



COURTESY OF NATIONAL FRAGILE X FOUNDATION

## Targeting Fragile X BY JAN ROSEMERGY

When a genetic syndrome is heritable, families are affected across generations. Fragile X syndrome (FXS) is the most common inherited cause of intellectual disability and autism spectrum disorder. (See Primer, p. 2.) Vanderbilt Kennedy Center clinicians and researchers are helping families through state-of-the-art diagnosis and evaluation, innovative research, and help in accessing the resources and support of the National Fragile X Foundation. This article summarizes the June 2011 FXS Forum for families and professionals (see [kc.vanderbilt.edu](http://kc.vanderbilt.edu), News/Events, Videos).

### Medical Perspective

The **Vanderbilt Fragile X Clinic** provides a comprehensive, multidisciplinary evaluation by a team of clinicians. The half-day evaluation includes medical and speech/language evaluations and an occupational therapy assessment. Features of FXS include physical characteristics, developmental delays in children, and behavioral issues, said **Nirupama Madduri**, M.D., Clinic director and assistant professor of Pediatrics.

Madduri indicated that the medical evaluation focuses on vision, with attention on strabismus (eye movement disorder) and far-sightedness; on hearing, because children with FXS are prone to ear infections, which must be well-managed to facilitate language development and prevent hearing loss; and on feeding, because feeding problems and reflux are common. Macro-orchidism (enlarged testicles) typically becomes apparent around age 9. Hernias may occur in about 15% of males. Childhood seizures occur in 13-18% of males and 5% of females. Madduri stressed the importance of monitoring for symptoms of seizures and, if present, pursuing evaluation and treatment.

“Fragile X features are continuously being defined,” Madduri said, “which makes it important to pay close attention to physical and behavioral health. Adults who are carriers [of the genetic mutation] are at increased risk of developing health issues.”

### Special Education Perspective

The Carolina Fragile X Project (U. No. Carolina, 1993-2008) involved multiple studies of boys with FXS. Deborah Hatton, Ph.D., now associate professor of Special Education

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## Joy of Music ACM Lifting Lives Music Camp BY JAN ROSEMERGY

The joy of making music was apparent on the faces of campers and celebrities alike each day of the week-long 2nd Annual ACM Lifting Lives Music Camp.

“We’ve had phenomenal support from our music community,” said Erin Spahn, executive director of ACM Lifting Lives®, the philanthropic arm of the Academy of Country Music dedicated to improving lives through the power of music. “Country superstars **Gary Allan, Little Big Town, Darius Rucker, Carrie Underwood** and **Wynonna** along with hit songwriters **Odie Blackmon** and **Brett James** and renowned producer **Mark Bright** volunteered their time with campers at various points throughout the week.”

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GETTY IMAGES/COURTESY OF ACM LIFTING LIVES

Timberly Bates and Darius Rucker before Grand Ole Opry performance

## A Stage of Hope Autism and Theatre BY COURTNEY TAYLOR

Eight-year-old Jalyn sits on the stage edge. He is panting from running around the theatre pretending to be a dinosaur. Jalyn knows a lot about dinosaurs. Actually, he knows *everything* about *all* dinosaurs. As a participant in the Vanderbilt Kennedy SENSE Theatre Camp for children and young adults with autism, he sits on the edge of the stage to chat about his camp experience.

**Q: Who are all these people, Jalyn?** Bradley, Eric, Antonio, Ella, Natalie... [He goes on to name each and every camper, peer, and counselor in the room]. These are my friends. All of them. I made my friends at camp. I did this.

**Q: What do you like most about camp?** My favorite thing about camp is everything. It is so much fun. I mean before I came to camp I was an Iguanodon, which is one

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JOE HOWELL/VANDERBILT

Antonio Johnson makes his move during a performance of *Bridges* at SENSE Theatre Camp.

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## Primer on Fragile X Syndrome

- Most common inherited cause of intellectual disability and of autism spectrum disorder.
- Caused by a mutation of a gene (FMR1) on the X chromosome responsible for making a protein that plays a role in brain development. When the gene is fully mutated, it becomes inactive and does not make the protein, which results in fragile X syndrome (FXS).
- Some persons may be premutation carriers without outward signs of FXS, yet they may pass it on to children or grandchildren.
- Identifiable physical characteristics tend to be less obvious in childhood but may become more so with age, and may include long narrow face, prominent jaw, noticeable ears. Other characteristics may include developmental delays and behavioral issues, e.g., anxiety, social difficulties, inattention, high activity, low adaptability.

### National Resources

- **National Fragile X Foundation (NFXF)**—Provides educational and emotional support, promotes public and professional awareness, and advances research toward improved treatments and cure. A comprehensive resource for FXS, including fragile X-associated tremor/ataxia syndrome (FXTAS) and fragile X-associated primary ovarian insufficiency (FXPOI). Offers toll-free helpline; email support; education through extensive website, quarterly journal, and other publications. Organizes international conferences, funds scientific research, and leads legislative advocacy. Contact (1-800) 688-8765, [www.fragilex.org](http://www.fragilex.org).
- **NFXF LINKS Network**—National volunteer program of NFXF. LINKS Groups are typically organized and run by parent volunteers to provide support, create awareness and educational opportunities, fundraise, and participate in advocacy. Each group sets its own priorities based on the needs of the families it serves with guidance and support from NFXF. See map and directory on NFXF website.

### Vanderbilt and VKC Resources

- **Vanderbilt Fragile X Clinic**, Developmental Medicine Pediatrics—Provides comprehensive, multidisciplinary evaluation. Contact (615) 936-0282, [jennifer.hamilton@vanderbilt.edu](mailto:jennifer.hamilton@vanderbilt.edu).
- Take part in research, including studies of potential treatments, by identifying FXS studies in **VKC StudyFinder** or register with **Research Family Partners**. Contact (615) 936-0448, [kc.vanderbilt.edu/studyfinder](http://kc.vanderbilt.edu/studyfinder).
- For Tennessee resources, contact **Tennessee Disability Pathfinder**. (1-800) 640-4636, (615) 322-8529, [www.familypathfinder.org](http://www.familypathfinder.org). ■

### TARGETING FRAGILE X *from page 1*

at Vanderbilt, was active in this research led by Don Bailey, Ph.D. Hatton summarized the project's major findings.

Behavior problems in children with FXS vary considerably and change over time. In fact, behavioral symptoms are often a greater challenge to families and teachers than child cognitive impairments. Behavioral characteristics include attention problems and low persistence, autistic behaviors, high activity, low adaptability, withdrawing behaviors, anxiety, and sensory sensitivity.

Hatton emphasized that consistent behavior management should be a top priority. If a child has co-occurring autism, formal diagnosis may provide access to services. Temperament and sensory needs should be considered. High expectations help children reach their potential. "See the positive and enjoy your child," Hatton said.

### Biological Perspective

Understanding the biology of FXS is fundamental to developing treatments. **Kendal Broadie**, Ph.D., Stevenson Professor of Neurobiology and professor of Biological Sciences, Pharmacology, and Cell and Developmental Biology, investigates the genetic, molecular, and cellular bases of FXS, with a focus on synapse formation and function.

"My research focuses on the molecular genetic mechanisms underlying coordinated movement, behavior, and cognition," Broadie said. "My long-term focus has been on the intercellular synapses that establish and provide communication among nerve cells. An increasing interest is to develop genetic models of human neurological diseases linked to inherited synaptic dysfunction. A primary focus is fragile X."

Broadie's research explores two theories of the biology of FXS, one focusing on hyper-excitation of neuronal communication and the other focusing on hypo-inhibition. The primary excitatory signal in brain synapses is the amino acid glutamate. There is excellent evidence that elevated activity in metabotropic glutamate receptor (mGluR) pathways is causative in FXS models—the mGluR theory of FXS. On the other hand, the primary inhibitory

signal in brain synapses is GABA. There is growing evidence that GABAergic processes are suppressed in FXS—the GABA receptor theory of FXS. "Genetic models of fragile X suggest problems with both classes of signaling," said Broadie.

Neurons integrate into communication circuits containing both excitatory (E) and inhibitory (I) synapses. Proper maintenance of the E/I ratio is critical to normal brain function. In genetic models of FXS, neurons are subtly overgrown, with too many sites of input on the dendrite and too many sites of output on the axon. "We believe that this over-elaboration is at least part of what's going wrong in fragile X," Broadie said.

Balancing the E/I communication is likely to be a critical part of the disorder. In FXS genetic models, if the mGluR glutamate pathway is blocked, cellular and behavioral symptoms improve. In addition, there is a global loss of inhibitory signaling via GABA pathways. Broadie suggested that loss of inhibition may be as important or more important than the perturbation of excitatory synapses. Broadie's lab is investigating the roles of both hyper-excitation and hypo-inhibition. "We need to understand the relationships between hyper-excitation and hypo-inhibition in fragile X if we are to develop effective treatments," Broadie said. "Right now, drug trials are targeting one side or the other of this dysfunction."

