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## Discovery

### Think Globally—Act Locally: The National Down Syndrome Research Plan

By Jan Rosemergy



Rachel Putnam, Will McMillan, and Jeanne Gavigan

"This is my 'clinic,'" said Karen Summar, M.D., showing a photo of her 18-year-old daughter and her two close friends, who also have Down syndrome. Summar was speaking not only as a parent of four daughters but also as "a baby doctor, a pediatrician, and a researcher." She was one of five panelists who summarized the goals of the National Down Syndrome Research Plan at a June 2008 forum for researchers, students, individuals with Down syndrome and family members, and disability advocates.

"The question is: What next?" Summar asked. "These people are not children anymore. They are young adults."

"What next?" is addressed by the National Institutes of Health (NIH) Research Plan, released January 2008. The Plan sets NIH research goals for the next 10 years that build upon earlier research advances fostered by the NIH. The forum's purpose was to summarize that plan and to mobilize within the Vanderbilt Kennedy Center (VKC), Vanderbilt University, and the community and state to contribute to achieving these national research goals.

"The NIH Roadmap for Research on Down Syndrome presents a wonderful opportunity for Vanderbilt and our research community," said Elise McMillan, J.D., co-director of VKC University Center for Excellence in Developmental Disabilities (UCEDD), forum moderator, and parent of three children, one of whom has Down syndrome. "The forum provided insight into the steps necessary here to grow research on Down syndrome. Community support for our efforts will be vital to our success."

"There are few if any places across the country with such a wide range of researchers interested in this syndrome as we have here at *Continued on page 2*

### Protein on "Speed" Linked to ADHD

By Leigh McMillan

A genetic change in the dopamine transporter—one of the brain's dopamine-handling proteins—makes it behave as if amphetamine is present and "run backward," Vanderbilt Kennedy Center investigators reported in July in the *Journal of Neuroscience*.

The altered function of the transporter gene variant, discovered in two brothers with attention deficit hyperactivity disorder (ADHD), supports a role for dopamine signaling in the disease.

ADHD is one of the most common mental health disorders in children and adolescents, affecting up to 5% of school-age children in the U.S.

"We believe that this is important evidence that ADHD can be caused by a functional deficit in the brain's dopamine signaling pathway," said Randy Blakely, Ph.D., Allan D. Bass Professor of Pharmacology, *Continued on page 3*



ADHD is one of the most costly health conditions in the U.S.—topped only by alcohol abuse and surpassing drug abuse. The annual cost for ADHD is \$77 billion compared to \$58 billion for substance abuse.

### Director's Message

### From Research to Public Policy



Pat Levitt, Ph.D.

Recently, I presented at our Developmental Disability Grand Rounds series with David Mills, Vanderbilt University's associate director of state policy and legislative affairs. The Grand Rounds series typically provides clinical and basic scientists across our campus with an opportunity to introduce the latest research findings to a diverse audience. David and I were charged with a different task. We highlighted our own experiences in working with State policy makers to provide them with the most accurate information possible, with the goal of helping legislators make informed decisions that impact the lives of millions of Tennesseans. *Continued on page 3*

## Think Globally from page 1

Vanderbilt and at the Vanderbilt Kennedy Center,” said Elisabeth Dykens, Ph.D., professor of psychology, VKC associate director, and co-director of the VKC UCEDD. “We’re already well on our way to contributing to the national goals here at Vanderbilt, and through the major national disability networks of which we’re a part. And we have all the ingredients we need to be well-positioned to be training the next generation of interdisciplinary researchers and clinicians.”

### Down Syndrome

According to the NIH, Down syndrome occurs in 1 out of every 800 births in the U.S. It most frequently results from an extra or third copy of chromosome 21 in the body’s cells. In most cases, this extra chromosome comes from the mother. In some cases, forms of Down syndrome can result from having an extra portion of chromosome 21. The chance of giving birth to a baby with Down syndrome increases as women age.

Infants with Down syndrome have certain characteristic physical features, such as short stature and distinctive facial features, and they are more likely to have health conditions like hearing loss, heart malformations, hypertension, digestive problems, and vision disorders. Although Down syndrome is the most common cause of mild to moderate intellectual disability, the condition occasionally is severe.

### The NIH Plan

The NIH Down Syndrome Research Plan is directed at advancing understanding of Down syndrome and speeding development of new treatments for the condition and associated medical problems.

The NIH’s *Eunice Kennedy Shriver* National Institute of Child Health and Human Development convened a working group of NIH scientists. Through a public comment process, the scientists listened to comments and suggestions from families of individuals with Down syndrome, as well as from Down syndrome research advocacy organizations. The NIH scientists then developed the research plan in collaboration with researchers in the national scientific community, which included two VKC investigators, Elisabeth Dykens, Ph.D., and Robert Hodapp, Ph.D. Both were forum participants.

The Plan is organized into five research areas whose objectives are short-term (0 to 3 years), medium-term (4 to 6 years), and long-term (7 to 10 years). Each of the forum’s presenters focused on one of the five research areas, providing commentary as well as summarizing objectives.

### Pathophysiology and Disease Progression

“The purpose of research in pathophysiology and disease progression is to understand how individual genes on chromosome 21 contribute to the specific features of Down syndrome,” said Aaron Bowman, Ph.D., assistant professor of neurology and VKC member. “But this is a gross

simplification of what really needs to be done,” he commented. “What we really need to know is how the spectrum of genes on chromosome 21 will interact with other genetic and environmental factors to culminate in the Down syndrome presentation. Everyone is different. This is true for persons with Down syndrome as well.”

This area’s goals focus on creating model systems, for example in mice, that will facilitate testing cognitive and synaptic function, studying whether the impact of aging on certain processes is greater than on others, and exploring the genetic and environmental determinants of cognitive function in Down syndrome throughout the lifespan.



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### Diagnosis, Screening, and Functional Measures

Research goals for diagnosis, screening, and functional measures were presented by Linda Ashford, Ph.D., assistant professor of pediatrics and psychology and VKC member, who sees children in the Vanderbilt Down Syndrome Clinic.

The goals in this area include identifying the cognitive phenotype of Down syndrome in a cohort throughout the lifespan, linking human and mouse cognitive studies relating to Down syndrome, and developing better measures of hippocampal and cognitive function.

Ashford stressed the complexity embedded in these goals. Some issues she identified were deciding what constitutes the minimum set of behavioral and imaging measures—across studies, age groups, and developmental and behavioral domains; determining the common domains to be assessed, across the lifespan; developing standardized methods to test synaptic and cognitive function in mice, and developing tests for the same cognitive function in mice and humans; developing technology for imaging the youngest children; and developing standard measures and techniques to study vulnerable brain regions.

### Treatment and Management

Karen Summar, M.D., director of the Vanderbilt Down Syndrome Clinic, provided a “history lesson to remind us of where we have been and where we should be going.”

John Langdon Down was the first, in 1866, to carefully describe people with Down syndrome. Just 10 years later, Fraser and Mitchell reported a relationship between Down syndrome and Alzheimer’s disease. In 1959, Jerome Lejeune discovered that trisomy 21—the extra gene on chromosome 21—causes Down syndrome, a discovery that earned him a Nobel Prize. During the 1980s and 1990s, significant gains were made in treating associated medical conditions: heart and intestinal surgeries were perfected, treatment of leukemia improved. In 2000, the complete map of human chromosome 21 was determined, and scientists found that the chromosome has 400 genes.

“Not all these genes are directly related to Down syndrome,” Summar stressed, “and we know that at least three genes on chromosome 21 are related to Alzheimer’s disease. The medical community has made great gains in treating associated conditions, but that’s not enough. That’s why we’re here today.”

The NIH research objectives for treatment and management include increasing research on co-occurring psychiatric and medical conditions throughout the lifespan, learning from Alzheimer disease research regarding the best therapeutics, and investigating the impact of early intervention on psychomotor and cognitive development.

Summar stressed the need for research on adults with Down syndrome, in particular medical problems.

### Living With Down Syndrome

“Of all the NIH research areas, I believe this is the most important,” said Robert Hodapp, Ph.D., professor of special education and VKC UCEDD director of research. He emphasized the dramatic increase in lifespan for individuals with Down syndrome as one of the contexts, as well as increased participation in the community. “There’s been a sea change in how people with Down syndrome live,” he said.

