

Uvavanyo Lwezonyango



I-STEER OAV101B12301 Ishedyuli noMcwangcisi

**Lwabantwana abaneminyaka emi-2 ukuya
ngaphantsi kweli-18 abaNohlobo 2 lwe-
spinal muscular atrophy (i-SMA)**

Enkosi ngokujoyina uPhononongo lwe-STEER.

Olu phononongo luphanda unyango lwemfuza olubizwa nge-OAV101 ukubbona ukuba lukhuselekile nokuba lungaphucula iimpawu nentshukumo kubantwana abaneminyaka emi-2 ukuya ngaphansti kweminyaka eli-18 abaNohlobo 2 lwe-SMA.

Le ncwadana ichaza ngoko kuza kwenzeka kutyelelo lophononongo. Iphinde ibe nesithuba sokuba ubhale amadinga ocwangciso nolwazi oluluncedo. Kubalulekile ukuba umntwana wakho azimase lonke utyelelo lophononongo ukuze ugqirha akwazi ukubeka iliso kwimpilo yakhe kwaye aqonde ukuba i-OAV101 inokuwuchaphazela njani umzimba womntwana wakho.

Uthatho-nxaxheba lwakho lwaziswa kakhulu. Umntwana wakho usenokuzuza okanye angazuzi ngokungqalileyo ngokuba kolu phononongo, kodwa ulwazi olufundiweyo lunokunceda abanye abantwana abane-SMA kwixesha elizayo.

Njengawo onke amayeza, kukho ithuba leziphumo ezingalindelekanga. Umntwana wakho uza kubekwa iliso ngokusondeleyo ebudeni balo lonke uphononongo.

Iqela lophononongo liza kukonwabela ukuphendula nayiphi na imibuzo onayo. Khumbula, ukuthatha inxaxheba kwenziwa ngokuzithandela kwaye wena okanye umntwana wakho ningakhetha ukulushiya uphononongo nanini na.

Ngombulelo omkhulu,

Iqela loPhononongo lwe-STEER

Ixesha lophononongo kunye notyelelo

Umntwana wakho uza kuba kuphononongo ukusa kwiiveki elingama-72 (malunga neenyanga ezili-17) kwaye abe namatyelelo angama-29 ukuze kuhlolwe impilo neemvavanyo. Uninzi lotyelelo lophononongo lunokuthatha ukusa kwiiyure ezi-6 kuxhomekeka kwini lohlobo leemvavanyo.

Umntwana wakho uzophinde ahlale esibhedlela izihlandlo ezi-2 xa efumana unyango.

Uhlolo

Ukuya kwiintsuku ezingama-60 |
Ubuncinane bamatyelelo ama-2

Isiseko (ukuqalisa kophononongo)

Usuku olu-1 ngaphambi kokuqalisa konyango |
utyelelo olu-1

Ixesha 1 Lonyango

Ukuhlala esibhedlela

Ixesha 1 Lolandelelo

liveki ezingama-52 (unyaka om-1) | amatyelelo ali-18

Ixesha 2 Lonyango

Ukuhlala esibhedlela

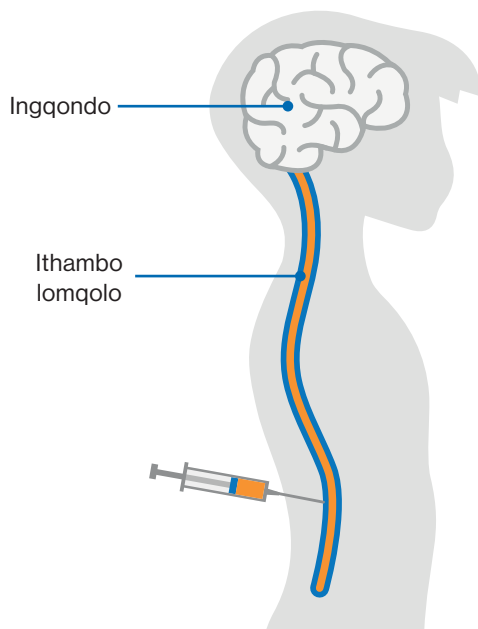
Ixesha 2 Lolandelelo

liveki ezili-12 (iinyanga ezi-3) | amatyelelo asi-8

Ekupheleni kophononongo, umntwana wakho uza kuba nokhetho lokubhalisela uphononongo lolandelelo lwexesha elide apho impilo yomntwana wakho iza kubekwa iliso iminyaka eli-15 eyongezelekileyo.

