

Webinars



European
von Willebrand Disease
Community

Von Willebrand disease

Topic on focus
ERN-EuroBloodNet

Women bleed too

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European
von Willebrand Disease
Community



**European
Reference
Network**
for rare or low prevalence
complex diseases
Network
Hematological
Diseases (ERN EuroBloodNet)

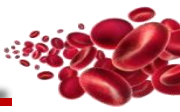


Co-funded by
the Health Programme
of the European Union



1. What constitutes a normal menstrual cycle, including the 7-2-1 rule, and how should abnormal periods be managed?
2. What types of bleeding are considered abnormal (e.g., vaginal bruising, sudden bleeding), and what are the recommended approaches for managing these cases?
3. What are the current treatment options for managing gynecological bleeding, including hormone therapy, tranexamic acid (TXA), and prophylactic measures?
4. How can families be prepared for a child's first period, and what is important to consider during the transition from pediatric to adult care?
5. What are the common psychosocial impacts of menstrual health issues (e.g., shame, lack of knowledge, stigma, missing opportunities due to bleeding), and what are the recommended approaches for addressing these challenges?
6. What are the available treatment options for managing iron deficiency and pain associated with menstrual bleeding, and what practical tips can be offered to support individuals?
7. How can fears related to sex be addressed, and what practical advice and tips should be provided for managing reproductive health issues in the context of menstrual disorders?
8. How can we improve the understanding of menstrual health issues and why is there an underrepresentation of women (e.g., where are the missing 50%) in registries and studies related to menstrual health?





Disclosure conflict of interest

- . Medical Trustee for Haemophilia Society (UK)
- . Treasurer for Haemophilia Nurses Association UK (HNA)
- . Previous work with Sobi, Pfizer, Roche Chugai, CSL Behring

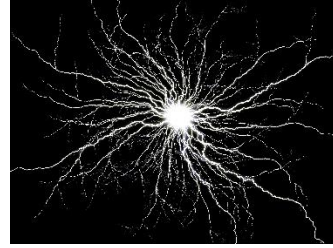


Birmingham Children's Hospital





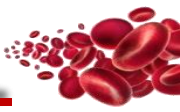
Cultural and Religious Beliefs



- In Ancient Greece and Rome menstruation was accorded great powers and a menstruating woman who uncovered her body could scare away hailstorms, lightening and whirlwinds
- Hinduism – first menstruation is viewed as positive, with celebrations and presents, but more conservative beliefs mean menstruating women are asked to stay away from domestic activity for 3 days and physical intimacy is prohibited
- Islam – women are relieved of their usual duties of prayer and fasting whilst menstruating
- In Sri Lanka, a girls first period is often celebrated with a “big girl” party.



Terminology and Product Choice



- Painters and decorators are in
- Time of the month
- Curse
- Aunt Flo
- Code Red
- Mother Nature's Gift
- In German – red week
- In French – ketchup week
- In Italian – red light
- In Danish – Lady Days

1



Menstrual cup
&



Reusable
menstrual disc

2



Reusable pad

3



Period underwear

4



Reusable tampon
applicator

5



Organic pads &
tampons

6



Tampons with
cardboard applicators

Honorable
mention



Menstrual sponge



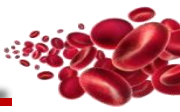
When does managing a first period start?



- It should start before the girl achieves menstruation
- In the UK, talks start with children in school year 4 which is age 8 to 9 years old
- Managing maternal anxieties and potential to normalise heavy bleeding
- Talking to the young girls in advance. Cultural challenges around this
- Utilise your nurses – they are a fantastic resource



Treatment Options



- TXA – don't underestimate its effectiveness
- Supplementary medications such as iron
- Hormonal Control - both progesterone only and combined pill
- Clotting Factor Concentrate
- Intra-Uterine System (IUS) eg Mirena Coil
- Blood Products
- Intravenous iron infusions
- Things you can do to help yourself



Things I can do to help myself



These will not make your periods lighter but they might help other symptoms of heavy periods such as cramps.

- Gentle exercise like yoga, swimming and walking, can help with period pain. Period pain is the result of the uterus (womb) cramping, like a contraction when giving birth. Gentle exercise can help relax tight cramped muscles.
- Keep a diary or use a tracking app to monitor your periods. Keeping a record of how your periods are, or how you're feeling, can sometimes help you see what's happening and decide what can help.
- Being a healthy weight can help manage periods. Include iron rich foods if you are bleeding heavily and regularly. Examples of iron rich foods are: red meat, fish, white meat such as chicken, lentils, beans, chickpeas, seeds, dark green vegetables, eggs.
- Pain medicines such as paracetamol can help with period pain. If you are having severe period pain that stops you doing normal activities, talk to your doctor.
- Warm baths or a hot water bottle on your abdomen (tummy) or back, or anything you find relaxing might help with pain and cramps.
- Rest if you feel you need to. Some people are tired around the time of their period, be kind to yourself.
- Take your Iron medication regularly

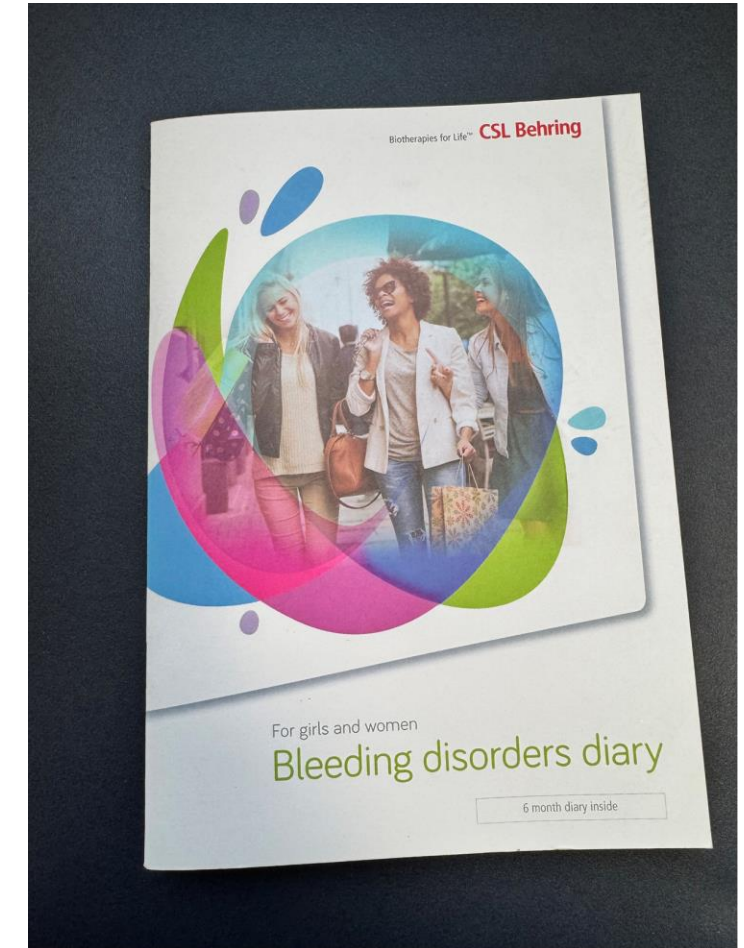


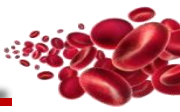
Ongoing Support



- Use of Know Your Flow website and the 7-2-1 rule
- Use of Bleeding Diary provided by CSL Behring
- Importance of taking any supplementary medication
- Toilet Pass and support in school
- Being honest with your Mom about blood loss
- Be honest with your nurses if you missed any medication

If we don't know the full story – we can't help you!!





- In the UK, this does vary from centre to centre.
- At BCH, our girls wait up to 18 months to see our gynae colleagues
- Quicker service if referred to local adult hospital
- We are experts in bleeding BUT have very little knowledge on the options used to manage HMB

Our long-term aim is to build better links with our colleagues and for our Advanced Nurse Practitioner to set up HMB clinics to see the girls as needed and provide support.



Transition



- Transition preparation should begin at age 11
- At BCH, patients are transitioned after their 16th birthday
- Transition is scary – often more so for the Moms!
- We see it as a positive step, as our adult colleagues have far more experience of managing HMB, as well as better links with Gynaecology and Obstetrics!





References

Cultural aspects and mythologies surrounding menstruation and abnormal uterine bleeding

Tan D et al

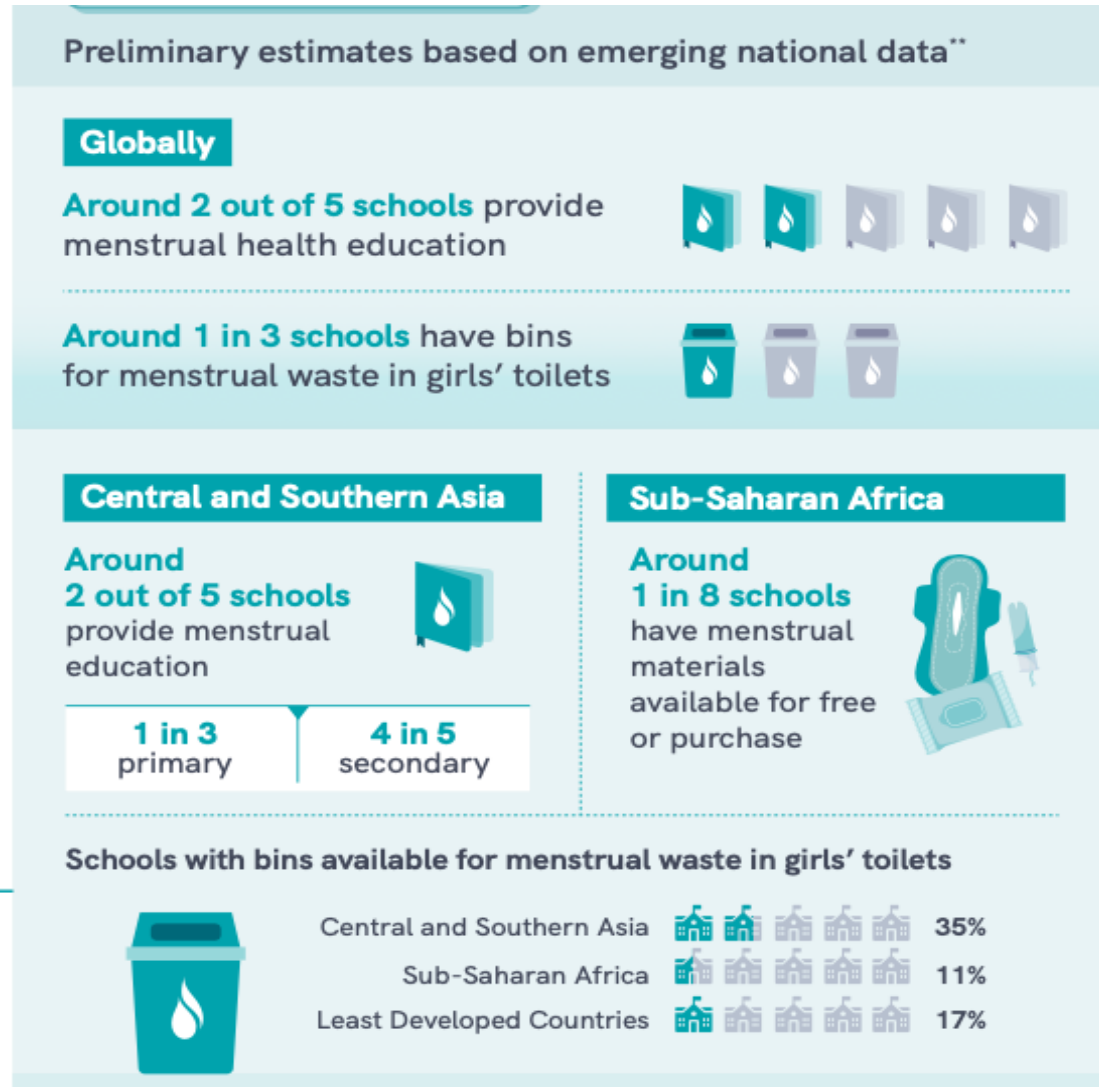
Best Practice & Research Clinical Obstetrics & Gynaecology

Vol 40 April 2017 p121-133

www.knowyourflow.ie

[Making a decision about: managing heavy periods \(england.nhs.uk\)](http://makingadecisionaboutmanagingheavyperiods.england.nhs.uk)



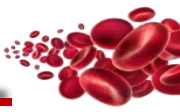


Progress on drinking water, sanitation, and hygiene in schools 2015–2023:
special focus on menstrual health
WHO/UNICEF 2024

Stigma related to menstruation remains widespread, with adolescents often feeling ashamed or unable to openly discuss the topic.

