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## Discovery

### Carell Gift Helps Families Challenged by Autism

By Courtney Taylor and Jan Rosemergy



The Carell family name is virtually synonymous with caring about children and families. Now they are caring for children and families affected by autism spectrum disorders. Thanks to their generous gift, the Ann and Monroe Carell Jr. Families First Program—a series of workshops offered at no cost to families—began in March.

“We are enormously grateful to Ann and Monroe Carell for this gift that is enabling TRIAD to provide specialized training for parents that will help them to enhance their child’s development and their family life,” said Wendy Stone, Ph.D., TRIAD director. “Susan Gray, a founder of the Vanderbilt Kennedy Center, was well-known for recognizing that ‘parents are a child’s first teachers.’ Parents know their child best and spend more time with their young child than anyone else. Parents of young children with autism are eager for reliable information, and to connect with other parents. The Carell gift is a gift for every parent and family who will be touched by Families First.”

Families First serves parents of children, ages 2-5, who have an autism spectrum disorder (ASD). The workshops provide specific instruction and skills to parents, focusing on enhancing social and communication skills as well as on managing challenging behaviors.

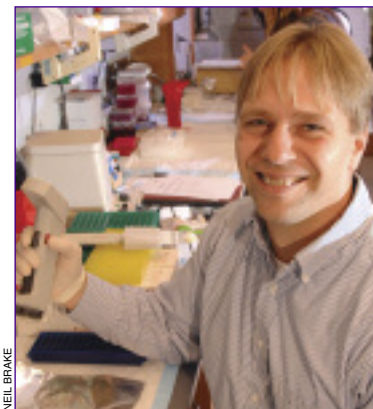
“No one has a greater love or affection for a child than the parents of that child,” said Mr. Carell. “We need to provide every possible source of help and information for those loving parents, since they are the best method of communicating with their children. I am hopeful that this program will provide parents some help and

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### Genetics and Schizophrenia Treatment

By Craig Boerner

A major obstacle for patients prescribed antipsychotic medications to treat schizophrenia is the trial-and-error process of pinpointing which drug will work best. It can take months, even years, of dealing with unwanted side effects—which can cause some patients to drop off their medications. Now, Vanderbilt Kennedy Center (VKC) researchers are using genetic links to predict the effectiveness of these drugs. Their findings were detailed in a multicenter study published in the January issue of *Biological Psychiatry*.



Research by Daniel Campbell, Ph.D., and others may one day help individualize treatment for schizophrenia.

“We found that these [RGS4] genetic variants predict how well individuals with schizophrenia react to a certain type of drug,” said Daniel Campbell, Ph.D., research assistant professor of pharmacology and lead author of the study. “Currently, individuals with schizophrenia are

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### Director’s Message

#### Dogged Pursuit of a Dream—Eunice Kennedy Shriver



Pat Levitt, Ph.D.

Our government recently made an unprecedented decision to rename the National Institute of Child Health and Human Development (NICHD) in honor of Eunice Kennedy Shriver. The National Institutes of Health (NIH) has 27 institutes and centers, and while programs within institutes have been named to recognize the critical contributions of an individual, NICHD is the very first institute to achieve such status. This decision speaks to the impact that Mrs. Shriver has had for almost

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## Carell Gift *from page 1*

confidence in working with that youngster whom they love so deeply.”

The series is sponsored by the Monroe Carell Jr. Children’s Hospital at Vanderbilt and the Vanderbilt Kennedy Treatment and Research Institute for Autism Spectrum Disorders (TRIAD).

“Negotiating educational and intervention service systems can be quite difficult, if not overwhelming, for families with young children recently diagnosed with an autism spectrum disorder,” said Zachary Warren, Ph.D., clinical assistant professor of psychiatry and director of the TRIAD Parent Support and Education Program. “The Families First program is designed to arm parents with information and concrete skills for enhancing their child’s behavior in the core areas of ASD vulnerability. The program recognizes that parents are the experts when it comes to their own children. Through it, parents desiring help for their child with an ASD will have a way to get that help.”

Parents are encouraged to attend an introductory workshop, “Working With and Developing Goals for Young Children with Autism.” This introductory session (8:30-10 a.m.) runs prior to each workshop session and allows parents to begin their participation at any point during the series.

The introductory session is followed by morning (10:15-11:45 a.m.) and afternoon (12:30 – 2 p.m.) workshops. Topics include: improving communication and play, engaging your child in social interactions, simplifying daily routines, understanding the basics of problem behavior, and addressing challenging behaviors.

During lunch, which is provided, leading clinicians, researchers, and advocates from Vanderbilt University and the surrounding community will speak on the most pressing issues and topics for families of children with autism. Lunch also will give families an



COURTESY OF MONROE CARELL, JR., CHILDREN'S HOSPITAL AT VANDERBILT

Monroe Carell, Jr.

opportunity to connect with other families who are facing similar issues.

The monthly workshops take place at the Vanderbilt Kennedy Center on selected Saturdays, which began March 15 and will conclude December 6. Registration is required.

In addition to Warren, the Families First leadership team includes Lisa Wallace, M.S., CCC-SLP, TRIAD speech pathologist; and Wendy Stone, Ph.D., professor of pediatrics and psychology, and director of TRIAD and the Marino Autism Research Institute.

For information or to register, contact [familiesfirst@vanderbilt.edu](mailto:familiesfirst@vanderbilt.edu), (615) 343-4275.

Monroe Carell and his wife, Ann, provided the lead gift and led the successful fundraising efforts that helped build the new Monroe Carell

Jr. Children’s Hospital at Vanderbilt. The Carells have dedicated their philanthropy to causes and purposes for children.

As a Vanderbilt University graduate, Carell has spent much of his time giving back to the Vanderbilt community. He currently chairs the *Shape the Future* Campaign, the most ambitious, comprehensive campaign in Vanderbilt’s history. Under Carell’s leadership, the original \$1.25 billion goal was surpassed 2 years ahead of schedule. Anticipating the Campaign’s success, he recommended to the Board of Trust that the goal be increased to \$1.75 billion, which the Trustees approved. In November 2007, Carell recommended the Campaign’s bequest goal be raised from \$100 million to \$150 million before December 2010, which the Board of Trust also approved. The *Shape the Future* Campaign will continue through December 2010.

Carell is a long-time member and past chair of the Children’s Hospital Board of Directors, and he is a member of the Vanderbilt Board of Trust.

The Carells are passionate supporters of undergraduate scholarships at Vanderbilt, and their scholarships currently support eight students on campus. Additionally, the Carells provide financial aid to students in a number of universities and K-12 schools in many cities.

Carell is the founder and former CEO and Executive Chairman of Central Parking Corporation. He sold his interests in the company in June 2007.

The gift to found the Families First program is the Carell family’s third major gift to the Vanderbilt Kennedy Center. Their 2006 gift to the TRIAD Parent Support and Education Program enabled the Center’s autism specialists to help more families of young children with autism. Their 2007 gift for the Ann and Monroe Carell Preterm Care and Diagnosis Discovery Grant is supporting research on biomarkers of preterm birth being conducted by Patricia Temple, M.D., M.P.H., professor of pediatrics. ●

## Social Work and Baptist Healing Trust *By Courtney Taylor*

**F**or many families with a child who has a newly diagnosed disability, navigating disability services and supports can be an overwhelming task. To make connecting with supports a little easier, the Vanderbilt Kennedy University Center for Excellence in Developmental Disabilities (VKC UCEDD)—thanks to a 1-year grant from the Baptist Healing Trust—has expanded social work support for families with children, birth to 12, with a diagnosed genetic syndrome. The grant allows the VKC UCEDD social worker and social work intern to do three follow-up visits with 50 families who receive services from several clinics of the Monroe Carell Jr. Children’s Hospital at Vanderbilt.

Currently, social workers administer psychosocial assessments, provide brief and general

counseling, and offer information and referral services during the clinic visit. Checking with families at 2 weeks, 6 weeks, and 3 months to see how they are coping and/or if they have encountered barriers to connecting with services should allow social workers to discern where Tennessee families need the most help.

