Nathalie Maitre demonstrates the “puffer system” in the VKC Psychophysiology Lab.

Tapping the Sensory System’s Power BY JAN ROSEMERGY

Nathalie Maitre is passionate about babies, especially infants cared for in neonatal intensive care units (NICUs). An assistant professor of Pediatrics in Neonatology and adjunct in Physical Medicine and Rehabilitation, Maître, Ph.D., M.D., is a clinician and translational researcher set on discovering interventions to help these infants flourish.

Maitre corrects the misperception that NICUs provide care only for premature infants. “We also care for babies with congenital abnormalities, cardiac problems, birth asphyxias or trauma, infections at birth, and more. Together, such infants contribute greater than 60% of children with cerebral palsy, vision and hearing problems, and intellectual disabilities.”

Maitre’s research focuses on early identification and rehabilitation of neurodevelopmental problems in high-risk infants. “My clinical duties allow me a unique perspective on care and rehabilitation and have influenced my focus on interventions that take advantage of neural plasticity in the early years,” she said.

Maitre focuses on the sensory system because it is the basis for learning in infancy. Brain processes involve not only developing specific senses like vision or hearing but connecting senses into networks. The development of these neural networks is the basis for more complex processes and higher order cognitive functions. “If you can make a difference at the beginning, in the first months and years of life, then hopefully it amplifies later in life,” Maitre said.

Among Maitre’s research collaborators is Sasha Key, Ph.D., associate professor of Hearing & Speech Sciences and VKC Psychophysiology Lab director. They are developing objective measures of neurophysiologic function in infants to validate early therapeutic interventions.

Maitre thinks of the brain less as a computer and more as a changing internet. The basic principle underlying her work, like most of her colleagues in this field, is that neural stimulation plus behavioral training can rewire the brain and the peripheral nervous system.

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Director's Message

Compassion—For Others and for Ourselves

The lure of a mother’s lullaby in a Neonatal Intensive Care Unit. Families and Ambassadors cheering as Next Steps at Vanderbilt students graduate. Wiping away tears while listening as families affected by autism share their stories. A mentor speaking words of encouragement to a postdoctoral fellow about to lead a professional symposium for the first time. LEND and UCEDD trainees sharing transformative leadership experiences from the past year. These are but a few instances of compassion that abound in the lives of Vanderbilt Kennedy Center researchers, clinicians, professional staff, trainees, and students.

Everyday, all of us in our VKC community work to make positive differences, directly or indirectly, in the lives of children and adults with developmental disabilities and their families. We are focused on giving support. To make that possible, we also support one another.

We support young student and postdoctoral researchers by engaging them in labs led by senior researchers, by featuring their research at VKC Science Day, by providing VKC Travel Awards to present their research at scientific conferences. We support young and seasoned researchers alike by partnering with donors to provide Nicholas Hobbs Discovery Grants to seed innovative research. We support journal clubs that bring together faculty, staff, students, and community members to learn and brainstorm. In “More About That,” program staff experience the broad range of our Center’s work. In “Developmental Disabilities Grand Rounds,” we hear the work of our own researchers and discover new possibilities for collaboration.

As I write, we are working on grant progress reports, submitting grant applications, recruiting for research studies, concluding semester exams and submitting grades, doing annual performance evaluations, and more. In the middle of these activities, as a community, we are grieving the loss of a long-time staff member and are comforting one another.

As we care for others, we also must care of ourselves, whoever we are, whatever we do. Each of us can learn and practice ways to take better care of ourselves by living attentively and finding things for which we can be grateful. Today we are grateful for this community.

Passionate About Developmental Disabilities Research 2013 Gatlinburg Conference

BY ELIZABETH TURNER

More than 200 students and professionals made their way to San Antonio, Texas, March 6-8, for the 46th Annual Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities. This year’s theme was “Newborn Screening for Intellectual and Developmental Disabilities.”

“The development and expansion of newborn screening has been enormously important in the prevention of developmental disabilities,” said Elisabeth Dykens, Ph.D., VKC director and Conference Chair.

The Gatlinburg Conference is the preeminent national conference on intellectual and developmental disabilities where both young and seasoned researchers, from graduate students to senior faculty, come together for vigorous dialogue.

“This was my first time attending this conference, and I was thrilled and honored that my proposal for a symposium on Infant Sensory Processing and Neurodevelopmental Outcomes was selected,” said Nathalie Maitre, Ph.D., M.D. (VKC/Vanderbilt U).

“Professionally, it was the first time I was given the opportunity to organize the content and structure of research to make it more meaningful and accessible to a diverse audience of scientists, advocates, and clinicians. It is a rare and wonderful opportunity to be learning and communicating with the few people in this country who feel just as passionately about disabilities research as we do!”

Vanderbilt participants included 12 faculty, 16 graduate students and postdoctoral students, 2 research staff members, and 4 VKC staff who coordinated the conference. This year’s conference was the third in the VKC’s 5-year coordination commitment with the Eunice Kennedy Shriver National Institute of Child Health and Human Development.

Elisabeth Dykens

Between the 4 plenary sessions were 12 symposia chaired and presented by professionals from universities around the continent. Topics ranged from mindfulness-based stress reduction to Rett syndrome to social vulnerability of those with intellectual and developmental disabilities.

Marisa Fisher, VKC postdoctoral fellow who received a Theodore Tjossem Postdoctoral Award to attend the Conference, chaired a symposium on social vulnerability. “I have attended the Gatlinburg Conference every year since I entered graduate school,” Fisher said. “As a postdoc, I was eager to chair a symposium. What came together was a wonderful group of researchers interested in the same topic. Our symposium was a success. Not only was it well attended, but also it generated more research questions and the promise of future collaborations with new colleagues.”

NICHD staff provided updates and a panel discussion. Questions asked included the possible effects of sequestration and the future of the grant application/renewal process.

In all, 21 travel awards were given to undergraduates, graduate students, and postdoctoral fellows, many of whom attended for the first time.

