SIMONS VIP CONNECT
VARIATION IN INDIVIDUALS PROJECT

Announcing an online community resource for individuals with genetic changes related to features of autism and developmental delay

Who are we? The Simons Variation in Individuals Project (Simons VIP), funded by the Simons Foundation, has been a family support resource since 2010. Initially focusing on deletions and duplications of 16p11.2 and 1q21.1, the community has now expanded to include over 40 genes that have been associated with features of autism and developmental delay.

Our Goal: The **Simons VIP Study** aims to describe the traits or characteristics associated with certain genetic changes that have been found in children with autism spectrum disorder or developmental delay. Because of advances in genetic technology, we are able to identify these genetic changes, but we don't have a good understanding of how they affect different people.

The Project: To learn more about how these genetic changes affect health and development, we are collecting information from families who have a qualifying genetics lab report. Information about learning, behavior, and development is collected through online research surveys. Participants also complete a phone interview to collect detailed medical and family history information. De-identified data can be requested by qualified scientists who want to study these genetic changes further. Data collection for 16p11.2 and 1q21.1 families has led to a better understanding of the features associated with these genetic changes.

Does your child have a change in one of the genes listed below? If so, join us to learn more!

ACT6LB	*ARID1B*	*CTNNB1*	*FOXP1*	*KMT2C*	*POGZ*	*SETD5*
ADNP	*BAF190*	*CUL3*	*GRIN2B*	*KMT2E*	*PTCHD1*	*SMARCC1*
ANK2	*BCL11A*	*DSCAM*	*KATNAL2*	*MBD5*	*PTEN*	*SMARCC2*
ANKRD11	*CHD2*	*DST*	*KDM6B*	*MED13L*	*REST*	*SUV420H1*
ASH1L	*CHD8*	*DYRK1A*	*DM5B*	*PBRM1*	*SCN2A*	*SYNGAP1*
						TBR1

Simons VIP Connect encourages registered families to:

- Connect with other families who have the same genomic variants from across the world.
- Take advantage of the "members-only" features, such as the quarterly newsletters, discussion forums, and the ability to connect with other families and send questions to our team of experts.
- Consider participating in research to expand our understanding of these genetic changes. **Remember, participating in the research study is voluntary; families are welcome to join the online community without participating in research.**
- Follow us on social media to hear the newest information about Simons VIP and the genes we study. www.facebook.com/SimonsVIPConnect | www.twitter.com/SVIPnews

We invite you to check out our website and encourage you to register to begin connecting with other families today! Please contact us at 855-329-5638 or coordinator@simonsvipconnect.org for more information.

www.simonsVIPconnect.org

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