

A Plea for Help!

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Steve Mallory had a massive brainstem stroke in 1994 at 36. His stroke caused quadriplegia and loss of speech. He was an Aerospace Quality Group Engineer for Martin Marietta. He lives in Abingdon with his wife and full-time stroke caregiver, Melissa. They have two children, Traci, 25, and Erin, 22. His personal homepage is at <http://www.strokenetwork.org/staff/stevemallory/> if you would like to read more about him.

help!

Our mission has always been to provide on-line stroke support and information. For the first 5 years I funded the organization out of my own pocket. I am medically retired and my wife is my full-time stroke caregiver, but somehow we managed to pay the organization bills and our household bills without any income. However, the organization bills kept increasing and we were growing each year by leaps and bounds. I knew that I had a great concept with on-line stroke support and information because our membership never stopped growing!

So, six years ago, I decided that I could not continue to fund Stroke Network by myself. I knew that my mission was critical and that somehow I needed keep my web site open. Providing on-line stroke support and information was definitely needed. Thus, I filed for non-profit status and with the help of my wonderful brother-in-law, sisters, mother, wife, daughters and numerous friends we were able to put together an annual fundraiser. That was the

I founded Stroke Network, over 11 years ago, when I had my stroke. After my hospital discharge, I came home and started playing on the computer for physical therapy to strengthen the movement of my arm. I soon could move my arm good enough to try accessing the Internet through America On-line. I searched the Internet looking for information about stroke and hoping to find someone my age that also had a stroke. I was not too hopeful. I found a small group of stroke survivors in an America On-line room; the Internet was grossly undeveloped in 1994. Most stroke survivors were between 30 and 55, I was 36. They all had the same question. How could a young person have a stroke? This chat room was an impromptu meeting place for young stroke survivors.

There is much more to the story and maybe one day I will get to tell you all about it. The short of it is, is that I founded the first on-line stroke support group on the Internet. Though quadriplegic, I taught myself html and have designed all of my own web sites. Despite the quadriplegia and not being able to talk I have been able to open the accounts and manage all of the Internet services associated with being one of the largest and best health related sites on the web. I purposely do not ask for any assistance unless my back is up against the wall. Now, after 11 years of doing it by myself I am making a plea for

first annual Stroke for Stroke golf tournament. We soon had money in the bank and a burning desire to use some of it! The site transformed, almost overnight, into one of the best health related web sites on the Internet.

I would estimate, including all the visitors we have had looking for information about stroke, that we have helped at least a minimum of a quarter of a million people, in all 11 years of our service. It feels so good to know that so many people, who were miserable and down-trodden, have found the safe sanctuary of Stroke Network. Many people email and send me feedback about how their life has improved after finding our web site, people from all over the world!

We started out 11 years ago with about two dozen people and, today, we have over 6,000 registered members. We are a failure of our own success, though. Our bills have increased proportionally with our membership. Five years ago, we could have one fundraiser per year and a handful of donations and it would pay all the annual bills. Each year, the revenue we have raised has paid the bills but what is left over gets smaller and smaller. We still have only one fundraiser per year and still receive a handful of donations but now the bills grow larger and larger, each year! This year, for the first time in 11 years, we have had to dig deep into the reserves of our bank account; I am deeply concerned.

What would happen if Stroke Network had to go out of business? I guess this is a common concern amongst small non-profit organizations! We have to fend for ourselves to raise money but with my physical limitations it is not like I can get out there and stimulate people to give. The bills are all paid for this year but next year we do not have the money in the bank! I have to plea for donations!

When you think about the costs of maintaining a web site, you probably just think about the annual hosting and domain name renewal fees. The problem is that it is not web site costs that are hurting us. It is all of the Internet expenses that are increasing.

I have stated that expenses increase proportionally with membership size. Let me give you two examples of what I mean:

Example 1: We have been publishing a monthly newsletter for five years. When we opened an account for newsletter publishing the membership was under 500 people and our annual fee was only \$230. Today, we have over 7,000 subscribers, with over 1,000 people who have subscribed but are not members of Stroke Network. The annual fee for 5,000 to 10,000 subscribers is \$608. Our annual expense has nearly tripled!

Example 2: Our organization has grown from about five volunteers to nearly 50. We have an excellent infrastructure with a fantastic human resources department. We have personnel records for every volunteer. Every volunteer is either a stroke survivor or stroke caregiver and not one, including myself, receives a salary. Anyway, our personnel records have to be managed with an on-line filing system. Our host unexpectedly stopped providing support for the file management application and we could not access any of our personnel folders! We had to do something about this and very quickly! I spent days searching for a system that would meet all of our needs. We had been using a basic file management system that had an annual fee of \$75/year. I finally came across a system that was called a virtual office. It had several features that our staff needed, in addition to the filing system. It is similar to an Intranet. When you manage a business with almost 50 employees, things like having good communication, managing organization records, and having the ability for timekeeping, is essential functions for any decent business structure, so I felt it was a necessary expense. Our volunteers are scattered all over the world. I did not go all out and agree on a membership for every staff member because that would have cost about \$5,000/year. I agreed that our Operations Department staff members, about 15 volunteers, needed to use this account. The annual fee is about \$1,300/year and we are only letting 1/3 of our staff use this service.

