

# DISCOVERY

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Vanderbilt Kennedy Center Special Issue

WHY?



VANDERBILT KENNEDY CENTER



This *Discovery* Special Issue addresses “Why?” Why is discovery needed in the field of intellectual and developmental disabilities? Why do persons with and without disabilities contribute to the field? Why do scientists and students choose their areas of work? Why do we blend research, service, training, and public policy? By answering such questions, we aim to illuminate the challenging pathway from ideas to practices and how families, researchers, clinicians, students, and trainees walk this pathway together. ■

## DIRECTOR’S MESSAGE: WHY DOES RESEARCH TAKE SO LONG?



Elisabeth Dykens

This question frequently arises from families, educators, and community members who eagerly await answers that will improve their lives or the lives of those they care about.

Discovery begins with ideas born of a deep knowledge of the research of predecessors and colleagues. Sudden insights do happen, but typically only after ideas ferment, after bouncing them about with colleagues, students, clinicians, families, in seminars, journal clubs, clinics, rounds, or over coffee. Vanderbilt and the VKC offer superb settings for forming ideas, collaborating in interdisciplinary teams, and using cutting-edge research facilities.

After honing ideas, they must be tested to justify larger federal or other investments. At this point, seed monies and Hobbs Discovery Grants become critically important! With preliminary findings in hand, scientists pour

their passion into grants to the National Institutes of Health (NIH), National Science Foundation, and other federal or philanthropic agencies. Writing and submitting a grant, getting reviews, resubmitting a revision, succeeding at funding is often a 2-year process.

Once funded, researchers deal with study logistics. They obtain approval by the Institutional Review Board, hire the best staff and students, recruit research participants or develop cell cultures or animal models. Problems are solved daily in the nitty-gritty of collecting and analyzing data. Finally, findings come in, but even the most exhilarating, groundbreaking findings must be checked and re-examined. Only then do scientists prepare their findings in manuscripts submitted to well-respected scientific journals for peer review. This process can take months, and it is sometimes a year or more until the article appears electronically or in print. Research participants, too, deserve to know what's been learned.

We became scientists because we love discovery, yet we also teach courses, mentor

students, serve on committees, and administer departments, centers, clinics, and programs. We review the studies of other scientists, serve on federal committees and review panels, and contribute to our field. All is in the service of science—but at a cost of time away from our labs.

Then, life and politics happen! Beyond experiencing life events we all share (ill parents, children with school difficulties), we are impacted by politics. As I write, on the first day of our nation's sequester, we await news from the NIH and other federal agencies about how they will cut budgets for the research we have painstakingly developed.

Now more than ever, please transform your impatience for research answers into actions to help us on the road to discovery. Donate to a Hobbs Discovery Grant Award, participate in a study, fund a student scholarship, or let your political representatives know how important research on developmental disabilities is for your family. Discovery requires all of us working together. ■

## FRAGILE X SYNDROME (FXS) DISCOVERY TIMELINE

*This timeline illustrates the lengthy, complex process of research in developmental disabilities. Although FXS was recognized in 1943 as an intellectual disability that “ran in families,” it took another 26 years to identify the genetic cause and another 10 years to develop diagnostic techniques. Fifty years later, the genetic complexity continues to be unraveled.*

*Not until the 1980s, 40 years later, did researchers characterize the behavioral complexity in males vs. females, carriers vs. affected offspring, with insights continuing today. Behavioral interventions were developed 50 years later; 70 years later, pharmacological interventions are emerging.*

*In the course of research, unexpected discoveries emerge, such as the way that previously thought “unaffected” carrier males are prone to Parkinson and other conditions. These advances lead to new directions, not only for the disorder being studied but also for other disorders and health conditions in the general population.*

*Progress on FXS has been made by many researchers over 70 years and continues today, with effective interventions still being sought—an example of discovery as a collaborative and cumulative process.*

Intellectual disability that “runs in families”

Characterized by “fragile” piece of X chromosome

Diagnostic cytogenetic techniques developed

FXS & autism linked

- FXS males have cognitive, linguistic, & adaptive strengths & weaknesses
- Older vs. younger males show more severe delays
- FXS females at risk for schizoaffective & affective illnesses

Sherman Paradox “skips generation” (unaffected carrier → fully affected son)

- Calming techniques useful
- Visual approaches (rebus symbols) for reading-math

- FXS male IQs decrease over time
- IQ decrease may relate to methylation

• Caused by expanding repeat in FMR1 gene

• PCR screen/diagnosis developed

- In older FXS persons, FXTAS gene leads to characteristics of Parkinson, Alzheimer, Charcot-Marie-Tooth syndromes
- Older gene male carriers at high risk of developing FXTAS
- Cerebellum atypical development related to FXS & autism phenotypes but different regions contribute to each phenotype

- In FXS young children, low receptive language may be marker for autism symptoms
- Autistic behaviors in FXS girls associated with poorer developmental outcomes
- Cf. FXS alone, children with FXS & autism have more difficulty with imitation

• Some females (vs. males) with full mutation mildly affected

• mGluR pathways underlie many FXS characteristics

mGluR5 negative allosteric modulator AFQ056 may improve aberrant behavior in adults with FXS who have full methylation of FMR1

• Arbaclofen may improve social function & behavior

- At equated cognitive levels, social reciprocity similar in persons with FXS vs. autism
- Parents of FXS children have higher rates of rigid personality

• Some females (vs. males) with full mutation mildly affected

• mGluR pathways underlie many FXS characteristics

Unexpected Discoveries

Interventions

Behavior

Genetics

1940

1960

1970

1980

1990

2000

2010

## WHY VKC SCIENTISTS ROCK!



**Shari Barkin, M.D.**  
Pediatrics  
PEDIATRIC OBESITY  
INTERVENTION AND  
PREVENTION



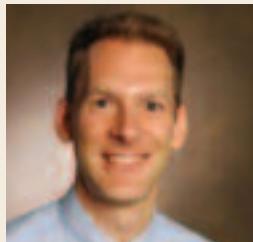
**Ana Carneiro, Ph.D.**  
Pharmacology  
MONOAMINE  
DYSREGULATION IN AUTISM,  
ADHD, AND OCD



**Roger Colbran, Ph.D.**  
Molecular Physiology &  
Biophysics  
CELL AND SYNAPTIC SIGNAL-  
ING DURING TYPICAL AND  
ATYPICAL DEVELOPMENT



