



Director's Update

Dear CARD Families and Friends,

Thank you for all your dedication to FAU CARD. We appreciate your unwavering support and collaboration. It has been a very busy and productive fall. We hope you and your families have a wonderful holiday season! We look forward with anticipation to the New Year and the many exciting, upcoming events.

We are so very appreciative to the families and friends of CARD for all they do to support us! The FAU CARD Homecoming 5K Fundraiser, held on October 21st on the Boca Raton campus, was a fun and exciting event. The weather cooperated this year and provided us an outstanding sunny and cool day! A huge thank you goes to all of you for supporting the event. Additionally, I want to thank Ali Cunningham, Assistant Director, the incredibly organized and hard working 5K Committee, volunteers, and our staff for all they did to make this event a huge success.

Our next fundraiser, the FAU CARD 4th Annual Wings of Hope CARDiGras Cocktail Reception will be held on Thursday, February 28th from 7:30-9:30pm at the Boca Raton Museum. The Boca Museum should prove to be an excellent venue. Last year's event was an incredible success and we anticipate this years event to be an even bigger success. The reception will honor Joe and Fran Eppy for all their dedication and long-standing support to FAU CARD

We have several upcoming training events I am very excited to share with you. January 16th and 17th we will be hosting a training provided by Ann-Marie Orlando from the University of Florida, Gainesville. This training will focus on educational planning across home and school environments for our constituents with Rett Syndrome. January 24th and 25th we will host Dr. Amy Esler from the University of Minnesota Amplatz Children's Hospital in the training of school district and

community professionals in the new ADOS-2 instrument. Saturday, April 20th we our hosting our 7th Annual Family Connections Conference. This event will feature a presentation by Dr. Peter Gerhardt, a national expert on autism, adults and transition. It is our hope that parents will be inspired and take away strategies to increase successful transition from pre-school to elementary school, elementary to middle school, middle to high school and from high school to post secondary options. The conference will host also feature an agency panel as well as sessions providing other practical strategies for parents to enhance their child's success. I hope to see you there!

Finally, FAU CARD is working with the Treasure Coast community and parents to host the 1st Annual FAU CARD Autism Awareness 5K Walk in Sewall's Point on April 27th. We are very excited to rally the community in this region to support this important cause and highlight FAU CARD's commitment to Martin County and the Treasure Coast.

FAU CARD has established a Parent Advisory Committee for the purposes of obtaining feedback from parents in a variety of areas. The Parent Advisory Committee is representative of our catchment area and meets bi-monthly. Please look for the link to our Parent Survey which will be sent to you in order to ensure we are conducting the kinds of activities, trainings and events at the most convenient time for you and your family. Please take a moment to complete the survey; your feedback is important to us!

Thank you again for all you do for FAU CARD! Have a wonderful spring! I hope to see you at some of our events.

Maryellen Quinn-Lunny, Ed.S. Director





CARD-I-GRAS

Honoring Fran & Joe Eppy

Thursday, February 28, 2013 7-9:30 p.m. Boca Raton Museum of Art

Proceeds to benefit





Executive Director's Update

This year marks the 20th anniversary of CARD in Florida. In 1992, it began as a pilot project by a group of parents and Dr. Glen Dunlap, a professor at the University of South Florida. CARD and his since grown to seven centers. FAU CARD, the newest of the centers, began as a satellite of the University of Miami in 2004. Beginning in 1993, CARD has sponsored a statewide autism conference. This year, the CARD Conference will celebrate it's 20th anniversary in St. Pete Beach on January 11-13. A very special roster of speakers will be featured including Glen Dunlap, Nancy Minshew, Lou Brown and Mark Durand, and many others.

I will be presenting at this year's conference on a topic very close to my heart – safety from unintentional injury (many call these accidents) for children and youth with autism. I was stunned several years ago when we had two drowning deaths of young children with ASD. These tragedies jolted me into awareness as to the scope of the problem. Drowning is the number one cause of death of young children up to age four and is likely to be the chief cause of death for children with ASD up to age 16 or 17. Based on a California study, we do know that unintentional injuries are 2.5 to 3 times more likely for children with ASD and some other developmental disabilities.

