LESSONS LEARNED

...from the GIST Community
LESSONS LEARNED

➢ Science is hard

➢ Cancer Science is very hard

➢ Rare Cancer Science is daunting
NOT CONTAGIOUS = NOT URGENT

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<td>COVID-19: 345,323</td>
<td>CANCER: 598,532</td>
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1. HTTPS://JAMANETWORK.COM/JOURNALS/JAMA/FULLARTICLE/2778234
CANCER CULTURE: NOT COLLABORATIVE

- Cancer culture has too many stakeholders to create collaboration
  - Pharmaceutical Executives, Pharmaceutical Scientists, and Pharmaceutical Investors
  - Government Regulators and Government Researchers
  - Individual Researchers and Research Publishers
  - Foundations
  - Patient Advocacy Organizations
  - Hospitals
  - Clinicians and Individual Doctors
  - Insurers

And as an after-thought... The patients and their caregivers
OUR SECRET ARMY

➢ Doctors – Dr. George Demetri
➢ Researchers – Dr. Lee Helman
➢ Innovators – Gilles Frydman
➢ Politicians - Ted Kennedy

➢ Scientists – Dr. James Watson
➢ Pharmaceutical Executives – Dr. Dan Vasella
➢ Advocacy Groups – The Life Raft Group
“…he (Norman) collected all of the data and he knew much more than we knew, because he had this pool of patients he would talk and look at, and how they would evolve and everything… he was quite amazing. And you know what…he was right, and we were wrong. The dose had to be higher.”

-Dan Vasella

Former CEO, Novartis
UNFINISHED BUSINESS: TRADITIONAL RESEARCH

➢ Bring researchers together to find an effective treatment for children and young adults - the commitment of the Life Raft Group at the Vice President’s Biden Cancer Summit

➢ Overcome treatment resistance for adult patients.

➢ Find a Cure
UNFINISHED BUSINESS: CLOSE THE LETHAL TIME GAP

Closing the lethal time gap between 
Scientific Advancement and Best Practices

➢ Connect the pertinent diagnostic test to the right targeted drug
➢ Make it available to the patient community
➢ Make it affordable to the patient community
➢ Help the patient manage the drug side effects
➢ Confirm the patient takes the drug
PERSISTENCE