RESEARCH INTERNATIONAL

EUROPEAN SURVEY

ON THE NEEDS, PRACTICES, HABITS AND CUSTOMS OF RARE DISEASE ORGANISATIONS FOR THE COLLECTION AND DISSEMINATION OF INFORMATION.

N° Questionnaire		Etude	0	2	1	3	7	5

Code pays				

IMPORTANT GUIDELINES
TO HELP YOU COMPLETE THIS QUESTIONNAIRE

It is really important that you complete the questionnaire as instructed. Complete this document by ticking the box corresponding to your answer like this ☑.

Some questions could contain several possible choices, but you must tick only one answer. The instruction ''ONLY ONE ANSWER'' will be mentioned below the question.

Some questions could contain several possible choices, and you can tick one or more answers. The instruction 'SEVERAL POSSIBLE ANSWERS'' will be mentioned below the question.

Among a list of possible answers, if none corresponds to your answer, you can tick
"Other":
Ex : Other............................☑

Certain questions will have specific instructions. In such a case, they will be mentioned right above the question, in bold. Keep an eye on the content of each question !!

A A SHORT PICTURE OF YOUR ORGANISATION…

1. In which country are your headquarters located?
SEVERAL POSSIBLE ANSWERS, I.E FOR FEDERATIONS.

Belgium ....☐
Czech Republic.......................................☐
Estonia ....☐
France..☐
Germany ....☐
Great Britain...☐
Greece ....☐
Hungary ....☐
Iceland ....☐
Ireland..☐
Italy ....☐
Netherlands ....☐
Portugal..☐
Spain..☐
Switzerland ....☐
Sweden ....☐
Other……………………………………….☐

2. In which country(ies) / part of the world are you operating?
SEVERAL POSSIBLE ANSWERS.

Belgium ....☐
Czech Republic.......................................☐
Estonia ....☐
France..☐
Germany ....☐
Great Britain...☐
Greece ....☐
Hungary ....☐
Iceland ....☐
Ireland..☐
Italy ....☐
Netherlands ....☐
Portugal..☐
Spain..☐
Switzerland ....☐
Sweden ....☐
South America…………………………..☐
North America…………………………...☐
Middle East…………………………………..☐
North Africa………………………………☐
Sub-Saharian Africa…………………………☐
South East Asia……………………………..☐
Asia…………………………………………...☐
Oceania………………………………………☐
Other…………………………………………..☐

3. What is the date of creation of your organisation ?

WRITE THE COMPLETE DATE : FOR EXAMPLE /_1_/_9_/_7_/_2_/

/____/____/____/____/

4. What is the type of your organisation ?

ONLY ONE ANSWER

Rare disease patient organisation (one disease)...................................... ☐
Rare disease patient organisation (several diseases).............................. ☐
Rare disease federation (one disease over several countries)................. ☐
Rare disease alliance (several diseases in one country).......................... ☐
Rare disease National helpline.. ☐
Other patient organisation... ☐
Other.. ☐

5. Is your organisation...?

ONLY ONE ANSWER

Specific to one disease.................. ☐
Covering 2 to 10 diseases............. ☐
Covering 11 to 50 diseases........... ☐
Covering more than 50 diseases..... ☐

6. Does your organisation employ anyone ?

ONLY ONE ANSWER – CIRCLE THE NUMBER CORRESPONDING TO YOUR ANSWER LIKE THIS ①

Yes ....1 => How many ? / _____ / _____ / ______ / paid staff
No..2

6bis. And does your organisation work with volunteers ?

ONLY ONE ANSWER - CIRCLE THE NUMBER CORRESPONDING TO YOUR ANSWER LIKE THIS ①

Yes ....1 => How many ? / _____ / _____ / ______ / volunteers
No..2

7. What are your areas of activity?

SEVERAL POSSIBLE ANSWERS

Information ☐
Services to patients ☐
Care ☐
Research ☐
Lobbying ☐
Other ☐

8. Does your organisation get funding from…

SEVERAL POSSIBLE ANSWERS

Members ☐
Private donors ☐
Penalty fees ☐
Charitable bequest and successions ☐
National governmental granting ☐
Regional or local government granting ☐
Health insurance funding ☐
Lottery ☐
Fundraising events ☐
Other Non profit Organisations ☐
Foundations ☐
Pharmaceutical industry ☐
European Commission ☐
International organisations or international foundations (World Bank, Rockefeller foundation…) ☐
Other ☐

9. Does your organisation receive funding for…

SEVERAL POSSIBLE ANSWERS

Its help line ☐
Information leaflets ☐
Its website ☐
Meetings ☐
Training ☐
Awareness campaigns ☐
Networking ☐
Projects ☐

B Information sources (for yourself or for your organisation)

