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Remarkable Journeys

AEP reconnected with many of the occupationally infected healthcare workers interviewed in these pages over the last decade, and heard stories of strength, courage — and the need to move on

By Jane Perry, M.A., and Janine Jagger, M.P.H., Ph.D.

When we started *Advances in Exposure Prevention* in 1994, one of our goals was to provide a voice for healthcare workers who had been occupationally infected with a bloodborne pathogen, so that the healthcare community could better understand the impact of needlesticks and blood exposures on individual lives. Over the past 10 years, we have interviewed and published personal accounts of 13 healthcare workers (eight nurses, three physicians, a phlebotomist, and a firefighter/paramedic) who, for the benefit of readers and the larger community, described in detail the events surrounding their exposures and infections.

Two of those we interviewed—Lisa Black and Karen Daley—were co-infected with HIV and hepatitis C virus (HCV) from their needlesticks. Of the others, five were infected with HIV—Patti Wetzel, “Jane Doe,” Marie Jasmin, Lynda Arnold, and “John Smith” (Steve Derrig, who, after the *AEP* article was published, allowed his name and identity to be published in the *Akron Beacon*), and six were infected with HCV (Marie Stevens, Diane Mawyer, Julie Naunheim Higgs, Vanessa Burkhart, “Dr. Jones,” and William Fiser). Their courage in sharing their experiences in *AEP* gave names, faces and a heart to the issue of needlestick injuries.

This year, as we mark a decade of publishing *AEP*, we wanted to reconnect with these remarkable

people. Our questions were simple: How are you? What are you doing now? What is important or meaningful to you at this point in your life? We talked to eight of the 13 we had interviewed in *AEP*; they were generous with their time and their thoughts. Here is what they told us.



Patti Wetzel

(interviewed in AEP in 1994)

Patti Wetzel, M.D., first came to public attention in September 1991. When she learned that she was infected with HIV as a result of a needlestick from a blood-drawing device, she announced her infection to the press and to the world with the words, “I will not live in shame and secrecy.” It was a bold move, in 1991, to publicly challenge the social rejection faced by many with HIV. For her, though, it was just a beginning. The path she has charted since then

has included being an advocate for HIV-infected women, a speaker and lecturer for at-risk healthcare workers, an educator in the humanities for medical students, a competitive athlete, a fund-raiser and an international ambassador for those infected with HIV.

At the time of Patti’s needlestick she had just finished her residency in family medicine and was directing the in-patient AIDS unit at John Peter Smith Hospital in Fort Worth, Texas. When we interviewed Patti in 1994, she had left clinical practice because of concern about exposure to pathogens that could put her at risk. She worked for Caremark, a pharmaceutical services company, for four years, advising the company on HIV infusion care and raising awareness on the subject of HIV and women. She has continued to lecture extensively in the U.S. on topics related to AIDS advocacy and the protection of healthcare workers from exposure to bloodborne pathogens.

Fortunately, Patti has never had symptoms from her HIV infection, although she has experienced side effects from the drugs she takes to control it. She started on AZT in 1992, then switched to protease inhibitors in 1996. The first combination drug regimens were so complicated that taking them was almost a full-time job, she says, but eventually they became more manageable. By early 2000, however, the protease inhibitors had caused her to gain 40 pounds. At that

point, she decided to get serious about physical fitness and hired a trainer who worked with her for 10 months. In October 2000, at age 40, on a perfect autumn day, she ran in the Chicago Marathon; she calls it “one of my greatest accomplishments.” She then switched to cycling because it was easier on her knees, and got involved in HIV fund-raising through Pallotta AIDSride. In 2001 she trained for and participated in a 560-mile, 5-½-day Heartland AIDSride from Minnesota to Chicago which, she says, was “one of the most phenomenal weeks of my life.” Then, in 2002 she and her husband, along with 120 others, took part in a Pallotta AIDS trek through rural South Africa. She was deeply affected by the villagers she met and the reality of living with HIV infection in that country. “These people don’t have the luxury of HIV medications. I got letters from people begging for even a few pills.” She added, “I would be there working right now if I could.”

