



**Your gift to advance Down syndrome research empowers change and creates possibilities.**

## The Impact

Every family's experience with Down syndrome is unique. While this journey is often filled with creativity and celebration, it also comes with uncertainties about the future. At the Down Syndrome Clinic and Research Center (DSCRC), we work to help individuals with Down syndrome thrive—maximizing independence and participation in family, school and community life.

Today, individuals with Down syndrome are living longer and healthier lives than ever before. However, aging brings new challenges, including an increased risk for mental health conditions. Additionally, adults with Down syndrome experience physical and cognitive aging earlier than those without the condition, including the risk of Alzheimer's disease:

By better understanding these processes, we aim to develop therapies that improve lives and create new opportunities for children and adolescents before they reach adulthood.

## Our Mission

Since 1989, the DSCRC at Kennedy Krieger Institute has provided comprehensive care to individuals with Down syndrome, from birth through adulthood. Our interdisciplinary team addresses developmental and neurobehavioral challenges, sleep difficulties, coexisting medical conditions and mental health needs. Through our clinical research programs, we are at the forefront of demystifying the complex nature of Down syndrome while training the next generation of scientists and clinicians.

Led by Dr. George Capone, an expert in novel treatments and groundbreaking research, our team has supported over 6,000 individuals. Collaborating with specialists like Dr. Mihee Bay and Dr. Clay Smith, we're exploring innovative solutions, from ADHD treatments in children with Down syndrome to studies that deepen our understanding of aging and dementia in adults with Down syndrome.



**Dr. Clay Smith** has been with the DSCRC since 2021. He has cared for individuals with Down syndrome from infancy to adulthood for many years and has recently begun seeing adult patients.



**Dr. Mihee Bay**, who has been with the DSCRC since 2012, continues to care for young children and adolescents with Down syndrome. She is a co-investigator in a clinical trial of an already-FDA-approved medicine—guanfacine—for treating ADHD in school-aged children with Down syndrome. She continues with her interest in identifying and managing children with the dual diagnoses of Down syndrome and autism spectrum disorder. She sees patients at Kennedy Krieger's Columbia location as well as at the Institute's downtown Baltimore location.

### The Hannah Rose Culotta Endowed Research Fund

With support from The Wawa Foundation, as well as from generous donations in support of Run for Hannah, this fund was created to honor **Hannah Rose Culotta** and enhance treatment approaches for individuals with Down syndrome across the lifespan. Since this fund's inception, we have raised over \$285,000! This ongoing initiative helps drive our mission forward and supports research initiatives such as the Adult Outcomes Study and others listed below.

### The Adult Outcomes Study

One of our key efforts in partnership with the Johns Hopkins Bloomberg School of Public Health is the Adult Outcomes Study, focused on individuals ages 19 to 39 who were seen at Kennedy Krieger as children. Through this study, we aim to:

1. Assess adult cognitive, behavioral and social functioning, as well as quality of life.
2. Understand which childhood challenges most impact aging and risk for developing Alzheimer's disease.
3. Develop preventive strategies and treatments to support healthy aging.

This work is possible because of donors like you. With your help, we can connect families to research opportunities through a new contact registry and build a foundation for long-term studies that will benefit future adults.

### Looking Ahead With Your Support

We are growing our initiatives to:

- Offer fellowship training for physicians who work primarily with adult patients to deliver care to adults with Down syndrome.
- Expand our partnership with Kennedy Krieger's Neurodiversity at Work department to help our families set their children up for success as they transition into adulthood. We have already begun planning our first webinar, "Setting Your Child Up for Success," with our Neurodiversity at Work partners. This webinar will be held June 3, 2025, and will be open to all families of the DSCRC, as well as the greater Down syndrome community. Further details will be available in early 2025, but you may email [Leslie Marsiglia](mailto:Leslie.Marsiglia) to ensure you receive an invitation.

### How You Can Help

Your gift today directly advances research and enhances programs of care for individuals with Down syndrome and their families.

Visit [KennedyKrieger.org/DownSyndrome](https://KennedyKrieger.org/DownSyndrome) or email Leslie Marsiglia at [Marsiglia@KennedyKrieger.org](mailto:Marsiglia@KennedyKrieger.org) to learn more and get involved.