The BRCA Gene and Your Family
A Guide to Talking about BRCA Mutations

Presenter: Emma Rinaldo, MSW, RSW
Ice breaker

If you were stranded on a desert island…

1. Who is the one person that you would want to be there with?
2. What book would you take?
3. What is one food would you like to have with you?
4. What’s the first thing that you would do?
5. What would you miss most about civilization?
Session goals

In this session, you will:

- Learn the several aspects of discussing familial gene mutations (i.e. BRCA) with your family including parent readiness, child readiness, timing, communication and environment.
- Become more comfortable discussing familial gene mutations with your family
- Learn strategies to help make these conversations more comfortable and effective
- Receive support and guidance from professionals and peers who have been there
- Take the time to process the impact of a BRCA mutation
Considerations: planning the talk

Some things to remember:

- The reason for, and the timing of your own genetic testing may influence your thoughts and decisions about talking with your children about the mutation.

- Discussions may be planned or unplanned.

- Discussions may happen in stages, over a period of time – don’t worry about getting it perfectly right the first time around.

- Remember, each family is unique and it’s important to find a path that works for all of you.
Parent readiness

Begin by examining your own readiness and remember that it can come in stages!

**Considerations:**
- Do you have all of the correct, factual information?
- Do you feel comfortable and confident to have a talk?
- Are you emotionally prepared to share the information with your child(ren)?
- Are your children ready?

**ACTIVITY:** Complete the flow sheet: “Are You Ready? A Decision Making Tool.”
Parent readiness: emotional preparedness and processing

Ask yourself:
- How have you been shaped by your experiences with a BRCA mutation?
- How have you been affected by cancer in your life?
- How do you feel about having inherited the BRCA mutation?

Suggestions:
- Take a look inward and be aware of your own feelings.
- Thinking about passing on a BRCA mutation can lead to complicated feelings of guilt, sadness, or anger.
- Processing our emotions and gathering information is an ongoing process.

HANDOUT: Read “Understanding My Comfort Level” and ask, how would you know if you felt comfortable? Let’s look at the signs of comfort and discomfort.

*Material from this slide is adapted from Talking About BRCA in Your Family Tree, National Society of Genetic Counselors, 2014*
My comfort level

Signs of Comfort

- I feel calm when I talk about the BRCA mutation
- I feel positive about the medical decisions I have made
- I am confident that we do what we can to avoid cancer
- The future holds more promise than the past
- I believe that knowledge is power
- I feel confident that my child(ren) can handle it

Signs of Discomfort

- The thought that my child(ren) inherited the mutation is unbearable
- I feel very emotional when I think about my children’s futures
- I try to avoid thinking or talking about it
- I often feel worried, guilty, fearful or angry about my family’s BRCA mutation

*Material from this slide is adapted from Talking About BRCA in Your Family Tree, National Society of Genetic Counselors, 2014*
Child readiness: are we there yet?

**General Principles**

- Children value being included in important conversations.
- It is important for children to get information honestly, in plain language and directly from the source.
- Many children are aware of important issues from an early age.

**TIP**

- Be strong and positive when speaking with children. Stress how lucky you feel to be empowered with information that can keep you.

*Material from this slide is adapted from Talking About BRCA in Your Family Tree, National Society of Genetic Counselors, 2014*
Communication

Consider developmental stages to help guide and approach the discussion:

**Elementary Age (6-12):** gaining new skills, relationships with friends, rules and fairness, belief that thoughts have the power to cause illness.

**Adolescents (13-18):** intellectual maturity, emotional immaturity, becoming independent, developing a unique identity, the importance of friends.

**Early adulthood (18+):** transitional time, gaining independence and responsibility, still needing family support.

*Material from this slide is adapted from Talking About BRCA in Your Family Tree, National Society of Genetic Counselors, 2014*
Communication (Cont’d)

Consider:
- When/where/who (together or separately with each child), how information will be shared between children, lean on past experiences with sharing difficult news.

Guidelines:
- Follow your child’s cues
- Keep it simple
- Welcome questions and know that it’s okay to “not know” the answer
- Children learn as much from what we do as what we say
- Correct common myths with factual information
- Evaluate the impact of the conversation
- Check in frequently

TIPS
- Consider reaching out to your child’s supports and let them know this discussion is taking place (i.e. teacher)
- Remember, communication is a gradual process that evolves over time and doesn’t need to be done in one conversation.
- Remember that good communication creates trust and confidence.

*Material from this slide is adapted from Talking About BRCA in Your Family Tree, National Society of Genetic Counselors, 2014*
Things to think about: talking to family

Ask yourself:

- Who needs to know about the BRCA mutation?
- Who would you like to tell about the BRCA mutation?

HANDOUT: Sample letters

TIP
- Make two lists; one of people who need to know and one of people you would like to tell.

*Material from this slide is adapted from Talking About BRCA in Your Family Tree, National Society of Genetic Counselors, 2014*
What if my family doesn’t want to talk?

- Your views and your family’s views may not align and every family is different.
- Not everyone’s reactions will be the same.
- Encourage them to share their feelings but don’t force a conversation to happen. They may need more time or more information.
- Consider making written information available to them (i.e. a link to National Society of Genetic Counselors or FORCE websites).

*Material from this slide is adapted from Talking About BRCA in Your Family Tree, National Society of Genetic Counselors, 2014*
Peer-to-peer
Take home activity: planning your talk

From the resource, “Planning My Talk:”
- Before The Talk
- Getting The Talk Started
- Recognizing Emotions
- The Children: Answering Their Questions
- Checking In With Yourself: After The First Talk
Take aways

- Turn to the person next to you and share a takeaway
- Join the group discussion and brainstorm
Resources

- **Women’s College Hospital**
  
  **Social Worker:** Emma Rinaldo, Tel. 416-323-7330 or emma.rinaldo@wchospital.ca
  
  **Peer Support:** Kate Mlodzik, Tel. 416-323-6274 or myccssupport@wchospital.ca
  
  **Genetics:** Nicole Gojska, Tel. 416-323-6400 ext. 2727

- **FORCE:** Facing Our Risk of Cancer Empowered

- **BRCAnet Toronto:** Support group for meet ups and connections

- **National Society of Genetic Counselors**

- **Bright Pink:** Organization for young women at high risk for breast and ovarian cancer

- **Your Family Doctor or General Practitioner Oncologist (GPO)**
The following is a complete list of resources available:

- Understanding My Comfort Level
- Are You Ready: A Decision Making Tool
- Activities for Children
- Sample letters for family members
- Planning My Talk (a take home activity)
- FAQ – Questions Your Children May Ask
- Resources
Questions?

The Peter Gilgan Centre for Women’s Cancers
Women’s College Hospital
76 Grenville Street
Toronto, ON M5S 1B2
Womenscollegehospital.ca/PeterGilganCentre
T. 416-323-6400 ext. 5987
E. petergilgancentre@wchospital.ca