In this Issue:

Participation Update
What are mitochondria?
Updating Your Profile
Privacy

Participation Update

What are mitochondria?

Mitochondria are located in the cytoplasm - fluid that surrounds the nucleus of the cell. There are each cell has thousands of mitochondria. Mitochondria convert the energy from food into a usable form. Mitochondria have their own DNA, which is called Mitochondrial DNA or mtDNA.

Did you know? Mitochondrial conditions can be caused by changes in either the mtDNA or the nuclear DNA.

Fun Fact: ClinGen has an Expert Panel dedicated to Mitochondrial Diseases. This group is working to better understand mitochondrial conditions and the genes and variants that cause them. Find more information here: http://bit.ly/mitodisease

Updating Your Profile

By updating your profile, we will know how to contact you and will be able to give you updates on things like genetic testing.

“How to” tips

You can access our secure personal dashboard 24/7 and update your information on the go.

Privacy

GenomeConnect is very serious about protecting the privacy of participants, while trying to make your information available for health providers, laboratories, and researchers.

The registry platform has tight security measures in place to protect the servers where your information is stored. These safeguards have achieved standards for compliance with the Health Insurance Portability and Accountability Act (HIPAA) and the Federal Information Security Modernization Act (FISMA), two federal acts that aim to protect individuals’ privacy.

You can find more information here: http://bit.ly/clingenprivacy

FAQs

Q: Who will be accessing the data? A: Identifiable information can only be accessed by a limited group of registry staff.

Q: What information will be shared? A: Your de-identified genetic test results & your health information.

Q: What information will NOT be shared? A: Your personal identifying information.

Contact GenomeConnect

GenomeConnect.org info@genomeconnect.org 855-322-7683