

# National programme for the development of care for patients with Rare Diseases in the Slovak Republic for the period 2016-2020 in terms of 9 fundamental priorities

Annex 1

## National programme for the development of care for patients with Rare Diseases in the Slovak Republic - for the period 2016-2020 in terms of 9 fundamental priorities

Task priority	Task	Deadline	Outcomes/indicators	Gestor	Cooperating parties	Financing/assumption	Financial requirements (EUR)	
							2016	2017
<b>1. Develop public awareness about the RD project</b>	1.1. Informing the professional and lay public concerning RD	2016-2020	Media, Campaigns, Collections and Auctions, Discussion forums, Seminars, Lectures, Leaflets	MZ SR, SAZCH, ÚDZS	EURORDIS, CEG RD, PO, OS, ZP	Multi-sourced funding, sponsors of public-private partnerships		
	1.2. Web portal SAZCH	2016-2020	Web portals	SAZCH	EURORDIS, The Commission MZ SR, CEG RD	SAZCH		
	1.3. Web portal NCZI	2016-2020	Web portals, information on RD, RD register	NCZI	CEG RD, The Commission MZ SR	NCZI		
	1.4. Orphanet Slovakia – national version development, mass media presentation, website usage support	2016-2020	Web page ORPHANET	DFNsP BA		In terms of the project ORPHANET		
	1.5. Information sources for the public as to neonatal and selective screening in the SR	2016-2020	Information sources for	MZ SR, SCN SR	SAZCH	MZ SR		
	1.6. RD Help line per the EU directive on patients' rights in cross-border healthcare, the development of cross-border healthcare	2016-2020	RD Help line	ÚDZS, MZ SR	OS, SAZCH	ÚDZS		
<b>2. Expand education of the professional public about RD</b>	2.1. Programme focused conference "Rare Diseases in the SR – education"	2017	Programme conference assessing current findings in the SR for the issue of RD	MZ SR	SLS, SSLG, SLK, NCZI, LF	MZ SR		10,000.00
	2.2. Implementation support of education in the area of RD as part of specialist study in the relevant specialized study programmes	2016-2020	Analysis	MZ SR	Educational institutions, which provide the due accredited specialized study programmes			

<b>3. Expand and enhance the diagnosis, treatment and care of patients with RD</b>	3.1. Support and development of healthcare – the development of the national specialized subject expert RD workplaces in the SR	2016 – 2017	1-2 full national specialized subject expert workplaces for RD in the SR, which will engage in the European reference network of specialized RD workplaces	MZ SR	The MZ SR Commission, OS, ZP, SLK, LF, SAZCH, ÚDZS	Open call by the MZ SR in order to provide subsidies within the meaning of § 2 (1) (d) of Act No. 525/2010 Coll. on the provision of subsidies in the field of competence of the Ministry of Health of the Slovak Republic in support of implementation of individual activities under the approved national programmes,	100,000.00	100,000.00
	3.2. Availability of high-quality treatment for patients with RD	2016-2020	Rolling upgrade of the list of available drugs for RD and elaboration of a professional guideline on treating patients with RD	MZ SR	ŠUKL, ÚDZS, ZP, FaFUK, the Association of producers/suppliers of Orphan drugs and healthcare devices			
<b>4. Screening and Prevention of RD</b>	4.1. Prenatal screening and prenatal diagnosis of RD	2016-2020	Proposals for the methodology, or upgrade of professional guidelines,	MZ SR	SLS, SSLG, SGPS, ZP			
	4.2. Extension and improvement of selective screening in the SR (e.g.: by DMP)	2016-2020	Purchase and implementation of technologies (2x analytical unit for tandem mass spectrometry with liquid chromatography, GC MS), as well as further laboratory equipment	MZ SR	SCN SR, OS, NG	Open call by the MZ SR in order to provide subsidies within the meaning of § 2 (1) (d) of Act No. 525/2010 Coll. on the provision of subsidies in the field of competence of the Ministry of Health of the Slovak Republic in support of implementation of individual activities under the approved national programmes,		
	4.3. Connecting SCN SR with the laboratory of DMP in the FNŠP FDR BB	2016-2020	Purchase and implementation of technologies (automatic analytical unit of amino acids, GC MS)	MZ SR	SCN SR, OS, NG	Open call by the MZ SR in order to provide subsidies within the meaning of § 2 (1) (d) of Act No. 525/2010 Coll. on the provision of subsidies in the field of competence of the Ministry of Health of the Slovak Republic in support of implementation of individual activities under the approved national programmes,		
	4.4. The organization of health care, follow-up to the neonatal screening	2016-2020	Workshop on the processing of binding rules of comprehensive care of patients selected by the neonatal screening-elaboration	MZ SR	SCN SR, OS, NG			

