



Stiff-Person-Syndrom
Selbsthilfe Deutschland e.V.
(Stiff-Person-Syndrome Support Group Germany)

www.stiff-person.de

Definition:

The Stiff-Person-Syndrome (SPS), or Stiff-Man-Syndrome (SMS), is an autoimmune disease of the central nervous system. It is characterized clinically by extreme muscle stiffness, sometimes leading up to complete immobilization and sudden, painful and often elongated spasms.

Further characteristic symptoms are:

- gait disorders with blockades and falls
- musculoskeletal disorders such as hyperlordosis
- increased startle response
- panic attacks
- fear of unaided walking (Agoraphobia)
- prominent muscle stretching reflexes
- dysfunction of body reactions (heavy perspiration, accelerated pulse)

This definition is oriented on the guideline „Stiff-Man-Syndrome“ of the Deutsche Gesellschaft für Neurologie (German Society for Neurology).

It is remarkable that many patients are afflicted with additional autoimmune diseases such as Diabetes type 1 or thyroid dysfunctions.

SPS is one of the so-called Rare Diseases, defined in Europe by a prevalence of 5 : 10 000 (meaning a max. of 5 afflicted persons in every 10 000 citizens). This means that there are about 200 to 300 SPS-patients in Germany.

Our goals are:

- to inform the afflicted, medical personnel and other interested persons about the disease „Stiff-Person-Syndrome“.
- to ease everyday life for the afflicted by offering relevant information.
- to raise the awareness of political decision-makers and the public about Rare Diseases and to make sure that the interests of the afflicted are mandated on all levels.
- to report (to the full extent of our means) the newest scientific findings.
- to support research centers with the full extent of our means in the exploration of the „Stiff-Person-Syndrome“

In order to achieve these goals, we are currently cooperating with national and international organizations such as EURORDIS, RareConnect, ACHSE and foreign SPS self supporting organizations.

We are offering means of information exchange not only through regular meetings, but also through electronic media (bulletin board, chat)

Partner of Medicine:

Due to the rareness of this disease, 90% of all neurologists will never be confronted with a patient suffering from Stiff-Person-Syndrome. This is one of the reasons which makes it so hard to get a diagnosis for SPS. That is why one of our goals includes spreading awareness of the disease among medical personnel.

Furthermore:

- we extend our partnership to suitable research projects.
- we sponsor suitable research projects to the full extent of our means.
- we publish experiences of patients
- we help patients to network with each other and scientists to network with patients
- we survey our members; any doctor's proposals are welcome
- we provide statistical information

The first cooperations with universities are starting to take on shape.

In 2016, we surveyed our afflicted members for the first time in reference to all aspects of their disease. Some neurological clinics showed great interest in the results.

Many of our members suffering from the Stiff-Person-Syndrome also have other neurological and/or autoimmune diseases. This enables us to offer ideal circumstances for studying the interrelations and similarities between these different afflictions.

Diagnosis & Treatment:

The complex and individual nature of the Stiff-Person-Syndrome, in regard to every patient, makes it very hard to diagnose. Furthermore, a few of the symptoms correspond with symptoms of other diseases. This is why there are many cases which are only diagnosed years after the initial symptoms.

But there are many different and successful treatments. Usually, these treatments try to influence the immune system positively and at the same time relax stiffened muscles.

An often used treatment is the so-called „high-dosage cortison infusion“ in combination with Benzodiazepin or Clonazepam (e.g. Rivotril). There are also long time therapies with immunoglobulin (certain proteins) which can be considered. Plasmapheresis (exchange of the blood plasma) has also been successfully executed.

Recently reports out of the U.S.A. have shown that a treatment with autologus stem cell transplantations (stem cells from the patient which, after preparational treatment and removal of exhausted cells, are reimplanted) might be successful.

Examples of successful treatments (stories of patients) can be found on our web-site.

The Stiff-Person-Syndrome Selbsthilfe Deutschland e.V., is a nation wide operating organization which was founded in June 1998 by afflicted persons.

Today, our organization consists of about 120 members, about 80 of which are suffering from the disease. During the last 12 month our membership has increased by 20%.

Key to our organization is that members interact with each another and trade experiences. We meet once a year in a general meeting, where we do not only consider formal aspects.

By the way, if you would like to support our work, here are our banking details:

Commerzbank
IBAN DE26 5008 0000 0781 7150 00 BIC DRESDEFFXXX
holder of the account: Stiff-Person-Syndrom Selbsthilfe Deutschland e.V.
The common public interest is confirmed.

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<http://www.stiff-person.de>

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