



4 *University Center for Excellence—Outreach Efforts Enter Religious and Spiritual Communities*



5 *TRIAD—Studying Social Interaction*



8 *Best Buddies—Greatest Week Ever*



11 *Telling Stories Through Songs*

Discovery

Celebrating VKC Science

By Jan Rosemergy



"Enjoy great science!" said Aaron Bowman, Ph.D., as he opened the Second Annual VKC Science Day, welcoming 225 graduate students, postdoctoral fellows, faculty, and staff to the day-long January event. Bowman, assistant professor of neurology, chaired the Planning Committee. "We come together from vastly different disciplines, crossing disciplinary boundaries."

Posters

Over 110 posters were presented by graduate students and postdoctoral fellows across three broad themes, each chaired by a member of the Planning Committee: Cellular and Molecular Neuroscience, Kevin Ess, Ph.D., M.D., assistant professor of neurology; Clinical, Behavioral, and Intervention Research, Courtney Burnette, Ph.D., assistant professor of pediatrics; and Systems Neuroscience, Daniel Polley, Ph.D., assistant professor of hearing and speech sciences. Theme chairs recruited 29 VKC investigators and members as judges. Posters represented labs of 52 VKC researchers.

From abstracts submitted, each theme chair selected one poster to be presented orally in the afternoon plenary session. Prizes in each area were presented by Vanderbilt Provost and Vice Chancellor for Academic Affairs Richard McCarty, Ph.D., and Elisabeth Dykens, Ph.D., VKC interim director. See sidebar (p.2) for presenters and prize recipients.

"I appreciated the opportunity to see so many researchers with different backgrounds collaborating well," said one participant. "I found some branches of research similar to mine, giving me some inspiration and opening my eyes."

Another commented, "Interacting with other students and researchers gave me better insight into my own research."

Poster presenters are eligible to apply for VKC Travel Grants to assist trainees and fellows with costs of attending scientific meetings where they are presenting their research.

Continued on page 2

Act Early Regional Summit

By Jan Rosemergy

Developing comprehensive state plans to improve autism identification and service systems was the goal of diverse teams of over 80 key stakeholders from Tennessee, Kentucky, North Carolina, and South Carolina who met in Nashville in January at the Act Early Regional Summit.

This Region 4a Summit was one of a series of regional summits jointly sponsored by the National Center for Birth Defects and Developmental Disabilities (NCBDDD) of the Centers for Disease Control and Prevention (CDC) and the Maternal and Child Health Bureau at Health Resources and Services Administration, and facilitated by the Association of University Centers on Disabilities (AUCD).

"In these Regional Summits, we're bringing together key state leaders," said George Jesien, AUCD executive director. "The aim is to enhance relationships and collaborations among these key stakeholders and their organizations. It is a forum to share information on the opportunities,"

Continued on page 3



Tennessee Act Early Team members at Region 4a Act Early Summit

MET Gene Linked To Autism, GI Disorders

By Craig Boerner



TRANIS MANLEY IMAGE FROM BISTOCKPHOTO.COM

A single gene variant may be responsible for both autism and gastrointestinal (GI) disorders in some children, according to a new Vanderbilt Kennedy Center study. The study "Distinct Genetic Risk Based on Association of MET in Families With Co-Occurring Autism and Gastrointestinal Conditions," published in *Pediatrics*, suggests that disrupted MET signaling may contribute to the co-occurring medical conditions in some families.

It is well-known that GI conditions are common among individuals

Continued on page 3

Celebrating VKC Science

from page 1



Aliya Frederick presented a poster on effects of in utero cocaine exposure on the brain.

Leadership

Assistant Vice Chancellor for Research Susan Wente, Ph.D., professor and chair of cell and developmental biology, opened the morning session. She commended the Vanderbilt Kennedy Center “for setting the standard for research and practice in developmental disabilities for more than 40 years, and for the collaborative spirit among faculty, students, and staff, which sets it apart.” She emphasized that Vanderbilt has a responsibility “to prepare tomorrow’s leaders in science, which is critical to the greater world, perhaps even more so in these economically challenging times. The Vanderbilt Kennedy Center is strongly positioned to play a role in rising to that challenge, preparing leaders who can translate science into practice and public policy.”

Communication and Down Syndrome

“Communication and Language Intervention With Children With Down Syndrome” was the topic of the keynote address by Paul Yoder, Ph.D., professor of special education. Yoder’s long-term research program on communication development and intervention is distinguished not only by careful research designs, carried out meticulously, but also by incorporation of brain imaging methods, specifically event-related potentials to speech as a means to predicting response to intervention. One goal of this line of ERP research is to be able to predict which types of intervention may be most effective for individual children across different disabilities.

Children with Down syndrome have particular problems with communicating requests, grammar, and speech intelligibility, said Yoder. Because they tend not to talk as much as their typically developing peers, research has demonstrated the benefit of using routines and topic-continuing questions to help them talk more often during therapy.

Doing so provides more opportunities to use adult responses that teach language through grammatical and phonemic recasts. However, ERP imaging suggests that inefficient speech processing may impair children’s ability to benefit even from grammatical and phonemic recasts. Current work is examining whether children with ERP-measured inefficient speech processing benefit more from alternative treatments than from grammatical and phonemic recasts.

Yoder’s research colleagues include Steve Warren (U Kansas), Stephen Camarata (VKC/VU), Marc Fey (U Kansas), and Dennis Molfese (U Louisville). Research funding includes NICHD, NIDCD, and Hobbs Discovery Grants.

Music and Williams Syndrome

“Music Magnetism: An fMRI Study of Music Processing in Williams Syndrome” was presented by Tricia Thornton-Wells, Ph.D., VKC postdoctoral fellow in the Biobehavioral Interventions Training Program, an NIH Roadmap initiative.

Individuals with Williams syndrome (WS) who attend the annual VKC Music Camp are invited to take part in research, since combining services, training, and research is a hallmark of VKC programs. Thornton-Wells has conducted several studies with the campers, initially on music perception, and now on auditory perception more generally.

In a series of studies, Thornton-Wells has investigated how musical interest, a phenotypic



Tricia Thornton-Wells, Postdoctoral Fellow in the Biobehavioral Intervention Training Program, presented “Music Magnetism: An fMRI Study of Music Processing in Williams Syndrome.”

strength, may relate to emotion processing associated with nonsocial anxiety and fears, a phenotypic weakness, and whether some basic auditory sensitivity may be giving rise to both aspects of this syndrome. Individuals with WS report having vivid visual imagery when listening to music. Findings in fMRI studies in WS indicate that early visual areas are activated by simple sounds. Thornton-Wells hypothesizes visual imagery experienced may be a way of making sense of extrasensory stimulation. A future research question is whether this is a result of atypical neural functioning or perhaps also atypical organization.

Multiple VKC collaborators on this research,

funded primarily through internal Vanderbilt grant programs, include Elisabeth Dykens, Elizabeth Roof, Sasha Key, John Gore, Adam Anderson, and Randolph Blake.

Research Helps Families

At the Day’s conclusion, Elisabeth Dykens, VKC interim director, applauded the broad-based basic and clinical research presented. “Everyone deserves awards for such amazing work,” she said.

Vanderbilt Provost McCarty thanked trainees, fellows, and faculty. “What you’re doing is so important. You’re a vote of confidence in the future.”

“The Vanderbilt Kennedy Center is more than research,” he said. “There are families who probably couldn’t make it without the Center’s services. It may not be obvious to you if you’re working in a lab that ultimately your work is helping families. That’s why the Kennedy Center is such an important part of Vanderbilt University. It is not restricted to a single school but is a truly transinstitutional enterprise. All research poster presenters are truly prize winners.” ●

Research Poster Awards

VKC mentors are noted parenthetically

Cellular and Molecular Neuroscience Awards

Richard Gustin, Predoctoral Trainee (Colbran)
Calcium-Calmodulin Dependent Kinase II (CaMKII)
David Lund, Predoctoral Trainee (Blakely)
Acetylcholine Release in Choline Transporter Heterozygous Mice Is Supported by Barium and Strontium as Well as Calcium
A. J. Baucum, Postdoctoral Fellow (Colbran)
Caveats of Proteomics Approaches in Identifying Novel Spinophilin Interacting Proteins
Brent Thompson, Postdoctoral Fellow (Blakely)
Beyond Prozac: Generation and Characterization of SSRI Insensitive Transgenic Mice

Clinical, Behavioral, and Intervention Research Awards

Robin Jones, Predoctoral Trainee (Conture)
Emotional Reactivity and Regulation in Childhood Stuttering
Natasha Matthews, Postdoctoral Fellow (Park)
Interaction Between Working Memory Load and Gesture Imitation Ability in Schizophrenia
Leslie Dowell, Predoctoral Trainee (Wallace)
Changes in Unisensory and Multisensory Temporal Processing in Autism Spectrum Disorders

Systems Neuroscience Awards

Ayan Ghoshal, Predoctoral Trainee (Ebner)
Early Sensory Deprivation Blocks the Development of Neuronal Synchrony in Barrel Cortex
Lisa de la Mothe, Postdoctoral Fellow (Hackett)
Connections of the Parabelt Auditory Cortex in the Marmoset Monkey
Jeremiah Cohen, Predoctoral Trainee (Schall)
Timing of Target Selection Between Visual Cortex and Frontal Eye Field

Undergraduate Award

Bryan Cawthon (Ess)
Requirement of the Tsc1 Gene for GABAergic Interneuron Formation

Act Early Regional Summit from page 1

challenges, and barriers for families and children with autism spectrum disorders (ASD) and related disabilities. The emphasis is on early identification, assessment, diagnosis, and intervention. Early identification is essential not just for autism but also for other developmental disabilities. As we improve systems for autism, we are improving systems for all children.”

