



DOWN SYNDROME CONFERENCE

Friday, November 3, 2023

Oak Lounge, Tresidder Memorial Union, Stanford University

PROGRAM

9am-9:15am **Welcome.** *Craig Heller and Chris Lemons, Co-Directors, Down Syndrome Research Center, Stanford University*

9:15-10:15am **Deciphering Post Secondary Education Options in California and nationwide.** Your student wants to go to college! But how? There is a growing number of college opportunities for students with intellectual and developmental disabilities. Do all the college programs look alike to you? There is great variation in the expectation and implementation of integrated college experiences. This session will help you identify programs both in California and across the country and help you understand the differences between them. *Chris Lemons, Assoc. Professor, Special Education, Graduate School of Education and co-director, Down Syndrome Research Center, Stanford Univ. and Belkis Choiseul-Praslin, Think College*

10:15 - 10:25pm **Break**

10:25am - 12:10pm **Your child is now (or will soon be) an adult. Now what do you do?** This multi-topic session will discuss the multiple areas you need to consider as your child transitions to adulthood. We will cover topics from practical and **legal considerations** to **living options** and **employment models** in the Bay Area and beyond. We will identify the full continuum, explore the pros and cons, and discuss what is available in the Bay Area and beyond. Session will be led by: *Aaron Carruthers, Executive Director, and David Grady, Central Coast Manager, State Council on Developmental Disabilities, and will include self-advocate guests to provide their input*

12:10 - 12:55pm **Lunch**

12:55 - 2:10pm **Mental Wellness - Strengths, Gifts and Challenges of People with Down**

Syndrome: Half of adults and children with Down syndrome will face a major mental health concern during their lives, similar to the US population (source: NDSS). The more common concerns are depression, anxiety, obsessive-compulsive disorder, oppositional behavior and tic disorders. Drawing on over 28 years of clinical experience with many thousands of individuals with Down syndrome (age 11 to 82), and their families, Dr. McGuire will discuss a treasure trove of findings on the challenges and gifts of this unique group of individuals, in a manner that may help to normalize and confirm the experiences and knowledge of participant families. Participants will be encouraged to ask questions and express their own experiences and suggestions at points throughout the session. *Dennis McGuire, LCSW, PhD, internationally renowned mental wellness expert for adults with Down syndrome*

2:10 - 2:20pm **Break**

2:20pm - 3:35pm **Down Syndrome Regression Disorder (DSRD).** More and more individuals are being diagnosed with Down syndrome regression disorder as young adults. This serious condition results in rapid loss of skills ranging from daily living and social skills, language, and movement. In this session, Dr. Santoro will review neurologic and psychiatric disorders in young adults and persons with Down syndrome; review the symptoms of Down syndrome regression disorder; discuss the potential etiologies for DSRD; and highlight cutting-edge therapies for this condition. Dr. Santoro will also talk about the role of early intervention and its influence on long-term outcomes and take time for audience questions. *Jon Santoro, Assoc. Professor, USC, Down Syndrome Neurology Program Team, The Neurological Institute, and Director Research, Neurologic Institute, Children's Hospital Los Angeles, nations' top Down Syndrome Regression Disorder*

3:35 - 3:45pm **Break**

3:45 – 5pm **Adult Medical Concerns & Aging:** Learn about the most common medical issues adults with Down syndrome face as they age, current protocols for Alzheimer's treatment in Down syndrome population, and hear a summary of the Global Down Syndrome Foundation's Adult Medical Guidelines. *Peter Bulova, Medical Director, Adult Down Syndrome Clinic, Univ of Pittsburgh/UPMC; Past President, Down Syndrome Medical Interest Group-USA board member; Co-investigator, Alzheimer's Biomarker Consortium-Down Syndrome, Univ of Pittsburgh*

SPEAKER BIOS

Peter Bulova, MD



Dr. Bulova is a Professor of General Internal Medicine who runs the University of Pittsburgh Adult Down Syndrome Center and co-directs the Magee Center for Women with Physical and Intellectual Disabilities. He completed his undergraduate training at Brown University. His medical school, internal medicine residency and chief residency took place at the University of Pittsburgh. He is a past president of the executive board of the Down Syndrome Medical Interest Group and speaks nationally of the care of adults with Down syndrome and care of adults with intellectual and developmental disabilities. He teaches medical students, residents and fellows at the University of Pittsburgh and was accepted into the University's Academy of Distinguished Educators in 2009. He is clinically involved in research on Alzheimer's disease in adults with Down syndrome and is an ad hoc reviewer for several journals including *The New England Journal of Medicine*, *the Journal of Intellectual Disability Research*, and *the American Journal on Intellectual and Developmental Disabilities*.

