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A NURSE WITH A MISSION: Lynda Arnold

Lynda Arnold received her nursing degree in May 1992. In September 1992 she sustained a needlestick that resulted in her seroconversion to HIV within six months. On February 28, 1996, at a press conference in Philadelphia, Lynda announced her decision to launch a national campaign asking for a written commitment from every hospital in the U.S. to provide protective catheters and blood-drawing devices to their employees, devices that could have prevented her infection. She tells us about her experience and what led her to undertake this campaign



Lynda Arnold

The Needlestick

ON SEPTEMBER 9, 1992, I WAS working as a registered nurse in the intensive care unit at Community Hospital in Lancaster, Pennsylvania. An aide brought us a very ill patient from the outpatient clinic and told us to use blood and body fluid precautions. That was her way of letting us know that the patient was probably HIV positive. We didn't know why he was admitted, since

we hadn't gotten his chart yet. But we were putting on a cardiac monitor and getting an IV line going, which was standard procedure in the ICU.

I had my gloves on and was starting the IV line, using a 20-gauge IV catheter. As I withdrew the needle from the patient, he jerked his arm, hitting my right hand and forcing the needle into the palm of my left hand. Soon after the needlestick, I found out he was a known AIDS patient with a history of abusive behavior toward the staff. He'd been admitted for pneumonia, and died two weeks later.

My immediate concern was to finish the procedure. If I lost the IV line, then someone

else would have to stick the patient. So I finished putting the heplock on, and disposed of the IV catheter. Then I went to the sink and took off my glove. The needlestick was moderate, but the needle had caused a kind of jagged tear as it went in, and there was blood. After I washed my hands with disinfectant, I went out to the desk and told the day-shift supervisor that I'd been stuck, and

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asked her what I was supposed to do. It was my first stick.

I had a little training in nursing school about needlesticks. We were made aware of the risk, and also that there were safety products on the market to prevent needlesticks. I later learned that a shielded IV catheter would have prevented my injury.

After the needlestick, everyone on my unit was very reassuring, telling me nothing would happen. Some told me about their own needlesticks, and said they'd never tested positive. The doctor in the emergency room was also reassuring. He was more concerned about my risk of getting hepatitis than HIV, because I hadn't yet completed my hepatitis vaccination series. He told me that the risk of HIV infection was one in 250. Of course, no one ever thinks they are going to be the one in 250 who becomes infected. Even though the doctor didn't seem that worried about my exposure, the other E.R. personnel seemed very concerned, even shaken. I remember looking into their eyes and seeing the fear, reading their thoughts—"It was bound to happen." They were familiar with the source patient and his history of aggressive behavior toward the staff, including biting and spitting. They seemed to have a sense of foreboding, and that scared me.

Although my identity wasn't revealed, word of my needlestick traveled quickly throughout the hospital. A couple of days later, I was at home talking to a friend who worked on another floor of the hospital, and she said, "Did you hear about that nurse who got stuck in the ICU?" And I said, "Yes, that was me."

Seroconversion

I was tested for HIV on the day of the needlestick, and the results were negative. At around three weeks I developed a fever, rash, and sore throat. The doctor I was referred to told me not to worry; again, he was more concerned about hepatitis. I did finish my hepatitis B vaccination series, and all the hepatitis tests came back negative. I wasn't taking AZT. At the time there wasn't any conclusive data about its benefits as a prophylactic drug. A few months before, another hospital employee had chosen to take AZT after an at-risk needlestick, and had gotten very sick as a result. So employee health wasn't very proactive about encouraging me to take it.

Around six weeks, the fever and sore throat reappeared, although they weren't as severe as before. But I also developed abdominal pains, with nausea and vomiting, which was diagnosed as appendicitis. I underwent surgery and it was discovered that I did not have appendicitis, but had moderate to severe abdominal lymphadenopathy. I was retested for HIV, and was still negative. At my three-month test I again tested negative, and I truly thought that the nightmare was behind me. I was told that if you tested negative at three months there was a 90% chance you didn't have it.

After I went in to get my blood drawn for my six-month test, I began to feel that something was wrong. With every other test, I'd gotten the results back within a couple of days. This time I waited and waited, and didn't hear anything. My phone calls were not returned. This went on for about 10 days.

I later learned that follow-up testing was being performed, but also that hospital administrators had numerous committee meetings, try-

ing to figure out what to do with me. I think they realized later that the process took too long, that it was very hard on me.

