



4 University Center for Excellence—Overweight Prevention



5 TRIAD—Autism Research Face Processing—An Early Marker?



7 Helping Children With Autism to Sleep Better

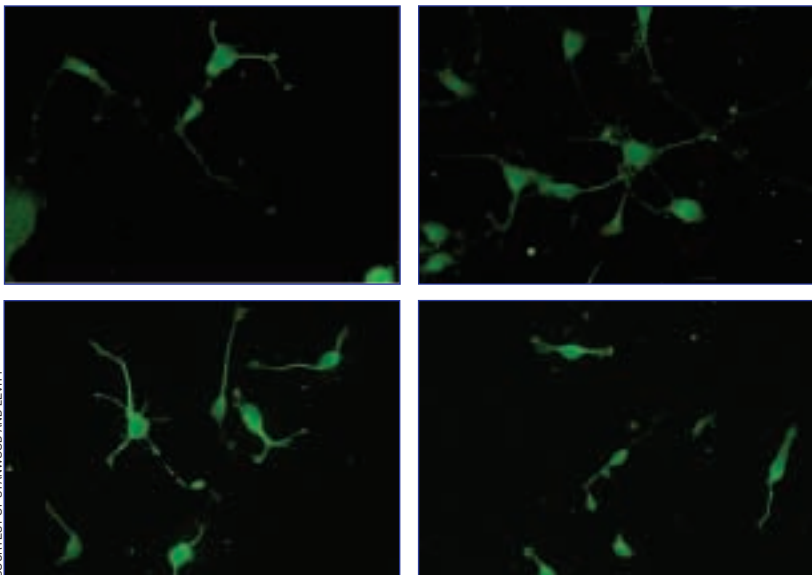


9 Families Plan for the Future

Discovery

Cocaine Exposure's Lasting Effects

By Melissa Marino



Four images illustrate that prenatal cocaine exposure affects the growth of neurons differently in different parts of the brain. The images on the right show cultured neurons that receive a prenatal exposure to cocaine while those on the left were unexposed. The top row of images show neurons taken from the frontal cortex while those on the bottom row show neurons taken from the striatum, a region of the brain that controls movement. Cocaine exposure stimulates cortical neurons to produce dendrites that are much longer than normal while it causes striatal neurons to produce dendrites that are shorter and stubbier than normal.

Although the “crack baby” hysteria of the 1980s was fed by a number of exaggerated claims of brain damage, there is little doubt that even low levels of cocaine use during pregnancy can cause subtle but disabling cognitive impairments, including attention deficits, learning disabilities, and emotional problems.

Exactly how cocaine exposure causes these long-term behavioral and neurological problems remains unclear. But now a study by Vanderbilt Kennedy Center investigators points to an unexpected form of brain disruption.

Writing in the January issue of the *Journal of Neuroscience*, Gregg Stanwood, Ph.D., and Pat Levitt, Ph.D., report that prenatal cocaine exposure in rabbits causes a long-lasting displacement of dopamine receptors in certain brain cells. The receptors themselves do not appear to be damaged, but the numbers that extend to the surface in neuron synapses are dramatically reduced, which interferes with the brain's ability to function normally.

Continued on page 2

Genetic Engineering and Angelman Syndrome

By Melanie Marino

Children with Angelman syndrome are often seen laughing and smiling, but this cheerful demeanor masks serious neurological problems—mental retardation, movement problems and seizures. New research in mice, however, suggests that many of these deficits could be alleviated.

Edwin Weeber, Ph.D., and colleagues reversed the neurological deficits in a mouse model of Angelman syndrome by preventing the inhibition of CaMKII, an enzyme highly expressed in brain regions affected by Angelman syndrome.

The results, which appeared in the March 2007 issue of *Nature Neuroscience*, reveal an important part of the mechanism underlying the condition and point to potential therapeutic targets for treating these symptoms.

Continued on page 3



Edwin Weeber is studying Angelman syndrome.

Director's Message

A Balancing Act



Pat Levitt, Ph.D.

The pressures of trying to put into place the best interventions that are available now, balanced with the pull that researchers feel to spend their efforts on making fundamental research discoveries that will better inform our treatment strategies, is an immense challenge to all of us in the field of developmental disabilities.

While I have recognized this as an ongoing issue, it became magnified even more at a recent meeting that I attended at the Institute of Medicine in Washington, D.C. There, scientists, policy makers and family advocates gathered to hear the latest evidence for the role of environmental factors in causing autism spectrum disorder.

Continued on page 3

Cocaine Exposure's Lasting Effects from page 1

Though this effect has not yet been assessed in children who were cocaine-exposed prenatally, the findings give researchers a place to start looking.

"The hysteria surrounding the 'crack baby' was sort of overblown," said Stanwood, research assistant professor of pharmacology and lead author on the study.

Incredibly high levels of cocaine—usually coupled with the abuse of other drugs—can lead to premature labor, preterm birth, and low birth weight, Stanwood said.

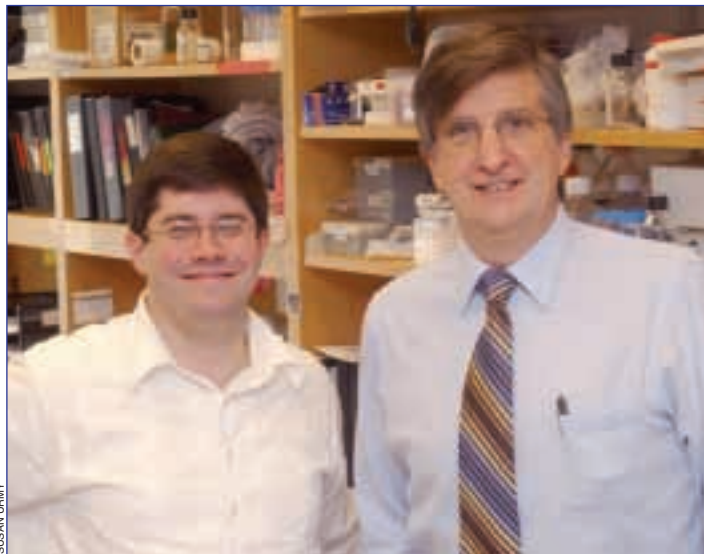
"But in women who have abused low 'recreational' doses of cocaine, it is actually very hard to distinguish those children at birth from children born to anyone else," he said. "However, as those children age, they do develop deficits in their cognitive and emotional development."

These children often exhibit attention and arousal problems, similar to children with attention deficit hyperactivity disorder (ADHD). However, the standard treatments for ADHD—Ritalin and other stimulants—may not be as effective in these children.

Studying the effects of prenatal cocaine exposure on the developing brain is difficult in human populations because cocaine abusers often abuse other drugs. Animal models can help determine how prenatal cocaine exposure might influence brain development to cause subtle cognitive and emotional impairments.

"We thought that it was important to set up an animal model that recapitulates a key feature of human abuse—that being intravenous exposure to low doses of cocaine," Stanwood said.

Stanwood and Levitt, Annette Schaffer Eskin, professor of pharmacology, and Vanderbilt Kennedy Center director, have established such a



Gregg Stanwood and Pat Levitt are studying the effects of prenatal cocaine exposure on the developing brain.

model in rabbits. They found that exposure to low levels of intravenous cocaine during a very short window of time during gestation—equivalent to the late first trimester and early second trimester in humans—caused specific alterations in brain circuits that use the neurotransmitter dopamine. Additionally, these cocaine-exposed offspring showed attention problems as well as insensitivity to stimulants like amphetamine, suggesting that cocaine exposure had altered the development of the dopamine pathways in the brain.

"In collaboration with Dr. Eitan Friedman of the City University of New York, we had previously shown a decrease in signaling of a particular receptor protein, the dopamine D1 receptor," Stanwood said. "We know that this receptor is involved in regulating the formation of cortical circuitry. It's also involved in the behavioral effects of amphetamines and cocaine. The current study was an attempt to look at the mechanism of this decrease in D1 receptor signaling."

In the current study, Stanwood examined the levels of D1 receptor in brain cells taken from "teenage" rabbits that were exposed to cocaine

during that short, sensitive prenatal period. He found that cocaine exposure did not alter the total amount of D1 receptor produced in the brain. However, there was a dramatic alteration in the location of the protein within the cell.

"It's not where it should be," he said. D1 receptors normally are found at the cell surface, but neurons from the cocaine-exposed animals showed the receptor was predominantly sequestered inside the cells.

"The fascinating thing is that this effect appears permanent," said Stanwood. This implies that cocaine exposure during a brief, sensitive period of neural development can lead to long-lasting effects at the cellular level.

This change also altered the growth of neuronal processes, suggesting that the altered D1 receptor trafficking may underlie the changes in neuronal architecture and behavior that Stanwood and others have previously observed.

What remains to be determined, he cautioned, is whether D1 receptor localization is affected in humans exposed to cocaine prenatally. If found in humans, "it gives us a new way to think about helping those children as they continue to mature," Stanwood said.

