



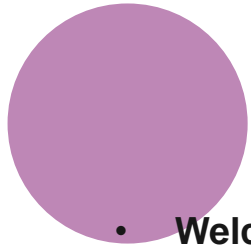
Joining forces for action

RCE-ESMO-ESO Training Course for Rare Cancer Patient Advocates

Patient Involvement in Clinical Research

Patient involvement in tumour banks

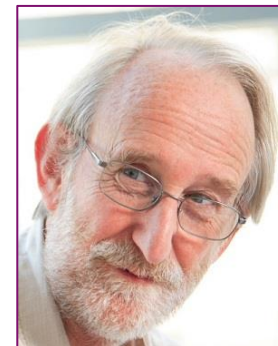
Today's Agenda...



- **Welcome**
- **What is a tumour bank and how does it help research?**
- **Why is patient involvement essential for a good tumour bank?**
- **Discussion / questions**
- **Conclusions**



Jayne Bressington
Patient Advocate



Professor Andy Hall
Tissue Bank Specialist

Declarations of interest

- Professor Hall is a director and shareholder for RareCan Limited
- Jayne Bressington has no conflicts of interest to report



Please:



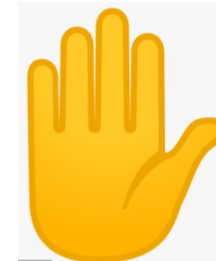
- **post questions via the chat box**

We will also take questions from the floor at the end

- **put your camera on during the question time.**

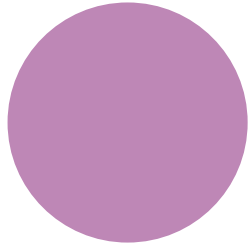


- **use the raised hand system to ask a question**



For **technical issues**, please send an email to rarecancerseurope@esmo.org and we will get back to you...

What is a tumour bank?



Professor Andy Hall

Tumour banking specialist



What is a tumour bank?

A tumour bank is:

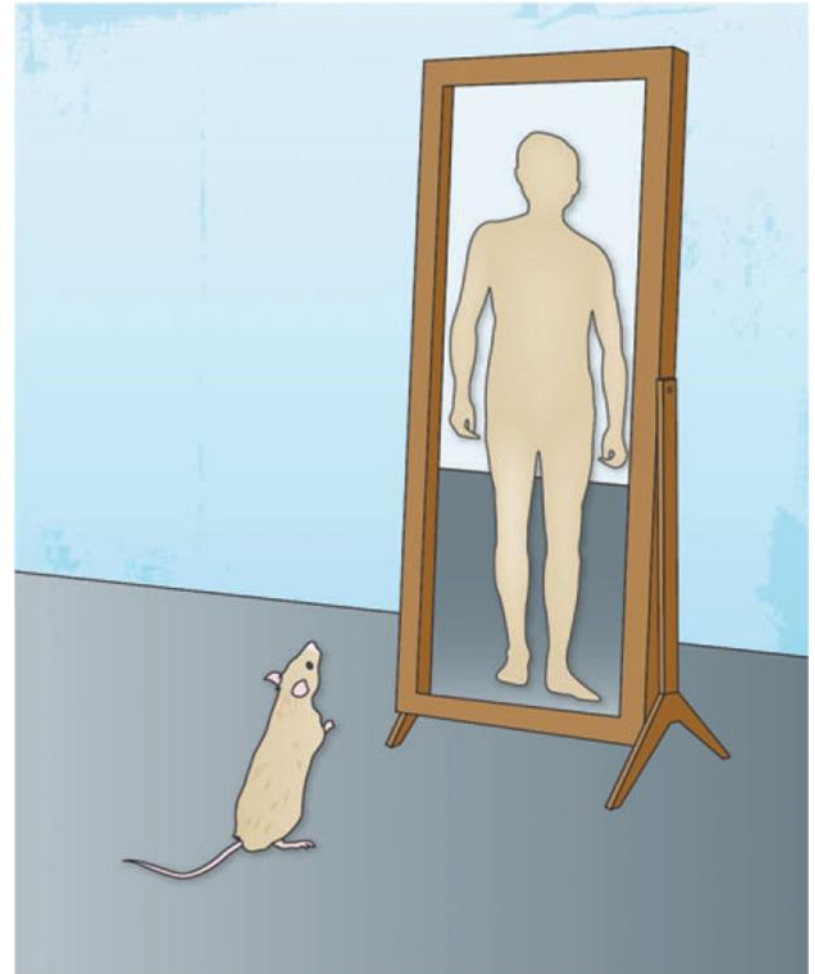
“a collection of samples from tumours, ideally with matching normal blood, for distribution to researchers to find new and better ways to diagnose and treat cancer”



