

What is Schaaf-Yang Syndrome ?

Schaaf-Yang syndrome (SYS) is a rare neurological disorder caused by a disruption in the MAGEL2 gene. Schaaf-Yang syndrome shares a lot of overlap with another genetic disorder, called Prader-Willi syndrome (PWS). Both SYS and PWS can lead to hypotonia (low muscle tone), developmental delay/intellectual disability, sleep apnea, and feeding difficulties. However, there are important differences between the two syndromes, as SYS patients have a higher prevalence of autism and joint contractures.

There are currently over 160 known cases of SYS worldwide.

For more information on SYS :

- Visit the page :
<https://www.bcm.edu/research/labs/christian-schaaf>
- Listen to the conference on :
<https://www.fpwr.org/schaaf-yang-syndrome/>

What are the aims of EASYS ?

The statutes of EASYS, adopted on October 26th 2017, define the aims of the association as follows :

- Raising awareness of the general public, the medical profession and the social and health authorities, in order to improve scientific and medical knowledge, to facilitate diagnosis, recognition and treatment of Schaaf-Yang syndrome.
- Bringing technical and moral assistance to families facing Schaaf-Yang syndrome.
- Contributing to medical research and improving care practices related to Schaaf-Yang syndrome.
- Improving quality of care for Schaaf-Yang patients.
- Integration of families facing Schaaf-Yang syndrome.



How can you help ?

Become a member of EASYS

Whether you are related to SYS or not, you can always help us by becoming a member of EASYS. The membership fee for 2018 is €10,- for family members of a SYS patient and €15,- for sympathetic members.

Help us raising awareness and gathering funds for SYS research

Follow us on Facebook in order to help raising awareness and raising funds for research on MAGEL2 ! We need volunteers to spread the word !

Become a SYS referee

Our major aim is to raise awareness on SYS in order to help families getting a diagnosis and to support these families. If you are willing to help, become a SYS referee in your country ! Contact us for more information !