“We will explore how the clinic visit went and try to gain a sense of how the family is functioning since receiving a new diagnosis,” said Carol Rabideau, L.C.S.W., VKC social worker.

While one goal of the program is to empower and strengthen families, another goal is to build skills in future generations of social workers by giving them experience in working with families with disabilities. The grant will

support direct training of two social work interns from the University of Tennessee School of Social Work and will allow Rabideau to share findings and collaborate with other social workers across Tennessee, including those at the University of Tennessee Boling Center for Developmental Disabilities, also a Tennessee UCEDD.

“What we learn from families about the importance and timing of follow-up will help us better train and inform other social workers and professionals supporting families,” said Rabideau. “Though this is not a research project, the data we collect should allow us to see where the gaps are in disability supports in Tennessee and should have public policy implications.” ●

## Genetics and Schizophrenia from page 1

given antipsychotic drugs, and the effectiveness of those drugs is unpredictable. Sometimes the chosen drug works, sometimes it doesn't, and sometimes it has bad side effects."

Researchers from Vanderbilt, University of North Carolina, Columbia University, and Stockholm's Karolinska Institutet applied genetic analysis to the National Institute of Mental Health (NIMH)-funded Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) in doing the study. The NIMH trial gave different antipsychotic drugs to more than 1,000 people with schizophrenia and studied how well they reacted. The new study used DNA samples from those same individuals to look at their genotypes in the RGS4 gene.

Campbell, Pat Levitt, Ph.D., Annette Schaffer Eskind Chair and professor of pharmacology, and

Philip Ebert, Ph.D., research assistant professor of pharmacology, reviewed data from 678 individuals with schizophrenia who participated in CATIE. Among the 678 subjects, the inferred ancestries were 29% "Africa only," 59% "Europe only," and 12% "Other."

An interesting finding of their research is that the genotype at the RGS4 gene predicted different effectiveness of the five antipsychotic medications studied between persons of African and European ancestry.

"Our long-term goal was always to see whether we could use these results to inform better treatment regimens for patients," said Levitt. "We were thrilled that our exploratory analysis revealed that there is some predictive value to the RGS4 genetic variants when we look at response to antipsychotic drug treatment in patients of African and European descents. This is a first successful step in realizing the hope of individualized care in psychiatry," Levitt said.

Campbell said the results, if replicated, would

allow doctors to get a blood sample from a person with schizophrenia, genotype them at RGS4, and make a better prediction about which drug to use.

"If we look at people with schizophrenia who are of African descent and have a particular genotype for RGS4, our data show that you really don't want to give these patients a drug called ziprasidone, because they won't stay on the drug very long, they will stop taking it, and while they are on it their symptoms may actually get worse," Campbell said. "For the same RGS4 genotype, ziprasidone doesn't look like it is any better or any worse than any other drug for patients of European descent."

In 2000 Levitt's lab discovered, using gene microarray technology, that RGS4 was one of the most consistently altered genes in the frontal lobe of individuals with schizophrenia. That was followed by genetic studies, identifying variants in the RGS4 gene that showed association with schizophrenia. ●

## Director's Message from page 1

five decades on the lives of individuals with developmental disabilities and their families.

The Vanderbilt Kennedy Center was the second research center in the NICHD program of mental retardation and developmental disabilities research started through legislation led by President John F. Kennedy prior to his assassination. With our 2005 designation as a University Center for Excellence in Developmental Disabilities, the VKC has grown to reflect fully the goals that Mrs. Shriver pursued so vigorously to bring best practices through the most rigorous research on disabilities and child development, and to train, inform and serve professionals, community groups and families who work on the front lines daily.

I remain in awe of Mrs. Shriver, because at a time when society preferred to ignore, sometimes maltreat, and even hide

those who have special needs, she was unwavering in her belief that individuals with intellectual and other developmental disabilities have much to contribute to their families and to our local and national communities. Mrs. Shriver's founding of Special Olympics also speaks to the magnitude of her insight into developing the most creative ways of impacting the lives of individuals with intellectual and other developmental disabilities and their families.

Over the years, the research supported by the Eunice Kennedy Shriver National Institute of Child Health and Human Development has led to many seminal discoveries, including the role of nutrition in prenatal and child health, the

development of life-saving treatments for childhood infectious diseases, and the role of genes and environment in influencing the developmental process.

Many of these achievements occurred under the watchful eye of Dr. Duane Alexander, currently the longest standing director of any NIH institute or center. When Dr. Alexander visited the VKC for our 40<sup>th</sup> anniversary celebration, and when I saw him at our most recent Center Directors' meeting, I noted an emotional tone to his voice when speaking about Mrs. Shriver and her children, including Timothy Shriver, who has taken up the mantle of his mother as chair of Special Olympics. Dr. Alexander's comments assist my own difficulty in truly understanding the magnitude of the impact that Mrs. Shriver has had on maternal

and child health nationally and worldwide. That accomplishment alone would be remarkable, but Mrs. Shriver also has been unrelenting in raising our consciousness about the unlimited possibilities that people with developmental disabilities have for achievement.

There is nothing more to do than to thank Mrs. Shriver and her family, to embrace the honor of being one of fourteen Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Centers, and to be as dogged as she would be in the pursuit of finding answers to the most challenging issues of human development and disabilities through doing the very best research. ●



Eunice Kennedy Shriver

## World Special Olympics



COURTESY OF SPECIAL OLYMPICS

Lynn Fuchs, Ph.D., Nicholas Hobbs Chair in Special Education and Human Development, was named to the **Presidential Delegation** and attended the Opening Ceremonies of the **Special Olympics World Summer Games** held in Shanghai, China. Clockwise from left: Lynn Fuchs; Ernie Banks, Member of the National Baseball Hall of Fame; Jennifer Polk Wardlow, International Global Messenger, Special Olympics; The Honorable Margaret Spellings, Secretary of Education; Dr. Timothy P. Shriver, Chairman of the Board, Special Olympics; Anne Sweeney, Co-Chairman, Disney Media Networks and President, Disney-ABC Television Group; The Honorable John H. Hager, Former Assistant Secretary of Education (Special Education and Rehabilitative Services); Michelle Kwan, Figure Skating Champion and American Public Diplomacy Envoy; Eunice Kennedy Shriver, Founder, Special Olympics; The Honorable Clark T. Randt, Jr., U.S. Ambassador to the People's Republic of China.

## Science Day Correction

### Undergraduate Award Winner

Anna Hus

Mentor—Chase Lesane-Brown (Psychology & Human Development)

# Vanderbilt Kennedy Center for Excellence in Developmental Disabilities

## Hospitalization of Infants With Down Syndrome

By Courtney Taylor

**O**n a snowy Wednesday morning at the Vanderbilt Kennedy Center (VKC), members of the Down Syndrome Journal Club sat in a circle to discuss Tennessee hospitalization records of infants born with Down syndrome between 1997 and 1999. The Journal Club's topic sprang from the article, *Hospitalization of Children and Young Infants With Down Syndrome: Evidence From Inpatient Person-Records From a Statewide Administrative Database* (*Journal of Intellectual Disability Research*, Dec. 2007), by VKC investigators Richard Urbano, Ph.D., research professor of pediatrics, and Robert Hodapp, Ph.D., professor of special education.

Each month, faculty, staff, and students from various disciplines and parents of individuals with Down syndrome attend the Journal Club. In this session, the group learned that Urbano and Hodapp have linked the birth and inpatient hospitalization records of over 200 infants born with Down syndrome. They have tracked the



children's health through their first 3 years to see if, when, and why they were hospitalized.

"Doing this type of inquiry will allow us to give a better picture to parents of what to expect," said Urbano. "Our findings have both reinforced and dispelled assumptions. Pediatricians expect the biggest health problem for a young child with Down syndrome to be congenital heart defects, or CHDs. Yet we found that only half of the children in our study were diagnosed with a CHD. We also

found that almost half of all of the children were hospitalized before age 3. Those with CHDs were 2.31 times more likely to be hospitalized than were the children without CHDs, and of those with CHDs, respiratory illnesses affected 64.9% of them."

