baggage claim area just beyond the second carousel.

Arriving at SMF Terminal B:

Proceed to the baggage claim area and claim your luggage. The SuperShuttle booth is located outside of the terminal between Terminals B-1 and B-2, just outside the food court.

Fares are \$13 per person to the Sheraton Grand. The return trip to the airport is also \$13. Please call (800) 258-3826 for more information.

Yolobus: This public bus is the least expensive way to get to downtown Sacramento. You can call (530) 666-2877 for schedules or more information. Detailed information is also available at: <http://www.yolobus.com/>

The bus runs about once per hour and takes less than 30 minutes to get to the stop at J Street and 11th Street. The Sheraton Grand is one block east at J and 12th.

****RIDE SHARE:** If you would like to check into the possibility of sharing a ride to or from the airport with another conference attendee, please send your arrival and departure dates and times along with the airport you'll be using to Sandi at sandi@pscpartners.org . Ride sharing cannot be guaranteed.

Rental Cars:

Most major car rental companies are located at the Rental Car Terminal: [Alamo](#) (800) 327-9633 [Avis](#) (916) 922-5601 [Budget](#) (800) 763-2999 [Dollar](#) (800) 800-4000 [Enterprise](#) (800) 736-8227 [Hertz](#) (800) 654-3131 [National](#) (800) 227-7366.

Catch a shuttle to the Rental Car Terminal at the marked shuttle stop island in front of Terminals A and B.

Since all the conference activities take place at the Sheraton Grand Hotel (except for the Friday brunch, which is a five minute walk), you will NOT need a car for the weekend.

Taxis:

There are taxi stands at both Terminals A and B. Taxis are operated under a contract with the airport.

Rates Effective May 18, 2010:

\$3 flag drop, \$2.50 for each additional mile

Rate to wait is \$25 per hour

Round-trip between airport and downtown Sacramento is \$56.00

Seniors and military personnel are eligible for a 20% discount

Contact information:

Reservations/Information
916-444-0008

Customer Service
916-284-6878

While at the airport, dial extension 24360 from a white courtesy phone for more information.

Ground Transportation from San Francisco International Airport

San Francisco International Airport is located about 25 miles south of the city and county of San Francisco. If you plan to visit San Francisco before going to Sacramento, you will need to take public transit, taxi, van or some other form of transportation. Because of heavy traffic, scarce parking and good public transit, many tourists do not drive in San Francisco.

CAR RENTAL:

Alamo, Avis, Budget, Dollar, Enterprise, Fox, Hertz, National and Thrifty car rental counters are located on the fourth floor of the SFO Rental Car Center, which is in a separate terminal. Air passengers can get to the SFO Rental Car Center via the AirTrain BLUE Line.

Note: Driving times from the San Francisco area to Sacramento are very unpredictable, due to frequent traffic jams. If there is light traffic, the drive can take two hours, but especially around the weekend, the drive could take up to four hours.

**Our Latest Fundraising
Challenge:
We Can Do It!**

Check our website map to
see how close we are to the
goal:

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



**Itching
for a Cure**
Road to Sacramento
Fundraising Challenge
PSC Partners Seeking a Cure

Bay Area Rapid Transit (BART):

Bart is a subway system that can take you to San Francisco, a few locations to the south, and numerous East Bay locations (Oakland, Berkeley, etc.) There are three BART terminals in the San Francisco airport. It takes about 1 hour to travel from the airport to downtown San Francisco. BART does not go to Sacramento but, there are several options for taking BART to either an AMTRAK Bus in San Francisco or the AMTRAK station in Richmond and transfer to an AMTRAK Capitol Corridor train to Sacramento. BART trains run frequently but, time between AMTRAK trains to Sacramento is over one hour.

If you plan to take BART and Amtrak to Sacramento, please consult the Amtrak Capitol Corridor website (<http://www.capitolcorridor.org/>) and the BART website (<http://www.bart.gov/>). Because this trip includes at least two transfers and limited AMTRAK trains, it is wise to plan this trip in advance.

The Sacramento AMTRAK station is a historic building located at 401 "I" Street @ 4th, about 1 mile from the Sheraton Grand. To walk to the Sheraton, walk east on I Street (the freeway should be at your back) until you get to 12th Street. Cross I Street and walk one block to the Sheraton Grand on J and 12th Street. There is no direct public bus service from the train station to the hotel.

