Successful researchers are at once both curious and competitive by nature. Our nation’s advances in health care and education can be linked to the remarkable research infrastructure that our nation has developed during the past half century. The scientists of the Vanderbilt Kennedy Center are among the best in competing for the funds that support research on campuses around the country.

What’s going on in the mind of a person with schizophrenia has been the subject of research for nearly a century. Affecting around one percent of the population worldwide, schizophrenia does not discriminate by race, socioeconomic status, or intelligence. Affecting 1 in 100 persons, the illness typically surfaces between adolescence and early adulthood, and may impact a person’s ability to think clearly, manage emotions, and interact with others. Most people with the disorder experience it chronically or episodically throughout their lives.

Though its cause is still uncertain, most scientists agree that schizophrenia is a problem with brain growth and development. Technological advances in neuroscience, genetics, and brain imaging are yielding convincing evidence of altered brain anatomy and chemistry. Yet the picture of when and how neurological...
Mood and Emotion  from page one
case, what those problems are like, and how we can intervene.”

Dykens moved to Vanderbilt from UCLA last summer, drawn by the number and caliber of
Vanderbilt Kennedy Center investigators in her field. “It’s wonderful to work with a center full of
colleagues invested in learning more about people with disabilities,” she said.

One of those colleagues is Judy Garber, Ph.D.,
professor of psychology and psychiatry. Garber
just completed a study looking at predictors of
depression in adolescents whose mothers varied in
their risk for depression. An ongoing study with
Kennedy Center investigators Richard Shelton,
M.D., in psychiatry, and Steve Hollon, Ph.D., in
psychology, follows children who have a parent in
treatment for depression. The idea is to see if
improvement in a parent’s depression impacts
children’s adjustment. Garber is starting a study to
determine whether a cognitive-behavioral
intervention can prevent depression in at-risk
children 13-17 years of age.

Dykens believes that studying people with
 genetic syndromes will sort out the relative con-
tribution of genetic and bio-psycho-social risk
factors for specific behavioral or emotional prob-
lems. “The idea is to use current findings to help
families and improve interventions,” she said. “In
the long term, these data should also help us find
links between genes, the brain, and behavior.”

On the flip side of the issue, says Dykens, there
is also a growing movement within the field to
look at “positive psychology”—the idea that
mental health is a matter of things we all aspire to,
such as creativity, altruism, integrity, or having
meaningful relationships. “One of the novel things
I’d like to do in our Mood and Emotion area is
actively tackle those issues as they apply to people
with mental retardation.”

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Medical Center Reporter, Oct. 31, 2003; edited
for length.

Schizophrenia’s Inner Chaos  from page one

Illustration of Pat Levitt’s
research using gene micro-
arrays. Color representation of
hierarchical clustering of gene
expression in comparing
subjects with schizophrenia
and controls. The columns
represent individual subjects
and the rows represent the
genes that cluster to show
decreases in expression across all
or a subset of subjects with
schizophrenia. For example,
the red cluster shows that this
particular group of genes are
decreased in expression, and
represents a genetic
’signature’ of the disorder.

snarls occur remain vague: Is nascent brain
circuitry affected in the womb or some time
later along the developmental timeline? Genes
are involved, but is the initiating event
biological or environmental?

“It’s a disorder that is complicated because
it affects two major mental domains, because
it is clearly multi-genic, and because it also
has environmental contributors,” said
Vanderbilt Kennedy Center director Pat
Levitt, Ph.D.

One subtle change in brain structure is the
decreased size of the frontal lobe. Since the
frontal lobe is the seat of many of the brain’s
higher cognitive functions, it has been a focus
for schizophrenia researchers, including
Kennedy Center investigator Sohee Park,
Ph.D., associate professor of psychology.

Park used a test to study spatial working memory in persons with
schizophrenia versus typical individuals and persons with bipolar
disorders, and found that only those with schizophrenia had difficulty
with the task. She expanded her studies to people with schizotypal
personality disorder, or schizotypy, a milder version of schizophrenia
often seen in first-degree relatives. “As might be predicted,” Park says, “the
performance of people with schizotypy falls in between that of typical
controls and people with the full-blown disorder.”

While at the University of Pittsburgh, Levitt and colleagues David A. Lewis
and Karoly Mimics investigated neural circuitry in the brain, specifically
the prefrontal cortex and related brain regions, and how it is altered
in schizophrenia.

“We were the first group to use gene microarrays applied to a major
brain disorder,” Levitt said, “and we focused on the dorso-lateral
prefrontal cortex, the area that mediates working memory, which is
disturbed in schizophrenia.”

Gene microarray studies allow for simultaneous screening of thousands of
genes to look for patterns of gene expression. Levitt and colleagues demon-
strated that expression of a certain class of genes—those encoding proteins
that control synapse function—is deficient in schizophrenia.

Knowing the genes at the root of schizophrenia will be useful for designing
targeted therapeutics, and may allow for early pharmacological intervention.
It may even point the way to future gene therapy.

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Autumn 2003; edited for length.

Primer

INTELLECTUAL DISABILITIES AND MENTAL
HEALTH DISORDERS

Relative to those without developmental delay,
people with intellectual or cognitive disabilities,
including mental retardation, are at increased risk
for behavioral, mood, and emotional disorders.

Estimated prevalence rates of overall mental
health disorders in people with intellectual dis-
abilities fluctuate widely, from a low of 10% to a
high of 70%; about 40% of persons seem to have clinically significant problems.

Prevalence rates for
Hyperactivity/ADD range from 7% to 20%
Autism/PDD from 2% to 41%
Depression 4% to 10%

Variability in prevalence rates can be attributed to
IQ, residential status, and type of disability, as
well as to measurement issues.

