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
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

www.rarecan.com
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”
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...

- **2010**: Identified need to collect tissue samples for PAWS-GIST project.
- **2011**: Introduced to Professor Andy Hall, Newcastle Biobanking Expert.
- **2012**: Started presenting existence of bank hosted in Newcastle CRUK bank to patients in GCUK meetings.
- **2013**: 1st fresh PAWS-GIST samples transported to the bank.
- **2014**: X4 fresh PAWS-GIST samples and x1 other fresh GIST sample transported to the bank.
- **2015**: Ethics committee give full approval for National GIST Tissue bank.
- **2016**: Tissue Bank moves to permanent home at Royal Marsden Hospital in London.
- **2017**: MAB/access committee established.
- **2021+**: Patients constantly reminded to donate tissue to the bank. Process still not standard practice... Working on this...
- **2021+**: 1st tissue samples received for research by Dr Ruth Casey in Cambridge UK.
My patient advocate role in making it work…

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
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:
  - Prof Eyal Gottlieb
  - Dr Henry Daebritz
- & 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 RareCan

www.rarecan.com

• 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…
Thank you!

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