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# The Duct

Bringing you news on PSC



research, education, and Support

PSC Partners Seeking a Cure Foundation, Late Summer 2010

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## Sixth Annual Conference Offered an Overflowing Agenda

From the 10:30 am Friday brunch to the opening of the technical presentations, when Dr. James Boyer, Ensign Professor of Medicine and Emeritus Director of the Liver Center, Department of Medicine at Yale University School of Medicine, first welcomed all 215 participants, to Ricky Safer's warm farewell at 12:30 pm Sunday, the days were jam-packed with information and opportunities to discuss our common disease.

Our good friend Ivor Sweigler, Chairman of PSC Support-UK, again briefly summarizes the technical

presentations for us in this issue. He's also shared news from his organization's annual Oxford meeting in July. We thank him and Lynda Hayward for the care with which they prepared the summaries.



Drs. Boyer and Cho answered questions during a Saturday morning Q/A panel.



Friday afternoon was devoted to Healthy Living Choices. A session by Mark Sherry on Laughter Yoga made us--you guessed it--laugh!

An Early Summer edition of *The Duct* focused on news from PSC Partners and the conference. This issue focuses on presentation summaries from distinguished Yale and Hartford Hospital presenters, community physicians, and others. Comprehensive slides from these presentations are at:

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

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# What Conference Speakers Told Us

I was extremely impressed by the energy and organizational strengths that this group has generated. The meeting was simply run extremely well.

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*Thank you for inviting me to speak. I had a wonderful time. Obviously you have touched patients and families around the globe.*

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All of us greatly enjoyed participating in this effort. I have had many comments from the faculty, commenting on how impressed they were with the PSC foundation and at the organization and commitment. I think the satisfaction went both ways and that is not easy to achieve. I wish PSC Partners continuing success.

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It was an honor to be part of the conference! You should know that the enthusiasm of PSC Partners is quite catching—it certainly gives me renewed energy.

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I think you have done an outstanding job creating PSC Partners. What a great resource and source of support. It was an honor for me to be involved in your conference. The program was excellent, and it was humbling to be among so many families living with PSC.

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**I was impressed by your group. In every session, I found intelligent, informed and involved people and it is very stimulating for us physicians to see how strong is the support of our patients and their families.**

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*You're invited to the*

*7th Annual Patient Conference held by PSC Partners Seeking a Cure*

*Sacramento, California  
April 29<sup>th</sup> to May 1, 2011*

*Check our website for more details, which should be uploaded in a few months:*

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

*Note: Comprehensive technical slides from Saturday morning presentations are at:  
<http://www.pscpartners.org/PSCConf10/index.htm>*

## Conference Session Summaries

*Reported by Ivor Sweigler, Chairman of PSC Support-UK, with support from Lynda Hayward*

### Overview of PSC: Making the Diagnosis

**Dr. Tamar Taddei, Assistant Professor of Medicine, Section of Digestive Diseases,  
Yale University School of Medicine**

Much of this is familiar so we are not going to repeat the whole presentation but select some areas with which we may be less familiar.

Slides were shown comparing healthy bile ducts with those of PSC patients. There was the familiar beaded appearance: thin stretches of bile duct, some of which may have been strictured, followed by inflated sections and in some parts of the biliary tree, parts had vanished.

PSC typically comes with other diseases, most notably inflammatory bowel disease: Crohn's and ulcerative colitis. PSC is defined by scarring and/or inflammation of the intra- and hepatic bile ducts. This eventually leads to cirrhosis of the liver. There is also a spectrum of disease.

From 1924 (when PSC was discovered) to around 1980, there are only 100 references to PSC in the medical literature. This has now multiplied enormously, not because the incidence of PSC has increased, but following the introduction of new diagnostic technology: endoscopy and then MRI.

Dr Taddei described PSC as a spectrum of diseases and went into some detail about small duct PSC. "Classic" PSC involves inflammation in both the small ducts inside the liver and the large extra-hepatic ducts. Small-duct PSC involves the intra-hepatic ducts only: like PBC, which is also a small duct disease. The prognosis is usually better for small-duct PSC and cholangiocarcinoma (CCA) is usually much rarer.

Presentation slides are at: <http://www.pscpartners.org/PSCConf10/PDFs/1-Taddei.pdf>



Dr. Taddei's presentation set the stage by reminding us about the basics of PSC.

# The Natural Course of PSC: Treatment and Managing Symptoms

Dr. Pramod Mistry, Chief, Pediatric Gastroenterology and Hepatology,  
Yale University School of Medicine

It's very important to look at PSC as a rare disease. This brings into play concepts of rare disease research, rare disease management, and registries, and rare disease advocacy, as PSC Partners has worked so hard to do.

There are less than 200,000 PSCers in the US. You're all familiar with the Mayo/Rochester study in 2003, where they estimated the incidence of PSC (i.e., new cases every year,) as one case per 100,000 U.S. population. At any one time there are 14 PSCers per 100,000 population, a total of about 40,000 individuals.

This comes into the US definition of rare diseases like cystic fibrosis. In the US The Rare Disease Act of 2002 defines rare disease, strictly in terms of prevalence, as "any disease or condition that affects less than 200,000 persons in the US," or about one in every 1,500 people.

*(Ivor's note: The European Commission on Public Health defines rare diseases as "life threatening or chronically debilitating diseases which are of such low prevalence that special combined efforts are needed to address them." Low prevalence is later defined to mean less than one in 2,000 people. Diseases which are statistically rare, but not also life threatening, chronically debilitating, or adequately treated are excluded. Wikipedia is good resource, under Rare Diseases. Remember that prevalence = total number of people with the disease at any time. Incidence = number of new diagnoses in any given year. There may be between 5,000 and 7,000 such diseases.)*

It's important to keep in mind that there are about only 200 US liver transplants per year for PSC patients. For every patient who needs a transplant there are 2,000 of you out there who don't need a transplant. It is important to keep this in mind: diagnosis of PSC is not a death sentence.

This is a highly heterogeneous disease. There's large duct PSC, small duct PSC, AIH/PSC, and IgG4 PSC that is associated with autoimmune pancreatitis. These conditions have a different natural history and different responses to treatment. With this disease every patient has a unique trajectory. It's a progressive disease, usually over many years. Those without symptoms may have a better prognosis. Because of this heterogeneity it is not really possible to predict outcomes in individual patients.

Short of a cure we have to do whatever can be done to prevent cancer, relieve symptoms, and introduce a program of careful follow up. It is important to be optimistic.

