



November 27, 2018

VIA EMAIL AND REGULAR MAIL

Aaron T. Shepley
Vice President
Senior Associate General Counsel
Northwestern Medicine
4455 Weaver Parkway
Warrenville, IL 60555



Re: Northwestern Medicine Chicago Proton Center's Use of Deceptive Patient Testimonials

Dear Mr. Shepley:

I am writing in response to your November 14, 2018 letter, which I received yesterday. The letter, among other things, claims that the Northwestern Medicine Proton Center patient testimonials in [TINA.org's database](#) are not deceptive and demands that TINA.org remove references to the Center from its website.

While we appreciate Northwestern Medicine Proton Center's opinion with respect to TINA.org's findings, we respectfully disagree and therefore will not be removing the entries in question from TINA.org's database.

Both entries in the database are Northwestern Medicine Proton Center YouTube videos that feature patients who were diagnosed before March 2015 (the date of original publication of the videos) with cancers that have a less than 50% five-year survival rate,¹ meaning patients with those types of cancers – brain and lung, respectively – are not likely to survive beyond five years. Despite these statistics, both videos feature patients who have seemingly beat the odds, completed their treatment and are doing well today. (Both of the videos are still up as of November 2018.) One of the patients, Hazeelat M., says "I had a brain cancer and it was in the middle of my brain. ... I probably don't know

¹ The overall five-year survival rate for brain cancer is 33.2% while the overall five-year survival rate for lung cancer is 18.6%. See <https://seer.cancer.gov/statfacts/html/brain.html> and <https://seer.cancer.gov/statfacts/html/lungb.html>.

where I would be without all the medical people [at Northwestern Medicine Proton Center] that helped me pull through,” clearly implying that she no longer has brain cancer. The other patient, Rozanne C., also intimates that her treatment has ended, and is shown doing well despite her lung cancer diagnosis.

What is missing from these Northwestern Medicine Proton Center marketing materials are clear and conspicuous disclosures that the patients portrayed in the videos experienced atypical results, what the typical patient (i.e., other brain and lung cancer patients) should expect to achieve, and what the risks and limitations of proton therapy are. Without this information, the videos are likely to deceive susceptible cancer patients who are oftentimes desperate to find a cure and may be willing to travel far distances and make significant sacrifices in pursuit of treatment that has been marketed as effective and curative.

In short, while TINA.org supports providing a hopeful message to cancer patients, that messaging must accurately reflect the typical patient experience in order to eliminate the possibility of consumer harm.

If you have any further questions, please do not hesitate to contact me. The quickest way to reach me is either by email (lsmith@truthinadvertising.org) or telephone (203-421-6210).

Sincerely,



Laura Smith, Esq.
Legal Director
Truth in Advertising, Inc.