

# FAU CENTER FOR AUTISM AND RELATED DISABILITIES

Florida Atlantic University

# Director's Update

We hope you've been having a great year! It is hard to believe that once again we are approaching the holidays. It has been a very busy and productive year at FAU CARD!

I would like to welcome Alison Bourdeau, Clinical Support Specialist, and Nancy Rhodes, Coordinator for Marketing, Information and Publications. Alison comes to FAU CARD with over 10 years in the teaching, mental health and social services fields, and has also worked as an ESE teacher with pre-K and elementary-age students. Alison is assigned to the Port St. Lucie office serving the Treasure Coast. Nancy Rhodes comes to FAU CARD with extensive experience and over 20 years in the field of marketing and communications. We are very excited to have someone with Nancy's background join us at FAU CARD. Nancy will also assist us with fundraising. Please take a moment to welcome them both, as you see them at our various events. Remember none of this would be possible without the increased funding from our Florida Legislators. As you meet with your legislators, please thank them for supporting FAU CARD and all of the CARD centers.

FAU CARD had several very successful events this fall. Marilee Emerson, consultant and expert on transition, presented on October 24th to an audience of family members and professionals on the components and the importance of Persons Centered Planning for individuals with autism. Transition planning for post-secondary education to adulthood is critically important for all individuals with disabilities, but essential for those individuals on the autism spectrum. I would encourage families to begin this process early. Persons Centered Planning is an excellent process to assist families and professionals in planning a smooth transition, focusing on the strengths of the individual.

On October 29, FAU CARD sponsored a DSM panel discussion about the new changes in the DSM-5 and the impact on individuals with autism, their families and serving professionals. I want to thank Dr. Judith Aronson-Ramos, Developmental Pediatrician; Dr. Christopher Kye, Adolescent and Childhood Psychiatrist; and Dr. Jill Kelderman, Neuropsychologist, for sharing their expertise and perspectives with the attending families and professionals. I also want to thank the FAU College of Medicine for allowing us to host the event in the College.

You may also notice some changes to the FAU CARD website. FAU CARD staff have been working diligently to create additional trainings and have posted those trainings to the FAU CARD website resource page. Please take a moment to visit the FAU CARD website <a href="https://www.autism.fau.edu">www.autism.fau.edu</a> and provide us with your feedback.

Please mark your calendar for the upcoming Wings of Hope Dinner and Auction on February 27 at the Addison in Boca Raton. This is an important fundraising event for FAU CARD. We hope we can count on your support.

Additionally, please note the Family Connections Conference will be held Saturday, April 12, on the FAU Jupiter campus. FAU CARD will be sponsoring researcher and author Dr. Mark Durand. Dr. Durand will be reviewing his research on Optimistic Parenting. Please see the FAU website for additional information on these and other upcoming important events.

Thank you for all of your support for FAU CARD. We appreciate all you do to help us! I hope to see you at some of our events.

Maryellen Quinn-Lunny, Ed.S. Director

PG. 2 SPRING 2014



http://card-usf.fmhi.usf.edu/CARDconference/register.html

PG. 3 SPRING 2014

# Executive Director's Update

We are coming to the end of another year of great accomplishments for FAU CARD. We have been very fortunate to receive an increase in funding from the Florida Legislature this year. Florida State Representatives Erik Fresen from Miami and Marti Coley from the Florida Panhandle area have both offered considerable support to help move an increase forward for 2014-15. We hope many of our local legislators will offer their support as well.

Coming soon, January 17-20, the 2014 statewide CARD conference will be held in Orlando. I want to urge all families, teachers, service providers and others to check out the program for this event. Check page 2 of this newsletter for the registration link. We have funds to provide partial support for some families and teachers to attend the conference. If this is of interest, please send an email to <a href="CARD@fau.edu">CARD@fau.edu</a>. This summer, we had our own Summer Teacher Academy at the FAU Jupiter campus attended by nearly 200 teachers and parents. We also had our annual Family Connections Conference in April.

FAU CARD also held the first-ever Palm Beach County Autism Leaders Breakfast in June. Over 75 leaders of autism programs in Palm Beach, and a few from Broward and the Treasure Coast, came together at our FAU University Club to hear Scott Badesch, the president of Autism Society of America, speak about the state of autism nationwide. We then heard updates from each of the autism organization leaders. While the services available are still not all we might want them to be, there can be no doubt we have seen a tremendous growth in the array of service providers and the scope of services offered in the last few years. I'd like to again thank our wonderful sponsors for helping make this event possible including Sandy Slomin and the Slomin Family Center, Michelle Rubin and Autism After 21, the Unicorn Children's Foundation and the Autism Project of Palm Beach County. I look forward to this breakfast becoming an annual event.