There are good data published in leading medical journals, by very solid investigators, that have shown that Ursodiol at low or medium dose does improve prognosis. He mentioned the 2009 Mayo trial (which set alarm bells ringing) when high dose Urso was used on PSC patients, the majority of whom had late stage 3 and 4 PSC. This, he said, indicates the problem of treating all PSC patients as if they were the same, whereas there is a huge variation. We are beginning to learn this in the era of personalized medicine.

My approach is that we should individualize Urso therapy and not follow the AASLD



recommendation that Urso should be stopped in every case. I may stop the treatment if, for example, a patient starts to itch (which a few patients report) and I look at the chemical responses. There are these tantalizing data that Urso may be chemo-protective with reference to colon cancer (and CCA). It has important effects on cholestasis, it is anti-inflammatory, and has several other positive features: a very attractive candidate for the treatment of PSC.

In the future, treatment of the FXR receptor, discovered in 1999, is likely to have an important role in PSC treatment. Evidence had been accumulating of its potential effectiveness. It targets an important transporter in the liver.

Presentation slides at: <http://www.pscpartners.org/PSCConf10/PDFs/2-Mistry.pdf>

## The Overlap Between Inflammatory Bowel Disease and PSC

**Dr. Judy Cho, Associate Professor of Medicine and Genetics, Director, Inflammatory Bowel Disease Center, Yale University School of Medicine**

Dr. Cho has studied genetics and inflammatory bowel disease (IBD), looking at the various aspects of pathogenesis in the inflammatory process. At this point we don't understand why people with PSC also have, in the majority, intestinal inflammation. But there is a clear process at work between the gut and the liver. The biliary tree transports bile to the first part of the intestines. PSC is about 10 times less frequent than IBD. Conversely about 4-5 percent of IBD patients will get PSC.

Inflammation is not designed to cause disease. It is an evolutionary beneficial response to fight harmful introduction of foreign invaders, including some cancers and to counter various forms of injury. Intestinal inflammation is normally beneficial in countering harmful elements. But in PSC and IBD this response gets out of control leading to fibrosis or a scarring process. The cause of these two diseases are not interrelated, but are they really the same disease? Dr. Cho is not sure. There is now a great deal of international cooperation in studying IBD and in the work on genome-wide associations.



Dr. Judy Cho focused on the genetics of autoimmune diseases related to PSC.

Dr. Cho's presentation slides are at: <http://www.pscpartners.org/PSCConf10/PDFs/3-Cho.pdf>

## Biology and Pathobiology of Cholangiocytes: The Key

**Dr. Mario Strazzabosco, Professor of Medicine, Director, Liver Center Program, Section of Digestive Diseases, Yale University School of Medicine**

Dr Strazzabosco dwelt at some length on CCA (cholangiocarcinoma), discussing the difficulties of detecting CCA early and managing this aggressive carcinoma.

He gave the following interesting information. Dr Avvero, of Rome, has published a very intriguing paper analyzing bile with several groups of patients. One group had benign stenosis of the biliary tree, one group with pancreatic cancer, and one with CCA. He measured the levels of ICS1 in the bile. ICS1 is a growth factor and is produced by the liver and involves metabolism and muscle growth and many other things. It's also a specific growth factor for the biliary tree for a reason we don't yet understand.

He found that by measuring ICS1 in the bile we can really differentiate CCA from other causes of jaundice. This is only the first record; in science findings have to be replicated by other people. But it's interesting and intriguing.

We still don't have a reliable way to identify or exclude CCA. If we see a stenosis it's still a matter of interpretation. We're never completely sure. A CT scan is sometimes used to stage a tumor.

There is a kind of glucose FDG which is taken up by several tumors in CCA, and in other cancers, including lung tumours. FDG-PET has a certain diagnostic efficacy and we can distinguish tumors which have high levels of FDG and those which do not.

Surgery is a possible option for some patients with CCA and an intact liver but it's not common with PSC because of concern about liver disease itself. Restrictive surgery means that a piece of liver is taken out. This may result in bile-duct damage in a biliary system, which is already compromised (and very often CCA has already spread.)

Dr Strazzabosco went into detail concerning treatment for CCA patients at the Mayo Clinic.

As the carcinoma grows it blocks the bile ducts. He uses brushings and FISH analysis and also utilizes the tumor marker, CA19-9. The problem with the test is it is not specific for PSC. It also goes up and down if you have cholangitis. CCA may be evident from MRI.

Presentation slides are at: <http://www.pscpartners.org/PSCConf10/PDFs/5-Strazzabasco.pdf>

Dr. Strazzabosco offered his insights regarding cholangiocarcinoma.



## Results of PSC Genome Studies in Norway

**Dr. Trine Folseraas, Norwegian PSC Center, Medical Department, Rikshospitalet, Oslo**

Dr. Folseraas came to Hartford especially to give us an update on the work of this unique institution. She explained that they were especially interested in the genetics of PSC, hence their ongoing genome study. In the case of a rare disease like PSC, international co-operation is of the greatest importance and

in Europe they were very happy to have close collaboration with Germany, Netherlands, UK and other countries.

(With a population of around 4.5 million Norway has the highest incidence of PSC in the world. In Norway 35 percent of liver transplants are for PSC patients. If the incidence of PSC in the US is one per 100,000, then, for a population of 600 million the incidence is only 6,000 although some believe the incidence is much higher. In the UK (pop. 60 million) the incidence is much higher and the incidence may be 4,000-6,000. This has meant that Americans of Norwegian and Scandinavian origin in general have a higher incidence of PSC than most other Americans.)

Presentation slides are at: <http://www.pscpartners.org/PSCConf10/PDFs/6-Folseraas.pdf>

## Panel Discussion: Selected Topics from the Audience

Drs. Boyer, Taddei, Mistry, and Cho

**Urso:** All doctors were in favor of treating PSC with Urso and ignoring the recommendations of the AASLD that all PSC patients should not be prescribed Urso. Urso does a lot of good and this whole question has arisen because of one single study (Mayo trial, 2009), using 28-30 mg/kg, a very high dose of Urso.

The panel felt the AASLS recommendation is an unfair recommendation because it's based on one single study. The European Association for the Study of Liver Disease (EASLD) came out with a more balanced view based on wider literature, that individuals could be considered for Urso treatment. On a show of hands *all* members of the panel would take Urso if they had PSC.

**On norUrso:** The audience was told the human trial is being directed by Professor Michael Trauner in Austria and is currently in phase I. It will enter phase II in 2011 and phase III in the following year.

**PSC Monitoring:** There was a question on what monitoring PSC patients should have. Dr Taddei said that it wasn't easy to give a clear answer because it depended on a number of factors, particularly the stage of the disease and what symptoms are being suffered. If you have advanced disease with varices, ascites, and cirrhosis, you may need to be monitored more regularly, perhaps every three months; otherwise every six months would be more appropriate.

