

# The European Network of Rare Diseases Help Lines Criteria & process for joining

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# An inclusive network

- Network members are
  - Large and well established help lines, or smaller ones
  - Working with volunteers and/or paid staff
  - Catering for only 1 to all RD
  - Run by governmental or non governmental organisations
  - Operating 24/24 7/7 or during office hours
  - In EU member states and other European countries

# To become a member (1)

- Your help line need to be registered in Europe
- It needs to be compliant with the legislation that protects the privacy of citizens and sensitive health information
- ➔ Document testifying respect of local data privacy legislation (legal attestation and/or authorisation relevant authority)

## To become a member (2)

- Your respondents will share information on potentially 6000+ rare diseases
  - Help lines need to share a common code for rare diseases
-  Use the OrphaCode developed by Orphanet and W.H.O for the future ICD

### ANNEX 3: LIST OF DISEASES - VERY ISOLATED PERSONS IN DENMARK AND IN FRANCE

France (Maladies Rares Info Services)

Denmark (CSH)

Number of patients	Name of disease	Number of patients	Name of disease
602		473	
	379		161
1		3	48XXYY
1	3C, syndrome	2	Aagenæs syndrom
1	3-hydroxyacyl-CoA déshydrogénase des acides gras à chaîne longue, déficit en	1	Adrenomyeloneuropati og Adrenoleukodystrofi
1	Aarskog-Scott, syndrome de	2	Aicardi_syndrom
1	Accident vasculaire cérébral, forme familiale	3	Alagille syndrom
1	Achalasie primaire	4	Albright_hereditær_osteodystrofi
1	Achondroplasie-agammaglobulinémie, type suisse	2	Alexanders sygdom
2	Acidémie méthylmalonique - homocystinurie	1	Amelogenesis imperfecta
1	Acidocétose par déficit en bêta-cétothiolase	7	Analatresi
8	Acromégalie	2	Aniridi
1	Addison, maladie d'	1	Aplasia Cutis Congenita
1	Agammaglobulinémie - microcéphalie - craniosténose - dermatite sévère	1	Argininoravsyreæmi
1	Agénésie du corps calleux - retard mental - colobome - micrognathie	8	Arnold Chiari syndrom
2	Agglutinines froides, maladie des	5	Arteriovenøse_malformationer
3	Algie vasculaire de la face	2	Ataxia Teleangiectasia
1	Alpha-1 antitrypsine, déficit en	1	Autoimmunt polyendokrint syndrom type 1

**Illustration when no common codes are used**

## To become a member (3)

- As a network, we need to demonstrate the social utility of the service at the European level
- Help lines need to document on their overall activity

 Participate in the Caller Profile Analysis

# calls	# respondents
1919	20

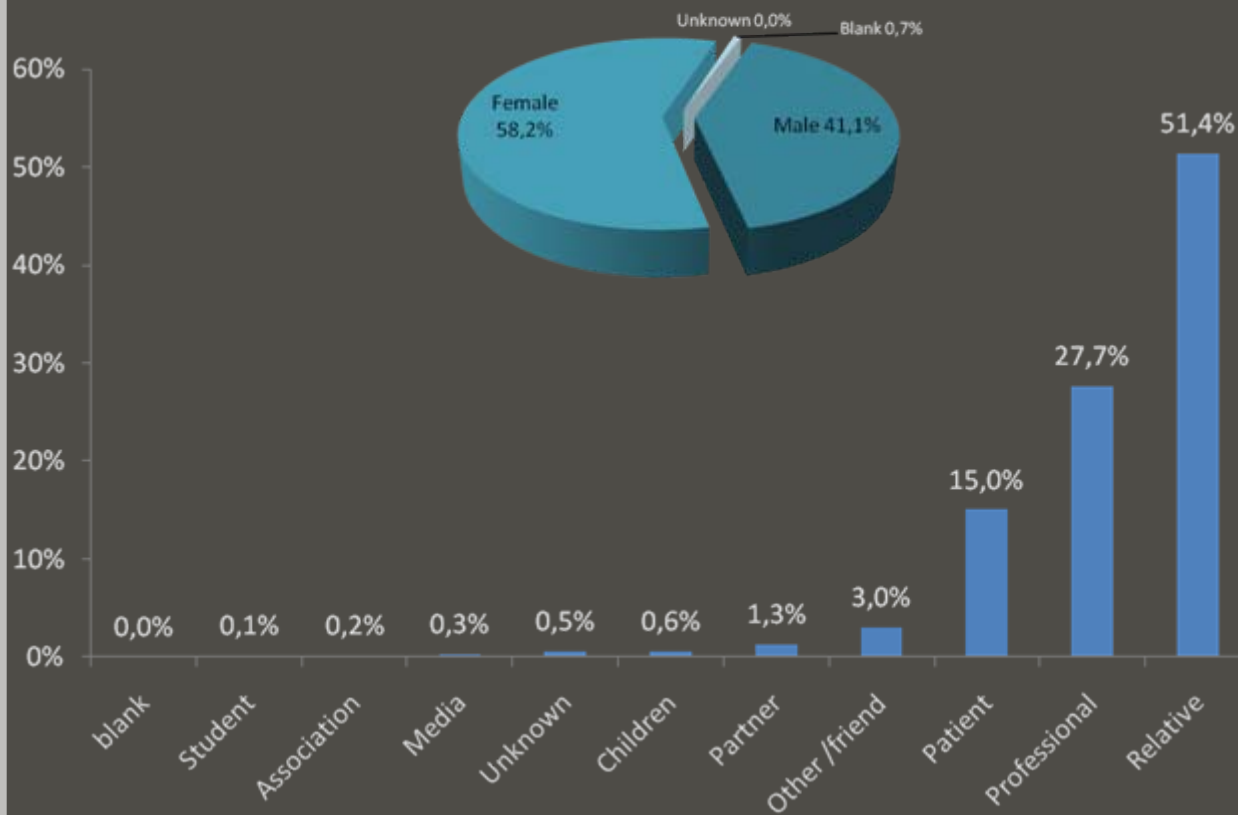
age of patient	
Unknown	38.0%
0-1	2.4%
2-4	4.5%
5-9	4.5%
10-14	2.9%
15-19	2.6%
20-29	10.2%
30-50	14.5%
>50	16.6%
missing	3.7%

