

NISONGER NEWS

OSU Nisonger Center

Volume 2, Issue 2

Consumer Advisory Committee gets update on Director search

The CAC plays a critical role in the overall governance of The Nisonger Center. By federal law, at least 51 percent of the CAC membership (see list below) must include consumers with intellectual or developmental disabilities (IDD) or their family representatives.

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On Oct. 29, 2007, Interim Director L. Eugene Arnold, MEd, MD, provided The Nisonger Center's Consumer Advisory Committee (CAC) with an update on the search for a permanent Nisonger Director.

As context for the search, Arnold discussed the basic philosophy of University Centers of Excellence on Developmental Disabilities (UCEDDs). We maintain high-quality training programs, provide clinical services, develop innovative service programs, conduct a broad program of research, and provide consultation and technical assistance to governmental and community agencies.

The Director position description was written with input from Nisonger staff, the community and the College of Medicine. It

has been posted on the AUCD and Nisonger websites and distributed to professional listservs. Quoting from the final description,

"The successful candidate should have a demonstrated record of accomplishment in education, service and scholarship in the field of IDD. Previous leadership experience within an interdisciplinary teaching and multidimensional program is essential, and previous experience within a UCEDD is highly desirable. The successful candidate must hold a doctoral or terminal degree and have a record of accomplishment to support an academic appointment at the rank of tenured professor. The Director will be responsible for the overall programmatic qual-

ity and financial management and will provide leadership for innovation, strategic growth and expansion of the programs within the Center, and its collaborations outside."

The Nisonger Center Leadership Group suggested 24 potential candidates from various disciplines, who received personal invitations to apply. Ads are being placed in the following journals:

- *Chronicle of Higher Education*
- *American Journal on Intellectual and Developmental Disabilities*
- *APA Monitor*
- *Journal of Developmental and Behavioral Pediatrics*

Applications will be accepted until February 1, 2008. **NN**

Nisonger Center Consumer Advisory Committee members

The following are members of the Nisonger Center Consumer Advisory Committee (CAC):

Marge Barnheiser – Family Rep & Exec Dir, Down Syndrome Assn of Central Ohio

David Beversdorf, MD – Asst Prof Neurology, OSU Medicine

Brenda Jo Brueggemann, PhD – Assoc Prof, OSU Humanities

James Bryant, MD – Bureau for Children with Medical Handicaps, Ohio Dept of Health

Pat Cloppert (observer), Family Rep & Nisonger Center staff

Charles Dillard – Consumer

Karen Hughes – Chief, Div of Family & Community Health Svcs, Ohio Dept of Health

Rebecca Jackson, MD – Prof & Assoc Dean, OSU Med Admin

Michael Kirkman – Exec Dir, Ohio Legal Rights

Patrick Lanahan – Deputy Dir, Ohio Dept of MR/DD

Amy Shuman, PhD – Family Rep & Prof, OSU Humanities

Patty Makowsky – Consumer
Peggy Martin – Family Rep &

Ohio Dept of MR/DD

Jed Morison – Superintendent, Franklin County Board of MR/DD, CAC Chair

Sonya Oppenheimer, MD – Exec Dir, Div of Developmental & Behavioral Pediatrics

Kim Oyer – Family Rep & Nisonger Center staff

Manuel Tzagournis, MD – Family Rep & Faculty Emeritus, OSU Med Admin

David Zwyer – Exec Dir, Ohio DD Planning Council **NN**



OSU Nisonger Center

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The RUPP group is currently accepting participants with autism spectrum disorders for four different clinical trials. The following clinical investigations are under way: (a) mecamylamine (Inversine) for core symptoms of autism, (b) fluoxetine (Prozac) for repetitive behaviors, (c) melatonin for sleep disturbance, and (d) aripiprazole (Abilify) for irritable behavior (mood swings, tantrums, yelling/screaming, aggression). A study of low-dose risperidone (Risperdal) for irritability is planned to start soon. Please visit <http://psychmed.osu.edu> or call 688-3848 for details.

The Ohio State University Nisonger Center

A University Center for Excellence in Developmental Disabilities

The mission of Ohio State University Nisonger Center is to work with communities to value and support the meaningful participation of people with disabilities of all ages through education, service and research. The Center provides assistance to organizations, families and service providers to promote inclusion of people with disabilities in education, health, employment and community settings.

The Nisonger Center was founded in 1966 as an interdisciplinary program of The Ohio State University. The United States Administration on Developmental Disabilities has designated Nisonger Center a "University Center for Excellence in Developmental Disabilities (UCEDD)." L. Eugene Arnold, MEd, MD, Professor Emeritus of Psychiatry, is serving as Interim Director while a search is under way for a permanent Director. For more information about The Nisonger Center, contact Maureen Meck at meck.1@osu.edu or 614-292-8365.

