Advocating for better access: a case study

Sarah McGoram –
GIST and Rare Cancers Patient Advocate
Australia
My Story

- 1996 Diagnosed with Pediatric Wildtype GIST (SDHB Positive)
- 2001 **Glivec** Trial
- 2003 Married
- 2006 Our Son born
- 2010 **Glivec** (Imatinib)
- 2012 **Sutent** (Sunitinib)
- 2015 – today **Stivarga** (Regorafenib)
- 2021 Celebrated 25 living with GIST
Australian System

- Medicare is Australia’s universal health insurance scheme. It guarantees all Australians (and some overseas visitors) access to a wide range of health and hospital services at low or no cost.  

- Great system for many and most.

- Rare and less common cancer treatments struggle to meet the approval criteria for government funding (Pharmaceutical Benefits Scheme – PBS).

- Glivec and Sutent are the only government funded GIST treatments in Australia.
**What Have We Achieved**

- **Qinlock to be funded by the Australian Government** and listed on the Pharmaceutical Benefits Scheme. (Dec 2021)

- **Why this was surprising:**
  - GIST drug therapies and a large number of Rare Cancer drugs struggle to meet the criteria of drug approval.
  - Stivarga (Regorafenib) failed twice and is still not funded;
  - Qinlock failed in its first attempt in March 2021;
**Our Challenge...**

Our challenge was to persuade the government to fund Qinlock. March 2021 Qinlock declined for government funding to subsidise cost for GIST patients (Pharma company given an offer of resubmission in July)

**...Our Strategy**

- Understanding the **approval process**
  - Reach out to experts
- **Identifying roadblocks**
  - Why had it failed?
    - Cost
    - Lack of understanding of the human impact
- **Gather Patient Stories** highlighting the human impact of funding Qinlock
- Mobilising patient community to **raise awareness**
Mobilising GIST Community

- **Explain the challenges** to the patient community
  - Share own story
  - Reach out to individuals
  - Respect boundaries
  - **Build trust**

- **Build on existing networks**
  - Personal
  - GIST patient Groups
  - Cancer patient and advocacy groups
  - Everyone’s story is **unique**
  - Support patients at every point of the process.
  - Keep GIST community up to date with each step of the process
Harnessing strengths of organisations

- Life Raft Group
  - International Experts on GIST

- Rare Cancers Australia
  - Australian lead in patient support for rare cancers, understanding government drug funding approval system, and connected to local patient networks

- Pharmaceutical Company – Specialised Therapeutics
  - Understands sticking points for funding approval

- Department of Health
  - Manage the PBAC approvals committee

- GI Cancer Institute, ACT Cancer Council and other research and charity organisations
  - Understand the disease, treatment and clinical trials. Connected to patient networks
Amplifying Patient Voices

• Media Strategy to raise awareness of campaign
  • Social Media
    • Facebook - GIST Community group, personal pages, organisations, media
    • LinkedIn – connect with industry, media and patient advocate groups
  • Traditional Media
    • TV
    • Radio
    • Newspapers

• Understanding the decision makers constituency
Lobby Decision Makers

- Call to Action amongst all GIST patients and their networks.
  - Everyone had a job
  - Clear call to action with simple and guided steps

- Demonstrate a national footprint.
  The GIST community:
  - Contacted 20 Federal Members of Parliament (MP’s)
  - Met face to face with 10 MP’s
  - Face to face meeting with Federal opposition Health Minister
  - Covered all States, 4 political parties (2 majors and 2 minor parties)
  - Local, State and Federal politicians
Results

• Qinlock recommended to be funded by Government.

• What changed between March committee & August
  • Slight change in economics
  • Compelling human impact from GIST patients
  • Significant outreach to Members of Parliament & Media

• GIST community strengthened during the campaign, as well as united for future advocacy, if required.
How did we advocate for CHANGE?

- Understanding **roadblocks** and how **patient stories** can help
- Understanding who **decision makers listen to**
- **Reached out to experts** and asked questions
- **Trust** is important for the patient community
- A **sense of community** amongst GIST patients helped build a positive campaign.
Thank you

Reach out and connect via email, LinkedIn or Facebook

sarahmcgoram@yahoo.com

Sarah McGoram (Fehon)