**Day 1  July 14th**

7:00 AM  *Registration Opens – Emerald Foyer*

8:00 AM  *Welcome from the 22q11.2 Society and Local Arrangements Committee – Emerald Ballroom*

  *Peter Scambler, Donna McDonald-McGinn, Anne Bassett, Jacob Vorstman, and Pooja Panwar*

**Session 1  Detection – Emerald Ballroom**

*Chairs: Peter Scambler and Donna McDonald-McGinn*

8:05 AM  *A Birds-Eye View of 22q – Chromosome 22q11.2 Deletion and Duplication Syndromes*

  *Donna McDonald-McGinn, MS, LCGC*

  *22q and You Center, Clinical Genetics Center, and Section of Genetic Counseling*

  *Division of Human Genetics*

  *Children’s Hospital of Philadelphia*

  *Perelman School of Medicine of the University of Pennsylvania*

  *Philadelphia, PA, USA*

8:20 AM  *Origin of the Chromosome 22q11.2 Deletion and Duplication*

  *Joris Vermeesch, PhD*

  *KU Leuven*

  *Leuven, Belgium*

8:35 AM  *Human and mouse studies to understand the cause of congenital heart disease in 22q11.2DS*
Bernice Morrow, PhD  
Albert Einstein College of Medicine  
New York, NY, USA

8:50 AM  **Effect of Missing or Extra Genes on Physical Development**  
Peter Scambler, MD  
University College London  
Great Ormond Street Institute of Child Health  
London, England, UK

9:05 AM  **Prenatal Findings and Reproductive Counseling**  
Nicole Philip-Sarles, MD  
Hôpital de la Timone  
Marseille, France

9:20 AM  **Frequency and What We Have Learned from Non-Invasive Prenatal Testing**  
Melissa Maisenbacher, MS, LCGC  
Natera, Inc.  
Virginia Beach, VA, USA

9:35 AM  22q & A

**Session 2  Care: Physical Health I – Emerald Ballroom**  
Chairs: Bernice Morrow and Kathleen Sullivan

9:50 AM  **The Heart**  
Marta Unolt, MD  
Ospedale Bambino Gesù  
La Sapienza University  
Rome, Italy

10:05 AM  **Infection and Autoimmune Disease**  
Kathleen Sullivan, MD, PhD  
22q and You Center  
Division of Allergy and Immunology  
Children’s Hospital of Philadelphia
Perelman School of Medicine of the University of Pennsylvania
Philadelphia, PA, USA

10:20 AM  **Calcium, Thyroid, and Growth**
**Lorraine Katz, MD**
22q and You Center
Division of Endocrinology
Children’s Hospital of Philadelphia
Perelman School of Medicine of the University of Pennsylvania
Philadelphia, PA, USA

10:35 AM  **Scoliosis**
**Jelle Homans, MD**
University of Utrecht
Utrecht, the Netherlands

10:45 AM  **22q & A**

11:00 AM  **Coffee Break – Emerald Foyer**

11:30 AM  **Family Breakout I: Preparing for the Fashion Show – Alpine A**
**Alice Bailey, Ania Fiksinski, Chrissy Gonzalez-Gandolfi, Stephanie Jeong, Caren Kelman, Tessa Koller, Daniel McGinn, MJ McGinn, Marta Unolt, Michael Weinberg, and Models**
Participants must be 16 years and older or accompanied by an adult

**Session 3  Care: Physical Health II – Emerald Ballroom**
**Chairs: Maria Mascarenhas and Cynthia Solot**

11:30 AM  **Ear, Nose and Throat**
**Steven Handler, MD**
22q and You Center
Division of Otolaryngology
Children’s Hospital of Philadelphia
Perelman School of Medicine of the University of Pennsylvania
Philadelphia, PA, USA
11:45 AM  *Speech and Palate*
*Cynthia Solot, MA, CCC*
22q and You Center
Center for Childhood Communication
Cleft Palate and VPD Clinics
Children’s Hospital of Philadelphia
Perelman School of Medicine of the University of Pennsylvania
Philadelphia, PA, USA

