The International 22q11.2 Family Meeting
hosted by the 22q11.2 Society

Le Méridien Lav Hotel
Split, Croatia - On the Dalmacijan Coast
June 26 - June 28, 2022
Day 1

**Saturday, June 25th**

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

**Sunday, June 26th**

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

7:00 Breakfast – Spalatum Restaurant

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**Session 1**  
Opening Ceremonies - Grand Dalmacija Ballroom  
*Session Chairs: 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*

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**Session 2**  
Setting the Stage - Grand Dalmacija Ballroom  
*Session Chairs: 22q11.2 Society Trustees*  
*Donna M. McDonald-McGinn, Anne Bassett, Bernice Morrow, Peter Scambler, Ann Swillen*

8:25 1 Family Voices  
From Sydney with Love  
Charlie Kamper

8:30 2 Change How You See – See How You Change  
*Rick Guidotti*

9:00 3 A Birds Eye View of 22q  
*Donna M. McDonald-McGinn*
9:30 4  **Bounce Back Better through Integrative Health**  
*Maria Mascarenhas*

9:45  **Q&A**

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

### Session 3  **A Focus on Wellness - Grand Dalmacija Ballroom**  
**Session Chairs: Maria Mascarenhas and Lisa Squires**

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 – Grand Dalmacija Terrace**  
**Lunch – Spalatum Restaurant**

### Session 4  **Of Mice and Men - Grand Dalmacija Ballroom**  
**Session Chairs: Loydie Jerome-Majewska and Beata Nowakowska**

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 5  **Getting to Know You - Grand Dalmacija Ballroom**  
**Session Chairs: Sixto Garcia- Miñaur and Gabriela Repetto**

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

14:50 11  **Family Voices**  
*Through my Lens*  
*Tessa Koller*
### Day 1

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
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<tbody>
<tr>
<td>15:00</td>
<td><strong>An International Panel of Experts</strong></td>
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<td><em>Australia – Maria and Mark Kamper</em></td>
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<td><em>Belgium – Paul Havelange and Ann Swillen</em></td>
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<td><em>Canada – Stephanie St. Pierre and Anne Bassett</em></td>
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<td><em>Chile – Patricia Jesam and Gabriela Repetto</em></td>
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<td><em>Ireland – Anne Lawlor and Lorna Kerin</em></td>
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<td><em>Italy – Daniela Aguglia and Bruno Marino</em></td>
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<td><em>Netherlands – Erik Boot and Sasja Duijff</em></td>
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<td><em>Poland – Beata Nowakowska</em></td>
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<td><em>Romania – Stela Pirvu</em></td>
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<td><em>Serbia – Vesna Vujicic</em></td>
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<td><em>Spain – Aldha Pozo-Rodriguez and Sixto Garcia-Minaur</em></td>
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<td><em>Sweden – RoseMarie Larsson and Solveig Oskarsdottir</em></td>
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<td><em>United Kingdom – Paul and Julie Wootton and Peter Scambler</em></td>
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<td><em>United States of America – Candice Hamilton and Donna McDonald-McGinn</em></td>
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| 16:00 | Afternoon Tea - Grand Dalmacija Terrace                                                   |

**Session 6**  
*Empowering Change for Good – Grand Dalmacija Ballroom*  
*Session Chairs: Greg Hedler and Sasja Duijff*

<table>
<thead>
<tr>
<th>Time</th>
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<tbody>
<tr>
<td>16:30</td>
<td><strong>Supporting Translational Possibilities</strong></td>
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<td><em>FAST (Foundation for Angelman Syndrome Therapeutics)</em></td>
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<td><em>Allyson Berent</em></td>
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| 17:00 | **Care4Parents: On Promoting the Psychological Health and Resilience of Parents**         |
|       | *Sasja Duijff*                                                                            |

| 17:30 | **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                           |

| 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 – Jim’s Foyer, Grand Dalmacija Ballroom
     Badge, Program and Bag Pick-up

Speaker Ready Room Open – Hvar

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

7:00  Breakfast – Spalatum Restaurant

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**Session 7**  
**Care Across the Lifespan – Grand Dalmacija Ballroom**

