

# FINLAND

## EUROPLAN NATIONAL CONFERENCE

### FINAL REPORT

21 September 2013, Helsinki

# 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.

## Introduction

Because the Finnish National Plan on rare diseases was drafted and commented in two parts, firstly in spring 2013 and then continued in fall 2013, EUROPLAN criteria have been commented in a more elaborate way in the **Finnish National Programme for rare diseases**, published in early 2014.

This report concentrates on the more in-depth comments of the representatives of patient organisations, concentrating on specific themes, described in previous chapters, and on the National Programme for rare diseases in entirety, before it was published in the beginning of year 2014.

## Main Themes

### **Theme 1 - Rationalization of clinical pathway and treatment processes of patient with rare disease.**

The Steering Group on rare diseases, which included representatives of patient groups, set by the Ministry of Social Affairs and Health, gave two draft measures in spring of 2013, for the commenting of this group:

#### *1. Clarification of the clinical pathway and treatment process of a patient with rare disease*

Objectives:

- To clarify the clinical and treatment pathways of patient with rare disease
- Every level of health care system is made aware of how the processes of diagnostics and treatment of rare diseases are organized. Patient with a rare disease have to have a care passport, either in Finnish or Swedish.

#### *2. Care unit for rare diseases in University hospitals*

Objectives:

- A unit that would be in charge of the diagnostics and coordination of care in a case when no clear specialist field can be identified for the disease.
- To ease the co-operation of University hospitals.
- Transition from paediatric care to adult care and basic health care has to be fluid.
- Possibility to work for diagnostics and care of rare diseases in the basic health care is guaranteed, even if it is often time consuming.
- Promotion of availability of information concerning rare diseases in social and welfare services.

## Theme 2 - Centres of Expertise of rare diseases.

The discussion focused mainly on these two topics:

- Better and more efficient care for patients with rare disease
- Foundation of centers of expertise for rare diseases and national centers of expertise, according to EU criterias.

Objectives:

- Clarification of possible needs of legislative changes, concerning the foundation of expertise centers.
- To start the foundation of centers of expertise for rare diseases in Finland, during the Programme period.
- Some of the centers of expertise have a strategy to fulfill the EUCERD criteria for centers of expertise.
- All levels of health care have knowledge of centers of expertise of rare diseases. Centers of expertise share their knowledge with all levels of social and health care services.

### Comments of the patients' organisations to the objectives of the Steering Group of the Ministry of Social Affairs and Health:

When centres of expertise are established, cost-savings are achieved by reducing the number of doctor appointments and hospitalisation periods. Change in the point of view is that appropriate and effective care is made more efficient, and costs of malpractice are reduced. There is no information about how the knowledge of the Finnish Network for Rare Diseases is surveyed. How to encourage different actors in the field to co-operate with Finnish Network for Rare Diseases? The working group of patients group is worried of the continuity. Hospitals are already bringing down operative and existing expert units, thus losing and dissolving the know-how. How to secure the knowledge of experts' centers in the future?

Patient co-operation and patient panel have to be involved already in the planning and development phases of the experts' centers. The Third sector has to be acknowledged as a resource for the experts' center. EU-level expert centres personnel consists of not just doctors and nurses, but other professionals as well physiotherapists and social workers for example. They spread knowledge concerning diagnostics, medical care, rehabilitation and social services. Rehabilitation is a major issue in treating rare diseases. The correct timing of rehabilitation and co-operation with hospital districts, Social Insurance Institution of Finland, SII, and insurance companies is essential.

At least one expert center is to be established during Programme for RDs period. All levels of health care system have to have knowledge of expert centres of rare diseases. Expertise has to be forwarded. Care units are obliged to forward rare disease patient to specialist care. Patient has to have a possibility to complain about the care.

Referrals arriving to expert centrals can be compared to diagnosed cases. Amount of consultations can be a sign of how well an expertise center is known of and considered of. Contacts with expert centers must be made easier through the use of phone and internet, for example e-doctor and crisis services after a diagnosis. Not everyone is in the need of top expertise immediately.