Finally, on April 7, 1993, I received a call asking me to come in for my results. This scared me, because previously I was given the results over the phone. As soon as I walked in the door of the employee health office, I knew. I looked at the nurse and she had tears in her eyes, and I started crying. It was all over.

I was the first employee in my hospital to seroconvert to HIV from a needlestick, and I was only the second on record in the state of Pennsylvania.

Aftermath

Once I was diagnosed as HIV-positive, I was referred to an infectious diseases specialist. There was a lot of lab work to be done. I asked for repeat HIV tests to confirm the diagnosis; I still couldn't believe I had it. Then they did lymph site subset panels to test my t-cells. The usual advice is to start AZT therapy when you're below 500, and mine were at 490. So I started AZT right away. I didn't react to it very well. After six months I started getting terrible headaches and nausea and went off it. Subsequently, I've been on DDI, DDC, and D4T, but have had serious adverse reactions to all of them and had to stop taking them. I haven't taken any drugs for over a year.

Although I do not have full-blown AIDS, I have been symptomatic almost from the beginning of my infection 3-1/2 years ago. I have had chronic fatigue and headaches, night sweats, insomnia, swollen lymph glands, yeast infections, and fungal infections of my feet. I've been hospitalized twice, once for meningitis and then for pancreatitis brought on by the

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DDI. I have had surgery for cervical dysplasia, and recently underwent a liver biopsy because my enzyme levels were elevated.

After seroconverting, I never returned to patient care. That was my choice, because the hospital had ruled that, based on CDC guidelines, I wasn't a threat to patients and could remain in the intensive care unit. But along with the t-cell test I had an anergy panel, which determines the level of your immune response. I was completely anergic, which means that something was wrong with my immune system early on. I decided to take an administrative job because I was fearful of being exposed to infectious diseases, particularly tuberculosis, in the ICU. The hospital supported my decision.

I stayed in the administrative job for about a year but found it unfulfilling, and also stressful having to hide my illness from others. I tried cutting back to part-time hours, but finally in April 1994, citing fatigue and abdominal pain from the lymphadenopathy, I resigned and went on permanent disability.

To a certain extent I regret the decision to leave patient care. I miss it every day. I had so much training and was just starting my nursing career, and I had dreams. I was thinking of becoming a nurse practitioner, and planned on getting a master's degree. My goals at the time were completely focused on my career. I became engaged shortly before I found out I was HIV-positive, but did not feel any urgency about getting married. After I seroconverted, my feelings changed. I wanted to get married while I was still healthy. I didn't want to go down the aisle in a wheelchair.

Everyone in my immediate circle of family and friends was shocked. They had never known anyone with HIV before. They were also angry. They wondered how this could have happened. There had been so much emphasis on AIDS education and awareness in 1992, and their feeling was, what about the health care workers? How come Lynda got stuck if

dren. We agreed that even a 1% risk was too high. So we decided to adopt. I didn't think having HIV would be a barrier to adoption, and for us it wasn't. It turns out, however, that we are the only "serodiscordant" couple in the country that has officially adopted a child—that's where one partner is HIV positive and the other is not. When we went to the adoption agency, we had to provide a lot of information about life with HIV and how we would deal with various contingencies. Finally, we came home with a newborn baby boy who is now 9-1/2 months old. For us, it worked out.

I do believe that honesty is the best policy. It's the key to everything. One of my favorite quotes is "Truth is not a secret to be hidden. It's a gift to be used." It's become a kind of motto for me as I launch my public campaign.

When I first learned I was HIV positive I was worried about the word getting out and someone burning down my house or throwing rocks at my car. But I was assured that things like that didn't happen anymore, and that the hospital would do everything it could to protect my identity. After that I really didn't give much thought to confidentiality. Certainly, after I left the intensive care unit and went to the administrative job, many people surmised what had happened. In a small hospital it's hard to keep things like that a secret. But my co-workers and the administration tried to protect my confidentiality. Finally, when I filed a lawsuit against the product manufacturer in March 1994, I made a decision to go public with my injury and illness. I was tired of the shame and secrecy. I needed to speak, but no one was listening. People were taking care of me, supporting me, protecting me, but that wasn't going to make it

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there was so much effort at prevention?

My fiance (now husband) got an HIV test, which was negative. The hospital requested it for workers' compensation, and the CDC wanted it for surveillance purposes. My husband is still HIV-negative.

My husband and I very much wanted to have a child, but we felt strongly that we did not want to risk having a baby born with HIV. Through my experience in the HIV community, I had seen the pain and suffering HIV can cause in chil-

An Appeal to the Nation's Hospitals

The following is an excerpt from Lynda Arnold's appeal read at a press conference in Philadelphia on 2/28/96.

