

Director's Update



Thank you to everyone who has provided support to FAU CARD over the course of this year. Your outreach to us is inspiring and we gratefully appreciate it. So many of you have joined us for our events as sponsors and volunteers.

The Dan Marino WalkAbout Autism was one such event, and it was an enormous success. According to our estimates nearly 10,000 people attended, raising approximately \$450,000 for local autism support agencies and schools. FAU CARD was one of the six benefiting agencies, and we can't thank the Foundation enough. Importantly, however, we were not the only to benefit. Any school that created a team earned 25% of what they raised, and many of them will receive thousands of dollars. As you know, this could not come at a better time considering all the budget cuts that schools and agencies are facing. This event was truly about keeping funding local.

The FAU CARD 2nd Annual Wings of Hope Cocktail Reception was held on April 9. This was a great autism awareness event that also raised funding to support FAU CARD. Activities such as these are so helpful during these difficult financial times. We thank the many sponsors of this reception, as well as our planning committee.

In other news related to FAU CARD, we have had a couple of staffing changes. Cheryl Checkers has moved on to other opportunities and we wish her the very best in her pursuits. Additionally, Ali Cunningham was recently promoted to Assistant Director of FAU CARD. Ali has been with us for several years and she has done an excellent job for our Center.

Please remember to check out our training and event calendar located in this newsletter and online at autism.fau.edu. Our annual Summer Academy will be offered on the Jupiter campus, July 25-27. This year's academy will feature Dr. Barbara Esch, BCBA-D, CCC-SLP, and Mr. Michael Fabrizio, BCBA. Dr. Esch will present strategies to increase the language skills of people with autism. Mr. Fabrizio will discuss strategies to improve academic success of students with autism and similar disabilities. Both presentations will be a full day. The Summer Academy is open to anyone including teachers, other professionals and family members. As always, I am available to speak to you. Have a great summer and I hope to see you at some of our events!

All the best,

Kyle Bennett, Ed.D., BCBA Director

5th Annual Summer Academy

presented by



When: July 25-27, 2011

Where: Florida Atlantic University-Jupiter Campus

(a) Life Long Learning Society Auditorium

This year the summer academy is scheduled for three days. The first two days are dedicated to advanced topics for veteran teachers, professionals and caregivers. The final day will focus on beginning topics for those new to working with and caring for individuals with autism and similar disabilities.

- July 25: **Dr. Barbara Esch, BCBA-D, CCC-SLP** will present advanced applications of verbal behavior to increase the communication skills of children with autism.
- July 26: **Michael Fabrizio, BCBA** will present evidencebased strategies to increase the academic performance of students with autism spectrum disorder.
- July 27: FAU CARD staff & our school district partners will present breakout sessions featuring beginning topics.

Registration for this event is free. Seating is limited and available on a first-come, first-serve basis.

Please email us at <u>CARD@FAU.EDU</u> to register for the event.



Executive Director's Update

Florida Atlantic University's Center for Autism and Related Disabilities (CARD) is one of seven such centers in the state. Currently FAU CARD has over 2,400 clients, mostly children diagnosed with autism or autism spectrum disorders (ASD) such as Asperger syndrome, or pervasive developmental disorder not otherwise specified (PDD-NOS). The focus of FAU CARD is to optimize the potential of people with autism and related disabilities by enabling them to learn, work, communicate and socialize. We have a pretty good handle on autism here at CARD. But in ongoing awareness efforts, autism is typically portrayed as a total mystery. We actually know a great deal about how to help a child make progress and learn. The mystery may be in why more of what is known is not widely used. CARD, with six clinical staff members, seeks to help parents learn the skills they will need to guide their child's development and select appropriate treatment options. CARD also offers an array of supports to schools and agencies. All services are provided at no charge.

April was Autism Awareness Month; however we seek to raise awareness all year. Our CARD families are very aware of autism. I want to encourage you to please help us spread the word about our services and about ASD. CARD's highly skilled autism professionals can help new families cut through what is often a complicated maze of conflicting claims. While FAU CARD does not endorse specific therapies we do rely on sound research in offering guidance. Unfortunately, we know that many families still do not know about us. Some families come to us years after they have received a diagnosis for their child and tell us they had no idea we existed. We have devoted resources to make sure parents know we are here to help them. We have sent hundreds of posters announcing our services in both English and Spanish to all schools in our region, and to pediatricians, therapists, law enforcement agencies and others. We have been and will continue to be at every heath and disability fair in our region.