This shame can affect their mental health and school attendance.





Investigating Young Women's Retrospective Perceptions and Experiences of Menstrual Health Education in School Settings, England.

- Lessons focussed on biological content
- Lack of practical information needed to help students manage menstruation and menstrual health
 - nearly seven in ten participants reportedly received no practical information.
- None of the participants were taught about menstrual health conditions and only 3.2 per cent learnt about abnormal symptoms.
- Serious long-term impacts were reported, as several participants put off seeking medical attention for debilitating symptoms because they thought their pain was normal, only to be later diagnosed with conditions such as endometriosis.

Taylor, P., & Greig, A. (2024). Investigating Young Women's Retrospective Perceptions and Experiences of Menstrual Health Education in School Settings, England. *Women's Reproductive Health*, 11(3), 697–716.





Investigating Young Women's Retrospective Perceptions and Experiences of Menstrual Health Education in School Settings, England. Investigating Young Women's Retrospective Perceptions and Experiences of Menstrual Health Education in School Settings, England.

- Overall, participants left school lacking basic knowledge and feeling ill-equipped with 62.4 per cent rating their education as 'poor' or 'very poor' in preparing them for managing menstruation.
- In extreme cases, some were so unprepared that when they started their periods, they thought they were ill or even dying.
- While schools were seen as an important source of information, many had to rely on other sources – particularly the internet and social media – which poses its own risks, as well as barriers for those who lack access to such resources

Taylor, P., & Greig, A. (2024). Investigating Young Women's Retrospective Perceptions and Experiences of Menstrual Health Education in School Settings, England. *Women's Reproductive Health*, 11(3), 697–716.





Education

collaborative -patient, guardian, and clinician

- educate prepubertal patients and their guardians on the progression of puberty and the development of the menstrual cycle.
- talk openly about the subject and dispel any fears or misinformation
- clinicians should convey that females will begin to menstruate approximately 2 to 3 years after breast development begins and that menstruation is a normal part of development.
- instruction on using period products and what is considered normal menstrual flow.





Abnormal Uterine Bleeding

Abnormal uterine bleeding (AUB)

Collection of symptoms that include intermenstrual bleeding and abnormalities in period duration, cycle length, and regularity

Chronic AUB is “bleeding from the uterine corpus that is abnormal in volume, regularity, and/or timing, and has been present for the majority of the past 6 months”

Acute AUB is “an episode of heavy bleeding that, in the opinion of the clinician, is of sufficient quantity to require immediate intervention to prevent further blood loss”

Acute AUB can occur in the presence of chronic AUB or as an independent episode.

Munro MG, Critchley HOD, Fraser IS, Committee FMD. The two FIGO systems for normal and abnormal uterine bleeding symptoms and classification of causes of abnormal uterine bleeding in the reproductive years: 2018 revisions. *Int J Gynaecol Obstet.* 2018; **143**: 393-408.





Abnormal uterine bleeding

FIGO created two systems for assessing and classifying AUB.

- FIGO System 1 defines the bleeding pattern
- FIGO System 2 provides a structured classification system of possible causes of AUB





FIGO System 1

Parameter	Normal	Abnormal	<input checked="" type="checkbox"/>
Frequency	Absent (no bleeding) = amenorrhea		<input type="checkbox"/>
	Infrequent (>38 days)		<input type="checkbox"/>
	Normal (≥ 24 and ≤ 38 days)		<input type="checkbox"/>
	Infrequent (<24 days)		<input type="checkbox"/>
Duration	Normal (≤ 8 days)		<input type="checkbox"/>
	Prolonged (>8 days)		<input type="checkbox"/>
Regularity	Normal or "Regular" (shortest to longest cycle variation: $\leq 7-9$ days)*		<input type="checkbox"/>
	Irregular (shortest to longest cycle variation: ≥ 10 days)		<input type="checkbox"/>
Flow Volume (patient determined)	Light		<input type="checkbox"/>
	Normal		<input type="checkbox"/>
	Heavy		<input type="checkbox"/>

Intermenstrual Bleeding (IMB) Bleeding between cyclically regular onset of menses	None		<input type="checkbox"/>
	Random		<input type="checkbox"/>
	Cyclic (Predictable)	Early Cycle	<input type="checkbox"/>
		Mid Cycle	<input type="checkbox"/>
		Late Cycle	<input type="checkbox"/>

Unscheduled Bleeding on Progestin \pm Estrogen Gonadal Steroids (birth control pills, rings, patches or injections)	Not Applicable (not on gonadal steroid medication)		<input type="checkbox"/>
	None (on gonadal steroid medication)		<input type="checkbox"/>
	Present		<input type="checkbox"/>

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Menstruation

- **Typical physiological menstruation**
 - occurs every 24–38 days
 - lasts less than 8 days
 - has a longest to shortest cycle variation of less than 7–9 days

The volume of typical menstrual bleeding should not interfere with quality of life.

- **Menstrual blood loss**

For clinical purposes, objective assessment of amount of blood lost during a period is not recommended





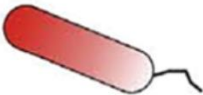

PBAC (Pictorial Blood Assessment Chart) is a simple tool to provide a semi-quantitative assessment of menstrual blood loss and can also help monitor responses to treatment in clinical practice.

HIGHAM, J.M., O'BRIEN, P.M.S. and SHAW, R.W. (1990), Assessment of menstrual blood loss using a pictorial chart. BJOG: An International Journal of Obstetrics & Gynaecology, 97: 734-739.





Pictorial Blood Assessment Chart

PADS	DAY							
	1	2	3	4	5	6	7	8
								
								
								
TAMPONS	DAY							
	1	2	3	4	5	6	7	8
								
								
								





Assessment of menstrual blood loss	Advantages	Disadvantages
Impact on the quality of life Any impact on the patient's quality of life as perceived by them	Subjective assessment; therefore, individually important to the patient Can be used clinically	Impacted by social and cultural perspectives on bleeding Can be unreliable Not comparable across a population
AH method Estimation of menstrual blood loss after collection of used menstrual products and laboratory assessment	Most reliable and accurate method available to date Good for research purposes	Challenge with patient compliance and collection variability Not possible to use clinically
PBAC Semiobjective evaluation of used menstrual products and passage of clots	Cheap, simple, quick to use Can be used clinically Semiquantitative assessment of menstrual blood loss	Can be unreliable Underestimates menstrual blood loss; therefore, not suitable for HMB
MP Semiobjective evaluation of specified menstrual products once used, based on their absorbancy	Cheap, simple, quick to use Can be used clinically Semiquantitative assessment of menstrual blood loss	Can be unreliable Menstrual products have changed over time to include superabsorbent polymers, making earlier menstrual pictograms obsolete

Note: AH = alkalin-hematin; HMB = heavy menstrual bleeding; MP = menstrual pictogram; PBAC = pictorial blood assessment chart.

Assessment of Menstrual Blood Loss

Silvia Vannuccini. From menarche to menopause, heavy menstrual bleeding is the underrated compass in reproductive health, Fertility and Sterility, Volume 118, Issue 4, 2022, Pages 625-636,





Heavy Menstrual Bleeding

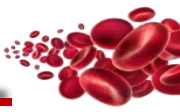
Traditionally defined as a loss of more than 80 mL of blood per cycle

“Excessive menstrual blood loss which interferes with a woman’s physical, social, emotional and/or material quality of life”

Hallberg L, Nilsson L. Determination of menstrual blood loss. Scand J Clin Lab Invest. 1964;16:244–248.

National Institute for Health and Care Excellence. Heavy menstrual bleeding: assessment and management. NICE guideline NG88. <https://www.nice.org.uk/guidance/ng88/resources/heavy-menstrual-bleeding-assessment-and-management-pdf-1837701412549> (2018).





Proposed definition of heavy menstrual bleeding

Menstrual bleeding meeting any of the following criteria:

- Lasting ≥ 8 days
- Consistently soaks through 1 or more sanitary protections every 2 hours on multiple days
- Requires use of >1 sanitary protection item at a time
- Requires changing sanitary protection during the night
- Associated with repeat passing of blood clots
- **Pictorial Blood Assessment Chart (PBAC) score >100**

All above significantly more prevalent in women with VWD compared to women in the general population

Nathan T. Connell et al. von Willebrand disease: proposing definitions for future research. Blood Adv 2021; 5 (2): 565–569.





Are My Periods Heavy?

Did you know that 1 in 5 women will experience heavy periods? In women with ongoing heavy periods, 1 in 5 may have a bleeding disorder. Signs of heavy periods include:



If your periods last for 7 days or more



Needing to change your pads/tampons more frequently than every 2 hours



Passing clots of blood larger than a €1 coin





Menstrual chart and scoring system

Date of start: day month year Score:

Towel	1	2	3	4	5	6	7	8
Clots/flooding Clots: size								

Tampon	1	2	3	4	5	6	7	8
Clots/flooding Clots: size								

Scoring system

Towels
1 point for each lightly stained towel
5 points for each moderately soiled towel
20 points if the towel is completely saturated with blood

Tampons
1 point for each lightly stained tampon
5 points for each moderately soiled tampon
10 points if the tampon is completely saturated with blood

