
The Duct

Bringing you news on PSC



PSC PARTNERS
SEEKING A CURE

research, education, and Support

PSC Partners Seeking a Cure Foundation Winter 2010

Time to Celebrate Our Fifth Anniversary!

As we join the world in welcoming a new decade with all its promise, let's join in a toast to the successful completion of PSC Partners Seeking a Cure's first half decade. PSC Partners Seeking a Cure was created in January, 2005, with a hopeful mission, and we've come a long way in our first five years. We have been able to form the partnership that we had originally envisioned: PSC patients and caregivers, physicians, researchers, nurses, pharmacists, nutritionists, pharmaceutical and other sponsors, all working together to educate and support PSCers, to raise funds for PSC research, and to promote organ donation. It's time to celebrate our fifth anniversary!

Looking back on our first five years, I'm so excited about our accomplishments:

We have attracted a group of dedicated volunteers nationally and internationally who act as a family to share their knowledge, practical advice, compassion and hope with others. *Continued on page 2*

Our Redesigned Website: A New Resource for PSCers!

Check it out at: www.pscpartners.org

Why did the board decide to revamp the website?

It was time. Our programs have grown amazingly in five short years and our outreach to members needed to stay current. In addition, we know members want to manage their PSC successfully, but often get confused and alarmed by what's on the internet. Much existing PSC internet information is out of date.

We stay on top of current research and treatment recommendations and we aimed to provide solid, sensible information. In addition we want a greater presence in the PSC research community and to enhance our fundraising efforts. *Continued on page 3*

- The **power of our group** continues to amaze me and to allow me to remain positive about living life with PSC.
- The **extensive PSC Literature Site** was developed in 2004 by David and Judith Rhodes, and is updated weekly. This unique website now contains over 128,000 abstracts and articles on all aspects of PSC and related diseases. It is a unique resource for PSCers, caregivers, physicians and researchers alike.
- We have put together a very knowledgeable and dedicated **Scientific/Medical Advisory Committee**, chaired by David Rhodes, which makes our all-important research decisions. The Scientific/Medical Advisory Committee has awarded research grants to prominent PSC researchers internationally. Thanks to everyone's donations in our first five years, we have been able to allocate \$317,706 specifically to PSC research! There is hope in our future.
- We have held five extremely successful **annual conferences** for PSCers and caregivers at different medical centers through the country. At our 2009 conference in Chicago held in conjunction with Northwestern Feinberg School of Medicine, we welcomed 185 participants from all over the United States, and also from Canada, England, Sweden and Israel.
- After each conference, on our website (www.pscpartners.org) we share **summaries of conference presentations and PowerPoint slides** from our conference speakers, so that people who weren't able to attend are able to access the educational materials.
- We are getting ready for **our sixth annual conference**, to be held May 14-16 in Hartford, Connecticut, in conjunction with The Liver Center at Yale University School of Medicine. It promises to be a wonderful weekend, as always!
- Thanks to David Rhodes and now Pat Bandy, we publish a **quarterly, free top quality online newsletter** that covers PSC treatments and research as well as coping suggestions and other advice from fellow PSCers. Be sure to sign up to receive each edition of the newsletter by joining our mailing list.
- We have created **three informative brochures** (*Living with PSC*, *Diagnosing PSC*, and our newest, *PSC Medications*) which we offer to physicians nationwide to hand out to their PSC patients.
- We have held **two local symposia**: *PSC: Treatment and Search for a Cure* in conjunction with Mount Sinai School of Medicine, Division of Liver Diseases, in September 2009, and *The Primary Sclerosing Cholangitis-Inflammatory Bowel Disease Link* in conjunction with the University of Colorado-Denver in October, 2009. These forums had speakers who were the top PSC specialists worldwide, and they were held free of charge. We plan to set up more symposiums in the future.
- As a foundation, we have gained **name recognition** in the PSC medical community.
- Thanks to a generous grant, we have just completed a year-long project to **expand and completely redesign our website** (www.pscpartners.org). Please take the time to check out our new website, which is packed with updated medical facts, practical information, and useful advice.
- We have **six local support groups** which meet periodically. All PSCers and caregivers are welcome.
- The Scientific/Medical Advisory Committee, Investment Committee, Member Communications/Database Committee, Individual Fundraising Committee, Corporate Fundraising Committee and PR/Marketing Committee are all **working actively on parts of our mission**. An Advocacy Committee will be started soon.
- A **Canadian affiliate** of PSC Partners is being formed.

Continued on page 16

New website, Continued from page 1

David Rhodes put us online with the original website back in 2005 and the site has served as our village square. At that time the foundation was new and the fact of the site's existence was significant. We're so grateful to David and others. It was a huge job to establish the site and to maintain it, as he's done for five years.

What's the goal of the new website?

We want PSCers to be knowledgeable. There's so much to know about our rare disease, PSC, and now the basics of what patients and families need to know are organized in one place for reference and information. As patients, we often feel alone in the medical system. Informed patients and caregivers who can advocate will clarify the best course for managing their disease with their medical team. The site will serve as a hub for information on PSC research, events, information, and outreach.

What are some features of the site?

We want to encourage scientists to study PSC and find a cure, so we've made it easier for researchers to find our grant application information and to review previous grant awards. We've listed all the support groups—local and online—that we're in touch with. There's an email sign up option so you'll be sure to receive the latest news from PSC Partners.

A special feature of the site is that it is member-written. Volunteer writers helped us with real-life information and tips. The site is unique for that reason. We promote advocacy from patients and caregivers, and that concept is the basis for the site.

What's new on the site?

Lots! We've added a section for the newly diagnosed (Understanding Your Diagnosis), although seasoned PSCers will find useful information there as well. We've added sections addressing pediatric, young adult, and caregiver issues. There's information on symptoms, meds, and coping. Tips on how to locate a specialist and questions to ask your doctors are also on the site now. We have a Q/A feature where a pharmacist volunteer will answer your questions on meds.

PSC PARTNERS SEEKING A CURE

HOME CONTACT US

Understand Your Diagnosis | Be An Informed Patient | Take Charge | Check the PSC Literature Site | Attend a PSC Patient Conference | Navigate Transplant Issues | Help Find a Cure! Donate Now | Join the Fight | Learn About Us

JOIN OUR MAILING LIST

Privacy by **SafeSubscribe™**

ASK A PHARMACIST

Apply for a Research Grant

Grants Previously Awarded

Research PSC Literature

Visit an Online Support Group

Read Our Newsletter

Help Us Find a Cure . . . Donate Now!

BACK TO TOP

Please note!
Information on this website has been written by persons without formal medical training. Therefore, the information 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 website is intended to be for medical diagnosis or treatment. The views and opinions expressed in the site are not intended to endorse any product or procedure.

PSC Partners Seeking a Cure • contactus@pscpartners.org
Home | Check the PSC Literature Site | Donate Now | Contact Us | Site Map
Copyright © 2010 PSC Partners. All Rights Reserved.

If you're living with primary sclerosing cholangitis (PSC), we're glad you're here.

This site is for patients, caregivers, families, physicians, and medical researchers.

Primary sclerosing cholangitis is a rare autoimmune bile duct disease that primarily affects people in the prime of their lives. It's not curable, but it's treatable.

PSC is often associated with ulcerative colitis, Crohn's disease, and related gastrointestinal and autoimmune diseases. Some PSC patients eventually require a liver transplant. Many PSCers, despite daily limitations and medications, are able to live full lives.

You probably never heard of PSC. It's a frightening diagnosis. The medical system is intimidating. The diagnostic tests can be daunting; the future may look uncertain.

Yet, there's hope. It's not easy having PSC, but we can help you manage through it. Those photos at the top of this page? They're not models. They're real people who have PSC. Our members.

We are a growing, unique all-volunteer foundation and we WILL find a cure. We include laypeople, medical professionals, and researchers. We offer education and support, with a strong emphasis on continuing to fund research on the disease. Read some comments by members about [how our group support has helped them manage](#) by clicking here.

We're together in the fight, whatever it takes. And it takes a lot to battle PSC.

It takes research, it takes money, it takes all of us—patients, caregivers, families, passionate volunteers, and educated physicians and researchers—to find better treatment and a cure.

Read our stories, learn about the disease, get tips on coping and how to talk to your doctor, join a discussion and support group, check out our newsletter, *The Duct*, attend our annual conference, and help raise funds to research a cure.

Working together to provide research, education, and support for people affected by primary sclerosing cholangitis.

Search this site:

Search

What's New?

- Online and Local/Regional PSC Support Groups
- Shop PSC Partners Seeking A Cure
- Download Our Brochures
- Previous Grants

Our home page now has quick links to what's new, the latest additions to the site, news about research opportunities, and upcoming events.

Other new sections include basic PSC facts, a listing of PSC and related autoimmune diseases, and links to medical glossaries and an encyclopedia, as well as a handy PSC-related medical abbreviation list. We have a comprehensive listing of valuable web sites to help you start researching PSC and its concerns.

There's information on transplant and the initial issues you'll face if that becomes a recommendation. We list online and local support groups all in one place. We review legal issues in chronic disease and offer resources for further investigation.

We've retained the popular links to our annual conference presentations, *The Duct* newsletter, and all our brochures. A new brochure, *PSC Medications*, is also on the site. Another brochure, *Pediatric PSC*, is in development and will be loaded onto the site later this year.

There's still a link to the massive PSC literature site developed and updated weekly by Judy and David Rhodes. This incredible resource covers medical information on all aspects of PSC and related diseases. We have an improved special section on donation to the foundation as well as information on opportunities for volunteering.

Who supported the effort?

With a grant and the help of numerous volunteers who contributed to the site, we now offer a patient-centered source for PSC information. Our web designer, Direct-Axis, in Pittsburgh, gave us special rate consideration and we are grateful to Dan O'Donnell for his generosity and creativity and to Mike for his attention to detail. PSC Partners thanks ALL member-volunteers who helped out on this huge project!

As you'll see, we drew on the knowledge of our members who helped write the site, offering good advice from their experience and research. There are Personal Stories sprinkled in various sections that offer inspiration as well as vital information. The site is our village square.

How long was the new site under construction?

The effort took more than a year: to conceptualize, design, coordinate, write, and upload.

SPREAD THE WORD: PSC RESEARCH GRANTS AVAILABLE

If your PSC specialist is interested in researching the disease, let him or her know PSC Partners offers research grant awards annually.

In 2009 PSC Partners gave seven research awards and will offer more in 2010. Because the awards are a recent foundation activity, some researchers may not know what we offer. Let them know! Here's the website: <http://www.pscpartners.org/apply> .

