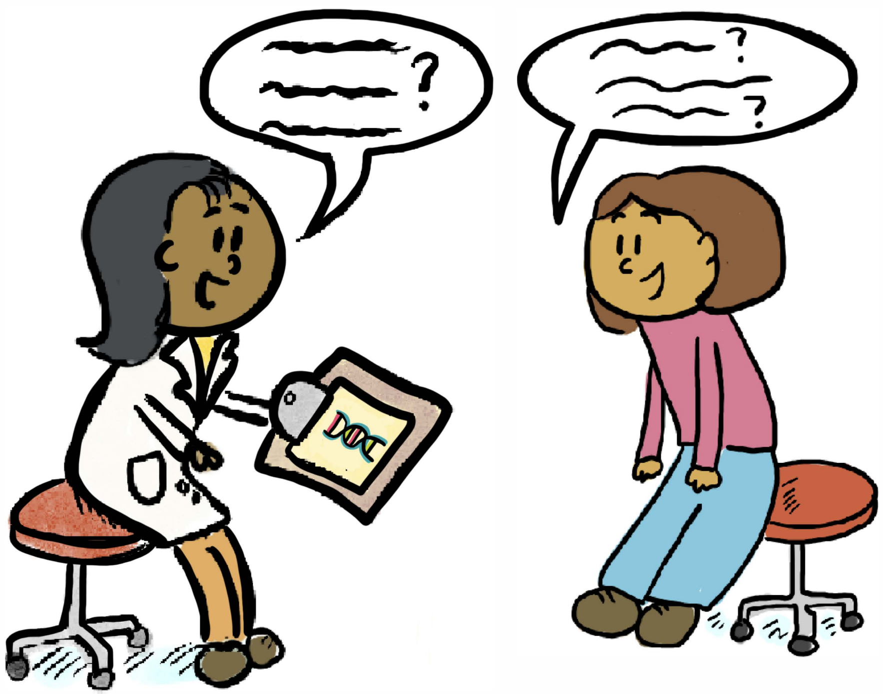
Possible Benefits
and
Risks of Genetic Screening



Age-Based Genomic Screening

Website: go.unc.edu/abgs

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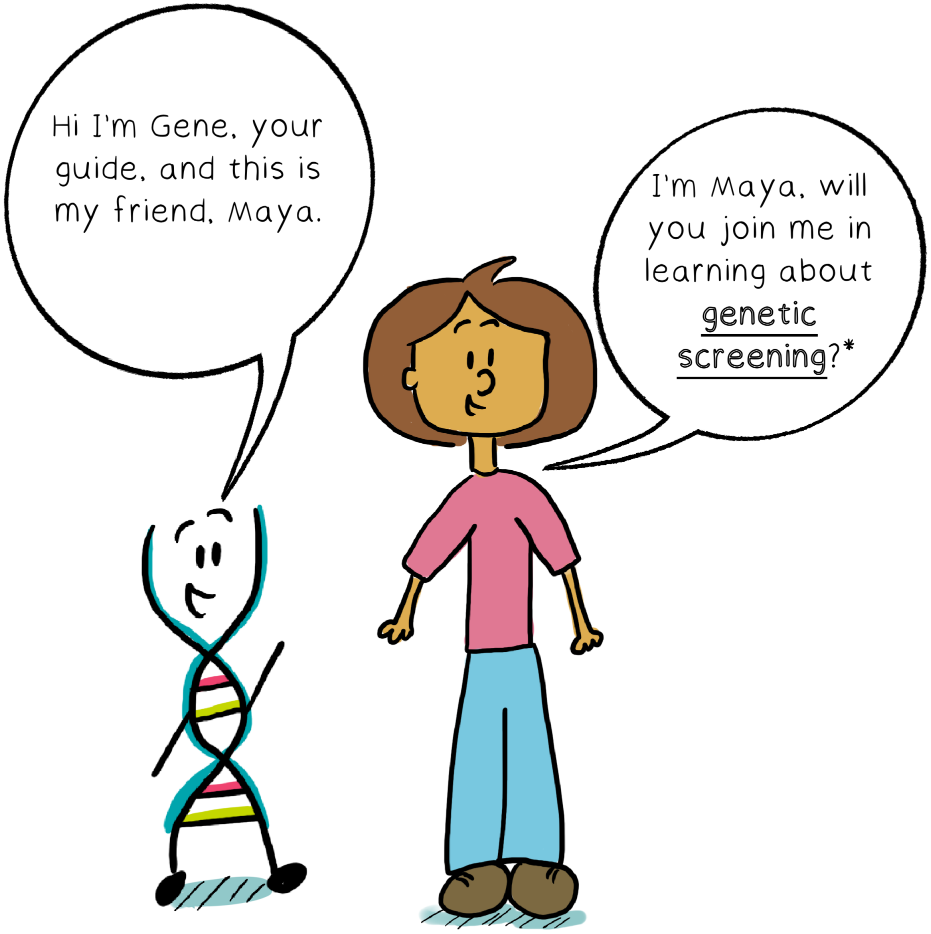
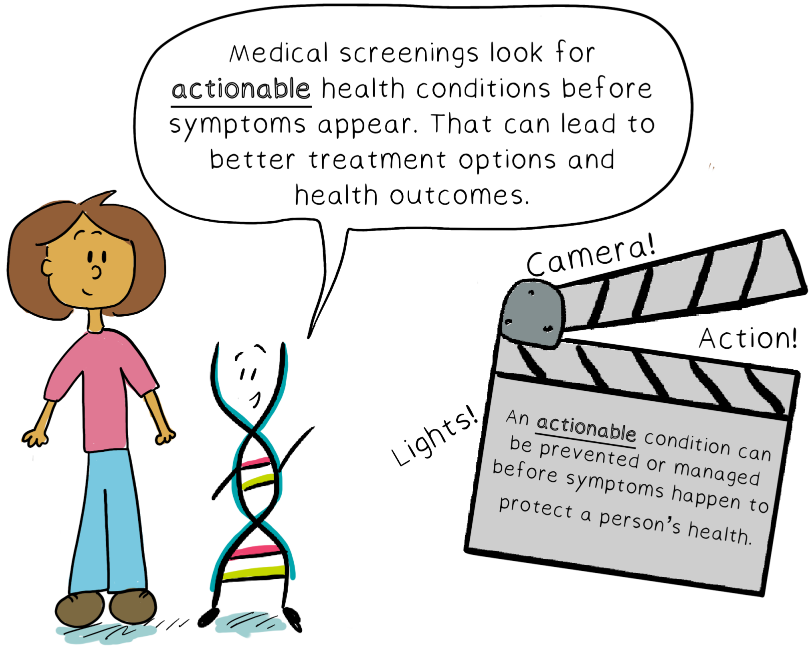
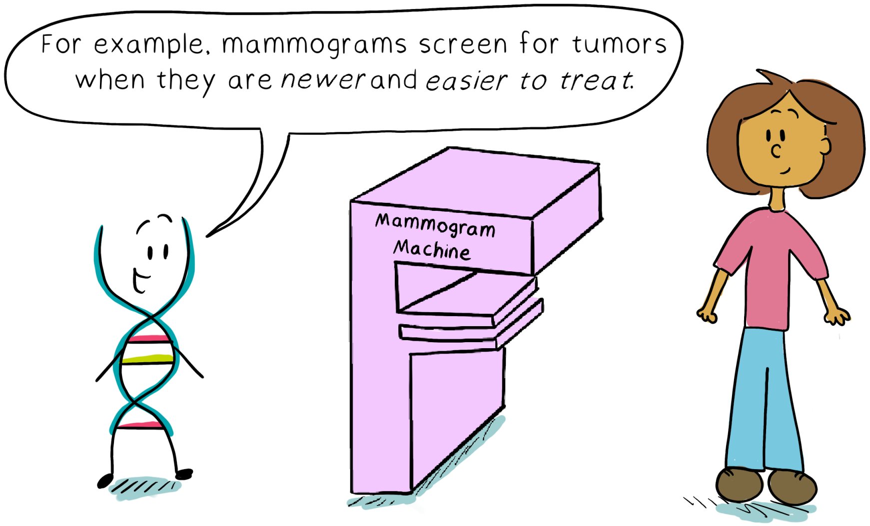
Website: oliludesigned.com

