

Interview with Cindy Hawkins

Interviewed by Venessa M. Fuentes

**Interviewed on March 31, 1995,
at Hawkins's home, Crystal, Minn.**

VF: What's your connection to AIDS and general background information?

CH: My son and I were diagnosed in the fall of '90 HIV positive, and I've been very actively involved in the community since then.

VF: Okay, how would others describe you?

CH: (Laughs) Let's see, in all the papers that have been done and articles, they describe me as an activist and outreach worker. I don't know; I consider myself an educator and somebody who wants to do their part to put an end to this epidemic.

VF: When did you first learn of AIDS?

CH: Well, I know that, you know, in the eighties, you saw little things here and there, but they always talked about gay men and always showed somebody close to death and dying, and I never thought that it was something I would have to worry about. And then when my doctor suggested running an HIV test on us, I really realized that I didn't know much about this. After laughing in his face and telling him that I wasn't at risk and him believing that I wasn't, we agreed to have the test run. I went and started calling the AIDS line and going to the library and all that other fun stuff--learning what I could learn.

VF: How would you say your definition of AIDS then differs from your definition of it now?

CH: Back then I didn't think that AIDS happened to women. I didn't think it happened to children unless they were hemophiliacs. I didn't think it happened to the heterosexual community unless they were hemophiliacs or bisexual. I didn't think I had anything to worry about.

VF: What is your general reaction to AIDS? Are you angry about it? Are you frustrated or sad?

CH: You know, that's so hard because obviously everybody's got some form of level of anger or fear, you know, and a lot of mixes of feelings and emotions. I don't think I had a whole lot of time to deal with a lot of different feelings and emotions because my son was sick already and ended up in the hospital just weeks after diagnosis, so I was forced to immediately deal with it.

I guess the biggest thing that I dealt with then was just the denial that I was at risk. During that time where you're waiting for your test results--you have a chance as you start learning more about HIV, going to the library and reading brochures and calling the AIDS line--you start realizing that, you know, that maybe I was at risk, and that this can happen to me. You kind of deal with that acceptance, and when you get a positive test result, I think my biggest fear was losing [my husband] George. And knowing that my son was going to die of a disease that I gave him unknowingly, because nobody told me I was at risk basically. That's part of the reason I decided to become an AIDS educator and activist, because I wanted people not to have the same excuses that I had.

As far as how I feel now about HIV, I don't know. [pause] I guess I'm mad because nobody ever told me that I was at risk and that this was out there. And I'm mad that the government waited so long to do something about it. But I also know that you can't go back and change the past, and that by educating and reaching out and sharing my story I can hopefully influence what happens in the future. I guess I try to look at it that way. But I still fear a lot that, you know, what if I infect my husband, or those types of things.

VF: Do you think this has changed his outlook on life, and different things in general? Has he been very supportive of the whole thing?

ch: He's been really, really supportive. The first year or so, it was very hard on our relationship: You have a sick child, he lost his job because of this, I had problems with my job--my doctor pulled me out on disability because I was facing discrimination problems there. So it was just tough on our relationship all around. My son had three

hospitalizations in two months right after he got diagnosed, and then he was in for twenty-four days just after his first birthday. And at that time they said he probably wasn't coming home. Obviously it's stressful on a relationship. With George, I think he's really come a long way. He gets really concerned if I'm sick now or if I get a cold or if I get stressed out. He's really supportive. So I'm fortunate because a lot of people don't have that.

The rest of my family is really caring. My mom and my dad, I can call them up anytime and they're there. My sisters and brothers, they're very caring, but they have their own lives, too. Do you know what I mean?

VF: Are they more aware now of the AIDS movement, or were they before?

CH: I think they were a lot like I was. Thought it was somebody else's disease like most of society thinks. As far as now, my family totally backs what I'm doing. I'm very fortunate in that. And like I said, I've heard so many horror stories and fears that I just consider myself very fortunate to have the family I do have.

VF: How would you define happiness or felicity, and where do you think you find it?

