FAQ

Who is eligible to participate?
The research registry is open to children and adults of all ages from Rhode Island and neighboring communities who have received a diagnosis of an autism spectrum disorder. ASDs include autism, Asperger’s disorder and pervasive developmental disorder.

I’m not sure if my or my child’s condition is on the autism spectrum. What do I do?
If you’re unclear about an individual’s diagnosis, you and your child may still enroll in the RI-CART registry. The registry assessment does not replace a careful clinical evaluation. Our resource specialist can provide you with information on local clinics that will help clarify the diagnosis.

My child gets anxious about new situations and places. What should we expect?
When a family expresses interest in joining the RI-CART registry, a staff member will communicate with them by phone or email to explain the project and answer any questions. RI-CART staff then sends the family a welcome packet, which includes research consent for them to review, with some basic forms to complete. When the family arrives for the appointment, a trained research team member will greet them and take them to the evaluation, which typically includes the ADOS, a brief interview and, if needed, help filling out forms. Research assistants are trained to work with children and adults who have ASD and pace the assessment to the needs of the participant. If the family wants to stop an interview and complete it at a later date, that’s fine.

My child is afraid of needles, can we still participate?
Absolutely. RI-CART staff has years of experience and will do their best to make sure your child is comfortable. However, you may choose to decline to participate in specific parts of the research.

Is there paperwork? Will someone be available to help me fill out the forms?
Before your appointment, paperwork will be sent to your home or email address, based on your preference. If you have difficulty completing the paperwork, RI-CART team members are available.

Who will see the assessment and testing results?
Your family’s information will be kept confidential; it will never be released to anyone without your consent.

Can my physician or other professionals receive a report of RI-CART’s assessment?
You may request a written summary of the RI-CART assessment that you can share with your doctor or service provider.

RI-CART is psychologists and parents, nurses and teachers, speech pathologists and psychiatrists, pediatricians, neurologists, scientists and researchers working tirelessly to help people with ASDs. Based at Bradley Hospital, we are members of Rhode Island’s leading hospitals, universities, government, community programs and parent groups.

For a full list of our partners, please see our website at AutismRI.org

www.autismRI.org

RI-CART
Bradley Hospital
1011 Veterans Memorial Parkway
East Providence, RI 02915
401-432-1200 • RCART@Lifespan.org
Your participation can change lives.
Let’s exchange information to further the understanding and treatment of autism in Rhode Island.

WHAT WE DO
We conduct research to better understand the causes, treatments, and supports for people with ASDs and their families. We connect parents, educators, researchers and other clinicians for the common purpose of improving the lives of people with ASDs. We support individuals with ASDs by facilitating their connection to community services and by working to improve opportunities for them.

WHAT IS THE RI-CART REGISTRY?
RI-CART’s registry will collect information volunteered by people with ASDs, from family demographics to clinical assessments. The information, which is kept in a secure database, will be analyzed to improve understanding of, and develop new treatments for, autism and related disorders.

WHY WE NEED YOUR HELP
Some 10,000 Rhode Islanders – enough to fill the Pawsox’s McCoy Stadium – are living with ASDs. Because individuals with ASDs are all different, your family’s participation in RI-CART will make a unique contribution to research and to all people living with autism. Your participation in the registry will help Rhode Island’s researchers, health workers, educators and parents better understand the needs of families like yours.

WHY WE ASK OF YOU
You may choose the level of participation in RI-CART that your family is comfortable with, from sharing basic information about family characteristics, to participating in clinical assessments and sharing genetic information with a quick blood draw. Participants are encouraged to have the Autism Diagnostic Observation Schedule (ADOS), the “gold standard” autism assessment, administered by RI-CART’s certified professionals. The ADOS is offered at no cost to all participating individuals and families.

WHAT’S IN IT FOR YOUR FAMILY?
When you join the RI-CART registry, you connect with a community of Rhode Island families living with ASDs. In addition to receiving the ADOS, families will be connected with a resource specialist whose job is to help them navigate all potentially useful information on ASD. RI-CART will also keep you posted on opportunities to participate in ongoing and upcoming research studies, and will report to families on the latest findings on new treatments and interventions.

PARTICIPATE AT YOUR CONVENIENCE
RI-CART strives to make participation in the registry convenient for all Rhode Islanders. Your connection to RI-CART will take just one appointment that will last a few hours. Appointment times are flexible and are offered at multiple Rhode Island locations. Transportation is available upon request.

HOW TO JOIN
To enroll in the registry or to learn more...
EMAIL: RICART@Lifespan.org
VISIT: www.AutismRI.org
OR CALL OUR RESEARCH ASSISTANT AT: 401-432-1200

www.autismRI.org