



THE EUROPEAN NETWORK OF RARE DISEASE HELP LINES

TOWARDS A UNIQUE EUROPEAN 116 NUMBER



The European Network of Rare Disease Help Lines (ENRDHLs) was created by EURORDIS in order to provide support and share experience and information between national or disease specific help lines across Europe. The network was set up during the Rare Disease Solidarity Project (RAPSODY - September 2006 to April 2008)¹.

EURORDIS, on behalf of the European Network of Rare Diseases Help Lines, has asked the European Commission DG Connect to reserve a unique six digit 116 phone number for help lines (HL) for rare diseases across Europe. If this is accepted, European citizens from all Member States, and patients and families in particular, will have one single number to dial wherever they are in Europe every time they need support or information on rare diseases.



The European Network makes it possible:

- for emerging HL services to be assisted in confronting the questions posed when setting up a new service
- for existing help line services to increase the quality of service they provide
- for help lines to compare their lists of isolated patients with other network members and increase the chance of patients meeting someone with the same diagnosis as them
- to benefit from cost saving technical support by for example, providing call information recording tools²
- to receive specifically focused training sessions
- for help lines to benefit from a single European 116³ number for rare diseases. This will allow patients to call a unique number from all over Europe.

WHICH SERVICES WILL OFFER THE 116 NUMBER?

The establishment of the single European number for information on rare diseases will be beneficial to patients and their families

- by allowing them to access reliable information and quality services in the Member State in which they reside or are visiting.
- It will allow them to be connected free of charge to the information service in their home country.

HOW IS THE 116 NUMBER FOR RARE DISEASES SUPPORTED BY EU POLICIES?

1. The Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions on "Rare Diseases: Europe's challenges" (11 November 2008).

5.2. Access to specialised social services

Centres of expertise may also have an essential role in developing or facilitating specialised social services which will improve the quality of life of people living with a rare disease. Help Lines, Respite care services and Therapeutic Recreation Programmes, have been supported and need to be sustainable to pursue their goals.

2. Council Recommendation of 8 June 2009 (Official Journal of the European Union 3.7.2009) on an action in the field of rare diseases (2009/C 151/02).

VI. Empowerment of patient organisations

19. Promote the activities performed by patient organisations, such as awareness-raising, capacity-building and training, exchange of information and best practices, networking and outreach to very isolated patients.

EXAMPLES OF OTHER 116 NUMBERS WHICH HAVE ALREADY BEEN GRANTED IN EUROPE

Five numbers have now been reserved for harmonised services of social value. As of January 2011, four of these numbers were operational, but not in all Member States:

- 116000 (Hotline for missing children) was functioning in 15 Member States
- 116006 (Helpline for victims of crime) in 2
- 116111 (Child helpline) in 17
- 116123 (Emotional support helpline) in 7
- 116117 Non-emergency medical on-call service.

1 - 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. Project supported by the European Commission, Executive Agency for Health and Consumers, the Government of Portugal in the context of the EU Presidency, Sigma Tau Pharmaceuticals, the Baxter International Foundation, Actelion Pharmaceuticals, Groupe Initiatives Mutuelles UGIM
2 - <http://rapsodyonline.eurordis.org>
3 - DG Information Society at the European Commission's Single EU numbers for Harmonised Services of Social Value programme

Help line	Location	Help Lines receive calls for the following diseases	Public number (only accessible within the country)	Public email
AFM Téléthon	France	Neuro-muscular	0 810 811 088	accueilfamilles@afm.genethon.fr
Coordinating Centre Veneto Region	Italy	All rare diseases	049 8215700	malattierare@pediatria.unipd.it
Croatian Help Line	Croatia	All rare diseases	08009966	rijetke.bolesti@gmail.com
ENERCA	Spain	Congenital anemia	934515950 outside of Spain, patients can access by dialing +34 before the number above	enerca@enerca.org
ICRDOD	Bulgaria	All rare diseases	32 57 57 97	URL: http://www.raredis.rog/
Linha Rara	Portugal	All rare diseases	707 100 200	linharara@rarissimas.pt
Maladies Rares Info Service	France	All rare diseases	01 56 53 81 36	Info-services@maladiesrares.org
Myasthenia Gravis Romania	Romania	Myasthenia Gravis	0744704399	asociatia.miasthenia@gmail.com
NORO Help Line	Romania	All rare diseases	360 103200	office@apwromania.ro
SIO-FEDER	Spain	All rare diseases	902 18 17 25	sio@feder.org.es
TVMR	Italy	All rare diseases	0800 89 69 49	tvmr@iss.it

NEXT STEPS TO BE ACHIEVED FOR THE 116 NUMBER TO BE RESERVED

The European Commission has recently increased the number of member states ready to provide the service from 5 to a "majority" (14 member states) and this new rule applies to the request of the 116 for Rare Diseases.

WHAT YOU CAN DO AS A PATIENT ADVOCATE?

Before the end of 2012, an ad hoc expert meeting will analyse our proposal.

At present we are confident to obtain the support from France, Romania, Italy, Portugal and Spain but 9 more states must express their interest for the request to be considered.

If you support this proposal, and as you may be organising or participating in a national conference on a National Plan for Rare Diseases or active at the national level with contacts with your ministry of health, we encourage you to pass the following messages:

1. Necessity to include the creation of a national help line for rare diseases, or its development when there is one, in the national plan (the help line can be operated by public services or by a patients' organisation), considering that:

- A National Help Line on Rare Diseases is a concrete achievement that has an immediate impact in the public opinion
- It is an easy to communicate about outcome
- It is not costly, as a service can operate with an annual budget of 150 000 – 250 000 € to start with, including the telephone costs if the calls are free for the users

- It is a measure that should appear as a top priority in all national plans for rare diseases
- A national help line already exists in Bulgaria, Croatia, France, Italy, Portugal, Romania, Spain; one will soon exist in Switzerland.

2. Importance of supporting the implementation of a 116 number for help lines for rare diseases at the next COCOM meeting (We are highlighting the initiative with the EU Committee of Experts for Rare Diseases. At the member state level, before the end of 2012, your ministry of health should contact their colleagues from the telecom ministry to make sure a minimum number of them will support our proposal when it will be reviewed by the COCOM experts).

REFERENCES AND ADDITIONAL INFORMATION

- EURORDIS. The European Network of Rare Disease Help Lines. http://rapsodyonline.eurordis.org/dev_rapsody/map/index/
- EURORDIS. The European Network of Rare Diseases Help Lines Caller Profile Analysis, November 2010. http://download.eurordis.org/documents/pdf/HelpLines_Network_analysis2010.pdf
- EURORDIS. Policy Fact Sheet on National Help Lines for Rare Diseases. http://www.eurordis.org/sites/default/files/publications/Factsheet_natl_helplines.pdf



EURORDIS
Rare Diseases Europe

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

www.eurordis.org



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