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# The Duct

Bringing you news on PSC



PSC PARTNERS  
SEEKING A CURE

research, education, and Support

PSC Partners Seeking a Cure Foundation

Fall 2009

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## We're on the Move

Thanks to the passion and hard work of our members, PSC Partners Seeking a Cure has been making huge strides in our educational, support, and research programs. Here's a summary of our most recent progress, which will benefit all PSCers and caregivers.

### Education And Support (Summer/Fall 2009)

I am so encouraged with all the increasing attention to our disease. In addition to the PSC Partners Seeking a Cure annual conference last spring, by next month, my husband Don and I will have had the pleasure of attending three PSC meetings during the summer and early fall (two of which PSC Partners co-sponsored). Please see our recent Special Focus issue of this newsletter (<http://www.pscpartners.org/DuctOSLOSinai09.pdf>) which gives a detailed report of the EASL conference held June 23-25 in Oslo, Norway and the Mount Sinai Forum held in New York City on September 8<sup>th</sup>.

**The EASL (European Association for the Study of the Liver) Conference in Norway:** The researchers at the Norway conference continue to collaborate in their research, and they hold out a lot of promise for making headway in eventually finding the elusive cure for PSC. Dr. Espen Melum from the Norwegian PSC Center will be speaking at our 2010 conference to bring us up to date on their progress.

**The Mount Sinai Forum** (co-sponsored by Mount Sinai Hospital and PSC Partners Seeking a Cure): At the Mount Sinai forum, an update on present PSC treatments was given, and an ongoing PSC support group was formed, that will be meeting at Mount Sinai in Manhattan. See page 11 for details. The Mount Sinai PowerPoint presentations are posted on our website ([www.pscpartners.org](http://www.pscpartners.org))

**University of Colorado Health Sciences Center Symposium:** I'm looking forward to an exciting all day interactive workshop for PSC patients and medical professionals titled, *The PSC-IBD Link*, to be held Saturday, October 3, at the University of Colorado Denver Anschutz Medical Campus. PSC

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Partners Seeking a Cure is putting on this symposium in conjunction with the Medical and Research Community of the University of Colorado Denver and The Children's Hospital of Denver. Keynote speakers will be Dr. Keith Lindor from the Mayo Clinic, Rochester and Dr. Tom Hemming Karlsen from Rikshospitalet University Hospital in Oslo, Norway. The program is complimentary and open to everyone, so please write to us at [contactus@pscpartners.org](mailto:contactus@pscpartners.org) if you'd like to attend. After the symposium, we will post summaries of the presentations.

I'd like to clarify that all PSC Partners board members and volunteers pay for all of our own travel and conference expenses.

## Research

**Research Grants:** Thanks to David Rhodes, the head of our Medical Advisory Board and the personal guru of most of our members, we are taking huge steps in PSC research. At our 2009 conference, David announced the winners of PSC Partners' first three research grants:

Dr. Konstantinos Lazaridis of the Mayo Clinic/Rochester who received a PSC Partners grant for his research entitled: *Examining the disease impact of genetic variation in logical candidate genes for PSC: a PROGRESS study.*

Dr. Pietro Invernizzi of the University of California Davis who received a PSC Partners grant for his research entitled: *Cholangiocarcinoma-associated serum micro-RNAs in PSC: Identification and prognostic potential.*

Dr. Cyriel Y. Ponsioen of The Academic Medical Center in The Netherlands who received a PSC Partners grant for his research entitled: *Aberrant homing of lymphocytes to the liver in patients with PSC: the missing link between the colon and liver.*

To learn more about these research projects, go to the Request for Proposals link on our website. We are excited to be supporting these three research grants.

In addition, we will be awarding our third annual prize at the upcoming annual meeting of the AASLD (American Association for the Study of Liver Diseases). The AASLD committee has chosen Dr. V.S. Teaberry as the most promising PSC researcher for her study: *Novel role for hedgehog pathway activation in the parthenogenesis of PSC.*

We want to announce that right now, our Medical Advisory Board is reviewing the next round of excellent research proposals that we have received. Watch for the upcoming announcement regarding our next research grant winners!

In related breaking research news, I have just received excellent news from Dr. Dennis Black of the STOPSC group, an important project that we have supported in the past. STOPSC has just received FDA funding for a three-year pilot Ursodiol withdrawal and reinstatement study in pediatric patients with

PSC to be performed in fifty patients through the STOPSC pediatric centers.

## **Fundraising**

Thanks to the generosity of our members and sponsors, we are able to continue expanding our all important PSC research efforts! If you would like to help us with our fundraising efforts, here are several suggestions:

- ✓ Join us for our Save the Day weekend October 3-4, a chance for everyone to hold local fundraisers of your choice. Please read Sandi's article in the Fundraising section of our website.
- ✓ George Schill, a very talented illustrator, has again volunteered to create two fantastic designs for our holiday cards. To choose your cards and place your order, go to [http://www.pscpartners.org/2009\\_holiday\\_card\\_announcement.pdf](http://www.pscpartners.org/2009_holiday_card_announcement.pdf) Please order your cards now, as the order deadline is November 4. All proceeds from the cards go directly to support PSC Partners Seeking a Cure programs.
- ✓ Ask your friends and family to donate to The Road to Connecticut, a fundraiser in support of our annual conference. See details on our website.

