

Hemophilia ke eng?



WORLD FEDERATION OF
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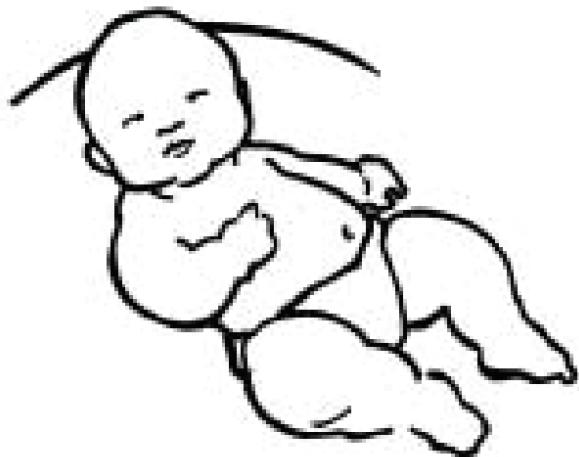
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HEMOPHILIA KE ENG?

- Hemophilia ke bolwetse jwa go dutla madi. Batho ba ba nang le bolwetse jo ga ba tswe madi ka bonako go feta mo go tlwaelesegileng, mme, moo ba kgona go dutla madikasebakaseseleele. Madi a bone ga a na karolwana e e dirang gore madi a gatsele kgotsa a ipope matlhole(clotting factor) ee lekaneng. Segatsetsa madi kgotsa karolwana ya madi e e dirang gore a gatsele le ke kotla e e agang mmele (Protein) e e laolang go dutla madi.
- Bolwetse jwa Hemophilia ga bo a tlwaelesega. Motho a le mongwe fela mo go ba le dikete tse di lesome o tsholwa a na le bolwetse jo.
- Mofuta o o tlwaelesegileng thata wa hemophilia ke hemophilia A. Se se raya gore motho o a bo a sena segatsetsamadiafactor VIII(8). Hemophilia Bke mofuta o mongwe mme one ga o a tlwaelesega thata. Jone bo nna teng fa motho a sena segatsetsamadi sa factor IX (9). Mefuta e ya Hemophilia ka bobedi jwa yone e ama motho ka tsela e e tshwanang ka gore mo go yone yotlhe motho o dutla madi ka sebaka se se leele go feta mo go tlwaelesegileng.

BATHO BA TSENWA KE HEMOPHILIA JANG?

- Hemophilia ke bolwetse jo motho a thsolwang ka jone . Ga bo tshelwane jaaka mohikela.
- Hemophilia ke bolwetse jwa lesika, se se rayang gore motho o bo tsaya mo batsading ba gagwe ka di-gene. Di-gene di tshotse melaetsa mabapi le ka fa mmele o tla golang jaaka ngwana a gola go nna motho yo motona. sekai, ke tsone tse di laolang mmala wa moriri le matlho a motho.
- Ka dinako dingwe, motho o kgonago nna le hemophilia mme e seyo mo lesikeng la gagwe. Mohuta o o bidiwa hemophilia e e itlelang fela (sporadic hemophilia). Selekanyo sa masome a mararo mo lekgolong (30%) sa batho ga ba tsenwa ke hemophilia ka lebaka la go e tsaya mo batsading ba bone. E bakilwe ke phetogo mo di-geneng tsa bone ka bonosi.



HEMOPHILIA E FETELA JANG MO MOTHONG?

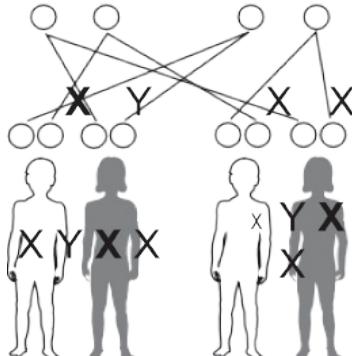
- Fa rrě a sena hemophilia mme mmě a na le yone, bana na bone ba basimane ga ba kake ba nna le yone. Lefa go ntse jalo, bana ba bone ba basetsana botlhe ba ya go nna le gene ya (segotso sa) hemophilia.
- Basadi ba ba nang le segotso sa hemophilia ba bitswa gore ba “tshotse” kgotsa di- carriers. Ka dinako dingwe ba supa dikai tsa hemophilia, mme ba kgonago go e fetisetsa mo baneng ba bone. Go na le kgonagalo ya 50% (sephato mo lekgolong) gore ngwana wa bone wa mosimane a nne le hemophilia le kgonagalo ya 50% ya gore wa mosetsana le ene e nne carrier ya hemophilia .
- Basadi ba ka nna le hemophilia fela fa borraabone ba na le yone mme bommaabone e le di-carrier. Le fa gontse jalo, se ga se a tlwaelesega.

