

Florida Atlantic University



Director's Update

Dear CARD Friends & Families,

We hope you had an opportunity for some well-deserved time with family and respite from your very busy schedules. It has been a very busy and productive summer at FAU CARD!

The FAU CARD 6th Annual Summer Academy was held July 30th and 31st at the FAU McArthur Campus in Jupiter. This annual collaboration with the Partnership for Effective Programs for Students with Autism (PEPSA) was a huge success with approximately 100 parents and professionals attending. FAU CARD was very excited to sponsor two national experts, Dr. Tim Knoster, who shared behavioral strategies for the classroom, and Dr. Elizabeth Laugeson, who informed on the evidencebased social skills program PEERS. Additionally, there were afternoon presentations on a variety of topics and feedback was overwhelmingly positive. I want to thank all of the professionals and parents who took time out of their summer to attend the conference, as well as the CARD staff for their hard work in organizing the event.

In collaboration with the IT department here at FAU, we have made some significant changes to our FAU CARD website. Please take a moment to visit our website and provide us with your feedback as we focus on making the website more user friendly. Additionally, CARD staff is working on creating prerecorded online trainings addressing our most requested topics. These trainings will be posted to our website and will be conveniently available for you to access. You will be notified when these trainings are complete and available.

As you may or may not know, FAU CARD is funded through the state legislature appropriated dollars and

legislatively required fundraising. As part of our FAU CARD Strategic Planning process, we have developed a comprehensive fundraising plan. FAU CARD was the beneficiary of two very successful fundraisers this summer! The 1st Annual Irishmen's Golf Tournament was held in July and the Hoopin' It Up Family Fun Day was held on August 11th. We are so very appreciative to our friends of CARD for all you do to support us! The FAU Homecoming and FAU CARD 5K Fundraiser will be held on October 21st on the Boca Raton campus. This event will again prove to be fun and exciting! Additionally, FAU CARD will be collaborating with various community businesses to hold monthly fundraising events which will also promote public awareness of our services. A percentage of sales during these events will go directly to FAU CARD. You will receive notifications via email. We hope that you will encourage family members, friends, neighbors and co-workers to patron these events benefiting FAU CARD.

A special thanks is given to Michele Weppner, Rebecca Everett, Veronica Pappas and Veronica Pakuris for their willingness to meet with our legislators this Summer and Fall to share the impact FAU CARD has had in their lives and the autism community. Additionally, I want to thank Rep. Mayfield in Vero Beach, Rep. Hager in Boca Raton and Rep. Berman in Delray Beach for taking time out of their very busy schedules to meet with us.

Please visit the FAU CARD website www.autism.fau.edu for additional information and upcoming Fall events. I hope to see you at some of our events!

Maryellen Quinn-Lunny, Ed.S. Director



Sunday, October 21, 2012 FAU Track & Field Complex

FAU CARD will be partnering with FAU Campus Recreation to host the 3rd annual FAU CARD Homecoming 5K/Walk. FAU CARD will be the benefiting charity and this event will highlight the new state-of-the-art facilities on campus, including the FAU football stadium! Last year's event brought over **1,200 runners and guests** to FAU making it one of the most highly attended 5K events in Boca ever!

This year's run will begin at 5:15 p.m. and activities will include:

- 5K race on a certified course
- 1 mile fun run/walk for adults and kids
- Kids races and bounce houses
- Prizes to the top adult and kid's costumes
- Prizes to top fundraising teams

To create a team or a fundraising page, please visit www.active.com/donate/faucard2012. For more information or to register, please visit www.active.com and type FAU in search bar. Sponsorships are available upon request.



Executive Director's Update

Dear CARD Families,

There are several new and exciting things on the horizon in our autism community!

First, FAU CARD was recently involved in an effort to establish a new chapter of the Autism Society of America (ASA) for Palm Beach and Martin Counties. Terri Neil, organizer, arranged for Scott Badesch, ASA president and former Palm Beach County United Way CEO, to speak at this meeting. Scott shared his vision for a more active ASA with enhanced supports for local and state chapters. Terri and other parents spoke to the need for such a chapter. Betsy Cohen, ASD professional in Belle Glade, and Ann Levine-Eisenberg, director of the Palm Beach School for Autism, and several other parents and professionals voiced support for this new organization. FAU CARD will actively assist in this process. I recognize the special value a local ASA chapter can offer to parents as well as the opportunity to provide special camps, outings, support groups and other events and services to individuals with an autism spectrum disorder.

If you are interested in joining this new chapter of ASA, please contact Terri Neil at 561-628-2538 or Terri@Terripr.com. I want to offer a special thanks to Terri for having the vision and energy in taking on the task of creating a new chapter of the Autism Society of America in our area.

