

DESCRIPTION

The National Reference Centre for People with Rare Diseases and Their Families is thought as an advanced centre in promotion, development and spreading of knowledge, innovative experiences and care methods for people with rare diseases, and highly specialized in families and carers supporting and preventing services, promoting personal autonomy and social involvement of people with such diseases.

This Centre will develop a double task:

- As a Reference Centre, it has been entrusted with functions of coordination, research, innovation, professionals training, spreading and sensitizing, supporting to other resources and other functions aimed at professionals, institutions, families and associations that will be developed.
- As a Centre specialized in the attention to people with rare diseases and their families, it will start different care and supporting programmes for families, caregivers and people suffering from different rare diseases, from a social and health point of view in order to improve their quality of life and social integration.



AIMS

- Promoting development, innovation and optimization of resources for people with rare diseases and professional qualification of people working with these groups.
- Giving support and highly specialized services serving as a reference to the rest of the sector resources and providing information and technical support to Public Administration, Institutions, public and private Organizations, professionals and other people interested in social and health care and social involvement of people with rare diseases and their families.
- Offering families, caregivers and people with rare diseases, guidance and support services, information and care training services, intensive rehabilitation services as well as periods of lodging for relief.

B u r g o s

NATIONAL
REFERENCE
CENTRE FOR
PEOPLE WITH
RARE DISEASES
AND THEIR
FAMILIES
(PROGRAMME)



Further information:
Telephone number: (+34) 947 253 950
Websites:

www.imserso.es

www.creenfermedadesraras.es

Address:

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OFFERED CENTRE SERVICES

As a Reference Centre specialized in Rare Diseases, it offers the following services:

REFERENCE SERVICES

- **RARE DISEASES INFORMATION AND DOCUMENTATION SERVICES:** specialized website, documentation centre, editing and/or spreading publications.
- **TRAINING EXPERTS AND INTERCHANGING SERVICES:** continuous training, experts' training, professional practices, interchanging network.
- **INNOVATION AND DEVELOPMENT SERVICES:** they promote and/or develop studies, research or pilot schemes collaborating with scientific or university institutions.
- **CONSULTING AND TECHNICAL SUPPORT SERVICES:** they develop other Administrations advice, collaboration and cooperation functions and technical support to other sector resources.



FAMILIES AND ONGs CARE SERVICES

- **ADVICE AND INFORMATION SERVICE:** meetings, conferences and forums about social, health, legal items...
- **PRACTICE AND CARE TRAINING SERVICE:** experts' conferences, workshops, round-tables, interchanging meetings...
- **FAMILY RESPITE PROGRAMME:** short stays that allow families to have free time or relief from daily caring.
- **CAREGIVERS SCHOOL:** practical training skills for better care and attention to people with rare diseases around them.
- **ONGS COOPERATION SERVICES:** they are programmes aimed at giving technical advice and setting up regular cooperation channels.



SOCIAL AND HEALTH CARE SERVICES

- **MULTIDISCIPLINE VALUATION SERVICE:** access forms valuation, personal programmes drawing up and periodic monitoring evaluations.
- **FUNCTIONAL AND COGNITIVE REHABILITATION SERVICES:** cognitive rehabilitation, physical rehabilitation, speech and language rehabilitation, affective/emotional rehabilitation.
- **DAILY-LIFE TRAINING SERVICES:** self-autonomy, basic social abilities, household chores, social and community life.
- **READAPTING TO FAMILY AND COMMUNITY ENVIRONMENT SERVICES:** they give information about community resources, planning of treatment discharges and programmed derivations, promotion and supporting to volunteers' organizations and self-help groups.

RESIDENTIAL ATTENTION AND/OR DAYTIME CARE

The centre has 48 residential places for people taking part in care services for families and 20 daytime care places for users of social and health care services. Stays will be temporary according to the planned programme users will take part in. During their stay, users will also have:

- **NURSERY AND MEDICAL CARE:** preventing and promoting health, clinical attention and nursery care.
- **PERSONAL CARE AND SUPPORT:** personal care, mobility and movements, communication and relationships, safety and protection, informal care.
- **TEMPORARY LODGING:** food, tidying, laundry and clothes care...

USERS

- Users of Reference Services are the different Public Administrations, public and private institutions and sectorial organizations, research and/or teaching centres, scientific and professionals' units and all those people who work for or are interested in rare diseases
- Users of Social and Health Care Services or Family Care ones are families with minors suffering from rare disease and adult people with these disorders next to, where appropriate, their families and/or carers or personal assistants, as well as sectorial non government organizations.

