

Membership Advantages

- ✓ Exchange of information and experience
- ✓ Support for affected persons and relatives
- ✓ regular meetings
- ✓ free participation in lectures, trainings and seminars
- ✓ reduced prices at patient days and events of the association
- ✓ advantages in making appointments with some specialists
- ✓ patient representative
- ✓ Advice on social matters (appeal, rehabilitation and care, severe disability, pension, ...)
- ✓ Benefits.de (platform, on which members in over 300 stores can buy cheaper)
- ✓ CarFleet24 (members receive a discount when buying a new car)
- ✓ Access to the forum
- ✓ Legal advice by an internal lawyer of the association possible
- ✓ English speaking consultation
- ✓ Information material available in English
- ✓ Consulting for other European countries

As our individual experiences show, the disease sensitizes us to reflect on our own way of life and on the context of our complaints. This reflection strengthens the ability to deal with the complaints to deal with the complaints successfully on our own responsibility.

We are members of:



About us

„Deutsche Syringomyelie und Chiari Malformation e. V.“ is a non-profit self-help organization on a national level, founded by affected persons for affected persons at the end of 2006. We advocate for the information, needs and interests of people diagnosed with syringomyelia and/or Chiari Malformation. Help and support for affected persons and their relatives are in the foreground. We are accompanied by medical specialists, lawyers, physiotherapists and many committed helpers. We are financed by donations, sponsoring, public donations and membership fees.

Patron

Prof. Dr. med. Peter Rieckmann was co-founder of the first German heart-brain center and has established a special unit for clinical neuroplasticity in the Neurorehabilitation. He is a member of the medical advisory board of the German Multiple Sclerosis Society (DMSG). For his scientific achievements, he has already received numerous awards.

Donation account

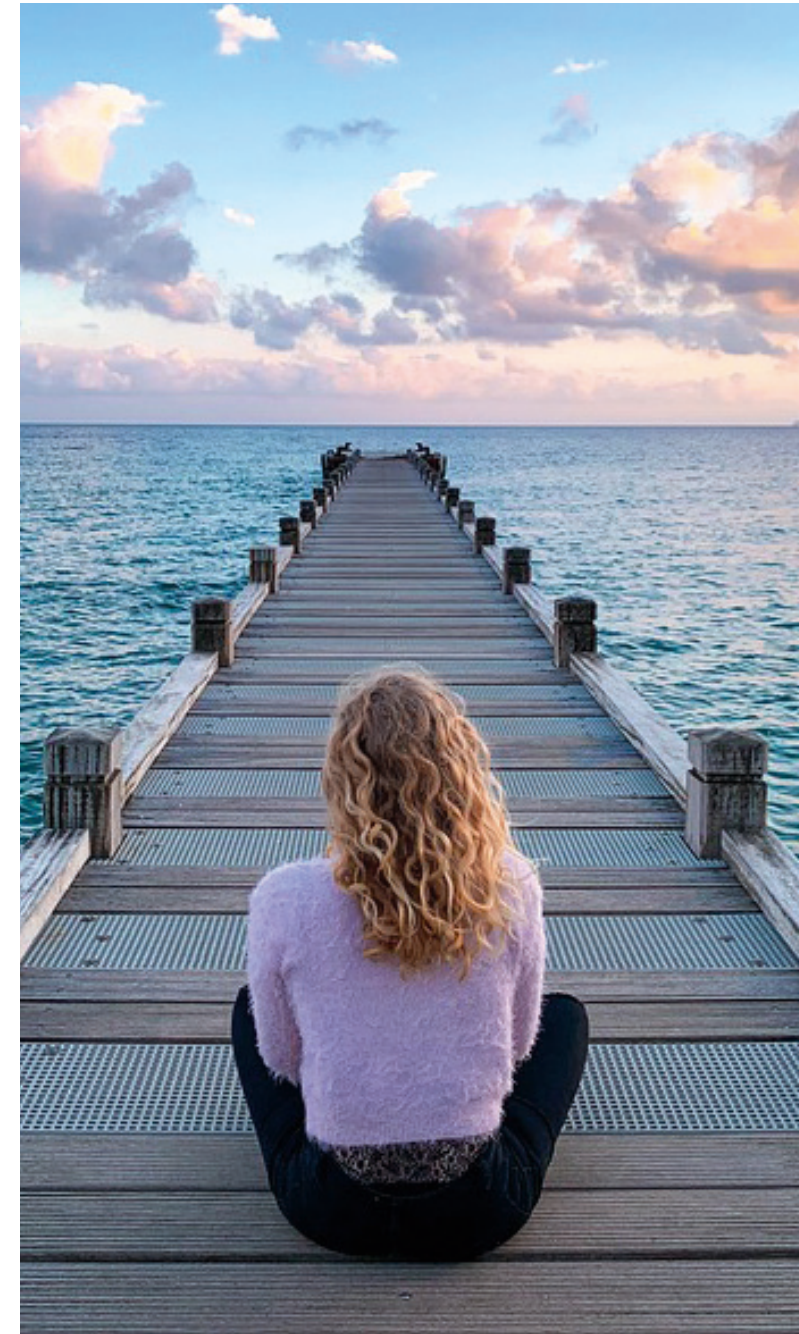
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Syringomyelie

