

CROATIA

EUROPLAN NATIONAL CONFERENCE

FINAL REPORT

27-28 February 2014, Zagreb

FOREWORD

The EUROPLAN National conferences are aimed at fostering the development of a comprehensive National Plan or Strategy 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 are jointly organised in each country by a National Alliance of rare disease patients' organisations and EURORDIS – the European Organisation for Rare Diseases. For this purpose, EURORDIS nominated 10 EURORDIS-EUROPLAN Advisors - all being from a National Alliance - specifically in charge of advising two to three National Alliances.

EUROPLAN National conferences share the same philosophy, objectives, format and content guidelines. They involve all stakeholders relevant for developing a plan/strategy for rare diseases. According to the national situation of each country and its most pressing needs, the content can be adjusted.

During the period 2008-2011, a first set of 15 EUROPLAN National Conferences were organised within the European project EUROPLAN. Following the success of these conferences, a second round of up to 24 EUROPLAN National Conferences is taking place in the broader context of the Joint Action of the European Committee of Experts on Rare Diseases (EUCERD) over the period March 2012 until August 2015.

The EUROPLAN National Conferences present the European rare disease policies as well as the EUCERD Recommendations adopted between 2010 and 2013. They are organised around common themes based on the Recommendation of the Council of the European Union on an action in the field of rare diseases:

1. Methodology and Governance of a National Plan;
2. Definition, codification and inventorying of RD; Information and Training;
3. Research on RD;
4. Care - Centres of Expertise / European Reference Networks/Cross Border Health Care;
5. Orphan Drugs;
6. Social Services for RD.

The themes “Patient Empowerment”, “Gathering expertise at the European level” and “Sustainability” are transversal along the conference.

I. General information

Country	Croatia
Date & place of the National Conference	27 th and 28 th February 2014, Hotel Dubrovnik, Zagreb
Website	www.rijetke-bolesti.hr www.rijetke-bolesti.org
Organisers	Croatian Alliance for Rare Diseases (patient organization) Croatian Society for Rare Diseases (of Croatian Medical Association)
Members of the Steering Committee	Dunja Skoko Poljak (Ministry of Health) Ingeborg Barišić (President of the Committee for the adoption and monitoring of the implementation of the National Plan for Rare Diseases; EUCERD representative) Darko Antičević (University Hospital Centre Zagreb) Darko Krnić (Agency for Medicinal Products and Medical Devices) Vlasta Zmazek (Croatian Alliance for Rare Diseases; EURORDIS Board of Directors, Advisor) Anja Kladar (Croatian Alliance for Rare Diseases; Orphanet Croatia) Katja Dumić Kubat (Children's Hospital Zagreb)
Names and list of Workshops	Workshop 1: Methodology, implementation and monitoring of the National Plan Workshop 2: Definition, codification and inventorying of rare diseases, information and education Workshop 3: Centres of Expertise/European Network of Centres of Expertise/ Cross border Healthcare Workshop 4: Research of rare diseases Workshop 5: Availability of drugs and therapies for rare diseases Workshop 6: Special Social Services

<p>Chairs and Rapporteurs of Workshops</p>	<p>Workshop 1: Moderator: Vlasta Zmazek Rapporteur : Ljubica Boban</p> <p>Workshop 2: Moderator: Anja Kladar Rapporteur : Branka Blagojević</p> <p>Workshop 3: Moderator: Željko Reiner Rapporteur : Tihana Kreso</p> <p>Workshop 4: Moderator: Anja Kladar Rapporteur : Tihana Kreso</p> <p>Workshop 5: Moderator: Jadranka Brozd Rapporteur : Marina Majoli</p> <p>Workshop 6: Moderator: Vlasta Zmazek Rapporteur : Branka Blagojević</p>
<p>Annexes</p>	<p>I. Press Coverage II. Programme III. List of participants</p>

Official opening

The 3rd National Conference on Rare Diseases was opened on the 27th February in Hotel Dubrovnik, Croatia, by opening speeches from the Mayor of the City of Zagreb, Mr. Milan Bandić, representative of the Ministry of Health, Dr. Dunja Skoko Poljak and the delegate of the President of the Republic of Croatia, Prof. Izet Aganović.

The Conference was organized by the Croatian Alliance for Rare Diseases, in cooperation with the Croatian Society for Rare Diseases of the Croatian Medical Association, European Organisation for Rare Diseases – EURORDIS, the Reference Centre for Medical Genetics and Metabolic Diseases in Children, the Reference Centre for Monitoring Congenital Anomalies and Reference Centre for Rare and Metabolic Diseases. It was organized under the auspices of the President of the Republic of Croatia, Prof. Ivo Josipović, the Minister of Health, Prof. Rajko Ostojić, and the Mayor of the City of Zagreb, Mr. Milan Bandić.

The Conference lasted two days, till mid-day of 28th February with the participation of about 190 participants (members of the Alliance, representatives of Croatian patient organisations, medical experts, representatives of institutions and representatives of the pharmaceutical industry).

The Conference was also attended by foreign experts and representatives (EURORDIS; Orphanet, European Commission, Italian High Institute for Health (ISS, Istituto Superiore di Sanità), DEBRA International, Newcastle University, University Children's Hospital Sofia, University Medical Centre Ljubljana, Children University Hospital Cluj-Napoca, University Children's Hospital Ljubljana and Fabry Center Slovenj Gradec.

The plenary session

In the plenary session of the Conference, participants were addressed by the Chief Operating Officer of DEBRA International and General Secretary, Mr. John Dart, and the president of the Croatian Alliance for Rare Diseases, also president of DEBRA Croatia, Mrs. Vlasta Zmazek.

Mr. Dart gave a short overview of EURORDIS, as a European umbrella organisation for rare diseases, and Mrs. Zmazek informed the participants about the EUROPLAN project and the Croatian National Plan for Rare Diseases.

