EUROPEAN COMMISSION
DIRECTORATE GENERAL HEALTH AND CONSUMER PROTECTION

New communication technologies (website) to the service of the rare disorders network and sharing of good practices in different help services to patients, already existing in Europe (hot line)
PARD 2

A project conducted by

EURORDIS
European Organization for Rare Disorders

Under the

Programme of Community Action on Rare Diseases

Contract n° SI2.325133 (2001CVG4-807)

Final Activity Report
March 2003

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I - Executive summary

The PARD 2 project is the second part of a long-term project initiated by Eurordis in the framework of the Programme of Community Action on Rare Diseases – 2000/2003, which objective is to create and animate a European trans-national network on rare disorders.

The first recommendations that came out of the PARD 1 project successfully carried out by Eurordis between 2000 and 2001 was to improve the access to information. It was highly recommended to offer by all possible means, including helplines and websites, information to patients and family members about the pathology, treatment, evolution, psychological considerations, put them in contact with other persons affected with the same disease or direct them to the corresponding association, should there be one.

The PARD 2 project therefore aimed at creating a web portal on rare diseases and orphan drugs which objectives would be to be the starting point on the Internet for anyone interested in rare disorders and to help build a trans-national and cross-disease community of patients affected by rare diseases in Europe.
Eurordis role was clearly identified as guiding people among the existing resources and giving them tools for action at national level rather than building new databases. Cooperation was therefore developed with already existing resources such as Orphanet and NEPHIRD.

The key focus areas of this web portal are:

- The user oriented approach (information on rare diseases will be easily accessible to visitors of various profiles including to handicapped people);
- The multi-lingual nature of the web portal (9 languages for version 1: English, Danish, Dutch, French, German, Italian, Portuguese, Spanish, Swedish),
- The overview opportunities (links to other sites on rare diseases and guidance)
- The community look and feel (a place where visitors can meet others to share experience and build a community, through forums for instance)
- The interaction opportunities (discuss, search, provide information, make requests ...)

but also:

- Extended tools for advocacy
- The European perspective (sharing information, connecting people)
- News
- Life style strategies.

After identifying the key requirements of the web portal (for phase 1 but also beyond, as it was essential to develop a system that could evolve with time) in accordance with national alliances' suggestions (June to October 2002), a call for tender was organised (November 2002) to select a provider to build, maintain and host the website. In the following weeks, Eurordis finalised the look and feel of the web portal and came to an agreement with the provider on detailed specifications. The prototype was then built in March 2003 and will be finalised by the end of May 2003. The objective is to present version 1 at the launch of the European Awareness Week on Rare Disorders on May 24th, 2003. As time goes by, further versions will be developed to fit new patient needs.

The whole process ensured a high level of quality and consistency with patients' needs.
No other web portal offers neither at the European level nor worldwide such a broad access to information on rare diseases in terms of content, countries and languages covered.

II - Progress summary

To set up a portal around rare diseases: such is the goal of the project entitled "New communication technologies (website) to the service of the rare disorders network and sharing of good practices in different help services to patients, already existing in Europe (hot line)", internally referred to as "PARD 2 project".
It is the second part of a long-term project initiated by Eurordis in the framework of the Programme of Community Action on Rare Diseases – 2000/2003, which objective is to create and animate a European trans-national network on rare disorders, linking patient associations, isolated patients, groups of associations, health care professionals and international organisations around structuring and motivating themes.
The project was planned to be conducted from December 1st, 2001 to December 1st, 2002.

It should be stressed that the PARD 2 project stands on two pillars. One is related to rare diseases: it falls in Eurordis responsibility and was completed on November 13th, 2002, as planned. The other one is primarily technical, and totally new for Eurordis, which understandably needs expert assistance to meet the European Commission criteria.

The original planning was to bring those two parallel processes to a common conclusion on December 1st, 2002. However, several events have delayed the project by a few weeks.

