

PSC Partners Seeking a Cure Newsletter

Vol. 1, Issue 9, October 2005

Edited by David Rhodes and Ricky Safer



www.pscpartners.org

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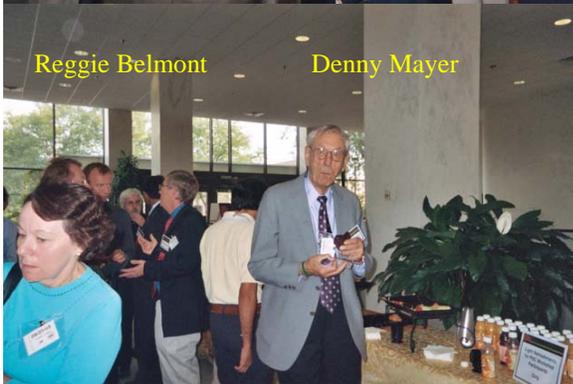
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PSC Partners Seeking a Cure Board Members:

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



Dr. Gregory Gores and Dr. Roger Chapman

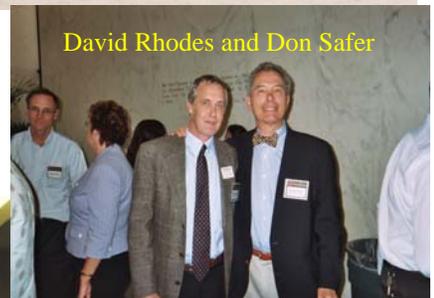


Reggie Belmont Denny Mayer



Conference Speakers

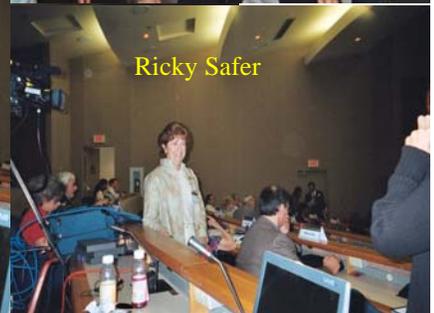
Collage of photographs from the NIH/Morgan Foundation PSC Conference in Bethesda, MD: Sept. 19-20, 2005



David Rhodes and Don Safer



William and Lee Bria



Ricky Safer

Photographs contributed by Lee Bria and David Rhodes



Dr. Keith Lindor



Dr. Giorgina Mieli-Vergani



Returning to a session

Reasons to Run

Unexpected Perspectives

by Marc Chalufour

(Excerpt from Running Times October 2005. To read the complete article visit www.runningtimes.com)

Todd Coulston

Todd Coulston was a competitive kid. From running the quarter- and half-mile for the local church league team, Coulston moved up to the mile in high school, and slowly the sport of running grew on him. "Just doing well and succeeding," he says, were all the motivation he needed to keep running. In particular, he admits—sounding slightly embarrassed—he was driven by the desire to run faster than his friends.

Coulston lived for the competition, and now laughs when he recalls his strong preference for racing over training: one competitive goal was leading directly into another. First it was earning a varsity letter, then breaking five minutes in the mile. Once he did that, he chased 4:50. A 10-minute two miler as a junior, he graduated a year later with a personal best of 9:24 and headed off for the University of California, Irvine, where he competed as a Division I athlete.

Coulston's competitive successes continued at UCI—running 5,000 meters in 14:35, gaining all-conference honors—but as running became more of a priority, his appreciation for the sport was evolving. "You get into it because you like the competition, you like the camaraderie of being with your friends and teammates," he recalls. Yet he was now enjoying the sport's benefits outside of the competitive arena. "I found real peace running out in the woods, thinking about life. It was kind of a place to get away. I've always needed places or time on my own, whether it was just shooting hoops in the back yard or going out on a run on a trail, just being alone with my thoughts, being introspective," Coulston says. "It's a perfect vehicle to do it. It's a very personal, selfish type of escape, where you can really think about your life and dreams, and really put everything together. I think that's the one thing about running and why I continue to do it and why I'll always do it if I'm physically able. It spurs you to do great things in all aspects of your life. It holds you accountable: if you don't do it for a while and you come back to it, it tells you. It just becomes a part of your lifestyle."

