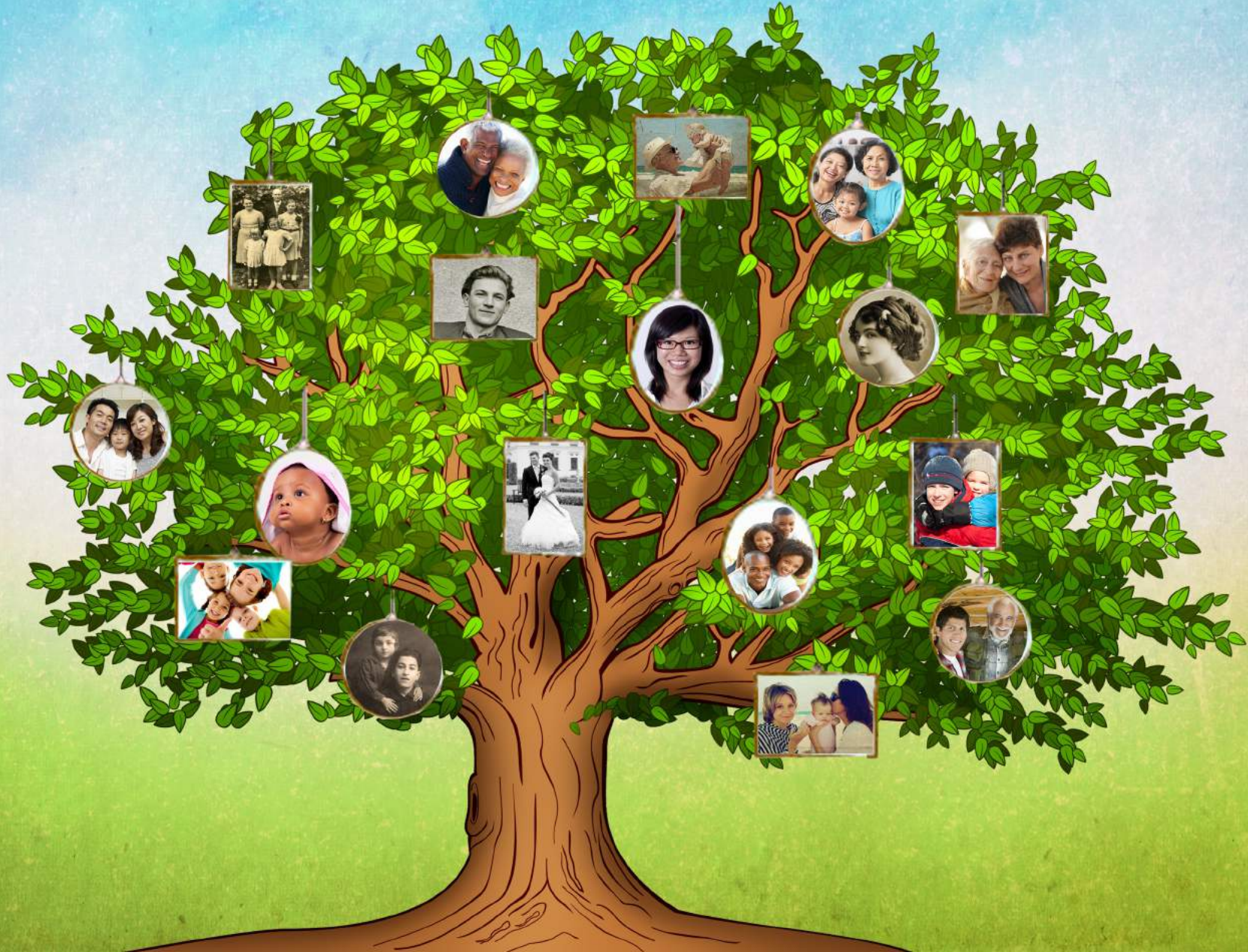


Talking About BRCA in Your Family Tree



**AUTHORS
ACKNOWLEDGEMENTS
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INTRODUCTION

This booklet is intended for parents who are preparing to discuss a familial BRCA mutation with their child or children. The goal of this resource is to help make these conversations as comfortable and effective as possible for you and your family members. It includes support and guidance from parents who have been there.



Each person's reasons for pursuing genetic testing are unique. Perhaps you were encouraged to get tested to help with decisions about cancer treatment or prevention. The decision may have been made quickly or come after a lengthy and thoughtful process. Many people have genetic testing for the benefit of their children. The reasons for and timing of your own testing may influence your thoughts and decisions about talking with your children about the mutation.

Discussions about the BRCA mutation may be planned or unplanned. Often the information is shared because of a major event like a cancer diagnosis or planning of a risk-reducing surgery. Discussions may happen in stages, over time. You don't have to get everything out in the first discussion and you don't need to "get it perfectly right" the first time.

Whether your family is just beginning or already in the middle of discussing the familial BRCA mutation, the information in this booklet may be helpful in preparing for or continuing this conversation.



This book examines several aspects of discussing a familial BRCA mutation with children. There are sections about parent readiness, child readiness, communication, and factual information. The glossary and resource sections provide additional information that may be helpful in this process.

