

Vanderbilt Kennedy Center for Research on Human Development



University Center for Excellence— Behavior Analysis Clinic



5 TRIAD— STAT Test Kit Available



Susan Gray School— All That a Playground Can Do



10 From Dinner to Discovery



Obesity, Diabetes, and Brain Function

By Jan Rosemergy

One of the most significant health risks shared by children and adults with developmental disabilities and by the general U.S. population is obesity. According to the national Centers for Disease Control and Prevention (CDC), roughly two-thirds of U.S. adults aged 20 and over are



overweight or obese, and the prevalence has increased sharply for both adults and children since the mid-1970s. Obesity rates remain high, at 31.9%, among children and adolescents ages 2-19 years.

Little is known about the national or state prevalence of obesity among persons with disabilities, because it is not routinely measured or reported. One study (Rubin et al., 1998) found that in a sample of 290 persons with Down syndrome, 45% of men and 56% of women were overweight using the criteria established in the *Healthy People 2000* report, a finding that suggests that the prevalence of obesity is likely to be even higher in persons with developmental disabilities than in the general population.

Obesity and Type 2 Diabetes

Obesity increases the risk for many diseases, including type 2 diabetes, hypertension, cardiovascular disease, respiratory problems, certain cancers, and lowered life expectancy. Among obesity-related diseases, national attention is being devoted to the increase in type 2 diabetes. According to the CDC, from 1980 through 2005, the number of adults aged 18-79 with newly diagnosed diabetes almost tripled from 493,000 in 1980 to 1.4 million in 2005 in the U.S.

"Obesity and diabetes not only are major health problems in and of themselves," said Kevin Niswender, M.D., Ph.D., "but they also have implications for mental health, depression, attention deficit hyperactivity disorder (ADHD), and even substance abuse."

Niswender, assistant professor of medicine and molecular physiology & biophysics, is a physician-scientist who conducts innovative research on diabetes and obesity. He has teamed with Vanderbilt Kennedy Center investigator Aurelio Galli, Ph.D., associate professor of molecular physiology & biophysics, who studies the mechanisms for how neurotransmitter imbalance leads to neurological disorders such as schizophrenia, ADHD, and addiction to substances of abuse.

"What Dr. Galli and other cutting-edge investigators have hit on is that addiction biology is involved to some degree in human Continued on page 2

Transition in VKC Leadership

By Craig Boerner and Jan Rosemergy

Transition in VKC Leadership

Vanderbilt Kennedy Center Director Pat Levitt, Ph.D., stepped down after 6 years to pursue other opportunities, effective November 1. Associate Director Elisabeth Dykens, Ph.D., is serving as VKC interim director while a nationwide search is conducted for Levitt's successor.

Levitt, the Annette Schaffer Eskind Chair, has accepted a position at the University of Southern California as Director of the Zilkha Neurogenetic Institute and Chair of the Department of Cell and Neurobiology at the Keck School of Medicine and



Pat Levitt, Ph.D.

Provost Professor of Neuroscience, Psychiatry, and Pharmacy.

The Vanderbilt Kennedy Center (VKC) has expanded greatly under Levitt's direction, more than doubling its extramural research portfolio, experiencing a fortyfold increase in philanthropy, being designated a University Center for Excellence in Developmental Disabilities, and assuming oversight of the LEND/MIND Training Program. Autism research and treatment programs also have seen dramatic growth through the Treatment and Research Institute for Autism Spectrum Disorders (TRIAD), the Marino Autism Research Institute, and related activities.

"In my view, many of the programs now require leadership in clinical research, clinical and translational services, and training areas, which are not my strengths," said Levitt, a professor of pharmacology. "I know that the Center will



Elisabeth Dykens, Ph.D.

benefit from fresh leadership. The administration has been very supportive, and I am not stepping down because of any problems."

"Pat has provided extraordinary leadership," said Dykens, also codirector of the VKC University Center for Excellence in Developmental Disabilities. "He gave priority to family and community needs. Pat and his colleague BethAnn McLaughlin built a relationship with the Dan Marino Foundation, which is now supporting the Marino Autism Research Institute at Vanderbilt and the University of

Miami. Working with deans and department chairs, he helped recruit 20 new scientists to Vanderbilt. Pat also built relationships with donors that have led to important programs for families like the Ann and Monroe Carell Jr. Families First Workshops for parents of young children with autism. In short, Pat has been an awesome leader."

Continued on page 3

Obesity, Diabetes from page 1

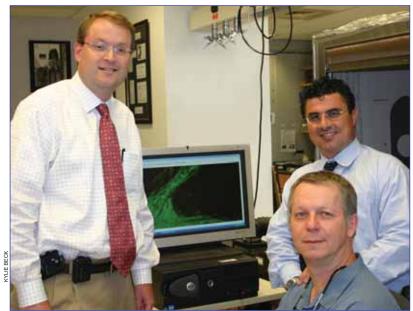
feeding behavior and potentially in the obesity and diabetes epidemics," Niswender said. "What is really phenomenal is that his work brings the process full

circle. The brain controls appetite, feeding, and ultimately insulin production. What we're beginning to understand is what happens downstream; insulin itself actually feeds back to the brain and regulates many of the processes involved in feeding and potentially addiction, cognition, and other aspects of neurological function that were previously not thought to be 'metabolically' regulated."

Brain Dopamine and Obesity

Food intake is regulated by several neurotransmitters, including dopamine, GABA, norepinephrine, and serotonin, as well as by peptides

and amino acids. Dopamine is of special interest because it seems to regulate food intake by modulating the "reward" circuitry of the brain. Drugs that block certain dopamine receptors increase appetite and lead to significant weight gain, while drugs that increase brain dopamine levels dampen appetite and lead to weight loss. The involvement of dopamine in pathological eating and obesity is not yet well understood, but it is an area of intense interest.



Kevin Niswender, Aurelio Galli, and Heinrich J. G. Matthies (seated)

Using mouse and rat models, Galli, in collaboration with Niswender, investigates how food intake regulates neurotransmitter transporters.

Neurotransmitter transporters are integral membrane proteins responsible for clearing the neurotransmitters (e.g., dopamine) from the synaptic cleft, to control the magnitude and duration of synaptic signaling. Neurotransmitter transporters include the dopamine (DAT) and norepinephrine (NET) transporters. Substances of abuse such as cocaine and amphetamine, or drugs with

clinical relevance such as Ritalin (used for treatment of ADHD), act upon these transporters to alter the concentration of dopamine in the synaptic cleft.

"The focus of my laboratory," Galli said, "is to try to understand the mechanisms of action of these drugs with the intent to improve the



pharmacological treatment of specific neurological disorders and substance abuse—and now perhaps also obesity and type 2 diabetes."

This latter goal is the result of a major finding by the Galli laboratory that insulin itself is a potent regulator of DAT function. By controlling DAT function, insulin fine-tunes dopamine levels in the brain and therefore reward. Most recently, Galli's research has moved to focus more broadly on reward processes in the brain.

Galli indicated that they are discovering that when an animal starts to become obese, the dopaminergic function that is involved in the reward process, as well as in cognition and motor activities, is altered. The dopamine transporter leaves the plasma membrane, affecting both dopamine clearance and brain dopamine levels. The group hypothesizes that because of brain insulin resistance that develops in obesity (or diabetes), the transporter can no longer be properly regulated.

Niswender explained that

animals and humans feed in response to what are termed "homeostatic signals" related to how much fat is present in the body. If one has too little fat, the brain signals strongly to eat more to restore fat mass in order to maintain healthy, optimum metabolism. When one has too much fat in the body, what typically should happen is that the brain should signal to eat less, in order to reduce fat mass, which can be detrimental.