Unfortunately, that lifestyle was threatened early on. Coulston contracted mononucleosis during his sophomore year at UCI, and his blood tests suggested that there was something wrong with his liver. The doctors were baffled, though, and for the next year they tested Coulston for a variety of illnesses. Finally, after a liver biopsy during the summer of 1992, he was diagnosed with primary sclerosing cholangitis (PSC). Coulston admits he was relieved to finally know what was wrong, and though PSC is a serious condition, he was still asymptomatic. "They said, 'Go live your life, and we'll keep monitoring you,'" he recalls. "I had the perception at that point that I wouldn't have to worry about this disease until I was 50 or 60 years old."

Though his health was fine, Coulston's running career soon came to a crossroads as he graduated from UCI. Reflecting on what he'd accomplished and looking ahead, he knew that he wasn't going to feed himself as an elite runner. The competitive component that had been so critical to attracting him to running in the first place had now been balanced by his enjoyment for the more tranquil side of the sport. "At that point I was ready—I knew I had done what I could; I knew that I had pushed myself pretty much to the max of my abilities and was pretty satisfied with that," he says. "That was a great chapter in my life. I really liked it, but I was looking for another arena where I could apply what I'd learned."

Law school and marriage followed over the next five years, and Coulston continued to seek a regular escape in his running, heading out for 50 or 60 minutes every day. He regularly competed in local road races, though he was no longer at the level he'd reached in college. Then, in the fall of 1995, Coulston decided to run the Los Angeles Marathon the following spring. He began upping his weekly long runs and running half marathons.

In Los Angeles Coulston had a typical first-timer's experience, cruising through 18 miles before hitting the wall. Still, he finished in 2:45:13. In hindsight, Coulston wishes he'd run the 1997 Boston Marathon, but by then he was in law school and training for a marathon would have been prohibitive.

Throughout the mid-1990s, Coulston's health was fine, then in 1999 the effects of PSC, which obstructs the bile ducts leading out of the liver, became noticeable. Slowly he became more fatigued and jaundiced. As the disease progressed, he lost weight and suffered frequent nosebleeds and broken blood vessels under his skin. "Even through the symptoms I was determined to keep running," he recalls. "[But] the disease started to impact me, and I started cutting days out of the week. I would maybe run four or five days a week. Then it was shorter time periods, only 25 or 30 minutes instead of an hour." The running still gave Coulston pleasure: "It was frustrating not to do more, but it was still good because at that point I'd started practicing law and maintaining a very hectic schedule as an attorney, so it was a relief to get the stress of the day out and try to clear my head a little bit."

Finally, he says, "by January of 2001 I pretty much had to shut down altogether." In July 2000, Coulston was told he had 18 to 24 months to live; by 2001, he was given just three to six. Now unable to run, Coulston no longer had the outlet he'd grown accustomed to over the past decade. "It just drives you nuts," he says. "You get used to that endorphin kick and that way it makes you feel, and not having that, you just feel sluggish and, probably, kind of on the edge emotionally. It was a little bit depressing." Running, however, was not the top priority. Coulston and his wife were expecting their first child, and now suddenly he was in danger of dying long before his name would reach the top of the transplant list. As a last resort, the couple temporarily moved to Florida, where the transplant list was shorter, and waited.

Barely two weeks into their stay, the Coulstons were woken at 4 a.m. by a call notifying them that a donor had been found. Within 24 hours surgeons had opened Coulston's abdomen from one side

(continued from p. 2)

to the other. Six hours later, he had a new liver.

Even through the diminishing haze of the anesthesia, Coulston remembers feeling an immediate difference when he awoke. Rehab began almost immediately—first with a few steps, then with progressively more laps of the ward. Though he laughs at the memory today, he recalls the frustration of feeling so helpless: "I would have those thoughts, that 'I used to be able to run 6.2 miles at all-out speed, and here I am and I can't even walk 10 feet down the hallway.'"

Coulston was going on daily walks outside by the time he returned to California, but he couldn't run yet. "I'd be tempted," he says. "I'd break out and jog, take a couple steps—but it's a weird feeling in your stomach after a surgery like that. It takes a long time to feel normal." Finally, in October, Coulston was given the OK to start running again. "I went to the neighborhood park and just ran a couple laps around the fields. I think I ran maybe seven, eight minutes," he recalls. "I was very excited. Pretty emotional, too."

Slowly Coulston worked his way back into a routine. First he ran about 10 minutes, three or four times a week. Then progressively longer. He'd already set a goal of competing at the 2002 U.S. Transplant Games. In fact, he'd known about the Games for nearly a decade, since first being diagnosed with PSC. "I had joked with my doctor, 'You should just do [the transplant] now so I can go and win all that stuff,'" he says with a laugh. Now his transplant was the motivation he needed to return to the track for the first time since college, to let those competitive instincts loose again.

