





## What We Do

### Discover

The Vanderbilt Kennedy Center is a place where science brings hope. We have been transforming lives by translating research into practice for over 50 years. Behavioral scientists, neuroscientists, educators, physicians, imaging specialists, and geneticists work together with families to unravel the mysteries of development and developmental disabilities.

### Learn

The Vanderbilt Kennedy Center trains individuals across the many professional fields that contribute to services and supports that enhance the quality of life of children and adults with disabilities in their communities.

### Share

Across our state, region, and nation, the Vanderbilt Kennedy Center shares innovative interventions and treatments through research studies, model services, helplines, websites, and publications.

### Shape the future

At the Vanderbilt Kennedy Center, we educate others to advocate for best practices, policies, and laws that will help create a world in which all children and adults with a disability are valued—are included in their schools and communities, at work, at play, and at worship. ■

**Pictured page 2:** (1) 2017 Next Steps at Vanderbilt graduates. Photo by Kristi Irving. (2) Elisabeth Dykens, Ph.D., Annette Schaffer Eskind Chair. **Pictured page 3:** (3) 2017 Volunteer Advocacy Project training. (4) Autism Awareness Day at the Nashville Zoo. Photo by Nathan Zucker.



## Of Endings and Beginnings Director's Message

**O**ur Next Steps at Vanderbilt graduates walked across the stage late April and will begin new jobs.

My oldest son graduated from high school in May and will begin college. My 9 years as director of this amazing Center are ending. In August, I begin a year's sabbatical. Every ending has a new beginning. So it is for the Vanderbilt Kennedy Center.

This *Discovery* special issue is a letter to you—our disability community small and large. Our work would not be possible without you.

We *discover* biological processes underlying developmental disabilities while simultaneously improving interventions for persons with autism, learning disabilities, genetic syndromes, and acquired and general intellectual disabilities.

We *learn* together, training the next generation of researchers, clinicians,

educators, and others who will help improve quality of life for persons with disabilities.

We *share* best practices by providing model services and by training community professionals.

We *shape the future* by collaborating with state and national partners as we promote improved services and supports.

Celebrating our Center's 50th anniversary with you in 2015 was an honor. Every experiment, study, model intervention, and demonstration project is a contribution to knowledge and practice. From microarrays of genes to cell cultures, from animal models to human studies, from brain imaging to engineering virtual reality interventions for autism, our creative scientists and clinicians—and the future researchers and practitioners they mentor—are inventing a better future for children and adults with developmental disabilities. Families are our partners every step of the way.

As I end my tenure as director, our Center begins a new chapter with the leadership of



Jeffrey Neul, M.D., Ph.D. He joins us from the University of California San Diego where he was division head of Child Neurology and vice chair for Developmental Neurosciences. His research program focuses on Rett syndrome, a rare non-inherited genetic neurological disorder that leads to severe impairments in almost every aspect of life.

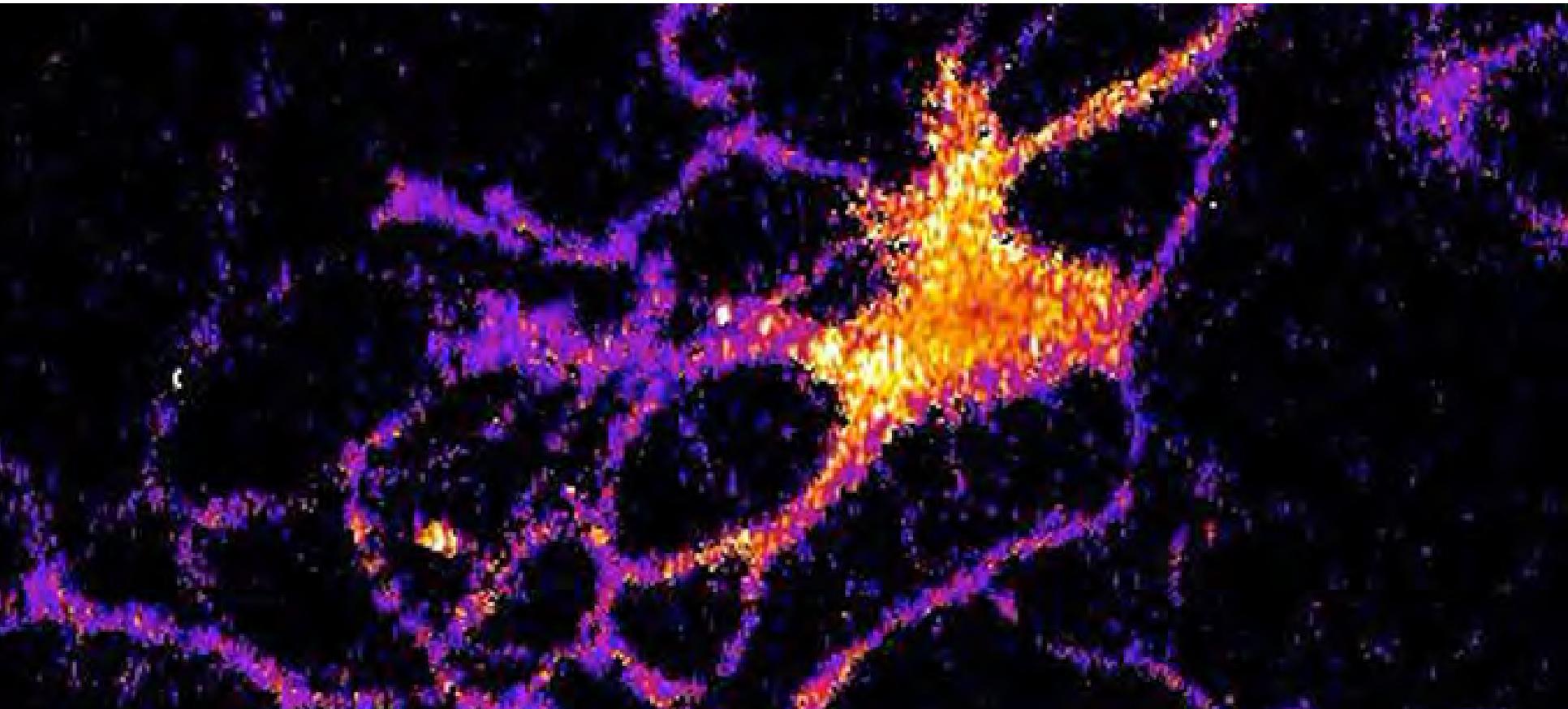
Dr. Neul is looking forward to meeting and listening to you as you work together to continue to advance the discovering, learning, and sharing that shape the future not only of this Center but also the future of children and adults with intellectual and developmental disabilities.

