



Lindsay Wilkins
Battle against ALS a personal one

Published: Wednesday, July 26, 2006 - 6:00 am

By Abe Hardesty
CITY PEOPLE WRITER
ahardest@greenvillenews.com

In addition to being one of the most cruel and mysterious diseases, Amyotrophic Lateral Sclerosis (ALS) is also among the most deadly.

The relentless disease strikes without warning, usually between the ages of 40 and 70, and leaves no survivors. It suffocates victims, emotionally crushing families along the way. It leaves no survivors for support groups to rally around.

About 5,600 people are diagnosed with ALS each year; most survive just two to five years after the diagnosis. Those most knowledgeable about its impact -- the families of victims -- are usually too emotionally drained to help others.

That was temporarily the case of Lindsay Wilkins, who knew nothing about ALS when her mother was diagnosed with the neurodegenerative disease in May 2000. Her education in the last nine months of Cathey Fayssoux's life, which ended in February 2001, left her exhausted.

But in the past year, she's taken up the fight -- raising awareness of ALS and more than \$50,000 for ALS research. In April, Wilkins served as chairman of Greenville's first Walk to D'Feet ALS, a

event at Furman University that raised Upstate awareness and funding for a newly-formed South Carolina ALS Association (ALSA) chapter.

"The goal was to raise \$40,000. I thought there was no way we'd get that," says Wilkins. "But we're up to more than \$52,000 now, and the donations are still coming in.

"I did a lot of begging to family and friends," says Wilkins, who turns 29 today. "We did it with all volunteers and no budget. It's hard to let people know we need the money."

The largest team was the 90-person group led by Wilkins in honor of her mother, who was 55 and healthy when ALS struck.

Wilkins is a Greenville representative of a state chapter headquartered in Charleston. The chapter also has a representative in Columbia.

Rebecca Jordan stepped in as the state's executive director in April. She says that "no other chapter has done so much in a short period of time" as the South Carolina group.

Jordan, who worked previously with North Carolina's ALSA chapter, says volunteers are hard to find because the disease leaves its families so physically and emotionally drained.

"A lot of them have told me, they need a break from it; they don't want to hear about ALS for a while," she says. "It's an all-encompassing disease that requires caregivers 24/7. After losing someone, most families do not have the energy or time to volunteer."

The new ALSA chapter needs volunteers in three areas: to help spread the word about support groups through e-mail, to help raise research funds through the annual walks, and to serve as committee members who plan fund-raisers and help support groups.

The next Walk to D'Feet ALS is scheduled May 12 at Furman.

The ALSA chapter has established a loan closet that provides wheelchairs and other transportation items for families of ALS victims.

Wilkins is among those trying to let victims and their families know that help is a phone call away.

"Three years ago, I couldn't talk about it," says Wilkins, "but now, I want to let people know about the new chapter. The (April) walk was to support patients and raise awareness, and I think we did that."

Wilkins is among those who know that both are needed badly. At the time Cathey Fayssoux was diagnosed with the disease in May 2000, there was nothing locally to help the ALS families.

"It would have been great to know of a support group to help deal with the frustration," says Wilkins. "It blind sided the whole family; we didn't know much. A local chapter and support group would have been a great resource."

More commonly known as "Lou Gehrig's Disease" for the Hall of Fame baseball player whose life was shortened by the illness 65 years ago, ALS strikes an average of 15 people a day. About 30,000 Americans suffer from the disease, which has no cure. An estimated 400 of those live in South Carolina, although the fledgling chapter is having trouble locating all the families involved.

The cause of ALS, which attacks nerve cells and pathways in the brain and spinal cord, is not known. It eventually paralyzes all muscle, including the lungs and heart.

In recent years, the drug Rilutek has proven to slow the progress of the disease in some cases, but it is extremely expensive.

"One of the good things about the chapter is that it lets people know there is help," says Wilkins, who meets often with a local support group of about 40 members. "One of the problems with a new chapter is, we don't know where all the ALS patients are.

"There are not a lot of places for these families to turn to," says Wilkins. "Helping others now is a healing source for me. It's a way to honor mom."