She currently lives in San Antonio with her husband, also a physician, and teaches in a humanities and medicine program at the University of Texas Health Sciences Center. She works closely with the San Antonio AIDS Foundation, volunteering services to HIV-infected members of the community, and has also become involved in HIV prevention initiatives in Africa.

Patti’s story over the last 13 years has been about taking charge of her life while giving generously to others. Reflecting metaphorically on her continued weight training and cycling, she says, “I definitely have some muscle.” Far from the shadows of shame and secrecy she rejected in 1991, she says of her present life, “I am my own master.”

Jane Doe

(interviewed in AEP in 1995)

Almost 17 years after she was infected with HIV from a needlestick, Jane Doe says that she is “profoundly

grateful” that she is still able to work at the institution where her injury occurred, San Francisco General Hospital, providing direct patient care. Like Patti Wetzel, Jane has been determined not to be defined or limited by her infection; as she says, “I’m not going to let HIV take anymore than it already has.”

Her needlestick—from a needle used to connect primary IV tubing to heplock tubing—occurred in July

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- Jane Doe

1987; six weeks later she tested positive for HIV. In September 1987, San Francisco General (SFGH) held a press conference to announce that for the first time one of its staff had been occupationally infected with HIV (Jane’s identity was kept secret, however). Her case was clear-cut and the workers’ compensation board of the City of San Francisco seemed likely to cover all her medical expenses—but refused to establish a confidential means for processing her claims. For the next 19 months, assisted by her pro bono attorney and the Service Employees International Union (SEIU Local 790), Jane waged a battle with

the city to limit to four the number of people in the workers’ compensation office who had access to her identity. After the *San Francisco Chronicle* publicized her plight—she received no benefits during the year and a half her case was pending—she finally won what she had sought. The hospital union negotiated to have the conditions of her settlement written into its contract so that other occupationally infected healthcare workers would receive the same level of confidentiality.

Since the resolution of her campaign to win confidential workers’ compensation, she hasn’t had to pay anything—no co-pays or deductibles—for her HIV medical care, and has always had ready access to caregivers. For this, she has “high praise for the city of San Francisco” for its commitment to HIV care.

During the 1990s, Jane continued to work as a bedside nurse and was active in promoting needle safety issues at SFGH. The hospital implemented a number of safety devices even before 1998, when California became the first state to pass a needle safety law—but Jane says many of them were first-generation devices. So she and other frontline healthcare workers, representing three different SEIU local unions, pushed to get an institutional process in place for evaluating new safety technology as it became available. After the 1998 legislation was passed, SFGH formed a joint labor-management committee on exposure prevention and safety devices; it has been very effective, she says, in dealing with both device and work practice issues.

In 1998 Jane married a colleague from SFGH and became the stepmother of two teenagers; her husband and family have been great sources of strength and support for her. She decided to maintain her confidentiality at her workplace and in the San Francisco area because she works in the field of maternal/child health and fears the potential repercussions from re-

vealing her HIV status. She has, however, done some public speaking about healthcare worker safety in other cities, using her real name.

How did she feel when the Needlestick Safety and Prevention Act was passed in 2000? “It was definitely bittersweet. I had a tremendous sense of victory, because it was something I’d waited for for a long time. I also felt profound respect for the people who worked so hard to get the bill passed—people like Lorraine Thiebaud, a recovery room nurse at SFGH who works with the SEIU. But I also felt grief for those we’d already lost. Over the years I’ve talked on the phone or met with a number of people who were occupationally infected with HIV—and five of them have since died of AIDS. One of them was a physician at SFGH.”

