

Press Release

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Europe's first clinic for rare cancers to be held at CUH Addenbrooke's

A UK wide team of experts in rare cancers is due to meet at CUH Addenbrooke's hospital in Cambridge next week for the first clinic of its kind in Europe.



The PAWS-GIST clinic will investigate very rare **Paediatric and wild-type GIST cancers** for which there is no successful treatment. The clinic will take place on **28th March 2014**.

Ten patients from across the UK will be invited to the clinic which will run for one day, three times a year and where clinicians will examine patients, and conduct further specialist investigations where needed, to help advance research and treatment.

Dr Ramesh Bulusu, Consultant Oncologist at Cambridge University Hospitals, is the national lead consultant for PAWS-GIST. His team hope that if it's successful, the UK clinic can expand to take patients from across Europe. He said "Oncologists in other parts of the country have not been able to gain enough experience of this disease as they only see one or two patients a year. Creating this national clinic and a network of PAWS-GIST cancer specialists will improve our knowledge about these rare cancers. The wider the field we work in, the more likely we are to be able to develop a treatment at some point in the future."



Dr Bulusu said: ***"We won't be taking over the medical care of the patients attending our clinics but hope to make recommendations, based on the information that we gather. We will be able to coordinate some services or tests that are not available to the patients locally."*** There is only one other clinic in the world for this rare cancer – at the National Institute of Health in Bethesda, Maryland, USA.

Bristol mum Jayne Bressington first approached Dr Bulusu four years ago after her daughter was diagnosed with PAWS GIST cancer. The idea of the clinic grew from there. **Jayne** said ***"The past four years have been very hard work. We are totally indebted to Dr Bulusu, Addenbrookes Hospital, the national PAWS-GIST alliance and everyone who continues to support our fundraising efforts to get this clinic up and running."***

The clinic is for anyone diagnosed with **GIST cancer in childhood or adolescence or who has been diagnosed with a Wild-type or Syndromic form of GIST as an adult.**

Applications to attend should be made via the clinic website **www.pawsgistclinic.org.uk** which also contains a wealth of information for patients, their families and those who are keen to support this ground breaking initiative.

Ends.

NOTES FOR EDITORS

1. GISTS, or gastro intestinal stromal tumours, are rare cancers of the digestive tract occurring in about 15-20 people for every million of the population - currently about 700-900 cases in the UK.
2. PAWS (Paediatric, Adolescent, Wildtype and Syndromic) GIST is an even rarer subgroup of the cancer among children and young adults, which accounts for around 15 per cent of GIST patients. About 100 patients per year in the UK fall into this category.
3. Picture Dr V Ramesh Bulusu Consultant Oncologist and UK Lead for PAWS-GIST Clinic.

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