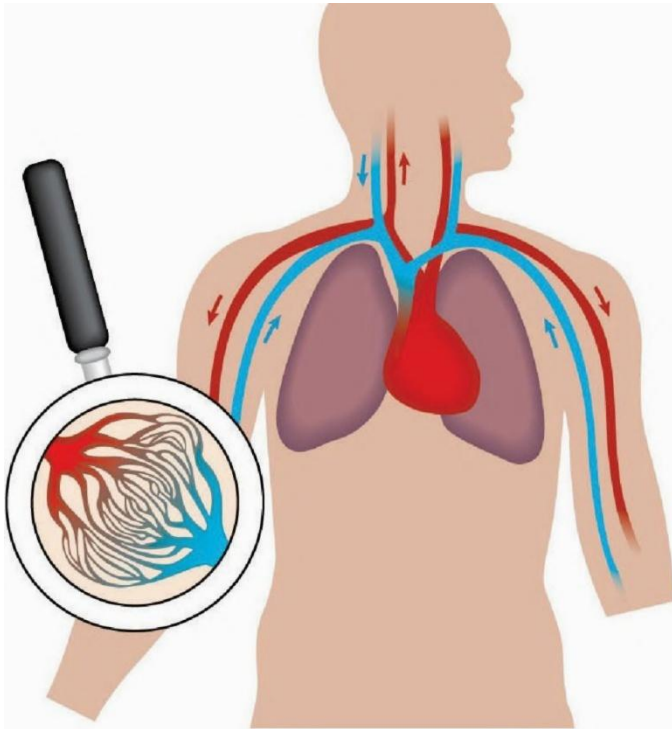




Indwara ya hemofiliya mu mashusho



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Iki gitabo cyanditswe kandi gisuzumwa ahanini n'abakorerabushake baturutse ku isi yose, abenshi muri bo bakaba ari abahanga mu bijyanye n'indwara ya hemofiliya kubera umwuga wabo cyangwa bakaba babana n'ubu burwayi. Abakorerabushake baturutse mu miryango irenga 75 ikora ku ndwara ya hemofiliya n'ibigo biyivura basubije ibibazo by'ubushakashatsi bwacu kuri hemofiliya mu mashusho (HIP). Abandi bakorerabushake nabo basuzumye porogaramu nshya ya interineti maze batanga ibitekerezo byabo ku bijyanye n'uburyo bisomeka kandi "binogera abakoresha porogaramu". Komite y'abaforomo ba WFH na komite yo mu bijyanye n'urwungano rw'amagufa n'imitsi bafashe igihe gihagije cyo gusuzuma edisiyo yo mu mwaka w'1998 ubundi bagira ibyo basaba byashyirwa muri verisiyo nshya.

Turashimira cyane itsinda rya HIP ryakoze ubu bushakashatsi. Aba banyamwuga bafashe umwana wabo n'ubuhanga bwabo nta gihembo mu cyiciro cy'amezi cumi n'abiri yose kugira ngo bizere neza ko ibirimo ari ukuri, byoroshye gusomwa kandi biri mu miterere ifatika.

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Indwara ya hemofiliya mu mashusho

Iki gitabo cyasohowe bwa mbere mu cyongereza na World Federation of Hemophilia (WFH), kikaba cyarahinduwe bitangwye uruhushya.

Inyandiko ihinduye cyangwa amakosa cyangwa impinduka runaka byaba byarakozwe ku biri mu nyandiko y'umwimerere y'icyongereza ntibireba WFH.

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Inyandiko y'umwimerere yakozwe ku bw'inkunga y'uburezi itagenzuwe ya Wyeth.

Iki gitabo cyahinduwe na South Texas Center for Bleeding Disorders. Itariki 2025.

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WFH irashishikariza imiryango idaharanira inyungu ifite hemofiliya mu nshingano zayo gukwirakwiza iki gitabo mu rwego rw'ubuhungu abantu. Kugira ngo ubone uruhushya rwo gusohora kopi zacyo, kuzikwirakwiza cyangwa guhindura ibirimo mu zindi ndimi, ugana n'ishami rishinzwe porogaramu no guhugura kuri aderesi ikurikira.

World Federation of Hemophilia

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Ibirimo

IGICE CYA 1: INGINGO Z'IBANZE KURI HEMOFILIYA

1. Ni gute amaraso atembera mu mubiri?
2. Ni gute kuva amaraso bitangira bikanahagarara?
3. Kuki rimwe na rimwe abarwayi ba hemofiliya bava amaraso agatinda gukama ugereranyije n'abandi?
4. Indwara ya hemofiliya ni imwe ku bantu bose?
5. Ni gute umuntu yandura hemofiliya?
6. Uruhinja ruba rufite ibyago bingana gute byo kuzarwara hemofiliya?
7. Indwara ya hemofiliya ni twibanire?

IGICE CYA 2: GUSUZUMA NO GUCUNGA IKIBAZO CYO KUVA

8. Bimwe mu bimenyetso rusange bya hemofiliya ni ibihe?
9. Ni iki gitera kuva amaraso mu ngingo?
10. Bigenda bite iyo umuntu ava mu ngingo?
11. Kuva mu ngingo bikunze kubaho ni ibihe?
12. Ni izihe ngaruka z'igihe kirekire zo kuva mu ngingo?
13. Ni iki gitera kuva mu mikaya?
14. Bigenda bite iyo umuntu ava mu mikaya?
15. Kuva mu mikaya bikunze kubaho ni ibihe?
16. Ni izihe ngaruka z'igihe kirekire zo kuva mu mikaya?
17. Ubwoko bwo kuva amaraso bubi cyane cyangwa bushyira umubiri mu kaga ni ubuhe?

IGICE CYA 3: KUVURA IKIBAZO CYO KUVA

18. Kuki kuva amaraso bigomba kuvurwa vuba? (igice A)
19. Kuki kuva amaraso bigomba kuvurwa vuba? (igice B)
20. Ni gute kuva amaraso bishobora kuvurwa mu butabazi bw'ibanze?
21. Ni gute kuva amaraso byavurwa hakoreshejwe gusimbuza poroteyine zibura cyangwa zidakora neza izindi?
22. Ubundi buryo bwo kubivura bwafasha ni ubuhe?
23. Abasirikare umubiri urema ngo barwanye icyo ukemanze ni iki, ni gute bashobora gucungwa?
24. Ibimenyetso by'uko kuva amaraso byahagaze ni ibihe?

IGICE CYA 4: KUBUNGABUNGA UBUZIMA NO KWIRINDA KUVA

25. Ni iki cyakorwa ngo umuntu abungabunge ubuzima?
26. Kuki ari byiza kugira ubuzima bwiza mu menyo?
27. Kuki ari byiza kugira ubuzima bwiza mu marangamutima?
28. Bigenda bite iyo hakenewe kubagwa?
29. Bigenda bite iyo hakenewe imiti cyangwa inkingo?
30. Bimwe mu bwivumbure bw'umubiri buterwa n'ubuvuzi ni ubuhe?
31. Amakuru ajyanye n'ubuvuzi agomba kwitwazwa ni ayaha?
32. Ni he abantu bashobora gukura ubufasha cyangwa inama zijyanye na hemofiliya?

UMUGEREKA: UBUVUZI BUTANGIWE MU RUGO NO KWINJIZA URUSHINGE MU MUTSI

33. Ubuvuzi butangiwe mu rugo ni iki?
34. Kwinjiza urushinge mu mutsi ni iki?
35. Ni ibiki bigomba gutegurwa mu buvuzi bwo gusimbuza ibice bibura cyangwa bidakora neza ibindi?
36. Ni gute ubwandu bwakwirindwa mu gihe cyo gutera umuntu urushinge?
37. Ni gute ubuvuzi busimbuza ibice runaka ibindi butangwa? (igice A)
38. Ni gute ubuvuzi busimbuza ibice runaka ibindi butangwa? (igice B)

IZINDI MFASHANYIGISHO

Ibisobanuro by'amagambo amwe n'amwe

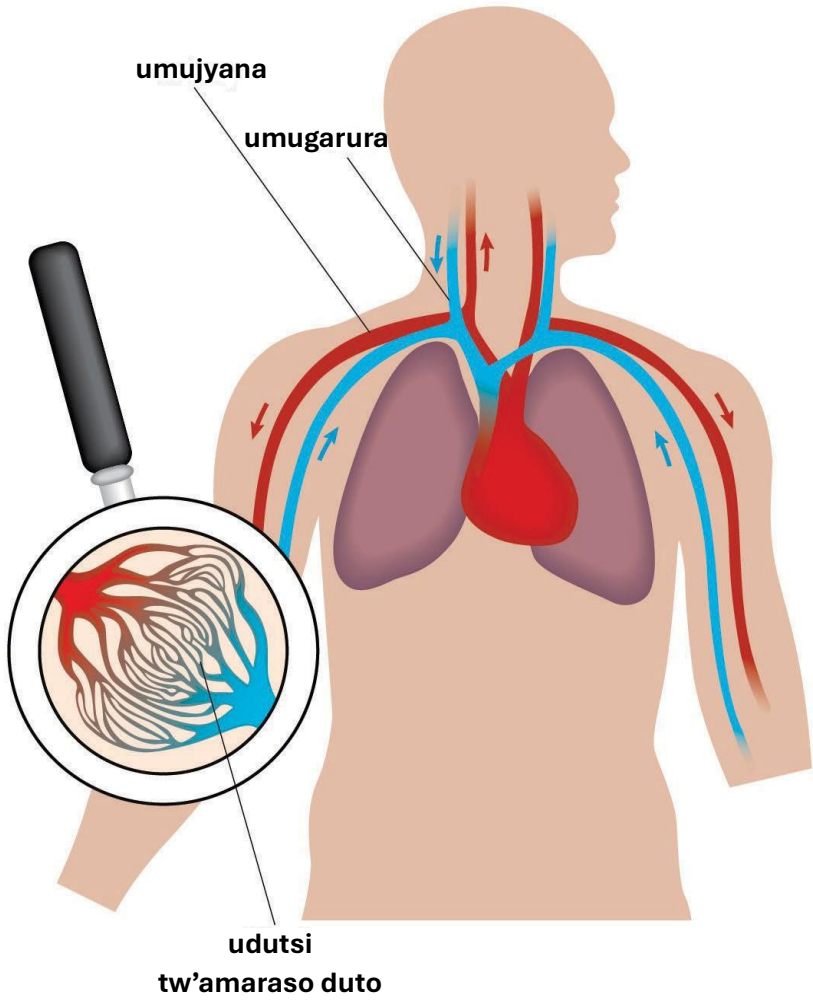


Igice cya 1

Ingingo z'ibanze kuri
hemofiliya

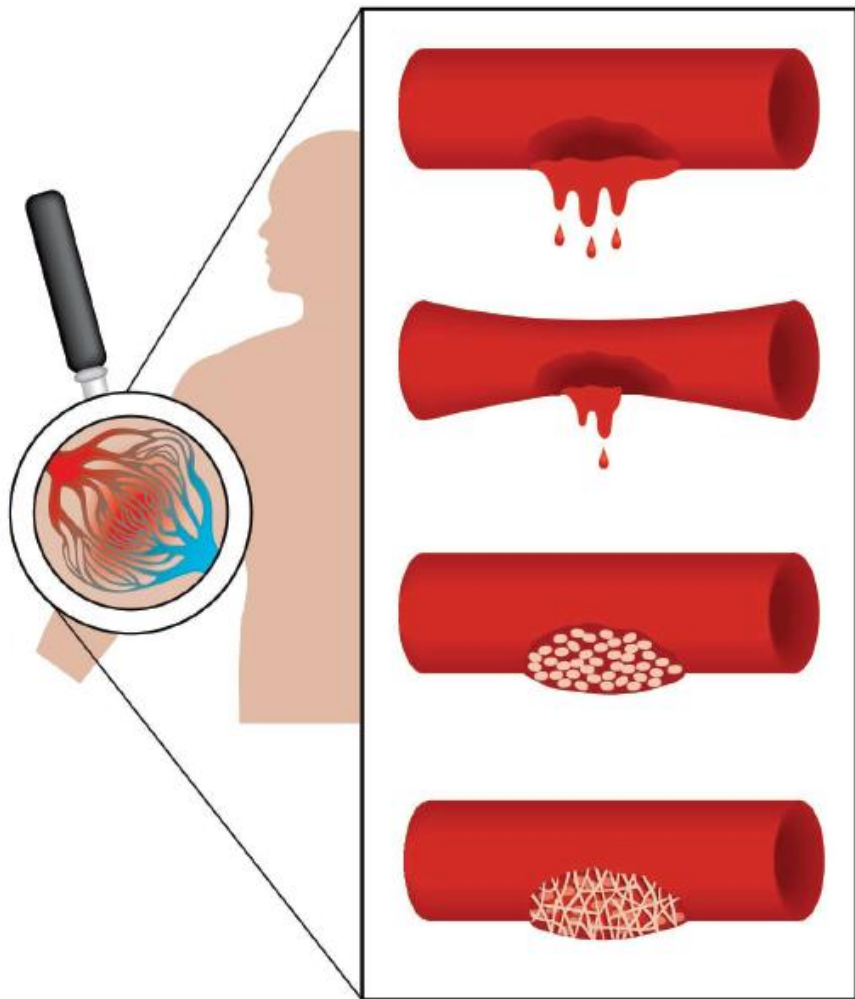
Ni gute amaraso atembera mu mubiri?

