

# CYPRUS

## EUROPLAN NATIONAL CONFERENCE

### FINAL REPORT

14 – 15 November 2013, Nicosia



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# 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.

## CYPRUS - EUROPLAN National Conferences 2012 – 2015

### I. General information

<b>Country</b>	Cyprus
<b>Date &amp; place of the National Conference</b>	14 – 15 November 2013. Cleopatra Hotel, Nicosia.
<b>Website</b>	<a href="http://raredisorderscyprus.com/">http://raredisorderscyprus.com/</a>
<b>Organisers</b>	Cyprus Alliance for Rare Diseases (C.A.R.D.) in collaboration with the National Committee for Rare Diseases (Ministry of Health)
<b>Members of the Steering Committee</b>	<p>Dr Androulla Eleftheriou (TIF Executive Director/C.A.R.D. Coordinator)</p> <p>Dr Violetta Christophidou Anastasiadou (Clinical Geneticist, Chair of National Committee for Rare Diseases /Cyprus EUCERD Representative)</p> <p>Dr Olga Kalakouta (Chief Medical Officer, Medical &amp; Public Health Services, Ministry of Health)</p> <p>Dr Myrto Azina (1<sup>st</sup> Class Medical Officer, Ministry of Health)</p> <p>Dr Vasos Scoutellas (Rheumatologist, Nicosia General Hospital)</p> <p>Dr Anthi Drousiotou (Head of Biochemical Genetics Department, Cyprus Institute of Neurology &amp; Genetics)</p> <p>Dr Eleni Zamba – Papanikolaou (Head of Neurology Clinic D, Cyprus Institute of Neurology &amp; Genetics, Board Member of Human Genetics Society)</p> <p>Dr Pavlos Pavlou (Director of Health Monitoring Unit, Ministry of Health)</p> <p>Georgia Karakiti, occupational therapist in replacement of dr Agathi Valanidou, Mental Health Services</p> <p>Dr Irene Kaoulla Gkasa (Pathologist, Representative of Cyprus Medical Association)</p>

	<p>Ms Christina Efstathiou - Ioannidou (Nursing Services Officer, Nursing Services, Ministry of Health)</p> <p>Ms Eleni Georgiadou (Clinical Pharmacist, Pharmaceutical Services)</p> <p>Ms Maria Ioannou (Social Inclusion Officer, Department for Social Inclusion of Persons with Disabilities, Ministry of Labour &amp; Social Insurance)</p> <p>Mrs Ioanna Mousioutta (Pan-Cyprian Volunteerism Coordinative Council)</p>
<b>List of Workshops</b>	<p><b>WORKSHOP 1: Strategy to Action Plan/ National Indicators</b></p> <p><b>WORKSHOP 2: Registries</b></p> <p><b>WORKSHOP 3: Social Inclusion</b></p> <p><b>WORKSHOP 4: Centres of Expertise &amp; European Reference Networks</b></p>
<b>Workshop Chairs and Rapporteurs</b>	<p><b>WORKSHOP 1: Strategy to Action Plan/ National Indicators</b></p> <p>Chairs: Myrto Azina &amp; Vasos Scoutellas Rapporteur: Christina Efstathiou – Ioannidou</p> <p><b>WORKSHOP 2: Registries</b></p> <p>Chairs: Pavlos Pavlou &amp; Eleni Zamba – Papanikolaou Rapporteur: Eleni Georgiadou</p> <p><b>WORKSHOP 3: Social Inclusion</b></p> <p>Chairs: Androulla Eleftheriou &amp; Pambos Papadopoulos Rapporteur: Lily Cannon</p> <p><b>WORKSHOP 4: Centres of Expertise &amp; European Reference Networks</b></p> <p>Chairs: Violetta Anastasiadou &amp; Anthi Drousiotou Rapporteur: Christina Efstathiou – Ioannidou</p>
<b>Annexes</b>	<p>I. Programme</p> <p>II. List of Participants</p>

## II. Main Report

### Overview

The Cyprus EUROPLAN National Conference for Rare Diseases was organized in the context of the EUCERD Joint Action Work Package 4, entitled National Plans, led by the Italian National Centre for Rare Diseases and supported by the European Organisation for Rare Diseases (Eurordis).

The Conference was held over 2 days on 14 & 15 November 2013, at Cleopatra Hotel in Nicosia. It was attended by 58 people, across a broad multi-stakeholder spectrum including the members of the National Committee for Rare Disorders, the Cyprus Medical Association, the major private and public universities, medical specialists and other healthcare professionals from the public hospitals and private sector, pharmaceutical companies, learned societies, patients/parents associations, and specialised healthcare centres (e.g. Cyprus Institute of Neurology & Genetics, Thalassaemia Centres, American Heart Institute, Karaiskakio Foundation - Cyprus Bone Marrow Donor Registry, Center for Preventive Paediatrics etc). In addition, a representative from the Greek Centre of Disease Control & Prevention (KEELPNO) also attended.

### Country Status

In Cyprus, the level of awareness regarding the issue concerning rare diseases (hereafter RD) both amongst the general public and the medical community is moderate. This is probably related to the small population size which makes even more the limited number of cases of a specific disease that medical specialists will encounter. Subsequently, expertise is concentrated in a few individuals and widely dispersed across health-providing centres, some being more specialised in some areas than others.

The Ministry of Health has been actively represented in various EU bodies such as the Task Force for Rare Diseases and later on in EUCERD while relevant reports have been indicating the way to the development of preparatory works (interdepartmental committee) for a national strategy in rare diseases. The establishment of the Cyprus Alliance for Rare Disorders (hereafter C.A.R.D.) in 2010 significantly enhanced patient participation and provided noteworthy momentum in advocacy issues concerning RDs in Cyprus. As a next step the Ministry of Health established a Steering Committee, in 2011, to develop a National Strategy for RDs and the inclusion of a representative of C.A.R.D., enhanced further the active participation of patients, the Cyprus Institute of Neurology and Genetics and the strong collaboration between all stakeholders. Following input from a multi-stakeholder group and public consultation of the document, the National Strategy was adopted by the Council of Ministers in November 2012. Subsequently, a National Committee for RDs was set up, comprising of 15 individuals. This is a multidisciplinary Committee, comprised of medical specialists and health professionals working in various fields, representative of the Department of Social Integration at the Ministry of Labour & Social Insurance and patient/parent association representatives.

This Committee has been commissioned to:

- Advise the Minister of Health on the development of policies for RDs;
- Develop an Action Plan based on the National Strategy, including methods of monitoring its implementation and;
- Ensure the cooperation and collaboration of all stakeholders in the promotion of this joint effort.