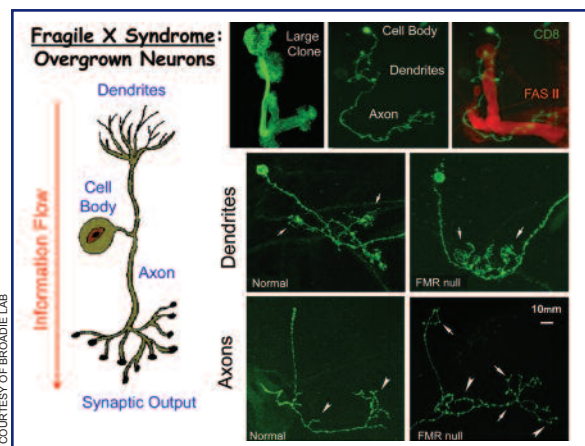
One drug treatment being tested is minocycline, which inhibits a class of secreted protease enzymes that act outside of nerve cells. The Broadie lab has just published a study showing the effectiveness of minocycline treatments in an animal model of FXS.

### Clinical Trials

Pharmaceutical companies are working with physicians on clinical trials. The **Vanderbilt Fragile X Treatment Research Program** is directed by **Jeremy Veenstra-VanderWeele**, M.D., assistant professor of Psychiatry, Pediatrics, and Pharmacology. Vanderbilt is among a number of international institutions testing medications that target the mGluR5 receptor or the GABA-B receptor.

Research in FXS animal models shows too much mGluR5 receptor signaling in the brain. Improvement in brain function and behavior is seen when this signaling is decreased, either by manipulating the gene or by using medication to block the receptor. Medications that block the mGluR5 are being tested in individuals with FXS. Other research shows abnormalities in the GABA system in FXS animal models. Improvements are seen when the GABA-B receptor is stimulated. Medications that stimulate the GABA-B receptor have been used to treat individuals with nerve and muscle problems and are now being evaluated to treat symptoms of FXS.

"There's reason for hope," Veenstra-VanderWeele said. "At the same time, we must not neglect behavioral and educational treatments. Right now that's the best thing we've got by far. The ideal future treatment may be the combination of behavioral or educational treatments with medicine that may improve attention or learning." ■



Left: Unipolar neuron structure showing communication flow from dendrites to axonal synapses. Right: Comparisons of dendrite and axon architecture in *Drosophila* neurons, showing normal structure and characteristic over-elaboration in dendrite and axon in FX null condition.



## Director's Message Reframing the Paradigm

Imagine the thrill of seeing Special Olympian runners at the 2011 World Summer Games dressed in blue and white passing the "Flame of Hope" up the Acropolis hillside in Athens to reach the Parthenon. I attended the Summer Games as a new Special Olympics Board member. The experience was extraordinary.

The World Games gathered not only athletes but researchers worldwide who shared challenges and opportunities in cross-cultural research. My challenge to our research community is to "reframe our paradigms."

First, let's focus on families, to move from documenting their stress and ill health to giving them tools that will empower them to cope and grow as healthy adults. If parent stress has not diminished in 40 years of providing interventions for children and adults with disabilities, isn't it time to rethink intervention models?

Second, let's shift the focus from the negative attributes of disabilities to a balanced view that gives equal research attention to the positive. Our field has



Elisabeth Dykens

long studied cognitive and adaptive deficits, maladaptive behaviors, poor social outcomes, and psychiatric disorders. More recently, our field has examined the genetic and neurobiological factors that underpin deficits. Disability professionals provide services that individuals with disabilities "consume."

Individuals with disabilities are not only "consumers" or "receivers"—they are "givers."

Let's expect reciprocity. Let's learn from the field of positive psychology and find ways to enhance and promote engagement and well-being. Let's examine strengths and positive internal states, and search with equal determination for the genetic and neurobiological factors underlying positive traits. Let's develop models of appreciating the "whole person," with a balanced view of *abilities* as well as *disabilities*.

Doing this will require us to move outside our comfort zones and to embrace complexities that come from a broader appreciation of people with intellectual/developmental disabilities (I/DD). Let us see how these individuals enrich, contribute, engage, teach, and give back.

Third, as researchers, let's be resolved to count all individuals with intellectual disabilities worldwide, to collect meaningful data, and to stop excluding them from our scientific agendas. An IQ of less than 70 is an exclusionary criterion for most research and intervention proposals. This represents lost opportunities for discovery. Instead, let's develop research registries, which have the potential to empower persons with I/DD and their families to dramatically change the current state of affairs.

The Special Olympics motto for the Athens Games was "I'm In." Let's create a new motto: "We Are In." Let individuals with I/DD and their families be *in*, collaborating on their inclusion in research and discovery and helping to set and direct our research agendas.

Let's put our advances in neurobiological interventions into a broader living context so that we develop interventions that improve quality of life. Let's move from individual research labs to an international movement for research inclusion and discoveries that make positive differences in the lives of people with intellectual/developmental disabilities and their families. ■

### A STAGE OF HOPE from page 1

of the first dinosaurs ever discovered.

**Q: And what were you after you came to camp?** An actor. [He nods his head definitively.] I was an actor of the play.

Jalyn is one of 12 campers with autism or other neurodevelopmental disorders who participated in SENSE Theatre camp. Not only does the camp offer its participants an opportunity to explore their creativity through the medium of theatre, it also aims to improve their social and emotional functioning and to reduce their stress levels. Like many Vanderbilt Kennedy Center (VKC) programs, the potential for meeting these aims is explored by combining full participation in an integrated, supportive environment while also conducting research.

Blythe Corbett, Ph.D., assistant professor of Psychiatry and director of SENSE Theatre, developed the model in California in 2009.

"Before becoming a clinical scientist, I spent many years in the theatre learning about verbal and nonverbal communication, character development, emotional expression, storytelling, and movement," said Corbett. "Acting requires expertise in many of the same skill sets that are significantly delayed or impaired in children with autism spectrum disorders. I began to wonder if the masters of human interaction, actors, could serve as teachers or expert models for youth with autism."

### Prior to Camp

Before the campers set foot on the stage, many of the program's components were being set in place.



SENSE Theatre campers, peer actors, counselors, and directors

In the SENSE Theatre intervention model, each camper is paired with a typically developing peer. In addition to performing in the final production alongside the campers, the peers provide individualized support while also receiving support from a camp counselor. Prior to camp, both peers and counselors underwent 4 days of intense training in autism and behavior strategies. Their knowledge of autism and their ability to implement individual supports were measured both before and after the intervention.

The majority of the peers were members of the University School of Nashville Theatre Guild, and Catherine Coke, USN Theatre Director, directed *Bridges*. Prior to camp and in addition to the training, these peers began rehearsals for the final production and also began filming modules for the intervention's video modeling component. The peers were recorded singing the songs, reciting the lines, and showcasing basic movements of the play.

These videos were then uploaded to a password-protected website so that the campers could watch

and practice from home. Video modeling is a highly effective behavioral intervention for teaching targeted behaviors to individuals with autism as shown in Corbett's previous research.

SENSE research components also began prior to day one of camp. Campers underwent full neuropsychological evaluations. Their diagnoses were clarified by a clinical psychologist, and they underwent IQ testing. They also completed tasks that measured their abilities to identify and remember faces, tasks related to theory of mind (a measure of perspective taking), and emotion recognition.

Their parents completed a number of questionnaires that supplied insight into the campers' sensory and adaptive functioning, their day-to-day living skills, stress, and general behavior. In addition, parents were trained in collecting saliva samples to measure cortisol, a hormone that increases in response to stress.

"Our research hypothesis is based on our initial study," said Corbett. "In response to the intervention, we predict that the children will demonstrate some improvement on the neuropsychological measures and show a reduction in stress as measured by parent reports and the cortisol sampling.

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## Expanding Self-Advocacy Efforts in Tennessee BY COURTNEY TAYLOR

When the Administration on Developmental Disabilities (ADD) approached national disability and self-advocacy organizations and called for the formation of state teams to expand self-advocacy efforts across the country, it was obvious that Megan Hart would be an effective team member to represent the Vanderbilt Kennedy Center (VKC). As coordinator of Education and Training Services at Tennessee Disability Pathfinder, Hart has been advocating for the rights of individuals with disabilities for years. However, her journey as a self-advocate began as a child.

