



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

CONFERENCE FOR PATIENTS AND CAREGIVERS APRIL 29-MAY 1 GRAND HYATT DENVER

Welcome to the first annual conference of PSC Partners Seeking a Cure. Thank you for joining us! Here is our agenda for the weekend. All events will take place in the Pinnacle Club by Grand Hyatt, which is a set of rooms in the building adjacent to the Grand Hyatt Hotel.

- Friday's reception and Saturday's and Sunday's meals will all be in the Staircase Foyer on the 37th floor of the Pinnacle Club.
- Saturday's and Sunday's meetings will all take place in the San Luis Peak Room on the 38th floor of the Pinnacle Club (which can be accessed by elevator or by the staircase in the Foyer.)

AGENDA

Friday, April 29, 2005:

- 5:30 PM - 7:30 PM Reception; Welcoming Remarks (Don and Ricky Safer; PSC Partners Seeking a Cure)
- 7:30 PM Dinner on your own

Saturday, April 30, 2005:

- 7:00 AM - 8:00 AM Continental Breakfast and display tables
- 8:00 AM - 8:15 AM Opening Remarks (Don Safer; PSC Partners and Arne Myrabo; PSC Support Group)
- 8:15 AM - 10:00 AM
 - Dr. Gregory T. Everson (Introduction to PSC: The Top Ten Clinical Issues for Patients and Families) 20 minute talk
 - Dr. James F. Trotter (Non-Surgical Management of PSC) 20 minute talk
 - Dr. Joel Levine (IBD in Patients with PSC) 20 minute talk
 - Panel (Dr. Everson, Dr. Trotter, Dr. Levine) Q and A for 45 minutes
- 10:00 AM - 10:15 AM Break/snacks and display tables
- 10:15 AM - 12:00 Noon
 - Dr. Igal Kam (Transplantation for PSC) 20 minutes
 - Dr. Lisa Forman (Post-Transplant Issues) 20 minutes

- Chris Klug (To the Edge and Back: My Story from Organ Transplant Survivor to Olympic Snowboarder) 20 minutes
 - Panel (Dr. Kam, Dr. Forman, Chris) Q and A for 45 minutes
- 12:00 Noon - 1:15 PM Box lunch, display tables, and Chris Klug book signing
- 1:15 PM - 2:30 PM
 - Dr. Lisa Corbin (CAM Therapies) 20 minute talk
 - Georgeane Vigue (Nutrition and PSC) 20 minute talk
 - Panel (Dr. Corbin, Georgeane) Q and A for 35 minutes
- 2:30 PM - 3:15 PM Marlene Murphy (Overview of Donor Awareness)
- 3:15 PM - 3:30 PM Break/snacks
- 3:30 PM – 4:40 PM
 - David Rhodes (PSC: Perspectives from a Care-Giver) 20 minute talk
 - Dr. Aubrey Goldstein (PSC: Perspectives from a Transplant Recipient and M.D.) 20 minute talk
 - Panel (David and Aubrey) Q and A for 30 minutes
- 5:00 PM Dinner on your own (See list of restaurants within walking distance in your conference bag)

Sunday, May 1, 2005: Come join us for roundtable discussions so that you can meet each other, and get ideas from each other on being PSC patients/caregivers/friends & family. We will have different sessions, where we will be: (a) splitting into two groups: patients and caregivers/friends/family and discussing issues of concern for each group, (b) splitting into regional groups and different interest groups to discuss future education, support, donor awareness and fundraising efforts for the foundation.

