

# **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 14<sup>th</sup>**

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*

- 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**      ***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, T. Blaine Crowley, 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*
- 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**
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**Day 2      July 15<sup>th</sup>**

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 16<sup>th</sup>**

**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!

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## 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/](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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