



GenomeConnect Summer Newsletter July 2016

IN THIS ISSUE

Dear GenomeConnect Participant,

Thank you for your continued participation in [GenomeConnect](http://GenomeConnect.org). We are glad to have you as a member of the registry and thank you for helping contribute to genomic discovery!

The GenomeConnect team wants to keep you updated about the registry and any other opportunities. To help keep you up to date, we are now sending regular newsletters!

This newsletter will tell you about our new **Participant Matching** feature, will give you **some updates and reminders** about participation in GenomeConnect, and will let you know how the GenomeConnect team celebrated **Rare Disease Day**!

Check out the New Participant Matching Feature



We are excited to announce that you can now connect with other participants via our **“Participant Matching”** feature on www.genomeconnect.org! Through this feature, you can sort by gene, *interested in connecting with others*. As of May 2016, 5% of GenomeConnect participants have the potential to match on gene, 26% could match on a specific diagnosis, and 86% could match on US State.

To search, you will first need to agree to participate in this feature. You can do that by signing in to your GenomeConnect account. On your profile page, click “Account Information” and, if you wish to participate in the matching system, select **“Yes”** to the question **“Would you like to join the GenomeConnect participant matching system, which will allow you to search for and contact other GenomeConnect members, and will allow other GenomeConnect members to contact you?”** If you do not wish to participate in this feature, just select “No.”

If you agree to participate in the feature, you can then search for participants based on diagnosis, gene, or US state. For each participant listed in the search results, you will see the participant’s age, gender, and location. To send a message - *just click “Contact.”* **The first message is sent through the online system but once both participants agree to connect, you can exchange personal contact information.** To check out this feature, go to your GenomeConnect Profile and click on “Member Matching.”

To make sure your matches can find you based on diagnosis and gene, update your “Health Reason for Registration” under your Account Information and be sure to upload a copy of your genetic testing report to your profile under “Attachments.”

Please contact the study coordinators at info@genomeconnect.org if you have any questions or need any assistance!

Check out the New Participant Matching Feature

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

GenomeConnect- 600 Participants!

GenomeConnect is growing!
Page 2

Have you completed the GenomeConnect Survey and Uploaded Genetic Testing Results?

Don’t forget to complete these important steps!

Page 2-3

Did You Celebrate Rare Disease Day?

Read about how GenomeConnect participated in Rare Disease Day 2016.

Page 3

A Message for Professionals Working with Children Who Have Undiagnosed Genetic Conditions

Read about how GenomeConnect participated in Rare Disease Day 2016.

Page 3

Don’t Forget to Follow GenomeConnect on Social Media!

Page 4

GenomeConnect- 600 Participants!

The GenomeConnect team is pleased to announce that we now have more than 600 participants from 20 countries! We continue to grow each day! Thank you for being a valuable member of our growing community!



Have you completed the GenomeConnect Survey and Uploaded Genetic Testing Results?



GenomeConnect Survey – If you haven't already done so, please complete the GenomeConnect Survey. This survey will ask about the type(s) of genetic testing you/your child may have had and questions about your/your child's health and development. We also ask that you update this survey once a year or if you/your child have any health changes.

To go to the survey, please login to www.genomeconnect.org. You will be directed to the Profile page. Click the link for the "GenomeConnect Survey" to complete survey.



Genetic Test Results – If you haven't already done so, please upload a copy of your/your child's genetic testing results. If you have a copy of your/your child's genetic testing, please be sure to upload it in the "Testing Results" section of your "Profile." Be sure to include all of the pages of the report and all four corners of each page so that we can be sure to collect all of the information needed. If you do not have a scanner, smart phones take great pictures of reports. You also can check out your local library to see if they may have a scanner for public use. If you do not have a copy of your/your child's genetic testing reports, the GenomeConnect team may be able to help you get one. Contact us at info@genomeconnect.org.

Did You Celebrate Rare Disease Day?

Every year at the end of February, families, researchers, and supporters spend a day raising awareness of rare diseases. This year, GenomeConnect coordinator, Jules Koenig, spread the word about GenomeConnect at the National Institutes of Health (NIH) in Bethesda, MD. Nearly 50 organizations presented original research posters or shared information about support resources for people with rare diseases. Several hundred people were in attendance, with parents, support groups, advocates, researchers, and clinicians all participating in the day's events.

Presenters included well known speakers, like Francis Collins- Director of the NIH, Senator Amy Klobuchar from Minnesota, and Mike Porath - Founder and CEO of "The Mighty") (<http://themighty.com/>). Many patient advocates came to tell the stories of their diagnosis and journey.

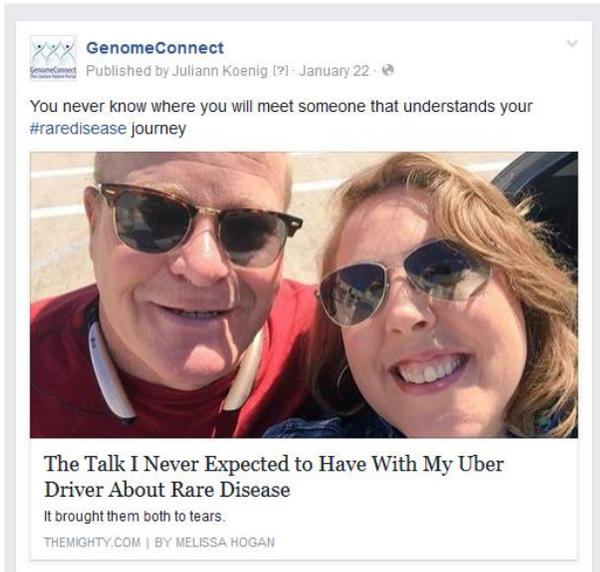
GenomeConnect is proud take part in events like this and we aim to help empower those who have had genetic testing to register and share their data to enable genomic discovery.

A Very Important Message for Professionals Working With Children Who Have Undiagnosed Genetic Conditions

Some individuals are thought to have a genetic disease so rare that doctors cannot diagnose them. This can cause frustration, fear, and a spectrum of other emotions. If your child is undiagnosed, here are some tips from SWAN UK and families just like yours to pass along to your medical professionals to help them understand how to best care for you and/or your child. <https://www.youtube.com/watch?v=9qan2bwb2Rk>

Don't Forget to Follow GenomeConnect on Twitter and Like our Facebook Page!

If you want to stay up to date with GenomeConnect in between newsletters, be sure to like us on [Facebook](#) and follow us on [Twitter](#)! Check out a few of our posts below:



GenomeConnect
Published by Juliann Koenig [?] · January 22 · 🌐

You never know where you will meet someone that understands your #raredisease journey



The Talk I Never Expected to Have With My Uber Driver About Rare Disease
It brought them both to tears.

THEMIGHTY.COM | BY MELISSA HOGAN



GenomeConnect @GenomeConnect · Apr 6

Researching #RareDisease can help provide insight to other diseases- both #rare and common



The Impact Of Rare Disease Research On The Development Of Ne...
Discovery of possible cures, treatments, or preventative tools are generally thought to be the only benefits of rare disease research. However, as his...
clinicalleader.com



info@genomeconnect.org



[570-214-1721](tel:570-214-1721)



[To Register](#)
[To Learn More](#)



[@GenomeConnect](#)



[GenomeConnect on Facebook](#)