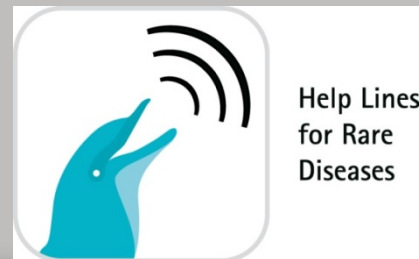


# European Network of Rare Disease Help lines

Why my patient group could be interested in joining the network? What are the tools that already exist?

Marie Claude Bergmann, MRIS (Maladie Rare Infoservice)



# Today

- My role within the network and at my help line
- Network benefits

## Advocacy initiatives on behalf of the network

- Help line service included in the text of the Commission Communication and the draft Recommendation to Member States by the Council of Ministers
- Application for a common 116 number for rare disease help lines.

# Visibility and promotion

- For Services:
  - Online listing of services with diseases catered for and calling hours.
  - Promotional leaflets for member services, e.g rare disease press pack
- For network
  - Public workshops (3 workshops in 18 months)
  - Rhapsody Brochure

# Technical benefits

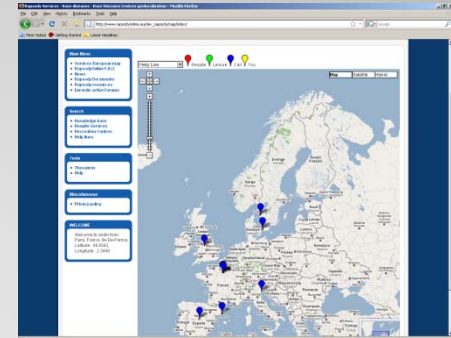
- Call data recording tools
  - Rapsodyonline offers full set of call recording tools with the possibility to automatically send data to central database for the caller profile analysis.
- Isolated patients system to ensure that help lines' isolated patient databases are being shared.

# Training and advice

- Training sessions on
  - 'How to find validated information on the internet'
  - Future themes:
    - Funding opportunities
    - Self evaluation best practices
- Annual workshop
  - Different training themes each year
  - Chance to network with other help line services

# For new members

- Step by step guide on how to set up your service
- Onsite visit by network members to present [www.rapsodyonline.eu](http://www.rapsodyonline.eu)



- Convergence plan for the help lines who do not meet the full membership requirements

**What do you want from our network in the future?**