Each family is unique. Your particular situation or concern may not be addressed in this resource, and it may be helpful to work with a genetic counselor, therapist or other healthcare provider with experience in this area.



PARENT READINESS

Am I ready for this?

While some people “just know when the time is right,” to begin the conversation about the BRCA mutation with their children, others are hesitant or ambivalent about when to begin. You may find it helpful to begin by examining your own readiness. “Readiness” for parents includes taking the time to understand the medical and genetics facts regarding BRCA mutations and feeling confident and emotionally prepared to share the information with your children and handle their reactions.

Readiness comes in stages. Which of these statements describes you?

1. I am not ready to talk to my child about BRCA yet

2. I have thought about it

3. I have talked to a friend, family member, or other person about my thoughts on having this conversation with my child

4. I mean to discuss this with my child soon

5. I have rehearsed the conversations in my mind

6. I've been thinking about when and where to discuss this

7. I've already had discussions about this with my child

Comfort With the Facts

You may want to review your own understanding about BRCA mutations before speaking with your children. You should feel comfortable and confident that you have *accurate and understandable* facts at hand. Talk to a genetic counselor or other healthcare provider to make sure you have up-to-date information to share with your child.



Signs you are confident about your understanding of the facts

- I have talked to a healthcare provider and have gathered the information I need to discuss this with my child
- I have explained the BRCA mutation to other people before
- I have a good understanding of what it means for me and my family
- I am comfortable talking about it

Signs you do not yet feel confident about your understanding of the facts:

- I find it confusing to explain it to other people
- I am not really sure what it all means
- I think I get it but I don't know how to explain it

Tip: Get the facts

If you are uncertain about which facts you want to share or if you feel that you need to review the facts about BRCA mutations, there are many resources available, including:

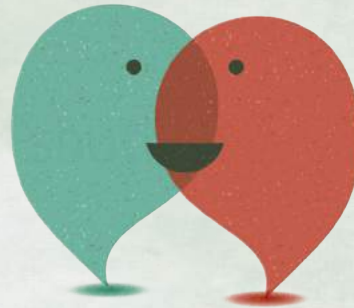
- Factual Background section of this booklet
- Glossary at the end of this booklet to help you explain the terms which are frequently used in discussing cancer and genetics
- Your genetic counselor. To find a genetic counselor, see www.nsgc.org. Even if you have met with a genetic counselor in the past, you may want to reach out to the counselor again for updates. There may be new information available since the time you first learned about BRCA mutations.
- FORCE (Facing Our Risk of Cancer Empowered) website www.facingourrisk.org
- See resource section of this booklet for other sources

PARENT READINESS

Am I ready for this?

Tip: Practice Out Loud

Even with a very good understanding of the facts that are important, many people find that explaining them to another person can be a challenge. It may be helpful to practice your conversation with a friend or relative before your discussion with your children.



Comfort With Your Emotions

Knowing the facts is a great first step. But beyond the science and the statistics, your personal experiences with cancer may affect your feelings about what it means to have a BRCA mutation and what to share with your children about that mutation. For example, consider these two very different situations:

My mother had cancer and went through treatment when I was 16. She died of heart disease in her 90s.

My mother had cancer and went through treatment when I was 16. The cancer came back and she died the year my first child was born.

Both experiences are significant, but their differences may lead to different feelings about cancer in general, about carrying a BRCA mutation, and about the impact on a child who might then fear that they are going to lose you at an early age too.

How has your family been affected by cancer? How has this shaped your thoughts and feelings about what the BRCA mutation means for you and your children? Thinking about questions like these is a first step toward being *emotionally prepared* to talk about BRCA with your child.

Tip: Remember that some advances in detection, prevention, and treatment may improve the likelihood of survival compared with cancers diagnosed 10-20 years ago.

Thinking about passing on a BRCA mutation to a child may lead to complicated feelings. Passing genes to our children is 'a package deal' - we do not choose which genes we pass on any more than we choose which ones we inherit from our parents. However, this is a matter in which "the heart does not always match the head." Parents may feel sad or guilty thinking that their child may have inherited their BRCA mutation. Some parents may be able to work through these feelings easily while other parents may feel very upset and burdened by that sense of guilt.

Before talking to your children about the BRCA mutation, think about how you feel about the inheritance issue. If the thought of passing on the BRCA mutation overwhelms you or fills you with guilt or sadness, it may be important to address these feelings before talking to your child.



Remember, for your own peace of mind, and in speaking to your child, that genetic inheritance is random – we cannot choose which genes are passed on to our children, and it is not influenced by lifestyle or any other choices we make.

PARENT READINESS

Am I ready for this?

Tip: Be aware of your own feelings and motives. Consider your need to share this information compared to your children's need to know at this particular time. If you are upset by the information, it may not be the right time to present it to your children.

