Advancing Down Syndrome Research  

Research that ultimately affects the lives of persons with Down syndrome or other developmental disabilities could not take place without the participation of children and adults with disabilities and their families. In turn, families and a wide array of professionals, from health care professionals to educators, benefit from the knowledge generated through research. This crucial relationship between families and researchers was apparent on a March evening when family members and VKC researchers gathered for a Community Forum to answer the question, "What’s on the Forefront of Down Syndrome Research?"

The impetus for the Forum came from VKC Leadership Council members Melissa Beasley, Anne Nesbitt, Margaret Spickard, and others who are the parents or grandparents of children with Down syndrome.

“I am the mom of a very lively 3-year-old with Down syndrome,” said Melissa Beasley, “and, as Ethan’s mom, I’m very grateful for the research that’s happened over the last several decades—research that has increased awareness, increased life expectancy, enhanced speech and language treatment techniques, and improved overall quality of life for persons with Down syndrome.”

On behalf of the crowded room and the many families who could not be present, she expressed gratitude for having, in Nashville, a Eunice Kennedy Shriver NICHD Intellectual and Developmental Disabilities Research Center. Four VKC researchers reported on their efforts to advance understanding of Down syndrome and speed development of new interventions.

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Dyslexia Linked to Differences in Brain Circuitry  

Children with dyslexia often struggle with reading, writing, and spelling, despite getting an appropriate education and demonstrating intellectual ability in other areas. New neurological research from Vanderbilt University has found that these children’s difficulties with written language may be linked to structural differences within an important information highway in the brain known to play a role in oral language. The findings were published in the June 2010 issue of Cortex.

VKC researchers Sheryl Rimrodt and Laurie Cutting and colleagues at Johns Hopkins University and the Kennedy Krieger Institute used an emerging MRI technique, called diffusion tensor imaging (DTI), to discover evidence linking dyslexia to structural differences in an important bundle of white matter in the left-hemisphere language network. White matter is made up of fibers that can be thought of as the wiring that allows communication between brain cells. The left-hemisphere language network is made up of bundles of these fibers and contains branches that extend from the back of the brain (including vision cells) to the front parts that are responsible for articulation and speech.

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Director’s Message

The announcement of the National Institutes of Health (NIH) Roadmap for Research on Down Syndrome in 2008 was a milestone for families and researchers alike. The Roadmap set forth short-term, medium-term, and long-term goals to achieve by 2018 in five research areas. At a Vanderbilt Kennedy Center Community Forum in June 2008, VKC researchers summarized the Plan and committed ourselves to contributing to achieving these national research goals.

On an evening in March 2010, we again gathered with families, advocates, and colleagues to share innovative work taking place here. In preparation, wanting to provide a national context for this Center’s work, I checked the NIH website to search for and to read abstracts related to Down syndrome.

Searching for grants relating to Down syndrome within the last year, I found only five national projects on questions related to children with Down syndrome—and two of

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Developing a Research Repository

Vanderbilt’s clinical services are poised to play an increasingly important role in supporting research on Down syndrome, said Tracy McGregor, M.D., director of the Down Syndrome Clinic in Vanderbilt Pediatrics Division of Developmental Medicine.

The Vanderbilt Down Syndrome Clinic provides comprehensive care and professional services to children and adults with Down syndrome. A multidisciplinary team of expert medical providers from different specialties are available in a single visit. Children’s services are provided through Pediatrics Division of Developmental Medicine, and adult services through Internal Medicine.

McGregor is working with VKC colleagues to develop a research infrastructure within the Down Syndrome Clinic. These efforts include development of a research registry of children and adults with Down syndrome, so that families can be contacted for future research. The Clinic also will facilitate a repository of medical, behavioral, demographic, social, and other data, which will be collected annually and can be collected by phone. The repository has been approved by Vanderbilt’s Institutional Review Board, which safeguards the rights of research participants, and data collection is beginning.

“Our goal is to be unselfish with the information,” McGregor said, “sharing data with investigators who propose studies on Down syndrome.”

The repository is being planned in a way that would allow it to be integrated into a national Down syndrome data repository, which is one of the goals of the National Institutes of Health Roadmap for Research on Down Syndrome (see Director’s Message).

Reducing Parental Stress

As a clinical psychologist, Elisabeth Dykens, Ph.D., has conducted studies that describe high levels of stress experienced by parents of children and adults with developmental disabilities, compared to parents whose offspring are typically developing.

“I wanted to do something about the stress,” said Dykens, who is VKC director and professor of Psychology and Psychiatry.

With ARRA funding, she is leading a study that compares two methods of stress reduction, a Positive Parenting curriculum and Mindfulness-Based Stress Reduction. The project is staffed by four parents, two of whom have children with Down syndrome. Data is being collected on parental health, positive and negative psychological states, and biomarker indices of stress during and following the group interventions.

Examining Early Aging

Dykens indicated that research on Down syndrome has tended to focus primarily on early childhood and late adulthood, the latter in large part due to interest in dementia in aging.

“We don’t know much about the healthy aging or older adolescents and young adults,” she said. Dykens is beginning research to examine the maturation process in this age group.

Sasha Key, Ph.D., assistant professor of Hearing & Speech Sciences, is using electrophysiological measures to investigate early markers of aging, since adults with Down syndrome are prone to premature aging. The study includes adolescents, ages 16–20 years, and adults, 35–40 years.

Memory loss is among the earliest markers of aging, but memory is not a strength in Down syndrome throughout the lifespan. Aging can also be associated with changes in emotional states, such as increased depression, but individuals with Down syndrome may lack expressive ability to describe inner states.

“As we use brain waves instead of behavioral responses, we are able to work around the intellectual disability,” Key said.

Participants with Down syndrome view several slide shows while a net of soft sensors records their brain activity. Because the brain responds differently to novel versus familiar stimuli, and is more sensitive to information that matches an internal emotional state, few behavioral response demands are placed on participants.