Clots
1 point for small clots
5 points for large clots

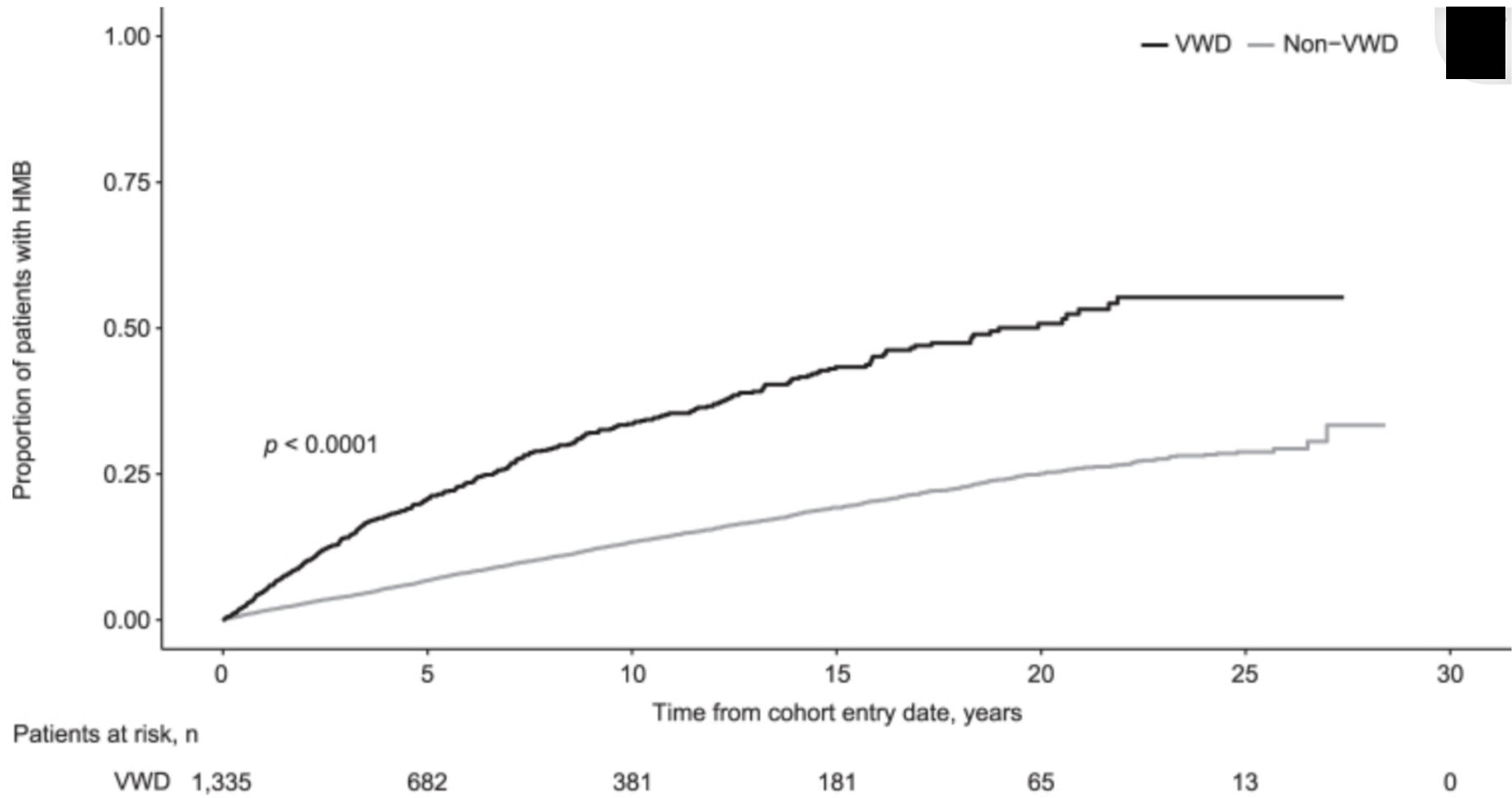
Source: U.K. Haemophilia Society, A Guide for Women Living with von Willebrand's

Using PBAC and a score of 100 and 185 as a cut-off for diagnosis of HMB, 74 and 71% of women with VWD were reported to have HMB, respectively

- Kadir R, Economides D, Sabin C, Pollard D, Lee C. Assessment of menstrual blood loss and gynaecological problems in patients with inherited bleeding disorders. *Haemophilia* 1999; 5 (1): 40–8.
- Siboni S, Spreafico M, Calo L, Maino A, Santagostino E, Federici A. Gynaecological and obstetrical problems in women with different bleeding disorders. *Haemophilia* 2009; 15 (6): 1291–9.



FIG. 1.



Hagberg K. Impact of von Willebrand Disease on Women's Health Outcomes: A Matched Cohort Database Study. J Womens Health (Larchmt). 2022 Sep;31(9):1262-1270. .





P olyp	
A denomyosis	
L eiomyoma	
M alignancy & hyperplasia	
	S ubmucous
	O ther

C oagulopathy
O vulatory dysfunction
E ndometrial
I atrogenic
N ot otherwise classified



FIGO Abnormal Uterine Bleeding (System 2)

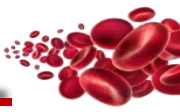
PALM-COEIN Classification system for
causes of AUB in the reproductive years.

PALM :objective structural criteria

COEIN: nonstructural anomalies

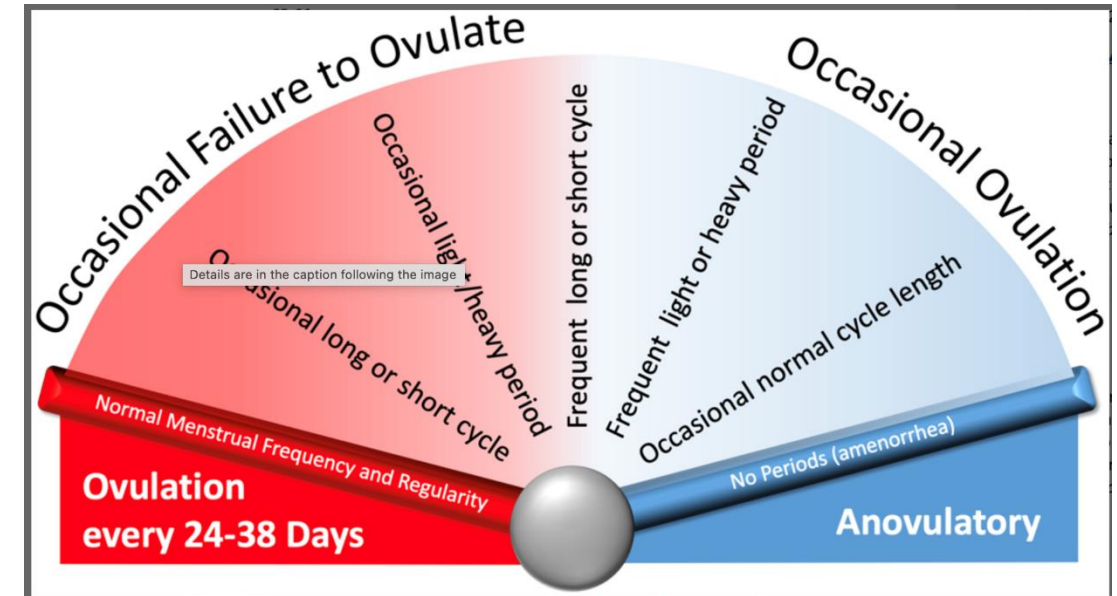
Contemporary evaluation of women and girls with abnormal uterine bleeding: FIGO Systems 1 and 2
Intl J Gynecology & Obste, Volume: 162, Issue: S2, Pages: 29-42, First published: 04 August 2023, DOI: (10.1002/ijgo.14946)





AUB –C :-secondary to congenital or acquired systemic disorders of haemostasis, with the most common disorder being von Willebrand disease.

AUB-O-: Ovulatory disorders exist on a spectrum that encompasses occasional delayed or failed ovulation to a chronic process that can cause amenorrhea or manifest with bleeding that varies in volume, duration, and frequency.



Shankar M, Lee CA, Sabin CA, Economides DL, Kadir RA. von Willebrand disease in women with menorrhagia: a systematic review. *BJOG*. 2004; **111**: 734-740
Ni P, Wu M, Guan H, et al. Etiology distribution of abnormal uterine bleeding according to FIGO classification system: A combined study of ultrasound and histopathology. *J Obstet Gynaecol Res*. 2022; **48**: 1913-1920





Adolescence

An underlying bleeding disorder is second only to anovulation as a cause of heavy menstrual bleeding in adolescence

Heavy menstrual bleeding at menarche and in adolescence may be an important sentinel for an underlying bleeding disorder.

The frequency of bleeding disorders in the general population is approximately 1–2%

Bleeding disorders are found in

approximately 20% of adolescent girls who present for evaluation of heavy menstrual bleeding

approximately 33% of adolescent girls hospitalised for heavy menstrual bleeding

Screening and Management of Bleeding Disorders in Adolescents With Heavy Menstrual Bleeding: ACOG COMMITTEE OPINION, Number 785. Obstet Gynecol. 2019 Sep;134(3):e71-e83.