Our website is easy to find and filled with valuable information including an extensive directory of service providers. We now, with the help of the Unicorn Children's Foundation, have begun to conduct screenings for ASD in young children in various locations with our mobile clinic. Even with these and other efforts I believe that parents sharing information with other parents has been and remains our best source of awareness advertising. You are our best partners for autism awareness and April is your month. Thanks!

Jack Scott, Ph.D., BCBA-D Executive Director





MEDICAL UPDATE

Autism and Genetics: New Information for Parents

Judith Aronson-Ramos, M.D.

Genetic Testing is a field of medicine that rapidly changes. Presently there is an explosion in new technologies and the information they provide. There is currently a developing case for a genetic basis to autism. However, there is not one specific gene. Inheritance is complex, there are unknown modifiers and we are a long way from knowing any specific genetic cause of autism.

What we do know from studies of twins is that autism is highly heritable. Meaning if one monozygotic (identical) twin is affected the chances are nearly 70% the other twin will be affected. However, the fact that the probability is not 100% points to the complexity of genetic inheritance of autism. There are factors impacting genes and inheritance including the environment (toxins, disease, etc.), variable expression of genes and acquired mutations that all play a role. The so called "environmental trigger" which may turn a gene off or on is a very active area of research. (At the University of California Davis, the MIND Institute is among the leaders in this effort,

www.ucdmc.ucdavis.edu/mindinstitute/.)

More evidence for the genetic basis of autism includes sibling studies. If one child has autism there is a greatly increased risk for a sibling to be affected (5-10%). And, the risk factor for additional children increases by 30% if two siblings have been diagnosed. There are also specific genetic syndromes that can co-occur with autism such as Fragile X (3-20%), Tuberous Sclerosis (1-3%) and Neurofibromatosis (0.2-14%). What these syndromes seem to underscore is the genetic linkage with autism.

So what is a parent to do with the current information? What is the standard of care? Does my child need to see a geneticist? At the present time it is fairly standard for any specialist to perform high-resolution chromosomal analysis and DNA testing for Fragile X.

Chromosomal microarray testing is the newest genetic test. It examines chromosomes for tiny duplications and deletions of DNA sequences. It is a highly sensitive genetic test which can detect small changes in the genome. Presently a microarray can pick up autism associated genes 10-20% of the time; this is a huge development. Some parents may choose to decline this testing due to a variety of reasons, one being insurance coverage if these tests are not covered by their health plan, they are generally expensive (\$1,500 and up).

The question remains, if a gene associated with autism is detected, how will it affect care or treatment? The answer is still elusive. In some cases, it may affect family planning; in others it may solidify a diagnosis. If you decide to look into this, basic genetic testing can be completed by your neurologist, developmental pediatrician or child psychiatrist. If you have serious concerns about a possible genetic syndrome, or want advanced genetic testing ask your physician refer you to a pediatric geneticist.

We are still looking for specific biomarkers or tests that can detect autism at any age. There is still diagnostic uncertainty in children between 12-34 months. If we can diagnose autism with certainty earlier, we may begin aggressive and targeted early intervention much sooner. With this among the goals, we are still searching to unravel the complex interplay of genetics.

For more information about autism and genetics, visit the following websites: www.geneclinics.org or http://www.cdc.gov/ncbddd/pediatricgenetics/index.html



Boca Raton Events - Groups Unless otherwise specified, all events will be held in the College of Education.	Date	Time
Kid's Club Children with an autism spectrum disorder ages 7-11 will	5/19 6/9	4:30 - 5:30 PM 4:30 - 5:30 PM
have the opportunity to make friends, play games and talk about issues in a safe and friendly environment. Room 447.	7/14 8/11	4:30 - 5:30 PM 4:30 - 5:30 PM
Parent Support Groups Parents and caregivers are invited to join us for open discussion, networking opportunities and problem solving. Room 411.	5/19 6/9 7/14 8/11	4:30 - 5:30 PM 4:30 - 5:30 PM 4:30 - 5:30 PM 4:30 - 5:30 PM
Teen Group Community Outings Teenagers with an autism spectrum disorder ages 12-17 will have the opportunity to meet others, make friends and problem solve issues that teenagers may experience. Teens and parents will meet in the community for fun activities. Locations TBA on our website and monthly bulletins.	5/19 6/9 7/14 8/11	6:30 - 7:30 PM 6:30 - 7:30 PM 6:30 - 7:30 PM 6:30 - 7:30 PM
Adult Group Adults with an autism spectrum disorder ages 18 and older are welcome. The group meets to discuss issues, problem solve and form friendships. Room 411.	5/16 6/20 7/18 8/15	7 - 9 PM 7 - 9 PM 7 - 9 PM 7 - 9 PM

REGISTRATION IS REQUIRED FOR ALL EVENTS.

