Good News for Kids

100 Day Kits from Autism Speaks Ease the Transition for Families of Children Newly-Diagnosed with Autism
By Arlette C. Suarez, Jr.

It is hard to imagine what it is like for a parent or guardian when their child is first diagnosed with autism. Not only do they have to deal with the initial shock and accept the reality of the diagnosis, but they have to cope with what Cathy Zenko, training coordinator at the UF Center for Autism and Related Disabilities (CARD) puts in one word: grief.

Zenko, who has been working with affected families for almost nine years now, explains that this grief has many cycles, just like the grief of losing a loved one. “The person isn’t gone,” she explains, “but accepting the diagnosis is an extremely difficult process with so many unanswered questions, and a cloudy view of what the future will bring.”

It is exactly this “cloudy view” and unanswered questions that autism centers all over the country work to alleviate. Centers such as CARD at UF (www.card.ufl.edu) and organizations such as Autism Speaks (www.autismspeaks.org) try to provide families as much support as possible close to the time of their child’s initial diagnosis. For many, the most useful support comes in the form of information. Even in this day and age, with Internet search engines allowing a person to be instantly exposed to hundreds of sources of information, the information may be difficult to navigate in that its sources are spread out across numerous sites. And for some caregivers and guardians, the Internet is not even an option. That is why, two years ago, Autism Speaks put together a group of professionals, researchers and a parent advisory committee to form a product that is known as the 100 Day Kit, an extensive resource for families.

Arlette Suarez is entering her senior year at the University of Florida and is completing a degree in English, along with completion of Pre-Med requirements. She serves as a Research Assistant on the Infant Sleep Study in the Division of General Pediatrics.

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Access ON PAR online!
Visit www.peds.ufl.edu; then click on ‘Research’ on the left-hand side. Click on the ON PAR link on the bottom right of the Research page.
Welcome Readers

As we move into the summer months and enjoy the myriad metamorphoses offered by nature, ON PAR is experiencing new growth of its own. In this, our fourth issue, we introduce three new writers and the host of fresh ideas they bring to the magazine. Graduate student and teaching assistant Tiffany Winston reports on the Medical Foster Care program and Ped-I-Care’s relationship to the children it serves. She also shares information on research she has conducted with a group of graduate students in the Public Health program. Arlette Suarez, a senior studying English and Pre-med, reports on Autism Speaks’ 100 Day Kits. She has additionally compiled a listing of online resources relevant to children’s health and vision needs. Senior Katrina Colbourne, who studies Psychology and Family, Youth, and Community Sciences, reports on the outstanding work and personal interests of Rosellen Dedlow, an ARNP in the Division of General Pediatrics. Each of these writers are scholars in their own right, with a host of academic and professional plaudits that serve them well in their various roles. Each contributor, for instance, serves as a Research Assistant on the Infant Sleep Study (led by Drs. Siraj Siddiqi and Lindsay Thompson). We have benefitted from their contributions to the study and are grateful for their work on this publication.

The next issue, our one-year anniversary edition set for release in September 2009, will feature an extensive list of resources for parents, as well as expanded sections on research news and opportunities, leaders in the field, and upcoming events. As always, we value and invite your submissions of news events, publication announcements, and other items of interest to pediatricians, researchers, and educators in all fields.

For the benefit of children,

Heidi Saliba
Editor, ON PAR Magazine

ON PAR Board Members:
Dr. John Nackashi
Dr. Kathleen Ryan
Dr. Lindsay Thompson
Dr. Marilyn Dumont-Driscoll

ON PAR news magazine is edited by Heidi Saliba, Coordinator of Research Programs in the Division of General Pediatrics at the University of Florida, College of Medicine. © 2009-2010 All rights reserved.