This noninvasive approach using EEG has yet to be widely used in Down syndrome research and should provide new clues about who is at risk for early aging among persons with Down syndrome and how to track age-related changes.

Generating Stem Cells

Aaron Bowman, Ph.D., assistant professor of Neurology, explained the use of mouse models and a new approach for Down syndrome research involving the creation of stem cell lines from skin samples of adults with Down syndrome.

Individuals with Down syndrome have an extra, or third, copy of chromosome 21. Each chromosome contains genes that are the basic building blocks of the body’s functions. Mouse models are useful in understanding Down syndrome because mice share large segments of the genes on chromosome 21. At the same time, mice are limited as models because even many copies of a given gene do not have the same behavioral effect as in humans.

Bowman is optimistic that the recent discovery that stem cells can be grown from a very small sample of adult skin will provide a new research strategy in Down syndrome. Stem cells can become any other type of cell. Bowman has been developing the technology in his lab to make it possible to produce stem cells from the skin cells of adults with Down syndrome. Stem cells can then be
**Down Syndrome Research** from page 2

differentiated into neuronal precursors and then neurons, the brain cells central to cognition.

“By being able to grow in the lab neurons derived from adults with and without Down syndrome, it will be possible to investigate differences in basic neurobiological processes,” Bowman said.

Dyekens thanked the Beasley and Greenfield families and other Nicholas Hobbs Society donors whose contributions support VKC Discovery Grants. Much of this innovative pilot research on Down syndrome, including the work of McGregor, Key, and Bowman, has been funded by Discovery Grants. Data generated help investigators compete successfully for NIH funding of larger projects.

Note: To view the Forum video, visit the VKC website—News & Events—Podcasts & Video. For a 4-page summary VKC Down Syndrome Research, visit Links—Printable Resources and Materials—VKC General Information.

**Director’s Message** from page 1

those are VKC studies. There were nine projects on adults with Down syndrome and aging in which Down syndrome is being used as a comparison to increase understanding of Alzheimer’s disease and dementia in the general population. Ten projects involved Down syndrome as a comparison group in studies aimed at better understandings of other conditions, such as fragile X syndrome, Williams syndrome, or autism spectrum disorders. Thirteen projects focus on the genetics of Down syndrome, many of which use animal or mouse models.

All of these studies are valuable. At the same time, if we are to achieve the research goals of the NIH Roadmap, more research needs to be funded that directly involves children and adults with Down syndrome.

The NIH Roadmap on Down syndrome declared, in essence, that this is a national priority. Funding is one reflection of priorities. Looking at NIH funding over the last year, roughly $1.38 million was devoted to research on autism spectrum disorders and $18 million on Down syndrome. We celebrate that a high level funding is being devoted to autism and other developmental disabilities—it’s important, it’s needed. But more funding for research on Down syndrome also is important and needed.

This national context makes the amount and quality of research being done at the Vanderbilt Kennedy Center all the more precious. Researchers at the Vanderbilt Kennedy Center are particularly fortunate that Nicholas Hobbs Discovery Grants, funded by generous gifts from individuals and families, are making innovative pilot studies possible. These small projects allow our investigators to gather data that are critical to being successful in obtaining NIH grants.

As researchers, we join our voices with those of families to call for a national commitment to the NIH Roadmap for Research on Down Syndrome.


**Dyslexia** from page 1

Rimrodt and Cutting used the DTI technique to map the course of an important white matter bundle in this network and discovered that it ran through a frontal brain region known to be less well-organized in the brains of persons with dyslexia. They also found that fibers in that frontal part of the tract were oriented differently in dyslexia.

“Finding a convergence of MRI evidence that goes beyond identifying a region of the brain that differs in dyslexia to linking that to an identifiable structure and beginning to explore physical characteristics of the region is very exciting,” Rimrodt said. “It brings us a little bit closer to understanding how dyslexia happens.”

Rimrodt is assistant professor of Pediatrics, Division of Developmental Medicine, and faculty director of the new VKC Learning Assessment Clinic. Cutting is Patricia and Rodes Hart Chair at Vanderbilt’s Peabody College and faculty director of the VKC Reading Clinic. The researchers completed the work at the Kennedy Krieger Institute with their colleagues there before moving to Vanderbilt.

The research was funded by the Johns Hopkins School of Medicine General Clinical Research Center, the Kennedy Krieger Institute’s Learning Disability Research Center, the E. M. Kirby Research Center for Functional Brain Imaging, the National Institute for Neurological Disorders, and the Eunice Kennedy Shriver National Institute of Child Health and Human Development.

The goal of this new clinic is to help families sort out their child’s unique pattern of abilities across an array of skills, including motor coordination, handwriting, reading, listening, verbal and visual learning, planning, use of strategies, and working memory.

The Clinic faculty director is Sheryl Rimrodt, M.D., assistant professor of Pediatrics.

The 1-day evaluation is conducted by a developmental pediatrician, a reading and language specialist, and a psychologist experienced in academic assessment. Parents return in 2 weeks for a 1-hour wrap-up discussion with the evaluation team. Parents receive a written report that includes interpretation and recommendations, which can be shared with educators, therapists, tutors, or health professionals.

Fee is paid by family in advance of assessment. Documentation is provided so that parents may submit a claim to health insurer.

For information, contact (615) 936-5118, patty.abernathy@vanderbilt.edu.
Identity, and Disability in Theological Terms.

Beyond Inclusion: Rethinking Normalcy, and included, and as a move toward discarding the shift away from thinking about disability as a body where we find solidarity. It is the beginning of the place of vulnerability as the starting point for discovering what we share and where we find solidarity. It is the beginning of the shift away from thinking about disability as a body gone wrong, as a problem that needs to be fixed and included, and as a move toward discarding the socially constructed view of what is ‘normal.’"

