



*Croatia*

**EUROPLAN NATIONAL CONFERENCE**

*in the framework of the EU Joint Action RD-ACTION*

*Zagreb, 7 November 2017*

**FINAL REPORT**



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# FOREWORD

The EUROPLAN national conferences or workshops are organised in many European countries as part of a coordinated and joint European effort to foster the development of comprehensive National Plans or Strategies for Rare Diseases addressing the unmet needs of patients living with a rare disease in Europe.

These National Plans and Strategies are intended to implement concrete national measures in key areas from research to codification of rare diseases, diagnosis, care and treatments as well as adapted social services for rare disease patients while integrating EU policies.

The EUROPLAN national conferences/ workshops are jointly organised in each country by a National Alliance of rare disease patients' organisations and EURORDIS–Rare Diseases Europe. **Rare Disease National Alliances and Patient Organisations have a crucial role to shape the national policies for rare diseases.**

The strength of EUROPLAN national conference/ workshop lies in its shared philosophy and format:

- **Patient-led:** National Alliances are in the best position to address patients' needs;
- **Multi-stakeholders:** National Alliances ensure to invite all stakeholders involved for a broad debate;
- **Integrating both the national and European approach to rare disease policy;**
- **Being part of an overarching European action** (project or Joint Action) that provides the legitimacy and the framework for the organisation of EUROPLAN national conferences/workshops;
- **Helping national authorities adhere to the obligations stemming from the Council Recommendation of 8 June 2009 on an action in the field of rare diseases.**

Since 2008, National Alliances and EURORDIS have been involved in promoting the adoption and implementation of National Plans and Strategies for rare diseases. Altogether, 41 EUROPLAN national conferences took place in the framework of the first EUROPLAN project (2008-2011) and the EU Joint Action of the European Committee of Experts on Rare Diseases – EUCERD - (2012-2015).

Within RD-ACTION (2015-2018), the second EU Joint Action for rare diseases, National Alliances and EURORDIS continue to get involved in a coordinated European effort to advocate for and promote integrated national policy measures that have an impact on the lives of people living with rare diseases.

The EUROPLAN national conferences or workshops taking place within RD-ACTION focus on specific themes identified by the National Alliances as the most pressing priorities to tackle with national authorities. These thematic priorities are addressed in sessions where all the stakeholders discuss relevant measures to be taken or ways to sustain the full implementation of already approved measures.

Each National Alliance prepares a final report on the national workshop, based on a common format such as the one that follows.

## GENERAL INFORMATION

<b>Country</b>	Croatia
<b>National Alliance (Organiser)</b>	Rare Diseases Croatia
<b>Date &amp; place of the national workshop/conference</b>	7th November 2017 Zagreb
<b>Website</b>	<a href="http://www.rijetke-bolesti.hr">www.rijetke-bolesti.hr</a>
<b>Members of the Steering Committee</b>	Doc.dr.sc. Sanja Perić, Rare Diseases Croatia Vlasta Zmazek, DEBRA Croatia Ivana Hrastar, Rare Diseases Croatia Tamara Kvas, Rare Diseases Croatia
<b>List of Themes addressed</b>	1. Centres of Expertise 2. Special Social Services
<b>Annexes :</b>	I. Programme in English II. List of Participants (by stakeholders' categories)

## FINAL REPORT

### I. Introduction/ Plenary session

Organized by the Rare Diseases Croatia on 7 November 2017, the conference entitled 'Integrated Approach to Care for People Suffering from Rare Diseases and their Families' was held in Zagreb.

The two main topics of the conference were Centres of Excellence and specialized services for rare diseases. Approximately 100 participants attended the conference. Government representatives, members of the Health Ministry's Committee for Drawing up and Monitoring Implementation of the National Program for Rare Diseases, representatives of the Agency for Quality and Accreditation in Health Care and Social Welfare, reference centres, Ministry of Demographics, Family, Youth and Social Policy, and associations of

patients suffering from rare diseases shared their stances and needs in the area of integrated care for patients suffering from rare diseases in Croatia.

The guest from Romania, EURORDIS and Romanian Centre for Rare Diseases representative, Dorica Dan presented the EUROPLAN project as well as purpose and need for development of specialized social services and expert networking. She presented the idea of integrated care for the patients and the work of Romanian NoRo Centre and the INNOVcare project aimed exclusively at developing social services and education of social care experts.

The topics were chosen due to lack of communication and understanding of social needs of people suffering from rare diseases. With lack of communication, it is difficult to coordinate information on rare diseases between medical and non-medical experts, which affects implementation of integrated care for people suffering from rare diseases. Encouraging the founding of specialized social services aimed at providing services to people suffering from rare diseases would play a key role in efforts to improve quality of life of people who live with these diseases and their families.