CH: Where do I find happiness? That's a really difficult thing because obviously I enjoy doing things [laughs] that anybody else enjoys doing. But I think, not so much happiness, but I think I appreciate more the little things in life.

When I do my speaking; I mean just today, if you'd have seen me just today I came home and I was just like stressed, with just a "Go away--don't bug me" type of attitude two hours ago. And I got my mail, and my mom just dropped a little card in there letting me know she's thinking of me and, and I get a whole envelope, this little stack here, in fact [laughs and gestures to a pile of letters] of thank you's and stuff from a talk I'd done a few weeks ago. And these kids were just saying "I'm sorry your son died" and "I hope you're feeling better," and things like that. That's just like a natural high. You know what I mean by that?

VF: Yes.

CH: And it keeps me . . . That's the kind of thing that keeps me happy and going, and it perks up my day. Knowing that I have a supportive family and stuff is real important. I don't think I could be very happy if I was stuck into being at home all the time just knowing I was going to die. I need to be involved, and that's part of it. Doing my part to, well, I guess, basically doing my part. [Laughs]

VF: Can you tell me what all your activism entails?

CH: Oh, you really want this whole list? [laughs] Can I go get it in the other room? [laughs] No, I'm just kidding! Actually, we went public with our diagnoses in October of '91, just a little over a year after we got diagnosed. I had already been involved with some things in the community. We had already been actively involved and advocating for some women's issues and some pediatric issues. We had gone to Washington, D.C., to the first Pediatric AIDS Awareness Day in June of '91 and met with Senators Durenberger and Wellstone¹ and things like that. From that point on I can't even tell you the newspapers and radios and TV's, there's just too many of them now. I was keeping track and it got out of hand.

I've done over four hundred public speaking engagements to high schools, junior highs, churches. I'd say about ninety percent of them are in the Twin Cities metropolitan area, and the majority of those are to either junior highs or senior highs, although I do a lot of colleges and churches and other types of groups. I just really want to make sure that people know that this is out there. You know when you lose a child and you watch the child that you brought into this world die, [pause] because of an illness that you gave him that you knew nothing of, you don't want to see anybody follow in your footsteps.

Every time I meet another newly diagnosed woman or child, I hear the same scenario: "I never thought I was at risk, how could this happen to me?" It just makes me want to get out there more and just advocate and make sure we're getting our services on one hand, but at the same time making sure that I can do my part to help prevent this virus from continuing.

VF: Do you think your activism and talking to women and

¹Republican David Durenberger and Democrat Paul Wellstone.

children about it helps you deal with the loss of your son?

CH: Oh, yes. I've never been a real spiritual person--I didn't have a spiritual upbringing--but with Nicholas, it really taught me that something really special happens. What exactly it is none of us are ever really going to know--we think we know and we hope we know, and we want to believe what other people share with us, you or what you read in your Bible, or whatever.

But Nicholas really taught me that something very special happens when the time comes that you die. And all I hope is that someday I'm with him, that we can be together again, and that there won't be any more sickness and no more owies and no more boo-boos--you know. He died at three years, three months old. He never learned to walk independently; he had a little metal walker, and he couldn't pull himself up to that hardly at all. He usually needed help to get across the room. He moved very, very slow.

It wasn't just something that you . . . [pause] He wasn't like a normal three-year-old; I mean I don't know how else to explain it. Three-year-olds are supposed to be able to ride trikes and ride these little big wheels and cozy coup cars and those types of things. And they're supposed to go up and down steps and play ball. Nicholas never learned to do that stuff. He never got to be a normal kid.

What was important to Nicholas was learning to run the VCR, and knowing he had two IV² lines in his chest, knowing that one was red and one was white, and which medicine went in which line, and that if the pump started beeping he'd tell you the pump was broke, because he knew that it was time for a new medicine and he didn't know how else to explain it. You know, things like that.

If the alarm would go off on the pump because of a air bubble or something, he'd say, "Uh oh, pump broke." That's not what a three-year-old is supposed to learn; they're supposed to be playing ball and riding trikes, and playing in the back yard and swinging. And he didn't have a normal life.

