The New Jersey Language and Autism Genetics Study
FACT SHEET

What is the study about?
NJLAGS is the continuation of a nine-year study focused on understanding how genes influence the development of autism. Using a combination of comprehensive behavioral testing, detailed family history information, and DNA, the study aims to better understand the genetic underpinnings of autism and related disorders.

Our study staff of geneticists, developmental pediatricians, psychologists, and speech language pathologists have many years of experience working with all ages and all types of developmental disabilities and welcome your questions and comments when they visit your home.

Who can participate?
To participate in the study, your family must:

✓ Speak English
✓ Have one member with ASD and language impairment
✓ Have at least one other member with language impairment
✓ Have at least 5 members willing to participate
✓ Agree to provide a blood sample

What do participants do?
All testing can be done in a single day or spread over several days in the comfort of your home and is based entirely on your own family’s schedule. We are available on weekends and evenings if that is your preference. Overall, testing should take 3-5 hours per family member.

<table>
<thead>
<tr>
<th>Who?</th>
<th>What?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family members with ASD</td>
<td>• ASD diagnostic testing</td>
</tr>
<tr>
<td></td>
<td>• Physical exam</td>
</tr>
<tr>
<td>Family members with language impairment</td>
<td>• Language impairment diagnostic testing</td>
</tr>
<tr>
<td>All family members</td>
<td>• Receive age-appropriate assessments</td>
</tr>
<tr>
<td></td>
<td>• Provide blood sample</td>
</tr>
<tr>
<td>Parents</td>
<td>• Fill out family history questionnaires</td>
</tr>
</tbody>
</table>

Once all family members have completed testing, each family member will receive a $25.00 gift card in appreciation for their participation.

For more information:
http://njlags.dls.rutgers.edu
autism@dls.rutgers.edu
Are there any risks or benefits to a family's participation?

Risks

- **Blood Draw**: Sometimes there might be slight pain or bruising from the blood draw.
- **Tests and Assessments**: There is a possibility that taking the tests or assessments may cause mild stress. These tests are similar to some standardized tests taken in school but sometimes adults feel a bit uncomfortable since they haven’t performed any of these tasks in many years.

Benefits:

- Parents will receive a letter for each child describing the standardized assessments they received. It is not a clinical assessment but describes each measure, your child’s score, and where the score falls in relation to scores of children of the same age. We also can offer recommendations if you require a referral for further testing.

*The most important benefit of your participation is in knowing that you and your family have made a significant contribution to the genetic study of autism that will impact future generations in so many important ways!*

Why is family participation important?

While a majority of cases of Autism Spectrum Disorders occur for the first time in a family, NJLags and other family-based studies provide crucial information about very specific genetic aspects of ASD. They allow scientists to look for detailed patterns of behavior within and over families as well as explore links in family histories that can then be combined with very valuable DNA data.

Participating families will help researchers identify gene variants and specific genes associated with autism and related disorders and aid investigators in learning how they influence the development of ASDs. This information could provide scientists, healthcare providers and agencies with needed information for educational programs, early detection, effective treatment, and support to families impacted by ASDs.

Funding

The NJLags study is made possible through the generous support of the New Jersey Governor’s Council for Medical Research and Treatment of Autism and the New Jersey Department of Health. With this funding, Dr. Linda Brzustowicz of the Human Genetics Institute of Rutgers University and her research team continue to explore the genetic components of autism with a special interest in language.

For more information:  
http://njlags.dls.rutgers.edu  
autism@dls.rutgers.edu