Hearing the news about the prevalent causes of hospitalization did not surprise one Journal Club parent member. His child—who does not have a diagnosis of a CHD—was in and out of the hospital before age 3 due to a variety of respiratory infections.

"I appreciate a forum for discussing research with parents, students, medical residents, and researchers from different disciplines," said Hodapp. "The Journal Club forces us to explain what we study and what we are finding in a way that is accessible to everyone. All too often, disability researchers speak 'to and for' other researchers, even though many of our findings are of intense interest to parents, the individuals themselves, and to state and national policymakers. Simply put, there is a sharing of ideas, perspectives, and experiences that is difficult to occur in other settings."

Drs. Urbano and Hodapp told the group they recommend that a higher emphasis be placed on the prevention and treatment of respiratory illnesses. Next steps for their research include developing a better picture of who the hospitalized children are, and determining the links between early adverse birth outcomes and later hospitalizations. They also will begin to explore how race and living in a rural area—67 of Tennessee's 95 counties are rural—may affect health outcomes.

For information on journal clubs facilitated by VKC researchers, visit [kc.vanderbilt.edu/kennedy/researchers/journalclub.html](http://kc.vanderbilt.edu/kennedy/researchers/journalclub.html). ●

## New Model Mental Health Program By Courtney Taylor

**R**elative to the general population, persons with intellectual disabilities are at much higher risk for experiencing behavioral, emotional, and psychiatric problems. Yet resources to treat individuals with developmental disabilities with mental health needs are scarce. Now, thanks to a 3-year grant from the John Merck Fund, the Vanderbilt Kennedy Center (VKC) and the Vanderbilt Department of Psychiatry are partnering to create a model treatment program to meet the mental health needs of youth and young adults with intellectual or other developmental disabilities.

"The need is monumental," said Elisabeth Dykens, Ph.D., principal investigator on the Merck grant. Dykens is professor of psychology, VKC associate director, and director of the VKC UCEDD.

"Approximately 40% of adults with intellectual disabilities also show severe mental health challenges that impede their everyday activities," Dykens explained. "As strange as it may sound, there are few such clinics operating nationally that

are well-equipped to treat the co-occurrence of intellectual disabilities and psychiatric problems. We are pleased to be able to provide high-quality mental health services to this incredibly underserved population through this new clinic."

Instead of developing a free-standing clinic, this specialized clinic will be located within the Department of Psychiatry's exemplary Mental Health Clinic. Cost-effectiveness is one of the model's benefits, which in turns makes the model more replicable. The clinic is expected to operate one day a week beginning in spring 2008.

The clinic will be staffed by an interdisciplinary, expert "Mental Health-Intellectual Disability Team," which includes a psychiatric nurse, a social worker, a behavior analyst, and a psychiatrist. The team not only will see patients in the clinic but also will travel to persons residing at home, in group homes, in residential facilities, or even in correctional facilities, as well as working with patients and care providers via telemedicine.

Another dimension of the model clinic will be the inclusion of "positive psychology" in its conceptualization of mental health.

"We are pleased to partner with Dr. Dykens and all of the VKC staff," noted Michael Cull, M.S.N., Outpatient Psychiatry administrative director and co-director of the Vanderbilt Center of Excellence for Children in State Custody. "We increasingly have been called upon to serve individuals with intellectual disabilities and mental health concerns, and now we can bring a trained, dedicated team to do this important work."

"Our goal is to institute a clinic that will be a world leader in care of persons with intellectual disabilities and mental health concerns," Dykens said. "Using the UCEDD national network to distribute our model, we can lead the way in upgrading services in rural and urban settings for a group that continues to be among the most underserved in the country." To contact the clinic call (615) 322-2028. ●



# Treatment and Research Institute for Autism Spectrum Disorders

## Parental Concerns Questionnaire *By Jan Rosemergy*

Parents rely on pediatricians and other clinicians to provide guidance not only for their child's physical health but also for their child's development and behavior. When a child has an autism spectrum disorder (ASD), guidance in educational therapies and treatment decisions is all the more crucial, but few rapid screening tools are available that encompass the range of common symptoms.

To address this need, Susan McGrew, M.D., and other Vanderbilt Kennedy Center colleagues developed and evaluated the Parental Concerns Questionnaire (PCQ). The Questionnaire is a brief screening checklist assessing the presence and severity of 13 developmental and behavioral concerns commonly expressed by parents of children with autism spectrum disorders.

Parents are asked to describe the extent to which a symptom has been a problem within the previous month with 1 representing no problem, 2 mild problems, 3 moderate problems, and 4 severe problems. The 13 items, or symptoms, are language use and understanding, compulsive behavior, anxiety, sensory issues, sleep disturbances, aggression, hyperactivity, attention span, mood swings, eating habits, social interactions, self-stimulatory behavior, and self-injurious behavior.

The research team examined the reliability and validity of the PCQ by having parents of children with ASD and parents of typically developing

children complete the PCQ as well as additional reliable and valid developmental and behavioral tests. Those tests were the Child Behavior Checklist,



the Child Sleep Habits Questionnaire, and either the Repetitive Behavior Scale or the Compulsive Behavior Checklist. A clinician administered the Peabody Picture Vocabulary Test and the Autism Diagnostic Observation Scale. The study included 101 children with a clinical diagnosis of ASD and typically developing children, ages 4 to 10 years.

The analysis of the PCQ showed that parents had good accuracy at identifying and quantifying language problems, and had good consistency in response for compulsive behaviors, daytime

anxiety, sleep disturbance, attention span, and hyperactivity. They were exceptionally consistent at identifying self-stimulatory behavior and self-injurious behavior.

The PCQ is designed for use in an outpatient setting to help clinicians rapidly identify many of the common problematic developmental and behavioral concerns in autism spectrum disorders.

"The PCQ also can be used as an educational tool to help parents recognize problematic issues in children with autism," McGrew added.

The study (*Pediatric Neurology*, 37:2), confirmed that a brief, focused questionnaire can be accurate at identifying problematic developmental and behavioral symptoms in children with autism spectrum disorders.

In addition to McGrew, assistant professor of pediatrics, co-authors were Beth Malow, M.D., associate professor of neurology; Lynnette Henderson, Ph.D., research assistant professor of pediatrics; Lily Wang, Ph.D., assistant professor of biostatistics; Yanna Song, M.S.; and Wendy Stone, Ph.D., professor of pediatrics and psychology.

Next steps involve evaluating the usefulness of the PCQ in larger and more heterogeneous groups of children with ASD, as well as in children with other neurodevelopmental disabilities and in typically developing children. ●

## Training Community Pediatricians for Autism Screening

*By Craig Boerner*

A Bureau of TennCare grant to the Tennessee Chapter of the American Academy of Pediatrics (TNAAP) has paved the way to help community-based pediatricians evaluate young children for autism. The grant will enable TRIAD to train community pediatricians to assess children suspected of having autism.

TennCare is pleased to help facilitate a new process to further assess children's development and, if necessary, to get them into early intervention for autism as soon as possible, said Jeanne Jordan, M.D., TennCare associate medical director and pediatrician. The earlier the diagnosis is suspected or made, the earlier a child can begin needed interventions.

Through this program, Screening Tools and Referral Training—Evaluation and Diagnosis

(START-ED), TennCare is leading the country's other state Medicaid agencies in addressing timely autism diagnoses.

"Since 2003, TennCare and TNAAP have partnered to provide office-based screening tools to primary care providers, in order to help them detect the early signs of possible autism," said Dr. Quentin Humberd, TNAAP president, developmental-behavioral pediatrician, and chief of the Exceptional Family Member Program, Blanchfield Army Community Hospital. "We determined that this screening initiative created an increased need for professionals who were able to accurately diagnose those children with an autism spectrum disorder, and this capability did not exist here or elsewhere in the country. We are very excited that

the TennCare Bureau allowed this unique collaboration between pediatricians, Vanderbilt autism specialists, and Tennessee's Early Intervention System, to address the very real need to provide early and accurate autism diagnosis right in the child's own community," Humberd continued.