I end this message with enormous *gratitude* for every member of our Vanderbilt Kennedy Center family and our disability community in Nashville, Tennessee, and our nation. This ending is a new beginning for us all. ■

## Accolades

- **Erin Barton, Ph.D.** (Special Education) received the 2016 Distinguished Early Career Research Award of the Council for Exceptional Children's Division of Research.
- **Erik Carter, Ph.D.** (Special Education) received the 2016 Research Award of the Council for Exceptional Children's Division on Autism and Developmental Disabilities.
- **Roger Colbran, Ph.D.** (Molecular Physiology & Biophysics) and **Robert Macdonald, M.D., Ph.D.** (Neurology) were elected Fellows in the American Association for the Advancement of Science.
- **Jeffrey Conn, Ph.D.** (Pharmacology), with colleague Craig Lindsley, received the 2017 Vanderbilt University Medical Center (VUMC) John A. Oates Award for faculty working collaboratively to address important biological processes.
- **Laurie Cutting, Ph.D.** (Special Education) received Vanderbilt University's 2017 Joe B. Wyatt Distinguished University Professor Award in recognition of her leadership in neuroscience and education.
- **Pablo Juarez, M.Ed., BCBA** (TRIAD), received the 2016 Educator of the Year Award of The Arc of the U.S.
- **Christopher J. Lemons, Ph.D.** (Special Education), received a 2016 Presidential Early Career Award, the Distinguished Early Career Research Award of the Council for Exceptional Children's Division of Research, and the 2016 Pueschel-Tjossem Memorial Research Award of the National Down Syndrome Congress.
- **Elise McMillan, J.D.** (UCEDD, Psychiatry) was elected President of the Board of Directors, The Arc of the U.S.
- **Maria Mello** (UCEDD Trainee) received the 2017 Student Award of the American Association on Intellectual and Developmental Disabilities
- **Bunmi Olatunji, Ph.D.** (Psychology) was elected Fellow of Association for Psychological Science.
- **Tyler Reimschisel, M.D.** (Developmental Medicine/Pediatrics), was selected as a 2016 Macy Faculty Scholar, a program to identify and nurture the careers of educational innovators in medicine and nursing.
- **Craig Smith, Ph.D.** (Psychology & Human Development) received Vanderbilt's 2016 Chancellor's Cup recognizing contributions outside the classroom to undergraduate student-faculty relationships.
- **Lauren Weaver, M.S., BCBA**, received the 2017 Full Community Inclusion Award of the American Association on Intellectual and Developmental Disabilities recognizing TRIAD's Community Engagement Program.
- **Danny Winder, Ph.D.** (Molecular Physiology & Biophysics), received the VUMC 2017 F. Peter Guengerich Award for mentoring postdoctoral fellows in the research setting.
- The Vanderbilt Rett Syndrome Clinic was named a Rett Syndrome Clinical Research Center of Excellence by Rettsyndrome.org; faculty receiving the recognition included **Colleen Niswender, Ph.D.** (Pharmacology), **Cary Fu, M.D.** (Pediatric Neurology), and **Sarika Peters, Ph.D.** (Pediatrics).
- Vanderbilt endowed chair recipients in 2016 are **Doug Fuchs, Ph.D.** (Special Education), Nicholas Hobbs Chair; **Lynn Fuchs, Ph.D.** (Special Education), Dunn Family chair in Psychoeducational Assessment; and in 2017, **Sachin Patel, M.D., Ph.D.**, James G. Blackmore Chair in Psychiatry.
- **Lyle Jackson**, Peabody College videographer and his collaborator Jack Isenhour won the Mid-South Regional Emmy for Informational/Instructional Program for *Creating Hope*, VKC 50<sup>th</sup> anniversary documentary. ■

The mission of the Vanderbilt Kennedy Center is to facilitate discoveries and best practices that make positive differences in the lives of persons with developmental disabilities and their families. The need is great. One in 5 children has a developmental disability, which lasts a lifetime. Roughly 20% of U.S. families have a member with a disability.



