At the Vanderbilt Kennedy Center, we don’t stop at the bench to bedside concept. To community has become part of our daily mantra as our faculty investigators and staff carry out the Center’s plan to integrate our efforts in research, intervention, and education for the local and national communities. This is a tricky balance, because at most universities, parallel streams of activity emerge. Unfortunately, their paths rarely cross. We don’t accept this standard operating procedure at the Vanderbilt Kennedy Center.

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**Waking Up to Sleep’s Importance**

By Jan Rosemergy

When a child routinely sleeps poorly, it affects not only the child’s health and behavior but distresses the entire family. In a study of 3,000 5-year-old children, those with sleep disordered breathing were more likely to have daytime sleepiness and problem behaviors, including hyperactivity, inattention, and aggressiveness. Although sleep concerns are common in children, researchers are discovering they are even more common in children with developmental disabilities.

Understanding and treating sleep disorders is the aim of Beth A. Malow, M.D., M.S., who joined Vanderbilt in 2003 to direct its new Sleep Disorders Center. She is an associate professor of neurology, a Vanderbilt Kennedy Center investigator, and a mother of two young boys, one a “somewhat challenging sleeper” and the other a “star sleeper.” The “star sleeper” has high functioning autism, which helped motivate Malow to study the overlap of sleep and autism spectrum disorders (ASD).

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**Team William Is a Winner**

By Stephanie Newton

Andrea McDermott combined her dedication to running with her dedication to William Spickard, an 8-year-old student with Down syndrome she was tutoring. McDermott, a graduate student in special education and a new member of the Vanderbilt Kennedy Center Leadership Council, sought sponsors for her April run in Nashville’s Country Music Marathon under the banner of Team William. She raised over $20,000 prior to the Marathon, kept going, and in July reached her goal of $25,000 required to endow a Vanderbilt Kennedy Reading Clinic scholarship fund for students with Down syndrome. With that marathon spirit, McDermott plans to keep Team William going and growing.

To join Team William, mail a check payable to Vanderbilt University (For: Team William) to Andrea Blake McDermott, c/o Vanderbilt Kennedy Reading Clinic, 1810 Edgehill Avenue, Nashville, TN 37212.

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**Building Legacies**

At the Vanderbilt Kennedy Center, we don’t stop at the bench to bedside concept. To community has become part of our daily mantra as our faculty investigators and staff carry out the Center’s plan to integrate our efforts in research, intervention, and education for the local and national communities. This is a tricky balance, because at most universities, parallel streams of activity emerge. Unfortunately, their paths rarely cross. We don’t accept this standard operating procedure at the Vanderbilt Kennedy Center.
Through the use of electrophysiological records of brain wave activity during sleep (polysomnography), we know that the brain is as active during sleep as it is during waking. Brain activity during sleep is related to immune system functioning, brain plasticity, and cognitive development. Sleep also is implicated in the consolidation of waking experiences into long-term memories. An examination of brain activity during sleep in individuals with developmental disabilities and across different syndromes—for example, epilepsy, autism, Down syndrome, fragile X syndrome—may provide important information for understanding the processes of learning and memory and even the role of genes in these processes.

Sleep in children with autism. The prevalence of sleep concerns in children with ASD ranges between 44% and 83%, compared with approximately 30% prevalence in infants and preschool children who are typically developing, with the percentage decreasing in school-aged children. Sleep concerns in ASD occur regardless of IQ and include later bedtimes, prolonged time to fall asleep, decreased sleep duration and continuity, increased arousals and awakenings, and early morning waking time. Short sleep duration has been associated with delays in social skills and with repetitive behaviors.

Symptoms of ASD that can influence sleep include increased sensitivity to touch, sound, and light; hyperactivity; and anxiety. Sleep is affected by family influences; for example, parents often tire to adhere to a bedtime routine. Co-existing conditions such as epilepsy, intellectual disability, or psychotropic medications also can affect sleep. Melatonin, a hormone that regulates the sleep-wake cycle, or circadian system, is deficient in ASD. Supplemental melatonin may improve sleep in children with ASD, suggesting that circadian rhythms may be altered.

Autism Sleep Study. Malow leads a study of sleep in children with ASD funded by Vanderbilt University, the National Alliance for Autism Research, and the General Clinical Research Center. Co-investigators are Wendy Stone, Ph.D. (pediatrics); Susan McGrew, M.D. (pediatrics); Craig Kennedy, Ph.D. (special education and pediatrics); Mark Harvey, Ph.D. (special education); Ramon Cuevas, M.D. (neurology); and Lynnette Henderson, Ph.D. (pediatrics). Sleep patterns in children with ASD, 4 to 10 years, are being compared to those in age-matched children who are typically developing and have no sleep concerns.

Preliminary findings. Parents of 32 children with ASD and 49 typically developing children have completed sleep surveys. On a questionnaire assessing parental concerns developed by McGrew, 38% of parents of children with ASD reported moderate to severe sleep concerns. On the Child Sleep Habits Questionnaire, compared to typical children, those with ASD had higher scores on "insomnia" related dimensions:

- Time to fall asleep was 107 minutes in the "poor sleepers" and 12 minutes in the "good sleepers."
- No clear-cut REM abnormalities were seen, but this may reflect the homogeneous sample (medication-free). One child was diagnosed with obstructive sleep apnea; after a tonsillectomy, she showed a marked improvement in sleep and daytime behavior, although she retained her autism spectrum diagnosis. For more information about Malow's study, please contact Karen Adkins, R.N., (615) 936-1646.

Behavioral treatments. For children with ASD who resist bedtime or have...
Enhancing Interactions, Building Hope

By Stephanie Newton

The spoken and unspoken communication between a child and a parent can be one of the strongest bonds of a lifetime. But for Jon and Michelle Moore, their link with their twin sons Cole and Alex was slow to develop and left them with uncertainty.

“When I went into the boys’ room each morning, Cole would rarely turn and look at me. He was usually in his crib with his back to me,” said Mrs. Moore. “When I looked at other kids with their parents, I usually got a sick feeling. Why didn’t Cole look at me like their siblings?”

