OPTIMIZING THE PATIENT JOURNEY IN VON WILLEBRAND DISEASE: EXPERIENCES AND LEARNINGS AS THE NAVIGATOR Audience survey responses*

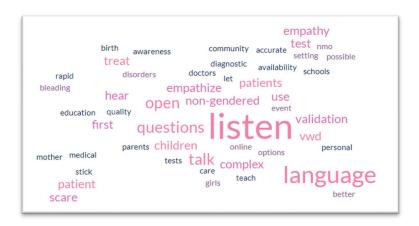
*The following responses are the raw data collected via audience participation, only corrected for spelling and duplicates removed. CSL Behring formulated the questions but have not contributed to or influenced the responses. These are intended to stimulate further discussion and do not represent formal recommendations or guide for clinical practice. 57 participants contributed to these results.

What in your opinion is the main topic to address in optimizing the patient journey for people with von Willebrand disease?



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Diagnosis
Heavy menstrual bleeding/menstrual bleeding
Access to treatment
Prophylaxis
Treatment choices
Women can have bleeding disorders
Proper treatment leading to a normal life
Support and shared decision-making
Listen
Don't know
Early diagnosis
Iron deficiency
Recognition of joint bleed
Better treatments
Recognize that there is a problem/ proper diagnosis
Treatment options-a smoother pathway
Important in my real world
Stop the war
Data to inform treatment options
Identification
Harmonisation for equity
Properly treating patient symptoms

How can the way trainees and physicians use language during clinical or outpatient care affect patients?



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Listen/ Listen and hear them/ Listen first!!/Listen and treat

Empathy/empathize

Open questions/ Open language

Test / Test children of VWD mother at birth

Validation/ Validation of opinions or not

Setting up an online event for girls with bleeding disorders in my NMO

Talk about all possible options to have a better care for our patients

Treat and let the patient have quality

Teach personal doctors about VWD

Availability of accurate rapid diagnostic tests

Do not stick to the medical community for awareness

Education at schools, children and parents

Explain and understand the patients point in life

Look non-verbal signals

Talk down

Show empathy, listen and use non-gendered language

Ask and listen and don't put your own idea first

Do not dismiss, but listen and hear

Giving time to talk freely

Overwhelm

By using language that describes women's health as complex - we reinforce the belief that women are complex and difficult

In every way: scare, validate, makes you question, be offensive

Asking negative questions, such as "but you don't have heavy menstrual bleeding" can affect the responses

Clear

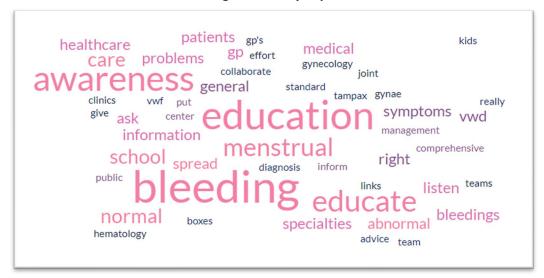
Influence perception

Could scare the patient

Use non-gendered language

Positive language

What can be done to reduce the diagnostic delay in persons with von Willebrand disease?



What can be done to reduce the diagnostic delay in persons with von Willebrand Disease?

Educate / Education, education, and more education

Improve education of HCPs/ other health care providers

Educate, Awareness /Spread awareness about VWD

Teach the world on bleeding symptoms / Publicity

Give information at school/ Information in schools 7/2/1

Heavy menstrual bleeding is NOT normal / Get tested /Learn on what is normal and not acceptable for menstrual bleedings

Education in medical school, GP's links with gynae teams / joint clinics

von Willebrand disease awareness, specially with some specialties (odontology, gynaecologist)/General awareness within the healthcare community

Put advice on Tampax boxes

Standard diagnosis for kids

Collaborate and make it really a team effort. GP, gynecology, hematology

Comprehensive care center management

Doctors and nurses from all specialties should investigate and ask about other bleedings when they see a patient with bruises, dental bleeding, intestinal bleeding, menstrual bleeding etc

Inform public of what is normal bleeding/ abnormal bleeding

Create awareness and make sure healthcare professionals listen to problems and show the willing to solve problems for patients instead of checking if they are right....

Pay attention to signs and symptoms, ask questions. Patients might not know the right words or descriptions of what is happening

Front line (GPs) need to be better at recognizing and referring

Talk to your primary care physician

Listen

Get VWD to textbooks for more than one page

Educate your colleagues as haematologists

Multidisciplinary approach

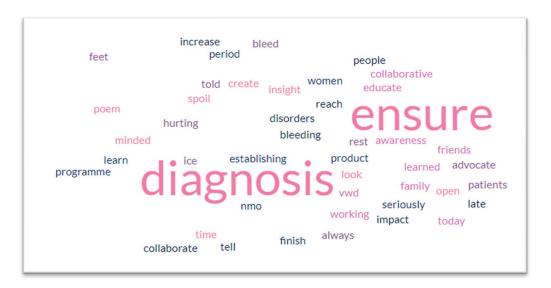
Treatment for all!

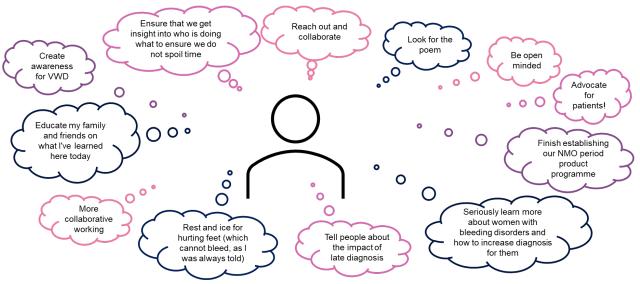
What can be done to optimize the treatment of persons with von Willebrand disease?



What can be done to optimize the treatment of persons with von Willebrand Disease?
Individualize treatment approach
Research and education to understand the disease better/ read guidelines
Treatment guidelines for every country
Stratification of bleeding risk/Treat bleedings and provide prophylaxis if bleedings come back
Prioritize care over cost of treatment
Aim higher- aim for normal clotting - not just prevention of bleeding that causes death
Education for all/ peer support and advocacy
Join European Reference Network for hematological diseases: EuroBloodNet
Lower prices for factors

What will be your first action after you've returned from WFH?





What will be your first action after you've returned from WFH 2024?

More collaborative working

Ensure that we get insight into who is doing what to ensure we do not spoil time

Look for the poem

Be open minded

Create awareness for VWD

Educate my family and friends on what I've learned here today

Rest and ice for hurting feet (which cannot bleed, as I was always told)

Advocate for patients!

Finish establishing our NMO period product programme

Seriously learn more about women with bleeding disorders and how to increase diagnosis for them

Tell people about the impact of late diagnosis