

New Family Orientation Brochure

What to Expect

- You've checked in to the hotel, you've gotten your packet and your schedule, what now?
- Who are all these people hugging each other?
- What does the dot on my name tag mean?
- Answers to these questions and more, coming right up.

Overview

The first Chromosome 18 Registry conference was held in 1994, in Schaumburg, IL, to support the families of people born with a Chromosome 18 syndrome. Many families come year after year, which is why they seem to know each other. But don't worry, they were all new attendees once (wearing the new attendee star on their badge) and they know how you feel. We will do all we can to put you at ease.

Badges

The color dot on your badge indicates the syndrome a person in your family has:

- 1) Blue = 18q-
 - 2) Red = 18p-
 - 3) Green = Tetrasomy 18
 - 4) Yellow = Ring 18
 - 5) Orange = Other (Trisomy, partial trisomy, translocations)
- This will allow you to find other families; you can ask questions, have dialogue, and enjoy sharing stories
 - Families attending for the first time will have a star on their badge.
 - Your hometown and state/country are listed on your badge. This allows you to find other families from your physical area to ask about doctors, insurance, school programs, etc.

Important Stuff

Don't miss the Welcome and opening remarks. It sets the tone for the conference and provides needed background information.

Note: One of the best parts of the conference is talking to other families. Try arriving to presentations with enough time to chat before or after, make meal plans with other families, etc.

Yearly Presentations

There are several presentations that occur at every conference. They change from year to year but may include; seizures and neurologic issues, financial planning for those with special needs, depression and anxiety issues, navigating special education, and more.

Research Update

Dr. Jannine Cody, Director of the Chromosome 18 Clinical Research Center, and Dr. Dan Hale, Medical Director of the Chromosome 18 Clinical Research Center, will provide an update on the current research being conducted relating to Chromosome 18 and the direction of future research.

The State of the Registry

We will provide an update on key Registry activities, operations, fundraising, and more. We are mainly a self-funded organization and need the help of our members and friends to continue the research and family support programs.

Syndrome Group Breakouts

Syndrome groups (check your dot color) meet in individual rooms to network with fellow parents and care providers. Each will have a facilitator to monitor and manage the discussions. (Adults only please, as much as practicable).

The breakout sessions are a means to learn about other families, what their children have gone through and are going through, and allow you to note who you would like to direct questions to during the conference.

Daycare

If your child(ren) will be in daycare, remember:

- Many of the daycare providers are volunteers – please respect the donation of their time and pick up your kids at the appointed time.
- Please allow enough time at drop off to get your child(ren) settled so that you are not late to the presentations.
- Follow the procedures required by Corporate Kids.