I would like to extend a special congratulations to our board member, John Miller, for being the recipient of the "Ability Award" from The Able Trust on June 15th in Tallahassee. John was nominated for this award for his efforts as an adult with ASD who exhibits community and nonprofit leadership. He demonstrates this by serving on the board of the Autism Society of Florida and FAU CARD as well as mentoring teachers, presenting at professional conferences and more. Thanks to John for representing individuals with ASD in our community so well!

As we approach 2013, there are two events to look forward to. The first is our 20th Annual Statewide CARD Conference which will be held on January 11-13, 2013 at the TradeWinds Island Grand Resort in amazing St. Pete Beach. Among the national speakers that will be featured, I am proud to announce that myself and two other FAU CARD staff will be presenting on issues such as safety, friendship skills and self-monitoring. Please visit http://card-usf.fmhi.usf.edu/card2013/ for more information on this wonderful training opportunity.

Save the date for February 28, 2013. The 4th annual Wings of Hope will be held at the Boca Raton Museum of Art in downtown Boca Raton. This charity reception, benefiting FAU CARD, will feature an open bar, lavish hors d'oeuvres, live and silent auctions and several art-themed activities. We have restructured this event in the hopes of reaching a greater number of our families. More information will be sent in the near future but mark your calendars for a great party and a chance to help contribute to FAU CARD!

Sincerely,

Jack Scott, Ph.D. Executive Director

Save the Date!



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/

For more information, please visit: http://card-usf.fmhi.usf.edu/card2013/



MEDICAL UPDATE

Starting the School Year Right: Enhancing Communication with Your Child's Team

Judith Aronson-Ramos, M.D., FAAP

Another school year begins; some families welcome the opportunity of new challenges and opportunities. Others are prepared to battle with the powers that be in a never ending struggle for services. What all families of children with autism share is the hope that their children will be valued for their unique abilities, stimulated to achieve their best, and pushed without preconceived limitations of their potential.

Communication between families, teachers, therapists and physicians is important for your child's success. It is important to find ways to facilitate this communication and the beginning of the school year is the optimal time. Everyone is fresh, hopefully rested, and often optimistic about a positive school year. It is beneficial to approach your child's teacher and find out his or her preferred method of communication. Email offers convenience to everyone, however some teachers prefer a daily log sent between home and school while others prefer a weekly behavior chart or summary. Asking the teacher how he or she prefers to communicate begins the dialogue in a friendly and courteous manner and helps create a spirit of collaboration and mutual respect from the beginning.

Communicating with therapists in the public school system can be more difficult as you may rarely have the opportunity to see or speak to them. Similarly, find a way to make initial contact via email or phone and from there establish a preferred method of consistent communication. Private therapists should also be brought into the loop and communication between therapists and teachers should be facilitated when appropriate. For example, speech, behavioral or occupational therapists addressing language and communication needs, behavioral challenges, fine motor deficits and sensory issues, may contain valuable insight and tips that can be shared with classroom teachers. Where feasible and appropriate, try and connect teachers to therapists if you feel it is helpful for your child. If this proves difficult you can always provide team members with the information yourself.

Physicians also like to be in the "loop". I know for my practice, the more specific and detailed the information from school and therapists, the more helpful it is in making clinical decisions. Physicians rarely rely on behavior or observations from an office visit exclusively. We factor in parent information, history, observations, direct examination and information from the child's activities and school. I will often look at direct teacher notes, behavior logs, progress reports and, whenever possible, direct communication from the teacher via phone or email. Similarly, reports from therapists and extracurricular activities are useful. Generally, as a physician I am looking for trends or patterns that signal a change in behavior or function that I may need to address or document. These patterns may reflect a need for changes in medical treatment and therapies, or call for new interventions.

Last, but certainly not least, talk to your child. Whether they communicate best verbally, in pictures, through play, sign language, or keyboarding, it is important to find out how they feel about their teachers and therapists. For some children, a behavioral change may signal a nonverbal expression of preference or protest. Resistance to demands placed needs to be investigated to assess whether a task is too challenging, there is a poor fit with a teacher or therapist, it is a signal for help, or the behavior is simply a maladaptive response to a challenge. Check in with your child, you know them best, and you will always be their best advocate.

In sum, welcome the new school year with an open mind and positive outlook. Capitalize on the spirit of optimism endemic to a new school year and make it work to your advantage. Sincerely believe in your power as a parent to be pivotal in your child's development. The goal is make this last throughout the year.