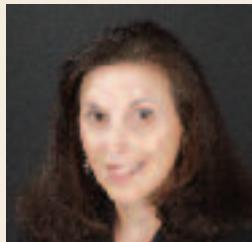
**Kevin Erreger, Ph.D.**  
Molecular Physiology &  
Biophysics  
DOPAMINE TRANSPORTER  
AND LEARNING, MEMORY,  
AND ADDICTION



**Kevin Ess, Ph.D., M.D.**  
Neurology  
CELLULAR MECHANISMS OF  
TUBEROUS SCLEROSIS COM-  
PLEX, SEIZURES, AND AUTISM



**Joshua Gamse, Ph.D.**  
Biological Sciences  
SCHIZOPHRENIA/XLMR  
GENES AND BRAIN ASYM-  
METRY USING ZEBRAFISH



**Judy Garber, Ph.D.**  
Psychology  
PREVENTION AND TREAT-  
MENT OF EMOTIONAL  
DISORDERS IN CHILDREN  
AND ADOLESCENTS



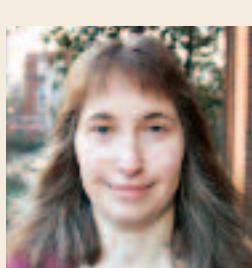
**Isabel Gauthier, Ph.D.**  
Psychology  
FACE AND OBJECT  
RECOGNITION IN AUTISM



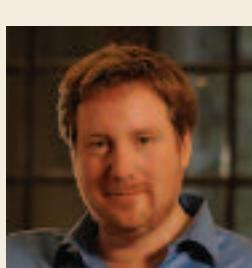
**Suzanne Goldman, Ph.D.**  
Neurology, Sleep Division  
SLEEP DISORDERS IN AUTISM  
AND IN ANGELMAN AND  
WILLIAMS SYNDROMES



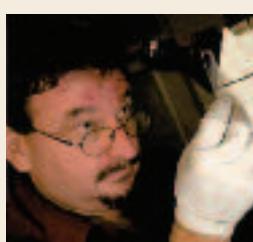
**Elizabeth Hammock, Ph.D.**  
Pediatrics  
GENES AND NEURAL  
CIRCUITS IN SOCIAL/  
EMOTIONAL DEVELOPMENT



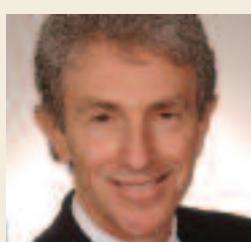
**Sasha Key, Ph.D.**  
Hearing & Speech Sciences  
BRAIN FUNCTIONING AND  
COGNITION IN GENETIC  
SYNDROMES AND AUTISM



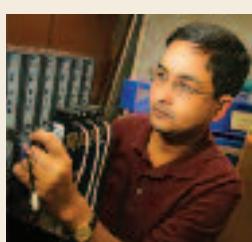
**Bruce McCandliss, Ph.D.**  
Psychology  
BRAIN DIFFERENCES AND  
BRAIN CHANGES RELATED TO  
LEARNING SUCCESS IN READ-  
ING, MATH, AND ATTENTION



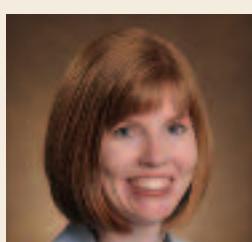
**Karoly Mirmics, M.D., Ph.D.**  
Psychiatry  
EFFECTS OF ENVIRONMENT  
ON GENE EXPRESSION IN  
AUTISM



**Paul Newhouse, M.D.**  
Psychiatry  
COGNITIVE IMPAIRMENT IN  
OLDER ADULTS WITH DOWN  
SYNDROME



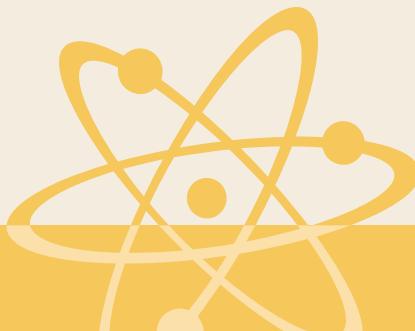
**Nilanjan Sarkar, Ph.D.**  
Mechanical Engineering  
ROBOTICS AND VIRTUAL  
REALITY FOR AUTISM  
INTERVENTIONS



**Julie Lounds Taylor, Ph.D.**  
Pediatrics  
YOUTH WITH AUTISM AND  
TRANSITION TO ADULTHOOD

The Rock Stars of Science (*Rock S.O.S.*) national campaign featured dramatic photos of scientists with celebrities. Initiated by the Geoffrey Beene Foundation, the goal was to raise awareness that science, science education, and science funding should be a national priority. In a *Rock S.O.S.* video, Anthony Fauci, M.D., director of the National Institute of Allergy and Infectious Diseases, described science as "a career of making contributions to society .... Society would benefit greatly if more people would go into science."

The Vanderbilt Kennedy Center celebrates the 210 faculty scientists from 26 disciplines who work daily to understand development and developmental disabilities and to improve the lives of persons with developmental disabilities and their families. Each mentors students who are the future of our nation's science. Here we highlight a few. Every VKC scientist is a Rock Star of Intellectual and Developmental Disabilities Science! ■



## WHY PERSONS WITH DISABILITIES AND FAMILY MEMBERS ARE PARTNERS



**Juan José and Ana Cardona**  
*Parents*

We are so thankful to be part of research. When our daughter started JEEP [Joint Attention, Enhanced Milieu Teaching, and Expanding Play], she was not talking, or playing. This project made a huge impact on her life and so ours as well. After a few months, she started saying some words and playing. We were so amazed of the improvement she had.



**Roxanne Kennerly**  
*Parent, Advocate*

Being involved with the VKC has been life changing, for my sons and myself. We have all taken part in studies. With each, we gained more knowledge, a new skill, or made contributions. Language studies for Ian have provided cutting-edge interventions. Liam has taken part in sibling research and SibSaturdays. I also feel satisfaction knowing that we are helping others.



**Tammy Vice**  
*Songwriter, Parent, Advocate*

Each of us has a role to play in life for which we are uniquely made. It has been sweet for me to help create songs for SENSE Theatre, but my favorite part is seeing what develops behind the scenes. Social growth happens when the kids begin to understand the importance of supporting each other. And hearing my daughter Morgan say, "I'm in the show!" and knowing that it's true.