- the project team has been completely changed between the time the project was structured and the moment it started;
- in July 2001, the specialised health division of Gemini Consulting counselling Eurordis in this project was suppressed, leaving it with no technical support for 6 months;
- the project coordinator hired at the end of February 2002 spent more time than anticipated on finalising the final report of the project obtained in 2000 ("Orphan Medicinal Products to the service of patients affected by rare disorders"), internally referred to as "PARD 1 project", finally joining the project team late .

Although many of the actions planned have been carried out in time, a little delay could not be avoided on the non-Eurordis side of the project.

Team and resources

The project team and steering committee were completed in May 2002, taking over from an interim team, which met twice in Copenhagen in order to prepare the launch of the project. On May 16th 2002, the Board of Officers officially named a new project coordinator and suggested new Steering Committee members.

1. Interim team

Project team

- Anders Olauson, Eurordis Director
- Gert Hebeltoft, Eurordis Director
- Yann Le Cam, Eurordis Chief Executive Officer

Board of Officers acting as additional Steering Committee Members

- Lesley Greene, Eurordis President
- Michele Lipucci, Eurordis Vice-President
- Jean Elie, Eurordis Treasurer
- Françoise Salama, Eurordis General Secretary
- Cordula Harter, Eurordis Officer

2. Final team

Project Manager
- Anders Olauson, Eurordis Director

Project Coordinator
- Claire Marichal, Eurordis Project and Administrative Officer

Technical Coordinator (October 2002-February 2003)
- Chris Kobler, Eurordis Trainee

Additional Steering Committee members
- Gert Hebeltoft, Eurordis Director
- Yann Le Cam, Eurordis Chief Executive Officer
- Frank Brunsmann, German National Alliance
- José Luis Plaza Lopez, Spanish National Alliance (*cannot travel*)

3. Investment and resources for the project

The contribution of the European Commission, complemented by AFM, the French Neuromuscular Association, and Eurordis own funding, covered the following:

- personnel costs including project team, administrative assistant and a consultant;
- travel and accommodation costs for the various project team and Steering Committee meetings;
- software such as Photoshop (needed for the design), Dreamweaver (needed to create HTML pages) and Systran (needed as a help for the various translations);
- a computer supporting the software bought and strong enough for the size of the content expected;
- the services of an IT company for building, maintaining and hosting the website (Medcost)
- the services of an IT company on accessibility (Funka Nu);
- the services of a law firm for preparing contracts (Alain Bensoussan Avocats);
- conference calls of the Steering Committee and project team.

Phase 1: Developing the main data structure and describing the main functions of the portal

To minimise the delay in launching the project, the first phases were quickly re-shaped in order to meet our main objectives. This has been the main purpose of the national alliances workshop of June 15th, 2002, and the first full steering committee meeting of June 28th, 2002.

1. Analysis of existing websites and remaining needs

A first survey was conducted in June 2002 among the national alliances, to identify the Internet situation in the various countries.
(See Annex 1)
It was then complemented by Eurordis in order to have an overview of the main websites.
(See Annex 2 for latest version as of March 2003)
This stocktaking phase has been successfully implemented.

2. Initiation of cooperation with national alliances

It appeared soon to the new team that representatives of the national alliances had to meet, to make sure that the portal would take into account their needs and their contributions. As no budget had been envisaged in this project for such a meeting, funds were taken from Eurordis own funding to organise this half-day workshop.

Date : June 15th, 2002

Location : Barcelona, Spain

Chaired by : Claire Marichal (Project Coordinator)

38 participants : 1-4 participants per national alliance (Belgium, Denmark, France, Germany, Italy, The Netherlands, Portugal, Spain, Sweden, UK), 1 participant from Greece, Eurordis Board members, CEO and staff.

The project coordinator first gave an overview of the project and the team, emphasising the major characteristics of the portal, i.e. a patient-oriented tool and a means to build a sense of community.