Fact-O-Rama

PSC Partners: Together in the Fight for Five Years

2005

- ✓ PSC Partners files Articles of Incorporation as a 501(c)3 organization on January 4.
- ✓ First online newsletter produced.
- ✓ Website launched; PSC Partners site links to PSC Literature site created by David and Judy Rhodes in 2004; 33,000 abstracts were on the site by the end of 2005.
- ✓ First annual conference in Denver—Attendance: 84.

2006

- ✓ Donation of \$20,000 to Morgan Foundation STOPSC research registry.

2007

- ✓ AASLD offers first annual \$3,000 PSC research award, funded by PSC Partners, to Dr. Tom Karlsen of Rikshospitalet University Hospital, Norway.

2008

- ✓ PSC research literature site reaches 100,000 abstracts specific to PSC.
- ✓ AASLD selects second annual joint awardees: Dr. I. Tornai, University of Debrecen, Debrecen, Hungary, and Dr. P. G. Blanco, Beth Israel Deaconess Medical Center, Boston, MA.
- ✓ Donation of \$20,000 to Morgan Foundation STOPSC research registry.

2009

- ✓ Fifth annual conference in Chicago—Attendance: 185.
- ✓ New logo introduced.
- ✓ First round PSC Partners research awards program launched; grants of \$40,000 over two years to each of three recipients: Dr. Konstantinos Lazararidis, Mayo/Rochester, Dr. Pietro Invernizzi, UC, Davis Medical Center, and Dr. Cyriel Ponsioen, Academic Medical Center, Amsterdam, Netherlands.
- ✓ PSC literature site reaches 128,000 abstracts specific to PSC.
- ✓ Dr. V.S. Teaberry, Duke University Medical Center, selected for third annual PSC Partners-funded award through AASLD
- ✓ Second round of research awards over two years given to: Dr. Christopher Bowlus, UC Davis Medical Center, Dr. Gregory T. Everson, University of Colorado, Dr. Richard M. Green, Northwestern University Feinberg School of Medicine, and Dr. Keith D. Lindor, Mayo/Rochester.
- ✓ Cumulative total of \$317,706 awarded to PSC researchers within past five years.

2010

- ✓ Revised website launched.



PSC Partners 2010 Conference Agenda



All conference events will take place at the Marriott Hartford Downtown
(200 Columbus Boulevard, Hartford, Connecticut).

Conference is in conjunction with the Liver Center at Yale University School of Medicine.

Conference registration form is on the website <http://www.pscpartners.org/nextannual>

Friday, May 14, 2010

- 10:30 a.m. **Pre-Conference event:** Brunch at Butler-McCook House, a Connecticut Landmark, at 396 Main Street
- 3-5 p.m. **Healthy Living Choices:** An interactive introduction to complementary therapies (come in casual or workout clothes)
- 5:30-7:30 p.m. **Registration and welcome dinner**

Saturday, May 15, 2010

- 7:30 – 8:30 a.m. Buffet Breakfast
- 8:30-8:35 a.m. **Opening remarks:** Don and Ricky Safer, PSC Partners Seeking a Cure Foundation
- 8:35-8:45 **Welcome/Meeting Objectives:** Dr. James Boyer, Ensign Professor of Medicine, Emeritus Director, Liver Center, Department of Medicine, Yale University School of Medicine
- 8:45-9:05 **Presentation 1: The PSC Diagnosis--Overview of PSC/Histology:** Dr. Tamar Taddei, Assistant Professor, Section of Digestive Diseases, Transplantation Center, Yale University School of Medicine
- 9:05-9:25 **Presentation 2: Treatment Issues/Managing Symptoms:** Dr. Pramod Mistry, Chief, Pediatric Gastroenterology and Hepatology, the Yale School of Medicine
- 9:25-9:45 **Presentation 3: The Overlap Between Inflammatory Bowel Disease and Primary Sclerosing Cholangitis:** Dr. Judy Cho, Associate Professor of Medicine and Genetics, Director, Inflammatory Bowel Disease Center, Yale University School of Medicine
- 9:45-10:20 **Question & Answer Panel:** Moderator, Dr. John Polio, Saint Francis Hospital and Medical Center, Connecticut Gastroenterology; Panel: Drs. Boyer, Taddei, Mistry and Cho
- 10:20 – 10:40 a.m. **Break/Snacks**

- 10:40 – 12:05 p.m. **Presentation 4: Overview of PSC Research:** Dr. James Boyer
- 10:55-11:10 **Presentation 5: Biology and Pathobiology of Cholangiocytes: The Key to Understanding PSC:** Dr. Mario Strazzabosco, Professor and Director, Transplant Hepatology, Yale University School of Medicine
- 11:10-11:25 **Presentation 6: Results of PSC Genome Studies in Norway:** Dr. Trine Folseraas: Norwegian PSC Center, Medical Department, Rikshospitalet, Oslo
- 11:25-11:35 **Presentation 7: PSC Partners Seeking a Cure Grants Program:** Dr. David Rhodes, Professor, Department of Horticulture and Landscape Architecture, Purdue University and PSC Partners Board Member, Chair of Scientific/Medical Advisory Committee and Dr. Don Safer, Clinical Professor, University of Colorado School of Dentistry, and PSC Partners Scientific/Medical Advisory Committee Member
- 11:35-12:05 **Question and Answer Panel:** Moderator: Dr. John Polio, Panel: Drs. Boyer, Strazzabosco, Folseraas, Rhodes and Safer
- 12:05 – 1:15 p.m. **Lunch**
- 1:15 – 1:35 p.m. **Presentation 8: How to Communicate With Your Physician** (Questions and answers following): Dr. Tom Ullman, Director, Center for IBD and Associate Professor of Medicine, the Mount Sinai School of Medicine
- 1:45 – 3:50 p.m. **Breakout Sessions:** Choose ONE speaker for each session. (See tentative list below)
- 1:45-2:20 **Session I**
- 2:30-3:05 **Session II**
- 3:05-3:15 **Break/Snacks**
- 3:15-3:50 **Session III**
- 3:50 – 4:00 p.m. **Wrap-up:** Don and Ricky Safer
- 6:30 – 9:00 p.m. **Banquet Dinner**

Sunday, May 16, 2010

- 7:30 – 8:30 a.m. **Buffet Breakfast**
- 8:30 – 9:15 a.m. **Open Forum**

8:30-8:40	Update on Dr. Chapman's Research: Ivor Sweigler, PSC UK Support Group
8:40-8:50	PSC Partners Foundation Financial Report: Deb Wente, Treasurer
8:50-9:15	Announcements and Foundation Updates
9:15-11:20 a.m.	Group Sessions in Breakout Rooms (Male PSCers/Female PSCers/Parents of pediatric PSCers/Parents of adult PSCers/Spouses and other caregivers of PSCers/Post-transplant PSCers/PSC teenagers/PSCers in their 20's & 30's)
10:15-10:35	Break/Snacks
11:30-12:30 p.m.	Open Forum Reconvenes
11:30-12:20	Feedback from Group Sessions
12:20-12:30	Closing Remarks: Don and Ricky Safer, PSC Partners Seeking a Cure Foundation

CHOICE OF BREAKOUT SPEAKERS AND TOPICS ON SATURDAY AFTERNOON (Choose one for each time slot. Current list is tentative and will be finalized before registration process.)

Pediatric and Adolescent PSC: Dr. Pramod Mistry Professor, Pediatric and Internal Medicine, Section Chief, Yale University School of Medicine and Dr. Karan Emerick, Pediatric Gastroenterology and Pediatric Surgery, Connecticut Children's Medical Center

Special Topics for 20s/30s Females: Dr. Tamar Taddei, Assistant Professor, Section of Digestive Disease, Transplantation Center, Yale School of Medicine

Special Topics for 20s/30s Males, Coping with PSC for PSCers and Coping with PSC for Caregivers: Dr. Dwain Fehon, Assistant Professor, Department of Psychiatry, Yale Medical School

Issues in Cadaveric Transplants: Dr. David Hull, Director of Transplantation, Hartford Hospital

Know Your Rights: Health Insurance and Know Your Rights: Employment: Jennifer Jaff, Esq., Advocacy for Patients with Chronic Illness, Inc. (www.advocacyforpatients.org) and Crohn's Patient

Treatment issues for PSC Patients with IBD: Dr. Debra Proctor, Professor of Medicine, Medical Director, Inflammatory Bowel Disease Program, Yale University School of Medicine

The Role of Good Nutrition in PSC: Anne Marie Rivard, Clinical Dietitian in Transplant, Yale New Haven Hospital

Future Plans for the Norwegian Research Center: Dr. Trine Folseraas, Norwegian PSC Medical Center

Endoscopic Diagnosis and Management of PSC: Dr. Priya Jamidar, Professor of Medicine, Associate Section Chief, Director of Endoscopy, Section of Digestive Diseases, Yale University School of Medicine

Patient Perspective on the Transplant Experience-From Pre-Transplant through Post-Transplant: Panel of PSC Partners Post-Transplant PSCers

Transplant Experience: Interactive Session for Post-Transplant PSCers: Dr. Aubrey Goldstein, PSC Partners Scientific/Medical Advisory Committee Member

Oncologic Complications of PSC: Dr. Mario Strazzabosco, Professor and Director, Transplant Hepatology, Yale University School of Medicine

Special Issues for PSC in Transplantation (Quality of life issues/MELD score and PSC): Dr. Pramod Mistry and Dr. Tamar Taddei

Living with PSC: Stories of Inspiration: Panel of PSC Patients

2010 Conference Information

PRE-CONFERENCE ACTIVITIES FOR FRIDAY, MAY 14

We hope that you'll consider arriving in Hartford by Thursday evening to participate in our two pre-conference activities. Last year, more than half of the conference attendees came early, and they greatly appreciated the chance to get acquainted (and re-acquainted) with the other participants before the official start of the conference.

BRUNCH at 10:30 a.m.: Please join us for an informal brunch at the Butler-McCook House to meet fellow PSCers and caregivers. The Butler-McCook House (1782) is the oldest surviving building in Hartford, and it portrays the life of four generations of the Butler and Mc Cook families with its original furnishings, art and antique collections. Its beautiful restored Victorian garden will be the setting for our brunch, if the weather cooperates! The Butler-Mc Cook House is a short five block walk from the Marriott at 396 Main Street (www.ctlandmarks.org).

