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 Can Be 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  Michele Lambert, MD  
Philadelphia, PA, USA  
*Bleeding and Malignancies*
11:30 AM  Jelle Homans, MD  
Utrecht, the Netherlands  
Scoliosis

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 and Swallowing

12:35 PM  Daniel Corwin, MD  
Philadelphia, PA  
Advocating During Emergencies

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**
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*

8:30 AM  
Elizabeth Illingworth, PhD  
Naples, Italy  
*Understanding the Brain*

8:45 AM  
Kathleen Sullivan, MD, PhD  
Philadelphia, PA, USA  
*Environmental Influences*

9:00 AM  
22q & A

9:15 AM  
Raquel Gur, MD, PhD  
Philadelphia, PA, USA  
*Report from the International 22q11.2 Brain and Behavior Consortium*

9:30 AM  
Hakon Hakonarson, MD, PhD  
Philadelphia, PA, USA  
*Personalized Behavioral Medical Therapies*

9:45 AM  
Maria Mascarenhas, MD  
Philadelphia, PA, USA  
*What Integrative Medicine Has to Offer Behavioral Management*

10:00 AM  
22q & A

10:15 AM  
Coffee Break
Session VII: Looking Out and Looking In

10:45 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, Jelle Homans, Lorraine Katz, Michele Lambert, Maria Mascarenhas, Donna McDonald-McGinn, Kathleen Sullivan, 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, Jelle Homans, Lorraine Katz, Michele Lambert, Maria Mascarenhas, Donna McDonald-McGinn, Erica Schindewolf, Kathleen Sullivan, 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  
**Nicole Philip-Sarles, MD**
Marseilles, France
The Importance of Having a Medical Manager
<table>
<thead>
<tr>
<th>Time</th>
<th>Speaker</th>
<th>Location</th>
<th>Topic</th>
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<tbody>
<tr>
<td>4:55 PM</td>
<td>Maria Kamper</td>
<td>Sydney, NSW, Australia</td>
<td><strong>A Patient Coordination Portal and Care App</strong></td>
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<tr>
<td>5:05 PM</td>
<td>Alice Bailey, BA</td>
<td>Philadelphia, PA, USA</td>
<td><strong>When Traveling for Care is the Only Option</strong></td>
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<td>5:15 PM</td>
<td>Anne Lawlor</td>
<td>Dublin, Ireland</td>
<td><strong>Developing Integrated Care: A Parent-Clinician Collaboration</strong></td>
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<td>5:25 PM</td>
<td>Linda Campbell, PhD</td>
<td>Newcastle, NSW, Australia</td>
<td><strong>Care for the Caregivers</strong></td>
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<td>5:35 PM</td>
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<td><strong>22q &amp; A</strong></td>
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<td><strong>Session X: Moving Forward Together</strong></td>
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<td>5:45 PM</td>
<td>Julie and Paul Wootton</td>
<td>Stourbridge, England, UK</td>
<td><strong>Still Honoring Max - While Raising His Siblings</strong></td>
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<td>5:55 PM</td>
<td>Sheila Kambin, MD</td>
<td>Matawan, NJ, USA</td>
<td><strong>Working Together Works: 22q at the Zoo and “My Child Has 22q”</strong></td>
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<td>6:05 PM</td>
<td>Donna McDonald-McGinn, MS, LCGC</td>
<td>Philadelphia, PA, USA</td>
<td><strong>When Will We See You Again?</strong></td>
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<td>6:15 PM</td>
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<td><strong>22q &amp; A</strong></td>
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<td>6:30 PM</td>
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<td><strong>Meeting Adjourned</strong></td>
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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:

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:

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/

Need Childcare for the 22q11.2 Biennial Family Meeting?

Contact Babysitting Whistler!

- For over 14 years, Babysitting Whistler has been providing experienced and loving childcare to local families and visitors to Whistler

- Nannies are each carefully selected for their fun outgoing attitude along with the reliability expected from a childcare professional

- Babysitting Whistler will send a temporary, on-call, occasional, short term, or a last-minute babysitter to the hotel

- Visit http://www.babysittingwhistler.com for booking!