

Welcome to our group! Our families are from across the globe and our children vary in age and abilities. We are a family network that continuously learns from each other. We are happy to connect with you! We hope you find this group as helpful for you as it was for each of our families.

ABOUT THIS GROUP

This group consists of families with loved ones diagnosed with PPP2R5D, PPP2R1A or PPP2R5C. We provide emotional and information support as appropriate.

See the many faces of our group: <https://vimeo.com/393562467>

Learn more about our group: <https://www.youtube.com/watch?v=tNUhvSLTK3M&app=desktop>

WHAT IS JORDAN'S GUARDIAN ANGELS?

Jordan's Guardian Angels is a nonprofit leading a large-scale research project to learn all of the impacts of PPP2R5D, PPP2R5C and PPP2R1A. The foundation was founded by Joseph and Cynthia Lang and named after their daughter, Jordan. Jordan was diagnosed with having the PPP2R5D mutation in 2015. You can learn more about the foundation at www.jordansguardianangels.org.

WHAT RESEARCH IS BEING CONDUCTED?

The research is seeking treatment to reduce the impacts of the mutation or even reverse it. A team of the best and the brightest has been assembled from 10 institutions to help solve the mystery of the syndrome through cutting edge technology methods.

Read more about the research: <http://jordansguardianangels.org/research-details-impacts/>

Meet the Research Team: <https://jordansguardianangels.org/our-research-team/>

HOW DO YOU JOIN THE RESEARCH?

You can join this research by joining [Simons Search Light](https://simonssearchlight.org). The complete process is outlined below:

1. Create an account on simonssearchlight.org
2. Create profiles for your child with the gene change and any other siblings under 18 that you wish to participate.
3. Complete the Simons Search Light Connect Questionnaire
4. Complete consent for yourself and all children participating
5. Send Simons Search Light your child's genetic testing results

Once steps 1-4 are completed, the family is then connected with Ashley for the medical history phone call and assigned baseline surveys. The genetic testing results do not hold up this process but are required before a family is considered enrolled.

Enrollment = Consent for parent and child with the genetic change, completed Simons VIP Connect Questionnaire and confirmed genetic lab results.

HOW DO YOU JOIN THE FAMILIES' DATABASE?

In order to organize the information within the families, we maintain an online database. You can join our database by filling the form: <https://forms.gle/z5AmCC54ZCoEkXvG7>

You can connect with the families by joining the private Facebook group at "PPP Families (PPP2R5D, PPP2R1A, PPP2R5C)".

WHAT RESOURCES ARE AVAILABLE?

You can access the password protected family resources page at: <https://jordansguardianangels.org/family-resources/>.

Please email info@jordansguardianangels.org or contact our Facebook admins to obtain the password.

KNOW THAT YOU ARE NOT ALONE!

This has been a journey of hope for our families; a lot of excitement is underway. If interested, we can match you with another family based on location, language, age, and/or variation. For any questions or comments, please contact us at info@jordansguardianangels.org or by phone/whatsapp at 1-720-725-1727.