HEALTHY LIVING CHOICES: AN INTERACTIVE INTRODUCTION TO COMPLEMENTARY THERAPIES from 3-5 P.M. (Held at the Marriott) This is a new program in 2010 which is targeted for both PSCers and caregivers. Come in casual or workout clothes and be ready for some new experiences. This is your chance to try stress-relieving activities such as meditation, yoga, Tai Chi, etc., and also to learn how to incorporate exercise into your life, no matter what stage of the disease you may be experiencing presently.

SUGGESTED INDIVIDUAL ACTIVITIES IN YOUR FREE TIME BETWEEN THE BRUNCH AND THE AFTERNOON SESSION

Attractions within walking distance from the Marriott: Wadsworth Atheneum Museum of Art, Old State House, Science Center, Bushnell Park

Attractions further afield: Mark Twain House and Museum, Harriet Beecher Stowe Center
Go to www.hartfordmarriott.com and click on the Visitor's Guide for more information

CONFERENCE FEES

Standard: (on or before April 12) \$150 per person, \$280 per couple, \$140 for each additional family member or caregiver

Late: (after April 12) \$170 per person, \$320 per couple, \$160 for each additional family member or caregiver

Friday pre-conference brunch: \$10 per person

Note: We try to keep our registration fees as low as possible, so that more people can afford to attend. Please note that PSC Partners and our 2010 conference sponsors subsidize a significant portion of your conference costs. (In 2009, the registration fee per person covered only half the cost for each attendee; the rest was covered by PSC Partners and our generous conference sponsors.)

Payment

There are two ways to pay for the conference, PayPal or by check, and information will be included in the online registration form, which will be uploaded soon.

IMPORTANT HOTEL INFORMATION

We are pleased to offer a room block at the luxurious Marriott Hartford Downtown (200 Columbus Boulevard). www.hartfordmarriott.com The special PSC Partners group rate is \$119 plus tax for a double room. This discounted rate is also available to our attendees three days before (May 11-13) and three days after the event (May 16-18). All conference events will take place at the Marriott.

The reserved room block will be allocated on a first-come, first-served basis. The **cutoff date for the discounted group rate is APRIL 23**. The special group rate will expire when all allotted rooms have been reserved or on April 23, whichever comes first. After April 23, the discounted group rate will only be offered depending on availability, so it is strongly advised that you make reservations as soon as possible to take advantage of the group rate. Individual cancellation will be allowed with no penalty if notice is received 24 hours prior to the arrival day.

To reserve your room:

By phone: Call toll free 866-373-9806 and request the "PSC Partners Seeking" group block.

Online:

Register here if you want two double beds: <http://www.marriott.com/hotels/travel/bdldt?groupCode=pscpsc&app=resvlink&fromDate=5/13/10&toDate=5/16/10>

Register here if you want one king bed: <http://www.marriott.com/hotels/travel/bdldt?groupCode=pscpsca&app=resvlink&fromDate=5/13/10&toDate=5/16/10>

2010 CONFERENCE SPONSORS

Platinum Premier Sponsors: Abe and Rachel Gomel

Gold Sponsors: The Liver Center at the Yale School of Medicine

If you're interested in becoming a conference sponsor, please contact Ricky at contactus@pscpartners.org.

ONLINE REGISTRATION FORM: will be posted soon. If you have any questions, send an email to Ricky Safer at contactus@pscpartners.org or to Reggie Belmont at ctpsc@hotmail.com.

TRANSPORTATION TO HARTFORD

We strongly recommend that PSCers and caregivers attending the 2010 conference in Hartford, CT fly directly to Bradley International Airport in Windsor Locks, CT, 20 miles north of Hartford. – Jeff and Reggie Belmont



Bradley is a full-service airport with connecting flights throughout the country. Bradley is serviced by Air Canada, American, Continental, Delta, Northwest, Southwest, United and US Airways as well as several commuter lines. For more information, go to www.bradleyairport.com and right click on “flights” to get a list of airlines, schedules, and prices.

Ground Transportation from Bradley Airport to Marriott Hartford Downtown

Bus: Connecticut Transit “Bradley Flyer” operates frequent bus service from 4:10 a.m. to 10:45 p.m. to downtown Hartford for \$1.25 per person. There are bus stops on the lower level of each concourse and the 30-minute ride will take passengers to the Old State House in downtown Hartford, a three-block walk to the Hartford Marriott. For schedules and route map see www.cttransit.com

Taxi: Taxis are always available, the fee is approximately \$40.

Rental Cars: All the major rental car agencies have counters at the airport. Enterprise is offering PSCers a special \$99 three-day weekend rental for a mid-sized car. (Once the conference starts, you won't need a car, because everything takes place at the Hartford Marriott Downtown.)

Directions: From Bradley International Airport, follow signs for I-91 South. Proceed on I-91 South for 12 miles. Take Exit 29A/Capitol Area onto Whitehead Hwy. Take first exit (on right) to Columbus Blvd. At the light, turn right; the hotel is on the right.

Other Transportation to Hartford

Train: There is AMTRAK train service to Hartford from Penn Station, New York City and Boston South Station. A transfer in New Haven is required. AMTRAK arrives at Union Station (Shuttle Stop 8) where you board the free Star Shuttle to the Marriott Hotel (Shuttle Stop 1). See details and a map below.

Bus: Greyhound Bus Lines and Peter Pan Bus lines offer service to Hartford and arrive at Union Station (Shuttle Stop 8) where you board the Free Star Shuttle to the Marriott Hotel (Shuttle Stop 1).

For information on transportation options, go to www.hartford.com and click on Get Around.

Driving: Hartford is an easy drive from all of the New England States and New York. It lies at the juncture of I-91 and I-84 on the west bank of the Connecticut River.

From Logan Airport, Boston to Hartford

Directions by Car:

Exit airport onto I-90 West, Mass Pike, 58.2 mi. to exit 9 (I-84) at Sturbridge MA. Follow signs for New York City and Hartford, CT.

Merge onto I-84 for 42.8 mi. to exit 54. At exit 54, on left, toward downtown Hartford 0.4 mi. Merge onto CT-2 West, 0.4 mi. Turn left (South) onto Columbus Blvd., 0.1 mi. Hotel is at 200 Columbus Blvd.

Estimated travel time: 1 hour 38 minutes (103 miles)

Rental Cars:

Logan is serviced by all of the rental car agencies. Costs begin at around \$50/day.

Enterprise Rent-A-Car: 617-561-4488	www.enterprise.com
Hertz Car Rental: 617-569-7272	www.hertz.com
National Car Rental: 888-826-6890	www.nationalcar.com
Budget Rent-A-Car: 617-497-3733	www.budget.com
Avis Rent-A-Car: 617-247-0613	www.avis.com
Alamo Car Rental: 800-327-9633	www.goalamo.com
Dollar Car Rental: 800-800-4000	www.dollar.com

From Downtown Boston to Hartford

By Bus:

Estimated travel time: Approximately 2 hours

Deluxe Coach Bus - \$15 pp (departs 177 Huntington Ave., Boston-arrives 369 Capitol Ave., Hartford)
www.bostondeluxe.com.

Greyhound – Multiple departures, \$24 pp, www.greyhound.com 1-800-231-2222 Peter Pan Bus Co. -
Multiple departures, \$27 pp, www.peterpanbus.com 1-800-343-9999

By Train:

Estimated travel time: 3 hours

Amtrak trains depart South Station in Boston. You must transfer to Hartford either in New Haven, CT or Springfield, MA.

Costs range in price, but start at \$26/each way

www.amtrak.com, 1-800-USA-RAIL

From train station in Hartford to Marriott: about 5 minutes travel time

FROM NEW YORK AIRPORTS TO HARTFORD

Approximate drive times (assuming no traffic delays) to Hartford:

La Guardia (LGA): 1¾ hrs.

John F. Kennedy International (JFK): 2 hrs.

Newark International (EWR): 2¼ hrs, but offers most public transportation options to Hartford. See below.

Rental Cars: All of the New York airports are fully serviced by all of the major car rental agencies. The best deals we found were from www.hotwire.com (1-866-468-9473). There is a "no cancellation policy" with this site but rates are typically the lowest. We are sure these prices might change, so hopefully these are still good (or you can find a better deal). Other options for renting a car:

La Guardia Airport: \$62/day

JFK Airport: \$53/day

Newark Airport: \$42/day

Limousine Service: This will be the most expensive option. Below are a few choices:

Connecticut Limo runs vans and buses from all three airports. It collects passengers from the terminals and makes several stops in Connecticut. CT Limo costs about \$93 pp, arrives at Hartford Holiday Inn, a 10 min. taxi ride to the Marriott: www.ctlimo.com 1-800-472-LIMO (1-800-472-5460). CT Limo has phones in all of the baggage claim areas for passenger pick up.

Premier Limo: (Private, chauffeured): www.premierlimo.net Base rate \$224 from LaGuardia
1-860-659-8600

Hy's Limo: (Private, chauffeured): \$250 for private chauffeured town car, www.hyslimo.com –
1-800-255-LIMO (1-800-255-6331)

GETTING TO HARTFORD FROM NEWARK AIRPORT BY TRAIN OR BUS

Only Newark Airport has direct bus and train service to Hartford.

Amtrak train:

Five trains per day run from Newark to Hartford (Cost: \$40-\$65 pp). Duration: 3.0-3.5 hours. Travelers may have to change trains at Penn Station or New Haven, CT.

For more information on train options, visit www.amtrak.com or call 1-800-USA-RAIL
(1-800-872-7245).

Bus transportation:

Greyhound runs 7 buses per day from Newark to Hartford (\$16-\$32 pp), discounts available with advance purchases. Duration of trip: 4-5 hours. For more information, visit www.greyhound.com or call 1-800-231-2222.

Peter Pan Bus Co. also serves Newark Airport. For information, contact: www.peterpanbus.com or call 1-800-343-9999

GETTING TO HARTFORD FROM MANHATTAN BY TRAIN OR BUS

In order to access buses or trains from JFK or La Guardia, travelers must go to either Penn Station or Grand Central Terminal in Manhattan.

