

EFFECTING CHANGE

Do you know the difference between “Informed Consent” for Treatment and “Informed Consent” for Saving Tumor Tissue, Clinical Trials, or Research Studies – Putting the Power into YOUR Hands

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Patients, this article is for YOU! Did you know you have the power to increase research and enhance the treatment of your brain cancer or any disease and INCREASE the number of treatment options offered to you? You can do this by simply asking for and signing a document called an “Informed Consent” form that includes the words “tumor tissue saved for research, clinical trials or research studies”.

Informed consent is a process for getting the patient’s permission before conducting a healthcare intervention or procedure. You need to be aware that the Informed Consent document you will be signing for having your tumor tissue saved/tested for research, clinical trials or research studies differs from the one you would be signing for regular Standard of Care. You also need to be aware that it’s critical to know which one you are being asked to sign PRIOR to signing.

Before moving forward with treatment, patients are typically asked to review and sign standard Informed Consent forms. What the patient/medical consumer needs to know is that anything outside of Standard of Care will most likely require signing a separate Informed Consent document. In the case of advanced treatment, the document you will be signing will contain words such as “tumor tissue saved

for research, clinical trials and/or research studies”. This will help to ensure that your brain tumor tissue after resection/surgery will be saved and tested for further treatment options and/or research. It will also increase personalized treatment options based on the specific molecular and genomic structure of your tumor including genomic therapy, vaccines and immunotherapy options. **This type of Informed Consent form must be asked for and signed PRIOR to surgery.**

Putting the power into your hands means **insisting** that the Informed Consent document you sign includes the words “tumor tissue saved for research, clinical trials and/or research studies”. Otherwise, you will most likely only be offered current Standard of Care as a treatment option for your disease. In that case, you will not have access to your tumor tissue, as it will most likely be thrown away. You could be excluded from future clinical trials/research studies that could potentially increase your quality of life and increase your survivorship.

If this option is not available to you where you are being treated or offered by your medical team, then be your own best advocate for your care and seek your treatment with a specialist at a research center that offers these potential lifesaving options.

You should be aware that in most brain tumor cases, you actually have more time than the typical three days given to you from diagnosis of an initial brain tumor to surgery. In most cases, it is acceptable and safe to disrupt the current practice that gives the patient only 72 hours between initial diagnosis and surgery. However, please be advised that there are some instances where the need for an emergency resection/surgery is the best option for the patient. Ask your doctor: Is it vital that I have surgery within 3 days or can I schedule surgery for a week or two from now? Then use the time to determine if you are at a brain tumor center and whether or not your tumor tissue will be tested and saved. We are here to help you explore and advocate for your best treatment options.

It is important to understand that the Pathway of Informed Consent for a Clinical Trial/Research Study/Investigational Drug or Procedure is Different from Consent for Standard of Care/Standard Treatment in both

what is offered and in terms of outcomes. Exactly how this Pathway differs from Current Standard of Care can be seen in the diagram below.

If you are a GBM patient, reach out directly to the EndBrainCancer Initiative | Chris Elliott Fund at www.EndBrainCancer.org or at 800-574-5703 to access our “Direct Connect” program and care coordinators. We will connect you to a top brain tumor neurosurgeon and/or neuro-oncologist based in the U.S. **prior to surgery**. We are here to help and to make these critical connections.

Finally, please remember wherever you are in this Journey, that the real power to increase research and enhance the treatment of your unique brain cancer rests in YOUR hands....and that those who insist on nothing but the best, are those who get the best!

