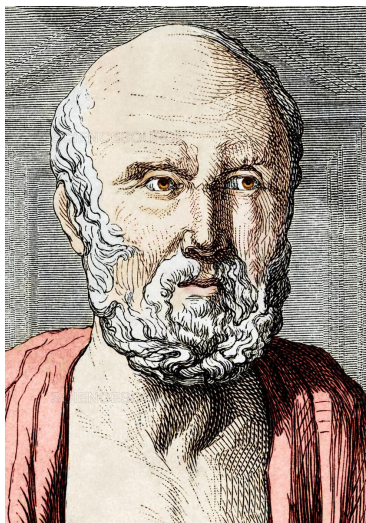




Ever heard of scleroderma?

It's unlikely. Literally it means "hard skin". However, it goes beyond the skin and is an unstoppable force in its systemic form.

Anyone at any age can be diagnosed with scleroderma. The localized form is very rare - about 200,000 Americans. It is usually a disease that reaches a quiet phase, doesn't typically involve internal organs but leaves behind lasting reminders of its activity on the skin and underlying tissues. It is the systemic form of the disease, affecting only 100,000, that creates the greatest fear and anxiety as the unstoppable form, either proceeding slowly over many years or progressing quickly, shortening life-span significantly.



centuries since Hippocrates' influence, very few people

Hippocrates knew scleroderma (400 BC) noting that the person seemed to "turn to stone". In the mid-1700's the first documentation noted skin hardness, small mouth and skin cool to the touch. We have learned over time that the disease affects nearly every organ with an overabundance of collagen, fibrosis and vascular changes. However,

are aware that the disease exists. We are still hearing "Sclero-What?". Over a physician's career, they may never see a scleroderma patient - ever. Scleroderma is still a disease with no known cause, limited treatments, no cure. It is life-threatening and certainly life altering - an unstoppable force. If there is so little awareness in the medical and general population - can we truly support those isolated few? Yes, we can.



June is Scleroderma Awareness Month.

The Scleroderma Foundation, with chapters across the country, has partnered with Scleroderma Canada and the Scleroderma Research Foundation

to educate and create disease awareness to help with the isolation patients and families feel. The campaign is called: Scleroderma. Hard Word. Harder Disease. (hardword.org)



Learn a little about scleroderma and its impact (Scleroderma.org and SclerodermaVideo.com).

Participate in awareness efforts! Share information with others. Be part of the [Thunderclap](#),

designed to create a wave of awareness on June 29th. These simple acts go a LONG way and they support our mission - to provide education and awareness, support patients, families and caregivers and to fund vital research so we can one day understand why no one has ever heard of scleroderma - **because together, we will finally stop the unstoppable.**



Mary Beth Bobik-Kadylak

Director of Patient Education & Support
Scleroderma Foundation, Tri-State Chapter