Nisonger Center's Online Orientation Program fills training gap

Five years ago, former Nisonger employee and self-advocate Ken Campbell noticed that many employees of Ohio's 88 county boards of MR/DD were not meeting a statutory requirement to fulfill an orientation program covering 12 specific areas. Rural counties that hire few workers found it especially difficult. He worked with former Professor Johannes Rojahn and then-Nisonger trainee Jim Wiltz to develop the new program.

They got the word out, and new employees across Ohio began to enroll. Ken died recently after a long illness. One of the many legacies he leaves behind is Nisonger's Online Orientation Program.

Currently taught by Jillian Ober, the Online Orientation Program is a two-week distance-learning course avail-

able to people throughout Ohio on a monthly basis. The program is endorsed by the Ohio Association of County Boards of MR/DD for new employees. It's also appropriate for employees of private providers and anyone who wants to know more about the field of IDD. We have trained hundreds of people, including beginners on the computer, located in over 100 Ohio towns and cities. The Online Orientation Program has these advantages:

- Flexibility: Employees can participate at home or at work
 - Lower enrollment costs for many counties
 - Quality control with testing
- Students learn about many types of developmental disabilities and the various

services and supports provided to people with IDD. The comprehensive course also covers historical events, laws on abuse and neglect, and important information about today's standards of practice. The course involves a considerable amount of copyrighted online reading material as well as two quizzes and two "office hours" or online chat sessions. Chat sessions give students the opportunity to interact with other new employees in the Ohio MR/DD system as well as the course instructor.

Students receive a certificate of completion once they successfully complete the course.

For more information about the Online Orientation Program, contact Jillian Ober at 247-6392 or ober.7@osu.edu. **NN**

More than 200 attend Williams Syndrome Regional Conference

The 2007 Williams Syndrome Great Lakes Regional Conference was held on Saturday, Sept. 29, 2007, in Columbus at the Holiday Inn Ft. Rapids Waterpark Resort. More than 200 people attended.

The children with WS and their siblings were looked after by 23 childcare workers, most of them graduate students at OSU. While the children were splashing in the water park and the adults with Williams syndrome were “chilling” in the lounge and game room, the parents were learning and sharing ideas with the guest speakers.

Guest speakers included Dr. Carolyn Mervis, Dr. Colleen Morris and Dr. Paige Kaplan, all internationally recognized experts in Williams syndrome.

Program director Dr. Marilee Martens said, “We were also thrilled to have Dr. Annemarie Sommer from the Nationwide Children’s Hospital join us on the WS panel.”

Additional expertise came from Dr. Tom Fish and Dr. Margo Izzo from the Nisonger Center; David Zwyer, Director of the Ohio Developmental Disabilities Council; Terry Monkaba, Executive Director of the National Williams Syndrome Associa-

tion; Michelle Self, advocacy specialist; Lisa Portune, Great Lakes Regional Chair; and Tonya Corso, music therapist.

The topics included up-to-date information on guardianship, medical issues, genetics, developmental issues, gynecological concerns, sibling concerns, music therapy options, and education and transition supports.

For more information about Williams syndrome, see www.williams-syndrome.org.

Contact Dr. Marilee Martens at 688-3112 or martens.22@osu.edu. **NN**



The **Williams Syndrome Clinic** has served clients from Columbus as well as Michigan and Illinois. This multidisciplinary clinic is a joint effort of The Nisonger Center and the Nationwide Children’s Hospital.

Contact sherry.feinstein@osumc.edu or 247-7190.

Nisonger ECE collaborates with OSU Child Care program

Nisonger ECE has expanded its Early Intervention Program by providing services to 12 children at the OSU Child Care Center. Children identified under Part C are able to receive early intervention services and child care at the same location. Debbie Wyatt, early intervention specialist, coordinates the services provided by occupational, physical, speech and vision therapists. The project

follows an itinerant model. Children may be enrolled as early as 6 weeks and continue to receive services until age 3.

The project was funded by the Franklin County Board of MR/DD. The OSU Child Care program is accredited by NAEYC and exceeds state and national standards for early care and education. Deb Schenerlein said, “It is a pleasure for the Nisonger ECE to collaborate

with such a distinguished program.” Requests for enrollment in the program go through a Franklin County Home Base specialist. Parents of Part C children do not have to be university employees to qualify for enrollment. Services are provided year-round with no break during the summer months.

