The Romanian Foundation for Lysosomal Diseases has reached 20 years after its establishment

The Romanian Foundation for Lysosomal Diseases (FRBL), founded in 1998 in Cluj-Napoca, has marked 20 years since its inception, through a series of activities that took place in Sibiu during 5-6 October and where patients with Gaucher disease participated, medical opinion leaders, representatives of local and community patient associations International. At this event, FRBL representatives also marked the International Day of Gaucher, celebrated on October 1 at the international level. The "RARE STARS: Hope and Life" conference, which opened the anniversary event was a moment of remembrance, along with invited guests from Romania and Europe that have been alongside the Foundation over time, and the activities it has carried out over the course of its 20 years of existence.

At the same time, they contributed with presentations within it specialists Regional Center of Medical Genetics at the Clinical Hospital Emergency for Children Cluj, as well as representatives of the organizations of patients with rare diseases in Romania and Europe. Among them there were counted Dr. Simona Bucerzan, Head of Works, Regional Center of Medical Genetics of the Clinical Emergency Hospital for Children Cluj, Assist. Univ. Dr. Bogdan Chiş, Medical Clinic II, Clinical Hospital County Emergency Cluj, Dorica Dan, president of ANBRaRo (Romanian Rare Disease Organisation) President and Lut De Baere, chair of the Patient Board of MetabERN, president of BOKS (Belgian PO metabolic diseases) and president of FIN (Fabry International Network).

Lysosomal diseases include multiple genetically transmitted diseases, such as Gaucher, Fabry, Pompe, Nieman-Pick, Type I, II, III and IV Mucopolysaccharides. Gaucher is the most spread among rare diseases in Romania, currently 86 patients being diagnosed.

"For 20 years we have done everything possible for patients with lysosomal diseases in Romania to live a life normal. From the perspective of a patient with Gaucher disease, I understand what the patients with rare diseases are facing and how important it is to get support. Lysosomal diseases, like any genetic disease, do not heal, but it is treatment, and, through appropriate treatment, the quality of life of the patients is considerably improved. Patient Gaucher becomes, after treatment, a perfectly integrated man in society and in the family. We want that, through this event, to draw attention to lysosomal diseases and the impact they have on patients and their families and, at the same time, to reinforce a sense of belonging among our members, with all patients, not to feel alone, "said FRBL President George Sîncă.

The Foundation is involved in the detection and treatment of patients but also has the role of informing and assisting patients and families
to be a moral support for them. In his work, FRBL benefits from both community support
medical and representative associations of patients at national and European level.
"To meet the complex needs of people with rare diseases, we have developed collaborative relationships with
numerous patient associations, such as the Romanian Foundation for Lysozyme Diseases. For Sanofi
Genzyme, commitment to rare genetic diseases is one for life. Beyond ensuring availability
specialized therapies, Sanofi Genzyme also contributes to improving access to methods and services
early diagnosis, vital in the efficient management of rare diseases and in improving the quality of life of patients. In the
as a health partner, we are glad to attend this celebration alongside the FRBL,
which we congratulate on efforts and work for 20 years, "said Dr. Doina Muşetescu, General Manager of Sanofi
Genzyme, Romania & Moldova.
FRBL has emerged as a necessity for the interaction between patients with the same conditions during the
the foundation of Gaucher disease being considered a disease without treatment. In Romania, the first patient with the disease
Gaucher was diagnosed only one year before he was established.
The first meeting of patients with Gaucher disease was organized by FRBL in Cluj in 2002, and from 2012 these
meetings take place annually. In 2018, FRBL joined the National Alliance for Rare Diseases in Romania, with whom
collaborate in 2013 in the interest of patients.