

# GEORGIA

## EUROPLAN NATIONAL CONFERENCE

### FINAL REPORT

17 April 2013, Tbilissi

# 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.

In Georgia, in the absence of a National Alliance of rare disease patient organisations, GeRAD - Georgian Foundation for Genetic and Rare Diseases – has been selected by EURORDIS to organise the EUROPLAN National Conference. GeRAD is a member of EURORDIS and meets all the criteria to organise a successful conference based on the common format and to bring together relevant patient organisations and other stakeholders in the field of rare diseases, including policy makers.

**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.

## General information

<b>Country</b>	<b>Georgia</b>
<b>Date &amp; place of the National Conference</b>	April 17, 2013 Sheraton Metechi Palace hotel
<b>Website</b>	<a href="http://www.gerad.ge">www.gerad.ge</a> (under construction)
<b>Organiser</b>	<b>Georgian Foundation for Genetic and Rare Diseases (GeRaD)</b>
<b>Members of the Steering Committee</b>	<p><b>Dimitry Khundadze</b>, Chairperson of the Health Care Committee of the Parliament of Georgia</p> <p><b>Mariam Jashi</b>, Deputy Minister of Labour, Health and Social Affairs of Georgia</p> <p><b>Amiran Gamkrelidze</b>, Director General of the National Center of Disease Control &amp; Public Health, Professor</p> <p><b>Ketevan Nemsadze</b>, President of the Georgian Academy of Paediatrics, Corresponding member of the Georgian Academy of Sciences</p> <p><b>Zaza Bokhua</b>, Tbilisi State Medical University, Institute of Post-Graduate Studies and Continuing Education</p> <p><b>Oleg Kvlividze</b> - Georgian Foundation for Genetic and Rare Diseases (GeRaD), EURORDIS Advisor in the frame of the EUROPLAN2 project</p>
<b>Names and list of Workshops</b>	<p><b>PLENARY SESSION 1:</b> TODAY’S SITUATION IN THE FIELD OF RARE DISEASES IN GEORGIA; WHY WE SO MUCH NEED THE NATIONAL PLAN;</p> <p><b>PLENARY SESSION 2:</b> DEBRIEF SESSION;</p> <p><b>WORKSHOP 1:</b> METHODOLOGY AND GOVERNANCE OF A NATIONAL PLAN;</p> <p><b>WORKSHOP 2:</b> DEFINITION, CODIFICATION AND INVENTORYING OF RD; INFORMATION AND TRAINING;</p> <p><b>WORKSHOP 3:</b> RESEARCH ON RD;</p> <p><b>WORKSHOP 4:</b> CARE - CENTRES OF EXPERTISE / EUROPEAN REFERENCE NETWORKS;</p> <p><b>WORKSHOP 5:</b> ORPHAN DRUGS;</p> <p><b>WORKSHOP 6:</b> SOCIAL SERVICES FOR RD</p>

<p><b>Workshop Chairs</b></p>	<p><b>CONFERENCE CO-CHAIRS:</b>  <b>David Sergeenko</b>, Minister of Labour, Health and Social Affairs of Georgia  <b>Dimitry Khundadze</b>, Health Care Committee of the Parliament of Georgia, Chairperson  <b>Oleg Kvlividze</b>, Georgian Foundation for Genetic and Rare Diseases; EURORDIS Advisor in the frame of EUROPLAN 2 project  <b>PLENARY SESSIONS AND WORKSHOPS CHAIRS:</b>  <b>Prof Amiran Gamkrelidze</b>, National Center of Disease Control &amp; Public Health;  <b>Mariam Jashi</b>, Deputy Minister of Labour, Health and Social Affairs of Georgia;  <b>Prof Irakli Pavlenishvili</b>, Tbilisi State Medical University;  <b>Prof Nana Tatishvili</b>, AIETI Medical School;  <b>Prof Oleg Kvlividze</b>, Georgian Foundation for Genetic and Rare Diseases;  <b>Prof Tamar Rukhadze</b> , Tbilisi State University, Faculty of Medicine;  <b>Prof Maka Ioseliani</b>, AIETI Medical School;  <b>Ms Rusudan Rukhadze</b>, Ministry of Labour, Health and Social Affairs of Georgia</p>
<p><b>Annexe</b></p>	<p>Programme</p>

