

Comments from the 2009 Conference Attendees

"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 doctors from Northwestern were very impressive and knowledgeable. Intelligent, honest, good-natured, human."

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

"This was the most professionally run conference I've ever attended. The speakers were authoritative, willing to take questions, up front. The breadth of topics was terrific too."

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

"I found the meeting uplifting...The speakers were informative and entertaining on a subject that could have been a real "downer".

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

"Speakers seemed to have good balance of humor mixed with relevant information."

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

"Even though everyone there is touched by the illness, I felt an air of optimism...it made me realize I am not alone. I thought the lunch with a doctor was the best part. A one on one with someone that spoke and was very interested in our situation."

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

"Exceeded my expectations both with regards to info content and support for one another. Thank you a thousand times for this wonderful gift."

"The speakers were experts in their respective fields-so knowledgeable and willing to answer questions."

"This conference was probably one of the most important events of my life. I am so grateful that you created this foundation and have recruited such talented and accomplished volunteers to actualize its potential."

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

"All the speakers were amazing. My favorite was Dr. Laurie Keefer. It was so validating to hear her discuss why it's difficult to deal with a PSC diagnosis...and talk about how it is not the kind of problem that we are taught to deal with -- no clear-cut solution with an end to the situation."

"Thank you a thousand times for this gift."

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"It was my first conference, and I thought it was wonderful.. It would be hard to improve on it since I enjoyed all the speakers and topics. On Sunday, I participated in the self-help group of PSC patients and heard their stories and found that session very useful."

"I cannot say enough in praise of PSC Partners Seeking a Cure!"

"Excellent sessions from doctors and professionals. I really enjoyed the opportunity to meet with others dealing with this chronic illness. My main goal of attending the conference was to get some good information and to FINALLY meet someone else with PSC. My spouse and I don't feel as isolated."

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

"This was the first time for my husband and myself. We found it to be very helpful with information. We now have more questions to ask our doctors and feel we can do it with confidence."

"It was wonderful. I recommend it to everyone. It helped me connect with others and feel a part of the PSC family. A big THANK YOU!"

"The best part was witnessing how the public advocacy and support groups create a grassroots network with Doctors and the medical community to address and troubleshoot this unique and rare disease."

"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 enjoyed the balance between pure academia and peer experiences; the free-flow question and answer sessions, the instant bond of friendship and support between old hands and newbies like myself, and the incredible amount of information that I can now use to improve my current quality of life and future medical adventures."

"I saw people who were diagnosed just a few months ago, and they were frightened. The group embraced them with love, encouragement and support. I saw 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."

"The opportunity to hear directly from doctors that are working on this disease has inspired me to want to give more. It was also extremely inspiring to hear what they are working on and where the research is going. I was a first time attendee and this event left me feeling empowered."

"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"

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experience but I was “pulled into” an atmosphere of hope, optimism, knowledge and friendship. It was wonderful!”

Also, the conference was run much more professionally than I expected for the cost...great location and meals, overall extremely well run.”

“I’ve been inspired in a way I’ve never been before.”

“I felt that all the speakers were excellent. It was an inspired choice to include the women who spoke on insurance and social issues.”

“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.”

“I have to admit that the Sunday morning go-around with other attendees was particularly helpful to me. The sessions on Saturday were also very important and well done. Even though the material presented by the speakers on Saturday was at times difficult to hear, I know the great value of my becoming more educated about the disease and its ramifications for both my daughter and the rest of our family.”

“Everyone I spoke to feels blessed to be able to have these conferences to meet others with similar issues and be able to hear from experts in their fields about issues that cause them fear and concerns. It allows those of us with PSC to take charge of our health in ways that aren’t possible without the conferences.”

“The best parts were meeting other parents, getting updated on different treatments and standard of care, generally getting more informed on the disease. I walked away feeling very positive. the message was hopeful and inspiring.”

(From one of our presenters) “I really loved being at your event. Great energy, nice people, really good mutual support....I drew lots of energy from your crowd.”

“The Sunday morning break-out sessions were tops. We were not planning to stay for that part, but so many people on Friday and Saturday told us it was the best part, and they were right. It was incredible to be in a room with people who understand the itching, the uncertainty.”

“It’s not often that I say I feel blessed to have PSC, but this conference and getting to be with everyone there is one time I’m proud to say I have it.” ☺

“I am extremely impressed by (and grateful for) the professional organization, the obvious amount of extended planning, and distinguished collection of speakers. The fact that the medical professionals were able and willing to do more than just dry lectures was very gratifying.”

“Getting Second City to perform Saturday night was a masterstroke!” “Laughter is so therapeutic!”

“I will definitely be coming back in the future. This conference exceeded my expectations.”

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"I was very impressed with the presentations from all the Northwestern Doctors and professionals. Made me wish I lived here!"

"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."