- Hemofiliya ni indwara yo kuva amaraso, ni yo mpamvu ari ngombwa gusobanukirwa urwungano rw'amaraso.
- Umutima ni wo upompa amaraso mu mubiri wose.
- Amaraso atembera mu mubiri anyuze mu miheha yitwa **imijyana**, **imigarura** n'**utundi dutsi dutwara amaraso mu mubiri**. Imwe muri iyi miheha iba ari minini (imijyana n'imigarura) naho indi ikaba mito (udutsi tw'amaraso duto).



Ni gute kuva amaraso bitangira bikanahagarara?

- Kuva amaraso bitangira iyo udutsi tw'amaraso dukomeretse ubundi amaraso akava.
- Agatsi k'amaraso gakomeretse karituna kugira ngo amaraso ava agende buke.
- Noneho uturemangingo tw'amaraso twitwa **udufashi tw'amaraso** tugakora agapfuko ko gufunga ahari akenye.
- Nyuma **poroteyine zituma amaraso avura zo mu mushongi w'amaraso** (kimwe mu bigize amaraso) zifatanya gukora urukoko rutwikira ka gapfuko. Ibi bituma agapfuko gakomera maze kagahagarika amaraso yavaga.



Kuki rimwe na rimwe abarwayi ba hemofiliya bava amaraso agatinda gukama ugereranyije n'abandi?

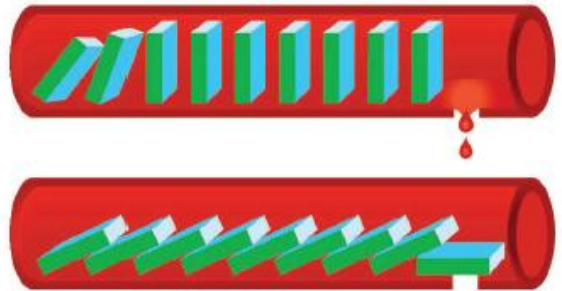
- Ikibazo cya hemofiliya kibaho iyo hari poroteyine ibura cyangwa ifite intege nke. Ibi bituma amaraso atabasha gukore urukoko, maze agakomeza kuva akamara igihe kirenze igisanzwe, mbese agatinda gukama.
- Kuba umushongi w'amaraso ugira poroteyine nyinshi zifasha amaraso kuvura, buri yose igira izina ry'umubare w'ikiromani.

Urugero:

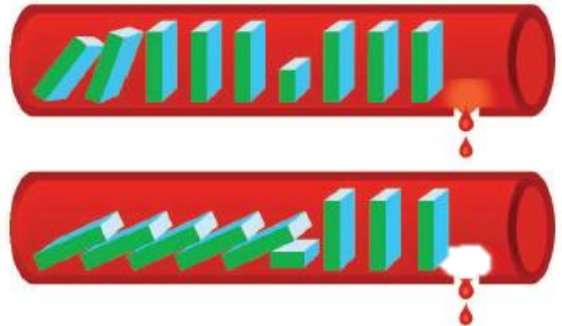
VIII = umunani


IX = icyenda

Uburyo busanzwe bw'ivura ry'amaraso



Ivura ry'amaraso ku murwayi wa hemofiliya



 = hemofiliya

Indwara ya hemofiliya ni imwe ku bantu bose?

- Abantu bafite inzego nto za poroteyine VIII (umunani) bagira **hemofiliya A**.
- Abantu bafite inzego nto za poroteyine IX (icyenda) bagira **hemofiliya B**.
- Hemofiliya ishobora kuba yoroheje, iringaniye cyangwa ikomeye bitewe n'imikorere ya poroteine zifasha amaraso gukama.

Inzego z'ubukana



Urwego rusanzwe

50 - 150%

Amaraso arakama bisanzwe



Hemofiliya yoroheje

5 - 40%

Iyo urwego rwa poroteyine rurenze 40%, akenshi igihe cyo kuva ntikirenga igisanzwe.

Iyo urwego rwa poroteyine ruri muni ya 40%, akenshi nyuma yo gukomereka cyangwa kubagwa amaraso ashobora gutinda gukama ugereranyije n'ibisanzwe.



Hemofiliya iringaniye

1 - 5%

Nyuma yo gukomereka cyangwa kubagwa amaraso atinda gukama ugereranyije n'uko bigenda ku bandi.

Kuzana ibirabagwe by'amaraso mu ruhu cyangwa kuva bishobora kubaho bworoshye.



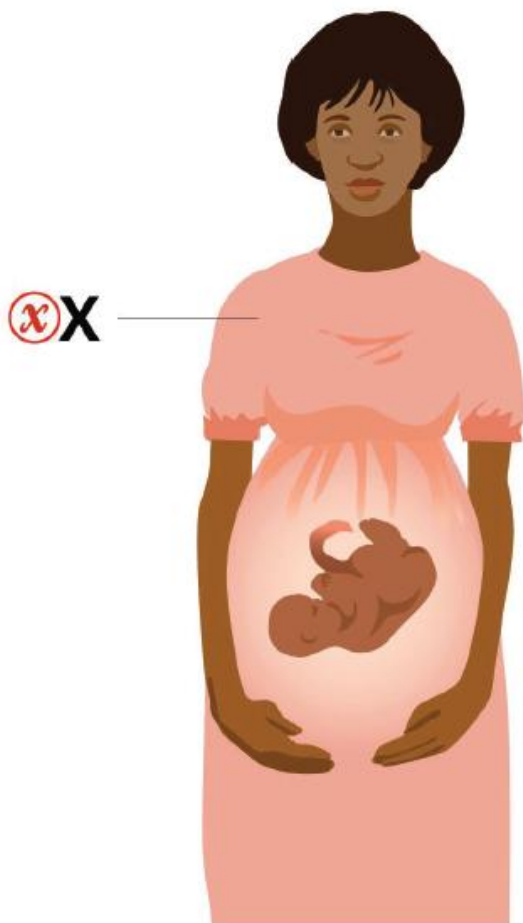
Hemofiliya ikaze

akenshi biba muni ya 1%

Umuntu ashobora kuva nta mpamvu igaragara ibiteye.

Ni gute umuntu yandura hemofiliya?

- Abarwayi ba hemofiliya barayivukana. **Ntibashobora** kuyanduzwa n'abandi.
- Akenshi hemofiliya irahererekanywa, bivuze ko umubyeyi ayanduza umwana binyuze mu **ngirabuzima fatizo z'iyoyoyoka**. Ingirabuzima fatizo z'iyororoka zitwara ubutumwa bw'ukuntu **uturemangingo** tw'umubiri dukora. Urugero, zigena ibara ry'umusatsi n'amaso by'umuntu.

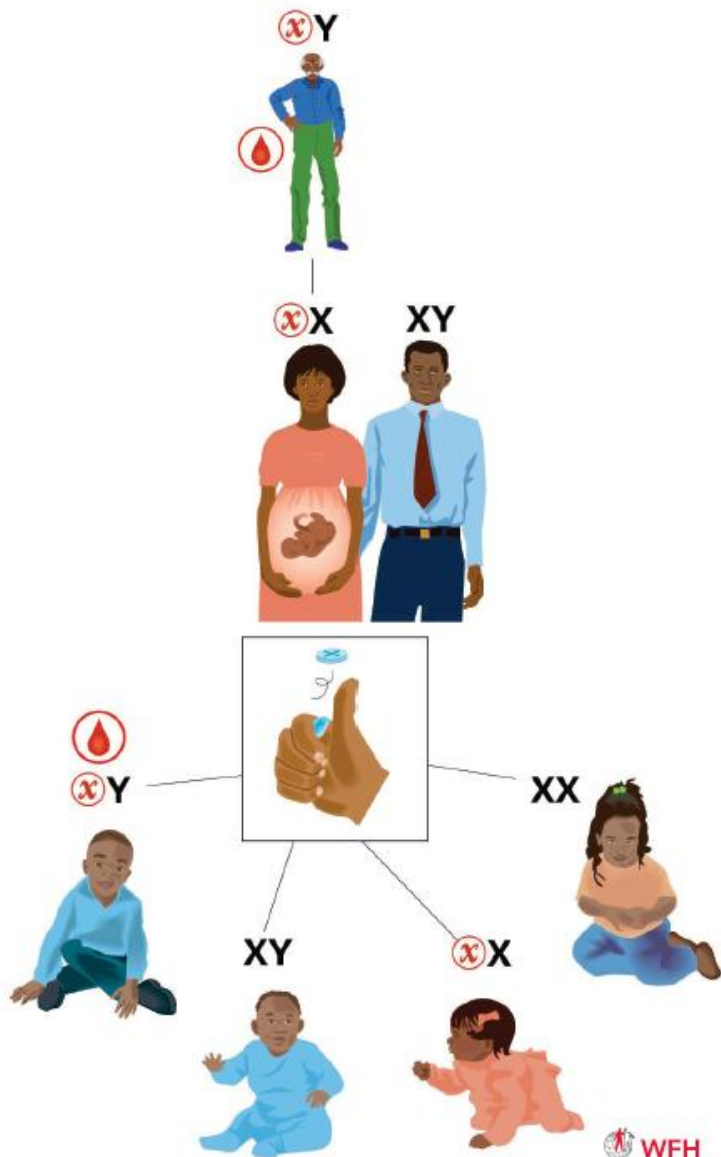


Uruhinja ruvukana ibyago bingana gute byo kuzarwara hemofiliya?

- Ingirabuzima fatizo z'iyororoka ziboneka muri **poroteyine z'iyororoka**. Ebyiri muri izi poroteyine z'iyororoka (zitwa **X** na **Y**) ni zo zigena igitsina cy'umuntu. Igitsina gore kivuka kuri X ebyiri. Igitsina gabo kivuka kuri X imwe na Y imwe.
- Ingirabuzima fatizo irimo hemofiliya igenda muri poroteyine X.
- Umugabo ufite ikibazo cya hemofiliya ayandura abakobwa abyaye bose, ariko nta muhungu we uyandura. Abakobwa be bitwa ko **bayifite batagaragaza ibimenyetso** kuko bafite poroteyine zirimo ingirabuzima fatizo z'iyoyoroka ziyifite.
- Iyo umugore ufite ingirabuzima fatizo irimo uburwayi abyaye, umwana aba afite rimwe kuri kabiri by'ibyago byo kuzayanduza abe. Niba ahereje iyi ngirabuzima umwana we w'umuhungu, uyu mwana azarwara hemofiliya. Niba ahereje iyi ngirabuzima umwana we w'umukobwa, uyu mwana azaba ashobora kuyanduza nka nyina.
- Hari igihe umwana avukana hemofiliya kandi nyamara nta ngirabuzima ya nyina iyifite. Bikaba biterwa n'uko ingirabuzima z'iyororoka za poroteyine VIII cyangwa IX zihinduriye mu mubiri w'umwana gusa. Uruhinja rumwe muri eshatu zivukana hemofiliya ntiruba rwayikuye ku babyeyi.



= poroteyine y'iyororoka ifite ingirabuzima irimo hemofiliya



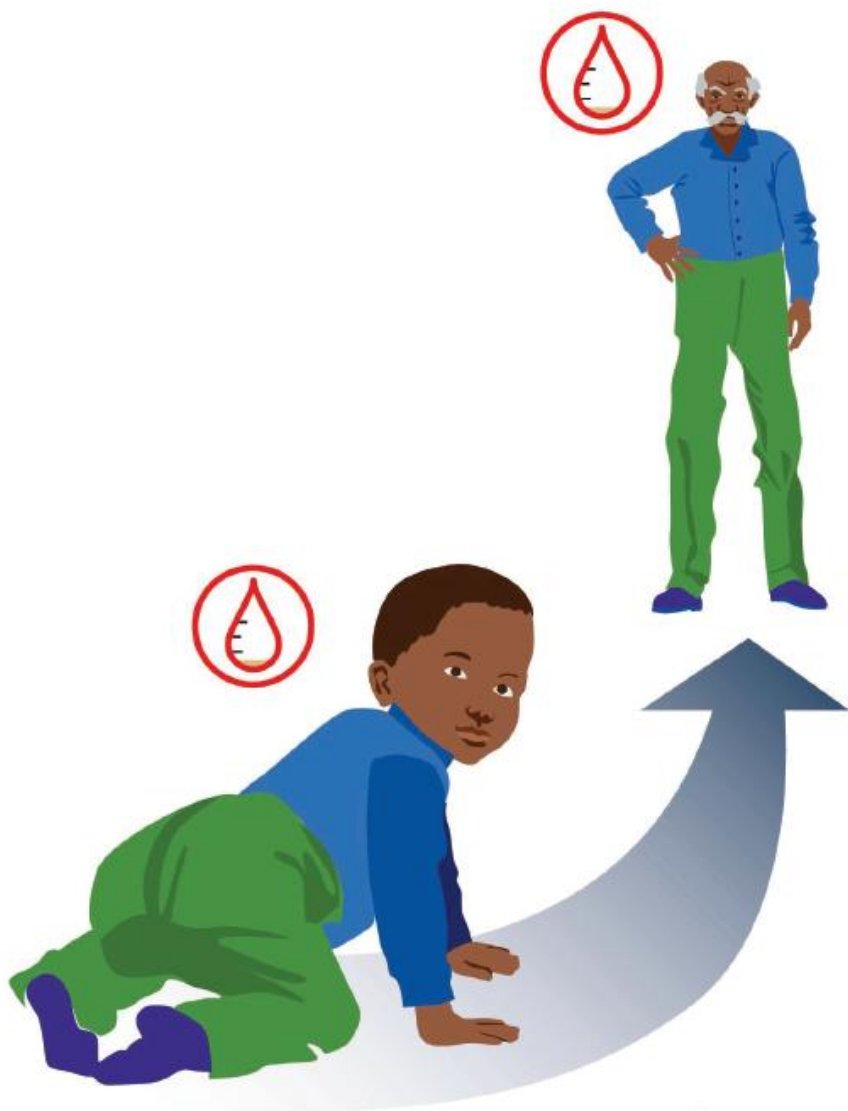
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Indwara ya hemofiliya ni twibanire?

- Umuntu uvukanye hemofiliya abana nayo ubuzima bwe bwose.
- Akenshi urwego rwa poroteyine VIII cyangwa IX mu maraso ye ntiruhinduka mu buzima bwe bwose.





Igice cya 2

Gusuzuma no gucunga
ikibazo cyo kuva

Bimwe mu bimenyetso rusange bya hemofiliya ni ibihe?

- Iyo umuntu afite ikibazo cya hemofiliya, aba ashobora kuva ahabonetse hose mu mubiri. Hari ubwo bishobora kugaragarira amaso ubundi ntibigaragare.
- Kuva bishobora kubaho nyuma yo gukomereka cyangwa kubagwa. Bishobora no kubaho nta mpamvu ifatika ibiteye. Ibi bikaba byitwa **kuva amaraso bitunguranye**.
- Impinja zifite hemofiliya ntizikunze kuva, ariko nyuma yo gusiramurwa zishobora gutinda gukama.
- Iyo umwana ari kwiga kugenda, umubiri we uzana ibirabagwe mu ruhu mu buryo bworoshye. Iyo akomeretse nabwo amaraso atinda gukama, by'umwihariko mu kanwa no ku rurimi.
- Uko umwana akura, ni ko kuva amaraso mu buryo butunguranye bigera aho bigahinduka ibisanzwe. Ibi bigira ingaruka ku ngingo no mu mikaya.

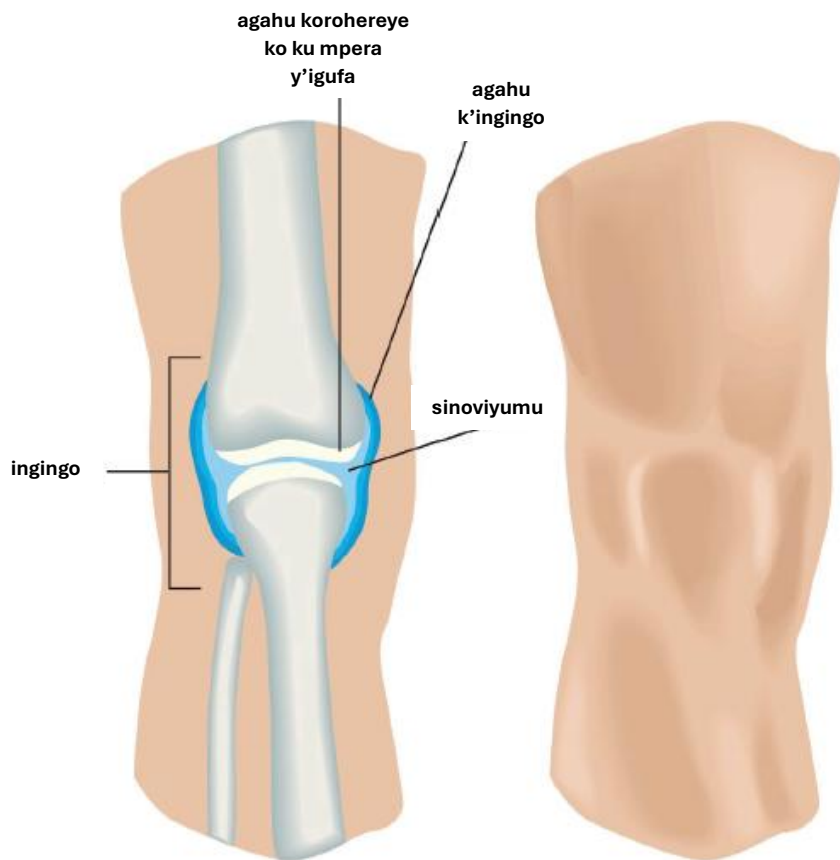
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Ni iki gitera kuva amaraso mu ngingo?

- Aho amagufa ahurira bahita mu **ngingo**. Aho amagufa arangirira haba hatwikiriwe n’**agahu korohereye**.
- Amagufa afatanywa ku mpande zimwe n’**agahu k’ingingo**. Agahu k’ingingo kagira akugara kitwa ‘**sinoviyumu**’ gafite udutsi twinshi (udutsi tw’amaraso duto). Gakora amatembabuzi arenduka ameze nk’amavuta atuma byorohera ingingo kuyega.
- Iyo udutsi tw’amaraso two muri sinoviyumu dukomeretse, amaraso arava. Akenshi nta mpamvu ifatika itera kuva, by’umwihariko ku muntu ufite hemofiliya ikaze. Ku bantu batarwaye hemofiliya, uburyo bwo kurema urukoko bukamisha amaraso vuba. Ariko iyo hari hemofiliya, kuva birakomeza. Ibi bitera kubyimbirwa mu ngingo kandi umuntu akaribwa.



Bigenda bite iyo umuntu ava mu ngingo?

- Iyo umurwayi wa hemofiliya atangiye kuva arabimenya kuko aba yumva hari utuntu tujombagura mu ngingo kandi hokera.
- Uko amaraso yuzura mu gahu k'ingingo, ni ko umuntu abyimbirwa mu ngingo, akagira uburibwe, bikamugora kuyega.
- Iyo utavuye, amaraso agera aho agakama kubera ko kubyimbira biba byahabyize. Nyuma uturemangingo tudasanzwe dusohora mu ngingo amenshi mu maraso yavuye.



Ibicuro
Utuntu tujombagura
mu mubiri
Ubushyuhe



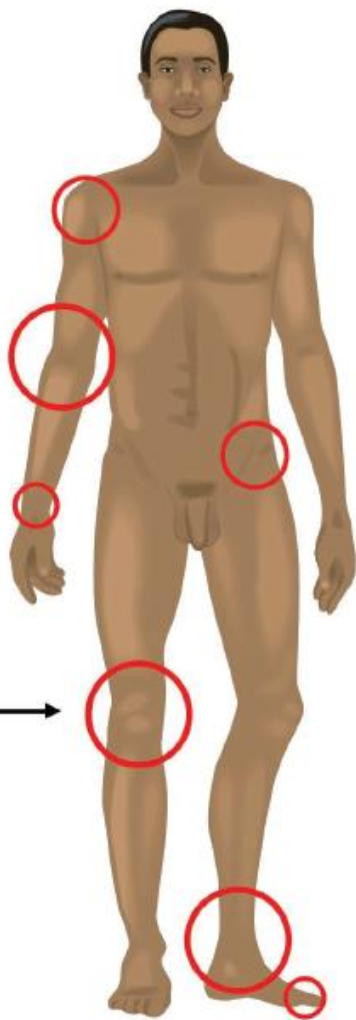
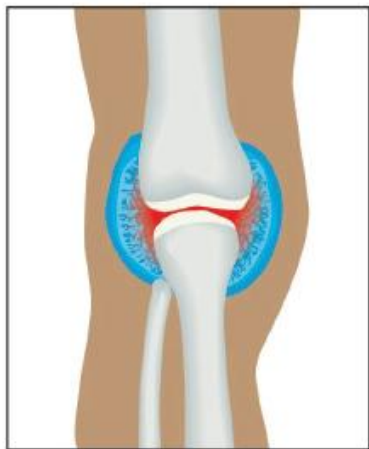
Kubyimirwa
Ububabare
Ubushyuhe



Hakandika nk'aharimo amazi
Habyimbiwe
Gutakaza imikaya
Umunaniri mu ngingo
Ububabare bw'akarande
Kutabasha kuyega neza

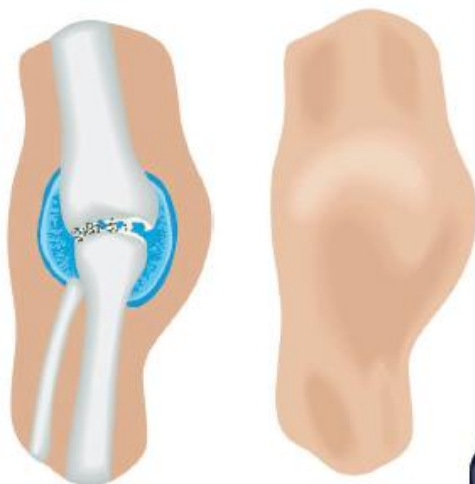
Kuva mu ngingo bikunze kubaho ni ibihe?

