

Stylized image of neurons and their axonal and dendritic projections that connect at synapses.

Discovering How Synapses Converse BY JAN ROSEMERGY

The naturalist and poet Diane Ackerman has described the brain as a “crowded chemistry lab, bustling with nonstop neural conversations” being conducted in “an electrochemical lingo all their own.” Understanding just how synapses communicate at a molecular level is the work of VKC investigator Roger Colbran, Ph.D., professor of Molecular Physiology & Biophysics.

“The thing that fascinates me, if you look at the mature brain, is that every synapse—and there are thousands of synapses on most of the neurons in the brain—can function and regulate itself independent of its neighbors,” Colbran said. “The genetic information in the cell nucleus encodes proteins that have to get out into the dendrites where the synaptic impulses are received. These processes have to be organized and coordinated so that the right proteins get to the right place at the right time to do their jobs efficiently. How all this happens is a huge question.”

Although synaptogenesis, the creation of new synapses, happens throughout the life of a healthy individual, synapse formation explodes during early brain development and then synapses are “pruned” by experiences that activate or deactivate neurons. (See p. 2 Neuroscience Primer.)

Postsynaptic calcium signaling is critical in the synaptic changes associated with development and with learning and memory. Calcium signaling is activated by a variety of different mechanisms, most notably through NMDA-glutamate receptors.

Colbran has chosen to focus on calcium/calmodulin-dependent protein kinase II (CaMKII), an enzyme that plays a central role in translating calcium signals into synaptic changes. CaMKII is highly abundant in the cerebral cortex and hippocampus, particularly at the synapse and in the dendritic spine, where many synapses are formed. The research literature over the last 25 years has established a key role for CaMKII.

Colbran is using biochemical, molecular, and genetic approaches to manipulate neuronal signaling *in vivo* in rodent models and in cultured mammalian cells. Cell imaging, electrophysiological, and behavioral tests are then used to assess the impact on CaMKII function in normal tissue and in models of neurological and neuropsychiatric disorders.

“As a biochemist, I was led into neuroscience by the properties of this fascinating protein, which drove me to understand how it works at a synapse,” Colbran said.

The complex regulation of CaMKII is initiated by calcium working through calmodulin, another abundant neuronal protein. Kinases work by phosphorylating (chemically modifying) specific downstream proteins, which induce a physiological change such as an alteration in synaptic function. In the case of CaMKII that has been activated by calmodulin,

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Director’s Message How Basic and Applied Translate

The cover page of this *Discovery* issue celebrates what a center can accomplish because it is a *center*, where the best of basic science and applied science are truly connected, each strengthening the other.

Basic science aims to understand the most fundamental mechanisms and processes of development, both typical processes and altered processes and their consequences. Roger Colbran’s elegant research exploring the complexities of how brain synapses communicate exemplifies the critical importance of basic research as we aim to understand development and disabilities.

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VKC UCEDD Celebrates Another Five Years

BY COURTNEY TAYLOR

At the end of its first 5-year grant cycle, the Vanderbilt Kennedy University Center for Excellence in Developmental Disabilities (VKC UCEDD) has provided or has been affiliated with over 46 training, service, research, and dissemination programs that support children and adults with developmental disabilities and their families. The Center’s faculty, staff, and students have shared information and implemented evidence-based practices in all of Tennessee’s 95 counties.

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Chryssy Billante, Next Step at Vanderbilt student, explores her career interest in a helping profession through an internship with Tennessee Disability Pathfinder.

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A Neuroscience Primer

Neurons, or nerve cells, are the primary components of the nervous system, which includes the brain, spinal cord, and peripheral ganglia. A neuron is a cell that transmits information through chemical and electrical signals. Neurons connect to each other to form networks. A typical neuron has a cell body (soma), dendrites (can be multiple), and a single axon.

Synapses are the structures that allow neurons to transmit signals to target cells. Most neurons transmit a chemical or electrical signal from their axons to the dendrites of other neurons at synapses. Presynaptic endings (often called terminals) of axons contain neurotransmitters and are separated from postsynaptic endings of dendrites by a cleft. These postsynaptic endings, in some cases formed into structures termed dendritic spines, contain receptors for appropriate neurotransmitters, such as glutamate.

Synaptic plasticity refers to the ability of a synapse between two neurons to change in strength. Synaptic plasticity is regulated by changes in the quantity of neurotransmitters released into a synapse and changes in how well neurons respond to those neurotransmitters. Synaptic plasticity is generally considered to be the neurochemical foundation for learning and memory.

Calcium ions (Ca^{2+}) play a critical signaling role in the biochemistry and physiology of all cells. In neurons, calcium controls the release of neurotransmitters from terminals, as well as the responses of neurons in dendritic spines.

Glutamate receptors are the proteins in dendritic spines that detect the glutamate released from an adjacent presynaptic terminal and become activated. There are multiple subtypes. Activated AMPA-glutamate receptors depolarize neurons and are responsible for normal synaptic communication. Activation of NMDA-glutamate receptors stimulates the increases in calcium that causes synaptic plasticity and learning and memory.

Biochemistry of synaptic plasticity. The biochemical mechanisms that cause synaptic plasticity involve alterations in the amount and activities of many proteins, including protein kinases. Protein kinases chemically modify existing synaptic proteins, such as glutamate receptors, by adding a phosphate group, changing their function.

In vivo (Latin “within the living”) is a research approach that involves using a whole, living organism. **In vitro** research (Latin “within

the glass”) is done in a controlled environment on isolated cells in a Petri dish or using purified proteins in a test tube. ■

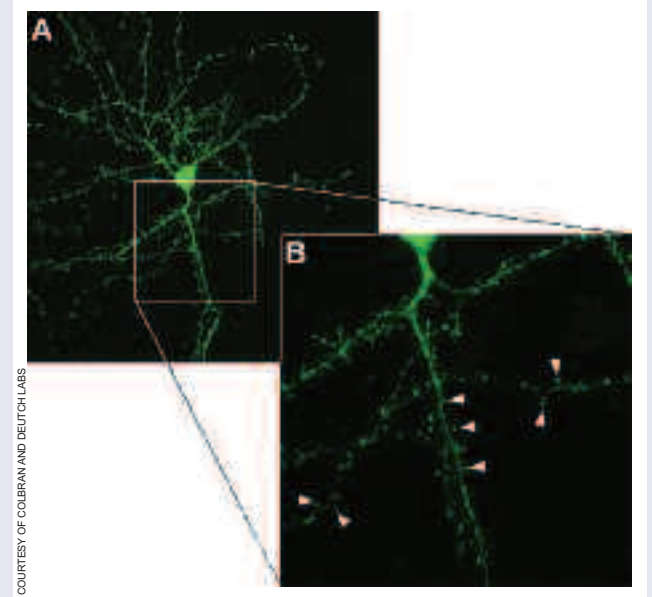


Image (A) of a neuron expressing a green fluorescent protein that is present in the central soma and throughout the dendrites. Higher magnification images of dendrites (B) show that the protein is present in a punctate pattern (arrowheads) because it is concentrated in dendritic spines.

DISCOVERING HOW SYNAPSES CONVERSE from page 1

the downstream targets include itself, through so-called autophosphorylation reactions.

“These complicated autophosphorylation reactions allow CaMKII to function at the right synapse at the right time by controlling CaMKII localization and modulating its activity,” Colbran said.

For over 15 years, Colbran’s lab has focused on the molecular basis for targeting to the synapse, investigating the protein-protein interactions that take CaMKII to the synapse and fine tune its localization and activity within the synapse.

Scaffolding Memory

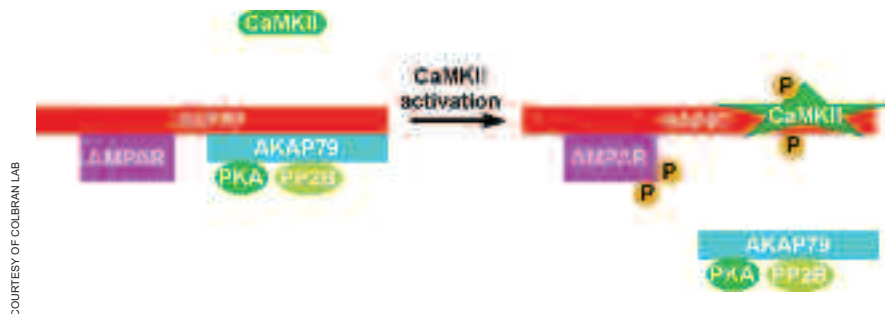
Colbran and colleagues added new details to CaMKII’s actions when they reported that CaMKII can bind to and phosphorylate a specific variant of the known synaptic protein SAP97 (*Journal of Biological Chemistry*, Jan. 2010). SAP97 joins a growing list of synaptic proteins that can interact with CaMKII, which also includes the NMDAR-glutamate receptor itself.