Since we are a volunteer organization, our administrative costs for 2008 were an amazingly low 2.2 percent, which means that 97.8 percent of all donations go directly to fund our research and educational programs. Please think about joining us in our quest to find the cure for PSC!

## **Upcoming Events**

PSC Partners Seeking a Cure Annual Conference (May 2010): Plans for our May 14-16 annual conference in Hartford, Connecticut are shaping up beautifully, and I hope that many of you will be able to join us.

Reggie and Jeff Belmont have been working closely with us to plan our sixth conference for PSCers and caregivers. It has been a pleasure planning the agenda with the hepatologists at the Liver Center at Yale University, headed by Dr. James Boyer.

They have helped us put together a comprehensive slate of excellent speakers and topics for Saturday, covering all aspects of PSC and coping mechanisms. I know that all the attendees will benefit greatly from the presentations, as all of the hepatologists at Yale who are working with us are not only experts in their field, but they are also truly passionate about helping PSCers.

When you mark your calendars for this weekend, please try to arrive early so that you can experience our expanded pre-conference activities this year. In the 2009 conference evaluations, we had many requests for more time together to get to know each other before starting the Saturday presentations. We have found a delightful venue for our Friday brunch, the historic Butler-McCook House and gardens, which are only a few blocks from our hotel, the Hartford Marriott Downtown.

Then, on Friday afternoon from 3-5 p.m., we'll be holding an interactive integrative health session, covering the importance of exercise and stress-lowering activities, both for PSCers and our caregivers as well. Attendees are invited to come in casual workout clothes and experience short introductions to activities of your choice, such as yoga, meditation, Tai Chi, etc.

If you have not attended one of our conferences in the past, I can promise you a positive life-changing experience, which will help you deal with life with PSC. It is hard to describe the feeling of being in a large group of people, all of whom understand your fears and concerns, and who are ready to share their personal experiences and advice. There is a very positive sense of well-being that accompanies our group, and we end the weekend with the feeling of being part of an incredibly supportive PSC family. Start saving your money now and try to join us in Hartford!!

✓ **New Local PSC Support Groups:** PSC Partners Seeking a Cure is also making progress in expanding our local support groups. In addition to ongoing groups in Connecticut and Sacramento, California, we now have new PSC support groups in New York City, the San Francisco Bay area, and the Southern U.S. Please check out the support group information on page 11.

✓ **New Volunteer Committees:** Thanks to new volunteers with specific expertise who attended our 2009 conference, we have started two new important committees: a PR/Marketing Committee and a Corporate Fundraising Committee. These two committees are working together to help us raise more money for research and also to raise awareness of PSC.

✓ **New and Improved Website:** We are still working away on completing our new expanded website, but we have run into some unexpected delays. We hope to launch the website before the end of the year. It is going to be a fantastic resource for all of us.

One last bit of news that I am pleased to announce is that the board of directors has voted to hire a part-time Development Assistant to help me keep up to date with all our projects. Amanda Robichaux has started working with me ten hours a week, and it has been an absolute pleasure. Amanda is also the Development Assistant at our local CCFA office, so she comes to us with valuable expertise.

Wishing you all good health and a refreshing fall season.

**Ricky Safer-President**  
**Together in the fight, whatever it takes**

## Transplant Center

# Organ Donor Registrations Rise; Transplant Myths Identified; Living Donation Booklet Available

Eighty million people in the United States are now registered organ donors, according to Donate Life America (DLA; website: <http://www.donatelife.net> ). Within an 18-month period within the past few years, nine million new donor designations were made. The 80 million figure—people who want to be organ donors—represents one fourth of the US population and 38 percent of licensed drivers.

Of the 80 million currently registered donors, 97 percent recorded their desire to donate at their Department of Motor Vehicles, illustrating how important it is for states to maintain an effective program of registration in those facilities.

DLA also reports that 47 states and the District of Columbia have what is called

“authorization registries” which record the legally binding decision of registered donors. Only that donor can revoke the choice.



DLA commissioned a survey this year that identified currently misunderstood transplant and organ donation policies.

Forty four percent of the 5,100 respondents believe a black market exists in the US in which patients can buy or sell organs.

More than half of those who participated in the survey, 57 percent, wrongly believe that a person who is brain dead can recover from underlying injuries.

And, half of respondents believe that a doctor will not

try as hard to save a life if they know the patient is an organ donor.

In addition, 72 percent of those queried said they want their donation decision to be honored, despite what family members may prefer.



The United Network for Organ Sharing (UNOS) has announced the publication of a 12-page booklet on living donation, which will help donors in their decision-making. The booklet explains the evaluation process, financial factors, types of living donation, and a description of risks and benefits. Go to [www.unos.org](http://www.unos.org) to download the booklet, *Living Donation: Information You Need to Know*.

