



Down Syndrome Clinic
and Research Center
at Kennedy Krieger Institute

2022 Year-End Update

At the Down Syndrome Clinic and Research Center, two concrete steps are underway in caring for our patients with Down syndrome:

1. Addressing staff shortages in adult medical and mental health services and geriatric care in older adults.
2. Applying for grants and working closely with Johns Hopkins Medical Institutes and the School of Public Health on several research endeavors.

The shortage of providers trained to care for children and adults is of paramount concern. We continue to mentor and train a steady stream of physicians in adult psychiatry through Johns Hopkins Medical Institutes and the departments of Pediatrics, Neurodevelopmental Medicine and Child Psychiatry at Kennedy Krieger Institute. We are collaborating with Johns Hopkins Medical Institutes to build a referral pathway for elderly adults with Down syndrome with concerns about dementia. Through our professional organization the Down Syndrome Medical Interest Group-USA, we mentor young physicians working in Down Syndrome Clinics throughout the U.S.A. and abroad.

Down Syndrome Clinical Trials Network

The Down Syndrome Clinic at Kennedy Krieger continues to participate in the Down Syndrome Clinical Trials Network, launched by LuMind/Research Down Syndrome Foundation (LuMind RDS) in early 2019. The DS-CTN is focused on organizing and funding clinical trials more efficiently to test novel therapies for co-morbid medical conditions such as autism and dementia.

More information about the network can be found [here](#).

Adult Research Sponsored by LuMind

We are continuing our work with the Longitudinal Investigation for the Enhancement of Down Syndrome Research (LIFE-DSR) study, which entails three visits over three and a half years. The LIFE-DSR study is an observational study with the goal of better understanding the cognitive, behavioral and health conditions found in persons with Down syndrome as they progress through adulthood. We are currently moving into the study's second phase—neuroimaging, otherwise known as brain scanning—by looking for biomarkers for dementia in pre-symptomatic adults. The goal is to work toward having an established center of care for elderly adults with Down syndrome.

We continue to be open for recruitment in this study. To learn more or to participate in the study, please visit [Research Initiatives at the Down Syndrome Clinic and Research Center | Kennedy Krieger Institute](#)

Personnel

I have been with the DSCRC since its inception in 1989, and I continue to care for children, adolescents and adults across the lifespan. My current interests focus on improving healthcare delivery and research opportunities for adults. In addition to expanding the program at KKI/JHMI, I serve on the safety and monitoring board for three independently funded research projects currently underway in the U.S.A. and serve on the Advisory Board for the Down Syndrome Medical Interest-Group-USA, the Global Down Syndrome Foundation, and the National Down Syndrome Society. While travel and speaking engagements have been curtailed during the pandemic, I participate internationally in virtual meetings.

Dr. Clay Smith has been with DSCRC for nearly a year and a half. He has cared for individuals with Ds from infancy to adulthood. Recently, he has been assisting with the LuMind LIFE-DSR study of adults. Through his research capacity in the study, he has begun seeing even more adult patients.

Dr. Mihee Bay, who has been with the DSCRC since 2012, continues to care for young children and adolescents with Ds. She has begun assisting in a random clinical trial of an already FDA-approved medicine—Guanefcine—for treating ADHD in school-aged children with Down syndrome. She continues with her interest in identifying and managing children with the dual diagnosis DS + Autism spectrum. She has been involved in ways to improve the delivery of care. Additionally, she continues to see patients offsite, at Kennedy Krieger Institute's Columbia location, with remarkable success.

Christopher Bramble, our DSCRC clinical coordinator, has been with the DSCRC since 2021. He manages the front office by providing administrative support to Dr. Bay, Dr. Smith and me, and exemplary customer service to our families. Although this is his first job in the healthcare field, he has over six years of customer service experience working alongside his family in their automotive repair business. Outside of Kennedy Krieger, he enjoys working with kids on the soccer field and has coached at two different travel soccer clubs since ending his career as a college player. He also has firsthand experience working with children with disabilities, from helping with the Special Olympics and Unified Sports when he was younger.

Shannon Schneiderman is the Down Syndrome Nurse Coordinator, and joined Kennedy Krieger in September. She provides nursing support to patients with medication concerns, behavioral concerns, and other issues, with the support of Down syndrome physicians. Shannon graduated from Towson University with a Bachelor of Science degree in Psychology in 2017. She earned her Master of Science in Nursing degree from the University of Maryland School of Nursing in 2020, and has experience working on a medical-surgical/cardiac floor in the hospital setting. She enjoys traveling, hiking and trying new restaurants in her spare time.

Bridget Gibbons is a psychology associate and board-certified behavior analyst with the Pediatric Psychology Consultation Program in the Behavioral Psychology department at Kennedy Krieger Institute. She has worked at Kennedy Krieger since 2006, and joined the Down Syndrome Clinic in April 2022. She is particularly interested in working with children and young adults with neurodevelopmental disabilities and with their families on coping with medical

care and related behavioral challenges. She serves the DSC on Tuesday mornings consulting with families. We are happy to have her in our clinic, reducing the need for consultation referrals and making our patients' visits easier.

We continue to be busy building out our team, training more young professionals, and constantly working to address unmet needs, particularly adult care in middle age (30-50 years old) and elderly (50+ years old) patients.

Currently, we evaluate over 150 new individuals each year in the DSCRC; about half are children under 18 years and the remainder are adults. We also provide follow-up to more than 450 individuals with DS of all ages, many with complex medical conditions and co-occurring behavior or mental health concerns. In-person clinical evaluation and virtual TeleHealth consultations are available.

In addition to the surrounding mid-Atlantic states (MD, VA, DE, NJ, PA), families often travel from New England, the Midwest or Southwest regions of the U.S.A.

To make a gift in support of the valuable work conducted by the Kennedy Krieger Down Syndrome Clinic and Research Center, please make a secure gift at

Gifts of all sizes are appreciated—you can make a difference!