We have stepped up our fundraising efforts. While we do get funds from the state of Florida, this amount is far short of what we need to meet the service needs throughout the region. As some of you may know,

virtually 100% of our state grant goes directly to employee salaries. All other costs such as travel, phone, books, software, etc. are now being covered by money we raise through events and donations. We simply cannot operate as we have without reaching out to the community for support. With our Boca 5K Run event inlate October, our Wings of Hope event each February and our Stuart 5K Walk-Run in May we have several ways to raise both funds and awareness for autism.

Each of the CARD centers is required to have a Constituency Board made up of parents of children on the spectrum or individuals on the spectrum. I am proud to announce that we have now increased our board to a total of 10 people with representation from the Treasure Coast area. This board helps me and our director, Maryellen Quinn-Lunny, set the direction for CARD and provide valuable input as to needed services and feedback on our effectiveness or suggestions for ways to improve what we do. Maryellen has instituted an additional advisory team with a Parent Advisory Group. This group meets with Maryellen and other staff periodically to look at training needs and how we deliver services. With both our Constituency Board and the new Parent Advisory Group, we have very strong and direct links with our regional families.

In closing, I would like to make one more pitch for everyone affected by autism in our area to attend the statewide conference in Orlando. The lineup of speakers is designed to accommodate the broadest array of parent and professional needs; and the conference setting is very conducive to learning, networking and building friendships.

Best wishes for a wonderful holiday season and a great new year and, as always, if you have any suggestions for how we may improve what we do here at FAU CARD please drop me a line.

Regards and best wishes,

Jack Scott, Executive Director jscott@fau.edu PG. 4 SPRING 2014

# FAU CARD Presents...

# **É iTechnology Camp**



# Do you own an iPad, iPhone, or iPod Touch?

# Are you interested in learning how your device can help your child or student with ASD?

With an increasing demand for support in using iDevices with individuals with Autism Spectrum Disorder, FAU CARD is now offering monthly workshops that will target various ways in which caregivers and professionals can utilize their iPad, iPhone, and iPod Touch to promote skills.

A series of workshops will introduce participants to iDevice features and apps that may be helpful in promoting deficit skills. Strategies for device management will also be discussed. Sessions will provide participants with a hands-on experience to enhance learning and skill development.

Due to limited access to devices, it is recommended that participants bring their own personal iPad, iPhone, and/or iPod Touch.

Child care will be provided therefore registration is mandatory.

# Spring 2014 dates and topics:

January 25 - Orientation to the iDevice and helpful features February 15 - Early Childhood- Writing & Expression March 29 - Early Literacy & Number Sense April 19 - Sensory Needs and Visual Supports 10:00 AM - 12:00 PM

FAU Boca campus, College of Education, Room 411 Course not Available Online

To register, please contact Elisa Cruz-Torres at ecruz4@fau.edu or 561-235-9078

PG. 5 SPRING 2014

Boca Raton & Treasure Coast Groups	Date	Time
Adult Women's Social Group		
Adult women age 18 or older with an autism spectrum disorder are	1/6	7 - 8:30 PM
	2/10	7 - 8:30 PM
welcome. The group meets to socialize, form friendships, share interests, and discuss concerns. Call 561-212-4930 or email <a href="mailto:nbalsamo@fau.edu">nbalsamo@fau.edu</a> to register	3/3	7 - 8:30 PM
or get more information.	4/7	7 - 8:30 PM
Boca Raton Adult Group	1/27	7 - 8:30 PM
Adults with an autism spectrum disorder ages 18 and older are welcome.	2/17	7 - 8:30 PM
The group meets to discuss issues, problem solve and form friendships. This	3/17	7 - 8:30 PM
group meets at the FAU High School or in the community.	4/21	7 - 8:30 PM
Treasure Coast Adult Group- Community Outings		
Adults with an autism spectrum disorder ages 18 and older are welcome.	1/30	7 - 8:30 PM
The group will meet at various community locations to discuss issues,	2/17	7 - 8:30 PM
problem solve and form friendships. Locations will be determined prior to	3/27	7 - 8:30 PM
outing date. For questions, please contact Cathy Allore, Clinical Support Specialist, at (772) 873-3367 or <a href="mailto:callore@fau.edu">callore@fau.edu</a> .	4/24	7 - 8:30 PM
Okeechobee Autism Support Group		
Parents of children with autism or Asperger's and adults with autism or	1/28	5:30 - 6:45 PM
Asperger's are welcome to attend a monthly meeting held at the Okeechobee	2/25	5:30 - 6:45 PM
Library at 206 SW 16th Street. We will be meeting once a month from 5:30	3/25	5:30 - 6:45 PM
to 6:45. For more information, check the event calendar at	4/22	5:30 - 6:45 PM
<u>www.autism.fau.edu</u> or contact Noelle Balsamo, Clinical Support Specialist, at (772) 873-3422 or <u>nbalsamo@fau.edu</u> .		
St. Lucie County Parent Support Group		
Parents who have special needs children will be able to network with	1.70	0.00 = 00 = 0
other parents, receive support and training via CARD staff and/or other	1/9	6:00 - 7:00 PM
professionals. Meetings will be held at Grace Therapies at 4715 Kirby Loop	2/13	6:00 - 7:00 PM
Road, Ft. Pierce, FL 34981. For questions, please contact Cathy Allore,	3/13	6:00 - 7:00 PM
Clinical Support Specialist, at (772) 873-3367 or callor@fau.edu.	4/10	6:00 - 7:00 PM