### *Set up Your Own Fundraiser for Save the Day!*

Get the gang together! Here's how to help find that cure for PSC by funding research. There are loads of great suggestions for local fundraising activities at our website: <http://pscpartners.org/fundraisers> and <http://pscpartners.org/sites/default/files/files/pdfs/Save-the-Day-intro-April-2010.pdf>

Register your idea with Sandi Pearlman at [kizzersmom@yahoo.com](mailto:kizzersmom@yahoo.com)

### **Would you like to propose your home town as the site for the 2012 PSC Partners Conference?**

**Deadline is January 15th, 2011 and  
here's the site to get you started:**

**[http://pscpartners.org/  
conferencelocations](http://pscpartners.org/conferencelocations)**

# Breakout Sessions

## The Role of Good Nutrition in PSC

Erin Paice, Certified Dietitian, Registered Dietitian–Nutritionist,  
Transplant Dietitian, Hartford Hospital

*Reported by Rachel Gomel*

Erin Paice gave an overview of what encompasses good nutrition for the general population with some guidelines for PSCers. Though she is experienced in liver diseases, her presentation reflected the lack of consensus and information on the specific nutritional needs of PSCers.

As relating to PSC, she discussed the importance of protein in regulating blood sugar and promoting bone health. She recommended using high biological proteins because the body uses those best. These include egg whites, yogurt, cottage cheese, meat, and poultry. For vegetarians, as good proteins, she listed beans, legumes, whole grains, and nuts.

Someone in the audience questioned whether peanuts were a misnomer and not really nuts, and Ms. Paice responded that other nuts such as almonds would be preferable to peanuts. She recommended 1-1.5 grams of protein per kilogram of weight or 25 milligrams per meal for someone weighing 125 pounds.

Since the longest time between meals is that between dinner and breakfast, and since most people do not eat protein for breakfast, it would mean that many go without protein from dinner to lunch. That is why a protein snack such as yogurt before bedtime would be beneficial.

With PSC, malabsorption of fat-soluble vitamins, that is, Vitamins A, D, E, and K, requires regular monitoring and can be solved through adequate and controlled supplementation. As for fats, one should choose polyunsaturated fats such as olive oil, avocados, and flax seeds, and should avoid whole milk and opt for nonfat milk instead.

One should be cautious with salt, especially with liver problems. Someone in the audience introduced an easy tip for choosing foods for their sodium content: “If the caloric content of a food is less than its sodium content, then do not eat it!” she said. Ms. Paice advised avoiding deli meats, canned foods, vegetable juices, packaged foods, soya sauce, and Chinese food (unless the soy sauce and other sauces have been left out). When asked about kosher salt and sea salt, she explained that though they are not as processed as regular salt, they are equally bad for the body. One should remember to use smaller quantities of these less processed salts as they have more flavor than you would find in the same quantity of regular salt.

PSCers require more calcium and more Vitamin D to absorb the calcium. Exposure to sun does not supply all of a PSCer’s Vitamin D requirement. She reminded us that the sun does not penetrate through clothes. She said that spending fifteen minutes in the sun is adequate to start the process, but that



supplementation is needed.

Weight changes may mean water retention. Make sure to double check that you are not consuming too much salt and are drinking enough water. Otherwise focus on portion control and adequate daily exercise.

**Q & A:** Generally dietitians are not specialized in PSC, said a conference attendee, and that causes serious concerns. The audience was in general agreement about this observation.

There was a question about fish oil, and she said that since American diets are not rich in Omega 3 and 6, it would be a good idea to take fish oil supplements.

For every calorie we eat, we should have one milliliter of water (about two liters a day).

Presentation slides are at: <http://www.pscpartners.org/PSCConf10/PDFs/BOS-Paice-Nutrition.pdf>.

## Treatment Issues for PSC Patients with IBD

Deborah Proctor, Professor of Medicine, Medical Director,  
Inflammatory Bowel Disease Program, Yale University School of Medicine

*Reported by Joanne Hatchett*

The Saturday afternoon breakout session on Treatment Issues for PSC Patients with Inflammatory Bowel Disease (IBD) was taught by Deborah Proctor, MD who is the Medical Director for the IBD Program at Yale University. Dr. Proctor opened the session with a case study of a 48 year old male with PSC and Crohn's ileocolitis who in 2006 had a normal colonoscopy. In 2008, his colonoscopy showed cancer.

The epidemiology of PSC (or How Common is It?) was reviewed.

- Incidence of PSC is 0.9 to 1.3 per 100,000 people
- Infants to 70 or 80 year olds are affected, but most commonly occurs between 25 to 45 years of age. Mean age is about 39 and females tend to be older at diagnosis
- 70 percent are men
- PSC without IBD is more common in females

- Non-smokers are more common than smokers
- 80 percent of patients with PSC have IBD
- 2.4 to 4.0 percent of those with Ulcerative Colitis have PSC
- 1.4 to 3.4 percent of those with Crohn's disease have PSC
- Of those who have both PSC and IBD,
  - 80 to 90 percent have UC
  - 10 to 15 percent have Crohn's Colitis or ileocolitis

Dr. Proctor described terminology as specifying the disease and where it is located, describing Crohn's as either ileitis or colitis and UC by the location of affected bowel.

Pathogenesis of PSC (or Why Do You Get It?):

- Genetic factors: HLA chromosome 6p21
- Immunologic factors
- We don't actually know what happens, but we do know that PSC is independent of GI symptoms. An individual can have

mild GI symptoms with mild liver disease, or someone can be ill from his or her GI disease, but have no or mild liver disease. Someone can also be asymptomatic from their GI disease, yet be quite ill from their liver disease.

An individual with PSC who is post-liver transplant can still develop UC or Crohn's Disease. PSC may precede any GI symptoms. UC or Crohn's can occur after liver transplantation. PSC may occur years after a total proctocolectomy for UC.

