

KALAFI YA THIBELO KE ENG



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50

YEARS OF ADVANCING
TREATMENT FOR ALL

WORLD FEDERATION OF HEMOPHILIA
Fédération mondiale de l'hémophilie
Federación Mundial de Hemofilia

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Prophylaxis ke eng?	5
Mefuta ya prophylaxis	6
Go fa molwetse kalafi le dinako tsa yone	8
Prophylaxis e e lebaganeng motho ka nosi	9
Metswako e a e berekang sebaka se se leele	9
Go baya leitlho maduo a kalafi	10
Go simolola le go emisa	10
Dikgoreletsi le dikgwetlho	12
Tlhwatlhwa le bokgoni jwa go fitlhelela kalafi	12
Go kgonas tsenya molemo ka ditshika	12
Go sala ditaello tsa botsogo morago/go lolama mo kalafing	13

A O N E O ITSE?

Prophylaxis ga e thuse go baakanya kgotsa go fodisa malokolo a a setseng a sule/golafetse.

Lefa go ntse jalo e fokotsa makgetho a go dutla madi, e fokotsa lebelo le malokololo a swang ka lone, e bile e ka tokafatsa boleng jwa botshelo.

Is 1% sufficient to prevent sub-clinical bleeding, or is it based on historical supply constraints, economics, and treatment protocol burdens?

KALAFI YA THIBELO (PROPHYLAXIS) KE ENG?

Prophylaxis ke go kenta motho ka digatsetsamadi kgapetsakgapetsa go thibela go dutla madi.

Mogopolo wa go dirisa prophylaxis o tlike morago ga go lemoga gore batho ba ba nang le hemophilia e e bonolo le ya bokete jo bo fa gare (ba ba nang le selekanyo sa bongwe mo lekgolong (1%) sa segatsetsamadi ga se gantsi ba itemogela go dutla madi mo go diragalang fela.

Fa e sale nako eo, dipatlisiso tsa botlhokwa di supa gore bana ba ba amogelang prophylaxis ba nna le go dutla madi mo go fokotsegileng e bile ba na le malokololo a a itekanetseng.

Mo malatsing ano, maikaelelo ke go dirisa prophylaxis e le yone kalafi ya batho ba ba nang le hemophilia e e bogale gore ba kgone go nna ba tlhagafetse le go dira ditiro tsa letsatsi le letsatsi.

MEFUTA YA PROPHYLAXIS

Kalafi ya thibelo kgotsa ya prophylaxis e farologana le kalafi e e fiwang fela fa go tlhokega, e e fiwang ka nako ya fa madi a dutla, prophylaxis yone e fiwa go thibela go dutla pele go ka simologa.

Go na le mefuta e le mokawana ya prophylaxis. Prophylaxis e e fiwang go sa emisiwe (primary, secondary, le tertiary) e fiwa ka mo Nakong ya lebaka le le lee le sebaka sa dikgwedi kgotsa dingwaga. Prophylaxis ya nakwana kgotsa kgabaga yone e fiwa ka sebakanyana se se khutshwane, gantsi sebaka sa dibeke kgotsa dikgwedi.

Mofuta wa Kalafi	Tlhaloso
Kalafi e e fiwang fa go tlhokega (Episodic/'on demand' Treatment)	Kalafi e e fiwang fela fa madi a dutla
Kalafi e e fiwang go sa emisiwe (Continuous treatment)	Kalafi e e fiwang nako tsotlhe pele ga tokololo e tona ya bobedi e ka dutla madi pele ngwana a nna dingwaga tse tharo.
Primary prophylaxis	Kalafi e e fiwang nako tsotlhe go sa emisiwe morago ga malokololo a le mabedi a matona a dutle madi mme e le pele ga bolwetse jwa malokololo bo simologa
Secondary prophylaxis	Kalafi e e fiwang nako tsotlhe mme e simololwa morago ga bolwetse jwa malokolo go kganela go tswela ka go gobotsa malokololo
Tertiary prophylaxis	Kalafi e e fiwang go kganela go dutla madi ka nakwana mo gantsi go diragalang, ka sekai, morago ga loaro.
Kalafi ya kgabaga (Intermittent ("periodic") prophylaxis)	

Adapted from: Guidelines for the Management of Hemophilia, World Federation of Hemophilia, 2012.

Note: These definitions are consistent with those published by the Factor VIII & IX Scientific Standardization Committee of the International Society on Thrombosis and Haemostasis. National or regional programs may rely on other definitions.

GO FA KALAFI LE DINAKO TSA TENG

Prophylaxis ke go kenta motho kgapetsakgapetsa ka digatsetsamadi ka maikaelelo a go oketsa selekanyo sa sone gore e nne sa bongwe mo lekgolong (1%) go ya kwa godimo ka nako tsotlhe, Go na le ditsela tse dintsi tse di ka dirisiwanggo fitlhelela se, le fa go ntse jalo, ka fa go dirwang ka teng go farologana go ya ka mafatshe, mme e bile mo lefatsheng le le lengwefela, e kgona go dirwa ka ditsela tse di farologaneng.

Dipatlisiso di santse di tswelletse go bona tsela e e siameng ya go fa kalafi (seno gape se bidiwa ditshetlana tsa tsamaiso (protocol))

Thulaganyo ya go fa kalafi e tshwanetse go akaretsa:

- Mofuta wa segatsetsamadi o o tlaabong o dirisiwa
- Selekanyo sa segatsetsamadi se se tlaabong se fiwa ka nako ya mokento mongwe le mongwe
- Makgetho a kalafi e fiwang ka one
- Nako (mo letsatsing kgotsa beke) e kalafi e fiwang ka yone

Go na le mefuta e mebedi ya ditshetlana tsa tsamaiso e e dirisiwang e go setseng go na le kitso ka yone:

- The Malmö protocol: Mokento wa selekanyo sa 25-40IU/kg se fiwa batho ba ba nang le hemophilia A gararo mo bekeng, kgotsa ga bedi ka beke mo go ba ba nang le hemophilia B.
- The Utrecht protocol: Mokento wa selekanyo sa 15–30 IU/kg o fiwa ba ba nang le hemophilia A gararo mo bekeng le gabedi mo bekeng go ba ba nang le hemophilia B

Mo mafatsheng a a tlhaelang ditlamelo, go fiwa selekanyo se se ko tlase kgapetsa-kgapetsa (sekai, mokento wa selekanyo sa 10-15 IU/kg gararo mo bekeng) e ka nna yone tsela e e siameng.

Le fa ditshetlana tseno e le tsone tse go setseng go ithutilwe thata ka tsone, tsamaiso ya konokono ga e ise e tlhalosege sentle (Bona karolwana e e buang ka kalafi e e lebaganeng motho ka nosi, fa tlase)

Kalafi e e lebaganeng motho ka nosi

Re tsena mo dinakong tse go kgonagalang go alafa motho e seng bolwetse ja gagwe. Gore e kgone go bereka sentle, tsamaiso ya prophylaxis e tshwanetse ya dirwa go lebilwe dingwaga tsa motho, gore sebopego sa go dutla madi ga gagwe, botsogo jwa ditokololo, bokete le mofuta wa itshidilo mmele e ba e dirang, selekanyo sa segatsetsamadi le gore motho o kgona go sala morago ditsamaiso tsa kalafi go le kae. Metswako le melemo ya kalafi ya prophylaxis e tshwanetse go fetoga le dinako go ya ka fa mabaka a molwetse le one a fetogang ka teng.

Go nna le kitso ya gore mmele wa molwetse o bereka jang go amogela, go anamisa le go ntsha molemo mo mmeleng e ka thusa gore tsamaiso ya kalafi e ka agelwa mo mabakeng a molwetse fa a ntse a fetoga.

Metswako e e berekang sebaka se se leele

Metswako e mesha ya digatsetsamadi e e kgonang go nna lebaka le le oketsegileng mo mmeleng e diretswe gore e kgone go tshegetsa selekanyo se se siameng sa segatsetsamadi mo mmeleng lebaka le le leele, se se rayang gore ga go thokege gore motho a kentiwe kgapetsa kgotsa go tlaa tlhokega palo e e kwa tlase ya mekentlo go fitlhelela maduo a a tshwanang. Go nna teng ga melemo eno, go ka fetola tsela e prophylaxis e fiwang ka yone. Seno se ka tokafatsa ka fa balwetse ba amogelang prophylaxis ka teng e bile se ka tokafatsa go sala ditaello tsa ba bongaka morago le go tokafatsa maduo.

GO BAYA MADUO LEITLHO

Dipatlisiso tse di dirilweng sebaka sa dingwaga tse di fetang masome a mararo di supile gore, prophylaxis e e sa emisiweng(e e tswelletseng) ke yone e e siameng go ka fokotsa makgetho a go dutla madi le go thibela go swa malokololo, go na le e e fiwang fa go tlhokega.

