



THE FIRST CLINIC OF ITS KIND IN EUROPE

Rare cancers are often misunderstood, misdiagnosed, poorly investigated and have few treatment options. It is a major challenge to find the right expertise and researchers to study them.

In 2010 the prognosis for Paediatric and Wild-type GIST patients was, “**No Treatment, No Cure and No Research**”. This was the catalyst for the PAWS-GIST Clinic at Addenbrookes hospital in Cambridge UK.

GIST Oncologist **Dr Ramesh Bulusu** and **GIST patient advocate Jayne Bressington** agreed to work as a novel partnership creating an action plan to address the unmet need of PAWS-GIST patients, improve treatment, provide specialised care plans and find a cure for this rare cancer.

Further to extensive national / international networking and fundraising they now work with a multi-disciplinary team of specialists aiming to deliver a service that facilitates collaboration between clinical, academic and industry researchers, improve understanding and identify effective treatments.

Patients who are preparing for operations are encouraged to consent for their tissue samples to be collected for the UK National GIST Tissue Bank so they are available for research to improve therapeutic options. Patients can receive support to cover travel expenses and accommodation to attend the clinic from charity, GIST Cancer UK.

In March 2024 we will be celebrating ten years since the opening of the PAWS-GIST clinic.

Recognised as a national centre of expertise, patients are referred from all over the UK via their doctor or they can apply directly via www.pawsgistclinic.org.uk.

Further to attending the clinic, patients are managed with an agreed treatment plan delivered by their own hospital, supported by the PAWS-GIST clinic team.



So, what have we achieved so far...

- Registration of all UK patients ✓
- A national GIST tumour bank ✓
- A specialist PAWS-GIST clinic ✓
- Comprehensive national dataset ✓
- PAWS-GIST research ✓
- PAWS-GIST clinical trials ✓
- SIRT treatment for SDH deficient GIST ✓

Work In progress...

- Growing PAWS-GIST cells “in vitro”
- Engaging with pharma and researchers
- National commissioning for PAWS GIST
- Find effective treatments

At the start there was no infrastructure to support PAWS-GIST research. Bi-products of our work are the **National GIST registry** (*in collaboration with Public Health England*), the **National GIST Tissue Bank** and the support of eight **PAWS-GIST related research projects**.

Over the past decade, histopathological and genomic screening has improved immeasurably. More accurate patient diagnosis is **growing the numbers of PAWS-GIST patients applying to attend the PAWS-GIST clinic** and collaboration with the International GIST community is helping to accelerate progress.

Having established an infrastructure to support GIST research, **we have created a place that is dedicated specifically to patients diagnosed with PAWS-GIST cancers**.

In 2010, clinical trials were an ambition, now in 2023 **clinical trials for PAWS-GIST patients in the UK are becoming a reality**. The PAWS-GIST team are working to find answers, improve treatments and outcomes for PAWS-GIST patients, offering hope and optimism for the future.

