



42 Broadway, Suite 1724
New York, NY 10004
PHONE 212.619.1400
FAX 212.619.7409
www.als-nv.org

February 25, 2021

New York State Senator Liz Krueger
Chair, Finance Committee
172 State Street, Capitol Building
Room 416 CAP
Albany, NY 12247

New York Assembly Member Helene E. Weinstein
Chair, Committee on Ways and Means
LOB 923
Albany, NY 12248

New York State Senator Gustavo Rivera
Chair, Committee on Health
172 State Street, Capitol Building 502C
Albany, NY 12247

New York State Assembly Member Richard N. Gottfried
Chair, Committee on Health
LOB 822
Albany, NY 12248

Dear Chairwoman Krueger, Chairwoman Weinstein, Senator Rivera, and Assemblyman Gottfried,

On behalf of The ALS Association Greater New York Chapter, I respectfully request your continued support of the \$200,000 appropriation from the Senate and \$50,000 appropriation from the Assembly in the Fiscal Year 2021-22 budget to provide ALS patient care and services. New York's two ALS chapters are on the front lines every day for people living with ALS, providing essential services for those in New York living with this disease.

The Greater New York Chapter serves approximately 600 people living with ALS from Suffolk County to the five Boroughs and throughout the Hudson Valley, while the Upstate New York Chapter serves approximately 400 people living with ALS throughout the remainder of the Upstate region.

During this global pandemic, our work has not stopped. It has only increased. Our nurses, social workers, and assistive technology specialists are working around the clock to ensure continuity of care for our ALS community, who are at an increased risk during this time. In New York State, nearly 1,000 people living with ALS, along with their caregivers and family members, depend on us every day for support, care, transportation, equipment and a myriad of other services.

This year we have seen advancements in research bring us closer to the development of effective treatments for ALS, we have advocated for health care legislation that impacts people with ALS and have

worked tirelessly to adapt our hallmark care service programs. We are maintaining essential care during the pandemic through contactless deliveries and virtual training for durable medical equipment and assistive technology, increased support of respite care to families and caregivers in need of home health aide care, and telehealth platforms for support groups, home assessments, and virtual clinic appointments.

New York's ALS chapters rely on public funding and support to ensure their services can continue and reach those who need it most. Both the Senate and Assembly have played a pivotal role in providing support for the state's ALS community, and I urge both chambers to continue their leadership by supporting ALS funding in this year's budget.

Thank you for your continued support and leadership on this important issue.

Sincerely,

Kristen Cocoman
President and CEO
The ALS Association Upstate New York Chapter