## COBRA Rules Change with Federal Stimulus Package

From the Department of Labor with regard to the Stimulus Package: Eligible individuals pay only 35 percent of their COBRA premiums and the remaining 65 percent is reimbursed to the coverage provider through a tax credit. The premium reduction applies to periods of health coverage beginning on or after February 17, 2009 and lasts for up to nine months for those eligible for COBRA during the period beginning September 1, 2008 and ending December 31, 2009 due to an involuntary termination of employment that occurred during that period. Website: <http://www.dol.gov/ebsa/cobra.html>

# Fact-O-Rama

## Hartford, Connecticut: Our host city for the 6th Annual PSC Partners Conference

☞ In Hartford, you may not, under any circumstances, cross the street walking on your hands!

☞ Connecticut is home to the oldest U.S. newspaper still being published: *The Hartford Courant*, established in 1764.

☞ Hartford has been the capital city of Connecticut since 1875.

☞ The city is nicknamed the "Insurance Capital of the World."

### CCFA Opens DNA Databank: Powerful New Resource to Advance Understanding of Disease Genetics

CCFA recently launched its DNA Databank, a newly-created resource containing DNA samples and detailed phenotype data for a large number of Crohn's disease and ulcerative colitis patients. Research into genetic markers is a priority for researchers, who are seeking to understand the underlying process of IBD in order to improve

treatment and prevention.

The new databank, made possible through a generous gift from the Donald W. Reynolds Foundation, is available to qualified investigators for innovative studies of genetic markers related to IBD. Interested investigators may view available phenotype data elements, obtain summaries of the numbers of affected patients and family or population controls, and submit research proposals at the DNA Databank website, [www.CCFADatabank.org](http://www.CCFADatabank.org).

### OPTN/UNOS Guidance Regarding H1N1 and Implications for Transplantation

The effect of the new H1N1 virus on transplantable organs is being studied. Based upon the most recent experience this year with the virus and its impact upon transplant in the Southern hemisphere, UNOS and OPTN have issued guidelines for organ procurement organizations (OPOs) and transplant centers regarding the safety of staff during an outbreak. Another concern is the safety of organs from infected donors. Specific screening of donors is recommended. A release on the topic is available at this site:

<http://www.transplantliving.org/community/news.aspx?id=1292>

# HOW TO FIND WHAT YOU'RE LOOKING FOR ON THE PSC LITERATURE SITE

by Arne Myrabo

Scenario: I was just diagnosed with a mouthful: Primary Sclerosing Cholangitis (PSC)! Since the only thing the ERCP (endoscopic retrograde cholangiopancreatography, another mouthful!) endoscopist said was, "You're going to need a liver transplant." (What?!) I naturally went to the internet and searched for the term.

Up to this point, the scenario is exactly what happened to me in 2000. I get LOTS of hits, including The National Institute of Diabetes and Digestive and Kidney Diseases, Mayo Clinic, American Liver Foundation, Medscape, Merck, etc., and one site called psc-literature.org. After looking at all the other overviews, THAT sounds like it might be a resource to investigate more details; according to the site statistics, over 115,000 abstracts on PSC! The literature site is updated weekly by David and Judy Rhodes and is a part of the PSC Partners web site.

The [www.psc-literature.org](http://www.psc-literature.org) home page: As in the other sites, I again see a brief description of PSC. I also see a link that says FAQ (Frequently Asked Questions). Clicking on the FAQ link, I find most of the questions I want to ask, the responses, links to support groups, more brochures – a gold mine! I open the “Diagnosing PSC” link, hoping to find more information on ERCP, as I had a fairly common reaction called pancreatitis (and I REALLY do not want to go through that again!). Unfortunately, this didn't really say much other than it's a possible side effect. I go back to the psc-literature home page, and click on “[Scientific Literature](#)”

I scroll down to “[pancreatitis](#)” and click on it. Over 1900 articles! I'm surely not going to read all these, so I do a find (ctrl-f or find in the browser) for “ERCP” as a starting point. One of the ones I get is:

Risk factors for post ERCP pancreatitis: prospective multi-center study. Am. J. Gastroenterol. 101: 139-147 (2006),

This sounds pretty interesting, but there are literally hundreds of hits for “ERCP”. Maybe I should restrict the search to “post-ERCP pancreatitis”? Now I get a more manageable list, which includes the above and:

Pharmacotherapy for the prevention of post ERCP pancreatitis. Am. J. Gastroenterol. 102: 52-55 (2007).  
Post-ERCP pancreatitis and its prevention. Nat. Clin. Pract. Gastroenterol. Hepatol. 3: 680-688 (2006).

Looking through these articles for 10-15 minutes, I learn that:

- post-ERCP pancreatitis occurs in 5-7 percent of patients

- pharmacological attempts to prevent it have not been successful, BUT
- rectal prophylactic NSAIDs look promising as a prevention
- stenting of the pancreatic duct looks promising as a prevention
- risk factors include previous post-ERCP pancreatitis, SOD, experience of the endoscopist, age of the patient (older is better )

Of course, I had to look up some of the items (like SOD : Sphincter of Oddi Dysfunction, NSAID non-steroidal anti-inflammatory drugs, etc.). Wikipedia is a pretty good resource for overviews (use the references if you want more details), or any medical reference.