"These are long-term homeostatic signals that function over days, weeks, months," Niswender said,

"but in humans, where food intake usually occurs in a discrete meal, there are many nonhomeostatic mechanisms as well. Eating foods that are high in fat and simple carbohydrates tickle the same parts of the brain that substances of abuse activate and that mediate addiction. The work of Dr. Galli and others

> shows that dopamine is one of the key neurotransmitters involved in addiction and now, we think, in feeding biology as well."

Insulin's role typically is associated with blood sugar control and diabetes. "The whole idea that insulin does anything in the brain is beginning to receive increasing attention," Niswender said.

The brain requires glucose, and the body requires insulin in order to use glucose effectively, he explained, but the brain does not require insulin for glucose metabolism. In fact, insulin in the brain reflects what the energy stores in the body are, so that the brain

can generate adaptive responses. If one fasts and the glucose level drops, insulin levels drop, and that reduction in insulin levels signals, in a homeostatic way, that one needs to eat.

"We think now that when one overeats, insulin has a different function," Niswender said. "Insulin acts on those areas of the brain where dopamine normally functions to decrease the reward aspect of food intake, thereby helping to limit food intake. It is likely that this novel function of insulin is compromised in obese people. It is intriguing to think that when people eat a high-fat, high-carbohydrate diet, their food intake stays elevated, because insulin resistance causes the dopamine system to no longer be able to be turned off and to compensate for the caloric intake and increased reward."

Galli's lab has identified the molecular pathway from the insulin receptor all the way through to the dopamine transporters in the brain, which Niswender characterized as "phenomenally novel and important."

Galli pointed out that diabetes has co-morbidity with other disorders, including ADHD, motor impairment, depression, and aggression. The underlying biological mechanisms of these disorders also are related to neurotransmitters like dopamine.

"What we're really studying," Galli said, "is how this impairment is happening. How are diabetes and obesity affecting dopamine transporter function? How does it affect the signaling pathway?"

Niswender indicated that in studies of obese persons who have had gastric bypass surgery to reduce weight, there have been reports of increased incidence of addiction to nicotine, amphetamines, cocaine, or other substances of abuse. He summarized, "The take-home message is that what we thought were separate universes of metabolism and addiction biology are now converging and overlapping quite remarkably. And certainly dopamine is a central player."

Transition in VKC Leadership from page 1

Dykens, Interim Director

Elisabeth Dykens, professor of psychology and human development, received a Ph.D. in clinical psychology from the University of Kansas. She completed a predoctoral internship and a postdoctoral fellowship at Yale University's School of Medicine, Child Study Center. After serving on the junior faculty at the Yale Child Study Center for 7 years, in 1995 she joined the faculty of University of California-Los Angeles, where she was associate professor and then professor-in-residence at the Neuropsychiatric Institute, and associate director for research and training at UCLA's Tarjan Center for Excellence in Developmental Disabilities.

Dykens's research is focused on both the mental health challenges and unique strengths of persons with genetic syndromes. Her work includes examining compulsive behaviors and overeating in Prader-Willi syndrome and heightened anxiety in Williams syndrome.

Dykens is principal investigator for the Center's renewal application to the *Eunice Kennedy Shriver*National Institute of Child Health and Human
Development as a national *Eunice Kennedy Shriver*Intellectual and Developmental Disabilities Research
Center (IDDRC). The 5-year competitive grant supports a wide range of genetic, neuroscience,

behavioral, and quantitative research services that are used by Center investigators. Scientific leadership of the IDDRC is one of the most crucial criteria for renewal, and Dykens will commit to her role as PI for 5 years. The Center has been continuously funded as an IDDRC since its founding in 1965 as one of the nation's original such centers.

Muglia, Interim Associate Director

Continuing the recent tradition of VKC leadership that integrates basic and clinical science, Dykens announced the appointment of Interim Associate Director, Louis J. Muglia, M.D., Ph.D.



Louis J. Muglia, M.D., Ph.D.

His research focuses on the importance of corticotropin-releasing hormone and glucocorticoids in neuroendocrine modulation, behavior, and perinatal development, and on the neurobiology and genetics of preterm birth.

"For leadership of the Center as an NICHDfunded Intellectual and Developmental Disabilities Research Center, his research strengths will complement my own clinical science strengths on behavioral phenotypes of genetic IDD syndromes," Dykens said. Muglia joined the Vanderbilt faculty in December as the Edward Claiborne Stahlman Professor of Pediatrics, Professor of Molecular Physiology and Biophysics, and Vice Chair for Research Affairs in the Department of Pediatrics.

Previously, Muglia served as Alumni Endowed Professor of Pediatrics and Professor of Developmental Biology and Obstetrics and Gynecology at Washington University School of Medicine, Director of the Division of Endocrinology and Diabetes in the Department of Pediatrics, and Director for the Center for Preterm Birth Research at Washington University. He also served as the Program Director for the NICHD-supported Child Health Research Center of Excellence at Washington University. Thus, in addition to research that reflects key priorities of the *EKS* NICHD IDDRCs, he also has substantial administrative experience that he will bring into his role of interim associate director.

"This is one of those occasions when a time of transition is proceeding smoothly," Dykens said. "Thanks to this Center's historical and contemporary strengths, the vision and dedication of its researchers, trainees, and staff, and Vanderbilt's commitment to pushing the frontiers of biomedical and behavioral research and practice to improve the lives of persons with disabilities and their families, the Center has never been stronger and is looking forward to continued accomplishments."

Hispanic Community Focuses on Down Syndrome



Tennessee Disability Pathfinder staff Claudia Avila-Lopez, Carolina Meyerson, and Cecilia Melo-Romie

Over 80 disability-service providers attended the 4th Annual Disability Services and the Hispanic Community Conference in November. The conference focused on information, treatment, and resources on Down syndrome relevant for service providers working with Spanish-speaking families and individuals with disabilities.

The conference was organized by Tennessee Disability Pathfinder Hispanic Outreach coordinators Carolina Meyerson, Claudia Avila-Lopez, and Cecilia Melo-Romie (pictured in photo). Sponsors were Tennessee Disability Pathfinder, Vanderbilt Kennedy Center for Excellence in Developmental Disabilities, and Tennessee Council on Developmental Disabilities.

For more information about the conference or other Hispanic Outreach activities, contact (615) 322-8529 ext. 1; claudia.avila@vanderbilt.edu.

Remembering Dr. Lloyd Elam

Loyd C. Elam, M.D., founder of Meharry Medical College's Department of Psychiatry, former president of Meharry, and a pioneer in drug and alcohol abuse treatment, died on October 4 of a heart attack while traveling. Dr. Elam was a valuable member of the Vanderbilt Kennedy Center's National Advisory Committee in the 1970s and 1980s, and worked closely with the Center's first three directors to promote community health care and research on child development and mental health. His advice was sought frequently and given freely and was a significant source of strength in the Center's early years.

A charter member of the Institute of Medicine of the National Academies, Dr. Elam had a positive influence on national policies and programs on mental health, medical education, substance abuse, health research, child development, and developmental disabilities. He and Kennedy Center founder Nicholas Hobbs, Ph.D., were the first two Nashvillians to be elected to the Institute.

Dr. Elam's gentle, self-effacing manner barely masked his aggressive determination to advance medical education, both at Meharry and across the nation, and to infuse expert health care into historically underserved areas. He was an equally determined promoter of the research budgets of the National Institutes of Health and could always be counted on to share his enthusiasm with congressional committees.

The Lloyd C. Elam Mental Health Center at Meharry continues Dr. Elam's dedication to mental health services, with particular emphasis on alcohol and drug abuse and child mental health.

The VKC thanks H. Carl Haywood, Ph.D., professor of psychology, emeritus, VKC member, and former director, for this tribute.

Access Nashville Replication Manual

The VKC UCEDD is pleased to announce the availability of the *Access Nashville Project Replication Manual: Creating an Accessibility Project in Your Community.* The manual provides assistance to nonprofit organizations in developing a low-cost project to evaluate restaurant accessibility. In addition, the manual provides a general model that can be used and adapted to provide accessibility information on other public facilities. The manual is free of charge and is available through the Access Nashville website at kc.vanderbilt.edu/accessnashville/index.html, or call (800) 640-4636 ext 13.

