NEW PHASE FOR RI-CART
Thanks for you help over all these years

DEAR RI-CART PARTICIPANTS AND FAMILIES
We are writing to share some important updates with you on the RI-CART study:
We have now reached our goal of enrolling over 1,800 individuals and their family members into the RI-CART network! This is a tremendous accomplishment and we want to thank you for your participation and support to make this possible.

Now that we have achieved our enrollment goal, we will be putting enrollment of new participants on hold for the time being. The next phase of the project will focus on compiling and analyzing our data, expanding the use of the RI-CART database by top autism researchers, and identifying gaps in our knowledge to inform future research questions.

We will keep families informed as RI-CART continues to develop and grow. In addition, our website will continue to be a place to find links to resources and information about RI-CART initiatives and opportunities for involvement (www.AutismRI.org). Our partners at The Autism Project (www.theautismproject.org) are always available to you for support, education and resources as well.

Thank you again for helping us to build the RI-CART community! Your participation has and will continue to help us make advancements across the clinical and research fields in autism and related conditions. In fact, your participation is essential to advancing knowledge, and we are grateful for the continued opportunity to partner with the community on this important initiative. Please feel free to contact us with any questions at (401) 432-1200 or RICART@Lifespan.org.

Sincerely, on behalf of the RI-CART team,

Stephen Sheinkopf, PhD
RI-CART Director and Principal Investigator
Associate Professor of Psychiatry and Human Behavior
Brown University

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LET NEW ADVENTURES BEGIN!

KAYLA PERKINS
SENIOR CLINICAL RESEARCH ASSISTANT

This fall, I will be returning to my home state of Connecticut to pursue my Masters of Social Work at the University of Connecticut. I look forward to using my degree to help empower families of children with special needs. I will miss the amazing Rhode Island beaches and all the great food in Providence, but am glad to be close enough to visit!

"My time at RI-CART was greatly shaped by our community events and friends at The Autism Project. These interactions with the community demonstrated the strength and resilience of the autism community in Rhode Island"

-Kayla Perkins

MONICA TREVIÑO
CLINICAL RESEARCH ASSISTANT

I will be heading to the University of Missouri – St. Louis to pursue a PhD in Clinical Psychology. After almost 6 years of living in Rhode Island, I will especially miss the beautiful beaches, the delicious food and coffee, and all the friends I've made during my time here.

"I will cherish all the memories I've made at RI-CART and I am so grateful to have been able to be a part of this incredible community that taught me so much about patience, hard work, and kindness."

-Monica Treviño
I am so excited to be starting my PhD in Human Development and Psychology at UCLA this Fall, but I’ll really miss Rhode Island’s delicious doughnuts! More seriously, the wonderful friends I’ve made here and Providence’s uniquely creative atmosphere will make it hard to move away. In spite of the cross-country move, I hope I’ll be able to visit Little Rhody again soon!

"I have really enjoyed my two years with RI-CART. In particular, it’s been powerful to see how much both families and researchers benefit from lasting community partnerships"

- Elaine B. Clarke

As the new phase of RI-CART begins, I will be continuing my career in the field of marketing as freelance, and I hope to continue helping the Hispanic community in RI through many initiatives, specifically focusing on research projects aimed to enhance clinical care for people with autism. I love Rhode Island and look forward to continuing enjoying this vibrant, unique and fun place.

"My experience with RI-CART for the past 1.5 years has enriched my professional and personal life. I’ll always be thankful for the opportunity to connect with the ASD community in RI and especially with the Hispanic population. Muchas gracias"

- Silvana Guerrero
RI-CART has evolved into a unique, public-private partnership, bringing together the state’s leading experts on autism research, education, health, and advocacy. It’s one of the first efforts of its kind in the nation.

**About Our Research Network**

Small group of interested parties began to meet at Bradley Hospital to discuss autism research and treatment in Rhode Island.

Thanks for your participation, our database has a good age range of participants, from 2 to 68 years old.

**Race & Ethnicity**

- Hispanic or Latino: 14.6%
- White (Not Hispanic or Latino): 70.4%
- Asian, American Indian, Alaskan Native, Native Hawaiian, Mixed Race, Other: 6.9%
- Black (Not Hispanic or Latino): 6.1%

**Demographics**

- 24% Women
- 76% Men
- 68% Children
- 21% Adolescents
- 11% Adults
The Transition in ASD: Planning for adult life

BY: GINA M. MARINI, MA, LCSW

FOR YOUTH WITH DEVELOPMENTAL DISABILITIES, TRANSITION IS THE PROCESS OF PREPARING FOR LIFE AFTER HIGH SCHOOL.

- In the educational setting, transition begins at age 14 and includes assessments that inform post-secondary goals centered on training/education, employment, and living skills. These goals guide the planning process, and determine which services are needed and appropriate. By law, a statement of transition services must be included in a youth’s Individualized Education Program (IEP).
- Starting at age 16, youth with developmental disabilities have the right to file an application for long-term adult disability services through BHDDH (Rhode Island’s Department of Behavioral Healthcare, Developmental Disabilities & Hospitals). Parents and/or guardians must adopt an active role in applying for said services.
- Two years prior to graduation, youth with developmental disabilities also have the right to apply for short-term employment services through ORS (Rhode Island’s Office of Rehabilitation Services). Parents and/or guardians are advised to contact ORS directly to schedule a meeting with a Vocational Rehabilitation Counselor (ORS counselors are assigned to each regional school district.).
- Parents and/or guardians are further encouraged to outreach the Rhode Island Parent Information Network (RIPIN), an agency dedicated to providing support to families advocating for special education services, healthcare, and more.

