

## Epilepsy “Rescue Medication” Survey results and \$2,500 donation to Epilepsy Foundation

More than 500 PatientsLikeMe epilepsy members recently took part in a survey we collaborated on with our partner Acorda® Therapeutics. It's all about learning how you control and respond to seizures using rescue medications (a type of medication used once a seizure starts to help end it faster or prevent further seizures). As a community, we achieved our study goal and, as promised, made a donation of \$2,500 to the Epilepsy Foundation to further research your condition!

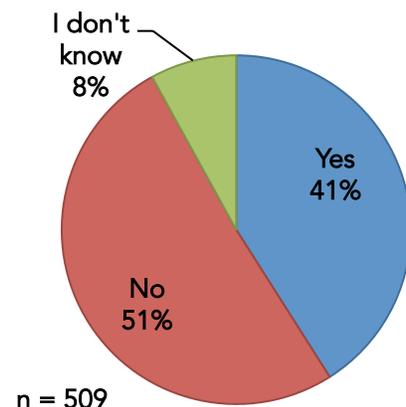
With our research, we always try to share the results with the community so everyone can learn from the experiences of everyone else. Here's what we found...

Nearly half of you (41%) who answered our survey said that in the past year you have had multiple seizures within 24 hours despite taking daily anti-seizure medication.

Rescue medications are intended to stop an ongoing seizure, prevent it from getting worse, or prevent more seizures from occurring in the next 12-24 hours. Rescue medications are typically given by caregivers or administered by patients themselves. You would use this type of medication when you feel a seizure is about to occur, when a prolonged seizure is occurring, or when there is a high likelihood of a seizure recurring within the next 12-24 hours.

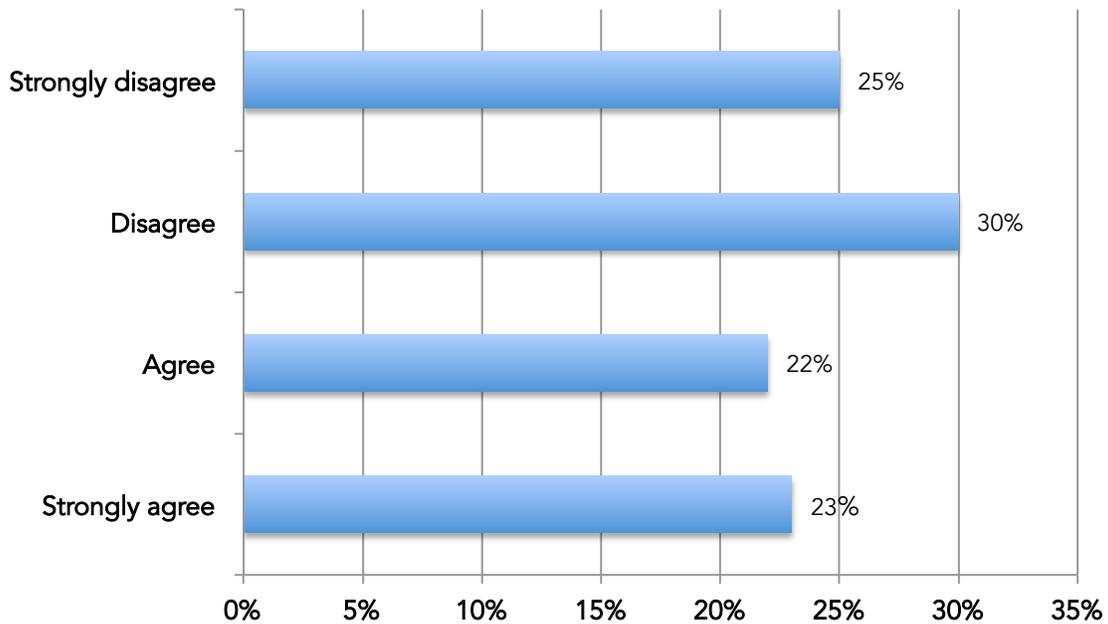
Almost half of you (45%) reported that you would not have access to medication that would stop a seizure.

Has there been any 24-hour period in the last 12 months when you experienced multiple seizures, despite taking your daily anti-seizure medication?



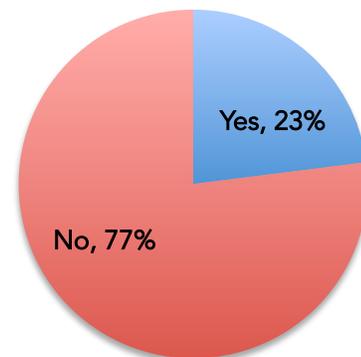
To what extent do you agree with the following statement?:

“If I had a seizure at home, work, or school, I’d have access to medication to help stop the seizure.”

