Battle against Amyotrophic Lateral Sclerosis goes on

By SUZANNE MILLER
Staff Writer

"The year was 1939. In front of 60,000 fans, inside of a packed Yankee Stadium, Lou Gehrig delivered his farewell speech to baseball.

Today I consider myself the luckiest man on the face of the earth, he told them. I might have been given a bad break...but I've got an awful lot to live for.

"He was already dying of Amyotrophic Lateral Sclerosis, but he wasn't giving up hope."

This information appeared in literature distributed by the National ALS Foundation located at 185 Madison Ave., N.Y. Its sole purpose is to find the cause and cure of ALS, often referred to as Lou Gehrig's disease.

The Foundation tells us that ALS is a progressive neuromuscular disease once thought to be rare, but now considered to be fairly common. Because little is publicly known about the disease, its victims are often caught unaware and unprepared.

Friends of victims of the debilitating illness may be equally in the dark. One recent victim related that all his friends kept asking, "You've got what?"

ALS is characterized by a degeneration of motor cells in the spinal cord and brain, leading to muscle weakness which may affect hand, foot, arm, leg, and tongue and other muscles.

The disease attacks the body and kills the victim a little at a time, usually in 3 to 5 years. Almost anyone is susceptible; known cases have ranged from ages 16 to 79. The first appearance of symptoms, however, most often come between the ages of 40 and 70.

The ALS Foundation is aware of three apparent forms of the disease. The most common form in the U.S. is Sporadic ALS, which may affect anyone. A second form is Familial, thought to be inherited. A suspected third form has been observed in Guam and the Trust Territories of the Pacific.

The Hunterdon-Sussex ALS Chapter was formed in January 1978 by two women who had lost family members to ALS, Joyce Coffman of Lebanon and Terry Bassett of Newton.

According to Mrs. Bassett, there are at least seven known families in Sussex County with a family member with the disease. There are an undetermined number of others who choose not to come forward to be identified.

The following case histories are from the files of the Hunterdon-Sussex ALS Chapter. The Sussex County families affected by ALS and described below have given their permission for this information to be used for the purpose of alerting the public to the gravity of this dread disease.

Carol Livingstone, 31, of Stillwater first noticed a weakness in her right hand in March 1977.

It was a year before the weakness that spread down her right side was diagnosed as ALS at St. Vincent's Hospital in New York. A young mother with a husband and two children, Mrs. Livingstone has participated in a research program to test the drug Levambesol for arresting the atrophy of muscles.

According to Mrs. Livingstone, she was put on Levambesol for six months because of headaches and stomach problems. She has had no symptoms over the last six months and no improvement.

The Livingstone's are preparing now for the future. They built a one-story home so that Mrs. Livingstone has easy access with a wheelchair.

Jim Livingstone describes the time from the diagnosis to the present as a period of adjustment. According to doctors at St. Vincents, Mrs. Livingstone's disease is progressing slower than usual.

"I feel like I'm buying time," she said, "but it's precious to us."

Rosemary, and Robert Walker, a young family living in Monroe, Hardyston Township, had never heard of Amyotrophic Sclerosis before July 1977 when Mrs. Walker was diagnosed at the Mayo Clinic, New York.

Gradually over the next two years she lost all body movement except for the eyelids. Her husband wrote of his wife's condition in a recent letter to friends of the Sussex-Hunterdon ALS chapter:

"It was in June of 1976 when Rosemary developed her first symptoms of ALS with a twitch in her right thumb and index finger. Months later her hand and arm became clumsy and she noticed difficulty in pronouncing words. One year after the first symptoms the diagnosis was confirmed...

"The disease has done about everything to her that it can. At 36 she cannot move any of her limbs, fingers or speak a word. She has a full-time nurse who sits her up in a wheelchair. This devastating, crippling disease has not broken her spirit. All who visit her marvel over the way she smiles and the sparkle in her eyes which radiates her love, faith, hope and trust in the Lord Jesus.

