

Cancer Patient Support Society "Dzīvības Koks" in cooperation with Pulmonary Hypertension Society and Patient Ombudsman

INTERNATIONAL CONFERENCE “CHRONIC DISEASES POSE A CHALLENGE TO 21st CENTURY EUROPE: PATIENT`S PERSPECTIVE AND ECONOMIC ACTIVITY”

19 – 20 MARCH 2015, LATVIA

The conference is organized within the framework of Latvian Presidency of the Council of the European Union

Preface: Currently chronic diseases are one of the heaviest burdens of health and social care systems in Latvia and Europe in general. The list of chronic diseases in 21st century has been complemented with diseases that were so far considered incurable, like as pulmonary hypertension and cancer. Considering ageing of the population and increase in life expectancy, regardless of the type of disease, these are interests of patients with chronic diseases to reintegrate in full-fledged social and economic life, and participate in the workforce as much as possible, thus becoming a long-term economic investment, not a burden. According to the “Europe 2020 strategy” the goal is to maintain 75% of the working-age population employed and productive. To facilitate this, it is important that patient organizations act in collaboration with professionals, decision-makers and other stakeholders, emphasizing issues at the national and international level, and offering action-oriented solutions at national and European levels thus contributing to a stronger, competitive and inclusive Europe.

Goal of the conference: to promote cooperation between patient organizations, professionals, decision-makers and other stakeholders at the European level; identify the issues of re-integration of patients with chronic diseases to stay active both economically and socially; to prepare action-oriented recommendations, which will be included in the final Resolution in order to improve opportunities of patients with chronic health conditions to participate in active economic and social life.

Expected results: The Resolution, which outlines action-oriented proposals for patients with chronic diseases to return back to economic and social life from the patients’ perspective. The Resolution will be forwarded to the European Commission, the European Parliament, the Council of the European Union and national governments.

MARCH 19, 2015
The Latvian Society House, Hall "Līgo"
Merķeļa Street 13, Riga, Latvia
13:00 – 18:00

Official language: Latvian and English (simultaneous interpreting provided)

MODERATOR: VALDIS MELDERIS

13:00 – 13:30 **PRESS CONFERENCE**

13:30 – 14:00 **OPENING OF THE CONFERENCE**

***Gunita Berķe**, the Chair of the Cancer Patient Support Society "Dzīvības Koks"*

***Guntis Belēvičs**, the Minister for Health of the Latvian Republic*

***Ingus Alliks**, Deputy State secretary of the Ministry of Welfare of the Republic of Latvia*

***Aiga Rūrāne**, Head, World Health Organization (WHO) Country Office in Latvia*

14:00 – 14:15 **Resolution: The Integral Character of Chronic Diseases, Chronic Disease Management and Economic Activity in Europe from the Perspective of Patient Organizations**

***Gunita Berķe**, the Chair of the Cancer Patient Support Society "Dzīvības Koks"*

14:15 – 14:40 **Specifics of Chronic Diseases in the 21st Century - Challenges and Opportunities**

***Denis Clément**, European Chronic Disease Alliance (ECDA), European Society of Hypertension*

14:40 – 15:05 **Chronic Patient Return to Active Social and Economic Life. Economic and Legal Aspects**

***Friedrich Mehrhoff**, Doctor in law, Head of Rehabilitation Strategies in the German Federation of Insurers against the Risks of Work and School Accidents and Occupational Diseases (DGUV)*

***Aivars Vētra**, Riga Stradins University, President of the Latvian Professional Associations of Rehabilitation (LRPOA)*

