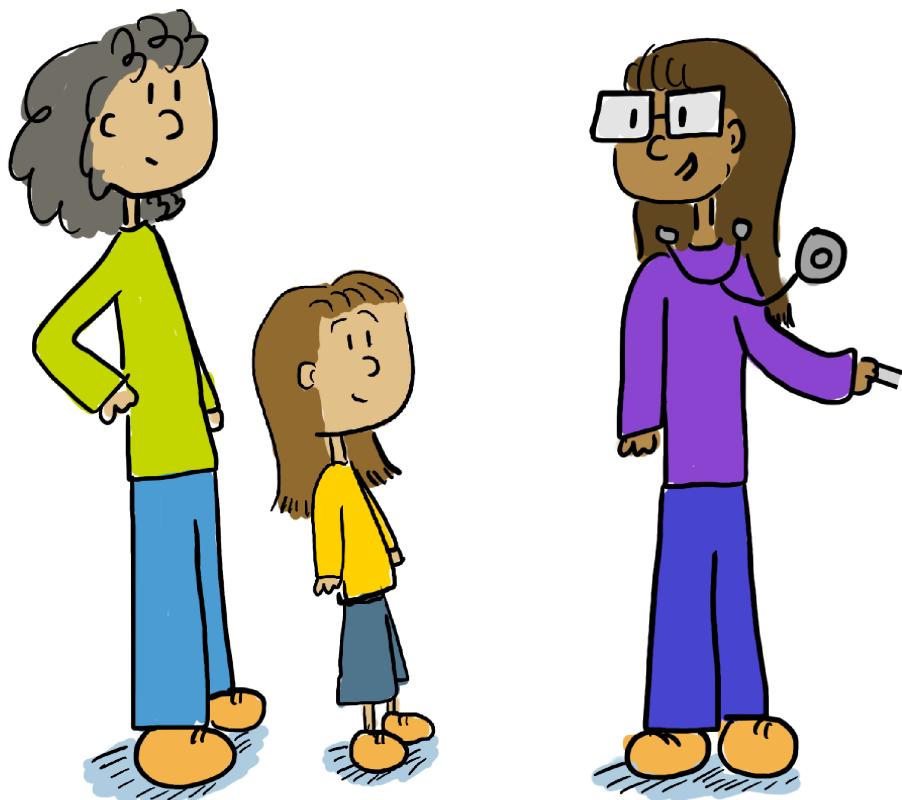


Consent Conversation



Age-Based Genomic Screening

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Website: go.unc.edu/abgs

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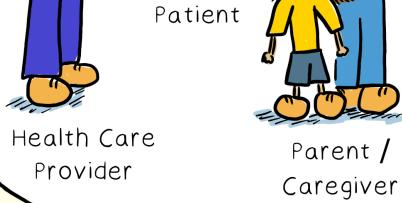
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This comic features the Age-Based Genomic Screening test as an example. Informed consent conversations for other screening tests will look different

Making informed decisions is an important part of receiving healthcare.

It means getting all the information you need to decide on the best health actions to take.

Both you and the health care provider have important roles. The health care provider will share information.

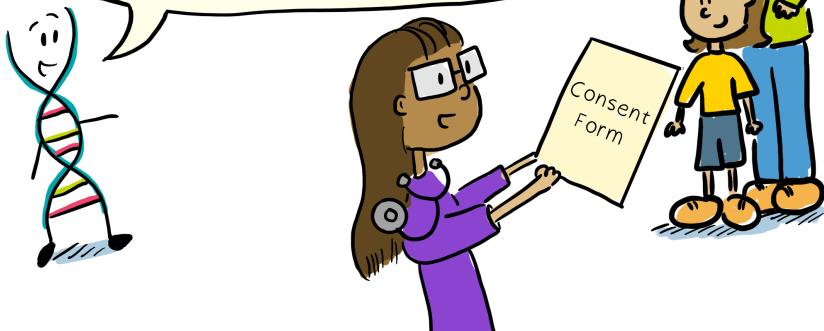


You can ask questions and share what matters most to you when making health decisions.