PG.6 SPRING 2014

Trainings & Parent Networking Opportunities All trainings will be available online Connect to all trainings by emailing card@fau.edu for details.	Date	Time
Training Series: iTechnology Camp		
FAU Boca Raton, College of Education, Room 411		
Orientation to the iDevice and Helpful Features	1/25	10 AM - 12 PM
Early Childhood: Developmental Exploration	2/15	10 AM - 12 PM
Early Childhood: Words & Numbers	3/29	10 AM - 12 PM
Sensory Needs and Visual Supports	4/19	10 AM - 12 PM
Behavior Basics FAU Jupiter, Education Classroom, Room 202c		
Participants of this training will learn about the basics of behavior, why it occurs, the functions of behavior, and basic strategies to address behavior in the home. This session is designed for parents of children with autism spectrum disorders and to provide a basic understanding of behavior.	1/3	12:00 - 1:30 PM
Collaborating Effectively with School Personnel		
*Online only Parents will learn how to develop a good home/school relationship with the professionals involved in their child's educational programming.	2/3	10:00 - 11:30 AM
IEP Basics for Parents		
*Online only  Parents and other caregivers are invited to learn the components of an IEP and develop an understanding of why an IEP is important.	2/6	10:00 - 11:30 AM



### REGISTRATION IS REQUIRED FOR ALL EVENTS.

PG.7 SPRING 2014

Opportunities  All trainings will be available online  Connect to all trainings by emailing card@fau.edu for details.		Time	
Making and Keeping Friends  FAU Jupiter, Education Classroom, Room 202c  Participants will learn the essential skills for teaching friendship skills to children, adolescents and adults with autism spectrum disorders. Parents, professionals and individuals with autism are welcome to participate and will gain skills to help with finding social opportunities, joining conversations, dealing with disagreements and teasing and more.	2/7	12:00 -1:30 <b>PM</b>	
Beginning Reading Skills  FAU Boca Raton, College of Education, Room 411  Parents and professionals will learn how to teach beginning reading skills to individuals with ASD. Strategies for teaching and specific examples will be utilized.	2/17	10 AM- 12 PM	
Increasing Independence & Self-Help Skills  *Online only  Participants will learn how to promote independence through a skill-building process. Parents and professionals will be taught how to break skills down into learning steps and will learn how to identify several techniques in order to choose what will be most effective.	3/3	10:00 -11:30 AM	
Transition Planning: Mapping the Future  *Online only  Participants will learn the importance of helping their teen or young adult with an ASD plan for their future.	3/6	10:00 -11:30 AM	
Navigating the Dating World  FAU Boca Raton, College of Education, Room 411  Did you know that most people are never actually taught how to be good at flirting, dating and having a successful romantic relationship?  Participants of these sessions will be learn about the complicated nature of the skills that can help make this process more successful.	3/6	5:00 - 7:00 PM	

PG. 8 SPRING 2014

Trainings & Parent Networking Opportunities All trainings will be available online Connect to all trainings by emailing card@fau.edu for details.	Date	Time
Feeding and Nutrition		
FAU Jupiter, Education Classroom, Room 202c  Guest speaker, Tania Koerber, Pediatric Nutrition Consultant, will	3/14	12:00 - 1:30 PM
discuss nutrition and feeding as they relate to individuals with autism. Some of the topics include the role of nutrition in childhood development, feeding challenges, nutritional planning and supplementation.		
Visual Supports		
*Online only  Participants will learn what visuals are, how to implement them, and which types to use.	4/3	10:00 - 11:30 AM
An Introduction to Social Stories: How to make them and when		
to use them		
This training will provide a general introduction to social stories/scripts, suggest appropriate situations in which they can be useful, and explain how to carefully choose language and images to enhance the effectiveness of the stories. Examples and additional resources will be provided.	4/4	12:00 - 1:30 PM
Preparing for Community Participation		
*Online only		
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.	4/7	10:00 - 11:30 AM

### REGISTRATION IS REQUIRED FOR ALL EVENTS.

PG. 9 SPRING 2014

# MEDICAL UPDATE

# Earliest Signs of Autism: How New Research Can Have a Wider Impact

Judith Aronson-Ramos, M.D.

