



Social Media Policy

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For more information, contact
Christina Relacion, Communications Manager
(800) 722-4673, Ext. 243
CRelacion@scleroderma.org

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Social Media Introduction

Unlike traditional media such as newspapers or television, social media is a two-way communication between users and a brand. In the past, we have been accustomed to the one-way communication between a consumer and the brand. With social media, the consumer has been empowered by digital mediums to interact with a brand's message and communicate with other users who have similar interests.

Social media is a variety of online tools including blogs (Blogger, WordPress), social networking sites (Facebook, MySpace), video sharing (YouTube, Vimeo), photo sharing (Flickr, Picasa) and microblogging (Twitter). These tools are characterized by their real-time operations that run 24/7, are user-generated, and provide a transparent, inside look at an individual person or brand.

Scleroderma Foundation employees, volunteers and members are using social media to educate others about this devastating disease and raise money to help find a cure. Social media creates a network of individuals who support the Foundation's cause and serve as our brand ambassadors.

This Social Media Policy is intended to help you understand:

- How the Scleroderma Foundation uses social media to achieve its goal and mission.
- The value that the Foundation finds from social media engagement.
- Your role and responsibility as an employee, volunteer or community member who engages and interacts through social media on the organization's behalf.

This document is for the Foundation's employees, chapter and support group leaders and volunteers so you can develop a better understanding of how the Scleroderma Foundation is leveraging social networking sites.

These guidelines will evolve as the years go on, especially as the Foundation finds new ways to enhance its presence online and through social media to increase its presence and awareness for scleroderma.

Application of the Guidelines

The Scleroderma Foundation's Social media policy outlines the appropriate and acceptable manners of social media use and participation by Foundation employees, volunteers and members.

While this policy does not include a definitive list of social media tools and sites, it does include a broad scope of tools that support various means of interaction, communication and information sharing, such as:

- Blogs
- Microblogs (Twitter)
- Podcasts

- Message boards and community forums (Inspire)
- Streaming and online video (YouTube)
- Web sites
- Social networking sites (Facebook, MySpace)
- Professional networking sites (LinkedIn)
- Media sharing (Flickr, Picasa, wikis)

For this policy, the terms “use” or “publish” will mean online interaction and communication or information sharing by social media users through:

- Comments
- Ratings
- Messages
- Blog or Twitter posts
- Status updates.
- Photographs and video uploads.
- Audio files or podcasts.
- Presentations
- PDFs
- Any other document or file that is published, posted to, uploaded to, downloaded from or accessible via social media tools.

The Scleroderma Foundation adheres to strict guidelines for its intellectual property (such as our logos, trademarks and copyrights), disclosure/confidentiality, defamation, harassment and invasion of privacy. These guidelines in this policy do not constitute any type of legal counsel.

This Social Media Policy is to be used as a helpful resource for employees, volunteers and members. We do not accept liability or responsibility for any actions that are taken by individuals in response to or under any of these guidelines.

Scleroderma Foundation’s Social Media Presence

The Scleroderma Foundation’s National Office is involved in several social media programs and tools. They include:

- **Inspire.com Discussion Boards.** The Foundation hosts a discussion board for members through Inspire at www.inspire.com/inspire/group/scleroderma-foundation/. This is an outlet for members to discuss and ask questions about the disease through an open forum.
- **Facebook.** The Facebook Page is located at www.facebook.com/SclerodermaUS. This area is for employees, volunteers, members and non-members to discuss scleroderma openly. Foundation employees post links to recent news and events to help keep followers engaged and informed.