“I have to give my family a lot of credit for encouraging me to become an effective self-advocate,” said Hart. “I was always encouraged to make choices and express and follow my interests. For example, when I went to public school, I required a personal assistant. My family made sure that I was always involved in deciding who that person would be. I’m not sure that always happens with school-age kids. I learned from a very early age to advocate in terms of my own participation. I have lived my life not allowing my disability to prevent me from reaching for my own needs and desires.”



Megan Hart presenting on Tennessee Disability Pathfinder resources at Vanderbilt LEND Training Seminar.

Hart defines self-advocacy as a process of speaking up for oneself and being empowered to express one’s own needs, goals, and desires. Moving beyond that and equally a part of the definition is speaking up on behalf of other self-advocates.

“I attended a college in Tennessee that did not have much in the way of disability services,” remembered Hart. “It was not a very accessible campus either, and I had a hard time getting to my classes and other activities. I advocated for more curb cuts and ramps into buildings. By the time I graduated there was a beautiful stone ramp leading into the chapel and elevators in the buildings. It is an example of how speaking up for my own needs allowed other college students who use wheelchairs to reap the benefits. This is advocating for my own needs and the need of others.”

The **ADD Southeastern “Allies in Self-Advocacy” Summit** was held March 10-11, 2011, and Hart was selected as the Middle Tennessee chair.

In addition to the VKC, organizations represented included the Tennessee Council on Developmental Disabilities, the Disability Law & Advocacy Center of Tennessee, the Tennessee Department of Intellectual & Developmental Disabilities, People First of Tennessee, National Youth Leadership Network, and University of Tennessee Boling Center for Excellence in Developmental Disabilities. In addition to Hart, members are Nicole Anderson, Leanne Boyce, Gina Brady, John Chase, Suzanne Colsey, Courtney Kelly, Gatha Logan, Jeness Roth, and Wanda Willis.

Hart reports that Tennessee’s representatives are committed to creating more opportunities for individuals with disabilities to become self-advocates by developing better access to information, resources, and training through a collaborative network of organizations. The first order of business is to develop a self-advocacy resource center.

“I see a lot of room for growth in our state,” said Hart. “Many organizations work on behalf of people with disabilities to provide services, but the people who are accessing the services are not expressing how services should be provided. I would like to see that changed. This is an exciting new initiative and I look forward to the important work ahead of us.”

For information on national self-advocacy summits, see ADD website [www.acf.hhs.gov/programs/add](http://www.acf.hhs.gov/programs/add). ■

## Volunteer Advocacy Influences Vocational Directions BY MEGHAN BURKE

Since Fall 2008, the Volunteer Advocacy Project has trained over 200 advocates. These advocates have attended 40 hours of in-classroom training about special education law and non-adversarial advocacy skills; shadowed experienced advocates at special education meetings; and worked with countless families of students with disabilities. With multiple sites across Tennessee—Nashville, Jackson, Martin, Memphis, Chattanooga, Knoxville, and Johnson City—the project spans the state in training special education advocates and, subsequently, supporting families.

An unexpected outcome of the training is that some graduates feel so passionate about special education advocacy that the field becomes their professional home.

Examples abound. Ann Curl (Spring 2009, Nashville, and VKC Community Advisory Council member) and Leigh Powell (Fall 2009, Nashville) currently work as educational advocates for The Arc Williamson County.

“I wanted to participate in the Volunteer Advocacy Project because my son had an extremely bad experience transitioning from elementary to middle school, which included inappropriate restraint,” said Curl. “I felt I needed more training to

enable me to be a better advocate for him. After completing the Project, I began volunteering as a student advocate in Williamson County during the 2010-11 school year. This spring, Leigh Powell and I will share the position of Student Advocate for the disAbility Resource Center of Williamson County. The Volunteer Advocacy Program was the first of many steps, including the LEND program and Partners in Policymaking, that has led me to this position. I look forward to assisting families—as others have assisted me in the past.

Other graduates who have entered the special education advocacy field are Amy Biggs (Fall 2008, Nashville), who works as an advocate for The Arc Davidson County; Esther McCoy (Fall 2009, Memphis), who works for STEP (Support and Training for Exceptional Parents); and Sandra Hawkins (Spring 2009, Memphis), an advocate for The Arc Mid-South. These graduates are going beyond the requirement of advocating for a minimum of four families by assisting even more families.

In addition to working in advocacy, some graduates have sought out additional training in the disability field. Curl, Lynise Parisien (Fall 2008, Nashville, and VKC Community Advisory Council member), and Christine Bagwell Sartain (Spring



Megan Burke leading a training session for volunteer advocates

2011, Nashville) have been trainees in the Vanderbilt Leadership Education in Neurodevelopmental Disabilities (LEND) training program. Nearly all of the graduates from Johnson City and some from Nashville have pursued degrees to become special education teachers.

For information about the Volunteer Advocacy Project, contact [meghan.m.burke@vanderbilt.edu](mailto:meghan.m.burke@vanderbilt.edu), (615) 585-1420. ■

*Meghan Burke is founder and coordinator of the VKC UCEDD Volunteer Advocacy Project and is a Vanderbilt doctoral student in Special Education.*



## Autism Registry BY JAN ROSEMERGY

Because the causes of autism are as yet unknown, and because evidence is needed to develop innovative, effective treatments and interventions, investigators and families alike know that research is crucial. The new VKC/TRIAD autism registry benefits families and researchers alike.

“Our registry is part of our larger process of partnering with families,” said Zachary Warren, Ph.D., TRIAD director and assistant professor of pediatrics. “We hope to grow to the point where all families coming through clinics will be offered the opportunity to be part of research.”

To date, over 1,000 families with a child diagnosed with autism who have been seen across a number of TRIAD-affiliated clinical and research

programs have given permission for their information to be included in the registry and to be contacted for future research. The registry has met the high research ethics standards, including confidentiality, required for approval by Vanderbilt’s Institutional Review Board.

The registry contains de-identified detailed data on the child with an autism spectrum disorder, including ADOS (Autism Diagnostic Observation Schedule) and diagnostic information, and cognitive, language, and adaptive behavior testing. These data are available to researchers for analysis and hypothesis generation.

“Research teams don’t have to duplicate

records and assessments for families, and families don’t have to repeat the same assessments over the course of several research projects,” said Warren.

The registry can be searched, for example, by child age, level of functioning, or specific symptoms. If there is a match for an intervention study seeking research participants, the family will receive information about that study and can consider participation.

“The registry is a more efficient way of offering support to families and to researchers to help us further the science,” Warren said.

For information, contact [allison.vehorn@vanderbilt.edu](mailto:allison.vehorn@vanderbilt.edu), (615) 343-9636. ■

## Focus on Family BY JAN ROSEMERGY

An autism diagnosis is not only about a child—it is about a family. Typically, it falls to parents, and most often, mothers, to coordinate intervention and other services for their child with autism.

Research indicates that parents of children with autism report higher levels of emotional distress and depression than parents of children with other developmental disabilities or parents of typically developing children. Since parents play such important roles in facilitating and even implementing autism interventions, understanding the factors impacting parental distress is crucial for the well-being of the entire family.

To better understand how families are affected by an autism diagnosis, Zachary Warren, Ph.D., assistant professor of Pediatrics and TRIAD director, and Julie Lounds Taylor, Ph.D., assistant professor of Pediatrics and Special Education, undertook a study of family functioning and reaction to diagnosis of an autism spectrum disorder (ASD).

Families whose children had received an ASD diagnosis through a TRIAD clinic were asked to complete an extensive mail survey over a year after their original diagnosis. The survey assessed parents’ experiences of initial disclosure of ASD diagnosis, subsequent service access and efficacy, parental depression and well-being, child behavior, and other areas of child and family functioning. Although the survey took about 2 hours to complete, 82 families completed it (41% response rate). Since respondents were primarily mothers, analyses were restricted to data from 75 mothers.

The study was retrospective, asking parents to think back in time to the period of the diagnosis and to report their memory of their experiences and feelings, as well as their current experiences and emotions. Almost 80% of mothers reported clinically significant depressive symptoms at the time of diagnosis, with 37% continuing to report clinically significant levels of depressive symptoms.

“It was not the child’s severity of autism or IQ

driving parental reaction,” Warren said. “Depression and distress were more related to problem behaviors in the child, as well as to parents’ feeling as though they experienced financial barriers to receiving autism services.”

A subsequent analysis of the survey data examined the association between beliefs regarding the impact of ASD and depression, anxiety, and well-being. More negative thoughts about future child and parent happiness were significantly associated with increased maternal distress, even when controlling for other factors like challenging child behaviors.

“Families are really experiencing distress, short- and long-term, in a way that may be possible to remediate,” Warren said. “There’s a well-established research literature on influencing thoughts through cognitive behavioral therapies.”

Warren drew a comparison with post-partum depression, for which there is routine clinical screening and follow-up. The evidence suggests vastly larger rates of depression among parents of children with ASD, yet clinical practice does not yet incorporate screening and supports.

