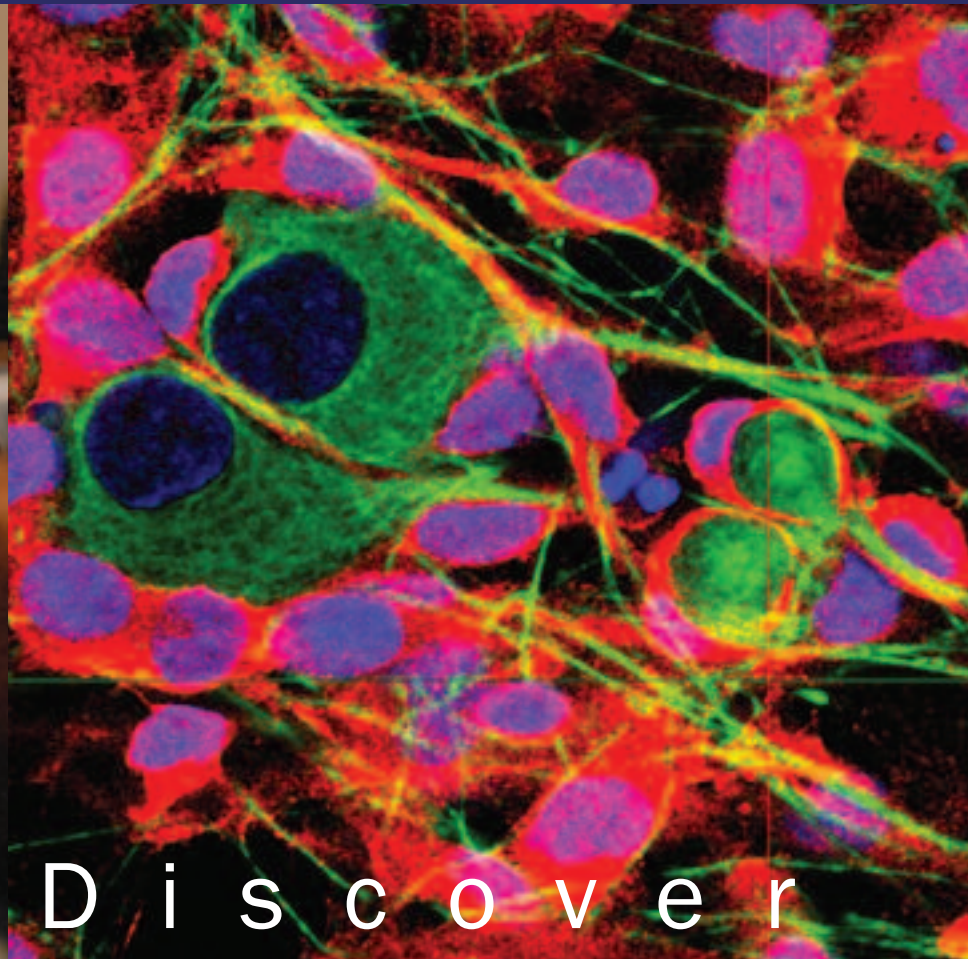


## Community Report 2008-2009



E d u c a t e



D i s c o v e r



E m p o w e r



G r o w

“There is no joy like the joy of unleashing the human spirit . . . . There is no purpose more noble than to build communities of acceptance for all.”  
—Eunice Kennedy Shriver (1921-2009)

Elisabeth Dykens, Ph.D., was named director of the Vanderbilt Kennedy Center (VKC) in September 2009, the seventh director in the Center's 44-year history.

"Elisabeth is an exceptional researcher of national stature, an experienced administrator, and an individual who cares deeply about the well-being of children and adults with developmental disabilities and their families," said Jonathan Gitlin, M.D., Assistant Vice Chancellor for Maternal and Child Health Affairs and Chair of Pediatrics. "Her broad expertise in interdisciplinary research on developmental disabilities, combined with her positive vision for integrating disability research, training, and services at Vanderbilt, made her an ideal choice."

Dykens has served as interim director since October 2008. She has co-directed the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (VKC UCEDD) since its founding in 2004. She is a professor



Director's Message

While my becoming the new director of the Vanderbilt

Kennedy Center was somewhat unexpected, my entire life has revolved around persons with disabilities. When my father was New Hampshire Commissioner of Mental Health, we lived on the grounds of a state hospital, where I had many friends with developmental and psychiatric challenges. From there, I became a clinical psychologist working to empower children, a researcher trying to discover how to understand these children and their families, and a professor educating the next generation of professionals.

So, too, does the Vanderbilt Kennedy Center discover, empower, and educate. As one of the country's original 14 Intellectual and Developmental Disability Research Centers, the Center attracts over 190 interdisciplinary researchers in disabilities. Geneticists routinely work with special educators, neurobiologists with pediatricians,

of psychology (Peabody College).

Dykens was recruited in 2003 as the Center's associate director. Previously, she served on the faculty of University of California-Los Angeles where she was a member of the Neuropsychiatric Institute. She was associate director for research and training at UCLA's Tarjan Center for Excellence in Developmental Disabilities. Earlier she served on the faculty of the Yale Child Study Center.

Dykens's research focuses on families of children with disabilities, including the mental health challenges and unique strengths of persons with genetic syndromes. Long term, these studies shed light on relationships among genes, brain, and behavior.

Dykens is married to Robert Hodapp, Ph.D., professor of special education and VKC UCEDD director of research. They have two sons, Alexander and Benjamin. ■

psychologists with engineers or musicians, all in the service of discovery. Spearheaded by our University Center for Excellence in Developmental Disabilities, the Center supports over 40 service and outreach programs that empower individuals and their families. Finally, as we embrace our need to educate the next generation, each of our programs offers research, outreach, clinical, or course experiences for young disability professionals.

With talented faculty and staff, Hobbs Discovery awards, new grants, and community partners, the Center is growing toward new goals in basic science, cognition and learning, health and well-being, and families. In this Community Report, we invite you to see how the Vanderbilt Kennedy Center is *growing* in its mission to *discover, empower, and educate*. See for yourself how we are building on 44 years of excellence to optimize the life successes of people with disabilities and their families. ■



Eunice Kennedy Shriver at VKC 30th anniversary

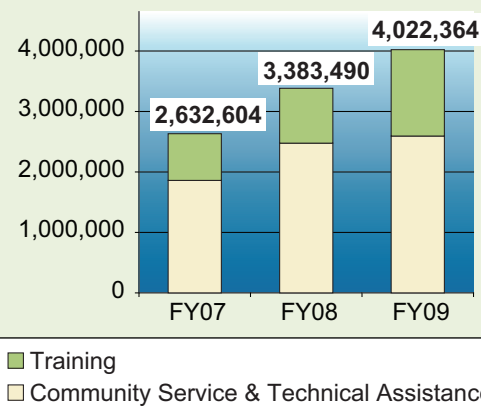
We celebrate the life of **Eunice Kennedy Shriver**, a champion of persons with intellectual disabilities. Her vision and efforts helped to establish the National Institute of Child Health and Human Development in 1962, as well as the Intellectual and Developmental Disabilities Research Centers. The Vanderbilt Kennedy Center, named in honor of President John F. Kennedy, was the second founded, with Mrs. Shriver and Sargent Shriver as National Advisory Committee members. Mrs. Shriver founded Special Olympics and the Shriver Sports Camps.