The Vanderbilt Kennedy Center and the University of Tennessee Boling Center for Developmental Disabilities were the Summit local hosts and were instrumental in forming the Tennessee team, with the support of the Governor’s Office of Children’s Care Coordination (GOCCC). Both are University Centers for Excellence in Developmental Disabilities (UCEDDs) and both have Leadership Education in Neurodevelopmental Disabilities (LEND) programs. UCEDDs and LENDs are key players in the nationwide effort to enhance the identification, assessment, service coordination, and provision of services for children with ASD and other developmental disabilities.

State teams included parents of children with ASD and members of family autism organizations; representatives of state departments of education, health, developmental disabilities, and social services;



COURTESY OF AUCD

UCEDD and MIND trainees and postdoctoral fellows served as Summit notetakers while gaining experience in public policy planning: (left to right) Colby Butzon (UT psychology), Meghan Burke (VU special education), Kjuanda Reynolds (UT speech-language pathology), and Elisabeth Wallace (VU audiology)

and university-based professionals from diverse disciplines. National organizations and federal agencies represented included Easter Seals, Inc., the Association of Maternal and Child Health Programs, the National Professional Development Center, and the National Conference on State Legislatures.

The Tennessee team of 22 members chose to target four activities: continuing team meetings to implement its plan, supporting family participation in the improvement and expansion of the ASD service system, promoting statewide public awareness using the CDC Act Early materials, and training preservice

professionals and community professionals.

“The Summit was an exciting opportunity to come together with key stakeholders in Tennessee and their counterparts in our region to share, discuss, and learn from each other,” said Terri Urbano, M.P.H., Ph.D., LEND director.

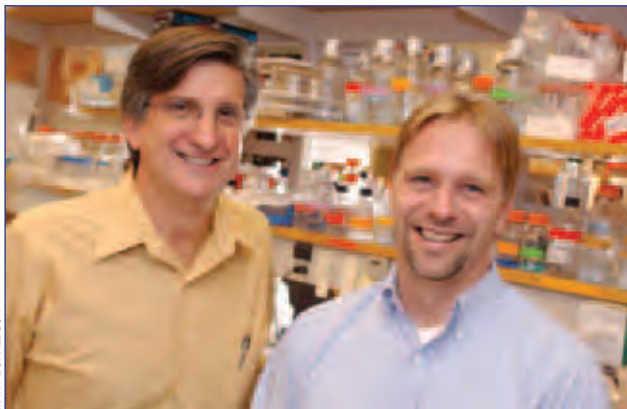
Under the leadership of Fred Palmer, M.D., UT Boling Center director, and in collaboration with the GOCCC, the Tennessee team met in advance of the Summit and developed a vision statement and inventoried state resources.

By the Summit’s conclusion, each state team had identified and prioritized activities to achieve their vision and designated individuals to lead those activities. States will report their progress periodically through their UCEDD and LEND programs to AUCD and NCBDDD.

John Shouse, a Board member of the Autism Society of Middle Tennessee, commented, “This is the first time in almost a dozen years as a parent and advocate that I can remember having such a gathering of key decision-makers in one place, with a singular focus on the question of how we can ‘advance the ball’ for autism clinical and diagnostic services across Tennessee for children with or at risk for an autism spectrum disorder.”

For information on the Act Early Regional Summits, see the Summits link at www.aucd.org. For information about the Tennessee Act Early Team, contact jan.rosemergy@vanderbilt.edu, (615) 322-8238. ●

MET Gene from page 1



MARY DONALDSON

Pat Levitt and Daniel Campbell

with autism, but not known if co-occurring GI conditions represent a unique autism subgroup.

Some speculate that GI dysfunction impacts brain development, or that altered nervous system development affects GI function. The MET protein participates in both brain

development and GI repair, suggesting that disruption of MET signaling may contribute to both medical conditions.

A total of 918 individuals from 214 Autism Genetics Resource Exchange families were studied, each with a complete medical history including GI condition report. Researchers concluded that a functional genetic variant in the MET gene is more strongly associated with autism specifically in those families where an individual had co-occurring autism and a GI condition.

Lead author Daniel Campbell, Ph.D., research assistant professor of pharmacology, said that the research is mounting evidence that the broad term “autism” will soon be divided into separate, more specific categories.

“For too long, people have been debating the validity of GI problems in children with autism,” said co-author Pat Levitt, Ph.D., Annette Schaffer Eskind Chair and professor of pharmacology. “GI disorders don’t cause autism. Autism is a disorder of brain development. However, our study brings together genetic risk for autism and co-occurring GI disorders in a way that provides a biologically plausible explanation for why they are seen so often together.” ●

Director’s Message

The Work Ahead



Elisabeth Dykens, Ph.D.

For the Vanderbilt Kennedy Center, now is a time of change and renewal. The Center is 44 years old, begun in 1965 as one of our nation’s original 12 Intellectual and Developmental Disability Research Centers (IDDRCs). Today, we are an IDDRC and more, changing and growing every day. As I write, we learned last week that our application for the IDDRC 5-year renewal was very favorably reviewed by the Eunice Kennedy Shriver National Institute of Child Health and Human Development. Yet even as we celebrate, we are planning our next steps.

Faculty are busily submitting grants to expand core research services and programs through the American Recovery and Restoration Act.

VKC TRIAD joins the nation in leading a variety of activities related to Autism Awareness Month.

Working with our Community Advisory Council and state and community partners, the VKC UCEDD is developing a 5-year plan for its competitive renewal through the Administration on Developmental Disabilities.

The VKC LEND is implementing new expanded training programs in autism and in pediatric audiology.

Several key ingredients contribute to these successes. First, we are a university-wide institute of Vanderbilt University, which continues to enthusiastically support the Center’s research, *Continued on page 6*

Vanderbilt Kennedy Center for Excellence in Developmental Disabilities

Outreach for Religious and Spiritual Support

By Courtney Taylor

“When a child is diagnosed with a disability, the first place the family turns is to their doctor,” said a parent in a focus group on disability, religion, and spirituality held at the VKC UCEDD last year. “The second place many people turn is to their spiritual community leaders, and that means these leaders need to be prepared to have a conversation with those families.”

The new VKC **Disabilities, Religion, and Spirituality Program (DRSP)** aims to provide training to current and future religious and spiritual leaders and educators, to support individuals with disabilities and families as they give expression to their religion and/or spirituality, and to encourage disability service providers to consider the religious and spiritual interests of individuals they serve. Activities include conducting research, meeting service and technical assistance needs, and developing and disseminating educational materials and best practices that encourage connectivity and individual, family, and community well-being.

The VKC UCEDD is secular; it is not affiliated with a particular religious thought or spiritual expression. This allows the DRSP’s endeavors and educational materials to be ecumenical in nature and thus accessible for all religious and spiritual communities and disciplines. Its activities are informed by 40+ years of experience in disability research, theory, and practice. Since religious participation and spiritual expression are quality of life issues, for many individuals, the DRSP is a natural fit within the VKC UCEDD.

Training Future Leaders

With a grant from the Vanderbilt Center for Medicine, Health, and Society, the DRSP reached across campus to the theological field education office of Vanderbilt Divinity School. Ministerial student Sue Francis, who was a pediatric nurse in her “former life,” completed an academic year-long internship assisting with the direction of the DRSP. Her belief that individuals with disabilities and their families should have access to communities of faith, should they so choose, led her to write her master’s thesis as a call to religious leadership to mediate the relationship between “the church” and persons with disabilities.

“I like to think communities *want* to include everyone,” said Francis. “I believe that most want to, but I think often they might be afraid to, or unsure of how to, or of what comes next once they have truly welcomed everyone to the table.”



One way to address the gap in what religious and spiritual leaders are prepared to address with regard to disabilities is to reach out to them prior to their professional congregational placements. During a recent UCEDD meeting of religious leaders, educators, and students, only 3 out of the 25 or so meeting participants had received any kind of disability-related training during their educations, and even that training was limited. By providing training opportunities and placements for future religious and spiritual leaders through the UCEDD, that essential, yet missing, piece of their education may be addressed.