**Megan Hart**  
*Advocate*

Self-advocacy is an important part of my life. I have been able to obtain education, pursue a career, and live a meaningful life based on my decisions and persistence. It is a disservice when the voices of others overpower the needs, desires, and goals that individuals with disabilities have for themselves. This is why Tennessee Allies in Self-Advocacy (TASA) is so important.

**It is reassuring to know somebody or something is there just in case life gets the best of some of us sometimes. Just knowing this has helped me today and for this I am thankful.**

—Caller to Tennessee Disability Pathfinder Helpline



**John Donovan**  
*Sibling and Advocate*

Through TABS [Tennessee Adult Brothers and Sisters], I've met other siblings with similar experiences. TABS also introduced me to other VKC programs and to organizations such as The Arc, Sibling Leadership Network, and many more. TABS has helped me become a better brother and has given me the opportunity to help others.



**Karina Scali**  
*College Student, Volunteer, Advocate*

I always felt that I was born into this world with Williams syndrome for a reason—to help in any way I can and to create awareness. When my mom found the ACM Lifting Lives Music Camp, I couldn't wait to go. I love country music, and I wanted to help with research on Williams syndrome. The country stars give their time to work with us. They make me feel valued and respected, and they shine a light on our abilities.

# WHY SCIENTISTS STUDY BEHAVIOR CHANGE



## (1) Understanding Genetic Syndromes

**Elisabeth Dykens, Ph.D. (Psychology, Psychiatry, Pediatrics)**

My father was a psychiatrist, and I grew up accustomed to being with people with disabilities. During my graduate training, I worked directly with children with genetic syndromes and autism. These experiences started me on the path to looking at genetic syndromes as a window for understanding connections among genes, brain, and behavior and ways to optimize interventions. We look for strengths to develop as well as difficulties to remediate, and for ways to promote well-being.

## (2) Promoting Language Development

**Paul Yoder, Ph.D. (Special Education)**

As a sophomore volunteer in a preschool for children with language impairments, I was fascinated by these bright children who had difficulty communicating. Doing developmental disabilities research combines my love of the scientific method, my desire to be a positive force in the lives of children with communication disabilities, and my passion for learning. Our lab works to understand the match needed between

language and communication therapy methods and the strengths and weaknesses that different children bring to therapy.

## (3) Treating Sleep Disorders

**Beth Malow, M.D., M.S. (Neurology, Pediatrics)**

As a sleep researcher and parent of sons on the autism spectrum, I realized that identifying and treating disordered sleep in autism, Down syndrome, and other developmental disorders could make a huge difference in the lives of children and families. My team focuses on improving methods for studying and treating sleep disorders. As director of the Vanderbilt Autism Treatment Network site, we collaborate with the other ATN sites to improve medical care.

## (4) Improving Autism Diagnosis and Treatment

**Zachary Warren, Ph.D. (Pediatrics, Psychiatry, Special Education)**

My clinical, research, and training interests revolve around improving systems of care for individuals with autism and their families, especially improving early identification and intervention.

Unfortunately, the process of developing initial concerns, discussing concerns with

providers, obtaining accurate diagnosis, and translating this information into effective treatment remains a complex, distressful one for most families. Families often must wait long periods of time to find out answers to questions they are desperate to know about. In my opinion, this process can and should be dramatically improved.

I spent most of my graduate training learning about the development of very young children who had experienced serious life stressors. This focus on early social and emotional development was matched with opportunities to work with young children with autism during my fellowship. Since then, I have worked with young families concerned that their child may have autism. It is a challenging and powerful experience to try to provide families with answers.

I am working on projects that study infants at high risk for autism in hopes of developing methods for earliest detection, which early behavioral intervention programs work best for specific children, as well as training programs for building system capacity for early accurate diagnosis and effective treatment for families in their own backyards. ■





## WHY SCIENTISTS STUDY NEURODEVELOPMENTAL DISORDERS



### (1) Investigating Related Gene Disorders • Sarika Peters, Ph.D.

**(Pediatrics)** I study two related single gene disorders, Rett Syndrome, which primarily affects girls, and MECP2 duplication syndrome, a similar syndrome that affects boys. My role is to better define what clinical concerns “look like” in these syndromes, in order to design more targeted interventions and supports to help improve quality of life. We also seek out non-invasive approaches (e.g., saliva, psychophysiology) for linking underlying biology to these behaviors. My interactions with families inspire my work.

**(2) Exploring Neurodevelopment and Neurodegeneration • Aaron Bowman, Ph.D. (Neurology and Pediatrics)** I am fascinated by the connections between neurodevelopment and neurodegeneration. My research focuses on degenerative processes affecting the basal ganglia, a brain structure necessary to control movement. We use both basic research models as well as new methods that convert human skin cells into personalized models of neurological disease and environmental health. By learning how genes and environment interact and influence

the development and maintenance of brain function, we hope to mitigate environmental risk factors of disorders and improve long-term health.

### (3) Studying Cognitive Impairment

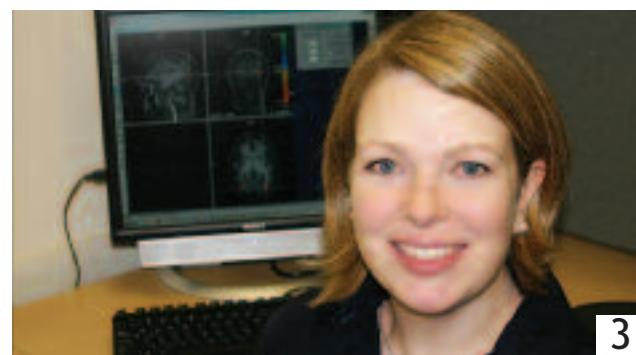
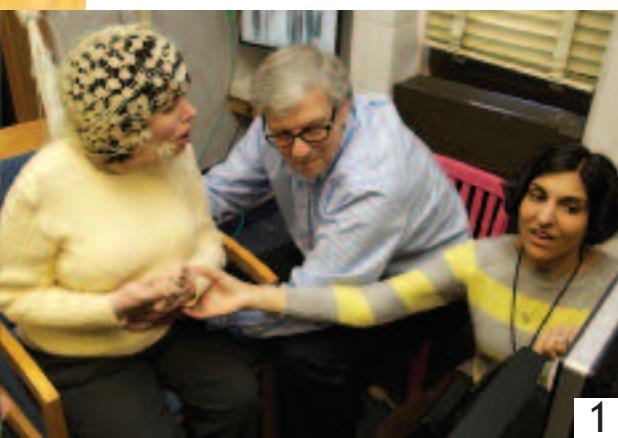
**Tricia Thornton-Wells, Ph.D. (Molecular Physiology & Biophysics)** I have long been fascinated with brain disorders, but my family history of Alzheimer disease (AD) has influenced my study of cognitive impairment. Why do some family members develop AD and others do not? What happens in the brain 10 to 20 years before a person shows signs of dementia? What can we do to prevent or postpone onset? Over half of persons with Down syndrome develop dementia by age 50. By studying AD in Down syndrome as well as in persons with typical neurodevelopment, we aim to advance neuroimaging, genetic profiling, and therapeutic targets.

