

## Coming of Age The Gatlinburg Conference

BY JAN ROSEMERGY

Adolescence and developmental disabilities—from neurobiology to interventions—was the theme of the 44th Annual Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities.

“We had outstanding content in every single symposium, great conversations, and made new connections,” said Elisabeth Dykens, Ph.D., VKC director and Conference chair.

Over 57% of participants were first-time attendees, likely a record number.

“Newcomers meeting veteran attendees is one of the more stimulating aspects of this conference,” Dykens observed.

The Gatlinburg Conference has developed into the premier research conference in the field of intellectual and developmental disabilities (IDD). It is supported by a 5-year grant to a *Eunice Kennedy Shriver* Intellectual and Developmental Disabilities Research Center (IDDRC) from the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD). Beginning in 2011 and for the next 4 years, the Gatlinburg Conference will be led by Dykens, Ph.D., a mark of the VKC’s continuing leadership in the IDD field.

Born when the modern research field of IDD was fledgling, and originally held in Gatlinburg, Tennessee, the Conference has developed a strong neurobehavioral and interdisciplinary orientation over the years. Recent Conference themes include risk and resilience, aging, families, animal models, fragile X syndrome, autism, and Down syndrome. The 2011 theme of adolescence and DD was highly rated by attendees. The Conference serves as a synergistic training and science venue for the network of IDDRCs.

### Conference Overview

Many attendees welcomed the focus on adolescence, contrasted to a specific syndrome, since it allowed many to expand their developmental knowledge. One attendee noted that IDD research often is focused on early development, so it was “fascinating to hear about the ‘what happens after.’” Better understandings of transition and adolescent risk-taking behavior also were noted.

Other attendees found that the hallmark multidisciplinary nature of the Conference was especially helpful, since it challenged them to approach their work with new insights. Still others appreciated the ability to network with other researchers on methods, to discuss existing research and new directions, to explore possible collaborations, and to talk personally with NIH program officers.

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## Building Authentic Communities Timothy Shriver

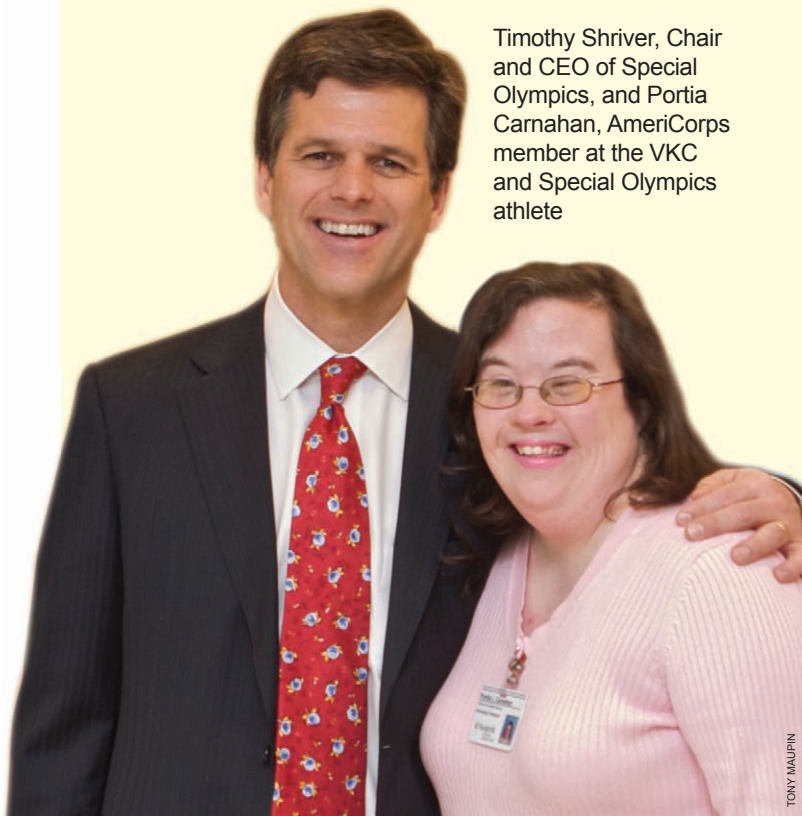
Timothy P. Shriver is a social leader, educator, activist, film producer, and business entrepreneur. He is Chair and CEO of Special Olympics, where he has led initiatives in athlete leadership, cross-cultural research, health, education, and family support. A new member of the VKC Scientific Advisory Board, Shriver visited Vanderbilt in April, when he was interviewed by Jennifer Wetzel, Sr. Information Officer.

### Q. What about the work being done here led to your decision to serve on the VKC Advisory Board?

The Kennedy Center takes seriously the needs and potential of persons with intellectual disabilities. My mother [Eunice Kennedy Shriver] became interested in this Center because, after scanning the country, she found almost no one—scholars, medical practitioners, political leaders—who really cared about persons with intellectual disabilities. This institution has a decades-long track record of standing up to that kind of indifference. This Center is committed to marshalling the best minds, the best scholars, the best community leaders to create the best science and the best practices that capitalize on the gifts of every citizen.

I’ve joined the Board not only because of my family legacy, but also because I think this place has such potential for the future. It can help to build authentic communities around this country and around the world for persons with intellectual

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Timothy Shriver, Chair and CEO of Special Olympics, and Portia Carnahan, AmeriCorps member at the VKC and Special Olympics athlete



TIMOTHY SHRIVER *from page 1*

disabilities and their families—and for all those who, as a result of this place, will not grow up afraid, will not grow up stigmatizing, will not grow up excluding people with differences from their lives.

**Q. To elaborate, what do you see that Vanderbilt and the VKC are contributing to the disability field and community?** Not only is the science being produced here important, but the approach is important. There is an integrated view. The Center has educators, medical practitioners, psychologists, basic researchers, translational researchers. They're all working together.

If you look at the lives of people with intellectual disabilities, they experience a range of services that are so frequently fragmented. They don't need a series of categorical service providers. They need a holistic approach to growth and development.

The leadership here is trying to provide a holistic approach to both research and practices in this field. That's the great promise. As much as we need to know more, we need to integrate more. We need to translate better. We need to be thinking about ways that people with intellectual disabilities can

contribute to their communities. That to me is the big question that we face in the future. The Kennedy Center can help answer that.

**Q. What is the impact of Special Olympics Healthy Athletes?** What we found in Special Olympics is that there are enormous disparities in the ways that people with intellectual disabilities are provided health care. There are preventable health problems that are not addressed simply because systems are not set up to do that. There's either active or passive bias in the system that excludes people with intellectual disabilities from health care systems. As a result, adults with intellectual disabilities end up having poorer health than would be the case if the care were just and fair.

We need to find ways to make the case that there are health disparities, because most Americans don't think there are. We need to find ways to make the case so that health care education institutions, medical schools, and professional schools will intensify the training that students receive related to people with intellectual disabilities. We need to make the case so that systems like health care

insurers and governments will respond to the gaps that exist for individuals with intellectual disabilities. We need to make the case so that parents become empowered within their communities to fight for better health care. We need to make the case so that people with intellectual disabilities themselves can be empowered by understanding their health needs and health histories and ultimately understanding ways to make themselves more healthy.

We have not made that case today. The gaps in information in this country and around the world are scandalous. Most countries don't track people with intellectual disabilities as a population. They don't track the health problems they have, they don't track the extent to which the health care is successful, they don't track or monitor interventions. No data means no policy, no policy means no remediation of the problems, no remediation of the problems means injustice in the health care system. If we can put the data together, if we can mine the data to make the case and learn how to better serve persons with intellectual disabilities and learn how to remediate the problems in the systems, then we

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## Gatlinburg Conference at a Glance

### Attendees

78% female, 22% male  
57.4% first-time attendees  
194 total attendees

### Professional Status of Attendees

37% university faculty  
34% graduate students  
9% postdoctoral fellows  
10.5% university staff  
9.5% other

### Institutions Represented

75 in U.S., Canada, South America, and Europe

### Vanderbilt/VKC Participants

17 Faculty  
6 Graduate Students  
1 Postdoctoral Fellow

### Program Overview

4 plenary sessions  
5 symposia  
61 posters in 2 poster sessions



COMING OF AGE THE GATLINBURG CONFERENCE *from page 1*

### Young Researchers Shine

From its beginning, a major feature of the Gatlinburg Conference was that presentations by graduate students and postdoctoral fellows were valued as much as those by established research faculty. The role that the Conference plays in career development is reflected in participants' comments.