Signs of comfort with your emotions:

- I feel calm when I talk about the BRCA mutation
- I feel positive about my medical decisions
- I am confident that we do what we can to avoid cancer
- The future holds more promise than the past
- Knowledge is power
- I know my daughter/son can handle it

Signs of not yet being comfortable with your emotions:

- The thought that my daughter/son inherited the mutation is unbearable
- I get upset when I think or talk about it
- I feel very emotional when I think of my children's futures
- I try to avoid thinking about it or talking about it
- I often feel angry, fearful, worried or guilty about my family's BRCA mutation



If you feel you need to process your emotions further, there are resources available, including:

- BRCA support groups or speaking one-on-one with other BRCA-positive parents. Check with your genetic counselor to find out about local resources. To find a genetic counselor, go to www.nsgc.org.
- FORCE website www.facingourrisk.org. FORCE has outreach groups that hold meetings in select cities, a toll-free helpline with trained peer volunteers, and online message boards where people can share with others who have faced similar concerns.
- Counseling with an oncology psychologist or other mental health professional.

CHILD READINESS

Are We There Yet?



Once you feel prepared from a factual and emotional standpoint, what next? How ready is your *child* for information about BRCA? In this section, we examine common questions about child readiness.

General Principles

Kids value being included in important conversations. Children are very observant and often sense their parents' feelings. Kids may feel left out if not included in discussions about important family issues.

Kids prefer to get information straight up, firsthand. Your child would prefer to hear important news – good or bad – from you rather than overhearing the news from another person. Research shows that children are likely to be upset when communication is not open. Without accurate information, children may form their own faulty beliefs to explain events and feelings.

Many children become aware of important issues going on around them from an early age. There can be advantages to discussing an important topic – such as a BRCA mutation in the family – from an early age. One advantage is allowing a child to develop a gradual understanding of the information over time. Younger children are not likely to understand the full meaning of something like a BRCA mutation, but that is okay; their understanding will develop over time.



Just as your experience with cancer in the family affects your feelings about the familial BRCA mutation, your child's experience with cancer will impact his or her reaction to the information you share about increased cancer risk in the family.



Child Development

As you know, there are many steps along your child's journey to adulthood. Your child's age and developmental stage will impact his or her understanding of and response to important information. Consider the stages below as you prepare to discuss the BRCA mutation with your child.

Note: the ages below are *general*. Each child develops at his or her own rate.

Children of elementary school age (ages ~6-12) are focused on:

- Gaining new skills
- Creating relationships with children their age
- Experiencing and responding to complex emotions
- Rules and fairness
- Beliefs that thoughts or feelings have the power to cause illness

How might this apply to the BRCA discussion with your young child? An example - if *fairness* is a focus for your child, it may be helpful to share this thought:

"All families have genes that affect their risks of getting certain diseases, such as diabetes, heart disease, or cancer. Many families don't know what those genes are. Knowing that there is a risk factor for cancer in our family has some advantages, because we can take steps to lower our chances of getting cancer."

CHILD READINESS

Are We There Yet?

Adolescents (ages ~13-18) experience many developmental challenges:

- Intellectual maturity combined with emotional immaturity
- Differences between what a teen understands and how a teen behaves
- Developing unique adult identity
- Starting to become independent
- Increasing connections with friends, distancing from family
- Developing physically



An example of inconsistency between intellectual maturity and emotional maturity is that an adolescent may understand intellectually that they are not at risk for developing cancer at this age, yet still be anxious about their short-term risk. Your child may or may not talk about this fear. This may be a good time to review healthy behaviors your child can learn now to help provide him or her with a sense of control over long-term health risks. For tools your son or daughter can use now, please see the Factual Background section of this booklet.

Your teen may worry that having a BRCA mutation in the family

makes them “different” from their friends, and at this age, acceptance by peers is important.

Tip: Watch for signs that your adolescent child feels embarrassed about having cancer in the family or having a gene mutation related to cancer risk in the family. Help him or her understand that these are not things to be ashamed of.

Early adulthood (~ages 18+) may be characterized by:

- Facing challenging transitions
- Gaining responsibility and independence
- Still needing parental support or comfort during these changes

During early adulthood, many will choose to be tested themselves for the BRCA mutation. It is important to let your young adult children know that you are available to support them through that process.

Tip: Remind your young adult child that seeking your emotional and/or financial support while pursuing their testing is not a sign of dependence. Even older adults turn to each other for support and advice about difficult decisions.

Note: since each child is different and each family's issues and needs are unique, there is no right or wrong age at which to introduce the BRCA information to your children. It is, however, recommended that you discuss this information with your female children by the time they are 25 years of age (35 for males), as some screenings and cancer risk management would begin at that age. For those with family members who have been diagnosed with breast or ovarian cancer in their mid-twenties, discussions about the BRCA mutation should occur at earlier ages.

COMMUNICATION

If you have decided to talk to your children about the BRCA mutation in your family, you may have questions about *when* to tell them, *what* to tell them and *how* to explain it to them. The following information should help make that discussion as comfortable and effective as possible for your children and you.

Where and When? – The Big Picture

If you feel prepared, and feel your child is ready, then what? Your conversations may 'just happen,' or you may make a specific decision about the time and place they will occur.