As many of you who are familiar with my practice know, I have long been interested in early intervention for ASD. My interest does not stop there; I treat children, teens and young adults. I also have the experience of assisting parents who realize they, also, are on the spectrum and help find tools and resources to guide them. We all know the spectrum is big, broad and growing. Sometimes an article about early signs can be quickly dismissed as it may feel we are becoming immune to new information about ASD.

The new research out of the Marcus Autism Center at Emory University is reason for us all to pause and think. The study's lead author Warren Jones, and his team, follow up on some of the original work of Ami Klin at Yale, who looks at eye tracking and autism. The new research contributes to the prior work in concluding that around age 2-6 months is when the decline in eye contact is first notable. The deficits in eye contact and gaze are measurable by research and correlate also with EEG abnormalities. The interesting and groundbreaking fact here is that the abnormalities are not at birth, but a few months later. Additionally there is not a complete absence of eye contact but an ongoing decline in eye contact and fixation of gaze. Does this provide an opportunity to intervene at the earliest of stages in ways that can impact outcome?

The team's goal was to look at the earliest precursors to abnormalities leading to ASD. The analogy is like treating heart disease preventatively with diet, exercise, and medication before the heart attack happens. If subtle but clear signs of ASD can really be detected as young as 2-6

months can we begin our early intervention process then? Can we aggressively promote engagement, reciprocal interaction, and back and forth gesturing through targeted play and attachment-based intervention?

There is plenty of room for thought here that extends beyond newborns. It highlights the critical role of engagement and looking as a means of developing our social understanding of the world, language and other key skills. Therapists who work with ASD individuals and families are well aware of atypical eye contact -- it is sometimes even an explicit goal in therapy. Yet just training an individual to "look" does not fix the problem or even result in natural gaze and appropriate non-verbal skills. Something deeper is needed to build the capacity to naturally use and sustain eye contact and gaze in social interactions.

What is interesting to me is that the impetus to look, the engagement that underlies our desire to make or avoid eye contact -- this is the piece that may be the deeper key to what is going on. The social brain wants engagement; feedback; contact, and back and forth exchanges -- this promotes learning and reciprocal skills. What may be unique in some of our ASD children is that this "natural" tendency is lacking, so how do we build this capacity? Is there a way tot make connections that can be so hard to acquire later in life?

Hopefully the team at Emory will continue their work and keep looking for practical clinical applications of their findings. In the meantime, this new research is worthy of our attention.

To read the original article published in Nature www.nature.com/nature/journal/vaop/ncurrent/full/nature12715.html

To learn more about Dr. Aronson-Ramos and provided services, please visit: <a href="https://www.draronsonramos.com">www.draronsonramos.com</a>

PG. 10 SPRING 2014



# **Adult Women's Social Group**

FAU CARD is excited to invite adult women with ASD to attend a new social group meeting on the FAU Jupiter campus beginning January 2014. The group will provide the opportunity for women 18 and over to enjoy the companionship and support of your female peers while participating in discussions and activities pertaining to your unique concerns and interests.

Please join us for an informational meeting and enjoy good company and light refreshments.

#### When:

Monday January 6, 2014, from 7:00-8:30 PM

#### Where:

FAU Jupiter Campus, EC 201, 5353 Parkside Drive, Jupiter, FL 33458

**Please RSVP** by calling Noelle Balsamo at (561) 212-4930 or email at nbalsamo@fau.edu for more information



PG. 11 SPRING 2014

# PALM BEACH COUNTY COMMUNITY NEWS



### PEERS® Teen Program in the Community

Over the last two years, the FAU CARD clinical staff have had the wonderful opportunity to be trained and facilitate the PEERS® program in two locations. The program teaches teens with autism and their parents how to make and keep friends in the current social world. We've thoroughly enjoyed the experience of running this ourselves and have been able to train so many professionals in the community as a result. In order to keep up the most effective, evidence-based programs coming to our community, we will be introducing another social skills curriculum at FAU CARD in 2014. Keep a look out for that!

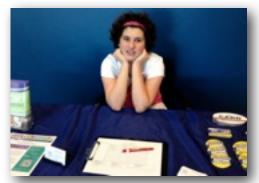
In order to continue to have the PEERS® program in our community and be more accessible to our families, we have partnered with three local agencies to continue this important service. We were able to train and consult with the Slomin Family Center for Autism, Palms West Children's Therapy Center and Palm Beach Behavioral Health and Wellness to fulfill this mission. They will be offering PEERS® with the same model we've been providing at FAU at a reduced fee as compared to most therapy.