A meeting of coordinators for rare diseases was held as part of the conference with the aim of improving cooperation and approach to care for patients suffering from rare diseases. A coordinator for rare diseases was appointed in each hospital in Croatia, a doctor who should help patients suffering from rare diseases solve problems, monitor their condition and purchase specific medicines.

## **II. Themes**

### **Centres of Excellence**

As part of the National Program for Rare Diseases for the period between 2015 and 2020, improving activities of reference centres is one of proposed measures. Reference centres should also act as centres of diagnostics and education, places where cooperation between all stakeholders should be the basis of multidisciplinary work. Reference centres should be centres for meetings and education of patients about rare diseases as well as centres for raising awareness about rare diseases, diagnostics and treatment. Reference centres should diagnose and engage in multidisciplinary treatment of rare diseases. Some reference or expert centres could tackle a group of similar rare diseases (such as rare solid cancers) or larger groups of rare diseases (such as hereditary metabolic diseases of children and grownups). These centres should make decisions on start of treatment of

patients suffering from rare diseases and monitor the conditions of these patients. Between these medical examinations, patients who live far from their reference centres should be treated in hospitals near their place of residence in cooperation with experts from reference centres. This would put to full use their knowledge and experience, as well as use of the available funds in the most efficient way.

There are regulations on activities that Centres of Excellence should perform. These are centres of knowledge, but there is no financial support that would allow them to devote to work with patients and focus on scientific work.

**Recommendation:**

Representatives of reference centres highlighted important area for future action; multidisciplinary approach, integrated care that can be achieved if all stakeholders are included. It is important to develop a model that will provide multidisciplinary and profound cooperation among all stakeholders. Both cooperation with all important institutions on European level and with all stakeholders within the country (patients, patient associations, all relevant institutions for health and social care) should be integrated. The Government have to realize the importance of financial support for implementation of National programme for Rare Diseases 2015 - 2020 and work on integrated care.

**Special social services**

At the conference, basic documents which were used for developing social policies and examples of good practice were presented. Mrs Vlasta Zmazek presented the Debra Resource Centre - a good example of care for people suffering from epidermolysis bullosa, which is one of the few examples of good practice in Croatia. Services provided to people suffering from the condition are not sustainable due to uncertainties in financing through project, lack of knowledge and understanding of relevant institutions for needs of those suffering from rare diseases and lack of cooperation between institutions.

Many rare diseases present severe health, economic and social burden. Even though it is common for many chronic illnesses, there are some characteristics which make rare diseases stand apart. Many rare diseases start in childhood or adolescence, which means that the burden on the patients, their families and the society lasts for life. Physical, mental, intellectual and sensory damage affects individuals from an early age, which is

why people suffering from rare diseases have specific social needs over extended periods, which requires continuous planned engagement.

For now, there are no social services dedicated to providing services to people suffering from rare diseases. They fulfil their needs through social care systems like other people suffering from chronic illnesses and people with disabilities. Providers of social services should be informed about specifics of some rare diagnoses and needs of members of families of the patients in order to secure adequate and quality services.

**Recommendation:**

Representatives of the Agency for Quality and Accreditation in Health Care and Social Welfare pointed out the need for quantitative and qualitative research of the current situation of life quality and care in patients' community. Three points should be measured: health outcomes, patient experience, cost and use of resources. There is a need for new economically viable models of integrated care for patients with multimorbidity that can adjust to various European health systems. It should cover: Evidence of health and financial effects, Financing schemes and payments that stimulate the integration of the chronic care model, Evidence of cost effectiveness and sustainability, Stimulate the capacity building of all relevant stakeholders in European states and raise awareness of the significance of these models for European health systems.

### **III. Conclusions**

Access to information on specific rare diseases is still limited, which illustrates the need for informing patients and their families as well as experts and State bodies. The goal of the conference was to educate participants on the need for integrated care for patients suffering from rare diseases and influence the way we recognize rare diseases in social care. The conference was also aimed at stressing importance of communication and cooperation among all parties with the aim of providing adequate social care. Participants were presented existing examples of good practices as well as future plans, aimed at ensuring better care for patients suffering from rare diseases.

Providers of social services need further education and cooperation with Centres of Excellence.

