Family Ties that Bind

Discovering ways to support families who have children with disabilities is a longstanding Vanderbilt Kennedy Center research tradition, but families are now in the forefront as never before with the launching of the Research Program on Families and the Vanderbilt Kennedy Family Outreach Center (see article p. 4).

“We will work in partnership and collaboration with families who will help us set the research agenda and support families who participate in Kennedy Center research,” said Ann Kaiser, Ph.D., professor of special education and the Center’s deputy director of the Research Program on Families.

Four emphases will characterize the Vanderbilt Kennedy Center family research initiative: a focus on sibling relationships, an interdisciplinary approach to sibling and family issues, research that follows family members over extended time periods, and a conceptual approach that focuses on positive adaptations and health features of sibling and family relationships sustainable over the life span.

“That siblings are affected by their brother or sister with a disability and are likely to affect that person throughout their lives is such an important idea,” Kaiser said. “One of our goals is to find ways to support families and siblings, to optimize relationships and life outcomes for both the family member with a disability and their brothers or sisters.”

Vanderbilt Kennedy Center family researchers are collaborating with Arc of the U.S. because of The Arc’s long-standing interest in sibling relationships throughout the life span. The Arc has collaborated with Kennedy Center researchers evaluating The Arc’s development of Sibshops, a model program of games and fun activities to support siblings of children with disabilities, which was developed by Dr. Don Meyer.

“Our emphasis on siblings ties together our clinical and outreach programs for families,” said Elisabeth Dykens, Ph.D., professor of psychology and deputy director of the Research Program on Mood and Emotion.

Test and Technology Center

The Peabody Picture Vocabulary Test. The Woodcock-Johnson Tests of Achievement and the Woodcock-Johnson Tests of Cognitive Abilities. Educators, psychologists, parents, all know these tests used nationwide to assess students’ skills and to identify students needing supports to develop and learn effectively. They may not know they were developed “right here in River City”—by Vanderbilt Peabody College faculty and Kennedy Center investigators who were doing research on language and intelligence and other domains of child development. These achievements of the past will be answered by achievements of the future—that’s the goal of the Vanderbilt Kennedy Center’s new Test and Technology Center, which was launched this summer.

“The Center has two purposes,” said its director Stephen Camarata, Ph.D., professor of hearing and speech sciences and Kennedy Center deputy director of the Research Program on Communication and Learning. “First, we will provide state-of-the-art assessment services to families of children with disabilities and support the assessment methodologies of Kennedy Center researchers. This purpose flows out of the Vanderbilt Kennedy Center’s primary mission to increase knowledge of development and disabilities.

“Second, we develop new test instruments and technologies in both the behavioral and biological sciences to improve the assessment of development and disabilities. Our researchers are already involved in this process. The difference is that this new Center provides a way to make these tools available to other researchers.”

Bright Start

Celebration of Families and Research

Dykens, Expert on Genetic Syndromes

Tomorrow’s Treatments, Today

“Bright Start” for Preschoolers

Celebration of Families and Research

Director’s Message

Tests—Windows into Development

Technology is the driving force behind advancements in any discipline of science and medicine. From new ways to assess complex cognitive functions and behavioral states in children and adults, to the cutting edge tools that will provide rapid discovery of novel biological targets for successful interventions, we depend upon the creativity of our Center’s scientists to bring these discoveries more rapidly to the community. And as our ability to gather more and more information improves, the challenges of understanding...
Family Ties from page one

Robert Hodapp, Ph.D., professor of special education, emphasized that the Research Program on Families “embodies the Center’s mission of providing ‘tomorrow’s interventions today.’ Family work in developmental disabilities has shifted dramatically over the past few decades. From an earlier view that all families necessarily experienced ‘bad things’ in response to bringing up a child with disabilities, we now know that both good and bad outcomes can occur. Our research task is to identify what’s needed to promote good versus poor family outcomes. Armed with that knowledge, we can then identify families more prone to have difficulties and develop effective supports.”

Hodapp indicated that in research he and Dykens have done across several genetic disorders, a child’s maladaptive behavior seems most related to parental coping difficulties. Other important variables include parents’ own styles of solving problems, formal and informal support systems and parent organizations, and parents’ pre-existing views of the nature of their child’s problems.

Family research here will be interdisciplinary and collaborative, Kaiser stressed. “Because of methodological advances in studying biobehavioral interaction, the time is right to apply these methods to understanding sibling and family relationships. We now have opportunities to study both genetic and environmental contributions to developmental outcomes,” she said.

Kennedy Center researchers are “looking at families through a host of lenses,” Hodapp said. “Geneticists are looking for genes in parents and extended family members that might predispose children to such disorders as ADHD or autism; others are using parents and siblings as interventionists for children with emotional and intellectual problems; still others are examining what both parents and teachers know about those behaviors characteristic of individuals with one of several genetic syndromes. In short, we have scarcely begun to understand the intricacies of families of children and adults with disabilities.”

In July, Vanderbilt Kennedy Center family researchers met with colleagues from other national centers for research on developmental disabilities, including the Waisman Center and UCLA, from St. Mary’s College of Maryland, and executive staff of The Arc of the U.S. to identify the core issues in studying siblings of individuals with disabilities.

“We all realized just how little sustained research attention has been paid to the well-being of the siblings of children—and adults—with disabilities,” Hodapp observed. “This issue has obvious intervention and policy consequences, particularly as the number of older adults with disabilities triples over the next few decades. Policymakers have not even begun to anticipate the consequences for these adult siblings as they assume caretaking responsibilities for their aging brothers-sisters with disabilities.”

Test and Technology Center from page one

In the United States, over 5.8 million children have disabilities. Most have brothers and sisters.