“Any one of these interactions controls a subset of the total effects of CaMKII,” said Colbran. “There may be a thousand or so proteins at these synapses that have to work in a coordinated way. CaMKII seems to be changing the composition of these complexes in a precisely controlled

way. It might also contribute to locking the AMPA- and NMDA-glutamate receptors at the synapse where they are needed to efficiently sense released neurotransmitters.”

SAP97 is already known to interact with the AMPA-glutamate receptor, the major receptor ion channel involved in excitatory synaptic transmission, and with several other regulatory/signaling proteins that are required for normal learning and memory.

“It is the long-term changes in the AMPA-glutamate receptor that give rise to learning and memory. This is one of the key downstream targets of CaMKII. By binding and phosphorylating SAP97, CaMKII can displace other signaling molecules to alter the properties of the AMPA-glutamate receptor.”



Colbran’s lab recently showed that CaMKII can regulate the composition of SAP97 protein complexes to increase the phosphorylation (P) of AMPA-glutamate receptors (AMPA) and enhance their activity. Such mechanisms make synapses stronger.

Developmental Perspectives

A VKC Nicholas Hobbs Discovery Grant helped Colbran’s lab develop a methodology to look at protein complexes in a more *in vivo* context that reflects brain activity in a living animal. This approach is being used to investigate CaMKII in animal models during the course of development.

The Colbran lab is conducting studies using a transgenic mouse model in which one of the autophosphorylation sites has been removed from the protein, so that CaMKII cannot regulate itself properly throughout development. Preliminary findings indicate that even during preadolescence, these mice have changes in synaptic properties and in cognitive function that are associated with changes in the amount of CaMKII in these synaptic complexes.

Other studies are examining the persistent impact on CaMKII signaling of abnormal developmental experiences that have long-term neurobehavioral consequences, such as transient exposure of young mice to stressful environments. Many genetic disorders also have a neurodevelopmental component, including Angelman syndrome, a genetic disorder that causes intellectual disability and neurological problems. ■



VKC UCEDD CELEBRATES ANOTHER FIVE YEARS *from page 1*

“I’m proud of the expertise and energy of our UCEDD faculty, staff, and trainees who have accomplished so much in supporting individuals with disabilities and their family members and in strengthening and creating collaborations to move Tennessee’s service system forward,” said Elisabeth Dykens, Ph.D., VKC director and UCEDD co-director.

The VKC UCEDD has received funding for 2010-2015 from the Administration on Developmental Disabilities, U.S. Health and Human Services, which supports this national network of 67 centers in all U.S. states and territories.

“I have always been a strong supporter of better education and health care of Middle Tennesseans with disabilities and their families,” said U.S. Congressman Jim Cooper. “The Vanderbilt University Kennedy Center is an incredible asset to our community, and I know that they will continue to build upon the success of these innovative programs.”

Plans for the next 5 years include continuing collaborative partnerships, adding employment as a fifth area of emphasis, and continuing to develop and improve innovative programs.

Collaborative Partnerships

As a member of the Association of University Centers on Disabilities (AUCD) Network, the VKC UCEDD connects with UCEDDs nationwide, starting in its own backyard. The University of Tennessee Boling Center UCEDD is located in Memphis and is a Tennessee Developmental Disabilities Network partner. Tennessee is one of only a few states that have more than one UCEDD. The collaborative projects between Tennessee’s two UCEDDs have been productive and many, including facilitating the Tennessee Autism Summit Team and expanding Hispanic outreach statewide through the Camino Seguro service provider database.

“We learned early on of the power of collaboration across the state and country,” said Elise McMillan, VKC UCEDD co-director. “Initially, it was extremely helpful to reach out through the AUCD network to other UCEDDs to find out what had worked and what had been challenging. Now it is a wonderful feeling when other UCEDDs contact us. It’s good to know that we can help one another.”

The VKC UCEDD also partners with leading community disability organizations. These Community Partners are invited by the VKC UCEDD and the VKC Leadership Council to collaborate on specific initiatives, programs, or events.

Community Advisory Council

Central to the VKC UCEDD is its partnership with its Community Advisory Council (CAC). Through these Councils, UCEDDs receive input on programming from self-advocates and family members, service providers, and state legislators. Members of the VKC UCEDD CAC, which meets quarterly, have been engaged actively in strategic planning, evaluation, and advocacy for systems change. One important outcome of the UCEDD and CAC needs assessment was the decision to add employment of adults with disabilities as an area of emphasis, in addition to continuing emphasis on education and early intervention, health and mental health, quality of life, and recreation and art.



Community Advisory Council

Employment—New Emphasis

In September 2010, the U.S. Department of Labor reported that only 21.6% of people with disabilities are in the labor force. By comparison, 69.9% of individuals without disabilities are employed. Increasing employment opportunities through training, research, and service will be a high priority of the VKC UCEDD in the next 5 years.

“It is a basic right to feel that you, as an individual, are contributing to society by having a job,” said Doria Panvini. “As CAC chair, I was thrilled to see the commitment of the Vanderbilt Kennedy Center to work to increase employment of persons with disabilities. Seeing CAC suggestions like emphasizing employment implemented and impacting the way the UCEDD is evolving makes us as CAC members feel highly valued.”

Employment-focused programming includes the development of a new position at the VKC UCEDD for an AmeriCorps member with disabilities (see p. 9), and continued collaborations with Project Opportunity, Vanderbilt University Medical Center, and the Statewide Secondary Transition Project. It also includes strengthening employment components in continuing programs such as Next Step at Vanderbilt.

UCEDD Accomplishments

Accomplishments of the last 5 years include major initiatives and projects begun after the VKC became

a UCEDD, as the following examples illustrate.

Public Policy. The UCEDD Public Policy Committee leads policy initiatives at the local, state, and national level. Accomplishments include dissemination of family stories to state legislators and annual advocacy training. UCEDD faculty lead the Mayor’s Advisory Council on Special Education and the State Task Force on Postsecondary Education for Individuals with Intellectual Disabilities.

Research. UCEDD faculty and trainees conducted a statewide needs assessment. Over 1,150 Tennesseans with developmental disabilities and family members identified the types of programs needed to support them in their homes and communities. Survey results are informing how the UCEDD and other Tennessee disability agencies think strategically about the service system.

Services and Training. In 2007, the UCEDD began its Disabilities, Religion, and Spirituality Program. Activities include developing ecumenical educational materials; conducting research; providing disability-related theological field education internship opportunities; and providing disability-related trainings and events for faith communities.

In 2008, the Behavioral Health and Intellectual Disability Clinic began in collaboration with the Vanderbilt University Department of Psychiatry. This model clinic helps individuals, ages 17 and up, deal with the behavioral and mental health challenges that can inhibit successful adult life in transitioning from school to community. Training is provided to students from a variety of disciplines. Services include applied behavior analysis, group psychotherapy, family or team consultation, psychopharmacological review, and medication management. A “tool kit” for behavioral health providers is scheduled for dissemination in 2011.

In 2009, the VKC UCEDD established Tennessee Adult Brothers and Sisters (TABS), a statewide network for adult siblings of individuals with disabilities. TABS has an active website and sibling support blog and an annual conference.

In January 2010, Vanderbilt welcomed six new students as the entering class of Next Step at Vanderbilt, a 2-year certificate program for students with intellectual disabilities. Students self-direct their Program of Study through Person-Centered Planning activities. The Program of Study is a unique, customized plan for achievement in academic areas, independent living skills, career development, and university life.

“Faculty, staff, and trainees involved in our VKC UCEDD programs are engaged in research, training, service, and dissemination,” said McMillan. “We look forward to another 5 years as a UCEDD and to formulating new goals and accomplishments with our partners.” ■



Expanding Educational Outreach

Britt Henderson Training Series BY COURTNEY TAYLOR

Education reform and accountability on the part of schools and teachers is a topic of vigorous national discussion these days. Yet for almost 15 years, Vanderbilt Kennedy Center (VKC) special education researchers have been working with school teams in Middle Tennessee to share innovative evidence-based methods to improve learning for diverse learners through the Britt Henderson Training Series for Educators.



