RI-CART
RHODE ISLAND CONSORTIUM FOR AUTISM RESEARCH AND TREATMENT

ASK A DOCTOR
SLEEP PROBLEMS IN CHILDREN WITH AUTISM

RI-CART SPOTLIGHT
MUSEUM WORK & CULTURE
WOONSOCKET, RHODE ISLAND

RI-CART ART EXHIBIT
THROUGH OUR EYES
MARCH 16 THROUGH APRIL 28

"MY BROTHER MY LION" BY ANDREW DISTEFANO
In this new edition of our first newsletter for this year we want to recognize all the fabulous artists in our community who are part of our art show, now in its third year. For us, it's a pleasure to exhibit these wonderful pieces from amateur and professional artists alike as a way to learn a little more about their thoughts and points of view. Thanks again for participating and helping us have an amazing exhibit throughout the years.
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

SENSORY FRIENDLY MOVIE AT CINEMAWORLD LINCOLN
On the first Saturday of every month, CinemaWorld Lincoln welcomes all families to enjoy a sensory-friendly film. In January, the sensory-friendly movie was Spider-Man: Into the Spider-Verse. Follow our Facebook page or our Instagram account to stay up-to-date about these movies. In April, the movie will be Dumbo, an American fantasy adventure film directed by Tim Burton.

CREATE AND CONNECT AT THE AUTISM PROJECT
In February, The Autism Project and RI-CART hosted Create & Connect, an afternoon out for parents and caregivers of children with special needs. We had an awesome afternoon painting with the parents while our research assistants provided child care for the kids during the activity. For more information about these activities, visit www.theautismproject.com

BOY SCOUT DISABILITIES AWARENESS MERIT BADGE
The Executive Director of the RI Special Olympics, along with representatives from the RI services for the Blind and Visually Impaired, The Autism Project and RI-CART were part of the group that did the training for earning the Disabilities Awareness Merit Badge at the Museum Work & Culture in Woonsocket. It was amazing to see how the kids were engaged in the topic and to hear their very good questions throughout this training.

QUARTERLY RI-CART MEETING
In our first quarterly meeting of the year, we had the opportunity to talk about the different events coming up in our community, such as the “Imagine Walk” organize by The Autism Project on April 28, the workshop about “Sexuality Education in Autism” by The Paul V. Sherlock Center on Disabilities, the September conference organized by Dr. Karen Cammuso focusing on dialectic behavioral therapy approaches for behavior management, and the hosting of the 17q12 International Family Meeting, which will be held in August in RI and where cutting edge research and clinical care talks will take place focusing on people with this rare genetic condition associated with autism and other developmental disorders (for more information visit www.chromo17q12.org).

We also talked about the current studies that are going on right now; we are very happy and grateful for the strong support of the RI-CART community that has been responding to the survey on attitudes and perspectives around genetic testing for autism and let us hear their voice. Thanks again to the community for joining us at the meeting! If you want to participate in the next one, please send an email ricart@lifespan.
THROUGH OUR EYES

This show highlights the creativity and talent of people with autism while having a unique opportunity to see the world through their eyes.

2017

This piece is called "The Fisherman", created by John M Williams for our exhibit.

2018

This piece is called "Split Intentions", created by Kimberly Gerry-Tucker for our exhibit.

2019

This piece is called "Marmalade" created by Anastasia O'Melveny© 2015.
CHARLES GROSMAN

"WALKING OFF THE FIELD OF ACTION WITH THE IMAGE IN HANDS"
In memory of this fantastic artist who participated last year in our art show and shared this last piece for his self portrait.
In essence it is the keen ability for subjects on the spectrum to communicate non-verbally which allows us to form a human-animal bond which I, (amongst others) believe is significantly stronger as compared to bonds made between "neurotypicals" (for lack of a better term) and animals. Perhaps autism is simply a reflection or a reminder of a long lost ability to communicate effectively in a non-verbal fashion. It is those abilities which have been championed by the likes of the authors, Temple Grandin (Animals in Translation), Monty Roberts (The man who listens to horses) and Tom Dorrance (True Unity).

