Anonymous No More

After four years of revealing the intimate details of her life in the pages of this magazine, POZ's "Anonymous" columnist discloses her status and becomes editor in chief. Here, she chats with Sean Strub, the magazine's founder about what it's like to be publicly positive

April 1, 2006 As told to Sean Strub

SEAN STRUB: So you've just disclosed on the cover of POZ. How does that feel?

REGAN HOFMANN: It feels good to be free. I've lived with HIV for nearly a decade, keeping it a secret from most people in my life.

SEAN: Who did you first disclose to?

REGAN: I told the man I suspected I had contracted the disease from (he tested positive). And I told my therapist. She sent me to an HIV support group of gay positive men.

SEAN: Had you had much exposure to gay culture before?

REGAN: Not much. But I got an education very quickly.

SEAN: Was that shocking for you?

REGAN: No, it was incredibly liberating. In my world, sex was either overly romanticized or people were too polite to talk about it. At the support group, I didn't talk about HIV much. I talked about sex a lot, because I had this great opportunity to learn. But I found out that disclosing to people about the disease doesn't mean that you talk only about sex—there's so much else that comes into play.

SEAN: Because HIV impacts your job, housing and every relationship in your life.

REGAN: Yes, and issues of what the future holds, how a partner's family might react, your own self-esteem.

SEAN: Has disclosing changed your relationships with the people you've told?

REGAN: Not really. Telling my family didn't change my relationship with them. My sister met me

at the train station, and as I reached out to hug her hello, she said, “You’re going to beat this thing.” Then we went to Burger King, and she dipped her french fries in my ketchup intentionally, as an act of letting me know that she knew about the disease and wasn’t afraid to catch it. From the beginning, my family treated me as if I didn’t have HIV and that made all the difference in the world. After that, I didn’t tell many people, just potential partners, until recently, when I took this job. The burden of the secret has always been the hardest part of the disease for me.

SEAN: So you lived like a spy. How did you react when you heard people make a negative reference to people with HIV or AIDS?

REGAN: It felt extremely hypocritical to be living with HIV pretending I didn’t have it. That rift made me uneasy. I would be at social events or sit at dinner parties listening to people say the most awful things about people living with HIV and realize that not so long ago I might have sat there—

SEAN: —And not even noticed that their comments were offensive or ignorant?

REGAN: Yes, and not even noticed it. Being positive tuned me into everything. With my diagnosis, I was pushed into a part of society that I had never understood before. Suddenly, I felt like I knew somewhat what it was like to be marginalized.

SEAN: A lot of us who have HIV are already marginalized in one way or another either because of the color of our skin or because of our sexual orientation or because we are impoverished or incarcerated, but you can pass as part of the white middle-class mainstream.

REGAN: Yes, but I was grateful to be shown other ways of looking at the world. I’ve been resensitized by HIV. In that regard, it was a great addition and change in my life.

SEAN: Talking about their diagnosis, people say things like, “Oh, it was the greatest gift I ever received. It did wonderful things and changed my life.” On the one hand, I want to react kinda like, “gag.” I mean, you just got a horrible disease you’re going to deal with for the rest of your life. But on the other hand, having HIV does give you awareness and a sensitivity that beforehand you didn’t have. It added a dimension to my life that has made me a better person.

REGAN: How has your diagnosis changed your life? Was it an instantaneous change for you?

SEAN: Well, mine was different, because I was already political and very much an activist. I had a healthy reservoir of outrage. And I was expecting it. From the very first time I heard about the disease in 1981 and I heard about the symptoms—weight loss, swollen lymph glands and night sweats—I knew I had it. I didn’t get tested until the test came out. The weekend after Labor Day 1985, I thought I had poison ivy from gardening, and it turned out to be shingles. I got tested and was diagnosed with AIDS Related Complex.

REGAN: ARC?

SEAN: Right, ARC. My doctor, who was a friend, cried when he gave me the diagnosis. He said, "Look, Sean, these days you can have two good years." Meaning that it was a good thing that I was diagnosed then, in '85, rather than earlier. He has since died from AIDS. I've outlived three of my doctors. Did you cry much or often after your diagnosis?

REGAN: Strangely, when I went home from the doctor's, I didn't cry for several hours. Days later, I was looking at my reflection in the bathroom mirror, and I just got so angry at myself. I freaked out. I smashed every piece of glass in the bathroom—including the medicine cabinet—to smithereens. Then I sat down on the floor in all this broken glass. I remember just looking at my hands and noticing I was bleeding. I don't know what happened exactly in that bathroom, but I decided I wasn't going to die and that I was going to fight. And I have never really been sad about it. Though I've lamented the loss of certain things in my life because of HIV.

SEAN: I like this image of you, sitting with your shattered life and shattered glass all over the bathroom floor, your clenched fists rising up as you say, "I will never let this disease defeat me!" I remember after I got the news, I was in shock. I walked down Broadway amid all these people going about their normal lives. It was a sunny day; the birds were chirping. I was thinking, "Oh, my god, my life has been turned upside down. And these people don't know."

