NEW YORK STATE SENATOR

Michelle Hinchey

New York State Senator Michelle Hinchey Introduces First-in-the-Nation Legislation to Create Frontotemporal Degeneration (FTD) Research Registry

MICHELLE HINCHEY May 15, 2024

Hinchey Hosts FTD Advocacy Day at State Capitol with Emma Heming Willis and the Association for Frontotemporal Degeneration to Raise Awareness of the Degenerative Disease and Call for Passage of the FTD Research Registry

Hinchey's FTD Research Registry Pioneers Comprehensive State-Level Understanding of Frontotemporal Degeneration and Accessible Resources for Affected Families

ALBANY, NY — Today, New York State Senator Michelle Hinchey unveiled legislation (S7874 /A9938) to establish the country's first statewide Frontotemporal Degeneration (FTD) Research Registry. The registry would help educate doctors on FTD — among the most common and yet little-understood forms of dementia, provide insight into the number of FTD diagnoses across New York, and create a public database of services and available resources for individuals and their loved ones facing an FTD diagnosis. Hinchey's bill serves as a nationwide model for other states, driving the fight for greater awareness within the medical community and society at large and, ultimately, to find a cure.

Senator Michelle Hinchey is the daughter of the late and widely regarded Hudson Valley Congressman Maurice Hinchey, whose battle with FTD before his passing in 2017 motivated the Senator to make FTD awareness an immediate priority upon her election to the State Senate in 2020. Hinchey has since emerged as the leading advocate for FTD in the State Legislature, focusing on closing the care gaps in New York and sponsoring the first-ever State Resolution acknowledging FTD Awareness Week. Hinchey's efforts have spurred similar actions in other states, including a Resolution in California being championed for passage by Emma Heming Willis, aimed at breaking the knowledge barrier around FTD.

Frontotemporal Degeneration gained widespread attention when actor Bruce Willis and his family disclosed his diagnosis in 2023, marking a pivotal moment in propelling global awareness of the disease. Senator Hinchey welcomed Emma Heming Willis to the State Capitol on Wednesday for a day of advocacy alongside advocates from the Association for Frontotemporal Degeneration (AFTD), and care partners. Following her husband's diagnosis, Emma Heming Willis has become a powerful advocate for FTD awareness, striving to enhance support for caregivers and families affected by the disease and advance research toward finding a cure.

“Today is a turning point in our fight for a world without Frontotemporal Degeneration (FTD) because today we’re announcing new legislation to establish the country’s first FTD Research Registry that New York will pioneer as a template for other states to follow,” **said Senator Michelle Hinchey.** “The FTD journey is often marked by grief, despair, and frustration due to the lack of understanding in our medical community, frequent misdiagnoses, and a shortage of affordable long-term care, especially in rural areas. Passing the FTD Research Registry this session will finally start to give us an accurate picture of the disease, its scale in New York, the healthcare and knowledge gaps we need to close, and promote the resources families need to navigate a diagnosis. This fight would be nothing without our partners at AFTD and without the families and caregivers, including Emma Heming Willis, who are courageously telling their stories and normalizing the conversation around FTD. I’m proud to introduce this legislation and work toward a collective understanding of this disease as we fight to end it once and for all.”

Emma Heming Willis said, “Today is a hopeful day for families, like mine, who are caring for a loved one with FTD. Treatments and a cure are possible, but only if doctors and researchers can document this devastating illness. That’s why this registry is so important. New York is on the cusp of making history and can be a model for the nation. I’m grateful to Senator Hinchey for leading the charge, and encourage all legislators to support the bill.”

“We are grateful to Senator Hinchey for her leadership and vision in authoring this landmark legislation, which comes at a pivotal moment in global awareness of FTD,” **said Susan Dickinson, CEO of AFTD**. “For too long, families have spent years trying to get accurate diagnoses, while their loved ones receive incorrect treatment and advice. This registry is a major step toward making sure that the medical community and the public have essential information about the disease. We hope that lawmakers in states around the country adopt it as a model for their communities."

"With delayed diagnosis and lack of easily available resources, Senator Hinchey's bill will be transformative in spreading awareness of FTD and helping people access care," **said Senate Deputy Leader Michael Gianaris.** "We must do everything in our power to help suffering individuals and families receive the help they need."

Assemblymember Amy Paulin, Chair of the Assembly Health Committee, said, "Frontotemporal Degeneration (FTD) is a debilitating disease and the most common form of dementia in people under 60. In order to find a cure for FTD, we must first understand it. I thank State Senator Hinchey, and the Association for Frontotemporal Degeneration for their staunch advocacy to pass this bill creating a statewide FTD registry – which is a needed first step to fully understand FTD and help those suffering from this terrible disease."

Frontotemporal Degeneration is a neurodegenerative disorder that causes the gradual breakdown of nerve cells in the frontal and temporal lobes of the brain. The progression of the disease can lead to significant disability over time, including extreme changes in personality, behavior, language, and motor skills that can impact daily functioning and require around-the-clock care and support. FTD typically strikes individuals between the ages of 40 and 65, but it can also occur in both older and younger individuals.

On average, it takes nearly four years for a person to receive an accurate FTD diagnosis as symptoms are often misdiagnosed as a psychiatric condition, Alzheimer's disease, or Parkinson's disease. This delay is often due to the medical community's lack of familiarity with FTD. Delays in diagnosis can also cause devastating financial hardships for families, with the economic burden of FTD being almost twice that of Alzheimer's disease, as individuals impacted are often compelled to leave the workforce during peak earning years. The absence of focused data collection on FTD greatly contributes to the low awareness among medical professionals and the public. Hinchey's nation-leading bill will provide New York with a better understanding of the disease and advance support for those affected.

Sponsored by Hinchey in the Senate and Assemblywoman Amy Paulin, Chair of the Health Committee in the Assembly, S7874/A9938 would authorize voluntary tracking of all FTD diagnoses in New York, directing hospitals and healthcare providers to report these diagnoses to the Department of Health (DOH). The DOH will create and maintain a webpage called the *New York State Frontotemporal Degeneration Research Registry*, where the public can access information on the incidence and prevalence of FTD and related epidemiological data. An FTD Advisory Committee will be formed to guide the development and implementation of the registry, comprised of medical professionals, caregivers, patients living with FTD, FTD researchers, and public health experts.

Annually, the DOH, with committee input, will issue reports to the Legislature and Executive, covering treatment advancements, demographics, FTD incidence by county, the resources available for patients with FTD by region, the average annual cost of care for a patient with FTD, the number of FTD patients previously misdiagnosed and the time taken to receive a correct diagnosis, among other priority areas. Importantly, the bill tasks the DOH with gathering and sharing essential resources for FTD-affected families. These resources, including support group details, government assistance programs, and helplines, will be easily accessible on the registry's website. This streamlined support aims to help families navigate the challenges of caring for loved ones with FTD.

Helpful FTD Resources

For guidance and resources regarding an FTD diagnosis, care, and support from social workers who understand, contact the Association for Frontotemporal Degeneration (AFTD) HelpLine at 1-866-507-7222 or email info@theaftd.org.

- Get connected to local resources and support groups.
- Learn more about FTD and Genetic Testing.
- Find out Ways to Participate in FTD research.
- Everyone can become an AFTD Advocate to educate their elected representatives and advance policy solutions.

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