## **UK National GIST Tissue Bank**





Jayne Bressington
Vice Chair GSUK
Patient Director – PAWS-GIST
Mother of a young GIST Patient
who was diagnosed in 2010

### UK National GIST Tissue Bank timeline...



Identified need to collect Tiussue Samples for PAWS-GIST project.

Started presenting existence of bank hosted in Newcastle CRUK bank to patients in GSUK meetings X4 fresh PAWS-GIST samples and x1 other fresh GIST sample transported to the bank.

MAB/ access committee established.

**Rules TBA** 

Patients constantly reminded to donate tissue to the bank.

Process still not standard practice...

Working on this...

Shared process documentation with US SDH deficient GIST colleagues

2010

2011

2012

2013

2014

2015

2016

2018+

Introduced to Professor Andy Hall Newcastle Biobanking Expert.

1<sup>st</sup> fresh PAWS-GIST samples transported to the bank

Ethics committee give full approval for National GIST Tissue bank Tissue Bank moves to permanent home at Royal Marsden Hospital in London.

The ROYAL MARSDEN
NHS Foundation Trust





- Collecting Fresh Frozen tissue & Blood samples for research
- Every patient advised all the time that we need Fresh frozen tissue and blood samples for research...







- Possibly the largest collection of SDH deficient GIST samples in Europe/World available to researchers.
- Currently supplying five research projects undertaking SDH deficient GIST research.
- Process being improved through time
- Hope to standardise so that <u>ALL GIST</u> patients being operated on at the RMH are consented for the NGTB.

### I needed a tissue bank...



- To find a cure for my daughter.
- To find a cure for other PAWS-GIST patients
- To find a cure for GIST patients as a whole.
- It's a no brainer
- Majority of patients think "these things already exist".
- It is incredibly frustrating as a patient when you realise they don't already exist.
- There is no greater motivation to doing everything to change that situation...



# We are still working to...



Increase Awareness of GIST



- We are now, actually creating a UK Infrastructure to stimulate GIST research aiming to find a cure...
  - The National GIST Tissue Bank is now nationally recognised in the National GIST guidelines
  - Mutational Analysis is now the national standard
  - GIST cell lines/Xenografts & trials W.I.P
  - A National GIST Registry now exists and growing
  - Grow/Support PAWS-GIST clinic we just held clinic 15
  - To offer GIST specific research grants.....





#### By January 2019 we had collected:

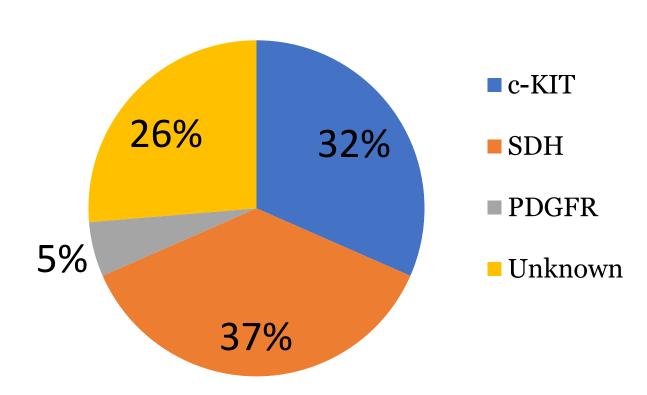
Total	Total	Total
number of	Number of	<b>Number of samples</b>
<b>Patients</b>	samples	dispatched to
donating	held in Bank	researchers so far
19	242	29

Have developed & refined the Standard Operating procedure.













Researchers at University of Cambridge:









**Dr Ruth Casey** 

**Prof Eammon Maher** 

**Dr Olivier Giger** 

**Dr Ramesh Bulusu** 

# Tissue being supplied to...



Researchers at:

**CRUK Beatson Institute in Glasgow:** 



**Dr Henry Daebritz** 



**Prof Eyal Gotlieb** 

& University of Sheffield



**Dr Karen Sisley** 

# Later this year...



 our tissue bank team have to apply for a reapproval of ethics for the bank.

•Once we have this approval we will be included on the National Cancer Research Institute (NCRI) register which will expose us to an even wider selection of researchers.

## On behalf of GIST patients in the UK...



