



10th International 11q Conference June 26-June 30, 2016

Courtyard San Diego Airport/Liberty Station
2592 Laning Road
San Diego, California 92106 USA
Phone: 1-619-221-1900

Sunday, June 26th

4:00-7:00pm: Family Meet and Greet

Individually scheduled times for families to sit down with doctors
(Grossfeld, Dalm, Paris, Akshoomoff, Mattson, Mattina)

Monday, June 27

8:30-9:00am: Introduction and Overview of the Conference

Dr. Paul Grossfeld, UCSD/RCHSD

9:00-9:45am: Keynote Speaker

Ms. Peyton Goddard: Living with autism

Session 1

10:00-11:00am: Immunology issues:

Dr. Virgil Dalm, M.D., The Netherlands and Dr. Ken Paris, M.D. LSU

11:00am-12:00pm: Bleeding issues/brain hemorrhage

12:00-1:00pm: Lunch

1:00-2:00pm: Panel Discussion on Medical Issues

Drs. Grossfeld, Dalm, Paris, Mattina

Session 2

2:00-3:00pm: Coping with a genetic diagnosis in your child

Mr. Ryan Sey, Head Chaplain, RCHSD

3:30-5:30pm: Free time/poster set-up

5:30-8:30pm: Family Dinner

11q talent show/performances

Poster session

Presentation thanking Jennifer Morrison

Tuesday, June 28

Session 3: Behavior and Cognitive Issues

8:30-9:30am: Neurologic assessment of children with chromosomal disorders

Dr. Jeffrey Gold, MD./Ph.D., UCSD/RCHSD

9:30-10:15am: Cognitive and behavioral profiles of JS: Clinical aspects

Dr. Natacha Akshoomoff, Ph.D, UCSD/Dr. Sarah Mattson, Ph.D., SDSU

Session 4: Therapies for Autism

10:30-11:15am: Reconnecting The Brain For Movements That Heal

Dr. Tommy John III, D.C., San Diego

11:15am-12:00pm: Medical therapy for Autism

Dr. Diane Chugani, Ph.D., Nemours

12:00-12:30pm: Kids Lunch (parents excused)

Session 5: Future Clinical Trials

12:30-2:30pm: Adult Lunch/Panel Discussion:

Genetics/Future clinical trials for intellectual disability, autism

Dr. Paul Grossfeld, UCSD/RCHSD/Dr. Marty Stein, Diane Chugani, Dr. Sarah Mattson, Dr. Natacha Akshoomoff, Dr. Jeffrey Gold

2:30-Free time/Family time

7:10pm Padres game vs. the Baltimore Orioles

Wednesday, June 29th

Session 6

8:30-9:15am: Endocrine issues

Dr. Thomas Kelly, M.D., RCHSD

9:30-10:15am: Breakout sessions

Session 1: Puberty and Sexuality in 11q

Session 2: Feeding issues in 11q

Session 3: Grandparenting

10:30-11:15am: ABA for Jacobsen Syndrome

Jessica Fekete, Behavioral Therapist and mother of a child with Jacobsen Syndrome

11:15am-12:00pm: Breakout sessions

Session 1: Transitioning to independence

Session 2: Advocating for “individualized” education (Led by Jessica Fekete and Linzee Carroll)

12:00-1:00pm: Lunch break

1:00-1:45pm: Breakout sessions

Session 1: Managing multiple medical issues (immunology, bleeding, cardiac, etc.)

Session 2: Managing anxiety and impulsive behaviors

1:45-2:30pm: Breakout Sessions

Session 1: Sibling Issues

Session 2: Finding joy in your journey

2:30-3:15pm: Breakout Sessions

Session 1: Special diets and natural remedies

Session 2: “Shut Up About Your Perfect Kid”

Thursday, June 30

Session 7: 11q R and R Business

8:00-9:00am: Business Meeting/fundraising

Session 8: Medical protocols

9:00-10:30am: Medical protocols/immunology, bleeding

Chuck Hehmeyer, Esquire, Raynes McCarty, Philadelphia

Session 9

10:30am-12:00pm: Music Therapy: Musicworks

12:30-4:00pm: 11q Family picnic NTC Park (adjacent to hotel)

On site cognitive/behavioral assessments are tentatively going to be performed at the hotel site. Skin biopsies will be performed at the CTRI at the UCSD campus in La Jolla. Specifics to be determined once we know who will be attending and wanting to participate. Initially, a questionnaire will be sent out to everyone to help determine which child should undergo which testing. We can't promise that everyone will be able to undergo testing. That will depend on how many families attend and want to participate.