The late **Senator Edward Kennedy** was unrelenting in his advocacy for education and health care for individuals with disabilities. He played a key role in every major law and public policy that positively impacts people with developmental disabilities.

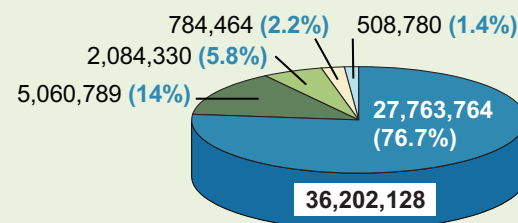
With the help of so many, we continue to work to make their vision a reality, inspired by Mrs. Shriver's and Senator Kennedy's example and spirit. ■

Financial Summary

Vanderbilt Kennedy Center Community Service and Training Activities Revenue Comparison by Fiscal Year



All Activities: Community Service, Training, and Research Total Revenues FY 2008-2009



Private Pay, State of TN, Charitable Gifts / Grants, Vanderbilt University, Federal Government

Includes revenues associated with Direct Costs only. VU fiscal year is July 1, 2008 - June 30, 2009.

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## ▼ Basic Mechanisms of Development

How can advances in basic science—chemistry, biology, genetics, and neuroscience—shed new light on the causes and treatments for autism, Down syndrome, and other developmental disorders? VKC researchers answer these pressing questions by studying how cells grow, develop, and interact in typical and atypical ways, and by discovering genes that turn these processes on and off.

## Discover

### Genetic risk zone for autism is discovered.

A multi-university team, led at Vanderbilt by Jonathan Haines, Ph.D. (Molecular Physiology & Biophysics), has identified the first common genetic variation associated with autism. This cutting-edge research points to a particular spot in the genome that may increase a person's risk for autism, and also suggests how molecules that form connections among brain cells are involved in autism.

FUNDING: NIH

### Genetic marker is associated with problem behaviors.

Up to 30% of adults with intellectual disabilities have problems with aggression or self-injury, and treating these problems costs millions. Craig Kennedy, Ph.D. (Special Education), Randy Blakely, Ph.D. (Pharmacology), and John Phillips, M.D. (Pediatrics), located a common variation of a gene involved in regulating serotonin (a neurotransmitter that influences mood and emotion in the brain) that is linked to behavior problems in these adults. By

identifying genetic risks for problem behaviors, we will discover new ways of preventing problem behaviors in adults.

FUNDING: U.S. Dept. of Ed. and VICTR

### Fragile X model suggests when best to intervene.

Fragile X syndrome is the most common inherited cause of intellectual disability. Using a drosophila (fruit fly) model, Kendal Broadie, Ph.D. (Biological Sciences), found that correcting an aberrant neural circuit that controls circadian rhythms was successful only during early to mid stages of drosophila development. These novel findings suggest that drug treatments for people with fragile X are more likely to be beneficial in children as opposed to adults, and highlight the importance of interventions for children.

FUNDING: NIMH

### Brain tissue analyses implicate altered immune responses in autism and schizophrenia.

Analyzing gene expression in postmortem brains of people with autism or schizophrenia, Karoly Mirnics, M.D. (Psychiatry), identified

a surprising immune system activation, suggesting that infections or other problems that spark a mother's immune system might contribute to these conditions later in life. Mirnics and colleagues confirmed that a "fake infection" midway through gestation in mice causes behavioral and tissue abnormalities reminiscent of schizophrenia and autism in the offspring. Knowing whether a mother had an infection during pregnancy might one day allow physicians to predict a child's later risk of developing a neurodevelopmental disorder and opens the possibility of interventions to prevent these disorders.

FUNDING: NIMH

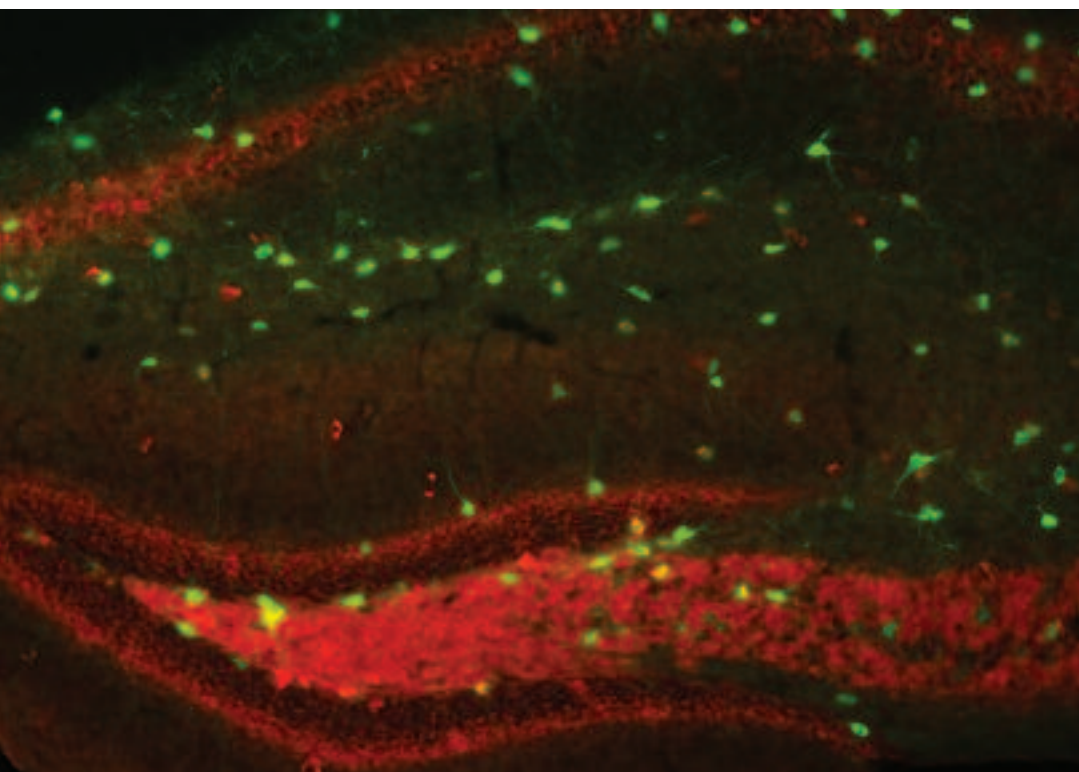
## Empower

### Laboratory researchers are empowered by meeting people with disabilities.

The VKC helps basic scientists create bridges from their labs to people with disabilities and their families, which provides motivation and a broader understanding of their work's significance for individual lives.

"Meeting children with Angelman syndrome has really put the basic science I do into perspective. Science and discovery is a slow process and cures may be a long time away—yet it is important to know who we are working for and to always carry that knowledge around."

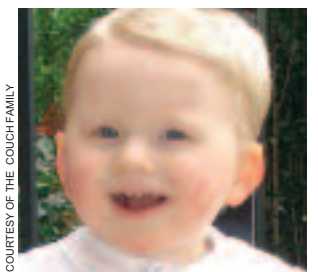
—Anthony J. Baucum II, Ph.D., Postdoctoral Fellow, Molecular Physiology & Biophysics



VKC researchers develop genetically altered animal models to study developmental disorders. Above, brain cells were stained to allow researchers to view the changed genetic activation. Photo courtesy of laboratory of Karoly Mirnics, M.D.

