

[isiXhosa]

Le ncwadana iyafumaneka nakwezinye iilwimi. Nceda buza nokuba ngubani ofumene lencwadana kuye, okanye fowunela u-447-9593.

Ingaba intombi yakho imfutshane kakhulu kunabanye abantwana abazintanga zayo?

Ingaba wayenezandla nenyawo ezidumbileyo xa wayezalwa?

Ingaba unesikhumba esongezelelweyo kumacala omabini entamo yakhe?

Ukuba umtsha, ingaba ukhule amabele mva okanye awakhange akhule kwakukhula?

Ingaba akakhange aqale kwixesha lokuhlamba okanye usuke wayeka?

Ingaba umfutshane kunamanye amabhinqa?

Ingaba awukhange ukwazi ukukhula amabele okanye uqale ixesha lokuhlamba ngexesha elinye njengamanye amantombazana?

Ingaba ukhule amabele waqalisa ukuhlamba, kodwa ukuhlamba kwakho kwayeka xeshikweni wawuselibhinqa elisakhulayo?

Ingaba okanye ube unaso isikhumba esongezelelweyo macala omabini entamo yakho?

Ingaba uyifumanise inzima into yokumitha?

Ukuba impendulo yakho iyavuma kuyo nayiphi na imibuzo kule, okanye intombi yakho inokuguquka kwento engamanga kakuhle emzimbeni (iTurner Syndrome). Nokuba kukuphela kwezinye zeempawu ezikhoyo, wena okanye intombi yakho nisenokuba nineTurner Syndrome. Thabatha lencwadana uyenayo kwisibhedlela sakho sasekuhlaleni okanye kugqirha, kwaye ucebise ukuba uvavanyo malenziwe ukulungiselela imeko enje ngale..

Ingaba kutheni kufuneka wenze uvavanyo?

Uvavanyo lulula. Lubandakanya ukutsalwa kwegazi elincinci ngobuninzi, eliza kuthi livavanywe ngaphezu kweveki ezintathu..

Ukuba wena okanye intombi yakho ineTurner Syndrome, kungcono kakhulu ukwazi. La mabhinqa ayaphila njengaye nabani na ongomnye. Angaphila ngokugqibeleleyo ubomi obuqhelekileyo..

Kodwa afuna ukuhlolwa ngenyameko ngugqirha owaziyo malunga nesiphazamisi. Oku kungenxa yala mantombazana namabhinqa anokuba sengozini yemeko zonyango ezithile –zonke zinokulawulwa zinyangwe Kodwa oogqirha bafuna ukwazi ukuba fanele bazihlole ezi.

Ingaba yintoni ezidalayo?

ITurner Syndrome ibangelwa yingozi encinane endalweni. Intombazana enye kwayi-2 500 iba nale meko.

Ilungu ngalinye lomzimba wakho lenziwe ngezigididi zeeseli ezincinane. Ngaphakathi kwiseli nganye kunemisontwana esesibindini seseli yomntu ekuxhomekeke kuwo ubunjani bakhe. Umsontwana osesibindini seseli yomntu ekuxhomekeke kuwo ubunjani bakhe uvelise icebo lomntu ngamnye. Basenza sifane sonke ngendlela ezininzi, kodwa bakwenza ngamnye abeyedwa.

Phakathi kwemisontwana esesibindini seseli yomntu ekuxhomekeke kuwo ubunjani bakhe yimisontwana esesibindini seseli yomntu ekuxhomekeke kuwo ubunjani bakhe besini. Ezi ziqinisekisa ukuba sikhula njengebhinqa okanye indoda. Amadoda anomisontwana osesibindini seseli yomntu ekuxhomekeke kuwo ubunjani bakhe engu-X no-Y, ngexa amabhinqa eno-X nomnye u-X.

Amantombazana aneTurner Syndrome azalwa eno-X omnye uphela. Oku akwenzi ubani oneTurner Syndrome abe ngahantsi kwebhinqa. Ayafana namanye amabhinqa.

Ingaba sisiphene sakho?

Hayi, ayisosiphene sakhe nabani na . Sidla ngokungadluliswa nangabazali. Xa umntwana esakhula eqandeni eligalelwa isichumiso siba yinto engekazalwa esibelekweni sikanina, iiseli zomntwana okhulayo zilahla u-X omnye okanye ilungu lika-X. Umntwana uyaqhubekeka ukhulisa iiseli ezino-X omnye kuphela

Ukuba iiseli zilahla kuphela u-X emveni kokuba umntwana eqalise ukukhula, zezinye kuphela iiseli zakhe ezinokuchaphazeleka. Emveni koko kuthiwa inendlela yemoziyakhi yeTurner Syndrome kwaye mhlawumbi ayizukonakaliswa kakhulu njengamantombazana aneTurner Syndrome egcweleyo kwaye

Le meko yenzeka kuphela kumantombazana ngenxa yokuba wonke umntu ufuna ubuncinane u-X omnye ukuze aphile. Ukuba iseli zomntwana oyinkwenkwe zilahla u-X, uza kushiyeke no-Y kuphela. Uya kufa ngaphambi kokuba azalwe.