Belkis Choiseul-Praslin, PhD



Belkis Choiseul-Praslin is a research associate with Think College at the Institute of Community Inclusion in UMass Boston. In her work, Belkis supports data collection from federally-funded, inclusive postsecondary programs for students with intellectual disability. Prior to this, Belkis was a special-education transition teacher and also worked with the Sooner Works program at the University of Oklahoma. Her research focuses on improving employment and independent living outcomes for students with disabilities.

Aaron Carruthers



Aaron Carruthers is the Executive Director of the California State Council on Developmental Disabilities. He has worked in civil rights policy and programs for over twenty-five years, including as an appointee of two Governors, for California's Attorney General, and in the State Senate. He is currently carrying out the Council's goals: health, home, and work. This includes phasing out subminimum wage and establishing a statewide Employment First Office. Last year, SCDD's work impacted more than 5.1 million Californians and it was named Employer of the Year for people with disabilities. He is a child of parents with developmental and other disabilities, is a person with disabilities, and is the parent of young man with disabilities. He is a graduate of the National Leadership Consortium on Developmental Disabilities and was a Coro Fellow in Public Affairs.

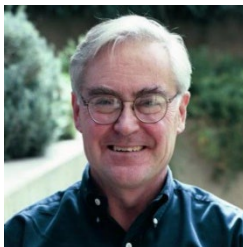
David Grady, MA, MFT



David Grady is the Regional Manager of the State Council on Developmental Disability, Central Coast. David's career and work as the Regional Manager is dedicated to promoting self-determination, independence, productivity, integration and inclusion for people with developmental disability in both their school and community life. As the SCDD Regional Manager for both the San Andreas and Tri-County Regional Center catchments, David collaborates with individuals, families, providers, teachers, policy makers and the community to accomplish system change and overall quality improvement throughout the developmental and behavioral service systems.

David has a full career that has included direct care and program management in residential, vocational, independent living, and quality assurance. David works with individuals and families to navigate the service system. He has a broad awareness of the services and supports in developmental services, as well as knows the obstacles and needs that are being faced by families and individuals with developmental disabilities.

H. Craig Heller, PhD



Prof. Craig Heller is the Lorry I. Lokey Business Wire Professor of Biology/Human Biology, Director of the Down Syndrome Research Center at Stanford University. He was recently the President of the Sleep Research Society and President of the Association of Professional Sleep Societies. At Stanford he is a member of Bio-X, Wu Tsai Neurosciences Institute, Wu Tsai Human Performance Alliance, and Cardiovascular Institute. He received the Kenneth M. Cuthertson Award for Exceptional Contributions to Stanford University and the Walter J. Gores Award for Excellence in Teaching. He has served as Assoc. Dean of Research, Chair of the Biological Sciences, Director of the Program in Human Biology, Chair of the Academic Senate, and Chair of the Wallenberg Global Learning Network Steering Committee. He is a William and Lynda Steer University Fellow.

Christopher J. Lemons, PhD



Prof. Lemons is an Associate Professor of Special Education in the Graduate School of Education at Stanford University. His research focuses on improving academic outcomes for children and adolescents with intellectual, developmental, and learning disabilities. His recent research has focused on developing and evaluating reading interventions for individuals with Down syndrome and other intellectual and developmental disabilities. His areas of expertise include reading interventions for children

and adolescents with learning and intellectual disabilities, data-based individualization, and intervention-related assessment and professional development. Lemons has secured funding to support his research from the Institute of Education Sciences and the Office of Elementary and Secondary Education, both within the U.S. Department of Education and from the National Institutes of Health. Lemons is a Senior Advisor of the National Center on Intensive Intervention and the Progress Center, both within American Institutes of Research (AIR) in Washington, DC. He also chairs the Executive Committee of the Pacific Coast Research Conference (PCRC) and serves as the President-Elect of the Council for Exceptional Children's Division of Research. Lemons is a recipient of the Pueschel-Tjossem Research Award from the National Down Syndrome Congress and the Distinguished Early Career Research Award from the Council for Exceptional Children's Division for Research. In 2016, Lemons received the Presidential Early Career Award for Scientists and Engineers (PECASE), the highest honor bestowed by the U.S. government on science and engineering professionals in the early stages of their independent research careers, from President Obama. Prior to entering academia, Lemons taught in several special education settings including a preschool autism unit, an elementary resource and inclusion program, and a middle school life skills classroom.

