

Preschool, Language, and Literacy Linked BY JENNIFER WETZEL

Preschool teachers' use of sophisticated vocabulary and analytic talk about books, combined with early support for literacy in the home, can predict fourth-grade reading comprehension and word recognition, new research finds.

The findings, published in *Child Development* and included in a review article in the August 19, 2011, edition of *Science*, present evidence that there are lasting, complex, and mutually reinforcing effects that flow from strong early childhood classrooms.

"We need to take very seriously the importance of teaching language in the preschool years," said David Dickinson, author of the study, professor of Education at Vanderbilt's Peabody College and a VKC member. "It's easy to look at tangible accomplishments such as counting or letter recognition but much harder to measure richness of vocabulary and language ability. Parents should take a careful look at what is happening in their kids' preschool classrooms and see if the teacher is engaging the child in conversations that are rich in language."

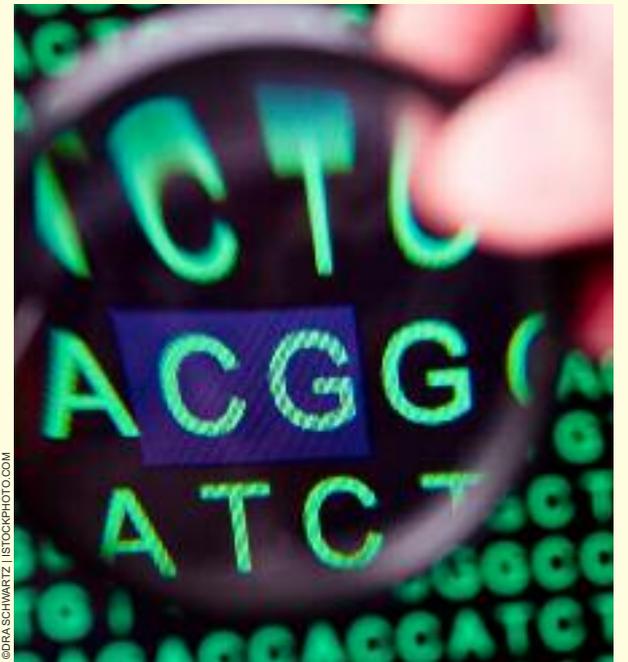
This latest research, co-authored by Michelle Porche of Wellesley College, reports results of a longitudinal study that examined in detail language experiences of children from low-income homes when they were in preschool. The authors sought to identify influences of these early experiences on children's language and literacy at the end of kindergarten and again in fourth grade.

Preschool teachers were audio- and videotaped, teachers were interviewed, and classrooms were observed for their support of language and literacy. Children were individually assessed, and parents were interviewed to learn about their education level and income and any family practices that foster language and literacy.

Although the sample was small, the researchers found robust relations between early classroom support for language and later language and reading ability.

One preschool teacher behavior that predicted children's growth was the frequency of sophisticated vocabulary use during informal conversations. Such exposure predicted children's kindergarten vocabulary, which correlated with fourth-grade word reading. Teachers' use of sophisticated vocabulary also correlated with children's kindergarten print ability, and through that word reading skill, the early vocabulary exposure indirectly affected grade-four reading comprehension.

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GODRA SCHWARTZ | ISTOCKPHOTO.COM

Number of Genes Associated with MS Doubled BY CRAIG BOERNER

An international team of scientists has identified 29 new genetic variants linked to multiple sclerosis, providing key insights into the biology of an important and debilitating neurological disease.

Multiple sclerosis (MS), one of the most common neurological conditions among young adults, affects around 2.5 million individuals worldwide. It is a chronic disease that attacks the central nervous system, which includes the brain, spinal cord, and optic nerves, and can cause severe symptoms such as paralysis or loss of vision.

Vanderbilt's Center for Human Genetic Research (CHGR) played an important role in the research published in *Nature* (August), which represents the largest MS genetics study ever undertaken and effectively doubles the number of genes known to be associated with the disease.

"We now know just how complex multiple sclerosis is," said Jonathan Haines, CHGR director and one of the principal researchers in this effort. He is T. H. Morgan Professor of Human Genetics, professor of Molecular Physiology and Biophysics, and a VKC investigator. "These new genes give us many new clues as to what is happening in MS and will guide our research efforts for years to come," Haines said.

Researchers studied the DNA from 9,772 individuals with multiple sclerosis and 17,376 unrelated healthy controls. They were able to confirm 23 previously known genetic associations and identified a further 29 new genetic variants (and an additional

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Director's Message Philanthropy Is Critical to Discovery

As parents and grandparents, teachers and friends, we all feel delight and wonder in the great “why?” and “how?” questions that children ask. Perhaps part of the joy in being a researcher is that one can continue to ask “why?” and “how?” Even better, we know that finding answers, even partial answers, one step at a time, can make positive differences in individual lives. At the Vanderbilt



Elisabeth Dykens

Kennedy Center, over 200 Vanderbilt faculty are asking crucial “why?” and “how?” questions on a daily basis in order to improve the quality of life of children and adults with disabilities and their families.

Our Center is fortunate to be part of a great university that values the research enterprise, just as it values the highest quality teaching and service. The Vanderbilt Kennedy Center, like Vanderbilt University as a whole, is making strategic decisions not just to maintain research strength but to improve it and is leading the way in ground-breaking discovery.

Yet the times are challenging for funding research. A recent estimate in *ScienceInsider* puts the success rate for grant applications submitted to the National Institutes of Health (NIH) at 17.4%, an historic low. Further, the paylines at the NIH institutes with which VKC researchers typically work also are at an all-time low; only grant applications that score among the top 10th percentile are considered for funding.

Against this backdrop, it is a tribute to the mission-focused and exceptional research conducted here that VKC researchers have continued to garner NIH and other funding. (See “Grants Awarded,” p. 10).

Our continued success likewise is a tribute to our donors—individuals and families who have joined with us in the “why” and “how” quest for discovery and have made private gifts to support the VKC Nicholas Hobbs Discovery Grants.

Our scientists need seed money to collect preliminary data to support their research ideas. These data allow them to compete more successfully for larger federal or foundation grants. The VKC provides stellar researchers with seed monies through the Hobbs Donor Society. Members contribute \$1,000 or more annually.

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National Recognition of Excellence

When awards were presented at the Annual Conference of the Association of University Centers on Disabilities (AUCD) in early November, 3 of the 12 awards were presented to individuals and representatives of the VKC University Center for Excellence in Developmental Disabilities (UCEDD).

The **Outstanding Achievement Award** was presented to **Elisabeth Dykens, Ph.D.**, VKC Director and VKC UCEDD co-director. She was honored for having “devoted her career to improving the lives of individuals with disabilities and their families through research, teaching, and community and public service.”

The **Anne Rudigier Award** recognizes an outstanding trainee or student. The 2011 recipient is **Meghan Burke**, a doctoral student in special education at Peabody College and a VKC UCEDD trainee. In the nomination letter, the UCEDD leadership wrote that “Meghan demonstrates an unparalleled combination of accomplishment and commitment to serving people with disabilities and their families.”

The **VKC UCEDD** was selected to receive the Association’s **2011 Council on Community Advocacy Award (COCA)**, nominated by COCA and the Center’s Community Advisory Council (CAC), who wrote “In the 6 years since VKC became a UCEDD, it has grown and expanded its training, community, research, and service in the community. The Community Advisory Council plays an integral role in advising and providing suggestions to the UCEDD faculty and staff. CAC input and suggestions are encouraged, listened to, and incorporated into UCEDD planning, supports, and services.”

“To receive this level of recognition after only 6 years is quite extraordinary,” said Elise McMillan, J.D., VKC UCEDD co-director. “We are so proud of Elisabeth’s and Meghan’s exceptional contributions. And for our UCEDD to be nominated by our own Community Advisory Council speaks to the remarkable partnership we have with these dedicated self-advocates, parents, and community members from across Tennessee.” ■

PRESCHOOL, LANGUAGE, AND LITERACY *from page 1*

Group book reading in preschool also had long-term associations with later reading. Conversations that included analysis of stories and discussion of words and teacher corrections of incorrect responses predicted receptive vocabulary at the end of kindergarten. This enhanced vocabulary ability was associated with better vocabulary in fourth-grade. Also, preschool teachers’ efforts to hold a child’s attention were related to fourth-grade comprehension skills.

“While raising the level of interaction in group activities is important, some of my stronger results in this study are seen from informal interactions between teacher and child, showing the importance of elevated language during times such as play and lunch,” Dickinson said.