Contact Deb Schenerlein at 292-9605 or schenerlein.1@osu.edu. **NN**



Mark your calendars for these upcoming events

Nisonger new hires since May 2005 take 2 mandated safety training programs:

- EOEP (Emergency Operations & Evacuation Plan)
- HAZCOM

Current Nisonger employees only need to take HAZCOM.

Note these other events:

- YATC seminar on how Dr. Martin Luther King, Jr., viewed disability & how other cultures view disability, Feb. 22, 2008, Rm 131 Hitchcock Hall.
- Ohio Transition Weekend, April 11-12, 2008, University Plaza Hotel, 3110 Olentangy River Rd; deadline to apply is Feb. 8, 2008. See Dr. Tom Fish, fish.1@osu.edu or 292-7550.

- ADA-Ohio Multiple Perspectives Conference, April 23-24, 2008, Blackwell Hotel Conference Center
- Ohio Rehabilitation Services Commission (RSC) Gateways V Conference, May 5-6, 2008.

See other news and events lists at OneSource; use your OSU Medical Center ID to log in. **NN**



Send notices of upcoming events to NISONGERNEWS editor Vicki Graff by email at graff.42@osu.edu. Each quarterly issue will appear approximately six weeks from the end of the calendar quarter (May, August, November and February).

NISONGERNEWS

Nisonger welcomes Young Adult Transition Corps members



Karla, Alisha (LEND trainee) and Molly with Women of Aspirations



Kelly painting faces at the Next Chapter Book Club Monster Mash

YATC is committed to the inclusion of members, participants and volunteers with all levels of ability.

If you've noticed some enthusiastic new faces at the Nisonger since September, you've most likely encountered YATC-Ohio!

Young Adult Transition Corps (YATC) is an AmeriCorps program of the OSU Nisonger Center. It is committed to improving the quality of life for youth with disabilities who are transitioning from school to adult life through activities that promote community service, community access and social skill development.

AmeriCorps is a network of local, state and national service programs that connects more than 70,000 Americans each year in intensive service to meet our country's critical needs in education, public safety, health and the environment. It's a program of the Corporation for National and Community Service, an independent federal agency promoting service opportunities for Americans of all ages and abilities.

Since their arrival, YATC members have offered their time and skills to a variety of programs, including Aspirations, the Next Chapter Book Club, P.A.L.S. (Partners Achieving Learning and Support for young adults with Down syndrome), Friendship Connection, Columbus State Community College Certificate Program, Community Connections, Way-to-Work E-mentoring and monthly Fun O'Rama activities.

YATC members collaborate with high school students in Special Education classrooms to develop service learning projects that will demonstrate the benefits of community service for young people with disabilities. The Upper Arlington High School class is throwing a holiday party for the residents at Westminster-Thurber. The Westerville North High School class raised over \$100 to buy gifts for a young person. The class at Gahanna-Lincoln High School adopted a family and is

running a school-wide toy drive for the holidays. The class at Dublin-Jerome High School will start a service project at an animal shelter in January.

Here are the 10 YATC-Ohio members:

- Benjamin Bossley
- Scott Brown
- Molly Edwards
- Kelly Ferrell
- Brandon Hixson
- Hillary Jones
- Karla Kmetz
- Sarah Priest
- Greg Roth
- Nick Ryan

Dr. Tom Fish is the program advisor and Jillian Ober is the program director. Jerra Knically is the program assistant.

Contact Jillian Ober at 247-6392 or ober.7@osu.edu. For details, see their website at www.YATCOhio.org. **NN**

Arnold undertakes initiatives as Interim Director



L. Eugene Arnold, MEd, MD, Interim Director

When Dr. Gene Arnold was named Interim Director of The Nisonger Center, he stated that his goals were "To maintain the momentum of the center, nurture esprit and teamwork, continue community collaboration, and above all, facilitate speedy recruitment of a permanent Director."

The CAC story on page 1 gives an update on the last of these goals. To meet the others, Dr. Arnold has undertaken several initiatives to share decision making and establish more transparent governance policies. A consultant recently recommended such policies, which will facilitate the transition to the new permanent Director.

One of the major duties of the Director is to serve as Principal Investigator for the Administration on Developmental Disabilities (ADD) grant that funds many of the Nisonger's programs; another is to maintain the core UCEDD functions.

Arnold's strategy is a team approach. He has formed an Executive Committee consisting of the following people:

Michael Aman, PhD – Assoc Dir of Research

Daniel Coury, MD – Medical Director

Margo Vreeburg Izzo, PhD – Assoc Dir of Community Collaboration

Maureen Meck – Administrative Manager

Edward Sterling, DDS – Assoc Dir of Internal Affairs

The Executive Committee meets bi-weekly to monitor the project's progress toward meeting its objectives and budget.

