

Scleroderma Foundation Social Media Guidelines

This document represents the official guidelines for social media at the Scleroderma Foundation. This guide applies to all Scleroderma Foundation employees, members, and/or individuals participating in and contributing to numerous blogs, social networking sites, or any other kind of social media both on and off www.scleroderma.org. We expect each and every individual who participates in social media on behalf of the Scleroderma Foundation to both understand and to follow these guidelines. An inability to do so will inevitably compromise one's future participation. As technology evolves, so too will the following guidelines, and so we advise that you routinely check back to ensure you are updated on the latest Scleroderma Foundation protocols for social media participants.

Participation & Etiquette

Social media is an evolving platform of interaction and communication that promises to alter the ways in which individuals relate to one another. Whether you are a Foundation member, staff person, volunteer or leader, you most likely have already begun using some form of social media and observing its effects. Indeed, social media can be used as a great tool to foster increased activism and collaboration within the organization and assist the Foundation in fulfilling its three-fold mission of support, education, and research.

With seemingly infinite social media outlets on hand, it is often easy to forget proper, reasonable etiquette and manners online. This is why the Foundation has developed the following *Principles of Etiquette* to ensure that both you and those you interact with have a positive experience.

Principles of Etiquette

- Write About Topics That You Are Familiar With. This rule of thumb can be applied to all online posts, not only those related to the Foundation.
- Always Provide Credit Where Credit Is Due. Whenever writing, make explicit your relation and background regarding the topic at hand. If you are writing about a topic that is related to the Foundation but you are not the spokesperson and/or authority on the issue, you should indicate this by posting the following quotation: "*The postings on this site/blog are based on my own personal thoughts and ideas and do not necessarily represent those of the Scleroderma Foundation or its respective affiliates.*"
- Write with (Mostly) Lowercase Letters. Avoid using all CAPS when typing your comments, as such characters suggest that you are shouting at others.
- Speak as Yourself. Always use "I" statements when stating your opinion or comments, (e.g. I believe that...). This prevents a great deal of misinterpretation.
- Be Humble. Suggestions, opinions and ideas can be useful conversation tools, but should never replace the advice and counsel of licensed medical personnel and other professionals.

- Practice A Good Volley. Whenever commenting in a social forum, be aware of the participation of others. Avoid dominating a conversation and instead invite individuals to comment or answer other's comments on your own.
- Refrain from Posting Spam. This is both a discourteous and offensive action towards your fellow social media participants and takes away from the discussion itself.
- Refrain from Using Inappropriate Language. Posting inappropriate comments and/or using foul, profane, or disrespectful language towards any party is strongly prohibited. The Foundation reserves the right to remove any and all persons and/or comments from any site that it classifies as offensive or disrespectful in nature.
- Be Truthful and Accurate. Accurate statements and truthful persons will ensure a healthy online experience for all.
- Think Before You Publish. Everything you publish online is your responsibility, so think and analyze all your responses before you publish them. If you are questioning something you are writing chances are others will, too.

For Board Members, Volunteer Leaders and Staff of the Foundation

As leaders and representatives of the Foundation, each of you is an ambassador that reflects the character of our organization. As such, you are held to a higher standard of conduct both in person and online. We ask that as ambassadors, you are all careful to present yourself in the best way possible, which can include but not be limited to:

- Using Proper Punctuation, Spelling, and Grammar. This lowers the chances of your words being misinterpreted.
- Speaking with Respect and Conducting Yourself in a Professional Manner. This includes stating your name and position with the Foundation.
- Stimulating Equitable, Friendly Conversation Within a Group. Knowing the precise answer is not as important as asking the right questions, or making the right suggestion. References can often be the most useful answer.
- Sharing Relevant Information Within a Group. This is important, as it ensures social media is being used as a practical tool not only for participants but also for the development of the Foundation's mission.
- Personal Business: As a representative of the Foundation, no solicitations for personal business or gain can be conducted.

Individual Accountability

All individuals will be held accountable for everything he/she writes in any online forum. Participation in social media outlets on behalf of or related to the Foundation is a privilege. Failure to abide by these guidelines could put your participation at risk. To ensure compliance with these guidelines, here are some helpful suggestions:

- Be Smart. At times, heated debates and/or rude comments will arise, and it is likely that you might be inclined to try and diffuse the situation alone. We advise that instead of posting any retaliatory or authoritative response, you contact a staff member of the Foundation's national office. Please include with your complaint the date, time, and name of the post(s) as well as any supplemental information

- you believe to be relevant to the situation and the Foundation will do its best to resolve the problem.
- Avoid the Hot-Button Issues. Topics regarding religion and politics are two examples of discussions that can often bring out heated and difficult debate. It is recommended that these topics and others of a similar nature be avoided to reduce the risk of offending others.
 - Own Up to Your Actions. Let's face it: nobody is perfect. We can all say things that can be misunderstood or worded incorrectly. When this happens, it's best to be honest, and publicly apologize to correct the situation.

Products, Trademark and Copyright Laws

Any and all products featured or posted online in relation to the Foundation are in no way endorsed by the Foundation. Any and all products must first receive approval through the national office by contacting Liz Dorsett at 1-800-722-HOPE ext. 42.

All brand, trademark, copyright, laws apply to social media and participants must adhere to these laws when engaging in social media. For questions, contact Robert Riggs, at 1-800-722-HOPE ext. 11.

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