In light of the current economic climate and the absence of specific funds for the creation of new infrastructures and services, the Committee has taken upon itself to focus on raising public awareness and educational activities, whilst promoting the implementation of specific goals outlined in the National Strategy (See section 1.3.), taking into account the lack of significant funds available for their materialisation.

### **Aims of the National Conference**

In this context, the organisation of a National EUROPLAN Conference in Cyprus aimed to:

- Revisit the policy and public service issues concerning RDs since the National Strategy had been adopted;
- Inform a wide range of stakeholders on the status quo regarding RDs;
- Assessing the impact of the financial crises on patients' rights & services;
- Bring to the forefront the developments on the European level since the public consultation in early 2012 – specifically the EUCERD Recommendations and the implementation of the EU Cross-border Health Care (CBHC) Directive;
- Focus on specific areas that require significant developments in Cyprus, such as Monitoring Indicators, Registries, Social Services, Centres of Expertise & European Reference Networks.

The Conference reflected these aims both in the plenary session and in the workshop discussions.

### **National Conference Overview**

The Plenary Session, comprised of two Keynote Speeches, focused mainly on the transition from a Strategy to an Action Plan with Prof. Odile Kremp (Director of Orphanet) providing the experience of the French National Plans. Furthermore, in order to provide the perspective on an EU level, Ms Lily Cannon (Eurordis/EUROPLAN Advisor) presented the EU Essential Documents for RDs. This incorporated a description of the EUCERD Joint Action, including the Work Package for National Conferences, the EUCERD Recommendations and most importantly the Council Recommendation on an action in the field of rare disorders (2009/C 151/02). Thus, these two presentations provided the participants of the National Conference with the experience of another country whilst at the same time offering a practical example of the transition from theory to action. In addition, the EU Documents for RDs granted the audience an up-to-date knowledge on current initiatives and recommendations at the EU level.

The Workshops were characterised by extremely productive and lively discussions in all areas. Following the Plenary Session, there were 4 consecutive Workshops to cover the topics/themes mentioned on page 2 of this report. All participants took part in all Workshops. Members of the National Committee for RDs and C.A.R.D. acted as Chairs and Rapporteurs for each Workshop. At the end of each Workshop the conclusions from the discussion were presented by the Rapporteur. The Horizontal themes of Sustainability, Patient Empowerment and Gathering Expertise on RDs were incorporated and discussed in all Workshops.

The summary of all Workshops, in accordance to theme are presented below.

## Report of Workshops

### Theme 1 - Methodology, Governance and Monitoring of the National Plan

#### WORKSHOP 1: Strategy to Action Plan/ National Indicators

The Workshop was initiated by a presentation from Dr Vasos Scoutellas on the EUCERD Recommendations on Core Indicators for RD National Plans/Strategies, providing background content for the discussions which followed.

The discussion, facilitated by Dr Myrto Azina, focused on the questions/topics posed in the Content Guidelines for 'Theme 1 - Methodology, Governance and Monitoring of the National Plan' (<http://download.eurordis.org.s3.amazonaws.com/rdpolicy/CG-THEME1-GOVERNANCE.pdf>). The questions/topics for discussion were translated into Greek prior to the Conference by the Secretariat of C.A.R.D. and distributed to participants. The Workshop Chairs had preselected several questions/topics on which to focus the discussion on.

In the case of this Workshop, please find below the sub-themes focused on and the responses from the discussion:

#### **1.1. Mapping policies and resources**

The level of awareness on RDs in Cyprus is rather minimal amongst the medical community, policy-makers and the wider society, as the area of focus is more on common diseases with larger patient populations. Furthermore, educational initiatives on RDs for healthcare professionals are sometimes met with resistance, as there is an intricate belief that more attention should be given to those diseases that affect more members of the public. This yields issues regarding the importance of multidisciplinary teams and groups as opposed to health professionals and medical experts today, who often do not communicate with each other to exchange ideas, knowledge and expertise.

The discussion in the Workshop brought forward several perceptions with regards to the awareness amongst the medical community on RDs. Indeed, so far RDs have not been included in the continuous education programme of the Ministry of Health. However, the National Committee for RDs has begun an educational campaign in the form of lectures from members of the Committee or other experts, for medical and paramedical specialists in public and private hospitals as well as for students of the medical and nursing university schools. As a consequence of this important campaign, which has demonstrated the importance of RDs, the Cyprus University of Technology (CUT) which houses the Nursing School, regularly includes in its curriculum training related to RDs, especially where screening, genetic counselling and prenatal diagnosis are concerned. Moreover, in certain cases, patients or parents inform doctors and health professionals regarding their RD and indicate pathways for further information which they can consult.

With respect to the level of awareness amongst policy-makers and the general public, there is considerable room for improvement with the National Committee for RDs, patient organisations and individual experts making significant efforts to raise awareness for RDs, e.g. publications, media, campaigns etc.

Perceptions on the evaluation and assessment of the unmet needs of patients are conflicting. Although during medical and other appointments an assessment of needs is conducted, often the lack of cooperation by the involved parties or the inadequate infrastructure leaves patients feeling isolated and unheard. Furthermore, in many cases it is unclear where one has to go to find the right information.

## **1.2. Development of a National Plan /Strategy**

As mentioned previously, a National Strategy has been adopted in Cyprus since November 2012: ([http://www.moh.gov.cy/MOH/MOH.nsf/All/CD61A07312284C0A422579DC0023AF8A/\\$file/Strategic%20Plan%20Rare%20Diseases.pdf](http://www.moh.gov.cy/MOH/MOH.nsf/All/CD61A07312284C0A422579DC0023AF8A/$file/Strategic%20Plan%20Rare%20Diseases.pdf))

The Strategy was developed based on the Council Recommendation on an action in the field of rare diseases (2009/C 151/02) covering the 7 areas outlined therein:

<http://eurlex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2009:151:0007:0010:EN:PDF>

- (i) The development of National Plans and Strategies
- (ii) Adequate definition, codification and inventorying of rare diseases
- (iii) Research on Rare Diseases
- (iv) Centres of Expertise & European Reference Networks for Rare Diseases
- (v) Gathering the expertise on rare diseases at European level
- (vi) Empowerment of patient organisations
- (vii) Sustainability



In the context of implementing the proposed actions of the Strategy, the National Committee on RDs is working towards the development of an action plan (see page 5 of this Report).

### **1.3. Structure of a National Plan /Strategy**

The National Strategy on Rare Diseases, drafted by a Steering Committee in 2011/12 and adopted by the Council of Ministers in November 2012 identifies in a clear, transparent way the existing infrastructures and services provided, in addition to making concrete proposals as to ways to move forward. The Strategy is structured across the 5 pillars as follows:

- (i) Prevention and Screening
- (ii) Early Diagnosis and Treatment
- (iii) Support Services and Integration
- (iv) Registries and Codification
- (v) Research

A detailed description of the status quo of each pillar is contained within the document as well as specific and general proposed measures to move forward.

