



Help Lines
for Rare
Diseases

**EUROPEAN NETWORK
OF RARE DISEASE
HELP LINES**

-NETWORK ANALYSIS 2010 -



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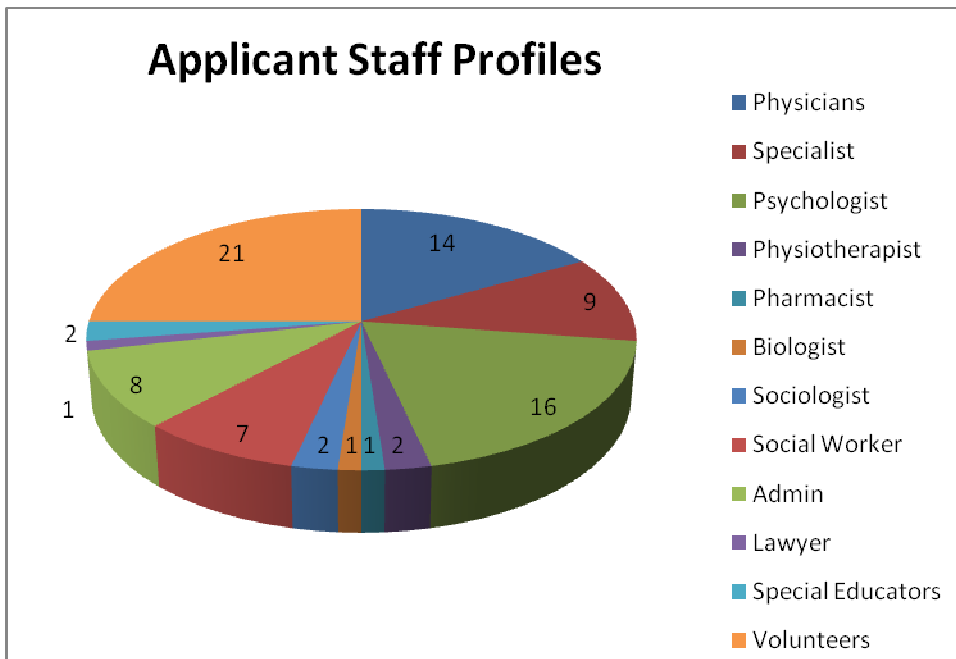
The following has been collated by the member services of the ENRDHLS. It is based on 1. the data provided by the help lines who applied to become a member of the European Network of Rare Disease Help Lines during the 2009-2010 period and on 2. the call data sent by the help lines who took part in the Caller Profile Analysis, November 2009.

1. ENRHLs Applications received May 2009 to May 2010

AFM	France
Association National Syndrome de Apert	Spain
ENERCA	Spain
ICRDOD	Bulgaria
FEDER SIO	Spain
MRIS	France
Rarissimas	Portugal
Romanian Myasthenia Gravis National Information Centre	Romania
Ronard	Romania
Telefono Verde Malattie Rare	Italy
Centre for Rare Diseases for the Venice Region	Italy

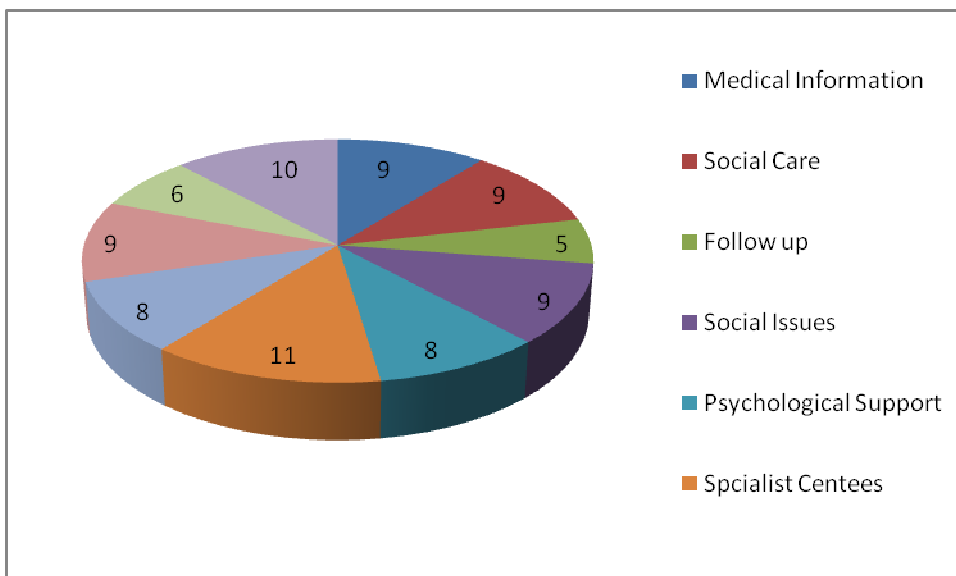
- 8 applicants already implementing the Orphacode system to record information about calls. 3 other services committed to implementing it.
- All 11 applicants committed to participating in the coming years' CPA. 6 Services already participated in 2009
- All 11 applicants are respecting the local data privacy legislation. 5 Applicants have provided documented proof of this
- All 11 applicants committed to attending network meeting once a year.
- 9 applicants committed to taking help line related decisions on an independent basis.