Warren and Taylor are undertaking another analysis of the survey data, this time focusing on the diagnostic process itself, how families experience it and how they would change it. For example, families indicated that they preferred to receive the diagnosis within the same visit at which the evaluation is done. By contrast, the common clinical practice is to



COURTESY OF TRIAD FAMILIES FIRST PROGRAM

Families learn practical strategies to use in their daily lives at TRIAD’s free Families First workshop sessions offered year-round.

evaluate a child and then to report findings to parents at a subsequent visit. How long families have to wait for an evaluation is a source of dissatisfaction and anxiety. Although families valued an in-depth evaluation at an autism diagnostic center, many would prefer being able to get a diagnosis in their own community by their child’s pediatrician.

“Findings like this

validate our initiatives in training community pediatric providers to screen for autism,” Warren said. “Having data from families can help us modify our practices.”

This research is part of understanding not only autism but developmental disabilities generally within a broader context. “There is a child with autism within a family, but this is a family,” said Warren. “The system of care within a family may be just as important as specific diagnostic thoughts.”

Taylor and Warren observed that there are other important points across the lifespan besides diagnosis that warrant similar study, such as transitioning from early intervention services to school, or exiting high school and transitioning into adulthood.

“Although we study these transitions separately, we may find that the underlying family processes are similar,” Taylor said.

“And we also may be able to translate findings into understanding processes in developmental disabilities more generally,” said Warren. “How we, as clinicians, integrate what we come to understand about family processes may not be that different.” ■



## Leading the Vanguard of Discovery

### Erik Carter, Ph.D.

Associate Professor of Special Education  
Vanderbilt Kennedy Center Investigator  
Joined Vanderbilt Kennedy Center 2011



#### Research Interests

My overarching research goal is to identify those skills, supports, and experiences that enable adolescents with significant disabilities (e.g., intellectual disabilities, autism, and multiple disabilities) to live rich and personally satisfying lives during and after high school. My research has followed three primary strands.

The first strand addresses interventions to support youth with significant disabilities socially and academically within inclusive schools. My research in this area has focused most heavily on the processes and outcomes associated with peer-mediated support strategies, along with careful examination of student, classroom, and other school factors that may influence students' educational and social success.

The second strand focuses on equipping middle and high school students with significant intellectual disabilities to transition successfully to life after high school. In this area, my research has focused on (a) assessing the transition-related needs of youth, and (b) identifying feasible and effective avenues for increasing students' access to career development and early work experiences.

The third strand focuses on increasing the capacity and commitment of communities to meaningfully include children and adults with significant disabilities, as well as engaging new partners in these efforts. Here, I have begun to explore novel and compelling approaches for engaging new partners—such as employers, community leaders, congregations, and family members—in wider community change efforts.

#### Principal Investigator

- Peer Support and Peer Network Interventions to

Improve Peer Relationships and School Engagement, Institute of Education Sciences

- Improving Summer Employment and Community Inclusion Outcomes for Transition-Age Youth With Disabilities, Institute of Education Sciences
- Natural Supports for Children Birth to 22, Center for Medicare and Medicaid Services

#### Honors and Awards

- Distinguished Early Career Research Award, Council for Exceptional Children, 2009
- Early Career Award, American Association for Intellectual and Developmental Disabilities, 2009
- Alice H. Hayden Award, TASH, 2003
- Fellow, American Speech-Language-Hearing Association

#### Education

- B.A., 1996, Christian Education, Wheaton College
- M.Ed., 1998, Special Education, Vanderbilt University
- Ph.D., 2004, Special Education, Vanderbilt University

#### Attraction to Developmental Disabilities Research

While an undergraduate, I received an invitation to spend my summers in the company of other young adults who happened to have intellectual and developmental disabilities. These unexpected encounters quickly transformed into deepening friendships. And I recall being struck by just how few opportunities there were for others who lived in my community—indeed, in communities across the country—to meet and to benefit from the friendship, talents, stories, and faith of people with significant

disabilities. My professional attention soon turned to identifying ways that schools, workplaces, neighborhoods, and congregations might begin to invite, welcome, and support people with disabilities and their families to participate more fully in the life of a community. Compelling research that is characterized both by rigor and relevance is essential to the success of these types of change efforts.

#### Reasons for VKC Membership

The barriers to meaningful school and community inclusion are often complex and pervasive. Addressing many of the prevailing challenges encountered by adolescents with disabilities and their families will require innovative and multi-faceted solutions. Interdisciplinary work draws upon the best of what we know, works from multiple fields, and incorporates the perspectives of a breadth of key stakeholders. This is critical to expanding opportunities, strengthening supports, and improving outcomes for youth and young adults with significant disabilities. The Vanderbilt Kennedy Center draws together in one place a constellation of compelling researchers, practitioners, policy makers, community leaders, and family members who share a deep and common commitment to enhancing quality of life for people with intellectual and developmental disabilities. For an early career scholar like myself, there is simply no better place to do this important work.

#### Selected Publications

- Carter, E. W., Austin, D., & Trainor, A. A. (in press). Predictors of postschool employment outcomes for young adults with severe disabilities. *Journal of Disability Policy Studies*.
- Carter, E. W., Moss, C. K., Hoffman, A., Chung, Y., & Sisco, L. G. (in press). Efficacy and social validity of peer support arrangements for adolescents with disabilities. *Exceptional Children*.
- Carter, E. W., Ditchman, N., Sun, Y., Trainor, A. A., Swedeen, B., & Owens, L. (2010). Summer employment and community experiences of transition-age youth with severe disabilities. *Exceptional Children*, 76, 194-212.
- Carter, E. W., Owens, L., Trainor, A. A., Sun, Y., & Swedeen, B. (2009). Self-determination skills and opportunities of adolescents with severe intellectual and developmental disabilities. *American Journal on Intellectual and Developmental Disabilities*, 114, 179-192.
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#### A STAGE OF HOPE from page 3

Of course, we are taking a different approach this time. Previously, the children were introduced to the intervention more gradually over a couple of months. The current camp model is an intensive 2-week learning process. Some might argue it is risky to expect improvements in such a short period of time. It will be interesting to see what our data yield.”

#### During Camp

Though they underwent cortisol sampling the first day of camp, for the campers, the SENSE model looked less like an intervention and more like a

summer camp. Each day began with physical and vocal warm ups and theatre games. Rehearsals for the final production, *Bridges: A Lyrical Play About Belonging*, which Corbett wrote, began immediately. Peer support also began the moment campers walked in the door.

The hierarchical support model of SENSE Theatre includes active shaping and fading of support. Initially, the clinical staff supported the counselors, peers, and campers. Once the staff thought that the counselors were confident and effective, support faded. Then, once the counselors

thought that the peers had established rapport and competence in supporting the campers, support from counselors faded. The peers could also fade their own support if their camper became comfortable within his or her theatrical role and within the community. Although each camper initially was assigned to one peer and one counselor, there was an understanding that if campers were naturally drawn to other peers or counselors, pairings could shift. In other words, the camp environment would allow for friendships among peers and campers to form naturally. *Continued on page 7*



## Path to Success BY KAROLY MIRNICS

I arrived in the States 21 years ago as a student, from what was to become the war-torn country of Yugoslavia. Twenty-one years later I am holding the new title of James G. Blakemore Professor and Vice Chair for Basic Science Research in the Department of Psychiatry at one of the most prestigious universities in the world. It is just incredible, isn't it?

So, how did it happen? Was it my skill, personality, dedication, ideas, luck? Perhaps in part, but there is much more to it.

When I look at my career, it is clear to me that scientific success it is not an individual achievement. Just as Vanderbilt rests on five "pillars" (its people, service, quality, growth and finance, and innovation), my career also rests on a number of critical supporting beams: mentors, colleagues, co-workers, family, organization, and society.

**Pillar 1—Mentors.** Mentors infused me with my love of science, curiosity, and opened my mind. They taught me to be patient, to try to understand the "big picture." They put up with my less-than-sophisticated (and sometimes outright dumb) ideas and questions, having faith that I would grow into a thoughtful researcher. Without them, I wouldn't know how to do good science or how to love my work.

**Pillar 2—Colleagues.** Over the years, colleagues shared ideas and resources with me, critiqued my work, and helped me polish my projects. We agonized over ideas, discussed different views, and passionately argued our points. In this process we became more than colleagues—we became friends. Without them, I could not grow as a researcher.

**Pillar 3—Co-Workers.** Research is a team endeavor, and good ideas can come from anyone on the research team. I had the privilege of working with many wonderful postdoctoral and predoctoral

trainees over the years. My lab members always gave their hearts and souls to the pursuit of the most intriguing questions of biological psychiatry. Without them, there would be no results or discovery.