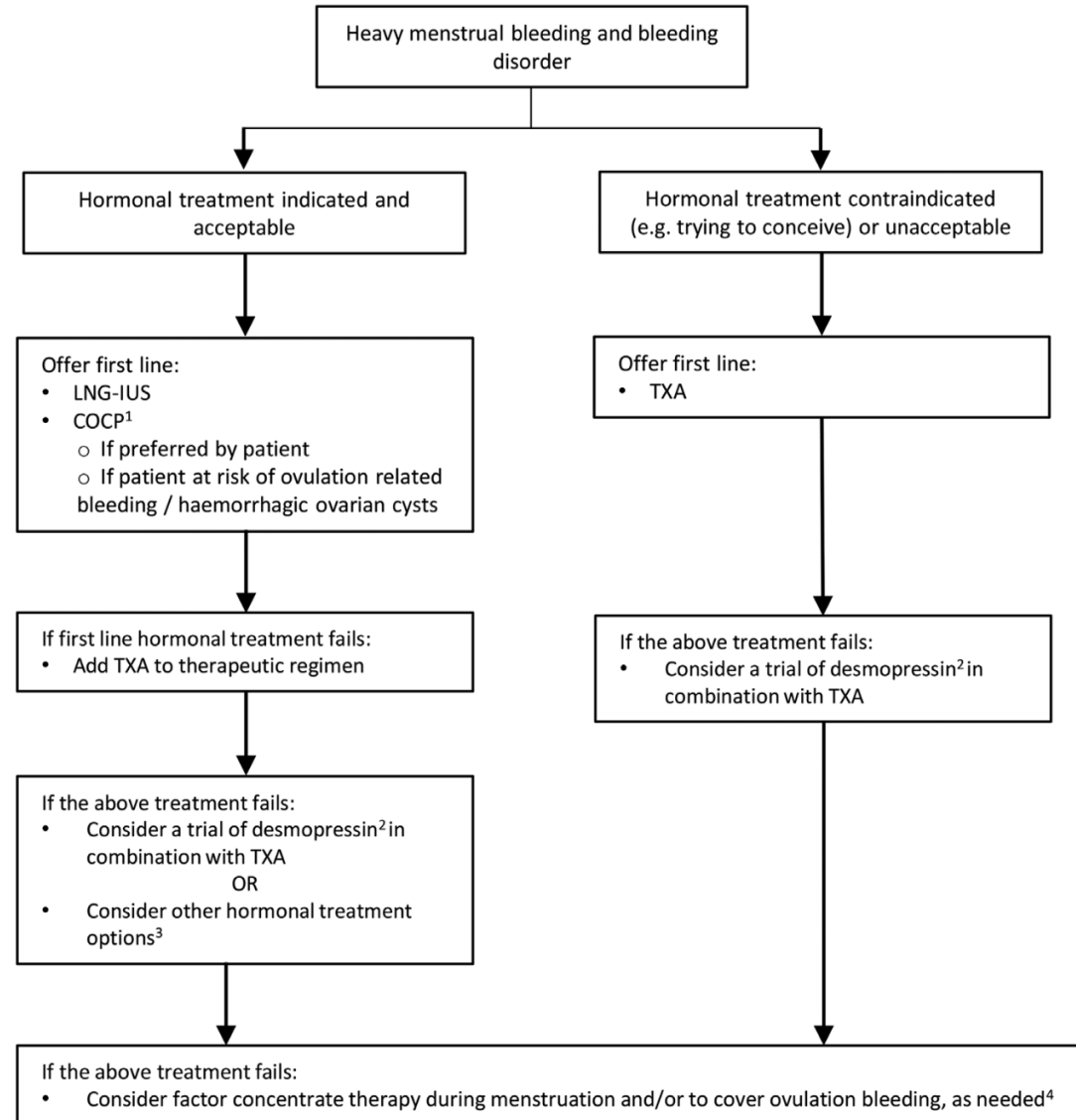
Treatment options for HMB in VWD

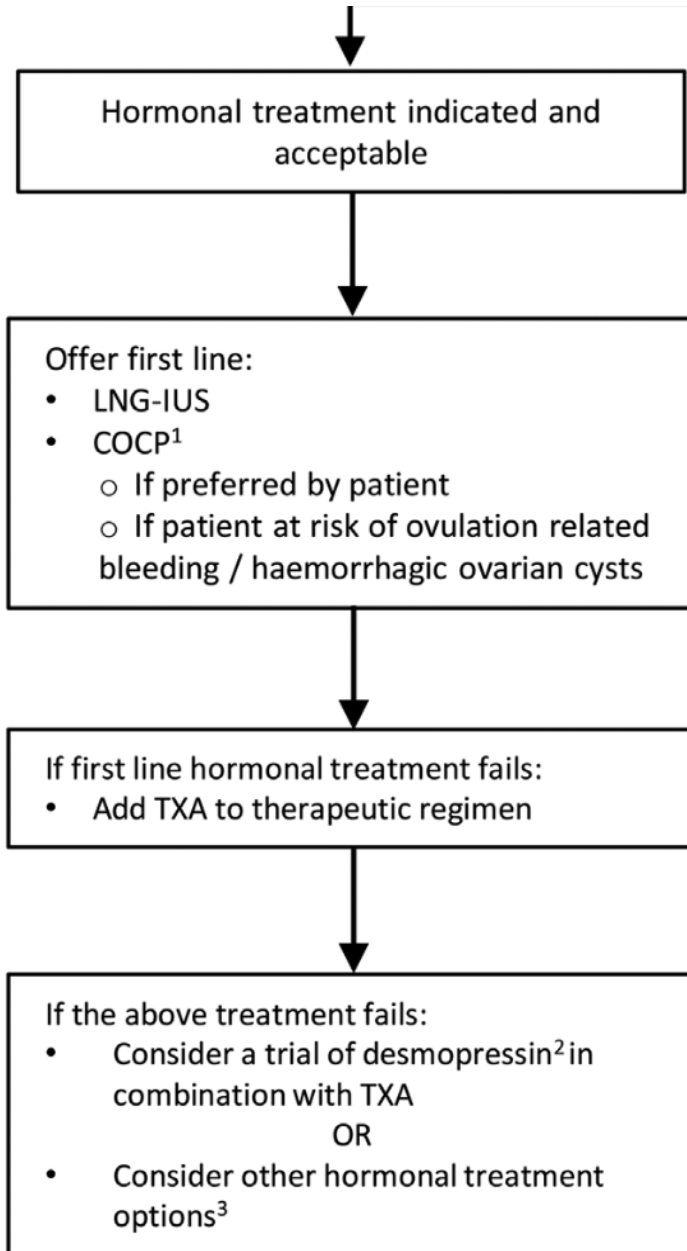
- All suitable treatment options and their benefits, side effects, and potential risks should be discussed to help the woman make an informed choice.
- The woman's age, whether she is trying to conceive, and whether she wants to retain her fertility and/or her uterus must be considered when discussing treatment options
- The woman's values and preferences, presence of other gynaecological symptoms such as pain and pelvic pathologies (such as fibroids, polyps, endometrial pathology, endometriosis, etc.), and the type and severity of VWD should also be considered

Presky K, Kadir R. Women with inherited bleeding disorders – challenges and strategies for improved care. Thromb Res 2020; 196: 569–78.

Heavy menstrual bleeding: assessment and management NICE (National Institute for health and Care Excellence) guideline Published. 2018. www.nice.org.uk/guidance/ng88.







levonorgestrel-releasing intrauterine system (LNG-IUS)

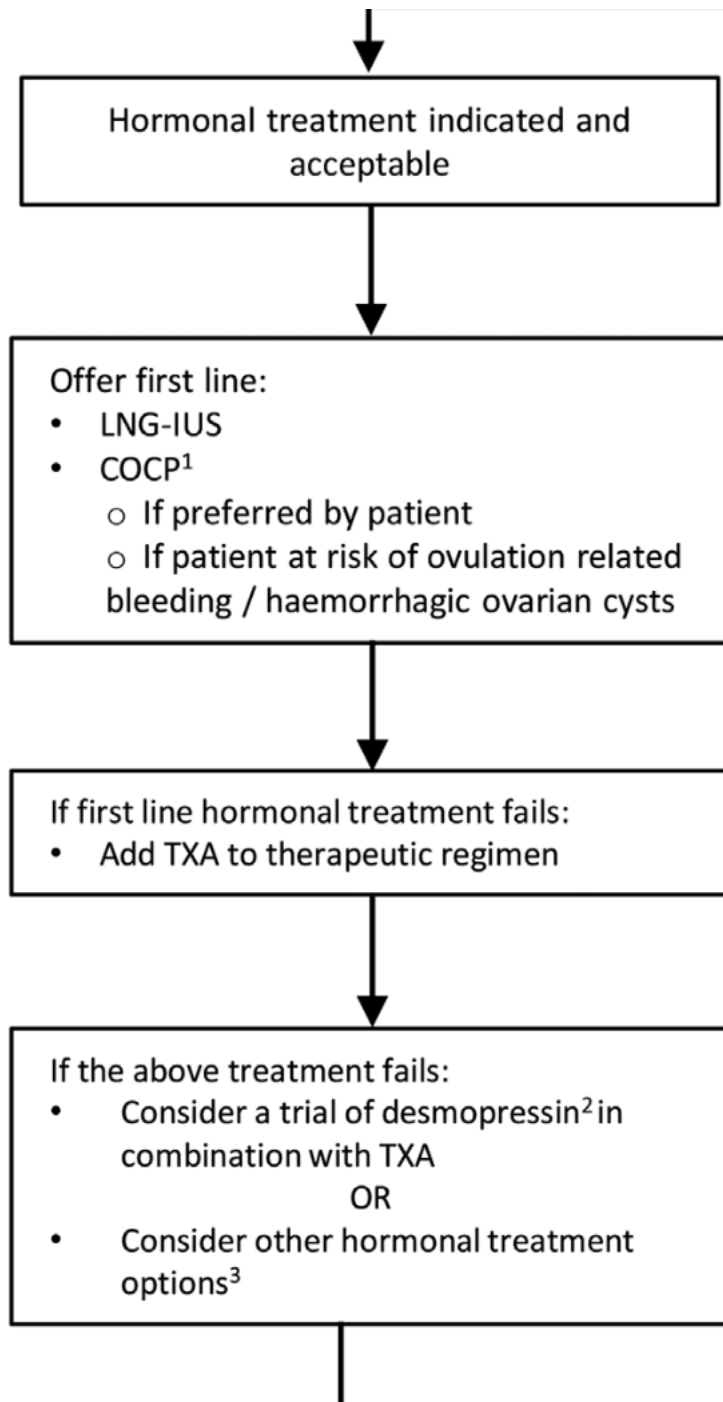
In inherited bleeding disorders

- significant reduction in PBAC scores
- amenorrhoea in 42% of users
- improvements in haemoglobin values
- improvements in QoL

Women may require additional treatment directed at bleeding symptoms for the first several menstrual cycles after placement of LNG-IUS

- irregular bleeding/spotting during the first year of use
- progestogenic side effects.
- expulsion
- malposition

Chi C, Huq F, Kadir R. Levonorgestrel-releasing intrauterine system for the management of heavy menstrual bleeding in women with inherited bleeding disorders: long-term follow-up. Contraception 2011; 83 (3): 242–7



CHCs are appropriate treatment options when

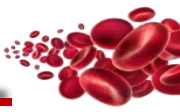
- LNG-IUS is not suitable/acceptable in women with recurrent ovulation bleedings because they inhibit ovulation.

The use of CHC pill has been reported to be effective in controlling HMB in women with all types of VWD with efficacy rates ranging from 24 to 88%

Extended administration of CHCs without discontinuation for 3 months or more can further reduce the MBL and improve bleeding patterns and menstruation-associated symptoms

Amesse L, Oral contraceptives and DDAVP nasal spray: patterns of use in managing vWD-associated menorrhagia. *J Pediatr Hematol Oncol* 2005; **27** (7): 357–63.

Archer D. Menstrual-cycle-related symptoms: a review of the rationale for continuous use of oral contraceptives. *Contraception* 2006; **74** (5): 359–66.

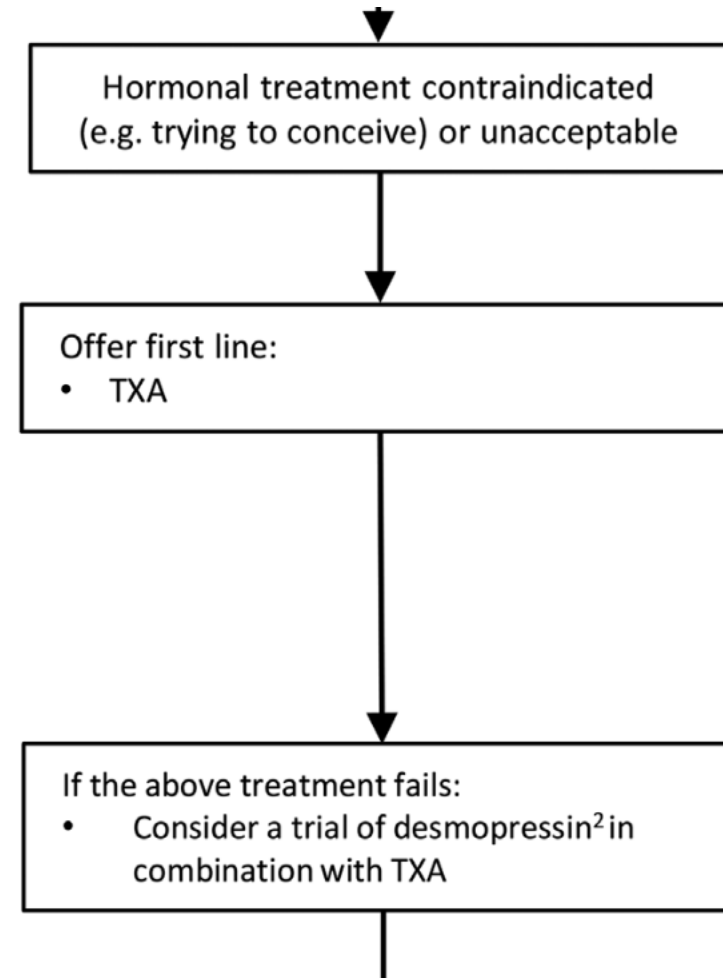


In a randomized cross-over study, both TXA and intranasal desmopressin were effective in reducing MBL (measured using PBAC scores) and improving QoL in women with abnormal haemostasis with a significantly greater reduction in PBAC scores with TXA.

Concomitant use of DDAVP with TXA is advocated to improve the efficacy of treatment without increase in adverse events

Kouides P, Byams V, Philipp C, et al. Multisite management study of menorrhagia with abnormal laboratory haemostasis: a prospective crossover study of intranasal desmopressin and oral tranexamic acid. Br J Haematol 2009; 145 (2): 212–20.

Kadir R. Menorrhagia: treatment options. Thromb Res 2009; 123: S21–9.





If the above treatment fails:

- Consider factor concentrate therapy during menstruation and/or to cover ovulation bleeding, as needed⁴

Other considerations:

- Factor concentrate prophylaxis may be required occasionally when hormonal contraception is stopped whilst trying to conceive
- Surgical and radiological therapeutic options should be considered in accordance with the NICE Heavy menstrual bleeding NG88 guidance (2021)[NICE, 2021]

COCp = combined oral contraceptive pill; LNG-IUS = levonorgestrel releasing intrauterine device; TXA = tranexamic acid; VWD = von Willebrand disorder





Adolescents

- The use of LNG-IUs as a first-line medical treatment for HMB in adolescent girls with low VWF or VWD is reported to be appropriate and effective by an international multidisciplinary working group of experts in the field of women with IBDs
- However, general anesthesia may be required for insertion in young adolescents The use of CHC pill has been reported to be effective in controlling HMB in adolescent girls with all types of VWD

36 Zia A, Kouides P, Khodyakov D, Dao E, Lavin M, Kadir R. Standardizing care to manage bleeding disorders in adolescents with heavy menses – a joint project from the ISTH pediatric/neonatal and women's health SSCs. J Thromb Haemost 2020; 18 (10): 2759–74.

37 Chi C, Pollard D, Tuddenham E, Kadir R. P53 Menorrhagia in adolescents with inherited bleeding disorders. Thromb Res 2010; 123: S155.





Single treatments attempted for the management of HMB.

Treatment type	Number of times used as sole treatment	Number of subjects who trialed treatment	Number of subjects who achieved control (n = 66)	Satisfaction % ^b
Combined contraceptive pill	77	47	17	36
Transdermal patch	6	6	1	17
Vaginal ring	8	8	0	0
Progesterone-only pill	12	10	1	10
Tranexamic acid	50	47	11	23
LIUS ^a	62	50	33	66
DMPA	15	14	2	14
Desmopressin	4	4	1	25
Surgery	27	27	n/a	n/a

DMPA, depomedroxyprogesterone acetate; HMB, heavy menstrual bleeding; LIUS, levonorgestrel intrauterine system.

^a52-mg levonorgestrel intrauterine system.

^bPercentage of subjects who achieved control per treatment type.





HRC 50 - EU Intervention: Panel discussion on Menstrual Hygiene Management, Human Rights and Gender Equality

Delegation of the European Union to the UN and other international organisations in Geneva

- The EU is concerned that menstruation continues to be surrounded by harmful gender stereotypes, stigma and discriminatory practices in every society.
- The full realization of menstrual health is key for the enjoyment of all human rights and the achievement of gender equality.
- The EU underscores the right to fully participate in all spheres of life during one's menstrual cycle, without any form of discrimination and or being hindered by socio-, economic- cultural or religious practices and restrictions.
- The EU further stresses the need for universal access to quality and affordable comprehensive sexual and reproductive health information, education, including comprehensive sexuality education and health-care services

https://www.eeas.europa.eu/delegations/un-geneva/hrc-50-eu-intervention-panel-discussion-menstrual-hygiene-management-human-rights-and-gender_en?s=62#:~:text=The%20EU%20continues%20to%20support,the%20European%20Consensus%20on%20Development.





Women and Girls with Bleeding Disorders (WGBD) face unique challenges. In order to optimise diagnosis, care and management of WGBD, the EAHAD Women and Bleeding Disorder working group have developed the following Principles of Care (PoC):



Equitable access and quality of care for all individuals with bleeding disorders, irrespective of gender



Timely and accurate diagnosis of bleeding disorders in women and girls



Awareness of the additional challenges faced by WGBD throughout life



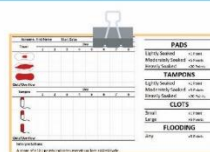
Comprehensive care of bleeding disorders requires a family centred approach which includes WGBD



Inclusion of a dedicated obstetrician and gynaecologist in the multidisciplinary team



Education of WGBD and their families regarding the challenges associated with the menstrual cycle and their management



Early recognition and optimal management of heavy menstrual bleeding



Provision of preconception counselling and access to prenatal diagnostics



Provision of a patient centred comprehensive management plan throughout pregnancy and the post partum period



Involvement of WGBD in registries, clinical research and innovation



**European
Reference
Network**

for rare or low prevalence
complex diseases

 **Network**
Hematological
Diseases (ERN EuroBloodNet)

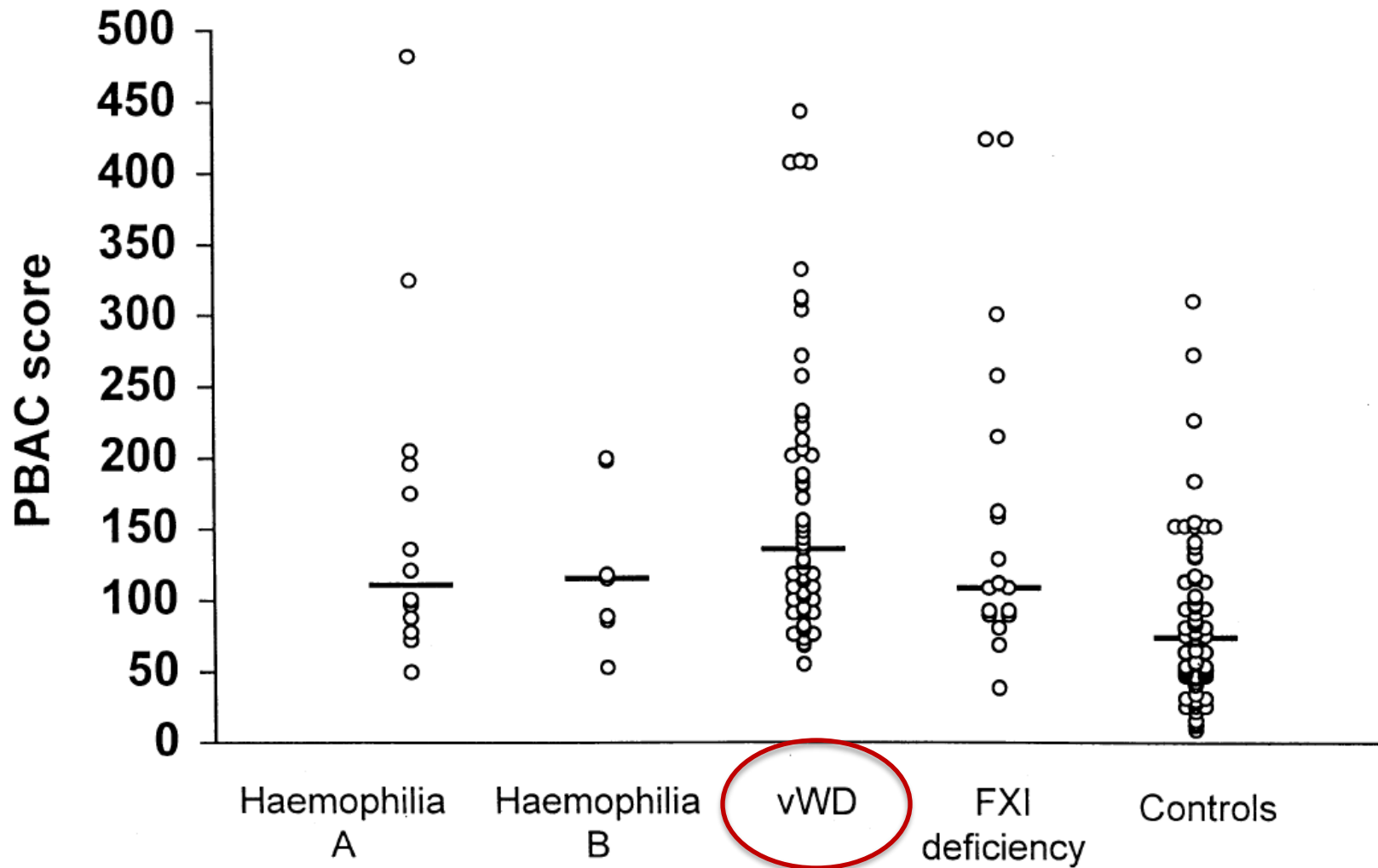


European
von Willebrand Disease
Community





Early recognition of HMB - PBAC



Early recognition and optimal management of heavy menstrual bleeding

VWD n=66
73% >100





Providing personalized treatment options



Early recognition and optimal management of heavy menstrual bleeding

Management aim - holistic approach - improve QOL

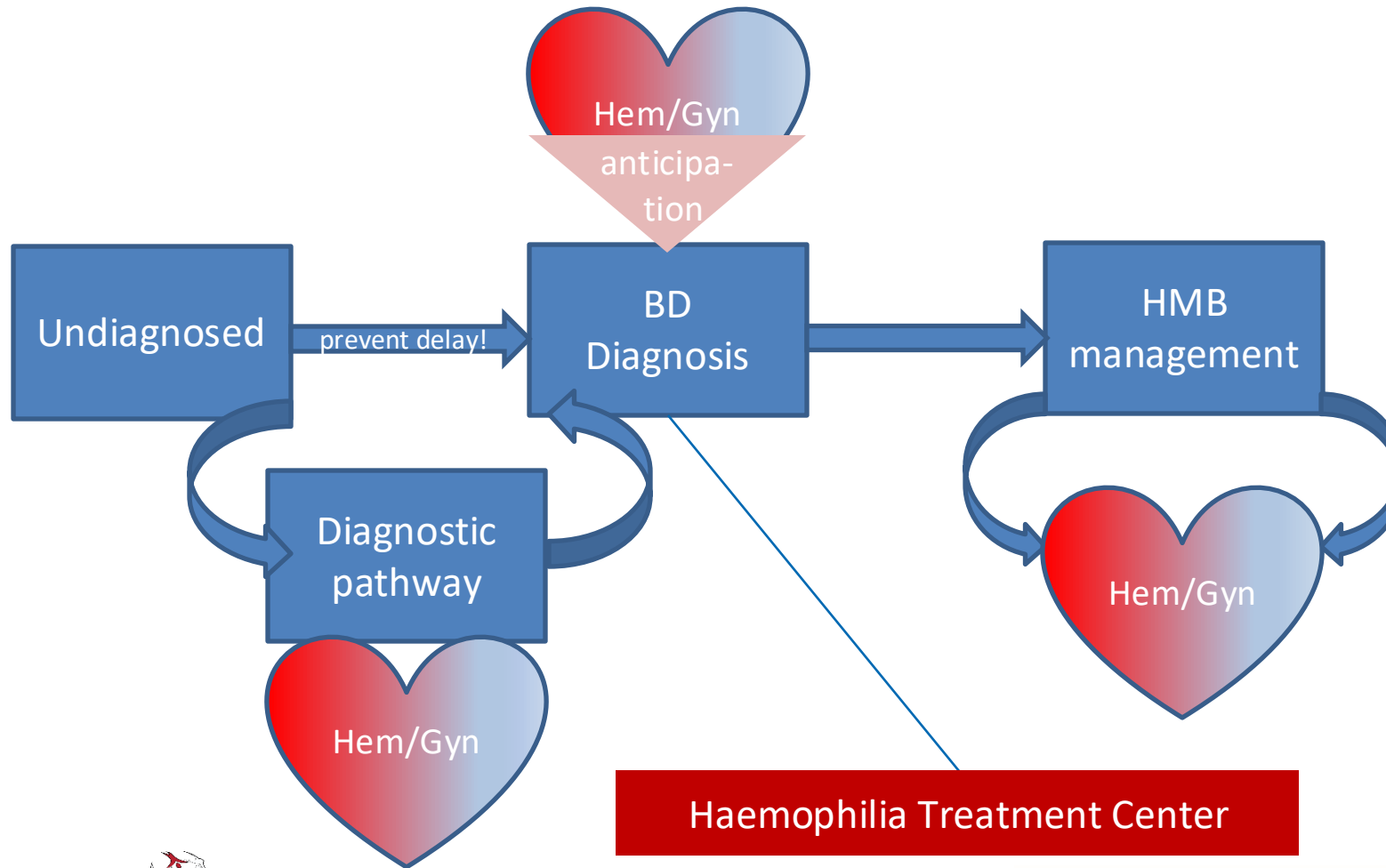
Taking in consideration

- Woman's fertility wishes
- Other gynaecological symptoms
- Underlying cause(s) for HMB
- Her acceptance of the treatment
- Her values and expectations