Ingaba kuthetha ukuthini ukuba neTurner Syndrome?

- Amabhinqa aneTurner Syndrome adla ngokuba mafutshane kakhulu kunamanye amabhinqa. I-avareji yobude bebhinqa elineTurner Syndrome yi-143 yeesentimitha (4ft 8in). Angaba mfutshane okanye abemdana kunoku, kuxhomekeke kubude babazali bakhe Ukukhula kwencindi yedlala kungenza lamantombazana abe madana, kwaye angashenxisa ubude bawo bube kuluhlu oluqhelekileyo ukuba baphendula kakuhle. Olu lunyango oluduru kwaye alunikezelwa kwiTS zizibhedlela zamaphondo. Kodwa amanye amancedo onyango ayalubhatalela. Buza ugqirha wakho akubhekiselele kwi-endokrinolojisti esibhedlela okanye kumsebenzi wabucala, ukubuza malunga nolunyango. Nokuba lamantombazana asemancinci, anokuphila asebenze ngempumelelo njengabanye abantu
- Izizalo zawo, ezivelisa iincindi zamadlala eziwenza angene kwixesha lokufikelela ebudaleni, zidla ngokukhawuleza ukuyeka kwangoko ebomini. Anganikwa incindi ezithe ngqo ukukhula njengamabhinqa. Ezi zifanele ukumiselwa kuphela ngugqirha owaziyo ngemeko. Amabhinqa amaninzi aneTurner Syndrome ngamadlolo. Fanele axoxe ngamalungelo okunyula wawo noogqirha bawo okanye iqela lokuxhasa (jonga iinkcukacha zokunxibelelana)

- Amantombazana namabhinqa aneTurner Syndrome angaba neziphene zentliziyo, zezinto neengxaki zothungelwano lwamalungu okuchama. Bangakhula nesifo seswekile okanye babe namanqanaba .asezantsi kakhulu ethiroyidi. Zonke ziyanyangeka.
- Amabhinqa amaninzi aneTurner Syndrome aba nobunzima obugqithisileyo. Kufanele axoxe iindlela zawo nogqirha babo. Fanele batye ukutya okunempilo basoloko beziqhelanisa rhoqo.
- La mabhinqa angaba nentloni kwaye athule, kuba kusoloko kuqulwa ngobungakanani bawo. Ingxaki yokukhula kwawo ingawenza angonwabi okanye adakumbe. Kungakhokelela kwingxaki zokuziphatha kumantombazana amatsha. Ezi zinto fanele zixoxwe nogqirha okanye iqela elixhasayo. Zingabhekiselelwa kumfundi negcisa lesayikholoji okanye unontlalontle.
- La mantombazana anokuhlakanipha okuqhelekileyo. Angenza kakuhle esikolweni njengaye nawuphi na umntwana. Kodwa abaninzi bayasilela kwezinye iinzima zokufunda. Loo nto ingenza nzima ukubhala ngokucocekileyo okanye ngokukhawuleza njengabanye abantwana. Bangakufumana kunzima ukunyamekela umsebenzi wesikolo, kwaye bangafumanisa izibalo zinzima. Asingawo onke amantombazana aneTurner Syndrome anezingxaki. Angalawuleka ngokufundiswa okulungileyo nangezinye iindlela. Xoxani ezi zinto nogqirha wakho, ootitshala neqela elixhasayo.

Ingaba iQela eliHlangannisayo leTurner Syndrome lenza ntoni?

Sinikeza ngolwazi nenkxaso kumantombazana namabhinqa aneTurner Syndrome kwakunye neentsapho zawo. Sizama ukwandisa ukuqonda nokuvelisa incwadi ethunyelelwa amalungu athile ukudibanisa amalungu ethu. Silapho ngokunikezela ngeengcebiso kwimeko nakucebiswano labantu xa befuna. Nabani na angaba lilungu.

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Ucetyiswano lwemvelo lungakunceda uqonde le meko. Kumahala kwabo bangenawo amancedo onyango. Iikliniki zisesibhedlela saseJohannesburg, eBaragwanath, esibhedlela iCoronation nakwiZiko loNyango iDonald Gordon. Izigqibo zokudibana zingenziwa kuZain kwa- 27-11-489 9224 okanye zain.jakoet@nhls.ac.za.

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