Parents, I know you face many challenges in raising your children, so please know the following:

- 1. Your child with ASD is at elevated risk for unintentional injury and even death. Maintain the careful supervision and monitoring that you now provide and be prepared to do so for a longer period of time than might otherwise be necessary for a typically developing child.
- 2. Expand your child proofing so as to anticipate safety issues over a longer period of time. Adapt your childproofing to your child's increasing age and physical capability.
- 3. Have working fire alarms in all bedrooms in your house and change the batteries at least once a year, more often if it begins to "chirp."
- 4. Hold practice fire drills in which you teach your child to react to the sound of the alarm by exiting the house and going to a safe place that you designate.
- 5. Be alert to the potential for wandering or elopement where the child leaves a safe area without your knowledge. Consider adding latches or door alarms and teach your child to tell you if they wish to go outside. Many families work with a home security company to install a system that, not only protects from intruders, but also provides immediate notice of unauthorized escape by your child.

- 6. If your child seems prone to elopement, consider obtaining an electronic tracking device. Project Lifesaver of Palm Beach County (www.pbcprojectlifesaver.org), in cooperation with the Palm Beach Sheriff's Office and other law enforcement agencies, now helps support vulnerable children by making these devices more affordable and improving the recovery time for missing children.
- 7. If you have a pool or water features nearby, carefully examine the barriers in place to keep your child safe, such as safety fences. However, no one device or barrier should be seen as the solution. Use multiple levels of protection coupled with careful supervision. Get swimming lessons for your child. The Drowning Prevention Coalition of Palm Beach County (www.pbcgov.com/drowningprevention 561-616-7068) has a free water safety swim program for eligible children. Registration is first come first serve so please take advantage of this wonderful opportunity, which opens on April 1, 2013.
- 8. Parents and other adults who have regular contact with your child should become First Aid certified, know child CPR and how to use an AED (Automated External Defibrillator). The Red Cross and other organizations make it easy to get this training.
- 9. Transport your child safely. Children with ASD often do not appreciate risk and the risks associated with traffic and vehicles can be very dangerous. Use the child safety lock on your vehicle's rear doors. Be sure you have the correct child safety seat and that your child is correctly secured. If your child fusses when it comes time to get buckled up, consult with a professional behavior analyst, occupational therapist, or someone to get this problem solved. If you currently have this problem please speak with your FAU CARD clinical support specialist.
- 10. Check the U.S. Centers for Disease Control and Prevention site for information on a new initiative, Protect the Ones you Love: Child Injuries are Preventable (www.cdc.gov/safechild), which seeks to raise the awareness of all parents to the various risks to injuries and preventive measure to keep their children safe.

As you can see, this topic is personally very important to me so thank you for taking the time to read this. Injury risks are lessened dramatically when parents become aware and take action. If FAU CARD can be of assistance, please contact me at iscott@fau.edu or at 561-251-4104.

Best wishes for a safe and healthy New Year.

Jack Scott, Ph.D. Executive Director



January 11-13, 2013

Don't miss Florida's premier ASD conference for professionals & families. What better place to have it than at the beach!

Join us at the fabulous TradeWinds Island Grand Resort in sunny St. Pete Beach, Florida.

Featured Experts

Glen Dunlap, Nancy Minshew, Lou Brown, Mark Durand, and many more...



Visit our website:

http://card-usf.fmhi.usf.edu/CARD2013/



The 20th Annual Statewide CARD conference is Florida's premier conference on Autism Spectrum Disorder for professionals and families. National experts and regional professionals offer informative and stimulating presentations on a variety of topics on research, innovation, and effective educational programs for people diagnosed with Autism Spectrum Disorder.

For more information about the conference and registration, please visit http://card-usf.fmhi.usf.edu.



MEDICAL UPDATE

Why Does Genetic Research in Autism Matter?

Judith Aronson-Ramos, M.D.

The explosion in genetic research in autism is both exciting and confusing. Even clinicians cannot keep up with the pace and vast body of information comprising genetic research in autism. Here is what we presently know: there are multiple genes involved, sometimes it is the location of the gene that matters, and environment modifies genes.

