The Vanderbilt Kennedy Center for Research on Human Development has received a $2.2 million, 5-year grant and designation as a University Center for Excellence in Developmental Disabilities Education, Research and Service from the federal Administration on Developmental Disabilities (ADD). The Center will use the funds to expand training and outreach and to improve disability services across Tennessee.

ADD Commissioner Pat Morrissey announced the award September 28 at the Vanderbilt Kennedy Center’s 40th Anniversary Community Celebration Luncheon at the Monroe Carell Jr. Children’s Hospital at Vanderbilt. “As a national center for research on developmental disabilities, the Vanderbilt Kennedy Center has already had a wonderful influence nationally on disability public policy and practices,” Morrissey said. “As part of our ADD network, we look forward to the Center making even greater contributions as it transfers research into innovative practice for Tennesseans and the nation.”

“The Vanderbilt Kennedy Center is proud to join the distinguished national Centers for Excellence network,” said Pat Levitt, Ph.D., Vanderbilt Kennedy Center director. “We will now be able to expand existing training and outreach programs and to develop new initiatives, with an emphasis on serving Tennessee’s poor and underserved minority and rural populations.”

With the advocacy of the national Association of University Centers on Disabilities, and with the support of the Tennessee delegation and other Congressional leadership, the U.S. Congress authorized expansion of the National Network of University Centers for Excellence on Developmental Disabilities (UCEDDs) in Fiscal Year 2005. Funding was

The Dan Marino Foundation announced a pledge of $1.2 million over 3 years to establish the Marino Autism Research Institute (MARI) as a joint partnership with the Vanderbilt Kennedy Center’s Treatment and Research Institute for Autism Spectrum Disorders (TRIAD) and the University of Miami Center for Autism and Related Disabilities (CARD).

“This will be the first philanthropically funded ‘virtual institute’ designed to sponsor cross-university collaborative research and community outreach on autism,” said Mary Partin, the Foundation’s CEO. “Dan and Claire Marino and the Foundation’s Board of Directors believe that this collaboration between two exceptional centers at national universities will provide a powerful means to address key questions about the nature of autism and to accelerate the discovery of new strategies for treating and preventing autism.”

Remember when you were a child and you shot up like a weed that one summer before school started? It seemed like some days the pain was so severe that all you wanted to do was stay home and rest your weary legs. Growing pains reflect our body’s attempt to prepare us for the next phase in life. This past year has brought with it a remarkable amount of growth at the Vanderbilt Kennedy Center, including new research programs with TRIAD and the University of Miami through the Dan Marino Foundation, a new National Institutes of Health training program for...
New TN UCEDD from page one

made available for three new centers for states or populations that are unserved or underserved due to such factors as population, high concentration of rural or urban areas, or a high concentration of underserved or underserved populations.

“I congratulate the Vanderbilt Kennedy Center on this achievement,” Rep. Jim Cooper said. “This designation is an important recognition of the national leadership provided by the Kennedy Center as well as its vital role in our community.”

“I was happy to be able to support the wonderful work that’s being done at Vanderbilt,” Rep. Marsha Blackburn said. “The community should be proud that Vanderbilt is really helping to lead the effort to improve the lives of those with developmental disabilities.”

UCEDD National Network

There have been just 61 such centers nationwide. Vanderbilt’s designation, along with the University of Tennessee Health Science Center’s existing designation, makes Tennessee one of just a handful of states to have two of these centers.

The UCEDDs have played key roles in every major national disability initiative over the past four decades. Issues such as early intervention, health care, community-based services, inclusive and meaningful education, transition from school to work, employment, housing, assistive technology, and transportation have directly benefited from the model services, research, and training provided by these centers.

The Vanderbilt Kennedy Center will work in partnership with Tennessee’s other ADD partners: the Boling Center for Developmental Disabilities, University of Tennessee Health Science Center; the Tennessee Council on Developmental Disabilities; and the Disability Law and Advocacy Center of Tennessee (formerly, Tennessee Protection and Advocacy, Inc.).

Emphasis and Leadership

The Vanderbilt Kennedy Center UCEDD will address four of the areas of emphasis described in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L. 106-402): education and early intervention, individual and family-centered supports, health and mental health, and recreation and the arts. In each area of emphasis, programs and activities will address the four UCEDD core functions of training, exemplary community service and technical assistance, research, and dissemination.

The Center’s UCEDD will be directed by Elisabeth Dykens, Ph.D., professor of psychology and human development. Vanderbilt Kennedy Center associate director, Elise McMillan, J.D., will serve as the UCEDD associate director. Coordinators of areas of emphasis and/or core functions include: Research—Robert Hodapp, Ph.D., professor of special education; Dissemination—Jan Rosemergy, Ph.D., director of communications; and Training and Health/Mental Health—Mary Theresa Urbano, Ph.D., R.N., formerly acting director of the University of Miami UCEDD.