12:00 PM  *Feeding, Swallowing and Other Gastrointestinal Differences*
*Maria Mascarenhas, MD*
22q and You Center
Division of Gastroenterology
Children’s Hospital of Philadelphia
Perelman School of Medicine of the University of Pennsylvania
Philadelphia, PA, USA

12:15 PM  *Advocating During Emergencies*
*Daniel Corwin, MD, MSCE*
Children’s Hospital of Philadelphia
Division of Emergency Medicine
Perelman School of Medicine of the University of Pennsylvania
Philadelphia, PA, USA

12:30 PM  22q & A

**Session 4**  *Care: Early Development and Brain Differences – Emerald Ballroom*

12:45 PM  *Language Development*
*Cynthia Solot, MA, CCC*
22q and You Center
Center for Childhood Communication
Cleft Palate and VPD Clinics
Children’s Hospital of Philadelphia
Perelman School of Medicine of the University of Pennsylvania
Philadelphia, PA, USA
1:00 PM  
**Seizures and Structural Brain Differences**  
Madeline Chadehumbe, MD  
22q and You Center  
Division of Neurology  
Children’s Hospital of Philadelphia  
Perelman School of Medicine of the University of Pennsylvania  
Philadelphia, PA, USA

1:15 PM  
22q & A

1:30 PM  
Group Photo followed by Fashion Show and Expert Tables Luncheon

*Designs by Tessa Koller – Emerald B*

2:15 PM  
**Family Breakout II: Preparing for the Family Voices Performance – Alpine A**  
Alice Bailey, Chrissy Gonzalez-Gandolfi, Rick Guidotti, Stephanie Jeong, Caren Kelman, Tessa Koller, Daniel McGinn, MJ McGinn, Michael Weinberg, and All Performers  
Participants must be 16 years and older or accompanied by an adult

**Session 5**  
**Care: Academic Achievement and Behavioral Health – Emerald Ballroom**  
Chairs: Jacob Vorstman and Edward Moss

2:15 PM  
**Understanding IQ Scores**  
Ania Fiksinski, MS  
University of Utrecht  
Utrecht, the Netherlands

2:30 PM  
**Making Sense of the Diagnostic Alphabet Soup in the School Setting**  
Emily Palen, MS, LCGC  
Geisinger Medical Center  
Danville, PA, USA
2:45 PM  **Putting the “I” in IEP: Education Across the Lifespan and Vocations Thereafter**

*Edward Moss, PhD*
Malamut and Moss, Inc.
Bryn Mawr, PA, USA

3:15 PM  **Behavioral Health in Children and Teens**

*Jacob Vorstman, MD, PhD*
Hospital for Sick Children
University of Toronto
University of Utrecht
Toronto, Ontario, Canada
Utrecht, the Netherlands

3:45 PM  22q & A

4:00 PM  **Afternoon Tea – Emerald Foyer**

4:30 PM  **Family Breakout III: Mindfulness towards Improving Performance – Alpine A**

Alice Bailey, Ania Fiksinski, Rick Guidotti, Caren Kelman, Daniel McGinn, MJ McGinn, Edward Moss, Jacob Vorstman

**Participants must be 16 years and older or accompanied by an adult**

**Session 6**  **Care: Mental Health and Functioning – Emerald Ballroom**

Chairs: Anne Bassett and Therese Van Amelsvoort

4:30 PM  **Optimizing Outcomes for Adults**

*Anne Bassett, MD*
Dalglish Family 22q11.2 Hearts and Mind Clinic
Center for Addiction and Mental Health
University of Toronto
Toronto, Ontario, Canada