### (4-5) Finding Pathways to New Treatments • Jeremy Veenstra-VanderWeele, M.D. (Psychiatry, Pediatrics, and Pharmacology)

My research focuses primarily on genetic mouse models of autism susceptibility, with the goal

of understanding the changes in the brain that lead to altered social communication and repetitive behavior in autism spectrum disorder (ASD). In parallel, our research group is testing new treatments based upon published findings in genetic mouse models of autism, including potential treatments in individuals with fragile X syndrome and in individuals with ASD without a known cause.

I grew up knowing that the son of a close family friend had autism. I came to empathize with this family's experience. This primed me for working in the lab of Dr. Ed Cook, a child psychiatrist launching a genetics lab, who encouraged his students also to see patients. As a result of these experiences and my own clinical work as a child psychiatrist, I find myself pulled to understand why social communication that feels so natural to some can be so unnatural for others. Seeing children who seem stuck in repetitive patterns of behavior makes me wonder what in the brain is causing this persistent behavioral “hiccup.” Mouse models of autism susceptibility offer a path to understanding how brain development and function are altered, with the hope that this path will lead to new treatments. ■



## WHY SCIENTISTS STUDY EDUCATIONAL CHANGE



**(1) Unraveling the Mysteries of Reading**  
Laurie Cutting, Ph.D. (Special Education, Psychology, Radiology & Radiological Sciences, Pediatrics)

When I worked in the classroom, one young boy had all the resources one could imagine but could not learn to read. From then on, I wanted to understand what was happening in the brain when children were experiencing reading difficulties. In my lab, we're trying to unravel the mysteries of how people comprehend well and what happens when they don't. We focus on which elements are most important, e.g., vocabulary, understanding grammar, structures of text, type of text, and how these relate to different brain systems.

**(2) Connecting Preschool and Literacy**  
David K. Dickinson, Ph.D. (Teaching & Learning) I'm seeking to understand features of preschool classrooms that foster language and literacy development and to describe the interplay between language and print-based knowledge. I'm especially interested in language development, because many children who struggle with reading lack the academic language skills required for the later elementary grades. I am developing an intervention in which teachers are coached in methods of teaching vocabulary through book reading and guiding children in book-connected play.

**(3) Improving Lives of Youth with Significant Disabilities** • Erik Carter, Ph.D. (Special Education) Young people with significant disabilities have wonderful strengths, aspirations, and friendships to share. Yet far too many people never have the opportunity to know these essential members of their communities. My research focuses on identifying ways that schools, workplaces, neighborhoods, and congregations might welcome and support people with disabilities and their families to participate more fully in community life. A recurring theme is that schools and communities that commit to inclusion find they are strengthened.

**(4) Matching Instruction to Individual Learner Needs** • Doug Fuchs, Ph.D., and Lynn Fuchs, Ph.D. (Special Education) We develop assessment and instructional methods to increase academic achievement of students with learning disabilities (reading and math), as well as of high-, average-, and low-achieving students without disabilities. To test the efficacy of these instructional methods, we conduct

large-scale, school-based randomized control trials. We work closely with hundreds of teachers and administrators in school systems in Tennessee and in other states. We also develop "differentiated" instruction (e.g., small group tutoring procedures) for children chronically unresponsive to the core reading and math instructional programs. In this regard, we are exploring how child characteristics moderate the efficacy of various instructional methods. Our goal is to understand how to match instruction to individual learner needs. Our collaboration with researchers in the VKC Psychophysiology Lab and the Vanderbilt Institute of Imaging Science has broadened our understanding of learning disabilities in important ways.

Each of us began our careers as general education classroom teachers, where we struggled to address the needs of students with learning disabilities. This motivated us to work hard over the years to provide general and special education teachers with methods that can help them address the needs of these students more effectively. ■



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## WHY SCIENTISTS STUDY MENTAL HEALTH

### (1) Understanding Brain Development

**Randy Blakely, Ph.D. (Pharmacology and Psychiatry)** To figure out how genetic and environmental factors interact to support typical brain development, scientists must understand how the brain works across many levels. I study neurotransmitter transporters, proteins involved in transmitting electrical signals through the brain. Transporter proteins are targets for therapeutic drugs, as well as drugs of abuse. We use our understanding of these proteins to develop animal models of autism, ADHD, and depression. We keep our eye on how our findings could lead to new therapies.

### (2) Identifying the Neurobiology of Temperament • Jennifer Blackford, Ph.D. (Psychiatry)

Individual differences in temperament—how we think, feel, and act—can either confer risk or provide protection from psychiatric disorders like anxiety and depression. My lab studies the neurobiological basis of these individual differences, using modern neuroscience methods such as neuroimaging and genetics. Our goal is to determine how differences in genetic variability and brain alterations may

confer risk or protection. Understanding the links between neurobiology and psychiatric disorders can inspire the development of novel preventions and interventions in high-risk individuals.

**(3) Coping with Stress • Bruce Compas, Ph.D. (Psychology and Pediatrics)** My research involves observing the effects of stress on physical health and psychopathology, and processes of coping and self-regulation in response to stress and adversity in children, adolescents, and adults. Out of this comes the development of interventions to enhance the ways that individuals and families cope with stress. My current work is focused on the psychological and biological processes of stress on children, adolescents, and families coping with cancer, chronic pain, or depression.

**(4-5) Understanding Cognition and Social Function • Sohee Park, Ph.D., (Psychology and Psychiatry)** As a child growing up in Seoul, I planned to be an anthropologist because I was fascinated by how seemingly unfathomable surface cultural differences could be bridged inside. After a

detour into physics and four countries later, I am still trying to solve the puzzle of the ‘other’ but in the context of severe mental illness.