**Pictured page 4:** (1) Individual neuron glowing with bioluminescent light produced by a new genetically engineered sensor. (2) Leisa Hammett with daughter Grace. **Pictured page 5:** (3) Left to right: Dendrite from a neuron expressing wild type CaMKII. Dendrite from a neuron expressing the ASD-linked E183V mutant CaMKII. (4) Brandon Roberson — a 16-year old on the autism spectrum — has been participating in preliminary studies of the driving simulator.

## Discover

### Family voices

Support services become more difficult to navigate once a youth with autism spectrum disorder (ASD) turns 18 and/or has graduated from the school system. Julie Lounds Taylor, Ph.D. (Special Education) developed the **Volunteer Advocacy Program-Transition (VAP-T)**, a model 12-week program, and is evaluating whether this training makes that transition smoother for parents and their son or daughter with ASD.

*Leisa Hammett, Parent*

“VAP-T offered an over-flowing treasure chest of information so desperately needed by parents navigating the turbulent and sometimes frighteningly uncertain waters



of post-22 autism adulthood. I am so grateful to have been chosen for this study. Even though my participation has been the year after actual transition for us, and even though I’ve immersed myself in all things disAbility in the 20 years since

my daughter’s diagnosis, this cleared a lot of confusion I had around the complex maze of adult services.”

**A TRIAD research study** led by Paul Yoder, Ph.D. (Special Education) and Amy Weitlauf, Ph.D. (Pediatrics) is testing which of two types of early intervention at two different levels of intensity are most effective for toddlers with ASD.

*Patricia Weldon, Parent*

“[This] has been life changing for our family.

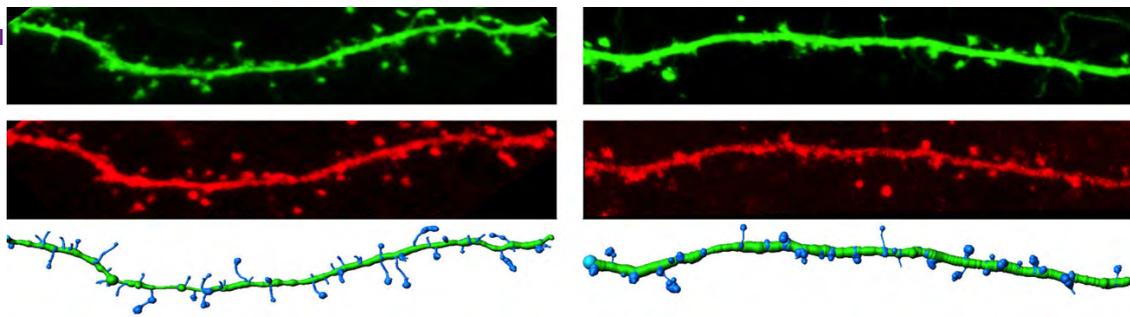
It has provided direction and answers for a diagnosis that left us lost and with questions. We are so truly thankful that we have been able to be a part of this amazing study! I cry thinking about how much improvement we have seen in our sweet Alaina Kate in such a short time.”

*Stephanie Maher*

“We would like to thank and praise all the TRIAD staff for helping us on our autism journey. They truly care for each individual and family. We would never have accomplished as much as we have without their help and support.” ■

### Improving speech therapy for children with Down syndrome

For children with Down syndrome, problems in comprehensibility of their speech may affect their ability to learn, to express themselves, to have relationships, to share their experiences, and to take part in community life. Clear Talk was a large-scale, randomized controlled trial comparing Broad Target Speech Recasts with a traditional speech therapy method. Researchers\* found that using speech recasts after child utterances that are understandable but incorrectly pronounced improved children’s ability to make themselves understood. This study provided strong evidence that speech comprehensibility of at least some school-age children with Down syndrome can be improved by providing them with 2 hrs/wk of individual therapy using this novel approach that is not focused on speech accuracy training. Moreover, both caregivers and educators could potentially be taught to incorporate this approach in their daily interactions with children with Down syndrome. Funded by IES grant R324A100225. \*P. Yoder, *Special Education*; S. Camarata, *Hearing & Speech Sciences*; T. Woynaroski, *Hearing & Speech Sciences* ■



VKC Hobbs Discovery Grant. \*R. Colbran, *Molecular Physiology & Biophysics; et al.* ■

### Virtual reality paves road to independence

VKC researchers\* are inventing ways to help teens and adults with ASD gain key life skills for independence—including the ability to drive. The RASL Lab has developed a virtual reality simulator to help teens with ASD gain the skills needed to drive safely. While “driving,” sensors are checking changes in heart rate, breathing, and brain waves, and a camera monitors eye gaze. The system is designed to give drivers immediate feedback when they make mistakes and to alter scenarios providing varying degrees of difficulty. Preliminary tests indicate that this approach can improve the rate at which participants learn. If this approach works, it could help large numbers of young people with ASD become independent, productive adults. An early Hobbs Discovery Grant helped launch research on robotics and autonomous systems in autism interventions. For video, see <http://tinyurl.com/vrdriving>. Funded by NSF grant 967170 and NIH grant 1R01MH091102-01A1. \*N. Sarkar, *Engineering*; J. Wade, *Engineering*; Z. Warren, *Pediatrics*; A. Weitlauf, *Pediatrics* ■

