

WEBINAR

# WFH GLOBAL VWD CALL TO ACTION: THE WORLD'S RESPONSE

Global  
VWD  
CALL TO  
ACTION

Dawn Rotellini

Magdy El Ekiaby, MD

Luisa Durante

Chedia Aroua

Cassie Osejo

Louise Ellwood

Wednesday, August 26, 2020



# SPEAKERS

---



Dawn  
Rotellini



Magdy  
El Ekiaby, MD



Luisa  
Durante



Chedia  
Aroua



Cassie  
Osejo



Louise  
Ellwood



WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOFILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA



# AGENDA

---

## 1. Introduction

Overview of VWD *Magdy El Ekiaby, MD*

The Global VWD Call to Action *Luisa Durante*

## 2. NMOs Share their Experiences

USA Experience *Dawn Rotellini (United States)*

Tunisia's Experience with VWD *Chedia Aroua (Tunisia)*

#YoSoyVWD Panama *Cassie Osejo (Panama)*

South African Response *Louise Ellwood (South Africa)*

## 3. Breakout groups

## 4. Q&A

## 5. A Call to Join! *Aleah Loney*



# WFH COVID-19 STATEMENTS



For practical recommendations, specific risks of COVID-19, humanitarian aid news, company statements, and more, visit:

<https://www.wfh.org/en/covid-19-communications>



# WEBINAR INFORMATION

- This webinar is in English. Breakout groups will be in English, French, Spanish, Arabic, and Russian
- Use the Chat to type your questions at any time during the webinar. Questions may be typed in English, French, Spanish, Arabic, or Russian
- Questions will be addressed as time allows during the Q&A period

A banner for a webinar. The top section is red with a white globe icon and the text "Global VWD" and "CALL TO ACTION" in white. Below this, the text "WEBINAR" is in white on a red background. The main title "WFH GLOBAL VWD CALL TO ACTION: THE WORLD'S RESPONSE" is in white. The speakers' names are listed on the left: Dawn Rotellini, Magdy El Ekiaby, MD, Luisa Durante, Chedia Aroua, Cassie Osejo, and Louise Ellwood. The date "Wednesday, August 26, 2020" is on the right. The WFH logo is at the bottom right. At the bottom, there are icons for "Participants" and "Chat", with the "Chat" icon circled in red and an arrow pointing to it from below.

WEBINAR

Global VWD  
CALL TO ACTION

WFH GLOBAL VWD  
CALL TO ACTION:  
THE WORLD'S RESPONSE

Dawn Rotellini  
Magdy El Ekiaby, MD  
Luisa Durante  
Chedia Aroua  
Cassie Osejo  
Louise Ellwood

Wednesday, August 26, 2020

WFH  
WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOFILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA

Participants Chat





# WEBINAR RECORDING



A recording of the webinar will be available on the WFH eLearning Platform.  
The webinar will be made available in other languages.

<https://elearning.wfh.org/>

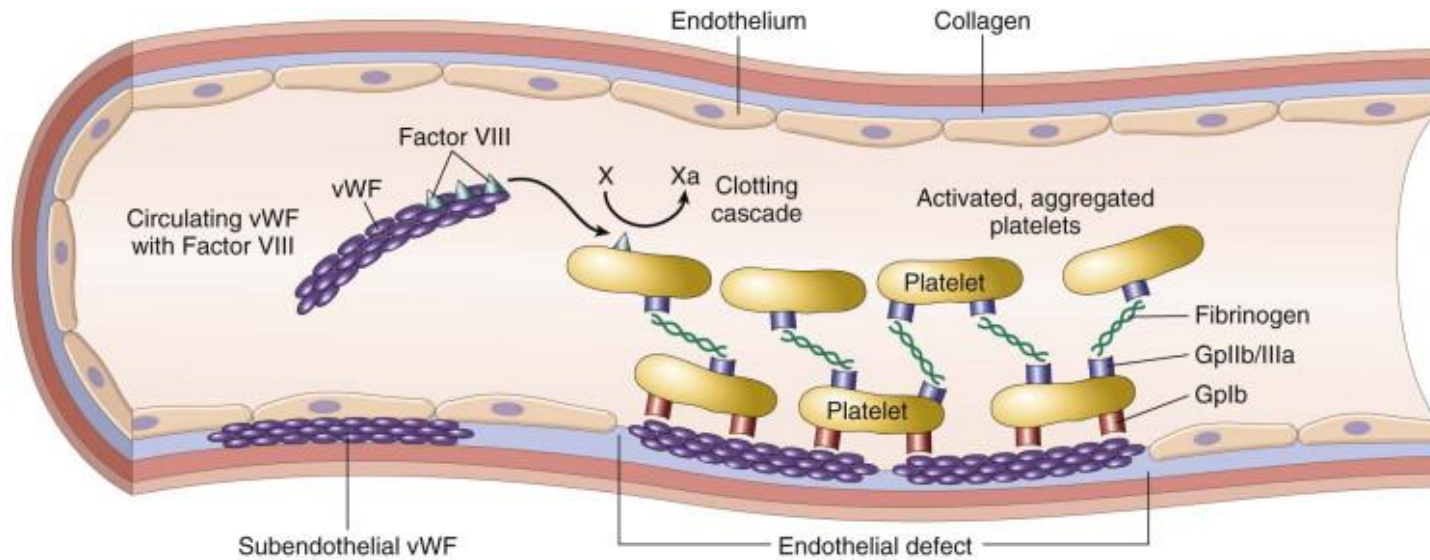
# VON WILLEBRAND DISEASE (VWD)

MAGDY EL EKIABY, MD

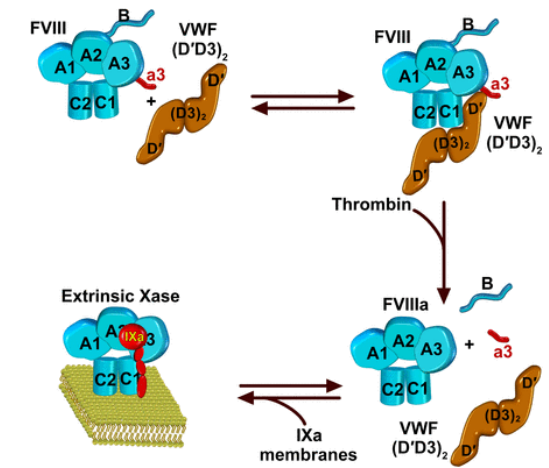


WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOFILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA

# VWF Function



- Mediate platelet adhesion to sites of vascular injury
- Facilitates platelet aggregation
- Protects FVIII from premature degradation

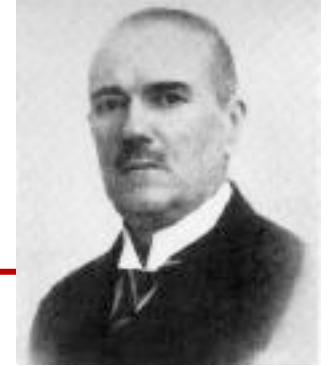






**VWD is  
the result of reduced  
amounts or abnormal  
forms of VWF in the  
circulation**

# Historical Perspective



First case was found in a family living on the island of Fötglö in the Åland archipelago in the Baltic Sea that was described by Finnish Dr. Erik von Willebrand, 1926





## COMPARISON OF KEY NUMBERS FROM THE REPORT ON THE ANNUAL GLOBAL SURVEY (1999-2018)

1999

65



NUMBER OF COUNTRIES in this survey

2018

125

+ 60 COUNTRIES

82%  
(65/79)



RESPONSE RATE  
from WFH National Member  
Organizations

89%  
(125/140)



NUMBER OF PEOPLE IDENTIFIED WITH:

HEMOPHILIA

53,864	HEMOPHILIA A	173,711
11,591	HEMOPHILIA B	34,289
13,174	HEMOPHILIA TYPE UNKNOWN	2,454

210,454

78,629

24,806

7,768

VON WILLEBRAND DISEASE

78,547

OTHER BLEEDING DISORDERS

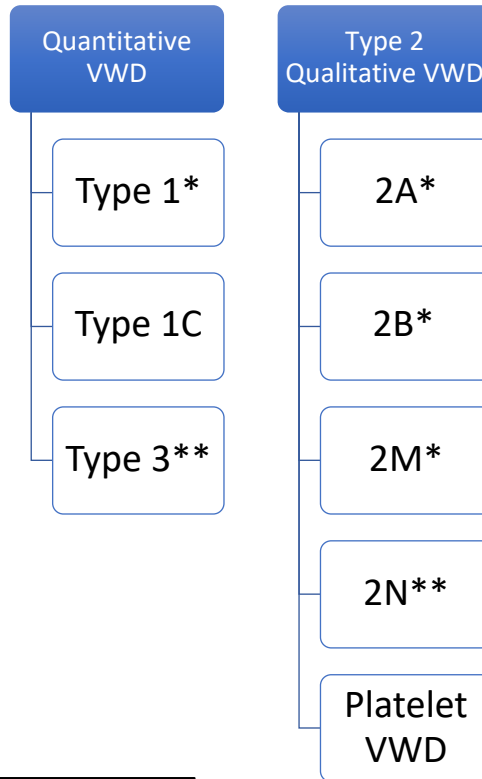
48,640

↑ 204% INCREASE IN NUMBER OF PEOPLE WITH BLEEDING DISORDERS IDENTIFIED SINCE 1999

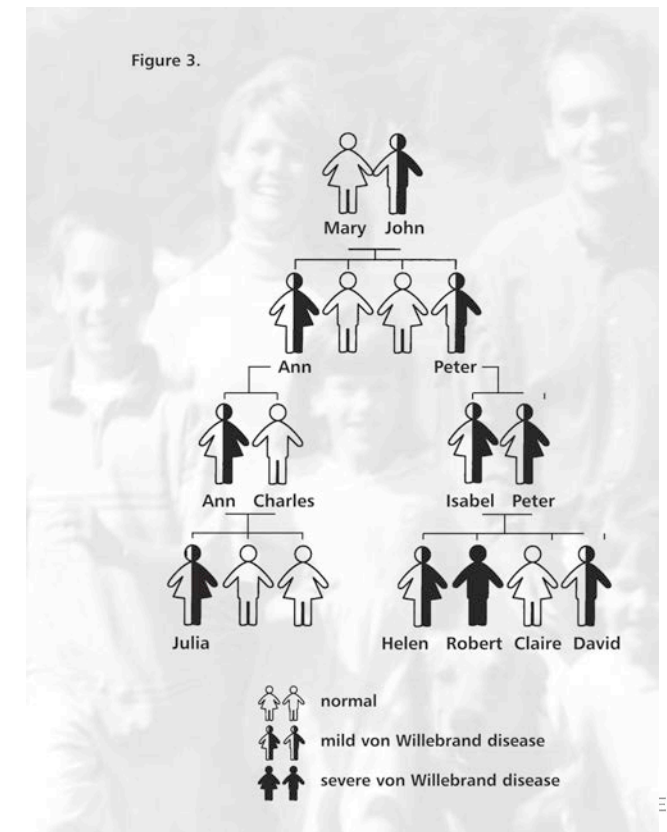
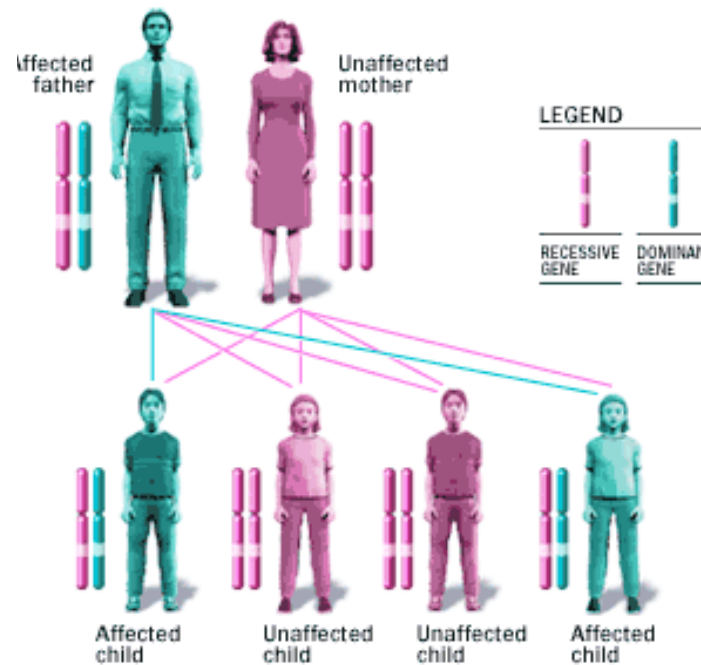


WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOFILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA

# Classification of VWD



Mode of Inheritance:  
\*Autosomal dominant  
\*\*Autosomal recessive



Acquired VWD

# Outreach for VWD



Family member of IBD  
patient

Family pedigree  
Bleeding  
Assessment tool\*

Hematological  
work up

Target population with  
bleeding symptoms

Bleeding  
Assessment tool\*

hematological  
work up

▣ \*WFH Compendium of Assessment Tools: MCMDM-1 VWD Bleeding Questionnaire, Pictorial Blood Loss Assessment Chart, ISTH Bleeding Assessment Tool. (\*<http://elearning.wfh.org/>)





# Basic needs of management

---

- Multidisciplinary team:
  - Hematologist
  - Nurses
  - Highly qualified lab capable of performing specialized VWD diagnostic tests
  - Obstetrician
  - Other needed specialties
- Treatment products:
  - DDAVP
  - Anti-fibrinolytics
  - VWF/FVIII concentrates or purified VWF concentrates

# GLOBAL VWD CALL TO ACTION

LUISA DURANTE  
PROGRAMS AND EDUCATION  
WORLD FEDERATION OF HEMOPHILIA



WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOFILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA



# WFH Global VWD Call to Action

**We seek to improve diagnosis and clinical management of VWD and create greater awareness of VWD in patient and medical communities around the world**

## Key Priorities of the Global VWD Call to Action

- ✓ Improve diagnosis
- ✓ Address the misconception that VWD is not a serious disease
- ✓ Facilitate the availability of safe, effective, easy-to-use treatments everywhere
- ✓ Encourage leadership and advocacy in medical and patient communities
- ✓ Establish a consensus on Standards of Care and global guidelines
- ✓ Request that organizations incorporate VWD into their work
- ✓ Destigmatize the discussion of women's health
- ✓ Empower patients everywhere



WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA

**Global VWD Call to Action**

At the World Federation of Hemophilia (WFH) meeting in Amsterdam, both world leaders and patient advocates gathered to discuss the needs of people with VWD. From January 27 – 29, 2017, patient organizations addressing the needs of people with VWD and medical professionals revealed common concerns. These include: lack of medical professionals; lack of information; feeling invisible as a patient; and a need for better access to care.

As a result of the meeting, the following areas were identified:

- Improve diagnosis
- Consensus on standards of care and global guidelines
- Address the misconception that VWD is not a serious disease
- Patient empowerment

The group calls on the medical and health care professions to incorporate VWD into their work. Each national member of the WFH is asked to take action by taking steps to improve the lives of those living with VWD.

ORGANIZATION

NOMBRE DE LA ORGANIZACIÓN

**Llamado a la acción mundial respecto a la EVW**

En la Federación Mundial de Hemofilia (FMH), se reunieron personas de organizaciones de pacientes y profesionales de la salud para discutir la importancia de la enfermedad de von Willebrand (EVW). La agenda abordó perspectivas comunes y consistentes que constituyen la planificación de acciones para que los pacientes con EVW tengan acceso a la atención médica adecuada. Estas incluyen: falta de profesionales de la salud; falta de información; sentirse invisible como paciente; y la necesidad de un mejor acceso a la atención médica.

Como resultado de la reunión, los participantes identificaron las siguientes ocho áreas prioritarias:

- Mejorar el diagnóstico
- Alcanzar un consenso sobre la atención y las guías mundiales (SC siglas en inglés, respectivamente)
- Abordar la idea equivocada de que la EVW no es un trastorno
- Empoderamiento para todos los pacientes

El grupo hace un llamado a la comunidad mundial de la coagulación, a las organizaciones de pacientes y profesionales de la salud, a incorporar la EVW en su trabajo. Cada organización nacional miembro de la FMH es invitada a tomar medidas para mejorar la vida de quienes padecen EVW.

NOMBRE DE LA ORGANIZACIÓN (EN MAYÚSCULAS)

NOM ET FONCTION DU SIGNATAIRE

**Appel mondial à l'action en faveur des personnes atteintes de la maladie de Willebrand**

À la Fédération mondiale de l'hémophilie (FMH), nous pensons que toutes les maladies hémorragiques rares ont leur importance. La maladie de Willebrand (mW) touche aussi bien les hommes que les femmes.

Du 27 au 29 janvier 2017, des représentants de la Fédération mondiale de l'hémophilie, du Consortium européen de l'hémophilie (EHC) et d'une douzaine d'associations de patients atteints d'hémophilie et d'autres troubles de la coagulation venus du monde entier se sont retrouvés à Amsterdam pour échanger sur la façon de répondre aux besoins des patients atteints de la maladie de Willebrand. Les points de vue exprimés par les patients et les associations ainsi que les enseignements tirés des expériences passées ont permis de dégager des problématiques communes qui expliquent les retards dans le dépistage et la prise en charge des patients et de leurs familles. Il s'agit notamment d'idées reçues, de méconnaissance et d'un manque de sensibilisation à la maladie de Willebrand parmi les professionnels de santé, d'une hétérogénéité de l'offre de soins et, souvent, d'une absence d'accès aux traitements. Les personnes atteintes de la maladie de Willebrand ont, en conséquence, l'impression d'être invisibles.