## Part II. Main Report

### Plenary Report – Opening Session

- **Country status** (was presented by representatives of MoH/Mariam Jashi, Academic Institution/Tamar Rukhadze, medical professionals/Tamar Mosulishvili and patients' organizations/Ketevan Saralidze)
- **European policy and guidelines** (e.g. EU document presentations and discussion, presentation of EUROPLAN, EUCERD and EUCERD Joint Action) (The opening Plenary Session was focused on the presentation of the European documents (2008 EU Communication; 2009 EU Recommendation; EUROPLAN recommendations, EUROPLAN recommendations and indicators)
- **Other plenary** (N/A)

### Report of Workshops

**Theme 1 - Methodology, Governance and Monitoring of the National Plan** (the themes listed below were presented by 1 speaker: Dr Oleg Kvlividze)

#### Sub-Themes:

- 1.1 Mapping policies and resources (Yes)
- 1.2 Development of a National Plan /Strategy (Yes)
- 1.3 Structure of a National Plan /Strategy (Yes)
- 1.4 Governance of a National Plan (Yes)
- 1.5 Dissemination and communication on the National Plan (Yes)
- 1.6 Monitoring and evaluation of the National Plan (Yes)
- 1.7 Sustainability of the National Plan (Yes)

**Theme 2 - Definition, codification and inventorying of RD** (the themes listed below were presented by 3 speakers: Prof Amiran Gamkrelidze, Prof Zaza Bokhua and Prof Karaman Pagava)

#### Sub-Themes:

- 2.1 Definition of RD (Yes)
- 2.2 Codification of RD and traceability in national health system (Yes)
- 2.3 Registries and databases (Yes)
- 2.4 Information on available care for RDs in general, for different audiences (Yes)
- 2.5 Help Lines (Partially)
- 2.6 Training healthcare professionals to recognise and code RD (No)
- 2.7 Training healthcare professionals (Yes)

**Theme 3 - Research on RD** (the themes listed below were presented by 2 speakers: Prof Ketj Nemsadze and Prof Irakli Pavlenishvili)

**Sub-Themes:**

- 3.1 Mapping of existing research resources, infrastructures and programmes for RDs (Yes)
- 3.2 Dedicated RD research programmes and governance of RD research funds (Yes)
- 3.3 Sustainability of research programmes on RD (Partially)
- 3.4 Needs and priorities for research in the field of RDs (Yes)
- 3.5 Fostering interest and participation of national laboratories and researchers, patients and patient organisations in RD research projects (Partially)
- 3.6 RD research infrastructures and registries (Yes)
- 3.7 EU and international collaboration on research on RD (Yes)

**Theme 4 – Care for RDs - Centres of Expertise and European Reference Networks for Rare Diseases** (the themes listed below were presented by 2 speakers: Prof Nana Tatishvili and Maya Kereselidze)

**Sub-Themes:**

- 4.1 Designation and evaluation of CE (Yes)
- 4.2 Scope and functioning of CEs (Yes)
- 4.3 Multidisciplinarity, healthcare pathways & continuity of care (Yes)
- 4.4 Access to information (Yes)
- 4.5 Research in CEs – How to integrate research on RDs and provision of care (No)
- 4.6 Good practice guidelines (Yes)
- 4.7 Diagnostic and genetic testing (Yes)
- 4.8 Screening policies (Yes)
- 4.9 European and international collaboration – Cross-border healthcare and ERNs (European Reference Networks) (Yes)
- 4.10 Sustainability of CEs (Partially)

**Theme 5 – Orphan Medicinal Products** (the themes indicated below were presented by 2 speakers: Nana Davituliani and Prof Maka Ioseliani)

**Sub-Themes:**

- 5.1 Support to Orphan Drug (OD) development (Partially)
- 5.2. Access to treatments (Yes)
- 5.3. Compassionate use programmes (No)
- 5.4. Off label use of medicinal products (Yes)
- 5.5. Pharmacovigilance (Yes)

**Theme 6 –Social Services for Rare Diseases** (the themes indicated below were presented by 3 speakers: Rusudan Rukhadze from MoH and Ana Bokolishvili and Khatuna Meskhi from patients’ organization)

**Sub-Themes**

- 6.1. Social resources for people with disabilities (Yes)
- 6.2. Specialised social services for rare diseases (Partially, international experience only)
- 6.3. Policies to integrate people living with rare diseases into daily life (Yes)
- 6.4. International–supranational dimension (No)

**Report of the Closing Session – Conclusions** (the Closing session was replaced by Debrief Plenary Session)

- **Overall assessment of the usefulness of the European guidelines and policy recommendations** (the usefulness of EU guidelines and policy recommendations and necessity to be guided by them were approved by participants of the Conference)
- **Identification of specific gaps, challenges and needs across all Themes** (The gaps and global challenges mainly related with financing problems and lack of proper information and international assistance as well as basic needs were identified; the specific issues will be discussed in the frame of the meetings of 6 working groups created accordingly with Workshops Themes).

