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2012 REPORT ON THE STATE OF THE ART OF RARE DISEASE ACTIVITIES IN EUROPE OF THE EUROPEAN UNION COMMITTEE OF EXPERTS ON RARE DISEASES

STATE OF THE ART OF RARE DISEASE ACTIVITIES IN CROATIA

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More information on the European Union Committee of Experts on Rare Diseases can be found at www.eucerd.eu.

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ACRONYMS

General

CAT - Committee for Advanced Therapies at EMA
CHMP - Committee for Medicinal Products for Human Use at EMA
COMP - Committee on Orphan Medicinal Products at EMA
DG - Directorate General
DG Enterprise - European Commission Directorate General Enterprise and Industry
DG Research - European Commission Directorate General Research
DG Sanco - European Commission Directorate General Health and Consumers
EC - European Commission
ECRD - European Conference on Rare Diseases
EEA - European Economic Area (Iceland, Switzerland, Norway)
EMA - European Medicines Agency
ERN - European reference network
EU - European Union
EUCERD - European Union Committee of Experts on Rare Diseases
EUROCAT - European surveillance of congenital anomalies
EUROPLAN - European Project for Rare Diseases National Plans Development
EURORDIS - European Organisation for Rare Diseases
FDA - US Food and Drug Administration
HLG - High Level Group for Health Services and Medical Care
HTA - Health Technology Assessment
IRDiRC – International Rare Diseases Research Consortium
JA - Joint Action
MA - Market Authorisation
MoH - Ministry of Health
MS - Member State
NBS - New born screening
NCA - National Competent Authorities
NHS - National Health System
PDCO - Paediatric Committee at EMA
RDTF - EC Rare Disease Task Force
WG - Working Group
WHO - World Health Organization

Pilot European Reference Networks

Dyscerne - European network of centres of expertise for dysmorphology
ECORN-CF - European centres of reference network for cystic fibrosis
Paediatric Hodgkin Lymphoma Network - Europe-wide organisation of quality controlled treatment
NEUROPED - European network of reference for rare paediatric neurological diseases
EUROHISTIONET - A reference network for Langerhans cell histiocytosis and associated syndrome in EU)
TAG - Together Against Genodermatoses – improving healthcare and social support for patients and families affected by severe genodermatoses
PAAIR - Patients' Association and Alpha-1 International Registry Network
EPNET - European Porphyria Network - providing better healthcare for patients and their families
EN-RBD -European Network of Rare Bleeding Disorders
CARE-NMD -Dissemination and Implementation of the Standards of Care for Duchenne Muscular Dystrophy in Europe project
ENERCA - European network for rare and congenital anaemia – Stage 3

GENERAL INTRODUCTION TO THE REPORT ON THE STATE OF THE ART OF RARE DISEASE ACTIVITIES IN EUROPE OF THE EUROPEAN UNION COMMITTEE OF EXPERTS ON RARE DISEASES

The 2012 Report on the State of the Art of Rare Disease Activities in Europe was produced by the Scientific Secretariat of the European Union Committee of Experts on Rare Diseases (EUCERD), through the EUCERD Joint Action: Working for Rare Diseases (N° 2011 22 01), which covers a three year period (March 2012 – February 2015).

The report aims to provide an informative and descriptive overview of rare disease activities at European Union (EU) and Member State (MS) level in the field of rare diseases and orphan medicinal products up to the end of 2011. A range of stakeholders in each Member State/country have been consulted during the elaboration of the report, which has been validated as an accurate representation of activities at national level, to the best of their knowledge, by the Member State/country representatives of the European Union Committee of Experts on Rare Diseases. The reader, however, should bear in mind that the information provided is not exhaustive and is not an official position of either the European Commission, its Agencies or national health authorities.

The report is split into five parts:

Part I: Overview of rare disease activities in Europe
Part II: Key developments in the field of rare diseases in 2011
Part III: European Commission activities in the field of rare diseases
Part IV: European Medicines Agency activities and other European activities in the field of rare diseases
Part V: Activities in EU Member States and other European countries in the field of rare diseases

Each part contains a description of the methodology, sources and validation process of the entire report, and concludes with a selected bibliography and list of persons having contributed to the report.

The present document contains the information from Parts II and V of the report concerning Croatia. A list of contributors to the report and selected sources are in annex of this document. For more information about the elaboration and validation procedure for the report, please refer to the general introduction of the main report[1].

