



PAUL BRIAN IMAGE FROM BIGSTOCKPHOTO.COM

## Preventing Preterm Birth BY JAN ROSEMERGY

“One of the fundamental unsolved questions in human biology is what determines the timing of birth,” said Louis Muglia, M.D., Ph.D., a physician-scientist who is searching for answers to that critical question. “We don’t know what clock mechanism signals that it is time for birth—whether there are constant signals that go back and forth between the mom and infant from the time of conception, or whether later in gestation signals occur to indicate that an infant is mature enough to survive outside the womb.”

Muglia joined Vanderbilt University in December 2008 as the Edward Claiborne Stahlman Professor of Pediatrics, Vice Chair for Research Affairs in Pediatrics, and Vanderbilt Kennedy Center interim associate director. Investigating the causes of preterm birth is one aspect of his research program. The other is understanding how exposure to early life stress predisposes an individual later in life to affective anxiety disorders, with the focus on understanding the endocrine stress response.

The question of the causes of preterm birth is not only a biological problem but also an enormous social and economic problem, affecting families, causing lifelong disabilities in many instances, and costing billions of dollars in health care and lifelong care.

“The most worrisome aspect of premature birth is that its rate of occurrence is constantly increasing in the U.S.,” Muglia said. The rate has been increasing about 10% per decade over the last four decades. “One out of eight babies is born too early, defined as less than 37 weeks of total gestation.”

Children born prematurely are at increased risk for chronic lung problems, bleeding in the brain that causes cerebral palsy, long-term cognitive effects, and poor growth. Perinatal disorders, of which preterm birth is the primary contributor, account for far more years over average lifespans with which individuals live with disabilities and lost years of life than other important common human disorders such as diabetes mellitus, cerebrovascular disorders, and cardiovascular disease.

“It’s twice as large as all those,” Muglia said, “because it starts at the very earliest times of life and persists throughout the individual’s lifetime. So by understanding the causes of preterm birth and by developing prevention measures, we could reduce developmental disabilities in a major way.”

For roughly half of preterm births, causes are understood, but for the remaining half, causes are unknown. “We think that this other half represents an intrinsic dysfunction of this clock mechanism that’s associated with the timing of birth.”

*Continued on page 2*

## Transitioning Into Adulthood

BY JAN ROSEMERGY

All life transitions offer both opportunities and challenges—especially so for youth as they transition from high school into adulthood. Young people with disabilities, like all youth, need support from families, educators, and their communities to make this transition successfully. Three quite varied Vanderbilt Kennedy Center programs are providing innovative models to facilitate that transition process.

### Peer Buddies

For almost two decades, Carolyn Hughes, Ph.D., has been developing a model of transition support for students with intellectual and other developmental disabilities preparing to leave high school. Hughes, professor of special education and a VKC researcher, is co-author, with Erik Carter, of *Peer buddy programs for successful secondary school inclusion* (Brookes, 2008).

“We have two overarching frameworks, based on transition research,” Hughes said. “One is building support into the environment—which is what we accomplish, in part, through peer buddies. The other is building the skills and competence of students with disabilities.”

Hughes initially developed and implemented the peer buddy program in all 11 comprehensive high schools of Metro Nashville Public Schools. General education students were taught to be supports for their peers with disabilities. The focus was on students with intellectual disabilities who attended “Life Skills” classrooms. The intervention occurred in school cafeterias, gymnasiums, hallways, and general education classrooms—settings where students with and without disabilities interacted.

The peer buddy model has two unique components. First, all the interventions are done in the high schools where students with disabilities are spending their days.

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ORANGE LINE MEDIA IMAGE FROM BIGSTOCKPHOTO.COM

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## Primer

**Preterm birth** is defined as a live birth before 37 completed weeks gestation.

Classifications include late preterm (34-36 weeks), moderately preterm (32-36 weeks), and very preterm (less than 32 weeks). Infants are at greater medical and developmental risk with decreasing gestational age.

- Every day 1 in 8 babies in the U.S. is born preterm.
- The rate of preterm birth in the U.S. increased by 36% between the early 1980s and 2006. The rate now stands at 12.8%.
- In nearly 40% of premature births, the cause is unknown. Main known routes leading to premature labor are infections/inflammation, maternal or fetal stress, or bleeding or stretching of the uterus.
- Preterm infants are at greater risk for lasting disabilities such as cerebral palsy, intellectual disabilities, learning difficulties, chronic lung disease, and vision and hearing problems. Half of all neurological disabilities in children are related to premature birth.
- The emotional toll of preterm birth on families is huge. Day-to-day life is disrupted. Families face financial stress.
- Preterm birth is a serious health problem that costs the U.S. more than \$26 billion every year, according to the Institute of Medicine. Costs include: \$16.9 billion for medical care, \$1.9 billion for maternal delivery, \$611 million for early intervention services, \$1.1 billion for special education services, and \$5.7 billion for lost household and labor market productivity.
- Every year around the world, more than 3 million stillbirths occur, and more than 1 million babies die because they were born preterm.

### Tennessee Preterm Births

- In 2006, 1 in 7 babies (14.8% of live births) was born preterm.
- Between 1996 and 2006, the rate of infants born preterm increased more than 17%.
- The rate of preterm is highest for black infants (19.4%), followed by whites (13.7%), Native Americans (13.0%), Hispanics (12.1%), and Asians (10.9%).

### Internet Resources

- March of Dimes – Prematurity  
[www.marchofdimes.com/prematurity](http://www.marchofdimes.com/prematurity)
  - Global Alliance to Prevent Prematurity and Stillbirth  
[www.gapps.org](http://www.gapps.org)
- Primer source: March of Dimes website. ■

## PREVENTING PRETERM BIRTH *from page 1*

### Animal Studies

Muglia's research program on preterm birth includes both animal and human studies. His first efforts, which began more than a decade ago, involved studying genetically altered mice as a means of defining the pathways for the timing of birth in mice. The studies revealed that the physiology of timing of birth in mice is controlled by physiological changes that lead to an abrupt fall in the circulating progesterone levels. Unfortunately, this discovery was not helpful for understanding human preterm birth, because in human pregnancy, the progesterone levels never fall and are at their very highest at the end of pregnancy.



### Human Genetic Studies

The next step in Muglia's research was to investigate whether there was evidence for a genetic contribution to variations in the timing of human birth. Muglia, who was then on the Pediatrics faculty of Washington University in St. Louis, used the Missouri Maternal Infant Birth Database to examine the risk of recurrence of preterm birth. That database includes 1.5 million births in Missouri from 1978 to 1997. His research team analyzed all pregnancies to a given mother during that time period. They found that one of the biggest predictors of preterm birth to a given mother was whether she had had a previous preterm birth. Moreover, for a mother who had had a preterm birth, her next preterm birth was likely to occur in the same gestational week as her previous preterm birth.

"It's difficult to envision a sporadic environmental influence that causes a mom to deliver preterm at the same time," Muglia said.

In his studies, Muglia also has examined racial disparity in preterm birth, which provides additional evidence of a genetic contribution to the timing of birth. "Understanding why African-American women in the U.S. have twice the risk for preterm birth as compared to Caucasian women is one of the most critical areas to understand," emphasized Muglia. He indicated that the risk persists even after adjusting for a variety of factors such as socioeconomic status, maternal age and education, and prenatal care.

In another of Muglia's studies, he found that the birth timing of identical twins is more similar than the birth timing of siblings who are not identical twins. This finding suggested that about 30% to 40% of birth timing was due to genetic factors.

