

This Spring 2010 issue features stories—the one below and four others listed in highlights—that provide personal perspectives of Vanderbilt Kennedy Center research, training, service, and philanthropy.

## Translational Experiences

BY EVON BATEY LEE

When I was 9 years old, my family moved from Tennessee to Germany for a year because my father received a Fulbright grant to study theology at the University of Tübingen. This journey turned out to have a powerful impact on my development for many reasons.

One critical factor was that my parents found housing in a small farming village and enrolled me in the local school—where I was the only “foreigner.” Other than a few phrases that my father had taught us prior to the voyage across the Atlantic, I spoke virtually no German upon arrival, so communication was a major challenge.

Besides the language barrier, I was clearly an oddity for these young German students. It was the early 1960s—just after the Berlin Wall was built—but before people had color televisions, the Internet, or instant messaging. My classmates’ primary exposure to Americans came from watching old westerns on black and white TV. Based on their experience and appraisal of me as a slight white girl who wore her hair in long dark braids, one of their initial questions was whether I was a “Cowboy” or an “Indian.” As we got better acquainted through studying and playing together, I was accepted with amazing kindness and hospitality.



Evon Lee at 9 years old in Germany

## A Psychologist in a Basic Science Lab

Fast forward four decades when I relived this experience of being a stranger in a strange land. Two years ago I was invited to join a VKC basic science lab studying the clinical genetics of neurodevelopmental and neuropsychiatric disorders. I was again an oddity, but this time, rather than being a grade school student, I was a middle-aged (no longer skinny) psychologist who did not speak the technical language of the basic scientists I was joining.

I had years of experience as a developmental psychologist performing diagnostic assessments of children with developmental disabilities and interacting with



Evon Lee, developmental psychologist and member of a basic science lab

professionals from various health-related fields. I had virtually no experience working directly with laboratory-based investigators. Despite my complete naïveté in this area, the lab director welcomed me into this new community and reassured me that I would have something useful to contribute.

This new adventure began with my sitting in on research meetings where the next steps of experiments were being planned and attending conferences where the results of these studies were presented. Because I was a novice and often had no clue about the topic being discussed, I sometimes passed the time by scribbling down technical terms to look up later, as well as jokes I wanted to remember.

Since psychologists often enjoy watching people, I was fascinated on multiple levels to observe this enterprise unfold. On one level, the lab itself had a personality that included

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## New Tool for Modeling Brain Disorders

BY LEIGH MACMILLAN

It’s hard to know if a mouse feels paranoid, hears voices, or experiences the cognitive symptoms of schizophrenia. So developing a mouse model for this disorder is tricky.

But mouse models (or any animal models) of schizophrenia and other complex brain disorders are precisely what are needed to unravel the pathology of these disorders and find more effective treatments.

Now, Karoly Mirnics, M.D., professor of Psychiatry, and colleagues have developed a novel strategy to generate mouse models for studying complex brain disorders. They used the new tool, described in the journal *Molecular Psychiatry*, to reduce the expression of a gene in a select set of neurons, to mimic one of the brain deficits observed in schizophrenia.

“As a field, we came to the conclusion that we can’t mimic schizophrenia in a mouse,” said Mirnics, who is also a VKC investigator. “What we can do is mimic certain pathophysiological processes that are related to schizophrenia in humans and then try to put together from many different mouse models what is really going on in the human brain.”

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## Building on Success

BY JAN ROSEMERGY



Elisabeth Dykens

“The Vanderbilt Kennedy Center is doing great—but we could be even greater,” said Elisabeth Dykens, Ph.D., in her first State of the Vanderbilt Kennedy Center address as VKC director. She reviewed the Center’s past and present success and challenged its

members to build on that success.

The Center’s impressive historical roots are a source of strength, Dykens said, pointing to its rich legacy as the second of the nation’s *Eunice Kennedy Shriver* Intellectual and Developmental Disabilities Research Centers (IDDRC).

Dykens enumerated the many factors today that contribute to the Center’s well-being, chief among them being a university-wide center within Vanderbilt. She also cited supportive, facilitative administration; talented, interdisciplinary faculty, trainees, and staff; federal grants that provide the VKC with a stable infrastructure; and mission-driven work.

“Our mission is to facilitate discoveries and best practices that make positive

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TRANSLATIONAL EXPERIENCES

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the humor and interactions of the lab members and their mentoring and shepherding by the lab director. On another level, there was the integration of multiple fields of study—cell biology, genetics, biochemistry, cognitive neuroscience. It was intriguing to see how a discovery in one area could inform or change the trajectory of research in another.

One specific area of interest for the lab was autism spectrum disorders (ASD). I presented information about measures that psychologists use to help make a diagnosis of ASD. This was useful because the lab had access to a large database that included behavioral data linked to genetic information about individuals with ASD, and I could explain how the measures were organized and scored.

Lessons Learned

Even at the end of the year, I understood only a small portion of the discussions, but this experience led me to explore journals I would never have touched before, to search websites I had never heard of, and to read books like *What's Wrong with My Mouse* and *Genetics for Dummies*. The experience also broke down stereotypes I had held about bench scientists.

I still have only the most tenuous grasp on these topics, but I experienced a metamorphosis. The generous acceptance of my ignorance coupled with the appreciation of what I actually could offer—clinical experience with “real” children and families, and knowledge of some of the psychological assessment tools—promoted a level of comfort that freed me to ask questions and to share my ideas. Through this process, I had the opportunity to make a small contribution to “science” and to build relationships with the lab members that will last—even though the lab has since moved to another university.

Reflecting on my adventures, my “take-away” messages are:

- Be open to new experiences.
- Enjoy watching how other disciplines approach problems.
- Don't worry about appearing stupid—ask questions.
- Learn a new basic vocabulary.
- Focus on building relationships.
- Look forward to “match-making”— i.e., introducing colleagues across disciplines.
- Appreciate that solving big problems requires multiple disciplines working together, and that although there are solitary moments, science is an inherently social enterprise.

If my mid50s have been this exciting, who knows what my 60s and 70s will hold!

*Dr. Lee is associate professor of Pediatrics and psychological assessment coordinator for the VKC Participant Recruitment and Assessment Core. She is most grateful to Pat Levitt, Ph.D., and the Levitt Lab members.* ■

NEW TOOL FOR MODELING BRAIN DISORDERS from page 1

To choose which pathophysiological processes to mimic, the investigators examined gene expression patterns in postmortem brain tissue from patients with schizophrenia. Mirnics explained that gene expression patterns reflect the “sum of lifetime events” that have occurred in the patient’s brain.

“Gene expression is a convergence point between genetic and environmental insults,” he said. “We don’t exactly know what those insults were, but we can see their ‘signature.’ If this signature is what produces the symptoms of the disease, then that’s what we want to mimic in an animal model.”

The most consistent findings in human postmortem brains have been deficits in “interneurons” that release the inhibitory neurotransmitter GABA, in particular a reduction in the levels of the GABA-producing enzyme GAD1. Interneurons are an “integrative force in the brain’s cortex—they likely define our working memory, which suffers devastating losses in schizophrenia,” Mirnics said.

He and his colleagues decided to systematically reduce GAD1 levels in different populations of mouse interneurons.

To do this, they created a new molecular strategy for making a transgenic mouse (a mouse with an introduced gene “construct”). Their construct included: a bacterial artificial chromosome (BAC) to direct expression to various subsets of interneurons; a microRNA to block expression of GAD1; and a gene for the fluorescent protein GFP to allow visual identification

of the targeted neurons by their fluorescent “glow.”

The researchers demonstrated that the new approach reduced the levels of GAD1 in interneurons that express a protein called neuropeptide Y. They also are targeting other groups of interneurons, and they are beginning to characterize the new mouse models and define “what

these neurons do in the brain, and how the mouse behaves if we inactivate these neurons,” Mirnics said.

Using multiple types of animal models, Mirnics hopes the team will be able to “dissect the functions of these specific populations of interneurons and how they relate to behavioral deficits in schizophrenia, and ultimately find drugs that will counterbalance the deficits in these neuronal populations.”

The new technology “has enormous potential for making animal models because it allows the researcher to target any gene for silencing in a cell type specific way,” Mirnics said. “It’s not limited to psychiatry disorders, but can be used for

virtually any type of disease model.”

