



Bare Witness

Stephen Gendin was the irreplaceable It Boy of AIDS and queer activism. His comrades, lovers, and friends explain.

October 1, 2000

Mark Aurigemma

Senior VP, Fenton Communications

My overwhelming feeling is that a terrible mistake has been made. The thought that it's even possible that Stephen Gendin has died seems ridiculous to me. He was not ready to die. Death held no charm or allure for him. He knew it was bullshit. The only thing that interested him was being alive.

I first saw Stephen 13 years ago at an ACT UP meeting, and I fell in love with him immediately. He was 21. He wore a very nerdy digital watch, the kind you could do calculations on. He had a very distinctive speech impediment. And he was transfixing.

He was a thick patch of contradictions. He was a dyslexic genius who could not write his letters properly. He seemed to have been born without guile, completely incapable of the disingenuousness that is the shared language of most of our lives. He truly was a radical, thinking completely beyond the strictures of conventional wisdom. He loved to shock people.

A few months into our relationship, Nils Fullerton painted on Stephen's black denim jacket in red Dracula-style letters: "Cocksuckers." Stephen wore that jacket everywhere. And when someone asked him what that was, he would say, "It's a gang."

Our relationship was tender, stormy, passionate, jealous -- the kind that people have when they're very young, if they're lucky, and then cherish for the rest of their lives. Being his partner was not always easy, especially for those of us who became -- and fell in love with -- radicals, at least in part as a reaction to our fundamentally conservative natures.

Stephen did more and gave more and had more of an impact for good in 34 years than most of us would have the interest or the capacity for if we live three times as long. He fought longer and harder than any of us could have expected or hoped because he loved life and was a true optimist. He fought the good fight, and because of that, he died a hero. In the end, your greatness is measured by the love you leave behind.

David Barr

Director, Forum for Collaborative HIV Research

Being a part of ACT UP in New York in the late '80s was like being inside the eye of a hurricane. The storm was raging all around us, but inside that eye of activism was a place that felt safe. ACT UP was a sexy place, too. The sexual energy that ran through the room at Monday night meetings is legendary. No one personified that energy for me more than Stephen. Not only was he stunningly beautiful, but he was a fierce activist, running with a banner at the FDA in his leather jacket (and knocking a policeman off his motorcycle in the process -- a felony arrest charge, later dropped).

From the moment I saw him, I had the worst crush. For several years, it was hard to speak to him and be in any way coherent. Thank goodness I got over it, because it was my discussions with Stephen that I will cherish forever. Stephen played the boy, sitting on the floor of the living room on Fire Island tenderly going through his comic books, standing on the dock waiting for the ferry wearing bell-bottoms illustrated with New Kids on the Block pictures. But underneath the boy persona was a man who taught me much about money, business, politics and God. It is hard for me to write about Stephen without mythologizing him. I loved him and miss him and nothing more needs to be said.

Kyle “Hush” McDowell

Massage therapist

Stephen was six-feet, two-inches tall. It mattered for the chemo, which didn't matter.

Stephen was strange. He was weird. He knew this, and he liked it.

Stephen was my lover, my brother, my boyfriend, my partner, my soulmate, my master and my daddy. Yes, and for others, too. Stephen was not my father.

July 2nd.

Stephen was my singular privilege.

Stephen was once Steve. He thought the “ph” was sexier.

Stephen's smile was unforgettable.

Stephen loved junk-food labels that read “processed” or “artificial.” He loved that.

Stephen loved sushi.

Stephen wore the same pants four days running. Exactly four days, usually, except when it was one or 10. I tried for years to get this ideal down to three. No use. It was four.

Stephen loved chenille and velvet. He loved all colors bright.

He hated umbrellas. He didn't mind the rain.

Stephen had style.

He was unbelievably smart.

Stephen particularly liked circuses. He liked dance, dances and dancing. And action-adventure films and the week of the Westminster Kennel Club shows. We would watch them together with our dog, Zoom.

Stephen adored Zoom. Stephen taught Zoom to be rightly selfish in seeking out good play and yummy food. They traveled together everywhere. Stephen snuck Zoom onto scores of flights to hundreds of places, thousands of trains to tens of thousands, perhaps hundreds of thousands, of stimulating odors. Perhaps even a million.