These are found below.

#### **PILLAR 1: Prevention & Screening**

*Inform / sensitize / educate the public through:*

- Public awareness programs
- Health Education / Promotion
- Integration of genetic counseling programs before having children
- Strengthening public participation in awareness programs before and during pregnancy
- Education for specific groups
- Training of health professionals

*Strengthening existing services:*

- Development of provided services
- Strengthening of the relationship between the Ministry of Health and other European and International Organizations
- Development of services of prenatal invasive medicine
- Strengthening existing services of Genetic Counseling
- Strengthening Environmental Control Services

*Population and Screening programs:*

- Strengthening existing screening programs
- Evaluation and expansion of screening programs of newborns
- Detection of high-risk groups

PILLAR 2: Early Diagnosis & Treatment

- Education and training of health professionals
- Further upgrading and enhancing existing related services and improving their accessibility
- Developing new services
- Reinforcement and introduction of multidisciplinary and scientific cooperation aimed at the comprehensive / holistic treatment of RDs
- Introducing new evidence-based screening programs for the population
- Recognition of existing centers of excellence and expertise on RDs
- Networking, European Reference Networks and International cooperation
- Introduction of practices and legislative regulations for accessing the necessary therapeutic interventions
- Creating awareness, informing and educating patients/the public and empowering and involving patients in various activities

PILLAR 3: Support Services & Integration

- Strengthening of psychological support
- Establishment of a special identity card for patients with rare diseases
- Involvement of the local municipalities or community boards
- Creation of multidisciplinary rehabilitation centers
- Further improvement of social welfare services offered by the Ministry of Labour and Social Insurance
- Patient Networking
- Development of Respite and Care Services
- Creation of multidisciplinary groups
- Development of structured palliative care services
  - Creation of a Coordinating Body
  - Education
  - Creation of a Homecare Network
  - Creation of a Palliative Care Centre
- Create Rehabilitation Service

#### PILLAR 4: Registries and Codification

- Formation of a Steering Committee / Coordinating body
- Feasibility Study
- International Collaborations
- Catalogue for Orphanet / ICD-11
- Creation of basic records for Rare Diseases
- Management of existing files
- Interlinking Records
- Adaptation of information systems
- Ability to register/record rare diseases

#### PILLAR 5: Research

- Increase of available resources for research
- Better use of existing resources
- Improve the level of networking and cooperation with the scientific and medical community in Cyprus and abroad
- Create Awareness for the need for research
- Active involvement of patients in research and specifically in decision-making.

Following the adoption of the National Strategy by the Council of Ministers, a National Committee for RDs was commissioned in order to formulate an action plan with clear timelines and deliverables. This Committee has been working since January 2013.

#### **1.4. Governance of a National Plan**

A National Committee has been appointed in January 2013, by the Minister of Health. It primarily has an advisory role towards the Minister of Health regarding the implementation of the RD strategy. It is a multi-stakeholder committee comprised of 14 individuals from across various disciplines and stakeholder groups that involve RDs including:

Paediatrics and Clinical Genetics

Medical & Public Health Services

Ministry of Health

( Adults Health Services ) Rheumatology

Biochemical Genetics (The Cyprus Institute of Neurology and Genetics)

Neurology (the Cyprus Society of Human Genetics Health Monitoring Unit, MOH

Mental Health Services

Pharmaceutical Services Clinical Pharmacology

Pathology (National Medical Association)

Nursing Public Nursing Services

Patients/Parents

Volunteers

This Committee has been commissioned to:

- (i) Advise the Minister of Health on the development of policies for RDs;
- (ii) Develop an Action Plan based on the National Strategy, including methods of monitoring its implementation and;
- (iii) Ensure the cooperation and collaboration of all stakeholders in the promotion of this joint effort.

Meetings are conducted once every two months, with the greatest transparency. An agenda is circulated prior to the meeting allowing members to prepare and the minutes, along with actions expected by each member, with clear deadlines are sent afterwards. An officer of the Ministry of Health has been assigned as the official Secretariat.

Members have been allocated, in accordance to their expertise, to Workgroups defined by the main themes of the National Strategy i.e. prevention & early diagnosis, treatment, social inclusion, research, registries/codification. Patient representatives are actively involved in all actions and decisions taken by the National Committee.

### **1.5 Dissemination and communication on the National Plan**

The National Strategy for RDs is available for public view on the website of the Ministry of Health.

The National Committee for RDs, commissioned to oversee the implementation and monitoring of the National Strategy, has already began to approach learned societies, professional associations and universities advocating for the inclusion of RDs in their educational events and initiatives. In addition, patient associations play a huge role of invaluable significance in providing information to the general public, especially through use of their own websites, social networking pages, and the media. In addition, more mature associations have proceeded to providing guidelines for health professionals.

### **1.6 Sustainability of the National Plan**

There is no specific budget allocation for the National Strategy for RDs in Cyprus.

The identification and acquisition of alternative funding sources is imperative for any RD activities in Cyprus in the context of the National Strategy. The discussion acted as a brainstorming exercise, with participants advocating for greater inclusion in the European Structural Funds (2014- 2020) and the Local Administration Grants provided in Cyprus. These would assist in the development of infrastructures that would truly help not only patients but also their families, medical specialists and carers.

## WORKSHOP PROPOSALS

- Development of a single portal to provide information for healthcare professionals;
- Closer collaboration of all stakeholders with the National Committee for RDs, in the context of developing/organising educational initiatives;
- Material developed by patient associations, especially for healthcare professionals, can be incorporated in the Orphanet Cyprus page;
- Raising awareness campaigns should be conducted in collaboration with the media, e.g. informative documentaries etc;
- Organise educational events at schools with the support of the Ministry of Education and parent-teacher associations. The audience could be pupils, teachers or even parents;
- Patient associations should recognize the benefits of joining C.A.R.D., both in terms of advocacy but also in joint projects that could secure financial contribution from the EU.

## Theme 2 - Definition, codification and inventorying of RD

### WORKSHOP 2: Registries

The Workshop was initiated by a presentation from Dr Pavlos Pavlou.

The presentation followed the template presentation on Theme 2 (<http://download.eurordis.org.s3.amazonaws.com/rdpolicy/PPT-THEME2-DEFINITION-CLASSIFICATION.pdf>), discussing the main documents concerning this Workshop (i.e. Council Recommendation on an action in the field of RDs and the EUCERD Recommendations on Core Indicators for RD National Plans/Strategies) providing background content for the discussions which followed. Furthermore, reference was made to the current situation in Cyprus with regards to Registries, which was the focus of this Workshop.