Symposium and poster abstracts are available at kc.vanderbilt.edu/gatlinburg. The 47th Annual Gatlinburg Conference will be held March 5-7, 2014, at the Hotel Allegro in Chicago. The theme will be “The Co-Occurrence of Mental Illness and Developmental Disability.”
Musical Pacifiers

It is common practice in NICUs to use special pacifiers to encourage infants to suck and thus learn to feed. Maitre’s idea was to harness the power of a baby’s mom singing a lullaby—an auditory stimulus—to strengthen neural connections among sucking, breathing, and swallowing. The lullabies sung were modified by a music therapist, Olena Chorna, MT, to fit patterns that an infant’s auditory system would recognize and respond to. “While the infants are sucking, they’re learning there’s a right rhythm and pressure, and that when they suck the right way, they get their mother’s voice singing, a positive stimulus for their developing brains.”

With support from a VKC Hobbs Discovery Grant, Maitre and Chorna conducted a randomized clinical trial of this pacifier-activated lullaby and measured how infants fed. After just 5 days, the infants with the musical pacifiers tripled their suck rate. They increased their number of feeds per day by three compared to baseline, while the comparison group increased their number of feeds per day by one. “Babies have eight feeds a day, so an increase of three is huge,” Maitre said. The infants with the musical pacifiers increased their feeding volumes, they had fewer days of tube feeding, and had decreased length of hospital stay.

Puffer System

Maitre and Key have developed a multisensory paradigm to measure the perception of light touch simultaneous with perception of a speech sound, which permits insight into touch and sound not as separate modalities but as the two combined. Wearing an ERP sensory “hat” to measure brain electrical activity and with a finger in a special mold, a seated child is distracted by a muted video while experiencing air puffs or speech sounds or simultaneous air puffs and speech sounds. They have found a significant difference between how touch is perceived alone and how touch is perceived in combination with sound.

“This work has treatment implications for developmental disorders like autism in which tactile or multisensory processing is affected,” Maitre said.

Maitre values the collegiality of Vanderbilt and the VKC. “I don’t feel lonely in how much I care about kids with disability anymore. It’s wonderful to belong to a community who also cares so deeply about them.”

Study of Strengths and Flourishing

As part of the VKC UCEDD Disabilities, Religion, and Spirituality Program, we are in the midst of a project focused on reshaping such introductions. We have been conducting a statewide study focused on faith and flourishing in the lives of youth and young adults with intellectual disabilities and autism in Tennessee. One of the study’s aims is to identify the strengths these young people might have to share with others in their community. The study is funded by the Martin McCoy-Jespersen Discovery Grant in Positive Psychology. Martin is remembered by his family and friends as “open, accepting, present,” whose “great purpose was to live a happy life” connected to others.

To identify strengths, we asked more than 450 parents to complete a short scale focused on enviable qualities of these youth and young adults. The Assessment Scale for Positive Character Traits (Woodard, 2009) includes 26 different statements, each addressing the extent to which their child shows characteristics like kindness, humor, gratitude, empathy, optimism, forgiveness, and courage.

Gathering this type of “positive” data has implications for fostering inclusion and community participation. What if we introduced young people to others by their strengths and gifts? Can we think of young people with intellectual and developmental disabilities in this way? Findings from our study to date suggest their parents can see many of these assets.

Drawing from the hundreds of parents and caregivers who participated, consider this small sampling of findings:

- 94% of parents described their child as happy.
- 86% say their child had a great sense of humor.
- 85% of these young people were described as thoughtful and helpful to others.
- 85% said their child shows kindness to others.
- 85% of parents said their child is thankful for life’s simple pleasures.
- 75% of parents described their child as courageous.
- 70% said their child keeps on trying even when things get hard.

How many businesses would benefit from hiring someone with qualities like honesty, persistence, and optimism? How many faith communities can find a place for someone known for her gratitude, empathy, and kindness? How many neighbors would be eager to develop a friendship with someone who is funny, happy, and thoughtful?

Does describing people in light of their strengths make any difference? Consider these two introductions: (1) Meet John. He has an intellectual disability, he can’t really read, and he is going to need lots of help to get around. (2) Meet John. He has an incredible sense of humor, he loves meeting new people, and he enjoys learning new things. By the way, he has an unforgettable bear hug. Which John would you be more eager to meet?

Youth and young people with disabilities have wonderful strengths and gifts to share. Too often those potential contributions get overlooked. As we strive to equip communities to more meaningfully include people with disabilities, let’s not overlook the introduction. Leaders and members of all our communities must see people first in terms of the gifts they have to bring.

Information from this study will be made available through a practical guide. To receive a forthcoming practical guide, email courtney.taylor@vanderbilt.edu. Courtney Taylor, M.Div., is VKC associate director of Communications and Dissemination. Erik Carter, Ph.D., is associate professor of Special Education.
Pathfinder’s Path

BY COURTNEY TAYLOR

Over the course of the last year, the staff at Tennessee Disability Pathfinder has provided information and referral assistance to over 2,000 callers from 87 of Tennessee’s 95 counties, 24 states, and 34 countries of origin. In addition to HELPline assistance, an analysis of the Pathfinder Web site indicates it had more than 54,800 visitors from 191 cities and towns across the state. These impressive numbers are a far cry from Pathfinder’s humble beginnings. With a current staff of 8, plus interns and Work Study students, Program Director Carole Moore-Slater, M.S., who recently announced she will retire in June, remembers when it was just herself and a part-time administrative assistant.

“At first, Pathfinder was just a toll-free helpline with a couple of people in the office,” said Moore-Slater. The program began with a grant written by VKC Director of Communications Jan Rosemary, Ph.D., funded by the Tennessee Council on Developmental Disabilities. “The first year I think we maybe had a couple hundred calls, mainly from folks in Middle Tennessee,” Moore-Slater said. “Our reach certainly wasn’t statewide and beyond like it is today, but we learned so much in that first year. We grew by gathering information about services in each county. We built a database and a Web site to house all that information. Then, we realized that to become a clearinghouse for disability-related resources and services, we had to get out from behind our desks and get into the communities. So, we began to network and build relationships to learn first-hand about what services were available.”

Outreach in the community paid off and eventually, the Pathfinder database grew to include over 2,100 agencies. Pathfinder’s programming also began to expand. Its growing staff began conducting community trainings on topics such as recreation and leisure, health care, and disability etiquette.