Please contact the agency closest to your area if you'd like to attend the PEERS® program with your teen. If you'd like to learn more about PEERS® in general, please visit our website <a href="https://www.autism.fau.edu">www.autism.fau.edu</a> or contact Ali Cunningham, Assistant Director at 561-235-8412 or <a href="https://acunnin5@fau.edu">acunnin5@fau.edu</a>.

# **Grand Opening for New Jupiter Office**

On October 2, 2013, CARD Staff celebrated the opening of the north Palm Beach county office on the FAU John D. MacArthur campus in Jupiter. The open house event had guests enjoying refreshments and conversation while touring the new office space located on the second floor of the Student Resources (SR) Building.

FAU CARD staff proudly exhibited the donated artwork created by Laura and Nick Drake of Stuart, FL. Visitors to the Jupiter office were cheerfully greeted by Laura and Nick's colorful pieces of work displayed throughout the office suite. We are grateful for the generous and creative contributions made by the Drake family and are proud to share our newly decorated walls with CARD families. In



Laura Drake greeting volunteers at the Open House in Jubiter

addition to donating her work, Laura volunteered her time to support the Open House by greeting visitors and providing assistance to CARD staff.

For more information about our Jupiter location, or to schedule an appointment with Noelle Balsamo, clinical support specialist, please contact her at:

Noelle Balsamo 561-212-4930 or nbalsamo@fau.edu. Center for Autism and Related Disabilities 5353 Parkside Drive, Bldg. MC03, Suite SR274 Jupiter, FL 33458 PG. 12 SPRING 2014

# PALM BEACH COUNTY COMMUNITY NEWS

### Behavior Analysis, Inc., Expands Services into Palm Beach County

Behavior Analysis, Inc., is pleased to announce it is now serving children in Palm Beach County. Ms. Nina Malagic, BCBA, has worked and studied with some of the leading behavior analysts in the country and is now head of the Palm Beach program. They expect every child with autism to make progress in their program. They are currently scheduling assessments and therapy. Please call at (561) 325-6070 for more information or to schedule an assessment. They accept most insurance. Visit them at <a href="http://www.behavior-analysis.org">http://www.behavior-analysis.org</a>

# Jupiter Campus Hosts Program on Educating Those on the Spectrum in the University Setting

FAU CARD collaborated with the Master Teachers Program of the FAU College of Arts and Letters and the Office for Students with Disabilities to sponsor the November 7th presentation, *On Educating Those on the Autism Spectrum in a University Setting* by author and award-winning journalist Barbara Fischkin. Fischkin, in addition to being an author and journalist, is the mother and advocate for 26-year old Daniel, who was initially diagnosed with Childhood Disintegrative Disorder at age five. Fischkin shared her journey of advocacy; working with the public schools and now the university to ensure Daniel is educated with his peers whenever possible. She is working with Empire State College of the State University of New York System to develop a university program for young adults on the Spectrum. Fischkin shared her dream that some day her son may also attend college. Daniel currently lives in a group home with three young adults, works at several jobs including one as an organic farmer; he also plays hockey and has a full recreational schedule.



Author and speaker, Barbara Fischkin.

PG. 13 SPRING 2014

# TREASURE COAST COMMUNITY NEWS

# **Support Groups**

# Puzzled Families of Indian River

Puzzled Families is a parent support group that meets to provide support and information for parents of individuals with autism spectrum disorders.

**When:** 2nd Monday of each month from 6:00-8:30 PM

**Where:** Sun Up Center, 2455 5th Street SW, Vero Beach, FL

**Dates:** January 13, February 10, March 10, April 14 **Contact:** <u>puzzledfamilies@gmail.com</u> or find them on Facebook under Puzzled Families of Indian River

# **Community Collaborative Partner**

FAU CARD Treasure Coast would like to say a very special thank you to our Fall Collaborative Partner. Grace Therapies collaborated with FAU CARD of the Treasure Coast to offer the much-needed Parent Support Group in St. Lucie County. Thanks to Grace Therapies and the entire staff for making the parents feel so welcome! The staff at Grace Therapies provided respite for the children so that parents could attend the support group. Thank you to Rhonda, Justin, and Mandy for all your efforts.

# New Afterschool Program in St. Lucie County

Ali's Place is a non-profit after school program for kids with special needs located at Treasure Coast Community Christian Academy in St. Lucie West. Trained caregivers at Ali's Place provide students the opportunity to socialize, participate in skill-building and job-placement courses, and build independence. Field trips are optional for students to participate in. Interns and volunteers from Indian River State College are available to assist children with projects or homework assignments. For more information or for enrollment, call Joann at 772-209-2086 or email her at <a href="mailto:irrox1000@vahoo.com">irrox1000@vahoo.com</a>.

