ORPHANET
Patient Services

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Webmaster for Patient Organisations
Orphanet
# Patient Services

<table>
<thead>
<tr>
<th>Needs</th>
<th>Solutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understand their disease and its implications</td>
<td>Encyclopaedia OrphaSchool</td>
</tr>
<tr>
<td>Identify resources</td>
<td>European Directory List of associations</td>
</tr>
<tr>
<td>Prevent isolation</td>
<td>Personal contacts</td>
</tr>
<tr>
<td>Find hope in future research</td>
<td>List of on-going research projects</td>
</tr>
<tr>
<td>Participate in clinical research</td>
<td>Information on research projects seeking volunteers</td>
</tr>
</tbody>
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ORPHANET 10 ans au service des maladies rares PARIS 15 Février 2007
Objectives

- Facilitate access to information
- Contribute to a better understanding
  - Summarizing texts
  - Collaboration with patient groups, centres of reference, and Maladies Rares Info Services (MRIS)
  - Methodology in accordance with recommendations from Haute Autorité de Santé (HAS)
  - Topics chosen together with centres of reference, MRIS, HAS…

Key figures

- 90 texts produced
- Between 160 and 220 downloads per month per text

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OrphaSchool
An Online Campus for Rare Disease Information

Objectives

- Respond to the need for information
- Make the mechanisms of rare diseases understood

A collection of lessons
- organised as independent modules
- present practical, formative, and useful information

A diverse audience
- Orphanet’s audience: health professionals, patients, and their friends and families
- Medical students, upper school students, teachers

Key figures

- 3 modules online explaining the transference of rare diseases, cytogenetics, inheritance …

Approximately 500 monthly visits

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Bringing Isolated Patients Together

Objectives

- Address isolation of rare disease patients
- Elicit mutual support
- Share medical and other relevant information
- Facilitate the creation of patient groups

Key figures

589 registered users
371 diseases
294 personal contacts made
Registration Service to
Stay Informed about Projects
Seeking Volunteers

Objectives

- Encourage recruitment
- Facilitate clinical research

Key figures

2175 registered users of which 1331 are in France
concerning 538 rare diseases
171 announcements of clinical studies
sent to patients in Europe
## Services for Patient Groups

<table>
<thead>
<tr>
<th>Needs</th>
<th>Solutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Be recognised</td>
<td>Referrals</td>
</tr>
<tr>
<td></td>
<td>European directory</td>
</tr>
<tr>
<td>Networking and communication</td>
<td>Web services</td>
</tr>
<tr>
<td>Identify experts</td>
<td>OrphaNews Europe</td>
</tr>
<tr>
<td>Access to scientific and policy updates</td>
<td>OrphaNews France</td>
</tr>
<tr>
<td>Create partnerships with professionals</td>
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</tbody>
</table>
Patients and their families represent 1/3 of Orphanet users

10.2% of information sought concerns patient groups

Objectives

- Facilitate access to patient groups
  - List of support groups by country
  - Elaborate directory of patient groups
  - Direct links to corresponding rare diseases

Key figures

- 305 patient groups listed in France
- 1543 patient groups listed in Europe concerning 1302 diseases
Objectives

- Allowing patient groups and professionals to be on the same page
- Make announcements of new diseases, genetic discoveries, health and research policies, meetings, patient group community
- Publish important information about patient groups
Web Tools for Patient Groups in France

A patient group, however modest, has the right to quickly and easily make itself accessible on the web
Web Services in France

Nestor
- Online interface
- User-friendly

Web kit
- Online interface
- Preinstalled system
- Open-source “Guppy”

Web-hosting
- Secure environment
- Free service
- Stable with support from DSI Inserm

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Web Services in France

For **305** registered patient groups in France

- **23%** use or have used the available services of creating and managing a website (not including web-hosting alone)
- **51** open accounts on Nestor
- **25** “web kit” sites installed

**Key figures**

- **193** open accounts on the Orphanet server

(Including Nestor, "web kits", web-hosting alone, patient groups and professionals)
Thank you for your attention