Because cocaine exposure seems to alter the distribution of the D1 receptor, Stanwood suggested that researchers might find a way to "steer" the receptor into the correct cellular location. That could provide new avenues for treating the attention problems in cocaine-exposed children, as well as in children with stimulant-resistant ADHD.

"Neither we nor anyone else has yet identified whether this mechanism occurs in the human population," Stanwood said, "so that is a critical next step."

Reprinted *The Reporter*, Vanderbilt Medical Center, Jan. 12, 2007, and *Exploration*, Feb. 9, 2007. ●

Primer

Angelman Syndrome

Angelman syndrome is a genetic disorder that causes developmental delay and neurological problems.

Infants with Angelman syndrome appear typical at birth but often have feeding problems in the first months of life and exhibit noticeable developmental delays by 6 to 12 months. Seizures often begin between 2 and 3 years of age. Speech impairment is pronounced, with little or no use of words.

Individuals with this syndrome often display hyperactivity, small head size, sleep disorders, and movement and balance disorders that can cause severe functional impairments. Many also have autistic behavior patterns, and almost all have an

apparent happy demeanor. Persons with this syndrome have typical life spans.

There is no specific therapy for Angelman syndrome. Medical therapy for seizures is usually necessary. Physical and occupational therapies, community therapy, and behavioral therapies are important in enhancing development. Early diagnosis and tailored interventions and therapies help improve quality of life. Source: National Institute of Neurological Disorders and Stroke

Internet Resources

- **Angelman Syndrome Foundation**
www.angelman.org
- **NINDS Angelman Syndrome Information**
www.ninds.nih.gov/disorders/angelman/angelman.htm
- **The Arc of the United States**
www.thearc.org
- **Epilepsy Foundation**
www.epilepsyfoundation.org

- **United Cerebral Palsy**
www.ucp.org

Vanderbilt Kennedy Center Resources

- **ABC Study for Angelman Syndrome**
kc.vanderbilt.edu/kennedy/research/angelman.html
- **SibSaturdays**
kc.vanderbilt.edu/kennedy/community/sibshop.html
- **StudyFinder**
kc.vanderbilt.edu/studyfinder
- **Tennessee Disability Pathfinder**
www.familypathfinder.org

Vanderbilt University Resources

- **Center for Child Development/Pediatrics**
www.VanderbiltChildDevelopment.us
- **Genetics Clinic**
http://www.vanderbiltchildrens.com/interior.php?mid=178
- **Pediatric Neurology Clinics**
http://www.vanderbiltchildrens.com/interior.php?mid=595
- **Vanderbilt Bill Wilkerson Center**
www.VanderbiltBillWilkersonCenter.com ●

Genetic Engineering

from page 1

Angelman syndrome, which affects approximately one in 15,000 children, is a debilitating neurological disorder characterized by mental retardation, severely limited speech, and movement and balance problems.

In 1997, researchers determined that Angelman syndrome was caused by a mutation in a single gene, called UBE3A. They subsequently developed a mouse model of Angelman syndrome by mutating this gene.

The finding was baffling, said Weeber, because UBE3A is a “housekeeping” gene, meaning that it broadly regulates cellular processes not particularly specific for any of the neurological deficits seen in these children. Specifically, the protein encoded by UBE3A “tags” other proteins for degradation by the cellular “garbage disposal,” the proteasome.

“The most difficult thing to rationalize was that this housekeeping gene—which nobody thought did anything—caused severe mental retardation,” said Weeber, an assistant professor of molecular physiology and biophysics and pharmacology, Vanderbilt Kennedy Center investigator, and senior author on the study.

“So we started trying to identify some of the protein’s molecular targets.”

In the process, Weeber and colleagues identified an abnormality in the Angelman syndrome mouse model—changes in an enzyme called calcium/calmodulin-dependent protein kinase II (CaMKII), which is important in the cellular processes that underlie learning and memory.



SUSAN URBRY

Edwin Weeber and his colleagues used a rotarod (pictured here) to test motor coordination in mice with a genetic “rescue” of Angelman syndrome.

They found that, in Angelman syndrome, CaMKII activity was reduced due to an inhibitory chemical modification (phosphorylation). Because of CaMKII’s prominent role in neuronal function, Weeber suspected that this might account for many of the neurological deficits seen in Angelman syndrome children.

Fortuitously, one of Weeber’s colleagues—Ype Elgersma, Ph.D., at Erasmus Medical Center in Rotterdam, Netherlands—had created a mouse with a mutation that prevented

this inhibition of CaMKII.

The researchers decided to breed the Angelman mice with the CaMKII mutant mice to see if counteracting the CaMKII inhibition would alleviate the neurological problems. The researchers then ran the resulting “double mutants” through a battery of neurological and cognitive tests.

Angelman mice performed poorly on learning and memory tasks and displayed impaired motor coordination. The double mutants, however, showed normal learning and memory and motor coordination. While the Angelman mice also were prone to seizures, the double mutants showed very low seizure susceptibility.

Weeber was surprised by the robust results. “We thought we might rescue some of the deficits that we saw in the mouse model,” he said. “We had no idea that we were going to rescue basically everything.”

Although impossible to apply to humans the genetic engineering used in the current study to correct these deficits in mice, Weeber thinks that the findings may point to new therapeutic targets for the disorder.

“It’s very conceivable that if we can figure out what lies between UBE3A and CaMKII—and if it’s a specific path—then that could be a therapeutic target.”

But the results may apply more broadly, Weeber said, to other types of mental retardation syndromes that remain unexplained and untreatable. “There are a lot of mental retardation syndromes that we still don’t understand. Maybe the changes in CaMKII associated with Angelman syndrome could be implicated in other mental retardation syndromes as well.”

Reprinted *The Reporter*, Vanderbilt Medical Center, Feb. 9, 2007 ●

Director’s Message from page 1

The meeting also was meant to stimulate discussion for what we need to do collectively to address the gene versus environment conundrum. Well, they heard loud and clear from me that it cannot be viewed as either one or the other. Like the nature-nurture debates of the last hundred-plus years, the battle lines have not been helpful in developing the best research strategies for defining the contributions of genetic factors that may increase risk for developing autism in the face of the thousands of chemicals, infectious agents, and other environmental factors that may also contribute, and to which all of us are exposed on a daily basis.

In the course of the presentation and discussion, we were constantly reminded by family members and advocates that the very

carefully plotted, long-term perspective that scientists normally take in designing a research study needs to be countered with resources that will support the pressing short-term view that certain fundamental questions need to be answered as soon as possible.

The hope is that by defining what, if any, role mercury, viruses, organophosphates, or other agents may play will help prevent future generations from experiencing what is clearly a dramatic increase in numbers of children diagnosed with autism spectrum disorder. The hope also is that defining the culprits, the genes and environmental factors, will lead to creating better strategies for early diagnosis and treatments.

This was the balancing act in action, and it was remarkable to witness how effective clear communication between groups was in

dissolving preconceived notions. Scientists are desperate to help, and I believe families saw, more than ever before, a sense of urgency that we rarely express.

Families and advocates also embraced scientists’ concerns about quality. Information from poorly designed research studies can do more damage than no information at all, leading all of us down paths that can drain the available limited resources.

The balance of efforts is struck when more scientists enter the fray, and more resources are available for working across disciplines to solve immensely challenging problems. There’s nothing that brings a smile to my face more than to recognize that these very efforts are the norm at the Vanderbilt Kennedy Center. I hope that you, too, will recognize them throughout this current issue of *Discovery*. ●

Vanderbilt Kennedy Center for Excellence in Developmental Disabilities

Overweight Prevention *By Courtney Evans*

Research suggests that, if current trends continue, by the year 2010 close to 50% of all children worldwide will be overweight. This staggering figure is due in part to the high caloric intake/low activity lifestyles of many children and families. The factors influencing being overweight and/or obese become even more complex for children with special health care needs.

Addressing the Issue

On March 8-9, the University of Tennessee Boling Center for Developmental Disabilities, in collaboration with the Atlantic Coast Consortium of University Centers for Excellence in Developmental Disabilities, presented a live video conference, "Overweight Prevention for Children With Special Health Care Needs." The conference was broadcast to eight sites across the country, including the University of Tennessee-Knoxville and the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities. The conference, for families and service providers, focused on causes, effects, and prevention techniques related to obesity in children with special health care needs.

Causes of Weight Gain

Although obesity is related to diet and exercise, children with special needs also must often grapple with treatment side effects that further contribute to weight gain. For example, many medications commonly prescribed to children with disabilities are known to promote weight gain by increasing appetite and slowing metabolism. Several antipsychotic drugs given to patients with bipolar disorder, schizophrenia, or autism can cause as much as a 7% increase in body weight. Antidepressants, antihistamines, and mood stabilizers, which also promote weight gain, may be prescribed in conjunction with antipsychotics, thus doubling the risk.

Other causes of weight gain are somewhat unique to children with special needs. First are food-reward systems for positive behaviors in place at many therapeutic and school settings. Second, oral-motor problems that might determine food types can adversely influence food intake. Finally, a child's inability to accurately indicate satiety may contribute to weight gain.