We took turns speaking for Zoom, personifying him. Now it's my turn: Zoom loves Stephen. Zoom says that he won't forget to love Stephen every day because his kind don't quite know of past tenses, but they remember so well.

Stephen Matthew Gendin.

Stephen was so cool and so funny. But he didn't laugh, actually, when I think about it. He smiled bigger.

Stephen was an optimist at heart. He had hope.

Stephen could get angry and he could invoke that in others.

Stephen was afraid. He was very, very scared. He had comfort from this, from time to time.

Stephen slept like a log anywhere he wanted or needed to. Stephen rested easy. He loved that.

Stephen loved kissing. Stephen loved fucking. Stephen loved cuddling and embracing.

Stephen was spiritual.

On his last bed, he asked if I had all his hair safe. The hair we had cut so hopefully on Sunday afternoon. He said of the "stuff" that I do, he liked my "hair stuff" the best. Because, you know, Stephen loved his hair.

Ajax Greene

President, Community Prescription Service

Was it the yin/yang thing? Or that opposites attract? What else could explain how a goofy, straight “business” man from the backwoods of New England could click so well with the notorious Stephen Gendin? I am not sure we were friends, but I know I loved him and I am pretty sure he felt the same for me. On our best days we created magic. In honor of Stephen, I feel full disclosure about our relationship is vital. At times, his self-involved, stubborn nature made me want to curse the ground he walked on. So here I sit in a puddle of guilt over the energy I wasted in anger, but most of all missing the magic of our partnership. Stephen’s biggest impact on my life was his need and ability to push the envelope. His risks made it OK for me to be myself in a way that might not have happened without him. What a blessing. He taught me, in ways I never dreamed of, to celebrate my own queerness. In a business meeting of starched white, buttoned-down shirts and ties, I felt so safe in my jeans and polo shirt because there was my hero in tie-dye pants, an ACT-UP t-shirt and green hair. His outfits are a poor metaphor for the amazing intellect, the bubbling passion and range of feelings that were Stephen. He is a hero because, in my mind, Stephen Gendin is the biggest queer of all.

Michael Warner

Author; professor, Rutgers University

The connections I had to Stephen made a kind of catalogue of the spaces of the queer world -- Fire Island, dance clubs, bars, political meetings, marches on Washington, protests, parades, parties. As I think back over the things he did and wrote over the years, I’m moved by his determination to live historically. Because of AIDS, he learned early that his life was going to have an unfamiliar shape. Experience for him was not going to be made familiar by cliché. It would not fit standard moral wisdom. Stephen was not a great writer and not a great political strategist, but his writing and his politics were made vital by his persistence in facing what was strange in his life, even when it was messy and difficult, and especially then. For this he was sometimes reviled. It took courage to endure reproach the way he did.

Stephen and I helped to found two organizations together, AIDS Prevention Action League and Sex Panic! Both were unpopular causes, easy to despise, and I learned quickly that he was the one person that I could always count on to show up in such a moment. The world without Stephen will be more conventional, more self-satisfied, more convinced that AIDS is over for anyone who counts, more eager to have gay men live by the dominant standards rather than by their own. He gave the better part of his life to shoring up a fragile world and to understanding the messy historical part of experience. Without him that world is more fragile and the times are more opaque. In mourning him, let’s attend to that world that meant so much to him.

Julie Boler

Lesbian activist; writer

The black hair bouncing asymmetrically conflicted with the crass business suit: raver meets conference vendor. It was 1994, the gay health conference in Houston. The suit, borne with pragmatic aplomb; the hair, a hint of the brilliant mischief lying within. Stephen promoted his

prescription service till the exhibit hall closed, put on his Docs, and went to find the party. These comfortably held contradictions, a first impression of Stephen that would last.

I found him embracing his contradictions for the next six years. He picked and chose pursuits and priorities based simply on what he found real. He enraged those less able -- they maligned Stephen rather than confront their own complicated, consequential choices. For Stephen, if more and different HIV meant he would die sooner, and exposure to it meant he would live more meaningfully, Stephen chose with clarity. If Ecstasy meant joy followed by days of hell, Stephen measured clear-eyed. Called reckless, impulsive and dangerous, Stephen confounded many by choosing pleasure over safety, glory over longevity.