Reynolds visited the VKC in March to speak on “Beyond Inclusion: Rethinking Normalcy, Identity, and Disability in Theological Terms.”

The lecture and visit with local clergy, educators, and families were co-sponsored by the Carpenter Program in Religion, Gender, and Sexuality at Vanderbilt Divinity School (VDS) and Faith for ALL.

Addressing a standing-room-only crowd at VDS, Reynolds argued that well-meaning efforts to include people with disabilities can, in actuality, be exclusionary if they uphold societal constructs of what is and is not normal. He urged a critique of the definition of “normal” in order to uncover aspects of our shared vulnerability, which he proposes as the starting point of true hospitality in faith communities.

To view a video, visit the VKC website—News & Events—Podcasts & Video.

Training Religious Educators

The VKC and the Ann and Monroe Carell Jr. Families First Program held a training session for Sunday School teachers and religious educators at Woodmont Christian Church in April during Autism Awareness Month. Autism educators provided information on disability etiquette, person-first language, and general definitions and characteristics of autism spectrum disorders. The session also included strategies for managing challenging behaviors and ways to modify curricula. Visit the VKC website—Services—Disabilities, Religion and Spirituality to view a PDF file of the PowerPoint presentation.

Congregational Inclusion Conference

The First Annual Congregational Inclusion Conference will be held on October 5 at the Holiday Inn Express in Nashville. Co-sponsored by Faith for ALL, the conference aims to empower congregational leadership, individuals with disabilities and their families, and disability service providers as all work to encourage full inclusion of persons with disabilities in communities of faith. Keynote speakers will include Becca Horstein, Executive Director of the Council for Jews With Special Needs, and Mark Crenshaw, Executive Director of Interfaith Disability Connection. Registration will open in August on the VKC website—Event Calendar and Registration.

The Vanderbilt Kennedy Disabilities, Religion, and Spirituality Program provides disability-related training to current and future religious leaders and educators, and supports individuals with disabilities and their families as they give expression to their religion or spirituality. For information, contact Courtney Taylor, M.Div., coordinator, at courtney.taylor@vanderbilt.edu, (615) 322-5658.
New Leadership BY JAN ROSENERGY

Zachary Warren, Ph.D., has been named as the new director of the Vanderbilt Kennedy Treatment and Research Institute for Autism Spectrum Disorders (TRIAD) and director of Autism Clinical Services for Vanderbilt Pediatrics Division of Developmental Medicine.

Warren joined TRIAD 4 years ago to develop clinical and research structures to better serve individuals with autism spectrum disorders (ASD) and their families.

"Zack has demonstrated time and again how deeply he’s committed to helping children with autism and their families,” said Elisabeth Dykens, Ph.D., director and Annette Schaffer Eskind Professor for the Vanderbilt Kennedy Center Research on Human Development, who announced the appointment. "Zack has been an integral part of TRIAD’s rapid growth and development over the last several years. This appointment will provide for a smooth transition in leadership and will facilitate TRIAD’s rapid development into new areas of service, training, and research."

Zachary Warren, TRIAD director, demonstrates testing for children who may be at risk for an autism spectrum disorder.

In addition to leading Vanderbilt autism evaluation and diagnostic clinics, Warren also will provide oversight of TRIAD Outreach and Training, in coordination with Nicolette Brigham, Ph.D., TRIAD Outreach and Training director.

"TRIAD is a focal point for providing services and training and conducting research on autism,” Warren said. “Our mission is to simultaneously advance services for individuals with autism and their families, while advancing our fundamental knowledge of the disorder, including the most effective treatments. While I’m very proud to have the responsibility of leading TRIAD, I’m also acutely aware of how much needs to be done for the children, families, schools, and communities we serve. I look forward to working with my Vanderbilt colleagues, existing community partners, and hopefully new scientific and clinical partners to advance our mission.”

Research will be a continued emphasis. "Vanderbilt is a local, national, and international leader in autism research,” Warren said, "so one of my priorities will be enhanced collaboration with Vanderbilt colleagues to streamline recruitment for research participation and to move forward with creating a functional regional database that works as a partnership between families and researchers.”

Training to increase the number of health professionals and psychologists prepared to serve families affected by ASD is another high priority. For the past several years, Warren has been involved in statewide initiatives to enhance screening and diagnostic services for young children with ASD within community pediatric practices. His work in this area has received substantial attention on a national level, with many states attempting to replicate training initiatives that TRIAD has advanced in Tennessee.

Warren will work closely with Tyler Reischchiel, M.D., director of the Division of Developmental Medicine.

"Dr. Warren is an excellent psychologist who is dedicated to the care of children with autism spectrum disorders and their families,” Reischchiel said. "I look forward to working with him to improve the clinical services, research opportunities, and outreach supports that we provide to individuals with autism spectrum disorders.”

Warren is assistant professor of Pediatrics and Psychiatry at Vanderbilt. He completed a doctorate in clinical psychology at the University of Miami, a clinical internship at Children’s Hospital Boston/Harvard Medical School, and postdoctoral training in the Division of Genetics and Developmental Pediatrics at Medical University of South Carolina.

Advance in Autism Genetics BY BILL SNYDER

A n international consortium of autism researchers, including two from Vanderbilt University Medical Center, has reported a significant advance in unraveling the genetics of autism spectrum disorders (ASD).

Reporting in the June 10 issue of the journal Nature, the researchers compared the DNA obtained from nearly 1,000 people with ASD to nearly 1,300 matched controls (people without ASD). They found that people with ASD tended to have more rare copy number variations (CNVs), deletions, or duplications of specific sections of DNA that potentially may affect gene expression.

“Our work has identified numerous genes with variants that cause or contribute substantial risk to carriers, but the CNVs identified were very rare,” said James Sutcliffe, Ph.D., associate professor of Molecular Physiology and Biophysics and of Psychiatry at Vanderbilt. “The number of different genes affected is large, and this further underscores the genetic complexity of ASD.”