Aida Miles, R.D., C.S.P., L.D., C.N.S.D., a pediatric dietician and consultant with the Marcus Institute, noted in her presentation on nutrition assessment that, in some instances, eating may be a "method of counteracting frustration for children with special needs, because it is something they can do by themselves and do well."

Obesity is associated with a number of



PHOTO COURTESY OF NCPAD

negative effects on the health and well-being of a child. Metabolic issues such as type 2 diabetes, accelerated bone age, and early puberty can occur. Cardiac problems include hypertension, heart failure, and stroke. Pulmonary problems include obstructive sleep apnea, hypoventilation, and asthma. Neuro-psychiatric conditions such as depression and anxiety, or bullying and social isolation, can add to the emotional discomfort.

Prevention Techniques

What can one do to encourage the prevention of obesity in children with special needs? George A. Burghen, M.D., professor of pediatrics and chief of the Division of Endocrinology and Metabolism, University of Tennessee-Memphis, told the conference participants that it takes a team to effectively approach the problem. Burghen suggested that families can help by sitting down and "eating dinner with children, creating a 'sacred space,'" rather than rushing through a distracted meal in front of the television. He noted that it is important to educate parents about nutritional guidelines and to encourage their incorporation in daily meal planning. He urged parents to demand that schools provide healthier items for vending machines and emphasized the need for people to limit processed and fast foods to no more than once a week.

Burghen also spoke about the responsibility that primary care physicians have to provide weight evaluations and information on overweight prevention for at-risk patients. All the conference presenters agreed that weight is a sensitive topic that physicians must handle with care, although still addressing proactively.

S. Casey Laizure, Pharm.D., associate professor of pharmacology, University of Tennessee-Memphis, spoke about avoiding drug-induced weight gain. He suggested that, short of avoiding these drugs altogether, one might consult with the

prescribing physician about the possibility of ordering the lowest possible dose. He also mentioned that, albeit not ideal, some drugs work to counteract the weight gain component of other drugs. Diet and exercise were identified as the best way to combat the effects of medications contributing to weight gain.

"We cannot predict who will be susceptible to drug-induced weight gain," Laizure said. "The weight increase is due to increased caloric consumption caused by the increased appetite. The real fix is maintaining a good diet and regular exercise. These actions will help reduce the risk."

"Exercise is known to promote better healing, to produce feelings of euphoria, to improve short-term awareness and cognition, and to improve sleeping patterns," said James H. Rimmer, Ph.D., director of the National Center on Physical Activity and Disability (NCPAD). "Participation in play, recreation, and sport has a major effect on overall growth and development, and all are critical elements for a satisfying childhood and adolescence."

NCPAD addresses the barriers that may prevent children with special needs from reaching their full exercising potential. One of its goals is to encourage and educate exercise facilitators to customize physical activities for individual needs and skill levels. Adaptive equipment systems are available. NCPAD aims to connect people with these resources.

"The resources for overweight prevention for kids with special needs are out there," said Rimmer. "You just have to know how to connect to them."

Web Resources

Overweight Prevention Self-Paced Course

Boling Center for Developmental Disabilities
www.utmem.edu/bcdd

Weight Management for Children Kid Shape

www.kidshape.com

Way To Go Kids

www.waytogokids.com

Physical Activity

National Center on Physical Activity and Disability

www.ncpad.org

Resources for Service Providers

American Dietetic Association

www.eatright.org

Bright Futures

www.brightfutures.org

Face Processing—An Early Marker of Autism Risk?

By Jan Rosemergy



Table-mounted eye-tracking camera records where infants look.

Babies gaze raptly at faces—but what exactly are they seeing? A related question is whether differences in face processing might be used as an early marker of risk for autism in infants younger than 24 to 30 months, the point at which children are typically diagnosed now. Until the causes of autism are understood, the earliest possible detection and intervention are the best hope.

Autism and Faces

Although the causes of autism are not yet known, scientists concur that genetic vulnerability, along with unidentified environmental factors, cause atypical brain development. The core features of autism are varying degrees of impairment in communication or language, in social abilities, and restricted or unusual patterns of activities and interests.

The observation that young children with autism seem to make less eye contact than typically developing children and often avoid looking at faces has led researchers to investigate whether individuals who are on the autism spectrum process faces differently than typically developing persons.

Face Processing

New technology for tracking eye gaze is enabling researchers to investigate facial processing more precisely. Data on eye tracking also can be correlated with data from brain imaging while viewing familiar and unfamiliar faces.

Research on face processing in typically developing children and adults indicates that when looking at faces, the region of the eyes receives the most attention. By contrast, children and adults with autism often avoid looking at the eyes. Instead they

may gaze more frequently and longer at the mouth.

Study of Infants' Face Processing

Researchers are investigating whether differences in face processing might be found in 9-month-old infants at low and high risk of autism.

The principal investigator is Alexandra Key, Ph.D., research assistant professor of hearing and speech sciences and director of the Vanderbilt Kennedy Psychophysiology Laboratory. Her

co-investigator is Wendy Stone, Ph.D., professor of pediatrics and psychology and TRIAD director.

The researchers are comparing face processing in two groups of infants, all 9 months of age. The low-risk group includes 20 participants with no family history of autism. The high-risk group includes, to date, 8 younger siblings of children with autism spectrum disorder, and recruitment efforts continue with the goal of enrolling at least 10 infants before the study concludes. It is important to note



Sensor net is an infant-friendly way to measure brain activity.

that not all infants at high risk will develop autism. Therefore, the researchers will carry out diagnostic assessments of these infants at 30 months to determine if any of them meet the criteria for diagnosis.

In this study, the researchers are examining face processing in infants using event-related potential (ERP) recordings, a measurement of the brain's

electrical activity in response to a stimulus. Infants wear soft sensor nets while looking at repeated presentations of a color photo of a smiling young woman ("standard face"), the type of face that infants are accustomed to seeing of mothers or other caregivers. On rare occasions, the eyes or the mouth of the standard face are replaced with corresponding parts from a different person. Brain activity of both groups of babies is measured during these different conditions. Measuring brain waves allows researchers to examine various aspects of face processing even in the absence of a behavioral response.

Researchers also used eye tracking technology to measure where on the screen the infants look, in what sequence, and for how long for each of the same three conditions: standard face, eyes change, mouth change.

Findings to Date

Although the two groups of infants shared many similarities in face processing approaches, differences were found in the impact of specific features.

Expected ERP markers of face processing were present over the left posterior sites of the scalp—presumed to reflect activity of the face processing area of the brain—in both groups of infants. In low-risk infants, face processing was mostly affected by the changes in the eye region. By contrast, ERPs of the high-risk infants showed greater variability and did not always resemble those of the low-risk group.

Eye tracking data indicated that the two groups were generally similar in where on the picture and how long they looked. Group differences were present only for the eye change conditions and were limited to the duration of gaze.

"Differences in face processing in babies at low and high risk for autism are evident in their brain waves," Key said. "In where and how long they looked, the differences were more subtle, but very specific."

While larger numbers of infants at high risk are needed to confirm the pattern of results, and a diagnostic assessment at a later age is needed to determine the predictive power of the measures used in this study, the results suggest that examination of face processing in infants may be useful in screening for autism.

Note: Parents of 8 ½- to 9 ½-month-old infants who have older siblings with autism who may be interested in taking part in this research project are invited to contact Susan M. Williams, (615) 343-1961, susie.williams@vanderbilt.edu.

Leading the Vanguard of Discovery



STEVE GREEN

DONNA WEBB, PH.D.

Assistant Professor of Biological Sciences
Vanderbilt Kennedy Center Investigator
Joined Vanderbilt Kennedy Center 2005

Research Interests

Understanding the molecular basis of brain disorders has been a long-term interest. A major focus in my lab is to identify the signaling molecules that regulate the formation of dendritic spines and synapses in the central nervous system (CNS). Dendritic spines, which are small actin-rich protrusions, are believed to mediate the synaptic plasticity that underlies cognitive functions such as learning and memory, underscoring their importance in the CNS. Changes in the number, size, and shape of dendritic spines are associated with neurological disorders, such as mental retardation, epilepsy, schizophrenia, and Alzheimer's disease. Our work has led to the hypothesis that local activation of Rac, which is a member of the Rho family of small GTPases, is central for synapse formation and spine morphogenesis. Consistent with our work, three of seven recently identified genes mutated in non-syndromic mental retardation are involved in Rho family signaling. We are currently using live cell imaging, as well as biochemical and molecular techniques, to identify the signaling pathways by which these actin regulators modulate spine morphogenesis and synapse formation in the brain's hippocampal neurons.