Stephen's contribution was an astonishing self-disclosure about everything from skin conditions and bowel movements to his politically incorrect erections and his darkest moments of self-doubt about what he did with his infected body fluids. For this he was attacked -- for stating nakedly, humbly: This is my experience, this I've learned, this I fear. Confessions of humanity met accusations of irresponsibility and malevolence.

The last time I saw Stephen, he was simultaneously cell-phoning work about a call from a Glaxo rep and cruising conference attendees pouring out of a Gay City workshop. And flashing that big silly grin.

Lynn Ayres

Teacher, Ypsilanti High School

I had my own occasionally unorthodox ways of teaching my freshman honors English class at Ypsilanti. Steve Gendin always sat in the front row, often wearing a sports jacket over his sweater, with his long legs comfortably stretched out. Even as a freshman, he was voted Most Likely to Succeed, and he looked the part. Later he fulfilled that promise by becoming valedictorian, a National Merit Finalist and going on to Brown University.

The year that Steve was in my English class, I'd noticed that my most capable students had difficulty dealing with frustration when they were given a challenge. I decided that we needed to talk about that issue, so I made up a short but impossible "quiz" that I never intended to collect or grade. I gave it to Steve's class. After I passed it out, I sternly told them to read directions, that they had 10 minutes to take the quiz, and that I was not going to answer questions. Then I observed their behavior.

Some kids earnestly tried to answer each question, a few refused to take it at all. I noticed that Steve calmly turned his quiz over and started writing on the back of it.

When I called an end to the "quiz," I talked about the ways they'd handled the situation. Eventually I said, "So, Steve, what was it that you were writing?"

"A letter to the school board," he replied.

Years later, Steve would occasionally send me copies of articles he'd written for POZ. It was very hard for me to read the stories in which he talked about being HIV positive, about being sick, and about the reactions of others. Still, I understood why he needed to write such searingly personal stories for publication. Steve would never accept being the victim in an unfair situation. Writing for POZ was his way of writing a letter to the school board.

Nils Fullerton

Artist

Stephen discovered he had HIV in 1986 after the end of his sophomore year at Brown University. I was devastated by the news. Not only was Stephen the first openly positive person I'd met, he was my boyfriend! He was more supportive of me than I was of him. He immediately set about answering the call to action, working tirelessly at the department of health and as a Samaritans Suicide Hotline volunteer, and founding ACT UP/Rhode Island, yet always taking time to go to Moonstone, the nude beach.

A distinct memory of that summer: We were watching *The Elephant Man* on a little black-and-white TV set, eating our bargain macaroni-and-cheese dinners. There is a scene where John Merrick is invited to tea with Dr. Treve's wife. He begins crying, she asks him what's wrong, and he says that he's never seen such a beautiful woman. He tells her that his mother was a beautiful woman and he understands why she would abandon him. With quiet grief, I began to cry and, to my shock and horror, so did Stephen. It was one of only three times I actually saw him cry.

Stephen and I remained fascinated with the metaphors of monstrosity and deformity in our friendship, and the connections to how we have been treated like freaks because of our sexuality. Ever-present, unique and Puckishly ironic, he would seem to torture me in my need to have him feel by having streams of tears drip out of those staring robot eyes, so thick with lashes, whenever they were tired, or if he had been walking a lot in cold weather, laughing in the Providence night with the glint of tears on his bad-boy cheeks. I always thought of myself as ugly compared to him, but even when he looked sick to me in later years, he remained strange and sexy, beloved and irritating and real.

Ann Northrop

Writer; ACT UP/NY activist

Stephen was one of the sweetest people I ever knew. He embodied such joy and peace, and that is what his activism and writing came out of, a fundamental joy. And I think Stephen was about love. He had the greatest smile in the world. And every time I saw him, his face would light up with that smile, and mine would light up in response automatically. There was just no alternative when running into Stephen. And I will miss that smile and that joy.

