

My Life With GIST

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Diagnosis, 2014:



- ▶ Initial symptoms - abdominal pain
- ▶ Diagnosed as “diverticulitis” - a bowel problem.
- ▶ Sent to Royal Surrey for CT scan (under 2 week rule!)
- ▶ Fully expecting to be told “It’s bowel cancer”
- ▶ Told it was a GIST - “Gastro-Intestinal Stromal Tumour”.

My Reaction?

- ▶ Google search
- ▶ GIST Support UK - website, email forum, telephone help-line, information days.



- ▶ Relief &

More Tests!

- ▶ Endoscopy with fine needle biopsy
- ▶ PT scan
- ▶ Massive GIST confirmed - too big for surgery (26 x19 cm)
- ▶ Shoved aside bowels, kidneys, collapsed lung (filled with fluid).
- ▶ “High risk”, on basis of size alone

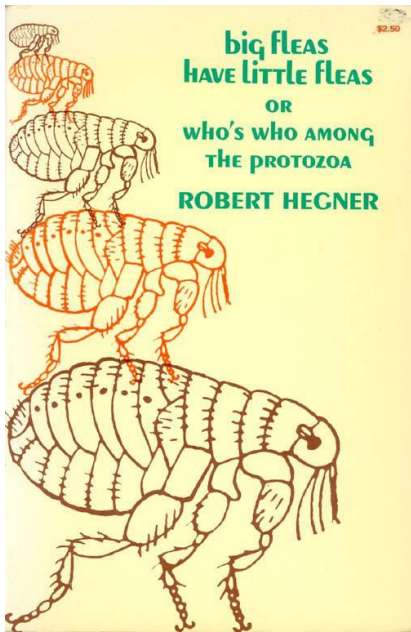


What is GIST?

- ▶ **“Gastro-Intestinal Stromal Tumour”**
- ▶ One of the sarcomas - a group of rare cancers.
- ▶ Cancer has many varieties, sarcoma has many varieties - so does GIST.
- ▶ So - GIST is a rare cancer, affecting the GI tract - especially stomach and intestines.



Big Fleas Have Little Fleas.....



- ▶ Similarly, with cancers:
- ▶ Cancer
- ▶ Carcinoma, Sarcoma, Lymphoma, Melanoma....
- ▶ Gist, Bone Cancer, ST Sarcomas, Desmoids
- ▶ Exon 11, Exon 13, Wild Type.....
- ▶

Treatment : Imatinib

(Modern “Wonder Drug”)

- ▶ Targeted, oral chemotherapy, to shrink the tumour
- ▶ Usual dosage 400mg (may vary), taken with food, water
- ▶ Numerous “possible” side effects - vary widely by patient.
- ▶ Side-effects may change over time.
- ▶ Usually taken for 3 - 5 years.
- ▶ Resistance usually sets in at some stage, followed by 2nd line or 3rd line drugs.
- ▶ NOT EFFECTIVE FOR ALL GISTS!

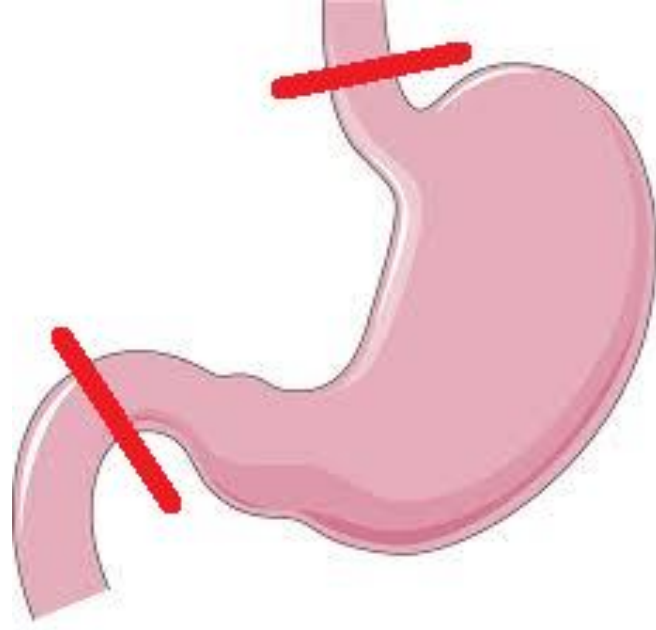


2015 Transfer to UCL Hospital (Specialist sarcoma centre)

- ▶ After 12 months, shrinkage stopped - surgery scheduled
- ▶ Asked for 2nd opinion from specialist centre
- ▶ Transferred to University College London Hospital.
- ▶ Surgery scheduled for February 2016.



Possible Gastrectomy?



- ▶ Warned I “might” lose all or most of stomach, spleen, part of pancreas, part of liver, part of diaphragm.
- ▶ In fact, lost stomach and spleen - but nothing else.

Implications of Gastrectomy

- ▶ Warned of:
 - ▶ Possible “dumping”
 - ▶ Initially liquid diet, build up slowly to solids
 - ▶ Small meals - 6/day
 - ▶ Avoid fizzy drinks
 - ▶ Don't drink with or immediately before meals.
 - ▶ Low energy levels
- ▶ My experience was much easier.



Survivorship: What works for me

- ▶ Taking ownership, finding information.
- ▶ Openness with family, friends, colleagues, and their support
- ▶ Support from fellow patients - GIST Support UK
- ▶ Confront my own mortality
- ▶ Offering support - Listserv email group / Trustee
- ▶ Conferences: New Horizons (Vienna 2018), SPAEN (Athens 2019, Milan 2020)
- ▶ Sense of Humour



GIST Support UK / PAWS GIST

(“PAWS” = paediatric, adolescent and wild-type)

▶ Patient Support

- ▶ Website
- ▶ Publications
- ▶ Email Listserv Forum
- ▶ Telephone Helpline
- ▶ Social Media

▶ Public Education / Awareness

▶ Clinical Research

Survivorship: What Else?

- ▶ Complementary therapies for quality of life
- ▶ Mental health strategies
- ▶ Faith, prayer
- ▶ Exercise
- ▶ New treatments



What Next?

- ▶ High Risk
- ▶ On imatinib “for life”
- ▶ Or -until it becomes ineffective. Then?
- ▶ Sunatinib/ Regorafenib?
- ▶ New drugs?
- ▶ Terminal?
- ▶ No recurrence?
- ▶ Something else?