Uphononongo lonyango

I-OAV101 inikelwa njengenaliti isihlandlo kube kanye kwinxalenye engezantsi yomqolo. Lento ibizwa **ngesitofu se-intrathecal**.



Amaqela ophononongo lonyango

Umntwana wakho uza kwabelwa ngokungacwangciswa ukufumana enoba yi-**OAV101** okanye **“inkqubo ye-sham.”** Awuzokwazi ukuba umntwana wakho ufumana oluphi unyango.

Inkqubo ye-sham ukuhlatywa ngenaliti kumqolo osezantsi. I-OAV101 ayitofwanga. Kubalulekile ukuba wenze inkqubo ye- sham ukuze iqhataniswe ne-OAV101 ukuze oogqirha baqonde bhetele uchaphazeleko lwe-OAV101.

Zombini isitofu se-OAV101 nokuhlatywa nenkqubo ye-sham zenzizwa esibhedlela apho umntwana wakho aza kuhlala khona ubusuku bonke iintsuku ezimbalwa.

Utyelelo lokuhlola

Utyelelo 1

Umhla: _____ Ixesha: _____

Utyelelo 2

Umhla: _____ Ixesha: _____

Ngaphambi kokuqala uphononongo, kuya kufuneka unikele ngemvume ukuze umntwana wakho ajoyine uphononongo ngokufunda nangokusayina **iFomu yeMvume enoLwazi**. Ngokuxhomekeka kwiminyaka yakhe, abanye abantwana basenokunikela ngemvume ngokwabo ngokutyikitya **iFomu yeMvume enoLwazi**.



Ugqirha wophononongo uza kuqokelela ulwazi aze enze iimvavanyo ukuqinisekisa ukuba uphononongo lulungele umntwana wakho kusini.

Uxilongo lwezempilo kunye neemvavanyo



Uvavanyo lwegazi



Ubunzima bomzimba



Uvavanyo lokuphefumla



Ukulinganiswa kwentloko



Umsebenzi wentliziyo



Umfanekiso wentliziyo



Ubude



Imbali yezonyango



Uhlolisiso lweyeza



Ukuhlola impilo yengqondo*



Isakhono sentliziyo



Uxilongo lwemithambo-luvo



Uxilongo lomzimba



Uvavanyo lokuginya



Uvavanyo lomchamo



Iimpawu ezibalulekileyo



Ubunzima



I-X-ray

*Ukuhlolwa Kwempilo Yengqondo kunokungasebenzi (kwabaneminyaka esi<7)

Utyelelo olusisiseko (Ukuqalisa kophononongo)

Utyelelo 1 Umhla: _____ Ixesha: _____

Umntwana wakho uza kufumana i-steroid (i-prednisolone) okanye usingayeza iiyure ezingama-24 ngaphambi kokufumana uphononongo lonyango, kuxhomekeka ukuba ukuba ukweliphi iqela.

Uxilongo lwezempilo kunye neemvavanyo

				
Uvavanyo lwegazi	Ubunzima bomzimba	Uvavanyo lokuphefumla	Ukulinganiswa kwentloko	Umsebenzi wentliziyo
				
Ubude	Uhloosiso lweyeza	Isakhono sentliziyo	Ukubeka iso intshukumo*	Iswabhu yempumlo
				
Uxilongo lwemithambo-luvo	Uxilongo lomzimba	Uvavanyo lwamathe	Uvavanyo lwelindle	Uvavanyo lokuginya
				
Uvavanyo lomchamo	Iimpawu ezibalulekileyo	Ubunzima		

*Abanye abathathi-nxaxheba basenokunikwa isixhobo esifana newotshi yesihlahla egcina intshukumo. Sona siza kunxitywa ekhaya.