Stages of PSC were described as:

- the asymptomatic phase – no symptoms, normal liver tests
- the biochemical phase – abnormal liver tests, but no symptoms
- the symptomatic phase – abnormal liver tests and symptoms including itching, fatigue, jaundice, cholangitis
- decompensated cirrhosis with ascites, encephalopathy, and/or variceal bleeding

For those with IBD, how do we screen for PSC (or How Do We Tell if You Have It?):

- Monitor liver tests each year if taking 5-ASA (mesalamine, asacol, pentasa)

- Monitor liver tests every 3 to 6 months if on immunosuppressant (6-MP, asathioprine) and biologics such as Remicade or Humira.
- Consider PSC if liver tests, especially Alkaline Phosphatase are elevated or if evidence of liver disease
- Check liver tests

Colon Screening is recommended:

- When there is a new diagnosis of PSC and no GI symptoms
  - Colonoscopy with multiple random biopsies
- With PSC and UC
  - Colonoscopy immediately after PSC is diagnosed
  - Then annual colonoscopy with surveillance biopsies
  - Continue colonoscopy screening after liver transplant
- With PSC and Crohn's disease
  - With Crohn's colitis with more than 30 percent of colon involved, screening is the same as for those with PSC and UC
  - Crohn's and ileal disease only requires increased surveillance, but the interval for colonoscopy is not as clearly defined

## Patients as Partners: How You Can Contribute to the Coming Era of Personalized Medicine

Dr. Tom Ullman, Director, Center for IBD and Associate Professor of Medicine, The Mount Sinai School of Medicine

*Reported by Pat Bandy*

Genetic or other personal biologic profiles can affect each person's risk for certain

diseases. Genetic makeup may even be predictive.

An explosion in genetic medicine is coming, Dr. Ullman said. Utilizing

personalized therapy, a person's genetic makeup will permit treatments specific to the needs of a patient. Genetic analysis will also be able to determine if there will

be an adverse reaction with a specific drug. The goal is to provide a patient with the right amount of the most effective treatment.

Efforts in personalized medicine are just beginning.

The Crohn's and Colitis Foundation of America is

working with the Center for Genome Sciences at Washington University to identify and create new molecular and bioinformatic tools to develop a cure for colon diseases.

Dr. Ullman illustrated his presentation with slides

showing genetic studies from two major research projects.

In the long term, future patients may take more genetic tests up front, before initiation of therapy. "It's where we're headed," he said. "A tool for your future cure might be in a vial of your own blood."

## Patient Perspectives on the Transplant Experience from Pre-Transplant through Post-Transplant

Moderated by Dr. Aubrey Goldstein, with panelists, Alison Cubbellotti, Melanie Scherder, Tom Butler, and Todd Clouser

*Reported by Fred Sabernick*

Dr. Goldstein introduced the session by describing his post-transplant experience. He felt better almost immediately after surgery. But, after six years, he began to experience moderate fatigue and resumed UDCA regimen. At ten years out, his liver function tests (LFTs) were all in the normal range. He continues to experience excellent quality of life post-transplant.

Alison Cubbellotti lives in CT, is 20 years old, and seven months post-transplant. She was diagnosed with Crohn's and PSC at age nine. Crohn's symptoms were immediate, including nosebleeds, fluid retention, ascites, and fatigue. Alison required strong pain meds and had little quality of life. She looked for a family member donor and underwent pre-transplant evaluation with her brother as a potential donor. During surgery to remove her brother's liver, he was disqualified as a donor candidate and the surgery did not go forward. Another donor who was fellow student at the same college came forward anonymously. After qualification of the second donor, Alison was transplanted immediately. She felt immediate improvement in some areas but said her recovery was slow. Although her donor initially wished to remain anonymous, he chose to meet her 10 days afterwards. (Read her story in the Early Summer newsletter.) Alison summarized her experience by saying she feels much better overall but every transplant patient will have some issues; there are widely different personal experiences.

Melanie Scherder began experiencing jaundice in 1981. In 1984 she was diagnosed with PSC and UC, and told that she would need a new liver within three to five years. Melanie felt the news was a death sentence. She managed many more years of life, even though she was sick, and was transplanted in 2008. After surgery her medical team decided to lower immunosuppressant dosages and subsequently Melanie's LFTs spiked. Doses of the meds were returned to the original level and she has had a good quality of life.

Tom Butler was diagnosed with PSC in 1999 because of elevated LFTs found during a routine physical. He was asymptomatic at diagnosis and remained blissfully ignorant until 2005 when he was diagnosed with Crohn's diagnosis. As a result, Tom said, "I know all the restrooms in a 50 mile radius." He experienced falling strength and energy levels and presented a sickly appearance. Crohn's caused oral and sinus cavity lesions that tended to rupture/bleed. No family members were qualified as donors. Tom was a self-professed "bad patient" with his caregivers, mainly his wife. He began to lose energy, was unable to eat, and underwent frequent hospitalizations. In June 2008 a potential donor was disqualified 1 hour before surgery. Because of his poor health, Tom experienced business hardships during this period, including the challenge of starting a new company. A fellow church member offered to donate a portion of his liver, and Tom had a transplant in December, 2008. He received two-thirds of his donor's liver. Tom had a difficult recovery with multiple complications including periods of rejection. Tom reminded participants, "We all may be complaining about transplant difficulties, but we are happy to be able to complain!" After four months, most of his recovery complications were under control. He's had two hospitalizations since the major surgery, but still experiences a hugely improved quality of life.

Todd Clouser had three transplants. Originally diagnosed with PSC and Crohn's in 2001, he underwent the first surgery in 2003, when his brother was a donor. Todd experienced immediate organ rejection and underwent a second cadaveric transplant ten days later. Recovery was less than ideal and he experienced a PSC recurrence. In November, 2009, he received the third transplant and has since regained strength (and the weight he'd lost previously). He said he has a much-improved quality of life now.

Questions from the audience and answers from the panel:

**Question:** What is the most important piece of advice you can give prospective transplant candidates?

Tom: You must have a support team, not just good doctors. Emotional and spiritual supports are musts.

Dr. Goldstein: Live your life to the fullest regardless of whether or not you may need a transplant in the future.

Alison: Don't expect your life to be 100 percent better after transplant. She was happiest that she had no joint pain almost immediately after surgery. Her mom was a huge support giver.

**Question:** What was the post-transplant experience for your donors?

Tom's donor had a rough couple of weeks but was back at work four weeks later, though he later needed surgical hernial repair. He's doing fine now.

Todd's brother donated during winter semester break, and was back at school for the start of the next semester.

Alison's brother, whose liver was not used, was fine six weeks after surgery. Her actual donor was fine four weeks after surgery.

**Question:** How quickly did the liver regenerate?

Panel: Within a couple of weeks.

An audience member commented she'd received a transplant 13 years ago. She still has Crohn's but enjoys a relatively good quality of life and is happy for the life she has.

**Question:** On how many transplant lists (regions) were you listed?

Panel (all): One.

