



Leading Bleeding Disorders Organizations and Key Stakeholders Gather This Week to Address Patient Safety

WASHINGTON, DISTRICT OF COLUMBIA, UNITED STATES, January 29, 2020 /EINPresswire.com/ -- [Hemophilia Federation of America](#) and the [National Hemophilia Foundation](#), two of the leading organizations in the United States dedicated to patients with bleeding disorders, joined forces this week in Washington, D.C., for a three-day Safety Summit beginning Jan. 29 designed to address concerns and improve communication on safety for bleeding disorders patients.

Those in attendance, including patients and patient organizations on local, national and international levels, medical professionals, pharmaceutical companies, specialty pharmacies and federal partners, such as the Centers for Disease Control and Prevention, are participating in open discussions to address the unparalleled number of product recalls and other product safety notices in 2019.

Last year's recalls and safety issues were unsettling to patients and echoed of tragedies in the community's past. While safety issues came to the forefront in 2019, other topics such as uncharted studies in gene therapy and other novel treatments left the community eager for better communication and standard operating procedures.

"Making sure our patients with bleeding disorders have safe therapies isn't the responsibility of just one group," said Sonji Wilkes, Senior Director of Policy and Advocacy for HFA. "Everyone, from the government to the pharmaceutical companies to organizations like ours to the patients themselves have a part to play."

HFA and NHF, along with the stakeholders attending this invitation-only meeting, are discussing expectations for monitoring product safety issues, ways to educate and communicate these issues to the community, and taking steps to set standard operating and communication procedures. The summit attendees are examining current regulatory requirements and reporting procedures, discussing who should be responsible for patient and product safety, identifying gaps in knowledge and understanding of current drug safety standards, developing educational resources to address the identified gaps, and identifying the role of patient organizations.

Following this week's Safety Summit, HFA and NHF plan to author a paper summarizing the Summit's results, such as best practices for communications safety issues, recommendations for standard practices, and the expectations of each stakeholder, including the responsibilities of patients.

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