Going Viral, Bleeding Out My Ass and #DoingItMyWay

July 20, 2018 By Shawn Decker

I recently spoke to POZ about a tweet that went viral. You can read about it here: https://www.poz.com/article/hiv-tweet-regarding-selfmade-billionaire-kylie-jenner-goes-viral

This is the story about the behind behind the story. The nitty-gritty details about the random acts of fate that lead to a viral tweet...

But before I go there I have to explain that Twitter is runt of my social media presence. A couple of months ago when we were talking to the folks behind the #DoingItMyWay HIV testing campaign, I was asked: "What about your Twitter?" I scoffed, "Oh, it's not ever worth posting over there, I get way more Likes on Instagram." Which was true—leading up to the viral tweet, I used Twitter primarily to exchange pleasantries with Matthew Modine and covertly read pro wrestling rumors from an account I don't even follow.

Last week that all changed. To tell this story I want to approach it the same way that filmmakers approached Halloween 3, which made the movie seem like it lasted a week. So bear with me. Like the movie, Michael Myers does not figure into any dramatic loss of blood.

12:34 pm Monday, July 9, 2018: I notice a peculiar darkening of my stool....

12:30 pm Tuesday, July 10, 2018: I go to the UVa hospital, where I get all of medical care (hematology, ID, etc). Only I'm not arriving as a patient- I'm arriving as someone living with HIV there to educate residents about my three decades of life with the virus and educate about some of the stigma that surrounds this particular medical condition...

One week later I'd be back to the hospital: THIS TIME AS A PATIENT.

2:41 AM Thursday, July 12, 2018: The stool has been a black tarry mess three-too-many times now. I inform Gwenn about what's been going on down there, and that I should begin treating myself with clotting factor—assuming that there's some kind of internal bleed happening.

1:12 PM Thursday, July 12, 2018: After having trouble sticking myself, I call in a friend with professional experience to help. If you ever need a good poke, don't hesitate to call on close friends with the skills to get the job done.

6:37 PM Thursday, July 12, 2018: Gwenn discovers on the internet that eating blueberries can cause dark stool. I'd just started eating a fuckton of blueberries around the same time as the butt drama began. Later that night I have a glass of wine with friends, celebrating the victory.

1:30 PM Friday, JULY 13th, 2018… that's right…

FRIDAY THE FUCKING 13th:

An appointment with my primary care physician, who seems to think it's just the blueberries. We decide a little labwork is a good call considering that I do have a bleeding disorder.

6:00 PM FRIDAY THE FUCKING 13th:

A few friends are about to come over. The phone rings. It's my hematologist.

"Oh yeah, I'm sorry I forgot to update y'all."

"Shawn-"

"Saw my primary care physician today, got some labs drawn…"

"HAVE YOU SEEN THE RESULTS?"

"No–"

I hear the results. I hear Gwenn return home from the grocery store. As my hematologist is giving me the gory details, I whisper to Gwenn: "Tell our friends not to come over…"

According to the labwork, I've lost five pints of blood over the course of 5 days. I spend the rest of the evening apologizing profusely to the blueberries for besmirching them.

4:13 PM Saturday, July 14, 2018:

Home-bound with a hemophilia treating schedule of two infusions a day, I pop onto Twitter. I see the New York Daily News tweet which asks: "What are you doing with your life?" I see that someone has answered the question, so I decide to do the same…

Figuring it's good for about 20 Likes, I close out the app and head over to Instagram to see who really truly loves me.

7:11 PM Saturday, July 14, 2018

I'm on the toilet scrolling through my Twitter. Since treating on Thursday my poo has rebounded to human tones. What a relief. As I'm finishing my business, I see that my tweet has hundreds of Retweets. "HOLY SHIT!"

The tweet just keeps snowballing through the night and into the next day. I do my best to respond and also get the naps I need considering how depleted I am.

Monday, July 16, 2018:

The tweet starts to slow down, as viral tweets often do. I'd heard that they have a 36-hour

lifespan. What I didn't expect was online articles about the tweet. My 43rd birthday is made unforgettable by the most severe bleed I've had in decades combined with a tweet that's being seen around the world.

2:02 pm Tuesday, July 17, 2018:

I get labwork done at hematology, which reveals that I need to replenish in the infusion center with a 30-minute iron drip. The nurse says, "It looks like blood." I say, "It looks like a bag of soy sauce to me..." She exclaims, "YOU'RE RIGHT, IT DOES!"

I feel like she's known for years it looks like something else more than it looks like blood. A feeling of accomplishment washes over me.

My hematologist recommends treating with clotting factor at home once-a-day until Friday. Which is the day that I'm writing this...

So, I'm about to do that. It's been quite a whirlwind, and this medical drama is happening just as I'm about to head out of town for a few days. But it's all good for now. I'm getting an endoscopy in early August to see if there's an ulcer or anything that might explain why the upper GI bleed happened. So I'll be sure to update on here.

As for the tweet. Well, as an HIV educator that kind of opportunity is priceless. These days I'm living a pretty quiet life all things considered, but I jump at the chance to do things like talk to the residents at UVa, or be a part of a social media testing campaign like #DoingItMyWay. But it's the moments you can't plan out that seem to have the most impact, whether it's a long unexpected talk with a friend or millions of strangers reading a 200-character Cliff Notes version of your life story.

Either way, it's a small world. So we should do our best to make every around us feel better about themselves and remind them that their true value is not measured in dollar signs, as suggested by The New York Daily News.

Positively Yours,

Shawn

Know your HIV status- to find a testing location near you, check out the Act Against AIDS Testing Locator.

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