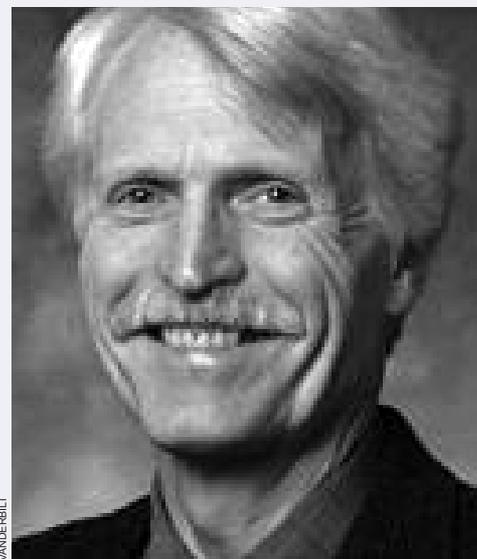
Dickinson says parents should carefully examine the nature of interactions happening at their child’s preschool to see if teachers are engaged in conversations that will stretch language and knowledge. He noted that in recent years preschool has become more of an academic setting, where previously the focus was primarily on socialization and children’s adjustment to groups.

The authors also found long-term effects of the home. Children whose parents reported providing more support for early literacy had stronger vocabulary scores in fourth grade. Finally, the structural complexity of children’s language at age 3 was associated with fourth-grade vocabulary.

Dickinson reviewed research on preschool interventions in the August 19, 2011, edition of *Science* and examined the role of adult support for language and challenges preschool interventions face when seeking to foster language growth.

Dickinson began working with Nashville preschool programs in August 2011 to develop an approach that can help provide teachers with skills to build language among their students. Specifically, he is examining how teachers can use discussions surrounding book reading in combination with teacher support for dramatic play to build language abilities. ■

Jennifer Wetzel is Senior Information Officer, Office of News and Communications, Vanderbilt Medical Center.



David Dickinson, Ph.D.



Grandparents—Catalysts for Discovery

BY JAN ROSEMERGY

Autism, like other developmental disabilities, affects not only a child but also the immediate family and extended family. Grandparents play important roles—loving caregivers, creative resource finders, dedicated advocates. And in some instances, grandparents may be able to provide gifts for research to find answers that may help create a better future for their grandchildren and for other children with developmental disabilities. This is the story of the **Robert E. and Donna Landreth** family.

As they searched for resources to help their daughter and son-in-law raise their son with autism, Mr. and Mrs. Landreth became connected with the Vanderbilt Kennedy Center. As an engineer and businessman from Midland, Texas, Bob Landreth understood the crucial role of research and development. The family understood the need to ask large questions in understanding and treating ASD. In 2009, their extraordinary generosity and foresight were embodied in the **Landreth Family Discovery Grant**, which was directed to studying sensory processing in autism spectrum disorders (ASD).

With support from the Landreth Family Discovery Grant, **Carissa Cascio**, Ph.D., assistant professor of Psychiatry, undertook research on the sense of touch in ASD, using both behavioral and brain imaging approaches. Since the early development of the touch system is guided by genes, she collaborated with **Jeremy Veenstra-VanderWeele**, M.D., assistant professor of Psychiatry. Now, almost 2 years later, their pilot work has yielded significant findings and has helped them garner federal funding for larger studies to continue this research.

“At birth, the touch system is more developed than other senses,” Cascio said. “Autism is develop-

ing in infancy, and touch plays a big role in social interaction between parents and infants. So differences in ways that infants with ASD experience touch can have serious cascading effects for later social development.”

The Cascio Lab uses DTI (Diffusion Tensor Imaging), a specialized form of Magnetic Resonance Imaging, to look at the way that touch is processed in the brain. A better understanding of the brain systems involved may lead to identifying early

sensory signals and measured how strong, or effective, those pathways were in conveying sensory information. She found that weakness in those pathways was associated with hypersensitivity to social touch, but not to nonsocial touch, in young children with ASD.

The Landreth Family Discovery Grant provided funding to enable Cascio to use the practice scanner and the MRI scanners in the Vanderbilt University Institute for Imaging Science. Since not all the children with ASD in the study could do a successful MRI scan, the Discovery Grant allowed the collection of behavioral data on all children. While MRI data collection is ongoing, behavioral findings will be published in *Research in Autism Spectrum Disorders*. The grant also supported Cascio’s collaboration with Veenstra-VanderWeele to investigate how genetic variation may affect defensiveness to touch.

“MRI technology is expensive, and even with our best guess of which children we’ll be able to scan, given the confining space and scanner noise, sometimes we lose data,” Cascio said. “This support was critical to me as a young investigator, allowing me to conduct the study and to gather preliminary data, which has helped me garner external NIH funding.”

Preliminary data provided by the Landreth Family Discovery Grant have helped both Cascio and Veenstra-VanderWeele compete successfully for new grants from the National Institute of Mental Health. Thanks to the Landreth family’s investment in discovery, these researchers will soon pursue their novel approaches on a larger scale. By leveraging their giving via a Discovery Grant, the Landreth Family may improve not only the future of their grandchild, but the future of many children with developmental disabilities and their families as well. ■



MEGAN ROBERTSKIDTALK



LARRY WILSON

Research funded by the Landreth Family Discovery Grant compared reactions to nonsocial touch (left photo) and social touch (right photo) in children with autism.

markers for autism, allowing earlier diagnosis and intervention, as well as the possibility of more effective behavioral or pharmacological interventions.

The Cascio Lab also uses behavioral testing to look at reactions to two types of touch. The first is “social touch,” where a child is touched by another person, e.g., lotion is rubbed on the skin, or a hand is stroked with a soft cloth. The second is a “internally controlled touch,” or “nonsocial touch,” where a child has control of what touches the skin and no other person is involved.

Using MRI, Cascio looked at two brain pathways that are known to be important in conveying

NUMBER OF GENES ASSOCIATED WITH MS DOUBLED *from page 1*

five that are strongly suspected) conferring susceptibility to the disease.

Many genes implicated in the study are relevant to the immune system, shedding light onto the immunological pathways that underlie the development of multiple sclerosis. One-third of the genes identified in the study have been previously implicated in playing a role in other autoimmune diseases such as Crohn’s disease and Type 1 diabetes, Haines said.

Previous studies also have suggested a link between vitamin D deficiency and an increased risk

of MS. Researchers in this study identified two genes involved in the metabolism of vitamin D, providing additional insight into a possible link between genetic and environmental risk factors.

The international team led by the universities of Cambridge and Oxford, and funded by the Wellcome Trust, includes contributions from nearly 250 researchers as members of



Jonathan Haines, Ph.D.

the International Multiple Sclerosis Genetics Consortium and the Wellcome Trust Case Control Consortium. ■

Craig Boerner is National News Director, Office of News and Public Affairs, Vanderbilt Medical Center.



Promoting Person-Centered Thinking BY COURTNEY TAYLOR

Incorporating person-centered thinking into planning with individuals with disabilities and their families is a growing movement within the disability field. Thinking in a person-centered way means recognizing what is important to a person, identifying strengths and gifts, and building bridges between identifying supports that will ensure success and the actual implementation of those supports.

Carol Rabideau, VKC social worker, was certified recently as a person-centered thinking trainer. She is infusing these elements into the work that she and others at the Center are doing with individuals with disabilities and their families. Funding for the training was provided by the VKC, the Tennessee Council on Developmental Disabilities, and the Tennessee Department of Intellectual and Developmental Disabilities.

“Person-centered planning is grounded in understanding what is important to or for a person from their standpoint,” said Rabideau. “It means trying to be creative as we help put in place things that help them feel happy and successful, as opposed to trying to plug people into our existing ideas or systems. All of us in the disability field want to do what is best, and we

often think we are person-centered, but at times we’re not and we’re not even aware of that.”

One illustration of how Rabideau is using the person-centered planning tools developed by the Learning Community for Person-Centered



KYLIE BECK

Person-centered planning meeting. Left to right: Betty Carnahan, paternal grandmother; Carol Rabideau; Laura Doutré, deputy director, Policy and Innovation, Department of Intellectual and Developmental Disabilities; Portia Carnahan, VKC AmeriCorps member; Cathy Rader, Metro Parks

Practices is how she lends support to Next Steps at Vanderbilt students. For each new student, Rabideau holds a person-centered meeting to understand what is important to them and for them, what their goals are for the next 2 years at Vanderbilt, and what their goals are for their own lives.

Rabideau assists the students in creating a series of 1-page profiles. The first profile usually focuses on different areas of their lives, e.g., leisure activities, family, school. When they approach completion of the 2-year program, Rabideau and each student develop a 1-page profile on employment. Through their internships, they learn about themselves and what is important to them. They have a better idea of their strengths in an employment setting, what people admire about them as employees, and what kind of support they need to be successful. Rabideau helps them document this knowledge and is optimistic about the usefulness of the profiles.

Rabideau also has used some of the person-centered tools with the first VKC AmeriCorps member.

In this case, a more detailed document was created.

