

Father's memory inspires a cross-country run to raise money for Lou Gehrig's disease

By **DEBORAH A. MILES**

As medical research advances, the odds of beating some diseases increase. But when someone is diagnosed with Amyotrophic Lateral Sclerosis, more commonly known as ALS or Lou Gehrig's disease.

"ALS is not an incurable disease, it is an underfunded one," said Steven Luther.

This PEF member who works for the state Education Department Office of Professional Discipline in Rochester is making a nationwide effort to get more ALS funding. He is organizing a team of 16 runners who will start a cross-country run from the Golden Gate Bridge in San Francisco and end at Coney Island in New York, a 3,300 mile route.

Finding a cure for ALS is a goal hardwired to Luther's heart.

"In March of 2011, my father Ray Luther was playing golf and fell a few times," Luther said. "During the next few months, he saw numerous doctors and was finally diagnosed with ALS in September. He died four months later. I am not going to describe how this disease physically destroys a person. I will tell you it is terrible to witness and even worse for the individual living with it."

Although Luther wants to help find treatments or a cure for ALS, he doesn't dwell on the disease that causes muscle weakness, paralysis and ultimately respiratory failure, but rather on his father's determination, generosity and accomplishments.

"Looking back at my father's life,

is caring for her husband following his open-heart surgery in late November. To donate leave to her, call 518-473-1090 and ask for the OTDA human relations department.

- **Audrey Tyson** is an insurance premium auditor 2 at the NYS Insurance Fund. She is receiving an organ transplant and faces a 12-week recovery. To donate leave to her, email the NYSIF personnel office at lyahm@nysif.com.

- **Richard Urys** is an information technology specialist 3 programmer at the state Office of Information Technology Services in the Capital District. He is being treated for stress



RUNNING FOR A CAUSE —
Ray Luther runs through the desert in 1982 to benefit a children's hospital. His son, Steven, prepares for a similar run planned for July 2016 for ALS awareness.



the man I remember was strong and independent, and not one who had to have every need attended to by someone else," Luther said.

There is another reason why Luther wants to run cross-country.

and complications following traumatic brain injury and surgery. To donate leave, email darci.boniewski@ogs.ny.gov or call 518-457-4272.

- **Cristie VanGorden** is a nurse 2 at Coxsackie Correctional Facility. She has severe tendonitis and severe tarsal tunnel syndrome in her feet as well as back pain. To donate leave, call the facility at 518-731-2781 and ask for the personnel office.

- **Lisa Wallace** is a nurse 2, psychiatric, at Mid-Hudson Forensic Psychiatric Center. She must have major surgery. To donate leave, call 845-374-8929.

- **Steven Willis** is a nurse

His father made a similar trek in 1982, when he and 15 other men decided to run from California to New York to raise money for the University of Rochester's Strong Memorial Hospital Children's Fund. All of the runners were over age 50, and a few became world record holders in the number of marathons they ran in their age group.

"That was an inspiration to me," Luther said. "The 2016 run will be in memory of my father and to raise awareness for ALS and money for the ALS Therapy Development Institute (ALS TDI), a bio-research facility in Cambridge, MA. It is the world's first and largest non-profit biotech laboratory that focuses 100 percent of its research on ALS to discover and develop treatments."

The expenses involved for the July, 2016 marathon will be substantial, but Luther is determined to raise \$100,000 for ALS TDI.

Dr. Fernando Vieira, TDI director of research operations and in vivo operations, will be one of the runners. Luther said the 18-day time commitment for this marathon requires runners to be dedicated to the cause. While he is seeking more runners to complete the team, he is starting to train for the event by running 30 miles a week, and plans to boost that to 60 miles a week in early spring.

If you would like to participate in or help support Luther's run, visit www.alsrelaycrossamerica.com or send him an email at alsrelayrun@gmail.com.

administrator 2, at Mid-Hudson Forensic Psychiatric Center. He has been treated for pneumonia, but still suffers from an undiagnosed underlying infection. To donate leave, call Patricia McMichael at 845-374-8700.

The rules for making and receiving leave donations are set forth on page 148 of the PS&T Contract. If you, or a PEF member you know, needs leave donations because of a medical issue, you may contact *The Communicator* to request publication of that need. Send requests to thecomunicator@pef.org, or call 800-342-4306, ext. 271. Be sure to provide your contact information.