



22q11.2 Society Family Meeting Program

Le Méridien Lav Hotel

Split, Croatia - On the Dalmatian Coast

Sunday, June 26 – Tuesday, June 28, 2022

www.22qsociety.org

Saturday, June 25th

**15:00 – 17:00 Registration Open: Badge, Program and Bag Pick-up – Jim’s Foyer, Grand Dalmacija Ballroom
Speaker Ready Room Open – Hvar**

Sunday, June 26th

**6:00 Registration Open: Badge, Program and Bag Pick-up – Jim’s Foyer, Grand Dalmacija Ballroom
Speaker Ready Room Open – Hvar**

7:00 Breakfast – Spalatum Restaurant

Session 1 Opening Ceremonies - Grand Dalmacija Ballroom

22q11.2 Society Trustees

Donna M. McDonald-McGinn, Anne Bassett, Bernice Morrow, Peter Scambler, Ann Swillen

8:00 Musical Prelude

Karen Ruckman-Lindsay

8:05 22q11.2 Society Welcome

22q11.2 Society Trustees

Donna M. McDonald-McGinn, Anne Bassett, Bernice Morrow, Peter Scambler, Ann Swillen

8:10 Croatia - Delighted to Greet You

Le Méridien Lav Hotel

Vana Kovacic

8:15 2020 and 2022 Inaugural Clodagh Murphy Unsung Hero Awards

In Loving Memory of Clodagh Murphy

Donna M. McDonald-McGinn, 22q11.2 Society Chair

On behalf of 2018 award recipient Ryan Dempster

Session 1 *Setting the Stage - Grand Dalmacija Ballroom*

- 8:25** **1** **Family Voices**
From Zagreb to Perth and Back again – A Mother’s Tale
Vesna Harcourt
- 8:40** **2** **Change How You See – See How You Change**
Rick Guidotti
- 9:10** **3** **A Birds Eye View of 22q**
Donna M. McDonald-McGinn
- 9:35** **4** **Bounce Back Better through Integrative Health**
Maria Mascarenhas
- 9:45** **Q&A**
- 10:00** **Coffee Break - Grand Dalmacija Terrace**
- 10:30** **5** **Family Voices**
A Different Life: Changing the Stigma Around Learning Differences
Quinn and Fabiola Bradlee
- 10:45** **6** **Enhancing Traditional Medicine with Complementary Therapies**
Greg Hedler
Maria Mascarenhas
Lisa Squires
- 12:30** **Group Photo and Lunch – Spalatum Restaurant**

Session 2 *Of Mice and Men - Grand Dalmacija Ballroom*

- 13:30** **7** **Results of Missing or Extra Genes on Human Development**
Peter Scambler
- 13:45** **8** **How Animal Studies Inform Healthcare in Humans**
Bernice Morrow
- 14:00** **9** **The Importance of Genes on the Unaffected Chromosome 22**
Beata Nowakowska
- 14:15** **10** **SNAP29 Mouse Model**
Loydie Jerome-Majewska
- 14:30** **Q&A**

Session 3 **Getting to Know You - Grand Dalmacija Ballroom**

14:45 **Musical Interlude**
Karen Ruckman-Lindsay

14:50 **11** **Family Voices**
Through my Lens
Tessa Koller

15:00 **12** **An International Panel of Experts**
Australia – Maria Kamper and Brian Harcourt
Belgium – Paul Havelange and Ann Swillen
Canada – Stephanie St. Pierre and Anne Bassett
Chile – Patricia Jesam and Gabriela Repetto
Denmark – Anete Norling
Ireland – Anne Lawlor and Lorna Kerin
Italy – Daniela Aguglia and Bruno Marino
Netherlands – Erik Boot and Sasja Duijff
Poland – Beata Nowakowska
Romania – Stela Pirvu
Serbia – Vesna Vujcic
Spain – Aldha Pozo-Rodriguez and Sixto Garcia-Minaur
Sweden – RoseMarie Larrson and Solveig Oskarsdottir
United Kingdom – Paul and Julie Wootton and Peter Scambler
United States of America – Candice Hamilton and Donna McDonald-McGinn