“As a social worker, I’ve wanted to work towards social justice for everyone no matter what their life circumstances, but especially for people with developmental disabilities, who may not have always had a voice in their own lives.” ■

Next Steps Students Receive Certificates BY COURTNEY TAYLOR

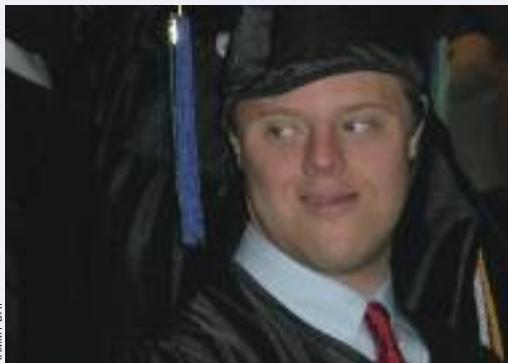
During their course of study, students in the Next Steps at Vanderbilt program have an opportunity to take classes at the Tennessee Technology Center at Nashville (TTC-N). Two students, Hallie Bearden and Edward Nesbitt, are pioneers who began working towards supplemental certificates in September 2010. In August, Bearden and Nesbitt participated in the TTC-N graduation ceremony. Each received a supplemental certificate that outlines proficiencies in their respective fields. Both students aim to work in an office setting.

In the Business Systems Technology program, Bearden and Nesbitt learned basic office procedures. They completed units in office safety, work ethics and professionalism, and keyboarding. They demonstrated mastery of clerical tasks like collating, basic data entry, email, and book and equipment inventory. At TTC-N, they worked at a reception desk, used copiers, prepared mailings, and did filing.

“The instructors at TTC-N are amazing, and we work so well together,” said Next Steps Director Tammy Day. “We identified office procedures that would be beneficial for our students to learn and found creative ways for them to practice those skills. The instructors did research and found a textbook

On August 12, Bearden and Nesbitt, wearing caps and gowns, participated in the TTC-N graduation ceremony.

“We are in the business of helping people, *all* people, become prepared for employment,” said TTC-N Director Mark Lenz.



TAMMY DAY



Edward Nesbitt and Hallie Bearden, the first Next Steps students to earn TCC-N Supplemental Certificates.

that was written at an appropriate level for our students. More important, they created a classroom environment that was accepting and modeled an inclusionary attitude to their other students.”

Next Steps at Vanderbilt currently has students working towards supplemental certificates in Automotive Technology and Early Childhood Education. Other students have participated in the Machine Tool & Die program and the Automotive Collision Repair programs.

Next Steps at Vanderbilt is a 2-year certification program for students with intellectual disabilities. Students self-direct the development of their Program of Study through initial and on-going person-centered planning activities. ■



“Smart” Technology for Teens with Autism BY JAN ROSEMERGY

The unfortunate reality is that despite intensive treatments and supports, many children and adolescents on the autism spectrum still experience difficulty with social learning. Nilanjan Sarkar, Ph.D., professor of Mechanical and Computer Engineering, and Zachary Warren, Ph.D., assistant professor of Pediatrics and Psychiatry, have partnered to develop new “smart” technologies that might provide highly individualized interventions—in a sense, “personalized medicine” for autism.

“We need to be developing not just incremental ways of improving treatments, but whole new treatment paradigms,” Warren said.

Impairments in social communication skills are among the core features of autism spectrum disorders (ASD). Research has shown that children with ASD show atypical viewing patterns during social interactions. Although several studies have used eye-tracking technology to monitor eye gaze for analysis offline, there has not been a real-time system that could monitor eye gaze dynamically and provide individualized feedback.

In their AUTOSLab, Sarkar and Warren have developed and are testing VIGART—Virtual Interactive System with Gaze-Sensitive Adaptive Response Technology. It is capable of delivering individualized feedback based on a child’s dynamic gaze patterns during virtual reality-based interaction.

VIGART collects physiological data as an individual engages with a virtual reality system

that uses computerized avatars to simulate real-world interactions. The system has the “intelligence” to change in response to the physiological data of the individual in order to enhance learning. To detect emotional responses, the physiological signals collected include electrophysiological skin response, heart rate, body temperature, and electromyography (EMG) for skeletal muscles, as well as eye gaze, pupil diameter, and eye blinking.

“This is technology-assisted autism intervention,” Sarkar said. “It combines eye gaze and other physiological data into one coherent understanding of how an individual is performing

and the level of engagement, and then responds by presenting a new task or level of difficulty in order to scaffold individual skills. It is a dynamic, not a static, system.”

The technology is able to collect data in microseconds during an intervention, something impossible to do in traditional behavioral observation, Warren pointed out.

In an early study, 6 adolescents with high-functioning autism, ages 12 to 17, watched computer avatars narrate a personal story. The avatars blinked like typical teenagers and had facial expressions appropriate to the story’s emotions. The system tracked how often and how long the teens looked at various regions of interest, e.g., a narrator’s face or an object. When participants were more engaged, they were about 14% more likely to look at faces and 60% less likely to look at background.

“Endowing a virtual reality with the ability to understand the physiology of how an individual with ASD is responding to a social environment could facilitate learning at a more rapid rate than a static technology that is just providing cues,” Warren said.

This innovative research was funded initially by a VKC Marino Autism Research Institute Discovery Grant. The current technology development and research are being supported by grants from the National Institute of Mental Health and the National Science Foundation. ■



Demonstration of Virtual Reality in AUTOSLab with a young child.

Helping Pediatricians and Families Identify Autism Earlier BY JAN ROSEMERGY

Awareness of the behavioral signs of autism has increased dramatically, along with the knowledge that early diagnosis is crucial in order to access early interventions. Yet too often families who seek an assessment find they have to travel to a large medical center and often wait weeks or even months for an assessment. Waiting lists can be long, since too few pediatricians or psychologists are trained for autism diagnosis. Meanwhile, families live with anxiety and the fear that they may be losing precious time in finding help for their child.

For 4 years, TRIAD leadership has collaborated with the Tennessee Chapter of the American Academy of Pediatrics (TNAAP), TennCare, the VKC LEND, and the Tennessee Early Intervention System to develop and implement a model program, STAT-MD, to train community pediatric providers to provide autism assessments in their local communities.

“Our aim is to drastically reduce the wait for diagnosis, and to make a significant impact not only on the child but also on the family,” said VKC TRIAD Director Zachary Warren, Ph.D., assistant

professor of Pediatrics and Psychiatry. “Without a formal diagnosis, families encounter barriers in obtaining early intervention or school-based services, or in getting insurance coverage for therapeutic services.”

From the outset, Warren and his colleagues, including Dr. Quentin Humberd, TNAAP - Pediatric Society Foundation President, have been tracking the success and impact of this statewide training program. Twenty-seven pediatric providers participated in a series of regional training activities over the past 4 years, with model implementation and practice change tracked across the entire sample well over a year following training. Those implementing the protocol documented significant shifts in within-practice diagnostic screening and consultation behavior, with a 65.5% increase in ASD-specific consultations reported in community pediatric settings over the study period. Accuracy of these consultations performed within practice was also quite high, with pediatric diagnostic judgments agreeing over 90% of the time with comprehensive assessments performed later.

“We wanted to be sure that accuracy was high and that this training truly made a difference, before we disseminated the model to other communities around the country that are struggling with the same issues,” Warren said.

After the training, pediatricians reported that they felt more comfortable discussing ASD diagnoses with families. They also reported that they thought it was appropriate for families to receive this diagnostic information from their primary pediatric provider in their home community. Feedback from families about the diagnostic process has been positive as well.

“Prior to training, the most common pediatric practice was to screen for autism but then to refer to a specialized center for diagnosis, often resulting in long waits. Now large practices are offering rapid enhanced diagnostic consultation within practice when screening or when parents bring up concerns.”

Warren expressed appreciation for the Tennessee Early Intervention System’s willingness to partner in this effort and to accept eligibility based on an autism diagnosis by a pediatric provider. ■



Leading the Vanguard of Discovery

Jeremy Veenstra-VanderWeele, M.D.

Assistant Professor of Psychiatry, Pediatrics, and Pharmacology • Vanderbilt Kennedy Center Investigator • Joined Vanderbilt Kennedy Center 2007



Research Interests

My current research involves development of genetic mouse models that probe abnormal serotonin system function in autism spectrum disorders (ASD). These efforts include collaborative work with Randy Blakely, Ph.D., and James Sutcliffe, Ph.D., analyzing the effects of serotonin transporter variants on behavior and brain development. Other studies focus on mice with mutations in other genes that have been implicated in the regulation of blood serotonin levels. The goal is to translate findings in these mouse models into new treatments for children with ASD. A parallel research arm is testing new treatments based upon findings in the mouse model of fragile X syndrome.

