

# The Post CARD

*A Publication of the Center for Autism and Related Disabilities  
at the University of Florida/ Gainesville*

Spring 2004

## **CARD UF/Gainesville Staff**

Ralph Maurer, *Executive Director*  
Greg Valcante, *Director*  
Art Wallen, *Associate Director*  
Donna Gilles, *Associate Director*  
Robbin Byrd, *Coord. for Educ./Training Programs*  
Jennifer Flanagan, *Coord. for Educ./Training Programs*  
Cathy Zenko, *Coord. for Educ./Training Programs*  
Ann-Marie Orlando, *Coord. for Educ./Training Programs*  
Caroline Raye, *Community Svcs Coord.*  
Margie Garlin, *Program Assistant*  
Leannis Maxwell, *Program Assistant*  
Kathy Robinson, *Visual Supports Specialist*  
Karin Marsh, *Volunteer Sibshop Coordinator*  
Carole Polefko, *Public Education Coordinator*  
Kurt Clopton, *Computer Consultant*  
Lisa Petransky, *Student Assistant*

## **Parent Partners**

Wendy Baugh, *Marion County*  
Pam Beville, *Citrus County*  
Cheryl Brenner, *Putnam County*  
Sylvia Miller, *Marion County*  
Amparo Perales, *Marion County*

## **Constituency Board**

Julia Arthur, *Vice-Chair*  
Sherry Dupree  
Pat Hawk  
Suz Letzig  
Ruth Lowery  
Diana Mathews  
Bobbi Okesson  
Martin Rifkin, *Chair*  
Shelly Voelker

## **Contact Information**

CARD UF/Gainesville  
PO BOX 100234  
Gainesville, FL 32610-0234  
352/846-3455 or 800/754-5891  
352/846-0941 (fax)  
www.card.ufl.edu

Dear Families and Friends of CARD,

I hope you enjoy our spring PostCARD. We have included some great information on resources available via the internet, two inspiring stories about constituents who have just graduated from high school, and a Sibshop update. As always, we encourage you to keep us informed of events in your communities and keep our newsletter in mind for stories that may be of interest to all our readers. Because of our engagement with Autism Awareness Month activities in April and, of course, maternity leaves, it has taken longer for us to complete this newsletter than we had hoped. We celebrated Autism Awareness Month by hosting a "thank you" luncheon for our donors and supporters. We also placed nearly 350 posters around our region, and distributed autism awareness flyers at local grocery stores and businesses. CARD staff members and Parent Partners had t-shirts made promoting autism and the UF CARD. There has been so much demand for the shirts that we are planning to make them available for sale through our office. Watch for more information on this in our next PostCARD.

This spring and summer bring additional personnel changes to our office. Jennifer Flanagan is returning from maternity leave, Cathy Zenko welcomed her new son, Spencer, on May 5th and will hopefully be back with us sometime this summer. Carole Polefko, our newsletter editor, should be delivering her 4th child by the time you receive this PostCARD. When Cathy returns, Caroline Raye will be retiring in preparation for the birth of her second child. We will all miss her.

All of us here at CARD are most grateful for the support of our families and friends. Please do not hesitate to let us know whenever you have creative thoughts about how we may be of service. We hope you have a great summer.

Sincerely,

*Greg Valcante*

## **SPRING 2004 Edition**

### **Page 2**

Interesting Places to Visit on the Web

### **Page 3-4**

High School Success Stories

### **Page 5**

What are Sibshops?  
Sibshop Update

### **Page 6**

Announcements

# Interesting Places to Visit on the Web

by Carole Polefko

## UF Health Science Center's *The Post*

### Article about Dr. William Luttge

<http://news.health.ufl.edu/post.shtml>

(Click on January 2004 Edition)

Learn more about Dr. Luttge who recently retired from his position as the Executive Director, of the McKnight Brain Institute of the University of Florida. Dr. Luttge was an important person in the development of CARD UF/Gainesville.

## L.I.N.K.S.

### Conference and Training Financial Assistance Fund

[www.fndfl.org/LINKShome.htm](http://www.fndfl.org/LINKShome.htm)

Self-advocates and/or family members can learn more about how to apply for stipends of \$600.00 for an instate or \$1,200.00 for an out of state conference.