Access Nashville, a service-learning project to assess the accessibility of local restaurants, began and would eventually train over 800 students and survey 500 restaurants, all of which are listed on the Nashville Convention and Visitors Bureau’s Web site.

Pathfinder also expanded its reach by hiring multilingual staff members, adding a database (Camino Seguro) of agencies that have a Spanish-speaking staff member, starting a support group for Spanish-speaking families, and holding annual cultural diversity conferences to address issues relevant to the growing number of immigrants and refugees who have family members with disabilities from diverse cultural backgrounds now living in Tennessee.

“The Multicultural Outreach Program is an incredible achievement,” said Moore-Slater. “What Pathfinder has done to improve services for immigrants and refugees living in Tennessee who have family members with disabilities is incredible. The support groups alone have contributed so much to the quality of life of the members. Our staff also has been instrumental in developing the Tennessee Multicultural Alliance on Disability, which is doing such great work with the help of agencies across the state to create better opportunities for immigrants and refugees. I am going to miss being a part of this.”

“Carole sees the important value of training through Pathfinder for the future generation of leaders in the disability field,” said Elise McMillan, J.D., Pathfinder faculty director and VKC UCEDD co-director. “Students from across the University have benefitted from working as Pathfinder trainees.”

Before taking on a leadership role 16 years ago and helping to build Pathfinder into what it is today, Moore-Slater worked as a social worker, as a parent support trainer, and as a teacher at the Susan Gray School. Looking back, she says one major common element of those positions was trying to find information about community services for the children and families, and the difficulty she had in finding them. In part, that is what drew her to Pathfinder’s mission.

“When I saw the position open, I was really excited about it,” said Moore-Slater. “Trying to streamline a path to our fragmented services in Tennessee was such an important endeavor. I knew it would be the perfect path for me and I have never looked back.”

“We are very thankful for Carole’s leadership over the last 16 years,” said Wanda Willis, executive director of the Tennessee Council on Developmental Disabilities. “She has been the driving force behind Pathfinder. Carole was hired as the first director and from that moment led with vision, creativity, and a fierce commitment to connecting Tennesseans with disabilities, their families, and supporters to information and resources. Pathfinder has been heralded nationally and replicated by other states, and a lot of that is due to Carole’s leadership. She is someone I personally admire and salute for her accomplishments. She will be missed, but leaves behind a great legacy.”

Tennessee Disability Pathfinder is a joint program of the VKC UCEDD and the Tennessee Council on Developmental Disabilities. Funding also is provided by the Tennessee Department of Intellectual and Developmental Disabilities and the Tennessee Department of Education.
New TRIAD Leadership Roles  BY JAN ROSEMERGY

TRIAD staff are assuming new leadership roles, announced Zachary Warren, Ph.D., TRIAD director and associate professor of Pediatrics, Psychiatry, and Special Education.

Pablo Juárez, M.Ed., BCBA, has been named administrative director of TRIAD Professional Development and Training. TRIAD’s team provides educational training and consultation to teachers, psychologists, administrative staff, and school districts throughout the state and region. This includes a contract with the Tennessee Department of Education to train educational staff in evidence-based educational practices for children with autism and related disabilities.

LaTamar Garrett, B.A., has been named the program coordinator for Early Childhood Training, which includes contracts with the Tennessee Department of Education to conduct regional training for early childhood educators. Garrett is focused on expanding the impact of such training through novel methods and systems, including potentially realizing model classrooms and distance modalities for training.

Whitney Loring, Psy.D., is now program coordinator of Families First, a free training series for parents of young children with autism. By May 2013, Families First will have served more than 2,500 family members across the region since the workshops began in 2008.

“We are very fortunate to have leaders who understand this critical need and have the vision to realize training programs of true meaning and impact.”

Testing Toddler Interventions  BY JAN ROSEMERGY

Although evidence supports the importance of early intervention for young children with autism spectrum disorders (ASD), more research is needed to identify which specific treatments are most helpful for which children and at what level of intensity. Now underway is a national multisite randomized clinical trial of early intervention for ASD to provide information on what effects the style and the intensity of treatment (number of hours per week) have on children's development. Led by Sally Rogers, Ph.D. (U California Davis MIND Institute), the project is a National Institutes of Health Autism Centers of Excellence (ACE) award.

The Vanderbilt site is led by Paul Yoder, Ph.D., professor of Special Education, with co-investigator Zachary Warren, Ph.D., associate professor of Pediatrics and TRIAD director.

The two styles of early intervention being compared are a play-centered model based on the Early Start Denver Model and the discrete trial focused model, both of which have shown effectiveness.

“This research could have important implications for families and health care systems seeking intensive and therefore expensive but needed treatment for children with autism,” Yoder said.

The Early Start Denver Model, which was developed by Rogers and colleagues, is a comprehensive behavioral early intervention approach for children with autism, ages 12 to 48 months. The program encompasses a developmental curriculum that defines the skills to be taught at any given time and a set of teaching procedures used to deliver this content. Its core features include naturalistic applied behavioral analytic strategies, sensitivity to typical developmental sequence, deep parental involvement, focus on interpersonal exchange and positive emotional expression, shared engagements with joint activities, and language and communication taught inside a positive, affect-based relationship.

The discrete trial focused model is based on work from Ron Leaf, John McEachin, and colleagues from the Autism Partnership program in California. Discrete trial training is a one-to-one instructional approach used to teach skills in a planned, controlled, and systematic manner. Each trial or opportunity has a definite beginning and end, with praise and/or tangible rewards used to reinforce learning. Early intensive behavioral interventions focused on discrete trial teaching have been used across many early intervention programs for the past two decades and have been highlighted in research reviews as some of the most powerful for preschool children with autism.

The Vanderbilt intervention study will be conducted in Clarksville, Tennessee, with Army families based at Fort Campbell. Children under 2 years of age will be randomly assigned to one of the two interventions and randomly assigned to receive either 15 hrs/week or 25 hrs/wk of in-home therapy over a year. In both interventions, parents will receive 1.5-2 hour training sessions, 2 per month. Parent-child interaction at home and a 24-hour child vocal record will be recorded monthly. Children's developmental progress will be assessed monthly at Vanderbilt. Therapists will be supervised by Board-Certified Behavioral Analysts.
Nancy Huffman, longtime VKC Coordinator of Grants Management and Fiscal Services, passed away on April 29. She was 61. VKC staff and faculty who worked with her for the last 36 years remember her expertise in grant budget development and grants management, as well as her warm smile and gentle personality. Co-worker Laura McLeod wrote, “If I ever needed something, even with all she had going on, I could walk into her office and know that she would greet me pleasantly and help me without complaint. People always felt comfortable approaching her. That’s a pretty powerful thing, as simple as it sounds. She was, quite simply, one of the kindest people I have ever met in my entire life.”