He knew he wasn't like other kids. When he got his walker, if you could have seen that kid--I mean, I could show you a

²Intravenous medical tubing.

video of this. He saw my nephews and nieces doing all the things that he couldn't do, and he was so dependent on somebody carrying him. He saw these kids running around. Well, when he got that walker and he knew he could keep up with those kids and be upright and be mobile, even though it was slow and he had to have that walker, it was like his face would light up because he was doing something. If you could just see, that you would understand what I'm saying.

He knew that he was different in that respect, but I don't think he totally understood that--I mean he was too young to understand what HIV and AIDS was. He was too young to totally understand what life and living and death and everything meant. We told him, you know, near the end, that he was going to get sicker and that the owies and pain would all go away and that he was going to go somewhere special. What else can you tell a three-year-old? They're not going to understand much more than that. I don't know. [laughs] Without seeing and really visualizing what he went with, it's hard to really explain.

VF: Do you think the activism that you're involved with in your work helps you deal with your son's loss? Is it gratifying for yourself to know all the lives that you're touching?

CH: Well, I know that if I can save that child or that teenager or that college student, whatever the case may be, if I can influence their actions for one day, that's great. If I can influence them for a couple weeks that's even better. If I can influence how they behave the rest of their lives, fabulous! But I'll never know that whole outcome. I may know that I influenced them for that day and maybe for a few days afterwards, and more than likely they'll remember me when the peer pressure hits to go make out in the back seat or have sex or do drugs or whatever. Maybe they'll say, "Oh, wait a minute, I don't want to live like Cindy and Nicholas." But the chance of them remembering that five or ten years down the line is pretty small.

I do it mostly for myself, and I'm doing it for Nicholas. Nicholas didn't have a chance. And I don't want the future kids to not have a chance. We had talked about having a large family--obviously that dream was shattered right away. The sad part was that growing up through high school and through college years in my early twenties, I wanted to find Mr. Right and have a family. You finally find Mr. Right and

you settle down and you start having your family, and then your dreams are taken away from you. Then you realize that there are a lot of people with this dream. I mean that's what's going to keep the world moving.

And to know that by sharing your story maybe you can have that impact to keep that world moving--it's what keeps me going. I say I do this for Nicholas because if it wouldn't have been for Nicholas I probably wouldn't be here right now. If Nicholas wouldn't have been sick, I wouldn't have gotten diagnosed, I wouldn't have had the last four-and-a-half years of medications or educating, or I wouldn't have touched those other kids' lives. I probably wouldn't have gotten diagnosed until I was in the hospital two years ago with pneumonia, and what's the chance I would've gotten diagnosed and survived through that with enough time frame. Probably not, I probably wouldn't have lived through it, and who knows if I would've gotten tested or not.

And if I did, I sure wouldn't be at the level that I'm at right now. I look at the services that I've helped get instated in the community, the programs that I've helped to get running, the people that I've been able to reach out to, and I say, "It's for Nicky," because he did this to me. Even though I don't have my child, it's because of him that I'm here now. And I have to really believe that. You know, when I do my talks I say that everyone is put on this earth for a purpose. And I think that's what his purpose was, it was to teach me. Do you know what I mean?

VF: Would you ever think of maybe adopting children?

CH: You know, I get asked that all the time when I do talks. And being an HIV infected woman, I know that with my T-cell counts³ at the level that they're at, I would never take a chance of having another child. Partially--even though with my being on AZT, knowing that the chance would drop; there's a number so many different factors--part is that my T-cell count are so low, they would probably drop down to zero; they're at sixty-seven right now. They would probably drop down to zero or close to that just from the stress of a pregnancy. The second thing is that I looked at the energy

³T-cell counts refer to a test measuring the level of CD4 cells in the blood. They are used to measure the degree to which the immune system has lost function.1 Normal counts are over 1,000; under 200 means an HIV-infected individual's immune system is compromised severely enough to be classified as having AIDS.

it took out of me to take care of Nicholas. If I'd had a healthy child I'd really have been in trouble!