There are certain forms of autism clearly associated with single gene mutations which includes: Tuberous Sclerosis, Fragile X and Rett Syndrome. While this accounts for a very small percentage of autism cases (less than 5%), children with these genetic disorders are 30 times more likely to have autism in addition to their genetic syndrome. This is relevant to every child on the spectrum as treatments and research on these genetic disorders may lead to treatments that could impact many more children with autism. This is most notably the case with Fragile X where medications are in phase 3 and 4 among clinical trials and may be available in the near future. Some of these medications may be effective at targeting some of the core features of autism in children both with and without Fragile X.

Last month, published genetic research demonstrated that there are de novo (brand new) mutations which are not inherited from either parent which are more often found in children with autism. The vast majority of these de novo mutations code for genes are involved in proteins which play a role in brain signaling. Some of these de novo mutations may be due to interaction of genes with the environment, advanced paternal age (more spontaneous mutations in sperm over time) and genes being turned on by auto-immune mechanisms.

Though we may not be closer to knowing the cause of autism, our knowledge base continues to grow and we now know the following:

- There are many different expressions of autism and likely many different routes to having ASD.
- Genes and environment both impact autism and affect each other.
- What turns genes off or on is vitally important to the expression of autism.
- What modifies genes will affect how we can target them with medications to impact autism.

Scientific research can be slow and painstaking. Yet as our understanding of autism spectrum disorders advances, bits and pieces fill in the puzzle. Understanding what is relevant from the environment such as food, geography, chemicals, water, etc., is an even more complex task. Research at the UC Davis Mind Institute and other institutions are trying to unravel the complex interplay of genes and environment so we can understand what may have the greatest impact on treatment. Internal environments, including auto-immune diseases and mechanisms, will likely also play a role. For now, we continue to use the best of emerging research to offer the best treatments and supports to

The following websites have more information on cutting edge research initiatives:

www.sfari.org - Simons Foundation Autism Research Initiative
 www.autismspeaks.org - Autism Speaks both funds and tracks autism research
 www.ucdmc.ucdavis.edu - University of California Davis Mind Institute

To learn more about Dr. Aronson-Ramos and provided services, please visit: www.draronsonramos.com







Birdies for Children allows local charities to team up with The Honda Classic offering their donor base a chance to win a Honda automobile while the charity gets 100% of the proceeds plus a 10% matching donation courtesy of The Honda Classic.

HOW IT WORKS:

Donors pledge \$20 or more to a participating charity for the opportunity to guess the number of birdies at the 2013 Honda Classic (no maximum on donations/30 birdies guess max).

100% of the donation PLUS a 10% matching donation will be awarded to the charity. Donors are eligible for the grand prize & other prizes; charities compete for additional rewards based on donation totals. Donor entries may be completed by submitting online at: www.thehondaclassic.com/birdies-for-children/donate/FAUCARD/.

CONTEST GRAND PRIZE:

A brand new 2013 Honda vehicle will be awarded to the person guessing closest to the actual number of birdies made the 2013 Honda Classic. (In case of a tie, a blind drawing from all correct guessers will determine the winner.)

PAST BIRDIE TOTALS:

2007: 1,116 2008: 1,144 2009: 1,180 2010: 1,181 2011: 1,041 2012: 1,279 *Maximum of 30 guesses per individual



Special Events / Trainings

ADOS-2 Training

The Autism Diagnostic Observation Schedule, Second Edition (ADOS-2) improves an instrument already viewed as "the gold standard" for observational assessment of autism spectrum disorder (ASD). This 2-day workshop will teach professionals how to use the ADOS-2 to assess and diagnose autism. Experienced workshop leaders describe the ADOS-2 and demonstrate administration and scoring, operationalizing diagnostic criteria for ASD. Attendees will have the opportunity to practice scoring while observing the instructor administer the ADOS-2 to a child with ASD. This workshop is for professionals unfamiliar with the ADOS-2.

Typically, this training costs \$450. FAU CARD and Palm Beach County School District are offering it for **free** to school district and charter school staff within the Martin, St. Lucie, Indian River, Okeechobee, and Palm Beach counties. The fee for private evaluators is \$200. All attendees are responsible for purchasing the required materials which include the protocols from Modules 2 and 3 and the ADOS-2 supplement and manual.