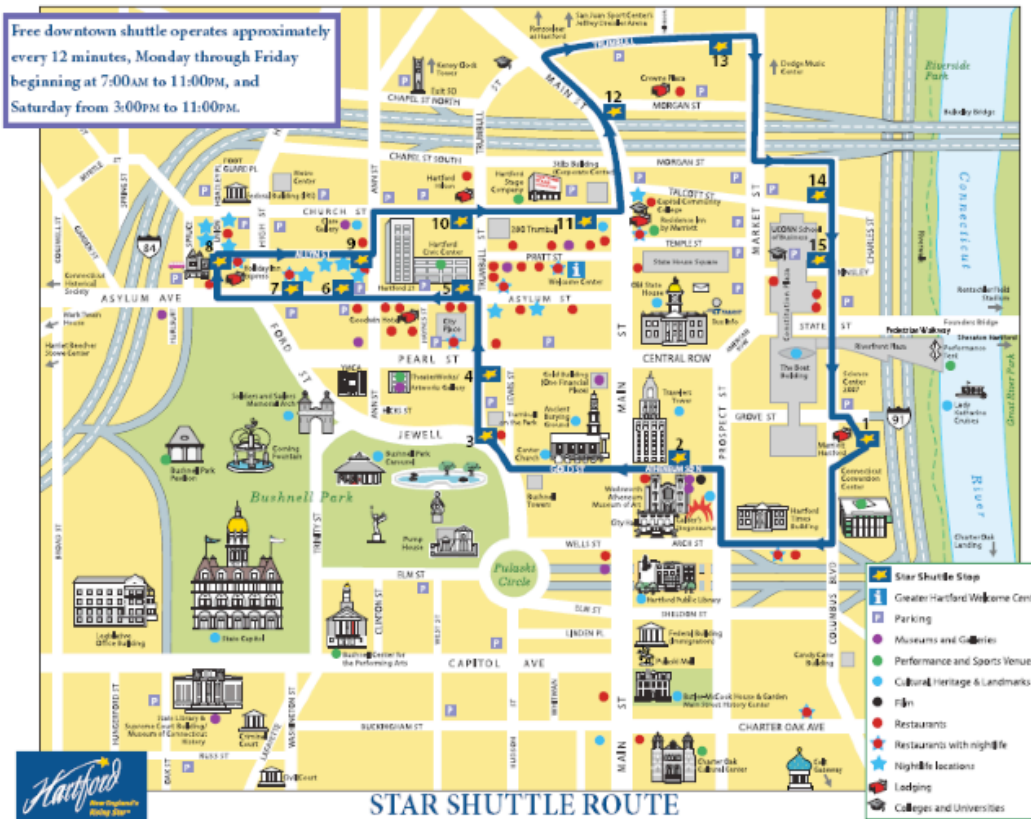
Amtrak runs fifteen trains per day which depart from New York's Penn Station to Hartford (\$16-32 pp), with discounts available with advance purchases. Duration of trip: 3 hours. www.amtrak.com

Metro North www.mta.info operates numerous commuter trains from Grand Central Terminal to New Haven, CT where one can change trains for Union Station, Hartford.

Greyhound Bus www.greyhound.com runs 15 trains during the day from New York Penn Station to Hartford (\$16-32 each way), with discounts available with advance purchases. Duration of trip: 2 1/2 -3 hours. 1-800-231-2222.

Check Peter Pan Bus www.peterpanbus.com or call 1-800-343-9999.

Getting Around Hartford



Hartford is an easy city to navigate on foot, and the Marriott Hartford is located in the heart of downtown. If you want to ride, there are taxis for hire, public buses and a free Star Shuttle bus that operates in a continuous loop, 10-12 minutes, around the city from 7 am to 11 p.m. Monday through Friday and 3 p.m. to 11 p.m. on Saturday. www.hartford.com

Parking

If you arrive by car, there are several parking options.

Hotel parking is offered at a discounted rate for PSC Partners: \$23 per day for valet parking. This fee is charged to your room. The rate for self-parking is \$19 per day. Parking ticket must be stamped at the front desk and paid when exiting the parking lot.

The Hartford Transit District offers reduced parking fees for the event, \$5 per day, at their lot on Spruce Street, across from Union Station which is serviced by the Star Shuttle (Stop 8). It is an open lot with an around-the-clock attendant. The Authority would prefer all-day parking. People using this lot will need a coupon every time they take their car out of the lot. Additional coupons will be available at the conference.

Many thanks to Scott Malat of New York and Nicola Parry of Boston who pulled together the travel options for their respective cities.

Thank you for attending the sixth 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.

\$5 Parking

PSC Partners Seeking a Cure
6th Annual International Conference

May 13, 2010 through May 16, 2010

Greater Hartford Transit Authority

One Union Place

*This coupon entitles the bearer to park at the Spruce Street Parking facility **across from** Union Station corner of Spruce St and Asylum Ave., at the rate of \$5 per 24-hour day.*

Ricky's message, continued from page 2

- A huge thank you to the members of our **Board of Directors** who have guided us in all our major decisions as a foundation.
- Since we're a volunteer foundation, we've been able to keep our **administrative costs amazingly low** as we grow: less than 3 percent! So about 97 percent of all donations go directly to PSC research grants and educational programs.

To learn more about our programs, please take a close look at our new website and read through this anniversary issue of our newsletter.

I would like to personally thank all our members who have contributed to our amazing growth during our first five years by sending in donations, volunteering your help in many ways, by attending our conferences, by supporting other PSCers and by being a PSC partner. Our PSC family is stronger than ever. On our fifth anniversary, I'm looking towards the future with the hopes of finding new treatments and eventually a cure for PSC. We're a determined, tenacious partnership, and we will succeed. Together in the fight, whatever it takes!

Ricky Safer
President
PSC Partners Seeking a Cure

Four Additional PSC Partners-Funded Research Awards Announced for 2009

The PSC Partners Scientific/Medical Advisory Committee announced late in 2009 that it was able, thanks to several generous donations, to support four additional competitive research awards on causes, treatments, and cures for PSC. The latest announcement brings to seven the projects funded by the foundation in 2009; three other awards were announced mid-year.

David Rhodes, Chair of the Committee, reported that since its launch five years ago, PSC Partners Seeking a Cure has invested \$317,706 in PSC research by the end of 2009. “Thank you to everyone who has contributed funds to PSC Partners Seeking a Cure. Your contributions have made these awards possible!”

“This has been one of the main goals for the foundation,” said president Ricky Safer. “We are seeking a cure for PSC. These additional research projects will shed new light on the disease. Our competitive awards program attracted a number of high quality projects this year. We are out there, making it known that PSC is worth studying. We also aim to interest early-career scientists in PSC, and perhaps shape their long-term research interests. We *must* find a cure.”

She added, “We especially want to thank Abe and Rachel Gomel and Ros and David Parry for their very generous contributions to this research.”

The four new awards are described below.

● **alpha4Beta7-Integrin Ligand Development for the Treatment of PSC.**

Christopher Bowlus, M.D., Associate Professor, Division of Gastroenterology, UC Davis Medical Center, 4150 V Street, PSSB 3500, Sacramento, CA 95817 [Collaborators: Ruiwu Liu, Ph.D. Assistant Research Chemist, University of California, Davis, 2700 Stockton Blvd., Suite 1400, Sacramento, CA 95817; Kit S. Lam, M.D., Ph.D., Professor and Chief, Division of Hematology and Oncology, UC Davis Cancer Center, 4501 X St., Sacramento, CA 95817; Mark Kurth, Ph.D., Professor, Department of Chemistry, University of California, Davis, CA 95616; Yoshikazu Takada, M.D., Ph.D.,

Professor, Department of Gastroenterology, University of California Davis Medical Center, Research III Suite 3300, 4645 2nd Avenue, Sacramento, CA 95817]. \$40,000 over 2 years.

This project will be entirely funded by a generous donation from Abe and Rachel Gomel.

Project Summary: Primary sclerosing cholangitis (PSC) is due in part to gut-derived lymphocytes trafficking to the liver in response to specific adhesion molecules and chemokines normally expressed in the gut. Specifically, alpha4Beta7-integrin expressing lymphocytes home to the PSC liver where its ligand mucosal addressin cell

adhesion molecule-1 (MAdCAM-1) is aberrantly expressed. Blocking alpha4 integrins has been successfully targeted by monoclonal antibodies for the treatment of Crohn's disease. However, the use of this therapy in PSC is hindered by the risk of progressive multifocal leukoencephalopathy (PML), believed to be due to the lack of specificity for alpha4Beta7. Vedolizumab (formerly known as MLN002 and MLN02), is a monoclonal antibody with specificity for alpha4beta7 that has shown efficacy in phase 2 clinical trials of moderately active ulcerative colitis and Crohn's disease. However, monoclonal antibodies have limitations. The antibody molecule is relatively large with a molecular weight of 160,000 kD requiring infusion or subcutaneous injection. In addition, even with humanized forms of these monoclonal antibodies, human anti-chimera antibodies (HACA) are frequently generated and are sometimes associated with a lower rate of response. Peptides are considerably smaller than monoclonal antibodies and generally do not illicit a humoral immune response. They are chemically stable and relatively easy to derivatize. Although peptides are susceptible to proteolytic degradation in vivo, this can be inhibited with blocking of their N- and C-termini, making them cyclized, or incorporating D-amino acids.

In this proposal, we will take advantage of our expertise in One Bead-One Compound (OBOC) combinatorial chemistry, integrin biology, immunology and PSC to identify novel lead compounds for the treatment of PSC. We have previously identified a high affinity, high specificity peptidomimetic ligand for alpha4Beta1-integrin that is currently under pre-clinical development. In this project we will use the same technology to identify lead compounds for alpha4Beta7 ligands. In Aim 1 we will design and synthesize a diverse combinatorial chemistry library based upon the known alpha4Beta7

binding motif. In Aim 2 we will use a whole cell method to screen this library with alpha4Beta7+ T cells from PSC patients. The specificity and binding affinity of these lead compounds will be assessed in Aim 3. Upon completion of this project we will have identified lead compounds that will be ready to proceed to functional testing. In addition, the knowledge gained will be used to design focused libraries which will be screened for additional ligands.

- **Non-invasive Assessment of Disease Progression in Primary Sclerosing Cholangitis.**

Gregory T. Everson, M.D., Transplant Center and Hepatology, Clinic Mail stop B, 154 Anschutz Outpatient Pavilion, 1635 N. Ursula Street, Room 7085, Aurora, CO 80045. [Collaborators: Steve Helmke, Ph.D.; Lisa Forman, M.D.]. \$40,000 over 2 years.

Project Summary: Current methods for monitoring primary sclerosing cholangitis (PSC) disease progression are insensitive, invasive, and nonspecific. We have developed a novel noninvasive technique to accurately measure liver function by quantifying portal-systemic shunting, the cholate shunt test. Our overriding hypothesis is that our liver function test will accurately monitor PSC disease progression.

- **The Role of Abcb11 and Fibroblast Growth Factor 15/19 in the Pathogenesis of Primary Sclerosing Cholangitis.**

Richard M. Green, M.D., Associate Professor of Medicine, Division of Hepatology, Northwestern University Feinberg School of Medicine. \$40,000 over 2 years.

