• The largest GIST registry in the world with over 1900 patients from more than 67 countries.

• Ongoing research study where GIST patients and caregivers volunteer their information regarding GIST.

• Information is used to understand the natural history of GIST, treatment outcomes, and to help accelerate research with our Real World Evidence Data.

• Enhanced by GIST/Prime, the web-based patient-facing front end of our registry.
PATIENT PROFILING

1981 GIST/PRIME MEMBERS
124 NEW GIST/PRIME MEMBERS
400+ GIST/PRIME DATA FIELDS

Average Age of Diagnosis: 51 years
Youngest diagnosed at 5 years old and the oldest at 98 years old

Median Overall Survival from Diagnosis: 12.5 years

36% Alive, 64% Deceased
RISK OF RECURRENTCE

Risk of Recurrence

- 68% Single Tumor at Diagnosis
- 32% Mets at Diagnosis

- 38% Risk Unknown
- 62% Know Their Risk

- 82.5%
- 6.5%
- 10.1%
- 0.9%

High Risk
Intermediate Risk
Low Risk
Very Low Risk

There are several different methods used to classify the risk of recurrence in GIST. The Patient Registry uses the Modified NIH Method, which looks at primary tumor size, mitotic count, and location.
675 Number of living patients on medication:

Generics: 95

10 patients entered a clinical trial this year
It is estimated that only 15-20% of GIST patients nationwide have mutational testing performed by contrast 52% of LRG Patient Registry members know their mutation.
MUTATIONAL BREAKDOWN

KIT 78%
PDGFRA 8%
OTHER 14%
Overall Survival (yrs.), Known vs Unknown mutation

Reflects total patients in the LRG Patient Registry, US and non-US.

A variety of factors may confound this data:
- LRG members tend to be more pro-active in their care
- The LRG Tissue Bank Initiative encouraged testing
- Testing may not be available in other countries

<table>
<thead>
<tr>
<th></th>
<th>Don’t Know Mutation</th>
<th>Know Mutation</th>
</tr>
</thead>
<tbody>
<tr>
<td>LRG Patient Registry</td>
<td>970</td>
<td>739</td>
</tr>
<tr>
<td>Median survival</td>
<td>10.3 yrs</td>
<td>17.0 yrs</td>
</tr>
</tbody>
</table>
Why was mutational test done in your case?

- My doctor suggested I have it done: 39%
- I asked my doctor: 26%
- I had it done as a part of a clinical trial: 31%
- Other: 4%

*Graph from LRG mutational test survey*
Why haven't you had mutational testing?

- Doctor never mentioned it: 50%
- Insurance/Cost of testing: 15%
- Not enough tissue: 32.5%
- Other: 2.5%

*Graph from LRG mutational test survey*
Why is Real World Evidence important?

Rich diversity of data collected from large samples of patients will yield to a more precise, better targeted, and therefore a more highly effective health care.
Real world data and resultant real world evidence is being utilized to enhance and complement traditional research.
Diagnostic Algorithm for GIST – NCCN guidelines

- LRG produced a diagnostic algorithm in Sept 2018
- A global pathology sub-committee was formed
- Revising guidelines for primary GIST as well as molecular testing
- Guidelines were completed and submitted to the College of American Pathologists (CAP) and Association for Molecular Pathology (AMP) in Feb 2019
• Genomic aberrations in cell cycle genes predict progression of KIT-mutant GIST
  Journal: Clinical Sarcoma Research, February 2019
• Mutational testing in gastrointestinal stromal tumors
  Journal: Current Cancer Drug Targets, March 2019
• Survival in advanced GIST has improved over time and correlates with increased access to post-imatinib TKIs
  Journal: Clinical Sarcoma Research, April 2019
• Frequent Rectal GIST Recurrences in the Imatinib Era: Retrospective Analysis of an International Patient Registry
• Journal: Annals of Surgical Oncology, submitted April 2019
THANK YOU!

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