Participants were split into four groups in order to get their feedback on each of the following subjects:
1. Patient needs
2. European website added value
3. National alliances contribution
4. Challenges to be met

Each group reported the results of their discussion, focusing on what the project team should take into account when building the portal.

a) Conclusions from Group 1 on "Patient needs"

- Information will cover different disabilities, must be accessible in all languages and easily printable.
- Forums will allow visitors to get expert answers, (both legal and medical), and to link with other people.
- When topics are regularly raised in the various forums, they must appear in the "Frequently Asked Questions" section.
- Patients must find information on where to find assistance (existing support groups, where to be treated, emergency helplines), legislation (both national and European), updated information on orphan drugs (link to European Commission and EMEA websites, clinical trials, list of countries where drugs are available), healthcare and therapy guidelines (indicating doctors and other health professionals)…
- A first aid information card for patients, containing treatment tips and doctor's phone numbers was also considered.

b) Conclusions from Group 2 on "European website added value"

- First benefit shall be the availability of information, in all European languages (medical terms in particular).
- Second, a central point shall guide people around websites scattered across various countries and shall provide easy access to information on all aspects of rare disorders (information about diseases, care, cure, where to find support, at home, in Europe, if necessary overseas.
- Last, very rare disorders will benefit from this pool of experience and insight around Europe.

c) Conclusions from Group 3 on "National Alliances contribution"

The website can't be successful without the National Alliances. They will contribute by:

- Giving addresses of websites at national level
- Identifying needs specific to their country
- Providing translation help
- Offering event calendars.

d) Conclusions from Group 4 on "Challenges to be met"
The purpose of the project and our positioning must be clear:
- Who are the users? (patients? families?, doctors and health professionals?)
- How to define a pilot study?
- What relationship do we want with pharmaceutical industry?

Legislation
- Legal obligations must be checked, taking into account that the central website will be accessible from many countries with possible differences in legislations.

Administrative issues
- Responsibility and supervision must be clearly established (including managing the dustbin).
- Updates must be regular.
- Languages will render all processes very complex.
- Cost issues (to update the website and to ensure quality control) must not be forgotten.

Content is key
- The information must be easily understandable.
- Standards in terms of access for disabilities may not be uniform across Europe.
- Do we want a portal with links only, or with some content on European resources, Orphan drugs and other topics?
- Should we build a traditional text-based website, or include forums to offer a meeting place for people with rare disorders?
- How should very rare disorders be tackled?

Building a sense of community
- It may be difficult to create synergies.
- How to make the website dynamic enough for people to visit the portal regularly and how to motivate specialists to answer hard questions?

3. Definition of priorities

Based on the feedback from the national alliances, the steering committee met twice for a discussion on the content they wished to see on the portal. First priorities were then identified among the final list.

Discussion on portal content - Part 1
Date : June 28th, 2002

Location : Paris, France

Chaired by : Anders Olauson (Project Leader)

Trainer : Stefan Johansson, consultant (Funka Nu)

6 participants : Project leader, project coordinator, 3 steering committee members, consultant

Discussion on portal content - Part 2
Date : September 10th, 2002

Location : Copenhagen, Denmark

Chaired by : Anders Olauson (Project Leader)

Trainer : Stefan Johansson, consultant (Funka Nu)

6 participants : Project leader, project coordinator, 3 steering committee members, consultant

(See Annex 3 for final report of both meetings)

4. Cooperation with Orphanet

ORPHANET is a relational database on rare diseases and orphan drugs for the general public. Its aim is to improve diagnosis, management and treatment of rare diseases. It contains an on-line encyclopaedia written by European experts and a list of services for patients and professionals. This list includes information about specialized outpatient clinics, diagnostic laboratories, current research projects and support groups.

As requested by the European Commission in the Grant Agreement SI2.325133 (2001CVG4-807), subject of the present report, in order to avoid duplication, Eurordis has entered discussions with Orphanet on a possible cooperation.
This actually led to a formal “collaboration letter of intent” submitted to the Eurordis Board of Directors signed by Ségolène Aymé (Orphanet) and Yann Le Cam (Eurordis). This collaboration started during the present project and will continue beyond it. The following paragraphs describe its content.