Principal Investigator

- Murine Genetic Models of Autism, National Institute of Mental Health
- Neurobiological Signatures of Social Dysfunction and Repetitive Behavior, National Institute of Mental Health
- Functional Studies of the OCD-Associated Neuronal Glutamate Transporter, Brain and Behavior Research Foundation (NARSAD)

Honors and Awards

- National Institute of Mental Health Outstanding Resident Award, 2003
- American College of Psychiatrists Laughlin Fellowship, 2005-06
- American Psychiatric Association Resident Research Award, 2006
- American Academy of Child and Adolescent Psychiatry Junior Investigator Award, 2009-11
- International Association of Child and Adolescent Psychiatry and Allied Professions Donald J. Cohen Fellowship Award, 2010

Education

- A.B., 1996, Psychology, Harvard University

- M.D., 2001, Medicine, University of Chicago Pritzker School of Medicine

Attraction to Developmental Disabilities Research

I grew up knowing that the son of a close family friend had autism, which at the time was a pretty confusing concept. I have a vivid memory of asking what being 'artistic' had to do with John hiding under the bed when we visited. As I grew older, I came to empathize with his experience, and with his family. I think that all of us can relate on some level to the extreme distress that he showed in a socially stressful situation, but most of us can only imagine what it is like to experience that distress so much of the time, with so little relief.

I guess this experience primed me for when, not knowing exactly what I wanted to do, I landed a summer job in the lab of Dr. Ed Cook, a child psychiatrist launching a genetics lab. Dr. Cook encouraged all of his students to spend some time seeing patients in his clinic. I remember one patient in particular who showed me the reward of hard-won connection. After my third or fourth visit with little indication that she was aware of my presence, she tapped her shoe in my direction. Her parents explained that she was asking me to tie her shoe, her way of reaching out to me across the social and communication divide presented by her autism.

As a result of these experiences, and my clinical work as a child psychiatrist with children with autism spectrum disorders, I find myself pulled to understand why social communication that feels so natural to some can be so unnatural for others. Likewise, seeing children who find themselves stuck in repetitive patterns of behavior makes me wonder what in the brain is causing this behavioral "hiccup." Mouse models of autism susceptibility offer a path to understanding how brain development and function are altered, with the hope that this path also will lead to new treatments.

Reasons for VKC Membership

I came to Vanderbilt for a postdoctoral research fellowship with the intent to learn molecular approaches that would prepare me for a new line of research. In deciding that Vanderbilt was the best place for further training, I had focused on the tremendous strengths and resources here in neuroscience research, but I had not spent much time learning about the Vanderbilt Kennedy Center and the tremendous variety of research focused on developmental disorders, from very basic neurobiology to clinical and systems research.

Upon arriving here, I discovered that Vanderbilt had much more to offer than "just" world-class molecular neuroscience. I found a terrific community of psychologists, physicians, and researchers focused on central questions related to autism spectrum disorders and other developmental disabilities. I continue to benefit from interactions with VKC members who bring different ideas and perspectives to the central problems with which children and families struggle. Those conversations have grown into collaborations, including work to evaluate medications based upon the mouse model of fragile X syndrome. I feel incredibly blessed to have found such a vibrant community of scholars and clinicians focused on how to better understand and serve individuals with disabilities.

Selected Publications

- Veenstra-VanderWeele, J., Kim, S. J., Gonen, D., Hanna, G. L., Leventhal, B. L., & Cook, E. H., Jr. (2001). Genomic organization of the *SLC1A1/EAAC1* gene and mutation screening in early-onset obsessive-compulsive disorder. *Molecular Psychiatry*, 6, 160-167.
- Veenstra-VanderWeele, J., & Cook, E. H., Jr. (2004). Molecular genetics of autism spectrum disorder. *Molecular Psychiatry*, 9, 819-832.
- Dickel, D. E., Veenstra-VanderWeele, J., Cox, N. J., Wu, X., Fischer, D. J., Van Etten-Lee, M., Himle, J. A., Leventhal, B. L., Cook, E. H., Jr., & Hanna, G. L. (2006). Association testing of the positional and functional candidate gene *SLC1A1/EAAC1* in early-onset obsessive-compulsive disorder. *Archives of General Psychiatry*, 63, 778-785.
- Carter, M. D., Shah, C. R., Muller, C. L., Crawley, J. N., Carneiro, A. M. D., & Veenstra-VanderWeele, J. (2011). Absence of preference for social novelty and increased grooming in integrin $\beta 3$ knockout mice: Initial studies and future directions. *Autism Research*, 4, 57-67.
- McPheeters, M. L., Warren, Z., Sathe, N., Bruzek, J. L., Krishnaswami, S., & Veenstra-VanderWeele, J. (2011). A systematic review of medical treatments for children with autism spectrum disorders. *Pediatrics*, 127, 1312-1321. ■

DIRECTOR'S MESSAGE from page 2

Some families have made gifts of \$25,000 or more and have directed their gifts to areas like autism or Down syndrome research. On page 3, you can read what has been learned about sensory responses in autism because of the Landreth Family Discovery Grant.

Hobbs Discovery Grants that have led to large federal or foundation grants represent an impressive

34:1 return on investment—a more robust return than many other investments. There is no way, however, to calculate the difference that this investment will make over time in the lives of individuals with disabilities and their families.

Within the next month, we will proudly announce the new recipients of 2011-12 Hobbs Discovery Grants. We have had a record number of

applications from VKC researchers who are pursuing creative, game-changing ideas. Yet we will be able to fund only a quarter of them.

A Hobbs Discovery Grant satisfies our collective curiosity—yours and ours—to ask "how" and "why" questions that lead to positive changes for children and adults with disabilities and their families. Join us in this quest for discovery. ■

**Accolades** BY AMY POTTIER

Leonard Bickman, Ph.D., Betts Chair and professor of Psychology; director, Center for Evaluation and Program Improvement (CEPI); professor of Psychiatry, **will receive the American Evaluation Association's 2011 Alva and Gunnar Myrdal Evaluation Practice Award**, given to an evaluator who exemplifies outstanding evaluation practice and has made substantial cumulative contributions to the field.

Aaron Bowman, Ph.D., assistant professor of Neurology, **presented an invited lecture for the Gordon Research Conference on Cellular and Molecular Mechanisms of Toxicity**. The title of his presentation was "Patient-Derived Stem Cells as a Translational Model of Toxicological Risk." He will also present the **keynote address at the 27th International Neurotoxicology Conference**. His keynote will discuss "Stem Cells ... Super Heroes or Super Villains of Neurotoxicology?"

Camilla Benbow, Ed.D., Patricia and Rodes Hart Dean of Education and Human Development, and **David Lubinski**, Ph.D., professor of Psychology and Human Development, will deliver a **keynote address at the 2011 annual convention of the National Association for Gifted Children**. The address will be titled "Critical Questions in Talent Development: Answered Through 40 Years of Longitudinal Research by Study of Mathematically Precocious Youth (SMPY)." On September 1, this longitudinal study of over 5,000 intellectually talented participants turned 40 years old.

Elisabeth Dykens, Ph.D., Annette Schaffer Eskind Chair and VKC director, has been **elected co-chair of the Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Centers Directors**. She also has been **appointed to the Scientific Advisory Board of the John Merck Fund**.

Kathryn Edwards, M.D., Sarah H. Sell and Cornelius Vanderbilt Chair and professor of Pediatrics, has received the **2011 Distinguished Physician Award of the Pediatric Infectious Disease Society**. The Society's highest honor, it is presented annually to a pediatrician who has an extensive, distinguished career in pediatric infectious diseases.

*Kathryn Edwards, M.D.*

Jonathan Gitlin, M.D., Cornelius Vanderbilt Chair and professor of Pediatrics, has been **elected to the Institute of Medicine of the National Academies**.

Megan Hart, M.Ed., coordinator of Education and Training Services for Tennessee Disability Pathfinder, **presented at the 2011 Alliance of Information and Referral Systems (AIRS) conference**. She discussed "Disability Etiquette and Accessibility: Providing I&R Services for People with Disabilities."

Katherine Hartmann, M.D., Ph.D., deputy director of the Vanderbilt Institute for Medicine and Public Health, director of Women's Health Research, and professor of Obstetrics & Gynecology and Medicine, has been **named associate dean for Clinical and Translational Scientist Development**.

Craig Anne Heflinger, Ph.D., associate dean for Graduate Education at Peabody College and professor of Human and Organizational Development, received the **Mentoring Award from Vanderbilt's Margaret Cuninggim Women's Center**.

Lynnette Henderson, Ph.D., VKC UCEDD associate director of Community Services and research assistant professor of Pediatrics, will deliver the **keynote address at the 2011 annual meeting of the Volunteer State Rehabilitation Association**.

Carolyn Hughes, Ph.D., professor of Special Education, was among 10 national researchers recognized for **Exceptional Service to the Field by the American Association on Intellectual and Developmental Disabilities**.

*Carolyn Hughes, Ph.D.*

The award recognized Hughes and colleagues from other national universities as authors of the *Supports Intensity Scale*, which was called a "game changing" contribution to the Association, the field, and the lives of people with intellectual and other developmental disabilities.