Why do researchers need access to patient samples?

- Mice (and cell lines) are not always like humans
- Tissue samples can be screened to find new drug targets

e.g. mutations in the KIT gene in Gastrointestinal Stromal Tumours (GIST)



Why are tumour banks particularly important in rare cancers?

- Reliable science depends on finding patterns and reproducing results
- This means finding as many cases of a particular cancer type as possible
- For rare cancers this is a problem as samples are scarce.
- If it is difficult to find the samples for research this can be a barrier for researchers and drug companies
- A tumour bank works by assembling enough samples to make research studies possible

What is the best way to maximise the value of tumour bank samples?

- **Common mistake** – lots of samples which are not accompanied by adequate clinical data.
e.g. a lack of histology which makes coming to a research conclusion impossible.
- **Better tumour bank set up** - present researchers with as much information as possible so they can target their research
- Ideally **screen patients** for relevant mutations

How do drug companies normally develop new drugs?

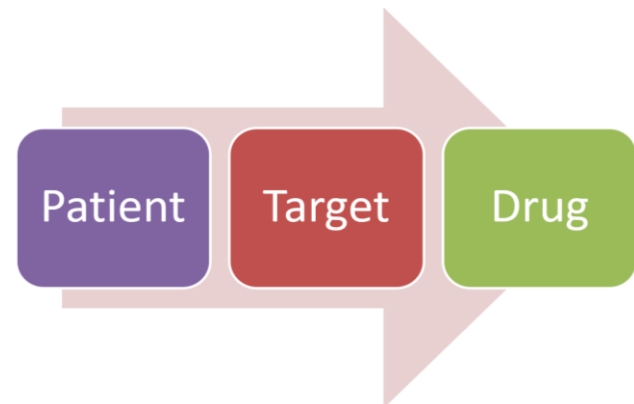
- **Step 1 – identify a target**
- **Step 2 - develop a drug**
- **Step 3 – find the patients and undertake a trial**



N.B. Rare cancer trials often fail at step 3 because insufficient patients can be found

How can a tumour banks make this work faster?

- **Step 1** – find patients of a particular rare cancer type
- **Step 2** – screen samples for target mutations
- **Step 3** – Undertake the trial using the patients recruited in step 1



Getting it right first time...

- **Obtain consent of patient at diagnosis** to collect samples and re-approach if drugs become available
- **Obtain patient tumour sample and screen them for targets** for drugs that are available
- **Retain DNA for rapid re-testing** when new drugs become available
- **Allow pharma companies to access** the “**anonymised**” tumour bank database.
- **With patient permission** involve their oncologist so that they can evaluate the potential benefit of clinical trials discovered to be relevant to their condition.

Taking this “Screen & Recruit” approach helps research by enabling...

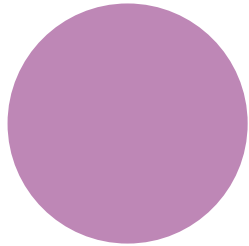
- More **rapid patient recruitment**
- More **rapid drug evaluation** (but greater up-front costs)
- **Reduced trial costs**
- Greater **patient involvement**
- **Hope** (not to be confused with false expectation)

What role do patients have?



