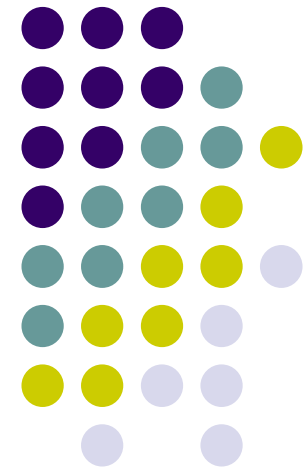


# Medical Education: pre-graduation training the role of patients



Christel Nourissier,  
Krakow, 14 May 2010

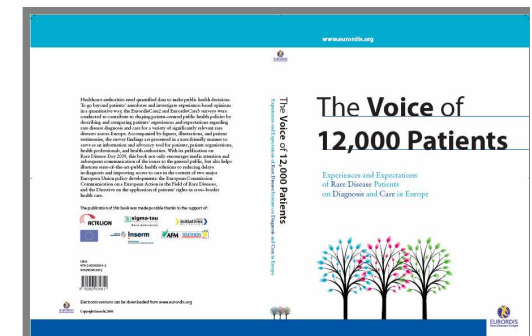


# Rare diseases give a lesson of humility to both professionals and patients



- Health care professionals cannot be taught neither know about 6 000 to 8 000 rare diseases
- Research, care and treatments progress every year
- Patients living with rare diseases experience difficult access to diagnosis, care and treatments\*, with severe consequences : unjustified and costly surgeries and psychological treatments, birth of affected siblings, inadapted family behaviour, loss of confidence in the health care system

● \* *The voice of 12 000 patients* » [www.eurordis.org](http://www.eurordis.org)



# Patients living with rare diseases become experts on their diseases



- Rare diseases are chronic, severe, often life threatening and disabling. They affect patients and their families in their everyday life, 24 hours a day. They often limit their participation in social life : school, workplace, other activities...
- They are very complex diseases : patients themselves and their families have a 360 °view of all their consequences on their life
- Patient groups break isolation, help building self-esteem again



# Raising awareness of medical students regarding rare diseases: the 1st French national plan experience (2004-2008)



- Inclusion of a two hours course on rare diseases was recommended:
  - To raise awareness
  - To provide some tools to students : Orphanet, centres of reference, patient associations websites
- After 5 years, it was not implemented in all medical schools : need for a 2<sup>nd</sup> national plan (2010-2014)

# The 20 hours pilot course on rare diseases in a Paris medical school (University of Necker-Cochin)



- It is an optional course that students choose to attend
- Started in 2008, more successful each year
- Students evaluate particularly well :
- The living experience of patients and their families (our 2 hours course)
- Learning about organisation of care for rare diseases: centres of reference and competence
- The discussion on how to announce a diagnosis to a family
- Learning more about compensation of disabilities

# Lessons given in 2010

## (2 hours sessions = 20 hours)



- Rare diseases: definition and specificities: epidemiology, policies, science : *Ségolène Aymé*
- Cystic fibrosis: realities and hopes : *Isabelle Sermet*
- Rare diseases, definition and specificities from the patients point of view : *Christel Nourissier and Agnés Laruelle*
- Diabetis in young children: how research changed treatments and care: *Mireille Castanet*
- Autoimmune diseases, rare diseases concerning adult patients : *Alice Berezne*
- Neuromuscular diseases : *Isabelle Desguerre*
- Lowe syndrome, a collaboration between patients, clinicians and researchers: *Rémi Salomon/ G.Baujat/ Mr Riou*
- Children at School: Integrascal website *Sonia Noel*
- Pluridisciplinary care for bone diseases of genetic origin: *Valérie Cormier-Daire/ Geneviève Baujat*
- Telethon and rare diseases : *Bruno Desbuleux*

