Syringomyelia Awareness Sheet

Definition:
A serious neurological disorder where a fluid-filled cyst, known as a syrinx, develops inside the spinal cord, stretching the cord and damaging nerve tissue

10 Things To Know About Syringomyelia
1. It is not known how many are affected, but estimates are as high as 200,000 people in the US
2. About 90% of cases are caused by a Chiari Malformation; spinal cord injury (post-traumatic SM), arachnoiditis, and tumors are other causes
3. Symptoms vary widely among individuals, but many people suffer from pain in the neck, shoulders, and upper back; numbness and weakness in the arms and legs is also very common
4. Additional symptoms include numbness in hands and feet; inability to feel hot and cold; pain and stiffness in the arms and legs; abnormal sweating; loss of bladder/bowel control; if left untreated can lead to permanent nerve damage and paralysis
5. Syrinxes are clearly visible on MRI’s (Magnetic Resonance Images); a neurological exam is used to assess damage to the nervous system
6. Decompression surgery is usually recommended for Chiari related syringomyelia, unless there are no symptoms
7. Surgery, performed by a neurosurgeon, involves removing part of the skull and spine, and often sewing a patch into the natural covering of the brain
8. Due to nerve damage, many people continue to suffer from symptoms - such as pain - after surgery; however up to 80% of people will experience some level of improvement or at least stabilize
9. Pain due to nerve damage, known as neuropathic pain, is very difficult to treat
10. Several theories on why/how syrinxes form; most have to do with the disruption of the natural flow of cerebrospinal fluid (CSF); none have been proven conclusively

Things We Don’t Know About SM:
- Why syrinxes form
- Why some people have a syrinx, but no symptoms
- Why decompression surgery works
- Who will improve with surgery and by how much
- What will happen to someone who doesn’t have surgery
- How to repair nerve damage caused by a syrinx
- How best to treat post-traumatic SM

Someone With SM May Not Be Able To:
- Be gainfully employed
- Lift heavy objects
- Stand or sit for any length of time
- Walk without assistance
- Drive a long distance
- Work on a computer without pain
- Feel that something is hot or cold with their hands
- Properly regulate their body temperature
- Perform fine motor tasks with their hands

For More Information Visit: www.conquerchiari.org

From Knowledge, Strength. Through Research, Hope.

This publication is for informational purposes only and is not intended as medical advice. Always consult a qualified professional for medical care.

© 2003-2012 C&S Patient Education Foundation