

# Stanford | Down Syndrome Research Center

## DOWN SYNDROME CONFERENCE

Friday, October 28, 2022

Bass 122, 327 Campus Drive, Stanford, CA

9am - 9:10am **Welcome/Opening Remarks**, *Chris Lemons, Faculty Co-Director, Stanford Down Syndrome Research Center, and Assoc. Professor, Special Education, Graduate School of Education, Stanford University*

9:10 - 9:15am **Heart research** – *Siyeon Rhee, Cardiovascular Institute, Stanford University*

9:15-10:15am **Education: ABC's of Effective Reading Instruction**, Overview of evidence-based strategies, resources, and activities for effecting reading instruction for students with Down syndrome, *Dana Halle, The Learning Program & National Down Syndrome Congress Executive Committee member, and Stanford Down Syndrome Research Center Advisory Board member*

10:15-11:15am **Transition: Post Secondary Education Options**, What educational options does your student have after high school? What to consider so there is a good fit between the program and the student? What the different types of programs are looking for in an applicant? *Beth Foraker, Co-Director, UC Davis Redwood SEFD Program and Stanford Down Syndrome Research Center Advisory Board member*

11:15-11:30am **Break**

11:30am-12:30pm **Inclusion through Technology for Today and Tomorrow**: Digital solutions have proliferated over the past few years. For example, Google has developed a personalized speech recognition tool for Android phones. Many of these tech tools can be critical in furthering the support, instruction, and overall facilitation for students with Down syndrome, and their peers, to be meaningfully included. Together, participants will explore readily available solutions and applications to the K-12 classroom and beyond. *Sean Smith, Professor, Special Education, University of Kansas & National Down Syndrome Congress Board of Directors, and Stanford Down Syndrome Research Center Advisory Board Member and Pan-Pan Jiang, Project Relate, Google.*

12:30-1pm **Lunch**

1-2pm **Medical**: Updated (2022) American Academy of Pediatrics guideline “Health Supervision for Children and Adolescents With Down Syndrome”, *Noemi Spinazzi, Asst Clinical Professor,*

*UCSF School of Medicine, Medical Director, UCSF Benioff Children's Hospital Down Syndrome Clinic (Charlie's Clinic) and National Down Syndrome Congress Board of Directors*

**2-3pm Transition: Supported Decision Making & Self Determination**, What is Supported Decision Making and Self Determination? What will be the impact of AB 1663? Protecting and affirming a self-advocate's voice and rights after they turn 18 yrs old. *Intro: Dr. Jennifer Pien, Clinical Assoc. Professor, Stanford University School of Medicine, Suzanne Bennett Francisco, Co-Chair Human Rights Community of Practice, TASH, President/CEO of Exceptional Rights Advocacy, Linda Chan Rapp, Stakeholder appointee to CA Dept of Developmental Services' Quality Assessment Advisory Group, Self Determination Advisory Committee, Harbor Regional Center (2015-2022), and Eden Rapp, self-advocate*

**3-3:15pm Break**

**3:15-4:15pm Education: Accommodations & Adaptations**; Learning how to work with teachers to develop and implement practical accommodations and adapted assessments, *Lakshmi Balasubramanian, Lecturer, Stanford Graduate School of Education*

**4:15-5pm Small group discussions** – Choose a small group to dig deeper into a topic

- ABC's Effective Reading – Dana Halle
- Tech Tools – Sean Smith
- Post Secondary Education – Beth Foraker
- Accommodations & Adaptations – Lakshmi Balasubramanian
- Supported Decision Making & Self Determination – Suzanne Bennett Francisco & Linda Chan Rapp

**5-6:30pm Reception (in courtyard)**

2022

## SPEAKER BIOS

### **Lakshmi Balasubramanian**

Lakshmi is a Lecturer and Researcher in the field of special education at the Graduate School of Education at Stanford University. She completed her Ph.D. in Special Education at the joint doctoral program at the University of California, Berkeley with San Francisco State University in May 2021. Her dissertation research examined the processes and practices of inclusive education for students with diverse disabilities in a school district in Northern California. Facilitators and barriers to inclusion were examined as they related to access, meaningful participation, and creation and provision of supports for all participants within their sociocultural context. She makes visible the ableist and disablist discourses and practices that sometimes frame the construction of disability and what it means to teach or parent a child with a disability within those confines. She currently manages two Institute of Education Sciences (IES) grants as part of the Lemons lab at Stanford. She also teaches the course on Dis/ability, Access and Inclusion at the Stanford teacher Ed program.