Van and Limousine Service:

You can take a pre-arranged van from the San Francisco airport to Sacramento. Visit <http://www.davisairporter.com/> for information and reservations for a shared van to Sacramento. Prices are about \$85 to \$105 per person.

There are a number of limousine services that will drive passengers from San Francisco International Airport to Sacramento. Numerous limousine services are listed at <http://www.flysfo.com/web/page/tofrom/transp-serv/limo/index.html>. Limousine services should be reserved in advance. The airport web site cautions against accepting offers of limousine transportation made at the airport.

Ground Transportation from Oakland International Airport

BART:

There is an AIRBART shuttle located between Terminals 1 and 2 that will transport passengers to the nearby Oakland Coliseum/Oakland Airport BART station. At this BART station, passengers can transfer to a Capitol Corridor AMTRAK train to Sacramento. Because of the limited number of trains to Sacramento, advance planning is recommended. Check the websites listed in San Francisco Ground Transportation above.

Shuttles and Limousines:

There is a list of limousine companies and shuttle companies that serve Oakland Airport. The chart

listing shuttle services notes several that provide door-to-door service to Sacramento.

There is a list of limousine companies and shuttle companies that serve Oakland Airport. The chart listing shuttle services notes several that provide door-to-door service to Sacramento: <http://www.flyoakland.com/shuttles.shtml>

MAP OF DOWNTOWN SACRAMENTO, CALIFORNIA



PARKING AT THE SHERATON GRAND SACRAMENTO

If you are driving to Sacramento, here is parking information for meeting attendees:

Directions to enter the Sheraton Grand Sacramento Hotel Garage:

On J Street, turn left at 13th Street

On 13th Street, turn left into the garage.

Rates:

Self Park:

\$1.50 each ½ hour

\$13 per 24 hours (registered guest)

\$6 flat fee 6 p.m. -1 a.m.

Valet:

\$6 for the first hour

\$4 for a fraction thereof

\$25 per 24 hours (registered guest)

Rates apply at the Sheraton Grand Hotel Garage only and are subject to change without notice.

OTHER PARKING OPTIONS

A Downtown Sacramento Parking Lot map can be found at http://www.cityofsacramento.org/transportation/dot_media/parking_media/pdf/Off_Map.pdf

Public Garages within a short walk of the Sheraton Grand are:

City Hall Garage (entrances on 10th and 11th Streets between J and I)

Capitol Garage (entrances on 10 and 11th Streets between L and K)

Memorial Garage (entrances on 14th and 15th Streets between L and K)

East End Garage (entrance on 17th Street between L and Capital (same as M) (about 5 blocks from Sheraton)

Public Open Lot:

Lot D (entrances on 13th and 14th Streets between I and H)

Rates: The hourly rate at the Capitol and City Hall Garages is \$1.50 per 1/2 hour. Weekdays Capital and City Hall Garage Maximum is \$15.00 and on weekends Maximum is \$5.00. Weekdays the Memorial Garage Maximum is \$14.00 and weekends and weeknights (after 6 p.m.) it is \$6.00. The Memorial Garage hourly rate is \$1.50 per 1/2 hour for the first hour and \$1.00 per 1/2 hour thereafter. The East End Garage is free the first 90 minutes and \$1.00 per hour thereafter. The East End Maximum is \$5.00.

Lot D has a flat rate of \$8.00.

Some facilities use automated payment machines that require a credit card.

NOTE: On Friday and Monday, these garages and lots may be full or crowded with monthly parkers and cars parked for other conventions. There should be sufficient parking on Saturday and Sunday. There are a number of private lots and parking garages near the Sheraton Grand.

There are also public parking facilities further away. A map of all city-owned garages and lots can be found at http://www.cityofsacramento.org/transportation/dot_media/parking_media/pdf/Off_Map.pdf

Sanity Street

by Sandi Pearlman, who will attend her fourth PSC Partners conference this year

Do you remember the opening song to Sesame Street? It goes something like this: “Sunny day, sweepin’ the clouds away. On my way to where the air is sweet.”

I mean, sure, in the case of the song it’s all about how to get to Sesame Street. But I think we can co-opt it a bit and substitute “Sanity Street” instead.

Because the lyrics to the song are so fitting it’s almost like they were written for a PSC Partners conference. The air is sweet and everything is always A-Okay when we’re together.

