Best practices, how to advocate for better access

Florence Thwagi, Elo Mapelu
Henzo Kenya Kenya
About us

- Made up of CML and GIST patients, about 300 GISTers.
- Key Mission: Awareness, Support and Advocacy
- We hold regular meetings in clinic set-ups
- Webinars
- Professional Continuing Medical Education for HealthCare professionals
How it started

- Glivec available as the only drug
- Administered at a central location
- Travel time and cost up to 6 days and US$100 for one patient from far flung areas
- Low awareness especially among healthcare workers.
- No support from the National Hospital insurance fund
The Progress

- Glivec + Sutent now available
- We have decentralized clinics in major towns
- Reduced the travel time and cost by half
- Sustained improvement in awareness, especially through fliers and direct engagement during Continuing Medical Education sessions
- National Hospital Insurance Fund now covers some elements of GIST treatment, surgery, and Hospital stay.
How does success look like?

- More medicines to be made available
- More administration centers opened reducing travel time and cost further.
- Create a central point of information for GIST
- National Hospital Insurance Fund to develop a comprehensive care pack for GIST patients. Recent legislative change provided for a wider resources pool to enable such development.
- Persuade our Medical fraternity to embrace mutation testing.
Key success factors

- Partnerships; with other organizations, other cancer advocates, Pharma, donor agencies and research bodies
- Information sharing among patients, Health Care Professionals and public.
- Resources mobilization for awareness, support and advocacy.
Challenges

- Limited resources for patient’s monitoring and follow ups.
- Government Bureaucracy delays policy implementation and drugs delivery.
- We only have access to 1\textsuperscript{st} and 2\textsuperscript{nd} line treatments which is a challenge for patients with advanced Gist and non responsive mutations.
- No mutation testing.
Asante sana (Thank you)