How many call  
How many respond

Age of the patients

July 2008: data received from 5 help lines (AFM-Myoinfo, Climb, CSH, Feder SIO, MRIS)

Gender of enquirer

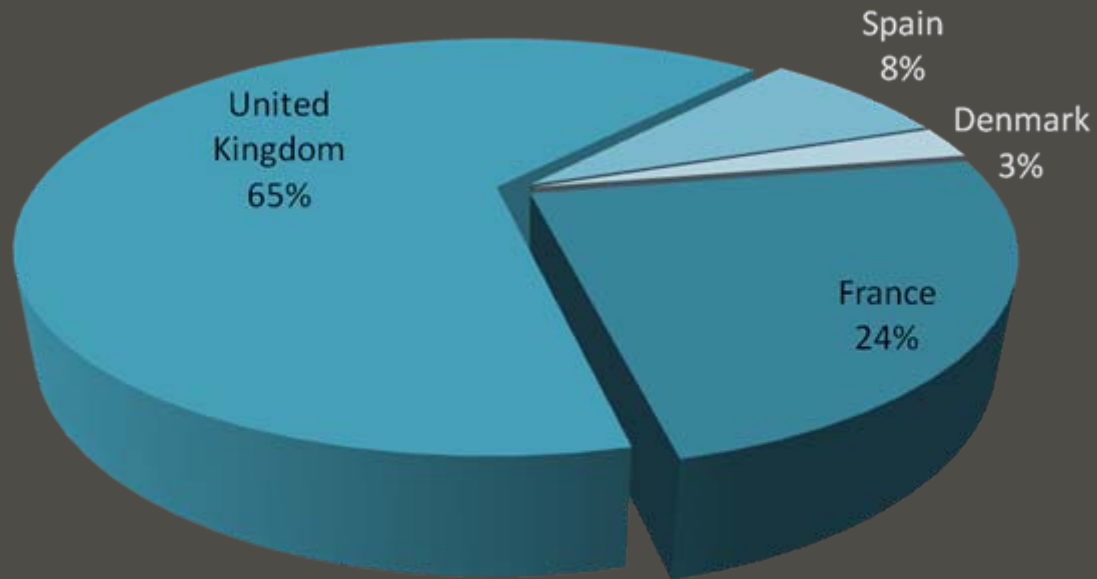


Gender of caller

Category of caller

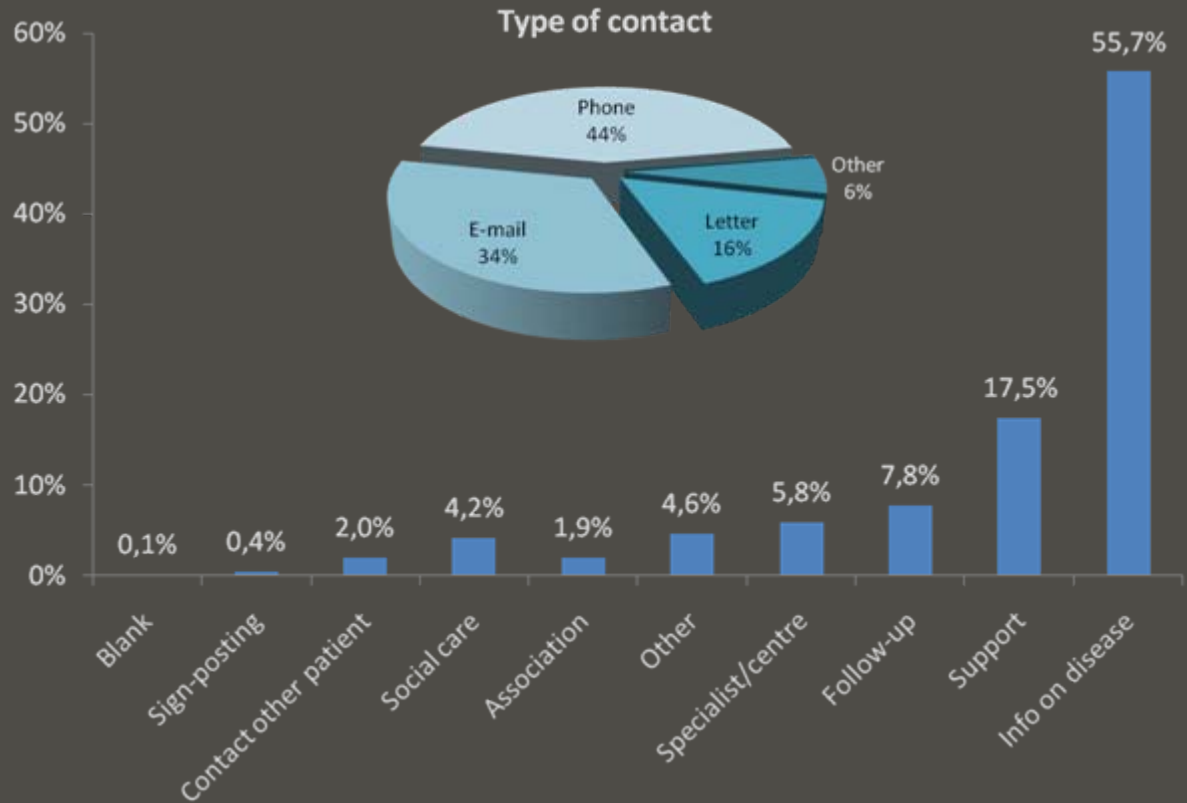
July 2008: data received from 5 help lines (AFM-Myoinfo, Climb, CSH, Feder SIO, MRIS)

## Origin of calls during period



Caller Profile Analysis  
1919 calls  
July 2008

July 2008: data received from 5 help lines (AFM-Myoinfo, Climb, CSH, Feder SIO, MRIS)