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Research News and Announcements

Publications and Presentations
Accepted for Oral Presentation at the 2009 International Health Economics Association:
Disparities in Pediatric Hospice Care
Caprice Knapp, Vanessa Madden, Micrea Marcu, Elizabeth Shenkman, Joe Terza

Parents’ Experiences in Choosing a Health Plan for Their Children with Special Health Care Needs
Caprice Knapp, Vanessa Madden, Phyllis Sloyer, Elizabeth Shenkman

Accepted for Oral Presentation at 2009 AcademyHealth: Effects of an Integrated Care System on Children with Special Health Care Needs
Caprice Knapp, Vanessa Madden, Phyllis Sloyer, Elizabeth Shenkman

IRB Update
Renee Collins has been hired by UF’s IRB-01 as the Coordinator of Research Programs to assist with first-time submissions. She may be contacted at rbcollins@ufl.edu.

News from the 2009 PAS Meeting
UF Researchers in the Division of General Pediatrics presented several posters at this year’s Pediatric Academic Societies’ annual meeting. Drs. Lindsay Thompson, Kathleen Ryan, Sanjeev Tuli, Maria Kelley, Sara Slovin, Ganga Srinivas, and Nicole Paradise Black were first authors of topics such as insurance and satisfaction, developmental screening, MRSA skin infections, residents’ learning styles, tobacco education, newborn education, breastfeeding practices, and quality improvements in resident education.

GCRC Announces Summer Course Dates
UF’s General Clinical Research Center is holding its annual Clinical/Translational Research Course July 15-29, 2009. Classes begin at 1 pm every day. Contact Eve Johnson at 846-1228 or eve11@ufl.edu, or visit http://www.gcrc.ufl.edu/.

Dr. Janet Silverstein participated in a debate on whether pediatricians should advise parents to feed their children organic foods. The next PAS is scheduled for May 1-4, 2010 in Vancouver, Canada. The deadline for workshop proposals is August 14; original science is November 18.

Photos from 2009 PAS: Top right – Drs. Lindsay Thompson and Kathleen Ryan; Middle right – ship at Baltimore’s Inner Harbor; Middle Left – Dr. Janet Silverstein; Bottom left – Dr. Sara Slovin (photo by Dr. Lindsay Thompson).
Tribute to an Unsung Hero:
Celebrating the Contributions of Rosellen Dedlow, ARNP

By Katrina Colbourne

E. “Rosellen” Dedlow has dedicated more than thirty years of service to the nursing profession. As a nationally certified pediatric nurse practitioner, she currently works with the University of Florida General Pediatrics department in the ADHD/Child Development Clinic and the UF Craniofacial Clinic.

Ms. Dedlow developed a passion for serving children with special health care needs (CSHCN) after she cared for her niece, Patty, who was born with low muscle tone and who had to be placed on a ventilator for assistance with breathing. With the growth in her academic career, Ms. Dedlow also focused on becoming a child health advocate, incorporating her desire to serve others into her daily lifestyle.

Current focus:
Providing excellent clinical care to her patients is Ms. Dedlow’s most important priority. However, she is also involved with a few research projects concerning children’s growth and spends a lot of time coordinating with schools, working with parents and the educational system.

Greatest challenges as a nurse practitioner:
In Florida, nurse practitioners face several obstacles that are not present in other states, such as not being able to prescribe controlled substances that patients need and not being able to bill some insurance companies directly. Ms. Dedlow explained it can be difficult to establish independence in an institutional setting and that some nurse practitioners struggle with feeling valued by doctors and other healthcare professionals.

(Continued on next page as ‘Dedlow’)
Dedlow, continued

However, she feels extremely valued by her colleagues in her department, and because she serves underserved populations, she knows that all the children she loves interacting with need her.

Ingredients for success:
Ms. Dedlow states that she is successful in her career because of self-motivation, good organization, communication skills, a passion for kids, confidence, and the ability to make decisions and know her own limits.

I have been working with Ms. Dedlow for past two years and appreciate very much her dedication and caring for the needs of our patient population. She has improved the quality of our service significantly, and she is well-liked by the staff and our patients. – Dr. Siraj Siddiqi

Importance of community service:
As a nurse practitioner, Ms. Dedlow knows that community service is essential. She is always thinking of how she can make children better, helping all instead of one. She has participated in the Stop! Children’s Cancer Fantasy Event, Health and Allied Health Assessment Advisory Committee, and “Operation Disaster Relief” for the victims of Hurricane Andrew.