Rre yo o nang le hemophilia

Father with hemophilia



Noncarrier mother

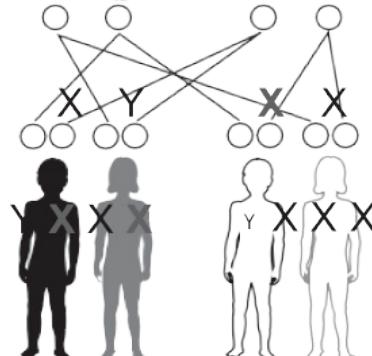


Mme yo o tshotseng gene ya hemophilia

Nonaffected father



Carrier mother



GO NA LE DIKAROLO TSE THARO TSA BOKETE JWA BOLWETSE.

Bokete bo tlhalosa ka fa seemo se leng maswe ka teng.

Gore bolwetse bo bokete go le kafe go laolwa ke gore selekanyo sa segatsetsamadi se tlhaela go le kae mo mading a motho

SEEMO SE SE TLWAELESEGILENG=selekanyo sa 50% go ya go 150% sa karolwana e e dirang gore madi a ipope matlhole sa clotting factor VIII(8) kgotsa clotting factor XI(9).

HEMOPHILIA E E KOTASE

Selekanyo sa 5%
go ya ko go 30%
sa segatsetsamadi

- }
- Go ka nna le go dutla madi lebaka le leleele morago ga loaro kgotsa fa go na le kgobalo.
 - Bothata jwa go dutla madi bo ka ema gotlhelele.
 - Go dutla madi ka sewelo
 - Go dutla fela fa go na le kgobalo

HEMOPHILIA YA BOKETE JO BO FA GARE

Selekanyo sa
1% go ya 5% sa
segatsetsamadi

- }
- Go ka nna le go dutla madi ka lebaka le leleele morago ga loaro, kgobalo kgotsa kalafi ya meno.
 - Go dutla madi gangwe fela mo kgwedding.
 - Go dutla go sena lebaka go direga ka sewelo

HEMOPHILIA E KO GODIMO

Selekanyo se
se ko tlase
ga 1% sa
segatsetsamadi

- }
- Go dutlela madi mo mesifeng le mo malokolong (bogolo thata mo mangoleng, dikgono/dijabana kgotsa manyenyana).
 - Go dutla madi gangwe kgotsa gabedi mo bekeng.
 - Go dutla madi fela go sa re sepe

Dikai tsa hemophilia ke di fe?

Dikai tsa hemophilia A le B di a tshwana.

- Go nna le matšadi a matona;
- Go dutlela madi mo mesifeng le mo malokololong, bogolo jang mangole, dikgono/dijabana le manyenyana;
- Go dutlela madi ka ko teng mo go itelang fela kwa ntle ga lebaka;
- Go dutla madi ka lebaka le le leelee morago ga go segwa ke sengwe, go ntsha leino kgotsa morago ga loaro; le
- Go dutla madi lebaka le le leelee morago ga go bona kotsi, bogolo jang fa kgobalo e le mo tlhogong

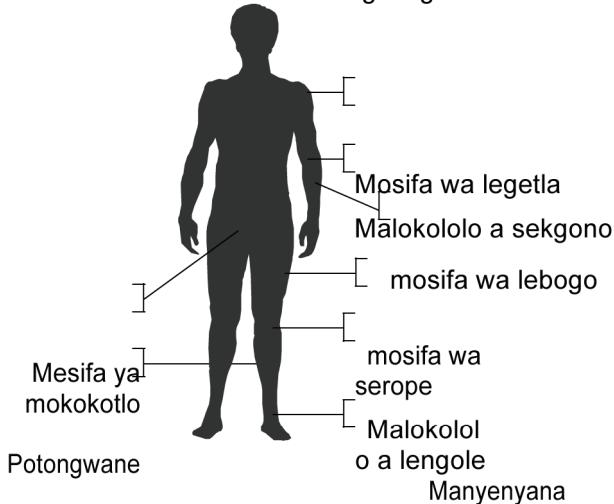
Go dutlela madi mo malokololong kgotsa mo mesifeng go ka baka:

- Go opa kgotsa go sa ikutlwa sentle;
- Go ruruga;
- Botlhoko le go gagamala; le
- Go palelwa ke go dirisa tokolo kgotsa mesifa

Madi a dutla gantsi fa kae?

