

HLH STEERING COMMITTEE REPORT - JULY 2019

July 20, 2019

Members: Michael Jordan and Kim Nichols (Acting Co-Chairs), Itziar Astigarraga, Scott Baker, Stephan Ehl, Jan-Inge Henter, AnnaCarin Horne, Gritta Janka, Kai Lehmborg, Elena Sieni, Zhao Wang

Additionally, the following individuals are joining the committee, effective 2019: Ed Behrens, Rafal Machowicz, Rebecca Marsh

Organizational updates: The committee thanks Stephan Ehl for his leadership. Stephan elected to step down as committee chair in 2018 to focus on other commitments. Kim and Mike are serving as acting co-chairs, in a temporary capacity and according to Society bylaws, a Board member cannot head a Steering Committee.

Activities:

- 1. International HLH registry:** The HS, in collaboration with ESID, has an ongoing international registry for patients with newly diagnosed HLH. The registry is open in 16 countries and over 90 patients have been enrolled. (contact person S. Ehl)
- 2. HLH in adults:** Congratulations on publication of recent article on this topic by the working group focusing on this topic (PMID: 30992265). (Contact person Paul LaRosee)
- 3. HLH subgroups:** A working group (led by Melissa Hines) aiming to describe HLH in the ICU is nearing submission of a paper. Additional projects in this area include better describing HLH in immune suppressed patients and development of subgroup guidelines (contact K. Lehmborg).
- 4. HLH diagnostics:** Can we improve diagnostic criteria for HLH? An international collaboration has been initiated to examine this idea (contact JI Henter). We will discuss further at the HS meeting this fall in Memphis.
- 5. Long term follow up of patients with HLH:** A working group has prepared a systematic review which was presented at the last EBMT congress. Publication is anticipated soon. An additional project is ongoing through CIBMTR and EBMT (contact S. Baker and Karin Beutel).
- 6. 2019 HS meeting:** We are planning for the HS 2019 meeting in Memphis. During the "pre-meeting" there will be a closed Steering Committee meeting. We are also organizing an open session to discuss relevant topics in HLH. Initial suggestions include defining controversies and consensus with regards to HLH diagnosis and treatment as well as ongoing studies not presented at the main meeting. We also welcome agenda items from the HS community.

Membership Communication: Please send Mike (michael.jordan@cchmc.org) and Kim (kim.nichols@stjude.org) any comments or questions. Suggestions are appreciated for content for the HLH pre-meeting session in Memphis.