Every day five million health care workers like me, across the United States, face the risk of exposure to bloodborne pathogens despite the use of universal precautions. But no matter how cautious they are, they must use the equipment that their hospital provides to them. Over 800,000 needlesticks occur in our country each year. That is why hospital administrators and those making the purchasing decisions must fulfill their responsibility by providing the safest medical devices to their health care workers in order to protect them from needlesticks and occupational infections.

Safer devices are not a dream of the future. There have been more than 1,000 U.S. patents issued during the past decade in the area of safer needle technology to prevent needlesticks. Dozens of these safer devices are widely available today and have been shown to significantly reduce the risk of exposure to HIV, hepatitis B, hepatitis C, and other bloodborne pathogens. We know from data on occupational HIV transmission that not all needlesticks are of equal risk. In the majority of cases, health care workers have contracted HIV from blood-drawing devices or intravenous catheter needles because these are large needles that can hold significant quantities of blood. Therefore, I am focusing my efforts on these high-risk devices.

Today I am launching an appeal to hospitals and healthcare facilities across the nation to provide health care workers with devices designed to prevent needlesticks. Over the next 18 months, I plan to contact every health care facility in the country to ask that they sign a commitment to implement protective blood-drawing devices and IV catheters within one year of their sign-on date. I will be visiting hospitals, speaking to professional and community groups, sharing my story and providing information. I will make public the names of hospitals that make this commitment to protect their health care workers, and those that have not.

I am not alone in my conviction that health care facilities must change to safer needle devices. Hundreds of hospitals, including Community Hospital of Lancaster, are already successfully using these devices. I am calling on the nation's five million health care workers, and all who care about them, including their families, neighbors, and especially their employers, to join me in this effort to quickly put an end to a deadly occupational risk that we know is preventable today.

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better for anyone else. That's why I chose to use my actual name when I filed the suit. Our local newspaper published the headline "Nurse Gets AIDS Virus Through Needle" and included my name, age, and the hospital where I worked. From then on the silence was broken.

There was no explosion of media coverage, but people from the hospital and in the community felt free to offer their support. They expressed compassion and solidarity. My fears about adverse reactions turned out to be groundless. I was sure that I had done the right thing and it was a relief to be out in the open. I wanted to make a difference, to try to ensure that what happened to me didn't happen to someone else.

I sought the advice of Patti Wetzel [*see AEP, 1:1, p. 3*] soon after I learned I was infected. I sent her a letter, she wrote back, and since then we've had several conversations. She's been a role model for me. She was the only occupationally infected health care worker I knew of who was speaking publicly about her disease. I wanted to know why she had made the decision to go public, and whether she felt she was making a difference. I am very interested in the idea of some kind of national support network for occupationally infected health care workers.

Compensation

I have received complete compensation for my injury and illness, 100% care. I've gone to the doctors of my choice, seen specialists, gotten psychological counseling. All of my labwork and hospitalizations have been covered. I also received back pay for the period when I was hospitalized before I seroconverted. I now receive about 2/3 of my former salary in work-

ers' compensation benefits.

I think the key to getting compensation is documentation. Without the documentation, what would they have had to go on? I was a 23-year-old single heterosexual female. I could have gotten HIV from another route. But my case was thoroughly documented. Of course I realize that for other occupationally infected health care workers, the path hasn't been so smooth, and my heart aches for them. I'm one of the few who has gotten full coverage. I've come away from this experience luckier than most. I have full medical care; I have family and friends and an employer who support me; and I have the right to go back to my job. Most people with HIV don't have that.

I don't have anything negative to say about the workers' compensation system. I did have to answer every embarrassing question you can think of. But I didn't want any doubt about my case. The issue was not whether I would get compensated, but how. How would my confidentiality be protected and an HIV infection be handled under workers' compensation? I was asked whether I wanted the paperwork to refer to my illness in vague terms like "blood virus." I said I wanted it written up as "HIV infection from needlestick that occurred on 9/9/92." I didn't want any grounds for confusion in the records, because my case would set a precedent for how the next occupationally infected health care worker in Pennsylvania was treated under workers' compensation.

I believe that health care workers in patient care who have an occupationally acquired disease should be allowed to stay at their job as long as they don't pose a risk to patients. I do think their status needs to be evaluated

on a six-month basis. But health care workers need to be protected, and they need to have a choice. In my case, because of the course of my disease, I chose not to work. But that decision should be up to the health care worker. By the same token, however, nurses and other health care workers should not be able to refuse treatment to an HIV-positive patient.