The NIH research objectives include developing a more complete demographic knowledge base, studying real-world outcomes for families with a member with Down syndrome, and exploring new intervention research, especially during transitional stages in the lifespan.

“Despite the fact that we have known about Down syndrome for 150 years, scientists don’t even yet understand the basic demographics,” Hodapp said, stressing the need to create a national registry. He also emphasized disparities in health related to race.

### Research Infrastructure

“My task,” said Dykens, “is to suggest how to develop an infrastructure to make this broad array of research happen.”

NIH objectives in this area include improving and expanding availability of animal models, discussing the best mechanisms *Continued on page 3*

## Think Globally from page 2

to use in fostering cross-disciplinary research, and including cohorts of people with Down syndrome in longitudinal studies.

Dykens highlighted some of the specific needs: establishing a mouse core to improve and develop mouse models and to share those models; establishing brain, cell, DNA, and RNA banks; expanding NIH tissue banks; supporting database development; and instituting a national registry across the lifespan of families willing to take part in research, which must have demographically representative and diverse samples.

Woven throughout is the need for families to be involved. She applauded the participation of families and Down syndrome advocacy groups with the NIH work groups.

Dykens highlighted the steps that the Vanderbilt Kennedy Center and Vanderbilt University have already taken. Through its work as a *Eunice Kennedy Shriver* Intellectual and Developmental Disabilities Research Center, a University Center for Excellence, and a Leadership and Education in Neurodevelopmental Disabilities Program, the VKC is training the next generation of interdisciplinary scientists and clinicians, as well as collaborating with other scientists in these national networks. The VKC is well-positioned for research using linked Tennessee health databases. Families can easily find research opportunities through the VKC StudyFinder website, or through registering with the VKC Research Family Partners or with Vanderbilt Clinical Trials. Vanderbilt Medical Center's pediatric and Continued on page 9

## Protein on "Speed" Linked to ADHD from page 1

professor of psychiatry, and director of the Center for Molecular Neuroscience.

The researchers propose that because the altered transporter runs backward and pushes dopamine out into the space between neurons—like normal transporters do when amphetamine, or "speed," is present—it alters dopamine signaling and contributes to the symptoms of ADHD.

"It is like these kids are on amphetamine all the time," said Aurelio Galli, Ph.D., associate professor of molecular biology and biophysics.

Variations in brain dopamine signaling have long been suspected to participate in the development of ADHD and other neuropsychiatric disorders. Dopamine has roles in brain circuits linked to attention, motor function, reward, and cognition. Drugs that target dopamine transporters and receptors are used to treat ADHD, bipolar disorder, and schizophrenia.

Using a sensitive technology called amperometry that uses a small carbon fiber to "listen in" on how single cells release or transport dopamine, the Galli and Blakely laboratories discovered that the altered transporters were running backward at an exaggerated rate, literally pushing dopamine out of the cell.

To their surprise, the investigators also found that amphetamine blocks the leak of dopamine through variant transporter. Normally, amphetamine does just what the mutation does—it causes the dopamine transporter to run in the reverse direction.

The findings offer a new perspective on a

conundrum in the ADHD field—the fact that two of the medications that successfully treat the condition have opposing effects on their molecular target, the dopamine transporter. With the normal dopamine transporter, methylphenidate (Ritalin) blocks the ability of amphetamine (Adderall) to make the transporter run backward, yet both drugs are equally beneficial to individuals with ADHD.

But when the transporter runs backward of its



DANA JOHNSON  
Randy Blakely, Aurelio Galli, Erica Bowton (graduate student, Galli lab), and, on screen, Michelle Mazei-Robison (former graduate student, Blakely lab)

own accord—as it does with this rare mutant version—both agents act as blockers and stop the leak of dopamine.

"This observation unifies the action of these drugs and strongly suggests that backward-running transporters may be an important mechanism in ADHD, even for those who do not have this particular mutation," Blakely said.

M. Mazei-Robison, Ph.D., and E. Bowton at Vanderbilt, and collaborators at the Medical University of Vienna, contributed to the current study. The research was supported by the National Institute on Drug Abuse and the National Institute of Mental Health. ●

## Director's Message from page 1

David and I come at this problem from different perspectives—although we share a strong connection as fellow "Jersey Boys" who have a passion for trying to make a difference.

I shared my flops and successes in working with the National Scientific Council on the Developing Child (NSCDC) at Harvard, Frameworks Institute in Washington, D.C., and State

legislators from across the United States to find the most effective ways to communicate what neuroscience tells us about brain and child development. The conclusion—words and first impressions matter.

Legislators care, but they typically are not content experts. They are not interested in scientists who are advocating for a particular program. They meet with dozens of advocates weekly, and making choices often comes down to legislators trying to be as



David Mills

informed as possible. Legislators embrace scientists as knowledge brokers who can give them the straight story in our own area of expertise. The words *perhaps*, *maybe*, or *possibly* do not help them draw clear conclusions.

There is no need to stray from one's own comfort zone of expertise. I have established boundaries in what I discuss—the impact of early negative and positive experiences, such as toxic stress or strong social-emotional

support, on developing brain *architecture*. The frame matters.

When the questions venture into advice regarding specific early childhood programs, I make it clear that I do not perform research in program evaluation. But I can help by directing legislators to other members of the NSCDC, who can provide them with up-to-date research on program effectiveness.

David highlighted for scientists and practitioners what I have learned the hard way. Do not

underestimate how important it is to come prepared, to know as much as possible about the legislators whom one will meet, to answer questions directly, to be respectful, and to be forthright in one's commitment. Do not be afraid to show that, in fact, one does care and recognizes the responsibility to try to contribute.

Not everyone is comfortable providing testimony, but all researchers can participate in some way to help inform our community leaders about scientific findings that can make a difference in developing policies that are best for children and families.

Finally, do not feel that you need to do it on your own. Partnering with legislative and policy experts like David Mills makes the challenge that much more achievable.

Be ready to be hooked. To me, nothing has been more satisfying than knowing that I've contributed beyond publishing a journal article or obtaining a new grant. And you meet great and committed people like David Mills. ●

# Vanderbilt Kennedy Center for Excellence in Developmental Disabilities

## VKC UCEDD Training Enters the Courtroom *By Courtney Taylor*

As a University Center for Excellence, the Vanderbilt Kennedy Center is in a unique position to facilitate the flow of disability-related information between community and university to build the capacity of communities to sustain all their citizens. In recent months, the VKC UCEDD has collaborated with community partners to provide disability-related information and training to those in the legal community, and to advocates for families.

### Training Judges

Administrative Law Judges who conduct special education mediations and due process appeals are required to undergo annual trainings in special education law and disability-related issues. In 2007, psychologists and special educators from the Vanderbilt Kennedy Center conducted a training session for judges in Tennessee that included overviews of IDEA (Individuals with Disabilities Education Act), developmental disabilities, and assessment services and procedures related to developmental disabilities. In 2008, the training became a bit more specialized.

"Autism is probably the most common disability seen by our judges in the IDEA cases filed with the Administrative Procedures Division [APD]," said Thomas Stovall, director and Chief Administrative Judge of the APD. "As judges hearing these cases, we need to know what autism is. We need to understand that it is a spectrum, and that it can look different in different people. We need to know about assessment and treatment options. We thought an entire day of training on autism would be very beneficial. It certainly was."

The autism training for the judges was led by Evon Lee, Ph.D., associate professor of pediatrics, and Courtney Burnette, Ph.D., clinical assistant professor of psychiatry. Both are psychologists with the Vanderbilt Kennedy Treatment and Research Institute for Autism Spectrum Disorders (TRIAD). Lee and Burnette trained 32 judges from Tennessee, North Carolina, South Carolina, Michigan, and Minnesota with a focus on diagnosis, assessment, and intervention, as well as "hot topics in autism."

"We tried to illustrate the spectrum of autism spectrum disorders," said Lee. "We wanted to broaden their perspectives and give them concrete examples of what these kids look like. We talked about 'hot topics,' about the way autism has been portrayed in the media. We wanted them to understand that they should be very cautious and take an evidence-based approach. We wanted to be sure they knew to look carefully



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and not just get swept up by the media frenzy."