My lab focuses on understanding the neural bases of schizophrenia, bipolar disorder, and related conditions, while always being mindful of the subjective experiences of the people whose lives are disrupted by psychosis. We believe that disturbed sensory and perceptual processing in the brain cascades into anomalous cognitive and social functioning in these conditions, and that training the brain to process incoming information more efficiently could lead to improvements in cognition and outcome. Such interventions are more effective if they begin early, for example, during adolescence, because this is the period during which the behavioral signs of psychosis emerge.

Our goal for the next decade is to develop noninvasive and effective interventions that are firmly grounded in psychology and neuroscience. To reach that goal, we are collaborating with other VKC investigators, including Bruce Compas, Nilanjan Sarkar, Tricia Thornton-Wells, and Adam Anderson. ■

CLINICIANS  
STUDENTS

W H Y ?  
W H Y ?



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## WHY INTEGRATE SERVICES, RESEARCH, TRAINING, AND PUBLIC POLICY



**SENSE Theatre—A Unique Autism “Lab” • Blythe Corbett, Ph.D. (Psychiatry), SENSE Theatre Founder and Director** Most people think of theatre as a home for creative actors who were magically born for the stage. I think of theatre as an engaging environment in which to teach social communication. SENSE Theatre Camp, an intervention for children and youth with autism, has three components: peers, play, and performance. The typically developing peers are young actors conceptualized as developing “experts” on social communication, flexible thinking, and empathy—all areas of challenge in autism. With supervision, they engage the SENSE campers using theatre games, improvisation, and play rehearsal, which culminates in public performances.

Most of our SENSE campers are evaluated before and after the camp to identify changes in functioning. The research allows us to test the intervention, refine it, and eventually to determine the best responders.

Since our program is peer-mediated, we train the typically developing youth. We teach camp counselors who are the next generation of psychologists, educators, and scientists. Whether working on the stage with our campers or behind the scenes collecting data, students experience applied research.

SENSE Theatre is among the more unique lab experiences students may have and one of the most profound for understanding the extraordinary gifts and challenges of autism.

**Prader-Willi Syndrome—Piecing the Big Picture • Elizabeth Roof, M.A., Senior Research Specialist** Although I trained and worked as a clinician, in 1995, I became research coordinator for a multi-year study of Prader-Willi syndrome (PWS). After a few short months, I was hooked. The people who enrolled came for 3 days. I learned to listen,

to read body and vocal cues, and to anticipate problems. Their parents accompanied us throughout the 20 assorted physical and psychological assessments. I heard their stories of the struggles and joys of living with a child with special needs.

I could fully listen to what families needed with some ability and resources to make a difference. The more data we collected, the more I could see the big picture: when behavior problems emerged, what periods were critical for intervention, when helping with IEP/vocational and residential placements made the biggest difference in behavior and learning. Now in research led by Elisabeth Dykens, we are focusing on behavior and psychiatric issues.

Over the years, we have trained students. Some have gone on to study PWS in their own labs. Others have studied how PWS may be related to autism and other developmental disorders.

We have a trusting relationship with families, which allows us to collect amazing data that can truly change lives. I wanted to make a difference. I get to do it every day. ■



### Connecting With Public Policy Makers • Elise McMillan, J.D., VKC UCEDD

**Co-Director** Why do we work to connect research, training, and service models to developmental disabilities public policy? We hear this question over and over again about connecting evidence-based practices with work in our schools and communities. The VKC University Center for Excellence offers a wonderful opportunity to make those connections. One of our charges is to inform policy makers about best practices.

We do that on the local level through participation in activities like the Mayor's Advisory Council on Exceptional Education, at the state level through projects like Tennessee Works and the Employment Systems Change Grant, and at the federal



level as we take part in national disability organizations.

This happens through testimony, shared articles, and professional development in areas

of autism, Down syndrome, and other genetic syndromes. We are a vehicle for sharing research findings and recommended practices with public policy makers at the local, state, and national levels.

When the Tennessee Legislature was developing policies about insurance coverage for autism treatment, they turned to the VKC. When expertise is needed to conduct statewide needs assessments, VKC UCEDD faculty and trainees are there, using research tools like REDCap developed at Vanderbilt.

With the support of university students and faculty, we have collected family stories and shared with public policy makers, so they will understand how disabilities affect the citizens they represent.

And the work continues. ■

## WHY GRADUATE STUDENTS AND POSTDOCS ROCK!

The *Rock Stars of Science (Rock S.O.S.)* national campaign (see p. 3) encouraged youth to pursue careers in science. As a Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Center, the VKC plays a leadership role in training predoctoral and postdoctoral investigators in intellectual and developmental disabilities (IDD) research. Below we highlight a few. All our predoctoral students and postdoctoral fellows are the Future Rock Stars of IDD Science!

**(1) Courtney Wright, Doctoral Student in Special Education, Kaiser KidTalk Projects** Coming from speech pathology, I knew about development and assessment, but not much about how to help young children and their families. Now I have learned a number of evidence-based practices for teaching a variety of skills to young children with disabilities. I feel confident within my clinical work and my ability to include and teach families strategies to use in their everyday lives. I look forward to passing these newly acquired skills on to future practitioners.



can be addressed and the frontiers of science pushed forward.

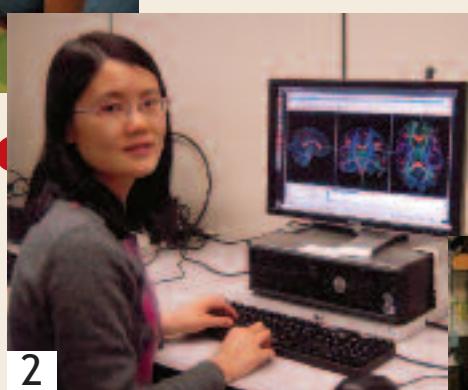
**(3) Marc Mergy, Doctoral Student in Neuroscience Graduate Program, Blakely Lab** I chose neuroscience research because the brain and many brain disorders remain an elusive "black box." There is plenty left to learn! My own work focuses on a new mouse model of ADHD that I have used to further our understanding of the molecular mechanisms underlying this disorder. It's a great feeling to know that my work has developed a useful tool for future research.