The American Academy of Pediatrics has mandated that children be screened for autism at 18 and 24 months of age. While the latest estimates are that 1 in every 150 children is on the autism spectrum, professionals trained to diagnose autism in young children are scarce, which often results in lengthy waiting lists. START-ED works to increase the number of diagnostic options for parents because time is of the essence. *Continued on page 6*

# Leading the Vanguard of Discovery



## RANDOLPH BLAKE, PH.D.

Centennial Professor of Psychology  
Vanderbilt Kennedy Center Investigator  
Vanderbilt Vision Research Center Investigator  
Joined Vanderbilt Kennedy Center 1993

### Research Interests

My research interests include aspects of human visual perception, including binocular vision, motion perception, and perceptual organization. Recently, my research has focused on the roles of knowledge and intention on the resolution of perceptual ambiguity, on the role of temporal structure in visual grouping, on the perception of biological motion, and on synesthesia. A focus also has been on biological motion and binocular rivalry. In collaboration with colleagues, my research has been extended to include individuals diagnosed with autism, Williams syndrome, schizophrenia, and bipolar disorder.

### Principal Investigator

- Binocular Rivalry in Human Vision, National Eye Institute
- Effective Connectivity in Brain Imaging Vision, National Eye Institute
- Mechanisms of Perceptual Organization in Human Vision, National Eye Institute
- Imaging Brain Areas Involved in Biological Motion Perception, National Science Foundation

### Clinical Interests

Over the years, my work has touched on several significant clinical conditions. My findings on binocular vision, in particular interocular suppression, bear on the nature of the neural mechanisms of strabismic suppression, the disruption of typical, coordinated binocular vision that occurs when the two eyes are misaligned. In recent years, my basic research on perception of visual motion has been applied to several clinical populations, including individuals with

autism, with schizophrenia, and with bipolar disorder. The overarching conclusion from that work is that deficits in cognitive and social functioning characteristic of these disorders may be attributable, in part, to deficits in basic visual abilities that alter the way these individuals interpret events in their visual world. In addition, a technique invented by me for studying visual form perception based on temporal structure has been utilized to study losses in visual capacity with aging.

### Honors and Awards

- William Evans Professorship, Otago University 1995
- Centennial Professor, Vanderbilt University
- Earl Sutherland Prize, Vanderbilt University 2000
- Distinguished Alumni Award, University of Texas, Arlington 2002
- Distinguished Faculty Award, Vanderbilt University 2002
- Chancellor's Research Award, Vanderbilt University 2004
- Elected Fellow, American Academy of Arts and Sciences, 2006

### Selected Publications

#### *Binocular Vision*

- Blake, R., & Logothetis, N. (2002). Visual competition. *Nature Reviews Neuroscience*, 3, 13-23.
- Blake, R., Sobel, K., & Gilroy, L. A. (2003). Visual motion retards alternations between conflicting perceptual interpretations. *Neuron*, 39, 869-878.
- Lee, S. H., Blake, R., & Feeger, D. (2005). Traveling waves of activity in primary visual cortex during binocular rivalry. *Nature Neuroscience*, 8, 22-23.
- Blake, R., Tadin, D., Sobel, K. Chong, S. C., & Raissian, R. (2006). Strength of early visual adaptation depends on visual awareness. *Proceedings of the National Academy of Sciences, USA*, 103, 4783-4788.

#### *Motion Perception*

- Grossman, E., & Blake, R. (2002). Brain areas active during visual perception of biological motion. *Neuron*, 35, 1167-1176.
- Blake, R., Turner, L. M., Smoski, M. J., Pozdol, S. L., & Stone, W. L. (2003). Visual recognition of biological motion is impaired in children with autism. *Psychological Science*, 14, 151-157.
- Kim, J., Doop, M. L., Blake, R., & Park, S. (2005). Impaired visual recognition of biological motion in schizophrenia. *Schizophrenia Research*, 77, 299-307.
- Blake, R., & Shiffrar, M. (2007). Perception of human motion. *Annual Review of Psychology*, 58, 47-73.
- Blake, R., Rizzo, M., & McEvoy, S. (in press). Aging and perception of visual form from temporal structure. *Psychology and Aging*.

### Education

B.A., 1967, Psychology, University of Texas, Arlington  
M.A., 1969, Psychology, Vanderbilt University  
Ph.D., 1972, Psychology, Vanderbilt University

### Attraction to Developmental Disabilities Research and Reasons for Vanderbilt Kennedy Center Membership

For decades my work has concentrated on visual function in normal, adult populations. That work has culminated in several theoretical papers in which neural models were developed to account for how the brain registers and interprets visual information. Yet I have always believed that by studying normal function, we also were providing the necessary background work for examining visual disorders and their role in clinical conditions. But it wasn't until I developed collaborations with Vanderbilt Kennedy Center investigators that I was able to be involved in realizing the potential of that basic science work. I have been very fortunate to have as colleagues Wendy Stone, who spurred me to study vision in children with autism, and Sohee Park, who was able to see connections between my work and possible bases for disorders in people with schizophrenia. Most recently, I have enjoyed the opportunity to work with Elisabeth Dykens and her lab group on a project involving vision in people with Williams syndrome. It is gratifying indeed to see the fruits of years of my work actually providing some insight into factors contributing to developmental disabilities and, hopefully, to compensation strategies that will allow these people to lead rich, productive lives. ●

## Training Community Pediatricians

from page 5

"The mandates are ahead of our knowledge and resources," said Wendy Stone, Ph.D., TRIAD director and professor of pediatrics and psychology. "So we have to catch up—and the only way to do that is a full-court press."

Five Middle Tennessee pediatricians are participating in the 6-month pilot, which began with a 2-day training workshop. Pediatricians are learning how to assess the children and interview their parents to make a diagnostic determination. They also are videotaping autism assessments from their own practices and are receiving feedback from Zachary Warren, Ph.D., who also provides an independent diagnostic evaluation to determine the accuracy of the pediatricians' judgment.

"The potential service impact of this program is enormous," said Warren, assistant clinical professor of psychiatry and director of the TRIAD Parent Support and Education Program. "Even a small number of well-trained pediatricians could affect delivery of diagnostic and intervention services for young children with ASD across our state." ●

# Accolades

**Meghan Burke**, Special Education doctoral student (Robert Hodapp, Ph.D., advisor) received the **Beth Goodman Scholarship** to attend the annual **Council of Parent Attorneys and Advocates (COPAA) Conference** in Anaheim, California. Burke is a Vanderbilt Kennedy University Center for Excellence trainee in disability public policy.

**Amy Casey** has been awarded a **Head Start Graduate Student Research Grant** by the Administration for Children and Families, U.S. Department of Health and Human Services. This highly competitive program funds Casey to study "Receipt of Feedback as a Predictor of Teachers' Use of Recommended Practices." Casey is a predoctoral trainee in the Developmental Disabilities Research Training Program, funded by a National Research Service Award, Eunice Kennedy Shriver National Institute of Child Health and Human Development.

**Edward Conture**, Ph.D., professor of hearing & speech sciences, **co-authored *Stuttering and Related Disorders of Fluency***, 3rd edition (Thieme), with Richard F. Curlee, professor emeritus of speech & hearing sciences, University of Arizona-Tucson.

**David Dickinson**, Ed.D., professor of education, has been named **interim chair** of the **Department of Teaching and Learning**. Dickinson participated in a **seminar in Brasilia**, Brazil, informing the National Brazilian Parliament on the role that early childhood education plays in fostering language development in children, birth to 3.



Ronald Emeson, Ph.D.

**Ronald Emeson**, Ph.D., Joel G. Hardman Professor of Pharmacology, professor of molecular physiology and biophysics, was named **deputy director** of the **Vanderbilt Center for Molecular Neuroscience**.

**Dale Farran**, Ph.D., professor of education and psychology, with Peabody's Department of Teaching and Learning, **hosted 15 Irish educators** who visited pre-K programs in Nashville in which Peabody College is involved.

**Douglas Fuchs**, Ph.D., and **Lynn Fuchs**, Ph.D., professors of special education and Nicholas Hobbs Chair in Special Education and Human Development, are **senior consultants** to the new **National Center on Response to Intervention**, funded by a 5-year grant to American Institutes for Research from the U.S. Department of Education Office of Special Education Programs.

