

Breadcrumb

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Entity Print

The Committee is composed of patient advocates of EU patient organisations representing patients with haematological diseases, and national patient associations as well as a representative of the EBMT Nurses Group from the country where the upcoming Annual Meeting is taking place to participate in the organisation of Patient, Family and Donor Day.



Bregje Verhoeven
PATIENT ADVOCACY COMMITTEE CHAIR
Netherlands

Major achievements

The patient advocacy committee (PAC) is chaired by Bregje Verhoeven. Since 2020 it is divided into the three subcommittees: Advocacy by Natacha Bolanos, Education by Sarah Hutton and the sub-committee Science by Andrea Linke. Since its foundation in 2018 the activities of the committee are growing steadily.

Our mission is Patient engagement voicing the patient perspective, as an integral part of EBMT organization including governance and activities to help safe patients' life and better QoL.

Our vision is building a stable committee with a diversity of members, which is visible and representative in EBMT organization and its (scientific) activities including activities with other related stakeholders.

The main activity of the committee is the organisation of the Patient Family Donor Day and the Patient Advocacy Sessions program at the Annual Meeting. Since the foundation of the PAC in 2018, we have seen an increase in active collaboration with various Working Parties, Committees and Nurse Group. PAC members are being invited as speakers at educational events, join studies of the TCWP. Co-authorship in publications took place twice and has decreased compared to 2020.

The PAC conducts monthly teleconferences in order to follow the evolution of all the activities. We continued to keep strong links with European Patient Organisations to promote EBMT activities and to provide patient expertise to EBMT. On Twitter we have grown to 224 followers.

The PAC is also strongly committed to educational activities and we continuously encourage EBMT members to be open to the possibilities of patient engagement.

Key activities

Oral presentations

1. “A perspective on health inequalities: inequalities in access to bone marrow transplant” ED&I session Annual Meeting
2. “The patient perspective” 6th International Transplant Course 3-4 September 2021
3. “Patients' perspective” EBMT Summit on Covid-19 - 29 June-1 July 2021
4. “Patient & carer perspective on Social Media”, Annual Meeting 2021
5. “Going through the bone marrow transplant process in-hospital period”, Nurse Group International Training Course - 4 September 2021
6. “Patient Involvement and Patient Recruitment in research” at the 5th EBMT Nurses Group Research Study Day - 8 October 2021

Publications

The EBMT/EHA CAR-T Cell Handbook: : co-author of the chapter *“What do patients want? The importance of patient reported outcomes”* (H Shoemans, L Warwick, N Bolaños) April 2021

Hematopoietic stem cell transplantation for autoimmune diseases in the time of COVID-19: EBMT guidelines and recommendations. *Bone Marrow Transplantation* (2021)

Abstract

OS14-2 ONE THOUSAND VOICES ADDRESS PATIENT ENGAGEMENT IN HEMATOPOIETIC STEM CELL TRANSPLANTATION AND CELL THERAPY: RESULTS OF A SURVEY FROM THE EBMT Helene Schoemans (Belgium)

Patient Member of the:

1. Clinical Outcomes Group
2. SAAWP
3. Equality, Diversity & Inclusion (ED&I)
4. Patient Engagement Task Force

Annual Meeting

1. Program, host, chair and present at Patient, Family and Donor Day
2. Program, host, chair and present at Patient Advocacy Sessions

Other participations

1. European Health Data Space Consultation – July 2021 (Digital health data and services) provided the patient perspective to build, by consensus, the answer to the Open Consultation.
2. 4th EBMT-EHA European CAR T-Cell meeting input SCP
3. EBMT-EHA GoCART multi-stakeholder coalition
4. T2Evolve WG3

Studies

Visit the Patient Advocacy Committee Webpage