The assessments section of the training included demonstrations of some of the toys and tools that psychologists use when administering the Autism Diagnostic Observation Schedule (ADOS). Having a tea party, blowing bubbles, and shooting balloons across the room gave judges a concrete view of what an actual assessment looks like.

"It sounds silly to think of law judges watching bubbles float around the room," said Burnette. "Yet, it showed them exactly what we do. Rather than it being a vague diagnostic instrument we just talked about with them, that portion came to life and gave them insight into what a child might experience during an assessment."

Lee and Burnette both expressed an appreciation for the difficult position the judges are in as they hear the IDEA cases. Balancing the needs of a child with what the law says, and at times in the context of distressed parents who only want what is best for their child, is not an easy task. So the training provided an opportunity for them, as psychologists, to paint a clearer picture of what families experience as they receive a diagnosis, navigate through treatment options, or receive confusing messages from the media.

### Training Attorneys

The Vanderbilt Kennedy University Center for Excellence (VKC UCEDD) is partnering with The Arc of Davidson County to train attorneys interested in working with families who are considering going to due process or who are having trouble accessing services within their school district. Relatively few attorneys in Tennessee specialize in special education law, and for those who have this area of expertise, the cost of legal services may not be affordable for many families.

In 2007, Erin Richardson, director of the Legal

Advocacy Project for The Arc of Davidson County, set out to remove these obstacles by recruiting lawyers working in other areas of law and developing a training program to educate them on special education law matters.

"The training was developed to build a larger base of attorneys who are educated in special education law and who can represent families on a pro bono basis," said Meghan Burke, the training coordinator and a doctoral candidate in special education at Vanderbilt. "We ask the attorneys to commit to working with one family who is considering going to due process. Erin works with many families, and building this base of attorneys allows her to make referrals confidently. And it is not an overwhelming commitment on the part of the attorneys, because generally, he or she can meet with the family and the school district and hammer out the issues before going to due process."

For information, contact: [meghan.m.burke@vanderbilt.edu](mailto:meghan.m.burke@vanderbilt.edu) or [erichardson@arcadc.org](mailto:erichardson@arcadc.org), (615) 321-5699.

### Training Advocates

The Arc of Davidson County and the VKC UCEDD are partnering to train individuals who are willing to become advocates for families and attend IEP meetings. Currently, no certification to become an advocate is available, so the intent is to better prepare those who are willing to provide advocacy support and assistance. Representatives of other organizations such as DLAC and STEP also are participating in the presentations.

"We are training individuals who are willing to work with families on a variety of levels," said Burke. "Having an advocate is important because when you have a child with a disability, you have so much going on that navigating the whole special education maze is a whole other issue. It is hard to understand what your rights are, how you apply them, and how to be assertive, yet not aggressive, in an IEP meeting. Advocates can assist families in knowing where those boundaries are."

While the first advocacy training took place last year, a second 11-week session began in September 2008. Community advocates meet every Thursday for 4 hours and will celebrate with a graduation ceremony on November 20. They will study special education legislation and regulations on both the federal and the state levels, and they will shadow advocates to gain firsthand experience.

For information, contact: [meghan.m.burke@vanderbilt.edu](mailto:meghan.m.burke@vanderbilt.edu), (615) 936-8852. ●



# Treatment and Research Institute for Autism Spectrum Disorders

## Vanderbilt Autism Clinic Provides One-Point Entry *By Jan Rosemergy*



NEIL BRAKE

Vanderbilt University is making it easy for families and professionals to find autism services by introducing the Vanderbilt Autism Clinic—a single helpline staffed by an autism expert who can make referrals to what's needed.

Vanderbilt recruited Sarah Zombek to serve as family services coordinator. She held a similar position at Massachusetts General Hospital in an

autism clinic with a national reputation for family-centered care.

“Sarah has exceptional experience and expertise in autism spectrum disorders, and we are so fortunate to have her help us launch the Vanderbilt Autism Clinic,” said Wendy Stone, Ph.D., professor of pediatrics and psychology and director of the Vanderbilt Kennedy Treatment and Research Institute for Autism Spectrum Disorders (TRIAD).

The Vanderbilt Autism Clinic is a gateway to a broad range of Vanderbilt clinical and research programs and resources, as well as those in the community, state, and region. It serves individuals with autism, families, caregivers, clinicians, educators, and others looking for a single, reliable source to find the help needed.

Available resources include autism-specialized diagnostic, medical, early intervention, educational, behavioral, and counseling services for

children, adolescents, and adults with autism spectrum disorders.

“Trying to find services can be stressful for a parent or professional,” Zombek said. “Whether a person needs a diagnostic evaluation or is seeking services, navigating service systems can be a challenge. We hope that the Vanderbilt Autism Clinic will be able to alleviate some of the stress and confusion. I’m happy to be part of this valuable program and look forward to serving our community.”

The Vanderbilt Autism Clinic is brought to the community by VKC TRIAD and the Vanderbilt Medical Center. Vanderbilt is a member of the national Autism Treatment Network, a 15-site network of medical centers dedicated to establishing medical standards of care for children with autism.

To contact the Vanderbilt Autism Clinic, call 322-7565 (local), toll-free 1-877-ASD-VUMC (273-8862), or email [autismclinic@vanderbilt.edu](mailto:autismclinic@vanderbilt.edu).



KYLIE BECK

Sarah Zombek

## Individualized Family Consultation *By Jan Rosemergy*

Family life for parents who have a child with an autism spectrum disorder (ASD) can sometimes be difficult. Moreover, every family is different, with its own strengths, values, routines, and challenges. Parents of children with ASD now have a new resource to turn to—TRIAD’s Individualized Family Consultation (IFC) Program.

“We developed this program because families expressed the need,” said Lisa Wallace, M.S., CCC-SLP. “Even when families take part in the Ann and Monroe Carell Jr. Families First Workshops, or other group training, they feel the need for specific problem solving unique to their own family. Families really wanted home-based, individualized, goal-directed intervention from autism behavior experts.”

The IFC Program serves parents of children with ASD between the ages of 18 months and 5 years. TRIAD behavior consultants assist families in developing individualized goals for their child and in learning a variety of teaching strategies to achieve those goals.

The behavior consultants teach parents how to use evidence-based techniques to increase their



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child’s social and communication skills, to improve their child’s ability to participate in everyday family routines, and to anticipate and to prevent challenging behaviors.

For families who live within 30 miles of Vanderbilt, the IFC sessions can be provided in the home, in the community, or at Vanderbilt. For families living outside the 30-mile radius, IFC sessions are held at Vanderbilt or in the community, depending on the family’s goals.

Services are provided as a package of five

sessions. Families can arrange for additional packages of five sessions, consecutively or over time, as the need arises.

“We sit down with a family and identify their main goals for the five sessions,” Wallace said. “The focus is on communication, social interaction, play, imitation, and behavior—the core developmental areas in which children with ASD have difficulty.”

Daily routines in the home and in the community are the ideal settings to help children improve in these key areas, Wallace explained. Daily routines allow for repetition and structure, which are important features in teaching young children with ASD. In addition, by teaching functional skills in natural settings like the home and community, in contrast to a clinical setting, the need to address generalization of learning is decreased; generalization of skills is a particular challenge for children with ASD. (Generalization refers to the ability to learn a skill in one setting and then transfer or use it in another setting, e.g., between home and school.) Finally, parents are empowered by having the knowledge *Continued on page 6*

# Leading the Vanguard of Discovery



**AARON B. BOWMAN, PH.D.**

Assistant Professor of Neurology  
Vanderbilt Kennedy Center Member  
Joined Vanderbilt Kennedy Center 2006

## Research Interests

I study the development and maintenance of brain function and processes leading to its dysfunction and degeneration. My current research focuses on degenerative processes afflicting the basal ganglia, a brain structure necessary for proper control of movement. In addition, I am examining methods to convert patient-derived skin cells into novel cellular models of neurological disease.