- **Firstgiving.** The Scleroderma Foundation uses Firstgiving to allow employees, volunteers and members to set up personal, online fundraising pages at www.firstgiving.com/scl-national (for the National Office), www.firstgiving.com/scleroderma-striders (for run/walk events) and www.firstgiving.com/sclerodermafoundation (for Cooking Up A Storm events). Several chapters and support groups also use the site to promote third party events and online philanthropic giving during the year.
- **Twitter.** The official Twitter account is [@scleroderma](https://twitter.com/scleroderma). Foundation employees post news and other information on behalf of the organization through this tool. Several chapters and support groups operate their own Twitter accounts.
- **Flickr.** The Scleroderma Foundation posts photos from events such as “Stepping Out To Cure Scleroderma” walk/runs at www.flickr.com/photos/sclerodermaus/. We also invite the public to post their photos in our various groups so we could potentially use them in future publications or marketing campaigns. Several chapters and support groups operate their own photo-sharing accounts through Flickr, Picasa or other online tools.
- **YouTube.** The Foundation posts a variety of video content at www.youtube.com/sclerodermaus. Several chapters and support groups operate their own YouTube accounts.

Engagement – Using Social Media to Communicate

a. *Know Your Audience*

Develop a clear understanding of the audience who interacts with the Scleroderma Foundation online. When you know your audience, you can create content that is beneficial to those users, as well as identify the proper social media outlets in which to reach them. Your goal is to create content that your audience finds interesting, useful and beneficial. Your focus should be on creating content that users will want to share with others. You should avoid solely selling your audience products, services and events that the Foundation offers.

b. *Write What You Know*

Everyone has his or her own certain amount of expertise or wisdom that we have accumulated through the years. Our interactions, conversations and comments on social media sites should always reflect our areas of expertise. Most importantly, you should stick to what you know and discuss or post information on topics within your area of expertise. If you choose to discuss a topic, which you are not a content expert, make it clear to your readers that you are not an expert, and that your information is opinion, instead of fact. If possible, guide your readers by posting links to a content expert in that specific area.

c. *Contribute Value*

When you want people to engage with your community online and share your information with others in their online communities, it is essential that you write things that interest and deliver value to your followers. The information that you

post should entice them to share your thoughts with others, as well as welcome their own feedback on the information on which you post. Information should be stimulating and build a community that thrives on dynamic conversations. Social media, unlike traditional media outlets, is a two-way street. Your content should enable online users to learn more about a topic, make wise decisions and feel comfortable with a dialogue with your online community. The Foundation does not allow promotion of other Web sites on social media sites including advertisements, for sale/for rent posts, links or blatant promotion. Repeated or excessive posting of the same URL to social media sites also is not permitted. Self-promotion of websites is not permitted.

d. *Be Conversational*

Social media is a personal communication platform. As such, it should reflect the personalities of the people behind the computers or mobile devices who are creating and sharing content. Write your content as if you're having a conversation. If your language is too formal, you could miss an important opportunity to engage in dynamic and passionate dialogue with your community. Don't be afraid to bring your own personality into the mix. Social media is not a boardroom or a formal business report. It is a great resource to widen the conversation about serious and complicated topics such as scleroderma. Also, remember in your posts to cite similar bloggers or social media users who also are the content experts of the area in which you are posting information. When you include these citations or resources, your posts and content are more likely to be shared through different online communities.

e. *Avoid Starting Fires*

Many social media users are very passionate about the causes that he or she follows. It's a good practice to invite differing points of view without inciting others. There is a fine line between a healthy debate and harsh reaction. It is not necessary, and sometimes impossible, to respond to every criticism in social media communities. Still, you want to listen and monitor the conversation at all times. This doesn't mean that you should not address issues that arise. However, if you are constantly in debate with your followers, it can appear that you are being defensive.

Sensitive topics are everywhere online. It's important to be cautious and considerate of other opinions and reactions. Once a response is posted on the Web, it is there forever. Many times, that reaction will be shared with others. It is advised to err on the side of caution and keep potentially inflammatory discussions harnessed, because once the information is shared online, it can spread rapidly.

A good tool to use is the "Social Media Triage Chart¹" to check what your course of action should be for positive and negative feedback, as well as comments that fall into a Breach of Policy for the Scleroderma Foundation. The chart is available for Foundation employees and chapter/support group leaders.

f. *Wait a Few Seconds*

There are times you will second-guess a status message, Tweet or blog post. If you feel any bit unsure, trust the voice of reason inside of you. Take a minute to reread what you wrote and think through any potential ramifications that could occur. If in doubt, run it by a coworker or a friend to gauge his or her reaction to your comments. In the end, each of us who uses social media is responsible and accountable for our thoughts, actions, words and opinions that appear online.

g. *Take Ownership. Be Transparent.*

Everyone makes mistakes. If you make a mistake, a best practice is to admit your mistake quickly, correct it and move on. If you have provided the wrong information, go back and give the correct information. If you are correcting a blog post by modifying content, let your readers know that you have done this. Many bloggers strike through content that is incorrect and place the updated content next to it. Others label new content as "Update."

