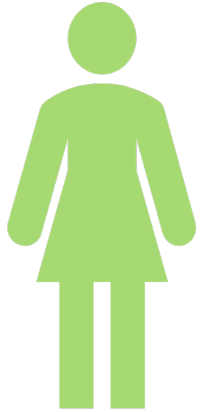


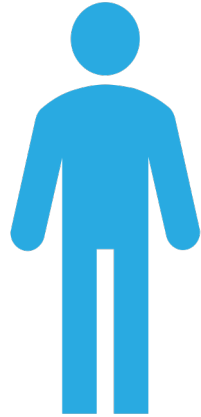


GIST PATIENT REGISTRY IN REVIEW 2021

GIST: THE BASICS



53%
(*n= 1283*)



47%
(*n= 1158*)

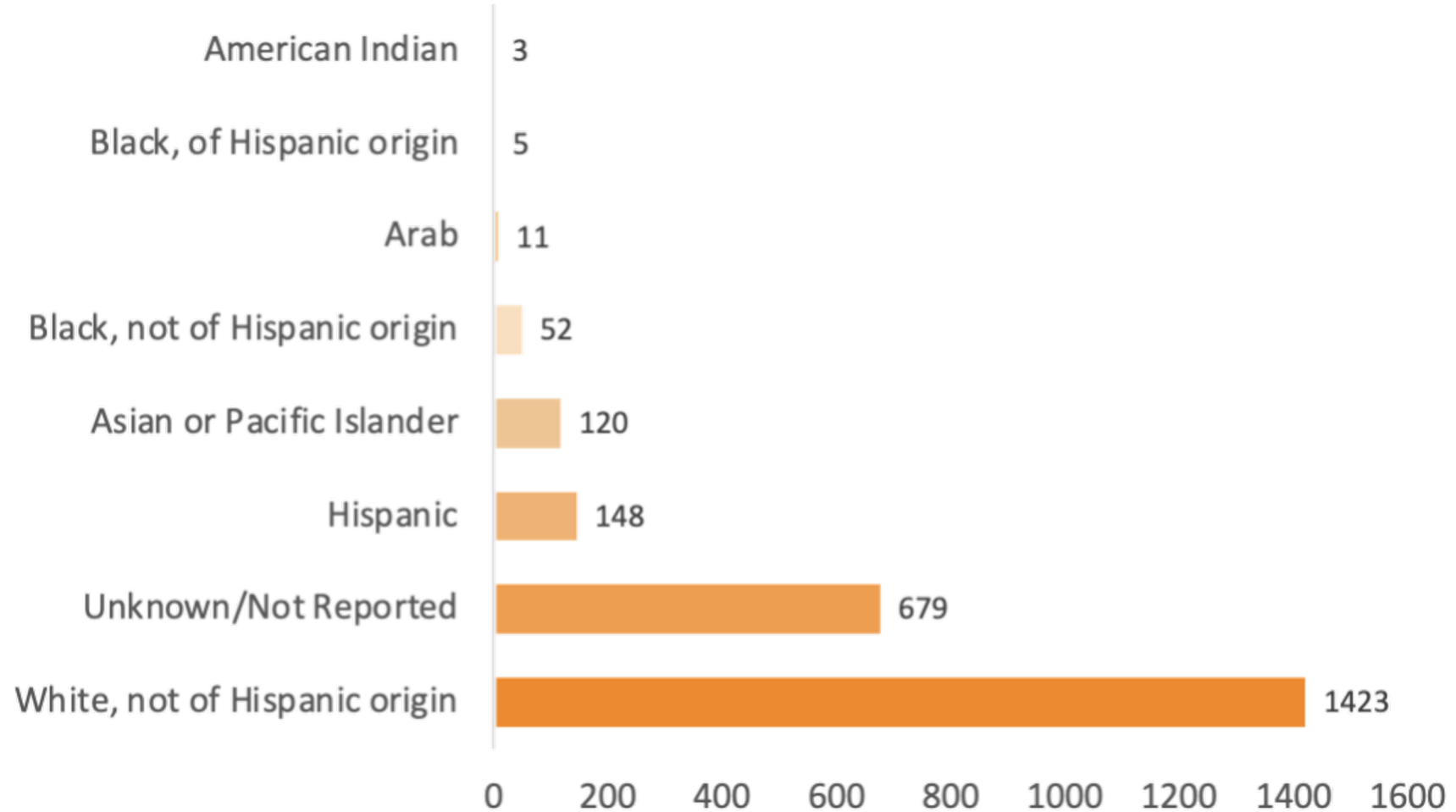
2441 Patients
currently enrolled in our
GIST Patient Registry

189 New patients enrolled in 2021

AGE AT DIAGNOSIS (YEARS)

Average Age of Patients	51
Average Age of Females	50
Average Age of Males	52.5
Youngest Patient	5
Oldest Patient	94

DEMOGRAPHICS



TUMOR DETAILS

Primary Tumor Locations:



Stomach
1072



Small Intestine
887



Rectum/Anus
70

Tumor Type at Diagnosis:

Single	1687
Multi focal	79
Mets	644
*Unknown	31

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

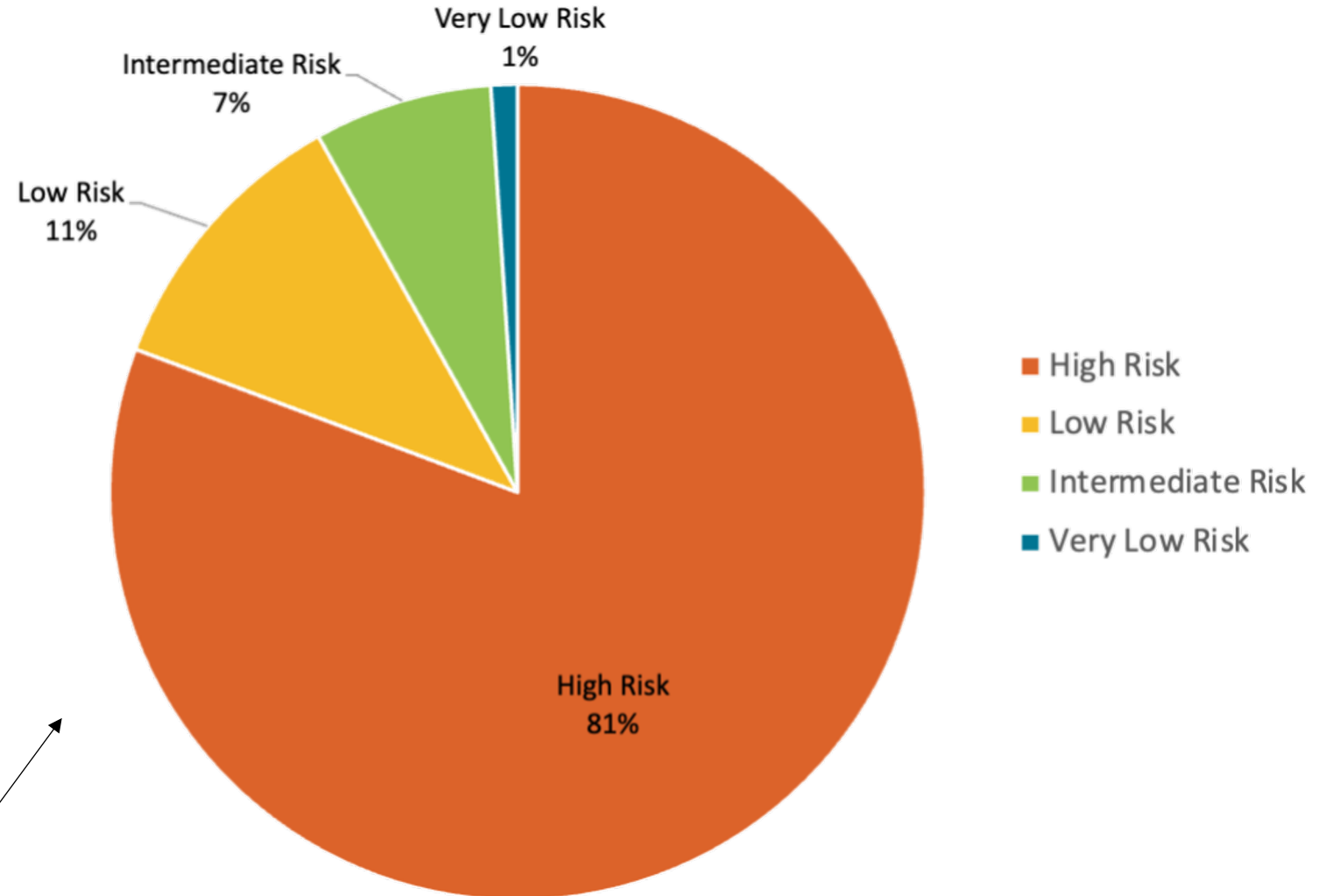
RISK OF RECURRENCE

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.



TISSUE BANK

486

Tissue Bank Members*



957

Total Number of Tissue

* All tissue bank members are part of the LRG Patient Registry so that we are able to connect clinical data to all tissue samples in our Tissue Bank

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](#)

GIST PRIMARY MUTATIONS



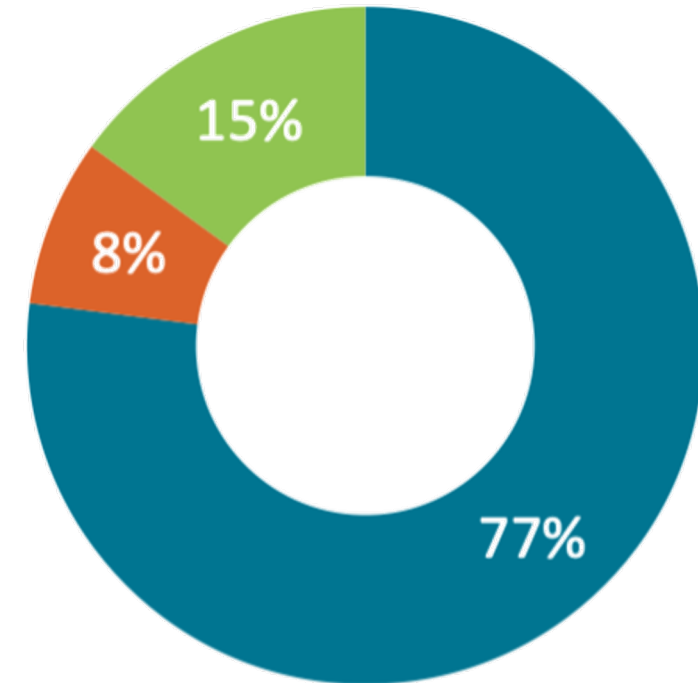
55%

of Registry members
reported their mutation

1341

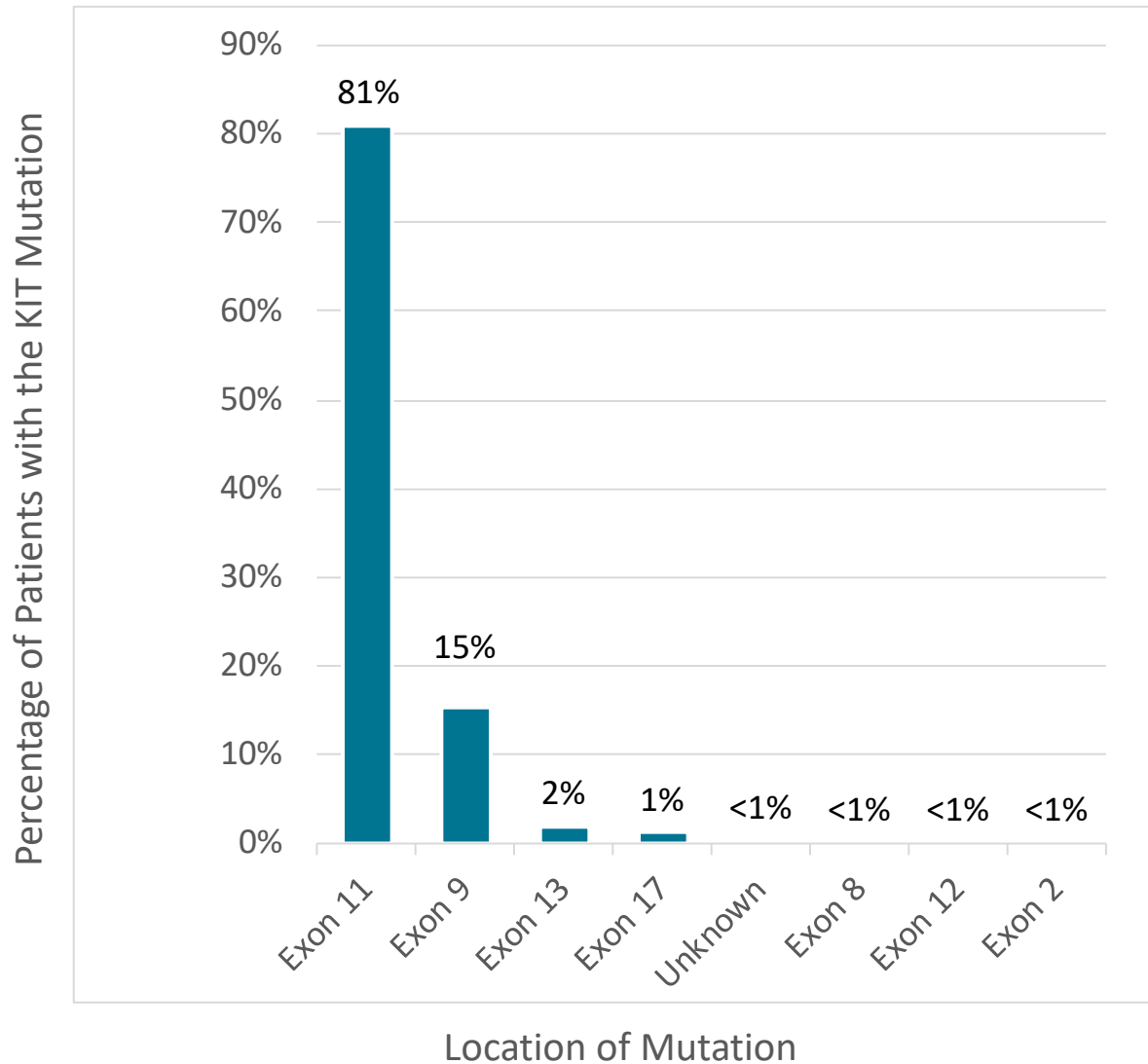
patients reported
a **primary mutation**

TYPES OF PRIMARY MUTATIONS

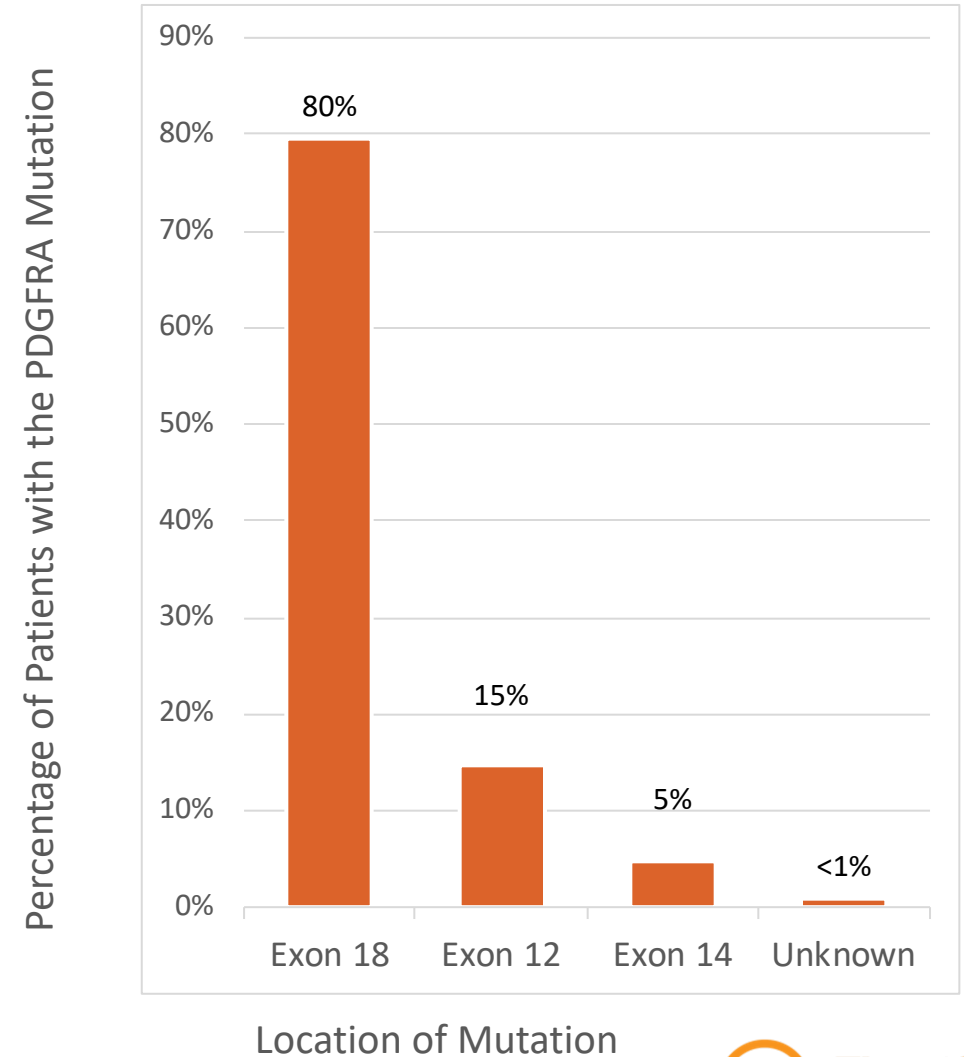


■ KIT ■ PDGFRA ■ Wildtype

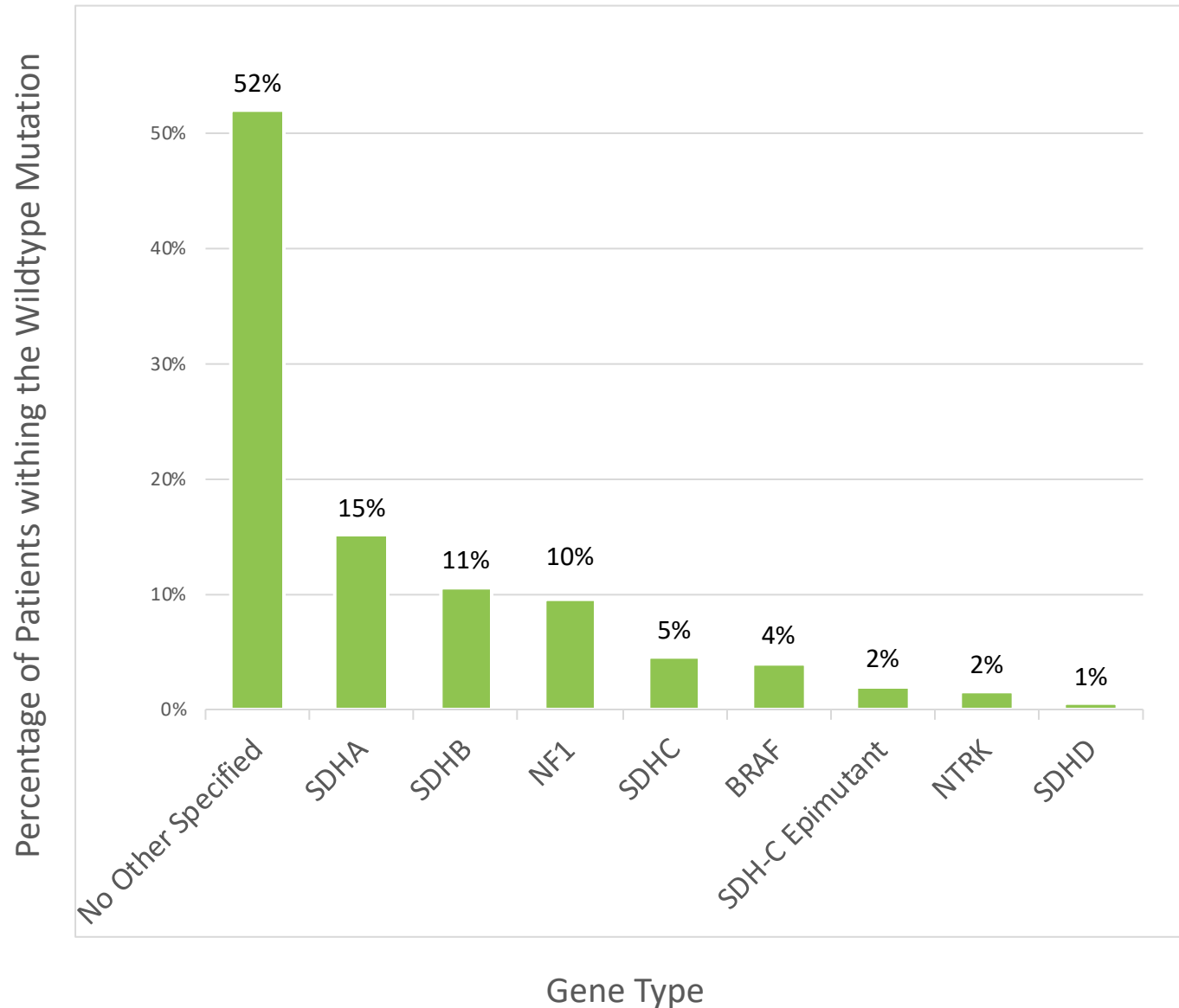
KIT PRIMARY MUTATION



PDGFRA PRIMARY MUTATION



WILDTYPE PRIMARY MUTATION



