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# The remarkable story of Virtualtrials.com

**Al Musella, DPM**

Founder and President, The Musella  
Foundation and Virtualtrials.com (USA)

**IBTA:** Al, what brought you into the brain tumor information and advocacy area?

**AM:** It all started when my sister-in-law, Lana, was diagnosed with a glioblastoma multiforme (GBM) in 1992. She had surgery and radiation, and then the first post-radiation MRI showed the tumor had grown [bigger] than it was before the surgery, and we were told it was hopeless. This was before Temodar [Temodal], Avastin and even Gliadel were available.

Lana had four young children at the time who really needed their Mommy. When we looked into clinical trials, we were told that there were none for her as her tumor was too large. She was told there was no chance that she would make it to Christmas. The only options they offered were do nothing or use BCNU (carmustine), and we were told it wouldn't make much of a difference.

I couldn't and wouldn't accept that there were no options.

I found that there was no centralized database of all clinical trials. The National Cancer Institute (NCI) had a database of the large trials, but not

online. You had to telephone them and wait for them to mail you a list. They didn't even have the technology to fax it or email it to you! They didn't have the smaller trials. They said there were no trials that Lana qualified for because the tumor was too large.

I looked online for a brain tumor support group and there were none, only general cancer forums. So I started the first online support group dedicated to brain tumors on Compuserve and then AOL.

Our members helped me create a database of clinical trials by surveying every major hospital in the USA. We found more than twice as many trials as the NCI had in their database. I published the database online, which was the first brain tumor trials website, and one of the first database-driven websites of any cancer type. The NCI became interested in my website and used it as the model for clinicaltrials.gov.

We found many trials that Lana was eligible for. She tried two of them and did much better than expected. She lived eight years, most of which were in good health, which was unheard of back then.

Then, my father was diagnosed with a GBM in 1999. This time we were more prepared, but it was still a horrendous experience. He died in about six months because the tumor progressed so fast that he wasn't able to complete radiation.

**IBTA:** The Virtual Trials website must take up a lot of your time. What are you trying to achieve with it?

**AM:** Yes – it takes a lot more work than you would imagine. I add something to the website daily, and



*Dr. Al Musella receiving the "Voices Award" from Voices Against Brain Cancer, a US brain tumor organisation*

also respond to emails and phone calls from the website and our ten online support groups seven days a week.

I am trying to do two things with my Foundation.

First, speed up the search for the cure by raising money for brain tumor research and helping direct research. I have had many ideas to improve treatments and found researchers willing to work on them – and then I funded them.

I also found researchers with exciting projects who couldn't find money to do them, and I help fund them or find other organizations to fund them. I can't fund them all, so I (along with the Brad Kaminsky Foundation and Unlocking Brain Tumors) formed a group called the Grey Ribbon Crusade, which has over 60 brain tumor foundations working together to help fund research projects.

We also track the treatments being done and the outcomes in our Brain Tumor Virtual Trial so we can get an early warning if a new treatment or combination of treatments are working or not.

The second thing is to help families deal with the diagnosis of a brain tumor. This is one of the most devastating things that can happen to a family.

Immediately, the entire family goes into shock when they understand what a diagnosis of GBM or DIPG (diffuse intrinsic pontine glioma) means. Then they are called upon to quickly make the biggest decisions of their lives – which doctors to use, which trials to enter – without enough information to make a rational decision, without



*Al Musella attending a brain tumor conference in Ashland, Oregon which he co-organised*

understanding the terminology and while being in shock.

I see a lot of people who find too many options and waste valuable time trying to find the answers – so much time that they lose the battle without having made a decision.

My aim with the website is to allow people to become educated about the disease so they better understand the choices out there, and so that they can better understand what the doctors are talking about, and therefore make more educated choices. We help people – both through the support groups and individually - go through the choices they have and help them choose.

We also had success with advocacy issues such as helping get Temodar and Avastin approved by the FDA, and getting Medicare to pay for Temodar and Gliadel.