### Theme 3 - Developing social support and rehabilitation of patient with rare disease

Comprehensive support and fortifying inclusion of patients

Objectives:

- Cooperation between health-, social and rehabilitation services has to be more systemized and closer, in order to evaluate the needs of patients comprehensively.
- Patients, and family, if needed, participate in the planning of services, and can influence organisation of services.
- Service plan is made for patients in need of multi professional services.
- Up-to-date information concerning rehabilitation and social services is readily available, and it is distributed to social- and health care professionals and patients.
- All new information about rare diseases is distributed to SII, patient organisations, insurance companies and organizers and producers of social and health care services.
- Opportunities for patient organisations to organise peer activities are reinforced.

#### Comments of patient organisations to the objectives of the Steering Group of the Ministry of Social Affairs and Health:

Centers coordinating treatment for rare diseases cannot be left only as a responsibility of University hospitals; Government level guidance and responsibility is essential.

The proposed multi-professional work group treating the patient, and liaison person for the patient, is a very positive feature, as well as closer cooperation between different operatives. Different concrete examples of cooperation are needed. Data privacy issues and patients' rights have to be acknowledged as the cooperation is getting closer.

Social support in the national Programme can be seen coming only from the system. One documented objective should be social support for the family, work, study, hobbies etc., acknowledging the fact that patients with rare diseases might need special support. Psychological support and support for the family and friends should be considered. A remarkable proportion of social support comes from patient organisations, and through that, peer support. Funding of the organisations is a problematic issue, since groups of rare diseases are small, and organisations have to be national, which in turn means that no support is available from municipalities. Solutions for funding are needed.

The Service plan, which was introduced in the RDs National Programme, is very important, but it has to be implemented, too. Expertise of the patient has to be listened to while making different plans. An authentic encounter is essential to know and acknowledge the needs of the patient, not just what is available at that moment. Pre-emptive measures and promptly timed support actions are essential, and time limits for taking the different decisions concerning patient care needs have to be introduced.

The Social Insurance Institution of Finland, SII, needs to have more expertise on rare diseases. The planning groups of SII should include patients' point of view already in the planning stages, and also after that. An evaluation panel, evaluating existing services is not enough. SII's standards, for example those concerning adaptation training and rehabilitation, cannot be applied straight as they

are, to patients with rare disease. Patients have a need for rehabilitation courses specific to their diagnosis and for expert-level tailored rehabilitation. It would also be recommendable to clarify, what exactly term “rehabilitation” covers in the National Programme. Patients often have a need for versatile rehabilitation, for example music therapy and riding therapy.

An operator gathering information of rare diseases is an asset. The meaning of experience in training is important when distributing information. While distributing information to professionals, also the patients have to be included, especially children, adolescents and those with a need of plain language information.

#### **Theme 4 - The functionality of social- and health care system for patients with rare diseases. Functionality compared in the view of the National Plan for the years 2014-2017.**

This working group commented on the National Programme for rare diseases.

##### Comments of the representatives of the patient organisations:

The National Programme brings all sectors and components together. Getting information on rare disease is made easier. A remarkable feature of the planning is the inclusion of patients' organisations in the planning, implementation and evaluation stages. Equality between different diagnose groups is promoted by the Programme, and the outcome of the National Programme is beneficial for professionals, authorities and patient groups alike.

Planning of the implementation of the National Programme is demanding, and regional imbalance in Finland is a fact. Having an operator, coordinating operations, is essential. Deficiency in information and service purchasing systems is problematic. The responsibility of the officials, concerning patient with rare diseases should be put in place. Recording patient data uniformly, and based on needs, is essential. Lack of time resources, when patient is meeting professionals, is an issue. Patient data bases should be further developed, funding of the treatment of rare diseases needs to be held under discussion and have more visibility. It is also essential to know who makes the decisions. Do professionals have enough information? Is the expertise of patients or their family utilised?

Personal knowledge trough experience and the expertise of the patient needs to be put forward, for example through participating in experience training, and clarification of the communication is essential.

Facts and emotions have to be separated. By participating in regional civic forums, rare disease patient organisations promote their issues. Peer support, crossing diagnostic borders, is beneficial to patient.

## Theme 5 - Reinforcing the inclusion of patient and patient organisations

The Steering Committee for rare diseases of the Ministry of Social Affairs and Health set a Programme proposal in the National Plan. This proposal is commented by this work group.

