



Down Syndrome Clinic
and Research Center
at Kennedy Krieger Institute

Down Syndrome Clinic and Research Center

**Your gift to advance Down syndrome research
will make an immediate difference!**

The Impact

Having a family member with Down syndrome is a unique and personal journey. Although this journey can be a blend of beauty, creativity and joyous celebration, families also encounter uncertainties about what the future may hold. Our mission is to help all patients pursue all that's possible in their lives and function as independently as possible in family, school and community life.



Today, people with Down syndrome are living longer and are healthier than at any other time in the past. However, as adults with Down syndrome grow older, they are at an increased risk for a variety of mental health disorders, including depression, anxiety, obsessive-compulsive disorder and behavioral disturbances. Additionally, it is expected that adults with Down syndrome will show physical, medical and cognitive signs of aging much earlier than will individuals without the condition.

Another sobering statistic is that nearly all people with Down syndrome show signs of Alzheimer's disease sometime during their sixth decade of life (i.e., in their 50s). However, the underlying processes leading to early Alzheimer's disease are well known to be underway much earlier. Having a more detailed understanding of these events will open new possibilities for people with Down syndrome and help pave the way for new therapies for children with Down syndrome before they reach adulthood.

Dedicated to Making a Difference

Established in 1989, the Down Syndrome Clinic and Research Center at Kennedy Krieger Institute strives to optimize the health and quality of life of individuals with Down syndrome by providing comprehensive, interdisciplinary evaluations and services, from birth through adulthood, to patients with challenges that include pediatric developmental delay, complex neurodevelopmental and behavioral conditions, and adolescent and adult mental health issues. The center's clinical research programs play a direct role in patient care as well as in finding and developing effective therapies for a variety of conditions that can co-occur with Down syndrome.



The center is led by Dr. George Capone, an international expert in developing novel treatments and cutting-edge research for this population. His expertise has endeared him to his patients and their family members alike. He has served on many prestigious committees, has been instrumental in developing national guidelines for treating adults with Down syndrome, and has served as an expert for legislators crafting laws to advocate for individuals with Down syndrome. Since the center's opening, Dr. Capone and his team have provided diagnosis and treatment services to over **6,000 individuals**.

Research is the Key

Through its research work, the center is evaluating and developing new and innovative therapies and interventions to improve care for millions of children and families around the world. Research also offers opportunities for younger scientists and clinicians to be trained and mentored by the center's experienced faculty members.

What Will It Take?

Inspired by the dedication and expertise of Dr. Capone, The Wawa Foundation recently created [The Hannah Rose Culotta Endowed Research Fund](#), which will support the development of enhanced treatment approaches for individuals with Down syndrome throughout their lives. The fund is named in honor of the daughter of longtime donor Jay Culotta, a retired Wawa executive, who has raised hundreds of thousands of dollars for Down syndrome research over the past two decades.



The Wawa Foundation not only made the initial donation to establish the fund, they have also agreed to **match Jay Culotta's funds raised through his annual fundraiser, "Run for Hannah" for the next two years. Please consider making a gift today to add your impact to the novel research at Kennedy Krieger to improve the lives of individuals with Down syndrome.**

Funding Is Needed Now

Two research studies happening right now at Kennedy Krieger that would benefit from funding from The Hannah Rose Culotta Endowed Research Fund are a study on aging and dementia in people with Down syndrome, and a study on how a medication commonly prescribed for children with attention-deficit/hyperactivity disorder (ADHD) may benefit children with Down syndrome and ADHD.

1. Aging and Dementia

One of our newest studies in need of support is the **Adult Outcomes Study**, for people with Down syndrome between 19 and 39 years old who are living in the Mid-Atlantic region, and who were seen at Kennedy Krieger in childhood (i.e., before turning 18) between 1990 and 2002. The goal of this study is to learn from participants and their families about participants' current levels of functioning and cognition, how they're doing behaviorally and socially, and about their employment, leisure activities and quality of life.

Through this study, we will:

- Gather data from a large representative cohort of individuals about their adult levels of functioning
- Consider if earlier challenges with development, learning, behavior, sleep and other childhood medical conditions increase the chances of atypical ageing and Alzheimer's disease in people with Down syndrome
- Determine a course of treatment and preventive strategy as these same adult individuals progress into elder adulthood

2. ADHD Medication Clinical Trial

In keeping with our long-standing interest in neurobehavioral conditions in children, Dr. Capone and neurodevelopmental pediatrician Dr. Mihee Bay are examining the safety and efficacy of a commonly prescribed medication (Guanfacine) for ADHD in children with Down syndrome. Kennedy Krieger is one of approximately 12 sites chosen to carry out this multicenter study. The study is anticipated to begin in early 2024 and is funded in part by The Hannah Rose Culotta Endowed Research Fund, along with funding from the Pediatric Trials Network of the Eunice Kennedy Shriver National Institute of Child Health and Human Development.

Building a Research Infrastructure

The Down Syndrome Clinic and Research Center has already received limited funding from the National Institutes of Health to begin creating a **research contact registry** that will allow us to connect with current and legacy families to gauge their interest in participating in future research studies sponsored by Kennedy Krieger and The Johns Hopkins Hospital.

Our priority will be to build our team to launch recruitment for the **Adult Outcomes Study**. The contact registry team will maintain a database of contact information on families with children seen at the center so the team can easily tell families about upcoming research opportunities. Our goal is to identify families interested in participating in the study and retain each family

throughout the lifespan of their loved one with Down syndrome. Assembling a cohort of individuals whom we may track from childhood through adulthood will remain an invaluable resource upon which to advance our research and programmatic goals.

Research is the only way to evaluate the safety and efficacy of promising new therapies and innovative treatment approaches for older individuals with Down syndrome. Simultaneously, this work advances the training and mentorship of our younger physicians and researchers, who will carry this work into the future.

How You Can Help

Your gift today will make a lasting difference in helping to grow the research endowment for Down syndrome. Please join the Wawa Foundation and Jay Culotta in raising funds for research that will make an immediate impact on furthering the research and make an immediate difference in the lives of our Ds patients and their families.

For more information and to get involved, please visit our website at **[KennedyKrieger.org/DownSyndrome](https://www.KennedyKrieger.org/DownSyndrome)** or contact Leslie Marsiglia at **Marsiglia@KennedyKrieger.org**.