Patients are the driving force!

Why patient involvement is essential for a good tumour bank



Jayne Bressington

**Vice Chair - GIST Cancer UK
Patient Director – PAWS-GIST**

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

UK - National GIST Cancer Tissue Bank



When my daughter was diagnosed with SDH deficient GIST cancer we were told:

- **No effective treatments**
- **No research in UK**
- Many unanswered questions
- **“lack of infrastructure”** to support GIST research in the UK
- I could not accept this situation so I decided to:
“find a way to change it”
I wanted to find a cure for my daughter

The network that we developed...



Working with specialists such as Dr Ramesh Bulusu & Prof. Andy Hall we...

- identified what was needed
- Created a “wish list”
- Created a “project plan”



Paediatric, Adolescent, Wild-type & Syndromic GIST

PAWS - GIST
improving treatment & finding a cure for rare GIST cancer in young people

Background

In 2009 & 2010 there were several new cases of Paediatric GIST diagnosed in the UK.

As parents we have found it almost impossible to comprehend that there is no specialist treatment available in the UK for our children or older wild-type patients.

We have joined forces with a group of specialist GIST doctors and GIST Support UK to form PAWS - GIST



Fig. 1
Stacey McAuliffe's plea for action Spring 2010

Project Aims

By pulling together the combined knowledge of GIST experts in the UK, USA & Europe we hope to:

- pool & share knowledge
- define the most effective treatments
- improve life expectancy / quality of life
- ultimately find a cure for Paediatric / Wild-type GIST

We would also like to find an appropriate way to include Paediatric GIST patients in clinical trials of drugs that could provide the cure or at least the best treatments.

PAWS - GIST

Project Implementation

- made contact with **gist**
- met with Dr Su Young Kim, NIH Washington DC
- composed a letter explaining our plight and what we hope to achieve
- searched to find UK based Oncologists, Surgeons & Pathologists with GIST experience.
- sent letter to 33 UK based doctors asking if willing to form a specialist Paediatric & Wild-type GIST Focus group
- 11 responded saying YES....
- inaugural PAWS-GIST meeting Nov 2010





Agreed Actions

- registration of all UK patients & data collection
- growing wild type GIST cells "in vitro"
- minimum doctors data set before seeing patients
- research to achieve better outcomes and a cure
- human tissue, biopsy & blood sample management
- create specialist PAWS-GIST treatment centres
- include Paediatric GIST patients in clinical trials
- break down the Sarcoma & GI MDT barriers
- find a cure

Project Results so far...

- found 25 UK PAWS-GIST patients
- found Professor in Dublin researching PAWS-GIST
- have key GIST clinicians working on PAWS-GIST
- raised c.£18,000 by fundraising since June 2010
- widened our network in the UK, USA & Europe
- yet to find a source of GIST cell lines in the UK
- still a long way to go....

Project Attribution

Dr Ramesh Bulusu, Dr Stephen Lewis, Dr Michael Leahy, Dr Ramesh Bulusu, Dr Michael Leahy, Professor Ian Jordan, Dr Su Young Kim, Janet Sheehy, Julie Tattersall, Lugh McKeown, Stacey McAuliffe

For more information please contact Jayne Bresington
 j.bresington@paaws-gist.org.uk 077143 40211 www.paawsorguk.com/qaawstheassociation/101

Our Objectives in 2010 ...

- registration of all UK patients & data collection
- growing wild type GIST cells “in vitro” ongoing
- minimum doctors data set before seeing patients
- research to achieve better outcomes and a cure
- **tissue, biopsy & blood sample management**
- **A National GIST Tissue bank”**
- **create a specialist “PAWS-GIST clinic”**
- include Paediatric GIST patients in clinical trials
- break down the Sarcoma & GI MDT barriers
- Gain “Specialist Commissioning Status” for GIST patients in the UK
- find a cure

How did we start The UK National GIST Tissue Bank?