Au terme de cette rencontre, les participants ont recommandé d'intensifier les actions dans le domaine de la maladie de Willebrand et ont recensé les huit domaines prioritaires suivants :

Améliorer le diagnostic	Renforcer les capacités de leadership et de plaidoyer auprès des professionnels de santé, des patients et des organisations connexes
Convenir d'une offre de soins et de lignes directrices mondiales	Encourager les organisations à inclure la maladie de Willebrand dans leur périmètre d'action
Combattre l'idée reçue que la maladie de Willebrand n'est pas une pathologie grave	Libérer la parole sur les questions médicales liées aux femmes
Permettre l'autonomie des patients et leur donner le pouvoir d'agir	Permettre l'accès à des traitements sûrs, efficaces et faciles à utiliser partout dans le monde

Le groupe invite l'ensemble de la communauté mondiale concernée par les troubles de la coagulation, notamment les associations de patients et les professionnels de santé, à intégrer la maladie de Willebrand et les autres maladies hémorragiques rares dans leur périmètre d'action et à reconnaître pleinement l'existence de cette communauté de patients.

Chaque des organisations nationales membres de la FMH est invitée à signer le présent Appel mondial à l'action, l'objectif étant de reconnaître le travail qui reste à accomplir dans le domaine de la maladie de Willebrand et des autres troubles de la coagulation, de s'engager à le réaliser en renforçant les actions de sensibilisation et les ressources correspondantes et d'améliorer l'existence de tous ceux et toutes celles vivant avec la mW.

NOM ET FONCTION DU SIGNATAIRE

**WFH**



# WFH Global VWD Call to Action

---



**VWD is the most common type of bleeding disorder**



**VWD affects men and women**



**Research has shown that as many as 9 out of 10 people with VWD have not been diagnosed**

The Global VWD Call to Action is an **act of solidarity** amongst WFH national member organizations (NMOs) to recognize VWD and break the stigma and isolation that can exist for people living with VWD. It promotes **adequate care and treatment** for people with VWD.

Since the World Federation of Hemophilia (WFH) unanimously adopted the Global VWD Call to Action in 2018, **visibility and recognition has increased worldwide.**



WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOFILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA



# 48 NMOs have signed on to the Global VWD Call to Action!



WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA



# NMOS SHARE THEIR EXPERIENCES



# NHF – USA: Where Did We Start?

---

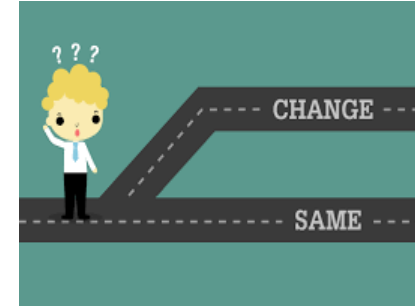
**2014 - NHF hosted a VWD Summit to LISTEN and understand the issues and challenges with diagnosing and treating VWD.**





# Where Did We Go? **Inclusiveness**

---



- After Summit, systems put into place for creation of:
  - VWD MASAC Working Group
  - Full VWD Track at Annual Meeting
  - Educational working groups
  - Educational resources on VWD not just WWBD
- New logo – **For All Bleeding Disorders**
- March – **Bleeding Disorder** Awareness Month
- New **Unite** Walk!



# Bilingual Education

---



- ❑ **Bilingual Educational (English & Spanish) Materials:**
  - Lab Testing Brochure, Lab Test Log for Patients
  - Healthcare Diary
  - Undiagnosed for Teen Girls brochure
  - Brochures for providers (OB/GYN, PCP, Pediatrician, etc.)
- ❑ **Better You Know Webinar:**
  - Worked with healthcare providers to create 4 on-demand webinars for non-hematologic medical providers about bleeding disorders.
- ❑ **Website created by NHF for **undiagnosed** women and men with bleeding disorders, specifically VWD.**
  - This is an assessment tool for **both men and women** to take to determine if they are “at risk” for a bleeding disorder or not.
- ❑ **Better You Know Advocates “BYKA”**



# Print, Face to Face, Support

---

## Print Materials:

- “Welcome Kit” for **families**
- A brochure about navigating life for **adults** with VWD
- A fun brochure that teaches about VWD through games and puzzles, an icepack and colored pencils for **children**
- Booklet for **teen** girls with VWD on puberty
- Basics of VWD brochure for **ALL**

## Face to Face Programs: (English & Spanish)

- NHF offers on-the-ground programs for its 53 chapters across the country – VWD focused
- NHF’s Annual Bleeding Disorders Conference – VWD track and pre-con (virtual in 2020)

## Mini-Grants to Chapters:

- Seed money to help create outreach programs to undiagnosed women with VWD at the local level



WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOFILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA





# Global VWD Call to Action: Chapters!

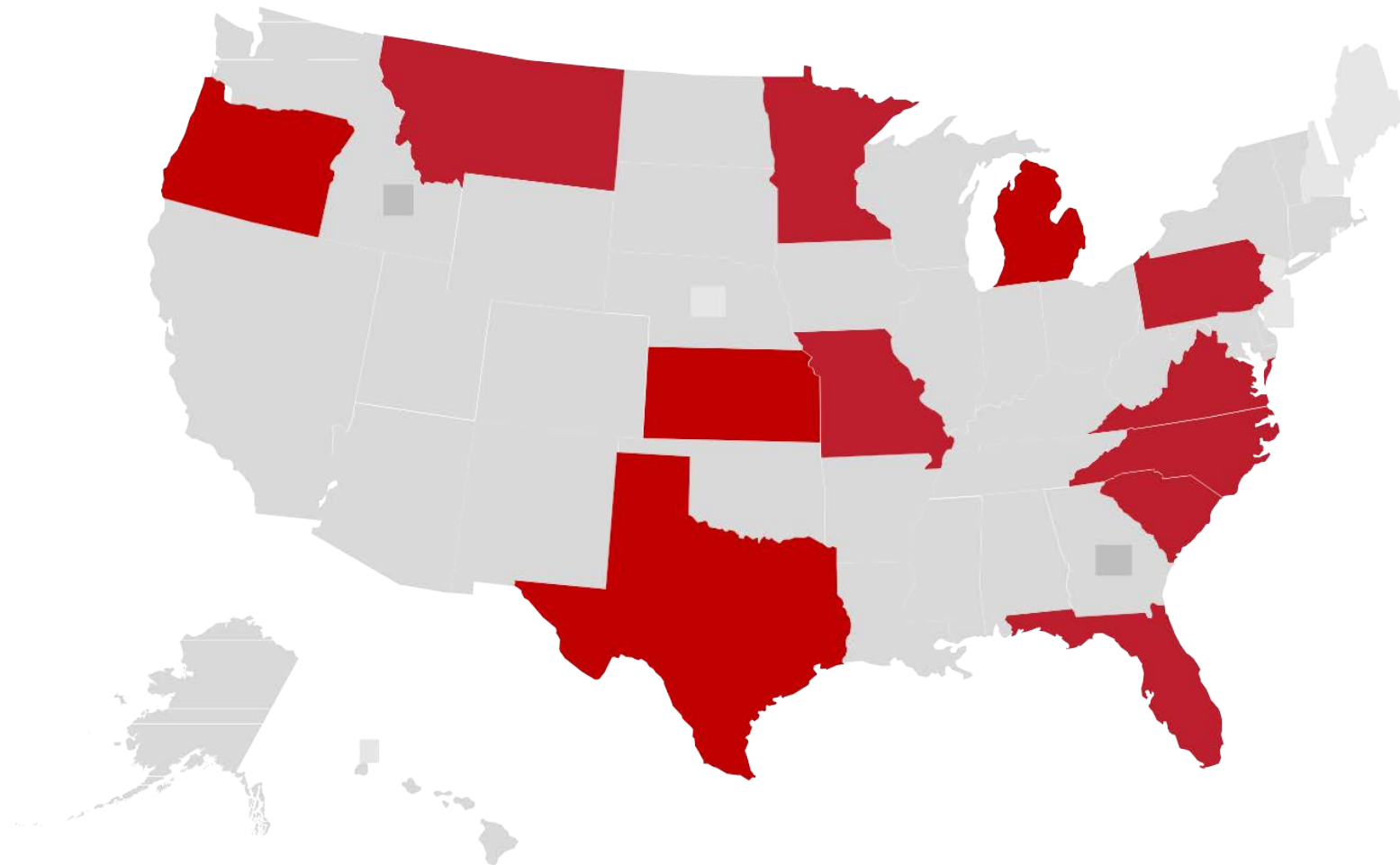
---





# Global VWD Call to Action: USA

---



WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOFILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA



# www.hemophilia.org

---

- ☐ We know that more awareness of VWD is needed for both men and women and outreach focused online and to medical providers.
- ☐ We know that more education and support is needed for both men and women surrounding their bleeding disorder. NHF is working on creating our strategic plan for the next 10 years and part of that vision is **health equity and breaking down barriers for all people with bleeding disorders.**
- ☐ NHF will continue to pursue outreach efforts and creation of resources for men and women with VWD. **We believe in #treatmentforall.**



# TUNISIA'S EXPERIENCE WITH VWD

CHEDIA AROUA  
ASSOCIATION TUNISIENNE DE L'HÉMOPHILIE



**ATH**

الجمعية التونسية للهيموفيليا  
Association Tunisienne de l'Hémophilie  
Tunisian Association of Hemophilia



WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA



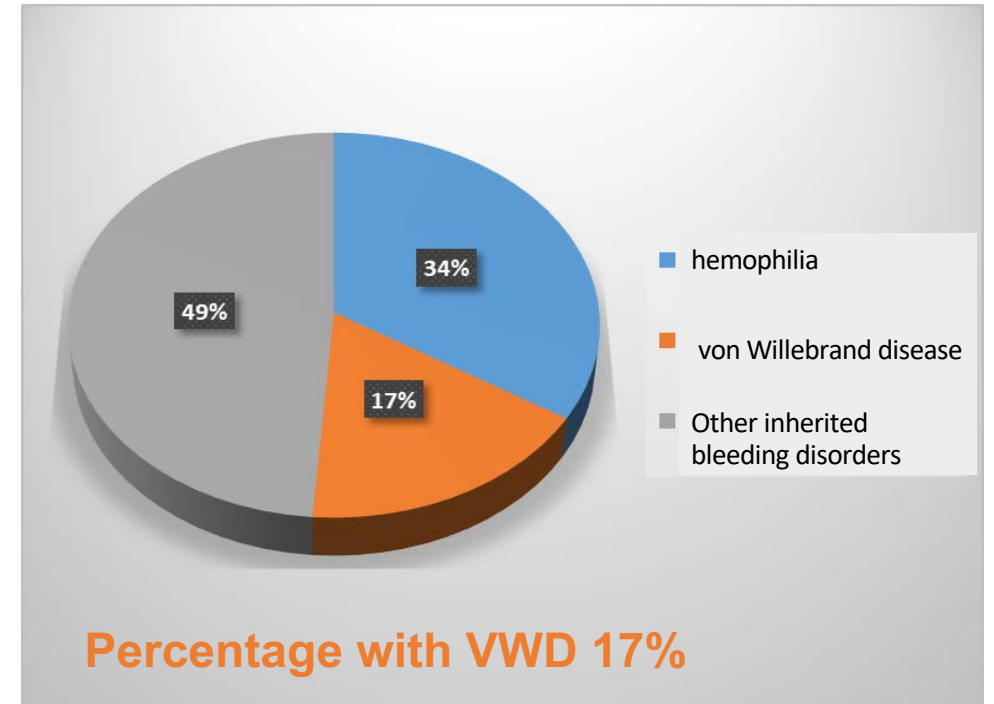
# Statistics

The last census carried out by ATH (December 2019) estimates the following numbers:

**550** Total number of people with hemophilia A and B  
- 437 Hemophilia A  
- 113 Hemophilia B

**225** Number of people with von Willebrand disease

**747** Number of people with other inherited bleeding disorders







# Interest of the Tunisian Association of Hemophilia in VWD

---

The ATH Board of Directors is made up of different profiles of members who have close ties to hemophilia as well as von Willebrand disease.

Since 2017, ATH Vice-President has been a very active young girl with VWD disease, Najiba Chayah.