Other than a bout with post-seroconversion illness shortly after she was infected which kept her out of work for a month, and a severe case of jaundice from Nevirapine, a reverse transcriptase inhibitor, Jane has remained in relatively good health, with a low viral load and “decent” t-cell count. Although she has experienced numerous side effects from her HIV drugs over the years, she credits them with keeping her alive—and knows she is fortunate to have access to them.

While she feels lucky that she can still work as a bedside nurse, Jane is deeply worried about the state of healthcare in the U.S., particularly access to care for the uninsured. And given the current nursing shortage, she is concerned about both patient and worker safety. “In a way, I feel like healthcare workers are the canaries in the coal mine—their on-the-job health and safety, or lack thereof, is symptomatic of the state of the healthcare system in general.”

Why does Jane continue to do bedside nursing? “It has been rewarding to work with HIV-positive moms and witness the progress we’ve made in preventing vertical transmission.

And I love helping people when they are going through something intense, whether it’s an illness or a birth. Working with mothers and their infants is still a great thrill for me.”



Lisa Black

(interviewed in AEP in 1999)

Lisa Black’s needlestick and seroconversion—first to HIV and then, 2-1/2 months later, to HCV—is one of a small number of documented occupational HIV/HCV co-infections. Some studies indicate that HIV/HCV co-infection in the source patient increases the risk of HCV transmission for exposed healthcare workers. With an estimated 38% of HIV-infected source patients for occupational exposures also infected with HCV, according to data from the CDC’s National Surveillance System for Healthcare Workers (NaSH)*, occupational co-infection has become a subject of increasing concern in recent years. Co-infection has certainly made Lisa’s long-term care more challenging—and her personal accomplishments in the last six years all the more remarkable.

When Lisa was assigned to care for a patient with end-stage AIDS in October 1997, he was already hooked up to an I.V. system requiring needle access. The I.V. catheter was occluded by a blood clot, and as she attempted to flush it with a needle/syringe assembly, the patient jerked his arm and

the needle dislodged from the port, sticking her in the palm.

Within two hours of her injury, Lisa started HIV postexposure prophylaxis (AZT, 3TC and Crixivan), and her 3-month follow-up test was negative. But nine months after her needlestick she was hospitalized with a high fever, and ultimately was diagnosed with HIV. Ten weeks later, she got even worse news: tests confirmed that she was also infected with HCV—presumably from the same patient, although the HCV test he had after her needlestick was negative. (Subsequent studies have found that false-negative HCV tests are not uncommon in HIV/HCV co-infected individuals.)

For about five years after her seroconversions, Lisa was prescribed a triple combination HIV drug therapy, but when her t-cell count declined to 200 two years ago, she switched to Combivir and Sustiva—a relatively recent HIV drug. Her t-cell count is now between 600 and 700, which is considered adequate, and she experiences far fewer side effects from the drugs.

Her HCV infection was treated with combination interferon and ribavirin therapy, which she took on and off for four years. At one point she was taking a total of 22 pills a day for treatment of her HIV and HCV. She experienced constant, debilitating side effects from the HCV drugs, and finally stopped taking them in 2002. Since then her viral load, while not undetectable, has remained stable, and the disease shows no signs of progressing.

Because Lisa had several abnormal screening results in the last two years, and because HIV infection increases the risk of cervical cancer, her doctors recommended a hysterectomy. While in the hospital this past spring recovering from that operation, her doctors detected a problem with her gall bladder, and that was removed as well. During her prolonged hospital stay, she developed a bloodstream

*CDC, unpublished data, 2001; as referenced in Beltrami E, et al. Transmission of HIV and hepatitis C virus from a nursing home patient to a health care worker. *Am J Infect Control* 2003;31:168-75.

infection, and remained hospitalized for three weeks.

