

## **2014 REPORT ON THE STATE OF THE ART OF RARE DISEASE ACTIVITIES IN EUROPE**



## **STATE OF THE ART OF RARE DISEASE ACTIVITIES IN CROATIA**

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The European Union Committee of Experts on Rare Diseases (EUCERD) was established in 2009 and its mandate ended in 2013. It is replaced from 2014 by the Commission Expert Group on Rare Diseases. The EUCERD Joint Action continues to support the activities of the new Expert Group until 2015.

More information on the activities of the former European Union Committee of Experts on Rare Diseases and the EUCERD Joint Action can be found at [www.eucerd.eu](http://www.eucerd.eu).

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## ACRONYMS

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  
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

## GENERAL INTRODUCTION

This document 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 European Union Committee of Experts on Rare Diseases (EUCERD) was established in 2009 and its mandate ended in 2013. It is replaced from 2014 by the Commission Expert Group on Rare Diseases. The EUCERD Joint Action continues to support the activities of the new Expert Group until 2015.

The present 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 2013. 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 Commission Expert Group on Rare Diseases. The reader, however, should bear in mind that the information provided is not exhaustive and is not an official position of the European Commission, its Agencies or national health authorities.

The report is split into six parts:

Part I: Overview of rare disease activities in Europe

Part II: Key developments in the field of rare diseases in 2013

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

Part VI: Activities at National level in each EU Member State and other European countries in the field of rare diseases

Parts I – V also include a description of the methodology, sources and validation process of the entire report, and 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.

Each year, there are around 15 000 downloads of the different sections of the report combined.

# 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 officially adopted strategy or plan in Croatia regarding rare diseases. In 2008, the Croatian Society for Rare Diseases<sup>1</sup> 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, 2012 and 2013 the Committee met on the regular basis which resulted in creating the national plan for rare diseases.

The Croatian national plan for rare diseases has been 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 draft was presented to the Croatian Society of Patients with Rare Diseases in December 2012 and further amended in 2013 after public consultation. The Croatian national plan is currently awaiting the final acceptance by the MoH. The presentation to the Parliament was scheduled for 2014.

The First National Conference on Rare Diseases (17-19 September 2010)<sup>2</sup>, 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 for orphan medicinal products that are on the "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-

<sup>1</sup> <http://www.rijetke-bolesti.org>

<sup>2</sup> [http://download.EURORDIS.org/europlan/2\\_EUROPLAN\\_Guidance\\_Documents\\_for\\_the\\_National\\_Conference/FINAL%20Report\\_Croatian%20EUROPLAN%20NC%202010%20-%20Report%20Package.pdf](http://download.EURORDIS.org/europlan/2_EUROPLAN_Guidance_Documents_for_the_National_Conference/FINAL%20Report_Croatian%20EUROPLAN%20NC%202010%20-%20Report%20Package.pdf)

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 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. The funding and designation of centres of expertise will be a focus of the national plan for rare diseases, according to EUCERD Recommendations.

### **Registries**

Currently, there is neither a national registry for rare diseases in Croatia, nor a national committee dedicated to registries for rare diseases nor designated registries for rare diseases. There are plans to establish a national registry in the future. However, many patients are registered through the mentioned referral centres and patient organisations (phenylketonuria, other inborn errors of metabolism in children, Prader-Willi syndrome, osteogenesis imperfecta, epidermolysis bulosa, etc.) or international on-line registries. These types of registries are not financed. The exception regarding financing are the E-IMD registry for urea cycle defects and some organic acidurias and the E-HOD registry for homocystinurias, folate metabolism disorders and methylation defects and which are parts of the related EC financed E-IMD and E-HOD projects. As a part of EUROCAT network of congenital anomaly registries, Zagreb Registry covers four regions of Croatia (17% of annual births) and this initiative was 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.. Croatia also contributes to the European registry EUROCAT, EUROCAT CF, PID, European registry for intoxication type metabolic diseases (E-IMD), European network and registry for homocystinurias and methylation defects (E-HOD) 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. In 2013 Committee for the Neonatal Screening of the Ministry of Health has been established in order to improve regulation of neonatal screening and foster the screening activities.