- Ingingo zikunze kuva ni mu tugombambari, mu mavi no mu nkokora.
- Umuntu ashobora no kuva mu zindi ngingo zirimo amano, intugu n'ibibero.
- Ingingo z'ibiganza ntizikunze kuva keretse iyo zikomeretse.



Ni izihe ngaruka z'igihe kirekire zo kuva mu ngingo?

- Kuva mu ngingo byisubiyemo bitera sinoviyumu (akugara) kubyimbirwa no kuva mu buryo bworoshye.
- Hari amaraso asigara mu ngingo nyuma ya buri kuva. Sinoviyumu irekera aho gukora ya matembabuzi areduka ameze nk'amavuta afasha ingingo kuyega.
- Ibi byangiza ka gahu koroherewe ko ku mpera y'igufa. Ingingo zirumagara, umuntu yayega akababara, kandi ntihatekane. Ntihaba hameze neza kuko imikaya yegereye ingingo icika intege.
- Igihe kiragera ka gahu koroheherewe kakamanyagurika, amwe mu magufa akangirika. Hari n'igihe mu ngingo haba hatakibasha kuyega na gato. Iyi nzira yose yitwa ***rubagimpande ya hemofiliya***.



Ni iki gitera kuva mu mikaya?

- Kuva mu mikaya bibaho iyo udutsi duto tw'amaraso turimo dukomeretse.
- Rimwe na rimwe impamvu yo kuva iba izwi ariko hari n'ubwo byizana.

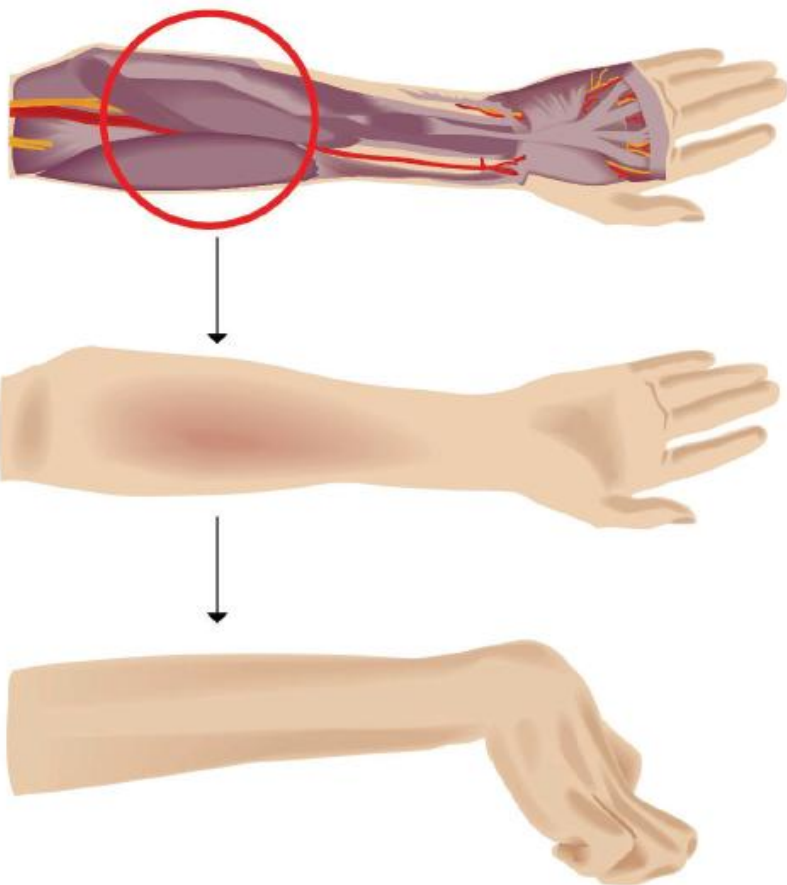
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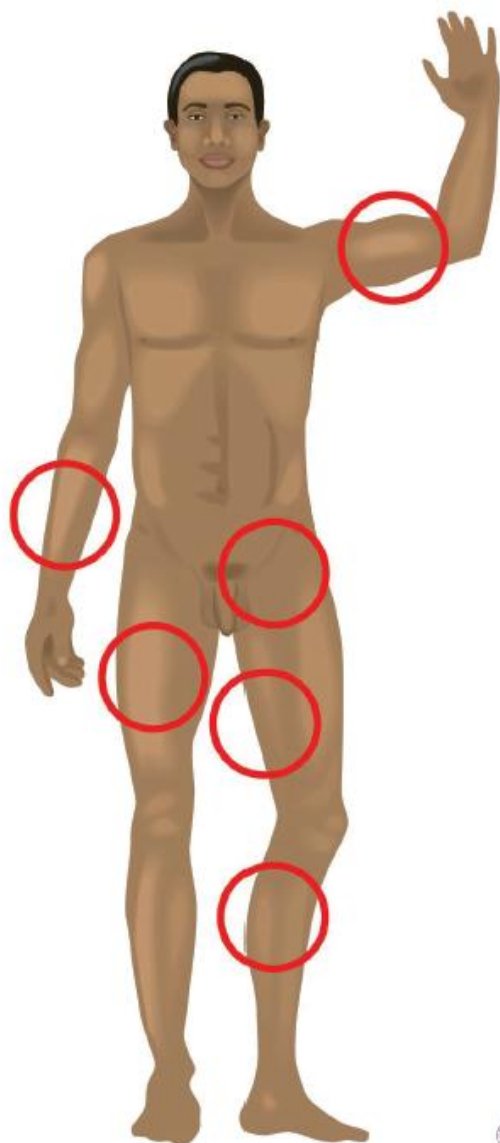
Bigenda bite iyo umuntu ava mu mikaya?

- Iyo umuntu ariho ava, imikaya iragagara kandi hakababaza.
- Kuva bitera kubyimbirwa hakokera kandi hakababaza igihe umuntu ahakoze. Iyo kuva biri kubera ahagereye uruhu, umuntu azana ibirabagwe by'amaraso ku ruhu.
- Mu mikaya imwe n'imwe y'imbere, kubyimbirwa bishobora kubyiga **imyakura cyangwa imijyana**, bigatera uburyaryate n'ibinya.
- Imikaya irituna mu rwego rwo kwirinda. Ibi babyita **kwituna k'umukaya**. Igikurikiraho ni uko ingingo zari zisanzwe ziyega kubera uyu mukaya zitongera kuyega neza.



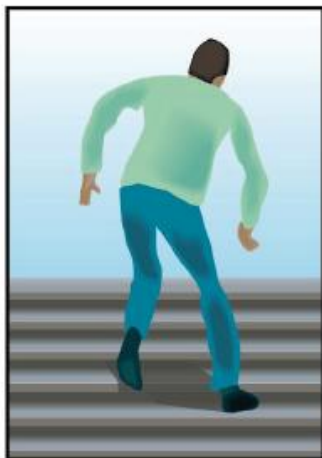
Kuva mu mikaya bikunze kubaho ni ibihe?

- Kuva mu mukaya bibera mu **nyama y'abagabo, mu kibero** no **mu kizigira**.
- Na none bikunze kubaho mu **mwakura wambukiranya intantu n'imyakura yo ku kuboko imbere munsu y'inkokora**. Uku kuva bishobora kunaniza imyakura n'imijyana maze hakangirika burundu.
- Kuva mu myakura y'ibiganza ntibikunze kubaho keretse iyo hakomeretse.



Ni izihe ngaruka z'igihe kirekire zo kuva mu mikaya?

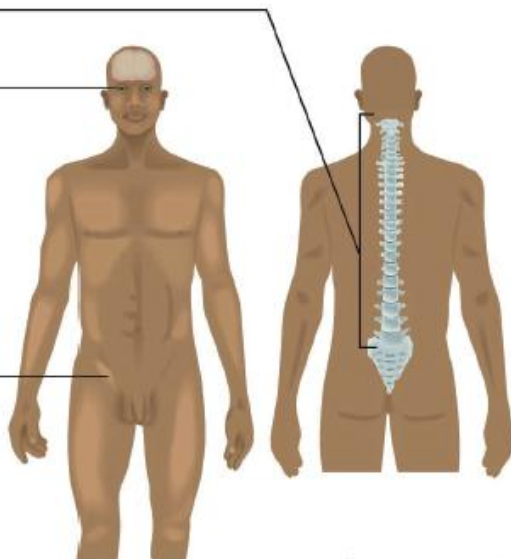
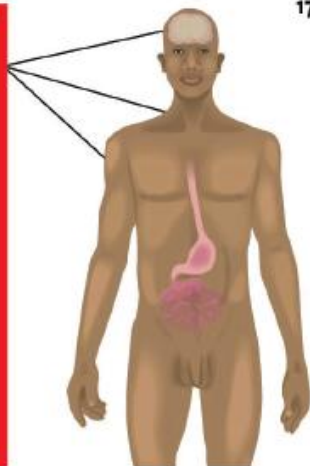
- Iyo kuva bigiye byisubiramo, imikaya ishobora gucika intege, kwikanga no kwikunja (hari igihe biba burundu). Iki gihe ntiba ikibasha kurinda ingingo.
- Ingingo zo hejuru z'izo muni y'umukaya ntiziba zikibasha kuyega neza. Iba ishobora kurushaho kuzajya iva.
- Iyo imyakura yangiritse mu gihe imikaya iva, umukaya ushobora gucika intege cyangwa ukaba wanagagara.
- Kwangirika burundu kw'ingingo, imikaya n'imyakura bigira ingaruka ku myicarire y'umuntu, uburyo ahagarara n'uko atambuka.

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Ubwoko bwo kuva amaraso bubi cyane cyangwa bushyira umubiri mu kaga ni ubuhe?

- Kuva mu mutwe (bikunze guterwa no gukomereka) ni yo ntandaro nini y'urupfu ku bafite hemofiliya, by'umwihariko ku bana. Kuva mu mutwe bishobora gutera umutwe, isesemi, kuruka, guhondobera, urujijo, kugusha ibyo ufite utabishaka, gucika intege, gususumira no guta ubwenge.
- Kuva mu muhogo bishobora guterwa n'ubwandu runaka, gukomereka, guterwa urushinge mu menyo cyangwa kubagwa. Kuva mu muhogo bitera kubyimbirwa, yewe no kunanirwa kumira no guhumeka.
- Kuva mu buryo bukomeye bishyira umubiri mu kaga. Ntibisanzwe ku barwayi ba hemofiliya, keretse umuntu akomeretse cyangwa bitewe n'ubundi burwayi.
- Kuva ahandi bishobora kuba bikabije ariko ntibishyire ubuzima mu kaga, twavuga nko kuva mu myakura y'amaso, uruti rw'umugongo n'umwakura wambukiranya intantu.
- Kwihagarika inkari zirimo amaraso birasanzwe ku muntu urwaye hemofiliya ikaze, ariko ni gake bishyira umubiri mu kaga.

