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NORTH AMERICAN AGENCIES PARTNER DURING NATIONAL SCLERODERMA AWARENESS MONTH TO GROW “KNOW” COMMUNITY

SAN FRANCISCO, BOSTON and HAMILTON, Ontario, JUNE 6, 2014—Some of North America’s leading scleroderma advocacy and research organizations today announced they are joining forces during June’s Scleroderma Awareness Month, with a social media campaign to compel more people to learn more about the little-known and often misunderstood disease.

The primary partners are Scleroderma Foundation, Scleroderma Research Foundation and Scleroderma Society of Canada.

The campaign is named “Hard word. Harder disease.” The theme touches on the complexity of the word and the gravity of scleroderma, a rare disease with no known cause or cure. It will run across partner Facebook and Twitter channels (#hardword) throughout the month of June, with visuals and copy that educate and challenge people to take a pledge to learn more. A microsite, sclerodermaaware.org, serves as the landing page for the pledge and general information about scleroderma with links to additional resources.

“Individually our foundations are working hard to raise awareness, provide support and critical funds for research,” said Amy Hewitt, executive director for the Scleroderma Research Foundation. “Collectively, in the United States and Canada, by uniting our voices and social media strategies, we stand to make an even greater impact.”

Scleroderma is a crippling autoimmune disorder characterized by a thickening and hardening of the skin that is so severe, it steals away the use of patients’ fingers, hands and limbs. As it advances across their bodies, the uncontrolled growth of fibrous tissue can damage patients’ hearts, lungs and other organs, often leading to a prolonged and painful death.

“Not only do scleroderma patients struggle with a disease, but they struggle with a disease that not many know about,” said Maureen Sauve, president of the Scleroderma Society of Canada. “Isolated and alone with scleroderma, many patients feel they suffer in silence. Together during this campaign, we hope to broaden our community.”

The campaign will leverage key opportunities throughout the month, notably World Scleroderma Day on June 29. The campaign also complements a digital billboard on 42nd Street in New York City that will run June 1 to July 15.

“Our strategy is to compel those who are not immediately impacted by scleroderma to

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relate to the disease, and therefore be more likely to empathize,” said Robert J. Riggs, chief executive officer for the Scleroderma Foundation. “To this end, the messaging will attempt to make an emotional connection with anyone who encounters it—particularly those who may know little or nothing about it.”

Scleroderma Foundation

The [Scleroderma Foundation](#) is the national organization for people with scleroderma, their families and friends. Headquartered in the metro Boston area in Danvers, Mass., the Foundation has a network of 23 chapters and 150 support groups committed to carrying out the three-fold mission of support, education and research. The Scleroderma Foundation is the largest nonprofit funder of peer-reviewed medical research, making available at least \$1 million per year in new research grants to find the cause, better treatments, and a cure for scleroderma.

Scleroderma Research Foundation

The [Scleroderma Research Foundation](#) (SRF) was established in 1987 by patient turned activist Sharon Monsky when research on this potentially life threatening illness was nearly nonexistent. Since our founding, we’ve stood firm in our belief that the best way to help scleroderma patients is to fund medical research aimed at improved therapies and a cure. Today, we are the nation’s largest nonprofit investor in scleroderma research. Patients and their loved ones find hope in the fact the SRF is dedicated exclusively to funding medical research that will help them live longer, fuller lives.

Scleroderma Society of Canada

The [Scleroderma Society of Canada](#) serves as an advocate nationally for those affected by the disease and works collaboratively with regional scleroderma organizations and the international scleroderma community to achieve common objectives. The Scleroderma Society of Canada is committed to promoting public awareness, supporting those affected by scleroderma and funding research to find a cure. Until then, we will work to improve the quality of life for those with scleroderma.

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