When I approached, he seemed to not notice or acknowledge me. “When I went into the boys’ room each morning, Cole would rarely turn and look at me. He was usually in his crib with his back to me. The feelings that Moore expressed are apparent that much time and effort had to be put into each interaction, and communication skills; learn different strategies for teaching a child new skills; and incorporate teaching activities into everyday routines.

“Our experience with the EI class raised the level of hope we have for both our boys. When we implemented their suggestions, the boys’ level of functional communication immediately went up,” said Moore. “It took work to implement EI’s suggestions, but we started out small and gradually added on. Seeing the progress our boys are making gives us the motivation to keep going.”

At the end of the classes, parents have been uniformly pleased with their experience. One family reported that they “feel more confident in implementing skills, feel better prepared, and more educated.” Another parent reported that she learned “so many great techniques for instructing and interacting with all my children . . . this should take a lot of stress out of every day and help our family to work better as a whole.”

TRIAD’s EI classes are offered to families of children under 3 years through a contract with the Tennessee Department of Education, Division of Special Education. This contract also provides funds to support training of service providers across the state through TRIAD’s regional, 5-day Enhancing Interactions Academies. For information, please contact (615) 936-1705.

TRIAD, in partnership with the Vanderbilt Kennedy Center, held a 3-week day camp. June 13-July 1, to help children with autism spectrum disorders acquire important social and communication skills during structured lessons, sports and crafts, and special events. Typically developing peers ages 6 to 12 served as models and interactive partners, as well as taking part in fun activities. The annual camp is sponsored by TRIAD, the Vanderbilt Kennedy Center, the Center for Child Development/Pediatrics, and the Monroe Carell Jr. Children’s Hospital at Vanderbilt.
Leading the Vanguard of Discovery

• Ad Hoc Reviewer, NINDS Clinical Trials Section

Selected Publications


Education

B.S., 1984, Medical Science, Northwestern University
M.D., 1986, Medicine, Northwestern University
M.S., 1997, Clinical Research Design and Statistical Analysis, University of Michigan

Attraction to Developmental Disabilities Research

Sleep is an integral part of health and influences daytime behavior in a variety of neurological disorders. After 10 years of studying the effects of sleep disorders on epilepsy, I decided to apply this model to autism spectrum disorders.

A major influence on me was my 6-year-old son, Austin, who is on the spectrum and, thankfully, is an excellent sleeper. I became immersed in understanding autism spectrum disorders and saw the disabling daytime behaviors associated with this condition not just in my own son but in others. It was then that I realized that identifying and treating disordered sleep in autism could make a huge difference in the lives of affected children and their families.

Reasons for Vanderbilt Kennedy Center Membership

The Vanderbilt Kennedy Center has provided me with many resources to carry out my work. The most important resource is the network of collaborators within the Center, including: Wendy Stone [pediatrics and psychology], Craig Kennedy [special education and pediatrics], James Sutcliffe [molecular physiology & biophysics], and Carl Johnson [biological sciences], who have all assisted me in developing ideas for sleep research projects and allowed me to integrate behavioral, genetic, and circadian measures into my research program.

The Graphics core service has been phenomenal in assisting with posters and figures for manuscripts, Linda Dupré has been very helpful with grant applications, and Jan Rosemergy has been eager to assist with recruitment for our studies.}

New Grants

Using baby books to promote maternal and child health
Leonard Bickman, Ph.D. (psychology)
National Institute of Child Health and Human Development

Regulation of serotonin transporters
Randy Blakely, Ph.D. (pharmacology)
National Institute on Drug Abuse

Synaptic mechanisms of neurodegenerative disease
Kendal Broadie, Ph.D. (biological sciences)
National Institute of Neurological Disorders and Stroke

Psychotropic medications and pharmacogenetics in persons with Prader-Willi syndrome
Elisabeth Dykens, Ph.D. (psychology & human development)
National Prader-Willi Syndrome Association

Children with disabilities and sibling hospitalization
Robert Hodapp, Ph.D. (special education), Richard Urbano, Ph.D. (pediatrics), and Karen Summar, M.D. (pediatrics)
National Institute of Child Health and Human Development

MR [magnetic resonance] studies of alcohol-induced brain injury and recovery
Peter Martin, M.D. (psychiatry) and John Gore, Ph.D. (radiology & radiological sciences and biomedical engineering)
National Institute on Alcohol Abuse and Alcoholism

Neurocognitive consequences of cannabis use
Sohee Park, Ph.D. (psychology) and Ronald Cowan, Ph.D. (psychiatry)
National Institute on Drug Abuse

GH alternative splicing: Mechanisms and disease
John Phillips, M.D. (pediatrics)
National Institute of Diabetes & Digestive & Kidney Diseases

Saccade target selection: Frontal cortex
Jeffrey Schall, Ph.D. (psychology)
National Eye Institute

Dopaminergic influences on brain formation & function
Gregg Stanwood, Ph.D. (pharmacology)
National Institute on Drug Abuse

Developing a client assignment model for reaching educators, children, and parents
Bahr Weiss, Ph.D. (psychology) and Thomas Catron, Ph.D. (psychiatry)
National Institute of Mental Health

Regulation of systematic transmission in BNST [bed nucleus of stria terminalis] by alcohol
Danny Windler, Ph.D. (molecular physiology & biophysics)
National Institute on Alcohol Abuse and Alcoholism

Effects of intensity of early communication intervention
Paul Yoder, Ph.D. (special education; PI Subcontract) and Steven Warren, Ph.D. (University of Kansas; PI Project)
National Institute on Deafness and Other Communication Disorders
Waking Up  from page two

difficulty falling asleep, Malow recommends the following: (a) establish a 20- to 30-minute bedtime routine, using visual supports to encourage this routine; (b) keep to a regular bedtime and wake time; (c) avoid stimulating activities before bedtime (e.g., computer, TV); (d) encourage children to get enough daytime exercise; (e) assess the sleeping environment to maximize comfort and to minimize anxiety (e.g., leave a door open, use a nightlight); and (f) teach children to fall asleep on their own so they will be able to return to sleep when they awaken at night. For some children, a weighted blanket may be helpful in promoting sleep.

