

Dr Martin S. Tallman, MD, President
Dr Jane N. Winter, MD, President-Elect
AMERICAN SOCIETY of HEMATOLOGY
2021 L Street NW, Suite 900,
Washington, DC 20036, USA

Subject: barriers to patient advocate attendance at the ASH Annual Meeting

Dear Dr Tallman and Dr Winter,

As representatives of patient advocate organizations focused on hematological malignancies and non-malignancies, we write to highlight the current situation which is preventing patient advocates from attending the American Society of Hematology (ASH) Annual Meeting and Exposition.

We believe that the attendance by patient advocates at the ASH annual meeting is of the utmost importance given:

- the substantial challenges and opportunities in hematology,
- the innovative development of therapies in hematology
- ASH's pivotal role at the forefront of these issues globally,
- the myriad of existing patient organizations focused on hematologic conditions that, among other things, communicate with and assist many thousands of patients and families annually,
- the acute need to support access to clinical trial information for both patients as well as general hematologists,
- the repeated request by individual pharmaceutical companies (but also industry groups like ABPI), and regulatory authorities (FDA and EMA) to involve 'patient experts' at every level of drug development, to ensure the 'patient voice' is captured,
- that ASH accepts posters based on research conducted by established patient groups, and as such, already unequivocally recognizes the scientific value of data published by these groups and patient experts,
- the fact that an increasing number of patient advocates regularly contribute their expertise in academic and industry-based research projects, on a par with clinicians and researchers,
- the fact that ethics boards frequently reject research projects which have not been reviewed by patient groups or patient experts.

Currently there is no category for patient advocates to register their attendance at the meeting, meaning those who wish to attend must register as a 'Non-Member' with fees of \$750-950, as per the virtual attendance at the recent 2020 meeting. This creates an impossible barrier to accessing information on the latest research and development on which our patient communities desperately rely.

We ask that patient advocates be urgently recognized in the registration categories (as is already the case for other major scientific congresses e.g., EHA, EBMT, ESMO, ASCO, etc.) with registration available free to non-profit organization representatives from around the world.

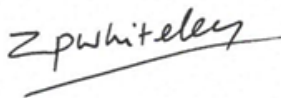
Our overall objective is to enable patient advocates – from registered non-profit organizations – to take part in the annual ASH meetings with the goal of advancing essential patient advocacy of those living with hematological conditions in such critical areas as patient education, collaboration in research and development processes, stakeholder engagement, clinical trial recruitment and advocating for clinical research.

Therefore, we would encourage the ASH board to take the next logical step in embracing the scientific collaboration with patient advocates further, and grant them full congress access, with a recognized status and free or at least, a non-for-profit registration rate.

We hope these submissions will help to explain our renewed efforts on this topic. We invite the ASH board to discuss this request with us, with a view to implementing a formal registration process for not-for-profit patient organizations ahead of the next December 2021 meeting.

Thank you for your consideration of this request. We look forward to hearing from you as soon as convenient.

Yours Sincerely,



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