The discussion, facilitated by Dr Eleni Zamba-Papanicolaou, focused on the questions/topics posed in the Content Guidelines for *'Theme 2 - Definition, codification and inventorying of RD'*. The questions/topics for discussion were translated into Greek prior to the Conference by the Secretariat of C.A.R.D. and distributed to participants. The Workshop Chairs had preselected several questions/topics on which to focus the discussion on.

In the case of this Workshop, please find below the sub-themes focused on and the responses from the discussion:

**2.1. Definition of RD**

Cyprus has formally adopted the definition of RDs as laid out in Council Recommendation on an action in the field of RDs (2009/C 151/02) and in the Orphan Medicinal Products Regulation (141/2000/EC), as 1 in every 2000 people.

Disorders such as thalassaemia, that are indigenous and highly prevalent in Mediterranean countries, such as Cyprus, and lie on the ‘fringes’ of the RD definition, are included in the National Strategy for RDs. Further to the fact that the voice of patients with thalassaemia in Cyprus have a long history and great expertise since in addition to the Cyprus Thalassaemia Association, the Headquarters of the Thalassaemia International Federation (TIF) are also located in Cyprus, both these associations are amongst the founding members of C.A.R.D. Due to the implementation of a national programme for thalassaemia in 1983, the number of patients has severely declined over the past two decades. Subsequently, thalassaemia now lies just outside the definition of RDs. However, this should not be a reason to exclude them from RDs as they are not as frequent as other diseases. The National Strategy for RDs makes clear references to the inclusion of thalassaemia as well as to other disorders that are equally multifaceted and require a complex, multidisciplinary approach.

**2.2 Codification of RD and traceability in national health system**

Cyprus uses a classification system entitled ICD-10 CY which was prepared in collaboration with the Health Insurance Organisation through a DRG system. Unfortunately this does not cover RDs.

The Orpha code is not used; however, it is crucial that it is utilized in order to increase the visibility and traceability of RDs in Cyprus.

Cyprus is a member of Orphanet with a dedicated site administered by the Genetics Clinic at the Archbishop Makarios III Hospital, headed by Dr Violetta Anastasiadou.

The Statistical Service in collaboration with the Ministry of Health is the responsible body for the implementation of the ICD-11, once it is finalized by the World Health Organisation.

**2.3 Registries and databases**

There are only a few centrally operating registries in Cyprus at the moment (e.g. for cancer, cause of death, mammograms etc). There are nevertheless a number of registries at specialised hospital clinics. The data in these registries, both central and local, has yet to be evaluated as codification has not yet been completed. In addition, although identity card numbers are used to identify each person, there are a few instances of duplication. Hence, there is a need to determine a unique number for each diagnosis rather than patient (one patient may be diagnosed with more than one RD).

There is legislation currently pending to formalize the Health Monitoring Unit, at the Ministry of Health, as the central body for collecting and handling data. This needs to take into account the

confidentiality of information as well as mechanisms for the correct inputting of data to avoid duplications and overlapping. These constituent parts are imperative for correct and valid data to be used and extrapolated for epidemiological and other uses.

The inputting of data should be conducted by specially trained professionals rather than health professionals and medical specialists who have a multitude of responsibilities. The submission of data should be done by dedicated individuals with statistical and information technology knowledge.

In addition, information should also be collected from the private sector.

#### **2.4. Information on available care for RDs in general, for different audiences**

Several patient associations are equipped with their own websites and/or social networking sites which provide information to patients and their families. In addition, larger associations, with funds, are able to organise information workshops, publish educational material etc. Several associations are informed of European and international news via EURORDIS and/or Orphanet, but many are not aware of these portals.

Rare Disease Day is commemorated each year by C.A.R.D. since 2009 and in recent years in collaboration with the Steering Committee for RDs (2012) and National Committee for RDs (2013).

A significant number of patient associations have unofficial registries, maintained on a volunteer basis.

Networking between patient organisations is achieved mainly at events and in an informal environment.

#### **2.5 Help Lines**

National help lines for specific RDs or group of RDs do not exist. Several patient associations or individual patients may respond to requests on an ad hoc basis, directing persons to the best of their knowledge what to do or where to go, but this is not a formal service. Some patient associations engage the services of psychologists or social workers to support families but not in the sense of a help line.

Help lines for health professionals are non-existent.

A lack of coordination, funding and networking were identified as the main reasons for this.

## **2.6 Training healthcare professionals to recognise and code RD**

There is a need to train and educate healthcare professionals on the importance of classification and codification of RDs.

The presence of medical schools in the public and private sector enables education on the importance of registries, codification and classification to begin early on. Indeed, participants suggested investigating the possibility of including this subject in the curriculum.

The discussion furthermore focused on methods of training practicing healthcare professionals. Several suggestions were put forward such as a workshop on codification for healthcare professionals in collaboration with the Cyprus Medical Association in order to ensure participation.

### **WORKSHOP PROPOSALS**

- Development of a national registry for RDs, taking into account issues of funding, administration and infrastructure development;
- Use of Orpha code in existing registries, at least until ICD-11 is available and its implementation begins;
- Legislation for the determination of a unique identification number for each case. This can be the identity card number, passport number, social security number etc;
- Actions on behalf of the National Committee for RDs to the Parliament for amendments to the legislation regarding the assignment of the Health Monitoring Unit as the central body responsible for all registries, in order to make the use of the Orpha Code in registries mandatory;
- Identification of dedicated individuals, specifically trained professional in charge of inputting data in the registry;
- Organisation of a series of educational workshops on registries, codification and classification for healthcare professionals;
- Investigation to include a module on registries and codification in the curriculum of the medical schools located in Cyprus.



## Theme 4 – Care for RDs - Centres of Expertise and European Reference Networks for Rare Diseases

### WORKSHOP 4: Centres of Expertise & European Reference Networks

The Workshop was initiated by a presentation from Dr Violetta Anastasiadou on Centres of Expertise (hereafter CE) and European Reference Networks (hereafter ERN), discussing the EUCERD Recommendations on Quality Criteria for Centres of Expertise for RDs and the CBHC Directive, thus providing background content for the discussions which followed.

The discussion, facilitated by Dr Anthi Drousiotou, focused on the questions/topics posed in the Content Guidelines for *'Theme 4 – Care for RDs - Centres of Expertise and European Reference Networks for Rare Diseases'* (<http://download.eurordis.org.s3.amazonaws.com/rdpolicy/CG-THEME-4-CoEs-ERNS-STANDARDS-of-CARE.pdf>). The questions/topics for discussion were translated into Greek prior to the Conference by the Secretariat of C.A.R.D. and distributed to participants. The Workshop Chairs had preselected several questions/topics on which to focus the discussion.