He noted that the new approach is faster and less costly than mouse knockout technologies, and that it offers investigators the advantage of being able to see the cells that have been targeted (because of the fluorescent marker). He also suggested that a single construct could include multiple microRNAs to block the expression of more than one gene in a targeted cell.

Krassimira Garbett, Ph.D., Szatmar Horvath, M.D., Ph.D., and Phil Ebert, Ph.D., were key to the success of the studies. The research was supported by the National Institutes of Health, the VKC, and NARSAD. ■



Karoly Mirnics, Krassimira Garbett, and colleagues are developing new ways to generate animal models to study complex brain disorders.

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differences in the lives of persons with developmental disabilities and their families,” Dykens said. “That 1 in 5 children has a developmental disability provides a renewed importance of our mission.”

Dykens summarized key features today of the VKC as an IDDRC, a national University Center for Excellence in Developmental Disabilities (UCEDD), and a national Leadership Education in Neurodevelopmental Disabilities Training Program. She stressed how these distinct components are woven together in VKC research, service, and training missions.

The VKC today has 285 faculty and staff in over 20 academic departments across 5 Vanderbilt schools or colleges. The UCEDD has 46 programs that, collectively, serve all of Tennessee’s 95 counties. Its programs address education and early intervention, health and mental health, quality of life, recreation and the arts, and will soon address

employment of persons with disabilities.

Dykens offered ideas for next steps in research on basic mechanisms, for example, focusing on shared mechanisms across IDD etiologies, using induced pluripotent stem cells to elucidate basic mechanisms, focusing on 15q genetic disorders, and building on Vanderbilt’s strengths in personalized medicine.

In the areas of health and mental health, next steps may include building research infrastructures related to Down syndrome or autism. Dykens laid out the need to reduce disparities in health and mental health research and treatment.

“We are an eclectic group of seasoned and new researchers and staff,” Dykens summarized, “and I challenge us all to work together so that, to borrow the words of founding director Nicholas Hobbs, the Vanderbilt Kennedy Center has a tremendous thrust forward for the good.”

Dykens’s address is available on the News and Events section of the VKC website (kc.vanderbilt.edu). ■





## VKC Says Goodbye to Longtime Colleague BY CRAIG BOERNER

Wendy Stone, Ph.D., built Vanderbilt's autism treatment and research program from the ground up during her 22 years in Nashville, but she left May 1 for the University of Washington where she will direct its Autism Center.

Stone, founding director of TRIAD, is known around the globe for her breakthrough autism research in early diagnosis and intervention.

"Wendy's caring for children with autism and their families has motivated her many extraordinary achievements," said VKC Director Elisabeth Dykens. "TRIAD has grown into an outstanding array of assessment and educational services. With her leadership, excellent training programs have been developed for parents, educators, and health professionals. Finally, she has conducted groundbreaking research in early diagnosis, as well as fostering research collaboration at Vanderbilt. We appreciate all that she has accomplished at Vanderbilt and in working with the autism community locally and in Tennessee, and her national leadership in promoting evidence-based practices. We will miss her greatly but wish her well on this next chapter in her career."



Wendy Stone

The field has changed dramatically during Stone's career, and now the CDC estimates that an average of 1 in 110 children in the U.S have an autism spectrum disorder.

"I literally was the only person doing it at Vanderbilt when I started," Stone said. "There were no services in the 1980s, nobody had heard of autism. I often heard parents out in the community say it was great that I was working with 'artistic' children. The field has changed dramatically."

"Vanderbilt has been a great place to make a career," Stone continued. "And I have been in one place for 22 years, which is unusual."

TRIAD, which was established in 1998 with modest startup funds, will continue after Stone's departure. Zachary Warren, Ph.D., has been appointed director of TRIAD Psychological Services, and Nicolette Brigham, Ph.D., director of TRIAD Outreach and Training.

The Vanderbilt Autism Clinic remains a gateway into services not only for the family and child but also enrollment and involvement in research.

Dykens is chairing a Search Committee for a faculty member to lead autism research at Vanderbilt. ■

## Sleep Parent Education Classes Assist Children and Families BY CRAIG BOERNER

Vanderbilt researchers are testing the effectiveness of a series of parent education classes designed to address sleep issues for children ages 2-10 with autism spectrum disorders (ASD).

Beth Malow, M.D., M.S., professor of Neurology and Pediatrics and VKC investigator, is piloting the sleep education program, intended for future dissemination to pediatric practices across the country. Her colleagues on the project are Niru Madduri, M.D., assistant professor of Pediatrics; Courtney Burnette, Ph.D., assistant professor of Pediatrics and VKC member; and Kim Frank, M.Ed., TRIAD educational consultant.

Children with ASD have a high prevalence of insomnia due to multiple causes including poor sleep habits, which are often underemphasized, and also difficulties understanding their parents' expectations regarding sleep, the researchers said.

"Our hypothesis is that parent education will result in better sleep in children with ASD and that enhanced sleep will result in improved behavior," said Malow, principal investigator for the study. "Parents also will be empowered by their successes in the sleep arena to tackle other aspects of their child's behavior, and will have reduced levels of stress."

Malow and Susan McGrew, M.D., associate professor of Pediatrics and VKC member, previously found that parents of children with ASD who took just 6 hours of sleep education classes reported improved sleep patterns and daytime behavior for their children. Their work was published in *Journal of Child Neurology* (August 2009).

Malow is looking at whether several hours of classes are necessary, or if a shorter teaching session would be sufficient, before recommending community-wide

application. Her team also is determining the effectiveness of group sessions versus individual sessions before converting the training materials into a manual that can be disseminated to pediatric practices.

The multi-site project is funded by the Health Resources Services Administration and the Autism Treatment Network (ATN) and is being carried out in three phases over a 3-year period. Sites include Vanderbilt, Cincinnati Children's Hospital, University of Colorado, and University of Toronto. It is the first treatment trial within the ATN, a science project of Autism Speaks dedicated to the development of standards of care for children with ASD. Vanderbilt is one of 14 ATN sites across North America.

Enrollment is almost completed for the initial phase of the study, where parents are given a sleep education pamphlet with no further intervention. Sleep patterns are measured using actigraphy, in which children wear activity meters that resemble wristwatches.

The second study phase will compare two trained educator-led sleep interventions of 50 children with ASD, gauging the effectiveness of group sleep education sessions versus 45-minute individualized sessions. Enrollment will be starting soon for this phase, with Kay Artibee, R.N., conducting the intervention.

The final phase of the study will compare the study's selected sleep education program against the sleep education pamphlet with no intervention and will begin in 2011.

"In the final phase, we want to determine whether the preferred intervention demonstrates efficacy as indicated by improved sleep latency (time to fall asleep) in a larger study, across four sites with a total of 150 children," Malow said. "We also have secondary goals to examine the impact of improving sleep on measures of daytime behavior, pediatric quality of life, and parent perception of competence."

Karen Adkins, R.N., CCRC, project manager, said that the study also aims to identify parent and child characteristics that predict success with the intervention.

Malow and colleagues are carrying out related protocols of sleep in autism, including a melatonin treatment trial and a study examining the role of naturalistic, home-based devices to measure sleep.

For more information or to enroll contact Debbie Wofford, (615) 936-2004, [autismsleepresearch@vanderbilt.edu](mailto:autismsleepresearch@vanderbilt.edu). ■



COURTESY OF MALOW LAB

Sleep patterns are measured using actigraphy, in which children wear activity meters that resemble wristwatches.





## Best Buddies and Next Step Students Rock on Spring Breaks



LAURA PEVAHOUSE

Miami group at Reflection time, one of the rewarding experiences each day for all three Spring Break groups.



LAURA PEVAHOUSE

Visiting headquarters of Best Buddies International and meeting its chairman Anthony Shriver (foreground, left) was a highlight of the Miami trip.

College Spring Breaks are notorious for “fun in the sun,” but some students opt for community service and learning—still with plenty of fun. Students in Next Step at Vanderbilt joined members of Vanderbilt’s Best Buddies chapter on not one but *three* Spring Break trips that included community service, disability advocacy, and, yes, fun in the sun. Excerpts of student blogs are shared here. To read more, see [bbspringbreak.blogspot.com](http://bbspringbreak.blogspot.com).