Prior to joining Stanford, Lakshmi worked as a special education teacher and inclusion specialist in a large public school district for 14 years. During this time, she spearheaded the design and implementation of inclusive education programs at the school district in grades K-12. Additionally, she has worked as a professional development facilitator nationally and internationally on a variety of topics related to inclusive education and Universal Design for Learning (UDL).

### **Suzanne Bennett Francisco**

Suzanne is the President of Exceptional Rights Advocacy, an author, speaker, disability rights and special education advocate. She is also a subject matter expert on Supported Decision-Making (SDM) a voluntary way to protect, empower and support adults with disabilities *without the court*. Suzanne is the proud single mother of three young adult children with intellectual and developmental disabilities who are non-speaking, use Augmentative Alternative Communication (AAC) and practice Supported Decision-Making (SDM).

It has been her passion and privilege to advocate in collaboration with key disability rights stakeholders nationally, statewide and at the local level. Suzanne has educated and trained self-advocates, families, supporters and professionals across community, education, healthcare and legal disability fields on “less restrictive alternatives” in order to slow the automatic flow into overbroad and undue conservatorships – legally meant to be used only as a *last resort*. She has served on coalitions and advisory committees, worked with on grant projects and/or provided education alongside disability rights advocates and agencies including the UCSF Office of Primary Developmental Care, the UCLA Disability Studies Program, the Stanford Law School Mental Health and Intellectual Disabilities Studies programs, the SFASA Conference for Adults with Autism at Stanford, the Burton Blatt Institute of Syracuse University, the UC Davis MIND

Institute, Disability Rights California, the ACLU, the State Council on Developmental Disabilities, Disability Voices United and others.

Suzanne serves as the Co-Chair of the TASH Human Rights Committee, on the California Coalition for Conservatorship Reform that worked to pass AB1663, a law signed by Governor Newsom, and on her local San Andreas Regional Center Self Determination Advisory Committee.

### **Beth Foraker**

Beth Foraker and her husband, John, are alumni of UC Davis. Beth and John are parents to four children: Jack, Mary Kate, Patrick, and Caroline. Their third child, Patrick, has Down Syndrome. Patrick was fully included in school, earned a California high school diploma and is now a senior at an inclusive college program at George Mason University in Virginia. Beth has been an educator for over thirty years and worked for fifteen years for UC Davis in the School of Education with beginning teachers in their Multiple Subject Credential/Masters Program.

Today, she is the Co-Director of the UC Davis Redwood SEED Scholars Program – a four-year, residential, inclusive college program – the first of its kind in California. She works to build what she calls Continuums of Inclusion: communities that offer preschool through college inclusion so that independent adulthood - inclusive living and inclusive employment - and full belonging are possible. With the launch of the UC Davis Redwood SEED Scholars Program, the City of Davis is now one!

### **Dana Halle**

Dana Halle is Co-Founder and Executive Director of Down Syndrome Foundation of Orange County. She also developed and continues to expand The Learning Program and LP Online, educational platforms which improve academic outcomes for learners with Down syndrome. She currently trains and supports Down syndrome organizations across the nation in their delivery of local educational programming. Dana also provides weekly direct instruction on literacy, math and social skills to students (ages nine through twenty-three) in DSF's Learning Center in Irvine, California. Dana attended Pomona College, where she earned a B.A. in Public Policy Analysis & Psychology and the University of California, Hastings School of Law, where she earned her J.D. Dana practiced law as a business litigator for ten years before taking time off to parent her three children, the youngest of whom, Nick, has Down syndrome. Soon after Nick's birth in 1998, Dana began advocating on behalf of children with Down syndrome and their families.

### **Pan-pan Jiang**

Pan-Pan Jiang is a Technical Program Manager on the Google Project Relate team. She earned a PhD in evolutionary biology from Harvard University, before joining Google to help catalyze research for building health and accessibility products.