II. Main Report

Theme 1 - Methodology, implementation and monitoring of the National Plan

Sub-Themes

1. Dunja Skoko Poljak (Ministry of Health): Croatian National Plan
2. Odile Kremp (Orphanet): French experience in the implementation of national plans
3. Petia Nenova (European Commission): Possibilities of using structural funds in the health sector

Dr. Dunja Skoko Poljak, Head of Public Health office at the Ministry of Health, highlighted the need for the government authorities to make financial frameworks for the Croatian National Plan for Rare Diseases, as soon as possible. This will facilitate the presentation to the Government and the implementation of the Plan. Dr. Skoko Poljak also noted that the adoption of the Plan is expected in the second trimester of 2014.

Dr. Odile Kremp, Director of Orphanet, gave a short overview of the French national plans for rare diseases, and gave an example of how good cooperation between all stakeholders can lead to great results. Multidisciplinary and multi-sector cooperation is essential for realising all aspects of health and social care for patients living with rare diseases.

Mrs. Petia Nenova, from the European Commission presented the possibilities of using structural funds in the health sector. Mrs. Nenova noted that is essential for the negotiators to adequately present their projects that are aimed for different aspects of rare diseases, so that it becomes possible to get resources from Structural Funds.

Conclusion: The National Plan is written, presented and a public hearing has been conducted. Unfortunately, the Plan is not yet accepted by the Government, due to some problems in defining the budget. Namely, it is very important to have a plan with a budget, as a financial framework for allocating funds for the implementation of the plan. Also, we are aware of the importance of multidisciplinary work and multi-sector cooperation and communication in defining the budget and implementing the plan.

Post-Conference note: the Croatian National Plan for Rare Diseases has been finalised, but, to date (3rd December 2014) it still awaits adoption by the government. In the meantime, the Ministry for Health set up a Committee in charge of the “development and monitoring of the National Plan for RD”, composed of medical doctors and one patient representative from the Croatian National Alliance.

Workshop 1

Moderator: Mrs Vlasta Zmazek

Rapporteur : Mrs. Ljubica Boban

Date, time, place: 27th February 2014, 4:45PM – 6:15PM, conference room Zrinski

Evaluation by the EUCERD Recommendations on Core Indicators for Rare Disease National Plans/Strategies

INDICATOR	Short answer	Detailed answer
1. Existence of Regulations/Laws, or equivalent official national decisions that support the establishment and development of a RD plan	In progress /in development	The National plan is written, the public hearing has been conducted, but the Plan is not yet accepted by the Government.
2. Existence of a RD advisory committee	YES	YES, exists and meets regularly and includes all relevant stakeholders
3. Permanent and official patients' representation in plan development, monitoring and assessment	YES	YES, at all stages
4. Adoption of the EU RD definition	YES	YES, it was accepted in 2009 and the NP/NS measures are applied using the EU definition

Theme 2 - Definition, codification and inventorying of rare diseases, information and education

Sub-Themes

1. Rosa Giuseppa Frazzica (ISS, Italy): EPIRARE: activities and results
2. Tomislav Benjak (Croatian National Institute of Public Health): Problems in organizing registries of rare diseases
3. Ingeborg Barišić (Croatian Society for Rare Diseases): Codification of rare diseases in Croatia and presentation of the Croatian registry for Rare Diseases

Dr. Rosa Giuseppa Frazzica, from the Italian High Institute for Health, ISS, presented the project EPIRARE and showed the importance of forming and put in operation platforms for rare diseases registries, as well as the sharing all relevant information about registering rare diseases. The conclusions of the EPIRARE project were presented on the final conference held in March 2014 in Rome.

Dr. sc. Tomislav Benjak, head of the Public Health office at the Croatian National Institute of Public Health, confirmed that the Institute has a registry of people with disabilities, within which there is 2463 persons living with rare diseases, according to the ICD-10 classification (International Classification of Diseases). Dr. Benjak also stated that there is no ICD-10 number for all the diagnoses and that is essential to start using the Orpha codes as well.

Professor Ingeborg Barišić, president of the Croatian Society for Rare Diseases of the Croatian Medical Association gave a short overview of Croatia's current situation in the field of codification of rare diseases. She noted that the ICD-10 codification is used in Croatia and that is essential to define quality criteria for the registry of rare diseases and to adapt the information system in hospitals to use Orpha codes as well. She also gave an example of a form for gathering information about patient's history and clinical data.

Conclusion: It is very important to start using the Orpha codes in Croatia, because the ICD-10 code that is used today is not very precise, as there is no ICD-10 code for all the diagnosis. It is also essential to make a RD registry in Croatia, so the information on RDs, patients and treatments will be available to all relevant stakeholders.

Workshop 2

Moderator: Mrs. Anja Kladar

Rapporteur: Mrs. Branka Blagojević

Date, time, place: 27th February 2014, 4:45PM – 6:15PM, conference room Frankopan

Evaluation by the EUCERD Recommendations on Core Indicators for Rare Disease National Plans/Strategies

INDICATOR	Short answer	Detailed answer
11. Type of classification/coding used by the health care system	ICD-10, OMIM	The use of ORPHA code is planned in the National Plan
12. Existence of a national policy on registry and data collection on RD	NO	There is no official policy, but it is planned in NP

Theme 3 - Centres of Expertise/European Network of Centres of Expertise/ Cross boarder Healthcare

Sub-Themes

1. Prof. Željko Reiner (University Hospital Centre Zagreb): Organization of Centres of Expertise for rare diseases in Croatia
2. John Dart (DEBRA International): European network of Centres of excellence – EB - Clinet project
3. Rosa Giuseppa Frazzica (ISS, Italy): A bottom-up approach is a key to total care management of RDs
4. Kristina Roginek (Croatian Institute for Health Insurance): Cross-border health care in Croatia

Prof. Željko Reiner, Head of the Department of Internal medicine at the University Hospital Centre Zagreb, made a short overview of the reference centres in Croatia. He highlighted that there are more than 130 reference centres in Croatia, of which six are involved in diagnosing and treatment of rare diseases. Also, there are three centres that are exclusively specialized for rare diseases. Two of them are designed for children (one at the Children’s Hospital Zagreb and the other at the Clinical Hospital Centre Zagreb) and one is aimed for adults (at the Clinical Hospital Centre Zagreb). The role of reference centres will be further empowered, after the adoption and implementation of the National Plan, as well as with the continuous education of doctors and patients.