Remembering Nancy Huffman

J. Robert (Bob) Newbrough, Ph.D., a founder of the field of community psychology, died January 2. He was 78. Newbrough, professor of Psychology, emeritus, directed the Center for Community Studies (1966-1980), an early research unit of the Kennedy Center, and later served as the Kennedy Center’s associate director (1981-1983). Newbrough’s contributions to community psychology earned him many accolades. He was named fellow the American Psychological Association’s Division of Community Psychology (1972), was elected Division president (1978), received the Division’s award for Distinguished Contributions to Community Research and Theory (1994), and edited the Journal of Community Psychology (1974-1988). The Inter-American Society of Psychology honored him (1989). He co-founded Peabody’s innovative Transactional Ecological Psychology Doctoral Training Program in the early 1970s and directed it until 1986. He established and directed Peabody’s nationally known doctoral program in Community Psychology. During the late 1990s, he developed and directed the doctoral program in Community Research and Action in Human and Organizational Development.

Friend and colleague Dee Newman wrote, “what distinguished [Bob] . . ., beyond his intellect, was not just his courage and integrity, his kindness and generosity, . . . it was simply his concern and willingness to listen and offer help and compassion to others.”

Remembering Bob Newbrough

Research Interests

My research interests focus on enhanced early detection and intervention for young children as well as the development of technologies to enhance the lives of individuals with autism. I am working on projects that study infants at high-risk for autism in hopes of developing methods for earliest detection, which early behavioral intervention programs work best for specific children, as well as training programs for building system capacity for early accurate diagnosis and effective treatment for families in their own backyards.

Investigator

• Adaptive Response Technology for Autism Spectrum Disorders Intervention, National Institute for Mental Health
• Autism Treatment Network; Cooperative Multi-Center Program for Research and Treatment of Autism, Autism Speaks
• Early Detection of Developmental Disorders, National Institute of Child Health and Human Development

Clinical Interests

My clinical interests revolve around improving systems of care for individuals with autism and their families, especially improving early identification and intervention. Unfortunately, the process of developing initial concerns, discussing concerns, obtaining accurate diagnosis, and translating this information into effective treatment remains a complex, distressful one for most families. I believe there is a great opportunity to improve this challenging context and to link families, providers, and systems of care under the shared mission of acting early and effectively to improve the lives of children with autism.

Education

• B.A., 1998, Psychology and Philosophy, The College of William and Mary
• M.S., 2002, Clinical Psychology, University of Miami
• Ph.D., 2005, Clinical Psychology, University of Miami

• Clinical Internship, 2004-2005, Children’s Hospital Boston/Harvard Medical School
• Postdoctoral Fellowship, 2005-2006, Medical University of South Carolina

Attraction to Developmental Disabilities Research

I spent most of my graduate training learning about the development of very young children who had experienced serious life stressors. This focus on early social and emotional development was matched with opportunities to work with young children with autism during my fellowship. Since then, I have worked with young families concerned that their child may have autism. It is a challenging and powerful experience to try to provide families with answers to questions regarding autism and other developmental concerns. In my opinion, this represents an opportunity to understand how we can exceptionally join with families to create systems of care of meaning and value.

Reasons for VKC Membership

I have been fortunate in that I have been actively involved with the Kennedy Center since arriving at Vanderbilt some 7 years ago. My continued attraction to the VKC is linked to the Center’s ability to help form partnerships among researchers, clinicians, educators, and families in a manner that truly impacts communities. The ability to collaborate and work alongside leading scientific experts in behavior, education, genetics, and neuroscience who share a focus on pushing science of impact and meaning is so very fulfilling. I also am fortunate in that increasingly I have been able to intersect with the powerful training programs (i.e., LEND, UCEDD, TRIAD) supported through our Center that provide exceptional training to our next generation of scientific and clinical leaders. In my experience, few places are capable of bringing together current and future leaders in the field of developmental disabilities in such powerful ways.

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Accolades by Elizabeth Taylor

Erik Carter, Ph.D., associate professor of Special Education, received the 2012 Young Professional Award at the AUCD Conference Dec. 2012, in recognition of his “advocacy, commitment, and promise.” His work was described as having “an extraordinary impact on preparing youth and young adults with severe disabilities for self-determined lives with meaningful work and strong community support.”


Carolyn Hughes, Ph.D., professor emerita of Special Education, and Erik Carter, Ph.D., associate professor of Special Education, published The New Transition Handbook: Strategies High School Teachers Use That Work! (Baltimore: Paul H. Brookes Publishing), which provides more than 500 researcher-based, teacher-tested support strategies.

Evon Batey Lee, Ph.D., associate professor of Pediatrics, Psychology, and Psychiatry, was named director of Training for the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities. She succeeded Terri Urbano, Ph.D., professor emerita of Clinical Pediatrics, who retired in December. Lee was also named associate director of Vanderbilt LEND Training.

Autism Speaks has released the ATN/AIR’s “Quick Tips for Improving Sleep for Children With Autism,” created by Beth Malow, M.D., M.S., Burry Chair in Cognitive Childhood Development, professor of Neurology and Pediatrics, and director, Vanderbilt Sleep Disorders Division.

The Tennessee Supreme Court launched an online advocacy video for the public and lawyers as part of its Access to Justice Initiative. Providing Legal Services to Persons With Disabilities was developed by the Disability Law & Advocacy Center of TN and the VKC, and features Elise McMillan, J.D., VKC UCEDD co-director and senior associate in Psychiatry.

Velma McBride Murry, Ph.D., Betts Chair and professor of Education and Human Development, was recently honored with the Society for Research in Child Development’s 2013 Distinguished Contributions to Cultural and Contextual Factors in Child Development Award. The award recognizes an SRCD member’s lifetime contributions to the role of culture and context in the understanding of child development.