### **Jennifer Pien**

Dr. Jennifer Pien is a Clinical Associate Professor through the Department of Psychiatry and Behavioral Sciences, Stanford School of Medicine. She cofounded Puente Clinic through the San Mateo County Medical System, an innovative subspecialty clinic offering mental health services devoted to the care of adults with developmental disabilities. Her clinical work is in physician well-being through WellConnect as well as in the area of developmental disabilities. Her interests include medical humanities and the intersection of creative writing and medicine.

### **Linda Chan Rapp**

Linda is an educator and lifelong learner. One of her favorite teachers has been her daughter Eden, who has taught her about unconditional love, sign language, homeschooling, flexibility, supported-decision-making, perseverance, math, music, person-centered planning, speechcraft, Down syndrome, and more. Together they have presented at national Down syndrome conventions, volunteered in the community, and lobbied for policies to transform and support the lives of individuals with developmental disabilities. Currently Linda serves as a Down Syndrome Association of Los Angeles' mentor parent and assists with its Facebook page. She served on the local Self-Determination Advisory Committee at Harbor Regional Center from 2015-2022, and is a stakeholder appointee to the Department of Developmental Services' Quality Assessment Advisory Group. She also facilitates UpVoice, sits on the board of Friends of Lomita Library, and assisted with the host committee of Matthew Foundation's Super Fest 2022.

### **Siyeon Rhee**

Siyeon Rhee is an instructor working with Dr. Joseph Wu at Stanford Cardiovascular Institute. After getting his Ph.D. in developmental biology at UMass, Amherst, he joined Kristy Red-Horse's lab in the Stanford Biology Department where he studied cardiovascular development. During his postdoc, he focused on studying congenital heart disease, called LVNC (left ventricular non-compaction) using mouse embryos and culture models.

His current research interests include [1\) utilizing patient iPSC cells to investigate the mechanism of Down Syndrome congenital heart disease and 2\) adult heart disease](#). He will give a short overview of the current DS project and talk about how blood donation helps Down Syndrome-CHD research.

### **Sean Smith**

Sean J. Smith, Ph.D., is a Professor in the Department of Special Education at the University of Kansas. He is also the Past-President of the technology division for the Council for Exceptional Children, Innovations in Special Education Technology (ISET), and member of the Board for the National Down syndrome Congress. Dr. Smith's research interests focus on innovations and technology solutions to support struggling learners and those with disabilities, particularly interventions aligned with the Universal Design for Learning (UDL) Framework. At present, Dr. Smith is the Principal Investigator on a federally funded project exploring the impact of virtual reality on struggling learners in the area of social emotional development. Sean has authored over 100 books and articles, given hundreds of scholarly presentations both nationally and

internationally, and serves on various boards for journals, organizations, and parent groups focused on enhancing the lives of individuals with disabilities. Dr. Smith, with a variety of collaborators, has received and managed over \$25 million of external research and development funds. Most importantly, Sean is the father of four children, one having Down syndrome. It is through this work as a father that Sean has sought to apply his knowledge of effective practices with parents, family members, and similar stakeholders as we look to enhance the lives of our children, ALL of our children!

### **Noemi Spinazzi**

Noemi Spinazzi, MD is the co-founded and is Medical Director of UCSF Benioff Children's Hospital Oakland Down Syndrome Clinic (Charlie's Clinic). She is also on the National Down Syndrome Congress Board of Directors where she co-chairs the Down syndrome-Autism Dual Diagnosis subcommittee. She works closely with California Children's Services (CCS) and with the East Bay Special Needs Committee. She is also the co-director of the developmental and behavioral pediatrics resident rotation at UBCHO.

Dr. Spinazzi is very involved in medical education. She is a member of the UCSF Diversity and Equality Committee, and she is passionate about mentoring the next generation of healthcare providers. Dr. Spinazzi has a member of the American Academy of Pediatrics since her residency, and has been actively involved in advocacy efforts at the local, state, and federal level.

She received her medical degree from the University of Pennsylvania in Philadelphia, Pennsylvania. She completed her residency at UCSF Benioff Children's Hospital Oakland, where she was the Chief Resident