In the case of this Workshop, please find below the sub-themes focused on and the responses from the discussion:

#### 4.1 Designation and evaluation of CE

There are no designated CE in Cyprus. However, many centres function in accordance, to a greater or lesser extent, to the quality criteria defined by the EUCERD. Formal evaluation by a central body does not take place but many centres, upon evaluation, would be found to meet most of the quality criteria and as such be designated as CE. The added value of developing and designating CE must be recognized by the government and specifically the Ministry of Health. The strengthening and further developing of existing centres will not only benefit the public, but will primarily lead to a reduction of expenses as planning of services will be more targeted. Unfortunately, decisions in the healthcare field are made based on the number of patients rather than the needs of patients.

Regarding the level of expertise on RDs in Cyprus, opinions are divergent. Participants agreed that there is a level of expertise both in the private and public sector; however, due to the small population and therefore limited number of cases it is difficult to determine 'expertise' as such.

A preliminary mapping of services which provide expertise on RDs was conducted by the Steering Committee in 2011/12 when drafting the National Strategy for RDs. For example, the Cyprus Institute of Neurology and Genetics (hereafter CING) which concentrates most of the rare

neurological diseases in terms of treatment, diagnosis and research is equipped with a high level of expertise and provides continuous professional development to healthcare professionals on all these aspects. It also provides diagnostic laboratory services and carries out research on a large number of rare diseases. In addition, the Cyprus Thalassaemia Centre is endowed with immense expertise on all aspects of the disease (diagnosis, treatment, prevention, monitoring etc). However, despite these 'hubs' of expertise, there is a significant lack of coordination in the form of an umbrella-body.

A Committee will be commissioned by the Council of Ministers in order to determine national criteria for designating CE. This Committee should take into consideration the EUCERD Recommendations on Quality Criteria for CE for RDs and should be comprised of experts in this field with the necessary expertise. The opportunity should be provided to interested centres to present their candidacy. Furthermore, Cyprus should be one of the compulsory members of ERN due to its small size.

Taking into account findings of the preliminary mapping of services, the best way to rationalise existing resources rather than creating new ones, whilst at the same time ensuring compliance to the agreed quality criteria, is to coordinate activities and promote the organisation of services in addition to updating and expanding existing services.

Patient participation and representation in decision-making processes is increasing (e.g. National Strategy for RDs, National Action Plan for Rheumatic Disorders etc). As the endreceivers of services, it is therefore expected and mandatory that patients are actively represented in the designation processes. Patients/parents are able to provide valuable insights to the daily use of services thus providing valuable support. On a European level, support for the development new, or strengthening of, existing services is patient satisfaction; therefore patient involvement in throughout the course of the procedure is imperative.

Formal assessments and accreditation by external evaluators is conducted at regular intervals in some centres (e.g. CING, Karaiskakio Foundation – Cyprus Bone Marrow Donor Registry). Other centres should seek out assessment and accreditation.

#### **4.2 Scope and functioning of CEs**

The scope of CE needs to be defined. The definition and scope outlined in the EUCERD Recommendations for Quality Criteria for CE for RDs should be taken into account but a national definition and scope should be sought. This must reflect the distinctiveness of Cyprus as a small country, with a specific expertise and a limited number of cases per disease. Indeed some diseases are not represented at all. Therefore the definition and scope need to be clear but flexible with mechanisms to adjust accordingly. CE should be inclusive, providing access to care for all RD

patients, rather than exclusive to pre-determined disorders and/or disease areas.

A vivid discussion ensued during this Workshop, on the most appropriate way to measure the level of clinical expertise. At the international level, expertise is most commonly measured in accordance to the number of peer reviewed articles published by the medical specialist. However, in areas/regions/countries, such as Cyprus, where there is a scarcity of patients and resources, the number of publications may not be representative of the clinical experience. Medical specialists in such areas/regions/countries are more focused on providing healthcare services.

The transfer of expertise from CE to primary healthcare clinics is currently done on an ad hoc basis.

#### **4.3 Good practice guidelines**

Good practice guidelines are available in many cases and must be implemented by healthcare professionals; however, these should not limit the care provided to the patient. Furthermore, patient associations in collaboration with the medical community often publish good practice guidelines and distribute them accordingly (e.g. Thalassaemia International Federation, Cyprus Primary Immunodeficiency Association & Friends, Cyprus Antirheumatic Association, Myasthenia Gravis Association etc).

A dedicated legislation or procedure should be put in place together with the designation of CE, directing the centres to follow good practice guidelines.

#### **4.4 Diagnostic and genetic testing**

Specialist labs at the CING, Cyprus Thalassaemia Centre and Karaiskakio Foundation –Cyprus Bone Marrow Donor Registry- have been collaborating and networking with other CE abroad for many years.

Genetic testing and genetic counselling should be legislated in Cyprus, as should the assessors of the results, as there are currently gaps in their provision.

#### **4.5 Screening policies**

Nationwide schemes for population screening (thalassaemia carriers), neonatal screening and prenatal diagnosis have been in place in Cyprus for more than twenty years. A National Committee for Newborn Screening has been formed for evaluating the current neonatal screening programme in Cyprus and making suggestions for a possible expansion, bearing in mind the report of the EU tender “Evaluation of population newborn screening practices for rare disorders in Member States of the European Union”.

#### **4.6 European and international collaboration – Cross-border healthcare and ERNs (European Reference Networks)**

Some centres have already established close collaboration and networking with expert centres in Europe and beyond. Networking where possible, occurs also within Cyprus between centres (e.g. CING and Cyprus Thalassaemia Centre).

#### **4.7 Sustainability of CEs**

The collaboration of all stakeholders and pooling of resources (government, specialists, patient associations) will enable the sustainability for CE. In accordance to the criteria for the establishment of CE's, sustainability should be ensured by the joint contribution of the government and the individual centre, in addition to any supplementary funds obtained via research proposals and participation in national/regional/international consortia.

#### **WORKSHOP PROPOSALS**

- The National Committee for RDs to monitor developments at the Ministry of Health with regards to the establishment of a Committee to define the national criteria for CE and once the Committee is in place, advocate for the consideration of the EUCERD Recommendations on Quality Criteria for CE for RDs to be taken into account. In addition, it was suggested that the possibility of a representative of the National Committee for RDs to observe the discussions should be investigated;
- C.A.R.D. must ensure patient representation during the entire process of determining national criteria for CE and the eventual assessment and designation of CE;
- A dedicated legislation or procedure should be put in place along with the designation of CE, directing the centres to follow good practice guidelines.

### **Theme 6 –Social Services for Rare Diseases**

#### **WORKSHOP 3: Social Inclusion**

The Workshop was initiated by a presentation from Mrs Dorica Dan on the importance of social inclusion, outlining the initiatives at the European level on specialised social services including the dedicated Work Package in the EUCERD Joint Action. This was followed by a presentation from Dr Androulla Eleftheriou in accordance to the template presentation on Theme 6 (<http://download.eurordis.org.s3.amazonaws.com/rdpolicy/PPT-THEME6-SOCIAL-SERVICES-for-RD.pdf>), discussing the main documents concerning this Workshop (i.e. Council Recommendation on an action in the field of RDs and the EUCERD Recommendations on Core Indicators for RD National Plans/Strategies), thus providing background content for the discussions which followed.

The discussion, facilitated by Dr Androulla Eleftheriou, focused on the questions/topics posed in the Content Guidelines for *'Theme 6 –Social Services for Rare Diseases'*. The questions/topics for discussion were translated into Greek prior to the Conference by the Secretariat of C.A.R.D. and distributed to participants. The Workshop Chairs had preselected several questions/topics on which to focus the discussion on.

In the case of this Workshop, please find below the sub-themes focused on and the responses from the discussion:

### **6.1. Social resources for people with disabilities**

Persons and families with disabilities are supported by a dedicated department, the Department for Social Inclusion of Persons with Disabilities ([http://www.mlsi.gov.cy/mlsi/dsid/dsid.nsf/index\\_en/index\\_en?OpenDocument](http://www.mlsi.gov.cy/mlsi/dsid/dsid.nsf/index_en/index_en?OpenDocument)) at the Ministry of Labour and Social Insurance. The services provided by this Department are primarily monetary benefits and there are no specific schemes that are targeted to the needs of persons with RDs.

Support is also provided by other Ministries, such as Medical Cards entitling patients to free or subsidized healthcare provided by the Ministry of Health.

At the moment, the acute financial crisis has mandated drastic reforms both at the Ministry of Labour and Social Insurance and at the Ministry of Health. Subsequently, many benefits are being slashed. There is an increasing focus on meeting budget targets than providing services required by patients and their families. Due to the complexity of RDs, a plan should be implemented to differentiate disabilities arising due to RDs.

The flexibility of services to adapt to the needs of RD patients is rather limited. Departments are staffed with transient officers moving on to other posts within a few months; hence the staff are uninformed both with regards to individual cases as well as the complexity of diseases. At a particular disadvantage are those with asymptomatic diseases where the disability cannot be objectively assessed (e.g. back pain).

The design and implementation of a new system of assessing disability and functioning and the development of a national disability registry are already underway. These aim to establish a scientific, reliable and credible database for the assessment of disability and functioning that is commonly accepted and used by state services.

A mapping of social services available to persons with RDs was conducted in the context of

drafting the National Strategy. However, due to alterations in the availability of services, this needs to be amended. This will enable decision-makers to identify the gaps and make provisions to bridge them. There is a need however for society to move from a benefit-based model to a service-based model, thus investing in infrastructures.

The absence of one coherent list of social services available to patients with RDs including those from the public sector but also private sector initiatives, makes it extremely difficult for patients and their families to be informed of their rights. A trans-ministerial committee to ensure the collaboration of all government departments is necessary in order to coordinate these efforts.

## **6.2. Specialised social services for rare diseases**

There are services available; however, these are in the form of monetary benefits with the purpose that patients will purchase the necessary services required. Moreover, where service structures exist they are not specialised for RDs.

Several initiatives were referred to in the discussion such as adapted housing for persons with mental retardation that is supported by volunteers, school escorts etc. In addition, the absence of respite care centres was duly noted. The development of respite care centres was attempted by patient associations in the past; however, due to the complexity of organisation and necessary resources, these were not successful.

Special management and education needs must be identified by both the Ministry of Health and Ministry of Labour and Social Insurance. A collaborative and cooperative approach is necessary in order to fully understand the breadth of issues which concern RD patients, including medical aspects, but also issues of disability, social and occupational inclusion. Basic initiatives from patient organisations are available but these do not universally cover all the arising necessities. Decision-makers need to understand the added value of developing specialised service centres and to move towards the coordination of existing services and the creation of supplementary ones. The absence of representatives from the individual departments of the Ministry of Labour and Social Insurance at the National Conference is indicative of the lack of recognition of the issues at hand.

The development of specialist services is imperative to meet the growing needs of RD patients. It is important that these efforts are coordinated so duplication is avoided and resources are utilized more appropriately. An accurate mapping of available services and sociological research can assist the work of identifying gaps that need to be filled.

### **6.3. Policies to integrate people living with rare diseases into daily life**

At present, the available services are not adequately visible within the system and this means that judgements cannot be made about the needs of patients with RDs and their families, nor can decisions be put implemented to develop or strengthen services.

There are several policies in place, e.g. Co-ordinating Early Childhood Intervention Service for young children with developmental disorders, supporting the inclusion of children into education. These are joint initiatives of the Ministry of Health and Ministry of Education. Other such policies include the availability of specialist physiotherapists, speech therapy, special education programmes, companions for children with special needs etc. None of these are working superbly but they maintain an adequate level of activity.

Furthermore, persons with disabilities are also provided with laptops, ramps for the support of their educational and/or professional capabilities.

A scheme based on early intervention aimed at children 0–6 years with developmental challenges was developed independently of the Ministry of Labour and Social Insurance. However, it is now in its final stages, due to a lack of funding for its long-term sustainability, and it must be shut down.

These are schemes of added value to patients with RDs and their families; however, actions need to be taken to create more coordinated programmes with adequate funding, thus ensuring sustainability.

### **6.4. International–supranational dimension**

The actual definition of ‘disability’ in the legislation presents obstacles for patients with RDs. The introduction of the new method of measuring and assessing disability and functioning will go a long way to improve the situation. This is expected to be implemented in early 2014.

Networking and collaboration with other service providers across the EU will be of immense benefit to patients and families who feel marginalised and isolated.

There is an array of available services in Cyprus, both in the public and private sector; yet, there is a lack of understanding of the true needs of persons with disabilities. Therefore, a common and united voice needs to be engaged along with a prioritisation of needs, taking example from European counter-parts such as France, Denmark, Romania, Sweden, to name a few.

## **WORKSHOP PROPOSALS**

- Engage in more frequent and productive collaboration with the Ministry of Labour and Social Insurance, and in particular the Department for Social Inclusion of Persons with Disabilities, in order to inform and sensitize policy-makers about RDs;
- Support the implementation of the new system of assessing disability and functioning;
- Repeat the mapping of social services available, including public and private sectors, aiming to develop a single, comprehensive list of all available resources;
- Establishment of a trans-ministerial committee to ensure exchange of information and cooperation;
- Collaboration with specialised services in other European countries – networking with other service providers;
- Patient associations should present a stronger and unified voice to decision-makers (Parliament and Ministers) in order to recognise the importance of building long-term infrastructures rather than providing basic monetary solutions.

