

Advocating, Educating, Mobilizing

We secure policy change at federal, state, and local levels to make ALS a livable disease for everyone, everywhere until we find a cure.



3 Certified Clinics

1,194 People

Living with ALS Served by Medicare

or Medicare + Medicaid

- 2 Affiliated Clinics
- 1 VA Clinic



Veterans are twice as likely to be diagnosed with ALS compared to those who haven't served in the military.

Genetic forms of ALS represent between 10-15% of all cases.

Opportunity Alert

Illinois has not passed the Genetic Testing Protection Act (GTPA), which would protect Illinoisans from being denied or charged more for long-term care, disability, or life insurance policies based on their genetic testing results.

State Affairs Priorities



Increase access to affordable and non-discriminatory insurance coverage, telehealth services and genetic testing



Expand state funding for ALS research, clinics and care services



Increase access to and affordability of medications and equipment

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Being an advocate has helped me take back my power even as my physical strength has diminished. It has truly transformed my life and my future.

Jessy Ybarra
Advocate Living with ALS