"Of all the conferences I have attended, the Gatlinburg conference has been the most influential to my career development," said Julie Lounds Taylor, Ph.D., assistant professor of pediatrics and special education and VKC investigator. Before joining Vanderbilt in 2008, Taylor was an NICHD postdoctoral fellow and assistant research scientist at the University of Wisconsin's Waisman Center, an IDDRC.

"The smaller size and friendliness of this conference make it perfect for students 'to get their feet wet' in presenting their research," Taylor continued. "As a graduate student, I presented my first poster and my first paper. These formative, positive experiences played a large part in why I feel confident in presenting my research today. It also is a valuable conference for making connections with other IDD researchers, from students through senior faculty. The Gatlinburg Conference has provided a place for me to brainstorm and generate new ideas with other young colleagues from across the country. At the same time, it has provided me with the opportunity to develop enduring ties with senior researchers in the field."

Vanderbilt graduate student Carolyn Shivers, in her third year attending, took part for the first time in a symposium: "Adult Siblings of Individuals with Disabilities: New Perspectives." "The audience was so engaged and brought up wonderful points of interest, questions, and suggestions for future directions," Shivers said. "As a graduate student, I felt very comfortable and welcomed giving a presentation in front of some of the top researchers in the field."

### NIH Workshop

A highlight was the NIH Workshop with three sessions: (1) Behind Closed Doors: What Really Happens at an NIH Study Section, (2) Tips and Tricks for Successful NIH Funding with Q & A, and (3) "And Now, the Rest of the Story." Panel participants assumed roles to illustrate the salient aspects of the grant review process, e.g., comment sheets, role of a Project Officer, roles of reviewers, rules and procedures used in Study Sections, rubric and comments made by seasoned PIs.

Many attendees commented that this was the most helpful part of the conference, and several especially enjoyed the mock review, starring Anita Grant (played by Melissa Parisi, Chief of IDD Branch, NICHD). One attendee remarked that this session was "invaluable for young researchers." ■

*View program and abstracts at [kc.vanderbilt.edu/gatlinburg/Files/program2011.pdf](http://kc.vanderbilt.edu/gatlinburg/Files/program2011.pdf)*



TIMOTHY SHRIVER *from page 2*

have a chance to make a difference in the life outcomes of persons with intellectual disabilities.

**Q. What changes are needed in our thinking about disability?** For too long we've seen people who are "different" as people who have problems. That language has crept into the way people think. As we think, so we will respond. We will help "them." We will fix "them"—as though "they" were the problem.

Being around the Special Olympics Movement for most of my life, I have come to believe that some of the greatest moments of personal transformation exist when people who don't have disabilities see for the first time that differences are not negatives, that a vulnerability is not an evil, that openness, courage, and bravery are not qualities limited to those who are strong in body. And so I am a firm believer that people with intellectual differences can become powerful agents of healing and hope for their communities. Movements like the Special Olympics movement are fundamentally about healing the misunderstanding and intolerance and fear that separate us all. ■

## Director's Message From One Generation to the Next

As parents, we think often of what we want to pass on to our children and grandchildren, and in turn what's been transmitted to us by previous generations. This generational thinking is at the heart of science and research, as well.

As fledgling scientists, each of us benefitted from great teachers and passionate mentors. In turn we seek to nurture our students. Discovery is most often an incremental process in which seasoned scientists and junior researchers partner. This interdependence has been brought home to me as my colleagues and I experienced our own Center's Science Day in February, and then the national Gatlinburg Conference in March.

Science Day and the Gatlinburg Conference are great venues for training the next generation of young, interdisciplinary scientists in the field of intellectual and other developmental disabilities (IDD). On campus, our students and faculty look forward to sharing ideas, sharing data, and brainstorming together across disciplines. The

Gatlinburg Conference has a similar goal. We are a community of dedicated researchers, young and mature researchers together, sharing knowledge and ideas.

Our experiences at Science Day and Gatlinburg also sharpen the realization that our science is a two-way street, an interaction between what knowledge and insights that we as researchers can generate and what children and adults with disabilities and their families teach us.

Whether we study model systems, basic mechanisms, or people, at the end of the day we want our discoveries

to benefit those with IDD. At the same time, we learn an enormous amount from people with IDD, not only understanding underlying molecular or genetic differences but also how their strengths and challenges inform us and even change us.

Science Day and the Gatlinburg Conference remind us all of the importance of the next generation of IDD researchers—and the importance of thinking in novel ways about disabilities. ■



MARY DONALDSON/VANDERBILT

Elisabeth Dykens

## VKC Science Day 2011 BY JAN ROSEMERGY

The Fourth Annual VKC Science Day broke attendance and participation records, attracting 105 poster presentations and a crowd of about 200 Vanderbilt students, faculty, and staff.

"You are all gems," VKC director Elisabeth Dykens, Ph.D., said as she presented the research poster awards to undergraduate and graduate students and postdoctoral fellows in the three theme areas of cellular and molecular neuroscience; clinical, behavioral, and intervention research; and systems neuroscience.

Melissa Parisi, M.D., Ph.D., chief of the Intellectual and Developmental Disabilities Branch of the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), sent a statement, which was read during the opening session by Donna Webb, Ph.D., Science Day chair and assistant professor of Biological Sciences.

"We at NICHD are thrilled that so many young people are pursuing research in science and, in particular, putting their blood, sweat, and tears into research on intellectual and developmental disabilities," Parisi wrote. "This is a profession that is both incredibly worthwhile and personally fulfilling. There is no single 'right' way to craft a career in this field—it is a series of opportunities, chance events, encounters with amazing people, and persistence, hard work, and a sprinkling of luck."

"Research is the ultimate health care reform," said Jonathan Gitlin, M.D., assistant vice chancellor for Maternal and Child Health. "Discovery is all that will eventually make a difference in the lives of

Ronald Emeson, Ph.D., Joel G. Hardman Professor of Pharmacology. The junior faculty presentation was "Trajectories of Autism Spectrum Features in Angelman and Rett Syndromes" by Sarika Peters, Ph.D., assistant professor of Pediatrics.

Comments from participants provide a window into the Science Day experience:

- Bringing together so many types of research gives a great perspective of the whole of research in developmental disabilities.
- VKC Science Day is the best poster session on campus. Attendance is high, meaning you actually get to discuss your ideas with other people. It's cross-discipline, meaning you also get to discuss your ideas across disciplines.

- As a faculty member and judge, I really enjoyed talking with students about their work. It was really exciting to see the range of topics being investigated, and to feel the enthusiasm that students felt about their research.
- I appreciated the wonderful, collaborative atmosphere. Everyone was so excited about their projects and felt truly inspired to find answers and help the world in some way. ■

For award recipients and topics, photos, and research abstracts, visit [kc.vanderbilt.edu/scienceday](http://kc.vanderbilt.edu/scienceday).



KEN BECK

people with intellectual and other developmental disabilities."

Dennis Hall, Ph.D., vice provost for Research and dean of the Graduate School, noted that Vanderbilt ranked 20th in 2007 in federal science and engineering support, according to the National Science Foundation, and placed 17th in the 2011 National University Rankings published by *U.S. News and World Report*. "This shows what we can accomplish when we work together," Hall said.

"Prader-Willi Syndrome and the Tyranny of Evidence" was the topic of the keynote address by





## Remembering Al Baumeister

Alfred A. Baumeister, Ph.D., a national spokesman for intellectual disabilities research and former director of the Vanderbilt Kennedy Center, died March 14 in Tuscaloosa, Ala. He was 76. Baumeister, professor of Psychology, emeritus, directed the Center from 1983 to 1990.

