

FAQ (Frequently Asked Questions) About the PSC Partners Seeking a Cure Annual Conference

What can I expect at a PSC Partners' Conference?

I don't think it's overstating to say that you can expect a life-changing experience at a PSC Partners' conference. There is always a lot of great information, updates on treatments, research, grants and more. But for most PSCers and their loved ones, the real magic of the weekend is being in a room with people who really, truly get it, people who have either been where you are or who know what may be to come. It seems like a conference dedicated to talking about disease, and a currently incurable one at that, would be dark and depressing and overwhelming. The truth is the conference is overwhelming. It's overwhelming in joy and friendship and camaraderie. There will most likely be information that's hard to hear, but hearing it in a room full of people who are dedicated to wiping PSC out for good, well, that's got to be the best place possible to learn what we're up against, right?

What is the dress code?

There is no set dress code for the conference. Most attendees wear jeans or slacks. Because conditions can vary due to air conditioning, etc. a sweater or sweatshirt is strongly advised. Every conference hosts a Saturday night banquet. You may dress up for this if you choose. It is not a formal event. Dress slacks or casual dresses are perfectly appropriate but not required.

Will I be able to understand the lectures?

Some of the lectures may contain complicated materials. Every effort is made to make sure that content is understandable to the layperson since this is a conference for PSCers and caregivers, and not for medical professionals. Q&A sessions are always offered throughout the various lectures to clear up any confusion or lingering questions. In addition, we're a large, friendly group and we are happy to share definitions and explanations among each other. Chances are, if you have a question or something you're confused about, you'll be able to get a good answer relatively fast!

Will there be time to talk and get to know other PSCers?

One of our major goals at PSC Partners is to connect PSCers to each other so nobody feels alone in their fight. To facilitate this, we offer social activities throughout the weekend and leave free time to be able to mingle. We can't stress enough what a friendly, open group of people attend these conferences.

Will there be PSCers in my age range there?

The answer to this depends on the age range and the yearly group of attendees. The PSC conference has a wide range of attendees, from teenagers on up. The largest proponent of the conference is made up of those 20+, but every year we have more teens join us and it couldn't make us happier. As of this point, children have not

attended the conferences and it is probably not recommended for anyone under the age of 16.

What types of people attend the conferences?

Our conferences are largely made up of PSCers, parents of PSCers (both adult and pediatric), siblings of PSCers, spouses of PSCers and caregivers not fitting into the aforementioned groups. Speakers are experts in their fields, which can range from hepatology to psychology to nutrition, legal matters and more. Every conference strives to bring speakers who are interesting and relevant to the lives of PSCers and their loved ones.

What happens if I don't have enough energy to make it through a whole day?

Nobody understands being tired and worn out quite like a PSCer. There is no penalty for missing a lecture and no problem if you need to be excused during one. As long as you don't create a disruption for the speaker or those who are enjoying the presentations, you can enter and leave the rooms as need be.

Can my dietary needs be accommodated?

We do our best to make sure dietary needs are met. On the conference registration form, we offer both vegetarian and gluten free options. If you need something other than those options, feel free to write to us at contactus@pscpartners.org and we'll see if arrangements can be made.

Are all conference activities in one place or will I have to rent a car?

All conference activities are in one location. We do offer pre-conference excursions such as brunches or special activities at most conferences. These are reachable by foot or taxi or else alternative transportation is provided. Conferences are generally located within a short drive or cab ride from major public transportation or airports. It is up to you to get from the airport or train station to the conference locale. No shuttle service will be provided.

Is the conference only for PSCers or can a caregiver come without a PSCer?

Anyone is welcome at our conferences whether you come alone, with a PSCer or with a support system. Caregivers and PSCers are equally welcomed with open arms.

Are there any hidden charges once I arrive?

There are NO hidden charges once you arrive. There may be opportunities to purchase things through fundraisers, but no other funds are required to attend the conference once your registration fees, hotel room fees and excursion fees, if you so choose, have been paid.

What do my conference fees go towards?

Your conference fees go 100% towards the cost of the conference. We try to keep our registration fees as low as possible. Please note that PSC Partners Seeking a Cure and our generous conference sponsors subsidize a significant portion of your conference costs (about 50%).

Must I stay at the recommended hotel?

You may stay wherever you choose. However, most PSCers and caregivers prefer to stay at the recommended hotel in order to remain close to the activities and to further communication and socialization with other attendees. We always try to get the most reasonable group rates possible for rooms. Please be sure to reserve your hotel room as soon as possible in order to secure the group rate.

Will the conference be too much for me emotionally?

Conference topics can and often do cover some very sensitive issues for PSCers and can be overwhelming. We'd encourage all attendees to stay throughout the weekend, however, since talking together about these findings can help to make them a bit more understandable and a lot less scary. In addition, we strive to make our weekends balanced and to temper the seriousness with lots of time to bond, ask questions, relax, and even laugh together. We've been told time and time again that conference attendees leave with a much more positive attitude about life with PSC and with lifelong friends and an extra support system to boot!

Do I need to register ahead of time or can I register the day of the conference?

All attendees MUST register prior to the conference. Registration fees cover the cost of the conference and logistics must be set with the hotel and caterers prior to the conference start date.

Do I need to stay for the whole conference or can I just come for one day of it?

PSC Partners strongly recommends that you attend the conference as a whole. The weekends are structured in order to learn and digest all the information presented and to get to know other PSCers. To miss any day of the conference is to do yourself a disservice. That being said, attendees may choose to attend only a portion of the conference, but the conference fees can not be prorated and must be paid in advance in full.

We can't wait to see you at our next PSC Partners Conference! If you have questions not addressed in this section, please feel free to write to us at contactus@pscpartners.org and we'll be glad to do our best to help you.