Coordination between hematologist and gynecologist



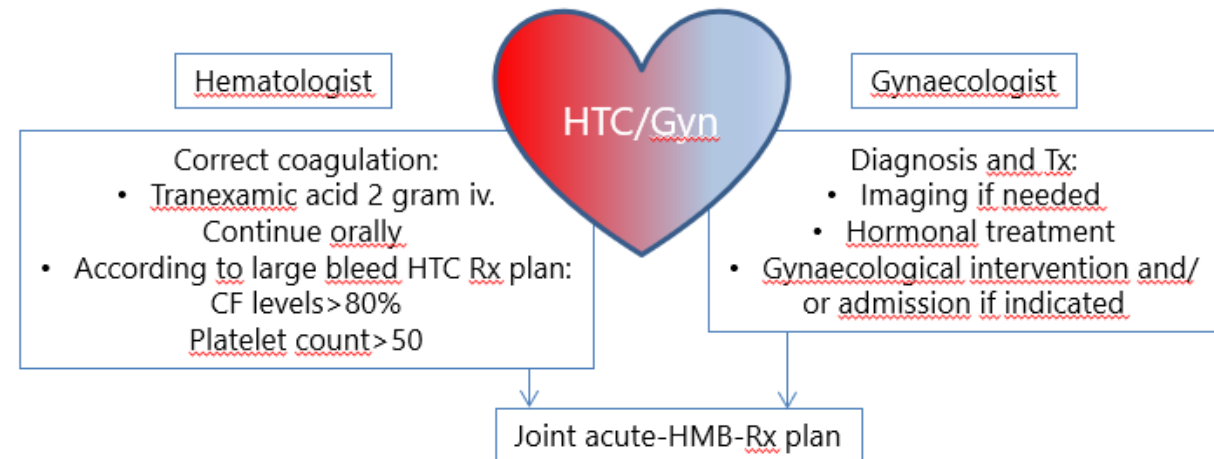


HMB management in VWD – acute HMB

- Acute HMB
 - Drop in Hb level
 - Hemodynamic consequences

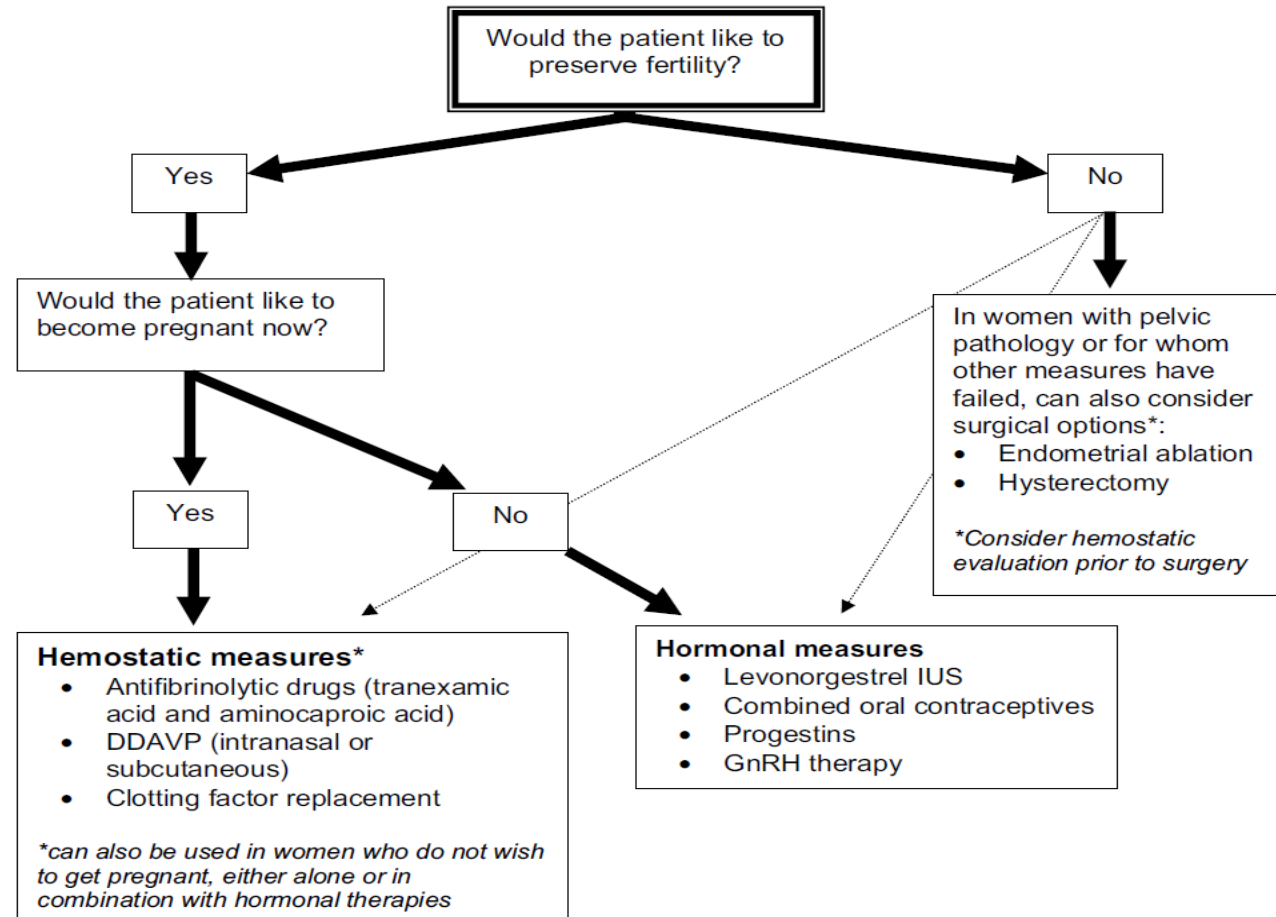


Early recognition and optimal management of heavy menstrual bleeding





Chronic HMB management options in VWD





Treatment outcome in adolescents with low VWF- associated HMB

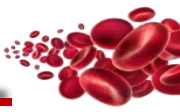
- Multicenter observational cohort study: n=111
 - age <21yrs, PBAC >100, low VWF on 2 occasions VWF:Act 30-50%
 - 94% bleeding phenotype: ISTH-BAT >2
- Treatment modality
 - 37% only hormonal – wide variety, most COC 53%, LG-IUD 11%
 - 14% only hemostatic – most antifibrinolytics / desmopressin, only 2% VWF conc
 - 45% combination
- Outcome recorded: n=103
 - 12% HMB resolved
 - 56% improvement
 - 30% no change
 - 2% worsening



Complications

60% iron deficiency
21% anemia
12% bloodTx
10% hospitalization



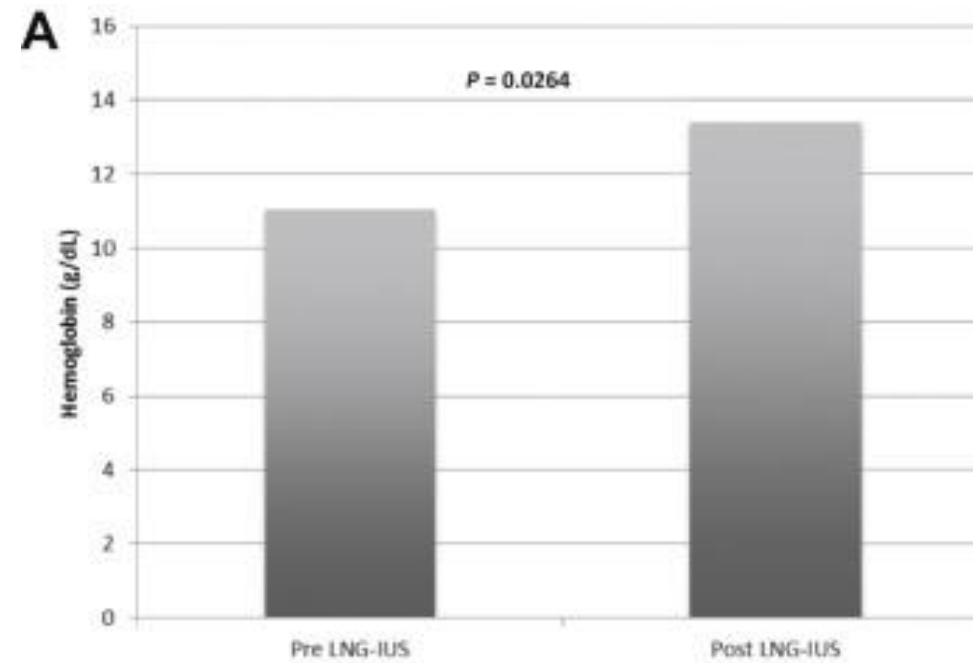


Levonorgestrel IUD in adolescents with BD

- 13 adolescents with HMB/BD*
 - n=11 VWD
- General anesthesia
- Hemostatic prophylaxis
- No complications
- All improved
 - 62% amenorrhea
 - Mean time to improvement 94±69d

Concerns..

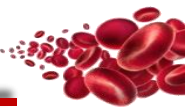
- high expulsion rate? 13%**
- typical breakthrough bleeding 1th <6m*



*Adeyemi-Fowode et al. J Pediatr Adolesc Gynecol. 2017:479

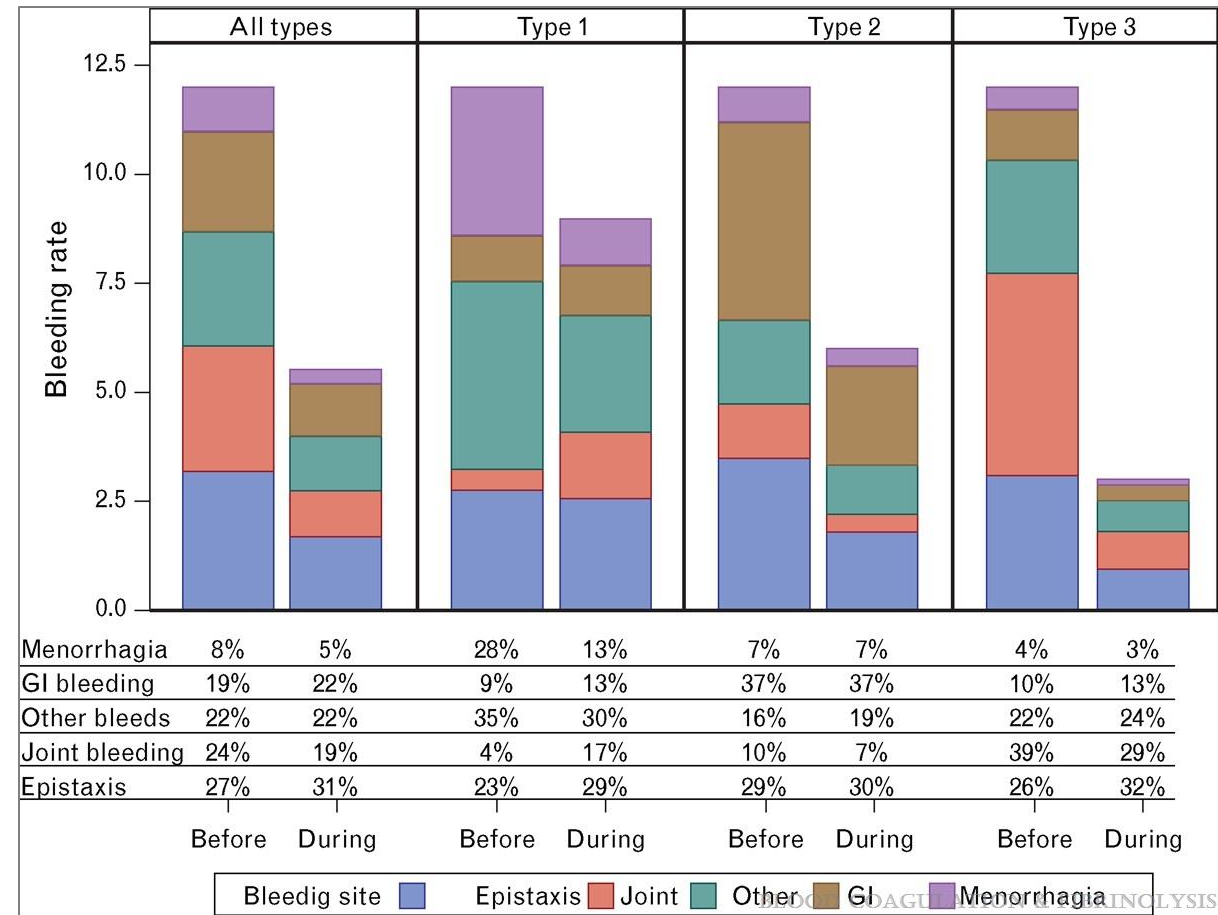
* O'Brien Blood 2018;132(20):2134

**Huguelet et al. J Pediatr Adolesc Gynecol. 2022:147



Periodic prophylaxis

- Very few and low quality data
- Holms: VWD Prophylaxis Network
 - **52 females** included - retrospective