BOOK
Special Siblings: Growing up with Someone with a Disability by Mary McHugh (2nd edition, Paul H. Brookes Publishing Co., 2003)

WEB RESOURCES

Sibshops www.thearc.org/siblingsupport/sibshoppage.html

Sibshops at Vanderbilt Kennedy Center kc.vanderbilt.edu/kennedy/community/sibshop.html

Sibs Encounter www.sibspace.org/homeframe.html

An online support group for brothers and sisters of people with disabilities

KidsHealth www.kidshealth.org/
Provides explanations of types of disabilities and medical conditions at levels for parents, kids, and teens; site by medical experts of Nemours Foundation

clinicians, and educators, to extend our reach nationally and internationally.”

The Center’s first product now available nationally is ProcoderDV, a technology developed to facilitate data collection from digital media. It was designed for behavioral researchers to analyze video and audio taped events, but could be used to by anyone who needs to analyze time-based events in detail, e.g., sports.

ProcoderDV was developed by Jon Tapp, the Center’s director of computer services, and has been beta tested by researchers here and in other developmental disability research centers. For details on testing and purchasing ProcoderDV see www.procoderdv.com.

“ProcoderDV models how the Test and Technology Center operates as an entrepreneurial enterprise,” said Camarata. “The Vanderbilt Kennedy Center provides support to researchers and research support staff as they develop innovative ideas into viable products, which can then be made available to others. We work closely with Vanderbilt’s Office of Technology Transfer. The ultimate purchase cost for a product and percentage of sales income generated that will be shared by the researcher and the Vanderbilt Kennedy Center are negotiated for each product.”

“Dr. Lloyd Dunn, who with his wife Leota, and other colleagues, developed the Peabody Picture Vocabulary Tests, is advising us, along with Dr. Richard Woodcock, developer of the Woodcock-Johnson tests and a Kennedy Center visiting scholar. So we have incredible expertise available to us as we launch this new enterprise.”

Seed funds also will be available to Vanderbilt Kennedy Center researchers who have innovative methodologies and assessments to propose for development.

“Vanderbilt Kennedy Center investigators have national and international impact, and the research they conduct directly and indirectly benefits individuals with disabilities and their families,” Camarata said. “By sharing technologies and assessments our researchers develop, we are extending our reach in ways that will help so many more.”
Leading the Vanguard of Discovery

ELISABETH M. DYKENS, PH.D.
Professor of Psychology (Peabody College)
Vanderbilt Kennedy Center Deputy Director of Research Program on Mood and Emotion

J oined Vanderbilt Kennedy Center 2003

Research Interests
Identification of psychopathologies and profiles of cognitive and adaptive strengths and weaknesses in people with Prader-Willi syndrome, Down syndrome, Williams syndrome, and other genetic syndromes, and linking profiles to treatment

Principal Investigator for
• Obsessions and Compulsions in Prader-Willi and Other Syndromes, National Institute of Child Health and Human Development
• Prader-Willi Syndrome: Correlates of Compulsivity, National Institute of Child Health and Human Development

Clinical Interests
• Director of Vanderbilt Kennedy Family Outreach Center, supported by the Lili Claire Foundation

National Service
• Executive Committee, NICHD Gatlinburg Conference on Research and Theory in Mental Retardation and Developmental Disabilities
• Research and Evaluation Committee, Special Olympics International
• Scientific Advisory Board, Prader-Willi Syndrome Association (USA)
• Professional Advisory Committee 5p- Society (Cri-du-Chat syndrome)
• Science Board of PRISMS: Parents and Researchers Interested in Smith-Magenis Syndrome

Honors
• Associate Editor, American Journal of Mental Retardation
• Associate Editor, International Review of Mental Retardation

Books
Genetics and Mental Retardation


Education
Ph.D. Clinical Psychology, University of Kansas
Postdoctoral Fellowship, Yale University School of Medicine, Yale Child Study Center

Attraction to Developmental Disabilities Research
My father was a psychiatrist, and as a young child, I spent Saturdays at his clinic and so was accustomed to being with people with disabilities. Later, when my father was New Hampshire director of mental health, we lived on the grounds of a state hospital, where I had many friends with different types of developmental and psychiatric difficulties. I wanted to better understand their lives and stories. During my graduate training, I worked directly with children with mental retardation and autism. At the Yale Child Study Center, where I did pre- and post-graduate training, I met a family who had a child with fragile X syndrome and became interested in what that meant in terms of treatment and research. My experiences with children with fragile X syndrome started me on the path of looking at other genetic syndromes, as they offer unique windows for understanding the connections among genes, brain, and behavior, as well as specific ways to optimize interventions with individuals and families.

Reasons for Kennedy Center Membership
My husband Robert Hodapp and I moved from UCLA to Vanderbilt because we wanted to be part of a community of researchers and other people dedicated to understanding people with developmental disabilities on a number of different levels—genetics, brain science, treatments, supporting families, public policy, and advocacy. The Vanderbilt Kennedy Center embodied all of that in one place. Even within the national network of such centers, the Vanderbilt Kennedy Center stands out as an exemplary interdisciplinary community devoted to understanding developmental disabilities.
The dream of a Family Outreach Center has become a reality because of the gifts of two families.

The Lili Claire Foundation. Keith Resnick and Leslie Litt-Resnick learned about the complex issues facing a family with a genetic syndrome when their daughter Lili Claire was born with Williams syndrome. Lili Claire died when she was five-and-a-half months old after undergoing surgery to correct a severe heart condition common to Williams syndrome. Had she lived, Lili Claire would have had to cope not only with physical but also cognitive disabilities.

To make the way easier for other families and to honor Lili Claire’s memory, the Resnicks established the Lili Claire Foundation in 1998. The Foundation seeks to improve the lives of people living with Williams syndrome and other neurogenetic birth disorders through a variety of programs.