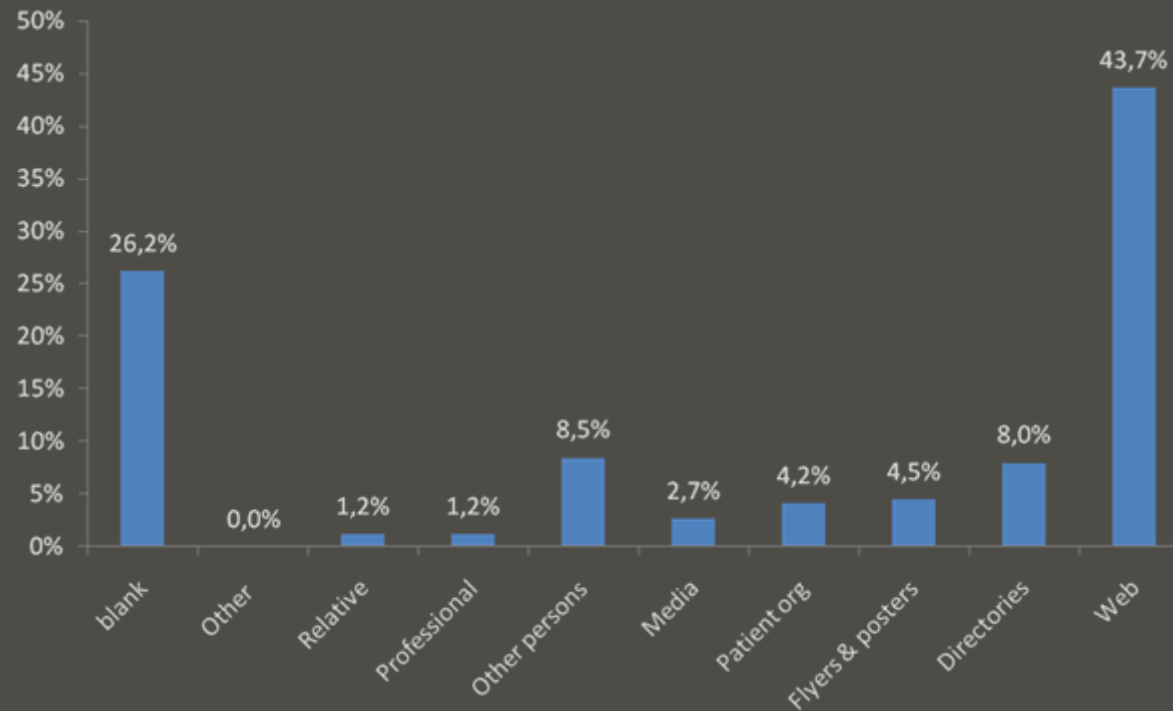


Type of contact

Purpose of calls

July 2008: data received from 5 help lines (AFM-Myoinfo, Climb, CSH, Feder SIO, MRIS)

## Type of contact



How did you hear about help line?

July 2008: data received from 5 help lines (AFM-Myoinfo, Climb, CSH, Feder SIO, MRIS)

**AFM ( Accueil Familles - Ligne AZUR - Website AFM - Actions médicales - Myoinfo)**

16/03/07 - 30/04/07

Respondent	Date	Name of disease	Age of inquirer	Gender	Category of inquirer	Type of contact	Purpose of contact	Region	Type of response given	Heard about helpline	Score
WB	19/03/2007	Unknown genetic disease	Not known	Female	Relative	Email	Specialised treatment centres	Bordeaux	Genetic Centre	Internet (AFM)	7
TNB	19/03/2007	Sclerodermia	Not known	Female	Relative	Email	Medical info about clinical trials	Not known	Info by Orphanet	Internet (AFM)	7
MD	19/03/2007	Neuromuscular disorders	Not known	Not Known	Relative	On site	Information about disease	SR Aquitaine	Info by medical website	Patient association	7
MD	19/03/2007	Myotonic dystrophy	Not known	Male	Relative	Email	Information about disease	Not known	Info by medical website	Patient association	7
CF	20/03/2007	Jarcho Levin syndrome	Not known	Male	General pub	Call	Social matters		Refer to MR Info Service	Media (Telethon)	5
CF	20/03/2007	Polyomyelitis	Not known	Female	Patient	Call	Social matters		Refer to patient association	Media (Telethon)	5
ML	20/03/2007	Neuromuscular disorders	Not known	Male	Relative	Call	Social matters		Refer to AFM regional services	Internet (AFM)	7
ML	20/03/2007	Not known	Not known	Female	Relative	Call	Information about disease		Refer to AFM headquarters	Patient association	7
ML	20/03/2007	Neuromuscular disorders	Not known	Male	Relative	Call	Information about disease	IDF nord	Refer to AFM regional services	Patient association	7
ML	20/03/2007	Neuromuscular disorders	Not known	Female	Patient	Call	Information about disease	Rhône-Alpes	Refer to AFM regional services	Patient association	7
ML	20/03/2007	Neuromuscular disorders	Not known	Male	Patient	Call	Social matters	IDF nord	Refer to AFM regional services	Other user	7

**CPA is a listing of all calls over period**

## To become a member (4)

- Demonstrate the commitment of your management board to support the network
- Network decisions need to be implemented




Signed letter of Agreement

## To become a member (5)

- Share experience and issues with network participants
- Participate in at least one annual network meeting
- ➔ Provide written commitment of your board / director to attend a meeting

## To become a member (6)

- Share common tools and good practices
  - Participate in the development of new good practices
-  Record calls using [ww.rapsodyonline.eu](http://ww.rapsodyonline.eu) services (optional if you have your own system)

## Application

- Application form
- One month CPA data
- By laws, reports
- Legal attestation
- Board commitment

### Evaluation:

- Network coordinator

### Validation:

- Steering Committee

## The process

## If approved

- Signature Letter of Agreement
- Fee payment
- Login to services

## If not

- Agreement on a convergence plan
- Or observer status



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