



Research ■ Patient Support & Education ■ Advocacy

Advancing Health Data

What's the Point of Health Data?

Although there are other health data projects already underway, there is an enormous need for a service which provides a 360 degree utility to address the needs of ALL players in the space — **RESEARCHERS, PATIENTS and INDUSTRY.**

Drug Development now takes an average of **\$2.5 Billion** and **10+ years**¹
Resulting in treatments that **take too long** to get to market and **cost too much** to produce.

\$300+ Million has been invested to date in “mega registries”
Yet we are still **not** where we need to be.



¹ <http://cen.acs.org/articles/92/web/2014/11/Tufts-Study-Finds-Big-Rise.html>

Why Are Registries Needed?

- First-hand information
- Increase understanding of disease
- Track trends of diseases and treatment
- Determine the disease's natural history



But most importantly....

They provide the entire patient experience

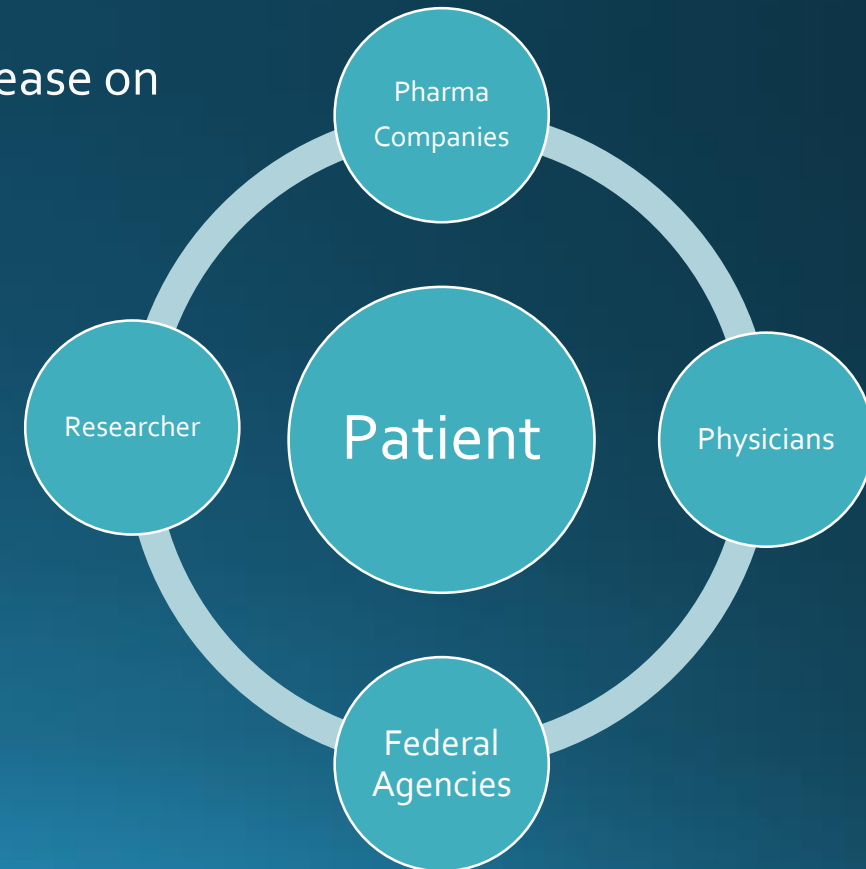
Patient-Reported Outcome

- **Patient- Reported Outcome (PRO)** – any outcome evaluated and reported directly by the patient themselves and is based on the patient’s perception of a disease and treatment

Example Data: Symptoms, severity of disability, impact of disease on daily life, feelings towards the treatment

Key Goals

- Improve clinical decision-making
- Measures Risks and Benefits of Treatments
- Help patients make more informed decisions
- Improve quality and safety of clinical research
- Putting patients at the center of decision making



Patient-reported outcome (PRO)
measures bridge the gap between the
clinical reality and the patient world



PRO in Clinical Practice



IMPROVE**CARE**NOW

- ImproveCareNow

- Patient reported outcomes and clinical data to improve results for children with inflammatory bowel disease
- Since establishing the network in 2007 remission rates have improved from 55% to 77% for 17000 in 30 states

Power of the Patient Voice

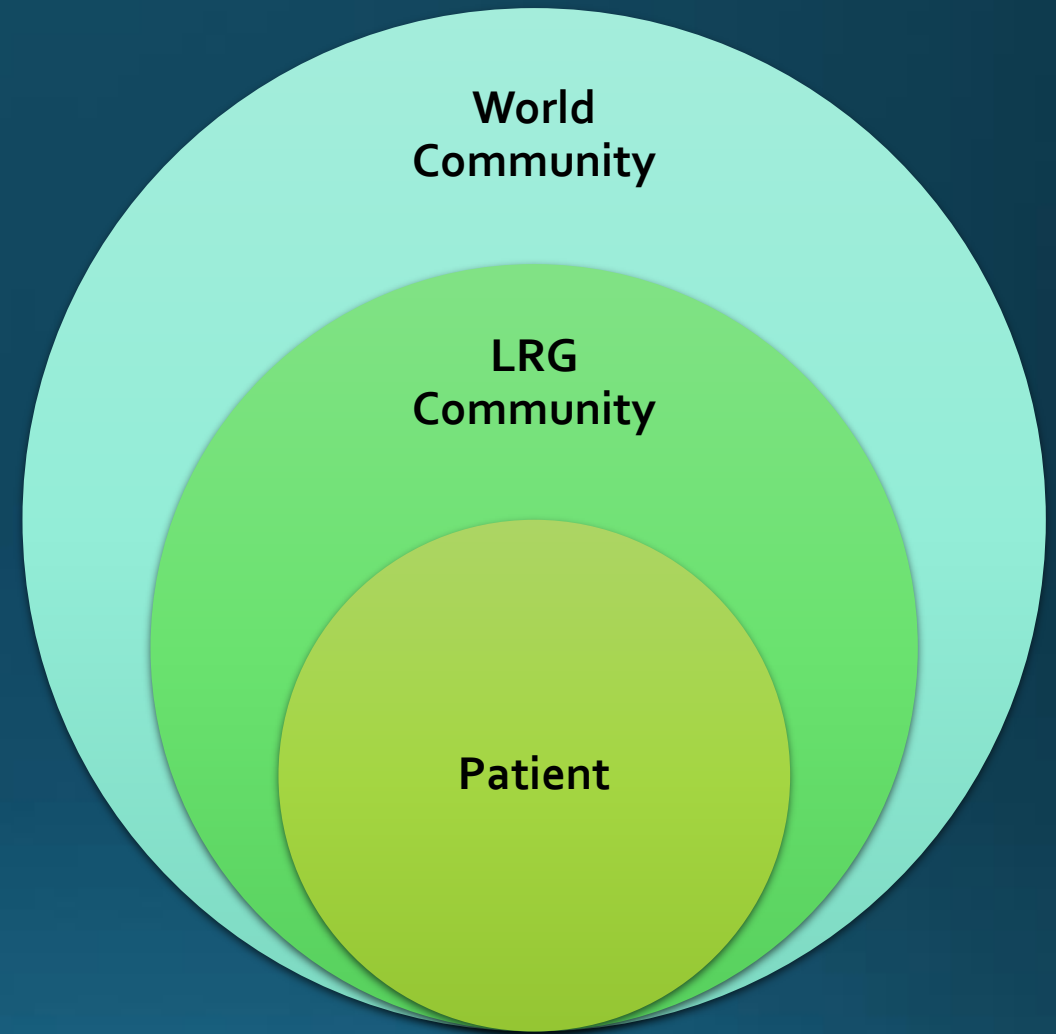
- Become an expert patient
 - Track, manage and thrive
 - Feel comfortable speaking with physicians
- Gain access to information that you might not otherwise have
- Become part of a community who understands you
 - 1 in 5 internet users have gone online to find others like them ¹
- Help your fellow patients



¹Fox, S. (2011). Peer-to-peer Health Care. *Pew Research Center*. Retrieved from www.pewinternet.org

LRG Patient Registry

- **Patient**
 - Understanding of their disease
 - Comprehensive report of treatment
- **LRG community**
 - Aggregate data analyzed to notice trends within the community
- **World Community**
 - Patient-Reported Outcomes from GIST patients throughout the world
 - Enhance existing clinical data to help advance research



Benefits extend from the patient towards to the larger GIST community.

Expanding the Registry

Registry data is effective in providing information on natural history and patient management strategies. The more information we have the more robust research becomes.



So we are making it easier... We are making it **interactive**

Introducing



GIST/PRIME

THE LIFE RAFT GROUP PATIENT REGISTRY



GIST/PRIME

THE LIFE RAFT GROUP PATIENT REGISTRY

Benefits of an Interactive Registry

YOU have access to your own data anywhere

YOU input your own updates

YOU can monitor your treatments and evaluations

YOU see real time updates

LRG Patient Registry

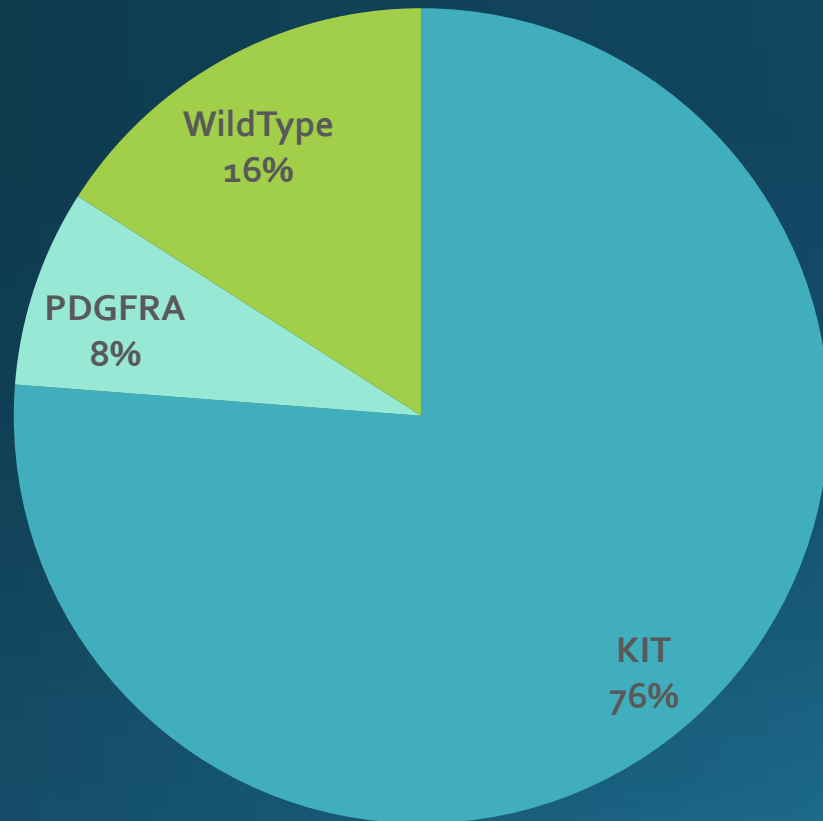
1684 Patients

 844 Male |  840 Female

 1277 United States | 407 International 

86 Ages 35 or under | 155 Ages 36-45 | 347 Ages 46-55
507 Ages 56-65 | 589 Ages 65+

Mutational Analysis



44%

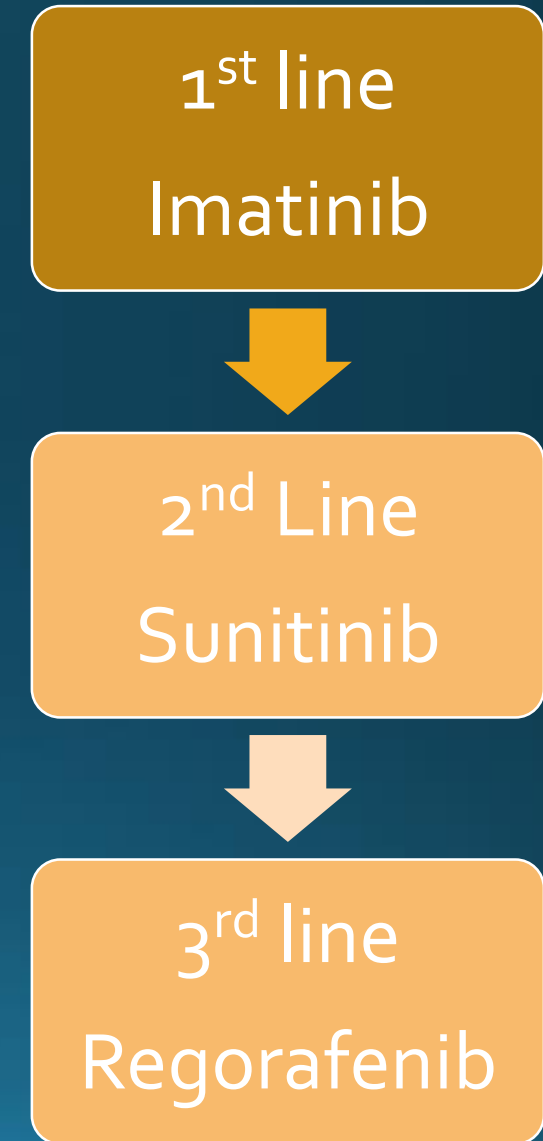
LRG Patient Registry
Members know their
mutation

Compared to the 8-10% of the
general US population

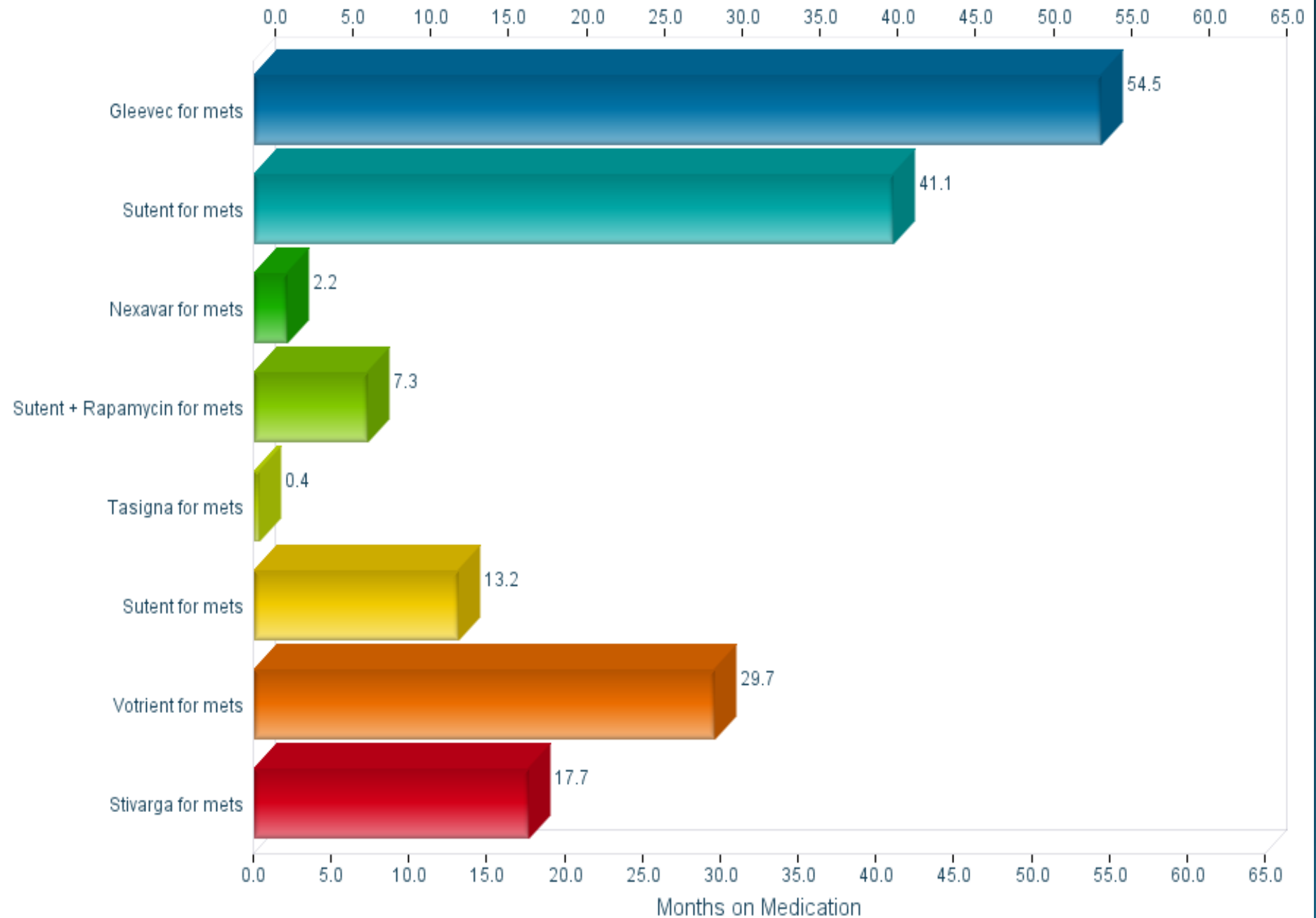
Treatment Lines

- Treatment lines compare effectiveness of a given sequence of drug therapies
- Treatments given early should be compared to other treatments given early, late vs. late etc. (i.e. 2nd line to other 2nd line, 3rd line to other 3rd line)

FDA Approved Drug Sequence



INDIVIDUAL PATIENT TREATMENT LINE EXAMPLE



Thank you!



Michelle Durborow
mdurborow@lifteraftgroup.org