Genetic Counseling FAQs

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What is a genetic counselor?
A genetic counselor is a healthcare provider with special training in medical genetics and counseling. They work as part of a medical team to provide care for patients. Genetic counselors can do many things to help patients and their families. Genetic counselors often collect family histories. They use this information to determine who in a family is at risk of having leukodystrophy and who has an increased chance of having a child with a leukodystrophy. Genetic counselors educate families about genetics and inherited conditions. They are also responsible for helping patients and family members get genetic testing and interpreting the results. Genetic counselors provide patients and families with supportive counseling and are advocates for their patients.

What decisions can a genetic counselor help me make?
Genetic counselors can help patients and families decide if genetic testing is right for them. They can help families understand how genetic testing might impact them. They also educate families on the benefits and limitations of genetic testing. Genetic counselors can help families process a genetic diagnosis and make decisions about patient care.

What can’t a genetic counselor do?
Although genetic counselors are healthcare providers, they are not doctors. Therefore, they can’t do physical exams, treat patients, prescribe medications, or make medical recommendations.

Genetic counselors and geneticists are different types of healthcare providers. Although they both have special training in human genetics, geneticists are doctors.

Why might I consider genetic testing?
When a genetic counselor tries to determine who in a family is at risk of having leukodystrophy, it is helpful to know the genetic diagnosis. Having a genetic diagnosis can also be important for family planning.

Many leukodystrophies do not have a treatment, but researchers are trying to find one. For researchers to explore treatment options, they need to have patients with leukodystrophies in their studies. Being involved in a research study usually requires a genetic diagnosis.

How should I prepare for a genetic counseling appointment?
If your family member has had genetic testing, bring the results to your genetic counseling appointment. This information will help the genetic counselor understand the diagnosis or decide if more testing is appropriate. Also, be prepared to provide information about your family history, although it is okay if you do not have all the details.