Najiba participated in the Global NMO Training at the WFH World Congress in 2018.

In 2018, Najiba and I joined the international VWD Global Group and **the ATH signed the Global VWD Call to Action.**



# Achievements

---

## ✓ Participation in the WFH VWD Global Group

This group raises awareness and works to identify patients of VWD through the experiences of different countries participating in this project.

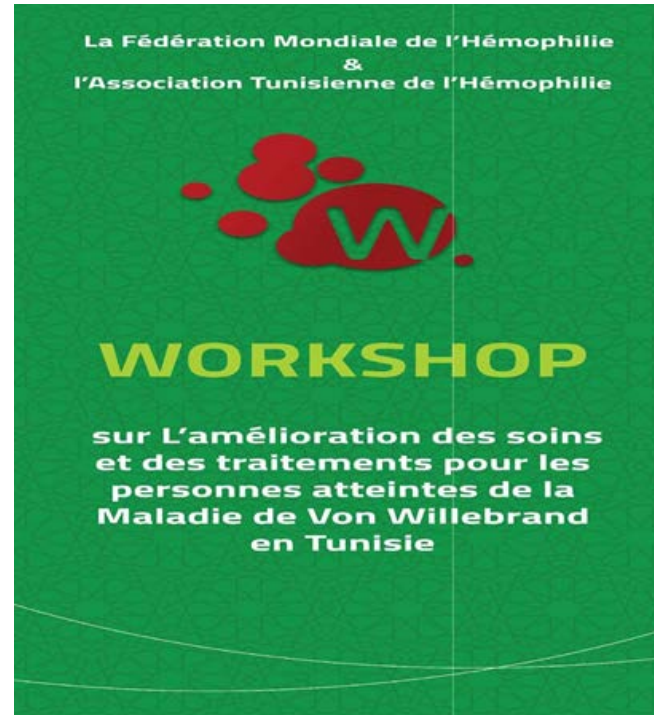




# Achievements

---

- ✓ **2019 Workshop: Improving care and treatment for people with von Willebrand disease in Tunisia**



29 | NOVEMBRE  
30 | 2019  
A. Tunis



WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOFILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA

# Achievements

- ✓ **Workshop 2018: Improving the skills of nurses for the management of hemophilia in Tunisia**
  - von Willebrand disease (VWD)
  - woman with a bleeding disorder
  - person with VWD with an inhibitor (case study)







# Achievements

## ✓ Outreach and Education

- Talk to the general public about VWD via social media
- workshop dedicated to women with bleeding disorders
- Create a VWD Whatsapp group for Q&A for patients, families and doctors with different specialties

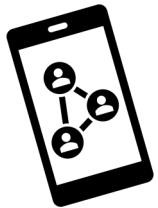
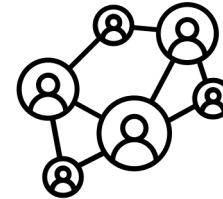




# Challenges and experiences to share

---

- Increase the number of patients diagnosed with von Willebrand disease
- Create a specific national registry for patients with VWD
- Defend the right to prophylaxis
- Develop social activities for patients with VWD
- Develop social media groups to educate and support patients with VWD



WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOFILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA



# #YOSOYVW PANAMA

CASSIE OSEJO  
FUNDACIÓN PANAMEÑA DE HEMOFILIA



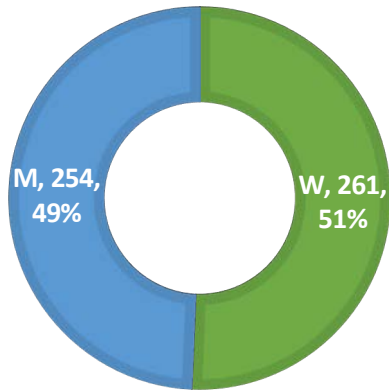
WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOFILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA



# VWD IN PANAMA



515 PEOPLE IDENTIFIED  
WITH VWD



- ☐ Registry of patients with von Willebrand disease since 1980.
- ☐ People with VWD in Panama have complete treatment.



# #YOSOYVW CAMPAIGN

---

## Objectives:

- ☐ Empower people with von Willebrand
- ☐ Educate the Panamanian population and health entities, providing them with all the necessary information about VWD.
- ☐ Make people with VWD more involved with their condition and care.
- ☐ Encourage people to join us as volunteers.



WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOFILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA



# Home visits and treatment

---

- ❑ We made home visits with the purpose of locating new people with VWD to update the database.
- ❑ Purchase of treatments for VWD, Hemophilia and other congenital coagulopathies in the country by the National Ministry of Health.

Upgrade of  
database  
records for  
patients  
with VWD.



WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOFILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA





# WHD2019-VWD Educational Day

Celebrating World Hemophilia Day 2019, the Panamanian Hemophilia Foundation held the first exclusive seminar about VWD. That included the participation of teachers, doctors from different health centers, people with VWD and their families.



# Seminars, talks and courses

---

- ❑ "Summer Educational Day" for children.
- ❑ Seminar for young men to strengthen the psycho-emotional state and responsibility in the care of their disease.
- ❑ "Home therapy" courses.







# Information sharing on social media sites

- ❑ Information on VWD on our web site.



[funpahemofilia.com/](http://funpahemofilia.com/)

- ❑ Informational videos about VWD on our social media.



Fundación Panameña de Hemofilia



@funpahemofilia





# Challenges and solutions

---

## Challenges

Lack of information on VWD

Treatment accessibility

COVID-19

## Solutions

Information sharing

Lobby

Virtual sessions



WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOFILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA



# TIPS

---

1

## Database

---

- ☐ Work on identifying people with VWD in your country.

2

## Meetings

---

- ☐ Have meetings to listen to the needs of people with VWD.
- ☐ Do activities about VWD for parents, patients, medical staff, educators, nurses, others.

3

## Social Media

---

- ☐ Use social networks to share exclusive information about VWD.