You know, there's no way I can keep up with my nieces and nephews more than a day here and there. I don't have the energy anymore. If I was healthier, if I could take the health level that I was at four years ago when we got diagnosed, or four and a half years ago, and put that into today, I would probably consider adopting a child. But I don't think I could ever take the chance of bringing another child into this world personally. Knowing the risk--and everybody says, "But the chance drops to eight percent,"⁴ and I say, "But that's just the preliminary studies, and yes, the report was released because it's been so effective. But that doesn't necessarily mean that child is going to be in that ninety-two percent." That child could very easily still be in that eight percent, and I couldn't do that. I could never put another child intentionally through what Nicholas went through. It's just not fair to the child; I just couldn't do it.

When Nicholas first died, I told George that maybe we should adopt a HIV-infected child or be a foster mother or something, and then I thought: I couldn't do it. I couldn't sit and watch another child die. And two months after Nicholas died, two of my very good friends that I met through my support group, their children died, eight weeks after Nicholas. Those two died a day apart, and being there watching those two kids suffer, watching what those parents were going through was like going through Nicholas all over again. I couldn't do it.

There's no way to explain what it's like to watch a child die; there's just no way. And it doesn't matter if that child is days old or three years old or twenty years old or fifty. Nobody should have to watch their own child die, and especially needlessly for a disease like this.

VF: Do you think that you find a sense of family, or extended family and kinship ties through support groups that you just mentioned?

CH: Actually, I get asked what my family is like. My blood family, I guess you would want to say it is very, very

⁴Recent findings suggest that taking the drug AZT during pregnancy reduces the risk of transmission through pregnancy.

supportive. But if you look at my support family, if you want to classify it as that, I have so much support out there. I have speaking engagements that I do every year, twice a year at some of these schools. And it's like when Nicholas got sick and when Nicholas died, they were all there for me. At his funeral I had teachers from schools that I'd done talks at, students from some of the talks at the colleges and the high schools and stuff that saw on TV that Nicholas had died and came to support me. And it's like that's my extended family, you know what I mean?

I don't necessarily keep in touch with all of them except for the teachers--I mean obviously I'm only one person, I could only do so much--but to know that I have that support there if I need it.

I can call any one of them up at any point in time and say, "I just need to talk." They know who I am; they know what I'm about. And I think in my case I'm very fortunate because I'm so open about this and I'm such an activist that people know me. That I do have a support system. A lot of women that I know, whether they're newly diagnosed or been diagnosed for a couple years, haven't been open and shared with other people, and they haven't gotten the support back.

I end up being the support and the shoulder for a lot of people so that I don't get as much support back from, but I get it elsewhere.

VF: How do you think people would've described him, like I asked you at the very beginning of the interview, "How would you describe yourself?" How would people have described Nicholas?

CH: I'm thinking about what people have said when they've talked about Nicholas, and [pause] I don't know. Basically, people just say that he's just a little angel, that he was sent here with a purpose. And his mission was done and now he's letting me carry on--that type of a thing. Nicholas was a very loving, affectionate, cuddling child. Without really watching the videos, I don't know how to really put it in words, because he's my child, you know. I have my own viewpoints, but I think of the things that other people have said. People that have known Nicholas in his life were touched by Nicholas, and you can't help but cherish what they say. And when they say that this kid had a mission, or he was an angel, or he was just the sweetest kid--and he was, I mean you can look at the pictures and see that he was a very cute kid.

I don't know. Nicholas was my kid and any mother is going to say that their child is cute and precious, you know, especially at that age. And I can't describe him any other way, besides what other people say. He was my child, he was, I guess, my savior and my angel; and I still consider him my little angel; he takes care of me every day.

He's what keeps me going; he's what gives me the energy to go out and do these talks. His picture and everything is with me every day saying, "Mom, I'm here with you and we're going to do this together." I can't do my talks without fidgeting with his button. I have a button that has his picture on it, and I fidget with it through my whole talks every time. And it's just what keeps me going.