So now I know some questions to ask the next time I need an ERCP. Obviously, internet research does not substitute for years and years of medical training, but I'm surely more informed now than I was!

## 20-30 Somethings

### The Happiness Plan

by Sandi Pearlman

By now, even the man in the moon knows my mantra of "If it's got to be laugh or cry, pick laugh," and he's even getting ready to tell me to shut the, ahem, heck up as I repeat it to myself maniacally in doctor's offices, waiting rooms, at the supermarket, basically whenever life hands me a problem that I just don't feel equipped to handle, you know, like waking up.

Sure, some might consider it a personality disorder at this point, but I prefer to think of it much more like Ally McBeal's dancing baby or internal theme song, a reminder of something that I want that's eventually going to be within my reach. (And, yes, I'm fully aware that many of you are too young to remember Ally. Go rent the DVDs, trust me on this, you'll enjoy it.) But I think internal theme songs and stupid sitcoms and rocking out with your hairbrush in bed (or the hallway a la Tom Cruise--yeah, I'm old,

check out *Risky Business*) are the things that make life more livable. PSC has taken so much control of so many of our lives. I think it's time we take some power back. I think we should make a group pledge.

Place your hand(s) over your hearts. I'll wait. I see you there in the papasan: hands up! This is important. Repeat after me, "I vow to do one thing every single day to make myself ridiculously happy." There was that so hard? And for those of you with roommates, spouses, children or animals who are now looking at you like you're a nutter, admit it, looking at their confused faces is sort of enjoyable, right?

So, how do we get to this great beacon of happiness on the days where PSC has positively screwed cheer? It's not that hard or complicated. Think about it, what makes you giggle? Feel beautiful or handsome or hot? What makes you forget, even for a second, about your PSC and upcoming colonoscopies and itching and RUQ pain?

Well, for me, that's largely anesthesia (which I am completely in love with. You know how some



women fantasize about marrying doctors or lawyers or cowboys? I think my fantasy involves an anesthesiologist who quite literally can take me away from all of this madness. But I guess that's between me and my therapist, right?) Anyhow, here are some tried and true happiness guaranteed suggestions. Find one you like. Steal it. Wanna try one on? Borrow it. Have one of your own. Go for it!

### **Guaranteed Happiness Plan # 1:**

On days when fatigue won't let you get out of bed, give in. Make a day of it. Every once in a bit, let the fatigue monster win, but on your terms. Cuddle up under a generous comforter (there's a reason they're called that) and watch some bad TV or pop your favorite DVD into the laptop or player. Wanna wallow? *Terms of Endearment, Hancock and An Affair to Remember* work for me.

I have a guy friend who denies it but ALWAYS cries at the ends of *Rent* and *Titanic*. *Marley and Me* and *Steel Magnolias* are good choices too. Want to laugh? Try *Some Like it Hot* or *Bringing Up Baby* or *Elf*. Fill in the blanks. You know you have a movie that makes you smile from ear to ear and, if you don't, might I suggest just about anything with Haley Mills?

In any case, commit yourself to the plan. It's not fatigue's or your body's choice to lie in bed all day. It's yours. You're in control and if you want to sneak a bit of ice cream or popcorn in there with you, who's going to know? And for those of you with kids or a hubby, make it an event. Bring them on in and introduce the kiddos to *Mary Poppins* or *The Wizard of Oz* or watch old family movies. I have no idea why, but children will sit still for HOURS just to watch themselves on TV!

### **Guaranteed Happiness Plan # 2:**

Next time you're out and about, buy yourself a coloring book of your choice and the good pack of crayons. You know which ones I'm talking about, the yellow and green box that has the sharpener built into the back. Now, before you stop reading and decide that lack of sleep and medication have made me a loon, think about it. There's a reason why therapists use coloring as a tool to help kids work through issues.

First, it's hard to be angry or stressed or overwhelmed while you're coloring. Second, if you are any of those things, chances are that focusing on your coloring will help you sort out the issues that are bugging you or give you a safe place to vent rage: coloring Mickey Mouse a moldy green color or making Prince Charming have buck teeth can be strangely soothing.

### **Guaranteed Happiness Plan # 3:**

Okay. I stole this one from Oprah who, I'm sure, stole it from somebody else, but, hey, she's Oprah and we all know she can get away with stuff like that. Start a happiness journal. Write down three things every single day that made you happy. I don't care if it's making a traffic light on your way to work that you usually miss, a really good Bacon, Egg and Cheese Biscuit at the local fast food place, or that your dishwasher magically unloaded itself. Whatever the reason, write it down.