Born in Fairbanks, Alaska, Baumeister received his B.A. from the University of Alaska in 1957. Having earned his M.A. in 1959 and Ph.D. from Peabody College in 1961, he joined the Peabody faculty for the first time as an assistant professor of Psychology in 1961. He returned to Peabody in 1973 as a professor of Psychology, where he also served as director of the Institute on Mental Retardation and Intellectual Development. After stepping down

as Center director in 1990, he continued to serve on the Peabody Psychology faculty until his retirement in 2000.

Baumeister's contributions to the fields of intelligence theory, developmental

disabilities, epidemiology, and ethics in genetics are known through his more than 230 publications, his service in federal policy making, and the many awards he received. (See complete Vanderbilt obituary at [news.vanderbilt.edu](http://news.vanderbilt.edu)) ■



YU SPECIAL COLLECTIONS AND UNIVERSITY ARCHIVES

## VKC Partners On Transition Summit

The Third Annual Transition Summit, held during the 2011 Division of College & Career Readiness Annual Special Education Conference in February, offered a wealth of information for school staff, families, and agencies working in the area of transition.

Keynote speaker Amy Dwyre, M.A., CRC, Senior Associate at TransCen, Inc., spoke about job carving and customized employment. Summit Collaborators included VKC UCEDD, University of TN Boling Center UCEDD, TN Council on Developmental Disabilities, TN Division of Vocational Rehabilitation Services, and TN Department of Intellectual and Developmental Disabilities. ■



GAYLE FELTNER

## “Spread the Word to End the Word” BY DAVID LEE

Walking out of a class, I hear, “Ugh! I can’t believe I forgot we had a quiz. I’m so retarded.”

The word “retarded” has found a place in our everyday language as a casual term to mean “stupid,” “nonfunctional,” or “misguided.” Many of us understand instinctively why we shouldn’t use the r-word synonymously with “stupid”—it is offensive and derogatory to people with intellectual disabilities. Others, however, argue that it isn’t an issue about intellectual disabilities but freedom of speech and the meaning of our words.

Campaigns such as Best Buddies Vanderbilt’s recent “Spread the Word to End the Word” event do not aim to censor anyone’s speech. The campaign’s purpose is to ask that people be more mindful of their everyday language.

A common argument against the ending of the r-word is that it no longer refers to people with intellectual disabilities. People who use the word do not consciously intend to offend people with intellectual disabilities.

People who make this argument forget that the movement is not about words—it’s about people. For a person with intellectual disabilities, hearing the r-word in any setting may bring painful memories and make them feel ostracized. It doesn’t matter if much of our society uses the r-word without a thought of people with intellectual disabilities—there are people with intellectual disabilities who will be hurt by the word for a long time.

So if it requires so little for us to stop using the word and it hurts so much for them to hear the word, why not restrain ourselves from saying the word? Even when I’m not around people with intellectual disabilities, I cannot use the word without directly disrespecting my friends who have intellectual disabilities.

The second common argument against ending the r-word is expressed by columnist Christopher Fairman of the *Washington Post*: “If the goal [of ending the word] is to protect intellectually disabled individuals from put-downs and prejudice, it won’t succeed. New words of insult will replace old ones.” Fairman observes the irony of the r-word originally being a relabeling of more pejorative terms like “imbecile,” “moron,” and “idiot” in the psychological community in 1959. He argues that just as the medical terms “idiot” and “retard” were hijacked to become derogatory, “intellectual disability” will eventually suffer the same fate. What good does it do to end the use of the r-word if 50 years from now we’ll be campaigning to end the words “intellectual disability”?

Fairman accurately describes the history of how terms referring to people with intellectual disabilities have been distorted to become derogatory. I believe that there is a way to end this cycle. In the past, words to refer to people with intellectual disabilities were hijacked because people did not understand or did not respect people with intellectual disabilities.

“Spread the Word to End the Word” hopes to end the cycle not only by ending the word, but also by ending the negative perception of people with intellectual disabilities. The campaign aims to educate the general public that people with intellectual disabilities are wonderful people who lead productive and enriching lives.

By giving people with

intellectual disabilities a platform to be heard, “Spread the Word to End the Word” hopes to dispel misconceptions that the public still holds about people with intellectual disabilities and replace them with a positive and yet real impression of them.

At Vanderbilt’s “Spread the Word to End the Word” event, I, along with a few hundred other students, had the privilege of enriching our lives by hearing the stories of those with intellectual disabilities and seeing their artistic talents. I was struck speechless after the rendition of “Don’t Stop Believing” by the Melodores and some of the Buddies. I was moved to tears as I heard the testimony of some of the Buddies, and I cheered louder than I ever had for the Best Buddies dancers. As long as the r-word remains in our vernacular to mean “stupid,” these talented and wonderful people will remain categorized as second-class citizens.

“Intellectual disabilities” may be another meaningless change of words to you, but to us it represents a hope that we can change the public perception of people with intellectual disabilities. We want to say “people with intellectual disabilities” so that we get another chance to undo negative connotations. We want “intellectual disabilities” to be associated with people who are valuable, compassionate, and worth listening to. We want “intellectual disabilities” to be associated with the things in our world that are inspirational and give us hope. We want “intellectual disabilities” to evoke stories of overcoming obstacles and fulfilling one’s full potential. Ending the r-word is ultimately about fighting prejudice, not choosing words. ■

*David Lee is a rising senior at Vanderbilt and Chapter Buddy Director of the award-winning Vanderbilt Best Buddies. Elise McMillan, J.D., VKC UCEDD co-director, is the Chapter’s faculty advisor.*



David Lee and his Best Buddy, Jacob Webne, at a 5k race hosted by Best Buddies Tennessee.

BEST BUDDIES TENNESSEE



## Better Tools Needed to Target Autism Treatments BY CRAIG BOERNER

VKC researchers evaluating existing treatments for children with autism spectrum disorders (ASD) found that although there were positive results in some studies, there is little information to target the right treatments to specific children.

Findings from the three review articles, which examined research conducted between 2000 and May 2010 on children ages 12 and younger, were released in April by the journal *Pediatrics*. More studies are needed to identify which specific treatments are most helpful for specific children, researchers said.

“In autism research, like in other areas, we need to be very careful to draw conclusions only after we have sufficient evidence to make a clear judgment,” said Jeremy Veenstra-VanderWeele, M.D., assistant professor of Psychiatry, Pediatrics and Pharmacology and co-author of the report. “Too often, we reach premature closure, thinking that we know something before the data are really clear.”

Early interventions, including the UCLA/Lovaas approach and the Early Start Denver model, showed improvements, including dramatic responses for some children, in individual studies, but there is not enough research to be confident of just how effective the interventions are, or for which children.

Research about less intensive interventions that primarily provide parent training is inconsistent and preliminary.

Two atypical antipsychotic medicines, risperidone and aripiprazole, did help address challenging and repetitive behaviors but should be reserved for children with severe impairment because of potential side effects that include drowsiness and significant

weight gain. No medications improved social behaviors or communication skills, and secretin, which has been used to address peptic ulcers, is ineffective.

“The more high-quality information we can disseminate to parents and clinicians the better,” said co-author Zachary Warren, Ph.D., TRIAD director and assistant professor of pediatrics. “Many parents want to do everything they can to help their child—it’s a tricky position to be in. There is a lot of information that is helpful, and some that is not so helpful. We are only going to get better and better at identifying specific interventions for children, but much work remains to be done.”

Vanderbilt researchers hope the report will add to the ongoing discourse about how to best care for children with autism.

“Some children experience dramatic and positive effects, but many others do not,” said co-author Melissa McPheeters, M.P.H., Ph.D., co-director of the Vanderbilt Evidence-Based Practice Center. “Given that almost all children with autism are going to be treated with multiple approaches, figuring out which treatments are likely to help which kids is critically important.”