The first year of this project will be funded by a generous donation from Ros and David Parry.

Project Summary: Primary sclerosing cholangitis (PSC) is a hepatic disease of unknown etiology that can lead to cirrhosis, cholangiocarcinoma and the need for liver transplantation. It is characterized by inflammation and fibrosis of cholangiocytes, the cells that compose the liver bile ducts.

Unfortunately, no effective therapy has been shown to slow disease progression, in part because the pathogenesis of primary sclerosing cholangitis remains poorly understood. By enhancing our understanding of the pathogenesis of PSC, one can better design rational therapies for this potentially devastating form of chronic liver disease.

The cholangiocytes that form the bile ducts are exposed to extremely high concentrations of bile salts, which induce signaling changes in cholangiocytes. The high bile salt concentrations in bile are created by the ATP-dependent secretion of bile salts from the liver into the biliary system. Our laboratory has a long-standing interest in identifying the mechanisms by which hepatocytes (liver cells) secrete bile salts into the biliary system. We, along with other investigators, have determined that bile salts are secreted by the liver canalicular membrane transporter Abcb11. Furthermore, we have cloned Abcb11 and developed a transgenic mouse that over-expresses Abcb11 in the liver. In addition, the level of expression of Abcb11 in humans is highly variable (by a factor of over 10) and therefore it is likely important in the manifestation of many cholestatic liver diseases. However, the impact of high levels of Abcb11 expression on primary sclerosing cholangitis is poorly understood.

A recently identified gut-derived hormone named fibroblast growth factor 15/19 (FGF15/19) is secreted by the ileum in response to bile salt stimulation and subsequently interacts with hepatocytes and cholangiocytes to

regulate their function and maintain normal cellular homeostasis. Although FGF15/19 has been shown to be an important physiologic regulator of ductular cells in the gallbladder and for gallstone formation, the function of FGF 15/19 in other biliary tract diseases remains unknown. In the proposed studies, we will explore the role of Abcb11 and FGF 15/19 in biliary tract disease; since our enhanced understanding of these physiologic processes will allow for the design of rational, novel therapeutic targets for treating patients with PSC

- **A Pilot study of Vancomycin or Metronidazole in patients with Primary Sclerosing Cholangitis.**

Keith D. Lindor, M.D., Mayo Clinic, 200 First Street, SW, Rochester, MN 55905.

[Collaborators: Marina G. Silveira, M.D.; Andrea Gossard, C.N.P.; Roberta Jorgensen, R.N.; Jill C. Keach; Janice Petz, R.N., Division of Gastroenterology and Hepatology, Mayo Clinic and Foundation, Rochester, Minnesota]. \$25,706 over 2 years.

Project Summary: Primary Sclerosing cholangitis (PSC) is a progressive liver disease without effective medical treatment. Although treatment with ursodeoxycholic acid (UDCA) improves serum liver tests and is prescribed frequently for PSC patients, this drug appears to have no beneficial effect on the course of the disease. Recent results of UDCA used in high doses have been most disappointing.

Various antibiotics have been tested sporadically for the treatment of PSC over the years with promising results reported. The numbers of cases were small, sometimes single case reports, and the duration of follow up has been variable but often short. In the current protocol, we propose the assessment of potential beneficial effects of the antibiotics vancomycin and

metronidazole on liver biochemistries, liver related symptoms and Mayo risk score in 40 patients with PSC. The patients will be randomized into four groups of ten patients: one group will receive low dose vancomycin, one group will receive high dose vancomycin, one group will receive low dose metronidazole and one group will receive high dose metronidazole. Each group will be treated for three months. Liver biochemistries, C-reactive protein (CRP)

and Mayo risk score will be determined at three weeks and three months and compared to baseline values as well as values at 3 months in the placebo group (n=74) from the recent high dose UDCA study. A positive study based on significant liver biochemical improvement will establish the basis for further evaluation of one or both antibiotics in a larger number of patients for a longer time period within a randomized controlled trial.

FDA Funds Urso PSC Pediatric Study

The Food and Drug Administration (FDA) has funded a \$600,000 multi-center study on the usefulness of a bile acid in treating children with PSC. Leading the study will be Dr. Dennis Black, of the STOPSC project.

The project will look at whether the use of ursodeoxycholic acid, known as UDCA or Urso, can benefit children with PSC. UDCA is normally found in small amounts in humans. When administered orally to humans, the drug slows down liver cell death, acts as an anti-inflammatory agent and stimulates bile flow. UDCA has been approved by the FDA to treat gallstones and primary biliary cirrhosis in adults, but not PSC, although it is widely used in both children and adults with PSC.

In the study, children already on UDCA will have their dosage decreased by 50 percent for four weeks and then will be taken off for eight weeks. Then, those children will receive regular doses again.

Throughout this process, researchers will measure liver inflammation, blood tests and various other markers to determine the consequences of being off of the UDCA. The information collected from this pilot study will help in the design of a longer controlled, prospective trial in children.

Dr. Black hopes to attract 50 children for the three-year study. Those subjects will come from eight pediatric facilities around the United States and Canada that make up the STOPSC registry with Le Bonheur Children's Medical Center in Memphis, serving as the lead center.

For more information regarding the study, contact Dr. Black at 901-287-5355.



**Itching
for a Cure**

The Road to Connecticut

Help PSC Partners find a cure for this disease. Every \$100 collected will take us one mile closer to our destination. Keep an eye on our map (at this link: <http://www.pscpartners.org/fundraisers>) to see how many miles we continue to cover on our way to Hartford. Every donation, no matter the amount, helps us reach our goal. Every mile earned is another step toward a cure.

AASLD's Most Promising PSC Research Award, 2009

In our last issue we announced the winner of the PSC Partners-sponsored annual award through the American Association for the Study of Liver Disease (AASLD). The abstract of the winning study is below.

The 2009 PSC Partners Seeking a Cure Award for Most Promising PSC Research (\$3,000) was awarded to Dr. V. S. Teaberry, for the following presentation:

Novel Role for Hedgehog Pathway Activation in the Pathogenesis of Primary Sclerosing Cholangitis

V. S. Teaberry; 1; G. F. Karaca; 2; R. P. Witek; 2; W. Syn; 2; A. Omenetti; 2; Y. Jung; 2; S. S. Choi; 3; A. Diehl; 2.

1. Surgery, Duke University, Durham, NC, USA. 2. Medicine, Duke University, Durham, NC, USA. 3. Medicine, Durham VA Medical Center, Durham, NC, USA.

Abstract Body

Background/Hypothesis: Primary sclerosing cholangitis (PSC) is a poorly understood cause of progressive liver damage that culminates in cirrhosis and liver cancer. Loss-of-function mutations in the hepatocyte phospholipid flippase *mdr3* have been associated with PSC. Mice with targeted deletion of *mdr2* (the murine ortholog of *mdr3*) develop progressive liver injury, cirrhosis and primary liver cancer, providing a model to investigate the pathogenesis of PSC-related liver disease. We used *mdr2*^{-/-} mice to evaluate the hypothesis that cirrhosis and liver cancer develop during PSC because *mdr2* deficiency causes

activation of the Hedgehog (Hh) pathway. Hh ligands are known to promote the growth of myofibroblasts and various types of progenitor cells. Myofibroblasts cause cirrhosis, and progenitors have been implicated in hepatocarcinogenesis.

Methods: Male *mdr2*^{-/-} and control FVB/NJ mice were sacrificed at 2, 4, 12, and 16 weeks of age. These time points antedate the appearance of liver cancers, which emerge around 52 weeks. Liver injury (serum AST, ALT; activated hepatic caspase 3), fibrosis (Sirius red, alpha-SMA staining), Hh pathway activity (expression of Hh ligands and target genes), and progenitor expansion (AE1/AE3 staining, CK7 immunoblot) were compared. Results: *mdr2*^{-/-} mice had greater expression of Hh ligands and target genes than age-matched controls from as early as 2 weeks of age. From 4-16 weeks of age, AST, ALT and caspase 3 activity were consistently greater in *mdr2*^{-/-} mice than controls. This was paralleled by progressive accumulation of myofibroblasts (alpha-SMA(+) cells) and liver progenitors (AE1/AE3/CK7(+) cells), as well as steady increases in liver fibrosis (Sirius red staining) in the *mdr2*^{-/-} group.

Conclusions: Deficiency of *mdr2* activates the Hedgehog pathway. This is accompanied by repair responses that are governed by Hh signaling, including accumulation of myofibroblasts and liver epithelial progenitors. The former promotes liver fibrosis, and the latter may contribute to liver carcinogenesis in PSC.

Looking for the 2010 Conference Registration form?

It'll be uploaded to the web soon!

Two New Fundraising Opportunities: Get Going!

by Sandi Pearlman

We've set up two new fundraising opportunities--that's in addition to the Itching for a Cure/Road to Connecticut fundraising effort and Save the Day (see below for details). These new fundraisers involve Cool Stuff. Read on.

Picture This Fundraiser

Picture this: You can do a little shopping while raising funds towards better treatment and a cure for PSC. K Pearlman Photography, the official photographer of the 2009/2010 PSC Partners Seeking a Cure Conferences, is thrilled to offer a fabulous deal to help us take PSC out of the picture for good. So, whether you need a holiday gift, a birthday gift, one for an anniversary or just because, now you can get a great present and make a difference in the lives of PSCers everywhere! A photo keepsake is a wonderful way to remember special moments in our lives and is practically guaranteed to create smiles. So, whether you want to reminisce over your morning cup of coffee or tea or crack up at your favorite little ones in puzzle form, PSC Partners and K Pearlman Photography have made it a snap!

Below is a listing of some of the products K Pearlman Photography offers. All prices include shipping and handling* and 100 percent of the proceeds from any Picture This fundraiser purchased will go directly to PSC Partners Seeking a Cure for use in education and research.

Here's the details: You can choose any non-copyrighted image of your choice or the PSC Partners Logo. Contact Karen at www.kpearlmanphotography.com or at www.kpphotography@aol.com with any questions or orders. She'll tell you how to best

get your image to her (generally a jpeg file online) and then your work is done!

Coffee Mugs:

\$20 for first

\$35 for two

+\$5 for lettering (on either side of the mug)

**please specify whether you'd like a left or right-handed mug (picture facing you or not)

Mousepads:

\$20 for first

\$35 for two

+\$3 for lettering

Puzzles:

\$31 (252 pieces 10 1/2 by 13 1/2)

Keychains:

\$15 (single-sided)

\$20 (double-sided)

Coasters:

\$35 (set of four)

Orders, checks and questions can be sent to Kpphotography@aol.com or you can reach Karen at www.KPearlmanPhotography.com Credit cards cannot be accepted.