Bi-weekly meetings with all faculty enable faculty and staff to be fully aware of the center's programs and activities.

Arnold also has formed a 17-member Leadership Committee whose purpose is to promote communication among the faculty and staff and wide participation in carrying out the mission of the center. **NN**

Peggy Porter Award: Thanks for dedication of direct service staff

At the October conference of the Ohio Provider Resource Association (OPRA), **Pat Cloppert**, parent representative on the Consumer Advisory Committee, introduced the Peggy Porter Award. As most people in the Nisonger community are aware, Pat is the parent of an individual whose home was engulfed in flames and whose caregiver perished as a result. The first Peggy Porter Award will be given at next year's OPRA Conference. These comments are reproduced from ODMRDD *Pipeline* newsletter, Nov. 14, 2007; Vol. 1, Issue 22 (Thanksgiving issue). **NN**

Thank you to the Ohio Provider Resource Association (OPRA) for this opportunity to share my thoughts on the initiation of the Peggy Porter Award.

It's a cliché to say "It's not a job, it's a calling," but that was exactly the attitude Peggy Porter had towards her care of my son, John, and Brenda Braithwaite's late son, Tony.

Peggy had been married and had been pregnant several times, once with twins, but she never carried to term. She told me that she decided that caring for our sons was part of God's plan for her. While this belief was certainly paramount in shaping her exceptional approach to caring for my son, there were other characteristics she possessed that also made her an outstanding caregiver. Peggy brought a number of notable strengths with her to this task.

Peggy had been the director of housekeeping at several large hotels before seeking what she thought might be a less stressful job environment. The keen observational skills that noticed an extra washcloth was missing also meant she picked up the sometimes subtle cues given by individuals with limited ability to communicate.

She paid attention to the details

In the weeks before our sons moved into their Creative Housing home, she watched what Brenda and I fed them, asked where we bought their clothes, what they liked to wear, picked up on what was appropriate for various family functions, saw how and when we prepared their meals. She accompanied us to medical appointments and then often took the young men by herself to doctors' appointments.

After they moved into their home, she alerted me and John's then pediatrician to the need for his hernia surgery. She noticed that the medication from his dermatologist had the same label, but that the pharmacy had given out pills with a different color – a mistake that meant an unintended dosage.

When John moved on to our family physician, he was very impressed by her involvement with John and Tony and told her what a great thing he thought she was doing for our young men.

A former professional seamstress, Peggy worked to decorate their home as if it were her own. She covered chairs and made draperies. She shopped for knickknacks and wall hangings. She told me when John's bedspread looked tired, although I strongly suspected that the "tired" part was that she was tired of looking at it!

We had different cultural backgrounds, and hers was a bit more direct. I came to value that, because when she gave you a compliment, you knew she really thought you deserved it. My hus-

band Fred, Brenda and I would sometimes go to Peggy's 3rd or 4th of July parties. We were made as welcome as the many family members and friends she always seemed to entertain. Her hospitality meant her house was the gathering place.

She was a superior advocate

I'm an only child. After four or five years with our sons, when Peggy left me a message at home, my husband would say, "Your sister called." We developed quite a bond in our common focus.

Sometimes, she was a more ardent advocate than I was. Sometimes she advocated to me. I have seen that in one or two providers since then, and have come to appreciate the kind of courage that it must take in that position to say, in effect, "Have you thought this through?" "Are you sure your son is still the person who would want this done this way?" Sometimes it is merely a question of a misunderstanding between two people, but sometimes it is taking the risk of challenging a family's opinion in the interest of the consumer. I have come to respect that greatly.

And,

Even if we don't agree, the direct care provider who will advocate to me for my son can certainly be counted on to look out for him should the unanticipated happen.

This litany of praiseworthy characteristics pales in the face of the circumstances that took Peggy from us. She gave that "last full measure of devotion" with

courage that I don't know that I have and pray that might never be tested. If she wanted to get out of that house as the smoke and heat enveloped them, she certainly could have done so. She knew Tony's health was not good and John's coordination was very poor, so she stood her ground to protect them. What set her apart was not only her professionalism, but her love for those who couldn't defend or protect themselves.

Brenda and I had so incorporated her into our thoughts that for weeks afterward we would look at something or hear something and think we must tell Peggy, she would like that or find that amusing, or want to go see that. Now our sister sees whatever she wants to see and knows what we will never know while we are on Earth.

May this award inspire other direct care professionals to exemplify those qualities of compassion and caring above and beyond what could possibly be expected.