The research review was funded by the Agency for Healthcare Research and Quality (AHRQ). ■



ANNE RAYNER/VANDERBILT

TOP: Zachary Warren, Jeremy Veenstra-VanderWeele, and Melissa McPheeters BOTTOM: Zachary Warren and Nilanjan Sarkar are developing emotion-sensing technology for use with children with ASD.

*Craig Boerner is National News Director, Vanderbilt University Medical Center News and Communications.*

## New Workshop Series on ASD in Early Childhood BY NICOLETTE BRIGHAM

Beginning August 2011, TRIAD and the Tennessee Early Intervention System (TEIS) will begin a collaboration to provide a series of workshops directed to parents of young children with ASD and their TEIS service providers.

“Early intervention is a critical service for young children with autism in order to promote communication and social development,” said Zachary Warren, Ph.D., TRIAD director. “Parents can do great things for their children when armed with the right tools. Ideally, parents and early intervention providers form a partnership to promote a child’s optimal development. TRIAD is grateful to TEIS for partnering on this innovative model involving both parents and providers.”

Workshop topics are based on the TRIAD Families First training series and will include:

- Family Daily Activity Routines. In this workshop, parents learn strategies to teach adaptive behaviors as well as to manage challenging behaviors during their daily routines. The focus is on increasing participation and independence during meals, baths, and bedtime. Parents are provided visual supports to

implement at home during these routines.

- Communication 101. This workshop is designed for parents of children who have not yet begun to use words. The emphasis is on the use of visual supports and nonverbal communication to help a child move toward more intentional and specific communication forms and to pave the way for future verbal speech development.
- Addressing Challenging Behaviors. This workshop is targeted to parents of children who display

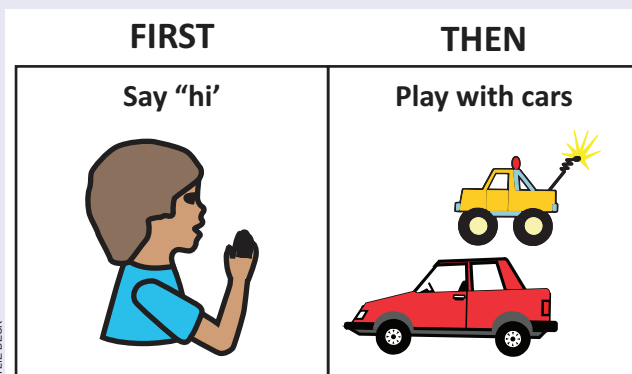
challenging behaviors such as noncompliance, aggression, elopement, or other behaviors that impact their ability to learn and function within the family. Basic strategies based on Applied Behavior Analysis (ABA) are taught, and parents are given visual supports to help teach new adaptive behaviors to replace challenging ones.

Each of these workshops will be provided to approximately 45 participants in Middle Tennessee, including 15 professionals identified and selected by TEIS and 20 to 30 families.

As part of the collaboration, TRIAD consultants also will train and mentor the selected TEIS providers in workshop replication. This effort will include the development of a training manual and DVD.

For information, contact [nicolette.brigham@vanderbilt.edu](mailto:nicolette.brigham@vanderbilt.edu), (615) 936-2163. ■

*Nicolette Brigham, Ph.D., is director of TRIAD Outreach and Training and assistant professor of clinical pediatrics.*



Above is a sample of a visual support strategy that is included within the workshops.





## Leading the Vanguard of Discovery

### Edward Gage Conture, Ph.D.

Professor of Hearing and Speech Sciences  
Director of Division of Graduate Studies  
Vanderbilt Kennedy Center Investigator  
Joined Vanderbilt Kennedy Center 1999



#### Research Interests

For nearly 40 years, I have been empirically investigating stuttering in young children. These investigations have focused on motoric, psycholinguistic, emotional, and their combined contributions. Our most recent program of study, in collaboration with Tedra A. Walden, Ph.D. (Psychology and Human Development), is addressing emotional and linguistic contributions to childhood stuttering.

#### Principal Investigator

- Emotional and Linguistic Contributions to Childhood Stuttering, National Institute of Deafness and Other Communication Disorders (NIDCD)
- Emotional Reactivity, Regulation and Childhood Stuttering, NIDCD
- Linguistic Processes of Children Who Stutter, NIDCD
- Stuttering and Disordered Phonology in Young Children, NIDCD

#### Honors and Awards

- Clinical Achievement Award, American Speech-Language-Hearing Foundation, 1988
- Fellow, American Speech-Language-Hearing Foundation, 1991
- Margaret O. Slocum Professor of Education, Syracuse University, 1993-1997
- Malcolm Fraser Award, Stuttering Foundation of America, 2003
- Honors, National Student Speech-Language-Hearing Association, 2005
- Frank R. Kleffner Clinical Career Award, American Speech-Language-Hearing Foundation, 2005
- Distinguished Alumni Award, Department of Speech Pathology and Audiology, University of Iowa, Iowa City, 2007
- Honors of the Association, American Speech-Language-Hearing Association, 2007
- Candidate, Fulbright Specialist Roster, 2010
- Grantee, Fulbright Specialist Program, Public/Global Health, Bulgaria, 2011

#### Education

- B.S., 1967, Communication Sciences and Disorders, Emerson College, Boston, MA
- M.A., 1968, Speech-Language Pathology, Northwestern University, Evanston, IL

- Ph.D., 1972, Speech-Language Pathology, University of Iowa, Iowa City, IA

#### Attraction to Developmental Disabilities Research

Born with a bilateral cleft of the lip, hard and soft palates, from an early age I experienced the challenges of living with a disability. As part of this experience, I interacted with oral-facial surgeons, audiologists, otologists, orthodontists, and speech-language pathologists. Over time, I came to appreciate that one could gain unique perspectives about disability from coping with a disability. This turning-lemons-into-lemonade perspective led me to consider careers through which I could pursue and blend my scientific and humanistic interests. As an undergraduate, I became interested in communication sciences and disorders.

Maintaining that interest through graduate school and into my career as a teacher-scholar, my Ph.D. students and I began to focus increasingly on stuttering, a complex problem requiring concurrent empirical exploration of speech acoustics and physiology, neuro-physiology, and psycholinguistics together with emotional, developmental, environmental, psychological, and social perspectives. These explorations led me to believe that stuttering, not unlike other human problems, most likely results from a complex interaction between a child's environment (nurture) and a child's skills and abilities (nature).

As part of these research experiences, I have become increasingly intrigued with how researchers from different disciplines, shining their individual and collective light on a common problem, can often produce discoveries not always possible by a single investigator.

Through such interdisciplinary efforts, our research team has been able to push back some of the frontiers of basic and applied knowledge regarding stuttering. By so doing, I hope that other children, especially those who stutter, might travel a smoother developmental highway than was available to me as a child.

#### Reasons for VKC Membership

In so many different ways, the VKC carries out the work near and dear to the Kennedy family, a family interested in disabilities long before such

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## Accolades BY AMY POTTIER

Many VKC distinguished researchers recently have been **named to Vanderbilt endowed chairs**, including: **Ellen Wright Clayton**, J.D., M.D., Craig-Weaver Chair in Pediatrics; **Kathryn M. Edwards**, M.D., Sarah H. Sell and Cornelius Vanderbilt Chair; **Jonathan Haines**, Ph.D., Louise B. McGavock Chair in Human Genetics; **Steve Hollon**, Ph.D., Gertrude Conaway Chair in Psychology; **Carl H. Johnson**, Ph.D., Stevenson Chair in Biological Sciences; **Karoly Mirnics**, M.D., James G. Blakemore Chair in Psychiatry; and **Sohee Park**, Ph.D., Gertrude Conaway Chair in Psychology.

**Michael Aschner**, Ph.D., Gray E. B. Stahlman Professor of Neuroscience, **received the 2011 Society of Toxicology Merit Award** for his distinguished contributions to toxicology. Aschner is a worldwide authority in the field of metal neurotoxicity.



*Michael Aschner, Ph.D.*

**Shari Barkin**, M.D., director of the Division of General Pediatrics, authored a **paper that was selected as the best abstract at the Global Consensus in Pediatrics International Meeting in Paris, France**. The abstract, "Changing Growth Trajectories in Early Childhood with Overweight Latino Preschoolers," was selected from among 400 submitted.

