

Principles of haemophilia care: The asia pacific perspective. Response

Dear Editor,

We have carefully noted the issues raised in the two letters^{1,2} regarding the Asia-Pacific perspective on the principles of haemophilia care and thank these authors for bringing us back to these matters, which were extensively discussed within the APHWG before finalizing this paper.³

First, we would like to point out that a document describing the principles of care is always intended to be futuristic and aspirational and not just a catalogue of current realities. So while fully recognizing the challenges and limitations of haemophilia management in many countries within this region, what is recommended by the group is what we would like to see happen sooner than later. Only then can this document be used for advocacy for improvement. In fact, this is not different from what was done in the paper, which described the European principles of haemophilia care in 2008⁴ followed by an evaluation of the adherence to those principles in several countries five years later.⁵ It was obvious that even in those centres selected for compliance review, not all were following/able to follow all the enunciated principles. They therefore needed to improve—exactly fulfilling the purpose of the original document in providing a benchmark. Even today, ten years later, if we evaluate all haemophilia treatment centres in Europe, it is very likely that many centres would still be far from meeting all proposed principles of care. This does not in any way diminish the purpose and value of the original proposals but rather confirms their utility as benchmarks against, which to continuously compare and improve performance.

With regard to the use of cryoprecipitate in haemophilia management in the Asia-Pacific region, we acknowledge the views expressed by the two authors but do not share their perspective. As mentioned in the paper already, we reiterate that we are fully aware of the need to use blood bank products under unavoidable circumstances. However, we would sincerely want that situation to change as soon as possible, so that people with haemophilia in all of Asia-Pacific can receive the same care as those in Luxembourg and Taiwan, whence these authors originate and where cryoprecipitate is not used at all for the treatment of haemophilia. Most critically, at a time when it has been clearly established that prophylaxis is the only way to alter the natural history of severe haemophilia⁶ and we are strongly advocating for clotting factor concentrates (CFCs) for the same, we do not want to distract attention of the health authorities with wet cryoprecipitate which can hardly be used for prophylaxis.

For replacement therapy, we have clearly mentioned that both plasma derived and recombinant CFCs may be used, based on availability. We believe that a detailed discussion on their relative merits

particularly in the context of inhibitor development is beyond the scope this document. Our recommendations are consistent with current realities of product availability and costs, the positions of other international organizations and conclusions of major regulatory agencies after consideration of available evidence.⁷

Finally, we urge that just as we appreciate and respect the efforts of altruistically motivated people around the world to help those living under the economic constraints of developing countries, mutual respect for people living in those regions who are trying to define their own future should be the norm.

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