FACT: Parents are generally more likely to answer questions than to start a conversation.



Tip: Think of communication as a gradual process rather than a one-time event.



Many discussions are not planned, so be prepared if the topic comes up at a time when you were not necessarily planning to discuss it. You do not have to fit everything into one discussion. You do not have to "get it all right" the first time. For many children, learning about BRCA mutations is a gradual process that happens over time. Bringing up this discussion can feel like 'The Talk.' Remember that there will be many opportunities for further discussion once you have opened the door.

"If kids are aged 6-12, don't stress too much on the specifics. Keep it simple...As they grow up, you can provide more information as needed or if they ask. No need to share everything you know all at once."
(SC from Lafayette Hill, PA)

If you have not yet begun discussing BRCA with your child, how and when and where do you begin? If you are thinking of beginning or continuing the discussion, consider the following: What is going on in your lives right now, and how do those things impact the timing of this discussion? Remember, an event that may *prompt* the BRCA discussion in one family may be a reason for *not* having the discussion in another. Consider the following examples:

"I was in the middle of cancer treatment, and my hair loss really bothered my daughter. It seemed better to wait until after treatment was done and things were more back to normal before getting into a discussion about my BRCA results."



"I was in the middle of cancer treatment, and had just lost my hair. Since my daughter and I were talking a lot about cancer, it turned out to be a natural time to discuss the genetic findings."

Here are other situations that may be **opportunities** or **barriers**.

- Having a family member in active treatment
- A new cancer diagnosis in the family
- Planning a surgery to lower cancer risk
- A death in the family
- Other family events (moving, vacation, divorce, etc.)
- School or other life events for your child (major exam, sports championship, audition for a play, etc.)
- A family reunion, holiday meal, or other gathering

COMMUNICATION

Where and When? – Details

The details of “where” and “when” are important parts of “how” we communicate.

Where do you have your best conversations with your children?



In the car



In bed at the end of the day



Around the dinner table



On a walk



When is a good time of day for your child?



“Fresh” in the morning vs. winding down at night



Weekends vs weekdays



What else is going on that may influence timing (relationship issues, tests at school, etc.)?

Should the conversation be one-on-one, or should it be with more than one child or other family members?

If discussing the BRCA mutation with more than one child at a time, what things will affect the tone of the conversation?

- Similarities/differences in ages, maturity level, intellectual ability, or coping skills?
- Styles of responding to and dealing with important events?
- Is their relationship with each other supportive or do they “push each other’s buttons”?
- Will it help them to be able to discuss this information with each other?



Consider how the information will move between your children as you determine whether they should hear it first as a group or separately or in some combination of these two approaches.



COMMUNICATION



Tip: Learn from earlier experiences.

Think about how you've dealt with other important issues with your child. Have you talked with them in the past about important things like moving to a new home, starting at a new school, divorce, or expecting a new sibling?

What worked well during those conversations? How does your child handle "tough stuff"? Is your child:

- Focused more on the facts or on emotions and the meaning of the event?
- More likely to be concerned about how this affects *you* or about how it may affect *him or her*?
- Worried about medical issues or content to leave "that stuff" to you?



Tip: Good communication early on creates trust and helps your child feel confident that family members will support each other at every step of your family's BRCA journey.

How could you tell if your child was troubled or worried following other difficult conversations? Did your child ask you multiple questions? Did you see any change in his or her behavior or did you see physical symptoms such as headaches or stomach aches? Keep an eye out for similar reactions after your discussions about the familial BRCA mutation.



COMMUNICATION

General Communication Guidelines

Follow your child's cues

- Allow your child to indicate how much or how little he/she wants to know at any one time.
- "Read between the lines" for underlying questions or concerns.
- Pay attention to your child's body language.
- Respect your child's wish to *not* ask questions or not talk about the information.

"My girls are very different in age and personality. It's very important to pay attention to how much they want to know about the situation and not push the information too soon... Keep it brief and light, especially if they're young. Tell them that they can ask any questions and that you are there for them."
(LF from Newtown, PA)

Find the right words - keep it simple

- Use clear, age-appropriate terms.
- Use real words; euphemisms can lead to confusion.
- Avoid words that have more than one meaning.
- See the glossary of terms at the end of this booklet.
- Remember that in addition to the words you use, children will pick up on your tone and body language.

Welcome questions

- All questions are good questions.
- Questions may come at the time of the initial discussion or may come days or weeks later.

Some answers can wait

- Not all questions require an immediate answer.
- Your child may raise issues for you both to think about over time.

"I don't know" is a fair answer.

- . . . especially when followed with, "but I think we can find out." This provides a great opportunity to develop your child's problem-solving skills. Together you and your child can look for answers. You can meet with your genetic counselor or healthcare provider. See the resource section at the end of this booklet.

Some big questions have no answers

- 'Nobody knows' is an honest answer to many questions. Avoid making unrealistic promises or giving false comfort. Trusting your child with truthful answers to difficult questions shows your confidence that together, you and they can handle whatever comes.

Kids learn as much from what we do **as from** what we say

- Your child will look to you as a role model for how to handle difficult information and challenging situations.