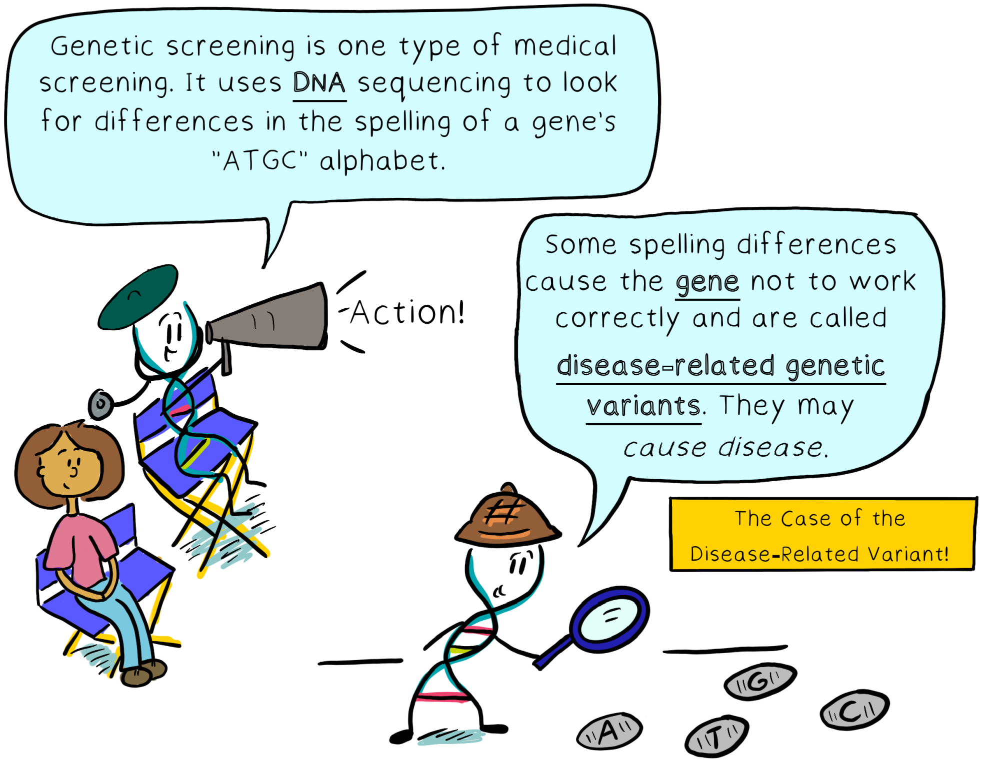
Chapter 1:
What is genetic screening?

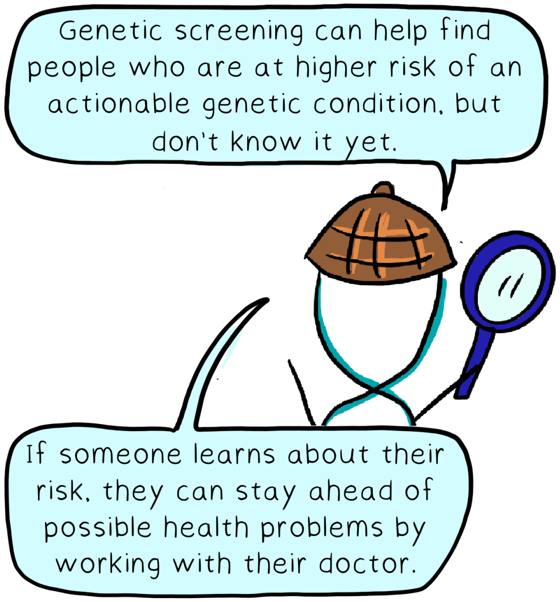


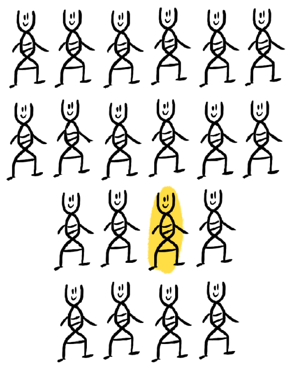
*Highlighted vocabulary words are defined in the Glossary at the end of this comic.



