



Rules of the TS Alliance Online Community

Please note: It is impossible for the TS Alliance or OCA to review every message posted. The postings express the views of the author of the message, and not necessarily the views of the TS Alliance. The TS Alliance does not actively monitor or screen and is not responsible for all of the messages and responses posted on the listservs. We do not guarantee the accuracy, comprehensiveness or usefulness of any message. If you find a posted message objectionable, you are encouraged to immediately contact the TS Alliance at (800) 225-6872, the OCA Leadership Team, Discussion Support Team (DST) members and/or the Technical Working Group (please see below for contact information).

Message Rules

1. You remain solely responsible for the content of your messages, and you agree to indemnify and hold harmless the TS Alliance with respect to any claim related to or arising from transmission of your message(s). We also reserve the right to reveal your identity in the event of an informal or formal complaint or legal action arising from any message posted by you.
2. By subscribing to this service, you agree not to post any messages or responses that are false, inaccurate, abusive, offensive, obscene, sexually oriented, threatening or invasive of a person's privacy or otherwise against any law. Further, you agree not to post any copyrighted material unless you are the owner of the copyright.
3. Messages that overtly advocate for a political point of view that is not directly related to tuberous sclerosis complex or that is potentially divisive should not be posted.
4. Please note that solicitations, advertisements, chain letters, polls, surveys, and other material unrelated to the purposes of these listservs are inappropriate and should not be posted here.
5. It is never permitted to provide or submit anything that could be construed as the giving of medical advice to other members. Such advice can and should only be obtained from medical professionals and physicians.
6. It is neither legal nor permissible to request to share medications or to offer to share medications on the email listservs. For more information and guidance on how to legally obtain medications such as Vigabatrin, please contact the TS Alliance at (800) 225-6872 or info@tsalliance.org.
7. By subscribing to the OCA listservs, you agree to not use the medium to submit fraudulent or falsified information of any kind, impersonate any other person or entity, and/or misrepresent a connection or affiliation with any other person or entity. The TS Alliance reserves the right to pursue all appropriate actions regarding this practice.

The TS Alliance reserves the right to remove anyone from the listservs who does not follow the above rules. To assist you, please review the following

tips for understanding and adhering to the above rules listed below the following netiquette items.

Netiquette

The successful and smooth operation of listservs requires some degree of lubrication through social norms. For the most part, these norms are obvious modification of normal social norms to the online world. However, the special nature of mailing lists requires some special considerations. To help the OCA to support the mission of the TS Alliance, we respectfully ask for your cooperation in the use of netiquette.

Always remember that many other people will see anything you write. The listservs currently include several hundred subscribers. This means:

- You should consider how anything you write might be taken by many people you do not know and who may differ in view and outlook from you.
- Every message you write has to be read and dealt with by many others who all have many other responsibilities.
- From time to time there are posts that have little to do with tuberous sclerosis complex, the TS Alliance will not normally restrict limited exchanges of information of interest to our members but reserves the right to do so in the event such messages take up a significant volume of the listserv or other resources.

Please help by following these appropriate netiquette methods, which are also intended to make your message as effective as possible:

1. **Make sure your subject line is informative.** The list often sees missing subject lines, or subject lines that have little to do with the mail content. If you are replying to someone else's message, please check if the subject line still makes sense, or needs to be changed.
2. **Please "trim" quoted text.** When you respond to someone, don't automatically include the full text of the message you are responding to. Delete it if possible, or merely leave a line or two of their message for context. Consider using reply prefixes. In this style, the portion of the message you are replying to is prefixed, generally with a ">" character. This makes it easy to "have a conversation" with the original message, rather than forcing the reader to scroll down to find the context for your message. At least please try to trim the text and items at the end inserted by the listserv and any email service the original poster used. Not only does the extra text make it harder for readers of your message to know what you are responding to, it also makes it more expensive for the TS Alliance, which generously funds the archives.
3. **Feel free to reply privately.** Often, posts are to the effect of "good point" or "congratulations" or "prayers are being sent your way." While these messages do create a feeling of community, it may be more appropriate to send them directly to the person you are responding to, rather than to the entire group.
4. **Please don't write messages that are in ALL CAPS.** It is generally frowned upon because it is hard to read and feels like "shouting" to many people. If you have trouble using the Shift key, an all lower case message is easier to read and more polite than an all upper case message, but a normal mixed case message is preferable.

5. **For the sake of your privacy and online safety, please try to avoid posting your personal contact information (phone number, address) directly into list e-mails.** The messages go into the archives and can then be accessed by the general public. Personal contact information is better shared in private e-mail.
6. **Please avoid copying/pasting the full contents of web pages to listserv messages.** If a web page appears to have direct benefit for those affected by TSC and its content does not risk violation OCA message rules, an Internet link to the page can be posted in the body of a message. There may be exceptions to this request; when in doubt, please inquire of your Discussion Support Team.
7. **It's important to remember that the online community consists of subscribers of many creeds and orientations, and they will have varied personal beliefs.** Please respectfully try to ensure that your messages will not offend someone who might not share your personal religious beliefs.