Kathleen Lane and Andrea Cappizi, Henderson Series co-directors

The Britt Henderson Training Series was founded in 1996 and is available to participants at no cost through an endowment created by Carol Henderson and her late husband, Bob Henderson, and their family, in memory of son Britt Henderson.

During much of the history of the Henderson Series, the VKC hosted year-long trainings for a small number of school teams. In 2009-10, a new model was introduced to open participation to a broader audience. In 2010-11, Andrea Cappizi, Ph.D., assistant professor of Special Education, joins the Series as co-director.

“Rather than hosting year-long trainings for a smaller number of teams, we are offering 8 different stand-alone topics,” said Kathleen Lane, Ph.D., associate professor of Special Education and faculty co-director of the Henderson Series. “Teams and individuals from public schools, private schools,

agencies, or parents may attend. We are able to provide more general information with less of a time commitment so that a larger number of people might attend and recognize issues and ideas that they can implement in their schools or homes.”

A technical assistance grant called Project Support and Include (PSI), which is being conducted by Lane and Wendy P. Oakes, Ph.D., has allowed for additional training and implementation support to systems beyond those offered through the Henderson Training.

“PSI offers services for support to 17 counties in Middle Tennessee,” said Lane. “We report directly to Linda Copas, director of Behavioral & Autism Services for the Tennessee Department of Education. The Henderson Series and PSI technical assistance offerings are wonderful ways to connect even more schools and individuals with desired supports.”

Participation in a workshop is followed up with relevant content information. The goal of the new format is to introduce a range of topics and strategies so that when teams or teachers think that their school might benefit from a particular strategy, they can then be connected with other supports.

The workshop topics for 2010-11 include: Functional Assessment; Setting Up Your Classroom for Success; Behavior Screening Tools; Using School-Wide Data to Identify Non-Responders; Using Self-Monitoring in Academic Interventions; Differentiating Instruction; Using Simple Strategies to Increase Student Engagement; and Mentoring Faculty to Improve Implementation of the Primary Plan.

All workshops are free, thanks to the Henderson Family endowment. Registration is required. For information, contact mary.crnobori@vanderbilt.edu, (615) 343-0473. ■

Autism Resource Line

Vanderbilt Autism Resource Line is the new name of the helpline formerly known as the Vanderbilt Autism Clinic. It remains an initial access portal to Vanderbilt autism-related clinical and research programs and resources.

Contact (615) 322-7565 or toll-free 877-ASD-VUMC [877-273-8862]. For autism-related resources external to Vanderbilt University, contact Tennessee Disability Pathfinder: (615) 322-8529 or toll-free 800-640-INFO [4636]. ■

DIRECTOR'S MESSAGE from page 1



Elisabeth Dykens

Applied research aims to solve practical problems. The renewal of the VKC UCEDD means that for another 5 years, we will provide training, services, research, and dissemination to improve the daily lives of children and adults with disabilities and their families.

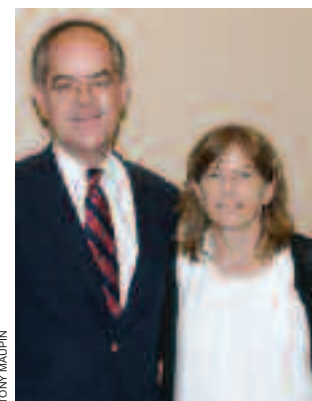
Basic and applied science are equally vital as researchers and clinicians, service providers and individuals with disabilities and family members, all work together to solve the puzzles of complex developmental disabilities. One perspective alone doesn't get the job done.

VKC Science Day will be held on February 15, 2011. This event will celebrate what VKC faculty, graduate students, and postdoctoral fellows have discovered through basic and applied research over the past year.

Translational research is more than a buzz word. It has real meaning. We are a center where researchers and researchers-in-training work together across disciplines, always in ultimate partnership with individuals with disabilities and family members. We translate “bench science” into interventions to improve lives. ■

Congressional Visit

U.S. Representative Jim Cooper of Tennessee's 5th District and staff member Peter Boogaard visited the Vanderbilt Kennedy Center on October 12 to mark the renewal of the VKC University Center for Excellence on Developmental Disabilities. In addition to meeting with Elisabeth Dykens, VKC director and UCEDD co-director, Elise McMillan, UCEDD co-director, and Jan Rosemergy, VKC deputy director, Rep. Cooper visited VKC faculty and staff in the Treatment and Research Institute for Autism Spectrum Disorders, the Family Outreach Center, Tennessee Disability Pathfinder, and the Parent Stress Intervention Project.



U.S. Representative Jim Cooper and VKC Director Elisabeth Dykens

The latter is an ARRA-funded research project that both employs parents whose children have disabilities and provides interventions to parents of children with disabilities. ■



“In my spare time I do research” Taking Part in Baby Sibling Research with Your New Baby!

BY ELIZABETH CATANIA

What is it like to participate in a study that starts when your baby is 6 months old and follows them, over multiple visits, all the way to their third birthday? TRIAD has two ongoing studies that enroll babies who have an older sibling with an autism spectrum disorder (ASD).

Because younger siblings of children with ASD are at higher risk for being diagnosed with autism and other developmental disorders, studying these infants allows us to learn critical information about their social and emotional development and how to improve early diagnosis of ASD. During study visits, babies play with their parents and investigators in assessments that probe social, cognitive, play, and emotional behaviors.

We talked to the mother of one our baby sibling participants about her experience in our research. Tonie’s baby, Sariyah, has been enrolled in the study since she was 12 months old and recently came to Vanderbilt for her visit at 2 years old.



COURTESY OF TRIAD

Sariyah’s play is an indicator of her developmental progress.

Tonie first saw the study on the VKC StudyFinder website (kc.vanderbilt.edu/studyfinder). She decided to enroll her infant in the study because she liked the idea that her baby’s development would be tracked through regular visits.

“I thought it would give me a sense of peace, knowing that she would be around people that could diagnose her early if applicable,” Tonie said.

Tonie enjoys bringing Sariyah for her study visits and observing her during assessments with the research staff.

“It is fun to see her interact with some other people. A lot of times you’re with your kids, so you don’t really get to see them socially with someone else,” she said. She believes that Sariyah, who likes showing off for the cameras, enjoys it, too.

Tonie’s least favorite part of the study was filling out a packet of information forms and questionnaires about her child for each visit.

“It was long—and at the end [of the visit], undoubtedly, every time, I would have to go back and still finish.” But even the packet had its upside. She says that when filling out the forms, “You have a really good snapshot, ‘Oh, this is where she was last time. She couldn’t even say these things,’ so it’s cool to get to really see, according to the data, how much she picked up over time.”

Overall, Tonie really enjoys being a part of the baby sibling study and absolutely recommends that other parents participate with their babies.

“Is she or isn’t she?” is a big question once you have a child’s who’s diagnosed,” Tonie said. “I think it will just give other parents a whole lot of peace of mind, which is invaluable.”

For information, contact Elizabeth Catania, elizabeth.catania@vanderbilt.edu, (615) 343-3723. TRIAD particularly invites parents of babies who are 6 months old or younger but also has studies open to babies up to 30 months old. ■

Elizabeth Catania, Ph.D., TRIAD Research Fellow

Helping Early Childhood Educators Teach Young Children with Autism BY JAN ROSEMERGY

Early childhood is a wonderful, yet vulnerable, time that sets the stage for a child’s future learning and sense of self. While all children can benefit from high-quality early childhood education, it is especially critical to the future development of young children challenged by an autism spectrum disorder (ASD).

Although early childhood special educators receive training to work with children with developmental delays, they may lack the specialized training needed to promote maximum development in young children with ASD. This need is being addressed in Tennessee by a new TRIAD program to train early childhood educators, which is being funded by the Tennessee Department of Education.

“The Tennessee Department of Education has partnered with TRIAD now for several years to provide training for teachers and school administrators throughout Tennessee,” said Linda Copas, director of Behavior/Autism Services, Tennessee Department of Education. “We’re excited to partner again with TRIAD to extend this high-quality training to early childhood educators.”

The training, which will be conducted annually in each of Tennessee’s three grand regions (East, Middle, West Tennessee) for the next 3 years, was proposed in response to feedback from

teachers of young children who wanted training specifically targeted for their needs, said Nicolette Brigham, Ph.D., director of TRIAD Outreach and Training.

“It’s important to provide training in early childhood education because so much can be done in these early years to promote later development,” Brigham said. Early childhood refers to children 3 to 5 years.

