

# Von Willebrand Disease (VWD) Patient Conference in response to the 2014 Strategic Summit on VWD

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## Introduction and Objectives

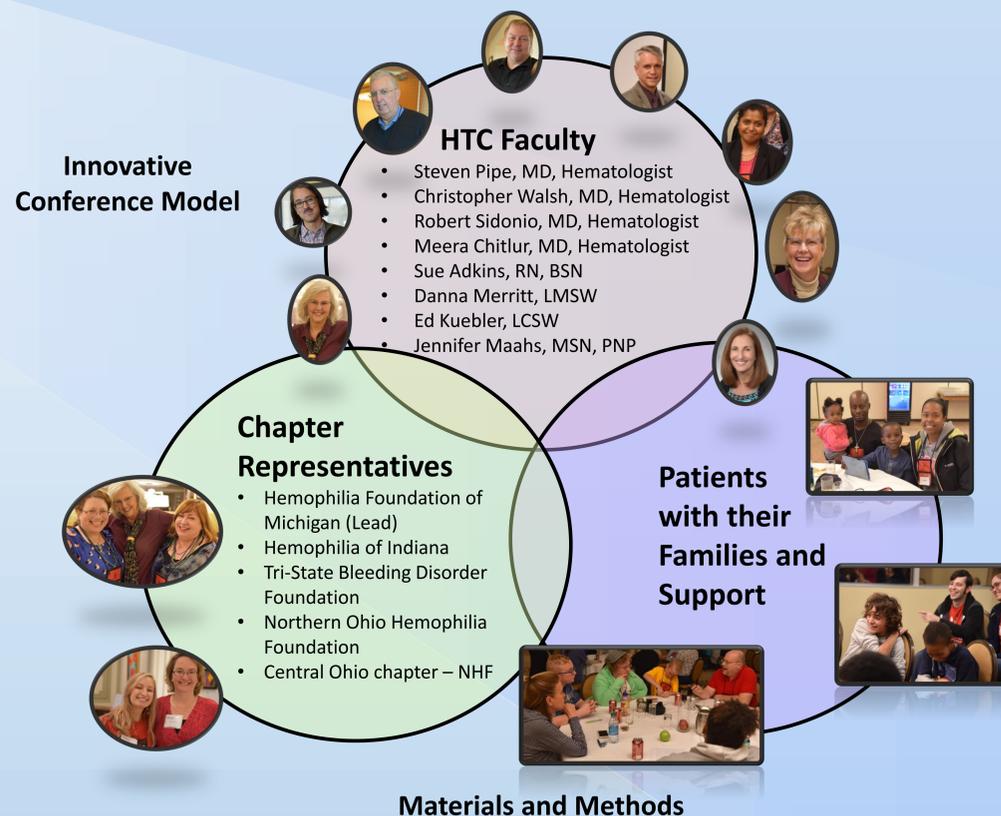
The 2014 National Hemophilia Foundation (NHF) Strategic Summit on VWD concluded that recognizing and addressing stigma, apathy and clinical marginalization should be included in future educational activities in order to improve VWD patient care. In response to this vision, a two-day regional conference was developed. The conference incorporated innovative features to facilitate educational opportunities for patients, their families, and Hemophilia Treatment Center (HTC) providers. Conference goals included focused objectives for both patients and providers :

Patients: Bring together people with VWD that live in the Michigan, Indiana and Ohio (Region V-East) in order for them to gain knowledge of relevant medical and psycho-social issues.

- Increase patient's medical knowledge of VWD and related complexities of VWD diagnosis and treatment
- Increase patient's awareness of national initiatives aimed at improving patient care such as ATHNdataset, 2014 VWD Summit Report and current research on VWD
- Encourage patients to use material presented at the conference to enhance communication with their providers at home
- Provide a safe environment to allow for sharing of personal experiences with fellow attendees and faculty
- Share ideas and resources for tackling the psychosocial challenges of living with VWD

Providers: Bring together healthcare professionals in the bleeding disorder provider network to discuss with patients current medical and psychosocial challenges regarding VWD diagnosis and treatment.

- Enhance patient provider relationship by providing opportunities for small group discussions between patients and HTC providers
- Utilization of conference attendees as a focus group providing information to providers about their lived experiences with VWD, which could potentially spark further research
- Create opportunities for continued VWD education by providing support for future local programming
- Create an open environment for providers to share their perspective on current challenges they facing in diagnosing and treating VWD in an effort to better patient/provider collaboration and understanding.



In November 2015, Hemophilia Foundation of Michigan received an a unrestricted grant from Octapharma to fund the first Regional VWD Conference. Region V-East Chapters and HTCs were welcomed to participate.

- These Chapters and HTCs were invited to a planning meeting for this Conference in August 2015 to discuss potential educational sessions at the Conference and to strategize on logistics for outreach to potential attendees. A faculty of presenters was established including doctors, nurses and social workers from HTC's, reflecting the Comprehensive Care Model.
- During online registration, patients were asked what medical and psychosocial issues they find most challenging. This information was provided to the faculty in aggregated form prior to the Conference. Faculty were then able to organize their presentations based on the questions and concerns the attendees articulated.
- The conference consisted of 30 minute general sessions followed by 15 minute discussions, and a choice of four of six 45 minute breakout sessions. Session topics were developed to address the objectives and goals of the Conference.
- A post-conference written survey was distributed to attendees to gauge effectiveness of the Conference in relationship to the goals and objectives.
- An electronic audience response system (ARS) was in place during the conference to encourage lively discussion, provide opportunity for their experiences and opinions to be acknowledged and further evaluate the attendees' learning experience.
- Post conference, participating Chapters received educational grants to further provide VWD programming in their local area.

## Results

Ninety patient and family members attended the weekend event. Five NHF Chapters were represented and the Faculty consisted of providers from 6 HTCs. Forty-two written evaluations were received at the end of the conference (out of 70 distributed). Data from the ARS was compiled from the 41 patient participants reflecting and an average response rate of 89%.

- When asked if their pre-conference questions were answered, 90% responded with either "yes" (58%) or "no, but now know how to get my question answered" (32%).
- Eighty-two percent (82%) did not know about the 2014 NHF VWD Summit prior to the conference, 67% responded they intended to read the resulting VWD Strategic Summit Report.
- Ten percent (10%) stated they were enrolled in ATHN Dataset. After a discussion on the importance of participating in HTC data collection, 43% stated they were open to discussing enrollment with their providers.
- Ninety-two percent (92%) would attend this event again and 90% indicated they will use information gained at this conference when meeting with their healthcare team.
- At the start of the conference, 38% of responding patients rated their medical knowledge of VWD as "excellent" or "good". When asked the same question at the end of the conference, 53% responded "excellent" or "good".

## Conclusions

Assessment of the patients' responses indicates an increase in medical knowledge, awareness of community issues, and intention to act on information received. Patients overwhelmingly indicated a resolve to further attend educational events to continue in their pursuit of gaining further knowledge concerning living with VWD. The conference model was an effective tool in providing information and resources to improve the quality of life for families living with VWD.

## Faculty Comment

*"Awareness of Von Willebrand Disease is now being raised to the level of Hemophilia care, with anticipated better diagnosis and treatments. This VWD conference model is an excellent example of how education can aid this transition of improved care."*

Christopher Walsh, MD, PhD, Associate Professor and Director of the Hemophilia Program in the Division of Hematology and Medical Oncology at Mount Sinai School of Medicine, NY.

