



2018 International 22q11.2 Family Meeting

Conference - July 14 – 15, 2018 🍁 Family Fun Day – July 16, 2018

The Westin Resort & Spa
Whistler, BC, Canada

Day 1 **July 14th**

7:00 AM **Registration Opens**

8:00 AM *Welcome from the 22q11.2 Society*
Peter Scambler and Donna McDonald-McGinn

8:05 AM *Welcome from the Local Arrangements Committee*
Anne Bassett, Jacob Vorstman, and Pooja Panwar

8:10 AM *An International Welcome*
Sheila Kambin, Stephanie St. Pierre, Julie Wootton, Maria Kamper, and Anne Lawlor

Session I: *Setting the Stage*

8:15 AM *Donna McDonald-McGinn, MS, LCGC*
Philadelphia, PA, USA
A Birds-Eye View of 22q – Chromosome 22q11.2 Deletion and Duplication Syndromes

8:35 AM *Joris Vermeesch, PhD*
Leuven, Belgium
How the Chromosome 22q11.2 Deletion and Duplication Happen

8:50 AM *Bernice Morrow, PhD*
New York, NY, USA
Important Genes within the Chromosome 22q11.2 Region

9:05 AM **Peter Scambler, MD**
London, England, UK
Missing or Extra Genes Effect Physical Development

9:20 AM 22q & A

Session II: Detection

9:35 AM **Melissa Maisenbacher, MS, LCGC**
Virginia Beach, VA, USA
Frequency and What We Have Learned from Non-Invasive Prenatal Testing

9:45 AM **Erica Schindewolf, MS, LCGC**
Philadelphia, PA, USA
Prenatal Findings: Important Clues to the Diagnosis

9:55 AM **Nicole Sarles-Philip, MD**
Marseilles, France
Reproductive Counseling and Newborn Screening

10:10 AM 22q & A

10:20 AM Coffee Break

Session III: Care I – Physical Health

10:50 AM **Marta Unolt, MD**
Rome, Italy
The Heart

11:00 AM **Kathleen Sullivan, MD, PhD**
Philadelphia, PA, USA
Infection and Autoimmune Disease

11:10 AM **Lorraine Katz, MD**
Philadelphia, PA, USA
Calcium, Thyroid, and Growth

11:20 AM **Jelle Homans, MD**
Utrecht, the Netherlands
Scoliosis

11:30 AM **Daniel Corwin, MD**
Philadelphia, PA, USA
Advocating During Emergencies

11:40 AM 22q & A

11:55 AM **Steven Handler, MD**
Philadelphia, PA, USA
Ears, Nose and Throat

12:05 PM **Cynthia Solot, MA, CCC**
Philadelphia, PA, USA
Speech

12:15 PM **Maria Mascarenhas, MD**
Philadelphia, PA, USA
Gastrointestinal Differences

12:25 PM **Peggy Eicher, MD**
Patterson, NJ, USA
Feeding, Swallowing and Treatment Strategies

12:35 PM **Solveig Oskarsdottir, MD**
Goteborg, Sweden
Fatigue

12:45 PM 22q & A

1:00 PM **Lunch and “Celebrity” Fashion Show – Designs by Tessa Koller**

Session IV: Care II – Development and Schooling

2:00 PM **Cynthia Solot, MA, CCC**
Philadelphia, PA, USA
Language Development: From Babbling to Brainstorming

2:10 PM **Madeline Chadehumbe, MD**
Philadelphia, PA, USA
Seizures and Structural Brain Differences

2:20 PM **Ania Fiksinski, MS**
Utrecht, the Netherlands
Understanding IQ Scores

- 2:30 PM** *Emily Palen, MS, LCGC*
Danville, PA, USA
Integrating the 22q11.2 Diagnosis into the School Setting
- 2:40 PM** *Edward Moss, PhD*
Bryn Mawr, PA, USA
Putting the “I” in IEP: Education Across the Lifespan and Vocations Thereafter
- 3:05 PM** 22q & A
- 3:25 PM** **Afternoon Tea**
- Session V: Care III – Mental Health and Functioning**
- 3:55 PM** *Jacob Vorstman, MD, PhD*
Toronto, Ontario, Canada and Utrecht, the Netherlands
Mental Health and Treatment in Children and Teens
- 4:20 PM** *Anne Bassett, MD*
Toronto, Ontario, Canada
Optimizing Outcomes for Adults
- 4:45 PM** *Therese van Amelsvoort, MD, PhD*
Maastricht, the Netherlands
Mental Health and Treatment in Adults
- 5:10 PM** 22q & A
- 5:30 PM** *Tessa Koller*
Chicago, IL, USA
Family Voices
- 5:40 PM** 22q & A
- 5:45 PM** **Day I Adjourn**
- 7:30 PM** *Dinner, Family Dancing, and International Silent Auction*
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Day 2 **July 15th**

7:30 AM **Registration Opens**

8:00 AM **Pooja Panwar, DMD**
Duncan, British Columbia, Canada
Family Voices

Session VI: Developing Novel Interventions

8:15 AM **Antonio Baldini, MD**
Naples, Italy
Correcting Birth Defects Prenatally

8:35 AM **Elizabeth Illingworth, PhD**
Naples, Italy
Understanding the Brain

8:55 AM **22q & A**

9:10 AM **Raquel Gur, MD, PhD**
Philadelphia, PA, USA
Report from the International 22q11.2 Brain and Behavior Consortium

9:25 AM **Hakon Hakonarson, MD, PhD**
Philadelphia, PA, USA
Personalized Behavioral Medical Therapies

9:40 AM **Maria Mascarenhas, MD**
Philadelphia, PA, USA
What Integrative Medicine Has to Offer Behavioral Management