### Growth hormone treatment in Prader-Willi syndrome

Prader-Willi syndrome (PWS) is a complex, rare genetic disorder. It affects growth, metabolism, appetite, behavior, and overall development. Persons with PWS have an insatiable appetite that leads to life-threatening obesity. Although studies have shown that growth hormone treatment in children with PWS benefits growth and body composition, its effects on cognition have not been well-studied. Three VKC studies\* examined effects of growth hormone treatment in children with PWS ages 4 to 12 years and provided evidence of cognitive and adaptive benefits over time, providing an additional justification for growth hormone treatment in children with PWS. Funded by NIH grants HD035681, HD015052, TR000044. \*E. Dykens, *Psychology & Human Development*; E. Roof, H. Hunt-Hawkins ■

### Gene mutation discovery may hold autism clues

A team led by a VKC investigator\* has identified what may be a genetic “smoking gun” for autism spectrum disorder (ASD)—a mutation in the gene for the critical neuronal protein CaMKII. While no single mutation can explain the immensely complicated picture presented by ASD, this study is the first to link a naturally occurring mutation in the *CAMK2-alpha* gene with a specific neuropsychiatric disorder. Further characterization of the biochemical consequences of this mutation likely will provide novel insights into the molecular mechanisms underlying ASD and may suggest new approaches to improve early diagnosis and/or treatment of the disorder. Funded by NIH grants MH107765, MH109196, MH063232, NS078291, and

### Glowing brain cells

A new kind of bioluminescent sensor causes individual brain cells to imitate fireflies and glow in the dark. The probe, which was developed by a team of Vanderbilt scientists\*, is a genetically modified form of luciferase, the enzyme that a number of other species including fireflies use to produce light. This novel technique that combines luminescence and optogenetics offers a powerful tool for studying brain activity. Funded by NIH grants R21 DA034446, R21 MH107713, R01 GM092914; and NSF grant DBI-1450897, and a grant from the Vanderbilt Brain Institute. \*C. Johnson, *Biological Sciences*; D. Webb, *Biological Sciences*; D. Winder, *Molecular Physiology & Biophysics; et al.* ■



**292**  
Research publications by VKC Investigators in 2016-17



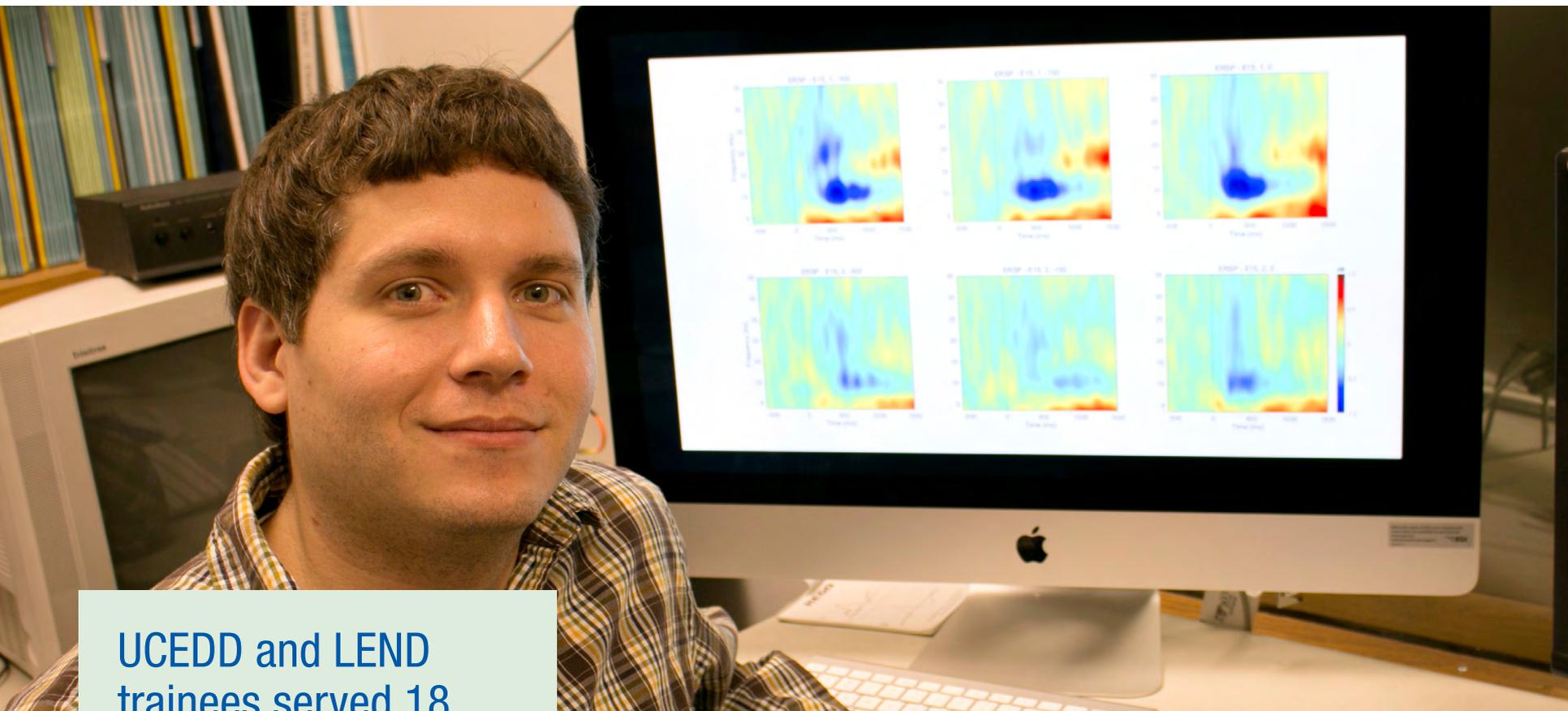
**109**  
research posters presented at 2016 VKC Science Day