Mr. John Dart, General Secretary of EURORDIS and Chief Operating Officer of DEBRA International presented the European Reference Networks for rare diseases. He noted that these networks have to be multidisciplinary, but also flexible, so that all participating countries can adjust to their conditions. It is very important to share information, communicate and work together. As an example of a good network, Mr. Dart presented the project EB-CLINET (EB Clinical Network), which gathers 51 partners from 43 countries.

Dr. Rosa Giuseppa Frazzica, from Istituto Superiore di Sanita (Italy), gave a presentation about the bottom-up approach as a key to total care management of RDs. She said that in the field of RDs, the

most important thing is to work together and have a multidisciplinary approach and the cooperation of relevant stakeholders, from patients, family doctors and specialists to government institutions.

Mrs. Kristina Roginek, Head of the Office for International Cooperation at the Croatian Institute for Health Insurance, presented the possibilities of using cross-border health care in Croatia. She gave detailed information about laws and regulations that regulate this type of health care and presented the methods and conditions for fulfilling the request for gaining the right to cross-border health care.

Conclusion: There are more than 130 reference centres in Croatia, of which six are involved in diagnosing and treating rare diseases. Also, there are three centres that are exclusively specialized for specific rare disease. Two of them are designed for children (one at the Children's Hospital Zagreb and the other at the Clinical Hospital Centre Zagreb) and one is aimed for adults (at the Clinical Hospital Centre Zagreb). It is important to further strengthen the role of reference centres, after the adoption and implementation of the National Plan, as well as with the continuous education of doctors and patients. It would also be useful to connect with European Reference Networks to exchange knowledge and experiences.

Regarding cross border healthcare, a system is established in Croatia and there are laws and regulations. The procedure of obtaining the right to cross border healthcare is complicated and it demands a lot of documents and approvals. After Croatia joined the EU, things became even more complicated, because some regulations and procedures are not yet harmonised.

Workshop 3

Moderator: Academician dr. Željko Reiner

Rapporteur : Mrs. Tihana Kreso

Date, time, place: 27th February 2014, 4:45PM – 6:15PM, conference room Mažuranić

Evaluation by the EUCERD Recommendations on Core Indicators for Rare Disease National Plans/Strategies

INDICATOR	Short answer	Detailed answer
5. Existence of a national policy for establishing Centres of Expertise on RD	YES	YES, existing, fully implemented
6. Number of national and regional Centres of Expertise adhering to the national policy	6	6 CEs complying with the national policy
7. Participation of national or regional centres of expertise in European Reference Networks	NO	CEs cooperate with different international centres/networks but are not formally in any ERN
8. NP/NS support to the development of/participation in an information system on RD	YES	In national information system, in the process of placing information on national language
9. Existence of Help lines for RD	YES, supported by public funding and by private funding	YES, only for patients and it is run by PO
10. Existence of a national policy for developing, adapting and implementing clinical practice guidelines	YES	YES, a policy exists for developing CPGs

Theme 4 - Research of rare diseases

Sub-Themes

1. Anja Kladar (Croatian Alliance for Rare Diseases): Possibilities of support for scientific research of rare diseases planned within the National Plan
2. Gordan Lauc (Genos d.o.o.): How to obtain funding for a European project?

The Croatian Alliance had invited the Minister of Science, Education and Sport, Prof. Željko Jovanović, to participate in this Workshop and to present the opportunities of support for scientific research in the field of rare disease. Unfortunately, he was prevented due to other commitments. In his absence the vice president of the Alliance, Mrs. Anja Kladar, presented how the support for research programmes is designed in the National Plan.

The recommendations in the National Plan are:

- ✓ Encourage initiatives for epidemiological, clinical, basic and translational researches in the field of RDs;
- ✓ Give advantage to research on RDs and encourage national and international projects in that field;
- ✓ Improve and maintain the infrastructures essential for research in the field of RDs;
- ✓ Encourage networks of reference centres and centres of expertise to participate in the research of RDs and coordination on that field.

Activities needed in this field:

- ✓ Development of a national network of scientists involved in the research on RDs (identification and list of scientific teams and projects);
- ✓ Determining existing national research programmes in the field of RDs (basic, translational, clinical, public health and social research/projects) and establishing of a specialised fund for securing the sustainability;
- ✓ Ensuring that the scientific programmes on RDs can be easily identified within wide national programmes;
- ✓ Regular update of lists of existing and new scientific projects in the field of RDs;
- ✓ Support from the Ministry of Science, Education and Sport for the equipment of reference centres and other research centres involved in the research on RD;
- ✓ Specific programmes of funding and/or involving young scientists/junior researchers in projects in the field of RDs;
- ✓ National coordination of research programmes in the field of RDs and their connection with other national programmes in EU;
- ✓ Participation in international scientific projects in the field of RDs (E-rare, Rare Connect, IRDiRC, Horizon2020, ERIC).

Prof.dr.sc. Gordan Lauc, Chief Executive Officer of the firm Genos d.o.o., which operates in the field of laboratory analysis of DNA, presented the process of writing and applying for funds for research projects to be performed at the European and global level. He highlighted that it is possible to obtain funding for a European project, but a lot of effort and national and international cooperation is needed.

Conclusion: There are no research programmes for RDs in Croatia and there is very little participation in European and international programmes. The National Plan mentions the recommendations and the activities that are needed to improve the situation in the field of research, but it is also important to improve the possibilities of financial support for these activities.

