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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 NORWAY

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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 Norway. 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 NORWAY

Definition of a rare disease

In Norway a medical disorder is considered rare when there are less than 100 known cases per million inhabitants. In Norway this corresponds to fewer than 500 known cases. Some medical disorders with a higher prevalence may also be considered rare if only a small number of people have been diagnosed or because of scarcity of knowledge among service providers.

National plan/strategy for rare diseases and related actions

There is ongoing political and practical activity in the field of rare disorders In Norway.

Services for people with rare disorders and their families have been an area of priority in the government's plans of actions for the disabled (1990-1993 and 1994-1997). In the following years these action plans have been implemented, followed up and developed to meet current needs.

As users of long-term, coordinated health care and/or social services, patients are entitled to an Individual Plan, which is a personal overall plan for service provisions. Particularly relevant to rare disorders patients, and not conditional on any particular diagnosis or age, this plan will contain an outline of the objectives, resources and the services the patient requires. Despite the various resources available to rare disease patients in Norway, a study reveals that more specialist knowledge is needed, along with an "integrated approach" to health care.

In 2008, the Regional Health Authorities (RHA) initiated a revision of the current national resource functions (including the resource centres for rare disorders). The aim was to identify in a five year perspective which centres of expertise are needed and where in the specialist health services they should be placed. The revision suggests a complete review of the system and services directed to patients with rare disorders. This also includes the distribution of allocated resources. One of the main goals is to facilitate the expansion of the services to include a wider range of rare disorders.

In 2010 the Ministry of Health requested a report on how to reorganise the centres for rare disorders under one administration. The working group led by the Directorate of Health delivered the report[2] on 1 December 2010. The recommendations were supported by the Directorate, with some following remarks. In March 2012 the Ministry announced that the South-Eastern Norway Regional Health Authority.(RHF) shall establish a national competence service for rare diagnosis and disabilities to administrate all the national services in this field today, except the services for dual sensory impairment (for which the Ministry will conclude later). The RHF will receive resources to establish this unit in 2013.

In addition to this the Regulation on *"Approval of hospitals and national services"*, which includes centres of expertise for rare disorders, was enforced from the start of 2011: this Regulation imposes the same criteria and demands on centres of expertise for rare disorders as on other national centres of expertise. The document has been translated to English and published[3].

Centres of expertise

National competence service

In Norway there are 16 different state-financed centres of expertise for people with rare and less known disorders. 12 of the centres are national competence services, providing services for more than 16'000 persons with more than 300 different rare disorders which lead to disability. In order for a service to be established for a rare disease, the condition must furthermore meet the criteria of being "congenital and complex/compound, and there must be a need for multidisciplinary and cross-institutional services". These centres also facilitate the development and dissemination of expertise, and they provide forms of support unmet by standard services. The centres are administered under the Regional Health Authorities as specialist health care services. The grants to the centres are ear marked to the RHAs through the state budget. The centres report to the Regional Health Authority and to the Directorate for Health. See section 4, §4-5 and §4-6 in the above mentioned regulation for requirements and responsibilities for the national competence services. §4-3 and §4-4 regulate requirements and responsibilities for national and multi-regional treatment services.

[2] http://www.helsedirektoratet.no/vp/multimedia/archive/00316/Revidert_rapport_Sa_316599a.pdf

[3] Unofficial translation: http://www.regjeringen.no/upload/HOD/SHA/forskrift-eng-270911.pdf

The Norwegian Directorate for Health has also received the results of a commissioned survey[4] carried out by marketing research firm Ipsos MMI (previously Synovate) that sought to explore the knowledge of 11 of the national centres of expertise for rare disorders in Norway. The survey shows an over-all demand for a centralised telephone/postal resource for the centres of expertise, and a global lack of knowledge of where to obtain information on rare disorders. The Norwegian Directorate of Health is the country's competent authority, responsible for technical as well as certain administrative duties. The Rehabilitation and Rare Disorders Department at the Directorate maintains a free help-line for rare conditions available to patients, family members and service providers. The results from the survey show that this service should be better marketed.

There are several departments of medical genetics in Norway. Genetic counselling and genetic testing is available on demand as public health care services. In Norway many specialised health care services (e.g. surgery and specialised medical treatment) are centralised to one or a few units in addition to the Centre of Expertise.

Pilot European Reference Networks

Norwegian teams participate/participated, in the following European Reference Networks for rare diseases: Dyscerne, Paediatric Hodgkin Lymphoma Network, EPNET and Care-NMD.

