

First National USA Type 3 Von Willebrand Disease (VWD) Conference

Authors: Jeanette Cesta, Edward Kuebler, MSW, LLC, VWD Connect Foundation, Inc.

Objectives:



It is estimated there are approximately 300-400 Type 3 Von Willebrand Disease patients in the United States. These patients often experience severe bleeding episodes and many psychosocial challenges. Being a rare disease state, both experienced medical and psychosocial support is not always readily available to patients. Patients are often isolated from other Type 3 VWD patients, resulting in a lack of peer support. In response, the First National USA Type 3 Von Willebrand Disease Conference was held in May 2017 in Florida, USA. The goal of the conference was to connect patients with each other, medical professionals and the bleeding disorder community in a safe and supportive environment.

Methods:

Eighty Type 3 VWD patients, along with a companion(s), were provided a conference to connect, learn and share experiences. Patients came from over 30 different states and ranged in age from one to seventy-five years old. A twenty-two member faculty and a staff of fifteen presented educational programs and facilitated social activities throughout the conference, resulting in a total attendance of 240. The conference faculty included doctors, nurses, social workers, physical therapists and bleeding disorder educators and represented a variety of medical specialties including hematology, gynecology, dentistry, genetics, pain management and psychology. To guide the educational content, patients were asked at registration what medical question they would like answered at the conference and what is their biggest challenge living with Type 3 VWD. The conference consisted of ten full-assembly sessions and a choice of seven breakout sessions offering nineteen different topics. An electronic audience response system (ARS) monitored the attendees' comprehension and material's effectiveness along with collecting patient data.



Hematologists on faculty for the conference:

Stacy Croteau, MD
Robert Montgomery, MD
Steven Pipe, MD
Robert Sidonio, MD
Christopher Walsh, MD
Michael Wang, MD
Tung Wynn, MD

Results:



Sixty-five patients participated in the ARS. When asked if their pre-conference questions were answered, 93% responded with either “yes” (81%) or “no, but know how to get it now” (12%). Additionally, 47% stated they have never met another Type 3 VWD patient outside of their own family. Ninety-eight percent would attend this event again. When asked if they felt safe at the conference and that their privacy was respected, 100% responded “yes”.

Conclusions:

Assessment of the patients' responses indicate an increase in medical knowledge and community resources and intention to act on information received. To further serve this patient group's needs, VWD Connect Foundation, Inc. was established in August 2017. A 2nd USA National Type 3 VWD Conference is scheduled for June 2018. Plans are in development for regional education programs throughout the year.