### Miami

► I am having fun in Miami. I go to the beach, Camillus House, Children’s Museum, Coconut Grove, and the church. Meeting Anthony Shriver was my favorite time on this trip. The headquarters of Best Buddies is here in Miami. Anthony Shriver is handsome. He took us out to lunch...I’m not a morning person. It’s hard getting up. The beach is relaxing for me. I hope I get to go on a Best Buddies spring break trip next year. I love you mom and dad. —*Carrie DePauw*

► Wow! What a spring break!...Quite a few things did not go as scheduled, but it is precisely that fact that really allowed our group to learn more about each other and grow in friendship as we were forced to adapt—whether it was late nights and early mornings, missing out on the Everglades to expand our Best Buddies world with founder and president (and great guy) Anthony Shriver, or getting stuck in traffic and learning how to handle Miami drivers...I learned a lot about myself, about the workings of the world around me, and about all 10 of the other people on the trip. Each holds a really special place in my heart now because of all the memories and stories we have together. —*Nick Davidson*

► This trip has been truly unforgettable—easily the best consecutive 7 days of my college career. Serving meals at the Camillus House, hanging out at South Beach, eating delicious home-cooked meals, meeting Anthony Shriver and the other amazing employees at Best Buddies headquarters, ...spending quality time with the most accommodating people at Plymouth Congregational Church, ...getting to know my peers during REFLECTION TIME!!, and appreciating the talents of other group members during spontaneous talent shows and dance parties are what I would term the highlights of the trip. I have come to the conclusion that the reason we were able to enjoy all of these highlights is because of the genuine relationships and open minds we had toward each other. —*Stephanie*

► [On meeting and hearing Prudence, star of the 2010 Oscar-winning short documentary, *Music by Prudence*] Her disability, known as arthrogryposis, renders her body bound to a wheelchair, but definitely not her soul. Because of this congenital disorder, most of her family shunned her...she was not allowed to attend a regular educational institution (until one was implemented and funded for people with physical disabilities). Despite such adversity, Prudence honed her passion for singing, her one solace; her steadfastness helped her rise and touch people with her extraordinary talent...Prudence said to the Best Buddies, ‘Disability does not mean inability. Look inside yourself and look through yourself—everyone has a talent that needs to be shared.’ —*Shawn Love*



LAURA PEVAHOUSE

The Miami group was inspired by meeting Prudence, star of the 2010 Oscar-winning short documentary, *Music by Prudence*.

The mission of Best Buddies Vanderbilt is to enhance the lives of individuals with intellectual disabilities by providing opportunities for one-to-one friendships. Next Step at Vanderbilt is a 2-year nonresidential certification program for students with intellectual disabilities, providing individualized Programs of Study in education, social skills, and vocational training.

For more information about Best Buddies at Vanderbilt or the Spring Break trips, contact Elise McMillan, J.D., the Chapter’s faculty advisor, at [elise.mcmillan@vanderbilt.edu](mailto:elise.mcmillan@vanderbilt.edu), (615) 343-2540.

**BEST BUDDIES®**



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LAURA PEVAHOUSE





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The New Orleans group celebrated in front of Jackson Square.



Team cooking is fun in the kitchen of Carrollton United Methodist Church, which hosted the New Orleans group.

New Orleans

► We are having an AMAZING time in NOLA! The weather is great. The company is awesome. The food—to die for. Life is good :) ....We've been volunteering all morning long raking leaves, weeding, making a compost pile and having fun. —*Camila*

► ...we went on a tour of the Lower Ninth Ward (the hardest hit area of NOLA)...After five years, houses remained destroyed, the roads were in poor condition, weeds were endless, and buildings served as reminders of businesses that once were....Jeremy commented on how lucky he was to have a home in Nashville....After the tour we headed straight for the French Quarter. Our first stop: Café du Monde for some delicious beignets. —*Camila*

Washington, DC

► We met with Bobby Silverstein this morning. It was very interesting how he wanted us to have the proper way to present and to pass the bill to get more money for Best Buddies and Special Olympics and the Eunice Kennedy Shriver centers....Tomorrow we're going to talk to senators and representatives. I feel good about that and confident that I can give a speech. —*Christy Martin*

► Something about standing on the steps [of the Supreme Court] and walking through the doors...really helps to bring the reality...to light. We talked about a few of the cases that we had all heard of and tried to grasp the power the courts have to transform our country and work towards truly seizing liberty and justice for all. —*Ashley*

► We had the chance to see two different sides of Washington DC, the real and the political. We began the day by going to Emmaus, an umbrella non-profit for several organizations that serve the elderly. The group was divided into three and sent to different nursing homes where we made paper bag puppets using characters from books.

These books will be given to children through Jumpstart, an AmeriCorps project that prepares kids for school. This project is notable because it involves the youngest and oldest people. By doing service with the elderly for

children, we were able to serve two groups. —*Michael Feldman*

► [We] did some community service with old people, that was the best when I spent time with an old black woman and I brought a smile onto her Face and she had Fun when I hugged her and she gave me a kiss onto my cheek. —*Adrian Ewing*

► WE ARE IN DC, BABY! ....The best part of the day was Arlington Cemetery....Being there reminded me that I should live life to the fullest and to never stop fighting for what I believe in. I will leave you with this quote from Robert Kennedy's grave that stuck with me, 'a tiny ripple of hope.' So let us be that ripple of Hope!!!! —*Ripple of Hope* ■



The DC group at the Washington Zoo



Will McMillan at grave of Robert F. Kennedy at Arlington Cemetery



Edward Nesbitt, Next Step students, and Buddies teach a yoga position to Tim Shriver (upper left), chairman and CEO of Special Olympics International.





## Leading the Vanguard of Discovery

Laurie E. Cutting, Ph.D.

Patricia and Rodes Hart Associate Professor of Special Education  
Associate Professor of Psychology, Radiology, and Pediatrics  
Vanderbilt Kennedy Center Member  
Director of VKC Reading Clinic  
Joined Vanderbilt Kennedy Center 2009



### Research Interests

Cutting's research program is directed at understanding brain-behavior relations involved in learning and communication in children and adolescents. Her research is particularly focused on reading disabilities, language, and executive function. She also studies the cognitive and neurobiological profile of Neurofibromatosis Type 1, a genetic disorder that is commonly characterized by learning disabilities in childhood. To investigate these questions, she uses methodologies such as neuropsychological testing in combination with various neuroimaging techniques (e.g., DTI, fMRI) and experimental measures. Some of her studies also include intervention components.

### Principal Investigator

- Cognitive and Neural Processes in Reading Comprehension, *Eunice Kennedy Shriver National Institute of Child Health and Human Development*
- Neurobiology and Treatment of Reading Disability in NF-1, National Institute of Neurological Disorders and Stroke
- Reading Disability in Grades 3-8: Neurocognitive Factors, *Eunice Kennedy Shriver National Institute of Child Health and Human Development*

### Honors and Awards

- White House Fellow Regional Finalist, 2005
- Invited member of International Academy for Research in Learning Disabilities, 2001
- Council for Exceptional Children, Division of Learning Disabilities Dissertation of the Year Award, Minneapolis, MN, 1997

### Selected Publications

Clements-Stephens, A., Rimrodt, S. L., Gaur, P., & Cutting, L. E. (2008). Visuospatial processing in children with neurofibromatosis type 1. *Neuropsychologia*, 46, 690-697.

Cutting, L. E. & Scarborough, H. S. (2006). Prediction of reading comprehension: Relative contributions of word recognition, language proficiency, and other cognitive skills can depend on how comprehension is measured. *Scientific Studies of Reading*, 10, 277-300.

Locascio, G., Mahone, E. M., Eason, S. H., & Cutting, L. E. (in press). Executive dysfunction among children with reading comprehension deficits. *Journal of Learning Disabilities*.

Petrill, S. A., Hart, S. A., Harlaar, N., Logan, J., Justice, L. M., Schatschneider, C., Thompson, L., DeThorne, L. S., Deater-Deckard, K., & Cutting, L. (in press). Genetic and environmental influences on the growth of early reading skills. *Journal of Child Psychology and Psychiatry*.