Based on these two examples alone, we went from an annual newsletter and filing management expense of \$305/year to the current expense of \$1,908/year! You do the math. I should note that this does not include things like printing fees, which are at least another \$700/year; postage and shipping expenses are about \$300/year; and administrative expenses, hardware and software expenses, this year, are about \$4000 this year. Our current Internet expenses are \$5,400/year so add all of this together and the operating expenses equals \$9,400 for 2007!

If our operating expenses are \$9,400/year, and we grow by at least 2,000 new members each year, I can easily extrapolate that out and in five years we will have added another 10,000 members and our operating expenses will increase to about \$25,000/year! Then, when I figure that we should have at least five years of money in our bank account, to pay for our future operating expenses, therefore, **we need to raise at least \$100,000!** This is my target goal. The money is definitely not for my personal use. This is for my organization! Society needs my organization!
Can you help us please?

I know that you probably think, "Why can't they donate to their own organization?" This is a valid question! I usually do ask for donations every year amongst my members but only a handful of people can afford to donate. Most cannot work and were prematurely forced to retire. I can absolutely understand this; most of my members are permanently and severely disabled. Most have cognitive deficits; short-term memory loss, loss of reading comprehension and math skills affects practically every stroke survivor, impulse control, emotional problems such as crying at inappropriate times, easily being frustrated and anger management issues are incredibly frequent. Speech deficits can be a very widespread problem, too. All of these deficits are deficits faced daily by stroke survivors. Just about all stroke survivors cannot and are not allowed to drive any longer. Isn't life with stroke exciting? I am being facetious, of course, but you get my point! You do not appreciate what you have until you no longer have it!

Millions of lives have been destroyed by stroke; over 700,000 Americans have a stroke each year. Probably 98% of these people are discharged from the hospital without the possibility of attending a local stroke support group. I know because I have visited several local groups myself and have seen how low attendance is in the groups. It is not the hospitals fault. Stroke survivors cannot attend for various reasons. Lack of transportation, inconvenient meeting times, driving distance, and communication problems at the meetings are just some of the universal reasons that stroke survivors and even stroke caregivers have told me that they do not attend local stroke support groups.

The reasons that I have stated above, combined with the permanent disabilities that stroke survivors face, are the reasons that stroke survivors have turned to on-line stroke support. Many want to find out if anybody else has the same kind of deficits as them. Empathy is one of the big motivators that cause any type of survivors to flock together. Look at heart disease or cancer! Aids, MS and SCI are like this, too! Why not stroke? It is the number one cause of permanent serious disability. The World Health Organization estimated that in 2001 there were over 20.5 million strokes worldwide and 5.5 million of the people died. High blood pressure contributes to over 12.7 million strokes per year worldwide.

Our members eagerly want to empathize and provide support to their brothers and sisters in stroke. Practically every exchange results in the swapping of personal stories, dishing out of practical suggestions and ends with a motivating comment. All of these communications happen via message boards, live chat rooms, email and instant messages. Since we received our non-profit status five years ago, our message board has logged almost 40,000 such discussions.

The Stroke Network has helped hundreds of thousands of people with our services. We need your help! We cannot make it by ourselves. We are a non-profit organization and that means that we have to generate revenue through fundraisers and donations. What I am asking is that you take an interest in our organization. Please help

us by donating to The Stroke Network. We need donations from you, your families and friends and through the donations of private businesses.

Almost everyone will eventually somehow be affected by stroke. Roughly everyone, at some point in time, will understand the grief and awfulness of someone who has had a stroke. Stroke does not discriminate. Stroke knows no borders. *It is the number 1 cause of permanent serious disability.* Rest assured, if Steve Mallory has anything to do with it, Stroke Network will be there to support you!

Our organization does not pay salaries to our volunteers. We do not have office space, either. We operate on our personal computers out of our homes. Our overhead expenses are zero so 100% of donations go directly towards paying our ever increasing Internet expenses.

We need your help! We need donations! We need to raise funds! If anybody contributes and then needs our Employer Identification Number, EIN, it is 26-0040447. Employers should be aware that we are setup for gifts in-kind and payroll deductions. I can be scheduled to provide awareness classes on stroke reduction. Please email me to schedule a class.

Please help me raise \$100,000! Our donation web page is at <http://www.strokenetwork.net/donation/> and, if you like, you can find out more about our organization by reading our Media Kit at <http://www.strokenetwork.net/media/>. Please help before it is too late! We have thousands more who need our help! **Time is running out!**