## USF CARD's

### Web Based Training Modules

<http://card-usf.fmhi.usf.edu/visum.asp>

Free to Florida residents, modules are intended to provide information about four steps in a positive behavior support process

## On-Line Newsletter from Future Horizons

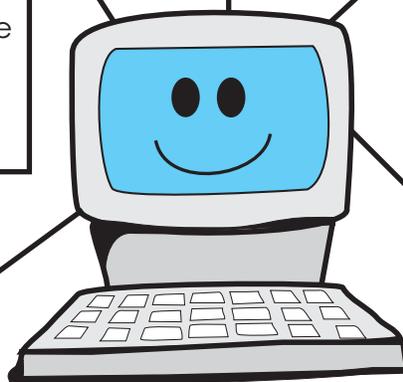
[www.autismspectrum.net](http://www.autismspectrum.net)

Links to recent stories about autism from various news sources, inspirational stories, featured artist of the month

## Temple Grandin's New Website

[www.templegrandin.com](http://www.templegrandin.com)

View Ms. Grandin's schedule of speaking engagements, learn more about her books and videos, and read her latest installment of *Autism - The Way I See It*.



## Dan Marino's ChildNett.tv

[www.childnett.tv](http://www.childnett.tv)

The mission of Childnett.tv is to reach out globally to families, clinicians and educators, connecting them through the internet, to information related to autism and other neurological disorders

Established in 2003, Childnett.tv is an internet access web channel that broadcasts interactive programming 24/7 via the internet. Our lineup includes streaming video related to autism and other neurological disorders.

Families, clinicians and educators can witness the latest therapies and treatments, seminars, as well as personal stories - all for free. The Dan Marino Foundation is funding Childnett.tv, to improve the lives of families around the world. It is our hope the information you see will help ensure every child with developmental disabilities reaches his or her highest potential.

# Beating the Odds

by April Curtis

ORIGINALLY PRINTED IN  
The Palatka Daily News - 4/14/2004  
<http://www.palatkadailynews.com/pages/04142004/odds.html>

Michael Bass, 17, loves high school.

The senior at Interlachen High is on the senior executive board and is in the National Honor Society. He is also involved in the drama club, wanting to audition for the role of Theseus in A Midsummer Night's Dream.

His intelligence is evident. According to school officials, Bass takes honors courses and is in the gifted program. He an honor student, making all "A's" on his last report card, said his mother, Bobbi Okesson. He is ranked 35th in his graduating class of 175, putting him in the upper 20 percent of Interlachen seniors.

It is enough to make any family proud, but what makes each success sweeter is the uphill battle he has fought to reach this point.

He is autistic.

In the 10 years since his diagnosis, Bass has done what many thought he could not: attend mainstream classes and graduate from "regular" school.

"No one thought Michael would have a successful future," said Okesson. "They said, 'Don't hope for that.'"

Okesson knows how far her son has come. At age 3, he could not hold a conversation. He would read the labels on cards and children's books out loud, but not talk to people. "He would grunt and point like a 1-year-old when he wanted something," she said. Okesson began taking him to a round of doctors who gave different diagnoses for what was troubling her son - typical for those suffering with autism, according to Cheryl Brenner, a representative for The Parent/Partner Center for Autism and Related Disabilities at the University of Florida.

Autism is not always recognized, said Brenner. The disability is exhibited by such a variety of symptoms that other diagnoses such as hearing loss, speech problems, mental retardation and neurological problems must be ruled out first.

Bass was first diagnosed with obsessive-compulsive disorder, which he still has, and Tourette's syndrome - a misdiagnosis because of some facial and arm tics, said Okesson. He was diagnosed with autism at age 7, when he was seen by a specialist. It was a relief, said his mother, to finally get a diagnosis and be able to move on to helping him.

Bass has had to struggle for acceptance in a "normal" world, which for those with autism can be a challenge.

His directness is disconcerting. He answers questions literally and factually with little expression, a trait that is perhaps at odds with his expressed future goals.

"I may major in acting or television production," Bass said. "I have a lot of interest in entertainment." Noises bother him and he still has some panic attacks, but he has learned to cope with everyday situations, according to Okesson.