2. Staff Profiles at member Help Lines



- 7 out of 11 applicants organising training sessions at their service

3. Number of help lines offering the following type of expertise



4. Cost Structure of service

7 out of 11 services charge local call fees.

4 out of 11 services charge free phone fees.

Services are funded from a diverse range of sources, including:

- National public funding
- European public funding
- National Telethon
- Association Membership fees,
- Private funding
- Overarching Association
- Donations

5. Diseases covered by service

Other than general rare disease services:

- Neuromuscular diseases
- Craniosynostosis e.g. Craniofacial Malformations,
- Rare Anaemias
- Myasthenia Gravis and related neuromuscular junction disorders, including 3 diseases: Autoimmune Myasthenia Gravis (ORPHA 589), Lambert Eaton Myasthenia Syndrome (ORPHA 43393)

6. Languages covered by help lines involved in the network

Network members can answer questions in the following languages:

French- Spanish- English-Catalan Italian-German-Portuguese-Greek-Dutch-Bulgarian
Portuguese-Romanian-Hungarian.

7. Caller Profile Analysis 2009

One of the goals of the European Network of Rare Disease Help Lines is to allow member help lines to exchange data across Europe. One of the criteria that members are asked to adhere to before becoming a member of the network is to record core call information in a uniform manner. This makes it possible to compare data and exchange information amongst the network members. The exercise is complimented by the online call information recording tool rapsodyonline. All help lines who decide to use this application will be using the same tools to record call information. This will allow them to exchange information about specific requests through a common online platform and to provide information for the CPA automatically. Whenever a request cannot be answered by a national help line they will have the opportunity to share the question with the other users thereby increasing the chance of finding an answer. If all help lines are entering the orphacode each time they record information about the disease for each query the exchange of information will be facilitated. The initiative is particularly important considering the scarcity of available information on rare diseases.

This is the third time the CPA exercise has been attempted. Although there have been improvements in the quality of data there is still a lot of work to be done by the participating help lines in order to ensure that it will be possible to make activity reports for the network as a whole. These activity reports will serve as an advocacy tool when convincing policy makers to allocate financial resources to information services.

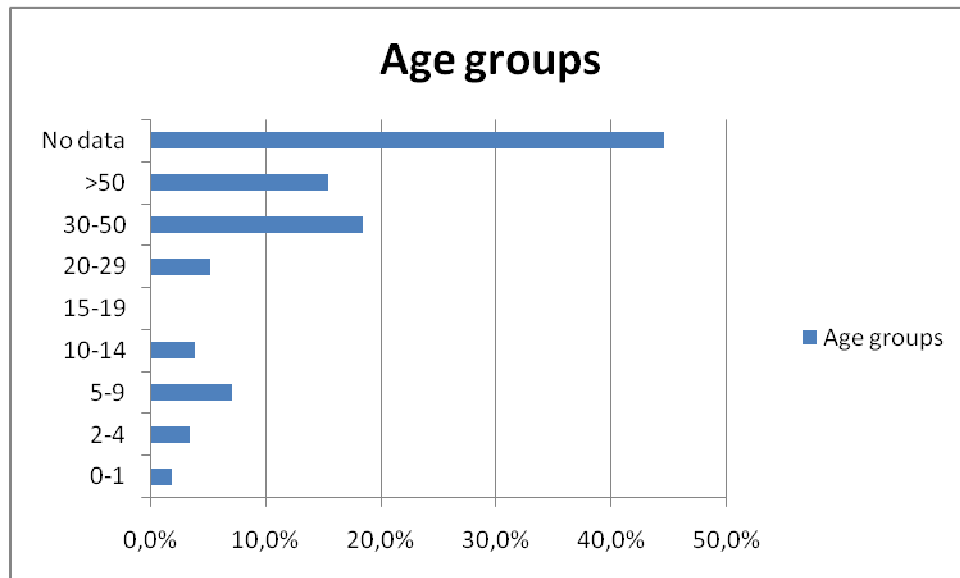
This year the following 8 help lines took part in the exercise. Four out of nine services are still not recording the orphacode each time they enter a disease. In order to become a full member of the ENRDHLS they are required to record the orphacode.