**John W. Brock III**, M.D., was **named the Monroe Carell Jr. Chair and surgeon-in-chief** for the Monroe Carell Jr. Children's Hospital at Vanderbilt.



*Vivien Casagrande, Ph.D.*

**Vivien Casagrande**, Ph.D., professor of Cell and Developmental Biology, was **named a fellow of the American Association of Anatomists**. The honor recognizes "excellence in science and in . . . overall contributions to the anatomical sciences." She is the first fellow from Vanderbilt.

**Ellen Wright Clayton**, J.D., M.D., Craig-Weaver Chair in Pediatrics, **received the 2010 William G. Bartholome Award for Ethical Excellence**. The American Academy of Pediatrics Section for Bioethics gives the award in recognition of significant impact on public discussion of ethical issues in pediatrics.

*Continued on page 7*



## ACCOLADES from page 6

Two VKC researchers were recognized at the Spring Faculty Assembly. **Bruce Compas**, Ph.D., Patricia and Rodes Hart Professor of Psychology and Human Development, **received the Joe B. Wyatt Distinguished Professor Award**. The award recognized Compas's research on depression in adolescents, psychological adjustment of children with cancer, and neurocognitive deficits of children with cancer or sickle cell disease.

**Bunmi Olatunji**, Ph.D., assistant professor of Psychology, **received the Ellen Gregg Ingalls Award for Excellence in Classroom Teaching**. This award is determined by the Chancellor based on nominations from students.

**Edward Conture**, Ph.D., professor of Hearing and Speech Sciences, was **named to the Fulbright Specialist Roster**. He will remain on the roster for 5 years, during which time he will consult with overseas governments or universities in the area of speech-language pathology/applied linguistics.

**Ronald Cowan**, M.D., Ph.D., associate professor of Psychiatry, became a **member of the Vanderbilt Academy for Excellence in Teaching**.

**Elisabeth Dykens**, Ph.D., Annette Schaffer Eskind Chair and director of the Vanderbilt Kennedy Center, was **named to the Special Olympics International Board of Directors**.

**Douglas Fuchs**, Ph.D., and **Lynn Fuchs**, Ph.D., Nicholas Hobbs Chairs in Special Education and Human Development, published an **article that was selected by Thomson Reuters Essential Science Indicators<sup>SM</sup> as a featured Fast-Breaking Paper** in the field of Social Sciences, indicating that it is one of the most-cited papers in its discipline published during the past 2 years. The article, "The 'Blurring' of Special Education in a New Continuum of General Education Placements and Services," co-authored with Pamela Stecker (Clemson U.), was published in *Exceptional Child*.



Alfred George, Jr.,  
Ph.D.

**Alfred George, Jr.**, Ph.D., the Grant W. Liddle Professor of Medicine, was **elected a fellow of the American Association for the Advancement of Science**.

**John Gore**, Ph.D., Hertha Ramsey Cress Chair in Medicine, Chancellor's University Professor of Radiology and Radiological Sciences, was **elected to the National Academy of Engineering** for his contributions to the development and applications of magnetic resonance and other imaging techniques in medicine. Gore was also **elected a fellow of the American Association for the Advancement of Science**.

Three VKC researchers **won the 2010 Young Investigator Awards from NARSAD**, the world's leading mental health research charity. The three were **Elizabeth Hammock**, Ph.D., instructor in Pediatric Endocrinology; **Jeremy Veenstra-VanderWeele**, M.D., assistant professor of Psychiatry; and **Qi Zhang**, Ph.D., assistant professor of Pharmacology. Each will receive 2-year funding for innovative brain and behavioral studies of serious psychiatric disorders.

**Steven Hollon**, Ph.D., Gertrude Conaway Chair in Psychology, **received the 2011 Florence Halpern Award for Distinguished Professional Contributions to Clinical Psychology, Society of Clinical Psychology (APA Division 12)**.

**Linda Hood**, Ph.D., professor of Hearing and Speech Sciences, was **co-author on the poster titled Auditory Neuropathy/Auditory Dys-synchrony, which won a first-place award at the**



John Gore, Ph.D.

**Early Hearing Detection and Intervention Conference**. The poster provided a timeline of intervention for children with auditory neuropathy spectrum disorder and highlighted the importance of a multidisciplinary team in intervention.

**Cassandra Newsom**, Psy.D., assistant professor of Pediatrics, was **named director of psychological education for the VKC TRIAD**.

**Carol Rabideau**, L.C.S.W., social worker with the VKC UCEDD, **received a Commitment to Service Award from the University of Tennessee College of Social Work**.



Carol Rabideau,  
L.C.S.W.

**Elaine Sanders-Bush**, Ph.D., professor emerita of Pharmacology, **received the 2011 Julius Axelrod Award from the American Society for Pharmacology and Experimental Therapeutics**. The award is one of pharmacology's highest honors.

**Tricia Thornton-Wells**, Ph.D., assistant professor of Molecular Physiology and Biophysics, was **recognized as one of "Tomorrow's PIs" by the magazine Genome Technology**. The publication profiled 24 young investigators from around the world who are rising stars among principal investigators (PIs) in the fields of genomics and systems biology.

**Georgene Troseth**, Ph.D., and **Bethany Rittle-Johnson**, Ph.D., associate professors of Psychology, were **interviewed about their research for the national Mind in the Making initiative**, which aims to share the science of children's learning with families and professionals. A video based on research interviews will be available to families and academics. ■

## VANGUARD – EDWARD CONTURE from page 6

interest was popular. In particular, the Kennedy Center's support of interdisciplinary collaborations has been crucial to my research as well as to that of many other VKC investigators. Indeed, the VKC has been a cornerstone in the development of Vanderbilt's strong culture of collaboration. Specific to my work, for some time I have been convinced of the salience of emotional processes to a comprehensive understanding of childhood stuttering; however, we lacked the necessary expertise to launch a meaningful program of study of emotion. Through the VKC, the necessary

expertise was found in Dr. Tedra A. Walden. The resulting collaboration has led to an NIH-supported program of study and promising line of investigation for several years to come. Without the VKC, this collaboration would not have occurred, a collaboration that has made a difference in my research that will, I believe, make a difference in the lives of people who stutter and their families.

## Selected Publications

Arnold, H., Conture, E., Key, A., & Walden, T. (in press). Emotional reactivity, regulation and childhood stuttering: A behavioral and electrophysiological study. *Journal of*

*Communication Disorders*.  
Byrd, C., Conture, E., & Ohde, R. (2007). Phonological priming in young children who stutter: Holistic versus incremental processing. *American Journal of Speech-Language Pathology*, 16, 43-53.  
Conture, E., & Walden, T. (in press). Dual Diathesis-Stressor Model of Stuttering. Chapter to appear in Beliakova, L., & Filatova, Y. (Eds.). *Theoretical Issues of Fluency Disorders*. Moscow: Vidos.  
Coulter, C., Anderson, J., & Conture, E. (2009). Childhood stuttering and dissociations across linguistic domains: A replication and extension. *Journal of Fluency Disorders*, 34, 257-278.  
Johnson, K., Walden, T., Conture, E., & Karrass, J. (2010). Spontaneous regulation of emotions in preschool-age children who stutter: Preliminary findings. *Journal of Speech, Language, and Hearing Research*, 53, 1478-1495. ■





## “Every Voice Is Important”

The Vanderbilt LEND, like other national LENDs and UCEDDs, prepares future health care and related professionals to be leaders in improving systems of care and services for persons with developmental disabilities and their families. Leadership preparation includes providing experiences in educational advocacy with state and national legislators. Two LEND Trainees describe recent advocacy experiences.

### Family Trainee Perspective

BY LYNISE PARI SIEN

As a parent of a child with a disability, I have been vaguely aware of how disability policies impact my family. With my daughter only 8 years old, my focus has been on her current and short-term needs rather than seeing the larger, long-term picture.