16:00 **Afternoon Tea - Grand Dalmacija Terrace**

Session 4 **Empowering Change for Good – Grand Dalmacija Ballroom**

16:30 **13** **Supporting Translational Possibilities**
FAST (Foundation for Angelman Syndrome Therapeutics)
Allyson Berent

17:00 **14** **Care4Parents: On Promoting the Psychological Health and Resilience of Parents**
Sasja Duijff

17:30 **15** **Build your Best Self Through Food – Anti-Inflammatory Nutrition**
Greg Hedler
Maria Mascarenhas
Lisa Squires

18:00 **Dinner and Anti-Inflammatory Cookbook Signing – Grand Dalmacija Terrace**

20:00 **Integrative Health Experiential – Korcula**
Release Your Day Through Body and Mind Practices
Greg Hedler
Maria Mascarenhas
Lisa Squires

Monday, June 27th

6:00 **Registration Open: Badge, Program and Bag Pick-up – Jim’s Foyer, Grand Dalmacija Ballroom**
Speaker Ready Room Open – Hvar

6:30 **Sunrise Yoga – Meet in Korcula at 6:25**

7:00 **Breakfast – Spalatum Restaurant**

Session 5 **Care Across the Lifespan – Grand Dalmacija Ballroom**

8:00 **16** **Optimal Heart Health**
Bruno Marino

8:15 **17** **Infections, Vaccines, Allergies and Asthma**
Caterina Cancrini

8:30 **18** **Calcium, Thyroid, and Growth**
Lorraine Katz

8:45 **Q&A**

9:00 **19** **Feeding, Swallowing and Gastrointestinal Problems Across the Lifespan**
Maria Mascarenhas

9:15 **20** **Bones**
Steven de Reuver

9:30 **21** **Brain and Spinal Cord**
Sarah Hopkins

9:45 **Q&A**

8:00 – 10:00 **Concurrent Breakouts A**

Breakout 1A **Healing through Art: Photography – Brac I and II**
Rick Guidotti

Breakout 2A **Healing through Art: Drawing – Vis**
Tessa Koller

Breakout 3A **Positive Caregiving I – Korcula**
Designed for Parents, Grandparents and Other Caregivers
Greg Hedler
Lisa Squires

10:00 **Coffee Break - Grand Dalmacija Terrace**

Session 6 **Preschool to Employment and Everything in Between - Grand Dalmacija Ballroom**

10:30 **22** **Family Voices**
22q Ireland - Young Expert by Experience Panel (YEPP) with Lorna Kerin and Anne Lawlor
Emma Brady
Oisín Crotty
Amy Ellis
Sarah Fitzpatrick
Aine Lawlor
Niamh Moran

10:45 **23** **Delays in Emergence of Language**
Cindy Solot

11:00 **24** **Early Development and Academic Achievement**
Ann Swillen

11:15 **25** **Understanding Standardized Test Scores**
Ania Fiksinski

11:30 **26** **Neurological Differences in Adults**
Erik Boot

11:45 **27** **Education Across the Lifespan**
Ed Moss

12:00 **28** **Fatigue and its Impact on Everyday Life**
Elfi Vergaelen

12:15 **Q&A**

10:30 – 12:30 Concurrent Breakouts B

- Breakout 1B** **Seeing the Beauty in Everyday Life – Brac I and II**
Rick Guidotti
Tessa Koller
- Breakout 2B** **Creativity to Calm: Embellishing Notebooks – Vis**
Greg Hedler
Lisa Squires
- Breakout 3B** **Healing through Nature – Korcula**
Maria Mascarenhas
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12:30 **Lunch – Spalatum Restaurant**

