IZINKOMBA NEZIMPAWU ZESIFO SE-GAUCHER

I-Gaucher iyisifo esiyimvelakancane esitholwa ngofuzo, esibangelwa ukuntuleka kwama-enzyme. Izimpawu ziyashiyana kusukela kwezimaphakathi kuya kwezinamandla futhi zingavela noma nini, kusukela ebunganeni kuya ekugugeni. Zingase zihlanganise ukuntuleka kwamaseli abomvu egazi (i-haemoglobin ephansi), ukukhathala (ukutubeka), ukulimala kalula kanye nomkhuba wokopha. Kungase kube khona ukuvuvukala kwesplini nesibindi kanye nokukhukhumala kwesisu, ubuthakathaka nokuba lula kwamathambo kanye nokuminyana okunengozi eyengeziwe yokuphuka.

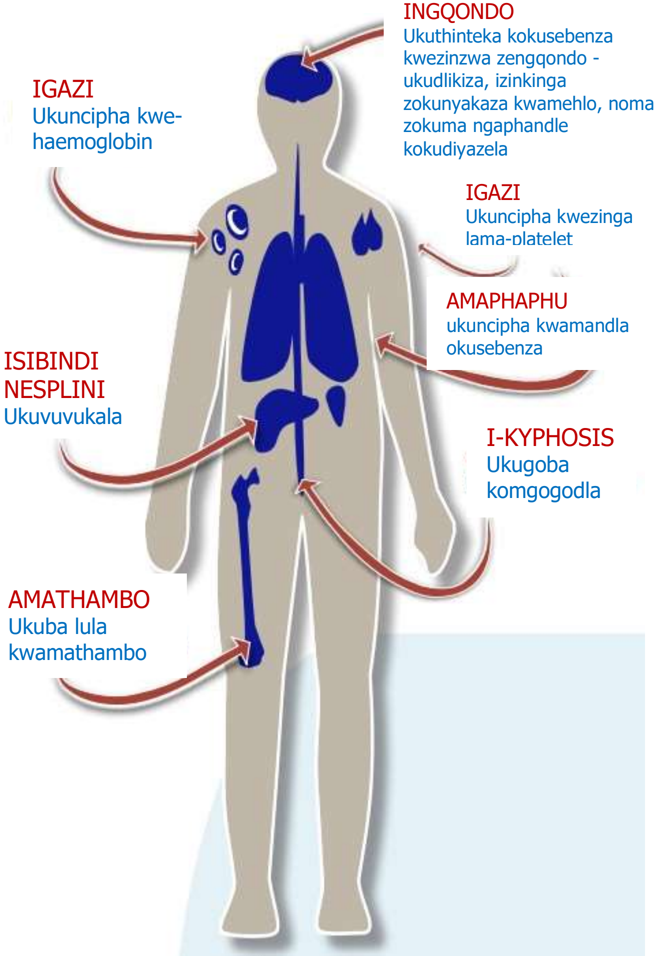
Abantu abanesifo se-Gaucher bantula ukusebenza kahle kwe-enzyme ebizwa ngokuthi i-glucocerebrosidase. Le enzyme isiza umzimba ukwazi ukuhlakaza amaseli asephelelwe amandla okusebenza, okubangela ukwakheka kokuthile okungamafutha okuthiwa i-glucocerebroside ngokuvamile kusplini, esibindini, emnkantsheni wamathambo, kwezinye izimo ezingavamile emaphashini kanti uma kunohlobo oluthile lwe-Gaucher ingahlasela nezinzwa zokusebenza kwengqondo nomgogodla.

Uhlobo 1 lwesifo se-Gaucher wuhlobo oluvame kakhulu oluhlasela o-1 kwabangu-100,000 emphakathini ovamile. Abantu abaningi abanohlobo lwesifo se-Gaucher 1 abanazo izimpawu futhi baphila ukuphila okuvamile.

Skena ukuze udawunilode ibhuku lethu elinolwazi olugcwele ukuze ufunde kabanzi noma uvakashele ku- bit.ly/gdinfor

Uhlobo 2 lwesifo se-Gaucher wuhlobo lwesifo se-Gaucher olungavamile, olubhebhetheka ngokushesha oluhlasela izinzwa zokusebenza kwengqondo nomgogodla kanye nesplini, isibindi, amaphaphu namathambo.

Uhlobo 3 lwesifo-Gaucher 3, noma isifo se-neuronopathic Gaucher esingelapheki, simaphakathi kohlobo 1 nohlobo 2. Iziguli ziphathwa yikho kokubili ukuhlaselwa kwezicubu zomzimba (amaphaphu, isibindi nesplini) kanye nezinzwa (ingqondo). Nokho, ukuhlaselwa kwezinzwa akubi namandla kakhulu kunasohlotsheni 2 lwesifo.



INTERNATIONAL GAUCHER DAY 1 OCTOBER

International Gaucher Alliance

Amandla olwazi ekutholakaleni ngesikhathi kwesifo Ukwakha ikusasa elingcono

IZINKOMBA NEZIMPAWU ZESIFO SE-GAUCHER

SITHOLWA KANJANI ISIFO SE-GAUCHER?

