

# The Duct

Bringing you news on PSC



research, education, and Support

PSC Partners Seeking a Cure Foundation  
Part 1, Summer 2009

## SPECIAL ISSUE

## EVENTS AND NEWS FROM THE 2009 ANNUAL CONFERENCE

### Spinning a PSC Cocoon: A Message from Ricky Safer, President of PSC Partners

It's been several weeks since our fifth annual PSC conference, and bit by bit, I'm still trying to absorb all the information and emotions from that amazing weekend. After a year of planning the conference with Becky Long, I'm still basking in the positive vibes and energy. Becky and I were able to put together a phenomenal group of physicians



Ricky Safer, Lee Bria, and David Rhodes received plaques for five years of devotion and commitment to PSC Partners.

### A Note from the Editor

There's so much to report from the annual conference that we broke this Summer issue into two parts. We've produced a special issue on the medical/educational presentations (Part 2), thanks to Rachel and our good friend Ivor Sweigler, of PSC-Support UK, who took excellent notes for all of us to learn from the valuable information given by the Northwestern University team.

This issue (Part 1) focuses on news from PSC Partners, photos of events, recollections of the weekend, and commentary on the conference. There's a lot going on in the world of PSC. We're together in the fight, whatever it takes!  
Pat Bandy

to educate us, but our attendees set the tone the minute they arrived.

It's hard to describe the incredible spirit and power of our group when we gather together. I have never been part of a group where everyone is so knowledgeable, compassionate, generous, and gracious. It felt like living in a warm cocoon for three days. Imagine spending a weekend surrounded by others who, without questioning, understand the ups and downs of your unpredictable daily life: your concerns about the future, your constant fatigue, your abominable pruritus, your desire to lead a "normal" life.

It's a place where you can share your innermost thoughts and fears with anyone around you, knowing that you will be understood and accepted. Tears and laughter are interspersed freely in every conversation, and no one is a stranger. To quote one of our members, Tim Wholey: "The power of this group is not just in fundraising, research, health information or computer support.

The power of this group is in watching each other's back whether with prayer or just understanding. I always equate our group to a large family."



Dr. John Martin, of Northwestern/Feinberg, and Becky Long, Conference Co-Chair, listen to a presentation.

Within this cocoon, amazingly strong bonds of friendship form during the weekend, and they continue throughout the year.

Becky and I were both humbled and inspired by the huge turnout at the conference this year, our largest ever! We are a tenacious group who can't be slowed down by the economic crisis, the swine flu epidemic, or anything else that comes our way.

Our 185 attendees were a diverse group, coming from 29 states, Canada (sixteen participants), the UK, Sweden, and Israel. It was wonderful seeing old PSC friends again and also having the opportunity to welcome so many new PSCers and caregivers to our group.

Becky, I can't begin to thank you for all your work and personal friendship while working with me as conference co-chair. I appreciated your intelligence, dedication, creativity, advice, generosity, and kindness. You are a special person, and we're lucky to have you on board!!

I'd like to thank our top conference sponsors who made this weekend possible:

Gold Level: Illinois Tool Works and Mobile Doctors (Dike and Rilee Ajiri)  
Silver Level: Roche, Axcan Pharma and Ken and Patty Shepherd  
Bronze Level: First Church in Wenham, MA, and Theresa Shanks  
Copper Level: Steve and Joanne Grieme

Thank you also to our long list of other local conference sponsors, weekend volunteers and mentors who helped us in various ways. We are indebted to all of you.

For those of you who weren't able to attend the conference, here's a summary of the weekend agenda, which was packed full and which also offered the flavor of Chicago.

On Friday morning, we started our pre-conference activities with a complimentary brunch in a spectacular venue with an unbelievable view of Lake Michigan and downtown Chicago.

Thank you to the Grover and Wenthe families who were gracious enough to host the brunch in their condo. This was a wonderful setting for everyone to start getting acquainted informally before the conference started.

After the brunch, attendees had a choice of going to the Cubs game or taking an architectural boat tour of Chicago. Friday evening, we had our welcome reception with Chicago style pizza. Mark Stivers was kind enough to provide background piano music for us.