**(2) Qiuyun Fan, Doctoral Student in Biomedical Engineering, Cutting Lab** I study the neurocorrelates of reading ability in the brain using magnetic resonance imaging. I am developing new imaging and analysis techniques to study how neural tissues are organized in the brain, and how brain regions with distinct functions collaborate to underpin complex cognitive behavior. At the VKC, I have unique opportunities to take advantage of this platform where engineers, psychologists, pediatricians, educators, clinicians, and others brainstorm ideas, so that interdisciplinary questions

**(Above) Christopher Muller, Doctoral Student in Neuroscience Graduate Program, Veenstra-VanderWeele Lab** Earlier, I worked in a human genetics laboratory involved in collecting DNA samples from families with a history of autism. Although I enjoyed it, I was frustrated that I could not do more for families. I searched for neuroscience graduate programs with strength in translational autism research, which led me to Vanderbilt, where I am doing research in a lab developing and characterizing novel animal models of autism. If my work can somehow someday help a family affected by autism, it will be worth the struggle. ■



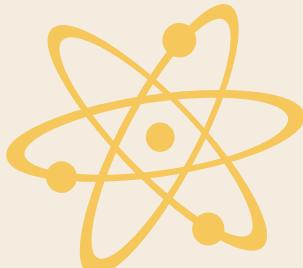
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## WHY LEND AND UCEDD TRAINEES ROCK!



The Vanderbilt LEND is part of a national network of Leadership Education in Neurodevelopmental Disabilities (LEND) programs. Their goal is to improve the health of infants, children, and adolescents with neurodevelopmental and related disabilities through leadership training. The Vanderbilt LEND prepares graduate and postgraduate students in 13 health-related fields, and provides specialized training in autism and pediatric audiology.

The VKC University Center for Excellence in Developmental Disabilities (UCEDD), also part of a national network, trains university students, practicing professionals and direct care providers, individuals with disabilities and family members, disability advocates and policy makers.

Below we highlight a few LEND and UCEDD trainees. Collectively, VKC LEND and UCEDD trainees are future educators, researchers, clinicians, service providers, and advocates.

(1) Cong Van Tran, 2011-12 TRIAD and LEND Psychology Trainee The

VKC has rich resources—experts, seminars, training, tools, tests, facilities—that facilitated my learning. Most important was developing professional and personal relationships with psychologists and autism and disability specialists. Now I'm doing disability training in my home country of Viet Nam.

**(2) Kelsey Bush, 2012-13 UCEDD Cognitive Studies and Human & Organization Development Trainee**

I knew from a young age that I wanted to work with individuals with intellectual and developmental disabilities. I've learned that even small acts can have huge ripple effects. I have had amazing opportunities working in the Prader-Willi syndrome project and in VKC Communications. These experiences showed me different ways in which I could contribute to the field.

**(3) Hilary Davis, 2011-12 LEND Pediatric Audiology Trainee** Last week, I had a 4-year-old light up with excitement and high-five me once he got his new hearing aid—he was hearing things he had never heard before! I work in schools,

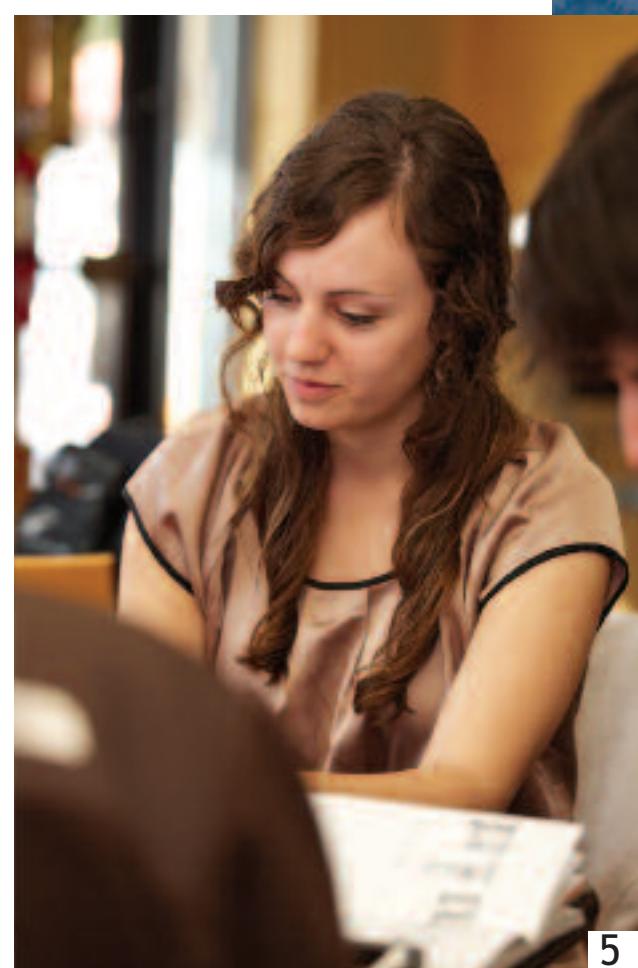
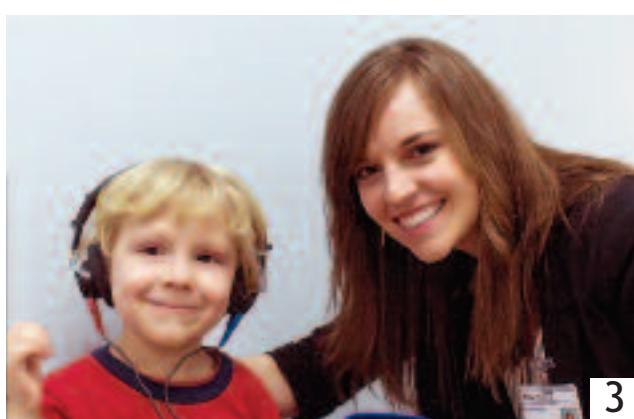
teaching about hearing loss and how to improve classroom settings. These moments remind me that I am passionate about kids and their success.

**(4) Matthew Brock, 2012-2013 UCEDD Special Education Trainee**

There is an enormous gap between evidence-based practices and the reality of day-to-day special education practice. I get excited every time I am able to help a teacher or paraprofessional use a new intervention strategy effectively, and then measure (and celebrate with them) the difference that it makes for a student with a disability.

