

## OUR IMPACT

- Research funded by the FD Foundation identified the FD gene in 2001. Genetic testing, now available to all, means **thousands of healthy babies born every year** to carrier families.
- Scientists working with the Foundation are currently pursuing a number of promising **treatments aimed at slowing or stopping progression of the disease** and are optimistic that one or more may soon be ready for testing in the clinic.
- Researchers studying FD are also learning about the cellular and molecular pathways that cause neuronal death in Alzheimer's, Parkinson's, ALS and multiple sclerosis; **treatments for FD may be effective in these more prevalent diseases as well.**



## YOUR IMPACT

Because FD is so rare, the Foundation **depends on the generosity of family and friends LIKE YOU** who know and love someone living with the disorder.

Your philanthropic support enables the Foundation to fund top-notch **medical care** at the Dysautonomia Center, invest in cutting-edge **scientific research** to discover treatments, provide programs and services that **enhance quality of life** for people who have FD and **promote awareness** campaigns to ensure that no more babies will be born with FD.

The Familial Dysautonomia Foundation strives to  
make life better for people living with FD

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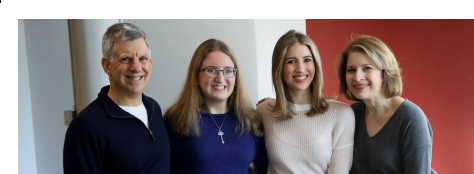
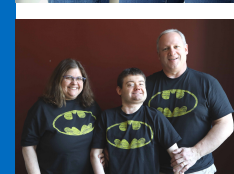
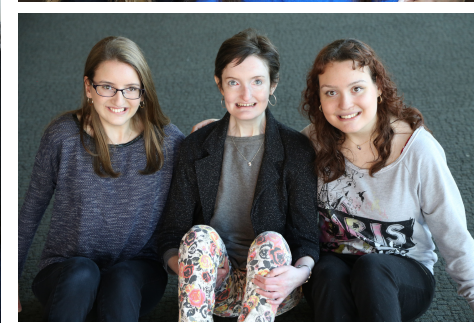
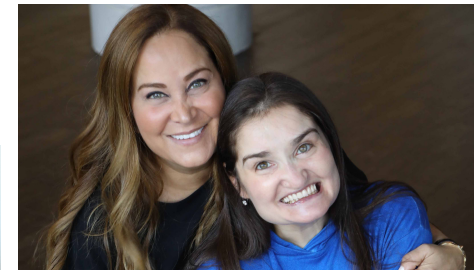
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**FAMILIAL  
DYSAUTONOMIA  
FOUNDATION, INC**



**Familial Dysautonomia Foundation:  
the leader in FD treatment and  
research**



## ABOUT FAMILIAL DYSAUTONOMIA

FD is a genetic disorder affecting the autonomic and sensory nervous systems. It is found almost exclusively in people with Ashkenazi Jewish heritage (about 1:19 are carriers). FD is an ultra-rare disease--fewer than 320 people are currently living with the disorder worldwide.

**Every day is a challenge for people who have FD and for those who love and care for them.**

Symptoms begin in infancy, including inability to suck. Many need a feeding tube. FD affects almost all organs of the body and impairs nearly every major bodily function including breathing, swallowing, blood pressure regulation, temperature control, producing tears and balance.

Symptoms increase in number and severity with age, which can lead to: kidney and heart problems, lung infections, severely impaired vision, scoliosis, poor growth and weak muscle tone and learning difficulties. Many experience unpredictable attacks known as autonomic crises, which can last for hours or days.

While improvements in treatment and research have increased life expectancy, **FD remains a life-threatening disease with no cure.**

# FAMILIAL DYSAUTONOMIA IS A GENETIC DISORDER AFFECTING THE AUTONOMIC AND SENSORY NERVOUS SYSTEMS

## ABOUT US

### Our Mission

To raise funds and operate programs to pursue the best possible medical treatment, scientific research, public education and social services for the benefit of those affected with or at risk for familial dysautonomia.

### Our History

Founded more than 70 years ago by parents who had nowhere to turn for help in caring for their severely ill children, the FD Foundation strives to make life better for people living with FD.

In 2001, scientists funded largely by the FD Foundation identified the gene that causes familial dysautonomia, opening the door to carrier testing and prenatal screening, resulting in a generation of healthy babies born to FD affected families.

In addition to funding ongoing work at the Dysautonomia Center at NYU Langone, the Foundation also promotes scientific research, hosts an annual symposium for families, offers programs to enhance the mental health and well-being of our population, builds community and serves as a resource for affected families.

### Dysautonomia Center at NYU Langone

In the 1970s the Foundation was instrumental in establishing the Dysautonomia Center at NYU Langone, now the world's premier site offering medical treatment for and clinical research on FD. Founded by Dr. Felicia Axelrod, the Center is now headed by Horacio Kaufmann, MD, the world-renowned authority on familial dysautonomia. Staffed by an interdisciplinary team of physicians, nurses and other professionals, the Center offers stellar medical care, both on site and virtually through telemedicine; conducts clinical research; consults with patients' personal physicians and manages the FD Natural History Study.

The Center has successfully transformed FD from a once fatal childhood disease into a chronic condition. Thanks to advances in care, people with FD who once had a 50% chance of reaching age 5, now have a 75% chance of living to 40 years old.