

## Results of Eisai Inc. and Epilepsy Foundation National Survey Shed Light on Unmet Needs in Epilepsy Community

Findings of a survey among 250 patients and 250 caregivers suggest the need for improved education efforts within epilepsy community and beyond to address misperceptions about the disease

### The Epilepsy Community Wants Improved Disease Information

Epilepsy patients and their caregivers expressed their desire for a better understanding of the disease, whether through educational resources or more meaningful discussions with their doctor.

- Nearly 9 out of 10 patients and caregivers say there are aspects of epilepsy even they don't completely understand. Topics they would like a better understanding of include:
  - Seizure triggers (62%)
  - Side effects of treatments (58%)
  - Types of treatments (49%)
- 55% stated information about lifestyle modifications for managing epilepsy needs improvement.
- 63% reported information about conditions or health problems associated with epilepsy needs improvement.

### Epilepsy Education Is Needed to Increase Understanding and Help Reduce Stigma

There are many aspects of epilepsy that remain misunderstood, and misperceptions about the disease may be driving stigma.

- 89% of epilepsy patients and caregivers think there is a stigma associated with the condition; this may be caused by a lack of understanding about the disease.
- More than 2 in 5 (44%) epilepsy patients report experiencing discrimination due to their epilepsy.
- 40% of epilepsy patients report difficulty making or keeping friends, and 28% experience lack of family support.
- 58% of patients have kept their condition a secret for fear of being treated differently; if patients do decide to tell someone new in their life about their disease, they wait 2 months, on average, before speaking about it.

### Support Services for People with Epilepsy Can Be Helpful, But Could Be Improved

Managing a complex disease like epilepsy goes far beyond medical treatment. The availability and accessibility of support services such as counseling programs, transportation services and employment assistance are crucial.

- More than half (51%) of epilepsy patients and caregivers do not have services for people with epilepsy in their area, or do not know if they are available.
- Those who have services in their area identify programs that need improvement:
  - Employment services (43%)
  - Educational services (42%)
  - Support groups (42%)
- While improvements are needed, 91% of patients and caregivers who have support services available and have used them found them to be helpful.

## Epilepsy Can Have a Serious Impact on Daily Life

Survey results confirmed that epilepsy can affect the day-to-day lives of patients and caregivers

- 89% of epilepsy patients report experiencing difficulty with a daily life activity due to epilepsy, including:
  - Driving (59%)
  - Work (57%)
  - Socializing (52%)
- Similarly, 83% of epilepsy patients have avoided doing or attending something because of their epilepsy, including:
  - Driving (54%)
  - Work (34%)
  - Social gatherings (38%)
- The vast majority (89%) of epilepsy patients are worried about experiencing future seizures.
- And, 96% of caregivers report that their loved one's epilepsy has taken an emotional toll on them.

## Key Takeaways

- Lack of understanding about epilepsy is widespread, and improved education efforts are needed to help combat stigma associated with the disease.
- Epilepsy patients need better information about their disease, whether from educational resources or more meaningful dialogue with their doctors.
- When it comes to support services for people with epilepsy, it's not just about availability of services—quality is important too, and patients and caregivers identified a number of services that need improvement.

## About the Survey

- Eisai Inc. and the Epilepsy Foundation partnered to survey epilepsy patients and caregivers.
- The survey was conducted by Wakefield Research among 250 epilepsy patients and 250 caregivers ages 18+. It was fielded between March 28th and April 14th, 2014, using an email invitation and online survey.
- Among the respondents, 54% were female and 46% were male, with 43% under the age of 40 and 57% age 40 or older.