All day Saturday we listened to a variety of fantastic presentations from the physicians at Northwestern Feinberg School of Medicine (Dr. Rich Green, Dr. Michael Abecassis, Dr. John Martin, Dr. Terry Barrett, Dr. Laurie Keefer), Dr. Jenny Heathcote

from the University of Toronto, Canada, and Dr. Konstantinos Lazaridis from the Mayo Clinic in Rochester.

After a presentation by Jennifer Jaff, a lawyer who specializes in advocacy for patients with chronic diseases, we had breakout sessions led by Dr. Jeff Brown, Dr. Alfred Baker, Ms. Janet Aminoff, Dr. Jennifer Trainor, Dr. Aubrey Goldstein, and Ms. Beth Doerfler.

All the question and answer sessions were lively and very informative. I'd especially like to thank Dr. Green and Dr. Martin, who worked with Becky and me to put together this brilliant slate of presenters and topics. We all learned a lot!

If you would like to view the PowerPoint presentations from

Here's a group shot of some of the folks who took the pre-conference boat tour.



Saturday's sessions and get updated about the newest information on PSC, please go to the 2009 conference website at [www.pscpartners.org/PSCConf09/index.htm](http://www.pscpartners.org/PSCConf09/index.htm).

By Saturday evening, even the caregivers were feeling fatigued, so we had planned a lively banquet for everyone. Thanks to the generosity of Ken, Mary Ann, Becky and Allison Long, we were treated to an Improv performance by four Second City players. Laughter truly is the best medicine, and we all enjoyed ourselves with some great belly laughs. A huge thank you as well to the Roz and David Parry family for securing Illinois Tool Works as our banquet sponsor.

After a delicious meal, there were some exciting

announcements. David Rhodes, head of our Medical Advisory Committee, announced the winners of our first research grants: Dr. Konstantinos Lazaridis, of the Mayo Clinic in Rochester, Dr. Pietro Invernizzi of the University of California Davis, and Dr. Cyriel Y. Ponsioe of the Academic Medical Center in Amsterdam, The Netherlands. To learn more about these promising PSC research projects, please read the article in Part 2. This is a huge step for PSC Partners Seeking a Cure!

Next, Lee Bria, our Fundraising Chairperson, announced the results of our Itching for a Cure/Road to Chicago fundraiser. We are still receiving more donations, but we will probably end up at a total of about \$100,000!!! When we add in the \$45,000 in matching donations from our anonymous donor, our total will be approximately \$145,000, all to be put towards PSC research.

Thank you to everyone who donated to this fundraiser, and a very special thank you to our anonymous donor!!! As we always say: Together in the fight, whatever it takes!!!

After that, Pat Bandy and I gave a preview of the bold look of our new expanded and personalized

Those wacky Second City Players kept us in stitches.



Board members at the conference, from left to right: Dike Ajiri, Lee Bria, Becky Long, Joanne Grieme, Ricky Safer, David Rhodes, Deb Wenthe, and Scott Malat.

website that we hope to launch by the end of the summer.

Our final announcement was the long-awaited information about the location of our 2010 conference. Reggie and Jeff Belmont, my 2010 conference co-chairs, introduced everyone to Hartford, Connecticut and the physicians at Yale University. I am happy that we'll be holding our first conference in the New England area, which is especially beautiful in the springtime.

On Sunday morning, we broke into our groups (Male PSCers, Female PSCers, PSCers in their 20s/30s, Spouses of PSCers, Post-transplant PSCers, Parents of adult PSCers and Parents of pediatric PSCers) to discuss issues that were pertinent to each of us. From the conference evaluations we've received, it seems like these sessions were especially helpful to everyone.

When we regrouped, a representative gave a summary of what had transpired in each session. I was impressed with the heartfelt reports that were presented, and I, like everyone, was especially

moved by the post-transplant group.

Unfortunately, we didn't have enough time to do justice to Ivor Sweigler's talk, updating us on PSC progress in the UK, so we have printed Ivor's report in Part 2.

Lastly, Sandi Pearlman introduced our new fall fundraiser called Save the Day. We have set aside the weekend of October 3-4 for members to do individual fundraisers locally. All money collected internationally and sent to us will be used to support more PSC research.

