Dear GenomeConnect,

Thank you for your participation in our patient registry!

Since our last newsletter, GenomeConnect has continued to grow because of all our wonderful participants (like you!) who want to share their data, connect with others, and help promote genomic discovery! We now have more than 1000 participants from 28 countries. Thank you for being a part of our registry.

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Update Your Account Preferences

GenomeConnect allows you to control your participation in some parts of the registry. Be sure to update your preferences!

You can decide:

If you would like to connect with other participants based on characteristics such as diagnosis, gene, or US state by joining the participant matching system.

If you would like to hear about potential updates to your genetic testing results from the GenomeConnect team.

Learn more about these features and update your preferences by logging into your GenomeConnect account and clicking "Update" under "Account Information." Then scroll down to "Contact and Sharing Preferences" to set your preferences.
The GenomeConnect team is currently recruiting for the GenomeConnect Participant Advisory Committee. This committee of individuals, parents, and patient advocates will collaborate with the GenomeConnect team to inform future GenomeConnect policies.

The goals of the committee include:

- To provide participant perspectives to ensure that the needs, interests, and priorities of participants are considered in GenomeConnect decisions.
- To promote collaboration and partnerships between participants and study staff.
- To encourage opportunities for participants to give feedback and suggestions to the GenomeConnect study staff.
- To provide participant perspectives on other ClinGen research policies as needed.

Anyone who is enrolled or has a child enrolled in GenomeConnect, has a diagnosis of or a child with a genetic condition, has had or is a parent of a child who has had genetic testing, or someone who has patient advocacy experience is eligible to apply.

How do I apply?
You can apply online
Or you can email us to request a paper application.
To Enable Genomic Discovery

Sharing a copy of your genetic testing report can help our team collect information about any genetic changes that may have been found. Sharing your genetic and health information can help doctors, genetic counselors, researchers, and genetic testing labs better understand the impact of genetics on health and disease.

To Connect With Other Participants and Researchers

GenomeConnect allows you to connect with other participants based on a number of characteristics, including gene. If you don't upload a copy of your report, others will not be able to match with you based on gene.

Also, if any researchers are interested in your particular gene or genetic variant, we will not be able to let you know about their research opportunities if you don't upload a copy of your report.

Login to your account and upload a copy of your genetic testing report under "Test Results." If you no longer have a copy of your report, email us and the GenomeConnect staff may be able to help you get one.

Be sure to upload all of the pages and all four corners of each page.

Additional Research Opportunity

IMAGINE ID

IMAGINE ID is a novel research study aiming to increase understanding of children and young people with intellectual disability.

The IMAGINE ID team is interested in learning more about the link between behavior and rare genetic conditions. The study, led by University of Cambridge, University College London and Cardiff University, has over 1,250 families already and hopes to collect information from over 5,000 families by 2019.

To participate, children should be aged 4 and over with intellectual disability, learning difficulty or developmental delay that has a genetic cause. Learn more on the IMAGINE ID website: http://imagine-id.org/

Taking part harnesses parent’s expertise and involves families completing secure online questionnaires about their children’s development and behavior from the comfort of their own home. If families do not have internet access, the research team can help. After completing this, families receive a personalized summary report based on the answers they have given which may be useful for children when undergoing assessments for services, school or specialist treatments.

If you would like more information, please contact the IMAGINE ID team at imagineid@cimr.cam.ac.uk or visit their website http://imagine-id.org/

Facebook: https://www.facebook.com/imagineid.study/ Twitter: @imaginemednews

IMAGINE ID is not directly affiliated with GenomeConnect, but is another research opportunity that may interest you.

Registry Platform

Invitae Genome Network

As you may know, GenomeConnect uses a vendor platform, PatientCrossroads/AltaVoice, to support our registry. Recently, this vendor became a part of Invitae Corporation and is now known as the Invitae Genome Network.

It is important for you to know that your participation in GenomeConnect will not change as a result of this merger. GenomeConnect will continue to use the registry platform as it is currently designed. You still control your data sharing and contact preferences.