For children who wake in the night: (a) review bedtime habits (has child learned to fall asleep on his/her own?); (b) minimally interact with child when entering room or when returning child to bed to avoid reinforcing night wakings; and (c) provide a reward in the morning for sleeping through the night.

Behavioral treatments should be tried first. If they are not successful, a sleep evaluation may be appropriate. Although in some instances medications are used successfully, including over-the-counter melatonin, they should be given only under the guidance of a physician.

In summary, sleep concerns are common in children with developmental disabilities. Developing effective treatments depends on establishing causes of sleep disorders, which involve many factors. Identifying and treating sleep disorders may result not only in better sleep but also may positively affect daytime behavior and learning and reduce family stress.

We are interested in having families of children with autism contact us about our research study. You and your child’s involvement can range from completing short surveys to undergoing sleep testing in your home or at Vanderbilt.

There is no cost for participation and compensation is provided to families who qualify. Families who are interested in the study or have additional questions may contact Karen Adkins, R.N., (615) 936-1646.


Accolades

Barbara Clinton, M.S.W., Center for Health Services director, received the 2005 Mary Jane Werthan Award in recognition of her “inspiring and visionary impact on the lives of women at Vanderbilt and beyond,” given by the Vanderbilt Margaret Cuninggim Women’s Center.

Edward Conture, Ph.D., professor of hearing & speech sciences, was awarded the 2005 Honors of National Student Speech Language Hearing Association, its highest award, in recognition of his work expanding educational and preprofessional opportunities for students in communication sciences.

Michael Cooper, M.D., assistant professor of neurology, received a Basil O’Connor Starter Scholar Research Award from the March of Dimes. This prestigious competitive award supports young scientists embarking on research careers.

Doug Fuchs, Ph.D., and Lynn Fuchs, Ph.D., Nicholas Hobbs Chair in Special Education and Human Development, have been awarded the Distinguished Researcher Award from the Special Education Special Interest Group, American Educational Research Association.

Steve Graham, Ed.D., and Karen Harris, Ed.D., Curry Ingram Chair of Special Education, pictured above, received the Council for Exceptional Children’s Career Research Award.

Carolyn Hughes, Ph.D., professor of special education, and former graduate student Erik Carter have published Success for All Students: Promoting Inclusion in Secondary Schools through Peer Buddy Programs (Allyn & Bacon, 2006).

Kathleen Lane, Ph.D., assistant professor of special education, has received the 2005 Early Career Research Award, Division of Research, Council for Exceptional Children.

Pat Levitt, Ph.D., professor of pharmacology and Vanderbilt Kennedy Center director, was appointed as a member of the Dana Alliance for Brain Initiatives. The Autism Society of America selected him as their 2005 Research Champion.

Elise McMillan, J.D., Vanderbilt Kennedy Center director of community outreach, was elected to the Board of The Arc of the U.S. The Vanderbilt Best Buddies Chapter received a Vanderbilt Affirmative Action and Diversity Award, accepted by Vanderbilt student and chapter president Kathy Lawton and McMillan, advisor.

Robin McWilliam, Ph.D., professor of pediatrics and the Center for Child Development director, was elected vice president of the Division for Research, Council for Exceptional Children. He will serve as president-elect in 2006.

Paul Morgan, recent doctoral graduate in special education, received the 2005 Doctoral Dissertation Award, Division of Learning Disabilities, Council for Exceptional Children.

Daniel Reschly, Ph.D., professor of education and psychology and chair of Peabody’s Department of Special Education, is president-elect of the Division of Research, Council for Exceptional Children. He received a Vanderbilt Affirmative Action and Diversity Award in recognition of his work on behalf of the disproportionate number of minority children who are diagnosed with learning disabilities. Reschly also was named most frequently cited person in school psychology textbooks and journals over the 2002, 2003, and 2004 years.

Elaine Sanders-Bush, Ph.D., professor of pharmacology, psychiatry, and director of the Vanderbilt Brain Institute, was named president-elect of the American Society for Pharmacology and Experimental Therapeutics.

Karen Summar, M.D., former Vanderbilt Kennedy Center research fellow, has been appointed as the first postdoctoral fellow in MIND (Mid-Tennessee Interdisciplinary Instruction in Neurodevelopmental Disabilities).

Joseph Wehby, Ph.D., assistant professor of special education, was named co-editor of the Journal of Behavioral Disorders.

Careesa Young, Ph.D., Vanderbilt Kennedy Reading Clinic coordinator, presented at the Learning Disabilities Association (LDA) conference; her presentation was “The irrelevance of intelligence in predicting response to reading interventions—or not?” Young is president-elect of the Tennessee branch of the International Dyslexia Association.
This summer, a group of Vanderbilt nursing students participated in a service learning component during the summer semester. The students worked with the staff at various sites in Nashville and Davidson County, including the Susan Gray School (SGS), a centrally located on a dynamic university campus that offers a unique training opportunity. As part of the SGS's mission of service, training, research, and demonstration, the School is available to the entire Vanderbilt community for field experience opportunities. One such experience involved students from the Vanderbilt School of Nursing, who used the School as a setting for developing and implementing an educational program aimed at increasing young children's knowledge of healthy nutrition.

“The nursing students will become professionals who work with young children in many different capacities, and the School offers a unique training opportunity for them,” said Ruth Wolery, Ph.D., SGS director. “Not only do the nursing students gain experience with a variety of disability conditions, they have the opportunity to observe the benefits of an inclusive environment for young children with disabilities. What better way for the students to learn that inclusive early interventions are effective?”

Community Health Nursing

All Vanderbilt University School of Nursing pre-specialty students complete a total of 100 service hours in community health over the spring and summer semesters. This requirement enhances the students’ academic experience while providing volunteer services to Vanderbilt community health sites. Nursing students can participate in a variety of health care settings within Metropolitan Nashville and Davidson County. In conjunction with the staff at the various sites, a service learning project is planned, which the students then put into practice during the summer semester.

Teaching Nutrition Early

This summer, a group of Vanderbilt nursing students conducted their service learning project at the SGS. Their focus was good nutrition for all children, and their project goal was to teach children to make healthier food choices. Using age-appropriate and entertaining games and skits, the nursing students presented their program to the early learners at the SGS.