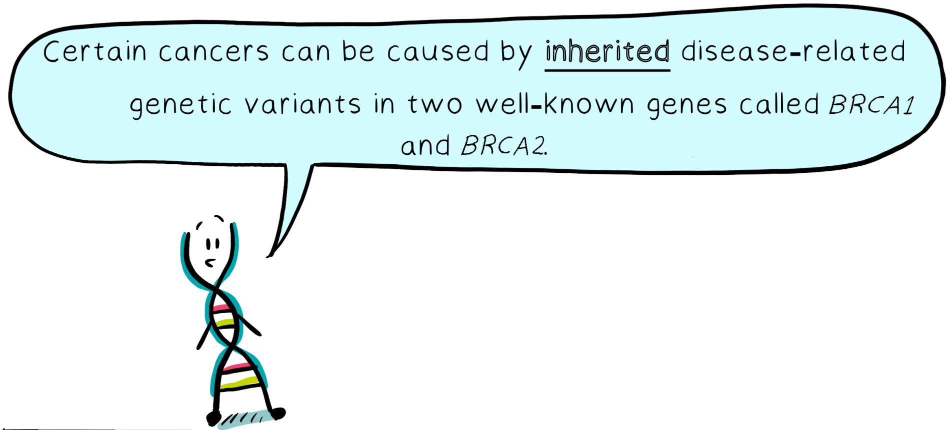






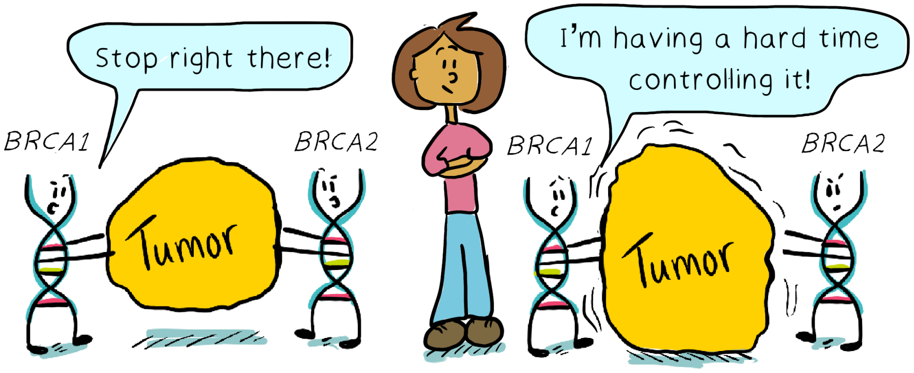


About 1 in 20 people has an actionable genetic condition



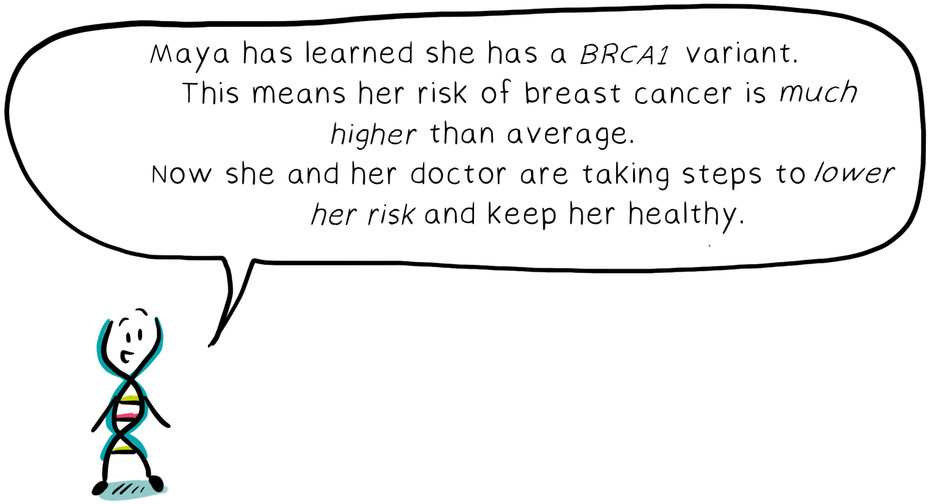
The job of the *BRCA1* and *BRCA2* genes is to help our body stop tumors from growing.

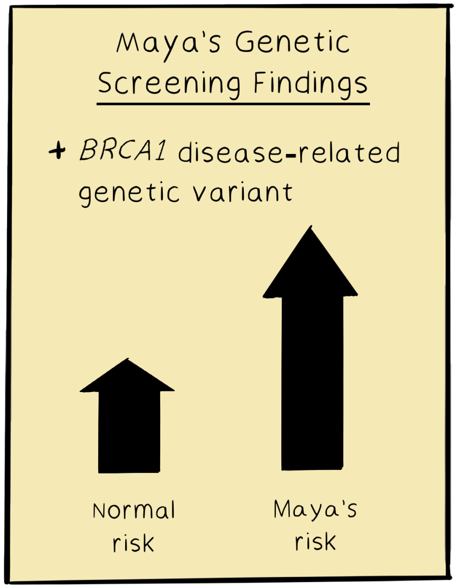
People who **inherit** disease-related variants in their *BRCA1* or *BRCA2* gene are more likely to develop breast and ovarian cancer.