## Principal Investigator

- Gene-Environment Interactions Between Manganese Exposure and Huntington Disease, National Institute of Environmental Health Sciences
- Human-Induced Pluripotent Cells for the Study of Neurologic Disorders, National Center for Research Resources

## Honors and Awards

- Lucille P. Markey Fellow in Biomedical Sciences, 1995-2000
- Life Sciences Research Foundation Postdoctoral Fellowship, 2001-2003
- Hereditary Disease Foundation Postdoctoral Fellowship, 2003-2006

## Selected Publications

Bowman, A. B., Lam, Y. C., Jafar-Nejad, P., Chen, H. K., Richman, R., Samaco, R. C., Fryer, J. D., Kahle, J. J., Orr, H. T., & Zoghbi, H. Y. (2007). Duplication of *Atxn11* suppresses SCA1 neuropathology by decreasing incorporation of polyglutamine-expanded ataxin-1 into native complexes. *Nature Genetics*, 39(3), 373-379.

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inclusion formation. *Human Molecular Genetics*, 14(5), 679-691.

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\*co-first authors

Lim, J., Crespo-Barreto, J., Jafar-Nejad, P., Bowman, A. B., Richman, R., Hill, D., Orr, H. T., & Zoghbi, H. Y. (2008). Opposing effects of polyglutamine expansion on native protein complexes contribute to SCA1. *Nature*, 452(7188), 713-718.

## Education

B.S., 1995, Microbiology, Brigham Young University

Ph.D., 2000, Biomedical Sciences, University of California-San Diego

## Attraction to Developmental Disabilities Research

Individually, we are a product of our own history. Genetic and environmental factors modulate our developmental history, thus shaping our emotional, cognitive, and mental health. I believe that by discovering how these factors modulate neuronal function, we can understand the causes of neurological dysfunction and improve the quality of life for people of all ages. I was attracted to research on developmental disabilities because I believe that without an understanding of the facets of human development that modulate neurological function, we lose sight of a valuable tool to improving human health—our own history.

I am fascinated by the connections between neurodevelopment and neurodegeneration. My research focuses on how functional changes in genes and vulnerabilities to environmental factors beginning very early in development can lead to degradation of normal neurological function later in life. For example, a pathogenic expansion of DNA in the Huntington disease gene before birth sets the stage for degeneration of specific brain structures later in life. The greater the expansion of DNA, the earlier overt degeneration begins—with large expansions leading to a juvenile form of Huntington's disease with childhood onset. By learning how genes and environmental factors acting throughout life influence the development and maintenance of human health, we may be better able to identify key early steps critical for functional development and long-term health.

## Reasons for Vanderbilt Kennedy Center Membership

While access to world-class resources and services is fundamental to my research, it is the people of the Vanderbilt Kennedy Center who are at the heart of why I became a member. Whether it is its highly collaborative Principal Investigators, or its dedicated

support staff, or the integrated and meaningful connections with families and friends of the VKC—I have experienced and benefited firsthand from the dedication and zeal of those around me.

My connection to the Center is the life-blood of my research program. Engaging in conversations on scientific detail with VKC Investigators has enabled my research to expand in novel directions. The availability of interdisciplinary journal clubs at the Center, such as the Down Syndrome Journal Club, brings fresh ideas and fosters new research programs. The integration of families, educators, clinicians, and researchers coming together in the Journal Club to talk about our current state of knowledge and working together to understand what needs to be done next are unlike anything I have seen in my training—and bring an air of excited anticipation for the future. Finally, it is the VKC leadership and its early recognition of the advantages afforded by transdisciplinary approaches that has guided the growth of this diverse, interactive, and productive research center. I came to the VKC in 2006 having just a glimpse of the highly collaborative and supportive research environment I have come to know. The VKC has more than met my expectations, and I suspect it will continue to exceed them. ●

## Individualized Family Consultation from page 5

they need to teach their young child with ASD, which helps parents become more confident in their ability to connect with and to teach their child.

Examples of family goals are as diverse as families. Parents may want their child with ASD to be able to sit and play with their siblings, or to play productively by themselves for a time. A family might want their child to have a way to communicate his or her basic wants and needs, or to sit with them at the dinner table.

"Parents are an integral part of choosing goals to work on, which makes the results meaningful for their family," Wallace said.

For parents within the 30-mile radius, the ability to receive help in the home or in the community is an advantage. If problem areas are at bedtime, for example, the behavior consultant can be in the home, working with the parents to find solutions—or on the playground or at the grocery store, or wherever behaviors are occurring that interfere with family life.

The IFC Program is fee-based, with a flexible payment schedule. For information, contact Mary Hamilton (mary.m.hamilton@vanderbilt.edu), (615) 343-4275. ●

# Accolades

**Camilla Benbow**, Ed.D., Patricia and Rodes Hart Dean of Education and Human Development and professor of psychology, received the **2008 Distinguished Alumna Award** from **Johns Hopkins University**. She delivered the Johns Hopkins School of Education's commencement address May 22.

The **Vanderbilt Chapter of Best Buddies** won an **Outstanding Chapter of the Year Award** at Best Buddies International's 19th Annual Student Leadership Conference, July 2008. Vanderbilt was chosen as 1 of 18 college chapters from more than 400 college programs throughout the world for its dedication to enhancing the lives of people with intellectual disabilities by providing opportunities for one-to-one friendships. Elise McMillan, J.D., VKC UCEDD co-director and senior associate in psychiatry, is the Vanderbilt Chapter Faculty Advisor.



Randy Blakely, Ph.D.

**Randy Blakely**, Ph.D., Allan D. Bass Professor of Pharmacology, professor of psychiatry, and director of the Center for Molecular Neuroscience, received two awards from the American Society for Pharmacology and Experimental Therapeutics (ASPET). At the Experimental Biology

Meeting in San Diego, April 5, Blakely received the **2008 ASPET Julius Axelrod Award** for outstanding scientific contributions in research and mentoring, and an **ASPET-Astellas Award in Translational Pharmacology**. Blakely also gave an **interview on National Public Radio** "Science Friday" about his recent study of ADHD, co-written with **Aurelio Galli**, Ph.D., associate professor of molecular physiology and biophysics, which appeared in the July 9 *Journal of Neuroscience*.

**Elisabeth Dykens**, Ph.D., professor of psychology and human development, associate director of the VKC, and director of the VKC UCEDD, was the **keynote speaker** at the **National Association for the Dually Diagnosed** conference September 17-19.

Three VKC faculty were honored at the 2008 Spring Faculty Assembly. **Dale Farran**, Ph.D., professor of education and psychology, received the **Alexander Heard Distinguished Service Professor Award**, which recognizes a scholar whose work has and will continue to have wide influence in the solution of contemporary social problems. **John Gore**, Ph.D., University Professor of Radiology & Radiological Sciences and Biomedical Engineering, professor of molecular physiology & biophysics, professor of physics, and director of the Institute of Imaging Sciences, received the **F. Peter Guengerich Award**, in recognition of his mentoring of postdoctoral fellows or residents in the research setting. **Herbert Meltzer**, M.D., Bixler/May/Johnson Professor of Psychiatry and

professor of pharmacology, received the **Grant W. Liddle Award** for outstanding contributions in clinical research.



Doug Fuchs, Ph.D.,  
Lynn Fuchs, Ph.D.

**Douglas Fuchs**, Ph.D., and **Lynn Fuchs**, Ph.D., Nicholas Hobbs Chairs in Special Education and Human Development and professors of special education, received the **Council for Exceptional Children (CEC) Division for Learning Disabilities' Jeannette E. Fleischer Award for Outstanding Contributions to the Field of Learning Disabilities** at the CEC Annual Meeting, April 2-5, in Boston. In addition, a study by the Fuchs and Sarah Kazdan was the **only study on strategy instruction at the high school level that met the rigorous, scientifically based standards to be included in a report by the Mid-Continent Regional Educational Laboratory**. The report, which was commissioned by the Institute for Education Sciences, U. S. Dept. of Education, concludes that peer-assisted learning strategies (PALS) can have a substantively important positive effect on struggling high school students' reading comprehension.

**Carol Greenwald**, Ph.D., received the **Memphis Women's Magazine's 50 Women Who Make a Difference Award** on August 25. Greenwald is past president of The Arc of Tennessee and serves on other state and local disability groups, including the VKC Community Advisory Council.