Help Line	Orphacode
France- MRIS	No
France- MyoInfo	No
Spain- Feder	Yes
Belgium- Radiorg	Yes
Portugal- Rarissiamas	Yes
Romania- Ronard	No
Denmark- CSH	No
Italy- Uniamo	Yes

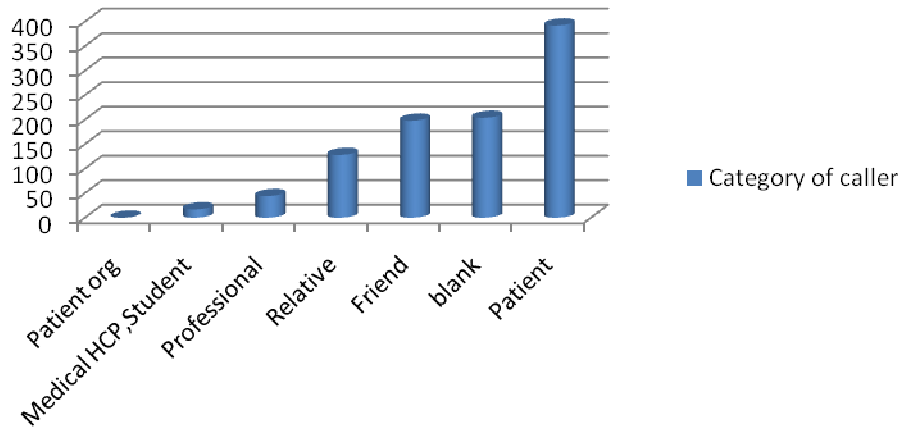
The following graphs show the proportion of calls regarding 'category of caller', 'type of contact', 'reason for calling' 'age group' and 'gender'. The information was gathered by each help line over the month of November 2009. It is based on a total of 1129 calls.

Data received from 9 help lines (AFM-Myoinfo, CSH, Feder SIO, Maladies Rares Info Services, Ronard, Rarissimas, Radiorg, Uniamo):

# calls	# respondents	Age of enquirers	
1128	25	0-1	1,86%
		2-4	3,43%
		5-9	7,16%
		10-14	3,93%
		15-19	0,00%
		20-29	5,20%
		30-50	18,45%
		>50	15,41%
		No data	44,55%



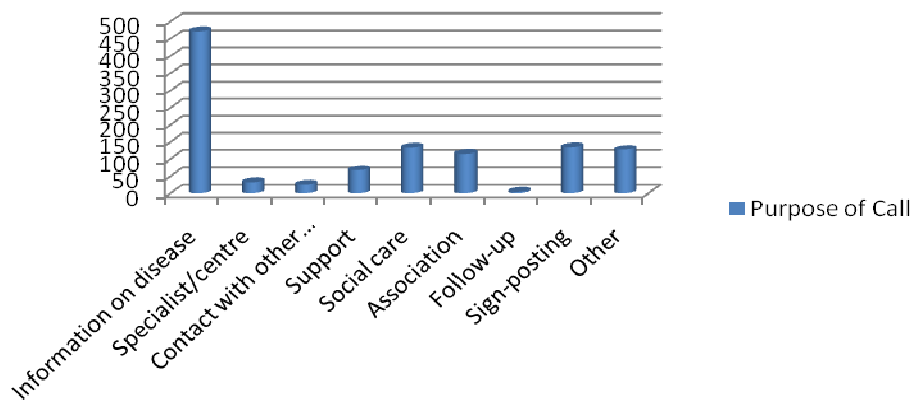
Category of caller



Category of caller

Patient org	0	0,0%
Medical HCP, Student	17	2,9%
Professional	44	7,4%
Relative	128	21,7%
Friend	198	33,5%
blank	204	34,5%
Patient	392	0,0%

