

Scholarship Allows Patient to Attend Cinderblocks2

By Carly Medosch



Cinderblocks2 image painted by Regina Holiday.

Don't call Cinderblocks a retreat. Founder and organizer, Regina Holliday told us that she doesn't retreat, she attacks. Still, the event had the feel of a retreat or a revival – a small group of patients, advocates, health care providers, and some fantastic industry sponsors assembling in the mountains of western Maryland (right near the borders with West Virginia and Pennsylvania). The event, held in the bucolic town of Grantsville, Maryland even featured a meditation workshop, fire dancers, and Regina energetically preaching her patient story under a tent in the middle of a field. With all due respect to Regina, when people ask where I went on my “vacation,” I have been telling them I attended a retreat.

Grantsville has a population of 825, and only 3 restaurants (according to Yelp). The peaceful mountain setting was a stark and welcome

contrast to the interior, basement rooms of the Marriot Wardman Park where I attended Health Datapalooza earlier in the same week. Approximately 2,000 people attended Datapalooza, and despite attending each day and going to at least one reception every night, I was only able to talk with a few of them. I was able to attend Datapalooza for free because I serve as a member of the Consumers' Circle and it's a local event, so I don't have to worry about travel costs. Datapalooza has strong ties to the federal government and attracts lots of big names – Todd Park, Sylvia Burwell, Karen DeSalvo, DJ Patil, Farzad Mostashari. The keynotes were disappointingly the same or similar to ones we heard last year, or a few months ago at HIMSS. There were no patient keynotes, but in an improvement spurred by the Consumers' Circle there was a patient/consumer session track and several patients featured on panels. Overall, the vibe from the stage at Datapalooza is one of being “talked at” instead of a participatory discussion.

The name Cinderblocks comes from Regina's experience building DIY bookshelves with her fifth grade class. The full story is in her new book, “The Writing on the Wall.” The do it yourself aspect of the bookshelves made from cinderblocks and wooden planks made them all the more special to the children in Regina's class.

The conference shares that same spirit. There is no budget for fancy decorations, the presenters are mostly chosen from the group of attendees. Many talks were customized to the audience of passionate advocates, with Kym Martin helping us understand how to better think of our

advocacy in business terms, and e-Patient Dave deBronkart telling the story of his long road to becoming a well-known advocate and speaker.

I greatly prefer the vibe of Cinderblocks2, smaller, friendlier than the usual conference. But don't confuse smaller, and DIY as worth less. There were so many great presentations, that I was disappointed I didn't have a clone to attend both concurrent session tracks each afternoon. The attendees numbered in the dozens, not thousands, but I still was unable to meet, or talk with everyone there. The few conversations I was able to have were much more meaningful, ranging from talking about deeply personal issues to business strategy in the course of an hour.

Cinderblocks2 was two days and a half of presentations on health topics ([agenda here](#)). But there was also a night of songs, fire dancers, and a bonfire. Volunteers created luminaries representing every single jacket in The Walking Gallery and the first night our group walked across a bridge lined with these lights. During the day I had found a few representing the jackets of friends and posted them to Twitter. It seemed like for every image I sent, I got requests to find 2 more. I found a jacket from South Africa, was asked to find one from Canada, and so on. From the tiny town of Grantsville, I was connected with people around the globe. Everyone was so happy to have been kindly included by Regina and her helpers. We were a community.

Also at Cinderblocks2 was a presentation on zombie fitness, a group art project, and a patient panel featuring long-time patient Robb Fulks. Robb was one standout of the conference for several reasons – he's smart, funny, and passionate, he's an expert in his own patient experience – but best of all is we were able to see a shift take place as he felt the importance of telling his story. Look for great things from Robb in the future. Regina knows Robb from her pre-advocacy life. She invited him to Cinderblocks2 and probably changed his life. One of my favorite things about Regina Holliday is how she keeps reaching back to help people up the ladder behind her.

Regina asked me to perform at [Pecha Kucha](#) night in the nearby town of Accident, Maryland. I was able to tell one of the stories from my 21 years of chronic illness. This is the hidden story in my new Walking Gallery jacket (the pills form the number 911). You can watch the 6 minute presentation [here](#). I didn't know what Pecha Kucha was, and my illness has made memorization difficult, but I was smart enough to know to agree to whatever Regina came up with. I'm glad I did. It's a lesson more people ought to learn.

Cinderblocks2 was generously sponsored by Lilly Clinical Innovation, Lifetime Health Diary, and the Kanter Family Foundation. Patient tickets were offered for a discounted price. Patient scholarships were provided by the Society for Participatory Medicine's travel fund. You can view a Storify of tweets from #Cinderblocks2 [here](#).

–Carly Medosch

Carly is a chronic illness advocate. By day she is a program analyst in Washington, DC. By night, she is a support group leader, 21-year chronic illness patient, former designer, and MBA. She blogs occasionally at blog.chronicarly.com and tweets about her pet bunnies at @CarlyRM.