“The Susan Gray School is a community health site for our nursing clinical rotation course,” said Liz Greenfield, a nursing student. “When we were given the assignment to provide a community health intervention for this population, we wanted to focus our efforts on an area specific to nursing. Nurses provide a vital role in health education and preventative care. In light of the childhood obesity problem in the U.S., we decided to focus on nutrition. It is our hope that this early nutritional education will lay the foundation for healthy food decisions that will last a lifetime.”

Throughout the summer, nursing students visited the SGS and presented their planned nutrition program to the various classes. They were able to incorporate their information into the course of a typical school day for the children. SGS students were interested and eager to learn about the different foods through various games that involved active participation.

The Food Pyramid and Chef the Puppet

In the Emerald Forest preschool classroom, the nursing students discussed the food pyramid with the help of a Chef puppet. After learning about what makes food healthy and the different food groups, the children were given a chance to show what they had learned. Each child placed a flashcard with a food picture on it into the specific divisions of the pyramid. The nurses taught tricks to help the children recognize healthy foods and incorporate them into their lives.

“The children were very receptive toward the nurses and their program because they love to participate,” said Loretta Morris, lead teacher of the Emerald Forest classroom. “The nursing students were very patient with the children and were able to incorporate everyone, typically developing children and those with a disability.” While the children were focused on the fun aspect of the presentation, the nursing students focused on the long-term effects their program could have on a child’s lifetime nutrition.

“With obesity at an all-time high within the pediatric population, we as health care providers must become active participants in the process of holistic health promotion,” said Amy Edwards, R.N., a lecturer for the Vanderbilt School of Nursing. Edwards and the nursing students hope that further implementation at the SGS as well as other schools in the area will encourage life-long healthy living.

Edwards believes that long-term goals for the nutrition project would be to use this knowledge in other community health centers to promote a solid foundation for permanent, healthy lifestyles. Parents would provide an additional perspective and provide additional positive support for the children and encourage a change in the home.

“This project has made me more aware of the role of the Susan Gray School within our community. It is composed of compassionate caregivers who truly desire to have a positive impact on these children’s lives each and every day,” said Edwards. “They are to be commended for their efforts in providing such an invaluable service to the children of the Nashville community.”
The Susan Gray School provides inclusive education for young children with and without disabilities and support for their families. Its fourfold mission is providing high-quality service, supporting research, contributing to the training of future teachers and researchers, and demonstrating recommended practices as a national model. It is a program of the Vanderbilt Kennedy Center and Peabody College.

Holidays Around the World

By Stephanie Newton

On Saturday, December 3, the Susan Gray School (SGS) will kick off a new fundraiser by adding a fun twist to a favorite long-standing tradition. The annual cultural event Holidays Around the World now will become SGS’s primary fundraiser.

“Over the years, Holidays Around the World has been a fun way to get the parents to the school and let them see what the children are doing while celebrating different countries and holidays,” said Suzanne Pendergrass, an SGS outreach teacher. “But we are now taking it to a different level, and it will become our annual fundraiser. We hope to tap into more of the resources on campus to help us grow.”

As in years past, each of the SGS classrooms will represent a different country of the world. In all, 10 countries will be represented by the students, with help from teachers and parents. Throughout the year, students learn about their countries and their learning culminates at the Holidays Around the World event. With the help of families and friends, each group of children presents information, prepares native food, and offers insight into the culture and diversity of their designated nation.

Holidays Around the World 2005 will be moving to a larger venue and will include a fundraising component. In addition to the children’s presentations, other activities will include cultural entertainment, ethnic foods, a silent auction, and a craft sale. The SGS is calling on parents with various talents to lend their skills to help the school provide one-of-a-kind items for purchase by the community.

“We have family and friends of the Susan Gray School who make wonderful jewelry, sew detailed quilts, and build woodcraft items,” said Ruth Wolery, Ph.D., SGS director. “We hope that each family will find their own way to contribute to the success of the event.”

Several prizes have already been donated for the silent auction. Items secured include, among others, free bagels for a year from Panera Bread, a family pass to the Frist Center for the Visual Arts for one year, a one-night stay and dinner for two at Loews Vanderbilt Hotel, and a gift certificate from Dan McGuinness.

The December 3 event’s activities will begin at 4 p.m. To accommodate a large participant group, Holidays Around the World is moving from the School to the Vanderbilt Commodore Ballroom. The Ballroom is located in Vanderbilt’s new Student Life Center located on 25th Avenue South by Memorial Gymnasium. Tickets are currently on sale and prices vary. All proceeds from the event will go to support the SGS Scholarship and Therapy Fund. Everyone is welcome.

The celebration also will serve as a final drop-off location for the annual SGS Angel Tree. Angels will be available starting November 3, and all gifts need to be returned by December 3. For information on tickets or how to make a donation to the Holidays event or the Angel Tree, please call (615) 322-8200.

Summer Olympic Games

The Susan Gray School held its Summer Olympic Games June 6-10. Students spent the week enjoying a variety of activities and sporting events while their family and friends encouraged them from the sidelines. Students participated in an obstacle course and a T-ball game while individually competing in the discus throw, cycling, and several track and field events. At the end of the week, everyone received a gold medal for outstanding achievement.
Hispanic Disability Outreach

By Traci Fleischman

Tennessee Disability Pathfinder’s Project Conexión connects the unserved and underserved Hispanic community of Metropolitan Nashville and Davidson County to disability resources, thanks to a partnership among the Vanderbilt Kennedy Center, the Tennessee Council on Developmental Disabilities, and the Woodbine Community Organization.

“Conexión builds on the Tennessee Disability Pathfinder program, which offers a Web site in Spanish and a bilingual social worker,” explained Elise McMillan, J.D., project director and director of community outreach for the Vanderbilt Kennedy Center. “We were able to develop this model program as part of a grant from the Administration on Developmental Disabilities to the Tennessee Council on Developmental Disabilities.”

Individuals from the Nashville community and surrounding areas come to the Woodbine Community Center to meet with the Pathfinder staff, an injury that allowed her to gain another perspective.

“I could see what patients [in particular, Hispanic patients] had to go through. People with disabilities feel more confident and at ease when approaching me because of my own experience—we now have a connection. I can talk to people, agencies, and public workers and tell them that I understand. I have been in the patient’s place as a person with a disability, and I have been on the medical side of it as well,” stated Yu-Morales.