"People tell me I get a look on my face when I'm running, or if I'm in a competition—a dead-serious, don't-mess-with-me type of look," Coulston says. "The only time when I've felt that look is back on the track, at the Transplant Games. When that gun fires, you almost get to a different state of mind. Back in high school and college, that's why I was doing it—to win, and have fun hitting the times and running fast. But it definitely changed, and in that process I came to love it and really see that it didn't just apply to that context but to my lifestyle and daily life. That's the greatest aspect of running."

Coulston's entire family was in the stands cheering as he placed second in his division of the 1500m, running 5:37.31. Following the race, Coulston says he saw his father crying for the first time that he could remember. Though his pace didn't even match that of his collegiate 10,000m best, that didn't matter any more.

"Now the goals are more 'What can I accomplish?' and not necessarily 'How fast can I go?'" Coulston says. "It's rejuvenated things—it's a whole new challenge. Now that I've had a major organ removed from my body, what can I do now? It's definitely motivating."

(article contributed by Jeff Belmont)

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

Fundraising Update

Thank you to everyone who is helping us by refilling and swiping their Kroger cards!! I hope that you all feel as good as I do each time you use your card knowing that you are helping PSC Partners Seeking a Cure. We have kind people in CA, CO, IL, IN, MI, NE, OH, and the great state of Tennessee helping us. If you also live in an area with a Kroger store [check our web site for a list of their other participating stores] please join us in this effort to raise funds to fight PSC. Please remember to recharge your card when shopping as this is the only way to add to our funds.

As always we are looking for other area fundraisers. Please contact me if you have a fundraising idea or if you would like a Kroger card.

We are also looking to get a letter writing campaign under way. Please email mariapamom@comcast.net if interested in sending out some form letters or if you can recommend a business where you know someone we can contact.

A tax deductible donation of _____	
In honor of _____	

CAN BE SENT TO: PSC Partners Seeking a Cure 5237 So. Kenton Way Englewood, CO 80111	email: pscpartners@yahoo.com www.pscpartners.org
WITH A CHECK MADE OUT TO: PSC PARTNERS SEEKING A CURE	<i>Thank you for your generosity.</i>

The business size donation cards are back in and up to date with our address and web site. If you would like any, please contact me at the email below. I can send 10 of them for regular postage. I use them to send to friends and relatives as I have arranged with those close to me to send in one of these cards with a donation on gift-giving occasions. Donating instead to Partners is the best gift they can give me. I also hand them out with a ribbon attached to the wristband, a great idea from Denise.

Our AAA Environmental fundraiser is off to a great start! So far we have collected 77 cell phones, 143 ink jets and 9 laser cartridges that passed. Let's keep up the good work and grow this fundraiser, so that by the next quarter we will receive a nice check. You are all not only helping raise money for Partners, but you are helping the environment as well. Go team, go!

Lee Bria

ldbria@comcast.net

or visit our web site

www.pscpartners.org

Living with Primary Sclerosing Cholangitis Brochure

The PSC Partners Seeking a Cure Foundation published its first brochure in September, 2005: "Living with Primary Sclerosing Cholangitis (PSC)."

The brochure is available in .pdf format at the following URL:

<http://www.pscpartners.org/PSCBrochure.pdf>

To order printed copies of the brochure, please send an e-mail with your name, mailing address and desired quantity to Barb Henshaw at: pscbrochures@yahoo.com. If requesting more than 50 brochures, please let us know how you plan to distribute them. Please allow 1-2 weeks for delivery.

Barb Henshaw

PSC Research and Conference in California

Hello everyone,

I am working with PSC researchers at U.C. Davis. They are doing research on atypical pANCA (an autoantibody found in most people with PSC) and are establishing a PSC registry and DNA bank. The registry and DNA bank will facilitate research on PSC. They need as many participants as possible, but they have not had many PSCers agree to participate. If you are interested in helping these projects, please contact Dr. Christopher Bowlus at:

clbowlus@ucdavis.edu

The American Liver Foundation, in coordination with Dr. Bowlus, has kindly agreed to host a support meeting in the San Francisco Bay area for people with PSC and PBC. There will be expert speakers. They have not set the date, but it will probably be early in 2006, on a date that will not conflict with the Pittsburgh meeting. Hopefully this will be the beginning of a new era of ALF support for PSC research and education. I will keep the group posted when they set a date and place for the meeting.