For answers to frequently asked questions about the ADOS-2, please visit: http://portal.wpspublish.com

Dates: January 24-25, 2013 from 8:00 AM - 4:00 PM

Location: FAU MacArthur Campus, Jupiter, AD Building Room 119

Registration information will be announced soon.

Family Connections Conference

The 2013 Family Connections Conference, sponsored by FAU CARD, will be held on Saturday, April 20, 2013 at FAU campus, Jupiter in the Lifelong Learning Center. Featuring Dr. Peter Gerhardt, a national expert on autism, adults and transition, it is our hope that parents will be inspired and take away strategies to increase successful transition from pre-school to elementary school, elementary to middle school, middle to high school and from high school to post secondary options. The conference will also feature an agency panel, as well as sessions providing other practical strategies for parents to enhance their child's success.

FAU CARD 5K in Sewall's Point

The Treasure Coast community and parents are teaming up to host the 1st Annual FAU CARD Autism Awareness 5K Walk in Sewall's Point in Martin County on April 27, 2013. More information to follow.

FAU CARD NEWSLETTER - PG. 8		SPRING 2013
Boca Raton - Groups & Trainings / Parent Networking All trainings will be held in Room 411 in the College of Education. Connect to all trainings live online by emailing card@fau.edu for details.	Date	Time
Adult Group	1/28	7 - 9 PM
Adults with an autism spectrum disorder ages 18 and older are	2/18	7 - 9 PM
welcome. The group meets to discuss issues, problem solve and form	3/18	7 - 9 PM
friendships. This group meets at the FAU High School	4/15	7 - 9 PM
iPad Features & Apps Presenter will educate parents and professionals on iPad accessibility features and apps which focus on developing areas of communication, social skills, behavior management, and more.	1/18	11:30 AM - 1:30 PM
Bedtime Struggles & Nighttime Awakenings This workshop discusses current state-of-the-art methods for treating children who struggle at bedtime, do not fall asleep on their own, and/or do not sleep through the night.	2/1	11:30 AM - 1:30 PM
Enhancing Communication & Social Interaction Skills		
Participants will learn research-based interventions to promote communication and social development in young children with an ASD.	2/8	11:30 AM - 1:30 PM



REGISTRATION IS REQUIRED FOR ALL EVENTS.

FAU CARD NEWSLETTER - PG. 9		SPRING 2013
Boca Raton - Groups & Trainings / Parent Networking All events will be held in Room 411 in the College of Education. Connect to all trainings live online by emailing card@fau.edu for details.	Date	Time
Preparing for Adulthood: Transition Resources Parents, professionals and individuals with ASD themselves will learn about the local resources available for those who are preparing for post-high school life. Resources covered will include employment opportunities, residential options and more.	3/8	11:30 AM - 1:30 PM
Enhancing Engagement in Science Participants will be taught the importance of making science lessons multi-modal and fun for the student. Examples of easy "scientific" lessons will be given and an introduction to several tablet applications that could be used at home and within the school will be shared.	3/29	11:30 AM - 1:30 PM
Precision Teaching: Using Fluency to Teach Basic Math Skills This training will teach participants how to use precision teaching strategies to help children learn faster and retain what they learn longer, resulting in a reduced need to re-teach math skills.	4/26	11:30 AM - 1:30 PM



REGISTRATION IS REQUIRED FOR ALL EVENTS.

