ART EXHIBIT
The artists each have a unique view of the world, and the collection as a whole allows visitors to catch a glimpse of life as seen by people on the spectrum.

RI-CART SPOTLIGHT
Meet our Genetics Counselor Molly Goldman.

FEATURED STUDY
New RI-CART Survey about perceptions about genetic testing. Watch your email for a personal invitation.

UPCOMING EVENTS
Take a look at the events that we have been a part of in these last months.
After a long winter, we are pleased to see that Spring has finally arrived! With trees blossoming everywhere, there is no better time to get out there and enjoy our wonderful state, and RI-CART is happy to help you plan your schedule with many fun and interesting things to do.

In our June newsletter, we are highlighting some of the great upcoming events, as well as news from our studies and our community. In our “Ask A Doctor” section, we have the opportunity to learn about genetics in autism and its clinical use, a question shared by many of our members. We have also been hard at work at getting the autism resource guide ready for prime time, and we are pleased to announce that it is out and being used by clinicians around the state. We’re excited to bring this newsletter to you and hope you like reading it as much as we enjoyed working on it for our growing RI-CART family!

If you are not part of RI-CART, and are interested in learning more, please call us at 401-432-1200 or visit our website, www.AutismRI.org.
During April, for Autism Awareness Month, we visited several libraries around RI to spread awareness about autism, share information with families about the importance of participating in research, and work with the community so we can advance our knowledge about autism. We had the opportunity to share great material from the Organization for Autism Research that explains the importance of understanding the signs of autism and inclusion in social and academic activities at school. We also shared the RI-CART Resource Guide we created to help families find information quickly about places that offer services for people with autism and related conditions. Thank you to each library for partnering with us to help families find information about autism and research.

This material was created by Organization for Autism Research. For more information visit www.researchautism.org
WHAT WE’VE BEEN UP TO

Are you planning an event and would you like RI-CART to participate? Please send an email to us at RICART@LIFESPAN.ORG.

Transition Fair at Lincoln Public Schools
Our research assistant Becca enjoying the Transition Fair at Lincoln Public Schools. Thanks to all who stopped by our table!

ART OPENING: THROUGH OUR EYES -SELF-PORTRAIT
During March and April, kids and adults with autism and other disorders let us see their perspective of themselves and their world. We displayed over 45 pieces of unique art at the Museum of Work and Culture. Thanks so much to all artists who participated in our exhibition. If you missed it, visit www.autismri.org/through-our-eyes to see all the pieces.

WORKING TOGETHER TO DEVELOP EFFECTIVE IEPs FOR STUDENTS WITH ASD!
Thanks to all who came out to learn about Working Together to Develop Effective IEPs for Students with ASD! And a huge thank you to our wonderful panelists: Trish Martins, Leslie Brow, Sue Constable, Christine Marinello, Amy Laurent, and Katie Torres and our partner The Paul V. Sherlock Center on Disabilities at Rhode Island College.

BROWN BRAIN FAIR 2018

IMAGINE WALK AND FAMILY FUN DAY

WWW.AUTISMRI.ORG • (401) 432-1200 • @AUTISMRI
Pathfinder

Pathfinder is a fantasy role-playing game. For the first time, RI-CART and The Autism Project organized a time for groups to play. There was a Game Master to guide this fun day. Our Research Assistant Becca played too, and shared her character with us. Check back soon for a summer date!

Annual Community Health Fair & May Breakfast

This year’s theme was Healthy Mind, Healthy Body. We had the opportunity to learn about local resources and hands-on activities. Thank you to Progreso Latino for inviting us and thanks to all who stopped by our table, including the mayor of Central falls, James Diossa.

Different Not Less Autism Training

One day training for Parents/ Caregivers and professionals to learn more about evaluation and appropriate resources for children, youth, and adults with autism or related conditions.
Ms. Goldman is a certified genetic counselor with experience in a variety of genetic counseling environments, including both clinical and research. Prior to joining Bradley Hospital, she worked at Columbia New York Presbyterian Children’s Hospital providing guidance and counseling to individuals and families. She received her master’s degree from Mount Sinai School of Medicine in 2008.

Currently, Molly is working with Dr. Daniel Moreno De Luca and Dr. Eric Morrow and the Hassenfeld Child Health Innovation Institute in an effort to use genomic information in the diagnosis and clinical care of children with Autism Spectrum Disorders (ASDs) and related neurodevelopmental disorders. An initiative underway is a survey of members of RI-CART to better understand the barriers, challenges, and opportunities of clinical genetic testing for ASD. Molly is working with Dr. Moreno de Luca to establish a Neurogenetic Psychiatry Consultation Service of the Bradley Hospital Center for Autism and Developmental Disabilities (CADD). Patients with ASD and other related neurodevelopmental disorders are offered genetic counseling and followed to identify and carry out specific clinical recommendations involving their psychiatric and medical treatment based on their genetic results.

NEW RI-CART GENETICS SURVEY
Share your unique voice.
We invite you, as members of the RI-CART community, to complete a short survey that will help us understand the barriers, challenges, and opportunities of clinical genetic testing for ASD. We would like to get the widest perspective possible and would appreciate knowing from people who are in favor or against genetic testing for ASD, from people who have been tested and those who haven’t, and from people familiar with genetics concepts and those for whom all of this is new information. In appreciation of your prompt participation in this survey we will provide you with a $20 or $10 gift card.
Thank you for your partnership in helping the ASD community! If you have any questions about our study or want to learn more about any of the areas included here, please don’t hesitate to contact Dr. Daniel Moreno De Luca at (401) 432-1200 or ricartlifespan.org.