David Lubinski, Ph.D., professor of Psychology and Human Development, received the **2011 MENSA Senior Investigator Award for Research Excellence** for his publication, Lubinski, D. (2009). Cognitive epidemiology: With emphasis on untangling cognitive ability and socio-economic status. *Intelligence* 37, 625-633.

Beth Malow, M.D., professor of Neurology and Pediatrics and medical director of the Vanderbilt Sleep Disorders Center, was **named the Burry Chair in Cognitive Childhood Development**. This chair focuses on the early detection and treatment of cognitive

*Beth Malow, M.D.*

syndromes with genetic characteristics, such as Asperger's syndrome. Malow is also the **Principal Investigator on NeuroNEXT, a consortium of academic medical centers** that will be participating in neuroscience clinical trials involving both adults and children, including those with neurodevelopmental disorders.

Bruce McCandliss, Ph.D., Patricia and Rodes Hart Chair and professor of Psychology and Human Development, and colleagues **organized a conference for the New York Academy of Science on Education and Cognitive Neuroscience**.

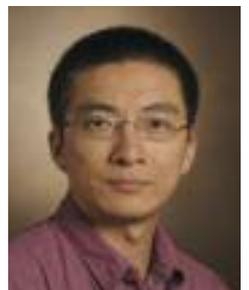
*Bruce McCandliss, Ph.D.*

Carol Rabideau, L.C.S.W., has earned recognition as a **Certified Trainer of Person-Centered Thinking** by the Learning Community for Person-Centered Practices.

Jeremy Veenstra-VanderWeele, M.D., assistant professor of Psychiatry, Pediatrics, and Pharmacology and director of the Fragile X Treatment Research Program, received a **Biobehavioral Research Award for Innovative New Scientists (BRAINS) award from the National Institute of Mental Health**. These awards support innovative and groundbreaking research projects led by early stage investigators to explore the complex mechanisms underlying mental disorders, novel treatment, and/or prevention strategies. Since 2009, 7-12 investigators have been selected annually. Veenstra-VanderWeele is the first Vanderbilt faculty member to receive this award.

David Zald, Ph.D., associate professor of Psychology and Psychiatry, was one of six Vanderbilt faculty members to receive a **Chancellor's Award for Research for outstanding contributions to research and scholarship**. He received the award for his work on the relationship between individual differences in dopamine functioning and personality traits associated with risk for drug abuse.

Qi Zhang, Ph.D., assistant professor of Pharmacology, is one of 49 researchers nationwide to win a **2011 National Institutes of Health Director's New Innovator Award**. The award is given each year "to catalyze giant leaps forward" in biomedical research and the betterment of human health. ■

*Qi Zhang, Ph.D.*



Tennessee and Beyond—Vanderbilt LEND Renewed BY JAN ROSEMERGY

Tennessee and the nation face an urgent need for leaders in health care for children and youth with neurodevelopmental disabilities. The renewal of the Vanderbilt Leadership Education in Neurodevelopmental Disabilities (LEND) training grant will mitigate that need. Funding from the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Services, is for \$2,932,500 over 5 years.

The Vanderbilt LEND is part of a national network of 43 programs, including the Boling Center for Developmental Disabilities (University of Tennessee-Memphis). George Jesien, Ph.D., executive director of the Association of University Centers on Disabilities, characterized the LENDs as "among the best in the country in providing preprofessional, interdisciplinary training for a wide range of health and allied health professionals that serve children and adolescents with developmental disabilities, including autism."

Vanderbilt's LEND is led by Director Terri Urbano, Ph.D., M.P.H., R.N., professor of Clinical Pediatrics and VKC UCEDD director of training. A name change from MIND (Mid-Tennessee Interdisciplinary Instruction in Neurodevelopmental Disabilities) to Vanderbilt LEND reflects Vanderbilt collaborations, the statewide and national scope of the program, and is consistent with other LENDs. Key programmatic concepts include advanced clinical knowledge and skills; interdisciplinary, family-centered, and community-coordinated care; advocacy, policy, research, and leadership.

Interdisciplinary

LEND graduate and postgraduate trainees are in audiology, pediatric audiology, deaf education, families, nursing, nutrition, occupational therapy, pediatric medicine, pediatric dentistry, physical therapy, psychology, religion, social work, and speech/language pathology. To incorporate this breadth of disciplines, Vanderbilt collaborates with Belmont University, Meharry Medical College, Tennessee State University, the University of Tennessee, and Family Voices of Tennessee (part of the Tennessee Disability Coalition).

"I was exposed to many aspects of working with children with neurodevelopmental disabilities and their families that I would not have experienced through my discipline-specific work alone," said former LEND trainee Whitney Loring, Psy.D., now assistant professor of Pediatrics at Vanderbilt. "This training allowed me to be a part of an interdisciplinary team that explored components of leadership."

Family-Centered

"Children develop within families," Urbano said. "The entire family is affected when a child has a neurodevelopmental disability. Professionals must understand developmental challenges, related health and family needs throughout the lifespan."



PAM GRAU

2011-12 LEND trainees (above)



LEND leadership (left): Terri Urbano, Ph.D., M.P.H., R.N., Director; Tyler Reimschisel, M.D., Associate Director; and Anne Marie Tharpe, Ph.D., Pediatric Audiology

support organizations and community agencies, meetings with families of children with special needs, and a simulation of difficult conversations.

Each year LEND has a family trainee (a parent of a child with a neurodevelopmental disability) and a family faculty member from Family Voices. In partnership with the Junior League Family Resource Center (Monroe Carell, Jr. Children's Hospital at Vanderbilt), trainees are mentored by a family of a child with a disability. "The family is the teacher in this situation," Urbano said. "Trainees learn directly about experiences of daily life from culturally diverse families."

Pediatric Residents

Training future physicians is a critical component. LEND training for pediatric residents is led by Associate Director Tyler Reimschisel, M.D., assistant professor of Pediatrics, director of the Division of Developmental Medicine, and co-director of the Residency Training Program. Through these positions, he is able to weave content and experiences into a variety of didactic and clinical experiences.

Over 15% of children have a developmental disability. "The LEND is making considerable impact on the care that children with developmental disabilities receive by educating the health care professionals who care for them," Reimschisel said. For example, during the required rotation in Developmental Medicine, pediatric residents learn to evaluate and care for children with developmental disabilities through direct patient care in the Center for Child Development, small group discussion sessions, visits to family

Pediatric Audiology

A Pediatric Audiology Supplement of \$65,000 from MCHB for LEND FY2012 has been renewed and will fund this subspecialty focus. Approximately 95% of all newborns in the U.S. are screened for hearing loss. Relatively few audiologists are trained to assess and manage these young babies.

"The renewal allows Hearing and Speech Sciences to continue to provide scholarships to graduate students in audiology who are committed to working with these children and their families," said Anne Marie Tharpe, Ph.D., P.I., professor and chair of Hearing and Speech Sciences, Vanderbilt Bill Wilkerson Center associate director, and LEND faculty member. This training fosters the skills required to diagnose hearing loss, to fit appropriate hearing technology, and to counsel families about the impact and management of childhood hearing loss.

Outreach

Outreach throughout Tennessee and the Southeastern U.S. is through interdisciplinary continuing education programming, and monthly videostreamed distance education to community professionals, in collaboration with the Tennessee Department of Health, Maternal and Child Health. LEND-developed educational materials are disseminated statewide and are available online (see kc.vanderbilt.edu, Resources, Autism-Related Materials). ■



VKC UCEDD Reaching Out BY COURTNEY TAYLOR

► Tennessee Kindred Stories

Everyone has stories of life experiences to share with others. In advocating for improved services and supports for persons with disabilities and their families in Tennessee, disability organizations have learned that sharing family stories is one of the most powerful ways to demonstrate what does and doesn't work.

The annual Tennessee Disability Days on the Hill is a time for families to share their stories in person with their State representatives and senators. Often national disability organizations hold meetings in Washington, D.C., coupled with attendees meeting with their U.S. Congressional representatives or staff.

While sharing stories face to face is powerful, so, too, are sharing family stories via a publication. In recent years, The Arc Tennessee has partnered with the Vanderbilt Kennedy Center to publish *Tennessee Family Stories* booklets and to share them with legislators.

Discussions with the VKC UCEDD Community Advisory Council revealed how important family stories are in bringing about change. So with the Council's urging, the VKC UCEDD and The Arc Tennessee have created a website to provide a way to make it easy for Tennessee families to share their stories. The website is searchable by disability, age range, storyteller perspective, county, and topic. Topics illustrate what families experience in areas like education, transition, employment, wait lists, and Family Support. We've named this website **Tennessee Kindred Stories of Disability**.

