

# GenomeConnect Newsletter

## Summer 2019

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Participation Update



Reconsent at age 18



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### ~Participation Update~

2458

GenomeConnect Participants



969

Unique Variants Submitted to Publicly Available Databases

#### Did you know?

GenomeConnect staff members present data related to GenomeConnect at national & international conferences, including:

- American Society of Human Genetics
- American College Medical Genetics
- Curating the Clinical Genome
- National Society of Genetic Counselors

7 Posters & Presentations in 2018-2019

### ~Reminder: Reconsent at Age 18~

When an account is created for someone who is under the age of 18, the consent is only valid until that individual turns 18. Once the individual turns 18, we need to update consent. Consent can be updated in different ways, depending on your specific situation:

#### If you are the parent of a child who just turned 18 and you do not have legal guardianship:

- Your child will need to update his or her account contact information and retake the GenomeConnect survey to consent to participate in GenomeConnect.
- If your child no longer wishes to participate, he or she can contact us by phone (855-322-7683) or email at: [info@genomeconnect.org](mailto:info@genomeconnect.org).

Retake Survey

Update Account Information

#### JANE DOE

##### MEDICAL SURVEYS

Complete Surveys	History
Cardiomyopathy Survey <input checked="" type="checkbox"/>	History
Arrhythmia (Heart Beat) Survey <input checked="" type="checkbox"/>	History
GenomeConnect Survey <input checked="" type="checkbox"/>	History
Heart Defect Survey	History

##### ACCOUNT INFORMATION

<input checked="" type="checkbox"/> Update
Jane Doe
JaneDoe@janedoe.org

#### If you are the parent of a child who just turned 18 and you have legal guardianship:

- Please let us know by sending an email to the GenomeConnect team at: [info@genomeconnect.org](mailto:info@genomeconnect.org).
- This will allow us to record that you have legal guardianship.
- We also encourage participants to retake the GenomeConnect survey each year so that we can collect information about any health changes.



If you do not update the account in one of the ways listed above, the account may be de-activated.

### ~What are Candidate Genes?~

A candidate gene is a gene that could potentially be linked to a disease, but more information is needed.

#### Did you know?

Candidate genes are also called genes of uncertain significance (GUS) since their relationship to disease is unclear.

★ Candidate genes are usually categorized as uncertain test results.

★ Further research is needed to determine whether a candidate gene is responsible for the symptoms of a disease.

★ GenomeConnect is the ClinGen patient registry. **ClinGen** is working to understand the genome to improve patient care. ClinGen is working to understand the relationship between genes and diseases through their expert panels.

★ You can read more about ClinGen's expert panels here: <http://bit.ly/ClinGenExpertPanels>

GenomeConnect submits data to **Matchmaker Exchange** via **GeneMatcher** to encourage research & a better understanding of a gene's relationship with disease.

### Meet the Team Spotlight: Kelly Toner



Kelly earned her Bachelor of Arts in Psychology at Muhlenberg College in 2015 and her Master of Arts in Psychology at the University of West Florida in 2018. Kelly currently works at Geisinger's Autism & Developmental Medicine Institute as a Genomic Medicine Assistant. In addition to her work as a member of the GenomeConnect team, she assists genetic counselors with their clinic duties and coordinates expert panels and working groups for the ClinGen.



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