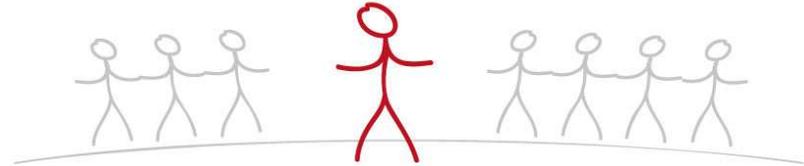


**We take  
rare diseases  
personally**



RECORDATI GROUP

# Orphan Europe



- Fondé en 1990 à Paris
- Fait partie du groupe Recordati S.p.A. depuis Décembre 2007
- En Europe: 9 médicaments (7 avec une AMM, 5 avec le statut médicament orphelin)
- Une présence directe en Europe, USA, MENA. Partenariats avec des distributeurs dans d'autres pays
- Une croissance régulière du chiffre d'affaire et du nombre d'employés (environ 200 en 2013)

## Product portfolio – 100% Orphan Drugs

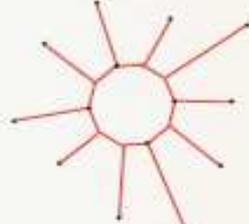
Brand Name	INN	INDICATION	Domaines thérapeutiques	Nb. de patients traités en Europe
<b>Adagen®</b>	Pegademase	Deficit SCID-ADA	Immunologie	<b>50</b>
<b>Carbaglu®</b>	Acide Carglumique	Déficit en NAGS Aciduries organiques	Maladie Métabolique	<b>100</b>
<b>Normosang®</b>	Hémine Humaine	Porphyrie aigue intermittente	Maladie Métabolique	<b>500</b>
<b>Cystadane®</b>	Betaine	Homocystinurie	Maladie Métabolique	<b>1 000</b>
<b>Pedea®</b>	Ibuprofene i.v.	Canal artériel persistant	Cardiologie pédiatrique	<b>20 000</b>
<b>Cystagon®</b> <b>Cystadrops®</b>	Cysteamine bitartrate	Cystinose Néphropathique	Maladie Lysosomale	<b>800</b>
<b>Vedrop®</b>	Tocofersolan	Vit E hydrosoluble dans les deficit en vit E dans les cholestases chroniques	Gastroentérologie	<b>500</b>
<b>Wilzin®</b>	Zinc acetate	Maladie de Wilson	Maladie Métabolique	<b>1 000</b>

***There is no better place to  
be a “good citizen” than for  
rare diseases***

# Show your personal commitment take part!

“Overall  
I'd recommend  
the experience to anyone”

Paula Sule, Region South Manager



ORPHAN EUROPE  
staff volunteering  
programme



All of us at Orphan Europe are committed to improving the lives of people who have, or are caring for someone with, a rare disease. We all show our dedication every day in our jobs, but to take this to the next level, why not take part in the Orphan Europe staffvolunteering programme for 2013?

Participants work at sites in the West of Scotland on three European's recreational programmes for children with various illnesses and their families. You can volunteer on your own time and your hours taken will be rewarded.

How can I participate?

For an application form, please contact:  
Suzanne Parker, support@orphaneurope.org  
+373 01773 95 210

Taking part not only helps children and families, but you will bring your unique experience into your role at Orphan Europe.



RECORDATI GROUP

# *Orphan Europe répond aux besoins de formation dans les maladies rares*



Recordati  
Rare Diseases Academy  
Fondation d'entreprise

Advancing knowledge in rare diseases:  
independent, professional education and training



# Les patients sont rares, les experts aussi

**European Porphyria Network**

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Search

**For patients and families**

- Introduction to porphyria
- Acute porphyrias
- Congenital Erythropoietic Porphyria (CEP)
- Erythropoietic Protoporphria (EPP)
- Porphyria Cutanea Tarda (PCT)

**For healthcare professionals**

- The Porphyrias
- Laboratory diagnosis
- Investigating the family
- Treatment
- Pain Management
- Congress Abstracts
- EPNET experts

**Drugs and acute porphyrias**

- Background information
- How to use the information?
- Common prescribing problems
- Selecting a drug

**About EPNET**

- About EPNET

**News**

- RARE DISEASE DAY 2011
- Porphyria international conference, Cardiff 2011

**Newsletter**

Enter your e-mail:

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Last update: May 2011

**EIMD**  
European registry and network for  
Intoxication type Metabolic Diseases

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**Latest News**

**First News title**  
Aenean suscipit malesuada arcu pretium laoreet. Praesent sodales suscipit felis vitae rutrum.

**Second News title**  
Nunc sit amet ipsum sed metus rutrum pretium non et libero. Aliquam tempor sapien id ipsum semper consequat. Praesent non.

**Third News title**  
Vivamus et dui quis ipsum adipiscing consectetur. Ut eget mi eget ipsum dictum malesuada ac at lorem.

**All the news**

**Subscribe to the Newsletter**

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Ut interdum risus eget neque vehicula ultrices. Morbi non lorem eget mi sodales lacinia ac eu est. Aliquam dapibus, justo quis hendrerit accumsan, mi quam elementum mauris.

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**EuroWilson**

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**REPORT A NEW CASE**

Report a new case of Wilson's disease

**LATEST NEWS**

**Title 1**  
Donec commodo fringilla dui. Vestibulum dui. Pellentesque eu tellus. Aenean nisi tortor, tristique non, sollicitudin.