**(5) Carrie Spero, 2012-2013 LEND and UCEDD Social Work Trainee**

As a UCEDD trainee, I have worked with Next Steps students and others and increased my knowledge of disabilities. Through LEND, I have seen the influential power that individuals, teams, and communities can have in working toward change. I feel more confident every day in my ability to serve the community. ■



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## ACM Lifting Lives Experience at Vanderbilt

Nashville's music entertainment industry offers a wide range of vibrant careers. Beginning March 2013, a small group of young adults with intellectual and developmental disabilities will have a unique opportunity to experience the entertainment industry and the various support roles that "make the music happen." Sweet! • This innovative program is a creative partnership between **ACM Lifting Lives**, the charitable arm of the Academy of Country Music, and the VKC.

*Discovery* is a quarterly publication of the Vanderbilt Kennedy Center designed to educate our friends and the community, from Nashville to the nation. The Center is 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 Intellectual and Developmental Disabilities (AIDD). *Discovery* is supported in part by Grant No. HD 15052 from EKS NICHD, AIDD Grant #90DD0595, and LEND Training Grant No. T73MC00050 MCHB/HRSA.

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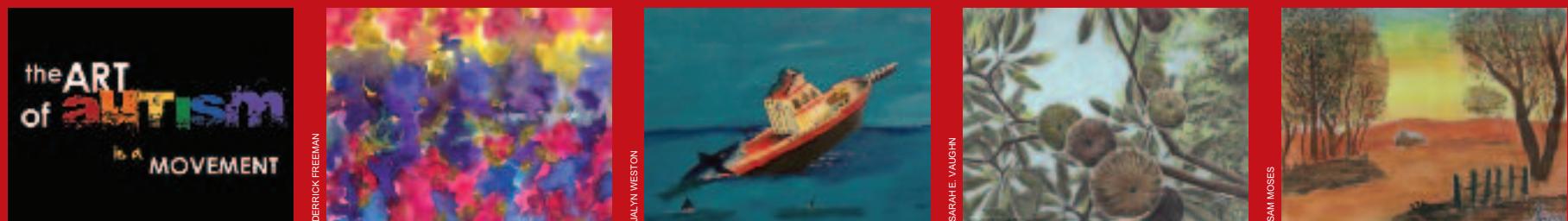
**Photographers:** *VKC*: Kylie Beck, Pam Grau, & Tony Maupin; *Vanderbilt*: Neil Brake, Daniel Dubois, Steve Green, Joe Howell, Dana Johnson, Anne Rayner, & Susan Urmy; *Other*: Dr. Bill Kenner, John Donovan, Crystal Finley, Gamse Lab, & Kennerly Family

**Art:** *Cover*: ©Russell Tate/istockphoto.com; *Hexagon Abstract*: ©Roman Okopny/istockphoto.com; *DNA*: Barbara Martin

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**Giving** [kc.vanderbilt.edu/giving](http://kc.vanderbilt.edu/giving)

# CALENDAR OF EVENTS | APRIL-JULY 2013



*The ART of AUTISM showcases the artistic gifts of individuals with autism. April-July, the VKC is exhibiting work by participating artists from Tennessee and neighboring states.*

Unless otherwise noted, events are free and open to the public. Events are subject to change. Please check the website calendar at [kc.vanderbilt.edu](http://kc.vanderbilt.edu) or contact (615) 322-8240 or toll-free (1-866) 936-VUKC [8852].

Please keep this calendar and check the Event Calendar on the VKC website for updates. If you wish to receive event announcements by email, send your email address to [kc@vanderbilt.edu](mailto:kc@vanderbilt.edu).

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

\*Event will be held in Room 241 Vanderbilt Kennedy Center/One Magnolia Circle Bldg (110 Magnolia Circle).

\*\*VKC Member or Investigator

## ■ APRIL 3\*

*Developmental Disabilities Grand Rounds*  
**Big Strokes in Little People: Biology and Clinical Considerations**  
 BethAnn McLaughlin\*\*, Ph.D.  
 Assistant Professor of Neurology  
 Lori Jordan\*\*, Ph.D., Assistant Professor of Neurology. Register at [kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration) Wednesday 12 p.m.

## ■ APRIL 5-6

*Fifth Annual Tennessee Adult Brothers and Sisters (TABS) Conference*  
 Sibling keynote speakers:  
 (Fri) Scott Modell, Ph.D., Deputy Commissioner of Policy & Innovation, TN Dept of Intellectual & Developmental Disabilities;  
 (Sat) Nancy Webster, President of The Arc. For adults who have a sibling with a disability, siblings-in-law, cousins, professionals interested in sibling issues. \$50 (\$25 students) includes meals. Register at [kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration) Contact [info.tabs@vanderbilt.edu](mailto:info.tabs@vanderbilt.edu) Holiday Inn Nashville-Vanderbilt, 2613 West End Avenue Friday 12-7:30 p.m.  
 Saturday 8:30 a.m.-1:30 p.m.

## ■ APRIL 10

*Neuroscience Graduate Program Seminar Series*  
**Epigenetics at the Interface of Genetics and Environment in Autism**  
 Janine LaSalle, Ph.D.  
 Professor of Medical Microbiology and Immunology, University of California Davis. Co-sponsor Vanderbilt Brain Institute 208 Light Hall Wednesday 4:10 p.m.

## ■ APRIL 11\*

*Augmentative and Alternative Communication (AAC) Presentation*  
**Assistive Technology for Students With Disabilities: The Legal Ins and Outs**  
 Erin Richardson, Co-Director for Advocacy, Special Education Advocacy Center. Free and open to the public. Register at [kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration) Thursday 6:30-8 p.m.

## ■ APRIL 12\*

*Augmentative and Alternative Communication (AAC) All-Day Workshop*  
**AAC Assessment: Making the Match**  
 Karen Casey, M.A., CCC-SLP  
 \$175 professionals, \$50 students  
 \$125 group rate for 2 or more from same agency/school. Register by April 5 at [kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration). Friday 8 a.m.-3:30 p.m.

## ■ APRIL 13\*

*SibSaturday*  
 For siblings 5-7 and 8-13 years who have a brother/sister with a disability  
**Games, friends, conversation**  
 \$10/child, \$20 max/family (assistance available). Register at [kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration) (required in advance)  
 Info (615) 936-8852 or [laurie.fleming@vanderbilt.edu](mailto:laurie.fleming@vanderbilt.edu) Saturday 10 a.m.-2 p.m.

