



Carbone Cancer Center

UNIVERSITY OF WISCONSIN
SCHOOL OF MEDICINE AND PUBLIC HEALTH

11/16/18

Truth in Advertising
ATTN: Laura Smith
P.O. Box 927
Madison, CT 06443

Dear Attorney Smith:

Your October 22, 2018, letter to Kelly Wilson, Senior VP and Chief Legal Officer for UW Health, was forwarded to me as Director of the UW Carbone Cancer Center. Please note that the Carbone Cancer Center is operated by the University of Wisconsin-Madison.

In your letter, you state that the UW Carbone Cancer Center uses patient testimonials deceptively “by promoting anecdotal, atypical patient results without clearly and conspicuously disclosing what the generally expected results for a patient in a similar situation would be.” You also assert that many cancer centers promote clinical trials and novel treatments without “clearly and conspicuously disclosing their limitations, risk and relative rarity.”

You list seven patient stories from the Carbone Cancer Center in support of your contention. They include one about pancreatic cancer; one about stage 4 colon cancer; two about metastatic melanoma; and three about lung cancer (one metastatic case.)

First, let us be clear: we do not dispute that patients should know the general statistics about their type and stage of cancer. This information is readily available on any number of Web sites, including that of the National Cancer Institute. Many patients conduct their own extensive online research when they are diagnosed, and some do not find that helpful; patient Terry in one of our stories advises other patients not to Google their condition because in his experience it takes away hope. Nonetheless, every patient who receives treatment at the Carbone Cancer Center is fully informed of the likely risks, benefits and viable alternatives of any and all treatments, as well as for any investigational drugs available through a clinical trial in which they might be interested.

Several of the stories discuss patients who did enroll in clinical trials and the stories include important qualifying information. For example, in Glen Melby’s story, it is made clear that his tumor was one of only four percent that have a particular genetic mutation that might respond to crizotinib. And as stated in the story about Shelly Casey, a patient with colon cancer, her surgeon told her there was only about a two percent chance the cancer wouldn’t come back. These examples refute your contention that the stories do not reflect the realities of cancer treatment and survival.



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We should also point out that in several of our stories, the clinical-trial drugs the patients received were so effective that they were subsequently approved by the FDA and are now available as part of standard treatment. That is how scientific progress is made, and we need patients – informed and willing patients – to take part in clinical trials so that more and better treatments can be developed. It is the only way to do it, and for most of the patients in our stories, they had no realistic standard therapy alternatives and chose clinical trials participation over the equally presented choice of symptom-management only.

Finally, we are, without apology, advocates for hope. We accept the weighty responsibility of telling patients the full story, which includes the overall survival picture in the context of that patient's cancer type, stage, general health, etc. The stories we use do illustrate successful outcomes – but they do so while acknowledging that treatments do not always work and they have side effects. No statistic can capture a patient's individual story, just as no story can ever capture the full range of patient experiences. Ultimately it isn't just about presenting accurate statistics to patients, it is about presenting accurate and meaningful information for each individual patient in a way that enables them to make the best treatment decision. What our patients tell us is "I want realistic information I understand and, if possible, hope that I can do better than the books say".

Our stories are accurate descriptions of individual experiences and the patient information to which we link – including the NCI patient guides – provide a wealth of background information to provide additional perspective from what they hear from our providers. However, we appreciate the perspective you have shared and while we disagree that the presentation is deceptive, we will take your point of view before our advisory council of patients and families for their consideration. Their feedback will be used to inform any decisions we make regarding existing stories and when developing any new stories.

Sincerely,

Howard Bailey, MD
Director, UW Carbone Cancer Center

Cc: Kelly Wilson, Senior VP and Chief Legal Officer, UW Health
Lisa Wilson, Senior University Legal Counsel, UW-Madison
Lisa Brunette, Director of Media Relations, UW Health