Jarrod is a local artist who has submitted photography and collage pieces to the Through Our Eyes exhibit in previous years and we asked him about his point of view on the theme this year.

"First of all I believe the subject matter "animals" is a topic that hits very close to home to many children and adults on the spectrum. As you may know it is much easier for us to communicate with animals than often times it is to communicate with humans. I suspect the subject of "Animals" will immediately strike a familiar chord with many children and adults on the spectrum and I suspect that proverbial chord, all comes down to our ability for us to communicate (with animals) in a world where communication is improperly defined as the ability to speak using verbal language as opposed to the universal, non-verbal language which once existed between humans and animals."
RI-CART SPOTLIGHT

MUSEUM OF WORK & CULTURE

The Museum of Work & Culture tells the story of the men, women, & children who immigrated to the Blackstone Valley in the late 19th & early 20th century. The museum opened in 1997, and was designed to share the stories of immigration and labor through immersive exhibits. We spoke with Assistant Director Sarah Carr about inclusion and accessibility at the museum.

Why have inclusion and accessibility been priorities for the Museum?
The Museum's initial design was focused on the people of our community—both in terms of sharing their stories and ensuring they felt engaged in our spaces. When we began noting an increase in demand for tours from all ability groups five years ago, we wanted to ensure we were doing everything we could to meet the needs of those visitors. We worked with educators from Meeting Street School to adapt our exhibits, and began work with The Autism Project to provide tools for visitors on the autism spectrum.

What are some of the inclusion and accessibility initiatives the Museum has taken on?
We were so lucky to have incredible partners when we launched our SensAbilities programs. Both RI-CART and the Autism Project allowed us to grow our offerings in ways we would not have been able to on our own. What began as tools like social stories and first/then boards, paired with sensory sensitive hours, Made to Order Monday series of art and music therapy programs, work with RI PBS & Sesame Street Workshop to bring Walkaround Julia to the museum, and, of course, RI-CART's annual Through Our Eyes exhibit. We have also been able to grow our inclusive offerings through partnerships with other organizations as the RI Services for the Blind and Visually Impaired to bring devices to the Museum to improve our accessibility. We're also collaborating with other organizations to create offerings for visitors with memory loss and dementia.

What have you enjoyed most about hosting RI-CART's "Through Our Eyes" art exhibit each year?
Our approach to all of our inclusive programming is "nothing about us, without us" and Through Our Eyes is the best example of that philosophy. Being able to act as a showcase for the vibrant work that these artists create is such a pleasure. And, while those on the spectrum may sometimes struggle with expressing themselves, it is an important reminder of their rich internal worlds and the incredible ways they can share those thoughts and feelings.

What advice would you have for other local organizations that want to create more accessible or sensory friendly programming?
My practical advice would be to reach out to partner organizations, like RI-CART, for guidance. Often I think the stumbling block for organizations is the fear of not knowing where to begin or doing the wrong thing. Having the support of experts in the field removes those barriers and makes the work more effective and more enjoyable. I would also say that they should consider how they are measuring success. Often it is easy to get caught up in numbers, like how many people you have served. But what truly matters is impact. While that can be harder to quantify, it matters so much more. It is a mind shift that will improve all of the work you are doing for the better.

WWW.AUTISMRI.ORG ∙ (401) 432-1200 ∙ AUTISMRI
IT'S TIME TO VISIT
"THROUGH OUR EYES" ART SHOW

You are going to the Museum Work & Culture, in Woonsocket to visit the RI-CART art show.

The exhibit is on the second floor in the Gallery Room.

The theme for the show is “Animals and the Human-Animal Bond”. You can see different kinds of works.

If the room is crowded and you need a break, you can walk through the other exhibits and come back.

If you need fidgets or earphones to continue your visit, the museum has a special bag with these that can help you.