**197**  
VKC Investigators & Members in **32** departments in 7 Vanderbilt schools/colleges



**42**  
VKC investigators in IDDRC leading **68** projects funded by NIH & other agencies



## UCEDD and LEND trainees served 18 projects in 2016-17

- ACM Lifting Lives Music Camp—Williams syndrome
- Britt Henderson Training Series for Educators
- Disability Day on the Hill—Tennessee
- Huntington's Clinic
- Next Steps at Vanderbilt
- Next Steps at Vanderbilt Summer Institute
- Reading Clinic
- SENSE Theatre
- Social Skills Group—Prader-Willi Syndrome
- Social Skills Group—young adults on autism spectrum
- Tennessee Adult Brothers and Sisters (TABS)
- Tennessee Allies in Self-Advocacy (TASA)
- Tennessee Autism Summit Team
- Tennessee Behavior Supports
- Tennessee Disabilities By the Numbers
- TennesseeWorks Community Conversations
- TRIAD Telemedicine
- Volunteer Advocacy Project
- Volunteer Advocacy Project—Transition
- Youth with Special Health Care Needs Advisory Council ■

**Pictured page 6:** (1) David Simon analyzes spectrally transformed EEG data showing brain activity under different conditions. **Pictured page 7:** (2) LEND and UCEDD trainee Megan DeWaard with Next Steps at Vanderbilt student Nila Huddleston. (3) Gloria Han, UCEDD trainee. (4) 2016-17 LEND Trainees.

## Learn

### Journey from volunteer to autism researcher

*David Simon, Neuroscience Graduate Student, Vanderbilt University*

After majoring in psychology as an undergraduate, I volunteered at the MIND Institute at the University of California Davis, a research center focused on autism spectrum disorder (ASD) and other neurodevelopmental disorders. Initially, I worked there with children and families participating in research. At the MIND institute, I met faculty member Blythe Corbett and became a research-focused volunteer and then a research assistant. When she joined Vanderbilt's faculty, she offered me a position to assist with her research on ASD, stress, and theatre as an intervention. As I did this behavioral intervention work, my interest grew in measuring precisely what the brain is doing, and how we can use electrophysiology to tell us more about developmental disorders. Today I am in Vanderbilt's Neuroscience Graduate Program, where I work with Mark Wallace, who directs a project investigating sensory and

multisensory contributions to ASD [VKC Intellectual and Developmental Disabilities Research Center project]. On this project, I perform experimental design, data collection, and data analysis for studies involving EEG and MRI. I have been fortunate to accrue broad experience exploring multiple facets of research in developmental disabilities including direct contact with families and children, intervention research, and physiological research. ■

### Connecting research and service

*Gloria Han, UCEDD Trainee and Doctoral Student in Clinical Psychology*

I have been interested in autism and other developmental disabilities since I was an undergraduate at Washington University in St. Louis. As a counselor for a residential summer camp, living with my campers was transformative. I loved seeing how being in a supported yet challenging environment helped my campers grow as individuals, build confidence, and learn new skills. These experiences led me to Vanderbilt, where I have pursued dual research interests in quantitative methods and autism. In my quantitative research, I am interested in understanding how to best capture unique



## Vanderbilt LEND Consortium trainees' group projects 2016-17

- Whole exome sequencing
- Collaborative approach to assessment and intervention of children with feeding disorders
- Interprofessional assessment of children with neurodevelopmental disabilities for intermediate trainees
- Development of Youth Advisory Council for Tennessee's Title V Children with Special Health Care Needs Program
- Start a "Go, Baby, Go" program
- TRIAD Community Engagement
- Development of care navigation practicum ■

developmental trajectories and longitudinal outcomes. This complements the overarching theme that drives my continued clinical work and research in autism, which is to showcase the abilities of individuals with disabilities—a mission aligned with the Vanderbilt Kennedy Center. To me, this involves active roles in research, community involvement, and advocacy. As a trainee, I've gained a deeper knowledge of how research informs clinical practice and vice versa. Helping parents become more effective parents and advocates for their child has been empowering. This summer, I am conducting autism research at National Taiwan University as an awardee of the East Asia Pacific Summer Institute NSF grant. As a first-generation Asian-American, I feel that I am in a unique position to facilitate a cross-cultural understanding of autism, especially between Western and Asian cultures. ■

