ORPHANET
Services for Health Professionals

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Orphanet
# Services for Health Professionals

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**ORPHANET 10 ans au service des maladies rares PARIS 15 Février 2007**
Literature on Rare Diseases

- Indexation of rare diseases
- Publication of abstracts written by Orphanet or other experts and validated by the editorial committee

Key figures

5500 rare diseases
2017 abstracts in French and English
Translations into 4 other languages
French Language Encyclopaedia

- **Review articles** written by French experts and submitted to the editorial board
- **Co-publication in journals** indexed on Medline (since 2006)

Key figures
- 249 review articles
- 11 co-publications
- 77 articles under review

ORPHANET 10 ans au service des maladies rares PARIS 15 Février 2007
Key figures

51 articles published in 2006
20% highly accessed
More than 10,000 visitors per month
Partnership with the European Journal of Human Genetics (*Nature Publishing Group*)

- Articles on the practical applications of genetic research in the *Practical genetics* series

Key figures

- 6 publications
- 20 articles under review
Improving Patient Care

System facilitating diagnosis:

- Cross search with multiple clinical signs
- Resulting narrowed-down list of diseases in order of probability
- Link to information on each disease

Key figures

Thesaurus of 887 clinical signs

2,300 diseases indexed by clinical sign
Overview of the Treatment Process

Identification of:

- Diagnostic laboratories
- Consultations with specialists

Continuous updates of these entries

Key figures

1,137 diagnostic labs for 1,315 diseases
2,370 specialist consultations
Dissemination of Best Practice Recommendations in France

Collaboration with HAS

- National protocols of diagnosis and treatment (PNDS)

Collaboration with the French Ministry of Health

- Personalized treatment and emergency cards

Orphanet "Urgences"

- 24 h consultations by emergency professionals for information on best practices
Rare Disease Updates: OrphaNews

Scientific News
- New diseases
- Genetic discoveries
- Basic and clinical research results
- Orphan drugs

Policy News

Events
- Meetings and symposiums
- Calls for proposals
Thank you for your attention