Congregational Survey

A primary DRSP activity, with which Francis assisted, has been the development of an interfaith statewide survey that asks religious leaders and educators, individuals with disabilities and their families, and congregation members about their experiences with inclusion in religious and spiritual communities.

Survey questions explore barriers to participation that were well-defined by Peabody College alumnus, Erik Carter, Ph.D., in *Including People With Disabilities in Faith Communities: A Guide for Service Providers, Families, & Congregations* (Brookes, 2007). Carter says individuals with disabilities and their families might not feel welcome in a community if architectural, attitudinal,

communication, programmatic, and/or liturgical barriers are present. Survey findings should prove helpful in developing practical tools for congregations. Findings will be reported in group form and disseminated in Fall 2009.

Technical Assistance

In February, William Gaventa, M.Div., director of community and congregational supports and associate professor of pediatrics at the Elizabeth M. Boggs Center on Developmental Disabilities, Robert Wood Johnson Medical School, visited the VKC to deliver a public lecture and participate in small group discussions with families, disability service providers, religious educators, leaders, and students.

Gaventa’s talk, “Where Personal, Professional, and Communal Ethics Meet: The Challenge and Promise of Inclusive Spiritual Supports With People With Developmental Disabilities and Their Families,” was a meditation on the parallels that may be drawn between fundamental spiritual questions and values at the heart of disability services.

Gaventa noted that the spiritual questions of identity, purpose, and community—“Who am I?” “Why am I?” and “Where do I belong?”—are remarkably similar to values of independence, productivity, integration, and self-determination that motivate the work of disability service providers. He challenged attendees to embrace their capacity to journey with others, and not to shy away from the tough ethical and spiritual questions that disability may raise.

While discussing the topic of full inclusion during a meeting of religious and spiritual leaders, educators, and students, Gaventa introduced the promise of *radical hospitality*.

“Congregations must be socially engaged and reaching out to the very people who may appear to be out of their reach,” said Gaventa. “This is a justice issue, and religious bodies, at their best, are skilled at addressing injustices. When religious leaders can engage a kind of radical hospitality and fully include individuals with disabilities and their families, and I mean an integrated type of participation, grace will transform their ministry into one of ministering *with* rather than one of ministering *to*.”

For information, contact Courtney Taylor, M.Div., courtney.taylor@vanderbilt.edu, (615) 322-5658, toll-free (866) 936-8852. ●



Treatment and Research Institute for Autism Spectrum Disorders

Social Interaction—Not Motivating or Aversive? *By Jan Rosemergy*

A “castle” is built for young children. It has a yellow room and a green room, and both have books, puzzles, and toys. The yellow room has someone who reads the books aloud, plays with toys, and works puzzles. The green room just has books, puzzles, and toys. Will typically developing children prefer the yellow room, with someone to play with? Will children with autism spectrum disorders (ASD) prefer the green room, with just the toys?

The scenario just described will be the third stage in a set of studies using the behavior paradigm of “conditioned place preference.” The studies are aimed at answering the question: Is social interaction aversive or not motivating for children with ASD?

The project is being conducted by Barbara Thompson, Ph.D., postdoctoral fellow in pharmacology. What’s unique is that the study involves testing *in children* the paradigm of conditioned place preference, which has previously only been used in animal behavioral research.

“The strength of the paradigm,” Thompson explained, “is that it allows us to distinguish whether something is reinforcing, not reinforcing, or aversive.”



TONY MALPIN

There are two main hypotheses about social interaction in children with ASD: one that it is not reinforcing, and the other that it is aversive.

“From a clinical perspective, it’s really important to get at the difference because intervention strategies would be different if social interaction is nonreinforcing versus aversive,” Thompson said.

Thompson indicated that the study also is important from a biological perspective in that the brain circuitry that underlies nonreinforcing versus aversive behavior is different. “If we knew where to look in

the brain, we could begin to tease out the biological signaling circuits.”

The study will proceed in three stages. The first stage involves establishing conditioned place preference, without the variable of social interaction, in typically developing children. In stage two, social interaction is added, still with typically developing children. In the third stage, comparisons will be made between the place preference of typically developing children versus children with ASD. Findings will help inform effective interventions as well as guide biological research investigating differences in brain circuitry.

“We need both clinically based research and biological research—and we need the two interacting,” Thompson said. “Scientific discovery needs to go both directions.”

Study participants will be typically developing children, 3-5 years, and children with ASD, 3-6 years. Each of the three experiments requires only a single session, the longest about 2.5 hours. Families will be reimbursed for their time. Call (615) 936-3865. The study is funded by a Marino Autism Research Institute Discovery Grant. ●

Building ASD Educational Capacity *By Jan Rosemergy*

As more young children are diagnosed with an autism spectrum disorder (ASD), public school systems are serving more children with ASD—making training in ASD a critical need for school administrators and teachers. TRIAD provides a variety of services to address this need, ranging from child-specific consultations to system-wide training.

“Lack of autism-specific training is a common concern in schools,” said Nicolette Brigham, Ph.D., TRIAD outreach coordinator. “Providing appropriate services is a challenge because there is a particular set of educational and behavioral strategies that work well for students with autism.”

Collaborative child-focused consultation is available to school personnel who want to address the academic or behavioral performance of individual students with ASD. A team approach is used, with TRIAD specialists, teachers, and parents working together to understand student strengths and needs in order to design and implement the optimal program.

Program consultation assists teachers and other school personnel in developing and implementing

specialized programs for students with ASD. Programs may have an educational, social skills, or behavioral focus, such as developing a coordinated plan for positive behavioral supports.

In collaboration with the Tennessee Department of Education, TRIAD offers district-wide *TRIAD Teacher Training* workshops, which are hands-on and involve direct work in classrooms.

“We are able to customize our workshops and training for school systems to meet their needs,” Brigham said. “Some systems may want an introduction to autism, while others may have specific interests such as applied behavior analysis or how to integrate different methodologies—whatever the school system identifies as their biggest concerns.”

Also in collaboration with the Tennessee Department of Education, TRIAD provides 2-day *Administrator Academies* to 15 administrators, e.g., principals, assistant principals, and special education directors, in each of the three grand regions of the state. The workshops combine lectures, small group activities, and roundtable

discussions. Continuing education credit is offered. Administrator Academies are provided to other states and school systems by request.

“The goal is to provide information on best practices and basic tools that will enable them to evaluate their ASD programs and to support their teachers,” said Kim Frank, TRIAD educational consultant. “We talk a lot about the antecedents and consequences of behavior, and the role of administrators in supporting teachers. For example, in one Academy, after discussion, a principal realized that having the student sent to him was actually reinforcing the child’s inappropriate behavior.”

TRIAD recently held an Administrator Academy in Little Rock, Arkansas. “This has been one of the most, if not the most, beneficial training I have attended in my 15 years as an educator,” one participant commented.

When responding to training requests, TRIAD gives priority to school systems with whom TRIAD has contracts. For information on fee structure, contact (615) 936-2163. ●

Leading the Vanguard of Discovery



LOUIS J. MUGLIA, PH.D., M.D.

Edward Claiborne Stahlman Professor of Pediatrics
Vice Chair for Research Affairs in Pediatrics
Interim Associate Director, Vanderbilt Kennedy Center
Vanderbilt Kennedy Center member
Joined Vanderbilt Kennedy Center 2009

Research Interests

The Muglia laboratory has advanced the *in vivo* analysis of regulation of the endocrine stress response, i.e., activation of the hypothalamic-pituitary-adrenal axis and characterization of glucocorticoid action, using novel genetically altered mutant mice. These studies have elucidated the importance of corticotropin-releasing hormone and glucocorticoids in neuroendocrine modulation, behavior, and perinatal development. Of particular interest is how dysregulation of glucocorticoid and neuropeptide action in the central nervous system can contribute to the genesis or exacerbation of psychiatric disorders.

A second major research area is elucidation of the timing mechanism for birth in humans, and how this mechanism malfunctions to result in preterm birth. Studies are underway to identify the genetic determinants predisposing to prematurity.

Principal Investigator

- Amygdala Glucocorticoid Receptor Function in Stress, National Institute of Mental Health
- Dissociated Agonists of the Glucocorticoid Receptor: Mechanisms and Novel Applications, Pfizer, Inc.
- Genetic Analysis of Human Preterm Birth, March of Dimes Foundation
- Burroughs Wellcome Fund Research Consortium on Preterm Birth

Clinical Interests

Muglia is a physician-scientist with expertise in pediatric endocrinology. He served as director of the Division of Endocrinology and Diabetes, Department of Pediatrics, Washington University, prior to joining the faculty at Vanderbilt. His clinical interests include neuroendocrine (pituitary) and adrenal disorders, as well as endocrine disorders in newborns.