Registries

Each national resource centre has its own registry: they report to their respective Regional Health authority, as well as to the Directorate of Health. Public Health Registries also exist (such as the medical birth registry, cause of death registry, national patient registry and social security registry). Norway contributes to the EURADRENAL, EUROCAT, EPR (European Porphyria Registry) and EUROCARE European registries.

Neonatal screening policy

Neonatal screening for phenylketonuria and congenital hypothyroidism, as well as newborn hearing screening, has been in place for several years. A report presented to The Norwegian Directorate of Health in March 2009, suggested an expansion to include biochemical screening for in total 23 different conditions. The Government concurred with the recommendations and sanctioned in October 2010 newborn screening for the following conditions: Propionic acidemia, Methylmalonic acidemia, Isovaleric acidemia, Holocarboxylase synthetase deficiency, Biotinidase deficiency, β-Ketothiolase deficiency, Glutaric acidemia type I, Medium-chain acyl-CoA dehydrogenase deficiency, Long-chain L-3-Hydroxy dehydrogenase deficiency, Trifunctional protein deficiency, Very long-chain acyl-CoA dehydrogenase deficiency, Carnitine uptake defect, Carnitine palmitoyltransferase I deficiency, Carnitine palmitoyltransferase II deficiency, Carnitine acylcarnitine translocase deficiency, Glutaric acidemia type II, Maple syrup urine disease, Homocystinuria, Phenylketonuria, Tyrosinemia type I, Congenital adrenal hyperplasia, Congenital hypothyroidism and Cystic fibrosis. The expansion of the program was to be implemented following a revision of the legal regulation on genetic testing. The new regulation was sanctioned in December 2011 with effect from January 1, 2012. Under this regulation, prior to newborn screening, it is expected that the parents are well informed about tests, methods and possible consequences. Newborn screening will be based on informed consent, and residual samples may be kept in a diagnostic bio bank for 6 years. Consent is also required for later use of demographic data, analytical results and information related to diagnostic follow-up and treatment. This information will be stored in a quality register for evaluation of the screening program. Parents can decline storage or use of remaining samples in research. In general, use of screening samples in research will require an approval from an ethical committee and a signed agreement from the parents.

Genetic testing

The portal http://www.genetikkportalen.no gives an overview of the genetic tests/analysis available in Norway at any time. The portal is administered through Department of Medical Genetics and Molecular Medicine, Haukeland University Hospital, Bergen, Norway. When there is no test available in Norway, samples are sent to laboratories abroad.

Diagnostic tests are registered as available in Norway for 110 genes and an estimated 117 diseases in the Orphanet database[5].

[4] http://www.helsedirektoratet.no/funksjonshemminger/etterlyser_felles_sentral_for__sjeldensentrene__685144

[5] Information extracted from the Orphanet database (September 2011).

National alliances of patient organisations and patient representation

There is currently no alliance of rare disease patient organisations in Norway, but the Norwegian Federation of Organisations of Disabled People (FFO) is recognised as the co-ordinating body for organisations of disabled people, including many rare disease patient organisations. The government contributes financially to many patients organisations. There must be at least 250 members in an organisation to qualify for government co-funding. The Directorate of Health initiated a project in 2009 (which has since been finalised) to bring together smaller organisations in order to qualify for financial support, as organisations with less than 250 members may merge with others in order to qualify for government financial support. The Directorate will follow up this report.

Sources of information on rare disorders and national help lines

Orphanet activities in Norway

Since 2006 the national coordinator for Orphanet in Norway is based at the Norwegian Directorate of Health and is in charge of collecting data on rare disease related services for entry into the Orphanet database. The Orphanet Norway[6] national website in Norwegian is maintained by the coordinator.

Official information centres for rare diseases

The centres of expertise develop and revise professionally reviewed information about the different syndromes for which they provide services[7]. This information is published on their websites and in paper copies, often available on site at the Centres from staff dedicated to informing patients and family members.

Help line

Since 1999, the Norwegian Directorate of Health services a free help line for rare disorders. To date, the help line has answered calls for about 800 different rare disorders.

Other sources of information

The Directorate's website also makes publications concerning rare diseases available to the public. Norway is also part of Rarelink (www.rarelink.no), a Nordic website which contains a compilation of links to information on rare disorders, published by organisations commissioned by the governments of Sweden, Finland, Denmark and Norway. Another important source of information is the Directorate's website[8].

Good practice guidelines

The centres of expertise are involved in the preparation and implementation of guidelines and guides for rare disorders.

Training and education initiatives

Several of the national competence services are involved in different educations and training, such as medical schools, odontology training, nursing schools etc. Some centres administrate web-based courses for specific diseases (e.g. http://www.sjeldnediagnoser.no/?k=sjeldnediagnoser/home&aid=10960).

