# REGISTRIES TO JOIN



# GRIN2B Foundation Contact Registry:

grin2b.com/register

#### What is it?

GRIN2B Foundation's internal contact registry for families. This database gives us a better understanding of how many families we represent and where they're located.

# How does this help my family now?

You'll receive our mailings, newsletters, event and research announcements and you'll gain access to our Closed Facebook Parent Support Group.

**Questions?** Contact brittaney.crider@grin2b.com

If you access this registry using Google Chrome, you can use Google Translate.

# Date registration completed:

### UNIVERSITY OF COLORADO and UNIVERSITY OF LEIPZIG

#### **GRIN Variant Registry:**

grin-portal.broadinstitute.org

#### What is it?

This is the primary patient registry to support a comprehensive understanding of all different GRIN variants. The data from the registry is needed in order to inform the broader community, especially industry and the FDA, in order to design and implement successful clinical trials in the years to come.

# How does this help my family now?

Once enrolled, your child's variant will be added to the queue to have functional analysis performed. The results of this analysis help researchers understand how your child's variant functions and will inform what types of medications and clinical trials may best help your child.

#### **Questions?**

If you are from North or South America or Australia, contact GRINResearch@cvanschutz.edu

If you are from Europe, Asia, Africa or other, contact: GRIN@medizin.uni-leipzig.de

# Date registration completed:

#### SIMONS SEARCHL&GHT

# Simons Searchlight GRIN2B Registry:

www.simonssearchlight.org

#### What is it?

Simons Searchlight is an international research program with the goal of accelerating science and improving lives for people with rare genetic neurodevelopmental disorders, including GRIN2B.

They collect different information than the GRIN Variant Registry so it is important to enroll in both.

### How does this help my family now?

You'll receive quarterly reports with registry data and Amazon gift cards for each survey completed.

**Questions?** Contact coordinator@simonssearchlight.org

Registry available in English, Spanish, Dutch and French

### Password & user information:

# Date registration completed: