The mission of the Life Raft Group is to ensure the survival of GIST patients through a comprehensive approach connecting individual patients' needs, the worldwide community of GIST advocates, and the global health and research environment. The Life Raft Group focuses on three key areas: research, patient support & education, and advocacy.

Membership Application

All information provided will be kept strictly confidential and is for the Life Raft Group only. We are committed to protecting the privacy of our members. Any data or information that we share in any way is always cleansed of identifying information to protect confidentiality. The Life Raft Group has been approved by the Institutional Review Board (IRB), which enforces that all human subject research conducted is in accordance with all federal, institutional, and ethical guidelines.

Please fill out this form to the best of your knowledge and check the appropriate options.

You may mail or fax this form to our office at:

The Life Raft Group
155 US Highway 46
Ste. 202, Wayne Plaza II
Wayne, NJ 07470
Fax to: (973) 837-9095
E-mail to: liferaft@liferaftgroup.org

***If you have any immediate needs or questions please call us at 973-837-9092 (9a.m.-5p.m. ET)**

I am a:

○ GIST Patient ○ Family / Caregiver / Friend of a GIST Patient ○ Other _____

I am interested in:

☐ Newsletter ☐ Patient Registry ☐ Fundraising Activities
☐ Volunteering ☐ Tissue Bank ☐ GIST Expert Patient Training
☐ Listserv Email Community ☐ Local Support Groups ☐ Virtual GIST Tumor Review Board

How did you hear about us? ☐ LRG Member ☐ Internet ☐ Doctor ☐ Other _____

Contact information:

Full Name: _____

Patient's Name (if different): _____

The Patient is my: _____

Home Address: ○ Self ○ Patient

House #, Apt #, Building, Street _____

City _____ State _____ Zip _____ Country _____

Home Phone: (_____) _____ Mobile: (_____) _____ Fax: (_____) _____

Primary Email: _____

Secondary Email: _____

Additional Patient Information *(We use this information for better research)*

Date of birth: _____

Birthplace: (Country):_____

Race: ☐Alaskan Native ☐Black, not of Hispanic origin

☐American Indian ☐Black, of Hispanic origin

☐Arab ☐ Hispanic

☐Asian or Pacific Islander ☐White, not of Hispanic origin

Marital Status: ☐Single ☐Married ☐Domestic Partnership ☐Divorced ☐Widowed ☐Separated

Gender: ☐Male ☐Female

Comments and Notes

Please tell us something about yourself or the patient professionally and/or personally. Include any special skills or interests.

_____

_____

_____

Other General Remarks or Questions

_____

_____

_____

Patient Registry Options

We utilize the data from this registry to identify critical areas that require further investigation in the GIST research environment or by the traditional cancer research community, we de-identify your personal info to comply with HIPAA (Health Insurance Portability and Accountability Act).

Would you like to participate in the Patient Registry?

○ Yes *(please continue filling out the form)* ○No, contact me later *(submit only up to here)*

*Complete the rest of the application below **after you have read and signed the Information and Consent Form (IRB)**. Please provide answers to the best of your knowledge. If you cannot answer any question completely, leave it blank and an LRG Patient Registry staff member will contact you to follow up.*

MEDICAL HISTORY

DIAGNOSIS DETAILS:

GIST Diagnosis Date: m___/d____/y____

Were you misdiagnosed with another type of cancer that was later diagnosed as GIST? ☐Yes ☐ No

If yes, when? m___/d____/y____ What was the misdiagnosis? _____

How did you find out you have GIST? *(Please provide details of symptoms, events, evaluations leading to GIST diagnosis)*

_____

_____

Please tell us if you have any pre-existing conditions *(i.e. diabetes, heart problems, blood pressure, other cancer diagnosis, self or family history of cancer, etc.)*

_____

_____

Primary Tumor *(Original, or first, tumor found in the body)*

Did you have? ☐ Single tumor ☐ Multiple tumors_____

Tumor location/site in the body: _____ Mitotic rate: _____ /_____hpf

General size and/or exact measurements: _____

Comments: _____

Metastasis / Local Recurrence

Have you had a Local Recurrence? *(Tumor/s that has returned at or near the same site as the primary tumor)*

☐Yes Local Recurrence date: m___/d____/y____

☐No

Have you had Metastasis / Mets? *(Tumor/s that spread to another body part or organ)*

☐Yes Metastasis Date: m___/d____/y____

☐No

Please provide details about your Local Recurrence or Metastasis, if any (i.e. number of tumors, location, size, measurements, how did they find it/them?