Researchers need to learn why children and adults
with intellectual disabilities are at increased risk
for other disorders. Hypotheses include genetic
causes, neurological deficits, personality styles,
family factors, and social stigma. Of these
hypotheses, genetic and neurological issues hold
particular promise.

Source: Dykens, E. A. (2000). Annotation:
Psychopathology in children with intellectual
disability. Journal of Child Psychology and

WEB RESOURCE
National Association for the Dually Diagnosed
For persons with developmental disabilities and
mental health needs
www.thenadd.org

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Director’s Message from page one

The federal government appropriates billions of dollars for biomedical and educational research. While only a small fraction of these funds are devoted to projects related to developmental disabilities, the amount represents a sizeable national investment. We all expect that these investments will be made wisely and will attract the best that researchers have to offer.

Investigators at the Vanderbilt Kennedy Center and other academic research centers compete for federal research grants that are awarded by peer review committees. There is a perception that a great idea is all one needs to get in the research ‘game.’ The Catch-22 to this process is that investigators need substantial pilot data to compete for federal support. Gathering this preliminary information requires critical funding to help seed the efforts of our researchers.

Private support from donors can solve this Catch-22. By supporting exciting and innovative ideas that are just emerging, donors will expedite the funding process and will ensure that some of the most promising lines of research do not lie dormant due to lack of funding. At the Vanderbilt Kennedy Center, we call these Discovery Grants. We have our best and brightest scientists assist in reviewing the creative ideas that investigators bring to these pilot research programs. Discovery Grants represent a unique opportunity for our supporters to make a significant impact on the future of disability research—research that can translate into promising new treatments and interventions.

A fully funded Discovery Grant is a $30,000 investment. Subsequent funding from the NIH can range from several hundred thousand dollars into the millions, providing a return on investment that would be the envy of Wall Street. By funding a Discovery Grant, in total or in part, the real payoff, of course, is to children, families, and millions of Americans who depend on science for answers and for hope.

2003-04 Hobbs Discovery Grants

Effects of prenatal cocaine on frontal dopamine circuits
John Gore, Ph.D. (Radiology & Radiological Sciences)

Identification of an autism susceptibility gene on chromosome 19p
James Sutcliffe, Ph.D. (Molecular Physiology & Biophysics)

EEG power and growth in joint attention in children with autism spectrum disorders and their siblings
Paul Yoder, Ph.D. (Special Education)

Leading the Vanguard of Discovery

KENDAL S. BROADIE, PH.D.
Professor of Biological Sciences
Vanderbilt Kennedy Center
Deputy Director of Research Program on Developmental Neurobiology & Plasticity

Joined Vanderbilt Kennedy Center 2002

Research Interests
Genetic dissection of nervous system development, function, and plasticity

Principal Investigator for
• Genetic Analysis of Synapse Formation and Function, National Institute of General Medical Sciences
• Neurological Function of Fragile X Gene in the Drosophila Genetic Model System, National Institute of Child Health and Human Development
• Synaptic Mechanisms of Neurodegenerative Disease, National Institute of Neurological Disorders and Stroke

Clinical Interests
• Inherited neurological disorders that impact the development of the nervous system
• Diseases affecting synapse formation in the nervous system, for example, fragile X syndrome
• Reasons for underlying synaptic dysfunction and eventual neuronal cell death in childhood-onset neurodegeneration disorders, such as Niemann Pick Type C Disease

National Service

Honors
• Fulbright Scholar (1989-1990)
• Young Cell Biologist of the Year (1992), British Society for Cell Biology, United Kingdom
• Larry Sandler Prize Thesis (1994), Genetics Society of America
• Searle Scholar, Searle Scholars Program, Chicago, IL
• CAREER Fellowship, National Science Foundation
• EJLB Scholar, EJLB Foundation, Montreal, Canada

Publications
The ubiquitin-proteasome system acutely regulates presynaptic protein turnover and synaptic efficacy, with Speese, S., Trotta, N., Rodesch, C., and Aravamudan, B. (Current Biology, May 2003).


Integeins regulate DLG/PASII via a CaM Kinase II dependent pathway to mediate synapse elaboration and stabilization during postembryonic development, with Beumer, K., Matthies, H. J. G., and Bradshaw, A. (Development, July 2002).


Education
B.Sc. University of Oregon, Eugene, OR
Ph.D. Neurosciences, Genetics, University of Cambridge, UK
Research Fellow, Girton College, University of Cambridge, UK

Attraction to Developmental Disabilities Research
One motivation behind my interest is to help people who have neurological disorders. I am a developmental neurobiologist using a genetic approach to study the molecular mechanisms of neuronal function. My primary interest is in understanding the formation of neural circuits and the adaptive plasticity of these circuits that drive behavioral change.

Reasons for Kennedy Center Membership
The Vanderbilt Kennedy Center is a key foundation of neuroscience research at Vanderbilt. It brings together people at all levels (clinicians, intervention therapists, neuroscientists) to work together on discovering the causes of neurological disease and devising treatments and cures. It is a particularly valuable resource to me, as a fundamental neuroscientist, in providing contacts with other groups of researchers who provide unique insights and perspectives that would otherwise not be available. It also provides a foundation on which we can build, by working together to recruit the best possible future faculty and developing the best possible neuroscience research facilities in common core centers. The Kennedy Center also brings to Nashville the world’s leading experts in the fields of neurogenetics and neurobiology to provide seminars and additional highly valued interactions. Last but not least, the Kennedy Center provides an avenue of interaction with children and families affected by developmental disabilities, and I greatly value the stimulation and encouragement this provides me.