15:05 – 15:30 **The Role of Health Economics in Curbing Chronic Diseases**

***Daiga Behmane**, Head of the Health Economics Association, the Adviser to the Minister of Health*

15:30 – 15:45 Coffee break

- 15:45 – 15:55** **Chronic Diseases: Social Affairs and Employment Aspects**
Aija Barča, the President of the Social Affairs and Employment Matters Committee of the Saeima of the Latvian Republic
- 15:55 – 16:10** **Goal setting issues in rehabilitation**
Volodymyr Golyk, MD, Ph.D., Ukrainian State Institute of Medical and Social Problems of Disability Ministry of Health of Ukraine, Ukrainian Society for Neurorehabilitation, Board Chairman, Neurologist.
- 16:10 – 16:35** **The Role of Patient Non-Governmental Organizations to Influence the Quality of Chronic Patients' Reintegration in Active Economic and Social Life - the European Experience**
Rafal Swierzewski, Member of the Board of the European Cancer Patient Coalition (ECPC)
- 16:35 – 17:00** **The Changing Nature of Chronic Diseases. Cancer: a Pressure or a Challenge?**
Dace Baltiņa, Chief Oncologist at the Riga East University Hospital
- 17:00 – 17:25** **Face to Face with Rare Disease**
Ieva Plūme, President of Latvian Alliance for Rare Diseases, Chairperson of Pulmonary Hypertension Society
- 17:25 – 17:40** **Summary and conclusion of the first day of the conference**
Gunita Berķe, the Chair of the Cancer Patient Support Society "Dzīvības Koks"
- 18:00** **Bus to the next day conference venue**
- 20:30** **Dinner for the participants of the conference at the "Hotel Tigra", social event and entertainment activities**

MARCH 20, 2015
Hotel "Tigra", Priekuļi, Cēsu region
9:30 – 17:30

Official language: English

- 9:00 – 9:30** **Registration, coffee break**
- 9:30 – 9:45** **Opening of the second day of the conference**
Gunita Berķe, the Chair of the Cancer Patient Support Society "Dzīvības Koks"
- 9:45 – 11:00** **TEAM LEADERS REPORTS**
- 9:45 – 9:55** **Looking Forward to Better Health Policy and Economic Activity: Patients Perspective**
Anna Broka, Head of Governance Studies at Vidzeme University of Applied Sciences
- 9:55 – 10:05** **Patient Rights, Work Environment and Labour Rights**
Marta Augucēviča, Representative of the Patient Ombudsman
- 10:05 – 10:15** **The Package of Rehabilitation Services: Vision, Experience, Legislation and Finance**
Aivars Vētra, Riga Stradins University, President of the Latvian Professional Associations of Rehabilitation (LRPOA)
- 10:15 – 10:25** **The Multi-Dimensional Nature of Rare Diseases**
Ieva Plūme, President of Latvian Alliance for Rare Diseases, Chairperson of Pulmonary Hypertension Society
- 10:25 – 10:35** **Is Oncology Perceived as a Chronic Disease in the Mind of the Public?**
Dace Baltiņa, Chief Oncologist at the Riga East University Hospital
- 10:35 – 11:00** **POSTER & VIDEO PRESENTATIONS**
- Ludmila Popovici, RCTV Memoria IRCT Council member, Psychosocial rehabilitation and medical care for survivors from GULAG. The art to live after trauma, with PTSD and chronic deceases.*
- Ūla Lunevičiūtē, Giedre Bulotiene, National Cancer Institute in Lithuania and Psychosocial Oncology Association in Lithuania. Poster: Analysis of the Rehabilitation Services in Lithuanian National Cancer Institute.*

Loreta Blazeviciene, Ruta Azarinskiene, National Cancer Institute in Lithuania and Psychosocial Oncology Association in Lithuania. Poster: Specificity of social services for patients in National Cancer Institute and their family members.

Carina Schey, Health economist, Global Access Market Solution. Poster: Multi-criteria decision analysis (MCDA): Testing a proposed framework for orphan drugs.

11:00 – 11:15 **Coffee break**

11:15 – 14:00 **GROUPS OF WORKSHOPS**

I GROUP: Looking Forward to Better Health Policy and Economic Activity: Patients Perspective

KEY WORDS: Health economics, integrated health care, chronic disease management, e-health, health as investment in economics

CHAIR:

Anna Broka, Head of Governance Studies at Vidzeme University of Applied Sciences

EXPERTS:

Gunita Berķe, Latvian Cancer Patient Support Society “Dzīvības koks”. “Health Care Aspects from Patient Organization Point of View”

Giedre Bulotiene, M.D., Ph.D., Psychiatrist, Psychotherapist, Psychosocial Oncology Association in Lithuania. “Communication about cancer from patients’ and health care specialists’ perspectives”

II GROUP: Patient Rights, Work Environment and Labour Law

KEY WORDS: project „Pain Patient Pathway Recommendation”, patient rights and responsibilities, labour rights for persons with disabilities, social and economic support

CHAIR:

Marta Augucēviča, Representative of the Patient Ombudsman

EXPERTS:

Mariano Votta, Active Citizenship Network - director. „Patient Rights and Responsibilities in European Union”.

