

European Network for Teenagers and Young Adults with Cancer Meeting

Report from the Leadership Group (March – December 2020)

Dear All,

We hope this message find you well in these unusual and difficult times.

Following our meeting on 9 March 2020 in Brussels, the leadership group consisting of Marie Balsat (FR), Ivana Bozovic (RS), Anna Castleton (UK), Johan De Munter (BE), Andrea Ferrari (IT), Ashley Gamble (UK), Assia Konsoulova-Kirova (BG), Katie Rizvi (RO), Carina Schneider (AT), Dan Stark (UK), Josefien Vermeersch (BE) and Anita Kienesberger (AT), have met on three occasions to discuss upcoming initiatives and activities that were suggested during the meeting in Brussels.

The key objective is to rebuild a network function across professional disciplines, consumers, charities and national groups to focus upon AYA cancer care and improving their outcomes across Europe, with the aim of widening the set of people who are aware and making use of the ongoing European collaborations in AYA cancer care and to widen the team of people and organisations who can play a part in ongoing and future collaborations in AYA cancer care

Please find below an update on the activities undertaken so far:

Survey 1 - HCPs

The purpose of this initiative is to survey the state of development in terms of providing age-specific care across Europe to TYA. Endorsed by SIOPE, ESMO, EONS. The aims are to understand the challenges and their geographical and cultural distribution (the data), the engagement with stakeholders, and to map progress sequentially. The survey would be repeated every couple of years to distribution channels such as national and international society members (SIOPE, ESMO, EONS, EHA), the haematology community (EHA, EBMT), ERN PaedCan members, and perhaps some others. This survey aims to reach individuals, specifically HCPs, and not organisations. The survey is nearly finalized and the aim is to circulate it by March 2021 and to analyze and publish the survey results in June 2021.

Survey 2 - NGOs

The purpose of their second survey is to reach NGOs and parent/patient organisations in different countries in order to obtain a catalogue of NGOs and other organisations that have a stake in AYA activities. The survey content will relate to the professional survey so that sensible but limited comparisons can be carried out.

This survey is also nearing completion and will be launched at the same time as the HCP survey. Results will be analysed and compared.

Common position statement/paper

A short, broad editorial is currently being drafted, expressing our wish to work in this very broad manner, to engage actively with all of paediatric and adult oncology organisations, adult haematology, nursing, NGOs, and parents/survivors. The purpose of this editorial is to make the position of the group clear and to invite others to join this initiative. We want to avoid a description of challenges and problems. The target audience is global AYA-interested professionals and NGOs. We expect to have a first draft of this editorial at the end of 2020.

EU consultations/policy

The group has explored possible channels to influence policy and will draft a policy statement with endorsement of SIOPE, EONS, ESMO and CCI-Europe, following the publication of the position paper.

Stakeholders

We are in the process of making formal agreements with SIOPE, ESMO, EONS, EHA, and others in order to ensure optimal collaboration and buy-in to the network. We've had requests from several other groups who wish to be part of this initiative. The structure of the network requires further thought, to make sure all stakeholders are included and the network runs effectively.

Next steps

We propose to hold a meeting by Zoom with the group who met in Brussels in order to get feedback about the above initiatives, proposals for new initiatives and input on the structure of the network.

We very much look forward to continuing our fruitful collaboration with the aim of better addressing the specific needs of teenagers and young adults with cancer.

Should you have any further questions, please don't hesitate to contact us.

Sincerely,

Dan Stark, on behalf of the ENTYAC Leadership Group

Andrea Ferrari, on behalf of the SIOP Europe AYA Committee