I've had days where I've written down this list: (1) Didn't throw up for three hours. (2) Cat purred and gave me a kiss. (3) New episode of *The Biggest Loser* was on tonight. As you can see, it doesn't have to be earth-shattering stuff. But here's the kicker. One, I love my little happiness journal. It's brown and has a fabric fastener and looks like something Hemmingway

would've had. Two, just making myself sit down at the end of the day (or continue laying down but with a pen in my hand this time) and thinking of and writing down three things that made me happy that day makes me feel like a nerd, but a happy one. And three, remember how we talked about the days when you need a good laugh, try rereading your journal. I guarantee it'll make you smile. Oh, and remember it's one of the Big O's (not that one) favorite things to do. You don't want to defy her now, do you?

#### **Guaranteed Happiness Plan # 4:**

Be honest with yourself and others. So many young PSCers I talk to want to hide their PSC away like it's a secret shame. I get that. I really do. It's such a hard thing to tell somebody or to make them understand. We want to protect those around us. We don't want to be a burden. Plus, to tell our truth, we have to think of timing and be ready for the risk of rejection and be willing to open ourselves up for judgement on something that is so much bigger than a secret stash of girlie magazines or bridal porn (which is what those of us in the industry call all of those bridal mags).

The only problem is that by hiding what is and what will always be such a large part of ourselves, we're perpetuating a myth that we're flawed and unlovable. We're telling others by our very evasiveness that we expect them to judge us and find us lacking. It's hard to bite the bullet. You might lose people who you thought were your friends. But in the end, instead of carrying around a bucket of evasions and creating a circle for yourself where there's no real support, you'll have ties that won't break.

You'll have truth instead of lies. You'll have compassion and understanding when you need it. There will be hands to hold in waiting rooms and people to celebrate real triumphs like improving

LFTs and no longer looking like a banana after a fit of cholangitis and jaundice. In addition, what better way to advocate towards research and a cure than to be a walking billboard? If you don't advocate for yourself and make it known how important organ donation and funding are, who will? And how happy and fab will you feel when PSC stands for problem so cured.

#### **Guaranteed Happiness Plan # 5:**

Spoil yourself. I know belts are tightening all around these days and not just from PSC weight loss. But I urge you to make the investment in yourself.

You can treat yourself to weekly or monthly pedicures (guys, trust me, if you're thinking this suggestion is too girly, you haven't experienced the loveliness of a pedicure for badly itching feet) or buy yourself a bottle of your favorite polish and do an at-home version.

Love to read? When you have the energy, hit your local library. I'm a former librarian and to me books are the be-all/end-all. But frequent hospitalizations and travel make lugging books back and forth a trial, so I'm thinking about succumbing to one of those e-readers and thinking of the expense as one for my emotional and physical sanity.

Grab a blanket and go for a picnic in the park with the kids and count stars or cloud-spot. Run through the sprinkler in the backyard. Stop by an animal shelter and take a lonely dog for a walk. Host a potluck if you're too tired to go out to dinner. Log on to Bluefly.com or QVC or UncommonGoods.com and shop till you drop without moving much more than a finger muscle (and best of all, you don't even have to purchase anything!). Get a massage. Color your hair. Whisk (or have your significant other whisk you)

away on a romantic weekend in your own town. See a movie you've been dying to see. Designate a game night (can't go wrong with Clue, Monopoly or Scrabble in my book). Subscribe to your favorite magazine. Spend an entire day in bed watching Food TV. In short, it doesn't matter what you do, just make sure you do it and enjoy every second of it.

### **Guaranteed Happiness Plan # 6:**

You tell me. Log on to PSC Partners Facebook ([www.facebook.com](http://www.facebook.com) then search PSC Partners to find the group) and add what makes you deliriously, wickedly, convulsively happy. Then sit back, smile and know you've done a good deed for the day, you've made someone else smile.

## **The Information You Want to Know**

### **. . . About the 2010 PSC Patient Conference**

**It's coming in the Winter newsletter:**

**All you need to know about the conference, the program, the pre-conference activities, the hotel (great rates!), the speakers, and fun things to do in Hartford.**

## **PSC Support Group Update**

We're expanding the number of local PSC support groups, each of which is run by a PSC family.

### Ongoing support groups:

#### **Connecticut group:**

Contact person: Reggie Belmont  
[ctpsc@hotmail.com](mailto:ctpsc@hotmail.com)

Next meeting: November 7

#### **Sacramento, CA group:**

Contact person: Jennifer Soloway  
[Jennifer@markstivers.com](mailto:Jennifer@markstivers.com)

Next meeting: January 2010

### Newly formed support groups:

#### **Southern chapter/Greenville, SC:**

Contact person: Carolyn B.

