



I-Prader–Willi syndrome

AYIQONDWA KAHLE NGOBA IVAME UKUNGAXILONGWA.

Ake uzicabange uhlale uzizwa ulambile! Abantu abaphila ne-Prader-Willi syndrome bahlale belwisana nomuzwa wendlala nomaphi lapho beya khona ... okungaphumela ekutheni umuntu akhuluphale ngokweqile, okuyisimo esisongela ukuphila. Uma lesi simo singaqashelwa futhi singalawulwa kahle, bangaqhubeka nokuphila kodwa bengaqondwa, babizwe ngamagama ayiziswana futhi bangakwazi ukujabulela ukuphila ngokuphelele.

Iyini?

I-Prader-Willi syndrome yisimo esiyinkinga yofuzo, okusho ukuthi umuntu uzalwa nayo. Sihlupha okungenani umuntu oye-1 kwabangu-10 000 kuya koye-1 kwabangu-15 000, kokubili abesilisa nabesifazane bazo zonke izinhlanga. Ngisho nomzali akufanele asolwe ngalokhu, futhi lesi simo singenzeka kunoma yimuphi umkhaya – nakuba kaningi kuyoba yingane eyodwa kuphela ethintekayo.

Izimpawu

Ukuncipha kokunyakaza noma ukunganyakazi nhlobo esibeletweni ngaphambi kokuba umntwana azalwe Umntwana uzalwa entekenteke, ulwa kanzima ukuba aphile. Ingane ikhala sengathi ikhathele futhi kunzima ukuba incele Izitho zangasese ezingakhulile Ngokwanele.

Enganeni endala:

Ukukhula ibe mfushane, ibe nezandla nezinyawo ezincane Ukwephuza ukukhula isib. ukuhlala, ukuhamba, nokukhuluma Ukulangazelela ukudla okwedlulele nokukhuluphala okweqile kusukela eminyakeni emi-2 kuya kwemi-3 ubudala Ukuzondelela ukudla nokuthi njalo ithande noma ifune ukudla Inkinga yokuziphatha, isheshe ithukuthele – ikakhulukazi ngokudla Umehluko ekucabangeni nasekufundeni.

Aselapheki lesi simo.

Noma kunjalo, kubalulekile ukuba sisheshe sitholakale futhi silawulwe kahle. Ukuze unqande ukukhuluphala ngokweqile, kubalulekile ukulawula njalo ukudla, imikhuba yokudla kanye nokujima. Ngenxa yokuthi lesi simo silawulwa kahle futhi siyaqondwa, abantu abane-Prader-Willi syndrome manje baphila badlule ngale kweminyaka yobudala emaphakathi uthi banikela ngamakhono amaningi emiphakathini yangakubo.

I-Prader-Willi Syndrome Association of South Africa yasungulwa ngo-1990 futhi ihlose ukunikeza ulwazi nokusekela okungokomzwelo ngalesi simo. Noma ubani wamukelekile ukuba abe ilungu lale nhlangano.

Uma Usola Ukuthi Ingane Yakho Inalesi Sifo

Khuluma nomsebenzi wezempilo noma umtholampilo wangakini ngokuthi ingane yakho ithole ukuxilongwa okufanele.

Ukuze Uthole Eminye Imininingwane, Sicela Uthinte:

www.praderwilli.org.za

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U-PWSA (SA) yilungu lokulandelayo:

International Prader-Willi Syndrome Organisation (IPWSO) www.ipwso.org

South African Inherited Disorders Association (SAIDA) www.saida.org.za

Western Cape Forum for Intellectual Disability (WCFID) www.wcfid.co.za

The South African Association for the Scientific Study of Mental Handicap (SAASSMH)

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PBO Exemption no. 930 016 853