

NATIONAL HELP LINES FOR RARE DISEASES



EURORDIS
Rare Diseases Europe

Any rare disease patient organisation, healthcare institution or governmental organisation that offers 1) information about a given rare disease or rare disease related topic or 2) psychological support to the patient, can be classified as a rare disease (RD) help line (HL).



Traditionally, user enquiries and HL answers are phone-based, although they can also exist in the form of emails, letters and on site face-to-face interactions. Responses can in turn be given orally, in writing (for example, via email). Individuals who require the service provided by HLs include patients, patient carers, family members, friends, social and healthcare professionals, and the media. The primary role of a HL is to provide information and support to the callers.

WHY ARE NATIONAL HELP LINES FOR RARE DISEASES REQUIRED?

The European Commission's Communication, "Rare Diseases: Europe's Challenges"¹, documents the need for specialised services for rare disease patients around Europe, including HLs, to be sustainable in order to pursue their goals. The European Project for Rare Diseases National Plans Development (EUROPLAN) recommendations² underscores the importance of supporting information networks (web-based information, help line, information centre). The existence of RD information systems for both patients and professionals is an aspect that has been identified as an indicator of the success of the RD National Plans.

WHY ARE NATIONAL HELP LINES IMPORTANT TO RARE DISEASE PATIENTS?

Rare Disease patients are frequently faced with a critical lack of information and support. Upon hearing their diagnosis, their first point of contact is often the local patient organisation for their disease. If a patient organisation does not exist in their area or cannot supply the correct, validated information, the patient is often left feeling isolated. The patient is often in desperate need of psychological support and it is essential that this is available once the diagnosis has been made. The patient may also have social questions that can only be addressed by someone who is familiar with the social system of their country. HLs are a service that can not only offer solutions to these needs, but also identify unmet needs in the daily lives of RD patients and provide a basis for advocacy work to eliminate them.

HOW TO ADDRESS THE ISSUE?

SCOPE OF ACTIVITY OF A RARE DISEASE HELP LINE

A HL service can take many forms:

- Professional vs. volunteer or a mix of both
- Governmental vs. private
- Specialised disease service vs. general RD service
- A range of opening hours (e.g. 24 hour services, ad hoc unspecified hours, one day per week)
- Listening and information provision only, or direct action to help the caller.

HL services should provide information on the following:

- medical care and treatment
- social services
- research
- genetic testing
- counselling
- directing to additional service providers (e.g. Centres of Expertise, Respite Care Services, patient organisations)
- how to contact a person with same disease when no organisation exists.

1 COM (2008) 679 Communication from the Commission to the European Parliament, the Council the Economic and Social Committee and the Committee of the Regions on Rare Diseases: Europe's challenges.
2 Draft recommendations for the development of strategic plan for rare diseases including methodological guidance. 28 October, 2009. Final recommendations available on the EUROPLAN website, www.europlanproject.eu

Aspects that may need to be supported and funded when setting up a HL service include:

- operational support (e.g. call centre, overhead costs)
- support for respondents, (e.g. training needs, debriefing)
- representative staff profiles; e.g. psychologist, social worker, administrative staff, doctors, volunteers
- data management needs, e.g. the appropriate call detail recording software
- gathering validated sources of information for respondents.

Whatever the level of development, there are certain approaches that HL should adopt from the beginning:

- development of a database to record caller data
- recording each call with the Orphanet³ code for rare diseases classification
- providing information for the European Network of Rare Disease Help Lines (ENRDHL) Caller Profile Analysis⁴ on a regular basis
- ensuring familiarity with and adherence to local level data protection policies
- disseminating as wide a communication plan as possible to ensure that the HL number is available to the general public
- learning from the expertise that already exists for inspiration in setting up their service.

HELP LINES IN THE NATIONAL STRATEGY ON RARE DISEASES

The guiding principles of rare disease HLs are directly linked to the main pillars of national strategies on rare diseases and European strategies. They play an essential role in the healthcare systems to inform and guide patient's families and healthcare professionals. In the context of a national plan for RD, HL should:

- provide quality information to customised individual needs
- provide support for rare diseases patients
- orientate towards Centres of Expertise or specialists
- provide information on existing orphan drugs and other treatments
- provide information on clinical trials and research
- provide information on genetic testing, genetic counselling, neonatal screening
- provide access to existing patient organisations and online communities
- provide support to very isolated patients with very rare diseases by matching them with similar patients in their country or around Europe
- participate in the ENRDHL where common approaches to the day today management of HLs are proposed. Public financial instruments to create and support national HLs for RD should be available.

RELATED ISSUES

SCOPE OF ACTIVITY OF A RARE DISEASE HELP LINE

HLs are one of the most useful and cost effective RD services, and should be a priority in the national plans/strategies or rare diseases.

- Although there is often a perception that creating a HL service is expensive, starting a basic HL that offers quality information is inexpensive and requires little staff or resources. Costs can be minimised by taking advantage of expertise that already exists through the ENRDHL.
- An internet site with an email address cannot replace a HL service. The psychological support that a HL respondent can offer a patient who needs to talk to somebody who understands their situation is not available through the internet.
- An internet presence can complement a HL service and often, patients find HL numbers through the internet.
- In registering information about callers or calls, a HL exposes itself to local data protection laws. This aspect should be looked at before setting up a service. The ENRDHLs can help you with this process.
- Comprehensive HLs can require intensive technical assistance. Fortunately, tools and expertise have been refined over the years and are available through the ENRDHL⁵.

REFERENCES AND ADDITIONAL INFORMATION

- EURORDIS. The ENRDHL Caller Profile Analysis, 2011. http://download.eurordis.org/documents/pdf/4_Nat_Initi%20for116_number.pdf
- EURORDIS. Policy fact sheet – European Network of Rare Disease Help Lines. http://www.eurordis.org/sites/default/files/publications/Factsheet_euro_network_helpines_0.pdf
- Orphanet. Database of information on rare diseases and orphan drugs for all publics. <http://www.orpha.net>

3 - Orphanet is a European database of information on rare diseases. Each rare disease is given an orphan code number corresponding to the 10th international classification of diseases established by the WHO where available.

4 - Common call recording tool established within the EURORDIS led Rare Disease Solidarity project (RAPSODY) in which members of the ENRDHL can continue to record information regarding calls in a standard way. This tool gives members access to call recording methods that have been tried and tested compiling call data on a European level, which may eventually be used for public health policy purposes, <http://www.rapsodyonline.eurordis.org>.

5 - To benefit from Rapsodyonline call recording tools visit <http://www.rapsodyonline.eurordis.org> to become a member of the European Network of Rare Disease Help Lines



EURORDIS
Rare Diseases Europe

eurordis@eurordis.org
+33 1 56 53 52 10

www.eurordis.org



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