[verviersbe@gmail.com](mailto:verviersbe@gmail.com)

Next meeting: November 7 in Greenville

#### **New York City:**

Contact person: Eileen Solomon

[Eileen.Solomon@mountsinai.org](mailto:Eileen.Solomon@mountsinai.org) (Please put "PSC" in the subject line)

Next meeting : October 19 from 6-7:30 p.m. at 1425 Madison Ave. at 98<sup>th</sup> St./ Third floor/Room 50

#### **San Francisco Bay Area:**

Contact person: Tom Hill [tphill@1lifeplace.com](mailto:tphill@1lifeplace.com)

First meeting: October 4 from 1:30-4:30 p.m. in San Jose



## **A Virtual Lecture from CCFA: Balancing the Risks and Benefits of Treatment for Inflammatory Bowel Diseases**

The content of this FREE virtual lecture was derived from a live, educational teleconference/webcast presented by the Crohn's & Colitis Foundation of America on Tuesday, June 9, 2009. The virtual lecture format enables you to view presentation slides and listen to the audio simultaneously, as well as download a transcript of the presentation and a copy of the presentation slides.

Inflammatory bowel diseases (IBD) are a serious and complex group of chronic intestinal diseases that often requires a lifetime of medical care. This complimentary online educational activity will answer important questions about treatment options for IBD including:

What are the side effects of IBD medications?  
When should surgery be considered?  
How can I decide on the treatment that is right for me?

The content of this FREE online activity was derived from a live educational teleconference/webcast presented on June 9, 2009 by Corey A. Siegel, MD. Dr. Siegel is Assistant Professor of Medicine at the Dartmouth Medical School and

Director of the Inflammatory Bowel Disease Center at the Dartmouth-Hitchcock Medical Center, Section of Gastroenterology and Hepatology in Lebanon, New Hampshire. To participate in this activity presented by the Crohn's & Colitis Foundation of America, please visit [www.RMEI.com/CCFA139VL](http://www.RMEI.com/CCFA139VL).

### **SYSTEM REQUIREMENTS**

Hardware/Software requirements include:

- Windows 95, 98se, ME, XP, NT 4.0, 2000
  - Internet Explorer 4.0+
  - Netscape Navigator 6.2+
  - AOL 8
  - Mozilla Firefox 1.0+
- Macintosh 9.2, OS X 10.1+
  - Safari 1.1+
  - Netscape Navigator 6.2+
  - Internet Explorer 5.2+
  - Mozilla Firefox 1.0+
- Additional Requirements
  - Macromedia Flash Player 7
  - Internal/external speakers
  - Broadband connection (DSL/cable) recommended

## **6<sup>th</sup> Annual Conference for PSC Patients and Caregivers**

**Hartford Marriott Downtown, Hartford, Connecticut, May 14-16, 2010**

The purpose of the conference is to provide a forum on the latest medical advances in the search for a cure and new treatments, and to offer PSC patients and caregivers the opportunity to network with speakers and fellow PSCers in an informal setting. Co-sponsored by the Section of Digestive Diseases and the Yale Liver Center at the Yale University School of Medicine.

Dr. James Boyer, Ensign Professor of Medicine, Director of Yale Liver Center, Dr. Mario Strazzabosco, Professor and Director, Transplant Hepatology, Dr. Pramod Mistry, Professor and Chief of Pediatric GI and Hepatology, Dr. Tamar Taddei, Assistant Professor of Hepatology, Guest Speaker: Dr. Espen Melum, The Norwegian PSC Research Center and other speakers to be announced

For conference information, visit [www.pscpartners.org](http://www.pscpartners.org) or write to [contactus@pscpartners.org](mailto:contactus@pscpartners.org)

## MY WORDS, MY STORY

### Post-Transplant Life Isn't Perfect, But I Love It

*By Tom Butler, who had his living donor transplant at Georgetown University late last year.*

My donor and I met today. Larry and I try and arrange these meetings as often as we can. We think our brethren livers need to be in the same place sometimes. Today's venue was one that we have not visited together in nearly nine months: Georgetown University Hospital.

It is not by choice. I am a patient. Last time I was a paying customer here, I was fighting some bad complications following my transplant. This time, after a seven-month run of mainly healthy-feeling days, I woke up with many of the same severe symptoms I had prior to the transplant: spiking fever, severe chills, disabling fatigue, extreme pain and on and on and on and on. The tests indicate that I have some rejection issues. Fixable but very inconvenient.

Post-transplant life, or at least the first nine months of it, has been filled with more than my share of physical and emotional roller coasters. The outside view may be that once the transplant is done the recipient has no complaints. I can certainly understand that viewpoint, because I often felt that way myself. How can someone given this brand new start at life have any issues whatsoever?

Physically there is not much to discuss. Outside of this bout of rejection, I feel better than I have in ten years. I have a new focus and discipline on diet, exercise, medication compliance, and healthy living. I am in the best physical condition of my life. My quality of life is vastly better than just one year ago. And even though I am pretty

sick right now, when the admitting nurse says that I have an athletic physique and look years younger than my stated age, how bad can things really be?

For me, the emotional issues relating to this experience are more numerous, more complex, and much more interesting than I anticipated. I have no formal psychological training. Just real life experience. So I submit, for your reading and dancing pleasure, some of the many emotions I experienced and continue to face today, all written from a hospital bed.