Please read Sandi's explanation of the fundraiser on page 18 and create your own project for October 3-4. We'll be announcing an incentive program for our participants, so please join us and help us get closer to finding that elusive cure.

The most difficult time of the weekend is having to say goodbye to everyone and leaving that warm welcoming cocoon where we all share so much positive energy. I love seeing our new attendees, many of whom arrived tentatively on Friday, fearful of what was to come, and leaving on Sunday armed with hope,

new medical information and lifelong friends.

Many lives are changed as a result of the conference every year, including mine. If you would like to view photos of the entire weekend, click on [http://kpearlmanphotography.com/client\\_gallery/PSC%20Partners/](http://kpearlmanphotography.com/client_gallery/PSC%20Partners/) to view the amazing photo gallery that Karen Pearlman, a very talented professional photographer, created and donated for us to enjoy all year long. Thank you Karen for sharing your talents with us!

There are so many members who helped us make this weekend a success, and I want to thank all of you. Here are some other miscellaneous thank yous:  
To our board of directors for their continual guidance  
To David, our guru, for creating and continuing to update the PSC Literature site every week, in addition to answering everyone's scientific questions online with detailed explanations  
To Sandi Pearlman for chairing our new mentor program, for creating the Facebook group, and for convincing so many Facebook members to join us at the conference  
To Ivor Sweigler for his update on PSC progress in the UK and for preparing summaries of the

physicians' presentations for the newsletter with Rachel  
To Wim Ruyten for his amazing fundraiser biking from his home in Tennessee all the way to Chicago  
To Allison Long for completing a run in honor of her sister Becky with donations sent to PSC Partners  
To Tiffany Kitts who started the Yahoo online support group in 1998 and still is the head moderator  
To Ken and Patty Shepherd for their incredibly successful fundraising project  
To Arne Myrabo for moderating the Yahoo online group with Tiffany and for creating our 2009 conference website  
To Paula Tallon for being the IT person for our Constant Contact communications  
To all our new and talented attendees for already volunteering to share their expertise with us to make our foundation stronger  
To all the attendees who were able to join us at the conference and support our efforts  
To whomever I may have forgotten--please forgive me. We are grateful to everyone who lent a hand to help us have a successful conference.

Reggie, Jeff and I are already busy at work preparing for the

2010 conference in Hartford, Connecticut, and plans are shaping up for another phenomenal weekend. I'm looking forward to working with Reggie and Jeff, who have been strong supporters of PSC Partners Seeking a Cure ever since our first conference.

Don and I recently spent five days with Reggie and Jeff in Hartford, touring the area, visiting hotels for the meeting and historic places for our brunch. We had a terrific meeting with the doctors at the Section of Digestive Diseases and the Yale Liver Center at the Yale University School of Medicine, who are extremely eager to work with our group.

The dates have been set for May 14-16, 2010, so please mark those dates in your calendar and try



Ken and Patty Shepherd, of Virginia, were recognized for their fundraising efforts.

to join us. I promise you a very uplifting and positive experience that will energize you for months afterwards. We'll be sending out periodic updates.

For all our members who weren't able to make it to the 2009 conference, feel free to visit our conference website online to read about the most updated information on PSC and take a look at Karen Pearlman's photo gallery to experience the feel of the weekend.

We hope that you'll be able to join us in 2010. For all the 2009 attendees, try to retain that renewed spirit that we all took home with us, and stay in touch with your PSC family. Here's to good health and a fun summer for everyone!

Ricky Safer, President  
Together in the fight, whatever it takes!

& & &

From Becky Long, 2009 Conference Co-Chair

I echo Ricky's sentiments and sincere thanks to the participants in Chicago. Your enthusiasm to greet friends and make new connections was evident. The physician presentations were outstanding and as always attendees gained invaluable advice and support from one another during group sessions. Thanks especially to Drs. Green and Martin for making this weekend possible with Northwestern.

A huge thank you to those who helped with set up, including the Parry, Belmont, and Pearlman families, Joanne and Steve Grieme, Bud and Betty and Harlow, Jeff Hagglund, and Yvette Matthews. Special



thanks to Second City performer Rachel Miller for meeting with me to plan Saturday's banquet festivities. A good time was had by all and the upbeat antics were much appreciated after an action packed day. Thanks to the Cubs who treated fans to a Grand Slam and home team victory: we ordered that special for 1st time Wrigley Field visitors! Last but not least, thank you to my parents and sister for their support, patience, and assistance this past year.