**Pillar 4—Family and friends.** I deeply believe that a happy researcher is the most productive researcher. And the most important source of happiness is a fulfilling family life, a home that can help overcome all the challenges that life and research endeavors can

and threaten to leave to be named to an endowed professorship. The leaders of our organization thought that the quality of my work and my involvement in the life of the Vanderbilt community were an asset and that this warranted a reward. I know very few institutions around the world that function this way. I am proud to be a part of this community. Without a great organization, there would be no progress.

**Pillar 6—Society.** There is no more welcoming and inclusive society than the United States. This is the only society that allows foreign students, without any backing or power, to rapidly rise through a merit-based system. The National Institutes of Health funded my projects, caring only about the quality of the science I proposed, and the philanthropists never cared about my ethnic origins. Furthermore, regardless of my accent, peculiar European habits, and different views on life, I was always welcomed as part of the community—from the University to the local chess club or school PTA.

In summary, being a smart and hardworking lad is not enough to become successful—someone has to groom you, support you, perform the work with you, invest in you, and recognize your achievements. So, as I and other faculty are appointed to new endowed chairs, we celebrate our community spirit, our joint achievements, our University, and our society that made all this possible. ■

*Karoly Mirnics, M.D., is James G. Blakemore Chair in Psychiatry, professor and vice chair for Basic Science Research in Psychiatry, a Vanderbilt Kennedy Center investigator and director of VKC Neuroscience Services.*



DR. BILL KENNER

throw at you. My wife has always been an invisible partner in my scientific endeavors, a source of love, steadiness, and strength when things were bleak and when I considered giving up my research career. My children have always been an endless supply of joy, and their unconditional love has taught me how to be a better person. Without them, success would not be worth anything.

**Pillar 5—Organization.** It is not enough to be an excellent researcher. Someone has to recognize value and achievement. I believe that Vanderbilt is unique in this regard. I did not have to demand promotion

### A STAGE OF HOPE from page 6

"Eric and I ended up together," said USN student and peer model Sam Douglas. "When I met him on the first day, I was really nervous. Eric was really energetic. He ran around a lot. It was overwhelming. I had never worked with kids with autism before and it was all so new to me, but... Eric turned out to be this wonderful person. I mean over the course of these 2 weeks, we have become friends. I really like him. I feel like we have a connection, and I think it has been that way for everybody at camp. You come in and the energy is so high—for the kids, the peers, and the counselors—and it's really incredible that we put a show together in 2 weeks. That amazes me. And we did it with kids who people would think we couldn't do it with."

### After Camp

"Oh my, I have seen such a change in Nicholas,"

said his mother. "He has a lot more self-confidence. Over the past 2 weeks, I have watched him become interested in how teenagers work. He is more interested in personal hygiene, and last night he came to me with his costume in his hands and he said, 'I'm going to wash this.' He has never wanted to wash clothes before, but he is taking on more responsibility. I am seeing a more confident young man. Just a few minutes ago, I saw two counselors ask him to take their picture. He has never taken a picture in his life, but I watched him take the camera from them and take a picture like a professional. I couldn't believe it. I see him talking to people, people who are his friends, and see him feeling like a part of the group. It's just like what the play is about, just feeling like a part of the gang."

Regardless of whether the standardized measures show a change in such a short time period, peers,

counselors, and parents have reported clear signs of improvements for campers.

"We are including a measure based on behavior observation done at the beginning and at the end of camp," said Corbett. "For example, we are looking at behaviors such as cooperation, making eye contact, and sharing. This measure is much more sensitive to changes that take place over a short period of time."

An independent statistician will analyze the data for Corbett and the SENSE Lab to interpret and report once the findings are available. Whatever the results, the camp was a truly remarkable experience that enabled new friendships, increased self-confidence, and even allowed for one camper's unique transformation from dinosaur into actor. ■



## Brain Imaging May Hold Clues to Help Children Improve Grammar BY MELANIE MORAN

New research combines brain imaging and language interventions to help children with language delays improve their grammar. VKC researchers have found that by using brain imaging they can not only accurately measure children's language processing speed, but also predict how well the children will respond to intervention.

"We would like to understand the source of a child's language impairment and then select a grammatical treatment that will help," said Paul Yoder, Ph.D., professor of Special Education. "Once we know it's a speed issue, we can target the treatment and also predict how well the treatment will work. To our knowledge, this is the first time that speed of speech processing has been shown to predict how effective different treatments will be in helping preschoolers with language



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impairments improve their grammar."

Some children process what is said to them too slowly, which causes them to miss what is in the middle of a sentence or to miss word endings. However, measuring this speed has been difficult, particularly in very young children.

Yoder and his colleagues measured speech processing speed directly from children's brain activity. They used event-related potential (ERP), a noninvasive way of measuring the brain's response to stimuli within milliseconds through electrodes placed on the scalp. They then used electrical neuroimaging analysis to evaluate the ERP data from across the entire scalp.

Using these methods, the researchers measured speech processing speed in 48 preschoolers with

language impairments and 57 typically developing preschoolers. They found that the typically developing children processed language faster than the children with language impairments. They then randomly assigned the children with language impairments to one of two treatments to improve their grammar, Milieu Language Teaching (MLT) and Broad Target Recasting (BTR). Both methods have been shown to be effective at helping children with a variety of disabilities improve their grammar.

After 6 months, processing speed improved in both groups. Those who began treatment with particularly slow speech processing learned more grammar through MLT than through BTR. Although all the children improved, those who still had grammar trouble were also still processing language more slowly than their peers.

"It is not difficult to imagine a future in which a child's brain responses are assessed and compared to normative data to identify the extent to which speech processing is slow for their age, which can then be used to inform clinical decisions," said Yoder. ■

*Melanie Moran is associate director of News Service, Vanderbilt Public Affairs.*

## Genes and Prematurity BY LEIGH MACMILLAN

Evolutionary changes that make us uniquely human may have "pushed" human birth timing earlier and can be used to identify genes associated with preterm birth, a new study suggests. Investigators from Vanderbilt, Washington U., and the U. of Helsinki report that variations in a gene with accelerated evolution in humans, the follicle stimulating hormone receptor (FSHR), may increase a woman's risk for delivering her infant prematurely. The findings in *PLoS Genetics* (April 14) point to a novel biological pathway that may influence birth timing.

More than half a million babies per year in the U.S.—1 in 8—are born prematurely (before 37 weeks gestation). Premature babies face an increased risk of death and serious short-term and long-term medical complications, yet there are no adequate therapies to prevent preterm birth.

"We don't understand the fundamental biology of human pregnancy and birth timing," said Louis Muglia, M.D., Ph.D., Edward Claiborne Stahlman Professor of Pediatric Physiology and Cell Metabolism, vice chair for Research Affairs in Pediatrics, and VKC associate director. "We don't know if preterm birth in humans is the normal process gone awry, or if it's an entirely distinct process."

Muglia and his colleagues proposed that our large heads and narrow pelvises have put pressure on human pregnancy "to adapt and shift the time of birth to the earliest time compatible with optimal

survival for both the mom and the fetus."

To explore whether this idea had merit, the researchers compared gestation length in humans and nonhuman primates. They show in the current study that gestation length has decreased in the evolutionary lineage leading to modern humans. They also compared body and brain sizes at birth in humans and nonhuman primates and demonstrated that human gestation is shorter than would be predicted based on this comparison.

"We think there is good evidence that human gestation has been pushed to shorter times, which means there should be a 'signature' in the human

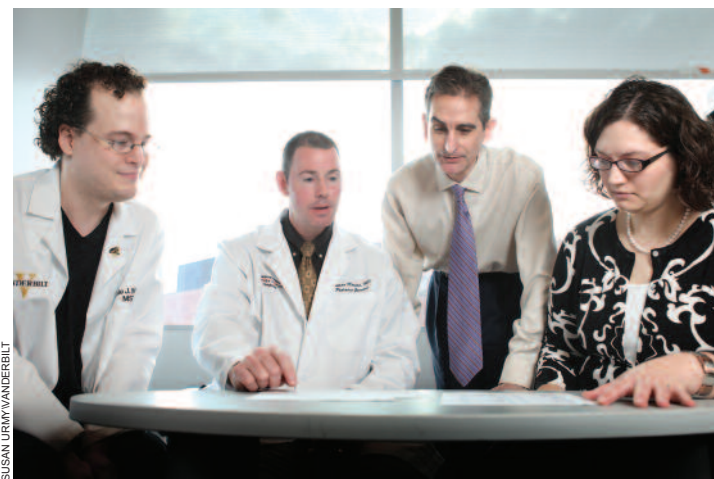
genome—genes with accelerated evolution to accommodate this process," Muglia said.