When my doctors told me two years ago to seriously consider searching for a live donor, my response was a shoulder shrug. I was already listed for transplant. I fought the PSC battle for many years and was still feeling OK overall. Why rush? I liked the attention from those familiar with my condition. That I was an apparent long term successful fighter was great for the ego.

But infrequent hospitalizations eventually degraded to a six-week cycle. I started to struggle physically, and it was getting tougher to run my accounting and tax practice. I finally swallowed my pride and admitted that it was time. Hours of discussion resulted in no prospects within my family. We put out an appeal for a donor through our church, and Georgetown was flooded with inquiries. That should have been humbling and satisfying, but due to some twisted logic in my melon it was not.

I was on the outside looking in. I could not participate in the screening process, and decisions seemed to be made for me and not by me (anathema to a control freak). Things were proceeding at a pace that was no longer leisurely, and I did not appreciate the urgency. I had no control. Then, too, was the ongoing question: Were we jumping the gun? Was it too early to do this? Should I wait longer? What happens if I wait TOO long? What if something happens to me? To my donor? I just wanted everything over, and if it could not be over, all I wanted was an escape. I know every imperfection in my bedroom ceiling, having stared and pondered these questions night after night.

A compatible donor was found, and surgery was scheduled for June, 2008. There was no time for me to be afraid. I only found out three weeks beforehand. I reluctantly agreed to proceed and started the scramble to tie all of the loose ends together in my life.

Twelve hours before the surgery, my phone rang. The transplant was canceled. We knew that the donor's organ was slightly undersized for me, a small risk. A new clotting factor problem arose during the final testing, and that second minor risk added up to one major risk. No new liver. At least not now.

Devastating.

You try to prepare emotionally, spiritually, physically, logistically, and every other "-ally" out there. With a live donor and all of the pre-testing, you don't expect something to go sour, particularly at the eleventh hour. But it did.

That was a long, hot summer, an emotional blow that would not heal overnight.

We were back at square one.

Once again, the appeal went out in church. Once again, Georgetown was flooded. Once again, I was in the dark. Unbeknownst to me, Larry was one of those who made that crucial call.

What I did know was that by this time, I was hospitalized monthly. Working a consistent schedule and serving clients was impossible. An already bad working relationship with my business partner terminated suddenly at the end of August, 2008 when I walked out without notice after being accused of faking my illness, among other iniquities.

In the middle of the stress caused by the health issues, I had to find a new source of income. And fast. I immediately started a new practice with someone from the old firm who shares my values and standards, and who truly appreciates and understands the physical and emotional battles I faced. Thankfully, that would turn out to be one of the best decisions I ever made. (Con't on p.15)

### ***Cris Klug's Fourth Annual Summit for Life: Dec 11-12***

Chris Klug, a PSC Partners board member, holds his fourth annual Summit for Life event at Aspen Colorado December 11-12.

The event aims to spread the message that becoming an organ donor is important and that transplant recipients and living donors can lead active healthy lives.

Events of the weekend include parties and a nighttime uphill race on Aspen Mountain.

Details are available at this website:

[www.summitforlife.com](http://www.summitforlife.com)

Time went on, and like before, I found out about the new transplant schedule a couple days before Thanksgiving. Maybe they did that so I would not over-think the situation. The transplant happened on December 4, 2008.

Physical recovery was tough. It was almost four months before I felt good consistently. That's me. Why do something the easy way when there is a hard way available?

But I finally started feeling great every day. I was not used to that, and strangely, I did not know how to respond. So I got cocky. For instance, before forcing myself into a Pavlovian response to the clock, I felt so good that I would let critical medicine schedules slip periodically, sometimes by several hours. Dumb, and very out of character for one who is all about discipline.

As I felt better physically, I found stress levels going up. Being a solid Type A personality, I thrive on that. Here is the battle in my skull: I have years of lost time to make up. Too much was left undone because I was too sick to do anything. The new business, started during severe illness and in a deep economic recession, is not as successful as it needs to be. There are things I want to do with family and friends that are long overdue. I need to stay in good physical condition—no turning back. (This rejection episode is killing me in that regard.) I have big obligations to my family and my profession and cannot be slowed down by the side effects of anti-rejection meds. There are worlds that need conquering. The question I do not want to face yet is why I feel the need to accomplish all of that today.

Realistically, I may be in the hospital now because I let some early rejection signs linger. I slowed down noticeably over the last couple weeks, but I dismissed the aches and fatigue to

something passing. A couple bad workouts are normal. Just rub some dirt on it and move on. Another lesson: Yes, I feel good overall, but some more attention to subtle and emerging issues is not hypochondria. It is prudent.

Wow.

What a set of issues.

Good thing I still have a supportive circle of family and friends who inexplicably (and thankfully) can look beyond these ongoing struggles and see me as the lovable, adorable guy I am.

None of this causes me the slightest regret. I am so many orders of magnitude better off today than I was before the transplant that it is not worthy of serious discussion. What I am saying is that life after transplant has a set of challenges on its own. Those of us who have gone through the process, and those who face transplant in the near future, need to acknowledge that life can be nothing short of wonderful after transplant, but like any solution to any problem, there are always unforeseen issues to face.