At UCLA, the Resnicks met Elisabeth Dykens, Ph.D., and Robert Hodapp, Ph.D., whose research was devoted to understanding genetic syndromes and supporting children and families affected. Together they created the Lili Claire Family Resource Center at UCLA. Later when Dykens and Hodapp told the Resnicks of their plans to join the Vanderbilt Kennedy Center, the Resnicks saw an opportunity to extend the Foundation’s work. Out of our shared vision, the Vanderbilt Kennedy Family Outreach Center began.

The Foundation also is supporting the Lili Claire Life Skills Center in partnership with the University of Nevada at Las Vegas. It provides life skills and job preparation training to young adults with Williams Syndrome and other neurogenetic disabilities.

The Brooks Family Discovery Fund. The late Sam Brooks, his wife Linda, and their children Ashley, Wendy, and Dan, have been part of the Kennedy Center family since the 1970s. Wendy, who has Down syndrome, was enrolled in the Infant-Toddler Learning Project in the Center’s Experimental School (now the Susan Gray School). This pioneering research and demonstration project laid the foundation for inclusive early childhood education, now the national practice. Today, Wendy is a part-time staff member of the Susan Gray School, with wide-ranging interests, including writing poetry. The Brooks family provided the lead gift for a fully accessible playground, and they are members of the Nicholas Hobbs Donor Society.

In 2003, the Brooks family endowed the Brooks Family Discovery Fund to support initiatives to advance research and treatment in development and disability. A portion of this wonderful gift is being used to help support the Reading Clinic and Behavior Analysis Clinic, programs that exemplify translating innovative research into practice.

Supporting Families

“Our vision for the Family Outreach Center is to create a bridge between research and practice,” said Elizabeth Dykens, Vanderbilt Kennedy Center deputy director of Research on Mood and Emotion, who has been instrumental in the founding of this family resource center. “Our goal is to provide children and families with the most effective and appropriate interventions, to connect our clinical research services and this family resource center.”

The Family Outreach Center will provide support and counseling for families when a social worker comes on board in January. Families will be connected with research projects that offer promising treatments and advance knowledge. In turn, families who take part in research will be referred to the center.

“Every individual who takes part in research comes from a family,” said Ann Kaiser, Ph.D., deputy director of the Vanderbilt Kennedy Center’s new Research Program on Families. “A core idea is that when we invite a child or adult with a disability to take part in research, our intention is to support their family.”

A New Home at 1810 Edgehill

“Programs of the Family Outreach Center are open to any family,” said Elise McMillan, Vanderbilt Kennedy Center director of community outreach. A small brick building at 1810 Edgehill is housing the clinics and programs of the Family Outreach Center. “The facility has a reception area for families, and a computer work station where families can access Internet resources with staff assistance,” McMillan said. “Disability Pathfinder staff are housed here, along with the Reading Clinic coordinator. Most rooms are used in the late afternoon for Reading Clinic tutorials. The Behavior Analysis Clinic has a family reception area and clinic space. And it’s less than a block away from the Vanderbilt Kennedy Center.”

When Vanderbilt Children’s Hospital opens, the Family Outreach Center will have a space in the main lobby shared with the Jr. League Family Resource Center. “We’ve been working together closely to assure that services are not duplicated,” McMillan said. “Having a presence in the wonderful new Vanderbilt Children’s Hospital will be a great way to connect with families who might not otherwise find us.”

Reading Clinic

One in five children has difficulty learning to read. Reading failure begins in kindergarten and is difficult to remediate beyond the primary grades, which argues for intervening early and intensively. The
Supported by the Lili Claire Foundation

Vanderbilt Kennedy Reading Clinic addresses this need by providing intensive, one-to-one instruction for children who are experiencing reading problems. Clinic tutors use reading instructional methods that have been proven to enhance children's acquisition of reading skills. The Clinic serves students in the early elementary grades.

“The Reading Clinic is a terrific program, one of the best things we've done,” said parent Susan Larson. “Our son's tutors have all been excellent. They provide useful reports, they work well with him, and they're always prepared. His reading has improved tremendously.”

Faculty leadership is provided by Douglas Fuchs, Ph.D., and Lynn Fuchs, Ph.D., Vanderbilt Kennedy Center investigators and Special Education faculty.

Behavior Analysis Clinic
Many children and adults have serious behavior problems that interfere with typical development or functioning. The Vanderbilt Kennedy Behavior Analysis Clinic provides comprehensive health, educational, and behavioral assessments to identify causes of behavior problems and develops person-centered interventions. This new clinic serves individuals with developmental disabilities, initially beginning with adults and then expanding to serve children. Clinicians follow up in schools and homes, training care providers in the recommended interventions.

The Clinic is a joint venture with Vanderbilt's Department of Psychiatry and School of Nursing. It also serves as a training site in behavior analysis for Peabody College students.

The Clinic's director is Craig Kennedy, Ph.D., associate professor of special education and pediatrics and Vanderbilt Kennedy Center investigator.

Disability Pathfinder
Disability Pathfinder provides information and referral for children and adults with disabilities, family members, service providers, and advocates. Service is provided in English or Spanish. The Pathfinder database has over 1,600 Tennessee disability services and supports, which can be searched by county and type of service at www.familypathfinder.org. The Tennessee Disability Services and Supports Directory is published for East, Middle, and West Tennessee.

Disability Pathfinder is a project of the Vanderbilt Kennedy Center and the Tennessee Council on Developmental Disabilities. Staff are Carole Moore-Slater, M.S., director; Solange Bishop, information specialist; and Emmy Hubbard, program assistant.

Sibshops
Sibshops are opportunities for brothers and sisters of children with special health and developmental needs to obtain peer support and education within a recreational context. Developed by Don Meyer and a project of The Arc of the U.S., they involve information and discussion interspersed with games, activities, and special guests.

Vanderbilt Kennedy Center Sibshops, for brothers and sisters of children with special needs, 8 to 12 years, are held Saturdays, 10 a.m.–2 p.m. (lunch provided). Upcoming dates are December 8 to 12, January 13, February 14, and April 10. Cost is $10.00 per person per meeting.