Rimrodt, S. L., Clements-Stephens, A. M., Pugh, K. R., Courtney, S., Gaur, P., Pekar, J. J., & Cutting, L. E. (2009). Functional MRI of sentence comprehension in adolescents with dyslexia: Neurobiology beyond the single word. *Cerebral Cortex*, 19, 402-413.

### Education

B.A., 1993, Literature, American University  
M.A., 1995, Communication Sciences and Disorders, Northwestern University  
Ph.D., 1997, Communication Sciences and Disorders, Northwestern University

### Attraction to Developmental Disabilities Research

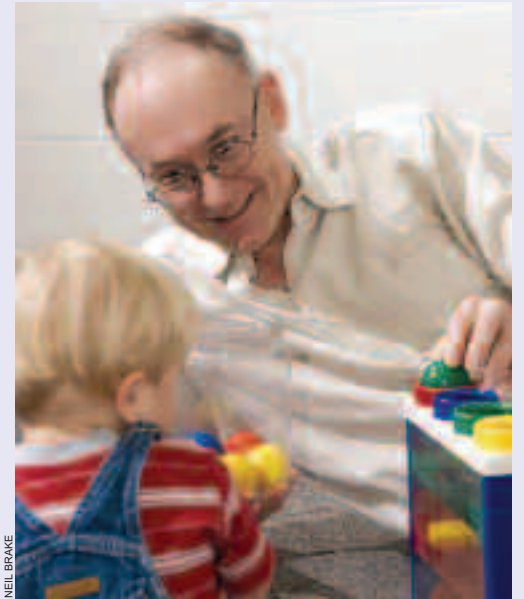
I became attracted to developmental disabilities research after working in the classroom. There was one young boy who had all the benefits you could possibly imagine in terms of resources who could not learn how to read. He did not have any connections between sounds and letters—he had no awareness at all. I thought this student was fascinating, and it was distressing to see him struggle so much. From then on, I wanted to understand what was happening in the brain when children were experiencing learning difficulties. Although my lab does some work with younger readers, much of our research is with older readers, who are supposed to be gaining information from reading, rather than learning how to read. For these older children, it's a somewhat different task with a heavier focus on comprehension. In my lab, we're trying to unravel the mysteries of how people comprehend well and what happens when they don't. We're also focused on which elements are the most important, such as vocabulary, understanding grammar, structures of text, type of text, and how all those things relate to different systems in the brain. Reading, especially understanding what one has read, is such an important life skill. Basically, my reasons for being attracted to developmental disabilities research is because I want to make children's lives better, and to contribute knowledge to the research base that will ultimately allow them to have more opportunities in life.

### Reasons for Kennedy Center Membership

I wanted to join the Kennedy Center because my overall research program is highly relevant to the Center's mission of improving the quality of life of children and adolescents with disorders of learning. My work focuses on understanding both the neurobiological and behavioral aspects of these disorders, with the goal of better understanding their etiology in order ultimately to design the most optimal interventions. The opportunities for collaboration with colleagues conducting similar research, as well as having access to the resources at the Kennedy Center, made me seek membership. In particular, I am looking forward to taking an active role in the continuation and expansion of the Reading Clinic. ■

## Observing and Measuring Behavior

BY JAN ROSEMERGY



Paul Yoder, Ph.D., VKC investigator, is co-author of *Observational Measurement of Behavior*.

One of the significant ways in which the national *Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Centers* contribute to scientific discovery is by developing and disseminating advances in research methodology. Paul Yoder, Ph.D., and Frank Symons, Ph.D., are the authors of *Observational Measurement of Behavior* (Springer, 2010). This comprehensive textbook instructs graduate students—the nation's future researchers—in how to competently conduct, observe, and measure behavior.

The textbook is unique in that it not only details the techniques and mechanics of observational methods but also covers the theoretical and conceptual foundations of these methods.

"We tried hard to provide an honest, scholarly, systematic treatment of topics that are long overdue and frequently needed by users of observational measurement methods," Yoder said.

The observational methods described can be applied in both single-subject and group-design studies. The authors guide students in how and when to use both methodologies. They also provide practical exercises and electronic media files of a sample observation session to code with multiple behavior sampling methods.

Topics covered include: (a) improving measurement of generalized characteristics through direct observation and the generalizability theory, (b) developing coding schemes and designing or adapting coding manuals, (c) determining sampling methods and metrics for observational variables, (d) training observers and assessing their agreement, (e) performing sequential analysis on observational data, and (e) assessing the validity of observational variables.

Yoder, professor of Special Education and long-time VKC investigator,

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**Grants Awarded** \*Competing renewal funded

**High Resolution MRI Mapping of CNS Plasticity**

Malcolm Avison, Ph.D. (Radiology & Radiological Sciences)  
National Institute on Drug Abuse

**Transgenic Mouse Model to Address Heterogeneity in Autism Spectrum Disorders**

Randy Blakely, Ph.D. (Pharmacology)  
National Institute of Child Health and Human Development

**Tennessee Discretionary Training Grant for Early Childhood Providers**

Nicolette Brigham, Ph.D. (Special Education)  
Tennessee Department of Education—Special Education

**Evaluation of Sensory Integration Treatment in ASD**

Stephen Camarata, Ph.D., Mark Wallace, Ph.D. (Hearing & Speech Sciences)  
National Institute on Deafness and Other Communication Disorders

**Control of Shh Activity and Signaling in the Neural Tube\***

Chin Chiang, M.D., Ph.D. (Cell & Developmental Biology)  
National Institute on Neurological Disorders and Stroke

**Targeted Peer Victimization and Development of Negative Self-Schemas in Youth**

David Cole, Ph.D. (Psychology & Human Development)  
National Institute of Child Health and Human Development

**Conventional vs. Mindfulness Intervention in Parents of Children with Disabilities**

Elisabeth Dykens, Ph.D. (Psychology & Human Development)  
National Center for Complementary and Alternative Medicine

**Molecular Mechanisms of Stimulant Abuse\***

Aurelio Galli, Ph.D. (Molecular Physiology & Biophysics)  
National Institute on Drug Abuse

**Development of Psychopathology: From Biopsychosocial Processes to Intervention\***

Judy Garber, Ph.D. (Psychology & Human Development)  
National Institute on Mental Health

**Role of Expertise in Object Perception\***

Isabel Gauthier, Ph.D. (Psychology)  
National Eye Institute

**Leadership Preparation Program in Learning Disabilities: Scientifically Based Academic Practices, Cultural Diversity, and the General Education Curriculum**

Steve Graham, Ed.D. (Special Education)  
U. S. Department of Education

**Biological Models of Molecular Pathogenesis in Hereditary Spastic Paraplegia**

Peter Hedera, M.D. (Neurology)  
National Institute on Neurological Disorders and Stroke

**High School Inclusion Program for Students with Autism Spectrum Disorders**

Carolyn Hughes, Ph.D. (Special Education)  
Organization for Autism Research

**Experimental Evolution of Circadian Oscillators**

Carl Johnson, Ph.D. (Biological Sciences)  
National Institute of General Medical Sciences

**Functional Organization of the Somatosensory System\***

Jon Kaas, Ph.D. (Psychology)  
National Institute on Neurological Disorders and Stroke

**Functional Organization of the Visual System\***

Jon Kaas, Ph.D. (Psychology)  
National Eye Institute

**Model System for Abnormalities in Electron Transport Genes in Bipolar Disorder**

Christine Konradi, Ph.D. (Pharmacology)  
National Institute on Mental Health

**Project Support and Include: Staff Development and Technical Assistance to Support Students with Emotional and Behavioral Challenges in Inclusive Settings**

Kathleen Lane, Ph.D. (Special Education)  
Tennessee Department of Education

**Dynamic Regulation of Inhibitory Synaptic Transmission Through GABA Metabolism**

Gregory Mathews, M.D., Ph.D. (Neurology)  
National Institute on Neurological Disorders and Stroke

**Inter-Areal Cooperativity During Perception of Visual Contours\***

Anna Roe, Ph.D. (Psychology)  
National Eye Institute

**Gene Networks in Neural Crest-Derived Innervation of the Lower Urinary Tract**

Michelle Southard-Smith, Ph.D. (Hearing & Speech Sciences)  
National Institute of Diabetes and Digestive and Kidney Diseases