After her needlestick Lisa was unable to return to bedside nursing because of her compromised immune system, and for nearly four years she lived on her workers' compensation benefits and took care of her two girls, now ages 9 and 13. She volunteered with the Nevada Nurses Association (NNA) and worked on legislative issues, in particular a law that creates a statutory presumption of occupational transmission if a healthcare worker is infected with a bloodborne pathogen or tuberculosis after reporting an occupational exposure. The law, passed in 2001, makes it easier for occupationally infected healthcare workers to gain access to workers' compensation benefits to cover their treatment costs. Lisa also spoke at nursing and infection control seminars in the U.S., Europe, and Asia, wrote several articles, and maintained a website on needlestick injury prevention.

In the summer of 2002, Lisa accepted a position as executive director of the NNA. In the last few years, she also worked on an M.S. in nursing at the University of Nevada-Reno, receiving her diploma in December 2003. Her master's thesis was on patient perceptions of HIV-infected nurses. Approximately 80% of the patients she interviewed said they had a right to know their nurse's infection status, and a "fairly large percent" did not want any level of care from an HIV-infected nurse, according to Lisa.

As part of her M.S. program, Lisa taught basic clinical skills to beginning nursing students, which brought her back into a healthcare setting for the first time since shortly after her needlestick. She enjoyed being back at the bedside, and was amazed at "how fast my nursing skills came back—it's like riding a bike, something you never forget." Based on that experience, she thinks she would like to do part-time clinical work in combination with a nursing faculty position.

As a step towards the goal of becoming an academic, Lisa enrolled in a Ph.D. program in health policy at the University of California-San Francisco in 2003, and was awarded a training grant in HIV/AIDS studies from the National Institutes of Health. For her dissertation she plans to extend her M.S. research and focus on the policy implications of HIV-infected healthcare providers in the workplace.

The hospitals where Lisa taught as part of her M.S. work, both in the Reno area, were almost "completely converted" to safety-engineered devices, she says. The one device category where safety seemed to be lacking was disposable syringes—an area, she thinks, where nurses have been most resistant to change. But overall, "It's been very satisfying to see the progress" in conversion to safety devices.

Reflecting on her academic and professional accomplishments over the last few years, Lisa says: "For a long time it seemed like my life revolved around my health. I needed to reclaim my life and focus on other things." Although she still does some work on needlestick prevention with the American Nurses Association, most of her energy is now directed towards achieving her long-term goals and continuing her education.

Diane Mawyer (interviewed in *AEP* in 2000)

Diane worked as an OR scrub and circulating nurse from 1976 to 1981, and as supervisor of a blood bank from 1981 to 1993; over the course of her career, she had at least six documented needlesticks (two in the OR, four at the blood bank) and innumerable blood exposures. At the blood bank, where she routinely performed phlebotomy, her hands were exposed to blood from up to 20 donors a day, until glove use became standard practice in 1985.

For most of Diane's career (until 1989) there was no test for hepati-



Diane Mawyer

tis C. When she was diagnosed with HCV in December 1993—after finding out in 1992 that she had cirrhosis of the liver—there was no source patient she could trace her infection to.

Diane stopped working shortly after her diagnosis and underwent a liver transplant the following spring. Her new liver failed and she had a second liver transplant, along with a kidney transplant, in June 1999. (HCV can damage the kidneys as well as the liver.) From fall 2000 through fall 2002, she took two courses of combination interferon and ribavirin therapy, the second with pegylated interferon.

Diane has finally achieved a measure of stability in her health, and has had an undetectable viral load since December 2002. However, a kidney biopsy indicated that her transplanted kidney was failing—in part because of damage from her HCV infection—and she had to start dialysis treatment in 2003. She goes for dialysis three times a week, with each session lasting four hours—almost a part-time job, she wryly notes. But she reports that she feels better now than at any time since she was first diagnosed with HCV in 1992.

Diane "really savors her life" and takes particular pride in her daughter, who graduated from the University of Virginia and lives and works in Charlottesville, Virginia, not far from Diane. Diane says she has gained a lot from the experience of having HCV, and she has had an opportunity to share her insights on the dangers of blood exposures at conferences in the U.S. and at talks spon-

sored by medical device companies in Greece, Germany, the Czech Republic, and the U.K. She has also participated in a video produced by a company in Germany on needle safety.