- Batho ba ba nang le hemophilia ba ka dutlela madi ka ko teng kgotsa kwa ntle.
- Fa madi a ka dutlela gantsi mo tokololong e le nngwefela, tokololo ya go nna jalo e ka nna botlhoko kgotsa ya golafala/senyega
- Go dutla madi kgapetsa-kgapetsa go ka baka mathata a mangwe a botsogo a a tshwanang le bolwetse jwa ramatiki (arthritis). Seno se ka baka gore go nne bokete go tsamaya kgotsa go dira ditiro tse e seng tsa sepe. Lefa go ntse jalo, malokololo a diatla ga se gantsi a amiwa ke hemophilia(eseng jaaka mefuta e mengwe ya arthritis).

Malokololo le mesifa e e amiwang ke go dutla madi.



Hemophilia e alafiwa jang?

- Mo malatsing a gompieno, kalafi ya hemophilia e bereka sentle thata. Molwetse wa hemophilia o kentiwa ka lemao go tsenya segatsetsamadi mo mmeleng. Go dutla madi go a ema fa segatsetsamadi se se lekanyeng se goroga fa lefelong le le dutlang madi.

- **Alafa go dutla madi ka bofeko !**

Go bona kalafi ka bofeko go ka fokotsa botlhoko le go gobala ga mesifa le dikarolo tse dingwe tsa mmele. Fa go dutla madi go alafiwa ka bonako, ga go tlhoke segatsetsamadi se se kalo go ka emisa go dutla madi.

- **Fa o belaela, alafa!**

Fa o belaela gore o ka tswa o dutla madi, batla kalafi le fa o ise o tlhomamise. O SEKA wa emela go utlwa tokololo e fisa, e ruruge kgotsa e nne botlhoko. **O SEKA** wa tshwenngwa ke gore o tlaa bo o senya kalafi.

- Go santse go sena kalafi ya sennela ruri ya hemophilia, mme ka kalafi e e teng, batho ba hemophilia ba kgora go tshela matshelo a a itekanetseng. Kwa ntle ga kalafi, batho ba ba nang le hemophilia e e bogale ba ka nna le bothata jwa go ya sekolong kgotsa go ya tirong malatsi otlhe. Ba kgora go nna le bogole le go palelwa ke go tsamaya kgotsa go dira ditiro tse di motlhoho -kgotsa ba tlhokafala ka bonana.

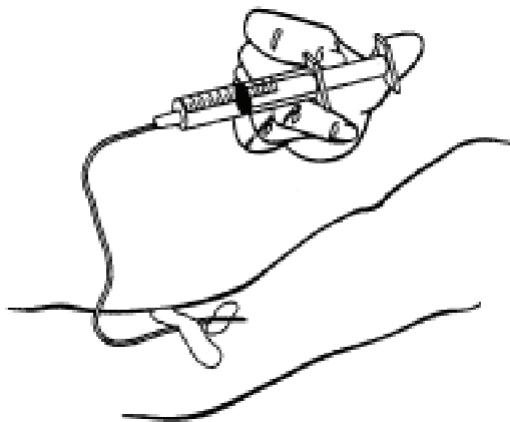
Kalafi e ka fiwa leng?

Kalafi e fiwa fa:

- Go na le go dutlela madi mo malokololong;
- Go na le go dutlela madi mo mesifeng, bogolo jang mo maotong le mo mabogong;
- Go na le kgobalo ya molala, molomo, leleme, sefatlhego kgotsa leithlo
- Go itewa ke sengwe mo tlhogong le tlhogo e e opang mo go feteletseng ;
- Go na le go dutla madi ka bokete kgotsa mo go sa emeng mo karolong epe fela
- Botlhoko jo bo feteletseng kgotsa go rurga mo karolong epe fela ;
- Dintlhho tsotlhe tse di bulegileng di tlhoka go rokiwa
- Go nnile le kotsi epe fela e e ka bakang go dutla madi.