Spring 2004 • Discovery
Schall Appointed to Ingram Chair of Neuroscience

By Melanie Catania

Brain research received significant new support through the creation of the E. Bronson Ingram Chair of Neuroscience. In November, Kennedy Center investigator Jeffrey D. Schall, Ph.D., was named as the holder of the new endowed chair, which was established with the goal of improving the lives of children through brain research.

The chair was created by the donation of Robin and Richard Patton in memory of Mrs. Patton’s father, Bronson Ingram, a Nashville corporate and civic leader who served as president of the Vanderbilt University Board of Trust from 1991 until 1995.

In addition to his role as E. Bronson Ingram Chair of Neuroscience, Schall is professor of psychology, director of the Center for Integrative and Cognitive Neuroscience, and director of the Vanderbilt Vision Research Center. He studies various aspects of cognition, including how the brain processes visual information, produces attention and awareness, controls actions, and knows when it makes a mistake. Work like his holds great promise for addressing challenges such as vision impairment, learning disorders, and Alzheimer’s disease.

“Jeff embodies what is unique about our outstanding faculty at Vanderbilt,” Vice Chancellor for Academic Affairs and Provost Nicholas Zeppos said. “He is engaged in important research that will have a profound effect on the lives of people; he is a committed and inspiring teacher of undergraduates, who actively participate in his research; and he is deeply committed to being part of a community engaged in serious and civil debate on basic questions of science, research, and higher education. We are fortunate that Robin and Richard Patton stepped forward to allow us to recognize Jeff and his outstanding work.”

Schall has been a Vanderbilt faculty member since 1989 and Kennedy Center investigator since 1990. He has received national and international recognition for his work, including an Alfred P. Sloan Research Fellowship, a McKnight Endowment Investigator Award, and the 1998 National Academy of Science’s Trolland Research Award, the only Academy award given in psychology and the most prestigious award given to an experimental psychologist under the age of 40 years.

Reprinted with permission of the Vanderbilt Register, Nov. 17-30, 2003; edited for length.

New Books by Kennedy Center Researchers

Translating knowledge into practice, and disseminating information to scientists, practitioners, families, and community leaders are among the core values of the Vanderbilt Kennedy Center. Four Kennedy Center researchers have recently published books that exemplify these values.

Processing visual information is complex—the visual cortex comprises almost 25% of the human brain. The Primate Visual System (CRC Press, July 2003) provides an extensive 20-year overview of advances that contribute to understanding the visual system. Edited by Jon Kaas, Ph.D., Distinguished Professor of Psychology and professor of cell and developmental biology, and Christine E. Collins, research associate in psychology, the book synthesizes current knowledge on the anatomical and functional organization of the primate visual system and proposes new directions for research. In addition to Kaas, Kennedy Center researchers contributing chapters include Randolph Blake, Ph.D., Vivien Casagrande, Ph.D., Isabel Gauthier, Ph.D., and Jeffrey Schall, Ph.D.

Including Students with Severe Disabilities (Pearson Allyn & Bacon, October 2003) is both a methods text and general resource on research-based recommended practices of inclusive general education. Edited by Craig H. Kennedy, Ph.D., associate professor of special education and pediatrics, and Eva Horn, Ph.D. of the University of Kansas, who also contributed chapters, the book covers collaboration, family-centered practices, access to the general education curriculum, paraprofessionals, social relationships, systematic instruction, positive behavior supports, communication, and sensory/motor skills. Examples of how to infuse these areas into real-world contexts are provided in chapters written by experts, including Ann Kaiser, Ph.D., on preschool, elementary school, middle school, high school, and transition services.

School-Based Interventions: The Tools You Need to Succeed (Pearson Allyn & Bacon, September 2003) is a guide for educators, clinicians, and researchers in implementing proven and effective intervention practices for all students who need them. Kathleen Lane, Ph.D., assistant professor of special education, and co-author Margaret Beebe-Frankenberger, Ph.D. of the University of Montana, guide practitioners through implementing and documenting interventions that address a range of concerns such as student academic, social, behavior, or emotional issues. They provide real-life examples, vignettes, and forms. They emphasize methods of social validity, treatment integrity, and generalization and maintenance in the treatment process.

How Can You Say That? (Pleasant Company Publications, September 2003), by Amy Lynch with Linda Ashford, Ph.D., assistant professor of pediatrics, explores the parent-daughter relationship. It provides scenarios and offers advice from experts on how to turn hurtful conversations into exchanges that promote forgiveness.
Taking Part in Research

Family Perspectives on Research

Families are researchers’ most important partners. Research could not happen without them. Below, two parents share their family experiences of participating in research in the hope that other families will consider volunteering. The Dunn family has 4-year-old twins who were born prematurely. The Bolander family has a 26-year-old son with Prader-Willi syndrome, a genetic condition associated with a severe eating disorder, often accompanied by mental retardation.

THE DUNN FAMILY
The nurses at Vanderbilt Neonatal Intensive Care Unit told us about the Susan Gray School, where both Jack and his twin Rosemary went, although only Jack has taken part in research studies. Jack was very delayed—both receptive and communicative speech—so I jumped at having him in the Child Language Intervention Program’s Milieu Training Project. It was clear that it was voluntary and that it didn’t prohibit us from doing other therapy. I might have been concerned about a research project involving medications, but this was spending time working with him. Everyone was so nice. My hope was that he would make progress in being able to communicate. He is starting to talk a lot more than he did.

Jack also is taking part in a study on improving engagement in preschoolers with disabilities. He doesn’t sit and attend to one thing unless it is something he really likes. Learning to take turns or finish a task—he is not particularly motivated to do that. My hope for the improving engagement study was to move him toward school readiness. That seems to be the hope for the improving engagement study was to move him toward school readiness. That seems to be.

