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Scleroderma walkers have reason to celebrate!

The Scleroderma Society of Ontario is now a New Registered Charity.

This year the walkers at the 7th Annual Scleroderma Society of Ontario (SSO) *Walk 'n Talk* really will have something to talk about. This will be the first event to take place under the auspices of their own newly received charitable designation.

The SSO was founded in 1985 to increase awareness, to advance patient wellness, and to support research into the causes and cure of this disease. It was The Arthritis Society (TAS) that provided the assistance and administrative support to enable the SSO volunteers to get started and grow over the years. With an increasing membership and the experience gained under TAS guidance, it was time in 2007 to begin the process of applying for charitable designation and to venture out as a new and separate organization. This process was finalized in April 2008.

“Ask ten people on the street what they know about Scleroderma and it would be surprising to get even one knowledgeable response,” says Maureen Sauvé, president of the Scleroderma Society of Ontario. Although considered a rare disease, there are more people in Canada living with Scleroderma than with Multiple Sclerosis. “This is why we must raise funds to increase awareness, and find a cure.”

Scleroderma is a connective tissue disease, auto-immune in nature and affecting the skin, the blood vessels, and frequently the major organs such as lungs, heart, kidneys, GI tract. It is frequently difficult to diagnose and often patients will suffer many symptoms before they get a definitive diagnosis. The most characteristic feature is the hidebound fibrosis, or thickening of the skin. Less visible but of major importance are the lesions that occur in small blood vessels (vascular lesions), which may involve major organs. The natural course of scleroderma varies widely. Forms of the disease that affect

primarily the skin without major organ involvement have a better long-term outlook. The form of scleroderma that involves major organs, such as the heart and kidney, is potentially more severe with possibly less desirable long-term outcomes. That is why for some individuals scleroderma is a nuisance which allows a fairly normal life with minor modifications, while for others the disease is life-threatening and may severely shorten the normal life span.

At present, although there is no known cure, patients can be optimistic that eventually one will be found. Much work is currently being done and even now some of the medications in use have been able to slow or control the progress of the disease enough to give patients more hope than ever.

But it all takes money – money for research, money for communication to increase awareness, money to provide resources with which to support patients. The money is raised through various events and activities throughout the province, including walks, barbeques, gala events, raffles, etc. It doesn't take money however to recruit and encourage the many people who volunteer within the SSO. Volunteers include patients, families, friends, and other interested supporters. The volunteers hold Board positions, conduct the Support Group meetings, liaise with key opinion leaders, and organize and run the various fundraising activities. At this time there is only one part-time administrative position within the SSO yet enough money has been raised to support several ongoing research projects which are trying to find the causes and cure of this dreaded disease.

Many cities and businesses throughout Ontario will support the organization by proclaiming **June as Scleroderma Awareness Month**, and this will be one more significant event for this young organization as it continues its journey.

The following are events that the Scleroderma Society of Ontario is hosting during June; Scleroderma Awareness Month:

- Walk in Memory of Kathryn Stillaway on Sunday June 1st, 2008
- Hamilton Walk 'n Talk for Scleroderma on Saturday June 7th, 2008
- Walk with Colby on Saturday June 21st, 2008

More information on Scleroderma and the Society's fundraising events can be found at www.sclerodermaontario.ca.