EHA-SWG Annual Report 2017

MAIN SECTIONS (NOTE: sections 1-4 will be used for publication on EHA website)

1. Name of the SWG: Quality of Life and Symptoms

2. Focus and mission of the SWG (this section will be published also as SWG short presentation on the EHA website)

The goals of the SWG are:
1. to promote the evaluation of patient reported outcomes (PROs) in haematology in daily clinical practice and in clinical trials.
2. international networking of haematologists, researchers, patient representatives and patient research partners to share data and experience
3. educational activities in PRO assessment
4. to promote PRO research in haematology.

Research activities since 2012 include the creation of a new tool for the evaluation of PROs in patients with haematological malignancies (HM-PRO), research in the field of impact of disease and treatment in patients with congenital pyruvate kinase deficiency and in Gaucher’s disease.

3. SWG highlights of past calendar year

The creation of the HM-PRO in UK English is a long process that is employing hundreds of patients with haematological malignancies, haematologists from the UK, international patient representatives and researchers in a teamwork since 2012. The prototype has been created and is undergoing final validation according to international standards. The tool will be made available in several international languages and will be finalized in the next year.

Another important project initiated in 2017 is the collaboration with the Italian QOL-ONE Association to create a new instrument for the measurement of PROs in Gaucher Disease.

4. Chair and affiliations: Esther Natalie Oliva, Grande Ospedale Metropolitano Bianchi Melacrino Morelli, Reggio Calabria, Italy

5. Board members and terms: Sam Salek, Co-Chair 2018; Tatyana Ionova, Secretary 2018.

6. Conflicts of interest of the board:

7. Membership list with names and email addresses:

List of members:

- Monica Else - Monica.Else@icr.ac.uk
- Denis Fedorenko - den_f76@mail.ru
8. List of scientific activities

SWG session at EHA congress 2017, entitled "Present and future of quality of life and symptom assessment in daily clinical practice in haematological malignancies". The Chair of the Session was Prof. Tatyana Ionova. The goal of the session was to inform attendees about the achievements in the field of measuring patient reported outcomes in haematology in daily clinical practice. Speakers were Esther N Oliva, who underscored the value of PRO measures in clinical trials versus daily practice, Adele Fielding, who discussed barriers and solutions in the assessment of PROs, Anita Waldman, who highlighted the role of the patients’ voice in patient journey and Sam Salek, who presented the pilot HM-PRO instrument to the attendees. There were more than 150 attendees.

Presentations at national and international meetings
The SWG was among the sponsors of the V Eurasian Hematology Forum, which was held in St. Petersburg, April 6-9, 2017. Within the Forum Andrei Novik Memorial Symposium took place. It was chaired by Prof. Anton Hagenbeek and included A. Novik Memorial lecture by Prof. Boris Afanasiev, who highlighted the role of allo HSCT in relapsing/remitting Hodgkin disease as well as the talks by Dr. Esther Oliva, who discussed QoL issues important to patients with haematological malignancies, Prof. Tatyana Ionova, who covered the approaches to assess QoL in
patients with haematological malignancies and the talk by Dr. Denis Fedorenko, who presented the model of comprehensive evaluation of the outcomes of autologous hematopoietic stem cell transplantation in Non-Hodgkin lymphoma patients. The Forum was attended by more than 200 hematologists, researchers and patient representatives from 18 countries.

Clinical trials promoted by or involving the SWG
1. HM-PRO - The EUROPEAN HEMATOLOGY ASSOCIATION Scientific Working Group “QUALITY OF LIFE AND SYMPTOMS” Project to Develop Treatment–Related Patient-Reported Outcome Measure in Haematological Malignancies for Use in Clinical Practice
2. QOL-ONE PRO1G - Observational Study to Develop a Treatment–Related Patient-Reported Outcome Measure in Gaucher Disease

Other social & public activities

9. List of publications from or related to the SWG


In 2017, the following relevant abstracts have been presented as posters/oral presentations at international conferences:


Links to EHA-SWG websites to HM-PRO project:
https://www.lymphomas.org.uk/lymphoma-trialslink/find-trial/lymphoma-hm-pro-trial