The Duct

Bringing you news on PSC

research, education, and support

PSC PARTNERS
SEEKING A CURE

PSC Partners Seeking a Cure Foundation, Early Summer 2010

Ricky Safer, Dr. Boyer of Yale, and
Don Safer begin Saturday's activities.

2010 Annual Conference

A Celebration of Hope for the Blue Dots

Our sixth annual conference for PSCers and caregivers, held May 14-16 in Hartford, Connecticut, was a huge success for everyone who attended. That special "something" that appears every time that our group gets together was alive and well all weekend. There was a positive healing energy that was flowing and even the speakers noticed it. Our conferences are planned to be a celebration of hope for the blue dots (the PSCers): a time to become more educated about our disease and also a time to learn so much from each other, both caregivers and PSCers. These are the three days every year when the blue dots rule the world, rather than being the ones that people speak about in hushed tones as "the one with that strange, rare disease." Every year, I return home feeling inspired, renewed, empowered, and comforted by our PSC family, yet so sad to leave everyone.

Thank you to all the PSCers and caregivers who were able to join us this year. Our attendance was the largest ever—205 members who came from throughout the United States and internationally. We had eighteen Canadians as well as participants from the United Kingdom, Sweden, Norway,

Conference co-chairs Reggie and
Jeff Belmont are recognized.

The Netherlands, Israel and Australia. We had a jam-packed weekend, balancing brilliant educational presentations by the faculty of The Liver Center at Yale University School of Medicine with time to share our concerns, fears, experiences and suggestions with fellow PSCers and caregivers. It's an amazing experience to spend three days with a room full of people who all understand what life is like every day for a PSCer.

Here are some of the **personal highlights** of the weekend for me:

The medical presentations from our speakers were succinct, clearly presented, and thought provoking. I was particularly struck by the speakers' personal concern and compassion for PSC patients. To quote Rachel Gomel, one of our board members: "This time I felt something new had happened at the conference. I felt that the physicians from the Yale team embraced the audience as their equal, honestly, kindly, and at moments, even bravely. It is rare to see physicians treating their patients (and caregivers) as their equals. It was liberating to feel the current that was being transferred back and forth between the audience and the physicians."

All year long, I look forward to the chance to reconnect with my old PSC friends. We all share a bond that is indescribable. Even though we haven't seen each other for a year, the conversations start up as if we have always been together. We cry, we laugh, we hug; we encourage each other.

I love meeting the newbies each year and watching their transformation during the weekend. We see them arrive on Friday, often fearful and wondering what possessed them to come to the conference. Most newbies have never met another PSCer before, and they expect the weekend to be depressing. By Sunday, they have learned a lot about PSC and how to live with our disease, and they have also made close friendships within the group. This year's newbies ended up being enthusiastic, open-minded and passionate about our shared mission.

As a PSCer, I know how important our caregivers are to us. They're the ones who help us live the most normal life possible while encouraging us to think positively and be proactive in fighting our battle with PSC. I am touched by the amazing family groups as well as caregivers of all relationships who shared the weekend with us. Please know how much we appreciate all of you!

I was thrilled on Saturday evening when we reached and surpassed our $100,000 goal for the Road to Connecticut, which meant that (after the matching donation of our anonymous donor) we had raised over $200,000 for PSC research!!!! Although I was a little embarrassed by "Shameless Don's" fundraising dance, it was an exciting moment for all of us.

It's an overwhelming feeling for me each time that I get in front of our group and look at the sea of faces who are so eager to learn and to help others. I adore the volunteer spirit of our members, who are passionate in helping us reach our shared goal of finding a cure for PSC. You are the most amazing group of people that I have ever worked with. You are brave, positive thinking, educated, and compassionate. Everyone is welcomed into our PSC family. You are the reason that our foundation has accomplished so much in our first five years!

THANK YOUS: I'd like to thank all the people who made this conference possible. This year's conference sponsors were:
PREMIER PLATINUM SPONSORS:

Illinois Tool Works/Permatex (Recipients of our Corporate Citizenship Award for 2010)
Abe and Rachel Gomel

GOLD SPONSORS:
The Liver Center at Yale University School of Medicine
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Don and Ricky Safer

SILVER SPONSORS:
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I can't thank The Liver Center at Yale University School of Medicine enough for being the co-sponsor of the weekend. Thank you to all our wonderful speakers, and especially to Drs. Boyer, Taddei, Mistry, and Strazzabosco who helped us plan Saturday's agenda.

I'd like to again thank our 2010 conference co-chairs Reggie and Jeff Belmont. After having attended every one of our first five conferences, Reggie and Jeff applied to be this year's conference co-chairs. Thank you for all of your help and your passionate volunteering spirit.

Mike Zimmerman, of Illinois Tool Works, a Premium Platinum Sponsor and recipient of the 2010 Corporate Citizenship Award, expressed his support for PSC Partners.

Becky Long has been my close adviser in planning this year's conference, and Meegan Carey has efficiently managed the logistics of the registration process for us.

Thank you to the board members who also helped in the conference planning: David Rhodes, Dike Ajiri, Becky Long, Joanne Grieme, Lee Bria, Scott Malat, Deb Wente, Rachel Gomel, and Tom Butler.

The list of other members who volunteered this weekend is too long to mention everyone, but I'd like to especially thank Ros and Nicola Parry, the Long family (Ken, Mary Ann, Alison, and Becky), the Pearlmans (Sandi, Karen, and Mike), Jecy Belmont, Arne Myrabo, and Joanne and Steve Hatchett, and Ivor Sweigler.

On behalf of all our PSCers and caregivers, I'd like to send out a huge thank you to our anonymous donor who so very generously offered to match the first $100,000 that was raised for the Road to Connecticut. Thanks to this donor, we ended up raising over $200,000 for PSC research!!!

Special thanks go out as well to:
Connecticut Division of the American Liver Foundation
Gilead
Starbucks at City Place
Sam Baytar
Arlene Ghent
Jeffrey Musumano and Michelle Ley at the Marriott
All of our conference volunteers!