# ¡Gracias!

---



Fundación Panameña de Hemofilia



@funpahemofilia



[funpahemofilia.com/](https://funpahemofilia.com/)



Fundación Panameña de Hemofilia



**WFH**

WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOFILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA

# **SOUTH AFRICAN RESPONSE**

LOUISE ELLWOOD  
SOUTH AFRICAN HAEMOPHILIA FOUNDATION



WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOFILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA

# Overview - South Africa

- Multi-ethnic society of c.60m people
  - 9 Provinces
  - c.20m rural population
  - 11 official languages
- Economy<sup>1</sup>
  - Upper-middle-income economy
  - Newly industrialised
  - GNI per capita – US\$ 6,040  
(USA US\$ 65,760)

1. Source - World Bank 2019







# My Story

---

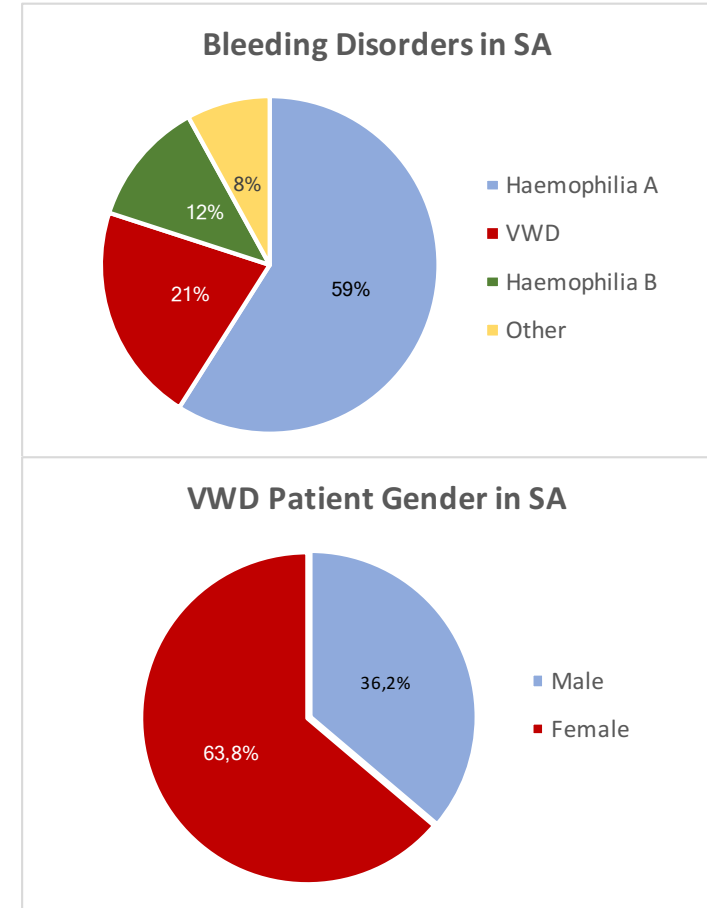
- Born in Manchester, UK
- Moved to South Africa in 1990
- 3 sons, now in 20's, 2 have type III VWD
- Diagnosed at a young age
- Central Region SAHF committee member
- Prepare quarterly newsletter
- Became VWD ambassador after SAHF joined WFH VWD Global Call to Action in 2018





# Prevalence of VWD

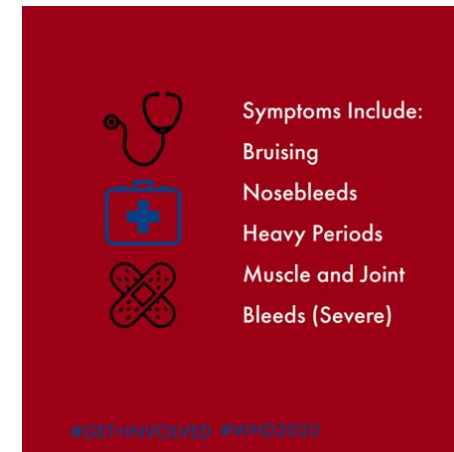
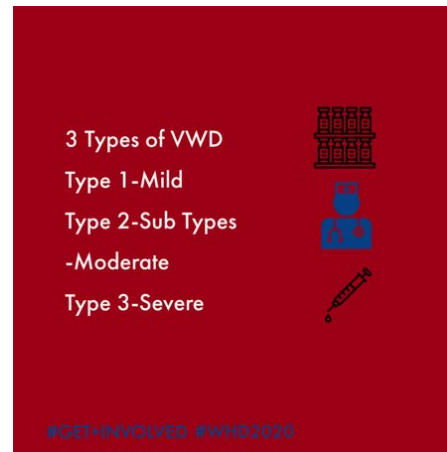
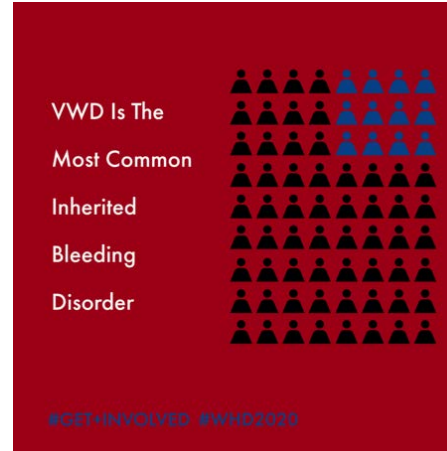
- 21% of bleeding disorder patients
- Diagnosis capability only in major academic centres
- Current treatments available
  - Desmopressin (DDAVP)
  - Factor VIII/VWF concentrate (Haemosolvate Factor VIII)
  - Tranexamic acid (Cyklokapron)
  - Oral contraceptives





# Social Media Successes

- Facebook Group – Von Willebrand's Community SA
- Instagram - vonwillebrandscommunitysa
- WhatsApp Group
- **#WHD2020** - week of infographics on VWD





# Social Media Successes

---



Community posted red mask photos on social platforms

#Get+involved

#REDTIECHALLENGE



WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOFILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA





# SAHF COVID-19 Initiatives

- SAHF recognised need to “digitise” beginning February 2020
  - Virtual meetings
  - Use of Social Media
  - Educational Series - “In discussion with....”
  - MASAC in November 2020 - one day “lay-session”
- Personal Protective Equipment (PPE)
  - SAHF initiative to design and make PPE
  - In house design from materials at hand
  - Designed for comfort
  - Distributed to all HTC’s and patients