THE BOLANDER FAMILY
Our son Joe was born with failure-to-thrive, floppy muscle tone—so there were problems from the beginning. As he’s grown up, there have been many medical issues and the need for specialists. He wasn’t identified as having Prader-Willi syndrome until he was 12.

Our first research experience was in taking part in a comprehensive study of Prader-Willi syndrome at the Vanderbilt Kennedy Center a few years ago.

Parents are always advocates for their child. We wanted to make sure we understood all the testing to be done, why it was necessary. Any child with a disability has already been through a lot. You don’t want them to experience anything that is discomforting or painful. A lot of it is communicating with the researchers, working with the family, getting good information, being comfortable with them. You have to weigh what’s involved versus what can be found out through the research.

We became involved in a new study on Prader-Willi syndrome through Elizabeth Roof, coordinator of the new study who had also been coordinator of the previous study in which we had taken part. This new project is a study of behavior and development in young and older people with Prader-Willi syndrome. The researchers have given Joe visual and verbal tests, and they’ve asked me a set of questions as his parent. It was no big deal.

Joe is now older and involved in the decision process. We have to make sure he’s comfortable with it, that it’s explained to him. Joe has a great attitude.

We definitely recommend taking part in research to other families. It takes extra time, but we look at the benefits of helping others down the road as well as our own family member. We want to help make the world a better place. The more knowledge, the better off we are.
The Legacy of Dr. Susan Gray: Inventing the Future

The Susan Gray School is celebrating its 35th anniversary. Pioneering research and demonstration projects here have shaped the field of early childhood education and intervention. Graduate students trained here have become national leaders in the field. For over three decades, children and families have received high-quality, research-based services that have helped create a brighter future. An exhibit of archival photographs and publications is on display at the Vanderbilt Kennedy Center through the April 1–2 anniversary celebration (see insert for details). The stories below provide a window into the early years in this remarkable record of achievement. Contributors are Diane Bricker, Ph.D., professor of special education, University of Oregon; Rebecca Fewell, Ph.D., former professor of special education, Peabody College, and recently retired professor of pediatrics and psychology, University of Miami; Paula Goodroe, School coordinator, 1971–1982; and H. Carl Haywood, Ph.D., professor of psychology, emeritus and Kennedy Center director, 1971–1983.

Roots in The Early Training Project. “In 1959 Susan Gray, with Rubert Klaus, designed a summer educational program for 4- and 5-year-olds from families at the poverty level. Widely respected for this pioneering research on early education, Susan Gray was said to have provided the intellectual impetus for Head Start.” –H. Carl Haywood

Founding. When the Kennedy Center was founded in 1965, Gray, a Peabody developmental psychologist, urged that it include an on-campus school devoted to education research. In 1986, the Experimental School was renamed in her honor.

“Everyone involved in planning the Center’s construction grant wanted to incorporate education—specifically, first-class space for a school. The School has always included children with developmental disabilities. From the outset we determined that we would not run segregated education, that children with and without disabilities would be educated together. That was rare—no other place did it.” –H. Carl Haywood

DARCEE. The Demonstration and Research Center on Early Education was one of the Kennedy Center’s original programs. Led by Gray, DARCEE researchers taught disadvantaged children and studied influences on children’s intellectual and social development. They developed, evaluated, and disseminated a model curriculum for preschool education, and a home visiting model to enhance parenting skills and child development. Gray saw that parents are “a child’s first teacher.”

“Part of our student training was involvement in DARCEE. We were testing educational models to determine which were most effective. One was classroom instruction with no parent involvement, another involved parents coming to class for training as well as direct instruction of children, and another was home visits only, with no direct teaching of children. The first DARCEE classroom was at the Preston-Taylor Homes in urban Nashville, the second at Peabody, and the third in rural Fairview. Dr. Gray asked me to direct the that the model was working, we extended downwards to younger children.

At that time, professionals were skeptical that toddlers could be served in center-based classrooms. Many felt it was developmentally
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.

Inappropriate. No curriculum existed and few assessment tools. We paid attention to the children and developed what is now characterized as activity-based intervention. We learned to map onto the children, following their interests, so that they learned skills in a meaningful context. It’s taken the field 30 years to learn how to do this better.

The field of early childhood special education was all new. We were a team figuring out what to do, and without one another we would not have gotten to where we are. We were free to innovate.” –Diane Bricker

“The Brickers’ coming on the scene was one of the most important events in the School’s history. We were looking for a way to focus the Experimental School program. Bill and Diane designed a program. From that moment, the School’s mission was inclusive preschool education. Bill and Diane were successful because they were dedicated to the idea that content was not the only goal of learning. There are certain content fundamentals, but the process—how to learn—is the important goal. They combined theory and research without ever losing their service orientation. Bill was criticized by colleagues for time spent in a ‘service system.’ He replied, ‘When I’m working with children, I get the most important questions that send me chasing back to the lab.’” –H. Carl Haywood

Center for Assessment of Children with Deaf-Blindness

“I directed a new center in the School for the assessment of children with deaf-blindness, founded by Verna Hart and Randall Harley. I was responsible for bringing in children from all over the U.S. for a week at a time in the classroom. Each child was evaluated by relevant specialists. Each family brought with them a community service provider. I trained family members and service providers so that the interventions could be implemented when families returned home. Later we expanded the program to include children with multiple disabilities. The center was well-respected, one of three in the country. We used a house nearby

where two families stayed each week. This allowed them to form enduring, supportive relationships.” –Rebecca Fewell

Peabody Developmental Motor Scales. “Many tests were developed in the School, including the Motor Scales, which I developed in 1974 with Rhonda Folio. This test continues to be used today by occupational and physical therapists, and teachers. It is a national standardized assessment of motor development skills in young children. It is used to determine whether children qualify for OT and PT, and how to move from assessment to intervention. It is both a scale and a program.” –Rebecca Fewell

