

How patient groups can “Contribute to Research”

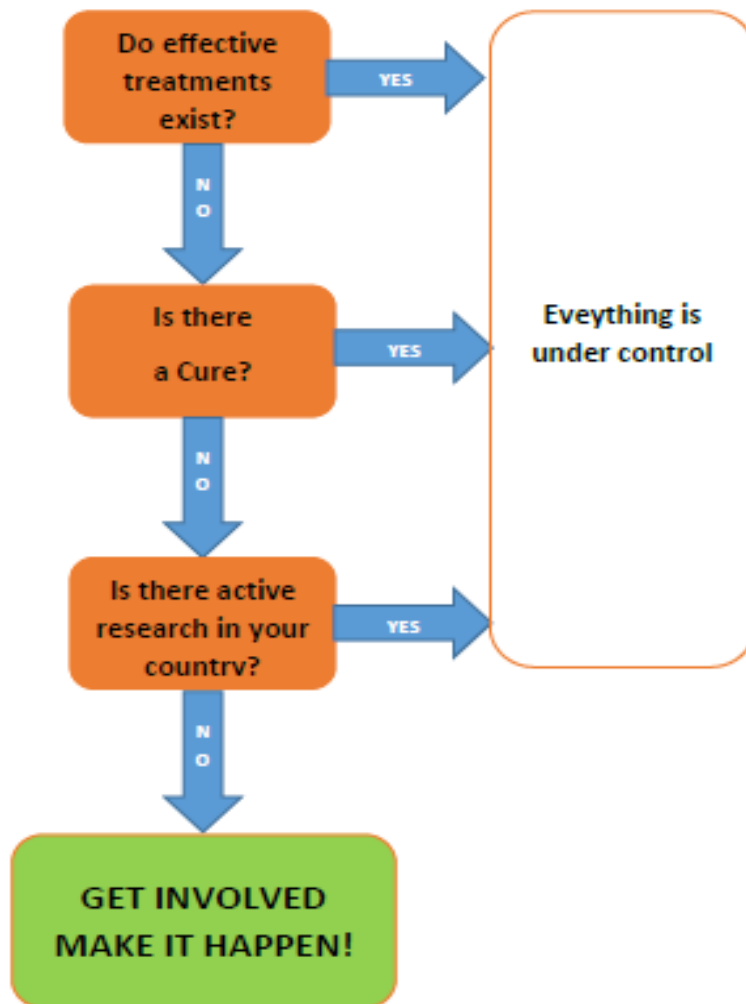


Disclosure slide

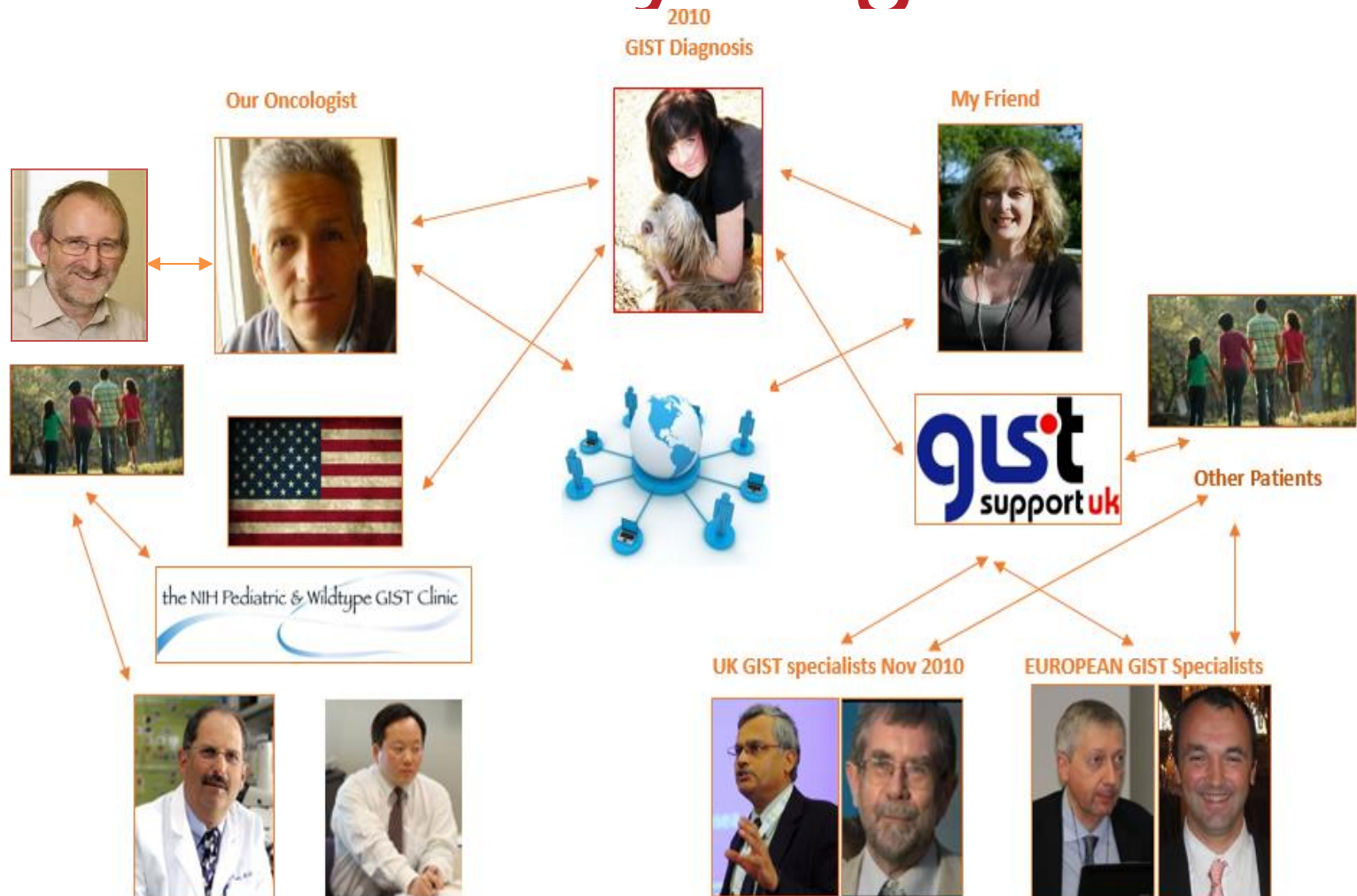
Jayne Bressington



What currently exists ?



Our story begins...



In our case we found...

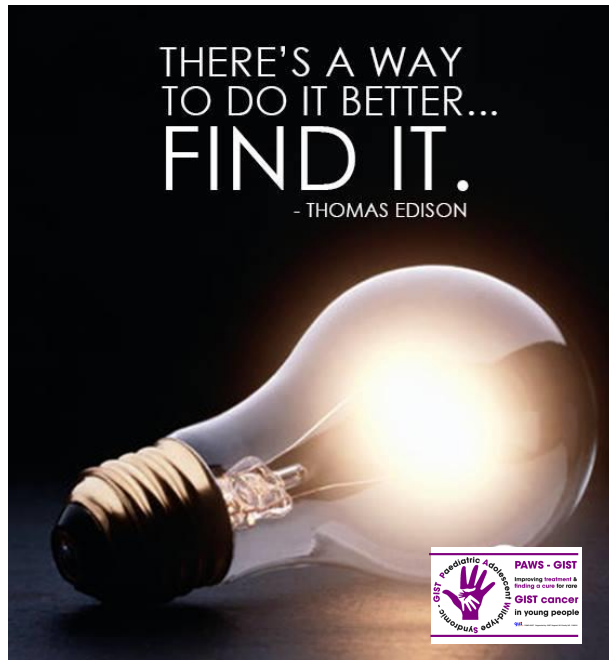
- No effective treatments
- No research in UK
- Many unanswered questions
- “lack of infrastructure” to support GIST research in the UK



– Similar picture in mainland Europe

Options....

– Accept how it is...



or

- Find a way to improve it!

Work with specialists

- Identify what is needed
- Create a “wish list”
- We created a project plan



Paediatric, Adolescent, Wild-type & Syndromic GIST

PAWS - GIST Empowering 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 Slacey McCully's plea for action Spring 2010

Project Implementation

- made contact with **gist** in Washington DC
- 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
- enable specialist PAWS-GIST treatment centres
- include Paediatric GIST patients in clinical trials
- break down the Sarcoma & GI MDT barriers
- find a cure

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.

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.£16,000 by fundraising since June 2010
