



Help Lines
for Rare
Diseases

**EUROPEAN NETWORK
OF RARE DISEASE
HELP LINES**
-APPLICATION FORM HANDBOOK-



EURORDIS
Rare Diseases Europe

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The ENRDHLs has identified your service as having the potential to become a member of the network. The following document aims to familiarise you with the benefits of the network and assist you in filling out the attached **application form**.

I. Introduction to the European Network of Rare Disease Help Lines.

Information on rare diseases is one of the most important services that patient groups can provide, however barriers exist in accessing appropriate information that is validated and accurate. Many rare diseases are complex syndromes with several definitions and synonyms and this makes finding appropriate, validated information sources essential.

The ENRDHLs (European Network of Rare Disease Help Lines) was created in the context of Eurordis' European Commission financed, RAPSODY project (Rare Disease Solidarity Project, September 2006 to April 2008), where the priority was to increase the quality of services provided by European rare disease help lines¹. Five different types of Information services² from around Europe came together to share their expertise and to propose ways that the network could support other services around Europe.

Over time the network has built up a series of tools and support mechanisms that are being offered to its members. However for these tools to work there are certain criteria that you are required to agree to before becoming a member. The attached application is designed to allow us to establish what type of an information service you are running and to what extent you meet the network criteria and on the basis of this information offer support in improving your service.



II. Network Objectives

The long term objectives of EURORDIS' European Network of Rare Disease Help Lines are the following:

- Increase the quality of service provided by rare disease help lines across Europe by sharing expertise and creating a common approach.
- Provide support to help line services across Europe.
- Improve the visibility of help line services at European and national level.
- Increase funding opportunities for member services and the network itself.

¹¹ Beneficiaries of the Rapsody project: Eurordis, AFM Telethon, Barretstown, Children Living with Inherited Metabolic Diseases (CLIMB), Federacion Espanola de Enfermedades Raras (FEDER), Frambu, Orphanet, Fundacio Doctor Robert, Rare Disorders Denmark and State Institute for Drug Control Czech Republic

² Climb UK, MRIS France, FEDER SIO Spain, CSH Denmark, AFM MyoInfo France, Uniamo Italy, Enerca Europe, The Swedish Information Centre for Rare Diseases Sweden.

- Implement a membership policy that is as inclusive and representative as possible (consistent with the range of services that exist, e.g. volunteer, professional and national help lines) while still ensuring that standards of excellence are part of the admissions procedure.
- Show the utility of the service by compiling overall activity reports including as many member help lines as possible through the caller profile analysis.
- Take advantage of new technologies to promote and increase the visibility of the network. For example the 116 Common Number for Harmonised Social Services initiative.

III. Governance of the Network

A provisional Steering Committee has been appointed until the first network meeting in Krakow in May. It is composed of Rosa Sánchez de Vega of Feder François Houyez of Eurordis and Shane Lynam of Eurordis. This Provisional Steering Committee will be composed of a mix of EURORDIS staff and external experts currently involved in the management of the network. This committee will have a mandate until there are enough full network members to elect representatives from the network members themselves. **The Steering Committee will meet face to face** a minimum of once a year and validate the incoming year's action plan.

The steering committee has been asked to carry out the following tasks in their role as representatives of the ENRDHLs

1. To elaborate a roadmap for the 2010-2015 period with general and specific objectives.
2. To discuss and validate the yearly action plan (see attached) and budget (validated by EURORDIS management and board of directors), drawn up before the EURORDIS Annual Membership Meeting.
3. To review and approve/refuse membership applications.
4. To ensure that the actions undertaken are in line with what is described in the EURORDIS action plan, roadmap 2010-2015
5. To ensure that the network is progressing at an appropriate speed and in line with the general objectives set out above.

IV. The Application Process

For a flow chart of the process, please see Table 2 at end of document.

Interested services will either be contacted directly, asked to submit an expression of interest or make contact with the network through the EURORDIS website or the Rapsodyonline website.

The interested help line will then receive a pack including the application form and several annexes necessary for completing the application.

The help line will then send back an application which will include a filled in application form and a letter signed by the director/board committing the help line to do the following: implement the Orphanet coding system at their help line, send information for the CPA at regular intervals and commit to attend at least one network meeting a year. It should also include a document testifying respect of local data privacy legislation.

The Steering Committee will then review the application and grant either, the maximum full membership or an accredited membership depending on the type of service applying. The memberships will be stratified depending on the type of help line applying. A convergence plan with specific advice on how to improve the quality of service will be drawn up. The service will then be invited to make the necessary changes to meet the full membership requirements. A third category of observer status can also be granted to those organisations who currently do not run a help line but envisage setting one up in the future.

See Chapter VIII for an application glossary.

V. *Network Benefits*

There are a range of services that you will benefit from by becoming a member of the network. The network has build up common solutions over time in four activity areas. All of the following was developed in accord with the original Rapsody project participants.

1. Advocacy
2. Communication
3. Technical tools
4. Training and support

1. **Advocacy: European level**

The Network offers a range of advocacy opportunities for the network and its members. Certain goals have already been achieved by network advocates:

The publication of **the European Commission's Communication on Rare Diseases, November 2008** and **The European Recommendations to Member States by the Council of Ministers, June 2009**. Both of these documents advocate for the long-term sustainability of infrastructures developed in the field of information, research and healthcare for rare diseases and the Commission Communication specifically mentions the need for Help Lines at national level.

2. **Advocacy actions at national level**

The network is also involved in initiatives to implement the European policies on help lines for rare diseases at national level, this includes:

- **EUROPLAN project,**

This European project includes 16 national workshops where 'information services' will be specifically requested to be included in national plans.

- **Fact sheets**

The goal of these documents is to provide the Council of National Alliances, the Council of European Federations and individual patients and their representatives with advocacy tools encouraging the implementation of elements included in the European Commission's Communication on Rare Diseases and the Council of Minister's Recommendations regarding help lines.

3. Communication:

One of the most important aspects of a help line policy is the dissemination plan. It is essential that the patient community is aware of your help line number so that they can avail of your service.

Printed Communication: the network provides its members with brochures promoting their services. Indeed a new brochure with updated PARD 3 (guidelines on how to develop an information service) will be published in 2010. The network will also publish the results of the Caller Profile Analysis 2010. A Rare Disease Days Press Pack is also planned for interested help line services in 2010

- **Online Communication**

A listing and Cartography of involved services on www.Rapsodyonline.eu. This will be linked to the new Eurordis site. There are also plans for the development of a Help Lines blog and an online community. www.rapsodyonline.eu will be translated into as many languages as necessary. Eurordis also publishes a series of help line articles in its Newsletter every year.

- **Face to face promotional events**

In the past we have organised the following help line events:

ECRD, Lisbon, 2007: workshop (35 participants),

Eurordis Annual Membership Meeting ,Copenhagen, 2008: workshop (25 participants),

Eurordis Annual Membership Meeting , Athens, 2009: network meeting and workshop (34 participants)

In the years ahead, we will continue to host at least one help line workshop a year where, as a member you will be invited to attend and add your contribution.

4. Technical tools

At the centre of the tools we have developed for our network is the provision of technical support:

- **The CPA (Caller Profile Analysis).**

A statistical exercise that we will carry out every year to assemble your help line's call information into a common database in order to create reports regarding the mass of activity that European help lines represent. It is imperative that all members use the **orphanet code** for listing diseases to ensure the success of the **Caller profile analysis**. These reports will contribute to the advocacy and communication potential to the network.

