

Reprinted from *Brain Tumour, World Edition 2010*, produced by the International Brain Tumour Alliance, [www.theibta.org](http://www.theibta.org).

# The remarkable story of Virtualtrials.com

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

**IBTA:** AI, 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, but 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 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 created a 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 included 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. AI 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 ideas and 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



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

understanding the terminology and while being in shock.

many options and waste valuable 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 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 database-driven format which was easily searchable and sortable.

For example, you could now list them by state, or list only a certain 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 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 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 to run the Musella Foundation.

I still work part time as a podiatrist. Podiatric medical school are the 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.

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

I also did the programming for the 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> ]*

Reprinted from **Brain Tumour, World Edition 2010**,  
produced by the International Brain Tumour Alliance, www.theibta.org.

version of Medline. I got into creating  
k YVgJHgVUW\k \Yb'BYrgWdY Úfghi  
came out – around the same time  
@JbU'k Ug'X]U[ bcgYX" HAY Úfghia U'cf'  
website I created was for brain tumors  
which later became 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. (I did have help with  
the graphics).

5bX ÚbU`nãa mYI dYf]YbW'cZ[ c]b[ '  
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 AI 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.

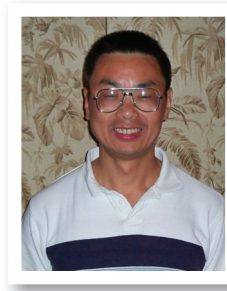
=cj Y'hc [ c'Úg\]b[ "' =\Uj Y'U'VcUHz'  
and try to get out on it as much as  
possible just to unwind. I have invited  
onto the boat a lot of brain tumor  
doctors, researchers and patients,  
and it is a nice way to get to know  
people and discuss things in peace  
and quiet in an unrushed situation.  
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



I'5'fi bg HAY ÚfghUbX' HAY'a cghi  
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.

