

LETTERS TO THE EDITOR OF NEUROLOGY NOW MAGAZINE:

I decided to post the letters that I wrote to Neurology Now since I was diagnosed with MS in October of 2006.

I find it interesting how my letters that talked about different things were published in a matter of weeks (in the next issue) while the ones that I started writing about CCSVI haven't been published and they never received an answer...

“MULTIPLE SCLEROSIS”

My name is Angela and I was diagnosed with multiple sclerosis (MS) two years ago.

I had my first attack three days after I was told that I might have this serious chronic disease.

In the course of these past two years, I had to change medications three times and I have experienced three serious relapses. I have been able to learn a lot about MS by reading Neurology Now and I found the articles about MS very interesting.

Instead of getting down on myself and letting fear of the unknown take over, I created a project that I called Flowers4MS.

It allows me to raise awareness and funds for MS research. The project keeps me going and makes me feel grateful for each and every day. I share my story on the web site at www.flowers4MS.com.

Thank you for your informative coverage of such a debilitating disease.

Angela Cleary

Help support research to find a cure for MS!

Flowers4MS.com

**WRITTEN IN THE MONTH OF OCTOBER OF 2008 AND
IT WAS PUBLISHED ON THE NOVEMBER/DECEMBER ISSUE OF
THE SAME YEAR.**

“UNSUNG HEROES”

This letter is in response to your question in “From the editor” (May/June 2009) asking us about the unsung heroes in our lives. I was diagnosed with multiple sclerosis (MS) in October of 2006.

I would like to talk about a doctor that has become my hero. He showed me that a scientist can have a wonderful and caring heart.

His name is Benjamin Greenberg and he works at Southwestern Medical Center in Dallas, TX.

Was started as a second opinion, became the best choice I made in my MS life!

He was always willing and open to answering my questions, regardless of the time of the day. Dr. Greenberg was able to learn the type of support I needed from a doctor. He tailored his treatment to me as a person. I never felt like I was just another patient, because he took the time to learn who I am.

In fact, I created a video that I call “the Unsung Heroes” where I celebrate the wonderful work of the many scientists that I admire and that are dedicating their lives to finding a cure for MS and for the many other rare neurological diseases.

You can see my video on my website flowers4MS.com where I help raise funds for MS research.

Angela Cleary

WROTE THIS LETTER IN AUGUST OF 2009 AND IT WAS PUBLISHED IN THE SEPTEMBER/OCTOBER OF THE SAME YEAR.

“CCSVI AND THE LIBERATION TREATMENT”

December 3, 2009

Dear Editor,

My name is Angela Sergio Cleary and I have suffering from Multiple Sclerosis for the past 3 years. I am originally from Italy and I have been

living in the United States for many years. I was diagnosed with MS in October of 2006 at the age of 33 and I had my first relapse 3 days later.

From the beginning, I felt the need to be active in getting better, in raising awareness for this disease and to raise funds for research so we could find a cure on the near future. After my second major relapse, in September 2007, I created a project that I call Flowers4MS. In April 2008, I launched a website, called www.Flowers4MS.com, where I sell floral greeting cards. I donate 100% of the proceeds to support the scientists engaged with MS

research. Since its inception, and despite several more MS relapses, I have raised over \$29,000. In October 2008 I also began posting videos on Youtube where I share my story, my experiences and the latest news in research.

During the course of learning about this disease, I recently came upon the work of an Italian doctor, Dr. Paolo Zamboni of the University of Ferrara, Italy. I am interested in letting the public know about his discovery. He shocked the MS community by saying that this disease is not only an autoimmune disease but is related to the flow of blood to and from the brain, making it a vascular disease.

As it stands right now, this is the latest surrounding his work. Recent reports from Italy that a correctible vascular condition may be the cause of MS, or contribute to its progression, have grabbed the attention of the MS community.

A vein condition dubbed Chronic Cerebrospinal Venous Insufficiency (CCSVI) has been the focus of research led by Dr. Zamboni, a former vascular surgeon and professor at the University of Ferrara. He has discovered, using ultrasound, that almost all MS patients he viewed had blocked or twisted veins in their necks and upper chest. Healthy people do not typically have this condition.

In people with CCSVI, Dr. Zamboni theorizes, blood fails to properly drain from the brain and can even flow back upwards into the brain. There, the blood could be depositing iron, a substance that is toxic to the brain's grey matter. This excess iron could be what sets off a host of immune reactions -- and possibly, the symptoms of MS.

He has tested a procedure he calls the "Liberation Treatment" that he says can open those blocked veins using a balloon inserted in the vein, in much the way surgeons repair coronary arteries in angioplasty. The hope is that the treatment allows blood to drain properly and arrests the progression of MS.

Dr. Zamboni has begun publishing research on CCSVI, hoping that other doctors would take a look at his theory. His work caught the attention of Dr. Robert Zivadinov, at the University of Buffalo, who is also now conducting research on the prevalence of CCSVI.

A Buffalo team of researchers, led by Dr. Zivadinov, plans to recruit 1,100 patients with MS and 600 other volunteers as controls who are either healthy or have neurological diseases other than MS. Using Doppler ultrasound, they will scan the patients to see if they can find any blockages within the veins of the neck and brain. If they can prove Dr Zamboni's theory of "chronic cerebrospinal venous insufficiency," they say it will change our understanding of MS.

I am for your assistance in spreading this news and to ask the MS community to urge the National Multiple Sclerosis Society and their doctors to learn more about and to support these studies. I feel this is a very promising field of research and deserves our utmost attention.

I look forward to the day when people will stop suffering from this disease and be able to return to living their normal lives.

Thank you and take care,

Angela Sergio Cleary

I WROTE IN ON DECEMBER THIRD AND IT WAS NEVER PUBLISHED...

“CCSVI, CHRONIC CEBROSPINAL VENOUS INSUFFICIENCY”

April 13th, 2010

My name is Angela, I have been reading Neurology Now since I was diagnosed with MS in October of 2006 and I have written to you many times before. I have found your magazine quite interesting and useful but I have to tell you that I am very disappointed that there has been no coverage on a potential new treatment for Multiple Sclerosis that the MS world is very excited about.

This new discovery called CCSVI, Chronic Cerebrospinal Venous Insufficiency, it refers to a narrowing or blockage of the primary veins draining blood from the brain to the heart and it was discovered by Dr. Zamboni at the University of Ferrara in Italy. CCSVI has been found in MS patients tested world-wide and while it is still being studied, it's bringing patients a lot of hope.

I hope that you will write about it in the next issue.

Thank you,
Angela

I WROTE IT ON APRIL 13TH OF 2010 AND IT WAS NEVER
PUBLISHED...