I think continuing on in activism is less about being angry than about finding that core of peace and joy. I don't have the slightest doubt that Stephen felt the peace of doing what he knew was

right every single day. And that's what I'd like all of us to do. I can tell you the name of the chairman of Pfizer, William Steer, and I can tell you that I walked right into his office on 42nd Street and Second Avenue with ACT UP and scared the shit out of him. And we aren't stopping. We're continuing to go after them. And I will give you an idea: Walk into the office of the CEO of any drug company, pull out a water pistol and see how fast those drugs are made available to people around the world.

I do the activism I do out of my own joy in doing it on a daily basis. I think it's a way to live a life, and I think that's the life Stephen lived.

Conrad Rippy

Entertainment lawyer

Stephen loved facts. His amazingly detailed factual knowledge of treatment strategies and drug trials was the most powerful weapon in his personal HIV-fighting arsenal. And he used other kinds of facts as ammunition in his public activism. But mostly, he just loved to know things.

On the day Stephen died, he had several pieces of paper crumpled up in his pocket. On them, neatly typed, was question after question about the lymphoma with which he'd been diagnosed the week before. Am I positive or negative? What is the role of radiation? And, heartbreakingly, a likelihood of a cruise starting on December 7? On the back, in Stephen's unmistakable scrawl, were some of the answers -- more facts as weapons. It would never occur to me to approach any treatment of mine with such thoroughness. But it was so Stephen.

Rebekka Armstrong

Playboy Playmate; safer-sex educator

The first time I saw Stephen, at a POZ Life Expo a few years ago, I thought, "Who is that sexy guy with the crazy hairdo?" I had no idea that he would become my friend and mentor. Stephen had been through so much and was so connected that I always called him when I was in a quandary -- if anyone knew, Stephen Gendin would. He knew all the beneficial health stuff and all the dirt, too. He always had the answers or knew where to get them. He helped me figure out my latest anti-HIV combination. Aside from that, he was so real to me and so much fun to hang out with. No sugar coating, just tell it like it is! I will miss that greatly and so much more.

Shawn Decker

POZ columnist; musician

The first time I saw Stephen Gendin, he was sleeping on a couch at the POZ Life Expo -- an interesting-looking fellow with bright-red hair and a little white dog with a red-dyed tail to match. The first thought that went through my mind was "Now I feel like I'm in New York City," and the second was, "I gotta meet this dude!" We were introduced and immediately we hit it off. I took pictures of my big New York adventure back home to Virginia and remember one of my girlfriends

saying, upon seeing Stephen's smile in a photo, "Who is this guy? He's hot!" Unfortunately, I informed her, he was gay -- and that made me a little sad as well, as I am straight and would never have a chance at hunky Stephen Gendin.

A few months later, Stephen offered me a job at Community Prescription Service. I had been on disability but jumped at the opportunity to have my first job. My only qualification was that I was HIV positive. I will always be thankful that Stephen saw something in this kid from small-town Virginia. The move and job made me realize that I should be educating in schools back home in Virginia, where I soon returned as an activist -- a result of my time with Stephen in New York.

I was upset to learn, on the morning that I was restarting my antiretroviral therapy, that Stephen had passed to spirit. The irony of this timing was not lost on me. In death, as in life, he helped me overcome my fears and step into my future.

Mike Barr

Editor, Treatment Action Group's TAGline

This time, this death, I'm not going to cry because that was never our style, Stephen's and mine. Soggy, sloppy emotions. We were much more methodical, planners and fixers. Stephen was the Energizer rabbit who took a licking and kept on ticking. Two or three times we had been certain that he was going to end up in the hospital, and he always proved us wrong. We had begun to first accept -- and then expect -- his spectacular turnarounds. With Africa planned for July and South America for fall, there was no room on the agenda for clinical complications. That's the way he wanted it, and that's the way it would be.

