

**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 ***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

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*  
*Victoria, 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***

**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**



*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, 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*

**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-scavenger-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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