



Syringomyelia

The following excerpt has been taken from the Christopher & Dana Reeve Foundation Paralysis Resource Center website.

http://www.christopherreeve.org/site/c.mtKZKgMWKwG/b.4453407/k.DBDF/Syringomyelia_Tethered_Cord.htm

Post-traumatic syringomyelia and tethered spinal cord can occur following spinal cord injury. It can occur from two months to many decades after injury. The results can be devastating, causing new levels of disability long after a person has had a successful rehabilitation. The clinical symptoms for syringomyelia and tethered spinal cord are the same and can include progressive deterioration of the spinal cord, progressive loss of sensation or strength, profuse sweating, spasticity, pain and autonomic dysreflexia (AD).

In post-traumatic syringomyelia (syr-ING-o-my-EE-lia) a cyst or fluid-filled cavity forms within the cord. This cavity can expand over time, extending two or more spinal segments from the level of SCI.

Tethered spinal cord is a condition where scar tissue forms and tethers, or holds, the spinal cord to the dura, the soft tissue membrane that surrounds it. This scar tissue prevents the normal flow of spinal fluid around the spinal cord and impedes the normal motion of the spinal cord within the membrane. Tethering causes cyst formation. Tethered cord can occur without evidence of syringomyelia, but post-traumatic cystic formation does not occur without some degree of cord tethering.

Magnetic resonance imaging (MRI) easily detects cysts in the spinal cord, unless rods, plates or bullet fragments are present.

Post-traumatic tethered cords and syringomyelia are treated surgically. Untethering involves a delicate surgery to release the scar tissue around the spinal cord to restore spinal-fluid flow and the motion of the spinal cord. In addition, a small graft is placed at the tethering site to fortify the dural space and decrease the risk of re-scarring. If a cyst is present, a tube, or shunt, is placed inside the cavity to drain the fluid from the cyst. Surgery usually leads to improved strength and reduced pain; it does not always bring back lost sensory function.

In experiments at the University of Florida, people with spinal cord cysts were treated with injections of fetal tissue. It is unlikely this technique will find its way to the clinic any time soon, but the tissue grew, filled the cavities and prevented further loss of function.

Syringomyelia also occurs in people who have congenital abnormality of the brain called a Chiari malformation – during development of the fetus the lower part of the cerebellum protrudes from the back of the head into the cervical portion of the spinal canal. Symptoms usually include vomiting, muscle weakness in the head and face, difficulty

swallowing, and varying degrees of mental impairment. Paralysis of the arms and legs may also occur. Adults and adolescents with Chiari malformation who previously showed no symptoms may show signs of progressive impairment, such as involuntary, rapid, downward eye movements. Other symptoms may include dizziness, headache, double vision, deafness, an impaired ability to coordinate movement and episodes of acute pain in and around the eyes.

Syringomyelia can also be associated with spina bifida, spinal cord tumors, arachnoiditis and idiopathic (cause unknown) syringomyelia. MRI has significantly increased the number of diagnoses in the beginning stages of syringomyelia. Signs of disorder tend to develop slowly, although sudden onset may occur with coughing or straining.

Surgery results in stabilization or modest improvement in symptoms for most people. Delay in treatment may result in irreversible spinal cord injury. Recurrence of syringomyelia after surgery may make additional operations necessary; these operations may not be completely successful over the long-term. Up to one half of those treated for syringomyelia have symptoms return within five years.

Source

National Institute of Neurological Disorders and Stroke, American Syringomyelia Alliance Project

Web Sites

American Syringomyelia & Chiari Alliance Project (ASAP)

<http://www.asap.org>

PO Box 1586

Longview, TX 75606 -1586

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Email: info@ASAP.org

ASAP is a nationwide clearinghouse for information regarding Chiari (CM) and syringomyelia (SM) and related disorders. ASAP sponsors an annual medical conference linking the top medical professionals in the field with those affected. ASAP reviews and funds research annually. In addition, they promote awareness by hosting community fundraisers throughout the nation. Together with its membership, ASAP works toward fulfilling its mission to improve the lives of persons affected by syringomyelia, Chiari malformation and related disorders while we find the cure.

ASAP member Marc D would like to start a local support group in the Northern NJ area. If you are interested please email Marc at midavis03@verizon.net.

Chiari & Syringomyelia Foundation

www.CSFinfo.org

29 Crest Loop

Staten Island, NY 10312

718-966-2593

Dorothy Poppe, Executive Director dpoppe@CSFino.org

Christopher S. Burton Syringomyelia Foundation

<http://www.thesmfoundation.org/>

3701 NW 5th Ave.

Fort Lauderdale, FL 33309

Duke University Medical Center, Dept. of Neurology's Syringomyelia Web Page

www.syringo.org/

Information on syringomyelia, its causes, diagnosis, and treatment.

National Institute of Neurological Disorders and Stroke: Syringomyelia Information Page

www.ninds.nih.gov/health_and_medical/disorders/syringomyelia_short.htm

Information includes prognosis, current research, links to related organizations.

National Institute of Neurological Disorders and Stroke: Syringomyelia Fact Sheet

http://www.ninds.nih.gov/disorders/syringomyelia/detail_syringomyelia.htm

Causes and treatment of syringomyelia.

Medline Plus

www.nlm.nih.gov/medlineplus/syringomyelia.html

Offers overview, disease management, clinical trial information.

eMedicine

www.emedicine.com/NEURO/topic359.htm

Clinical information and treatments are offered.

UAB' s Fact sheet on Syringomyelia

<http://www.spinalcord.uab.edu/show.asp?durki=21563&site=1021&return=21571>

Causes and treatments are discussed here

Chiari & Syringomyelia News

<http://www.chiari-syringo-news.org>

Online publication

The Chiari Institute

865 Northern Blvd.

Great Neck, NY 11021

516-570-4400

A center for the management of patients suffering from Chiari malformations, syringomyelia and related disorders.

Wishes and Rainbows

<http://www.wishesandrainsbows.org/>

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A non-profit organization devoted to helping those with ACM, SM and other chronic conditions.

The following books and videos are available for free loan from the PRC library. For more information, please see www.paralysis.org and click the Lending Library tab.

Books

- **Masterpiece Recipes from the American Syringomyelia Alliance Project.** Longview, TX: ASAP.
- **Bobby Jones—Stroke of Genius: The Movie and the Man.** Latham, NY: British American Publishing, Ltd., 2004.
Pro golfer Bobby Jones had syringomyelia.
- Klekamp, Jorg and Madjid Samii. **Syringomyelia – Diagnosis and Treatment.** New York, NY: Springer, 2002.
- Oro, John J. and Diane Mueller. **The Chiari Book: A Guide for Patients, Families and Health Care Providers The Chiari I Malformation and Syringomyelia.** John J. Oro & Diane Mueller, 2007.
- Parker, James N. and Philip M. Parker. **The Official Patient’s Sourcebook on Syringomyelia.** San Diego, CA: ICON Health Publications, 2002.
- Tamaki, N., U. Batzdorf, and T. Nagashima. **Syringomyelia: Current Concepts in Pathogenesis and Management.** New York, NY: Springer, 2001.

CD-ROM

Breathe, Relax and Heal. 2004. Narrated by Rachel Greene. Produced by Mary G. Parker (Email for purchasing info: marygparker@cox.net) Recorded for the American Syringomyelia Alliance Project. Audio CD.

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