*Session Chairs: Bruno Marino and Caterina Cancrini*

- **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**

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**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*

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**10:00**  
**Coffee Break - Grand Dalmacija Terrace**
### Session 8  
**Preschool to Employment and Everything in Between - Grand Dalmacija Ballroom**  
**Session Chairs: Ann Swillen and Ed Moss**

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<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Title</th>
<th>Presenters</th>
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<tbody>
<tr>
<td>10:30</td>
<td>22</td>
<td>Family Voices</td>
<td>22q Ireland - Young Expert by Experience Panel (YEEP) with Lorna Kerin and Anne Lawlor</td>
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<tr>
<td></td>
<td></td>
<td><strong>Emma Brady</strong></td>
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<td><strong>Oisin Crotty</strong></td>
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<td><strong>Amy Ellis</strong></td>
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<td><strong>Sarah Fitzpatrick</strong></td>
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<td><strong>Aine Lawlor</strong></td>
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<td><strong>Niamh Moran</strong></td>
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<td>10:45</td>
<td>23</td>
<td>Delays in Emergence of Language</td>
<td>Cindy Solot</td>
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<td>11:00</td>
<td>24</td>
<td>Early Development and Academic Achievement</td>
<td>Ann Swillen</td>
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<td>11:15</td>
<td>25</td>
<td>Understanding Standardized Test Scores</td>
<td>Ania Fiksinski</td>
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<tr>
<td>11:30</td>
<td>26</td>
<td>Neurological Differences in Adults</td>
<td>Erik Boot</td>
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<tr>
<td>11:45</td>
<td>27</td>
<td>Education Across the Lifespan</td>
<td>Ed Moss</td>
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<tr>
<td>12:00</td>
<td>28</td>
<td>Fatigue and its Impact on Everyday Life</td>
<td>Elfi Vergaelen</td>
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<td>12:15</td>
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<td>Q&amp;A</td>
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### Concurrent Breakouts B

<table>
<thead>
<tr>
<th>Breakout 1B</th>
<th>Seeing Beauty in Everyday Life – Brac I and II</th>
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<tbody>
<tr>
<td></td>
<td><strong>Rick Guidotti</strong></td>
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<td><strong>Tessa Koller</strong></td>
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<tr>
<th>Breakout 2B</th>
<th>Creativity to Calm: Embellishing Notebooks – Vis</th>
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<tr>
<td></td>
<td><strong>Greg Hedler</strong></td>
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<td><strong>Lisa Squires</strong></td>
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<tr>
<th>Breakout 3B</th>
<th>Healing through Nature – Korcula</th>
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<tr>
<td></td>
<td><strong>Maria Mascarenhas</strong></td>
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**12:30**  
**Lunch – Spalatum Restaurant**
Session 9  Understanding Behavior – Grand Dalmacija Ballroom  
Session Chairs: Anne Bassett and Therese van Amelsvoort

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  34  Cognitive Behavioral Therapy  
Sandra Meier

15:30  Q&A

14:00 – 16:00  Concurrent Breakouts C

Breakout 1C  Organizing a Photoshoot – Brac I and II  
Rick Guidotti  
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
## 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
- Therese van Amelsvoort
- Efi 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
- Pratishtha Panigrahi
- 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 – Jim’s Foyer, Grand Dalmacija Ballroom
     Badge, Program and Bag Pick-up

     Speaker Ready Room Open – Hvar

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

7:00  Breakfast – Spalatum Restaurant

**Session 10  Managing Craniofacial Differences – Grand Dalmacija Ballroom**
   Session Chairs: Jill Arganbright and Oksana Jackson

8:00  35  Ears, Nose and Throat
      Lisa Elden

8:15  36  Hearing
      Jill Arganbright

8:30  37  Speech
      Cindy Solot

8:45  38  Palate
      Oksana Jackson

9:00  39  Breathing and Sleep
       Christopher Cielo

9:15  40  Bleeding
       Michele Lambert

9:30  Q&A
### Day 3

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

**Breakout 1E**  
**Writing for Relaxation – Vis**  
* MJ McGinn

**Breakout 2E**  
**Flourishing through Fatherhood – Brac I and II**  
Designed for Fathers, Grandfathers, and other Caregivers  
* Greg Hedler

