

**5th european conference
on rare diseases
2nd day - May 14th**

Theme 4 - Session 5 :

**HELP LINES
FOR RARE DISEASES**

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Introduction

Provided services

Quality of the service

Number of requests

INTRODUCTION

Association dedicated to information, training and communication on rare diseases

Emanation of patients association :

→ French Alliance, Eurordis, AFM

Created in 2001

One board and one President : Jacques Bernard

A professional team of experts :

- 1 paediatrician and geneticist**
- 1 general practitioner**
- 1 scientific documentation specialist**
- 1 biologist and listening supervisor**
- 1 assistant**
- 1 general delegate**

Full time equivalent :

- 3,1 for the information service**
- 4,6 in all**

In 2009, funding from :

- French agency for health prevention : 200 000 €**
- French Association against Myopathies : 195 500 €**
- French Health Ministry : 60 000 €**

- 350 000 € for the information activities**
- 100 000 € for the operating of the French Rare Diseases Platform**

The French Rare Diseases Platform :
a diversity of stakeholders
→ patients representatives, professionals of health and research, public actors

Building up a synergy between all the members

National service of information and support :

- **By phone :** - open every working day
from 9am to 6pm
- cost of a local call
- **By email :** question by a pre-filled form on
the website

- ✓ **6000 / 7000 requests per year : 5500 calls and 1500 emails**
- ✓ **Answer to requests about all the rare diseases (more than 750 in 2009) and all their issues**
- ✓ **Individual question, personalized answer**
- ✓ **Most of the requests can be treated by any respondent**
- ✓ **Users : 90 % are patients or relatives, only 5% of prof.**
- ✓ **Sources of information : websites (Orphanet) and internal documentation**

PROVIDED SERVICES

The users :

- 50% of patients and 40% of relatives
- 5% of professionals + 5% of “others”
- Two thirds are women

What are the expressed needs ?

- ✓ Information about disease = 61%
- ✓ Orientation to an expert medical center = 21%
- ✓ Support = 16%
- ✓ Direction toward an association = 14%
- ✓ Information about social process = 11 %

What are those services ?

**Information about disease = 49% (of the answers)
→ make accessible some complicated information
(popularizing work / high qualification)**

**Orientation to expert medical centers = 33%
→ capability to identify the good one**

**Support = 27% (by listening, make the people express...)
→ one precondition : to know the disease**

**Confirmation about the relevance
of care and social support = 23%
→ large field of different issues**

**Information about social process = 13 %
→ necessity to master all the process**

What do all those services mean ?

- **Useful services : more than 90 % of persons used or will use the contacts of association or medical centers**
- **Complementary services : to the associations, professionals, websites...**
- **Satisfaction of the users : 96% have a good opinion of the service**
- **Added value : thanks to an expert team and a personalized relation**

Some limits :

- **No diagnosis**
- **No individual prognostic about the disease evolution**
- **No therapeutic advice**

Other activities :

- ✓ **Service for isolated patients : for patients without association, service proposed with Orphanet to make them get in touch (very rare disease)**
- ✓ **Organism of training on rare diseases : share the expertise**
 - on rare diseases and their issues
 - on patient path
- ✓ **An observatory on patients and relatives issues : use the contact with patients and their relatives to assess the evolution of their situation from year to year**

QUALITY OF THE SERVICE

Until 2008 : quality approach

Based on several tools such as :

- A precise monitoring of our information activity
- An annual satisfaction survey on the calls
- Advises of an internal comity composed of experts

Decision of the board in march 2008

→ to obtain a quality certification before June 2009

4 goals :

- ✓ To confirm the quality of the already proposed service
- ✓ To reinforce the continual improvement
- ✓ To make the service better well known
- ✓ To be recognized as an essential actor by stakeholders

Choice of the standard : ISO 9001
→ **goal of customer satisfaction**

Construction of the management quality system

- **Brainstorming about our organization, skills, service...**
- **Cartography of the service : the elements which make the added value**
- **Redaction of process, procedures, instructions...**

Examples of new tools :

- ✓ **Targets to respect**
- ✓ **Complete annual survey (calls and emails)**
- ✓ **Monthly monitoring of the mistakes**
- ✓ **Evaluation of the trainings**

New way of working :

- Using new tools**
- Evolution of the mind too :**
→ **central demand to satisfy users and to fit onto their needs**

Certification attributed in July 2009
No reservation
A large majority of strong points
Few points of improvement

**For users : the
guarantee of the
relevant and reliable
information and
support**



**The first health
information
service
certificated in
France**

And now ?

The most difficult has started... To confirm the certification
To carry on with the continual improvement
Make the quality system work well

NUMBER OF REQUESTS

What's the issue ?

- Real help and added value of the service
- Necessity to be known when a potential user needs the service
- Communication actions to have visibility and to build notoriety

- ✓ To be seen where the patients are → use relays such as medical centers, social services... Mailing of posters and flyers
- ✓ To have articles or reports in the mass media → press relationships
- ✓ To build a strong and visible position on internet → good referencing in the search engine + website encouraging people to contact the service

What's the situation today ?

The callers know the service thanks to :

- Internet = 48%
- Phone book = 14%
- Media = 12%
- Relatives = 6%
- Posters and flyers = 5%
- Associations = 5%

Internet = half of the requests

Complementarity :

- between general information on websites and personalized information service ;
- all the means must be used to be more visible and well known.

- **Maladies Rares Info Services = from 6000 to 7000 requests per year**
- **Comparison with similar services in other countries → optimum estimated around 20000 annual requests. Far from it...**

How to increase the number of requests?

- ✓ **Any patient or relative must know that a website and an help line, expert on rare diseases, can inform, orientate (medical centers or associations) and support him**
- ✓ **Awareness by all the actors of the complementarity of each of our activities**
- ✓ **Develop exchanges, partnerships... and gain new funds**

Prospect of the European phone number on rare diseases

→ **better services for European citizens**

→ **will make the help line service on rare diseases more visible**

THANK YOU

FOR YOUR ATTENTION !

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