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 – 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  Important Genes within the Chromosome 22q11.2 Region
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  Non-Invasive Prenatal Testing and Newborn Screening  
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 Communication Disorders and Cleft and Craniofacial Clinic  
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  
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 Communication Disorders and Cleft and Craniofacial Clinic  
Children’s Hospital of Philadelphia  
Perelman School of Medicine of the University of Pennsylvania  
Philadelphia, PA, USA
<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>1:00 PM</td>
<td><strong>Seizures and Structural Brain Differences</strong></td>
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<tr>
<td></td>
<td><em>Madeline Chadehumbe, MD</em></td>
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<td>22q and You Center</td>
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<td>Division of Neurology</td>
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<td>Philadelphia, PA, USA</td>
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<td>1:15 PM</td>
<td>22q &amp; A</td>
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<tr>
<td>1:30 PM</td>
<td><strong>Fashion Show and Expert Tables Luncheon</strong></td>
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<td><em>Designs by Tessa Koller – Emerald B</em></td>
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<td>2:15 PM</td>
<td><strong>Family Breakout II: Preparing for the Family Voices Performance – Alpine A</strong></td>
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<td><em>Alice Bailey, T. Blaine Crowley, Rick Guidotti, Stephanie Jeong, Caren Kelman, Tessa Koller, Daniel McGinn, MJ McGinn, Michael Weinberg, and All Performers</em></td>
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<td>Participants must be 16 years and older or accompanied by an adult</td>
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<td><strong>Session 5</strong></td>
<td><strong>Care: Academic Achievement and Behavioral Health – Emerald Ballroom</strong></td>
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<td><em>Chairs: Jacob Vorstman and Edward Moss</em></td>
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<td>2:15 PM</td>
<td><strong>Understanding IQ Scores</strong></td>
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<td><em>Ania Fiksinski, MS</em></td>
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<td>University of Utrecht</td>
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<td><strong>Making Sense of the Diagnostic Alphabet Soup in the School Setting</strong></td>
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<td><em>Emily Palen, MS, LCGC</em></td>
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<td>Geisinger Medical Center</td>
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<td>Danville, PA, USA</td>
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<td>2:45 PM</td>
<td><strong>Putting the “I” in IEP: Education Across the Lifespan and Vocations Thereafter</strong></td>
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<td><em>Edward Moss, PhD</em></td>
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<td>Bryn Mawr, PA, USA</td>
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<td>3:15 PM</td>
<td><strong>Behavioral Health in Children and Teens</strong></td>
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<td><em>Jacob Vorstman, MD, PhD</em></td>
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<td>Hospital for Sick Children</td>
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<td>Toronto, Ontario, Canada</td>
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<td>3:45 PM</td>
<td>22q &amp; A</td>
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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

5:30 PM  
22q & A

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

7:30 AM  Registration Opens – Emerald Foyer

8:00 AM  Family Voices – Emerald Ballroom
Pooja Panwar, DMD
Duncan, British Columbia, Canada

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

8:15 AM  Correcting Birth Defects Prenatally
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
Ed 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*
*Founder and Director, Positive Exposure*
*New York, NY, USA*

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*  
*Hospital for Sick Children*
*University of Toronto*
*Toronto, Ontario, Canada*

12:00 PM  **Advocacy Skills for Teens and Young Adults**  
*Cheryl Cytrynbaum, MS*  
*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 B:
   The Early Years – General Medical Issues: Ages 0 - 10 years
   Alice Bailey, Daniel Corwin, Steven Handler, and Donna McDonald-McGinn

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

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

5:55 PM  
**Working Together Works – 22q at the Zoo Worldwide Awareness Day, Etc.**
*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

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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/

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

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- 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!