7:00 AM - 8:00 AM Continental Breakfast

- 8:00 AM – 12:00 noon Round-Table Discussions: Discussion leaders Lee Bria, David Rhodes, and Ricky Safer
- 10:00 AM - 10:15 AM Coffee Break/Snacks
- 12:00 PM Adjourn

Speaker Affiliations:

Gregory T. Everson, M.D. ¹
 Professor of Medicine
 Director of Hepatology

¹ Division of Gastroenterology and Hepatology, Department of Medicine, University of Colorado Health Sciences Center (USHSC), Denver, CO

James F. Trotter, M.D.¹
Associate Professor of Medicine
Associate Medical Director of Liver Transplantation

Joel Levine, M.D.¹
Professor of Medicine
Interim Division Head

Igal Kam, M.D.²
Professor of Surgery
Chief of Division of Transplant Surgery

Lisa Forman, M.D.¹
Assistant Professor of Medicine
Associate Director of Gastroenterology and Hepatology Training Program

Chris Klug
Professional Snowboarder, Olympic Medal Winner, Liver Transplant Recipient,
and Author

Lisa Corbin, M.D.
Medical Director, The Center for Integrative Medicine, University of Colorado
Hospital, Denver, CO

Georgeane Vigue RD, CNSD
Clinical Dietitian at University of Colorado Hospital, Denver, CO

Marlene Murphy
Executive Director of the Donor Awareness Council, Denver, CO

David Rhodes(PSC Support Group)
Professor, Department of Horticulture and Landscape Architecture, Purdue
University, West Lafayette, IN

Aubrey Goldstein, M.D. (former PSC Support Group member)
Chronic Care Physician, St. Vincents Hospital
Ottawa, Canada

DISPLAY TABLES

The following groups will have display tables set up in the Staircase Foyer SATURDAY morning from 7a.m. through lunchtime (1:15 p.m.) Please take the time to pick up brochures and ask all your questions.

Axcan Pharma

² Department of Surgery, University of Colorado Health Sciences Center, Denver CO

Procter and Gamble
Salix Pharmaceuticals
Donor Awareness Council
Crohn's and Colitis Foundation of America (CCFA)
American Liver Foundation

SPONSORS

We would like to thank our sponsors for making this weekend possible.

Thank you to:

Axcan Pharma-Gold level sponsor
Don and Ricky Safer-Silver level sponsor
Citi Cards-Bronze level sponsor
Jon Shapiro-Bronze level sponsor
Procter and Gamble-Copper level sponsor
Salix Pharmaceuticals-Copper level sponsor
Jason Drasner-Copper level sponsor

We are indebted to all the speakers who have agreed to contribute to this conference, especially Dr. Gregory T. Everson and his colleagues from the University of Colorado Health Sciences Center.

We also thank all those members of the PSC support group, and their family, friends and caregivers, who have generously donated their time and funds to the PSC Partners Seeking a Cure foundation.

MORE THANK YOUS

Thank you to Joanne Grieme (Pennsylvania) for her generous donation of our beautiful PSC Partners Seeing a Cure conference bags.

Thank you to Bill Wise for spearheading the wristband project.

Thank you to Ali Lingerfelt-Tait for designing the PSC Partners all-purpose greeting cards.

Thank you to Patti Smith (a friend of the Safers) for creating and donating the candle bookmarks.

Thank you to the Donor Awareness Council for the Donate Life pins, pens, and wristbands in your conference bags.

Thank you everyone from the co-founders David Rhodes, Lee Bria, and Ricky Safer.

GENERAL INFORMATION

If you have questions about nearby restaurants or places to take a walk, feel free to ask the concierge at the Grand Hyatt (303 295-5878) or any of our Colorado attendees.

We've also included a list of nearby restaurants and a Denver information booklet in your conference bags.

If you are from outside of Colorado, you may feel some effects from Denver's mile high altitude (even more than the usual PSC fatigue and/or headaches.) Take it easy your first day here and be sure to drink a lot of water because of our dry climate.

If you have any other questions about the conference, please ask Ricky or Don Safer, Lee Bria, or Dave Rhodes.