Tyler Reimischiel, M.D., assistant professor of Pediatrics and Neurology and director, Division of Developmental Medicine and LEND Training, was recently named Vice Chair for Education, Department of Pediatrics.

Courtney Evans Taylor, M.Div., VKC associate director of Communications and Dissemination, received the Integrity Values Award of The Arc Tennessee for her positive impact in the lives of people with intellectual and developmental disabilities.

Jeremy Veenstra-VanderWeele, M.D., assistant professor of Psychiatry, Pediatrics, and Pharmacology, was among researchers invited to take part in the press conference of the May International Meeting for Autism Research (IMFAR) in Spain, where he highlighted his study “Promising Results on Arbaclofen for Treating Autism Social Withdrawal.”

Two VKC investigators received awards at the annual meeting of the American Association on Intellectual and Developmental Disabilities (AAIDD). Zachary Warren, Ph.D., associate professor of Pediatrics and Psychiatry, received the AAIDD 2013 Early Career Award. Paul Yoder, Ph.D., professor of Special Education, received the AAIDD 2013 Research Award.

Several VKC researchers have been honored with endowed chairs. Ariel Deutch, Ph.D., professor of Psychiatry and Pharmacology and director, National Parkinson Foundation Center of Excellence, was named the James G. Blakemore Chair in Psychiatry. Isabel Gauthier, Ph.D., professor of Radiology & Radiological Sciences and Psychology, was named the David K. Wilson Chair. Paul Newhouse, M.D., professor of Psychiatry, Pharmacology, and Medicine and director of the Center for Cognitive Medicine, was named the Jim Turner Chair in Cognitive Disorders. R. Jay Turner, Ph.D., professor of Sociology, was named the Harvie Branscomb Chair.

The research of multiple VKC investigators was cited in the update of the Interagency Autism Coordinating Committee Strategic Plan for Autism Spectrum Disorder Research, U.S. Health and Human Services. Included was the research of Suzanne Goldman, Ph.D. (Neurology, Sleep Division); Beth Malow, M.D. (Neurology); Melissa McPheeters, Ph.D. (Obstetrics & Gynecology); James Sutcliffe, Ph.D. (Molecular Physiology & Biophysics); Julie Lounds Taylor, Ph.D. (Pediatrics); Lily Wang, Ph.D. (Biostatistics); Zachary Warren, Ph.D. (Pediatrics); Jeremy Veenstra-VanderWeele, M.D. (Psychiatry); and Paul Yoder, Ph.D. (Special Education). Malow, Warren, and VKC director Elisabeth Dykens, Ph.D. (Psychology), were part of the external strategic planning group for the federal report. Dykens said the extensive citing of Vanderbilt research reflects ”Vanderbilt’s leadership role in helping our nation answer the urgent questions ‘what do we know?’ and ‘what do we need?’ across the lifespan for the growing number of individuals on the autism spectrum.”

Vanguard – Zachary Warren from page 6

Selected Publications


Dykens said the extensive citing of Vanderbilt research reflects “Vanderbilt’s leadership role in helping our nation answer the urgent questions ‘what do we know?’ and ‘what do we need?’ across the lifespan for the growing number of individuals on the autism spectrum.”

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New LEND Leadership BY JAN ROSEMERGY

The new year began with new leadership for the Vanderbilt LEND Training Program, with the January appointment of Tyler Reimschisel, M.D., as director and, in February, Evon Lee, Ph.D., as associate director.

“Tyler was chosen for his deep commitment to interdisciplinary training in developmental disabilities and his experience with the LEND as associate director since 2008,” said Elisabeth Dykens, VKC director.

Reimschisel is assistant professor of Pediatrics and Neurology, director of the Division of Developmental Medicine and the Center for Child Development, associate director of the Pediatric Residency Program, and vice chair for Education, Department of Pediatrics.


“The mission of the Vanderbilt LEND is to reduce and prevent neurodevelopmental and related disabilities in children and youth and to increase access to family-centered, community-based, culturally competent, interdisciplinary services. The Vanderbilt LEND is federally funded by the Maternal and Child Health Bureau, U.S. Department of Health and Human Services.

The LEND program focuses on preparing health professionals to assume leadership roles and to develop interdisciplinary team skills, advanced clinical skills, and research skills, in order to meet the complex needs of children with neurodevelopmental and related disabilities. The Vanderbilt LEND includes faculty from Vanderbilt University, Belmont University, Tennessee State University, Meharry Medical College, and the University of Tennessee, as well as affiliates from Family Voices of Tennessee. During the 2012-13 academic year, the LEND had 20 trainees in deaf education, developmental/behavioral pediatrics, nursing, occupational therapy, pediatric audiology, physical therapy, psychiatry, psychology, social work, speech-language pathology, and a family trainee.

LEND and Psychiatry—A Good Match BY ELIZABETH TURNER

Vanderbilt LEND trainees typically come with backgrounds in audiology, occupational and physical therapy, and nursing, among other fields, but this year, LEND welcomed its first trainee in psychiatry.

Danica Denton was inspired at a young age by her father, a therapist who always wanted to go to medical school. She found her niche in psychology at the University of Arizona and pursued medical school after working alongside psychiatrists as a case manager at a community mental health agency in Tucson.

“I tried to keep an open mind during my medical school rotations and not pigeonhole myself to psychiatry,” Denton said. “However, when I asked my husband if he thought I should go for surgery or pediatrics, he replied that my eyes always lit up when I talked about my psychiatry rotations and that I was much happier there than on any other service.”

Denton was matched with Vanderbilt for her residency. “My first experience with children came on my very first rotation as an intern on the Child and Adolescent Inpatient Unit at the Vanderbilt Psychiatric Hospital, where I had two patients with autism. I really enjoyed working with them, and I realized that it took a team approach to care for these patients.”

After indicating her interest in autism to Psychiatry Department chair Stephan Heckers, M.D., Denton was put in contact with VKC autism researchers in Psychiatry, Blythe Corbett, Ph.D. and Jeremy Veenstra-VanderWeele, M.D.