**Elucidating the Genetic Architecture of Autism by Deep Genomic Sequencing**

James Sutcliffe, Ph.D. (Molecular Physiology & Biophysics)  
National Institute on Mental Health

**Collaboration with the Vietnamese Academy of Social Sciences**

Bahr Weiss, Ph.D. (Psychology & Human Development)  
Fogarty International Center

**Somatization and Treatment in Vietnamese Youth**

Bahr Weiss, Ph.D. (Psychology & Human Development)  
Fogarty International Center

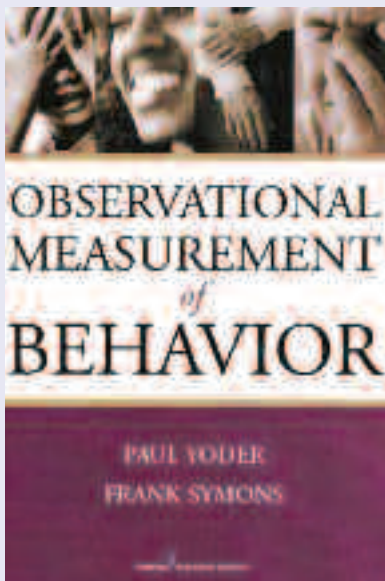
**Noradrenergic Regulation in the BNST\***

Danny Winder, Ph.D. (Molecular Physiology & Biophysics)  
National Institute on Drug Abuse

**Preparing Personnel for Intervention with Young Children With Autism**

Mark Wolery, Ph.D. (Special Education)  
U. S. Department of Education

**OBSERVING AND MEASURING BEHAVIOR** from page 6



is the past director of the VKC Observational and Quantitative Methods Core (now the Statistics and Methodology Core). He has consulted with VKC researchers on single-subject and group-design studies for over 20 years. He has conducted methodological studies and written methodological and measurement articles and chapters, including simulation studies relevant to sequential analysis. He continues to use observational measurement in his own research on early communication in children with developmental disabilities.

Frank Symons is associate professor of Educational Psychology at the University of Minnesota where he directs the Observational Methods Lab. He, too, has published a wide variety of methodological articles and co-edited a book on the application of direct observational research methods in research on individuals with intellectual and other developmental disabilities. He is a graduate of the Developmental Disabilities Research Training Program, a VKC-administered program funded for over 50 years by the Eunice Kennedy Shriver National Institute of Child Health and Human Development. ■





## Growing in Leadership BY COURTNEY TAYLOR

Children with neurodevelopmental disabilities and their families receive services from many types of professionals, who need to work together to provide care that is family-centered, community-coordinated, and culturally competent. The national network of LEND programs is preparing the next generation of these professionals. The Vanderbilt LEND is known as MIND (Mid-Tennessee Interdisciplinary Instruction in Neurodevelopmental Disabilities). We're proud to share personal perspectives by three 2009-10 trainees.

—Mary Theresa Urbano, Ph.D., M.P.H., R.N., LEND Director and UCEDD Training Director



Heather Porter

### Building Relationships

The MIND Program has helped to focus the lens of translational research that I hope to one day be able to accomplish. We are given multiple opportunities to visit

interdisciplinary clinics, and my visit to the Down Syndrome Clinic allowed me to see clinical and research needs related to hearing loss in children with Down syndrome.

Through professional and leadership development training, I've learned specific techniques for making the most of meetings with busy people, and these skills have become an invaluable tool in my repertoire.

As part of my training I was asked to lead a student meeting at the national Early Hearing Detection and Intervention Conference. The MIND Program created a space on their Wiki that we used for planning, which was opened to all students attending so they could communicate before we all met in Chicago.

The relationships I've built through MIND are too many to count. An introduction has often grown into collaboration for research projects, journal clubs, and publication opportunities. With colleagues from several agencies, I am preparing a session on self-advocacy and effectively using health care resources.

Having many different perspectives has not only helped make our session useful for families of children with special needs, but the process has helped me to see

new ways to give insights to my sister to encourage self-advocacy and to make the most of every health care visit.

—Heather Porter, Audiology doctoral student, Vanderbilt Department of Hearing & Speech Sciences

### Making Journeys Easier for Families

As the parent participant in this year's MIND program, I am first and foremost impressed that the program exists—and that so many talented trainees invest their time and energy learning how to best serve individuals and families coping with neurodevelopmental disabilities. My role is to provide the perspective of a parent of a family member with a developmental disability.

My son was diagnosed with attention deficit/hyperactivity disorder and obsessive compulsive disorder at age 5, and with Asperger syndrome, an autism spectrum disorder, at age 8. We have struggled over the years to find the best resources to help us

understand, support, and advocate for Tommy. Most of our information has come from our own efforts and from a local parent support group. It has, at times, been a difficult and frustrating journey.

In the first month of our MIND training program, we toured the Junior League Family Resource Center at the Monroe Carell Jr. Children's Hospital at Vanderbilt. Shortly thereafter, I heard another trainee comment, "I never knew about the Family Resource Center. I have referred many families there since our tour." That comment was music to this mother's ears. Just one month into the program, trainees were already offering parents information about resources they had only recently learned about through the MIND program. It made me realize just how important, and effective, this training is for professionals who have a desire to help individuals and their families obtain resources and services.

The program's emphasis on interdisciplinary instruction, particularly the areas of family-centered care and family/professional partnerships, gives me hope that future parents will have an easier journey finding the best available resources for their families.

—Ann E. Curl, Parent



Ann E. Curl

### Making Connections

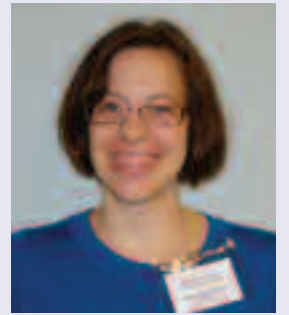
The MIND program is all about making connections. My experience has involved learning how to work collaboratively with professionals of different disciplines, sharing perspectives within our different disciplines, and coming together as a team while also recognizing our own personal strengths and weaknesses. These are connections I anticipate I'll maintain long after I have completed this program.

These connections have included working with families and learning how to approach children and their families from a whole-child, whole-family viewpoint. It is important to recognize that the service or care you are providing is just one aspect of a child's life or their family's lives, and to examine what is needed to best provide care for that child and their family. It is just one small piece of the larger puzzle.

These connections have included exploring the different resources that our community has to offer children and adults with special needs. These families need more connections, and it is important for us to be able to share these resources with the children we serve and their families.

The experiences and opportunities I have gained have helped me communicate more effectively with children and their families, and fellow providers. It definitely has changed the way that I approach providing care for my families. Hopefully all these additional connections have helped me grow to be a better audiologist.

—Lindsey Rentmeester, Audiology doctoral student, Vanderbilt Department of Hearing & Speech Sciences



Lindsey Rentmeester

The VKC LEND Program is a collaboration among faculty from the Vanderbilt Department of Pediatrics, Division of Developmental Medicine, and the Department of Hearing & Speech Sciences. It also has formal affiliations with Belmont University, Family Voices of Tennessee, Meharry Medical College, Tennessee State University, and the University of Tennessee. ■

## Dykens Honored by Davidson County Mental Health Court

The Davidson County Mental Health Court honored Elisabeth M. Dykens, Ph.D., VKC Director, at its graduation ceremony held April 15. Pictured right are Steven Murff, Director of the Mental Health Court Program; Dr. Dykens; and Judge Daniel Eisenstein, the Presiding Judge for the Mental Health Court.

Dykens has worked with Judge Eisenstein for the past 4½ years to develop a program for

participants in the Davidson County Mental Health Court, which implements and supervises a year-long structured probation treatment program for over 150 people who experience serious and persistent mental illness. Many of these individuals also have developmental disabilities and substance abuse problems. ■



COURTESY OF DAVIDSON COUNTY MENTAL HEALTH COURT





## Horses, Children, and Ministry BY LORI-JENE BRAZIER



Lori-Jene Brazier

**W**hy is a Divinity School student doing a field placement at Saddle Up!? Because everything I've done has led up to it. My first real encounters with spirituality were when my horse and I were riding in the orange groves, trails, and national forests of Florida. In college, I studied religion while working in special education and nonprofit development. Now, at Vanderbilt Divinity School, my colleagues and I share a mission to re-envision the practice of ministry.