- reduced 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 Norval Baker, Dr Stephen Lewis, Dr Wilfred Leary, Dr Andrea Blake, Dr Jonathan Staley, Professor Ian Judson, Dr Su Young Kim, April Thompson, 2010 National Legi Healthcare, Nancy Seckley

PAWS - GIST

For more information please contact **Jayne Bessington**

j.bessington@paws-gist.org.uk tel: 077143 48241 www.gistsupportuk.com/paediatriccommunity.htm

Networking and Communication

- Find out who is doing what
- Find allies
 - Doctors with the same vision
- Work to facilitate the vision



Our Objectives - 2010

- **registration of all UK patients & data collection - WIP**
- **growing wild type GIST cells “in vitro” – WIP**
- **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 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**
- **find a cure - WIP**

Current Status 2014...

-  **PAWS - GIST Clinic** launched 2014
- National GIST Tissue Bank
- Register started...
- x4 attempts to grow cell lines this year so far...
- Building a PAWS-GIST patient data set
- Work continues...



Patient groups CAN “Contribute to Research”

- 4 years so far... not yet reached our goal....
- Creating infrastructure to support research
- Patient data and tissue samples – rare
- Formula:

Patients + Doctors + Fundraising =



Organise, Focus, Communicate, Network

Where there's a will, there's a way!