**Frank Harrell Jr.**, Ph.D., chair of biostatistics, **presented three keynote speeches** in 2 months. He delivered the keynote address at the **Statistical Science Awards Ceremony, Centers for Disease Control and Agency for Toxic Substances and Disease Registry** in Atlanta in July. In May, he delivered the keynote addresses for the annual meeting of statisticians of the **Cleveland Clinic, Case Western Reserve University, and Ohio State University**, and at the **Biostatistics Annual Talk at the Medical College of Wisconsin**. The **Department of Statistics, Glasgow University, Scotland**, recently named Harrell the **2008 Mitchell Lecturer**.

**Karen Harris**, Ph.D., and **Steve Graham**, Ph.D., Currey Ingram Chairs in Special Education and professors of special education, have been selected **co-editors** of the first edition of the American Psychological Association's **Educational Psychology Handbook**.

**Carolyn Hughes** was selected as **Associate Editor of Research and Practice in Severe Disabilities** (formerly *JASH*) for 2008-2011. Also, she is serving as **Expert Reviewer** on the U.S. Department of Education Office of Special Education Programs (OSEP) **Validation**

## Study of Evidence-Based Practices in Secondary Transition.

**Kathleen Lane**, Ph.D., was **promoted to associate professor of special education** with tenure. Lane studies the connection between academic underachievement and emotional and behavioral disorders.

**Robert Macdonald**, M.D., Ph.D., chair of neurology, professor of pharmacology and molecular physiology & biophysics, presented the **2008 Robert Wartenberg Lecture** for outstanding clinical research at the annual **American Academy of Neurology** conference April 15 in Chicago. This is the highest honor given by the AAN.

**Douglas McMahon**, Ph.D., professor of biological sciences, received a **Chancellor's Award for Research**, which recognizes excellence in research, scholarship, or creative expression.



Doria Panvini

**Doria Panvini** received the **Roger Blue Memorial Award of The Arc of Tennessee** during the Tennessee Disability MegaConference Awards Banquet on May 30, in recognition of decades of volunteer service. Panvini is chair of the VKC UCEDD Community Advisory Council.

**Wendy Stone**, Ph.D., professor of pediatrics and psychology, director of TRIAD and the Marino Autism Research Institute, was **co-creator** of the **Autism Speaks 100 Day Kit** to assist parents during the 100 days following a diagnosis of autism.

**Karen Summar**, M.D., M.S.C.I., has been **named director** of the **Vanderbilt Down Syndrome Clinic**.



Mark Wallace, Ph.D.

**Mark Wallace**, Ph.D., associate professor of hearing & speech sciences and psychology, has been **named director** of the **Vanderbilt Brain Institute**.

**Carol Westlake** received the **Justice for All Disability Rights Award** from the American Association of

People with Disabilities in Washington, D.C., on July 23. Westlake is Executive Director of the Tennessee Disability Coalition, a VKC Community Partner.

**Lain York**, local artist, director of Zeitgeist Gallery, preparator of exhibitions at the VKC, was recognized as the **2008 Distinguished Artist and Outstanding Arts Advocate** at the **Watkins College of Art 2008 Founder's Day dinner** April 26. ●

# Siblings—Life's Longest Friendship By Ashley Coulter

**“W**here there’s a will, there’s a way.” This is a saying I grew up hearing, because it’s a saying that my family always associated with my brother Will.

When I was 4 years old, our family had a new addition—my little brother! At that young age, I didn’t realize that he was born 11 weeks too early. I recall having to shake him whenever his monitor started beeping to ensure that he was breathing. I remember having to go to all of the therapies during the summertime, in the hope that they would allow Will some independence. Though I have these memories that most siblings do not, I also have memories of telling each other secrets, watching movies together, going to our favorite restaurants, and making up games to play—the “typical games” of siblings during childhood.

My brother has been a straight-A student. He enjoys music, computers, baseball, bowling, and oh yeah, he has cerebral palsy. He also has more determination than anyone I know and an outlook on life that I truly believe we all should adopt.

At age 2, Will already had some goals. He wanted to walk, which became a focus in his physical therapy sessions. More recently, he decided he wanted to walk at his high school graduation. As his sister and his friend, I could not have been prouder than the moment I saw an entire arena full of people on their feet and clapping for my brother as he walked across the stage to receive his high school diploma, which included recognition as a member of the National Honor Society. I show the video of this accomplishment as often as I possibly can because I think Will is such an inspirational individual.

When I was a freshman at Auburn University, I decided I wanted to work with people with disabilities. As we learned about the services that exist in different communities, I thought that there needed to be a single point of entry where families learn where they need to go next. I graduated with a degree in Rehabilitation and Disability Studies and soon thereafter began working at Tennessee Disability Pathfinder, which provides statewide information and referrals to people with disabilities, family members, service providers, and advocates. It is truly amazing that I am where I am today.

I know that there are many other adult brothers and sisters of individuals with disabilities who have had similar experiences and who are so proud of what their siblings have accomplished. Thanks to Don Meyer, director of the Sibling Support Project and creator of SibShops, light is being shed on these important relationships. Research tells us that there are many

“common traits” of siblings of people with disabilities, or “sibs.” These traits, both positive and negative, include patience, maturity, appreciation, empathy, favoring vocations in the helping professions, jealousy, embarrassment, anger, grief, anxiety, and isolation. Meyer states, “The sibling relationship is deeply significant and is the longest-lasting bond we will likely ever have,” yet most

siblings do not have a support system in place to deal with the challenges they face.

As a sibling myself, I believe that there need to be groups where sibs can come together and talk about all of the emotions, both good and bad, associated with having a sibling with a disability, which is exactly what SibShops provide. I was trained to be a facilitator and now am the Lead Facilitator for the SibSaturday program at the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (VKC UCEDD). As I discovered more about the research surrounding sibling issues, I learned about the Sibling Leadership Network, which was organizing a conference to discuss and to develop policy papers about sibling issues.

In November 2007, over 80 siblings, advocates, funders, and other professionals convened in Washington, D.C., to discuss services and supports, research, and public policy. From these discussions, and continued meetings over the next year, three policy papers resulted. “Their ultimate goal is to create opportunities for siblings to partner with government and service providers to ensure the highest quality of life, now and in the future, for their entire families,” said Tamar Heller, Ph.D., of the University of Illinois-Chicago.

After attending this meeting, several parties were interested in starting a Tennessee adult sibling group. A Sibling Work Group at the VKC UCEDD is meeting monthly to plan and take “next steps.” Working with collaborators across Tennessee, the first statewide sibling conference will be held in April 2009.

I’m trying to do all I can at this point in my life to be as prepared as possible down the line for any responsibility I may take on in coordinating care for Will. My dream for Will is for him to have a job he enjoys—he is currently taking online courses resulting in a Microsoft Engineer Certification—to live independently, and to just live life to the fullest. Knowledge and support is power, in my book, and each day I hope to learn a little bit more so I can help him fulfill his dreams. ●

Ashley Coulter is Program Coordinator for Community Outreach and Training, Tennessee Disability Pathfinder. This article first appeared in *Breaking Ground*, No. 42, May 2008, newsletter of the Tennessee Council on Developmental Disabilities, a VKC Community Partner.

See inset for quotations from siblings from the VKC Tennessee Sibling Study, conducted by Ann Kaiser, Ph.D., professor of special education, and Ann Morse, funded by the Tennessee Council on Developmental Disabilities.



CANDIE FERRELL

Will Ferrell and Ashley Coulter

*I love my sister dearly. She has helped me grow and learn so much about her world and the people in it. I have an open mind and a desire to help those in need because of my relationship with her. I am very fond of her and have always been very protective of her, even through sibling rivalry.*

\*\*\*\*\*

*I never thought much about it...my brother was treated as much like the rest of us as was possible...he played with us, went places with us on our bikes, he followed us around like little brothers do; he went to special ed classes in school, he did chores around the house that he could, we had fights just like all the rest; he was happy, he'd get mad; he was just another brother but a little special.*

\*\*\*\*\*

*My sister is my favorite person in the world. I call her when I need a lift in my day, and she calls me when something sad or scary happens (like a thunderstorm) or something exciting (like a fire drill at school). Basically, it's just like any sister relationship.*



# Tennessee Adult Brothers and Sisters

By Courtney Taylor



VANDERBILT KENNEDY CENTER  
FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES

Tennessee Adult Brothers and Sisters (TABS) is a newly established group for adult siblings of individuals with disabilities. The TABS founding meeting was held following sessions of the Sixth Annual Tennessee Disability MegaConference in May 2008, and it drew 10 siblings who were eager to take part. Since then, Ashley Coulter, program coordinator for community outreach and training at Tennessee Disability Pathfinder, TABS founder, and an adult sibling herself, reports that 61 adult siblings have expressed an interest in TABS and that she continues to receive inquiries daily via the TABS webpage.