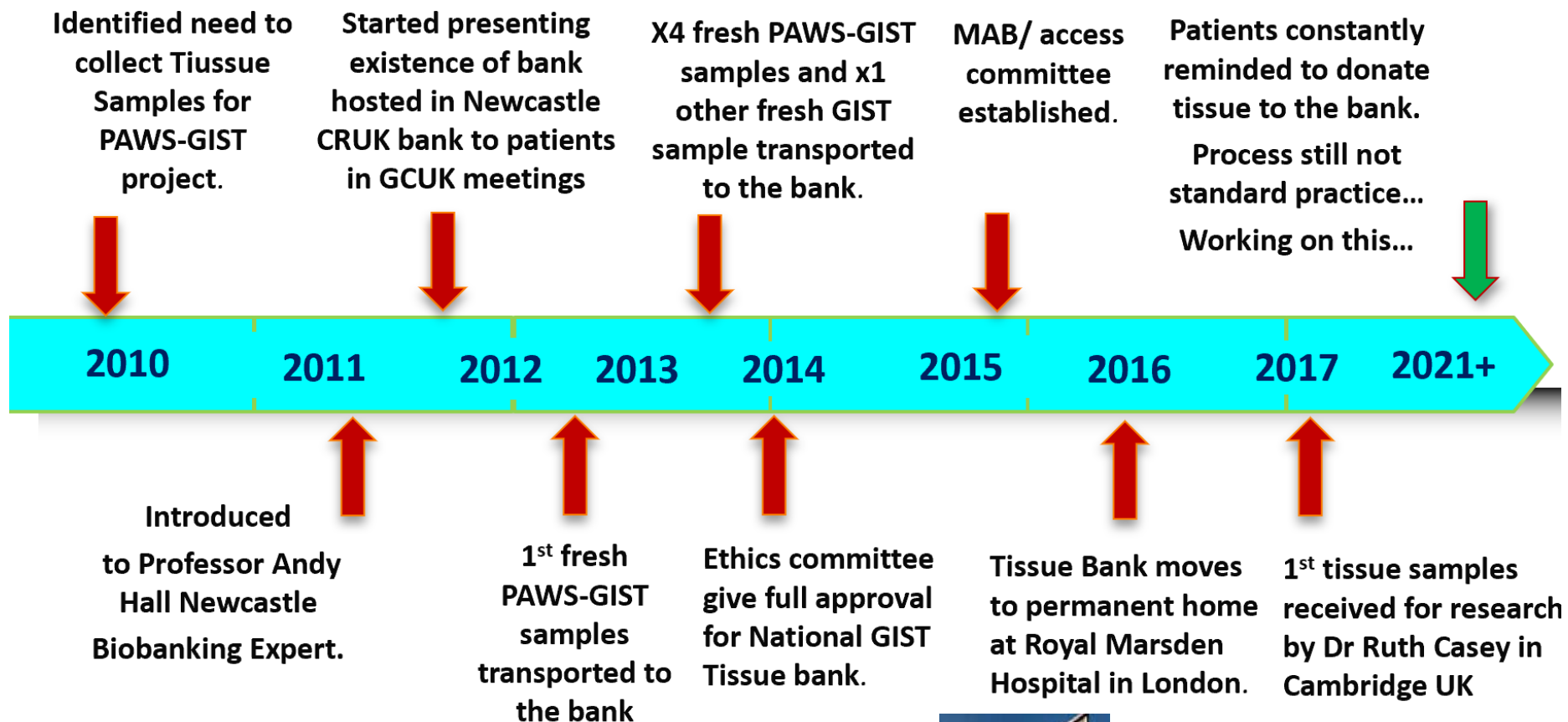
- Professor Hall managed a Tissue Bank in Newcastle
- He provided consent forms & advised about how to engage with patients to collect **Fresh Frozen** tissue & Blood samples for research
- **I advised patients all the time that we needed** - Fresh frozen tissue and blood samples for research...
- The first samples were collected from my daughter

NOBODY WANTS GIST TUMOURS

WE DO....