Goals for the next several years:
As someone who has always been committed to furthering her education, Ms. Dedlow is interested in a new degree that has developed in the nursing profession: the Doctor of Nursing Practice (DNP). This degree has been recommended by the American Association of Colleges of Nursing to replace the Master’s of Science in Nursing as the entry-level requirement for advanced practice by 2015. Ms. Dedlow has been accepted into the Doctor of Nursing Practice Program at the University of Florida for Fall 2009 and will continue in her position in General Pediatrics.

Report from the Field:
Graduate Students Study Campus Mental Health Services

By Tiffany Winston
‘Assessing the Prevalence of Anxiety among the University of Florida Students and their Awareness, Utilization, and Satisfaction with Campus Mental Health Services’
By Tiffany Winston B.A., Chandylen Pendley B.S., Tamara Crawford BSHE, Pachia Dixon PharmD, and Farheen Akbar B.S.

We are a team of Public Health graduate students at the University of Florida who conducted a needs assessment during the Fall 2009 semester under the assistance of Dr. Dennis Thombs, a professor in the College of Public Health and Health Professions. The needs assessment focused on the prevalence of anxiety among UF students as well as their awareness, utilization, and satisfaction with campus mental health services.

While we conducted our extensive literature review, we found that mental health disorders are more frequent among children than many people recognize. Due to the failure to recognize many childhood mental disorders, oftentimes children are not being treated and their illness is carried over into their college years. Therefore, it is not a surprise that college campuses are experiencing an influx in the use of mental health services.

We created a tool and administered it to 194 students including both undergraduates and graduates. We found that 79.4% of students self-reported that they suffered from anxiety during their time at UF. Of those students, only 10.9% have been clinically diagnosed with an anxiety disorder by a health care provider.

(Continued on page 12 as ‘Report from the Field’)
Graceful Growth Along the Road to Excellence: Successes of the Medical Foster Care Program and Ped-I-Care’s Connection to Total Child Health

By Tiffany Winston

When they were first looking to adopt a child, one family in the Medical Foster Care (MFC) program was initially thinking of a healthy child. But after counseling from their adoption agency and consideration of the fact that one of their relatives is deaf, the family decided to consider a child with a hearing loss. “Our daughter had more issues than hearing loss, and we decided this was a great opportunity to provide a child a home regardless of what the issues were,” the mom said. “This has been just a great experience from day one; the process was smooth and now our daughter is doing exceptionally. She has blown away the minds of a lot of doctors who didn’t think she’d be able to do the things she is doing,” she said. As one of the greatest success stories of the MFC program, this family helps support the direction of MFC, which is to “enhance the quality of life for medically complex foster children allowing them to develop to their fullest potential in a home-based program” (Children’s Medical Services, 2008).

History
Identification of the need for foster families to care for children with special needs was addressed in June 1980, which was followed by a five-year pilot study (conducted in Pensacola, Tampa, and St. Petersburg) that ended in 1993. Because of the success of the study, legislature granted funding for the program. Today, there are 17 area offices located throughout the state and the program continues to grow. Each area office has a medical director, registered nurse, and social worker on their team. In the Gainesville office, for example, Dr. Don Fillipps is the medical director; Linda Brown is the RN and Doris Harvey is the social worker. CMS works collaboratively with the Medical Foster Care program by coordinating foster parent recruitment and placements and providing oversight of the program (Children’s Medical Services, 2008).