VF: I understand, I understand. Let's see. Do you have any really fond memories? I mean I'm sure you have a ton!

CH: How do you even begin to describe? I think all of the memories I have are precious. I think the most special ones that I usually share, depending on how much time I have obviously [laughs]--one of the most special ones is when we were in D.C. at the Pediatric AIDS Awareness Day. He was crawling around on the floor, and we had his diaper bag on the back of his stroller so it flipped back. And he comes over and crawls himself up into the wheel part of the stroller. And he's walking around, using it like a walker, and we were joking around then: "Oh, he needs a little walker," and stuff, and my ma has this on video. And it's really cute, because he's pushing this flipped-over stroller to stand up and be upright. He was just so excited that day.

And it was exactly a year later when he got his little walker, when he was getting treatment out at the National Institute of Health, in Bethesda, Maryland. He was part of the pediatric AIDS studies out there where they did drug studies and research and stuff on him. And it was June of '92 when he got his walker from out there. And when we stood him up at that walker, he looked at me like: "Yeah?" And I was like, "Come on, try taking a step," and once he took one or two steps, that kid didn't want to stop until he got all the way down that hall. It took him forever, but he didn't want to stop once he realized "Hey, I can do this." And to see his face light up--you'd say anytime, "Nicholas, you want to walk?" especially like if he was at his physical therapy at the school, or at the hospital where there's a long

hallway or anything, "Nicholas, you want to walk?" "Yeah!" His face would just light up. It was just . . . you know.

I think the other thing that really reminds me that I have good memories is the last day Nicholas was at NIH in March of '93. We had just gotten approval the day we were leaving for Nicholas to go to Disney World for his Make A Wish Dream.⁵ They had asked us if we could stick around because there was a surprise that afternoon, and that surprise was Mickey Mouse. And Nicholas was so afraid of Mickey Mouse!

[Laughing] And I'm thinking, "I'm taking this kid to Disney World?" Give me a break, you know? Mickey Mouse came in and tried shaking his hand, and Nicholas started crying and pulled his hands back so I shook his hand. And he wouldn't talk to him; he'd tell me what to say in my ear and I'd tell Mickey Mouse. Came time for pictures, and Mickey Mouse tried to stand next to Nicholas and the stroller, and Nicholas was pushing him away, and I'm like, "Oh no," and he's just scared and petrified. So finally I calmed him down and I stood between them in this picture. But all the way home [from Maryland] on the plane, and when we got home that night, Nicholas was telling everybody that he saw Mickey Mouse and he was going to Mickey Mouse's house.

He sat on the corner of this couch watching videos most of the day when he was awake, unless there was somebody here to play with or entertain him because he wasn't very mobile. And when you've got IV pulls, you're really limited. And he loved watching all the different Disney movies. He had the whole collection at that point in time. At the beginning they'd always show the Disney Castle, and he'd say, "Mee-mouse house!" every time at the beginning of each thing. So, we tried to explain that that's what Disney Land, Disney World, was. Tried to get him to understand the whole concept that he was going to go there and see Mickey Mouse and Minnie Mouse and Donald Duck and everybody. And he was all excited.

Well, then, when he saw Mickey Mouse [in Maryland], he was petrified. So on the way home on the plane, he was telling everybody that he was going to Mickey Mouse's house, and that he saw Mickey Mouse. And he was showing his picture off to everybody and it was so funny. [Both laugh] Well, that night, when we got home--I don't know if you've ever seen a little kid refuse to wear something; they'll, like, be

⁵The Make A Wish Foundation arranges trips for terminally ill children.

adamant--and he kept taking off his pajama top and saying, "No, Mee-Mouse shirt!"

And we were like, "No, wear this shirt, Mickey Mouse shirt is dirty." "No, Mee-Mouse shirt!" And he kept throwing it off--finally we put his Mickey Mouse shirt on him. I have a picture; the picture I take with me to my talks is him standing on the corner of the couch here, wearing his Mickey Mouse shirt, holding his little Big Bird flashlight thing, and he's just got the biggest glow on his face, like "I got my way!" [Laughter] You know? And he was all excited and stuff. It was just hours later--he never got to go to Disney World, he never went back to NIH--just hours later he ended up in the hospital sick, and five weeks later, he died.