"*Kindred Stories* has the potential to be of great benefit in many ways," said Carrie Guiden, executive director of The Arc Tennessee. "For families, it gives them an opportunity to share their stories and to connect to other families with similar experiences. For advocacy organizations like The Arc, it helps us to 'personalize' our advocacy with legislators by sharing real stories of people in their districts and to identify where the support systems are working and failing. For educational institutions, it provides an opportunity to determine needs and to develop best practices to address them. For state agencies, it helps them identify with the realities of families supporting people with disabilities. The possibilities are great—provided that people take advantage of this tool."

Individuals and agencies can help this project in three ways:

- **Share your story.** Stories may be submitted on the website or by mail. See the website for submission details.
- **Encourage others to share their stories.**
- **Become a project partner.** Disability agencies may become partners in the Kindred Stories project and use the database to coordinate targeted or general story projects.

To submit a story or to learn more about the project, visit kc.vanderbilt.edu/kindredstories, or call (615) 322-5658.

► Connecting Adult Sibs

The VKC UCEDD is committed to growing the reach and resources of **TABS**, or **Tennessee Adult Brothers and Sisters**, a support network for adult siblings in Tennessee who have a brother or a sister with a disability.

One way the group is extending its outreach is by holding informal monthly gatherings in restaurants or coffee houses. Called **TABS Third Thursdays**, these gatherings are held in Memphis, Nashville, and Knoxville, to reach out to siblings in West, Middle, and East Tennessee. Locations and times are posted on the TABS Facebook page. Future plans include developing groups in each of Tennessee's 9 Developmental Districts (a way in which State agencies organize services statewide).

In the months ahead, the TABS Executive Committee plans to develop a county network of Tennessee sibling "ambassadors" who will serve as a resource and liaison between local communities and TABS.

"We are excited to see TABS grow and truly believe that by creating the role of the sibling ambassador, we will better support siblings across the state," said Ashley Coulter, VKC Sibling Supports coordinator.



Siblings network at annual TABS Conference.

County sibling ambassadors will help to connect adult siblings to one another on the local level so that they can be of support to one another, sharing resources and providing social and emotional support. Ambassadors also have the potential to serve as resources for research, training, and service

activities of the VKC UCEDD and the Tennessee Developmental Disabilities Network by identifying supports needed at a local level.

In August, the TABS Executive Committee held a planning retreat, where regional groups and county ambassadors were discussed as ways to extend the network. For information on TABS Third Thursdays or TABS County Ambassadors, contact ashley.coulter@vanderbilt.edu, (615) 343-0545.

► Inclusive Congregations

Religious leaders and educators, individuals with disabilities and family members, and disability service providers gathered on October 11 for the **Second Annual Disabilities and Congregation Inclusion Conference**. Held in Nashville, attendees came to discuss strategies to improve the inclusion of people with disabilities in their congregations.

Co-sponsored by Faith For All, the Conference included a presentation by Erik Carter, Ph.D., Vanderbilt associate professor of Special Education and VKC investigator. Carter is invested both personally and professionally in this area. He challenged attendees to think beyond building ramps to building relationships. He posited that true inclusion means welcoming and encouraging full participation both inside the congregation's doors on Friday, Saturday, or Sunday, and outside the doors on the other six days of the week.

"Congregations are well-positioned to offer a venue in which individuals with disabilities and their families can flourish," said Carter. "They can partner with individuals and families to support their spiritual lives and to help them explore ways to strengthen their spiritual connections in the congregation and in activities of their choice."

In order to assist attendees in assessing where their congregations are in the process of being truly welcoming of individuals with disabilities, Carter encouraged them to think about where they are on the ministerial continuum of "ministry apart, ministry to, ministry among, ministry with, and ministry by."

The Conference also included a presentation by Paul Leichty, who founded the Congregation Accessibility Network (CAN), a

Community Conversation, and lunchtime programming that allowed attendees to share their success stories. For information on activities of the VKC Disabilities, Religion, and Spirituality Program, contact courtney.taylor@vanderbilt.edu, (615) 322-5658. ■



Story of a Mother's Journey BY COURTNEY TAYLOR

“When James was born and we found out he had Down syndrome, my world fell apart,” said LynnMarie Rink. “I knew I wasn’t fitting into what I felt like was the mother role. People would ask me ‘Have you bonded with your son yet?’ and I would lie and say, ‘Oh, yeah, you know.’ Very rarely would I admit the truth to anyone. But when I finally did bond with him—and it took four and a half years—it was amazing. Being James’s mother is amazing.”

Not only is Rink James’s mother, but she is also a Grammy-nominated polka musician. The depression that took over her life after the birth of her son kept her from focusing both on her family and on her career. However, she has returned in full force in her one-woman show, “Wrap Your Heart Around It – A Journey from Depression to Dessert.” The show chronicles her experience as a parent of a child with Down syndrome and her journey out of depression.

“It’s been a long journey,” said Rink. “You always hear people say that people with disabilities are not broken. I realize now that he wasn’t, but his disability made me realize that I was.”

While entering therapy was the central catalyst in Rink’s journey to her son, she also vividly recalls two turning points that gave her strength along the way. The first moment occurred while she was looking out the window watching her neighbor’s children playing in their yard.

“As I sat watching them, I felt anger and self-pity rise up within me,” remembered Rink. “I thought, ‘why can’t I have a typical child?’ I went through a list of all the things he probably was not going to get to do and be. And I was so mad at God at that

moment. I heard myself yelling out loud, ‘God, I cannot wrap my head around the fact that I have a child with special needs.’ And in that moment, I heard back from somewhere deep inside of me, ‘I’m not asking you to wrap your head around it. I’m asking you to wrap your heart around it.’ Now, I didn’t immediately walk away and say, ‘Oh, I get it.’ I got it, but I still didn’t know how to do it. For me, the how came with finding a really great therapist.”

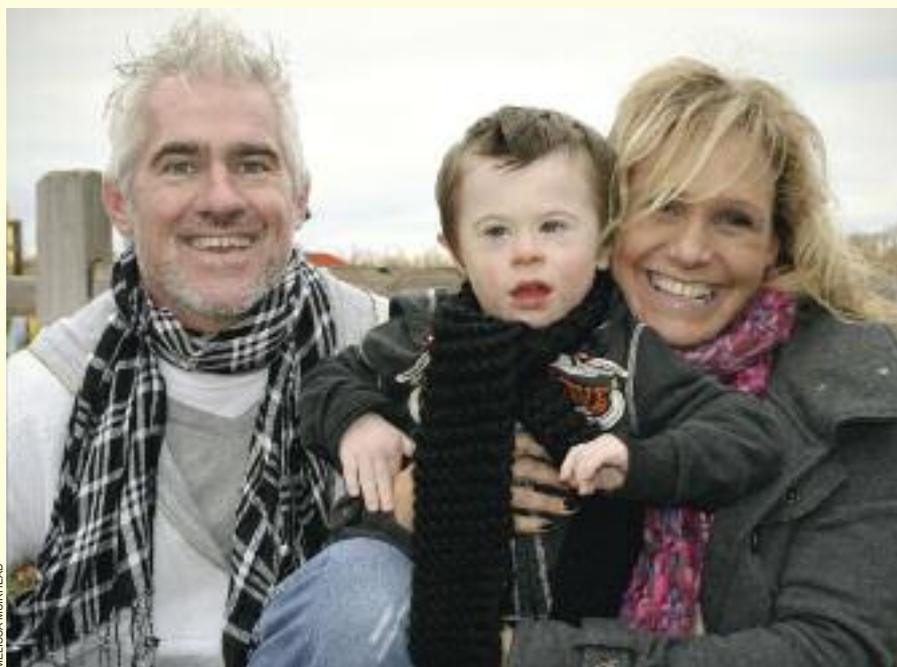
promise you, if you can find a way to not look into the future, not think into the future, not live in fear, and live in just this day, right now, you are going to feel more love than you’ve ever imagined.’ So she’s crying and I’m crying, even the saleslady is crying. After we left and were in the car, I saw James in the rearview mirror. I looked at him and I don’t know... but I looked at him and I heard myself telling him ‘I love you, just the way you are.’ And I really meant it.”

At the urging of her therapist, Rink began keeping a journal. Not long after that she began shaping the entries into the stories that would become the content of her one-woman show. Proceeds from the tour opening, which took place on October 16, benefitted the Susan Gray School for Children, where James is a student.

“The Susan Gray School was a life saver,” said Rink. “They didn’t know it, but they were taking care of me as well as James. It was all I could do to get him to school and pick him up while I was sitting at home in my bathrobe depressed. They cared for him when I couldn’t.”

Proceeds from the remainder of the 6-city tour will benefit each city’s local Down syndrome organization.