[1] http://www.eucerd.eu/upload/file/Reports/2012ReportStateofArtRDActivities.pdf

RARE DISEASE ACTIVITIES IN CROATIA

Definition of a rare disease

Stakeholders in Croatia accept the European Regulation on Orphan Medicinal Products definition of a prevalence of no more than 5 in 10'000 individuals.

National plan/strategy for rare diseases and related actions

There is currently no official strategy or plan in Croatia regarding rare diseases. In 2008, the Croatian Society for Rare Diseases[2] was established as part of Croatian Medical Association, with the aim of preparing a proposal to be presented to governmental authorities (including the parliament and the Ministry of Health and Social Welfare of Republic of Croatia) for the development of a national plan for rare diseases. Since this initiative, the Ministry of Health and Social Care established the National Commission for Rare Diseases in May 2010 in order to elaborate a National Plan for Rare Diseases. This Committee includes three representatives of civil organisations for rare diseases. During 2011 the Committee met on the regular basis which resulted in some progress in creating the national plan for rare diseases.

The Croatian national plan for rare diseases is being developed around of the following nine priority areas:

1. Promotion of the knowledge and the availability of information on rare diseases;
2. Support of rare disease registries and securing of their sustainability;
3. Facilitation of referral centres and centres of expertise activities;
4. Improvement of the availability and quality of health services for rare disease patients (prevention, diagnosis, treatment);
5. Improvement of access to treatment with orphan medicinal products;
6. Securing the availability of special social services for rare diseases patients.
7. Empowerment of patient's organisations;
8. Encouraging research activities in the field of rare diseases;
9. International networking in the field of rare diseases.

The First National Conference on Rare Diseases (17-19 September 2010)[3], organised by the Croatian Association for Rare Disorders, under the auspices of the President of the Republic in the scope of the Europlan conference, allowed stakeholders to meet and discuss priorities for the plan. General proposals and guidelines for actions at national level were agreed on by the participants: to improve access to health care and social services, including the protection of patients' social rights and their right to multidisciplinary approach to care; to ensure the introduction of the category of rare diseases in the legal acts of health and social care; to establish a registry for RD and ensure its long term sustainability by providing ongoing funding; to establish a network of Centres of Expertise or a network of physicians working with RD patients; to aid the empowerment and support for patient organisations: to support international networking and cooperation in the field of rare diseases. The Second National Conference on Rare Diseases was held on 8 October 2011. Like the previous conference, it was again the meeting of all national stakeholders. Numerous problems were discussed. The need to strengthen efforts and accelerate the activities to fulfill the goals outlined during the previous conference was emphasised.

There is currently no earmarked budget for rare diseases in the national health care budget, but special funding is available however for orphan medicinal products and there is a "List of Especially Expensive Drugs".

Centres of expertise

There are currently three Referral Centres for rare diseases acknowledged by the Croatian Ministry of Health and Social Welfare: the Referral Centre for Birth Defects (Children's University Hospital Zagreb, Decision UP/I-510.01/02-01/18, No 534-05-01/8-03-10), the Referral Centre for Rare Diseases and Metabolic Disorders (Department of Internal Medicine, Clinical Hospital Centre Zagreb; Decision UP/I-510-01/08-01/11, No 534-07-1-2/6-08-12), and the Referral Centre for the Medical Genetics and Metabolic Diseases in Children (Department of Paediatrics, Clinical Hospital Centre Zagreb, Decision UP –I-510-01/95-01/0005, No534-02-10-99-0003). These centres of expertise foster a multidisciplinary approach to rare disease patient care adhering to high

[2] http://www.rijetke-bolesti.org

[3] http://download.EURORDIS.org/europlan/2_EUROPLAN_Guidance_Documents_for_the_National_Conference/FINAL%20Report_Croatian_%20EUROPLAN%20NC%202010%20-%20Report%20Package.pdf

medical standards. There are some other centres dealing with particular diseases, for instance the Referral Centre for Haemophilia, Referral Centre for solid tumours in children, etc.

Pilot European Reference Networks

Croatian teams participate, or have participated, in the following European Reference Networks for rare diseases: TAG and TREAT NMD and Care-NMD.

