A World AIDS Day Without Mom #WorldAIDSDay #Heroes #PamDecker #WAD2022

December 1, 2022 By Shawn Decker

A year before World AIDS Day was first recognized in 1988, just about every day was World AIDS Day for my family after my HIV diagnosis. I was 11 and my brother, Kip. My parents had a good relationship- humor and laughter was all part of growing up under their roof. My friends called them by their first names, at the insistence of my mother!- “Pam and Bud”. When I started making friends, and spending the night at their houses, I always thought about how cool my parents were when a adult in this house was a lameass or kind of over kids in general.

Which, from these 47-year old eyes, seems a perfectly reasonable coping mechanism.

Before HIV, hemophilia was the medical condition that shook up The Deckers. At age 2, when I was finally diagnosed with the rare bleeding disorder I’d been born with, my Mom took the lead with me and the Medical Wing of the household, while Dad manned the Teaching the Boy to Throw a Ball and Not Say “SHIT!” In Public territory with Kip. But even when their second son brought a rare disease, hemophilia, to the table… whatever came their way, my Mom and Dad were either up to the challenge or they were quick to learn and quick to react.

Mom told me stories of those days, when I had mysterious bumps and bruises that had never plagued Kip during his first bumbling days in his newly-minted soul shell. When they took me to the hospital, worried and confused as to why I was crying and how I managed to get a bruise the size of my kneecap. They faced accusations of child abuse- the first medical-related stigma that you only know about if you’re in the position. Of course, it’s easy to see why someone would be concerned, seeing a child crying and writhing in it’s parents arms because of the physical discomfort that comes with a bleed.

The first couple of years my parents were overprotective by their own admission. But who could blame them? If I’d been in their shoes I would have created a giant bubble-wrap ball for the kid to roll around in. At age 4, my brother criticized a parenting style that he hadn’t received. He told Mom that they didn’t let me have fun the way he gets to. It was bad enough that I was younger and dumber than him, developmentally, but anytime a game got fun a parent would rush in to sweep me away from my big brother.

You can understand, from each perspective, why it went down that way and the responses that were conjured.

While hemophilia presented medical and physical dilemmas, my HIV diagnosis brought a particular set of skills that made those hemophilia-related child abuse whispers in the hospital pale in comparison. With about two weeks of 6th Grade left- the last year of Elementary School- my mom told my 6th Grade teacher about my medical news. My teacher was concerned, and contacted her higher ups… who immediately hit the panic button. The next day at school, a random Monday in late May, I was called to the office over the intercom. Mom says when she picked me up, I had tears in my eyes and said, "I didn't do anything wrong!"

See, I'd gotten in trouble before… earlier that year I traded a clubbing blow at Bible Class, those weird one-off days when you were herded onto a bus and driven to a church for a hour or two. You know, 80s shit.

Anyway, on this day I hadn't gotten involved in any nonsense. Mom says she took me home and told me about my HIV diagnosis. I blocked it out. That day is a distant blur. The most vivid memory I have of that saga is the Elementary School Graduation Ceremony that my mom had to fight in order for my presence to be allowed. I remember standing in the hallway, dressed up nice, outside of a closed classroom door. When the door opened my entire class came out. "Shawn!" one friend after the next said, surprised to see me. Just about everybody gave me a hug…

It's a sweet memory once I get past the absolute heartbreak of the scenario, particularly the stress of it all that fell primarily on my Mom's shoulders. She'd spend the whole summer trying to get me into Junior High School. When she threatened a lawsuit with a week left until the first day of school, the doors magically flung open. But not without a catch- on the first day of school I was stunned when a notice landed on my desk informing me that someone at school had HIV… the flyer also discussed the link between hemophilia and HIV transmission.

I was devastated. I wanted nothing more than to get back to school and be "a normal kid".

Instead, I spent over a hundred days of that school year at home. To her credit, my mom gave me the space to process the life-changing news we'd all received that year. She never pressured me to go to school. She implored my teachers to only send home assignments that really mattered in terms of me staying on the learning curve and keeping up with my classmates. By the second half of the school year, I was starting to feel social again. My parents encouraged this change in attitude by letting me have my own phone line in my room. Which basically made me a teenager from the future with instant access to any friend I wanted to communicate with.

As a result of my incredible gift of gab, I made a lot of new friends. And in 8th Grade I even hosted a couple of popcorn and movie nights that, gulp, included the presence of girls! That year I had a life-long and never-again-to-be-achieved again four girlfriends in one year, two of which I even kissed. The low point of that year? Easy- it was when someone told my girlfriend that I "had AIDS".

It was the first time I'd ever lie about my HIV status. I never really had to do it often, but there was

no way I'd ever admit to it. In the smalltown I grew up in, I never wanted there to be the definitive proof that it was me that a confession would all but insure. Ultimately, my teenage years with HIV were a lot like my childhood years with hemophilia. Which is to say, I enjoyed the typical suburban American white boy existence, sprinkled with the drama that my medical conditions could provide from time to time.

I didn't really have a post-high school plan. My mom got her wish, which was the longshot of seeing me graduate from high school five years after my diagnosis. Anything after that was gravy for her. Unlike my brother, I didn't have the pressure of having the grades to attend college. Later, Mom admitted that she didn't push that because, as she said, "colleges are gross, you would have never survived dorm life."