“This is a happy story,” said Rink. “If you had seen me four years ago, you probably would have thought ‘just throw in the towel.’ It was pretty scary. But now, my whole life as a person and as an artist has turned around. There is a responsibility to share my story so others can hear it and be encouraged. If I thought polka music was fun and happy before, well now I have a story that will make them happy. And where polka was fun and happy on the surface, hopefully this will be fun and happy in their hearts.” ■



Jim, James, and LynnMarie Rink

The second moment occurred while shopping for a dryer at Sears with her son. She noticed a woman with tears in her eyes staring at them. The woman approached and began telling them about her own son with Down syndrome who had recently passed away.

“He had been 60 years old,” said Rink. “She told me how the doctors had told her she should put him in an institution, but she didn’t listen. She kept him at home with her. And then she said, ‘Can I tell you something? I know how hard it is right now, but I

Grants Awarded *Competing renewal funded

Improving Prematurity-Related Respiratory Outcomes at Vanderbilt (IMPROV)
Judy Aschner, M.D. (Pediatrics)
National Heart, Lung, and Blood Institute

Mechanisms of CaM Kinase II Signal Transduction* Roger Colbran, Ph.D. (Molecular Physiology & Biophysics)
National Institute of Mental Health

Functional Brain Imaging with Oscillating Gradient DW-MRI
John Gore, Ph.D. (Radiology)
National Institute of Neurological Disorders and Stroke

Circadian Programs in Bacteria*
Carl Johnson, Ph.D. (Biological Sciences)
National Institute of General Medical Sciences

Preventing Prematurity and Poor Pregnancy Outcomes Training Grant
Judy Aschner, M.D. (Pediatrics)
National Institute of Child Health and Human Development

Hereditary Defects in Human Sodium Channels*
Alfred George, M.D. (Medicine)
National Institute of Neurological Disorders and Stroke

Training Program in Quantitative Ocular Genomics Jonathan Haines, Ph.D. (Molecular Physiology & Biophysics), National Eye Institute

Cellular Correlates of Human Consciousness: How Many Neurons Are in the Cortical Areas That Are Most Involved in Awareness? Jon Kaas, Ph.D. (Psychology), Mathers Foundation

Regulation of the Serotonin Transporter Function by Integrins in the Mouse Brain
Ana Carneiro, Ph.D. (Pharmacology)
National Institute of Mental Health

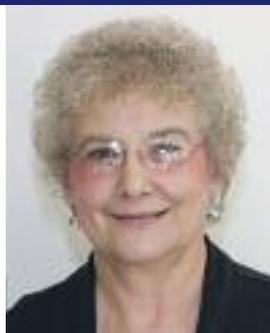
Training Program in Ion Channel and Transporter Biology*
Alfred George, M.D. (Medicine)
National Institute of Neurological Disorders and Stroke

National Center on Quality Teaching and Learning Mary Louise Hemmeter, Ph.D. (Special Education)
Administration for Children and Families, U.S. Health and Human Services

Pathophysiology and Treatment of GABRG2 Nonsense Epilepsy Mutations* Robert Macdonald, Ph.D., M.D. (Neurology), National Institute of Neurological Disorders and Stroke



Ron Butler, Nashville



Joyce Sievers, Smithville



Luz Belleza-Binns, Hermitage



John Chase, Memphis



John Donovan, Fairview



Joey Ellis, White House



Omegbhai Uriri, Antioch

Goodbye and Hello—Community Advisory Council Transitions BY COURTNEY TAYLOR

With respect and gratitude, we say goodbye to Ron Butler and Joyce Sievers as they step down from their roles on the VKC UCEDD Community Advisory Council (CAC). Butler and Sievers were instrumental in the initial development of the CAC, even before the VKC became a UCEDD in 2004. Both served two 3-year terms.

Butler has an adult son with an intellectual disability and cerebral palsy. He is a past president of The Arc Tennessee and a current board member. He also is a board member of Mid-TN Supported Living, Inc.

Sievers, too, joined the CAC as a parent and has been involved in the disability field for over 45 years. She serves on the Executive Committee of the Tennessee Council on Developmental Disabilities (TCDD) and is on the Advisory Council of Tennessee Disability Pathfinder. Since its inception in 1993 and for 15 years, Sievers coordinated the Family Support Program for 12 Upper Cumberland counties. She directed an art program for adults with developmental disabilities at Pacesetters, Inc., in Cookeville, Tennessee, for 6 years.

“Ron knows the importance of work and employment for youth with disabilities, and was one of those on our CAC who encouraged adding Employment as an Area of Emphasis,” said Elise McMillan, J.D., VKC UCEDD co-director. “Joyce is responsible for the VKC having the great privilege of sharing art exhibits by the talented artists of Pacesetters. She is responsible for helping us expand

our work outside of Middle Tennessee. We so appreciate the work they have done with us over the years.”

Welcoming New Members

Luz Belleza-Binns is the mother of two children, one with autism. She works with Metro Nashville Social Services, where she provides case management to families in need, especially those who are homeless and/or have children with disabilities. She is a graduate of the TCDD’s Partners in Policymaking and is an advocate in many IEP meetings in the local school system. Currently, she serves on the boards of the Nashville Area Chamber of Commerce Education Report Card Committee, Family Advisory Council on Special Education with Metro Nashville Public Schools, TN Disability Pathfinder Hispanic Outreach Project, the Salvation Army Hispanic Ministry Board, and the TN Hispanic Chamber of Commerce, for which she serves as Chairman of the Latinos En Accion professional network.

John Chase was diagnosed with autism at age 4. He graduated from Concord Academy high school in 2006, and in 2010 earned a bachelor’s degree from Visible Music College, where he now works as an assistant librarian. Since 2006, he has been a music intern at Independent Presbyterian Church, where he works with the boys’ junior high and senior high choirs. He also has been a member of the adult choir since 2005.

John Donovan is the guardian of his brother, who, after a series of brain aneurysms, is paralyzed

on one side. Donovan’s volunteer activities include serving on the Planning Committee for the 2011 Tennessee Adult Brothers and Sisters (TABs) Conference, as well as supporting Special Olympics and MDA fundraisers. He is a system administrator at Vanderbilt University Medical Center and has children and grandchildren in Florida and Germany.

Joey Ellis has a mild form of cerebral palsy, which inspired him to pursue a degree in special education, and to teach for 5 years. In July, he joined STEP (Support and Training for Exceptional Parents), where he enjoys assisting families who have children with disabilities. He believes that if it were not for his parents standing up for his rights throughout his childhood, he would not be where he is today.

Omegbhai Uriri has a daughter with autism. She has completed training programs through TRIAD, Tennessee Voices for Children, STEP, and Volunteer Advocacy Training. She is a board member-at-large for The Arc Tennessee. With the assistance of Meharry Medical College and Tennessee Disability Pathfinder, she began a support group for African immigrant families who have children with disabilities. She hopes to open avenues for better opportunities for individuals with disabilities, especially minorities.

The CAC advises the UCEDD leadership and is a full partner in planning, implementing, and evaluating activities. ■

Vanderbilt Site for Network of Excellence in Neuroscience Clinical Trials
Beth Malow, M.D., M.S.
National Institute of Neurological Disorders and Stroke

Research Training in Diabetes and Endocrinology* James May, M.D. (Medicine), National Institute of Diabetes and Digestive and Kidney Diseases

Adaptive Response Technology for Autism Spectrum Disorders Intervention
Nilanjan Sarkar, Ph.D. (Mechanical Engineering), National Institute of Mental Health

Saccade Target Selection Frontal Cortex* Jeffrey Schall, Ph.D. (Psychology)
National Eye Institute

Patterns and Environmental Predictors of Employment and Independence Among Adults with ASD
Julie Taylor, Ph.D. (Pediatrics)
Autism Speaks

Risk and Resiliency for Youth with Autism During the Transition to Adulthood
Julie Taylor, Ph.D. (Pediatrics)
National Institute of Mental Health

Neurobiological Signatures of Social Dysfunction and Repetitive Behavior
Jeremy Veenstra-VanderWeele, M.D. (Psychiatry)
National Institute of Mental Health

Imaging Synapse Formation Using Novel Microfluidic Platforms
Donna Webb, Ph.D. (Biological Sciences)
National Institute of Mental Health

A Signaling Integrator Plays a Critical Role in Regulating Cell Migration
Donna Webb, Ph.D. (Biological Sciences), National Institute of General Medical Sciences

Anhedonia and the Neural Basis of Effort-Based Decision Making in Depression
David Zald, Ph.D. (Psychology)
National Institute of Mental Health

Dopamine Influences on Self-Regulation and Impulsivity
David Zald, Ph.D. (Psychology)
National Institute on Drug Abuse ■



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Mrs. Elise McMillan
Dr. Louis J. Muglia
Ms. Linde Pflaum
Dr. Jan Rosemergy
Mr. Tim Stafford



Sign of Our Times

The building formerly known as “MRL” has a new name—One Magnolia Circle

The building houses many Vanderbilt offices and activities, as well as Peabody College’s Department of Special Education and the Susan Gray School for Children. A new name was selected to leave behind outdated disability language. See kc.vanderbilt.edu News and Events, News Releases for related story.

