

### Center for Autism and Related Disabilities - Jacksonville

# CARD-NEWSLETTER

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#### **Constituency Board Officers**

Rom Alderman - Chair
Ron Timonere - Vice-chair

CARD serves Baker, Clay, Duval, Flagler, Nassau. & St. Johns County.

We offer services to family, schools, and community organizations who's lives come in contact with the autism community. CARD also provides services to individuals with vision or hearing impairments or dual sensory impairments.

All CARD services are at no cost to the individual.

## **UF Developmental Pediatric Programs Deliver the Dream**

The UF Developmental Pediatric Center for Autism & Related Disabilities (CARD) recently partnered with the Deliver the Dream Foundation for their annual *Deliver the Dream Weekend Autism Retreat* on April 19th to the 21st.

This once in a lifetime opportunity is offered for families statewide for children with autism spectrum disorder or a related disability. Up to 15 families are invited each year to attend the three-day weekend adventure filled with structured family-centered activities and all lodging expenses, events, and meals at no cost to the individuals. Staff and volunteers are constantly on hand to oversee events and offer respite, relaxation activities, and recreation for all.

The event takes place each year at The Cerveny Conference Center located on 500 beautiful acres in Live Oak's Camp Weed.

When one person in a family is sick, the entire family is impacted and there are very

## **Upcoming Events**

June 07-09 15th Annual Family Cafe

June 17 CARD Summer Academy:

Helping Students with Autism Succeed in Regular

Ed. Classrooms

June 20 CARD Summer Academy:

Positive Behavioral Interventions and Outcomes for Students with Autism Spectrum

Disorders

To be added to the CARD Mailing List email <a href="mailto:anthony.rhodes@jax.ufl.edu">anthony.rhodes@jax.ufl.edu</a>





few organizations nationwide that focus on the whole family unit like Deliver the Dream.

### CARD's Mission

To educate and empower individuals and families throughout the lifespan by providing support, assistance, and awareness within the community; with the goal of optimizing the potential of all individuals with autism and related disabilities.

## Letter from the Division Chief:

As we end another year, the UF Jacksonville CARD program has made significant gains.

Our staff has conducted more trainings, more clinical interventions and more service provisions than last year. The intro CARD 101 is offered every month both during the day and in the evenings. The Drum program is moving forward and the group recently had their 1<sup>st</sup> (of many to come) public performance. The Seasons of Hope Dinner increased from 30 to 50 families. The Fall Festival almost doubled in size and the arrival of the Fire Truck was exciting- when they came, when they roared away to answer a call- and when they came back. The Dunk Tank was, well- a dunking... The Deliver the Dream Retreat was another success with families learning they are not alone and they can be amazing resources among themselves. Our Evening with Santa, Valentine's Party and Spring Fling continued to provide families with the opportunity to participate in social and community events.

The Adolescent and Adult programs with Dr. Tapia and Anne Wilson continued to expand with Breakfast Clubs, Workshops, Support Groups, Internships and Adult Transitions. There were several major trainings, with the highlight perhaps being the whole day learning the iPad applications for Autism.

And our amazing partnership with Walgreen's continued. We could not have the Seasons of Hope Dinner or the Fall Festival without their support. Financially they have been so great, but it is the Walgreen's staff who come out and help with all the events which really makes everything come together. This year CSX volunteers wrapped over 500 presents for the Season's of Hope Dinner. We could never have made it without these volunteers and all the others.

And to our staff- who work evenings until 8pm to allow families to come after work/school hours for visits-who give up weekends to provide support and services and events- what can I say but- thank you. From the administrative support to the clinicians, every member of the Division of Developmental Pediatrics remains dedicated to supporting our mission of serving families.

But, as with everything change continues.

We are saying good-bye to Elisha (Landers) Munago. Elisha is planning on her 1<sup>st</sup> baby and moving to a position at Providence High School. Elisha has been a critical member of our program, and while we are happy for her, we will miss her terribly.

But, there is also good news. Through the efforts, statewide of all the CARDs, including many of our families, the legislature has added \$2.5 million to the CARD Centers overall. In the funding formula developed to distribute the increases fairly, we are anticipating over \$150,000 in additional funding. We are planning to add 2 clinicians, and a part-time Speech/Language Pathologist to our staff.

Fundraising is also a major responsibility, both for our Constituency Board and the Center as a whole. We raised over \$1800 this year in a program honoring Tyler Rounds, an adult with Autism who is one of our most valued employees. These funds are slated to serve as seed money for a run next April during Autism Awareness Month.

All in all it has been an exciting year with progress, improvements and successes.

But, in the end, without each of you, the families who live each and every day with Autism, the

CARD program wouldn't have a mission. You are what makes this Center alive, vibrant and meaningful. And to each of you we say thank you- for

what you live, and how you live each day.

David O. Childers, M.D.