**IBTA:** Give us some background on the virtualtrials.com website.

**AM:** The website started out as the file library of our Compuserve cancer forum in 1993, which had a file listing all available clinical trials for brain tumors as well as important articles and educational material.

When the web was launched with Netscape the next year, I started experimenting with the web and moved the library to a website and added an

online forum. We changed from using a text file for the trial listings to using a database-driven format which was easily searchable and sortable.

For example, you could now list them by state, or list only a certain phase or type of trial, or find all trials by a particular doctor or hospital, or trials that allowed or didn't allow prior surgery, radiation or chemo.

Back then domain names were expensive, so I piggybacked off of the website of one of my friends. Then in 1996 I took the plunge and registered the domain name virtualtrials.com. The name came from our Brain Tumor Virtual trial project. We used .com instead of .org because this was before we became a non-profit organization, which we did on March 15, 1997. At that point we added the domain name virtualtrials.org which points to the same website as virtualtrials.com, but we had so many links in publications and on the web that pointed to the .com version that we just kept it as the main domain name.

The website has grown every day in size, and now is made up of over 13,000 files, taking over 8 gigabytes of space, not including the 20 gigabytes of video in our video library. We use an MS Sql server database that now has over 600 megabytes of data.

In the last year, we had 2.6 million visitors from 203 countries (36,000

visitors from Australia!), generating 26 million hits.

We have some exciting plans for the future of the website and welcome suggestions and submissions of articles or videos.

**IBTA:** What is your background?

**AM:** There were three factors in my background that influenced my ability to run the Musella Foundation.

I still work part time as a podiatrist in New York. The first two years of podiatric medical school are the same as the first two years of medical school. Some of the courses we studied included pharmacology, neurology, neuroanatomy, surgery, radiation, immunology, biochemistry, and research methods. I even dissected a few human brains. I also read many brain tumor articles and books, and attend brain tumor conferences to keep up with changes in the field.

I was a computer geek in high school and college and worked my way through college doing research on artificial hips at a medical school. I designed the computer software and testing apparatus used to develop a new type of hip replacement.

I also did the programming for the first version of the orthopedic index – which became the model for the online

*Continued on next page*



Ben Williams

"When I began researching treatment options on my own, it quickly became clear that the best way to disseminate that information was via AI's website, rather than develop a competing website. Part of AI's value comes from his being very well-known, and widely respected, in the neuro-oncology community, which allows him access to a great deal of "insider information" that is not available from journals and conference proceedings."

Ben Williams

[Editors' note: Ben Williams, PhD, is a 14 year survivor of a GBM, having been diagnosed in 1995. He has written a book about his journey titled: **Surviving Terminal Cancer: Clinical Trials, Drug Cocktails, and Other Treatments Your Oncologist Won't Tell You About**. The book can be purchased online via Amazon.com and a regularly updated report by Ben Williams on GBM treatments is available here: <http://virtualtrials.com/williams.cfm> ]

version of Medline. I got into creating websites back when Netscape first came out – around the same time Lana was diagnosed. The first major website I created was for brain tumors which later became [virtualtrials.com](http://virtualtrials.com). Since then, I formed a company to create websites and have created a few other major websites. I wrote 100% of the code that runs [virtualtrials.com](http://virtualtrials.com). (I did have help with the graphics).

And finally, my experience of going through this ordeal multiple times enabled me to see the problems and concerns that pop up and how best to handle them. Aside from Lana and my Dad, my Mother died of lymphoma which had spread to her brain, and I currently have two brothers-in-law dealing with benign brain and spinal cord tumors.

**IBTA:** It can be an emotionally challenging area in which to work, how do you cope with the environment? Do you have a hobby or sport totally unrelated to brain tumors?

**AM:** I get close to a lot of people and



*"Few people realize the enormous role Al plays in the brain tumor community, not only providing information and conferences for patients, but using his considerable fundraising skills to fund key research at the pilot stage."*

John Williams

*[Editors' note: John is a patient advocate and brain tumor community organizer living in Ashland, Oregon, USA]*

it really hurts when they die. It is bad enough when it happens to an adult, but when it happens to a child, it is really heartbreaking. I have two healthy children and I couldn't imagine the pain of having a child go through this. This continually motivates me to speed up the search for the cure.