Batho ba ba nang le hemophilia ba tlhoka go tlhatlhabiwa ka nako tsotlhe go tlhomamisa gore kalafi e bereka sentle fitlhelelwale gore go dirwe diphetogo fa go tlhokega. Ditlhatlhobo tse di akaretsa:

- Botsogo kgotsa seemo sa ditokololo
- Makgeto a go dutla madi
- Go palelwa ke go dira ditiro
- Tirisano mmogo ya motho le babangwe mmogo le tikologo

Go na le di dirisiwa di le mmalwa/mokawana tse di ka dirediwiwang go tlhatlhoba le go baya leitlho seemo sa ditokololo le go bereka ga tsone, tsela e go dutla madi go diragalang ka yone, le boleng jwa botshelo. Dintlha ka botlalo mabapile didirisiwa tseno tsa tlhatlhoba, o ka etela website ya: WFH's online Compendium of Assessment Tools (www.wfh.org/assessment_tools).

Go tshwanetse ga bewa leitlho kgotsa ga elwa tlhoko go nna teng ga dingwe tse di kgoreletsang kalafi go bereka(inhibitors). Go nna teng ga di-inhibitor go tlwaelesegile thata mo bathong ba ba nang le hemophilia e e bogale mo di-kalafing tsa ntlha tse di masome a supa le botlhano tsa digatsetsamadi. Go feta masome a matlhano mo lekgolong (50%) a di-inhibitor di diragala mo malatsing a ntlha a lesome lebotlhano (15) morago ga go sena gosimolodisiwa kalafi.

GO KA SIMOLOLWA LE GO EMISA LENG

Go santse go na le maikutlo le dikakanyo tse di farologaneng mabapi le nako e e siametseng go ka simolodisa le go emisa prophylaxis.

Tsela e e seng turu ke go simolola kalafi ya prophylaxis go santse go na le nako gore ditokololo di se ka tsa amega, di nne mo seemong se se

siameng/tshwanetseng. Prophylaxis e ntse e le yone tsela e balwetse ba tlhokomelwang ka yone mo dingwageng tse di fetang masome matlhano mo mafatsheng ale mantsi a Europe, le fa go ntse jalo tlhwatlhwa ya yone e e kwa godimo e dira gore go nne thata/bonya gore e ka dirisiwa ka bophara.

Go kgona go fitlhelela selekanyo se se ntsi sa digatsetstamadi tse di tlhokafalang gore prophylaxis e nne teng go botlhokwa thata mo go direng tshwetso ya gore kalafi e ka simololwa leng le gone gore e tlaa tsaya nako e e kafe.

Mo mafatsheng a kalafi e bonalang motlhofo, bontsi bo dumela gore prophylaxis e tshwanetse go simololwa pele ditokololo di senyegela ruri mo di ka se tlholeng di alafesega. Bongaka bangwe ba dumela gore e tshwanetse go simolodisiwa morago fela tokololo ya ntlha e se na le go dutla madi , kgotsa mo dingwageng tse di rileng (go le gantsi ngwaga tse pedi go ya go tse tharo). Ba bangwe ba gakolola gore go ka emiwa go fitlha go ditokololo tse pedi kgotsa go feta di se na go dutla.

Kwa e leng gore digatsetsamadi ga di bonale motlhofo, go ka tlhophiwa go dirisa selekanyo se se kwa tlase sa prophylaxis e fiwa kgapetsa-kgapetsa. Gore go kgonagale gore batho ba le bantsi ba fitlhelele kalafi, go ka nna botlhokwa gore go dirwe ditshekatsheko tsa go bona gore kalafi e e tlhwatlhwa e kwa tlase ke e fe gore go bonwe kalafi e e ntshang maduo mme e se tlhwatlhwa e kwa godimo, se se ka thusa gore batho ba bantsi ba bona kalafi.

Ga go ise go tlhomamisege gore a balwetse botlhe ba tshwanetse go dirisa prophylaxis ba sa emise fa ba ntse ba gola. Le fa gone dingwe dipatlisiso di supa gore bagolo bangwe ba dingwaga tse di kwa tlase ba kgona go tshela sentle go sena prophylaxis, go tlhokafala dipatlisiso tse di oketsegileng pele ga go ka tsewa tshwetso e e maleba.Go le gantsi balwetse ke bone ba itseelang tshwetso ya gogore a ba tla tselelela kgotsa ba tla emisa go tsaya prophylaxis.

DIKGORELETSI LE DIKGWETLHO

Tlhwatlhwa le Bokgoni jwa go fitlhelela kalafi

Sekgoreletsi se se tona sa prophylaxis ya sebaka se se leele ke tlhwatlhwa ya yone. Prophylaxis e ka kgonega fela fa tlhokomelo hemophilia e ka fiwa ditlamelo tse di lekaneng. Le fa go ntse jalo, e thusa go fokotsa ditshenyegelo ka gore e fokotsa ditlhwatlhwa tsa go tlhokomela ditokololo tse di golafetseng ebile e tokafatsa boleng jwa botshelelo.

