

World Scleroderma Day is June 29

On June 29, we celebrate the life and death of Paul Klee and all those who struggle with scleroderma.

We campaign for a world in which equal rights, treatments and care are offered to people with scleroderma, and in which such diseases are not forgotten, but afforded the consideration and attention of other more widely known diseases.

Having a disease that nobody has heard of is a lonely business.

So World Scleroderma Day was created to raise awareness of what it means to have this disabling disease.

June 29 is a day to recognise the bravery of those who live with this disease and to demand equal treatment and equal care for people with scleroderma.

What is scleroderma?

A disease of the immune system, blood vessels and connective tissue, scleroderma can attack many body systems or just a few. It is very hard to diagnose because each person may have a different combination of symptoms, and the disease progresses at different rates for everyone.

While some symptoms are visible, like hard puffy skin on the hands, Raynaud's, and tightened joints in systemic forms, the most serious symptoms are hidden, and the person with scleroderma may look quite well to outsiders. Inside that person, the lungs, heart, kidneys and gut are only some of the systems that may be affected. On

the other hand, sometimes the face alters significantly although the organs are healthy, and facial changes may be hard to accept.

What happens in scleroderma?

The causes of the different types of scleroderma are not known, but we do know what happens: the auto-immune system malfunctions, so that the body places excess collagen on its connective tissue which makes up the skin, joints, tendons and parts of the internal organs. Damage to the blood vessels, meanwhile, causes them to constrict and stiffen, and weaken the organs they supply.

What can be done?

Thankfully, there are now very successful treatments that can halt the progress of scleroderma, but each of these applies to specific symptoms. There is no overall cure. It is extremely important that diagnosis is made as early as possible, so that treatment can begin.

How can scleroderma be diagnosed?

An informed doctor can diagnose scleroderma through a combination of medical history, physical examination, blood tests and non-invasive investigations such as capillaroscopy.

Who gets scleroderma?

It is thought that scleroderma affects one in every 10,000 people.

We know that women are affected four times as often as men. It is not contagious or infectious.

Research and donations

Early diagnosis of scleroderma saves lives and leads to control of the disease.

To raise awareness about the condition, Scleroderma Australia has adopted the sunflower as the national icon. The sunflower is symbolic, as, like the sunflower which turns towards the sun for warmth, people with scleroderma are usually more comfortable in warmer weather.

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