“While I was planning my fourth year of residency, Dr. Veenstra-VanderWeele described LEND to me. I was immediately fascinated because I had felt for some time that a multidisciplinary approach in the treatment of children and adolescents with ASD was important,” she said. “LEND does a great job of allowing everyone who has an interest in ASD to show how their experience can complement everyone else’s to benefit patients.”

Denton also is working on autism research projects with Veenstra-VanderWeele. One study involves the use of the Autism Treatment Network (ATN) database to look at differences between children who are and are not prescribed atypical antipsychotics.

“I have learned a huge amount from others in LEND. I have learned how each discipline contributes to the care of children with ASD and how what each of us contributes can complement all the other pieces,” Denton said.
(1) Proud Graduates
Next Steps at Vanderbilt graduated its third class of students on April 24. Carrie DePauw, Will McMillan, and Matthew Moore completed this 2-year certificate program for students with intellectual disabilities, which aims to develop academic, social, and independent living skills and to broaden career options. Family, friends, Ambassadors, and Vanderbilt faculty and staff were in attendance to celebrate what Cynthia Cyrus, associate provost for Undergraduate Education, coined “cheerful change.” “We come together with joy in what you have accomplished,” Cyrus said. “We take pride in the person you’ve become, and we celebrate now in anticipation of what you are yet to do.”

(2) Advocating on "The Hill"
Advocacy activities abound. The VKC and The Arc Tennessee collaborated to produce a booklet for legislators sharing the stories of families on the waiting list for home- and community-based waiver services. VKC UCEDD and LEND trainees and Next Steps students joined several hundred others for Disability Day on the Hill and Vanderbilt Day on the Hill on January 30 at Legislative Plaza. VKC Community Advisory Council members attended the Disability Policy Seminar in Washington, D.C., in mid-April and visited Tennessee legislators.

(3) Education Advocates for Families
The Volunteer Advocacy Project (VAP) graduated its 10th group of advocates on April 15. Across multiple Tennessee sites during 11 weekly sessions, the project trains volunteers in special education law and advocacy strategies. In turn, these trained volunteers assist parents of children with disabilities as they advocate for educational supports. To date, the VAP has trained 293 advocates, and 350-400 families have been referred through The Arc and STEP.

(4) Showing What’s Possible!
Two public awareness videos have been produced through the VKC. *I’m Thinking College, Even With My Disability* showcases the experiences of four students enrolled in Next Steps at Vanderbilt and was a collaborative project with the Tennessee Alliance for Postsecondary Opportunities for Students With Intellectual Disabilities. *Connecting to the Future: Employment and Disabilities* was developed in collaboration with the Tennessee Developmental Disabilities Network. It highlights two advocates who have jobs based on their own personal interests and the steps they took to get those positions. Both videos were created by Kyle Jonas and can be viewed at kc.vanderbilt.edu.

(5) NOLA Community Service
“As a senior, I get to experience a whole lot of new things. One of which is how I went to New Orleans for the Best Buddies Spring Break. The things we saw were amazing. We saw buildings that were destroyed by Katrina. Katrina was one of the worst tragedies that happened to New Orleans. It was hard to see them, but it reminded me of what happened to us here in Nashville during the flood. While we were there, we helped a church by cooking and building bookshelves, but I like cooking more! I got to hang out with all of the Best Buddies. I had a really good time. Sometimes we got lost, but it was ok!” ~ Will McMillan, Next Steps at Vanderbilt Class of 2013
Grand Ole Heart Pete Fisher by Courtney Taylor

Pete Fisher, Vice President and General Manager of the Grand Ole Opry, remembers the first year the ACM Lifting Lives Music Campers performed on the Opry stage. After the performance, he received a phone call from the manager on duty, who told him that a couple and their daughter wanted to speak with him. The family was visiting Nashville and had come to the Opry not knowing the campers would be performing. He learned that their daughter had Williams syndrome, and she had never before met another person with Williams syndrome. “They were beyond excited,” said Fisher. “We just had to bring them backstage and, of course, all the campers hugged her. It really blinded us. I’d be lying if I said it wasn’t a leap of faith to have them on the stage, but when we saw that first performance and when that family came forward, it was total and complete validation that we should be doing this. We have extraordinary moments every single week at the show, and when the campers are here it’s one of the highlights of the year.”

Fisher is no stranger to celebrating the skills and talents of people with disabilities. His wife of 25 years, Hope, has a sister with Down syndrome. He has witnessed first-hand some of the challenges that she and the family have had finding supports and garnering greater understanding in the community. Fisher and his wife also have two boys, Sean, who is 24 and lives in Los Angeles, and 18-year-old Chris, who will be heading off to college in August.

“Both of our boys are drummers,” said Fisher. “They have received very powerful experiences and benefits from music education. I’ve been involved in an annual fundraiser at their high school called Music 4 Music. It just stems, quite honestly, from an indebtedness that I feel to music education. Music is powerful. All of us here at the Opry have a passion for music and for putting smiles on people’s faces. I think the campers help us develop an even deeper appreciation. Upon observing them and seeing the love they have for music and their experience on the Opry, you can’t help but look inward. You can’t help but be reminded that music is a gift and that the Opry is a really special place.”

Fisher is a graduate of the Leadership Music Program, which serves as a model for the new ACM Lifting Lives Series at Vanderbilt. The 9-session, 8-month series gives participants with disabilities an opportunity to learn about different aspects of the music industry, while providing opportunities for enhancing vocational and social skills. Fisher serves on the board of the Lifting Lives Foundation and is excited about the new series, especially since he believes it will expand and extend the benefits of the week-long camp experience.

“The Nashville music industry is extremely giving of its time, its resources, and its people,” said Fisher. “You know, there was a time when I thought I had limited capacity, but when I realized my capacity was much larger than I thought it was, it was transformative. Have you ever noticed that the most fulfilled and happiest people are the people who give of their time and resources? Giving back fulfills me more than anything else I do. It’s a cliché, but you hear it all the time that it’s better to give than to receive. And it is! I truly believe that if you want to realize your greatest potential, it has nothing to do with receiving. It has everything to do with giving.”