**Steven Gabbe**, M.D., School of Medicine dean, professor of obstetrics and gynecology, medical and education administration, has been **elected** to a 3-year term as a representative on the **Executive Council of the Council of Deans, American Association of Medical Colleges**.

**Isabel Gauthier**, Ph.D., associate professor of psychology, was one of two **2008 Troland Research Award** winners, **National Academy of Sciences**. The \$50,000 prize recognized Gauthier's "seminal experiments on the role of visual expertise in the recognition of complex objects including faces and for exploration of brain areas activated by this recognition."

**Craig Anne Heflinger**, Ph.D., associate professor of human and organizational development, has been named **associate dean for graduate education** at **Peabody College**.

**Robert Hodapp**, Ph.D., professor of special education and director of research, VKC UCEDD, has been named the **editor** of the ***International Review of Research in Mental Retardation***, the longest-running review journal in the intellectual disabilities field.

**BethAnn McLaughlin**, Ph.D., assistant professor of neurology and VKC faculty director of community and special projects, received the **New York Academy of Sciences' Young Investigator Award in Cellular and Molecular Neuroscience**. This award recognizes those who have developed innovative research programs, are highly regarded for their scientific service, and have highly promising academic careers.



BethAnn McLaughlin, Ph.D.

**Robin McWilliam**, Ph.D., professor of pediatrics and director of the Center for Child Development, has been **appointed Chair of the Protection and Advocacy for Individuals with Mental Illness (PAIMI) Council**, a program of the Disability Law and Advocacy Center of Tennessee.



Carole Moore-Slater

**Carole Moore-Slater**, Tennessee Disability Pathfinder director and technical assistance coordinator, VKC UCEDD, and **Ellen Gayeski**, a graduate student in Special Education and a VKC UCEDD trainee, were selected as **primary**

**presenters** at the **Gulf-South Summit on Service Learning and Civic Engagement Through Higher Education** for their presentation "Access Nashville: Accessibility is Good Business."

**Cathleen Pettepher**, Ph.D., professor of cancer biology and cell and developmental biology, was **selected** for membership in the **Vanderbilt School of Medicine's Academy for Teaching Excellence**.

**Daniel Reschly**, Ph.D., professor of education and psychology, **presented invited testimony to the U.S. Commission on Civil Rights** concerning minority over-representation in special education in Washington, D.C.

**Wendy Stone**, Ph.D., professor of pediatrics and psychology, director of TRIAD, and director of the Marino Autism Research Institute, received the annual **Outstanding Alumni Award** from the **Psychology Department at the University of Miami**. Stone is **co-editor** of ***Social and Communication Development in Autism Spectrum Disorders: Early Identification, Diagnosis, and Intervention*** (Guilford Press). The book includes chapters co-authored by Stone, **Paul Yoder**, Ph.D., professor of special education, and **Tedra Walden**, Ph.D., professor of psychology.



Wendy Stone, Ph.D.

**James Sutcliffe**, Ph.D., associate professor of molecular physiology & biophysics and psychiatry, has been **appointed** as a **member** of the **Developmental Brain Disorders Study Section** for the **National Institutes of Health Center for Scientific Review**. Sutcliffe also is an **associate editor** for ***Autism Research***, the flagship journal of the International Society for Autism Research (INSAR).



Zachary Warren, Ph.D.

**Zachary Warren**, Ph.D., clinical assistant professor of psychiatry and director of TRIAD's Parent Support and Education Program, was **invited to Amman, Jordan**, to teach a pediatric review course, deliver a keynote address on the early assessment of autism, and present on other disabilities as well as cancer treatment in young children.

# Tennessee Survey of Adult Siblings By Courtney Taylor

**H**ow do siblings of individuals with disabilities and other family members cope with adolescent to early adulthood transitions out of the home? What information and services would be helpful in support of these transitions and the continuing sibling relationship? These are two questions that Vanderbilt Kennedy Center investigator Ann Kaiser set out to answer when she and her colleagues undertook the Tennessee Survey of Adult Siblings.

Funded by the Tennessee Council on Developmental Disabilities, the survey was completed by over 180 adult siblings, 18 to 71 years. Siblings provided basic information about themselves, their siblings with disabilities, and their families. They were asked about joint activities and involvements, and about their siblings' support needs, both past and present. Survey questions also covered the overall well-being of the sibling without a disability, as well as allowing for open-ended reflections about the sibling relationship. Finally, respondents indicated whether they were willing to be interviewed.

The survey's questions were structured to allow Kaiser and colleagues to identify where resources may be lacking in Tennessee in order to make recommendations for family support programs and policy.

"Although Tennessee has numerous organizations that provide support to families, the emphasis usually is on parents and/or the family member with the disability," said Kaiser, Ph.D., Susan Gray Chair in Education and Human Development, and professor of special education and psychology. "In order to better understand the types of supports that siblings might need and to determine if sibling support activities have a positive impact on both the sibling and the brother or sister with a disability, it is important that we gather information from Tennessee families in the context of the services and supports now offered in their communities."

## Sibling Relationship Dynamics

For the most part, how healthy and well-functioning a family is strongly predicts how well-functioning the sibling relationship will be. When a sibling with a disability has significant behavior problems that interfere with family functioning and those problems are not effectively addressed, this dynamic can make it more difficult to have a positive sibling relationship. The issue is not the severity of the disability but about the behavior problem and its treatment.

"For example, some cases of autism spectrum disorders make it harder for siblings to have a relationship at all, let alone a positive relationship," said Kaiser. "Some siblings who have had brothers or sisters with significant mental health or behavior problems say, 'I'd like to be closer to my sibling, I'd like to do things with him, but it's really hard

to take him out in public because he has these outbursts.' The message in such cases is that we need to do better in providing good behavioral interventions. Siblings who can't take their brother or sister to the movies need help in figuring out how to deal with their brother or sister's behavior problems *now*. Regardless of what happened in the past, they



Ruth Roberts, Vice Chair of VKC Community Advisory Council, and her sister, Merry Jensen

want to have relationships that involve doing normative things. They want to participate in the community."

Behavior problems also can make it difficult for families to find respite care. Parents who have a child with a significant mental health or a behavior problem report that they feel there is nobody they can ask to take care of their children. That can affect the time spent with typical siblings, the parents' mental health, and various family activities and relationships.

## Information and Support

Although survey data are still being analyzed and recommendations are preliminary, Kaiser already envisions different means and methods of getting information and supports to siblings as they need it.

"At one level, searching for services is a very complex process, and at another level, it's just the life we live," said Kaiser. "We cope with it, just like we cope with everything else. We bring the same sorts of strategies to the search that we bring to everything else in our lives. We use emotional strategies, we use problem-based strategies, and we network with each other. It helps a lot when it's easy to find information and when it's easy to understand the information that we find. It would be enormously helpful to have people who could serve as consultants to families, especially during transition times. It may be worthwhile to develop a model program for that."

Another means of getting information to families might be through a national sibling website, Kaiser indicated. It could link national organizations and serve as a clearinghouse for general information, provide information on futures planning, and allow for easier access.

"Most siblings have the regular life stuff going on," said Kaiser, "job changes, getting married, having

kids, and life goes on. Most siblings are having lives that are fairly similar to what their age contemporaries have—except that, almost to a person, they have this overriding concern about getting services, about living situations, about employment, about leisure time activities, about inclusion in the community, and about health care for their sibling with a disability."

Most (about 80%) of the siblings surveyed seem to be doing very well, Kaiser indicated. It is the 20% that concerns her and drives her to explore future sibling research topics. Agencies that fund research on disabilities mainly are interested in funding projects that directly benefit individuals with disabilities. Because of this, finding funding sources for sibling research or a model service program is difficult.

