

Patient/Family Education

Xaalada cudur ee Sturge-Weber (Somali)

Waa maxay xaalada cudur ee Sturge-Weber Syndrome?

Xaalad cudur waa dhibaatooyin dhawr ah oo mar wada dhaca. Dhibaatada ugu caadisan ee dadka qaba xaalada cudurka Sturge-Weber Syndrome waa angiomas (boogo hoose ama buro jidhka hoostiisa oo ka samaysan xididada dhiiga).

Xaalada cudur ee Sturge-Weber syndrome (SWS) waa dhif. Waxay ku dhacdaa 1 qof 50,000 caruura ee dhashaba. Hase ahaatee, dad badan oo qaba xaalada SWS ayaan ogayn in ay qabaan, markaas waxa laga yaabaa in ay intan ka caadisan tahay. SWS wuxuu isku mid ah u saameeyaa jinsi kasta iyo jaad kasta dadka.

Sidee lagu ogaadaa?

Waa adag tahay sida lagu garto xaalada cudur ee Sturge-Weber syndrome. Baadhista dhiiga laguma garan karo, mana jiraan liisto calaamado ah oo la odhan karo **waa in** laga helo qofka qaba SWS. Tusaale ahaan, dadka qaba SWS badidoodu waxay leyihiiin bar gaduuda sida khamriga nabiidka, laakiin daka leh barta noocas ahi ma wada qabaan xalada cudur ee Sturge-Weber syndrome.

Raajada MRI ayaa sida badan lagu eegaa in ay qofka xidido badani ka soo baxeen maskaxda dusheeda.

Sturge-Weber syndrome (English)

What is Sturge-Weber syndrome?

A syndrome is a group of problems that occur together. The most common problem in people with Sturge-Weber Syndrome is angiomas (cysts or tumors composed of blood vessels).

Sturge-Weber syndrome (SWS) is rare. It is present at birth in about 1 in every 50,000 babies. However, many people with SWS probably never know they have it, so it may be more common. SWS affects all races and both sexes equally.

How is it diagnosed?

Sturge-Weber syndrome can be hard to identify. There is no blood test for it, and no list of signs that **must** be present to decide that a person has SWS. For example, most people with SWS have a port-wine stain, but not all people with a port-wine stain have Sturge-Weber syndrome.

An MRI is often done to see if the person has too much blood vessel growth on the brain's surface.

Isku-tag calaamadaha qaar ayaa laga heli doonaa:

- bar guduuda (casaan barxan, casaan, ama bar basali ah wajiga dushiisa)
- angiomas
- madax-xanuun
- indho-xanuun sida glaucoma (cadaadis indhaha ku kordha)
- dhibaatooyin habdhiska dareemada
- dhibaatooyin xagga xubnaha jidhka
- suuxitaan (qalayl)
- dhacdooyin sida faalijka (qayb ka mid ah wejiga ama jidhka oo bakhtiya muddo gaaban)
- dhibaatooyin xagga dabeeecada sida is-dhimida fejignaanta ee (ADHD)
- koriinka iyo garashada (fekirka) oo daaha

SWS miyuu qoys ahaan u socdaa?

Maya. SWS ma keeno hidda-waduhu. Waa naadir in qoys laga helo qof wax ka badan oo qaba cudurkaas.

Some combination of these signs will be present:

- port-wine stain (large pink, red, or purple birthmark on the face)
- angiomas
- headaches
- eye problems such as glaucoma (increased pressure in the eye)
- nervous system problems
- problems with other body organs
- seizures
- stroke-like events (part of the face or body is paralyzed for a short while)
- behavior problems, such as attention deficit hyperactivity disorder (ADHD)
- developmental delay or cognitive (thinking) delay

Does SWS run in families?

No. SWS is not caused by a gene. It is very rare for a family to have more than one person with it.

Maxay tahay daaweyntu?

Ma jirto si lagu saadaalin karo dhibaatoyinka uu qabi doono qofka qabaa SWS, ama halista ay dhibaatooyinkaas noqon doonaan.

Raysasho ma leh. Daaweyntu waxay ku xidhan tahay dhibaatooyinka uu qofku qabo oo ay ka mid noqon karaan:

Dhibta	Daaweynta
ADHD	dabiib ah dawo ama dawo-la'aan ah
daahitaanka koriinka	waxbarsho gaara, dib-u-
indho-xanuun “glaucoma”	dhibcaha indhaha ama jeexitaan (qalliin)
madax-xanuun	hab daawo ama daawo la'aana
bar guduuda	daaweynta layserka
suuxitaan (qalayl)	daawo ama qalliin
dhacdooyinka sida faalijka ah	dawo looga hortago guntinta dhiiga

Sideen ilmahayga u daryeelaa?

Dhakhtarkooda joogtada waxa dheer in dhammaan dadka qaba SWS uu sannad kasta arko dhakhtar ama kalkaaliye caafimaad oo aqoon u leh xaalada. Waxa laga yaabaa in loo baahdo tilmaamid khabiir.

Goorma ayaan u wacaa kiliniga?

- wixii xanuun cusub ee joogta
- walaac xagga aragtida iyo madax xanuun
- walaac xagga waxbarashada iyo anshaxa

What is the treatment?

There is no way to predict what problems a person with SWS will have, or how serious those problems will be.

There is no cure. Treatment depends on the problems the person has, and may include:

Problem	Treatment
ADHD	medicine and non-medicine therapies
developmental delay	special education, rehabilitation
glaucoma	eye drops or surgery
headache	medicine and non-medicine methods
port wine stain	laser treatments
seizures	medicine or surgery
stroke-like events	medicine to prevent blood clotting

How should I care for my child?

In addition to their regular doctor, all people with SWS should be seen yearly by a doctor or nurse practitioner familiar with this condition. Referrals to specialists may be needed.

When should I call the clinic?

- any new and persistent pain
- concerns about vision or headaches
- learning or behavior concerns

Su'aalo?

Xaashidani gaar kuma aha ilmahaaga, laakiin waxay bixinaysaa macluummad guud. Haddii aad wax su'aalo ah qabto, fadlan wac kilinigaaga.

Wixii akhris dheeraad ah ee la xidhiidha arrintan iyo mawduucyada kale ee caafimaadka, fadlan wac ama booqo kaydka-buugaagta ee Xarunta Qoyska “Family Resource Center”, ama booqo goobtayada internetka www.childrensmn.org/A-Z.

Questions?

This sheet is not specific to your child, but provides general information. If you have any questions, please call your clinic.

For more reading material about this and other health topics, please call or visit the Family Resource Center library, or visit our website: www.childrensmn.org/A-Z.

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