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Rare Disease Patient Groups in Europe:

- Rapidly growing number of patient groups
- Steep increase in number of members
- Broader diversity of rare diseases covered
- Wider scope of activities
- Primary source of support for affected families, who have become isolated because of the disease.
- Comprehensive approach to patient needs, based on the experience of living with a rare disease.



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Rare Diseases Europe

RARE DISEASE PATIENT GROUPS IN THE EUROPEAN UNION

HOW TO FIND A RARE DISEASE PATIENT GROUP?

Search for Eurordis' members
[http:// www.eurordis.org](http://www.eurordis.org)

Contact a European national alliance
(they can be found on the Eurordis website)

Search the Orphanet database (EU)
[http:// www.orpha.net](http://www.orpha.net)

Search the NORD database (US)
<http://www.rarediseases.org>

Search the Office of Rare Diseases database (US)
<http://ord.aspensys.com/asp/diseases/>



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A patient group is run by people who are parents of a sick child or patients themselves. Patient groups vary in size from very small (a few people) to very large.

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COMMUNICATION

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Rare Diseases Europe

RARE DISEASE PATIENT GROUPS IN THE EUROPEAN UNION

RARE DISEASE PATIENT GROUPS IN EUROPE CAN REPRESENT:

- one disease in one country
- a group of diseases sharing similar symptoms in one country
- all rare diseases in one country (known as national rare disease alliances)
- one disease across several countries (known as European rare disease specific networks or federations)
- a group of diseases sharing similar symptoms across several countries (often called umbrella organisations, coalitions, platforms or alliances)
- all rare diseases across Europe: EURORDIS

RARE DISEASE PATIENT GROUPS HAVE THREE MAIN ROLES:

- 1 Be an essential source of information on the disease and on how to live with it
- 2 Offer direct personal support for individuals living with a rare disease
- 3 Improve healthcare for the community as a whole:
 - promotion of research
 - support development of therapies and drugs
 - funding for research activities
 - support to centres of expertise on the disease they represent
 - awareness raising and knowledge sharing on the disease
 - advocacy for patients at local, national and international levels

Rare disease patient groups are often both a patient support group and a patient advocacy group

A EUROPEAN SURVEY OF PATIENT GROUPS

Eurordis conducted a survey of the information services of 370 patient groups in 20 European countries in 2003.

SOME OF THE KEY FINDINGS

- Members, private donors and fund-raising events are the main sources of funding of patient groups
- Only when organisations reach 10 years of age can they receive financial recognition from public authorities
- 63% of helplines rely on volunteers, and 76% use the information they collect from enquirers to promote improvement in care, policy, and legislation
- Information on clinical trials is hard to find, even for information services
- Rare diseases cause chronic impairment or disabilities that require high quality daily care that can optimally be provided at home
- Partnering with healthcare professionals is beneficial

The complete report can be downloaded at:
www.eurordis.org

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