Vanderbilt Kennedy Center for Excellence in Developmental Disabilities

Behavior Analysis Clinic: A Turning Point for Families

By Courtney Taylor

was exhausted," said Angela Bechtel. "Our home was a very stressful place. Chase was throwing tantrums, was not following instructions, and it was not uncommon to witness the two of us involved in a physical struggle. Though we had been working with behavior consultants, I can see now it was a real problem that we did not have a behavior plan set in place. Chase would scream and one person might say, 'stop it,' another person might ignore it, and yet another might scream right back at him. We weren't able to see what was motivating him to hit or to throw a tantrum. We didn't understand the motivation behind his behaviors."

After years of working with behavior consultants, and with no long-term improvements in Chase's behavior, Bechtel contacted the Vanderbilt Kennedy Behavior Analysis Clinic (BAC). The BAC works with children and young adults, ages 3 to 18, who have been diagnosed with a developmental disability, and who also engage in problem behavior.

It is estimated that 17% of children and adolescents with developmental disabilities have behavior problems. Services at the Clinic are supervised by Board Certified Behavior Analysts, who provide functional behavior assessments, develop behavior intervention plans (BIP) based on the assessments and observations, and provide training in the home to support families and caregivers in the implementation of the BIP.

"What makes the services provided by a behavior analyst different from many of those provided by other types of behavior consultants is that, when we intervene, we use research-based interventions, rather than hypothetical constructs that aren't based in the hard sciences," said Clinic coordinator, Nea Houchins-Juarez, M.A., B.C.B.A. "We observe behaviors, manipulate environmental variables, and take data to develop our interventions. We repeat measures to be sure that the interventions are socially significant for the people they affect. A behavior analyst will never put something in place that has not been shown to be effective for a particular issue or scenario."

Chase entered the BAC to address issues of noncompliance (saying "no," or engaging in another form of verbal delay to ignore instructions), tantrums, physical aggression, elopement (leaving the room or area without permission), and a habit of putting his fingers in his ears. On his first visit, an analogue functional analysis (AFA) was conducted. Eight 5-minute conditions were carried out in which

Chase interacted with the BAC staff. During the different conditions, consequences such as



Angela and Chase Bechtel

"attention" were provided. After the AFA was complete, the staff indicated that Chase's target behaviors were maintained primarily to escape demands and to access attention.

"Having someone point out why Chase was doing what he was doing was so liberating," remembered Bechtel. "Knowing *why* allowed us to move forward in how to address his behaviors. I was so tired of guessing. It was incredible to have someone tell me why he was doing what he was doing, and then even more incredible for them to tell me, 'This is what you do when Chase does this or that.' It was absolutely liberating."

In Chase's behavior intervention plan, Clinic staff outlined positive procedures for the Bechtels that could be implemented to potentially prevent problem behaviors. They recommended that a picture schedule be set in place to allow Chase to anticipate future activities and to know when he would be separated from his mother. They recommended precise methods of problem solving, of prompting, and of reinforcement. They also outlined detailed instructions of how to react effectively when Chase's problem behaviors could not be prevented.

"I won't lie," said Bechtel. "At times, it is difficult to follow the plan. It's difficult for everyone to be on the same page even when it's right in front of you. Like my daughters found it very difficult to ignore Chase when he came up and hit them. That's a hard thing to ignore. Having my child hitting me feels so unnatural, and sometimes I couldn't ignore it, you know? And I was supposed to ignore it. I knew he hit when he wanted attention, so if I didn't reward him with the attention, eventually he wouldn't find hitting a worthy path. When I did ignore it, the aggression would subside. The plan would work when I followed it. It was just hard sometimes."

Bechtel is not alone. Houchins-Juarez says that although many parents are relieved to have the guidance of a behavior plan, they often experience difficulty in maintaining them. All have good intentions, yet many may find themselves falling into a pattern of thinking that their child should behave just because they should know better. Others may find themselves thinking that because their child has a disability, they could not possibly know better. It also is common for parents to follow the plan carefully at first, notice improvements in their child's behaviors, and then gradually

become lax in the implementation.

"It takes a lot of resolve and commitment," said Bechtel. "It's tiring, but you know there is a payoff. If you stick to this thing, you're going to see results as opposed to hoping you will see results when you're guessing at what to do. I knew it was the best option we had, so that gave me a sense that we were doing the right thing. When you know you are doing the right thing, it motivates you. I felt desperate. I knew I was working with the top people in the field, and if they think this is what needs to be done, then I am going to do it. And we have."

Bechtel reports that Chase is doing very well. She says they still have their moments, but that, for the most part, his behaviors have improved dramatically.

"There will be times when I'm tired and won't follow the plan," said Bechtel. "Then, I'll begin to notice a little bit of the behaviors coming back and that motivates me to get back to the plan and be disciplined. I can see what happens when I am not disciplined. He starts to regress and I think, 'Oh no. I don't want to go down that road again!' It's just so amazing that when you follow the plan, it really does work. The more time you spend following the plan, the easier it does get. The behavior plan was a definite turning point for our family."

For information about the BAC, contact (615) 322-9007 or bac@vanderbilt.edu.



Treatment and Research Institute for Autism Spectrum Disorders

STAT Test Kit Now Available By Jan Rosemergy



STAT Test Kit

campaign directed at the early recognition of signs of possible developmental disabilities such as autism. Diagnosis of autism is dependent on assessing and observing a child's behavior. A challenge to the field has been the availability of a valid screening tool that could be used by a wide variety of professionals. To address this crucial need, TRIAD researchers devoted more than 10 years of research and evaluation to develop the STAT—Screening Tool for Autism in Toddlers and Young Children. The STAT Test Kit is now available.

The STAT is an interactive measure to screen for autism in children between 24 and 36 months of age, and it now also includes a provisional scoring system extending downward to 14 months. The STAT consists of 12 items and takes about 20 minutes to administer. Activities assess key social and communicative behaviors, including imitation, play, requesting, and directing attention. The STAT Test Kit includes: a web-based Training Tutorial, User's Manual, Scoring Sheets, Test Materials, and Test Protocols. The STAT is designed for use by community service providers who work with young children in assessment or intervention settings and who have experience in autism.

"The STAT Test Kit can be used in diverse clinical and research settings," said Amy Swanson, M.A., coordinator of STAT Training and Development, "for example by speech-language pathologists, developmental pediatricians, or birth-to-three service providers."

The STAT Training Tutorial, included in the Test Kit, is an interactive, web-based application that provides thorough instruction on item administration and scoring, and includes video examples and practice tests. Information about interpreting the STAT results and explaining results to parents is provided.

Certification for independent use of the STAT can be obtained by successful completion of the Tutorial Posttest. One-day STAT Training Workshops also are available periodically at the Vanderbilt Kennedy Center.

"As a community provider who uses the STAT, I find this tool adds significantly to aid early identification of children referred with social communication concerns and suspected autism," said Quentin Humberd, M.D., FAAP, developmental behavioral pediatrician and chief of the Exceptional Family Member Program, Blanchfield Army Community Hospital, Ft. Campbell, Kentucky.

The STAT was developed by TRIAD director Wendy Stone, Ph.D., professor of pediatrics and psychology, with Opal Ousley (now at Emory University), with grant support from the U.S. Department of Education's Office of Special Education and Rehabilitative Services.

Development of the Training Tutorial was funded by a National Institute of Mental Health Small Business Innovation Research Grant to Ken Kobak.