Registries

Currently, there is neither a national registry for rare diseases in Croatia, nor a national committee dedicated to registries for rare disorders. However, many patients are registered through the mentioned referral centres and patient organisations (phenylketonuria, Prader-Willi syndrome, osteogenesis imperfecta, epidermolysis bulosa, etc.) or international on-line registries. These types of registries are not financed. The exception regarding financing is the E-IMD registry for urea cycle defects and some organic acidurias which is part of the EC financed E-IMD project. As a part of EUROCAT network of congenital anomaly registries, Zagreb Registry covers four regions of Croatia (17% of annual births) and this initiative is extended during 2011 to two new regions. This activity is funded as a part of Joint Action EUROCAT 2011-2013 by the Public Health Programme 2008-2013 of the European Commission. The establishment of the National EUROCAT Committee is in progress. A project to develop epidemiological data on patients with rare tumours in Croatia via a registry is underway in collaboration with the Croatian patient organisation for cancers "Za novi dan". Croatia also contributes to the European registry EUROCAT, EUROCARE CF, PID, European registry for intoxication type metabolic diseases (E-IMD) and TREAT-NMD.

Neonatal screening policy

Neonatal screening is centralised in Croatia and is an obligatory part of health care. Neonatal screening is provided for phenylketonuria and hypothyroidism. In addition, in 2003 national screening for hearing impairment was implemented and covers the whole of the country. Preliminary activities to extend the newborn screening program by tandem mass spectrometry are underway. The national screening laboratory has been renovated and equipped with tandem mass spectrometry equipment. The remaining problems to extend the screening are to clarify legislation and funding of the running costs.

Genetic testing

Genetic testing is available for the most common genetic conditions in laboratories of clinical hospitals or research institutes. Genetic testing is covered by the Croatian Institute for Health Insurance: when a certain test is not available in Croatia, a second medical opinion from 2-3 medical professionals is needed before a sample can be sent abroad. However there are still some problems with these sorts of cross-border services.

Diagnostic tests are registered as available in Croatia for 28 genes and an estimated 37 diseases in the Orphanet database[4]. There are no national guidelines for genetic tests although there have been activities of Croatian Society for Human Genetics in this sense.

National alliances of patient organisations and patient representation

Since its registration as a non-profit humanitarian organisation in April 2007, the Croatian Society of Patients with Rare Diseases[5] has been working on developing relations with the stakeholders who have an impact on the lives of rare diseases patients. The Society is a coalition of patient groups and NGOs. The Society cooperates with the Ministry of Health and Social Welfare, the Croatian Institute for Health Insurance and other national health institutions, national and European-level civil society organisations, and medical professionals who work with rare disease patients. In 2011 the Society elected a new president, and was supported by an employee. The Society works to raise general awareness concerning rare diseases and lobbies political stakeholders. Thanks to the initiatives of the CSPRD, the Croatian President declared 2008 the Year of Rare Diseases and offered assistance for future actions.

Patient organisation activities are supported by the government and other non-governmental bodies: this financial support is intended for capacity building, networking activities, dissemination of information and information sharing and events.

Representatives of patient organisations are also invited to participate in the meetings of the Croatian Society for Rare Diseases when policy issues (and other issues of interest are discussed). Financial support is

[4] Information extracted from the Orphanet database in September 2011.

[5] http://www.rijetke-bolesti.hr

available for patients to attend these meetings. Most patient organisations' boards usually include a medical professional involved with patients in consultations, policy making etc.

Sources of information on rare diseases and national help lines

Orphanet activities in Croatia

Since 2006, there is a dedicated Orphanet team in Croatia, currently hosted by the Zagreb University School of Medicine. This team is in charge of collecting data on rare disease related services (specialised clinics, medical laboratories, ongoing research, registries, clinical trials and patient organisations) in their country for entry into the Orphanet database.

Official information centre for rare diseases

Apart from the national Orphanet team there is no official information centres on rare diseases in Croatia. However, from 2011 the new office of the Croatian Society for Rare Diseases, part of the Croatian Medical Association, started to function as an information center, financed primarily by donations. This service has the support of the government and is consulted by governmental institutions, but it is not designated as an official information centre.

Help line

There is currently no national rare disease help line in Croatia. Informal help lines run by patient organisations provide general information for rare diseases diagnostic and management. The national alliance has started the preparations for the official help line. It should be available in 2012 after the education of volunteers and a media campaign. It will be financed through the project and by donations.

Other sources of information

Information on rare diseases is provided by the Croatian Society for Rare Diseases and by institutions hosting the mentioned referral centres. There are also certain public information sources on rare diseases, including help lines and websites run by patient organisations and non-governmental organisations. The site run by the Croatian Society of Patients with Rare Diseases (http://www.rijetke-bolesti.hr/) includes information on certain diseases and groups of diseases. The Croatian Society for Rare Diseases has developed a website which contains comprehensive information for professionals and patients (www.rijetke-bolesti.org).

