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

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.

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

**Board Members’ conflicts of interest**

None.

**Scientific Advisory Board**

- James Armitage - Professor, Dept. of Internal Medicine Hematology / Oncology, Nebraska Medical Center, Omaha, USA
- Athanasios Fassas - Dept. of Hematology and Bone Marrow Transplantation Unit, Cell and Gene Therapy Unit, George Papanicolaou Hospital, Exokhi, Thessaloniki, Greece
- Gary Gorodokin - President, New Jersey Center for Quality of Life and Health Outcome Research, Saddle River, NJ, USA
- Anton Hagenbeek - Professor of Hematology, Dept. of Hematology, Academic Medical Center, University of Amsterdam, Amsterdam, the Netherlands
- Gergely Krivan - President of Hungarian Society of Pediatric Oncology and Hematology, Budapest, Hungary
- Andrew Lister - Emeritus Professor of Medical Oncology, Barts Cancer Institute, Barts and the London School of Medicine and Dentistry, Queen Mary University, London, UK
- Geraldine Padilla - Professor, Emeritus School of Nursing University of California, San Francisco, CA, USA

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

1. Patrick Hayden - Department of Hematology, St James’s Hospital and University of Dublin, Trinity College, Dublin, Ireland; e-mail: haydenpj@eircom.net

2. Thomas Osborne – Clinical Research Fellow, Department of Palliative Care, Policy and Rehabilitation, King’s College, London; e-mail: thomas.osborne@kcl.ac.uk
3. Monica Else – Hemato-Oncology Research Unit, Division of Molecular Pathology, The Institute of Cancer Research, Sutton, UK; e-mail: Monica.Else@icr.ac.uk

4. Paul Imbach – Pediatric Oncology/Hematology Medical Faculty, University of Basel, Switzerland; e-mail: Paul.Imbach@unibas.ch

5. Floortje Mols – Department of Medical Psychology and Neuropsychology, Center of Research on Psychology in Somatic diseases (CoRPS), Tilburg University, The Netherlands; e-mail: F.Mols@uvt.nl

6. Robert Klaassen – Department of Pediatric Hematology/Oncology, Children’s Hospital of Eastern Ontario, Canada; e-mail: rklaassen@cheo.on.ca

7. Denis Fedorenko – Pirogov National Medico-Surgical Center, Moscow, Russia; e-mail: den_f76@mail.ru

8. Anita Waldmann – Myeloma Euronet, Ruesselsheim, Germany; e-mail: info@myeloma-euronet.org

9. Sylvia von Mackensen – Institute of Medical Psychology, University Medical Centre Hamburg-Eppendorf, Germany; e-mail: s.mackensen@uke.uni-hamburg.de

10. Sophie Wintrich – MDS UK Patient Support Group, Bessemer Wing King’s College Hospital, Denmark Hill, London, SE5 9RS UK; e-mail: SWinrich@mds-foundation.org

11. Christen L. Andersen – Department of Hematology, Roskilde Hospital, University of Copenhagen, Koegevej 7-13, 4000 Roskilde Denmark; e-mail: christenla@gmail.com

12. Natalia Shablovskaya – Multinational Center for Quality of Life Research, St-Petersburg, Russia; e-mail: qlife@rambler.ru

13. Felice Bombachi – CML Patient Advocacy Group, Rome, Italy e-mail: felice.bombaci@ailpazienti.it

14. Agostino Cortelezzi - Fondazione IRCCS Ca’ Granda Ospedale Maggiore Policlinico, University of Milan, Milan, Italy; e-mail: agostino.cortelezzi@unimi.it
List of activities

- Workshop “Use of quality of life information in routine practice to aid treatment decision making”, 19th EHA Congress, June 2014, Milan, Italy
- Annual meeting of the EHA SWG within the 19th EHA congress, 13th June, 2014, Milan, Italy
- Brain-storming meeting with the patient members and invited patient guests to discuss the progress and patients’ input (as research partner) in “the development of a treatment-related patient-reported outcome measure in haematological malignancies for use in clinical practice”, 16th October, 2014, Berlin, Germany.

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
Poster presentation in Cancer/Hematology session at the 21st ISOQOL annual conference, 16-18 October, 2014, Berlin, Germany