Face them. Keep the fight going, but keep a healthy perspective, too. Even the healthiest person has some ongoing struggles. Life would not be life without them.

I know me. This is much easier said than done. My bet is that I can do it. I will get through this big pothole, and while it is quite depressing to take a big step backward, it would not be nearly as fun if the road was completely smooth.

Onward!

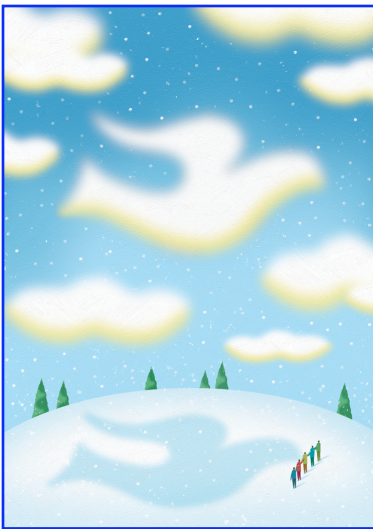
## Original 2009 HOLIDAY CARDS Now Available

Orders must be received by November 4, 2009!

We are delighted to offer two unique holiday cards for sale again this year. They were designed by American Greetings artist and writer George Schill especially for PSC Partners Seeking a Cure. All proceeds from the sale of these cards will benefit our research, educational, and support programs. Please send in your order now!

The holiday cards are available in packs of 25 at a cost of \$35 per pack plus shipping and handling. For domestic orders (USA), shipping and handling is \$5 for an order of 1-2 packs and \$10 for 3 packs or more. For international orders, please email [contactus@pscpartners.org](mailto:contactus@pscpartners.org) and a shipping quote will be provided.

Choose from “Dove” and “Starry Tree” designs.



Message inside both cards is the same:

May the peace and joy of the holiday season be with you always.

Message on the back of each card is also the same:

Proceeds from the sale of these cards benefit the research, education, and support programs of PSC Partners Seeking a Cure.

To learn more about Primary Sclerosing Cholangitis, please go to [www.pscpartners.org](http://www.pscpartners.org)



To order cards, please fill in the order form provided at:

[http://www.pscpartners.org/Holiday\\_card\\_order\\_form.pdf](http://www.pscpartners.org/Holiday_card_order_form.pdf)



## **Fundraising: Save the Day**

# Fundraising for PSC at the 50-Mile Weekend Garage Sale

*by Sara Brazo, who is Jackson's mother*

When our nine year-old son Jackson was diagnosed last year with PSC, PSC Partners Seeking a Cure was the first place we found information and support we needed. Doctors offered very little information and were very vague. We were devastated and scared. The PSC Partners website offered us hope and helped us learn as much as possible about this challenge we all face. We attended the conference in Chicago and were welcomed into the PSC family with great care and support. We heard about the Save the Day fundraising event at the conference and immediately started planning. We found two ways to raise money.

Each year our community holds a giant garage sale. Central New York's Route 90 sale extends 50 miles from Homer to Montezuma NY and lasts an entire weekend. In the past the children have earned money for summer vacations selling brownies and lemonade. This year they were happy to fundraise for PSC Partners.

For large birthday parties in the past, we have asked for book donations or supply donations for local charities. This year for his ninth birthday Jackson asked for a small donation to PSC Partners in lieu of a gift. Thirty of his friends attended to celebrate his current health and well being.



Jackson mans his post along route 90, raising funds for PSC research.

The early birds do get the worms. Through the party and the bake sale, Jackson was able to raise \$385 for research and this will become \$770 thanks to the amazing generosity of our anonymous donor matching those funds. Jackson, his family, and his friends are so excited to report this successful fundraiser and they hope to inspire others from the PSC family to find ways to Save the Day. Together in the fight whatever it takes.

Jackson is a fourth grader from Homer, NY. Even though challenged by PSC and Crohn's disease, he is able to remain active in school, sports, and clubs. He participates in baseball, soccer, and ice hockey; loves cub scouting, is learning to play the trumpet, and remains a top student in his class. He is living life to the fullest. We need to find a cure to help him and others like him continue to live full lives.

## Update on the PSC Partners Revised Web Site

We promise the new website will be worth the wait!

Working with a generous grant for design activities, the website is progressing, Content development is an all-volunteer effort: from personal stories about how to manage and understand the disease to lists of useful web sites for patients and caregivers.

Some of the new web sections will include: Understand Your Diagnosis, Be An Informed Patient, Take Charge, Research PSC. There will be sections on PSC Partners past and future conferences, information on navigating the transplant process, as well as tips on fundraising for and volunteer opportunities with the foundation.

Stay tuned! We're aiming to upload the site at the end of the year, if not sooner.

### 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

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### The Duct Newsletter

Editor: Pat Bandy  
([newsletter@pscpartners.org](mailto:newsletter@pscpartners.org))

Contributors to this issue: Pat Bandy, Sara Brazo, Tom Butler, Arne Myrabo, Sandi Pearlman, Ricky Safer