EHA SWG “Quality of Life and Symptoms”
Annual Report
March 2017

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, Grande Ospedale Metropolitano 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, Grande Ospedale Metropolitano Bianchi Melacrino Morelli, Reggio Calabria, Italy
- Sam Salek – Professor of Pharmacoepidemiology, University of
Hertfordshire, Hatfield, Herts, United Kingdom

- Anita Waldmann – Chair, LEUKÄMIEHILFE RHEIN-MAIN E.V. Patient Organization, Ruesselsheim, Germany.

**Membership list with names and e-mail addresses**

1. Thomas Osborne – Clinical Research Fellow, Department of Palliative Care, Policy and Rehabilitation, King’s College, London; e-mail: thomas.osborne@kcl.ac.uk
2. Monica Else – Hemato-Oncology Research Unit, Division of Molecular Pathology, The Institute of Cancer Research, Sutton, UK; e-mail: Monica.Else@icr.ac.uk
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4. Sylvia von Mackensen – Institute of Medical Psychology, University Medical Centre Hamburg-Eppendorf, Germany; e-mail: s.mackensen@uke.uni-hamburg.de
5. Sophie Wintrich – MDS UK Patient Support Group, Bessemer Wing King’s College Hospital, Denmark Hill, London, SE5 9RS UK; e-mail: SWintrich@mds-foundation.org
6. Tatiana Nikitina – Multinational Center for Quality of Life Research, St-Petersburg, Russia; e-mail: qlife@rambler.ru
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8. Agostino Cortelegetti - Fondazione IRCCS Ca’ Granda Ospedale Maggiore Policlinico, University of Milan, Milan, Italy; e-mail: agostino.cortelegetti@unimi.it
9. Roger Else – Patient Research Partner, Melton Keynes, United Kingdom. Roger.else@gmail.com
10. Pushpendra Goswami – Research Fellow, School of Life & Medical Sciences, University of Hertfordshire, Hatfield, United Kingdom. Pg15aas@herts.ac.uk.
11. Tatyana Ionova – Chair of Board, Multinational Center for Quality of Life Research, St-Petersburg, Russia.
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
1. **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 Maligancies in Routine Clinical Practice”- 5 stages of the project have been finalized.

2. Workshop” Quality of life and symptoms: transferring the science of assessing response to treatment in hematological malignancies: a PRO Perspective”, 20th EHA Congress, 11 June 2016, Copenhagen

3. Meeting with Patient Organizations, 11 June 2016, Copenhagen

4. EHA SWG Panel meeting, 25-26 July 2016, Frankfurt

5. EHA SWG brain storming “Content validity” meeting, 3 October 2016, London

**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**


Measure in Haematological Malignancy for Use in Routine Clinical Practice: Item Generation. Blood 2016 128:5985


List of activities and presentations at national and international meetings

EHA 2016 annual meeting E-poster (E1447) The impact of hematological malignancy on patients’ health-related quality of life and symptoms: A qualitative
study. -
QOL-ONE MDS and AML meeting, Reggio Calabri, 16-17 September, 2016
Sam Salek Quality of life in Haematological Malignancies
QOL-ONE MDS and AML meeting, Reggio Calabri, 16-17 September, 2016
Ionova T. Quality of life in patients with MDS
- Eurasian Hematology Congress. St.Petersburg, 6-9 April 2017 Oral presentation
OLIVA E. Quality of life issues important to patients with hematological malignancies: physician perspective
- Eurasian Hematology Congress. St.Petersburg, 6-9 April 2017 Oral presentation
Ionova T. Quality of life assessment in patients with hematological malignancies: why and when?