

Questions to Ask Your Genetic Counselor

Sometimes it takes a conversation ahead of time to figure out whom you should see. If your child has a metabolic condition, for example, it's important that you go to a clinic with a metabolic care team (dietitians, metabolic geneticists, etc.) Consider asking:

Before you make an appointment

- Who provides the care here?
- Do you have geneticists?
- Do you have genetic counselors?
- Do you have advanced practice providers?
- What should I expect when I meet with the genetic counselor?
- How many appointments will I need?
- What should I send over before the appointment, or bring with me?
- Will my insurance pay for the counseling? Are there assistance programs?
- Is genetic testing part of the first session? If so, what will you sample?
- How will my privacy and the privacy of my family members be protected?

At your first session

- What type of genetic testing is available?
- What is involved in the process?
- How will I know if I need to have genetic testing done?
- What are the benefits and limitations of these tests?
- What information will the tests provide and how will I receive the results?
- How will this information help us?
- We have had genetic tests in the past that didn't provide answers. What will be different now?
- What is the chance that testing will provide a diagnosis?
- Could I be exposing myself or my family to discrimination based on genetic information?
- How will I pay for testing?

After testing

- What does this result mean for my family?
- Does this result mean I'm definitely going to get sick?
- Is there a treatment for this?
- You found this genetic change. Is there a way to correct it?
- Could I pass this on?
- What are the chances that my children, my siblings, my parents are affected by this?
- What is happening in the world of clinical trials around this?
- Do you know of other families or organizations you could connect me with?
- Who should I share my results with?
- I didn't receive a diagnosis. What's next?