Dennis McGuire, PhD



Dr. McGuire helped to establish the Adult Down Syndrome Center, in suburban Chicago, which has served the health and psychosocial needs of over 6,000 teens and adults with Down syndrome since its inception in 1992. More recently he served as a senior consultant for the Global Down Syndrome Foundation in Denver Colorado to assist in the development of a center for adults with Down syndrome and the Health Care Guidelines for teens and adults. He co-authored two books on “Mental Wellness of Adults with Down Syndrome: A guide to emotional and behavioral strengths and challenges” (2nd Edition 2022) and “The Guide to Good Health for Teen and Adults with Down Syndrome” (2010) published by Woodbine House Press.

Jonathan D. Santoro, MD



Dr. Santoro serves as the Director of Neuroimmunology and Demyelinating Disorders Program and Director of Research for the Neurologic Institute at Children's Hospital Los Angeles. He is also an Associate Professor of Neurology and Pediatrics at the Keck School of Medicine at USC. Dr. Santoro completed his undergraduate, masters, and medical degrees at Tulane University. He completed residencies in pediatrics and child neurology at Stanford University which was followed by sub-specialty training in neuroimmunology at Harvard Medical School. Dr. Santoro is one of only a handful of national clinician-scientists who treats neurologic disorders associated with Down syndrome. He has been instrumental in identifying systemic vascular abnormalities in persons with Down syndrome and moyamoya disease, a rare stroke disorder

which affects persons with Down syndrome 26 times more frequently than the general population. Dr. Santoro also has clinical research expertise in neuroinflammation as it is related to cerebrovascular disease and neurocognitive disorders such as Down Syndrome Regression Disorder (DSRD), of which he has spoken internationally. In addition to his clinical and research activities, Dr. Santoro advocates for persons with disabilities at both the state and federal level through the American Medical Association and the American Academy of Neurology.

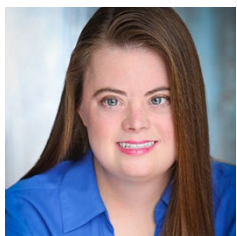
Jared Schmidt



Jared Schmidt is a Martial Arts (Tae Kwan Do) coach of school children and a facility custodian at Break the Barriers in Fresno, CA. He has been employed there for over 15 years. He is also on their "Travel Team." They have traveled to 10 countries, as well as all over the U.S. spreading their message of hope and inclusion, addressing governments, schools and churches, and demonstrating choreographed dance/gymnastic routines and speaking at many events. Jared is also a Global and Health Messenger for Special Olympics and has won many medals in skiing, gymnastics and swimming. Jared most recently was awarded Athlete of the Year from Fresno County Office of Education. He also serves on the Superintendent's

Community Advisory Council. He wants you to keep an eye out for his future book "Never Give Up."

Caley Versfelt



Caley Versfelt promotes acceptance and inclusion as an advocate, public speaker, actress, model, and correspondent. Caley dreams big and never gives up. Caley promotes, "Kindness is Contagious," through her business Tides of Kindness.

Her entertainment interests are limitless. Caley guest starred on *The Good Doctor*, performs bimonthly in the opening improv act in *The Sound of Musical* in Hollywood. Caley is a correspondent at multiple events including live co-hosting the Media Access Awards.

As a model, Caley did a photo shoot with Miss USA's Elle Smith for SeneGence cosmetics and recently walked the runway for Sky Cubacub and Kyle Denman during LA Fashion Week.

Caley works at Entertainment Industry Foundation. Her picture lit up Time Square for their Delivering Jobs kickoff campaign.

Caley's advocacy work extends over many organizations. She is a Global Ambassador for Best Buddies International and a previous Los Angeles Advisory Board member. For Special Olympics Southern California, Caley is a Global Ambassador and prior Board of Directors

member. She was a Games Associate and a Media Correspondent for Special Olympics World Games Los Angeles.

Her awards are numerous, including being an Honorary Mayor for Manhattan Beach, California, the Spirit of Courage Award from Best Buddies International, the Richard Van Kirk Outstanding Outreach Achievement Award from Special Olympics Southern California, the SunDown Voice Award from the Down Syndrome Association of Los Angeles, the Hero's and Me Award from Westside Regional Center, and was delighted to be a California Miss Amazing Queen. Her volunteerism began at a young age, earning the Girl Scouts Gold Award. She represented Girl Scouts in the Pasadena Tournament of Roses Parade on their 100th Anniversary float.

Caley surprises people with her talents, multiple interests, and outgoing personality. She inspires people to believe in themselves and the abilities of others, affirming we all have talents and value.