

# NEW RESEARCH STUDY FOR MEN PATIENTS

## LOOKING FOR PATIENTS WHO GOT AN UNEXPECTED GENETIC RESULT RELATED TO MEN

### About the Study

A new study is recruiting people who had genetic testing done **for some other reason** and received results related to MEN. The goal of this program is to learn more about how people use results like this.

### What is Involved for People who Join?

**We want to know what you did about your result.** If you join the study, the first phase is a survey and phone interview. We will ask you about any changes you made to your healthcare based on the result. We will also ask if there were recommendations you did not follow and why. Finally, we will ask questions about sharing the result with your family members. You may be invited to the second phase of the study, which could include extra testing for you and/or your family members at the NIH or in your area. Being in the study and having testing done at the NIH is free. If we ask you to come to the NIH, and you live in the United States, we will pay for your travel and a hotel.

**We provide a basic explanation of your result and may offer more.** You will get basic information about what your result means. You will also get a checklist of health actions you should take. You may get extra information, counseling or other support to get the healthcare that we recommend.

**Help us improve care for future patients.** Results like yours are added to genetic testing reports with the hope that they will make families aware of important health risks so they can get the healthcare they need. We know that this does not happen for all families. We intend for our results to help more patients benefit from these results. For example, we hope to learn what makes it hard for patients to get care that they need and how healthcare providers can help.

**Please partner with us.** Our study would not be possible without patients like you! Only 2 out of 100 people who have genetic testing get an unexpected result, so every patient is valuable to our project.

### The Study is Open to...

People who speak English or Spanish and got a genetic testing result related to MEN even though they were not having genetic testing to get information about these conditions. This may include people who have results related to the genes listed below:

- *MEN1*
- *RET*

If you have a result in another gene, please contact us and we can decide if you can join the study.

Common things that make someone ineligible for the study are:

- Having genetic testing to find out about risk for MEN.
- Having a genetic result related to risk for Alzheimer's disease and not MEN

**Study Contact Information**

For more information, please visit [www.genome.gov/GSRP](http://www.genome.gov/GSRP). If you are interested in joining or want to see if you are eligible, please contact us at [gsrc@nih.gov](mailto:gsrc@nih.gov), 301-402-6871, <https://www.surveymonkey.com/r/gsrcpreferral>, or by scanning the QR code below.