Henderson Series for Educators
The Britt Henderson Training Series is made possible by an endowment from the Henderson family in memory of their son Britt. Its purpose is to provide training for general and special education teachers, in order to improve the quality of education for students with diverse learning needs. In 2003-04, the Henderson Training Series is assisting selected school teams in designing a Positive Behavior Support plan to better serve all students.

Disabilities and the Arts
The Vanderbilt Kennedy Center sponsors exhibits of art by or about persons with disabilities. Exhibits are in the lobby of the Vanderbilt Kennedy Center and work is displayed in the Family Outreach Center.

“Welcome opportunities to share this art with the community,” said Elise McMillan, who coordinates the arts initiative. Art by Tennesseans with autism is invited for a Spring 2004 exhibit co-sponsored with the Autism Society of Middle Tennessee.
A “Bright Start” for SGS Preschoolers

If you could look in the four Susan Gray School preschool classrooms, you would likely hear lots of questions—and active children thinking up good answers. Last year these classes began using Bright Start, a cognitive early education curriculum that teaches fundamental thinking, learning, and problem-solving principles to help children become more effective academic and social learners.

“We’ve come full circle,” said Susan Gray School director Ruth Wolery, Ph.D. “The initial work to develop this curriculum began here in our preschool classrooms 20 years ago. The next step was to take it to other Nashville preschools, followed by a period of national replication and outreach. Today it’s even used in other countries—and now we’ve brought it back home. It’s a great example of how research and demonstration in the School can impact not only our own practice but early education nationally and internationally.”

Wolery selected Bright Start a year ago when she was looking for a curriculum that provided high-quality pre-academic preparation for typically developing children while at the same time addressing the needs of children with developmental delays. She likes the curriculum’s focus on language and the way it builds on children’s strengths.

Bright Start is flexible and is designed for use with children at developmental levels from 3 to 6 years. Its goal is to broaden children’s understanding and thinking processes, thereby increasing their educability. It relies heavily on a “mediational teaching style.”

The curriculum defines mediational teaching as a way for teachers to interact with children so as to help them generalize important thinking processes to their everyday lives. This emphasis on teaching style, the adult-child interaction, was one of the reasons Wolery selected the curriculum.

“It’s asking a lot of open-ended questions,” explained lead teacher Yolanda Mara. “It’s building on what children say, helping them to think about what they’re doing.” Carol Howard, another lead teacher, added, “To begin with, children don’t know the answers, so we’re giving the information and helping it make sense to them, so it’s useful to them.” Howard was parent educator with the original curriculum development project. She was enthusiastic about using the curriculum again, which had become a part of her teaching style.

Mara described the Fast and Slow game, which helps children learn self-regulation. “We start with clapping hands and talk about doing it slow and fast. I say, ‘Listen closely, because when I say fast, you have to clap your hands fast.’ Then we generalize. ‘What other things do you do fast?’ After outside time, they’ll think of answers like running, riding bikes, swinging. ‘What about slow?’ I’ll ask. They said, ‘Inside use walking feet.’ All right! To bridge thinking processes to everyday applications, a teacher will ask children such questions as: When is another time that you use models in order to know what to do? What are some other situations in which you need to have rules and to follow them?

“The curriculum emphasizes learning to follow a model,” Howard elaborated. “Looking carefully, listening carefully, and following directions are all key components. We use models throughout the day—in drawing, exercises, block building. We distinguish following a model from art where children make their own creations and use their own ideas.”

Howard explained that when identifying something, for example, a dog, the emphasis is less on labeling and more on how you know through description and comparison.

Reflecting on differences in children after a year of cognitive education, Mara said, “They could answer more questions. They could think more independently. At first, if you had one child in a group who could answer a question, the rest would say the same thing. By the end of the year, they could all think of something different and appropriate.”

“They learned to be supportive of each other,” Howard said. “They learned to give themselves a pat on the back when they did a good job, or tell another child spontaneously, ‘That was a good answer.’ That’s great to see.”

Both felt that children in their classes who had Individualized Education Plans to address developmental and educational goals also progressed well. “They improved in being able to join a small group,” Mara said, “stay for the whole time, and take part with some support and modification.”

“They felt like a contributing member of the group,” Howard added.

Howard and Mara are coaching new preschool lead teachers Sue Ford and Suzie Clark, who are enthusiastic about using Bright Start for the first time.

Bright Start consists of seven cognitive units, each targeting a basic aspect of cognitive functioning of preschool children: Self-Regulation, Number Concepts, Comparison, Role-Taking, Classification, Sequence and Pattern, and Letter-Shape Concepts.

Although the units can be taught in groups of 4 to 10 children interacting with a teacher, the School’s preschool lead teachers are teaching them in groups of 4 children, while co-teachers engage the other 8 children in the classroom in another activity. Small groups make possible an intensive experience in focused logical thinking and having every child participate directly in the activities.

Two of Bright Start’s authors, H. Carl Haywood, Ph.D., professor of psychology emeritus, and Penny Brooks, Ph.D., professor of psychology emerita, both Vanderbilt Kennedy Center scholars, donated their time to train the Susan Gray School preschool staff. Haywood indicated that mediational teachers do several things more regularly than nonmediational teachers, including:

• Asking many questions.
• Asking process questions: How? Why? How else? How do you know?
• Accepting as much as possible of children’s responses.
• Bridging (make logical)

Continued on page 7
SGS News

BIRTH-DAY PARTY!
It was difficult to decide how many candles to put on the cake—1 candle for the birth-day of the new Children’s Library or 35 candles for the anniversary of the Susan Gray School. Both were celebrated at a party on October 10.

Each party-goer donated a new book—including a very special guest, the Honorable Margaret Giannini, M.D., Director of the Health and Human Service Office on Disability. Appreciation was expressed to Peabody librarians and students who are organizing a book drive.

