

# THE LIFE RAFT GROUP RESEARCH MODEL

## Real World Evidence in Action



### Real World Data

"Data relating to patient health status and/or the delivery of health care routinely collected from a variety of sources."

-FDA



### Real World Evidence

"The clinical evidence regarding the usage and potential benefits or risks of a medical product derived from the analysis of real world data (RWD)."

-FDA

Traditionally, data used in drug research & development has come from the gold standard – Randomized Clinical Trials (RCTs).

With the onset of the 21<sup>st</sup> Century Cures Act, there has been an increased demand for real world data and real world evidence – the post-market insights into drug effectiveness and safety after clinical trials.

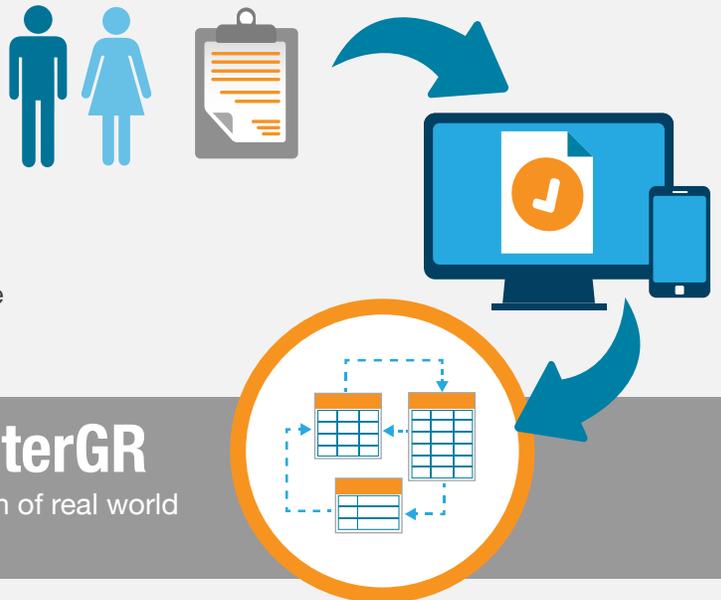
Born out of a desire to learn more about this rare cancer called GIST, our **Patient Registry** started by gathering patient information on index cards.

### Early on...

We conducted a Side Effects Survey, where we applied our own quality of life scale. We discovered valuable evidence that in our patient population, side effects improved over time. This data was shared with the pharmaceutical company that developed the primary treatment for our patients. This complemented the data from the early clinical trials.

Since the Year  
**2000**

this patient-provided, patient focused data has been the core of the LRG's own research



## Now, we developed Project InterGR

A way to foster collaborative research through the collection of real world data on multiple platforms.



**Patient Registry** - The largest GIST registry in the world with over 1800 patients from more than 60 countries.

Tracks patients over time across institutional and international boundaries.



**Pediatric & SDH-Deficient GIST Consortium** - Collaborative effort of leading Pediatric and SDH-Deficient GIST experts aiming to dramatically impact patient survival and quality of life through data and tissue sharing.



**SideEQ** - Interactive side effects management platform that provides further insights into key issues that impact patient compliance and treatment outcomes.



**GIST Collaborative Tissue Bank** - Housed at Stanford University, vital tissue samples that provide researchers with valuable insights into this rare disease are paired with detailed clinical histories from our Patient Registry.



**GIST Clinical Trials Database** - Provides current information about clinical studies focused on GIST in an easy to use format to aid patients in making key decisions about their disease management.



**Project Surveillance** - A collaborative platform where GIST experts can share real world, real time observations.



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