PRESENTATIONS: If you weren't able to attend the conference, you will be able to access summaries in the next edition of our newsletter and the Power Point slides from all the presentations are already posted on our website (http://www.pscpartners.org/prevannual).

SAVE THE DATE: Start planning now so that you can join us at our seventh annual conference which will be held in Sacramento, California in conjunction with the University of California Davis. The conference will take place April 29-May 1, 2011 at the Sheraton Grand Hotel in Sacramento. Our conference co-chairs are Joanne Hatchett, Jennifer Soloway, and Tom Hill. It's already shaping up to be a terrific weekend, so please save the date!

Thank you to all the blue, green, and yellow dots who attended the conference. As one attendee just wrote to me: "The dots identified a category, but to me, everyone was a star!"

Together in the fight, whatever it takes!

Ricky Safer, President

Three PSC Partners Ambassador Awards Given at Conference

PSC Partners is run by volunteers. Three energetic people, who all provide critical assistance to the organization, were given the first Ambassador Awards from the organization at the conference in May.

Pat Bandy was cited for her two years editing the newsletter as well as developing the revised website. Arne Myrabo volunteers as the organization's new webmaster and is a moderator on the Yahoo! discussion group. The third awardee, Sandi Pearlman, an active PSCer, started and nurtured a Facebook page for the organization along with her many other roles as a volunteer extraordinaire.

Congratulations to them all!


Well-deserved recognition for Arne!

Conference presentations are ready to view . . .

Slides from the 2010 conference medical and technical presentations are now uploaded to the website!

Click here: http://www.pscpartners.org/prevannual

Conference Photos Have Been Uploaded

Remember the fun, the laughter, the hugs, the breakout sessions, the delicious food, the presentations? Check out the photos at these sites:

http://tinyurl.com/2010PSCConferencebrunch

http://tinyurl.com/2010PSCFridayevening

http://tinyurl.com/PSC2010Saturdaymorning

http://tinyurl.com/2010PSCSaturdayeveningSunday

Thank You to Our 2010 Conference Sponsors:

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Theresa Shanks

In the next edition of *The Duct*:

We'll have summaries of medical sessions from the conference, which will include Saturday morning's presentations from physicians as well as selected afternoon breakout sessions. Available in Late Summer/ Early Fall.

Meantime, check our website for slides of the presentations. Click on the 2010 Conference link:
http://www.pscpartners.org/prevannual

Fact-O-Rama

2010 PSC Partners Conference Statistics

Total number of conference attendees in 2010:	208	(In 2009: 185)
Number from outside the United States:	29	(In 2009: 18)
First time attendees:	110	(In 2009: 116)
Attended pre-conference activities:	98	(In 2009: 90)
PSCers:	75	
Transplanted PSCers:	10	(In 2009: 10)
Number of caregivers:	117	(In 2009: 102)
Spouses:	31	(In 2009: 37)
Other caregivers:	17, and 7 were siblings (In 2009: 12)	
Parents total:	69	(In 2009: 53)
Parents of pediatric PSC patients:	9	(In 2009: 13)
Parents of adult PSC children:	60	(In 2009: 40)
20-30-Something group:	37, and of those 18 were male and 19 were female (In 2009: 30, and of those 13 were male and 17 were female)	

California, Here We Come!

University of California/Davis will be our partner for the 2011 conference, April 29-May 1 in Sacramento. Stay updated by checking the website: http://www.pscpartners.org/nextannual.

The Annual Conference Experience

We asked four participants at the conference to share their experiences.

I Refuse to Miss One of These Gatherings

By Tom Butler, PSC Partners Board Member. Tom wrote these thoughts on his blog following the conference.

I often judge the quality of an educational seminar or other conference by how long afterward I think about it. My dirty little secret is that very few Continuing Professional Education seminars have me lighting up my cell phone and waving it in the air at the end.

Kathy and I fought traffic up I-95 past New York and on into Connecticut for the annual PSC Partners Seeking a Cure Conference in Hartford. The decision to go despite my poor physical condition was still an easy one. I refuse to miss one of these gatherings, and this one had me so inspired that I've thought about it every day since.

It wasn't the presentations from medical professionals, or the breakout sessions, or the beautiful accommodations. They were all great, even if some of the doctors' presentations reminded me of continuing education classes.

Something else goes on with this group every year, something I have never observed in the dozens of other organizations that had the courage to take the risk of letting me in the door. And, it was much more than the joy that comes from renewing old friendships and seeing people whom we haven't seen since the last conference. It’s something that I can't easily describe.

Some wonderful spirit that comes from knowing that everyone else present, whether a patient or caregiver, is in the battle of their lives. Put aside the politics of health care reform, a phrase never uttered within earshot of me all weekend. Forget about the academic debates as to the true cause of PSC and which treatment appears to be the most promising.

Yes, we were all there to learn, but we got so much more than book knowledge. I think one of the prime goals of every PSC patient is to *just be normal*. Sure we try to hide things and are all experts at disguising the fatigue, itching, GI problems, or replying to the "You don't look sick" comments. We know we're not normal now, and deep down we know that even after transplant, we're not normal and never will be, at least not in the way that society defines the term. It's quite a lonely feeling, and it's no wonder so many of us are treated for depression.

But when we're together, everyone is fighting the same enemy, everyone has similar issues, and so with over 200 people in the room, we actually *are* normal, if for but a weekend. Frankly I was feeling pretty crummy every day of the conference. The fatigue was crushing, I had little appetite, and it was tough to get out of bed each morning. Kathy was convinced I was going to pass out at any moment, poor thing! And so many people who read my blog and who were in attendance already knew that I was struggling and offered to help me with whatever my heart desired.

I met so many wonderful people who were at their first conference, just recently diagnosed, fearful, and who came away knowing that there are others out there fighting, too. Hope is there, and being together as a group is, well, a real damn great time. To me, there is nothing better than the dozens of hugs and heartfelt expressions of care and friendship among everyone in attendance. I don't know how one could attend and not come away with faith restored and with new friends that will be there for life.