"(Your children) are going to observe you as they begin anticipating their own journey. Role modeling appropriate responses, that sometimes include sadness and fear but more often stress resilience and coping skills, will be observed and are in some ways more important than the words themselves."
(LD from Olney, MD)

COMMUNICATION



Evaluate Impact and Understanding

It can be tricky to know when someone is listening, and even harder to know what they are hearing or understanding.

- What does your child's body language tell you?
- Does it match his or her words?
- Ask your child to repeat back what he or she understood you to say.

Tip: Identify misunderstandings by asking questions.

Correct common myths

Some common myths and misunderstandings about inheritance are shown here:

"I look just like her, so I probably have the mutation, too"

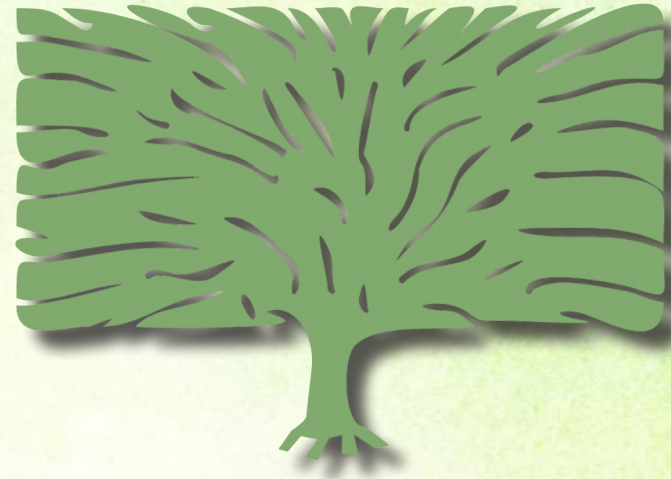
CORRECTION: Genes for looks and body type are inherited separately from cancer risk genes.

"I'm almost the age she was when she got cancer . . . it will likely happen to me then."

CORRECTION: A BRCA mutation increases cancer risk but does not predict IF or WHEN a cancer will occur.

"If I inherited the BRCA mutation I will get cancer."

CORRECTION: Not everyone who has a BRCA mutation gets cancer.



If you are estranged from your child

If you are not in contact with your child due to estrangement, adoption, or other reasons, consider making written information available to them if possible. This information can be sent directly to the child, to another family member with whom you both have contact, to a lawyer, or to an adoption agency. This will allow you to fulfill any ethical obligation to provide your child with information about the BRCA mutation and allow him or her to decide based on facts how to address it. Be sure to include:

- a copy of your test result. If you have privacy concerns, you may send a copy from which your name has been removed.
- a copy of your genetic counseling notes, family tree, and risk management recommendations you may have been given (again, this information can have your name removed.)
- a link to the NSGC website (www.nsgc.org) to help your child access reliable information and/or facilitate testing.
- a link to the FORCE website (www.facingourrisk.org) to help your child access reliable information and/or support.

FACTUAL BACKGROUND

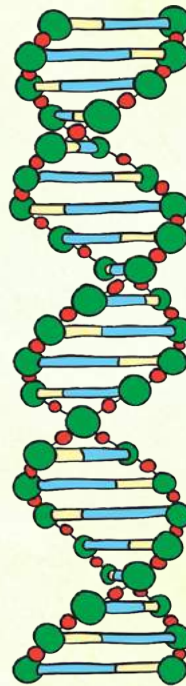
This section is not meant to be an in-depth review of genetics, hereditary cancer, and BRCA mutations. Instead, this section will give you general background information that may be helpful for you to review and to share with your children when you are talking to them about the BRCA mutation in your family. There are many other resources available with more in-depth information. Some of them are listed in the “Resources” section of this booklet. Meeting with a genetic counselor is also a helpful option.

FACT: Like diabetes, heart disease, and high blood pressure, cancer is a common disease, especially among older adults. Many cancers can be cured if caught early.

Genes and Cancer

Our bodies are made up of millions of cells, and in nearly every cell, we have tens of thousands of genes. Half of our genes come from our father and half from our mother. Genes carry the instructions that tell our bodies how to grow and how to work. Our genes affect what we look like, how we learn, and our chances of getting certain diseases. A change in a gene is called a mutation. There are some gene mutations that cause an increased risk for certain types of cancer.

A hereditary cancer syndrome results from a person inheriting a gene mutation that causes an increased cancer risk. Most cancers happen by chance in people with no family history of that cancer. But about 10% of all cancers are hereditary – caused by gene mutations that run in the family.



BRCA1 and BRCA2 mutations

Your family has a mutation in one of the genes called BRCA. BRCA1 and BRCA2 stand for **B**reast **C**ancer 1 (the first one discovered) and **B**reast **C**ancer 2 (the second one discovered). When the BRCA genes work as they should, they help stop cancers from forming. Mutations in BRCA1 or BRCA2 stop these genes from working correctly and are what cause Hereditary Breast and Ovarian Cancer (HBOC) Syndrome. Women with HBOC have a higher than average risk of breast and ovarian cancers. Men with HBOC have an increased risk of prostate and breast cancers, although these risks are not increased as much as the risks are for women. There are other cancers that may be seen in families with HBOC. If this is the case for your family, you may want to discuss these risks in more detail with your children.