"Establishing TABS is an important step," says Coulter. "The need for support does not go away just because you get older. Sibling support programs exist for younger people, but before



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TABS, there has been nothing in Tennessee to provide an outlet of support for adult siblings of individuals with disabilities. We have a lot of programming ideas."

## Tennessee Adult Sibling Conference

A conference for adult siblings in Tennessee will be held April 3-4, 2009, in Nashville, and planning is well under way. A committee is

considering conference topics such as futures planning/conservatorship, caring for the caregiver, family support, research, legislation and advocacy, and family dynamics/relationships.

"At the first TABS meeting, we asked siblings what topics were most important to them," said Coulter. "Having this list of topics of interest will enable us to create a conference program that meets direct needs. In fact, almost everyone who attended that initial meeting is on the conference planning committee. It is an

amazing thing to be surrounded by organizers who 'get it.'"

For TABS information, contact Ashley Coulter at (615) 322-8529 x15, or email [ashley.coulter@vanderbilt.edu](mailto:ashley.coulter@vanderbilt.edu).

Visit the TABS webpage and register to receive updates on TABS activities: [kc.vanderbilt.edu/kennedy/community/adultsiblings.html](http://kc.vanderbilt.edu/kennedy/community/adultsiblings.html). ●

# Sibling Leadership Network

By Courtney Taylor

Historically, little attention has been given to research on the concerns of siblings who have a brother or a sister with a disability. Fortunately, this trend has shifted and more research, supports, and policies are now being considered with sibling issues in mind. The Sibling Leadership Network (SLN), established in 2007, consists of siblings, researchers, service providers, and policymakers across the nation who are intent upon being at the forefront of addressing issues that affect siblings and their families.

The SLN mission is "to promote a broad network of siblings who share the experience of disability and people concerned with sibling issues by connecting them to social, emotional, governmental, and provisional supports across the lifespan enabling them to be effective advocates with their brothers and sisters, to serve as change agents for themselves and for their families."

The first meeting of the SLN convened for 2 days in Washington, D.C., in November 2007, with more than 80 people in attendance. The Vanderbilt Kennedy Center was a co-sponsor. Representing the VKC were Ann Kaiser, Ph.D., Susan Gray Chair in Education and Human Development, professor of special education, a VKC investigator, and co-director of the National Sibling Research Consortium; and Ashley Coulter, program coordinator for community outreach and training at Tennessee Disability Pathfinder.

Presentations addressed: Reviewing and Ratifying the Mission, Purpose, and Values of the

SLN; Sibling Issues Across the Lifespan; Future Planning Issues; Federal Agency Perspectives on Research; an International Roundtable; and Leaders' Perspectives on Policy. Participants met in three work groups to identify action steps and to develop "white papers" on the topics of sibling policy, sibling research, and sibling services and supports.

"An example of an issue the policy group is working on is that, currently, siblings are not specifically mentioned in the federal Developmental Disabilities Act," said Coulter. "The SLN is arguing that the term 'family' needs to be expanded to include 'siblings' and that funding needs to be provided for sibling programs."

## Second National SLN Meeting

In November 2008, the 2nd Annual Meeting of the SLN will be held in Columbus, Ohio. The meeting includes presentations by Jeff and Cindy Daly, creators of the documentary *Where's Molly?*; Stan Klein, disability policy advisor to Barack Obama; Michael Wehmeyer, on sibs and self-determination; and others, including Tom Fish, Don Meyer, Tamar Heller, Emily Marino, Cathy Allen, and Katie Keiling. The VKC continues to be a co-sponsor.

To view the 2008 conference program, visit [www.siblingsupport.org](http://www.siblingsupport.org). For more information on VKC sibling programs and research, visit [kc.vanderbilt.edu/kennedy/community/sibsprograms.html](http://kc.vanderbilt.edu/kennedy/community/sibsprograms.html). ●

# Think Globally

from page 3

adult Down Syndrome Clinics are providing specialized care. Vanderbilt is a national leader in areas such as imaging research, genetics, and brain science, all of which are central in the NIH Research Plan.

Finally, Dykens stressed the need for researchers to include those with Down syndrome in their research. Since her own area of research involves psychological strengths and problems in persons with genetic syndromes, she illustrated the point by looking at publications related to women and depression. From 2005 to 2007, there were 703 articles on women and depression; for the same period, only 4 articles on women with disabilities and depression. "These are missed opportunities for better understanding depression in women with Down syndrome or other developmental disabilities," she said.

"We need to recruit faculty with Down syndrome research agendas," she said, "but we also must encourage our colleagues to include those with Down syndrome in their research. We must lead the way in national registry development. We must think globally—but act locally."

NIH Research Plan for Down Syndrome—see [www.nichd.nih.gov/publications/pubs/upload/NIH\\_Downsndrome\\_plan.pdf](http://www.nichd.nih.gov/publications/pubs/upload/NIH_Downsndrome_plan.pdf) ●

## Spotlight

# Steadfast Commitment

**SISSY ALLEN**

By Courtney Taylor

"I knew I wanted to be a part of the Vanderbilt Kennedy Center at my first Leadership Council meeting. As I sat listening to Dr. Pat Levitt speak on the many details of the autism spectrum and where we were with research, his knowledge just absolutely fascinated me," said Sissy Allen, Relocation Director for Fridrich & Clark Realty and Leadership Council member for 5 years. "I knew that day I wanted to join the Vanderbilt Kennedy Center Leadership Council and wanted to play a part in making a difference."

Allen serves on the Leadership Council's Outreach Committee and last year was the co-chair of the Hobbs Society Dinner to Discovery.

"Co-chairing the Hobbs Dinner was a wonderful learning experience," said Allen. "I had the honor and pleasure of co-chairing with the highly professional Barbara Gregg Phillips, and was kept afloat day-to-day by the incredible wit and talent of 'Doc' McLaughlin, better known as BethAnn. I learned very quickly what BethAnn had in mind for Barbara and me. She wanted us to bring in new Hobbs Society members, to generate donations for



*Sissy Allen*

future grants, and to serve something chocolate as the event dessert. As long as we accomplished those three goals, we were in pretty good shape!" Allen was raised in Nashville, attended Julia Green and Parmer Elementary Schools, St. Cecilia Academy, and George Peabody College, majoring in Business Education. She has a son, Tommy, a rising freshman at Franklin High School. She also has two step-daughters from a previous marriage, Katie, a registered nurse at Vanderbilt University Medical Center, and Mary, who will graduate from Auburn University this year with a fashion design degree and a promise from a New York designer for future work.

Allen stays busy with her family, her work, and her volunteer activities. She spent 4 years on the Board of CABLE, an organization connecting women with opportunity and working to increase the number of women serving on corporate boards. For several years she was co-chair of both the Membership and the Logistics Committees and presently is in her 8th year role as the Banquet Chair for the YWCA's upcoming Academy of Women of Achievement.

Though Dr. Levitt's speech affirmed for Allen that she wanted to serve on the Leadership Council, it was being witness to the many challenges that her sister faced having three boys with disabilities that drew her

to the mission of the Center in the first place.

"I have three nephews who have each been affected by ADD [Attention Deficit Disorder] or ADHD [Attention Deficit Hyperactivity Disorder]," said Allen. "Luckily for them, their mom, my sister, graduated from the University of Alabama with a degree in Special Education. Having this educational background certainly proved helpful. I am proud to say the boys are doing remarkably well now, but have certainly had their fair share of struggles along the way within the private and public school system. It is important for me to be here, involved on behalf of my family as well as the Vanderbilt Kennedy Center."

When Allen is not at the Center or at work assisting professionals in relocating to Nashville, she is at the baseball field watching her son play baseball. She also makes time for gardening, which she finds most therapeutic, and dabbles in antiques when time allows.

