Foundation to help UA fight ALS

By Inger Sandal
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Jim Himelic's fight against a fatal degenerative nerve disease has grown in the year since the Juvenile Court judge's death.

His family and friends have established a foundation in his name to establish a department at the University of Arizona dedicated to amyotrophic lateral sclerosis research.

Commonly called Lou Gehrig's disease after the famed baseball player who died of it in 1939, ALS is a progressive degeneration of the nerve cells in the brain and spinal cords that control voluntary muscles. It was discovered 150 years ago, but doctors still don't understand what causes it or how to treat it.

"I'm hoping the foundation will bring awareness to how horrific this disease truly is," said Diana Himelic, who watched her husband basically become trapped in his own body as it withered from 175 pounds to about 80.

Jim Himelic would have turned 54 today. Diana Himelic is president of the foundation's board of directors. The oldest two of the couple's six children also serve on the board.

"The rewarding part about working on the foundation is we've been able to create something good from tragedy and at the same time keeping Jim's name alive," Himelic said.

She credits Bob Winefer, a retired executive who volunteered as her husband's bailiff for three years, with starting the foundation, which does its tax-deductible fund raising through the UA Foundation. UA baseball coach Jerry Kindall, whose wife died of ALS, is the honorary director, and a number of other friends and community leaders are involved.

"It is a special effort and we're very appreciative of the work this group is doing," said Heather Pierce of the Arizona Health Sciences Center.

The first major fund-raiser is a golf tournament slated for June 1 at the Omni Tucson National Resort. The annual event also includes dinner, entertainment and a silent auction. Organizers hope to raise $50,000 the first year. "We think we can make this snowball and more and more people will participate as time goes on," Winefer said.

Attorney Elliott Glicksman has agreed to be master of ceremonies. He described Jim Himelic as the "sort of person you were proud to know and a wonderful representative for what all lawyers ought to be in the community."

"I think he'd be thrilled to know his memory lives on and in his name people are going to continue the individual fight he had against ALS," Glicksman said.

Himelic was diagnosed with ALS in April 1996 after he had started to stumble while jogging. Doctors initially hoped Himelic had a form of ALS that would allow him to live 10 years, but the illness progressed much more rapidly.

Himelic used a leg brace when he arrived at juvenile court in 1997. A cane then gave way to a walker. In April 1998 he resigned himself to using a wheelchair full time. He worked until just a couple months before his death on Feb. 12, 2000.

"We know so little about this disease. In the big scheme of things, ALS is considered a very rare disease," said Dr. Valerie Cwik, an assistant professor of neurology at the UA. Cwik, on staff at University Medical Center, already sees most of the ALS patients in Southern Arizona and would run the research department.

There are currently about 50 ALS patients in varying stages — some are newly diagnosed while others are in hospice care. The Tucson program is regarded as an equal to any other in the nation, but the Jim Himelic Foundation could make it a research leader.

Cwik was not Himelic's doctor, but Himelic volunteered in a research project that used an MRI to measure chemical signals from the brain. "Even in the later stages of disease, during which it was clearly a struggle for him to participate, he did not miss a visit," said Cwik, who is analyzing that research.

"I'm just too overwhelmed right now taking care of patients to really focus enough time and energy on the research end of things to build that to the level we would like," she said.

In ALS, the neurons in the brain and spinal cord that control the ability to perform voluntary movements degenerate. That produces severe and progressive wasting and weakness in the muscles. "Eventually the arms will be weak, the hands will be useless, the legs will weaken, people can lose the ability to speak or swallow…and eventually the neurons that control the diaphragm which allows us to breathe, degenerate. When that happens people basically develop respiratory failure," she said.

Two people per 100,000 get the grim diagnosis each year. The average life expectancy is two to five years from the onset of symptoms.

Most people are diagnosed in their 40s and 50s, she said, but it occurs in every adult age group and is found in every race and ethnic group. "There is some concern that ALS is increasing in the population," she said.

Up to 10 percent of the cases are genetic. Himelic was one of the estimated 90 percent with sporadic ALS, which means it just happens out of the blue – it had not occurred earlier in his family.

Researchers want to learn more about the genetics of the disease, whether environmental factors may be involved, and how to treat it. The only drug approved by the FDA to treat ALS has only a modest effect on the disease. It promotes survival about three months and costs about $800 a month.

Donations can be made through the University of Arizona Foundation, 621-5590.

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