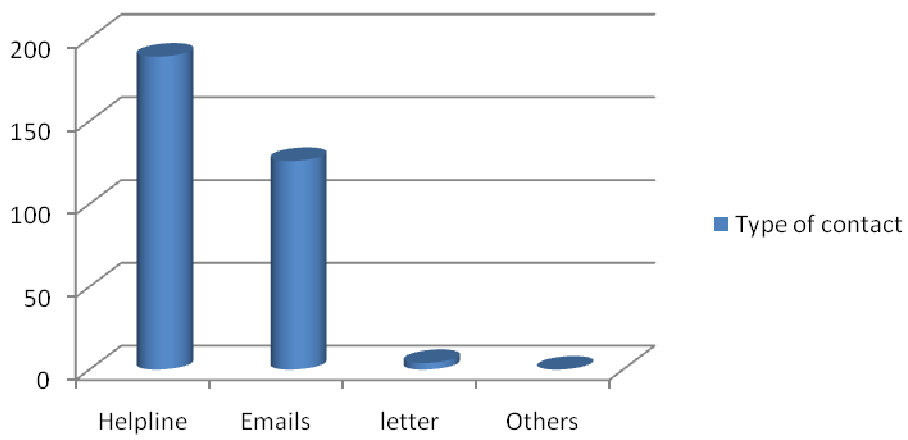
Purpose of Call



Purpose of Call

Information on disease	473	21,2%
Specialist/centre	33	1,5%
Contact with other patient	26	1,2%
Support	67	3,0%
Social care	134	21,2%
Association	114	6,0%
Follow-up	4	0,2%
Sign-posting	135	6,1%
Other	127	5,7%

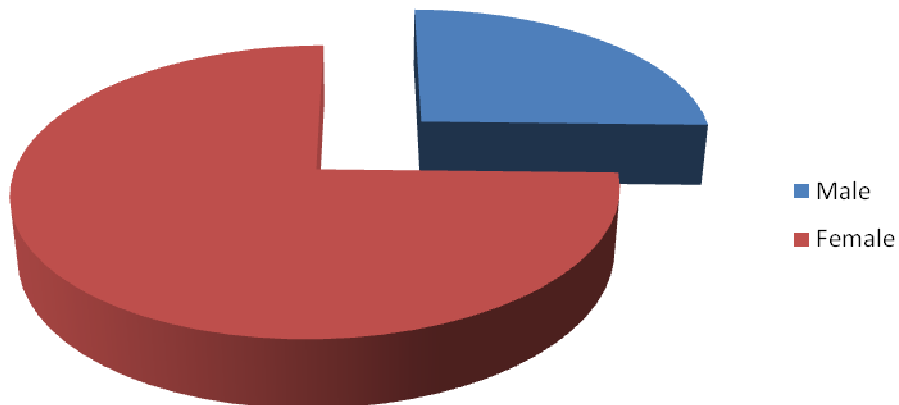
Type of contact



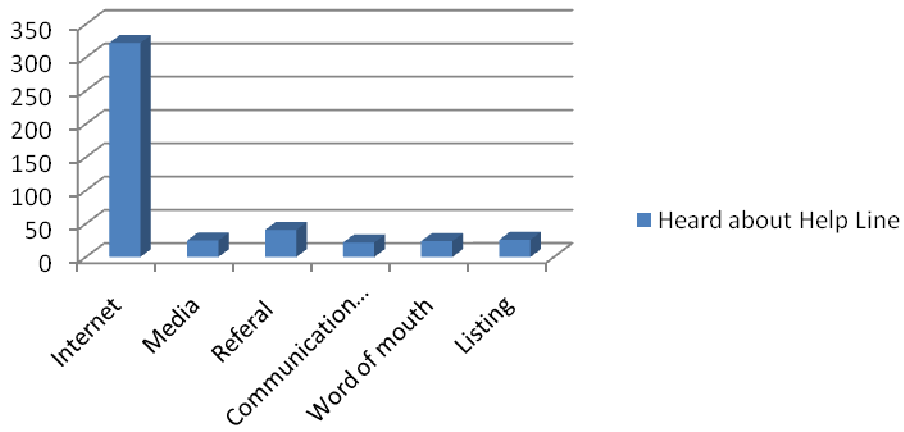
Type of contact

Help line	189	33,3%
Emails	126	22,2%
letter	4	0,7%
Others	0	0,0%
blank	248	43,7%

Gender



Heard about Help Line



Heard about Help Line

Internet	322
Media	25
Referral	41
Communication campaign	22
Word of mouth	24
Listing	26