Wildtype refers to any mutation that is not found in the KIT or PDGFRA genes

GIST SECONDARY MUTATIONS

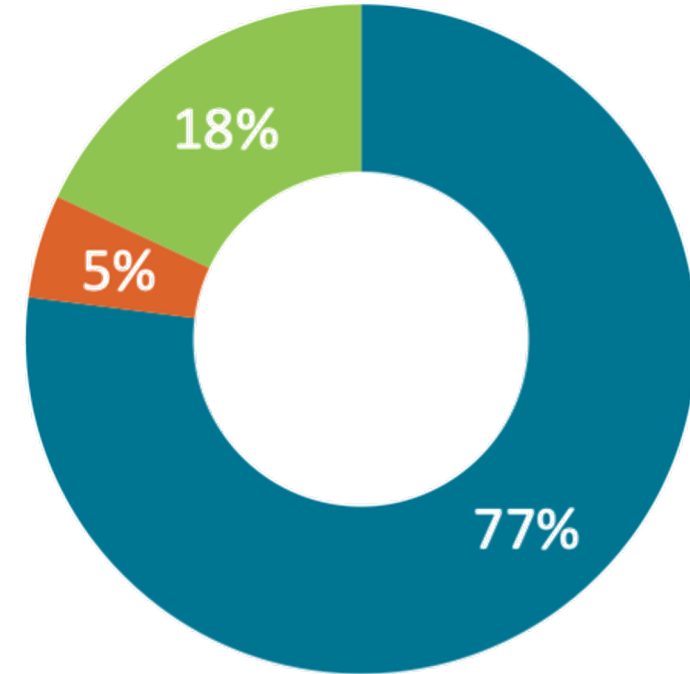


TYPES OF SECONDARY MUTATIONS

111

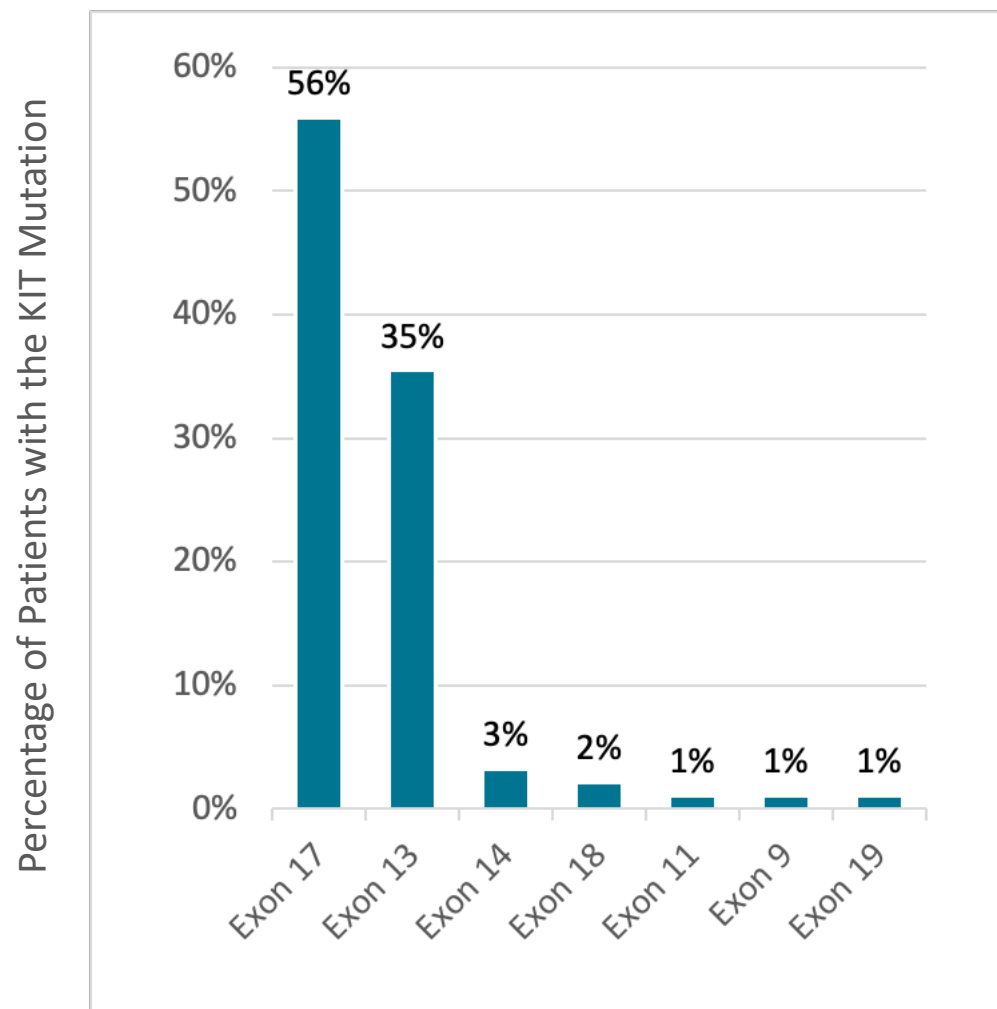
patients reported at
least one **secondary**
mutation