“The genetics of autism has been very difficult to understand. It is heartening that we are now beginning to make progress, and this will open the door for further research in understanding the genetic underpinnings of autism,” added Jonathan Haines, Ph.D., director of the Vanderbilt Center for Human Genetics Research, who also participated in the research.

Both are VKC investigators.

Autism is a spectrum of developmental disorders characterized by impairments in communication and social interaction, and patterns of repetitive, restricted, and stereotyped behaviors. It occurs in up to one in every 150 children in the United States, and is more common in males.

Most studies to date have focused on common genetic variation, which causes only slight increases in risk. The findings reported in this study add to a growing body of evidence that suggests ASD is caused in part by many rare variants impacting numerous biological pathways. Some of these variants may affect genes involved in transmitting signals among nerve cells in the brain, while others have previously been implicated in intellectual disabilities.

Identification of these rare variants and the biological pathways they may affect was made possible by the Autism Genome Project (www.autismgenome.org), which recruited a large number of research participants throughout the world.

The project is opening up new areas of research and new targets for genetic testing, the researchers concluded. Potentially these studies could lead to the development of new treatments for ASD.
that determines how much oxidative and energetic stress a brain cell can endure. “The study shows that p66shc is really a triple threat, by altering energy, free radicals, and increasing protection. It also brings us one step closer to our goal, which is to design therapies around how a cell would protect itself. We know that therapeutically the closer we stay to insulins that would normally kill them. The research team found that a protein called p66shc acts as an essential gatekeeper molecule that determines how much oxidative and energetic stress a brain cell can endure.

Stoke is the third leading cause of death in the U.S. and a rampant problem in the Southeast.

McLaughlin credits the success of this work to the diverse and committed team members in Neurology, Pharmacology, and Medicine who conducted the studies. Authors were J. E. Brown, S. L. H. Zeiger, J. C. Hettinger, J. D. Brooks, B. Holt, J. D. Morrow, E. S. Music, G. Milne, and B. McLaughlin.

Research Interests
Neural bases of multisensory processes; development and plasticity in sensory and multisensory systems; developmental disabilities

Principal Investigator
• Development of Multisensory Cortex: Role of Experience, National Institute of Mental Health and ARRA Supplement
• Multisensory Processing in Autism Spectrum Disorders, Marino Autism Research Institute
• Evaluation of Sensory Integration Treatment in Autism Spectrum Disorders, National Institute of Deafness and Other Communication Disorders
• Multisensory Processing Alterations in Schizophrenia, NARSAD
• Training in Fundamental Neuroscience, National Institute of Mental Health
• Research Alliance for Training in Neuroscience, National Institute of Neurological Disorders and Stroke

Honors and Awards
• James P. Carnell Award for Outstanding Graduate Teaching, Temple University, 1989
• National Research Service Award, 1990-1993
• Fellow, Winter Conference on Brain Research, 1995-1997
• Fellow, European Brain Research Organization, 1997
• Outstanding Young Investigator in the Basic Sciences, Wake Forest University, 1997
• Faculty Excellence Award, Wake Forest University, 2003

Selected Publications

and Currey Ingram Chair in Special Education, were selected as AERA (American Educational Research Association) Fellows “in recognition of their exceptional scientific or scholarly contributions to education research or significant contributions to the field through the development of research opportunities and settings.”

Elisabeth Dykens, Ph.D., Annette Schaffer Eskind Professor for Vanderbilt Kennedy Center for Research on Human Development and professor of Psychology, received the CABLE Power of Inclusion Award “in recognition of exceptional leadership to promote diversity and inclusion in the community.” CABLE is Tennessee’s largest and most established network of diverse professionals committed to connecting women and opportunity.

Lynn Fuchs, Ph.D., and Doug Fuchs, Ph.D., professors and Nicholas Hobbs Chairs in Special Education and Human Development, were included in Fortune Magazine’s list of Revolutionary Educators—“14 visionaries who are shaking up how we educate our most disadvantaged kids.”

Stephen Graham, Ed.D., professor and Currey Ingram Chair in Special Education, is a panel member (through 2012) on the National Advisory Panel for the National Writing Project’s Early History Project.

Megan Hart, education and training services coordinator for Tennessee Disability Pathfinder, has been appointed to the Tennessee Technology Access Program’s Statewide Advisory Council.

Robert Macdonald, Ph.D., M.D., professor and chair of Neurology, has been elected president of the American Neurological Association.

Ralph Ohde, Ph.D., professor of Hearing and Speech Sciences, is Vanderbilt School of Medicine’s 2010 recipient of the Robert D. Collins for Excellence in Teaching Award.

Tyler Reimischel, M.D., assistant professor of Pediatrics and Neurology, director of the Division of Developmental Medicine, and associate director of the MIND (LEND) Training Program, has been elected to the Academy of Excellence in Teaching.

Jessica Solomon, an undergraduate student in Special Education at Peabody College, received the Founder’s Medal at Vanderbilt’s graduation ceremony. The Founder’s Medal is given to one student from each of the colleges at Vanderbilt. Selection is based on academic achievement, service work, and future plans. Solomon has performed service work for individuals with disabilities through the Vanderbilt Best Buddies chapter and the VKC UCEDD.

The Interagency Autism Coordinating Committee (IACC) and Office of Autism Research Coordination announced the 2009 IACC Summary of Advances in Autism Spectrum Disorder Research. The IACC Summary of Advances is a collection of brief summaries of the 20 research articles that the IACC regarded as the most significant contributions to autism biomedical and services research in 2009. James Sutcliffe, Ph.D., associate professor of Molecular Physiology and Biophysics; Sarika Peters, Ph.D., assistant professor of Pediatrics; and Jonathan Haines, Ph.D., T. H. Morgan Professor of Human Genetics and director of the Center for Human Genetics Research, were co-authors on one or more articles.

