



# SAN DIEGO BRAIN TUMOR FOUNDATION

Supporting the Needs of Patients & Families

## SECOND OPINIONS: WHY, WHEN, AND WHO

### Why

First, you can get a different perspective on your options. Some doctors are more conservative and others more aggressive. There may be good arguments for several different options; getting a second opinion can be a good way to hear some of them. Another doctor might come up with a completely different and promising option - one that your first doctor didn't think of, or didn't know about. It happens - no doctor can know everything or make the right decision all the time. A second opinion can also serve a general quality check - to make sure you're really getting the most up to date, most effective treatment.

### When

Here is a list of some reasons why you might want a second opinion. This should help focus your thinking, but there is no cookbook answer for when you need a second opinion. So you'll need to consider your situation and think about whether you might benefit.

#### **If You Have Been Given No Hope**

Many patients are told there's no hope and that no further treatment can be of benefit. In this case, there's certainly nothing to lose by getting a second opinion, but there is a chance, however small, for a huge gain, since if your doctor is in error, a second opinion could save your life. Sometimes tumors deemed inoperable by one surgeon are found to be operable by another. Sometimes close examination of the case could change the diagnosis from one kind of cancer to another, more treatable type. Sometimes another doctor will know of a promising treatment that the first one didn't know about. All of these things have happened. You don't know until you check.

#### **If There is Something "Borderline" About Your Case**

If your tumor is almost operable, but not quite, or conversely almost inoperable but not quite, you might want a second opinion. You might either save yourself unnecessary surgery or you might save your life. Similarly if your tumor is on the borderline of requiring adjuvant chemotherapy you might want a second opinion.



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## **If You Live in a Rural Area**

If you live in a rural area and get treatment as a small hospital, it may pay to get a consult from a major hospital. I'm not saying you can't get good treatment from a small rural hospital, but I have heard some real horror stories.

## **If You Are an HMO Member**

Although HMOs can and do offer fine care in many cases, there is a fundamental conflict of interest between an HMO and its members. The more money the HMO spends on you, the less it makes, so there is an incentive to give less expensive care, and an incentive not to refer outside the network. As a consequence, HMO members may not be told of clinical trials, or other promising new treatments. They may also be discouraged from trying expensive treatments that have only a small chance of success - even if that chance is real. Actually it's worse than that. Some HMOs actually prohibit their doctors from telling their patients about options that aren't available through the HMO. According to an article in *Oncology Times* (5/96 P22), "virtually all" HMOs have a "gag rule" in the contract between them and their doctors that discourages them from, "fully informing patients about options not included in their coverage." The AMA calls this practice "unethical" which it surely is. The contract between an HMO and its doctors is not a public document, so there's not even an easy way to tell if your HMO doctor is operating under a Gag Rule. While I think public outcry has probably reduced the number of HMOs which have Gag Rules, the very fact that Gag Rules were once common, and may still exist, is very strong evidence that HMOs are not always motivated to inform patients of the best possible treatment. Given this, I think don't think any HMO patient can assume that they are getting the best treatment, or that they have been informed of all of their options. Therefore, I think that any HMO member should have their treatment plan reviewed by an outside oncologist. You'll probably have to pay for the opinion yourself, but it's worth the expense. I recommend getting the opinion at a major cancer center or university hospital.

## **If Your Doctor Wants You to be in His Clinical Trial**

If your doctor wants you to take part in a clinical trial that he is participating in as an investigator, then I think you ought to get a second opinion before signing up. One of the toughest things about running clinical trials is finding patients to participate. So the doctor has an interest in having you sign-up that goes beyond his interest in getting you the best treatment. Sometimes there is a



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financial incentive or other pressure to accrue patients. Don't get me wrong. I'm not saying that all doctors who want to sign you up for their trial are just doing it to have another body. Many if not most, physicians enter patients who they feel would benefit from the trial. Many trials are "multi-center", that is they are done in many hospitals across the country participate in the trial. If the trial you are being proposed for is like that, the experiment probably wasn't your doctor's idea to begin with. But it is natural for a doctor to be excited about a new treatment especially if it was his idea. An objective second opinion is in order! Clinical trials vary tremendously in their promise. A trial that was in essence randomly selected (Because your doctor just happens to be participating) may well not be the most promising one out there. For this reason, I also think you ought to research all of your options in clinical trials rather than automatically accepting the one your doctor happens to be offering. For much more, see CancerGuide's Clinical Trials Section.

## **If You Have a Rare Cancer**

If you have a rare cancer, it definitely pays to get a second opinion. What you really want is to find an expert in that form of cancer. If such an expert is local then you should probably switch to that doctor, if the expert is far away, which is likely, your doctor may be able to work with him via telephone consultations. If you have the good fortune to already be under treatment by an expert, then, of course, you don't need a second opinion to get expert advice. Even if your cancer isn't all that rare, you may very well benefit from finding someone with a special interest in your cancer. My cancer, kidney cancer, is not really rare, but it's not exactly common either. But in my experience, many patients with this cancer do not get the latest and greatest treatment. Finding a real expert is never a bad idea! For more, see my article on Rare Cancers.