9:55 AM **22q & A**

10:10 AM **Coffee Break**

Session VII: Looking Out and Looking In

10:40 AM **Rick Guidotti**
New York, NY, USA
Positive Exposure

- 11:15 AM** **Leanne Magee, PhD**
Philadelphia, PA, USA
Body Image
- 11:25 AM** **Linda Campbell, PhD**
Newcastle, NSW, Australia
Approaching Anxiety
- 11:35 AM** **Marta Unolt, MD**
Rome, Italy
Transition to Adulthood
- 11:45 AM** 22q & A
- 12:00 PM** **Andrea Shugar, MS**
Toronto, Ontario, Canada
Keeping Safe as an Emerging Adult
- 12:10 PM** **Cheryl Cytrynbaum, MS**
Toronto, Ontario, Canada
Advocacy Skills for Teens and Young Adults
- 12:20 PM** **Caren Kelman, MSW**
Philadelphia, PA, USA
Supporting Patients, Families and Siblings
- 12:30 PM** 22q & A
- 12:45 PM** **Lunch**
- 1:30 PM** **Michael Weinberg and Company**
Newtown, PA, USA and across the globe
Patient Voices: A Panel and Performance

Session VIII: Concurrent Breakouts – Addressing Age Specific Questions

- 2:00 PM** **Group A – General Medical Issues: Ages 0 - 10 years**
Daniel Corwin, Peggy Eicher, Steven Handler, Lorraine Katz, Maria Mascarenhas, Donna McDonald-McGinn, Marta Unolt
- Group B - Brain and Behavior: Ages 11- 17 years**
Madeline Chadehumbe, Ania Fiksinski, Hakon Hakonarson, Ed Moss, Emily Palen, Cindy Solot, Jacob Vorstman

Group C – General Medical Issues: Ages 18 and Older

Anne Bassett and Erica Schindewolf

Group D – A Place for Patient Voices - Ages 16 and Older

Alice Bailey, Linda Campbell, Cheryl Cytrynbaum, Raquel Gur, Caren Kelman, Leanne Magee, Andrea Shugar, Therese van Amelsvoort

3:00 PM Transition Break

3:15 PM Group A – Brain and Behavior: Ages 0 - 10 years

Madeline Chadehumbe, Ania Fiksinski, Hakon Hakonarson, Emily Palen, Cindy Solot, Jacob Vorstman

Group B – General Medical Issues: Ages 11 - 17 years

Daniel Corwin, Peggy Eicher, Steven Handler, Lorraine Katz, Maria Mascarenhas, Donna McDonald-McGinn, Erica Schindewolf, Marta Unolt

Group C – Brain and Behavior: Ages 18 and Older

Anne Bassett, Raquel Gur, Leanne Magee, Ed Moss, Andrea Shugar, Therese van Amelsvoort

Group D – A Voice for Families: Parents, Grandparents, Siblings, and Caregivers

Alice Bailey, Linda Campbell, Cheryl Cytrynbaum, Caren Kelman, Leanne Magee, Andrea Shugar

4:15 PM Afternoon Tea

Session IX: Caring for the Whole Family

4:45 PM Anne Bassett, MD

Toronto, Ontario, CA

The Importance of Having a Medical Manager

4:55 PM Maria Kamper

Sydney, NSW, Australia

A Patient Coordination Portal and Care App

5:05 PM Alice Bailey, BA

Philadelphia, PA, USA

When Traveling for Care is the Only Option

5:15 PM **Anne Lawlor**
Dublin, Ireland
Developing Integrated Care: A Parent-Clinician Collaboration

5:25 PM **Linda Campbell, PhD**
Newcastle, NSW, Australia
Care for the Caregivers

5:35 PM **22q & A**

Session X: *Moving Forward Together*

5:45 PM **Julie and Paul Wootton**
Stourbridge, England, UK
Still Honoring Max - While Raising His Siblings

5:55 PM **Sheila Kambin, MD**
Matawan, NJ, USA
Working Together Works: 22q at the Zoo and “My Child Has 22q”

6:05 PM **Donna McDonald-McGinn, MS, LCGC**
Philadelphia, PA, USA
When Will We See You Again?

6:15 PM **22q & A**

6:30 PM **Meeting Adjourned**

Day 3 **July 16th**

9:30 AM ***Family Fun Day Monday (hosted by Pooja Panwar and Family)***

Wildwood Pacific Bistro at the Crystal Lodge

- Separate registration required
- Includes breakfast and entertainment for children
- See Registration Form for details

11:30 AM Breakfast Adjourns but feel free to linger outdoors, stroll to the Olympic Plaza Playground, cool off under a sprinkler, practice your putting, or just mix and mingle!



Examples of additional activities:

Whistler Golf Club:

Located directly across from the Westin Hotel and Spa

Park Bridge Mini Golf:

<http://www.parkbridge.com/en-ca/rv-cottages/riverside-resort/facilities-activities/riverside-green>

Whistler Farmer's Market:

Located in Upper Village Stroll at the base of Blackcomb Mountain

Open Sundays 11:00 AM – 4:00 PM

DIY Scavenger Hunt:

<https://www.whistler.com/pdf/scavengerhunts/whistler-summer-savenger-hunt.pdf>

Yoga:

Located at the Four Seasons Hotel: https://m.fourseasons.com/whistler/services_and_amenities/other-facilities---services/fitness_facilities/

The Brew House:

Located across from Millennium Place

Free tours and beer sampling every Saturday at 3:00 PM <http://www.mjg.ca/brewhouse/>

Forged Axe Throwing:

Located 15 minutes south of Whistler Village in Function Junction

\$35/person <https://www.forgedaxe.ca/>

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