### Next Steps

With evidence of a genetic predisposition to prematurity, Muglia is now seeking to isolate the genes involved in preterm birth. Over the past 5 years, his research team has begun collecting biological samples from families in which there have been multiple spontaneous episodes of unexplained preterm birth. These families are being compared to families in which all the children have been born full-term. In addition to U.S. families, families are being recruited in Finland, where there is high-quality prenatal care, a low rate of preterm birth, less disparity in socioeconomic factors or risks related to maternal age or health habits, and the population is relatively homogeneous genetically.

This research is proceeding on the hypothesis that the genes involved in the timing of human birth would have the specific signature of rapid

evolution in humans as compared to other mammals, including higher primates, since the human genome varies in only about 1% of its genetic coding. A human infant head is roughly three times the size of that of a chimpanzee, in comparison to their body weights, but at the same time the human pelvis is relatively narrow to accommodate bipedal locomotion. Thus, human gestation may have had to push to the earliest time compatible with infant survival while the infant head can still be delivered through a narrow birth canal.

This line of research is being funded by the March of Dimes and the Burroughs Wellcome Fund. Muglia also is chair of the Burroughs Wellcome Initiative on Preterm Birth, one of whose goals is to attract investigators to the field.

Muglia points out that until recently, research funding nationally has been focused primarily on improving treatment of premature infants—which has advanced remarkably—but without addressing the need for preventing preterm births. Two years ago, the Institute of Medicine and the American Academy of Sciences targeted the prevention of preterm births as a major area for analysis.

"Right now there is no medicine that has proven effective in stopping preterm labor once it starts," Muglia indicated. "It would be great to have an intervention to minimize the likelihood that preterm labor starts or, if it does, to keep the process from progress to early birth. That's what we hope will happen through our studies." ■



TRANSITIONING INTO ADULTHOOD *from page 1*

The second is that these teachers are not adults but their high school peers.

With funding from a Marino Discovery Grant, Hughes is now adapting and piloting this peer buddy model for high school students on the autism spectrum. (See article p.5)

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**Postsecondary Education**

“Postsecondary education for students with intellectual disabilities is a national movement that has gained momentum over the last 5 years,” said Robert Hodapp, Ph.D., professor of special education and research director of the VKC UCEDD. The impetus comes from two directions, he explained. School systems serve these students from 3 to 22 years, but research demonstrates that after students leave school, “not a lot is happening.” Employment rates are very low. The second impetus is from these students themselves—like their peers, many want to have a college experience.

Currently the U.S. has more than 150 programs where students with disabilities attend college or have a college-like experience (see [www.thinkcollege.net](http://www.thinkcollege.net)), but Tennessee has lacked such programs. In 2006, with leadership from the Tennessee Developmental Disabilities Network, the Tennessee Postsecondary Education Task Force was organized to work with colleges and universities to develop Tennessee options. In 2008, the Tennessee Council on Developmental Disabilities issued a call for proposals; the Vanderbilt Kennedy Center

applied and received funding for 3 years to develop a model program that can be replicated at other Tennessee colleges and universities. Elise McMillan, VKC UCEDD co-director, and Hodapp are continuing to work with the Tennessee Task Force and a national consortium of universities to help develop other programs in Tennessee.

Next Step at Vanderbilt, the VKC postsecondary program, will enroll its first group of eight students in January 2010, who will attend for 2 years.

Next Step will have three components. Students will enroll in (1) a Vanderbilt course based on student interests and skills, (2) an independent living skills course, and (3) one of nine vocational programs at Tennessee Technology Center of Nashville (a Next Step partner), with related internships. Students will be supported by Vanderbilt students in Special Education and in the Vanderbilt Best Buddies Chapter.

“Next Step will provide a college experience as well as work training, with one of the desired outcomes being employment,” Hodapp said. For information, contact Tammy Day, Next Step director, (615) 343-0822, [tammy.day@vanderbilt.edu](mailto:tammy.day@vanderbilt.edu).

**Transitions Clinic**

For youth with co-occurring intellectual disabilities and mental health issues, the transition from school to adult life can be especially stressful. With funding from the Merck Fund, the VKC and the Department of Psychiatry collaborated to establish the School to Adult Transitions Clinic at

Vanderbilt (SAT-V), which is directed by Bruce Davis, Ph.D., assistant professor of psychiatry. Elisabeth Dykens, Ph.D., professor of psychology, is principal investigator.

“The partnership with Psychiatry is crucial,” Davis said, “because it’s so important to connect youth with developmental disabilities with mental health treatments.” He emphasized that the transition from school is further complicated by a transition from school-administered services to a complex adult service system. “We help bridge that gap,” he said.

Clinic services include individual as well as group therapy, in which youth learn core social skills that are valuable in work and community living. The Clinic also provides applied behavior analysis services and psychopharmacological treatment and consultation.

Training future professionals is an additional program goal. Special education students are Clinic interns in preparation for certification as behavior analysts. In Fall 2009, Vanderbilt doctoral students in clinical psychology will complete a Clinic practicum.

“We’re developing a model that can be replicated elsewhere in the country and is an efficient, streamlined multimodal model of support,” Davis summarized, taking into account medical, psychiatric, psychological, and environmental or behavioral perspectives as youth are supported.

For information on the SAT-V Clinic, contact (615) 343-9710, [kellye.a.carman@vanderbilt.edu](mailto:kellye.a.carman@vanderbilt.edu). ■

**Director’s Message Engagement and Happiness**

For the past several decades, our field has been consumed by de-institutionalization and community inclusion. We still have a great distance to travel, even though special education and family support services have expanded, as have community-based programs. In some instances, these programs also are embracing the concept of self-determination, empowering individuals with intellectual or other developmental disabilities to make their own life choices.

Now, as community inclusion evolves, the time is ripe to shift to an increased focus on positive internal states. It is time to ask what persons with intellectual or other developmental disabilities need in order to live a happy, fulfilling life. Quality-of-life researchers have done well asking how satisfied people are as “consumers” of services, but have done poorly asking about happiness, engagement, and well-being.

Breaking tradition with the usual focus on what is wrong with people, positive psychology instead asks what contributes to people doing well, beyond the

amelioration of psychological distress. Positive psychology offers a framework for research and intervention. It is a way of thinking that jolts us away from the negative and toward the positive.

Just as people with specific syndromes are prone to particular problems, so, too, are they prone to unusual areas of strength. Examples include the abundance of positive affect in children with Down syndrome, the strengths in visual-spatial tasks in persons with Prader-Willi syndrome, and musical interests and skills in persons with Williams syndrome. At the Vanderbilt Kennedy Center, increasingly research and practice consider ways to explore and to build strengths of individuals as well as how to assist with challenges.

At a recent VKC Leadership Council meeting, our community ambassadors heard about three VKC programs that focus on building the positive skills of young persons with intellectual or other



Elisabeth Dykens

developmental disabilities (see article p.1). In high schools, peer mentors will be learning to help students with autism gain the social skills to be more fully included. Soon students with intellectual disabilities will be learning on the Vanderbilt campus and gaining the education and skills for them to be successful in their work and leisure lives as adults. Finally, young persons whose

future success is at risk because of serious psychological or behavioral issues are being supported through the School to Adult Transitions Clinic at Vanderbilt.

The Vanderbilt Kennedy Center joins hands with partner organizations in national networks as well as with our local partners to focus on strengths as well as challenges, so that individuals with disabilities will increasingly lead fulfilling, meaningful lives in our communities. ■



## Siblings Share Their Stories BY COURTNEY TAYLOR

**“M**eeting other siblings who have brothers or sisters with disabilities was so important to me. It was a beautifully humbling experience to see the incredible devotion to loved ones that permeated that room.” - TABS Conference attendee

On April 3-4, 2009, adult brothers and sisters who have siblings with disabilities gathered for the First Annual Tennessee Adult Brothers and Sisters (TABS) Conference. Joined by students and professionals interested in sibling issues, attendees learned about the myriad issues pertinent to the lives of siblings, became more familiar with supports available in Tennessee, and were given an opportunity to meet other adult siblings.