As the 2010-11 LEND Family Trainee, I attended the 2011 Disability Policy Seminar in Washington, DC, sponsored by several national disability organizations. As I sat there alongside the other 600 advocates, parents, and individuals with disabilities, reality started to sink in. I realized that the policies that are being implemented now will be reaching maturation by the time my daughter graduates from high school and will potentially need these services.

Our federal and state governments are focused on reducing spending, which means that funding for important programs to help individuals with disabilities and their families are at risk of funding reductions or even elimination. This includes helping individuals with disabilities find affordable housing, health care, training skills for jobs, and finding jobs.

The first two days were information sessions about the federal budget and what we might address with our U.S. Representatives and Senators. The third day was “on the Hill.” Personally, I have never been interested in politics or even wanting to meet with politicians—but I must say it was an interesting experience.

A long time ago when I realized that what I was doing for my daughter was considered advocacy, it put a whole new perspective on standing up for her needs and rights. I started to understand the importance of fighting for her needs and learning to assertively request those needs. It is no different sitting with legislators and their aides. It really comes down to helping legislators understand how programs impact

individuals with disabilities and their families and what the ramifications would be if funds were cut.

I went with a small group to see three Tennessee legislators. They were in session and unable to meet with us directly, so we met with aides. The first aide was interested in what we had to say and was up to speed on our organization. It was an easy conversation to share some personal stories and how cuts would impact families. The second was unfamiliar with why we were there and was distant. It wasn't until we were able to make it real by telling personal stories that we created some traction in showing the importance of funding these programs. The final session was with a legislator who continues to support programs for individuals with disabilities. The aide spoke with

our message will go much further. It was a whirlwind of information, but overall it was a wonderful experience. I look forward to learning more about these programs, keeping up with the budget cuts, and continuing to advocate for my daughter and others with disabilities and their families.



NiCole West

### Social Work Trainee Perspective

BY NICOLE WEST

I attended Middle Tennessee Disabilities Day on the Hill in March. I arrived at Legislative Plaza early and visited the disability tables. Individuals with disabilities were there ready to meet with their representatives. At The Arc Tennessee table, we gathered materials to give to legislators with whom we were meeting and we discussed proposed legislation, such as limits on restraint and isolation in school settings.

In our first meeting with a State Representative, I discussed how I came to know about the disability world and what makes me want to continue in the field. We shared information about the bills in which we were interested and gave information about disabilities and their impact on families.

Our State Senator was in a Committee Meeting, so we left materials with his staff. I wish we had been able to present the material and provide a fresh perspective and different thinking.

Observing a Committee Meeting, I was able to see some of Tennessee's legislators in action. Their differing viewpoints showed me how important it is for all of Tennessee to be represented, because what might work for big cities, like Nashville, does not necessarily work for rural towns, like mine.

This was a wonderful experience. I left feeling I could make a difference and that there was not really anything to keep me from going to Legislative

Plaza and learning about what my legislators are doing. I became aware that it is possible to go and speak directly to my representatives, and that I do have a voice in the State of Tennessee. I also learned that because I have a voice, I need to speak up for those who are not able to do so for themselves. This is the only way that every voice will be heard—because every voice is important. ■



Lynise Parisien and daughters Rachel (age 11) and Brooke (age 8)

us for about 30 minutes and then the legislator joined us, spending about 10 minutes listening to our stories and suggesting ways to address our initiatives.

My takeaway: one person can make a difference. Politics will be politics, but if we learn to have meaningful conversations with our representatives,





## VKC UCEDD Reaching Out BY COURTNEY TAYLOR

### Third TABS Conference

Bringing together adult siblings who have a brother or a sister with a disability to share experiences, gather information, and grow a statewide network of support was the aim of the Third Annual TABS Conference, April 8-9. Presentations and sessions covered Person-Centered Thinking and Planning, TennCare Rights, Caring for the Caregiver, Sibshops, Inclusion in Faith Communities, Future Planning, and more.

Keynote speakers were Don Meyer, director of the national Sibling Support Project and creator of Sibshops, and Dee Dee Eberle, The Arc-US director of Chapter Organizing and Advocacy.

“Don Meyer, whom I affectionately refer to as ‘the godfather of sibling supports,’ kicked off the conference,” said Ashley Coulter, VKC Sibling Programs coordinator. “As he was speaking, I felt an audible sigh of relief from the group as they realized that they are not alone and that their feelings are normal, regardless of what their current role might be in the lives of their siblings. It was a wonderful opening to an empowering two days.”

Co-sponsors included the Tennessee Council on Developmental Disabilities, The Arc Tennessee, University of Tennessee Boling Center for Developmental Disabilities, TigersEye Advisory LLC, Tennessee School for the Deaf, Siblings United, East Tennessee State University, and Holiday Inn at Vanderbilt.

**Sibling Leadership Network.** The national Sibling Leadership Network (SLN) Board gathered in advance to draft a practical vision of success for SLN over the next 3 years. Goals were set to recruit more members, establish new state chapters, and expand partnerships with disability agencies across the country. The SLN mission is to provide siblings information, support, and tools to advocate with their brothers and sisters with disabilities and to promote issues important to them and their families.

For more information on TABS or SLN, contact (615) 343-0545, [ashley.coulter@vanderbilt.edu](mailto:ashley.coulter@vanderbilt.edu).

### Second AAC Workshop

In the U.S., an estimated 2 million children are unable to communicate using natural speech. Augmentative and alternative communications (AAC) are effective methods that can allow these children to express themselves and connect with families, teachers, and friends. The Second Annual AAC Workshop was held at the VKC April 1-2. For families, an evening panel of three sets of parents whose children have various types of disabilities and who use AAC presented parent perspectives on acquiring and using AAC.

For professionals, a 1-day workshop addressed “Curriculum Adaptations for

Students with Complex Communication Needs,” led by Pati King-DeBaun, M.S., CCC-SLP, founder of Creative Communicating.

Workshop co-sponsors were Special Education, Vanderbilt Peabody College; Hearing and Speech Sciences, Vanderbilt Bill Wilkerson Center; Vanderbilt LEND Training Program; Disability Law & Advocacy Center of Tennessee; Technology Access Center (TAC); and Prentke Romich Company (PRC).

For AAC information, contact TAC, (615) 248-6733, (1-800) 368-4651; [www.tacnashville.org](http://www.tacnashville.org).

### United Through Colors

In addition to its support meetings, held at Southminster Presbyterian Church, the VKC Support Group for Spanish-Speaking Families organizes social activities. These opportunities have proven to be important since some parents

report feeling isolated, largely due to language and cultural barriers. Previous activities included outings to sporting events and museums. The latest provided families an opportunity for creative expression through art.

Each participant created an individual image, which Colombian artist Jorge Yances arranged into a collage. In describing his work, Yances creates art that “invites the viewer to make up his or her own story and allows them to see beyond the obvious into a world of endless possibilities.” This is an apt description of *United Through Color*, on display in the VKC (see calendar insert).

“It was nice to see families come together and create images that represent what the support group means to them,” said Carolina Meyerson, Spanish Services coordinator, Tennessee Disability Pathfinder. “I am so proud of them and of the beautiful painting they created.” For information on Multicultural Programs, contact (615) 875-5083, [alexander.santana@vanderbilt.edu](mailto:alexander.santana@vanderbilt.edu).



Colombian artist Jorge Yances creating art with Hispanic families.

### Alternative Spring Breaks

Next Steps at Vanderbilt students, Vanderbilt undergraduates, and members of Vanderbilt Best Buddies traveled to Denver and Miami over Spring Break to do community service. They did clean-up in the Everglades, worked at a Miami homeless shelter, served at a Denver food bank, and helped with the Colorado Special Olympics Winter Games. A special treat of the Miami trip was meeting with Anthony Shriver, founder and leader of Best Buddies International.

Next Steps at Vanderbilt students were asked to blog about their experiences; two posts follow.