Community Advisory Council

A Community Advisory Council will advise the UCEDD leadership and will be a full partner in planning, implementing, and evaluating UCEDD activities. This Council is chaired by Doria Panvini, parent of an adult son with intellectual disabilities. Panvini is well-respected in Tennessee as an effective advocate for individuals with disabilities and their families. Although members are still being recruited, 13 members have already been appointed. The Council has met twice and is finalizing its by-laws. Interests and concerns can be communicated to Panvini by emailing vkcac@vanderbilt.edu.

Initiatives

One priority will be collaborating with the Maternal Infant Health Outreach Worker project (MIHOW), a long-time program of Vanderbilt’s Center for Health Services. MIHOW improves child and family health through peer mentoring; local women serve as mentors during monthly home visits from pregnancy until the child is 3 years old. MIHOW serves 21 high-poverty, mostly rural communities in six states, primarily in Appalachia and the Mississippi Delta. UCEDD staff will train MIHOW workers to screen babies for delays and behavioral concerns, and will provide outreach workers and families with technical assistance and supports.

Another UCEDD priority will be Hispanic disability outreach. Plans call for continuation and expansion of Tennessee Disability Pathfinder’s Project Conexión, a model ADD project.

Updates about the UCEDD will be available on the Web site at kc.vanderbilt.edu.

Director’s Message from page one

postdoctoral fellows with the Vanderbilt Center for Human Genetics Research, and new outreach and service initiatives through the University Center for Excellence in Developmental Disabilities.

Are we prepared? I thought as a 12-year-old that I would have all the answers once I became a teenager, and that I could anticipate anything that came up. But we all know that you never really know what life brings until you get there. Your family and your experiences prepare you for handling what lies ahead.

In completing the 40th anniversary celebration of the Vanderbilt Kennedy Center, it is evident that we have plenty of history to prepare us.

Here at the Center, we do a lot of planning. Our strengths lie in the commitment and ingenuity of an exciting group of investigators and staff to lead efforts in new research, education, and clinical activities. Yet even with all our talented individuals, perhaps the greatest asset we have is the desire to work together collectively in our efforts. Each of the new programs listed above has a major new partner. I often talk about this current “personality” of the Vanderbilt Kennedy Center—we play well together in the sandbox with our friends.

The growing pains that we are now exhibiting are an outcome of our successes, and with them, a new set of responsibilities and need for additional staff, facilities, and resources. Rest assured that we have a plan. The University will be investing in new facilities. We continue to recruit outstanding researchers from other universities and to attract current Vanderbilt faculty members into the world of developmental disability and mental health research. Our Leadership Council is leading the way more successfully than ever before to help raise both friends and funds that will ease those growing pains a bit.

The anticipation of what lies ahead for 2006 brings great excitement, a bit of nervousness, but a real sense of security that we are prepared.
One-On-One with TRIAD

By Stephanie Newton

Judy Pierson is a special education teacher at Karns Middle School in Knoxville, Tennessee. Four students in her class have autism spectrum disorders, and because two are nonverbal, it has been frustrating for both the students and Pierson as they tried to communicate with one another. She wanted to reach her students, and her desire to do so was in her thoughts even when she left school for the day.

A Friend's Suggestion

While talking to her special education supervisor, Pierson learned about TRIAD and the TRIAD Teacher Training program (TTT). Through a collaboration between the Tennessee Department of Education, Division of Special Education, and TRIAD, district-wide in-service training workshops are held for school personnel.

Teachers receive 3 days of hands-on classroom experience with TRIAD professionals geared toward developing expertise through a training-of-trainers model. School districts are asked to select teams of individuals who will be trained and will train others in their school system. “The training sessions came highly recommended,” said Pierson. “I spoke to a couple of teachers who had attended previous TRIAD trainings, and they said it was a very positive and helpful experience.”

Attendance is open to general and special education teachers, speech-language therapists, related-services personnel, behavior consultants, paraprofessionals, or any other school personnel involved in educating students with autism.

“TRIAD and the Tennessee Department of Education have worked together for the past 6 years to provide these workshops, and it has been a wonderful partnership,” said Wendy Stone, Ph.D., director of TRIAD and professor of pediatrics and psychology. “What makes these workshops unique is their hands-on emphasis in which participants learn and practice new skills with real students in real classrooms. TRIAD is fortunate to have extremely talented, creative, and energetic consultants who have the experience and expertise to make these trainings fun as well as enriching.”

While attending a TTT, teachers cover a variety of topics on autism, including characteristics, assessment, methodologies, communication, and behavior. “I received very practical information such as how to use reinforcement effectively, the importance of a personal schedule for each student, information on helpful Web sites and books, how to set up my classroom, and intervention strategies to use with children with autism,” said Pierson.

This is hands-on training, and participants have the chance to plan intervention strategies and to work with assigned children.

Something for Everyone

During the 2005-06 school year, eight TTT workshops will take place, four of which are aimed at grades K-6 and the other four geared toward grades 7-12. There is no cost for the training, but participants pay their own travel costs.