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 facilitates discoveries and best practices that make positive differences in the lives of persons with developmental disabilities and their families. 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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Jan Rosemergy, Ph.D., *Deputy Director and Director of Communications*
Tim Stafford, *Director of Operations*

UCEDD
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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
Terri Urbano, Ph.D., M.P.H., R.N., *Director*
Tyler Reimschisel, M.D., *Associate Director*

Treatment and Research Institute for Autism Spectrum Disorders
Zachary Warren, Ph.D., *Director*

Discovery
Editor/Writer: Jan Rosemergy, Ph.D.
Graphic Designer: Kylie Beck

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CALENDAR OF EVENTS | DECEMBER 2011-MARCH 2012



Disability Mentoring Day at Vanderbilt celebrated October as National Disability Employment Awareness Month.

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 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 kc@vanderbilt.edu.

For disability-related training and other events statewide and nationally, see the Pathfinder Disability Calendar www.familypathfinder.org.

*Event will be held in Room 241 Vanderbilt Kennedy Center/One Magnolia Circle

■ TRIAD FAMILIES FIRST WORKSHOPS

Free monthly workshops serving parents of children of all ages diagnosed with an autism spectrum disorder and professionals Register at kc.vanderbilt.edu/registration. Information (615) 322-6027 or families.first@vanderbilt.edu

• DECEMBER 5*

Communication in Children Who Are Talking
Monday 6-8 p.m.

■ BRITT HENDERSON TRAINING SERIES FOR EDUCATORS

For school teams, individuals, parents Register at kc.vanderbilt.edu/registration Information (615) 936-8852 Wednesday 5-7 p.m.

• NOVEMBER 30*

Effective Inclusion

• JANUARY 11*

Conducting Valid Functional Behavioral Assessments

• JANUARY 18*

Designing and Implementing Effective Functional Assessment-Based Interventions

• FEBRUARY 22*

Transition for Individuals with Co-Occurring Disorders

• MARCH 14*

Secondary Interventions: Behavior Contracting and Self-Monitoring

■ DECEMBER 2*

Community Advisory Council Meeting

For details contact (615) 936-8852 Friday 9 a.m.-2 p.m.

■ DECEMBER 10*

SibSaturday

For siblings 5-7 and 8-13 years who have brother/sister with disability

Games, friends, conversation Advance registration required. 2012 dates to be announced.

Contact ashley.coulter@vanderbilt.edu, (615) 343-0545

■ DECEMBER 14*

Developmental Disabilities Grand Rounds

Impulsivity: When the Gas Pedal Is Stronger Than the Brakes

David Zald, Ph.D.

Associate Professor of Psychology and Psychiatry Co-Sponsor Department of Psychology

Wednesday 12 p.m.

■ THROUGH DECEMBER 31

Arts and Disabilities Exhibit Creative Expressions XVII

Jointly sponsored with Nashville Mayor's Advisory Committee for People with Disabilities

Monday-Friday 7:30 a.m.-5:30 p.m. Lobby VKC/One Magnolia Circle Information contact (615) 936-8852

■ JANUARY 2-APRIL 27

Arts and Disabilities Exhibit Art by VKC Summer Program

Participants

Monday-Friday 7:30 a.m.-5:30 p.m. Lobby VKC/One Magnolia Circle Information contact (615) 936-8852

■ JANUARY 11

Neuroscience Graduate Program Seminar Series

Genetic Syndromes [general topic] Sarah Elsea, Ph.D.

Associate Professor of Pediatrics, Virginia Commonwealth University Co-sponsor Vanderbilt Brain Institute Room 1220 MRB III Lecture Hall Wednesday, 4:10 p.m.

■ JANUARY 18*

Developmental Disabilities Grand Rounds

Stress and Coping [topic]

Bruce Compas, Ph.D.

Patricia and Rodes Hart Professor of Psychology and Human Development Co-Sponsor Department of Psychology & Human Development Wednesday 12 p.m.

■ JANUARY 23*

Martin Luther King Jr. Commemorative Lecture Free at Last: The Meaning of Liberty in Intellectual and Related Developmental Disabilities

Rud Turnbull, LL.B./J.D.

Marianna and Ross Distinguished Professor, Co-Founder and Co-Director of Beach Center on Disability, University of Kansas Monday 4:10 p.m.

■ JANUARY 31*

Statistics and Methodology Core Training Seminar

Item Response Theory

Sun-Joo Cho, Ph.D.

Assistant Professor of Psychology and Human Development Jennifer Gilbert, Ph.D., Research Associate in Special Education Tuesday 12:30 p.m.

■ FEBRUARY 8*

Developmental Disabilities Grand Rounds

Autism Interventions Review [topic]

Zachary Warren, Ph.D.

Assistant Professor of Pediatrics;



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TRIAD Director

Melissa McPheeters, M.P.H., Ph.D., Assistant Professor of Obstetrics and Gynecology; Co-Director, Vanderbilt Evidence-Based Practice Center
Jeremy Veenstra-VanderWeele, M.D., Assistant Professor of Psychiatry, Director of Fragile X Treatment Research Program
Co-Sponsor Pediatrics Division of Developmental Medicine
Wednesday 12 p.m.

■ FEBRUARY 15*

Educate to Advocate
For trainees and others interested in disability-related legislative advocacy
Register at kc.vanderbilt.edu/registration. Information 936-8852
Wednesday 11:30-1 p.m.

■ FEBRUARY 16*

Lectures on Development and Developmental Disabilities
Autism [general topic]
Sally J. Rogers, Ph.D.
Professor of Psychiatry and Behavioral Sciences, University of California-Davis MIND Institute
Thursday 4:10 p.m.

■ FEBRUARY 22

Neuroscience Graduate Program Seminar Series
Multisensory Integration of Taste and Smell [tentative topic]
Dana Small, Ph.D.
Associate Professor of Psychiatry and Psychology, Yale University
Co-sponsor Vanderbilt Brain Institute
Room 1220 MRB III Lecture Hall
Wednesday, 4:10 p.m.

■ FEBRUARY 28

Vanderbilt Kennedy Center Science Day
Details and registration forthcoming at kc.vanderbilt.edu
Vanderbilt Student Life Center
Tuesday 11 a.m.-4:30 p.m.

■ MARCH 1*

Lectures on Development and Developmental Disabilities
Cognitive and Neurobiological Mechanisms in Reading Disability [topic]
Ken Pugh, Ph.D., President and Director of Research, Senior Scientist, Haskins Laboratories, and Associate Professor of Linguistics, Yale University; Director, Yale Reading Center; Professor of Psychology, University of Connecticut
Thursday 4:10 p.m.

■ MARCH 7-9, 2012

45th Annual Gatlinburg Conference on Research and Theory in Intellectual Disabilities
Theme: Rare and Neglected Intellectual and Developmental Disabilities: A Case Study in 15q
Loews Annapolis Hotel, Annapolis, MD
Information and register at kc.vanderbilt.edu/Gatlinburg
(615) 343-5322

■ MARCH 14*

Developmental Disabilities Grand Rounds
The Elephant in the Room: Poverty, Disability, and Employment
Carolyn Hughes, Ph.D.
Professor of Special Education
Housing First: People Experiencing Homeless and Mental Illness
Marybeth Shinn, Ph.D.
Professor and Chair of Human and Organizational Development
Wednesday 12 p.m.

■ MARCH 26*

Statistics and Methodology Core Training Seminar
Title TBA
Lily Wang, Ph.D.
Assistant Professor of Biostatistics; Biostatistics Coordinator, VKC Statistics and Methodology Core
Monday 12:30 p.m.

■ 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

■ LEARNING ASSESSMENT CLINIC

Multidisciplinary academic assessments of students, 5-25 years, to identify learning strengths and challenges and to recommend strategies to improve academic learning; Contact (615) 936-5118
patty.abernathy@vanderbilt.edu

■ NEXT STEPS AT VANDERBILT

A 2-year certification postsecondary education program for students with intellectual disabilities providing individualized Programs of Study in education, social skills, and vocational training. Information (615) 343-0822, NextSteps@vanderbilt.edu

■ READING CLINIC

Assessment and tutoring for students through middle school
Contact (615) 936-5118
patty.abernathy@vanderbilt.edu

■ 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@tn.gov, (615) 741-7790
See also www.state.tn.us/education/speced/announcements.shtml

- DECEMBER 5 (Knoxville) East Institute
- MARCH 7-9 (Middle Tennessee) Teacher Training Advanced K-12

■ TAKE PART IN RESEARCH VKC 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 ■ MULTI-CULTURAL OUTREACH

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 TN Council on Developmental Disabilities



COURTESY OF NEXT STEPS AT VANDERBILT

Next Steps at Vanderbilt students celebrated Memorial Madness.