I would like to acknowledge our founders Ricky Safer, David Rhodes, and Lee Bria for their dedication to PSC Partners and congratulate them on their achievement awards. Along with Don, Ricky Safer's vision has brought hope and support to so many, and empowered each of us who has been touched by PSC Partners. I'm so grateful for having had the opportunity to host this important event. It's a pleasure and privilege to be a part of this generous, open-minded, compassionate, and open-hearted bunch. I'm so excited to see you again in Hartford!

### 2009 Annual Conference Sponsors

We'd like to thank the physicians at the Northwestern University Feinberg School of Medicine, especially Dr. Rich Green and Dr. John Martin, who have worked closely with us in planning the conference.

Many thanks as well to all our wonderful speakers who will broaden our perspectives and understanding of PSC. We are also indebted to our conference sponsors:

#### Gold Level

Illinois Tool Works  
Mobile Doctors--Dike and Rilee Ajiri

#### Silver Level

Roche Pharmaceuticals  
Axcan Pharma  
Ken and Patty Shepherd

#### Bronze Level

First Church in Wenham MA  
Theresa Shanks

#### Copper Level

Steve and Joanne Grieme

#### Additional Sponsors:

Marilyn Alioto  
American Liver Foundation, Great Lakes Division  
Ruth and Doron Blatt  
Chicago Caregiver Magazine  
Dominicks  
Chris Klug Foundation  
Bruce and Carol Grover  
Jeff and Reggie Belmont  
Kahler Hotel Group  
The Long Family  
Lululemon Athletica  
The Parry Family  
K Pearlman Photography  
Don and Ricky Safer  
Sigma Tau Pharmaceuticals  
Starbucks Coffee  
Swirlz Cupcakes  
Trader Joe's  
Walgreens Specialty Care Pharmacy  
The Wentz Family

#### Special Thanks To:

Improv Performers Tim Baltz, Rebecca Hanson,  
Rachel Miller, and Tim Ryder

### 2009 Conference Medical Presentations are on our Website

If you'd like to view videos of events and slides of medical presentations made at the conference, they are available on the web at this address: <http://www.pscpartners.org/conferences.htm>

Presentations from the conference are available on the website, free of charge. The Board has decided to offer all past conference presentations free of charge as well.

See also the Summer 2009 Vol. 2, presentations edition of *The Duct* for summaries of conference sessions.

## Fact-O-Rama

### 2009 PSC Partners Conference Statistics

Total number of conference attendees in 2009: 185 (up from 115 in 2008)

Number from outside the United States: 18  
First time attendees: 116  
Attended pre-conference activities: 90  
Transplanted PSCers: 10

Number of Caregivers: 102  
Spouses: 37  
Other caregivers: 12  
Parents total: 53

Parents of pediatric PSC patients: 13  
Parents of adult PSC children: 40  
20-30-Something group: 30 (Male 13; Female 17)

## Attention All Potential Fundraisers (and really, who doesn't that include?)

Get your game faces on for a little friendly competition! PSC Partners is proud to announce a challenge we think is pretty darn grand. So, if you're young or old, tired or on a coffee high, get those fundraisers moving! Check our website for pre-approved fundraising ideas. There's more on page 18. Anyone whose Save the Day fundraiser earns over \$10,000 will receive a FREE registration for the 2010 conference in Hartford, CT, 100 percent paid for! All you do is show up!

For those of you whose fundraisers earn over \$15,000, you'll not only get free registration to the next conference, you'll also receive a complimentary hotel room at the selected venue. And for those of you under 18, well, get your smiles ready and plan what you'd like to say.

The fundraiser who earns the most money will be featured in an upcoming PSC Partners newsletter and on the website. Along with a photograph, an article will be written letting everyone know all the great things about you and what you've done to make the world a better place for PSCers!

So, on your mark, get set, go! Find a fundraiser and get a move on. The competition is fierce, the cause is fabulous and the prizes rock!