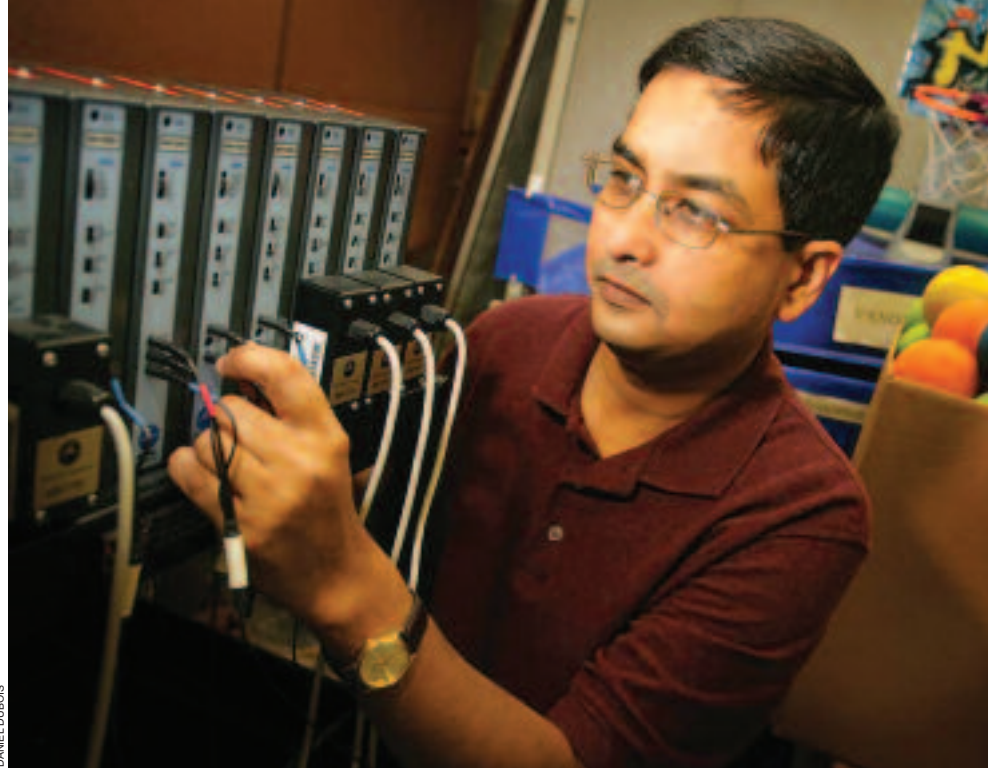
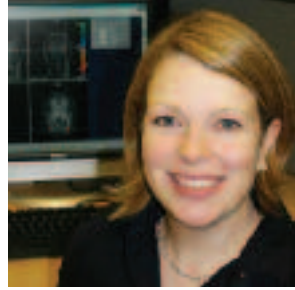
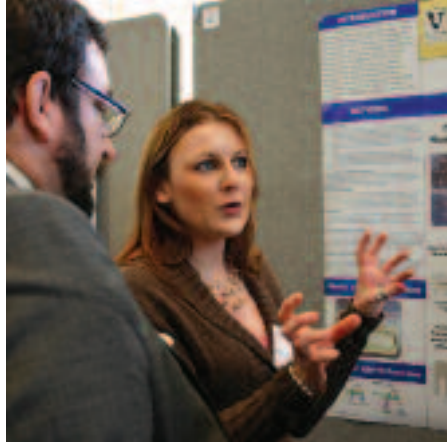


COURTESY OF THE NATIONAL FRAGILE X FOUNDATION



COURTESY OF THE COUCH FAMILY

By understanding developmental mechanisms, VKC investigators aim long-term to improve the lives of individuals with fragile X syndrome (left), Angelman syndrome (above), and other developmental disorders.



I believe the future of research on neurodevelopmental disabilities involves links between genetics and brain structure and function. I came in with expertise in statistical genetics, and the Biobehavioral Interventions Training Program has provided me with the crossdisciplinary training in neuroimaging that I need to conduct such research. I am now well-positioned to become a leader in this burgeoning field.

-Tricia Thornton-Wells, Ph.D., Former BITP Fellow

TOP LEFT: Graduate student Jeannette Stankowski presented a research poster on cell fate after stroke at VKC Science Day, which promotes interdisciplinary research and training. BOTTOM LEFT: Tricia Thornton-Wells. RIGHT: Nilanjan Sarkar, an engineer, is exploring the use of robotics in autism interventions, thanks to a Marino Autism Research Institute Discovery Grant.

### Renewal of IDDRC Center Grant provides critical services to researchers.

Researchers need resources to conduct their experiments, and the VKC provides these to over 90 researchers through a 5-year grant that was renewed this year. This grant designates the VKC as one of 14 national *Eunice Kennedy Shriver* Intellectual and Developmental Disabilities Research Centers (IDDRC) and provides core research services: Basic Neuroscience, Statistics and Methodology, Clinical Neuroscience, Participant Recruitment and Assessment, and Administrative Services. The competition is open to universities across the nation, and the VKC competed with a record number of applicants. Of the 14 IDDRCs, the VKC is among the few who also are University Centers for Excellence in Developmental Disabilities and who have a Leadership Education in Neurodevelopmental Disabilities training grant. FUNDING: NICHD

### VKC Science Day creates collaboration.

Researchers need to share ideas, and VKC Science Day accomplishes just that. Over 100 trainees and faculty presented research posters at VKC Science Day 2009. Posters represented labs of 52 VKC researchers in cellular and molecular neuroscience, clinical and behavioral science, and systems neuroscience. Selected presenters earned awards, and all became VKC Affiliates, eligible to apply for VKC Travel Awards. To date, 20 Travel Awards have been given to young investigators to present their work at national scientific meetings.

## Educate

### Training grant prepares new disability researchers.

Training the next generation of researchers is a top priority for the VKC and the disability field. The Biobehavioral Interventions Training Program (BITP) trains postdoctoral fellows who are eager to learn new research strategies that unravel the mysteries of developmental disorders. BITP enlists faculty mentors in psychology, education, genetics, medicine, and neuroscience who foster interdisciplinary studies by trainees on the causes and best interventions for children and adults with developmental disabilities.

FUNDING: NIH Roadmap Initiative

### "Teachable moments" empower through research and training events.

Over 70 VKC lectures each year and a dozen journal clubs provide venues for researchers, trainees, clinicians, staff, and community members to come together to learn from one another.

## Grow

### Hobbs Discovery Grants are a 30:1 return on investment.

Scientists need seed money to collect preliminary data to support their research ideas, and these data allow them to successfully compete for larger federal or foundation grants. The VKC provides stellar researchers seed monies through the **Hobbs**

**Donor Society.** Members contribute \$1,000 or more annually. Hobbs Discovery Grants have led to an astounding 30:1 return on investment, and there's no way to measure the difference that this investment makes in the lives of individuals with disabilities. In one exemplary Discovery Grant, Kevin Ess, Ph.D. (Neurology), developed technology to convert skin cells to stem cells, which can become any of the body's many cell types. Now Ess is among 14 physician-scientists nationally to receive a 2009 Clinical Scientist Development Award from the Doris Duke Charitable Foundation to expand this research advance, which may lead to new therapies for children with neurological disorders.