“Establishing TABS and holding our first Conference are such important steps,” said Ashley Coulter, Sibling Programs coordinator. “Sibling support programs exist for younger people but, before TABS, there was nothing in Tennessee to provide an outlet of support for adult siblings of individuals with disabilities. The need for support does not go away just because you get older. If anything, needs get more nuanced and more difficult to navigate on your own.”

### Sibling Issues

The Conference included sessions on sibling research, futures planning, legislation and advocacy, caring for the caregiver, and family dynamics.

Julie Lounds Taylor, Ph.D., assistant professor of pediatrics and special education at Vanderbilt, reported on her current research using the Wisconsin Longitudinal Study, specifically as it



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pertains to the life course impacts of having a sibling with mild intellectual disabilities.

In the session on futures planning, panelists reported that the greatest obstacles to planning for the future are not knowing when, where, and how to start the process, and not knowing the social services system. Siblings in attendance were encouraged to work with life and estate planners, sooner rather than later, and to revisit and adapt plans frequently to meet changing needs.

Tennessee State House Representative Mark Maddox shared advice on how to best reach and have an impact on legislators. William Edington, public policy director of the Tennessee Council on Developmental Disabilities, educated siblings on current legislation that could impact their lives and the lives of their brother or sister.

Pam Bryan, interim executive director of the Brain Injury Association of Tennessee, in a session on caring for the caregiver, reminded siblings to take care of themselves. She offered techniques on managing stress, avoiding isolation, and asking for and accepting help.

### Personal Stories

“I want to encourage each of you to tell your story,” said Carolyn Baker, Ed.D., a sibling and author of *Last To Leave Home*. “I told our story because I wanted to honor my brother. I wanted to help others who might be making major decisions about their loved ones with special needs. I wanted to reach out to those who have never known a person with special needs, and to educate them on the positives—as well

as the challenges—of living with someone with disabilities. Will you tell your story?”

Keynote speakers Doreen Croser, executive director of the American Association of Intellectual and Developmental Disabilities, and Laurie Stallings-Vanderpool, the sibling of John Mark Stallings, both shared stories about their experiences having a brother with a disability and shared words of encouragement.

“I don’t know what is ahead for my brother and me,” said Croser. “I’ll continue to do the best that I can and that’s what I encourage you to do. Develop a plan and voice that plan to others. Learn about your options and encourage your loved one to live a satisfying life. Our brothers and sisters are depending on us.”

The TABS Conference was sponsored by the VKC UCEDD, Tennessee Council on Developmental Disabilities, University of Tennessee Boling Center for Developmental Disabilities, Harwood Center, TigersEye Advisory, Siblings United, and East Tennessee State University. For information on TABS, link to Services at [kc.vanderbilt.edu](http://kc.vanderbilt.edu). ■

## Art Through the Eyes of Autism BY COURTNEY TAYLOR



Burtonwood the Frog, by Ben Liske

**“**I colored and painted Sponge Bob and Patrick,” said 7-year-old Jaylon Weston, speaking at a reception honoring artists featured in the exhibit,

Art Through the Eyes of Autism. “I colored Lightning McQueen. Can you draw a picture too? April 2nd was Autism Day. I had a cartoon class. Bradley, Ashley, Derrick, Cody, and Jake are drawers too. Thank you.”

The Art Through the Eyes of Autism exhibit showcases visual artists with autism living in Middle Tennessee. It is co-sponsored by the Vanderbilt Kennedy Center, the Autism Society of Middle Tennessee, and VSA Arts Tennessee.

“This exhibit is exciting and unique because we have such a range of talents, abilities, and media,” said Gretchen Herbert, recreation and arts coordinator at the Vanderbilt Kennedy Center. “The artists range in age from 7 to 43.

Some are just getting started and some are professionals with gallery backing. We have everything from wall sculpture to photography and pencil sketches. We are very proud of this diverse and exciting show.”

The exhibit is open April 1-July 31, 2009. It is located at the Vanderbilt Kennedy Center Exhibit Area in the lobby of the 2nd floor. A portion of the exhibit, with artwork produced at a VSA Arts Tennessee cartoon workshop with cartoonist Timothy Olyphant, is being showcased at the Tennessee Performing Arts Center.

For information on the VKC Arts and Disabilities Program, contact [gretchen.herbert@vanderbilt.edu](mailto:gretchen.herbert@vanderbilt.edu), (615) 321-8761. ■



## High School Peer Mentoring BY JAN ROSEMERGY



**H**igh school is a period in development when fitting in or belonging becomes all important. Being included is a challenge for students on the autism spectrum, since difficulty with social relationships is a hallmark feature of this neurodevelopmental disorder. Now pilot work is underway on an innovative model to promote the inclusion of high school students with autism spectrum disorders (ASD).

“We’re using proven practices to teach social skills,” said Carolyn Hughes, Ph.D., professor of special education, who has devoted her career to developing ways of helping youth with intellectual or other developmental disabilities make a successful transition from school to adult life. “What’s unique, we think, is that peers will be the teachers of the social skills in various settings across the high school, which should help the students with ASD generalize what is learned in one setting to another.”

Hughes’s co-investigator on this Marino Autism Research Institute Discovery Grant is

Nicolette Brigham, Ph.D., TRIAD Outreach and Education coordinator and research associate in special education.

The program has three components: (1) teaching valued social skills to students with ASD, using strategies such as direct instruction, modeling, and role plays; supporting peer mentors and building their knowledge of autism; and (3) peer mentors “brokering” opportunities for social interactions in varied situations.

“The curriculum will be individualized,” Brigham said, “since for students with ASD, each may have quite different social behavior.” Because intervention research on social skills training has tended to focus on adults teaching young children, this intervention at the high school level using peer mentors represents a novel approach.

“Schools are more tolerant of individual differences than the workplace,” Hughes said. “In adulthood, social skills make it or break it.” ■

## START-ED for Pediatricians BY JAN ROSEMERGY

**“L**earn the Signs—Act Early”<sup>\*</sup> is a call to be alert to young children’s developmental milestones, especially those that may indicate risk of autism spectrum disorders (ASD), and to obtain an assessment if there are developmental concerns. Children with developmental delays should begin receiving early intervention services quickly in order to maximize their development. Too often families experience long waits for assessments for ASD before initiating intervention services. Since the majority of young children see pediatricians or family physicians for “Well Child” visits, START-ED was initiated to train pediatricians to perform rapid autism diagnostic consultations to expedite appropriate early intervention services when concerns about ASD are present.

### First Stage

The impetus for Screening Tools and Referral Training—Evaluation and Diagnosis (START-ED) came from the Tennessee Chapter of the American Academy of Pediatrics (AAP), in response to the AAP recommendation that pediatricians screen for ASD at 18 and 24 months, as well as to the need in Tennessee for more ASD assessment options. With initial funding from a TennCare grant, TN AAP leadership collaborated with TRIAD to pilot START-ED.

Five Middle Tennessee community pediatricians were invited who had practices in underserved geographic areas, had previously completed training to use clinically validated screening tools, and were



willing to commit to all the program obligations. The end goal was the ability to assess children, 2-3 years, for ASD within a 1-hour time frame. Training included use of the M-CHAT (Modified Checklist for Autism in Toddlers), STAT (Screening Tool for Autism in Two Year Olds and Young Children), and developmentally sensitive interviewing.