Recommended resources:

FAU CARD NEWSLETTER - PG. 6		FALL 2012
Boca Raton - Groups &		
Trainings / Parent Networking		Time
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.		
Adult Group	0./17	7. 0 PM
	9/17	7 - 9 PM
Adults with an autism spectrum disorder ages 18 and older are	10/15 11/19	7 - 9 PM 7 - 9 PM
welcome. The group meets to discuss issues, problem solve and form	11/19	7 - 9 PM 7 - 9 PM
friendships.	14/1/	/ - 9 FM
Building a Positive Home-School Relationship		
Parents will learn how to develop a good home/school	9/14	11:30 AM - 1:30 PM
relationship with the professionals involved in their child's educational	11/9	11:30 AM - 1:30 PM
programming.		
How to Make Friends		
Participants will learn the essential skills for teaching friendship		
skills to children, adolescents and adults with autism spectrum	9/28	11:30 AM - 1:30 PM
disorders. Parents, professionals and individuals with autism are	11/30	11:30 AM - 1:30 PM
welcome to participate and will gain skills to help with finding social	117 50	11.50 7 MVI - 1.50 1 WI
opportunities, joining conversations, dealing with disagreements and		
teasing and more.		
Increasing Independence & Self-Help Skills		
Participants will learn how to promote independence through a	10/5	11:30 AM - 1:30 PM
skill-building process. Parents and professionals will be taught how to	12/7	11:30 AM - 1:30 PM
break skills down into learning steps and will learn how to identify	, •	



several techniques in order to choose what will be most effective.

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 Linda Peirce, Clinical Support Specialist at (772) 873-3422 or	9/12 10/10 11/14 12/12	7 - 8:30 PM 7 - 8:30 PM 7 - 8:30 PM 7 - 8:30 PM
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 .	9/11 10/9 11/13 12/11	5:30 - 6:45 PM 5:30 - 6:45 PM 5:30 - 6:45 PM 5:30 - 6:45 PM
Social Skills Training Parents and professionals will learn about current social skills research as well as social skill instructional strategies to teach and support their child or young adults at home, in the community, and at school.	9/18	11:30 AM - 1:00 PM



REGISTRATION IS REQUIRED FOR ALL EVENTS.

Treasure Coast Events - 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
Visual Supports Participants will learn about visual strategies to support individuals with autism spectrum disorders at home, school, and in the community.	9/19	3:00 PM - 4:30 PM
Functional Skills to Promote Independence Parents and professionals will learn procedures and behavioral analytic instructional routines to teach daily living skills to promote independence and increase self-help skills.	10/16	11:30 AM - 1:00 PM
Preparing for Community Participation Participants will learn to identify necessary tools and strategies to use when taking children or students into the community to make the experience more meaningful and enjoyable.	10/17	3:00 PM - 4:30 PM
Behavior Basics Participants will learn basic behavior management strategies that can be used in the home and the community to promote positive behaviors.	11/13	11:30 AM - 1:30 PM
Preparing for Adulthood: Transitioning Presenter will review the TIEP, diploma options, and a portfolio to help showcase the student and get them ready for life after high school	11/14	3:00 PM - 4:30 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.



NEW TO THE AUTISM COMMUNITY

In this section we feature providers, organizations, agencies or individuals who are new to the area and new to serving the specialized needs of children with autism. Please note, we are not endorsing but rather helping to welcome these new services to the regional autism community.

For newcomers wishing to be noted in this section, please contact Dr. Jack Scott via email at iscott@fau.edu.

Bachelor's Degree Designed for Students with ASD

The Sage Colleges of Albany and Troy, New York, introduces a new bachelor's degree program that directly targets the specific needs of individuals with autism and Asperger's. This 120-credit degree program is delivered entirely online and includes up to 3 hours per week of one-to-one mentor support from a Board Certified Behavior Analyst (BCBA). Faculty are specifically trained and supported in meeting the needs of learners with autism, all content is delivered in multiple modalities and students are able to select among a variety of assessments to best meet their needs.

Students in Florida can access their courses utilizing the fully online format and will receive one-on-one support from a BCBA weekly via Skype, telephone or email. Each student in the Achieve Degree can individualize his/her experience in a number of ways as all content is available in different formats. Since the idea of attending college can be challenging, Sage offers the opportunity for students to take their first 8-week online course in the program as a "trial course" at no cost or obligation to continue in the program.

Coursework is delivered in 8-week terms, year-round. Breaks are brief, so students do not lose momentum and good habits. Life Labs are special courses designed to support individuals with autism in particular areas, including time management and organization, writing skills, social communication, using technology for socialization, personal finance, job seeking and interviewing skills, and personal goal-setting. All other courses are from the Sage College of Albany academic catalog. The program of study is designed to provide students with a broad education in liberal studies, with an emphasis on coursework in Computer Science that will enable them to enter a variety of work experiences, including working from home and self-employment, as well as more traditional work environments.