Treasure Coast - Groups & Trainings / Parent Networking **Trainings will be held live via web on Adobe Connect.** Connect to all trainings live online by emailing card@fau.edu for details.	Date	Time
Adult Group- Community Outings		
Adults with an autism spectrum disorder ages 18 and older are welcome. The group meets to discuss issues, problem solve and form friendships. Adult Group will meet at various community locations. Specific information will be forthcoming. For questions, please contact Cathy Allore at (772) 873-3367 or callore@fau.edu or Linda Peirce, at (772) 873-3422 or lpeirce@fau.edu .	1/28 2/25 3/25 4/29	7 - 8:30 PM 7 - 8:30 PM 7 - 8:30 PM 7 - 8:30 PM
Okeechobee Autism Support Group Parents of children with autism or Asperger's and adults with autism or Asperger's are welcome to attend a monthly meeting held at the Okeechobee Library at 206 SW 16th Street. We will be meeting once a month from 5:30 to 6:45. For more information, check the event calendar at www.autism.fau.edu or contact Linda Peirce, Clinician and Behavior Analyst, at (772) 873-3422 or lpeirce@fau.edu .	1/14 2/11 3/11 4/15	5:30 - 6:45 PM 5:30 - 6:45 PM 5:30 - 6:45 PM 5:30 - 6:45 PM
Behavior Basics		
Participants will learn basic behavior management strategies that can be used in the home and the community to promote positive behaviors.	2/20	11:30 AM - 1:00 PM
Managing Bullying and Teasing		
Parents and professionals will be educated on various forms of bullying and learn how to look for signs of possible bullying. Strategies and resources in teaching your child how to handle situations involving bullying and teasing will also be shared.	4/24	11:30 AM - 1:00 PM

REGISTRATION IS REQUIRED FOR ALL EVENTS.

ALL GROUPS AND TRAININGS ARE SUBJECT TO CANCELLATION DUE TO LACK OF REGISTRATION. PLEASE CALL **772-873-3367**, **772-873-3422**, OR E-MAIL **CARD@FAU.EDU** TO REGISTER FOR EACH EVENT.





ACEing Autism began in 2008 and was founded by the husband and wife team of Richard Spurling, a tennis professional, and Dr. Shafali Jeste, a pediatric neurologist. They saw an opportunity to help address the lack of quality recreational programs available to children on the autism spectrum by combining their professional expertise and personal passion.

ACEing Autism is a 100% volunteer-based, non-profit organization comprised of autism professionals, tennis enthusiasts and families of children with autism with the purpose of "Connecting Kids Through Tennis". The mission is to make the sport of tennis available to children with autism and to use tennis as a means to enhance health and fitness, hand-eye coordination, motor development and improve the social skills for children with autism. Of course, making sure kids have fun in the process is also important!



For more information, visit <u>www.aceingautism.com/poloclub.html</u> or contact Lisa Pugliese at <u>lisa.pugliese@palmbeachschools.org</u>.

Social Skills Program

For boys and girls ages 6-10 and 11-14 at Don Estridge High Tech Middle School

Any child who may benefit from our *Therapeutic Social Skills Program* is welcome to participate. Each session includes a lesson targeting identified skills, cooperative play time, and discussion organized to practice and enhance targeted skills. Fun social skills games, activities and projects are utilized to reinforce positive, appropriate behaviors that can be generalized to other settings. Program also includes a detailed "Weekly Topic Updates" and Individualized Progress Report for parents.

Targeted Skills:

Making and keeping friends Positive self-talk Transitioning Flexibility
Self-advocacy
Sharing

Talking on topic
Showing interest in peers
And much more!

For more information, please visit: http://www.supportfortheautismspectrum.com, email: ejnach@gmail.com, or call (954) 290-4612.



Florida Atlantic University



FLORIDA

www.thescottcenter.org

(321) 674-8106 x1



An Innovative Approach to Employment for Some People on the Autism Spectrum Jack Scott, Ph.D, BCBA-D

Thorkil Sonne is the father of a child with autism who noted his son's amazing ability to remember detailed information. As an Integrated Technology (IT) specialist, Thorkil knew that such skills could, if appropriately channeled, be very useful in the tech world. This realization led Thorkil to establish the "Specialisterne" (the "Specialists" in Danish) program for young adults in his native Denmark. Young adults with ASD with an interest and capability in computers and software participate first in five months of focused job training, followed by a brief internship and, finally, employment with Specialisterne earning living wages as a consultant to contracting organizations. Specialisterne provides training for employers and on-going coaching, both in job and life skills. The program now operates in Poland, Iceland and the US, most notably in Minneapolis, MN and Fargo, ND. Fargo is the location of a major Microsoft facility.

While the Danish social services systems fund training costs in that country, in the US families are asked to cover the costs of initial training. Once on the job, the employee is paid competitive wages and benefits as an employee of Specialisterne.