I love to go fishing. I have a boat, and try to get out on it as much as possible just to unwind. I have invited onto the boat a lot of brain tumor doctors, researchers and patients, and it is a nice way to get to know people and discuss things in peace and quiet in an unrushed situation. Some important connections were made in this way which may result in exciting things to come!

I also enjoy taking the family on weekend trips. I try to schedule them around meetings or try to visit our scientists while in the area.

For example, I took the family to Hershey Park in Pennsylvania, and stopped by Hershey Medical Center to talk to the inventor of one of the drugs in a major trial. We had a nice conversation and he told me he has the next generation of the drug in a test tube, but he can't get funding to work on it until the other drug trials end in a few years, so I wound up funding the early development of it and it is now getting close to human trials. That little side trip cut years off of the process for this drug!

**IBTA:** What do you regard as your most useful contribution to the brain tumor community?

**AM:** Probably the online support groups. Our largest group, the "brain-temozolomide group" was started when Temodar was in clinical trials. After the trials ended, it changed into a general brain tumor group with an emphasis on GBMs. (At that point in time, we merged the CompuServe brain tumor forum, the AOL brain tumor group and our web based forums into the "brain - temozolomide group". We kept the name "brain-temozolomide" because it was linked to from all around the world and in



*"Al runs the first and the most comprehensive Internet site serving brain tumor patients and caregivers. He is a great mentor as well as a great friend."*

Hong

*[Editors' note: Hong is a caregiver.]*

government publications).

All cancer online support groups have ups and downs in terms of bickering since all of the members are under so much pressure handling the disease. We kept it on topic by splitting out a few subgroups – like "brain-community" and "bt-faith" where people can talk about jokes, politics, religion or whatever (and keep it off the brain-temozolomide group). I learned how to handle these support groups so they now run smoothly. Our medical advisory board members are available to handle questions that aren't answered in the group.

We have had many instances where the group has helped patients. We had noticed through the group and the virtual trial, that patients taking Temodar during radiation did better than expected, so many of our members tried that "off trial", a year before the paper came out saying it should be the standard of care.

We also had several instances of possible blood clots in the leg in the middle of the night when people post that they have a problem and are not sure if it is urgent enough to go to the Emergency Room, and other members tell them to go to the ER – which they may not have done if they didn't realize how serious it was.



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We also had questions about which treatment options are available, how treatments work, which options are best, which doctors are best, over dosages of drugs, missed drugs, how best to take drugs, handle nausea and constipation and how to handle end of life issues.

I would say that every family dealing with a brain tumor should have at least one family member join the group at <http://virtualtrials.com/temozolomidelist.cfm>. Most families have never dealt with a brain tumor diagnosis before and don't know anyone who had one. Joining the group allows them to communicate with over 2,000 other families going through the same thing.

**IBTA:** What do you see happening in the future as regards research and treatments?

**AM:** I am very encouraged. I have been immersed in brain tumors for about 17 years. There have been amazing changes in attitude among the brain tumor researchers.

Years ago, there was no optimism that a cure could be found, and they really set their sights low – like trying the same drugs over and over in slightly different ways hoping for a small improvement and there were very few new ideas. Now many researchers believe they are working on the potential cure. There is an amazing array of new treatments being developed. I feel that a cocktail of a few of the currently available treatments will be the ultimate cure.

The hot topic in neuro-oncology now is personalized treatment. I waver back and forth on the issue. Sounds good, but I would prefer a standard cocktail that works on most tumors.

I worry that if you personalize a treatment, the tumor may be able to evolve around the treatment. If you find a combination of treatments that work in different ways, there is less of a chance for evolution of the tumor.

Unfortunately, due to the terrible economy, some of the most promising brain tumor treatments are stalled – just waiting for funding.

My biggest fear is the possibility of a cure being out there and not knowing about it in time to help our friends and families. That is the main purpose of our brain tumor virtual trial and our online support groups – to identify when something is working and spread the word quickly! ■



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