A general description of SWG focus and mission

The EHA SWG “Quality of Life and Symptoms” was formed within the European Hematology Association in 2006. The mission of the SWG is to disseminate knowledge among physicians and researchers with a view to maintaining high shared standards in the field of quality of life research, to develop both practical and clinical research recommendations on quality of life and symptom assessment in hematology.

The aims and objectives of the EHA SWG are:

- Promotion of all aspects associated with quality of life and symptom research in the field of hematology;
- Standardization of quality of life and symptom assessment in clinical trials in hematology;
- Improvement of quality of clinical trials and post-marketing research with a PRO component in hematology;
- Development of approaches to implement PRO in clinical practice in hematology;
- Verification of the areas of patient-reported outcome application in hematology.
- Promotion of educational and training initiatives in patient-reported outcomes research;
- Exploration of similarities and differences in cultural, and linguistic aspects of symptom and quality of life research;
- Identification of hurdles and solutions for implementation of patient-reported outcome measures in routine clinical practice.

Chair and affiliations

Esther Oliva – Head of Myelodysplastic Syndromes and Anemia Section, Hematology Division, Azienda Ospedaliera “Bianchi-Melacrino-Morelli”, Reggio Calabria, Italy; President of Associazione QOL-ONE, Reggio Calabria, Italy

Board members and terms

Sam Salek, PhD - Professor of Pharmacoepidemiology, University of Hertfordshire, London; Director of Institute for Medicines Development, Cardiff; Vice-President of PharmaTrain Federation, Brussels; and Visiting Professor, Estate of Hessen, Germany - Co-Chair, 2018

Tatyana Ionova – Chair of Board, Multi-national Center for Quality of Life Research,
St-Petersburg, Russia—Secretary, 2018.

Board Members’ conflicts of interest
Esther Oliva:

- Advisory Board - Amgen, Novartis
- Speakers' Bureau - Novartis, Celgene
- Consultancy - La Jolla

Scientific Advisory Board

Chair of Board

Anton Hagenbeek - Professor of Hematology, Dept. of Hematology, Academic Medical Center, University of Amsterdam, Amsterdam, the Netherlands

Board members

- Christen L. Andersen – Senior Researcher, Department of Hematology, Copenhagen University Hospital, Rigshospitalet, Denmark
- Gary Gorodokin - President, New Jersey Center for Quality of Life and Health Outcome Research, Saddle River, NJ, USA
- Kirstie L Haywood - Senior Research Fellow, University of Warwick, Coventry, United Kingdom
- Tatyana Ionova – Chair of Board, Multinational Center for Quality of Life Research, St.Petersburg, Russia
- Robert Klaassen – Professor, Department of Pediatric, Division of Hematology/Oncology, University of Ottawa, Children's Hospital of Eastern Ontario, Ottawa, Canada
- Esther Oliva – Chair of Hematology Division, Azienda Ospedaliera Bianchi-Melacrino-Morelli, Reggio Calabria, Italy
- Sam Salek – Professor of Pharmacoepidemiology, University of Hertfordshire, Hatfield, Herts, United Kingdom
- Anita Waldmann – Chair, LEUКДМИEHILFE RHEIN-MAIN E.V. Patient Organization, Ruesselsheim, Germany.

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12. Esther Oliva – Hematology Division, Azienda Ospedaliera Bianchi-Melacrino-Morelli, Reggio Calabria, Italy
13. Sam Salek – Professor of Pharmacoepidemiology, University of Hertfordshire, Hatfield, Herts, United Kingdom

List of activities
1. From 2012 Performance of the project “The Conceptualisation, Development and Validation of a Patient-Reported Outcome Measure For Patients with Haematological Malignancies in Routine Clinical Practice”
2. Annual meeting of the EHA SWG within the 20th EHA congress, 13th June, 2014, Milan
Workshop” Quality of life and symptoms: Practical considerations in using patient-reported outcome information in routine clinical practice to aid treatment decision-making”, 20th EHA Congress, June 2015, Vienna
List of grants obtained by the EHA SWG

- Research/educational grant from Novartis for “the development of a treatment-related patient-reported outcome measure in haematological malignancies for use in clinical practice” and to arrange/conduct meetings of the EHA Quality of Life and Symptoms SWG.

- Research/educational grant from Sanofi for “the development of a treatment-related patient-reported outcome measure in haematological malignancies for use in clinical practice” and to arrange/conduct meetings of the EHA Quality of Life and Symptoms SWG.

- Research/educational grant from BMS for “the development of a treatment-related patient-reported outcome measure in haematological malignancies for use in clinical practice” and to arrange/conduct meetings of the EHA Quality of Life and Symptoms SWG.

List of publications from or related to the EHA Quality of Life and Symptoms SWG


List of activities and presentations at national and international meetings

- EHA 2015 annual meeting E-poster (E1436) Quality of life in patients with lower risk Myelodysplastic Syndromes with severe thrombocytopenia treated with Eltrombopag: Interim results of a randomized, placebo-controlled prospective trial.
- ISPOR European Annual meeting 2015. SALEK S, Kamudoni P, Oliva E, Ionova T. Quality of Life Issues Important to Patients with Haematological Malignancies. Value in Health 2015; Ab 709
• 57th American Society of Hematology Annual Meeting 2015 poster presentation. Quality of Life in Elderly Patients with Acute Myeloid Leukemia Undergoing Induction Chemotherapy. Ab 2120.

• Eurasian hematology Congress. St.Petersburg, 3-5 March 2016 Oral presentation OLIVA E. Treatment strategies and quality of life in elderly AML patients

• Eurasian hematology Congress. St.Petersburg, 3-5 March 2016 Oral presentation SALEK S. Using patient-reported outcome information to aid treatment decision making in patients with hematological malignancies

• Eurasian hematology Congress. St.Petersburg, 3-5 March 2016 Oral presentation OLIVA E. Quality of life issues important to patients with hematological malignancies

• Eurasian hematology Congress. St.Petersburg, 3-5 March 2016 Oral presentation IONOVA T. Application of quality of life and symptom assessment in hematooncology.