



Simons VIP Connect & SETBP1

Partnering families and researchers to learn about SETBP1



Our goal is to collect natural history information for individuals identified with SETBP1 variants. Participating in a registry is an important method for increasing what we know about rare genetic conditions, and advocating for future treatments and therapies. Data shared through Simons VIP is made available to researchers across the world.

What is Simons VIP?



Simons VIP (Variation in Individuals Project) is a study, funded by the Simons Foundation, that aims to collect natural history information for families with specific genetic changes that have a known association to neurodevelopmental disorders, like seizures, developmental delay, and/or features of autism.

By collecting long term data about natural history, we can improve our understanding of genetic conditions, and ultimately contribute to future research. It's important to share your child's history so we can begin to understand the spectrum of features associated with different genetic diagnoses.



We provide support by hosting a secure place to share your genetic, developmental, and medical information. Much of the data collected through Simons VIP is available to families through our website. Curated data sets are made available to interested researchers.



Genetic (and other!) experts are available to answer your questions through the "Ask an Expert" tool.



The first step is to indicate your interest in joining the research project and registry. Visit our website and click "Register." Consent is completed online. Questions? Call 855-329-5638 for help.

Register to participate at www.simonsvipconnect.org

Getting Started

Simons VIP participants complete all research activities from home. Families from all over the world are welcome to join. As long as you are able to speak, read, and write English, have access to the internet, and have telephone access, you may register.

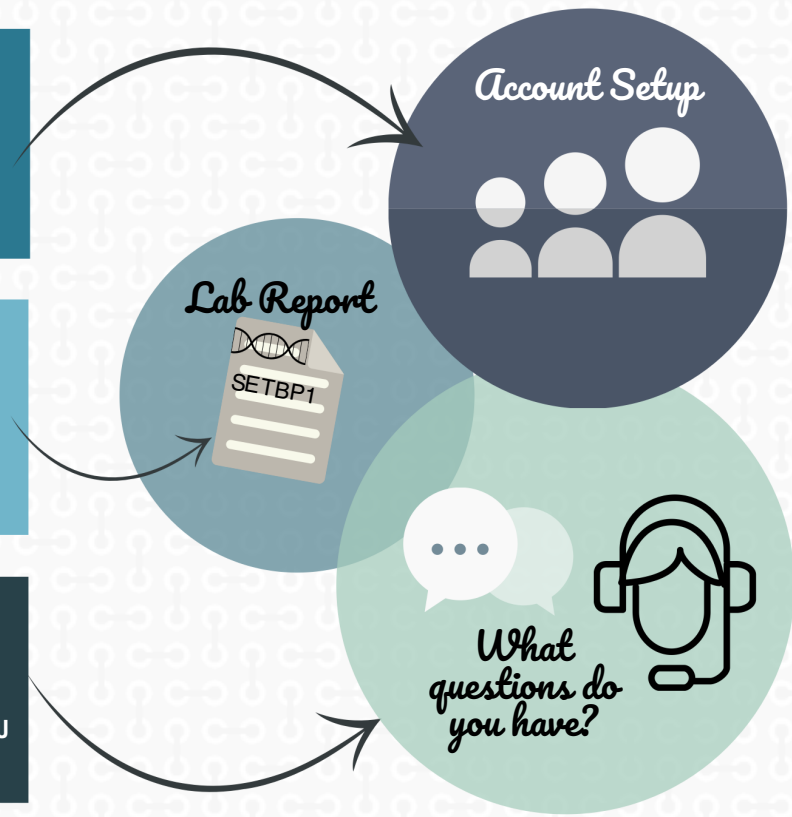
STEP 1: Register Online.

Complete an online consent form and include your immediate family members (your child with SETBP1 and his/her siblings) on your account.

STEP 2: Share your Genetic Test Report. Email your child's genetic test report to coordinator@simonsvipconnect.org or fax to 570-214-7327. Let us know if you need help requesting a copy!