"An unanswered question, which is not an easy question methodologically, is 'How does a positive sibling relationship affect a sibling with disabilities?'" said Kaiser. "And it goes back to that general idea that siblings are doing well when the family is doing well. Individuals with disabilities are doing well when their families are doing well. Family dynamics seem to matter a great deal." ●

## National Survey of Adult Siblings

**T**he Tennessee Survey of Adult Siblings is an outgrowth of the National Survey of Adult Siblings conducted by the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities, supported by The Arc U.S. The help of other organizations was invaluable, including the Association for University Centers on Disabilities and Don Meyer's Sibling Support Project.

Over 1,300 surveys were received from all 50 states and DC. The average age of sibling respondents was almost 37 years, with ages ranging from 18 to 85. Overall, siblings of adults with disabilities are doing well. Siblings report that, as a group, they spend a fair amount of time with, feel very affectionate and close to, and have benefited greatly from their brother/sister with disabilities. Most reported that their physical health was very good or excellent, and only small percentages reported being depressed or blue.

For summary: <https://kc.vanderbilt.edu/FamilyResearch/AdultSiblingSurveyResults.pdf> ●



# Brothers and Sisters

By Courtney Taylor

**VANDERBILT KENNEDY CENTER**  
FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES

The transition from adolescence to adulthood is a challenging time. Little is known generally about siblings who have a brother or sister with a disability, and even less is known about this important transition time when life decisions are being made.

"There have been studies of siblings who were asked to *look back* upon their transition years, but we were interested in siblings who were *going through it now*," said Ann Morse, director of the Tennessee Sibling Study. "We wanted to hear from typically developing siblings deciding where to go after high school, who to marry, and/or if they would settle close to home. We wanted to know if they were thinking about how their relationships with their brothers and sisters might change as the years passed. So we set out to interview 18- to 30-year-old siblings."

The Tennessee Adult Sibling Survey, conducted over 6 months by Morse and Vanderbilt Kennedy Center investigator Ann Kaiser, Ph.D., was funded by the Tennessee Council on Developmental Disabilities. The survey closed in February 2008, and data are still being analyzed. Although 18- to 71-year-old siblings completed the survey, only siblings between the ages of 18 and 30 were interviewed. Most were not yet a primary caregiver for their sibling with a disability, and most of the siblings with disabilities were still living in the family home.

How much the siblings are thinking about the future relationship with their sibling with a disability depends on a number of factors.

"First of all, if you're in that age group, your sibling still could be quite young," said Ann Kaiser, Ph.D., Susan Gray Chair in Education and Human Development, and professor of special education and psychology. "There is a real difference in how siblings without a disability are thinking about the future when their sibling with a disability is still in school versus a situation where the sibling has left high school. The concerns and knowledge of siblings are driven a lot by the age and the placement of their brother or sister with the disability. Some of the 29-year-olds are 'old' and some of them are 'young.' Some are in graduate school and don't have families, and some have been divorced and have three kids. What they are thinking about the future depends on where they are in their own lives, and whether their sibling is still in school."

## Future Caregivers

There are noticeable trends about whether a sibling will assume the role of future primary caregiver. One factor is whether the sibling without a disability is the only other sibling.

Another factor is the gender of the sibling. Female siblings tend to become caregivers more often than male siblings. In addition, a sibling's proximity to the family home can determine whether an active caregiving role will be adopted. Many of the siblings without disabilities who were interviewed were living close, if not still in, the family home. Of siblings in college, many came home every weekend or even every day. If siblings chose to attend college far from home, most moved back or planned to move back after graduation.



Scotty Twyman and his sister, Lori Pope

Morse and Kaiser are curious about how much these trends have to do with having a sibling with a disability and how much it has to do with the importance placed on family in the South.

"We wonder whether our sample is different than a national sample," said Kaiser. "Because family seems to be enormously important to people living in Tennessee and they speak readily about the closeness in their families, does this trend reflect the culture? We don't know yet. It will be interesting to compare."

## Advice From Siblings

"I am struck by how mature the siblings were," said Morse. "Their responses were extremely thoughtful. They had a lot to say about what worked and what didn't work growing up. We asked them what would have made it easier to support their siblings when they were growing up and what would make it easier to support their siblings in the future."

Siblings told Morse that parents need to be able to take breaks from the family. One sibling gave this advice:

"Make more time for your marriage. Arrange a time each week to go on a date. When you're connected with your spouse, it is easier to balance the tasks of parenthood. Having a child with a disability can be very tiring, draining, and challenging. Take a break!"

Other siblings reported that open and frequent communication about the sibling's disability is important. Although some parents

reported that they purposely withheld things from their children to spare them the burden, siblings want to be kept informed. They want to have functional information about how to access or qualify for and how to manage services and supports. Yet, perhaps the most frequent responses from siblings about what helped or what would have helped was about family and/or individual counseling and the need for peer support.

"The folks who were most positive about their past experiences were folks who said, 'My parent(s) celebrated the achievements of all the kids in the family,'" said Morse. "There was a child with disabilities, and we knew we needed to pay special attention to him or her, but my parents also gave a lot of attention to us. We had activities we did together and activities we did separately. While siblings may have wanted more attention than they received, they understood why it was so."

On the whole, Kaiser and Morse report that siblings tend to be doing very well. Preliminary findings show that they feel they have more compassion, empathy, and respect for others. They feel they may be more aware of injustices, may be more responsible, and may be more open to learning new things because they have a brother or a sister with a disability. ●

## Resources for Siblings

**The Sibling Support Project**, a national effort dedicated to the life-long concerns of brothers and sisters of people who have special health, developmental, or mental health concerns  
[www.siblingsupport.org](http://www.siblingsupport.org)

**KidsHealth** information for kids, teens, and parents  
[www.kidshealth.org](http://www.kidshealth.org)

**SibSaturdays** provide siblings, ages 5 to 13, with the opportunity to play games, meet friends, and take part in group discussions. Contact Vanderbilt Kennedy Family Outreach Center (615) 936-5188.

**Tennessee Disability Pathfinder** resources include information on sibling support groups available in Tennessee communities.  
[www.familypathfinder.org](http://www.familypathfinder.org)  
(1-800) 640-INFO [4636]

## Spotlight

## A Mission to Volunteer

JEAN ANN BANKER

By Courtney Taylor

In 1893, Jean Ann Banker's great-great-grandfather founded the Stewart Home School for individuals with intellectual disabilities in Frankfort, Kentucky. Many decades later, growing up on the farm where the School still stands today, Jean Ann would play with the students, later teach in the classrooms, and eventually develop a remarkable and intentional passion for volunteering.

"My home was on the farm in the middle of the School's campus," said Banker. "I grew up surrounded by the students and the School's staff, who taught me that we are all unique and that we all have gifts that are ours to give. I also learned at a very early age that we can learn from everybody. Volunteering is such a wonderful way to meet and learn from people who are different from and who are similar to whom we happen to be."

Banker left the farm and her great-great-grandfather's school to attend high school in Virginia. She spent much of her time in Washington,



Jean Ann Banker

DC, checking out books from the Library of Congress, working on Capitol Hill, and studying the paintings in the National Gallery. Her love of art led her to Nashville, where she studied art history at Vanderbilt University.

Now married and with three grown children, Banker remains in Nashville sharing her skills and passion for volunteering with the Vanderbilt Kennedy Center and with numerous other community organizations. Banker is a member of the Metropolitan Nashville Arts Commission and a Trustee for West End United Methodist Church. She is past president of the Friends of the Monroe Carell Jr. Children's Hospital at Vanderbilt. She is co-chair of the Iroquois Steeplechase and has volunteered with the Girl Scouts of America, the Junior League of Nashville, and the Frist Center for the Visual Arts. Harpeth Hall School also benefits from her time and generous commitment. To be sure, the list of organizations she has worked with is long and certainly has not been exhausted here.

"I am drawn to organizations where I feel passionate about their mission," said Banker. "So when I feel that connection, I participate. I feel I have

a responsibility to improve the quality of life in the community in which I live. Volunteering is stimulating, enriching, and thought-provoking for me. It enriches my life, and I feel a profound sense of accomplishment when involved. Alone, I am one person, but when we volunteer together, we are many. Much can be done when we are many."