### Dan Marino Foundation created MARI to power up autism research.

Understanding how autism affects families, the **Dan Marino Foundation** funded the Marino Autism Research Institute (MARI) as a partnership between VKC TRIAD (Treatment and Research Institute for Autism Spectrum Disorders) and the University of Miami's Center for Autism. In 2009, MARI supported nine projects. In one such award, Nilanjan Sarkar, Ph.D. (Mechanical Engineering), collaborated with Wendy Stone, Ph.D. (Pediatrics), to develop a technology for robots to "read" and react to the emotional states of children with autism. These robots are fun for children and increase their communication and interactions, two of the core areas affected in autism. ■

Grow  
Educate

## ▼ Cognition, Language, and Learning

How can we optimize the language, learning, and problem-solving skills of children and adults with developmental disabilities? VKC researchers tackle this pressing question at many levels, from the development and function of brain systems that underlie learning and memory to interventions to improve cognition and language in children and adults.



## Discover

**RTI helps meet academic needs of students with serious learning problems.**

Response to Intervention (RTI) is an alternative method for identifying learning disabilities in school-age children. Doug Fuchs, Ph.D., Lynn Fuchs, Ph.D., and Donald Compton, Ph.D. (Special Education), are developing a new generation of screening, progress-monitoring measures, and dynamic assessments in reading and math, as well as specific programs to target reading comprehension in first-graders and word-problems capacity in third-graders. These researchers are leading the nation in RTI approaches. FUNDING: NICHD, IES, OSEP

**KidTalk intervention helps at-risk children develop language skills.**

Communication disorders can isolate children from their social and educational surroundings, making it essential to provide timely intervention. Enhanced Milieu Teaching (EMT), a naturalistic communication intervention, has been shown to help children with intellectual disabilities improve their communication

skills. Led by Ann Kaiser, Ph.D. (Special Education), EMT is now being extended to Head Start children who have low rates of language use, toddlers with language delays, and children with autism. FUNDING: NICHD, US Dept of Ed, Autism Speaks

**Measuring speech processing can improve grammatical treatments.**

Children with specific language impairments (SLI) have particular difficulty with grammar and are slower processors of speech. Because behavioral measures of sound differentiation are inadequate, Paul Yoder, Ph.D. (Special Education), and Stephen Camarata, Ph.D. (Hearing & Speech Sciences), have measured sound differentiation using event-related potentials (ERPs). An ERP is a visual representation of the brain's electrical responses to an "event" or stimulus. Children who showed better efficiency of speech differentiation in their ERPs responded better to treatment. This study shows that brain function measures can be used in treatment studies, which will lead to better treatments for children with SLI. FUNDING: NIDCD

## Empower

**Door opens for postsecondary education for students with intellectual disabilities.**

Students with intellectual disabilities can now go on for postsecondary education in the Next Step program at Vanderbilt, a 2-year certificate program. The Next Step program is transforming the campus community as Vanderbilt becomes the first college in Tennessee—and the first top-20 university nationally—to offer this initiative. Next Step was made possible through a 3-year grant from the **Tennessee Council on Developmental Disabilities** and the philanthropy of **Mrs. Linda Brooks**.

**Learning to read makes reading to learn possible.**

Struggling readers are at great educational disadvantage and need intervention early. In 2008, the Reading Clinic helped 83 students (K-4th grade) from 7 Middle Tennessee counties make progress in reading, including students with Down syndrome, autism, and other developmental disabilities. Tutors provided intensive, systematic, evidence-based



"My daughter was soooo far behind and had soooo many obstacles that she has had to overcome. She was headed down a road of giving up on reading. The Reading Clinic is a blessing because she is improving each session. Thank you, thank you, for the tutors, the scholarships and the time you have given her. PS: She got her first certificate ever for most improved reader in her class."

—Parent of Reading Clinic student



LEFT: At the Reading Clinic, students become more fluent readers, and Peabody students prepare to become effective reading teachers. RIGHT: In 2009-10, volunteers are being trained in Nashville, Memphis, Jackson, and Johnson City to serve as advocates during the Individualized Education Plan process.



LARRY WILSON



MEGAN ROBERTS

**“I am a good, high-quality student, and I would like to go to college any day!”**

*—Edward Nesbitt  
Next Step Class 2011*



*TOP LEFT: Carol Henderson. The Britt Henderson Training Series for Educators supports school teams in implementing evidence-based practices to meet the diverse learning needs of students. BOTTOM LEFT: Edward Nesbitt. RIGHT: KidTalk provides intervention to young children with language delays through ongoing research and demonstration projects.*

instruction and assessment. The supervised tutors were largely Peabody College students in special education, whose Reading Clinic training helped prepare them to be effective teachers. Scholarships were provided thanks to the **Dollar General Literacy Fund, CVS Caremark Charitable Trust, SunTrust,** and the **Team William Endowment Fund.**

### **TRIAD Outreach trains educators and families throughout Tennessee.**

As more young children are diagnosed with an autism spectrum disorder (ASD), school systems are serving more of these children—making training a critical need for administrators and teachers. In the last year alone, TRIAD staff led Full-Day Workshops for 1,182 parents and professionals in Middle, West, and East Tennessee; Parent Workshops for 94 families; and Administrators Academy, Para-Educator Workshops, and Teacher Training for 160 professionals in 53 counties. Collectively, TRIAD educators are meeting pressing needs for school-based training in ASD. FUNDING: TN Dept of Ed and school systems

a program to train 20 masters-level students annually to work in schools as SLPs. The program helps to minimize the shortage of school-based SLPs and to better prepare them to meet the complex language and literacy needs of students. FUNDING: US Dept of Ed

### **Trained advocates lighten the load for parents in the IEP process.**

Each child receiving special education has an Individualized Education Plan (IEP), which is updated annually. Many parents want advocates to accompany them to these yearly IEP meetings, but there are not enough well-trained advocates. Along with community partners, Meghan Burke, a special education doctoral student, co-developed an advocacy training program and trained 28 advocates in Nashville and Memphis, who then provided advocacy services to 70 families.

### **VKC contributes to disability and special education training for judges and attorneys.**

Tennessee’s Administrative Law Judges, who conduct all of the state’s special education mediations and due process appeals, are required to have annual training in special education law and disability issues. In 2008, VKC faculty and staff provided autism-related training for judges. Partnering with community disability organizations, the VKC also provides training to attorneys who work with families regarding educational services.

## **Grow**

### **A Family Discovery Grant will advance understanding of sensory sensitivity in autism.**

As the grandparents of a grandson with an autism spectrum disorder, **Bob and Donna Landreth** and the **Landreth Family** understand the varied challenges faced by individuals with autism spectrum disorders (ASD) and their families. The Landreths’ interest in Vanderbilt’s cutting-edge work on autism has led to the Landreth Family Discovery Grant. The recipients, Carissa Cascio, Ph.D., and Jeremy Veenstra-VanderWeele, M.D. (Psychiatry), will conduct studies on sensory sensitivity in ASD, with the long-term goal of improving treatment and therapy options.

