

About This Foundation

Several of my dear friends have assisted me in establishing this foundation and have been graciously volunteering their time to fulfill my wish and hope that no other person would **EVER** have to endure the pain and suffering that I have due to ignorance of SM in the medical community.

There are approximately 250,000 known diagnosed cases in the United States alone and it is my belief that there are far more undiagnosed cases due to the widespread lack of knowledge of this disorder.



Christopher S. Burton
Founding President

Our Mission

- ✓ **Raise and distribute** funds to those who are diagnosed with SM and can demonstrate a financial and medical need;
- ✓ **Assist** with short or long term financial assistance while social services are pending or insufficient;
- ✓ **Raise awareness** in the general public in hopes of finding a cure someday soon, and;
- ✓ **Educate** the medical community.

Currently there is no mechanism in place for immediate financial assistance for those who need it, like Christopher. We hope to bridge that gap for others so they do not have to suffer and learn the hard way too.

Resources and References

National Organization for Rare Disorders (NORD)

http://www.rarediseases.org/search/rdbdetail_abstract.html?disname=Syringomyelia

Washington University School of Medicine

<http://neuromuscular.wustl.edu/spinal/syrinx.htm>

National Institute of Neurological Disorders

<http://www.ninds.nih.gov/disorders/syringomyelia/syringomyelia.htm>

Cleveland Clinic

<http://www.clevelandclinic.org/health/health-info/docs/1300/1352.asp?index=6126>

Mayo Clinic

<http://www.mayoclinic.com/health/syringomyelia/A000464>

University of Maryland Medical Center

<http://www.umm.edu/ency/article/001398.htm>

Cedars-Sinai Institute for Spinal Disorders

<http://www.csmc.edu/5749.html>

The Alfred I. Dupont Institute

<http://gait.aidi.udel.edu/educate/syrsc0.htm>

eMedicine.com

<http://www.emedicine.com/neuro/topic359.htm>

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CHRISTOPHER S. BURTON

**SYRINGOMYELIA
FOUNDATION**

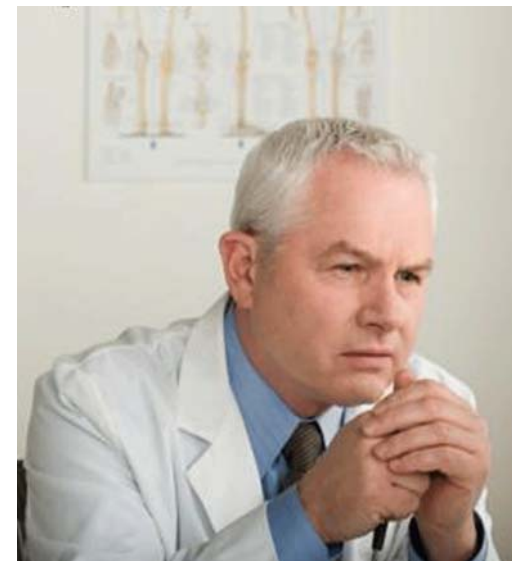
P.O. Box 100335, Fort Lauderdale, Florida 33310

954.727.5137 954.636.2409 Fax

<http://www.SyringomyeliaFoundation.org>

Sear Ingo My What?™

It's called Syringomyelia
(Sear-IN-Joe-My-E-Lee-Uh)



*An Informational Guide to Help
Medical Professionals Understand
Syringomyelia (SM) and its effects*

Courtesy of...

CHRISTOPHER S. BURTON

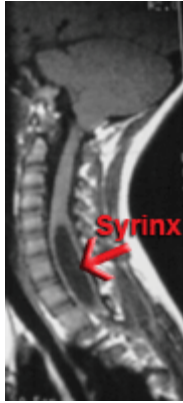
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Syringomyelia (SM)

(Sear-IN-Joe-My-E-Lee-Uh)

SM, is a chronic disorder of the spinal cord which consists of the formation of a syrinx (a pocket of cerebral-spinal fluid sometimes referred to as a cyst, hydromyelia, or syringohydromyelia) inside the spinal cord cavity. The syrinx may expand and elongate as it encroaches on the spinal cord and can easily cause deterioration of the nerves. SM is sometimes progressively degenerative and typically has a slow onset, however, symptoms can very easily rapidly progress due to strain or by trauma to the spine. It can easily yield very painful neurological symptoms of varying intensities and at varying times. In fact, most patients with SM are quickly dismissed as being psychosomatic.



Side Effects

A variety of neurological side effects including severe pain, possible pain induced vomiting, temporary or permanent loss of feeling in various parts of the body, sharp tingling or throbbing pain in un-isolated parts of the body, loss of hot and/or cold sensations in some areas of the skin, sudden hot and cold sweats, shooting pain in the arms and/or legs, weakness and/or wasting of the upper extremities, persistent extremely bad headaches, and in some cases stroke, blindness, paraplegia or quadriplegia can result.

Causes of SM

A syrinx may be caused by **Trauma to the spine** or by a **Chiari I Malformation** (key-are-E), or "**CM**" (respectfully named after Arnold Chiari), a congenital malformation of the hindbrain area of the skull that allows the brain to protrude beyond the base of the back of the skull. For reasons just now being understood, this causes a disruption in cerebral spinal fluid, the primary known cause of SM. It is currently estimated that CM results in approximately 70% of all currently known SM cases, however, due to the lack of knowledge of SM in adults, that number is likely to be inaccurate. The only way to diagnose CM or SM is with an MRI. With the introduction of MRI technology and more people surviving car accidents with spinal cord trauma these days, it is very likely that a large number of adults have trauma induced SM and are unaware of it.

Can SM be Treated?

Although there is currently no known cure for SM there are some treatment options, however, very limited. A neurologist who is familiar with SM should be consulted for evaluation, continuing check-ups, and any possible treatment options. Since **the primary symptom of SM is pain**, many cases are handled by pain management doctors or non-surgical orthopedics until such time as surgery becomes necessary, if it's even a possibility for the patient. For patients where surgery is possible it is not uncommon for multiple surgeries to be performed over time to drain the syrinx.

Why You Need To Know About SM

Misdiagnosis Prevention – SM can yield a myriad of neurological anomalies which can result in what may appear to be symptoms of other things you may be familiar with, such as meningitis, narcotic withdrawal, or stomach viruses. SM is almost always mistaken for something else in the Emergency Room. Only an MRI can show the presence of a syrinx or SM.

What are the Symptoms? – Symptoms can be vast and extreme like muscle/body aches, muscle spasm, extreme and persistent headaches, nausea, vomiting, sharp pains and numbness in extremities typically associated with spinal disk problems, loss of feeling in areas of the skin and many more neurologically triggered problems. These neurological anomalies can actually cause the patient to become physically ill as a result of the neurological symptoms. There have been patients known to have had things from stroke to complete blindness result due to complications.

What if I Have a Patient with SM? – You should always carefully review their complete medical history before performing any intrusive treatments to the spine. Spinal taps are not recommended for patients with SM. It is not uncommon for misdiagnosis to occur in an emergency situation based on what could be an outward display of neurological anomalies of SM. Consider the patient's neurological problems, medications, and their pain and their possible role in symptoms, as well. There is no cure for SM and this is still a lot to learn. Refer to a Neurologist if you're unsure.

Medications – Always be aware that patients suffering from SM will likely already be medicated for pain and/or nerve problems. In an emergency situation, patients are often denied their medication until the doctor realizes that it's likely a neurological side effect of SM.