During the Debrief session the participants systematized, analyzed, and interpreted information provided during each of the workshops. They have carefully considered national realities and European recommendations for creation of a national plan and optimal management of rare diseases.

**Workshop #1:** The participants devised main directions of activities in the field of Methodology, Governance and Monitoring of the National Plan

- Advocacy for inclusion of rare diseases in the list of main directions of healthcare development in Georgia for 2014;
- Defining development priorities within the National Plan;
- Promotion of effective activities, coordinated with the Healthcare decision makers and among the working groups;
- Control and coordination of their activities by the patients’ community;
- Maintaining compliance with the EUCERD recommendations.

**Workshop #2:** The participants devised priorities in terms of definition, codification and inventorying of RD; Information and training:

- Advocacy for introduction into the national legislature by the end of 2013 of the corresponding with the European Commission on Public Health definition of rare diseases (1:2000 population);
- Development and advocacy for ratification by the Ministry of Health of the list of priority rare diseases for Georgia (presumably the government will take on the responsibility for treatment of patients with the listed diseases);
- Advocacy with the National Center of Disease Control & Public Health (NCDC) for

creation of the registries in the field of rare diseases (NCDC is currently working on the registry of oncological diseases). Promotion of collaboration between NCDC and RD patients' organizations; Integration into the international programs and projects on creation of registries of rare diseases (particularly, EpiRare).

- Enhancement of educational programs in rare diseases for resident students as well as GP in the capital city and the regions;
- Development of the information awareness system (particularly, a care system) for RD patients' parents.
- Development of the Internet and other, alternative information resources on RD according to existing European standards.

**Workshop #3:** The participants devised main postulates of the national strategy in the field of Research on RD:

- Integration into the international RD Research professional community (namely, Georgian membership in IRDiRC)
- Providing Georgian scientists with the opportunities to study at the RD research centers internationally;
- Advocacy with the government for initiation of the process of financing RD research through the development of DNA diagnostics (namely, acquisition of modern equipment and organization of personnel training)
- Advocacy for inclusion of Georgian patients into the international and national research programs;
- Inclusion of rare diseases among the Georgian science development priorities in the nearest future.

**Workshop #4:** The participants devised main directions of the national strategy in the field of Centers of Expertise / European Reference Networks:

- Set up a diagnostic center of rare diseases specializing in the management of pathologies recorded in the list of priority diseases, in Tbilisi, on the basis of one of the large pediatric clinics.
- In that center making diagnostics of rare diseases available for patients through implementation of up-to-the-date methods as well as through collaboration with international diagnostic centers
- Implementation of rare diseases educational programs for medical professionals in the center;
- Promotion of the center's status as such of National Centers of Expertise/Reference Center on Rare Diseases;
- Establishment of new and furtherance of existing relationships with Centers of Expertise on rare diseases worldwide. Integration in European Reference Networks;
- Adherence to EUCERD recommendations on creation and management of such centers.



**Workshop #5:** The participants devised main directions of the national strategy in the field of Orphan Drugs:

- Optimization of existing regulations on import, registration, and realization of orphan drugs;
- Intensification of the policy of inviting international pharmaceutical companies produced orphan drugs to the Georgian market and their inclusion in the process of access to treatment for RD community;
- Advocacy for optimization of existing and creation of new RD treatment programs;
- Adherence to the EUCERD recommendations on the development orphan drugs policy while taking into consideration national specificities;

**Workshop #6:** The participants devised main directions of the national strategy in the field of social service for RD:

- Advocacy at the state and municipal levels for creation and implementation of governmental programs in the field of social service for RD for the nearest years;
- Inviting of non-governmental sector (NGOs, international and local humanitarian and commercial organizations) to participate in creation of social programs for RD
- Formation of a group of patients' community representatives that will monitor creation and implementation of such programs;
- Enhancement of the institute of social workers equipped with knowledge and motivation for working with RD patients;
- Studying of best European practices in the field of Social Service for RD in order to adopt them adequately in Georgia;
- Adherence with the EUCERD recommendations on the development of Social Service for RD policy while taking into consideration national specificities.