### **A family-endowed memorial gift has contributed to improved education for many.**

When **Robert Henderson, Sr.,** and **Carol Henderson** wanted to honor the memory of their son Britt, they endowed the Britt Henderson Training Series for Educators. Since 1996, school teams have been trained in evidence-based methods to improve instruction and to support positive behavior. Led by Kathleen Lane, Ph.D. (Special Education), the Henderson Series enables schools to make use of the best of educational research in a practical and feasible way. ■

## **Educate**

### **Speech-language pathologists help prevent lifelong disabilities.**

Speech-language pathologists (SLPs) know that if a child has difficulty learning to speak, it may be just the tip of the iceberg for other issues in language and literacy. Melanie Schuele, Ph.D. (Hearing & Speech Sciences and Vanderbilt Bill Wilkerson Center), leads

# **Grow Educate**

## ▼ Health and Well-Being

What medical conditions are associated with specific disabilities, and how are they best treated? Beyond treating problems, how do we promote health and social and mental well-being in people with developmental disabilities? The VKC tackles these public health challenges through innovative research and programs in mental and social health, sports, music, and the arts.



## Discover

### Melatonin treatment improves sleep disorders in children with autism.

Children with autism spectrum disorders (ASD) often have difficulty sleeping. Beth Malow, M.D. (Neurology), reasoned that children with ASD who have decreased melatonin also have decreased levels of deep sleep. Released during sleep by the pineal gland, melatonin affects sleep rhythms. Malow used melatonin to treat 100 children with ASD who were diagnosed with sleep disorders, and parents reported sleep improvements in 85% of these children. A **Hobbs Discovery Grant** contributed to the discovery of melatonin as a safe and effective treatment. FUNDING: NICHD

### Age and genetics matter in Prader-Willi syndrome.

Prader-Willi syndrome (PWS), the most common known genetic cause of life-threatening obesity in children, is caused by several types of abnormalities on chromosome 15. Elisabeth Dykens, Ph.D. (Psychology & Human Development), compared health, obesity, and problem behaviors in 142

children and adults with PWS. Health and mental health problems waxed or waned depending on both age and the specific type of chromosome 15 anomaly. Findings allow more careful treatment planning and highlight the importance of taking a life-span perspective. FUNDING: NICHD

### Cognitive behavioral program helps prevent depression in at-risk teens.

Teens whose parents have a history of depression are at high risk of becoming depressed themselves. Judy Garber, Ph.D. (Psychology & Human Development), led a large randomized trial at four national sites that compared usual care with an 8-week cognitive behavioral program that teaches realistic appraisal of stress and problem-solving skills. Teens in the program had fewer episodes of depression over 9 months, especially when their parents were not depressed when the treatment began. Clinicians treating depressed parents should inquire about their children's well-being, as well as the reverse. FUNDING: NIMH

### Premature infants need less manganese.

Although manganese (Mn) is an essential

nutrient for proper health, it is toxic in high doses. Sick infants requiring intravenous nutrition may be at increased risk for Mn neurotoxicity. Judy Aschner, M.D. (Pediatrics), is comparing unexposed children to infants and young children receiving prolonged Mn-supplemented intravenous nutrition to determine if exposed children perform differently on neurodevelopmental and psychophysiological assessments. Improved understanding of the relationships between Mn exposure and developmental outcomes will lead to altered clinical practices. FUNDING: NIEHS, Gerber Foundation, VICTR

## Empower

### Model mental health clinic helps teens and adults with intellectual disabilities.

Persons with intellectual disabilities are at high risk for behavioral, emotional, and psychiatric problems. Treatment gaps exist because too few mental health professionals have expertise in intellectual disabilities. Elisabeth Dykens, Ph.D. (Psychology & Human Development), Bruce Davis, Ph.D. (Psychiatry), and a team of interdisciplinary



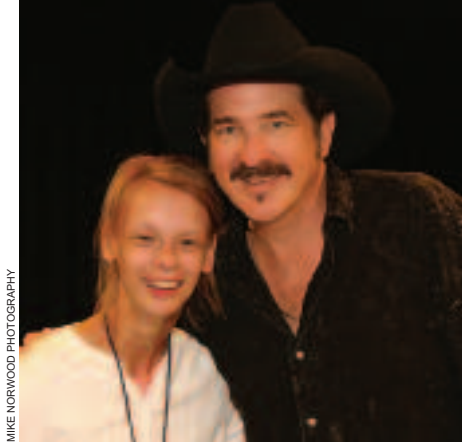
"My family and I want to thank you for all your wonderful hard work. You made us feel like stars. Your activities were fun and challenging. I hope someday my participation and all your research effort will benefit future generations."

—A California participant in research on Prader-Willi syndrome



LEFT: Research contributes to interventions to improve the health and mental health of individuals with Prader-willi and other genetic syndromes. Photo courtesy of Lindsey Family. MIDDLE: Neonatologist Judy Aschner works to improve the developmental outcomes of premature infants. RIGHT: Olivia Rose DeCaria created expressive art at the Shriver Transitions and Sports Camp with the help of a Frist Center educator.





MIKE NORWOOD PHOTOGRAPHY



DANIEL DUBOIS

**“You all are beyond wonderful!!! Thank you to every single person who had a hand in my son's life during this experience. To those who have donated so that my son could attend camp, a special thanks because this will change his life!”**

*—Parent of TRIAD Camper*



*TOP LEFT: Kix Brooks of the award-winning Brooks & Dunn duo was among the many volunteers from Nashville's music community who made the Music Camp a spectacular learning experience for campers with Williams syndrome. BOTTOM LEFT: Artist Mary Jane Swaney's gifts help artists with disabilities develop and exhibit their work. RIGHT: TRIAD campers gain social skills as they have summer fun.*

experts created the School-to-Adult Transitions Clinic at Vanderbilt (SAT-V), a replicable model that includes training, research, and services. The team is creating a tool kit for national dissemination of best practices for psychiatric care in persons with intellectual disabilities. **FUNDING:** John Merck Fund

### **TRIAD Camp fosters social skills.**

TRIAD Social Skills Camp fosters social interaction skills in children, teens, and young adults with autism spectrum disorders. Campers with autism and typically developing peers participate side-by-side in specially designed, age-appropriate activities that provide an enriching and fun learning experience. The **Neighbor's Keeper Foundation** and **Ann Bernard** provided scholarships for campers.

### **Children and adults with disabilities create and exhibit art.**

The VKC shines a light on the artistic abilities of persons with disabilities, which often remain hidden. Community partnerships bolstered the reach of this art, with exhibits at the Tennessee Performing Arts Center and the Frist Center, as well as collaborations with the Nashville Mayor's Advisory Committee for People With Disabilities, Pacesetters, Inc., Autism Society of Middle Tennessee, Davidson County Mental Health Court, and Park Center East. The Education Outreach Program of the Frist Center for the Visual Arts created art with youth in VKC camps, which will be exhibited at the W. O. Smith Music School.

## Educate

### **LEND prepares trainees for future leadership in improving disability services.**

Diverse health care providers often lack training in disabilities. Leadership Education in Neurodevelopmental Disabilities (LEND) prepares graduate-level health trainees in 13 disciplines to assume leadership roles in service provision for children with neurodevelopmental disabilities. Directed by Terri Urbano, Ph.D. (Pediatrics), LEND includes faculty from Vanderbilt, Belmont, Tennessee State University, Meharry Medical College, and University of Tennessee. In 2008-09, LEND prepared 75 trainees, and received supplemental funding to expand training in autism and pediatric audiology. **FUNDING:** MCHB/HHS

### **The STAT™ Test Kit, Tutorial, and workshops train pediatricians to screen for autism.**

Too often parents who suspect their young child may have autism are confronted by long waits for assessments because not enough trained professionals are available. A wide variety of professionals can now become certified for independent use of the STAT™ (Screening Tool for Autism in Toddlers & Young Children) through successful completion of the on-line STAT™ Training Tutorial. Developed by Wendy Stone, Ph.D. (Pediatrics), and Opal Ousley, Ph.D., the STAT™ is an empirically derived, interactive, 12-item measure to screen for autism in children, 24 to 36 months. The STAT™ will meet the pressing need for autism screeners.