Do not use social media anonymously. Avoid using pseudonyms or false screen names in Scleroderma Foundation communities. We believe in transparency and honesty. Use your real name and be clear who you are. If you work for the Foundation, identify yourself as an employee or volunteer. Do not say things that are dishonest, untrue or misleading. If you have a stake in a topic you are discussing, point it out. However, remember to be smart about protecting yourself and your privacy. The things that you publish online will be around for a long time. Consider the content that you post carefully, and be cautious about disclosing any personal details with individuals that you do not know personally.

Participation – Know the Rules of Social Media

In general, what you publish on social media sites is widely available to the public and may be archived indefinitely (the Library of Congress started archiving all Tweets in 2010²), kept by others, or reposted and shared with others without asking for your permission.

Because your words and actions reflect not only on you but also on the Scleroderma Foundation, please be thoughtful and conscientious with the content you publish. Foundation employees, leaders and volunteers are obliged to uphold our social media policies and err on the side of transparency and disclosure.

a. *The Three Rs: Representation, Responsibility and Respect*

- i. *Representation.* Certain employees, leaders and volunteers of the Scleroderma Foundation have been authorized to represent the Foundation in social media forums. This includes "Tweeting," posting comments to articles and blog posts, and posting "likes" on Facebook.

If you represent the Foundation online, you must disclose your connection to the Foundation (National, Chapter, Support Group, member, etc.) Only

public information should be shared in online communities. You should not discuss planning programs, marketing or public relations initiatives, financial data or other news, unless it is already in the public domain. Please consult with the Communications Manager at the National Office if you are unsure what information you are able to disclose.

If you express a personal point of view when discussing the Scleroderma Foundation, it must clearly state that your comments or posts are your opinions and do not necessarily reflect the official policies or position of the Foundation.

- ii. *Responsibility and Respect.* As a Scleroderma Foundation employee, leader, volunteer or member, you have a responsibility to ensure that the information, materials and resources you publish are factually accurate, clear, topical and relevant. You should also be aware of these other social networking responsibilities:
 - Do not knowingly publish content that is untrue, misleading or deceptive. Take any responsible steps necessary to ensure that the information you publish on social media sites is current, accurate, complete and relevant.
 - Answer questions and provide comments and opinions only in those areas in which you are a content expert. If you are asked to comment on an unfamiliar situation or topic, refer the question to a subject matter expert elsewhere in the National Office, or your nearest chapter or support group.
 - Post only information or content that is socially acceptable and reflects well on the organization. Material should not be offensive, harassing by nature, defamatory, obscene, discriminatory or otherwise in poor taste.
 - Disclose only information that is yours to share, or that is part of the public domain. Excerpts of information created by others can be shared only with the proper credit and attribution. In addition, it's critical that you not share information about your employees, associates, competitors and vendors.
 - You should be polite and respectful of other opinions, even if you do not agree with them.

b. ***Creating Social Media Content***

You should avoid publishing any of the following types of information in any social media outlet, including those owned by or affiliated with the Scleroderma Foundation:

- Photographs, graphics, music, videos, artwork, written expressions of ideas or any other copyrighted materials in their entirety, without the advanced

permission of the author/creator/owner of such materials, regardless of whether or not they are explicitly marked as “copyrighted.” To the extent you use such material, use as little of it as possible and cite the original source.

- Trademarks, without the advanced permission of the trademark owner. This includes the use of Scleroderma Foundation trademarks and logos, regardless of whether they are explicitly marked as “registered.”
- Personal, private or confidential information or content about other companies, organizations, groups or individuals.
- Confidential Scleroderma Foundation information such as membership information, customer lists/data, company data, partner and/or supplier data, financial information, e-mail communications and other information that isn’t generally available to the public.