"Further to several contacts heading in the meeting of September 4th, 2002 in the framework of the PARD 2 project, it has been decided to reinforce the collaboration between Orphanet and Eurordis around the new Eurordis portal and the Orphanet website through the search for synergies and complementary approaches in the benefit of users.

Within the PARD 2 project *"New communication technologies (website) to the service of the rare disorders network and sharing of good practices in different help services to patients, already existing in Europe (hot line)"* this collaboration will be implemented in various areas:

1. Directory of patient organisations
The directory of patient organisations designed and updated by Orphanet will be complemented with additional fields and with information from other countries with no Orphanet team.
Right now the information displayed on associations and organised by disease includes name of association, president name, address, telephone, link to web page. Added fields could include the main types of actions and services (clickable list of max. 10 items) or information on existing patient groups.

Orphanet will:
- enable the access to the database from both websites
- increase the number of fields to fit with Eurordis needs
- give full responsibility for data collection and data release to partners in countries not yet covered by Orphanet national teams
- provide tools to update the database from these remote sites
- provide training to the partners on how to use the tool

Eurordis will
- identify possible partners in new countries and cover costs implied by training in Paris
- identify possible partners in countries already covered by Orphanet to work with the national Orphanet teams.

The job of the partners would be to:
- be trained to the updating tool and to the procedures to be followed
- identify associations concerned in their country

- send them a questionnaire
- check the diseases covered
- punch the data
- update the data once a year
- liaise with an Orphanet or a Eurordis employee for any issue.

Forecasted implementation timing: from December 2002 to January 2003 for database changes, 2003 onwards for integration of data from new countries

2. Links between the two websites
Whenever possible links will be built between the two websites to avoid duplication and increase exchanges.
Forecasted implementation timing: from December 2002 on an ongoing basis

3. Content building
Orphanet agrees to cooperate with Eurordis on content pages of the Eurordis website and links to useful databases.
Forecasted implementation timing: from December 2002 on an ongoing basis

This collaboration will be further extended in the second quarter of 2003 within the PARD 3 project *"Pan-European Patient Network for Information on Rare Diseases and Orphan Drugs"* and the development of the Eurordis portal.
In particular four areas of collaboration in that framework could be:

a) collaboration on the development of forums
Orphanet and Eurordis will enter a discussion to develop guidelines for managing forums (like rules for accepting or refusing a message and possibly for changing the title of a message to improve understanding…) and to commission a specialist for programming such a tool. On a case by case basis, forums could be identified as Orphanet only, Eurordis only, or showing both logos and being accessible from both sites.

b) common access to an event management interface

c) the extension to other European countries of the NESTOR computer system, presently implemented in France, giving associations or national alliances the possibility to build and host their websites free of charge;

d) the joint development of a tool to facilitate individual contacts between isolated patients/persons with very rare diseases.

The two partners will also invite a member of the other organisation to meetings discussing topics of potential mutual interest. "

5. Cooperation with NEPHIRD

NEPHIRD (Network of Public Health Institutions on Rare Diseases) is a project funded by the European Commission. The project is coordinated by the *Istituto Superiore di Sanità - Italy.*
The main objectives of this project are:
- to develop a model for epidemiological data collection at European level
- to identify the ongoing national activities on Rare Diseases in the participating Countries
- to establish a European network for epidemiological and health care data collection on rare diseases
- to design, build and run the NEPHIRD Website (http://www.cnmr.iss.it/)

As requested by the European Commission in the Grant Agreement SI2.325133 (2001CVG4-807), subject of the present report, in order to avoid duplication, Eurordis has investigated possibilities for cooperation with NEPHIRD.

Whenever possible links will be built between the two websites to avoid duplication and increase exchanges. This may be complemented by other measures as other opportunities arise.

Phase 2: Specifications for data structure and functions of the portal

1. Main requirements of the portal

On the basis of the final report of the Steering Committee meetings of June and September 2002, a document was drafted by the project team to summarise the main portal requirements.
(See Annex 4)
Eurordis commissioned an external consultant to add technical specifications and finalise this requirement document in preparation of a request for proposal, according to European Commission procedures. This document was then approved by the Steering Committee.
(See Annex 6)
As it was essential to make sure that the system developed could evolve with time, requirements included functions needed for phase 1 but also beyond.