Principal Investigator

GIT1 regulates spine morphogenesis and synapse formation, National Institute of Mental Health

National Service and Awards

- National Institutes of Health Developmental Biology Training Grant # HD07528-01, 2000-2003
- Virginia Department of Rehabilitation Services Grant to study nerve regeneration, 2003-2005
- Member of the Society for Neuroscience, 2003-present

- Content Adviser on Microscopy for Neurogenesis and Cell Fate NIH/CSR, 2006-present

Selected Publications

- Webb, D. J., Zhang, H., Majumdar, D., & Horowitz, A. F. (2007). $\alpha 5$ integrin signaling regulates the formation of spines and synapses in hippocampal neurons. *Journal of Biological Chemistry*, 282, 6929-6935.
- Webb, D. J., Mayhew, M. W., Kovalenko, M., Schroeder, M., Jeffery, E. D., Whitmore, L., Shabanowitz, J., Hunt, D. F., & Horowitz, A. F. (2006). Identification of phosphorylation sites in GIT1. *Journal of Cell Science*, 119, 2847-2850.

Zhang, H., Webb, D. J., Asmussen, H., Niu, S., & Horowitz, A. F. (2005). A GIT1/PIX/Rac/PAK signaling module regulates synapse formation and spine morphogenesis through MLC. *Journal of Neuroscience*, 25, 3379-3388.

Education

B.S., 1989, Chemistry, James Madison University
Ph.D., 1995, Biochemistry, University of Virginia

Attraction to Developmental Disabilities Research

Developmental disorders touch the lives of almost everyone in some way. These disorders can be devastating and can significantly affect the quality of life for individuals, their families, and society as a whole. Yet developmental brain disorders remain poorly understood. A better understanding of the molecular basis of these disorders could lead to novel strategies for their treatment and prevention. This is a challenging task that will require a concerted effort on the part of researchers and clinicians, who are working together to find a solution. I want to be a part of this effort, and I hope that I can contribute in some small way. Hopefully, through research we can find better treatments for these brain disorders and improve the quality of life for individuals with developmental disabilities.

Reasons for Kennedy Center Membership

One of the things that attracted me the most to the Vanderbilt Kennedy Center was its integrative approach toward understanding and treating developmental disorders. Under the leadership of Drs. Pat Levitt and Elisabeth Dykens, the Kennedy Center has brought together top researchers, clinicians, and educators, who are working to develop effective treatments for developmental disorders. The Kennedy Center also recognizes the importance of engaging families and the community as a whole in our effort to prevent, to diagnose, and to develop effective treatments for developmental disabilities. Working together as a team, we can make a difference in the lives of individuals and families with developmental disabilities. ●

Grants Awarded

Parent-child communication about cancer

Bruce Compas, Ph.D. (Psychology & Human Development)
National Cancer Institute

Kinases in ion co-transporter function

Eric Delpire, Ph.D. (Anesthesiology)
National Institute of General Medical Sciences

Regulation of RNA editing in the central nervous system

Ronald Emeson, Ph.D. (Pharmacology)
National Institute of Neurological Disorders and Stroke

Functional organization of the auditory cortex

Troy Hackett, Ph.D. (Hearing & Speech Sciences)
National Institute of Deafness and Other Communication Disorders

Function/trafficking of Alpha1Beta2y GABAARs with y2 subunit truncation

Robert Macdonald, Ph.D., M.D. (Neurology)
National Institute of Neurological Disorders and Stroke

Neocortical transcriptome changes in schizophrenia

Karoly Mirnics, M.D. (Psychiatry)
National Institute of Mental Health

Neural crest contributions to the bladder

Michelle Southard-Smith, Ph.D. (Medicine)
National Institute of Diabetes and Digestive and Kidney Diseases

Developmental outcomes of pediatric chronic abdominal pain

Lynn Walker, Ph.D. (Pediatrics)
National Institute of Child Health and Human Development

Special Ed Leader Honored



DANIEL DUROIS

Peabody College honored Melvyn Semmel, Ed.D. '63, as its 2007 Distinguished Alumnus. Semmel founded departments of special education at State University of New York-Buffalo and at University of California-Santa Barbara. He has had a profound influence on preparation of special education teachers and federal policies relating to people with disabilities.

Investigators Seek to Help Children With Autism Sleep Better

By Craig Boerner



Dr. Malow's son, Austin, after placement of sleep sensors for home sleep study

Vanderbilt Sleep Disorders researchers are launching a study to determine if melatonin, an over-the-counter and relatively inexpensive dietary supplement taken for insomnia and jet lag, is effective in treating children with autism who have difficulty falling asleep.

Autism Speaks, in conjunction with the Dana Foundation, is contributing \$100,000 over two years to support the pilot clinical trial led by Beth Malow, M.D., M.S. Malow is associate professor of neurology, medical director of the Vanderbilt Sleep Disorders Center, director of the Vanderbilt Sleep Research Core, and Vanderbilt Kennedy Center investigator.

Melatonin is a chemical substance in the brain that promotes sleep, Malow said, and children with autism have been shown to have deficiencies with melatonin so there may be a biological reason why the supplement works. Studies have shown melatonin to be associated with minimal side effects.

The melatonin study includes a parental stress index to determine if better sleeping patterns for the children actually translate into less stress for parents.

"If a child is sleeping better, then the parents are sleeping better. They feel better about themselves and what they can do for their child during the day, so it translates into things like limiting behaviors that may be counterproductive for a child," Malow said. "It makes the whole family unit better because the parents feel empowered, and they have a sense of control over their child's sleep and behavior."

Malow said very few sleep studies have been conducted involving children with autism, in part because mainstream thinking has been that the experience would be too overwhelming due to tactile sensitivities.

"If little tags on their clothes bother them, how

could you possibly put electrodes on them?" said Malow, who published her latest autism sleep research in the December issue of the journal *SLEEP*. "But we found a high degree of success in these studies. The key was having child-friendly sleep technologists who made the experience fun for the child, providing sticker books and other rewards."

Research coordinator Karen Adkins, R.N., said home visits to help the child and parents get accustomed to the sleep study experience

also have been successful. "The parents prepare their child with a storybook illustrated with photos of children having sleep studies," she said.

Malow's research has concluded that some children with autism sleep better than others, and the good sleepers do better on behavioral measures, which opens the door to a realm of possibilities.

Malow's group also is recruiting for a parental educational/behavioral techniques sleep study that



An actigraph, or movement sensor, measures movement and helps researchers track sleeping and waking patterns without doing sleep studies.

does not involve medication, which is funded by the Organization for Autism Research.

"We really don't want to limit inclusion, either in our study or down the road. We don't want to make it sound like you have to take medicine because there are alternatives," she said. "In our sleep clinics, we start with behavioral therapy before we give an adult or a child medication. We start with sleep habits and good sleep practices because it's always best to avoid medicine for any condition, even if it's a benign supplement like melatonin."

Together the two studies will serve as the foundation for a large, federally funded multicenter trial.

Adkins said the Vanderbilt Sleep Center is currently seeking 20 children with autism whose

parents report that sleep disorders are a major problem to participate in the melatonin study, and 30 children for the parental education/behavioral techniques study.

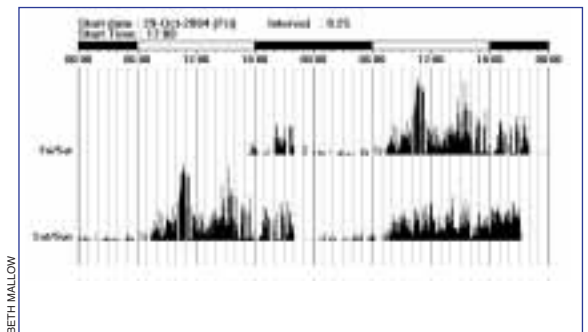
The parental education study will require a total of five visits—a pre-assessment, three sessions of education, and a post-assessment.

The melatonin study is seeking participants who are seizure-free. It requires weekly contact with the parents over the phone or via e-mail and visits to Vanderbilt during a 17-week period.

Parents will record their child's sleep patterns through "sleep diaries," their child's behavior, and parental stress levels. Then, parents will begin giving their child liquid melatonin in gradually increased doses.

Children will wear activity meters (watch-like devices) on their wrists that quantify movement and rest as a surrogate for wakefulness and sleep. Through the pilot study, the researchers will determine optimal dose, safety, and tolerability of melatonin, and will determine any needed modifications in the behavioral and stress scales to be used in the anticipated randomized clinical trial.

Malow's collaborators include Susan McGrew, M.D., assistant professor of pediatrics and Vanderbilt Kennedy Center member; Wendy Stone, Ph.D., professor of pediatrics and director



This graph shows when a child is asleep and awake based on movement patterns. When a child is asleep, there is little movement, indicated by a flatter line.

of Vanderbilt Kennedy Treatment and Research Institute for Autism Spectrum Disorders (TRIAD); Lily Wang, Ph.D., assistant professor of biostatistics and Vanderbilt Kennedy Center member; Suzanne Goldman, Ph.D., F.N.P., instructor in the School of Nursing; Lynnette Henderson, Ph.D., research assistant professor of pediatrics and Vanderbilt Kennedy Center member; and Peter and Pagan Howard, research sleep technologists.

