

Online Survey of Parents of Children with Lennox Gastaut Syndrome (LGS) Executive Summary

Purpose and Methodology

Through an educational grant from Eisai Inc., the Epilepsy Foundation launched a new internet sub-site, [www.lgsandmychild](http://www.lgsandmychild.org) on September 15th, dedicated to the needs and concerns of parents of children with LGS. To help inform the development of the content for this new sub-site, an online survey was conducted. This report highlights the major findings of that survey.

Survey questions focused on capturing the experiences and concerns of parents of children with this rare and difficult to manage form of childhood epilepsy. Major topics in the survey questionnaire included:

- Level of satisfaction with the child's current treatment
- Ratings of five aspects of the child's quality of life
- Expectations for the child's future quality of life
- Preferred sources of information about LGS

Between June 8, and September 1, the survey was promoted on the main website of the Epilepsy Foundation, the Foundation's website for parents of children with epilepsy, www.epilepsyandmychild.org and on the Lennox Gastaut Syndrome Foundation's website. As of September 28, 165 parents had completed the survey.

This report presents six conclusions about the implications of the survey's major findings. These conclusions focus on clarifying how these survey data have been used--and can continue to be used -to optimize the further improvements our website, www.lgsandmychild.org. These conclusions also help guide us to future strategies to respond to the needs of this target population:

1. Parents want information about new treatment options, especially those that reduce seizure frequency, behavior issues and side effects.
2. Parents are eager for help in addressing concerns about how their children are treated in schools and social situations.
3. Parents are very uncertain about their children's futures and are more likely to be focused on coping with LGS from day-to-day.
4. Tools, like www.lgsandmychild.org, are needed to help parents find ways to connect with each other.
5. The tone of voice in sharing information with these parents should convey an appreciation of the strength it takes to cope with the severity and unpredictability of this condition.
6. These parents rely on the internet, but few can name more than one or two specific sites addressing LGS topics. Those who do name a specific site are most likely to mention the Epilepsy Foundation.