

Scleroderma Foundation

New England Chapter

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The New England BEACON
Published quarterly by SFNE

462 Boston Street, Suite 1-1
Topsfield, MA 01983

SFNE is a 501(c) (3) organization. All contributions are tax deductible and should be sent to the above address.

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DISCLAIMER: SF/New England Chapter in no way endorses any drugs or treatments reported in this newsletter or at SFNE sponsored meetings. Information is provided to keep readers informed. Because the manifestations and severity of scleroderma may vary among individuals, personalized medical management is essential. Therefore, it is strongly recommended that all drugs and treatments be discussed with the reader's physician(s) to assure proper evaluation and treatment.

FALL RIVER GROUP SHARES STORY

By: Deborah Allard at the Herald News, South Coast, MA



Herald News photo/Deb Allard

Pictured above: (L-R) Sue Camara, Diane Moreira, Arlene Furtado, and Donna Bernier

Recently Fall River Support Group leader Donna Bernier arranged for Deborah Allard, a reporter from the Herald News, to attend one of their groups and report on their story about scleroderma. The story Deb reported appeared in the Herald News, and was then picked up by several news outlets, including WCVB.com.

This spread of information helped others living with scleroderma in remote New England locations to reach out to SFNE for assistance and information. We thank Donna for coordinating this incredible step forward in awareness. Below is Donna's and the Fall River's group members' "sharing" story, as reported by Deb Allard.

FALL RIVER, Mass. When Arlene Furtado got sick, her ailment was referred to as "cement disease."

"I couldn't move my arms or legs," Furtado said. "I couldn't open my mouth or eat." That was three decades ago. Furtado, a hairstylist, was 42.

What the doctors were referring to in non-technical terms was

scleroderma, an autoimmune disease that causes the body's immune system to attack its own tissues and to over-produce collagen. It hardens the skin like "cement" and can even cause organs to stop functioning.

Collagen is produced as part of the body's natural healing process, but when produced in excess can cause scar tissue that damages the skin and organs.

For three years before Furtado was diagnosed, she suffered without knowing the cause. When it affected her skin, she wore Vaseline and gloves so she could continue to work.

For Donna Bernier, it started with her hands. Then she lost muscle at an alarming rate, and even her hair. "I was losing eight to 10 pounds of muscle every month," Bernier said. "I became 100 percent disabled in 2006." Bernier, 44 at the time, said scleroderma has "many different symptoms."

People who suffer [with this] rare disease are often first misdiagnosed because of the range

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FALL RIVER GROUP

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of symptoms and its similarity to some other autoimmune diseases.

"It's important that you find a specialist," Bernier said.

Some 300,000 Americans suffer with scleroderma, according to the Scleroderma Foundation. The disease can be localized to the skin, or may be systemic and can affect the internal organs, like the lungs, kidneys and bowels.

Scleroderma can vary widely in terms of severity. It affects both sexes of all ages, including children, though occurs more frequently in people between the ages of 25 and 55. Women often see their first symptoms around the time of perimenopause. Bernier said the disease seems to be more fatal for men than women. There is no known cause and treatments are few.

The symptoms of scleroderma are generally worse in the first few years, and then taper off, though victims are never free of the disease and often suffer lingering pain and illness.

Diane Moreira started experiencing symptoms of scleroderma following a trauma from a car accident in 2007. "Nobody knew what was wrong with me," Moreira said. In a year, she lost 115 pounds. "If I keep losing, I'm going to fade away," Moreira said.

Sue Camara, when diagnosed in her early 30s, was told the disease was fatal and that she would be

dead within seven years. That was in 1995. She suffers from painful calcifications that have permanently bent her hands and fibrosis of the lungs. "It was a horrible time in my life," Camara said.

Bernier, and co-leader Christine Maroney, started a local support group for people with scleroderma several years ago. The group has 15 to 20 members today.

Bernier said education is a big part of the group's goals. Because the disease is considered fairly rare, most people don't know the symptoms or where to go for help and support.

Bernier said scleroderma is a life-changing disease. "It's a pretty serious thing," Bernier said. "You do feel isolated."

Furtado, now 72, continues to work as a hairdresser, a career she has held for the last 53 years, despite scleroderma. "I'm still kicking," Furtado said.

The Scleroderma Support Group meets on the third Tuesday of each month at Stop & Shop, 501 Rodman St., Fall River, in the second floor conference room. New members are welcome to attend.



In everyone's life, at some time, our inner fire goes out. It is then burst into flame by an encounter with another human being. We should all be thankful for those people who rekindle the spirit.

~ Albert Schweitzer

SFNE SUPPORT GROUPS

Maine

Maine One-on-One Support
Contact Lori Chason at 207-892-7323
or e-mail her at chason.lori@yahoo.com

Massachusetts

Boston Support Group
Boston University
Medical Center - Shapiro Building
First Floor Conference Room
Meets the 3rd Sunday
of every month
Group Leader: Carol Taylor
774-233-0558, cvsing@comcast.net

Fall River Support Group
Meets the 3rd Tuesday of every month
6:30 - 8:30pm

Co-Leaders: Donna Bernier
Donnabdab2@hotmail.com
774-488-6775

Christine T. Maroney, 508-675-4152

North Shore Support Group (Topsfield)
Meets the 2nd Wednesday of most months
Group Leader: Roberta Mauriello,
781-324-7426

Worcester Area Support Group
Meets once a month on Sunday
Group Leaders: Nancy Velleco
and Mary Ann Persson
Please contact Nancy for specific dates.
508-869-2997

New Hampshire

Granite State Support Group
(Hampstead)
Meets the last Saturday of the month
Co-Leaders: Carla King
978-884-4866
granitestate@scleroderma.org
Jean Chapman
chappybear@charter.net

Vermont

Burlington Vermont Support Group
(Williston)
Meets the 3rd Tuesday of most months
Group Leader: Blythe Leonard
802-878-0732, b.leonard@myfairpoint.net

Brattleboro Area Support Group
Meets the 2nd **Wednesday** of each month
Brattleboro Memorial Hospital, 6:00 - 7:30pm
Group Leader: Ilene Wax
802-464-5847
ilenevax@gmail.com

Connecticut

Greater Enfield Support Group
Group Leader: Sharon LeDue
860-741-5028 or EnfieldCT@scleroderma.org