ROMANIAN NATIONAL ALLIANCE FOR RARE DISEASES - RONARD

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Representing patients’ organizations for rare diseases in România since 2007.

Reality
• It is time for public authorities to consider rare diseases as a Public Health priority and take action to concretely support patients and families affected by rare diseases.

Goals
• Unite the efforts of the different rare disease patient organizations in Romania.
• Work to end the ongoing isolation for rare disease patients that the health system, mass media, and scientific researchers in our country foster.
• Advocate for an adequate national strategy, to ensure better health care, educational and social services for our patients.

Partners
• Romanian Society for Medical Genetics
• Medical Universities from Timisoara, Cluj-Napoca, Iasi, Oradea, Târgu Mures and Bucharest
• EURORDIS
• National Center for Studies in Family Medicine Romania
• Romanian Ministry of Health

Achievements
• Apart of Council of National Alliances at European level in EURORDIS.
• First National Conference on Rare Diseases in Romania titled, RD: From Evaluating Needs to Establishing Priorities, in Zalau in November 2007.
• Organized efforts in Romania for the European Rare Disease Day 2008 and the First International Rare Disease Day 2009.
• Organizing training courses for organizational development and project management for the patient organizations, through a project funded by CEE Trust.
• RPWA, RONARD and Romanian Society for Medical Genetics have initiated the National Plan for Rare Diseases in Romania and on February 29th, 2008, we signed a partnership agreement with the Ministry of Health to implement a National Plan for RD in Romania.

Next steps
• Organizing Balkan Congress on Rare Disease in Cluj-Napoca in June 2009 and a EUROPLAN conference in 2010.