Jennifer Soloway, Sacramento, CA
(dx PSC UC 2001)

2006 Conference

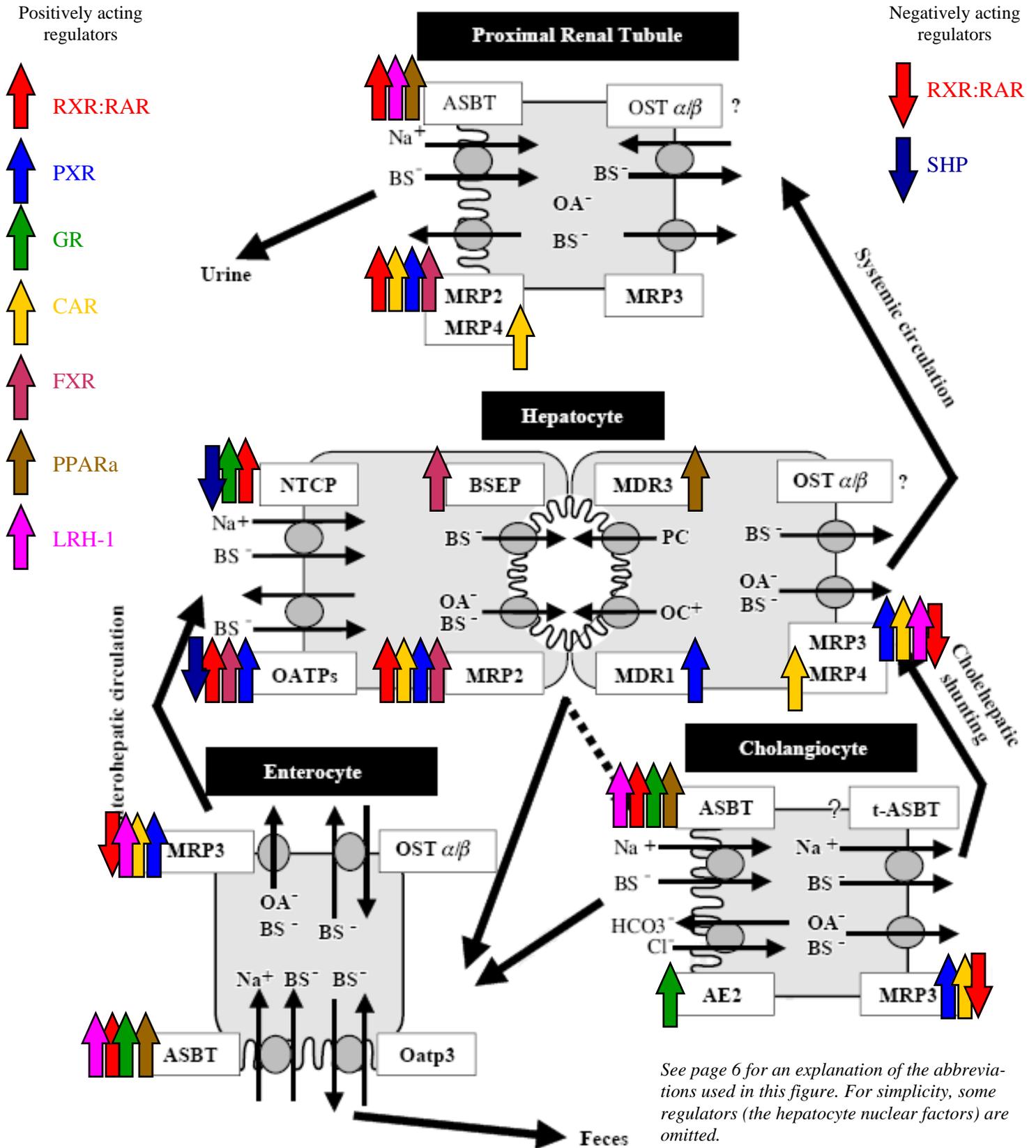
The PSC Partners Seeking a Cure Foundation will hold its 2nd annual conference for PSC patients and caregivers in Pittsburgh, PA, from April 7-9, 2006. Further details will be announced as they become available.

