The European Conference on Rare Diseases
2010 Krakow
European Conference on Rare Diseases
13 - 15 May, Krakow, Poland

Universitatea de Medicina şi Farmacie "Victor Babeş" Timişoara

Research in rare diseases, a common effort of professionals and patients in Romania

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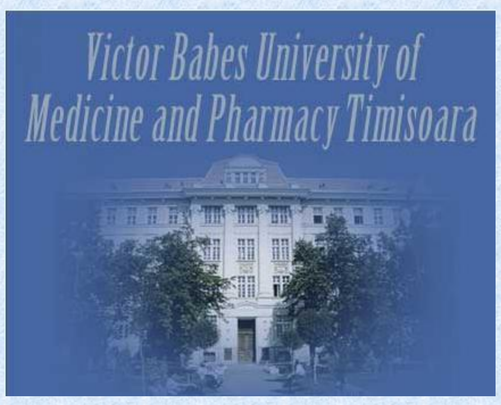
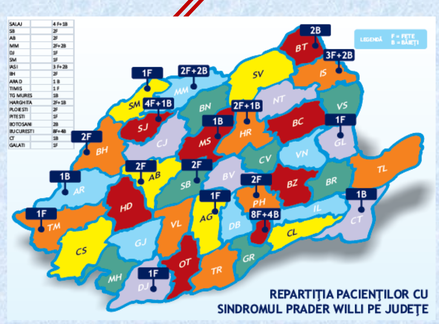
Rare diseases patients became a priority for European Parlament. Rare diseases need a common effort and a common approach at EU level.

In Romania, the raised interest and awareness in rare diseases is thanks to the efforts of patient organisations (Romanian Prader Willi Association- RPWA and then Romanain National Alliance for Rare Diseases - RONARD).

Romanian National Alliance of Rare Diseases

University of Medicine and Pharmacy "Gr. T. Popa" Iasi, Romania





Emergency Children's Hospital "Louis Turcanu" Timisoara, Romania

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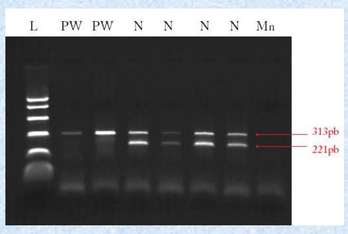
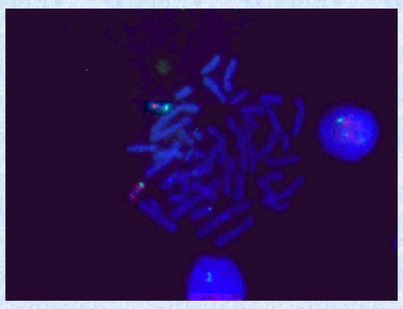
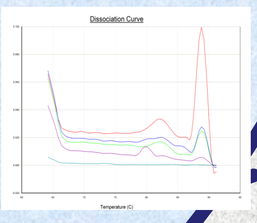
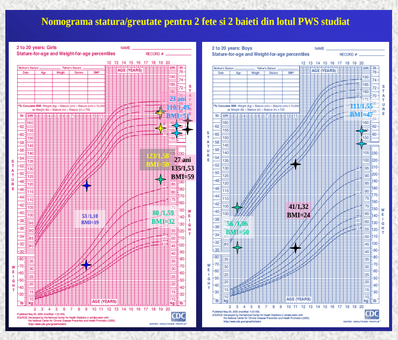
University, Bucharest, Romania

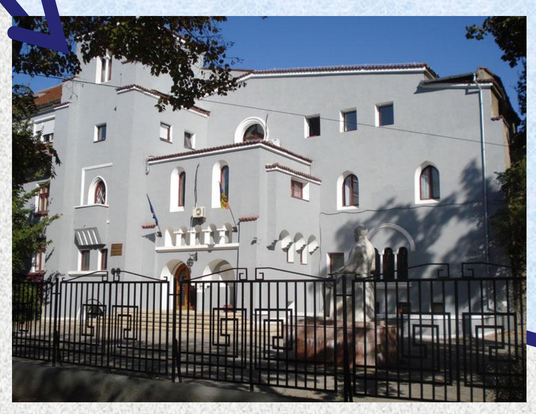
But their efforts have to be completed by medicals' community. In this context, a group of Romanian professionals have initiated the research project " Corelation of clinic, genetic and epigenetic aspects implicated in the etiology of Prader Willi/Angelman syndroms: model of multidisciplinary abordation for rare diseaseas in Romania".











Parhon Institute, Bucharest, Romania

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CONCLUSION

The project is remarcable because of the development of an efficient cooperation and partnership among important institutions for medical education, universities, research institution and patient organisation (RPWA) in order to solve some problems related to diagnostic , complex treatment and prevention in RD.

Our project promotes a new model of partnersip among researchers and patients and will prove at national level the efficiency of network approach in RD and cooperation for both, patient interest and research.

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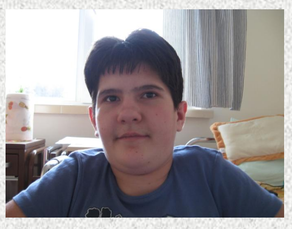
SIMTEX-OC ISO 9001 REGISTERED C.1933.1
CENTRUL NATIONAL DE MANAGEMENT PROGRAME

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