Developing a "Health and Medicine Blogs" collection at the National Library of Medicine





Christie Moffatt, July 24, 2012

Background

- Began collection of blogs in June, 2011
- Aimed to gain an understanding of Web archiving processes and how this activity could expand the Library's collecting strategy
- Activity of the NLM Web Collecting and Archiving Working Group
- Includes blogs of physicians, students, nurses, administrators, and patients

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March 1, 2012

Handful of HOPE

Filed under: <u>Awareness, Creative Expression, Inspiration, Treatments & Cure</u> — Tags: <u>Awareness, Creative Expression, inspir, Treatments & Cure</u> — Lee Ann @ 12:39 pm

Blood Glucose: 121

There's an initiative on Facebook called <u>Write Hope on Your Hands for Diabetes</u>. Technically, it's supposed to be hope for a cure, and while I do hope and believe there will be a cure someday, I have no delusions that I'll ever see it. It's better for me to accept that this is how it is, and I can live a fabulous life with diabetes even if I'm never cured. We all do what we need to do to make the best of it, and this is what works for me.



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& ART THERAPIST

Diabetes Art Initiatives



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Create Blog Sign In

WHEELCHAIR KAMIKAZE

THE RANTS, RUMINATIONS, AND REFLECTIONS OF A MAD MS PATIENT

WHEELCHAIR KAMIKAZE VIDEOS

WHEELCHAIR KAMIKAZE PHOTOS (SHOT FROM WHEELCHAIR MOUNTED CAMERA-CLICK IMAGE FOR FULL SIZE PHOTOS) WEDNESDAY, APRIL 29, 2009

Becoming the Guy in the Wheelchair

I've recently heard from several people who are on the verge of needing wheelchairs, saying that my Wheelchair Kamikaze videos have helped them and their friends and families see that being in a wheelchair does not diminish the person sitting in it. That's a very hard and important realization to come to, and I don't mind saying that wrapping my mind around the fact that I was now "the guy in the wheelchair" was one of the most difficult adjustments I've ever had to make.

As I wrote in my previous post, the process of getting my wheelchair was a nightmarish twelve-month struggle of dealing with inept and corrupt wheelchair providers, and legions of insurance company hellions. The grand irony of the struggle was that I was fighting tooth and nail for something I was actually terrified of. Logically, and physically, it was clear that I needed a motorized power chair. Emotionally, on the other hand, it was anything but clear. Me, in a wheelchair? The thought left me feeling gutted.

In a way, the fact that I had to fight so hard to get the appropriate chair kept me from focusing too much on what getting that chair actually meant. On the day that the chair was finally delivered, I felt a momentary thrill of victory, followed by much longer moment of deep shock. So, this was my new normal. I was now the guy in the wheelchair.

I was well aware of how the healthy me usually interacted with people in wheelchairs. Or, rather, how I didn't interact with them. As my MS progressed, of course, I became more and more aware of the humanity of the individuals I saw in wheelchairs and on scooters, or struggling with walkers and other assistive devices. I knew all too well that their minds and personalities weren't broken, only their bodies, but that realization was a case of "it takes one to know one".

E-MAIL ME





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SUNDAY, JUNE 27, 2010

How Much Time Do I Have?

I think that is the hardest question I have ever been asked. The emotional weight that goes along with asking how many days are left in a child's life is staggering. I have been asked this question many times during my career, and I still don't know how to answer it.

Some doctors answer this question based on disease-specific statistics. For example, since most patients diagnosed with a brainstem glioma die within a year of diagnosis, some will tell the family of a patient who receives this diagnosis that the child has less than a year to live.



ABOUT ME



DOCTOR DAVID

The purpose of this blog is to write informally for

anyone who is interested in pediatric oncology, cancer research, cancer treatments, and breaking medical news. If you'd like to reach me directly, my email address is: loebda@jhmi.edu. Feel free to take a look at my professional bio and my not-soprofessional bio.

VIEW MY COMPLETE PROFILE



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Lessons learned so far

- Able to capture selected blogs well
- Challenges include frequent links to outside, "out of scope" content, content protected by passwords, and some types of video files
- Value of early attention to scope, crawling frequency, and duration
- Importance of test crawls, and a thorough quality review
- Determining collection scope, permissions, and monitoring when blogs end, change focus, or move to a new URL

Thank you!