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The Scleroderma Association of Qld Inc, INVITES YOU to DONATE to or REGISTER for their 'WALK FOR SCLERO' EVENT at NEW FARM PARK in 80's theme costume on the 9th of October, 2022 at 11.30 for a 12pm start.
<https://www.mycause.com.au/events/walkforsclero>

(Scleroderma Qld, (pronounced Sklero-derma), Asks the Public and Media to Shine A Light On This Rare Autoimmune Disease and SLOW WALK to help us raise funds so we can collate our national numbers)

Brisbane, Qld: Today, Scleroderma Qld and NT started a nationwide push to make this complex, rare, auto-immune disease a household name. It's relatively unknown, though was first described in 1753 by Carlo Curzio, and causes the body to overproduce collagen, the protein that firms the skin. There are at least 6,000 people who live in Australia with Scleroderma, but the true statistics could be much greater than this given there are at least 5 living in the small postcode of 4005 (New Farm/Teneriffe), and at least 5 living in 4552 (Maleny). We are in the process of raising funds to carry out a national project through ASIG (Australian Scleroderma Interest Group) of collating deidentified test results of all Australians with a Medicare card to find out our accurate numbers. 80% of people living with Scleroderma are women. Around 8% of Australians live with rare diseases. Scleroderma Qld and Australia challenge you to remember their name and voluntarily register at www.sclerodermaaustralia.com.au if you have the disease.

Beth Leach, the Advocate for Awareness for Scleroderma Qld and NT, and board member for Scleroderma Australia said, "We recognise that through advocacy comes greater awareness and having accurate disease statistics is imperative. We need to raise \$40,000 in order to collate these statistics because we don't know how many of us there are. When we complete the collation project a broader picture will emerge that will help us attract medical research funding and hopefully, ultimately lead to a cure for Scleroderma. So, we're asking Australians to remember the tricky-to-pronounce name, Scleroderma, and learn a little bit about this complex disease.

To do this Scleroderma Qld has challenged Aussies to:

1. Remember their name and some 'fun facts' for a not-so-fun rare, auto immune disease.
 - 1.1 Like, 95% of people with Scleroderma have Raynaud's (Ray-nose) Phenomenon which makes them extremely sensitive to the cold. It's a neat party trick at first but the small blood vessels narrow, thicken and blood can't get to these parts of the body. Nasty ulcers can occur, and little bits of fingers or toes can drop off due to infection or need an amputation.
 - 1.2 Limited Scleroderma can have mild symptoms, like cold, stiff fingers, and minor things visible on their faces. Or there may be severely disabling symptoms from the collagen, extensive skin involvement, internal organ involvement, and restricted joint mobility due to tendon contracture. The medical approach is to suppress the disease and immune system with pharmaceuticals.
 - 1.3 Diffuse Scleroderma is much less common, is extremely serious and becomes acute rapidly as collagen is laid down in the body and internal organs. Stem cell transplant through chemotherapy to kill all the bone marrow is a trial treatment for the lucky few accepted into these medical programmes. The patient's own stem cells are then injected back into them.

About the Scleroderma Association of Qld Inc: Almost 30 years old, this not-for-profit organisation is a partner of the peak body representing rare diseases at a federal level, Rare Voices Australia. Scleroderma Qld encourages awareness through advocacy, invites awareness and research funding, and pledges to work tirelessly towards a world free of Scleroderma and Raynaud's.