Chief, Developmental Pediatrics & Executive Director of CARD

Center for Autism and Related Disabilities

### **CARD Seasons of Hope Dinner Event**

A chance for families living with autism or related disabilities to have a full, rich holiday experience: That's what staff at the Center for Autism and Related Disabilities (CARD) wanted last year for the 43 families attending the annual Seasons of Hope Dinner event.

Last December the dinner, sponsored by the UF Division of Developmental Pediatrics and the Walgreens Corporation, featured a fully catered meal, pictures with Santa and Mrs. Clause, individualized sacks of presents for every child, and the raffling of copious grown up gifts for the parents.

Many families of children with disabilities tend to shy away from public holiday events. The Seasons of Hope Dinner was specifically designed to create a welcoming atmosphere featuring a cartoonist, face painter, and balloon artist along with sensory play areas and trained professionals providing families with a safe fun environment.

The dinner was held at no cost to individuals or family members.

All toys and games for the event were acquired through community donations by way of the UF CARD Toybank (which receives toys year round for children with autism and related disabilities).

For more information about next year's Seasons of Hope dinner or the CARD Toybank contact
Autumn.Ohnimus@jax.ufl.edu



## **Get Your Plate in Shape**

In an effort to make it easier for parents to figure out how to feed their kids nutritious, balanced meals, the U.S. Department of Agriculture (USDA) has introduced an easy-to-follow food guide icon: *MyPlate*.

The colorful divided plate includes sections for vegetables,

fruits, grains, and foods high in protein. It's an improvement upon the complex and confusing MyPyramid that previously detailed the USDA's dietary guidelines.

With MyPlate, forget about measuring out serving sizes and trying to remember whether a piece a chicken should be the size of a fist or a golf ball. MyPlate's user-friendly, interactive website provides simple messages parents can readily grasp, such as:

- Fill half your child's plate with vegetables and fruits
- Make at least half the grains you serve whole grains, like oatmeal and brown rice
- Serve fat-free or low-fat (1%) milk and water rather than sugary drinks
- When buying pre-packaged foods, choose ones low in sodium
- Don't serve oversized portions

### From Pyramid to Plate: What's Changed?

At first glance, it was difficult to tell how much of each food group should be in a healthy diet. That's where MyPlate really makes meal planning easier. Just by looking

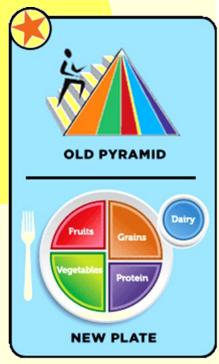
at the icon, you know right away that vegetables and fruits should take up half the plate (with the veggie portion being a bit bigger), and grains and protein foods should take up the other half (with more grains on this side). And with a side helping of dairy, you're reminded that kids also need a serving of milk or another dairy food (like cheese or yogurt) at each meal.

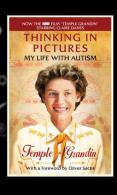
Because MyPlate is a divided plate, no one food group overpowers the others. That's because dietary guidelines encourage eating a variety of foods and discourage "super-sized" portions, which can lead to weight gain and obesity.

Although the food guide icon has changed, the USDA's message about eating well has stayed the same. Kids still need to eat lots of fruits, vegetables, and whole grains, along with lean meats or other forms of protein and low-fat dairy products.

Exercise is no longer included in the icon, but it's still an important component of a healthy lifestyle. Starting at 2

years of age, kids need at least 60 minutes of moderate to physical activity each day. For more information on the new guidelines and interactive activities, please visit <a href="http://kidshealth.org/">http://kidshealth.org/</a>





## **Thinking In Pictures** by Temple Grandin

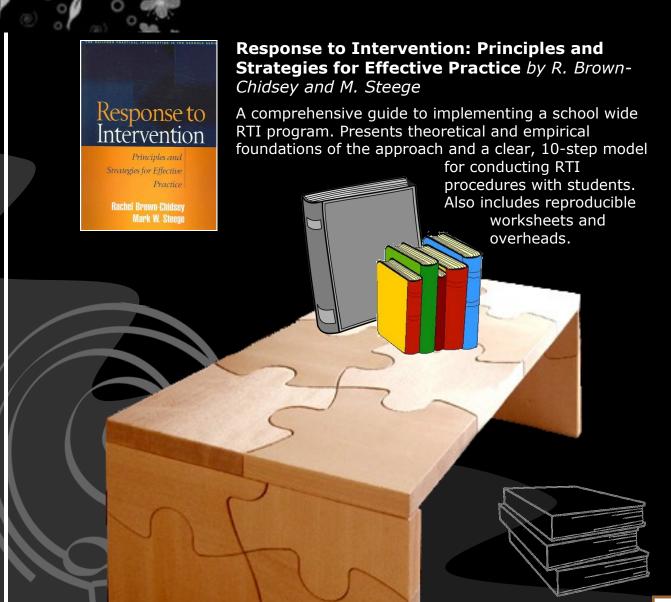
The classic text, reprinted for the HBO film.