10. When you want to gain information about the disease(s), what sources do you rely on…

SEVERAL POSSIBLE ANSWERS

	ALL SOURCES SEVERAL ANSWERS	MAIN SOURCE ONLY ONE ANSWER
Specialist practitioner (hospital or private practice) as an external consultant	☐	☐
Your organisation Medical advisory Board (if any)	☐	☐
Your own physician	☐	☐
Nurse / medical staff	☐	☐
Rare Disease Network (including web sites)	☐	☐
Other support groups	☐	☐
Pharmaceutical industry	☐	☐
Governmental organisations	☐	☐
Leaflets / booklets	☐	☐
Medical press	☐	☐
Scientific conferences, symposiums	☐	☐
General press	☐	☐

10B And what is the main source that you use to gain information about the disease(s)…

ONLY ONE ANSWER

11. Who do you think the most reliable sources of information are for enquirers…?

SEVERAL POSSIBLE ANSWERS

Social services ☐
Hospital staff ☐
Doctors ☐
Pharmacists ☐
Scientists/researchers ☐
Health magazines ☐
Web sites ☐
Patient organisations ☐
Peers ☐

12. According to you, what could prevent people from giving information?
For each source / person, we have identified 2 kind of reasons for not giving information. Either the information is not available, or people are reluctant to give information. Please indicate the answer closest to your view.

TICK IN THE APPROPRIATE BOX – ONLY ONE TICK PER LINE

They do not provide information because…	No information is available	They are reluctant to give information
Social services	☐	☐
Hospital staff	☐	☐
Doctors	☐	☐
Pharmacists	☐	☐
Scientists/researchers	☐	☐
Websites	☐	☐
Patient organisations	☐	☐

C Information needs

13. According to you, who is the primary enquirer ?

ONLY ONE ANSWER

The patient.. ☐
The mother .... ☐
The father .... ☐
The brother .... ☐
The sister .... ☐
The grandparent .... ☐
The friend .... ☐
The medical professional .... ☐

14. What do you think the information needs of your members are?

SEVERAL POSSIBLE ANSWERS

	Q14 **ALL NEEDS** several answers	**Q14BIS** **THREE MAIN NEEDS** Only three answers
Specific information on disease	☐	☐
Prognosis	☐	☐
Treatment/clinical management	☐	☐
Understanding of mechanics (biochemistry/cellular) of the disease	☐	☐
Expert doctors	☐	☐
Centres of excellence	☐	☐
Clinical trials	☐	☐
Current research	☐	☐
Scientific conference dates/registration	☐	☐
Medicinal products	☐	☐
Dietary products	☐	☐
Alternative medicine, herbal medicine	☐	☐
Aids and equipment, devices and small accessories	☐	☐
Home care	☐	☐
Transport, auxiliaries	☐	☐
Genetic services	☐	☐
Psychological services	☐	☐
Welfare benefits	☐	☐
Special education needs	☐	☐
Community care	☐	☐
Respite care	☐	☐
Local support groups	☐	☐

14bis. According to you, what are the <u>three most important</u> information needs of your members ?

15. What in your opinion is the impact on your members of insufficient/late information ?

SEVERAL POSSIBLE ANSWERS

Inappropriate care of child ☐
Insufficient financial support ☐
Distraction from the needs of other family members ☐
Negative impact on career ☐
Isolation ☐
Anger ☐
Frustration ☐
Powerlessness ☐
Incompetence ☐
Fear ☐
Wrong decision-making ☐

D Information tools

16. What means do you use to deliver your information ?

SEVERAL POSSIBLE ANSWERS

Specifically written leaflets.. ☐
Relevant medical texts... ☐
Direct One to one telephone advice.................................... ☐
Referring enquirer to an expert .... ☐
Face to face meetings, one to one discussions .... ☐
Emailed advice.. ☐
Website .... ☐
General purpose letters.. ☐
Person-to-person letters... ☐
Group meetings .... ☐
Newsletter.. ☐

17. For each kind of information, tell us whether your organisation provides information on it or not :

TICK IN THE APPROPRIATE BOX – ONLY ONE TICK PER LINE

		Yes	No
1	Specific information on disease	☐	☐
2	Prognosis	☐	☐
3	Treatment/clinical management	☐	☐
4	Understanding of mechanics (biochemistry/cellular) of the disease	☐	☐
5	Expert doctors	☐	☐
6	Centres of excellence	☐	☐
7	Clinical trials	☐	☐
8	Current research	☐	☐
9	Scientific conference dates/registration	☐	☐
10	Medicinal products	☐	☐
11	Dietary products	☐	☐
12	Alternative medicine, herbal medicine	☐	☐
13	Aids and equipment, devices and small accessories	☐	☐
14	Home care	☐	☐
15	Transport, auxiliaries	☐	☐
16	Genetic services	☐	☐
17	Psychological services	☐	☐
18	Welfare benefits	☐	☐
19	Special education needs	☐	☐
20	Community care	☐	☐
21	Respite care	☐	☐
22	Local support groups	☐	☐

18. Is there a <u>help line</u> in your organisation ? By help line we mean any kind of information delivery, whether it is run from a home or from an office, by phone, e-mail or regular mail.