Banker joined the Leadership Council because she felt a connection with the mission of the Vanderbilt Kennedy Center [To improve the quality of life of persons with disorders of thinking, learning, perception, communication, mood and emotion caused by disruption of typical development]. She especially appreciates the Vanderbilt Kennedy Summer Camps and the Arts and Recreation Program.

"I also am very impressed by the research that takes place at the Center," added Banker. "To be able to make a diagnosis at an early age, to be able to make discoveries that prevent certain disabilities or aspects of disabilities greatly enhances the quality of life of these individuals and their families. I applaud the amazing discoveries."

The faculty and staff of the Vanderbilt Kennedy Center are honored to work with Jean Ann Banker. Continuing to carry the torch of her great-great-grandfather's Stewart School's mission into the labs and clinics of the Vanderbilt Kennedy Center and into the community at large is a true testament to her dedication to improve the quality of life for all. ●

## Kennedy Center Donors

## Nicholas Hobbs Society Members

New since December 21, 2007  
(\$1,000 and above)

A complete list is found at  
[kc.vanderbilt.edu/kennedy/giving/give2hobbs.html](http://kc.vanderbilt.edu/kennedy/giving/give2hobbs.html)

Mr. Dee Hamilton

## Honor and Memorial Gifts

**In Honor of Mr. Monroe Carell Jr., Easter Seals Tennessee 2008 Nashvillian of the Year**  
Dr. and Mrs. Pat Levitt

**In Memory of Mr. Clarence Neidert**  
Mr. and Mrs. William D. McCord

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Mrs. Marjorie Weber Zager

**In Honor of Mr. William Hart Spickard, IV**  
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Through their gifts, Hobbs Society members advance groundbreaking research in human development. For information about joining the Hobbs Society or making Honor or Memorial gifts, contact (615) 343-5322.

Every effort has been made to ensure the accuracy of this report, which reflects Honor and Memorial gifts **December 21, 2007-February 15, 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.

## TN Ambulance Service Survey



Terri Urbano and Mark Finucane, Assistant Chief, Johnson City Fire Department

**T**erri Urbano, Ph.D., M.P.H., R.N., Director of Training & Health for the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (VKC UCEDD), serves on the TN Functional Needs Emergency Preparation Committee. At the recent Ambulance Services Association meeting, T. Urbano, VKC UCEDD colleagues Robert Hodapp, Ph.D., and Richard Urbano, Ph.D., and Special Education student Samanta Goldman surveyed perceptions of barriers and enhancements to emergency preparedness for those with functional needs. Surveys also will be distributed at regional training events. Findings will be shared with State officials for future training and emergency planning. ●

# Passion for Outreach

By Jan Rosemergy

For the past three summers, for one magical week each year, youth and young adults with Williams syndrome have come to “Music City USA” to share—and to develop—their love of music. They stayed in a Vanderbilt dormitory. They had music sessions at Vanderbilt’s Blair School of Music. Together they composed an original song with the help of Nashville’s award-winning songwriters. They recorded that song in a Nashville studio supported by Nashville musicians and award-winning producers. And as if that wasn’t enough—their week concluded with a live performance on the stage of the Grand Ole Opry.

In 2008 this incredible learning experience that connected extraordinary young people, who have a disability, with Nashville’s extraordinary music community was threatened by lack of funding. Music Camp 2008 will happen come July 13—in part because of the generosity of **John and Lorie Lytle**, and their dedication to connecting with other individuals willing to financially support Music Camp. The Lytles are a Nashville family who has nurtured the Music Camp since its inception. They are the parents of 9-year-old Eden, 7-year-old Luke, and 4-year-old Christina. John is the owner of Lytle Management Group, a professional artist management company located on Music Row.

“The Vanderbilt Kennedy Center is enormously appreciative of the many ways that Lorie and John Lytle have supported the work of the Vanderbilt Kennedy Center,” said Elisabeth Dykens, Ph.D., VKC associate director and Music Camp faculty director. “The Lytles’s recent donation demonstrates how a single family’s gift can make the critical difference in enabling the Center to provide a new or continuing program for families. This young, dynamic family is increasingly representative of a critical, emerging commitment by vibrant young professionals in the Center. We are inspired by their generosity and take stewardship of this gift as a sign that we are growing in a positive direction with our young families.”

Like many families who donate their time, expertise, or financial resources to the Vanderbilt Kennedy Center, the Lytles first found the Center when they were searching for help for their child. At 2½, Luke had been diagnosed with expressive-receptive language disorder, which poses a problem in processing what is being said, as well as expressing it. Luke’s inability to communicate left both him and his parents frustrated. A language intervention research project of the Vanderbilt Kennedy Center and the Vanderbilt Bill Wilkerson Center helped Luke’s language development.

“I saw first-hand the difference early intervention can make in a child’s life. Luke is now 7, and there are no traces left of language delay,” Lorie said.

John and Lorie Lytle are believers in “giving back.” In June 2004, Lorie joined the Vanderbilt Kennedy Center Leadership Council, and she and John became annual members of the Nicholas Hobbs Donor Society.

Lorie had been involved with the Nashville music industry since 1987 as a publicist. She connected her love of music and her skills as a

Camp will include opportunities for campers and their families to take part in research, and will provide training opportunities for young people who staff the camp.

This blend of model service, training of a new generation of professionals, and research is a hallmark of Vanderbilt Kennedy Center programs, including the TRIAD Social Skills Camp for students with autism spectrum disorders and the Camp Shriver Transitions and Sports Camp for students with intellectual disabilities.



COURTESY OF LYTLE FAMILY

John, Lorie, Christina, Eden, and Luke Lytle

publicist by chairing the community committee for the first Vanderbilt Kennedy Center Music Camp—and she has done that every year since.

“John and I believe in the vision of the Vanderbilt Kennedy Center to help families through research and model service programs, and we have great confidence in Pat Levitt’s leadership,” Lorie said. “We love that the Center’s faculty and staff focus not just on disabilities but also on *abilities*—and not just on individuals but on *whole families*.”

## Music Camp

Lorie describes her and John’s involvement in Music Camp as “a natural fit.”

“Nashville’s music community is generous, willing to lend time and service,” Lorie said. She has recruited award-winning songwriters, performers, and producers to work with Music Camp—knowing that, in turn, the involvement of celebrities like Lee Ann Womack, Joe Nichols, and Dierks Bentley, to name only a few, help the Vanderbilt Kennedy Center connect with media who, in turn, can help connect families to the Center.

In July 2008, the week-long Music Camp will serve not only young people with Williams syndrome but also those with other developmental disabilities who have experience with and a keen interest in music. As in previous years, the Music

## Arts and Disabilities Program

Lorie also chairs the Vanderbilt Kennedy Center Arts and Recreation Committee and is an enthusiastic supporter of the Center’s efforts to expand its outreach in the visual arts.

The VKC Arts Program began in 1994 with exhibits of art by individuals with disabilities shown in the lobby of the VKC/MRL Building on campus. Many exhibitions have included panel discussions and presentations to promote and support creative expression, as well as workshops to bring artists with and without disabilities together to create art. Work by

artists with disabilities also has been

showcased in the community, notably at the Tennessee Performing Arts Center, the Nashville Main Library, and at the annual receptions of the Mayor’s Advisory Committee for People with Disabilities.

The Frist Center for the Visual Arts has organized a statewide exhibit highlighting adult artists with disabilities. Gretchen Herbert, VKC coordinator of recreation and arts, has served on the planning committee, and artists whose work has been shown at the Vanderbilt Kennedy Center will be included in the Frist exhibit, which opens May 16 and continues through September 16.

“The Vanderbilt Kennedy Center’s contributions to the Frist exhibit represents one more way to shine a light and lead families to the Center,” Lorie said.

## Valuing Outreach

“My first passion is really outreach,” Lorie continued. “Sometimes I daydream about a time when every family who needs the services of the Center will know about those services and will be able to receive them. Until that day happens, we’ll just have to keep putting one foot in front of the other. John and I know that God blesses our lives so abundantly, and we count our involvement with the work of the Vanderbilt Kennedy Center among those blessings.” ●

## Leadership Council of Vanderbilt Kennedy Center

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## Hold the Date

**Friday, May 16, 2008**

8 a.m. Shotgun Start

### Waddell & Reed Financial Services Charity Golf Tournament

Vanderbilt Legends Club's Roper's Knob Course

Benefiting the Vanderbilt Kennedy Center

A great morning of golf, door prizes,  
cold beverages, and lunch

Entry fee \$125/player

Contact (615) 343-5322



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.

