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SCIENCE IN SERVICE OF RARE DISEASES IN SERBIA

"We are children, too". Children with Hunter syndrome playing with Serbian artists.

According to the EU Committee of Experts for Rare Diseases, rare diseases affect fewer than 1 in 2 000 individuals. Still, 6-8% of people in the European Union are affected (about 30 million). Rare diseases comprise a heterogeneous group of disorders. About 6-8.000 types are listed, 80% attributed to genetic heritage. They are chronic and degenerative and often require life-long treatment.

World Rare Disease Day is an annual observance held on the last day of February to raise awareness for rare diseases and improve access to treatments and medical representation for affected individuals and their families. The seventh international Rare Disease Day will take place around the globe on February 28th, 2014. A great number of awareness-raising activities are planned in 70 countries, under the slogan "Join Together for Better Care".

NORBS (**www.norbs.rs**), a National Organization for Rare Diseases of Serbia, is a member of European Organization of Rare Diseases – EURORDIS. NORBS, the umbrella organization gathered existing patients' associations and individuals with various rare diseases in 2010, aiming to improve the quality of life of persons with rare diseases. Neither types of rare diseases nor their incidence are different for Serbia, affecting estimated 0.5 million.

European Commission has recognized the importance of dealing adequately with rare diseases and consistently funds research in this area.

Institute of Molecular Genetics and Genetic Engineering (IMGGE), University of Belgrade, (www.imgge.bg.ac.rs) is one of the leaders in Serbia in molecular biology, molecular genetics, biomedicine and biotechnology. Knowledge in these fields is crucial for development of molecular diagnostics and progress in treatment of rare diseases.

Currently, at IMGGE rare diseases are studied through a project "Rare diseases: Molecular Pathophysiology, Diagnostic and Therapeutic Modalities and Social, Ethical and Legal Aspects" and an EC project **"Strengthening the Research Potential of IMGGE through Reinforcement of Biomedical Science of Rare Diseases in Serbia – en route for innovation"** (FP7 REGPOT-CT-2013-316088-**SERBORDISinn, www.serbordisinn.rs**).

Through SERBORDISinn, a well-equipped center for research and innovation is formed in IMGGE, run by highly competent experts and aided by international partners. IMGGE has become the centre of excellence for genetics on rare diseases.

IMGGE and Golden Helix Foundation will join efforts in organizing Symposium entitled "**Genomics of Rare Diseases**" (31 Oct - 2 Nov 2014), which will gather in Belgrade many world class experts in the field of rare diseases and strengthen their connections with researchers from Western Balkan countries.

Many distinguished individuals in our history suffered from rare diseases. It is our goal to provide treatment to all people affected with rare diseases, to improve their quality of life, allowing each and every of them to realize their full potentials.

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Establishment of Serbian and Balkan rare disease specific biobanks is one of the major goals of the SERBORDISinn Project.

Sophisticated research equipment, such as Next-generation sequencing system, enabled implementation of cutting-edge methodology for the study of molecular markers of rare diseases in the IMGGE.