ONLY ONE ANSWER - CIRCLE THE NUMBER CORRESPONDING TO YOUR ANSWER LIKE THIS ①

Yes .... 1 ➔ **Go to Q 19**
No.. 2 ➔ **Go to Q 21**

19. Are the operators trained for this purpose ?

ONLY ONE ANSWER - CIRCLE THE NUMBER CORRESPONDING TO YOUR ANSWER LIKE THIS ①

Yes 1
No.. 2

20. How long is your help line available ?

SEVERAL ANSWERS

24 hours .... ☐
Office hours.. ☐
Evening .... ☐
At weekend .... ☐
In the morning.. ☐
In the afternoon.. ☐

20bis. Here are some questions about the monitoring of your help line. For each of them, please answer by yes or no.

TICK IN THE APPROPRIATE BOX – ONLY ONE TICK PER LINE

		Yes	No
1	Do you use volunteers to operate the help line?	☐	☐
2	Are volunteers trained?	☐	☐
3	Are volunteers supervised?	☐	☐
4	Is the help line in a confidential area/atmosphere?	☐	☐
5	Do you have procedures?	☐	☐
6	Do you have a guideline on confidentiality?	☐	☐
7	Do you hold directories of patient groups?	☐	☐
8	Do you hold directories of hospital and social services?	☐	☐
9	Do you keep track of enquirers to call them back?	☐	☐
10	Do you use the information you collect from enquirers to promote improvement in care, policy, legislation?	☐	☐

E *Best practices*

21. Now you are going to read a list of questions about the collecting and supervising of your information. For each question, please answer by yes or no.

TICK IN THE APPROPRIATE BOX – ONLY ONE TICK PER LINE

		Yes	**No**	**Not concerned**
1	Do you have a medical advisory board (MAB) ?	☐	☐	☐
2	Do specific advisors answer specific questions ?	☐	☐	☐
3	Does your MAB assist in creating leaflets/web pages/e-mail responses?	☐	☐	☐
4	Do you scan medical texts/journals for information?	☐	☐	☐
5	Do you read other rare disease group newsletters?	☐	☐	☐
6	Do you know how to do a web-search?	☐	☐	☐
7	Does your MAB regularly monitor your information?	☐	☐	☐
8	Do you tailor the information you send to enquirers according to their needs?	☐	☐	☐
9	Do you have a volunteer to collate information?	☐	☐	☐
10	Do you have a paid staff member for information-delivery?	☐	☐	☐

22. Do you search for information on the web?

ONLY ONE ANSWER - CIRCLE THE NUMBER CORRESPONDING TO YOUR ANSWER LIKE THIS ①

Yes .... 1 ➔ **Go to Q 22bis**
No.. 2 ➔ **Go to Q 23**

22bis. Were you trained for this purpose ?

ONLY ONE ANSWER - CIRCLE THE NUMBER CORRESPONDING TO YOUR ANSWER LIKE THIS ①

Yes 1
No.. 2

F *Access to information*

23. Regarding access to information, how do people reach your organisation ?
For each statement below, please answer by yes or no.

TICK IN THE APPROPRIATE BOX – ONLY ONE TICK PER LINE

		Yes	No
1	Health professionals refer patients to you	☐	☐
2	Patients reach you through other organisations	☐	☐
3	Patients reach you through a website	☐	☐
4	Clinics/hospitals display your information	☐	☐
5	Medical centres welcome the presence of a group representative	☐	☐

24. Do you have an outreach strategy?

ONLY ONE ANSWER - CIRCLE THE NUMBER CORRESPONDING TO YOUR ANSWER LIKE THIS ①

Yes 1
No.. 2

25. There are different kinds of information your organisation can provide. Among the list below, please tell us which kind of information you provide :

SEVERAL ANSWERS

Support .... ☐
Genetic counselling... ☐
Medical information .... ☐
Social information .... ☐
Contact with organisations.. ☐
Contact with other patients... ☐
Directory (hospital lists, doctors' contact details…) .... ☐

G Awareness raising and education

26. Here are some questions about how you raise awareness about your organisation. For each question, please answer by yes or no.