Temple Grandin is a leader in the field of animal science. She also lectures widely on autism — because she is autistic.

Writing from the dual perspectives of a scientist and an autistic person, she tells us how autism is experienced and how she managed to function in the outside world.

The new addition includes an updated text and a forward by Oliver Sacks.

(904) 633-0760



www.hscj.ufl.edu/pediatrics/autism

### A Little Child Shall Lead Them

Eight Things My Autistic Kids Have Taught Me by Leo Zanchettin

According to the most recent statistics, approximately one in every one hundred and ten children is diagnosed as being on the autism spectrum.

Those are the numbers, the odds, the averages. So Katie and I must be overachievers. Out of our six children, four are on the spectrum. That's 67 per cent of our kids and 50 per cent of our family. Granted, they're high-functioning, but they show many of the classic signs: narrow focus of interest; strong perseveration; social awkwardness; and a repetitive actions.

When Katie and I first started receiving the diagnoses about three years ago, we did what any normal couple would do under the circumstances: We panicked. Then we grieved. Then we read. Books, blogs, articles—we devoured them all. But nothing can replace what we have learned from simply living with these amazing people. So I thought I'd share some of the things our kids have taught us.

### 1. It's Not All about Autism.

When our kids started getting diagnosed, I began to look at them through the lens of autism. "He's so skinny. Must be the PDD-NOS." "All her struggles at school are because she's aspie." "It must be the autism that has made him a late bloomer." But sometimes a cigar is just a cigar. Maybe he's just a late bloomer. Maybe she struggles in Math because she's right-brained. Don't look at them as your autistic kids. They're your kids, and they happen to be on the autism spectrum. It doesn't define them, and it doesn't have to limit your expectations for them. Autism should never be an excuse.

### 2. Breathe.

I can spend so much time and energy trying to help my kids. Are they getting the right therapies? Have I been aggressive enough in advocating for them? Am I up on the latest research or behavioral intervention? But at the end of the day, my kids are going to be who they're going to be, and I won't be a bad parent if I slow down and enjoy them for who they are. It's not up to me to try to "fix" them. It's up to me to enjoy them and help them become the best versions of themselves possible. They're not "broken," they're beautiful, inspiring children.

#### 3. Say What You Mean. Mean What You Say.

Autistic kids tend to take things very literally. Irony is lost on them, and so are simile, metaphor, exaggeration, and many other figures of speech. It works the other way around, as well. They can be very blunt, not out of a cold heart but simply because they don't get how their words might affect someone else. Learning how to talk with them has made me more straightforward. And, unexpectedly, it has given me a thicker skin.

### 4. Be Gentle.

Any parent of kids on the spectrum knows how sensitive these children can be. Loud noises and raised voices can set them off. Trying to rush them out the door usually backfires. Correcting them too harshly (especially when I'm upset myself) only leads to meltdowns. I've learned the supreme value of soothing tones of voice, gentle rubs on the shoulders, and plenty of lead time before a new activity. You really do catch more flies with honey than with vinegar!

### 5. No One Knows Like You Know.

It never ceases to amaze me how eager teachers, neighbors, and family members can be to offer diagnoses and prognoses. And it shouldn't surprise me, but it still does, to hear a school administrator or a well-intentioned church member tell me how to raise my kids. The world is filled with "experts." But in the end, it's your child, and you know him better than anyone else. Of course you should get advice from real experts. But at the end of the day, you have to go with your gut.

### 6. "How" Is Better Than "Why."

When Tommy was first diagnosed, I felt devastated. Then Emma got her label. Then Michael. Then Mark Damien. But rather than dwell on why my children have these disorders, I've found that it's better to ask how. How do I raise them in a way that affirms their dignity and builds their self-assurance? How do I advocate for them? How do I help their unaffected siblings understand the challenges they face and embrace the gifts they bring? I don't have time to ask the metaphysical questions. There's work to be done, right here and right now, and I can accomplish much more for them by doing that work instead of asking why.

### 7. You Deserve It.

No, not punishment. What you deserve is time for yourself. You work hard for your kids. You worry about them. You pray for them. Your have endless conversations with teachers, insurers, and therapists. It can be easy to burn out. Don't let that happen! Take time for yourself. Find a hobby. Pursue a passion. Reconnect with friends. If you're married, get out of the house with your husband or wife once a week. Even if it's for a walk around the block after bedtime or a joint trip to the grocery store, do it. Keep your horizons big so that you don't collapse in on yourself. Your kids will thank you for it!

## 8. Don't Worry about Getting It Right the First Time.

You'll have lots of opportunities, and kids are pretty forgiving.

Leo Zanchettin lives in Saint Johns, Florida.