You see, the other reason people go to the PSC Partners conference is to restore hope. To see that people can have great lives while they're fighting this war. That people actually do get through transplants and go on to being energetic again, and in my case, more fit and better looking than ever before.

This was Kathy's first conference, and I'm so grateful that she finally had the opportunity to go with me. Even when we got lost around New York and I took it all in stride, she remarked at how calm and peaceful I was. That was because I knew that we were bound for an experience that would be great for both of us, and nothing would put a damper on what we were about to experience hand in hand, side by side. Yes, she'll go next year with me, and I'm already pricing flights to Sacramento for us.

Sure, all weekend I was still sick and going through the normal recovery that comes from those periodic, rare, mysterious flare-ups of something unknown. But who doesn't get sick sometimes? All it took was a greeting from my old buddy Tim from North Carolina, or seeing my best transplant friend, Dave, again, and the cares and symptoms were dismissed from the table.

This group had that special spirit when it was small, and it's amazing that it has an even stronger passion and energy now in a group of over 200 attendees. That's a congratulations to Ricky Safer, the founder of PSC Partners, and also to too many other names to mention here who share that vision of being together in the fight, whatever it takes.

I finally started feeling better yesterday. I've actually worked two full days in a row, and I'm rapidly becoming more of a helper and less of a burden again to my colleague, Jacqui. And I'm not asleep on the sofa ready for bed when Kathy gets home from work. The joy is back, aided in part by a group of people that will always hold a special place inside this old heart.

Impressions of a Newbie From Across The Pond

By Lynda Hayward, who lives in the UK.

In December I retired from my job as a teacher, a job which very much restricts when you can travel, so although I had seen the conferences on the Internet I had never been in a position to attend one. So my retirement, along with the fact that my nephew lives near Hartford was how my husband Denis and I came to join this year's conference.

When I came I hoped I would gain practical advice about ways in which I could improve my health and delay the progression of my symptoms. I also felt I needed to be around people who were like me. The isolation of being a PSCer has been hard for me to cope with; the mental side causes me far greater problems than the physical side. I also thought it would help Denis gain a better understanding of why, at times, I can be so difficult to live with.

So those were the expectations we came with and all I can say was that for me the weekend has been a life changing experience. How can a group of volunteers stage an event like this?

It's hard to believe how 200 strangers can come together and so quickly bond into such a warm friendly family. Family is the only way to describe it, I feel in those few short days I made closer and more intimate relationships with total strangers than with people who have known me for years.

I know that I might not see many of them again but the Internet will keep us in touch. For five years I have sat on my own, usually in the middle of the night and cried about my situation, but at the conference I soon made 'crying buddies'.

And I know that from now on I must choose to laugh but to be with someone who doesn't need to say anything but will just cry with you because they know exactly how you feel inside is great.

All the people we met were totally inspirational; seeing how people who are far worse off than me but are coping much more positively has been a real wake up call. The amazing thing about the conference was, that apart from a couple of people who did look really poorly, the rest of us looked just great and you couldn't actually tell who the sufferers were.

If you'd walked into that hotel and seen our conference you wouldn't have thought from the laughing, joking and good humor that we were a load of sick folks! Seeing how the young ones were enjoying each others company was really uplifting, and made me realize that that's what this conference is really all about, the opportunity to interact with others who share your suffering and anxieties.

I enjoyed everything, the Friday afternoon sessions that introduced us to a range of complementary and alternative therapies was interesting for me because if I'd been at home I'd have dismissed them as a waste of time, but I am definitely going to look for classes in my area.

The medical experts that had been assembled for us to listen to were amazing. I don't think I've ever been in the presence of so many people with such long lists of qualifications. That's not to say I understood all they had to say. In fact most of the time I hadn't got a clue what they were talking about.

However, it does seem that currently there is a lot of exciting research taking place around the world by a lot of people who are really enthusiastic about our condition. This can only lead to a greater understanding and awareness of PSC, and hopefully a cure.

I've learned a huge amount about the management of PSC but it wasn't the doctors or speakers who taught me the most. It was the PSCers who I talked with, who shared their experiences, good and bad, and made recommendations about what they had found helpful.

I can't thank all of the conference goers enough for their friendship and advice. The conference organizers must be just about the most amazing group of volunteers in the world. And finally Ricky is such a truly inspirational person.

Stay in touch. See you all in Sacramento.

The PSC Conference 2010: Words Just Can’t Describe

By Cameron M. Wohl, who calls Morris Plains NJ home.

There is no better name for this organization other than "Partners Seeking a Cure" because it is indeed, just that.

As I try to put into words what this conference meant to me personally it's hard because only someone who has attended one can really understand how this family of people can put aside any differences and can come together based on one thing, and one thing only. That thing is PSC.

Whether you are a care giver or patient of PSC you know it makes a huge impact on your life. This conference was the first time I was ever able to put all the other stresses of everyday life aside and just be at peace with people going through the exact same things as me. Whether I was hearing a specialist talk about new research and how it is being advanced, or I was just hanging out with other people my age with PSC I really felt at home.

For anyone reading this who isn't familiar with who I am I would like for you to know that I was diagnosed with PSC, UC, and later on Autoimmune Hepatitis at the age of 13. I am now 21, so I have been living with this illness for almost eight years.

Before having attended the conference I had never met one person in my life with PSC. It seemed to be a very rare and unfortunate thing I had to deal with on my own. After arriving in Connecticut I realized I was very wrong.

Dealing with something like PSC does not have to be a solo battle. I was stubborn for quite sometime, having been introduced to the organization some years ago.

I bickered at my mom telling her, "I don't need any organization or conference; it's not going to make me any better!" But I was so wrong.

Attending this conference made me realize there are people all over the world going through the very same struggles that I go through. As soon as I walked through the door I was welcomed with open arms and brought into this phenomenal family of people.

I think we can all agree that one of the most important things in life, no matter what it may be is support. By ourselves we can do great things, but with a little support one can do anything imaginable. Often times we hear about people getting through some of the toughest times of their lives thanks to a great support group.

Well if there was one group that could help you cope with PSC that I would recommend to someone it would most definitely be PSC Partners Seeking a Cure.