### Benefitting from interprofessional perspectives

*Megan De Waard, LEND and UCEDD Trainee; Graduate Student, University of Tennessee College of Social Work, Nashville*

Disabilities have always been part of my world. My mom worked with persons with disabilities, so growing up, I would go along with her and then worked with different groups throughout high school and college. Because of this experience, I chose the Vanderbilt Kennedy Center for my social work practicum. Throughout this year, I've led service projects and co-taught the Senior Capstone course for Next Steps at Vanderbilt students in which they identify a problem they're passionate about and then find a way to give back or address that problem. Most of my previous work has been with adults who are less independent than our Next Steps at

Vanderbilt students, so it's fun to see that side—fostering employment and independent living dreams. It's also challenging for me because it's a different way of interacting, teaching, and encouraging. I've also worked in the Huntington's Disease clinic, learning about the genetic disorder, its psychological and social impact on patients and families, and how different professions support patients and families. I've loved being a trainee, learning the perspective of other professions. Social work is a unique blend of looking at people, families, and systems. As trainees, we could share our perspectives and learn from each other. Being in an educational setting for a practicum has been really beneficial. Everyone at Vanderbilt encourages curiosity, being inquisitive, and exploring how to improve systems of care. ■



**685** teachers, caregivers, and other providers of services to children with autism were served through TRIAD workshops



**7** TN universities provided trainees in **15** disciplines in the Vanderbilt Consortium LEND Training



**3,100** individuals received UCEDD continuing education



**54** long-term UCEDD and LEND trainees in 12 disciplines provided over **16,200** hours of service in 2016-17



**Pictured page 8:** (1) Maria (parent) and Cecilia Melo-Romie, Multicultural Outreach. **Pictured page 9:** (2) 2017 TennesseeWorks Employment Summit career fair. (3) Paul, Kristi, Jackie, and Jason van Wulven. (4) Autism Awareness Day at the Nashville Zoo. Photo by Nathan Zucker. (5) Art by Tabitha West from the VKC Arts and Disabilities program.

## Share

### Family voices

VKC programs share evidence-based practices through a variety of training and service programs. Program participants share their experiences:

#### TRIAD Families First workshops and early intervention

- “The information provided by the Families First presenters is priceless to our family. We are truly blessed to have the opportunity to learn and use these tools which will help enable our grandson to thrive. You guys are awesome!” -*Shirley Hicks*
- “TRIAD has been a safe place for our family. Everyone we have worked with has been welcoming, positive, and encouraging.” -*Amy Murphey (parent of twins)*

#### TRIAD workshops for Tennessee educators

- “I really love to learn more and more about how I can help my students! I appreciate the support and training that TRIAD offers! Thank you!” -*Special Education Teacher, Maryville City Schools*
- “I have attended several TRIAD trainings and I learn something new every time that helps me teach ALL of my students.” -*General Education Teacher, Shelby County Schools*

#### Britt Henderson Training Series for Educators

- “I am so grateful for the quality training I received.” -*Participant*
- “I enjoyed hearing practical ways to implement peer supports at our school. The notebook with a flash drive of materials is so valuable.” -*Participant*

#### TennesseeWorks Employment Summit

- “Really enjoyed meeting the employers and talking with them about their interactions with individuals with disabilities on their teams.” -*Attendee*
- “The career fair for students was great and led to some good connections.” -*Attendee*

#### VKC Arts and Disabilities program

“This program has given my daughter an opportunity to get her artwork out into the community, which also raises awareness about the abilities of artists who happen to have disabilities. It has also strengthened her confidence and led to even more art exhibits for her.” -*Karen West* ■

#### Help along the path

Carlos was 9 years old when he received a diagnosis of an autism spectrum disorder.

His mother, Maria, wanted to make sure he had the supports he needed, but she found that his school was uncooperative, and she was not sure what to do. Because Spanish was Maria’s first language, Conexión Américas connected her with Cecilia Melo-Romie at Tennessee Disability Pathfinder’s Multicultural Outreach Program.

“I told Cecilia my son has autism. She connected me with STEP [Support and Training for Exceptional Parents], and they helped me get good IEP goals for Carlos. I learned so much. The last time I asked the teacher about some help for Carlos, she told me she could not help. I thought, ‘That is her answer, but I do not have to take it.’ And so I asked again, because Carlos has a mom and that is me.”

In addition to school supports, Cecilia invited Maria to attend Pathfinder’s workshops in Spanish, which provide educational and networking opportunities for parents of children with disabilities.

“I learned about different ideas from specialists who know about autism,” said Maria. “I learned good ways to communicate with my son. Also, the workshops have taught me that other moms have the same problems. Cecilia helped me with resources, and she also



helped me to understand that I am not alone.

When Cecilia learned that Carlos loves music, she told Maria about the Nashville Opera's modified performance of *Three Little Pigs*, a collaboration with VKC TRIAD. The performance included storyboards and social stories that prepared Carlos.