"Even though Rosemary cannot speak a word," Walker continues, "she has been able to communicate to all members of the family." Through the help of Alice Nutter of Swartswood, the Walkers were assisted in teaching Mrs. Walker a communication system using the alphabet.

The alphabet is divided into four rows of letters. By blinking her eyes or nodding her head, Mrs. Walker can communicate a key word and give the family a clue to the thought she is trying to get across. "It's kind of like a quiz program you night see on television," Walker said.

The letter continues, "The other day she (Mrs. Walker) wanted our 6-year-old daughter, Kim, who was homesick from school, to have an egg for breakfast. Kim was able to spell out the word her mother was communicating by using the above system. Since Kim is just learning to read, Kim's next problem was sounding out what she had spelled. From there she told the nurse what her mother wanted her to have for breakfast. Our other children, Paul, 8, and Hope, 12, also use the system."

The Walkers continue to function as normally as possible. In a specially equipped van, Mrs. Walker attends school-related activities, goes shopping at the malls and attends church with family and friends, as well as attending chapter functions.

Mrs. Walker's ability to cope with her situation was recently described to a member of the chapter through the alphabet signaling system: "One day at a time."

"Before Rosemary's affliction our spiritual lives were at a peak," says Walker. "In this crisis and it is a crisis, above all things we have sought faith. We have been provided with all sorts of support."

The Walkers are active members of the Lafayette Federated Church. A Wednesday morning Bible Study group still meets regularly at the Walker home. Friends assist the family when necessary and members of the Monoe Bible Chapel visit regularly to help Mrs. Walker pass the time.

According to Mrs. Bassett, public education is essential to early ALS detection. "People must know what it is and where to turn; if it's a secret, we can't do anything about it."

(Pat Conklin photo)

FAMILY LIFE goes on in the home of the Robert Walker family of Hardyston Township, despite Rosemary Walker's battle with Amyotrophic Sclerosis. They are, from left, Kimberly Ann, 7, Robert Walker, Rosemary Walker, Hope Suzanne 13, and Paul Alan, 9.

Early diagnosis means better family preparation and understanding of how they will cope with the situation. The ALS clinic at Mt. Sinai Hospital helps prepare and counsel families in group sessions and assists with the loan of small equipment.

Research and patient services supported by the National ALS Foundation, Inc. totaled $247,223 in 1978. Ongoing research is now being conducted in five areas of the country.

In Boston, tests are being conducted with lesithin to see if the chemical, acetycholine, which carries the signal for contraction from motor nerve to muscle, can be increased. Medical researchers believe there may be some abnormality of protein or energy metabolism that is responsible for the motor nerve degeneration in ALS. Poliovirus is also known to be present in ALS patients.

Doctors in Rochester, N.Y. are trying to identify change in muscle blood flow in different stages of ALS to develop a treatment to slow down or halt progress of ALS.

In California ALS research is centered on a possible viral cause, such as poliovirus. Doctors believe that if ALS is caused by a virus it is likely that the ALS agent is genetically related to poliovirus, according to a report in a recent issue of National ALS Update newsletter.

Brain chemicals, or neurotransmitters, are the target of research conducted in Colorado. Doctors here are trying to identify specific chemical abnormalities induced by viral invasion in an attempt to learn how to reverse the chemical change.

Maryland researchers are studying the neural regulation of muscle properties to advance the knowledge of the pathogenesis of ALS.

The Hunterdon-Sussex ALS Chapter meets the fourth Thursday of each month at the Monroe Bible Chapel on Route 94. Present fund raising plans include the Second Annual Antiques at Christmas show to be held Dec. 1 and 2 at the Round Valley School, Cokesbury Road, Lebanon.

A First Annual Kids Stuff Sale will also be held Dec. 1 in Newton, at the Christ Episcopal Church on Main Street. Children's clothing, toys and furniture will be sold to benefit the Hunterdon-Sussex chapter.

Because of the Thanksgiving holiday, the next chapter meeting will be held Nov. 29 at 7 p.m. at the Monroe Bible Chapel, Rt. 94.