## Annexes

### ANNEXE I: PROGRAMME

CROATIA  
EUROPLAN NATIONAL WORKSHOP  
'INTEGRATION OF RARE DISEASE INTO MAINSTREAM  
SOCIAL SERVICES AND SOCIAL POLICIES'  
Zagreb, 7<sup>th</sup> November 2017

SPEAKERS AND TOPICS
1. Dunja Skoko - Poljak, Ministry of Health – National Plan for Rare Diseases 2015 - 2020
2. Dorica Dan, NoRo/EURORDIS – Social services and policies for people living with a RDs, EURORDIS – INNOVCare (Innovative Patient – Centred Approach for Social Care)
3. Agency for Quality and Accreditation in Health Care – SELFIE project
4. Ivo Baric, Željko Reiner, Branka Marinović – Centres of Expertise
5. Dorica Dan, NoRo – Social innovation in RDs (case study: NoRo Center)
6. Vlasta Zmazek, Debra Croatia - DEBRA Resource Centre
7. Diana Muacevic - Katanec – RD Coordinators
8. Institute for Expert Evaluation, Professional Rehabilitation and Employment of People with Disabilities - Expert Evaluation of RD Patients
9. Ministry of Demography, Family, Youth and Social Policy – Social Services for RD Patients in Croatia
10. Sanja Peric, Rare Diseases Croatia – Support Centre for RD Patients and Families
11. Discussion on integrated care
12. RD Coordinators Meeting



## ANNEXE II: LIST OF PARTICIPANTS

LAST NAME	FIRST NAME	INSTITUTION
<b>Dan</b>	Dorica	EURORDIS
<b>Erčević</b>	Darija	Agency for Quality and Accreditation in Health Care and Social Welfare
<b>Erhatic</b>	Saša	Rare Diseases Croatia
<b>Grenković</b>	Renata	Agency for Quality and Accreditation in Health Care and Social Welfare
<b>Kvas</b>	Tamara	Rare Diseases Croatia
<b>Novosel</b>	Tomislav	Bjelovar Organization Of People With Physical Disabilities
<b>Pavlović Cvetkov</b>	Nevenka	University Hospital Centre Zagreb
<b>Perić</b>	Sanja	Rare Diseases Croatia
<b>Perić</b>	Florentina	PKU Croatia
<b>Pletikosa</b>	Marija	Ministry of Demographics, Family, Youth and Social Policy
<b>Sever</b>	Zrinka	Social Care Center Ivanec
<b>Vrček</b>	Damir	Social Care Center Ivanec
<b>Zmazek</b>	Vlasta	DEBRA Croatia
<b>Bastalić</b>	Romana	Home for Seniors Dubrava
<b>Krznar</b>	Mateja	DEBRA Croatia
<b>Bandić</b>	Davor	County General Hospital Vukovar hospital and the Croatian Veterans
<b>Barić</b>	Ivo	University Hospital Centre Zagreb



<b>Boban</b>	Ljubica	Children's Hospital Zagreb
<b>Karahasanović Strmečki</b>	Alija	retired doctor
<b>Marinović</b>	Branka	University Hospital Centre Zagreb
<b>Martinović</b>	Martin	General Hospital "Dr. Josip Benčević" Slavonski Brod
<b>Muačević - Katanec</b>	Diana	University Hospital Centre Zagreb
<b>Obradović - Kuridža</b>	Neven	General Hospital Virovitica
<b>Reiner</b>	Željko	University Hospital Centre Zagreb, Croatian Parliament
<b>Skoko - Poljak</b>	Dunja	Ministry of Health
<b>Stilinović</b>	Antonija	General Hospital Gospić
<b>Šimunović</b>	Marina	General Hospital Bjelovar
<b>Šojat - Cvitanović</b>	Ljerka	Zavod za vještačenje
<b>Tandara Haček</b>	Romana	Agency for Quality and Accreditation in Health Care and Social Welfare
<b>Bačić Jozić</b>	Ljiljana	Social Care Center Zagreb, Branch Office Črnomerec
<b>Bošnjak</b>	Mira	Social Care Center Zagreb, Branch Office Dubrava
<b>Bošnjak - Galina</b>	Ivanka	Social Care Center Zagreb, Branch Office Gornji grad - Medveščak
<b>Buljevac</b>	Marko	Faculty of Law Zagreb - Social Work Study Centre
<b>Bužančić</b>	Anita	Social Care Center Zaprešić
<b>Crnjac</b>	Ivana	Social Care Center Zagreb, Branch Office Donji Grad
<b>Cvitanić</b>	Andrea	Social Care Center Zagreb, Branch Office Črnomerec
<b>Čović</b>	Nikolina	Rare Diseases Croatia