STEP 3: Talk with us.

Before we begin your participation, one of our study coordinators will talk with you by phone or email to answer any questions you might have and to learn about your family.



Participation

The majority of your participation takes place online. After consent is complete, the research surveys will be assigned to your profile, beginning with the Medical History Review. Research activities usually take a couple of hours per family member.

STEP 4:

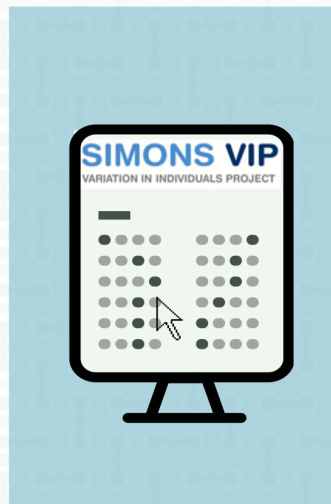
Complete Medical History Review Survey



- Registry -

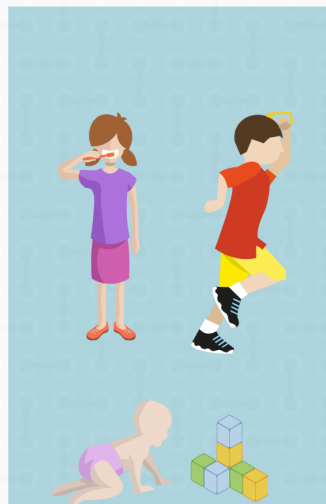
STEP 5:

Complete Additional Surveys Online



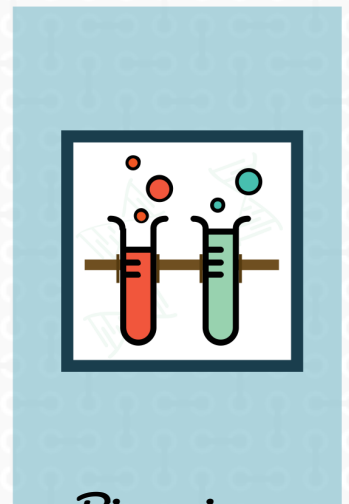
STEP 6:

Share developmental history over the phone



STEP 7:

Contribute samples for future research.



- Biospecimen -

Common Questions

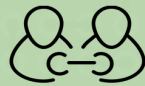
How to Add Family Members and Set up your Account

When you first register, you will consent for yourself. You can then add your child with the SETBP1 gene change and any biological siblings to the account. You will see that consent forms are automatically assigned to each family member's name. Children over 10 will also be assigned an assent form.

Your spouse/partner will then consent for him/herself by completing a separate registration. (Do not add him/her to your profile.) Your spouse/partner will not add children to his/her account, since they've already been consented through yours.

How do I connect with others?

You can identify other families with SETBP1 variants through Simons VIP Connect. Under the "Members" tab, click "Connect with Other VIP Families." If anyone has agreed to be contacted by others, contact information will appear on this list.



When do I earn gift cards?

Gift cards earned through study participation are awarded by email.

Surveys completed during the month are awarded early the next month. For example, surveys completed during the month of May are awarded in early June.

If you think you should have earned a gift card, but did not receive it, first check your spam folder. This happens more than you'd think!

If you don't find anything in your spam folder, contact the study team.



How much time does it take to participate in Simons VIP?

Each research survey varies in length, with most taking less than 30 minutes to complete. Online surveys can be completed at your convenience, but we estimate that participation for each person with the genetic change will take about 2-3 hours per year. Participation for family members usually takes less than 1 hour per year.

Are there benefits to taking part in the study?

While there may not be a direct benefit to you, by sharing your information, you are helping to improve our understanding of these rare genetic changes. This data may help researchers in the future develop management guidelines, treatments, and therapies.

Some families enjoy participating in research because they know they're helping others. It can be rewarding to know you're making a difference.