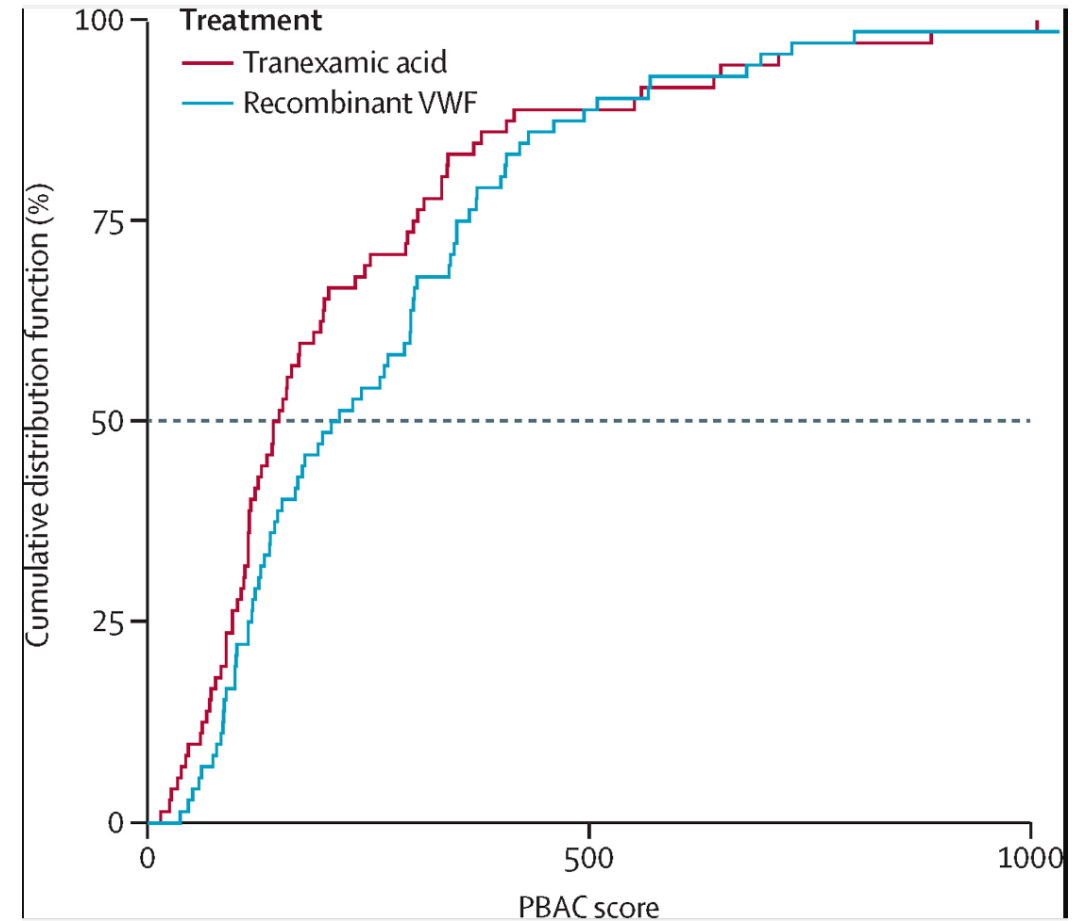
Holm et al. Blood Coagul Fibrinolysis 2015





Recomb VWF vs. TXA for HMB in mild-moderate VWD

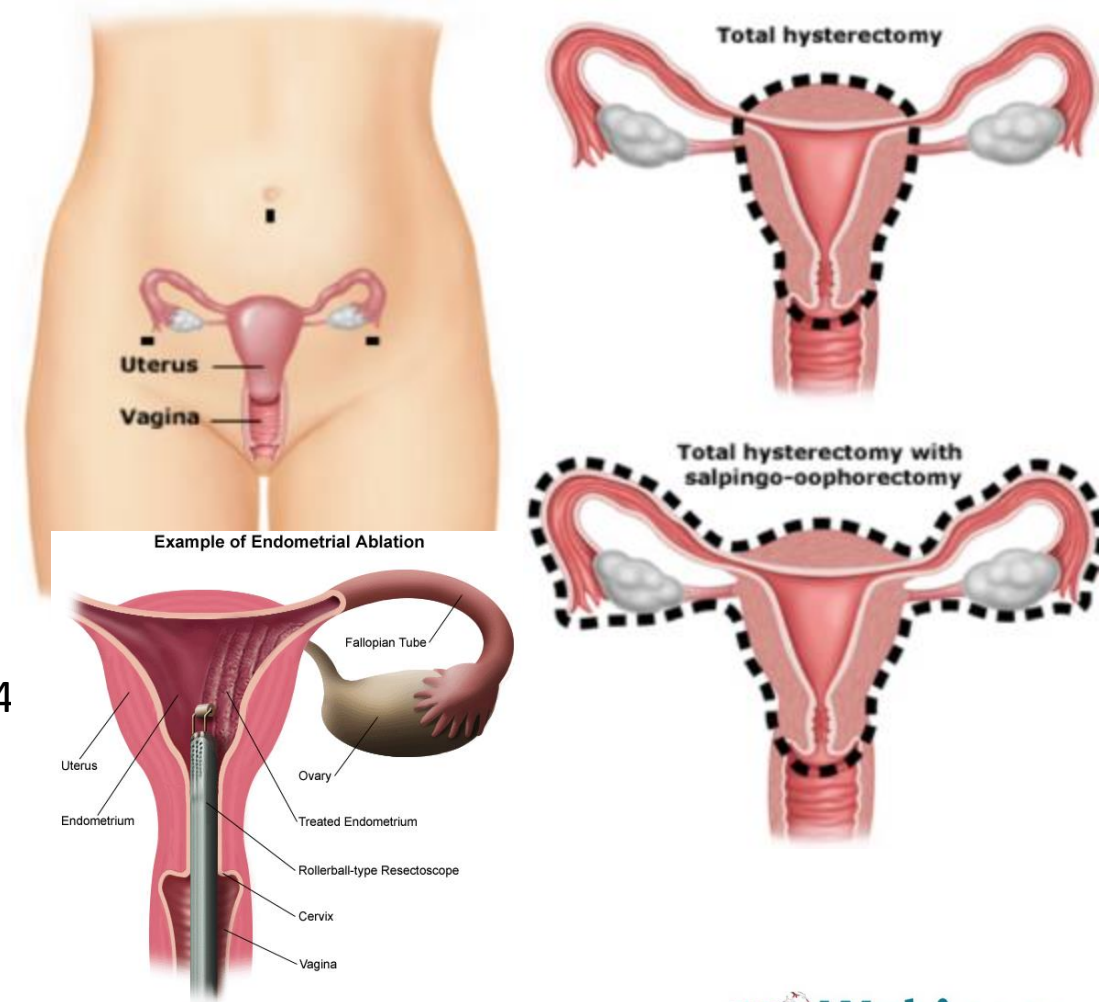
- A phase 3 open-label RCT
- 13 HTCs USA
 - Inclusion: n=39 VWF <50%, PBAC >100
 - rVWF 2x 40iu/kg at day 1 vs. TXA 1300mg t.i.d. day 1-5
 - n= 17 received rVWF then TXA
 - n= 19 received TXA then rVWF
 - Trial stopped early due to slow recruitment <3 yrs
 - Unplanned interim data suggest that rVWF is not superior
 - Median PBAC on TXA 146 (95% CI 117–199)
 - Median PBAC on rVWF 213 (95% CI 152–298, p=0.04)





Optimal per-operative management – systematic review

- 11 cohort studies + 1 case-report
 - 691 operative procedures for HMB in VWD
- Overall low quality data
- Prophylaxis to prevent bleeding
 - Endometrial ablation 30/30
 - Hysterectomy prophylaxis described in 4% (24/661)
 - Bleeding complications despite prophylaxis 13% (3/24)

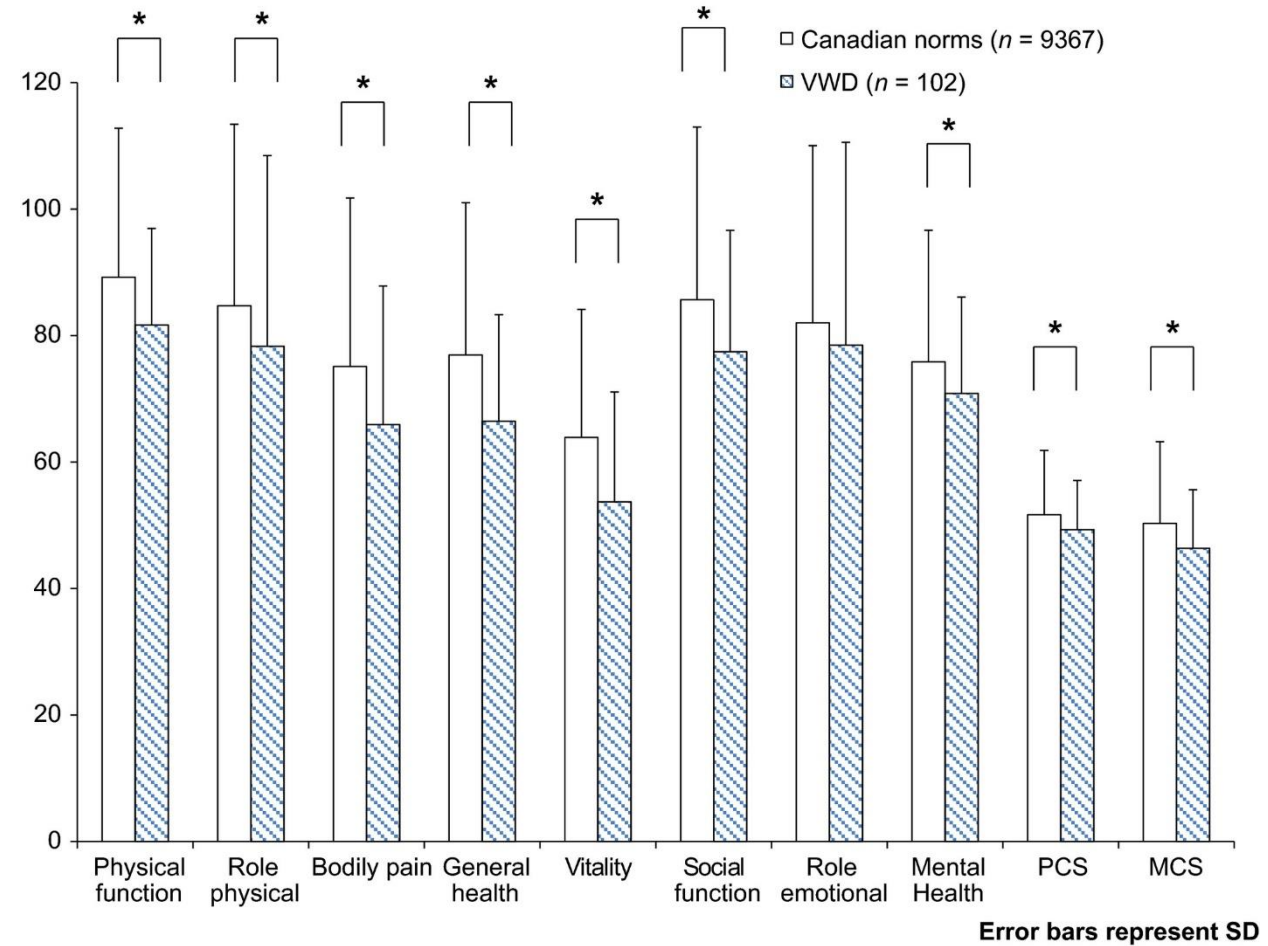




QoL in VWD and iron deficiency

- 78% women
- 41% iron level available < 4wks
- Trend towards lower SF-36 domain of vitality among patients with ferritin <15 ng mL⁻¹ vs. patients with ferritin was >15 ng mL⁻¹ (44.6 vs. 56.4, *P* = 0.08)