When I learned about the Vanderbilt Kennedy Center and explored the possibility of working at Saddle Up!, a local nonprofit whose mission is "to provide children and youth with disabilities the opportunity to grow and develop through recreational activities with horses," I realized the potential for exploring the roots of my spirituality while re-envisioning what ministry can mean in a secular setting.

### Hope

For many, religion and spirituality give hope—hope that diminishes the fear and confusion that come in life. That is not to over-simplify all the world's religions, but it is to raise a commonality and to explore it through the work done at Saddle Up!

Saddle Up! gives children and parents an extraordinary gift of hope in their child's abilities—to communicate with a horse and with other people, to control their own bodies and the body of a powerful animal.

I witnessed examples of this hope at the annual Super Show, a competitive event for children in the program. On one side of the arena was a line of wheelchairs, abandoned while the kids who typically occupy them rode their horses.

As a volunteer, I walked alongside a few riders through their events. As one rider and I left the arena, his father shared that his son would never talk or interact

with them before but that once he started riding, it seemed that suddenly he had something he wanted to talk about and a reason to interact. This father, like many others, was left with a sense of hope that his child could enjoy riding so much that it might improve the quality of the rest of his life.

### The Dis-Abing of Normalcy

Saddle Up! revealed itself as a fascinating world of possibilities where the idea of "disability" gets turned around. The volunteers and instructors are the ones who seem to have the disabilities, because of the ways we are used to doing and talking about things, which are not always effective with the kids. We have to learn their rules, their ways of doing and talking.

The horses do not seem to have any problem doing this. They listen to the kids who are grooming, sitting on, and riding them. They listen to how each child communicates. They see them all as equally deserving of attention and respect. They pay attention to the unique needs, wants, and abilities of each child, thus allowing the child to flourish.

The horses have taught me that all children are "able" in some way, if only we pay attention. All have something to communicate, if only we listen and put aside our "normal" ways of communicating. "Normalcy" is the disability that keeps us from paying attention.

### What has Saddle Up! done for my ministry?

Saddle Up! is a safe and orderly space. Almost every action is part of a ritual. Everyone is honored, respected, and forgiven. Everyone belongs. At the end of each lesson, many caregivers and kids say that this was the best part of their week. Ideally, those are the qualities of a faith community.

If faith communities are not accessible, safe, and welcoming for persons with disabilities, then perhaps their leaders can join me at Saddle Up! and bear witness



Lori-Jene Brazier assisting a Saddle Up! rider

to a community that is safe, orderly, ritualistic, educational, and spiritually enriching. If children can benefit from a recreational activity like horseback riding, they surely would benefit from traditional spiritual activities like prayer, sacraments, and worship. If all children are equal in the saddle, all children could be equal in the pew. If Saddle Up! is a place where parents

feel comfortable bringing their children to do something independently, then surely faith communities could be the same.

Ultimately, I realized that if I want to get to know these kids, or anyone else, I have to make myself vulnerable to what each one has to teach me. At Saddle Up!, if I am going to be vulnerable to each child, I have to make myself vulnerable to the realization that I am the one with the disability. Here, I am dis-abled by the assumptions and expectations I put on others. I am dis-abled by the way I usually communicate. I am dis-abled by the way I stand and move around. What can the church learn from this? How might we re-envision ministry as a means of dis-abling certain habits, assumptions, and expectations in order to recognize one another as fully human?

I have learned through this placement to move out of my habits of normalcy, and to give all of my attention, and none of my dis-abling assumptions or expectations, to each child. That means I need to kneel down to one and stand far off from another; it means I need to speak to one and stay silent for another; it means I need to make eye contact with one and not with another. It means I need to let each child show me how to be present on their terms.

*Through its Disabilities, Religion, and Spirituality Program, the VKC UCEDD provides field placement opportunities for Vanderbilt Divinity School and seminary students, including within VKC Community Partner Agencies. ■*

## In Memory— Sigourney Cheek

**S**igourney Woods Cheek, "author, antique dealer, community leader, and inspirational spirit to all whom she touched," passed away on April 26. She was a member of the Vanderbilt Kennedy Center's founding Leadership Council. She supported many of Nashville's community nonprofit organizations with her leadership and deep commitment, and she will be missed greatly.

"Sigourney and Anne Whetsell co-chaired our very first VKC Leadership Dinner honoring the members of the newly established Nicholas Hobbs Donor Society," said Elise McMillan, J.D., VKC UCEDD co-director. "She worked tirelessly on the dinner and to promote the Center and to recruit some of the first members of the Hobbs Society and Leadership Council who are still active today."

Annette Eskind, founding chair of the Leadership Council, said, "We spoke of the Vanderbilt Kennedy Center often. She was a very special lady, and her interest in children and children with disabilities was very important to her. She wanted to learn and do."

Vanderbilt Kennedy Center faculty and staff and the Vanderbilt Kennedy Center Leadership Council express their deep sympathy to her family and friends. ■



## A Courageous Mother's Legacy



COURTESY OF MOTHERAL FAMILY

Susan Putman Motheral

As the parents of two daughters, Victoria and Abbey, Susan and Paul Motheral were a strong team. Their daughter Abbey is on the autism spectrum. In 2009, Susan died of breast cancer. Here, Paul Motheral relates his wife's courageous struggle to help Abbey. Along the journey, their lives were touched by Vanderbilt clinical and research programs on autism spectrum disorders. Paul wanted a living memorial for this extraordinary wife and mother, a Memorial Fund that would touch the lives of other families living with autism. Their community of McKenzie, Tennessee, responded and over 60 gifts, some even from school children, have been received for the **Susan Motheral Memorial Fund**. We thank Paul, Victoria, Abbey, and family and friends for these gifts that help Susan Motheral's legacy live on.

—Laura Pevahouse, VKC Director of Development

### Honoring Susan Putman Motheral A Mother's Crusade for Her Daughter

BY PAUL MOTHERAL, Pharm.D.

When Susan and I were first faced with the mysterious specter of autism, it was 1999. Seemingly overnight, our 2-year-old daughter Abbey had been taken from us. This once gregarious infant, who had responded to our smiles with a blinding one of her own, no longer showed interest or recognition. Soon she was well within her own world, no longer seeking our attention but turned inward, avoiding eye contact. She played compulsively with a small set of figurines, which she spent hours lining up and taking down, only to begin all over again. She ignored our calls to her.

As hard as it is to believe now, there was nothing on the news or certainly anything locally in our small town that spoke of autism. For a frantic period of time, we consulted many doctors, only to experience a constant series of disappointments. After all this effort, we were left very alone.

Abbey's behavior became very difficult. We spent days, weeks, and months dealing with a little girl who, when not completely engulfed in her own world, would scream a high-pitched wail as if in agony. Some nights,

this could go on until sunrise. Abbey would not let us comfort her, and all too often she would finally find sleep through sheer exhaustion. The best comparison for Abbey's behavior is the well-known behavior problems of Helen Keller, who was blind, deaf, and mute, before Annie Sullivan, the famous "miracle worker," broke through these barriers by teaching her sign language to communicate and connect with the world.

Further trips to medical offices ensued—medical tests, EEGs, MRIs, all which showed normal results. During this time, the only "diagnosis" that we were able to get was the all too mysterious PDD-NOS [Pervasive Developmental Disorder-Not Otherwise Specified].

Susie had graduated from Knoxville with a degree in early childhood development. This was a great blessing and provided the roots to begin what became her mission: to help Abbey overcome whatever this was, or at least to provide her with every possible means to allay the frustration and agony that our family dealt with on a daily basis.

Susie put her ear to the ground and learned of a girl in Jackson who had similar symptoms. Soon she had the name of the person who had been instrumental in helping this child. Susie contacted him and, since he lived in St. Louis, we agreed to pay his expenses and fees. This was the first time I had heard of a Behavior List.

Truthfully, the first day this man came to our home, I was skeptical. I felt I better see something miraculous or I would not be paying for many flights to and from St. Louis. But this intervention was one of our first major successes. During those few days, Susie was like a sponge, learning the basics of behavioral therapy, the building blocks of what is now known as Applied Behavioral Analysis (ABA). Susie learned enough to begin designing her own behavioral hybrid of ABA.

