



The Cost of Living *The Business of Cancer*

By Matthew Zachary

Life is about choice. Remission is not a cure. Survivorship is all the rage.

Why we fight ...

I received a horribly disaffected and disturbing email today from a friend and fellow survivor about how she was more or less completely cast asunder and emotionally stomped upon by the Susan G. Komen breast cancer group for trying to be collaborative and support others at a Race For The Cure event. And I quote, "This is on top of not being able to do the 3-Day because I "only" raised over \$1100, and not the minimum of \$2100. They told me I knew the minimum, and my response was this: would they rather I, and others, not try at all, because it's too daunting?" That's \$1100 they didn't have before. I just feel like what's really important - providing help, info, and resources for patients, caregivers, loved ones, and survivors - has gotten lost somehow with Komen."

My response:

Sadly and truthfully, cancer, like anything else, is a business. Komen and American Cancer Society (ACS) are the biggest stakeholders in this game and they have the most to lose by diluting their brand equity in the market.

Yes, we're a market. These two groups take in billions of dollars each year and as such, they don't have to play with others in the sandbox because they don't need to. There's nothing in it for them. They also have the caché to play "evolution" and weed out those who don't meet their fundraising demands, which, I think is the coldest and most dispassionate cut of all. But now it's a game that we're all catching on to.

Again, there's just no value proposition for collaboration because there's no way to collateralize any opportunities without compromising their "stakeholdership" and "shareholder" value. Yes, we're emotional stakeholders and shareholders, too.

For over a combined 100 years, these two organizations have been the only major games in town to associate with and feel part like you're part of a community. Then Lance Armstrong Foundation (LAF) blasted on to the scene, broke the mold, made cancer advocacy hip and attracted a new crowd of passionate people who realized, like any other consumer-driven sector, we have choice.



I'll say it again - we have choice in who we donate our time, talent and treasure to. It's not a two-store big box mart anymore. On a scale not seen before, hoardes are flocking like geese (really smart geese) to other charities whom they simply have a better affinity with.

We are witnessing for the first time a balloon-deflation effect with the big box groups. They're losing human capital because they're old school. They have not kept up with the times and, in my personal opinion, they operate in a vacuum with no finger on the pulse of our social change needs. In fact, Komen recently re-branding as "For The Cure" it's just another example for me to reevaluate my own personal social investments.

Heavens forbid while at a Relay For Life (RFL) or Race For The Cure (RFC), a young survivor discovers other incredible support resources such as i[2]y. Tamika & Friends, PopSmear, Planet Cancer, LifeLab, Fertile Hope, SAMFund, Ulman Fund, The Wellness Community, CancerCare, etc...

ACS and Komen might lose loyalty. People might take their interests elsewhere. I can see it now. "Oh mercy the confusion! I'm holding a Tamika and Friends brochure while at a Race For The Cure? What direction to I run?" Where'd everybody go? Where's my shoe?"

I am now compelled to point out the elephant in the room. Ask LAF if you could bring support materials from any of the above young adult groups to LIVESTRONG Day (LSD) and they will say "no" for the exact same reasons as Komen and ACS would. Confusion of funding. I know from personal experience. We have a cadre of passionate young adults (2,500 strong), some of whom will be attending LSD and most of whom, under their own volition, wanted to hand out I[2]y benefit CD/toolkits and were rejected.

Now, I believe in LAF very strongly if only for one reason alone - they're not about "the cure". They're about living. It's not about the "cure" anymore, it's about survivorship: better medical technology with a major shift in focus to quality of life and social networking. Lance is the new Magic Johnson who destigmatized a nation's preconceived notions about an epidemic disease and created social change. LAF upped the bar and put the responsibility for changing cancer into the powerful hands of the people - because it certainly ain't coming from "W".

That said, LAF is in an unenviable position and walking a tightrope. We want them to be successful and smash down barriers (which they've already done so well). But at the same time, we, as consumers, are demanding collaboration and cooperation on the part of our national advocacy groups which does not seem to mesh well with their strategic plans. There's just no money in it for anyone - except the smaller groups, perhaps - to collaborate.



So what do we do? We demand and foster change with our wallets our calendars and our advocacy. If you don't like an organization for it's non-collaborative policies, stop giving of your time, talent and treasure. Just walk away and let your shadow do the talking. (And then be sure to blog about it and let them know what changed your loyalty.)

Now the NYC-cynic in me feels compelled to say that, since they take in billions, they'll probably won't care about one person but they'll take notice when attendance starts plummeting nationwide.

We are at a tipping point. Social change is all around us. Cancer, which was once considered an immediate death sentence for most, is now considered a life sentence for many, meaning, the elusive "cure" that Nixon, NCI, ACS and Komen have been magically racing for is looking more and more like a chronic condition coupled with a lifetime of vigilant self advocacy, disease management, and social networking support.

Like I said in the beginning of this diatribe, we are a market. And we're 30,000,000 strong. If you don't like what's on TV, change the channel. Yes, it's as simple as that. Is your charity up with the times? Do they give you what you need?

Are they still representative of your interests?

You have a choice. Now make it.