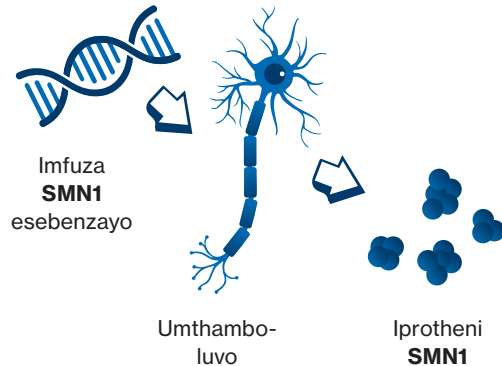


## Yintoni injongo yoPhononongo lwe-STEER?

Injongo Yophononongo lwe-STEER kukuqonda enoba uphando **lonyango lwemfuza OAV101** lukhuselekile kusini kwaye luokuba nenzuzo kubantwana bobudala beminyaka emi-2 ukuya ngaphantsi kweminyaka eli-18 Abanohlobo 2 SMA.

I-OAV101 lunyango lwemfuza oluqulethe ikopi esebenzayo yemfuza ye-**SMN1** edingwa yimithambo-luvo ukuze yenze iprotheni ye-SMN. Usukelo kukuba konyuswe isixa seprotheni ye-SMN ukuze kuthintelwe naluphi na uphulikano lwemithambo-luvo.



## Enkosi ngokucingela uphononongo lwe-STEER

Uphononongo lwezonyango luziintlobo zophononongo lophando ezenzelwe ukufunda nakumbi malunga nendlela umzimba osabela ngayo kwichiza elithile ngokukhethekileyo okanye kwimeko yezonyango.

Umntwana wakho usenokuzuzisa okanye angazuzi ngokungqalileyo ngokuba kolu phononongo, kodwa ulwazi olufundiweyo lunokunceda abanye abantwana abane-SMA kwixesha elizayo.

Ukuba kuphononongo lwezonyango kokokuzithandela. Wena nomntwana wakho ningayeka ukuthatha inxaxheba nanini na.

Ukuba unomdla wokufunda okungakumbi malunga Nophononongo lwe-STEER, qhagashela

ku \_\_\_\_\_

Uvavanyo Lwezonyango



## Ukuqonda Uphononongo lwe-STEER OAV101B12301

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

## Lolukabani uphononongo?

**Abantwana abaneminyaka emi-2 ukuya ngaphantsi kweminyaka eli-18 Abanohlobo 2 lwe-SMA aba:**

- Abakwaziyo ukuzihlalela ngaphandle koncedo kodwa abangazange bakhe bazihambela ngaphandle koncedo.
- Abaqala ukubonisa iimpawo ze-SMA ebudaleni beenyanga ezi-6 okanye ngaphazulu.
- Abangekafumani naluphi unyango olonyusa i-SMN.

## Kwenzeka ntoni ngexesha lophononongo?

Xa kufaneleka, umntwana wakho uza kuba kuphononongo ukuya kwiiveki ezingama-72 (malunga neenyanga ezili-17) kwaye abe notyelelo olumanjunga nama-29 ukuze avanyelwe impilo. Umntwana wakho uza kuphinda ahlale esibhedlela izihlandlo ezi- 2 ukuz afumane unyango.

### Uhlobo

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.

## Lunikezelwa njani uphononongo lonyango?

- I-OAV101 inikelwa njengenaliti isihlandlo kube kanye kwinxalenye engezantsi yomqolo. Lento ibizwa ngesitofu se-intrathecal.
- Umntwana wakho uza kufumana uphononongo lonyango esibhedlela kaye uza kuhlala ubusuku bonke iintsuku nje ezimbalwa.

### Ixesha 1 Lonyango

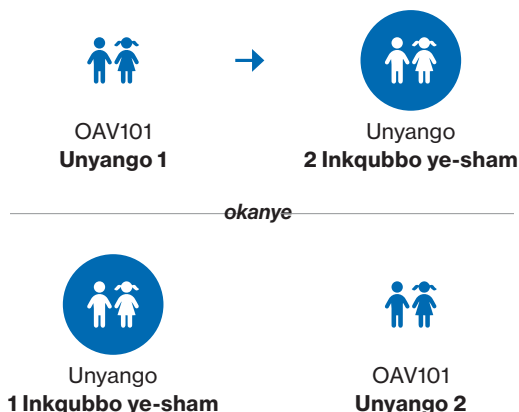
Umntwana wakho uza kwabelwa ngokungacwangciswanga ukufumana enoba yi- OAV101 okanye “inkqubo ye-sham.”

- Inkqubo ye-sham ukuhlatywa ngenaliti kumqolo osezantsi. Akukho yeza linikelwayo. Inkqubo ye-sham ibalulekile ukuze oogqirha baqonde bhetele imiphumo ye-OAV101 engalindelekanga.
- Wena nogqirha wophononongo ngekhe nazi ukuba umntwana wakho ukweliphi iqela. Oku kunceda ekugcineni uphononongo lunobulungisa kwaye lingenamkhethe.

### 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 abenze inkqubo ye-sham ngoxa bekuqhubeka Ixesha 1 baza kufumana i-OAV101 ngoku.
- Abantwana abafanelekayo abafumene i-OAV101 ngoku baza kufumana inkqubo ye-sham.



## Ntloboni yeemvavanyo eziza kwenziwa emntwaneni wam?



Uvavanyo lwegazi



Uvavanyo lokuphefumla



Umsebenzi wentliziyo



Umfanekiso wentliziyo



Umvavanyo yokusebenza komthambo-luvo



Uxilongo lwemithambo-luvo



Uxilongo lomzimba



Inaliti yethambo lomqolo



Uvavanyo lomchamo



I-X-ray

Umntwana wakho akayi kuzenza zonke ezi mvavanyo kutyelelo ngalunye. Kusenokubakho ezinye iimvavanyo ezongezelekileyo. Thetha nogqirha wophononongo wakho ukufumana ulwazi oluthe kratya.