# 7th Annual Okeechobee Family Health and Safety Expo

The health fair will provide information to the community to promote health and safety to residents of Okeechobee through the display of first responder vehicles, health screenings, fun activities and vendor booths, and will have entertainment and giveaways.

Details: Saturday, January 25, 2014 from 9am—2pm at the Agri-Civic Center located at 4601 Highway 710, Okeechobee, FL. If you have questions or need additional information, please contact Sharon Vinson at 863-462-5000 ext. 257, Donny Arnold at 863-634-6464 or Candace Pope at 863-447-9140.

PG. 14 SPRING 2014

# **FAU CARD NEWS**



Greetings! I am thankful to have this opportunity to formally introduce myself to members of the FAU CARD community and its partners. My name is Alison Bourdeau and I am the new Clinical Support Specialist for Martin and Okeechobee Counties.

I moved to Palm Beach County over three years ago, spending the previous twelve years in Miami. I attended the University of Miami and earned a Bachelor's Degree in Elementary Education and Psychology. I currently hold a Master's Degree in Early Childhood Special Education and Marriage & Family Counseling. I am working toward licensure as a marriage & family therapist in the state of Florida. My particular interests are individuals with Autism Spectrum Disorder and the Family Systems dynamic post-diagnosis.

In the past I have worked as a teacher, researcher, counselor, and case manager. I learned a great deal about working with families, school staff, and other members of the multi-disciplinary team. I spent time developing and fostering relationships, and I consider relationship building a critical component of this job. Working for FAU CARD allows me to fully utilize all of my skills, and I consider myself very fortunate to be in a position where my past experiences so seamlessly contribute to my current work.

I look forward to continuing to develop my relationships in both Martin and Okeechobee Counties. I have had excellent experiences thus far, and look forward to new opportunities to share information about FAU CARD and all of the wonderful services we provide to the community.

#### **Board Member Moves**

CARD has new constituency board members slated to join its roster. We're excited to make this announcement when it can be official! Details coming soon! We honor Joe Cardenas for his work on the FAU CARD Constituency Board. Joe was a founding and active member of our board since 2005, is a past chairman, and could be counted on to support CARD unyieldingly. He has been a tireless advocate for autism services for the FAU region and the entire state having traveled to Tallahassee to share his views with the legislature. Joe moves on to serve on the FAU College of Education Board, but we know CARD will always be in his heart and on his mind!



Maryellen Quinn-Lunny presents Joe Cardenas with well-deserved recognition plague.



Judi Donoff and CARD Executive Director, Jack Scott. Judi Donoff is a community leader and generous supporter of FAU CARD and many agencies supporting the autism and human services community. Judi has been instrumental in furthering and improving the quality of life for individuals with Autism and was the Honoree of FAU CARD's 2012 Wings of Hope Event. She too, leaves our board, but we know she will always support CARD in any way she can.

CARD does not endorse specific programs or points of view presented in this newsletter.

PG. 15 SPRING 2014

# **FAU CARD NEWS**



The Annual Wings of Hope Dinner on February 27, 2014, at the Addison, is CARD's biggest annual fundraiser. This year, the event honors a special CARD couple, Tricia and Glen Stein, and will include a cocktail hour, silent and live auction, and full dinner. This seminal event makes it possible for our clinical specialists to continue their important work serving families, professionals and the community across a five-county expanse.

You can sponsor this important event, buy tickets and purchase program ads by clicking on the website below:

#### https://fauf.fau.edu/NetCommunity/SSLPage.aspx?pid=2421

Wings of Hope honorees, Tricia & Glen Stein, and their sons, Levi & Jordan.

Among others supporting this event are The Albert Family, Dr. and their sons, Levi & Jordan. Greg Albert, and his wife Laina. Laina has taken the initiative to provide a professional PR agency to promote both attendance at the event and awareness of the CARD program. The Albert's youngest child, Morgan, was initially diagnosed with Autism Spectrum Disorder at the young age of two. The family was referred to CARD by their physician; and from there they immediately knew they were in the best of hands.

"CARD was so knowledgeable where others were not," says Laina, "They provide a level of services to

families that is unparalleled...and that is a gift. They recommended a course of therapies that allows Morgan to function beautifully in our family and in the world. We now have a child who knows who we are and can feel our love. You cannot ask for anything more with an autistic child." The Albert family was featured in Michael Williams's ongoing Impact 5 television series on Autism; an in-depth, at-home glimpse at how a family has benefitted so greatly from the extraordinary services of FAU CARD. Dr. Albert will introduce the emcee that evening, He is a well-known and respected South Florida plastic surgeon, and she a dynamic business woman; both of whom devote all of their spare time to their two beloved children.



The Albert Family at home.