FACT: Getting cancer before age 30 is rare, even for someone with a BRCA mutation.

It is important to keep in mind that the increased cancer risks for people with BRCA mutations are spread out over a whole lifetime. Although someone with a BRCA mutation is more likely to develop cancer at a younger age than people who don't have that mutation, childhood cancers are not seen with BRCA mutations, and it is rare to see any of the BRCA-related cancers before the age of 30.

- Kids and teens with BRCA mutations do not get cancer more than other kids.
- You can have a BRCA mutation and never get cancer.

Tip: If your child is interested in learning more about the familial risk, consider sitting down with him or her and doing research on the internet together. This is a good time to talk about how to find information you trust. The resources listed at the end of this booklet are a good place to start.



FACTUAL BACKGROUND

FACT: If a parent has a BRCA mutation, each child has a 50-50 chance of having the same mutation.

Each child has the same 50-50 odds or 50% chance of inheriting the mutation. Although flipping a coin has 50-50 odds of landing on either 'heads' or 'tails', you can get 'heads' several times in a row. Passing on the BRCA mutation is a new "coin flip" for each child of a BRCA-positive parent. The gene mutation can be inherited from someone's mother or father, and can be passed on to male or female children.



Tip: If your child is having a hard time understanding genetics or inheritance, it may be helpful to talk about other events that are random or exploring other genetic conditions that have nothing to do with cancer.

A special blood or spit test can tell a person if she or he inherited a BRCA mutation. The genetic test is an option for people over the age of 18, but many people wait until they are a bit older to be tested.

Cancer Risk Management

FACT: People with BRCA mutations can take steps to lower their risks of cancer or detect it early.

These steps usually begin after age 25, and many of them would not take place until much later. Risk management would begin earlier for women whose family members had breast or ovarian cancer in their mid-twenties. A BRCA-positive **adult** can consider these options to manage or lower his or her cancer risk:

- Have earlier screenings and have screenings more often. Screening tests help to find cancer before it causes symptoms, when it is more likely curable. People with an increased risk for certain cancers should begin screening for those cancers earlier than someone at average risk and should use extra screening methods that may not be used by everyone.
- Think about taking medication to reduce cancer risk.
- Think about having surgery to lower cancer risk.

Emphasize with your child that because of medical research and new developments, they will likely have more and better options for risk management and risk reduction than you had.

"Be strong
and positive when speaking with children.
Stress how lucky you feel to be empowered with information
that can help keep you healthy."
(SC from Lafayette Hill, PA)

Your child may be curious about which options you have chosen to manage your risk. Think about a way you could explain in one sentence why you have chosen your path. Talking about this with your children may help them build healthy coping skills that they will be able to use when they face their own challenges in life.

FACTUAL BACKGROUND

Tip: Review normal breast development and breast self exam with your daughters and sons. Speak to a healthcare professional about the most appropriate time for a female to begin breast self exams. More is not always better, and it is not necessarily a good thing to start breast self exam too soon. A young female's breasts are typically somewhat lumpy, and this could cause unnecessary concern for an adolescent female who is at risk of inheriting a BRCA mutation and may be concerned about her risk for breast cancer. A helpful resource about breast self exam is a book called *Taking Care of the Girls*, by Marisa Weiss, MD (see the resource section at the end of this booklet). Your son may also have questions about his breast development that you may not have expected. A healthcare professional may be able to help answer your son's questions.

FACT: Guidelines and recommendations for cancer risk management and risk reduction for high risk individuals are updated every year.

Recommendations may be very different in a decade or two. For someone who has, or might have, a BRCA mutation, genetic counseling is recommended at about age 25. During this visit, the genetic counselor will go over in detail cancer risks and screening recommendations.

FACT: There are many healthy choices that everyone – with or without a BRCA mutation – can make to lower the chances that they will develop cancer.

- **Don't smoke.** If you smoke, quit. If you don't smoke, don't start.
- Keep a **healthy body weight**.



- **Exercise** for at least 30 minutes at least five days per week. Find an activity that keeps your body moving that is fun for you.

- **Eat a balanced, healthy diet.**

- **Protect your skin.** When outside, apply sunscreen, avoid mid-day sun, wear clothing that protects you from the sun, and stay in the shade when the sun is

strong. **DO NOT USE TANNING BEDS!**

- Wait until you are an adult to drink alcohol, and if you drink, **use moderation**.



RESOURCES

This is not meant to list every available resource related to BRCA mutations. It is a list of some of the key resources, in a variety of formats, which may be helpful to families with BRCA mutations. Many of these resources will point you to other sites which may also be helpful if you or your children are looking for more or different information.