When I do public speaking—and I've spoken to over 6,000 people locally in the last year—inevitably there are people who come forward and say, "My uncle was a surgeon who we believe was infected on the job, and he died of AIDS," or "My sister was a nurse who was infected on the job, and she's never gotten any compensation for it because her injury wasn't documented." I hear these stories, not in the medical community, but from the general public, and that's just in my local area. It makes you wonder about the true number of occupational infections, and how many health care workers are afraid to reveal their infections and seek compensation.

The other side of the coin is that there are health care workers who get HIV through transmission routes other than their jobs, but they or their families choose to say that they got it through work because an occupational infection is perceived as somehow "innocent," "not your fault." I think that attitude is wrong. Everyone with HIV deserves equal compassion and support.

Ignorance and Denial

What is the greatest barrier to a safer workplace? Ignorance and denial, on the part of hospital administrators, product evaluation committees, purchasing departments, and health care workers themselves. Health care workers need to be made aware, not only

that there are occupational risks, but also that those risks can be reduced. They need to have the power to influence purchasing decisions. Health care workers are the consumers and users of products. If there is a safer product available, they should have a right to demand it.

Whether or not hospitals and health care workers are reacting appropriately to the risk of occupational exposure varies. There are three major hospitals in the Lancaster area. Since March 1993, my hospital has been using shielded IV catheters in most units. Neither of the other two hospitals in the Lancaster area, however, currently use these kinds of safety devices.

Since my needlestick, my hospital has made greater efforts to educate staff about exposure prevention and risk reduction. The impetus for that has come not only from the administration but from the nurses themselves. Their attitude is, "We support Lynda, but we're not going to be the next ones." At the time of my injury, the hospital had a needlestick prevention committee, but there is greater employee participation now. There is also more participation in the nursing standards and protocols committee.

Appeal to the Nation's Hospitals

Since leaving my job at the hospital in April 1994, I have done extensive HIV education in the Lancaster County area, mostly with public schools, colleges, and community groups. I chose not to address the medical community while my court case was pending.

I pursued a legal remedy because I wanted to increase awareness and make hospitals and manufacturers sit up and take notice. But a motion for summary judgement by the manufacturer

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was granted, which meant that I never got my day in court. The case was then settled out of court. Since I didn't have an opportunity to speak out in court, I am now launching a public appeal.

My immediate goal is to promote a safer workplace for health care workers. I am making a public appeal to the nation's hospitals and medical centers, as well as to medical device manufacturers, to unite and work together to fully implement safety IV catheters and blood-drawing devices. *[An excerpt from Lynda's appeal accompanies this article.]* This will include asking hospitals across the country to sign a pledge agreeing to convert to these kinds of safety devices within a year's time. Research has shown that IV catheters and blood-drawing devices are associated with the highest-risk injuries. It makes sense that hospitals should focus their efforts on these device categories. Of course, it's of special importance to me since I was infected via an IV catheter.

I don't want this campaign to be seen as one woman's platform.

This is for all health care workers, and for their children who may someday become health care workers themselves. It is also for all those HIV-positive people who have made such enormous efforts to further HIV awareness and education. This is just another step in that process. Implementing safer devices in the health care workplace will help not only health care workers, but also HIV-positive people who are their patients, by reducing the fear and discrimination they sometimes experience in the health care environment.

Some injuries will continue to happen, but that doesn't mean that the risk of infection can't be reduced. Health care workers, whether they are nurses, physicians, aides, or maintenance workers, have the right, and the responsibility, to demand safer products and a safer work place. And hospital administrators, purchasing departments, and manufacturers need to provide better access to safety products.

The final issue I'd like to touch upon is cost. There is so much debate about the cost of implementing safety devices, so many people who say that they are

too expensive, especially with hospital budgets and staff being cut. But all they need to do is pick up the phone and call Community Hospital of Lancaster; my infection alone will cost hundreds of thousands of dollars. Even without an infection, however, the cost of following up occupational exposures is high, including the medical treatment, lab work, counseling, lost work time, and the fear and stress that take their toll. Hospital administrators need to look at the total picture.

My hospital is a small, private, financially challenged facility. If it can make the switch and find the money for safety devices, then any hospital can do it. It's impressive when you hear about large hospitals implementing safety devices, but it's more impressive when small hospitals make that kind of commitment. My hospital did it because the administration understands the economic impact a needlestick injury can have. Of course, I wish my hospital had implemented safety devices before my injury. But I'm glad they have them now, because there won't be another case like me. And for that I am grateful.