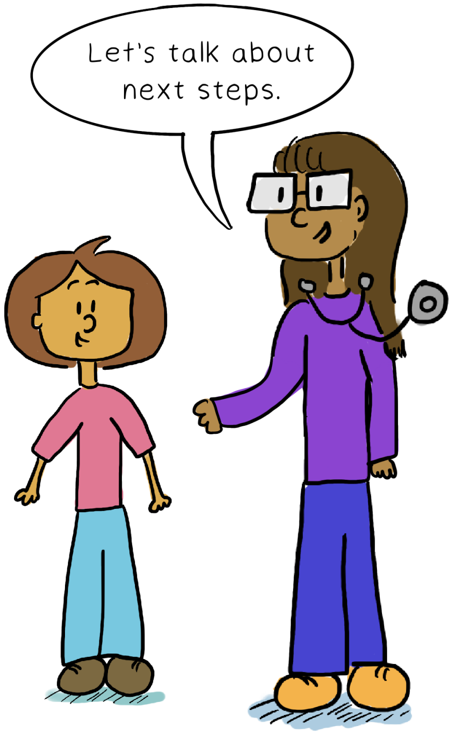


Genetic screening can check for harmful variants in these and certain other genes to catch any issues early.

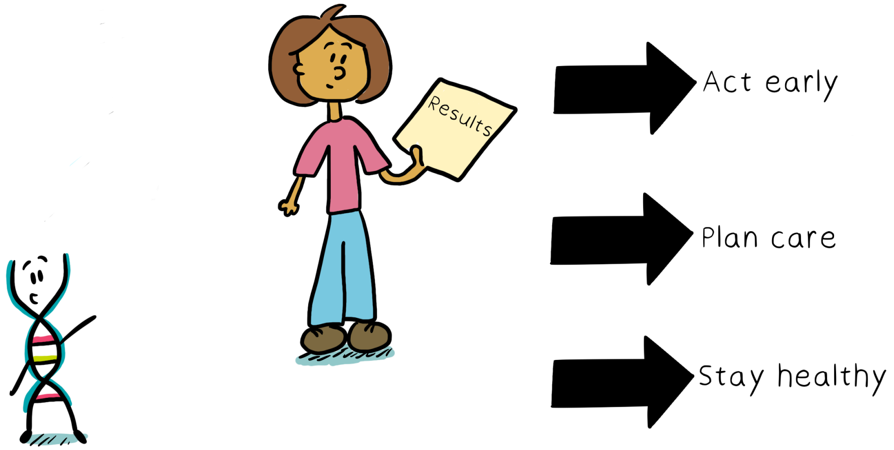
Chapter 2:
Benefits of Screening



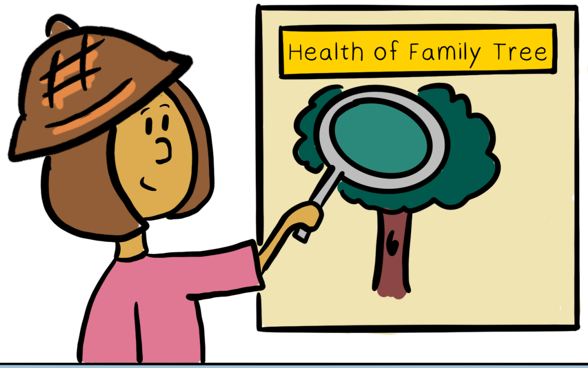




1. Genetic screening can find health risks early so you and your doctor can plan checkups or early treatment before symptoms start.

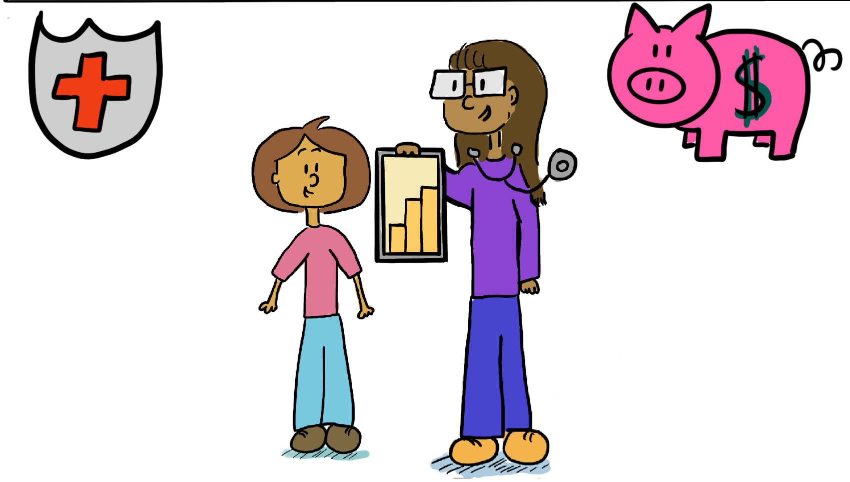


2. Since we share genes with *blood relatives*, your genetic screening results can give your family *helpful clues* about their own health.



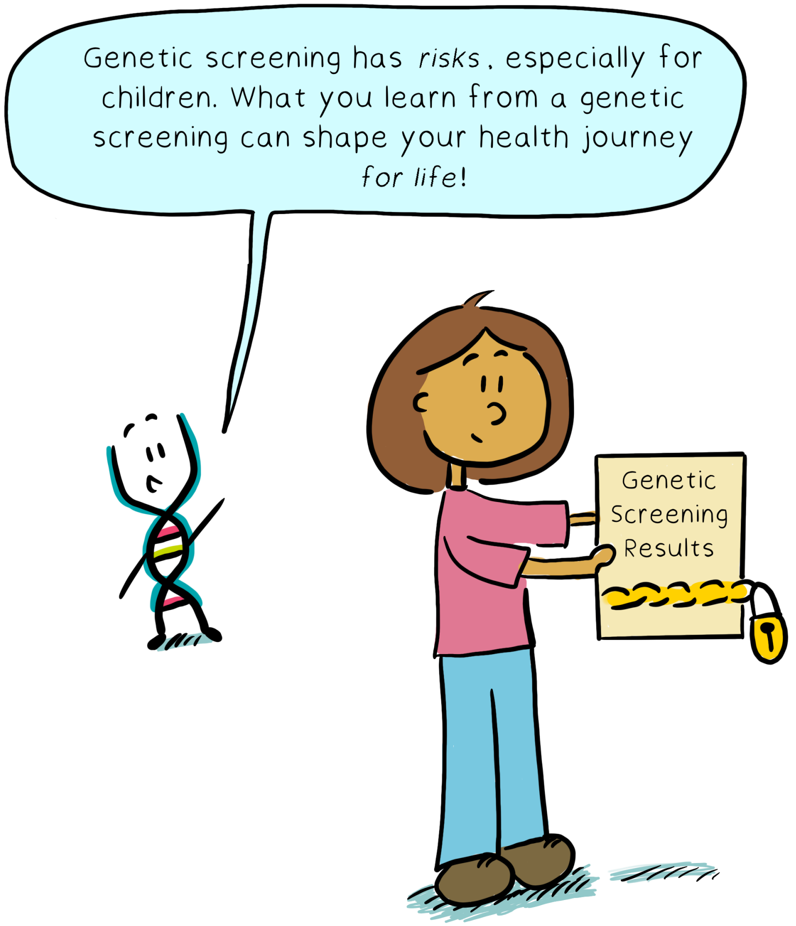
3. Genetic screening can also provide information about health risks for people *who don't know their family medical history*, like those who are adopted.