Each 2-day training session will enroll a maximum of 40 early childhood educators. The 2011 training workshops will be held in January. Early childhood educators include not only classroom teachers but also a wide range of professionals, for example, speech/language pathologists, physical and occupational therapists, and psychologists.

The training will focus on the core deficit areas of ASD: communication, social interaction, play, and behavior. Training will incorporate videos of young students in actual classrooms to help educators brainstorm and develop learning goals and which strategies can be used to meet those

goals. In addition, attention will be given to ways to collaborate and communicate with parents.

“An advantage of early diagnosis is that teachers can start early to provide autism-specific intervention, as well as to coach parents on how best to meet a child’s goals at home,” said Lisa Wallace, M.S., CCC-SLP, TRIAD program leader of the Monroe Carell Jr. Families First Workshops. “For children with ASD, we know that building play skills has a huge impact on their later cognition, communication, and social interaction. It’s also important to get in there early to manage and minimize challenging behaviors.”

“We’ll help teachers look at each child individually, develop goals that not only are tied to core deficits in ASD but also are individualized based on that child’s strengths, interests, and personality, and then apply strategies that will fit that child,” Wallace said.

Interested early childhood professionals should contact linda.copas@tn.gov, (615) 741-7790. ■



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Accolades BY AMY POTTIER

Camilla Benbow, Ed.D., Patricia and Rodes Hart Dean of Education and Human Development, Peabody College, **co-authored a report with the National Science Board**, which sets policy for the National Science Foundation and advises the White House and Congress. The report found that the nation's brightest students are often overlooked.



William Bernet, M.D.

William Bernet, M.D., professor of Psychiatry and director of the Division of Forensic Psychiatry, has **authored the book *Parental Alienation, DSM-5 and ICD-11***, published by Charles C. Thomas.



Peggy Chatfield

Peggy Chatfield, Vanderbilt Kennedy Center coordinator of facilities and reservations, received a **Vanderbilt University Commodore Award**, the University's highest staff honor awarded annually to two fulltime staff members. The Award recognized

Chatfield's exceptional work managing the recent renovation of the VKC/MRL Building lobby and event room, with a high level of attention to detail, commitment, determination, and integrity that is characteristic of her performance.



Linda Dupré

Linda Dupré, Director of VKC Grants Development Services, received the **Vanderbilt University Medical Center 2010 Research Staff Award for Contribution to Multi-Investigator Teams**. The award was in recognition of her outstanding

performance in supporting grant submissions for complex, multi-investigator grants such as center grants, research training grants, and grants involving investigators across multiple universities.



Kathryn Edwards, M.D.

Kathryn Edwards, M.D., Sarah H. Sell Professor of Pediatrics and director of the Vanderbilt Vaccine Research Program, was recently **elected to serve on the Executive Committee of the Board of Directors for the Society of America** as the organization's secretary.

Continued on page 7

Leading the Vanguard of Discovery

Jonathan Haines, Ph.D.

T. H. Morgan Professor of Human Genetics
Professor of Molecular Physiology & Biophysics
Director of Center for Human Genetics Research
Vanderbilt Kennedy Center Investigator
Joined Vanderbilt Kennedy Center 1997



Research Interests

Localization and identification of genes involved in human disease, with a primary focus on neurological and eye disease, including studies of Alzheimer disease, multiple sclerosis, autism, amyotrophic lateral sclerosis, epilepsy, age-related macular degeneration, and adult-onset glaucoma.

Principal Investigator

- Molecular and Genetic Epidemiology of Autism, National Institute of Mental Health (PI of subcontract)
- Unifying Genetics Epidemiology of Macular Degeneration (PI of subcontract)
- Genetic Epidemiology of Alzheimer Disease Among African-Americans (PI of subcontract)
- Genomic Convergence in Alzheimer Disease (PI of subcontract)
- Genetic Epidemiology of Multiple Sclerosis, National Institute of Neurological Disorders and Stroke
- Genetic Examination of Age-Related Macular Degeneration in Midwestern Amish
- Genetic Studies of Dementia in Amish, National Institute on Aging
- Training Program on Genetics Variation

Honors and Awards

- Distinguished Alumnae Award, Indiana University, 1992
- Zenith Award for Excellence in Alzheimer's Disease Research, Alzheimer's Association, 1993
- Best of What's New Award (Science and Technology), *Popular Science*, "Discovery of Alzheimer Gene," 1993
- Sidney P. Colowick Award for Research in Diverse Areas, Vanderbilt University Medical Center, 2005
- Fellow, American Association for Advancement of Science, 2009

Education

B.A., 1979, Biology, Colby College, Waterville, Maine
Ph.D., 1984, Genetics, University of Minnesota-Minneapolis

Attraction to Developmental Disabilities Research

I have always been fascinated by two things. The first is how the simple building blocks of genetics, the DNA sequence, and its inheritance can be

combined to generate the wonderfully complex system that is a human being. The second is how the brain works in its equally complex ways. Investigating the role of genetics in developmental disabilities, and in particular autism, gives me the opportunity to combine these interests.

My work is specifically focused on trying to identify the genetic variations that underlie autism. This takes a multidimensional effort that includes recruiting individuals and their families into our studies, examining their DNA in ever increasing detail, and analyzing both the genes and behaviors to find meaningful correlations. Bringing these efforts together gives us a much better understanding of the causes of autism.

Reasons for VKC Membership

The Kennedy Center is a fabulous environment for my research. The interdisciplinary nature of the research supported through the Kennedy Center really helps both to focus our research and to generate new and interesting questions. Equally important is the highly collaborative culture that is fostered by the Kennedy Center. This makes it easy to take crazy ideas, discuss them with other experts, and refine them into exciting research avenues. It also provides an excellent way to reach out to the broader community and to translate what we know in ways that can make a difference to both individuals and society.

Selected Publications

Haines, J. L., Hauser, M. A., Schmidt, S., Scott, W. K., Olson, L. M., Gallins P., Spencer, K. L., Kwan, S. Y., Noureddine, M., Gilbert, J. R., Schetz-Boutaud, N., Agarwal, A., Postel, E. A., & Pericak-Vance, M. A. (2005). Complement factor H variant increases the risk of age-related macular degeneration. *Science*, 308, 419-421.

International Multiple Sclerosis Genetics Consortium. Hafler, D. A., Compston, A., Sawcer, S., Lander, E. S., Daly, M. J., DeJager, P. L., deBakker, P. I., Gabriel, S. B., Mirel, D. B., Ivinson, A. J., Pericak-Vance, M. A., Gregory, S. G., Rioux, J. D., McCauley, J. L., Haines, J. L., Barcellos, L. F., Cree, B., Oksenberg, J. R., & Hauser, S. L. (2007). Risk alleles for multiple sclerosis identified by a genomewide study. *New England Journal of Medicine*, 357(9), 851-862.

Wang, K., Zhang, H., Ma, D., Bucan, M., Glessner, J. T., Abrahams, B. S., Salyakina, D., Imielinski, M., Bradfield, J. P., Sleiman, P. M., Kim, C. E., Hou, C., Frackelton, E., Chiavacci, R., Takahashi, N., Sakurai, T., Rappaport, E., Lajonchere, C. M., Munson, J., Estes, A., Korvatska, O., Piven, J., Sonnenblick, L. I., Alvarez Retuerto, A. I., Herman, E. I., Dong, H., Hutman, T., Sigman, M., Ozonoff, S., Klin, A., Owley, T., Sweeney, J. A., Brune, C. W., Cantor, R. M., Bernier, R., Gilbert, J. R., Cuccaro, M. L., McMahon, W. M.,

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Grants Awarded *Competing renewal funded

Improving Prematurity-Related Respiratory Outcomes at Vanderbilt (IMPROV)

Judy Aschner, M.D. (Pediatrics)
National Heart, Lung, and Blood Institute

Growing Right Onto Wellness (GROW): Changing Early Childhood BMI Trajectories

Shari Barkin, M.D. (Pediatrics)
National Heart, Lung, and Blood Institute

Linking Clinical Translational Science Award Sites to Improve Pediatric Research

Shari Barkin, M.D. (Pediatrics)
National Center for Research Resources

Predictors and Subtypes of Reading Disabilities: Implications for Instruction of "Late-Emergers"

Donald Compton, Ph.D. (Special Education)
U.S. Department of Education, Institute of Educational Sciences

Identification of Glioma Tumor-Initiating Cells

Michael Cooper, M.D. (Neurology)
National Institute of Neurological Disorders and Stroke

