WORKSHOP FOR BROTHERS AND SISTERS OF THOSE WITH AN X OR Y VARIATION
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INTRODUCE OURSELVES AND SAFE SPACE AGREEMENT
X and Y chromosome variations are characterized by a wide variation in symptoms and severity among individuals:
- Behavioral challenges
- Social difficulties
- Cognitive impairment
- Communication deficits
- Learning difficulties
- Autism spectrum disorder
- ADHD/ADD
INTRODUCTION

- Medical considerations
  - Medication management
  - Clinic visits
  - Hospitalizations
- Impacts the level of independence of the individual
- Affect the sibling
- Long-term implications
  - Ability to finish school, settle into careers, and live independently as adults
OLDER SIBLING

- Adapting to change of new sibling
- New sibling has increased needs
- Attention of parents may be diverted
- Previous life before sibling now changed
All they’ve known is living with their older sibling with x and y variation

“Growing up in the shadow of x and y variation”

Fear of increased parental expectations
HOW DO SIBLINGS FEEL?

- Identity
  - Other than the sibling of an individual of x and y variation
  - Role confusion
  - Had to grow up faster
HOW DO SIBLINGS FEEL

- Frustrated and angry
  - May perceive sibling with x and y variation to have less responsibility and accountability
- Extra responsibilities
- “Held to a higher standard”
HOW DO SIBLINGS FEEL?

- Jealousy
  - Sibling is getting the attention
  - Perceived less attention paid to them by parents

- Guilt
  - As they meet milestones, leave home, move out knowing the other is not
  - Guilt over their emotions, including jealousy
  - Guilts later in life as they look back on their emotions and actions
HOW DO SIBLINGS FEEL?

- Pressure or anxiety
- Perceived increased scrutiny
- “Set a good example”
- Reports of feeling like a 3rd parent
- What does the future have in store?
HOW DO SIBLINGS FEEL?

- Difficulty sharing their feelings
  - Tend to listen more than talk
  - Fear of judgement
  - Saying aloud confirms what is happening or that their feelings are real
  - Guilt
  - Fear of disappointment
  - Disregarded when providing input or suggestions
IMPACT ON SIBLINGS

- Throughout childhood, but intensified during teenage or transition years
- Stress
  - Stress is how the brain and body respond to any demand
  - Increased in siblings of individuals with chronic illness and developmental disabilities (e.g., x and y variations)
  - Effect physical and mental health
# COMMON EFFECTS OF STRESS

<table>
<thead>
<tr>
<th>On your body</th>
<th>On your mood</th>
<th>On your behavior</th>
</tr>
</thead>
<tbody>
<tr>
<td>Headache</td>
<td>Anxiety</td>
<td>Overeating or undereating</td>
</tr>
<tr>
<td>Muscle tension or pain</td>
<td>Restlessness</td>
<td>Angry outbursts</td>
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<tr>
<td>Chest pain</td>
<td>Lack of motivation or focus</td>
<td>Drug or alcohol misuse</td>
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<tr>
<td>Fatigue</td>
<td>Feeling overwhelmed</td>
<td>Tobacco use</td>
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<tr>
<td>Change in sex drive</td>
<td>Irritability or anger</td>
<td>Social Withdrawal</td>
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<tr>
<td>Stomach upset</td>
<td>Sadness or depression</td>
<td>Exercising less often</td>
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<tr>
<td>Sleep problems</td>
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</tbody>
</table>
IMPACT ON SIBLINGS

- Physical health
  - High blood pressure
  - Heart disease
  - Obesity
  - Diabetes
IMPORTANT FOR SIBLINGS

- Speak up
  - Advocate on your own behalf
- Seek support
- Take care of your self
  - Mental health
  - Physical health

Consideration for Transition

- Participating in transition discussions
- You always have a choice
- Planning
- Optimal discussions starting at 14
IMPORTANT FOR PARENTS

- Create an opportunity for siblings to focus on their feelings
- Provide an opportunity for siblings to discuss reactions to their sibling’s diagnosis
- Beginning at age 6 provide information about their siblings diagnosis
- Discuss how to explain their siblings behavior/diagnosis to others
SIBLINGS-CELEBRATE YOURSELF

- Siblings of x and y variation are more likely:
  - To accept differences in other people
  - To be a loyal friend and partner
  - To be smarter and more mature than kids their age
  - To adapt to different situations
WHAT SIBLINGS HAD TO SAY

Try to spin everything to a positive

Don’t dwell on any short comings

They can really make your life better rather than be a burden

They drive us crazy but we can’t live without them!!

Cherish them!!
SUPPORT

- Social media support groups
- Other online support groups
- Teletherapy
- Traditional in-person support groups
SIBLING SUPPORT

- http://www.theotherkid.com
  - Resources for siblings of children with disabilities
- https://www.siblingsupport.org
  - Siblings of people with special health, developmental, and mental health concerns.
- https://genetic.org/im-adult-looking-answers/support-groups/
  - Axys- international, national, local, online, condition specific groups
SUMMARY

- Having a sibling with x and y variations can be accompanied with certain challenges
- BUT consider all the advantages they give you
  - Patience
  - Empathy
  - Friendship
  - Love
  - Compassion
  - Acceptance
[SUMMARY]

- You are **not** alone
- Seek out support groups
- Allow your voice to be heard
- Share with others
- In return, support others
- Consider participating in planning
- Take care of yourself
- Everyone feels stressed from time to time
THANK YOU