4. Genetic screening gives your doctor a clearer view of your overall health.



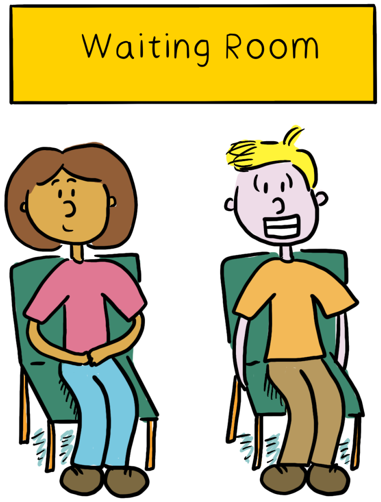
5. This may help *prevent serious illness or lower medical costs.*

Chapter 3:
Risks of Screening

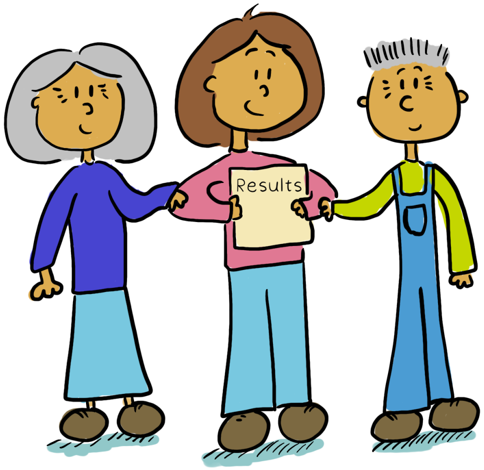


1: Your DNA carries *sensitive information* about your health, your family, and even your future. Ask *where your data will go* and what control you'll have over it.

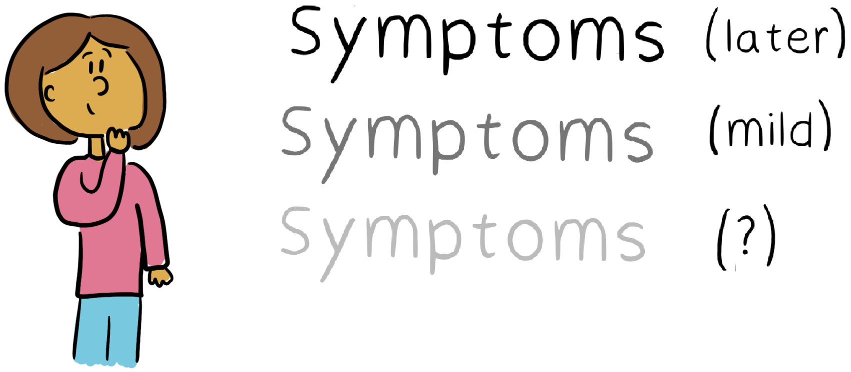
2: Waiting for results or learning about a possible health risk can feel *overwhelming*. Some people feel *empowered*, others feel *anxious*.



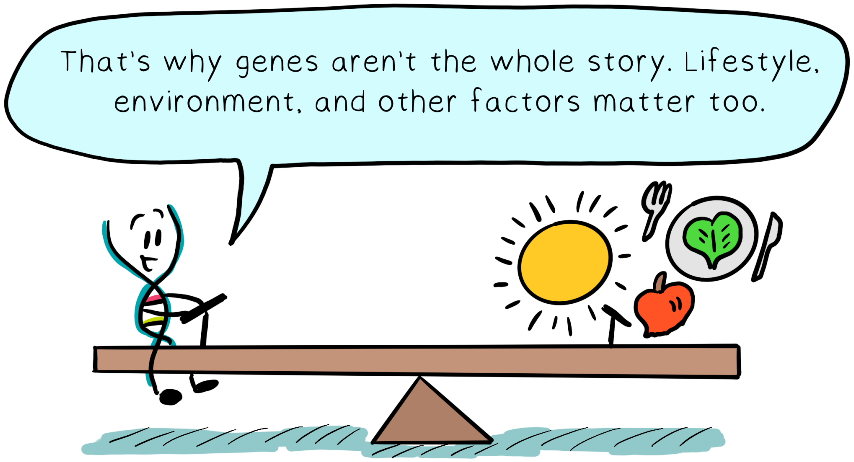
3: Your results could show something that also matters for your family members' health.



4. Sometimes results aren't clear or they need more follow-up.

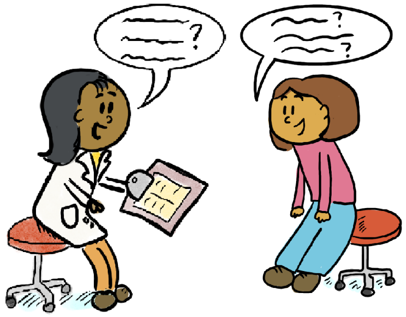


5. Not everyone experiences a harmful gene variant the same way. One person may have mild symptoms, another more serious ones, or not at all.