Major Hepatobiliary Transporters and Their Regulators

There is growing interest in the role of hepatobiliary transporters in PSC and other cholestatic liver diseases. Particular attention is being given to the nuclear receptors that regulate these transporters. The figure on page 5 summarizes the major hepatobiliary transporters and how they are regulated by various nuclear receptors. The following color coded abbreviations are used to indicate the involvement of the various receptors in the regulation of the transporters in the figure. Each of the receptors is in turn activated by various drugs/medications/supplements, some of which will be familiar to PSC patients. Recent research suggests that RXR and PPAR α may be activated by components (or metabolites) of fish oils. Rifampin, dexamethasone and phenobarbital are often used to control pruritus, and are believed to act by activating the pregnane X receptor and constitutive androstane receptor. Ursodeoxycholic acid (ursodiol) is thought to activate the glucocorticoid receptor, farnesoid X receptor, and the pregnane X receptor.

Abbreviation:	Nuclear Receptor:	Activated by:
RXR:RAR	Retinoid X receptor: retinoic acid receptor	Retinoids, docosahexaenoic acid (DHA) (in fish oil)
PXR	Pregnane X receptor	Rifampin/rifampicin, dexamethasone, ursodiol
GR	Glucocorticoid receptor	Glucocorticoids, ursodiol
CAR	Constitutive androstane receptor	Phenobarbital
FXR	Farnesoid X receptor	Ursodiol
PPAR α	Peroxisome proliferator-activated receptor alpha	Fibrates, fatty acids, eicosanoids, fish oil metabolites
LRH-1	Liver receptor homologue-1	Tumor necrosis factor alpha
SHP	Short heterodimer partner	?

Major hepatobiliary transporters and some of their regulators



Adapted from: Wagner M, Trauner M (2005) Transcriptional regulation of hepatobiliary transport systems in health and disease: implications for a rational approach to the treatment of intrahepatic cholestasis. *Ann. Hepatol.* 4: 77-99. <http://www.medigraphic.com/pdfs/hepato/ah-2005/ah052c.pdf>

Update on Donations to PSC Partners Seeking a Cure

(by Ricky Safer)

Here is a list of our recent individual donors:

In honor of:

William F. Bria

Donor:

Cyril Grum
Christine and Thomas Sisson
Tammy Clark and Akinlolu Ojo
Margaret Gyetko
Marilynn and Robert Paine III
Tarun and Vibha Lama
Jennifer and Jeffrey Horowitz
Mary and Paul Christensen
Lois and William Solomon
Barbara and Dean Carpenter
Diane and William White
Echo and Thomas Reed
Colleen and Fernando Martinez
Michael Coffey
Janet and Marc McMorris
James Beck and Robert McGranaghan
Mary Elizabeth and Thomas Ball
Mary and John Weg
Karen Chapel and Douglas Arenberg
Catherine Meyer
Michele and Daniel Pushies
Catherine Meldrum
Vivian Knieper
Katherine Mendeloff and Jeffrey Curtis
Rosemarie Bria
V.M. and G.K. Mc Master
Dorothy Szyniszewski
James Miller
Gail and Richard Hammond
Jeffrey Dwain Jackson
Cathleen Bolek and Gary Levin
Cheryl and Alec Isaacson

Ricky Safer

Daniel Kantor

Kevin Bray

Jason Drasner

In memory of:

Darrell Falk

(Father of HillbillyBob)

Donor:

Shirley and Robert W. Falk
Mrs. Darrell Falk and Family
Shari and Monte Wilson
Melanie and John Falk
Jane and Glen Riley
Mrs. George D. Skelton
Kansas Dept. of Ag. Employees
Robert Falk
Juliet Good
William Olmsted

Thomas A. Rogers

*Thank you to all our donors for helping us reach our ultimate goal
of finding a cure for PSC!*

Abbreviations used in the figure on p. 5

AE2, anion exchanger 2 [works with the cystic fibrosis transmembrane conductance regulator (CFTR) to exchange chloride (Cl⁻) and bicarbonate (HCO₃⁻)]; ASBT, apical bile acid transporter; BS⁻, bile salt; BSEP, bile salt export pump; CAR, constitutive androstane receptor; FXR, farnesoid X receptor/bile acid receptor; GR, glucocorticoid receptor; LRH-1, liver receptor homologue-1; MDR, multidrug resistance protein; MRP, multidrug resistance-associated protein; Na⁺, sodium; NTCP, Na⁺/taurocholate cotransporter; OA⁻, organic anion; Oatp, organic anion transport protein OC⁺, organic cation; OST, organic solute transporter; PC, phosphatidylcholine or phospholipids; PPARα, peroxisome proliferator-activated receptor alpha; PXR, pregnane X receptor; RAR, retinoic acid receptor; RXR, retinoid X receptor; SHP, short heterodimer partner.