Ixesha lonyango (Ukuhlala esibhedlela)

Umhla: _____ Ixesha: _____

Umntwana wakho uzofumana i-OAV101 okanye inkqubo ye-sham esibhedlela nobusuku bonke iintsuku ezimbalwa.

Uxilongo lwezempilo kunye neemvavanyo



Uvavanyo lwegazi



Uhlolisiso lweyeza



Iswabhu yempumlo



Uxilongo lwemithambo-luvo



Uxilongo lomzimba



Uvavanyo lwamathe



Inaliti yethambo lomqolo



Uvavanyo lwelindle



Uvavanyo lomchamo



Iimpawu ezibalulekileyo



Ubunzima

Umntwana wakho uza kuqhubeka nokubekwa iliso ebudeni balo lonke uphononongo ngayo nayiphi imiphumela engalindelekanga kwiyeza lophononongo.

Ixesha 1 Lolandelelo (unyaka om-1)

Ebudeni beli xesha, umntwana wakho uza kuba namatyelelo ali-18 eemvavanyo: kube kanye ngeveki kwinyanga yokuqala, kanye qho eevекini ezi-2 ukususela kwiiveki 5 ukusa kwi-12, kuphinde kube kanye qho eevекini ezi-4.

Umntwana wakho akazokwenziwa lonke uvavanyo kutyelelo ngalunye.

Uxilongo lwezempilo kunye neemvavanyo

				
Uvavanyo lwegazi	Ubunzima bomzimba	Uvavanyo lokuphefumla	Umsebenzi wentliziyo	Umfanekiso wentliziyo
				
Ubude	Uphuculo lwengqaku	Uhlolisiso lweyeza	Ukuhlolwa impilo yengqondo**	Isakhono sentliziyo
				
Ukubeka iso intshukumo*	Iswabhu yempumlo	Uxilongo lwemithambo-luvo	Uxilongo lomzimba	Iphepha lemibuzo
				
Uvavanyo lwamathe	Uvavanyo lwelindle	Uvavanyo lokuginya	Uphawu lwengqaku	Uvavanyo lomchamo
				
Iimpawu ezibalulekileyo	Ubunzima	I-X-ray		

Umntwana wakho uza kuqhubeka nokubekwa iliso ebudeni balo lonke uphononongo ngayo nayiphi imiphumela engalindelekanga kwiyeza lophononongo.

*Abanye abathathi-nxaxheba basenokunikwa isixhobo esifana newotshi yesihlahla egcina intshukumo. Sona siza kunxitywa ekhaya. **Ukuhlolwa kwempilo yengqondo kusenokungasebenzi ebantwaneni abangaphantsi kweminyaka esi-7.

Ixesha 1 Lolandelelo

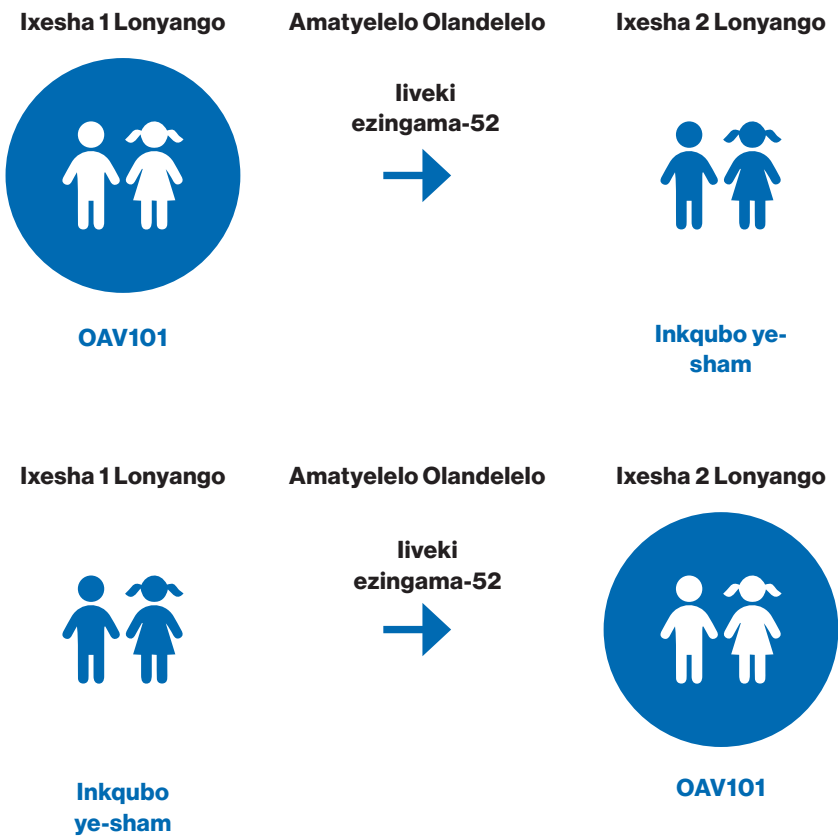
(amatyelelo ali-18)