• “On my Spring Break trip, I went to Miami. My favorite memories were playing basketball with my friends [and] telling a story about my life. . . . I thought working at Camillus House and helping serve food to homeless people was a nice way to help . . . . At the Everglades National Park, we picked up trash around the canal, and I saw a gator in the river. I thought the overall experience was fun because I discovered new things.”—*Sean Faulkner*

*Faulkner*

• “For my Spring Break I went to Denver. One of my favorite memories was bowling because I beat Tammy by one pin and my highest score was a 129! We had to get up at 5:45 in the morning and go to the Special Olympics . . . . Then another thing we did was called the Food Works and we unloaded boxes and sorted them . . . . This was my first Spring Break with Best Buddies and it was awesome!!!!”

—*Michael Heroux*

For more Spring Break blog entries, visit [kc.vanderbilt.edu/nextstepblog](http://kc.vanderbilt.edu/nextstepblog). For more on Next Steps at Vanderbilt, contact (615) 343-0822 [nextsteps@vanderbilt.edu](mailto:nextsteps@vanderbilt.edu). ■



Volunteering at Food Works in Denver on Alternative Spring Break.





## Leadership Council Working “from the Heart” BY JAN ROSEMERGY

When they needed advice on their child’s late talking, Lorie and John Lytle learned about the Kennedy Center from a neighbor.

A long-time Nashville resident, Lorie realized that if she didn’t know about the VKC, many other families probably didn’t know either. She joined the VKC Leadership Council and—with a career as a publicist—set out to work with other

Council members and the VKC leadership “to shine a light” on the Center. For evidence that she has succeeded beyond her wildest dreams, see the ACM Lifting Lives Moment (p. 11).

Each Leadership Council Member has a story to share—as a parent, grandparent, sibling, or friend. Over time, disability touches all our lives. In the words of the

Music Camper’s song, Leadership Council members work “from the heart.” They serve as community champions on behalf of the VKC.

“Our Council members play an increasingly important role in connecting the Kennedy Center with the community at both a local and regional level,” said Donna Eskind, Council Chair. “They have an important impact on the Center’s ability to serve individuals with disabilities and their families.”

With Eskind’s leadership, the Council committed itself in 2010 to working in five areas between its regular Spring and Fall meetings.

One of the great achievements of the Council has been its growth of the **Nicholas Hobbs Donor Society**. Members are individuals who donate \$1,000 or more in a year. Since 1998, Council chairs and members have been

instrumental in increasing donor giving. Funds raised through the Hobbs Society support **Hobbs Discovery Grants**, innovative, interdisciplinary pilot research grants that play an important role in the success of VKC investigators in garnering larger federal grants. LC members serving on the **Hobbs**

**Society Committee**, chaired by Shirley Speyer, assist in identifying individual donor prospects and help raise awareness of the impact that these gifts have collectively on the lives of children and adults with disabilities and their families.

To keep “shining that light” on the VKC, the Council’s **Lunch and Learn Committee** organizes 2-hour mid-day events a few times each year. LC members invite family members, friends, and

colleagues to learn about the Center over lunch. Each time the program varies, highlighting a fascinating research program, a service program that is helping families, and hearing directly from a parent, grandparent, or individual with a disability how the VKC has affected their lives.

“These events have been truly beneficial in creating new friends for the Kennedy Center,” Eskind said.

The **Major Gifts Committee** identifies individual or corporate prospects. Committee members also introduce interested persons and help build relationships. To facilitate this process, Council members host small receptions or dinners, often in their homes, where interested persons can get to know VKC leaders.

The **Nominating Committee** helps maintain the Council’s vitality by annually reviewing membership, identifying and recommending prospective members, and assisting in recruiting members.

The **Marketing and Development Committee**, chaired by Melissa Beasley, is charged with educating and raising community awareness about the VKC and its programs. Collaborating with VKC Communications and Dissemination staff, members provide advice and support on strategic marketing initiatives, and help strengthen and expand community partnerships.

For additional information about the VKC Leadership Council, contact Linde Pflaum, [linde.pflaum@vanderbilt.edu](mailto:linde.pflaum@vanderbilt.edu), (615) 936-1627. ■



Linda Brooks, Elisabeth Dykens, Madge Bass

## Hobbs Society Donors Honored by Vanderbilt Kennedy Center

The Vanderbilt Kennedy Center Leadership Council thanked members of the Nicholas Hobbs Donor Society with a reception on April 27 at the home of Gail and Jeff Jacobs.

The generosity of Hobbs members supports innovative research on the causes and treatments of disabilities such as autism, Down syndrome, and other genetic syndromes.

Donna Eskind, Leadership Council chair, opened the evening’s program. Shirley Speyer, chair of the Hobbs Society, thanked members whose gifts support Hobbs Discovery Grants. Promising

findings from these innovative “seed” grants help researchers obtain federal grants for larger studies.

Professor Mark Wallace described how a Hobbs Discovery Grant enabled him to extend his studies of sensory processing to understanding sensory issues in children on the autism spectrum. Findings from the Hobbs Grant were instrumental in his receiving federal funding for a larger study that is evaluating sensory integration treatment.

Jeff Balsler, Vanderbilt Vice Chancellor for Health Affairs and Dean of the School of Medicine, thanked Hobbs Society members for

their important role in supporting scientific discoveries.

Jimmy Clark shared his experiences at the ACM Lifting Lives Music Camp at the Vanderbilt Kennedy Center and the Music Campers’ recent performance with Darius Rucker on the Academy of Country Music Awards Show.

VKC Director Elisabeth Dykens thanked the many Hobbs Society members who fund groundbreaking science that over time may lead to improvements in the quality of life for children and adults with disabilities and their families. ■



Jeff and Donna Eskind, Shirley and Stuart Speyer



Jeff and Gail Jacobs, Jeff Balsler, Bernice and Joel Gordon



John and Lorie Lytle, Sissy Allen





## Our ACM Lifting Lives Moment!

Chart-topping country music star **Darius Rucker** and ACM Lifting Lives® partnered for a once-in-a-lifetime musical event that benefited the Vanderbilt Kennedy Center. Performing together for the first time, 25 ACM Lifting Lives Music Campers with Williams syndrome or other developmental disabilities joined Rucker on the Academy of Country Music (ACM) Awards stage to sing “Music from the Heart,” a song the campers wrote collectively last summer with ACM Lifting Lives Music Camp songwriters **Brett James** and **Chris Young**. The special moment was performed during the 46th Annual ACM Awards, and was broadcast live by CBS from the MGM Grand in



Musician Darius Rucker (center) and the AMC Lifting Lives Music Campers Chorus perform onstage at the 46th Annual Academy of Country Music Awards held at the MGM Grand Garden Arena in Las Vegas on April 3.

Las Vegas, April 3. Rucker and the Campers were introduced by Young and **Julianne Hough**, Music Camp friend and country singer. View the Moment at [kc.vanderbilt.edu/acmawards](http://kc.vanderbilt.edu/acmawards).

The performance by Rucker and the Campers not only moved the audience but viewers from around the country and even other countries, as Facebook comments by families and service providers showed. Ability and talent were in the spotlight. The response of many was hope for better quality of life for individuals with disabilities.

The gratitude felt by all of us at the Vanderbilt Kennedy Center is wonderfully expressed in the letter below by Monica Schmidt, mother of Karina Scali, a Music Camper from Oakville, Ontario. ■

## We Love You

Dear Friends,

*You have lifted our lives, and our hearts will never be the same.* We are so full of love for all of you. Experiences are the best gifts because they are forever etched in memory. You have created an awareness in the world that has moved so many people. Our children will never forget it.

We are so grateful to all our American friends at the Academy of Country Music and the Vanderbilt Kennedy Center including *Erin Spahn, Bob Romeo, Lori Christian, Lorie and John Lytle, Elisabeth Dykens, Laura Pevahouse, Elizabeth Roof, Jenny Plume, Darius Rucker, Brett James, Chris Young, all the ACM officers, everyone on the Board of Directors.* Also, *to everyone we don't know who worked so hard behind the scenes to make this happen.* Thank you for making my daughter's and our dreams come true.

