



# GenomeConnect Winter Newsletter

## January 2017

### IN THIS ISSUE

Dear GenomeConnect Participant,

Can you believe it is already 2017? In the last year, [GenomeConnect](#) has continued to grow because all of our wonderful participants like you that want to share their data, connect with others, and help promote genomic discovery! Thank you for being a part of our registry.

We now have more than **815 participants** from **22 countries** and **48 US states**. We also have had some exciting updates in 2016 including the launch of our Participant Matching Feature, the addition of additional resources and research opportunities to our website, and the opportunity to spread the word about GenomeConnect at several local and international conferences! More about these exciting updates is included below.

## Connect with Others: GenomeConnect Participant Matching Feature

Our Participant Matching Feature is up and running! This feature allows GenomeConnect participants to search by gene, diagnosis, and/or US state and view all GenomeConnect participants who are interested in connecting with others.

**Be sure to upload your/your child's genetic testing report so that you can search and match by gene**

The Participant Matching Feature relies on you to upload your/your child's genetic testing report so that our study coordinators can curate the reports and update the searchable database. Genetic testing results can be uploaded to the "Testing Results" section of your Profile. Be sure to include all pages of the report (with all four corners of each page) to help us obtain all of the information that we need. If you need assistance uploading or obtaining copies of your genetic testing report or if you have questions about participating, please contact the study coordinators at [info@genomeconnect.org](mailto:info@genomeconnect.org).



**We would love to hear from you if you have used the Participant Matching Feature and connected with others. Send us your stories and let us know how the feature is working for you!**

## Connect with Others: GenomeConnect Participant Matching Feature

Learn more about GenomeConnect's Participant Matching Feature and how you can connect with others through the registry. **Page 1**

## Additional Research and Resources

If you are interested in other research opportunities, be sure to check out the "Research" tab on the [GenomeConnect](#) website. **Page 2**

## NIGMS Human Genetic Cell Repository at Coriell

The [NIGMS Human Genetic Cell Repository](#) at the Coriell Institute for Medical Research accepts blood and tissue sample donations from individuals with genetic conditions for use in research. **Page 2**

## How did we Spread the Word about GenomeConnect in 2016?

In 2016, members of the GenomeConnect team were able to spread the word about GenomeConnect with clinicians, patients, and researchers at several conferences. **Page 3**

## Coming up in 2017!

We will be sending out another survey in the coming weeks! Be on the lookout and help us learn about how you use social media! **Page 3**

## Additional Research and Resources

If you are interested in participating in additional research or exploring other resources, click on the “[Research](#)” tab at the top of the GenomeConnect homepage. There you will find other research opportunities and resources from groups affiliated with GenomeConnect, including [Unique – The Rare Chromosome Disorder Support Group](#), [Simons VIP Connect](#), [Genetic and Rare Disease Information Center](#), and [Imagine ID](#).

Additionally, we are planning to create and provide educational resources to our GenomeConnect participants. Are there aspects of your genetic testing report that you would like to know more about? Do you want to know what a variant of uncertain significance or a candidate gene is? What is the difference between a gene panel, a chromosomal microarray, and whole exome sequencing?

**To best serve our GenomeConnect participants, we would like to hear from you about what educational resources you would find most helpful. Please email us at [info@genomeconnect.org](mailto:info@genomeconnect.org) and let us know!**

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## NIGMS Human Genetic Cell Repository at Coriell

The [NIGMS Human Genetic Cell Repository](#) at the Coriell Institute for Medical Research accepts blood and tissue sample donations from individuals with genetic conditions for use in research by scientists around the world to discover genes and their function, further study known genes, and for the development of new genetic tests.

As part of participation in the NIGMS Human Genetic Cell Repository, participants are asked to submit their genetic and health information. If you have donated blood or tissue to the NIGMS Human Genetic Cell Repository or would like to donate a sample in the future, you can easily share the genetic and health information you have submitted to GenomeConnect with the NIGMS Repository.

If you want to participate in the NIGMS Human Cell Repository and would like your information in GenomeConnect shared with the researchers at Coriell, you can let us know by completing the “Optional NIGMS Human Genetic Cell Repository at Coriell” survey in your online profile.



## How have we Spread the Word about GenomeConnect in 2016?

In 2016, members of the GenomeConnect team were able to spread the word about GenomeConnect with clinicians, patients, and researchers at several conferences including the Curating the Clinical Genome Conference in Hinxton, England, Stanford Medicine X in Stanford, California, the American Society of Human Genetics annual conference in Vancouver, Canada, and the National Society of Genetic Counselors annual education conference in Seattle, Washington. At each conference, we hope to share the importance of data sharing and how valuable patients are in advancing genetics!



## Coming Up in 2017!

In early 2017, we will be sending out an invitation for a survey to help us collect information about how social media might help you learn more about your or your family member's genetic diagnosis or genetic testing. Your anonymous responses will be used to help GenomeConnect and other patient groups better understand how individuals and families are using social media. Be on the lookout for this survey coming soon!

Happy New Year,

The GenomeConnect Team



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