

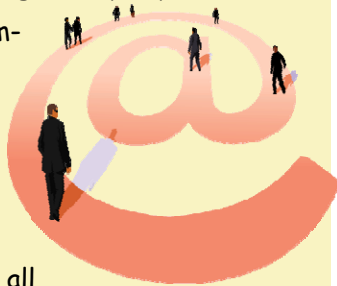
Introduction

The Life Raft Group developed from a small group of patients and caregivers sharing experiences and information related to a common disease (gastrointestinal Stromal tumor, GIST) and a clinical trial (STI571) via an email community. Since its inception, it has expanded dramatically and now offers many additional services which can be explored on the LRG website at www.liferaftgroup.org. This pamphlet is focused on the email community.

An email community takes a single message sent from one person and sends it to all of the people that have joined the group.

You are not required to be a part of the email group in order to be a member of the LRG. You can continue to receive other emails, such as newsletters and webcast announcements.

The LRG maintains a private community in order to protect the confidentiality of our members. Only patients and caregivers are in the group. Doctors and other professionals cannot join unless they are GIST patients themselves. This allows our members to discuss any topic they wish, including doctors and medical facilities.



Publications & Resources

Copies may be requested by contacting the Life Raft Group office or through the website.

GIST Pamphlet

(Also available in Spanish & Hebrew)

GIST Specialist Directory

Newsletters

Pediatric GIST Pamphlet

(Also available in Spanish)

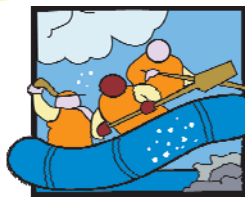
Navigating GIST Clinical Trials

Annual Report



Donate to the LRG

The Life Raft Group depends on the generous donations of its members and other supporters. Membership is free. Without the support of kind donors the LRG would be unable to provide the lifesaving services described in this pamphlet. Thank you.



The Life Raft Group

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The Life Raft Group

Email Community Frequently Asked Questions

The LRG email community connects patients and caregivers around the world to each other, providing a unique support system for people affected by a rare disease, GIST.



*Ensuring that no one has
to face GIST alone.*

Email Community Frequently Asked Questions

How do I send a message to the community?

To send a message to everyone in the email community, simply send an email to

STI571-GIST@listserv.acor.org. Please note that all emails are converted into plain text formatting. This means that pictures and fancy fonts will not be seen. In order to protect against viruses, attachments are not permitted.



How do I search the archives?

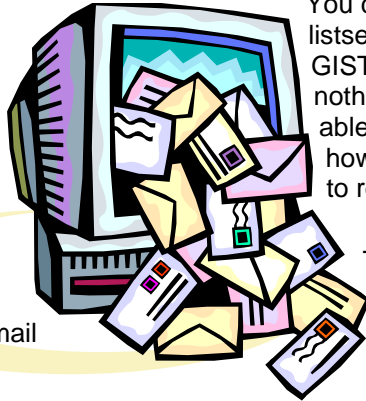
To look at old posts in the archives, go to <http://listserv.acor.org/archives/STI571-GIST.html>. The first time you visit the site you will be asked to create a password. The archives are a great place to look for answers to questions you may have. Searching here first may give you an answer faster than posting your question and waiting for responses. The address for the archives is listed at the bottom of each email.

Is there a way to reduce the volume of emails I receive?

There are two ways to participate in the email community.

Traditional: Each post to the group arrives in your inbox as a separate email.

Digest: All of the posts for a day are collected and sent to you in a single email for just that day.



Many of our members have chosen to get a separate email account from a company like Gmail or Yahoo for only their community emails. Another option for dealing with email volume is to set up a folder in your email and use an automatic filter to sort the emails into the folder as they arrive.

If you would like to change how you receive postings, you may email us at liferaft@liferaftgroup.org or

send a plain text email to listserv@listserv.acor.org with one of the following commands as the text and nothing in the subject field:

For Traditional: SET STI571-GIST NODIGEST

For Digest: SET STI571-GIST DIGEST

How do I change my email address?

To change your address, please email us at liferaft@liferaftgroup.org.

How do I temporarily stop delivery of posts?

If you are going to be away from your computer for a while, we can suspend email delivery for you so that it doesn't fill up your inbox. Just send us an email at liferaft@liferaftgroup.org. When you are ready to have emails delivered again, just send another email to us.

You can also send a plain text email to listserv@listserv.acor.org with SET STI571-GIST NOMAIL as the message text and nothing in the subject field. You will still be able to access the archives and post, however you will need to look in the archives to read any responses to your post.

To turn delivery back on send a plain text email specifying your preferred delivery format as described in the section on reducing email volume.

How do I cancel my subscription?

You may send an email in plain text format to: listserv@listserv.acor.org with SIGNOFF STI571-GIST as the text of the email and nothing in the subject field. Note that once you unsubscribe from the community, a moderator must sign you back on. Also, you can choose to email a request to be removed from the email community directly to us.

Please send any of these requests to liferaft@liferaftgroup.org.

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Who should I contact if I need help?

If you need help, you can email us at liferaft@liferaftgroup.org or call our office at (973) 837-9092.



Email community etiquette

As with any community, there are certain social protocols to follow.

When using your reply button, delete unnecessary text. This is important so that everyone does not receive multiple copies of the same email. When this is not done, the digest emails get very lengthy with repeated text. It also uses a significant amount of storage space, which may fill up member's inboxes regardless of the format they receive posts in.

Change the subject of the message when you change the topic of conversation. This makes it easier to follow a topic. Topic specific subjects also make it easier to search the archives.

If you are sending a personal note to a member of the community, consider sending it to them individually. This will help reduce the volume of emails members receive.

Religion and politics never fail to be volatile subjects. Please be sensitive to this. Practice a little extra kindness in this community. If something is posted that you find upsetting, take a step back and a deep breath. Remember that typed words don't always sound the way they were meant.