Terri Urbano, Ph.D., M.P.H., R.N., professor of Clinical Pediatrics, director of VKC UCEDD Training and the MIND (LEND) Training Programs, will serve on a grant review for the LEND Planning Grants, to be submitted to states preparing for a LEND competition.

Jeremy Veenstra-VanderWeele, M.D., assistant professor of Psychiatry, has been selected for the International Association of Child and Adolescent Psychiatry and Allied Professions (IACAPAP) Donald J. Cohen Fellowship, which will provide support to attend and present research results at the annual IACAPAP International Congress in Beijing, China.
Empowering Families With Young Children in Transition  

BY COURTNEY TAYLOR

When children with disabilities leave early intervention services at 3 years of age and enter public school special education services, it can be a major transition for which families may not be prepared. They may not know what will happen, why things will happen, who does what, and what their roles will be.

To resolve some of the mystery, the Susan Gray School (SGS) now offers the training series “Knowledge Is Power: Keys to Successful Education for Children with Disabilities.” The series educates families on this early transition period. It is made possible by a Morris Family Foundation grant.

The series is facilitated by Wendy Tucker, J.D., an attorney well-versed in special education law, and parents of a child with a disability who has already made the transition from SGS into the school system. Tucker had been working with SGS families who had legal questions for some time when she was approached to lead the series.

“I was honored to be asked to be a part of such a useful and important project,” Tucker said. “I think parents of children with disabilities need to know that they have a lot of power when it comes to their children’s education. When you know your rights, you walk into transition and IEP meetings feeling empowered. These relationships do not have to be adversarial. There can be good communication, and it starts with knowing what your rights are. It benefits everyone if parents know what their rights are, what the law says, and how the system is supposed to work.”

Response to May Floods

Following the May floods in Middle Tennessee, the VKC UCEDD and Tennessee Disability Pathfinder compiled and posted flood recovery information for individuals with disabilities and their families. The Pathfinder webpage quickly became a hub of information collection and sharing used by disability agencies across Tennessee. See www.familypathfinder.org.

The VKC held a Community Forum on May 26 to help individuals with disabilities and their families cope with the aftermath of the floods. Family members shared their experience of coping with the loss of their home during tornado. A panel of health care professionals presented resources and tips for coping with stress. The event was co-sponsored by the Ann and Monroe Carell Jr. Children’s Hospital at Vanderbilt and the Down Syndrome Association of Middle Tennessee.

To view a video or to download free resources, see the VKC website (www.kc.vanderbilt.edu) –News and Events.

The content of the training series was gathered from a parent survey and is divided into six modules. The modules focus on what to expect in transition meetings, in evaluation processes, and in IEP (Individualized Education Program) meetings. Modules also cover education beyond preschool, educational rights under the law, and long-term planning issues.

While there is an informational lecture-like portion of the training, parents have been especially excited about Tucker’s incorporation of role playing scenarios, which were drawn from her background in theater.

“The best thing for me is learning through the scenarios,” said Heather Satterfield, a parent participant. “We are thrust into a situation that might actually happen, and we learn about what we might say in return. You can give us a booklet and a PowerPoint, but I am given so much of that stuff that it all starts to run together. The scenarios allow us to practice demanding our rights.”

Tucker says the role-playing gives parents an opportunity to be in the “hot seat.” It helps them to be better prepared. Parents have so much to learn about when they find out their child has a disability. Then they are dealing with medical issues, early intervention, their emotions, and explaining things to their families, so to walk into this transition from early intervention feeling like they don’t have any power is unfortunate.

“I hope that parents become empowered from participation in these exercises,” said Tucker. “I think that active participation is where you learn. In this case, it is where you learn that your child has a right to a free and appropriate public education.”

Heather Satterfield certainly feels a large sense of empowerment from the training. “I like the title of the series, ‘Knowledge is Power,’ because I want power. That is my right. I’m the mother. That is my kid. I don’t have another child who has gone through the school system, so going through this training is a chance for me to get a step ahead of the system. This is a way for me to go in and say this is how it’s going to be. This is who Lillian is, and this is where Lillian is going to go. It gives me control of an out-of-control situation.”

For information about future scheduling of the series, contact (615) 322-8200.
Self-Determination Through Art and Music  

BY COURTNEY TAYLOR

In addition to taking classes, developing peer relationships, and working in employment-focused internships, the first group of Next Step students at Vanderbilt had opportunities to express their creativity. Collaborative projects with Sarratt Art Studios and with the Country Music Hall of Fame® and Museum Words & Music Program encouraged students to ask questions about themselves and to tell stories that, in effect, proved to be powerful self-determination tools. Self-determination involves knowing one’s own strengths and challenges, as well as having the knowledge and skills needed for adult living.

Reflections in Collage, Reflections in College

Next Step students worked with Elizabeth Garlington, Sarratt Art Studios artist, to create three collages over three sessions. Garlington chose collage as a means of self-expression because she has found it to be a fail-proof genre in which nonartists can comfortably create. The pieces were then combined to create a holistic picture of the journeys the students embarked upon during their first semester at college.

The first in the series displays fragments representing the students’ lives prior to college. Pictures of themselves and their families, past events, hobbies, and events that brought the students to Vanderbilt adorn the canvas. The second collage explores the students’ lives at college. Course schedules and descriptions, stubs from basketball games, and ice cream receipts are sprinkled throughout. The third collage focuses on the future. The students explore their hopes and dreams for careers, families, and living situations.

The project was made possible by Sarratt Art Studios and a gift from Mary Jane Swaney, said Elise McMillan, Next Step faculty director. “It was amazing to see the evolution of the students throughout the process of creating these collages,” said Tammy Day, Next Step program director. “During the first session, there was such an attitude of ‘Am I doing this right?’ I would watch them looking around at everybody to measure their choices. By the time they were creating their last collage, everyone was so much more certain about what they wanted on the collage, where they wanted items to be placed, and what looked good. They were making choices with certainty, and that was the goal of the project—self-exploration and self-determination. We saw that.”