Deciding about screening means weighing both the benefits and the risks and having support to choose what feels right for you and your family.

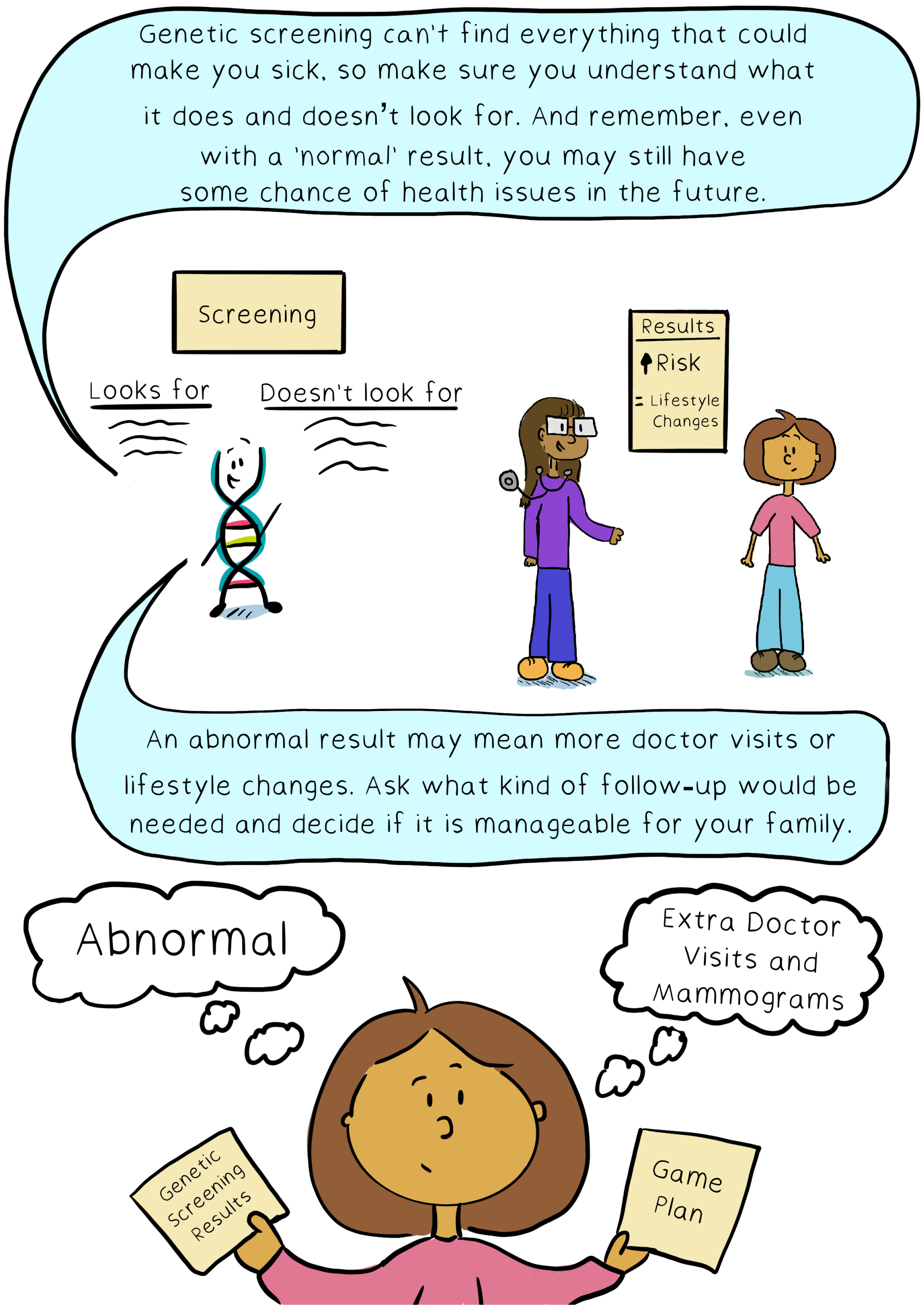
Your doctor can help you make an informed decision before you move forward with a genetic screening. You may also want to consult with a genetic counselor.



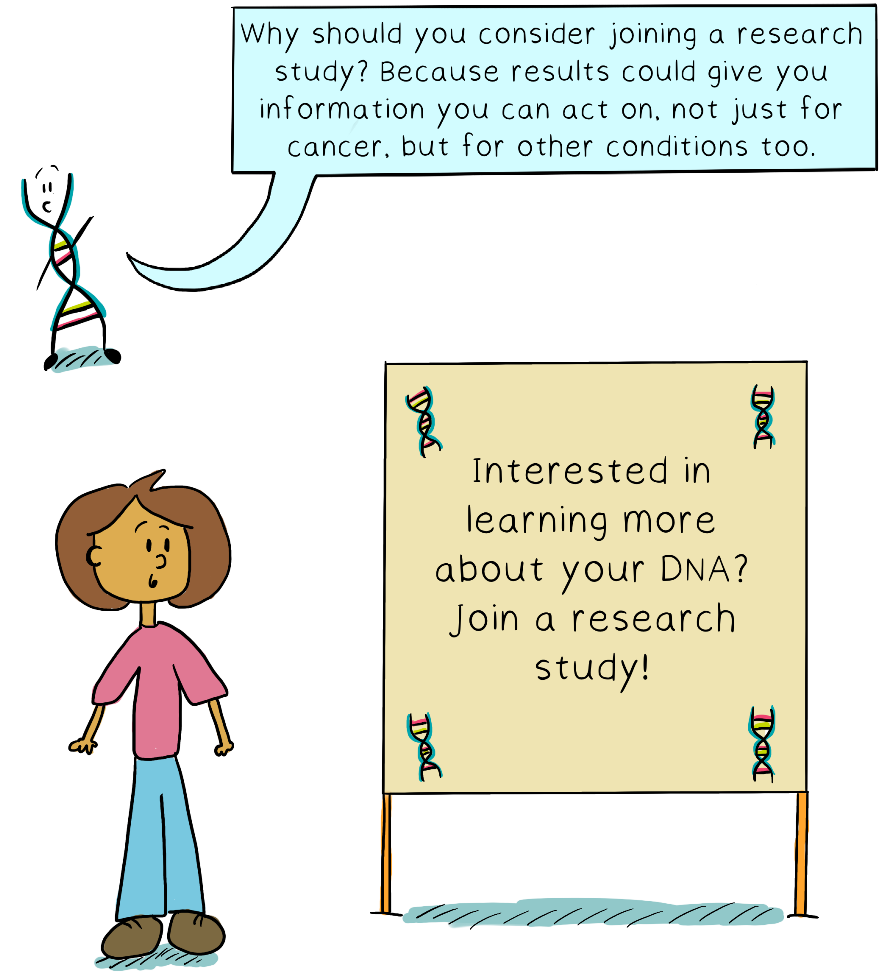
Genetic screening gives you a chance to *plan for* and possibly *prevent* future health problems, but it also means learning about them sooner, which can be *stressful*! Ask what support is available to deal with anxiety or worry this might cause.