Half of the training workshops are considered basic, designed for new teachers, paraprofessionals, and school personnel with little or no previous training. These begin with characteristics of autism. The other half are advanced, designed for more experienced personnel who have some training and a bachelor’s degree or higher. These go into more depth on communication, behavior, instructional strategies, and social skills, with an emphasis on assessment.

“Because the information was so practical, I have been able to use it in my classroom with positive results,” Pierson said. “I have learned techniques and strategies to keep the students more engaged in learning.”

On-Site Guidance

Participants who have completed either the basic or advanced workshops can request a site visit to their classroom. Written feedback is provided. Persons who have completed the advanced training can also request that their own training activities be observed and evaluated.

“When I had my site visit, they were so helpful and supportive,” said Pierson. “They offered suggestions and strategies that I could use to make the classroom run more smoothly and further benefit my students. Everything about the training was to encourage teachers and to better equip them to work effectively with their students with autism. I feel I could call or email any one of them with a question or request for help.”

For information on TRIAD teacher workshops, call (615) 936-1705, or see the TRIAD Web site www.TRIADatVanderbilt.com.

Fort Campbell Supports TRIAD Research

The Fort Campbell Autism Support Group and the Department of the Army Exceptional Family Member Program teamed up to support TRIAD. A donation of $2500 was collected at Fort Campbell’s Eagles 5K Fun Run/Walk for Autism in April. The donation will be used to purchase equipment and toys for TRIAD’s research project on the social development of younger siblings of children with autism. It will enable the set-up of an additional videotape coding station (doubling the speed of analyzing videotape data) and the purchase of new toys for the TRIAD waiting room. The Fort Campbell Autism Support Group provides support and continuing education for families affected by autism in the Fort Campbell community and surrounding areas. The Exceptional Family Member Program works with other military and civilian agencies to provide comprehensive and coordinated medical, educational, special housing accommodations, community support, and personnel services to families with special needs. To contact the Fort Campbell Autism Support Group, email shelley-taroli@comcast.net or jennywks@cs.com; for the Fort Campbell Army Exceptional Family Member Program, email sharon.fields@mwrcampbell.army.mil.
Leading the Vanguard of Discovery

**Randy D. Blakely, Ph.D.**
Allan D. Bass Professor of Pharmacology
Professor of Psychiatry
Director of the Center for Molecular Neuroscience
Vanderbilt Kennedy Center Investigator
Joined Vanderbilt Kennedy Center 1997

**Research Interests**
Regulation of neurotransmitter inactivation; molecular genetics of mental illness

**Principal Investigator**
- A chemical genetic screen for modifiers of presynaptic choline transport, Zenith Award
- Alzheimer’s Association
- MERIT Award, National Institute of Mental Health
- Postdoctoral training program grant in neurogenomics, National Institute of Mental Health

**Clinical Interests**
Genes targeted by antidepressants and drugs of abuse and how these targets support psychiatric and addiction disorders

**National Service and Awards**
- Daniel H. Efron Award for Basic Science Research, The American College of Neuropsychopharmacology
- Charles R. Park Prize for Research, Vanderbilt University
- Distinguished Investigator Award, National Alliance for Research on Schizophrenia and Depression

**Selected Publications**

**Education**
B.A., 1981, Philosophy, Emory University School of Medicine
Ph.D., 1987, Neuroscience, Johns Hopkins School of Medicine
Postdoctoral Fellowship, 1987-90, Molecular Neurobiology, Yale University School of Medicine

**Attraction to Developmental Disabilities Research**
I received my Ph.D. under Dr. Joseph T. Coyle at Johns Hopkins. He exposed me to aspects of early brain development and their disorders and provided opportunities to connect the two via molecular/cellular approaches. After I left Coyle’s lab, I focused more on fundamental neurobiology and identifying genes and proteins that impact chemical signaling. But I never forgot those initial lessons. In my own lab, I identified a gene whose chromosomal location was in the locus for Batten’s disease, a tragic, degenerative, and fatal childhood brain disorder. Although the gene turned out not to be relevant to the disorder, I was touched by the plight of parents of these children, particularly as my son had just been born. A close colleague in the field lost his son to a similar disorder and the convergence of all this made me want to contribute.

**Reasons for Vanderbilt Kennedy Center Membership**
I was impressed early on with the breadth of talent assembled by the Kennedy Center. My own work is very specialized, yet the disorders we address are complex. My contribution is just one step, and my efforts could be wasted if not embraced in a larger context. I am fascinated by the behavioral and educational efforts of my colleagues at the Kennedy Center and hope to absorb some of their lessons as I move my research program into more translational areas. I started my translational efforts with a Discovery grant from the Kennedy Center and have been excited to see the efforts blossom. This grant started with developing approaches to scan human transporter genes for mutations, efforts that help some of my colleagues who study important genes in developmental disabilities and neurological disorders. In collaboration with Steve Couch, my research team and I identified new mutations in the dopamine transporter in ADHD. Additionally, with James Sutcliffe, we identified multiple genetic alterations in males with autism. These mutations are under active study, and I am confident that our findings can be used to develop detailed hypotheses about these prevalent disorders and to guide a new generation of therapies.