“I’ve met some occupationally infected healthcare workers who were bitter and angry about what happened to them. I’m glad I don’t feel that way—I don’t want to ruin my life with bitterness,” she says. Considering the physical and emotional toll of her infection (the cost is covered by a settlement from her former employer), those words are particularly remarkable.



Matthew Hipps

Julie Naunheim Hipps

(interviewed in AEP in 2000)

Perhaps more than any other published account of an occupationally infected healthcare worker, that of Julie Naunheim Hipps can be linked to a specific policy change regarding needle safety. Julie’s was the first documented case of a healthcare worker injured by the “back end” of a phlebotomy needle and subsequently infected with a bloodborne pathogen. Her case was publicized in October 2000; by early 2001, OSHA was reviewing its stance on reuse of blood tube holders, a practice which necessitates removing the phlebotomy needle from the holder and exposing the contaminated back end of the needle.

OSHA’s November 1999 revised compliance directive for the bloodborne pathogens standard did

not include specific wording on this issue, but a second updated directive, issued in November 2001, explicitly prohibited the practice of removing phlebotomy needles after use from blood tube holders. OSHA followed up in June 2002 with a standard interpretation letter restating that prohibition, and reiterated its position once more in an October 2003 Safety and Health Information Bulletin.

Julie’s occupational infection was remarkable not only for its impact on needlestick safety policy, but also as a case study in postexposure treatment of HCV. Her injury occurred in October 1999 while she was working as a home healthcare nurse in St. Louis, Missouri; three weeks later she began experiencing extreme fatigue, and on December 10—only five weeks after her needlestick—she learned she was infected with hepatitis C.

The spread of HCV has been called the “silent epidemic,” because those who have it often don’t experience symptoms for years—but because Julie had postexposure follow-up testing her infection was detected very early and she was able to start treatment within a week of her diagnosis.

After undergoing six months of combination therapy with interferon and ribavirin, her viral load was undetectable and liver enzymes normal. Despite experiencing severe side effects from the drugs, she completed the full 12 months of therapy in November 2000; but two months later she learned her viral load had risen again. In June 2001, she started experimental treatment with pegylated interferon (it didn’t receive FDA approval until October 2002), in combination with ribavirin. This time, the treatment worked: since completing her second round of HCV therapy in May 2002, her viral load has remained undetectable. And without the side effects from interferon and ribavirin, she started to feel good again for the first time in several years.

During the first two years of treatment Julie was unable to work, but during that period she was active in advocating for healthcare worker safety. She worked with the Missouri Nurses Association and the SEIU on getting a state bill passed to extend the protections of the bloodborne pathogens standard to workers in the public sector (she was present when the bill, S.B. 266, was signed into law in July 2001). She also spoke at conferences about her needlestick and the need to protect workers from unsafe needles.

After completing her B.S.N. in 2003 (she was only a few credits shy of graduating when her needlestick occurred), she took a big step and went back to work as a bedside nurse. She got a job on the oncology unit of a St. Louis hospital (not the one she was working for when her needlestick occurred); it is the only union hospital in the city, Julie says, which she feels offers a degree of protection, especially on issues related to needle safety.

Still, returning to work, even at a union hospital, was a difficult transition. Being around contaminated needles again—many not disposed of properly—caused her tremendous anxiety during the first few months. But volunteering to do in-services for co-workers on sharps safety has given her a sense of empowerment as she helps change the attitude that “it can’t happen to me.” During these sessions she shares her own story and discusses what colleagues can do to prevent sharps injuries. She created a needle safety bulletin board on her unit with accounts of other occupationally infected healthcare workers, and recently she helped organize and conduct an evaluation of a safety catheter for central line insertions, a common procedure on oncology units that is high risk for bloodborne pathogen transmission.