A prime example of the magnitude of the impact that Pathfinder’s Project Conexión has on the Hispanic community is the story of Simplicio Guerrero, a father who came in to see Yu-Morales at the Woodbine Community Center. He told her about his son, who is in his mid-40s, and was diagnosed with polio as a child; he is blind and uses a wheelchair.

“They came asking us for help finding a wheelchair because his current wheelchair was falling apart,” explained Yu-Morales.

Avila-Lopez and Yu-Morales went to the client’s home and assessed the situation. Yu-Morales quickly got in touch with Greg Cox at United Cerebral Palsy of Middle Tennessee (UCP), and they donated a custom-fitted recliner wheelchair, a shower chair, and other necessary items.

Pathfinder social worker, Avila-Lopez, was born in Chihuahua, Mexico, and moved to Midland, Texas, 12 years later. Her primary role is to develop Pathfinder’s Hispanic outreach program around the state, including Project Conexión. Avila-Lopez joins Yu-Morales at the Woodbine Community Center once a week.

On April 20, Avila-Lopez and Yu-Morales hosted the first conference for agencies that work within the Hispanic community in the Nashville area. “The conference far exceeded our expectations. Forty bilingual professionals learned how to better communicate with individuals with disabilities and with service providers,” explained Avila-Lopez.

Conference attendees included, among others, the Mental Health Association of Middle Tennessee, Catholic Charities of Tennessee, Metro Social Services, Tennessee Protection and Advocacy, Tennessee Infant Parent Services, Outlook Nashville, and the Knowles Senior Center.

With the collaboration between the Vanderbilt Kennedy Center and the Woodbine Community Center, disability resource materials are identified, and staff are developing and disseminating bilingual information and referral resources to Spanish-speaking Tennesseans. The partners bring awareness, information, and referral of disability information to Hispanics through the Woodbine community and provide a model that can be used in other communities and states.

Wanda Willis, executive director of the Tennessee Council on Developmental Disabilities, summarized the initiative’s impact: “Project Conexión and our partnership with the Vanderbilt Kennedy Center has accomplished more toward connecting disability advocates and systems to the Hispanic community than anything else the Council has sponsored.”

Mayra Yu-Morales and Claudia Avila-Lopez, staff for Pathfinder Hispanic disability outreach

Mayra Yu-Morales, a disability resource worker, and Claudia Avila-Lopez, Pathfinder’s bilingual social worker. Individuals and families are interviewed and referred to appropriate community resources.

“Mayra has to be creative when sending a person to an agency because there are not a lot of resources in the surrounding areas that can help. One of the biggest challenges is trying to get individuals with disabilities more involved and aware of the resources that are available. Families come into the Woodbine Community Center needing legal, housing, financial, and health care assistance. Each case is unique,” explained Avila-Lopez.

Yu-Morales is very involved in the Woodbine community—she lives, works, and volunteers in the neighborhood. She is originally from Mexico City and after moving to the U.S., she became a nurse’s assistant and worked closely with individuals with disabilities. Last year she received a prime example of the magnitude of the impact that Pathfinder’s Project Conexión has on the Hispanic community is the story of Simplicio Guerrero, a father who came in to see Yu-Morales at the Woodbine Community Center. He told her about his son, who is in his mid-40s, and was diagnosed with polio as a child; he is blind and uses a wheelchair.

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The Guerrero family with Pathfinder’s Mayra Yu-Morales at United Cerebral Palsy of Middle Tennessee, which donated a custom-fitted wheelchair

Conexión

El proyecto conexión del Disability Pathfinder es un programa de información y referencia para individuos con discapacidades que está localizado en el Centro Comunitario de Woodbine. La meta del proyecto es ayudar a las personas hispanas con discapacidades y a sus familias incrementando el conocimiento de los servicios disponibles mientras mejora el acceso a programas existentes. Los objetivos incluyen: (a) ayudar a individuos a entender los sistemas de discapacidades y asegurar servicios comunitarios disponibles, (b) crear recursos de información y referencia en agencias locales para conectar a individuos hispanos a recursos que ya existen, y (c) proveer entrenamiento técnico de discapacidades en la comunidad. Para más información llame a Mayra Yu-Morales en Woodbine (615) 850-3448 o a Claudia Avila-Lopez en la oficina del Disability Pathfinder (615) 322-7830.
The first Vanderbilt Kennedy Center Music Camp provided a unique opportunity for individuals with Williams syndrome to focus on what they love and do well—music. The 1-week residential camp for young adults with Williams syndrome, which took place July 24-31, was co-sponsored by Vanderbilt University’s Blair School of Music and the National Williams Syndrome Association.

Goals included learning and practicing new skills in music performance, receiving instruction in music enrichment and appreciation, socializing with mentors and peers, discussing careers in music, feeling connected and empowered, and providing family support and information.

The camp included 11 adults from 10 different states. Programming built on Nashville’s strengths in music and incorporated throughout the week’s activities the rich variety of music from the film soundtrack of *O Brother, Where Art Thou?* Campers toured music venues such as the Country Music Hall of Fame and Museum. They worked directly with professional musicians on Music Row to write and produce a song, to cut a CD, and to perform live on the Grand Ole Opry.

While most summer camps for persons with developmental disabilities are purely recreational, the Vanderbilt Kennedy Center camp successfully blends a three-fold mission of training, skill development, and research.

Future camps will include young musicians without disabilities and those with other developmental disabilities.

Williams syndrome is a common genetic disorder characterized by cardiac problems, mild to moderate intellectual disabilities, and difficulties with visual-spatial tasks—but also by strong social and verbal skills, empathy, and keen interests in music. Some persons are quite musically talented, while others have an incredible zest and love of music.

The Music Camp was a huge success and allowed a creative and educational outlet for highly skilled and talented individuals.

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**My Life, My Choice, My Plan**

In partnership with the Down Syndrome Association of Middle Tennessee and The Arc of Williamson County, the Vanderbilt Kennedy Center held an intensive 2-week day camp, June 20-July 1, for teens and young adults with Down syndrome. Based in Williamson County, the camp provided training in social and adaptive skills to guide campers toward clarifying their strengths, advocating for themselves, and developing life goals and plans.

