

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 ***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 15th

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

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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:

<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/

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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