EUROPEAN COMMISSION
DIRECTORATE GENERAL HEALTH AND CONSUMER PROTECTION

Pan-European Patient Network for Information on Rare Diseases and Orphan Drugs
- PARD 3 -

A project conducted by

EURORDIS
European Organization for Rare Disorders

and co-funded by

European Commission

AFM
TÉLÉTHON

Under the

Programme of Community Action on Rare Diseases

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Final Activity Report
June 2004

II - Executive Summary

The objectives of the "PARD 3 project" were:
- to gather information needed to contribute to building a public policy on rare diseases,
- to improve the access to quality information on rare diseases and orphan drugs.

The methodology was based on **a survey**, including both a qualitative and a quantitative phase, **workshops** both at European and national level, **an awareness action** through the first European Rare Disease Awareness Week and **the writing of guidance and pedagogical documents.**

This project involved over 500 organisations from 19 European countries and largely mobilised and interested the rare disease community in Europe around the key topic of information.
The work accomplished is therefore very much the result of sharing experiences. The collaborative work accomplished reflects opinions from all around Europe. Tools are adapted to the European situation whilst taking into account the disparity of administrative and legal contexts between the countries. The project approach was to keep the patient at the heart of the process.

Deliverables planned have been achieved.

- The manual in English, divided into three booklets and guidelines available in 10 languages published are visible and practical tools to achieve improved quality and greater access to information on rare diseases and orphan drugs.
- Pilot training sessions in new European Union member states have enhanced the educational dimension of the project.
- The comprehensive report as a result of the quantitative survey contains valuable evidence from which to distil specific reports and guide future policy for rare diseases.
- Face-to-face contacts with individuals and groups interacting at European level have improved communication and joined-up thinking for policy shaping for rare diseases.
- Each activity attached to the outcomes of this project was achieved with the patient at the heart of the process.

The project has created a solid basis from which information on rare diseases can be further improved. It has initiated a dialogue on the importance of information quality and availability between the various organisations concerned with a common pan-European reference.