

# Rare patients: "How can I know other people with my same health problem..."

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## ABSTRACT

The Clinical Research Centre for Rare Diseases Aldo e Cele Daccò is the Coordinating Centre of the Network for Rare Diseases in Lombardy Region, an area of 9 million inhabitants in Northern Italy. Since the beginning, the Centre has established close collaboration with Italian patient associations. Since not all rare diseases have dedicated associations, we have reasoned that it could be of help to promote meeting of people with these ultra-orphan disease and encourage the birth of new association.

Whenever we are contacted by people whose disease has not an association, we ask patients if interested in meeting other people with similar problem. If they agree, they send us a written authorization. The research nurses favour the exchange of experiences between interested parties, by contacting their patients.

To investigate the interest and effectiveness of the service, we sent a questionnaire to 146 families.

The aims were:

- to verify the usefulness of this specific service
- to investigate about general and demographic characteristics of these patients
- to investigate major problems for the families related to the lack of an association

We received 125 completed questionnaires (86% response rate). The greatest part of respondents (N = 83) were patients' relatives.

This experience mainly contributed to the knowledge about the disease and to give psychological support. In 7 cases, it was possible to create a new association; 4 other families, remarked the role of the service in creating self-help support groups.

A service like the one here described, seems useful to stimulate the establishment of support groups or specific Associations for rare diseases.

