



Winter Newsletter

Dear GenomeConnect,

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! We now have more than 850 participants from 22 countries and 48 US states. Thank you for being a part of our registry.



In this Newsletter:

**Connect with Others: GenomeConnect
Participant Matching Feature**

Additional Research and Resources

NIGMS Human Genetic Cell Repository at Coriell

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

Coming up in 2017!

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.

Additional Resources and Research

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 you, we would like to hear from you about what educational resources you would find most helpful. Please email us at info@genomeconnect.org and let us know!

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.



CORIELL INSTITUTE
FOR MEDICAL RESEARCH

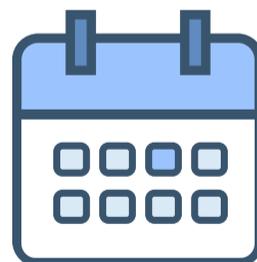
Spreading the Word about GenomeConnect in 2016



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!



Connect with us via social media, phone, and email!

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