He never got to come back home, he never got to have his dream. And I have to keep telling myself that maybe what I thought his dream was wasn't his dream. He got to see Mickey Mouse; he just didn't realize that Mickey Mouse was so big! And just to see how excited he was about that made my day. It's really sad, because you look at this picture--it's five weeks before he dies, he doesn't look sick; he doesn't look like a child fighting for his life. And here it is, this child had gone ten months with zero T-cells, on 24 hours a day IV meds on one line, and 16-18 hours a day IV meds on the other line, fighting for his life. [He] ends up in the hospital and dies five weeks after this picture was taken. You just [pause]--it's too unbelievable.

You know, you know, and I think if I was going to send one message out to the community it's that nobody is immune from this unless you're a hundred percent abstinent. But we know in life that people fall under peer pressures and insecurities, maybe failed to be educated, or whatever the case may be. We need to be able to teach them that [they] are going to have to deal with some very difficult situations: everything from learning to say "no," not just to drugs and drinking anymore, but leaning to say "no" to sex or to know how to protect yourself if you can't say "no," or realize that even if you do practice safer sex practices, you're still at risk, because that's not a hundred percent guaranteed. But if you do that, put yourself at any risk, or have no protection and put yourself at very high risk, you're going to end up like Nicholas and I. Fighting for our lives.

VF: It's hard to describe. Like certain things that you

can't describe to me about losing your child, I can't describe to you about being a younger person in this generation, and how scary it is.

CH: Well, the pressure and the fear of "if I don't give in, is he going to leave me?" And am I going to lose this relationship? And to get individuals to understand that if he or she truly loved you, that you'll know that the time is right and you'll both be consenting, and hopefully it'll be safe. And to know that, whatever happens with your body, it has to be a decision that you made.

VF: There are even issues of rape where you hear that one out of every four college-age women students gets raped, which is really scary, because that's me. I'm twenty and I could get raped anytime. There is a whole other thing that if I do get in a situation where I'm going to be raped, I can't--you've heard of things lately where women say, "Well, if you're going to rape, me use a condom," and then they turn around and put the blame on her like "Well, she asked for it. She said that I could go ahead and rape her as long as I wear a condom, so she was consenting, so it's not rape."

CH: Yes, and it's scary .

VF: It's terrible!

CH: The other message, I guess, if I wanted to get them out there, was is that to learn that if you're in a relationship where one person is HIV-infected, one of the hardest things that George and I've had to learn is that you can show a lot of love and affection without having intercourse, and that if you are going to be sexually active, that applying a condom and using safer sex practices can be very sensuous, and it's going to be one of the hardest things you're going to learn in a relationship, especially if it's one that hasn't been that way and you had to change it to that way. It's one of the hardest things we've had to learn.

But it's also really strengthened our relationship a lot. And the other thing is to just understand that you can't tell when somebody's infected. You know, look at me, do I look sick? I've been infected nine or ten years and I don't look sick. Look at Nicholas in these pictures. This picture here was the day after he got out of the hospital, after twenty-four days in there, and they had us talking funeral arrangements. I mean, does it look like a sick kid?

You can't always tell when somebody is sick. You can't just always say, "Oh, it'll go away later, it's just a cold." You need to really look deep inside and look at your past and get tested and take precautions from that point on in your life. To understand that you can't tell if somebody's infected and to not treat anybody differently, because, if it hasn't already, it's only a matter of time before it's going to affect your life. And, you know, they say by the year 2000 everybody is going to know somebody.

I truly believe it. I do an annual talk in a rural community. Two years ago when I was out there, right before Nicholas died, there was only one kid in all the classrooms I'd done that day who knew somebody that was HIV infected. I was just there a couple weeks ago, which are where these letters are from [gestures to pile of mail on table], and between the three classrooms that I did, there had to have been at least fifteen hands that went up, that they knew somebody.

