

**Paediatric Adolescent Wild type &
Syndromic (PAWS) GIST Clinic
United Kingdom**

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Lead Clinician for PAWS GIST Clinic

PAWS-GIST

- Paediatric
- Adolescent
- Wild-type
- Syndromic
 - **SDH GISTs**
 - Neurofibromatosis 1 GISTs

- PAWS-GIST – idea born in a pub in
- Oxford in 2011
- Patient & Carer led initiative

The Eagle Pub in Cambridge



Victoria Arms-Marston Oxford



PAWS GIST Clinic



**PAWS - GIST
Clinic**

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WHAT'S HAPPENING IN THE UK?

The PAWS-GIST national alliance was formed in the UK in 2010 as a joint effort between patients, carers and health care professionals, to raise awareness, improve treatments, stimulate research, understand the causes and mechanisms of GIST in children, young people and those with wild-type GIST and ultimately to find a cure for this subgroup of GIST patients.

[Read more](#)

Newsletter & Updates

stay informed
learn about PAWS-GIST
find helpful resources
take action to find a cure

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Register for the Next Clinic

27th & 28th March 2014



Donate to PAWS GIST

Help find the cure



Latest

Operating within the NICR in Newcastle, the GIST Tumour Bank will coordinate the collection, storage and distribution of a variety of paediatric and adult biospecimens...

[Read More](#)

Welcome to the PAWS-GIST Clinic Website!

PAWS-GIST is a UK based alliance of medical specialists, GIST Support UK and Patients. We have

What is GIST?

Gastrointestinal Stromal Tumours (GIST) are very rare cancers effecting about 15 people in every million. They are most common in people aged over 50. GISTs belong to a group of cancers called sarcomas.

PAWS - GIST

Improving treatment & finding a cure for rare

GIST cancer

in young people

www.pawsgistclinic.org.uk

Register for the Next Clinic

Title: First Name: Surname:

Address: City: Postcode:

Telephone: Mobile:

Email:

NHS No: DOB:

Age at Diagnosis: Year diagnosed:

Primary Tumour location: GIST tumour type: Wildtype

Hospital:

Oncologist Name: Email address: Tel No:

Can we contact oncologist?: Yes No

Surgeon Name: Email address: Tel No:

Can we contact surgeon?: Yes No

I am happy for my details to be shared with the Patient Director of the PAWS-GIST Initiative: Yes No



PAWS GIST-Clinical data

- 12 Clinics so far
- 70 pts
- Male:Female 23:47
- Median age 38 yrs Range 14-76 yrs
- Heterogeneity is the hallmark
 - SDH Deficient
 - Quadruple Negative
 - NF1 GISTs
 - KIT mutations !

Research Focus in PAWS GIST

- Collaboration
- Innovation
 - Think differently
 - Think outside the box
 - Tailor the treatment to the patient
- GIST Tumour bank established for researchers
- Active engagement with pharma
- Two trials at NIH—Aim to bring in to UK
- **Regional, National, International cooperation**

SDH Deficient GIST patients

- A Phase II Trial of the DNA Methyl Transferase Inhibitor, **Guadecitabine** (SGI-110), in Children and Adults with **Wild Type GIST**, Renal, Pheochromocytoma and Paraganglioma associated With **Succinate Dehydrogenase Deficiency**
- ClinicalTrials.gov Identifier: NCT03165721
- Principal Investigator: John W Glod, M.D. (NCI)
- Estimated Enrolment : 70 participants
- Allocation: Non-Randomized
- Masking: None (Open Label)
- Subcutaneous inj 45mg/m²/day x 5 days on a 28-day cycle.

NF-1 GISTS

- **Oral MEK 1&2 Inhibitor Selumetinib in Neurofibromatosis Type 1 (NF1) Mutated Gastrointestinal Stromal Tumors (GIST)**
- ClinicalTrials.gov Identifier: NCT03109301
- Principal Investigator: Brigitte C Widemann, M.D. (NCI)
- Estimated Enrollment : 20 participants
- Allocation: Non-Randomized
- Masking: None (Open Label)
- Oral tablets 50 mg twice daily continuous daily dosing