*“Come and play
Everything’s A-OK
Friendly neighbors there*

That’s where we meet”

Every year the PSC Partners conference changes locations and, this year, we’re in sunny Sacramento, the capital of California. It’s a place known for an abundance of sunshine and nothing could be more apropos in this particular case.

Too often PSC can make us feel like we’re in the shadows, like we have to search for sunlight and happiness. We’re others. We’re alone and we’re trying to navigate a world in which we’re the Oscar the Grouches of Sesame Street, the ones who are always left out of the fun and freedom the rest of the world so easily enjoys.

We’re stuck in our little “trashcans” dealing with what our bodies have handed us and have trouble



NEW THIS YEAR—JUST FOR CONFERENCE FIRST-TIMERS!!!

We’ve set up a Friday afternoon 30-Minute Newcomer Orientation exclusively for those attending our conference for the first time.

Get the scoop on who’s who, an overview of the medical presentations you’ll hear, learn about our dot ID system, what to wear, and ask the questions you might be reluctant to ask in front of the larger group.

The whirlwind session will give you a chance to meet other first-timers and get a head start on a positive conference experience.

realizing that all we have to do is accept the wonders of the world in order to feel we're more than and not less than.

At a PSC Partners conference, there's just no chance to feel like an outsider. We come from all over the world and speak many different languages. We're in all stages and all have different levels of knowledge about PSC and what it means. Some of us are well-informed, some of us just beginning our PSCer journeys. It doesn't make a difference.

Upon walking in, the love is so overwhelming that there's no chance to feel estranged or removed and the warmth is so empowering that we simply can't shut our lids tight and not experience it all.

Whether we itch or can't get through the day without a nap or a caregiver, there's somebody else who not only gets it but who lives it. There are real-life experiences, answers, empathy and compassion and it's all there just for all of us.

We're not just strangers in the same place because of circumstances; we're family, caregivers, and PSCers.

We're one and the same, brothers and sisters together in a fight for all of our lives and determined to find the joy and power in each and every day.

*"It's a magic carpet ride
Every door will open wide
To happy people like you--
Happy people like
What a beautiful sunny day"*

Every conference includes experts in the field and this one is no different. We've got doctors from a renowned PSC clinic attending,

researchers who are dedicated to helping us unravel the mysteries of PSC, experts in hepatology. We have psychologists who know the best ways in which we can help ourselves understand the enigma of our illness and what PSC is doing to our bodies and minds.

We have physicians and PSCers alike who are all too ready and willing to share the ways in which we can be proactive and ask all the right questions of our medical facilities back home.

We have question and answer panels and a chance to make our voices heard. We discuss the ups and downs of searching for a cure and all the aspects that worry us and bring us cheer when it comes to discoveries that are being made every single day. All of this is vitally important.

But perhaps even more so, we're together, PSCers and caregivers. We laugh and we cry. There may occasionally be tears streaming down our faces but also laughter so loud that it's hard to believe that we're an alcohol free group dealing with the realities of a disease for which there is really no known treatment or a cure as of yet.

We're free to be ourselves in a way that is judgment free and unavailable anywhere else on the planet. Every cell, every breath, every thought is lit up with love and understanding and when there's fear or doubt or worry, there are hundreds of willing shoulders to lean on and arms to wrap around you.

It's okay to be a PSCer. It's okay to be scared. It's okay to be you, no matter what that means.

*"Sunny Day
Sweepin' the clouds away
On my way to where the air is sweet
Can you tell me how to get,*

How to get to Sesame Street...”

The air is sweet at a PSC Partners conference. And even better, like the famed Sesame Street, we are all neighbors no matter where we come from. We’re bonded like Bert and Ernie, feel over 8 feet tall like Big Bird and are free to revel in the little joys and victories like Cookie Monster when he finds a cookie.

For those that have been to a conference before, you know all too well that it changes you down to your very core, making life at once easier to deal with and so much more hopeful.

For those of you who haven’t yet experienced it, please join us. I guarantee you won’t regret it. You may feel as though all hope is lost, but the sun shines bright here and the clouds really do get swept away.

Oh, and the best part: our version of Sesame Street, is without end. It stretches from Israel to Australia, Louisiana to Victoria, Stockholm to South Dakota and Florida to Fiji. It’s without end and we’ve definitely got room for you on our street and in our lives.

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

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

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The Duct Newsletter

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