## Grow

### **Artist's gift spreads the gift of art.**

**Mary Jane Swaney** and her late husband C. Robb Swaney honored the memory of a friend's son, Keith Crabtree, by designing and helping to fund an accessible playground for the Susan Gray School. Mrs. Swaney also has infused her love of art into the VKC. An artist herself, her philanthropy has made it possible for the VKC to continue community exhibits of art by children and adults with disabilities and to conduct inclusive art workshops, where the joy of art flourishes.

### **Donors, volunteers, and the Nashville music community are dream-makers.**

For one glorious summer week, individuals with Williams syndrome who love music came from around the country to take part in Music Camp. Campers participated in research, and with the guidance of Nashville songwriter Thom Schuyler and the inspiration of LeAnn Rimes and Kix Brooks, campers wrote an original song that they recorded at Westwood Sound Studio with producer Blake Chancey and special guest Eddie Montgomery. They sang “Keep on the Sunnyside” at the Grand Ole Opry to a standing ovation. The Nashville music community made this happen—from the dynamic leadership of **Lorie Hoppers Lytle**, to gifts from the **Academy of Country Music Lifting Lives Foundation**, **Neighbor's Keeper Foundation**, **Grand Vista**, and **Ann Bernard**. ■

Grow  
Educate

## ▼ Impact of Disabilities on Families Over the Lifespan

How do we best support families of children with disabilities as those children grow into adulthood? What unique gifts and challenges do children and adults with disabilities bring to their families and communities? VKC researchers and clinicians are charting new territory by studying and supporting family members touched by diverse disabilities.



## Discover

**Baby siblings of children with autism show cognitive and social delays.**

Younger siblings of children with autism spectrum disorders (ASD) are at increased risk for ASD. Wendy Stone, Ph.D. (Pediatrics), Paul Yoder, Ph.D. (Special Education), and Tedra Walden, Ph.D. (Psychology & Human Development), found that baby siblings of children with ASD show weaker performance in nonverbal problem-solving, directing attention, using gestures, and understanding words and phrases. The overall weaker performance of baby siblings may represent an emerging broader autism phenotype that can be used for earlier diagnosis and intervention. FUNDING: NICHD

**Interventions should be sensitive to ethnic/racial differences in Down syndrome.**

Ethnic/racial differences among mothers of children with Down syndrome (DS) are not well understood. Using State of Tennessee Birth Records, Robert Hodapp, Ph.D. (Special Education), and Richard Urbano, Ph.D. (Pediatrics), examined maternal age, education

levels, marital status, ethnicity/race, and neighborhood median income. They found differences between African-American mothers and mothers of European descent. Their findings point to the need for targeted health care and social support services for African-American mothers specifically, and young mothers generally, who give birth to children with DS. FUNDING: Jim and Michele Greenfield and Family in Memory of Mark Greenfield, Health Resources and Services Administration

**In pediatric cancer, parent-child communication has long-lasting effects.**

One of the most difficult questions facing parents of children with cancer is how to talk with their child about cancer. Bruce Compas, Ph.D. (Psychology & Human Development), is observing communication between parents and children as they discuss the cancer diagnosis, as well as their coping and adjustment over time. This work will provide health care professionals with evidence-based recommendations for facilitating parent-child communication about cancer and decreasing their psychological distress. FUNDING: Hobbs Discovery Grant, National Cancer Institute

## Empower

**The Ann and Monroe Carell Jr. Families First Program provides practical, expert help to parents.**

Accessible and affordable services for families of young children with autism are too few. The **Carell Family's** generosity made it possible to help parents through free Saturday workshops. Later, at parents' request, more intensive 4-week evening workshops were added. Over 200 family members have taken part. While most live in Middle Tennessee, many have come from East and West Tennessee, and over 20% have travelled from other states.

**Tennessee Disability Pathfinder helps families navigate the service system.**

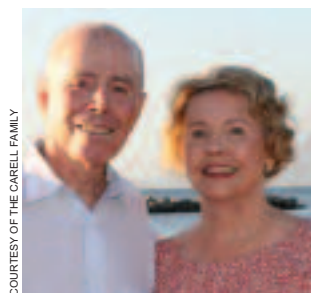
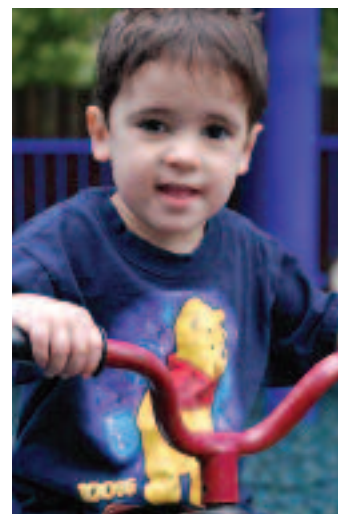
Tennessee Disability Pathfinder, a partnership with the **Tennessee Council on Developmental Disabilities** and the VKC, helps families navigate complex service systems. Pathfinder is a statewide helpline in English and Spanish for all types of disabilities and all ages. Its resources include a website with a database searchable by county and service type, a calendar, and a resource library. In 2008, Pathfinder assisted 1,845 callers,



Children and parents in the Hispanic Outreach support group celebrated at the Opening Ceremony of the 2009 Tennessee Special Olympics. Photo courtesy Tennessee Disability Pathfinder.

**"You put air back into our lungs, hope into our hearts, and most important, the fight back into our spirit. Not only that, you gave us the key to unlock any lock. You gave us information, educated us, and brought families together."**

*—Families First participant and mother of a three-year-old boy with autism*



COURTESY OF THE CARELL FAMILY

**▲ Monroe Carell, Jr. and Ann Carell's gifts bring expert knowledge to parents of young children with autism through the Ann and Monroe Carell Jr. Families First Workshops led by TRIAD's autism specialists.**



TOMMY LAWSON



“I truly don’t know what I would have done had the staff at Pathfinder not been so supportive. My family has never had anyone to fall back on but ourselves, and it is such a breath of fresh air to know that there is someone out there willing to help us out.”

–Pathfinder caller



TOP LEFT: Wendy and Ashley Brooks exemplify the sustaining, lifelong ties between a sibling and a sister or brother with a disability, a bond nurtured by the Sibling Support Program. BOTTOM LEFT: Ethan Beasley, whose family’s Discovery Grant is being invested in innovative research on Down syndrome. RIGHT: Music camper Seth Link helped accept Exceptional Parent Magazine’s 2009 EP Maxwell J. Schleifer Distinguished Service Award presented to the Vanderbilt Kennedy Center.

made 7,440 calls to find help, had 165,000 searches of its website, and served persons from 83 Tennessee counties, 27 states, and 3 countries.

### The VKC Hispanic Outreach Program supports Spanish-speaking families.

The disability and social service systems are complex to navigate even without language and cultural barriers. Thanks to the **Tennessee Council on Developmental Disabilities**, Spanish-speaking families can now connect through Hispanic Outreach and Tennessee Disability Pathfinder’s Spanish helpline. Services include case management, a support group for parents of children with autism, and Camino Seguro, a web-based directory of services provided by agencies with staff who speak Spanish.