2. Specifications of data structure

A first structure of the website was included in the requirements document. It was then checked and validated by representatives of national alliances.
(See Annex 11)
Outside of the PARD 2 project, an Editorial Board comprising representatives of national alliances, Orphanet and Eurordis staff will be created to build on this structure and define procedures and priorities for the gathering and validation of the content until - and beyond - the official launch of the web portal.

Phase 3: Development of user interfaces and design

1. Call for tender process

16 companies were contacted by Eurordis between November 7th and November 14th and asked whether they would be interested in receiving the requirements document.
Eurordis received 13 positive answers. The final requirements document was sent to them between November 13th and November 15th. They were asked to submit their bids on November 29th, 5 p.m. at the latest. An additional company contacted Eurordis on November 25th to be included in the bidding process.
In the end, six companies out of 14 submitted offers.
(See Annex 5)

Those six answers have been analysed by the Project Coordinator and the consultant, Pieter van der Linden, and presented to the Steering Committee in a table for synthesis with all key elements.
At this stage the various Steering Committee discussions took place by phone.

- After the first discussion on December 9th, 2002, the Steering Committee participants (Anders, Frank, Claire and Yann) decided to eliminate two companies and ask further questions or start negotiations with the remaining four companies.
- On December 17th, the same four members of the Steering Committee, with the assistance of Pieter van der Linden, carefully reviewed the answers. Two more companies were eliminated. These were the two suppliers initially most considered for potential collaboration: Funka Nu (who has worked with Anders for Agrenska and who is a reference in Sweden for websites for people with disabilities) and GFI (the company hired by INSERM for Orphanet who made a proposal including free of charge hosting and maintenance on the Orphanet website).

- On December 18th, after further request for information and time to balance the arguments we came to a final choice between the two remaining companies: HDIS (United Kingdom) and Medcost (France). Eurordis opted for Medcost.

2. Decision

This decision included a recommendation to only develop the Forum in version 1 of the Portal, and not the Events database.
The Steering Committee agreed that for the implementation phase, the Project Coordinator needed not only to have a stronger delegation for a quick and efficient management of the supplier, but additional support too.
The Steering Committee therefore recommended hiring a) the services of Pieter van der Linden for further technical assistance, in particular to check the final specifications; b) the services of Stefan Johansson (Funka Nu) for consultancy on best accessibility for people impaired or with disabilities; c) the services of a lawyer (Alain Bensoussan Avocats) to prepare the contract with Medcost.

Grounds of the decision by the Steering Committee

This decision was difficult to reach.

The Steering Committee felt that **HDIS** was providing the best service according to Eurordis requirements and needs. In addition it was felt that they had a tool ready for use by Eurordis, that as a small company they would be more customer-oriented and flexible to work with Eurordis. HDIS was more committed to delivery and with shorter deadlines.
However, HDIS is a small company, with only 3 persons at their London headquarters and with 5 developers working for them in Russia. For that reason their delivering capacity and technological durability were in question, and they had little guarantee in case some of the key staff left the company or if the company ran out of business.

Medcost ranked 2nd. It was felt that Medcost's assets were a larger business base, the fact that they are located in France, their experience in working in the medical sector and with non-profit clients. We all felt that Medcost was obviously more expensive, might be less flexible, with longer delays to develop and adapt a product fitting our requirements and therefore tighter deadlines to stick to our commitments to the European Commission. However we would have a dedicated team for our project with a Chief developer and one or two collaborators.

Eurordis was particularly concerned by some practical operational and financial elements. It was recommended to select Medcost because of their track record, their base in Paris (which might be important when it came to the training of the future webmaster for instance), and most of all because of a better long-term sustainability. The final decision at the end was reached by a majority vote.

