

Voices of Females with von Willebrand Disease: Patient Satisfaction with U.S. Hemophilia Treatment Centers



Females with von Willebrand Disease (VWD) are the fastest growing population obtaining care at Hemophilia Treatment Centers (HTC) in the United States¹.

When the first National HTC Patient Satisfaction Survey (PSS) was conducted in early 2015, over 5,000 patients or

caregivers from around the country reported on HTC services they received in calendar year 2014.

How many females with VWD completed the 2014 National PSS?

While men and boys make up about 70 percent of HTC patients in the U.S., many inherited bleeding disorders affect females.

Twenty-nine percent who completed a survey were female. Of all the females

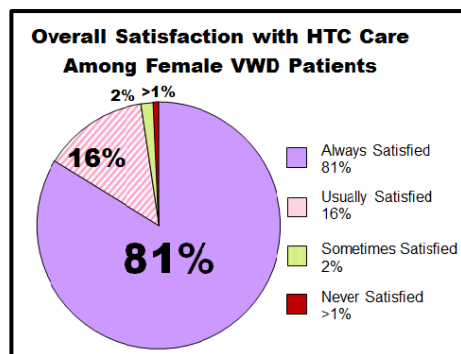
returning a PSS, 868 persons—more than half—had a diagnosis of VWD. This translates to nearly 1 out of 5 patients at HTCs who responded to the survey.

"Caring and compassionate care-always."

64 year old woman with von Willebrand Disease, Nevada

This confirmed that significant numbers of girls and women obtain treatment for VWD at an HTC and are an important segment of the overall HTC patient population. Their feedback is valuable to discover if their needs are met.

Are females with VWD generally satisfied with HTC Care?



Yes. Women with VWD and the parents of girls with VWD reported high satisfaction with overall HTC care, matching the general PSS

responses nationwide. Nearly all female VWD survey respondents reported being either "always" or "usually" satisfied with their overall HTC care.

More specifically, 99 percent of women with VWD, or parents of girls with VWD, reported that HTC staff 'always' or 'usually' treated them with respect. Similarly, 95 percent reported it was 'always' or 'usually' easy to get the information they needed, and 93 percent reported that HTC clinic staff 'always' or 'usually' coordinated their care with other specialists or providers. These high positive results from patients tell us that many things at our HTCs are meeting the needs of this group.

"My daughter is in wonderful hands."

Mother of 10 year old girl with von Willebrand Disease, Maine

What else did we learn?

The survey asked what HTCs are doing well, how HTCs could improve and invited participants to share anything else. Many did, providing helpful insights into areas that were working or needed improvement.

HTCs received many complimentary comments. The positive feedback was more than double the number of comments identifying problems. However, there were some recurring responses that shed light on challenges HTCs could improve upon.

"HTC can communicate better with patients."

22 year old woman with von Willebrand Disease, New York

Some of the most common problems mentioned were:

- difficulty communicating with their HTC
- scheduling appointments
- long wait times
- problems with billing or insurance
- distance to the HTC
- needing bilingual assistance

What's next?

Each HTC has the data and feedback from the anonymous responses of the patients at their center. This information is a tool to help each HTC find ways to improve their quality of care.

Regional HTC leadership thanks all patients and parents who participated, and the HTCs for their valuable input.

For more information and additional articles about the results of this survey go to: www.htcsurvey.com.

1. Baker et. al. *Haemophilia* 2013. 19: 21-26.