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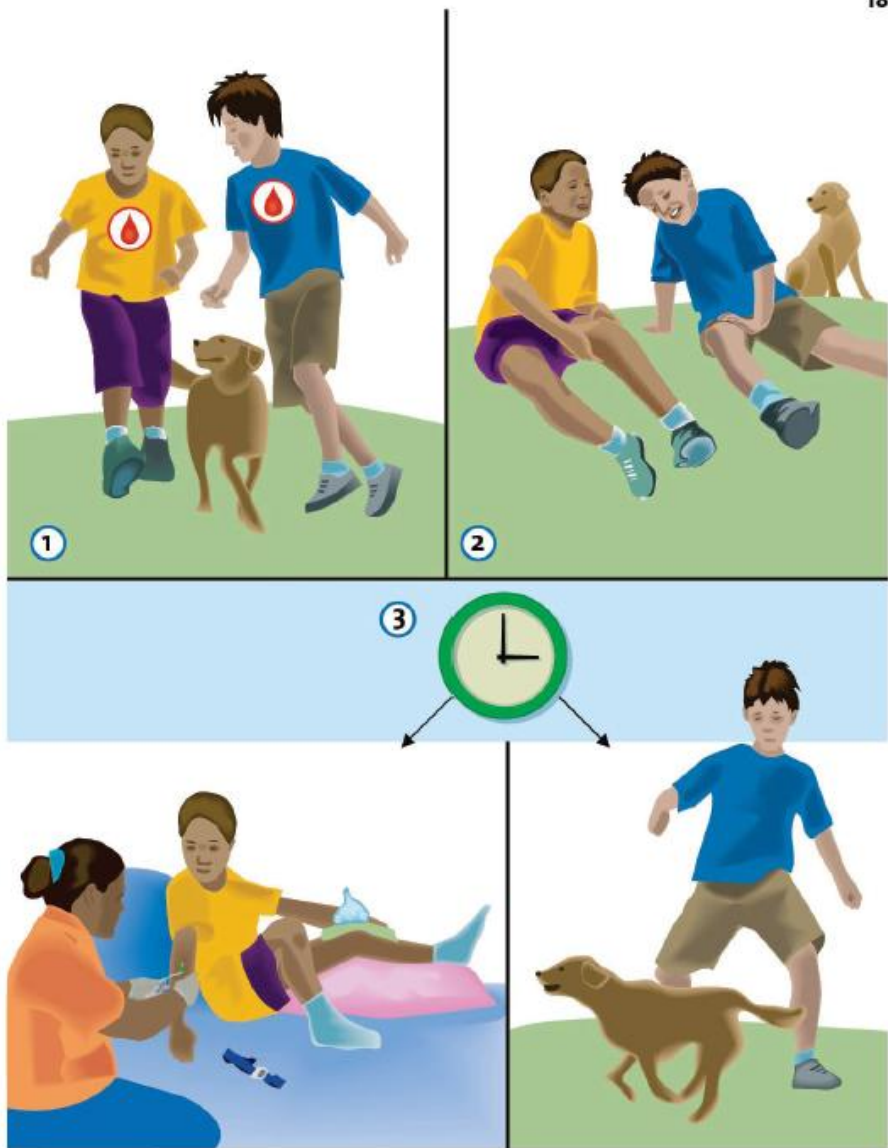
Igice cya 3

Kuvura ikibazo cyo kuva

Kuki kuva amaraso bigomba kuvurwa vuba?

(IGICE A)

- Kuva bigomba kuvurwa vuba kugira ngo umuntu akire vuba maze yirinde ko hari ibyangirika.
- Niba ukemanga, ivuze. Witegereza!



Kuki kuva amaraso bigomba kuvurwa vuba?

(IGICE B)

- Iyo utinze kuvurwa, kuva bitinda gukira kandi bigasaba ibindi bikoresho by'ubuvuzi.



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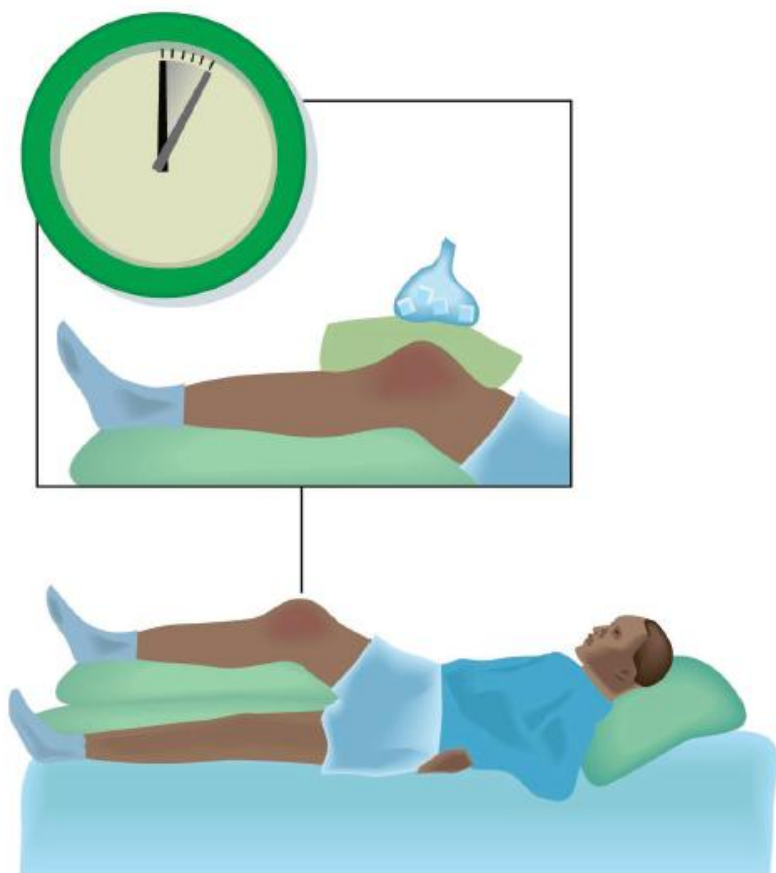

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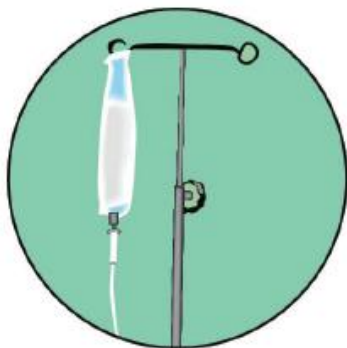
Ni gute kuva amaraso bishobora kuvurwa mu butabazi bw'ibanze?

- Hera ku butabazi bw'ibanze vuba bishoboka kugira ngo ugabanye amaraso ameneka no kwangirika. Kora ibi n'ubwo gusimbuza poroteyine izindi byaba bizakorwa.
- **KURUHUKA:**
Ukuboko cyangwa ukuguru bigomba kurambikwa ku musego cyangwa mu gitambaro gifashe ku rutugu cyangwa bande. Ingingo iri kuva ntigomba kuyega cyangwa gushyigikira ikindi gice cy'umubiri.
- **BARAFU:**
Fubika ipaki irimo barafu mu gitambaro cy'isuku gitose maze ugishyire ahari kuva. Nyuma y'iminota itanu, kuraho barafu umare nibura iminota icumi. Komeza kubisubiramo: mazaho iminota itanu, kuraho umare iminota icumi, kugeza wumvise mu ngingo hashyushye. Ibi bishobora gufasha kugabanya ububabare no kuva.
- **GUHAMBIRA:**
Ingingo zishobora gufubikwa muri bande isanzwe cyangwa ikweduha. Uku kuhabyiga bishobora kugabanya amaraso ava no gufasha ingingo. Hambiriza agatambaro witonze ku mikaya iri kuva niba bikekwa ko umwakura wakomeretse.
- **KWIGIZA HEJURU:**
Kuzamura ahari kuva hakigira hejuru y'umutima. Bishobora kugabanya amaraso ameneka kuko umunaniro waho ugabanuka.



Ni gute kuva amaraso byavurwa hakoreshejwe gusimbuza poroteyine zibura cyangwa zidakora neza izindi?

- Akenshi hemofiliya ishobora kuvurwa hinjizwa mu mubiri poroteyine iburamo binyuze mu mutsi. Umuti utuma amaraso avura ntushobora kunyobwa.
- Imiti ituma amaraso avura wayisanga mu bicuruzwa by'ubuvuzi bitandukanye, nka **cryoprecipitate** na **factor concentrate**. Mbere yo kubikoresha wagombye kwitega ko hashobora kubaho ingaruka.
- Abarwayi ba hemofiliya yoroheje A (cyangwa ubundi burwayi bwitwa indwara ya von Willebrand) bashobora kuvurwa n'umuti witwa **desmopressin** cyangwa DDAVP. Ishobora kwinjizwamo batera urushinge mu mutsi, batera urushinge munsu y'uruhu cyangwa bapuriza mu mazuru.
- Akenshi biba ari ngombwa guhora wivuza.

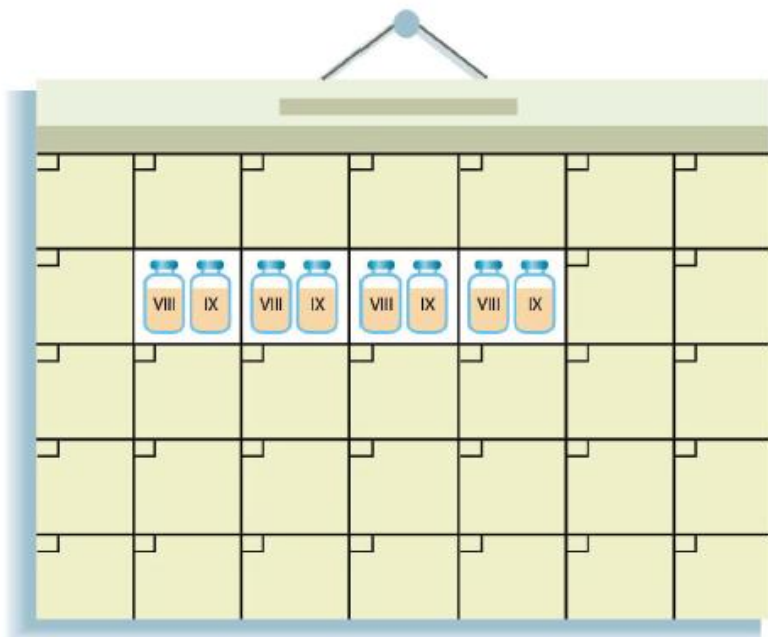
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Ubundi buryo bwo kubivura bwafasha ni ubuhe?

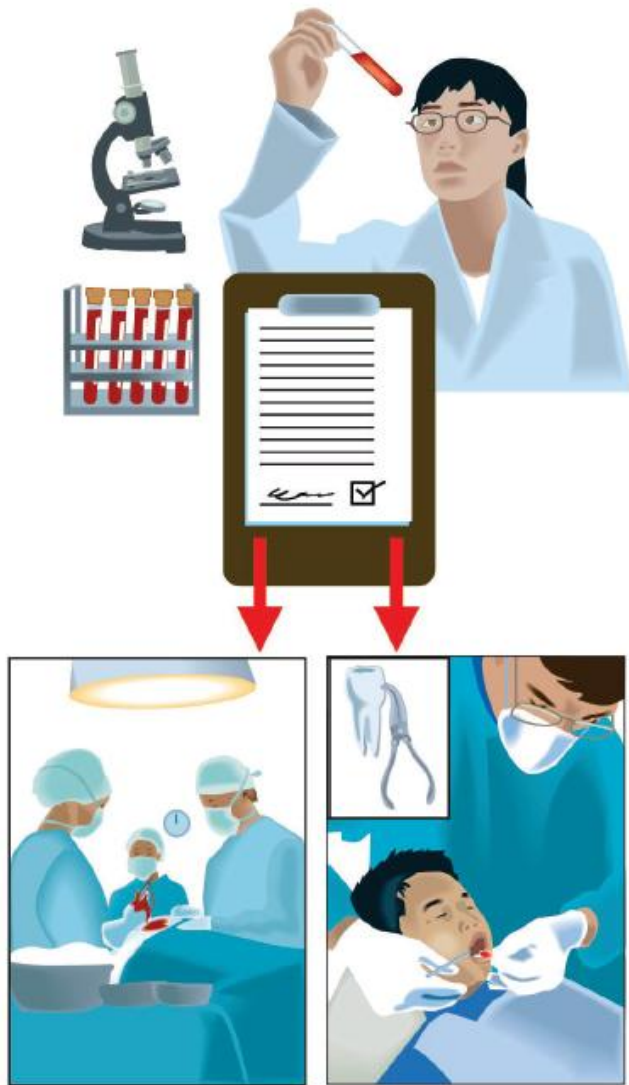
- Ubundi buvuzi nabwo bushobora gufasha, burimo:
 - Imiti igabanya ububabare;
 - **Imiti igabanya ibimenyetso** kugira ngo ahabyimbiwe habyimbuke;
 - Guhindura igipimo cyangwa ingengabihe ya poroteyine; n’
 - Ibipimo byisubiyemo bya poroteyine VIII cyangwa IX.