The travelling exhibit, Reflections in Collage, Reflections in College, will be shown at the Sarratt Student Center (May 24-July 30), the University School of Nashville (August 16-October 10), the Vanderbilt Student Life Center (November 1-December 17), and the Vanderbilt Kennedy Center (January 10-April 1).

Next Step Words and Music

Participation in the Country Music Hall of Fame® and Museum Words & Music Program gave Next Step students a chance to explore themselves as burgeoning songwriters. They participated in a 6-week course in songwriting basics led by seasoned songwriters Tammy Vice and Trent Jeffcoat. At the end of the process, Jeffcoat and Vice put the students’ words to music, and the course concluded with a tour of the Country Music Hall of Fame® and an opportunity to hear their songs performed live. “The students are so proud,” said Day. “They should be! Both the songs and the collages are wonderful expressions of who they are. The projects gave them such amazing opportunities to value themselves as capable people.”

So many people with disabilities don’t get enough chances to do that—to see that they can produce things of quality that people will respond to and enjoy. It is wonderful to watch these students noticing themselves. They are noticing what choices they are making, noticing the competence that they have, and noticing what future planning they are thinking about as they are growing into themselves on campus. Art can be a wonderful tool to aid in this process of noticing. If people take the time to listen to their songs and to look at the collages, I mean really look, they will get to know a lot about these students.”

Stanwood Honored for Volunteer Efforts

BY AMY POTTIER

Tennessee is known as “The Volunteer State”—and the VKC has an exceptional volunteer in Gregg Stanwood, Ph.D. He was recently honored for his hours of volunteer work for the flood relief coordinated by Hands On Nashville. Mayor Karl Dean’s Office of Recovery selected Stanwood and two other “regular citizens having done extraordinary things” for flood recovery. On June 10, the Mayor unveiled a sculpture honoring Nashville’s grassroots efforts during the recovery and the volunteers who made exceptional contributions. Stanwood is assistant professor of Pharmacology and a Vanderbilt Kennedy Center investigator.
Dollar General—“Saving Lives” by Supporting Literacy

BY JAN ROSENERGY

Dominique Miller is a proud mom—proud of her daughter McKenzie, a bright, social, fun child who has worked so hard to learn to read. Miller, who shared her story at a VKC Lunch and Learn, was aware early on of McKenzie’s difficulties and worked intensively with her daughter at home and with her daughter’s teachers. “Still, she could not read,” Miller said.

Then Miller heard about the Reading Clinic. McKenzie, now 10, began at the Reading Clinic when she was 8—and that Christmas asked her mom to buy her a book. She’s now become a reader.

Miller summarized their experience: “This Reading Clinic is a life saver. Thank you, thank you, thank you.”

Miller’s thank you is not only to the Clinic’s director and the Peabody students who have tutored her daughter. This thank you is for the donors who provide scholarship support for McKenzie and so many other students.

Dollar General Gift Helps Many

Dollar General Corporation generously has awarded a $50,000 grant from the Dollar General Literacy Foundation to provide scholarships for the Reading Clinic so that no family is turned away because of financial limitations.

Based in Tennessee, Dollar General is the nation’s largest small-box discount retailer. They build and operate convenient-sized stores to deliver everyday low prices on products that their customers use daily.

Literacy is such a high priority for Dollar General that they founded the Dollar General Literacy Foundation, recognizing that “Literacy is the foundation for improving the quality of life for many Americans.”

“We are enormously appreciative of Dollar General for the difference that this grant is making in the lives of the many students served by our Reading Clinic—and their parents share this deep gratitude,” said Laurie Cutting, Ph.D., faculty director of the Reading Clinic.

Spotlight: “A Big Fan” Pat Wallace

BY COURTNEY TAYLOR

The playful nature of Vanderbilt Kennedy Center Leadership Council member Pat Wallace is contagious. One feels energized just being around her. Though she says that no one would ever suspect she held a lead role in a high school production of The Pirates of Penzance, it is not at all difficult to believe it. Her personality sparkles and commands attention. She is vivacious, dynamic, and engaging. She has eight grandchildren!

Wallace moved to Nashville in 1962 as a new bride. She met her husband, the late Jodie Wallace, at Duke University, where she studied American history and psychology. In Nashville, she taught history at both the elementary and the high school levels. She and Jodie would go on to have three children—Barbara, Paul, and Tim—in only 3 years.

“We all grew up together,” remembered Wallace. “I’m serious. Our family grew up at the same time. People would always ask my husband how he got to be so helpful around the children, and he would tell them that once the third one had come along, I had run out of arms so he had to pitch in.”

In the 1970s, Wallace volunteered for the Regional Intervention Program (RIP), which was then housed on the ground floor of the Vanderbilt Kennedy Center/MRL Building where the Susan Gray School is today. RIP teaches behavior management strategies to parents through hands-on experience with their own children and the children of other families. Wallace served on the Board for many years after the program moved off-campus and began its statewide expansion.

In 1990, Wallace served as director of Alumni and Development for Peabody College, which then included the Vanderbilt Kennedy Center. Wallace remembers feeling drawn to the people and to the mission of the Center.

“It was the Decade of the Brain,” said Wallace. “Researchers who specialized in neuroscience and brain research were flocking to the Vanderbilt Kennedy Center. Brain research would become a very important topic for our family.”

Wallace’s granddaughter developed a rare autoimmune disorder called Hashimoto’s encephalopathy. The disorder involves neurological inflammation and seizures, but has been well managed due to the remarkable care of doctors from Vanderbilt Medical Center and the Monroee Carell Jr. Children’s Hospital at Vanderbilt. Wallace identifies the Vanderbilt Kennedy Center’s dedication to brain research as the reason she joined the Leadership Council and as the motivation for being an ambassador for the Center.