"I love to go antiques," said Allen. "I wouldn't consider myself to be a great decorator, but I really enjoy pretty things and making things look nice."

It is Allen's steadfast commitment to the Vanderbilt Kennedy Center and her generous and warm encouragement that make her such a welcome presence.

"I am so proud to be a part of this talented organization," said Allen. "I honestly feel the Vanderbilt Kennedy Center holds now, and in the future, the key to research and programming that will shape the future for families affected by disabilities. The day will come when I look back and can proudly say that I played a very small part in the success of this wonderful organization." ●

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Every effort has been made to ensure the accuracy of this report, which reflects Honor and Memorial gifts **May 15-August 28, 2008**. If an error has been made, we offer our sincerest apology and ask that you bring it to our attention by contacting (615) 343-5322. ●

# Campers Unpack Meaning from Art Trunks By Courtney Taylor

Adolescents and young adults who attended Camp Shriver Transitions and Sports Camp and TRIAD Social Skills Camp this summer were exposed to art in unique and meaningful ways thanks to programming provided by the Frist Center for the Visual Arts, a Vanderbilt Kennedy Center Community Partner. Andee Rudloff, educator for outreach at the Frist, brought a three-session program called an "Art Trunk" to Vanderbilt Kennedy Center campers.

"I developed a special workshop for Camp Shriver and for the teens in the TRIAD camp based on our *Color as Field* exhibition," said Rudloff. "The first week we studied and painted shapes and discussed two-dimensional composition relationships. The second week we focused on color. Using paint, we mixed colors and discussed complementary colors and color theory. The final week, campers visited the exhibition in the morning. In the afternoon, each camper completed a 3-by-5 painting based on shape, color, and their experience in seeing the work of the *Color as Field* artists."

According to Rudloff and the mission of the Frist educational outreach programs, Art Trunks are "educational kits" that "provide unique opportunities for participants to become more informed about works of art, their meanings, and the artists who created them." Participation in an Art Trunk encourages "a higher level of



DANIEL DUBOIS  
Andee Rudloff of the Frist Center teaches campers about color and painting.

understanding and appreciation of art by allowing participants to look at historical influences on the artwork and the artists, by investigating the concepts of value and beauty as related to art, and by the production of a piece of artwork in order to better understand the process of creation."

Gretchen Herbert, Vanderbilt Kennedy Center Arts and Recreation coordinator, said campers were thrilled to participate in the Art Trunk and were enthusiastic about asking questions and driving conversations.

"The program really helped campers understand what they see when they look at a work of art," said Herbert. "The process allowed them to use their critical analysis skills and their creativity to express their own unique understandings. I have to say that

the campers absolutely loved participating in the Art Trunks and looked forward to it every week."

Adolescent campers in the TRIAD Social Skills Camp participated in a separate Art Trunk based on the Frist exhibition, *The Artist's Voice: An Exhibition of Tennessee Artists with Disabilities*. Approximately 40 works by adult artists with disabilities are showcased in the exhibit. The painting "Angel of Hope" by Anne Ambrose, an artist who has shown her work in many Vanderbilt Kennedy Center exhibits, was selected and studied by the younger campers.

"Both the younger and the older campers were ready to take risks with the medium of painting," said Rudloff. "They demonstrated a comfort with the subject and with the materials. I loved hearing their perspectives, and their creativity is encouraging and inspiring. I think the Art Trunk program offered just enough structure, exposing them to possibly unfamiliar artists and art styles, to give the campers ownership of the process and the material."

A Vanderbilt Kennedy Center exhibition of the artwork created by the young adult artists/campers is being planned for 2009. For information on VKC Art and Recreation activities, contact [gretchen.herbert@vanderbilt.edu](mailto:gretchen.herbert@vanderbilt.edu), (615) 322-8529 x3. For more on the Frist Center's Art Trunk, contact [arudloff@Fristcenter.org](mailto:arudloff@Fristcenter.org), (615) 744-3254. ●

## Borders Books Benefit Helps VKC Reading Clinic

Thanks to Borders Books, book (and music) lovers were able to use a Borders 10% discount coupon to purchase items at Borders Books at 2501 West End Avenue on September 12-13. The Vanderbilt Kennedy Reading Clinic received 10% of the profits generated from the coupons to help support scholarships for struggling readers tutored at the Reading Clinic (615-936-5123). Thank you, Reading Clinic supporters, and thank you, Borders Books!

To donate to the Reading Clinic or other Vanderbilt Kennedy Center programs, contact Laura McLeod ([laura.mcleod@vanderbilt.edu](mailto:laura.mcleod@vanderbilt.edu)), (615) 343-5322.



LAURA MCLEOD  
Liane Proctor, Corporate & Educational Specialist, and Randy Schiller, General Manager, Borders Books

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## TN Disability Pathfinder

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[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)

### Disability Calendar

Internet calendar of training and other  
disability-related events

[kc.vanderbilt.edu/tnpathfinder/calendar.html](http://kc.vanderbilt.edu/tnpathfinder/calendar.html)

### Statewide Directory

*2007-2008 Disability Services and Supports*  
West, Middle, and East Tennessee volumes  
\$25 per directory  
Contact (615) 322-8529 ext. 15  
[ashley.coulter@vanderbilt.edu](mailto:ashley.coulter@vanderbilt.edu)

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Karoly Mirnics, M.D., Developmental Neurobiology & Plasticity  
Stephen Camarata, Ph.D., Communication & Learning  
Elisabeth Dykens, Ph.D., Mood & Emotion  
Ann Kaiser, Ph.D., & Robert Hodapp, Ph.D., Families  
Wendy Stone, Ph.D., Autism Spectrum Disorders (TRIAD)*

### UCEDD

*Elisabeth Dykens, Ph.D., Director  
Elise McMillan, J.D., Co-Director; Services  
Terri Urbano, Ph.D., Training  
Robert Hodapp, Ph.D., Research  
Jan Rosemergy, Ph.D., Dissemination*

### Discovery

*Editor/Writer: Jan Rosemergy, Ph.D.  
Writer: Courtney Taylor  
Graphic Designer: Melanie Bridges, B.F.A.*

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## Calendar of Events

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].

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

### Ann and Monroe Carell Jr. Families First

Free workshops serving parents of children, ages 2-5, diagnosed with an autism spectrum disorder. Held in Room 241 Vanderbilt Kennedy Center/MRL Building  
Information (615) 343-4275  
[familiesfirst@vanderbilt.edu](mailto:familiesfirst@vanderbilt.edu)  
Registration [kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration)

#### Free monthly Saturday workshops

10:15 a.m.-2 p.m.

Orientation session 8:30-10 a.m. on all dates.

**NOVEMBER 15 + 2009 dates to be announced**

**Addressing Challenging Behaviors**

**DECEMBER 6 + 2009 dates to be announced**

**Improving Communication**

**2009 dates to be announced**

**Enhancing Social Interactions**

Advance registration required:  
[www.kc.vanderbilt.edu/registration](http://www.kc.vanderbilt.edu/registration)  
Information (615) 322-8529 x11  
Knowles Senior Center, 174 Raines Avenue  
Wednesday 8:30 a.m.-2 p.m.

### December

#### DECEMBER 3

**Developmental Disabilities Grand Rounds  
Multisensory Processing and Its Possible Role  
in Developmental Disabilities**

**Mark Wallace**, Ph.D., Associate Professor of Hearing & Speech Sciences and Psychology; Director, Vanderbilt Brain Institute  
Co-Sponsor VKC Interdisciplinary Training Council and Pediatrics  
Light breakfast provided  
Wednesday 8 a.m. Room 241  
Vanderbilt Kennedy Center/MRL Building

#### DECEMBER 12

**Community Advisory Council Meeting**

For details contact (615) 936-5118

### November

#### NOVEMBER 5

**Developmental Disabilities Grand Rounds  
Plasticity of the Nervous System After  
Sensory Loss**

**Jon Kaas**, Ph.D., Distinguished Professor of Psychology, Professor of Cell & Developmental Biology

Co-Sponsor VKC Interdisciplinary Training Council and Pediatrics

Light breakfast provided

Wednesday 8 a.m. Room 241

Vanderbilt Kennedy Center/MRL Building

#### NOVEMBER 11

**Vanderbilt Kennedy Center Leadership Dinner**

Tuesday 6:30-9 p.m. Loews Vanderbilt Hotel  
Table Sponsorships—Contact [kc@vanderbilt.edu](mailto:kc@vanderbilt.edu) (615) 343-5322

Proceeds support Nicholas Hobbs Discovery Grants

#### NOVEMBER 12

**4th Annual Disability Services and the  
Hispanic Community Conference**

Co-sponsors Tennessee Disability Pathfinder and Tennessee Council on Developmental Disabilities  
\$20 fee to cover lunch and workshop expenses

### January

#### JANUARY 19

**Lectures on Development and  
Developmental Disabilities  
Martin Luther King Jr. Commemorative Lecture  
Making Progress Happen for People with  
Disabilities—Past, Present, and Future**

**Robert (Bobby) Silverstein**, J.D., Director, Center for the Study and Advancement of Disability Policy; Principal, Powers Pyles Sutter & Verville, P.C.

