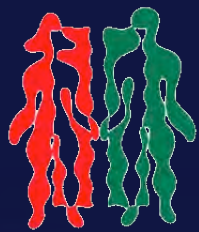


# The Portuguese Programme on Rare Diseases

**José Marques Robalo**

Deputy Director-General of Health  
Ministry of Health  
Portugal





# THE PORTUGUESE PROGRAMME ON RARE DISEASES

**The Portuguese Programme  
on Rare Diseases  
has been approved  
by the Minister of Health  
on November 12th, 2008**



# THE PORTUGUESE PROGRAMME ON RARE DISEASES

**How was this Programme prepared?**





# THE PORTUGUESE PROGRAMME ON RARE DISEASES

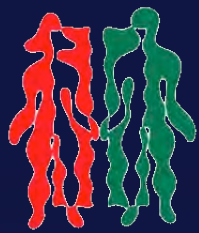
The first draft of the Programme was developed by a workgroup of 7 experts from these fields:

- health care,
- medical research,
- clinical laboratories,
- orphan drug agency,
- administration.



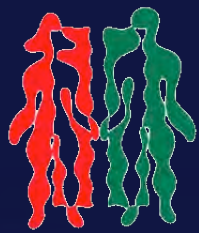
# THE PORTUGUESE PROGRAMME ON RARE DISEASES

- This programme was on public consultation until January 31<sup>st</sup>, 2008
- Workshops were held with the stakeholders (health care professionals, researchers, drug industry and patient associations).



# THE PORTUGUESE PROGRAMME ON RARE DISEASES

- The final draft incorporated all the inputs from the public consultation and from the stakeholders.



# THE PORTUGUESE PROGRAMME ON RARE DISEASES

## MAIN GOALS

- Improve the national response to non-satisfied health needs of people with rare diseases and their families;
- Improve health care quality for people with rare diseases.

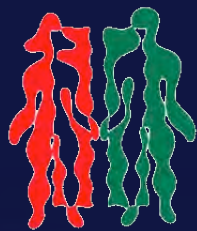


# THE PORTUGUESE PROGRAMME ON RARE DISEASES

## ***THREE MAIN PILLARS***

- **Intervention**
- **Training**
- **Collect data and analyse information**





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