<b>Di Capua</b>	Zvezdana	Social Care Center Pula
<b>Draščić Gašparec</b>	Kristina	Home for Seniors and Sick Adults Buzin
<b>Đukanović</b>	Maja	Social Care Center Bjelovar
<b>Đurić</b>	Anka	Social Care Center Zagreb, Branch Office Novi Zagreb
<b>Erak</b>	Ana	Caritas of the Zagreb Archdiocese
<b>Filipović</b>	Snježana	Home for Seniors Bistra
<b>Golac Čelap</b>	Jadranka	Social Care Center Zagreb
<b>Golemac - Mihanović</b>	Silva	Social Care Center Velika Gorica
<b>Gorički</b>	Romana	Social Care Center Zaprešić
<b>Hrastar</b>	Ivana	Rare Diseases Croatia
<b>Ivanković</b>	Viktorija	Social Care Center Zagreb, Branch Office Novi Zagreb
<b>Jagar</b>	Mirela	Social Care Center Zagreb, Branch Office Trnje
<b>Jandrić</b>	Maja	Social Care Center Zaprešić
<b>Janžek</b>	Zrinka	Social Care Center Ivanec
<b>Jereb-Arih</b>	Branka	Social Care Center Pula
<b>Ježić</b>	Anica	Ministry of Demographics, Family, Youth and Social Policy
<b>Jović</b>	Katarina	Social Care Center Zagreb, Branch Office Maksimir
<b>Kohar Vitez</b>	Asja	Social Care Center Medveščak
<b>Kolić</b>	Katarina	Social Care Center Jastrebarsko
<b>Kozjak</b>	Ana	Hope for Seniors Ježdovec
<b>Lacković</b>	Davorka	Special Hospital for Medical Rehabilitation Stubicke Toplice

<b>Lazarić Kolar</b>	Petra	Social Care Center Pula
<b>Leskovar</b>	Ivana	Social Care Center Zagreb
<b>Mačešić</b>	Maja	Social Care Center Bjelovar
<b>Majer</b>	Tajana	Dom Bistra
<b>Majić</b>	Marina	Social Care Center Zagreb, Branch Office Novi Zagreb
<b>Marković</b>	Mirela	Social Care Center Zagreb, Branch Office Dubrava
<b>Mihelčić</b>	Petra	University Hospital Centre Zagreb
<b>Mikinčić</b>	Nada	Social Care Center Velika Gorica
<b>Milošević</b>	Sandra	Social Care Center Pula
<b>Mlatilik</b>	Sanela	Social Care Center Bjelovar
<b>Morić</b>	Ana	University Hospital Centre Zagreb
<b>Negran Malenovski</b>	Marina	Social Care Center Zagreb, Branch Office Novi Zagreb
<b>Penava Šimac</b>	Marija	Ministry of Demographics, Family, Youth and Social Policy
<b>Pest</b>	Jasmina	Home for Seniors Vinkovci
<b>Petrović</b>	Silvica	Social Care Center Križevci
<b>Pirša</b>	Štefica	Social Care Center Velika Gorica
<b>Prebeg</b>	Višnja	Social Care Center Zagreb, Branch Office Novi Zagreb
<b>Predojević</b>	Dubravka	Social Care Center Velika Gorica
<b>Prosinečki</b>	Nina	University Hospital Centre Zagreb
<b>Ramljak</b>	Ružica	Caritas of the Zagreb Archdiocese
<b>Raos</b>	Marina	Social Care Center Zagreb, Branch Office Trešnjevka

<b>Saili</b>	Elvira	Social Care Center Zagreb, Branch Office Novi Zagreb
<b>Sitar</b>	Irena	Social Care Center Bjelovar
<b>Skender</b>	Natalija	Social Care Center Zagreb, Branch Office Trešnjevka
<b>Slaviček</b>	Gordana	Social Care Center Zagreb, Branch Office Susedgrad
<b>Sokač</b>	Štefanija	Social Care Center Križevci
<b>Soldo</b>	Mladenka	Social Care Center Zagreb, Branch Office Trešnjevka
<b>Sudec</b>	Gordana	Education and Training Center "Vinko Bek"
<b>Šimunić</b>	Dijana	Social Care Center Zagreb, Branch Office Novi Zagreb
<b>Škorić</b>	Ivana	Social Care Center Zagreb, Branch Office Novi Zagreb
<b>Štritof</b>	Tatjana	Social Care Center Zagreb, Branch Office Trešnjevka
<b>Šumelj</b>	Đurđica	Social Care Center Zagreb, Branch Office Maksimir
<b>Tomašković Penić - Ivanko</b>	Martina	Social Care Center Jastrebarsko
<b>Trpeza</b>	Jelena	Social Care Center Ivanec
<b>Vajagić</b>	Vesna	Social Care Center Zagreb, Branch Office Maksimir
<b>Valent</b>	Ljiljana	Social Care Center Zagreb, Branch Office Trešnjevka
<b>Varga</b>	Ljiljana	Social Care Center Zagreb, Branch Office Črnomerec
<b>Vratan</b>	Ivana	Home for Seniors Dubrava
<b>Vudrag</b>	Vesna	Institute for Expert Evaluation, Koprivnica
<b>Vukov Trifunović</b>	Ema	Social Care Center Zagreb, Branch Office Donji Grad
<b>Zubić</b>	Ivana	Social Care Center Zlatar Bistrica
<b>Živković</b>	Andreja	Social Care Center Zagreb, Branch Office Susedgrad