## **If you have "Cancer of Unknown Primary Site"**

In some cases, the doctors are unable to tell what kind of cancer the patient has. Typically metastatic tumors are found, the type of which can't be determined from examining the cells, and no primary tumor is found. Or perhaps it's just not clear which is the primary tumor. Cancer treatment varies greatly depending on the type of cancer, so if a diagnosis can be established, you may be able to get much more effective treatment. In this case, I think it makes sense to get a second opinion to make sure that all appropriate tests have been done. You should also consider a pathology second opinion in this situation.

## **Pathology Second Opinions**



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Most people never consider the possibility of getting a second opinion on the pathology report from which the diagnosis was made, but the entire plan of treatment depends on what kind of cancer you have and how far it has spread, both of which usually depend in part or whole on the pathologists interpretation of the biopsy or surgical specimen. Changes in the interpretation of the pathology can dramatically change both the treatment and the prognosis. At the same time, most patients probably do not need a second pathology opinion. There are some common sense cues that can let you know if it might make sense. I think that if you have a really rare cancer, it is always advisable to get a second pathology opinion. It is likely that the pathologist had little or no experience with that particular kind of cancer, so the chance for an error may be higher. If your pathology report doesn't give a definite diagnosis, a second opinion is probably in order. But also if the pathology report describes something as unusual, or you find that it is unusual based on your knowledge of the disease, it may be more likely than usual that there was an error. I met one patient who had just had surgery for a large kidney cancer. The diagnosis was renal cell carcinoma. He told me that the tumor was "well differentiated" which, while not impossible, is not at all usual for large renal cell carcinomas. He also said that the pathology report described the tumor as an "atypical renal cell carcinoma". He got a second opinion on the pathology, and it turned out that he had a completely different and extremely rare cancer called a "renal carcinoid". This totally changed his follow-up schedule, his prognosis as well as the treatment of any future problems. As a basic step, you should obtain a copy of the appropriate pathology report from your doctor. See Dr. Ed. Uthman's Biopsy Report for the basics of understanding a pathology report. One place with an superlative reputation in pathology is the Armed Forces Institute of Pathology (AFIP). You can get contact and other information at AFIP's Web Page [FindCancerExperts](#) is a free, not-for-profit service which will refer you to expert pathologists with special experience in the pathology of your tumor. They also have excellent patient oriented information about when to get a second pathology opinion and about pathology in general.

## Who

### **Independent Doctors**

You want your second opinion to be independent - so you should choose a doctor who doesn't have a close relationship with your doctor. Doctors who practice together are likely to think similarly, and might tend defer to the opinions of their colleagues. What you want is a fresh perspective. I'd go so far as to recommend finding a doctor who practices at a different hospital. A



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research hospital or major cancer center is usually a good place to get a second opinion since they should be up on the latest in treatment and diagnosis.

## **Tumor Boards**

There is a special kind of second opinion that, while not independent, is worth considering because it's a great way to get a wide range of opinions all at once. This is the "tumor board" or tumor conference. Most hospitals have a tumor board which is a regular meeting of a group of doctors to consider the best treatment for specific cases presented by members of the group. Typically, doctors from several specialties such as surgery, radiation oncology, and medical oncology will attend. If your doctor doesn't seem to have a clear recommendation for you, consider asking if he could present your case to the tumor board. The R.A. Bloch Cancer Foundation has been instrumental in setting up a program of "multidisciplinary second opinions" which works much like a tumor board, but the patient is actually present when their case is discussed. This is intended for patients who have been diagnosed with a new cancer or a recurrence within the last three weeks. Their information on Multidisciplinary Second Opinions includes a listing of participating centers.

## **A Different Specialist**

Many types of cancers are treated by several different types of specialists. For instance, prostate cancer is treated by urologists, who are surgeons, by radiation oncologists, and by oncologists who use drug treatment. After doing some basic research on your type of cancer, you will probably know what specialists treat it. It often makes a lot of sense to see one of the other types of specialist to get a different perspective. For instance, a surgeon may be convinced that "he got it all" and that you need no more treatment. At the same time, an oncologist may have more detailed knowledge of studies that show benefit from adjuvant treatments such as chemotherapy or radiation. Similarly, a surgeon may have a better idea than an oncologist of whether a tumor is operable or not. Very often, one specialist will call in another for a consultation, so you may not have to do anything to get this second opinion. But I have heard from patients who didn't get a needed consultation, and who missed out on potentially life saving treatment.

## **A World Class Expert**

In some cases, what you need is world class expert - a surgeon who does operations most others don't - an oncologist who is in the forefront of research in a new and promising area that applies to you. Or an expert in a rare cancer. In many cases, expertise is quite narrow - Dr. X is skilled at removing a particular type of brain tumor. Dr. Y is an expert in biological therapy for melanoma. It's



We can make  
a difference!

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not as simple as just finding someone who's got a reputation as a good doctor. I know of no foolproof way to find the expert you need (If you do, please let me know!). Doctors often do know who the experts are, and your doctor may be able to give you a referral. You can also research the medical literature to see who's published papers relating to your particular problem. Often, this will be quite effective.