Family Involvement. “We learned from parents. As professionals, our perceptions of parents have changed dramatically. At that time, we were trained to think of ourselves as the professionals and assume that parents would do our bidding. Instead, we learned to pay attention to parents and learned that parents are the experts on their children. What parents know is extraordinarily valuable. When parents are not involved, educational interventions are less successful.” –Diane Bricker

Regional Intervention Program. “Another classroom was a forerunner of what became the Regional Intervention Program. It was headed by John Ora and Ron Wiegerink. The original goal was to provide intervention for young children with autism, but at that time [early 70s] few children under 5 years were identified. That led them to broaden the scope to young children with behavioral issues, knowing that children with autism would fall within that group.” –Rebecca Fewell

Interdisciplinary Training. “The School was a very important place of learning for graduate students. Some of the finest people in the field today got their training there. Susan Gray was a mentor to us all. She set the standard for excellence in teaching, research, and service to the community.” –Rebecca Fewell

“From the outset the School served as a practicum site for students in psychology, special education, and early education. Peabody music faculty and students worked with the School’s teachers to develop music programming and art faculty and students were similarly involved.” –H. Carl Haywood

Uniting Threads. “Three continuous threads run throughout the School’s history. First is the importance of helping children learn to manage their own behavior. Second is language development, which plays an important role in cognitive development, including the finding that motor imitation is an important step in acquiring language, especially for children with severe disabilities. The third thread is curriculum development—finding what works in education and exporting it.”

–H. Carl Haywood

Contributions of University Demonstration Schools. “Demonstration schools are critical for the development of teachers as well as for faculty and other professionals for the future of the field. They are the place where the quality of the teaching is outstanding, where new ideas can be developed and cutting-edge research can go on. A demonstration school makes possible controlling research samples in a way that is not possible in public settings. These schools play critical roles. They cannot be a substitute for what the community offers. They are a place where additional knowledge can be gained through high-quality research that will direct our field for the better, generating ideas for the future.” –Rebecca Fewell
Living with disabilities can be a constant search for answers. With so many different resources, it is easy to feel overwhelmed by the wide range of possibilities. Now, countless resources can be reached by placing one simple phone call.

Tennessee Disability Pathfinder (formerly known as Tennessee Disability Information and Referral Office) is one of the many services available at the Vanderbilt Kennedy Family Outreach Center. Located at 1810 Edgehill, Pathfinder is a statewide, comprehensive information and referral program with resources on disability providers throughout the state. Referral services are provided free of cost to persons with disabilities, family members, service providers, and advocates.

Staff members are available weekdays from 8 a.m. to 5 p.m. to provide information through the Pathfinder toll-free hotline. In the Nashville area call 322-8529 or statewide call 1-800-640-INFO [4636]. The staff can respond to calls in either English or Spanish. Persons who are deaf or hard of hearing can call the TDY at 1-800-273-9595.

“We typically answer 450 calls per quarter,” said Carole Moore-Slater, Pathfinder coordinator. “We’ve been able to give information to callers from 79 Tennessee counties and 13 states.”

Every other year the Pathfinder staff publishes the Tennessee Disability Services and Supports Directory in three volumes—East, Middle, and West Tennessee. Resources for each county in Tennessee are described and contact information is provided. The 2004 directory will include over 1,600 agencies and can be purchased, at cost, for $30.

The all-inclusive Pathfinder website can be accessed at www.familypathfinder.org. Through the site, persons can search the database of 1,600 agencies by Tennessee county and type of service. The site provides not only comprehensive resources for Tennessee but also outstanding national resources.

Pathfinder staff also provide support for the Tennessee Disability Training website, www.disabilitytrainingtn.org, which lists Tennessee and national disability-related events.

Tennessee Disability Pathfinder is in its sixth year of service as a partnership of the Tennessee Council on Developmental Disabilities and the Vanderbilt Kennedy Center.

Vanderbilt’s extraordinary new Monroe Carell Jr. Children’s Hospital is up and running. This state-of-the-art facility for children and families, among the finest in the nation, is especially welcoming to families with children with developmental disabilities, thanks to the presence of a satellite office of the Vanderbilt Kennedy Family Outreach Center within the Junior League Family Resource Center.

Located on “Main Street” of the Children’s Hospital, this new branch of the Family Outreach Center, sponsored by the Lili Claire Foundation, will be staffed by a social worker who will work one-on-one with families needing services and supports.

The Junior League Family Resource Center, which has been a part of Children’s Hospital for a decade, is a centralized place where families, friends, health professionals, educators, and other members of the community can obtain information and resources on chronic illnesses, disabilities, and severe injuries of children and related issues.

The Vanderbilt Kennedy Family Outreach Center will augment their resources, focusing on developmental disabilities and also linking families to research opportunities.

Elise McMillan, director of community outreach for the Vanderbilt Kennedy Center, explains why being centrally located at the Children’s Hospital is so vital to those in need.

“Speaking as a parent, when my son was undergoing heart surgery, all of my focus was at the hospital. It would have been wonderful to have all the services in one location.”

The Family Outreach Center social worker will divide time between the satellite office at Children’s Hospital and the Center’s main location at 1810 Edgehill, so that both families in the hospital and those in the community are served well.

For more information, contact teresa.turnbo@vanderbilt.edu, 615-936-5118.
Sibshops—Fun and Support

The bond between brothers and sisters can be one of the most gratifying relationships of a lifetime. When a sister or brother has a disability, it can create unique relationship opportunities. The Arc of the United States has formed a special program to cultivate the significant sibling bond and to strengthen family ties.