(See Annex 7 for Medcost proposal of November 29th, 2002)

3. Collaboration with the provider

An official commissioning fax was sent by Eurordis to Medcost and countersigned by Medcost for approval on December 24th, 2002.
(See Annex 8)

Samples of the look and feel were prepared by Eurordis trainee webmaster and sent to Medcost together with layout templates and styles, thus providing a useful basis for the design of the website.
(See Annex 12 for design of Eurordis web portal as of February 2003 and Annexes 9 and 10 for specific layout templates for national helplines and national alliances)

The emphasis was also put on accessibility issues. Recommendations from Stefan Johansson (Funka Nu), the consultant hired by Eurordis on accessibility issues, were taken into account when designing the web portal and included by Medcost in the detailed specifications.

Medcost had selected SPIP, a product that seemed to fit best Eurordis needs. It then took several weeks to discuss the adaptation of the tool to the requirements defined by Eurordis.
This discussion resulted in a second version of the proposal and detailed specifications.
(See Annex 13 for Medcost proposal # 20021228_2 sent on March 17th, 2003 and Annex 14 for detailed specifications version 2.1 of March 27th, 2003)

Phase 4: Prototyping (user interfaces, selected functions of the portal)

The first prototype of the website was built on March 17th and should be finalised by May 12th, 2003, according to the planning delivered by the provider. Functions need to be developed, languages added and design must be fine-tuned according to the styles chosen by Eurordis.

The prototype consists of two websites: one is accessible to the public, the other one (Eurordis back office) is accessible to Eurordis authors and administrators for content management.
(See Annex 15 for screenshots)

The objective is then to present version 1 of the web portal on May 24th, 2003 on the occasion of the launch of the first European Awareness Week. Until then, the main problem will be the lack of resources to hire a webmaster.

III - Description of the results achieved

The main objectives of the project were:

1) To develop a portal site on rare disorders in Europe which provides a single, browser-based approach to finding useful information – no matter where the information comes from and how it is created -, in particular:

   - To gather all existing sites about rare disorders in Europe in the portal (associations, databases, clinical trials, etc…)

   - To provide access to information on rare disorders which matches different user profiles (Alliances/patients, researchers, media, access for GPs, for public authorities, access for other actors…)

   - To develop and support a comprehensive approach to information on rare diseases in Europe, ensuring information on e.g. rehabilitation centres, support services and psycho-social information resources.

2) To provide a sense of community and organisation for the persons or groups of persons directly or indirectly affected by rare diseases.

3) To develop help line services in member states where National Alliances already exist.

4) To become a hub on rare disorders in Europe, to be the reference in rare disorders in Europe.

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1. To develop a portal site on rare disorders in Europe which provides a single, browser-based approach to finding useful information

The approach we have chosen is not only to give visitors access to useful resources through links but also to help them search for information on the website of on the Internet, whatever their interest, their profile or their computer literacy.

1.1. To gather all existing sites about rare disorders in Europe in the portal (associations, databases, clinical trials, etc…)

Links are provided:
- in the “Resources” section, giving access to several resources according to their nature (regulatory bodies inside and outside Europe, national research institutes, industrial partners, medical references, national helplines….)
- within each specific section to fit with different visitor approaches. For instance, visitors can access the EMEA website from the “Resources” or the “Orphan Drugs” section.

Guidance is provided on how to use search functions on the website and on the Internet through the "Resources" section to search and select information.

1.2 To provide access to information on rare disorders which matches different user profiles

The content posted on the web portal is meant to cover the needs of various profiles. Here are some examples of information needs that can be answered by the Eurordis web portal by linking the visitor to the right resource:

- Patient organisations may want information on Eurordis and activities of national alliances in various countries,
- Individual patients may be looking for medical information or for patient organisations contact details,
- Carers may want to share experience with others through a forum
- Journalists and the general public will find in the "Media Centre" a compilation of items from other pages of the web portal for a quick access to major information
- Doctors might be looking for centres of diagnostic or rehabilitation services for given diseases
- Teachers looking for the best learning method according to a given handicap might want additional medical information or contacts with patient organisations…

1.3 To develop and support a comprehensive approach to information on rare diseases in Europe, ensuring information on e.g. rehabilitation centres, support services and psycho-social information resources.

