



2009: Labelling 11 French Reference Expert Networks for Rare Cancers in Adults

Dr J-M Bréchet

- **Difficult diagnosis - misdiagnosis**
- **Lack of medical expertise**
- **Neither guidelines nor recommendations**
- **Disorientation of the patient and his family**

- **Dedicated hospitals (CHU-CLCC) authorized to practice oncology**
 - **A reference center**
 - **Collaborating with a high level cancer research center**
- **A network with one competence center in each administrative region**

- ***Diagnosis*** : Systematical « second » analysis of the biopsy by an expert network
- ***Care*** : regional and national multidisciplinary expert teams :diagnosis, treatment and follow-up
- ***Treatment*** : facilitating access to new therapeutical approaches
- **Clinical *guidelines*** publications
- ***Epidemiology*** : rare cancers databases

The tasks of the reference centers

- ***Research*** : Clinical trials, translational research, Biobanks
- ***Information*** : to oncologists, General Practitioners, patients and their families, patients' organisations

Reference centers for rare cancers - 2009

<i>Rare cancer</i>	<i>Reference center</i>	<i>Coordination</i>
Soft tissue and visceral sarcomas	Centre Léon Bérard, Lyon	Pr Blay
Soft tissue and visceral sarcomas: pathology	Institut Bergonié, Bordeaux	Pr Coindre
High grade oligodendrogliomas	Pitié-Salpêtrière, AP-HP, Paris	Pr Delattre
Refractory thyroid carcinomas	Institut Gustave Roussy, Villejuif	Pr Schlumberger
Adrenocortical carcinomas	Cochin, AP-HP, Paris	Pr Bertagna
Von Hippel Lindau and genetic predisposition for renal malignancy	Bicêtre, AP-HP, Paris	Pr Richard

Reference centers for rare cancers - 2009

<i>Rare cancer</i>	<i>Reference center</i>	<i>Coordination</i>
Peritoneal tumors	CH Lyon-Sud, Pierre-Bénite	Pr Gilly
Malignant pleural mesotheliomas and peritoneal tumors: pathology	CHU Caen	Pr Galateau-Sallé
Rare malignant neuroendocrine tumors	CHU La Timone, Marseille	Pr Niccoli
Rare Neuroendocrine tumors: pathology	CHU Edouard Herriot, Lyon	Pr Scoazec
Gestational trophoblastic neoplasia	CH Lyon-Sud, Pierre-Bénite	Pr Raudrant / Pr Golfier