And for four or five of them it was somebody within their household or blood relationship basically; it was somebody in their family. One of them, their own mother was infected. I mean that's just a small town here, you know, small-town rural Minnesota. When my son died--some friends that I grew up with are now living up in Grand Rapids--and at that time they said, "Well, I don't need to worry about AIDS and take precautions up here, because it doesn't happen up here." And I'm like, "YES IT DOES!" And they called me up maybe six, eight months ago, and one of their best friends had died of AIDS.

They were just, like, "Oh, my God," and they said, "We know so many people up in this area now; we never thought it'd happen here." And I'm like, "Wake up!" Why does it take the death of so many people for people to open their eyes? Why does it take the death of a child for people to want to listen to my story?

VF: What do you think your vision of America as a whole is, as far as maybe dealing with the whole AIDS epidemic?

CH: You know, that varies, because I think the majority of people in society Okay, ten years ago, I think everybody in society really thought that this was a gay disease, unless they knew somebody, obviously. I'd say

probably ninety-five percent of society in my opinion thought that this was a gay disease and they deserved it, okay?

Five years ago, people were starting to realize that it happened periodically to other people, but they were "bad" people. If it happened to somebody that wasn't gay, they were still "bad" people. They were either classified as gay, bisexual, had sex with somebody that was an IV drug user or they were IV drug users, or had sex with somebody that was a bisexual; or they were prostitutes.

I don't consider myself as being a prostitute. I made a couple bad decisions in my life, I had a couple relationships that were sexually active before I got married. I'm not the only person in the world that has done that, I'm not the only person in Minnesota that has done that, I'm not the only person in Minneapolis that has done that. You go out to the night clubs any night of the week, and you see people meeting people that night and going home with them. When I see that I just want to take them and say, "Wake up!" and just shake them and say, "Do you know what you're doing?" And then again, I can only do so much and do I have the right to do that?

There's so many sides to it. I think society as a whole right now, the majority of people in society that have met somebody with HIV, have a better understanding about it. I guess that it's just too bad that it takes to know somebody or meet somebody; and I think that if we can get out there and educate these people so that they have a face--I like to say the face of AIDS--and that face could be your neighbor, could be your brother, could be your sister, could be your child. To put a face on it, somebody who is not stereotypical, what society thinks of either IV drug user or gay man, to put a different face on it and have it say, "This is our future, that's being destroyed here." Maybe we can help educate these people before it's too late. But, like I said, by the year 2000 everybody is going to have met at least one person and more than likely it will be somebody close to them. It's only a matter of time.

In February of '92, I did this interview for this fundraiser, and I said then, it's only a matter of time before we meet somebody, whether it's a relative, a neighbor or friend, a co-worker, or somebody we just meet at a bar, or a restaurant or an event. It's only a matter of time before everybody has met somebody with HIV and it's going to take till then before

we open our eyes to society and say we have to do something.

And I think the more we get inner city and the more people have met somebody, we're a little more open; but you still get out to these rural communities and unless it's hit their community, [the attitude is] "Oh, that's somebody else's disease," and that's really sad that we still have so much of that.

I did a talk this past fall in South Dakota--they couldn't find a speaker in South Dakota to come and speak; they had to come to Minneapolis to get a speaker. I'm going back there again next month to speak, but I get all the way out there, I do some of my talks, and these parents are raising Cain because, "How dare this HIV-infected woman who talks about condoms and talks about unsafe sex, and doesn't talk about anything except abstinence, come in and speak to our kids. This doesn't happen here!"

Oh yes, you have teen pregnancies in this little town, thank you, and yes, you do have cases in this county; you have ten cases in this county according to the local Red Cross. It happens here, people! And the students at the school where my talk got canceled because of parents complaining have complained so much and has been so much controversy that now all the neighboring communities on top of this all want me out there. So now they're talking and having me come out there two or three days!

VF: It's almost a blessing in disguise that there is so much controversy; that they raise so much hell.