Honors and Awards

- Pfizer Postdoctoral Award in Endocrinology, 1993
- Clinical Investigator Award, National Institute of Diabetes and Digestive and Kidney Diseases, 1994
- Society for Pediatric Research Young Investigator Award, 1999
- American Society for Clinical Investigation, 2003
- American Pediatric Society, 2008
- National Institute of Child Health and Human Development Board of Scientific Counselors, 2008

Selected Publications

Kolberm, B. J., Roberts, M. S., Howell, M. P., Wozniak, D. F., Sands, M. S., & Muglia, L. J. (2008). Central amygdala glucocorticoid receptor action promotes fear-associated CRH activation and conditioning. *Proceedings of the National Academy of Sciences*, 105, 12004-12009.

Plunkett, J., Borecki, I., Morgan, T., Stamilio, D., & Muglia, L. J. (2008). Population-based estimates of sibling risk for preterm birth, preterm premature rupture of membranes, placental abruption and pre-eclampsia. *BMC Genetics*, 9, 44.

Kistka, Z., Palomar, P., Lee, K. A., Boslaugh, S. E., Wangler, M. F., Cole, F. S., DeBaun, M. R., & Muglia, L. J. (2007). Racial disparity in the frequency of recurrence of preterm birth. *American Journal of Obstetrics and Gynecology*, 196, 131.e1-131.e6.

Education

B.S., 1981, Biophysics, University of Michigan
Ph.D., 1986, Molecular Genetics, University of Chicago
M.D., 1988, Medicine, University of Chicago

Attraction to Developmental Disabilities Research

I am attracted to developmental disabilities research for many reasons. First and foremost, the opportunity to improve the quality of life, by innovation and discovery in children's health, has formed the foundation for my career as a physician-scientist. Knowledge gained by exploring some of the most fascinating unresolved questions in biology – What comprises cognition? or What determines the timing for birth? – will provide new avenues to impact on common disorders such as autism, childhood psychiatric diseases, and the many adverse sequelae of prematurity. This increase in understanding will better allow us to predict, to treat, and ultimately to prevent problems that compromise well-being over a lifetime.

Reasons for Kennedy Center Membership

I am honored to be a member of the Vanderbilt Kennedy Center because of the rich history to investigation, education, and implementation around developmental disabilities, along with the vibrant community of investigators of which it is comprised. The diverse approaches utilized by VKC colleagues impressively span basic sciences, clinical research, and education, and exemplify how multidisciplinary efforts can bring fundamental discovery through to community intervention. This cross-fertilization of ideas among neuroscientists, psychologists, educators, and clinicians is unique. ●

Down Syndrome and Ethnicity

By Jan Rosemergy

A Vanderbilt Kennedy Center study of mothers of newborns with Down syndrome (DS) shows a need for health care and social services policies to address differences related to ethnicity/race and age of mothers. The study, which appeared in the *Journal of Policy and Practice in Intellectual Disabilities* (2008, Sept.), was conducted by Robert Hodapp, Ph.D., professor of special education, and Richard Urbano, Ph.D., research professor of pediatrics.

Little research has been done on ethnic/racial differences among mothers of young children with DS. The researchers used official Tennessee birth records from 1990 to 2002 to examine ethnic/racial differences among mothers of young children with DS. They looked at mother's age when the infant was born, education levels of mothers, marital status of mothers, and neighborhood median income.

They found differences between African-American mothers and mothers of European-heritage descent. Compared with European-heritage mothers, African-American mothers of newborns with DS were of lower socioeconomic levels and were younger, with many more African-American mothers giving birth at 23 years or younger. In both groups, the young mothers had the highest percentage of women who had not graduated from high school and who were unmarried. From earlier studies, mothers who are unmarried and who have not graduated high school show greater support needs, even as they are less likely to know about and to make use of available services.

These findings point to the need for targeted health care and social support services for African-American mothers specifically, and young mothers generally, who give birth to children with DS, especially since an array of health issues most often accompany DS. ●

Director's Message from page 3

training, and service activities. Second, we are successful due to hard-working staff members who are intensely dedicated to the work of the Center. Third, across a variety of disciplines, the Center attracts creative, cutting-edge scientists.

Finally, the Center is "mission-focused." Through research, service, and training, the VKC creates positive differences in the lives of people with disabilities and their families. Our shared mission, in turn, leads to creative programming and scientific discoveries, and to renewed excitement for the work ahead. ●

Accolades

Camilla Benbow, Ed.D., Patricia and Rodes Hart Dean of Education and Human Development and professor of psychology, has been **appointed to the Committee for the Assessment of Education Research Doctorate Programs**, which will oversee the first assessment conducted jointly by the American Educational Research Association and the National Academy of Education to examine education research doctorate programs in the U.S.



Meghan Burke

Meghan Burke, Special Education doctoral student (**Robert Hodapp**, Ph.D., advisor), received the **Trainee Volunteer Scholarship from the Association of University Centers on Disabilities (AUCD) to attend the 2008 AUCD Annual Meeting and Conference**.

Burke is a Vanderbilt Kennedy University Center for Excellence (VKC UCEDD) trainee in disability public policy.

Kathryn Edwards, M.D., Sarah Sell Professor of Pediatrics, has been **elected to the Institute of Medicine, National Academy of Sciences**.



Kathryn Edwards, M.D.

Steve Graham, Ed.D., professor and Currey Ingram Chair in Special Education, has been appointed as a member of the National Research Council's Committee on Adult Literacy. Graham and **Karen Harris**, Ed.D., professor and Currey Ingram Chair in Special Education, have **developed Self-Regulated Strategy Development (SRSD)**, a tool used to improve children's writing, which was the focus of a special issue of the journal *Exceptional Children*. A team of experts from the University of Oregon and Southern Methodist University reviewed SRSD and found it to be strongly evidence-based; few such practices to date have received such status.

H. Carl Haywood, Ph.D., professor of psychology, emeritus, has been **appointed to the Committee on the Impact of Mobility and Change in the Lives of Young Children, Schools, and Neighborhoods**. The committee is a part of the Board on Children, Youth, and Families, a **shared activity of the National Research Council and the Institute of Medicine**.

Community Health Charities of Tennessee honored the following individuals as **Champions in Health**: **Lynnette Henderson**, Ph.D., research assistant professor of pediatrics and VKC research participant recruitment coordinator, for her volunteer work for the Autism Society of Middle Tennessee (ASMT); she is vice president of the ASMT Board of Directors, has chaired its Education Committee, and currently serves on its Advisory Board for Education Programming. **Carolina Meyerson** for her volunteer work for the Mental Health Association of Middle Tennessee; she is a Hispanic Outreach specialist for Tennessee Disability Pathfinder. **holly lu conant rees** for her volunteer work for The Arc of Tennessee; she is a member of the VKC UCEDD Community Advisory Council.

Jon Kaas, Ph.D., Centennial Professor of Psychology, received the **2008 Award for Excellence in Graduate Mentoring** at the College of Arts and Science faculty assembly.

Craig Kennedy, Ph.D., professor and chair of special education, **co-authored Peer Support Strategies for Improving All Students' Social Lives and Learning**. The purpose of the book is to translate research undertaken over the last 20 years in classrooms across the country into a guide that teachers can use to structure and implement peer support programs.



Craig Kennedy, Ph.D.

Kathleen Lane, Ph.D., associate professor of special education, **co-authored Developing Schoolwide Programs to Prevent and Manage Problem Behaviors: A Step-by-Step Approach**.

The Mayor's Advisory Committee for People With Disabilities honored several individuals and organizations in its 2008 Awards ceremony: **Beth Malow**, M.D., professor of neurology and director of the Vanderbilt Sleep Center, received the **Health Care Provider Award** in recognition of her service and research on the treatment of sleep disorders in individuals with developmental disabilities. **Carole Moore-Slater**, M.S., Tennessee Disability Pathfinder director, received the **Professional Award** in recognition of her dedication to identifying disability-related resources and services. The **family of John and Janet Shouse**, VKC Community Advisory Council member, received the **Family Award** honoring their many volunteer advocacy activities on behalf of individuals with autism and other developmental disabilities. The **Frist Center for the Visual Arts**, a VKC Community Partner, received the **Organization Award** for its activities promoting art by and art education for individuals with disabilities.

BethAnn McLaughlin, Ph.D., assistant professor of neurology, has been **appointed an Associate Editor of the Journal of Neuroscience** in the Cellular and Molecular section for a 3-year period. The appointment recognizes McLaughlin's expertise and her service as a reviewer for the *Journal*.



BethAnn McLaughlin, Ph.D.

Eunice Kennedy Shriver received the first *Sports Illustrated Sportsman of the Year Legacy Award* on the 40th anniversary of the first Special Olympics. Shriver founded Special Olympics and has used athletics to change the world for people with intellectual disabilities.

