What is *SATB2*-associated Syndrome (SAS)?

SAS is a genetic condition that is caused by alterations of the *SATB2* gene. Individuals with SAS typically have delayed developmental milestones with very limited speech. Other commonly reported problems include behavioral issues, low muscle tone, feeding difficulties, cleft palate, abnormal dentition, bone abnormalities, and seizures.

What is the SAS Clinical Registry?

The SAS registry is a centralized database that compiles the clinical and developmental histories of people with SAS. It's a way to learn how SAS affects people which, in turn, helps determine what types of treatments and management will benefit individuals with SAS. The goal is for this knowledge to improve patient care. Joining the registry also ensures that you will be made aware of future research opportunities for individuals with SAS.

How can I join the SAS registry?

There are several steps for parents and/or guardians to take to join the registry:

1. Contact Katie Bosanko (kbbosanko@uams.edu) or Dr. Yuri Zarate (yazarate@uams.edu) to let them know that you're interested in enrolling your child in the registry.
2. Consent paperwork will be sent to you to review. The consent form gives detailed information about the study and all procedures involved.
3. We will set up a phone call to review these documents and walk through where to sign. Then, you will send us the completed consent paperwork.
4. Once we receive the signed consent forms, we will send you a hyperlink that will take you to the online database where you enter information about your child's medical and developmental histories.
5. We will work to obtain your child's medical records, and we will use those to complete the questionnaire. That's it!

Why is it important to join the SAS Registry?

We are not able to learn more about SAS without getting as much information from as many people with the condition as possible. The registry is a centralized way to do this. It helps us make steps forward in knowing how to care for individuals with SAS.

To learn more, please visit www.satb2gene.com.