Sebenzisa itshati engezantsi ukuze ubhale phantsi ucwangciso lotyelelo lomntwana wakho nolwazi olubalulekileyo ukuze wabelane ngalo ngogqirha wophononongo.

Tyelela	Iveki	Ucwangciso lomhla/ixesha	Amanqaku nezikhumbuzo
1	1		
2	2		
3	3		
4	4		
5	6		
6	8		
7	10		
8	12		
9	16		
10	20		
11	24		
12	28		
13	32		
14	36		
15	40		
16	44		
17	48		
18	52		

Ixesha 2 Lonyango

Emva kokugqiba unyaka om-1 wolandelelo lotyelelo, umntwana wakho uza kuhlolwa impilo izihlandlo embalwa ukuqinisekisa ukuba uyakufanelekela ukungena kwiXesha 2 Lonyango. Abantwana abafanelekayo abafumene i-OAV101 ebudeni beXesha 1 Lonyango baza kwenza inkqubo ye-sham kwiXesha 2 Lonyango. Abantwana abafanelekayo abafumene inkqubo ye-sham ebudeni beXesha 1 Lonyango ngoku baza kufumana i-OAV101.



Ixesha 1 Lonyango (Ukuhlala esibhedlela)

Umhla: _____ Ixesha: _____

Umntwana wakho uza kufumana i-OAV101 okanye inkqubo ye-sham esibhedlela kwaye uza kuhlala ubusuku bonke iintsuku ezimbalwa.

Uxilongo lwezempilo kunye neemvavanyo



Uvavanyo lwegazi



Uhlolisiso lweyeza



Iswabhu yempumlo



Uxilongo lwemithambo-luvo



Uxilongo lomzimba



Uvavanyo lwamathe



Inaliti yethambo lomqolo



Uvavanyo lwelindle



Uvavanyo lomchamo



Iimpawu ezibalulekileyo



Ubunzima

Umntwana wakho uza kuqhubeka nokubekwa iliso ebudeni balo lonke uphononongo ngayo nayiphi imiphumela engalindelekanga kwiyeza lophononongo.

Ixesha 2 Lolandelelo (iiveki ezili-12)

Ebudeneni beli xesha, umntwana wakho uza kuba namatyelelo asi-8 eemvavanyo: kube kanye ngeveki, aphinde kanye rhoqo eevekini ezi-2. Umntwana wakho akazokwenziwa lonke uvavanyo kutyelelo ngalunye.

Uxilongo lwezempilo kunye neemvavanyo



Uvavanyo lwegazi



Ubunzima bomzimba



Umsebenzi wentliziyo



Umfanekiso wentliziyo



Ubude



Uphuculo lwenqaku



Uhlolisiso lweyeza



Ukuhlolwa impilo yengqondo**



Isakhono sentliziyo



Ukubeka iso intshukumo*



Iswabhu yempumlo



Uxilongo lwemithambo-luvo



Uxilongo lomzimba



Iphepha lemibuzo



Uvavanyo lwamathe



Uvavanyo lwelindle



Uvavanyo lokuginya



Uphawu lwenqaku



Uvavanyo lomchamo



Iimpawu ezibalulekileyo



Ubunzima

*Abanye abathathi-nxaxheba basenokunikwa isixhobo esifana newotshi yesihlahla egcina intshukumo. Sona siza kunxitywa ekhaya.