The **Division for Research of the Council for Exceptional Children** selected **Karen Sandmel**, Special Education doctoral student (**Karen Harris**, Ph.D., advisor), to participate in the inaugural cohort of **Doctoral Seminars in Special Education Research**, an online seminar designed to foster connections among students at different universities and to raise research standards.

Tennessee Disability Pathfinder was featured on the website of the **Southeastern/Atlantic Region of the National Network of Libraries of Medicine**. Pathfinder is a project of the Tennessee Council on Developmental Disabilities and the VKC UCEDD.

The **Vanderbilt Kennedy Center** was recognized at the Autism Speaks 2008 Inaugural Tennessee Awards Reception as a **Gold Level Fundraiser at the Autism Speaks Walk Now for Autism** in November. The VKC was the second highest team fundraiser in the state. The individual top fundraiser for the Walk was **Allison Nahmias**, research assistant on the TRIAD Hanen© More Than Words Project.

Volunteer Tennessee and members of the Tennessee National Service Inclusion Advisory Team received the **Excellence in Partnering Award at the 2008 National Conference on Disability Inclusion and National Service** in Alexandria, Virginia. The award recognized the building of a team of 30 agencies across the state to include more people with disabilities in national and community service. **Whitney Griffin**, Tennessee Disability Pathfinder, represented the VKC UCEDD at the award ceremony. **Elise McMillan**, J.D., UCEDD co-director, and **Courtney Taylor**, M.Div., associate director of communications, are members of the Tennessee Advisory Team. ●

LEND Pediatric Audiology Training By Jan Rosemergy

Vanderbilt University is one of six programs selected nationally to receive additional funds to expand training for the treatment of infants and children with hearing disabilities through its Leadership Education in Neurodevelopmental Disabilities (LEND) program, said program director Terri Urbano, Ph.D.

“This funding is of major importance to Tennessee because our state, like so many others, lacks enough trained professionals in pediatric audiology to provide early identification and intervention to infants and children with hearing disabilities,” said Anne Marie Tharpe, Ph.D., professor of hearing and speech sciences and pediatric audiology project co-director. “This additional funding will enhance our abilities to train the next generation of pediatric audiologists and will provide continuing education to practicing professionals.”

Vanderbilt will now collaborate with other Maternal and Child Health Bureau (MCHB) Audiology training programs across the country to provide continuing professional education, videoconferences, and web-based programs.

At the state level, the increase will expand



COURTESY OF LEND

Vanderbilt LEND audiology trainees and trainees from other national LEND programs at National Early Hearing Detection and Intervention Meeting

continuing education programs offered to Tennessee Department of Health personnel and will provide trainees with practical experiences in interdisciplinary research projects across several universities.

The funding allows Vanderbilt’s LEND program to add five long-term and five intermediate trainees in Audiology each year for 3 years, with expanded emphasis on children with hearing loss.

Funding also provides for cultural and ethnic diversity training to be increased for MIND faculty and additional trainees from diverse

backgrounds recruited. Specialty interdisciplinary training will be provided through Vanderbilt’s Center for Experiential Learning and Assessment.

New annual funding over a 3-year period is made possible through a contract to the Association of University Centers on Disabilities from the MCHB of the Human Resources and Services Administration.

Tharpe and faculty from MCH-funded pediatric audiology programs at the University of North Carolina-Chapel Hill and Utah State University developed and implemented training in a series of student orientation sessions

at the National Early Hearing Detection and Intervention Meeting in Dallas, March 2009. Over 75 trainees, from universities across the country who are funded by the LEND programs and the Pediatric Audiology Subawards, and their faculty mentors were in attendance.

The national LEND program, known locally as the Mid-Tennessee Interdisciplinary Instruction in Neurodevelopment Disabilities (MIND), teaches interdisciplinary graduate and postdoctoral trainees spanning 12 health professions to provide services to children with neurodevelopmental disabilities.

For more information call (615) 936-6915. ●

“Greatest Week Ever”

When Spring Break arrives at Vanderbilt University, while some students head to the beach, others take part in Alternative Spring Break (ASB), the largest completely student-run organization on campus. ASBs provide service learning opportunities for over 400 students every March. This year, the Vanderbilt Chapter of Best Buddies, a student organization that works to enhance the lives of individuals with intellectual disabilities by providing opportunities for one-to-one friendships, offered an ASB. To read their blog, visit bestbuddiesspringbreak.blogspot.com.

Best Buddies President Jessica Solomon

In one week, I learned more about the needs, desires, and ways of adults with intellectual disabilities than I ever could have learned in any classroom experience. While my Peabody and Special Education curricula have provided me with tools for working with adults with intellectual disabilities, my Best Buddies Spring Break experience has provided me with a means through which to implement and to test those tools.



VANDERBILT BEST BUDDIES

Best Buddies Will McMillan, Ashley Pasquariello, Jeanne Gavigan, and Clay Searcy help plant a community garden on Alternative Spring Break.

On our trip to Knoxville, Tennessee, we combined inclusive social activities with community service. In the mornings, we volunteered at Beardsley Farm and converted previously useless green spaces located in urban parking lots into edible gardens where families can grow their own food to eat. In the afternoons, we continued our service with AmeriCorps volunteers assisting with after-school

programs for inner-city youth.

Some of our social activities included a girls/guys night out, a basketball tournament with the Carson Newman Best Buddies Chapter, concerts at Knoxville’s Blue Plate Special, including Bela Fleck, and a Lady Vols vs. Lady Commodores basketball game, thanks to the Vanderbilt Kennedy Center! While we managed to have a lot of fun, the best part, according to our Buddies, was the opportunity to serve.

Buddy Member Adrian Ewing

From this past first day of Saturday, I really didn’t know what to expect, not until me, Chris, Josh, Clay and Portia, with the Best Buddies of the world such as Jesse, Richie, Jordan, Travis, Ashley, Emmie, Honora, Alice—as the best and funnest outgoing fun people to be around, from the good times to the bad times—we had the greatest time . . . We worked together on a project for people that is less than us, to just having fun working with each other, helping me and my life. This is the greatest week ever. ●

Reaching Out

 **VANDERBILT KENNEDY CENTER**
FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES

Postsecondary Education

The **VKC Postsecondary Education Program (PSE)** is well into its initial planning year and will accept its first students in January 2010. Its implementation is being led by Tammy Day, M.Ed., program director, Elise McMillan, J.D., UCEDD co-director, and Robert Hodapp, Ph.D., professor of special education and UCEDD research director.

Day, who joined the VKC in April, previously was a special education liaison and compliance specialist and a coordinator of transition programming and training in Rutherford County Schools. She has been a member of the Tennessee Task Force for Postsecondary Education for Students With Intellectual Disabilities since May 2007. During her career, she has had extensive experience working with students with diverse needs and their families. She is a graduate of Peabody College of Education and says she was drawn back to the Vanderbilt University campus and to the PSE “because the mission of the program is at the heart of my life’s work.”



Lorie Lytle, Dennis Lord and Erin Spahn of the Academy of Country Music, Shirley Speyer, and Donna Eskind celebrate ACM Charitable Fund's gift to the VKC Music Camp.

further develop their life skills, gain vocational skills, and participate in extracurricular activities with other college kids. I am thrilled to play a part in helping postsecondary education become a reality for students with intellectual disabilities.”

The Tennessee Council on Developmental Disabilities awarded a 3-year grant to the Vanderbilt Kennedy Center to plan and coordinate a model Postsecondary Educational Program that is integrated, successful, sustainable, and replicable by other Tennessee colleges and universities. For information contact tammy.day@vanderbilt.edu.

The VKC also is part of a national consortium of universities working to expand opportunities for students with intellectual disabilities; for information see thinkcollege.net.

Arts and Recreation

The VKC Disabilities and the Arts Program honored artists whose work was showcased in the exhibition, “Expressions Through Color” (January-March 2009), at a reception and musical celebration.

The artwork was created with support from art educators at the **Frist Center for the Visual Arts**, who worked with campers in the 2008 **VKC Camp Shriver Transitions and Sports Camp**. Campers were exposed to color theory, learned how to express themselves using color, and visited the Frist Center to view the exhibit “Color As Field.” Later, each camper created a large, abstract color expression on canvas, which culminated in the “Expressions Through Color” exhibit. The paintings will be available for viewing again in 2010, in the Frist exhibit, “Responding to Art.”

In addition to honoring the artists, VKC leaders thanked the **Academy of Country Music Charitable Fund** for its gift to fund scholarships for the VKC Music Camp, a week-long residential camp for individuals with Williams syndrome from across the country.

With the help of Nashville songwriters and producers, the campers write an original song and record it on Music Row. The camp culminates with a “dream come true”—performing at the Grand Ole Opry.

For information on VKC Recreation and Arts, contact gretchen.herbert@vanderbilt.edu, (615) 321-8761.