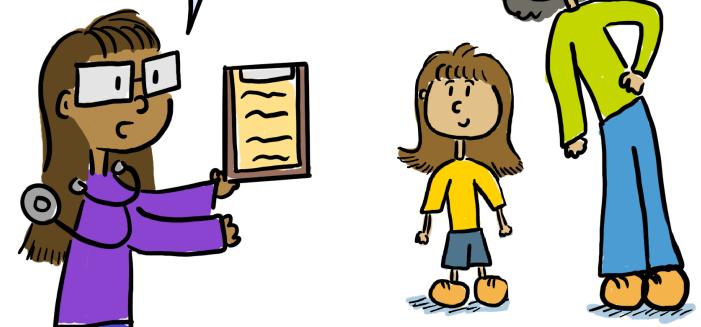
This shared decision-making often happens in a short talk. However, if the health care provider is offering something new or complex, it might take a little longer.

Sometimes you might need to sign paperwork, which is often called a consent form.

Genomic screening is an example of a health screening where you might have a longer discussion with the health care provider..



Today's exam was great. Everything looks right on track! As part of today's visit, I want to talk to you about a screening test.



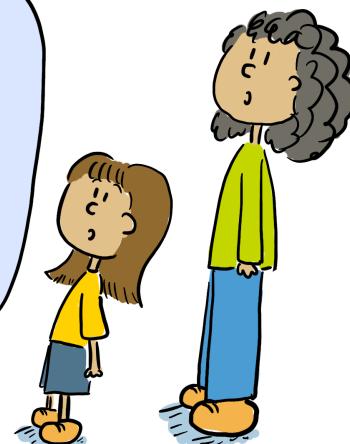
ABGS Screening Test

Example Conditions

- Wilson disease
- Marfan Syndrome
- Familial Adenomatous Polyposis
- Etc.

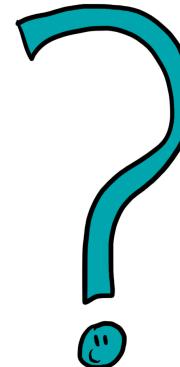
This screening test looks for several genetic health conditions. The conditions were all chosen by experts.

Finding these conditions early, before symptoms start, allows us to do more to improve or protect the child's health. I offer this screening to all my patients at this age.

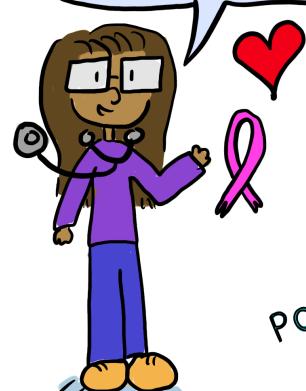


What questions can I answer for you?

What kinds of conditions does the screening test look for?



Many of the conditions increase the chance of developing a heart problem or cancer in childhood. Experts believe the benefits of finding and managing these conditions early outweigh possible risks.



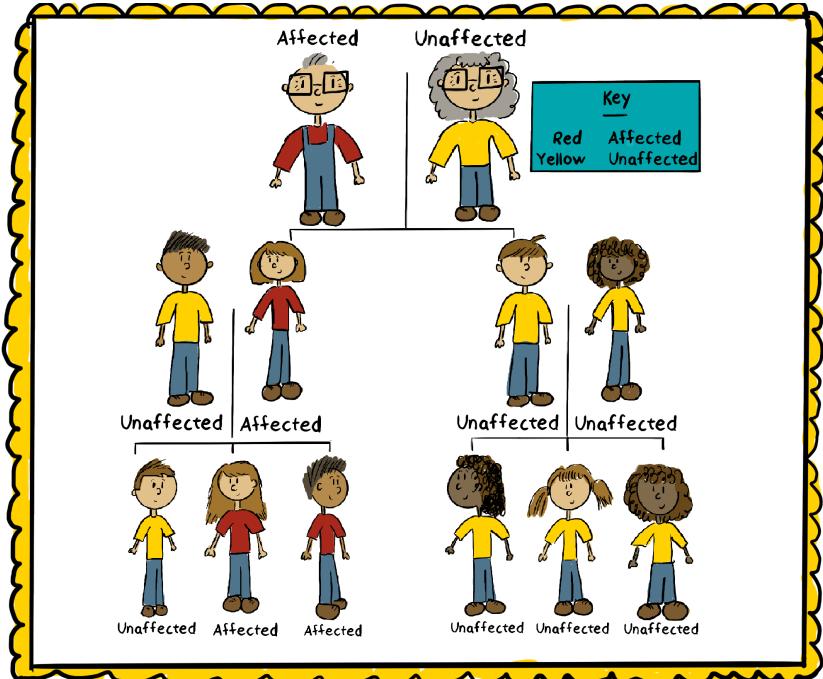
You can learn more about the conditions included by scanning the QR code or visiting this website:

go.unc.edu/abgs



Possible Risks





We don't have anything like that in our family. Is there still a chance my kid could have one of these conditions?