David Rhodes

Making Donations to PSC Partners Seeking a Cure

Tax-deductible donations can be sent to:

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

with a check made out to:

PSC Partners Seeking a Cure

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

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

We offer several levels of sponsorship

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

Thank you for your generosity!

Thank you to our new bronze level sponsor:

James Miller

Thank you also to Procter and Gamble for their grant to support our brochure project.

Thank you to Deb Wenthe, our treasurer, who purchased and donated a copy of Quickbooks for the foundation.

When I attended the PSC Research Conference in Bethesda, MD in September, I had dinner with an old friend, Prof. Philip Filner. When I returned home, I was very touched to find this thoughtful article (PSC For a Lay Audience) from Phil in my Inbox. Phil has much experience in explaining diseases in layman's terms. He has worked as a volunteer and scientific advisor for the Macular Degeneration Foundation, monitoring research progress and writing reports designed to communicate that progress to an intelligent lay person. Most of his reports are still posted at www.eyesight.org. Thank you for this contribution, Phil.

David Rhodes

PSC For a Lay Audience

What is Primary Sclerosing Cholangitis?

The medical profession has a habit of giving diseases names whose meanings are not obvious to non-physicians. Primary Sclerosing Cholangitis, or PSC, is an example.

Cholangia is another name for ducts in the liver through which bile moves, including the bile duct, the big one by which bile leaves the liver, to be stored in the gall bladder or released into the beginning of the small intestine, the duodenum.

The "-itis" ending implies an infection or inflammation.

Sclerosing means scarring.

What is bile?

Bile is a mixture of biomolecules synthesized in the liver. The two major groups of these molecules are the bile salts and the bile pigments. Bile salts are synthesized from the sterol cholesterol. The major bile salts are cholic acid and deoxycholic acid. Bile pigments are synthesized from heme, the molecule in hemoglobin which makes blood red. Heme is a molecule of protoporphyrin IX to which an iron atom is bound. Protoporphyrin IX contains four pyrrole rings (each containing 4 carbons and a nitrogen) in a super-ring. When the bile pigments are synthesized, the super-ring of the cyclic tetrapyrrole is opened up to form a linear tetrapyrrole. The major linear tetrapyrroles of bile pigments are biliverdin and bilirubin. These pigments give feces their characteristic brown color.

Polarity is a property of all molecules. A highly polar molecule is one which has local areas within it of positive or negative charge as a consequence of having electrons unevenly distributed in the molecule. A molecule with little polarity, known as a non-polar molecule, has its electrons more evenly distributed, so that there is very little localized charge within the molecule. Polar molecules tend to have an affinity for polar molecules such as water and sugars, and non-polar molecules tend to have an affinity for non-polar molecules such as fats. Bile salts and bile pigments are non-polar

Laughter is the Best Medicine

Can it be a mistake that "STRESSED" is "DESSERTS" spelled backwards?

After two days in the hospital, I took a turn for the nurse. - W.C. Fields

PSC Partners Seeking a Cure Notecards

Notecards can be purchased from "PSC Partners Seeking a Cure":

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

Alternatively, notecards can be ordered on-line via PayPal (<https://www.paypal.com/>) email:

pscpartners@yahoo.com

If choosing this route, please indicate the number of notecards you wish to purchase, and give your name and shipping address.

The purchase price of the notecards is dependent upon the number ordered, as follows:

- 1 bundle of 6 cards \$10.00 plus \$1.00 shipping and handling
- 2 bundles (12 cards) \$20.00 plus \$1.75 shipping and handling
- 3 bundles (18 cards) \$30.00 plus \$2.00 shipping and handling

These S&H numbers are for domestic orders only. For international orders please email

pscpartners@yahoo.com

and a shipping quote will be provided.

(Notecard concept by Ali Lingerfelt-Tait)



molecules, so they can bind to fats. However, bile salts and bile pigments are conjugated, i.e. covalently linked to, small polar molecules in the liver, so that one end of the conjugated molecule is non-polar, and the other end is polar. That is the basic structure of molecules we call detergents. They can bind to fat at one end, and to water at the other end, thereby making it possible to mix non-polar, water-repelling fat with water, a process called emulsification.

The function of the bile salts and bile pigments in our bodies is to emulsify the fatty foods and vitamins, e.g. vitamin K and E, we ingest and require for good health. Emulsification makes it possible to absorb them across the wall of the intestine into the blood stream. Without emulsification, the fatty materials pass straight through the intestine and out the other end.