## Part IV. Final List of Participants

- Academic/Researcher – 23 persons from Tbilisi State Medical University, Tbilisi State University, Dept. Of Medicine; AIETI Medical School; National Forensics Bureau, Institute of Biotechnology, Institute of Haematology and Blood Transfusion etc
  - Clinician/GP – 82 medical professionals from various Tbilisi and regional clinics (paediatricians, endocrinologists, haematologists, dermatologists, orthopaedists, geneticists, gynaecologists, GPs, gastroenterologists, etc
  - Healthcare Professionals (other than clinician or GP) – 12 representatives of the National Center of Disease Control & Public Health and laboratory doctors;
  - Industry – 9 representatives of pharmaceutical companies;
  - Insurers – 3 representatives of National Insurance companies;
  - Medical /Learned society – lot of the representatives of professional Medical Societies (the same people that clinicians or researchers);
  - Patient representatives – 18 representatives of patients organizations (Georgian Foundation for Genetic and Rare Diseases; Parent Committee of Children with Juvenile Arthritis; Association of Hemophilia and Donors; Aid Center for Patients with Phenylketonuria; EB and OI patients’ groups in the frame of GeRaD);
  - Politicians –3 (Minister of Labour, Health and Social Affairs of Georgia; Chairperson and his Deputy of the Health Care Committee of the Parliament of Georgia);
  - Public administration – 7 representatives of MoH, Director and Deputy of the National Center of Disease Control & Public Health;
  - Social worker - No
  - Other – 6 representatives of the local and international NGO (Alliance for Rare Diseases, UNESCO, OSGF, UNDP)
1. **David Sergeenko**, Minister of Labour, Health and Social Affairs of Georgia;
  2. **Mariam Jashi**, Deputy Minister of Labour, Health and Social Affairs of Georgia;
  3. **Rusudan Rukhadze**, Ministry of Labour, Health and Social Affairs of Georgia, Head of the Healthcare Department;
  4. **Lela Serebryakova**, Ministry of Labour, Health and Social Affairs of Georgia, Head of the Program Implementation Department;
  5. **Tea Tavidashvili**, person responsible for rare diseases, Ministry of Labour, Health and Social Affairs of Georgia
  6. **Dimitry Khundadze**, Chairperson of the Health Care Committee of the Parliament of Georgia;
  7. **Prof Rima Berishvili**, Vice-Rector of the Tbilisi State Medical University,
  8. **Gia Abesadze**, Vice-Rector the Tbilisi State Medical University;
  9. **Prof Zaza Bokhua**, Director of the Institute of Post-Graduate Studies and Continuing Education, Tbilisi State Medical University;
  10. **Prof Aleksandr Tsiskaridze**, Dean of the Faculty of Medicine, Tbilisi State University;
  11. **Prof Ketevan Nemsadze**, President of the Georgian Academy of Paediatrics, Corresponding member of the Georgian Academy of Sciences;
  12. **Prof Amiran Gamkrelidze**, Director General of the National Center of Disease Control & Public Health;