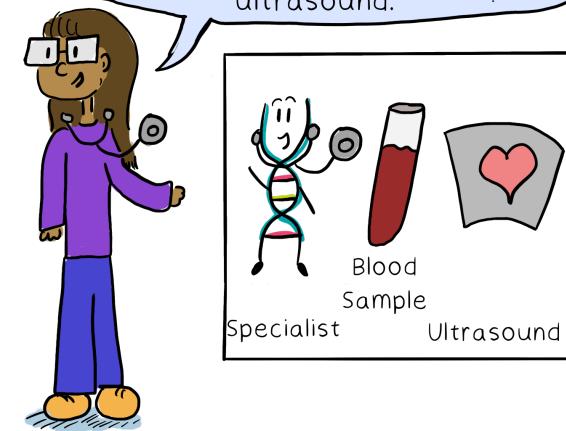
Yes. This type of screening was started because family history can't always predict these conditions. In some cases, a child could be the first person in the family to have one.

These conditions are rare, and most kids will not have one. But for the small number who do, early medical care can make a big difference.

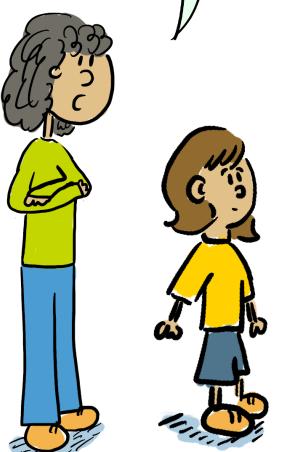
If you find a condition, what happens next?



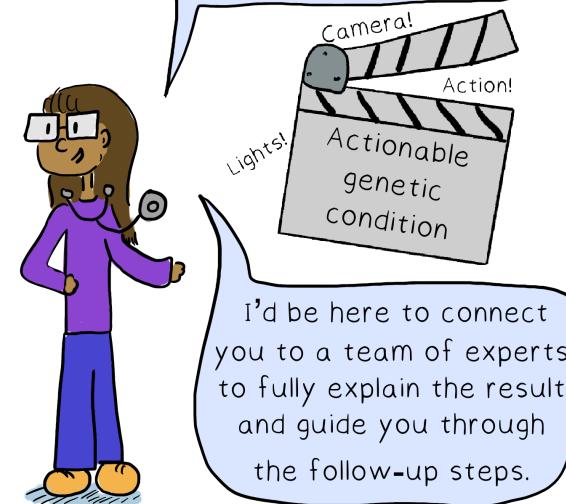
It depends on what condition is found. Often, the first step is to look for early symptoms. This may involve a visit with a specialist, blood work, lab tests, or imaging like an ultrasound.