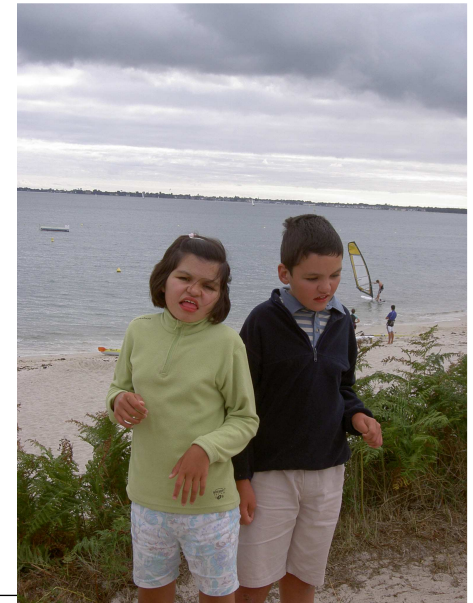
# 2008: 2 mothers became teachers

## How do we prepare our course?



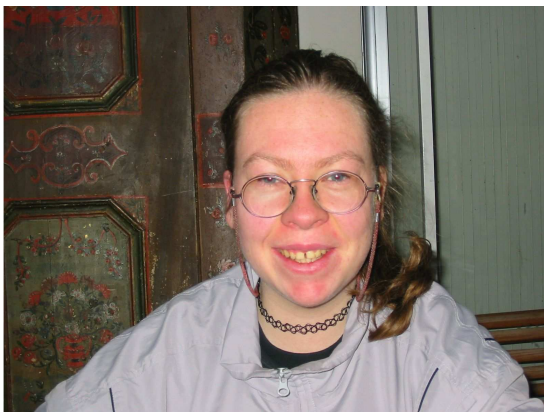
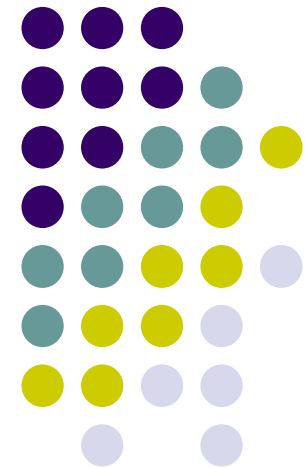
- We use the relevant figures of the Eurordiscare studies (the voice of 12 000 patients) to show that our individual experiences are similar to those of thousands patients across Europe.
- We present our daily experiences with our children and discuss the individual experiences of the students : lively exchanges
- We present and discuss the complexity of a comprehensive approach for rare diseases

# Living with a rare disease



Benoît (15) and Guillemette (13) live with  
an extremely rare metabolic disease  
hyperphosphatase alcalin with mental  
deficiency