The Wings of Hope Committee is:

Lloyd Bucher, Chairman, WPTV; Dr. Gergory and Laina Albert; Rhonda Altschuler; Fran and Joe Eppy,; Sonia Kay; Nancy Rhodes; Shelby Rogerson; Lee Rosenfeld; Debra Rosenfeld; David Rossman; Candace Spitz; Glen and Tricia Stein; Nedda Farro Stellmach; Michele Weppner; Barbara Wolk.

PG. 16 SPRING 2014



#### **ASK EPPY**

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With special needs planning, there are **no do overs.** I often hear parents say, "I don't need to do special needs planning yet, my child isn't 18." But there is no guarantee that nothing bad will happen to them before their child turns 18. The good news is special needs planning can't cost another penny of allocation as everyone already allocates 100% of their cash flow. First, let's talk about income. Every dollar of income entering a household goes into one of three buckets: bills, taxes or savings. Next, let's talk about assets and their growth. If you have an asset that makes five dollars of interest there are only three things you can do with it -- spend, reinvest, or put it in a different bucket. So, 100% of all cash flow is allocated, even the growth on your assets. Regardless of income level or assets accumulated, there is never extra cash flow. We must understand this because, there are **no do overs**.

So what issues must we tackle? There are many but the major ones are: the Letter of Intent; principles of guardianship; the life plan; legal documents including a special needs trust; and, proper funding for the special needs trust. A Letter of Intent is the most important non-legal document in special needs planning and can be considered the instruction manual for the next guardian. It provides important personal details such as likes, habits, and quirks. This document can be easily completed and updated as needed. There is simply no excuse today for not having a well-structured and well-prepared Letter of Intent. For a free copy of Mass Mutual's Letter of Intent, please contact us.

When a child is a minor, the natural parent is the guardian and can make all important decisions. However, when an individual turns age 18, they are emancipated as an adult regardless of disability. The issue with guardianship before 18 is that most states have prerequisites to be able to serve as a non-natural parent guardian. Additionally, in order to direct guardianship of a minor, one must have a will. To simplify the process, most states offer a form advocacy, which is less expensive and less restrictive than other options. A letter from the doctor defines the disability, and states that financial, health and living decisions still need to be made by the guardian. Once it is in place, then the successors can be arranged to ensure there is no gap in provided care.

Special needs trusts are designed to protect the benefits and the assets from the \$2,000 rule, which states there is a \$2,000 limit on assets left to an individual with a disability. If the family makes the mistake of bequeathing more, it is likely the beneficiary will lose important benefits until the money is spent below \$2,000 and a five-year look back has been satisfied. The benefits that special needs trusts protect are SSI, Medicaid, and Medicaid Waiver. First-party special needs trusts, also called D4A, are used when the assets belong to the person with the disability and require reimbursement to government entities for all benefits before funds can be released. A preferred option is the third-party trust, which is set up so that assets are assigned to someone other than the actual person receiving the benefits. Understanding how this central piece of a special needs plan works is paramount, as there are **no do overs** 

This brings us to the question of funding sources for the special needs trust. There are two choices -- hard assets that transfer at death or life insurance. Life insurance is much more cost efficient as it can be purchased for pennies on the dollar. How the funds are taxed coming out of the trust is the biggest issue. Irrevocable special needs trusts, like all irrevocable trusts, pay the highest income tax rates. Currently, for \$11,000 or more of income, that number is between approximately 40% and 60% depending on the state. Using products that provide tax preferred or tax-free income is crucial. The biggest goal of the trust is to provide ample net income to the beneficiary to maintain lifestyle and quality of care. This is the peace of mind a caregiver needs.

There are many aspects to a special needs plan. No mistakes can be made. The world of financial planning for people with special needs mandates families and caregivers seek the most professional advice available. You would not think of having someone who has never attended medical school perform surgery on you. Neither should you consider listening to someone who has no training and experience in the special needs arena advise you on planning for the future of your loved one with a disability. Because, after all...you guessed it, there are **no do overs.** 

PG. 17 SPRING 2014

# **FAMILY PERSPECTIVES**

### A Mother's Viewpoint: Transitioning

Cathy Allore

The 18th birthday is a rite of passage for teens as well as a time to celebrate. However, like me, if you are a parent of a teen with a developmental disability, the time to celebrate can also be a time to fear the future. Many questions may run through your mind as your child becomes an adult. For me the questions are addressed below.

#### 1. What happens after high school ends in four years? Will he live with me forever?

Ian is still in high school and has one more year after this one. After high school, his dad, sister, and I have decided that he will attend an adult day-training program and participate in community outings with us and his friends. One year ago, when Ian was 19, I made the difficult decision to move him to a group home. He has excelled and grown in ways I never expected. For years, I would break down instructions in explicit steps, but he showed me how his understanding of language was developing. I recently had him for an overnight visit and he communicated beautifully with me. Instead of going to the kitchen cabinets and pulling out food, he referred to picture symbols to request lunch when he was ready. One year ago this did not happen even on a sporadic basis. I have to admit I sheltered him and protected him, as parents do. However, in doing so, I made him more disabled than he needed to be or truly was.