Justin Fay, Ph.D. (Washington U.), co-leader of the study, developed comparative genomic methods to identify genes that are most altered in humans compared to six other animals. The researchers identified a set of 450 human accelerated genes and narrowed the list to 150 genes that were plausible for having a role in human pregnancy. They examined variations in these 150 genes in a cohort of Finnish mothers and found that certain variations in the FSHR gene were more frequent in mothers who had experienced preterm birth. The same variations may also be associated with preterm birth in African-Americans, further analyses suggested. The FSHR gene has not previously been implicated in birth timing.

Studies in larger cohorts could point to additional accelerated genes with roles in birth timing and provide new targets for therapeutic or preventive measures, Muglia said. "That would really have an impact on infant mortality and long-term complications."

The March of Dimes and the Children's Discovery Institute at Washington U. supported the research. ■

*Leigh MacMillan is science writer, VUMC News & Public Affairs.*



Louis Muglia, second from right, and colleagues, from left, Jude McElroy, Thomas Morgan, and Tracy McGregor, are studying genes associated with preterm birth.

SUSAN URMY/VANDERBILT





## VKC UCEDD Reaching Out BY JAN ROSEMERGY

### Henderson Series for Educators

Teachers strive to be effective in helping every child learn and progress. Researchers aim to share practices shown to be effective in promoting school learning. These objectives come together in the **Britt Henderson Training Series for Educators**, which is continuing in 2011-12 with new topics and new faculty leadership.

Three modules, each with two or more sessions, will be offered to school teams of general and special educators and administrators. Individuals also are welcome. The 2-hour evening sessions will be held monthly (except December) in the evenings at the VKC.

An **Instructional Module** will address (a) preparing a supportive classroom, (b) planning and delivering effective instruction, (c) training and using paraeducator support, and (d) effective inclusion.

A **Behavior Management Module** will include (a) functional assessment, and (b) self-monitoring. A **Transition Module** will cover (a) planning for transition, and (b) transitions for individuals with

co-occurring developmental disabilities and mental health disorders. Depending on sessions attended, participants could receive credit for certification by the Behavior Analyst Certification Board.

“We’re very grateful to the Robert Henderson Family, who endowed this wonderful series in 1996 in memory of their son Britt Henderson,” said Elise McMillan, J.D., VKC UCEDD co-director. “We appreciate the outstanding leadership that Dr. Kathleen Lane has provided and wish her well as she leaves Vanderbilt for the University of North Carolina. We’re excited that three outstanding faculty will lead sessions.”

Faculty leadership will be provided by Andrea Capizzi, Ph.D., assistant professor of the practice of Special Education, Erik Carter, Ph.D., associate professor of Special Education, and Bruce Davis, Ph.D., assistant professor of Psychiatry and director of the Behavioral Health and Intellectual Disabilities Clinic at Vanderbilt.

For information contact Mary Crnabori, (615) 936-8852, [mary.crnabori@vanderbilt.edu](mailto:mary.crnabori@vanderbilt.edu).

### Pathfinder and Camino Seguro Unite

Two related but separate databases of Tennessee disability services and resources have become one, providing improved searches for both Tennessee Disability Pathfinder and Camino Seguro.

Providing callers and Internet users with disability resources and services has been the purpose

of Tennessee Disability Pathfinder since its founding in 2000. In addition to its helpline, Pathfinder’s website has had a database searchable by service type and county or region.

In 2007, Pathfinder launched the Camino Seguro Middle Tennessee database in collaboration with the Mental Health Association of Middle Tennessee and Metro Social Services. This database provided information on agencies who had bilingual



Educators receive training in evidence-based practices at the Britt Henderson Training Series for Educators.

staff who were able to assist Spanish-speaking families. In 2008, Camino Seguro West began, in collaboration with the Boling Center on Developmental Disabilities and other West Tennessee partners. Camino Seguro East followed, again with multiple collaborators.

Camino Seguro information has been merged with the Pathfinder database. After selecting search criteria, users can see at a glance the number of providers found and know whether to narrow or widen their search. A new feature is the ability to easily share an information page through email, Facebook, or Twitter.

To access the database, visit [www.familypathfinder.org](http://www.familypathfinder.org). For questions, call (615) 322-8529, or toll-free (1-800)640-INFO [4636].

### Microboards as a Support Model

Microboards are functioning well in Tennessee. That is the conclusion of a study by VKC UCEDD researchers that was initiated and funded by the Tennessee Council on Developmental Disabilities. Study authors were Marisa H. Fisher, Ashley Terrell-Rea, Allison Summer, and Robert M. Hodapp, Ph.D., professor of Special Education and VKC UCEDD director of research.

In the U.S., Tennessee has been at the forefront of implementing microboards as an alternative to traditional service models. The concept, which originated in Canada in the mid-1980s, is a way to

form a tiny, nonprofit organization and receive agency-level funding to provide supports for the focus individual.

The focus individual and others close to that person (e.g., family members, close friends) comprise a board of directors who work together to make decisions. The members are a natural circle of support carrying out a person-centered planning process. The individual and microboard have the

freedom to make life decisions and the authority to receive and spend public funds and to recruit, supervise, and terminate paid support staff.

The study combined information from in-depth interviews with four microboards, identified by the Tennessee Association of Microboards and Cooperatives, Inc. and from a web-based questionnaire completed by many of the state’s 30+ microboards that provide home- and community-based services. The four microboards were located across the state, were organized and operated differently, existed for differing amounts of time, and served individuals with different needs.

Board members, direct support professionals, and focus individuals themselves all saw microboards as a welcome addition to the service delivery system. For focus individuals, microboards allowed individuals greater degrees of choice, independence, and self-determination. Board members and direct support staff also reported that their focus individuals gained behaviorally.

Board members reported that microboards were an important, successful part of their lives. It allowed them to serve their loved ones in concrete, effective ways. By selecting, hiring, and supervising their own direct support professionals, microboards were able to create another “family,” a word that microboard members and their direct support professionals used often. For direct support professionals, microboards proved a more fulfilling way to work.

Challenges are several. Forming a microboard is time-consuming, and serving as a microboard member is a long-term commitment. Anxiety also was expressed about potential State funding cuts. The study cautioned that, as with any service model, not all microboards may be successful.

Future directions are to determine which internal and external factors help or hinder effective microboard performance, to use those factors in developing and evaluating microboards, and to scale up what seems to be an effective service-delivery option for many individuals with disabilities.

For information on microboards, contact the Tennessee Association of Microboards and Cooperatives, Inc., [tnmicroboards.org](http://tnmicroboards.org). For a report copy, contact [tnddc@tn.gov](mailto:tnddc@tn.gov), (615) 532-6615. ■



Spotlight: Reaching the Entire Family Melinda Balser BY COURTNEY TAYLOR



Jimmy, Jillian, Maddie, Melinda, and Jeff Balser enjoying visit to New York City.

College, and upon graduating worked in telecommunications. Eventually, she and her husband, Jeff, who is now Vice Chancellor for Health Affairs and Dean of the School of Medicine at Vanderbilt, moved to Maryland and had three children.

Their eldest child, Jimmy, attends Tulane University and is headed for a semester abroad in Morocco. Their middle child, Jillian, attends DePauw University in Indiana and runs

track. Maddie is their youngest child and she attends Brentwood Academy. Balser expresses great pride in her children and says that she very much enjoys following their sporting and academic endeavors.

Balser has chaired the Friends of Monroe Carell Jr. Children's Hospital at Vanderbilt (VCH) Outreach Committee for 2 years. She assists in bereavement services within VCH. She has chaired the scholarship committee for the Vanderbilt Women's Club for 3 years, which gave \$30,000 in scholarships last year. She volunteers with her

church, Brentwood United Methodist, in their outreach programs. She has served as a Court Appointed Special Advocate (CASA), and as a volunteer for the Aliza Brandwine Center for Parent-Infant Development Program, which provides support for families, some of whom include children with developmental disabilities.

The seeds of her outstanding work on the VKC Leadership Council began after witnessing some of the challenges faced by friends who have children with disabilities. After attending a Hobbs Leadership Dinner, she says she was so impressed by the work happening at the Center that she knew right away she wanted to become involved.

"I am determined to be sure that more people know about the work that is being done through the Vanderbilt Kennedy Center," said Balser. "It is an amazing resource for the entire family. That is what strikes me the most. The support provided is not just about the child or the adult with the disability. It's really about the entire family unit. When I think about the Kennedy Center, I think of it as a Center at Vanderbilt with arms that reach into every department. They reach in and use all of the resources to touch the entire family." ■

VK Leadership Council member, Melinda Balser, is excited. In Fall 2011, she will begin to pursue a M.T.S. (Masters in Theological Studies) from Vanderbilt Divinity School, something she has been thinking about doing for 25 years.