TICK IN THE APPROPRIATE BOX – ONLY ONE TICK PER LINE

		Yes	**No**
1	Does your group target information to professionals ?	☐	☐
2	Do you hold conferences for All Interested Parties (inter-face conferences i.e. parents, patients, professionals at one meeting) ?	☐	☐
3	Do you offer workshops/information tools for non-specialist professionals ?	☐	☐
4	Do you offer workshops/information tools for decision-makers ?	☐	☐
5	Do you offer workshops/information tools for the media ?	☐	☐
6	Do you liaise with medical schools to define university programmes	☐	☐

G Perspectives / additional questions

27. Here are statements regarding some perspectives/additional points. For each of them, please tell us whether you agree / disagree /or if you do not know :

TICK IN THE APPROPRIATE BOX – ONLY ONE TICK PER LINE

		I Agree	**I Disagree**	**I Do not know**
1	Partnership with other help lines could be useful to solve language issues	☐	☐	☐
2	My organisation is familiar with telemedicine[1]	☐	☐	☐
3	My organisation plans to develop telemedicine services	☐	☐	☐
4	Patient mobility is not a problem in the European Union	☐	☐	☐
5	My organisation is advocating to improve patient mobility	☐	☐	☐

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[1] The European Commission's health care telematics programme defines telemedicine as: "rapid access to shared and remote medical expertise by means of telecommunications and information technologies, no matter where the patient or relevant information is located."

		I Agree	**I Disagree**	**I Do not know**
6	Information on European Court of Justice decisions on patient mobility is largely available	☐	☐	☐
7	A unique European toll-free number for help lines would be helpful	☐	☐	☐
8	Training is necessary for operators to respond to sensitive questions accurately	☐	☐	☐
9	The Internet is helpful as an open, free and large source of information	☐	☐	☐
10	The Internet is generating too much information and this creates confusion	☐	☐	☐
11	Sharing internally validated information with other patients' groups helps ensure quality.	☐	☐	☐
12	There is more information available on US based web sites compared to EU ones	☐	☐	☐
13	Language is an obstacle to access information on the Internet	☐	☐	☐
14	I feel frustrated when I access a web site with restricted information	☐	☐	☐
15	Workload can be increased with e-mail traffic/dialogue as compared to a telephone service	☐	☐	☐
16	The Internet is an alternative and a useful tool for information on rare diseases.	☐	☐	☐
17	The Internet is an alternative and a useful tool for communication.	☐	☐	☐
18	The Internet should not be used exclusively as a source of information.	☐	☐	☐
19	The use of video-conferences would be a great benefit to NGOs.	☐	☐	☐
20	The use of telephone-conferences would be a great benefit to NGOs.	☐	☐	☐
21	Isolated patients with no group for their disease can benefit from belonging to a group representing other rare diseases.	☐	☐	☐
22	The approach to the training of help line operators is different for those with professional education and those with patient or parent experience.	☐	☐	☐
23	Data protection makes it impossible to recontact enquirers when needed.	☐	☐	☐

27bis. According to you, who should fund the information services ?

SEVERAL POSSIBLE ANSWERS

National governments .... ☐
Regional governments .... ☐
European Commission .... ☐
Pharmaceutical industry .... ☐
Other .... ☐

28. Do you mind if someone from Eurordis contacts you in the near future?

ONLY ONE ANSWER - CIRCLE THE NUMBER CORRESPONDING TO YOUR ANSWER LIKE THIS ①

Yes 1
No... 2

If yes, please print contact details on the next page

Thank you for your collaboration.

Your name:____

Your surname :____

Your address :____

____

____

____

Country :____

Your telephone number (international code/number):

____

Your mobile phone number (international code/number):

____

Your e-mail address :___________________________________

October 2003

Dear Sir, Dear Madam,

We thank you for having accepted to participate in our big European survey on information needs and practices in the area of rare diseases. This survey is conducted in 16 European countries and about 500 patient organisations will answer this questionnaire.

The information you are going to provide us with will help Eurordis to better understand how various types of organisations (national alliances, European disease specific federations, national help lines,…) are providing information on rare diseases and how they are collecting data which could be used to build a public health policy in the field of rare diseases, orphan drugs and new therapies.

All these data will then help us to make an accurate picture of your expectations and needs and provide efficient ways of collecting and disseminating information.

This questionnaire contains specific questions about information services and should therefore be completed within your organisation by a member of the board or a person in charge of information services with board approval.
Please read carefully the questions on the attached document and answer them by following instructions.
It is very important for the success of this survey that you answer all of the questions. If you cannot give an exact response, please give the one closest to your opinion.
When you have completed this questionnaire, please send it back by post to Research International. We have chosen this company to gather and analyse the data.

Should you have questions, we remain at your disposal. Please contact Claire Marichal at Eurordis in Paris: Tel: +33 1 56 53 52 11, e-mail: claire.marichal@eurordis.org

Should you receive this questionnaire from different sources, please only complete one and send it to Research International.

Thanks again for your participation.

Best regards,

Eurordis and its partners