**Ukuhlolwa kwempilo yengqondo kusenokungasebenzi kubantwana abangaphantsi kweminyaka esi-7.

Ixesha 2 Lolandelelo (amatyelelo asi-8)

Sebenzisa itshati engezantsi ukuze ubhale phantsi ucwangciso lotyelelo lomntwana wakho nolwazi olubalulekileyo ukuze wabelane ngalo ngogqirha wophononongo.

Tyelela	Iveki	Ucwangciso lomhla/ixesha	Amanqaku nezikhumbuzo
1	53		
2	54		
3	55		
4	56		
5	58		
6	60		
7	62		
8	64		

linkcukacha zoqhagamshelwano zophononongo

Igama logqirha wophononongo:

Inombolo yomnxeba:

Igama lomlungelelanisi wophononongo:

Inombolo yomnxeba:

I-imeyile:

Qhagamshela iqela lophononongo ukuba unayo nayiphi imibuzo okanye udinga ukucwangcisa idinga kwakhona.

Uluhlu lwamagama



Uhlolo lwegazi: lisampuli zegazi ziza kuthathwa ukuze kujongwe iiseli zegazi nokuba lenza ntoni iyeza lophononongo ngaphakathi emzimbeni. lisampuli zegazi zinokulinganisa ukuba lingakanani iyeza lophononongo elisemzimbeni nokuba linokuchaphazela njani ezinye iinxalenye zomzimba. Abathathi-nxaxheba abasele besiya exesheni bazotsalwa igazi ukuze bavavanyelwe ukukhulelwa.



Ubunzima bomzimba: Ugqirha wophononongo uzobala ukuba mangakanani amafutha emzimbeni womntwana wakho ngokunxulumene nobude nobunzima bakhe.



Uvavanyo lokuphefumla: Umntwana wakho uza kuphefumlela kwityhubhu encanyatheliswe kwikhompyutha ukuze kulinganiswa ukuba ungakanani umoya akwaziyo ukuwutsala nokuwukhupha emiphungeni yakhe nokuba uwukhupha ngokukhawuleza kangakanani umoya emiphungeni yakhe.



Ukulinganiswa kwentloko: Iqela lophononongo liza kusongela iteyiphu yokulinganisa enwebenkayo entlokweni yomntwana wakho ukubona ukuba inkulu kangakanani intloko yomntwana wakho.



Umsebenzi wentliziyo: Uvavanyo olulula olubizwa nge-electrocardiogram (ECG) luza kusetyenziswa ukuhlola umsebenzi wombani (isigqi) entliziyweni yomntwana wakho. Kolu vavanyo, umntwana wakho uya kungqengqa kwaye iipads ezincinci, ezincangathi (ii-electrode) ziya kuncamathiselwa esifubeni sakhe. Iiphedi zidiyaniswe namacingo zaxhunyuwa kwikhompyutha.



Umfanekiso wentliziyo: Uvavanyo olungaqaqambi olubizwa nge- echocardiogram isebenzisa amaza esandi ukubona indlela empompa ngayo intliziyo yomntwana wakho nokubetha kwaye ngaphathi emzimbeni.



Ubude: Ugqirha wophononongo uza kusebenzisa iteyiphu yokulinganisa alinganise ubude bomlenze womntwana wakho (ukususela edolweni ukuya kwiquakala) ukuze abale ukuba mde kangakanani umntwana wakho.



Inqaku lempucuko: Iqela lophononongo liza kusebenzisa inkqubo yokufumana amanqaku ukuze lilinganise enoba iphucuka njani i-SMA yomntwana wakho.



Imvume eyazisiweyo: Ukuba uyavuma ukuba umntwana wakho ajoyine uphononongo, uotyikitya iifomu ukuze unikele ngemvume. Umntwana wakho unokunikela ngemvume yokujoyina ngokutyikitya ifomu yemvume.



Imbali yezonyango: Ugqirha uza kubuza imibuzo emalunga nempilo yomntwana wakho, kuquka ne-SMA yakhe nalo naluphi utyando akhe walwenza.