			of professional guidelines, for all types of RD screenings					
	4.5. Archive of samples of dry drops of blood in the SCN SR	2016-2020	Archive of samples of dry drops of blood in the SCN SR	MZ SR, SCN SR		MZ SR		
<b>5 Support of science and research in the area of RD</b>	5.1. Departmental research in the RD field – implementation of new technologies (e.g.: arrayCGH technology and NGS) into clinical practice of RD diagnosis	2016-2020	Support for applied research under the grant scheme at Departmental level i.e. support of research projects, aimed at the issue of RD	MZ SR	MZ SR Commission, MZ SR Scientific Council, SLS, OS	Open call by the MZ SR in order to provide subsidies within the meaning of § 2 (1) (a) of Act No. 525/2010 Coll. on the provision of subsidies in the field of competence of the Ministry of Health of the Slovak Republic in support of research and development in the field of healthcare		
	5.2. Departmental research in the field of RD oncological diseases – implementation of new technologies (e.g.: arrayCGH technology and NGS) into clinical practice of RD diagnosis	2016-2020	Support for applied research under the grant scheme at Departmental level i.e. support of research projects, aimed at the issue of RD in relation to the oncological diseases	MZ SR	MZ SR Commission, MZ SR Scientific Council, SLS, OS, Oncogenetic departments	Open call by the MZ SR in order to provide subsidies within the meaning of § 2 (1) (a) of Act No. 525/2010 Coll. on the provision of subsidies in the field of competence of the Ministry of Health of the Slovak Republic in support of research and development in the field of healthcare		
	5.3. National support for science and research in the area of RD	2016-2020	Support of research projects, i.e. engagement of the SR in the E-rare project and in many other international research projects,	MZ SR		MZ SR		
<b>6. Collection of data about patients with RD and the creation of an RD register</b>	6.1. The project of a virtual national registry of RD, drawn up on the basis of the cooperation of NCZI and OS	2017	Implementation of a pilot project	MZ SR, NCZI	OS, SLS	MZ SR		40,000.00
<b>7. Caring for the quality of life and social inclusion of patients with RD (support and strengthening of PO for RD in the SR)</b>	7.1 Support for PO activities at the local and national level, awareness-raising. of the lay and professional public	2016-2020	Web portals, Media (electronic and print), Seminars, Lectures, Occasional publications, Leaflets, Wellness stays, associated with education, Workshops (examples of good practice)	SAZCH, PO	The MZ SR Commission, OS	Multi-sourced funding, sponsors of public-private partnerships		
	7.2. Support for activities at	2016-2020	Participation of SAZCH	SAZCH	PO, MZ SR Commission.	Multi-sourced fundina.		

	international level, international cooperation		the MZ SR Commission,		OS, LF, FaFUK	sponsors of public-private partnerships		
<b>8. Inter-Departmental cooperation in the subject matter of RD and the Departmental commission</b>	8.1 Coordination of the performance of the activities under the Departmental action plans for the period spanning 2015 – 2020	2016-2020	Action by the Commission of the MZ SR in relation to the meetings of the CEG RD	MZ SR	The MZ SR Commission,	as per the Commission statute MZ SR		
<b>9. International cooperation in the RD area</b>	9.1. Support for international cooperation in the field of RD	2016-2020	Member participation of the MZ SR Commission, as befits, also of other specialists about key international initiatives	MZ SR	The MZ SR Commission, OS, SAZCH, NCZI, WHO	MZ SR		
<b>TOTAL</b>							<b>100,000.00</b>	<b>150,000.00</b>
<b>TOTAL for the years 2016 and 2017</b>							<b>250,000.00</b>	

**Explanatory notes to abbreviations:**

**ArrayCGH** Array comparative genomic hybridization

**CEG RD** Commission Expert Group on Rare Diseases

**DFNsP BA** University Children's Hospital, Bratislava

**DMP** Inherited metabolic disorders

**EURORDIS** European Organisation for Rare Diseases

**FaF UK** Pharmaceutical Faculty of Comenius University in Bratislava

**FNsP FDR BB** F. D. Roosevelt University Hospital, Banská Bystrica

**MZ SR Commission** The Commission of the Ministry of Health of the Slovak Republic for Rare Diseases (RD)

**LF** Faculty of Medicine

**MZ SR** The Ministry of Health of the Slovak Republic

**NCZI** National Health Information Centre

**NGS** Next Generation Sequencing

**ORPHANET** portal for information on Rare Diseases and orphan drugs (European website on RD and RD treatment)

**OS** Professional societies

**PO** Patient Organizations

**SAZCH** Slovak Alliance for Rare Diseases

**SCN SR** Screening Centre for the Newborn in the Slovak Republic

**SGPS** The Slovak Gynaecological and Obstetrical Society

**SLK** Slovak Medical Chamber

**SLS** Slovak Medical Association

**SSLG** Slovak Society for Medical Genetics

**SZU** Slovak Medical University in Bratislava

**ŠUKL** State Institute for Drug Control

**ÚDZS** Healthcare Supervisory Authority

**RD** Rare Diseases

**ZP** Health Insurance Companies