The Role of Ped-I-Care
Ped-I-Care’s connection to MFC is central to the healthcare of children who are enrolled in the program and also living in Duval County. Debbie Leer, a Senior RN Supervisor with Children’s Medical Services (CMS) in Jacksonville, explains Ped-I-Care as the Integrated Care System for the Medicaid Reform program and Kidcare/Title 21 (SCHIP) program. (Continued on next page)

Tiffany Winston is a graduate student at the University of Florida, pursuing a Master’s of Public Health degree. She serves as a Research Assistant with the Infant Sleep Study in the Division of General Pediatrics and plans to study pediatrics or obstetrics upon completion of her MPH.
“This program works in conjunction with CMS to provide the necessary benefits and health insurance that children need to receive the proper medical services,” she said. With children enrolled in Medical Foster Care, this helps provide the most complete and appropriate level of care.

“Medical Foster Care...protects these children by getting them the best care possible,” said Sharon Surrency, Executive Community Health Nursing Director with CMS. “It provides a very structured program and is a win-win situation for everyone.” Surrency explained that CMS’s goal is to reunite families, and that nurses and social workers coordinate supports to the family to teach them what they need to know in order to properly care for their child. The program was started because of the increasing number of foster children who had extended visits in the hospital due to medical conditions. There were not enough families available who were properly trained to care for the hospitalized children, which drove up medical costs because of extended hospitalizations. In addition to the accruing costs, children were not able to experience the warmth of a nurturing and loving family, an element that is essential for every child to thrive. The role of the medical foster parents is important and crucial to aiding in the successful developments of the child.

Foster parents are required to go through a week-long specific training on how to care for children as well as attend a CPR and First Aid class. Once they are assigned a child for their home, they undergo additional training for that specific child to teach them how to provide their care. A comprehensive in-home record book is given to all parents with instructional information that may be used as a guide.

Over the years, the MFC program has seen an increase in utilization of the program with 644 children served in 2006, 689 children served in 2007, and 744 children served in 2008. In addition to the increase in utilization, a high rate of 65% of children discharged from the program became adopted or reunified with their family. Arguably, this growth is due to well-trained staff and foster families, intensive 24-hour care from the staff, and ongoing improvements of the program which benefit everyone (Children’s Medical Services, 2008).

Debbie Leer along with Deborah Holmes (an MCF Nursing Consultant) and other staff members have all contributed to the program’s positive development by dedicating their time and energy to its creation and by maintaining up-to-date information about its progression. Also, collaboration with the Child Welfare and Community Based Care Program, the Agency for Health Care Administration, and the CMS Network has played an integral role in this program (Children’s Medical Services, 2008).

Overall, MFC has been a growing success. There is still a great need for the services MFC provides. Through the continuous improvements, developments, and possible expansion of the MFC program, more children will be able to benefit.
Online Resources for Parents and Physicians
Compiled by Arlette Suarez, Jr.

GatorSHADE www.gatorshade.ufl.edu/
Dr. Carol Ash, eminent scholar in the UF College of Nursing, started the program after going to her first UF football game. GatorSHADE was started as a curriculum designed for elementary school students aiming to educate them about the hazards of overexposure to the sun. Now, GatorSHADE founders have decided to share their program with the world through an interactive website, designed to make the GatorSHADE curriculum available to both educators and consumers. The website includes educational videos, games and engaging activities.

The SunWise Program (US Environmental Protection Agency) www.epa.gov/sunwise/
Just enter zip code to get the UV Index for your area. The UV Index determines the sunburn potential around noon, and helps people determine appropriate sun protective behaviors. Resources are also available for children, educators, and the community.

Prevent Blindness America www.preventblindness.org/
June is Vision Research month. The Prevent Blindness America website features home eye tests for children and adults and offers a guide to children’s first vision appointments. The Super Specs program provides free tip sheets to help children take care of their glasses. Additional information on sports eye safety, advocacy, and macular degeneration are available via links on the home page.

Children’s Vision Information Center www.childrensvision.com/
This website offers a symptom checklist to help detect vision problems that can hinder school performance. Additionally, you may find a doctor near you via zip code entry. The Links page within the site contains listings of other websites which offer information on vision therapy programs and information on certain vision disorders. Links to children’s interactive learning sites are also available.

Send us Your Submissions! ON PAR is now collecting Community Bulletin Board notices for the August/September 2009 issue. Contact Heidi Saliba at hsaliba@peds.ufl.edu with your public calendar items.