ATTITUDES, PERSPECTIVES, AND RESULTS OF GENETIC TESTING IN AUTISM SPECTRUM DISORDERS
I JUST FILLED OUT THE SURVEY... HOW ABOUT YOU?
We are very appreciative of your effort filling out this survey, as it will allow us to continue working together as a team of researchers and families.
I have heard about genetic testing for autism, but it seems unclear what the benefits are. How would that information be useful for my child and the doctors? Is this a different way to diagnose autism?

A genetic cause for autism can be detected in up to 30% of people; that percentage can be even higher if there are other accompanying diagnoses such as intellectual disability or seizures. But before we discuss the benefits, we should make important points:

- Autism is a clinical diagnosis, meaning that it is given based on the observations by the doctors during an office visit, or with additional psychological testing, such as the Autism Diagnostic Observation Scale (ADOS). That means that genetic testing is not used to diagnose autism; it is recommended after the diagnosis of autism has already been made to uncover potential causes.
- The decision about carrying out genetic testing should be a joint process with your medical team, and the decision to proceed is entirely in the hands of each family.

For autism, the recommended genetic tests are:

- **Chromosomal microarray testing.** This test looks for missing or extra pieces of genetic material across the genome, called deletions and duplications, or also known collectively as copy number variants (CNVs)
- **Fragile X testing.** This test looks for changes in a gene called FMRP. These changes involve extra or repeated sections of this part of a person’s DNA (technically, these changes are called trinucleotide repeat expansions).

With that information in mind, here are a few examples of the potential benefits that genetic testing may bring:

- Finding an explanation and underlying cause for the autism in a given family and putting an end to the diagnostic odyssey.
- Identifying risk for other behavioral and medical conditions associated with a given genetic change, such as cardiac or renal abnormalities, which may in turn impact clinical management, including additional workup and medication choice.
- Obtaining genetic counseling and risk assessment for family planning for parents and siblings of someone with autism who might want to have children of their own one day.
- Having a clearer picture of areas of strengths and vulnerabilities based on information from other families with the same genetic abnormality and accessing specific medical resources.
- Connecting with support groups of other families with the same genetic abnormality.
- Being eligible for clinical trials targeting a specific genetic abnormality.

All the examples above encompass what we now call precision medicine – the ability to use precise individualized information for tailored clinical management. Remember, the decision of getting genetic testing is entirely up to you and your family and should be a joint process with your doctor. Hopefully, the information above can help you and your family decide on what is right for you!
Upcoming Events

**SENSORY STORY TIME CLASS AT THE PAWTUCKET PUBLIC LIBRARY**

This is a monthly program (June 23rd, July 21st, August 4th) for children who are on the Autistic Spectrum Disorder or other developmental disabilities. Program will include: picture schedule, songs/rhymes, movement, fun stories sensory activities! Great for families looking for a small group. Best for ages 3-8 year olds, but any child is welcome. Registration Required. Call at 401-725-3714 x209 or Email: mcttoepawtucketlibrary.org.

**SENSORY FRIENDLY DAYS AT CAROUSEL VILLAGE AT ROGER WILLIAMS PARK ZOO**

We invite those with Autism Spectrum Disorders (ASD) and sensory processing differences to explore and enjoy Carousel Village. The Carousel, bounce house and playground will be open to the public, as well as train and pony rides (weather permitting). Standard activity pricing applies. For more information click here.

**SENSORY FRIENDLY DAYS AT ROGER WILLIAMS PARK ZOO**

Join us for an hour of nature play before the zoo opens: designed for families who have a child with sensory sensitivities, come and play in Hasbro’s Our Big Backyard from 9 to 10 a.m. Build mud pies, watch boats float downstream and climb high in a treehouse. Try something new: Imagination playground, a large-scale building toy, will be available for guests to use during this time. The activity room will be available with books and carpet squares for families who need a quiet space during the event. For more information click here.

Are you planning an event or you know an event that other families can enjoy? Send us a email and we'll put it in our events update!
BOSTON CHILDREN’S MUSEUM
MORNINGSTAR ACCESS PROGRAM

Offers children with special needs or medical needs the opportunity to enjoy the Museum in an uncrowded environment with few other visitors. Experience The Power of Play! Admission for non-members is $8 (half off the regular price!) and is free for members. Please visit www.BostonChildrensMuseum.org/Morningstar to register. Registration is required.

LOCATION: 308 Congress Street, Boston, MA.
DATE: Sunday, June 24th Time: 4:00–6:00pm

PATHWAYS PIONEERS
SUMMER PROGRAM

This program serves as a extension to the public school calendar with students age 3-21 from a variety of districts who are either traditional candidates for ESY service or who are looking for a different an exciting opportunity this summer. For more information—Mackenzie Milner at 401-615-2775 ext 415, mmilner@trudeaucenter.org.

CAMP WANNAGOAGAIN!
THE AUTISM PROJECT SUMMER CAMP

Designed to provide a chance for real life experiences and learning new leisure skills while meeting new friends, our camp program offers a safe and fun environment that includes traditional camp activities like swimming, arts and crafts, and nature walks with trained, highly skilled staff. For more information, click here or call 401-785-2666.

WEDNESDAY, JUNE 27TH - RI-CART SPEAKER SERIES:
ISSUES AFFECTING ADULTS WITH AUTISM SPECTRUM DISORDER

Save the date! Dr. Laura Lewis’s primary research focus is on Autism Spectrum Disorder in adulthood. She is particularly interested in symptom variance among underrepresented populations of individuals with ASD including adults and females, improving diagnostic instruments for these populations, promoting self-advocacy among adults with ASD, and improving quality of life for couples affected by ASD.

LOCATION: Bradley Hospital, East Providence
TIME: 3:30pm–5:00pm

WWW.AUTISMRI.ORG • (401) 432-1200 • @AUTISMRI
Resource Guide

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

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!