Many of the resources are aimed at parents more than children and may not be appropriate for all children. *You may want to preview these resources before sharing them with your children.*

Websites

www.nsgc.org **National Society of Genetic Counselors**

www.facingourrisk.org **FORCE (Facing Our Risk of Cancer Empowered)** – National, non-profit organization dedicated to improving the lives of individuals and families affected by hereditary breast and ovarian cancer. The website includes information about BRCA, discussion boards, webinars, and opportunities to connect with other BRCA-positive parents

www.brightpink.org **Bright Pink** - Organization for young women at high risk for breast and ovarian cancer

www.stupidcancer.org **Stupid Cancer** - (“I’m Too Young for This! Cancer Foundation”) – organization for young adults with cancer.

www.mghpact.org/home.php **PACT (Parenting at a Challenging Time)** – A Massachusetts General Hospital-Cancer Center website designed to provide parenting tools to parents with a cancer diagnosis.

www.youngsurvival.org **Young Survival Coalition** - Young women facing breast cancer together.

www.cancer.gov **National Cancer Institute**

www.cancer.org **American Cancer Society**

www.ncbi.nlm.nih.gov/books/NBK1116 **Gene Reviews** - from the U.S. National Library of Medicine – a resource for medical genetics information.

Books

Confronting Hereditary Breast and Ovarian Cancer: Identify Your Risk, Understand Your Options, Change Your Destiny (2012), by FORCE Executive Director, Sue Friedman, D.V.M., Rebecca Sutphen, M.D., and Kathy Steligo. With its combination of the latest research and expert advice, as well as moving personal stories, this resource gives individuals and families the guidance they need to face the unique challenges of hereditary cancer.

Positive Results: Making the Best Decisions When You’re at High Risk for Breast or Ovarian Cancer (2010), by Joi Morris and Dr. Ora Gordon. A thorough source of information and advice to help women (and some men) at high risk for breast and for ovarian cancer because of family history and genetic traits.

Taking care of your “Girls” (2008), by Marisa C. Weiss, M.D. and Isabel Friedman. A thorough and supportive breast health guide for teens.

RESOURCES

DVD

In The Family - A film by Joanna Rudnick

<http://www.pbs.org/pov/pov2008/inthefamily/fullfilm.html>

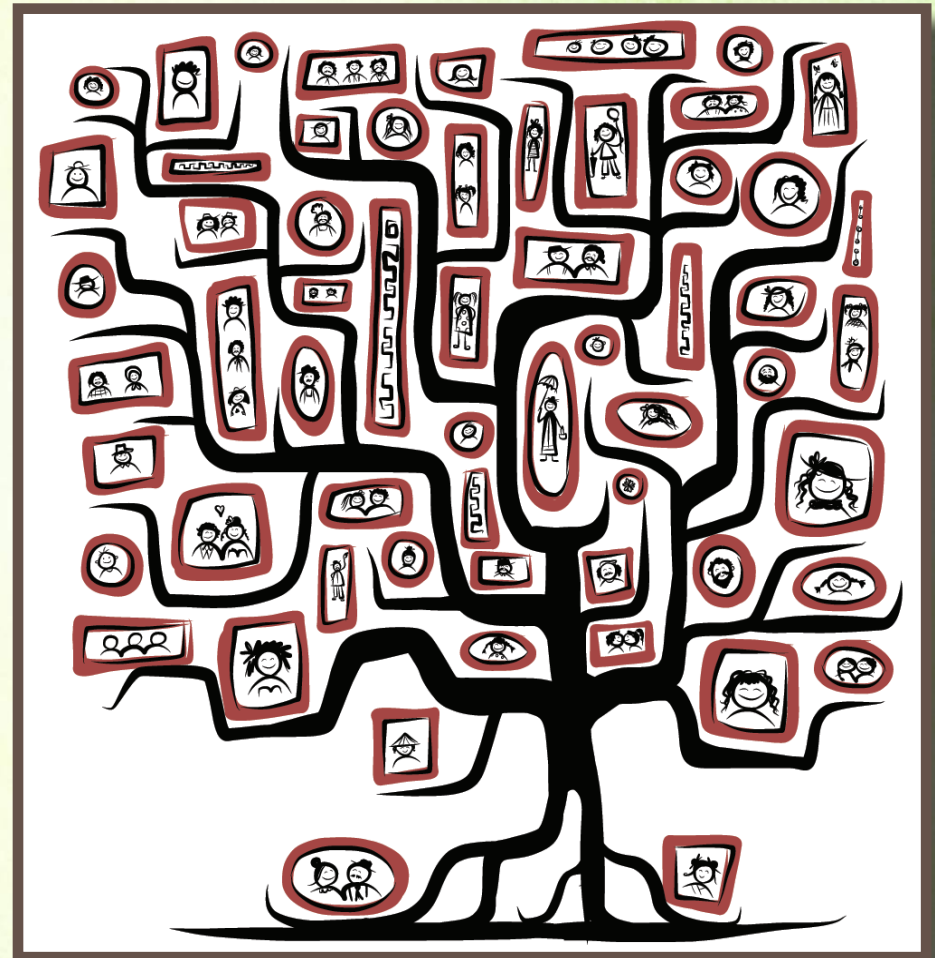
Intensely personal and timely, *In The Family* is a groundbreaking investigation that attempts to answer the question: How much do you sacrifice to survive?

