November 2026, Issue #2

ELUCID Study Newsletter

Message from the Director

Dear ELUCID Participants,

It's been another exciting year for the ELUCID Study! Since our last newsletter, we've continued to grow our study community and learn more about late-onset unexplained seizures. As of October 2026, over 200 participants have now enrolled and completed their first study visit across our study sites. We've added 3 new study sites this year as well, expanding our work to California and Virginia. On behalf of our entire ELUCID Study Team, I want to thank you for being an important part of this growing research effort!

Over the past year, ELUCID researchers have been busy studying the data you've provided, examining results of your questionnaires, cognitive testing, blood work, MRIs, and EEGs. This kind of careful analysis takes time, but we are excited to already be uncovering new findings that significantly advance our understanding of late-onset unexplained seizures. We are sharing some of these results with you in this newsletter, and we expect to share even more of these findings with you at our next ELUCID Webinar in the spring.

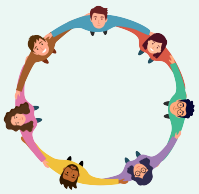
Our work isn't stopping there. We've been developing new ways for participants to engage with ELUCID beyond their regular study visits. This includes the opportunity to receive your ELUCID blood test results, explore other ELUCID-related research opportunities, and share your perspective through our Participant Advisory Board.

We're incredibly grateful for everything you've contributed to ELUCID so far. Every visit, conversation, and piece of information you share helps us build a better understanding of late-onset unexplained epilepsy and brings us one step closer to improving brain health for future generations.

With much appreciation,

Alice Lam, MD, PhD
Principal Investigator, ELUCID Study

Study Progress:



205 people enrolled



10 sites participating



161 EEGs performed



153 MRIs performed



308 completed follow-ups

ELUCID Study Updates:

What have we learned so far?

We have been examining what factors are associated with cognitive performance at the first ELUCID study visit. We examined a wide range of clinical factors that spanned demographics, seizure characteristics, cardiovascular risk factors, mood, and more. Here is a summary of what we found:

Associated with better cognition:

- Younger age
- Female sex
- Higher level of education
- Unknown seizure localization

Associated with worse cognition:

- Concern that memory has worsened
- Depression
- Smoking
- Diabetes
- Taking 2 or more seizure medications

Let's delve into the two seizure-related factors that were associated with cognitive performance:

1

Unknown seizure localization was associated with better cognition.

"Unknown seizure localization" means we could not determine where in the brain a person's seizures began. This was often the case for participants whose convulsive (grand mal) seizure occurred during sleep or without a witness, and whose EEG was normal. We do not yet know why these participants performed better on cognitive tests at their first study visit or whether this difference will continue over time. This new finding offers an important clue to understanding why some people with late-onset seizures experience more (or less) cognitive difficulties than others.

2

Taking 2 or more seizure medications was associated with worse cognition.

Don't blame the medications yet, though! People who take multiple seizure medications may have more frequent seizures or seizures that are harder to control. It is possible that these kinds of seizures, rather than the medications, are what contribute to worse cognition. We will be investigating this finding in more detail as we continue to collect more data on long-term seizure control and seizure medication use at follow-up visits. Stay tuned!

You may have noticed that there are many factors outside of seizures that are associated with cognition. Combining these factors can help us to identify those at risk for early cognitive impairments after developing late-onset unexplained seizures. More importantly, understanding these factors could help us develop new treatments to bolster thinking and memory in people with late-onset unexplained seizures. **We will be sharing these findings with other scientists at the upcoming American Epilepsy Society Meeting in December. These findings will also be published shortly and shared with the broader scientific community.**

A bit about you...