**Title 2**  
Donec mattis purus congue odio. Integer fringilla nunc non nibh. Proin posuere ornare diam. Mauris.

**All the news**

**NEWSLETTER**

Coming soon

**LIVING WITH WILSON'S**

- Wilson's disease for younger people
- Guide to Wilson's disease

Select a language: English

**FOR MEDICAL PROFESSIONALS**

- Clinical presentation
- Diagnosis
- Treatment
- Pregnancy
- Laboratory services

**ABOUT EUROWILSON**

- Project summary
- Clinical database
- Contacts

EuroWilson is an academically governed organisation which received support from the European Commission Framework 6 Programme.

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**E-HOD**  
European Network and Registry for  
Homocystinurias and Methylation Defects

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SEARCH

**Patients and Families**

- Information for children
- Information for adults, parents & carers
- List of patients organizations
- Centres of clinical care

**Health care professionals**

- Information for health care professionals
- Laboratory services
- Guidelines and recommendations

**About E-HOD**

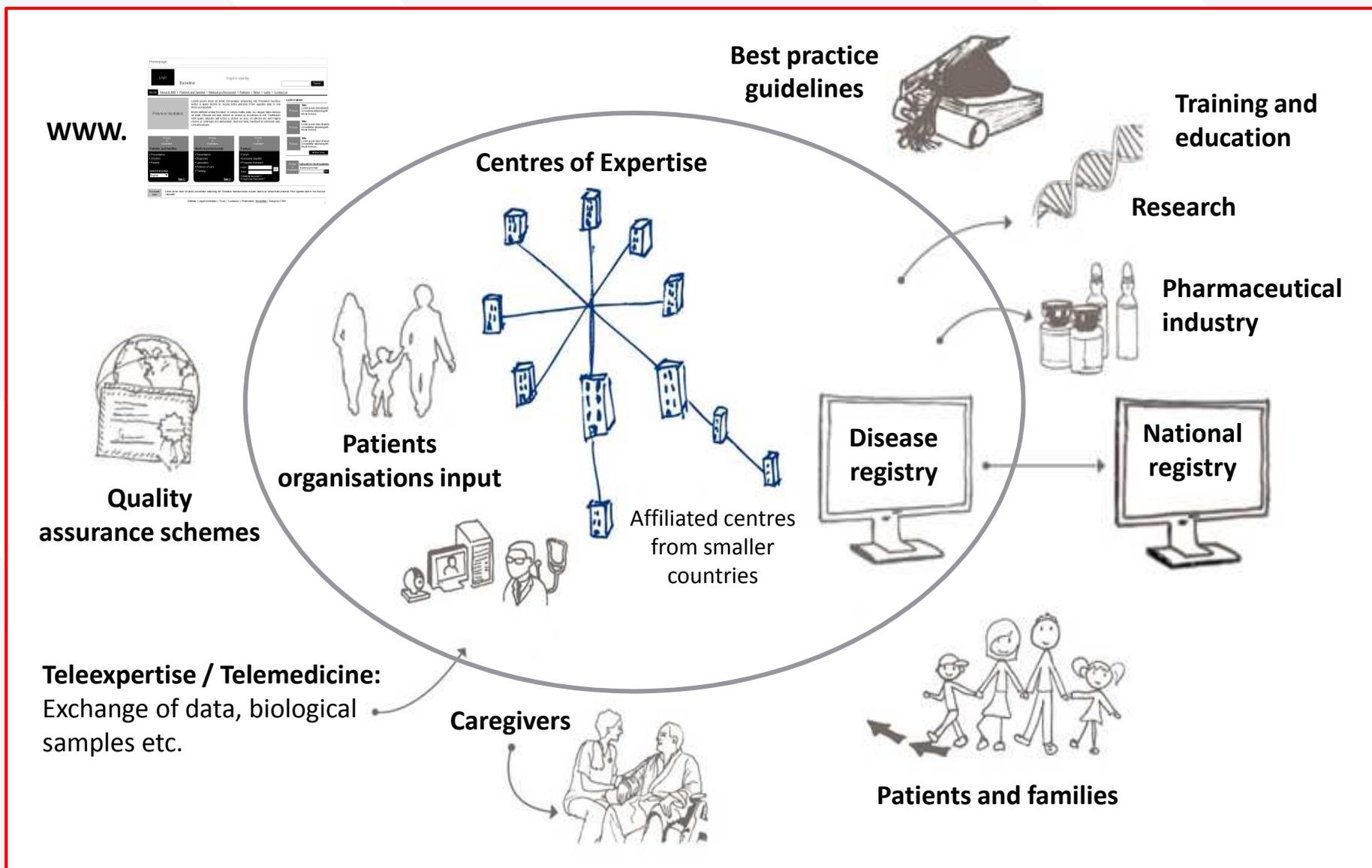
- Description of the project
- Partners
- Link to registry and statistics
- Partners' section

**Latest news**

**Newsletter**

E-HOD is now on facebook

# Orphan Europe : Une expertise dans le développement des réseaux



## *Perspectives futures*

- ✓ Continuer notre engagement historique dans les maladies métaboliques et développer notre expertise en onco hématologie
- ✓ Lancement de la fondation d'entreprise pour améliorer le diagnostic et la prise en charge – source d'innovation.
- ✓ Développer de nouveaux modèles de recherche par une approche collaborative entre les académies, industrie pharmaceutique, associations de patients...
- ✓ Favoriser le volontariat dans l'entreprise permet de développer des valeurs stratégiques pour le futur, à améliorer les compétences internes, et surtout apporter personnellement un soutien aux enfants qui souffrent de maladies rares.

# We take rare diseases personally



RECORDATI GROUP

## A shared conviction

Every one of our staff members shares a personal conviction that each person with a rare condition has the right to the best possible treatment. We all pledge to pursue treatment options for people with rare disorders, because for us, it's personal.