Aging and Cognition in Down Syndrome Hobbs Discovery Grant by Jan Rosemergy

Although Down syndrome is the most common genetic cause of intellectual disability, it has received less research attention than autism and other less common disorders. Thanks to advances in medical care, most especially corrective surgery for heart defects, life expectancy for individuals with Down syndrome has increased to 50 to 60 years. Unfortunately, over 50% of adults with Down syndrome develop dementia by age 60. This makes age-related dementia in older adults with Down syndrome an urgent public health concern.

Paul Newhouse, M.D., known nationally for his research on aging and cognition, is now exploring an innovative therapeutic approach for dementia in Down syndrome, thanks to a VKC Nicholas Hobbs Discovery Grant. Newhouse is Jim Turner Professor of Cognitive Disorders and professor of Psychiatry, Pharmacology, and Medicine.

Newhouse was recruited to Vanderbilt to direct the Center for Cognitive Medicine. The Department of Psychiatry. The Center for Cognitive Medicine conducts research and clinical activities that focus on disorders of cognition (memory, thinking, and learning). A major focus is on the aging brain. The Center also studies late-life cognitive disorders, including Mild Cognitive Impairment (MCI) and Alzheimer disease. MCI is the stage when others notice that an individual is developing mild memory or thinking problems. Many persons with MCI go on to develop Alzheimer disease.

In 2012, Newhouse published study findings in Neurology that suggested wearing a nicotine patch may help improve memory loss in older adults with mild cognitive impairment. Nicotine stimulates cholinergic receptors in the brain that are important for thinking and memory, and it may have neuroprotective effects. People with Alzheimer disease lose some of these cholinergic receptors.

Newhouse and VKC director Elisabeth Dykens, Ph.D., are conducting a memory treatment research study for adults with Down syndrome. The study will examine the treatment of memory using low-dose nicotine patches.

Earlier research has shown that brain changes characteristic of Alzheimer disease occur prior to symptoms of memory loss. This suggests that for treatments to be effective, they must begin early. This study will focus on adults with Down syndrome ages 35 and over who are non-smokers and have only mild changes in memory, behavior, and functional independence. The study will involve 6 visits to evaluate medical status, level of functioning, cognitive status, and changes in cognitive ability, memory, attention, and brain wave activity. Treatment will be a 1-month trial of low-dose, FDA-approved nicotine patches. Interested families may contact (615) 322-2082, asante.kamkwalala@vanderbilt.edu.
The Vanderbilt Kennedy Center and its Leadership Council thanked members of the Nicholas Hobbs Donor Society at a reception on April 23 at the home of Sue and Andy Spickard. The generosity of Hobbs Society donors supports innovative research on the causes and treatments of disabilities such as autism, Down syndrome, and other genetic syndromes.

Dr. Bob Dittus, associate vice chancellor for Public Health and Health Care at Vanderbilt Medical Center, described the Kennedy Center as a “beacon of hope.” He expressed gratitude to Hobbs Society members whose philanthropy is vital to the Center’s mission of facilitating discoveries and making positive differences in the lives of persons with developmental disabilities and their families.

VKC director Elisabeth Dykens thanked members whose gifts support Hobbs Discovery Grants. Across types of disabilities and across the life span, she gave several examples of how promising findings from these innovative “seed” grants are a good investment.

Donna Eskind, Leadership Council chair, closed the evening’s program, thanking Hobbs members for their important work.

Honoring Hobbs Society Members

Grants Awarded

- Genetic Analysis of Synapse Formation and Function
  Kendal Broadie, Ph.D. (Biological Sciences)
  National Institute of Mental Health

- CamKII Endocannabinoids, Synaptic Plasticity and Motor Function
  Roger Colbran, Ph.D. (Molecular Physiology & Biophysics)
  National Institute of Neurological Disorders and Stroke

- Word Problems, Language, and Comorbid Learning Disabilities
  Lynn Fuchs, Ph.D. (Special Education)
  National Institute of Child Health and Human Development

- Development of a Manualized Wireless Moisture Alarm Intervention for Toilet Training Children With Autism
  Whitney Loring, PsyD. (Pediatrics)
  Organization of Autism Research

- Functional Mapping of Cortical Networks in Primates With Laser Stimulation
  Anna Roe, Ph.D. (Psychology)
  National Institute of Mental Health

- Sox 10 Alleles for Functional Analysis of Gial Lineages
  Michelle Southard-Smith, Ph.D. (Medicine)
  National Institute of Neurological Disorders and Stroke

- Study of Oxytocin in Autism to Improve Reciprocal Social Behaviors
  Jeremy Veenstra-VanderWeele, M.D. (Psychiatry)
  National Institute of Child Health and Human Development

- Translating OCD Gene-Association Studies Into Mice to Examine SLC1A1 Function
  Jeremy Veenstra-VanderWeele, M.D. (Psychiatry)
  National Institute of Mental Health

VKC Nicholas Hobbs Discovery Grants

- Treatment Effects on Face Processing in Autism
  Blythe Corbett, Ph.D. (Psychiatry)

- Oxytocin and Multisensory Integration in the Neonate
  Elizabeth Hummack, Ph.D. (Pediatric Endocrinology)

- Randomized Clinical Trial of Pacifier Activated Lullaby (PAL)
  Nathalie Maitre, Ph.D., M.D. (Neonatology/Pediatrics)

- Linking Vanderbilt Autism Research Registry to State Databases
  Richard Urbano, Ph.D. (Pediatrics)

- Adaptive Robotic Intervention Architecture for Autism Spectrum Disorders
  Zachary Warren, Ph.D. (Pediatrics)

- Nicotinic Treatment of Age-Related Cognitive Decline in Down Syndrome: A Pilot Trial
  Paul Newhouse, M.D. (Psychiatry)
Breakthroughs in Developmental Disabilities Research

View a brief video of 11 national experts in developmental disabilities research reflecting on the most exciting breakthroughs of the last decade and what holds the greatest promise for the future.

kc.vanderbilt.edu/DDbreakthroughs

Video produced by Blythe Corbett, Ph.D.
Tony Maupin, videographer

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Elisabeth Dykens, Ph.D., Kennedy Center Director; Karoly Mirnics, M.D., Ph.D., Associate Director; Jan Rosemergy, Ph.D., Deputy Director and Director of Communications; Tim Stafford, Director of Operations

UCEDD: Elisabeth Dykens, Ph.D., Co-Director; Elise McMillan, J.D., Co-Director; Eron Lee, Ph.D., Training; Robert Hodapp, Ph.D., Research; Jan Rosemergy, Ph.D., Dissemination

LEND: Tyler Reimuschiel, M.D., Director, Eron Lee, Ph.D., Associate Director

TRIAD: Zachary Warren, Ph.D., Director

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JUNE 22*
TRIAD Families First Workshops
Developing Successful Sleep and Feeding Habits
Register at kc.vanderbilt.edu/registration. Info (615) 322-6027 or families.first@vanderbilt.edu
Saturday 9 a.m.-12 p.m.