East TN Hispanic Outreach

The Vanderbilt Kennedy Hispanic Outreach program hosted the **East Tennessee Disability Services and the Hispanic Community Conference** in April 2009. Conference programming educated service providers who work with Spanish-speaking families on

issues of cultural competence and enhanced their skills in navigating the Camino Seguro Middle and West resource database systems. The Conference also provided a platform for implementing a Camino Seguro East database.

Planning Committee members were Katy Alexander, Disability Law and Advocacy Center of Tennessee; Patricia Valladares, Support and Training for Exceptional Parents; Dr. Coral Getino, Autism Society of East Tennessee and HoLa Hora Latina; Dr. Loida Velázquez, Hispanics in Education and Training; Dr. Lori Celaya, University of Tennessee-Knoxville; and Claudia Avila-Lopez and Cecilia Melo-Romie, Tennessee Disability Pathfinder.

For information on Hispanic Outreach activities, contact claudia.avila@vanderbilt.edu, (615) 322-8529, toll-free (800) 640-4636.

Orientation to Disabilities

In April 2009, the Vanderbilt Kennedy Center and the Monroe Carell Jr. Children’s Hospital at Vanderbilt offered two free 2-hour disability orientation sessions, **Journeys in Disability**. The first session was provided for parents/caregivers of children under 12, and the second was for adults and high school students with disabilities, their families, and support personnel.

Journeys sessions provide information on important terms, definitions, and relevant laws. They educate people on people-first language and civil rights issues, and on choices that lead to positive outcomes. Participants leave the sessions able to identify federal, state, and local nonprofit agencies that may be able to provide support, and with a notebook of resources. For information on future Journeys sessions, offered twice yearly, contact lynette.henderson@vanderbilt.edu, (615) 936-0448, toll-free (866) 936-8852.

For information on these and other VKC programs, see the Services link at kc.vanderbilt.edu.



Artist Olivia DeCaria with her painting at reception for Expression Through Color exhibit

“Tennessee is well overdue to have postsecondary education programs for students with intellectual disabilities,” said Day. “The program will help these students attain their goals. They will be able to continue their education alongside their same-age peers. This is huge for us in Tennessee! The students will have an opportunity to take college classes,

Spotlight

Tireless Dedication

BECKY AND CHRIS LINK

By Courtney Taylor

Becky and Chris Link lead busy lives managing their business, Imagination Branding, which provides promotional items for businesses. As if that weren't enough, Becky does smocking and embroidery on children's clothing, does cross stitching, reads, scrapbooks, teaches at her church, spends time with her family—and she and Chris volunteer their time as members of the Vanderbilt Kennedy Center Leadership Council.

"Becky Link is one of the most genuinely kind and compassionate people I know," said Elizabeth Roof, research coordinator for VKC studies on Prader-Willi and Williams syndromes. "She has an open and loving heart and approaches everything with a smile and a quiet determination. I marvel at her tireless dedication to the Vanderbilt Kennedy Center mission, and at her ability to juggle it all in her special, unpretentious way."

Becky Link was born, raised, and still resides in Gallatin, Tennessee. Chris and Becky have three children. Ethan is 22 years old, graduated from Centre College in May 2008, and currently works as an organizer for Service Employees International Union on a healthcare initiative. Sarah is 11 years old, is in the sixth grade, and enjoys dancing, writing, and drawing. Seth, 19 years old, graduated from Gallatin High School in May 2008 and is participating in Project Opportunity through the Monroe Carell Jr. Children's Hospital at Vanderbilt.



LINK FAMILY

"We first discovered that Seth has Williams syndrome when he was in the second grade," remembered Becky. "Later, that is how we came to find the Vanderbilt Kennedy Center. I was looking at a publication on Williams syndrome, and I saw a listing for Music Camp at Vanderbilt. I just knew Seth had to be involved in that. One of his first toys was a drum. He loved it so much, and he would sit alone and be content just keeping a rhythm. We got him his first real drum set when he was in the third grade."

Seth has been involved in VKC Music Camp each year, and he continues to share his gift for drumming with both the Vanderbilt and the Nashville communities. Chris notes his involvement in Music Camp as a springboard for his continual involvement in research.

"Seth's involvement in research on Williams syndrome has really opened my eyes," he said. "Research is so important, way more important than I ever imagined, and we encourage participation whenever we can. I feel that what the Vanderbilt Kennedy Center has given us runs way

deeper than what we have or ever will be able to give back, so I just try to look for new ways to help out when we can."

"While we've offered peer support to families on an individual basis before, we hope to start, with Elizabeth Roof's guidance, a support group for families who have a family member with Williams syndrome," Becky said. "I think that would be very enriching and helpful. Getting involved and sharing with people who know what you are going through is so important for the

whole family. When you see a person with Williams syndrome who is meeting another person with Williams syndrome for the first time, which happens at Music Camp all the time, it really pulls at your heart strings."

Since joining the Leadership Council 3 years ago, the Links have served on the Arts and Recreation Committee, and their company has supplied T-shirts for Music Camp, TRIAD Social Skills Camp, and Camp Shriver Sports and Transition Camp. The tie-dyed shirts from the 2008 Music Camp are very popular among campers and VKC staff and faculty—"coveted" might be an even better word.

"Everyone loved the T-shirts from Music Camp," said Ashley Coulter, Sibling Project coordinator. "I loved them so much that I made sure to find out who made them so we could use the same company for the Tennessee Adult Brothers and Sisters Conference T-shirts. They're awesome!"

The Vanderbilt Kennedy Center and its programs benefit greatly from the talented and committed presence of the Link family. ●

TN DD Network Honors Lois Curtis *By Courtney Taylor*

TONY MALPIN

Lois Curtis

Self-advocate and folk artist Lois Curtis was honored at a reception at the Vanderbilt Kennedy Center on April 2. Curtis spoke about her art and her involvement as a plaintiff in the Olmstead Decision.

Curtis had spent much of her life as a resident in state-

operated institutions. Following denial of her repeated requests to live in the community, she, along with Elaine Wilson (now deceased), initiated a lawsuit against the State of Georgia.

In 1999, their case came before the United States Supreme Court. The Olmstead

Decision established a national mandate to free tens of thousands of people with disabilities from institutionalization.

Curtis was very excited to let reception attendees know that she hopes to own her own home soon. She spoke with joy about spending her days making art and going shopping. Curtis has enjoyed great success as a folk artist. Her art has been exhibited in many galleries in Georgia, where she lives, and across the United States. Samples of her artwork were available for sale at the reception.

When asked about her life in an institution, Curtis remarked, "If it happens again, call the police. I made something of myself."

The reception was hosted by the Tennessee Developmental Disabilities Network, which includes the Tennessee Council on



TONY MALPIN

Lois Curtis and Elisabeth Dykens

Developmental Disabilities, Disability Law & Advocacy Center of Tennessee, University of Tennessee Boling Center for Developmental Disabilities, and Vanderbilt Kennedy Center for Excellence in Developmental Disabilities. ●

Telling Stories Through Songs By Courtney Taylor

What is a song? Essentially, it is a story that has a beginning, a middle, and an end. Songwriting is a venue for telling a story and for sharing mood and expressing feeling. It is a form of communication that can allow a songwriter, and his or her experiences, to be known, heard, and understood.

Tammy Vice is a songwriter. She also is a Vanderbilt Kennedy Community Advisory Council (CAC) member and former trainee of the VKC LEND, Mid-Tennessee Interdisciplinary Instruction in Neurodevelopmental Disabilities Training Program. While participating in a CAC breakout group on the topic of expanding arts and recreation programming, Vice proposed connecting students with disabilities with the Country Music Hall of Fame® and Museum Words & Music Program.

The Songwriting Process

In the Words & Music program, classroom teachers follow a curriculum that guides students in writing or co-writing song lyrics. Students also visit the Museum, where they are matched with a professional songwriter, who adds the music and melodies to their lyrics.

The Words & Music program had never been used in a classroom that included students with disabilities. So Vice and fellow songwriter Steve Nelson (who wrote the theme song to “Winnie the Pooh”) decided to volunteer their time to adapt the Words & Music Program to accommodate a group of budding songwriters with disabilities.

“When Tammy Vice approached us about participating in the Words & Music program, I was hesitant,” said Adrienne Parks, classroom teacher in the John Paul II (JPII) Hand in Hand Program. “Tammy is a professional songwriter and a parent of a child with autism, and she was absolutely convinced that the program would be beneficial for the students in my classroom. I was concerned that our students’ writing would not be strong enough to work with the songwriters. I am so glad that I did not give in to my doubt. This turned out to be an amazing opportunity for our students.”

When the program is implemented for typically developing students, the songwriters do not participate in the process until the very end, upon the students’ visit to the Museum. To accommodate the students with disabilities in the writing process, Vice and Nelson committed to visiting the Hand in Hand classroom once a week for 6 weeks. Also present and ready to assist during the process were “peer buddies,” students who had sung with the Pope John Paul II High School choral program and who had knowledge about music to share with the students.