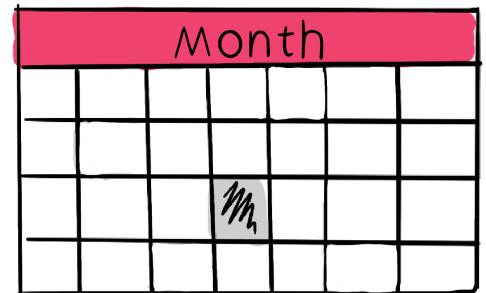
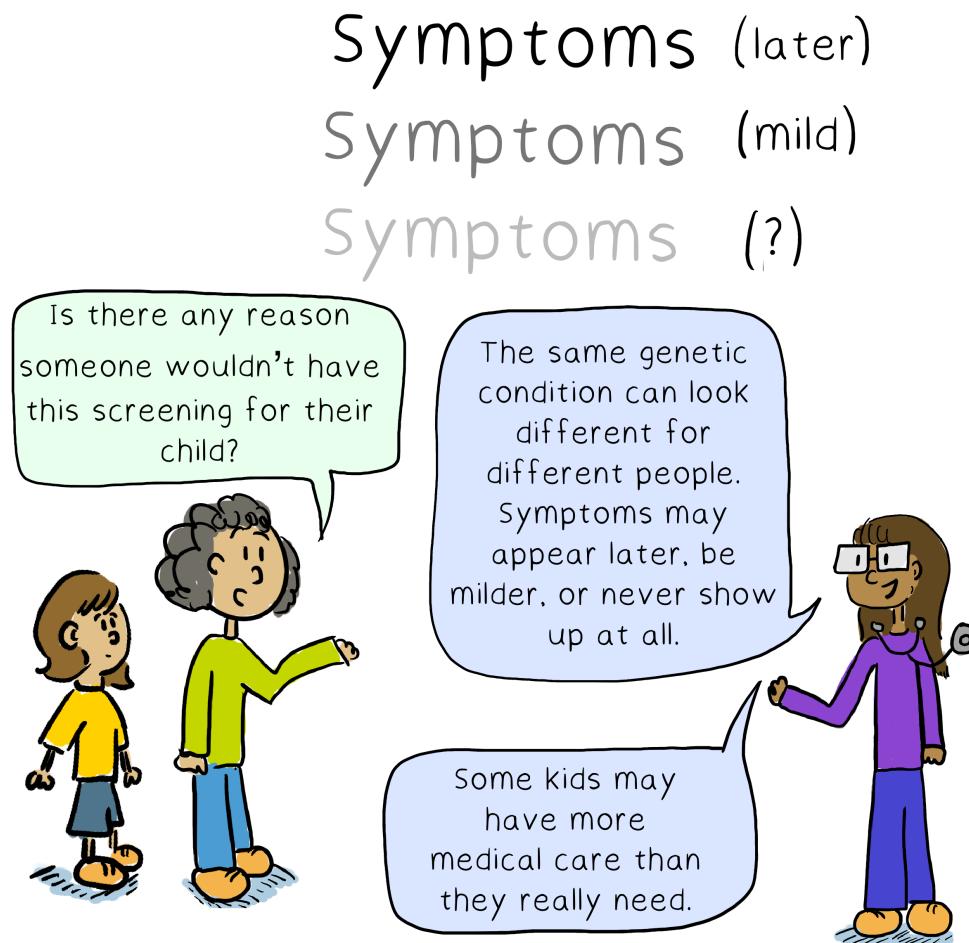
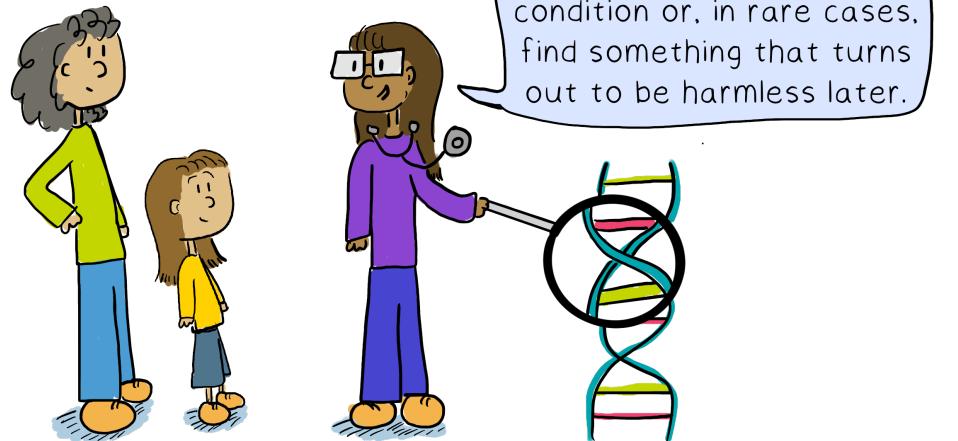
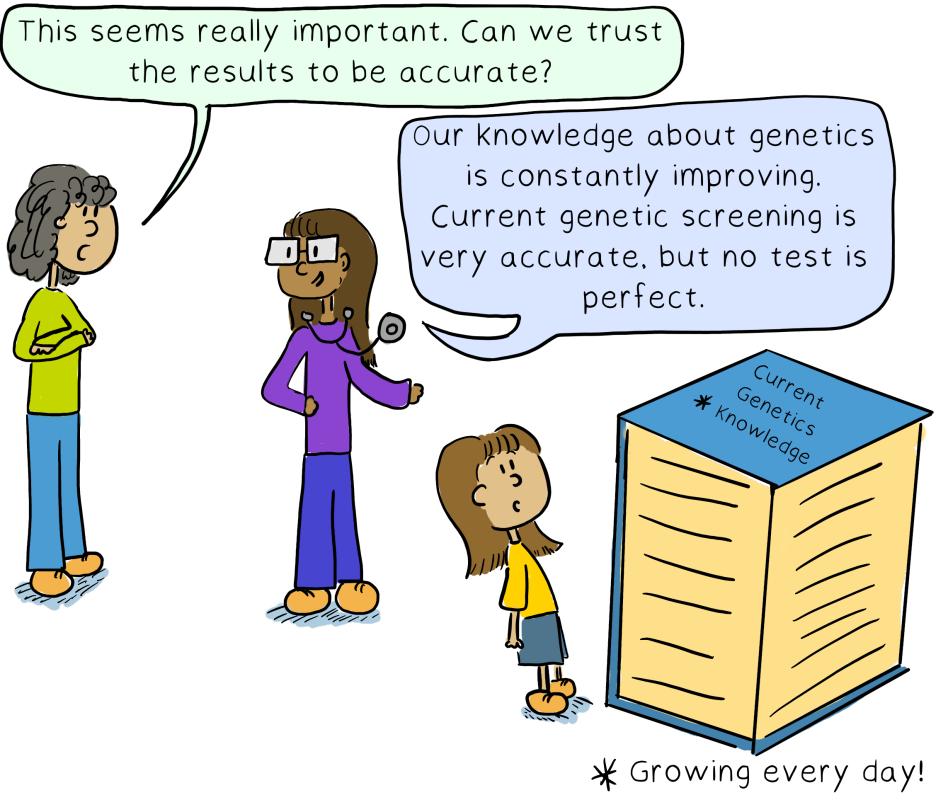