Workshop 4

Moderator: Mrs. Anja Kladar

Rapporteur : Mrs. Tihana Kreso

Date, time, place: 28th February 2014, 11.00AM – 12:30, conference room Frankopan

Evaluation by the EUCERD Recommendations on Core Indicators for Rare Disease National Plans/Strategies

INDICATOR	Short answer	Detailed answer
13. Existence of a RD research programmes/projects in the Country	NO	No
14. Participation in European and international research initiatives	YES	YES, others

Theme 5 - Availability of drugs and therapies for rare diseases

Sub-Themes

1. Nikolina Čović (CARD): Patient's experiences in treatment with orphan drugs
2. Darko Krnić (Agency for Medicinal Products and Medical Devices): The role of the Agency in improving orphan drugs availability after joining the EU
3. Natalija Kožnjak (Croatian Institute for Health Insurance): Possible solutions to the problems of availability of therapy for rare diseases

Mrs. Nikolina Čović, social worker in the Alliance, presented the problems of our members with the availability of drugs, therapies and medical aids. She highlighted that today a bigger problem is to get a medical aid than to get an Orphan drug.

Mr. Goran Tudor, president of the Association for support to patients with multiple myeloma, presented some examples of treatment in Croatia, where the patients' rights to treatment are violated because the hospital committee approval or denial of treatment depending on the hospital's budget.

Dr. Mirjana Huić, from the Agency for quality and accreditation in health and social care, was also invited to speak in this workshop, but unfortunately she was prevented.

Dr. Darko Krnić, from the Agency for Medicinal Products and Medical Devices, informed the participants about the role of the Agency in improving the availability of drugs in Croatia after the acceptance to EU. Unfortunately, in Croatia only 38 orphan drugs are available at present.

Dr. Natalija Kožnjak, from the Croatian Institute for Health Insurance, was intended to give as a vision of the solutions to therapies availability problems. Unfortunately, she only gave information about the possibilities and restrictions within the Institute. Because of the lack of funds, slow law regulations and lack of interest from drug developers and distributors for this small area of users, it is difficult to obtain therapy and it seems like there is no solution for these problems.

Conclusion: There are 38 Orphan Medical Products (OMPs) with a European Union marketing authorisation available in Croatia and patients get their therapy on a regular basis. But, other therapies for RDs that have no orphan status are not easily available, there are still a lot of patients without therapy because the guidelines for getting the drugs are not precise and are often misunderstood and interpreted in different ways by different stakeholders. Of course, there is a lack of funds and it seems like there is no solution for these problems.

Workshop 5

Moderator: Mrs. Jadranka Brozd

Rapporteur : Mrs. Marina Majoli

Date, time, place: 28th February 2014, 11.00AM – 12:30, conference room Zrinski

Evaluation by the EUCERD Recommendations on Core Indicators for Rare Disease National Plans/Strategies

INDICATOR	Short answer	Detailed answer
15. Number of Orphan Medical Products (OMPs) with a European Union marketing authorisation and available in the country (i.e. priced and reimbursed or directly supplied by the national health system)	38	
16. Existence of a governmental system for compassionate use of medicinal products	YES	

Theme 6 – Special Social Services

Sub-Themes

1. Anders Olauson (Agrenska,EPF): Agrenska centre
2. Gordana Šimunković (Firefly - association for helping children and families facing malignant diseases): The role of civil society in the management of patients and their families
3. Lea Devčić (Croatian Association of Guiding Dogs and Mobility): Presentation of the therapy dog project

Mrs. Milanka Opačić, Minister of Social Policy and Youth, was invited to speak in this workshop, but the Alliance never got any answer from the Ministry.

Mr. Anders Olauson, from Agrenska centre, made his presentation by Skype. He presented Agrenska centre, which celebrates 100 years of existence this year. At first, it was just an ordinary vacation house, but through the years, it developed to a centre which is used by 36 patients with different RDs today.

Some of the programmes are:

- ✓ Programmes for RD patients' families
- ✓ Programmes for adult patients
- ✓ Respite care programmes, including summer camps for all disabled people
- ✓ Programmes including staff with disabilities – day centre
- ✓ Personal assistants programmes
- ✓ ADHD consulting
- ✓ Programmes of education for experts
- ✓ Research

- ✓ Conferences
- ✓ Projects/Development

Mrs. Gordana Šimunković, from Firefly (association for helping children and families facing malignant diseases), presented the role of civil society in care for patients and their families. She highlighted the importance of patient organisations' support and presented the programmes conducted by Firefly.

Mrs. Lea Devčić, from the Croatian Association of Guiding Dogs and Mobility, presented the therapeutic dog programme, which is conducted in Firefly from this year, as one the most important social services in the care for patients, no matter the disease.

Conclusion: There are no specialised social services for RDs in Croatia. There are some general programmes for people with disability, but they are not completely adjusted to the needs of people with RDs. It is also important to improve the existing services and the cooperation and communication between patients advocacy groups and institutions.

Workshop 6

Moderator: Mrs. Vlasta Zmazek

Rapporteur : Mrs. Branka Blagojević

Date, time, place: 28th February 2014, 11.00AM – 12:30, conference room Mažuranić

Evaluation by the EUCERD Recommendations on Core Indicators for Rare Disease National Plans/Strategies

INDICATOR	Short answer	Detailed answer
17. Existence of programmes to support in their daily life RD patients integration	YES	YES, people living with RD can access general programmes for persons with a disability, but their special needs are still unrecognised

Further evaluation by the EUCERD Recommendations on Core Indicators for Rare Disease National Plans/Strategies

INDICATOR	Short answer	Detailed answer
18. Existence of a policy/decision to ensure long-term funding and/or sustainability of the measures in the RD plan/strategy	NO	
19. Amount of public funds allocated to the RD plan/strategy	NO	
20. Specific public funds allocated for RD research	NO	
21. Public funds specifically allocated for RD research actions/projects per year since the plan started	NO	

Conclusion of the Final Report

The general conclusion of the Conference is: there is still an enormous lack of communication and collaboration between sectors and centres. The cooperation between the Croatian Alliance for RDs and the Croatian Society for RDs in the preparation of this Conference is a very good practical example how things are much easier when we all work together.

