

# ALS United Greater New York's 6th Annual ALS Resource & Education Summit Begins May 12th

*ALS Research Summit Expands to Four Days with Evening Research Event at New York Genome Center and First-Ever Partnership with Her ALS Story*

NEW YORK, NY, UNITED STATES, May 5, 2026 /EINPresswire.com/ -- [ALS United Greater New York](#) today announced its [Sixth Annual Education and Resource Summit: Navigating the ALS Journey](#), May 12–15, 2026, featuring two significant new additions: an in-person evening research plenary and a first-of-its-kind programming partnership with [Her ALS Story](#), a national network dedicated to young women living with ALS.



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*Kristen Cocoman*

The expanded Summit will bring together leading ALS researchers, clinicians, advocates, and community members across four days of in-person and virtual programming, offering comprehensive education and resources for individuals living with ALS, their caregivers, and families throughout the Greater New York region.

The Summit will open on Tuesday, May 12, with an in-person Plenary Session, "An Evening of Insight:

Advancements in ALS Research," held at the New York Genome Center from 6:00 to 8:30 PM. Experts from The Eleanor and Lou Gehrig ALS Center at Columbia University, Target ALS, and the New York Genome Center will present updates on the most recent developments in ALS research. RSVP is required for the in-person event.

Also new this year, Wednesday, May 14 programming has been developed in partnership with Her ALS Story, an organization founded in April 2021 to create a network and community for young women living with ALS. Representatives from Her ALS Story will join ALS United Greater

New York staff and guest speakers for a series of intimate, interactive panel discussions exploring four topics that are deeply personal to many in the ALS community: Body Image, Parenting, Intimacy, and Caregiving for a Partner.

"ALS research is moving faster than ever, and our community deserves to be at the center of that momentum. This four-day Education & Resource Summit marks a milestone for our community, and we've designed every day with intention. We kick off with an in-person research session, bringing researchers and the people they are fighting for into the same room. On

day two, we are honored to partner with Her ALS Story, an organization doing powerful work for young women living with ALS, ensuring their voices and experiences are woven into everything we do. This summit is more than an event, it's a statement that we are stronger together, and that the progress happening right now belongs to all of us," said Kristen Cocoman, President and CEO, ALS United Greater New York.

"People with ALS have needs beyond medical equipment and managing symptoms, which is why the discussions planned at the ALS United Educational Summit are so important," said Alex Cavaliere, President of Her ALS Story. "Shining a light on all aspects of life while living with ALS is core to our mission at Her ALS Story because you're not just a person with ALS. You may be a parent, a partner, and you're still an individual with various physical and emotional needs. We're honored to have our members contribute to the conversation and let others living with ALS know they're not alone."

"These conversations reflect our ongoing commitment to addressing the full human experience of living with ALS," said Cocoman.

The Summit continues virtually on Thursday, May 15, and Friday, May 16, bringing together experts from across the region to address a broad range of timely subjects. Sessions will cover Feeding Tubes and Nutrition, Medical Aid in Dying Update, and Caring for Yourself While Caring for Others. These sessions are designed to give attendees the knowledge and resources they need to navigate every stage of the ALS journey.

Registration and full event details are available at [als-ny.org](https://als-ny.org).

**6TH ANNUAL VIRTUAL**  
**Education & Resource Summit:**  
**Navigating the ALS Journey**

**TUESDAY, MAY 12, 2026**  
AN EVENING OF INSIGHT:  
ALS RESEARCH ADVANCEMENTS  
6:00 PM - 8:30 PM

**WEDNESDAY, MAY 13, 2026**  
HER ALS STORY  
ONLINE WORKSHOPS  
10:00 AM - 2:00 PM

**THURSDAY, MAY 14, 2026**  
ONLINE WORKSHOPS  
9:00 AM - 5:30 PM

**FRIDAY, MAY 15, 2026**  
ONLINE WORKSHOPS  
9:30 AM - 2:30 PM

ALS United  
Greater New York

6th Annual ALS Education & Resource Summit

## About ALS United Greater New York

ALS United Greater New York is one of the largest local ALS patient service organizations in the nation. Its mission is to support and empower the ALS community through a collaborative approach to fostering bold research initiatives, advancing national and state advocacy, and providing comprehensive care to individuals and families affected by ALS. The organization serves more than 1,200 people with ALS and their families living in New York City, Long Island, the Lower and Mid-Hudson Valley, Westchester County, and northern and central New Jersey, in partnership with 10 regional ALS clinics and centers. A member of ALS United, ALS United Greater New York is part of a national network of independent nonprofit organizations guided by a shared vision: Together, We End ALS. For more information, visit [als-ny.org](http://als-ny.org).

## About Her ALS Story

Her ALS Story is a nonprofit community and advocacy organization founded in April 2021 to create a network for young women living with ALS. Founded by Leah Stavenhagen, who was diagnosed with ALS at age 26 and recently passed from the disease, the organization grew from a small group of 10 women into a global community of more than 120 members. Her ALS Story works to educate the public that ALS does not discriminate by age, gender, race, or location, and provides a supportive space where young women with ALS can share experiences, access resources, and advocate together for better therapies and a cure. The organization partners with leading ALS nonprofits, including I AM ALS, Project ALS, and ALS TDI. For more information, visit [heralsstory.org](http://heralsstory.org).

Tiffany Card

ALS United Greater New York

+1 212-720-3045

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