GIST: THE BASICS

53% (n=1283) 47% (n=1158)

2441 Patients currently enrolled in our GIST Patient Registry

189 New patients enrolled in 2021
# AGE AT DIAGNOSIS (YEARS)

<table>
<thead>
<tr>
<th>Category</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average Age of Patients</td>
<td>51</td>
</tr>
<tr>
<td>Average Age of Females</td>
<td>50</td>
</tr>
<tr>
<td>Average Age of Males</td>
<td>52.5</td>
</tr>
<tr>
<td>Youngest Patient</td>
<td>5</td>
</tr>
<tr>
<td>Oldest Patient</td>
<td>94</td>
</tr>
</tbody>
</table>
TUMOR DETAILS

Primary Tumor Locations:

- Stomach: 1072 cases
- Small Intestine: 887 cases
- Rectum/Anus: 70 cases

Tumor Type at Diagnosis:

- Single: 1687 cases
- Multi focal: 79 cases
- Mets: 644 cases
- *Unknown: 31 cases

*No specific tumor type reported by patient or stated in patient's clinical report
RISK OF RECURRENCE

There are several different methods used to classify the risk of recurrence in GIST.

The LRG GIST Patient Registry uses the Modified NIH Method, which looks at primary tumor size, mitotic count, and location.

Of our patients who had a single tumor at diagnosis, 32% of these patients have an unknown risk and 68% of these patients have a known risk.

This chart is the breakdown of risk in the 68% of patients who have known risk and single tumor at diagnosis.
The Life Raft Group launched a **Tissue Testing Initiative** in 2021 to improve the understanding of biomarker testing among the GIST cancer community and increase the number of patients tested by providing FREE Next-Generation Sequencing (NGS) to eligible patients.

**Learn More About Our Initiative**
55% of Registry members reported their mutation

1341 patients reported a primary mutation

GIST PRIMARY MUTATIONS

TYPES OF PRIMARY MUTATIONS

- KIT: 77%
- PDGFRA: 15%
- Wildtype: 8%
**KIT PRIMARY MUTATION**

- **Percentage of Patients with the KIT Mutation**
  - Exon 11: 81%
  - Exon 9: 15%
  - Exon 13: 2%
  - Exon 17: 1%
  - Unknown: <1%

- **Location of Mutation**
  - Exon 11
  - Exon 9
  - Exon 13
  - Exon 17
  - Unknown

**PDGFRA PRIMARY MUTATION**

- **Percentage of Patients with the PDGFRA Mutation**
  - Exon 18: 80%
  - Exon 12: 15%
  - Exon 14: 5%
  - Unknown: <1%

- **Location of Mutation**
  - Exon 18
  - Exon 12
  - Exon 14
  - Unknown
Wildtype refers to any mutation that is not found in the KIT or PDGFRA genes.

**Wildtype PRIMARY MUTATION**

Percentage of Patients within the Wildtype Mutation

- No Other Specified: 52%
- SDHA: 15%
- SDHB: 11%
- NF1: 10%
- SDHC: 5%
- BRAF: 4%
- SDH-C Epimutant: 2%
- NTRK: 2%
- SDHD: 1%

Gene Type
111 patients reported at least one secondary mutation.

**Note:** the total number of secondary mutations is greater than the number of patients reporting due to some patients having more than one secondary mutation.
KIT SECONDARY MUTATION

<table>
<thead>
<tr>
<th>Location of Mutation</th>
<th>Percentage of Patients with the KIT Mutation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exon 17</td>
<td>56%</td>
</tr>
<tr>
<td>Exon 13</td>
<td>35%</td>
</tr>
<tr>
<td>Exon 14</td>
<td>3%</td>
</tr>
<tr>
<td>Exon 18</td>
<td>2%</td>
</tr>
<tr>
<td>Exon 11</td>
<td>1%</td>
</tr>
<tr>
<td>Exon 9</td>
<td>1%</td>
</tr>
<tr>
<td>Exon 19</td>
<td>1%</td>
</tr>
</tbody>
</table>

PDGFRA SECONDARY MUTATION

<table>
<thead>
<tr>
<th>Location of Mutation</th>
<th>Percentage of Patients with the PDGFRA Mutation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exon 12</td>
<td>50%</td>
</tr>
<tr>
<td>Exon 18</td>
<td>33%</td>
</tr>
<tr>
<td>Exon 14</td>
<td>17%</td>
</tr>
</tbody>
</table>

The Life Raft Group
Wildtype refers to any mutation that is not found in the KIT or PDGFRA genes.
PATIENTS ON MEDICATIONS IN 2021

- 891 living patients on medication in 2021
- 31 patients were on clinical trials in 2021
- 240 patients on a generic in 2021

**Note:** the total number of medications equals 895 because 4 patients are on combination drugs.
TOP SIDE EFFECTS BY MEDICATION

**Gleevec** (imatinib)
- Cramping
- Edema
- Diarrhea

**Sutent** (sunitinib)
- Diarrhea
- Hand & Foot
- Fatigue

**Stivarga** (regorafenib)
- Hand & Foot
- Diarrhea
- Cramping
- Fatigue

**Qinlock** (ripretinib)
- Fatigue
- Hair Loss
- Cramping

**Ayvakit** (avapritinib)
- Edema
- Cognitive Impairment
- Fatigue
Top 10 Countries:
1. USA
2. Canada
3. United Kingdom
4. Netherlands
5. Australia
6. India
7. Chile
8. Mexico
9. Germany
10. Italy

82
Total Countries in our Registry

Note: Countries highlighted orange represent the countries patients in our registry reside in.
Our GIST Patient Registry has decades of experience capturing key Real World Data and we are passionate about moving GIST research forward. This longitudinal data has played an instrumental role in bridging the gap between patients and researchers who are eager to understand the natural causes of GIST.

With our Registry data we:

• Provide **data-driven insights** of FDA approved medications, as well as off-label medications, and clinical trial medications.

• Facilitate a **precision-medicine** approach to better understand the possible connection of mutations and treatments among all GIST patients.

• Illustrate the **patient’s experience** through the evaluation of patient-reported outcomes by monitoring patient’s quality of life and suggesting side effect management recommendations.

• Gather patient insights to **generate patient-centered data** through all the stages of GIST and drug development to facilitate a better understanding of the disease.

• Collaborate **globally** to publish research findings and translating research findings into actions.

• Share data on **general patterns** reported in Registry to other LRG GIST patients.
USEFUL LINKS

• [Join Our Patient Registry](#)

• [Update Your Existing Patient Registry Record](#)

• [Participate in the Tissue Testing Initiative*](#)

• [Donate to #GISTresearch](#)

*Must be eligible for the initiative
THANK YOU!

We are grateful for all our patients, caregivers, and key stakeholders that continue to support our efforts to move GIST research forward. We are not able to do it without you.

- The LRG Data Management & Research Team

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