

Mob Sturge-Weber syndrome (Hmong)

Yam mob Sturge-Weber syndrome yog dab tsi?

Ib qho mob (syndrome) yog hais txog ib pawg teeb meem uas muaj ua ke. Qhov teeb meem uas nquag muaj tshaj rau cov tib neeg muaj tus mob *Sturge-Weber Syndrome* mas yog *angiomas* (cov hlwv los sis nqaij hlab ntawm hlab ntshav).

Tus mob Sturge-Weber syndrome (SWS) kuj muaj tsawg tsawg. Nws muaj rau thaum yug uas raug rau 1 leej ntawm 50,000 leej tus menyuam mos. Tiam sis, coob tus tib neeg uas muaj mob SWS tej zaum kuj tsis paub hais tias lawv muaj, yog li no tej zaum tus mob no kuj yuav muaj ntau dua. SWS raug rau txhua haiv neeg thiab poj niam thiab txiv neej sib npaug zos.

Nws yuav kuaj li cas thiaj pom?

Yam mob Sturge-Weber syndrome kuj yuav tshawb nrhiav tau nyuaj. Kuj tsis muaj qhov kev kuaj ntshav, thiab tsis muaj cov tsos mob uas **yuav tsum** pom muaj kom thiaj txiav txim tau tias ib tus tib neeg muaj mob SWS. Piv txwv li, cov tib neeg feem coob uas muaj SWS mas muaj ib qho tsuas daim tawv nqaij liab tsaus, tiam sis kuj tsis yog tias txhua tus uas muaj tsuas tawv nqaij liab tsaus ces muaj tus mob Sturge-Weber syndrome.

Feem ntau mas yuav tau xoops fais fab (MRI) kuaj seb tus tib neeg puas muaj hlab ntshav hlab ntau ntau rau ntawm ib ncig cov paj hlwb.

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.

Yuav muaj qee yam tsos mob pom xws li ntawm no:

- tsuas tawv nqaij liab tsaus (muaj cov ntaus cim loj loj ua kob paj yeeb, liab, los sis tsam xem nyob rau ntawm lub ntsej muag)
- hlav nqaij raws hlab ntsha)
- mob taub hau
- qhov muag muaj teeb meem xws li mob *glaucoma* (nruj nruj rau lub qhov muag)
- teeb meem rau lub nrog cev tua kab mob
- teeb meem rau lwm cov siab-plab-hnyuv hauv nrog cev
- chua leeg li qaug dab peg
- mob xws li hlab ntsha tawg (ib qho ntawm ntsej muag los sis lub cev tuag leeg tsis muaj zog mus ib ntus)
- teeb meem coj cwj pwm, xws li tswm xeeb tsis tau zoo (ADHD)
- loj hlob qeeb los sis lub hlwb (kev xav) hlob qeeb

Mob SWS puas mob raws yim neeg?

Tsis raws. SWS tsis yog xeeb txawm los ntawm ib ceg noob. Nws tsawg tsawg kawg uas ib yim neeg thiaj li muaj ntau tshaj ib leej neeg muaj tus mob no.

Qhov kev kho yog dab tsi?

Nws tsis muaj ib txoj kev los kwv yees qhia tau rau yav tom ntej tias ib tus tib neeg uas muaj SWS yuav muaj cov teeb meem zoo li cas, los sis seb cov teeb meem ntawd yuav mob luaj li cas.

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.

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.

Tsis muaj ib yam tshuaj kho kiag tau. Kev kho nyob ntawm seb tus tib neeg cov teeb meem muaj li cas, thiab tej zaum kho muaj raws li nram no:

Teeb meem	Kev kho
ADHD	tshuaj thiab kev cob qhia uas tsis siv tshuaj
loj hlob qeeb	qhia ntawv tshwj xeeb, kev cob qhia hloov
<i>glaucoma</i>	tshuaj tso rau qhov muag los sis phais mob
mob taub hau	tshuaj thiab kev kho uas tsis siv tshuaj
tsuas tawv nqaij liab tsaus	siv sab fais fab (laser) tua
chua leeg	tshuaj los yog phais kho
mob hlab ntsha tawg	tshuaj pab kom ntshav tsis txhob txhaws

Kuv yuav tsum tu kuv tus menyuam li cas?

Ntxiv rau lawv tus kws kho mob, tag nrho cov neeg uas muaj SWS yuav tsum mus ntsib kws kho mob los sis kws tu mob uas paub txog yam no ib xyoos ib zaug. Tej zaum yuav muaj xa kom mus ntsib lwm tus kws kho mob ib cag.

Thaum twg thiaj tsim nyog kuv hu rau chaw kuaj mob?

- yog muaj mob tshiab thiab tsis txawj zoo
- txhawj txog tias tsis pom kev los sis mob taub hau
- txhawj txog kev kawm los sis koj cwj pwm

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

Lus nug?

Daim ntawv no tsis yog sau cob coos rau koj tus menyuam, tab sis muab lus qhia thoob plaws xwb. Yog tias koj muaj lus nug dab tsi, thov hu rau koj lub tsev kho mob.

Yog xav tau ntaub ntawv nyeem txog yam no thiab lwm yam kho mob, thov hu los sis mus xyuas lub tsev qiv ntawv Family Resource Center, los sis mus xyuas peb daim website: 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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