Webinar, Articles

<http://www.facingourrisk.org/events/webinars/2010-05-05-sharing-risk-info.php> FORCE: Sharing risk information with children: an archived webinar recording presented by Karen Hurley, PhD, Memorial Sloan Kettering Cancer Center.

This session focuses on feelings that parents commonly experience when dealing with the possibility of risk to their children, strategies for coping with these feelings, guidelines for communication with children about risk, and other resources that parents can use to support their children while balancing their own needs.

<http://www.cancer.org/Treatment/ChildrenandCancer/HelpingChildrenWhenaFamilyMemberHasCancer/DealingWithDiagnosis/dealing-with-diagnosis-toc> - Helping Children When A Family Member Has Cancer: Dealing With Diagnosis - from the ACS - Families with young children or teens may be concerned about how children will react to a diagnosis of cancer in a family member. Here we discuss how to help children understand and deal with a parent or close family member's cancer diagnosis.



GLOSSARY

Benign - Not cancerous

BRCA1, BRCA2 - two genes associated with hereditary cancer risk. Normal BRCA1 and BRCA2 genes help *prevent* the growth of tumors. Mistakes, or “mutations”, on either of these genes increase the risk for certain cancers, particularly breast, ovarian, and prostate cancers.

Cancer - cells growing without normal genetic controls. Cancer cells make more copies of themselves than the body needs. *Invasive* cancer can push into neighboring cells. *Metastatic* cancer can move into distant parts of the body.

Cells - the smallest living units that make up our bodies. Different parts of our bodies have different types of cells - blood cells, skin cells, brain cells, etc.

Chemotherapy - treatment of cancer using medicine

Chromosome - A long bundle of DNA that contains hundreds to thousands of individual genes. Humans usually have 46 chromosomes (23 pairs) in each cell of our bodies.

DNA - the material that makes up our genes and chromosomes. DNA stands for deoxyribonucleic acid.

Gene - The gene is the basic unit of inherited information. Genes are passed from parents to children. They are the instructions that tell our bodies how to do the things they do. Genes are carried in our bodies on structures called chromosomes.

Genetic counselor - A healthcare professional specially trained to talk to families about genetic conditions.

Hereditary - inherited; a trait which can be passed down in a family from one generation to the next

Inherited - see hereditary

Malignant - cancerous

Mammogram - an X-ray of the breast that checks for cancer or other diseases

Mutation - a change in the genetic code. Mutations can prevent a gene from working correctly.

Ovary - part of the female body that makes eggs

Predisposition - having a higher chance than usual of developing a disease

Prophylactic - preventative, able to lower the chances of developing a disease

Prostate - a part of the male body that adds fluid to semen

Radiation therapy - medical treatment that uses radiation

Risk factor - a trait, behavior, or exposure that increases the chances of a particular outcome (such as getting cancer)

Salpingo-oophorectomy - removal of a woman's ovary or ovaries by surgery.

Screening (or cancer screening) - testing for disease in people who have no signs or symptoms. Types of cancer screening include blood tests, doctors' examinations, x-rays, ultrasound, MRI and other tests.

Surgery - an operation performed by a specially trained doctor to fix, change, or remove something from inside the body


Syndrome - a collection of traits that tend to occur together and are associated with a specific disease

Tumor - a growth or lump in the body that results from uncontrolled cell division. Some, but not all, tumors are cancerous.

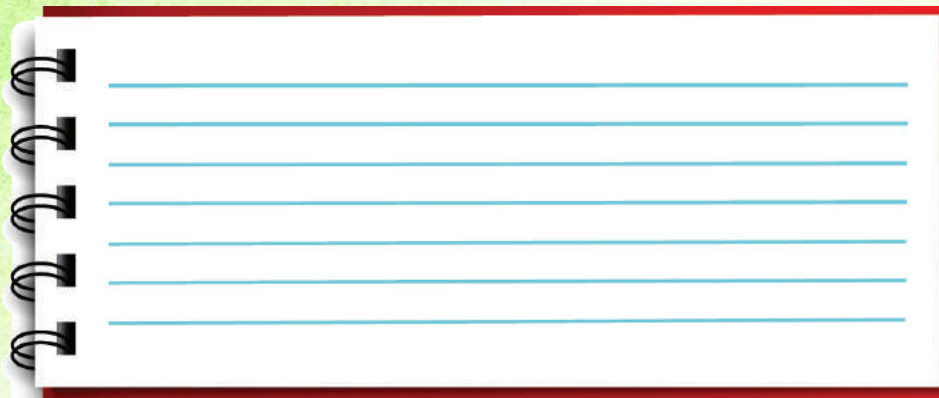
NOTES

This is a place to record thoughts as you read through this booklet. It may be helpful to copy these pages for each child so you can tailor your notes to each one, knowing that they may each have different questions, concerns, and reactions to the information.

Am I ready?



Is my child ready?



How will we communicate?



What questions do I have about the facts?



What resources do I want to look at?

