



# The NoRo Center

## SECTOR

Integrated care services

## LOCAȚIE

Romania, Sălaj County, Zalău

## ORGANISATION

The NoRo Centre was established by the Romanian Prader Willi Association, a nongovernmental patient organization having the goal of raising the quality of life of patients with rare diseases.

## CONTACT

Dorica Dan, President of Romanian Prader Willi Association / Romanian National Alliance for Rare Diseases / Romanian Association of Rare Cancers; member of the Board of Eurordis; Coordinator of the NoRo Centre, [dorica.dan@eurordis.org](mailto:dorica.dan@eurordis.org)  
[office@apwromania.ro](mailto:office@apwromania.ro), Tel.: +40-260-610033

## DESCRIPTION

The NoRo Centre is a **resource center** providing therapeutic and medical services. Its main objective is to provide **integrated** social, health and care services to people affected by rare diseases and their families through improving access to care, information, research, and education. The NoRo Centre regularly organizes **training for patients**; groups of 12-14 patients with the same rare disease participate in one-week sessions where they are provided with therapy, education and rehabilitation. It also provides training for people with intellectual disabilities with the aim to teach them **independent life skills**. Moreover, the Centre is in charge of a day care center that organizes **individual and group therapy** for around 60 children with rare diseases and autism spectrum disorders. A **help line** is available for clients or professionals looking for information and support. The Centre has set up a network of videoconference facilities with seven medical universities across Romania, contributing to continuity of care and direct access to information and meetings between patients and professionals while avoiding travel costs. **Sharing knowledge** and exchanging good practices on remote management consultations, medical and social advice and training are essential in the sector of rare diseases, since expertise is scarce. To make this project a success, the Centre **cooperates** with nongovernmental organizations, health care providers, social workers, teachers, employers, and several institutes with expertise in rare diseases. At local level, the Centre organizes meetings with kindergarten and schools where children from the day care center are integrated.



The Centre also works in **partnership with public authorities** and stakeholders at national level, which is important to promote positive measures in the areas of health, education, fighting poverty and social exclusion. It collaborates with the Ministry of Health, the National Authority for Disabled People, and the Romanian National Alliance for Rare Diseases (RONARD). The day care center is partly funded by the Local Council and the County Council, and the medical outpatient clinic of the Centre has a contract with a health insurance company.

### **AN INTEGRATED APPROACH**

Through collaboration with experts, medical universities and social services at different levels, the Centre is able to bring together new ideas. It also contributed to the European Union's **INNOVCare project**, representing an innovative care pathway that brings together national resource centers for rare diseases. As a one-stop-shop style service, NoRo Center is able to offer a holistic approach. The activities undertaken by NoRo Center are meant to empower people and strengthen their skills and capacity. The objective is to enable them to fully participate in community life and advocate for their fundamental rights; for example, through access to therapists who conduct home visits to families in order to help parents to continue care interventions for their children. The Centre embraces a preventive approach through the therapeutic education of beneficiaries and by connecting with other services to ensure continuity of care. For people living with rare diseases early and continuous intervention is very important. Once combined, these factors produce a return on investment in the long-term, since family members are more likely to remain in employment as their child or relative is well cared for and provided with the necessary skills for an independent life.

### **MAIN ACHIEVEMENTS**

Thanks to the high quality social and integrated services the Centre provides, it is now recognized by the Ministry of Health as a health care provider and a specialized social service with research capacity. Every year more than 200 people register to its therapies and therapeutic education services. Many other beneficiaries take part in information and training services.

NoRo Center is designated as a Center of Expertise in Rare Diseases, is part of the national network RO-NMCA ID, member of ITHACA ERN and of the European Network of Resource Centers for Rare Diseases -RareResourceNet.

### **LOOKING FORWARD**

Securing funding from local and national authorities for the medium- and long-term will be important for the Centre. Public authorities should provide support equivalent to at least the minimum costs standards for service provision established by the Ministry of Health and the Ministry of Work in Romania. Moreover, having one point of contact for accreditation and recognition of integrated services and another for funding integrated care would make the work of the Centre much easier. Through the INNOVCare project, opportunities to upscale the model of integration were analyzed with the intention of extending it to other Member States and beyond rare diseases. Partnerships between public, private, and civil society organizations will also have to be strengthened.