REGAN: After my diagnosis, I walked out into the parking lot, and I almost got run over by a Mercedes and literally had to do a Starsky and Hutch onto the hood of a parked car. I remember thinking, "You know? I can still die every other way, too.

SEAN: It's the cliché of clichés: Even though you have HIV, you can still be hit by a speeding car.

REGAN: I just decided that they hadn't told me anything I didn't already know. That I was gong to die—someday. You asked me how different it is to tell people now, ten years later. It's taken me nearly a decade to be comfortable with the fact that I have the disease. Now, when I tell people, I am impervious to their reactions. I know that their reactions can change, and I know their reactions don't affect the way I view myself anymore. I'm not looking for their reaction to tell me how I should feel about HIV. I know how I should feel about HIV. That's what's enabled me to step up now. Sure, I fear the unknown and people who don't have any reason to be benevolent toward me.

SEAN: Since you accepted the job at POZ, you've disclosed to all sorts of people. What were the reactions?

REGAN: Largely supportive. Though the stigma is still strong, people are well educated about how you get the disease. There's less fear now. I do less explaining now to people—that you can't get it through tears or spit or casual contact or kissing.

SEAN: Have you felt the fear of anyone else in terms of touching your hands or sharing towels or utensils or anything like that?

REGAN: Here and there, but people understand better how it's transmitted. There's this great irrational fear that has been around for so long that it's hard for that to go away. Things were very different when you were diagnosed.

SEAN: Yes, it was a bizarre time. Then there was so much anger and much less understanding. People were dropping like flies all around my life and the lives of my friends. There were times when there were two or three memorial services in a day. So much of my time was spent fundraising and organizing events and auctions and running for U.S. Congress and producing the play The Night Larry Kramer Kissed Me. But all this came from the same AIDS-related energy expressed in every way I could find, to try to impact people and to create change. I was very angry, particularly at gay men who I felt weren't doing enough about the epidemic. I was very self-righteous, I guess. Since I had the disease, I expected everyone else to care about it. I think my views have changed a lot since then. But I do remember being at dinner parties where if I started talking about AIDS I'd be shushed and someone would say, "Can't we talk about happy things tonight?" I ended up migrating to people who shared my values and were as interested in doing something about AIDS as I was. My AIDS friends were my new friends, and gradually, I forgot about the old friends who drifted away. Some weren't friends after all. But HIV has also opened up the door to all sorts of new relationships that have been very rewarding for me.

REGAN: What happened when you disclosed?

SEAN: I was already out to my family and friends about being gay, and I was already doing AIDS activist work, and I already assumed that I was positive, so I don't think it had as much shock value. But there were some times that I told people out of frustration or desperation, when I was not in a calm, good place. Sometimes, my panic or paranoia or fear ended up getting reflected back to me through the reactions of the people I told.

REGAN: Is telling someone you have HIV a litmus test for knowing how someone really feels about you? I've found that sharing my diagnosis flushes out people's feelings pretty quickly. It's a weird thing to do: talk to someone whom you've just met about whether they would be willing to be by your side when you're sick or dying, whether they can live with you if you don't have kids or if you have positive kids, not to mention whether they're willing to risk their life to be with you.

SEAN: It'd be a good test exercise. It would be an interesting experiment for someone who is HIV negative to tell the person they are dating that they have HIV—I guess if they can handle that, they can handle anything.

REGAN: Are you glad you became such a public activist?

SEAN: Yes. There is tremendous power in disclosing one's HIV status and being an activist. Not everybody has the same ability or luxury or freedom to be able to share this news, because there are different risks people face. I don't advocate anybody disclosing their status until they're prepared to handle the consequences and think through what those consequences might be, negative or positive. There are a lot of positive consequences, like what it does for your own

mental health and bringing truth to the relationships in your life. But there can also be complicating consequences.

REGAN: What should I watch out for?

SEAN: Some relationships are going to change, even with family and close friends. Some will get stronger. The news can bind you closer, and you'll feel more secure in those relationships. You become more certain about what you mean to them and what they mean to you. But others may go the other direction. Some people may be frightened or be unable to handle it because of their own
issues or ignorance. Sometimes that's painful and sometimes it just requires some education. The most painful thing—and I've had this happen—is feeling like you're an embarrassment to someone. I've had the experience of being with people in social situations when I knew they'd have preferred if I'd not been so matter-of-fact about my serostatus in front of their other friends.

REGAN: I never dreamed I'd be an activist. Yet AIDS has fallen off the radar screen in the media and pop culture, and as someone with the disease, I just can't sit here and be angry when I won't do anything. I caught myself saying, "Where have all those people gone? Besides the fact that many have died, where are the others who were doing so much?" I realized with horror that I was waiting for someone else to save me. The first step is to get people talking about it again. I've seen in my own life when I've shared my status what can happen.

© 2026 Smart + Strong All Rights Reserved.
http://beta.docker.poz.com/article/Anonymous-No-More-2789-7798