EPILEPSY FOUNDATION®
empowER&D™
EMPOWERING EPILEPSY RESEARCH & DEVELOPMENT

Frequently Asked Questions

General Questions

What is EmpowER&D™?
EmpowER&D is the Epilepsy Foundation's new research program aimed at reimagining the epilepsy research & development process to help create and advance groundbreaking solutions that will significantly improve the lives of individuals with epilepsy. EmpowER&D establishes a centralized platform for collecting, analyzing, and leveraging real-world data from patients, healthcare providers, and researchers.

What is the goal of EmpowER&D?
EmpowER&D aims to spark meaningful change and improve the lives of people living with epilepsy through greater understanding of and access to data. This initiative paves the way for a future where cutting-edge, patient-centered solutions are within reach for all people affected by epilepsy.

Why should I consider participating?
By participating in the EmpowER&D program, individuals have the chance to turn their experiences into something meaningful that could help drive better care and treatments for others living with epilepsy. By sharing your data, you not only have the opportunity to contribute to important research advancing epilepsy care, but also to join a community that values your voice and lived experience. Your input adds context that is often lacking in research data. You can help ensure that new treatments are useful and responsive to what individuals living with epilepsy really need. With the Epilepsy Foundation and our partners, your story can help shape solutions that truly value individual people as partners in innovation.

What makes this program different from other patient registries?
As part of EmpowER&D, you are choosing to participate in a living data set. This means that we may reach out to you again in the future to ask follow-up questions or ask you to be part of another part of the study. This allows our partners to ask questions that specifically help them solve the problems they are addressing and make progress towards new treatments for epilepsy, which many registries cannot accomplish.

Is this for adults and children? Can I participate if I don't have epilepsy but know someone who does?
Yes, adults and children are all welcome to participate in EmpowER&D. If you have a child or someone else you care for who is living with epilepsy, you may choose to participates a caregiver as well as on their behalf.

Will participating affect my medical care with my doctors?
No, you will not change any of your medical care by participating in EmpowER&D.

What information are you asking from me? Can I choose what Information I share?
You may be asked to complete electronic questionnaires on seizure frequency, medication use, quality of life, and healthcare utilization. We may also ask you to share information directly from your Electronic Health Record, or EHR. All data will be stored securely and made anonymous. Though we encourage you to share EHR data in addition to completing questionnaires, you are in control of what information you share, and you can choose to participate however feels comfortable for you.

You may choose to change your mind and withdraw from EmpowER&D at any time. To un-enroll from EmpowER&D, please submit a request to empowerd_support@efa.org. When you un-enroll, you may select to have any information you've previously provided removed from the data registry or choose to allow your existing information to remain.

What if I don't know all my medical information? Can I still participate?
Even if you don't know all your medical information, we encourage you to participate in EmpowER&D if you are interested in doing so. Many of the questions we may ask you are about your day-to-day life in addition to questions about your medical care. We appreciate any information you are open to sharing and are happy to help guide you in gathering information where we can.

How is my personal information protected?
No one will receive your personal identifying information. After you register, your data is assigned a special ID number instead of using your name. Your name, address, phone number, and contact details are removed from the data. This means your information is de-identified. Only this ID number are used to connect your data across studies. Because of this, doctors, researchers, hospitals, and companies cannot see who you are or contact you. They only see anonymous, de-identified information used for research purposes. You can also request to remove your data from the registry at any time.

Who uses my data and for what purpose?
Your information will be shared directly with the Epilepsy Foundation of America. We will remove any information that identifies you as you, known as your Protected Health Information, before sharing anonymous, or de-identified, data with our registry partners. Approved researchers, partner pharmaceutical companies, and healthcare innovators may use your de-identified data to develop solutions to improve epilepsy care.

What can I learn from participating in EmpowER&D?
In addition to helping provide valuable data to researchers to advance care for epilepsy, we hope that participating in EmpowER&D will give you the opportunity to be part of a community of individuals who live with epilepsy and those who care for individuals with epilepsy as well. In the future, we hope to provide this community with insights we learn from each other, updates about what researchers have learned from your data, clinical trials that are created from the registry and new treatment options that result from this work.

Will I be contacted about research studies?
No pharmaceutical company or academic institution will receive your contact information or be able to contact you directly. The Epilepsy Foundation may notify you about clinical trials you could qualify for, but it's entirely up to you if and how you choose to get involved.

Does joining EmpowER&D mean I'm enrolling in a clinical trial?
No pharmaceutical company or academic institution will receive your contact information or be able to contact you directly. The Epilepsy Foundation may notify you about clinical trials you could qualify for, but it's entirely up to you if and how you choose to get involved.

Where can I find more information about the program for myself and if I would like to share with others?
You can visit epilepsy.com/empowerd to learn more or sign up. If you would like to talk to someone about the program, you can reach out to the EmpowER&D team at empowerd_support@efa.org. Our Helpline is also available at 1-800-332-1000 (select option 1) so you can speak to someone directly.

Revised 02/2026

Technical Questions

How do I add my Electronic Health Records (EHR)?

To add your Electronic Health Record to your survey, click “Health Info”, then “Manage EHR Connections”. This will bring up a screen to connect your records. You may do this for as many EHRs as you have and would like to connect. If you have any questions, reach out to our Help Line at 1-800-332-1000 (select option 1). Someone can talk you through the steps in your EmpowER&D participant portal.

If I have technical issues while trying to participate in the EmpowER&D program You can reach out to the EmpowER&D team at empowerd-support@efa.org

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Revised 02/2026