## **Report of the Closing Session – Conclusions**

The Workshops took into account all the major European policies and recommendations, and proposals aspired to work along their predicaments, whilst tailoring them to the national situation.

Feedback from the Rapporteurs to the plenary took place at the end of each Workshop and the proposals are outlined within the body of this Report. A summary of these proposals, in accordance to theme are provided below:

### **Theme 1 - Methodology, Governance and Monitoring of the National Plan**

- Development of a single portal to provide information for healthcare professionals;
- Closer collaboration of all stakeholders with the National Committee for RDs, in the context of developing/organising educational initiatives;
- Material developed by patient associations, especially for healthcare professionals, can be incorporated in the Orphanet Cyprus page;
- Raising awareness campaigns should be conducted in collaboration with the media, e.g. informative documentaries etc;
- Organise educational events at schools with the support of the Ministry of Education and parent-teacher associations. The audience could be pupils, teachers or even parents;
- Patient associations should recognize the benefits of joining C.A.R.D., both in terms of advocacy, but also in joint projects that could secure financial contribution from the EU.



### **Theme 2 - Definition, codification and inventorying of RD**

- Development of a national registry for RDs, taking into account issues of funding, administration and infrastructure development;
- Use of Orpha Code in existing registries, at least until ICD-11 is available and its implementation begins;
- Legislation for the determination of a unique identification number for each case. This can be the identity card number, passport number, social security number etc;
- Actions on behalf of the National Committee for RDs to the Parliament for amendments to the legislation regarding the assignment of the Health Monitoring Unit, at the Ministry of Health, as the central body responsible for all registries, in order to make the use of the Orpha Code in registries mandatory;
- Determination of dedicated individuals for inputting of data in the registry;
- Organisation of a series of educational workshops on registries, codification and classification for healthcare professionals;
- Investigation to include a module on registries and codification in the curriculum of the medical schools located in Cyprus.

### **Theme 4 – Care for RDs - Centres of Expertise and European Reference Networks for Rare Diseases**

- The National Committee for RDs to monitor developments at the Ministry of Health with regards to the establishment of a Committee to define the national criteria for CE and once the Committee is in place, advocate for the consideration of the EUCERD Recommendations on Quality Criteria for CE for RDs to be taken into account. In addition, it was suggested that the possibility of a representative of the National Committee for RDs to observe the discussions should be investigated;
- C.A.R.D. must ensure patient representation during the entire process of determining national criteria for CE and the eventual assessment and designation of CE;
- A dedicated legislation or procedure should be put in place along with the designation of CE, directing the centres to follow good practice guidelines.

### **Theme 6 –Social Services for Rare Diseases**

- Engage in more frequent and productive collaboration with the Ministry of Labour and Social Insurance, and in particular the Department for Social Inclusion of Persons with Disabilities, in order to inform and sensitize policy-makers about RDs;
- Support the implementation of the new system of assessing disability and functioning;
- Repeat the mapping of social services available, including public and private sectors, aiming to develop a single, comprehensive list of all available resources;
- Establishment of a trans-ministerial committee to ensure exchange of information and cooperation;

- Collaboration with specialised services in other European countries – networking with other service providers;
- Patient associations should present a stronger and unified voice to decision-makers (Parliament and Ministers) in order to recognise the importance of building long-term infrastructures rather than providing basic monetary solutions.

## Annexe I - Final Programme of the National Conference



# EUROPLAN NATIONAL CONFERENCE - CYPRUS

Cleopatra Hotel – Aphrodite Hall  
14 – 15 November 2013

## Programme

### DAY 1: Thursday 14 November

#### 08.00 – 08.10 Welcome Messages

Panos Englezos (C.A.R.D. President)  
Violeta Anastasiadou (Chairman National Committee on RDs)

08.10 – 08.15 Introduction: EUROPLAN National Conference Structure (Androulla Eleftheriou – Coordinator of C.A.R.D. )

#### 08.15 – 09.00 Keynote Presentations

08.15 – 08.35 Development on an Action Plan (*O.Kremp – Head of Orphanet*)  
08.35 – 09.00 EU Essential Documents (*L. Cannon – Eurordis, Europlan Advisor*)

#### 09.00 -11.00 WORKSHOP 1: Strategy to Action Plan/ National Indicators

Chairpersons: Myrto Azina – Vasos Scoutellas

09.00 – 09.15 Presentation: Core Indicators for National Rare Disease Plans/ Summary of experience from Rome Conference, March 2013 (*Vasos Scoutellas*)

09.15 – 11.00 Discussion and completion of relevant questionnaire based on Content Guidelines

**11.00 – 13.00 WORKSHOP 2: Registries**

Chairpersons: Pavlos Pavlou – Eleni Zampa-Papanikolaou

11.00 – 11.15 Presentation: Activities/Actions/Programmes to date (*Pavlos Pavlou*)

11.15 – 13.00 Discussion and completion of relevant questionnaire based on Content Guidelines

**13.00 – 13.45** Conclusions from morning workshops

Workshop 1: Myrto Azina

Workshop 2: Eleni Zampa-Papanikolaou

**13.45 – 14.30** ~~ Lunch ~~

**14.30 – 16.30 WORKSHOP 3: Social Inclusion**

Chairpersons: Androulla Eleftheriou – Pambos Papadopoulos

14.30 – 14.50 Special Presentation: The importance of social inclusion (*Dorica Dan*)

14.50 – 15.05 Presentation: Activities/Actions/Programmes to date (*Androulla Eleftheriou*)

15.05 – 16.30 Discussion and completion of relevant questionnaire based on Content Guidelines

**16.30 – 17.00** Conclusions from afternoon workshops

Workshop 3: Pambos Papadopoulos

**17.00** End of 1<sup>st</sup> day

**Day 2: Friday 15 November**

**08.00 – 10.00 WORKSHOP 4: Centres of Excellence & European Reference Networks**

Chairpersons: Violeta Anastasiadou – Anthi Drousiotou

08.00 – 08.15 Presentation: EUCERD Recommendations on Quality Criteria for CoE for RDs Diseases in MS (*Violeta Anastasiadou*)

08.15 – 10.00 Discussion and completion of relevant questionnaire based on Content Guidelines

