***Brain Aneurysm Lobbying Speech***

***2012***

Dear Representatives and Government Officials!

I am here to address you on behalf of The Brain Aneurysm Foundation and those whom it helped, helps, and will help. Today I am going to talk about brain aneurysm awareness. When it comes to brain aneurysms, awareness is the most important word. It is not the disease which is critical, – it is the awareness. There are two important groups in our country that *need* to know about brain aneurysms: the general public and YOU, public officials and society’s guardians.

Society is doing fine within the limits of its power, but when it comes to assistance from state-controlled health care services, people with brain aneurysm often crash upon the wall of impotence. The disease demands early detection to give people a hope for a better future, or a future at all.

When it comes to brain aneurysms, life appears to be a roulette which makes early detection an important part of educating society about a brain aneurysm. But, many brain aneurysms go undetected, due to the inability of health care professionals to diagnose a brain aneurysm. This is how it happens: patients suffering from a brain aneurysm go to the emergency room and are seen by an ER doctor. Often, they are not diagnosed properly. Many times, the patients are sent home, stuffed with painkiller prescriptions to calm the pain in their heads. But this is totally wrong. These painkillers fight the effects, not the causes. We need to educate Emergency Room doctors and teach them to perform a CT scan on patients, or to do an MRI or MRA, if the problem demands this kind of examination.

In instances where an individual is properly diagnosed with an aneurysm at its early stages he or she must then navigate the complicated treatment path of a brain aneurysm. Treatment is expensive, and working with health insurance companies is complicated and stressful. Health insurance companies do not want to pay for proper procedures to treat brain aneurysms, even though patients are paying for their own health care. Dealing with these issues makes it difficult for brain aneurysm patients to move forward with both treatment and their everyday lives. If society, doctors and healthcare companies had more awareness, brain aneurysm patients could enjoy a better quality of life, knowing that a happy, pain-free future is possible with the right care and treatment. Like a giant organism with a collective mind, society can apply collective effort to heal its people, to help those who need help. The institute of family attempts to carry the burden. This is how it happened in my case.

I am one of the unlucky, dealt the hand of a grade four ruptured brain aneurysm. The likelihood of my survival was slim and my condition was hardly compatible with life. Fourteen hours of emergency brain surgery gave me a chance to continue my life, but I would not have succeeded if not for my family. My parents and my 10 brothers and their families came to support me, to give me a helping hand. I also had teams of caregivers from the hospital, and therapists from the rehabilitation center, where I spent four months of my life. This collective group of people helped me make my first steps, relearn the basics of walking, speaking like I did when I was a child. I started a new life.. I was reborn.

Thanks to my family and caregivers I made it through months of therapy. But I was also helped by our institute of Public Health, specifically the Brain Aneurysm Foundation. The Brain Aneurysm Foundation, also known as B-A-F, became my second family. Especially Dede Buckley, and my fellow survivor and friend, Norm Belanger.

The Brain Aneurysm Foundation (BAF) is the world's only nonprofit organization solely dedicated to providing critical awareness, education, support and research funding to reduce the incidence of brain aneurysm ruptures. The BAF helps people accept their condition, and never give up on themselves. The foundation’s website and all its members possess the precious knowledge regarding brain aneurysm, its symptoms, treatment and post-treatment rehabilitation to help educate the rest of the world about our condition.

Today, I serve on the BAF board, and I am a proud non-profit caregiver helping to educate and promote awareness to supplement the lack of care and support many brain aneurysm patients have felt from the state’s health care system. For the past 10 years, I have been calling brain aneurysm survivors and their families who are new to this disease and want to learn more about a brain aneurysm, its treatment and recovery. I have also made plenty of visits to Mass General Hospital to speak to families caring for their loved ones dealing with the aftermath of a brain aneurysm. My family was in the same boat when I was diagnosed, and my two families helped me row that boat, pushing it forward. This is how people help each other. But we are only humans, and human powers are limited. That is why I am now appealing to you today, representatives of both the society and the state with the power to help us row faster and farther.

With brain aneurysm disease, the numbers are very powerful, sometimes more powerful than words.

* An estimated 6 million people in the United States have an unruptured brain aneurysm, or 1 in 50 people.
* The annual rate of rupture is approximately 8 – 10 per 100,000 people. In other words about 30,000 people in the United States suffer a brain aneurysm rupture.
* A brain aneurysm ruptures every 18 minutes.
* Ruptured brain aneurysms are fatal in about 40% of cases. Of those who survive, about 66% suffer some permanent neurological deficit.

* The aggregate lifetime cost associated with SAH - brain aneurysms is $5.1 billion. The cost of treating a patient post rupture more than doubles when being clipped, and increases by 70% when being coiled. Again, appropriate screening can save lives and lesson the economic burden to a family and society.
* More funding is needed for research. Brain aneurysm research is greatly underfunded:

     Funding\*

            AIDS:                           $3.05 Billion

            ALS: $ 44 Million

Breast Cancer:             $715 Million

            Prostate Cancer:          $284 Million

            Aneurysms:                 $ 1.61 Million

\*(Based on 2011 NIH funding)

The numbers are shocking. The help received is not enough. That is why I am now lobbying for brain aneurysm awareness, early detection and the importance of adequate research funding. I believe it is our combined awareness that will help us diagnose brain aneurysms earlier, treat brain aneurysms more effectively, and provide the kind of support to brain aneurysm survivors and their families that is so badly needed to help them toward a happy future. Thank you for your time today.