



VOOR MENSEN MET EEN WIJNVLEK  
OF STURGE-WEBER SYNDROOM

I'm more  
than just a  
birthmark...





### What is a port-wine birthmark or Sturge-Weber syndrome?

Sturge-Weber syndrome is a rare congenital condition in which the port-wine birthmark on the face is immediately visible at birth. Glaucoma and epilepsy may occur later. Other symptoms related to the syndrome, such as jaw problems and developmental disorders, can also be part of the disease.

Sturge-Weber can have a major impact on a patient's life. This is why the Dutch Sturge-Weber Association was founded in 1980. As an association, we represent the medical, psychosocial and social interests of patients. Because the disorder can have a major impact on family life, we also support their parents and carers.



### The condition and the symptoms

Sturge-Weber occurs in one in every 20,000 to 50,000 people and is caused by a change (mutation) in the GNAQ gene on chromosome 9. This mutation occurs in an egg cell after fertilisation and appears equally in boys and girls.

How the syndrome manifests itself differs per person. Most patients are born with a port-wine birthmark in the eye area. Over the years, this mark can darken and thicken. The overgrowth of the blood vessels can damage the brain, resulting in epilepsy, muscle problems and developmental disorders.



## Available information

It is important to know what the condition entails and what the developments in the medical world are. We therefore provide information in various ways.

- Our website contains a lot of information about the various aspects of the condition, including (para)medical specialists and other experts in the field. We also keep you informed of activities, invitations from third parties and other useful information. There is a section available especially for members which contains more information, including a newsletter archive and a forum where members can share information with each other.

- Members receive our newsletter four times a year.
- On Facebook, you can join our private group to exchange experiences.
- We organise meetings where specialists talk about the symptoms and possible treatment methods.
- With a special lesson package, we make it easier for secondary school students to talk about their condition. This leads to more understanding and acceptance.



[www.wijnvlek-sturgeweber.nl](http://www.wijnvlek-sturgeweber.nl)

Come to  
the national  
children's day;  
we organise one  
every year!



## 1. SHARE WITH FELLOW PATIENTS

You meet fellow patients and can have relaxed discussions with others. A national contact day is organised every year for all members, during which information is also provided by medical specialists and other experts.

## 2. KIDS FOR KIDS

Every year the association organises a Children's Day. Here children can share their experiences with each other. It is nice to talk to peers and to feel that you are not alone.

## 3. BACKGROUND INFORMATION AND TIPS

As a member you will have access to the association's private extranet and receive regular email information about Sturge-Weber syndrome, association activities and other relevant information. Members receive a newsletter four times a year and the Heel de Huid (Heal the skin) magazine four times.



Why become  
member of the  
NV WSWs?

3 good  
reasons...

Sign up via the website!

[www.wijnvlek-sturgeweber.nl](http://www.wijnvlek-sturgeweber.nl)





### Contact with fellow patients

To ensure that patients and their family members can meet, we organise gatherings such as:

- Days especially for children under the age of 12 at a location where they can get together during a fun activity.
- An annual family day with, besides the General Members' Meeting, various lectures and fun activities.



### Support, collaboration and advocacy

We continuously work on projects to actively support members.

- We made an animated film, 'I am more than a port-wine birthmark', with one of our young members.

- The Port-wine Birthmark Guide is a tool to make it easier to make choices when it comes to available treatments.
- We set up a choir with association members of all ages. We use video recordings of this for publicity.

As an association, we ensure that members' interests remain on the agendas of (para)medical and sister associations at home and abroad. Thanks to our large network we keep up-to-date on the latest therapies and treatments.



## Membership

Would you also like to become a member of the association? You can sign up easily via our website: [www.wijnvlek-sturgeweber.nl](http://www.wijnvlek-sturgeweber.nl). The contribution is € 25 per year. As a donor you can also support our association with a voluntary contribution.



## Contact

Do you still have questions? Contact our secretariat by sending an email to **[info@wijnvlek-sturgeweber.nl](mailto:info@wijnvlek-sturgeweber.nl)** or call **033 247 14 66**.

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Facebook: [fb.me/NvWSWs](https://fb.me/NvWSWs)

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