"I can't wait," says Balser. "I love school and am thrilled to be able to pursue this for myself. The timing just never worked out before now."

To be sure, Balser's life has been full. She grew up in Rhode Island, studied psychology and English first at Tulane University and then at Wellesley

JOY OF MUSIC from page 1

The Camp—a week-long residential program open to individuals with developmental disabilities talented in music from around the nation—has a dual purpose of studying Williams syndrome and other developmental disabilities and providing music enrichment through performance and education. ACM Lifting Lives funds the costs of the Camp, enabling the VKC to advance its mission of improving the lives of individuals with developmental disabilities through research, training and service. This year, 31 campers from 13 states and Canada took part.

Campers created an original song "In Harmony" in a songwriting workshop with Gary Allan, Odie Blackmon, and Brett James. They recorded their song in a Music Row studio with Mark Bright—and Carrie Underwood stopped by and sang several of her hits with campers. Other highlights were a visit with Little Big Town, and karaoke with Wynonna.

The dream week ended Friday night when campers performed live on the stage of the Grand Ole Opry with Darius Rucker, singing "In Harmony" and "Music from the Heart," their 2010 song performed with Rucker on the ACM Awards Show in April.

"The 2011 Camp was the most magical yet," said Lorie Lytle, a VKC Leadership Council member who has been dedicated to this program. "Partnering with ACM Lifting Lives has propelled the Music Camp to a whole new level. It is beyond what any of us could have ever imagined, and so many people with developmental disabilities are benefitting from that collaboration."

Campers stayed in a Vanderbilt residence hall. Many camp sessions were at the **University School of Nashville (USN)**.

"Vince Durnan and the USN staff were so gracious and accommodating," said Laura McLeod, VKC Summer Programs coordinator. "USN is a

great partner in this program."

For these campers with a passion for music, the experience is a dream fulfilled.

Parent Kim McFarland wrote, "Holt couldn't have had a more enjoyable experience, and we couldn't have been happier to hear the joy in his voice each time he called to update us on the day's activities. The opportunities he had will remain in our hearts and minds always. I can't adequately express how full my heart was as he took the Opry stage. Even though I could see that he was taken back by the size of the audience, I immediately saw him transform as he heard their applause and acceptance. To witness your child, who has been marginalized by so many, be front and center on the hallowed stage of the Grand Ole Opry is breathtaking. Holt said it best when he called me at 6 a.m. that morning to say, 'Today's the day, Mom. The day I get to live my dream.'" ■



Brian Johnson, Graham Burns, Ryan Goodwin, Timberly Bates (back), Brian Warner, Darius Rucker, Channing Cason, Trent Gomaz (back)



Carrie Underwood with Music Campers at recording session



Brigitte Anderson singing karaoke with Wynonna



## Joy of Discovery The Martin McCoy-Jespersen Discovery Grant in Positive Psychology

BY JAN ROSEMERGY

Everyone wants to experience happiness and well-being. Some find it easy and natural to do so, and they will have a positive influence on the lives of others. This is what Martin McCoy-Jespersen did. Now his legacy is embodied in the Martin McCoy-Jespersen Discovery Grant in Positive Psychology. The grant was given in Martin's memory by his parents, David Jespersen and Leila McCoy, "to support research to understand the positive internal states of individuals with intellectual disabilities while identifying and promoting positive attributes that contribute to their well-being."

After Martin's death, his parents privately recognized a few of the individuals who had worked most closely with Martin, providing a memorial gift and a statuette with an etched image of Martin and the inscription, which applied to Martin and the recipient alike: "Your light shines for all to see, brightening connections you knew were always there and will always be."

Early in 2010, Martin's parents came across a groundbreaking article "Toward a Positive Psychology of Mental Retardation" (*American Journal of Orthopsychiatry*, 76, 2, 185-193), published in 2006 (the year of Martin's death), by Elisabeth Dykens, Ph.D., now VKC director.

"The article described what we were looking for—a way of promoting positive attributes of people with intellectual disabilities, which is what Martin was doing by just being Martin," Jespersen said. The article led the family to Dykens and the Vanderbilt Kennedy Center.

### Positive Psychology and Intellectual Disabilities

Positive psychology is a recent branch of psychology research. The Positive Psychology Center (U. Pennsylvania) defines positive psychology as "the scientific study of the strengths and virtues that enable individuals and communities to thrive." Its three central concerns are positive emotions, positive individual traits, and positive institutions.

Reflecting on positive psychology in relationship to intellectual disabilities, Dykens observed that intellectual disability is "a diagnosis based on negatives—on what people *do not* have." She proposed a conceptual shift to "a future research

and practice agenda based on positive *internal* states, including happiness, contentment, hope, engagement, and strengths."

Two outstanding applications were received for the Martin McCoy-Jespersen Discovery Grant in Positive Psychology, and both will be funded, Dykens announced.

### Joy of Theatre

A Martin McCoy-Jespersen Discovery Grant in Positive Psychology has been awarded to **Blythe Corbett, Ph.D.** (Psychiatry), for research being conducted at the SENSE Theatre Summer Camp (see article p. 1).

The project involves assessing the effectiveness of this theatre experience as a social-emotional treatment for children on the autism spectrum. Assessment methods include use of standard neuropsychological measures of social perception and biological measures of stress over the course of the theatre experience.

SENSE Theatre was held June 6-18, and data were collected throughout the camp, which will be

analyzed over the next year, but all who saw the two performances saw joy and happiness in abundance.

### Spirituality and Well-Being

A second Martin McCoy-Jespersen Discovery Grant in Positive Psychology has been awarded to **Erik Carter, Ph.D.** (Special Education), to study spirituality, supports, and well-being of youth and adults with significant disabilities.

Research has shown that spirituality, faith, and involvement in a congregational community contribute substantively to a sense of happiness, well-being, and overall quality of life. Yet youth and young adults with significant intellectual and other developmental disabilities are not thriving. The spirituality and faith of people with significant disabilities are often overlooked, poorly supported, or actively ignored.

"We're missing opportunities for individuals with significant disabilities to contribute their talents, gifts, and strengths within a caring community of faith," Carter said.

In the study's first phase, Carter will conduct a large-scale exploration of the spirituality, internal

strengths, and well-being of 500 young Tennesseans (14-25 years) with intellectual disabilities and/or autism. Information will be collected from parents, congregational representatives, and young adults themselves (when appropriate). In the second phase, individual interviews will be done with at least 50 participants and their parents/caregivers.

### A Gift with Purpose

Martin's parents continue to be inspired by how positive a person Martin was and how much he valued all his connections. Through the Martin McCoy-Jespersen Discovery Grants in Positive Psychology, they are "providing the opportunity to discover how others experience happiness and well-being and to find each, in their own way, the fullness of life." ■



Alexi McCoy-Jespersen, Leila McCoy, Martin McCoy-Jespersen. Back: David Jespersen.



Martin McCoy-Jespersen

## Martin's Way of Being Happy\*

Martin McCoy-Jespersen brought exceptional joy and love to his family and all who knew him. He was described as a bright light and always upbeat...Martin demonstrated what it's like to be open, accepting, present, and able to enjoy the moment and how sharing the joy of simply being enhances our relationships and enriches the lives of those around us...Martin's great purpose was to live a happy life, engaging others and communicating to learn more about them and what they might have in common, often with humorous comments, all with the intent to experience the connections and develop relationships. He took every opportunity to fulfill this purpose and persisted in this endeavor every day of his life.

Martin taught by example. He showed us that all we need to do is discover and enjoy being connected. Martin brought people together, because he knew instinctively that was what people needed...Martin was doing the most important work of all—demonstrating that there is joy in simply being, and sharing that joy brightens the connections that are already there for all of us.

When Martin's parents, David and Leila, created and raised this child, they anticipated and experienced tremendous joy and love for Martin that kept out any disappointment or sadness related to the disability...Being fortunate to live in a society that is much more tolerant and accepting of people with intellectual disabilities than it used to be, Martin let people know who he was—a person who wanted to talk, have fun, and enjoy being connected. ■

\*Excerpts from memorial provided by David Jespersen and Leila McCoy



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Front: Josh Putman,  
Alice Byrne,  
Back: Jeanne  
Gavigan, Jessi  
Solomon

COURTESY OF J. SOLOMON

# Team Vanderbilt

Riding tandem bikes, "Team Vanderbilt" — Josh Putman and Alice Byrne (Vanderbilt '07), and Jeanne Gavigan (Next Steps at Vanderbilt student) and Jessica (Jessi) Solomon (Vanderbilt '10 and Vanderbilt School of Medicine student) — completed a 20-mile bike ride in the 12th Annual Audi Best Buddies Challenge-Hyannis Port. Best Buddies International is a global volunteer movement that creates opportunities for one-to-one friendships, integrated employment, and leadership development for people with intellectual/developmental disabilities. See [kc.vanderbilt.edu](http://kc.vanderbilt.edu) for video.