For information on these studies, please contact Karen Adkins at (615) 936-1646 or autismsleepresearch@vanderbilt.edu.

Reprinted *The Reporter*, Vanderbilt Medical Center, Feb. 2, 2007. ●



Susan Gray School *Where Knowledge Meets Nurture*

Peabody College of Vanderbilt • Vanderbilt Kennedy Center

Friends Feed You

By Courtney Evans

Jacob sits on the lap of his teacher, Erin Staal (Ms. Erin). He steadily holds a spoon full of baby food in front of his friend Brooke's mouth with the hope that Brooke will soon eat it. Brooke covers her mouth and slowly turns her head. She does not want to eat it. Brooke does not eat much. In fact, her parents have just informed Ms. Erin that she has barely eaten in two days. Jacob is patient as he holds the spoon out for Brooke.

"Here, Brooke," Jacob says, his pitch high and soothing. "Here, Brookie."

He jumps off Ms. Erin's lap and walks around to the other side of Brooke with the spoon and situates it yet again in front of her mouth. He remains patient and keeps the spoon perfectly still, even though there is much excitement building in the room over the playing (banging and screeching) of musical instruments. Jacob looks around the room with great interest and yet continues to hold the spoon in front of Brooke.

Jacob is a typically developing 4-year-old. Brooke is 4-years-old and is developmentally delayed.

Brooke's eating issues began when she was an infant. She experienced severe acid reflux and needed to be fed through a gastrointestinal tube. Eating was difficult and sometimes painful for her. Now, eating is one of her goals in school. Several times a day, Ms. Erin and, on most days, Jacob (sometimes pals Ana or Ananda will help) sit down at a table with Brooke and encourage her to eat.

Playing with a beautiful purple necklace is Brooke's reward if she takes a bite. Brooke enjoys fingering the necklace, and today she has taken three bites. After she does, Jacob screams out in joy congratulating her.

"I believe they started using the necklace as a reward for eating last year," says Ms. Erin. "Brooke picked it out, and we continue to use it now. Jacob and Ana have been helping Brooke eat at school for two or three years. They are a great help. They are true friends."

Most social behavior theories purport that friendship relationships typically do not begin to emerge until the preadolescent period when the need for acceptance arises.

Mark Wolery, Ph.D., professor of special education and a Vanderbilt Kennedy Center member, says that "friendships" between children as young as 4-years-old might be



identified as such by asking a mere handful of questions: Do the children stay close to one another? Is it *often* that they stay close to one another? When the interactions are between a typically developing child and a child with disabilities, does the typically developing child "look out" for the other child? Would the adult looking on label it a friendship?

"In the 1970s, we thought that if we educated these kids together in inclusive classrooms, then these friendships would emerge through social interaction," says Wolery. "What we found is that doesn't necessarily happen with young kids. The typically developing kids tend to play more with other typically developing kids than with the kids with disabilities. Needless to say, this was a very disappointing discovery. Disappointing, but not surprising. Friendships are based in reciprocity. Some kids with developmental disabilities find it challenging and at times impossible to give and/or take in the relationships, so it becomes difficult to find and maintain the balance needed for friendships to take hold."

It became clear in the field of special education that typically developing children in inclusive classrooms would need to be taught and trained to develop and maintain consistent interaction with the kids with developmental disabilities. Wolery points to the work of early systematic studies that involved training typically developing kids to interact.

"These studies used three rules to train the

typical kids," Wolery recalls. "Stay by them, play with them, and talk to them. That's it. And that's been pretty successful in getting them in the habit. We can't just assume these friendships are going to form. The cards are stacked against it. Children have to be taught. And that's one reason why I'm such a fan of inclusive classrooms, because when you separate them, you don't have a prayer. You have to get them together and that's necessary, but, I have to add, not always sufficient."

It was Bri Klibbe (Ms. Bri), Jacob's and Brooke's former teacher, who first encouraged Brooke's peers to help with feeding her. It was one of many methods implemented, and one that seemed to work well and consistently.

"One of the things we found with Brooke is that she was very motivated by her peers, and not so much by adults," says Ms. Bri. "We started with different kids,

and we said to them, 'Oh! Why don't you try feeding Brooke?' You know, just to see, to experiment, and it worked off and on. We were looking for anything to motivate her and that happened to motivate her for awhile. The kids would clap and get excited for her when she would decide to eat, so we started building on that."

The process of recruiting classmates began simply by choosing whoever happened to be sitting near Brooke at the time. If the child was interested in helping, they would be encouraged to do so and would be praised along with Brooke if a bite was taken. It became a class activity to help feed Brooke.

"The kids were never forced to participate. If they were willing to help, we encouraged it. Ana, Ananda, and Jacob were especially willing. It's funny because I always think I have a classroom full of future therapists. They watch what the people who come into the room do, and then they do those things. We fed Brooke, and then they fed her as well."

Back in the classroom, Brooke has finished eating an entire jar of mashed carrots for lunch. Jacob is sitting next to her finishing his second helping of pineapple chunks. When asked if he is happy when Brooke eats, Jacob leaps up and runs to Brooke and hugs her, shouting out an emphatic, "Yes!"

"I love Brooke," he says. "I checked her ears this morning. She is healthy." ●



Calendar of Events

Unless otherwise noted, events are free and open to the public. Events are subject to change.

Please check the calendar on our website kc.vanderbilt.edu or contact (615) 322-8240 or toll-free (1-866) 936-VUKC [8852].

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

September

SEPTEMBER 5

Developmental Disabilities Grand Rounds Molecular Genetics of Obsessive Compulsive Disorder

Jeremy Veenstra-VanderWeele, M.D.
Instructor in Clinical Psychiatry
Light breakfast provided
Wednesday 8 a.m. Room 241
Vanderbilt Kennedy Center/MRL Building

SEPTEMBER 19

Neuroscience Graduate Seminar Series Environmental Influences on Brain Development and Function

Paul H. Patterson, Ph.D., Anne P. and Benjamin F. Biaggini Professor of Biological Sciences, California Institute of Technology
Co-Sponsor Vanderbilt Brain Institute
Wednesday 4:10 p.m. Room 1220
MRB III Lecture Hall

October

OCTOBER 3

Developmental Disabilities Grand Rounds Mechanisms of Selective Neuropathology Using Mouse Models of Disease

Aaron Bowman, Ph.D., Assistant Professor of Neurology
Co-Sponsor Center for Child Development, Pediatrics
Light breakfast provided
Wednesday 8 a.m. Room 241
Vanderbilt Kennedy Center/MRL Building

OCTOBER 10

Neuroscience Graduate Seminar Series Title TBA

Mark Noble, Ph.D., Professor of Genetics, University of Rochester
Co-Sponsor Vanderbilt Brain Institute
Wednesday 4:10 p.m. Room 1220
MRB III Lecture Hall

OCTOBER 15

Lectures on Development and Developmental Disabilities



Mixed media art in exhibit "Common Ground II: Celebrate the Jewel in Your Heart"

Of Monkeys & Men: What Can the Former Tell Us About Perceptual Development and Experience in the Latter?

David Lewkovitz, Ph.D., Professor of Psychology, Florida Atlantic University
Monday 4:10 p.m. Room 241
Vanderbilt Kennedy Center/MRL Building

OCTOBER 24

Vanderbilt Kennedy Center Leadership Dinner

Wednesday 6:30-9 p.m.
Tickets available for purchase
Proceeds support Discovery Grants
Loews Vanderbilt Hotel
Contact kc@vanderbilt.edu
(615) 343-5322

November

NOVEMBER 7

Developmental Disabilities Grand Rounds The Sounds of Emotion

Jo-Anne Bachorowski, Ph.D., Associate Professor of Psychology
Co-Sponsor Center for Child Development, Pediatrics
Light breakfast provided
Wednesday 8 a.m. Room 241
Vanderbilt Kennedy Center/MRL Building

NOVEMBER 12

Lectures on Development and Developmental Disabilities Functional Imaging of Social Communication in Autism

Susan Y. Bookheimer, Ph.D., Associate Professor of Psychiatry and Biobehavioral

Sciences, University of California, Los Angeles
Monday 4:10 p.m. Room 241
Vanderbilt Kennedy Center/MRL Building

NOVEMBER 15

Vanderbilt Kennedy Center Special Lecture Everyday Life and Health as an Intelligence Test—Throughout Evolution

Linda Gottfredson, Ed.D., Professor of Education, Co-Director of Delaware-Johns Hopkins Project for the Study of Intelligence and Society, University of Delaware
Thursday 4:10 p.m. Room 241
Vanderbilt Kennedy Center/MRL Building

December

DECEMBER 5

Developmental Disabilities Grand Rounds The Role of Inborn Errors of Metabolism in Developmental Disabilities

Marshall Summar, M.D., Associate Professor of Pediatrics
Co-Sponsor Center for Child Development, Pediatrics
Light breakfast provided
Wednesday 8 a.m. Room 241
Vanderbilt Kennedy Center/MRL Building

Arts & Disabilities

Vanderbilt Kennedy Center Exhibits

Monday-Friday 7:30 a.m.-5:30 p.m., Lobby
Vanderbilt Kennedy Center/MRL Building

JUNE 4- SEPTEMBER 28

Common Ground II: Celebrate the Jewel in Your Heart

An exhibition created out of a collaborative music and visual arts workshop held at the Renaissance Center in Dickson, Tennessee, facilitated by artists from Full Circle Art for artists with various cognitive disabilities served by Developmental Services of Dickson County.