The Children’s Library is a new collection focused entirely on books for children age 5 and under. It augments the Paula Goodroe Library, a collection for parents and teachers, which honors the School’s long-time coordinator.

To donate books to the new Children’s Library or to contribute gifts to purchase bookcases and furnishings for a children’s reading area, contact 615-322-8200 or marva.d.greenwood@vanderbilt.edu. Donations to the Paula Goodroe Library are also welcome.

THE SINGING COWBOY
Susan Gray School children enjoyed the Singing Cowboy Joel Reese thanks to a gift from Gregg Stanwood, Ph.D., and BethAnn McLaughlin, Ph.D., Susan Gray School parents and Vanderbilt Kennedy Center researchers.

BE AN ANGEL!
The School is planning its angel tree for December 2003; please contact 615-322-8200 or marva.d.greenwood@vanderbilt.edu if you can help. Hallmark Jeep Volkswagen Hyundai provided wonderful gifts for 60 “angels” on the Susan Gray School tree in December 2002.

Our thanks to Hallmark’s wonderful employees and to the many others who sponsored “angels.”

References:

Winter 2004

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.

connections) concepts, principles, and rules to many applications in children’s daily lives.

- Refraining from giving answers or telling children the rules or principles, in favor of guiding the children’s discovery of rules and principles.
- Emphasizing order, structure, and predictability.

Research on Bright Start shows strongly positive effects on cognitive development, motivation for learning, and subsequent school achievement in the primary grades. Bright Start is available in nine languages and is used with thousands of children in fifteen countries. Initially developed for use with children who are socially or economically disadvantaged, it is now used as well with children with mental retardation, emotional disorders, sensory impairments, autism, and cerebral palsy.

“We’re still learning how to implement the curriculum,” Wokery said. “When a school adopts a new curriculum, it takes an extended time of training, sharing, observation, and support for true implementation.”

Howard drafted a letter to parents to share her enthusiasm for the curriculum: “We can be confident that these children will have a head start toward making good choices in their lives. This can set them up for success in whatever they encounter. They are learning to ‘Stop and Think!’—about what materials they need, how to make a plan of action, how their attitudes and actions affect themselves and others, how to generalize information in useful ways, how to learn from mistakes and not repeat them... Thank you for sharing your wonderful child with us. We take the responsibility very seriously.”

This will be another great year.

Barbara Gregg in her career and now as the incoming chair of the Leadership Council of the Vanderbilt Kennedy Center.

Gregg was invited to be a Council member by Annette Eskin, the Leadership Council’s founding chair. “When I make a gift of my time,” Gregg said, “I want it to be only for things I feel are very worthwhile. Knowing how children learn and how they adjust to learning challenges is so critical and it fits my interests. It’s what I care about. So working on the Leadership Council is important.”

Gregg praises Eskin’s accomplishments in increasing community visibility of the Vanderbilt Kennedy Center. “Our next thrust is to support the initiatives outlined in the Strategic Plan. Two important goals are community outreach to families, and then expanding fundraising.”

The Leadership Council now has two committees focused on these goals. Gregg has found that Council members are eager to be involved. “There’s so much interest in perpetuating the work of the Kennedy Center with families,” she said. “Whatever we do at the Kennedy Center is for all our children, everywhere, because of the national and international influence of Kennedy Center research.”

Gregg is a Nashville native. After graduating from college, she taught English at Hillsboro High School. She found that some of her students, although they were very bright, had difficulty with writing or spelling, or had specific disabilities. “I didn’t know what to do about that or how to help them, even though I knew they were intelligent,” Gregg explained. This motivated her to change direction from a master’s degree in English to one in special education at Peabody College, at a time when the Kennedy Center was newly launched.

“I became fascinated with how people learn and how to accommodate for disabilities,” Gregg continued. During her graduate study, she worked with a broad spectrum of children in the Child Study Center, a Kennedy Center clinic that provided educational assessment, a reading clinic, and related services.

About that time, Westminster Point Construction, and his daughters Lauren and Natalie Gregg, sixth and first graders, are very interested in starting a class for children with special needs. As a graduate student in 1969, Gregg worked with that initial class of six children. Over the next three years, the program was formalized and then received State accreditation as Westminster School of Nashville. Peabody Special Education faculty and Kennedy Center researchers were heavily involved with the School, Gregg said. When she left her leadership role with Westminster School, it had 170 students. Today it continues as Currey Ingram Academy.

Gregg’s next step was to form Barbara Gregg and Associates, a private practice focused on educational evaluations and school placement consultations. In addition to this practice, she works with Vanderbilt Medical Center in the recruitment and relocation of new faculty, including assistance with school placements for their children and career integration for their spouses.

In reflecting on her enduring commitment to students with diverse learning needs, Gregg recalls her younger brother who struggled to learn, although today he’s successful. “I can remember trying to teach him his letters, and now I realize he was probably dyslexic.”

Gregg’s son Billy Gregg, president of Center Point Construction, and his daughters Lauren and Natalie Gregg, sixth and first graders, are very supportive of Gregg’s interest in children’s learning differences. “My granddaughters are very sensitive to this in their schools,” Gregg said, “sometimes asking if there is a way to help when someone has a harder time with their learning.”

Throughout her involvement on the Leadership Council of the Vanderbilt Kennedy Center, Gregg said she’s been impressed by the strong commitment of director Pat Levitt and all the staff. “As a volunteer, you’re energized and want to be a part of that.”

Gregg thinks of the involvement of Leadership Council members as a legacy. “You want to be selective about what you give your time and your interest and your heart to,” she said. “The Kennedy Center is that kind of legacy.”