Developed by Don Meyer, director of the Sibling Support Project at The Arc, Sibshops are activity-based workshops for children who have a sibling with special health or developmental needs. The Sibshop experience works to foster peer support and education through participation in exciting activities.

In collaboration with several other disability groups, the Vanderbilt Kennedy Center sponsors a series of Sibshops for children ages 7 to 12 in the Nashville area. During the sessions, children take part in a variety of projects such as games, exercises, and art activities while meeting new friends and special guests. In October participants enjoyed time with the education staff from the Frist Center for Visual Arts. Together the Frist Center staff and the Sibshop participants created a unique quilt to hang in the main entrance of the new Monroe Carell Jr. Children’s Hospital.

“Immediately, the children realize that there are others in the same boat with them. They develop a network of friends experiencing some of the same things they are experiencing,” explained Elise McMillan, director of community outreach for the Vanderbilt Kennedy Center.

“At Sibshops, children are able to talk about some of the challenges they face and, at the same time, some of the rewards of having a brother or sister with a disability.”

The fourth Sibshop for the 2003-04 academic year will be Saturday, April 10, at the Vanderbilt Kennedy Center, 10 a.m. to 2 p.m. (lunch provided). Cost is $10 per session to cover the cost of materials and food.

For information, call Elise McMillan at (615) 343-2540 or visit kc.vanderbilt.edu/kennedy/community/sibshop.html.

Art activities with children help establish a network of friends.

Reading Clinic Scholarships, Thanks to Bridgestone/Firestone Gift

Many children need more help learning to read than their schools are able to provide. The Vanderbilt Kennedy Reading Clinic’s nonprofit tutorial program has a proven track record in helping struggling readers, but for some families cost is a barrier. Now a generous gift from Bridgestone/Firestone, Inc. will provide Reading Clinic scholarships for students in grades kindergarten through 4.

“Reading is a foundational skill for advanced learning, and children who don’t learn to read are enormously disadvantaged,” said Dr. Pat Levitt, Kennedy Center director. “We know the Vanderbilt Kennedy Reading Clinic can help, and now, thanks to the wonderful generosity of Bridgestone/Firestone, families who need this help will no longer be deterred by financial obstacles.”

Under the direction of Drs. Doug and Lynn Fuchs, nationally known for their research in the area of reading, elementary school children can receive intensive one-on-one tutoring sessions to improve reading performance.

“One in five children has difficulty learning to read,” said Dr. Doug Fuchs. “These scholarships will provide broader access for families in our community.”

Children at the Reading Clinic, located in the Vanderbilt Kennedy Family Outreach Center at 1810 Edgehill Avenue, meet with experienced undergraduate or graduate student tutors 2 times a week for 60 minutes. Tutors are closely supervised by Caresa Young, an experienced reading specialist who is Clinic coordinator.

For more information on the Clinic and the developing scholarship program, contact Ms. Young at caresa.j.young@vanderbilt.edu or 615-936-5123.
Planning Your Legacy

By Barbara Gregg Phillips, Leadership Council Chair

We all want to leave legacies to our family, to those we have loved most, those to whom we have devoted our lives. This is an extension of ourselves to our progeny. But most of us also desire to contribute to causes and institutions larger than ourselves and our families. We know that by merging some of our means and bequests with those of others, we can make a global difference. Making these “giving” decisions now ensures that we continue to give to what we treasure beyond gifts to our families and friends.

Granted, most of us do not have the means by ourselves to leave funds for naming buildings or endowing faculty chairs or programs. But because we care so much about children and families served by the Vanderbilt Kennedy Center, we aspire to leave gifts for research and services that we have cared about over the years. We can do this by planned giving (see Mary Jane Swanson’s story for inspiration) and by combining our gifts and bequests with those of others who share the same dream. According to our specific “heart interest,” the Kennedy Center can channel our gifts for:

• reading scholarships for children whose lives will forever be different as they understand the written page;
• research and programs for children whose autism keeps them from connecting with the world of peers and family; these gifts also provide parent guidance and family support;
• scholarships for summer camps for adolescents with cognitive disabilities; at camp they learn, have fun, and interact with friends—social experiences that other teens take for granted;
• research and clinics on language, communication, and behavior disorders where children and their families learn to learn together;
• community outreach and information and referral through the new Family Outreach Center and Tennessee Disability Pathfinder, as well as an exciting Sibshop for brothers and sisters of children with disabilities;
• outdoor activities and play/recreation equipment;
• transportation to reach the outside world;
• equipment for state-of-the-art research; and
• recruiting and retaining the world renowned-scientists and teachers of the Vanderbilt Kennedy Center.

Of course, the Kennedy Center needs larger gifts for endowed chairs, for buildings, for centers for specialized research, and for strategic priorities unknown at this time. However, the real message is that we don’t have to make bequests of millions or even six-figure gifts for our gifts to serve the needs of children we love. Just as the Leadership Council has a number of people combining our gifts and interests to support the Kennedy Center, our bequests will blend with those of our colleagues and friends to make a great difference. We can decide to keep on giving to those we love. Our legacy will be to all our children.

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For information about joining the Nicholas Hobbs Donor Society or making Honor or Memorial gifts, contact the Development Office at 615-322-8244.

Every effort has been made to ensure the accuracy of this report. If an error has been made, we offer our sincerest apology and ask that you bring it to our attention by contacting the Development Office.
Swaney Planned Gift Is Investment in Children

New Playground

Swaney Planned Gift Is Investment in Children

Mrs. Swaney, Susan Gray School children, and Tracy Tatum, School facility coordinator.

