

# GenomeConnect Newsletter

Winter 2019

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## Participation Update

1,984  
Total # of Participants



NEW

581  
Participants  
joined in 2018

## What are mitochondria?

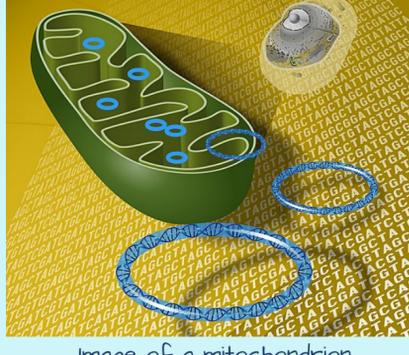


Image of a mitochondrion

Mitochondria are located in the cytoplasm - fluid that surrounds the nucleus of the cell

There are  
**37**  
genes in mtDNA

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 upload your **Genetic Test Results** by pressing the (+). Once you upload your results, a genetic counselor will review them. If you chose to participate in the matching feature, your gene would then be added to the searchable gene list. This will allow you to connect with other participants using the participant matching feature based on your results! Here is a short video explaining how to upload your results: <http://bit.ly/uploadingtesting>

Make sure that you are on the "Profile" page

PatientCrossroads™ Home About View Data Profile Logout

Jane Doe

MEDICAL SURVEYS

Incomplete Surveys  
Optional NIGMS Human Genetic Cell Repository at Coriell Start  
GenomeConnect Survey (1%) Complete

ACCOUNT INFORMATION

Update  
Jane Doe  
janedoe@email.com

FAMILY MEMBERS

+ Add  
Add your dependents and manage their accounts

TESTING RESULTS

+ Add  
Genetic Test Result (1)

MEMBER MATCHING

Click [here](#) to search for others with the same diagnosis, gene, or geographic location.

HEALTHCARE PROVIDERS

+ Add  
Add your doctors and healthcare providers

INVITATIONS

+ Invite Others  
Invite friends or extended family members to join.

You can access each of the surveys by clicking on the title. Filling out these surveys helps us learn more about you!

Press the pencil to update your email address. You can also update your contact preferences.

## Privacy

### 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.

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 (HIPPA) 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>

CONTACT  
US!