The Nicholas Hobbs Donor Society ($1,000 and above)

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In memory of Kathy Lewis’s mother
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For information about joining the Nicholas Hobbs Society or making Honor or Memorial gifts, contact the Development Office 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.
Leadership Dinner

“A Celebration of Families and Research”

Over 150 Nicholas Hobbs Society members and friends attended the Vanderbilt Kennedy Center Leadership Dinner, chaired by Alyne Massey and Clare Armistead. Dr. Pat Levitt, Vanderbilt Kennedy Center director, and Dr. Harry Jacobson, Vanderbilt vice chancellor for health affairs, honored Annette Eskind, chair of the Center’s Leadership Council, for her volunteer leadership and unstinting support of what she described as “the Kennedy Center in Nashville for performing miracles for children.” The dinner’s theme was “A Celebration of Families and Research,” and highlighted in video and photos families whose lives have been touched by the Center’s innovative research on communication disorders and treatments, early childhood intervention, and reading clinic. The evening’s keynote speaker was Sue Swenson, a parent of a child with a disability who is the assistant director of The Arc of the U.S., former commissioner of the U.S. Administration on Developmental Disabilities, and the former executive director of the Joseph P. Kennedy Jr. Foundation.
“Shaping the Future” of the Vanderbilt Kennedy Center

I’m motivated by being close to the mission and values of what an institution is raising money for,” said Garvin S. Maffett, Ed.D., something he’s found in his new role as director of development for the Vanderbilt Kennedy Center.

“I love children,” said Maffett, the father of a 10-year-old son. “Every day when I’m here, I see the children on the playground or coming to take part in clinical research. I don’t have to be reminded why I’m here. It never leaves your presence.”

Most recently, Maffett was vice president for advancement and college relations at Meharry Medical College. Earlier he held development positions at the University of Maryland School of Medicine (1994-2001), where he was associate dean for development, and at Yale University (1989-1994), where he was associate director for leadership and major gifts during Yale’s successful campaign to raise $1.5 billion.

Maffett is excited about opportunities here. “What we need is a strong base of philanthropic donors. That was begun during the seven years of development leadership that Elise McMillan provided.” He noted the founding of the Leadership Council and the Nicholas Hobbs Donor Society as significant accomplishments that lay the foundation for the future.

“The Vanderbilt Kennedy Center goal within Vanderbilt’s Shaping the Future campaign is to raise $20 million over the next five years—$9 million for faculty support, $4 million for research and intervention initiatives, and $7 million for clinical programs for children and families.” Maffett is confident that together Center researchers, staff, and donors can accomplish this.

“The faculty, staff, and community volunteers here are sincerely passionate and committed,” he said. “It’s a belief system. And that’s unique.”

Maffett has an M.B.A. from the University of New Haven and an Ed.D. from Columbia University. In 1997 he chaired the Leadership Development Committee of the Association of American Medical Colleges. He is a member of the Leadership Nashville Class of 2003 and serves on the Middle Tennessee Council Boy Scouts of America Executive Board.

Maffett looks forward to getting to know the many people who want to be involved in “Shaping the Future” of the Vanderbilt Kennedy Center. He invites persons to call him at 615-322-8244 or email garvin.maffett@vanderbilt.edu.

More than 65 golfers—more participants than any previous tournament—participated September 12 at Waddell & Reed’s Charity Golf Tournament benefiting the Vanderbilt Kennedy Center. The tournament was held at Greystone Golf Club in Dickson, Tennessee. The Vanderbilt Kennedy Center expresses its deep appreciation to the Waddell & Reed Golf Committee: Laurie L. Sisk, member of the Leadership Council of the Vanderbilt Kennedy Center; Patrick Sites; Chad Rogers; and Rick Erickson, Division Manager and head of the Golf Committee. Sisk was instrumental in bringing this opportunity to the Vanderbilt Kennedy Center through her work on the Leadership Council. Through the hard work of all involved, the event raised $4,300 to support the Vanderbilt Kennedy Center.
New Faculty

The Vanderbilt Kennedy Center announces the appointment of three new Vanderbilt faculty who add to the Center’s research strengths.

Laurie Greco, Ph.D., assistant professor of pediatrics, Division of Adolescent Medicine and Behavioral Science, School of Medicine. Completed residency in pediatric psychology at Cincinnati Children’s Hospital Medical Center (2002-03) and received Ph.D. in child clinical psychology from West Virginia University (August 2003)

Research: Pediatric anxiety and pain; peer and family relationships; risk and resilience, particularly among children and teens with chronic medical conditions; child and adolescent behavior therapy.

Julia S. Noland, Ph.D., research assistant professor of psychology, Peabody College, and of pediatrics. Formerly National Research Service Award postdoctoral fellow and senior research associate at Case Western Reserve University.

Research: Prenatal exposure to substances of abuse and effects on cognitive functioning in infancy and early childhood that may be moderated by environmental variables.

Jane Y. Wu, M.D., Ph.D., associate professor of pediatrics and cell biology, School of Medicine. Formerly postdoctoral fellow in biochemistry and molecular biology at Harvard University, then on the faculty of pediatrics, molecular biology, and pharmacology at Washington University School of Medicine.

Research: Understanding how genetic mutations affect the expression and function of genes that are important for cell death and are critical for the pathogenesis of neurodegenerative diseases.

Spotlight

HHS Disability Director Visits

Margaret J. Giannini, M.D., F.A.A.P., director of the new Health and Human Service Office on Disability, visited the Vanderbilt Kennedy Center and Vanderbilt Medical Center October 9 and 10. The Office on Disability oversees the implementation and coordination of disability programs, policies and special initiatives for 54 million persons with disabilities. Dr. Giannini delivered public lectures on the delivery of health care services for persons with disabilities and on disability public policy issues, and met with faculty, students, public policy leaders, and family members affected by disability. In her remarks at the Vanderbilt Kennedy Center, Dr. Giannini spoke of “the need to translate research into service delivery. All of us have the responsibility for doing that.” She emphasized “our shared commitment to opening doors and tearing down walls. We must work to provide greater independence for all our citizens with disabilities.”

