Issues facing Rare Cancer Patients in Europe

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These are Rare Cancer Patients...
“Everyone”
can be a rare cancer patient “tomorrow”
One day this was my family......
Next day we were this.....
The “challenges” that face you when you are diagnosed with a rare cancer...

- Most patients learn that there is NO CURE
- Nobody knows what causes them
- They are not preventable
- Most doctors have not heard of them
- Difficult to find doctors who are expert in them
- Often misdiagnosed / late diagnosis allowing progression and other “avoidable” disasters
- Difficult to accrue enough patients for clinical trials
And when you try to look further and do something...

- Little research or funding for research
- You are told that your numbers are too small to attract help
- Few treatments and limited access to innovative therapies
- Treatments are very expensive
- Difficult to obtain clinical data: Numbers are small & dispersed
- Hard to find other patients
- Poor survival rates
- Rarely any specialist centres with experienced staff
What is important to rare cancer patients?

» Correct diagnosis
» Information and Support
» Effective Treatments and Access to these
» Research to find innovative treatment options
» A cure

and

» Confidence that “the system” is actively geared to support this!
The most pressing needs...

» Improved access to existing treatments:
  • **Educate doctors** - recognise rare cancers earlier (primary care / GP’s)
  • **Improve diagnosis** – standardise 2\textsuperscript{nd} opinions, scans & mutational analysis

» An infrastructure supporting translational research / cross border cooperation:
  • **Tumour banks & easy tissue transfer for research**
  • **Clinical trials on an International scale to maximise patient numbers.**
  • **Harmonised European patient data registries**

» **Drug approval by EMA:**
  • **New methods and approaches for rare cancers**
  • **Development & protection of Orphan drugs**
  • **Re-use of existing drugs** – already approved for other diseases
  • **A re-examination of benefit v risk**
Continued...

» Please remove the barriers inhibiting.....

• Cross border transfer of tissue and patient data
• Drugs approval for small groups
• Re-imbursement for off label use of existing drugs across Europe
• Access to patient data – data protection regulation should facilitate access for health research

Help!!!!! Please remove the RED TAPE.....

The patient is the owner of the tissue and data, so in the end, only his or her consent matters
Rare cancers are......

» Fundamental cancers

» Understanding Fundamental cancers will provide insight and understanding into Common Cancers.

» Rare cancer communities are very good at "proving the case" for innovative research and can do so with a very small budget.

» Translational research into rare cancers can serve as a role model.
What rare cancer patients need in Europe

» Cross border collaboration to make small national patient groups become a larger international group.

» Cross border collaboration to offer the best existing treatment to all rare cancer patients

» Remove barriers and use common sense regarding:
  • legislation on tissue & bio-banking
  • patient data registries
  • cross border treatment and re-imbursement
  • drug approval
  • re-use and off label use of approved drugs

» Make it attractive to research into rare cancers in Europe
Rare Cancers –
more common than you think ...

Thank you for your help