

# **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 conference was held in 1994, in San Antonio, TX, 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 (with the new attendee star on their badge) once, they know how you feel and they will do anything to put you at ease.

## **Badges**

- The color dot on your badge indicates the syndrome a person in your family has
  - Blue = 18q-
  - Red = 18p-
  - Green = Tetrasomy 18
  - Yellow = Ring 18
  - Orange = Other (Trisomy, partial trisomy, translocations)
- This will allow you to find other families to ask questions of - and ask away – there really isn't anything that most people will not answer.
- Families attending for the first time will have a star on their badge.

## **Badges II**

- Your hometown and state/country are listed on your badge.
- This allows you to find other families from your physical area to ask about Dr.'s, insurance, school programs, etc.
- Younger kids get stick-on name tags. (More on daycare later.)

## **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 and get 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.

## **Research Update**

- Dr. Jannine Cody and Dr. Dan Hale will provide an update on the current research being conducted relating to Chromosome 18 and the direction of future research.

## **Fundraising and Recognition**

- Claudia Traa, Executive Director, (aka Ross's Mom) and Gloria Ellwanger, Administrative Director of the Chromosome 18 Registry & Research Society, will provide an update on fundraising activities. We are mainly a self-funded organization and need the help of all involved to continue the research and the wonderful benefits of this group.

## **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 kids have gone through / are going through and allow you to note who you would like to ask questions of in the next few days.

## **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.