Conference images can be found at: http://kpearlmanphotography.com/client_gallery/PSC%20Partners/

* International shipping may be extra

Goodsearch Fundraiser

Want an easy way to make a difference in the fight against PSC each and every day? Well, it doesn't get much simpler than this! Goodsearch, a free online search and shop engine (think Google), lets us click our way towards a cure every single day. Through no cost to the user, log onto www.goodsearch.com and choose PSC Partners Seeking a Cure, Englewood, CO as your charity and save it (if your computer doesn't automatically do so). From that point on, every search you make through Goodsearch will generate \$ for PSC Partners and there's no limit on what we can earn! So, search away. Need the lyrics to a tune you can't get out of your head?

Goodsearch it. Want a recipe for dinner tonight? Goodsearch it. Better yet, need to buy something? Use Goodshop (www.goodshop.com). Goodshop hosts a number of stores (both megastores like B&N and Amazon and smaller ones like UncommonGoods or QVC). Simply click on the store you'd like to shop and not only will Goodshop donate a portion of your purchase (at no cost to you) back to PSC Partners Seeking a Cure, they'll even show you if they have any coupons to use! Couldn't get much easier than this. So, click on over today and make your searches do some good!

Save The Day is Now an Annual Event!

Our first Save the Day fundraiser, held the first weekend in October, 2009, was so incredibly successful (raising \$16,785) that we've decided to make it a yearly event!

PSCers far and wide found out just how easy and fun it is

to work together towards a common goal from the comfort of our own hometowns!

Not only that, but together we've already earned some phenomenal funds to help us find a cure and better treatments against our nemesis, the uber-villain PSC.

Save the Day allows you to come up with your own local fundraiser of choice.

Whether you choose to hold a bake sale, a yard sale or donate all the change you collect between now and next October, it's all making a difference in the fight!

Here are some tried and true fundraisers that our fellow PSCers found fun and profitable:

- \$\$\$-- Yard Sales
- \$\$\$-- Personal Change Jars
- \$\$\$-- Tapas dinner
- \$\$\$-- Bake Sales
- \$\$\$-- Movie night at someone's home
- \$\$\$-- First-Giving Pages
- \$\$\$-- Walkathon
- \$\$\$-- Golf tournament
- \$\$\$-- In-home Silent Auctions
- \$\$\$-- Donation of Las Vegas winnings

Let's Do It Again in 2010!

Save the Day Fundraising Project

Bekky's Bake Sale: She's Determined to Help PSCers

By Kerrie Goldsmith, who is Bekky's baker, lives in Victoria, outside Melbourne, Australia.

This year my daughter, Bekky, 11 years old, decided she wanted to raise some funds for PSC research, so, when she asked me at the start of the year, "How can I help other people with PSC?" I flippantly suggested she email Ricky Safer, not expecting for one moment that my shy little girl who struggles to talk even to other adults she knows would follow through. It wasn't long before, with some ideas from Sandi Pearlman, she was on track with a bake sale, which she "had" to hold outside our local shops.

We had a number of setbacks along the way, including a couple of trips to hospital, and there were times when I must admit I hoped she'd say it was too hard. But she never once contemplated not going through with it.



So, on October 3rd, Bekky and her friend Ali went up to the local shops and sold some of the cakes. One of our setbacks had been she wasn't allowed to set up where she had wanted, due to some public liability laws, so she had set up in a quieter area where there were few sales made.



After a couple of quiet hours I brought the girls home, set them up with a trolley loaded with cakes and they spent the next few hours door knocking and selling the remainder of the cakes. Remember, this is the girl that normally won't say boo! She was exhausted by the end of it, but was soon thinking about her next project.

For those interested in her medical background: at 5 months old she became unwell, by a year old we had a diagnosis of PSC, and since then has been immunosuppressed with various meds and undergone a total colectomy for ulcerative colitis and has lived the roller-coaster of poor health and fatigue that goes with chronic illness. Bekky is learning a valuable lesson, that is, not to be defined by her illness, but instead be inspired to do great things.

Transplant Center

Winter Reading

Transplant Living has compiled a list of books on a variety of transplant topics (<http://www.transplantliving.org>). The list below is a sample of their recommended reading. Clicking on the titles will take you to Amazon.com, where you can read reviews, look inside the books, and order if you wish.

Many of the books cover kidney, heart, and lung transplants. Our own board member, Chris Klug, has written a book on how he managed through liver failure from PSC, a journey to transplant, and then to victory in the 2002 Olympics. His book is: [To the Edge and Back: My Story from Organ Transplant Survivor to Olympic Snowboarder](#).

Living Donation

[A Gift of Life: A Page From the Life of A Living Organ Donor](#), by Lynn Chabot-Long, Paul Jenkins (Editor)

[Black & White & Red All Over](#), by Martha McNeil Hamilton and Warren Brown

[Hanging by a String](#), by Marilyn Gibson

[Mr. Right and My Left Kidney](#), by Joan Saltzman

Children's Books

[How Will They Get That Heart Down Your Throat? A Child's View of Transplants](#), by Karen Walton, Allison Patrice Peterson (Illustrator)

[Precious Gifts: Katie Coolican's Story. Barklay and Eve Explain Organ and Tissue Donation](#), by Karen L. Carney

[Organ Transplants: A Survival Guide for the Entire Family \(It Happened to Me\) \(Hardcover\)](#), by Tina P. Schwartz

[A Whisper of Springtime: Jason's Heart Transplant Miracle](#), by Tedi Tuttle Wixom

Immunosuppressive Issues

[Coping with Prednisone: It May Work Miracles, But How Do You Handle the Side Effects](#), by Eugenia Zukerman, Julie R. Ingelfinger

Organ Specific

[Laura's New Heart: A Healer's Spiritual Journey Through a Heart Transplant](#), by Laura Fine

[Will I Live, Will I Die?](#), by Patricia Kuhn

[A Change of Heart: A Memoir](#), by Claire Sylvia

[Change of Heart](#), by Brian Hartford and Peggy McCardle

[Mr. NewHeart \(New Heart\): Heart Attack to Transplant and Beyond](#), by David Hollar

[The Climb of My Life: Scaling Mountains with a Borrowed Heart \(Hardcover\)](#), by Kelly Perkins

[Living a Miracle](#), by Randy Sims

[I'm Glad You're Not Dead: A Liver Transplant Story](#), by Elizabeth Parr

[Final Exam: A Surgeon's Reflections on Mortality \(Vintage\)](#), by Pauline Chen

[Stories of the Heart: Reflections on the Heart Transplant Journey: Stories of Hope and Inspiration](#), by Nancy Siemers (Editor)

[Life In Limbo: Waiting for a Heart Transplant \(Paperback\)](#) by Lisa Stiles Nance

[When Crickets Cry](#), by Charles Martin

General Subject

[Coping with an Organ Transplant: A Practical Guide](#), by Elizabeth Parr, Ph.D. and Janet Mize, R.N.

[Giving Life, Inspirational Stories of Hope for Organ Donors and Recipients](#), by Tom Falsey

[Transplant: From Myth to Reality](#), by Nicholas Tilney, M.D.

[Resilience: Faith, Focus, Triumph](#), by Alonzo Mourning and Dan Wetzel

[What's Possible!](#), by Daryn Kagan

[Anatomy of an Illness as Perceived by the](#)

Patient, by Norman Cousins
Life Row: A Case Study of How a Family Can Survive a Medical Crisis, by Ed Linz
The Gift That Heals: Stories of hope, renewal and transformation through organ and tissue donation, by Reg Green
The Transplant Patient: Biological, Psychiatric, and Ethical Issues in Organ Transplantation, by Paula T. Trzepacz (Editor), Andrea F. DiMartini (Editor)
Patient To Provider: A Patient's Guide To Transplantation, by Jeffrey W. Young, Jr. MSN FNP APN-BC

The Nicholas Effect: A Young Boys Gift to the World, by Reg Green, Linda Lamb (Editor)
Many Sleepless Nights: The World of Organ Transplantation, by Lee Gutkind
Organ Transplants: Making the Most of Your Gift of Life, by Robert Finn, Reg Green, Linda Lamb (Editor)
The Puzzle People: Memoirs of a Transplant Surgeon, by Thomas E. Starzl
The Waiting Game, by Norbert R. Hoferichter
Coping with an Organ Transplant: A Practical Guide, by Elizabeth Parr and Janet Mize

An Effort for Presumed Consent in Illinois

By Joe Berry, Liver Recipient, 2007

Recently our local newspaper, *The Journal Star* in Peoria, IL, had an article about a kidney transplant patient. That patient had a transplant at Northwestern Memorial Hospital in Chicago, the same transplant center where I had my liver transplant. The reporter for that article, Clare Howard, did a great job, so my wife Flo emailed her. My wife is passionate about caregivers and the lack of support that is available during the transplant journey. In that email, Flo suggested that Clare do a story on caregivers; to educate and create awareness for caregivers, both from a financial and an emotional perspective. Flo's forum for caregivers can be found using this URL: [http://](http://www.transplantcafe.com/group/care)

www.transplantcafe.com/group/care.

Shortly after Flo's email, Clare contacted her to arrange an interview with both of us. We spent five hours with Clare. She wanted the story of our journey from the beginning. It started in 1987 when I had my first symptoms of PSC. In 1990 I was diagnosed with both PSC and ulcerative colitis. After three to six months for the treatment plan to get both diseases under control I was asymptomatic until 2007. I had my gall bladder out in July, 2007 and began having PSC symptoms in August. After an ERCP in early September, I was told that I would need to go to a transplant center for an evaluation. From that point forward my health declined

rapidly and I was transplanted on October 17, 2007 at Northwestern Memorial Hospital in Chicago.

The more we talked with Clare the more she kept asking why there were not more organs available. After our interview she called Dr. Anton Skaro, a transplant surgeon at Northwestern. He said that education and awareness would increase the pool of donors. Clare's research found that only thirty eight percent of licensed drivers are registered organ donors in the United States. Dr. Skaro said that maybe it was time for us to develop a presumed consent policy for organ donation. One of the best qualities of this program would be the reduction or elimination of the

waiting list for transplants. Organs would get to patients in a more timely fashion, which means better clinical outcomes and reduced medical expenses. Another critical improvement would be the reduced number of deaths for those who would currently die on the waiting list due to organ shortages. This is the way that organ donations are handled in many other countries; for example, Spain and Belgium. In Belgium less than 2 percent of the population opted out.