We have already completed a CPA in July 2008 and November 2009 with our help line contacts which will be repeated on an annual basis. This first exercise provided data on 1900 calls for 6 help line and the report can be provided on demand. See more in Membership Criteria

- **Common software:**

Rapsodyonline call recording interface and database:

This service is for any help line that becomes a member of the network. The interface and approach has been designed with the help of the more advanced services involved in the network. If you are starting out as a help line and are wondering how best to record data about the calls you are answering, we will adapt the tool to suit your needs. The tools can be translated into new languages on demand.

Platform for isolated patient databases

This allows member help lines to compare their lists of VIPs (Very Isolated Patients) with other lists around Europe

We ensure that **isolated patients lists** are being compared on a regular basis. In order for this to work the network needs to reinforce the need for all members to be using the same codes for recording information about diseases.

5. Training and support

- Training sessions have been organised so far on the following topics:
 - 'How to find validated information sources online', Spain May 2007
 - 'Rapsodyonline user training', Copenhagen 2008
 - Upcoming: One validated information session to take place in Cluj Napoca in December 2009.

- **Onsite visits** to set up rapsodyonline and train users

5 training visits have already taken place to help lines Uniamo and the Veneto Registry Helpline Italy, Feder SIO Spain, Ronard Romania, Rarissimas Portugal and Radiorg Belgium. These sessions are being offered to new start up help lines that would like to avail of an introductory session on how to use the Rapsodyonline tool and eventually how to become a member of the network and provide good Caller Profile Analysis data.

VI. Membership criteria

(This part applies to part 2 of the application form, technical data about your help line)

1. Use Orphanet code to record information about disease

Your respondents will share information on potentially 6000+ rare diseases. By recording the name more and importantly the Orphanet code each time you enter information about a disease, you will allow other help lines around Europe to search your queries on a particular disease and related subject and then contact you to find out more information. It also makes the Caller Profile Analysis a lot stronger as it allows us to include information about diseases in the network reports. This is why we require you to use the OrphaCode developed by Orphanet and W.H.O for the future ICD.



2. Local Registration

Your help line needs to be legally registered in Europe. Your service needs to be compliant with the legislation that protects the privacy of citizens and sensitive health data. To ensure this, we ask you to provide a document testifying respect of local data privacy legislation (legal attestation and/or authorisation relevant authority)

3. Caller Profile Analysis CPA

As a network, we need to demonstrate the social utility of the service at the European level. European Help lines need to document on their overall activity. By sending us basic information about every call for a month you will be contributing to a network activity report. We required the following information:

Name of Disease (with orphanet code), Age of enquirer, Gender, Category of enquirer, Type of contact, Purpose of contact, Region/Country, Heard about helpline

By participating in the Caller Profile Analysis your service will make our group report data stronger.

4. Attend National Workshop

Share experience and issues with network participants; participate in at least one annual network meeting, share common tools and good practices. In annex to letter of agreement we require you to provide written commitment of your board /director to do this.

5. Commitment of board

Demonstrate the commitment of your management board to support the network Network decisions should be taken on an independent basis and implemented as asked. We need to include a Signed Letter of Agreement to this effect.

VII. The Application Process

For a flow chart of the process please see Table 2 at end of document.

Interested services will either be contacted directly, asked to submit an expression of interest or make contact with the network through the EURORDIS website or the Rapsodyonline website.

The interested help line will then receive a pack including the application form and several annexes necessary for completing the application, e.g. the Caller Profile Analysis (CPA) template and a form explaining the legal requirements that the service is asked to meet before joining.

The help line will then send off an application which will include a filled in application form, one month filled in Caller Profile Analysis, and a letter signed by director/board committing the help line to do the following: implement the Orphanet coding system at their help line, send information for the CPA at regular intervals and commit to attend at least one network meeting a year. It should also include a document testifying respect of local data privacy legislation.