Predicting Late-Emerging Reading Disabilities: Neurobiological and Cognitive Factors

Laurie Cutting, Ph.D. (Special Education)
National Institute of Child Health and Human Development

Predicting Phenotypic Trajectories in Prader-Willi Syndrome*

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

University Center for Excellence in Developmental Disabilities*

Elisabeth Dykens, Ph.D. (Psychology & Human Development)
Administration on Developmental Disabilities, U.S. Health & Human Services

Preservice Preparation of Teachers of Students with Visual Impairments

Deborah Hatton, Ph.D. (Special Education)
U.S. Department of Education

Bone Conduction Testing for Newborn Hearing Screening

Linda Hood, Ph.D. (Hearing & Speech Sciences)
National Institute on Deafness and Other Communication Disorders

Leadership Training in High-Need Students with Severe Disabilities/Autism

Carolyn Hughes, Ph.D. (Special Education)
U.S. Department of Education

Vanderbilt Early Childhood Special Education Doctoral Leadership Training Program

Ann Kaiser, Ph.D. (Special Education)
U.S. Department of Education

Dyslexia in Postsecondary Students: Imaging of Neural Circuits and Learning

Sheryl Rimrodt, M.D. (Pediatrics)
National Institute of Child Health and Human Development

Spectral Features of Raphe fMRI Time Series Data in Depression

Ronald Salomon, M.D. (Psychiatry)
National Institute of Mental Health

Novel Adaptive Transactional Virtual Reality-Based Assistive Technology for Autism Intervention

Nilanjan Sarkar, Ph.D. (Mechanical Engineering) & Zachary Warren, Ph.D. (Pediatrics)
National Science Foundation

Dopaminergic Modulation of Brain Development

Gregg Stanwood, Ph.D. (Pharmacology)
National Institute of Mental Health

Signaling Integrator Plays a Critical Role in Regulating Cell Migration

Donna Webb, Ph.D. (Biological Sciences)
National Institute of General Medical Sciences

Addressing the Need for a Next Generation of Special Educators Capable of Providing Most Intensive Instruction (Type A)

Joseph Wehby, Ph.D. (Special Education)
U.S. Department of Education

Alcohol Action on Extended Amygdala Glutamate Synapses

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

Efficacy of Broad Target Speech Recasts on Students with Down Syndrome

Paul Yoder, Ph.D. (Special Education)
U.S. Department of Education, Institute of Education Sciences

ACCOLADES from page 6

Five VKC researchers have been recognized for 25 years of service to Vanderbilt. They are **Douglas Fuchs**, Ph.D., Nicholas Hobbs Chair in Special Education and Human Development; **Lynn Fuchs**, Ph.D., Nicholas Hobbs Chair in Special Education and Human Development; **Judy Garber**, Ph.D., professor of Psychology; **Steven Hollon**, Ph.D., professor of Psychology; and **Richard Shelton**, Ph.D., James G. Blakemore Research Professor of Psychiatry. **Garber** also received a **Chancellor's Award for Research**, for her article, "Prevention of Depression in At-Risk Adolescents: A Randomized Control Trial," published in the *Journal of the American Medical Association* (June 2009).

Lynn Fuchs, Ph.D., Nicholas Hobbs Chair in Special Education and Human Development, is among the collaborators in the new **Center on Improving Mathematics Instruction for Students with Mathematics Difficulties**, funded by a grant from the Institute of Education Sciences, U.S. Department of Education.

Craig Anne Heflinger, Ph.D., associate dean for graduate studies at Peabody College, was awarded the **Lifetime Invisible Child Award by Tennessee Voices for Children**. The award recognizes a person who has been an advocate for children's mental health issues and has made a significant impact on the children's mental health system in Tennessee.



Craig Anne Heflinger, Ph.D.

Elise McMillan, J.D., Vanderbilt Kennedy Center director of Community Outreach, co-director of the University Center of Excellence in Developmental Disabilities, and senior associate in Psychiatry, has been invited to serve on the **Disability and Language Barriers Advisory Committee of the Tennessee Supreme Court Access to Justice Commission**.

Jan Rosemergy, Ph.D., has been appointed **Vanderbilt Kennedy Center Deputy Director**, and continues as VKC director of Communications and Dissemination.

Anne Marie Tharpe, Ph.D., professor and chair of the department of Hearing and Speech Sciences, has been invited to serve on a national steering committee to discuss the nature and direction of the **2010-2015 strategic plan for Maternal and Child Health Bureau training**.



Anne Marie Tharpe, Ph.D.

VANGUARD – JONATHAN HAINES from page 6

Miller, J., State, M. W., Wassink, T. H., Coon, H., Levy, S. E., Schultz, R. T., Nurnberger, J. I., Haines, J. L., Sutcliffe, J. S., Cook, E. H., Minshew, N. J., Buxbaum, J. D., Dawson, G., Grant, S. F., Geschwind, D. H., Pericak-Vance, M. A., Schellenberg, G. D., & Hakonarson, H. (2009). Common genetic variants on 5p14.1 associate with autism spectrum disorders. *Nature*, 459(7246), 528-533.

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Celebrating a Momentous 75th Birthday—Title V of the Social Security Act

BY TERRI URBANO

October 15, 2010. On that day, Lucas was 4 years old. A momentous day for any child but especially significant for Lucas, who has Down syndrome. Lucas has experienced health challenges common to many children with Down syndrome. But thanks to a loving, supportive family, exemplary medical care, and intensive early intervention, he is living a full, happy life. Even more important, he faces a bright future in which he can be an integral, functioning member of society.

Fortunately for Lucas, he was born recently. If he had been born 75 years ago, doctors would have recommended that his parents not become attached to their new baby. He probably would have been sent to an institution to live an impoverished life.

Significant changes in the fields of maternal and child health and disabilities have occurred because *people* made a difference—people who had a vision of better pediatric health care for America's children, especially those with disabilities. Change agents included parents, professionals, policy makers, and organizations working together for a common goal. Title V legislation has been a facilitator in this process.

Title V Accomplishments

On October 20, 2010, the Health Resources and Services

Administration, Maternal and Child Health Bureau (MCHB) celebrated the 75th anniversary of Title V of the Social Security Act. It remains the longest lasting public health legislation in our country. Through Title V, the federal government committed to support maternal and child efforts through state health departments.

Projects of significance influenced standards of prenatal care, nutritional guidelines, and strategies for promoting the health, safety, and well-being of our nation's children. Initiatives also have included social, emotional, and physical care of children with disabilities. In recent years, emphasis has been placed on family-centered, community-based systems of care, especially in unserved or underserved areas. Initiatives address the needs of persons from culturally and ethnically diverse areas, as well as women and children with disabilities, including autism spectrum disorders. They also target national concerns about infant mortality and health care access.

Training Health Professionals

A critical component of improving maternal and child health services is the development of professionals with the requisite knowledge, skills, and dedication. Through the MCHB, Title V funds a national network of Leadership Education in

Neurodevelopmental Disabilities (LEND) programs. LENDs provide interdisciplinary training to graduate and professional students in health-related disciplines. Major foci are interdisciplinary, advanced family-centered clinical services, research, technical assistance, and teaching.

A priority is the development of leadership skills in the provision of health and related care for children with autism and related developmental disabilities or children with other special health care needs and their families. Faculty come from many

employees in remote areas in a timely way, thus improving access to state-of-the-art care for all Tennesseans.

LEND collaborates with VKC Communications to develop quality educational materials related to autism. These materials undergo a rigorous review process, including input from family members and representatives of advocacy organizations. Materials are distributed throughout the state and nation (see VKC website, Resources).

As a major partner, the Vanderbilt Department of Pediatrics collaborates in training, clinical, and research opportunities for LEND. Such real life experiences in an interdisciplinary setting provide invaluable experiences for future leaders in the field of maternal and child health.

Tennessee Challenges

Yet, even with knowledge and skills, LEND and other graduates of interdisciplinary training programs will face challenges in Tennessee. Its rural nature and high poverty rate mean many cannot access health care, especially complex services needed for children with disabilities and/or special health care needs.

Tennessee's child outcome rates are not optimal. While the national *Kids Count Data Book* (Annie E. Casey Foundation) documents the best outcomes Tennessee has seen in 21 years, it still ranks in the

bottom 10 states overall. The state has shown dramatic improvements in infant mortality, child and teen death rates, teen birth rate, and percent of teens not in high school and not high school graduates. Yet Tennessee still faces increases in the percentage of low birthweight infants (at risk for subsequent disabilities), number of children in poverty, and percentage of children in single parent homes. (Source: datacenter.kidscount.org/databook, 2010).