The START-ED training had three phases. It began with an intensive 2-day workshop, which included a series of interactive training experiences as well as real-time evaluations of children. Next, videotaping of practice assessments was done within each practice. A TRIAD clinician reviewed tapes and provided feedback. Finally, each pediatrician conducted ASD assessments independently, completed a diagnostic certainty checklist, and referred families for independent evaluation by TRIAD clinicians. Referred families

received a no-cost evaluation conducted by TRIAD without knowledge of the pediatrician’s previous diagnosis.

“The most promising finding was that many young children with ASD could be accurately identified within the 1-hour basic consultation model,” said Zachary Warren, Ph.D., director of the TRIAD PSEP Clinic and assistant professor of clinical pediatrics and clinical psychiatry.

### Second Stage

In March 2009, with funding from the VKC LEND grant from the Administration on Developmental Disabilities to expand ASD training for health care professionals, a second START-ED training workshop was conducted with 10 practitioners, including a pediatric neurologist and a pediatric nurse practitioner, and a physician each from East and West Tennessee. “Our ultimate goal is to have a state network where young children can be screened and referred,” Warren said.

The training model was similar, with the addition of a procedure to find out how families perceive the process.

“This type of model could be powerful in changing the problematic waiting period that currently results in delays in ASD diagnosis and intervention. What matters most is getting children the help they need.”

<sup>\*</sup>Centers for Disease Control and Prevention, [www.cdc.gov/ncbddd/autism/ActEarly](http://www.cdc.gov/ncbddd/autism/ActEarly). ■



## Grants Awarded

### Molecular Analysis of Presynaptic Choline Transporters

Randy Blakely, Ph.D. (Pharmacology)  
National Institute of Mental Health

### Mechanisms of Apoptotic Neuron Clearance in the Peripheral Nervous System

Bruce Carter, Ph.D. (Biochemistry)  
National Institute of Neurological Disorders and Stroke

### Multisensory Interactions in the Lateral Geniculate Nucleus

Vivien Casagrande, Ph.D. (Cell & Developmental Biology)  
National Eye Institute

### Visual System Organization and Development

Vivien Casagrande, Ph.D. (Cell & Developmental Biology)  
National Eye Institute

### The Role of Claustrum in Substance Abuse and Cognition

Ariel Deutch, Ph.D. (Psychiatry)  
National Institute on Drug Abuse

### Prevention of Depression: Impact on the Transition to Early Adulthood

Judy Garber, Ph.D. (Psychology & Human Development)  
National Institute of Mental Health

### RTI for Determining Risk, Providing Prevention, and Identifying Reading Disability

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

### Responsiveness-to-Instruction to Strengthen the Academic Performance of Students With Reading and Math Disabilities

Doug Fuchs, Ph.D. (Special Education)  
Institute of Education Sciences

### Dynamic Assessment to Predict First Graders' Mathematics Development

Lynn Fuchs, Ph.D. (Special Education)  
Institute of Education Sciences

### An Efficacy Trial of Enhanced Milieu Teaching Language Intervention for Toddlers With Language Delays

Ann Kaiser, Ph.D. (Special Education)  
Institute of Education Sciences

### The Auditory Phenotype of Kv Channel Gene Mutations

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

### Physiology of Periaqueductal Gray Dopamine Neurons

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

### Predicting Useful Speech in Children With Autism

Paul Yoder, Ph.D. (Special Education)  
National Institute on Deafness and Other Communication Disorders

## Leading the Vanguard of Discovery

Kathleen Lynne Lane, Ph.D.

Associate Professor of Special Education

Vanderbilt Kennedy Center Investigator

Joined Vanderbilt Kennedy Center 2005



### Research Interests

Lane's research interests include studying the relation between academic and social behavior with children at risk for emotional and behavioral disorders, and developing multilevel interventions to prevent the development of and response to instances of emotional and behavioral disorders.

### Principal Investigator

- Project SUPPORT & INCLUDE, State of Tennessee Department of Education
- Project WRITE: The Effects of Strategy and Self-Regulation Instruction on Students' Writing Performance and Behavior: A Preventative Approach, Institute for Educational Sciences
- Project Prevent: Screening and Intervening to Prevent the Development of Learning and Behavior Problems, U.S. Department of Education, Office of Special Education and Rehabilitative Services
- Project PBS: A Three-Tiered Prevention Model to Better Serve All Students, U.S. Department of Education, Office of Special Education and Rehabilitative Services

### Clinical and Training Interests

Lane's clinical interests involve working with schools to design, implement, and evaluate comprehensive, three-tiered models of prevention to prevent and respond to learning problems. Lane is faculty director of the Britt Henderson Training Series for Educators, a VKC UCEDD program.

### Honors and Awards

- Early Career Research Award, Division of Research, Council for Exceptional Children, 2005
- Outstanding Educator, Outstanding Leadership Honoree of Peabody College, 2004, 2006
- Shining Apple Award, service award, Williamson County Schools, 2008

### Selected Publications

Lane, K. L., Kalberg, J. R., & Menzies, H. M. (2009). *Developing school-wide programs to prevent and manage problem behaviors: A step-by-step approach*. New York, NY: Guilford Press.

Lane, K. L., Kalberg, J. R., & Shepcaro, J. C.

(2009). An examination of quality indicators of function-based interventions for students with emotional or behavioral disorders attending middle and high schools. *Exceptional Children*, 75, 321-340.

Lane, K. L., Kalberg, J. R., Parks, R. J., & Carter, E. W. (2008). Student Risks Screening Scale: Initial evidence for score reliability and validity at the high school level. *Journal of Emotional and Behavioral Disorders*, 16, 178-190.

### Education

B.A., 1988, Psychology, University of California, Riverside

M.A., 1992, Special Education, University of California, Riverside

Ph.D., 1997, Special Education, University of California, Riverside

### Attraction to Developmental Disabilities Research and Reasons for Membership

Serving students with antisocial behavior patterns poses a major challenge to teachers, school psychologists, and administrators alike. These students exhibit academic underachievement—particularly in the area of reading—and demonstrate a host of maladaptive behaviors that make it difficult to serve these children in general education settings. My research program focuses on exploring the relation between academic achievement and behavior patterns in an effort to design, implement, and evaluate multilevel, school-based interventions to (a) prevent the development of learning and behavior problems for students at risk for antisocial behavior and (b) remediate the deleterious effects of existing problems exhibited by students with antisocial behavior.

I have been impressed with the social validity and scientific rigor of the quality of the studies conducted by VKC investigators. I hope that the work that my project staff and I are conducting will be equally meaningful to the research and teaching communities. ■



## The Reading Clinic: A Parent Asks For Help

BY COURTNEY TAYLOR

“I promised McKenzie I wouldn’t cry,” said a crying Dominique Miller to an audience of Vanderbilt Kennedy Reading Clinic graduates, their families, and reading tutors. “Every single one of you should be very proud of your accomplishments. I know I am so proud of McKenzie. As a parent, I want to encourage McKenzie to be the best McKenzie that she can be. I want her to realize that to be the best she can be sometimes means she will need to ask for help. I couldn’t help McKenzie with her reading. I tried and tried. Nothing was working until finally, we decided to ask for help.”

Miller realized that McKenzie was having trouble learning to read when she was in kindergarten. McKenzie’s teacher, and subsequent teachers, said that while McKenzie was bright, while she had a large vocabulary, and while she had a great willingness to learn, she experienced great difficulty in mastering the skill of reading. One in five children experiences difficulty when he or she is learning to read, and 75% of struggling readers in the third grade will still be struggling in the ninth grade.