Now it’s time to see and enjoy the amazing art created by kids and adults with autism.

WWW.AUTISMRI.ORG • (401) 432-1200 • @AUTISMRI
**GOOD SLEEP HYGIENE RECOMMENDATIONS FOR**

**SLEEP ENVIRONMENT**
The bedroom should be dark, quiet and cool. As children with ASD might be particularly sensitive to noises and/or have sensory issues, the environment should be adapted to make sure things are as comfortable as possible.

**BEDTIME ROUTINE:**
The routine should be predictable, relatively short (20 – 30 minutes) and include relaxing activities such as reading or listening to quiet music. Avoid the use of electronics close to bedtime such as TV, computer, video games, or other things that can be stimulating making it difficult for your child to fall asleep.

**SLEEP/WAKE SCHEDULE:**
The schedule should be regular with not much of a difference between the weekday and weekend schedule.

**EXERCISE:**
Daytime exercise can make it easier to fall asleep and people who exercise tend to have deeper sleep. Avoid exercise too close to bedtime as it can make falling asleep difficult.

**AVOID CAFFEINE**
It can be alerting, making it difficult to fall asleep, especially if taken close to bedtime. Caffeine is found not only in coffee, but also in tea, chocolate and many sodas.

**NAPS**
Although they may be helpful for pre-school children, they can interfere with sleep for everyone else, especially if taken later in the afternoon.

Researchers with the Autism Speaks ATN have developed and tested autism-specific strategies for improving sleep, like the ones modified and presented here. These can be found in three ATN/AIR-P guidebooks: visit: www.autismspeaks.org/sleep

---

**ASK A DOCTOR**

**WHAT’S GOING ON WITH SLEEP IN ASD?**

Individuals on the autism spectrum often have difficulty falling and staying asleep. Between 44 and 83 percent of children with autism have disordered sleep (e.g., sleep apnea, insomnia; nocturnal awakenings). By comparison, between 10 and 16 percent of children in the general population have difficulty sleeping.1 People with autism tend to have insomnia: It takes them an average of 11 minutes longer than neurotypical people to fall asleep, and many wake up frequently during the night.2 Sleep in people with autism may also be less restorative than it is for people in the general population. They spend about 15 percent of their sleeping time in the rapid eye movement (REM) stage, which is critical for learning and retaining memories. Most neurotypical people, by contrast, spend about 23 percent of their nightly rest in REM.3 There is mounting evidence that too little sleep can exacerbate autism features, such as poor social skills. Children who do not get enough sleep often have more severe repetitive behaviors and a tougher time making friends than other people on the spectrum. Children who do not get enough sleep tend to score lower on tests of intelligence. However, it is unclear whether these problems stem from poor sleep, contribute to it or both.

**MEDICAL WORKUP**
First, clinicians can assess sleep problems by interviewing families and asking them to maintain sleep diaries. They will also consider the person’s height and weight, as people who are overweight are at increased risk to have sleep apnea, an abnormal breathing pattern at night, often associated with snoring, which can interfere with sleep. They can also order some tests, such as iron levels, which can be abnormal in people with other conditions that interfere with sleep, such as restless legs syndrome. In addition, some rare genetic conditions that can be found in people with autism, such as Smith Magenis syndrome, are associated with an abnormal sleep pattern. These can be detected with genetic testing, such as chromosomal microarray testing. Finally, they may order overnight in-lab testing in which a device worn on the wrist records a person’s movements throughout the night (actigraphy).

**TREATMENT**
In some ways, the fix can be straightforward: Establishing a routine, such as an order of activities at bedtime, can often help a person fall asleep; so can changing the temperature or lighting in a bedroom. Sticking with regular bed and wake times can put the brain and body on a schedule that makes sleep more reliable.