13. **Maya Kereselidze**, Head of the Statistics Dept., National Center of Disease Control & Public Health;
14. **Prof Marina Abashidze**, Director of the Institute of Haematology and Blood Transfusion;
15. **Prof Elene Abzianidze**, Genetics Dept., Tbilisi State Medical University;
16. **Prof Ivane Bokeria**, My Family Doctor’s Net;
17. **Ana Bokolishvili**, Parent Committee of Children with Juvenile Arthritis;
18. **Inga Bulia**, Alliance for Rare Diseases;
19. **Prof George Galdava**, National Center of Dermatology and Venereology;
20. **Prof Tina Kituashvili**, National Center of Dermatology and Venereology;
21. **Prof Marina Gordeladze**, Paediatric Academic Clinic of Tbilisi State Medical University;
22. **Temur Topuria**, Director of the Institute of Biotechnology;
23. **Prof Paata Imnadze**, Deputy of the National Center of Disease Control & Public Health;
24. **Prof Maka Ioseliani**, AIETI Medical School; Center of Allergy and Rheumatology, Institute of Pediatrics;
25. **Eka Kvaratskhelia**, David Metreveli’s Medical Center, Georgian Foundation for Genetic and Rare Diseases;
26. **Nino Manjaparashvili**, Alliance for Rare Diseases;
27. **Prof Karaman Pagava**, Pediatrics Dept., Tbilisi State Medical University;
28. **Prof Irakli Pavlenishvili**, Institute of Post-Graduate Studies and Continuing Education, Tbilisi State Medical University;
29. **Lali Margvelashvili**, Medical Center “New Life”, Georgian Foundation for Genetic and Rare Diseases;
30. **Prof David Metreveli**, David Metreveli’s Medical Center;
31. **Prof Irakli Metreveli**, The Jo Ann Medical Center;
32. **Ketevan Saralidze**, Georgian Foundation for Genetic and Rare Diseases;
33. **Khatuna Meskhi**, Aid Center for Patients with Phenylketonuria;
34. **Tamuna Mosulishvili**, Bakur Kotetishvili Psychoneurological clinic; Georgian Foundation for Genetic and Rare Diseases;
35. **Prof Tamar Rukhadze**, Tbilisi State University, Faculty of Medicine; Georgian Foundation for Genetic and Rare Diseases;
36. **David Rekhviashvili**, Director General of the Children’s New Clinic; Georgian Foundation for Genetic and Rare Diseases;
37. **Prof Jenara Kristesiashvili**, Scientific Research Center for Reproductive Health and Immunological Infertility “Embriotox”;
38. **Prof Nino Kochashvili**, Tbilisi State Medical University; Levan Samkharauli National Forensics Bureau;
39. **Romanoz Khomasuridze**, Association of Haemophilia and Donors;
40. **Prof Nana Tatishvili**, Head of the Department of Neurology and Epilepsy of the Central Children’s Hospital; AIETI Medical School;
41. **Nana Davituali**, Ministry of Labour, Health and Social Affairs of Georgia, Procurement expert;
42. **Tsitsino Parulava**, Children’s New Clinic;
43. **Sophio Kereselidze**, Autism Center, Ilya State University.
44. **Ketevan Gambashidze**, National Center of Disease Control & Public Health;
45. **Vepkho Odisharia**, Saint Joachim and Ann Maternity House of Patriarchate of Georgia, Georgian Foundation for Genetic and Rare Diseases

**Annexe : Programme**

<b>April 17, 2013</b>		
<b>SHERATON METEKHI PALACE, TBILISI, GEORGIA</b>		
<b>9.00 – 15.00</b>	<b>REGISTRATION</b>	
<b>10.00 – 11.00</b>	<b>PRESS-CONFERENCE</b>	
<b>11.00 – 11.30</b>	<b>OPENING OF THE CONFERENCE: Welcome speeches</b>	
11.00 - 11.10	David Sergeenko, Minister of Labour, Health and Social Affairs of Georgia	
11.10 - 11.20	Dimitry Khundadze, Chairperson of the Health Care Committee of the Parliament of Georgia	
11.10 - 11.30	Oleg Kvlividze, Georgian Foundation for Genetic and Rare Diseases (GeRaD); EURORDIS Adviser in the frame of EUROPLAN 2 project	
<b>11.30 – 12.30</b>	<b>PLENARY SESSION 1: TODAY'S SITUATION IN THE FIELD OF RARE DISEASES IN GEORGIA; WHY WE SO MUCH NEED THE NATIONAL PLAN (Chair: Prof Amiran Gamkrelidze, National Center of Disease Control &amp; Public Health)</b>	
11.30 - 11.50	Mariam Jashi, Deputy Minister of Labour, Health and Social Affairs of Georgia	Georgian Governmental Policy in the field of rare diseases: Current situation and prospects
11.50 - 12.10	Tamar Rukhadze, Tbilisi State University, Faculty of Medicine, Professor	EU and EUCERD documents for Rare Diseases
12.10 - 12.20	Tamar Mosulishvili, Georgian Foundation for Genetic and Rare Diseases	Physician, patient and government structures: improvement of the mechanism of cooperation and coordination
12.20 - 12.30	Ketevan Saralidze, Georgian Foundation for Genetic and Rare Diseases	Rare diseases in Georgia – a view of the patient and the patient's parents
<b>12.30 – 13.00</b>	<b>WORKSHOP 1: METHODOLOGY AND GOVERNANCE OF A NATIONAL PLAN (Chair: Mariam Jashi, Deputy Minister of Labour, Health and Social Affairs of Georgia)</b>	
12.30 - 13.00	Oleg Kvlividze, Georgian Foundation for Genetic and Rare Diseases; EURORDIS Advisor in the frame of EUROPLAN 2 project, Professor	International experience on creation of the National plans for rare diseases, methodology and management
<b>13.00 – 14.00</b>	<b>WORKSHOP 2: DEFINITION, CODIFICATION AND INVENTORYING OF RD; INFORMATION AND TRAINING (Chair: Prof Irakli Pavlenishvili, Tbilisi State Medical University)</b>	
13.00 - 13.20	Amiran Gamkrelidze, Director General of the National Center of Disease Control & Public Health, Professor	Issues of definition, codification and registration of rare diseases
13.20 - 13.40	Zaza Bokhua, Director of the Institute of Post-Graduate Studies and Continuing Education, Tbilisi State Medical University, Professor	Education and informing problems in the field of rare diseases among doctors, nurses, students and patients
13.40 - 14.00	Karaman Pagava, Tbilisi State Medical University, Pediatrics Dept., Professor	Tbilisi State Medical University Rare Diseases Information Center: our experience
<b>14.00 – 15.00</b>	<b>COFFEE-BREAK</b>	
<b>15.00 – 15.40</b>	<b>WORKSHOP 3: RESEARCH ON RD (Chair: Prof Nana Tatishvili, AIETI Medical School)</b>	
15.00 - 15.20	Ketevan Nemsadze, President of the Georgian Academy of Paediatrics, Corresponding member of the Georgian Academy of Sciences	Scientific researches in the field of rare diseases; an international review and national opportunity
15.20 - 15.40	Irakli Pavlenishvili, Institute of Post-Graduate Studies and Continuing Education, Tbilisi State Medical University, Professor	National achievements in the field of rare diseases research