**Grants Awarded**

- **Evaluating a multicomponent reading program designed to address the diverse needs of struggling readers in late elementary school**
  Donald Compton, Ph.D. (special education)
  Institute of Education Sciences

- **Vanderbilt Kennedy University Center for Excellence in Developmental Disabilities**
  Elisabeth Dykens, Ph.D. (psychology & human development)
  Administration on Developmental Disabilities

- **Molecular physiology of KCNE potassium channel subunits**
  Alfred George, Ph.D. (medicine)
  National Heart, Lung, and Blood Institute

- **Prevention of recurrence in depression with drugs and cognitive therapy (renewal)**
  Steven Hollon, Ph.D. (psychology)
  National Institute of Mental Health

- **Functional organization of the visual system (renewal)**
  Jon Kaas, Ph.D. (psychology)
  National Eye Institute

- **Functional organization of the somatosensory system (renewal)**
  Jon Kaas, Ph.D. (psychology)
  National Institute of Neurological Disorders and Stroke

- **Biobehavioral Intervention Training Program**
  Pat Levitt, Ph.D. (pharmacology)
  National Institutes of Health Roadmap Initiative

- **Defining the physiological and behavioral components of insomnia in children with autism spectrum disorders**
  Beth Malow, Ph.D. (neurology)
  National Alliance for Autism Research

**Visit StudyFinder**
The Vanderbilt Kennedy Center welcomes the participation of children and adults, with and without disabilities, in research studies.

StudyFinder is a Web-based tool to identify Vanderbilt Kennedy Center projects seeking participants.

http://kc.vanderbilt.edu/studyfinder
(615) 936-0448
The formal announcement was made at the inaugural meeting of MARI on September 26 in Fort Lauderdale, Florida. “The Dan Marino Foundation has developed a really exciting and novel approach to stimulate scientific and clinical interactions, and to take advantage of the great research and treatment efforts that are occurring at Vanderbilt University and at the University of Miami,” said Pat Levitt, Ph.D., director of the Vanderbilt Kennedy Center.

“We are thrilled to have the opportunity to work with the University of Miami to build collaborative research and clinical programs that will ultimately improve the lives of children with autism and their families,” Stone said. “The autism programs at Vanderbilt and the University of Miami are complementary in many areas. Our partnership will strengthen each program individually as well as create a synergy between the programs that will accelerate our understanding of the causes and treatments of autism.”

Starting in January 2006, MARI will leverage the skills of an exceptional combination of distinguished researchers in psychology, neuroscience, medicine, and special education from both universities to answer key questions regarding the causes of autism, the earliest behavioral and biological markers of autism, and the development of more creative, evidence-based treatments designed to improve the lives of children with autism and their families.

This latest donation continues a long history of support by the Marino Foundation for community services for people with autism. In conjunction with Miami Children’s Hospital, the Foundation developed the Dan Marino Center in Weston, Florida, in 1998 to provide services for children with autism and related neurodevelopmental disorders. The Foundation then developed a partnership with the University of Miami to support the work of UM-CARD clinicians at the Marino Center. In May, the Foundation expanded its national impact through a gift of $100,000 to the Vanderbilt Kennedy Center to create the Dan Marino Foundation Fellowships and Dan Marino Foundation Discovery Grants and to support the Center’s autism community service programs. The additional pledge to found MARI will enable the Foundation to expand over the coming years to help more children in more places, from its South Florida home community to the entire nation.

“BITP brings together various fields that have a stake in better diagnosis and treatment of developmental disorders that impact cognition and mental health,” said Levitt. “The NIH Roadmap Initiative was designed to stimulate such crossdisciplinary interactions. We at Vanderbilt University are fortunate to have outstanding researchers who believe in the value of training a new generation of scientists who will become facile at moving across behavioral and biomedical disciplines.”

Postdoctoral Training in Biobehavioral Intervention
By Stephanie Newton

The National Institutes of Health (NIH) Roadmap Initiative has awarded the Vanderbilt Kennedy Center and the Vanderbilt Center for Human Genetics Research a new 5-year postdoctoral research training grant entitled the Biobehavioral Intervention Training Program (BITP). The goal of BITP is to provide postdoctoral trainees with an understanding of the relationships between behavioral characteristics and biological markers of specific developmental disabilities and to define the predictive value of these relationships for eventually developing and applying successful interventions. Four postdoctoral trainees will be supported for 5 years.

The new training program is led by principal investigator Pat Levitt, Ph.D., and co-principal investigator Elisabeth Dykens, Ph.D., Vanderbilt Kennedy Center director and associate director, respectively. Vanderbilt faculty representing 15 departments from the School of Medicine, Peabody College, and the College of Arts & Science also serve on the training program as faculty preceptors, providing a unique interdisciplinary approach.