To obtain the STAT Test Kit, contact (615) 322-6533, STAT@vanderbilt.edu, TRIAD.vanderbilt.edu/STAT.●

Wow! Look There! Baby Sibs and Joint Attention By Jan Rosemergy

The most effective treatments for autism spectrum disorders (ASD) involve early intervention—and the earlier intervention begins, the greater the potential benefit. A challenge to "acting early" is that the developmental signs of autism before age 2 are not yet clear—which is why autism researchers are studying the development of "baby sibs."

"Younger children of siblings on the autism spectrum are at elevated risk for autism, although risk is still low," said Wendy Stone, Ph.D., TRIAD director and professor of pediatrics and psychology. Later-born siblings of children with ASD show varied social-communication developmental outcomes, ranging from ASD behaviors, to less serious symptoms like language delay, to no detectable symptoms.

Stone is directing a new study that examines joint attention, an aspect of social and emotional development. Impairments in social and emotional development are a core feature of ASD.

"Joint attention is the ability to attend to an event or object and to share that experience with



another person, usually with a positive emotional expression like a smile or laugh," explained Elizabeth Catania, Ph.D., the study coordinator.

Joint attention has two components. First, it involves the ability to shift one's attention away from one thing and toward another. Second, it involves being able to share enjoyment in an object or event. Even a baby can show joint attention by gazing from dad to a teddy bear and back to dad while smiling, cooing, or arm waving.

"We're investigating how these two skills

combine and develop over time in infants who have an older brother or sister with autism and in infants with older siblings who are typically developing." Catania said. "We want to understand how these two skills develop over time and the extent to which each of them contributes to the development of joint attention involving positive affect—like smiling—and social engagement with others, and how it affects later development of language and social skills."

Infants enter the study at either 6 or 12 months of age, and are followed at regular intervals. The study involves five to seven visits at 6, 9, 12, 15, 18, 24, and 36 months of age. Each visit includes a variety of interactive social and play activities, as well as measures of brain activity. Families will be compensated for their time and expense.

Families interested in taking part can contact (615) 343-3723 or babysibstudy@vanderbilt.edu. The project is supported by a grant from the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development. ■

Leading the Vanguard of Discovery



FRANK E. HARRELL, JR., PH.D.

Professor of Biostatistics and Chair of the Department Director of Vanderbilt **Kennedy Center** Statistics and Methodology Core Vanderbilt Kennedy Center Member Joined Vanderbilt Kennedy Center 2006 Mitchell Lecturer, Department of Biostatistics, Glasgow University, 2008

Selected Publications

The first two publications listed below are the #1 and #3 most cited publications in the 27-year history of Statistics in Medicine.

Harrell, F. E., Lee, K. L., Califf, R. M., Prior, D. B., & Rosati, R. A. (1984). Regression modeling strategies for improved prognostic prediction. Statistics in Medicine, 3, 143-152.

Harrell, F. E., Lee, K. L., & Mark, D. B. (1996). Multivariable prognostic models: Issues in developing models, evaluating assumptions and adequacy, and measuring and reducing errors. Statistics in Medicine, 15, 361-387.

Osman, O. A., Harrell, F. E., et al. (2007). Case complexity scores in congenital heart surgery: A comparative study of the Aristotal Basic Complexity score and the Risk Adjustment in Congenital Heart Surgery (RACHS-1) system. Journal of Thoracic and Cardiovascular Surgery, 133, 865-874.

Stukenborg, G. J., Wagner, D. P., Harrell, F. E., et al. (2007). Present-at-admission diagnoses improved mortality risk adjustment among acute myocardial infarction patients. Journal of Clinical Epidemiology, 60, 142-154.

Research Interests

Statistical analysis Clinical prediction Statistical models Statistical computing and open-source software Statistical graphics Statistical reporting Research data management Cardiovascular disease Medical applications of statistics Clinical trials Clinical safety assessment and analysis in pharmaceutical trials Risk adjustment Health services and outcomes research Pharmaceutical research Medical diagnosis and prognosis

Clinical Interests

My interests are primarily focused on statistical and graphical methods for biomedical research and study design. Before joining Vanderbilt in 2003, I was involved primarily in cardiovascular disease diagnosis, prognosis, and treatment. I remain very involved in drug development, randomized clinical trials, and assessment of pharmaceutical safety. Since coming to Vanderbilt, I have become involved in sports medicine research, basic research, and a host of other areas, including developmental disabilities.

Principal Investigator

- Study to Understand Prognoses Preferences Outcomes and Risks of Treatment, Robert Wood Johnson Foundation. I am director of the Statistical Center for this multi-center study of endof-life decision making.
- I have been co-investigator on many NIH grants, e.g., in the areas of cardiovascular disease, orthopedics, statistical methodology, health services research, pulmonary disease.
- I direct the Design Biostatistics and Research Ethics Core for the Vanderbilt Institute for Clinical and Translational Research.

Honors and Awards

Fellow, American Statistical Association, 2005 Distinguished Alumnus Award, School of Natural Sciences and Mathematics, University of Alabama-Birmingham, 2005

Education

B.S., 1973, Mathematics, University of Alabama-Birmingham

Ph.D., 1979, Biostatistics, University of North Carolina-Chapel Hill

Attraction to Developmental Disabilities Research and Reasons for VKC Membership

It was a great opportunity to assist the Vanderbilt Kennedy Center in enlarging its Statistics and Methodology Core, to add more methodologists to the Core to cover more areas of expertise, and to allow the Vanderbilt Kennedy Center to make maximal use of the Department of Biostatistics, formed in 2003, which I chair. The primary motivations are to increase the quality, efficiency, and quantity of research done in the Center and to have an opportunity to collaborate with talented Center investigators. Besides the research opportunities and serving the needs of Center investigators, it is heartening to be involved in research in an incredibly important area that affects the lives of individuals with disabilities and their families

Grants Awarded

Manganese Exposure and Huntington Disease

Aaron Bowman, Ph.D. (Neurology) National Institute of Environmental Health Sciences

Visual System Organization and Development Vivien Casagrande, Ph.D.

(Cell and Developmental Biology) National Eye Institute

Calculations, Word Problems, and Algebraic Cognition

Lynn Fuchs, Ph.D. (Special Education)

National Institute of Child Health and Human Development

National Children's Study-Vanderbilt Medical Center Site

Bettina Beech, Dr.P.H., M.P.H. (Medicine) [PI]; Katherine Hartmann M.D., Ph.D. (Obstetrics and Gynecology) [co-PI]; Robert Hodapp, Ph.D. (Special Education) and Richard Urbano, Ph.D. (Pediatrics) [collaborators]

Parent-Based Sleep Education Program for Children with Autism Spectrum Disorders

Beth Malow, M.D. (Neurology) Autism Intervention Research Network on Physical Health (AIR-P), Health Resources and Services Administration

Vitamin C Transporters in the Brain

James May, M.D. (Medicine)

National Institute of Neurological Disorders and Stroke

David Miller, Ph.D. (Cell and Developmental Biology) National Institute of Neurological Disorders and Stroke

ences of In Vivo Neocortical GAD67 Downregulation

Karoly Mirnics, M.D. (Psychiatry) National Institute of Mental Health

onal Development of Infants at Risk for Autism Spectrum

Wendy Stone, Ph.D. (Pediatrics)

National Institute of Child Health and Human Development

LEND Pediatric Audiology Subaward to MIND Training Program (Mid-Tennessee Interdisciplinary Instruction in Neurodevelopmental Disabilities)

Anne Marie Tharpe, Ph.D. (Hearing and Speech Sciences) Maternal and Child Health Bureau, Health Resources and Services Administration

LEND Autism Expansion Award to MIND Training Program (Mid-Tennessee Interdisciplinary Instruction in Neurodevelopmental Disabilities

Mary Theresa Urbano, M.P.H., Ph.D., R.N. (Pediatrics) Maternal and Child Health Bureau, Health Resources and Services Administration

Serotonin Transporter Variant Associated With Autism

Jeremy Veenstra-VanderWeele, M.D. (Psychiatry) Autism Speaks

VKC Nicholas Hobbs Discovery Grants

The Carrell Family Discovery Grant Thalomocortical Pathways and Sensory Processing

Carissa Cascio, Ph.D. (Psychiatry)

Donna and Jay Richards Discovery Grant Impact of Sleep on Behavior and Family Functioning in Angelman Syndrome

Suzanne Goldman, Ph.D. (Nursing)

Generating Patient-Derived Pluripotent Stem Cells for the Study of

Aaron Bowman, Ph.D. (Neurology)

A Targeted Proteomic Approach to Identify Proteins Underlying the Pathogenesis of Angelman Syndrome

Kevin Haas, M.D., Ph.D. (Neurology)

Marino Autism Research Institute Discovery Grants

Reaction to Diagnosis and Parental Well-Being in Families of Young Children Recently Diagnosed With ASD Zachary Warren, Ph.D. (Psychiatry)

Is Social Interaction Aversive or Not Motivating for Children with Autism Spectrum Disorders?