Everyone is different in this world, and as for me I am extremely lucky to have a close group of friends and family that provide me with support, especially when it comes to me living with PSC. Even though I have been blessed with such great people in my life, some of these people can only empathize for me because they imagine what I go through, but can't truly relate.

At the PSC conference this wasn't the case at all. To be able to discuss issues with people knowing exactly what I'm talking about because they have gone through it at some point is one of the most fulfilling feelings. These conference-goers feel true sympathy because they can relate to anything and everything you choose to talk about.

Like I said before, to put the feelings I had about this conference into words is really hard for me so instead I will try and explain how I felt when I had left.

It was as if I had the weight of the world lifted off my shoulders. I left that conference with a feeling as if I could now approach anything in life with a new mind set. The impact that a couple hundred people can have on you in a matter of three days is something that can't be put into words. Its magical how they made me feel. I was optimistic, touched, relieved, and excited when I got in the car to return back to my everyday life. The conference was the most inspirational event I have ever gone to, and the things I took away from it can never be lost. I think a couple times a week about how awesome next year's conference is going to be, and I look forward to it so much!

The conference reminded me that I am just like everyone else in the world. It reminded me that I can do whatever I want to do, and to live every day like it is my last, even when I know I am in good hands with all of the advances being made thanks to countless research being done.

For anyone considering attending a conference, but isn't sure if it is for them for any reason I strongly urge them to speak with someone who has experienced one first hand, and I am sure that if they do attend one they will strongly agree that there is no better feeling than to be able to put all the troubles of their lives behind them for a couple days and just relate.

The conference is fun! Never did I expect to have such a great time and meet people that will forever be my friends until the day I leave this world. To say that in three days I met people that I will call my friends for the rest of my life is truly something special. For anyone who doesn't know how they feel about attending a conference I urge them to contact me first hand at wohl.cameron@gmail.com.

You'll be happy you did!

A note from Ricky Safer: Since our inception, we have been an all-volunteer organization, but early this year, I realized that I needed some help in our office because we have expanded our programs and membership enormously. I was lucky to have found the perfect Development Assistant in Meegan Carey, who helps me with every aspect of all our programs. After attending our 2010 conference and getting to know many of the participants, Meegan wanted to share her impressions with everyone.

What I Experienced at the Conference Was A Family

By Meegan Carey, PSC Partners Development Assistant

When I first heard about PSC Partners Seeking a Cure I did not comprehend how integral the word partner is to both the mission and character of this unique group. In January 2010, I was hired by Don and Ricky Safer to work in the office and assist Ricky with the myriad of projects she manages.

Even though I have only been with the organization a few months, I continue to be impressed with Ricky's ability to effectively multi-task within the organization. She nurtures the PSC Partners Seeking a Cure community just as she does her own family. Her sincere compassion for others and the desire to find a cure for PSC permeate every aspect of this unique organization.

Working in the office with Ricky gave me a glimpse of what the PSC Partners community was about but it was not until I attended the annual conference in May 2010 that I had the chance to experience the true partnership for myself.

I will confess that I was very anxious about attending my first PSC conference. My perspective is different than most who attend because before coming to the conference, Ricky was my only direct connection to PSC. I was not sure what to expect given the number of PSCers attending and having been a caregiver myself for three family members with serious illnesses. I was concerned that the weekend would consist of depressing discussions and events.

Instead, what I experienced was a "family" of amazing and inspirational people. I was impressed by everyone I met from the attendees to the presenters. The commitment to finding a cure was evident in every person I met at the conference.

Not a moment is taken for granted in this family because life is precious. Each and every minute and relationship is meaningful. These qualities permeated the conference and they were contagious. I believe this is the most powerful and healing element of this unique PSC Partnership.

I arrived at the conference as a hesitant individual and I left a new member of the family. I came away with a renewed spirit and I know I was not the only one to do so.

Also, I carry with me a sense of urgency shared by the group. Seek the best right now, whether it is taking time to educate yourself, to nurture your body or experience life more intensely.

The partnership of a passion for life and the desire to pay careful attention to everyone around you are lessons I quickly assimilated from the people I met. Seek the best in life, always. I know these gifts should be a given but somewhere along the line they had became dull to me. My new family has rekindled my spirit and I am thankful for all of the PSC partners. I promise to keep up my part and do my best for us.

We are partners and I will never take this gift for granted again.

We thank our official conference photographer, Karen Pearlman, of K Pearlman Photography, for covering the conference with cheer and with great talent. She is generously donating receipts received for photos you purchase to PSC Partners. Her website is: http://kpearlmanphotography.com.

A Gift from an Angel

by Alison Cubbellotti

I am a nursing student at Sacred Heart University in Connecticut. At first glance, I appear to be a typical college student. But, dig deeper and you will find that I am anything but typical. I am told that I am a remarkable 20 year old who has met and triumphed over very grave circumstances.

This past fall, after bravely battling primary sclerosing cholangitis (PSC) and Crohn's disease for over 10 years, I was dying and needed a liver transplant.

People learned of my plight, through a desperate email search by my parents. A remarkable young man, who at first chose to stay anonymous to my family, would be the last of over a dozen individuals to be tested as my living liver donor. Later, the young man, who later became known as John, said he could not "look away."

Within weeks, John was being tested as a potential living donor and on October 19th, gave a portion of his liver to me and saved my life. My family, who refer to John as our "angel," looks to him and his supportive family as true testaments to "all that is good in the world."

Their compassion and John's unselfish giving are commendable, to say the least. Today, only a few short months after the transplant, both our families have become extremely close. We all feel truly blessed to have been drawn together by this amazing miracle.

Friends of my family, the Lachiomas, who own the Performing Arts Center of Connecticut, in Trumbull, CT, offered their services and talents to put on a benefit concert to raise money. I decided to have the raised funds go to families at Yale-New Haven Children's Hospital who are facing the day-to-day challenges of liver disease and transplantation, and their donor families.

Costs such as meals, gas, parking, hotel stays, and more can become quite overwhelming; we hope to lighten these financial burdens, allowing families to focus on what truly matters. I also hoped to educate the community about organ donation, liver disease, particularly primary sclerosing cholangitis and the need for research.