Thorkil spoke at FAU at the Jupiter campus on November 3 to our audience of about 100 parents, professionals and others. He shared his vision of expanding the program to South Florida. He also spoke in Miami that same weekend and was again greeted by a large audience. With sufficient interest, we may see the creation of a South Florida branch of Specialisterne. Thorkil is now hoping to find a volunteer coordinator for the Florida development effort. If you or someone you know would be interested in helping on this project, contact Tim Hanson, Chair of Specialisterne Midwest, at 763-227-3571 or tim.hanson@specialisterne.com.

Specialisterne is only appropriate for a sub-set of adults with ASD. But they offer an innovative, if not revolutionary, approach to assessment and training and then high-quality employment. If you know of other innovations offering employment opportunities for individuals on the autism spectrum, please contact me at jscott@fau.edu.





TRANSITIONS 2013: HIGH SCHOOL TO HIGHER EDUCATION

Options for Students with Learning Differences





Friday, Feb. 1, 2013

A conference for guidance counselors, principals and headmasters, special education teachers, educational consultants, psychologists, parents and students

www.lynn.edu/transitions





IN ASSOCIATION WITH







ASK EPPY

Common Assets to Review

Fran Eppy

As you may know, having more than \$2000 in assets in the name of a person with a disability will disqualify that person from their government benefits. It is often a tiresome process to attempt to figure out on your own what you may need to evaluate in order to make sure your documents are in proper order. In some cases, your next of kin is the automatic beneficiary and you will need to be aware of these situations.

Here is a list of documents to help get you started thinking:

- Life Insurance: remember, you may have a policy through your employer
- Annuities
- IRA's or 401k's or other retirement benefits
- · Savings Bonds
- Property
- Inheritances
- · Cash gift or any gift
- Bank Accounts
- Real Estate
- Collectibles, antiques, jewelry
- Personal Injury or wrongful death proceeds, or for that matter proceeds from any type of law suit
- Homestead laws that give the surviving spouse a life estate and the minor children a vested interest (as is the case in Florida in certain instances)
- Final paycheck
- Deeds
- Accidental death or travel insurance benefits provided through credit cards when a plane ticket is purchased using that card, etc.
- · State mandated distribution of an estate without a will

These assets should be reviewed to make sure they will not be paid or given directly to the individual with special needs. In most cases, a special needs trust can be used to hold these assets for the benefit of the individual with special needs. There is much to know about trusts: which type to choose, how to fund it, who will manage it, how funds are dispersed, and more. But it can be one of the most valuable tools you put into place to ensure the ongoing care and well being of the person you care for - for many years to come.

A trained financial professional can offer you critical information and help to prepare you and your loved one for the future.

Eppy Financial Group, Inc. 1000 Corporate Drive 7th Floor Fort Lauderdale, FL 33334

Joseph Eppy, President of Eppy Financial Group is dedicated to helping families with special needs and can be contacted at <u>j.eppy@eppyfinancial.com</u> or by calling 954-689-9476.



CONTACT US

Statewide CARD Toll Free Number: 1-800-9-AUTISM (288476)

FAU CARD Toll Free Number: 1-888-632-6395

Website: <u>autism.fau.edu</u> e-mail: <u>card@fau.edu</u>

Boca Raton Campus <u>Treasure Coast Campus</u>

777 Glades Road 500 NW California Blvd. Boca Raton, FL 33431 Port St. Lucie, FL 34986

Main Line: 561-297-2023 St. Lucie and Indian River Counties:

772-873-3367

Fax: 561-297-2507

Martin and Okeechobee Counties: 772-873-3422

Fax: 561-297-2507

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*Effective immediately, phone numbers have changed for these Boca Raton campus personnel.



Thank you!

We would like to express our most sincere gratitude to all of the families and professionals who recently participated in our third annual 5K Run/Walk. Thank you for all your support in making this such a successful event!



If you or your organization would like to contribute to FAU CARD, donations can be made out to:

FAU Foundation - CARD

and mailed to our office at:

FAU CARD
Department of ESE
777 Glades Road
Boca Raton, FL 33431

Or visit:

https://fauf.fau.edu/NetCommunity/SSLPage.aspx?&pid=1151 and select Center for Autism & Related Disabilities (C.A.R.D.) as the designation.