“This training partnership between the Center for Human Genetics and the Vanderbilt Kennedy Center speaks to our ability to leverage our strongest programs across the University to attract the most competitive funds to educate the scientists of the future,” said Jeffrey Balser, M.D., Ph.D., associate vice chancellor for research.

BITP includes research efforts that are particularly relevant to the goal of developing better tools for diagnosis and new interventions for children, adolescents, and adults with developmental disabilities. The program facilitates ongoing, interdisciplinary application of interventions, either behavioral (e.g., cognitive training) or biological (e.g., pharmacological), in the community.

“BITP brings together various fields that have a stake in better diagnosis and treatment of developmental disorders that impact cognition and mental health,” said Levitt. “The NIH Roadmap Initiative was designed to stimulate such crossdisciplinary interactions. We at Vanderbilt University are fortunate to have outstanding researchers who believe in the value of training a new generation of scientists who will become facile at moving across behavioral and biomedical disciplines.”

Web Links
Dan Marino Foundation
www.danmarinofoundation.org
TRIAD
www.TRIADatVanderbilt.com
Vanderbilt Kennedy Center
kc.vanderbilt.edu
University of Miami CARD
www.umcard.org
From a Parent’s Perspective

By Stephanie Newton

The following are the perspectives of two families—one with a child with a disability and one with a child who is typically developing. While each chose to send their children to the School for different reasons, the main objective is the same—to find a nurturing environment for their children.

Ability Not Disability
Amy Wallace is a stay-at-home mom and her husband Dave is a computer network engineer at Saint Thomas Hospital, but now they have a Vanderbilt connection. Both of their sons, Ryan, age 3 1/2, and Nathan, age 2, are students in the Susan Gray School (SGS).

If you see the Wallace boys in the hallway they look like typical brothers—blond bundles of energy who are eager each day when mom drops them off and picks them up from school. Excited about counting numbers, seeing bright colors, and drawing different shapes, their days are filled with anticipation.

The Wallace family’s involvement at Vanderbilt started when Ryan was diagnosed with autism. Mrs. Wallace explained, “Ryan was diagnosed at age 2 1/2 by Dr. Linda Ashford, assistant professor of pediatrics and psychology, Center for Child Development, and Vanderbilt Kennedy Center member. Since that time we also have been involved with the Treatment and Research Institute for Autism Spectrum Disorders [TRIAD].”

After Ryan’s diagnosis of autism and evaluation through the Tennessee Early Intervention System (TEIS), the Susan Gray School Outreach program was recommended in addition to physical and occupational therapy. When the time came for Ryan to go to preschool, the Susan Gray School was one program on the top of the list.

The reasons the Wallace family chose the School might be overlooked by some families. “It was important that there was a locked gate out front as well as locked hallways. We wanted to know that Ryan would be safe,” said Mrs. Wallace. “The classrooms were bright and colorful, and the therapists could come to the school and integrate therapy into Ryan’s everyday life. We also have opportunities to take part in new research studies when they are available.”

Ryan has been at the School for over a year, and his mother is pleased with the results. “He has shown so much improvement. He sits still more and takes an active part in his classroom’s activities. His biggest improvement is his vocal skills. He communicates with us now.”

Ryan’s brother Nathan joined him at SGS last spring. Since that time his mother has seen tremendous development but in different ways than Ryan. Since Ryan was the peer example in his family, Nathan was behind in some developmental areas. But after attending the School, he has caught up to his typically developing peer group and is more socially active.

Overall, the outlook for both the Wallace boys is better than their mother could have imagined. “Before I was thinking about what to expect from the disability. Now I think more about the ability.”

Location, Location, Location
For BethAnn McLaughlin and Gregg Stanwood, finding SGS just took a short walk across the street. The parents of Cole, age 4, and Amelia, age 2, are both members of the Vanderbilt University faculty and are Vanderbilt Kennedy Center investigators. “We relocated to Vanderbilt when Cole was 1 1/2, and it was terrific to find the School and have our children so close to us during the day,” said Stanwood.

McLaughlin and Stanwood heard about SGS during their recruitment to the Vanderbilt Kennedy Center, and they were intrigued by its connection to both the Center and Peabody College. The presence of SGS and its early childhood educational opportunities were a key facet of their decision to relocate to Middle Tennessee.

Other than the wait list to get their children into SGS, the admissions process was seamless, and their children were quickly enrolled.

Cole and Amelia enjoy all that SGS has to offer, but their particular favorites are music, reading, nature, and having fun with their peers. For McLaughlin and Stanwood, it was the variety that made the School enticing. “There is such diversity throughout their peer group,” said Stanwood.

“There are different cultures, socioeconomics, abilities, and interests, and it was these factors that make the Susan Gray School a place we want our children to be.”

