

The Portuguese Programme on Rare Diseases

José Marques Robalo

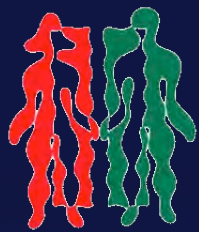
Deputy Director-General of Health
Ministry of Health
Portugal





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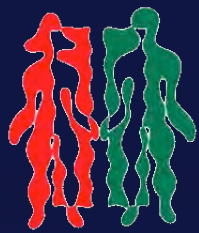
**The Portuguese Programme
on Rare Diseases
has been approved
by the Minister of Health
on November 12th, 2008**



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How was this Programme prepared?





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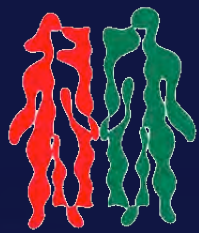
The first draft of the Programme was developed by a workgroup of 7 experts from these fields:

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



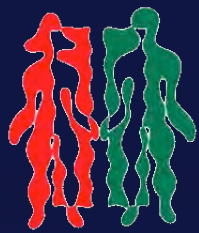
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- This programme was on public consultation until January 31st, 2008
- Workshops were held with the stakeholders (health care professionals, researchers, drug industry and patient associations).



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



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MAIN GOALS

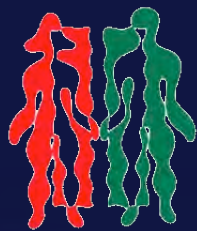
- Improve the national response to non-satisfied health needs of people with rare diseases and their families;
- Improve health care quality for people with rare diseases.



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THREE MAIN PILLARS

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



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