The Disease

In PSC, the bile salts and bile pigments are synthesized in the liver, but are not transported efficiently to the gall bladder and duodenum. Also, they probably are not fully conjugated in the liver. The non-polar character of the unconjugated bile salts and bile pigments enable them to dissolve in and make holes in cell membranes, which makes the cells leaky, thereby weakening and eventually killing the affected liver cells. Another type of damage in the liver is the scarring and possible blockage of the internal ducts of the liver. Also, the unconjugated bile salts and pigments are able to move via abnormal, uncontrolled paths into the blood and elsewhere in the body, causing damage.

Thoughts on Possible Causes of PSC

Failure to efficiently conjugate bile acids or bile pigments in the liver may be the starting point of PSC. Another possibility is failure to transport the bile acids and bile pigments out of the liver cells in which they are synthesized. This could be a secondary effect of a deficiency of conjugation, or because of a primary malfunctioning of the transport system which normally would move the conjugated molecules across the cell membrane and into the internal ducts of the liver. Another possibility is overproduction of bile acids or bile pigments as a result of failure of a normal control of the biosynthetic rate in the liver.

Research Goals

The many symptoms of PSC are generally attributable to an excess of unconjugated bile pigments or bile acids

in places in the body where they should not be, and where they have toxic effects. The first research goal should be to identify the primary malfunction which leads to the many symptoms of PSC. When that primary lesion is found, it will almost certainly suggest methods of intervening in the sequence of events by which PSC does its damage, and will provide the basis of assaying in either animal model systems, or in test tubes, for effectiveness of drugs designed to provide the desired intervention.

It would not be surprising if a hereditary form, or at least a hereditary component, of PSC were discovered. Studies of hereditary forms of other diseases have proven very fruitful in elucidating disease mechanism, by making it possible to discover the specific protein which is malfunctioning, thereby creating the possibilities of testing effects of proposed drugs on that protein, and of a genetic engineering approach to dealing with the disease.

The key to achieving these research goals is to build a critical mass of researchers who address all aspects of the disease, and share in a timely fashion, their findings with all within the critical mass of researchers.

Philip Filner, Ph.D.

CCFA Educational Brochures

The Crohn's and Colitis Foundation of America (CCFA) has published a series of newly revised Education Brochures on inflammatory bowel diseases:

- Living With Crohn's Disease
- Living With Ulcerative Colitis
- A Guide for Parents
- A Guide for Teachers and Other School Personnel

Other CCFA brochures include:

- Medications
- Maintenance Therapy
- Diet and Nutrition
- Emotional Factors
- Complications
- Understanding Colorectal Cancer
- Surgery
- Sexuality
- Women's Issues
- A Guide for Children and Teenagers

All of these brochures are available as .pdf files from the CCFA web site:

<http://www.ccf.org/info/brochures/>

The Word is Getting Out!

Thanks to all of you PSCers and caregivers who continue to help us in so many different ways, we are getting out the message about PSC Partners Seeking a Cure and reaching out to people throughout the country and beyond. Here are a few of the exciting recent happenings:

- On the PSC online support group (which was in existence years before our foundation was started), there are new members logging on each week at:

<http://health.groups.yahoo.com/group/psc-support/>

The bad news is that there are so many new people being diagnosed with PSC, but the good news is that these newly diagnosed PSCers are finding out about our existence and receiving support from all our online members who have so much knowledge to share. How I wish that I could have discovered this group soon after my diagnosis, when I was in a state of disbelief and fear!

- This is the ninth edition of our newsletter, and our readership is increasing. We are hearing from PSCers, caregivers, physicians and researchers who are benefitting from each edition. If you would like to be notified by e-mail when a new newsletter edition is available, please register on our homepage at www.pscpartners.org.

- The PSC literature website (www.psc-literature.org) continues to be updated every week, and is the ultimate resource available with easy access to a vast body of scientific literature concerning PSC and allied illnesses. Newly diagnosed PSCers can benefit greatly by starting with the FAQ section.

- Each week, we are being contacted both at www.pscpartners.org and at pscpartners@yahoo.com by people searching for more information both about PSC and about our foundation.

- About twelve PSC Partners Seeking a Cure members attended the NIH conference on PSC research which was held in mid-September. (Please see the last edition of our newsletter for a summary of the presentations.) We were all able to speak with the researchers personally and hand out our wristbands, newsletters, bookmarks, and new brochures. The researchers encouraged us in our efforts to offer support and education to PSCers/caregivers, to promote organ donation, and to raise funds for PSC research. They were also pleased to learn of our existence, especially since we mentioned the willingness of our members to be part of future research projects. I was very touched the second day to see these brilliant researchers from all over the globe wearing our wristbands in support of our efforts. Now, these researchers continue to contact us personally.

