



AUTISM GENETIC RESOURCE EXCHANGE FREQUENTLY ASKED QUESTIONS

WHAT IS AGRE?

The Autism Genetic Resource Exchange (AGRE) is a program that collects genetic, clinical and medical information from people with autism and their family members. Scientists from around the world who are studying autism can access this information from AGRE, which helps them find the causes of autism faster.

AGRE is a science program of Autism Speaks. Autism Speaks is a non-profit organization dedicated to raising public awareness and funding global biomedical research for autism.

WHAT WILL I HAVE TO DO IF I CHOOSE TO PARTICIPATE IN THIS RESEARCH?

Different people on the research team will come to your home about 3-4 times for the following:

- Each of your children with autism will be tested by trained professionals. This will take about 4 hours with each child that can be done over a couple of days. The people who do the testing know how to work with children with autism.
- Parents (one or both of them) will be interviewed and asked to complete questionnaires about their child's growth, behavior and development. This will take about 4 hours that can be done over a couple of days. Some questionnaires can be on your own time and mailed back to the AGRE office.



- All family members give blood (3 small test tubes = 3-5 tablespoons). A trained laboratory technician will draw blood from everyone in your family. The lab technician knows how to work with children with autism. This may take 1-2 hours to finish.
- A medical doctor will call you on the phone and ask you questions about your child's medical history and important medical history of all family members. This may take about 1-2 hours to finish.

WHERE DO I HAVE TO GO FOR THE TESTING AND LAB WORK?

AGRE will travel anywhere in the United States and will come directly to your home for the visits. We will work with you to schedule these visits at a good time for you and your family. Because there are several steps to the study and we schedule each step on a different day, families may wait up to a year or more to finish everything.



WHAT INFORMATION WILL YOU SHARE WITH ME?

AGRE will give you a letter that has the results of the diagnostic tests we did with your children with autism. This letter may be useful to your child's school, pediatrician or anyone else involved in his/her life.

AGRE will also give your doctor of choice information if we find anything abnormal with your child's blood. Your doctor will notify your family and explain what it is.

WHO IS PAYING FOR THIS?

AGRE receives federal funding from the government (National Institute for Mental Health (NIMH)) and additional funding from Autism Speaks. It will not cost you anything to participate – just some of your time.



SHOULD I GET A BABY SITTER WHEN AGRE IS VISITING MY HOME FOR THE DIAGNOSTIC TESTING?

Some of the testing can take a long time and it is important that you and your children with autism are able to concentrate. If you can find someone (a babysitter or a family member) to take care of your other children while AGRE is visiting your home, AGRE will gladly reimburse you for your expenses up to \$75.00 (per family).

WHAT WILL BE SHARED WITH SCIENTISTS?

All your family's information will be kept anonymous to scientists. The scientists will never know your names and will never contact you, unless you want them to. No one will know your family has participated with AGRE unless you tell them.

