THE IMPORTANCE OF SECOND OPINIONS FOR SARCOMA

By Elizabeth Goldstein-Rice

Because sarcoma is a rare cancer, most physicians may only encounter a few instances of it in their lifetime, if any at all. Patients need to be diagnosed and treated by physicians and interdisciplinary teams that have experience with sarcomas.

If you are diagnosed with sarcoma, we encourage you to obtain a second opinion about your initial diagnosis and your proposed treatment plan from a sarcoma center. Good physicians are not offended when patients seek a second opinion about a rare cancer; it is fairly standard procedure. Moreover, some insurance companies require a second opinion before they will reimburse costs for a proposed treatment plan.

Patients, family and caregivers dealing with cancer get advice from a lot of people. They get advice about their eating habits (where to buy food, how to cook it, what’s healthy, and what’s not), their lifestyles (not enough of this, too much of that, too dangerous, too sedentary), the way they manage changes to their bodies (especially their hair! wig, no wig?) and how to settle their affairs (not just legally, but with the great beyond).

They also get advice regarding whether or not they should get a second opinion. While getting a second opinion is generally considered a useful thing to do, there is a common misconception that it is a time-consuming and possibly expensive activity that often produces no change to treatment plans or long-term prognosis. However, several studies show that, for sarcoma patients, getting input from more than one medical professional can indeed make a difference, not only in medical decision-making, but also in the patient’s ultimate outcome. This article examines evidence which proves the value of obtaining a second opinion from a sarcoma specialist at critical junctures in the diagnosis and treatment of sarcoma.

SECOND OPINION OF THE INITIAL DIAGNOSIS

Once a lesion has been determined to be a tumor that requires further evaluation, the patient’s journey begins. Getting a precise clinical assessment and finding out the exact type of a tumor is essential in getting patients onto the right treatment path quickly. The ideal time for a second consultation is before any incision has been made into the tumor.

In a 2005 article "Surgical Management of Soft Tissue Tumors: Avoiding the Pitfalls," Drs. Fritz and Frederick Eilber of the UCLA School of Medicine state that, "In the presence of any clinical features that raise the suspicion of a sarcoma, appropriate cross-sectional imaging and tissue diagnosis are critical in guiding additional care." They go on to specify that "CT-guided core biopsy is the best method to obtain an accurate tissue diagnosis"[1]. Because the biopsy is guided by CT imaging, surgeons are able to collect samples with precision, improving the accuracy of the initial diagnosis [1]. The view that excisional biopsy is superior to needle biopsy is at best controversial and not reflective of practice at most major centers.

The authors of a study conducted by researchers at St Thomas Hospital in London, England link the use of excisional biopsies (in which an attempt is made to remove the entire lesion or tumor), instead of needle biopsies, to contamination of surrounding tissue, making it difficult to ensure that sufficient margins are achieved during initial surgery for soft tissue sarcoma [2].
Further support for a second opinion of an initial diagnosis is found in a study of over 600 patients having sarcoma-related surgery at BG University Hospital Bergmannsheil in Bochum, Germany [3]. The researchers first note the difficulty in obtaining a definitive diagnosis for soft tissue sarcoma because there are so many different types, stating "approximately 50 different histological subtypes of soft tissue sarcomas have been described" [3]. The results of their study reveal how important it is that the diagnosing pathologist has experience with the pathology of sarcoma. The findings of expert second opinions agreed with those of the primary diagnosis, by non-expert pathologists, as follows:

### Comparing Initial Diagnosis with Expert Second Opinion

<table>
<thead>
<tr>
<th>Type of Initial Diagnosing Institution</th>
<th>% Concordant with Expert Second Opinion</th>
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</thead>
<tbody>
<tr>
<td>Private Clinics</td>
<td>28.3%</td>
</tr>
<tr>
<td>Hospitals</td>
<td>29.6%</td>
</tr>
<tr>
<td>Academic Medical Centers</td>
<td>36.8%</td>
</tr>
<tr>
<td>Department of Pathology at BG University Hospital</td>
<td>70.5%</td>
</tr>
</tbody>
</table>

These results make a striking case for review of initial diagnosis before treatment is selected. Regarding treatment, one popular web-based medical information resource, WebMD, lists a rare cancers diagnosis as the number one reason to see a specialist for a second opinion on the diagnosis. "After all," the authors state "the diagnosis will determine which treatment is best" [4].

Another very interesting study advocates for mandatory second opinions of the original tissue samples before any treatment is given. This study, "Mandatory Second Opinion Surgical Pathology at a Large Referral Hospital" was conducted at John Hopkins Medical Institution in Baltimore, MD. In this study, a changed diagnosis was defined as one that "resulted in a significant change in therapy or prognosis" [5]. It found not only that, "Of 6,171 cases reviewed, second opinion surgical pathology resulted in 86 changed diagnosis (1.4%)", but also estimates that "The financial benefit averaged $2-4 saved for every $1 spent to obtain the second opinion!" [5]

The studies discussed above certainly make the case that initial diagnoses can be wrong and should be double-checked. The question then becomes: what difference does it make if a sarcoma diagnosis is a bit off, maybe just in the determination of subtype or grade? How different are sarcoma treatment protocols? Are these differences significant? We will now address these questions.

