Understanding GIST

• Rare cancer: 4000-6000 US cases per year
• Occur anywhere in the GI Tract
• 80% mutations are in the KIT gene
  • Remaining 20% consists of PDGFRα and Wildtype
• Surgery and approved targeted drug therapy
Index card record keeping system (1998)
25 records

Information transferred to Microsoft Excel Spreadsheet (2004)
>100 records

Establishment of Tissue Bank with Stanford (2007)

First operating database on Microsoft Access (2008)
>500 records

Online Platform created using SQL (2013)
>1600 records

Launch Web-based Interactive Patient Registry Database and Side Effects Module (2016)
Registry Population

- More than 1600 participants globally
- Over 14 years of self-reported data collection encompassing 35 years of patient history
- Ages 5 - 82 representing 12 mutational types
Data Collected

- Demographics
- Diagnosis events
- Evaluations/Scan reports
- Treatments and Side effects

Treatment Patterns
Treatment Outcomes
Better Disease Management
Benefits of Membership

- **GISTory**
  - Portable medical history
  - Tracks patient history across institutional boundaries

- **Patient Support**
  - Local support groups
  - Email community
  - Virtual Tumor Board

- **Education**
  - Expert Patient Course
  - Advocacy Training

- **Research**
GIST Collaborative Tissue Bank

One tissue donation can reach the world's leading GIST research scientist
600 tissue donations linked to clinical histories in the Patient Registry
In the United States it is estimated that only 8-10% of GIST patients have mutational testing performed...by contrast 41% of LRG Patient Registry members know their mutation
Power of the Tissue Bank

• 20% of the tissue from Latin America was shown to have been misdiagnosed (unintended benefit)
• Increased GIST diagnosis
• Paved the way to build testing capacity in Latin America
Role of Country Leaders

“Boots On The Ground”

• Key point person for patients

• Collect medical information to update in Patient Registry

• Coordinate with the LRG to help facilitate the collection of tissue for mutational analysis

Global Representatives in 60 countries
Moving Forward
Presenting InterGR
The cure is in the numbers
The Problem

Despite having insufficient data and tissue to draw meaningful conclusions by themselves, there is an alarming lack of collaboration in rare cancer research.

Other voices are not being heard—Patient Groups gather richer, more honest and more comprehensive data which can cross institutional boundaries.
InterGR provides an interactive cloud-based platform for global researchers and patient groups to store, visualize, share and analyze health data to foster rare cancer research collaboration.
Thank you!

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