Determined to beat those odds, Miller enrolled McKenzie in a Vanderbilt Kennedy reading research project and later was referred to the Reading Clinic. Coordinated by Caresa Young, Ph.D., the Reading Clinic uses evidence-based reading instruction developed by Doug Fuchs, Ph.D., and Lynn Fuchs, Ph.D., the Clinic faculty



Caresa Young, McKenzie Broyles, and Dominique Miller

directors and professors of special education.

Reading Clinic services are supported by family fees. Thanks to philanthropy, need-based scholarships also are available.

“I was honest with Dr. Young when I called,” said Miller. “I didn’t have the money to send McKenzie, but I was so grateful when I found out there was a scholarship available for her. There are a lot of kids who need this service who can’t afford it. Reading is so important and when kids struggle with it they can have low self-esteem. We all know that can lead them to make poor decisions.”

Students receive one-on-one intensive instruction. Tutors are Peabody College undergraduate and graduate students who are preparing for teaching careers. Tutors gain

experience in evidence-based best practices in reading instruction and assessment.

“McKenzie is such a great student to tutor,” said graduate student Megan Bourgal. “She works so hard to achieve the high standards she sets for herself.”

Miller noticed a difference in McKenzie almost immediately after she began her tutoring sessions. The changes became noticeable when McKenzie came from her sessions smiling. Then she began smiling on the way to the sessions. When they would read together at home, McKenzie would get stuck on a word and instead of getting anxious and putting the book down, she would sound it out and read the word. When McKenzie asked for books for Christmas, Miller said her heart filled with joy.

“It’s just so good to see her trying,” said Miller. “It’s also such great exposure for her. She has had two different tutors who come from different states. Not only is she learning to read better, but she is also meeting people from all over the country who are pulling for her to succeed. She is also seeing all of the Vanderbilt college students walking to class. She is being exposed.”

McKenzie’s improvement in reading and her higher confidence levels have been recognized by her teachers at school. She went from making Cs and Ds to being on the honor roll. At the graduation ceremony, Miller announced that McKenzie had received a school award, for the student “most improved in reading.”

For information contact Caresa Young, Ph.D., (615) 936-5123, [caresa.l.young@vanderbilt.edu](mailto:caresa.l.young@vanderbilt.edu). ■

## Siblings Face Challenges

People who have a sibling with a mental health disorder are more likely to experience episodes of depression at some point in their lives, say researchers who analyzed four decades of data. Additionally, they found that people who have a sibling with low IQ are more likely to live near that brother or sister but to be somewhat emotionally detached from that sibling. The findings were reported in the *Journal of Family Psychology* (December 2008).

“So little is known about the impact that a person with low IQ or mental health disorder has on the psychological and social development of his or her siblings, especially beyond childhood,” said the study’s lead author, Julie Lounds Taylor, Ph.D., assistant professor of pediatrics and special education and VKC researcher. “Our findings highlight the need for siblings of persons with mental health disorders to be aware of their own mental health

needs throughout their lifetimes.”

The study was conducted by researchers at the University of Wisconsin–Madison, where Taylor was an NICHD postdoctoral fellow and assistant research scientist at the Waisman Center. The team identified 351 people from the 46-year Wisconsin Longitudinal Study who had at least one sibling with either a low IQ or a mental health disorder. The comparison group had 791 people who did not have a sibling with a mental health disorder or low IQ.

The researchers found that people who had siblings with a mental health problem were 63% more likely to report having a depressive episode during their lifetime. They also found that siblings of persons with low IQs were 18% more likely to live in the same state as their brother or sister than those in the comparison group. However, they were significantly less likely to have contact with the sibling with intellectual disability, reporting an average of 13

fewer contacts a year with that sibling than the comparison group. In addition, they reported feeling less emotionally close to their siblings.

The researchers found that those who had a brother with a mental health disorder had lower levels of psychological well-being than those in the comparison group. They did not see this effect when looking at those who had a sister with a mental health disorder. This suggests that genetics may not be the only link to poorer mental health among siblings of persons with mental health disorders, but that the social environment also is important.

“Our study suggests that environmental and social factors also play a role in why these siblings may be at a greater risk for poor mental health,” said Taylor. *Article is based on American Psychological Association March 2009 news release.*

Note: Tennessee Adult Brothers and Sisters (TABS) is a sibling support and networking system; contact [ashley.coulter@vanderbilt.edu](mailto:ashley.coulter@vanderbilt.edu), (615) 343-0545. ■



## Claire Speaks Up BY COURTNEY TAYLOR

Claire is dressed up in a lion suit and she is roaring. She is crawling on all fours through large rings being held by her Susan Gray School (SGS) classmates. Each time she crawls through, she stands back up on her own two feet, opens her mouth really wide and she ROARS! Claire is 3 years old.

Claire's preschool teacher, Ms. Mullins, moves away from the "circus" station and puts on a sound-field amplification system headset. She turns the system on and sings a song about cleaning up the classroom. Claire hears the song and immediately begins to sing along. She takes off the lion suit and joins her classmates in tidying up the classroom.

"We discovered that Claire had hearing loss when she was about 4 ½ months old," said Claire's mother Michelle. "I always credit my husband with her early detection, because as early as 2 months of age, he was telling me he didn't think she could hear. I didn't want to believe that was true. I just kept saying, 'Oh no, she's fine... she's fine.' Well, one day I was holding her in the kitchen and she was facing me. Matt blew his coach's whistle, and she didn't flinch. She did not turn to see where the noise was coming from. She did not jump—nothing. That was the turning point for me to think maybe we needed to look into it."

Claire's parents discovered that she had not received a newborn hearing screening at the hospital when she was born. Then mandatory in 43 states, newborn hearing screenings were not required in Tennessee. Claire's parents, disheartened to learn of the omission of the testing, eagerly sought out the opinions of audiologists at Vanderbilt who diagnosed Claire with having profound sensorineural bilateral hearing loss. Claire received her first cochlear implant a week after her first birthday, and her second about 5 months later.

### Preschool

Claire's parents enrolled her in the Susan Gray School after her Tennessee Early Intervention System (TEIS) service coordinator recommended the program.

"We were thrilled when Claire started at the Susan Gray School," said Michelle. "Right from the start, there was never a question in my mind that it was a good fit. The environment was so nurturing. They were there with Claire and with us throughout her surgeries. They went through the process of her getting one implant, and then getting the second implant. They had never had a



TONY MAUPIN

student with cochlear implants, so they were learning right along with us."

Because hearing loss, when not detected early, can lead to delays in speech, language, and cognitive development, Claire's parents worked with their TEIS service coordinator, therapists, and SGS teachers to develop an Individualized Family Service Plan (IFSP). Though Claire was about 13 months old chronologically when she began at SGS, her "hearing age" was said to be zero. Claire's IFSP spelled out goals and strategies to help raise her hearing age.

"We've worked with Claire in the classroom to be sure she is actively listening and responding to us with words and not gestures," said Ms. Mullins. "We have also worked with Claire to be sure she is using her voice to tell us and to tell her peers what she wants and how she feels. 'It's my turn now.' 'Please give me a cookie.' We work to encourage her to expand her use of language. If she says 'help,' I might mirror her and add 'help me, please.' We want her to use words as much as she can. It was also a goal of her IFSP to teach her to consistently wear her implants in group settings, and to teach her to use her words to tell an adult if they stopped working or fell off. 'Oh no! My ears fell off.

Help me to put them on, please.'"

Claire's classmates understand that they are not to touch the external portions of Claire's implants that sit behind her ears. The teachers formally educated the class on "Claire's ears." They know the implants are not toys and that they help her hear. Her classmates were a bit curious when the teachers first began using the sound-field fm system, but now they barely notice it. They know it is a tool that allows Claire to hear the teacher's voice better. Now they only mention it when they want to remind the teachers not to forget to put the headset on so that Claire can hear.

