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ALS support group is a wish fulfilled

Joan Dancy's dying wish to aid patients is reality

BY ALISON HERGET, KEYPORT BUREAU



Glenn Barney (right) of Red Bank has been living with ALS for almost seven years. With him is his wife, Ellen, and son, John. Thanks to the Joan Dancy and People with ALS Support Group, the family gets help from the Visiting Nurses Association of Central Jersey.



Joan Dancy's doctor told her she was just going through menopause. Another even suggested she see a psychiatrist.

But Terry Magovern knew something was gravely wrong with his fiancée. After seeking advice from a variety of medical professionals, Dancy received her final diagnosis — amyotrophic lateral sclerosis, more commonly known as ALS, or Lou Gehrig's disease, a progressive neuromuscular disorder that has no known cure.

Almost four years later she was dead — at the age of 54.

But before Dancy, a Middletown resident and mother of two, passed away on July 16, 2005, she passed along a wish to her fiancé: to have a grassroots organization established to help patients and families dealing with ALS, an always-fatal disease.

"She didn't want anyone else to go through what she went through," said Magovern, 60, of Rumson. He said he and Dancy had to turn to the Greater Philadelphia Chapter of the ALS Association for help because local resources were nowhere to be found.

Dancy's wishes have come to fruition. With the help of Riverview Medical Center, Red Bank, and local businesses and organizations, Magovern has recently been able to start the Joan Dancy and People with ALS Support Group. It is one of a handful of support groups in the state for ALS, which he and experts often call "the silent disease" because there is little public awareness about it. There is a group in Egg Harbor Township and another in Lawrenceville.

The nonprofit organization awards direct grants to ALS patients and their families to help with transportation costs, medical care or any other services needed as a result of the illness. It also holds monthly support meetings at Riverview Medical Center for those affected by the illness.

"Not only the patient has ALS, the family has ALS," explained Jeffrey M. Welch, vice president of operations at Riverview, who said caring for an ALS patient often requires the help of many.

Ellen Barney, 51, of Red Bank can attest to that. Her husband, Glenn Barney, 49, has been living with ALS for almost seven years.

He now has trouble speaking and has lost the use of his arms. He needs assistance when eating, shaving and bathing, among other daily activities, his wife said.

“We’ve been blessed because we have a lot of good people in our lives,” said Ellen Barney, who has to balance taking care of her husband with caring for her 9-year-old son and working a full-time job as a sales representative for Quest Diagnostics. “It’s a very difficult disease to deal with. I think all the time about people who have to deal with this alone. I don’t know how they do it.”

The support group was able to facilitate visits from a nurse with the Visiting Nurses Association of Central Jersey. The nurse comes to the family’s house to give Glenn Barney a meal and keep him company during lunchtime.

Fulfilling Dancy’s dying wish has also been possible with the help of Saker ShopRites, a member of the ShopRite supermarket cooperative. It has been collecting donations at check-out stands in its 26 stores in central New Jersey since after Labor Day. Sunday will be the last day of this leg of the campaign.

Customers are being asked to contribute from \$1 to \$4. If the shopper makes a \$4 donation, the company matches it and all proceeds go directly to the Joan Dancy and People with ALS Support Group, said Richard J. Saker, president and chief executive officer of Saker ShopRites.

More than \$110,000 has already been raised, which includes the company-match amount, Saker said.

“This is the type of program that doesn’t break anybody,” Saker said. “This is the kind of program that makes a difference.”

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