I last saw Stephen the Thursday night after he first got his preliminary diagnosis of lymphoma. He was to have a CT scan the next day, a bone-marrow biopsy and spinal tap on Monday. By the end of the week he would have begun half-dose CHOP and suffered no side effects. He insisted that this would be just one more inconvenience in his life. We had a terrible dinner at a tourist trap on West 44th Street. He was surprised and happy to have an appetite and gobbled down some trendily prepared salmon steak. We rushed out to catch an 8:30 showing of Shaft at one of those sparkling-clean theaters on the new 42nd Street. Stephen asked the usher whether the concession stand on the second floor was open, and off he went for an icie -- the dyed frozen crystals were the only thing that soothed the pain caused by the tumor in his throat. After the movie we paused out front so he could show me the chameleontic flashing sign atop the Lowes marquee. He explained to me, in detail, the cost and workmanship that had gone into it. Stephen was still Stephen, fascinated by gadgets and numbers.

It is only now that I see how much my present life was steered by his. Stephen was one of my first ACT UP friends, and remained one of my closest -- even throughout this last part of his life, when he seemed crazier every year and what a friend diplomatically described as "complicated." Stephen was strange and complicated as a child and as a young man. How could anyone expect Stephen the grownup -- it is stretching reality to ever characterize Stephen as grownup -- to be any less colorful, any less eccentric? I don't know when the reality will finally hit me that Stephen

is gone, but when it does, I may need a shoulder because I'm afraid I'll cry after all.

David Parrish

Associate attorney

Stephen's memory tastes like microwaved White Castle hamburgers with Pop Tarts for dessert. His memory smells like sweating boys at the Chelsea Gym and chlorine from the pool at 504 Bass Walk, Fire Island Pines. And Stephen's memory is always dancing -- at the Black Party, the Roxy, the Brown gay and lesbian student dances, the Pavilion -- and wearing bright purple pants.

When Stephen's memory gets bored at a party, it curls up into a ball on the floor and falls asleep until it's time to go. It watches action-adventure movies and listens to Erasure and Depeche Mode. It comes with a soundtrack album and special software upgrades. Stephen's memory is illustrated as a comic book printed in psychedelic colors.

Stephen was gentle, smart, analytical and determined. Stephen had the strength of his convictions. Stephen always built his life to order -- nothing off the shelf -- not only after he tested positive (but maybe then with new determination). Stephen was always strong for his friends. With Stephen, things always seemed all right.

Thomas Keane

Attorney

I have never known anyone so modest, even shy, with so much about which he justly could have boasted: curling, night-sky locks falling over infinite eyes; a movie-star's profile; a restless, diamond-edged mind, never satisfied with less than the truth; a heart that failed no one until it failed him. Certainly, Stephen never failed me as a friend, no matter how often or excessively I leaned upon him. His ears were always open, his advice unmatched and his generosity unreasonable. No fool, he reflected all the wisdom of one who could still experience the wonder of the everyday. At 34, in every way a man -- accomplished, self-reliant, steadfast and, yes, sexy -- Stephen was nevertheless still a boy: amazing in his capacity to be amazed, a joy to others for his ability to feel, and even radiate, joy. I can only guess what magic the world holds that now, without Stephen to perceive it and to share it with me, I will pass by unaware.

Howard Grossman, MD

Primary care physician

Stephen and I were partners in his health care. I remember so many moments with him and so much that I learned. I learned how much we could disagree and still be close. I remember the year Stephen decided not to do any meds. Each time he came in, I felt it was my responsibility to talk about whatever was new and coming out. Finally one day he said, "Howard, just shut up for a while. I don't really want to talk about it this time." I loved that we had that kind of relationship.

Stephen taught me a lot about the lack of vanity. Here was somebody who carried his beauty so naturally for so long, and then watched it get eaten up by this disease in so many ways. Except for once, I never remember him complaining or wishing it was any different. There are a lot of painful memories of Stephen with the diarrhea and the incontinence and the weight loss and trying to keep things together. But there are a lot of joyous memories that I've been trying to hold on to.

Everything Stephen did was a legacy. He left institutions. He left the work he did with CPS and the articles he wrote for POZ. If only he'd been able to see the reception in Africa for the work he and his compatriots have done, getting drugs to people. That mission is going to save so many people, and it could save millions if we could get drugs into their hands. It took a lot to get him to not go to the Durban conference. I tried to twist his arm to stay in New York because Stephen never let his disease stop him. He never let it slow him down. He was always working, and his work was always for others. It was always in the moment. His work always said that one person could make a difference, that we didn't have to wait until everything was in place, that one person could make it happen.