FIGHTING BRAIN DISEASE STARTS WITH YOU

Your story can help others like you.

One in six of us has a story about living with brain disease, such as stroke, migraine, neuropathy, Parkinson’s disease, Alzheimer’s disease, multiple sclerosis, or ALS. Each of our stories is unique. Fighting any one of these diseases alone is impossible.

But what if we combined our stories in hopes of improving the care we receive and finding cures?

That’s the power of the Axon Registry®. By combining all stories into one neurology registry, we are trying to improve treatments and discover cures for the one in six people affected by neurologic disease.

Because your neurologist and treatment team participate in the Axon Registry, you may already be benefiting from the neurology experiences of other people. The people benefiting may also include your loved ones or people you don’t know but may need your help.
What is the Axon Registry?
The Axon Registry is a quality improvement database that securely collects and analyzes medical and treatment data from the electronic health records (EHRs) of people living with neurologic disease.
The information is used to help neurologists improve the quality of care for you and other patients, and may help identify new and better treatments for all patients with similar neurologic conditions.
The Axon Registry complies with all applicable laws to protect your privacy.
The Axon Registry was developed by the American Academy of Neurology, the world’s largest association of neurologists and neuroscience professionals. The American Academy of Neurology is a non-profit organization dedicated to promoting the highest quality patient-centered neurologic care.

Why am I getting this information about the Axon Registry?
Your neurologist and treatment team participate in the Axon Registry. Secured, identifiable information about you and your care is provided to the Axon Registry to help your neurologist make improvements in your quality of care, and the care of others.

How does the Axon Registry help me?
Your neurologist can compare your treatment to other patients like you to determine if there are ways to improve your care. De-identified data from the Axon Registry may also help identify new and better treatments for all patients with similar neurologic conditions.

How does the Axon Registry help others?
Each time you receive care from your neurologist and treatment team, information about your visit is recorded and stored in your EHR which is then added to the Axon Registry. You contribute to a growing body of information within the Axon Registry to help identify new and better treatments for all patients with similar neurologic conditions.

Who can see my identifiable data in the Axon Registry?
Only a small number of highly trained staff from the Axon Registry are authorized to work with, and must keep confidential, identifiable information within a secured environment to protect your privacy. This small number of people includes staff from the Axon Registry technology partner, Figmd, and data curation partner, Verana Health.

What information about me is part of the Axon Registry?
The Axon Registry collects data about you that already exists in your EHRs.
The information collected through the Axon Registry may include:
- General information, such as your name, gender, date of birth, and ethnicity
- Clinical information, such as your medical history and test results
- Therapy information, such as your treatment plans, drug regimens, and the outcomes of your treatment
- Other information, such as your address and occupation

Where does the Axon Registry data come from?
The data in the Axon Registry are extracted directly from your electronic health record—and are stored securely to protect your privacy. The Axon Registry complies with all applicable laws to protect your privacy.

What is the difference between “identifiable” and “de-identified” information and how is each used?
Electronic health records typically contain identifiable personal health information. Your doctor may record personal information about you, your condition(s), and your treatment progress. Identifiable information is used for your treatment and to help your doctor improve the quality of your care. De-identified data is health information that does not identify you and with respect to which there is no reasonable basis to believe that the information can be used to identify you. Combining de-identified data for many

If you have questions about the Axon Registry, contact registry@aan.com or visit AAN.com/view/registry.
patients has proven to be an effective way for researchers to more quickly identify and solve complex treatment challenges. De-identified data from the Axon Registry will be used to help identify new and better treatments for all patients with similar neurologic conditions.

Will my data be used for generating new knowledge?
Your anonymous, de-identified information may be used along with tens of millions of other de-identified patient visits to answer questions that can lead to new and more effective treatments and preventions for neurologic disease.

In addition, the American Academy of Neurology also collaborates with Verana Health, a company structuring and curating health care data to accelerate innovation for patients. Verana Health develops and delivers de-identified clinical data solutions for use by Axon Registry participants, partners, and the broader neurologic community—aiming to improve treatments and discover cures for the one in six people affected by neurologic disease. More information is available on AAN.com/view/registry.

Who pays for the Axon Registry?
There are no financial charges to you or your neurologist and treatment team as the Axon Registry is fully supported by the American Academy of Neurology.

As a member of the American Academy of Neurology, your neurologist participates in the Axon Registry as a member benefit to provide better quality care for you, the patient.

How does the American Academy of Neurology benefit from the Axon Registry?
A portion of the revenue generated from Verana Health’s sale of de-identified clinical data, which does not include individual patient identifiable information, will help support the Academy’s mission in several ways, including: (1) all US American Academy of Neurology members will continue to be able to participate free of charge in this important, but expensive, service to improve quality of care, (2) all participating members will have access to best-in-class analytical tools to manage and improve the quality of care for their patients, and (3) the Academy and others will be able to conduct research projects using de-identified clinical data to ultimately benefit and provide hope for patients.

What should I do if I do not want my data to be in the Axon Registry?
Let your neurologist know in writing if you decide not to participate in the Axon Registry. Your neurologist will work with the American Academy of Neurology to have your identifiable data removed from the Axon Registry. Any anonymous data already in the system will remain.

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