In my case, had a liver been available when they determined that I needed one in early September, 2007, I would not have had four inpatient hospitalizations prior to transplant. The total cost of those was almost \$100,000 when you include the additional prescriptions and costs associated with these stays. I know I would have been in better health. I base that on my lab values at the

time of transplant and those from early September.

Clare contacted Illinois State Sen. Dale Risinger, R-Peoria. She had to leave a message with his office; however, she received a call back within an hour. He showed interest and said he would research the policy and draft legislation to introduce in January 2010. The legislation would not be in final form, but he said they would be able to hold hearings and get input from the public. Senator Risinger added, "Just for the record, I'm a donor. I think most people would be donors. With presumed consent, anyone would have the opportunity to opt out. My guess is only a small percent would opt out." We later learned that Illinois Sen. Dave Koehler, D-Peoria, said he would co-sponsor the legislation.

I wanted to get some sort of public reaction to the article in the local paper. I have read all

of the comments that people have left. Most of the thirty comments are positive. Other issues raised in the comments are the "pre-existing" condition clauses in insurance plans that prevent transplant recipients from getting health insurance, one thought this plan would be unconstitutional, and some talked about healthcare reform and how this would impact that. I think the best comment was, "I wish the best for Joe Berry, and hope his work toward increasing the pool of donor organs will get a fair hearing in Illinois."

Regardless of where you live, please contact your representatives, state and federal. Ask them to adopt and support this type of legislation. Currently this is only being done in Illinois, but it would be great to have it at the federal level. I am sending a copy to the creators of the legislation in addition to my federal congressman.

New! Shop PSC Partners: Logo & Customized Images Mugs, Keychains, Mouse Pads, Coasters, Puzzles

Check our new website under the Help Find a Cure tab for an assortment of cute PSC Partners logo items friends and family will love to use! Show your support for the cause of finding a cure. K Pearlman Photography is generously offering 100 percent of sales revenue to the foundation. Note cards available are available, too at the website under Shop PSC Partners: <http://www.pscpartners.org/shop>.



Round-up of PSC Online Support Groups

An **online PSC support group** was established in 1998. This is a message board (forum) on Yahoo/Health, where PSC patients and caregivers can exchange information and lend support/advice to one another: <http://health.groups.yahoo.com/group/psc-support>

In the **United Kingdom**, there is a similar PSC support group that publishes a newsletter and holds an annual meeting in Oxford with Dr. Roger Chapman, a leading PSC expert: <http://www.psc-support.demon.co.uk/>

There is also a **parent's support group**, especially helpful for parents of young children, as PSC presents itself differently in pediatric patients, and is treated accordingly. This group is found at: <http://health.groups.yahoo.com/group/pscmoms/>

Pre-teen kids and teens with PSC can get acquainted with others through a new online board: <http://health.groups.yahoo.com/group/psckids-support/>

For **post-transplant PSC patients**, there is a support group with discussions based on the special needs of being post-surgical, immunosuppressed, and having an "at-risk" status. You may join this group at: <http://health.groups.yahoo.com/group/Livertx-PSC/>

For **social networking**, sharing, and learning about living with PSC in your 20s and 30s, check out Facebook. You may join the group at: <http://facebook.com/group/php?gid=39847120173>
To join the group go to facebook.com and type in URL above

For PSCers and caregivers in **Israel**, there is an Israeli Facebook group. <http://facebook.com> Follow the prompts to set up a free account. Then type in PSC SUPPORT IN ISRAEL in the Search box and the group should pop right up.

Local Groups

Connecticut group:

Contact person: Reggie Belmont
ctpsc@hotmail.com

Sacramento, CA group:

Contact person: Jennifer Soloway
Jennifer@markstivers.com

Southern chapter/Greenville, SC:

Contact person: Carolyn B.

verviersbe@gmail.com

New York City:

Contact person: Eileen Solomon
Eileen.Solomon@mountsinai.org

rg (Please put "PSC" in the subject line)

San Francisco Bay Area:

Contact person: Tom Hill
tphill@1lifeplace.com

Israeli support group:

Contact people: Ellen and Chaim Boormeester
psc.support.il@gmail.com or hetzknasim@gmail.com

International Affiliate

A **Canadian affiliate** of PSC Partners Seeking a Cure is being formed. For more information or to help, contact Eve Jedrzejewska at eveandre@rogers.com

A Life of Movement

By Julianne Vasichek, who will be leading an exercise workshop on Friday afternoon at our 2010 Conference in May.

Hello PSC Newsletter Readers! My name is Julianne Vasichek and I currently live in Duluth, Minnesota. I am writing an article spawned by the interest of people with primary sclerosing cholangitis and their exercise needs. This is the first installment in a series of articles coming forth on this topic.

Besides introducing myself in the Winter Issue of *The Duct*, I want to lay a foundation for this article. My hope is that everyone can take at least one thing from these articles and apply it to their own lives. Most importantly, I hope this article gives you greater strength to live your life at all stages of this disease. Along with our caregivers and families, we are courageous community!

I was first diagnosed with PSC in April of 2008. However, I have lived with Ulcerative Colitis since July of 2001. At this time, I was starting my first year of college at the University of Minnesota Duluth (UMD), pursuing my Bachelor in Exercise Science while playing Division 1 ice hockey. I was able to calm my UC through diet and Asacol and contribute to two National Championship teams while also playing for five years at various levels of the United States National Team Program. I was an elite athlete coping with a digestive disorder.

Three years removed from playing competitive ice hockey, I began itching intensely in January of 2008. In March, I saw a doctor and was diagnosed with PSC in April of 2008.

Today, I am finishing a Masters in Education while working at UMD as an Assistant Director of Sports Performance for Women's Ice Hockey and Women's Soccer. Regarding PSC, I live in a state of information gathering and varying symptoms similar to many of you. I had a temporary stent placed last October, which was removed a month later. Since then, my itching has subsided for the most part. I have felt more energetic and completed my second marathon on June 20.

This being said, I am ever aware of the dull RUQ pain, foggy brain, and fatigue that come and go. I am a 26-year-old with PSC who at times has trouble motivating myself to exercise. Indeed there were times during training for the second marathon that I did not think I could do it because I was tired, unmotivated, and feeling the disease. This has been a new beginning for a person whose life was spent exercising. As you traverse this process of introducing stable exercise into your lives, so am I.



We know the symptoms of PSC influence us through impairing exercise, motivation, and energy levels. PSCers are also on a variety of medications that may help or hinder exercise. We are also looking at people who are preparing for transplant and transitioning their body through

recovery. It is important then to think of these symptoms in context with exercise. As a PSCer we must define the term “exercise” and rethink how we view it.

I ask you the following questions, what do you think of when I say exercise? Do you picture yourself on a treadmill at the gym or on a hiking trail? Do you picture yourself lifting weights or doing housework? Do you dread this word or does it make you feel good? Do you think exercise is relaxing, such as wandering your favorite museum? How much time does it take to exercise? What are issues that hinder you from exercise? What do you feel like while exercising and after? What happens inside your body when you exercise?

In the Spring article, I will begin to answer some of those questions and solve the puzzle of exercise and PSC through research and facts that can be pulled together in the context of PSC. In the next few months, I ask that you help contribute by sending me an email on what ‘PSC and exercise’ means to you. Use the above questions as a guide. I would like to build a good feel for our attitudes toward exercise.

For this installment I leave you with this thought. I want you to begin thinking of exercise as a way of life. I think too often exercise is viewed as something we “have” to do. Our society has helped create this. Many years ago and still today there are people who do not get up and go to the gym but exercise everyday. How can we generate a change in thinking?

Make exercise a part of your everyday life. For example, my job requires me to be on foot for many hours of the day, so I consider this a physical activity. My bones are getting some weight bearing movement, I am lifting and moving many objects during the day, and I am often only lacking in some flexibility and cardiovascular work.

Some days I also walk to work, clean around the house, walk in the trails, go for light bike rides, or go walk around my favorite shops downtown. This is the first step in creating a life of exercise.

I challenge you to incorporate movement into your lives 7 days a week for 30 minutes a day by the Spring issue. This can be 6 periods of 5 minutes or 3 of 10. Whatever works for you! In addition, two times a week add 15 minutes of activity at a pace where it is hard to carry on a conversation. I often do this by walking to work because my house is on top of a hill and I work at the bottom.

Hill or stair walking is an easy way to get your heart rate up, or add 2 heavy books to a backpack and speed up your walking pace if you live in North Dakota (it’s flat there!). Don’t forget to drink water during exercise as well. Keep a journal on your activity, to track what you are doing and to see how that interacts with your symptoms.

Most of all be proud of what you accomplish!

You? A PSC Partners Sponsor?

We’re on a roll at the five-year anniversary mark, and we’re making a difference in helping to fund research to find a cure for PSC. We know we’ll get there because of the determination we all share to fight this disease. Consider becoming a sponsor for an annual conference, for a research award, or for general support. Check the website: <http://www.pscpartners.org/becomeasponsor>.

**General Donations
to PSC Partners
September 12-December 10, 2009**

DONOR

Angela Roehrich
Von Welch
David Szugaj
Clifford Wald
Peggy Nance
Michael Knapek
David Rhodes
Javon Evanoff
Tamara Miller
Michael Zaloudek
Crissa Lee
Darcy Ward
Katelyn Darna
Caroline & Aubrey Goldstein
Paul Hain
Ricky & Don Safer
Roy Toutant
Laura Perkins
Elizabeth Michaud
Dr. Dennis Black
Jeanette Rempel
Christopher Decker
Rhonda & Daniel Detzel
Hope & Paul Hedberg
Barb Henshaw
Barb Henshaw
Barb Henshaw
Cindy Rogers
Reggie & Jeff Belmont
Steve Lafayette Jones
Debbie Grotewiel
Ros & David Parry
Reggie Belmont
Patricia Bandy
Mimi & Bob Safer
Stephen Winber
Sue and Adam Safer
Margery & Howard Seid
Betty Hume
Umesh Agarwal
Maureen Barton
Reggie & Jeff Belmont
Sandra & Stephen Lehrman

IN HONOR OF

PSC Partners

Teresa & Annie
John J. Ross (Jack)
Matt Detzel
Peder Hedberg
David Rhodes
Stefan Grant
Rick Kamp
Jessica Bates
Alison Cubbellotti
John & Rita Lafayette
Mike Boyd
Nicola Parry
Todd Clouser
Ricky & Don Safer

Sandi Pearlman

Celebration of Diwali
John Shepherd
Jecy Belmont
Brian, April, Chase,
Sandra & Stephen Lehrman

DONOR

Alex Amplo
Lee & William Bria
Lisa & Earl Kennedy
Ricky & Don Safer

IN MEMORY OF

Fred Hussey

Ways to Donate

We welcome and appreciate donations of any amount to support our programs. Except for our annual conference, all of our educational and support programs are offered free of charge to everyone.