Disability crosses many borders, and you have all been so gracious, loving, and inclusive of Karina. I cannot help but feel that this was a divine intervention. It began last Spring. I was searching for music camps for people with disabilities in the U.S. Because of visits to the Vanderbilt Estate in North Carolina, I recognized the Vanderbilt Kennedy Center name at the top of my search engine results and on their site found the ACM Lifting Lives Music Camp. We decided we would drive from Asheville to Nashville so that Karina could experience your wonderful Music Camp.

When I was 17, I survived a tragic car accident. I lost four of my dear friends. To honor my best friend Karen, I named my only baby girl Karina.

Karina embodies Karen's joyful happy spirit and her infectious smile. When I first found out that Karina had Williams syndrome, I threw myself on the floor in tears, asking God why.

Parents who have a child with a disability mourn what our children could have been. There are constant reminders. Karina sees her friends driving cars, dating and partying, while she sits at home and wishes this were her reality. It has been a long and difficult journey. We have done whatever we could to enrich Karina's life.

Every day when Karina goes into the world, she is faced with whispers, teasing, and social isolation. She wants everyone to be her friend and is so inclusive. Ironically, in elementary school she was awarded the Spirit of Inclusion Award from the Halton District School Board but throughout elementary school, she only ever had one other friend—he also had a learning disability. They were both isolated on the playground which helped perpetuate that stereotype in the minds of others, that if you are different, you don't belong with us.

When I saw Karina standing there on that huge stage, with all her American friends, sharing



Camper Karina Scali

their message of awareness through music, it was so moving that it brought tears to my eyes. There is a God, and, now I understand why my life was spared and why Karina was born. It was to stand in unity with her American friends, to create awareness by creating and singing “Music from the Heart.”

Karina told me after she sang that she felt so connected, so loved, like everyone was her family. At school and on her Facebook page, and in the community, she felt like a superstar. ACM Lifting Lives has made such a difference in our

lives. I am typing through tears.

We have always taught Karina that she should be proud of who she is, and we prayed for those who do not understand. “Music from the Heart” touched so many people, and I know it will leave a legacy. Darius sang it beautifully. Please hug him for us. Karina had a wonderful spiritual connection with Brett James, Chris Young, and the Campers, when they wrote the song together—one that will be hard to duplicate. We are forever grateful to all of you. You are part of our extended family, our friends. “Thank you” just isn't enough. Now let's take it back across the border into Canada—folks still need to know.

Gratefully yours, hugs from Canada,  
Monica Schmidt & Frank and Karina Scali



Leadership Council of Vanderbilt Kennedy Center

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Dr. Jan Rosemergy  
Mr. Tim Stafford



# Light It Up Blue at VU

Faculty and staff of the Vanderbilt Autism Treatment Network, TRIAD, Division of Developmental Medicine (DDM), and others joined Autism Speaks in their April Light It Up Blue campaign to “shine a bright spotlight on the public health crisis of autism and improve the future” for persons with autism.

*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.

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Tim Stafford, *Director of Operations*

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Elise McMillan, J.D., *Co-Director; Services*  
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Jan Rosemergy, Ph.D., *Dissemination*

LEND  
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# CALENDAR OF EVENTS | JUNE-SEPTEMBER 2011

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 [amy.pottier@vanderbilt.edu](mailto:amy.pottier@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.



*United Through Colors*, a collage on exhibit at the VKC, celebrates the individual work of children and parents of the VKC Support Group for Spanish-Speaking Families. See story, p. 9.

■ **JUNE 18**

*Interprofessional Course in Developmental and Behavioral Pediatrics*

For pediatricians, family physicians, pediatric and family nurse practitioners, nurses, occupational and physical therapists, speech-language pathologists, audiologists, social workers, and clinical and developmental psychologists

Co-Sponsors Developmental Medicine, Dept. Pediatrics; VKC LEND, Dept. Nursing Ed. & Prof. Dev., VUMC. Advance registration required. Register at [kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration) Information (615) 936-0262 Saturday 8:15 a.m.-4:30 p.m. Vanderbilt Bill Wilkerson Ctr, 8th Flr Medical Ctr E—Rm 8380A

■ **JUNE 17 AND 18**

*SENSE Theatre Performances*  
Public is welcome at this original play (with music) performed by students

on the autism spectrum and peer actors in USN Theatre Guild.

\$10 admission. Co-Sponsor University School of Nashville Friday and Saturday, 7:00 p.m. Auditorium, University School of Nashville, 2000 Edgehill Avenue

■ **JUNE 18, AUGUST 20\***

*SibSaturday*  
For siblings 5-7 and 8-13 years who have brother/sister with disability Games, friends, conversation \$10/child or \$20/family Financial assistance available. Advance registration required. Contact [ashley.coulter@vanderbilt.edu](mailto:ashley.coulter@vanderbilt.edu), (615) 343-0545

■ **JUNE 20\***

*What's on the Forefront of Fragile X Syndrome Research? Community Forum*  
For families, researchers, and service providers  
Co-Sponsor National Fragile X

Foundation. Register at [kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration) Monday 6-7:30 p.m.

■ **JUNE 29**

*Neuroscience Graduate Program Seminar Series Hypoxia Inducible Genes and Repair in the Newborn Brain*  
Donna M. Ferriero, M.D., M.S., W. H. and Marie Wattis Distinguished Professor and Chair, Department of Pediatrics; Physician-in-Chief, Benioff Children's Hospital, University of California-San Francisco  
Co-sponsor Vanderbilt Brain Institute Wednesday, 4:10 p.m. Room 1220 MRB III Lecture Hall

■ **JULY 7-9**

*Sib Camp*  
A 3-day overnight camp in Knoxville for siblings ages 8-13 who have a brother or a sister with a disability  
Contact (865) 579-2429 [tinap@tsd.k12.tn.us](mailto:tinap@tsd.k12.tn.us)

■ **JUNE 13\***

*Families First Workshop Family Activity Routines: Cooking, Chores, and Family Games*  
For parents of young children diagnosed with autism. Register at [kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration) Information (615) 322-6027 [families.first@vanderbilt.edu](mailto:families.first@vanderbilt.edu) Monday 6-8 p.m.

See website calendar for topics on July 30, August 27, and September 28





# CALENDAR OF EVENTS | JUNE-SEPTEMBER 2011

## ■ 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 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

## ■ SAVE DATE

• **October 11**

*Second Annual Disabilities & Congregation Inclusion Conference*

Co-Sponsor Faith for All

Information (615) 322-5658

## ■ 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

## ■ 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

## ■ 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

## ■ READING CLINIC

Assessment and tutoring for students through middle school

Summer Sessions available

Contact (615) 936-5118

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, (615) 741-7790

See also [www.state.tn.us/education/speced/announcements.shtml](http://www.state.tn.us/education/speced/announcements.shtml)

## ■ 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

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

[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

• **JUNE 23, JULY 28\***

*Autism Education Workshops*

Child care available with

advance request

Thursday 6:30-8:30 p.m.

• **JULY 21, SEPTEMBER 15\***

*Autism Orientation*

Child care available with

advance request

Thursday 6:30-8:30 p.m.

## ■ COMMUNITY EVENTS

• **JUNE 2-3**

*Tennessee Disability MegaConference*

Nashville Airport Marriott

[www.tndisabilitymegaconference.org](http://www.tndisabilitymegaconference.org)

• **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*

## ■ DSAMT EVENTS

*Down Syndrome Association of Middle Tennessee*

[www.dsamt.org](http://www.dsamt.org)

DSAMT event information

(615) 386-9002

• **JUNE 9**

*Caleb Thompson Memorial Golf Tournament*

7 a.m.-1 p.m.

Vanderbilt Legends Club

• **JUNE 16, JULY 21,**

**AUGUST 18**

*DADS*

Monthly gathering for fathers

6:30-8 p.m.



Next Steps at Vanderbilt students performed with singer/songwriters Tammy Vice and Trent Jeffcoat at the VSA Tennessee 10th Anniversary Celebration. They sang a song that they co-wrote about self-advocacy. Over 600 school children with disabilities attended the event to learn about the arts.