As her minister nephew eulogized his Aunt Peggy,

"Greater love hath no one than this: that she lay down her life for her friends."

Thank you again – *Pat Cloppert*

"Greater love hath no one than this: that she lay down her life for her friends."

NISONGER NEWS

Dr. Mulick and Nisonger students speak at autism symposium

Pat Cloppert was recently elected president of the Governing Board of the Ohio Coalition for the Education of Children with Disabilities. She is also president of the Central Ohio Chapter of the Autism Society of America, a regional organization Pat represents on the Executive and Governing Boards of the Ohio Coalition.

Ineffective or even dangerous fad treatments for autism seem to be growing more pervasive as autism diagnoses grow.

"Developmental disabilities like autism are a magnet for all kinds of unsupported or disproved therapies," said James Mulick, professor of pediatrics and psychology at OSU. Mulick chaired a symposium on "Outrageous Developmental Disabilities Treatments" Aug.

20 in San Francisco at the annual meeting of the American Psychological Association. The symposium included presentations by several of Mulick's students at Nisonger who participated in a graduate seminar on fad treatments in autism.

"There's no cure for autism, and many parents are willing to believe anything if they come to think it could help their child," Mulick said.

Tracy Kettering, a doctoral student in special education at OSU, said a Google search for the phrase "autism treatment" yields more than 2.2 million matches. "But very few of these treatments have any evidence to support them."

Other presenters at the symposium included OSU graduate students Anne Snow, Cristan Farmer, Megan Norris, Andrea Witwer and Jill Hollway. **NN**

Welcome new hires! (July, August, September)

Jeff Siegel started Sept. 25 as part-time program coordinator for Aspirations. Last year Jeff was a LEND Trainee and received his Masters in Social Work in June 2007. He holds bachelor degrees in education and music. Jeff has served as Cantor of Congregation Beth Jacob for 15 years and directs Jewish programming and religious services for Shalom houses (group homes for people with intellectual disabilities). Jeff has had extensive experience as an educational and youth director. He co-facilitates a Next Chapter Book Club in Columbus and participates in program development. Jeff is married and has a son and a daughter.

Chris Watts started Sept. 17 as a Behavior Support Specialist with the Adult BSS program. She earned a BA in anthropology and sociology from the College of Wooster and continued her education at Cincinnati State. She previously worked for the Franklin County Board of MR/DD and the Pickaway County Board of MR/DD. Chris plans to get her Masters in Social Work from OSU. She enjoys running, reading and playing volleyball.

Beth Wilmer started on Sept. 10 as a Behavior Support Specialist in the Adult BSS program. Previously she worked at Goodwill Columbus for 5½ years as a case manager in the PACE program. Beth holds an AAS in Occupational Therapy Assisting from Cincinnati State and a BS from Francis Marion University in Florence, S.C. She plans to pursue a graduate degree in Social Work at OSU. Beth is married with 2 dogs and enjoys running and reading in her free time.

Deborah Wyatt started Aug. 22 as early intervention specialist for Nisonger ECE. She works with infants and toddlers at the OSU Child Care Center in the morning and teaches an infant/toddler class at McCampbell Hall in the afternoon. She first worked at Nisonger years ago after completing her MA in special education. She has since taught for public schools in Columbus and Worthington. Debbie holds certifications in birth to three and preschool special education. She is married and has two sons.

Karin Xander started Aug. 6 as part-time dentist assistant at the Johnstown Rd. facility. She was born in Lima, Peru, and graduated as a Surgeon Dentist from the University San Martin de Porres. She worked in a general practice clinic for six years and volunteered as a dentist in poor rural areas. Last year Karin married an American and moved to Canal Winchester, Ohio. She re-entered dental school at OSU to earn the certifications to become a dentist in the US. Karin is fluent in Spanish, English and Portuguese.

Congratulations to Dr. **Marilee Martens**, administration, on her new position as Asst. Professor of Psychology at OSU-Newark campus. Marilee will still work for Nisonger one day a week and also during the summer months.

Jennifer Jacobs, formerly in ECE, moved to Michigan.

Shenae Russell-Lipsey left ECE because her husband was transferred out of state.

Jim Wiltz, administration, took a position in Indiana. He is still working 20% time until spring.

Jenna Schlauch and her husband Nathan delivered a baby girl, Jadyne Renee, on Sept. 6 at 10:44 pm. She weighed 6 lb. 14 oz.

Ashley Jones married Seth Reno on Aug. 25. She now is Ashley Reno.

JoLynn Rosebrook married Brian Wheatley on Aug. 11. She is now JoLynn Wheatley.



...and other staff news...