Focusing on the Future Exhibit

Helen Keller, the social activist, had a teacher. Stevie Wonder, the musician, had a teacher. Marla Runyan, the Olympian runner, had a teacher. These individuals who shared the experience of having a visual impairment had one or more teachers in their lives who could teach them how to learn in the visual world. Today, due to a critical shortage of these special teachers, too many children who have a visual impairment, blindness, or low vision, are not receiving a free and appropriate public education.

The exhibit Focusing on the Future of Students with Visual Impairments: Teachers in Action is an effort to recruit new students into undergraduate, endorsement, and master’s programs that prepare teachers and orientation and mobility instructors. Sponsored by the Vanderbilt Kennedy Center, the exhibit was developed by the Special Education Program in Visual Disabilities at Peabody College.

The photographs show teachers of students with visual impairments and orientation and mobility instructors engaged with students of all ages in active learning. Thanks to the Brentwood Camera Club, we are able to highlight the remarkable work of these professionals.

Photographs were taken in local schools in Middle Tennessee and in three special schools.

The exhibit will be on display at the Vanderbilt Kennedy Center November 2003 through January 2004. It will then be available to travel to other universities and to schools where it can tell the story of professionals who have an exciting and fulfilling career.

For information contact the exhibit’s organizer, Anne L. Corn, Ed.D., professor of special education, ophthalmology and visual sciences, and Vanderbilt Kennedy Center member, 615-322-2249, anne.corn@vanderbilt.edu.
New Art Gift Cards

The Vanderbilt Kennedy Center has available its second set of original cards for honor or memorial gifts and note cards featuring artwork created by artists with disabilities—“Blossom” by Doug Lauer, “Cupcakes” by Laura McNellis, “Rainbow” by Ali Pilkerston, and “Sunflowers” by children of the Susan Gray School. Note cards are available in packages of eight for a suggested $10 contribution to the Center. Honor/memorial cards can be purchased for any denomination. The Vanderbilt Kennedy Center Development Office will mail a card to honor/memorial recipients or donors can complete the card. Contact 615-322-8235 or julia.wickerham@vanderbilt.edu.
Spring 2004 Calendar of Events

Unless otherwise noted, events are free and open to the public. Events are subject to change. 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.  denotes a Vanderbilt Kennedy Center-sponsored or co-sponsored event.

January

JANUARY 1
Arts and Disabilities Exhibits
On display through January 23
Focusing on the Future of Students with Visual Impairments: Teachers in Action Exhibit organized by Peabody Vision Special Education Program, photographs by Brentwood Camera Club
Monday-Friday 7:30 a.m.-5:30 p.m.
Lobby of Vanderbilt Kennedy Center/MRL Building

JANUARY 7
Grand Rounds
The Molecular Neurobiology of Depression
Richard Shelton, M.D., Professor of Psychiatry and Pharmacology, Vanderbilt Kennedy Center Investigator
Light breakfast provided
Co-Sponsor Center for Child Development, Pediatrics
Wednesday 8 a.m. Room 112 Vanderbilt Kennedy Center/MRL Building

JANUARY 22
Martin Luther King Jr. Commemorative Lecture
Exposure to Violence: The Science and Some Personal Reflections
Felton Earls, M.D., Professor of Social Medicine, Harvard Medical School
Thursday 4 p.m. Room 241 Vanderbilt Kennedy Center/MRL Building

February

FEBRUARY 1
Arts and Disabilities Exhibits
Learning Together: Susan Gray School Celebrates 35 Years
Photo history of landmark research and demonstration, and celebration of children and families
On display through March 31
Monday-Friday 7:30 a.m.-5:30 p.m.
Lobby of the Vanderbilt Kennedy Center/MRL Building
Related events to be announced

FEBRUARY 4
Grand Rounds
Visual Attention in Individuals Who Are Deaf
Anne Marie Tharpe, Ph.D., Associate Professor of Hearing and Speech Sciences, Vanderbilt Kennedy Center Member
Light breakfast provided
Co-Sponsor Center for Child Development, Pediatrics
Wednesday 8 a.m. Room 112 Vanderbilt Kennedy Center/MRL Building

FEBRUARY 14
Sibshop
For siblings, 7-12 years, of children with disabilities. Games, friends, discussions.
Contact linda.dunn@vanderbilt.edu, (615) 343-2540
Advance registration required, $10 fee (lunch provided). Scholarships available.
Saturday 10 a.m.-2 p.m. Room 241 Vanderbilt Kennedy Center/MRL Building

March

MARCH 2
Vanderbilt Brainstorm
Eating Disorders
Roger Cone, Ph.D., Senior Scientist, Vollum Institute, Associate Professor of Cell and Developmental Biology, Oregon Health Sciences University
Contact Vanderbilt Brain Institute
(615) 936-3736
Tuesday 7 p.m. Adventure Science Center

MARCH 3
Grand Rounds
Puzzles, Music, and Parents: Insights from Prader-Willi and Williams Syndromes
Elisabeth Dykens, Ph.D., Professor of Psychology and Human Development, Vanderbilt Kennedy Center Deputy Director
Robert Hodapp, Ph.D., Professor of Special Education, Vanderbilt Kennedy Center Member
Light breakfast provided
Co-Sponsor Center for Child Development, Pediatrics
Wednesday 8 a.m. Room 112 Vanderbilt Kennedy Center/MRL Building

MARCH 4
Lectures on Development and Developmental Disabilities
Development of Antisocial Behavior
Terrie Moffitt, Ph.D., Professor of Psychology, University of Wisconsin, Maudsley Institute of Psychiatry
Thursday 4 p.m. Room 241 Vanderbilt Kennedy Center/MRL Building