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Ann Kaiser, Ph.D., & Robert Hodapp, Ph.D., Families  
Wendy Stone, Ph.D., Autism Spectrum Disorders (TRIAD)

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

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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).

### April

**APRIL 22**

#### Environment and Autism Etiology Scientific Symposium

Sponsor Marino Autism Research Institute  
For researchers, clinicians, graduate/postgraduate trainees  
8:30 a.m.-6:30 p.m.  
Vanderbilt Student Life Center  
Information on cost, registration  
[kc.vanderbilt.edu/kennedy/marisymposium](http://kc.vanderbilt.edu/kennedy/marisymposium)



TRIAD Social Skills Camp

**JUNE 20**

#### Community Advisory Council Meeting

For details contact (615) 936-5118

### May

**MAY 16**

#### Statistics & Methodology Core Seminar R and Reproducible Results

**Theresa Scott, M.S.**, Biostatistician,  
Vanderbilt Department of Biostatistics  
Lunch provided  
Register by May 13  
[kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration)  
Friday 12 noon Room 241  
Vanderbilt Kennedy Center/MRL Building

**MAY 16**

#### Waddell & Reed Financial Services Charity Golf Tournament

Benefiting Vanderbilt Kennedy Center camps  
Friday 7 a.m. registration, 8 a.m. shotgun start, 12 p.m. awards luncheon  
Vanderbilt Legends Golf Club  
Contact (615) 343-5322  
[kc.vanderbilt.edu/golf](http://kc.vanderbilt.edu/golf)

### June

**JUNE 6**

#### Neuroscience Graduate Seminar Series Neonatal Amygdala Lesions and Social-Emotional Behavior

**Jocelyne Bachevalier, Ph.D.**, Professor of Psychology, Emory University  
Co-Sponsor Vanderbilt Brain Institute  
Friday Time to be announced  
Cheekwood Botanical Gardens

### 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 x 3

**FEBRUARY 4-MAY 9**

#### Looking Forward

Co-Sponsor Park Center

### Camps

The Vanderbilt Kennedy Center for Excellence in Developmental Disabilities, with national and community organizations, sponsors summer camps. Costs vary; scholarships available. See [kc.vanderbilt.edu/kennedy/community/summercamps.html](http://kc.vanderbilt.edu/kennedy/community/summercamps.html). Contact (615) 322-8529 x 3, toll-free (866) 936-8852  
[gretchen.herbert@vanderbilt.edu](mailto:gretchen.herbert@vanderbilt.edu)

**JUNE 9-27**

#### Camp Shriver Transitions and Sports Camp

For youth, ages 16-22, with intellectual disabilities  
Day camp at University School of Nashville

**JUNE 9-27**

#### TRIAD Social Skills Camp

For students, ages 6-21, with autism spectrum disorders  
Day camp at University School of Nashville

**JULY 13-18**

#### Music Camp

For individuals, ages 16 and up, with developmental disabilities and with experience in and a passion for music  
Residential camp at Vanderbilt University

### SibSaturdays

**APRIL 12, JUNE 14, AUGUST 16**

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 Location varies



## Take Part in Research

### Vanderbilt Kennedy Center Research Studies

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

### Research Family Partners

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

### StudyFinder

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

## TN Disability Pathfinder

### Phone, web, print resources

www.familypathfinder.org  
English (615) 322-8529  
Español (615) 322-8529 ext. 11  
Toll-free (1-800) 640-INFO [4636]  
tnpathfinder@vanderbilt.edu

### Disability Calendar

Internet calendar of training and other disability-related events  
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

Project of Vanderbilt Kennedy Center for Excellence in Developmental Disabilities and Tennessee Council on Developmental Disabilities

## Community Events

### APRIL 13-19

#### National and Nashville Week of the Young Child

Nashville Area Association for the Education of Young Children, Vanderbilt University, Nashville community organizations  
For Nashville events, contact (615) 383-6292  
kc.vanderbilt.edu/kennedy/woyc

### APRIL 24-25

#### Tennessee School-Wide Positive Behavior Support Conference

Radisson Hotel Opryland, Nashville  
For more information, contact (865) 974-2760 or nward2@utk.edu

### APRIL 26

#### The Ultimate Race: Literacy for Children with Down Syndrome

Andrea McDermott (VU M.Ed., 2006) will run in the Country Music Marathon to raise money for Team William. All funds go into the Team William endowment fund, and interest on the endowment provides a scholarship for a child with Down syndrome for tutoring at VKC Reading Clinic. With collective support, McDermott has raised just under \$100,000. For more information or to make a donation, visit [www.teamwilliam.org](http://www.teamwilliam.org)

### MAY 16-SEPTEMBER 14

#### Frist Center for the Visual Arts Exhibit

Highlighting Tennessee adult artists with disabilities  
Visitors may view this gallery space free of charge  
[www.fristcenter.org](http://www.fristcenter.org)

### MAY 17

#### Angelman Syndrome Foundation Walkathon

Saturday 9 a.m. Centennial Park  
For information, contact [terry.jo.bichell@vanderbilt.edu](mailto:terry.jo.bichell@vanderbilt.edu)

### MAY 28-30

#### Sixth Annual Tennessee Disability MegaConference

Nashville Airport Marriott  
Registration deadline May 12  
For more information and to register, see <http://www.tndisabilitymegaconference.org>

### SEPTEMBER 13

#### Walk Now for Autism

Registration 8:30 a.m., Walk 10 a.m.  
Nashville Speedway, Lebanon, TN  
Information and registration—Autism Speaks  
[www.worknowforautism.org](http://www.worknowforautism.org)  
(888) 777-6227 x7357, (704) 561-0003 or [tennessee@autismspeaks.org](mailto:tennessee@autismspeaks.org)

## ASMT Events

### Autism Society of Middle Tennessee

[www.tnautism.org](http://www.tnautism.org)  
ASMT event information (615) 385-2077  
Registration is requested for all events  
ASMT members free; nonmembers \$5/family

### APRIL 17

#### Vanderbilt as an Autism Treatment Network Site: How It Works and What It Means for Families

Beth Malow, M.D., Associate Professor of Neurology, and Wendy Stone, Ph.D., Professor of Pediatrics and Psychology  
Thursday 6:30-8:30 p.m. Room 241  
Vanderbilt Kennedy Center MRL Building

### MAY 22

#### Restricted and Repetitive Behaviors: Understanding and Working With, Through, and Around Them

Jeremy Veenstra-VanderWeele, M.D., Instructor in Clinical Psychiatry, and behavioral consultant  
Thursday 6:30-8:30 p.m. Room 241  
Vanderbilt Kennedy Center MRL Building

### JUNE 26

#### Let's Have Fun! Making Verbal and Nonverbal Connections With Your Child

Lisa Wallace, M.S., CCC-SLP, TRIAD Families First Program Leader  
Thursday 6:30-8:30 p.m. Room 241  
Vanderbilt Kennedy Center MRL Building

## DSAMT Events

### Down Syndrome Association of Middle Tennessee

[www.dsamt.org](http://www.dsamt.org)  
DSAMT event information (615) 386-9002

### APRIL 19

#### Circle of Friends and Circle of Friends for Kids

RSVP required

### MAY 16

#### Caleb Thompson Memorial Golf Tournament

Contact DSAMT if you are interested in participating.

## Fulfill the Promise

Throughout Tennessee communities, people with developmental disabilities other than intellectual disability have few programs to assist them. Over the past year, the VKC UCEDD, along with other disability organizations, participated in a Statewide Task Force to assess needs. For Tennessee Developmental Disabilities Task Force Report, "Fulfill the Promise," to the TN Legislature, facts sheet (English and Spanish), and Campaign updates, see [www.fulfillthepromise.org](http://www.fulfillthepromise.org).