OCTOBER 8- JANUARY 25

Creative Expressions XIII

Co-sponsor Mayor's Advisory Committee for People With Disabilities



SibSaturdays

AUGUST 11, OCTOBER 20, DECEMBER 15

A Vanderbilt Kennedy Center for Excellence in Developmental Disabilities program for siblings of children with special needs, ages 5-7 and 8-13 years
Games, friends, conversation
\$10/child or \$20/family
Financial assistance available
Advance registration required
Contact (615) 936-5118
roxanne.carreon@vanderbilt.edu,
Saturdays Room 241
Vanderbilt Kennedy Center/MRL Building



SibSaturdays bring together siblings of children with special needs for fun and support.

Community Events

AUGUST 3-4

Early Childhood Education Conference Teach Today, Touch Tomorrow

Sponsored by Nashville Area Association for the Education of Young Children
Contact snaaeyc@aol.com, 383-6292
First Baptist Church, 1807 7th Avenue South, Nashville

SEPTEMBER 6-7

2007 TN-NADD Conference Celebrating Individuality

Conference of Tennessee-National Association for the Dually Diagnosed
Contact Bruce E. Davis, Ph.D.
brucedavisphd@bellsouth.net
Thursday-Friday
Radisson Hotel at Opryland,
2401 Music Valley Drive, Nashville

ASMT Events

Autism Society of Middle Tennessee

www.autismmidtenn.org
ASMT event information (615) 385-2077
Registration is requested for all events
ASMT members free; nonmembers \$5/family

JULY 19

Autism Orientation

Thursday 6:30-8:30 p.m.
Vanderbilt Kennedy Center/MRL Building

JULY 24

Managing Challenging Behaviors

Thursday 6-9 p.m. Room 241
Vanderbilt Kennedy Center/MRL Building

DSAMT Events

Down Syndrome Association of Middle Tennessee

www.dsamt.org
DSAMT event information (615) 386-9002

OCTOBER 20

Buddy Walk

Band Shell at Centennial Park
Family day of raising awareness and funds
Games, food and music!
Registration and sponsorship (615) 386-9002
dsamt@bellsouth.net

Take Part in Research

StudyFinder

Children and adults, with and without disabilities, are invited to take part in research. See kc.vanderbilt.edu/studyfinder
Contact Lynnette Henderson (615) 936-0448; toll-free (1-866) 936-VUKC [8852]

Disability Pathfinder

Phone, web, print resources

www.familypathfinder.org
English (615) 322-8529
Español (615) 322-8529 ext. 11
Toll-free (1-800) 640-INFO [4636]
tnpathfinder@vanderbilt.edu

Disability Calendar

Internet calendar of training and other disability-related events
kc.vanderbilt.edu/tnpathfinder/calendar.html

Statewide Directory

2007-2008 Disability Services and Supports

Published in 3 volumes:

West, Middle, and East Tennessee

\$25 per directory

To order, contact

(615) 322-8529 ext. 15

ashley.coulter@vanderbilt.edu

Project of Vanderbilt Kennedy Center for Excellence in Developmental Disabilities and Tennessee Council on Developmental Disabilities

Frist Exhibit

Adult Artists with Disabilities Exhibition 2008

The Frist Center for the Visual Arts announces a statewide Call for Works for an exhibition highlighting Tennessee adult artists with disabilities, May 16-September 14, 2008. Entries are open to emerging and professional artists, 18 and older, and must be submitted by October 1, 2007. See www.fristcenter.org/site/community/aawd.aspx. Contact (615) 744-3351, selder@fristcenter.org.

Survey TN Adult Siblings

Survey of Adult Siblings of Individuals With Disabilities in Tennessee

We would like to know more about the relationship between individuals with disabilities and their adolescent or adult brothers or sisters. If you are 18 or older and have a brother or sister with disabilities who lives in Tennessee, we invite you to complete a survey.

The survey takes 25-30 minutes to complete. All your answers are private. You may be interviewed later, if you are willing. The online version of the survey is at <https://kc.vanderbilt.edu/SiblingResearch>

Paper copies also are available. Call (1-888) 322-5339 [free] or email SiblingResearch@vanderbilt.edu.

The survey is being conducted by the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities with funding by the Tennessee Council on Developmental Disabilities.

Families Plan for the Future

By Courtney Evans

For individuals with disabilities and their aging caregivers, planning for the future can be a complex and at times a daunting process. Seventy-five percent of individuals with disabilities live at home with their parents, and 25% of those parents are over the age of 60. Yet research shows that less than half of all families with adult offspring with disabilities have adequately made arrangements for the future. The barriers to planning are numerous (e.g., too emotional, a lack of information, not knowing where to begin) and are in part what inspired the curriculum and the need for the Futures Planning Workshop, recently provided by social work staff of the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities.

The five-session (2.5 hours per session) workshop used a curriculum created by a team of researchers at the University of Illinois at Chicago's Rehabilitation and Training Center on Aging With Developmental Disabilities.

"The Chicago team's curriculum grew out of reviewing materials on the subject that were already out there and choosing the best practices from them," said Whitney Griffin, workshop co-facilitator and Vanderbilt Kennedy Family Outreach Center social work intern. "They didn't want or need to reinvent the wheel. They wanted to create a process that would help families work through the barriers and get them thinking and talking about the future."

Fifteen families (over fifty people) gathered at the Vanderbilt Kennedy Center to share ideas and experiences, to become educated about the resources and options available, and to learn to work together to create a future that meets the needs of all involved.

In each session, a specific topic was explored through the use of films, guest speakers, and/or group discussions. Topics included: identifying personal barriers in the planning process; exploring housing options; how to build relationships and skills; work and leisure activities; and asking and trying to answer the question, "Who will be the keeper of the dream?"

"An important aspect of the curriculum is that it gets the individual with the disability empowered and involved in the planning process," said Carol Rabideau, L.C.S.W., workshop co-facilitator and Vanderbilt Kennedy Family Outreach Center social worker.

"In each session, the families have the opportunity to separate into smaller groups [individuals with disabilities in one group and parents and caregivers

in another] to share their experiences with their peers and within the context of each topic. This has been very helpful in many unexpected ways. For instance, one of the participants with a disability was having a hard time separating from his family to join the smaller group discussions.

By the end of the session on housing, after hearing from his group about some of the positive aspects of independence, he spoke with his parents about moving out on his own in the near future. This was an important step for them."

One of the biggest steps in the workshop is creating the "Letter of Intent." Though not a legal



Carol Rabideau and Whitney Griffin, Futures Planning Workshop leaders

document, the 33-page letter lays out the future desires, wants, and needs of the individual and the family that should influence legal matters and plans.

"Also, the Letter includes details families might not realize they need to think about," Griffin said. "It's a list of likes and dislikes, behaviors to be aware of, certain difficulties, strengths, and challenges—things they can do on their own or things they need help doing. It's specific information about doctors. What doctors have been good to work with? What are their dreams and fears?"

"The Letter records the family story as well," added Rabideau. "They know the story and some people know it, but not everybody knows it. And that is something you want to pass along, to have whoever is helping to care-take help the individual remember the family stories over time. It records the family traditions and how certain occasions are celebrated. It keeps the family story alive."

While the curriculum is geared toward families with adult family members with disabilities, Rabideau recognizes the need for these kinds of resources for

families with younger children.

"We received calls from parents with children of all ages," said Rabideau. "The issue is that the curriculum focuses on adults with disabilities. Some of the subjects are just too difficult for younger children to face. It's hard enough for the adults to face. Nobody wants to talk about their own or their parents' mortality. That is a definite barrier to planning. It is a tough subject to start talking about."

Rabideau would like to see adapted curricula for people of all ages, and even one that focuses on training people to facilitate the workshop themselves. She welcomes the possibility of holding the workshop again in the future, and mentions a desire to collaborate with community partners to widen the net to reach more families.

"This is an important experience for families," Rabideau said. "Group experiences are very helpful. One parent remarked to me that she is becoming a better listener. Another family came in one week and announced that their daughter had quit her job. They were understandably upset. However, as a group we worked together to explore why she quit. It turns out she was bored. She didn't like her job. So we discussed what she liked to do, what she was good at doing, and we thought about how she could find a job that used her likes and skills. We were talking about her future."

For information about upcoming Futures Planning workshops, please contact familyoutreach@vanderbilt.edu, (615) 936-5118.