INFORMATION ABOUT PSC PARTNERS SEEKING A CURE

PSC Partners Seeking a Cure is a 501(c)3 nonprofit organization that endeavors to find a cure for Primary Sclerosing Cholangitis. The mission of PSC Partners Seeking a Cure is to: (i) raise funds with which to research the causes and cures of PSC; (ii) promote PSC and organ donor awareness; and (iii) provide education and support to PSC patients and their families.

PSC Partners has started to reach out to PSC patients and their caregivers, friends and family. We have expanded our already existing PSC literature site (described below), which includes over 24,500 research abstracts. Physicians studying PSC have already consulted the site as a resource, and requested files. Through our website, we are reaching new PSCers throughout the United States and in many foreign countries. We have also published and distributed three editions of our PSC newsletter, and will continue to publish these newsletters periodically. In the next year, we are hoping to start regional PSC support groups. PSC Partners members have also begun to work on organ donor awareness programs at their place of work, school, and within their communities.

PSC Partners has been very excited with all the support it has already received. Thanks to the leadership of Lee Bria, we have received many corporate and individual donations, and are in the process of kicking off a fundraising campaign. We are currently working on fundraising projects selling foundation wristbands and all purpose notecards.

This is our first conference and we are pleased to announce that we have 80 attendees from 21 states in the U.S., from Canada, and the U.K.

To learn more about the foundation, please log on to <http://www.pscpartners.org>.

OTHER RECOMMENDED PSC RESOURCES

Many of the original members of PSC Partners met through a PSC online support group at <http://health.groups.yahoo.com/group/psc-support/>. This message board (forum) which was established in 1998, is a place where PSC patients and care-givers can exchange information and lend support/advice to one another. We welcome you to join us in this online group—it is a very positive community of PSCers who are very knowledgeable about the disease and very compassionate about helping each other.

The Yahoo support group is closely affiliated with the PSC support group in the U.K. (with a membership of about 300). The latter group publishes a wonderful newsletter (PSC News) and holds an annual meeting in Oxford with a leading world expert on PSC,

Dr. Roger Chapman. <http://www.psc-support.demon.co.uk/> Many members of the U.K. support group participate in the Yahoo forum, and many members of the Yahoo forum subscribe to (or contribute articles to) the U.K. PSC News newsletter. Ivor Sweigler, the head of the UK group, is in attendance with us this weekend.

The PSC Literature web site was developed in 2004 by David and Judith Rhodes and continues to be updated to provide PSC patients and caregivers with easy access to a vast body of information available on the Internet concerning PSC and allied diseases.

<http://www.psc-literature.org/> This site includes links to hundreds of www resources, and links to over 24,500 research abstracts (organized by keyword, authors and dates) for those interested in exploring the scientific literature in detail. This site currently serves about 1,900 distinct hosts per month; the hosts are located in over 40 different countries.

Here are some other useful links for PSCers.

Crohn's and Colitis Foundation of America: <http://www.ccfa.org/>

Coalition on Donation – Donate Life: <http://www.donatelife.net/>

PSC Literature: <http://www.psc-literature.org/>

IBD Patient Community: <http://ibd.patientcommunity.com/>

PSC Partners Seeking a Cure: <http://www.pscpartners.org/>

United Network for Organ Sharing: <http://www.unos.org/>

American Liver Foundation: <http://www.liverfoundation.org/>

Falk Foundation: <http://www.falkfoundation.com/>

PSC Support U.K.: <http://www.psc-support.demon.co.uk/>

British Liver Trust: <http://www.britishlivertrust.org.uk/>

PSC Support (Yahoo): <http://health.groups.yahoo.com/group/psc-support/>

PBCers: <http://pbcers.org/>

Canadian Liver Foundation: <http://www.liver.ca/english/index.html>

Centers for Disease Control and Prevention: <http://www.cdc.gov/>

Clinical Trials: <http://www.clinicaltrials.gov/ct>

TransWeb.org: <http://www.transweb.org/>

We hope that you enjoy the conference, and we welcome you to join PSC Partners Seeking a Cure in the future as we continue to reach the goals of our mission.