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*Singing “Keep on the Sunny Side of Life,” the campers performed on the Grand Ole Opry stage on July 29 and received a standing ovation.*

*Campers learned grooming techniques during “Self-Care Day.”*
Promoting Knowledge

By Traci Fleischman

The Vanderbilt Kennedy Center has expanded its expertise in development, outreach, and research by adding five experienced staff members.

Sheila Jacobs, director of development, joined the Vanderbilt Kennedy Center staff in May. Jacobs’s father owned Gallaudet Drug Store across from Gallaudet University for deaf, hard of hearing, and hearing students, so she grew up signing before she could speak verbally. This led her to pursue a degree in speech pathology and special education from the University of Maryland. Her career has come full circle, and she now is joining her early training to the knowledge she has developed in both marketing and fundraising over the years.

Jacobs spent the majority of her career in marketing and fundraising in health care, and served clients such as the Mayo Clinic, Henry Ford Health System, Johns Hopkins Hospital, and Lovelace Health Systems. Ten years ago, she decided to venture full-time in fundraising and served as the vice president of development for the Arthritis Foundation of the Greater Southwest, and most recently as the chief development officer for a medical school in Phoenix, Arizona.

“I have always had an interest in human development. The Vanderbilt Kennedy Center director, Dr. Levitt, and the researchers at the Center are world class, and the opportunity to raise funds to further these efforts made my decision to come to Vanderbilt easy,” explained Jacobs.

Sara Rich, coordinator of camps and art, joined the Vanderbilt Kennedy Center in March. Rich has worked closely with various chapters of The Arc over the years, and was given the opportunity to run her own camp in North Carolina. She started working with adults with disabilities as part of their day program and taught art, life skills, and mathematics. This internship led to Rich creating her own program called Summers with Sara. “We spent nine weeks navigating the community and experiencing Winston-Salem, North Carolina, to its fullest, both vocationally and recreationally,” explained Rich.

Since relocating to Nashville, Rich has become a much-needed building block in the camps and art areas of the Center. The camps and art programs are a vital part of the disability community, and Rich has set many aims for them.

“My goals for the camps next year are to repeat, but improve. For example, I would love to be able to offer the TRIAD [Treatment and Research Institute for Autism Spectrum Disorders] camp to a larger number of children,” said Rich. “The body of knowledge in the Vanderbilt Kennedy Center is so great and the backing and support I receive are amazing—I would like to be able to share that with more people.”

Rich has similar aspirations for the art program. “I would love to connect with more artists in the community, to expand our gallery space, and to host more receptions for the art program.

I look forward to working hard at forming community relationships and broadening the art program.”

Lynnette Henderson, Ph.D., research participant coordinator, came to work for the Vanderbilt Kennedy Center in August after completing a postdoctoral fellowship at TRIAD.

“I have always loved the Vanderbilt Kennedy Center. I think what we do is really important. Not enough people in this part of the country know how important what we do is and what kind of resources we offer to the community. I want to help get that word out,” stated Henderson.

Henderson has a strong background in early childhood and elementary education, as well as in disabilities and individual differences. Henderson received her Ph.D. in special education from Vanderbilt University, and her dissertation led her to become interested in autism. After teaching at Austin Peay State University for 3 years, Henderson missed research and decided to make the transition back to Vanderbilt, where she completed a postdoctoral fellowship in autism to strengthen her expertise. While working on her fellowship, Henderson began recruiting participants for studies at TRIAD with Wendy Stone, Ph.D., which led to this new position for the Center.

“My goal is to connect families, educators, pediatricians, and others in the community with researchers and new research projects. Both researchers and families... Continued on page 11

Driving for the Green

Vanderbilt Kennedy Center director Pat Levitt, Ph.D. sounded the horn to start the morning’s tournament at the Vanderbilt Legends Golf Club in Franklin on June 17. Waddell & Reed Financial Services sponsored the tournament benefiting the Vanderbilt Kennedy Center for the third year.

Vanderbilt University football head coach Bobby Johnson; Tommy Bernard, son of Vanderbilt Kennedy Center Leadership Council member, Ann Bernard; and Waddell & Reed advisor Pat Blair waited to tee off at the tee box. The annual golf tournament was a huge success, raising more money this year than in years past.
Promoting

from page ten

can benefit from this interaction,” explained Henderson. “It is my job to build the scaffold that allows researchers and new projects to get off the ground a lot sooner.”

Evon Batey Lee, Ph.D., joined the Center in September as the psychological assessment coordinator for the Center’s Clinical Research and Assessment Core. She is familiar with the Vanderbilt community, having worked for the Center for Child Development as a developmental psychologist for nearly 25 years. “I am particularly excited by the multidisciplinary collaborations [within the Vanderbilt Kennedy Center] that are growing and hope that I will be able to contribute to their success,” stated Lee.

Melissa Fortson, disability resource specialist, joined the staff of Tennessee Disability Pathfinder in June. Pathfinder is a gateway for Tennessee disability services and resources and for selected comprehensive national disability-related Internet sites.

“As a resource specialist, I’m always on the lookout for community resources. I can already see that people are the greatest resource at Pathfinder and at the Vanderbilt Kennedy Family Outreach Center. I’m looking forward to simply learning from them,” said Fortson. “Pathfinder and the Outreach Center take knowledge and make it accessible, and it feels good to be a part of that—whether it be a social worker making a referral to a resource in our Pathfinder comprehensive database or a tutor’s practice of a technique to help a child to read in our Reading Clinic.”

As the staff at the Vanderbilt Kennedy Center continues to grow, so do the ideas of responsibility and working well with others. She has taken on the big responsibility of chairing the annual Leadership Council Dinner for the second year.

“Going into the Dinner planning, I had no expectations and no preconceived notions as to what to expect. It turned out to be a good thing and it is all about one’s personal involvement,” explained Eaden.

