

Mont Belvieu resident raising awareness on rare disease

Story

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The month of June is National Scleroderma month and Mont Belvieu resident Karen Padgett is spreading awareness on this rare disease.

Scleroderma is an incurable autoimmune disease, which means that the body's immune system attacks its own tissue, affecting approximately 300,000 people in the U.S.

Padgett, who is a board member for the Scleroderma Foundation Texas Bluebonnet Chapter, was diagnosed with the disease 20 years ago.

"I may have had the disease longer than 20 years," Padgett said. "Most people are misdiagnosed because it closely resembles arthritis."

Padgett and the Bluebonnet Chapter are doing what they can to spread awareness. Locally, they will have a booth at the Bayer Health and Wellness fair today and they sent out information about scleroderma to area nursing schools.

"The public needs to know about this autoimmune disease because it's rare and unknown in the public eye," said Padgett. The word scleroderma means "hard skin" due to the fact that tissue gets hard or thick and can cause swelling and pain in the muscles and joints.

There are two main classes for scleroderma, which include localized and systemic.

Localized means that the disease affects only certain parts of the body while systemic means that it can affect the whole body.

Typically, localized types of scleroderma are limited to the skin and related tissues and, in some cases, the muscle below the affected area.

Localized scleroderma cannot affect internal organs and it never turns into systemic scleroderma.

Systemic scleroderma, also known as systemic sclerosis, is a form of the disease that not only includes the skin but the tissues beneath, the blood vessels and the major organs. Scientists don't exactly know what causes scleroderma but know that it is not contagious or inherited.

With scleroderma, the immune system stimulates cells called fibroblasts so they produce too much collagen, which forms thick connective tissue that builds within the skin and internal organs interfering with their function.

Scleroderma does not have a cure but symptoms and damage can be reduced.

A rheumatologist may lead you to a health care team and refer you to other health experts for problems with skin, kidneys, heart, digestion, lungs, teeth, movement and speech. Living with the disease and its effects day to day has a significant impact on patient's quality of life but Padgett continues to be optimistic of the situation.

"Some days it's hard to breathe and difficult to get out of bed," Padgett said. "But I don't give up hope and I still feel that I'm very blessed."

Board member for the Scleroderma Foundation Texas Bluebonnet Chapter Jacob Davila, along with Padgett, have a support group for people with the disease to listen to what they say and to give them hope. They also have guest speakers, who are at times doctors, come and speak about the disease.

Support group meetings are from 2 p.m. – 4 p.m. every second Saturday of the month at Memorial Herman Hospital, 11800 Astoria Boulevard.

For more information about the support group, contact Jacob Davila at [281-706-6232](tel:281-706-6232) or email him at

jdavila@scleroderma.org. You can also contact Karen Padgett at [281-385-2502](tel:281-385-2502) or email her at deacon77520@verizon.net.