## 512 Miles of Spreading the Word and Raising Research Money

reported by Sandi Pearlman

What do you get when you take a man diagnosed with both PSC and UC who suffers from chills, fatigue, itching, and the like? Well, you'd be more likely to guess couch potato than superstar biker—but you'd be wrong. In the case of our own Wim Ruyten, superstar biker is the correct answer!

Despite Wim's exhaustion, symptoms, and the sheer magnitude of what he wanted to do, he dove in headfirst to make an amazing four-state, 512-mile long bike ride in the name of PSC Partners. Armed with his trusty bike, a backpack full of necessities and meds, a few weeks worth of biking stamina training and a will that Superman would envy, Wim biked his way from state to state advertising our plight, making some local headlines (and even scoring himself some lunch money on one occasion).

Wim pedaled up at our Friday morning brunch in high style to be greeted by many of his adoring fans (most wearing t-shirts that touted his efforts and served as a nifty fundraiser)! Wim's fundraiser not only brought new attention to our far-too-little-known disease, but also earned some nice donations to keep the research wheels turning. Thanks, Wim, for all you did and do! We're so lucky to know you and have you as a partner in fighting the fight!

The gang welcomed Wim at the end of his amazing 512 mile trip.



## Itching for a Cure

Road to Chicago  
PSC Partners Seeking a Cure Conference

### HOW'D WE DO IN THAT FUNDRAISING CHALLENGE?

(HINT: WE WERE AMAZING!)

reported by Sandi Pearlman

We always knew that there was no challenge that PSCers couldn't take on and beat. We fight incredible odds every single day and smash them with a glancing blow even when some of us are too tired to tie our shoes.

So, it should come as no surprise that when we were challenged to raise \$45,000 to be matched by some generous and anonymous donors, we ran with it! In fact, we flat-out crushed it. We left that \$45,000 in the dust and earned an amazing \$91,666 and that was before the matching funds were even added. With the match money of our super-secret and much appreciated benefactors, we raised more than \$139,044--and contributions are still arriving. Go us!

### Next PSC Partners Conference:

May 14-16, 2010 in Hartford, Connecticut

In conjunction with the Section of Digestive Diseases and the Yale Liver Center at Yale University School of Medicine

Co-Chairs: Jeff, Reggie, and Jecy Belmont with Ricky Safer of PSC Partners Seeking a Cure Foundation

Hotel: Hartford Marriott Downtown  
Details to be announced in early 2010

**PSSSsst! Looking for summaries of the conference's medical presentations?**

**There's so much to report, we have a second part of the Summer 2009 Duct. Check it out!**

## Once More With Feeling: My Return Trip to the PSC Partners Seeking a Cure Conference

by Sandi Pearlman

The thing I love about life-altering experiences is that even when you expect them, they can still turn out to surprise you with the myriad of ways they can touch your heart.

I mean, I knew my first PSC Partners Conference had made me into a much-improved person from the shell-shocked PSCer who walked through the doors that first Friday afternoon. I'd been given confidence, a purpose, friendships that have stood the tests of time and frequent hospitalizations.

So, when Chicago rolled around, for months on end I proudly stepped forward and touted the glories of the conference to every prospective attendee for as long and as loud as I could. I figured I knew, so to speak, what I was getting into, what would await others. I mean, I was no longer a first timer.

I already knew about the warmth of the attendees, the staggering intellect of the speakers and PSCers combined, the sheer breadth of topics covered and even a good number of the people I would see. My goal for this year's Chicago conference was to help make sure others got that life-changing experience and to sort of live it vicariously through them.

And then I arrived and realized that life changing isn't just once in a lifetime and it's not just for those who have never been a part of a PSC Partners Conference before.

To be honest, I'm not sure when it hit me. It may have been when the first attendees started wandering the halls. It may have been as we were packing up and preparing goody bags to hand out. It doesn't really matter. All that matters is that suddenly, I was at ease.

I felt relaxed and happy and whole. I wasn't the sick girl in the room. I wasn't the one people were whispering about with the rare incurable disease. I wasn't even the only one exhausted and scratching and itching and forgetting my words before they could come out of my mouth.

