

# UK National GIST Tissue Bank



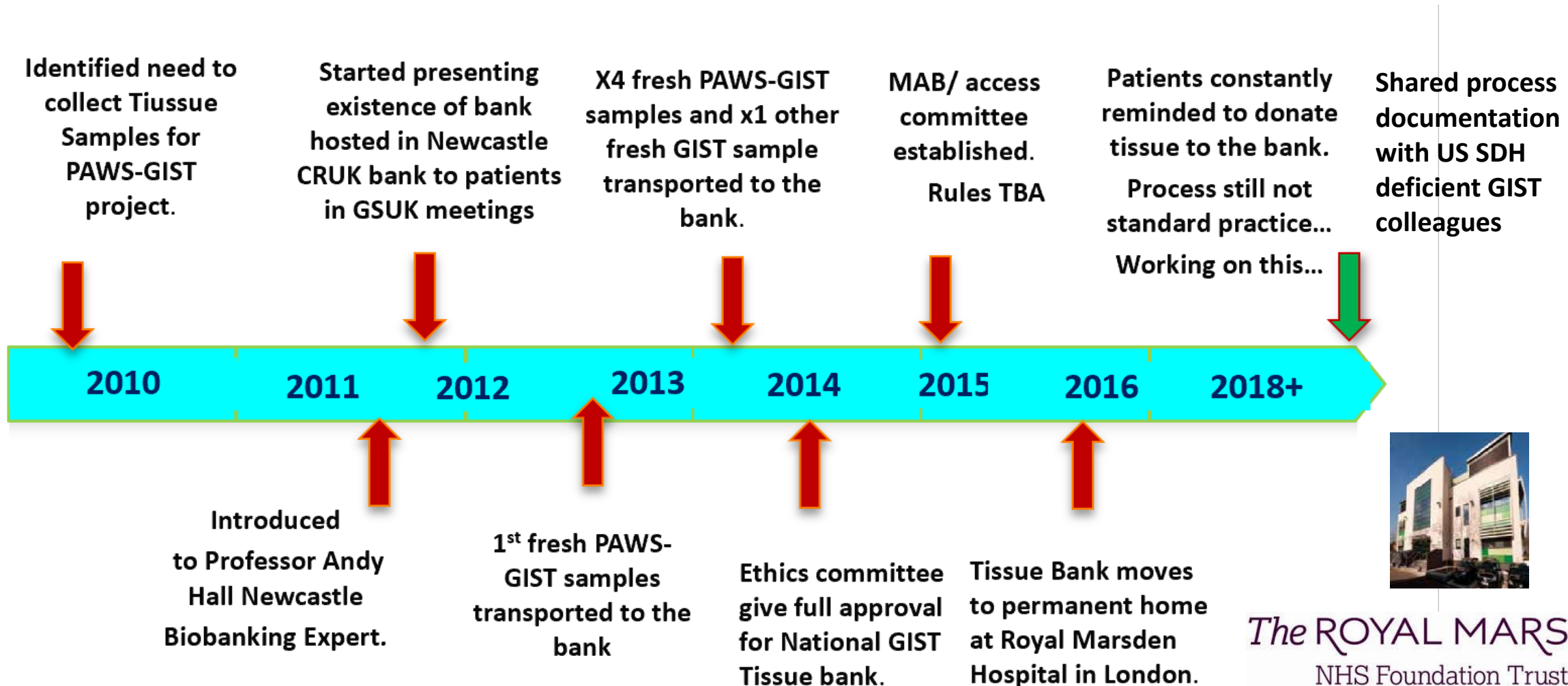
**Jayne Bressington**

**Vice Chair GSUK**

**Patient Director – PAWS-GIST**

*Mother of a young GIST Patient  
who was diagnosed in 2010*

# UK National GIST Tissue Bank timeline...



# National GIST Tissue Bank...

- 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...

**NOBODY WANTS GIST TUMOURS**

**WE DO....**

**NATIONAL GIST TISSUE BANK**

# National GIST Tissue Bank 2019...

- 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 ALL GIST 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.....**

# Since then...

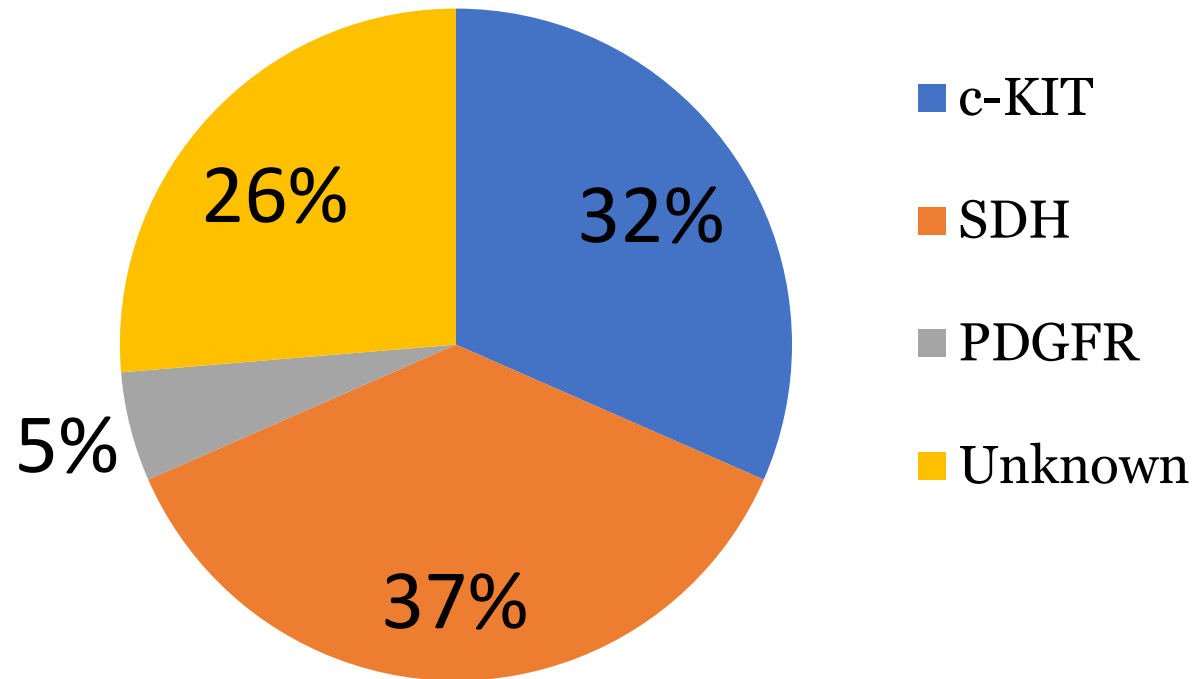
**By January 2019 we had collected:**

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

*Have developed & refined the Standard Operating procedure.*

# Sample types collected...

**Mutation Types**





# Tissue being supplied to...

- **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:**

**& University of Sheffield**



**Dr Henry Daebritz**



**Prof Eyal Gotlieb**



**Dr Karen Sisley**

# Later this year...

- our tissue bank team have to apply for a **re-approval 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...

