



High Risk Baby Sibling Autism Research Project

WHO:

The *High Risk Baby Sibling Autism Research Project* is a partnership between NAAR and the National Institutes of Health (NIH), led by the National Institute of Child Health & Human Development (NICHD). NAAR, which began funding baby sibling research in 1997, has committed \$700,000 to the collaboration. Part of this commitment includes a \$100,000 gift to NAAR from the Dan Marino Foundation.

WHAT:

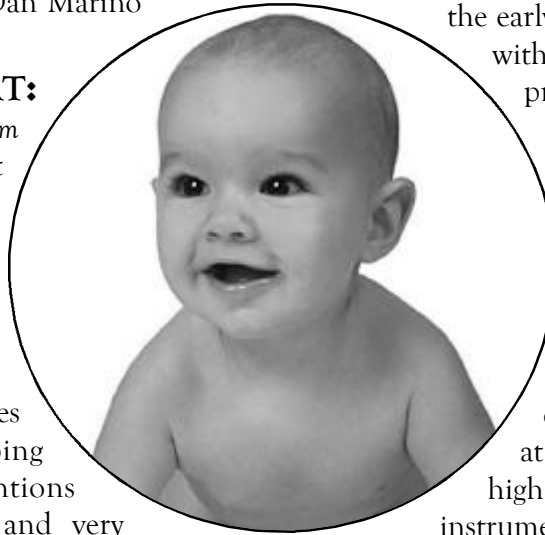
The *High Risk Baby Siblings Autism Research Project* is a multi-site project designed to identify behavioral and biological markers for autism and eventually enable clinicians to make a more definitive diagnosis earlier than ever before.

In addition, the project also focuses on determining and developing specialized behavioral interventions specifically designed for infants and very young children.

The genesis of this partnership originated with pilot studies funded by NAAR over the past several years that focus on a population at high-risk for developing autism: the infant siblings of children with autism. This research is commonly known as "Baby Sibs" studies.

In an effort to enhance this research, NAAR approached the NIH in 2003 to discuss the possibility of transforming the initiative into a large, collaborative effort with an expanded size and scope. The NIH recognized and welcomed the opportunity to partner with a national, parent-led research advocacy group on a topic that is a high priority at the Institute: early diagnosis of autism spectrum disorders.

It is a collaboration that the NIH plans to integrate with two ongoing NIH-funded autism research networks: the Collaborative Programs of Excellence in Autism (CPEA) and Studies to Advance Autism Research and Treatment (STAART) program.



The NIH, NAAR and the investigators taking part in this partnership are working to develop new collaborative projects that leverage the collective expertise and data set of the research consortium.

WHY:

Autism has a recurrence rate of between 5 - 10% in families with one autistic child - a rate about 50 times higher than the general population. By tracking the early development of siblings of children with autism, it is hoped that clinically predictive behavioral and biological markers can be identified and correlated with the potential onset of autism.

Before the first infant siblings studies were conducted, there was little or no information about children with autism prior to their diagnosis, which typically was made at two or three years of age. Since then, high risk baby sibling research has been instrumental in enabling clinicians to diagnose the disorder much earlier - at 14 months in some cases.

The *High Risk Baby Siblings Autism Research Project* has the potential to enable clinicians to diagnose autism even earlier, which will further improve the prognosis for children and their families affected by autism. Providing a definitive, biological diagnosis will also make it easier for more parents to seek early intervention and may also provide important clues to autism's etiology.



RESEARCH. HOPE. COMMITMENT.

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