

Conclusions of Rare Disease Help Lines Workshop

Athens

7th of May 2009



What kind of a network is needed?

- As inclusive as possible while ensuring that standards of excellence form part of the application procedure
- www.rapsodyonline.eu
- More on site visits to member services
 - 3 visits already confirmed
- Training themes:
 - Getting funding
 - Coding
- Pursue the 116 common number initiative and ensure that the national governments respect the council recommendations on funding information services.

Some of the problems that startup help lines face today

- How to record call details
- Training respondents
- Finding funding (especially long term)
- Publicising the help line number

Major Conclusions

- Our helplines are diverse, but we can gain from those with more experience.
- tools exist, please use them!