During my speech at the benefit show, I said, "We are here tonight to celebrate the amazing gift that my donor, John, has so generously given me: the gift of LIFE. It continues to amaze me that this 21-year-old Sacred Heart University student, who I am now honored to call my friend, would undergo such a life-altering feat to save the life of someone that he didn't even know. Such an act takes an incredible individual with an enormous heart. I am forever thankful to John, he is the most amazing person I have ever met; without him I would not be here today; he is truly my angel."

The night was a huge success, and the concert was able to raise over $13,000 for the cause.

Pre-Conference Friday Afternoon Break-Out Sessions

Healthy Living Choices:

An Interactive Introduction to Complementary Therapies

Sessions offered: Tai Chi, Therapeutic Massage, Laughter Yoga, Mindfulness Stress Reduction, Yoga, and Starting an Exercise Program

Ather Ali, MD, MPH, introduced the breakout sessions, *Healthy Living Choices* that opened our very busy conference weekend.

Dr. Ali is Assistant Director of Integrative Medicine at the Yale-Griffin Prevention Research Center where he supervises Complementary and Alternative Medicine research, and Associate Research Scientist in the Department of Pediatrics Yale School of Medicine.

He stressed the importance of safety in using alternative medicine and explained how the loose definitions of unconventional medicine allow ancient medical therapies to be paired with often untested and potentially unsafe fad therapies.

But because 40 percent of the US population uses one or more types of alternative medicine, educating oneself on the safety of these alternative means is of utmost importance.

He said that integrative medicine centers (which combine treatments from conventional and alternative medicine) such as his center, monitor risks and safety and are much more conservative with their chronic disease patients.

He advised the audience to assess alternative treatments by checking for consistency, safety, level of training on the part of advisors, therapy hierarchy (patients should ask if another therapy works better), and by evaluating whether the offered treatment clashes with conventional medicine.

He enumerated the red flags to watch for when evaluating alternative therapy: Conspiracy theories ("Pharmaceutical companies are conspiring against the patient," or "Doctors do not know," for example), "secret knowledge" ("I have the secret for your recovery"), exclusivity ("I alone have this information"), "bad news" ("The environment is killing you"), and sales pitches. Watch out for vested interests, he said. He warned us to be wary of treatments that position alternatives against conventional care.

Ricky Safer and Dr. Ather Ali introduced the Healthy Living sessions.

(*Summarized by Rachel Gomel*)

Laughter Yoga: Mark Sherry

Mark Sherry, Certified Laughter Yoga Leader, and Educational Psychologist who has worked in the field of education for 25 years, led an amused and intrigued group of PSCers and caregivers into a laughter session. Yes, we all laughed ourselves silly as Mark had us, with our tongues way out, turn into lions clawing and roaring away.

During the group session Mr. Sherry led laughing exercises, such as The Lion Laugh, The Vowel Movement, The Credit Card Bill, and Ants in My Pants. At the breakout session participants laughed with The Lawn Mower, The Roller Coaster, High Pitch, Low Pitch, Follow Me, and many others.

He explained that in fourteenth-century France, surgeons used laughter as part of their remedy and that today, some cancer centers use this funny treatment as therapy. In his 1976 book, *Anatomy of Illness*, Norman Cousins, a journalist, described how he healed himself with positive thoughts and a positive attitude.

Today we know that laughter decreases the stress hormone cortisol (a corticosteroid hormone), raises some immunoglobulin and T-cell levels, increases energy by boosting oxygen intake, and raises endorphins (the feel-good hormones). Also with laughter, all muscles and organs are massaged, he said. Currently, there are over 8,000 Laughter Clubs in the world.

He told us that laughter has nothing to do with telling jokes. It does not matter what makes us laugh. As we have all experienced at one time or another, simple eye contact will make belly laughter contagious.

Laughing so much also gave us a great workout. It is supposed to burn 400 calories an hour. Burning 400 calories while having so much fun can't be beat.

We witnessed the laughter phenomenon throughout the conference. PSCers did not have to be prodded to turn the PSC acronym into everything *but* Primary Sclerosing Cholangitis and roll with laughter with the slightest excuse!

(*Summarized by Yvette Matthews and Rachel Gomel*)

Starting an Exercise Program: Julianne Vasichek

Julianne Vasichek, a PSCer and professional women's hockey, soccer and softball Strength and Conditioning Coach, who has taken each of her teams to victory at the University of Minnesota Duluth, and who will undoubtedly do the same in her new position as Strength and Conditioning Coach for the women's hockey team at the University of Vermont, led this session.

She is a two-time women's hockey All-American and two-time Division 1 U.S. National, a gold medalist at the 4 Nations Cup, in short, a model of excellence for our PSCers. Each of her words of advice was gold as she led PSCers and caregivers to a mini-program of warm-up and cool-down exercises that could be done right at home. She showed us how these exercises, executed in place, would elevate our heart rate and prepare us for any kind of workout. And in no time, we were ready to run/bike/dance through the halls of the Marriott.

Other than showing us that an efficient warm-up requires little space and equipment, the biggest take-away was that as PSCers and caregivers, we should be listening carefully to our body and not try to stick to a strict training regimen. She reminded us to keep our goals flexible and to enjoy whatever level of exercise we have accomplished on a given day. Addressing all PSCers and caregivers, she remarked, “You trump my elite athletes.”

To share her expertise and advice with all of us, and as a fundraiser for PSC Partners, she will be creating a DVD including programs for all levels of fitness for PSCers.

For those who missed this session or could not be at Hartford, you will be able to purchase her DVD on our PSC Partners site, at: www.pscpartners.org. Watch for details.

Her sensitivity to the needs of PSCers and caregivers, and her professionalism make it easy for me to highly recommend her upcoming DVD.