"He is hypersensitive to sound. He used to have a panic attack at fire drills," she said. "The sound still bothers him, but he can cope."

It is an understatement if you knew his past behavior, according to Okesson.

"The Michael you see now is very different from what he was," she said. "There has been huge growth. He is self-motivated and wants to succeed."

The changes began, when in fifth grade, Bass was mainstreamed into regular classes, said Okesson, a process that took her five years of presenting his case to school officials.

"We had to prove he could handle it," she said.

It was not easy, because Bass's behavior in exceptional education was not always understandable.



(continued on next page)

# Congratulations, Josiah!

by Carole Polefko

UF CARD/Gainesville would like to congratulate Josiah Doran, a constituent who was diagnosed with Asperger Syndrome at the age of nine. Josiah graduated from Bronson High School this May with straight "A"s and was included on the Principal's List. In addition to excelling academically, Josiah also participated in a school based vocational training program. Due to his diligent work he received the "Employee of the Year" award. His father reports that Mr. Al, the head custodian, at Bronson High School, enjoyed having Josiah work for him because "he always knew exactly what to do". Due to this training opportunity Josiah has decided that he would like to pursue a job as a high school custodian. He plans to look into the local vocational training program and possibly assisted living.

But life at Bronson High School was not all school work and job training. Josiah also participated in the fun school activities. He took his girlfriend to Senior Prom and Grad Night at Disney World. Congratulations, Josiah, and good luck in pursuing your career!

## **(Beating All Odds continued)**

"When he was in ESE, he would scream all day and not sleep at night," she said. "He would also be self-abusive, biting his hands."

According to Okesson, it was the ESE environment that affected his behavior.

"We knew he was extremely intelligent," she said. "We found a teacher, Ms. Boyette, who was willing to work with him."

The year was a turning point. Bass won his school's spelling bee and was selected as Putnam County's "Dreamer and Doer."

High school has not been a challenge intellectually, but perhaps socially. While Bass said he has "made good friends," they are not exactly friends in the same sense as others mean it.

"He is not invited to sleepovers or the movies," Okesson said, "but everyone knows who he is. I hope when he becomes an adult, he will become a friend to someone."

Bass' maturity level is equal to a 12-year-old's, said his mother.

"He makes a lot of faux pas," said Okesson. "He's still learning common sense."

His disability places him apart from his peers - a realization that bothers him, said Okesson. He wants to fit in, she said.

Part of Bass' autism and OCD is that he finds comfort in keeping things in order, like lists. He keeps lists of household rules on his bedroom wall. He also believes in absolute chronology of events - such as girlfriends, college, marriage and so on. It is an issue that is hard for him to understand, his mother said, when things don't happen in that order for him. It is part of the autistic psyche that is hard to grasp.

He does not drive, nor hold a part-time job, as many teens do. It is a coming-of-age ritual that right now is beyond him. Okesson does not see it as impossible, however. She wants independence for her son.

"I want him to have a life of his own - a house, a job, a car," she said.

"I agree, that's what I want," Bass interjected. "Work is something I must do."

Thomas Bolling, assistant principal at IHS, sees Bass as an asset to the student body.

"He's a good all-around kid," he said. "I wish we had 800 more like him. He is always willing to do whatever is asked of him. He is a joy to have here."

Bass' plans may take him to St. Johns River Community College at first. He hasn't totally decided what to do.

There is time, his mother said. The future remains unwritten.

"I just think it will take longer for Michael," she said. "He writes his own book, so to speak."

It has not been a bed of roses, Okesson said, but there are sweet moments that she records in a diary.

"I still remember the day when he said he loved me and meant it," she said. "He was 7. Each thing is so special."

Bass has brought his family a different view on life.

"As a family, we are close-knit and tolerant," said Okesson. "I think we also laugh more than most - you have to. You've got to appreciate what you have."

# What are Sibshops? / Sibshop Update

by Karin Marsh



As the academic year ends and the summer approaches, I thought it would be a good time to reintroduce the concept of sibshops.

## What Are Sibshops?

Sibshops offer brothers and sisters the opportunity to meet other siblings of people with special needs, share common joys and concerns, and learn more about the implications of their siblings' disability—in a lively, recreational setting.

