# Five Takeaways from HealtheVoices 19

As I reflect on this year's HealtheVoices, I discover five big takeaways.

April 17, 2019 By Justin Birckbichler

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Now in its fifth (and biggest) year, HealtheVoices is an annual conference sponsored by Janssen Pharmaceuticals to bring health advocates from various conditions together in one place. The conference was hosted in Dallas this past weekend, with 140 e-advocates present, representing over 60 health communities.

Under the leadership of Caroline Pavis, the conference has four main goals: providing inspiration, connection, education, and empowerment to health advocates. Last year, I had the opportunity to participate in the fourth HealtheVoices in Chicago, and I was invited back this year.

Filling an unmet need is what drove many of us to start advocating and compel us to continue.

The night before the conference officially began, the cancer advocates were invited to dinner and telling of six word stories. In true ABSOT fashion, mine was "From two to one — vital mission." Jack Aiello shared a powerful phrase: "Living a second life with cancer."

Afterwards, we had a chance to share our specific area of cancer advocacy, what propelled us to start, and why we continue doing it. Similarly, in meeting with the other (and less cancery) advocates the next morning, we had an opportunity to learn about their journeys and missions.

Between both sets of introductions, one thing became abundantly clear. Many of us began advocating because we couldn't find the resources we wanted when we were first diagnosed. Rather than bemoan this, we did something about it.

We took it upon ourselves to fill that need. Once we got started, we couldn't stop helping others and growing our efforts. It mirrors the story of how ABSOT came to be: initially as the guide for newly diagnosed testicular cancer patients that I wished I had.

Your story helps you and others.

During the first panel discussion, Kelly Wilson, a PTSD advocate, talked about how sharing her story led to healing for her and her community. She discussed how talking about our health and personal journeys can help develop resilience, acknowledge traumatic events, process your thoughts and feelings, and connect to other people.

Whenever someone reaches out to me for guidance in their own cancer journey, I encourage them

to share when they feel ready, as I've experienced how it helps heal myself and others.

Kelly finished with wise words: "Your words and actions are a life raft to someone else."

"Change how you see, see how you change."

During dinner, we heard from keynote speaker Rick Guidotti, a fashion photographer who founded the non-profit Positive Exposure to show the often underlooked beauty in various conditions. Rick spoke with such passion as he shared his stories of unlocking the gorgeousness within those with various conditions that often are unfairly looked upon with disgust.

His mantra for Positive Exposure is "Change how you see, see how you change," and that line lingered in my mind all weekend. When you are handed a life changing diagnosis, it's easy to look at the world with despair. You may become isolated and see the worst in the world.

However, if you change how you see your diagnosis — from a terrible thing to a new opportunity — you'll find yourself changing. I experienced this personally, as I reframed the initial discouragement of losing my left testicle into a new life's mission.

Self-preservation is needed for advocates.

The final session of HealtheVoices was a self-preservation panel discussion by the HealtheVoices Advisory Panel, with moderation from The Mighty's Sarah Schuster.

Self-care is a word thrown around a lot, and I've even written a post about it here. Sarah had an excellent thought in differentiating between self-care and self-preservation. Self-care is what you do day to day to take care of yourself, while self-preservation involves strategies to take breaks from work. They discussed their tips for both and ways to avoid burnout. Some of the profound responses from panelists included:

- Self-preservation includes taking care the basics, like rest and hydration. It's critical for your overall care." — Lisa Deck, stroke advocate
- "Do self-care when you're feeling good." — AnnMarie Otis, breast cancer and mental health advocate
- "I know burnout is coming when the passion is still there, but the fire is gone." — Shawn Bethea, IBD and mental health advocate
- "When I'm experiencing burn out, I find myself thinking, 'I know this is what I'm supposed to be doing, but is it what I want to be doing?' When that happens, I disconnect and fully engage in

something unrelated to my work and my screen." — Gabriel Nathan, mental health advocate

The best parts of HealtheVoices happen outside of the conference rooms.

The sessions, covering topics such as branding, writing memoirs, and more, are awesome, but what I was looking forward to most is reconnecting with my tribe. Though to be fair, a close second is the Open Mic Night — video of my stand up set will be forthcoming!

Though this is only my second year at HealtheVoices, I truly feel like it's a family. I got to see old friends from the cancer community, including Kyle Smith of CHECK 15 (aka my other half), Jennifer Campisano of Booby and the Beast, and AnnMarie Otis of Stupid Dumb Breast Cancer.

In addition to missing in various body parts (and having stellar advocacy names), we are truly the family we never knew we were missing. We text year round, but you can't replace in person interactions, which involved walks both around and up and down in the hotel, shared conversations, and of course… lots of ball/boob puns.

Beyond my "No Boobs, Two Balls" squad, I also got to see many other old connections and form new bonds with advocates from both the cancer space and other communities. I'd go and list them all, but I would be afraid of dropping the ball and leaving someone out. If we had a conversation this weekend, know that I truly cherished it and learned a lot with you.

Finally, a message of gratitude for my HealtheVoices experience

Thank you to Janssen, Evoke PR, and everyone else who attended and/or helped make this such an amazing weekend. I'm truly blessed and stoked to know so many of you and I hope to be back for the sixth annual HealtheVoices.

Additionally, I'd be remiss if I didn't thank the conference organizers for providing an incredible session on how, why, and when to use humor in advocacy, led by a wildly attractive, witty, and extremely humble testicular cancer advocate (whose name rhymes with Dustin).

In the honor of Kyle's favorite pre-surgery song…

I'm glad you came.

Disclosure: Janssen Global Services, LLC, paid for my travel expenses for the conference. All thoughts and opinions expressed here are my own.

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