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



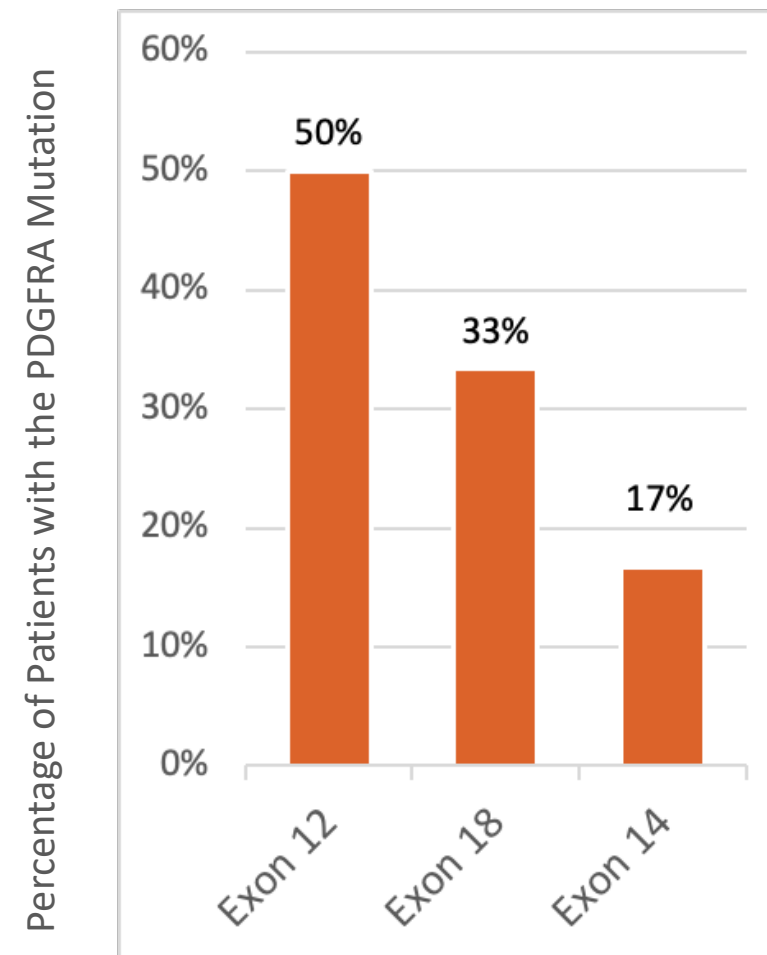
■ KIT ■ PDGFRA ■ Wildtype

KIT SECONDARY MUTATION



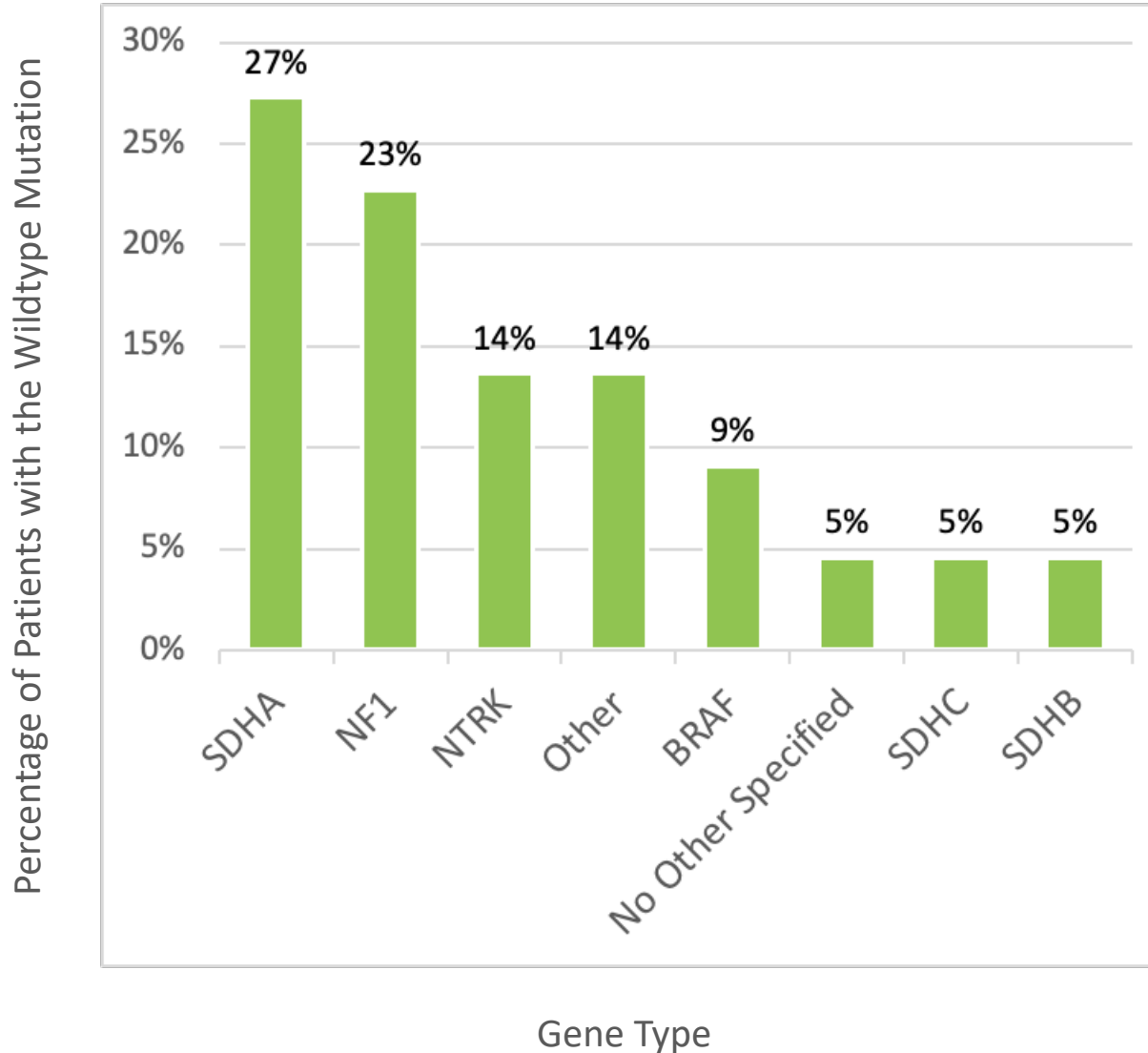
Location of Mutation

PDGFRA SECONDARY MUTATION



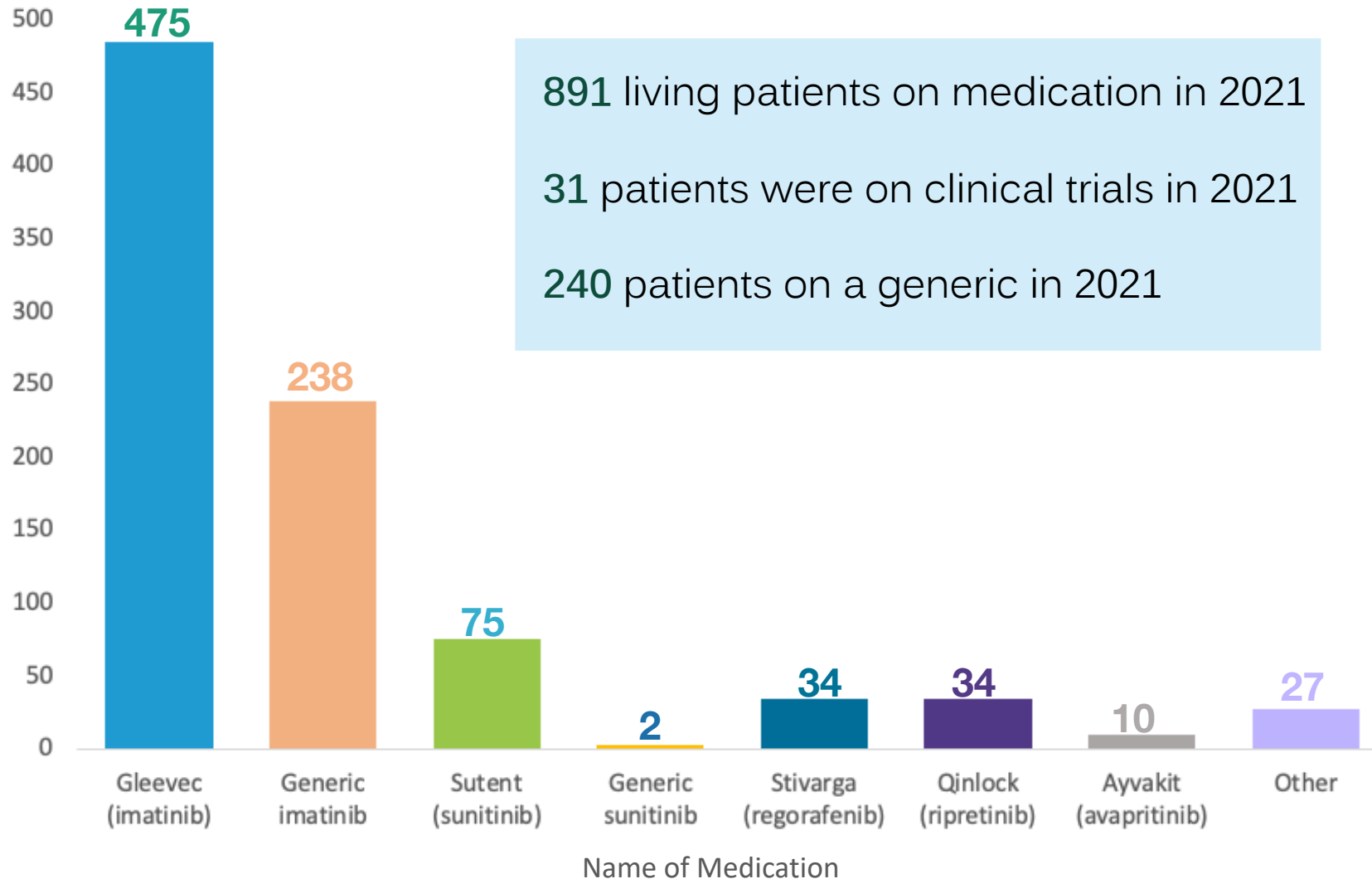
Location of Mutation

WILDTYPE SECONDARY MUTATION