## ■ APRIL 20\*

*TRIAD Families First Workshops*  
**Developing Basic Communication**  
 Register at [kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration). Info (615) 322-6027 or [families.first@vanderbilt.edu](mailto:families.first@vanderbilt.edu) Saturday 9 a.m.-12 p.m.  
 See website for Summer workshops

## ■ MAY 2-3

*Phonological Awareness Workshop*  
 Melanie Schuele\*\*, Ph.D., CCC-SLP, Associate Professor of Hearing & Speech Sciences  
 For general and special education teachers, speech-language pathologists, reading specialists. Parents welcome. 1-day \$70 (.65 ASHA CEUs), 2 days \$120 (1.3 ASHA CEUs) Register at [kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration). Info [languagelab@vanderbilt.edu](mailto:languagelab@vanderbilt.edu) 8th Flr Lecture Hall, Vanderbilt Bill Wilkerson Center, Medical Center East. Thursday-Friday 8:30 a.m.-4:15 p.m.

## ■ MAY 17

*Next Steps at Vanderbilt Open House*  
 Info (615) 322-5658. Register at [kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration) Friday 2-4 p.m.

## ■ MAY 30-31

*11th Annual Tennessee Disability MegaConference*  
 Deep Roots, Broad Branches, and Strong Wings  
 World-class speakers, interactive workshops, educational sessions, exhibits. Info at [www.tndisabilitymegaconference.org](http://www.tndisabilitymegaconference.org) (includes breakfast/lunch)  
 \$105 one day (Thursday or Friday)  
 \$195 for 2 days (Thursdays-Friday)  
 Nashville Airport Marriott, 600 Marriott Dr (615-889-9300)

# CALENDAR OF EVENTS | APRIL-JULY 2013



## ■ JUNE 5

*Neuroscience Graduate Program Seminar Series*  
Using Music to Change the Way the Brain Processes Language  
Aniruddh D. Patel, Ph.D.  
Senior Fellow in Theoretical Neurobiology, Esther J. Burnham  
Senior Fellow, Neurosciences Institutes, LaJolla, CA  
Co-sponsor Vanderbilt Brain Institute Room 1220 MRB III Lecture Hall Wednesday 4:10 p.m.

## ■ JUNE 14\*

*Community Advisory Council Meeting*  
Info (615) 936-8852 Friday 9 a.m.-2 p.m.

## ■ JUNE 25-26\*

*Autism Diagnostic Observation Schedule (ADOS-2) Clinical Training*  
TRIAD workshop for psychologists, pediatricians, behavioral specialists, and SLPs. Fee: \$300. Register at [kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration). Info [amy.r.swanson@vanderbilt.edu](mailto:amy.r.swanson@vanderbilt.edu), (615) 322-6533. Tuesday-Wednesday 8 a.m.-4:30 p.m.

## ■ JUNE 29\*

*Clinical Genetics for Health Care Professionals*  
Workshop by Vanderbilt Pediatrics Developmental Medicine Division for health care professionals who are not geneticists. \$50 (includes lunch) 7 CME & APA CE. Register at [kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration) Info [pam.grau@vanderbilt.edu](mailto:pam.grau@vanderbilt.edu), Saturday 8 a.m.-2 p.m.

## ■ JULY 30-31\*

*School Speech-Language Pathology Conference*

Two lunch-time plenary sessions and selection among 6 (90-minute) small group sessions (1.1 ASHA CEUs) Register at [kc.vanderbilt.edu/registration](http://kc.vanderbilt.edu/registration) Info [languagelab@vanderbilt.edu](mailto:languagelab@vanderbilt.edu) Tuesday-Wednesday 8:30 a.m.-3 p.m.

## ■ VKC SUMMER PROGRAMS

Info [laura.mcleod@vanderbilt.edu](mailto:laura.mcleod@vanderbilt.edu) ♦Registration is closed. Contact TN Disability Pathfinder for information on summer activities.

### • JUNE 3-15

**SENSE Theatre Camp**♦ For youth, 7-18 years of age, with and without autism spectrum disorders

### • JUNE 23-29

**ACM Lifting Lives Music Camp**♦ Residential camp for individuals with Williams syndrome (16 yrs+)

### • JULY 14-19

**Next Steps at Vanderbilt Summer Institute.** Residential college transition program for rising high school juniors, seniors, and young adults with developmental disabilities up to age 24

## ■ READING CLINIC SUMMER SESSION

• JUNE 3-JULY 15  
**(no sessions Wk July 4)**  
Tutoring students through middle

school. 24 (40-minute) sessions, ranging 8 a.m.-12 noon Monday-Thursday Space limited. Apply early. Contact (615) 936-5118, [readingclinic@vanderbilt.edu](mailto:readingclinic@vanderbilt.edu)

## ■ ARTS AND DISABILITIES EXHIBIT

Monday-Friday 7:30 a.m.-5:30 p.m. Lobby VKC/One Magnolia Circle Bldg. Info (615) 936-8852

### • APRIL THROUGH JULY

**ART of AUTISM**

## ■ AUTISM TRAININGS FOR K-12 SCHOOL PERSONNEL

With the Tennessee Department of Education, TRIAD offers free autism-specific workshops for school personnel, parents, and the community in locations across the state. Dates/locations TBA; see [kc.vanderbilt.edu/TRIAD/events](http://kc.vanderbilt.edu/TRIAD/events).

## ■ 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. Info (615) 936-5118

## ■ 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. Info (615) 322-5658 or [NextSteps@vanderbilt.edu](mailto:NextSteps@vanderbilt.edu)

## ■ TAKE PART IN RESEARCH

### VKC Research Studies

For children and adults, with and without disabilities Lynnette Henderson (615) 936-0448 Toll-free (1-866) 936-VUKC [8852]

### • Research Family Partners

[kc.vanderbilt.edu/rfp](http://kc.vanderbilt.edu/rfp)  
Register and be notified of research studies

### • StudyFinder

[kc.vanderbilt.edu/studyfinder](http://kc.vanderbilt.edu/studyfinder)  
View lists of studies, criteria, and contact information

### • See also VUMC Clinical Trials

[www.vanderbilthealth.com/clinicaltrials](http://www.vanderbilthealth.com/clinicaltrials)

## ■ TENNESSEE DISABILITY PATHFINDER ■ MULTI-CULTURAL OUTREACH

Helpline; Web site with Searchable Database, 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

## ■ TENNESSEE WORKS

Web hub for information related to employment of people with disabilities

[TennesseeWorks.org](http://TennesseeWorks.org)  
(615) 936-0448