### Siblings of brothers and sisters with disabilities benefit from support.

Brothers and sisters will likely be involved in the life of an individual with a disability longer than anyone, including parents. Siblings share most of the same concerns as their parents and can benefit from support. VKC SibSaturdays support siblings, ages 5 to 13. Teen Fusion is a social group for teen siblings, and Tennessee Adult Brothers and Sisters (TABS) is a support and networking group for adult siblings. TABS held its first statewide conference in 2009, and members are active in national efforts aimed at developing policies for adults who care for their siblings with disabilities.

## Educate

### LEND Family Trainees ensure a family perspective is always in the picture.

The Leadership Education in Neurodevelopmental Disabilities (LEND) Training Program each year includes a Family Trainee. Directed by Terri Urbano, Ph.D. (Pediatrics), the program prepares health professionals from many disciplines to lead clinical and research advances in the disability field. Family Trainees, who are parents of children with disabilities, help all trainees to see their own disciplines through a family prism and to incorporate family members in service planning. Lessons from families make a long-lasting impact on LEND trainees.

### Family Stories inform public policy makers.

Family stories are powerful tools to inform public policy makers about what works well and what is lacking in disability policies and services. The challenge is how to collect family stories and make them available. Meeting this challenge, students in a VU Special Education Families Studies course interviewed families referred by The Arc of Tennessee, and learned firsthand of family encounters with services in education, health care, housing, and employment. *Family Stories 2008* was distributed to legislators. By sharing their stories, families have educated students and policymakers, necessary steps in building better public policies.

## Grow

### Families generate new knowledge by donating gifts for Discovery Grants.

Through Discovery Grants, donors provide essential seed funding for the discovery of new knowledge that will improve the lives of people with disabilities. VKC researchers use Discovery Grants to gather novel data that will strengthen their ideas and competitive edge in obtaining larger federal or foundation grants. **Mr. and Mrs. Thomas W. Beasley** and **Mr. and Mrs. John E. Beasley**—two generations—know that Ethan will have the best possible future, both because of their advocacy and love, and because they are supporting innovative research through the **Beasley Family Discovery Grant**.

### Supports are launched for inclusion in religious and spiritual communities

When families share their disability journeys, their stories often include how a faith community has been a crucial support—or has failed to support them. Religious and spiritual leaders and their congregations need training in ministering to persons with disabilities. With support from the **Frank Boehm Family**, the VKC is launching a speaker series, *Inclusion in a Faith Community*, to help meet this need. Findings from a VKC survey on Disability, Religion, and Spirituality will inform lectures, community discussions, and field placements. The VKC is among a handful of centers nationwide to support spiritual and religious needs of persons with disabilities and their families. ■

# Grow Educate



Leadership Council of Vanderbilt Kennedy Center

Leadership Council members serve as community champions on behalf of the Center and the children and adults with disabilities and their families served through the Center's research, training, and services. Council members play an invaluable "friend and fund" raising role, helping to identify diverse sources of partnership and support for the Center's activities. Leadership Council members have generated growth in the Hobbs Donor Society and have guided the Leadership Dinners.

- Mrs. Donna G. Eskind, Chair
Mrs. Cathy S. Brown, Past Chair
Mrs. Annette S. Eskind, Past Chair
Mrs. Barbara Gregg Phillips, Past Chair

- Mrs. Honey Alexander, Mrs. Lorie Hoppers Lytle
Ms. Sissy Allen, Mrs. Jack C. Massey
Mrs. Jean Ann Banker, Ms. Andrea Blake McDermott
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Mrs. Melissa Beasley, Ms. Pat McNellis
Mrs. Ann Bernard, Mrs. Thomas E. Nesbitt, Jr.
Mrs. Barbara T. Bovender, Mrs. Pat Patten
Mrs. Linda Brooks, The Honorable Andrew Shookhoff
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Mrs. Bernice Gordon
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Ms. Lucile Houseworth, Dr. Elisabeth Dykens
Ms. Bethany Jackson, Mrs. Elise McMillan
Mrs. Gail Gordon Jacobs, Dr. Louis J. Muglia
Mr. Chris and Mrs. Rebecca Link, Ms. Laura Pevahouse
Mrs. Michael F. Lovett, Mr. Tim Stafford

- Front cover photos clockwise:
Attendees at the MARI Scientific Symposium. Photo by Michael Hopkins, Gerlinde Photography.
Glial cells. Photo courtesy of laboratory of Bruce Carter, Ph.D.
Annette Eskind. Photo by Larry Wilson.
Families First workshop participant.



Community Advisory Council

Community Advisory Council members are individuals with disabilities, parents, siblings, and community partners. They reflect Tennessee's diversity and provide guidance to the VKC on community and state needs and concerns. They are partners in needs assessment, strategic planning, and evaluation.

- Doria Panvini, Chair
Ruth Roberts, Vice Chair
Ernestine Bowers, June Phillips
Ron Butler, Tina Prochaska
Lori Ceyala, Loria Richardson
Suzanne Colsey, Janet Shouse
holly lu conant-rees, Joyce Sievers
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Carol Greenwald
Charles Hall, Ex-Officio
Merry Jensen, Elisabeth Dykens
Belinda Martinez, Elise McMillan
Mark Montgomery, Roxanne Carreon
Sharon Peters

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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Louis Muglia, M.D., Ph.D., Associate Director
Tim Stafford, Director of Operations
Jan Rosemergy, Ph.D., Director of Communications

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

- LEND
Terri Urbano, Ph.D., M.P.H., R.N., Director
Tyler Reimschisel, M.D., Associate Director

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

- Discovery
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# CALENDAR OF EVENTS | DECEMBER 2009-MARCH 2010



*Shriver Transitions and Sports Camp*

Unless otherwise noted, events are free and open to the public. Events are subject to change. Please check the calendar on our website [kc.vanderbilt.edu](http://kc.vanderbilt.edu) or contact (615) 322-8240 or toll-free (1-866) 936-VUKC [8852].

Please keep this calendar and check the Event Calendar on the VKC website for updates. If you wish to receive event announcements by email, send your email address to [amy.pottier@vanderbilt.edu](mailto:amy.pottier@vanderbilt.edu).

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

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

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

Free monthly Saturday workshops serving parents of children, ages 2-5, diagnosed with an autism spectrum disorder

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

Register at

[kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration)

Information (615) 343-4275

[families.first@vanderbilt.edu](mailto:families.first@vanderbilt.edu)

- **DECEMBER 5\***  
Addressing Challenging Behaviors
- **JANUARY 30\***  
Improving Communication in Children Who Are Talking
- **FEBRUARY 27\***  
Family Activity Routines: Cores, Cooking, and Family Games
- **FEBRUARY 2, 9, 16, 23\***  
Beginning Toilet Training Series  
Tuesdays 6:30-8:30 p.m.

## ■ BRITT HENDERSON TRAINING SERIES FOR EDUCATORS

Free annual workshop series for school teams of general and special educators

5-7 p.m. Wednesdays

Register at

[kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration)

Information (615) 343-0706

- **JANUARY 27\***  
Self-Monitoring
- **FEBRUARY 17\***  
Behavioral Contracts
- **MARCH 3\***  
Brushing Up on the Basics: Proactive Classroom Management Strategies That Work

## ■ DECEMBER 2\*

*Developmental Disabilities*

*Grand Rounds*

The Teaching Pyramid: Supporting Young Children's Social Emotional Development and Addressing and Preventing Challenging Behavior

Mary Louise Hemmeter, Ph.D., Associate Professor of Special Education  
Wednesday 8 a.m.