Eaden truly follows her statement by becoming more involved with the Center each year. She is now a member of the Special Events Planning Committee and is working with other Leadership Council members, Becky Chickey and Bethany Jackson, in planning the Share Our Story (SOS) events. SOS events are hosted by members of the Vanderbilt Kennedy Center’s Leadership Council to help increase awareness about the Center. The events are a perfect time for individuals not familiar with the Center to learn about the history, the presence, the research, and the scientists affiliated with the Center.

“We are working on spreading awareness nationally and increasing our Hobbs Society members. I didn’t know about the Vanderbilt Kennedy Center and I was great friends with the chair of the Leadership Council, Barbara Gregg Phillips. I figured if I didn’t know about this wonderful place, many other people were not aware either. I have made it a Council mission to raise awareness,” stated Eaden.

“I have learned so much about Vanderbilt Kennedy Center programs over the past year and can now talk about them to other people because I am more knowledgeable. The Center is a place of hope and a place of action. It is a true inspiration to see the children and the daily progress they make,” stated Eaden.

“The staff is caring and helps bring research to reality. So much research is hard for the lay person to understand, but the people at the Vanderbilt Kennedy Center really make an effort to make their research truly beneficial and explain what they are doing and why they are doing it. I think that is great.”

Spotlight

Raising Awareness

ANN EADEN

By Traci Fleischman

Ann Eaden is a prominent member of the Nashville community as well as the community of the Vanderbilt Kennedy Center. As vice president of Beaman Automotive, Eaden knows all about responsibility and working well with others.

As the staff at the Vanderbilt Kennedy Center continues to grow, so do the ideas of hope, development, outreach, and research.

Kennedy Center Donors

New Nicholas Hobbs Society Members

as of January 1, 2005 ($1,000 and above)

Ms. Mary Partin

Mr. and Mrs. Gary Lee Price

Mr. Mark Pitter

Mr. and Mrs. Steven Sheehan

Dr. and Mrs. William Anderson Spickard III

Drs. Wendy Stone and Mark Jacobs

Honor and Memorial Gifts

In memory of Dr. Irwin B. Eskind

Mr. and Mrs. Lawrence Pollack

In memory of Mrs. Barbara C. Hofstetter

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Dr. and Mrs. Pat Leviit

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Ex-Officio Members
- Dr. Elisabeth Dykens
- Ms. Sheila Jacobs
- Dr. Pat Levis
- Mrs. Elise McMillan
- Mr. Tim Stafford

40th Anniversary

September 28
40th Anniversary Community Celebration
Luncheon 11:30 a.m.-1 p.m.
By invitation; contact (615) 343-5322

Keynote Address 4-5 p.m.
Pat Morrissey, Commissioner of Administration on Developmental Disabilities
Room 241 Vanderbilt Kennedy Center/MRL Building
Free and open to the public; information (615) 322-8240

October 26 – 6:30-9 p.m.
Vanderbilt Kennedy Center Leadership Dinner
Loews Vanderbilt Hotel
By invitation; contact (615) 343-5322

November 30 – 1-5 p.m.
Scientific Symposium Celebrating 40th Anniversary
“Science and Leadership in Developmental Disabilities”
Vanderbilt Student Life Center
For speakers, see Calendar listing
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Discovery is a quarterly publication of the Vanderbilt Kennedy Center for Research on Human Development designed to educate our friends and the community, from Nashville to the nation. The Vanderbilt Kennedy Center is committed to improving the quality of life for persons with disorders 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; and a National Institute of Child Health and Human Development designated National Mental Retardation and Developmental Disabilities Research Center.

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Kendall Bronic, Ph.D., Director of Neurobiology and Plasticity Research Program
Stephen Camarota, Ph.D., Director of Communication and Learning Research Program
Ann Kaiser, Ph.D., Director of Families Research Program
Robert Hodapp, Ph.D., Co-Director of Families Research Program
BethAnn McLaughlin, Ph.D., Faculty Director of Community and Special Projects
Tim Stafford, Director of Operations
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Jan Rosemergy, Ph.D., Director of Communications

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**Fall 2005 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 Web site kc.vanderbilt.edu or call (615) 322-8240. For disability-related training and other events statewide and nationally see the Disability Calendar on the Tennessee Disability Pathfinder Web site www.familypathfinder.org.

## September

### JULY 15-SEPTEMBER 16
**Arts and Disabilities Exhibit**
**Concert of Children**
Portraits of youth with Down syndrome by Nashville artist Allison Putnam
Monday-Friday 7:30 a.m.-5:30 p.m.
Lobby
Vanderbilt Kennedy Center/MRL Building

### SEPTEMBER 7
**Developmental Disabilities Grand Rounds**
**Autism, Developmental Delays, and Language Disorders: Effects of Talking Late on Assessment and Intervention**
Stephen Camarata, Ph.D., Professor of Hearing & Speech Sciences, Associate Professor of Special Education, and Director of Research Program on Communication and Learning
Light breakfast provided
Co-Sponsor Center for Child Development, Pediatrics
Wednesday 8 a.m.
Room 241
Vanderbilt Kennedy Center/MRL Building

### SEPTEMBER 20-OCTOBER 28
**Arts and Disabilities Exhibit**
The Science and the Hope: Celebrating 40 Years of Discovery
Photo history of Vanderbilt Kennedy Center landmark research
Monday-Friday 7:30 a.m.-5:30 p.m.
Lobby
Vanderbilt Kennedy Center/MRL Building

### SEPTEMBER 26
**Lectures on Development and Developmental Disabilities**
**Specific Reading Disability (Dyslexia): What Have We Learned in the Past Four Decades?**
Frank Vellutino, Ph.D., Professor of Psychology, University at Albany-State University of New York
Monday 4:10 p.m.
Room 241
Vanderbilt Kennedy Center/MRL Building

### SEPTEMBER 28
**40th Anniversary Community Celebration**
Pat Morrissey, Ph.D., Commissioner of Administration on Developmental Disabilities
• Luncheon by invitation; call (615) 343-5322
Wednesday 11:30 a.m.
Children’s Hospital at Vanderbilt
• Keynote Address
Wednesday 4:10 p.m.
Reception following
Room 241
Vanderbilt Kennedy Center/MRL Building

