



Cancer's Dirty Little Secret

For Survivors Under 40, Nothing's Changed

By Matthew Zachary

There's a dirty little secret in cancer. The past 30 years of research have yielded amazing strides. On the whole, according to the National Cancer Institute (NCI), remission rates have increased significantly and survivorship rates are at an all time high.

Great news, right? Sure... if you're 65. Or 9. You see, cancer survival in young adults, aged 15-39, shows little progress across the past 30 years, according to reports from the NCI ("Closing The Gap", Fall 2006), The New England Journal of Medicine ("Chronic Health Conditions in Adult Survivors of Childhood Cancer", 10/06) and the journal Science ("In Their Prime and Dying of Cancer", 08/07).

Allow me to reinforce it this way: When I was diagnosed with brain cancer 12 years ago while a College senior, I was given 50% chance to live for five years. You'd figure that, 12 years later, with all of the progress we've made, should I or anyone else get that same brain cancer today, that 50% would be a lot higher.

It isn't – and the same would be true if I had leukemia, colon cancer, breast cancer, osteosarcoma or any other cancer. Bottom line – if you are diagnosed between 15 and 39 today, just pretend it's 1977 when disco was king and the average 5-year remission was 50%.

Yes, cancer's dirty little secret isn't just that we're treating the symptoms and not the cause, or that no one really knows where the billions we donate to charity actually goes, but that the young adult community has been left out, cast aside and fallen through the cracks by the machine that is the cancer healthcare continuum.

The following are solid NCI figures... Out of the 1.3 million cancer diagnosis each year, less than 80,000 occur in pediatrics, adolescence and young adulthood, representing ~6% of all incidence.

On top of this, it's important to note that, while there are approximately 9,500 new cases of pediatric cancer annually, there are close to 70,000 cases of young adult cancer annually.

Now, what's really going to bake your noodle is that, while 94% of all cancer incidence occurs over age of 40, 1 in 10 survivors is actually under age 40. That's over one million young adult survivors in the US alone. But wait - there's more. Out of these one million, roughly one third are long-term survivors of pediatric cancer, rather than having been diagnosed in their 20s or 30s.



This is generational cancer disparity at it's most powerful.

The part that is most surprising is that Gen X (born between 1964 and 1979) and Gen Y (1979-present) have demonstrated remarkable consumer behavioral trends when it comes to mobilizing and organizing, albeit sometimes involving issues such as voting on a reality show instead of in an actual national election.

However, these 124 million Americans (Brookings Institute) are the ones who brought us Google, FaceBook, YouTube, Flickr, and Second Life. Yet again, they're the same ones who turned a video of a dramatic prairie dog (<http://youtube.com/watch?v=jHjFxJVeCQs>) into a global viral phenomenon. (It was a hysterical little clip.)

Did you know that a 2006 youth culture consumer market research report by The Intelligence Group indicated that young adults list cancer as their number one public health issue.

So where is everyone? Why isn't there a Gen X/Y revolution in the streets, across social networks or spreading virally on the tubes of the Interweb? Or are they all focusing their efforts in the wrong places? (and I don't mean World of Warcraft.)

Consider this my fellow Gen X/Y'ers: It is this writer's belief that the young adult cancer problem is only going to be solved by and within the young adult community.

By this, we need to recognize that the leadership of the big box cancer organizations, as well as a large percentage of cancer researchers are boomers and WWII generation folks who are out of touch. (Example: I had a recent conference call with a regional committee for a big box cancer group and they never heard of YouTube.) It is our job not only to motivate these people to change but develop our own "me generation" philanthropy model to solve our own problems with the same fervor we had for Sanjaya.

So, the next time you help raise money for a big box cancer organization, ask them if they support young adults affected by cancer and/or if they focus even a fraction of their research billions on young adult oncology. Is it just a random, token support group, or a singular one-time effort, or do they have an actual policy about rectifying our public health inequities?

I can pretty much assure you that the answer will be no. Why? Because no one does any clinical research in young adult oncology, nee a small handful of under-funded and under-recognized researchers and investigators. Correct me if I'm wrong but I know most of the leading young adult oncologists practicing today and they are all in consensus. Hell, they helped to write to those aforementioned scathing public health reports.



Are we're screwed?

Will no one answer the call of young adult cancer research? Because unless someone does something, in another 12 years, whoever gets diagnosed with my brain cancer will still only have a 50% chance.

Wake up GenX/Y'ers – this is our cancer, our fight, our calling. We have to take care of our own because no one else does. No one has yet risen to the occasion until we figure out how to turn this cause into the next "so-retarded-yet-I-can't-look-away" rodent video.

Yes, we're invincible and 'this can't possibly happen to us' – but it can, it does and it's scary as hell, especially since there's been no progress in 30 years. Let's rethink where we donate our time, our talent and our money. Does your cancer charity care about young adults? Do they simply get it? Do you even have a cancer charity?

We are The I'm Too Young For This Cancer Foundation For Young Adults – and we advocate on behalf of over one million survivors under 40 as well as over 200 cancer advocacy resources just for young adults. We're 'all the things you never know you always wanted' and we're only about survivors under 40. We are the new kid in town and we are your gateway. We're also TIME Magazine's Best 50 Websites 2007 so we must be doing something right after only 8 months of operation.

Our mission is to end isolation and we are doing just that. We have the sheer numbers, the voting power and the influence to change the rules. With your help, we can be that organization who emerges as the cancer research pioneer in young adult oncology.

This is why we fight - because remission is not a cure and survivorship is all the rage.

Stupid cancer. Survivors Rule.