Session 7 Understanding Behavior – Grand Dalmacija Ballroom

- 14:00** **29** **Family Voices**
Growing Together
Marc and Michael Weinberg
- 14:15** **30** **Behavioral Health in Children**
Jacob Vorstman
- 14:30** **31** **Optimizing Outcomes for Adults**
Anne Bassett
- 14:45** **32** **Behavioral Health and Treatment in Adults**
Therese van Amelsvoort
- 15:00** **33** **Social Difficulties in Adolescents and Young Adults**
Maude Schneider
- 15:15** **30** **Cognitive Behavioral Therapy**
Sandra Meier
- 15:30** **Q&A**
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14:00 – 16:00 Concurrent Breakouts C

- Breakout 1C** **Finding Beauty Within – Brac I and II**
Rick Guidotti and Tessa Koller
- Breakout 2C** **Irish Family Support – Vis**
YEEP Group

Breakout 3C **Movement and Massage – Korcula**
Greg Hedler
Lisa Squires

16:00 **Afternoon Tea - Grand Dalmacija Terrace**

16:30 – 18:00 **Concurrent Breakouts D**

Breakout 1D **Early Childhood – Korcula**
Caterina Cancrini
Sasja Duijff
Lisa Elden
Emily Gallagher
Sarah Hopkins
Lorraine Katz
Bruno Marino
Maria Mascarenhas
Donna McDonald-McGinn
Gabriela Repetto
Cindy Solot

Breakout 2D **School Aged – Brac I and II**
Jill Arganbright
Madeline Chadehumbe
Christopher Cielo
Steven de Reuver
Ania Fiksinski
Sixto Garcia-Minaur
Michele Lambert
Solveig Oskarsdottir
Maude Schneider
Lisa Squires
Ann Swillen
Jacob Vorstman

Breakout 3D **Adolescence and Adulthood – Brac III**
Anne Bassett
Natalie Blagowidow
Erik Boot
Raquel Gur
Greg Hedler
Ed Moss
Lisa Palmer
Erica Schindewolf
Therese van Amelsvoort
Elfi Vergaelen

Breakout 4D

Healing through Fashion and Performance – Grand Dalmacija Ballroom

Sarah Donoghue
Kim Gaiser
Victoria Guinta
Rick Guidotti
Catherine Hillin
Chloe Katz
Deirdre Kessler
Tessa Koller
Lauren Lairson
Alex Lambert
Lee Lambert
Daniel McGinn
Karen Ruckman-Lindsay
Michael Weinberg

18:00 **Gooshter Beach Club Dinner**

20:00 **Integrative Health Experiential – Korcula**
Release Your Day Through Body and Mind Practices
Greg Hedler
Maria Mascarenhas
Lisa Squires

Tuesday, June 28th

6:00 **Registration Open: Badge, Program and Bag Pick-up – Jim’s Foyer, Grand Dalmacija Ballroom**
Speaker Ready Room Open – Hvar

6:30 **Sunrise Yoga – Meet in Korcula at 6:25**

7:00 **Breakfast – Spalatum Restaurant**

Session 8 **Head’s Up! – Grand Dalmacija Ballroom**

8:00 **31** **Ears, Nose and Throat**
Lisa Elden

8:15 **32** **Hearing**
Jill Arganbright

8:30 **33** **Speech**
Cindy Solot

8:45	34	Palate <i>Oksana Jackson</i>
9:00	35	Breathing and Sleep <i>Christopher Cielo</i>
9:15	36	Bleeding <i>Michele Lambert</i>
9:30		Q&A

8:00 – 10:00 **Concurrent Breakouts E**

Breakout 1E	Narrative Medicine: Writing for Relaxation – Vis <i>MJ McGinn</i>
Breakout 2E	Flourishing through Fatherhood – Brac I and II Designed for Fathers, Grandfathers, and other Caregivers <i>Greg Hedler</i>
Breakout 3E	Mindfulness and Movement – Korcula <i>Maria Mascarenhas</i> <i>Lisa Squires</i>