- In addition to existing in cyberspace, we now exist in the real world as well, with the first printing of our informative brochure entitled "Living with Primary Sclerosing Cholangitis." I'd like to thank our writers Deb in VA and Dave Rhodes,

our graphic designer Sue Safer, Chris Klug for his permission to use his photo and quote on the cover, Dr. Gregory Everson for reviewing the text, and Procter and Gamble for their grant helping us with our brochure project. A huge thanks goes out to Pat McBride of Envision Printing in Marietta, Georgia who donated the entire printing job for us!! (Thank you to Shelley Hussey who connected us to Pat.) If you haven't seen the brochure, please log on to the homepage of www.pscpartners.org. To order copies of the brochure to hand out to your hepatologist, liver center, CCFA office, ALF office, etc., please send an email to Barb Henshaw at: pscbrochures@yahoo.com. Please include your name, mailing address, and desired quantity of brochures. If you would like more than fifty brochures, please tell us how you plan to distribute them. Please allow one to two weeks for delivery.

- PSCers, their caregivers, family, friends, and colleagues continue to send in donations and to support our many fundraisers (wristbands, Krogers cards, AAA recycling, PSC notecards, CD from our 2005 conference). If you would like to receive fundraising updates and notices, please register on our homepage.

- We have two members who have started local PSC Partners Seeking a Cure support groups: Reggie Belmont in Connecticut and Jennifer Soloway in California.

- Our first conference for PSCers and caregivers in Denver in April this year was such a success that we are soon to announce details of our conference in Pittsburgh the week-end of April 7-9, 2006. Joanne Grieme, who is hosting the conference, is finalizing details with the hotel and with the wonderful speakers from the University of Pittsburgh Medical Center and the Thomas E. Starzl Transplantation Institute. As soon as the details are complete, we will post all the information. All of us who attended last spring can attest to the incredibly upbeat feeling we left with, after hearing the presentations and having the chance to interact with each other in person. Many incredible friendships were initiated, and I can't wait to see you all again and to meet the new PSCers and caregivers who plan to join us in 2006.

In all these venues, our foundation is making a difference. The combined enthusiasm, experience, and talents of all our members are helping us make huge progress in achieving our goals. Thank you to everyone!

Ricky Safer

P.S. On July 29, the IBD Research Act of 2005 was introduced in the House of Representatives. The proposed act would dramatically expand IBD research at the National Institutes of Health, with a focus on pediatric research. If you would like to support this effort, please write to your legislators and/or join the IBD Day on the Hill 2005 on November 9-10.



2005 Conference CD

Copies of the 2005 Conference CD (\$25 each in the U.S./\$30 abroad; this includes shipping and handling) can be purchased from:

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

Please make checks out to: **PSC Partners Seeking a Cure**
Please include your name and mailing/shipping address when you place your order! Thank you!

Conference CD Disclaimer

PSC Partners does not provide specific medical advice, is not engaged in providing medical or professional services and does not endorse any medical or professional service obtained through information provided on this CD. Use of this CD does not replace medical consultations with a qualified health or medical professional to meet the health and medical needs of you or a loved one.

Additional Contact Information

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

pscpartners@yahoo.com

Submitting Newsletter Articles

If you would like to contribute an article to a future issue of this Newsletter, please e-mail it to David Rhodes:

rhodesdavid@insightbb.com

or use the "Submit Newsletter Article" form on the www.pscpartners.org web site.

Courage Quotations

Courage is not the towering oak
That sees storms come and go,
It is the fragile blossom
That opens in the snow

(Alice MacKenzie Swaim)

Strength and courage aren't always
measured in medals and victories.
They are measured in the struggles
they overcome. The strongest people
aren't always the people who win,
but the people who don't give up
when they lose.

(Ashley Hodgeson)

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



GiveLife

Note to Readers

Articles in this newsletter have been written by persons without formal medical training. Therefore, the information in this newsletter is not intended nor implied to be a substitute for professional medical advice. Please consult with your doctor before using any information presented here for treatment. Nothing contained in this newsletter is intended to be for medical diagnosis or treatment. The views and opinions expressed in the newsletter are not intended to endorse any product or procedure.