When the Vanderbilt Kennedy Center was founded in 1965, Dr. Susan Gray urged that it include an on-campus school devoted to educational research. Working in partnership with the School’s teachers and families, Vanderbilt Kennedy Center researchers have been pioneers in early childhood and special education. The access to Vanderbilt Kennedy Center professionals also has been an asset to McLaughlin and Stanwood.

“It was only after Cole was at the Susan Gray School that we realized through talking to his teachers that he was experiencing significant communication problems. His attendance at the School allowed us to...”

Continued on page 7
access the best interventionists. Stephen and Mary Camarata were instrumental in developing a language enhancement program for Cole."

Since Center members and investigators often assist teachers in the classroom, students are able to reap the benefits of ever-changing and improving practices. McLaughlin now shakes her head and laughs when she says, "If you see him now, it is abundantly clear that getting him to talk is no longer a problem!"

Since their first day at the School, McLaughlin and Stanwood have noticed major differences in their children that they will be able to take with them for a lifetime. "Our children have developed empathy for individuals while noticing each friend’s strengths and weaknesses. The mix of typical and atypical developing peers helps the typical children just as much as those with disabilities."

**What About You?**

The Susan Gray School is an inclusive early childhood education program serving young children under 5 years, with and without disabilities, on site and in the community. If you would like more information about the School or its admissions process, tuition, programs, and events, contact Tracy Tatum, (615) 322-8200, tracy.tatum@vanderbilt.edu, www.peabody.vanderbilt.edu/sgs.©
Teamwork in Genetics

By Traci Fleischman

The Division of Medical Genetics at the Monroe Carell Jr. Children's Hospital at Vanderbilt and the Vanderbilt Kennedy Center work together to provide care for patients and their families in the Genetics Clinic. The Clinic provides evaluation, diagnosis, treatment, and genetic counseling related to familial disorders, birth defects, chromosomal disorders, or concerns about personal or family medical histories.

The experienced staff of the Genetics Clinic consists of expert physicians in genetic medicine, a nurse practitioner, a nutritionist, genetic counselors, and a social worker. The social worker at the Clinic is Carol Rabideau, L.C.S.W., who is also a Vanderbilt Kennedy Center social worker funded by the Lili Claire Foundation. Rabideau’s role is quite different from that of the genetic counselors.

“Genetic counselors work closely with families to get background information for family trees to discover possible family histories of medical or developmental problems. They counsel about specific genetic disorders and may make referrals to agencies, for example, to the Tennessee Early Intervention System (TEIS) for a child who is newly diagnosed,” explained Rabideau.

“As a social worker, I do assessments to help families understand how things are going within their actual family, whether there are financial concerns, need for services and resources, or insurance issues. I take the time to do psychosocial family assessments, and work with immigrants who need an interpreter.”

Rabideau checks to see how parents are coping, because sometimes in a medical setting when a child is the patient, the focus is on the patient rather than the family as a whole.

“When I ask how a parent or a couple is managing, the response is so appreciative. I then have the opportunity to talk with parents about having a child with special needs and how many disorders may affect families in terms of stress and financial burdens. These issues can affect relationships and individuals’ mental health. As a social worker, I can provide support, make referrals, and help families actually access services.”

The interdisciplinary team at the Genetics Clinic helps people get answers and decide on treatment, interventions, or services that may be the most helpful for a child or family member. The Clinic staff helps coordinate care of family members in the Vanderbilt Kennedy Center by working collaboratively, for example, with the International Adoption Clinic, the Center for Child Development, the Down Syndrome Clinic, Neurology, Orthopedics, or Radiology.

“Sometimes just understanding what is causing a developmental or health problem brings some peace—just knowing the answers. I think it is often hardest for parents to see their children with struggles or delays and not know why. The Clinic can help people not blame themselves and understand that genetic mutations are no one’s fault—it can help relieve guilt or wondering if they could have been better parents,” said Rabideau. “Having a diagnosis can help families more specifically understand their family members’ needs as well as access services.”

An example of a case that called for Rabideau’s coordination as a social worker with both the Vanderbilt Kennedy Center and the Genetics Clinic concerned a family of undocumented immigrants. The family came to the Clinic because their child had speech delays.

The family met with Rabideau and an interpreter. As Rabideau did a family assessment, she realized that the child needed a hearing screening that previously had been recommended, which was able to coordinate with the family’s pediatrician through TennCare. She also was able to connect the family with Claudia Avila-Lopez, the Vanderbilt Kennedy Center’s bilingual social worker with Tennessee Disability Pathfinder.

Avila-Lopez provided job... Continued on page 9
information for the child’s father and explained how having a job that provides documentation of his income would help his family access services. She connected the family with early intervention programs for their child within the Metropolitan Nashville Public Schools and got answers to school zoning questions. She also was able to help the mother find help for her ongoing depression and headaches.