Susie found some of the best people and taught it to them. This was the beginning of helping lead Abbey from the woods into our world. A dedicated speech therapist provided vital speech lessons. Susie began leading what would be the start of years of working with Abbey in this manner. Her behavior wasn't magically fixed. It took many years of hard work. Susie read every book that she could find and amassed an impressive library. More impressive was that she learned good things from these books and constantly applied them to Abbey's "work."

Our next great step was taking Abbey to what is now the Autism Medication and Behavior Management Clinic in Vanderbilt Pediatrics. There we met Dr. Susan McGrew, as well as a whole center of autism professionals [VKC Treatment and Research Institute for Autism Spectrum Disorders]. They filled in large holes in our knowledge, and, for the first time, we were able to discuss what we had been living through with professionals who understood.

Susie just got stronger and better from each experience in helping Abbey. After many hard years of slow progress, our daughter was becoming a much calmer, well-behaved, focused little girl, who also happened to

have the most important thing: Abbey was happy!

Today, Abbey is still nonverbal and still has autism, but she is a happy and overall well-behaved child whose trajectory for the future seems to grow exponentially every year. Susan Motheral, Abbey's mother, is directly responsible for this. It took love, heartache, determination, great intelligence, and a tremendous will to never give up for our family.

Susie became an autism advocate. She organized local autism walks and auctions to raise money and awareness. With another family who has a child with autism, we began a nonprofit organization. Bethel College in our hometown aided us by providing a building for our use. There we helped parents who are new to the game learn to network with behavioral and speech professionals, and we provided tons of information in a variety of ways as well. For a time, we had support groups where parents could meet other parents of children with autism, to encourage them and possibly save them going down some of the dead ends we traveled in order to know they were dead ends. Susie had even begun doing interviews with a local television station and, without preparation, could give a great interview that connected with so many people.

Susie was about to catch fire, possibly to be a local or regional star in the fight against autism—which is why I've set up the Susan Motheral Memorial Fund to benefit the important work of the wonderful staff of the autism programs at the Vanderbilt Kennedy Center and Vanderbilt Pediatrics.

At age 40, to be on the safe side, Susie went in for a mammogram. We learned that she had Triple Negative Breast Cancer and upon diagnosis was already in Stage 4. As we had been partners in raising our two beautiful daughters and also in battling autism, Susie and I fought against this cancer for a year and a half. We lost her this past August 31, 2009. In lieu of flowers or other gifts, we asked that contributions be sent to the Memorial Fund that I had set up with the kind people of the Vanderbilt Kennedy Center.

I knew that Susie would be pleased to know that in her memory, precious funds would be going to help bewildered parents who come in so new to autism. It is very stressful when one of your children is in any sort of distress. The stress breaks up marriages, and when there is a child with autism, many marriages end in divorce. Maybe with more help for children as well as for their parents, that number can be decreased.

I wish you could have known Susie. You would have soon come to know her magnetism and charm, and her dedication not only to Abbey, now 12, but also to our oldest daughter Victoria, 17. Both our daughters are a testament to how powerful a mother she was. We miss her terribly. Some days, I miss her self-taught autism doctorate when I have run into a particular challenge. You had to know her to truly understand the miracle she was.

I hope that the Susan Motheral Memorial Fund can help children and families in need. It makes me very proud that her name is associated with one of her greatest qualities—the capacity to love others in a genuine and giving way. ■





Spotlight: The Gavigan Legacy of Service Charlotte Gavigan BY JAN ROSEMERGY



Charlotte and Bill Gavigan with Isabella and Billy, who decorated this family photo with stickers

Family ties brought Charlotte Gavigan to Nashville, and family ties brought her to the Vanderbilt Kennedy Center Leadership Council.

Gavigan's mother-in-law, Mollie Gavigan, who passed away in November 2006, was a member of the Leadership Council, as was Mollie's husband Dr. William ("Bill") Gavigan, III, before her. As aunt, Charlotte continues to play an important role in the life of Mollie and Bill's daughter, Jeanne, now 21, who is enrolled in Next Step at Vanderbilt, the new VKC postsecondary program for students with intellectual disabilities.

"At a family dinner, Mollie said that she wanted the Gavigans to continue to be involved in the Leadership Council, and she asked me to do it. Of course, I said yes," said Charlotte, who joined the Council in 2007.

Charlotte serves on the Council's Outreach Committee, whose members, she said, "work to influence the community, to have people become aware of what the Vanderbilt Kennedy Center does. We lend our support to activities."

She is appreciative of the range of knowledge and experience that members of the Outreach Committee bring, not only to the Leadership Council but to the community at large, ranging from a real estate agent who can help families of children with disabilities when they're moving to Nashville to financial services advisors who can help families make financial plans to provide security for a family member with a disability.

She also appreciates that as a member of the Leadership Council, she is receiving a scientific background in development and disabilities, which she can use within her extended family and share with others.

Charlotte also helps support Hand in Hand, the program for students with intellectual disabilities at Pope John Paul II High School. Mollie was instrumental in founding the program.

"Mollie really made a big difference," Charlotte said. "I'm just following in her footsteps and hope to make her proud."

In addition to caring for her two children, Billy, age 7, and Isabella, age 4, Charlotte is a diamond broker, a

natural outgrowth of her grandfather's diamond business in the Netherlands, where Charlotte was raised. Her husband Bill works in health care.

"In Holland, children and adults with disabilities receive stipends and the government provides housing, schools, programs. Here it's up to the individual, to the parents. It was a culture shock. If there weren't places like the Kennedy Center involved, then who would be? It's very scary to think about that."

Charlotte's dream for the Vanderbilt Kennedy Center is for it to have the breadth of community support that the Nashville Symphony or other major Nashville institutions have.

"I'm always blown away at every Leadership Council meeting at what the Kennedy Center has achieved," she said. "I just wish everybody knew. People who don't have children with special needs don't necessarily want to be involved. I'm doing the best I can to create awareness."



Jeanne and Mollie Gavigan

Honor and Memorial Gifts to the Vanderbilt Kennedy Center

October 24, 2009-April 13, 2010

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Ms. Catherine G. Vettors  
Mrs. Frances G. Vettors  
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In Honor of Ms. Abbey Motheral

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In Honor of Mr. Paul T. Motheral

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Mr. and Mrs. Patty Oakley

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Mr. Thomas Walker Brown

In Honor of Mrs. Judy P. Roberson

Mr. Thomas Walker Brown

In Honor of Mr. Bryan Simmons

Ms. Catherine G. Vettors

In Honor of Mrs. Jennifer Lynne Smith

Mrs. Jo Parker Lynch

In Honor of Dr. Wendy Stone

Ms. Gabrielle Alyse Levine

In Honor of Mrs. Frances G. Vettors

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Ms. Sarah C. Vettors

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In Honor of Mrs. Patricia W. Wallace

Ms. Mary Ganier McGrath

Through their gifts, Nicholas Hobbs Donor Society members (annual gift of \$1,000 or more) advance groundbreaking research in development and disabilities. For information about joining the Nicholas Hobbs Society or making Honor or Memorial gifts, contact (615) 343-4176.

Every effort has been made to ensure the accuracy of this report. If an error has been made, we offer our sincerest apology and ask that you bring it to our attention by contact (615) 343-4176.



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<http://tinyurl.com/vkcfacbook>

Dollar General and NASCAR's Braun Racing Visit VKC

Dollar General is a generous supporter of scholarships for students in the Vanderbilt Kennedy Center Reading Clinic. Students there had a treat on March 31 when special guests came to visit and share good books. Visitors were Dollar General's Tammy Buscher and Braun Racing's NASCAR driver Reed Sorenson, his crew chief Trent Owens, and Braun Racing's Jody Jennings and T. J. Puchyr. The visitors also met with VKC researchers using brain imaging to better understand reading processes and reading disabilities, and with VKC autism researchers.



NASCAR driver Reed Sorenson (left) and crew chief Trent Owens share a good book with VKC Reading Clinic students.

*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. *Discovery* is supported in part by Grant No. HD 15052 from EKS NICHD, Administration on Developmental Disabilities Grant #90DD0595, and LEND Training Grant No. T73MC00050 MCHB/HRSA.

