

## LETTERS TO THE EDITOR

### LKS controversy

**Editor's Note:** In 1991, ARRI published several articles and letters about Landau-Kleffner Syndrome (LKS), a disorder which causes loss of speech and receptive language. The disorder also can cause autistic symptoms, and children with LKS often are (mis?)diagnosed as autistic. While the disorder is generally believed to be quite rare, some researchers and parents speculate that it is underdiagnosed. ARRI has reported on both surgical and non-surgical treatments for LKS.

To the Editor:

In reply to Dr. Stefanatos' letter to the editor [recommending caution in performing surgery on children with LKS], I beg to differ on certain points of what I consider to be a very speculative concept.

Deonna et al. theorized that Landau-Kleffner syndrome cases can be divided into three distinct categories and that because each probably has a different cause, the differing prognoses for recovery can be explained. Stefanatos has found persistent abnormalities despite the disappearance of epileptiform activity in those children who fall into Deonna's second and third categories and who continue to manifest comprehension disabilities. He concludes that these children did not recover due to some other pathology underlying the epilepsy and goes on to speculate that children in Deonna's second and third categories would not benefit from surgical intervention. It is this attitude which keeps many physicians from aggressively treating our children.

As I see it, the questions are: Which came first, the underlying pathological disorder or the epileptic condition? And, can this be proven? Working backward to prove Deonna's theory, while interesting, does not prove anything. Some of these children have over a thousand seizures a day for periods of over ten years. Knowing that seizures can cause retardation, impair motor functioning, change cell metabolism, and cause abnormal growths and connections to form, I am not at all surprised that abnormalities and even permanent brain damage result from the severity of this epileptic disturbance.

On February 6, 1988, Dr. Richardson et al. presented a case of LKS to the Southern Child Neurology Society entitled *Epileptic Aphasia of Landau-Kleffner*. The study mentioned a child who fit into Deonna's third category, characterized by a lack of seizures, early onset and fluctuations which did not correspond to EEG recordings. No notable recovery was achieved on drug or speech therapy. Over a period of two years this child completely lost all verbal and auditory comprehension, both fine and gross motor functioning deteriorated, chewing and swallowing abilities were impaired, cognitive skills decreased and behaviors (including

many not associated with language) became autistic-like. Many physicians concluded, as would Stefanatos, that this child could not be helped and it was not worth trying.

*They were wrong!* This is my child and he is doing great, making all A's in a normal classroom!

Stefanatos assumes that the goal of surgery is to restore speech and hearing capabilities. Many LKS parents choose neurosurgery as a last resort in an attempt to stop the damaging epileptiform activity. The most that they dare to hope for is that the

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*Many physicians concluded . . . that [my] child could not be helped and it was not worth trying. They were wrong!*

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surgery might prevent further deterioration and stabilize behavior. The return of speech and auditory comprehension was a bonus.

Let me challenge researchers to consider that perhaps the varying symptoms and prognoses of LKS are dependent upon the level of cognitive abilities at onset, the focus of abnormal activity, the frequency, the intensity and the duration of the epilepsy. Perhaps, as in my son's case, the abnormal activity is so deep within the temporal lobe that it does not adequately register on a conventional EEG recording and requires implantation of subdural electrodes utilized in combination with PET and SPECT scan evaluations to enhance a clearer perception.

Consider the quality of life, not the category label. Speculation can be a dangerous thing if it is wrong and discourages progress.

Jane Rudick  
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Montgomery, Al 36106

*Dr. Stefanatos replies: While I could take issue with several of the points Jane Rudick presents, I am most concerned that her conclusions regarding neurosurgical treatment of LKS are based on some seriously faulty reasoning. The essence of her viewpoint can be summarized as follows: My child was diagnosed LKS, he benefited from surgery, therefore all LKS children could benefit from surgery. The rationale that led to the widespread use of lobotomy, a procedure believed to show initial promising results in treating behavioral problems, followed disturbingly similar lines. This kind of ill-based logic led to the performance of approximately 35,000 frontal lobe surgeries in the years from 1936-1978, and the results of this series can at best be regarded as questionable, at worst devastating.*

*Arguing from the specific (her case) to the general (LKS), as Rudick does, is particularly dangerous since it is apparent that there are features to her son's history (e.g.,*

*loss of chewing and swallowing skills, cognitive deterioration) that distinguish him from the vast majority of LKS children, much less Deonna's third category. Such circumstances contribute significantly to the consideration of neurosurgical intervention, as would a host of other features such as the EEG (scalp or subdural) and evoked response findings, the results of functional neuroimaging (SPECT or PET scans), and neuropsychological evaluations. The critical point in her case is that the unusual history and the results of the studies were sufficient to establish the necessary correlation between the behavioral deterioration and the observed epileptiform activity. Presumably it was focal in origin, was demonstrated to be intractable and therefore was amenable to surgical intervention.*

*As an active member of a multidisciplinary service involved in the neurosurgical treatment of epilepsy, I am clearly not opposed to the procedure. However, based on our current knowledge, neurosurgery is certainly no panacea for LKS children, and I would continue to caution that it cannot be regarded as a primary solution to the problems of these children. Neurosurgery is a very invasive, costly and irreversible procedure that has associated risks and is appropriate only under particular conditions.*

### Vision Therapy

To the Editor:

Many autistic children are functionally blind. My son, Michael, was such a child. He has been receiving vision therapy since September 1991, and has already made dramatic progress.

He had been filled with rage and could not understand cause and effect. The rage is gone, replaced with excessive silliness. His understanding is much better and he is much happier. He now draws a human figure proportionally, and is getting along with other children much better. He no longer hits. We still have a long way to go, but there are no more knives, or talk of killing people.

How could I in good conscience remain silent when my "autistic" child is becoming more normal through vision therapy?

Karen Gimson  
Greenwich, CT

*Editor's Note: Other parents have written similar letters. ARRI would like to hear from parents and professionals who are aware of vision therapy having been used — effectively or ineffectively — with autistic children.*

### DMG, B6 successes

To the Editor:

I am extremely excited by the news about my 23-year-old autistic son, Bruce, since he has been on DMG. Today is his ninth day on DMG, and his third day on three capsules a day. As you can imagine, we have tried every conceivable remedy and method known to man for the last 23 years.

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