Thanks to the volunteer nature of our foundation, we have been able to keep our administrative expenses at less than 3 percent in order to direct your contributions directly to research grants and patient services. We're serious about finding a cure for PSC, and your contribution will bring us closer to our goal.

General Donations

To make a tax-deductible donation, please write a check out to PSC Partners Seeking a Cure and send it to:

PSC Partners Seeking a Cure

5237 So. Kenton Way
Englewood CO 80111

Please send all international donations in United States dollars.

Let us know if your check is in support and/or in honor of someone or in memory of someone, and include their address so that we can send them an acknowledgement of your donation. Please include your email address as well.

Or alternatively, to donate with a credit card, you may donate via PayPal by clicking here:

<http://www.pscpartners.org/waystodonate>

Carrie & Donald Brazil
 Deborah Lee
 Martha Gerschefski
 Valerie & Peter Arnsten
 Reggie & Jeff Belmont
 Sheldon Harper
 Elizabeth & Roderick Odom
 Susan & Jesse Irwin
 Susan Felices
 Mariellen Jacobs
 Barb Henshaw
 Alison & Brian White
 Deborah Massa
 Heather & Graham Milligan
 Rachel Gomel
 William Olmsted
 Cindy Rogers
 Mark Maiewski
 Tammy Rock
 Rachel Gomel
 Jean Yeager
 Katy Miller Family
 Miller

Thomas A. Rogers

John Markham
 Arthur Bough

Katy

Fundraising Donations

Save The Day

DONOR

Barbara Blistein
 Bek Goldsmith
 Joanne Hatchett
 Joanne Grieme
 Barbara Stout
 Helen Pertesis
 Kristy Agli
 Kristine Arbo
 Kathleen Ayr
 Jecy Belmont
 Carol Blackman
 Guay Chatfield
 Mary Jayne Chillemi
 Lia & Bryan Donahue
 Carmela Donahue
 Janet Galati
 Bonnie Goldberg
 Eileen Colihan
 Marilyn Hirsch
 Betty Horn
 Kathryn Jack
 Scott Jungeblut
 Alma Michaud
 Nancy Brown
 Sara Gillette
 Arlette Nicaise
 Catherine Petraiulo
 Jeslie Powers

IN HONOR OF

PSC Partners

Stock Donations

As another donation vehicle, we have a brokerage account at Charles Schwab. Now, in addition to your cash gifts to PSC Partners Seeking a Cure, you can gift appreciated stocks which we can then sell and turn into cash. The tax benefit to you is enormous. Let's say, for example, that you bought 100 shares of XYZ at \$10 per share, and it has now appreciated to \$30 per share. Instead of selling it and paying capital gains taxes on the \$2000 profit, you can transfer the shares electronically to our account at Charles Schwab. You can then take a tax deduction for the full market value of the security on the date of transfer WITHOUT incurring any capital gains tax.

Here's how to do it:

Just instruct your broker to use the following information for the securities you wish to donate:

Charles Schwab, DTC #0164, code 40
 For credit to: PSC Partners Seeking a Cure
 Charles Schwab 7110-4814

Send us a note (at contactus@pscpartners.org) informing us of your donation.

For transfer of stock from a current Charles Schwab account, simply submit a letter of authorization. To contact Charles Schwab directly, call 800 435-9050, 24 hours/day, 7 days/week.

As always, please consult your tax advisor before making contributions of securities.

- Jennifer Recker
- Gina Rocca
- Yolanda Belmont
- Thomas Salemm
- Joann Thompson
- Edward Thompson
- Cathi Waas
- Joyce Willig
- Ann & Arthur Yost
- Debra Palmeri
- Jeannie Mullen
- Amy Richardson
- Elizabeth Howden
- Bryan McKay
- Carmelle & Michael Giblin
- Cindy & Dennis Cary
- Michelle Archambault
- Chrissy Newcomb
- Susan & Philip Gresh
- Sara Gutierrez
- Lynn & Richard Broyles
- Robert Pedra
- Nicola Parry
- Constance Gourdeau
- Kathleen Hansen
- Sharon Brady
- Yolanda & Hector Villanueva
- Steven Liu
- Eileen & Michael Pearlman
- Karen Pearlman
- Joy Salmon
- Maryann & William Casterline
- N.E. Waugh
- Julie & Dennis Morgan
- Betsy Labar
- Mary Bohmke
- Sarah Kittredge
- Fern Dasilva
- Beth Falk
- Shawnee Ryan
- Rebecca Case
- Rita Berkey
- Rhonda Fried
- James Correia
- Jane Hicks
- Karen Blake
- Joyce Waugh
- Tara & Tina Bell
- Phyllis & Victor Russillo
- Jean & Paul Hudson
- Patricia Thiel
- Beth & Steve Senter
- Lee & William Bria
- Martha Metzler
- Deborah & Dick Wittenberg
- Teresa Hoff

Nicola Parry

Sandi Pearlman

Libbie Bailey

Billy Bria
Teresa Hoff

Matching Gifts

If your company has a Matching Gift Program for charitable organizations, please sign up and forward the forms for us to fill out. This is a wonderful way to make your donation multiply in value.

Thank you again to all our donors who continue to support us in our fight against PSC. Together in the fight, whatever it takes!

Some Easy Fundraisers

Kroger Community Rewards Program – Michigan and Ohio only

If you live in Michigan or Ohio and do your grocery shopping at Kroger, please take a minute to join our Kroger Community Rewards Program. Register with us to get your Kroger Plus Card, and then a percentage of every purchase that you make from now on at Kroger will be donated to PSC Partners Seeking a Cure. To get started, write to Debbie Thompson at designingdebbiet@yahoo.com, and she will send you the required bar code. Just take this to your local Kroger store, and they will issue your Kroger Plus Card.

Create Your Own Fundraiser

We welcome suggestions from supporters who would like to create their own fundraiser for PSC Partners Seeking a Cure. If you have an idea, please fill out the short Project Proposal Form on our website and send it to leedeubert@gmail.com or to Ricky at contactus@pscpartners.org.

Road To Connecticut

DONOR

Sue & Scott Malat
Betty Horn
V.M. McMaster
Jeffrey Belmont
John Patterson

IN HONOR OF

PSC Partners

Billy Bria
Jecy Belmont
Allison
Cubbellotti

DONOR

Joanne Hatchett

IN MEMORY OF

Fred Hussey

New Sponsors

PLATINUM PREMIUM LEVEL SPONSORS:

Rachel & Abe Gomel
Ros & David Parry
Ricky & Don Safer

GOLD LEVEL SPONSOR

Lee & William Bria
Sue & Scott Malat
Katy Miller Family
Joane and Ross Anderson

SILVER LEVEL SPONSOR

Reggie & Jeff Belmont
Clifford Wald
Sandra & Stephen Lehrman
Chrissy Newcomb

BRONZE LEVEL SPONSOR

Steve Lafayette
Darcy Ward
Dr. Stephen Winber
Joanne and Steve Grieme
Barbara Stout
Barb and John Daniels
Lynne Cutter

COPPER LEVEL SPONSOR

Pat & Bill Bandy
Dr. Dennis Black
Rhonda & Daniel Detzel
Judy & David Rhodes
Gay and Eugene Crowley
Eileen and Mike Pearlman
Theresa Hoff
Penny and Tim Romlein

PSC Medications Brochure Now Available

Released this month: PSC Partners has printed a new educational brochure on medications used to treat patients with PSC. The brochure is another in the series of patient education materials published by the foundation. The brochure is on the website, <http://www.pscpartners.org/brochures> or available through order at this address: brochures@pscpartners.org



YOU'RE MAKING A DIFFERENCE: WE'RE WORKING TOWARD A CURE

We're itching for a cure and we're all together in the fight, whatever it takes! Through your donations and fundraising efforts we've been able to support PSC research in the past five years with \$317,706! Consider doing your part to help us raise more funds to support our educational programs and especially to find better treatments and that elusive cure for PSC. You can donate any amount, join one of our fundraising events, set up your own local fundraiser, or just ask friends and family to join the cause.



**PSC PARTNERS
SEEKING A CURE**

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 a cure of PSC, and provide education and support to PSC patients and their families, and promote PSC and organ donation awareness.

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

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

/Scientific/Medical Advisory Committee

Dr. Dennis Black, Dr. Christopher Bowlus, Dr. Kapil Chopra, Dr. Steven Deitch, Dr. Greg Everson, Dr. Richard Green, Dr. Aubrey Goldstein, Dr. Denise Harnois, Dr. Gideon Hirshfield, Dr. Stephen Miller, Dr. Don Safer, and David Rhodes, Ph.D., (Chair)

The Duct Newsletter

Editor: Pat Bandy (newsletter@pscpartners.org)

Contributors to this issue: Pat Bandy, Joe Berry, Jerrie Goldsmith, Sandi Pearlman, Ricky Safer, Julianne Vasichek

New on Our Website:

“PSC-IBD Link” Summary and Slides from Denver’s October Workshop

A Summary of the “The Primary Sclerosing Cholangitis/Inflammatory Bowel Disease Link: An Informative and Interactive Workshop for Medical Professionals and Patients” is now on the website at this link: http://www.pscpartners.org/sites/default/files/files/Denver_10-03-09.pdf. We thank Rachel G., who prepared the summary. PowerPoint slides from the presenters are also on the site <http://www.pscpartners.org/pscconferences>

The workshop took place at the University of Colorado-Denver medical and research center. Keynote speakers were Dr. Keith Lindor, of Mayo Clinic, and Dr. Tom Karlsen, of NoPSC, at the Norwegian PSC Research Center.

Topics covered included the promising research of Dr. Sean Colgan, head of mucosal inflammation research at UCHSC, innovations in non-invasive techniques for staging liver disease led by Dr. Greg Everson, head of hepatology; and discussions with Dr. Brian Doctor, Dr. Steve Helmke, Dr. Alan Baird, Dr. Lisa Forman, Dr. Raj Shah, Dr. Jeffrey Campsen, Dr. Jesus Rivera-Nieves, Dr. Aliya Hasan and pediatric hepatologists, Dr. Shikha Sundaram, Dr. Ron Sokol, and Dr. Cara Mack.

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.