National rare disease events in 2011

There are meetings organised at all the resource centres, and annual contact meetings between each centre and their respective regional health authority. Conferences and congresses are organised on special occasions such as Rare Disease Day.

Frambu Resource Centre for Rare Disorders marked the Rare Disease Day 2011 by organizing an interview with two families having a child with a rare disease. The interview was broadcasted by the Norwegian Broadcasting Association in their evening news. The interview was located at Frambu and we also got the possibility to inform about the struggle for people diagnosed with a rare disease. Another interview with a third family was made by the Norwegian News Agency (NTB) who published the story in different newspapers all over Norway.

Hosted rare disease events in 2011

No other rare disease events were hosted by Norway in 2011.

[6] http://www.orpha.net/national/NO-NO/index/kort-om-orphanet/

[7] Accessible on these sites amongst others http://www.sjeldnediagnoser.no/ and http://www.frambu.no/

[8] http://www.helsedirektoratet.no/helse-og-omsorgstjenester/sjeldne-tilstander/Sider/default.aspx

Research activities and E-Rare partnership

National research activities

National centres of expertise are involved in a number of research projects on rare disorders.

Participation in European research projects

Norwegian teams participate/participated in European rare disease research projects including: CHEARTED, ECFR, EUROCRAN, EURAPS, EURADRENAL, EUROBONET, HUE-MAN, MYELINET, NEUROXSYS, NEUROKCNQPATHIES, SIOPEN-R-NET and VITAL.

E-Rare partnership

Norway is not currently a partner of the E-Rare project.

IRDiRC

Norweigan funding agencies are not yet committed members of the IRDiRC.

Orphan medicinal products

Orphan medicinal product committee

There is no orphan medicinal product committee in Norway.

Orphan medicinal product incentives

As an EFTA/EEA member, the EU orphan medicinal product regulation is fully implemented in the EEA agreement, including the orphan designation incentives. As yet no additional national program has been put in place for granting incentives specifically for the development of orphan medicinal products.

Orphan medicinal product market availability situation

By the end of December 2011, 48 orphan medicinal products were marketed in Norway. These drugs are: Aldurazyme, Arzerra, Atriance, Busilvex, Cystadane, Diacomit, Duodopa, Elaprase, Esbriet, Evoltra, Exjade, Firazyr, Gliolan, Glivec, Increlex, Inovelon, Kuvan, Litak, Lysodren, Mepact, Mozobil, Myozyme, Nexavar, Nplate, Orfadin, Pedea, Prialt, Revatio, Revlimid, Savene, Soliris, Somavert, Sprycel, Tasigna, Tepadina, Thalodimide Celgene, Tobi Podhaler, Torisel, Tracleer, Ventavis, Vidaza, Volibris, Votubia, Vpriv, Wilzin, Xagrid, Yondelis and Zavesca. Other orphan products with an EEA marketing authorisation, but not yet marketed in Norway, can nevertheless be readily dispensed by the pharmacy when a doctor provides a specific medical prescription form.

Orphan medicinal product pricing

Norway has a structured system for pricing, and orphan medicinal products follow these overall principles.

Orphan medicinal product reimbursement

Norway has an extensive reimbursement system for pricing and reimbursement, and orphan medicinal products follow these overall principles outlined in Article 3 "Blåreseptforskriften". The payer is the National Insurance Administration. However, special consideration can be made for chronic rare diseases (i.e. prevalence < 1/10,000) after individual application for reimbursement.

An open-access article[9] appearing in the *British Medical Journal* depicts the attitudes in Norway towards orphan medicinal product funding, finding that *"despite strong general support for statements expressing a desire for equal treatment rights for patients with rare diseases, there was little evidence that a societal preference for rarity exists if treatment of patients with rare diseases is at the expense of treatment of those with common diseases".* The authors, working from the premises that *"drugs for rare diseases (orphan drugs) seldom meet standard cost effectiveness thresholds used to evaluate new drugs [and that] some studies suggest that only a societal preference for rarity would justify granting exceptions to cost effectiveness thresholds for orphan drugs"*, sought to determine whether a preference for rarity justified ignoring considerations of cost-effectiveness. Using a cross-sectional web-based survey, over 1500 Norwegians between the ages of 40 and 57 were queried on their opinions toward funding for rare versus common diseases and the allocation of funds when rare disease treatments were costlier. The authors conclude that there exists, *"…little compelling evidence … to support the existence of a societal preference for rarity in itself, a finding that*

[9] http://www.ncbi.nlm.nih.gov/pubmed/20861122

supports the view that treatments for rare disease should not be exempt from standard considerations of cost effectiveness." However, the authors point out that there could be *"unexplored ethical reasons"* that would support a special funding status for orphan medicinal products. Furthermore, the authors concede that *"…majority opinion is not necessarily a good measure of what is ethical".*

Orphan devices

The National Insurance Act[10] (folketrygdloven) gives rights for the use of assistive devices (orphan and common) for daily life activities and work.