She's probably right. My health had always been okay. It just took me twice as long as my brother to get over a cold, or whatever else was going around. My t-cells were checked every four months or so, and they'd bob up and down, floating around 200 or so. But after I graduated high school, I definitely noticed fatigue more. My new best friend had two years of high school left after I graduated, which was a godsend, but I remember that first winter after graduation... when the show came, I didn't go sledding with my friends because all I could think about was the daunting climb back up the hill, as opposed to the joyful ride down it that most 18-year olds would fixate on.

At age 20, I remember feeling really down. It felt like all of my friends were taking the next steps in their lives and I didn't really have any idea what I was going to do or be. I remember thinking that HIV hadn't gotten me yet, and it was within reason that I was only halfway through my mortal journey... in effect, I had a mid-life crisis of sorts. I was obsessed with music, but I was too shy to sing and was aware that experimental synth-drudge wasn't going to land me on MTV anytime soon.

Speaking of MTV, around that time Pedro Zamora was as much of an inspiration as Depeche Mode and Nirvana were. He'd passed a year and a half before I opened up about my status. I remember being moved by Pedro's Real World castmate Judd Winick. During a Real World Reunion special, he implored viewers to do something about HIV. He was so visibly shaken by the fact that his friend had passed... that there was a reunion happening without the presence of an important factor in what made the San Francisco season of the reality show so special. Judd honored Pedro's absence and life of activism by calling on a televised audience to pick up Pedro's torch.

Shortly after that Reunion special, I remember feeling really down after posting some embarrassingly low scores in bowling league with my dad. That was the first time I thought about something I never thought I could do: "What if I talked about being HIV positive?"

I remember telling my mom, expecting her to fall out of her shoes over the revelation. She paused, then asked me if that was what I really wanted to do. After I said yes, she said that I need to be prepared for all of the reactions. "How are you feeling? How are you doing?" I laughed it off and she saw that I was serious. Then she got serious. "Shawn, I always knew you'd talk about it... when YOU were ready." I responded like any 20-year old would: "You're full of shit, Mom!" I could tell

that she was relieved, and surprised when I took her advice and called my doctor- the one she had to literally drag me to for so many years- to give him the news.

After I put up a website named after a Nirvana lyric (My Pet Virus), things really took off. I was invited to New York City to be interviewed by POZ Magazine. Then I started writing a column for the magazine, and going to conferences to talk about my experiences with HIV. Though my Real World audition tapes were ignored, I did eventually appear on MTV on a one-off educational program. More things like that would happen over the years, and I could tell how happy Mom was to see me just being me, but instead of keeping HIV a secret I was proudly displaying my status on my sleeve and trying to educate people about the stigma that everyone with HIV experiences.

The first World AIDS Day after I opened up in 1996, my Mom decorated the Christmas tree with a ton of little red ribbons. She put red lights on a white tree… which I called "The Pepto Bismol Tree". She laughed, "You're right, son, it does look like a bottle of Pepto!" She was just so happy and proud, and loved all of my new HIV positive friends I was making online and at POZ Magazine.

I'm consistently overwhelmed with gratitude for the life I've had. A loving family. Understanding friends. Gwenn, the love of my life who I'd have never met if not for my HIV educational work. One of my favorite memories of the early days of our relationship is a night when we had my mom and dad over for dinner. When I cleared the table after dinner, my Mom's jaw hit the floor. "GWENN," she said, wide-eyed and with a smirk. "How did you get him to put a dish in the dishwasher?!" I was embarrassed at the time, and her surprise in that moment at my domestication was the suprise I was expecting her to exhibit five years earlier when I told her I was going to put up a website and splash my HIV status all over the internet and beyond.

This World AIDS Day is my first without Mom. She passed on the last day of June earlier this year after a steady decline in health. My dad took care of her at home after she was unable to leave the house. Her passing wasn't unexpected, which is to say that I had what so few have the opportunity to do: I got to say thank you. I also got to tell her that she's been the best mom I could have ever hoped for, and that the life I love so much is a result of her hard work… her love.

Her last wish for me was simple: take care of my brother. She said he doesn't handle "these kinds of things", meaning death, like I do. She knows that I've had to think about mortality since the first terrifying near-death experience I had, which was at the age of 6. She's the one who taught me about spirituality and her feelings on an after-life, as we counted the hours until we could return home to my brother and dad from the hospital.

This Saturday, my niece is getting married. Where I gave mom the exciting life of a travellin' HIV educator and author, Kip gave her the experience of being a grandmother to two wonderful children, who are now a teenager and a young woman about to take the next big journey in her life…

And I feel like Mom will have the best seat in the house, smiling down proudly on her family. "To live on in the hearts of those who love us is not to die", is the inscription at the gravesite where

her soul shell rests... but her soul? I've felt it guiding me through the toughest times since her passing. I felt it in the moments of great joy. I'm sure it'll hit me Saturday, because I recognize so much of her spirit in the family I am so honored to call my own.

Happy World AIDS Day, Mom. I'll see you on the other side. Until then, I'll do what you told me to do: enjoy this life.

"That's my boy."

Thanks, Mom.

Positively Yours,

Shawn (AKA "Pookie")

© 2026 Smart + Strong All Rights Reserved.

http://beta.docker.poz.com/blog/world-aids-day-without-mom-worldaidsday-heroes-pamdecker