(*Summarized by Rachel Gomel*)

Tai Chi: David Chandler

David Chandler is no less than a USA Tai Chi Grandmaster and a member of the Martial Arts Hall of Fame. He introduced Tai Chi to a large group that filled a room. David is a Tai-Chi teacher at Yale University, the Actors and Directors Group of the Netherlands, and is currently teaching in various theater schools and in his own centers around Hartford. With his imposing martial arts physique, he had us join him in a few basic Tai Chi moves while he explained the physiological benefits of Tai Chi in promoting relaxation, balance, harmony, and exercise for our muscles and organs.

He talked about the extraordinary health applications of soft movement martial arts like Tai Chi and focused on the activation of the brain that such an art promotes. He said that Tai Chi leads to an increase in coordination and energy in the body.

Though not curative, the practice of Tai Chi, he said, increases the fighter T-cell population by 13 percent, and raises bone density. He said that Tai Chi is prescribed for autoimmune diseases, for Parkinson’s, and amplifies the body’s ability to take pain. At Mayo Clinic, Tai Chi is one of the top ten recommended healthy lifestyle activities.

He showed us the principle behind mind-over-matter exercises by applying light and fast hand rubbing to produce an effect of increasing the size of one hand over the other.

He showed us a simple Tai Chi technique of massaging our weakest body location—in our case, the liver. Zen music accompanied his flowing moves and explanations. To describe the practice of Tai Chi, he used the word “playing” Tai Chi, alluding to the beauty of Tai Chi that must be played as if it were a musical instrument and not as a series of regimented moves.

The interest he created was visible as people surrounded him with an array of questions and words of appreciation. You can email him for information at david.1.chandler@sbcglobal.net and visit his site at www.eaglesquesttaichi.com.

(*Summarized by Rachel Gomel*)

Mindfulness-Based Stress Reduction: Led by Carol Tyler, MA, RD

Mindfulness Based Stress Reduction focuses on the present, clearing out the past and thinking about the future in favor of the here and now. It is being in tune with our own bodies in the present moment without judging anything we're feeling or experiencing, merely recognizing it as it occurs.

To demonstrate or execute a state of mindfulness stress reduction, Ms. Tyler encourages participants to sit in a chair, feet on the floor, hands comfortably in lap or on your abdomen. Closing one's eyes is encouraged as it can help to block out unneeded and un-useful stimuli.

We began by noticing our breath as it entered and left our bodies. If we noticed our minds beginning to wander, we were encouraged to refocus on our breathing to bring us back to the present. Then, we went bit by bit, noticing our bodies in the moment.

We began with our feet, ankles, calves, knees, on up. Ms. Tyler encouraged us to notice aches, pains, muscle movement, the sensation of our clothing against our skin, any and all details. We were not to be distracted, merely to notice and acknowledge.

The purposes of Mindfulness Based Stress Reduction include cultivation of a sense of curiosity, openness to the world around us, and an invitation to "wake up to our lives."

A resource shared included:

www.umassmed.edu/cfm/mbsr - a site to help find Mindfulness Based Stress Reduction Instructors in your area.

(Summarized by Sandi Pearlman)

Therapeutic Massage: The Power of Touch

Susan Forster, MPA, LMT

Susan Forster reviewed the benefits of Therapeutic Massage and how powerful touch can be for all of us.

Key points she discussed included:

- Touch is a tactile language which is the first of all languages, beginning in-utero
- Touch is the humanizing sense, for it is the sense that from the very beginning puts us into contact with others
- Skin is the largest organ of the body
- The skin is more important for survival than any of the other sensory receptors
- Massage decreases the effects of anxiety, depression, tension and itching
- Massage lowers the heart rate and blood pressure, increases blood circulation and lymph flow, and relaxes muscles
- Massage helps us become more aware of our bodies and the sources of pain
- Massage has an impact by virtue of human touch

Carol and Maria Eberle, an RN from St. Francis Hospital in Hartford, then had each of us partner with another person. They led us through a hand massage which each of us gave to our partner.

We generously applied lotion to our partner's hands, then used both gentle and deep massage to each finger and joint, plus the entire palm and back of the hand. Carol encouraged massaging each and every area of the hand and to NOT feel shy with using pressure and deep massage. There was no "right" or "wrong" method to our hand massage.

Resources given included:

The Center for Integrative Medicine
For information call:
860-714-4450
www.stfranciscare.org

Finding a massage therapist who can best meet your needs, can be found through

American Massage Therapy Association at: www.amtamassage.org.
A book by Ashley Montagu, *Touching: the human significance of the skin*, 2nd ed. New York: Harper & Row, 1978.

Carol closed by reading the following:

May today there be peace within your soul. May you trust that you are exactly where you are meant to be. May you not forget the infinite possibilities that are born of faith in yourself and others. May you use the gifts that you have received, and pass on the love that has been given to you. May you be content with yourself just the way you are. Let this knowledge settle into your bones, and allow your soul and allow the freedom to sing, dance, praise, and love. It is there for each and every one of us.

(Summarized by Joanne Hatchett)

Harmony Yoga
Carol Shwidock MA, OTR, RYT

Yoga with Carol Shwidock offered a 30-minute overview of the benefits of yoga for everyone. Carol's background includes nearly 30 years of experience as an occupational therapist. She teaches yoga to students of varied backgrounds. Her husband, Brad, has had PSC for 20 years. Carol shared the experience of seeing the healing effects of yoga both pre- and post-liver transplant. During our session she shared some yoga techniques to facilitate the relaxation response, which is beneficial in autoimmune disease.

Carol worked with us on our breathing technique (see attached "Take a Breathing Break" handout). Throughout the session, she focused on stretching both up and down the body and stretching with gentle twisting motions. She led participants through some balancing exercises as a group. During one segment we were standing in a circle, hands on each others shoulders, standing tall as trees, building on each others' strength. Then we stood as individuals, balancing without the assistance of others.

The session ended with a relaxation exercise using guided imagery, which left us relaxed yet with renewed energy. Carol ended this session beautifully thanking us for participating with her and allowing her this opportunity to be with us.

The stretching, breathing and mindful relaxation left us feeling great. Carol's session was a motivating experience to find a yoga instructor near you and begin participation.

(*Summarized by Joanne Hatchett*)

Join Team PSC!