I was just in a room with a bunch of people like me who were proudly wearing their blue dots (PSCers) and their yellow dots (caregivers) and their red dots (first-timers) and green ones (transplant) all declaring that we were members of the same group, of the same family—that we were the ones who belonged.

The conference was filled with well-credentialed speakers and researchers. Some of the news was grim and some was grand. But for me, the magic of the experience was the sheer number of us.

It seemed no matter where in the room you looked, there was another 20/30 something. We were there. We were listening. We were in this together. For those of us who knew each other before, seeing each other again was like seeing a family member whose presence you'd missed without realizing it until you saw their face. Sort

of like having a part of you filled in when you hadn't even realized you missed it.

One of my beautiful PSC pals said to me, you know, I feel like you're all my best friends who I can share everything and anything with, even though I only get to see you once a year or so. And she's right. Except I'd say that what we feel goes beyond friendship really, to sort of a more familial level.

There is such a safety in the room, in that group of individuals. There's no hiding of symptoms or exhaustion. There's no embarrassment or accusation. There's just overwhelming support and love and understanding. And the thing is, it isn't limited. It's not just blue dotters (PSCers) to blue dotters but also blue to red (first-timers) and blue to yellow (caregiver) or green (transplant) or whomever.

By the end of the first day, the dots didn't matter. We were a PSC family old and new and all together. We'd known each other a year, ten years, ten minutes. It didn't matter and it never would again.

Some of what we heard at the conference was rough. Some speakers hammered us over and over again with the fact that many of us might likely die before we'd ever get a cadaveric donor. Some spoke about trials that we'd had our hearts and minds invested in as though they were somewhat laughable.

And some validated us. One speaker in particular spoke of the exhaustion that pervades so many of our lives and told us that exhaustion is real, that we're not lazy. That exhaustion is mental, physical, emotional and pervasive. I know several 20s/30s who would have stood up and applauded at this, you know, had they not been so exhausted.

Another speaker spoke about SSDI and advocating for yourself and how FMLA can be your friend. At this, one 20/30 something pulled me aside and just said he felt as though he'd been given a new lease on life, that he actually saw that he wasn't alone, that there was help. What could be bigger than that? And while he didn't cry, I can tell you I came darn close to it!

But for most of us, no matter how fabulous the speakers are (and they are) or how many statistics and studies are named, the true healing and education comes not in the doctors' speeches or through the painstakingly made presentations. No, those educate. Those give us food for thought. But those aren't the true reason that the conference means what it does.

Quite simply, it's the togetherness. Whether through breakout groups or just hanging out in hotel lobbies, the real miracle of the conference for all of us, at least in the 20s/30s group, is each other.

For those of you who weren't present at the conference or who just couldn't make this year, each conference offers a breakout session. More than one, actually, but we'll leave that be for the moment. The 20s/30s breakouts were separated into 20s/30s males and 20s/30s females and while it broke my heart to leave all those handsome men in another room, those breakouts are breakthroughs.

The first day's breakouts were Lunch with a Physician. The guys adored their session. The girls. Well, maybe not so much. But day two, when we once again resumed those breakouts, there wasn't enough time in the day to talk, to laugh, to cry, to ask questions, and share stories.

For the guys and girls alike, topics spanned the social front. For the men, drinking came into

focus, the should you/ shouldn't you question. For the women, we talked a lot about fertility and family and what PSC meant for us in the traditional/societal sense of being a woman and in the physical sense as to what may or may not be possible given our PSC.

But both the 20s/30s men and women found themselves in similar circumstances as we discussed dating and how to tell someone and when to tell someone you have PSC. We talked about how fatigue affects work and friendships and, to some extent, self-esteem. We talked about medications and treatments we've tried. We talked and we talked and we talked. And had we not had to go back to the main room, who knows, we may have been talking still.

We asked questions of the 20s/30s siblings and caregivers

who joined us. We mined their souls for clues as to how the "healthy" see us, to know what our diseases do to our loved ones and how we can help them or thank them for helping us. We talked as though there wasn't a tomorrow coming because our tomorrows will come but we won't be together. We'll go back to being the sick man or woman in the room.