Ms. Mullins also is kept informed of what Claire is working on in her therapy sessions, in order that she might continue the work in the classroom. Michelle and Claire's father, Matt, are very grateful that Claire's teachers are willing and enthusiastic about working with her therapists, and are happy to report that at 3 years of age, Claire is now hearing within the typical range.

### Claire's Law

In addition to staying busy with Claire's surgeries, therapies, and education, Claire's parents made it a priority to contact their local legislators to express their interest in putting together a bill to make newborn hearing screenings mandatory in Tennessee. They worked with the

Tennessee Disability Coalition to draft the bill and were pleased to see it introduced before the State Legislature in January 2008, with an amendment instructing that the law be called "Claire's Law." Claire's Law passed and went into effect on July 1, 2008.

"When we found out that Claire didn't receive a newborn hearing screening, and when we found out that 43 other states had a law requiring that children be screened for hearing before they left the hospital—we just... That upset us," said Michelle. "We felt like there was really nothing we could do about not knowing about Claire's hearing loss, but working on that bill was a way to make something positive come from our situation. We feel good knowing that babies in Tennessee won't leave the hospital without having a hearing screening. It doesn't guarantee things, because there are conditions that are progressive, and things can happen, but even the awareness, even the fact that parents know that there is such a thing—because we didn't, when we left the hospital—is very comforting. Early intervention is so important. Claire's Law will help families to learn about their options as early as possible." ■





## Five Life Lessons for Dyslexia

BY NICOLE DAVIS AND GREG DAVIS



THE DAVIS FAMILY



THE DAVIS FAMILY

Greg and Nicole Davis, as children and now

**G**reg and Nikki Davis are a brother-sister team who for the last 5 years have spoken at conferences about lessons for success for persons with dyslexia. A successful businessman in his mid-thirties, Greg has severe dyslexia. Nikki is a postdoctoral fellow at Vanderbilt University investigating the neurobiological correlates of learning disabilities (LD). Together, they provide families with a positive message about dyslexia, in which Greg uses stories to convey his life lessons and Nikki presents supporting research.

### Lesson 1: Support your child with dyslexia.

Greg was diagnosed with dyslexia in the fourth grade, long after his parents began the process when he was 5 years old. "Getting an accurate diagnosis was frustrating," Greg says. "I consistently scored within the average range on clinical tests." Eventually, Greg's disability became severe enough to qualify for services. Test results from the fourth grade explain, "In comparison with previous testing, problem areas were not so clearly defined because [Greg] was able to compensate...." Greg completed 2 years of intensive, phonologically based reading intervention; however, he required specialized instruction and classroom accommodations for the rest of his schooling. Today, he remains a slow reader.

Three decades of research findings show that dyslexia is caused by a weakness in the phonological component of language. Unfortunately, as in Greg's case, phonological weaknesses tend to go unnoticed in school until a severe reading disorder develops. Therefore, a major part of supporting a child with dyslexia is a comprehensive evaluation of cognitive and linguistic skills, intensive instruction, and

classroom accommodations for the processing weaknesses, usually through college.

### Lesson 2: Help your child face challenges.

A significant challenge caused by Greg's poor reading ability was a strong dislike of books. "Just being in a bookstore made me uncomfortable. I could not understand what people saw in the jumble of words." Greg's parents read books to him and encouraged him to read on his own. Greg remained a reluctant reader until he entered the Peace Corps after college. With few distractions, he read over 60 books by the time he left Honduras. He is happy to say that now he reads books for pleasure.

Years of research show that children with dyslexia spend less time reading than their same-age peers. This results in fewer exposures to the words, sentence structures, and world knowledge contained within books, which is a major part of literacy development. Children who spend less than 1 minute a day reading tend to score around the 10th percentile on standardized language tests, while children who read 20 minutes a day score in the 90th percentile (Shaywitz, 2003). Fortunately, research indicates that reading to children can compensate for their diminished time spent reading.

### Lesson 3: Teach your child to educate others.

During his freshman year in high school, Greg's parents encouraged him to take responsibility for telling his teachers about his disability and advising them on ways that they could support his weaknesses in the classroom. "At first I was afraid, but I realized that the worst thing they could say was 'no.' I also realized that if I did not ask them for help, then I would never hear 'yes.'" This realization had a significant effect on the way he conducted the

rest of his life: "People like to help others succeed; they just need to know how to do it."

Related to Greg's story, a topic that is often stressed in LD research is the importance of becoming a self-advocate. A self-advocate demonstrates awareness of the disability, is aware of his/her legal rights, and demonstrates competence in communicating rights and needs to authority. With regard to school-age LD, self-advocacy can have a significant effect on remediation because teachers are the best intervention strategy available to children.

### Lesson 4: Success outside of school is important.

Greg struggled to feel successful in school: "A big problem was that I consistently scored below my friends on assignments and tests, although I had spent much longer studying." In fact, he eventually forgot what being successful *felt* like. As he grew older, he began to excel at leadership positions in student government and sports. Greg believes that "the rewarding experiences outside of school provided me with the self-confidence that I needed to push through the challenges I faced everyday in the classroom."

Consistent with Greg's story, individuals with LD have a vague notion of their academic strengths and weaknesses, frequently underestimate their potential as a result of frustration, and consequently have low levels of self-esteem. Research explains that setting attainable goals within and out of school will increase self-confidence levels, because it helps a child to form a definition of what it means to be successful.

### Lesson 5: Teach your child to exceed expectations.

People often ask Greg if he would take a pill to get rid of his dyslexia. He says "no" and thinks that his passion to exceed expectations results from having dyslexia. "I was bad at school and that defined me for a while," Greg explains. "But it motivated me to set goals beyond others' expectations of me. Nothing gets in my way. All individuals with dyslexia have the same potential."

There is no specific research to support this final lesson. It is an accumulation of Greg's experiences and feelings about success. Unfortunately, few studies have been done on individuals with dyslexia who are successful, although Greg is definitely not the only one.

### Resources

\*Shaywitz, S. E. (2003). *Overcoming dyslexia: A new and complete science-based program for reading problems at any level*. New York: Knopf/Random House.

International Dyslexia Association  
[www.interdys.org](http://www.interdys.org)



## Spotlight: A Passion for Education Sue Spickard BY COURTNEY TAYLOR



COURTESY OF SPICKARD FAMILY

Andy and Sue Spickard

**S**ue Spickard became involved with the Vanderbilt Kennedy Center (VKC) and its programs when her grandson, William, was born with Down syndrome. However, William's birth was not the first contact Sue had with programming to support individuals with disabilities and their families. Her career and volunteer activities reveal a remarkable journey from working with at-risk students in the classroom to co-founding a nonprofit organization that generates supports within the community to benefit Nashville public schools.

Spickard received her training in sociology and

elementary education from both Northwestern University and Vanderbilt University. After graduating from Vanderbilt, Spickard began teaching fourth grade in Baltimore, Maryland, at an inner-city school, and eventually transferred to teach classes at the Sidwell Friends School in Washington, D.C.

"You would think my experiences teaching at the two schools would be glaringly different," remarked Spickard. "One was in an area that relied on the steel mills, where parents had been on strike and continually experienced economic hardships. The other, as we all know, now has President Obama's girls enrolled in it. On the surface, you might think the students would be different. I promise you that even though I taught a class of 39 students in that Baltimore school, their ability to learn was no different from the students I taught at Sidwell Friends School. Those two experiences, juxtaposed, taught me a lot about individual capabilities and about nurturing young people as learners."