The Steering Committee will then review the application and grant either, the maximum full membership or an accredited membership depending on the number of points the application has been awarded. The membership will be stratified depending on the type of help line applying. A convergence plan with specific advice on how to improve their service will be drawn up. The service will then be invited to make the necessary changes to meet the full membership requirements. A third category of observer status can also be granted to those organisation who currently do not run a help line but envisage setting one up in the future.

VIII. Application form glossary.

Table 1. Application form guide

Field	Comments
1.1 Official Name of your Service	Legal name on your public documentation
1.2. Creation date	Legal creation date
1.3 Acronym	If different from official name
1.4 Director	Director at date of signature
1.5 Address	of your organisation
1.6 Country	of your organisation
1.7 Postal code	of your organisation
1.8 City	of your organisation
1.9 Telephone	of your organisation(with international code)
1.10 Fax	of your organisation
1.11 e-mail	of your organisation
1.12 Website	of your organisation
1.13 Contact person for ENRDHLs	
1.14 Contact e-mail	for contact person
1.15 Telephone	for contact person(if different from the organisation number)
1.16 Address	for contact person(if different from the main office)
1.17 Methods of communication being used by enquiries	For each example please indicate the number from the previous year where available.
Email address	Help line email (if different from organisation)

Website visits	Help line website (if different from organisation)
Phone number	Help line phone number (if different from organisation)
Onsite visits	Onsite visits address (if different from organisation)
Postal address	Help line postal address (if different from organisation)
1.18 Type of membership requested Full Membership Observer	If you are in the implementation phase of a help line project. If you are in the planning stage of a help line project.
1.19 Does your help line organise trainings/workshops?	Any training events for your respondents.
1.20 Number of paid staff working at your help line?	(Please indicate the profile of your staff, e.g psychologist, doctor, social worker..)
1.21 Number of volunteers working at your help line?	
1.22 What is the governance structure at your helpline	Does your help line/ organisation implement a board structure for example?
1.23 Membership in other overarching organisations:	Please include here your level of autonomy in terms of decision making.
1.24 How is your help line/ organisation financed and what are the sources of financing in percentages?	Please be as accurate as possible and please include as much information as is possible. This will of course be kept confidential.
1.25 What is the cost structure for help line's phone calls?(free calls, local call, flat rate or full rate)	

2. Technical information regarding your help line	
2.1 Is your service dealing with general or specific diseases?	
2.2 If it is a group of diseases please mention how many diseases this covers?	
If it is a specific disease please name the group?	
2.3 What languages are spoken by your help line respondents?	
2.4 Number of calls emails/emails/letter/visits per annum?	Please include information from previous year. Please include percentage where available
2.5 Do you currently have a system in place to record the details of isolated patients?	Please mention how many patients are included in your isolated patient's list
2.5 Current call management database system in place	Please be as detailed as possible, leaving the details of the person directly responsible for this aspect at your organisation
2.6 Does your help line offer information or support on the following topics.	Please tick where you feel your staff are qualified enough to respond to questions related to the proposed headings
2.7 Upon joining the network, your help line will:	Please tick if you will provide the item. Please see part VI above.
1. Adopt the Orphanet disease coding system for all call management at your help line	Please attach letter signed by Director or Board showing validation of this decision ³ .
2. Ensure that your service is respecting local data privacy legislation	Please attach document from lawyer or relevant authority

³ 1, 3,4 and 5 can be included in the same letter

3. Participate in the Caller Profile Annual Analysis by sharing information on callers, their genders, their relation to the patient, the purposes of the call, the diseases, the types of responses given.

Please attach letter signed by Director or Board showing validation of this decision. This information does not include any personal information regarding the caller.