MARCH 6
Vanderbilt Brainstorm
Brain Blast
Variety of hands-on activities led by Vanderbilt neuroscience undergraduates, graduate students, and faculty. Museum entry fee.
Contact Vanderbilt Brain Institute
(615) 936-3736
Saturday 11 a.m.-2 p.m.
Adventure Science Center
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<tr>
<th>Date</th>
<th>Event</th>
<th>Details</th>
<th>Contact Information</th>
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<tr>
<td>MARCH 18</td>
<td>Vanderbilt Brainstorm</td>
<td>Neuroethics</td>
<td>Patricia Churchland, B.Phil., Professor of Philosophy, University of California at San Diego</td>
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<td>Contact Vanderbilt Brain Institute</td>
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<td>(615) 936-3736</td>
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<td>Thursday 4 p.m. Location to be announced</td>
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<td>MARCH 23</td>
<td>Vanderbilt Brainstorm</td>
<td>The End of Stress As We Know It</td>
<td>Bruce McEwen, Ph.D., Alfred E. Mirsky</td>
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<td>Professor, Rockefeller University</td>
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<td>Contact Vanderbilt Brain Institute</td>
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<td>(615) 936-3736</td>
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<td>Tuesday 7 p.m. Adventure Science Center</td>
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<td>MARCH 25</td>
<td>Vanderbilt Brainstorm</td>
<td>Lectures on Development and Developmental Disabilities</td>
<td>Klaus A. Miezek, Ph.D., Professor of Psychology and Neuroscience, Tufts University</td>
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<td>Co-Sponsor Vanderbilt Brain Institute</td>
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<td>Thursday 4 p.m. Room 241 Vanderbilt Kennedy Center/MRL Building</td>
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<td>MARCH 31</td>
<td>Neuroscience Graduate Seminar</td>
<td>Regulation of Opiate Receptors</td>
<td>Chris Evans, Ph.D., Senior Research Specialist, Director of UCLA Neuropsychiatric Institute</td>
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<td>Co-Sponsor Vanderbilt Brain Institute</td>
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<td>Wednesday 4 p.m. MRB III Lecture Hall</td>
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<td>APRIL 8</td>
<td>Lectures on Development and Developmental Disabilities</td>
<td>Co-Morbidities of Dyslexia: ADHD and Speech/Language Disorders</td>
<td>Bruce Pennington, Ph.D., Professor of Psychology, University of Denver</td>
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<td>Thursday 4 p.m. Room 241 Vanderbilt Kennedy Center/MRL Building</td>
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<td>APRIL 10</td>
<td>Sibshop</td>
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<td>For siblings, 7-12 years, of children with disabilities. Games, friends, discussions.</td>
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<td>Contact <a href="mailto:linda.dunn@vanderbilt.edu">linda.dunn@vanderbilt.edu</a></td>
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<td>Saturday 10 a.m.–2 p.m. Room 241 Vanderbilt Kennedy Center/MRL Building</td>
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<td>APRIL 14</td>
<td>Neuroscience Graduate Seminar</td>
<td>Creating the Cortical Area Map</td>
<td>Elizabeth Grove, Ph.D., Assistant Professor of Neurobiology and Pharmacological and Physiology Sciences, University of Chicago</td>
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<td>Co-Sponsor Vanderbilt Brain Institute</td>
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<td>Wednesday 4 p.m. MRB III Lecture Hall</td>
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<td>APRIL 16-24</td>
<td>Nashville Week of the Young Child</td>
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<td>Vanderbilt and community sponsors</td>
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<td>Events to be announced. See kc.vanderbilt.edu/kennedy/woyc</td>
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<td>Contact NAAEYC (615) 383-6292</td>
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<td>APRIL 21</td>
<td>Neuroscience Graduate Seminar</td>
<td>MRI Studies of Childhood Disorders: Building Biological Models of Developmental Psychopathologies</td>
<td>Bradley S. Peterson, M.D., Deputy Director, Pediatric Neuropsychiatry Research, Suzanne Crosby Murphy Professor in Pediatric Neuropsychiatry, Columbia University</td>
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<td>Co-Sponsor Vanderbilt Brain Institute</td>
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<td>Wednesday 4 p.m. MRB III Lecture Hall</td>
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<td>APRIL 22</td>
<td>Eighth Annual Britt Henderson Training Series for Educators</td>
<td>Designing a Positive Behavior Support Plan to Better Serve All Students</td>
<td>Conclusion of year-long workshops for middle and high schools. Poster presentations and reception.</td>
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<td>Thursday 4 p.m. Currey Ingram Academy, 6546 Murray Lane, Brentwood</td>
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<td>APRIL 24</td>
<td>Opening of Vanderbilt Monroe Carrell J. r. Children's Hospital</td>
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<td>Following a Ribbon-Cutting Ceremony, a carnival-style celebration will be held with music and entertainment for children and their families</td>
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<td>Saturday 10 a.m.–1 p.m.</td>
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<td>APRIL 29</td>
<td>Art Through the Eyes of Autism Exhibit Panel and Artists Reception</td>
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<td>Co-Sponsor Autism Society of Middle Tennessee</td>
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<td>Thursday 5 p.m. Lobby of Vanderbilt Kennedy Center/MRL Building</td>
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<td>J JANUARY 15, MARCH 16</td>
<td>Autism Orientation</td>
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<td>Thursdays 6:30-8:30 p.m. Free admission. Registration required. Call to request child care.</td>
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<td>J JANUARY 23, FEBRUARY 26, MARCH 25</td>
<td>Autism Education Series</td>
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<td>Thursdays 6:30-8:30 p.m. Topics and speakers to be announced. Admission $5 for public, free for ASMT members. Registration requested. Call to request child care.</td>
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**Autism Society Events**

Autism Society of Middle Tennessee Events

For information and registration, contact ASMT (615) 385-2077.

**April**

**APRIL 1**

**Arts and Disabilities Exhibits**

**Art Through the Eyes of Autism**

On display through June 30
Co-Sponsor Autism Society of Middle Tennessee
Monday-Friday 7:30 a.m.-5:30 p.m.
Lobby of Vanderbilt Kennedy Center/MRL Building

**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

Light breakfast provided