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<b>15.40 – 16.20</b>	<b>WORKSHOP 4: CARE - CENTRES OF EXPERTISE / EUROPEAN REFERENCE NETWORKS (Chair: Prof Oleg Kvlividze, Georgian Foundation for Genetic and Rare Diseases)</b>	
15.40 - 16.00	Nana Tatishvili, Head of the Department of Neurology and Epilepsy of the Central Children's Hospital, Professor	National centers of expertise in the field of rare diseases, the European experience
16.00 - 16.20	Maya Kereselidze, Head of the Statistics Dept., National Center of Disease Control & Public Health	National Rare Diseases Reference Center – Georgian prospects
<b>16.20 – 17.00</b>	<b>WORKSHOP 5: ORPHAN DRUGS (Chair: Prof Tamar Rukhadze , Tbilisi State University, Faculty of Medicine)</b>	
16.20 - 16.40	Nana Davituliani, Ministry of Labour, Health and Social Affairs of Georgia, Procurement expert	Orphan drugs, ensuring availability
16.40 - 17.00	Maka Ioseliani, Institute of Pediatrics, AIETI Medical School, Professor	Orphan medicines in Georgia: achievements and challenges
<b>17.00 – 17.30</b>	<b>WORKSHOP 6: SOCIAL SERVICES FOR RD (Chair: Prof Maka Ioseliani, AIETI Medical School)</b>	
17.00 - 17.20	Rusudan Rukhadze , Ministry of Labour, Health and Social Affairs of Georgia, Head of the Healthcare Department	Experience and prospects of implementation of social service for patients with rare diseases
17.20 - 17.40	Ana Bokolishvili, Parent Committee of Children with Juvenile Arthritis Khatuna Meskhi, Aid Center for Patients with Phenylketonuria	Social service for children suffering with rare diseases – What we expect
<b>17.40 – 18.00</b>	<b>COFFEE-BREAK</b>	
<b>18.00 – 19.30</b>	<b>PLENARY SESSION 2: DEBRIEF SESSION (Co-Chairs: Oleg Kvlividze, GeRaD and Rusudan Rukhadze, Ministry of Labour, Health and Social Affairs of Georgia)</b>	
18.00 - 19.30	Objective: To identify needs, opportunities and measures to develop further the National Rare Disease Strategy/Plan Methods: Discussion; Wrap-up of the results of the conference; Adoption of a resolution; Working group formation	
<b>19.30-22.30</b>	<b>RECEPTION</b>	