Although it was not easy, we managed to organise and carry out the Conference and did another step forward. As there is still lack of open and transparent procedures in decision making, but awareness of need of cooperation with patients and patients involvement in these procedures is growing.

Media campaigning is each year bigger and the Alliance was present in all main TV programs as well as local TV and radio stations.

III. ANNEXES

ANNEXE I: PRESS COVERAGE

The Conference was announced in the following media:

- Radio stations: Obiteljski radio, Radio Sljeme, Slavonski radio, Radio Koprivnica, Radio Osijek, Hrvatski radio, Totalni FM
- TV stations: Z1 TV, HTV
- Online:

<http://narod.hr/zdravlje/hrvatska-jos-nema-nacionalni-program-o-rijetkim-bolestima-ministarstvo-zdravlja-kasni/>

<http://dalje.com/hr-zagreb/u-hrvatskoj-vise-od-200000-ljudi-boluje-od-rijetkih-bolesti/489256>

<http://www.dijete.hr/hr/naslovnica-mainmenu-1/1819-obiljeen-meunarodni-dan-rijetkih-bolesti.html>

<http://www.stampar.hr/7.MedunarodniDan>

<http://www.almp.hr/?ln=hr&w=novosti&d=2014&id=1024&p=1>

<http://huos.hr/udruga/3-nacionalna-konferencija-o-rijetkim-bolestima-27-2-28-2-2014/>

http://www.posi.hr/index.php?option=com_content&view=article&id=534:u-sklopu-obiljeavanja-meunarodnog-dana-rijetkih-bolesti-odrana-je-3-nacionalna-konferencija-o-rijetkim-bolestima-i-3-simpozij-za-rijetke-bolesti-hrvatskog-drutva-za-rijetke-bolesti-hrvatskog-lijenikog-zbora&catid=72:novosti

http://www.sdms.hr/cms/index.php?option=com_content&view=article&id=682:nacionalna-konferencija-o-rijetkim-bolestima-u-zagrebu&catid=15:dogaa&Itemid=42

The report and the photographs from the Conference are published on the website of the Alliance:

http://www.rijetke-bolesti.hr/3-nacionalna-konferencija/?preview=true&preview_id=1603&preview_nonce=59ffad6a74

ANNEXE II: PROGRAMME

3rd Croatian Symposium on Rare Diseases
3rd National Conference on Rare Diseases
27th and 28th February 2014
Hotel Dubrovnik, Zagreb

Organizing Committee: Dunja Skoko Poljak (Ministry of Health), Željko Reiner (Croatian parliament), Ingeborg Barišić (President of the Committee for the adoption and monitoring of the implementation of the National Plan for Rare Diseases; EUCERD representative), Darko Antičević (University Hospital Centre Zagreb), Darko Krnić (Agency for Medicinal Products and Medical Devices), Vlasta Zmazek (Croatian Alliance for Rare Diseases; EURORDIS Board of Directors, Advisor), Anja Kladar (Croatian Alliance for Rare Diseases; Orphanet Croatia), Katja Dumić Kubat (Children’s Hospital Zagreb)

Scientific Committee: Darko Antičević, Ingeborg Barišić, Ksenija Fumić, Antonio Juretić, Vjekoslav Krželj, Borut Peterlin

Thursday, 27th February 2014

12:30 - 13:30	Registration	
13:30 - 14:30	Conference Opening	
	Mayor of the City of Zagreb (Milan Bandić) Ministry of Science, Education and Sport (Željko Jovanović) Ministry of Health (Rajko Ostojić) Delegate of the President of the Republic of Croatia (Izet Aganović) John Dart, EURORDIS , general secretary Vlasta Zmazek, CARD – EUROPLAN project/National Plan	Moderator: Ana Tomašković
14:30 - 16:15	Symposium	Moderators: Ingeborg Barišić, Željko Reiner
14:30 - 14:50	Peterlin Borut: Improved health care for patients with rare diseases in Slovenia: national and regional approach	
14:50 - 15:10	Vujkovic Bojan: Fabry Centar Slovenj Gradec: od prvih koraka do modela	
15:10 - 15:20	Šimić Iveta: Smjernice za dijagnostiku i liječenje Gaucherove bolesti u odraslih	
15:20 - 15:30	Merkler Marijan, Pećin Ivan, Šimić Iveta, Muačević-Katanec Diana, Reiner Željko: Smjernice za dijagnostiku i liječenje Fabrijeve bolesti u odraslih	
15:30 - 15:45	Muačević-Katanec Dijana, Merkler Ana, Carrié Alain, Barešić M, Vučić Marijana, Reiner Željko, Couvert Phillipe: Nova mutacija <i>ABCA1</i> gena u bolesnika s Tangierskom i razvijenom koronarnom bolešću	
15:45 - 16:00	Škaričić Ana, Zekušić Marija, Bilić Karmen, Fumić Ksenija, Rogić Dunja, Petković-Ramadža Danijela, Ćuk Mario, Paležac Lidija, Sarnavka Vladimir, Barić Ivo: Primjena tandemске spektrometrije masa u dijagnostici nasljednih metaboličkih bolesti	
16:00 - 16:15	Usklađena rasprava	
16:15 - 16:45	Coffee Break and Posters Exhibition	

