



Q. What can I expect if I attend the Chromosome 18 Registry Annual Family Conference?

Each year we meet in different cities to listen to speakers, discuss concerns and problems, and offer families an opportunity to meet each other. We learn from educators, researchers and medical professionals, and mostly from each other. We strive to better understand our own children and what we can do to help them. We gain knowledge, perspective and hope. We also have a lot of fun meeting new friends and checking in with old ones from past conferences.

Q. When is the conference and how long does it last?

The conference is typically held in July. This is because some of the East Coast schools don't get out of school until the very end of June and many children in other areas go back to school in early to mid- August. This year we'll kick-off the conference on a Wednesday night with checks ins and a social. This gives us a chance to say hello, meet new and old friends, and get excited for the next three days.

Q. Who may attend the conference?

Everyone is invited to attend the conference. This includes parents, their children, extended relatives, friends, and professionals. Many siblings also look forward to attending conferences each year.

Q. Will childcare be provided?

Yes, we've always provided childcare. The conference chairs form a committee for childcare and are responsible for getting volunteers to help out with the children. This is not an easy task, but it is an extremely important one. In addition to the volunteers, we have also contracted Corporate Kids to help run our childcare program. We anticipate a program that the children will enjoy with many activities to keep them busy and happy. We know from experience that if parents know their children are happy, they can get the most out of the meetings.

Q. How old are the children in childcare?

We generally have children of all ages - from toddlers to 18. We have both typically developing children and our children who are affected with a chromosome 18 condition, in childcare.

Siblings are often helpful and nurturing as they know their brother or sister best. Infants and very young babies are usually with their parents in the session or the parents take turns. Many times families bring an extended family member or caregiver to help out. Please note that we cannot and do not provide one-on-one child care or nursing care. If a child needs to be closely monitored, he/she will come into the sessions with the parents or stay with their relative or caregiver. Of course, they are always welcome in the childcare room anytime with their caregiver.

Q. What is included in the price of registration?

The Registry recognizes that our annual conference is an extremely important educational and networking tool of our organization. Each family is responsible for their hotel room or lodging; it is not part of registration the registration fee. The registration fee includes the lunches on Thursday and Friday, dinner on Saturday at our Starfish Dinner & Dance, the facility for our sessions, childcare and related supplies, printed materials, and speaker costs. For many years, we have charged each attendee a very nominal registration fee for the conference. It is our desire to make it possible for as many families wishing to attend the conference to do so. We always offer a stipend to attendees who are current members. This means that, whatever the total cost is, the attendees cover a portion of it, and the Registry covers a portion. For example, if it is determined that the total expense per person is \$300.00, the attendee may pay \$175.00 and the Registry would cover \$125.00. Not everyone chooses to use the stipend because they know it is a Registry subsidy and would like to donate the stipend amount back to the Registry. Please note that the stipend is a benefit that is only available to those whose Registry membership is active.

Q. Can you explain what “stipend” means?

Think of the stipend as the choice of paying a much lower registration fee than it actually costs the Registry to execute. The Registry does not hand out money to its registrants; the registrant simply pays the lower fee and the Registry picks up the rest of the cost. So choosing to use the stipend means you are actually using Registry revenue that came from some other source/kind donor. (However, that revenue does not come out of fundraising dollars which go only to research.)

Q. What topics are included in the sessions?

The annual conference does not follow the same format each year. In the past, our conference chairs have done a fabulous job making each conference unique and appealing to as many attendees as possible. Some years the setting is a nice hotel in a large city. Other years have had a more rustic flavor in some sort of a camp setting. The same goes for the content of the conference. Some years there are many choices according to the age or developmental stage of

our children. Some years seem to be more sharing and networking. Other years are so full of educational information that attendees leave with pages of notes. However, some aspects of the conference remain consistent from year to year. For example, Genetics 101 and the Research Update will be part of the conference every year. A favorite of all of our members is our syndrome breakout session. This is when families break into groups according to their children's syndrome and share stories and information. It is an extremely empowering portion of our conference. We learn so much from each other in these sessions. You can visit the website and get a feel for what the conference will look like this year. The preliminary schedule is available on our website.

Q. How do I register for the conference?

You can register for the conference by going to our website home page and following the links. Registration usually opens by mid-April. Remember that registering for membership in the Registry is not the same as registering for the conference. In order to receive the conference stipend, you must be a current member. If you have a question about your membership you may call or email Leah at the office at office@chromosome18.org or 210-657-4968.

Q. Do I have to stay at the same hotel as the conference?

Being together at the same hotel is so important and lends itself to the very purpose of our conference. The opportunity to spend time with other families living the same life as you are is well worth the money saved, but time lost, in commuting to the hotel from other accommodations. Most people secure their hotel room first. We encourage you to do this early. In the past, there have been some very upset members who realized too late there were no more rooms at the host hotel. We encourage you to register for the conference at your earliest convenience. Although it has never happened to date, we cannot guarantee that if we are inundated with attendees that we will not enforce a cut-off. This would mean we have maxed out on numbers that can be accommodated properly. So please register early.

Q. If I am unable to attend the full conference, can I pay a reduced registration fee?

The Registry does not adjust the fee for days not attended. The registration fee remains the same whether you attend the conference for one, two, or three days.

Q. May I receive a refund if I am unable to attend the conference?

Under most circumstances, there will be no refund. When this has happened in the past, most families consider their fee a donation. If the conditions are extremely serious, feel free to contact the office to discuss the issue.

Q. Do I register and pay for my infant/toddler that I am bringing to the conference?

If your infant/toddler will NOT be going to daycare and/or will NOT be eating food provided at the conference, it is not necessary to register or pay for them to attend. However, if they go just once to daycare or eat one meal, then you are expected to pay for them to attend. You are welcome to bring your infant with you to the sessions; however, please respect others in the group by taking your infant out if he or she is causing a distraction.

Q. Grandma/caregiver is coming to watch our kids. Does she pay the registration fee?

Does she want to socialize with other families in the conference setting? Yes, she pays.

Will she be joining us for any meals? Yes, she pays.

Will she be attending any of the sessions? Yes, she pays.

Will she join us for the Social on at the close of the conference? Yes, she pays.

Not paying a registration fee for an individual present at the hotel and connected to a Registry family would indicate that person is taking care of the children (or vacationing) in an atmosphere that is not in any way a part of the conference.

Q. Will I be able to talk to Doctors and specialists about my child/child's condition?

While many of our speakers are professionals in their field and will be very willing to chat with you about your child, and discuss general aspects of current research, please remember that this is not a clinical setting and they cannot dispense individual medical care.

Q. Who do I contact with additional questions?

Please visit www.chromosome18.org or call 210.657.4968 or e-mail the Registry office at office@chromosome18.org.