- Umuganga ugorora ingingo ashobora:
 - Gutekereza uburyo bwo guha ingufu imikaya no kugarura iyega ry’ingingo;
 - Kuvuga ko niba nta kibazo wasubira mu mirimo isanzwe; no
 - Gutekereza uburyo bwo kwirinda gukomereka mu gihe kiri imbere.



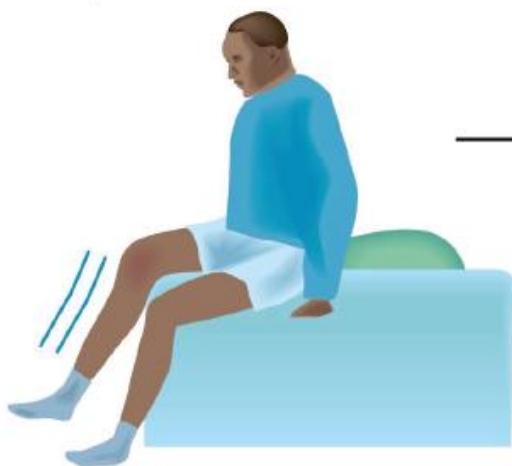
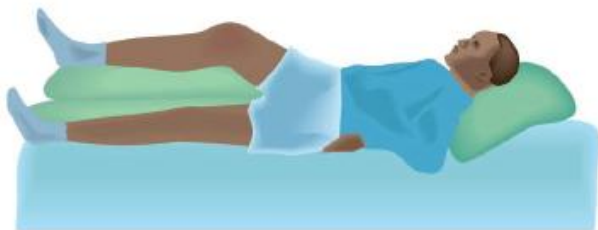
Abasirikare umubiri urema ngo barwanye icyo ukemanze ni iki, ni gute bashobora gucungwa?

- **Abasirikare umubiri urema ngo barwanye icyo ukemanze** ni abasirikare (poroteyine) umubiri urema mu rwego rwo kurwanya ibintu ubona nk'ibimanuka".
- Umubiri w'umurwayi wa hemofiliya ushobora kurema abasirikare barwanya poroteyine z'ibimanuka zo mu bicuruzwa by'ubuvuzi. Iyo aba basirikare bafite imbaraga, ubuvuzi busanzwe bushobora kudakora neza.
- Si buri mubiri urema abasirikare barwanya ibyo ukemanze. Ahanini baboneka mu bantu bafite hemofiliya ikaze A.
- Suzumisha abasirikare b'umubiri barwanya ibikemanzwe mbere yo kubagwa, harimo no kubagwa mu menyo.
- Hari ubuvuzi budasanzwe bwo kurwanya abasirikare umubiri uremye igihe wikanze.



Ibimenyetso by'uko kuva amaraso byahagaze ni ibihe?

- Kongera kuyega bisanzwe kw'ingingo n'imyakura.
- Kugaruka kw'imbaraga mu myakura.

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Igice cya 4

Kubungabunga
ubuzima no kwirinda
kuva

Ni iki cyakorwa ngo umuntu abungabunge ubuzima?

Ubuwuzi ni kimwe mu bigize ubuzima bwiza. Abarwayi ba hemofiliya bagomba:

- Gukora imyitozo ngororangingo no guhora bakomeye.
- Kwambara ibikwiye bibarinda mu gihe cya siporo cyangwa igikorwa runaka.
- Guhora bakoresha ibizami by'uko umubiri uhagaze, harimo no gupimisha ingingo n'inyakura.
- Guhabwa inkingo zose ziteganywa, harimo iza hepatitis A na hepatitis B.
- Kutarenza ibiro binogeye umubiri. Abantu badakora imyitozo ngororamubiri bakunda kugira ibiro birenze ibikenewe. Umurwayi wa hemofiliya agomba kugenzura ibiro kugira ngo atananiza ingingo ze, by'umwihariko iyo arwaye rubagimpande.



Kuki ari byiza kugira ubuzima bwiza mu menyo?

- Amenyi n'ishyamba bizima bigabanyaga gukenera kwivuzwa hemofiliya.
- Kwita ku menyo mu buryo buhoraho bigabanyaga guterwamo inshinge no kubagwa.
- Kwita ku menyo bigomba kubamo kuyozza, kwihaganyura no kubonana na muganyaga w'amenyi.

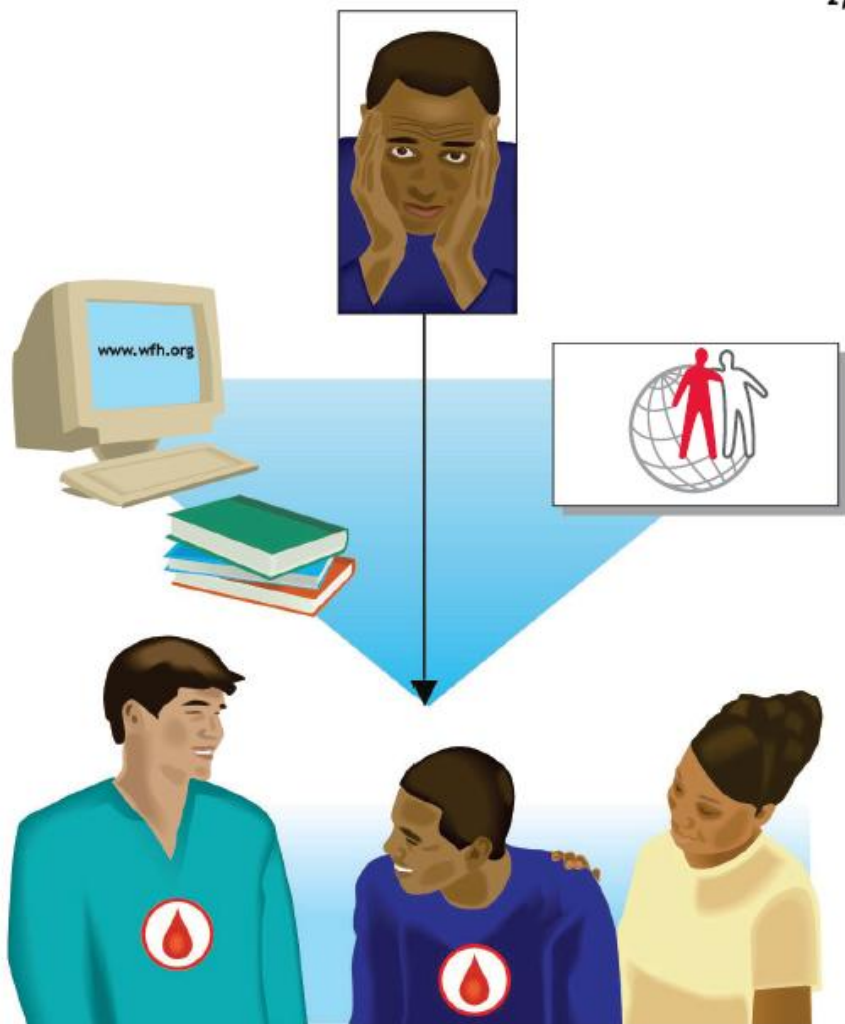


Kuki ari byiza kugira ubuzima bwiza mu marangamutima?

Kubana na hemofiliya bitera guhangayika. Uyu muhangayiko ugira ingaruka ku bagize umuryango no ku murwayi ubwe.

Bishobora gufasha:

- Kumenya uburwayi bwa hemofiliya uko bishoboka kose. Ubumenyi bufasha abantu kumva igenzuye.
- Kumenyana n'abandi barwayi ba hemofiliya. Gusangizanya ubumenyi bishobora kugabanya umuhangayiko.
- Kwinjira mu miryango ikora kuri hemofiliya.



Bigenda bite iyo hakenewe kubagwa?

Mbere yo kubaga, kubaga mu menyo cyangwa guteramwo urushinge, abakora mu buvuzi bagomba:

- Kwiyegereza ibikoresho by'ubuvuzi biza kubafasha gucunga amaraso ava no gufasha umurwayi gukira neza.
- Gukora ikizami cy'abasirikare umubiri urema ngo barwanye icyo ukemanze.
- Gutekereza ku yindi miti yafasha kwihutisha gukira, nk'igabanya ububabare. ***Imiti ikomeza urukoko rw'amaraso*** ishobora gukoreshwa mu guhagarika ubushobozi bw'umubiri buyabuza kuvura.



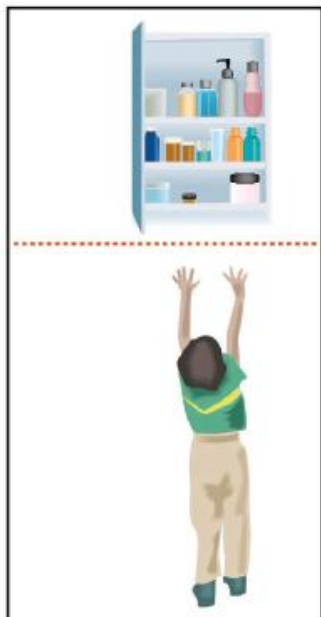
Bigenda bite iyo hakenewe imiti cyangwa inkingo?

IBYO GUKORA

- Gusuzumisha imiti yose ku mukozi wo mu by'ubuzima bujyanye na hemofiliya.
- Kubika no gukoresha imiti n'ibikoresho by'ubuvuzi ukurikije amabwiriza.
- Kubika imiti yose aho abana batagera.

IBYO KWIRINDA

- Ntugafate ASA (Aspirin®) iyo ari yo yose ngo uragabanya ububabare.
- Ntugafate **imiti itari steroide/ igabanya ibimenyetso (NSA/D)** utagishije inana muganga.
- Ntugaterwe inshinge mu mikaya. Niba ari ngombwa kwikingiza, bagomba gutera urushinge muni y'uruho.

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Bumwe mu bwivumbure bw'umubiri buterwa n'ubuvuzi ni ubuhe?