16:45 - 18:15	Workshops	
	Workshop 1: Methodology, implementation and monitoring of the National Plan Dunja Skoko Poljak (Ministry of Health): Croatian National plan Odile Kremp (Orphanet): French experience in the implementation of national plans Petia Nenova (European Commission): Possibilities of using structural funds in the health sector	Moderator: Vlasta Zmazek Rapporteur: Ljubica Boban
	Workshop 2: Definition, codification and inventorying of rare diseases, information and education Rosa Giuseppa Frazzica (ISS, Italy): EPIRARE: activities and results Tomislav Benjak (Croatian National Institute of Public Health): Problems in organizing registries of rare diseases Ingeborg Barišić (Croatian Society for Rare Diseases): Codification of rare diseases in Croatia and presentation of the Croatian registry of rare diseases	Moderator: Anja Kladar Rapporteur: Branka Blagojević
	Workshop 3: Centres of Expertise/European Network of Centres of Expertise/ Cross boarder Healthcare Željko Željko Reiner (University Hospital Centre Zagreb): Organization of Centres of Expertise for rare diseases in Croatia John Dart (DEBRA International): European network of centres of excellence – EB - Clinet project Rosa Giuseppa Frazzica (ISS, Italy): A bottom-up approach is a key to total care management of RDs	Moderator: Željko Reiner Rapporteur: Tihana Kreso
17:00 - 18:30	Satellite Symposium: Hunter Syndrome	Moderator: Ingeborg Barišić / Katja Dumić Kubat
	Barisic Ingeborg: Introduction Nascu Ioana: How to recognize a patient with Hunter Syndrome? Žerjav Tanšek Mojca: Management of Hunter Syndrome in Slovenia Tinceva Radka: Management of Hunter Syndrome in Bulgaria Al-Khzouz Camelia : Management of Hunter Syndrome in Romania Đorđević Maja: Management of Hunter Syndrome in Serbia Discussion and closing remarks	
18:30 - 19:15	Alliance's Assembly	
20h	Dinner	

Friday, 28th February 2014

08:30 - 10:15	Symposium	Moderators: Ksenija Fumić, Vjekoslav Krželj
08:30 - 08:45	Seiwerth Sven, Mišić Marija, Brčić Luka, Meljanac Salopek Kristina, Bonevski Aleksandra: Uloga patologije u dijagnostici i liječenju rijetkih bolesti	
08:45 - 09:00	Sarnavka Vladimir, Petković Ramadža Danijela, Škaričić Ana, Ćuk Mario, Fumić Ksenija, Barić Ivo: Koje bolesti su najbolji kandidati za novorođenački skrining u Hrvatskoj?	

09:00 - 09:15	Mišić Marija, Babić Damir, Birek Ivana, Brčić Luka, Canki-Klain Nina, Hrg Dinana, Kaloper Lovreković Ivona, Meljanac Salopek Kristina, Seiwert Sven: Molekularne metode u patološkoj dijagnostici rijetkih bolesti	
09:15 - 09:30	Murat-Sušić Slobodna, Husar Karmela, Skerlev Mihael, Štulhofer-Buzina Daška, Marinović Branka: Uloga Referentnog centra Ministarstva zdravstva i Socijalne skrbi za nasljedne bulozne epidermolize (EB) u zbrinjavanju bolesnika s EB i prikaz komplikacija bolesti	
09:30 - 09:45	Butković Soldo Silva: Duodopa u liječenju uznapredovale Parkinsonove bolesti u Hrvatskoj	
09:45 - 10:00	Kljenak Antun, Ivelj Renato, Pešorda Domagoj: Koliko je sati potrebno da bi netko postao ekspert za rijetku bolest?	
10:00 - 10:15	Usklađena rasprava	
10:15 - 10:45	Coffee Break and Posters Exhibition	
10:45 - 12:30	Symposium	Moderators: Antonio Juretić, Alenka Gagro
10:45 - 11:00	Juretić Antonio: Novi rijetki molekularni podtipovi tumora i personalizirana onkologija: primjer ALK pozitivnog adenokarcinoma pluća	
11:00 - 11:15	Grah Josip: Maligni gliomi moždanog debla u dječjoj dobi	
11:15 - 11:25	Mišir Krpan Ana, Rakušić Zoran, Bišof Vesna, Ruža Samardžić Kristina, Juretić Antonio, Lončar Krešimir: Germinom mozga: ekstragonadni tumor i njegov klinički značaj	
11:25 - 11:35	Stepan Giljević Jasminka, Butković Diana: Paliјativni pristup kod rijetkih bolesti	
11:35 - 11:45	Roganović Jelena, Mascarin Maurizio, Jonjić Nives, Grahovac Blaženka: Nazofaringealni karcinom	
11:45 - 11:55	Canki-Klain Nina: Klinička slika, genetika i epidemiologija pojasnih mišićnih distrofija (LGMD) u Hrvatskoj	
11:55 - 12:05	Gagro Alenka, Pasini Marija Agneza, Bonevski Aleksandra, Čepin Bogović Jasna, Marjanović Josip, Pustišek Nives, Žutelija Fattorini Matija, Kovačić Ksenija: Učinak bisfosfonata u liječenju autoinflammatoryh bolesti kostiju u djece	
12:05 - 12:15	Gjurašin Miroslav: Rijetke bolesti u neurokirurškoj praksi	
12:15 - 12:30	Usklađena rasprava	
11:00 - 12:30	Workshops	
	Workshop 4: Research of rare diseases Željko Jovanović (Ministry of Science, Education and Sport): Possibilities of support for scientific research of rare diseases Gordan Lauc (Genos d.o.o.): How to obtain a European project?	Moderator: Anja Kladar Rapporteur: Tihana Kreso
	Workshop 5: Availability of drugs and therapies for rare diseases Nikolina Čović (CARD): Patient's experiences in treatment with Orphan drugs, Patients' personal experiences (Agency for Quality and Accreditation in Health Care and Social Welfare): The role of patients in health technology assessment	Moderator: Jadranka Brozd Rapporteur: Marina Majoli

