False Hope From Lotto Safer Bet Than Some Medical Crowdfunding

By Jamie Wells, M.D. — October 24, 2018

As evidenced by my writing this article, I did not win tonight’s Mega Millions $1.6 billion lottery. Despite being out a few bucks, tantamount to much less than an evening’s entertainment or a meal, I made a fully informed choice that managed my expectations. The decision to do so didn’t alter my life in any adverse way, if anything it added a little excitement to my day. Had the alternative scenario been my reality, I am quite certain I would have adapted well to such newly-found good fortune. But, the stakes in this kind of gamble just aren’t as high as they are for those medically crowdfunding on social media these days to cover “scientifically unsupported, ineffective, or potentially dangerous treatments.”

Though taking some calculated risks is a part of living, according to a just published research letter in JAMA, “donors indirectly contributed millions of dollars to practitioners to deliver dubious, possibly unsafe care.” GoFundMe which occupies the lion’s share of medical crowdfunding platforms “reported that all campaigns raised $3 billion by 2016, an increase from $1 billion in 2015.” While much is tagged for outstanding insurance balances and specific, extensively tested therapies, the authors chose to explore how much is being used for more experimental, potentially harmful interventions.

The researchers performed a systematic review of the most trafficked sites permitting this type of fundraising and focused on five treatments known to be problematic, poorly studied and even detrimental.

They found
“More than 1000 medical crowdfunding campaigns for 5 treatments that are unsupported by evidence or potentially unsafe raised more than $6.7 million. Another study found that 408 campaigns raised more than $1 million for unproven stem cell interventions.”

**A couple examples of the crowdfunded potentially unsafe treatments**

Stem cell therapies have a very narrow therapeutic index for use. They are sold as the panacea for a host of conditions for which they have never been effectively researched or been proven to be safe, and they have caused harm (see here [3]). It is such an issue that an international team of medical experts published a global call to action in *Science Translational Medicine* [4] in an effort to curb the unethical, unsubstantiated use of stem-cell based therapies driving often ill-advised medical tourism.

Even the *U.S. Food and Drug Administration* [5] weighed in with oversight and a perspective piece for the *New England Journal of Medicine* (NEJM)

> “Outside the setting of hematopoietic reconstitution and a few other well-established indications, the assertion that stem cells are intrinsically able to sense the environment into which they are introduced and address whatever functions require replacement or repair—whether injured knee cartilage or a neurologic deficit—is not based on scientific evidence.”

Another category in the five selected was the fundraising for homeopathic or naturopathic cancer treatments. Unlike my somewhat rewarding and innocuous placebo with “almost” winning the lottery, a recent study in *JAMA Oncology* [6] found the use of complementary medicine (CM)

> “varied by several factors and was associated with refusal of conventional cancer treatment, and with a 2-fold greater risk of death compared with patients who had no complementary medicine use....Patients who received complementary medicine were more likely to refuse other conventional cancer treatment, and had a higher risk of death than no complementary medicine; however, this survival difference could be mediated by adherence to all recommended conventional cancer therapies.”

The authors maintain (**CCT= conventional cancer treatment**)  

> “approximately two-thirds of patients with cancer believe that CM will prolong life
and one-third expect it to cure their disease. Although it is possible that CM may improve outcomes by helping patients tolerate conventional medical care and complete their recommended therapy, CM may result in inferior survival as a result of delays to receiving proven CCT and refusal of other recommended CCTs.”

In the end

We know where our lottery ticket donations are going, but in the end there is little accountability [7] with these avenues for those who contribute as well as for those often in a desperate state who are seeking funds for such poorly studied "therapies." Delaying conventional care or forgoing it entirely to pursue what can amount to false hope by an unknown entity, decent or not, can yield much worse dividends than a few bucks lost in the lottery.