Contrary to outdated doctrine, Syringomyelie is neither a mental nor a psychological disorder, nor is it a mental illness. In syringomyelia, there is a usually elongated fluid-filled cavity (the syrinx) in the gray matter of the spinal cord that displaces the gray matter. Particularly in the cervical and thoracic spine, several or even only one syrinx may form. Possibly associated with this, but in any case causal is an impairment or even severe obstruction of the circulation of the cerebrospinal fluid.

Syringomyelie is diagnosed with the aid of imaging techniques. Nowadays, MRI plays the most important role. There is no correlation between the size of a syrinx or the number of Syringomyelie and the severity of the disease, nor is there usually a causal relationship between the location of the Syringomyelie and the severity of the disease. Causal relationship between the position of the syrinx and the symptoms can be established. The syrinx can, once can grow in size over the years.

The causes for the development of acquired Syringomyelie have not yet been conclusively clarified scientifically. What is certain, however, is that the cause of acquired Syringomyelie is always an obstruction of the nerve water circulation. If the nerve fluid circulation in the spinal canal is blocked at one point, the nerve fluid will seek another path in the narrow spinal canal and a syrinx will develop.

The reasons that can lead to blockage of the nerve water circulation are varied. It can be malformations or inflammations, the adhesions of the fine spinal cord membranes (cobwebs). Likewise, accidents, tumors and severe herniated discs can also be the reason for the blockage and development of a syrinx, whereby the syrinx does not have to occur the exact location of the injury.

Chiari Malformation

Chiari Malformation is one of the most common embryonic developmental disorders. As a rule, a Chiari Malformation is congenital and consequently a malformation during the growth phases of the fetus. She is not inherited. In rare cases, Chiari Malformation is acquired, for example, when a brain tumor or a severe birth injury has caused the cerebellum to be cerebellum into the spinal canal.

In Chiari Malformation, there is a depression of cerebellar parts (cerebellum, cerebellar tonsils), which extend into the occipital orifice (foramen magnum) and beyond, often leading to a circulatory disturbance of the cerebrospinal fluid. Sometimes an additional bony malformation of the skull at the transition to the spine and the first cervical vertebrae. This can also lead to a craniocervical instability of the craniocervical transition (region from the cervical vertebral body 0 to the motion segment between cervical vertebral bodies 1 and 2).

Due to the different manifestations, Chiari malformation is divided into different types/grades such as location and size. Which type/grade is present in an affected person can only be determined by a physician who is familiar with Chiari malformation based on examination results. Depending on the severity and the symptoms present, an appropriate form of treatment – conservative or surgical – is determined.

Information on doctors and hospitals who are familiar with Syringomyelie and Chiari Malformation and can help you further can be found on our homepage www.dscm-ev.de or call our office at 09231-87 97 050.



Therapy options

Chiari malformations - detected early - can be treated surgically with good long-term results. In the case of syringomyelia of other causes, the causes must be found and, if necessary, treated surgically. According to the cause, the results of the operations are highly variable among individuals. The discomfort caused by the syringomyelia can often only be alleviated. Basically, the focus should be on a pain therapy or symptom-related, drug therapy that meets the needs of the affected person. Early physiotherapeutic treatment is also important (therapy according to Vojta, Bobath, PNF etc.) with instruction of the patient in correct moving, lifting and sitting. In addition, acupuncture, relaxation therapies, osteopathic therapy, craniosacral therapy and various movement therapies can alleviate the manifold complaints.

Of course, those affected should avoid triggers of complaint amplification and take their body's signals seriously. Triggers can be stress, physical or psychological strain, for example.

