

Community members,

We understand the past few months have brought a lot of anxiety and uncertainty to our community as we've dealt with a variety of critical issues that have called into question the safety of the products we use, the type of partners we rely on for our health, and the type of community we want to be. Whether it was the Bayer Kogenate recall, issues with respect to needle size as reported by Genentech, or ongoing concern about health care in general, the level of concern in our community is high – and rightfully so. We are advocates for the health and well-being of each and every member of the bleeding disorders community and when we feel any of our voices are not heard, it is and should be a cause for concern.

As we gather this week, please know NHF and HFA leadership have been reflecting on these issues and how to best respond, moving forward; this reflection will no doubt go on in Anaheim as our many stakeholders come together, compare notes, and look to our community for strength and reassurance. We encourage these discussions and direct input to us on how we can best support you. We have created a shared inbox, "[The Patient Voice: Product Safety Issues](#)" where you can share thoughts, concerns and questions. We will respond to your questions as soon as possible.

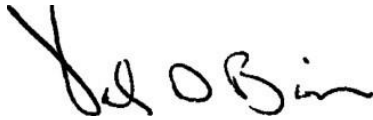
Importantly, we've also begun to work through how we will actively manage issues like these in the future and how we can meet your needs in the most effective way. To best look to the future of how we advocate, we want to engage the community in a discussion to see where we need to go. Together, NHF and HFA have engaged outside experts to help us and they will be providing guidance on effective communication, advocacy, and planning for the future.

Working with our outside experts, we have already taken several steps to help us move forward, including:

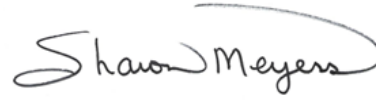
- A joint planning committee has been created to organize a Safety Summit in January 2020 to bring patient organizations and patients together with medical providers, government, and industry to review current standards and processes in place to address product safety and discuss how these measures may be improved or expanded.
- Assessing our communication processes so that we are meeting the needs of community members in terms of notification, information, advocacy, and input.
- Moving rapidly on the flow of information from our groups to industry and faster information from industry back to the community. We will continue to focus on the need for expedited and more robust communications among stakeholders.
- Assessing what it means to be both a change agent and an advocate. Our community is built on the voices of many before us and we will need many voices to carry us forward. We are looking at new ways to engage the bleeding disorder community in advocacy to drive change and better care for those we serve.

Our community has faced adversity and change before, but NHF and HFA believe taking a hard look at how we advocate and work together more effectively is in order. We are ready to listen, we are ready to discuss, and we are ready to move forward. We know we are all better when we speak with one strong and clear voice. Together we will be strong. Together, we make our community stronger for a better tomorrow.

Sincerely,



Val Bias  
Chief Executive Officer  
National Hemophilia Foundation



Sharon Meyers, M.S., CFRE  
Interim President & CEO  
Hemophilia Federation of America