## Coping With PSC for PSC Patients

Dwain Fehon, PsyD, Assistant Professor, Department of Psychiatry,  
Yale School of Medicine

*Reported by Allan Luks*

Dr Fehon described stress as a physical reaction caused by feelings of being overwhelmed. Stress exacerbates pain, disrupts sleep and concentration, lowers immune cell counts, and raises blood pressure and cholesterol levels. Stress can occur when an individual feels

overwhelmed; and that feeling is often experienced by PSC patients.

To deal with stress and avoid its consequences, to stop feeling overwhelmed, Dr. Fehon reviewed several strategies, including: regular exercise, yoga, and helping others.

## Adult and Pediatric PSC: Who and When to Transplant (MELD Score Advocacy)

Dr. Pramod Mistry, Chief, Pediatric Gastroenterology and Hepatology, Yale School of Medicine, and Dr. Tamar Taddei, Assistant Professor of Medicine, Section of Digestive Diseases, Yale School of Medicine

*Reported by Rachel Gomel,  
PSC Partners Board Member  
and Pat Bandy*

Drs. Mistry and Taddei expressed frustration concerning MELD scores in relation to PSCers seeking transplant. Their focus in this informal session was the progression of disease stage in PSC as it relates to these scores. They would like to see considerations relating to quality of life issues to change the scoring system, thus raising MELD scores for PSCers.

The United Network for Organ Sharing (UNOS) manages the national database of clinical

transplant information and assists the organ sharing system by developing organ allocation policies. UNOS has divided the country into 11 regions for administrative and operational purposes. The speakers' transplant center is in Region 1, New England. Dr. Taddei noted that some regions are richer in organs than others. She asserted that transplant for those with low MELD scores are more likely in areas that have a young population, higher traffic accident rates, and where a large percentage of people have signed organ donor cards. Dr. Taddei said that she often refers patients outside

Connecticut for transplant because of organ availability.

She expressed disappointment that sick PSCers with low MELD scores suffer greatly, but cannot be transplanted until their scores rise. Her experience in requesting PSC MELD exceptions for adult patients from her Regional Review Board has been frustrating because few exceptions are given for PSC listees. She introduced her patient Alison C., who described serious health issues that were insufficient to receive an exception. Alison had crushing fatigue, fluid around her lungs, was



bedridden, and threw up daily. She turned to a live donor transplant at a MELD of 14.

MELD calculations are based solely upon three laboratory test results for liver function. Dr. Taddei felt other rare liver diseases, which she did not name, receive exceptions for patients with low MELD scores. She said regional boards are inconsistent in granting exceptions, some being more lenient.

Dr. Mistry said an important Mayo Clinic study regarding MELD concluded that MELD scores accurately reflected end-stage liver disease. But, he, too, wants a universal exception from MELD for diagnosis of PSC because he feels the disease is poorly served by the scoring system.

He suggested altogether different parameters to

evaluate PSC patients. Elements such as quality of life and spleen size are very important prognostic models for PSC. Regional Review Boards do not consider quality of life aspects when awarding an exemption, he said.

An audience member asked whether there existed a similar score to MELD, one that took account of quality of life. Dr. Mistry said that this information had not been compiled. He feels the serious itching of PSC is undervalued and not taken into account, while it is an important factor in assessing quality of life.

The doctors would like a systematic study to show that quality of life is seriously sub-normal in the PSC population whose readiness for transplant cannot be represented through their MELD score. Dr. Taddei believes that many objective

markers could be used to advocate for PSCers. Dr. Boyer, who has had considerable experience with PSC patients, shared his perspectives on the discussion. He said that the need for transplant among PSCers is very uncommon, in fact, rare. That fact should bring some encouragement to PSC patients. He agreed that in cholestatic disease MELD scores generally do not serve the patient well and that we need data to change the norms for PSC.

They ended the discussion by noting the importance of physicians closely monitoring PSC patients. Dr. Mistry said that since markers like high ammonia and abnormal albumin levels do not figure in the MELD score, physicians should aim to understand each patient's particular disease trajectory.

## Coping with PSC for Caregivers

Dwain C. Fehon, Psy.D., Assistant Professor, Department of Psychiatry,  
Yale University School of Medicine

*Reported by William Bandy, caregiver*

Dr. Fehon is also the Chief Psychologist for the Yale-New Haven Hospital Behavior Medicine Service, which is a psychological consultation and intervention program, where he provides clinical care to liver transplant candidates and recipients, focusing on stress and quality of life issues. The following is a summary of the slides he presented, which can be found at: <http://www.pscpartners.org/PSCConf10/PDFs/BOS-Fehon-Coping-caregivers.pdf> .

#### Common Challenges for Caregivers:

- Dealing with guilt, disappointment, fear, and frustration
- Feeling hesitant to ask for help
- Coping with uncertainty
- Managing and fulfilling multiple changing roles
- Juggling increased responsibilities
- Emotional and physical isolation
- Managing stress and burnout
- Making time for your own health and wellbeing
- Keeping patience, faith, and courage

#### Warning Signs of Caregiver Burnout:

- Increased fatigue, feeling constantly exhausted
- Neglecting your own needs
- Your life revolves around care giving but it gives you little satisfaction
- Having trouble relaxing
- Increased impatience and irritation with the person you are caring for
- Feeling overwhelmed, helpless, and hopeless

#### Tips to Prevent Burnout:

- Learn as much as possible- knowledge is power
- Don't try to do it all alone, accept help
- Know your own limits and set boundaries
- Accept your own feelings- you have a right to them
- Confide in others
- Make time for yourself and take a break
- Seek emotional support
- Believe in yourself
- Stay mindful of the need for a balanced lifestyle
- Use stress management techniques
- Deal with problems; don't passively avoid them

#### Problem-Focused Ways of Coping with Controllable Aspects of a Problem:

- Problem solving
- Gathering information
- Decision-making
- Resolving conflicts
- Asking for help

#### Emotion-Focused Ways of Coping with Uncontrollable Aspects of a Problem:

- Rethinking the situation
- Reframing your thoughts

- Acceptance strategies
- Seeking support
- Exercise

Techniques for Maintaining Balance in Your Life:

- Keep your perspective on all aspects of your life
- Practice “mindfulness”, which is being in the moment

- Live life fully while accepting the realities of the moment

Create Your Own Website for On-Line Journaling:

- <http://www.caringbridge.org>
- <http://www.carepaggers.org>

On-line Information and Support Resources:

- <http://www.wellspouse.org>
- <http://www.transplantexperience.org>

## Special Topics for 20s/30s Males: Discussion

*Reported by Jecy Belmont*

For many of the young men it was the first time that they got a chance to meet others with PSC and talk to them in a private forum. There was an interesting split between those men who had been diagnosed at a young age, say early teens, and those that had been diagnosed in their late teens or 20s.