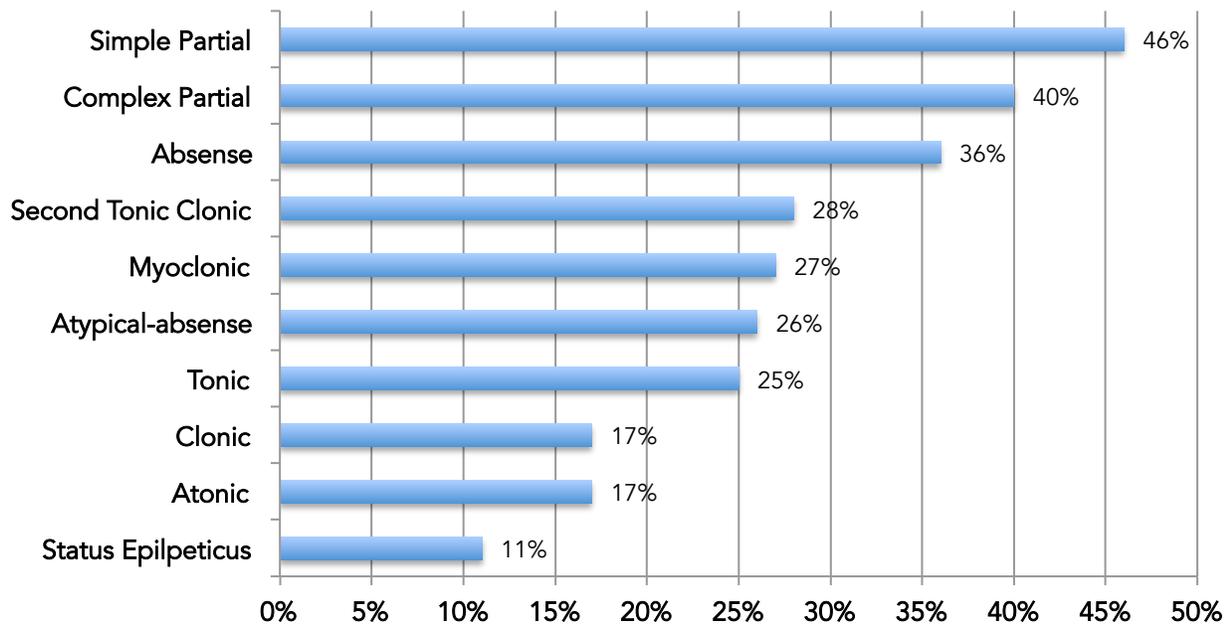


Three out of four people responding to this survey said they have never discussed rescue medications with their doctors. (We have already received feedback from some people who learned about rescue medication by taking our survey – which is great.) While rescue medication may not be right for everyone, some of you may benefit from asking your doctor about whether rescue medication may be an option for you.

Have you and the physician you see about your seizures ever discussed rescue medications like those described above for use in case of seizure emergencies?



We also asked what kinds of seizures you had in the past year and found that the PatientsLikeMe epilepsy community experiences many different types. The most common types of seizures people in our survey had over the past year were simple partial seizures (46%), complex partial seizures (40%), and absence or petit mal seizures (36%).



*\*See Appendix for description of seizure types*

Thanks again for sharing your voice in epilepsy research – your answers help researchers learn more about the condition and help other patients just like you. Keep an eye out for future invitations to take part in research on PatientsLikeMe. Your experience matters.

## Appendix

### \* Types of seizures

**Simple Partial Seizure:** Patients stay conscious with a simple partial seizure, and after the seizure they can remember what happened. Sometimes patients move their arms or legs, or have abnormal sensations or see things.

**Complex Partial Seizure:** These seizures may begin with an aura or warning. Though people may have their eyes open or speak, they aren't alert or aware. Sometimes people move or do things during the seizure (such as clapping, moving their mouths, or taking off clothes), called automatisms.

**Absence Seizure:** Brief episodes of staring that usually last less than 10 seconds but can be up to 20. Patients recover quickly from an absence seizure, and don't have an aura before one.

**Secondarily Generalized Tonic-Clonic:** These seizures seem to start one way (like with a warning or aura or other type of symptom) then change into a tonic-clonic seizure.

**Myoclonic Seizure:** Short sudden onset of muscle contractions, like a jerk. The seizure is so short, it is hard to tell if patients lose consciousness or not. The seizure might be so sudden that the patient falls, or so subtle it looks like a tremor.

**Atypical Absence Seizure:** Longer staring spells that can last from 5 to 30 seconds, often with a gradual beginning or end to the seizure.

**Tonic Seizure:** The body, arms, or legs make sudden stiffening movements. Patients can be conscious during a tonic seizure. Tonic seizures can also often occur during sleep.

**Clonic Seizures:** Clonic seizures consist of rhythmic jerking movements of the arms and legs. Clonic seizures are different from Tonic-Clonic seizures because they don't have stiffening of the muscles before the jerking. Unlike myoclonic seizures, they can vary in length.

**Atonic Seizure:** Also known as a "drop attack", the muscles suddenly lose strength (they can cause a person to fall) but last less than 15 seconds. The patient may stay conscious during this type of seizure.

**Status Epilepticus:** One continuous seizure lasting longer than 30 minutes.