Go botlhokwa go kgobokanya bosupi jo bo tlhomamisitsweng ke baitsaanape jo bo supang mabaka a go tura ga kalafi, le mo mafatsheng a a nang le ditlamelo tsa kalafi ya hemophilai e e tiileng ebile gona le lenaneo la prophylaxis le le tlhomameng tota.

Mo mafatsheng a metswako ya digatsetsamadi e sa bonaleng thata, bontsi ja balwetse ga ba kgone go bona prophylaxis. Le fa go ntse jalo, mafatshe mangwe a simolotse go dirisa selekanyo se se kwa tlase sa prophylaxis mo baneng. Kitso go tswa mo balwetseng ba e botlhokwa thata go tlhomamisa maduo a yon emo ditokololong tsa bone. Balwetse le badiri ba botsogo ba tshwanetse go bereka mmogo go buelela gore go nne le thulaganyo ya botlhe ya tlhokomelo ya ba ba nang le hemophilia le gore go rekwe metswako ya digatsetsamadi e e lekaneng.

Go fetola ditshetlana tsa tsamaiso e jaaka go fa balwetse selekanyo se se kwa tlase sa metswako ya digatsetsamadi kgapetsakgapetsa go ka thusa Go botlhokwa go dira dipatlisiso tse maikaelelo a tsone e leng go bona selekanyo se se ko tlase se se ka fiwang gore batho ba bone kalafi ya prophylaxis lefatshe ka bophara.

Go kgona go tsenya molemo ka ditshika

Prophylaxis ke kalafi e e tlhokang go kentiwa ga molwetse kgapetsa-kgapetsa, ka jalo go kgona go nna dingalo go bona tshika e e tshwanetseng mo baneng ba bannye thata ba ba nang le hemophilia.

Go dirisa sedirisiwa sa sennela ruri se se tsenngwang mo tshikeng (sekai

Port-A-Cath) go ka tlhofofatsa go fa bana ba bannye prophylaxis. Le fa go ntse jalo, go na le borai jwa go dirisa sedirisiwa seno mo go akaretsang go ka tsenwa ke megare fa go tlhabilweng teng ga mmogo le go ipopa ga letlhole la madi mo go ka bakang go thibana ga sedirisiwa se. Diphatsa tsa go nna jalo di tlhoka go sekasekwa go tshwangtshangwa le mosolawa go simolola prophylaxis e e tseneletseng go santse go na le nako. Mo baneng ba le masome a supa mo lekgolong (70%), prophylaxis e a kgonega go sa dirisiwe mokento o o tsennngwang mo ditshikeng. Go botlhokwa go tlhopha go simolodisa prophylaxis gangwe mo bekeng ka gore ga go tlhoke gore go tsennngwe sedirisiwa sa mo tshikeng sa Port-A-Cath, se se dirang gore kalafi e e nne motlhofo le go amogelwa ke balwetse le ba malapa a bone.

Go sala ditaelo tsa babotsogo morago

Go sala morago (kgotsa go ngaparela) thulaganyo e e dirilweng ya kalafi go tlhalosiwa e le ka fa molwetse tsayang melemo le kalafi jaaka a laetswe ke ba botsogo. Go ya ka la lekgotla la botsogo la mafatshefatshe (World Health Organisation), dipalo tsa batho ba ba sa tseyeng melemo le kalafi jaaka ba laetswe di magareng ga lesome le botlhano mo lekgolong (15%) le masome a robabongwe mo lekgolong (93%) fa bontsi bo wela mo palong ya masome a matlhano mo lekgolong (50%)

Gore prophylaxis e bereke sentle, go tlhoka gore go salwe ditaelo tsa ba botsogo morago. Prophylaxis e ntsha maduo fa e le gore segatsetsamadi se nna se le mo selekanyong se se beilweng kgotsa fa godimo. Go tlovisa kgotsa go emisa ka nakwana go ka dira gore selekanyo sa segatsetsamadi se wele kwa tlase, mme se sa oketsa kgonagalo ya go dutla madi. Go dutla madi ga molwetse ale mo kalafing ya prophylaxis go bitswa “breakthrough” (go dutla madi mo go itlelang fela nako nngwe le nngwe)

Balwetse le ba botsogo ba tshwanetse go bereka mmogo go tlhomamisa gore ditshetlana tse di dirisiwang ke tse molwetse le ba lelwapa la gagwe ba ka kgonang go di sala morago. Go sala ditaelo morago ga molwetse go tshwanetse ga sekasekwa ka nako tsotlhe fa a etetse kwa kokelwaneng le ditsela tsea ka tokafatsang seo ka tsone, go akaretsa go fetola ditshetlana

fa go tlhokega.

Go bona tshedimosetso e e oketsegileng ka hemophilia, etela website ya World Federation of Hemophilia: www.wfh.org



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