"Because Claudia speaks the family’s language and understands their culture, there was an automatic trust that helped open up conversations with the family. It is so nice for me to be part of both the Vanderbilt Kennedy Family Outreach Center and the Genetics Clinic in order to help families," explained Rabideau. These connections enable Rabideau to tell families about the Center’s ongoing research and to assist them in using StudyFinder to discover research studies that need participants. Rabideau informs families about the Vanderbilt Kennedy Reading and Behavioral Analysis Clinics. "I pull up Tennessee Disability’s Pathfinder Web site on a daily basis, since I work with families that need so many different types of services," said Rabideau.

The training of medical staff is another important aspect of the Genetics Clinic. The exposure to genetics and the various disorders and syndromes is extremely important. "Future doctors, nutritionists, and nurses are being trained so that they will be familiar with what these disorders and diagnoses mean to a person or a family, so they can be better informed providers in their future practices," Rabideau reports.

Because the genetics field changes so rapidly, all the doctors and counselors are current with the latest research literature, newest methods, and conditions for which there are new diagnostic tests. "The doctors think ethically all the time in their decisions about genetic testing," stated Rabideau. "The expertise and caring on this team is so incredible. I am constantly impressed by everyone involved with the Genetics Clinic."
He then attended the Susan Gray School until he turned 3. My other children have attended the Kennedy Center's Sibshops. "Sibshops are designed to provide support during childhood and provide a foundation that will foster long-term positive relationships across the life span.

Funk joined the Vanderbilt Kennedy Center's Leadership Council 3 years ago. "I decided to join the Leadership Council because I consider the Kennedy Center to be one of Nashville's greatest natural resources. I want to help increase Nashville's awareness of the Kennedy Center and find opportunities for the Nashville community to support the Kennedy Center," explained Funk.

The Funk's oldest son, Rob, is now 11 years old and attends Granbery Elementary. "I believe Rob's Down syndrome has contributed to the character development of every one in our family by making us all better people, more appreciative of diversity, and more understanding of the fact that every person has been blessed with a unique set of gifts." A perfect example of this contribution was illustrated by Funk's daughter, Mary Landon, several years ago, "When my daughter was in a prekindergarten class with a boy who had Down syndrome, the class was playing 'ring around the rosy.' A child next to the boy with Down syndrome would not hold hands with him. When my daughter heard this, she left her spot, walked over to the boy with Down syndrome and said, 'I'll hold your hand.'"

Mary Landon's instantaneous response to her new friend in her prekindergarten class is just one moment in the lives of Funk's children that he is proud of. "My children have provided me with countless proud moments. The Kennedy Center has had a profoundly positive impact on my son, Rob, and my entire family. Personally, the Kennedy Center serves as a productive outlet for my advocacy energies."
Leadership Dinner

Over 330 Nicholas Hobbs Society members and friends attended the Vanderbilt Kennedy Center Leadership Dinner on October 26 at Loews Vanderbilt Hotel. Chaired by Barbara Gregg Phillips, chair of the Vanderbilt Kennedy Center Leadership Council, and by Ann Eaden, vice president of Beaman Automotive and active community leader, the gala celebrated the Vanderbilt Kennedy Center’s 40th anniversary.

The program began with Seth Link and Ben Monkaba, participants in the Center’s first Music Camp for young adults with Williams syndrome, introducing the video “Heart to Heart,” a song the campers wrote and recorded with Nashville songwriters and musicians. A second video (both videos by Kent Communications), incorporated photos of Center research over the 4 decades and summarized the important lessons researchers learned from individuals with disabilities and their families.

Other children who assisted with the evening’s program were Lauren and Natalie Gregg and Katie and Matt Moore.

Andrea McDermott presented a gift of $25,000 that she raised with the help of family and friends to endow a Vanderbilt Kennedy Reading Clinic scholarship for students with Down syndrome. A graduate student in special education, McDermott was inspired by William Spickard, an 8-year-old with Down syndrome whom she tutored in reading.

Football legend Dan Marino capped the evening with a videotaped announcement of the founding of the Marino Autism Research Institute (see page 1 story).

In addition to Phillips and Eaden, the Dinner Committee included Ann Bernard, Linda Brooks, Cheryl Chunn, Annette Eskind, Carol Henderson, Jim Knestrick, Sally Scovill, and Laurie Lee Sisk.

A silent auction, chaired by Ann Bernard and assisted by Stephanie Newton, raised $20,500, significantly surpassing the previous year’s auction.

Table hosts were Beaman Automotive Group, Mr. and Mrs. Jobe Bernard, Mrs. Linda Brooks/LDB Foundation, Mr. and Mrs. Roy E. Claverie, Sr., Mr. and Mrs. Glenn Eaden, Mrs. Annette Eskind, Fridrich & Clark Realty and Relocation Services, Dr. and Mrs. William M. Gavigan, Barbara Gregg and Associates, Mrs. Carol Henderson, Mr. and Mrs. John K. Lytle, Mapco Express, Pinnacle Financial Partners, Regions Morgan Keegan Trust, Drs. Gregg Stanwood and BethAnn McLaughlin, Mr. and Mrs. Stuart Speyer, SunTrust Bank, Earl Swensson Associates, and Vanderbilt University Medical Center.

