

Eye Want 2 Know[®]...

How to talk to my family about pursuing genetic testing for my inherited retinal disease (IRD) and exploring options that may be available to us

If you'd like to discuss IRDs and whether genetic testing is right for you and your family, use these questions as a guide to get the conversation started.

- How important is it to determine the genetic mutation(s) in our family that may be linked to an IRD?

- What new information would we want to learn about possible genetic mutations in order to address potential health issues?

- Would we be interested in looking for clinical trial opportunities related to a specific gene mutation?

- Would we like to gain access to relevant supportive educational and social services?

- Would we be interested in connecting with others living with the same type of vision impairment?

- After genetic testing, would we be willing to speak with a genetic counselor to understand the test results and hear their guidance and advice?

Tips for discussing genetic testing for IRDs with your family

- Share with your family why you're interested in or have decided to pursue genetic testing.
- Communicate facts about genetic testing, the process, and how the knowledge may benefit you and your family.
- Ask questions about family medical history related to vision loss that may help as background for your healthcare professional or genetic counselor.
- Ask if any other family members—of any age—with vision loss are interested in pursuing genetic testing and offer to support them in navigating the process or connect them to additional resources.

What other questions do you have? Write them here or use this space to take notes.