



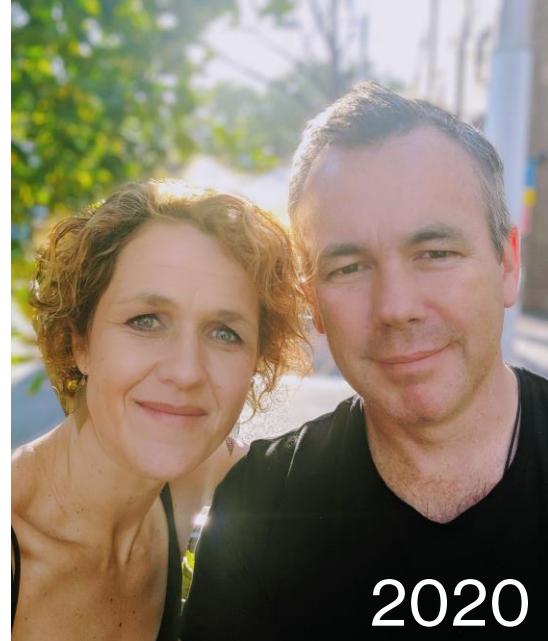
Advocating for better access: a case study

Sarah McGoram –
GIST and Rare Cancers Patient Advocate
Australia

My Story

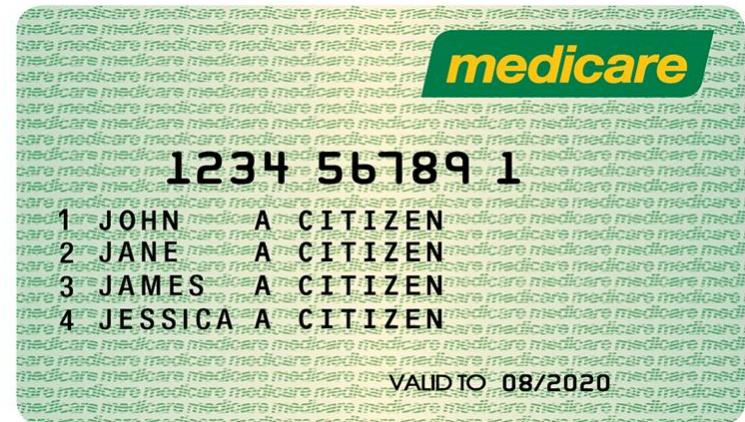


- 1996 Diagnosed with
Paediatric Wildtype GIST (SDHB Positive)
- 2001 **Glivec** Trial
- 2003 Married
- 2006 Our Son born
- 2010 **Glivec** (Imatinib)
- 2012 **Sutent** (Sunitinib)
- 2015 – today **Stivarga** (Regorafenib)
- 2021 Celebrated 25 living with GIST



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. <https://www.health.gov.au/health-topics/medicare>
- 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.



Canberra Region Cancer Centre



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;



deciphera™



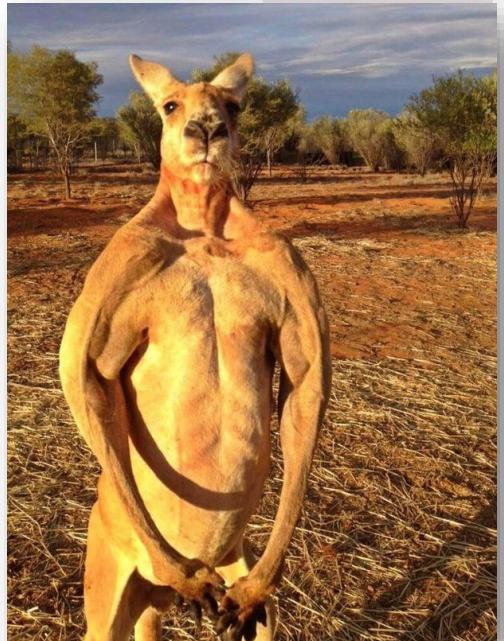
Our Challenge...

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**



*Understanding Roadblocks
within the Australian System*



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



A screenshot of a Facebook group page titled "Buy time for Sarah". The page shows a photo of a family with a dog, a bio, and tabs for About, Discussion, Topics, Events, Media, Files, and People. Below the bio, there's a "Media" section with a grid of photos related to the campaign.



Sarah McGoram (Fehon)
GIST and Rare Cancers Patient Advocate



AU-NZ GISTers

Private group · 189 members

A Facebook post from the page "2GB 873 - Sydney Talk Radio". It features a photo of a family and the caption: "Sarah McGoram's last hope to see her son graduate high school "just comes down to dollars". Below the post is another photo of the same family with the caption: "Rare cancer patient pleads with government to buy her more years - 2GB".



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



Over the past 6 weeks, #GIST patients have done everything they can to fight for #Qinlock to get funded by the PBS at today's PBAC meeting. We are a small group of patients with a #rarecancer. We are limited in what we can do as patients, but have the most to lose.

We are hopeful Qinlock will get funded today, buying us more time to live full and meaningful lives. Thank you so much to everyone who has written letters, spread the word and given up your time to help all GIST patients in Australia.

An extra thanks to the following MP's who gave up their time to meet with GIST patients:

Mark Butler MP (Hindmarsh), SA
Andrew Leigh MP (Fenner), ACT
Senator Katy Gallagher (ACT)
Alicia Payne MP (Canberra), ACT
Ben Morton MP (Tangney), WA
Dr David Gillespie MP (Lyne), NSW
Dr Katie Allen MP (Higgins), VIC
Matthew Thistleton MP (Kingsford Smith) NSW
Jason Falinski MP (Mackellar) NSW
Andrew Wilkie MP (Clark) Tas



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



Buy time for Sarah

Public group



Sarah McGoram (Fehon)