Good practice guidelines

No specific activity reported.

Training and education initiatives

Current university training courses do not yet provide specific training on rare diseases. Information on rare diseases is included in curricula for medical students, students at Faculty of Education and Rehabilitation Sciences and students at Faculty of Pharmacy and Biochemistry, University of Zagreb.

National rare disease events in 2011

In Croatia, there are regular professional meetings dedicated to rare diseases organised by the Croatian Society for Human Genetics, Croatian Society for Rare Diseases, the Section for Metabolic Diseases of the Croatian Paediatric Society and different professional and patient organisations.

A Rare Disease Day press conference was organised in Zagreb on 23 February 2011, by the Croatian Society for Rare Diseases. The main goal was to emphasise the issues we are dealing with, such as this year's topic - inequality. The press conference was held at the City Zagreb's Forum Venue and was supported by the City Zagreb's Department of Health. Rare Disease Day was once again supported by President Prof. dr. Ivo Josipović, who gave a video message to be conveyed to the public by TV in order to raise the public and media awareness about rare diseases.

In addition to this event, Croatia's four biggest cities (Zagreb, Split, Rijeka and Osijek) marked the Rare Disease Day with a range of activities. Information booths were placed in the square in four major cities informing the public about rare diseases. Public lectures were given in order to bring more clarity to the issue of rare diseases and to share experiences of those affected by rare diseases. A round table meeting took place with the participation of medical professionals, health administration representatives and rare diseases patient in Zagreb on 28 February 2011.

During the Fifth Croatian Congress on Human Genetics from 20 to 24 June 2012, there was a round table discussion dedicated to rare diseases, with participation of the experts and representatives of patients groups.

Hosted rare disease events in 2011

Rare disease related events hosted by Croatia included the 2nd Assembly of the European Myasthenia Gravis Association (EuMGA) in (26 February 2011, Zagreb), Ninth European Paediatric Neurology Society Congress (11-14 May 2011, Cavtat) and the Annual General Meeting of the Osteogenesis Imperfecta Federation Europe in (2-5 October 2011, Dubrovnik).

Research activities and E-Rare partnership

Research activities

There are around 40 projects funded by the Ministry of Science, Education and Sports for the investigation of genetic diseases and various other groups of rare diseases. Some pharmaceutical companies involved in the management of rare diseases support investigations of specific rare diseases. There is a database of clinical studies in Croatia (www.regpok.hr) in the Croatian language.

Participation in European research projects

Croatian teams participate, or have participated, in European research projects on rare diseases, including: EUROGLYCANET, European registry and network for intoxication type metabolic diseases, and EUROPEAN LEUKEMIA NET,

E-Rare partnership

Croatia is currently not an E-Rare partner and has not yet participated in these calls.

IRDiRC

Croatian funding agencies are not yet committed members of IRDiRC.

Orphan medicinal products

Orphan medicinal product committee

In Croatia there is no orphan medicinal product committee, although the Croatian Health Insurance Institute has a drug committee which controls drug use and makes any drug available if approved after individual request by selected national experts.

Orphan medicinal product incentives

No specific activity reported.

Orphan medicinal product market availability situation

The availability of orphan medicinal products has been improved since the establishment of the Fund for Expensive Drugs at the Croatian Institute for Health Insurance, and a regulation for orphan medicinal products is being prepared by a working group to be presented to the Ministry of Health and Social Care.

A tender for drugs for rare diseases was introduced in 2009. This resulted in introduction of only one drug for the treatment of a certain disease, for example for Fabry disease this is agalsidase alfa, whilst agalsidase beta was put on the hospital budget. This caused problems for patients treated with agalsidase beta, as hospital management has asked treating physicians to change the treatment to agalsidase alfa. These problems have recently been solved. The latest list of orphan medicinal products approved for treatment of rare and severe diseases (Decision, Narodne novine, 131/10, 24 November 2010) can be found on the web pages of the Croatian Agency for Drugs and Medicinal Products[6]. There is a detailed procedure regulating the inclusion of a drug on the List of Especially Expensive Drugs. The final decision is taken by the Board of the Croatian Institute for Health Insurance, based on the report of Committee for drugs and medicinal products.

Orphan medicinal product pricing policy

No specific activity reported.