# 2. He's too old for the pediatrician, now where does he go? What about medical and financial decisions?

I found out that my doctor and his partner see quite a few of the residents at Ian's group home, so they understand the needs of the residents, paperwork, facility needs, and how prescriptions need to be completed for state guidelines. This transition from pediatrician to general practitioner was right for Ian, despite my uncertainty.

# 3. Who will take care of him after I am no longer able? How do I protect him from being taken advantage of?

I also learned about guardianship options and chose Guardian Advocate for Ian. I am the decision maker for all major decisions. I have paperwork from the court and have provided copies to his school, medical providers, and the group home administrative office. The best part of the Guardian Advocate choice is that it restricts decision-making in major categories, but it doesn't declare mental incompetence and can be reversed later if need be. At the time of filing, there is an option to appoint a standby guardian. This is an important time to talk to your family or close friends about who should take this responsibility. Knowing the impact that a sibling with autism will have on your typically developing child's future, it's important that you engage the sibling in a conversation even if it's hard to talk about. Ian's sister, without hesitation, agreed to that appointment.

As your young adult reaches the age of majority, all rights will be passed over to him or her, so the Guardianship option needs to be reviewed and implemented so that no one is able to take advantage. I make it sound like a business transaction but truly, that is the best and easiest way to approach and get through it. There is time for tears after you are done taking care of these important decisions for your family member. Knowing that I've taken the actions necessary to make sure my son is well cared for and that his future is more assured has me breathing easier. Seeing him so happy every time I visit lets me know that I made the best decision for Ian.

PG. 18 SPRING 2014

# **FAMILY PERSPECTIVES**

### The Sibling's Perspective: Ian's Sister

Megan Allore

What I remember most about the birth of my brother is that my dad made spaghetti for dinner while my mom was in the hospital. I barely recall the fact that Ian was born with special needs. Only a few telling details stick out: I remember the shoe party we threw when he finally got his last casts removed after a series of surgeries to correct his clubbed feet. He had a person named Kathy visit him at our house to work on special skills; sometimes she brought me little toys or toothbrushes. I told my kindergarten extended day teacher that my brother had cerebral palsy, which is what he was diagnosed with before we knew he had autism.

I was involved in the major decisions of my brother's life before he was even born. While my parents negotiated over a name for their second child, I advocated as fiercely as a three-year-old could for the name Ethan. What we didn't know is that the name my parents settled on—Ian—would end up being the only name that could possibly fit him. What we didn't know is that my persuasive attitude would carry me to be president of my high school debate team. What we didn't know is that my concern for my new brother would be a critical part of the rest of my life.

I'm a sib. That makes me different than a sibling because a sib has unique concerns and considerations due to their brother or sister's abilities and needs. I had a very direct and intense caretaking role while we were growing up. I changed diapers and pull-ups into his teens, gave baths, administered medication, prepared and fed him meals. Now, I'm less hands on, but my role as a sib doesn't stop just because we're not living under the same roof. Like any typically developing siblings, our relationship has changed.

Through CARD, I've had the opportunity to speak about my experience growing up as a sib. I'm always struck by the reaction from parents to my story. They are hungry for information and advice on how to support their typically developing child. They're worried that they ask too much of him or her. They want to know that he or she is going to be okay in the long run.



PG. 19 SPRING 2014

Thank you!

We also thank the sponsors of our 5K Run: BBT; Chartwells; FAU Campus Recreation; FAU Weppner Center of Civic Engagement and Service; Florida Autism Treatment Centers; Runner's Edge; Stein Family; The Slomin Family Center, and Support for the Autism Spectrum. Also, a big thank you to the Irishmen Pub for hosting our annual golf tournament. We would like to express our most sincere gratitude to Lee and Debra Rosenfeld, Candi Spitz, Michele Weppner, and The World of Beer in Wellington for the fundraiser they held on behalf of FAU CARD. This event was able to raise just over \$2,000 for CARD by donating their second-year anniversary celebration proceeds to us. Special thanks to Lee and Debra Rosenfeld for their tireless efforts and determination that, this year, all event proceeds benefitted FAU CARD. We welcome Lee, Debra and Candi into the fold of FAU CARD volunteers, they have pledged their staunch support to CARD, and we can't wait to see what the future brings!



(from left to right): Maryellen Quinn-Lunny, Candi Spitz, Michele Weppner, Debra Rosenfeld, Jack Scott, Rebecca Rosenfeld

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

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