

# ARLINGTON HEIGHTS POST

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## The quest for a cure

Local family creates foundation to help those who suffer from strokes and epilepsy

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**Y**oung Matthew Filstead wanted to do what doctors couldn't: cure his mother.

Susan Filstead suffered a stroke the morning after Matthew was born seven years ago and developed a brain abscess that caused epilepsy, a condition characterized by recurrent seizures.

"She said her son has long been concerned about her health.

"His first prayer," she recalled, when he was 4 years old, was, 'Dear God, please make my mommy's arm and leg better.'"

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Later, she said, "For a couple of years, when he was 5 and 6, he was going to be a doctor, and he was going to find a cure for epilepsy. He would pretend that he was mixing up different ingredients. He was coming up with a new medicine that was going to take my seizures away."

His parents, an Arlington Heights couple who have been married for nine years, said Matthew was an important factor in their decision to form the Susan Eik Filstead Stroke and Epilepsy Foundation.

"That's really what this is all about," his mother said, "to show Matthew that we're doing something and that there is hope. And not just for ourselves but for all the other families that are affected by this."

"Matthew's real proud of Susan's foundation because he believes that it will help to find



Cathryn Scott/Pioneer Press

ways to deal with epilepsy," said his father, Bill Filstead.

"It's a great idea," agreed Dr. Jose Biller, Susan Filstead's neurologist at the Indiana University Medical Center in Indianapolis.

"She's a wonderful person," and she's very articulate about her concerns, Biller said.

The foundation has been good for both her and her family, he said.

### The Facts

**n WHAT:** The Susan Eik Filstead Stroke and Epilepsy Foundation.

**n GOALS:** Improve the quality of care, life and relationships for individuals and their families who live with the daily realities of stroke and epilepsy.

**n WEB SITE:** Under construction at [www.sefsef.org](http://www.sefsef.org) and scheduled to be fully operational by April 1.

Matthew Filstead sits on the lap of his mother, stroke survivor Susan Filstead of Arlington Heights.

Susan Filstead and her family live every day with the realities of her condition. They worry about her, as does Hans, the family's 10-year-old German shepherd.

"When I first came home after Matthew was born, (Hans) cried like a human," Susan Filstead said.

When she had extensive home therapy, she said, "Hans would

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## **Cure** *Continued from previous page*

allow us and watch everything. We wanted to make sure everything was OK.”

ans can sometimes tell before we can that a seizure is coming, he said.

usan Filstead said that the stroke she had when she was 38 years old was an intercerebral hemorrhage, a massive bleeding of the brain. It caused her to lose the use of her left hand and also affected her left leg.

usually get around the house without a cane,” she said, “but outside of the house I use a cane. If I’m going any great distance, I use a scooter.”

With the epilepsy, she said, “I usually start my day with the seizures, which leads to a headache. I take a lot of Advil.”

There are all sorts of seizures,” Susan Filstead explained. “I have several different types. And they required two ER visits last year.

Last June and last October I ended up at the emergency room at Northwest (Community Hospital) because of the seizures. They just would not stop.”

Two surgical procedures have not helped to control the seizures. Nor have medications, he said.

“We’ve been on just about everything out there that’s available, and in different combinations. Nothing worked. They still haven’t found the magic cure.”

Sometimes they use a phrase called ‘intractable epilepsy,’” Bill Filstead said, “meaning at it’s not controllable. Unfortunately, a fairly large percentage of people end up with intractable epilepsy.”

A striking number of (stroke) patients suffer from epilepsy,” said Biller, who serves as a member of the foundation’s

advisory board. “We are talking about serious conditions,” he said.

From 5 percent to 15 percent of people who have strokes develop epilepsy, Biller said, and stroke is the No. 1 cause of epilepsy in people past the age of 50.

He said about 3 million Americans have had strokes, which rank as the third-leading cause of death and disability in the nation.

Bill Filstead said making people aware of the avoidable health hazards associated with strokes is one of the foundation’s purposes.

Epilepsy affects about 1 percent of the population, Susan Filstead said.

“So many people think that epilepsy is just some plague that you’re born with,” she said. “It’s not that way at all. It can happen from any sort of brain injury.”

“People think of sort of a very rigid, shaking, maybe foaming at the mouth, scary picture of somebody with epilepsy,” Bill Filstead said, “and that’s basically the stereotype, which is really the exception as opposed to the kinds of disorders that people have. It takes many forms.”

The Filsteads want to increase public awareness of stroke and epilepsy.

“Hopefully,” Susan Filstead said, “we can inspire people to get involved with research to reverse the damages of stroke and also to find a cure for epilepsy.”

The foundation’s goals include improving the quality of care, life and relationships for individuals and families who live with the realities of stroke and epilepsy.

Bill Filstead said his wife has

spoken to groups of health-care professionals from the perspective of someone who is receiving care.

“I have a quote (from a book) that I’ve used in a talk: ‘Ask not what disease the person has but rather what person the disease has,’” Susan Filstead said.

“Unfortunately,” her husband said, “the way a lot of health care is given, you start off with the symptom or the illness and forget about who the person is who has it. We’d like to make physicians and others aware of the fact that these are people who need help, not just a condition to be treated.”

Susan Filstead has also spoken about parenting issues at the Rehabilitation Institute of Chicago and the Indiana University Medical School in Indianapolis.

“The focus was the impact of stroke on motherhood,” she said. “In my case, it’s stroke and epilepsy.”

The foundation, which held its first board meeting in January, will look to other organizations for possible financial support and partnering efforts.

For instance, Bill Filstead said, they’ve already been in touch with the Christopher Reeve Foundation about parenting issues.

Fund-raising efforts for the local foundation are still in the planning stages, the Filsteads said.

Besides the speaking engagements, they are looking at developing written materials and a day-in-the-life video.

And under construction, Bill Filstead said, is a Web site, at [www.sefsef.org](http://www.sefsef.org), that will include information about the foundation and links to other organizations.

“We should have it up and running by April 1,” he said.

The foundation, Bill Filstead said, will support institutions for education, training and research activities.

Susan Filstead said they hope to set up a fund at the Rehabilitation Institute of Chicago, where she underwent therapy, to provide money for things such as making patients’ homes handicapped-accessible or assisting with their medication expenses.

Or perhaps buying wheelchair batteries, her husband said.

The foundation’s ultimate goal is a cure for epilepsy.

“That may sound utopian,” Bill Filstead admitted. “On the other hand,” he asked, “why not shoot high?”

The Filsteads pointed to current research, involving the use of stem cells to treat injuries to the spinal cord, as possibly being applicable to epilepsy as well.

“They’re trying to use basically blank cells to copy the adjacent cells where they are attached so they can regrow the damaged tissue,” Bill Filstead said.

“We’re hopeful as well,” he said, “because in the last couple of years there’s been the most aggressive bringing to market of new epilepsy drugs.”

New classes of drugs represent “a different tool,” he said, and may be able to help control his wife’s seizures.

“So I’m very hopeful,” Susan Filstead said.

“You have to be,” her husband said.

“I feel I have to be,” she agreed “not only for myself, but mainly for Matthew. I have to be.”