The draft measure: Reinforcing the inclusion of patients

Objectives:

- Patient with rare disease and his/hers family and friends and professionals get enough information concerning social- and health services.
- Increased inclusion of patients and their families, while planning the service pathways.
- Increased ability of patient organisations to affect the development of service structures.
- Patient organisations take part in starting, evaluating and developing the centres of expertise.
- Patient organisations take part in evaluating and developing the services for patients with rare diseases.

Comments of the representatives of the patient organisations:

Patients with rare diseases need the support of a social worker in charge of each individual patient, for example in every hospital district.

Knowledge of professionals (for example physiotherapists and social workers) concerning rare diseases has to be improved. The therapy pathways of rare diseases are different, and require specialist knowledge.

Patient needs to have a personalised service plan, and their families have to be considered as an entity.

Local “communities” of rare disease patients should be built and developed. For example the hospital district could be responsible for gathering together local community of rare patients.

The main issue of these communities is coping with the everyday life, not health care and treatments. Patients with extremely rare diseases, could be involved in this way. Most patients with extreme rare diseases do not have a patient organisation of their own. This would differ from a centre of expertise, being more like a “support centre”, operating in close cooperation with centres of expertise.

Information concerning treatment of rare diseases has to be ensured to families and friends and social networks, by for example organising “first-hand information days” and different meetings. Distributing information cannot be the responsibility of patient organisations only.

SII needs to be more informed on rare diseases and injuries. SII should have responsible persons, taking care of issues of rare diseases, applications etc.

A reliable, clear and accessible database of rare diseases has to be created. A lot of information is already available, but it is scattered, in many locations and often inadequate and unreliable.

The needs of patients differ strongly, depending on disease or injury. Patients should be able to determine themselves their needs, and to be able to take part in decision making.

Payment commitment to another expert treatment facility does not realize well. The suggestions of patients themselves, concerning their treatment and treatment facilities have to be taken to consideration in a better way. Commitments have to be more available to treatment units providing best possible care and treatment for patients with rare disease. Basis of the rejection of the commitment have to be explained and dealt with patient.

Patient ombudsmen have to have more expertise on rare diseases. The roles of different professional groups (social workers, rehabilitation counsellors) in assisting patients have to be clarified and their practices unified.

The role of HARSO has to be strengthened, in a way that patients that have no patient organisation of their own, are also taken into decision making and processes. At the same time it should ensure cooperation between all patient organisations and networks. It is crucial to patients with rare diseases that objectives are common.

### Horizontal Themes

Working groups representing patient organisations discussed widely and openly, and any open questions and comments have been recorded under the five main themes. The substance of the discussions has been presented in previous chapters.

## Programme

### EUROPLAN – National Conference

Saturday, 21th September 2013, 8:30AM – 5:00PM

Hotel Holiday Inn Messukeskus, address Messuaukio 1, 00520 Helsinki, Finland

<b>8:30</b>	<b>Coffee Served</b>
<b>9:00</b>	<b><i>Opening the meeting and the basic views of national rare disease Program/ Plenary session</i></b> Katri Karlsson, chairperson of Harsory, Finnish rare disease alliance
<b>9:20</b>	<b>Basics of EUROPLAN meeting</b> Maria Gardsäter, EURORDIS EUROPLAN Advisor
<b>9:40</b>	<b><i>Greetings and Viewpoints of a working group of rare disease program in Ministry of social affairs and health in Finland</i></b> Jaakko Yrjö-Koskinen, lääkintöneuvos, STM
<b>10:00</b>	<b><i>Instructions of Workshops</i></b>
<b>10:15</b>	<b>Workshops</b> <b>Group 1: Care- clarifying care of a RD person in different periods of care process</b> <b>Group 2: Social and health care services for RD</b> <b>Group 3: Care - Rehabilitation for RD</b> <b>Group 4: Care - Centers of Expertise for RD</b> <b>Group 5: Empowerment of RD person and patient organisations</b>
<b>12:00</b>	<b>LUNCH</b>
<b>13:00</b>	<b><i>Workshop continued</i></b>
<b>14:30</b>	<b><i>Coffee Break</i></b>
<b>15:00</b>	<b><i>Discussion and summary</i></b>
<b>17:00</b>	<b><i>Closing the meeting</i></b>