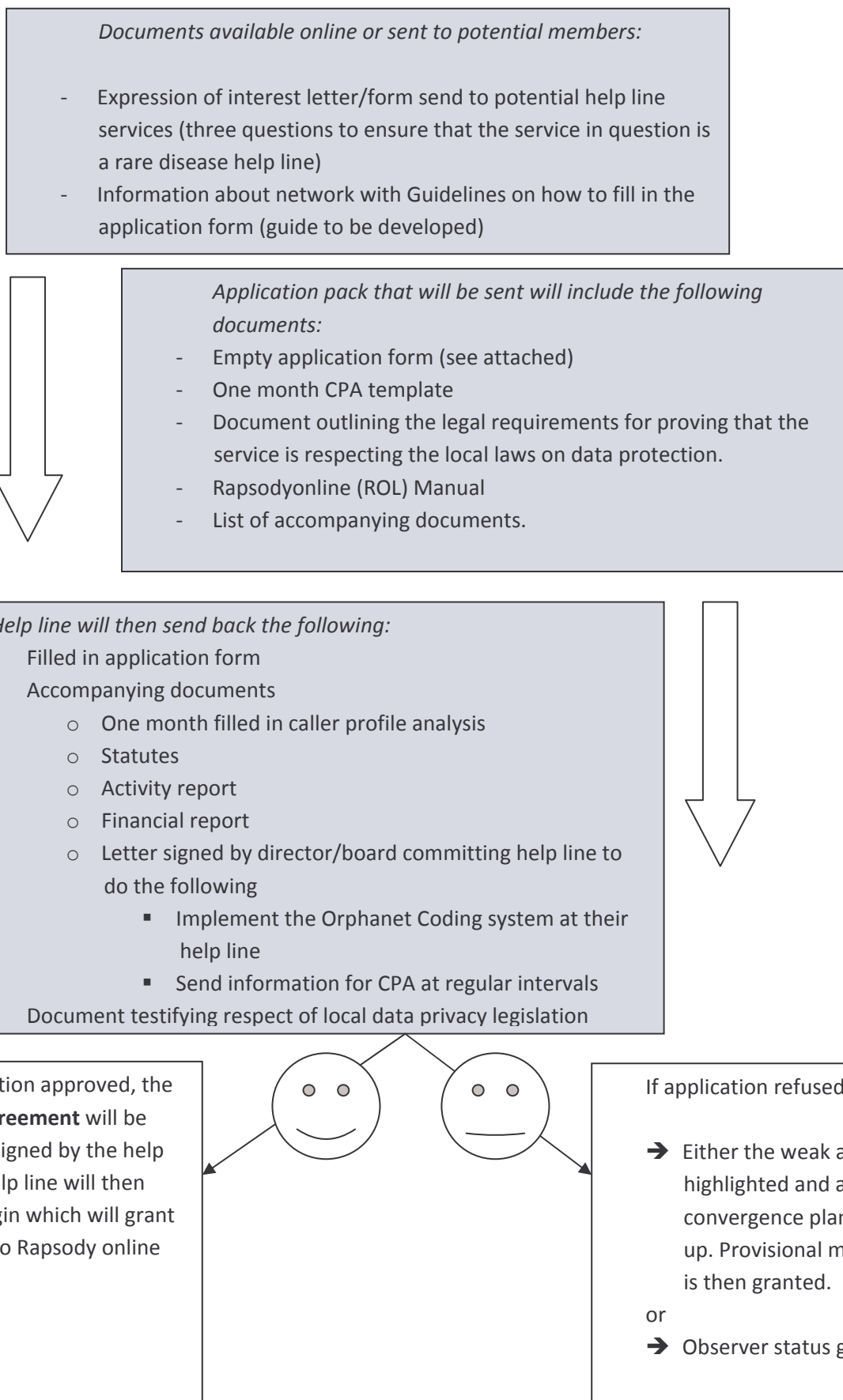
4. Agree to attend at least one workshop event every year

Please attach letter signed by Director and Board showing validation of this decision

5. Demonstrate the commitment of your management board to support the network. Decisions should be taken on an independent basis and implemented as asked.

Please attach a Signed Letter of Agreement to this effect.

Table 2: Flow chart of application process





Executive
Agency for
Health and
Consumers

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