CHRISTOPHER & DANA REEVE FOUNDATION
PARALYSIS RESOURCE CENTER

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 (sear-IN-go-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

http://www.asap.org/
American Syringomyelia & Chiari Alliance Project (ASAP)
PO Box 1586
Longview, TX 75606-1586
Phone: 903-236-7079, 800-ASAP-282 (Toll Free)
E-mail: info@asap.org
ASAP provides information regarding Chiari (CM) and syringomyelia (SM) and related disorders and support for people with these disorders and their families and caregivers. The organization also funds research and sponsors an annual medical conference.

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

http://www.csfinfo.org/
Chiari & Syringomyelia Foundation (CSF)
29 Crest Loop
Staten Island, NY 10312
Phone: 718-966-2593
CSF is an education and advocacy organization. There are currently six regional CSF chapters in the United States.

http://www.conquerchiari.org/
Chiari & Syringomyelia News
A newsletter published by the C&S Patient Education Foundation, known informally as Conquer Chiari. The website also includes general information on Chiari, updates on the latest research, and links to support groups.

http://www.chiariinstitute.com/
The Chiari Institute
865 Northern Boulevard
Great Neck, NY 11021
Phone: 516-570-4400
The Chiari Institute is a comprehensive, multidisciplinary center for the management of patients with Chiari Malformation, syringomyelia, and related disorders.

http://www.thesmfoundation.org/
Christopher S. Burton Syringomyelia Foundation
PO Box 100335
Fort Lauderdale, FL 33310-0335
Phone: 954-727-5137
E-mail: info@thesmfoundation.org
This site offers information on symptoms, causes, and diagnosis of syringomyelia. In addition, the Foundation provides financial assistance to people diagnosed with syringomyelia and works to raise public awareness and educates the medical community about the condition.

http://www.syringo.org/
Syringomyelia Facts
This site offers information on symptoms, causes, and diagnosis of syringomyelia, as well as links to other resources and information on a Duke University research study.

http://www.ninds.nih.gov/disorders/syringomyelia/detail_syringomyelia.htm
National Institute of Neurological Disorders and Stroke: Syringomyelia Fact Sheet
NINDS presents information on syringomyelia, including causes and treatment, current research and links to other organizations.

http://www.ninds.nih.gov/health_and_medical/disorders/syringomyelia_short.htm
National Institute of Neurological Disorders and Stroke: Syringomyelia Information Page
NINDS presents a condensed version of its Syringomyelia Fact Sheet.

http://www.emedicine.com/NEURO/topic359.htm
eMedicine: Syringomyelia
eMedicine presents clinical information on syringomyelia presentation and treatment.

http://www.nlm.nih.gov/medlineplus/syringomyelia.html
Medline Plus: Syringomyelia
This site offers an overview of syringomyelia, including information on disease management and clinical trials.

http://www.spinalcord.uab.edu/show.asp?durki=21563&site=1021&return=21571
Spinal Cord Injury Information Network: Syringomyelia Fact Sheet
This fact sheet offers information on symptoms, diagnosis and treatment of syringomyelia.

Wishes and Rainbows
http://www.wishesandrainbows.org/
A non-profit organization devoted to helping those with Arnold Chiari Malformation, syringomyelia 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 *Borrow from Our Lending Library* under PRC Quick Links.

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.
- Professional golfer Bobby Jones had syringomyelia.

- **Chiari Malformation and Syringomyelia: A Handbook for Patients and Their Families.** Ulrich Batzdorf, M.D., Editor. Raleigh, N.C.: Lulu.com, 2008.

- 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

Breathe, Relax and Heal. Narrated by Rachel Greene. Produced by Mary G. Parker. Recorded for the American Syringomyelia Alliance Project. Audio CD. 2004. (39 minutes) For purchasing information, contact the American Syringomyelia & Chiari Alliance Project by phone at 903-236-7079 or 800-272-7282, or e-mail info@asap.org.

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