### Family and Community Involvement

Spickard and her husband Andy moved back to Nashville 47 years ago. She left teaching after the birth of their first child, Susan. Her husband began a private medical practice and eventually joined the faculty at Vanderbilt. Susan is now living in Rocky Mountain, North Carolina, where she works as an emergency room nurse. The Spickards' second child, Anderson, is a member of the Vanderbilt Medical

School faculty, and their third child, David, is the founder and CEO of Jobs for Life, a nonprofit organization in Raleigh, which develops job training programs for underserved populations. Spickard and her husband have 11 grandchildren, and they just celebrated their 50th wedding anniversary.

In the 1970s, as a member of the Junior League of Nashville, Spickard began volunteering with Operation Early Bird. The program placed trained volunteers in kindergarten classrooms to test and to measure language and motor skills to identify students who might have learning disabilities. She also worked as an outreach coordinator with First Presbyterian Church and coordinated volunteers within Monroe Harding, a residential facility for at-risk teens, and in Room in the Inn, which attends to the food and shelter needs of individuals who are homeless.

Spickard also has worked with Renewal House, a long-term recovery community for women with substance addictions and their children. She has served as president of the Cumberland Valley Girl Scout Council and is a co-founder of the PENCIL Foundation, an organization that links community resources with Metro Nashville Public Schools.

"If I had to choose one issue that I am most interested in, I would have to say it is education," said Spickard. "It is what I am passionate about. PENCIL started in my living room. Twenty-seven years ago we had 37 partners. Now we have 500.

*Continued on page 11*

## "Running to Read"

**A**nna Spickard is the big sister with a big heart that any younger brother would be lucky to have. Spickard organized the Team William Mini-Marathon 5K, April 4, which raised \$4,700—see Anna's story. Proceeds benefited the Team William Endowment Fund.

Team William was begun by Andrea McDermott, who combined her love of teaching children with disabilities and her love of running after she began teaching reading to William Spickard, who has Down syndrome. McDermott invited family, friends, and supporters to donate to "Team William" as she ran the Music City Marathon. April 2009 was her fifth year—and although she's now a special education teacher in Washington, she's still in Nashville annually to support this "ultimate race—literacy for children with Down syndrome." Team William has now raised over \$100,000 and provides a scholarship for one student each year. If this year's fundraising goal is reached, the Fund will cover Reading Clinic tuition for two students per year. To donate to Team William, see [www.teamwilliam.org](http://www.teamwilliam.org). ■

## Team William Mini-Marathon BY ANNA SPICKARD

**W**hen I first came up with the Team William Mini-Marathon, I had no idea what I was getting myself into—yet with the help of many people, the event was a great success. My basic idea was to create a 5K race that would raise money for Team William, but I could not have conceived the depth of this undertaking. The Team William Mini-Marathon could not have taken place without the help of family, friends, volunteers, donors, and the support of the Kennedy Center.

I began with the seemingly simple task of choosing a date and location for the race. It was difficult to find a free spring weekend and to reserve an area of Edwin Warner Park. Other things to be done soon became apparent, such as arranging online registration, measuring a course, and obtaining the race clock. My original impression of event preparation dissolved. It was quickly obvious that immense amounts of time and thought would be put into the race. However, I was energized by the vision of the cause and could not have been more excited.

As the days passed, I realized I could not do this



COURTESY OF SPICKARD FAMILY

Anna and William Spickard

on my own. The Kennedy Center supported the cause wholeheartedly and proved to be a vital asset. My mom began working on several assignments, and I recruited a team of volunteers. The volunteer committees had specific jobs such as promoting the race, asking companies to donate food for race day, and running errands. The volunteers made this

*Continued on page 11*



SPOTLIGHT from page 10

It has been incredible to see it grow. It has a very similar philosophy to that of the Vanderbilt Kennedy Center. Both believe in the potential of every child. Every child should be treated well and equally. Children with disabilities should have the same opportunities as children without disabilities.”

William and the Reading Clinic

“We knew that William would be born with Down syndrome,” remembered Spickard. “When William was born, Margaret had specialists and family surrounding her and her beautiful baby. She also became involved at the Vanderbilt Kennedy Center right away. People would make home visits to help with feeding issues, and so our relationship with the Center was intentional very early on.”

William attended the Susan Gray School, has been involved with various research projects, has attended summer camp through the VKC Recreation and Arts Program, and was tutored in the Reading Clinic for 3 years. It was his involvement in the Reading Clinic, and the impression he made on his tutor, Andrea McDermott, that inspired the founding of Team William, an endowment to provide scholarships for students with Down syndrome in the Reading Clinic.

This year, Spickard’s granddaughter and William’s sister, Anna, organized the Team William Mini-Marathon, a 5K walk/run that raised over \$4,000 in scholarships for the Reading Clinic. “I am very proud of Anna,” said Spickard.

Continuum of Care

Spickard joined the Leadership Council in 2006. She serves on the Council’s Outreach Committee. When asked what aspect of the Center is most important to her, she is hard pressed to name just one, since William has been involved in so many.

“William’s needs are always changing,” said Spickard. “Perhaps it is the ability this Center has to provide a continuum of care that might be the most important aspect for William and our family. He is only 12 years old, so there is middle school, high school, and then life after that. We know we can continue to rely on the Center as we encounter these new challenges with William. The ability to offer care throughout the lifespan meets a great need.” ■

TEAM WILLIAM from page 10

event possible. The miniscule tasks compounded and were at times overwhelming, but this was not an issue because of the eagerness and willingness to help from volunteers. They allowed me to keep the big picture and ultimate goal in mind.

As race day approached, barriers were removed that had previously seemed impossible to overcome. The most rewarding part of the planning process had begun. Posters and t-shirts were delivered, and news of the event was seeping into the public. During the week before the Mini-Marathon, I was able to relax somewhat and watch as the results of everyone’s hard work were exposed.

On race day I woke up early and made my way to the site to set up. It was a beautiful spring morning. I could not believe that the Team William Mini-Marathon was actually taking place. People began to arrive. It was so rewarding to see the smiles on the faces of the participants. The general atmosphere was one of excitement and enthusiasm. So many stores had donated food and drinks that we amazingly had more than enough food for the large turnout!

The race began and I was off, driving around the course to insure that everything was in place. The race went smoothly, once again with the help of many volunteers.

Through the planning and execution of the Mini-Marathon, I learned so much about time management, patience, and communication. I also became more confident of myself in a leadership position. I became accustomed to asserting myself, instructing people, making requests, and speaking before large groups. The whole experience was surreal. I had never seen the fruits of my labor revealed more clearly! I was so pleased with the results of the 5K and was overjoyed to be able to impact the lives of one or more children with Down syndrome. Thank you to everyone who made this possible. ■

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

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- **AUGUST 29\***  
Developing and Diversifying Play Routines
- **SEPTEMBER 26\***  
Beginning Toilet Training

## ■ SEPTEMBER 2\*

*Developmental Disabilities*

*Grand Rounds*

Pilot Testing of an Intervention for Preschool Children With Attachment Impairments

Linda Ashford, Ph.D., Assistant Professor of Pediatrics and Psychology; Patti van Eys, Ph.D., Assistant Professor of Psychiatry  
Co-Sponsor VKC Interdisciplinary Training Council and Pediatrics  
Wednesday 8 a.m.