Wildtype refers to any mutation that is not found in the KIT or PDGFRA genes

PATIENTS ON MEDICATIONS IN 2021



Bezuclastinib (CGT9486/PLX9486)
Cabozantinib
Dabrafenib
Masitinib
Motesanib
Nilotinib
Pazopanib
Pembrolizumab
Selumetinib
Sorafenib
SRF617
Temozolomide
TNO155
Trametinib

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

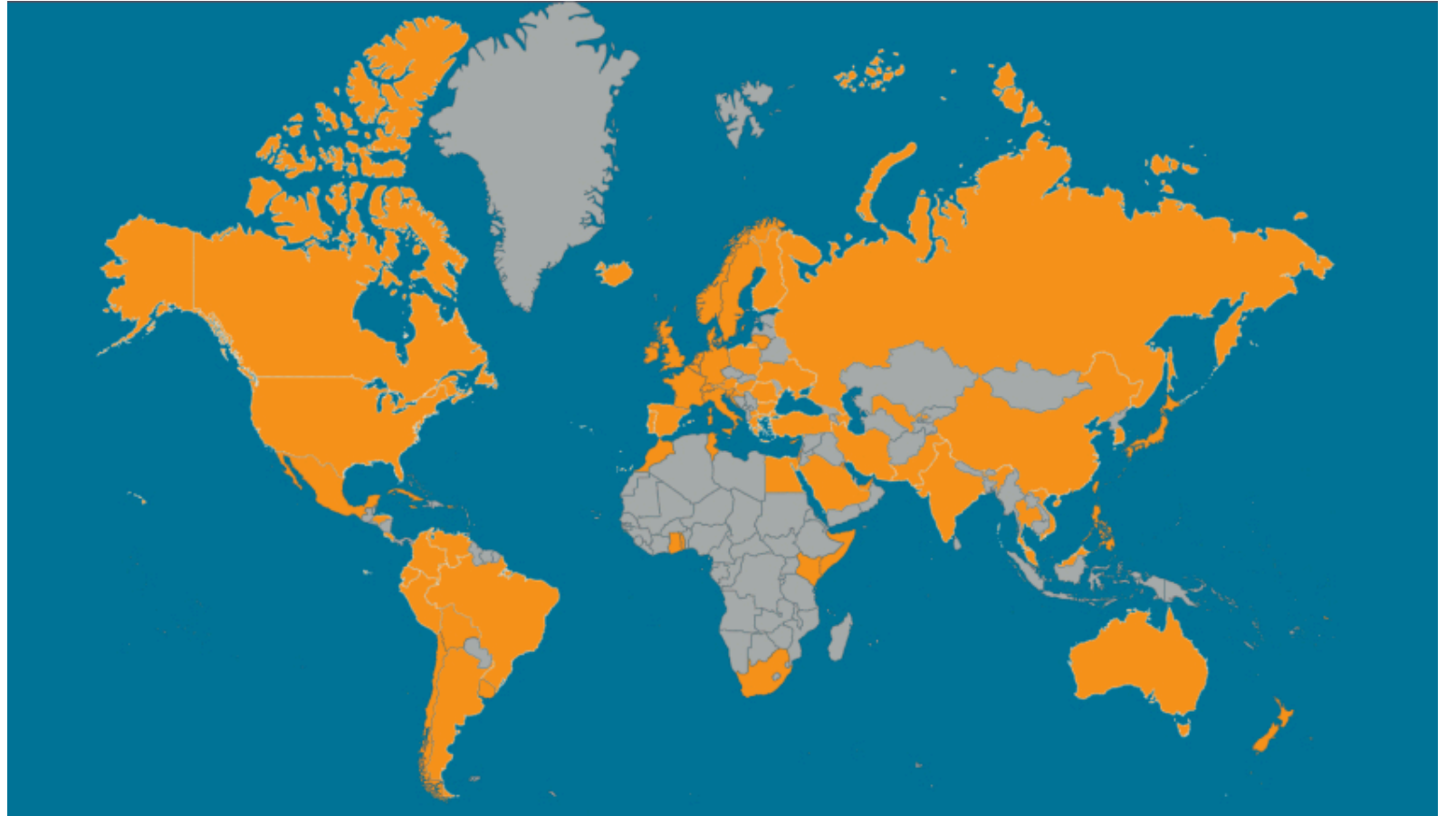
Top 10 Countries:

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

COUNTRIES



Note: Countries highlighted orange represent the countries patients in our registry reside

DATA OUTCOMES

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



973-837-9092

liferaft@liferaftgroup.org

www.liferaftgroup.org