The Scleroderma Foundation reserves the right in its sole and absolute discretion to decide how, where, when and to what extent you may use and disseminate its intellectual property through social media (regardless of whether the social media property is sponsored by, or otherwise affiliated with the Scleroderma Foundation).

c. ***Brand Consistency***

The Scleroderma Foundation’s [“Logo Guidelines”](#)³ were developed to maintain the integrity and the voice of the Foundation’s brand. As a Scleroderma Foundation employee, leader or volunteer, it is your responsibility to make certain that your chapter or support group protects and upholds the Foundation’s brand by complying with these guidelines.

Given the number of Scleroderma Foundation communities, and the level of autonomy with which they operate, it is paramount to communicate with a look, feel and voice that is consistent across the organization and indicative of the high quality standards of the Foundation. This includes, but is not limited to:

- Web sites.
- Blogs and other social media properties (such as avatars, hashtags, etc.)
- Press releases, publications, white papers, research studies and reports.
- Podcasts, videos and other branded content.

d. ***User-Generated Content***

When develop your own content such as videos or podcasts, be aware that:

- The official Scleroderma Foundation logo should be used in all videos, podcasts and other materials that are developed on behalf of the Foundation.
- The Scleroderma Foundation has the right to require removal of any user-generated content that is deemed inappropriate or improper, or if it fails to meet the Foundation’s branding and style guidelines.

e. ***Personal Use of Social Media***

First, make sure that your use of social media tools does not interfere with your job or your commitments to your programs. Personal use of social media unrelated to the Scleroderma Foundation is done at the individual's discretion. Please keep the following in mind when you conduct personal use of social media unrelated to the Foundation:

- If you publish anything related to the Scleroderma Foundation, you should clearly state that you are an employee, leader, volunteer or member. You should also make it clear that the views you express are your own, and not necessarily those of the Foundation.
- You should not use your Scleroderma Foundation e-mail or other Foundation contact information for registration or other purposes without prior written approval by the National Office. The Foundation may track anything posted, viewed, or otherwise distributed using Foundation computing equipment or networks.
- You should not register social media usernames that include "Scleroderma Foundation" or other Foundation taglines.
- The Foundation monitors social media outlets daily to gauge the conversations taking place, which may include those initiated or commented on by you.
- If, and to the extent that, any personal social media activity reflects upon the Scleroderma Foundation in a manner inconsistent with the spirit and letter of this policy, the Foundation reserves the right to take action.
- You are solely responsible for personal social media and Web postings found to be defamatory, harassing, an invasion of privacy or in violation of any other applicable federal or state law.

It is perfectly OK to talk about your work and have a dialogue with social networks and communities. However, it's not OK to publish confidential information such as details for unfinished projects, financial information or personal information about Scleroderma Foundation members. It is also dangerous and ill-advised to use your Facebook profile and other social media outlets to denigrate or criticize the Scleroderma Foundation, its community members, other companies or organizations, and your co-workers.

f. ***Legal Compliance***

Anything you publish in any social media outlet, including those owned by or affiliated with the Scleroderma Foundation, should comply with this policy, and all local, state and federal laws and regulations. Some of the most notable and relevant laws and regulations include:

- Copyright laws restricting use of photographs, and graphics created or owned by others without receiving the appropriate permissions.
- Trademark laws restricting when and how a third party's trademark(s) can be used without permission.

- Privacy laws restricting use and sharing of certain non-public or personal information about others.
- Defamation laws precluding reputational damage to others.
- Laws prohibiting statements that are obscene, discriminatory, threatening, harassing, false or misleading.

Specific Guidelines for Chapters and Support Groups

The following specific guidelines apply to Scleroderma Foundation chapters and support group social media and online communities:

General

- All Scleroderma Foundation social media communities should adopt and follow the Foundation’s Social Media Policy.
- Chapter and support group leaders are responsible for sharing the Social Media Policy with their members, making it available for download and enforcing its provisions.
- Any potential legal issues should be shared with the Foundation’s CEO, Director of Development and Research, and the Communications Manager, as soon as they become known.
- Scleroderma Foundation communities should not establish social media accounts, log-in names, handles, hashtags or other means of branded identification that could be misinterpreted as the Foundation’s National Office. Care should be taken that branded identifications does not duplicate or conflict with any other of the Foundation’s social media presence.
- The National Office will, from time-to-time, audit the social media properties of chapters and support groups to ensure they comply with the Social Media Policy. Examples of non-compliance will be brought to the attention of leaders and a timetable will be established for providing a remedy for unresolved issues.