"Carlos loved going to the opera," said Maria. "He made a video about it, and he was so excited and told his dad all about it when we got home. He talked about it for so long. We also went to the TRIAD event at the Nashville Zoo. He petted a kangaroo for the first time, and that was really great for him, too.

"I want the best for my son. Cecilia helped me to get on the right path and to understand my next steps and opportunities. I want to thank Cecilia and the Vanderbilt Kennedy Center for everything you do. You have made a difference in my life in every way." ■

### Steps along the way

On April 26, Jason van Wulven became a proud graduate of Next Steps at Vanderbilt and on May 1 an employee of McDonalds, where he had his final internship. Every journey has many steps, and this family's journey has included several VKC and Vanderbilt programs.

"We learned at birth that Jason has Down syndrome," said his dad Paul van Wulven. "We had no idea what this meant."

Jason began early intervention at 4 months with First Steps, and he received physical therapy. Because at 2 years Jason was delayed in using language, they connected with a VKC language intervention study involving Milieu Language Training, where interventionists work with children and parents, teaching parents how to interact in daily routines that promote language development.

"Because I worked on campus, I was the

logical one to do the language studies with him," van Wulven said. "We were committed to doing everything we could. Prior to that, Jason wasn't very verbal. The techniques we learned were just tremendous."

Jason attended Metro Schools from pre-K through high school, receiving speech and occupational therapy along the way. "That all built on what started here," said van Wulven.

At McGavock High School, Jason chose the Hospitality & Finance Academy, with an emphasis on culinary arts since he loves to cook. Living near Nashville Shores, Jason was there often during the summer and announced he wanted to work there. Summer 2017 will be his 4th summer working there.

Like other students leaving high school, Jason was interested in college and attended the VKC Next Steps at Vanderbilt Summer Institute, a weeklong residential college transition program.

"He loved being on campus, exploring everything. He was excited about going to college," van Wulven said. In Fall 2015, Jason began Next Steps at Vanderbilt.

Down syndrome has associated risks for medical conditions; for Jason that has been celiac disease. The Down Syndrome Clinic in Vanderbilt Pediatrics connects families with specialists, in this case from Vanderbilt's GI Clinic. Jason and his family have learned how to manage this well through a gluten-free diet.

Jason's sister Kristi also attended First Steps, where teachers noted some developmental concerns. At Vanderbilt's Genetics Clinic, she was diagnosed with Dandy-Walker syndrome, which has required some learning accommodations across her school years. She is attending the Summer 2017 Next Steps Summer Institute. The night before Jason's graduation, she opened her acceptance letter to Next Steps at Vanderbilt.

"It is fabulous being here at Vanderbilt and the Kennedy Center," van Wulven said. "For other families, I would advocate to come here, to check it all out, get involved where you can. Be that parent advocate." ■



**15,000** unique website visits, **142,000** page views, **2,027** helpline calls/emails for TN Disability Pathfinder in 2016



**1,170** Vanderbilt Autism Resource Line calls in 2016



**86** students received **1,376** hours of tutoring by **49** tutors in the VKC Reading Clinic



**26,500** copies of LEND guides on autism and other disabilities have been given to families and service providers since 2014



**Pictured page 10:** (1) Putting Faith to Work participants Courtney Taylor and Adrienne and Preston Vienneau. **Pictured page 11:** (2) Kindred Stories booklet. (3) Illustrating VKC health care activities. (3) Putting Faith to Work replication manual. (4) Vanderbilt ECHO Autism team shares expertise with primary care clinicians through case-based learning. Left to right: Bethany Drury, M.S.; Nina Harris, M.S.; Beth Malow, M.D.; Whitney Loring, Psy.D.; Andrea Huxtable, R.D.; and Quentin Humberd, M.D.

## Shape the Future

### Reducing health care disparities

Adults with autism, genetic syndromes, and other disabilities frequently face a cascade of health care disparities. Providing tools and training to address these issues is a priority. Accomplishments include:

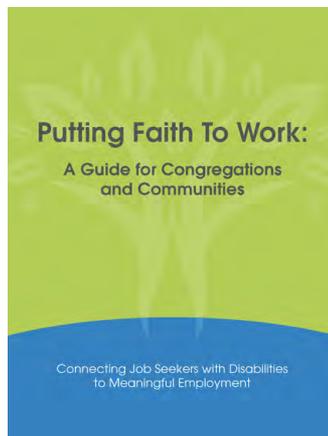
- **Website:** *Health Care for Adults with Intellectual and Developmental Disabilities: Toolkit of Primary Care Providers* ([www.iddtoolkit.org](http://www.iddtoolkit.org)) covers General Issues, Physical Health Issues, Health Watch Tables, and Behavioral and Mental Health Issues. Except for the Autism Health Watch table, these tools were adapted for U.S. use with permission of Surrey Place Centre, Canada. Since its launch in January 2014, the Toolkit has been accessed 99,972 times by 84,101 users, with 258,719 page views; 84% of site visitors are new users; accessed from 178 nations. Over the past 3 years, tools were downloaded 283,930 times. Funded by Special Hope Foundation.
- **Online training:** *Appropriate use of psychotropic medications for people with IDD: Helping individuals get the best behavioral health care—*

Since September 2015, 694 professionals (physicians, advanced practice nurses, registered nurses, psychologists, social workers, therapists, behavior analysts) have completed the training modules (total 90 min.), many receiving AMA, AAFP, or APA credit. Related online training was provided for family members and caregivers. Funded by TennCare and Tenn. Dept. of Intellectual and Developmental Disabilities.