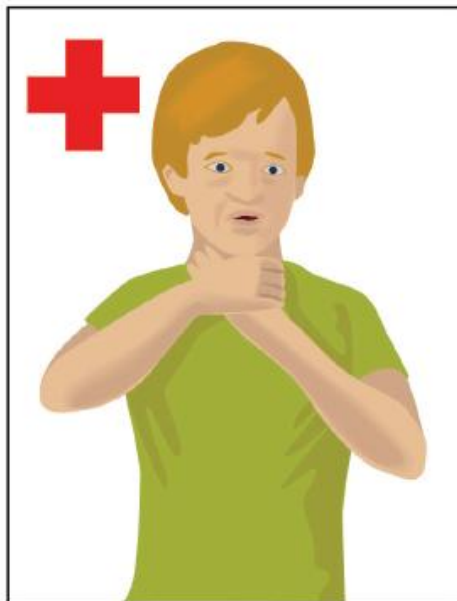
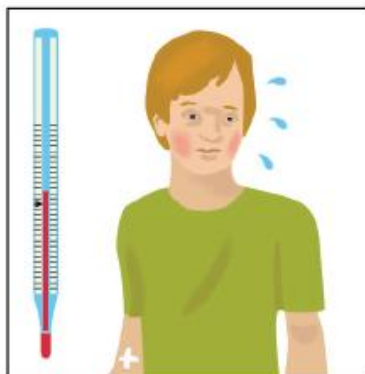
Hari ubuvuzi bushobora gutera ubwivumbure bw'umubiri bwatera:

- Umuriro
- Guhinda umushyitsi
- Gusesa ibiheri

Akenshi ubwivumbure bw'umubiri buba bworoheje. Buba bushobora koroha umuntu afashe **antihistamines** (umuti ukunze gutangwa mu makabusuru).

Ubufasha bw'abaganga buba bukenewe byihutirwa iyo habayeho:

- Guhumeka bigoranye
- Kumva umuntu afunganye mu gituzo



Amakuru ajyanye n'ubuvuzi agomba kwitwazwa ni ayahe?

- Umurwayi wa hemofiliya yagombye guhora yitwaje amakuru yerekeye ubuzima bwe, arimo ubwoko bwa hemofiliya, ubuvuzi bukenerwa n'ubwivumbure bw'umubiri.
- Hari amakarita y'uburwayi yo ku rwego rw'isi aboneka ku buntu binyuze muri World Federation of Hemophilia. Mu bihugu bimwe na bimwe hagurishwa ibirango byitwa Medic-Alert na Talisman.



Ni he abantu bashobora gukura ubufasha cyangwa inama zijyanye na hemofiliya?

Ubufasha n'inama biraboneka bitangwa na:

- Abakora mu buvuzi bwa hemofiliya.
- Imiryango ikora kuri hemofiliya (yanditse ku rubuga rwa interineta rwa WFH).
- Abandi barwayi ba hemofiliya n'imiryango yabo (binyuze mu manama no guhamagara kuri telefoni zabugenewe).
- Igitabo kivuga kuri hemofiliya.





Umugereka

Ubuwuzi butangiwe mu
rugo no kwinjiza
urushinge mu mutsi

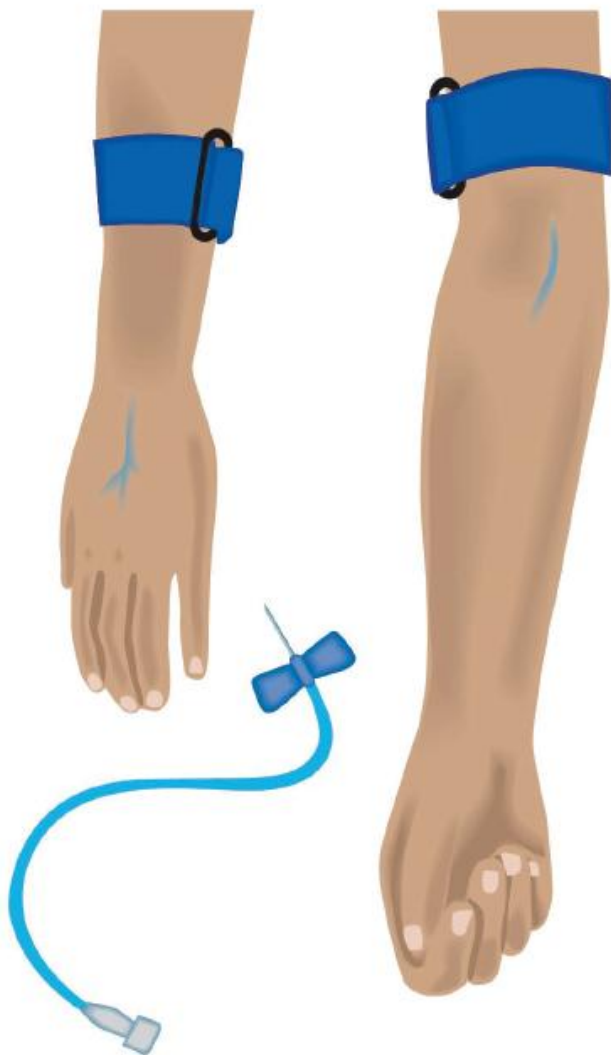
Ubuwuzi butangiwe mu rugo ni iki?

- Ubuwuzi butangiwe mu rugo ni **uburyo bwo kwinjiza umuti mu maraso** (urushinge) urimo poroteyine isimbura ibura/idakora neza bikorewe hanze y'ibitaro. Umurwayi wa hemofiliya ashobora guterwa imiti ari mu rugo, ku ishuri, ku kazi cyangwa ahandi hose.
- Ni ngombwa kwandika no kubika buri gikorwa cy'ubuvuzi.
- Umurwayi wa hemofiliya n'umuryango we bagomba gufatanya inshingano n'abakora mu buwuzi bwayo mu kwita ku buzima bwe.
- Ubuwuzi bukorewe mu rugo ntibusimbura kubonana na muganga.



Kwinjiza urushinge mu mutsi ni iki?

- ***Kwinjiza urushinge mu mutsi*** bivuze gufata urushinge ukarwinjiza mu mutsi. Ibi bishobora gukorwa mu gufata amaraso cyangwa mu gutera umuntu urushinge.
- Umutsi wose amaso abasha kubona cyangwa urutoki rwumva bitagoye waterwamo urushinge. Akenshi imitsi byoroha gukoresha ni iyo ku kiganza inyuma cyangwa mu nkokora imbere.
- Abana bato bafite hemofiliya bashobora kuva cyane iyo batewe urushinge mu mutsi wo ku ijosi cyangwa mu ntantu. Akenshi aha hantu abaganga bahakoresha bafata amaraso yo gupima. Ni ngombwa gutera ahandi ku bana bayirwaye, haba mu gufata amaraso yo gupima cyangwa mu buvuzi.



Ni ibiki bigomba gutegurwa mu buvuzi bwo gusimbuza ibice bibura cyangwa bidakora neza ibindi?

Gusoma amabwiriza yazanye n’umuti wa factor concentrate. Gukaraba neza intoki ukoresheje amazi n’isabune mbere yo kugira igikoresho ukoraho. Aho gukorera hagomba gusukurwa hakoreshejwe umuti wica udukoko. Agapfundikizo k’amazi ya Jeveri muri litiro y’amazi bitanga umuti mwiza wica udukoko. Reba neza ko amazi ya Javeri atarengeje igihe.

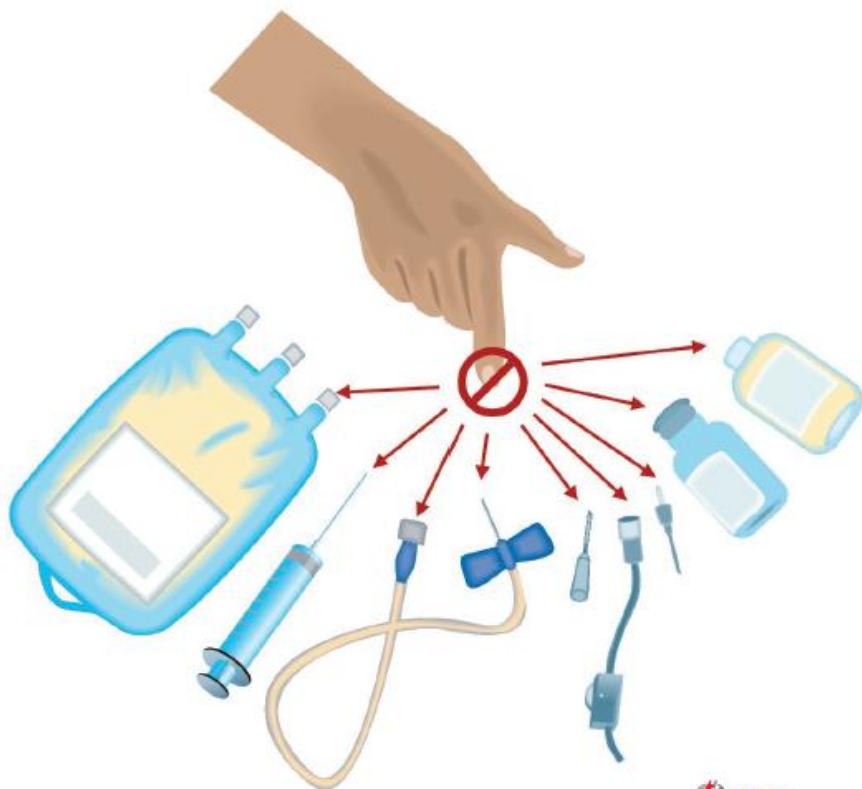
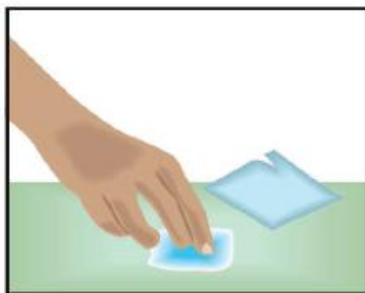
Ibikoresho bikenerwa mu buvuzi bukoresha factor concentrate:

- igikoresho cyo kujugunyamo ibikoreshejwe
- udutambaro two guhanagura
- agatambaro kinikwa muri arukoro
- bande
- utubure tw’ipamba
- sipuradara
- agakoresho gafunga ahanyuze urushinge
- urushinge rufite akagozi amaraso acamo
- urushinge rusanzwe
- agakoresho k’imitwe ibiri kimura amazi/agakoresho gashungura
- factor concentrate
- udupfukantoki twa kawucu
- **amazi yo gufungura** (amazi atarimo mikorobi) yazanye na concentrate



Ni gute ubwandu bwakwirindwa mu gihe cyo gutera umuntu urushinge?

- Gufata neza ibikoresho byose bigiye gukoreshwa. Gusukura intoki n'ibikoresho. Abafasha bagomba gukaraba intoki no kwambara udupfukantoki.
- Itonde! Igiza intoki kure y'imitwe y'inshinge, ibikoresho bityaye n'iminwa y'amacupa n'imifuka. Aha hantu hagomba guhora hasukuye cyane.
- Concentrates ntizigomba gufungurwa ngo ibisigaye bibikwe bizakoreshwe ubutaha.
- Gushyira inshinge zose zakoreshejwe mu gikoresho cyabugenewe.
- Gukuraho ibyamenetse hakoreshwe umuti wica mikorobi hakurikijwe amabwiriza y'abakora mu bijyanye na hemofiliya.
- Kujugunya uko bikwiye ibikoresho byose byakoreshwe mu gutera urushinge hakurikijwe amabwiriza yo muri ako gace. Kubaza ikigo cyangwa ivuriro muturanye rikora ku bijyanye na hemofiliya kugira ngo umenye amabwiriza yaryo.



Ni gute ubuvuzi busimbuza ibice runaka ibindi butangwa?

(IGICE A)

- Kugenzura neza ko intoki zawe zisukuye.
- Gukurikiza amabwiriza y'abakora mu buvuzi witonze.
- Gukoresha umuti wafunguwe wose. Kutagerageza kugabanya ibipimo by'umuti cyangwa kubika uzakoreshwa ubutaha. Ibigize umuti ufasha amaraso kuvura bitangira kuzimira nyuma yo kuwufungura (nyuma yo kuwuvanga n'amazi). Ikindi ni uko haba hari ibyago byinshi byo guhura n'ubwandu.

