

Rare disease patients: “How can I know other people with my same health problem?”

Patient driven innovative projects for rare diseases

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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 of its activities, the Centre has established close collaboration with more than 290 Italian associations. Unfortunately, not all rare diseases have dedicated associations, and we have reasoned that it could be of help, to these orphan patients (and their families), to promote meeting other people with the same health problem.

In our activity we routinely provide information and addresses of patients' support groups. Whenever we are contacted by people whose disease has not an association, we ask patients if they are 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 other 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 and to investigate major problems for the families related to the lack of a patient association. We received 125 completed questionnaires (86% of those sent). The greatest part of respondents (N = 83) were patients' relatives. After the contact with the service, it was possible to meet other people from 83 families. This experience mainly contributed to the knowledge about the disease and to give psychological support. In 8 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.

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