Accounts

- Personal accounts being used publicly on behalf of the Scleroderma Foundation should be deleted. A new account specifically for the Foundation’s community should be created following the Social Media Policy.
- Each social media account should have multiple managers or administrators who are currently engaged members of the community. This helps monitor the conversation but it also helps in the event that someone would leave the organization.

Use of the Foundation’s Logo

Adhere to the Scleroderma Foundation’s “Logo Guidelines” when using the logo in any medium. Remember the following:

- Do not alter or distort the logo.
- Use only approved Foundation colors.
- Do not add images, text or other graphics to the logo.

Social Media Tips

The following tips are not mandatory, but will help you be successful at social media:

- Be proper. Use the correct spelling, punctuation and grammar. It lowers the chance of your words being misinterpreted. Also, avoid using all CAPS. You come across as if you are yelling at the digital world.
- Think before you publish. Analyze your responses before you hit the “publish” button. If you question something you are writing, chances are others will, too.
- Avoid dominating the conversation. Be aware that others should be participating in social media, as well. Instead, invite others to comment.

References

1. The Scleroderma Foundation’s “Social Media Triage Chart” is based on an infographic created by ASCE that is posted at www.socialfish.org/wp-content/uploads/2010/11/ASCE_triage.pdf.jpg in November 2010.
2. “Twitter Donates Entire Tweet Archive to Library of Congress,” <http://www.loc.gov/today/pr/2010/10-081.html>, April 15, 2010.
3. The Scleroderma Foundation’s [“Logo Guidelines”](#) are available by request from the Communications Manager at the National Office.

Additional Resources

1. 50 Social Media Tactics for Non-Profits: <http://www.slideshare.net/chadnorman/50-social-media-tactics-to-help-nonprofits-meet-their-mission?from=ss>
2. 14 Free eBooks on Social Media: <http://www.ivanwalsh.com/social-media-strategy/14-more-free-ebooks-on-social-media/4730/>
3. Creative Commons: Information on media sharing and links to content that can be reused or redistributed. <http://creativecommons.org/>
4. HootSuite: Social media dashboard to manage your Twitter, Facebook and other accounts in one convenient place. <http://www.hootsuite.com/>
5. Common Craft: Twitter in Plain English. Short videos that answer your questions to new technology. <http://www.commoncraft.com/twitter>
6. Mashable: All things technology, Web and social media. <http://mashable.com/>

About Scleroderma

Scleroderma is a chronic, often progressive, autoimmune disease in which the immune system attacks its own body.

Scleroderma, which literally means “hard skin,” can cause a thickening and tightening of the skin. In some cases, it causes serious damage to internal organs including the lungs, heart, kidneys, esophagus and gastrointestinal tract. As scarring, or sclerosis, of these organs and organ systems progress, they work less effectively, and can lead to organ failure and death.

Some medications and treatments can help with certain symptoms, but there is still no cure for scleroderma, which affects about 300,000 nationwide. (By way of comparison, about the same number of people are affected by multiple sclerosis.)

About the Scleroderma Foundation

The Danvers, Mass. based Scleroderma Foundation is a 501(c)(3) non-profit organization dedicated to serving the interests of people with scleroderma. It has a network of 22 chapters and 145 support groups nationwide carry out its threefold mission of support, education and research. The Scleroderma Foundation funds an average of \$1 million in new grants each year to find the cause and cure for scleroderma.

For more information about the Scleroderma Foundation, visit www.scleroderma.org or call (800) 722-HOPE (4673).

For more information, contact:

Christina Relacion, Communications Manager
(800) 722-4673, Ext. 243

CRelacion@scleroderma.org