Specialised social services

National competence services (Centres of Expertise) offer residential training courses for patients, families and professionals. The courses include lectures, group discussions, consultations and joint activities. These courses are free of charge for patients and their families. Staff from the centres also visits people in their home environment, pass on information and hold guidance meetings, as well as making contributions to courses, conferences and seminars. Collaboration with local health services and staff ensures that people with a rare disorder and their families receive treatment, care and services appropriate to their needs within their local community.

Frambu[11] offers summer camps for four groups of around 50 children and adolescents each year, offering a chance to meet others in the peer's situation and build a network of friends and contacts. The centres of expertise for rare diseases provide these types of social services, which are meant to supplement generally available programmes.

DEVELOPMENT OF RARE DISEASE ACTIVITIES IN 2011 IN NORWAY

National plan/strategy for rare diseases and related actions

In 2010 the Ministry of Health requested a report on how to reorganise the centres for rare disorders under one administration. The working group led by the Directorate of Health delivered the report[12] on 1 December 2010. The recommendations were supported by the Directorate, and the Ministry's conclusion is expected in 2012. In addition to this the Regulation on *"Approval of hospitals and national services"*[13], which includes centres of expertise for rare disorders, was enforced from the start of 2011: this Regulation imposes the same criteria and demands on centres of expertise for rare disorders as on other national centres of expertise. The document has been translated to English and published[14].

Centres of expertise

In Norway centres of expertise are entitled national competence services**.** The Regulation on *"Approval of hospitals and national services"*[15] (section 4, §4-5 and §4-6) outline the requirements and responsibilities for the national competence services, and §4-3 and §4-4 regulate requirements and responsibilities for national and multi-regional treatment services.

Neonatal screening policy

The Government concurred with the recommendations and sanctioned in October 2010 newborn screening for the following conditions: Propionic acidemia, Methylmalonic acidemia, Isovaleric acidemia, Holocarboxylase

[10] http://www.lovdata.no/all/hl-19970228-019.html
[11] http://www.frambu.no/
[12] http://www.helsedirektoratet.no/vp/multimedia/archive/00316/Revidert_rapport_Sa_316599a.pdf
[13] Unofficial translation: http://www.regjeringen.no/upload/HOD/SHA/forskrift-eng-270911.pdf
[14] Unofficial translation: http://www.regjeringen.no/upload/HOD/SHA/forskrift-eng-270911.pdf

[15] Unofficial translation: http://www.regjeringen.no/upload/HOD/SHA/forskrift-eng-270911.pdf

synthetase deficiency, Biotinidase deficiency, β-Ketothiolase deficiency, Glutaric acidemia type I, Medium-chain acyl-CoA dehydrogenase deficiency, Long-chain L-3-Hydroxy dehydrogenase deficiency, Trifunctional protein deficiency, Very long-chain acyl-CoA dehydrogenase deficiency, Carnitine uptake defect, Carnitine palmitoyltransferase I deficiency, Carnitine palmitoyltransferase II deficiency, Carnitine acylcarnitine translocase deficiency, Glutaric acidemia type II, Maple syrup urine disease, Homocystinuria, Phenylketonuria, Tyrosinemia type I, Congenital adrenal hyperplasia, Congenital hypothyroidism and Cystic fibrosis. The expansion of the program was to be implemented following a revision of the legal regulation on genetic testing. The new regulation was sanctioned in December 2011 with effect from January 1, 2012. Under this regulation, prior to newborn screening, it is expected that the parents are well informed about tests, methods and possible consequences. Newborn screening will be based on informed consent, and residual samples may be kept in a diagnostic bio bank for 6 years. Consent is also required for later use of demographic data, analytical results and information related to diagnostic follow-up and treatment. This information will be stored in a quality register for evaluation of the screening program. Parents can decline storage or use of remaining samples in research. In general, use of screening samples in research will require an approval from an ethical committee and a signed agreement from the parents.

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Another interview with a third family was made by the Norwegian News Agency (NTB) who published the story in different newspapers all over Norway.

Research activities and E-Rare partnership

IRDiRC

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

LIST OF CONTRIBUTIONS[16]

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- Frambu Centre for Rare Diseases
  http://www.frambu.no/
- Rarelink
  www.rarelink.no

[16] 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.
[17] 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