JUNE 25-26*
Autism Diagnostic Observation Schedule (ADOS-2) Clinical Training
TRIAD workshop for psychologists, pediatricians, behavioral specialists, and SLPs. Fee: $300. Register at kc.vanderbilt.edu/registration. Info amy.r.swanson@vanderbilt.edu or (615) 322-6533. Tuesday-Wednesday 8 a.m.-4:30 p.m.

JUNE 29*
Clinical Genetics for Health Care Professionals Workshop by Vanderbilt Pediatrics Developmental Medicine Division for health care professionals who are not geneticists. $50 (includes lunch) 7.25 CME & APA CE. Register at kc.vanderbilt.edu/registration. Info pam.grau@vanderbilt.edu Saturday 7:30 a.m.-2 p.m.

JULY 20*
TRIAD Families First Workshops
Building Functional Social and Play Skills
Register at kc.vanderbilt.edu/registration. Info (615) 322-6027 or families.first@vanderbilt.edu Saturday 9 a.m.-12 p.m.

JULY 22*
Statistics and Core Methodology Training Seminar
Improving Research Using Advanced REDCap Interfaces
Scott Burns, Neuroimaging Analyst Register at kc.vanderbilt.edu/registration Monday 12:30-1:30 p.m.

JULY 30-31
School Speech-Language Pathology Conference
Two lunch-time plenary sessions and selection among 6 (90-minute) small group sessions (1.1 ASHA CEUs). Register at kc.vanderbilt.edu/registration. Info languagelab@vanderbilt.edu 8th Flr Lecture Hall, Vanderbilt Bill Wilkerson Center, Medical Center East Tuesday-Wednesday 8 a.m.-3 p.m.

AUGUST 17*
TRIAD Families First Workshops
Addressing Challenging Behaviors
Register at kc.vanderbilt.edu/registration. Info (615) 322-6027 or families.first@vanderbilt.edu Saturday 9 a.m.-12 p.m.

SEPTEMBER 13*
Community Advisory Council Meeting
Info (615) 936-8852 Friday 9 a.m.-2 p.m.

SEPTEMBER 18
Neuroscience Graduate Program Seminar Series
TBA
Stephen J. Smith, Ph.D., Professor of Molecular & Cellular Physiology Stanford University. Co-sponsor Vanderbilt Brain Institute Room 1220 MRB III Lecture Hall Wednesday 4:10 p.m.

SEPTEMBER 26*
Lectures on Development and Developmental Disabilities
Emotion and Survival: What’s the Relation?
Joseph LeDoux, Ph.D., Professor of Neural Science & Psychology, New York University Thursday 4:10 p.m.
CALENDAR OF EVENTS | JUNE–SEPTEMBER 2013

**Vkc summer programs**  
Info laura.mcleod@vanderbilt.edu  
*Registration is closed. Contact TN Disability Pathfinder for information on summer activities.  
• June 3-15  
**Sense Theatre Camp**  
For youth, 7-18 years of age, with and without autism spectrum disorders. Performances Friday, June 14 and Saturday, June 15, 7 p.m. at University School of Nashville Auditorium, 2000 Edgehill Ave, Nashville, TN 37212. Tickets $5.  
• July 14-19  
**Next steps at Vanderbilt summer institute**  
Residential college transition program for rising high school juniors, seniors, and young adults with developmental disabilities up to age 24.  

**Reading clinic summer session**  
• June 3-July 15*  
(no sessions wk July 4)  
Tutoring students through middle school. 24 (40-minute) sessions, ranging 8 a.m.-12 noon, M-Th. Info on fall sessions (615) 936-5118 or readingclinic@vanderbilt.edu  

**Arts and disabilities exhibit**  
Monday-Friday 7:30 a.m.-5:30 p.m. Lobby VKC/One Magnolia Circle Bldg. Info (615) 936-8852  
• through July 31  
**The art of autism** Artists of Tennessee and its Neighbors  
**August-September**  
Sandhill Cranes, Owls, and Elephants. Artists of Pacesetters, Inc.  

**Autism trainings for K-12 school personnel**  
With the Tennessee Department of Education, TRIAD offers free autism-specific workshops for school personnel, parents, and the community in locations across the state. For dates/locations, see kc.vanderbilt.edu/TRIAD/events  

**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. Info (615) 936-5118 or LAC@vanderbilt.edu  

**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/ikf  
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 works**  
Web hub for information related to employment of people with disabilities. Info (615) 322-4999  
TennesseeWorks.org  

**Tennessee disability pathfinder**  
**Multi-cultural outreach**  
Helpline, Web-Searchable Database with Calendar and Resource Library, Print Resources. Project of VKC UCEDD and TN Council on Developmental Disabilities  
www.familypathfinder.org  
English (615) 322-8529  
Espanol (615) 479-9568  
Toll-free (1-800) 640-INFO [4636]  
Tnpathfinder@vanderbilt.edu  

**Volunteer Advocacy Program**  
Fall 2013 training (11 weekly sessions) in special education law and advocacy strategies. Info lynise.parisien@vanderbilt.edu  

**ASMT events**  
Autism Society of Middle Tennessee Registration is requested for all events. ASMT members free; nonmembers $5/family. Vanderbilt Kennedy Center/One Magnolia Circle. Info (615) 385-2077  
TennesseeWorks.org  

**DSAMT events**  
Down Syndrome Association of Middle Tennessee  
Info (615) 386-9002  
www.dsamt.org  

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*Fifth annual TABS conference*, April 5-6, provided adult brothers and sisters of siblings with disabilities information, networking, and support.