Barbara L. Thompson, Ph.D. (Pharmacology)

Synergy in MIND Training By Jan Rosemergy

when Terri Urbano, M.P.H., Ph.D., describes the MIND Training Program, which she directs. Synergy is the energy that comes from a unique coming together of parts—and, in many ways, that's an apt description of MIND—Mid-Tennessee Interdisciplinary Instruction in Neurodevelopmental Disabilities.

A National LEND Program

MIND is Vanderbilt's LEND Program.
Each LEND—Leadership Education in
Neurodevelopmental Disabilities—
provides long-term, graduate-level
interdisciplinary training as well as
interdisciplinary services and care. Funded
by the Health Resources and Services
Administration, Maternal and Child
Health Bureau, LENDs aim to improve the
health of infants, children, and adolescents
with disabilities by preparing trainees from
diverse professional disciplines to assume leadership
roles in their respective fields and by insuring high
levels of interdisciplinary clinical competence. MIND
is among 34 LENDs in 27 states.

Established at Vanderbilt within the Department of Pediatrics' Center for Child Development, recently MIND moved administratively to the Vanderbilt Kennedy Center (VKC), a member of two national networks with whom LENDs partner. The VKC is among 14 national *Eunice Kennedy Shriver* Intellectual and Developmental Disabilities Research Centers and is among 67 University Centers for Excellence in Developmental Disabilities, which provide training, research, services and technical assistance, and dissemination.

"MIND is a perfect fit," said Urbano. "It's one leg of a three-legged stool, where interdisciplinary training, research, and service programs work together and serve as catalysts for innovation in all three areas. It's a comprehensive approach to meeting the needs of families."

Vanderbilt Pediatrics continues to be central to MIND, with Tyler Reimschisel, M.D., assistant professor of pediatrics and neurology and director of the Division of Developmental Medicine and Cognition, serving as MIND associate director. The Center for Child Development and other Pediatrics clinics serve as major sites of clinical experiences for MIND trainees.

MIND Training Program

The MIND Training Program has several components. An *academic component* involves course work specifically related to neurodevelopmental disabilities. Professionals from multiple disciplines, family members, and disability advocates present seminars on specific disabilities, early identification and screening, diagnosis and intervention. Various perspectives are included, e.g., disability policy and advocacy.



MIND Social Work trainee Justin Bucchio meeting with Roxanne Carreon, VKC Family Outreach Center Coordinator

The *family component* is equally crucial. Julie Sullivan, co-director of Family Voices of Tennessee and a parent of a child with a disability, is a MIND faculty member. In collaboration with the Families As Mentors Program of the Junior League Family Resource Center, Monroe Carell Jr. Children's Hospital at Vanderbilt, MIND trainees have experiences with families in their homes, where families are teachers. A family trainee is funded in part by the Tennessee Council on Developmental Disabilities, an example of the way in which MIND partners with Tennessee Developmental Disabilities Network members.

Trainees participate in *community settings*, where they learn about resources available to families and acquire leadership skills. "It allows us to bridge the gap between academic education and real-life community-based experience," Urbano said. Students also work with their faculty mentors in *clinical settings* in their own disciplines and take part in interdisciplinary clinics.

Trainees carry out *group projects* so that they gain experience in interdisciplinary teaming, and they do *individual projects* that prepare them for future leadership roles in academic settings or in community health care systems.

MIND includes faculty from Vanderbilt University, Belmont University, Tennessee State University, Meharry Medical College, and the University of Tennessee. Students enter via their respective graduate degree programs at these universities, and their faculty advisors, MIND faculty, recommend them as MIND trainees; MIND also accepts postdoctoral trainees.

Autism Expansion

The synergy created by MIND as a part of the VKC is exemplified by MIND recently receiving a competitive supplementary LEND grant to train professionals across disciplines to identify, assess, and provide services for children with autism spectrum

disorders. It was among only 18 universities and research organizations nationally to receive the funding.

"This funding is of major importance to Tennessee, since our state, like so many others, lacks enough trained professionals to meet the dramatically increasing needs of families affected by autism," indicated Urbano. The participation of the VKC Treatment and Research Institute for Autism Spectrum Disorders (TRIAD) contributed to this successful effort.

"TRIAD is key to MIND's expansion in training related to autism," Urbano said. "We'll now have additional trainees who are interested in acquiring diagnostic skills, gaining experience in our specialty autism clinics, and learning about clinical services. Additionally, trainees will gain knowledge

and skills in the development of research tools. We'll provide community professional education, as well as autism-related product development of public education materials."

In addition, the autism supplement allows MIND to expand distance training for the Tennessee Department of Health. The MIND Training Program has provided monthly distance education to Tennessee public health nurses and other public health personnel for several years. "Now we'll be able to have a specialized focus on autism. This is important because so many nurses work as 'first-line responders' in their communities, which often lack the resources for early identification and intervention," Urbano indicated. "This is a really unique opportunity to partner with a State agency and to contribute positively to the whole system of care."

Act Early Regional Summit

Still another example of synergy is the partnering of MIND, the VKC UCEDD, and the University of Tennessee Boling Center for Developmental Disabilities, which also is designated a UCEDD and a LEND, which hosted a regional Act Early Summit in January 2009. The Act Early Summit pulled together key stakeholders in Tennessee and their counterparts in Kentucky, North Carolina, and South Carolina to improve systems of care for children with autism. This regional summit was sponsored by the National Center for Birth Defects and Developmental Disabilities of the Centers for Disease Control and Prevention and the Maternal and Child Health Bureau. Human Resources and Services Administration, with support from the Association of University Centers on Disabilities.

"We would not have been positioned to host this Summit if we hadn't had pre-established working partnerships. These collaborations serve as a catalyst for statewide initiatives like the Act Early Summit," Urbano said.

For information on MIND, contact (615) 936-1104; MIND@vanderbilt.edu.

All That a Playground Can Do By Courtney Taylor

he two playgrounds at the Susan Gray School (SGS) do more than provide a fun and exciting outlet for children eager to exert their energy. They do more than facilitate an environment where the students can develop social and motor skills, focus their attention, and build self-confidence and self-esteem. They even do more than positively contribute to the students' health, imagination, and classroom performance. The playgrounds at Susan Gray School tell stories. They tell stories about overcoming grief through acts of generosity, and stories about learning how to advocate for one's place in a whole new inaccessible world.

When Sorrow Leads to Joy

C. Robb Swaney was an architect and a Nashville native. In 2001, Keith Crabtree, the son of the late Brenda Crabtree, with whom Swaney had worked for over 17 years, was tragically killed just 2 weeks after graduating from high school. Everyone in Swaney's office went into deep mourning, and Swaney and his wife Mary Jane decided to donate a gift to an organization to honor Keith's life. They chose to donate to the Susan Gray School. Keith had volunteered at SGS over a summer and had been deeply affected by his experiences there. Originally planning to donate a bench or a swing set, Swaney changed his mind after touring the school's playground.