For the first 2 weeks, the student songwriters engaged in a stream-of-consciousness, free-style kind



Words and Music class at Country Music Hall of Fame® and Museum with songwriter Tammy Vice (front row right)

of writing, listing their likes and dislikes. They identified the people who were important to them, the things they liked and did not like to do, and the causes that they found important. Once each student had a list from which to choose, they identified one item on the list and began to describe it. Was it a family pet? What color was the pet? What did the pet do that was funny, and how did the student feel about the pet?

“You never know what they will choose to write about,” said Vice. “Working with the students at JPII last year gave me permission, as a songwriter, to be more creative and to take risks. I would never think about writing a song about stale pizza, chores, or cleaning up dog poop in the yard, but these are the things the students are thinking about. They are unguarded and completely free to create. That’s why the arts are so effective. They encourage creativity and are about your personal best. There are no right and wrong answers in art. Your creation does not have to be anything but what is yours.”

Communication

“The students did learn about songwriting, but it was more than that,” said Parks. “They gained a greater sense of pride in their words because they were able to share very personal experiences with others through their songs. Some of my students have speech and language impairments, so communicating with others about important events in their lives can be more difficult for them than for their peers. It was amazing to see how excited they were to share their thoughts about important events and ideas.”

Once the students had written their songs and set them to music with the help of Vice and Nelson, they visited the Country Music Hall of Fame® and Museum and recorded a class album. The songs included: “I Am Going to School,” “Keep on Running,” “I Like Plays a Lot,” “My Season With the Team,” “What Love Is

All About,” and “Never Give Up.”

“Everybody needs to be heard,” said Vice. “I think that is the reason matching the Words & Music Program with students with disabilities is so important to me. I know these kids have the want and the ability to create, just like any other kid has. I see how proud they are when they create something that expresses who they are, something that is only theirs. I think we are so busy trying to fit people with disabilities into our world that often we do not think about what they want, what they like, and who they are. This program gives them a chance to think about and to share their ideas and wants. We are not different. We all like to be heard and we all have something to say.”●

Excerpts from JPII Words & Music CD

What Love is All About (© April 2008)

By Rachel Smolen (a peer buddy) & Tammy Vice

It feels like watching a movie with
“happy ever after”
Thinking about all the good times and
the laughter
High Fives with my twin, Rachel, Vandy scores
from buddy, Sean
Having treats for Jeanne’s birthday, and playing
board games are fun
Where I’m the one who ends up all confused
My friends are teaching me a whole new set
of rules

I know this is what love is all about
I can’t quite put it into words, but in my heart
there is no doubt
It cares beyond all boundaries, feels like a
gentle breeze
That warms me in my soul
I know this is what love is all about

Never Give Up (© 2008)

By Will McMillan (JPII Hand in Hand Program student) and Steve Nelson

I was a boy who was afraid of the monsters
I was never brave at all
The things inside me knocked me down
“Til one day I stood up tall and said:

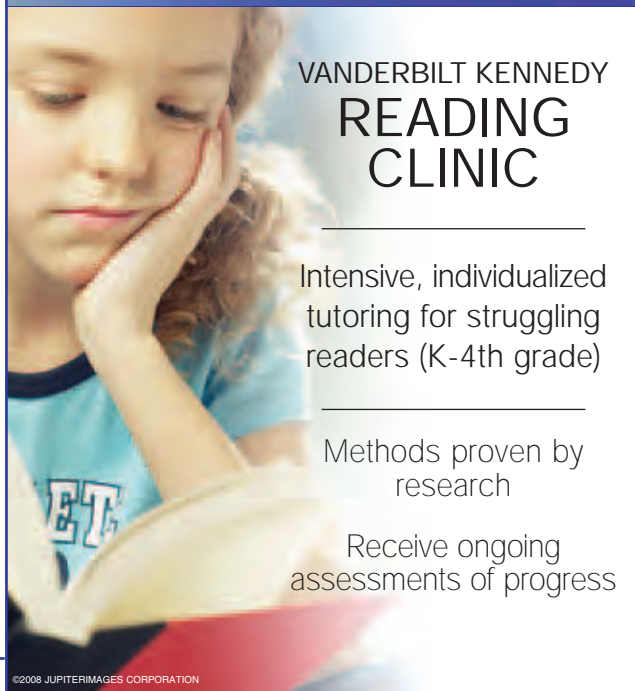
I will never give up
I’ll never back down
I won’t let anything turn me around
No, no...
I’ll never give up

Leadership Council of Vanderbilt Kennedy Center

Mrs. Cathy S. Brown, *Chair*
Mrs. Annette S. Eskind, *Past Chair*
Mrs. Barbara Gregg Phillips, *Past Chair*

Mrs. Honey Alexander	Mrs. Gail Gordon Jacobs
Ms. Sissy Allen	Mr. Chris Link & Mrs. Rebecca Link
Mrs. Dana M. Atkins	Mrs. Michael F. Lovett
Mrs. Jean Ann Banker	Mrs. Lorie Hoppers Lytle
Mrs. Madge Bass	Mrs. Jack C. Massey
Mrs. Melissa Beasley	Ms. Andrea Blake McDermott
Mrs. Ann Bernard	Ms. Pat McNellis
Mrs. Barbara T. Bovender	Mrs. Thomas E. Nesbitt, Jr.
Mrs. Linda Brooks	Mrs. R. Thomas Patten
Ms. Mary L. Carlson	The Honorable Andrew Shookhoff
Mrs. Juanita Cate	Mrs. Shirley F. Speyer
Mrs. Elizabeth Ginsberg Dreifuss	Mrs. Sue Spickard
Mrs. Ann Eaden	Mrs. Julie Carell Stadler
Mrs. Donna G. Eskind	Dr. Karen L. Summar
Mr. Glenn Funk	Mrs. Patricia W. Wallace
Mrs. Charlotte Gavigan	<i>Ex-Officio Members</i>
Mrs. Bernice Gordon	Dr. Elisabeth Dykens
Mrs. Carol Henderson	Dr. BethAnn McLaughlin
Mr. Robert W. Henderson II	Mrs. Elise McMillan
Ms. Lucile Houseworth	Dr. Louis Muglia
Ms. Bethany Jackson	Mr. Tim Stafford

SUMMER SESSIONS
JUNE 1-25 AND JULY 5-30
FALL SESSION SEPT 14-DEC 11



VANDERBILT KENNEDY READING CLINIC

Intensive, individualized
tutoring for struggling
readers (K-4th grade)

Methods proven by
research

Receive ongoing
assessments of progress

©2008 JUPITERIMAGES CORPORATION

For information on fees and services
contact (615) 936-5123
caresa.young@vanderbilt.edu

 VANDERBILT KENNEDY CENTER
FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES

Discovery is a quarterly publication of the Vanderbilt Kennedy Center designed to educate our friends and the community, from Nashville to the nation. The Center is committed to improving the quality of life of persons with disabilities of thinking, learning, perception, communication, mood and emotion caused by disruption of typical development. The Center is a university-wide research, training, diagnosis, and treatment institute. It is a Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Center funded by the Eunice Kennedy Shriver National Institute of Child Health and Human Development, and a University Center for Excellence in Developmental Disabilities (UCEDD) funded by the Administration on Developmental Disabilities.

kc.vanderbilt.edu (615) 322-8240 (1-866) 936-VUKC [8852]

Elisabeth Dykens, Ph.D., Interim Kennedy Center Director
Louis Muglia, M.D., Ph.D., Interim Associate Director
Tim Stafford, Director of Operations
Jan Rosemergy, Ph.D., Director of Communications

UCEDD

Elisabeth Dykens, Ph.D., Co-Director
Elise McMillan, J.D., Co-Director; Services
Terri Urbano, Ph.D., M.P.H., R.N., Training
Robert Hodapp, Ph.D., Research
Jan Rosemergy, Ph.D., Dissemination

LEND Training Grant (No. T73MC00050 MCHB/HRSA)
Terri Urbano, Ph.D., M.P.H., R.N., Director
Tyler Reimschisel, M.D., Associate Director

Treatment and Research Institute for Autism Spectrum Disorders
Wendy Stone, Ph.D., Director

Discovery

Editor/Writer: Jan Rosemergy, Ph.D.
Writer: Courtney Taylor
Graphic Designer: Melanie Bridges, B.F.A.

Discovery is supported in part by Grant No. HD 15052 from EKS
NICHHD and Administration on Developmental Disabilities
Grant #90DD0595

Vanderbilt University is committed to principles of Equal
Opportunity and Affirmative Action
© 2009 Vanderbilt Kennedy Center, Vanderbilt University

Please keep this Calendar insert and also check the Event Calendar on the VKC website for updates. If you wish to receive event announcements by email, send your email address to amy.pottier@vanderbilt.edu. Event announcements are no longer being direct mailed. Thank you.