*Debbie Payne, Commissioner, TN Department of Intellectual and Developmental Disabilities*

“The Department is thrilled to have partnered with the Vanderbilt Kennedy Center and TennCare to create the training videos, which have been received so well. Health care providers continue to receive little education about people with intellectual and developmental disabilities. An additional strength of the brief videos is the companion set oriented to families and other caregivers to empower them with knowledge and best practices.”

- **Telehealth training:** To improve clinicians’ ability to care for adults with intellectual and developmental disabilities (IDD), in 2016-17, the Center created a replicable model telehealth training program. Using technology, a panel of specialists experienced in care of adults with IDD provided didactic presentations on specific topics and used case-based discussions with the goal of building the capacity of community providers to care for adults with IDD. Funded by Special Hope Foundation.
- **ECHO Autism:** In June 2017, community physicians began working with VUMC/VKC autism subspecialists to better evaluate and manage patients with autism. Physicians attend a virtual telehealth ECHO clinic twice a month (total of 12 clinics) via smartphones or webcams. The site is a participant in national research study through ECHO Autism, a virtual learning network. Funded by Autism Intervention Research Network on Physical Health, HRSA. ■



### Putting Faith to Work

In 2014, the Kessler Foundation awarded a Signature Employment Grant to the VKC UCEDD (lead site) and 3 other UCEDDs focused on building the capacity of faith communities to support employment for members with disabilities. Each UCEDD worked with congregations to support individuals with physical and/or developmental disabilities to secure and maintain community employment. Across the 4 sites, staff worked with 27 congregational teams involving more than 125 team members who worked with 63 individuals with disabilities; 19 secured full-time work, 20 secured part-time work, and 2 found volunteer positions. A website ([puttingfaithtowork.org](http://puttingfaithtowork.org)) and a replication manual, *Putting Faith to Work: A Guide for Congregations and Community*, are available; more than 500 manuals have been purchased by congregations in 23 states. ■

### VKC and partners educating policy makers about Supported Decision Making

During the 2017 session, Tennessee lawmakers considered legislation that would give Supported Decision-Making (SDM) legal standing in TN Code. SDM is the nationally recognized, non-intrusive process of supporting adults with intellectual and developmental disabilities in making life decisions, and is a viable alternative to conservatorship and power-of-attorney. The VKC UCEDD worked collaboratively with the TN Developmental Disabilities Network, Statewide Independent Living Council, Family Voices of TN, and The Arc TN to educate legislators and the public on the benefits of establishing SDM as an option. The educational booklet *Supported Decision-Making: Creating a Continuum of Choice* was developed [[vkc.mc.vanderbilt.edu/vkc/resources/others/](http://vkc.mc.vanderbilt.edu/vkc/resources/others/)] as a resource. The Supported Decision-Making Agreement Act [<http://wapp.capitol.tn.gov/apps/BillInfo/Default.aspx?BillNumber=SB0264>] was deferred to Summer Study. ■

### Employment and Community First CHOICES Program

Employment and Community First (ECF) CHOICES is a home- and community-based services program for adults with intellectual and developmental disabilities to promote integrated employment and independent community living as the first, preferred outcome. The VKC UCEDD and TN Developmental Disabilities Network partners coordinated focus groups held prior to the program's launch so that stakeholders could offer input into its implementation. In mid-March, TennCare reported that 1,000 individuals had enrolled, and that 94% were planning or preparing for integrated employment. Additional State funding will serve up to 700 new people in the ECF CHOICES program next year. The VKC is a member of the Employment Roundtable led by the TN Council on Developmental

Disabilities, which aims to improve collaboration among State agencies that provide transition and employment services for students with disabilities moving from high school and postsecondary education into the workforce. ■

### Kindred Stories of Disabilities

Families sharing their stories is a powerful impetus for change. Since 2008, the VKC and The Arc Tennessee have collected family stories in 12 booklets and on a searchable website. Stories highlight the challenges and successes that children and adults with disabilities and their families experience as they navigate service systems. As college students interview families, they gain and grow from learning family perspectives. In 2017, *Kindred Stories: Access to Health Care* was shared with all 132 Tennessee legislators and the 11 members of the Tennessee Congressional Delegation. ■



- VKC programs reached all **95** Tennessee counties
- VKC partnered with **11** State of Tennessee Departments:
  - » Children's Services
  - » Council on Developmental Disabilities
  - » Economic and Community Development
  - » Education
  - » Health
  - » Higher Education Commission
  - » Human Services, Division of Vocational Rehabilitation Services
  - » Intellectual and Developmental Disabilities
  - » Labor and Workforce Development
  - » Mental Health and Substance Abuse
  - » TennCare



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In this monthly e-newsletter read about discoveries and best practices that are opening doors for children and adults with intellectual and developmental disabilities and their families. Send your email address to [kc@vanderbilt.edu](mailto:kc@vanderbilt.edu) to subscribe.

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