At a sibshop brothers and sisters of children with disabilities have a chance to meet and talk with other kids whose brothers and sisters have special needs. They have an opportunity to talk about the good stuff and not-so-good parts of having a sibling with a disability.

Brothers and sisters may have feelings that are difficult to express, even to a friend: sadness that a sister is unable to learn things that others take for granted, anger when a brother's problem behavior prevents the family from doing things other families do, or the special pride when a sibling with a disability learns a basic but important life skill after months or years of practice. At Sibshops, siblings will share these feelings with others who truly understand.

Most important, Sibshops are fun! Participants play new games, eat lunches, and make new friends!



## Sibshop Update

Our last sibshop was on 2/28 at the YMCA Camp McConnell. All who attended had a "swinging" good time! We all challenged ourselves on an amazing ropes course. We were then able to reflect on the challenges and rewards of conducting the course and of being a sibling.

CARD has been offering these workshops for the past several years. We feel that it is very important to acknowledge the sibling role and honor them. However, the attendance at these workshops has been dwindling. Unfortunately our sibshop scheduled in May for 5-8 year olds was canceled due to a poor response.

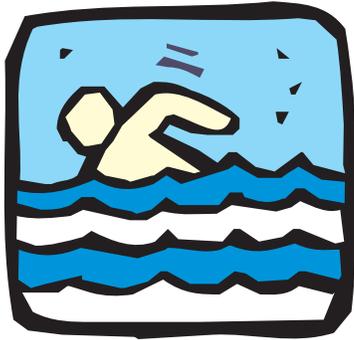
In order to continue these events, we need your help. How can we increase interest and attendance? All suggestions and input are valued and would be greatly appreciated. Please email your thoughts to [kandlmarsh@earthlink.net](mailto:kandlmarsh@earthlink.net). We need to work together to celebrate our brothers and sisters!

Thank you-  
Karin Marsh, Sibshop Coordinator



## Adapted Aquatics Program

The City of Gainesville's Department of Parks and Recreation is offering an Adapted Aquatics Program this summer for children and adults who could benefit from small group instruction.



30 minutes sessions

Mondays and Wednesdays / 9 - 11 AM

Beginning May 17

Northeast Pool Facility in Gainesville

Maximum 3 participants to 1 instructor

Cost is \$12 for 4 sessions

(This covers the pool use only. Trained volunteers from local schools and the University of Florida will be instructing)

There are no age or weight restrictions and individuals with ASD are welcome!

(Also, individuals from outside the Gainesville area are welcome)

NOTE: The time reserved is the slowest time for the pool, before it is open to the general public. A great opportunity for individuals who may be easily overstimulated to come enjoy the water!

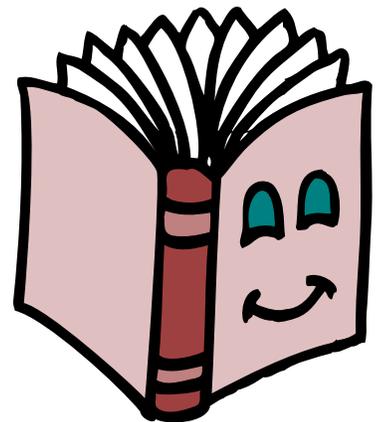
**Please contact Ian Dyar to register for sessions or to get more information.  
352/334-5067**

## Wanted: Used Books

Hello Everyone,

I hope your summers are a fun and enjoyable experience. Some families have asked us to start a book exchange program at the CARD office in Gainesville. Once you have donated books you would be free to take used books home. If you would like to donate your used books that you feel would help another family please contact me.

Robbin Byrd  
byrd@mbi.ufl.edu  
352/846-3700  
800/754-5891 ext.6



### **The Post CARD**

CARD UF/Gainesville  
PO BOX 100234  
Gainesville, FL 32610-0234  
352/846-3455 or 800/754-5891  
352/846-0941 (fax)  
email: cpolefko@mbi.ufl.edu  
www.card.ufl.edu

Go to

**www.card.ufl.edu**

for information about:

- \*current news about autism and related disabilities
- \*support groups
- \*trainings
- and more!