NON-PROFIT ORG.
U.S. POSTAGE
PAID
NASHVILLE, TN
PERMIT NO. 85

VANDERBILT UNIVERSITY 

Vanderbilt University
Vanderbilt Kennedy Center
Peabody Box 40
230 Appleton Place
Nashville, TN 37203
Return Service Requested



Calendar of Events

Unless otherwise noted, events are free and open to the public. Events are subject to change.

Please check the calendar on our website kc.vanderbilt.edu or contact (615) 322-8240 or toll-free (1-866) 936-VUKC [8852].

Please keep this calendar and check the Event Calendar on the VKC website for updates. If you wish to receive event announcements by email, send your email address to amy.pottier@vanderbilt.edu. Event announcements are no longer being direct mailed. Thank you.

For disability-related training and other events statewide and nationally, see [Pathfinder Disability Calendar www.familypathfinder.org](http://www.familypathfinder.org)

Ann and Monroe Carell Jr. Families First

Free workshops serving parents of children, ages 2-5, diagnosed with an autism spectrum disorder. Held in Room 241 Vanderbilt Kennedy Center MRL Building
Information (615) 343-4275
familiesfirst@vanderbilt.edu
Registration kc.vanderbilt.edu/registration

Free monthly Saturday workshops

8:30 a.m.-12 p.m.

Coffee and sign-in 8-8:30 a.m. on all dates

JUNE 27

Improving Communication

JULY 25

Addressing Challenging Behaviors

AUGUST 29

Developing and Diversifying Play Routines

SEPTEMBER 26

Beginning Toilet Training



Camp Shriver Transitions and Sports 2008

MAY 16

Alphabet Therapy Workshop

Introduction for parents and teachers of method of teaching school-aged children with Angelman syndrome the alphabet, numbers, colors, and shapes.

12-6 p.m. Room 241

Vanderbilt Kennedy Center/MRL Building

Register at kc.vanderbilt.edu/registration

Information (231) 740-4375

MAY 20

Special Lecture

Phenotypic Characterization in Angelman Syndrome Using Advanced Imaging Techniques

Sarika Peters, Ph.D., Assistant Professor of Pediatrics, Section of Developmental Pediatrics, Baylor College of Medicine

Wednesday 4 p.m. Room 241

Vanderbilt Kennedy Center/MRL Building

May

MAY 15

Waddell & Reed Financial Services Charity Golf Tournament

Benefiting Vanderbilt Kennedy Center Camps
Friday 6:30 a.m. Registration, 7:30 a.m. Shotgun Start, 11:30 a.m. Lunch

Hermitage Golf Course, The General's Retreat

Contact (615) 343-5322

kc.vanderbilt.edu/golf

MAY 16

Autism: From Science to Treatment—Presentation by Autism Treatment Network Clinical Specialists & Families First Information Session

Free event for families co-sponsored with Autism Speaks and Autism Society of Middle Tennessee
Register by May 11 at kc.vanderbilt.edu/registration
Limited free childcare available

Saturday 9 a.m.-12 p.m. Room 241

Vanderbilt Kennedy Center/MRL Building

September

SEPTEMBER 2

Developmental Disabilities Grand Rounds Pilot Testing of an Intervention for Attachment-Impaired Preschool Children

Linda Ashford, Ph.D., Assistant Professor of Pediatrics and Psychology; **Patti van Eys**, Ph.D., Assistant Professor of Psychiatry

Co-Sponsor VKC Interdisciplinary Training Council and Pediatrics

Wednesday 8 a.m. Room 241

Vanderbilt Kennedy Center/MRL Building

SEPTEMBER 16

Neuroscience Graduate Seminar Serotonin Modulation of Brain Development: Impact on Affective- and Anxiety-Related Adult Phenotypes

Jay Gingrich, M.D., Ph.D., Associate Professor of Clinical Psychiatry, Columbia University Medical Center; Director, Sackler Laboratory of Basic Science, New York State Psychiatric Institute
Co-sponsor Vanderbilt Brain Institute

Wednesday 4:10 p.m. Room 1220

MRB III Lecture Hall

SEPTEMBER 23

Neuroscience Graduate Seminar Title TBA

Denes Agoston, M.D., Ph.D., D.Sc., Associate Professor of Anatomy, Physiology, and Genetics, Uniformed Services University of the Health Sciences

Co-sponsor Vanderbilt Brain Institute

Wednesday 4:10 p.m. Room 1220

MRB III Lecture Hall

SEPTEMBER 24

Lectures on Development and Developmental Disabilities Title TBA

David Nelson, Ph.D., Professor of Molecular and Human Genetics, Baylor College of Medicine

Thursday 4:10 p.m. Room 241

Vanderbilt Kennedy Center/MRL Building

VKC Summer Camps

June 8-26

TRIAD Social Skills Camp

June 8-12, June 15-19, June 22-26

Three 1-week sessions for campers, ages 7-11

3-week session for campers, ages 12-21

June 8-26

Camp Shriver Transitions and Sports Camp

For campers with developmental disabilities, ages 16-25

June 28-July 3

Music Camp

For campers, ages 16 and up, with developmental disabilities



Arts & Disabilities

Vanderbilt Kennedy Center Exhibits
Monday-Friday 7:30 a.m.-5:30 p.m., Lobby
Vanderbilt Kennedy Center/MRL Building
For information contact (615) 321-8761

APRIL 1-JULY 31

Art Through the Eyes of Autism
Co-sponsored by VSA Arts of Tennessee and
Autism Society of Middle Tennessee (ASMT)

AUGUST 10-OCTOBER 2

Looking Forward II
Co-sponsored by Davidson County Mental
Health Court, Park Center East, Tennessee
Council on Developmental Disabilities,
Tennessee Division of Mental Retardation
Services, and Tennessee Department of Mental
Health and Developmental Disabilities



*City Scape by Susannah Mayhan, Art Through the
Eyes of Autism Exhibit*

See also SibSaturdays sponsored by Autism
Society of Middle Tennessee and Down
Syndrome Association of Middle Tennessee

JUNE 20, SEPTEMBER 12, DECEMBER 19

Teen Fusion
Ages 13-17
Locations and activities vary

Tennessee Adult Brothers and Sisters (TABS)
Contact ashley.coulter@vanderbilt.edu
Register online at
kc.vanderbilt.edu/site/services/disabilityservices/
tabs.aspx

Take Part in Research

Vanderbilt Kennedy Center Research Studies
For children and adults, with and
without disabilities
Lynnette Henderson (615) 936-0448
Toll-free (1-866) 936-VUKC [8852]

Research Family Partners
kc.vanderbilt.edu/rfp
Register and be notified of research studies

StudyFinder
kc.vanderbilt.edu/studyfinder
View lists of studies, criteria, and
contact information

TN Disability Pathfinder

Phone, web, print resources
www.familypathfinder.org
English (615) 322-8529
Español (615) 322-8529 ext. 11
Toll-free (1-800) 640-INFO [4636]
tnpathfinder@vanderbilt.edu

Disability Calendar
Internet calendar of training and other
disability-related events
kc.vanderbilt.edu/tnpathfinder/calendar.html

Statewide Directory
2007-2008 Disability Services and Supports
West, Middle, and East Tennessee volumes
\$25 per directory
Contact (615) 322-8529 ext. 12
tracy.pendergrass@vanderbilt.edu

Behavior Analysis Clinic

For families of children, 3-18, with
developmental disabilities
Contact (615) 322-9007

Reading Clinic

For students in kindergarten and early
elementary grades
Summer Sessions June 1-25 and July 5-30
Contact (615) 936-5123

Sibling Supports

For children, teens, and adults who have a sibling
with a disability, chronic health care issue, or
mental health concern
For all programs below, contact (615) 936-5118
roxanne.carreon@vanderbilt.edu

**JUNE 13, AUGUST 8, OCTOBER 10,
DECEMBER 12**

SibSaturdays
Ages 5-7 and 8-13 years
Games, friends, conversation
\$10/child or \$20/family
Financial assistance available
Advance registration required
Saturdays
Room 241 Kennedy Center/MRL Building

Community Events

MAY 28-30
Tennessee Disability MegaConference
Nashville Airport Marriott
For more information, visit
www.tndisabilitymegaconference.org

ASMT Events

Autism Society of Middle Tennessee
www.tnautism.org
ASMT event information (615) 385-2077
Registration is requested for all events
ASMT members free; nonmembers \$5/family

MAY 16, JULY 18
SibSaturday

MAY 21, JULY 16
Autism Orientation

Art Exhibit – see Arts & Disabilities, above

DSAMT Events

Down Syndrome Association of Middle TN
www.dsamt.org
DSAMT event information (615) 386-9002
MAY 15
Caleb Thompson Memorial Golf Tournament
MAY 16, AUGUST 22
Circle of Friends
JUNE 6
Annual Family Picnic
SibSaturdays – see above