Community Bulletin Board

Free Family Health Fair at Eastside Community Practice – June 27th, 9 am-12 pm
This event will feature free health screenings and fun activities for kids.

Save the Date
The Sebastian Ferrero Foundation’s second annual Noche de Gala is scheduled for Saturday, Oct. 3, 2009. The fundraising event, which sold out last year, will be held at the Besilu Collection in Micanopy, Florida. Visit www.sebastianferrero.org for more details.

Summer Learning at the Library
Visit www.aclib.us for a listing of fun summer learning activities for kids of all ages.

Call for Papers
The journal Epidemiologic Reviews has announced a call for papers for its 2010 theme issue on Epidemiologic Approaches to Global Health. Topics of interest include tobacco use, maternal and child health, nutrition, and economics and equity issues in global health among others. Manuscripts of up to 6,000 words are accepted; visit http://www.oxfordjournals.org/our_journals/epirev/about.html for journal information and a link to author’s instructions. Complete documents are requested for electronic submission during the month of July 2009.
The Ronald McDonald Family Room is located at Shands Children’s Hospital at The University of Florida. This facility serves as an in-hospital retreat for all families with children at Shands as well as for Ronald McDonald House families who cannot leave the hospital due to the fragile condition of their child.

The room includes a small kitchen, telephone, television and computer, plus a private room with sleeping chairs and recliners.

In addition to the Family Room, they operate the Ronald McDonald House of Gainesville located across the street from Shands. Since opening in 1982, they have welcomed 27,500 families, from all of Florida's 67 counties, plus 47 other states, and 34 foreign countries.

Each and every day, the house is filled with families from around the world whose seriously ill children are being treated at local medical facilities. Dedicated staff and volunteers handle the details of everyday life so parents may focus entirely on the needs of their children.

**Hours of Operation:**
Open 24 Hours a Day, Seven Days a Week, Including Holidays

The Ronald McDonald House and Family Room is an independent 501 (c) (3) with a local Board of Directors. They must raise 100% of our operating and program expenses through donations from businesses and individuals. All funds raised help offset the costs of operating our House and the Family Room.

Our Family Room is in need of your help. We are currently looking for volunteers.

Contact Hanan Bilal at 352-374-4404, ext. 225 or email at hbilal@rmhgainesville.org if interested in volunteering.

**Will You Help Us Help Our Families?**
In the Research Spotlight: 
Profile of Carolyn Carter, MD

Dr. Carolyn Carter, Assistant Professor in the Division of General Pediatrics, holds numerous research interests and enjoys collecting and analyzing data. She is currently involved in an obesity study with Dr. Marilyn Dumont-Driscoll; additional work includes participation in the Pediatrics After-Hours Study. “I’ve always had a fondness for PAH and think it’s a very good program,” Dr. Carter said.

Goals and interests: “It’s my goal to conduct meaningful research to benefit people. Research can make you think harder about certain things. For example, with obesity, talking about BMI makes me more aware that it needs to be documented and addressed, whereas if one is not involved with research, you may not think about the particulars. When you read an article you tend to look for those things in your own patients.”

Words of advice: “For budding researchers, carve out the time. This will benefit the patient groups and the researcher. It’s so easy to just be in clinical practice; it’s much more difficult to juggle things when you’re a researcher but in the end it’s worth it.”

She is working with Sheila Eyberg, PhD (of Clinical/Health Psychology) on a project in which was accepted for publication in The Journal of Psychology (2008). Dr. Carter additionally conducted a study with Deb Ringdahl (of Pediatric Neurology) on cerebral palsy. They wrote a chapter that will be published in the book Pediatric Neurology.

Calling all writers and photographers!

Would you like to see your work in print? Do you have a photo of an adorable child that you would love to share with the world?

Send your submissions to hsaliba@peds.ufl.edu for publication in the August/September 2009 issue of ON PAR.