Monday 4:10 p.m. Room 241

Vanderbilt Kennedy Center/MRL Building

#### JANUARY 21

**Developmental Disabilities Grand Rounds  
Trace Elements in Parenteral Nutrition: Trace  
Evidence for Nutritional Practices in the NICU**

**Judy Aschner**, M.D., Professor of Pediatrics; Director, Division of Neonatology  
Co-Sponsor VKC Interdisciplinary Training Council and Pediatrics

Light breakfast provided

Wednesday 8 a.m. Room 241

Vanderbilt Kennedy Center/MRL Building

#### JANUARY 21

**Neuroscience Graduate Seminar Series  
Synaptic Circuit Organization of Mouse  
Motor/Frontal Cortex**

**Gordon Shepherd**, M.D., Ph.D., Assistant Professor of Physiology, Northwestern University  
Co-Sponsor Vanderbilt Brain Institute

Wednesday 4:10 p.m. Room 1220

MRB III Lecture Hall

#### JANUARY 29

**Vanderbilt Kennedy Center Science Day**

Wednesday 8:30 a.m.-4 p.m.

Vanderbilt Student Life Center

**Keynote Speaker: Paul Yoder**, Ph.D., Professor of Special Education

**Trainee Presenter: Tricia Thornton-Wells**, Ph.D., Postdoctoral Fellow

Posters by Vanderbilt students, trainees, postdoctoral fellows

Poster prizes in 3 theme areas: Clinical, Behavioral, and Intervention Research; Cellular and Molecular Neuroscience; Systems Neuroscience

Poster abstracts accepted beginning October 7, due November 7

Register to attend and/or to submit poster abstracts: [kc.vanderbilt.edu/kennedy/scienceday/index.html](http://kc.vanderbilt.edu/kennedy/scienceday/index.html)

### February

#### FEBRUARY 4

**Developmental Disabilities Grand Rounds  
Baby Einsteins Everywhere: Young Children  
and Video**

**Georgene Troseth**, Ph.D., Associate Professor of Psychology

Co-Sponsor VKC Interdisciplinary Training Council and Pediatrics

Light breakfast provided

Wednesday 8 a.m. Room 241

Vanderbilt Kennedy Center/MRL Building

#### FEBRUARY 4

**Neuroscience Graduate Seminar  
The Effects of Early Psychosocial Deprivation  
on Brain and Behavioral Development**

**Charles A. Nelson III**, Ph.D., Professor of Pediatrics, Harvard Medical School; Richard David Scott Chair in Pediatric Developmental Medicine Research, Children's Hospital, Boston  
Co-sponsor Vanderbilt Brain Institute

Wednesday 4:10 p.m. Room 1220

MRB III Lecture Hall



## FEBRUARY 11

### Neuroscience Graduate Seminar Using Gene-Knockout Mice to Study Aggression: A Cautionary Tale

Randy J. Nelson, Ph.D., Distinguished Professor of Social and Behavioral Sciences, Professor of Psychology and Neuroscience, The Ohio State University School of Medicine  
Co-sponsor Vanderbilt Brain Institute  
Wednesday 4:10 p.m. Room 1220  
MRB III Lecture Hall

## FEBRUARY 5

### Special Lecture on Disabilities, Religion, and Spirituality/Research Ethics Grand Rounds Where Personal, Professional, and Communal Ethics Meet: The Challenge and Promise of Inclusive Spiritual Supports With People With Developmental Disabilities and their Families

Rev. William C. Gaventa, M.Div., Director of Community and Congregational Supports, Associate Professor of Pediatrics, The Elizabeth M. Boggs Center on Developmental Disabilities, Robert Wood Johnson Medical School  
Thursday 4:10 p.m. Room 241  
Vanderbilt Kennedy Center/MRL Building

## FEBRUARY 19

### Lectures on Development and Developmental Disabilities Early Intervention, Brain Plasticity, and the Prevention of Autism

Geraldine Dawson, Ph.D., Research Professor of Psychiatry, University of North Carolina-Chapel Hill; Chief Science Officer, Autism Speaks  
Thursday 4:10 p.m. Room 241  
Vanderbilt Kennedy Center/MRL Building

## FEBRUARY 26

### Special Lecture Future Affective Technologies and Applications to Autism

Rosalind W. Picard, Sc.D., FIEEE, Director of Affective Computing Research, Co-Director of Things That Think, Professor of Media Arts and Sciences, M.I.T. Media Laboratory  
Thursday 4:10 p.m. Room 241  
Vanderbilt Kennedy Center/MRL Building

## TRIAD School-Age Services

With the TN Department of Education, TRIAD offers free autism-specific workshops for parents, school personnel, and the community. These events are held in different locations across the state.

Information and registration, contact Linda.Copas@state.tn.us, (615) 741-7790. See also [tennessee.gov/education/speced/seannounce.shtml](http://tennessee.gov/education/speced/seannounce.shtml)



DANIEL DUBOIS

A Frist Center Art Trunk activity at the 2008 Camp Shriver Transitions and Sports Camp

## NOVEMBER 5-6

Para-Educator Workshop (Knoxville)

## NOVEMBER 7

Parent Workshop (Knoxville)

## NOVEMBER 19-21

TRIAD Teacher Training: Basic K-6  
(Murfreesboro)

## DECEMBER 2-5

Winter Institute on Integrating Different  
Methodologies (Nashville)

## JANUARY 14-16

TRIAD Teacher Training: Advanced K-12  
(Nashville)

## FEBRUARY 18-20

TRIAD Teacher Training: Basic K-6  
(Murfreesboro)

## FEBRUARY 27

Workshop for Special Educators and Parents  
(Knoxville)

## Arts & Disabilities

### Vanderbilt Kennedy Center Exhibits

Monday-Friday 7:30 a.m.-5:30 p.m., Lobby  
Vanderbilt Kennedy Center/MRL Building  
For information contact (615) 322-8529 ext. 3

## OCTOBER 10, 2008-JANUARY 16, 2009

### Creative Expressions XIV

A collaborative exhibition between the Vanderbilt Kennedy Center and the Mayor's Advisory Committee for People with Disabilities

## JANUARY 30-MARCH 27, 2009

### EXPRESSIONS THROUGH COLOR: CAMP SHRIVER 2008

## Behavior Analysis Clinic

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

## SibSaturdays

### OCTOBER 11, DECEMBER 13

A Vanderbilt Kennedy Center for Excellence in Developmental Disabilities program for siblings of children with special needs, ages 5-7 and 8-13 years

Games, friends, conversation

\$10/child or \$20/family

Financial assistance available

Advance registration required

Contact (615) 936-5118

[roxanne.carreon@vanderbilt.edu](mailto:roxanne.carreon@vanderbilt.edu)

Saturdays Room 241

Kennedy Center/MRL Building

SibSaturdays also are organized by the Autism Society of Middle Tennessee, (615) 385-2077, and by the Down Syndrome Association of Middle Tennessee, (615) 386-9002

## 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)

## Journeys in Disabilities

### Information and Support for Families

Free and open to the community, this new 2-hour orientation session provides support for families affected by all forms of disability. Covers important terms, definitions, relevant laws; people-first language and civil rights issues; sources of information/support. Experienced parent presenter discusses choices that lead to positive outcomes. Spring dates to be announced. Information (615) 936-8852.