PAWS - GIST
Paediatric, Adolescent, Wild Type & Syndromic GIST

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Improving treatment & finding a cure for rare GIST cancer in young people

February 20121
What can Patient Advocates do to drive clinical research on rare cancers?

My personal experience.....

- Believe that a **cure can be found**
- Join forces with relevant groups e.g.
- Make contact with other patients
- If a patient group does not exist – **make one**
- Engage with doctors who specialise in your disease
- Find a lead clinician for whom your disease is an “obsession”
What can Patient Advocates do to drive clinical research on rare cancers?

- Know no boundaries – Seek information and contacts world-wide
- Create a clear agenda e.g.
  - patient register, tumour bank
  - co-ordinate research with other research programmes in other countries.
  - Find cure
- Communicate, Network, Connect and be a Connector
- Raise funds for research – vital component
- Be inquisitive, energetic and fearless
The future......

- Engage with Government Health representatives
- Target medical Professionals who have the research skills and persuade them to help you. *Keep asking until they say yes*
- Don’t give up – the prize is well worth the effort.