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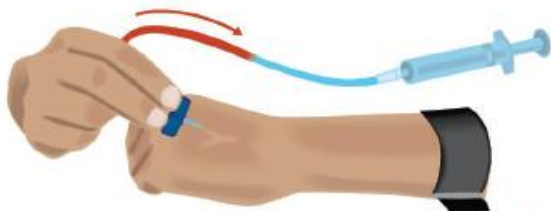
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Ni gute ubuvuzi busimbuza ibice runaka ibindi butangwa?

(IGICE B)

- Kurikiza amabwiriza y'abakora mu buvuzi witonze.
- Niba urangije, urushinge rutakikuri mu mutsi, wibuke gukanda aho urushinge rwanyuze nibura mu minota itanu.

5



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Izindi mfashanyigisho

Ibisobanuro by'amagambo amwe n'amwe

umuti ukomeza urukoko rw'amaraso, urup. rwa 28:
Umuti ushobora gufasha guhagarika icagagarika ry'urukoko rw'amaraso no gufasha kwihutisha gukira.

antihistamine, urup. rwa 30:
Umuti ufasha kugabanya cyangwa kwirinda ubwivumbure bw'umubiri.

imiti igabanya ibimenyetso, urup. rwa 22:
Umuti ushobora kugabanya cyangwa kurinda ububabare, guhisha k'uruho no kubyimbarwa byatewe no kubabara (imyitwarire y'umubiri ko biwubangamiye, ibikomere cyangwa ubwandu).

umujyana, urup. rwa 1 n'urwa 14:
Umuheha munini cyangwa umuyoboro w'amaraso uyakura mu mutima uyajana mu bindi bice by'umubiri. Umubiri ugira imijyana myinshi.

inyama y'abagabo, urup. rwa 15:
Igice cy'ukuguru kiri hagati y'ivi n'agatsinsino.

udutsi duto tw'amaraso, urup. rwa 1:
Uduheha cyangwa utuyoboro tw'amaraso twose dutwara amaraso dukora ihuriro mu kugeza amaraso mu mubiri wose. Umubiri ugira udutsi duto tw'amaraso twinshi.

uwibitsemu uburwayi, urup. rwa 6:
umuntu ufite ingirangango fatizo y'iyororoka itera uburwayi, akenshi atagaragaza ibimenyetso.

agahu korohereye ko ku mpera y'igufa, urup. rwa 9:
Agace korohereye gatwikiriye aho igufa rirangirira mu ngingo.

akaremangingo, urup. rwa 5:
Akantu gato cyane ku isi gafite ubuzima kigenga. Umubiri w'umuntu ugizwe na za miriyari z'utaremangingo.

poroteyine y'iyororoka, urup. rwa 6:
Agace karekare, gato, kameze nk'urudodo kagizwe na poroteyine ADN kaba rwagati mu turemangingo tw'umuntu, inyamaswa n'ibimera. Poroteyine z'iyororoka ebyiri (zitwa X na Y) ni zo zigena igitsina cy'umuntu. Abagore bavukana poroteyine z'iyororoka ebyiri za X (XX = ukukobwa). Abagabo bavukana poroteyine z'iyororokai X imwe na Y imwe (XY = umuhungu).

urukoko rw'amaraso, urup. rwa 2:
Agahu k'amaraso gakorwa na poroteyine ituma amaraso avura kugira ngo kuva bihagarare.

poroteyine ituma amaraso avura, urup. rwa 2:
Poroteyine zose zo mu mushongi w'amaraso zituma amaraso avura zifatanya gukora urukoko kugira ngo amaraso akame.

guhambira, urup. rwa 20:
Guhambira agatambaro ahari kuva bishatse kuvuga kuhabyiga cyangwa gukoresha akenda gakaweduka kugira ngo uhagarike ububuyimbirwe.

cryoprecipitate, urup. rwa 21:
Umuti ukorwa hifashishijwe umushongi w'amaraso. Ugizwe na poroteyine, nka poroteyine VIII (umunani) na poroteyine von Willebrand, ariko nturima poroteyine IX (icyenda). Uterwa mu mutsi nyuma y'igihe cyagenwe.

DDAVP cyangwa desmopressin, urup. rwa 21:
Ubwoko bw'umuti zamurwa urwego rwa poroteyine VIII (umunani) umuntu yisanganawe mu maraso, ariko si igicuruzwa cy'amaraso. Ushobora gukoreshwa mu kuvura hemofiliya yoroheje A n'ubundi bwoko bw'indwara ya von Willebrand.

amazayo gufungura, urup. rwa 35:
Amazi bavanga n'ifu y'umuti ufasha amaraso kuvura. Uruvange ruvuyemo barutera mu rushinge ngo bavure kuva.

kuzamaza umubiri, urup. rwa 20:
Mu butabazi bw'ibanze, kuzamaza umubiri bisobanura kwigizwa hejuru y'umutima igice cy'umubiri cyakomeretse. Ibi bifasha guhagarika amaraso no kubyimbirwa.

factor concentrate, urup. rwa 21:
Ubwoko bw'ubuvuzi busimbuzza poroteyine VIII (umunani) cyangwa IX (icyenda) zibura bazitera mu mutsi. Uyu muti ushobora gukorwa mu mushongi w'amaraso y'umuntu, ubundi ukumishwa ukagirwa ifu. Iyi fu barayifungura mbere yo gutera umuntu urushinge. Reba recombinant ubone ibisobanuro by'ubundi bwoko bwa factor concentrate.

imbere ku kuboko muni y'inkokora, urup. rwa 15:
Igice cy'ukuboko kiri hagati y'ubujana n'inkokora, ahari imyakura ikunze kuva.

ingirabuzima fatizo y'iyororoka, urup. rwa 5:
Ingirabuzima fatizo z'iyororoka zitwara ubutumwa bw'ukuntu uturemangingo tw'umubiri dukora. Urugero, zigena ibara ry'umusasi n'amaso by'umuntu. Hemofiliya iherekanywa mu ngirabuzima fatizo z'iyororoka.

hemofiliya, urup. rwa 3:
Ijambo rikoreshewa mu gusobanura uburwayi bwo kuva, aho umushongi w'amaraso y'umuntu uba ubura cyangwa ufite poroteyine VIII (umunani) cyangwa IX (icyenda) zituma amaraso avura zidahagije.

hemofiliya A, urup. rwa 4:
Uburwayi bwo kuva, aho umushongi w'amaraso y'umuntu uba ubura cyangwa ufite poroteyine VIII (umunani) ituma amaraso avura idahagije.

hemofiliya B, urup. rwa 4:
Uburwayi bwo kuva, aho umushongi w'amaraso y'umuntu uba ubura cyangwa ufite poroteyine IX (icyenda) ituma amaraso avura idahagije.

rubagimpande ya hemofiliya, urup. rwa 12: Ikitabazo cyo mu ngingo, gikunze kugendana n'ububabare no kubyimbirwa, kubera kuva kenshi. Agahu korohereye ko ku mpera y'igufa karamanyagarika, maze amwe mu magufa akangirika. Rimwe na rimwe ingingo ntibasha kuyega.

Ibisobanuro by'amagambo amwe n'amwe

ubuvuzi butangiwe mu rugo, urup. rwa 33:

Guterwa imiti mu nshinge cyangwa ubundi buryo buyinjiza mu maraso bikorwa akenshi umuntu ari iwe aho kujya ku bitaro.

kwinjiza umuti mu maraso, urup. rwa 33:
Urushinge rw'umuti ruterwa mu mutsi.

abasirikare umubiri urema ngo barwanye icyo ukemanze, urup. rwa 23:

Abasirikare umubiri ukora kugira ngo barwanye ibintu ubona nk'ibimanuka, bakaba barwanya umuti utuma amaraso avura.

IX (icyenda), urup. rwa 3:
Umubare w'ikiromani usobanura "9" (icyenda). Buri poroteyine yo mu mushongi w'amaraso ituma amaraso avura igira izina ry'umubare w'ikiromani.

ingingo, urup. rwa 9:
Aho amagufa abiri ahurira.

agahu k'ingingo, urup. rwa 9:
Ahantu cyangwa ikintu gifatanyiriza amagufa mu ngingo (aho amagufa abiri ahurira).

hemofiliya yoroheje, urup. rwa 4:
Uburwayi buterwa n'igikorwa cya poroteyine VIII (umunani) cyangwa IX (icyenda) cya 5% kugeza kuri 40% by'urwego rusanzwe mu maraso.

hemofiliya iringaniye, urup. rwa 4:
Uburwayi buterwa n'igikorwa cya poroteyine VIII (umunani) cyangwa IX (icyenda) cya 1% kugeza kuri 5% by'urwego rusanzwe mu maraso.

kwituna k'umukaya, urup. rwa 13:
Kwituna k'umukaya bibabaza umuntu atabasha kuzenzura.

umwakura, urup. rwa 14:
Utuntu tumeze nk'indodo twumva, dutanga ubutumwa mu mubiri, harimo n'ububabare.

NSAIDS cyangwa umuti ugabanya ibimenyetso utarimo steroide, urup. rwa 29:
Umuti, nka ibuprofen, ugabanya ububabare n'umuriro ariko utarimo ibyo bita steroide.

umushongi w'amaraso, urup. rwa 2:
Kimwe mu bigize amaraso kirimo fiburine na poroteyine zituma amaraso avura.

udufashi tw'amaraso, urup. rwa 2:
Utoremangingo tw'amaraso dukora agapfundikizo k'ahasohokeraga amaraso ku mijyana, imigarura n'utuyoboro duto tw'amaraso.

umwakura wambukiranya intantu, urup. rwa 15:
Umwakura wo hafi y'intantu ufasha ingingo z'amayungunyungu n'uruti rw'umugongo kuyega.

recombinant, urup. rwa 21:
Ubwoko bwa factor concentrate bukorerwa muri laboratwari aho gukorwa mu maraso y'umuntu. Poroteyine za recombinant ni kopi y'ubwoko bwa poroteyine runaka ziboneka mu maraso y'umuntu.

hemofiliya ikaze, urup. rwa 4:
Uburwayi buterwa n'igikorwa cya poroteyine VIII (umunani) cyangwa IX (icyenda) mu maraso, akenshi muni ya 1% by'urwego rusanzwe.

kuva bitunguranye, urup. rwa 8:
Kuva bibaho nta mpamvu isobanutse ihari (hatabayeho gukomereka cyangwa kubagwa).

sinoviyumu, urup. rwa 9:
Akugara k'agahu k'ingingo. Gakoze mu turemangingo tudasanzwe dukora amatembabuzi arenduka amezwe nk'amavuta atuma byorohera ingingo kuyega.

ikibero, urup. rwa 15:
Igice cy'ukuguru kiri hagati y'amayungunyungu n'ivi, imyakura yacyo ikaba ikunze kuva.

ikizigira, urup. rwa 15:
Igice cy'ukuboko kiri hagati y'urutugu n'inkokora, imyakura yacyo ikaba ikunze kuva.

umugarura urup. rwa 1:
Umuheha cyangwa umuyoboro ugurura amaraso yo mu mubiri mu mutima. Umubiri ugira imitsi myinshi.

kwinjiza urushinge mu mutsi, urup. rwa 34:
Gushyira urushinge mu mutsi. Ibi bishobora gukorwa mu gufata amaraso cyangwa mu gutera umuti mu mutsi.

VIII (umunani), urup. rwa 3:
Umubare w'ikiromani usobanura "8" (umunani). Buri poroteyine yo mu mushongi w'amaraso ituma amaraso avura igira izina ry'umubare w'ikiromani.

**Byakozwe ku bw'inkunga igamije kwigisha
itagenzuwe ya Wyeth**

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