



# European network for central hypoventilation syndromes: Optimizing health care to patients (EU-CHS)

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**Ha TRANG**

French Center of reference of Ondine syndrome  
Paris, France

ASSISTANCE  
PUBLIQUE  HÔPITAUX  
DE PARIS



# Central Hypoventilation Syndrome (CHS)

- Very rare disease (**1/200,000**)
- Genetic disease
- Abnormal central control of breathing >>> No spontaneous breathing, mainly during sleep
- Presentation at birth
- Life-support ventilation for lifetime
- Technology-based management
- High mortality rate



# EU-CHS project

## ➤ Project Coordination

- Ha Trang
- French Center of reference for Ondine syndrome (CCHS)
- Robert Debré hospital, AP-HP, Paris, France
- Animal and basic research labs



Institut national  
de la santé et de la recherche médicale



# EU-CHS project

## ➤ EU-CHS team

- Co-ordinated by **FR** (French Center of reference of CCHS, AP-HP, Ha Trang)
- Physicians from **12 EU** countries (**FR, IT, DE, SE, PL, UK, AU, SP, PT, CR, SL, CH**) + Patient groups
- Covering **75%** of EU population.



EAHC - Luxembourg -25-26/10-2011

Munich 2010

# EU-CHS project

## ➤ Main objective

- Improve health care to patients with CHS

## ➤ Specific objectives

- Identify patients (>> implement an EU-CHS register)
- List services and specialists for CHS
- Develop EU guidelines
- Develop a multi-lingual website
- Develop consensus-agreed info brochures
- Determine quality standards for a CHS center

# EU-CHS project

## ➤ Where are we now ?

- Web register developed
- Ongoing data collection
- Website created
- Specialists & services located
- Draft of guidelines
- Info brochures



**EU CHS NETWORK**

European CHS Network

EUROPEAN CHS - MAP

select different language

**The ICHS European Network**

**Central Hypoventilation Syndrome: Introduction**

**Respiratory Support Choices**

**Home Monitoring**

**Services for CHS**

This website has been created by the Euroean Network for Central Hypoventilation Syndromes : For patients and their families, clinicians, administrative authorities and all interested persons  
The mission of the European CHS Network is: Optimise health care to patients with CHS in Europe, Give information about Congenital central hypoventilation syndrome and the other hydiopathic syndromes with central hypoventilation, implementation of a European CHS register (EU-CHS register), as a critical mass of patients is required for high-quality epidemiological and clinical studies. Patients with CHS will be identified in the 11 actually participating EU countries. More partners from more countries will be recruited in order to expand the network towards Eastern Europe and Northern Europe.

# EU-CHS project : what is next ?

## ➤ Next milestone

- 4th International Conference on Primary Central Hypoventilation, 13-15 April 2012, Warsaw, Poland,



# EU-CHS project : what is next ?

## ➤ Science & Life of CHS 4th ICPCH.

- Update on knowledge
- Dissemination of EU-CHS outputs
- First forum on CHS care across the world (EU, N-AM, S-Am, Australia & Asia)



# EU-CHS project : what is next ?

## ➤ Perspectives

- At the EU level
  - Maintain the register
  - Set up clinical studies
  - Improve access to diagnosis
  - Expand the consortium
- At the international level
  - Upgrade to an International register
  - Develop exchange
- Seeking for financial support



Look forward to meeting you in  
Warsaw, Poland, 13-15 April 2012  
Science & Life of CHS

4<sup>th</sup> International Conference on Primary Central  
Hypoventilation.