She has identified some problem areas and key issues regarding sharps safety on her unit; for example, it still

uses conventional syringes for injections and drawing up meds, and the safety devices that are stocked for other procedures are not always easy to find or readily available. The unit has single-use blood tube holders, but some people still detach the phlebotomy needle in order to reuse them. She also finds that needles used to draw up saline solutions are often not disposed of properly in sharps disposal containers.

The pace of change is frustratingly slow at times, and the conversion to safety devices at her facility has been uneven: they are available for some device categories and procedures, but not all, and some colleagues have the attitude that safety devices are optional, not required. These are problems common to many healthcare facilities across the country. But Julie remains hopeful that things will gradually improve, with her effort and that of other committed colleagues.



Vanessa Burkhart

(interviewed in AEP in 2002)

Vanessa Burkhart was working as an emergency room nurse in a small Missouri hospital when a combative patient deliberately stuck her with a blood-filled I.V. catheter needle. Three and a half months later, in April 2000, Vanessa was diagnosed with hepatitis C, and began combination interferon and ribavirin therapy the following month. She has had an undetectable viral load since completing treatment in April 2001; if it remains undetectable through January

Lynda Arnold and Karen Daley

Lynda Arnold (interviewed in AEP in 1996): Having kick-started the movement in the U.S. towards implementation of safety devices with her national "Campaign for Health Care Worker Safety" in 1996, Lynda worked for several years for a medical device company and finished an M.B.A. in 2002. She now works full-time as assistant director of nursing at a nursing facility in Pennsylvania and does adjunct teaching at Eastern University in management and marketing ethics. Her biggest job, though, is raising her three children, who are 9, 7 and 5. Lynda says she is "relatively healthy" and is "trying to live my life and be a good mom."

Karen Daley (interviewed in AEP in 1999): "I have been doing well the past couple of years. I've been on a drug regimen that has kept my HIV and HCV viral loads in check, with minimal side effects. I returned to school two year ago and am currently enrolled full-time in an M.S./Ph.D. program at Boston College. I just completed my M.S.N. requirements, and have one year of Ph.D. coursework, after which I will focus on my dissertation. I plan to write about the psychosocial and attitudinal impact of high-risk versus low-risk needlestick injuries among nurses. In addition to my studies, I have been engaged in professional activities related to the establishment of a permanent Center for Nursing in Massachusetts that will address issues underlying the nursing shortage."

2005, her physician said she will not need further treatment or testing. She has hyperthyroidism associated with her HCV, and finds she gets sick more easily (last spring she had pneumonia)—but overall she feels good and is doing "very well."

Vanessa now works 50 to 60 hours a week as director of nursing at a rural hospital in Missouri (not the one where her needlestick occurred). She is still very aware of the consequences of her needlestick and the risk such injuries pose to others; when a co-worker was stuck recently, it suddenly seemed as if her own needlestick had "just happened yesterday." She has made sure that the staff knows about her injury and seroconversion, and she started a needlestick prevention program at her facility. Recently, she and others realized that the sharps containers in patient rooms were placed too high, which made it difficult to visualize the opening when disposing of used sharps; the containers are being moved to a more accessible location. Her hospital has converted to safety I.V. catheters and a needleless I.V. system, but is still in the process of

implementing other safety devices.

Vanessa is a compelling speaker and educator on the subject of needlestick prevention and sharps safety—not only at her own facility, but at seminars and conferences across the country and in Canada. Her work schedule is flexible enough to allow her time to do public speaking, as well as look after personal concerns. Her daughter, who sustained a brain injury in an automobile accident in her teens and now lives independently, needs Vanessa's help and supervision. Vanessa is close to her own mother and spends as much time with her as she can, and she visits her father, who recently had heart surgery, every other weekend. "I'm very protective of my free time. I like to be with my family as much as possible, and I try to deal with things as they come up and not worry too much about the future. When my husband and I take trips in the car, we stop along the way whenever we feel like it or see something interesting. That's how I want my life to be—enjoying the journey and not being in a big hurry to reach the destination." □