A Collaborative Approach to Clinical Practice Guidelines

ASH ISTH NHF WFH 2021 Clinical Practice Guidelines on the Diagnosis and Management of von Willebrand Disease
Meet The Speakers

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A Collaborative Approach to Clinical Practice Guidelines: The Patient Lens

Nikole Scappe
Manager of Education
National Hemophilia Foundation
Disclosures

N/A
OUR MISSION

The National Hemophilia Foundation (NHF) is dedicated to finding cures for inheritable blood disorders and to addressing and preventing the complications of these disorders through research, education, and advocacy, enabling people and families to thrive.

NUESTRA MISIÓN

La Fundación Nacional de Hemofilia (NHF) se dedica a encontrar curas para los trastornos sanguíneos hereditarios y a abordar y prevenir las complicaciones de estos trastornos a través de la investigación, la educación y la abogacía permitiendo que las personas y familias prosperen.
Goal: By the end of my presentation, I hope that you will see the direct impact that patient's involvement can have on the creation of guidelines and other similar documents and policies that affect the very lives of those patients.
Von Willebrand Disease (VWD)

- **Most common inherited bleeding disorder:**
  - VWD is the most common bleeding disorder, affecting up to 1% of the US population – or approximately 1 in every 100 people.

- **Can cause unusual bleeding**
  - From small wounds or “minor” procedures
  - Frequent nosebleeds and bruising into joints

- **Inherited equally by men and women**

- **Often impacts women disproportionately through**
  - Heavy or abnormal periods
  - Post-partum bleeding
Number of patients on panels:
  Diagnosis: 4
  Management: 3
VWD Guidelines: What They Mean For You

Nikole Scappe
Manager of Education

Wednesday Webinar Series

4-part Wednesday Webinar Series

- Wednesday Webinar: New Guidelines for VWD: Patient Perspective | National Hemophilia Foundation
- VWD Guidelines: Diagnoses | National Hemophilia Foundation
- The New VWD Guidelines: Management | National Hemophilia Foundation
- VWD Guidelines and Shared Decision-making | National Hemophilia Foundation
A Collaborative Approach to Clinical Practice Guidelines

Presentation by
Ellen Riker
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Disclosures

• Consultant to American Society of Hematology
• Consultant to National Hemophilia Foundation
2015

“A well-qualified and authoritative organization, or a consortium of such organizations, should develop a new or updated evidence-based clinical practice guideline on VWD.”

Report of November 2014 National Hemophilia Foundation Strategic Summit on VWD
Collaboration Gets Underway...

• ASH and NHF spoke about co-sponsoring the VWD Guidelines and together decided to include the international organizations – International Society of Thrombosis and Hemostasis (ISTH) and the World Federation of Hemophilia (WFH).
• NHF’s Medical and Scientific Advisory Council and Chapter leaders identified clinicians and people living with VWD to nominate to serve on the panel. Patient participation was critical to NHF
• As part of our MOU with ASH, NHF and the other organizations would allow staff to attend all panel meetings.
• Recognizing the limitations in the literature, NHF and WFH asked that we survey clinicians and people living with VWD internationally seeking their input on priorities related to the diagnosis and management of VWD.
Scoping Survey

- 71 countries
- 6 continents
- 601 participants
- 9,500 discrete comments
- 51% patients
- 49% healthcare providers
- 21% male
- 54% female
- 26% no gender identified
- 18% low/middle-income
- 82% high-income countries

Results - New ICD-10 VWD Diagnosis Codes

- Previously, one ICD-10 diagnosis code, D68.0, Von Willebrand disease, for VWD and all subtypes
- New clinical practice guidelines for diagnosis and treatment of VWD - recommendations varied by type of VWD
- Submitted to CDC ICD-10 Coordination and Maintenance Committee March 2021
- Proposal was accepted and codes were published in the Medicare Inpatient PPS proposed rule for FY 2023
New ICD-10 VWD Diagnosis Codes as of 10/1/22

- D68.00, Von Willebrand disease, unspecified
- D68.01, Von Willebrand disease, type 1
- D68.020, Von Willebrand disease, type 2A
- D68.021, Von Willebrand disease, type 2B
- D68.022, Von Willebrand disease, type 2M
- D68.023, Von Willebrand disease, type 2N
- D68.029, Von Willebrand disease, type 2, unspecified
- D68.03, Von Willebrand disease, type 3
- D68.04, Acquired von Willebrand disease
- D68.09, Other von Willebrand disease
Disseminating and Implementing Guideline Recommendations

Kailee Boedeker, MPH
American Society of Hematology
Disclosures

• N/A
Strategic Approach

- Raise Awareness
- Dissemination
- Implementation
Raising Awareness of the Guidelines

- Joint Press Release
- Social Media Campaigns
- E-newsletters
- Video Interviews with Panelists
- Presentation and Promotional Activities at Relevant Meetings
Dissemination Activities

- Infographics and Snapshots
- Translations
- Patient Summaries
- Mobile App
- Educational Teaching Slides
- Guideline International Library Repository
- Podcasts
- Community Workshops
Dissemination Activities

- Virtual Summits
- Commentaries
- CDC Blood Disorders
- Pocket Guides
- Annual Meeting Sessions
- Webinar Series
Implementation

- ICD Codes
- Patient Decision Aids
- Guideline Implementation Champions
- Examples of possible future activities
  - Quality Measures
  - QI Toolkits
  - Clinical Decision Support
Next Steps

- Impact Evaluation
- Monitoring and Updating
Thank You!

Questions?