For more information, please contact Achieve Degree Admission at (518) 292-8615 or visit www.sage.edu/sca/academics/achieve/





COMMUNITY NEWS



Local Clinical Research Study for Autism

The ConnectMe clinical research program is for children who are 6 to 12 years old and have autism, Asperger's Disorder and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). The intervention under current study is FDA-approved and is a measure of the effects of medication called memantine, an NMDA receptor antagonist taken as an oral capsule or can be sprinkled onto certain foods rather than swallowed whole if necessary.

Memantine is currently used to treat adults with Alzheimer's disease, but has been prescribed to over 80 children with autism. No serious side effects have been reported by these children or their parents and it is hoped that memantine may benefit the core symptoms in some children with autism such as socialization and communication.

The program includes an initial study which will last 14 weeks and will involve 8 visits to the Palm Beach Clinical Research Network in Wellington, each visit about two weeks apart. After completion of the initial study you and your child will have the option to continue for another 48 weeks.

For more information, including eligibility criteria, please visit <u>www.connectmeprogram.com</u> or call Palm Beach Clinical Research Network at 561-429-8367

S.T.A.R.S. Conference

The 8th Annual S.T.A.R.S (Start Transition And Realize Success) Conference will be held on Saturday, October 20 from 8:30 AM to 12:30 PM. This free conference is a collaborative event between United Way of Palm Beach County, the School District of Palm Beach County and local agencies serving students with disabilities.

The mission of the S.T.A.R.S. Conference is to help students with disabilities and their parents utilize school and agency services to transition from high school into adulthood and to reach their post-secondary goals. The day-long conference will feature targeted workshops to guide students and their families through a successful transition as well as fun activities to provide a break for the students.

Information on schedule and workshop topics will be forthcoming.



ASK EPPY

Creative Funding in a Special Needs Trust and Tax Efficiency Joseph Eppy

The "bucket" called a special needs trust was created in 1993. A person's bucket, or special needs trust, becomes irrevocable at the passing of the caregivers or owners of the trust. Unfortunately, the taxation for the money coming out of the trust will be at the highest income tax rate of that day. Today, that rate is 35.9% and chances are it is steadily increasing.

This makes the assets inside the trust quite precarious. The trust should ideally be funded with tax efficient assets. This typically leads one to think "municipal bonds". Sounds safe, doesn't it? Well, you might want to think again. Bonds, especially long term bonds, have always had interest rate risk. That means that when interest rates go up, they are forcing your bonds to drop in value and it causes a loss in inflation protection.

Today, there is a bigger problem with municipal bonds- they have credit risk. Cities or municipalities can file bankruptcy, whereas states cannot. But if that changes, and it may, there will undoubtedly be states that will file bankruptcy. We are all aware that our country has never had larger debts and deficits. How secure are the federal municipals bonds, especially if they are revenue bonds? There must be revenue to back the bonds; if not, there is a problem. Putting taxable investments in a trust can therefore be quite risky. The biggest danger is that by the time the trust is being utilized, you will be gone and therefore unable to fix this for your child. So, is there a solution? If so, what is it?

Good news! The solution involves the use of one specific annuity. This particular annuity has sic patents and two private letter rulings from the IRS. It is the only annuity that can be owned ultimately by a special needs trust. It is the only annuity that will not cause an income tax upon a caregiver's death. It also allows for the special needs beneficiary to be added as the annuitant. The beneficiary with the special needs will now receive a guaranteed lifetime income without losing access to the account value and the death benefit. The best news is that the income payout is on a tax-preferred basis. It is the most tax efficient bucket for the trust.

In conclusion, this particular annuity will help solve two big challenges. It will allow joint-life guarantees and tax-preferred income for the caregivers while also providing a guaranteed tax-efficient income for the surviving beneficiary with the special needs.



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

Boca Raton Campus

777 Glades Road Boca Raton, FL 33431

Main Line: 561-297-2023

Fax: 561-297-2507

Treasure Coast Campus

500 NW California Blvd. Port St. Lucie, FL 34986

St. Lucie and Indian River Counties: 772-873-3367

Martin and Okeechobee Counties: 772-873-3422

Fax: 561-297-2507

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Thank you!

We would like to express our most sincere gratitude to all of the families and agencies who have recently supported us through their contributions and fundraising efforts.



First place winners of the 1st Annual Irishmen Sports Pub & Eatery Charity Golf Tournament benefiting FAU CARD



The Bentz Family: Evan, Hannah (pictured), Steve & Abbi sponsored the Hoopin' It Up basketball tournament to benefit 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:

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