That sounds scary. I'm not sure how I'd feel if we got an unexpected result.



Learning about a genetic condition in your child can be scary, but it allows for action. All screened conditions have well-established treatment, medications, or follow-up care recommendations.





Some families may choose not to have screening because of this. However, the experts picked these conditions for screening in kids because they believe the possible benefits outweigh the risks.



Some people worry that genetic screening could affect their child's future, like getting a job or insurance. Remember that most people will have a normal screening result.



For the few who are found to have a genetic condition, a law called the Genetic Information Non-discrimination Act or GINA provides some protections.

GINA

GINA helps prevent health insurance and employers from not covering you or hiring you based on your genetic condition. However, it doesn't protect against everything, like getting life insurance.

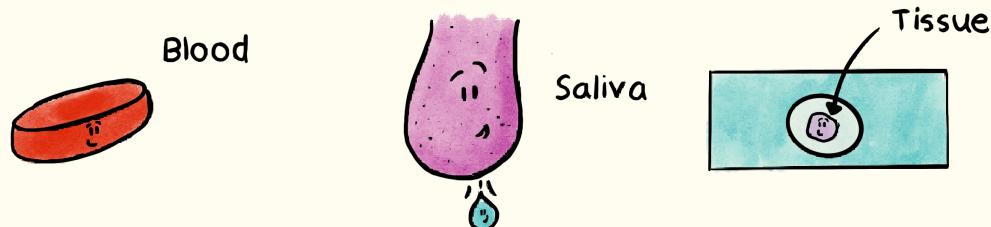
You can learn more about GINA here:



<https://go.unc.edu/ABGS-about-GINA>



Sample examples



INFORMATION

Now you have an idea of what to expect if you are offered genomic screening for your child. Remember, the goal is to give you the information you need to make the best decision for your child.



Hopefully the questions here give you an idea of what to ask and inspire your own questions!

QUESTIONS

To learn more -

Website: go.unc.edu/ABGS

Email: abgs@unc.med.edu