Resources

DeBrine, E. J., Caldwell, J., Factor, A., & Heller, T. (2003). *The Future is now: A Future Planning Training Curriculum for Families and Their Adult Relatives With Developmental Disabilities*. Chicago, IL: Rehabilitation Research and Training Center on Aging with Developmental Disabilities, University of Illinois at Chicago.

Clearinghouse on Aging With Developmental Disabilities

Department of Disability & Human Development
University of Illinois at Chicago
(1-800) 996-8845 (Voice)
(1-800) 526-0844 (TTY)
Email: rtrcmr@uic.edu
Web: www.uic.edu/orgs/rtrcamr/

Spotlight

Adventurer

BETH GINSBERG DREIFUSS

By Courtney Evans

Beth Ginsberg Dreifuss is going swimming with sharks. At the end of September, she and her husband Carl will leave the shores of Guadalupe, Mexico, on a boat with a naturalist in order that they might climb into cages and be lowered into the water in the midst of the great white shark migration.

"I've always been fascinated by sharks and I just thought it would be..." Dreifuss pauses, "... different. I mean how many opportunities do you get to do something like this?"

Dreifuss leads an adventurous life. She strikes one as the type of person who has mastered the ability to maintain the knowledge that life is most constructive when lived in awe and in wonder. She is bright, enthusiastic, upbeat, and a person who is not afraid to take action.

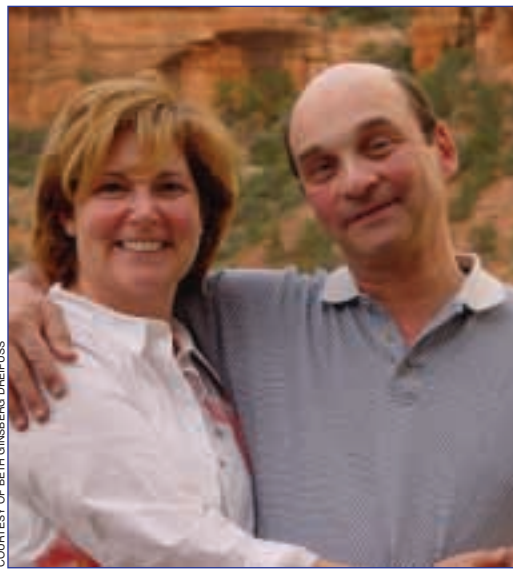
A Nashville native, Dreifuss practices law (formally a tax attorney, currently specializing in divorce law), is the co-founder of two health-care organizations, and all the while runs her family's real estate business.

"Some weeks I focus 100% of my attention on law and other weeks it's 100% on real estate," Dreifuss says. "Sometimes it is 50/50. You fit it all in. It's funny because no one really knows what I do. You talk to five different people and you will get five different answers. I have always enjoyed my work. I like being busy and I like my down time. I travel a lot, go scuba diving, dabble in photography. I enjoy myself and feel very blessed. Everything I have done I've enjoyed."

Dreifuss smiles as she speaks of her family. Her husband Carl is in real estate and runs a technology consulting company. She has two children. Her son is a sophomore at American University and is a former intern in the research lab of Pat Levitt, Vanderbilt Kennedy Center director. Her daughter will graduate from Currey Ingram Academy this year and has received early acceptance into American University where she will attend in the fall.

Dreifuss joined the Leadership Council for two reasons.

"First, I joined because Annette Eskind asked me



COURTESY OF BETH GINSBERG DREIFUSS

Beth Ginsberg Dreifuss and Carl Dreifuss

to join," Dreifuss says as she laughs. "I've never been able to turn down Annette Eskind and would not want to. Second, I joined because the Vanderbilt Kennedy Center supported and taught my daughter in the Reading Clinic. She was having difficulty reading, and they really made great progress with her when others were throwing up their hands. A lot of kids are so bright and have so much to give and if one or more of those initial building blocks—in this case

reading—is missing—if you don't catch it early and work with it—you might lose them forever. I appreciate that programs like this exist. My daughter is amazing and is going to college well-prepared."

Dreifuss believes the true charge of the Vanderbilt Kennedy Center is to make itself irrelevant. She cites the intelligence and the drive of the researchers and staff as making the success of that mission achievable.

When asked to describe the Vanderbilt Kennedy Center in four words Dreifuss lists: colorful, warm, different, and innovative. These four words could easily describe her as well. She is a true asset to the Center. ●

Kennedy Center Donors

Nicholas Hobbs Society Members

New since March 1, 2007
(\$1,000 and above)

A complete list is found at
kc.vanderbilt.edu/kennedy/giving/give2hobbs.html

Mr. and Mrs. Rickey Lemons
Mr. and Mrs. George Jewett

Honor and Memorial Gifts

In Memory of Robert Baskin

Mr. and Mrs. Bill Capucilli
Ms. Laura Capucilli
Mr. Peter Capucilli
Dr. and Mrs. Pat Levitt
Mr. Sam Levitt
Ms. Sara Levitt
Ms. Erica Satin
Ms. Ilena Satin
Ms. Judith Satin

In Memory of Brenda Crabtree

Dr. and Mrs. Pat Levitt

In Memory of Patricia Freers

Mr. James Freers

In Honor of Zelda and Alan Miller on the birth of Alexandra Lindsay, granddaughter

Dr. and Mrs. Pat Levitt

In Honor of Ms. Emma Camdyn Ridge

Mr. Geoffrey B. Ridge

In Honor of Mr. William Hart Spickard

Mr. and Mrs. Howell Adams, Jr.
Mr. Andrew Altman
Mr. and Mrs. Allen Altman
Mr. and Mrs. Lang Aston
Mr. Christopher Bauer
Mr. and Mrs. Rush Benton
Mary Bell Boltwood
Laurie Kathleen Brocato
Mrs. Charlotte A. Brown
Mr. Jay Cassell and Ms. Gay Weake
Mr. and Mrs. Larry Catlett
Church of St. Matthew Womens Club
Mr. and Mrs. David Connor
Mr. and Mrs. Walter William Davis
Mr. and Mrs. Ward DeWitt, III
Mr. and Mrs. Daniel S. Earthman
Mr. and Mrs. David Elliott

Ms. Mary Ann Farnsworth
Mr. and Mrs. Stephen C. Fitzmier
Ms. Harriet Foley
Mr. James E. Freeman
Mr. and Mrs. Isac Gutfreund
Mr. and Mrs. David Guthrie
Mr. and Mrs. Raul Guzman
Mr. and Mrs. Kenneth N. Haas
Mrs. Carolyn Hilsman Griffin Hall
Mrs. Marguerite T. Hall
Mr. Philip M. Hall
Mr. T. Hartley Hall V
Mr. and Mrs. John Hamilton
Mr. and Mrs. Langdon Hartstock
Mr. and Mrs. William Hawkins
Mr. and Mrs. Craig Heim
Mrs. Judith Hodges
Mr. and Mrs. William W. Horn
Mr. and Mrs. George F. Jewett, Jr.
Mrs. Barbara S. Leopold
Mr. and Mrs. Thomas Lewis
Mr. and Mrs. Douglas Markham
Mr. and Mrs. G. Bruce McDermott
Mr. and Mrs. Jerry McPherson
Mr. James A. Meyerhoeffer
Ms. Ruth K. Miehler
Ms. Magdalyn Z. Miller
Mr. William Morgan
Mr. Scott Moss

Ms. Mary Scott Early-Moss
Dr. and Mrs. Chetan Ravindra Mukundan
Mr. Derek A. Nittle
G. Gail Nittle
Ms. Janet S. Oh
Mr. and Mrs. John E. Perry
Mr. Paul Peterman
Ms. Julia Pinkston
Mr. John C. Pogue, III
Ms. Ann C. Poteet
Mr. and Mrs. Peter S. Pressman
Mr. and Mrs. William Y. Rice, III
Mr. and Mrs. Norbert Riediger
Mr. Mark A. Rizzie
Mr. Matthew Rizzie
Mr. and Mrs. Robert W. Rolfe
Mr. and Mrs. Steven Rollins
Mrs. Dan and Jan Rosemergy
Mr. and Mrs. Robert Sadler
Mr. and Mrs. Gilbert Salter
Martha Rogers Scudder
Mr. and Mrs. Robert Simpson
Ms. Ann M. Simon
Mr. and Mrs. Alden H. Smith Jr.
Dr. and Mrs. W. Anderson Spickard Jr.
Mr. and Mrs. Troy V. Tomlinson
Ms. Carol Whaling

Mr. and Mrs. William R. Wiley
William Spencer Company
Reed Trickett

The Nicholas Hobbs Society is made up of donors who give \$1,000 or more annually to the Center or one of its programs. Through their gifts, Hobbs Society members advance groundbreaking research in human development.

For information about joining the Nicholas Hobbs Society or making Honor or Memorial gifts, contact (615) 343-5322.