	Darko Krnić, Anela Kraljević (Agency for Medicinal Products and Medical Devices): The role of the Agency in obtaining drugs availability after joining the EU Natalija Kožnjak (Croatian Institute for Health Insurance): Possible solution to the problems of availability of therapy for rare diseases	
	Workshop 6: Special Social Services Milanka Opačić or Anica Ježić (Ministry of Social Politics and Youth): How to provide social welfare for people with rare diseases? Anders Olauson (Agrenska,EPF): Agrenska center Gordana Šimunković (Krijesnica): The role of civil society in the management of patients and their families Katalenić Lucija (Croatian Association of Guiding Dogs and Mobility): Presentation of the therapy dog project	Moderator: Vlasta Zmazek Rapporteur: Branka Blagojević
12:30 - 14:00	Lunch	
14:00 - 15:00	Working group on the adult type of Pompe disease	Moderators: Bilić Ervina, Ivan Pećin
	Bilić Ervina: Gdje tražiti Pompe bolesnika?	
	Pećin Ivan: Zašto je važno prepoznati Pompe bolesnika - uspjeh terapije	
	Studen Marko: Moja priča	
14:00 - 15:00	Symposium	Moderators: Ingeborg Barišić, Sanda Huljev
14:00 - 14:10	Kubat Ozren, Crnogaća Krešimir, Antičević Darko: Ishodi i problemi kod ugradnje intramedularnih elongirajućih implantata u bolesnika s osteogenesis imperfecta. Prikaz rezultata prvih dvadeset Fassier-Duval operacija	
14:10 - 14:20	Ćuk Mario, Petković Ramadža Danijela, Sarnavka Vladimir, Paležac Lidija, Fumić Ksenija, Bilić Karmen, Barić Ivo: Niemann-Pickova bolest tipa C- dijagnostički i terapijski izazov	
14:20 - 14:30	Barešić Ana: Rijetke bolesti u romskim populacijama Hrvatske	
14:30 - 14:40	Šundov Ivana: Mehanička insuflacija/eksuflacija	
14:40 - 14:50	Stavljenić-Rukavina Ana, Kladar Anja: Orphanet Hrvatska	
14:50 - 15:00	Discussion	
	Posters Exhibition	
15:00 - 16:00	Working group conclusions	
16:00	Debrief session	

ANNEXE III: LIST OF PARTICIPANTS

Name	Surname	Organization, company ...	Stakeholder group
Tomislav	Benjak	Croatian National Institute of Public Health	Institution
Branka	Blagojević	DEBRA Croatia	Patient representative
Ljubica	Boban	Children's Hospital Zagreb	Healthcare professional
Jadranka	Brozd	Croatian Society for Patients with Scleroderma	Patient representative
Nikolina	Čović	Croatian Alliance for Rare Diseases	Patient representative
John	Dart	EURORDIS, DEBRA International	Patient representative
Frazzica Rosa	Guisseppa	Instituto Superiore di Sanita Italy	Patient representative
Mirjana	Huić	Agency for Quality and Accreditation in Health Care and Social Welfare	Institution
Lucija	Katalenić	Croatian Guide Dog and Mobility Association	Patient representative
Anja	Kladar	Croatian Alliance for Rare Diseases	Patient representative
Natalija	Kožnjak	Croatian Health Insurance Fund	Institution
Anela	Kraljević	Agency for medicinal products and medical devices	Institution
Odile	Kremp	Orphanet	Patient representative
Tihana	Kreso	Croatian Alliance for Rare Diseases	Patient representative
Darko	Krnić	Agency for medicinal products and medical devices	Institution
Gordan	Lauc	Genos	Research laboratory
Marina	Majoli	Croatian Society for Patients with Scleroderma	Patient representative
Petia	Nenova	European commission	Institution
Anders	Olausen	Ågrenska, EPF	Patient representative
Dunja	Skoko Poljak	Ministry of health	Institution
Marko	Studen		Patient
Gordana	Šimunković	Firefly - association for helping children and families facing malignant diseases	Patient representative
Vlasta	Zmazek	Croatian Alliance for Rare Diseases, Eurordis	Patient representative
Kristina	Roginek	Croatian Health Insurance Fund	Institution

Renata	Alić	Croatian Alliance for Rare Diseases	Patient
Dominko	Antunović	Croatian Alliance for Rare Diseases	Patient
Katica	Antunović	Croatian Alliance for Rare Diseases	Patient
Mira	Armour	Association for Support Persons with Multiple Myeloma	Patient representative
Vjera	Badurina	Croatian Alliance for Rare Diseases	Patient
Domagoj	Bakota	Association of Students of Pharmacy and Medical Pharmacy and Biochemistry of Croatian	Student representative
Zorislav	Bobuš	Croatian Union of Associations of Persons with Disabilities	Patient representative
Jasminka	Brcko	Croatian Alliance for Rare Diseases	Patient
Ana	Bulović	Croatian Alliance for Rare Diseases	Patient
Dragica	Čančar	Croatian Alliance for Rare Diseases	Patient
Dubravka	Čizmić	Croatian Association for Myasthenia Gravis	Patient
Marko	Damjanović	IN-Portal	Media representative
Adrijana	Dorotić	Croatian Alliance for Rare Diseases	volunteer
Petar	Gatarić	Association of Disabled People Križevci	Patient representative
Marija	Genc	Croatian Society for Patients with Scleroderma	Patient representative
Victoria	Hedley	Newcastle University, EUCERD	Institution
Edin	Hedžić	Croatian Alliance for Rare Diseases	Patient
Lidija	Hedžić	Croatian Alliance for Rare Diseases	Patient
Safija	Horvat	Croatian Alliance for Rare Diseases	Patient
Zdenko	Horvat	Croatian Alliance for Rare Diseases	Patient
Zrinka	Hranjec	Croatian Alliance for Rare Diseases	Patient
Snježana	Ivaniš	Croatian Alliance for Rare Diseases	Patient
Danica	Ivanović	Miasthenia Gravis Society of Zagreb	Patient representative
Mila	Jelavić	Ombudsman for Children	Institution