_____

_____

C-KIT / CD-117 Test
GIST Diagnosis is confirmed most of the time by a C-KIT test

Have you had a test for ☐C-KIT/CD117 ☐CD34 ☐ DOG1 ☐Other _____

Date of the test: m___/d____/y____ Test Result: ☐Positive ☐Negative ☐I don't know ☐Inconclusive

Test Comments _____

Mutational Test
Identifying gene mutation in individual tumors is critical to improve efficacy of treatment with targeted drugs.

Have you had a mutational test? ☐Yes Date of the test: m___/d____/y____
☐No ☐I don't know

What was the result?

Gene: ☐Kit ☐PDGFRA ☐Wildtype ☐Other: _____

Exon: _____ Amino Acid: _____

GLEEVEC PLASMA/BLOOD LEVEL TESTING
Testing of levels of medication in a patient's blood plasma. For Gleevec patients only.

Have you had a plasma test? ☐Yes ☐ No ☐I don't know

Date of the test: m___/d____/y____ Result: Trough Level _____ ng/ml

TREATMENT
Surgery Details

Surgery Date/s: m___/d____/y____ Reason: _____

Clear Margin ☐ Yes ☐ No ☐ I don't know
Tumor Rupture ☐ Yes ☐ No ☐ I don't know

Please provide your surgery's details *(i.e. type of procedure, complications, how did you end up in the surgery room, etc.)*

_____

_____

_____

Other Surgeries that are GIST related

Surgery Date/s: _____ Reason: _____

Clear Margin ☐Yes ☐No ☐I don't know
Tumor Rupture ☐Yes ☐ No ☐I don't know

Please provide your surgery's details (i.e. type of procedure, complications, how did you end up in the surgery room, etc.)

_____

_____

Are you interested in donating your tumor tissue to the GIST Collaborative Tissue Bank to help with research?

○ Yes ○ No, please send me more info

Medication Details (*Please provide a chronological history of the medications you've taken to treat GIST)*

Current Medication name_____ Dosage _____

○ Continuous *(non-stop/daily)* ○ Cycling _____on _____off *Please circle:* days weeks

Start Date: m___/d____/y____ End Date: m___/d____/y____

Reason for stopping medication _____

Medication

Medication _____ Dosage _____

○ Continuous *(non-stop/daily)* ○ Cycling _____on _____off *Please circle:* days weeks

Start Date: m___/d____/y____ End Date: m___/d____/y____

Reason for stopping medication _____

Medication

Medication _____ Dosage _____

○ Continuous *(non-stop/daily)* ○ Cycling _____on _____off *Please circle:* days weeks

Start Date: m___/d____/y____ End Date: m___/d____/y____

Reason for stopping medication _____

Please provide additional medication details

(i.e. other medications, drug combination, alternative treatments, sequencing, experimental therapies, etc.)

_____

_____

_____

Additional Treatment

(Please check any other intervention/s or procedure/s you had or currently having for GIST)

☐ Radiofrequency Ablation (RFA) Date: m___/d____/y____

☐ Embolization Date: m___/d____/y____

Type of embolization (i.e. bland, chemo, radio) _____

☐ Radiation Date: m___/d____/y____

☐ Other _____ Date: m___/d____/y____

Comments: _____

_____

Are you part of a clinical trial/s? *If yes, please provide details.*

○ Yes ○ No

Trial Name _____ Trial Site/Location _____

Trial Doctor/s Name _____ Start Date: m___/d____/y____

Contact information for your Oncologist/Physician who treats your GIST

We use this information to help other GIST patients find doctors with GIST expertise and work with doctors who may not yet have the expertise.

Doctor's Full Name _____

Facility/Hospital _____

Doctor's Address _____

City _____ State _____ Zip Code _____ Country _____

Doctor's E-mail _____

Phone Number (_____) - _____

Fax Number (_____) - _____