**Breakout 3E**  
**Mindfulness and Movement – Korcula**  
* Maria Mascarenhas  
* Lisa Squires

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

#### Session 11  
**Caring for the Whole Person – Grand Dalmacija Ballroom**  
*Session Chairs: Erik Boot and Sólveig Óskarsdóttir*

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<tr>
<th>Time</th>
<th>Session</th>
<th>Presenter(s)</th>
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</table>
| 10:30 | **Family Voices**                            | Mother and Child Reunion  
* Karen Ruckman-Lindsay |
| 10:45 | **Pediatric and Adult Healthcare Recommendations** | Anne Bassett, Erik Boot, Donna McDonald-McGinn, and Solveig Oskarsdottir |
| 11:15 | **Advocating During Emergencies**            | Emily Gallagher                                                             |
| 11:30 | **Keeping Safe as an Emerging Adult – Internet Safety, Medical Power of Attorney, Sexuality...** | Lisa Palmer                                                                 |
| 12:00 | **Q&A**                                      |                                                                              |

#### 10:30 – 12:30
**Concurrent Breakouts F**

**Breakout 1F**  
**Finding Beauty Within – 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

#### 12:30
**Lunch – Spalatum Restaurant**
Session 12  Impact of Detection on Families - Grand Dalmacija Ballroom
Session Chairs: Natalie Blagowidow and Hakon Hakonarson

13:30  45  Family Voices
Everything’s Bigger in Texas
Suzi Beall Shaw

13:45  46  Improving Detection – Passing on the Chromosome 22q11.2 Deletion or Duplication
Sixto Garcia-Minaur

14:00  47  Preimplantation Genetic Diagnosis and Prenatal Testing
Natalie Blagowidow

14:20  48  Non-Invasive Prenatal Screening (NIPS) – Results of the SMART Study
Hakon Hakonarson

14:35  49  Newborn Screening
Anne Bassett
Hakon Hakonarson
Donna McDonald-McGinn
Julie Wootton

14:50  50  Reaching All the Lands
Gabriela Repetto

15:05  Q&A

15:20  51  The Promise of a Cure – Clinical Trials
Madeline Chadehumbe

15:35  52  Bedside to Bench and Back Again
Stas Zakharenko

15:50  Q&A

14:00 – 16:00  Concurrent Breakouts G

Breakout 1G  Performance Rehearsal – Brac I and II
Sarah Donoghue  Lauren Lairson
Kim Gaiser  Alex Lambert
Victoria Guinta  Lee Lambert
Rick Guidotti  Daniel McGinn
Catherine Hilllin  MJ McGinn
Chloe Katz  Pratishtha Panigrahi
Deirdre Kessler  Karen Ruckman-Lindsay
Tessa Koller  Michael Weinberg

Breakout 2G  Positive Caregiving II – Vis
Designed for Parents, Grandparents and Other Caregivers
Greg Hedler  Lisa Squires

Breakout 3G  Achieve your Best Health NOW – Korcula
Maria Mascarenhas
16:00  **Afternoon Tea - Grand Dalmacija Terrace**

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**Session 13  Moving Forward Together - Grand Dalmacija Ballroom**
*Session Chairs: Raquel Gur and Julie Wootton*

- **16:30  48**  
  **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*

- **17:00  49**  
  **Securing Government Funding**
  *Raquel Gur*
  *Sandra Meier*
  *Ann Swillen*

- **17:15**  
  **Q&A**

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**Session 14  Closing Ceremonies - Grand Dalmacija Ballroom**
*Session Chairs: 22q11.2 Society Trustees*
*Donna McDonald-McGinn, Anne Bassett, Bernice Morrow, Peter Scambler, Ann Swillen*

- **17:30**  
  **Family Voices**
  Performance  
  *Karen Ruckman-Lindsay, Michael Weinberg, Tessa Koller, and Company*

- **17:45**  
  **Closing Remarks - 22q11.2 Society Trustees**
  *Donna McDonald-McGinn, Anne Bassett, Bernice Morrow, Peter Scambler, Ann Swillen*

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**18:00**  
**Meeting Adjourn**