We PSCers have many talents and skills--but mostly we have big hearts. If you have a desire to contribute to the organization as a volunteer, let us know.

Check our website at: http://www.pscpartners.org/opportunities for ideas on where your talents and skills might fit in. Contact Dike Ajiri, our volunteer coordinator at: volunteers@pscpartners.org .

What You Said About the Conference . . .

Thank you…
For showing me I'm not alone in this fight,
For making me feel like I truly belong,
For showing me there is always hope,
But most of all,
Thank you for being the amazing people you are.

*

Coming to this conference is like coming into the sunshine on a very cloudy day.

*

The conference provides the opportunity to share experiences, open up on an emotional level with others who truly understand the issues/challenges we face, and to laugh and cry at the inspiring and stoic persons we meet.

When you leave the conference, you have a feeling of sadness like you do when you go off to college for a year. You leave physically tired at all the information and emotions expended, upbeat towards the future, inspired by the experiences and people you meet, and wish you could have just one more day!

*

I love that it's a full schedule, but with time here and there to just socialize…That is healing in itself.

*

This time I felt something new had happened at the conference. I felt that the physicians were not only a super harmonious team who obviously enjoyed working and building together, but also that they embraced the audience as their equal, honestly, kindly and at moments, even bravely. In our conferences, I feel strength from the attendees and am thankful for the information I gain from the physicians.

This time, I felt equally empowered by our PSC family as I did by the medical team whose readiness to embrace us was most heartwarming. It is rare to see physicians treating their patients (and caregivers) as their equals. It was liberating to feel the current that was being transferred back and forth between the audience and the physicians.

*

No brainer. Best weekend of my year, every year!

*

Overall, you are all incredibly amazing!!! I was completely in awe of your organization, of this big undertaking. Your ability to be so professional and yet "down to earth" at the same time was exceptional. You truly have changed my life and I will be forever grateful to you all!

*

The annual conference was outstanding. It was the first one I attended and will absolutely be in Sacramento next year. What we all learn from each other, in person, is priceless. Thanks for a very memorable and valuable experience.

Share Your PSC Story to Help Find the Path of Resilience!

If you are a patient with cholestatic liver disease (PSC/PBC) or an inflammatory bowel disease, take this opportunity to be heard regarding the impact of your illness on the story of your life, how you think and feel, and your ability to be resilient! You may also earn a $50 gift certificate as a thank you.

Take the survey online now (http://burkelab.siuc.edu/pscibd.html)!

The study is part of an important new research project being conducted by the Burke Narrative Studies Lab at Southern Illinois University at Carbondale.

They are examining the definition and nature of resilience, its relationship to your physical and psychological health, and how you make sense of your illness in the broader story of your life as one element of resilience. Our goal is to identify what you and your healthcare providers can do to improve the quality of your life.

Your participation may help find ways for people with chronic illness learn to be resilient. For individuals with PSC or PBC, you will also have the opportunity to take part in an interview about the story of your life and the role your illness plays in that story. For every 100 completed surveys, we will have a drawing for a $50 gift certificate. All you need to do is complete the survey.

If you want to take the survey but don't feel comfortable completing the survey online, just give us a call at (618) 453-3407 and we'll set it up for you. Thank you!

This project has been reviewed and approved by the SIUC Human Subjects Committee. Questions concerning your rights as a participant in this research may be addressed to the Committee Chairperson, Office of Research Development and Administration, SIUC, Carbondale, IL 62901-4709. Phone (618) 453-4533. Email: siuhsc@siu.edu.

Philip Burke, Ph.D. of SIU, is a PSCer himself.

Check out "Ask a Pharmacist" On Our Website

Do you have a question about your meds? About supplements? About drug interactions with food or other drugs? Side effects?

Our web site's home page offers a way to get those questions answered through our Ask a Pharmacist feature. You can ask your question, in confidence, and a clinical pharmacist will get back to you with an answer. It's easy to do. Check it out and talk over your issues with your doctor, too.

Attention PSC Scientific/Medical Researchers:

Deadline for the next round of research grant applications is August 1. Grants are for two years at $20,000 each year.

Our website has application guidance at this page: http://www.pscpartners.org/apply

The Conference: Magic, Family and Love

by Sandi Pearlman

There's a song by The Lovin' Spoonful that starts, "Do you believe in Magic [....] How the music can free her, wherever it starts . . ." And regardless of your mood, you sort of find yourself humming along and a bit peppier when those opening chords strike no matter your age or disposition or even musical leanings. I mean, true, when it's stuck in your head and won't leave it's not quite so magical, but I digress.

In any case, I dare to say that The Lovin' Spoonful had never heard of PSC and I'm utterly positive that they've never attended a PSC Partners Conference, and, yet, their upbeat, infectious, grin-inducing song perfectly encapsulates the magnetic kind of magic that emerges as soon as you cross the threshold into conference territory and take in your very first PSCer.

It doesn't matter if you've been to every conference or never before; if you're feeling old and crusty and cranky, like you've traveled too far to a destination you're not sure you wanted to reach. You can be open to it or closed off, but it'll still get you. It's actually more than magic. It's love, the kind we all dream about, not the kind with heaving bosoms, ripping bodices and ridiculous code words for all types of anatomy, but the real, lasting, unadulterated somebody knows me at my core and really, truly gets me kind of love.

Those who have never been to a conference before may doubt me. I don't blame you. I'd doubt me too. In fact, every year as the next conference grows closer, I do doubt me.

I wonder if my glasses have gotten a bit rosy and I'm remembering the conference like that of a long lost love: perfect, without flaw and ultimately impossible to have been real, let alone recapture.

Then that magic hits. It's not about the location or hotel or even that moment of arrival when you get that high from knowing a bed (or a bathroom or a Starbucks or whatever) is near. It's a physical thing, a shifting of organisms in our souls so deftly that our outlook is forever changed. It's that feeling that you're no longer alone.

You're not an outsider. For a few sweet, all-too-short days, you're—we're—not the other. We don't have to explain anything because to be too tired to carry on a conversation or so itchy that you can't stop scratching is the status quo. There's no explanation that you're fatigued and what that means. We know. We get it.