IGA INTERNATIONAL GAUCHER ALLIANCE
Driven by passion for patients

SITHOLWA KANJANI ISIFO SE-GAUCHER?

Inqubo yokuthola izifo eziningi, ikakhulukazi isifo se-Gaucher, ayivamile ukuba sobala.

Ngokuvamile, isiguli siya kobona udokotela ngenkinga ehlukile njengomkhuhlane, ubuhlungu obungaqondakali, noma ukwenza ukuxilongwa okuvamile. Nakuba kungenzima ukuthola isifo se-Gaucher, kodwa ezinye izimpawu zingase zifane nezezinye izifo. Udokotela angase aqale ngokuhlola izinto ezithile ukuze akhiphe ukugula okuvamile ohlwini lwezifo okungenzeka kube yizo.

Ngokwesibonelo, ezimweni lapho iziguli zinama-platelet aphansi, odokotela bangase bahlole ukuthi akuwona yini umdlavuza wegazi. Uma isiguli sikhala ngokuqaqamba kwamalunga, udokotela angase asole isifo samathambo. Ngezinye izikhathi odokotela abachwepheshile emkhakheni wezofuzo, udokotela onguchwepheshe kwezegazi noma onguchwepheshe emkhakheni we-metabolism, angaba usizo ekuhlukaniseni izimpawu zesifo se-Gaucher kwezinye izifo ezinezimpawu ezifanayo.

Isifo se-Gaucher singatholwa ngokuhlolwa okuvamile kwegazi – ngokukala izinga lama-enzyme egazini nangokuhlola ukuthi alukho yini ushintsho oselwenzekile esakhini sofuzo okuthiwa i-glucocrebrosidase.

Isifo se-Gaucher singase sisoleke kumuntu onokuvuvukala okungachazeki kwesplini, onomkhuba wokopha, onobuhlungu bamathambo noma bamalunga noma okuphuka kalula.

UDOKOTELA ONGUCHWEPHESHE WABANTWANA angase asithole lesi sifo emntwaneni okhala ngobuhlungu esiswini noma ovame ukuphathwa umongozini.

UDOKOTELA ONGUCHWEPHESHE KWEZEGAZI angase asithole lesi sifo kumuntu onegazi eliphansi noma onama-platelet aphansi.

UDOKOTELA ONGUCHWEPHESHE WAMATHAMBO angase athole isifo se-Gaucher phakathi nokwelapha umuntu ohlushwa ukwephuka okungachazeki.

Kungase kusolwe ngokuqondile isifo se-Gaucher kubantu abanamalungu omndeni okwaziwayo ukuthi anaso lesi sifo.

I-International Gaucher Alliance iyinhlangano eyinhloko emelela amaqembu eziguli emhlabeni jikelele.

Ukuze uthole ukuthi likhona yini iqembu ezweni lakini, nokuthola ulwazi oluvamile ngesifo se-Gaucher, vakashela iwebhusayithi yethu ku- www.gaucheralliance.org

IGA INTERNATIONAL GAUCHER ALLIANCE

Driven by passion for patients

I-IGA iyinhlangano yamazwe ngamazwe eholwa iziguli esiphenduke izwi lomhlaba wonke esifana 'nesiphephelo' ekukhulumeleni umphakathi wabangaphezu kwamaphesenti angama-90% emhlabeni jikelele futhi iye yazakhela igama ngokulalelisisa nangemiphumela ebe nesandla ezigulini nakubanakekeli bazo. Uma udinga ukuthola iqembu leziguli elisendaweni okuyo, ngena kwenye yamalinki ababambiqhaza anamalungu angaphezu kwabangama-50+ ukuze uthole ukwesekwa kwasendaweni, iziyalo kanye nezindaba, vakashela ku-visit gaucheralliance.org/member-directory.

UMBONO WETHU:

Umhlaba lapho zonke iziguli ezine-Gaucher zikwazi ukuthola usizo lwezokwelashwa nokunakekelwa ezikudingayo nalapho kunamathuba khona okuthola ikhambi

IZINDINGANISO ZETHU:

Thina: sigxile ezigulini, sinokwethenjelwa, sisebenzelana ngokubambisana, sinombono ocacile, sinokukhathalela

UMGOMO WETHU:

- ukuthuthukisa amalungu enhlangano
- ukulwela iziguli ezine-Gaucher
- ukuqinisekisa ukuthi uhlelo locwaningo lwe-Gaucher lugxile ezidingweni zeziguli okungakahlangatshezwani nazo
- ukuthatha izinyathelo sokubambisana ukuze kusingathwe izingqinamba iziguli ezine-Gaucher

emhlabeni jikelele ezibhekana nazo ekutholakaleni kwalesi sifo kusenesikhathi nasekutholeni ukwelashwa nokunakekeleka okungcono kakhulu.