

Quarterly magazine and newsletter

The Dutch Sjögren's Patients Association (NVSP) publishes a quarterly magazine called Ogenblikje.

A digital supplement to the magazine is published at regular intervals.

Peer Support

1. Every year on the first Saturday in October, the NVSP organizes its National Contact and Information Day for and by fellow sufferers with lectures and workshops by medical doctors and paramedics.

2. A team of experts by experience has been formed for telephone peer support. They offer a sympathetic ear, answer questions, give advice and information on dealing with the disease. You can indicate via www.nvsp.nl/bel-mij-terug that you would like to contact one of the team members. You will then be called at a time that is convenient for you.

3. To promote nationwide contact between fellow sufferers, we organize themed events in various regions of the Netherlands.

4. Social media

You can find us on

Facebook: www.facebook.com/www.nvsp.nl

Closed Facebook page: www.facebook.com/groups/sjogreninhetdagelijksleven

And on **Instagram:** [nvspinsta](https://www.instagram.com/nvspinsta)

YouTube channel: Nationale Vereniging Sjögrenpatiënten.

LinkedIn: Nationale Vereniging Sjögrenpatiënten.

Brochures

The NVSP has published a number of brochures on various aspects of Sjögren's disease. Brochures can be ordered at www.nvsp.nl/brochures.

Scientific Research

The NVSP has a special fund to stimulate scientific research. Every year we make a financial contribution to research related to Sjögren's disease. We are also involved as a patient partner in various studies.

Every two years, the NVSP presents the **Sjögren Award** to a promising and inspiring researcher. The Ronald Hené Public Award is also presented every two years.

The NVSP is assisted by a **medical advisory committee** consisting of professionals in the field of Sjögren's disease. The association is affiliated with Dutch patients' organisations and with Sjögren Europe.

You will find more information, including videos, on our website: www.nvsp.nl.

For **medical questions**, please email: vraagenvoord@nvsp.nl. For questions about health insurance reimbursements, please contact: zorgverzekeringen@nvsp.nl

Contact Information:

NVSP
Bisonspoor 3002 - B505
3605 LT Maarssen
Tel.: +31 346 - 55 63 76
info@nvsp.nl

With your annual subscription or donation, you enable us to do even more for Sjögren's patients. If you would like to become a member or donor, please register through our website.



SJÖGREN'S DISEASE

Sjögren's Disease

Probably around 0.5% of the Dutch population has Sjögren's disease. It is ten times more common in women than in men. The disorder usually manifests itself between the ages of 20 and 40. Sometimes, but by no means always, people with Sjögren's disease also have another rheumatic disorder such as rheumatoid arthritis (RA) or systemic lupus erythematosus (SLE).

This brochure briefly describes some of the main symptoms of the disease.

Autoimmune Disease

The immune system protects the human body from outside infections. In people with Sjögren's disease, the immune system is overactive, which means that it also targets and attacks healthy tissues. This creates anomalous inflammatory responses that occur mainly in tear and salivary glands, thus preventing them from functioning properly. The exact cause of Sjögren's disease is not known. That is why specialized doctors in many centres around the world, including the Netherlands, are conducting research into this condition.

Common Symptoms

Sjögren's patients suffer mainly from dry eyes and a dry mouth, but skin problems and respiratory and vaginal problems also occur. They often experience extreme fatigue with extensive muscle and joint pain. Swelling of the major salivary glands may also occur. Many people with Sjögren's disease quickly get numb white fingers and toes due to cold (Raynaud's) phenomenon

Fatigue

Fatigue is a very common complaint. Most people with Sjögren's disease report fatigue as the biggest and most difficult problem to manage. Fatigue can sometimes worsen suddenly for no apparent reason. Despite strict living rules, planned activities may have to be cancelled due to fatigue.

Reduced Production of Tear Fluid

Deficiency of tear fluid leads to dry eyes. The eyes may burn or itch. Sometimes people feel like there is a grain of sand in their eyes. Irritation and inflammation of the eyelids may occur. The eye may be hypersensitive to too much and bright light and to wind and smoke. In some cases, dryness can damage the cornea.

Reduced Production of Saliva

Too little saliva causes a dry mouth with a vulnerable mucous membrane. Lips and corners of the mouth can also be very dry. The oral mucous membrane is susceptible to fungous infection (candidiasis). Due to too little saliva or viscous saliva, people are sometimes sensitive to certain foods. Swallowing problems often make it impossible for people to eat without water. Swelling of the major salivary glands can be very painful. Due to too little saliva and/or anomalous saliva, the teeth are especially susceptible to tooth decay (caries).

Muscle and Joint Pain

This occurs in most Sjögren's patients. Joint inflammation is much less common and, very different from people with RA, generally does not lead to any damage or malformation of the joints.

General Symptoms

In addition to these symptoms, a variety of symptoms may occur, such as feeling like you have a touch of flu and having rising and falling body temperature.

Diagnosis

Some of the symptoms may have other causes. Diagnosis will require examination by an internist or rheumatologist. They will examine blood and urine and do further medical imaging tests. If appropriate, they may also include salivary gland tissue in the examination.

Impact

Sjögren impacts patients' lives in multiple ways. Dryness may have implications for intimate contact. Due to sudden fatigue, appointments sometimes have to be cancelled. Often one must adapt in life and work to the limits imposed by Sjögren's disease.

Research and Treatments

As long as Sjögren's disease cannot be cured, scientific research into underlying mechanisms and possible treatments remains of the utmost importance. Treating the symptoms with artificial tears and artificial saliva, for example, is also very important. Sharing experiences can be helpful in dealing with the disease.

The Dutch Sjögren's Patients Association

The NVSP gives information, promotes members' interests and encourages contact between fellow sufferers. We provide brochures and publish a quarterly magazine