# Challenges

---

- 1 Lack of VWD awareness and early diagnosis, especially in rural areas
- 2 Rural patients have limited access to HTC's and treatment
- 3 Delay of surgeries
- 4 Home therapy hindered by access to electricity, sterile environment, etc.
- 5 Limited disability benefits provided by the State
- 6 Bleeding disorders are stigmatised in some cultures - fertility and menstrual hygiene
- 7 Deaths and complications arising from male circumcision during initiation ceremonies





# Moving Forward

- Transport for clinic visits
- Delivering Factor and medications
- Delivering food parcels
- SAHF support group for women with VWD
- Leaflet aimed at women and bleeding disorders
- Continued free treatment through State infrastructure



### DID YOU KNOW THAT

**heavy, prolonged menstrual bleeding** may be a sign of a bleeding disorder in women?

**WHAT IS a bleeding disorder?**  
A bleeding disorder is the inability to form blood clots normally. The blood clotting process called coagulation is affected, resulting in bleeding excessively or for longer. Heavy or prolonged menstrual bleeding, also known as menorrhagia, can be a sign of a bleeding disorder.

Bleeding disorders have a significant impact on a woman's reproductive health and quality of life. Von Willebrand's disease (vWD) is the most common type of bleeding disorder in women. More women than men show symptoms of vWD because of menstruation and childbirth.

**WHAT IS Von Willebrand's Disease?**  
When a blood vessel is injured and bleeding occurs, the clotting protein called von Willebrand factor (vWF) binds to factor VIII (a key clotting factor) and to platelets in blood vessel walls, which help form a platelet plug during the clotting process to stop bleeding. People with vWD do not have enough vWF or the vWF does not work in the way it should, resulting in a longer time for blood to clot and bleeding to stop.

Women with vWD often bleed more or longer than normal during menstruation and following childbirth. Some women with vWD have a lot of menstrual pain or irregular menstruation. If left untreated, bleeding disorders increase your risk for anemia and dangerous bleeding after childbirth.

### TYPES OF Von Willebrand's Disease:

There are three main types of vWD. Within each type, the disorder can be mild, moderate or severe. Treatment is also different for each vWD type.

TYPE 1:	TYPE 2:	TYPE 3:
<ul style="list-style-type: none"> <li>There are lower than normal levels of vWF</li> <li>Symptoms are usually very mild however it is possible to have serious bleeding.</li> <li>Type 1 vWD is the most common form</li> </ul>	<ul style="list-style-type: none"> <li>There is a defect in the vWF structure, hence the protein does not work properly, causing lower than normal vWF activity</li> <li>Symptoms are usually moderate</li> <li>There are different Type 2 vWD defects</li> </ul>	<ul style="list-style-type: none"> <li>There is very little or no vWF</li> <li>Symptoms are usually more severe</li> <li>Type 3 vWD is usually the most serious form</li> </ul>

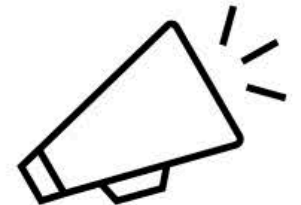
Normal blood clotting

Blood clotting with reduced von Willebrand Factor

# NMOs Moving Forward

---

- Small steps to build momentum
  - Support groups
  - Social media
- Adopt VWD guidelines
- Inclusion of bleeding disorder education at state / community level
- Prioritize awareness and diagnosis
- Encourage neighboring countries / NMOs to join 'Global VWD Call to Action'



# BREAKOUT GROUPS



# MEET THE MODERATORS

---



ENGLISH 1  
Luisa Durante



ENGLISH 2  
Aleah Loney



SPANISH  
Luis Melgar and Cassie Osejo



FRENCH  
Nicolas Giraud and Charline Madelaine



RUSSIAN  
Baiba Ziemele



ARABIC  
Chedia Aroua

- Breakout groups will be in English, French, Spanish, Russian, and Arabic
- At any time, you can use the “Ask for Help” button
- Please mute and wait for the moderator to begin the session, keep yourself on mute when you are not speaking

*Please enjoy this opportunity to discuss and ask questions about  
the WFH Global VWD Call to Action!*

# QUESTION & ANSWER PERIOD





# ASKING A QUESTION

- Please use the Chat to type your question
- Indicate if your question is directed to one speaker in particular
- Keep questions brief so that we can answer as many as possible
- Questions may be typed in English, French, Spanish, Arabic, or Russian
- We will address as many questions as time allows



# A CALL TO JOIN!

ALEAH LONEY  
WORLD FEDERATION OF HEMOPHILIA



WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOFILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA



## SIGN ON TO THE CALL!

**Step 1:** Review the Global Call to Action and discuss it with your NMO's Board of Directors

**Step 2:** Reflect on what actions your organization can implement

**Step 3:** Sign on! There are two options to sign on:

- **Submit the form online**

-OR-

- **Print the PDF and submit it via fax to the WFH at +1-514-875-8615. Follow up with an email to [vwd@wfh.org](mailto:vwd@wfh.org) to let us know you have signed on!**

**For more information, please contact [vwd@wfh.org](mailto:vwd@wfh.org)**



Join the 48 WFH National Member Organizations who have already signed on

The Global VWD Call to Action is a call to unite in raising awareness and taking steps to improve the lives of those living with VWD



WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOFILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA

Visit [www.wfh.org/vwd](http://www.wfh.org/vwd)

WEBINAR

# WFH GLOBAL VWD CALL TO ACTION: THE WORLD'S RESPONSE

Global  
VWD  
CALL TO  
ACTION



Thank you for your participation!  
Please fill out the short survey after this webinar



[www.wfh.org](http://www.wfh.org)



[eLearning.wfh.org](http://eLearning.wfh.org)



[news.wfh.org](http://news.wfh.org)



[facebook.com/wfhemophilia](https://facebook.com/wfhemophilia)



[twitter.com/wfhemophilia](https://twitter.com/wfhemophilia)