### **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 problems with these sorts of cross-border services. The reference laboratories in Croatia are based in the Children's University Hospital Zagreb and the University Hospital Centre of Zagreb's Clinical Institute for Laboratory Diagnosis, Clinical Unit for Molecular Diagnostics.

Diagnostic tests are registered as available in Croatia for 32 genes and an estimated 49 diseases in the Orphanet database<sup>3</sup>. According to data from Croatian Society of Human Genetics testing is available for 48 genetic disorders (some laboratories are not listed yet in Orphanet database). 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<sup>4</sup> has been working on developing relations with the stakeholders who have an impact on the lives of patients with rare diseases. The Society works to raise general awareness concerning rare diseases and lobbies political stakeholders. The Croatian Alliance for Rare Diseases, replacing the Croatian Society of Patients with Rare Diseases was established in 2012 as the umbrella organisation for rare diseases that gathers 19 other non-profit organisations and more than 300 patients with rare diseases and members of their families

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<sup>3</sup> Information extracted from the Orphanet database in January 2014.

<sup>4</sup> <http://www.rijetke-bolesti.hr>

who do not have patient organisation representation. At present there are more than 400 different rare diseases registered in the association.

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, as well as the Committee on Newborn Screening. Financial support is 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. There is an Orphanet national website which was launched in 2013<sup>5</sup>. Since 1 July 2013 Croatian Alliance for Rare Diseases is collecting data.

#### ***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 centre, 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***

A rare disease helpline was established in Croatia in 2012 by the Croatian Alliance for Rare Diseases. It will be financed through the project and by donations. Informal help lines run by patient organisations provide general information for rare diseases diagnostic and management.

#### ***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](http://www.rijetke-bolesti.org)).

#### **Guidelines**

Guidelines have been developed for the treatment of adult patients with Gaucher and Fabry disease.

#### **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 2013**

The Croatian Alliance for Rare Diseases organised a number of events to mark Rare Disease Day in 2013. Promotion of National plan and Help Line, as well as presentation of activities of patient organisations throughout 7 towns in Croatia was organised.

#### **Hosted rare disease events in 2013**

The EUROCAT 12th European Symposium on Congenital Anomalies was held on 14 June 2013 in Zagreb. The Eurordis Membership Meeting was held in Dubrovnik, 30 May – 2 June 2013.

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<sup>5</sup> <http://www.orpha.net/national/HR-HR/index/homepage/>

## **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](http://www.regpok.hr)) in the Croatian language.

### ***Participation in European research projects***

There is one rare disease related FP7 project with Croatian participation.

### ***E-Rare partnership***

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

### ***IRDiRC***

Croatian funding agencies have not yet committed funding to 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 Especially 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 later been solved. In 2013 Croatian Institute for Health Insurance released updates of the List of Especially Expensive Drugs which includes drugs for several rare diseases (drugs for multiple sclerosis, some cancers, rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis, home treatment of hemophyllia, peginterferon, growth hormone, enzyme replacement therapy). Orphan medicinal products approved for treatment of rare and severe diseases can be found on the web pages of the Croatian Agency for Drugs and Medicinal Products<sup>6</sup>. 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.

### ***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.

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<sup>6</sup>[www.halmed.hr](http://www.halmed.hr)



In 2010 the 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.

#### **Other therapies for rare diseases**

No specific activity reported.

#### **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. 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 2013, there were no new initiatives in the field of respite care.

## **DEVELOPMENT OF RARE DISEASE ACTIVITIES IN 2013 IN CROATIA**

#### **National plan/strategy for rare diseases and related actions**

During 2013 the National Committee for Rare Diseases met on the regular basis which resulted in creating the national plan for rare diseases.

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

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### **Neonatal screening policy**

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#### ***Orphanet activities in Croatia***

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### **Guidelines**

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### **Orphan medicinal products**

#### ***Orphan medicinal product market availability situation***

In 2013 Croatian Institute for Health Insurance released updates of the List of Especially Expensive Drugs which includes drugs for several rare diseases (drugs for multiple sclerosis, some cancers, rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis, home treatment of hemophyllia, peginterferon, growth hormone, enzyme replacement therapy).

## LIST OF CONTRIBUTIONS<sup>7</sup>

### Contributions in 2010

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<sup>7</sup> 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.

<sup>8</sup> All websites and documents were last accessed in May 2014.