5:00 PM  **Mental Health and Treatment in Adults**

*Therese van Amelsvoort, MD, PhD*
University of Maastricht
Maastricht, the Netherlands
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<tr>
<td>5:30 PM</td>
<td>22q &amp; A</td>
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| 5:45 PM | **Family Voices**  
Marc and Barbi Weinberg  
Holland, PA, USA |
| 5:55 PM | 22q & A                                                              |
| 6:00 PM | Day I Meeting Adjourn                                                |
| 7:00 PM | **Family Photos by Rick Guidotti** – Outdoor Plaza                   |
| 7:30 PM | **Dinner, Family Dancing, and International Silent Auction** – Outdoor Plaza |

### Day 2  July 15th

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<tr>
<td>7:30 AM</td>
<td><strong>Registration Opens</strong> – Emerald Foyer</td>
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<tr>
<td>8:00 AM</td>
<td><strong>Family Voices – Emerald Ballroom</strong></td>
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|         | Pooja Panwar, DMD  
Victoria, British Columbia, Canada                                      |

**Session 7  Developing Novel Interventions – Emerald Ballroom**  
Chairs: Antonio Baldini and Elizabeth Illingworth

<table>
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<tr>
<td>8:15 AM</td>
<td><strong>Correcting Birth Defects Prenatally</strong></td>
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Antonio Baldini, MD
Institute of Genetics and Biophysics
National Research Council
University Federico II
Naples, Italy

8:35 AM  Understanding the Brain: Is the TBX1 Gene Important?
Elizabeth Illingworth, PhD
Institute of Genetics and Biophysics
National Research Council
Naples, Italy

8:55 AM  22q & A

9:10 AM  Report from the International 22q11.2 Brain and Behavior Consortium
Anne Bassett, MD
Dalglish Family 22q11.2 Hearts and Mind Clinic
Centre for Addiction and Mental Health
University of Toronto
Toronto, Ontario, Canada

9:25 AM  Personalized Behavioral Medical Therapies
Hakon Hakonarson, MD, PhD
Center for Applied Genomics
Children’s Hospital of Philadelphia
Perelman School of Medicine of the University of Pennsylvania
Philadelphia, PA, USA

9:40 AM  What Integrative Medicine Has to Offer Behavioral Management
Edward Moss, PhD
Malamut and Moss, Inc.
Bryn Mawr, PA, USA

9:55 AM  22q & A

10:10 AM  Change How You See, See How You Change
Rick Guidotti
10:50 AM  22q & A

11:00 AM  Coffee Break

**Session 8  Looking Out and Looking In**

11:30 AM  *Family Breakout IV: PEARLS – a Novel Approach to Storytelling – Alpine A*
Ania Fiksinski, Rick Guidotti, and MJ McGinn
Participants must be ages 16 and Older or accompanied by an adult

11:30 AM  *Transition to Adulthood*
Donna McDonald-McGinn, MS, LCGC
22q and You Center, Clinical Genetics Center, and Section of Genetic Counseling
Division of Human Genetics
Children’s Hospital of Philadelphia
Perelman School of Medicine of the University of Pennsylvania
Philadelphia, PA, USA

11:45 AM  *Keeping Safe as an Emerging Adult*
Andrea Shugar, MS, CGC
Hospital for Sick Children
University of Toronto
Toronto, Ontario, Canada

12:00 PM  *Advocacy Skills for Teens and Young Adults*
Cheryl Cytrynbaum, MS, CGC
Hospital for Sick Children
University of Toronto
Toronto, Ontario, Canada

12:15 PM  *Approaching Anxiety*
Linda Campbell, PhD
The University of Newcastle
Newcastle, NSW, Australia

12:30 PM  **Supporting Patients, Families and Siblings**
**Caren Kelman, MSW**
22q and You Center
Division of Human Genetics and Social Work
Children’s Hospital of Philadelphia
Philadelphia, PA, USA

12:45 PM  **22q & A**

1:00 PM  **Patient Voices: A Panel and Performance**
**Michael Weinberg, Tessa Koller, and Company**
Holland, PA, USA, Chicago, IL, USA, and across the globe