Wallace also raises awareness for at-risk youth through her work with Youth Villages, and she is an advocate for persons who are homeless through the organization Matthew: 25. She is on the Board of the Other Lifelong Learning Institute at Vanderbilt.

Wallace serves on her church’s outreach committee. She is a member of two book clubs, is in an investment club, takes bridge lessons, and stays active by walking, doing water aerobics, and playing golf.

It is evident that retirement has not slowed Wallace down at all. She regularly attends Leadership Council “Lunch and Learn” meetings and has served on the Council’s Community Outreach and Music Committees. She says she is a “big fan” of the Vanderbilt Kennedy Center and that she is particularly drawn to its mission to move from the lab into the community. She also says she believes in the good hearts and intentions behind the work of the people at the Center.

The same can be said of her. Pat Wallace: We are a big fan of you.
A "Lunch and Learn" event in May gave community members an opportunity to hear first-hand about services, training, and research activities at the Vanderbilt Kennedy Center that are improving the lives of individuals with disabilities and their families.

Attendees were invited by members of the VKC Leadership Council. Leadership Council members are community champions on behalf of the Vanderbilt Kennedy Center and help connect the Center to community needs and concerns.

Dominique Miller shared how she found help for her daughter at the Reading Clinic. Families whose young children are on the autism spectrum are finding help through the Ann and Monroe Carell Jr. Families First Workshops. Lisa Wallace, M.S., CCC- SL P, described how these free Saturday and evening workshops address the practical issues that families face.

Vanderbilt Ambassador Rosie Landrau interviewed Edward Nesbitt, Next Step at Vanderbilt Class of 2011, about his first semester in this innovative program for students with intellectual disabilities. Edward’s work as an intern in the offices of Development and Alumni Relations was appreciated by his co-workers.

Gregg Stanwood, Ph.D., assistant professor of Pharmacology, explained how the VKC helps form networks and collaborations between basic and clinical scientists. He described how basic scientists studying the brain need to work at multiple levels of complexity, and how the VKC helps researchers translate their findings into new treatments.

For information on attending a Lunch and Learn, contact (615) 343-4176, laura.pevahouse@vanderbilt.edu.
On June 5, celebrities, athletes, individuals with intellectual disabilities, and others came together on bike and on foot to make a difference and change lives. The event featured cycling, running, walking, a lobster bake, a private concert, and a beachside celebration. Participants raised funds for Best Buddies, which is dedicated to enhancing the lives of individuals with intellectual disabilities by providing opportunities for one-on-one friendships and integrated employment. Alice Kim, Next Step program coordinator, and Josh Putnam represented the VKC and the Vanderbilt Chapter of Best Buddies.
CALENDAR OF EVENTS | AUGUST-OCTOBER 2010

■ ANN AND MONROE CARELL JR. FAMILIES FIRST WORKSHOPS
Serving parents of children, ages 2-5, diagnosed with an autism spectrum disorder. Fall Schedule to be announced. Register at kc.vanderbilt.edu/registration
Information (615) 322-6027 families.first@vanderbilt.edu
Free monthly Saturday workshops, 8:15 a.m.-12 p.m.
• AUGUST 14*
Toilet Training: An Introduction to The Rapid Method

■ SEPTEMBER 15
Neuroscience Graduate Program Seminar Series
Synaptic and Circuitry Mechanisms of Compulsive/Repetitive Behavior
Guoping Feng, Ph.D., Associate Professor of Neurobiology, Duke University
Co-sponsor Vanderbilt Brain Institute
Wednesday 4:10 p.m. Room 1220 MRB III Lecture Hall

■ SEPTEMBER 23*
Lectures on Development and Developmental Disabilities
Developmental Factors Underlying the Risk to Develop Anxiety and Depression
Ned H. Kalin, M.D., Hedberg Professor and Chair of Psychiatry, University of Wisconsin-Madison
Thursday 4:10 p.m.

■ OCTOBER 5
First Annual Congregational Inclusion Conference
Holiday Inn Express 921 Broadway, Nashville
Register at kc.vanderbilt.edu/registration
Tuesday 9 a.m.-4 p.m. (tentative)

■ OCTOBER 20
Neuroscience Graduate Program Seminar Series
Optimizing Behavior in Variable and Competitive Environments
Alla Y. Karpova, Ph.D., Janelia Farm Research Campus Group Leader, Howard Hughes Medical Institute
Co-sponsor Vanderbilt Brain Institute
Wednesday 4:10 p.m. Room 1220 MRB III Lecture Hall

■ OCTOBER 21*
Lectures on Development and Developmental Disabilities
Insights From Motor Control in Autism: Neurologic Basis and Therapeutic Intervention
Stewart H. Mostofsky, M.D., Associate Professor of Neurology and Psychiatry, Director of Laboratory for Neurocognitive and Imaging Research, Medical Director of the Center for Autism and Related Disorders, Kennedy Krieger Institute, Johns Hopkins University School of Medicine
Thursday 4:10 p.m.

■ TRIAD SCHOOL-AGE SERVICES
With the Tennessee Department of Education, TRIAD offers free autism-specific workshops for parents, school personnel, and the community in locations across the state.
Information and registration, contact Linda.Copas@tn.gov, (615) 741-7790
See also www.state.tn.us/education/speced/announcements.shtml
• AUGUST 25-26, SEPTEMBER 8-9, SEPTEMBER 15-16
Para-Educator Workshop
(Knoxville, Nashville, Jackson)
• SEPTEMBER 8-9, SEPTEMBER 30-OCTOBER 1, OCTOBER 26-27
Administrator Academy
(Knoxville, Nashville, Jackson)

Unless otherwise noted, events are free and open to the public. Events are subject to change. Please check the website calendar at kc.vanderbilt.edu or contact (615) 322-8620 or toll-free (1-866) 936-VUKC [8852].