Members of the Nicholas Hobbs Donor Society received the 2005 commemorative plate featuring “Paint the Tale” by Lisa Manus. This is the fourth in a series, initiated by Mrs. Harla Levitt, which features an artwork by a child or adult with a developmental disability selected from the Center’s annual art exhibits.

Lili Claire Foundation Benefit Dinner

The Eighth Annual Lili Claire Foundation Benefit Dinner was held October 15 in Beverly Hills, California. The event raises funds and awareness to support the Foundation’s community-based programs and services.

The Foundation was created in 1998 to honor the memory of the late Lili Claire Resnick, who was born with Williams syndrome. The Vanderbilt Kennedy Family Outreach Center supported by the Lili Claire Foundation was created in 2003. The Foundation’s purpose is to provide hope, resources, and purpose to children with special needs and the families who love them. A video featuring the work of the three centers nationally supported by the Lili Claire Foundation included two Nashville children served by the Vanderbilt Kennedy Family Outreach Center, Brian Clippinger and Hannah Nall.

The Dinner host was Friends star Matthew Perry. Many Nashville performers and country stars donated items to encourage bidders at a silent auction to support children with special needs.

Reba McEntire, country music and TV star, presented the Music of the Heart award to Universal Music Group, Nashville Chairman, Luke Lewis. Lewis praised the “amazing work” being done at the Vanderbilt Kennedy Center’s Lili Claire Family Resource Center: “They’re saving and changing lives of many children with special needs. It’s a wonderful facility.”
Summer Camps

For students with autism

June 6–June 23
TRIAD Social Skills Summer Camp I

June 26–July 18
TRIAD Social Skills Summer Camp II

For students with developmental disabilities

June 12–June 30
Transitions

For students with Down syndrome

July 5–28
Explorers Unlimited Academic Camp

For youth and young adults with Williams syndrome

July 27–August 3
Music Camp

For more information, call Camps and Art Coordinator (615) 322-8147
kc.vanderbilt.edu/camps
Spring 2006 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 kc.vanderbilt.edu/tnpathfinder.

January

JANUARY 9 through MARCH 24
Arts and Disabilities Exhibit
Gateway to Creativity
Co-Sponsor Enrichment Center, an affiliate of The Arc, and Metro Arts Commission
Monday-Friday 7:30 a.m.-5:30 p.m.
Lobby
Vanderbilt Kennedy Center/MRL Building

JANUARY 11
Developmental Disabilities Grand Rounds
Classroom-Based Interventions for Students with Emotional and Behavioral Disorders
Joseph Wehby, Ph.D., Associate Professor of Special Education 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

JANUARY 25
Neuroscience Graduate Seminar Series
Construction and Plasticity of GABAergic Circuits in the Mammalian Brain
Josh Huang, Ph.D., Associate Professor of Neuroscience, Cold Spring Harbor Laboratory
Co-Sponsor Vanderbilt Brain Institute and Center for Integrative & Cognitive Neuroscience
Wednesday 4:10 p.m.
Room 1220 MRB III Lecture Hall

February

FEBRUARY 1
Developmental Disabilities Grand Rounds
Neurodevelopmental Effects of Mercury
Michael Aschner, Ph.D., Professor of Pediatrics and Pharmacology 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

FEBRUARY 4
Silshop
For siblings, 6-12 years, of children with disabilities
Games, friends, discussions
Advance registration required
Information teresa.turnbo@vanderbilt.edu (615) 936-5118
Saturday 10 a.m.—2 p.m.
Room 241
Vanderbilt Kennedy Center/MRL Building

FEBRUARY 8
Neuroscience Graduate Seminar Series
Suicide, Serotonin, and Runaway RNA Editing
Claudia Schmauss, M.D., Associate Professor of Psychiatry, Columbia University College of Physicians & Surgeons
Co-Sponsor Vanderbilt Brain Institute
Wednesday 4:10 p.m.
Room 1220 MRB III Lecture Hall

March

MARCH 1
Developmental Disabilities Grand Rounds
Acceptance and Commitment Therapy for Adolescents with Chronic Health Conditions
Laurie Greco, Ph.D., Assistant Professor of Pediatrics and Vanderbilt Kennedy Center Member
Light breakfast provided
Co-Sponsor Center for Child Development, Pediatrics
Wednesday 8 a.m.
Room 241
Vanderbilt Kennedy Center/MRL Building

MARCH 2
Lectures on Development and Functional Disabilities
Early Diagnosis and Follow-Up of Children with Autistic Spectrum Disorders
Catherine Lord, Ph.D., Professor of Psychology and Psychiatry, Director of Autism and Communications Disorders Center, University of Michigan
Thursday 4:10 p.m.
Room 241
Vanderbilt Kennedy Center/MRL Building
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