## ■ DECEMBER 12\*

*Community Advisory Council Meeting*

For details contact (615) 936-5118

Friday 9:30 a.m.-2 p.m.

## ■ JANUARY 13\*

*Developmental Disabilities*

*Grand Rounds*

Understanding Why Infants Begin Reaching For Objects: Towards an Intervention for Infants with Visual Impairments

Amy Needham, Ph.D., Professor of Psychology  
Wednesday 8 a.m.

## ■ JANUARY 14\*

*Statistics and Methodology*

*Core Training Seminar*

Statistical Methods for Biomarker Discovery

Tatsuki Koyama, Ph.D., Assistant Professor of Biostatistics  
Thursday 12:30 p.m.

Register at

[kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration)

## ■ JANUARY 21\*

*Martin Luther King, Jr.*

*Commemorative Lectures &*

*Lectures on Development and*

*Developmental Disabilities*

The Epidemiology and Treatment of Silent Cerebral Infarcts in Sickle Cell Disease

Michael R. DeBaun, M.D., M.P.H., Professor of Pediatrics, Biostatistics, and Neurology, Washington University-St. Louis  
Thursday 12 p.m.

## ■ FEBRUARY 3\*

*Developmental Disabilities*

*Grand Rounds*

Pediatric Obesity: Diabetes

Prevention in the Latino Population

Shari Barkin, M.D., M.S.H.S., Professor of Pediatrics, Chief of the Division of General Pediatrics  
Wednesday 8 a.m.

## ■ FEBRUARY 16

*Vanderbilt Kennedy Center*

*Science Day*

Details and registration at

[kc.vanderbilt.edu](http://kc.vanderbilt.edu)

Deadline for poster abstract submission Friday, December 4 Tuesday 8:30 a.m.-3:30 p.m. Vanderbilt Student Life Center

## ■ MARCH 3\*

*Developmental Disabilities*

*Grand Rounds*

Dopaminergic Modulation of Brain Development and Behavior

Gregg Stanwood, Ph.D., Assistant Professor of Pharmacology  
Wednesday 8 a.m.

## ■ MARCH 3

*Neuroscience Graduate Program*

*Seminar Series*

The Role of the Medial Prefrontal Cortex in Mediating Resistance and Vulnerability to Adverse Events

Steven F. Maier, Ph.D., Distinguished Professor of Psychology, Director of the Center for Neuroscience, University of Colorado  
Co-sponsor Vanderbilt Brain Institute  
Wednesday, 4:10 p.m. Room 1220 MRB III Lecture Hall



CALENDAR OF EVENTS | DECEMBER 2009-MARCH 2010

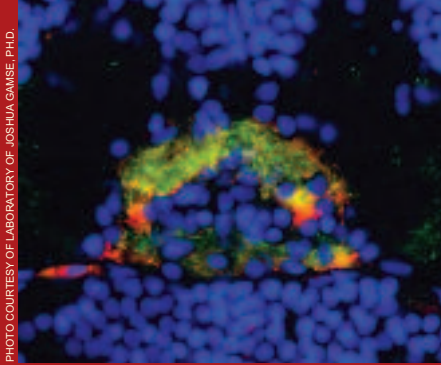


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**Grow**

■ MARCH 4\*

*Special Lecture for Vanderbilt & Brainstorm Lectures on Development and Developmental Disabilities*  
**Rett Syndrome: Linking Epigenetics to Neuronal Plasticity**  
 Huda Y. Zoghbi, M.D., Professor of Molecular & Human Genetics, Pediatrics, Neurology, and Neuroscience, Baylor College of Medicine  
 Thursday 4:10 p.m.

■ MARCH 12\*

*Community Advisory Council Meeting*  
 For details contact (615) 936-5118  
 Friday 9:30 a.m.-2 p.m.

■ MARCH 24\*

*Statistics and Methodology Core Training Seminar*  
**Data Preparation, Standards and Data Integrity: The Devil is in the Detail**  
 Ana Regina de Andrade, Ph.D., Senior Lecturer, Department of Economics; Research Associate, Center for Evaluation and Program Improvement  
 Catherine Smith, Assistant Professor of Psychology, Cumberland University  
 Wednesday 12:30 p.m.  
 Register at [kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration)

■ MARCH 31

*Neuroscience Graduate Program Seminar Series*  
**Role of MeCP2 & HDACs in Regulating Synapse Function and Behavior**  
 Lisa M. Monteggia, Ph.D., Assistant Professor of Psychiatry, UT Southwestern Medical Center at Dallas  
 Co-sponsor Vanderbilt Brain Institute  
 Wednesday, 4:10 p.m. Room 1220 MRB III Lecture Hall

■ TRIAD SCHOOL-AGE SERVICES

With the Tennessee Department of Education, TRIAD offers free autism-specific workshops for parents, school personnel, and the community in locations across the state.  
 Information and registration, contact [Linda.Copas@state.tn.us](mailto:Linda.Copas@state.tn.us), (615) 741-7790  
 See also [tennessee.gov/education/speced/announcements.shtml](http://tennessee.gov/education/speced/announcements.shtml)

■ ARTS AND DISABILITIES

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

- Through JANUARY 12, 2010  
**Creative Expressions XV**
- JANUARY 18-MARCH 29 2010  
**From Heartache to Hope: Middle Tennessee Families Living with Autism**  
 Photo exhibit  
 Reception 5-6:30 p.m.  
 Thursday, January 28

■ BEHAVIOR ANALYSIS CLINIC

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

■ READING CLINIC

For students in kindergarten and early elementary grades  
 Contact (615) 936-5123

■ SIBLING SUPPORTS

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

• SibSaturdays\*

DECEMBER 12  
 FEBRUARY 20

Ages 5-7 and 8-12 years  
 Games, friends, conversation  
 \$10/child or \$20/family  
 Financial assistance available

Advance registration required  
 SibSaturdays also are offered by the Autism Society of Middle Tennessee and the Down Syndrome Association of Middle Tennessee

• Teen Fusion

DECEMBER 19  
 MARCH 13

Ages 13-17, Activities vary

• Tennessee Adult Brothers and Sisters (TABS)

Contact  
[ashley.coulter@vanderbilt.edu](mailto:ashley.coulter@vanderbilt.edu)  
 Register online at [kc.vanderbilt.edu/site/services/disabilityservices/tabs.aspx](http://kc.vanderbilt.edu/site/services/disabilityservices/tabs.aspx)

■ TAKE PART IN RESEARCH

**Vanderbilt Kennedy Center Research Studies**

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

• Research Family Partners

[kc.vanderbilt.edu/rfp](http://kc.vanderbilt.edu/rfp)  
 Register and be notified of research studies

• StudyFinder

[kc.vanderbilt.edu/studyfinder](http://kc.vanderbilt.edu/studyfinder)  
 View lists of studies, criteria, and contact information  
 See also **VUMC Clinical Trials**  
[www.vanderbilthealth.com/clinicaltrials](http://www.vanderbilthealth.com/clinicaltrials)

■ TENNESSEE DISABILITY PATHFINDER

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