Please keep this calendar and check the Event Calendar on the VKC website for updates. If you wish to receive event announcements by email, send your email address to amy.pottier@vanderbilt.edu.

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

*Event will be held in Room 241 Vanderbilt Kennedy Center/MRL Building.
**CALANDER OF EVENTS | AUGUST-OCTOBER 2010**

- **ARTS AND DISABILITIES***
  Vanderbilt Kennedy Center Exhibits
  Monday-Friday
  7:30 a.m.-5:30 p.m., Lobby
  Information contact (615) 343-7046
  • APRIL 5-AUGUST 30, 2010
  GuiltArt by 2009 VKC
  Monday-Friday
  7:30 a.m.-5:30 p.m., Lobby
  Information contact (615) 343-7046
  • APRIL 5-AUGUST 30, 2010
  GuiltArt by 2009 VKC
  Monday-Friday
  7:30 a.m.-5:30 p.m., Lobby
  Information contact (615) 343-7046
  • SEPTEMBER 6, 2010-
  DECEMBER 15, 2010
  Creative Expressions XVI
  Mayor's Advisory Committee
  for People with Disabilities
  reception in October. Details TBA

- **BEHAVIOR ANALYSIS CLINIC**
  For families of children, 3-18, with
  developmental disabilities
  Contact (615) 322-9007
  n.houchins-juarez@vanderbilt.edu

- **BEHAVIORAL HEALTH AND INTELLECTUAL DISABILITIES CLINIC**
  For individuals with intellectual
  disabilities, ages 17 and up, with
  behavioral and mental health
  challenges
  Contact (615) 343-9710
  behavioralhealth@vanderbilt.edu

- **READING CLINIC**
  Assessment and tutoring for students
  through middle school
  Contact (615) 936-5118
  patty.abernathy@vanderbilt.edu

- **SIBLING SUPPORTS**
  For children, teens, and adults who
  have a sibling with a disability, chronic
  health care issue, or mental health
  concern
  Contact (615) 343-0545
  ashley.coulter@vanderbilt.edu

- **VOLUNTEER ADVOCACY PROJECT**
  Training program for persons willing
  to become special education
  advocates working with families
  Contact (615) 585-1420
  meghan.m.burke@vanderbilt.edu
  • SEPTEMBER 11 & 18,
  OCTOBER 2, 16, & 30,
  NOVEMBER 13
  Fall 2010 Training
  At Vanderbilt University and by
  video conference in Johnson City,
  Martin, Chattanooga, Memphis,
  and Knoxville

- **TAKE PART IN RESEARCH**
  Vanderbilt Kennedy Center
  Research Studies
  For children and adults, with and
  without disabilities
  Lynnette Henderson (615) 936-0448
  Toll-free (1-866) 936-VUKC [8852]
  • Research Family Partners
  kc.vanderbilt.edu/rfp
  Register and be notified of
  research studies
  • StudyFinder
  kc.vanderbilt.edu/studyfinder
  View lists of studies, criteria, and
  contact information
  • See also VUMC Clinical Trials
  www.vanderbiltheath.com/
  clinicaltrials

- **TENNESSEE DISABILITY PATHFINDER**
  Helpline, Web-Searchable Database
  with Calendar and Resource Library,
  Print Resources
  www.familypathfinder.org
  English (615) 322-8529
  Español (615) 479-9568
  Toll-free (1-800) 640-INFO [4636]
  tnpathfinder@vanderbilt.edu
  Project of VKC UCEDD and
  Tennessee Council on Developmental
  Disabilities

- **COMMUNITY EVENTS**
  • AUGUST 7
  2010 Walk Now for Autism Speaks
  Tennessee Kickoff
  Saturday 10 a.m.-12 p.m.
  Embassy Suites Nashville South -
  Cool Springs, 820 Crescent Centre
  Drive, Franklin
  • SEPTEMBER 11
  Walk Now for Autism Speaks:
  Tennessee
  Bicentennial Capitol Mall State
  Park, Nashville
  www.walknowforautismspeaks.org

- **ASMT EVENTS**
  Autism Society of Middle Tennessee
  www.tnautism.org
  ASMT event information
  (615) 385-2077
  Registration is requested for all events
  ASMT members free; nonmembers
  $5/family
  • AUGUST 26, SEPTEMBER 23,
  OCTOBER 28*
  Autism Education Workshops
  Child care available with advance
  request
  Thursday 6:30-8:30 p.m.
  • SEPTEMBER 16*
  Autism Orientation
  An informational session on
  autism and other pervasive
  developmental disorders
  Child care available with advance
  request
  Thursday 6:30-8:30 p.m.

- **DSAMT EVENTS**
  Down Syndrome Association of
  Middle Tennessee
  www.dsamt.org
  DSAMT event information
  (615) 386-9002
  • AUGUST 19, SEPTEMBER 16,
  OCTOBER 21
  DADS
  Monthly gathering for fathers
  6:30-8 p.m.
  • AUGUST 28
  Sip and Savor at the Kitchen
  6:30-9:30 p.m.
  The Sound Kitchen, Franklin
  • OCTOBER 6
  Caleb Thompson Memorial Golf
  Tournament
  8 a.m.-1 p.m.
  Vanderbilt Legends Club, Franklin
  • OCTOBER 23
  Nashville Buddy Walk
  Centennial Park

- **MARCH 2-4, 2011**
  44th Annual Gatlinburg
  Conference on Research and Theory in
  Intellectual and Developmental
  Disabilities
  Adolescence and Developmental Disabilities:
  From Neurobiology to Interventions
  Hotel Contessa
  San Antonio, Texas
  Check website
  kc.vanderbilt.edu/Gatlinburg
  frequently for updates,
  including Call for Papers