

## 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](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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# Living With SM™

## Syringomyelia (SM)

*An Informational Guide to Help  
Those Suffering from SM*



*Courtesy of...*

**CHRISTOPHER S. BURTON**

**SYRINGOMYELIA  
FOUNDATION**

[www.LivingWithSM.org](http://www.LivingWithSM.org)

## 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.

## Tips for Living with SM

Below, you will find a few tips to help make your life a little better.

**Neurologist** – The first thing you should do is find a neurologist, and not just any neurologist, a neurologist who is familiar with SM / CM. You may find yourself visiting several doctors before you find the right one for you as you should be very selective. After all, it's your health on the line.

**Health Insurance** – If you have health insurance, try not to lose it. Getting a new policy after a diagnosis of a chronic disorder such as SM can be difficult if not impossible. If you had health insurance at work and are no longer working due to your health problems, you should COBRA your policy. COBRA allows you to keep your existing policy for up to 18 (and possibly longer if disabled) months at your own expense.

**Medical Condition Alert** – You should always have something with you identifying your condition. SM can cause unexpected neurological problems and you may find yourself going to the hospital, and if that happens, you definitely want a doctor or nurse to know what they are dealing with to help avoid a misdiagnosis.

This foundation offers a low-cost "Emergency Medical Information" card that has all of your vital health information conveniently listed on a durable, 2 sided laminated card. This ensures hospital emergency room staff has all of the pertinent information to treat you. Please visit us at <http://www.theSMfoundation.org/medcard> for more information. Everyone should carry one!



**Medication List** – You should always have a current list of your medications handy in the event of an unexpected hospitalization.

**Medical Info and History** – Along with your list of medications, you should prepare a list of your past medical history with your social security number on it, your primary doctor's name & phone number and any allergy warnings. This too could save your life in the event of an emergency situation.

**Periodic Check-ups** – If you have a syrinx, it is very important to have periodic check-ups and possibly have an MRI done to monitor any changes that may be occurring.

**Pain Management** – Many people with SM suffer from a great deal of pain and are unable to have surgery done to alleviate pain. This could be due to the location of the source of the problem and the inherent risks of dealing with a spinal cord; therefore, they are referred to Pain Management.

If this is the case for you, it is very important to choose your Pain Management doctor carefully as many do not understand or have even heard of SM. Often times a good neurologist can refer you to a Pain Management doctor that will be able to adequately control your pain.

**Social Security Disability** – Once you have been diagnosed with SM it is a good idea to immediately apply for Social Security Disability. The application and approval process is long, but if you are currently having pain chances are it may get worse. If it does get worse, it could easily get to the point that you will not be able to work. Social Security may be able to assist you with Medicaid or Medicare which is health insurance sponsored by the United States Federal Government.

**Consult your Doctor** – It is imperative that you consult your primary care physician before and after seeing specialists, whenever you have a question, hospitalization, change in pain, weight gain or loss, or if you are experiencing signs of depression or anything new physically. Doctor's can better help you if you keep them informed.