The biggest question that came up was handling social situations and factors such as drinking, staying out late, or explaining the disease to friends. Those who had been diagnosed early said they didn't really feel the drinking pressure as they got older. Having always grown up with

PSC they already were aware of how damaging alcohol could be and that it was best not to drink.

Those of us who were diagnosed later in life talked about the self pressure to conform in social situations and how ignoring the problem and not taking it seriously isn't helpful. We also discussed how as we aged into our late 20s we found the drinking pressure to be less.

Some people talked about how they didn't take it seriously until they had major medical complications from the disease. With the short amount of time we didn't get a chance to cover all the topics we would have liked to.

## Endoscopic Diagnosis and Management of PSC

**Dr. Jamidar, Professor of Medicine, Director of Endoscopy, Associate Chief, Section of Digestive Diseases at the Yale University School of Medicine**

*Reported by Arne Myrabo*

In our session Dr. Jamidar talked about the therapeutic and diagnostic merits of both the MRCP (Magnetic Resonance Cholangiopancreatography) and ERCP (Endoscopic

Retrograde Cholangiopancreatography). He told us the MRCP is a good diagnostic tool that doctors prefer to use unless there is some need for therapeutic intervention. As an example, a

patient who is jaundiced and exhibits abnormal LFTs (liver function test) is probably a good candidate for ERCP.

Complications of PSC sometimes require the use of ERCP. Some of the

complications are stones, dominant strictures (stenosis of the extra hepatic ducts), cholangiocarcinoma, and cholangitis attacks. ERCP would also be used to retrieve tissue samples (w/biopsy forceps), brush cytology (cancer screening) and for placing short-term stents. Dr. Jamidar noted that doctors are not sure if these therapies improve survival or quality of life for patients.

Dr. Jamidar mentioned that balloon dilation was the preferred method for dilating strictures. Balloons are also very successful with the removal of bile stones. This method of dilation was a preferred therapy over stenting. Leaving stents in for too long can cause infections and do require another invasive ERCP to remove. This also opens the door for another chance at pancreatitis.

Stemming the tide of pancreatitis during ERCP is an important issue for Dr. Jamidar, his colleagues and

especially the PSC community. Dr. Jamidar advised us that 6 percent to 10 percent of patients get pancreatitis. Some major risk factors are narrow ducts and young-to-middle aged women. When presenting with jaundice or stones, risk is reduced. With an experienced endoscopist, success rate (no pancreatitis) is 95 percent.

Also, all patients should receive antibiotic therapy before and after the procedure as well as a strong course of hydration (300 cc per hour). The theory behind the hydration is that when dehydrated, gut ischemia can cause pancreatitis. Another method to avoid pancreatitis (when dye is injected into the pancreatic duct) is to use a stent that falls out on its own. After two weeks, x-rays would be taken to see if the stent is gone. This is becoming a normal course of action for Yale's endoscopists. Dr. Jamidar noted that, even after 10,000 ERCPs, adverse consequences are possible; a

humbling experience for him.

Eighty percent of ERCPs (for PSC) exhibit involvement of both the intra and extrahepatic ducts, 15 percent the common bile duct only, and 5 percent the intrahepatic ducts only. Dr. Jamidar emphasized the importance of treating dominant strictures. In his experience, it improves symptoms of pruritus and jaundice, and may improve time to transplant.

One of the new technologies being used by Yale is the "Spyglass." This is a steerable, disposable cholangioscope or confocal biliary endomicroscopy. It is used to evaluate indeterminate bile duct strictures. A real time histologic image is obtained of suspicious lesions and the cellular details of these lesions are studied to determine the potential for cancer.

Dr. Jamidar's slide presentation showed some of the issues discussed here and he was very accommodating to all in attendance.

\* \* \* \* \*

## PSC Support-UK: Report from the Annual Oxford Meeting With Dr. Roger Chapman, July 2010

*Reported by Ivor Sweigler, Chairman of PSC Support-UK*

**PSC Database**

The first presenter was Dr. Johnny Holliday, who had come from Melbourne to learn more about PSC and assist with the Registry. Dr. Chapman has gathered around 250 PSCers and the ongoing genome-wide PSC research project now has gathered 1300 patients on its registry, achieving a higher figure than had been thought possible.

The PSC database at the John Radcliffe Hospital had not been updated since 2004 and was begun in the 1980s. (Such is the deficiency in the NHS databases.) Dr. Jelena Djobvich from Serbia has recently spent four months updating it with me.

With 250 or so patients at the John Radcliffe we use the database to see how patients progress. Over the last 20 years we've had 250 patients whom we have cared for. Thirty-two of these patients have had small duct PSC. About 130 patients have UC, 36 have Crohn's, and 56 have had no IBD. Since 1990 about 40 have required surgery on their bowel: some due to active IBD and others due to cancerous lesions.

We're concentrating particularly on the connection between IBD and PSC and the relationship to cancer. This has never been systematically studied anywhere in the world. This work that I'm doing is not likely to produce definitive results but it will help us to develop further understanding.

### **Dr. Chapman's Presentation**

Dr. Roger Chapman then continued with his usual, lucid presentation of the main features of PSC, before answering dozens of questions.

In case we had not seen what PSC looks like he showed us, on the screen, the bile ducts of a healthy person and then the bile ducts of a PSC patients. The bile ducts were distorted or missing,

as a consequence of chronic inflammation, the development of fibrosis etc.

We try to avoid endoscopy (ERCP) which produces good results but which is invasive and patients can develop infection and cholangitis, and also involve the pancreas. MRI is preferred which is not invasive and we have a new scanner, which produces excellent images. (Although treatment of dominant strictures or other manipulation still require ERCP).

The good news is also that we rarely need to do liver biopsies apart from certain situations that we can deal with and that's because of improvements in MRI/MRCP.

The management of PSC is very complicated. Various complications can arise; lack of bile flow, development of cirrhosis ("which we rarely get, I'm pleased to say."). That requires specialist management. IBD also has to be managed and colonoscopy as well. In the US this would probably require 5 or 6 specialists, in the UK, one or two.

The high dose Urso trial in the US, ending in 2009, was halted after patients on Urso appeared to do worse than patients on placebo. (It should be noted that the dose was *very* high, 28-30mg/kg/day and that the majority of patients were in late-stage or end-stage PSC and might well have suffered serious complications whether they were taking Urso or not over the 6 years of the trial.)

We have shown that the chances of developing bowel cancer are reduced if you take a moderate dose of Urso, (but not more than 25 mg/kg/day) and at least 4 groups have shown that; but it must be said that we don't really know the dose that should be used for that. Confusion has arisen because two groups of guidelines have been published.