Here's the thing: Conferences are kind of like Vegas and you know the whole "what happens in" motto by now, I'm sure—and if not, you need to watch a bit more TV.

In any case, I can tell you this: sitting in a room with your fellow PSCers is freeing in a way even the best illicit drugs can't compete with (or so I'd assume). The trip we take with and from each other has monumental highs and crushing lows but it never waivers in its connection.

Deepest fears and secret goals are voiced without alarm about judgments. Hearts break and heal a bit better than before many times over. We stick to the horror movie rules that there's strength in numbers and take comfort in the fact that we're no longer wandering down those dark, creaky basement steps alone.

You can read throughout the rest of this newsletter about all the activities, speakers, presentations and everything else that our conferences are known for. This isn't small stuff and I don't mean to make it sound that way.
It's amazing and informative and every single year I attend the conference I come away with so much more knowledge than I possessed upon arrival and I'm a stronger PSCer and a more informed patient because of it. But as intoxicating as all of that is, it's not the true magic.

Here's what is: Suddenly, we're not PSCers with whispered tones. We're PSCers loud and proud and, quite frankly, the envy of many of the others in the room. We're the cool kids. We're the trendsetters and we're the norm. We relish our time together. We don't need words or labels or descriptions to understand. We just know.

Having PSC gives us a shorthand that defies the need for vocabulary. We're greedy for our time together. When the days' events end, we're still just beginning. It's when we're most free to put on our baggiest sweats and pull on our baseball caps and break out the ponytail holders and slippers. It's when we share the stories of our lives, the real details: we talk husbands, wives, lovers, friends, kiddos, pets, movies and all the rest; but we also talk pain, emotional and physical, and tell our medical stories, what led to diagnosis or a new medicine we've tried that works so well we actually get why we take it. Sometimes we cry, heaving sobs that require arms around the shoulders and a group hug.

Mostly though, we laugh. We talk and we listen. We gather in groups big and small and float in and out of conversations. We, who usually find ourselves ready for bed at 7 p.m. stay up until 1:00 or 2:00 in the morning just relishing the experiences of those who, like us, know what it's like to live our lives. By the end of the weekend, we're stronger. There's just no other way to put it.

We're stronger physically and emotionally. Our bonds are renewed and our faith in ourselves restored.

Some of us talk. We get it all out where we know we're safe and loved and our words are strong and taken in and kept close to everyone's hearts and confidences. But it's not even about being able to say the words yourself.

There are those of us who are still afraid to speak, too newly diagnosed to voice our deepest fears and, yet, when somebody else does it's the most heartbreaking, beautiful, freeing kind of pain you can imagine. Suddenly, something that preys on you, makes monsters out of the shadows in your mind is vanquished. No matter the fear, chances are another PSCer has it, has had it, or understands it.

Here, in the confines of the conference, of our newfound family, secrets are safe and fears hold no power. Alone, we're afraid, but together we're strong.

Together, we can make magic. We can raise funds and find cures and collapse and cry and laugh and hug and empower ourselves to make a difference, because now we know we're not only fighting for ourselves but for our family, our other selves from all over the globe who come together at least once a year to take a stand against the stigma of being the sick one, to forge friendships that stand the test of time and to realize that, like every fairy tale story I've ever heard, true love lets you slay the dragons, conquer the biggest of obstacles, and gives you wings to soar.

Our Silent Auction Winner Tells Us About Her Special Week

By Barbara Stout

Having PSC sometimes means that you don't have any control over your plans. Back in February, I had planned a winter getaway to the Florida Keys but my first official cholangitis episode decided that it was changing my plans for me and forced me to cancel my trip.

So when the PSC Partners Silent Auction was announced, I was interested since I had some airline credit to use and love the west coast. I was quite surprised that there weren't any other bidders on the auction since the starting bid plus the location were very attractive. However, it was nice to win the bid!

The Marriott Newport Coast was a beautiful property that was centrally located between San Diego and Los Angeles, making day trips to either of these areas quite easy. If just wanting to relax, it was no problem with a great salt-water swimming pool and hot tub right outside our villa.

The villa was very spacious and comfortable with awesome views to the ocean and overlooking the pool. The resort provided shuttle service to Crystal Cove beach if surf and sand is your thing.

The week away did provide me the opportunity to relax and unwind. Of course, prior to leaving for the trip I had the PSC excitement of trying to get another MRCP scheduled in order to determine if I have another blockage since some recent lab tests established my new abnormal highs. The test was not able to be completed prior to the trip and I spent one of my first days playing phone tag with the hospital due to a scheduling error on their end.

One thing is for sure, no matter how much you want to run and hide and just take a break from it all, sometimes you just cannot do it. PSC is always there, reminding you of its existence.

Dealing with it all while staying Marriott Newport Coast made it a bit easier. Many thanks to the generous donor for making their villa available for the silent auction. It was definitely worth it.

Save the Day Weekend: October 1-3, 2010

We're aiming for a BIG weekend this fall when we simultaneously hold local fundraisers for PSC Partners' research funding. Get organized and get moving! Every penny goes to research toward a cure!

Hold a yard sale, or a bake sale!
Collect change at the end of each day for a month or two.
Hold a walkathon or a golf tournament.
Donate your Bingo winnings.

Contact Joanne Hatchett at sjhatch@sbcglobal.net or Sandi Pearlman at kizzersmom@yahoo.com. They can provide support and get you started!

Shop PSC Partners and Help Fund Research for a Cure!

Every dollar you spend goes directly to PSC research and programs.

Check ordering instructions for each item. We have:

✓ PSC Note Cards

✓ PSC Holiday Cards

✓ PictureThis Custom photo or logo mugs, mouse pads, key chains, puzzles and coasters

✓ Exercise DVD for PSC patients and caregivers (Availability t be announced)

✓ Photo DVD from the 2010 Annual Conference (Availability to be announced)

Enter the PSC Partners Shop here: http://www.pscpartners.org/shop

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

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

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

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The Duct Newsletter

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