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LEND  
Terri Urbano, Ph.D., M.P.H., R.N., *Director*  
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# CALENDAR OF EVENTS | JUNE-OCTOBER 2010



TRIAD Social Skills Camp 2009

## ■ ANN AND MONROE CARELL JR. FAMILIES FIRST WORKSHOPS

Serving parents of children, ages 2-5, diagnosed with an autism spectrum disorder

Register at

[kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration)  
Information (615) 322-6027  
[families.first@vanderbilt.edu](mailto:families.first@vanderbilt.edu)

Free monthly Saturday workshops, 8:15 a.m.-12 p.m.

### JUNE 5\*

Developing and Diversifying Play Routines

### JULY 10\*

Addressing Challenging Behavior

### AUGUST 14\*

Toilet Training: An Introduction to *The Rapid Method*

Free weekly Monday workshops, 6-8 p.m.

### JUNE 7, 14, 21, and 28\*

Building Early Communication Skills

### ■ JUNE 19

*Conference—Developmental Medicine in the 21st Century*

For community pediatricians, family physicians, and nurse practitioners.

Practical approaches to identifying and managing global developmental delay, autism spectrum disorders, intellectual disability, learning disabilities, and ADHD.

Sponsors: Vanderbilt School of Medicine, Department of Pediatrics, Division of Developmental Medicine (Center for Child Development) and VKC MIND (LEND) Training Program  
Register at

[kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration)  
Information (615) 936-0269  
[yvonne.summers@vanderbilt.edu](mailto:yvonne.summers@vanderbilt.edu)  
Saturday 7:30 a.m.-4:30 p.m.

Theater (2nd floor), Monroe Carell Jr. Children's Hospital at Vanderbilt

### ■ JUNE 19\*

*Prader-Willi Syndrome Family Day Transitions into Adulthood*

Carol Rabideau, LCSW, Social Worker, VKC UCEDD  
Saturday, 12 p.m.

### ■ JUNE 23\*

*Alphabet Therapy Workshop*

Training for parents, caregivers, and teachers in teaching alphabet, numbers, colors, and shapes to school-age children with Angelman syndrome. Also see Event Calendar on VKC website for workshops in other cities.

Register at [kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration)  
Wednesday, 12:30 p.m.

### ■ TRIAD SCHOOL-AGE SERVICES

With the Tennessee Department of Education, TRIAD offers free autism-specific workshops for parents, school personnel, and the community in locations across the state.

Information and registration, contact [Linda.Copas@state.tn.us](mailto:Linda.Copas@state.tn.us), (615) 741-7790

See also [tennessee.gov/education/speced/announcements.shtml](http://tennessee.gov/education/speced/announcements.shtml)

### ■ VKC SUMMER CAMPS

**JUNE 7-18**—For ages 7-11 years

**JUNE 7-25**—For ages 12-21 years

[TRIAD Social Skills Camp](#) (day camp)

### JUNE 27-JULY 2

[ACM Lifting Lives Music Camp for People with Developmental Disabilities](#) (1-week residential camp)

### JULY 2

[Music Campers Perform at Grand Ole Opry](#)

Friday 7 p.m.

For ticket information, see [www.opry.com](http://www.opry.com), (800) 733-6779

Registration is closed for VKC Summer Camps. Contact Tennessee Disability Pathfinder for information on summer activities.

For information on VKC Recreation and Art, contact [gretchen.herbert@vanderbilt.edu](mailto:gretchen.herbert@vanderbilt.edu), (615) 343-7046

### ■ ARTS AND DISABILITIES

[Vanderbilt Kennedy Center Exhibits](#)

Monday-Friday 7:30 a.m.-

5:30 p.m., Lobby

Information contact (615) 343-7046

### APRIL 5-AUGUST 30, 2010

[GuitArt by 2009 VKC Music Campers](#)

### ■ BEHAVIOR ANALYSIS CLINIC

For families of children, 3-18, with developmental disabilities

Contact (615) 322-9007

[n.houchins-juarez@vanderbilt.edu](mailto:n.houchins-juarez@vanderbilt.edu)

### ■ BEHAVIORAL HEALTH AND INTELLECTUAL DISABILITIES CLINIC

For individuals with intellectual disabilities, ages 17 and up,

with behavioral and mental health challenges

Contact (615) 343-9710

[behavioralhealth@vanderbilt.edu](mailto:behavioralhealth@vanderbilt.edu)

### ■ READING CLINIC

Assessment and tutoring for students through middle school

Contact (615) 936-5123

[caresa.brooks@vanderbilt.edu](mailto:caresa.brooks@vanderbilt.edu)

Unless otherwise noted, events are free and open to the public. Events are subject to change. Please check the website calendar at [kc.vanderbilt.edu](http://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](mailto:amy.pottier@vanderbilt.edu).

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

\*Event will be held in Room 241 Vanderbilt Kennedy Center/MRL Building.

**Note:** Due to remodeling, June events may be moved to other locations. Check website calendar to confirm event location.



# CALENDAR OF EVENTS | JUNE-OCTOBER 2010

## ■ 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) 343-0545  
ashley.coulter@vanderbilt.edu

### JUNE 12, AUGUST 21, OCTOBER 16

- *SibSaturdays\**  
Ages 5-7 and 8-13 years  
Games, friends, conversation  
\$10/child or \$20/family  
Financial assistance available  
Advance registration required

### SEPTEMBER 4

- *Teen Fusion\**  
Ages 13-17 years  
Games, friends, conversation  
\$15/teen or \$25/family  
Financial assistance available  
Advance registration required

## ■ 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
- See also [VUMC Clinical Trials](#)  
www.vanderbilthealth.com/clinicaltrials

## ■ TENNESSEE DISABILITY PATHFINDER

[Helpline](#), [Web Searchable Database with Calendar and Resource Library](#), [Print Resources](#)

www.familypathfinder.org  
English (615) 322-8529  
Español (615) 479-9568  
Toll-free (1-800) 640-INFO [4636]  
tnpathfinder@vanderbilt.edu  
Project of VKC UCEDD and Tennessee Council on Developmental Disabilities

## ■ COMMUNITY EVENTS

### JUNE 3-5

[Tennessee Disability MegaConference](#)  
Nashville Airport Marriott  
www.tndisabilitymegaconference.org

### JULY 16-18

[CHARGE Syndrome/Deafblind Weekend for Families and Professionals](#)  
MeadowView Marriott  
Conference Resort and Convention Center, Kingsport  
<http://www.vanderbiltchildrens.org/interior.php?mid=2966>

### SEPTEMBER 11

[Walk Now for Autism Speaks: Tennessee](#)  
Bicentennial Capitol Mall  
State Park, Nashville  
www.walknowforautismspeaks.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

### JUNE 24, JULY 22, AUGUST 26, SEPTEMBER 23, OCTOBER 28

- [Autism Education Workshops](#)  
Child care available with advance request  
Thursday 6:30-8:30 p.m. Room 241  
Vanderbilt Kennedy Center/  
MRL Building

### JULY 15, SEPTEMBER 16

- [Autism Orientation](#)  
An informational session on autism and other pervasive developmental disorders  
Child care available with advance request  
Thursday 6:30-8:30 p.m. Room 241  
Vanderbilt Kennedy Center/  
MRL Building

## ■ DSAMT Events

[Down Syndrome Association of Middle Tennessee](#)  
www.dsamt.org  
DSAMT event information (615) 386-9002

## DATES TBA

- [Circle of Friends](#)  
Monthly gathering for teens and adults with Down syndrome  
Saturday 9 a.m.-2 p.m.  
Westminster Presbyterian Church

### JUNE 17, JULY 15, AUGUST 19, SEPTEMBER 16, OCTOBER 21

- [DADS](#)  
Monthly gathering for fathers of children with Down syndrome  
6:30-8 p.m.

### SEPTEMBER 11

- [Fall Fiesta](#)  
Details TBA

### OCTOBER 23

- [Nashville Buddy Walk](#)  
Centennial Park



During the 2009 Music Camp, campers created art, painting and decorating guitar-shaped wood. Their art and campers photos are on display at the VKC through August 30.