

Need Sparks Launch of a New Web site for Caregivers of Children With Lennox-Gastaut Syndrome

The hard facts:

Lennox-Gastaut Syndrome is a rare, difficult-to-treat condition that causes frequent, multiple types of seizures. It affects between 3 and 10 percent of children with epilepsy and is typically diagnosed when the child is between the ages of 3 and 5 years old. Less than 4 percent of children with epilepsy have LGS. Developmental delays, behavior problems and some mental retardation are common.

Caregivers asked for help. We listened. They wanted:

- Information about new treatment options that reduce seizure frequency, behavior issues and/or side effects
- Help in addressing concerns about how their children are treated in schools and social situations
- Tools to help them share their stories and connect with other caregivers and families living with LGS
- An appreciation of the strength it takes to cope with the severity and unpredictability of this condition

What we're doing to help:

Caregivers of children with any disability often feel isolated, that sense can be more profound in caregivers of children suffering from a severe disorder such as LGS. Lgsandmychild.org is tailored specifically to the needs of caregivers of children with LGS. Before launching the site, in order to best respond to caregivers' needs, the Epilepsy Foundation conducted a nationwide survey of caregivers of children with LGS. The responses included personal

testimonials tempered by words of hope, encouragement and—most importantly—advice.

This new site is designed to connect caregivers with one another and to provide the most reliable, up-to-date information on LGS available. Special features include *Ask the Experts* events on epilepsyfoundation.org that will allow caregivers to ask questions in real time with renowned LGS experts.

The Lennox-Gastaut Web site, sponsored by an educational grant from Eisai, Inc., will bridge a series of gaps caregivers of kids with LGS are feeling: a lack of information, resources and, especially, the need to connect with other caregivers. Visit us at www.lgsandmychild.org

The following are edited excerpts from our recent nationwide survey of caregivers of children with Lennox-Gastaut Syndrome:

LGS is heartbreaking at first. My son is only 4 and he's had seizures every day for the past 3 ½ years. At one point he was having more than 100 in a day. **I don't know what a normal day is**; to me a day full of seizures and medications is normal.

We have had this diagnosis for 8 years. **I gave up on finding information**, finding everything repetitive, depressing and not helpful.

Educate yourself! Search the Internet, read whatever you can get your hands on concerning epilepsy and **never give up fighting for seizure control** or reduction.

I have a 23-year-old with LGS. The journey has taken its toll. The depth of love has been intensely extraordinary—from wonderful to heart-wrenching—because of the helplessness and inability to stop the seizures and devastating effects. Throughout it all, **Jeremy has always been a remarkable boy who forever has my heart.**

LGS needs more public awareness because everyone I tell about my son has no clue what I'm talking about.

