

Posted July 14, 2003

## *Arlington Heights epilepsy sufferer sponsors conference in hopes of getting closer to a cure*

**S**usan Eik Filstead imagines life without seizures - not just for her, but for everyone with epilepsy.

The Arlington Heights woman suffered her first seizures after a stroke that struck as she lay in the hospital after the birth of her son almost 11 years ago.

For all of those years, she and her family have worked to help her get better, through months of rehabilitation, four brain operations and many drug regimens.

Yet, today Susan has what is called intractable epilepsy, or seizures that cannot be eliminated with medication. She suffers 10 to 30 seizures a day.

Despite that, her goals have broadened: Not just a treatment for her, but a cure for everyone with epilepsy.

In May, Susan and her husband, Bill Filstead, realized a long-held dream. Through their not-for-profit Susan Eik Filstead Stroke and Epilepsy Foundation Inc., they brought some of the top names in epilepsy research to a three-day conference in Lake Bluff.

Physicians and researchers specializing in neurology, genetics, pharmacology and even bioengineering came, paying their own transportation from places like Yale University School of Medicine, Dartmouth Medical School, the National Institutes of Health and the University of Southern California. The foundation covered the costs of their stay.

The reason: To brainstorm answers to one seemingly simple but maddeningly complex question: What do we need to know in order to find a cure for epilepsy?

"The goal was to encourage discussion that questions current assumptions about the cause and treatments of epilepsy," Bill Filstead said. "This was a chance to do something, to bring people together to think outside the box."

The opportunity provided by the Filsteads is rare. Most scientists focusing on epilepsy are very busy working on their own projects, said Dr. Michael A. Rogawski, head of research for the National Institute of Neurological Disorders and Stroke.

One researcher, Bill Filstead said, hadn't even met anyone with epilepsy until she met Susan.

Research into epilepsy's causes and cures is especially important to people over 60. A recent article published in the Weill Medical College of Cornell University Women's Health Advisor reported the occurrence of epilepsy almost doubles after age 60, with 100 cases per 100,000 people over that age. That compares to about 50 cases per 100,000 children age 5 or younger, the second group particularly vulnerable.

Often this disorder goes unrecognized or misdiagnosed if it occurs later in life, with many physicians mistaking symptoms for the effects of a stroke.

Epilepsy is the condition of recurrent seizures. Different types of epilepsy have different causes. Stroke is the No. 1 cause of epilepsy in people over 50.

The Filsteads, both of whom have health-care backgrounds, are perhaps uniquely suited to the daunting task of promoting research into this complex disorder. Susan has a bachelor's degree in psychology and was a health care manager for Lutheran General Health Systems. Bill was a professor in Northwestern University Medical School's department of psychiatry, where he met Susan, and later became a consultant for Lutheran General.

At the conference, researchers agreed that genetics might be the key, even for epilepsy triggered by trauma or brain tumors.

The foundation also has helped establish a fund at the Rehabilitation Institute of Chicago and supported research at the University of Indiana University School of Medicine's department of neurology.

This month, Susan will speak in Washington, D.C. at a conference titled "Living Well with Epilepsy."

She plans to tell her audience that she remembers what it was to live well - before epilepsy struck, before she had to give up her driver's license, before she had to take medication that calms the seizures and also numbs her mind. To live well with epilepsy, Susan says, one must find a way to eradicate it.

Susan's journey began at 38 when she had a stroke caused by untreated hypertension following the birth of their son, Matthew. After

two brain operations and 3 1/2 months at the Rehabilitation Institute of Chicago, Susan finally returned home to begin her long-awaited role of motherhood. Though her left side was paralyzed, she had beat the odds and defied physicians' predictions that she'd never walk again.

But six months later she began to have seizures that medication and two more brain surgeries could not control.

The public has long associated epileptic seizures with foaming at the mouth or rigid shaking. In fact, such seizures are far less common than non-convulsive seizures, which might result in a short lapse in consciousness, movement or changes in taste, sound or smell. They can last seconds or minutes. Susan's seizures range from mild to severe. The seizures, and the medication she takes, leave her exhausted, but she takes pride in never having missed any of Matthew's soccer games.



BILL ZARS/DAILY HERALD  
Matthew Filstead, 10, turns sheet music for his Mother Susan, who suffered a stroke after childbirth and now has epilepsy.

Shortly after she returned home from the hospital Susan bought a small porcelain box with this inscription: "Count your blessings by the flowers that bloom, not by the leaves that fall." That message is one she hopes to share with her son.

"I wanted to start this foundation to give Matthew hope," Susan said. After all, he's the one who's kept me going. Matthew and my husband are the ones who give me hope."

• For more information on the Susan Eik Filstead Stroke and Epilepsy Foundation, 126 E. Wing St., Suite 290, Arlington Heights, IL 60004, call (847) 632-1926 or visit [sefef.org](http://sefef.org)