



National Institute of  
Neurological Disorders  
and Stroke

## Epilepsy Program

NINDS/NIH  
10 Center Drive, Room 7-5680  
Bethesda, MD 20892-1414  
Epilepsy@nih.gov  
301-435-2952

How do we acquire patients?

- Self-referral
- Physician - referral

What patients do we serve?

- Patients who have seizures despite being on two or more medicines
- Patients in need/want epilepsy surgery
- Patients who want to contribute to science/medicine
- Patients who want a 2<sup>nd</sup> opinion
- Patients who are 8 years or older

What are the costs to the patients?

- There are no cost to the patient while enrolled in this research study. Study visits may include clinical and research related activities such as: doctor visit; imaging (ex. MRI, PET, MEG, fMRI); epilepsy surgery; medications are at no cost to the patient while enrolled in our research protocol

Why do patients have to be enrolled in a research protocol?

- The National Institutes of Health (NIH) Clinical Center is a research hospital; all patients must be enrolled in a protocol to receive care. The epilepsy protocol is standard of care.

Will my neurologist have access to my medical record at the NIH?

- Your participation will be kept confidential. If you want your neurologist to learn about your participation in the NIH study, you will have to sign a medical release document.

I am a referring neurologist how will I know what is going on with my patient?

- If your patient is admitted, we round daily and will give you updated and the option to participate in rounds as often as you like. If your patient becomes a surgery candidate, we will ask you to participate, as you know the patient best. If you are unable to participate, we will send a summary of the conference with our recommendations.

Will the patient be automatically enrolled in a drug trial?

- No – patients will never be automatically enrolled in any protocol.

What if the patient enrolls in a protocol and wants to withdraw?

- Patients may withdraw at their convenience and will not be penalized.



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The NIH is in Bethesda, Maryland (outside of DC), how does the patient get there?

- The NIH may provide support for transportation (ex. plane, train, bus) to the patient and a medical guardian. The NIH may also provide support for lodging.

If the patient needs/wants more information, who do they contact?

- They can call NIH Epilepsy program at 301-435-2952
- They can also email [Epilepsy@nih.gov](mailto:Epilepsy@nih.gov)