## ■ SEPTEMBER 16

*Neuroscience Graduate Seminar*

Serotonin Modulation of Brain

Development: Impact on

Affective- and Anxiety-Related

Adult Phenotypes

Jay Gingrich, M.D., Ph.D., Associate Professor of Clinical Psychiatry, Columbia University Medical Center; Director, Sackler Laboratory of Basic Science, New York State Psychiatric Institute

Co-sponsor Vanderbilt Brain Institute  
Wednesday 4:10 p.m. Room 1220  
MRB III Lecture Hall

## ■ SEPTEMBER 23

*Neuroscience Graduate Seminar*

Title TBA

Denes Agoston, M.D., Ph.D., D.Sc., Associate Professor of Anatomy, Physiology, and Genetics, Uniformed Services University of the Health Sciences

Co-sponsor Vanderbilt Brain Institute  
Wednesday 4:10 p.m. Room 1220  
MRB III Lecture Hall

## ■ SEPTEMBER 24\*

*Lectures on Development and*

*Developmental Disabilities*

Modeling Fragile X Syndrome and FXTAS in Mice

David Nelson, Ph.D., Professor of Molecular and Human Genetics, Baylor College of Medicine  
Thursday 4:10 p.m.

## ■ OCTOBER 7\*

*Developmental Disabilities*

*Grand Rounds*

Title TBA

Bruce McCandliss, Ph.D., Patricia and Rodes Hart Professor of Psychology and Human Development  
Co-Sponsor VKC Interdisciplinary Training Council and Pediatrics  
Wednesday 8 a.m.

## ■ OCTOBER 7\*

*Britt Henderson Training Series*

*for Educators*

Title TBA

Kathleen Lane, Ph.D., Associate Professor of Special Education  
Wednesday 5-7 p.m.

## ■ OCTOBER 8\*

*Lectures on Development and*

*Developmental Disabilities*

Psychosocial and Biological

Markers of Stress in the Lives of Mothers of Adolescents and Adults with Autism

Spectrum Disorders

Marsha Seltzer, Ph.D., Director, Waisman Center, University of Wisconsin-Madison  
Thursday 4:10 p.m.

## ■ OCTOBER 21\*

*Research Ethics Grand Rounds*

Ethics of Presymptomatic Genetic Testing in the Pediatric Population

Tyler Reimschisel, M.D., Assistant Professor of Pediatrics and Neurology; Director, Division of Developmental Medicine and Cognition; Associate Director, MIND Training Program  
Wednesday 12 p.m.

## ■ ARTS AND DISABILITIES

Vanderbilt Kennedy Center Exhibits

Monday-Friday 7:30 a.m.-5:30 p.m.,  
Information (615) 321-8761

### • AUGUST 10-OCTOBER 2

Looking Forward II

Co-sponsored by Davidson County Mental Health Court, Park Center East, Tennessee Council on Developmental Disabilities, Tennessee Division of Mental Retardation Services, and Tennessee Department of Mental Health and Developmental Disabilities

## ■ BEHAVIOR ANALYSIS CLINIC

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

## ■ READING CLINIC

For students in kindergarten and early elementary grades  
Fall Session September 14-December 11  
Contact (615) 936-5123

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

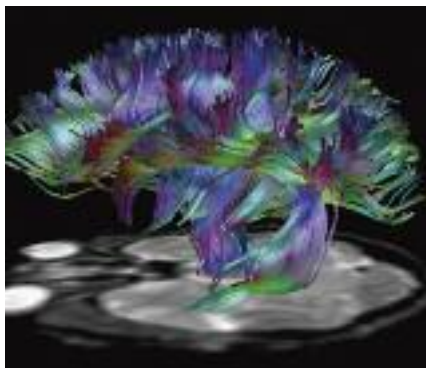
Please keep this calendar and check the Event Calendar on the VKC website for updates. If you wish to receive event announcements by email, send your email address to [amy.pottier@vanderbilt.edu](mailto:amy.pottier@vanderbilt.edu).

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

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



# CALENDAR OF EVENTS | AUGUST-OCTOBER 2009



## ■ SIBLING SUPPORTS

For children, teens, and adults who have a sibling with a disability, chronic health care issue, or mental health concern

For all programs below, contact (615) 936-5118

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

### • SibSaturdays\*

**AUGUST 8, OCTOBER 10**

Ages 5-7 and 8-12 years

Games, friends, conversation

\$10/child or \$20/family

Financial assistance available

Advance registration required

See also SibSaturdays sponsored by Autism Society of Middle

Tennessee and Down Syndrome Association of Middle Tennessee

### • Teen Fusion

**SEPTEMBER 12**

Ages 13-17

Locations and activities vary

### • Tennessee Adult Brothers and Sisters (TABS)

Contact

[ashley.coulter@vanderbilt.edu](mailto:ashley.coulter@vanderbilt.edu)

Register online at

[kc.vanderbilt.edu/site/services/disabilityservices/tabs.aspx](http://kc.vanderbilt.edu/site/services/disabilityservices/tabs.aspx)

## ■ TAKE PART IN RESEARCH

[Vanderbilt Kennedy Center](#)

[Research Studies](#)

For children and adults, with and without disabilities

Lynnette Henderson (615) 936-0448

Toll-free (1-866) 936-VUKC [8852]

## • Research Family Partners

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

Register and be notified of research studies

## • StudyFinder

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

View lists of studies, criteria, and contact information

See also VUMC Clinical Trials

[www.vanderbilthealth.com/clinicaltrials](http://www.vanderbilthealth.com/clinicaltrials)

## ■ TN DISABILITY PATHFINDER

[Phone, web, print resources](#)

[www.familypathfinder.org](http://www.familypathfinder.org)

English (615) 322-8529

Español (615) 322-8529 ext. 11

Toll-free (1-800) 640-INFO [4636]

[tnpathfinder@vanderbilt.edu](mailto:tnpathfinder@vanderbilt.edu)

### • 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

\$10 per directory

Contact (615) 322-8529 ext. 15

[tracy.pendergrass@vanderbilt.edu](mailto:tracy.pendergrass@vanderbilt.edu)

Project of Vanderbilt Kennedy

Center for Excellence in

Developmental Disabilities

and Tennessee Council on

Developmental Disabilities

## ■ COMMUNITY EVENTS

### • OCTOBER 17

[Tennessee Walk Now for Autism](#)

Nashville Super Speedway, Lebanon

For more information, contact

Autism Speaks at

[tennessee@autismspeaks.org](mailto:tennessee@autismspeaks.org)

or (615) 238-1625

[www.tndisabilitymegaconference.org](http://www.tndisabilitymegaconference.org)

### • OCTOBER 18-21

[The State of the Child](#)

[Conference 2009](#)

Scarritt Bennett Center, Nashville

For more information and to

register, visit [www.tnvoices.org](http://www.tnvoices.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

### • SEPTEMBER 17\*

[Autism Orientation](#)

An informational session on

autism and other pervasive

developmental disorders

Child care available with

advance request

Thursday 6:30-8:30 p.m.

Co-Sponsor DSAMT

## • SEPTEMBER 26

[Fall Conference: Successful](#)

[Transitions for Students with](#)

[Autism Spectrum Disorders](#)

John Thomas, M.Ed.,

David Lipscomb University

Watch [tnautism.org](http://tnautism.org) for

registration and additional

information.

## ■ DSAMT EVENTS

[Down Syndrome Association of](#)

[Middle TN](#)

[www.dsamt.org](http://www.dsamt.org)

DSAMT event information

(615) 386-9002

### • AUGUST 22

**SEPTEMBER 26**

**OCTOBER 24**

[Circle of Friends](#)

Monthly gathering for individuals

with Down syndrome

Saturday 9 a.m.-2 p.m.

Westminster Presbyterian Church

### • AUGUST 29

[Fall Fiesta Dinner and Auction](#)

Saturday

Time and location TBA

### • OCTOBER 17

[Buddy Walk](#)

Saturday 8 a.m.

Centennial Park, Nashville