Boca Raton Events - Trainings All trainings will be held in Room 411 in the College of Education.	Date	Time
Behavior Basics		
Parents and professionals will learn basic behavior management strategies that can be used in the home and the community to promote positive behaviors.	5/6 7/15	11:30 AM - 1 PM 11:30 AM - 1 PM
Enhancing Communication Skills of Individuals with ASD Participants will learn research-based interventions to promote communication and social development in young children with an ASD.	6/10 8/5	11:30 AM - 1 PM 11:30 AM - 1 PM
ASD: Characteristics, Education and Treatment A thorough review of characteristics of Autism, Asperger Syndrome, PDD-NOS, Rett Syndrome & Childhood Disintegrative Disorder will be presented. Education and treatment approaches will also be presented.	5/20 7/1	11:30 AM - 1 PM 11:30 AM - 1 PM
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.	6/24 8/26	11:30 AM - 1 PM 11:30 AM - 1 PM



REGISTRATION IS REQUIRED FOR ALL EVENTS.

Treasure Coast		
Events - Groups & Trainings All groups and training locations will be held on our Port St. Lucie	Date	Time
campus. Rooms will be announced upon registration.		
Family Support Day		
Parent Networking		
Parents and caregivers are invited to join us for open discussion,	5/10	6 - 7 PM
networking opportunities and problem solving.	6/14	6 - 7 PM
Kid's Club	7/12	6 - 7 PM
Children with an autism spectrum disorder ages 7-11 will have the	8/9	6 - 7 PM
opportunity to make friends, play games and talk about issues in a safe and friendly environment.		
Adult Group	5/17	7 - 8:30 PM
Adults with an autism spectrum disorder ages 18 and older are	6/21	7 - 8:30 PM
welcome. The group meets to discuss issues, problem solve and form	7/19	7 - 8:30 PM
friendships.	8/16	7 - 8:30 PM
Training Series: Bringing Out the Best in Your Child's		
Behavior		0 4 00 DV 5
1. Behavior Basics	5/4	3 - 4:30 PM
2. Parent's Assessment of Behavior Problems	6/7	3 - 4:30 PM
3. Developing & Implementing Behavior Intervention Plans	8/2	3 - 4:30 PM
4. Implementing & Evaluating Behavior Intervention Plans	8/30	3 - 4:30 PM
Visual Supports		
Participants will learn about visual strategies to support individuals with autism spectrum disorders at home, school and in the community.	5/24	6 - 7:30 PM



Treasure Coast Events -		
Training	Date	Time
All training locations will be held on our Port St. Lucie campus. Rooms will be announced upon registration.		
ASD: Characteristics, Education and Treatment		
A thorough review of characteristics of Autism, Asperger Syndrome, PDD-NOS, Rett Syndrome & Childhood Disintegrative Disorder will be presented. Education and treatment approaches will also be presented.	6/24	10 - 11:30 AM
Leisure Skills		
Participants will learn why leisure skills are important and how to develop them among adolescents and young adults with autism spectrum disorders.	6/28	6 - 7:30 PM
Toilet Training		
Strategies for beginning toilet training, working through accidents and problem behaviors will be presented.	7/8	10 - 11:30 AM
Functional Skills Development		
Parents, caregivers and professionals will learn procedures to teach routine activities of daily living to promote independence and increase self-help skills. Functional skills are applicable to the home, classroom, workplace and community.	8/23	6 - 7:30 PM

REGISTRATION IS REQUIRED FOR ALL EVENTS.



COMMUNITY NEWS

Florida Atlantic University





Surfers for Autism Season in Full Swing

Surfers for Autism is an organization that has introduced children to a safe environment where families are treated to a fun-filled day of surfing, paddle boarding, live music, face-painting and more. Upcoming surfing events will be held in Stuart on May 14 and Cocoa Beach on June 4. Visit their website, www.surfersforautism.org, for a complete list of events and details on this amazing organization!

100 Cities. One Night for Autism.

Wretches & Jabberers, a film by Gerardine Wurzburg, will be playing at the Parisian 20 in City Place on May 12 at 7:30 p.m. in limited release to 100 cities across the world. The film is about two men, Tracy and Larry, who have autism and embark on a global quest to change people's attitudes about disabilities and intelligence. FAU CARD staff will be introducing the film and hosting a question and answer session. Please visit our website for details, autism.fau.edu.