It’s our one-year anniversary and we’re looking to include as many voices and faces as possible!
We have completed numerous fundraisers that have brought in nearly $35,000 toward our goal. We will need an additional $65,000 to complete the construction project at the 2100 NW 53rd Avenue site.

Thanks to the generosity of so many, we have survived the past two months and are beginning to look forward. Each day is getting better! We

Ways to Help Now

Donations of gift cards for distribution to victims for items we kept in our pantry, preferably in $10-25 increments
• Food Stores (Publix™, Winn Dixie™, Ward’s™, Hitchcock’s™)
• Household Supply Stores (Wal-Mart™, Target™, Kmarts™)
• Gas Stations (Kangaroo™, BP™, Citgo™).

Cash donations to support the rebuilding efforts
• While the agency had insurance, it will likely cost more to rebuild than what the coverage will provide. We anticipate that the rebuilding efforts will require us to raise approximately $100,000 to replace the materials lost and to ensure that the building has adequate security to meet the agency’s needs. Thanks to many of you in the community, we have a start on this!

Thrift store support
• Continue to shop and donate to the thrift store. This valuable aspect of our services allows victims to access community donations for free and provides a small revenue stream to support agency efforts. Items can be dropped off at 2131 NW 6th Street, Tuesday through Thursday from 10 a.m. to 5 p.m.

The store is open Monday through Friday from 10 a.m. to 5 p.m. Larger items may be picked up by our staff with prior arrangement; call Barbara at 379-3133.

Our Timeline:
May 11, 2009: Demolition completed
May 15, 2009: Formal announcement of the contractor for the project
June 2009: Site planning and community meeting process
September 2009: Groundbreaking - watch for invitations to this big event
January 2010: Grand re-opening - look for announcements and join us

Throughout the process there will be ongoing fundraising and sponsorship opportunities starting at the $25 level. Please feel free to contact us by email or by phone at (352) 377-5690 and ask for Theresa.
100 Day Kits, continued from page 1
In addition to providing a valuable week-to-week plan for the first 100 days following diagnosis, the kit includes clear answers to leading questions, detailed outlines of what to expect, tips for specific family members, information on where to start with treatment, and pointers from experienced families. The kit is available free of charge via the Autism Speaks website, and it includes a local resource list specific to each family’s location. This March, the group celebrated the one-year anniversary of offering the free kit, and they are happy to announce that 3,135 have already been mailed out nationwide.

Sarah Murray, the Autism Speaks Community Manager for north central Florida, explains how the kit even helped her when she first started working with the organization. “All kinds of terminology was being thrown at me,” (which is similar to how some parents have reported feeling following their child’s diagnosis) “so I printed out the kit’s glossary and it was an amazing resource.” The detailed glossary is found at the end of the 100 Day Kit. Now, Murray says, she prints out extra copies and hands them out at autism events throughout the state.

The glossary is only one of the many wonderful things the kit offers, and centers such as CARD at UF have begun to include it as one of their main support tools for families. When asked about the kit, Cathy Zenko eagerly responds that she loves the resource. She explains that it gives the parents a plan to follow in small, ‘do-able’ steps, broken down day-by-day. According to the parents she’s talked to, “...in the beginning, day-by-day is how they had to be.”

Report from the Field, continued from page 5
Among the students assessed, only 8.8% knew where all of the campus mental health services were located and 17% reported using at least one of those services. The majority of students reported they were satisfied with the services (44.2%), while many still reported they were unsatisfied (26.4%). The remainder reported feeling either neutral or uncertain regarding their satisfaction with the services (29.4%). Our findings will be presented to our stakeholder, the Director of UF’s mental health services, in hopes that they will be able to utilize our results. We believe that future endeavors should focus more on increasing awareness of childhood mental illness to prevent untreated illnesses from carrying over into the college years.

References from Medical Foster Care Article, pages 6-7
- Children’s Medical Services (2008) Medical Foster Care. Retrieved April 22, 2009 from website:
  http://www.doh.state.fl.us/AlternateSites/CMS-Kids/providers/fostercare.html.
- Information and explanation of MFC office structure provided by Sharon Surrency.