It may have been a cold January day but the warmth of Mrs. Mary Jane Swaney was all the sunshine needed outdoors on the Susan Gray School playground where kids with and without disabilities play together. A gift from Mrs. Swaney and her husband, the late Mr. Robb Swaney, an architect, as well as their interest and hard work, made this accessible playground possible. Now Mrs. Swaney has established a charitable gift annuity for the playground's maintenance.

The Swaneys' interest in the Susan Gray School began with the idea of a gift in memory of Keith Crabtree, the teenage son of long-time employee in Mr. Swaney's firm and a dear friend. "Keith had volunteered at the Susan Gray School," Mrs. Swaney said, "a highlight in his very young life. We visited the School with the idea of contributing a piece of playground equipment in his memory. Then we saw the playground and knew that more was needed. Robb had done work in New York with children with special needs, and he volunteered to design an accessible playground, if they wanted. And they did want it."

Mr. Swaney and the School staff dreamed big and worked together to design a marvelous playground. In addition to donating professional services, Mr. and Mrs. Swaney made a financial gift and helped with fundraising to make this dream a reality.

"He died before the playground was dedicated but was able to see children playing there," Mrs. Swaney said. "It was his doing, not mine. I’m just a wife."

"Robby had many very nice experiences here," Mrs. Swaney continued. "He was in the Kennedy Center lobby one day when a Susan Gray School teacher and students came through. The teacher introduced the children to him as ‘the man who is building our playground.’ The children cheered ‘Hurrah, Mr. Playground!’"

Knowing that operational funding sources for the School cannot be used to maintain facilities, Mrs. Swaney, as both she and her husband wished, set up a charitable gift annuity to maintain the playground.

Mr. Swaney was a graduate of Montgomery Bell Academy, but his desire to become an architect led him out of state for his architectural education. The Swaneys returned to Nashville in 1960 for Mr. Swaney to establish his architectural firm. Soon Mrs. Swaney was able to pursue her own education, completing a BA and an MA in geography, both at Peabody College.

The Swaney’s first gift to Vanderbilt was to the Department of Psychiatry in memory of a friend associated with the Department. Over the years, they have established charitable gift annuities to benefit various areas of the University. They are members of Owen Associates, lifetime members of the Canby Robinson Society, and members of the Sarratt Society.

Another of the Swaneys’ charitable gift annuities was directed to the Vanderbilt Brain Institute. "My brother is a physicist," Mrs. Swaney explained, “and I was raised to understand that basic research is very, very important.”

Mrs. Swaney views the charitable gift annuities as much as an investment as a gift, and one with tax advantages as well. "We had old stock that we had held for a long time, whose value had risen, so it’s not as if we have really given so much," she said. "An annuity is an investment with a good return on it. It’s a very good vehicle for the person who does it.”

On a January morning, Mrs. Swaney was with children on the Susan Gray School playground and with them in classrooms as the Singing Cowboy, Joel Reese, entertained.

“When you see the mix of children with and without disabilities—it’s really a wonderful thing,” she said. “It’s truly worth putting your effort into.”

Charitable Gift Annuities

A charitable gift annuity can help you ensure your own financial security and provide support for the Vanderbilt Kennedy Center. In exchange for your gift, you receive fixed payments for life and the satisfaction of knowing that the Kennedy Center will benefit from this gift for years to come.

A charitable gift annuity can provide:
• Supplemental income payments for your lifetime (and the lifetime of your spouse or partner).
• Significant tax breaks when you make the gift—and every year thereafter.
• Vital support to the Vanderbilt Kennedy Center or other Vanderbilt interests for generations to come.
• If you want to receive income from assets, such as stocks that have appreciated significantly in value, a gift annuity can be particularly attractive.

If you would like to learn more about Charitable Gift Annuities, or to discuss other ways to meet your personal and philanthropic goals, please contact:

Planned Giving at Vanderbilt
Vanderbilt University
VU Station B #357756
Nashville, Tennessee 37235-7756
Phone 615-343-3113
Fax 615-343-8547
planned.giving@vanderbilt.edu
New Video

A new video is available portraying the work of the Vanderbilt Kennedy Center. Called “Letters from Home,” it features families sharing their experiences of our programs through letters to our investigators. Produced by Jackson-Kent, the video was recently awarded a Silver Addy by the American Advertising Foundation.

To order your complementary copy, please contact Stephanie Comer at stephanie.comer@vanderbilt.edu, or 615-322-8240.

United Way Giving


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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April-July 2004 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 www.disabilitytrainingtn.org.

April

The Legacy of Dr. Susan Gray: Inventing the Future

FEBRUARY 1 THROUGH APRIL 2
Art Exhibit
Exhibit of photographs and publications celebrates 35th anniversary of Susan Gray School (originally Experimental School) Lobby of Kennedy Center/MRL Building

APRIL 1
Susan Gray School 35th Anniversary Panel:
A History That Helped Invent the Future of Early Childhood Special Education
H. Carl Haywood, Ph.D., Moderator, Professor of Psychology, Emeritus and Vanderbilt Kennedy Center Director (1971-1983)
Diane Bricker, Ph.D., Professor of Special Education, University of Oregon
Rebecca Fewell, Ph.D., retired Professor of Special Education, University of Miami
Dara Howe, Director of Family Voices of Tennessee
Ann Kaiser, Ph.D., Professor of Special Education and Deputy Director of Kennedy Center Family Research Program

Thursday 4 p.m.
Room 241 Kennedy Center/MRL Building

APRIL 2
35th Anniversary Keynote Address:
The Way It Was and How It Might Be
Diane Bricker, Ph.D., Professor of Special Education, University of Oregon
Friday Noon
Room 241 Kennedy Center/MRL Building