10:00 **Coffee Break - Grand Dalmacija Terrace**

Session 9 ***Caring for the Whole Person – Grand Dalmacija Ballroom***

10:30	37	Family Voices Mother and Child Reunion <i>Karen Ruckman-Lindsay</i>
10:45	38	Pediatric and Adult Healthcare Recommendations <i>Anne Bassett, Erik Boot, Donna McDonald-McGinn, and Solveig Oskarsdottir</i>
11:15	39	Advocating During Emergencies <i>Emily Gallagher</i>
11:30	40	Keeping Safe as an Emerging Adult - Internet Safety, Medical Power of Attorney, Sexuality... <i>Lisa Palmer</i>
12:00		Q&A

10:30 – 12:30 Concurrent Breakouts F

- Breakout 1F** **Finding Beauty Within Photoshoot – Brac I and II**
Rick Guidotti
- Breakout 2F** **Writing for Stress Release – Vis**
MJ McGinn
- Breakout 3F** **Care4Minds: A Practical Workshop for Managing Parental Stress – Korcula**
Designed for Parents, Grandparents and Other Caregivers
Sasja Duijff
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12:30 **Lunch – Spalatum Restaurant**

Session 10 *Impact of Detection on Families - Grand Dalmacija Ballroom*

- 14:00** **40** **Family Voices**
Everything's Bigger in Texas
Suzi Beall Shaw
- 14:15** **41** **Improving Detection – Passing on the Chromosome 22q11.2 Deletion or Duplication**
Sixto Garcia-Minaur
- 14:30** **42** **Prenatal Clues to the Diagnosis**
Erica Schindewolf
- 14:45** **43** **Preimplantation Genetic Diagnosis and Prenatal Testing**
Natalie Blagowidow
- 15:00** **44** **Non-Invasive Prenatal Screening (NIPS) – Results of the SMART Study**
Hakon Hakonarson
- 15:15** **45** **Newborn Screening**
Anne Bassett
Hakon Hakonarson
Donna McDonald-McGinn
Julie Wootton
- 15:30** **46** **Reaching All the Lands**
Gabriela Repetto
- 15:45** **Q&A**
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14:00 – 16:00 **Concurrent Breakouts G**

- Breakout 1G** **Performance Rehearsal – Brac I and II**
Sarah Donoghue
Kim Gaiser
Victoria Guinta
Rick Guidotti
Catherine Hillin
Chloe Katz
Deirdre Kessler
Tessa Koller
Lauren Lairson
Alex Lambert
Lee Lambert
Daniel McGinn
MJ McGinn
Karen Ruckman-Lindsay
Michael Weinberg
- Breakout 2G** **Positive Caregiving II – Brac I and II**
Designed for Parents, Grandparents and Other Caregivers
Greg Hedler
Lisa Squires
- Breakout 3G** **Achieve your Best Health NOW – Korcula**
Maria Mascarenhas
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16:00 **Afternoon Tea - Grand Dalmacija Terrace**

- 16:30** 47 **The Promise of a Cure – Clinical Trials**
Madeline Chadehumbe
- 16:45** 48 **Bedside to Bench and Back Again**
Stas Zakharenko
- 17:00** **Q&A**
- 17:15** 49 **Moving Forward Together – The Power of a United Community**
Efforts from the IBBC and G2MH Network
Raquel Gur
Stakeholder’s Report
Donna McDonald-McGinn
22q Europe
Paul Havelange
22q Australia and New Zealand
Maria Kamper

Chromosome 22 Central
Stephanie Rese St. Pierre
International 22q11.2 Foundation, Inc.
Marc Weinberg
Max Appeal
Julie and Paul Wootton

17:45 **50** **Securing Government Funding**

Raquel Gur
Sandra Meier
Ann Swillen

18:00 **Q&A**

18:15 **Family Voices**

Performance
Karen Ruckman-Lindsay, Michael Weinberg, Tessa Koller, and Company

18:25 **Closing Remarks - 22q11.2 Society Trustees**

Donna McDonald-McGinn
Anne Bassett
Bernice Morrow
Peter Scambler
Ann Swillen

18:30 **See you in 2024 – Meeting Adjourn**

