Going the distance

by Anthony Mathenia

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Melvin Osburn of Jerseyville displays wide-leg pants worn prior to his lymphedema treatment. Osburn is planning a walk in advocacy of the Lymphedema Treatment Act.

ALTON — Melvin Osburn is on a mission to get the word out about lymphedema.

It is all about improving the quality of life for sufferers of the disorder, according to the Jerseyville native. Osburn, who has suffered ongoing leg swelling from the condition, is planning a marathon-length walk on April 22 to raise money and awareness for the Lymphedema Treatment Act.



Photo by Anthony Mathenia

Also known as lymphatic obstruction, the chronic condition results in extreme swelling and often pain in affected body parts. Lymphedema affects 3 to 5 million Americans.

"I've had big legs since I was a child," Osburn said. "(The condition) began in one leg after I was kicked by a horse. Then the other leg started swelling after a construction accident."

For many years, Osburn didn't know he suffered from the inherited disease.

"I always wore my cowboy boots to keep the swelling in check, but eventually I couldn't even find boots that fit me," he said.

Osburn underwent a treatment called complete decongestive therapy, which helped him lose 52 pounds of fluids. Part of his wardrobe also includes compression garments, which are used to restrict the flow of lymph fluid to the affected limbs.

"You learn to live with it," he said. "Any time I have to go someplace, I have to get ready three hours ahead of time."

The Lymphedema Treatment Act aims to improve access to compression garments. According to the act's website, "The act will improve coverage for the treatment of lymphedema from any cause by amending a Medicare statute to allow for coverage of compression supplies ... it would set a precedent for Medicaid and private insurers to follow."

U.S. Reps. Dave Reichert (R-Washington), Earl Blumenauer (D-Oregon), Leonard Lance (R-New Jersey), and Jan Schakowsky (D-Illinois) introduced the congressional bill.

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"We should be enabling seniors who suffer from lymphedema to have the best possible access to necessary treatments for their condition," Reichert said in a press release for the bill. "Making sure that Medicare covers compression garments is a common-sense way to give individuals real hope to fight back against this chronic condition and obtain their best possible quality of life."

In September 2014, Osburn traveled to the capital to meet with legislators to rally support for the legislation. He also volunteers at medical conferences. He says there have been advances, including specialized programs at OSF Saint Anthony's since 2004.

"Your therapist is your best advocate in this," he said. "I see my therapist once a month and we've become good friends. They are very caring people."

Osburn's current exercise routine, including multi-mile walks, is in preparation for the 26-mile trek beginning April 22 at the Piasa Bird and ending three days later at Pere Marquette State Park. When asked about his objective, he said, "I want to see the awareness out there and get the public behind this bill.

"This is not about me. This is about the Lymphedema Treatment Act. I'm really thankful that I'm getting support."

At its worst, Osburn's leg swelling had required specially tailored pants; after treatment, he was again able to buy off of the rack.

"Best of all, I can even wear my cowboy boots again," he says proudly, lifting up his pants legs to show off a pair of custom-made kicks.

For more information or to make a donation, visit www.lymphedematreatmentact.org.