"Robb was concerned that the playground for the 2- to 3- year-olds was in terrible shape," remembered Mary Jane Swaney. "After a tour of the School, he came home and declared he was going to design and coordinate construction of an entire new playground. I remember going on a tour of playgrounds across the city on a very dreary day. We learned all kinds of things about playgrounds. We learned about constructing a covering for the sandbox to prevent animals from adopting it as their restroom. We learned about creating a ground surface that is cushioned to prevent injuries. We learned also that many young children are afraid of large structures, and so scaling the pieces down became a part of Robb's design."

Swaney worked diligently designing, recruiting contractors, and raising funds. Along with the Swaneys' gift, generous gifts were received from Sam and Linda Brooks, from the Tennessee Titans, and from other private donors. During that time, Swaney became very ill and although he was able to witness children playing on the playground, he did not live to attend the dedication. C. Robb Swaney died in September 2002.

"He had given more than his strength," said
Mary Jane. "Though he grew weaker each day, the
amount of joy that he received in the
completion of the playground was boundless.



Amy Harris-Solomon, Mary Jane and Robb Swaney (front row), Mark Wallace and Hal Matern (back row)

The personal relationships we formed during that time were so important to all of us. We were like a family and were a part of something very special. Robb took a very tragic situation and transformed it into a gift that will enable joy in children for years to come."

When Watching From Afar Leads to Action

The Finan Family Playground—for the 4- to 5-year-olds at Susan Gray School—would be

designed, constructed, and dedicated 6 years later in 2008. Spearheaded by Kelly Finan, Vanderbilt senior and SGS volunteer, the new playground is barrier-free and accessible for all SGS students.

"I was doing crafts with the kids one day, and after we finished we headed out to the playground for playtime," remembered Finan. "While some of the children ran around freely, enjoying the playground equipment, the children with physical disabilities and I sat at the top of a dirt-covered hill just watching. We couldn't get to the equipment. I knew right in

that moment that something needed to be done."

Finan found herself empathizing with the children with physical disabilities in a very real and personal way. Health concerns, which had kept her in and out of the hospital during the year prior and had made walking without pain impossible for her, dictated that Finan return to Vanderbilt to complete her undergraduate degree using a wheelchair.

"I was going through a major life adjustment," said Finan. "Although I was getting healthier each

day, it was apparent that my life was forever changed. I knew the kids were receiving an excellent education, but I also knew that something about what I witnessed from the top of that dirt-covered hill was not fair. I met with Ruth [Wolery] and set to work."

Wolery, Ph.D., SGS director, was well aware of and distressed about the playground's inaccessibility, and had been working to raise funds for years, primarily through the SGS annual "Holidays Around the World" event. To begin her efforts and also to fulfill a requirement of a social justice class she was taking, Finan decided to develop a "mock grant proposal." She began brainstorming with Wolery, with her mentor Ann Neely, Ed.D, Associate Professor of the Practice of Education, and with Shan Foster, Vanderbilt senior and basketball player.

Finan's efforts paid off when Shan's coach, Kevin Stallings, and David Williams, J.D., vice chancellor for university affairs and athletics, became involved and pledged financial support from Vanderbilt Athletics. A number of private and anonymous donors also stepped in to help, as did Finan's parents, Tom and Mary.

"My parents are so amazing," said Finan.
"They knew how important the project



Kelly Finan with Sadye, Susan Gray School student

was for me, and their financial and emotional support and encouragement during the whole process was overwhelming. Once all the funding was in place, the work began on the construction. I went home for the summer, but I was able to watch the playground's progress over a webcam. I feel so lucky to have the playground as a tangible and effective way to leave my mark on Vanderbilt. After all that we have accomplished, I have come to realize that the physical situation I am in might not be so limiting after all."

Postsecondary Education VANDERBILT KENNEDY CENTER FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES Program Launched By Courtney Taylor



he Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (VKC UCEDD) has received a 3-year grant from the Tennessee Council on Developmental Disabilities (TN Council) to develop and coordinate a Postsecondary Education Program for students with intellectual disabilities at Vanderbilt University. The program will be the first of its kind in Tennessee.

The Council made a commitment to develop a pilot project on the campus of a Tennessee college or university for postsecondary students who have an intellectual disability and did not receive a high school diploma," said Wanda Willis, TN Council executive director. "Continuing education programs like this are increasingly available on college campuses across the country. At present, Tennessee does not have such a program. Our goal is to launch a demonstration project on the campus of Vanderbilt University on January 1, 2009."

Vanderbilt will accept its first students in January 2010, after an initial planning year. Working with University, Medical Center, and community disability organizations, VKC faculty, staff, and trainees will develop a day program that lasts for 2 years per student. Each year, eight young adults will take a mixture of undergraduate, life-skills, and



technical courses, as well as take part in campus extracurricular activities with Vanderbilt undergraduates. College courses will be provided through regular Vanderbilt undergraduate course offerings; life-skills courses with internships similar to programs such as Vanderbilt's Project Opportunity, with help from graduate students in Peabody College's Department of Special

Education; and technical courses through the Tennessee Technology Centers.

"Key components of the Vanderbilt program will foster the development of independent living and employment skills," said Elise McMillan, J.D., VKC UCEDD co-director. "As with nearly all of our programs at the Vanderbilt Kennedy Center, the postsecondary education program we develop will include research, training, and service. Having all three components will allow for the development and replication of model programs across the state."

McMillan and Robert Hodapp, Ph.D., VKC UCEDD director of research, are lead faculty on the grant. The VKC UCEDD also is part of the Administration on Developmental Disabilities' National Training Initiative on Postsecondary **Education for Students with Intellectual** Disabilities. The Initiative is led by the Institute for Community Inclusion, University of Massachusetts. Other participating universities include the University of Minnesota, UCLA, University of Hawaii, Ohio State University, and University of South Carolina.

For information contact (615) 343-2540; elise.mcmillan@vanderbilt.edu.

Teen Fusion Rocks! By Hillary Hamblen



These graduates of SibSaturdays have formed Teen Fusion.

n a December Saturday, a unique group of teens was enjoying bowling, eating, and talking marking the first event of Teen Fusion, a new Vanderbilt Kennedy Center sibling support program exclusively for teenagers.

Previously, these teens attended SibSaturdays, a sibling support group that includes games like "clothes-pin tag" and "knots," decorating holiday paraphernalia like trick-or-treat bags, and, of course, discussing their roles as siblings, with the help of the "Wheel of Feelings." Now Teen Fusion allows for these teen siblings to engage in more

age-appropriate activities but still have the support they value.

Ashley Coulter, an adult sibling and facilitator for SibSaturdays, says that the impetus for Teen Fusion was to provide activities and support for teens "who were aging out of SibSaturdays but didn't want to quit coming." This program, which gives the teens more support and

independence, is one of the first of its kind. "I would have appreciated that [kind of support] growing up," Coulter adds.

Another aspect of Teen Fusion is "Junior Facilitators," which gives teens an opportunity to help the 5- to 7-year-old siblings at SibSaturdays.

Discussion began slowly, but once they were asked where they wanted to go and what activities they wanted to do at their Teen Fusion meetings, voices chimed in and the participation and energy rose. Upcoming events may include rock climbing, ice skating, video gaming contests, and Vanderbilt sporting events.

With a swift segue into a discussion of siblings, it was soon discovered that everyone present was older than his or her sibling with a disability, chronic health condition, or mental health concern. With some adult-sized responsibilities of helping to care for their younger sibling, the teens expressed that they took these new duties in stride, and were glad that they knew a group of people who were going through some of the same things as they were.

Kendall Hill and Derek Putthoff, both long-time SibSaturday goers, were part of the first group of teenagers to experience Teen Fusion. Both said they were excited to visit new places and were happy to be around people their own age.