We must not rest on recent improvements, because our overall state health status for children is far from acceptable. We must all commit to individual, organization, and policy collaborations to promote education, service, and research in support of ever improving health for all Tennessee children and particularly those with disabilities.

Yes, Lucas, Happy Birthday. We are glad you have the potential to see many more. We pledge to work together to provide the gifts of health, happiness, and safety for all of Tennessee's and our nation's children. ■

Terri Urbano, Ph.D., M.P.H., R.N., is LEND Director. LEND's associate director is Tyler Reimschisel, M.D. Vanderbilt's LEND has been known as MIND (Mid-Tennessee Interdisciplinary Instruction in Neurodevelopmental Disabilities).



COURTESY OF RHYMEER FAMILY

Lucas is among the many children nationwide benefiting from Title V support of maternal and child health programs.

disciplines. Programs include formal classroom activities, practical supervised clinical and research experiences, teaching and administrative experiences, and exposure to advocacy and policy making. Since most programs have a family member as an integral part of the teaching team, values of family-centered care are emphasized.

Coordinated by the VKC, the Vanderbilt LEND has many collaborators: Pediatrics, Division of Developmental Medicine (Pediatrics, Nursing, Psychology); Hearing & Speech Sciences (Hearing, Deaf Education, Speech Pathology); VKC Treatment and Research Institute for Autism Spectrum Disorders; Vanderbilt Hospital Nutrition Internship; Belmont University (occupational therapy); Meharry Medical College (pediatric dentistry); Tennessee State University (physical therapy); University of Tennessee-Nashville (social work); and Tennessee Disability Coalition (Family Voices). This year, 21 trainees from these disciplines will participate in the LEND program. Last year, 100% of the trainees said they would recommend this program highly to others, indicating a highly successful program.

Vanderbilt's LEND provides professional continuing education, community training, and a monthly distance educational session to nurses and others in the Tennessee Department of Health. This collaboration allows up-to-date information to reach



VKC UCEDD Reaching Out BY COURTNEY TAYLOR

Welcome AmeriCorps Member Portia Carnahan

Upon entering the lobby of the Vanderbilt Kennedy Center (VKC), you will now be greeted by the smiling face of AmeriCorps member, Portia Carnahan. She is with the VKC thanks to a growing movement within the AmeriCorps program to include individuals with disabilities in their community service programs.

For individuals with disabilities, AmeriCorps service can be an effective way to gain employment skills and to share talents with the community. After the passing of the HEART Act in 2008, access to AmeriCorps became an even more feasible option for individuals with disabilities, since the law prohibits counting the AmeriCorps living allowance as income for those who receive Supplemental Security Income (SSI) benefits.

After a successful interview for the position, Carnahan began in August 2010. Her responsibilities include greeting visitors to the Center and helping them locate research and outreach programs and event rooms. She spends part of her time working with the Vanderbilt Coalition for Healthy Aging, Vanderbilt Center for Health Services.

"I love my job here," said Carnahan. "I'm so glad to meet new people and to help them. Everyone has been so sweet to me. It's been really good to get new responsibilities. I feel proud."

For Carnahan, working at the Vanderbilt Kennedy Center is a kind of homecoming, since her early education began in toddler and preschool classrooms of the Kennedy Center Experimental School, known today as the Susan Gray School for Children.

New VKC Clinic Assesses Learning Difficulties

The Learning Assessment Clinic provides academic assessments for students ages 5 to 25 who are experiencing academic learning difficulties. Because every child has unique patterns of cognitive strengths and challenges that affect school performance, strategies to overcome learning problems need to be modified to fit individual needs.

The goal of the academic assessment is to help families understand their child's unique pattern of abilities across an array of skills, including motor coordination, handwriting, reading, listening, verbal and visual learning, planning, use of strategies, and working memory.

"The Learning Assessment Clinic is here to help families find answers about why their child is not doing well in school and what can be done to help," said Sheryl Rimrodt, M.D., Clinic faculty director. "By having experts from specialties in

medicine, education, and psychology working together on the evaluation, this clinic gives a rich, multidimensional picture of the child's strengths and challenges in skills that affect learning and school performance."



Portia Carnahan, AmeriCorps member at VKC



Voting rights event honors Eunice Kennedy Shriver.

The initial time commitment for parents and students is a full workday and a 1-hour return visit for parents 2 weeks after the assessment. Parents receive a multidisciplinary written report, including interpretation and recommendations specific to their child. Parents may choose to share the reports with teachers, IEP committees, school districts, therapists, tutors, and/or medical professionals to assist parents in advocating for their child's educational needs.

The fee for this comprehensive service is paid by a family in advance of the assessment session. Information is provided at the final session that parents may use to submit an insurance claim.

For information, contact:
patty.abernathy@vanderbilt.edu, (615) 936-5118.

Creative Expressions

On the freshly painted walls in the newly renovated lobby of the Vanderbilt Kennedy Center hangs the latest installment of the annual art exhibit, Creative Expressions. Creative Expressions XVI, co-sponsored by the Mayor's Advisory Committee for People with Disabilities, will be on display through January 7, 2011. Art from the exhibit is also displayed at Tennessee Performing Arts Center.

The exhibit features work in a variety of media by artists with a wide range of abilities/disabilities and ages. The exhibit also can be viewed on the VKC website (kc.vanderbilt.edu).

Since its inception in 1976, the Mayor's Advisory Committee has promoted public education and awareness, and advocated for persons with disabilities and their family members. The artists were recognized at the 29th Annual Awards Celebration of the Mayor's Advisory Committee in October.

Eunice Kennedy Shriver Day Celebration

In celebration of the life and legacy of Eunice Kennedy Shriver, the Vanderbilt Kennedy Center, Next Step at Vanderbilt, Best Buddies of Tennessee, the Disability Law and Advocacy Center of Tennessee, and the Tennessee Disability Coalition hosted an evening focused on the importance of voting as a right, a responsibility, and an inclusive activity.

The celebration included a presentation of the contributions of Eunice Kennedy Shriver, information on voting rights and responsibilities, insight into the upcoming elections, information on disability issues in public policy, assistance in completing voter registration forms, and practice voting on paper ballots and on actual voting machines.

Eunice Kennedy Shriver Day is a national annual celebration of her life and a global call for people to commit actions of inclusion, acceptance, and unity for and with individuals with intellectual disabilities.

Next Step at Vanderbilt students Edward Nesbitt and Elizabeth Storey, and peer house staff member Sarah Sampson were involved in planning and coordinating the celebration.

"People need to know who Eunice Kennedy Shriver was and how she devoted her life to improving the lives of individuals with intellectual disabilities," Sampson said. "We wanted to honor her commitments through this event by encouraging a sense of empowerment to vote. Active citizenship means taking part in an inclusive community of American voters." ■



Rising to the Challenge A Parent Perspective on Next Step at Vanderbilt BY MARY LAYNE VAN CLEAVE

When my son Andrew was diagnosed with an intellectual disability, I was grateful that we were living in Nashville and that we had access to the Vanderbilt Center for Child Development. The team there provided me with much needed guidance. The best advice was always to remember that Andrew needs to be challenged—and that he can and will rise to the challenge. I kept that in mind throughout his schooling. I made sure he always was being challenged, and indeed he continually rose to those challenges.

Andrew always talked about attending college. When he graduated from high school, I looked for colleges appropriate for him. I found options in California, Massachusetts, and Virginia, but nothing in Tennessee. This was a huge disappointment for us.

We decided that he would go to the Tennessee Rehabilitation Center at Smyrna, where he had a good experience. He learned life and employment skills and lived in a dorm. However, two important things were missing: an academic track and being with typically developing peers. When I learned that Next Step at Vanderbilt was beginning, I felt it would add those two missing pieces. It did.



I have seen tremendous growth in Andrew. He is more independent, his self-advocacy has improved, and he is making new friends. Being part of campus life, taking classes, and living up to high expectations have allowed his skill levels and his confidence to increase significantly.

I can list three reasons why this growth has been possible for Andrew: the Next Step at Vanderbilt staff, the Ambassadors, and the Vanderbilt community.

Next Step at Vanderbilt staff have created a program for Andrew that focuses on his interests and skills. He is interested in police work, so he took a Vanderbilt criminology class in his first semester and clearly learned a lot.