The prevalence of ID(A) in VWD is unknown*

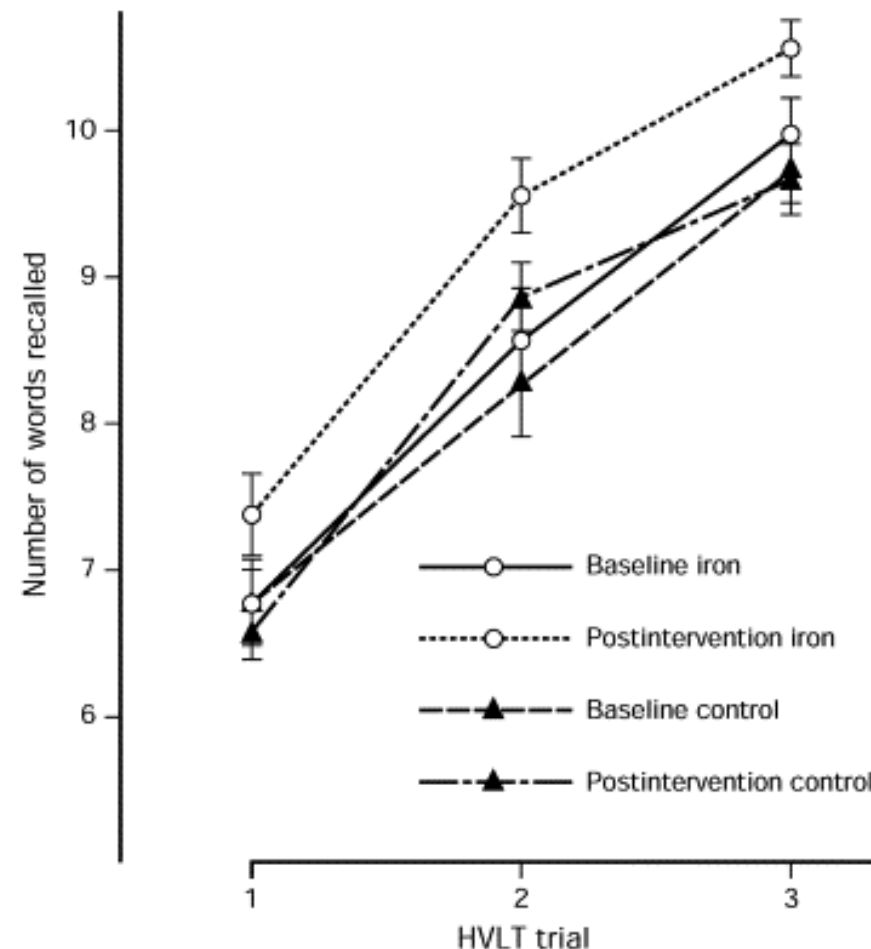
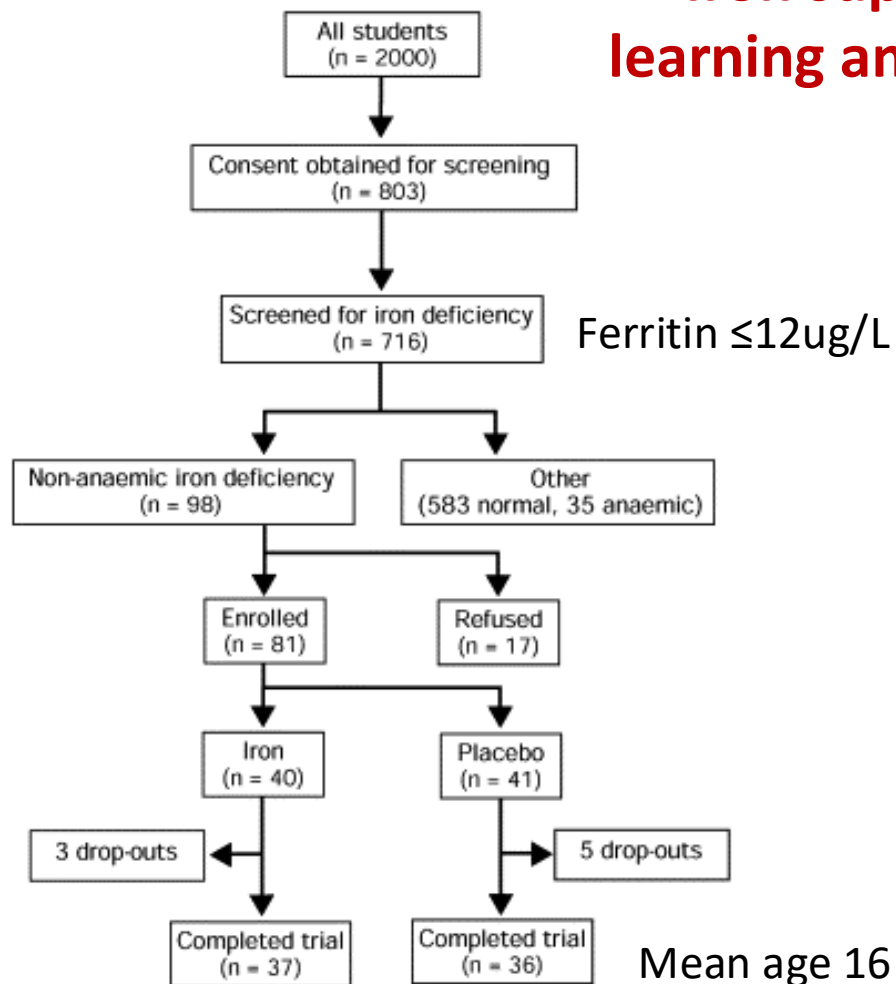


Deforest et al. Haemophilia 2016 (23): 115





Iron supplementation improves verbal learning and memory in ID without anaemia

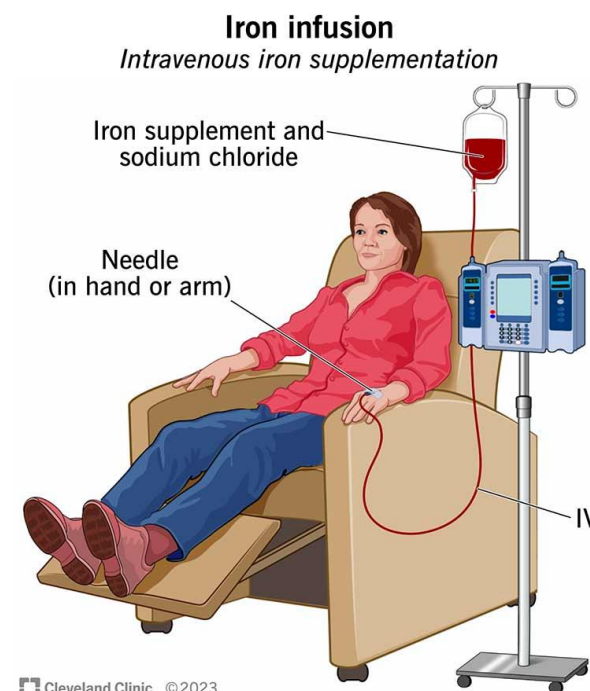




Iron supplementation

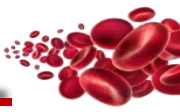
Table 1:
Selected Oral Iron Products

Generic name	Tablet size	Elemental iron provided per tablet
Ferrous sulfate	324 mg/324 mg	65 mg
Ferrous gluconate	300 mg	34 mg
	240 mg	27 mg
Ferrous fumarate	324 mg	106 mg
	200 mg	66 mg



Cleveland Clinic © 2023





Sexuality

- Many days of the month vaginal blood loss
- Tired or weak due to anemia and/or iron deficiency
- Contact bleeding
- Bleeding from sucking/biting/nibbling
- Self-image-body/confidence issues due to chronic illness



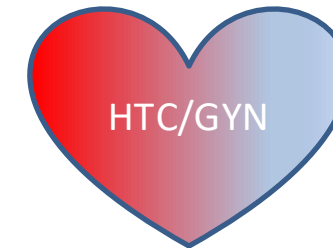


Take home messages

- **High awareness** is paramount to identify HMB in VWD
 - Bleeding history: ISTH-BAT
 - Family history
 - Laboratory testing: bloodcount AND ferritin
 - Expert consultation
- Diagnosis & treatment of HMB in VWD is **multidisciplinary** teamwork
 - In haemophilia treatment center – joint clinic
 - Research needed to find optimal strategies



Education of WGBD and their families regarding the menstrual cycle and management



Early recognition and optimal management of heavy menstrual bleeding





More on menstrual problems in IBD – EAHAD academy (free access)

The screenshot displays the EAHAD Academy website interface. At the top, the EAHAD logo is accompanied by the text 'European Association for Haemophilia and Allied Disorders' and 'Academy'. A navigation bar includes links for HOME, E-LEARNING, WEBINARS, CONGRESS RECORDINGS, and INTERVIEWS, along with a search icon. The main content area features a video player for 'MODULE 7: Menstrual problems and inherited bleeding disorders' by Karin van Galen. The video player includes a progress bar and a list of related content: '1.1 VIDEO LECTURE BACKGROUND', '1.2 VIDEO LECTURE Case Study', and '1.3 VIDEO LECTURE RECENT LITERATURE'. On the right side, there are three promotional banners: 'Gene Therapy in Haemophilia PHARMACY IN PREPARATION FOR THE GENE THERAPY', 'Get to know us: Psychosocial Professionals Committee', and 'Module 13.2: Surgery in patients with haemophilia with inhibitors'. The bottom of the page features logos for the European Reference Network, EHC, and the European von Willebrand Disease Community.





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[@EHC_Haemophilia](https://twitter.com/EHC_Haemophilia)



EHC - European Haemophilia Consortium



European Haemophilia Consortium



[@EHCTVChannel](https://www.youtube.com/@EHCTVChannel) EHC Youtube channel



**European
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for rare or low prevalence
complex diseases

 **Network**
Hematological
Diseases (ERN EuroBloodNet)



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[ERN-EuroBloodNet's EDUcational
Youtube channel](https://www.youtube.com/channel/UC...)



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Co-funded by the
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Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or European Health and Digital Executive Agency (HaDEA). Neither the European Union nor the granting authority can be held responsible for them.