Kalafi e ka fiwa pele ga:

- Loaro le le akaretsang kalafi ya meno;
- Tiro epe fela e e ka bakang go dutla madi.



Kalafi ga e tlhokafale fa go rileng?

- Letšadi le le sareng sepe le tlwaelesegile thata mo baneng ba ba nang le hemophilia, mme ga go kotsi. Le fa go ntse jalo, letšadi mo tlhogong le kcona go gakala, ka jalo le tlhoka go sekasekwa ke mooki kgotsa ngaka yo o itebagantseng le hemophilia.



Go rurubala
mo tlhogong go
tsaya phekelo e
sele

- Dintlhonyana tse di nnye le mangapo di dutla madi fela sebaka se se lekanang le sa tsa motho yo o senang hemophilia. Ga di kotsi gantsi.
- Dintlho tse di boteng tsone gantsi-mme e seng ka dinako tsot lhe-di dutla madi sebaka se se leeble go feta ka mo go tlwaelese gileng ka gone. Go dutla go ka emisiwa ka go gatelela ka se bakanyana fa go dutlang madi teng.
- Go dutla madi ka dinko (Go hophago tswa mokola) go ka emis iwa ka go tswala nko sebaka sa metsotso e metlhano. Fa seno se sa emise madi, go tlaa tlhokafala kalafi.

Dintlha tsa botlhokwa tsa batho ba ba tshelang le Hemophilia:

1. Alafa go dutla madi ka bonako!

Fa o emisa go dutla madi ka bonako se se ka go fokoletsa bot lhoko le go golafala ga malokololo, mesifa le dikarolo tse dingwe tsa mmele. Mo godimo ga moo, se se raya gore o tlaa seke o tlhoke kalafi e ntsi go laola go dutla madi.

2. Nna o itekanetse.

Mesifa e e nonofileng e ka go thusa thata go re o seka wa nna le bothata jwa malokololo le gore o se ka wa nna le go dutla madi mo go itlelang fela. Botsa ngaka wa gago wa hemophilia le moiit saanape wa tshidilo gore o siametswe ke metshameko le tsa ikatiso tsa mofuta mang.

3. O se ka wa nwa ASA (Aspirin®).

ASA (acetylsalicylic acid) e ka baka go dutla madi. Melemo e mengwe le yone e ka ama go ipopa ga madi. Botsa ngaka ya gago ka metlha gore ke melemo e fe e e babalesegileng.

4. Bona ngaka kgotsa mooki wa hemophilia nako tsotlhe.

Badiri ba kokelwana kgotsa lefelo la kalafi ya ba tlaa go thusa le go go fa dikgakololo ka fa o ka tlhokomelang botsogo jwa gago ka teng

5. Tila go dirisa mekento e o tlhabiwang mo mesifeng.
Mokento o go tlhabiwang mo mosifeng o ka baka go dutla madi mo go botlhoko. Lefa go ntse jalo, mekento ya itshire letso e botlhokwa e bile e babalesegile go ka dirisiwa ke motho yo o nang le hemophilia. Melemo e mengwe e ka nowa kgotsa ya fiwa ka drip mo teng ga tshika go na le go tlhaba mesifa.
6. Tlhokomela meno a gago.
Go tila mathata, sala morago ditaelo tsa ngaka ya gago ya meno. Mekento ya meno le loaro di ka baka go dutla ga madi mo go maswe.
7. Tsamaya o tshwere sesupo sa seemo sa botsogo ja gago ka nako tsotlhe.
Go na le karata ya bongaka e e kgethegileng go tswa ko go ba World Federation of Hemophilia. Mafatshe a mangwe a rekisa dikarata tsa itshupo tse di bidiwang “Medic-Alert” kgotsa “Talisman” tse di ka rwalwang mo molaleng kgotsa mo lebogong.
8. Ithute dintlha tsa botlhokwa tsa thuso ya ntlha. Thuso ya potlako e ka thusa go laola go dutla madi.
Gakologelwa gore dinthonyana, mangaponyana le matšadi a e seng a sepe ga a kotsi ka dinako tsotlhe. Ga se gantsi di tlhoka kalafi. Thuso ya ntlha e lekane.



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