Andrew's first-semester internship was a perfect fit. He is a sports fanatic and has a huge breadth of knowledge about college and professional sports. So he worked in the sports department of *The Hustler*, Vanderbilt's student newspaper, doing Vanderbilt sports statistics.

Andrew learned to prepare meals by planning and being responsible for a menu, making a shopping list, buying the food at the grocery store, and preparing a meal for his friends. He gained experience in managing money by using a meal card and his own debit card. He also learned to ride the Metro bus to get to special activities.

Art weekends allowed him to express his life in pictures. A songwriting experience allowed him to write the lyrics to his own song. He even went on an alternative spring break trip to Miami with a bunch of kids—not his parents. He had such a great time and when he returned, I thought he had advanced several years in maturity and responsibility.

Andrew has learned to use Facebook to communicate. He communicates freely with a tremendous number of friends and is much more connected to the world.

The Ambassador student volunteers who work with Andrew are among the most devoted and giving people I have ever met. While they fulfilled their commitments as Ambassadors (e.g., eating lunch together, working out, and helping with schoolwork and technology), they have become true friends to Andrew.

Finally, the commitment from the entire Vanderbilt community has been overwhelming. Because Andrew is so interested in police work, he was allowed to participate in some security exercises with the campus police and is doing an internship with them this fall.

Andrew's experience has already been life changing, and he has grown more in many ways over this last 6 months than I would ever have thought possible.

For information, contact nextstep@vanderbilt.edu, (615) 343-0822; website NextStep.vanderbilt.edu. ■

Spotlight: World Traveler Bethany Jackson BY COURTNEY TAYLOR

VKC Leadership Council member, Bethany Jackson, is a traveler. Her love of experiencing different cultures took her and her husband, Michael Cooper, M.D. (Neurology), last summer to Cortona, Italy, a Tuscan hill town. In November, she will visit Berlin, and next summer, she and her family will travel to France. Jackson has shared her love of travel with her children, now 13 and 11 years old. Her 13-year-old took his first trip to France when he was just 10 months old.

“What I like about traveling is the insight that it gives you into how other people live—what they value, how they spend their time, how they interact with one another, even what they eat,” said Jackson. “It gives you a perspective that you can't get from staying in the same place, doing the same things all the time. It has been wonderful to travel with the kids, because you get to see how excited they are by the different sights, sounds, smells, and tastes.”

After graduating from college, Jackson taught English in Madrid, where she had spent time

during college in a study abroad program. She lived and worked there for 3 years.

“When I was living in Madrid, I had a friend whose brother had Down syndrome. In Spanish, the word used in reference to people with disabilities then—it's probably not the current terminology—was ‘minusválido,’ which literally means ‘less valid.’ For native Spanish speakers, the term may seem as benign as a term like ‘invalid’ seems to us. Still, the label made me reflect on how we perceive individuals with disabilities.”

Jackson credits her father, a retired private practice pediatrician, for piquing her interest in disabilities. She is one of five children, and her parents were big proponents of family dinners where they shared the events of their days. Her father would often talk about the types of ailments or disabilities he saw in his work. Her father's stories led her to volunteer with Special Olympics in high school.



After college and living in Spain, Jackson entered law school. She practiced law for 12 years in New Orleans and Baltimore. She and her

husband then moved to Nashville, where Jackson stayed at home to care for her young children. She has continued to do *pro bono* work. She currently works for Barbara Gregg and Associates, helping families considering a move to Nashville.

In her volunteer work with the Leadership Council, Jackson served on the former Outreach Committee. She feels strongly that people need to know about the resources at the Center.

“Since I've been involved with the Kennedy Center, I have come to understand that there is no family, really, who has not been touched by disability,” said Jackson. “We are all affected.”

Jackson's presence and advocacy are greatly appreciated and valued. ■



ACM Lifting Lives® Awards Grant to Music Camp BY JAN ROSEMERGY

For the second consecutive year, ACM Lifting Lives® will support the Vanderbilt Kennedy Center ACM Lifting Lives Music Camp and provide scholarships for camp participants.

The camp is a week-long residential program serving individuals with Williams syndrome and other developmental disabilities, ages 16 and older. Campers celebrate music by participating in a songwriting workshop, recording session, songwriter's night, and a live performance on the stage of the Grand Ole Opry. Campers also are invited to participate in research. The next Music Camp will take place in the summer of 2011.

"We are enormously grateful for the continued investment that ACM Lifting Lives is making in the Music Camp," said Elisabeth Dykens, Ph.D., VKC director and UCEDD co-director. "The Academy of Country Music and the Vanderbilt Kennedy Center represent a unique partnership that celebrates, through education and research, the transforming



KEN BECK

Country music star Chris Young and Grammy Award-winning songwriter Brett James helped the 2010 Music Campers write an original song, later recorded on Music Row and performed live on the Grand Ole Opry.

effects of music in individual lives."

ACM Lifting Lives® is the philanthropic arm of the Academy of Country Music dedicated to improving lives through the power of music. Each year, ACM Lifting Lives provides grants to music therapy and music education programs. For more information, visit www.ACMLiftingLives.org. ■

Gift Fosters Creative Expression Among Next Step at Vanderbilt Students BY AMY POTTIER



TOMMY LAWSON

Mary Jane Swaney

Mary Jane Swaney is not only a practicing artist, she also nurtures the artistic growth of others, including young people with disabilities. Through her most recent gift, Mrs. Swaney helped make possible a workshop last spring with Sarratt Art Studios, which offers

art classes to the Vanderbilt community.

Visiting artist-in-residence Elizabeth Garlington led the workshop over three weekends for Vanderbilt faculty, staff, and students. Participants included six students from the first class of Next Step at Vanderbilt, a 2-year postsecondary certificate program for students with intellectual disabilities.

Mrs. Swaney's love of the arts is clear in her own activities, which include teaching and making art in mixed media. She has been a long-time supporter of the Vanderbilt Kennedy Center's art workshops, through which she opens the world of artistic expression to children and adults with disabilities. About her motivation to support these activities, she has said, "I have experienced these workshops, and it is such a joy to see the participants respond and just blossom. It is a beautiful, beautiful thing to see."

Mrs. Swaney and her late husband C. Robb Swaney, an architect, first became involved with the Vanderbilt Kennedy Center in 2001 when they explored making a memorial gift to the Susan Gray School in honor of Keith Crabtree, the son of a

longtime staff member and friend in Mr. Swaney's firm. The outcome was a new accessible playground for the toddler classrooms, designed by Mr. Swaney and accomplished through gifts from the Swaney, Sam and Linda Brooks, the Tennessee Titans, and other donors.

Mrs. Swaney continues to help people with disabilities grow and bloom, as they explore the many pathways of artistic expression.

The Next Step at Vanderbilt students' pride is evident when they share the collages they made during the workshop. These original works of art are now featured in the traveling exhibit, *Reflections in Collage / Reflections in College*.

In their collages, the students included photographs of the internships that are part of their certificate program, and they expressed their vision of future career possibilities, for example, a picture of a police car. Their collages expressed visually their memories and associations with loved ones, through vacation and prom photos and gifts from friends. Some students included items that remind them of their favorite Vanderbilt sports teams, or things they enjoy every day, such as a paper coffee cup symbolizing a love of coffee.

Tammy Day, M.Ed., Next Step at Vanderbilt program director, noticed that the quiet, shyer students especially found great pleasure in exploring new ways to express themselves. "Each week, they became more self-confident in their own artistic expression," said Day. One student "became more creative and certain about the artistic choices she made with her collage as we moved through the three sessions. She seemed to grow in the idea of seeing herself as a person who enjoyed art and had

some talent in this area."

Alice Kim Byrne, program coordinator, added, "The art workshops were a springboard for our students getting more involved with the arts and reflecting on their growth and experience of being a college student. The opportunity was incredible, and the final products so clearly represented themselves, and their hopes and dreams."

The legacy of Mrs. Swaney's gift does not end with the workshop and the exhibit. Some of the students in Next Step at Vanderbilt are now enrolled in Sarratt Art Studios courses. The summer orientation camp for incoming Next Step at Vanderbilt students now includes a tour of the Sarratt Studios. In addition to classroom education, vocational training, and development of life skills, Next Step at Vanderbilt students now include the arts in their individualized program of study.

The exhibit is on display at the Student Life Center (Board of Trust area), November 1-December 17, 2010. It will be exhibited at the Vanderbilt Kennedy Center, January 10-March 31. ■



AUDRY DEAL-NEEVER

Collage created by Elizabeth Storey, a Next Step at Vanderbilt student.