### The Impact of the Diagnosis on the Treatment Plan

Indeed, one significant risk of an incorrect or imprecise diagnosis is the impact on the treatment plan, including the choice to employ chemotherapy, whether to radiate, if and when to perform surgery and the surgical method to be used.

An area of particular concern is the risk of surgical error in the initial surgery done to remove the primary tumor. In the study "Surgical Resection of Primary Soft-Tissue Sarcoma," researchers from St Thomas’ Hospital in London examine records of patients who had previously undergone surgery to remove sarcoma tumors, but then had to have additional surgery because the initial surgery failed to remove all of the sarcoma cells from the area around the tumor [2]. Of the patients studied, over 56% were found to have residual tumor and 33% had tumors visible to the naked eye [2]. How does this happen?
What they found was that the first surgery had often used what is called a "shell out" procedure, done without having first obtained a complete pathological diagnosis [2]. They state "... the commonest reason was surgical excision without a prior biopsy for histological diagnosis, and ... this had led to the use of a shell-out procedure" [2]. The shell-out procedure is a surgical method used for benign tumors that are well-defined masses. They're easy to scoop out along the existing division between the tumor and the healthy tissue around it. Because some sarcomas look as if they have clear boundaries, surgeons can get the misleading impression that the tumor is benign and that it can safely be removed along its borders without excising additional tissue around it [2]. That study concludes, in part, that "surgical assessment of the adequacy of excision is very inaccurate and that most local recurrences are the consequence of inadequate primary surgery" [2].

See these related ESUN articles for more information:
- The Margin Matters: Someone’s Life Depends on It
- Salvage of the Unplanned Sarcoma Excision

The National Comprehensive Cancer Network provides Clinical Practice Guidelines in Oncology, which are detailed yet concise planning documents that are extremely useful in understanding how decisions are made in the management of sarcoma therapy [6, 7]. The guidelines cover the various activities and principles associated with sarcoma treatment, including initial diagnostic evaluation, primary treatment, pre- and post- surgical therapy, radiation therapy, chemotherapy, progressive and recurrent disease, and follow-up [6]. Unique guidelines exist for soft tissue sarcomas of the extremities, retroperitoneal/abdominal, intra-abdominal and desmoid types [6]. For bone-related sarcomas, there are separate guidelines for chondrosarcoma, Ewing’s sarcoma, osteosarcoma, plus some variants [7]. Even a quick overview of these guidelines makes it clear that the assessments of the disease must be accurate in order for treatment based on these guidelines to be effective.

**FINANCIAL ASSISTANCE FOR SECOND OPINIONS**

Patients, caregivers and families grappling with the enormity of their diagnosis and the strain of day-to-day care may not believe they have the means or the energy to advocate on their own behalf and actively search for the best source(s) of a second opinion. However, help is available. Sarcoma support groups are great resources to get up-to-date information from people who are familiar with the process. They can help members locate local resources as well as connect each other with national programs that provide assistance with the costs of travel, lodging, and other expenses that insurance won’t cover.

A good example is the Sarcoma Alliance’s Hand in Hand program. This program "offers financial assistance for second opinion consultations by reimbursing expenses related to travel, phone bills, costs of the evaluation, and related expenses."

Major sarcoma centers can supply information on the availability of free or discounted housing provided by organizations including The American Cancer Society’s Hope Lodge, the Ronald McDonald Houses, and the local hotel industry.

Expenses (and patient stress!) can be further reduced when a working relationship is developed between a local oncology practice and a major sarcoma center. Sarcoma centers are often willing to provide the expert diagnosis and the treatment protocol, which can then be carried out closer to the patient’s home. For adults, outpatient treatment may also be an option.

**SUMMARY**

In summarizing the results of the "Mandatory Second Opinion" study, John Hopkins researchers point out that "Although a policy of mandatory second opinion surgical pathology for referred
patients makes good clinical and risk management sense...current trends in medical economics has placed this and other quality assurance practice at possible risk.” [5]

From a caregiver perspective, this author sees that patients with a new sarcoma diagnosis need to be advised of the value of a second opinion on the diagnosis. There is always a great sense of urgency to begin treatment as soon as possible, so patients and their families may be wary of any delays. They need to be assured that expedited communication between the diagnosing facility and a major sarcoma center regarding diagnosis will reduce the amount of time between diagnosis and treatment and this is time well spent. No patient can afford to lose time pursuing the wrong treatment due to incorrect diagnosis. Remediating the effects of wrong treatments and procedures, after the mistake is recognized, cannot always be done.

References


4. **5 Diagnoses That Call for a Second Opinion**: Experts tell WebMD about situations in which another medical viewpoint may be priceless.

