EverythingALS and ALS United Partner to Expand National Coverage of ALS Clinical Trial Matching with SAVA AI

The partnership will connect more people living with ALS to personalized clinical trial information while building a de-identified map of gaps in trial access across communities

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SEATTLE, WA — EverythingALS and ALS United today announced a partnership to expand access to SAVA AI, EverythingALS' clinical trial matching platform, giving more people living with ALS and their families an easier way to identify clinical trials that may be relevant to them.

Through the partnership, ALS United will make SAVA AI available on its national website, creating a direct pathway for individuals searching for clinical trial opportunities. ALS United member organizations that opt in will be able to offer SAVA AI through local websites for the people and families they serve, extending the platform's reach into local communities across the country.

For people living with ALS, finding an appropriate clinical trial can be complicated by geography, eligibility criteria, disease progression and the challenge of identifying studies that may be a fit. SAVA AI is designed to simplify that process by helping users navigate available clinical trials based on information relevant to their individual circumstances, such as location, time since diagnosis and functional status. SAVA AI does not provide medical advice, and users are encouraged to review potential trials with their care team.

"Clinical trials can't move forward without the people they are ultimately designed to help, yet finding the right opportunity can still be incredibly difficult for patients and families," said Indu Navar, Founder and CEO of EverythingALS. "By working with ALS United, we can bring SAVA AI directly to more people in the ALS community, make trial discovery easier and learn where access gaps still exist so the broader community can work together to address them."

The collaboration will also generate de-identified, aggregate insights into how individuals are engaging with clinical trial searches, including geographic patterns, disease stage and areas where searches return no available trial. These insights will be shared with ALS United and can help participating patient organizations, researchers and trial sponsors see where clinical trial opportunities are reaching patients and where additional access, awareness or additional resources may be needed.

“When a family is impacted by ALS, they need care and support close to home and an easier way to understand which clinical trials might be right for them,” said Jerry Dawson, President and CEO of ALS United. “Our member organizations are already in communities across the country providing that local care and support every day. This partnership adds another resource to that relationship, giving people living with ALS and their families a simpler way to find clinical trials that may work for them.”

Beyond connecting individuals to existing trials, EverythingALS and ALS United hope the collaboration can provide a clearer picture of unmet need across the ALS community. Understanding where patients are searching, where trials are unavailable and where geographic gaps persist can help support future advocacy, research and efforts to improve participation in ALS clinical trials.

“Every search tells us something,” Navar said. “When someone finds a potential trial, that is an opportunity to move research forward. When someone can’t find one, that matters too. Understanding both sides can help us build a clinical trial ecosystem that reaches more people and leaves fewer patients behind.”

SAVA AI is part of EverythingALS’ Path to Trials initiative, which is supported by a consortium of biopharmaceutical and community partners working to make ALS clinical trials easier to find, faster to enroll and more representative of the people living with the disease. EverythingALS invites additional partners to support the next phase of the rollout to ALS United member organizations and the continued development of the access insights described above.

SAVA AI will be made available through an ALS United-branded pathway that directs users to EverythingALS’ platform. Individuals who choose to register will receive clear information about how their data may be used and shared, while aggregate reporting provided through the partnership will not identify individual users.

About EverythingALS

EverythingALS is a citizen-driven organization building regulatory-grade, trial-readiness infrastructure for ALS and other neurodegenerative diseases. Its programs, including Path to Trials, SAVA AI and ALSFRS-AI, connect people living with ALS to research while generating evidence that helps sponsors design and run better trials. A nonprofit 501(c)(3) organization operating under the Peter Cohen Foundation, EverythingALS has built a global ALS community network spanning more than 60 countries. www.everythingals.org

About ALS United

ALS United is a national partnership of 15 independent nonprofit organizations united in serving people living with ALS. Together, our member organizations serve approximately one in three people impacted by ALS in the United States, providing personalized care and support in communities across the country while working together to advance research, strengthen clinical partnerships, and advocate for policies that improve the lives of people affected by ALS.

https://www.alsunited.org/research/find-a-clinical-trial