JANUARY 10 THROUGH APRIL 30
Outreach Exhibit Related to VSA Art Exhibit
How Does Art Shape Your World?
Sponsored by Frist Center and Vanderbilt Kennedy Family Outreach Center
Includes 36 works by Nashville youth and their families. VSA exhibit includes more than 30 works by children nationwide. VSA Arts is an international organization that creates learning opportunities through the arts for people with disabilities.
Conte Community Arts Gallery, Frist Center for the Visual Arts, 919 Broadway, Nashville
Information Frist Center 615-244-3340

APRIL 7
Grand Rounds
Genetic Disorders That Cause Developmental Disabilities in 2004
John Phillips III, M.D., David T. Karzon Professor of Pediatrics, Professor of Biochemistry; Director, Division of Genetics; Vanderbilt Kennedy Center Investigator
Light breakfast provided
Co-Sponsor Center for Child Development, Pediatrics
Wednesday 8 a.m.
Room 112 Kennedy Center/MRL Building

APRIL 8
Lectures on Development and Developmental Disabilities
Co-Morbidities of Dyslexia: ADHD and Speech/Language Disorders
Bruce Pennington, Ph.D., Professor of Psychology, University of Denver
Thursday 4 p.m.
Room 241 Kennedy Center/MRL Building

APRIL 10
Sibshop
For siblings, 7-12 years, of children with disabilities. Games, friends, discussions. Advance registration required, $10 fee
(lunch provided), Saturday 10 a.m.–2 p.m.
Room 241 Kennedy Center/MRL Building
Information teresa.turnbo@vanderbilt.edu
615-936-5118

APRIL 14
Neuroscience Graduate Seminar
Creating the Cortical Area Map
Elizabeth Grove, Ph.D., Assistant Professor of Neurobiology and Pharmacological and Physiological Sciences, University of Chicago
Co-Sponsor Vanderbilt Kennedy Center
Wednesday 4 p.m.
Room 1220 MRB III Lecture Hall

APRIL 21
Neuroscience Graduate Seminar
MRI Studies of Childhood Disorders: Building Biological Models of Developmental Psychopathologies
Bradley S. Peterson, M.D., Deputy Director, Pediatric Neuropsychiatry Research, Suzanne Crosby Murphy Professor in Pediatric Neuropsychiatry, Columbia University
Co-Sponsor Vanderbilt Brain Institute
Wednesday 4 p.m.
Room 1220 MRB III Lecture Hall

Vanderbilt Kennedy Family Outreach Center
Opening Celebration
Entertainment and refreshments, information on programs for families, recognition of The Lili Claire Foundation and Community Partner Agencies.
Wednesday 4-6 p.m.
Room 241 Kennedy Center/ MRL Building
Information teresa.turnbo@vanderbilt.edu
615-936-5118

APRIL 22
Eighth Annual Britt Henderson Training Series for Educators
Designing a Positive Behavior Support Plan to Better Serve All Students
Conclusion of year-long workshops for middle and high schools. Poster presentations and reception.
Thursday 4 p.m. Currey Ingram Academy
6546 Murray Lane, Brentwood
Information Elise McMillan, J.D. 615-343-2540
May

MAY 1
Cinco de Mayo Benefiting Susan Gray School
Fiesta, food, drinks, live music, live and silent auction!
Tickets $30/person ($20 tax-deductible)
Patron tables of 8 available for $500
Saturday 7 p.m.
Vanderbilt Magnolia Circle Lawn
Information Susan Gray School 615-343-9351

MAY 21
Waddell & Reed Financial Services
Charity Golf Tournament Benefiting
Vanderbilt Kennedy Center
Great golf, door prizes, cold beverages, lunch provided! Entry fee $100 per player.
Variety of company sponsorship opportunities available at different levels.
Friday 8 a.m. Shotgun start
The Legends Club of Tennessee, Franklin
Information and registration 615-399-0128

MAY 21-22
50th Reunion for Mental Retardation
Research Training Program
Sponsored by Vanderbilt Kennedy Center and Peabody College
The first NIH-funded doctoral research training program in mental retardation in the nation is celebrating its 50th anniversary with a reunion of graduates and program faculty.
Friday evening and Saturday
Information linda.dupre@vanderbilt.edu
615-322-8253

MAY 5
Neuroscience Graduate Seminar
Molecular Mechanism of Neurotransmitter Release
Hugo Bellen, Ph.D., Baylor University
Co-Sponsor Vanderbilt Brain Institute
Wednesday 4 p.m.
Room 1220 MRB III Lecture Hall

MAY 12
Grand Rounds
A Drosophila Model of Fragile X Syndrome
Kendal Broadie, Ph.D., Professor of Biological Sciences, and Vanderbilt Kennedy Center Deputy Director
Light breakfast provided
Co-Sponsor Center for Child Development, Pediatrics
Wednesday 8 a.m.
Room 112 Kennedy Center/MRI. Building

June

JUNE 7-25
TRIAD Camp
Sponsored by Vanderbilt Treatment and Research Institute on Autism Spectrum Disorders
For children with autism spectrum disorders, ages 6-11. Focuses on social skills in a typical camp environment. Typical peer models included.
Program for ages 12-18 focuses on social skills and job skills.
University School of Nashville
Information TRIAD 615-936-0267
www.triadatvanderbilt.edu

JUNE 3-6 (PRE-CONFERENCE JUNE 2)
Second Annual Tennessee Disability Mega Conference
Sponsored by coalition of more than 50 Tennessee disability-related organizations, including Vanderbilt Kennedy Center
Nashville Airport Marriott Hotel and Conference Center
Information www.tndisabilitymegaconference.org

July

JULY 5-30
Explorers Unlimited Camp
Co-sponsored with Down Syndrome Association of Middle Tennessee
Arts education programming by the