

Shedding a tear at the movies may not seem so strange, but imagine breaking down crying while watching a health video. That's what happened to Denise Longo when she saw a tape that described the chronic pain she'd been living with most of her life.

Finally she had found the answer to her suffering. "It took me 30 years to find it. I have fibromyalgia. I tried just about everything," says Longo, a Miami business consultant. "Suddenly, I just cried."

Fibromyalgia is a condition without a known cause and without a cure. It's been called "invisible disability" because it affects everything, supernormal endurance and even whitening men's disease.

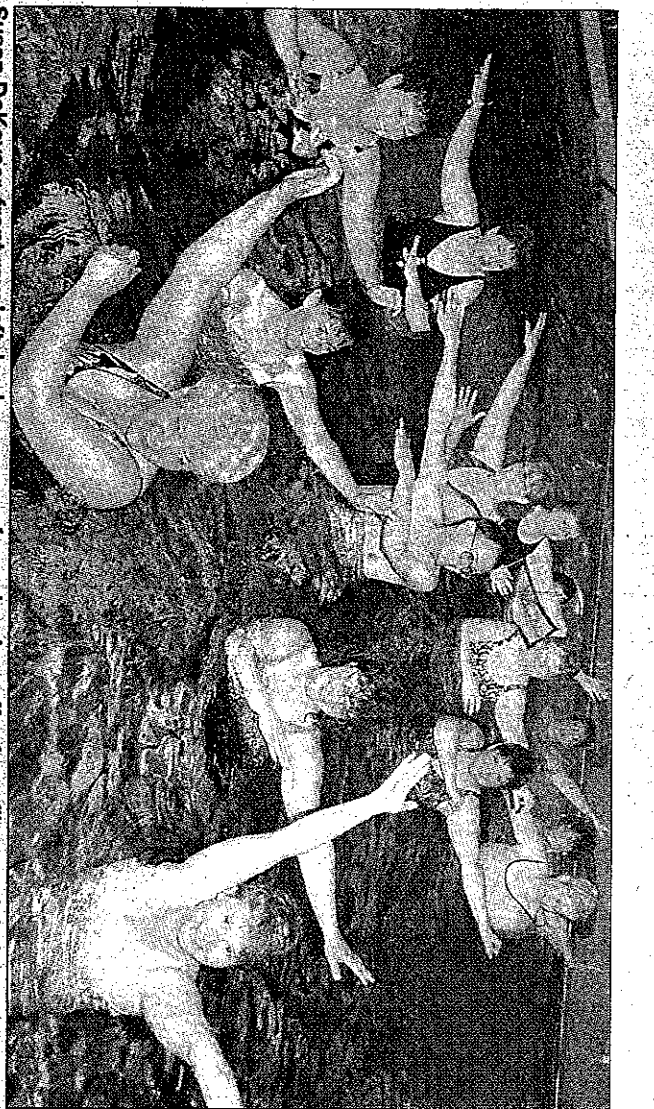
Dr. Truman Ropos calls it the bane of the rheumatologist's existence, of every physician's existence. "There's no anatomic abnormality, no concrete physical cause," says Ropos, a rheumatologist at Cleveland Clinic in Weston, Fla. Yet patients present it a wide range of symptoms, including chronic, sometimes crippling pain.

The beginning
Longo's pain began when she was 18. First, her knees ached much while on an errand for her first employer. She thought it wouldn't be able to go on for about a week. The pain mended about a week, then her hands, then her feet. Doctors gave her arthritis medication, but it didn't do any good.

The pain persisted for about years before moving into her back and neck, sometimes incapacitating her to the point she didn't walk at all. Soon it was in her knees, elbows, shoulders — just about everywhere.

It was awful because a lot of people around me thought it was all in my head, and I ended believing that. How could I be hurting in a different place every day? I couldn't make any sense of it. I volunteered in a food bank because how would I know if I'd be able to walk that day? I'd be able to walk that day? I'd be able to walk that day? You doubt yourself and you wonder whether you're losing your mind.

It's before diagnosis
Ropos treats patients for the condition, but like all physicians, can't diagnose it until it's been ruled out several other diseases.



Susan DeKeyser, front row left, leads a group of people who suffer from fibromyalgia in exercises at the Cerebral Palsy pool. File photo/Press-Gazette

For more information

Several organizations work with fibromyalgia patients and can provide information and support.

- National Institute of Arthritis and Musculoskeletal
- National FM Partnership, www.fmpartnership.org/
- Upledger Institute, www.upledger.com/

An estimated 4 million to 10 million Americans, 90 percent of whom are women, of all ages and all races, have fibromyalgia, doctors report. And sufferers often have other conditions as well, such as migraine headaches, irritable bladder and bowel, chronic fatigue, multiple chemical sensitivity, anxiety and depression — a long list of ailments that pile up to create a miserable way of life.

"It's a product of our society," Ropos says. "It's pretty frustrating when you have pain and you know you're hurting, but even the doctors will not take you seriously. You've got to find a doctor who will listen to you," says DeLore Burke, who visited more than a dozen doctors before finding Ropos and determining that she had fibromyalgia. Her worst point was when she couldn't get out of bed for two weeks.

"Pain," says Mary Jo McPhail, Brown, director of rehabilitation at JFK Medical Center in Atlantis, Fla., "is not a normal condition." Pain is a signal that you need help.

The good news is that even without cause or cure, there are successful management techniques that can relieve at least some of the pain of fibromyalgia.

McPhail-Brown offers a customized course, usually about six weeks long, to help fibromyalgia patients deal with all aspects of the condition. "Besides popping pills, what can you do to manage this? It's a multi-faceted syndrome, affected by many things — poor sleep, hypersensitivity to pain, touch, smell, noise, lights, temperature," she says. "When you don't reach that deep sleep, you don't get the restoration of hormones in your body, then it slips into hormone imbalance. That could affect your immune system and your brain, and your muscles don't act the way they should."

Physical trauma
Fibromyalgia can follow physical trauma — 45 percent to 70 percent of cases surface after an accident or injury — or be brought on by an illness such as osteoporosis, rheumatoid arthritis, or as in the case of Burke, from lupus, with which she was diagnosed 22 years ago.

The 41-year-old mother from Margate, Fla., uses anti-depressants to ensure a good night's sleep, an important part of treatment for most fibromyalgia patients. "That and physical therapy is really what got me back on track," says Burke.

"When I have a flare-up, the first thing I have to do is exercise. There's a lot of pain, but it's the best thing for you. The muscles become very hard and knotty, especially when you're tense or under stress — that makes it worse."

Burke has a long-standing date with physical therapist Nancy Croughwell, co-owner of OrthoSport in Davie, Fla. The routine includes regular paces of stretching and weight training, as well as electrical stimulation to increase circulation and reduce pain, something that patients can do at home with special equipment.

Finding treatment
Even after she'd determined the cause of her pain, it took Longo several years to find the proper combination of treatments to achieve a comfortable life. One doctor even treated her for hypochondria when she told him she thought she had fibromyalgia.

"I've noticed in group sessions that the people are always very high achievers, great family people who were giving so much they were forgetting themselves," says Longo, the mother of 9- and 16-year-old sons.

"You need to take care of yourself. You need to assess your life. My life was a continuous deadline; stress is a big trigger for fibromyalgia. I've had to simplify my life quite a bit. I've had to learn that sometimes things will not be perfect."

In the end, she says, "you end up with your own bag of tricks — not everything works all of the time, but there is always something that will help."

2002.0915