As shown above, information needs are not necessarily needs for medical information.

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2. To provide a sense of community and organisation for the persons or groups of persons directly or indirectly affected by rare diseases

Helping build a trans-national and cross-disease community of patients affected by rare diseases in Europe is one of the main objectives of the Eurordis web portal.
Here are some of the features that are meant to reach this goal:

- Moderated forums are designed for providing a sense of community. They will be a place for asking questions, sharing experience, meeting other patients.
- Sections like the "sub-section about and for patients with very rare or unknown diseases" will be useful for linking patients who would else be very isolated.
- Giving a glimpse of the various events across Europe also contributes to building a community.

3. To develop help line services in member states where National Alliances already exist

A page of the "Resources" section will list the already existing helplines. A special layout has been designed for the corresponding pages of the web portal, giving information about each of the helplines according to the same template.

4. To become a hub on rare disorders in Europe, to be the reference in rare disorders in Europe

By cooperating with already existing resources such as Orphanet and NEPHIRD, Eurordis will ensure there is no overlapping between its web portal and their respective websites. This will contribute to an integrated information network.

No other web portal offers neither at the European level nor worldwide such a broad access to information on rare diseases in terms of content, countries and languages covered.

IV - Overall assessment of the results and conclusions

On the implementation of the project

Although Eurordis is knowledgeable about rare diseases and orphan drugs, setting up a web portal in this area, particularly with such a multi-lingual emphasis, is only possible with the help of technical experts. Without the contribution of the European Commission, complemented by AFM, the French Neuromuscular Association, and Eurordis own funding, this project would therefore not have been possible.

Many of the actions planned have been carried out in time. Yet, a little delay could not be avoided on the non-Eurordis side of the project. An additional month has therefore been awarded by the European Commission.

On the achievements of the project

By working directly with patient associations, Eurordis has set up a web portal:
- which design and structure are accessible, both in terms of content, language and layout
- that meets patients' information and guidance needs
- that will help build a community across borders and across rare diseases
- that can evolve according to patients' new needs.

A long-term cooperation with Orphanet has been initiated, which both Eurordis and Orphanet greatly value. Results are already visible as far as the sharing of content building is concerned.

A prototype has been built. The first trial users consider that the portal is a major achievement for the rare disease community. Indeed no other web portal offers neither at the European level nor worldwide such a broad access to information on rare diseases in terms of content, countries and languages covered.

This prototype is now going to be progressively developed and filled with content until the opening of the official web portal. However Eurordis will still face a significant challenge by that time. This web portal must indeed be "living", which of course requires additional resources - not available at present - such as funds for a webmaster/web editor in order to manage content, liaise with the provider and visitors and suggest additional functions as required.
The objective is to present version 1 at the launch of the European Awareness Week on Rare Disorders on May 24th, 2003. As time goes by, further versions will then be developed to fit new patient needs.

V - List of annexes

N°	Type of document
1	Compilation of answers to the PARD 2 questionnaire
2	Overview of websites dealing with rare disorders as of March, 2003
3	Final report of workshops of June 28th and September 10th, 2002
4	Main Portal Requirements, Draft 5 as of October 16th, 2002
5	Overview of potential providers
6	Eurordis Request for Proposal of November 13th, 2002
7	Medcost Proposal # 20021129_1 of November 29th, 2002
8	Fax from Eurordis commissionning Medcost on December 24th, 2002
9	Special layout template for information on helplines
10	Special layout template for information on national alliances
11	Website structure as of March 2003
12	Eurordis Web Portal on Rare Diseases - Design by Eurordis as of February 2003
13	Medcost Proposal # 20021228_2 sent on March 17th, 2003
14	Detailed specifications version 2.1 of March 27th, 2003
15	Eurordis Web Portal on Rare Diseases - Screenshots of Prototype as of March 2003
16	Contract between Eurordis and Medcost