Roadmap to Research

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“Nobody knows about us and nobody is interested in us”

*Parent Participant 2015*

We want you to ask us

- What it is like to live this way
- What we want and need
- About our struggles
- How we can be involved in research
- How we can influence awareness
- Understand that we need your help now, not later.
Qualitative and Mixed Methods Approaches

• *Health Concerns of Women with Trisomy X*
  Wei & Close 2018

• *Adults with XXYY and Their Caregivers*
  Close, Blumling & Martyn 2019

• *For Parents: Understanding Non-Invasive Screening*
  Dimonda & Close 2017

• *Family Experiences Learning Diagnosis of X & Y variation in a Child*
  Close, Riggan, Weinberg, Gross & Allyse 2019

• *Relationship of Physical & Psychosocial Health on Quality of Life in Men with XXYY*
  Blumling, Talboy, Martyn & Close 2019
Future Research Informed By Recent Research

• Mental Health
• Physical Health
• Social Interaction
• School Issues
• Transition from Childhood to Adulthood
• Independent Living
• Caregiver Issues
### Focus and Expansion: Intervention Development

<table>
<thead>
<tr>
<th>Mental Health</th>
<th>Physical Health</th>
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<tbody>
<tr>
<td>• Depression</td>
<td>• Fatigue</td>
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<tr>
<td>• Self-Harm/Suicidality</td>
<td>• Pain</td>
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<td>• Anxiety</td>
<td>• Tremor</td>
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<td>• Substance and Media Addiction</td>
<td>• Immunity/Inflammation</td>
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<td>• Reproduction</td>
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### Social Interaction

- Facial Expression Recognition
- Communication Interpretation
- Communication Reciprocity
More Intervention Development

**Educational Issues**
- Comparative Educational Approaches
- Comparative Educational Settings
- Teacher Trainings

**Transition to Adulthood**
- Transition Toolkit Development
- Pediatric and Adult Provider Trainings

**Independent Living**
- Toolkit Development for Independent Living

**Support for Caregivers**
- Physical & Mental Health
- Respite Care
- Promotion of Social Networking
- Telehealth Support
Mapping the Research Landscape

- Discovering and **deeply investigating the Problem**
- **Individual** Team Inquiry
- **Team Collaborations**
- **Growing the Research Enterprise**
  - Promoting **“Interest Contagion”**
  - Attracting & Supporting New Researchers
  - Combine with Other Conditions Sharing Overlapping Features & Problems
“Sometimes it is the people no one can imagine anything of who do the things no one can imagine.”

Alan Turing 1912-1954
Logician, Philosopher & Theoretical Biologist

YOU are those PEOPLE
Let your needs and ideas be known
Partner with clinicians and researchers
Participate in research: Answers can be found there
Help with getting others to participate in research