

PAWS - GIST

Paediatric, Adolescent, Wild Type &
Syndromic GIST



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Improving **treatment** &
finding a cure for rare



GIST cancer
in young people

 **PAWS-GIST** Supported by: GIST Support UK Charity NO. 1129219

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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.