"I thought it would be more grown-up than SibSaturdays, and Teen Fusion was fun because we got to bowl," said Putthoff. Both Hill and Putthoff, along with seven other Teen Fusion peers, also are interested in becoming Junior Facilitators.

When asked what words of encouragement he might offer to a "new" sibling, Hill suggested that they "keep on going. It's all right, no matter the situation. Just have faith it'll be okay."

For information contact the Vanderbilt Kennedy Family Outreach Center, (615) 936-5118.

Hillary Hamblen is an AmeriCorps volunteer.

From Dinner to Discovery By Jan Rosemergy



Donna Eskind and Shirley Speyer, Nicholas Hobbs Committee Co-Chairs



Kelly and Kevin Clippinger, Honorary Chairs, and Cathy Brown, Leadership Council Chair



Harla and Pat Levitt



Suzanne Goldman and Jay and Donna Richards



Kevin and Gloria Churchwell, Jeffrey Balser, Jan and Harry Jacobson



Jonathan Gitlin, Julie and Frank Boehm

When Brian was 4 months old, he had open-heart surgery at Vanderbilt Children's Hospital, and I vividly remember thinking how lucky we were to have such a facility available to us," said Kelly Clippinger, addressing over 200 persons attending the Vanderbilt Kennedy Center Leadership Dinner. "I didn't realize then that we were equally lucky to have the Kennedy Center right across the street. The impact it has had on Brian's life is invaluable, and he will continue to benefit from the skills he has learned, through his adolescence and into adulthood."

The Clippinger family, the Dinner's Honorary chairs, were part of an inspirational night at the Dinner, held November 11 and attended by Nicholas Hobbs Society members and their guests. The Dinner is an annual celebration of community support for scientific discoveries to create a better future for individuals with disabilities and their families.

The Discovery Dinner was planned by Cathy Stewart Brown, Leadership Council Chair, with Donna Eskind and Shirley Speyer, Nicholas Hobbs Committee Co-Chairs, who led table sponsorships. Over \$100,000 was raised through Hobbs Society memberships and table sales.

Entertainment was provided by the W. O. Smith School Singers directed by Lynn Adelman, music director of the VKC Music Camp.

The funds raised support innovative Discovery
Grants for VKC researchers investigating the
causes and treatments of disabilities.

Hobbs Discovery Grants

The "Dinner to Discovery" theme was highlighted by VKC investigator Beth Malow, M.D., associate professor of neurology, who reported findings from her research on sleep disorders in children with autism and other developmental disabilities. Malow's Discovery Grant has led to funding by Autism Speaks of a larger study to investigate the use of melatonin to improve sleep in children with autism.

Discovery Grants for 2009-10 were announced. The Carell Family Discovery Grant was awarded to Carissa Cascio, Ph.D., assistant professor of psychiatry, to investigate brain pathways and sensory processing in autism. Suzanne Goldman, Ph.D., assistant professor of neurology, received the Donna and Jay Richards Discovery Grant, which she will use to study the impact of sleep on behavior and family functioning in Angelman syndrome. Discovery Grants also were awarded to Aaron Bowman, Ph.D., assistant professor of neurology, and Karen Summar, M.D., assistant professor of pediatrics and director of the Vanderbilt Down Syndrome Clinic, for research on the use of patientderived stem cells in the study of Down syndrome; and to Kevin Haas, M.D., Ph.D., assistant professor of neurology, to identify proteins relating to the genetics of Angelman syndrome.

MARI Discovery Grants

Marino Autism Research Institute (MARI) Discovery Grants were awarded to Zachary Warren, Ph.D., assistant professor of clinical psychiatry, who is examining reaction to diagnosis and parental well-being in families of young children recently diagnosed with autism; and to Barbara Thompson, Ph.D., postdoctoral fellow, who is investigating whether social interaction is aversive or not motivating for children with autism. The MARI Discovery Grants are supported by the Dan Marino Foundation.

Clippingers, Honorary Chairs

The Clippinger family served as Honorary Chair. Kevin and Kelly Clippinger shared their family's story of how VKC service and research programs have helped their son Brian, who has Down syndrome, and how their other children Patrick and Blythe have found their own VKC program in SibSaturdays.

"The Vanderbilt Kennedy Center has been a part of our vocabulary since our son Brian was born with Down syndrome 11 years ago," the Clippingers said. "The first local Down Syndrome Association meeting we attended was held at the Center, and at that time we had no idea what a constant and important role the Kennedy Center would play in our lives."

Brian attended Explorers Camp, where he took part in a pilot research study on a method of teaching children with Down syndrome to read. "At Explorer's Camp, the researchers taught Brian, without his realizing it was a lesson, and it was a fun and amazing experience for him. Only recently did we realize that the study was made possible by a Hobbs Discovery Grant." Continued on page 11

From Dinner to Discovery

The Clippingers shared that the VKC Reading and Behavior Analysis Clinics continue to provide the education, skills, and the support that helps

"We have been overjoyed with the progress Brian has made in reading over the last several years that he's been enrolled at the Reading Clinic—especially since we know that reading is an essential skill that will serve him the rest of his life. Reading is now his favorite subject at school, behind lunch and recess. Brian's progress in reading was confirmed when we received his first TCAP scores in August. We were thrilled to find that his overall reading score was just one point shy of qualifying him as 'proficient' for his grade level. We know Brian could not have accomplished this without the support of the Reading Clinic."

The Clippingers gave special thanks to VKC Leadership Council member Andrea McDermott and the Spickard family for endowing the Team William Scholarship for the VKC Reading Clinic; Brian was its first recipient.

"The Vanderbilt Kennedy Center is an example of a true team effort," the Clippingers summarized. "There is a synergy that is special and unique at the Center, and it is clear that everyone there is working to set all children up for success in the future."

Levitts Honored

Pat Levitt, Ph.D., outgoing VKC Director, was honored by Richard McCarty, Ph.D., Vanderbilt Provost, Jeffrey Balser, M.D., Ph.D., Associate Vice Chancellor for Health Affairs and Dean of the School of Medicine, and Harry Jacobson, M.D., Vice Chancellor for Health Affairs. Balser praised Levitt for his "power of crystal clear vision" and for his skill in the "art of the possible."

Jacobson affirmed Vanderbilt's commitment "to beat autism, Down syndrome, ADHD, and other developmental disorders," and its commitment to becoming "the leading center in the world to do that. It's one of the things that Vanderbilt is in a position to do, and Pat has moved us in that direction in a major way." He pledged to continue that effort. He commended Pat's leadership in philanthropic fundraising, which saw a fourfold increase during his tenure as director, and commended all those present, saying, "Because of you, because your hearts tell you to give—thank you for this."

Levitt and his wife Harla received a framed collage made up of all the commemorative plates featuring work by artists with disabilities, which have been gifts at each Dinner—an idea, along with art note cards, originated by Harla, who has shared Pat's dedication to the Center.

After recalling memories of his arrival at the Center and the needs identified—for more NIH funding, for community awareness of the Center's mission and activities, and for "centeredness"-Levitt shared a childhood memory that captures the spirit of the Center's mission and his own role as director: "There is a word in Hebrew, tzedakah, which is normally translated into English as charity. In the Jewish tradition, as a child, we learn about this concept from a very early age. I remember going to my grandmother's house, seeing the little tzedakah box on the counter and I would drop part of my ten-cent allowance into the box. However, the more accurate translation of the word is righteous, or justice, or fairness. Helping others is not a favor—it is our duty. It is an expectation that has been passed on to us. It is a responsibility that we have to individuals with disabilities and families—because it is the right thing to do."