You can also ask about a law called the Genetic Information Nondiscrimination Act or GINA that protects against genetic discrimination in health insurance and employment, but not in life, disability, or long-term care insurance.

Ask how much the screening and follow-up care might cost and if insurance will help cover it.

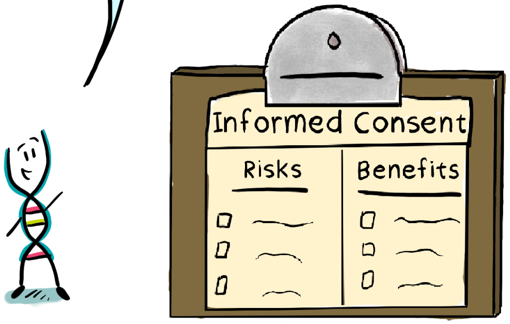


Right now, genetic screening is not yet widely available in everyday healthcare. For now, the most common way to get genetic screening is through <u>research studies</u>.

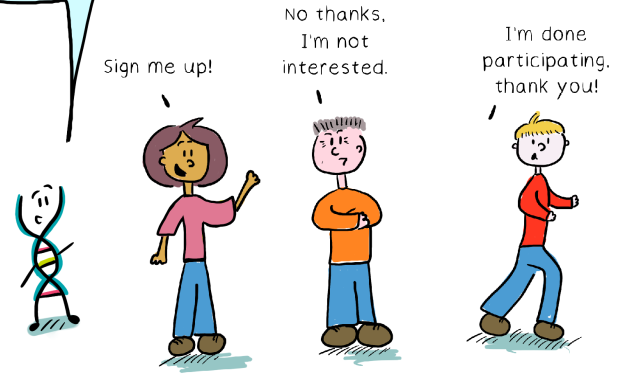


Chapter 4:
Research Studies

If you are getting genetic screening as part of a research study, you will start with **'informed consent.'** That's a conversation with the research team to explain what the screening involves, the possible benefits and risks, and how your information will be used and protected.

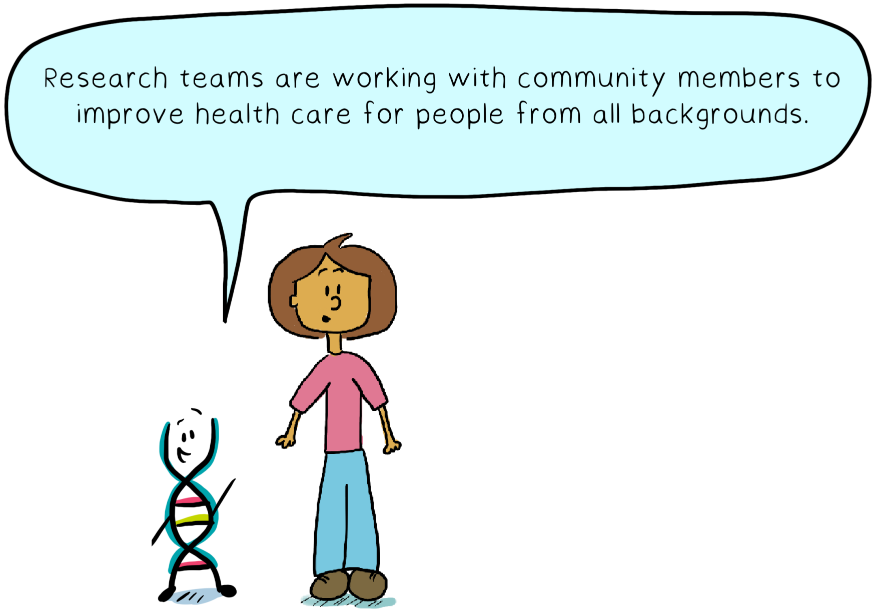


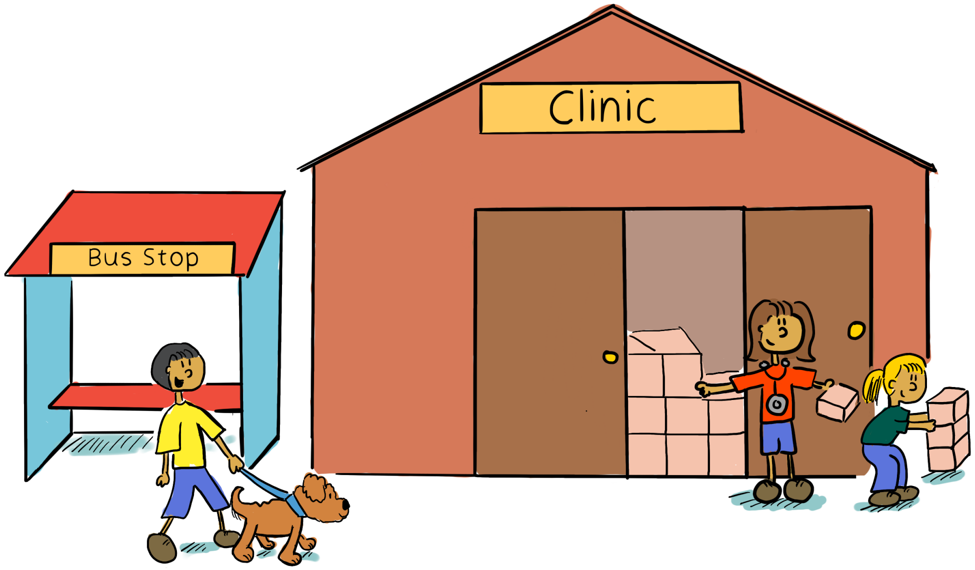
The decision to participate is yours alone. **Informed consent** helps you choose what feels right, so ask questions and get any guidance you need before deciding.



