
Online discussion group for the Novocure TTF system

AL MUSELLA (USA) hosts the Virtualtrials website, regarded by many as the most comprehensive web resource for brain tumour treatment information in the English language (www.virtualtrials.com) He is also the "father" of an email discussion group on the NovoTTF 100A System for brain tumour patients and caregivers.

IBTA: When and why did you commence the email group for brain tumor patients and caregivers using the Novocure NovoTTF 100A System?

AM: I started the "brain-novocure" online support group on 3 Jan 2010 as a way for people in the Novocure trial to discuss their experiences with the device. It is a unique treatment and there really was no other place for users to talk to other users since there were so few of them spread out across the world. The group is doing great. We keep it on topic. Most members are also in our "braintumor-treatments" online group so questions about general brain tumor problems are asked there.

IBTA: How do you believe the Novocure group has benefited its members?

AM: Technical questions pop up and others help them through it - such as how to go through airport security with a device that has wires and batteries or how to manage the recharging of the device's batteries in your car by getting an inverter that plugs into the cigarette lighter, or how to deal with irritation under the electrodes. One member found a perfect luggage carrier to use to move the device around with and shared it with the group.

IBTA: What else do the members discuss?

AM: There is talk about [USA health] insurance issues - luckily costs haven't been a problem yet. They also talk about the ups and downs of using the device - it is a hassle, but no nausea or major side effects. We hear about how the tumors are



Above: The Novocure TTF device (posed by a model). Photo courtesy of Novocure.

responding. It doesn't help everyone, but for some people it is helping a lot. We found that it takes time to show improvement. Many doctors took the patients off the device too quickly at first. We had people who had growth on the first scan after starting the device - who were told to come off of it but insisted on continuing, and in some it did turn around and start working. We now have some people who are combining it with other treatments and we are watching to see what happens.

IBTA: You have been involved with online discussion groups for a while. When did you first start?

AM: I have created a few online groups. I started the first online support group dedicated to brain tumor patients: "The Compuserve Brain Tumor Forum" back in March of 1992 on the Compuserve Cancer Forum when my sister-in-law was diagnosed with a brain tumor. There were no online resources for brain tumors at the time so I set it up. As the web developed, we moved from Compuserve

to an online forum on our website (www.virtualtrials.com) with separate forums for many tumor types and treatment types. As email became popular, we moved to online email based groups - and I set up separate groups for each of the forums we had on our website. Over time, some groups withered away and I closed them and created new groups as needed.

IBTA: You did something similar when temozolomide (Temodar/Temodal) was first introduced?

AM: When the big Temodar trial started, I added a new group focused on that particular trial, to see how it was doing, as well as to let people in the trial interact with each other and help each other. That group became so popular that our glioblastoma multiforme (GBM) group withered away and I combined them into the "brain-temodar" group. That became our major online support group for many years even after Temodar was approved. As the group grew in size it was hard to keep it focused so we split off several other groups where members could discuss non-medical aspects of having a brain tumor, such as the "brain-finance", "bt-faith", "braintumor-community" and others. This allowed the "brain-temodar" group to stay focused on medical discussions only.

Then as new treatments came into use, the focus of the "brain-temodar" group was changed to include all treatments for brain tumors, so we changed the name to "braintumor-treatments" and today it is (in my biased opinion) the best group for the discussion of brain tumor treatments.

As the Novocure device becomes more commonly used, it will make sense to combine that group back into "braintumor-treatments" as the information will become relevant to more people. But for now, having a small, tight group dedicated to this one topic is working out great! ■