The European guidelines (EASLD European Association for the Study of Liver Disease), of which I was a senior editor, and the US study from the AASLD (American Association for the Study of Liver Disease.) To which I was the first author and *they say completely different things*. What happens is that when you have guidelines you get together a group of so-called experts.

Basically if you ask a group of European hepatologists they all say that Urso should be used in the treatment of PSC. Apart from the very high dose that was used at the Mayo trial, Urso at moderate doses has proven to be very safe at around 22 mg/kg/day, all over the world. So the European guidelines favored the use of Urso. We each drafted proposals and then 8 of us met for 2 days in Holland to draw up the report.

We felt that we should use Urso but that we couldn't say, on the basis of the evidence, we could endorse it generally. We did say that we should use it because it may protect against colon cancer.

The American guidelines say that we should not use Urso in the treatment of PSC, *which is not what I wrote*. In the US process we were asked to submit recommendations; we didn't meet as a group at all. A final draft went out which was produced by Dr. Gores. What he wrote is a consensus of the American on the committee. I attended a meeting in Oslo and there's really strong disagreement on this between the US and Europe.

I don't think you can get away from the view that Urso protects the colon. I didn't see the final draft of the AASLD but it does reflect the American view. Talk to any European hepatologist and you'll find that they use Urso for PSC as do many American hepatologists as well. I don't think you should come off it and it's perfectly safe up to 25mg/kg/day. Paradoxically,

the Americans are involved in a large-scale study on Urso in children with PSC because it may be beneficial.

Dr. Chapman explained that the trial on norUrso is proceeding through Stage 1 in Austria. It appears to be more effective than Urso. The disadvantage is that it's very expensive. It works in a different way from Urso, in mouse models. It seems to get rid of the inflammation. At the moment it's the best thing coming along.

But these things take a long time for all sorts of reasons. It may take five to eight years to know whether it's any good or not. With chronic disease like PSC you can't get an answer, as you can, for example, with pneumonia, which can be cured in 3 weeks with antibiotics. We need trials of 5-10 years in PSC, a disease which goes on for decades.

In the genome-wide PSC research project our aim was to have DNA from 1500 PSCers. We've reached 1300, which is a great achievement. One thousand are already "in the bank." We're very grateful to the Norwegian group in helping finance this.

Another good piece of news is that three weeks ago in Oslo we formed a PSC International study group for all those around the world interested in PSC; we now have a steering committee. This will help to guide research. We will be able to share data from studies all over the world.

This is a major advance in the field in a disease, which is, fortunately, attracting great interest at the moment. PSC is an orphan disease, but its status as a rare disease of no interest to drug companies has been changing, thanks to financial support, not only from Norway but also from the US.

## Questions/Answers

**Question:** What's your response to some medical scientists who very recently, in the media, suggested that genome-wide research into human disease is highly significant science, that it isn't really medicine, that the number of patients who are likely to benefit has so far been very few and this is likely to be so in the future?

**Answer:** Well, I think that's a negative view. It's true that it hasn't yet been the Pandora's box that it may be. So far in Crohn's disease, 63 genes have been found to be implicated and in colitis, 43. But I think it will answer whether in PSC, IBD is a different disease from IBD without PSC.

I think it's actually a different disease, which will be a very important factor, and the genome-wide research may answer that. This will certainly be of interest to drug companies, which are pouring money into IBD research. For that reason alone it will attract money. The research may also throw up other genes as well. Light will be shed on mechanisms at work.

I also think that this is a negative view because people have realized that a lot of these autoimmune diseases have the same kind of mechanisms; PBC, PSC, etc., they have the same common immune mechanisms. You can then develop drugs, which can be effective in several diseases. So I would not share that view.

I think that what is disappointing is that it was thought that we could sort out completely the inheritability of the conditions. It hasn't done that. In Crohn's, while 63 genes are implicated, which is a large number, this only accounts for 28 percent of the inheritability. There are other things that are being missed in these scans, which are important. Once you know that you develop new techniques.

I think it will shed light on what causes diseases to progress and apart from anything else it produces a fantastic data base where we can draw on all the people in the country with PSC who have Crohn's. That's a knock on effect of connecting the DNA, so I don't think that's going to be negative at all. It's very positive.

**Question:** Should we be tested for celiac disease?  
**Answer:** We do that at the John Radcliffe although only 1-2 percent of patients have celiac disease.

**Question:** On the return of PSC post-transplant. Why does it return?

**Answer:** That's a fantastic question. I don't know. It comes back in 30 percent over 10 years. There are three reports from different transplant centers saying that despite that they all receive immunosuppressants. It comes back more commonly in males and especially in people who still have their colons. Two centers have shown that so it does appear that the gut has some role in the recurrence rate. We don't know why that should be. It's important because if we did know it would shed light on what happens in PSC in general.

**Question:** What is the difference between live donor transplants and cadaver transplants?

**Answer:** I don't know of any data on live donor transplants. There may be some. This is not widely used in the UK apart from children.

**Question:** I've just come back from Japan and was told that in PSC, 50 percent of live donor recipients have recurrent PSC. They think the reason is that PSC in Japan is a different strain.

**Answer:** I'm not sure that PSC in Japan is PSC that I know of. There are all sorts of reasons for that including IgG4 PSC.

**Question:** If you've had a liver transplant should you still be taking Urso?

**Answer:** It depends if you still have your colon. If you have UC, then definitely, yes. If your colon's been removed because of colitis it's more questionable, but if I I'd still take it.

**Question:** How often do you recommend having MRI?

**Answer:** At the moment we don't do it routinely. We do it when it may be needed clinically: when somebody has a change in their condition. The questioner said she has it every six months to monitor a dominant stricture. Dr. Chapman said that should be dealt with by balloon endoscopy.

**Question:** Do you prescribe Urso for all your PSC patients?

**Answer:** Not for those with small duct PSC. It doesn't respond very well to Urso and doesn't develop much anyway.

**Question:** When should you transplant a PSC patient?

**Answer:** In PSC transplantation is most difficult to get right. A doctor can look very silly if the patient appears to recover. I can remember a patient who was jaundiced for six months. I sent him to Birmingham for a transplant and he was returned perfectly normal, not jaundiced.

Why is it so difficult? It's because of dominant strictures. Thick bile can get stuck for a bit. Many things can cause you to get jaundiced and can then get resolved by themselves. It's a perplexing thing.

**Question:** Is there anything we should be doing about preventing or monitoring for cholangiocarcinoma (bile duct cancer CCA)?