The Organization for Autism Research developed the Life Journey Through Autism series, where they provide information about autism and the transition to adulthood. To get a copy visit: researchautism.org/resources/a-guide-for-transition-to-adulthood/

FOR MORE INFORMATION REGARDING TRANSITION PLANNING, CONTACT GINA M. MARINI, MA, LCSW:
Clinical Social Worker within Bradley Hospital’s Verrecchia Clinic for Children with Autism and Developmental Disabilities (401.432.1119).

Representatives from all three organizations (BHDDH, ORS, and RIPIN) are invited to participate in IEP meetings to promote collaboration, and to ensure a seamless transition for all youth with developmental disabilities. As part of the transition process, parents and/or guardians should also explore guardianship, or alternatives to guardianship; healthcare, and social security benefits.

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What happens with my participation now that RI-CART is pausing enrollment for new participants?
While we’re pausing enrollment for new participants, our research assistants will be working to organize and optimize our data base so that researchers may find information for their studies. RI-CART researchers are continuing to analyze the data and information that has been collected and are preparing manuscripts for scientific journals. These tasks are part of our continued effort to work together, advancing our knowledge of ASD.

When I participated in RI-CART I gave biosamples. What happened with this samples? Are we receiving any results?
RI-CART participants have generously shared biological samples (blood samples or saliva) as part of enrollment in the consortium. We now have thousands of samples, including both participants with ASD and their family members. We are actively working with our primary funder to process and analyze these samples. The main purpose of these types of tests is understanding more about the genetics of ASD and developmental disabilities. We will let participants know as a group when the genetic analyses of the RI-CART samples are completed. This is a complex process and we are working with our funder to define a timeline. Because this testing will be done by a research laboratory, these research analyses cannot serve as a clinical test, so individual participants will not receive specific results directly from us. This is because the analyses are not performed by a clinical laboratory with certified procedures for reporting results to patients.

I have some documents pending to send. Should I still send them?
YES! Please send any documents that you are completing. We really appreciate the time that you took to participate in our research study and fill out the surveys and questionnaires. As we transition to this new phase, it is very important for us to have your complete and updated information, which will allow us to advance in the process or learning more ASD in Rhode Island. We encourage you to finish the documents and send them to us as soon as possible. If you have questions, please contact us and one of our research assistants can help you (our phone number is 401-432-1200).

While new enrollment is on hold, will my information be available for other studies? Should I expect to receive additional calls to offer enrollment in future research as you mentioned initially?
New enrollment is paused, but RI-CART is still in operation, and that includes helping connect participants to research studies. This “matchmaking” role is an important part of our partnership with the community. If you agreed to be recontacted for other research, as a RI-CART member, you can continue participating in future research studies. Different studies have different criteria, and if your profile matches and you agreed to participate in additional research, a member of our team may call you and let you know. Of course, you can choose whether or not you want participate.

If I move or I change some of my information, what should I do?
We want to keep in touch and to be able to share important information with you in the future. You can contact us by phone 401-432-1200 or by email at RICART@LIFESPAN.ORG. It’s important for us to have your updated information as we periodically send communications about events around RI, talks, and new services and or other information that could be relevant for you and your family.

I have friends, family, or patients who would be interested in participating Can they still get in contact with RI-CART?
The RI-CART website remains active and is a great place for information about the project and about community resources. Families can visit the website to learn about the project and to find out when enrollment opens up again. Visit www.autismRI.org to learn more!
SENSORY FRIENDLY STORYTIME AT THE RI LIBRARIES

JESSE SMITH MEMORIAL LIBRARY
EXETER PUBLIC LIBRARY
BARRINGTON PUBLIC LIBRARY
WEST WARWICK PUBLIC LIBRARY

WOONSOCKET HARRIS LIBRARY
MT PLEASANT PUBLIC LIBRARY
HOPE LIBRARY
GREENVILLE PUBLIC LIBRARY
PAWTUCKET PUBLIC LIBRARY

For dates and more information visit the events page for the libraries
SUMMER CAMPS
FOR KIDS WITH AUTISM OR DEVELOPMENTAL DISABILITIES

ZOOCAMP AT ROGER WILLIAMS PARK ZOO
SAIL TO PREVAIL'S ADAPTIVE SAILING
SURFER HEALING CAMP
CAMP WANNAGOAGAIN

The Autism Project
SENSORY SENSITIVE MOVIES SCHEDULE

June 1: ALADDIN
July 6: TOY STORY 4
August 3: LION KING
September 7: ARTEMIS FOWL

The first Saturday of each month at 10 a.m. at showcase cinema (Warwick - Quaker Lane and Blackstone Valley).
EVERY MONTH

SENSORY SENSITIVE EVENTS

Low Light  Low Sound  Fewer Crowds

THE MUSEUM OF WORK & CULTURE
PRESERVATION FOUNDATION

- THE MUSEUM OF WORK & CULTURE
  FIRST SATURDAY EVERY MONTH AT 9-10 AM

- CHUCK E. CHEESE’S
  FIRST SUNDAY EVERY MONTH AT 9-11 AM

- CINEMAWORLD LINCOLN
  FIRST SATURDAY EVERY MONTH AT 10 AM

- LAUNCH WARWICK
  FIRST TUESDAY EVERY MONTH AT 6-8PM

- SHOWCASE CINEMAS
  FIRST SATURDAY EVERY MONTH AT 10 AM

- SKYZONE PROVIDENCE
  SECOND SUNDAY EVERY MONTH AT 8-10 AM

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The Resource Guide exists to help you navigate medical, educational and other resources that are available to you and your family.

Click here to get a printable copy of the Guide.

Access the Resource Guide online by opening the camera on your phone, and scanning this QR code or online at www.AutismRI.org/resources.

If you would like a printed copy, please let a research assistant know during your visit or call us at 401-432-1200, and we'll get one to you!