

Scler-Link

Support and Mentoring for Those with Scleroderma

Those of us living with scleroderma know how challenging the disease can be every day. For some, it took months or even years to get an accurate diagnosis and begin to identify and access appropriate medical care. Our families and friends don't always understand our needs and disabilities and scleroderma presents unique challenges to them as well. We've had to learn to accept the limitations the disease has put on us, and to build on the strengths we've gained through this acceptance. We believe we can help others, especially those newly diagnosed with scleroderma and those living with and caring for someone with the disease, by sharing our experiences and supporting one another.

The board of directors of the Scleroderma Foundation/Minnesota Chapter would like to build on this idea, and has outlined what we're calling **Scler-Link**. The idea is to offer individual peer assistance, especially with access to good information, services, and education. It's based on empathy, understanding, and support.

Scler-Link needs volunteers willing to be contacts for others – short term or ongoing, depending on each person's needs and wishes. It builds on individual and collective experiences and helps us affirm the successes of scleroderma patients by modeling independence, advocacy, and what we've learned about ourselves in the process.

Volunteers will be matched with others primarily through calls to the Foundation's hotline, referrals through medical professionals and clinics, and people we meet at special events. These matches may include whole families meeting one another. It could also involve case advocacy (guidance through doctor visits, for example, or assistance with insurance), or whatever any two matched individuals find helpful and important. Some volunteers may already be part of a support group and can help new folks get involved or start new groups.

Volunteers will receive an orientation and resource materials. We also plan to bring volunteers together periodically to share strategies, knowledge, and to identify areas of the state that could use a support group and more public education.

If you'd like to help others with scleroderma, aren't shy about meeting and connecting with new folks, are already involved in a support group or want to use **Scler-Link** as an opportunity to build a new group, we'd like to hear from you. Bobbi Larson has been handling the hotline since 19XX, and will coordinate this new **Scler-Link** project.

If you'd like to volunteer or be matched with someone, please return the form below to Bobbi or call her at 612-794-0347, or toll free at 877-794-0347. She'll match you with someone in your geographic area, someone with a scleroderma experience close to yours, or someone able to give you the help and support you'd like.

About 6,000 people in Minnesota have scleroderma. We're not great in number, but our needs are significant, and we have much to offer one another. We welcome your participation in **Scler-Link**, and your ideas to maximize the program's effectiveness.

Please return this form to Bobbi Larson, SFMC, 7400 Metro Boulevard, Suite 100, Edina MN 55439. You can also e-mail information requested to her at ntburda@aol.com. Someone will contact you as soon as possible.

[Please print]

Name _____

Address _____

Home phone (____) _____ Other daytime phone (____) _____

County of residence _____

E-mail _____

I'd like to be a Scler-Link volunteer mentor.

I'd like to be matched with a Scler-Link volunteer.

I'm interested in getting a support group started in my area; please call me.