NATIONAL GIST TISSUE BANK

UK National GIST Tissue bank timeline...



The ROYAL MARSDEN
NHS Foundation Trust

My patient advocate role in making it work...

How we collect tissue for the UK National GIST Tissue Bank (NGTB)

Patient is advised they will be having an operation:



- Patient tells tissue bank / GCUK they would like to donate tissue.
- Tissue Bank / GCUK send consent forms to patient to sign and return along with permission to contact their Surgeon.
- Tissue Bank / GCUK engage with surgeon to provide signed consent forms and make arrangement for collection of fresh tissue and blood samples (*not formalin fixed*).
- Everybody e.g., patient, clinicians Tissue Bank / GCUK, agree what is happening, when.
- GCUK organise and pay for the specialist courier to transport the tissue to the bank.
- Tissue bank re-confirm consent with patient

Operation Date:

- Surgeon confirms consent to donate tissue directly with patient.
- Anaesthetist takes x2 blood samples in EDTA tubes and labels them appropriately.
- Surgeon removes tumour and keeps it fresh. (*Not in formalin*).
- Tumour tissue & blood samples are sent to the histopathologist who has agreed to prepare the samples asap.



- Histopathologist receives and selects the diagnostic samples then prepares fresh / frozen samples for the NGTB.
- Courier arrives at appointed time to collect samples and transport them in specialist containers to the NGTB in London with relevant labels and documentation.
- NGTB confirm receipt of tissue samples and accompanying documentation.



A few weeks after the operation:

- NGTB/GCUK calls patient to see how they are recovering.
- Patient is asked to send their histopathology report to NGTB.
- Samples available to researchers who make an application | that is approved by the GCUK Medical Advisory board.



The NGTB is a UK based project

This picture gives an overview of how we have found a way to make it work.

Things will work differently outside of the UK

UK National GIST Tissue Bank 2021...

- Possibly the largest collection of SDH deficient GIST samples in Europe/World available to researchers .

- Tissue being supplied to:

- Researchers at University of Cambridge:



Dr Ruth Casey



Prof Eammon Maher



Dr Olivier Giger



Dr Ramesh Bulusu

- Researchers at:

CRUK Beatson Institute in Glasgow:



Dr Henry Daebritz



Prof Eyal Gotlieb

& University of Sheffield



Dr Karen Sisley

- Process being improved through time
- Ethics approval was renewed for 5 years in 2020.

Our next steps...

- GIST Cancer UK are now working in partnership with



- To grow its list of rare cancer patients who want to help with research into their cancer and speed research

I needed a GIST 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.
- Majority of patients think **“these things already exist”**.
- There is no greater motivation to doing everything to change that situation when your child is in danger...



Our UK National GIST tissue bank was only possible with:

- **guidance from “tissue banking specialist”** Professor Andy Hall...
- a great deal of hard work and persistence from **“a driven patient advocate”** (me).
- Significant **networking and communication**

Key tips for success:

- **Find Allies** - Doctors & Specialists with the same vision.
- **Work collaboratively & with purpose** to achieve the vision
- The two elements **cannot succeed independently**



Discussion / Questions?

Professor Hall:

- How many patient advocates have approached you about setting up a tissue bank?
- What did you do in the background to set up the UK National GIST Tissue Bank?

Jayne:

- What / who prompted you to set up a GIST tissue bank?

Questions to the floor...

- Do any of you have a tissue bank for your cancer group in your country?
- Have any of you tried to set up a tissue bank?
- What do you think are obstacles to having a tissue bank in your country?

Questions from the floor...



R CANCERS EUROPE E

Joining forces for action

Thank you!



www.gistcancer.org.uk
www.pawsgistclinic.org.uk