NEW! TOPSoccer in Martin County

The Hobe Sound Soccer Club is hosting a new 8-week program for children ages 4-17 with special needs. The soccer camp will be held at the South County Ball Park in Hobe Sound and will be on Friday evenings from 6:30 - 8 p.m. For more information please contact the Hobe Sound Soccer Club at 561-685-3714 or visit www.hobesoundsoccer.com.

PBSFA Middle School Expansion

The Palm Beach School for Autism is expanding again! The middle school program, which focuses on functional academics and community-based instruction, will be doubling in size to 24 students beginning Fall 2011. This program has proven to be very successful and will be a direct feeder into the school's high school program. There is currently a waiting list for this program. For more information about enrollment or The Palm Beach School for Autism, please contact Ann Levene-Eisenberg at (561) 533-9917 or AnnL@pbsfa.org. Feel free to visit their website at www.pbsfa.org and click on "Middle School".



COMMUNITY NEWS

Two Dynamic Summer Programs

Palm Beach County Parks & Recreation's Therapeutic Recreation

Center offers a variety of summer programs for children and adults with disabilities.

These programs include art and performance camps, social groups and athletic clubs. Visit www.pbcgov.com/parks/

therapeutic_recreation/

<u>community programs</u> for details about these interesting and fun activities specifically for people with developmental disabilities.



The *Pine Jog Environmental Education Center* is offering their Art & Nature Summer Camps to children ages 5-11 years old. The program is available for full days with breakfast and lunch included. For more information on how to get your child enrolled please contact Karen Nobel of "Kids Need more Art" at 561-339-1077 or kidsneedmoreart@yahoo.com

Save the Date

October 29, 2011

Join us for the 2nd Annual Pumpkin Run benefitting the Center for Autism & Related Disabilities at Florida Atlantic University. Last year, nearly 1,000 runners and their guests joined us for our inaugural race.

Activities available:

5K race on a certified course
Fun run/walk for adults and kids
Kids races and bounce houses
Costume contest

Contact Kyle Bennett at (561) 297-3052 or <u>kbennett@fau.edu</u> for sponsorship and volunteer opportunities. We'll see you at the race!



ASK EPPY

Give and you shall receive...

Hopefully, we have all experienced the inherent joy in giving. There is no more appropriate time of year then now to touch on the ways and benefits of charitable giving. By crafting your charitable gift carefully, you can use life insurance whereby protecting those you care about and achieving a greater philanthropic goal than perhaps you had imagined.

A life insurance policy is the wonderful vehicle by which you can make a charitable donation and turn your annual gifts into a lasting legacy.

The following are some of the benefits you may be able to achieve using life insurance in your charitable gift plan:

- A substantial contribution at a relatively low cost;
- A gift that may increase in value (certain insurance products increase over time); and
- You may be able to save taxes.

Using an experienced professional can help ensure the development of a plan that will maximize your gift while providing a legacy to your heirs. Some possible options include:

- Designate the charity as the beneficiary of the life insurance or annuity. By remaining the owner of the policy this option allows you to make changes to the amounts and the beneficiary at any time you desire. This also allows you to have access to the cash value. This option does not allow for any income tax deduction.
- Gift a life insurance policy to the charity. In this scenario, the charity owns the policy but you pay the premiums. By using a life insurance policy with a cash value component, your favorite charity can have access to the cash value during your life as well.
- · Establish a charitable remainder trust.
- Establish a charitable gift annuity.
- Establish a charitable lead trust. This allows the charity to use the money now and passes it back to your heirs, estate tax free, at the end of the lead trust.
- You may also want to make the charity the contingent beneficiary of your special needs trust (or a portion of it).

The gift of a life insurance policy is tax deductible and, in most cases, is exempt from gift tax as well. A gift to a charity may reduce your federal estate tax and there is no limit on the amount of the gift or estate tax deduction. In most situations, the charitable organization does not have to pay income tax on the earnings of the policy either. For any of these tax effects the charity must qualify under the Internal Revenue Code.

As you can see there are many options and they can become complicated. It is highly advised to use a professional to arrange any of these options. There is no time like the present to explore your opportunities.



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

Eppy Financial is a unique team of financial planners dedicated to helping families with special needs. Questions can be submitted to feppy@finsvcs.com or by calling 954.689.9482. We will answer all questions submitted either in the quarterly newsletter or with a personal response from one of our team members.



CONTACT US

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

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

Website: autism.fau.edu

e-mail: card@fau.edu

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Thank you! Thank you! Thank you!

We would like to express our most sincere gratitude to all of the families and professionals who recently contributed to FAU CARD.

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:

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