In more complex cases, medications and breathing devices can be prescribed by your doctor. Sleep is a crucial part of a healthy life, make sure to talk to your doctor if you have questions or concerns about this! Thanks to Dr. Stephen Sheinkopf, Dr. Todd Levine, Dr. Daniel Moreno De Luca, and Lauren Demoss for their insights on this important topic for the community.
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 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 ricart@lifespan.org.
Help us to understand hearing and language in autism!

Professors Eigsti and Large are studying music abilities and sound processing in kids with autism spectrum disorder (ASD).

- You will be interviewed by an experimenter, and play a computer game.
- You will also get to solve puzzles and play with toys.
- Total time will be approximately one hour.
- You will receive $10 for participating.

If you are interested, please contact us by email at dcnuconn@gmail.com or by phone at 860-486-0195. Please note that information communicated over email is not secure.
UPCOMING EVENTS

Saturday, March 16th until April 29th
Art Opening-Through Our Eyes
This show highlights the creativity and talent of people with autism while having a unique opportunity to see the world through their eyes. This year, we will get to see their unique perspective on the human-animal bond.
TIME: 1:00 p.m- 3:00 p.m
PLACE: Museum Work & Culture, Woonsocket

Coming Soon
Summer Camps around RI
CAMP WANNAGOAGAIN!
Applications Available Soon!
Camp WANNAGOAGAIN! is a two-week summer camp program for children with an autism, Asperger Syndrome or related communication disorder. Designed to provide a chance for real life experiences and learning new leisure skills while meeting new friends. More information visit: www.theautismproject.org.

Coming Soon
Pathfinder Society
PLACE: 1515 Atwood Ave, Johnston, RI 02919
The Autism Project

Sunday, April 28
Imagine Walk 2019 by The Autism Project
Family Fun Day Activities Please join us for a fun-filled family day to raise awareness and funding for Autism Spectrum Disorders. More Info visit www.theautismproject.org/events/imagine-walk
TIME: 9:00 a.m. - 1:00 p.m.
PLACE: Goddard Memorial State Park Warwick

Surfing Healing
REGISTRATION DATE: MAY 11TH-17TH, 2019
Attending these camps positively impacts children with autism; the experience helps instill confidence and calm. Yet over the years, Surfers Healing also has have a profound impact on parents. They are always hearing about what their children cannot do, but at a Surfers Healing camp, it’s all about what they can do. More information visit the website: www.surfershealing.org/
Dumbo Sensory Friendly Movie

CinemaWorld Lincoln Mall

April 06 10:00 AM
ORGANIZED BY PUBLIC LIBRARIES AROUND RI

SENSORY FRIENDLY STORYTIME

MARCH
18
WOONSOCKET HARRIS LIBRARY
TIME: 10:30am to 11:15am

23
MT PLEASANT LIBRARY
TIME: 10:30am to 11:30am

30
PAWTUCKET LIBRARY
TIME: 2:30pm to 3:30pm

APRIL
6
BARRINGTON PUBLIC LIBRARY
TIME: 1:00pm to 2:00pm

13
EXETER PUBLIC LIBRARY
TIME: 1:00pm to 2:00pm

15
WOONSOCKET HARRIS LIBRARY
TIME: 10:30am to 11:15am

20
MT PLEASANT LIBRARY
TIME: 10:30am to 11:30am

20
GREENVILLE PUBLIC LIBRARY
TIME: 1:00pm to 2:00pm

27
PAWTUCKET LIBRARY
TIME: 2:30pm to 3:30pm

SENSORY EXPLORATION FUN

MARCH
18
WOONSOCKET HARRIS LIBRARY
TIME: 4:00pm to 4:45pm

23
WEST WARWICK LIBRARY
TIME: 10:00 am to 10:45 am

APRIL
15
WOONSOCKET HARRIS LIBRARY
TIME: 4:00pm to 4:45pm

17
PAWTUCKET LIBRARY
TIME: 10:30am to 11:00pm

20
WEST WARWICK LIBRARY
TIME: 10:00 am to 10:45 am
SENSORY SENSITIVE EVENTS

EVERY MONTH

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

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