Every effort has been made to ensure the accuracy of this report, which reflects Honor and Memorial gifts March 1, 2007-May 15, 2007. If an error has been made, we offer our sincerest apology and ask that you bring it to our attention by contacting (615) 343-5322. ●

Hispanic Conference Addresses West Tennessee Issues

By Nick Williams

Language barriers, insufficient resources, and cultural misunderstandings are just a few of the many issues that prevent countless people from receiving the services and resources that they need. As their populations continue to grow, Hispanic and Latino communities are challenging the capabilities of organizations that work with disabilities, health care, and education in Tennessee and across the United States.

To address the challenges, disability and health care service providers, students, and community advocates from Memphis and West Tennessee met for the Memphis Area Disability Services and the Hispanic Community Conference on April 5.

The half-day conference included presentations by the bilingual staff of Tennessee Disability Pathfinder, a cultural competency lecture, and a networking and roundtable discussion.

The need for the Hispanic Community Conference was clear to the 70 people in attendance. At one point during the conference, attendees were divided into groups and asked to list barriers that their organizations face when trying to serve the Hispanic community. In just 15 minutes, enough items were listed to cover a large section of the conference room wall.

The conference was organized by Tennessee Disability Pathfinder, a project of the Tennessee Council on Developmental Disabilities and the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (UCEDD), in conjunction with the University of Tennessee Boling Center for Developmental Disabilities.

Conference objectives were to provide and gather information about disability and Hispanic resources in West Tennessee, to provide information about working with people from diverse cultural backgrounds, and to serve as a forum for information sharing and networking.

Collaboration and Resource Sharing

Tennessee Disability Pathfinder, an information and referral service in English and Spanish for individuals with disabilities, has been experiencing first-hand the need for collaborative efforts between professionals and organizations in order to serve the Hispanic community. Pathfinder's Hispanic Outreach program went from serving 80 individuals to 177 in only a year's time.

Pathfinder staff quickly identified a need for better resources for Spanish-speaking families, something that would require cooperation and

communication with other professionals in the area.

"The best way that we can work with individuals is by having a close relationship with other professionals," said Claudia Avila-Lopez, Pathfinder Hispanic Outreach Coordinator.

Avila-Lopez presented information about the services, training, and resources available through Pathfinder's Hispanic Outreach program and web site, www.familypathfinder.org.

Online resources include the *Pathfinder service*



NICK WILLIAMS

Barriers to serving Hispanic families and suggested solutions were identified at the Memphis Area Disability Services and Hispanic Community Conference.

provider database, which is searchable by Tennessee county as well as by types of services needed; *Pathfinder en Español*, which provides links to Tennessee and national websites in Spanish, and to *Caminoseguro.org*, a web-based directory of Nashville community organizations having a staff member fluent in Spanish, and disability or social service programs that specifically serve Spanish-speaking people. *Caminoseguro.org* is a collaboration of Pathfinder, Metropolitan Nashville Social Services, and the Mental Health Association of Middle Tennessee.

Pathfinder's success with the online resources in Nashville motivated them to spread the news to organizations in Memphis.

"I've been in this business over 35 years, in social work and special education and as a community social worker," Carole Moore-Slater said during her presentation about Pathfinder's online resources, "and having good and accurate information was always what I needed in all of my jobs."

Moore-Slater, UCEDD co-director of community services and technical assistance and director of Tennessee Disability Pathfinder, hopes the conference connected enough people to help Pathfinder expand its Hispanic resources to include Memphis and West Tennessee, as well as to expand regional use of Pathfinder's current resources.

Addressing Cultural Competency

Increasing understanding of Hispanic and Latino culture was the goal of a presentation by Espi Ralston, a native of Spain who instructs medical interpreters in West Tennessee. She spoke of how differences in concept of time, proximity, style of communication, family values, and even superstitions should be considered by service providers when dealing with families from another culture.

Ralston asked the attendees to answer questions about their understanding of Hispanic and Latino

culture. As people began to answer, it quickly became apparent that the culture itself can vary a lot depending on where in Latin America, South America, or Europe an individual is from. Ralston's discussion of culture was engaging to many of the attendees, who chimed-in frequently to make comments, ask questions, and share experiences.

"This will just help us to really understand the culture a little bit better, so that we can work more closely with these groups of people," commented Chandra L. Garrett, an AmeriCorp VISTA volunteer.

Cultural differences relate to issues with general policies and processes of service agencies.

Sometimes language barriers couple themselves with cultural barriers, and delivering services becomes even more complex, Ralston said.

Addressing Service Issues

The conference concluded with hands-on problem solving and information sharing roundtables. Attendees were divided into several groups. Each group received black markers, sticky notes, and large white posters with major discussion topics pre-selected by the conference organizers. Topics concerned major issues for the Hispanic community such as low-income health care options for Hispanic youth and adults with disabilities, how to reach children and youth with disabilities, how to organize an effective Hispanic network, and the best way to communicate when facing language barriers.

Participants listed the barriers associated with each topic and suggested solutions to barriers. Posters were hung on the wall and presented. Attendees used color-coded sticky notes to indicate first, second, and third priority in addressing barriers and implementing solutions.

Pathfinder will use the results from the roundtable activity to strategize the further development of its Hispanic Outreach resources and services. ●

Leadership Council of Vanderbilt Kennedy Center

Mrs. Cathy S. Brown, *Chair*
Mrs. Annette S. Eskind, *Past Chair*
Mrs. Barbara Gregg Phillips, *Past Chair*

Mrs. Honey Alexander	<i>Ex-Officio Members</i>
Ms. Sissy Allen	Dr. Pat Levitt
Mrs. John S. Atkins	Mrs. Hilrie Brown
Mrs. Jean Ann Banker	Dr. Elisabeth Dykens
Mrs. Madge Bass	Dr. BethAnn McLaughlin
Mrs. Ann Bernard	Mrs. Elise McMillan
Mrs. Terry Jo Bichell	Mr. Tim Stafford
Mrs. Barbara T. Bovender	
Mrs. Linda Brooks	
Ms. Mary L. Carlson	
Mrs. Juanita Cate	
Mrs. Beth Dreifuss	
Mrs. Ann Eaden	
Mrs. Donna G. Eskind	
Mr. Glenn Funk	
Mrs. Charlotte Gavigan	
Mrs. Bernice Gordon	
Mrs. Carol Henderson	
Mr. Robert W. Henderson II	
Ms. Lucile Houseworth	
Ms. Bethany Jackson	
Mr. Chris and Mrs. Rebecca Link	
Mrs. Michael F. Lovett	
Mrs. Lorie Hoppers Lytle	
Mrs. Jack C. Massey	
Ms. Andrea Blake McDermott	
Ms. Pat McNellis	
Mrs. Anne Nesbitt	
The Honorable Andrew Shookhoff	
Ms. Laurie Lee Sisk	
Mrs. Shirley F. Speyer	
Mrs. Sue Spickard	
Dr. Karen L. Summar	

Directory Available

2007-2008 Disability Services and Supports Directory

Available in 3 volumes:
West, Middle, or East Tennessee

\$25 per directory

Published by Tennessee Disability Pathfinder

To order, contact
(615) 322-8529 ext. 15
ashley.coulter@vanderbilt.edu



Discovery is a quarterly publication of the Vanderbilt Kennedy Center designed to educate our friends and the community, from Nashville to the nation. The Center is committed to improving the quality of life of persons with disabilities of thinking, learning, perception, communication, mood and emotion caused by disruption of typical development. The Center is a university-wide research, training, diagnosis, and treatment institute. It is a national Developmental Disabilities Research Center funded by the National Institute of Child Health and Human Development, and a University Center for Excellence in Developmental Disabilities (UCEDD) funded by the Administration on Developmental Disabilities.

kc.vanderbilt.edu (615) 322-8240 (1-866) 936-VUKC [8852]

Pat Levitt, Ph.D., Vanderbilt Kennedy Center Director
Elisabeth Dykens, Ph.D., Associate Director
BethAnn McLaughlin, Ph.D., Faculty Director of Community & Special Projects
Tim Stafford, Director of Operations
Jan Rosemergy, Ph.D., Director of Communications

Research Program Directors
Kendal Broadie, Ph.D., Developmental Neurobiology & Plasticity
Stephen Camarata, Ph.D., Communication & Learning
Elisabeth Dykens, Ph.D., Mood & Emotion
Ann Kaiser, Ph.D., & Robert Hodapp, Ph.D., Families
Wendy Stone, Ph.D., Autism Spectrum Disorders (TRIAD)

UCEDD
Elisabeth Dykens, Ph.D., Director
Elise McMillan, J.D., Co-Director; Services
Terri Urbano, Ph.D., Training
Robert Hodapp, Ph.D., Research
Jan Rosemergy, Ph.D., Dissemination

Discovery
Editor/Writer: Jan Rosemergy, Ph.D.
Writers: Courtney Evans, Nick Williams
Art Director: Melanie Bridges, B.F.A.

Discovery is supported in part by Grant No. HD 15052 from NICHD and Administration on Developmental Disabilities Grant #90DD0595

Vanderbilt University is committed to principles of Equal Opportunity and Affirmative Action
© 2007 Vanderbilt Kennedy Center, Vanderbilt University