## October

### OCTOBER 12
**Developmental Disabilities Grand Rounds**
**If Your Daily Clock Isn’t Happy, Nobody Is Happy**
Carl Johnson, Ph.D., Professor of Biological Sciences and Vanderbilt Kennedy Center Investigator
Light breakfast provided
Co-Sponsor Center for Child Development, Pediatrics
Wednesday 8 a.m.
Room 241
Vanderbilt Kennedy Center/MRL Building

### OCTOBER 17
**Lectures on Development and Developmental Disabilities**
Tilling the Terrain of Longitudinal Landscapes: Family, Disability, and Life’s Peaks and Valleys
Laraine M. Glidden, Ph.D., Professor of Psychology, St. Mary’s College of Maryland
Monday 4:10 p.m.
Room 241
Vanderbilt Kennedy Center/MRL Building

### OCTOBER 26
**Vanderbilt Kennedy Center Leadership Dinner**
Honoring leadership volunteers and members of the Nicholas Hobbs Donor Society
By invitation; contact (615) 343-5322
Wednesday 7 p.m.
Loews Vanderbilt Hotel

## November

### NOVEMBER 1-DECEMBER 31
**Arts and Disabilities Exhibit**
Creative Expressions XI
Co-sponsor Nashville Mayor’s Advisory Committee for People with Disabilities
Monday-Friday 7:30 a.m.-5:30 p.m.
Lobby
Vanderbilt Kennedy Center/MRL Building

### NOVEMBER 2
**Developmental Disabilities Grand Rounds**
Persistence of Minority Overrepresentation in Mild Mental Retardation Despite Court, Legislative, and Social Science Prohibitions
Daniel Reschly, Ph.D., Professor of Education and Psychology, Chair of Special Education, and Vanderbilt Kennedy Center Investigator
Light breakast provided
Co-Sponsor Center for Child Development, Pediatrics
Wednesday 8 a.m.
Room 241
Vanderbilt Kennedy Center/MRL Building
Community Events

Autism Society of Middle Tennessee Events
Information ASMT (615) 385-2077

SEPTEMBER 15 & NOVEMBER 17
Autism Orientation
Registration required
Thursday 6:30-8:30 p.m.
Room 241
Vanderbilt Kennedy Center/MRL Building

SEPTEMBER 22, OCTOBER 27, & NOVEMBER 10
Autism Workshop
Variety of topics
Registration required
Thursday 6:30-8:30 p.m.
Room 241
Vanderbilt Kennedy Center/MRL Building

DSAMT Events

Down Syndrome Association of Middle Tennessee Events

SEPTEMBER 17
Fall Fiesta
Dinner & Silent Auction benefiting DSAMT
A fun evening of festivities, food, and entertainment
Information Judy Anderson (615) 662-3763
Saturday 6 p.m.
Home of Linda Brooks

OCTOBER 1
Annual Buddy Walk
Information Teri Edmonson (615) 591-1884
Saturday 9 a.m.
Centennial Park

Taking Part in Research

The Vanderbilt Kennedy Center welcomes the participation of children and adults, with and without disabilities, in research studies. To view a list of projects seeking participants, see kc.vanderbilt.edu/studyfinder/. If you have questions about finding a study or taking part in research contact Lynnette Henderson (615) 936-0448.

November

Graduate Neuroscience Seminar Series
Presenilin 1 and the Brain Transcriptome
Karoly Mirnics, M.D., Assistant Professor of Psychiatry and Neurobiology, University of Pittsburgh
Co-Sponsor Vanderbilt Brain Institute
Wednesday 4:10 p.m.
Room 1220 MRBIII Lecture Hall

Lectures on Development and Developmental Disabilities
The Contribution of Temperament to Development
Jerome Kagan, Ph.D., Daniel and Amy Starch Professor of Psychology, Harvard University
Thursday 4:10 p.m.
Room 241
Vanderbilt Kennedy Center/MRL Building

Scientific Symposium Celebrating 40th Anniversary: Science and Leadership in Developmental Disabilities
Duane Alexander, M.D., Director, National Institute of Child Health and Human Development
Thomas Insel, M.D., Director, National Institute of Mental Health
Story Landis, Ph.D., Director, National Institute of Neurological Disorders and Stroke
Martin Seligman, Ph.D., Fox Leadership Professor of Psychology, University of Pennsylvania
Carla Shatz, Ph.D., Nathan Marsh Pusey Professor of Neurobiology, Harvard Medical School
Fred Volkmar, M.D., Irving B. Harris Professor of Child Psychiatry and Professor of Pediatrics, Yale Child Study Center
Wednesday 1-5 p.m. Reception following Vanderbilt Student Life Center Ballrooms

November 2

December

Holidays Around the World
Cultural events, food, drinks, live and silent auction!
Information Susan Gray School
(615) 322-8200
Saturday 4 p.m.
Commodore Ballroom, Vanderbilt Student Life Center

Explorers Unlimited Academic Camp 2005

December 7

Developmental Disabilities Grand Rounds
How the Brain Learns to Perform a Variety of Discriminations and to Direct Attention
Jeffrey Schall, Ph.D., E. Bronson Ingram Professor of Neuroscience, Professor of Psychology, and Vanderbilt Kennedy Center Investigator
Light breakfast provided
Co-Sponsor Center for Child Development, Pediatrics
Wednesday 8 a.m.
Room 241
Vanderbilt Kennedy Center/MRL Building

Graduate Neuroscience Seminar Series
Zooming Into Alzheimer’s Disease: From Memory Loss to Molecular Defects
Scott Small, M.D., Herbert Irving Assistant Professor of Neurology, Columbia University
Co-Sponsor Vanderbilt Brain Institute
Wednesday 4:10 p.m.
Room 1220 MRBIII Lecture Hall

Sibshops
A Vanderbilt Kennedy Family Outreach Center program for siblings of children with special needs, grouped by ages. Games, friends, discussions.
Ages 6-12: Saturdays, September 24, December 3
Room 241
Vanderbilt Kennedy Center/MRL Building
Advance registration required
Information teresa.turnbo@vanderbilt.edu, (615) 936-5118

Autism Orientation
Registration required
Thursday 6:30-8:30 p.m.
Room 241
Vanderbilt Kennedy Center/MRL Building

Autism Workshop
Variety of topics
Registration required
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