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Discovery is a quarterly publication of the Vanderbilt Kennedy Center designed to educate our friends and the community, from Nashville to the nation. The Center is committed to improving the quality of life of persons with disabilities of thinking, learning, perception, communication, mood and emotion caused by disruption of typical development. The Center is a university-wide research, training, diagnosis, and treatment institute. It is a *Eunice Kennedy Shriver* Intellectual and Developmental Disabilities Research Center funded by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, and a University Center for Excellence in Developmental Disabilities (UCEDD) funded by the Administration on Developmental Disabilities. *Discovery* is supported in part by Grant No. HD 15052 from EKS NICHD, Administration on Developmental Disabilities Grant #90DD0595, and LEND Training Grant No. T73MC00050 MCHB/HRSA.

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VANDERBILT UNIVERSITY
Vanderbilt Kennedy Center
PMB #0
230 Appleton Place
Nashville, TN 37203-5721



CALENDAR OF EVENTS | NOVEMBER 2010-FEBRUARY 2011



COURTESY OF PILKERTON FAMILY

Support for families affected by disability is available through educational programs and research. For example, see Journeys in Disability Orientation in January 2011, or the Parent Stress Intervention Project at kc.vanderbilt.edu/studyfinder, (615) 875-5080.

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 amy.pottier@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/MRL Building.

■ ANN AND MONROE CARELL JR. FAMILIES FIRST WORKSHOPS

Serving parents of children, ages 2-5, diagnosed with an autism spectrum disorder. Register at kc.vanderbilt.edu/registration Information (615) 322-6027 families.first@vanderbilt.edu Free monthly Saturday workshops, 8:15 a.m.-12 p.m.

- **NOVEMBER 13***
Improving Communication in Children Who Are Talking
- **DECEMBER 4***
Addressing Challenging Behaviors

■ BRITT HENDERSON TRAINING SERIES FOR EDUCATORS

For school teams, individuals, parents Register at kc.vanderbilt.edu/kennedy/henderson Information (615) 343-0706 Wednesday 5-7 p.m.

- **NOVEMBER 17***
Behavior Screening Tools
- **DECEMBER 1***
Using School-Wide Data to Identify Non-Responders
- **JANUARY 26***
Using Self-Monitoring in Academic Interventions
- **FEBRUARY 16***
Differentiating Instruction

■ **NOVEMBER 17***
Developmental Disabilities Grand Rounds
Angelman Syndrome and Rett Syndrome as Models of Autism Spectrum Disorders
Sarika Peters, Ph.D., Assistant Professor of Pediatrics, VKC Investigator
Wednesday 8 a.m.

■ **NOVEMBER 17***
Participant Recruitment and Assessment Core Training Series

Introduction to Brief Measures of Intelligence
Evon Lee, Ph.D., Associate Professor of Pediatrics; Psychological Assessment Coordinator, Participant Recruitment and Assessment Core; VKC Investigator
Register at kc.vanderbilt.edu/registration Wednesday 2:30 p.m.

■ **NOVEMBER 17**
6th Annual Disability Services and the Hispanic Community Conference
Fifty Forward, Knowles Senior Center, 174 Rains Avenue, Nashville \$30 for materials and lunch
Register at kc.vanderbilt.edu/registration Wednesday 8:30 a.m.-2:30 p.m.

■ **DECEMBER 1***
Statistics and Methodology Core Training Seminar
Using a GIS Approach to Better Understand Risk Among Individuals with Developmental Disabilities
Eva Pantaleoni, Ph.D., Visiting Scholar, Vanderbilt Kennedy Center
Register at kc.vanderbilt.edu/registration Wednesday 12:30 p.m.

■ **DECEMBER 3***
Community Advisory Council Meeting
For details contact (615) 936-8852 Friday 9 a.m.-1 p.m.

■ **DECEMBER 6***
Research Ethics Grand Rounds
Nothing About Us Without Us! Ethical Considerations of Including Persons with Disabilities in Conducting Research
Panel discussion
Monday 12 p.m.

■ **DECEMBER 8***
Developmental Disabilities Grand Rounds
Evaluating and Managing Patients with Auditory Neuropathy/Dys-Synchrony
Linda Hood, Ph.D., Professor of Hearing & Speech Sciences, VKC Member
Wednesday 8 a.m.

■ **DECEMBER 9***
Lectures on Development and Developmental Disabilities
Framing, Development, Prevention, and Policy in Youth Violence
Kenneth A. Dodge, Ph.D., William McDougall Professor of Public Policy, Professor of Psychology and Neuroscience, Director of the Center for Child and Family Policy, Duke University
Thursday 4:10 p.m.

■ **JANUARY 8***
Journeys in Disability Orientation Workshop
Information and Support for Families
Lynnette Henderson, Ph.D., CCRP, IDDRC Research Registry and Recruitment Coordinator; UCEDD Associate Director of Community Services; Research Assistant Professor of Pediatrics
Register at kc.vanderbilt.edu/registration Saturday 9-11 a.m. for parents of children 12 and under, 1-3 p.m. for family members, high school students and adults with disabilities, and support personnel

■ **JANUARY 12***
Developmental Disabilities Grand Rounds
Title TBA
Stephan Heckers, M.D., James G. Blakemore Professor and Chair of Psychiatry, VKC Member
Wednesday 8 a.m.



CALENDAR OF EVENTS | NOVEMBER 2010-FEBRUARY 2011

■ JANUARY 20*

Lectures on Development and Developmental Disabilities
Martin Luther King, Jr. Commemorative Lecture
Title TBA

Sharon Lewis, Commissioner, Administration on Developmental Disabilities, Administration for Children and Families, U.S. Department of Health and Human Services
Thursday 4:10 p.m.

■ JANUARY 26*

Legislative Advocacy Panel Discussion
Educate to Advocate: Strategies to Advance Disability Public Policies
Register at kc.vanderbilt.edu/registration
Wednesday 11:30 a.m.

■ FEBRUARY 9*

Developmental Disabilities Grand Rounds
Oxysterols in Pathophysiology of Smith-Lemli-Opitz Syndrome
Zeljka Korade, Ph.D., Research Assistant Professor of Psychiatry, VKC Member
Wednesday 8 a.m.

■ FEBRUARY 9

Neuroscience Graduate Program Seminar Series
Title TBA
Carol A. Mason, Ph.D., Professor of

Pathology and Anatomy & Cell Biology, Columbia University
Co-sponsor Vanderbilt Brain Institute
Wednesday, 4:10 p.m. Room 1220
MRB III Lecture Hall

■ FEBRUARY 15

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

■ 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

■ ARTS AND DISABILITIES*

Vanderbilt Kennedy Center Exhibits
Monday-Friday
7:30 a.m.-5:30 p.m., Lobby
Information contact (615) 343-7046

• SEPTEMBER 6, 2010- JANUARY 7, 2011

Creative Expressions XVI
Cosponsored with the Mayor's Advisory Committee for People with Disabilities

• JANUARY 10-APRIL 1, 2011

Reflections in Collage / Reflections in College
Presenting Next Step at Vanderbilt.
Reception for the artists will be held January 24 at 5 p.m.

■ BEHAVIOR ANALYSIS CONSULTING SERVICES

For school districts
Contact (615) 322-9007
n.houchins-juarez@vanderbilt.edu

■ BEHAVIORAL HEALTH AND INTELLECTUAL DISABILITIES CLINIC

For individuals with intellectual disabilities, ages 17 and up, with behavioral and mental health challenges
Contact (615) 343-9710
behavioralhealth@vanderbilt.edu

■ READING CLINIC

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

■ SIBLING SUPPORTS

For children, teens, and adults who have a sibling with a disability, chronic health care issue, or mental health concern
Contact (615) 343-0545
ashley.coulter@vanderbilt.edu

SibSaturdays

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

■ TAKE PART IN RESEARCH

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

• Research Family Partners

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

• StudyFinder

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

• See also VUMC Clinical Trials

www.vanderbilthealth.com/clinicaltrials

■ TENNESSEE DISABILITY PATHFINDER

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



SibSaturdays supports siblings who have brothers or sisters with disabilities.

■ MARCH 2-4, 2011

44th Annual Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities
Adolescence and Developmental Disabilities: From Neurobiology to Interventions

Hotel Contessa, San Antonio, Texas

Check website kc.vanderbilt.edu/Gatlinburg for details



"DOLL'S TEA PARTY" BY ANNE AMBROSE