[6] www.halmed.hr

Orphan medicinal product reimbursement policy

In Croatia, treatment for rare diseases was originally covered using the hospitals' budget and hospitals were reluctant to begin a therapy presenting such a heavy financial burden. After a long negotiation between patients´ organisations and professionals involved in the treatment of rare diseases with authorities, the Ministry of Health established in 2006 a "List of Especially Expensive Drugs" (Legislative Decree Class: 025-04/06-01/91, No: 338-01-01-06-1, Zagreb, 9. March 2006.) and the treatment of rare diseases is now covered from specially allocated funds from general state health system budget. Orphan medicinal products are thus now approved by the Croatian Institute for Health Insurance: all available orphan medicinal products are reimbursed by the Croatian health insurance fund ("expensive drug fund") for rare diseases.

In 2010 Croatian Institute for Health Insurance has introduced a regulatory method for the control of the consumption of drugs that are on the "List of Especially Expensive Drugs". Maximal spending budget is regulated by the 3-year contracts and monitored monthly. This policy sometimes makes difficult ensuring prompt treatment for newly discovered patients.

Other initiatives to improve access to orphan medicinal products

Compassionate use is possible from the time of diagnosis to the approval for the use of the drug. The importation of relatively cheap drugs is sometimes problematic, because there is no obligation for companies to provide the drug.

Orphan devices

No specific activity reported.

Specialised social services

There are possibilities for different types of social and respite care services in some parts of the country, although not specifically for rare disease patients, but for those affected with chronic disorders in general: these services are fully reimbursed by national health care. Therapeutic recreational programmes such as summer camps are organised by patient organisations (e.g. children's camps for those affected by rare forms of solid tumours and lymphomas): this is fully reimbursed by the patient organisation. Social and/or financial support for families and patients with disabilities is regulated by a number of legislative decisions/regulations. Fostering of employment for the integration of handicapped individuals in daily life is partly financed by the government. Recently the National Strategy for Equal Possibilities for Handicapped Individuals 2007-2015 (Class 562.01./07-01/02, No 5030108-07-1, June 2007) was introduced in order to regulate the area of services aimed at the integration of patients with handicaps in daily life. In 2011, there were no new initiatives in the field of respite care: some individual patient organisations and some groups of patients organised summer camps (e.g. PKU, haemophilia).

DEVELOPMENT OF RARE DISEASE ACTIVITIES IN 2011 IN CROATIA

National plan/strategy for rare diseases and related actions

During 2011 the National Commission for Rare Diseases met on the regular basis which resulted in some progress in creating the national plan for rare diseases.

The Croatian National plan for rare diseases is being developed around of the following nine priority areas:

10. Promotion of the knowledge and the availability of information on rare diseases;
11. Support of rare disease registries and securing of their sustainability;
12. Facilitation of referral centres and centres of expertise activities;
13. Improvement of the availability and quality of health services for rare disease patients (prevention, diagnosis, treatment);
14. Improvement of access to treatment with orphan medicinal products;

15. Securing the availability of special social services for rare diseases patients.
16. Empowerment of patient's organisations;
17. Encouraging research activities in the field of rare diseases;
18. International networking in the field of rare diseases.

The Second National Conference on Rare Diseases was held on 8 October 2011. Like the previous conference, it was again the meeting of all national stakeholders. Numerous problems were discussed. The need to strengthen efforts and accelerate the activities to fulfill the goals outlined during the previous conference was emphasised.

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Neonatal screening policy

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National alliances of patient organisations and patient representation

In 2011 the Croatian Society of Patients with Rare Diseases[7] elected a new president, and was supported by an employee.

Sources of information on rare diseases and national help lines

Official information centre for rare diseases

From 2011 the new office of the Croatian Society for Rare Diseases, part of the Croatian Medical Association, started to function as an information center, financed primarily by donations. This service has the support of the government and is consulted by governmental institutions, but it is not designated as an official information centre.

Help line

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[7] http://www.rijetke-bolesti.hr

Research activities and E-Rare partnership

IRDiRC

Croatian funding agencies are not currently committed members of the IRDiRC.

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[8] The contributors and validators of the report have contributed information which is accurate to the best of their knowledge. However, readers should take note that the contents of this report are illustrative and not exhaustive.
[9] All websites and documents were last accessed in May 2012. A more detailed list of sources is available in the full report: http://www.eucerd.eu/upload/file/Reports/2012ReportStateofArtRDActivities.pdf