CH: The sad part is that I didn't get in there to speak. But the best part is that I got that entire town talking. That entire community was talking AIDS, they were talking death, they were talking abstinence, they were talking condoms, and honey, they were talking! They were on the radio shows, it was in the newspaper, everything. I mean, the night that I was there--and my talk was canceled for the next day, but I had one in the morning the next day--I had some time and I had gone out that night, and it was the talk of where I was at; I didn't tell anybody that it was me right away, and I said, well, "I'm the talk of the town, I'm the woman with AIDS," and these people were like . . .

VF: "Oh, my God!"

CH: Mouths were dropping over everywhere, "Oh, my God, that can't be her." Nobody wanted to believe it was me, and it's like, "That's me! Don't believe me? Come hear me tomorrow." And some of them did. And I was like, if this is what it takes to get this town awake, and the sad part is that . . . The good part is that this community has now started a support group. [Laughs] The community that says, "It doesn't happen here" now has a support group, the town is talking. On World AIDS Day they had a couple of the different department stores in town where every employee in the store was wearing red ribbons,⁶ and they had literature available. They're having different community events each month. It's like things are finally happening in this community.

VF: That must be very gratifying.

CH: But it's like, I feel great because I know I did this, but the sad part is that what if I would've said, "No, I wouldn't go"? They couldn't find anybody else to go out there, and I just, like, "I'll go because it needs to be done." You know what I'm saying? What if I wouldn't have been here? Another thing: if it wasn't for Nicholas I wouldn't be here; that wouldn't have happened. How long would it have taken? More than likely, eventually it would have been somebody else along the line, but would it have had the same impact?

I may not be able to influence those actions, but I can at least get that town talking about AIDS and get them talking about risky behavior, and I can get them talking about condoms. It's like nobody should say that word! Well, we know, in reality, there are three choices we have to make in our lives: one is to remain abstinent, which is refraining to the exposure to the bodily fluids and having risky behavior; the second one is that, if you can't remain abstinent, to know that you can have safer sex practices--it's not a hundred percent guaranteed, but it's going to dramatically reduce your risk of pregnancy and other STDs including HIV and AIDS; or you can have risky behavior, which is what I did because nobody ever told me I was at risk. I didn't think I had anything to worry about, except for getting pregnant. If somebody would have told me I was at risk, maybe I would have acted different. I can't go back

⁶The red ribbon is a symbol of support for people with AIDS and AIDS awareness.

ten years and look at that, but more than likely I probably would have. Or at least would've thought twice, you know what I'm saying?

My biggest fear was getting pregnant, and if that happened, well, you dealt with it. Well, nobody told me that HIV and AIDS was something I had to worry about, and nobody told me that this was a deadly disease and they would never find a cure. We know that we won't find a cure in my lifetime or probably not in yours. It's probably not going to happen in many, many years, if ever. The sad part is that you hear people say the only way to put an end to AIDS is we're going to end up wiping out a couple of generations of people, except for those who remain abstinent until they were in committed relationships and remained committed. They're going to be the only ones that are going to be able to carry on this world, and that's really scary! That's very, very scary!

The chance of me being around [pause]--statistically, I probably won't be around more than a couple more years. I may be around another five years, not very likely, but I may be. I could die tomorrow--so could you. So I try to live each day the best that I can. But realistically, I know that, [pause] you know, I could die at anytime. Statistically, I probably won't be around more than a couple years. I could be around longer than that. I might be here in another five years, or probably not. You know, it depends on what illness I get, and how I take care of myself.

VF: Is that hard for you to comprehend or to deal with?

CH: I find myself not looking at five- and ten-year plans, how's that? [Laughs]. I find myself looking at "Okay, how am I going to deal with the next few months?" And even looking for, like, next Christmas, it's only March--the end of March--and I still find it hard to be thinking about next Christmas. I know I'll more than likely still be around at Christmas, but it's like I find myself wondering, "Is this going to be my last one?" And I'm thirty-three years old!

VF: Thank you very much.

CH: You're welcome.