**10.00 – 10.30** Conclusions from workshop

Workshop 4: Anthi Drousiotou

**10.30 – 10.45 Conference Conclusions** (*Androulla Eleftheriou/ Violetta Anastasiadou*)

**10.45** End of 2<sup>nd</sup> day

**10.45 – 12.00** Debrief Session – Invitation only

## Annexe II – List of participants

NAME	SURNAME	ORGANISATION	ROLE	STAKEHOLDER GROUP
Maria	Adamou	Famagusta General Hospital	General Practitioner	Clinician/GP
Violetta	Anastasiadou	Arch. Makarios III Hospital	Clinical Geneticist, Head of Genetics Clinic	Clinician/GP
Myrto	Azina	Ministry of Health	Medical Officer	Public administration
Marianna	Chairepeti	ZOI' Cyprus Anti-Leukemia Association	Member	Patient representative
Stalo	Charalambous	Novartis Pharma (Cyprus)	Business Unit Head Oncology	Industry
Maria	Charalambous	Cyprus Primary Immunodeficiency Association & Friends	President	Patient representative
Tonia	Chatzigeorgiou	N/A	Parent	Patient representative
Kyproulla	Christodoulou	Cyprus School of Molecular Medicine / Cyprus Institute of Neurology & Genetics	Professor/, Head of Neurogenetics Department, Senior Scientist	Academic/Researcher
Paul	Costeas	Karaiskakio Foundation - Cyprus Bone Marrow Donor Registry	Executive Director	Academic/Researcher
Eleni	Demetriou	Co-ordinating Early Childhood Intervention Service for young children with developmental disorders	Officer	Public administration
Anthi	Droussioutou	Cyprus Institute of Neurology & Genetics	Head of the Biochemical Genetics Department, Senior Scientist	Healthcare Professional (other than clinician or GP)
Androulla	Eleftheriou	Thalassaemia International Federation	Executive Director	Patient representative
Panos	Englezos	Thalassaemia International Federation	President	Patient representative
Eleni	Georgiadou	Pharmaceutical Services, Ministry of Health	Clinical Pharmacist	Public administration
Egli	Giapana	Nicosia General Hospital - A&E Department	Pathologist	Clinician/GP
Chryso	Giasoumi Kyriakou	Cyprus Antirheumatic Association	Member	Patient representative
Dimitris	Glikis	N/A	Patient	Patient representative
Patroula	Hadjipapa	Center for Preventive Paediatrics	Director	Clinician/GP
Christina	Ioannidou	Nursing Services, Ministry of Health	Officer	Public administration

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Georgia	Karakiti	Mental Health Services, Ministry of Health	Occupational Therapist	Public administration
Odile	Kremp	ORPHANET	Director	Public administration
Margarita	Kourouklari	Larnaca General Hospital	Pathologist	Clinician/GP
Katia	Kyriakou	MONADIKA HAMOGELA	Member	Patient representative
Loukas	Lambrinos	Cyprus Thalassaemia Association	Board Member	Patient representative
Maria	Loizidou	Electron Microscopy and Molecular Pathology Department	Laboratory Scientific Officer	Healthcare Professional (other than clinician or GP)
Andria	Loizou	MONADIKA HAMOGELA	Parent	Patient representative
Gioula	Maliou	Cyprus Primary Immunodeficiency Association & Friends	Member	Patient representative
Foula	Markidou	Cyprus Antirheumatic Association	Member	Patient representative
Giorgos	Markoullis	HIPPOCRATEION Private Hospital	Haematologist	Clinician/GP
Evi	Missouri	Ministry of Health	Coordinator of Education of Medical and Public Health Services	Public administration
Ioanna	Mousioutta	Pan Cyprian Volunteerism Coordinative Council	Member	Social Worker
Alexia	Nicolaou	Center for Preventive Paediatrics	Quality Manager	Academic/Researcher
Maria	Nikolaou	GlaxoSmithKline (Cyprus)	Market Access, Government Affairs and Patient Advocacy Manager	Industry
Pambos	Papadopoulos	Muscular Dystrophy Association	President	Patient representative
Maria	Papadopoulou	Cyprus University of Technology - Nursing School	Senior Lecturer	Healthcare Professional (other than clinician or GP)
Katerina	Papadopoulou	Adult Congenital Heart Defect Association Cyprus	President	Patient representative
Andreas	Papadouris	Cyprus Institute of Neurology & Genetics	Administration	Medical/Learned Society
Alkis	Papadouris	Cyprus Medical Association	Paediatrician	Medical/Learned Society
Louiza	Papazachariou	Molecular Medicine Research Center	Biologist	Academic/Researcher
Nektarios	Partassides	Cyprus Sociology Association	Vice - President	Social Worker
Pavlos	Pavlou	Health Monitoring Unit. Ministry of Health	Unit Director	Public administration

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Klaus	Pfannkvche	American Heart Institute	Anaesthesiologist	Healthcare Professional (other than clinician or GP)
Elli	Philippou			
Irene	Savvidou	Arch. Makarios III Hospital - Genetics Clinic		Clinician/GP
Vassos	Scoutellas	Nicosia General Hospital	Rheumatologist	Clinician/GP
Carolina	Sismani	Cyprus Institute of Neurology & Genetics	Head of the Cytogenetics and Genomics Department, Senior Scientist	Academic/Researcher
Maria	Sitarou	Thalassaemia Centre	Unit Director	Clinician/GP
Elena	Spanou-Aristeidou	Cyprus Institute of Neurology & Genetics	Genetic Counsellor, Clinical Genetics Clinic	Academic/Researcher
Giorgos	Tanteles	Cyprus Institute of Neurology & Genetics	Geneticist, Clinical Genetics Clinic	Academic/Researcher
Marios	Theodorou	Polis Chrysohous General Hospital	General Practitioner	Clinician/GP
Nicolas	Tsangarakis	Polis Chrysohous General Hospital	Pathologist	Clinician/GP
Lia	Tzala	Centre for Control & Prevention of Diseases - Ministry of Health (Greece)	Head of National Cancer & Rare Disease Registries	Public administration
Androulla	Tziokourou	Larnaca General Hospital - A&E Department	General Practitioner	Clinician/GP
Pantelitsa	Vakana	ASPIDA ZOIS' Association for Inherited Metabolic Disorders	Member	Patient representative
Marios	Vakanas	ASPIDA ZOIS' Association for Inherited Metabolic Disorders	President	Patient representative
Constantinos	Voskarides	Molecular Medicine Research Center	Biobank Coordinator, Medical and Evolutionary Geneticist	Academic/Researcher
Eleni	Zamba-Papanikolaou	Cyprus Association for Human Genetics / Cyprus Institute of Neurology & Genetics	Board Member/ Head of Neurology Clinic D, Neurologist	Clinician/GP
Florentia	Zeitouni	Famagusta General Hospital	General Practitioner	Clinician/GP
Vassileios	Zerris	University of Cyprus	Professor of Medicine	Academic/Researcher