*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 facilitates discoveries and best practices that make positive differences in the lives of persons with developmental disabilities and their families. The Center is a university-wide research, training, diagnosis, and treatment institute. It is a *Eunice Kennedy Shriver* Intellectual and Developmental Disabilities Research Center funded by the *Eunice Kennedy Shriver* 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. *Discovery* is supported in part by Grant No. HD 15052 from EKS NICHD, Administration on Developmental Disabilities Grant #90DD0595, and LEND Training Grant No. T73MC00050 MCHB/HRSA.

[kc.vanderbilt.edu](http://kc.vanderbilt.edu)  
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# CALENDAR OF EVENTS | AUGUST-OCTOBER 2011



Birds of Tennessee + One, images of native birds by artists of Pacesetters, Inc., is on exhibit through August 31.

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](http://kc.vanderbilt.edu) or contact (615) 322-8240 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 [kc@vanderbilt.edu](mailto:kc@vanderbilt.edu).

For disability-related training and other events statewide and nationally, see the Pathfinder Disability Calendar [www.familypathfinder.org](http://www.familypathfinder.org).

\*Event will be held in Room 241 Vanderbilt Kennedy Center/MRL Building.

## ■ TRIAD FAMILIES FIRST WORKSHOPS

Free monthly workshops serving parents of children of all ages diagnosed with an autism spectrum disorder and professionals Register at [kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration); Information (615) 322-6027, [families.first@vanderbilt.edu](mailto:families.first@vanderbilt.edu)

- **AUGUST 27\***  
Including Children with Autism and Other Developmental Disabilities in Religious Education Saturday 9-11 a.m.
- **SEPTEMBER 28\***  
Childcare Provider Workshop Wednesday 6-8 p.m.

## ■ AUGUST 20, OCTOBER 15\* *SibSaturday*

For siblings 5-7 and 8-13 years who have brother/sister with disability Games, friends, conversation Advance registration required. Contact [ashley.coulter@vanderbilt.edu](mailto:ashley.coulter@vanderbilt.edu), (615) 343-0545

■ **AUGUST 23\***  
*Advocacy Services*  
Tennessee Disability Pathfinder Community Education Series  
Co-sponsors: ASA East TN, East TN State U. Families & Siblings United Register at [kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration); Information (615) 875-582, [megan.hart@vanderbilt.edu](mailto:megan.hart@vanderbilt.edu)  
Tuesday 8:30-11:30 a.m.  
Boones Creek Christian Church, Gray, TN

■ **AUGUST 26\***  
*Community Advisory Council Meeting*  
For details contact (615) 936-8852 Friday 9 a.m.-2 p.m.

■ **THROUGH AUGUST 31**  
*Arts and Disabilities Exhibit*  
**Birds of Tennessee + One**  
A "Painting the Tale" special by artists and writers of Pacesetters, Inc. Monday-Friday 7:30 a.m.-5:30 p.m. Lobby VKC/MRL Building Information contact (615) 936-8852

■ **SEPTEMBER 8\***  
*Statistics and Methodology Core Training Seminar*  
Including Brain Activity Measures in Behavioral Research: Insights from the "Black Box"  
Alexandra (Sasha) Key, Ph.D. Research Assistant Professor of Hearing and Speech Sciences; Director, VKC Psychophysiology Lab Thursday 12:30 p.m.

■ **SEPTEMBER 14\***  
*Developmental Disabilities Grand Rounds*  
Improving Employment Outcomes and Community Engagement for Youth with Significant Disabilities  
Erik Carter, Ph.D., Associate Professor of Special Education Wednesday 12 p.m.

■ **SEPTEMBER 21**  
*Neuroscience Graduate Program Seminar Series*  
Title TBA  
Roger H. Reeves, Ph.D., Professor of Physiology, Johns Hopkins University School of Medicine, McKusick-Nathans Institute for Genetic Medicine Co-sponsor Vanderbilt Brain Institute Wednesday, 4:10 p.m. Room 1220 MRB III Lecture Hall

■ **SEPTEMBER 21\***  
*Britt Henderson Training Series for Educators*  
Preparing a Supportive Classroom  
For school teams, individuals, parents Register at [kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration) Information (615) 936-8852 Wednesday 5-7 p.m.

■ **OCTOBER 11**  
*Second Annual Disabilities & Congregation Inclusion Conference*  
Co-Sponsor Faith for All Register at [kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration) Information (615) 322-5658 Holiday Inn Express, 920 Broadway

■ **OCTOBER 12\***  
*Developmental Disabilities Grand Rounds*  
Title TBA  
Jennifer Blackford, Ph.D. Assistant Professor of Psychiatry Wednesday 12 p.m.



# CALENDAR OF EVENTS | AUGUST-OCTOBER 2011

## ■ OCTOBER 13\*

*Assistive Technology Fair*  
Co-Sponsor Technology Access Center  
Thursday 9 a.m.-2 p.m.

## ■ OCTOBER 17\*

*Special Lecture in Memory of Alfred A. Baumeister*  
William MacLean, Jr., Ph.D.,  
Professor of Psychology, University of Wyoming; Executive Director, Wyoming Institute for Disabilities  
Monday 4:10 p.m.

## ■ OCTOBER 26\*

*Britt Henderson Training Series for Educators*  
Planning and Delivering Effective Instruction  
For school teams, individuals, parents  
Register at [kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration)  
Information (615) 936-8852  
Wednesday 5-7 p.m.

## ■ 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](mailto:behavioralhealth@vanderbilt.edu)

## ■ LEARNING ASSESSMENT CLINIC

Multidisciplinary academic assessments of students, 5-25 years, to identify learning strengths and challenges and to recommend strategies to improve academic learning;  
Contact (615) 936-5118  
[patty.abernathy@vanderbilt.edu](mailto:patty.abernathy@vanderbilt.edu)

## ■ NEXT STEPS AT VANDERBILT

A 2-year certification postsecondary education program for students with intellectual disabilities providing individualized Programs of Study in education, social skills, and vocational training.  
Information (615) 343-0822,  
[NextSteps@vanderbilt.edu](mailto:NextSteps@vanderbilt.edu)

## ■ READING CLINIC

Assessment and tutoring for students through middle school  
Contact (615) 936-5118  
[patty.abernathy@vanderbilt.edu](mailto:patty.abernathy@vanderbilt.edu)

## ■ 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](mailto:Linda.Copas@tn.gov), (615) 741-7790  
See also [www.state.tn.us/education/speced/announcements.shtml](http://www.state.tn.us/education/speced/announcements.shtml)  
• **AUGUST 17-18 & 24-25, AND AUGUST 31-SEPTEMBER 1**  
Para-Educator Workshop  
(Knoxville, Nashville, Jackson)

## ■ 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](http://kc.vanderbilt.edu/rfp)  
Register and be notified of research studies  
• **StudyFinder**  
[kc.vanderbilt.edu/studyfinder](http://kc.vanderbilt.edu/studyfinder)  
View lists of studies, criteria, and contact information  
• **See also VUMC Clinical Trials**  
[www.vanderbilthealth.com/clinicaltrials](http://www.vanderbilthealth.com/clinicaltrials)

## ■ TENNESSEE DISABILITY PATHFINDER MULTI-CULTURAL OUTREACH

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

## ■ COMMUNITY EVENTS

• **SEPTEMBER 10**  
2011 Tennessee Walk Now for Autism Speaks  
Bicentennial Capitol Mall State Park  
600 James Robertson Pkwy  
[www.walknowforautismspeaks.org](http://www.walknowforautismspeaks.org)

## ■ ASMT EVENTS

Autism Society of Middle Tennessee  
[www.tnautism.org](http://www.tnautism.org)  
ASMT event information (615) 385-2077  
Registration is requested for all events  
ASMT members free; nonmembers \$5/family  
• **SEPTEMBER 15\***  
Autism Orientation  
Child care available with advance request  
Thursday 6:30-8:30 p.m.

## ■ DSAMT EVENTS

Down Syndrome Association of Middle Tennessee  
[www.dsamt.org](http://www.dsamt.org)  
DSAMT event information (615) 386-9002  
• **AUGUST 18**  
**SEPTEMBER 15**  
**OCTOBER 20**  
DADS

Monthly gathering for fathers 6:30-8 p.m.

• **OCTOBER 22**  
Buddy Walk  
Parthenon Lawn  
Centennial Park  
Nashville

A May picnic thanked and celebrated families who take part in KidTalk research and demonstration projects.



COURTESY OF KIDTALK