Marko	Jurković	Eksa group	Industry
Kristina	Karaturović Lađević	Croatian Alliance for Rare Diseases	Patient
Olga	Klapčić	Croatian Alliance for Rare Diseases	Patient
Lana	Kopjar Jelačić	Croatian Alliance for Rare Diseases	Patient
Ivana	Latković	Croatian Alliance for Rare Diseases	Patient
Ivana	Linde	Croatian Alliance for Rare Diseases	Patient
Krešimir	Mađaroši	Croatian Alliance for Rare Diseases	Patient
Milica	Mađaroši	Croatian Alliance for Rare Diseases	Patient
Marko	Marinić	Croatian Association of Hemophiliacs	Patient representative
Željko	Mihoković	"OKO" Association of Parents of Visually Impaired and Multi Disabilities Children	Patient representative
Marija	Miščančuk	Croatian Alliance for Rare Diseases	Patient
Damir	Modrić	Croatian Association of Hemophiliacs	Patient representative
Ljuba	Nikoliš	Croatian Alliance for Rare Diseases	Patient
Tomislav	Novosel	Bjelovar Organization of People with Physical Disabilities	Patient representative
Danijel	Peras	Croatian Alliance for Rare Diseases	Patient
Zdenko	Petrinović	Croatian Alliance for Rare Diseases	Patient
Milenka	Petrović Šekoranja	Croatian Alliance for Rare Diseases	Patient
Vesna	Pezić	Croatian Society for Patients with Scleroderma	Patient representative
Nikolina	Posuda	Bjelovar Organization of People with Physical Disabilities	Patient representative
Tomislav	Raguž	Croatian Association of Hemophiliacs	Patient representative
Antonia	Selak	Croatian Alliance for Rare Diseases	Patient
Ines	Seleš	Bjelovar Organization of People with Physical Disabilities / Croatian Association for Myasthenia Gravis	Patient representative
Renata	Šarić	Croatian Alliance for Rare Diseases	Patient
Mirjana	Šemper	Croatian Alliance for Rare Diseases	Patient

Robert	Šivak	Croatian Association of Hemophiliacs	Patient representative
Goran	Tudor	Association for Support Persons with Multiple Myeloma	Patient representative
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Božica	Vrabec	Croatian Alliance for Rare Diseases	Patient
Jasenka	Wagner	Croatian Alliance for Rare Diseases	Patient
Silvija	Žužul	Croatian Alliance for Rare Diseases	Patient
Antonija	Buhovac	Croatian Alliance for Rare Diseases	Patient
Sanja	Perić	Associations to Help the Families with Phenylketonuria	Patient representative
Dalibor	Dujmić	Associations to Help the Families with Phenylketonuria	Patient representative
Ana	Bežovan	Coalition of Association in Health Care	Patient representative
Nada	Bjelčić	"OKO" Association of Parents of Visually Impaired and Multi Disabilities Children	Patient representative
Helena	Kapitanović Vidak	Special Hospital for Children with Developmental Disabilities, Goljak	Healthcare professional
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Vesna	Kušaković	Croatian Alliance for Rare Diseases	Patient
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Camelia	Al-Khzouz	Childrens University Hospital Cluj-Napoca	Healthcare professional
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Krešimir	Lončar	University Hospital Centre Zagreb	Healthcare professional

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Ana	Stavljenić-	City Assembly of Zagreb	Politician

	Rukavina		
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Vladimira	Cvitanović Barišić	Special Hospital for Children with Developmental Disabilities, Goljak	Healthcare professional
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Ana	Merkler	University Hospital Centre Zagreb	Healthcare professional
Vesna	Milas	University Hospital Centre Osijek	Healthcare professional
Mirjana	Mladin-Čikara	Special Hospital for Children with Developmental Disabilities, Goljak	Healthcare professional
Leona	Morožin Pohovski	Children's Hospital Zagreb	Healthcare professional
Tena	Ormuž	University of Zagreb, Faculty of Education and Rehabilitation Sciences	Institution
Ante	Petrušić	Private Internal Medicine Ordination	Healthcare professional
Ljiljana	Podrug	Primary Healthcare Institution	Healthcare professional
Smiljana	Podrug	Croatian Pension Insurance Institute	Institution
Ljiljana	Popović Miočinović	Special Hospital for Children with Developmental Disabilities, Goljak	Healthcare professional
Ingrid	Prkačin	University Hospital Merkur	Healthcare professional
Silvija	Pušeljić	University Hospital Centre Osijek	Healthcare professional
Maja	Rakić	Faculty of Pharmacy and Biochemistry	Institution
Miljenko	Raos	Clinic of Pediatrics Alergovita	Healthcare professional
Martina	Rinčić	Croatian Institute for Brain Research	Institution
Mia	Romčević	Srčana, Clinic for Cardiovascular Diseases Prevention and Rehabilitation	Healthcare professional
Danica	Rožić Janković		Healthcare professional (retired)
Ivona	Sansović	Children's Hospital Zagreb	Healthcare professional
Ania	Sever Poljak	University Hospital Centre Zagreb	Healthcare professional
Sanja	Svalina	General Hospital Vukovar	Healthcare professional
Anastazija	Šanić	University Hospital Centre Sestre milosrdnice	Healthcare professional
Marija	Šoštarko	University of Zagreb, School of Medicine	Institution
Višnja	Tomac	University Hospital Centre Osijek	Healthcare professional
Zdenka	Tomičić	Polyclinic Prof.	Healthcare professional
Slavko	Trontl	Polyclinic Kocijan Hercigonja	Healthcare professional
Ivana	Unić	University Hospital Centre Split	Healthcare professional

Dubravka	Vajdić	Association of Educational Rehabilitators City of Zagreb	Patient representative
Anita	Vido	University Hospital Centre Sestre milosrdnice	Healthcare professional
Nika	Vukelić	Syncro Synergy Croatia	non-governmental organization active in the field of non- formal education
Dora	Vukušić	University of Zagreb, Faculty of Education and Rehabilitation Sciences	Institution
Željko	Biljan	University Hospital Centre Osijek	Healthcare professional
Aleksandra	Munjiza	University Hospital Centre Sestre milosrdnice	Healthcare professional
Hrvojka	Kostelac	Solpharm	Industry
Ivan	Bošnjak	Clinical Hospital Vrapče	Healthcare professional
Ninoslav	Kordić	General Hospital Vukovar	Healthcare professional
Matej	Katavić	University Hospital Centre Sestre milosrdnice	Healthcare professional