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Topics—includes 97 research and disability-related topics, each linking to related grants, services, researchers, news, and video or podcasts

StudyFinder and the Research Family Partners registry provide ways to take part in research

Subscription—includes RSS feeds so that website content can be syndicated to site visitor's personal feed reader program or online news aggregator

Website meets accessibility standards of Worldwide Web Consortium and includes an Accessibility Options troubleshooting section

Comments and suggestions welcome! Contact VKC webmaster nick.williams@vanderbilt.edu 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.

kc.vanderbilt.edu (615) 322-8240 (1-866) 936-VUKC [8852]

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

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Vanderbilt Kennedy Center for Research on Human Development

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 or contact (615) 322-8240 or toll-free (1-866) 936-VUKC [8852].

Please keep this calendar and also 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. Event announcements are no longer being direct mailed. Thank you.

For disability-related training and other events statewide and nationally, see Pathfinder Disability Calendar www.familypathfinder.org.

Ann and Monroe Carell Jr. Families First

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

Free monthly Saturday workshops

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

Coffee and sign-in 8-8:30 a.m. on all dates

FEBRUARY 21

Adapting Daily Routines: Mealtime, Bathtime, and Bedtime

MARCH 28

Creating Family Activity Routines: Cooking, Chores, and Games

March

MARCH 11

Developmental Disabilities Grand Rounds Siblings of Individuals with Intellectual Disabilities Over the Life Span

Julie Lounds Taylor, Ph.D., Assistant Professor of Pediatrics and Special Education Co-Sponsor VKC Interdisciplinary Training Council and Pediatrics Wednesday 8 a.m. Room 241 Vanderbilt Kennedy Center/MRL Building

MARCH 26

Lectures on Development and Developmental Disabilities Pediatric Anxiety: Current and Future Approaches to Therapeutics

Daniel Pine, M.D., Chief of Emotion and Development Branch, Chief of Section on Developmental and Affective Neuroscience, Chief of Child and Adolescent Research in the Mood and Anxiety Disorders Program, National Institute of Mental Health Thursday 4:10 p.m. Room 241 Vanderbilt Kennedy Center/MRL Building

April

APRIL 1

Developmental Disabilities Grand Rounds Immune Transcriptome Changes in the Temporal Cortex of Individuals with Autism Karoly Mirnics, M.D., Associate Professor of Psychiatry

Co-Sponsor VKC Interdisciplinary Training Council and Pediatrics Wednesday 8 a.m. Room 241 Vanderbilt Kennedy Center/MRL Building

ΔPRII 3-4

Tennessee Adult Brothers and Sisters (TABS) First Annual Conference

Keynote speakers:

M. Doreen Croser, Executive Director, American Association of Intellectual and Developmental Disabilities

Laurie Stallings-Vanderpool, Sibling
Topics include futures planning, caring for
caregivers, research, legislation and advocacy,
family dynamics and relationships
Co-sponsors Tennessee Council on
Developmental Disabilities, University of
Tennessee Boling Center for Developmental
Disabilities, Harwood Center, and TigersEye
Advisory, LLC

Friday-Saturday, Holiday Inn Select at Vanderbilt, 2613 West End Ave., (888) 465-4329 \$45 fee covers registration, meals, snacks, TABS t-shirt

Register (required) at kc.vanderbilt.edu/registration or contact (615) 322-8529 ext. 15

APRIL 15

Neuroscience Graduate Seminar Serotonin Modulation of Brain Development: Impact on Affective- and Anxiety-Related Adult Phenotypes

Jay Gingrich, M.D., Ph.D., Assistant Professor of Psychiatry, Columbia University; Director, Sackler Laboratory of Translational Neurogenetics, New York State Psychiatric Institute

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

APRIL 17

East Tennessee Disability Services and the Hispanic Community Conference

VKC Hispanic Outreach and Tennessee Disability Pathfinder Co-sponsor Tennessee Council on

Developmental Disabilities, AmeriChoice, Tennessee Division of Mental Retardation

Services, Support and Training for Exceptional Parents, Cherokee Health Systems

Register (required) at

kc.vanderbilt.edu/registration

or contact (1-800) 640-4636 ext. 11,

claudia.avila@vanderbilt.edu

Friday 8:30 a.m.-2 p.m. Cherokee Health Systems,

2018 Western Avenue, Knoxville

May

MAY 15

Waddell & Reed Financial Services Charity Golf Tournament

Benefiting Vanderbilt Kennedy Center Camps Friday 7:30 a.m. Hermitage Golf Course, The General's Retreat

Contact (615) 343-5322 kc.vanderbilt.edu/golf

TRIAD School-Age Services

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

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

MARCH 3

Full-Day Workshop for Special Educators and Parents (Jackson)

MARCH 6

Full-Day Workshop for Special Educators and Parents (Nashville)

MARCH 25-27

TRIAD Teacher Training: Basic Middle/High School (Nashville)



Vanderbilt Kennedy Center for Research on Human Development

VKC Summer Camps

Contact Gretchen Herbert, Recreation and Art Coordinator, (615) 321-8761

June 8-June 26

TRIAD Social Skills Camp

June 8-12, June 15-19, June 22-26 Three 1-week sessions for campers, ages 7-11 3-week session for campers, ages 12-21

June 8-26

Camp Shriver Transitions and Sports Camp

For campers with developmental disabilities, ages 16-25

July 5-10 Music Camp

For campers, ages 16 and up, with developmental disabilities

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) 321-8761

JANUARY 30-MARCH 27

Expressions Through Color

Co-sponsored by the Frist Center for the Visual Arts

APRIL 1-JULY 31

Art Through the Eyes of Autism

Co-sponsored by VSA Arts of Tennessee and Autism Society of Middle Tennessee (ASMT)

Reception at the Vanderbilt Kennedy Center on Thursday, April 23, prior to the ASMT educational workshop

Behavior Analysis Clinic

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

roxanne.carreon@vanderbilt.edu

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

APRIL 11, JUNE 13, AUGUST 8, OCTOBER 10, **DECEMBER 12**

SibSaturdays

Ages 5-7 and 8-13 years Games, friends, conversation \$10/child or \$20/family Financial assistance available Advance registration required Saturdays Room 241 Kennedy Center/ MRL Building

See also SibSaturdays sponsored by Autism Society of Middle Tennessee and Down Syndrome Association of Middle Tennessee

MARCH 14, JUNE 20, SEPTEMBER 12, **DECEMBER 19**

Teen Fusion

Ages 13-17 Fun field trips

Locations and activities vary

Tennessee Adult Brothers and Sisters (TABS)

Contact Ashley Coulter, (615) 322-8529 ext. 15 Register online at kc.vanderbilt.edu/site/services/ disabilityservices/tabs.aspx

See April calendar for conference details

Take Part in Research

Vanderbilt Kennedy Center Research Studies

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

Research Family Partners

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

StudyFinder

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

See also VUMC Clinical Trials www.vanderbilthealth.com/clinicaltrials

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

Team William Mini-Marathon (5K Run/Walk)

Saturday Warner Parks-Vaughn Road Registration 8 a.m. Race begins 9 a.m. Information 370-8115 aspickard@harpethhall.org Proceeds benefit Team William Scholarship Endowment, VKC Reading Clinic www.teamwilliam.org

MAY 28-30

Tennessee Disability MegaConference

Nashville Airport Marriott For more information, visit www.tndisabilitymegaconference.org

ASMT Events

Autism Society of Middle Tennessee

www.tnautism.org ASMT event and location information (615) 385-2077

Registration is requested for all events ASMT members free; nonmembers \$5/family

MARCH 19 & MAY 21, Orientation, 6:30-8:30 p.m. MARCH 21, SibSaturday, 10 a.m.-2 p.m. MARCH 26, Workshop: Make & Take It: Supporting Communication Through Visual Supports, 6:30-8:30 p.m.

Art Exhibit – see Arts & Disabilities section

DSAMT Events

Down Syndrome Association of Middle Tennessee www.dsamt.org

DSAMT event information (615) 386-9002

Fired Up! for Down Syndrome Biannual **Statewide Conference**

Friday-Saturday 9:30-11:30 a.m. Brentwood United Methodist Church

Number 23

Winter 2009