

The Genetics of Autism Studies



3 Studies Investigating the Role of Genetics in Autism and Autism Spectrum Disorders:

- **A Molecular Genetic Study of Autism and Related Phenotypes in Extended Pedigrees**
- **The Genetic Epidemiology of Autism: Family and Molecular Studies**
- **The Autism Genome Project**

What are these studies about?

These three studies are designed to search for the genes that make a person susceptible to Autism and Autism Spectrum Disorders (ASD). We know that genetics play a role, however, the cause of Autism remains a medical mystery. We believe that the susceptibility genes for Autism have been difficult to identify because the genetic basis for autism is very complex. For this reason, it is essential to collect as much genetic information as possible. The success of this research comes from parents, such as yourselves, who cope each day with the effects of ASD in their families.

The information from these studies will provide new insights into the genetic basis of Autism and ASD and offer new understanding into their biological mechanisms. Such understanding will lead to improved diagnosis and more effective treatments.

We are fortunate to be collaborating with the Hospital for Sick Children, in Toronto, Memorial University Health Sciences Centre, in Newfoundland, The University of Alberta, in Edmonton, and the University of North Carolina. Our information will be combined with data from these other centres to create a larger data set that will allow us to more rapidly identify the Autism susceptibility genes. These studies are funded by the Canadian Institutes of Health Research and Genome Canada.



Who Can Participate?

We are looking for:

- Children who have a diagnosis of ASD. This includes children diagnosed with Autism, Asperger Syndrome, or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS).

OR

- Families with two or more individuals affected with ASD – these may be siblings, cousins or any other extended relatives.

What kind of assessments will be conducted?

The child with ASD will take part in language, cognitive and behavioural assessment tasks. Parents will be asked to complete questionnaires and interviews. Depending on the study, parents and the unaffected sibling may be asked to complete a language measure. We will take a blood or saliva sample from all children, their parents, and their grandparents (if possible) for chromosomal and genetic analysis.

How long will the assessment take?

The assessment times will vary. For an individual with ASD, the total assessment time will range from 2 to 5 hours. The assessment can be divided into more than one session, if needed, and we can take breaks during sessions.

Parent interviews and language measures may take 3 to 5 hours to complete. Interviews can be done in person, or over the phone.

We will make every effort to schedule the assessment and interviews to best suit your schedule.

Where will the testing take place?

The testing and interviews can be completed at the Chedoke site of McMaster Children's Hospital in Hamilton, in your home, or at your child's school.

Will I receive a copy of my child's assessment results?

You will receive a research report summarizing the results of the assessments. This will provide information on your child's current level of functioning in cognitive, language, and adaptive skills.

What if a participant wants to stop before his/her part in the study is complete?

Participation in this study is voluntary. Participants can withdraw from the study at any time.

Is there any cost to individuals to participate in this study?

No. Families will be reimbursed for parking, travel, and other incidental expenses.

How will my family benefit from participating in this study?

You will receive...

- a **research report** summarizing the assessment results
- **newsletters** to keep you informed of the study's progress and the progress of other Autism research projects at the Offord Centre for Child Studies
- an **invitation** to our Annual Autism Research Conference for Parents
- and you will be offered a **consultation** about your child

Will My Privacy be Protected?

Yes! All information will be strictly protected and your family will not be identified in any way.

If you wish to participate, or if you know anyone who may be interested in participating in these studies please contact us at:

**905-521-2100 ext. 77372 or
toll free at 1-888-3AUTISM or
werners@mcmaster.ca**

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**This research is not possible without your generous participation.
We thank you for your interest in these studies!**