## How to put this into clinical practice?

### JY Blay

Medical Oncology, Lyon

EORTC

**Conticanet, EuroSARC** 

## We need

- To improve compliance to CPGs
- Reference centers
- More simple academic clinical trials
- Extensive database and series of patients and tumor samples
- To integrate research into routine

Θ

#### How can YOU help?

Sign our petition NOW ....

#### ...and ask FRIENDS, **COLLEAGUES** and CONTACTS ...

۲

...to support this initiative by SIGNING UP too!

The European Action Against Rare Cancers is a joint initiative based on a partnership between the European Society for Medical Oncology (ESMO), the European Organisation for Rare Diseases (Eurordis), the European Cancer Patient Coalition (ECPC), Conticanet, the Association of European Cancer Leagues (ECL), the Chronic Myeloid Leukaemia Support Group, the International Brain Tumour Alliance (IBTA), Orphanet, the Chronic Myeloid Leukaemia Advocates Network, the European Institute of Oncology (EIO) and the Fondazione IRCCS Istituto Nazionale dei Tumori, as well as Novartis Oncology as the founding sponsor.

The organisations collaborate as equal partners and all decisions are made on the basis of consensus. The initiative is moreover supported by eight corporate organisations.

For more information about this European initiative, please visit our Web site: www.rarecancers.eu

or contact us: **European Action Against Rare** Cancers c/o Robert Schaefer

Brunnenstrasse 178/179 10119 Berlin, Germany T+49 (0)30 288 797 55 F+49 (0)30 288 797 66

schaefer.robert@esmo.org www.rarecancers.eu



Collaborating Partners:

(izer) Oncology



UROPAB



Pharma

**RARE CANCERS: MORE COMMON** THAN **YOU THINK!** 

☑ Sign the call to **ACTION AGAINST RARE CANCERS** 

www.rarecancers.eu



**European Action Against Rare Cancers** 

### Conticanet

Connected as **jmcoindre** with **Centre data manager** privileges (**ConticaNET** : Bergonié)



#### Menu Home Charter Survey Export Patient ⇒ Audit ⇒ Online Help ⇒

#### Welcome to conticabase

#### The CONTICANET database and tumour bank

This database contains anonymised information describing the tumour, treatment and follow-up as well as tumour sample availability and molecular biology analyses for mesenchymal tumours except GIST and bone tumours.

The tool can be used as a local center database thanks to its rules for access to patient data and material. It will be maintained and updated centrally. Please follow this this link to fill the account application form

The guery tool allows users to ask guestions about the overall content of the database in order to evaluate the feasibility of specific collaborative studies.

We hope this database will become an important tool for increasing our knowledge on these rare tumours and for developing joint research programmes.

#### Website requirements

This website has been designed for both Firefox 3 (advised) and Internet Explorer 7 (or older versions). Please note that some features may not work correctly with other web browsers.

#### Content overview

conticabase currently contains the following data from **26** out of the **43** registered centres :

- 4804 Patients
- 4826 Tumours
- 5699 Samples (5493 Paraffins and 2600 Frozens)

## **Networks and PAGs**

- Health care Networks
- Reference centers, within quality control programs. They improve health care and they improve accrual in trials as well as clinical quality within clinical trials.
- Patient information about trials (what they are, where they are available). There is even a greater added value for the today patient in entering a trial.

### **18 SPAEN Full Members**



# A World Sarcoma Network is needed











German Interdisciplinary Sarcoma Group

## **Strategies**

• Simple prospective clinical trials

- Smart retrospective studies
  e.g. long responders
- Generate attractive hypotheses

### The World Sarcoma Network (2009)

### **Studies pipeline**

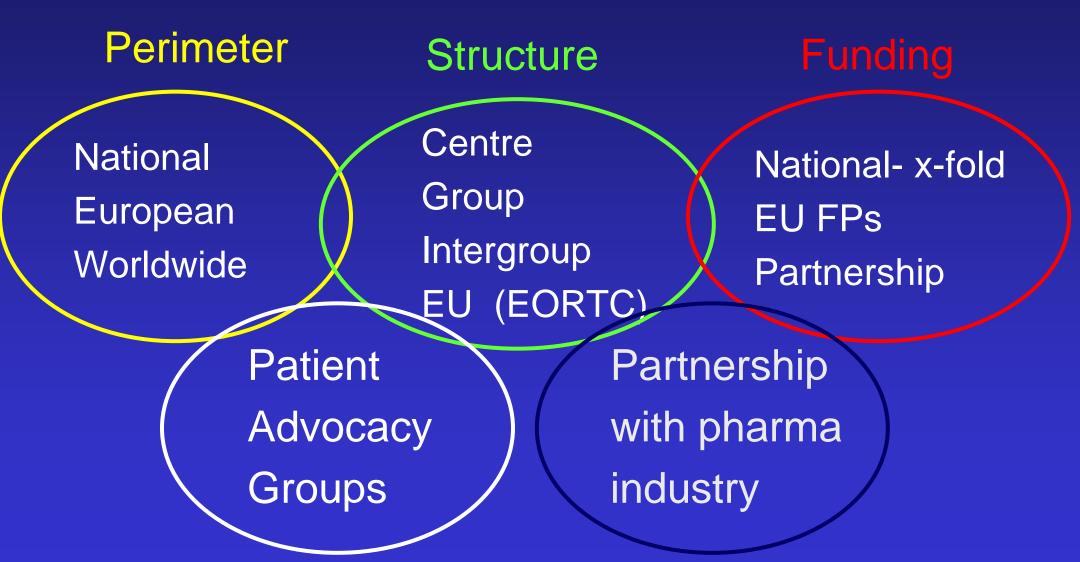
- nilotinib in PVNS with t(1,2) M-CSF-col6A3 fusion gene
- •mTOR inhibitors in PEComas, and in tumours of the TSC complex
- Aplidin in Dedifferenciated Liposarcomas with JUNK overexpression
- •Alk inhibitors in inflammatory myofibroblastic tumours with Alk amplification and over expression
- IGF1R inhibitors in GIST with IGF1R over-expression and amplification
- MDM2 inhibitors (nutlin3a) in WDLPS with MDM2 amplification
- MET inhibitors in sarcomas with translocation involving fusion genes encoding for abnormal transcription factors (ASPS, CCS)
- VEGFR2 inhibitors in ASPS

## **Strategies**

• Simple prospective clinical trials

- Smart retrospective studies
  e.g. long responders
- Generate attractive hypotheses

### How to improve collaboration ?



Thank you for your attention and your participation