



GenomeConnect

The ClinGen Patient Portal

Understanding more about GenomeConnect

GenomeConnect has been developed as a tool to connect people who are interested in sharing information in ways that make the information “usable” and “findable” to improve understanding of human health, while also protecting individual patients' privacy.

A patient portal (also called a registry) is a secure place for patients to voluntarily share and store detailed information about their health, so that connections can be made between that information and healthcare providers and researchers to learn more about human health. Registries are often open to a specific group of patients, for instance, patients diagnosed with a particular health condition or, like GenomeConnect, patients who have had or are considering genetic testing or have a relative with a genetic test result or diagnosis. Registries make medical discoveries possible by bringing together information from a large number of patients.

Purpose of GenomeConnect:

To partner researchers, clinicians, and patients with each other to learn about the effects of genetics on human health and disease. Patients will be the source of data studied, as they are the experts on their own health history and have (or can access) their genetic test results.

Who can participate?

GenomeConnect is open to adults (age 18 and older) and minors under the age of 18 who have the consent of a parent or legal guardian meeting at least one of the following criteria:

- *Have already had genetic testing*
- *Are considering genetic testing*
- *Are family members of someone who has had genetic testing*



Visit www.clinicalgenome.org and www.genomeconnect.org to learn more!



How can YOU get involved?

Finding out about GenomeConnect is the first step to take before deciding whether participating in GenomeConnect is the right choice for you.

If you are interested in learning more about GenomeConnect, please visit

www.genomeconnect.org

or email the study coordinator at

info@genomeconnect.org

to learn more about joining the GenomeConnect community and promote the advancement of knowledge about genomics and health.

About the Clinical Genome Resource

Technological advances are quickly allowing genetic testing to become commonplace in the care of patients. However, our ability to detect changes in DNA exceeds our ability to understand what they mean. Researchers, doctors, genetic counselors, and others are working to address this challenge. A National Institutes of Health (NIH) collaboration called the Clinical Genome Resource (ClinGen) has formed to work towards this goal. GenomeConnect is one of the projects ClinGen has created to move us closer to the promise of personalized genomic medicine.

www.clinicalgenome.org

Sharing Data.

Building Knowledge.

Improving Care.