Our blue dot status won't make us rock stars or one of the cool kids. It'll be life as we knew it...only, life a little better than before. Because, see, for the 20s/30s and, I'm willing to bet, the group at large, the magic moments of the conference have less to do with location and hotels and doctors pedigrees and more to do with depth of understanding and compassion and unity.

See, for some, PSC might stand for Primary Sclerosing

Cholangitis. For us, those of us in this wonderfully wacky, extensively varied and lovely and large family, PSC stands for Please Stay Close. As in, the bonds we made are not fleeting and we need each other come what may. For we are together in the fight, whatever it takes.

And to those of you who became a part of my PSC family this year or who came and renewed the bonds, I can't thank you enough for strengthening me and for allowing me to give to you.

And for those of you who haven't yet become a part of this fabulous family that no one wanted to be a part of and now couldn't dream of being without, well, we're waiting for you. We'll set an extra chair at the table and keep all the good stories humming for when we see you in Hartford.

### Canadian PSC Group to Form, Seeks Support

*reported by Ivor Sweigler*

Fifteen Canadians and Dr. Heathcote met to discuss the formation of a group to support the US PSC group and to raise funds for PSC research in the US. There is minimal PSC research in Canada. But setting up such a group has been complicated by legal issues and currently funding is needed to address them. Contact: Andre Altaras and Eve Jedrzejska at [eveandre@rogers.com](mailto:eveandre@rogers.com).

### Israeli PSC Support Group Underway

Chaim Boermeester hopes to form a group in Israel, with Arabs and Jews, and has identified five PSCers, with the Israel Foundation for the Health of the Liver. He has been in contact with several of them. The estimated PSC population in Israel is 200-300. Contact Chaim at [cboer@rugged.com](mailto:cboer@rugged.com).

## Conference Comments

While we were uncertain about what to expect going into the conference, we left knowing we couldn't have asked for more. We are well aware that there will be good days and difficult ones, but at least we can begin to let go because we are no longer alone.



**The conference was a real turning point in my journey with PSC. Now I see hope and options I never saw before!**



I cannot tell you how much I liked meeting so many wonderful, optimistic, kind people!



**It was good to hear the different voices, coping mechanisms, concerns and questions, especially when we remain so quiet outside this close-knitted community.**



At the conference, I felt privileged, honored and proud to have PSC. Everything made me feel special.



**The conference was absolutely exceptional. I cannot believe how much I learned and enjoyed everything.**



The speakers were experts . . . willing to answer questions.



**The speaker selection was outstanding. The information was up to date and thought-provoking.**

Our pre-conference brunch was held in a beautiful 55th floor lakeside apartment and offered an opportunity for conference first- and old-timers to meet informally and enjoy fabulous food.



Yvette Matthews was one of many vital pre-conference volunteers.





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Sandi Pearlman congratulated Wim Ruyten on his excellent bike ride.



❖  
The conference was so well organized. It was perfect...a great combo of information and personal exchanges!

❖  
**This was a very professional conference! I was very impressed with the caliber of topics, speakers and breakout sessions. I learned a great deal and I appreciate how much planning and careful thought went into the production of this meeting.**

❖  
I missed the last two years' conferences but after this weekend, I don't want to stay home from any such meetings in the future. We renewed old friendships, made new ones, laughed, cried, learned, and most of all, supported each other. I have never been part of any group where you can approach a total stranger, and five minutes later, it is as if you've known this person for years as an old, dear friend.

❖  
**I met people who were diagnosed just a few months ago, and they were frightened. The group embraced them with love, encouragement, and support. I met people who have had PSC for years and are still without major symptoms. They provided hope for those who don't know what the future holds.**

❖  
I figured I'd go to the conference on Saturday, get what info I could, hang around a little and leave. I'm not sure how it all happened as I try to process my conference experience but I was "pulled into" an atmosphere of hope, optimism, knowledge and friendship. It was wonderful!



Don and Ricky Safer found a moment to relax on the boat tour.

❖  
**It is just like a family reunion, only better in some ways. We are a family that wants to be together. There were even tears when we were saying goodbye and I have to admit that I was one of them. I am truly thrilled to see all the new people and know that if you weren't able to come this year, you will be welcomed with open arms next year.**