**Answer:** We normally check the blood for CA-19 (a tumor marker). Currently there's no good way of predicting. The genome-wide scan may prove helpful. When CCA is found, unfortunately it may be too late.

**Question:** Discuss PSC and survival.

**Answer:** If you have symptomatic PSC half such patients will require a transplant within 12 years of diagnosis. But that is to say that 50 percent will not. I can give you the odds but it's not possible to predict which half you will be in. That's when we come back to databases and genes to predict outcomes. In the future, we may develop new treatments to target people who are likely to progress. In the case of patients with no symptoms 75 percent will be well 15 years later.

**Question:** Talk about the success of transplants.

**Answer:** You can be up and active in five days after surgery. It's extra-ordinary how things move on and techniques have improved. Surgery has gone from using 15 units of blood to two and sometimes none. The success rate in the UK is around 80 percent for five year survival after a transplant. Once you get through five years you'll probably get through ten and then 20.

This was one of the most successful summer meetings for some years and we thank Roger for the clarity of his presentation and his patience in fielding so many questions.

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 In Loving Memory of Peder Hedberg

## Scenes from the 2010 Conference



Yoga was a popular choice for participants on Friday during the Healthy Living Choices session.

An introduction to Tai Chi as a stress reducing technique gave participants an idea of its benefits.





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 Darcy Melzer  
 Donald & Betty Nygaard  
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 Samantha Wentz  
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 Samantha Wentz  
 Joseph Hatchett  
 Joseph Hatchett  
 Samantha Wentz  
 Hatchett Family  
 Steve Hatchett  
 Lee Bria  
 Philip Burke  
 Hatchett Family



Patty Shepherd enjoyed the fun when bow ties were given out during the banquet to mimic Don Safer's signature accessory.

Don Safer was the emcee for a presentation of inspirational PSC stories on Saturday night. Left to right: Carter Gill, Nicklas Holmgren, Sandi Pearlman, Ruth Blatt, and Stephan Harris





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 Mike & Sue Mrdjenovich  
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 Shirley Cherniack & The Safers' Uncle & Cousin  
 Patricia Ann Merrill  
 Shirley Cherniack  
 Bob Safer

Lynda Hayward, from the UK,  
 and Corrine Perrett, of  
 Australia, reported from the  
 breakout session  
 on women and PSC.



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 Meegan Carey  
 Ernest & Sue Carriere  
 Jeanne Cooper  
 Stephen & Kelly Curtis  
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 Brian Doyle  
 Mary French & David Selledy  
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The introduction to Mindfulness Stress Reduction intrigued many.

Meegan Carey, the organization's Development Assistant, helped set up the brunch site on Friday morning.

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 David & Mary Ness  
 Caroline Parry  
 Edward Peebles  
 John Reilly  
 James Revkin  
 David & Rachel Rockafellow  
 Janet Rosa  
 Elizabeth Scharmer  
 Theresa Scheuermann  
 Elise Schostak  
 Richard Seifert  
 Klaus Selmayr  
 Suzanne Shilling  
 Jennifer Soloway  
 Heidi Stair  
 Randall Stephens  
 Brad Stokes  
 Barbara Stout  
 Dariusz Szydlo  
 Christopher & Tamar Taddei  
 Julie Terry  
 Michael Torzewski & Janeen Kwarciany  
 Joan Violante  
 Mary Wells  
 Stephen Winber  
 Cal Wise  
 Sheldon, Robin & Cameron Wohl  
 Michael & Deborah Zimmerman  
 Anonymous at 2010 Conference Banquet



Board members at the conference were, left to right:  
 Tom Butler, Dike Ajiri, Joanne Grieme, Scott Malat,  
 Becky Long, Ricky Safer, Lee Bria,  
 Rachel Gomel, and David Rhodes.



Anonymous  
Schwab Charitable Fund Grant  
Jackson Brazo Victory Fund

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**ADDITIONAL FUNDRAISERS**

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**NEW FOUNDATION SPONSORS**

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Jeff & Reggie Belmont  
William & Lee Bria  
David Caito  
Arne & Judy Myrabo

Joanne Hatchett and Rick Seifert  
practiced Therapeutic Massage under  
the direction of Susan Forster  
on Friday afternoon.



**IN HONOR OF:**

Cameron Wohl  
Cameron Wohl  
Cameron Wohl  
Cameron Wohl  
Cameron Wohl  
Cameron Wohl  
Cameron Wohl  
Cameron Wohl  
Cameron Wohl  
Cameron Wohl

Muncie Endurathon  
Exhibit Table at Conference  
Grocery Program

Julianne Vasichek showed us the best  
way to warm up before exercising.



David & Mary Ness  
Jennifer Soloway & Mark  
Stivers  
Stephen Winber  
Craig & Marybeth Wishart  
Schwab Charitable Fund Grant

#### **COPPER LEVEL SPONSOR**

William & Pat Bandy  
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Nancy Harper  
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Peder Wishart Hedberg  
Memorial Fund  
Stephen Miller  
Janet Rosa  
Elise Schostak  
Eileen Soloman

## **New Save The Day/ Fundraising Flyer**

Thanks to Sandi Pearlman, we have a new flyer that explains why we are raising funds for a cure. Check it out at:

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

### **Note to Readers:**

Articles in this newsletter have been written by persons without formal medical training. Therefore, the information in this newsletter is not intended nor implied to be a substitute for professional medical advice.

Please consult with your doctor before using any information presented here for treatment. Nothing contained in this newsletter is intended to be for medical diagnosis or treatment. The views and opinions expressed in the newsletter are not intended to endorse any product or procedure.



**PSC Partners Seeking a Cure** is a 501(c)3 nonprofit foundation that endeavors to find a cure for Primary Sclerosing Cholangitis.

The three-fold purpose of the **PSC Partners Seeking a Cure** foundation is to: raise funds for research on the causes and cures of PSC, promote PSC and organ donation awareness, and provide education and support to PSC patients and their families.

Ricky Safer is the principal contact person for the PSC Partners Seeking a Cure Foundation. Reach her at: [contactus@pscpartners.org](mailto: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](http://www.pscpartners.org)

#### **PSC Partners Seeking a Cure Board Members**

Dike Ajiri, Lee Bria, Tom Butler, Becky Long, Dr. Gregory Everson, Rachel Gomel, Joanne Grieme, Chris Klug, Scott Malat, David Rhodes, Ricky Safer, and Deb Wentz

#### **Medical/Scientific 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. Johannes Hov, Dr. Stephen Miller, Dr. Don Safer, and David Rhodes, Ph.D. (Chair)

#### **The Duct Newsletter**

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