Uluhlu lwamagama



Uhlolisiso lweyeza: Ugqirha uza kukubuza imibuzo emalunga namayeza umntwana wakho awasebenzisayo ngoku okanye akhe wawasebenzisa kwixesha langaphambili.



Ukuhlolwa kwempilo yengqondo: Umntwana wakho (xa engaphezulu kobudala beminyaka esi-7) uzophendula eminye yemibuzo emalunga nemo nezimbo zakhe nokuba uziva edakumbile kusini.



Isakhono sentshukumo: Iqela lophononongo liza kujonga ukuba uzenza kakuhle kangakanani umntwana wakho iintshukumo ezithile. Baza kukunika umntwana wakho amanqaku ngokuya kwezakhono zomzimba wakhe.



Ukubeka iliso intshukumo: Abanye abathathi-nxaxheba baza kukhethwa ukuba banxibe isixhobo esiqaphela intshukumo yabo esihlahleni sabo ngoxa besekhaya ukuze kujongwe intshukumo yabo.



Iswabhu yempumlo: Ugqirha uza kuqokelela isampuli ngononophelo ngokukhuhla ngaphakathi kwempumlo yomntwana wakho ngeswabhu yekotini.



Uxilongo lwemithambo-luvo: Ugqirha wophononongo uza kuhlola ukuze abone ukuba iinxalenye ezohlukeneyo zomzimba womntwana wakho zivakalelwa kakuhle kangakanani.



Uxilongo lomzimba: Ugqirha uza kuxilonga iinxalenye ezohlukeneyo zomzimba womntwana wakho, njengentliziyo, imiphunga, imisipha, nesisu.



Iphepha lemibuzo: Njengomnakekeli womntwana wakho, uzofumana iphepha lemibuzo emalunga nendlela i-SMA echaphazela ngayo ubomi bomntwana wakho bemihla ngemihla.



Uvavanyo lwamathe: Umntwana wakho uza kukhafulela ekomityini kwaye isampuli iza kuvavanywa ukuze kubonwe ukuba inoba lenza ntoni iyeza ngaphakathi emzimbeni womntwana wakho.



Inaliti yethambo lomqolo: Isixa esincinci sencindi endaweni ejikeleze ithambo loqolo womntwana wakho iza kususwa kusetyenziswa inaliti encinci. Incindi yethambo lomqolo iza kuvavanywa ukuze kubonwe ukuba umzimba womntwana wakho usabela njani kunyango.



Uvavanyo lwelindle: Isampuli encinci yelindle lomntwana wakho iza kuthathwa ize ivavanywe ukubona enoba lwenza ntoni unyango ngaphakathi emzimbeni.



Uvavanyo lokuginya: Ingcali iza kujonga ukuba umntwana wakho utya aze aginye kakuhle kangakanani.



Inqaku lempawu: Iqela lophononongo liza kusebenzisa inkqubo yokufumana amanqaku ukuze liliganise iimpawu omntwana wakho ze-SMA nokuba isichaphazela njani isakhono sakhe sokwenza imisebenzi yemihla ngemihla.



Uvavanyo lomchamo: Isampuli yomchamo womntwana wakho iza kuvavanyelwa izinto ezithile ezifana neswekil, iprotheni negazi. Amantombaza asele eqalise ukuya exeshen nawo aza kuvavanywa igazi ukuze kujongwe ukuba akakhulelwanga kusini.



Iimpawu ezibalulekileyo: Ugqirha wophononongo uzohlola iqondo lobushushu lomntwana wakho, izinga lokuphefumla, izinga lentliziyo (isigqi), nomfutho wegazi ukuze abone ukuba impompa njani intliziyo yomntwana wakho.



Ubunzima: Ugqirha wophononongo uza kulinganisa ubunzima bomntwana wakho esikalini ngaphandle kwezihlangu ngoxa enxibe impahla elula. Kukho umntu ozokunceda ukuba ume esikalini aze akubambe ngoxa elinganiswa ubunzima.



I-X-ray: I-x-ray isetyenziselwa ukuthatha imifanekiso emnyama nemhlophe yangaphakathi emzimbeni. Umntwana wakho uza kwenziwa i-x-ray esifubeni sakhe nasemqolo.

Amanqaku nezikhumbuzo

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This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