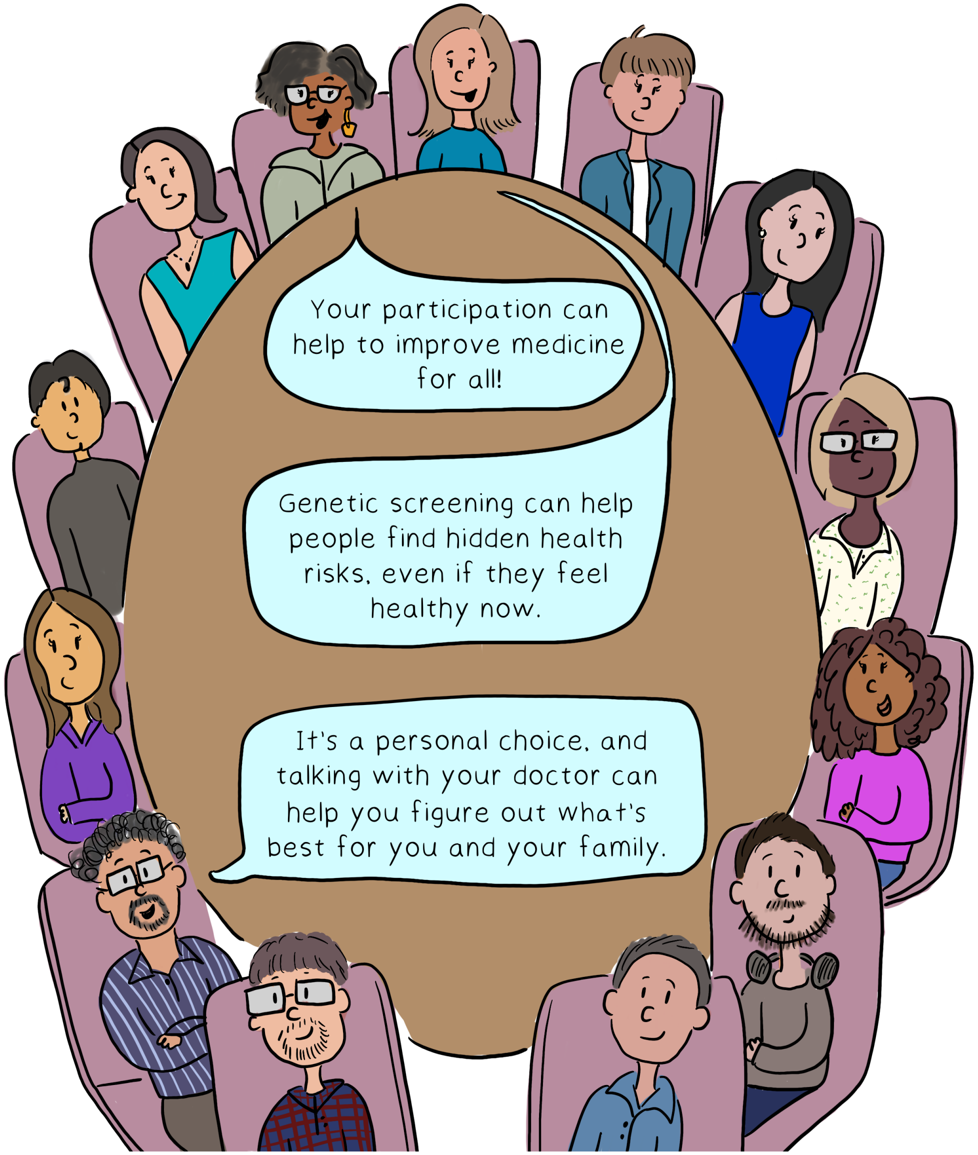
By participating in a research study, you are helping to make health care better for everybody! Not everyone has had the same access to research or health care. When studies leave out certain groups, results don't reflect everyone's needs and that can lead to care that doesn't work as well for everyone.

A key goal of modern research programs is to make genetic screening more understandable, available and useful to everyone. For screening to truly benefit all communities, everyone needs a fair chance to access it.





You can help too. Joining a study or sharing what you learn helps include more voices and builds a healthier future for everyone.



Plain Language Glossary

- **Actionable:** a condition that can be prevented or managed before symptoms happen in order to protect health
- **Disease-related genetic variant:** a spelling difference that causes the gene to not work correctly and can cause disease.
- **DNA:** the blueprint for a person which is written in letters "A, G, C, T" and inherited across each generation
Gene: a small piece of DNA that provide the code for specific functions or traits
- **Gene:** a small piece of DNA that provides the code for specific functions or traits.
- **Genetic and genomic research:** Research that looks at DNA and other types of data to help us learn more about how to detect and treat diseases in people
- **Genetic Information Non-discrimination Act (GINA):** A US law that provides protections against genetic discrimination in health insurance and employment
- **Genetic screening:** a specific type of population screening that involves reading a person's DNA to see if they have any potentially disease-causing or "pathogenic" variants
- **Inherited:** a trait, disease, or condition that is passed down through a family by each generation
- **Informed consent:** A conversation between a researcher and person interested in being part of a research study. The researcher will explain the risks and benefits of being a part of the study and answer any questions before a person can join the study.