Questions to Ask Your Doctor
Beginning Your GIST Education

The Life Raft GROUP

At Diagnosis:

- ☐ **Was any immunohistochemistry staining performed to confirm that I have GIST?** This includes c-kit/CD117, and/or DOG-1.
- ☐ **What is my Risk of Recurrence (ROR)/chance of tumor coming back?** ROR is measured by tumor size, location, mitotic count and tumor rupture - all of which can be found on the pathology report. ROR classification method/nomograms were developed for GIST, as some experts believe that all GISTs can have malignant potential. If recurrence or metastasis has already happened, ROR does not apply.
- ☐ **How many other GIST patients do you treat?**
- ☐ **If I have a question between appointments, will you be accessible? How can I reach you?** This includes outreach via phone or e-mail, or contact to the doctor's primary oncology nurse for questions and concerns between appointments.

After Surgery:

- ☐ **Did I have clear margins?** Clear surgical margins means that the tumor was removed without bleeding, and did not leave cancerous cells in the tissue.
- ☐ **How will this affect my quality of life?** Post-operative GIST patients may need to make changes in diet and lifestyle in order to avoid symptoms and perform daily activities.
- ☐ **Do I need to start a new diet?**
- ☐ **How often will I be having scans as follow-up?** According to the National Comprehensive Cancer Network (NCCN), it is recommended to have scans every three months for the first three years depending on the tumor staging (if it is single tumor or metastatic).

Starting a New Medication:

- ☐ **Do you know my mutation? Or will you perform a mutational analysis on my tumor?** The National Institute of Health (NIH) defines a gene mutation as a permanent alteration in the DNA sequence. Mutational testing can determine more details on a patient's GIST tumor, so that an individualized treatment plan can be established.
- ☐ **What role does my mutation play in treatment?** Some tumor mutations are more responsive to higher dosages of treatment, while others may not respond to treatment at all.
- ☐ **How does my GIST medication work?** Most GIST medications belong to the drug class Tyrosine Kinase Inhibitors (TKIs) which are targeted therapies inhibiting the enzymes that are part of cell growth and divison. Examples include imatinib, sunitinib, regorafenib.
- ☐ **What side effects should I expect?**
- ☐ **What should I do if I experience side effects?**
- ☐ **How and when should I take my medication?** This includes details such as coordinating medication around meals, or splitting dosages and managing frequency.
- ☐ **Am I starting at the lowest dose? Will I ever need to increase this dosage?**
- ☐ **How does my ROR affect how long I'll be on treatment?**