1:30 PM  **Age Specific Tables Luncheon – Emerald B**

**Session 9  Concurrent Breakouts: Age Specific Questions**

2:30 PM  **Group A – Alpine A:**
**Family Breakout V: Healing Through Art - A Workshop Employing Photography and Writing**
Ania Fiksinski, Rick Guidotti, and MJ McGinn
Participants must be ages 16 and Older or accompanied by an adult

**Group B – Alpine D:**
**The Early Years – General Medical Issues: Ages 0 - 10 years**
Alice Bailey, Daniel Corwin, Steven Handler, and Donna McDonald-McGinn

**Group C – Alpine E:**
**School Aged Children – Brain and Behavior: Ages 11-17 years**
Madeline Chadehumbe, Cheryl Cytrynbaum, Hakon Hakonarson, Caren Kelman, Daniel McGinn, Edward Moss, Emily Palen, Cindy Solot, Jacob Vorstman

**Group D – Emerald Ballroom C:**
**Moving into Adulthood – General Medical Issues: Ages 18 and Older**
Anne Bassett, Linda Campbell, Andrea Shugar, and Therese van Amelsvoort

3:15 PM  Transition Break

Session 10 Concurrent Breakouts – Age Specific Questions

3:20 PM  Group A – Alpine A:
Family Breakout VI: Healing Through Art 2 - A Workshop Employing Photography and Writing
Ania Fiksinski, Rick Guidotti, and MJ McGinn
Participants must be ages 16 and Older or accompanied by an adult

Group B – Alpine D:
Brain and Behavior: Ages 0 - 10 years
Madeline Chadehumbe, Hakon Hakonarson, Daniel McGinn, Emily Palen, Cindy Solot, Jacob Vorstman

Group C – Alpine D:
General Medical Issues: Ages 11 - 17 years
Daniel Corwin, Steven Handler, Donna McDonald-McGinn

Group D – Emerald Ballroom:
Brain and Behavior: Ages 18 and Older
Anne Bassett, Edward Moss, Andrea Shugar, Therese van Amelsvoort

Group E – Westin Lobby:
A Voice for Families: Parents, Grandparents, Siblings, and Caregivers
Alice Bailey, Linda Campbell, Cheryl Cytrynbaum, Caren Kelman

4:05 PM  Afternoon Tea – Emerald Foyer

Session 11  Caring for the Whole Family – Emerald Ballroom

4:35 PM  Family Voices
Carol and Louis Cavana
Woodbridge, NJ, USA
4:45 PM  The Importance of Having a Medical Manager
Anne Bassett, MD
Dalglish Family 22q11.2 Hearts and Mind Clinic
Centre for Addiction and Mental Health
University of Toronto
Toronto, Ontario, Canada

4:55 PM  A Patient Coordination Portal and Care App – The First of Its Kind!
Maria Kamper
Sydney, NSW, Australia

5:05 PM  When Traveling for Care is the Only Option
Alice Bailey, BA
22q and You Center
Division of Human Genetics
Children’s Hospital of Philadelphia
Philadelphia, PA, USA

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

5:25 PM  Making Sure to Provide Care for the Caregivers
Linda Campbell, PhD
The University of Newcastle
Newcastle, NSW, Australia

5:35 PM  22q & A

Session 12  Moving Forward Together

5:45 PM  Still Honoring Max - While Raising His Siblings: Storming the House of Parliament and Other Such Adventures
Julie Wootton
Stourbridge, England, UK
Sheila Kambin, MD
Matawan, NJ, USA

6:05 PM  When Will We See You Again?
Donna McDonald-McGinn, MS, LCGC
22q and You Center, Clinical Genetics Center, and Section of Genetic Counseling
Division of Human Genetics
Children’s Hospital of Philadelphia
Perelman School of Medicine of the University of Pennsylvania
Philadelphia, PA, USA

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:**  

**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/

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