Every participant brings something unique to the ELUCID study, and together, you make up a diverse and growing research community. We wanted to share a little more about who you are and the community you're part of. Take a look at a few interesting statistics about you and your fellow participants:



68

is the average age of participants enrolled in the study



Bachelor's Degree
is the most common degree held by our participants

On average, you get
7.5 hours
of sleep per night

60%
of study participants have had a convulsive seizure

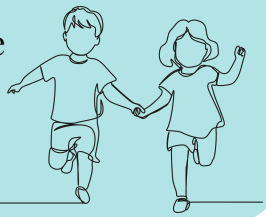


39%
of people in the study have experienced a seizure during sleep



27% of our participants experienced their first seizure after age 70

84%
of you have children





21%
of participants have concerns about their memory

On average, you get
3 hours
of moderate exercise per week

ELUCID Resource Bank



Stay up to date on study news. Visit the links below to view the official ELUCID Study Website, featuring our previous educational webinar and newsletters!

ELUCID Study Website ❋ ELUCID Spring 2026 Webinar ❋ Past ELUCID Newsletters

Have you ever wondered about donating your brain to science?

Brain donation is one way you can make a lasting contribution to research. Donated brain tissue provides valuable insights that cannot be obtained through other methods, helping researchers better understand late-onset unexplained seizures and their impact on the brain. As an ELUCID participant, you have the unique opportunity to extend the impact of your study participation beyond your lifetime by registering as a potential brain donor with the Harvard Brain Tissue Resource Center (HBTRC). For more information, please fill out this form: https://redcap.link/hbtrc.interest





Discover More Research:

Interested in learning about future research opportunities related to ELUCID and late-onset unexplained seizures? Join our registry to hear about studies that may be a good fit for you and help advance research on epilepsy and brain health. Sign up here: https://redcap.link/rrsoa

Join Our Advisory Board!

Share your experiences and perspectives to help shape the future of ELUCID. Our participant advisory board gives participants a chance to provide feedback and help make research more meaningful and participant-centered. Indicate your interest and share your ideas at the following link: https://redcap.link/epab.interest



Today's Tips: How to Prepare for Your Neurology Appointment

1. Keep a seizure log to track dates, symptoms, triggers, etc.
2. Write down questions you have to ask your provider
3. Track any new symptoms or side effects from your medications
4. Note any new symptoms you've been experiencing
5. Bring a list of your current medications and doses (include over-the-counter)
6. Keep your information in one place (e.g., phone, calendar, address book)

Team Member Spotlight: Meet Lex Hankerson!



Hi everyone! My name is Alexis “Lex” Hankerson, and I am a Clinical Research Coordinator II at Brigham and Women’s Hospital (BWH). I have been working on the ELUCID Study since the BWH site began enrolling participants in 2024. I earned my bachelor’s degree in Sports Medicine from Merrimack College and later received my Master of Public Health from the University of New England. Before transitioning into clinical research, I worked in rehabilitation and other patient-facing healthcare roles, which helped develop my interest in working directly with patients and contributing to research that can improve health outcomes.

What drew you to the field of clinical research?

My interest in clinical research is very personal. My father was diagnosed with stage 3 cancer and had the opportunity to participate in a clinical trial. The treatment he received through the trial helped reduce his risk of the cancer returning and played an important role in his recovery. Seeing firsthand the impact that clinical research could have on someone I love completely changed the way I viewed research. It inspired me to pursue clinical research so that I could give back and contribute to work that may one day give another patient or family the same hope that research gave me.

Although my initial connection to research was through cancer, working on the ELUCID Study introduced me to neurological research and the many unanswered questions surrounding seizures that begin later in life. I have especially enjoyed learning more about the relationship between epilepsy, aging, and memory, while working closely with the participants who make this research possible.

What is your favorite part of working with study participants?

My favorite part is getting to know the participants and hearing their stories. Some of our visits can be several hours long, which gives us time to talk about their lives, families, careers, and experiences. I’ve met so many interesting people through this study, and I really enjoy the connections we’re able to build along the way.

What do you enjoy doing outside of work?

Outside of work, I love staying active, especially playing flag football. I also love traveling, whether it’s for relaxation and exploring new places or to compete in flag football tournaments. When I’m home, I enjoy spending time with my fiancé and our pets, Milo and Mason.