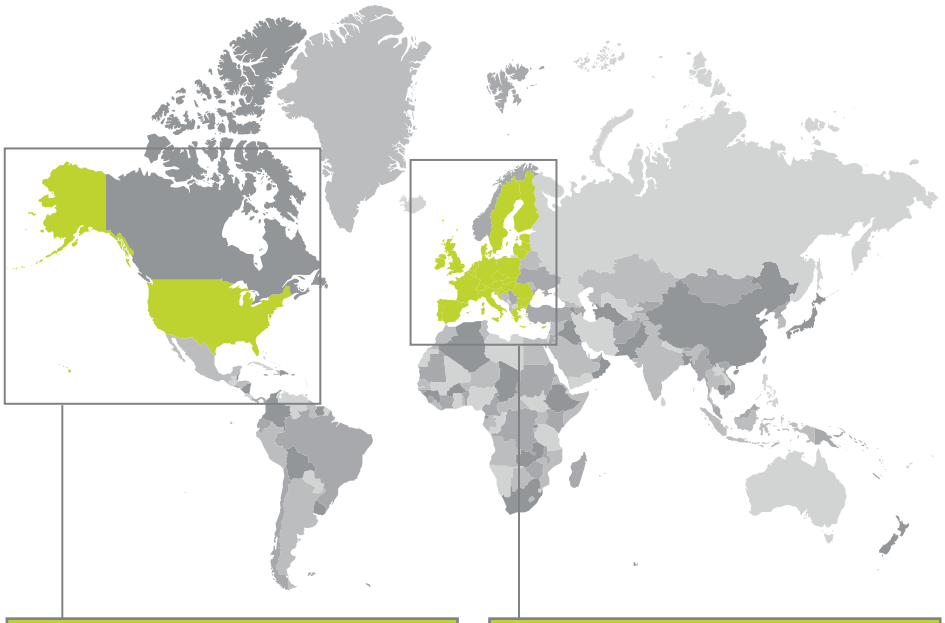
Helping today could lead to scientific advances for rare diseases tomorrow.

Why enroll in a rare disease registry?

Enrolling in a rare disease registry makes rare disease research possible. The goal of this research is to advance our understanding of rare conditions and to identify safe and effective treatments for those suffering from rare diseases.

Why is rare disease research important?

We need to fully understand rare conditions in order to develop treatments and recommendations for clinical care. Without rare disease registries, we would not understand the natural history of these rare conditions. If you have a rare disease or know someone with a rare disease, you can directly help advance scientific knowledge by joining a rare disease registry. Please help today!



10% of the US population has a rare disease. That's 25-30 million Americans.[1]

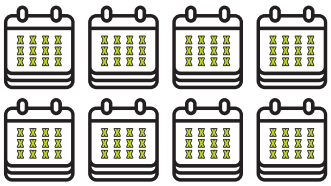
An estimated **30 million** people in the European Union have been diagnosed with a rare disease.[2]

350 million people suffer from a rare disease globally (greater than the population of the United States).[3]

8 in 10 rare diseases are due to genetic causes.[3]

8 years

The average time it takes for patients with a rare disease to receive an accurate diagnosis. Within that time period, they have seen over 10 specialists and been misdiagnosed 3 times.[3]



There are **7,000+** types of rare diseases.

95% of rare diseases **DO NOT** have a single FDA approved drug.[3]

1. *"Home | Rare Diseases Clinical Research Network." Home | Rare Diseases Clinical Research Network,* www.rarediseasesnetwork.org/.
2. *"Rare Disease Day 2020 - 29 Feb - Article." Rare Disease Day - 29 Feb 2020,* www.rarediseaseday.org/article/what-is-a-rare-disease.
3. *"RARE Facts." Global Genes,* globalgenes.org/rare-facts/.

Join the SATB2-associated syndrome registry today!

We need YOU parents and caregivers to help move research FORWARD! Here is how you can help!
Join Dr. Zarate's *SATB2*-associated syndrome (SAS aka Glass Syndrome) registry. Here's what you need to know!

1

Who?

Any parent or knowledgeable caregiver of someone diagnosed with SAS can help!

2

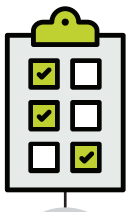
What do I need?

A computer or smart device with internet connection, an email, and a phone number.

3

How do I start?

Just say YES! Email Dr. Zarate, the lead geneticist studying SAS (see website below), and say you'd like to learn more about the study. He will arrange a phone call with you which lasts about 30-60 minutes.



4

What information is collected?

Information about medical issues and developmental milestones, as well as pregnancy and delivery information will be collected. The online survey takes about 15-60 minutes to complete. You are provided login information,so you can complete the survey at your convenience.

5

What do I have to turn in?

Diagnosis paperwork and consent form, as well as the results from any other lab tests or evaluations.

6

What about privacy?

Only approved researchers can see the registry data. You CANNOT be looked up by others in the registry. NO ONE ELSE can see that you have taken part in the registry.

7

Why should I do this?

We need to fully understand *SATB2*-associated syndrome in order to develop treatments and recommendations for clinical care. Without rare disease registries, like the one for *SATB2*-associated syndrome, we would not understand the natural history of these rare conditions. If you are the parent or caregiver of someone with SAS, you can directly help advance scientific knowledge by joining Dr. Zarate's *SATB2*-associated syndrome registry.

sat b2 gene foundation

Arkansas Children's
HOSPITALS · RESEARCH · FOUNDATION

THE UNIVERSITY OF RHODE ISLAND
COLLEGE OF PHARMACY

For additional medical and scientific information, as well as registry information, please visit **www.satb2gene.com.**

For more information about the SATB2 Gene Foundation, please visit **www.satb2gene.org.**