Amélie (32) lives with Prader Willi  
syndrome





# For you, What do rare diseases mean?

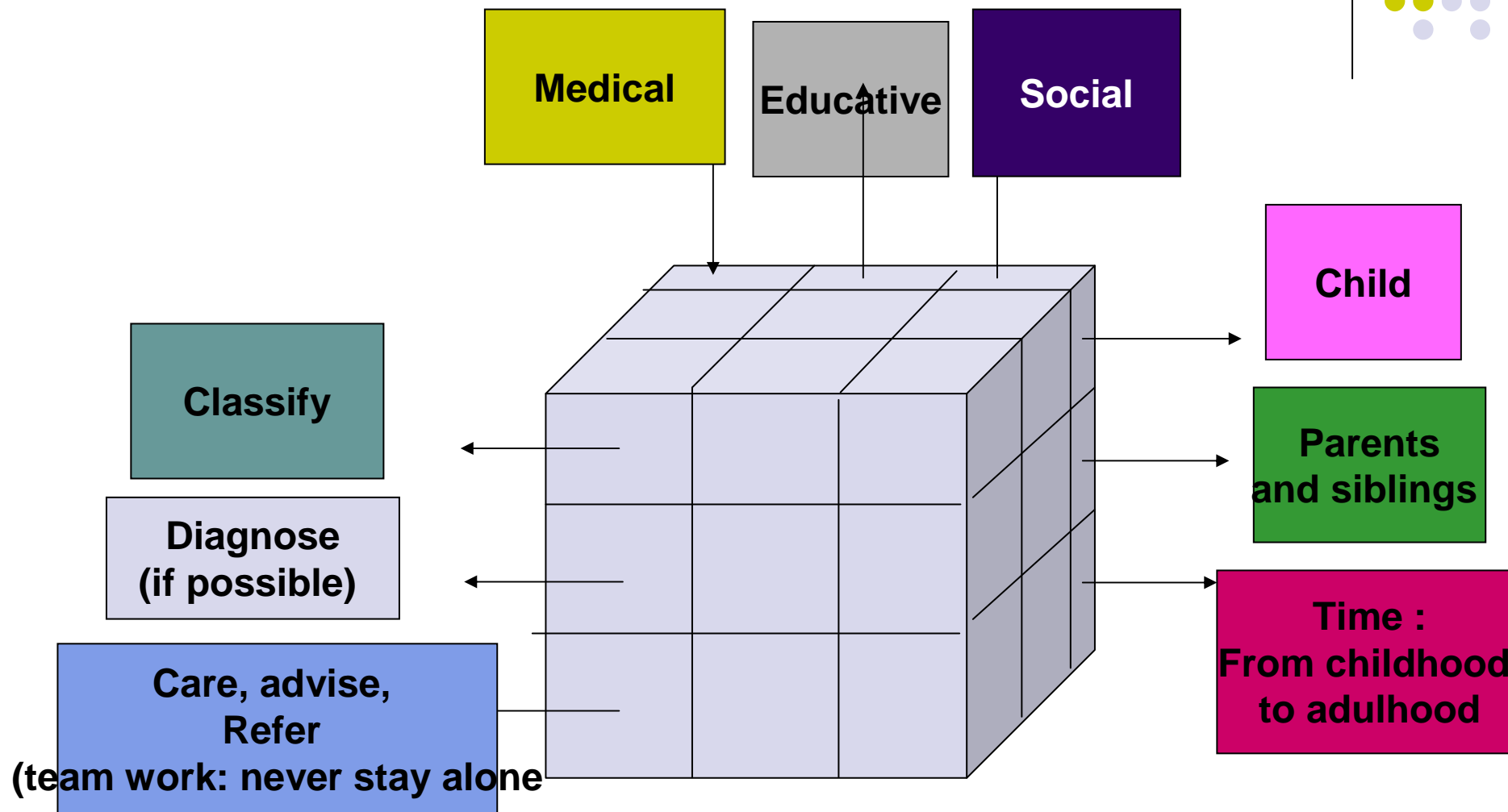
Something you discover?

Something you wish to know more  
about?

Research topics?

A pilot area for improvement of care?

You face a complex situations with multiple aspects  
Similar to a Rubik's cube

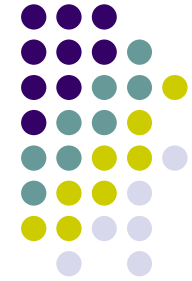


# Our conclusion: rare diseases are a model for progress in :



- Science: better understanding of the mechanisms of common diseases, development of new diagnosis and therapies for unmet and urgent needs
- Public health : pluridisciplinary care; specialised centres; regional, national and European networks; health professionals and patient mobility.
- Integration at school and in the society at large
- It helps us progress as individuals too!
- « *There is always something to do, even when nothing can be done* » Pr Arnold Munnich

# What I feared a lot on the 1st year, and now enjoy the most



- Coming back to Cochin hospital 30 years later, after I heard from a doctor :« We do not know the problem, but we guess that it is serious. You should leave your baby in the hospital and consider having another child »
- I was 25 years old and I left with my severely hypotonic two month old first daughter in my arms, without any idea neither recommendations on how to cope
- *This should never happen any more.*



- This presentation is dedicated to Agnès Laruelle children, Benoît and Guillemette, and to my daughter, Amélie.
- To all the patients and families who participated to the EurordisCare surveys
- And to the people living with rare diseases who will be teaching to medical students in the future, with my best wishes
- Our course (50 slides in French, to be translated) is available at your request:  
[christel.nourissier@eurordis.org](mailto:christel.nourissier@eurordis.org)