Clarification of this tip: It is acceptable to send requests for prayers or state that you will pray for someone if that is your way of needing or offering support. It would also be acceptable to write about how your faith and your experience with TSC have interacted. But sending general messages about a specific faith (for example, "Have faith in Jesus; He can pull you through this...") may offend or cause discomfort to someone who does not share that faith. Messages that judge, condemn, or seek to convert (for example, "You will be judged by God if you take this action..." or "If you accept Mohammed as your prophet, you will find the strength to survive this...") are not appropriate.

Tips: How to Follow the Rules

Generally speaking, the rules are easy to understand and are usually followed. Certain issues, however, come up from time to time. This section describes those situations and gives some do's and don'ts.

1. Medically Oriented Messages

One of the main purposes of the forums is to share helpful information; the line between helpful advice and impermissible information may not always be obvious.

You are on the right side of the line if you refer to what actually happened to you or your child. You are on the right side of the line if you refer to publicly available information (such as medical literature, drug labels, publications of the TS Alliance or other organizations, etc.). You may be on the right side of the line if you pass on information that you heard from someone else (such as your doctor, someone you heard at a conference, etc.), as long as you make it clear who and when you heard the information, and do not make further claims about its applicability to any other situation. Always remember that you are not a medical professional and may well be making a mistake in interpretation.

You will be on the wrong side of the line if you make categorical statements about what one should or should not do in a certain situation and will certainly be on the wrong side if you tell someone else what drugs they

should or should not be using. When in doubt, it may be helpful to include a disclaimer along the lines of "I am not a medical professional and am not giving medical advice. Please check any and all information with your doctor or another trusted medical professional."

For instance, the following statement would be permissible: "Many TSC experts believe that vigabatrin is the most appropriate first line therapy for infantile spasms in TSC, despite the risk of visual field defects. The following, however, would not be permissible: "All children with infantile spasms in TSC must be treated with vigabatrin."

Something that understandably often happens is over generalization from your or your child's particular experience. We are all experts in a limited area, and it is easy to assume that everyone's experience will be like ours. We need to remember, however, that TSC manifests itself differently in different people, drugs work differently in different people, etc., so our experience, while very valuable to share, is only completely valid for ourselves or our children.

For instance, if you have had great success with a particular drug, it is tempting to say, for example, "Lamictal is a wonderful drug for seizures in tuberous sclerosis. It stops them right away." What should be said, however (unless you have a reference to a journal article or medical expert who supports the claim), is "my child has done really well on Lamictal. It stopped his seizures right away." Likewise, we should not say, "Such and such does not work in tuberous sclerosis complex" and rather say, "here is my horrible experience with such and such."

Something that comes up from time to time is the making of requests to share medications. This happens most often for Vigabatrin, which is not licensed to market in the United States. It is neither legal nor a good idea to share medications. If you wish to ask for help in legally obtaining Vigabatrin or any other medication, it is certainly allowed to do so on the list. It is never permissible, however, to ask for or offer to share medications on the list.

2. Other Considerations

Members are requested to respect the fact that this is a community. People have come together online in these groups because the members share the common need to connect with others who want to improve the lives of those affected by TSC. As within any community, however, individuals will have a variety of personal beliefs and philosophies.

3. Politically Oriented Posting

While it might be acceptable for a writer to post about very direct efforts of this community's effort to lobby Congress for support for TSC, it would not be acceptable for a writer to post about political efforts which are unrelated to direct advocacy for TSC.

Online Rules Summary

You may never post any message to the list that violates these policies. If you wish, at any point, to provide ideas, help, or advice that violates the rules of this list, you must do so off-list (i.e., as a private message directly to a list member).

The Leadership Team has the responsibility of determining whether posts have met the terms of these rules. People who violate these rules can be removed from the list.

Minor or inadvertent violations will usually be first warned privately and may, at that point, be required to have postings reviewed by a list manager.

If you notice a posting that seems in violation of these rules, or has some other feature that disturbs you, it is better to write to the OCA Leadership Team members or to the Technical Working Group than to post a complaint to the list. Be assured that we will work to resolve the problem as quickly as possible; contacting us directly prevents an out-of-control situation and avoids hard feelings on the list itself.

In addition, you may always write a private email off-list.

Full Mailboxes and Other E-mail Failures

From time to time, especially if you are using free mail services such as Yahoo, AOL and Hotmail, you may experience full mailboxes. At that time, all messages sent to the list will not be able to reach you, and "bounce" messages indicating that failure will be sent to all of the technical working group members. This means that one full mailbox can generate 20-30 messages a day to each technical working group member. Needless to say, we don't like to see this happen. This can happen for other mailbox failures as well.

What we will do in such a situation is change your subscription to "digest" format. In this format, you will see only one email a day, containing all of the messages for the group for that day. If this happens to you, feel free to change your options back after you clean up your mailbox or fix whatever other problems might exist.

If the problem exists for a long time, we will delete your account. In this case, you need only re-subscribe when you fix the problem.