Sarmīte Rūtiņa – Rūtenberga, State Labour Inspectorate, Latvia. „Labour Rights and Environment for Persons with Disability”

Marta Augucēviča, Patient Ombudsman. „Research „Pain Patient Pathway Recommendation” Results – Suggestions for Improvement of Patient Rights”

Aldis Dudins, Latvia, Senior Expert, Ministry of Welfare. “Social Services for Persons with Disabilities in Latvia”.

III GROUP: The Package of Rehabilitation Services: Vision, Experience, Legislation and Finance

KEY WORDS: *Rehabilitation and economic activity, psychosocial rehabilitation, legislative initiatives, reduction of disability, ability to work*

CHAIR:

Prof. Aivars Vētra, *Riga Stradins University, the President of the Latvian Professional Associations of Rehabilitation (LRPOA)*

EXPERTS:

Prof. Volodymyr Golyk, *MD, Ph.D., Ukrainian State Institute of Medical and Social Problems of Disability Ministry of Health of Ukraine, Ukrainian Society for Neurorehabilitation, Board Chairman, Neurologist. "Legislative change initiatives in Ukraine and reduction of chronic health effects caused by disability"*

Dr. Evelyn Aaviksoo, *MD, PhStud, occupational health physician, East Tallinn Central Hospital: "Estonia's experience with legislative changes in disability and work expertise of the reintegration of the chronically ill into the labor market"*

Dr. Maija Kārklīņa, *Psychotherapist, Riga East University Hospital, Member of the Board of the Latvian Cancer Patient Support Society "Dzīvības koks"*

IV GROUP: The Multi-Dimensional Nature of Rare Diseases

KEY WORDS: *Rare diseases, Health care access, Economic and Human rights, Homecare, Cross-border Healthcare*

CHAIR:

Jānis Zvejnieks, *Director of the Department of Pharmacy, Ministry of Health of Latvia*

EXPERTS:

Carina Schey, *Health economist, Global Access Market Solution. 'The Economics of Homecare Delivery – Everyone is a Winner'.*

Juan Fuertes, *Member of the Drug Information, Transparency and Access (DITA) Task Force (EURORDIS), Advocacy and Access Delegate (PHA Europe). "Access to Care: Economic and Human Rights."*

Agnese Gusarova, *Deputy Director of E-Health and International Cooperation Department, National Health Service. "The Application of Patients' Rights in Cross-border Healthcare with regard to Rare diseases' patients".*

V GROUP: Is Oncology Perceived as a Chronic Disease in the Mind of the Public?

KEY WORDS: *Cancer as Taboo, Psychosocial Rehabilitation, Living with Diagnosis “Cancer”, Socializing, Advocacy, Raising Awareness*

CHAIR:

Prof. Dace Baltiņa, the Latvian chief oncologist at the Latvian Oncology Centre of the Riga Eastern Clinical University Hospital

EXPERTS:

Ene Tomberg, Europa Donna, Estonian Cancer Society. “Europa Donna activities in Estonia and some experiences from other countries”

Austra Ošleja, Riga Stradins University, Master Study Programme “Health psychology”. “Psychosocial Therapies for Patients With Cancer”

Jana Duhovska, Head of Riga Stradins University “Arts therapies” Study Programme “Art therapies”, Music therapist. “Arts therapies for improving psychological and physical outcomes in cancer patients”

14:00 – 14:30	Lunch
14:30 – 16:45	RESOLUTION: Conclusions of the Work Groups (Presentations, Questions and Discussions)
16:45 – 17:00	Closing of the Conference
17:00 – 17:15	Coffee break
17:30	Bus to Riga