# Abby Shevitz Transcript

ELISE BRENNER: And I'm going to announce that my name is Elise Brenner, and I'm the research fellow from the Women Who Dared Program. I'm here to interview Dr. Abby Shevitz here in her home in Sharon, Massachusetts. She's our 2004 Women Who Dared honoree. That's all.

ABBY SHEVITZ: Thank you.

EB: Now I'm going to ask you some questions about your family background. So I'd like to hear a little bit about your childhood in Baltimore.

AS: Okay, I grew up outside of the city of Baltimore in an area called Pikesville, which is very Jewish. My grandparents were strongly Jewish and affiliated and practicing, but my parents completely left the religion. So we were self-identified as being very Jewish. We were culturally Jewish. We celebrated all the holidays with my grandparents. But we were not officially connected in any way to the Jewish community. But we were outside of the city. It was a nice place to grow up. I had a very warm childhood, wonderful parents, and brother and sister.

EB: Brother and sister.

AS: Our biggest impediment was that we didn't have a lot of money. We struggled financially throughout my childhood. My parents did the best they could to not make that our issue as children, but we were certainly aware, especially in a Jewish community that was fairly well off, that we were different in that respect and that there were many things that we couldn't have or wouldn't have. And so we learned to readjust our roles and priorities.

EB: Class is very significant, isn't it?

AS: It is, it is.

EB: You know that in your work. And we'll probably make that connection a little bit later if that's okay for you. Now I understand your parents probably were working very hard. But did they have any activism in their communities?

AS: Not specifically. No. My father worked very, very long hours. He owned a furniture company that he had taken over from his parents. And my mother was a full-time mom working very hard to raise us. So there really wasn't time, opportunity to be involved outside of the home.

EB: You attended public schools?

AS: I did.

EB: No parochial schools, of course.

AS: Yes, public schools.

EB: When did you get married, if I may ask? Was that in Baltimore or here?

AS: That was much later.

EB: Much later. You came here.

AS: I was here. I should figure out how old I was before I say the wrong date. I was thirty-four when I was married. I was up here by that point.

EB: Of course. Because you came here for college?

AS: Right.

EB: What was that education journey like? Because I know there was Boston, then back to Baltimore, then back to Boston.

AS: Right. When I finished high school, I was very interested in math and science, and I decided to go to MIT [Massachusetts Institute of Technology]. So I came up here to attend MIT. I loved MIT. It was a wonderful educational opportunity. It was a wonderful cultural opportunity. There's a lot going on at MIT that many people don't realize, all of the extracurricular things. I had a fabulous time there. Afterward, I went back to the University of Maryland. I went back to Baltimore to attend medical school. So I was there, lived with my parents for one year of that, which worked out very well, and then afterward came up here for my residency at Boston City Hospital. I've been here ever since.

EB: Is that where you met the husband?

AS: No, I've known my husband since junior high school. We were friends in Baltimore. We were good friends in junior high school and high school. We dated for one year, and we went to the senior prom together. Then we each went our own way. I came up here. He went to Chicago for college and medical school. We had our own lives. Long periods of life in between there. And then we both ended up here and single about the same time. Started dating again. And we very quickly --

EB: And your parents played no role in that? "Hey, so-and-so is up here?"

AS: No, they actually did not. They did not. We knew. We had been in touch all those years.

EB: You had.

AS: Right. Yeah, we had remained in contact.

EB: It was fate, as they say sometimes.

AS: It was fate. It was.

EB: That's beautiful. And you have the little seven-year-old son now.

AS: That's right. Wonderful Ethan.

EB: Ethan. Now you said that your grandparents were probably Orthodox –

AS: Right.

EB: – by your description. But your parents were culturally identified as Jews but not particularly religious. In your upbringing, did you ever go to synagogue?

AS: We were entirely unaffiliated. So I had no Jewish education. The only time I ever attended synagogue was when a friend was being bar or bat mitzvahed or if I was invited to attend with a relative or with a friend for High Holidays. But that was very unusual.

EB: So, no Hebrew school.

AS: No Hebrew school.

EB: Jewish camps.

AS: Jewish camps, yes.

EB: Really.

AS: Yes, when I came to junior high school, most of the good – most of the decent summer camps in the area, the day camps, were Jewish.

EB: I'm going to let his thing be quiet.

AS: Yes, I can sit.

EB: So the Jewish camps in your area, you were saying – the camps in your area were Jewish.

AS: The day camps. Most of the day camps. So I attended Jewish day camp. I never went to sleepaway camp. But day camp was Jewish. As high school, late junior high school, came around, I became involved in B'nai B'rith. I became very involved. That was not through my parents, obviously. In fact, I'm not sure how I found out about it. I was somewhat disgruntled with the social activities at the public school, our particular high school, being very wealthy in general. I felt uncomfortable in the social situation. There were a number of things. It was, unfortunately a rather snobby kind of place. But I got very involved in B'nai B'rith, primarily as a social activity. But I became more and more involved, and I learned most of what I know about holidays and Judaism from being part of B'nai B'rith and planning Shabbat services and --

EB: Wow. What a switch. You didn't go to Hebrew school, and here –

AS: Right, no, I didn't.

EB: – you were planning services in high school.

AS: That's right. I learned about them for a couple of years, and then I started planning and –

EB: Now, when you went to MIT, was there any continuation with Hillel?

AS: I would go to High Holiday services at Hillel. I attended a couple of functions, but I wasn't very heavily involved.

EB: Interesting how you just from yourself, you found this. Did anybody get bar mitzvahed in your family? Bat mitzvahed?

AS: My brother did. When my brother turned twelve, my father decided that not only should my brother be bar mitzvahed, but that he should be bar mitzvahed Orthodox. He did that for the rest of the family out of respect for the relatives. My brother had a year of tutoring and had an Orthodox bar mitzvah. That was it. A crash course for my brother.

EB: How did he feel about it? Was he on board?

AS: He was willing to do it. He wasn't excited about it, but he was willing to do it.

EB: Well, seems reasonable. When you see your son, you think a few years from now, you see it's a very young age to find a deep meaning in it today. Any Zionism in your family? Visits to Israel? Or was that just out of the question?

AS: No, we have no relatives in Israel.

EB: No relatives.

AS: We did not travel because of the financial situation. But no, it was not a big part of my life until I became older. Not something I was very aware of.

EB: And now that you are a Jewish adult, how does Judaism play in your life today?

AS: It's become much more important to me over time. My husband and I started doing the Shabbat thing on Friday nights even before my son was born, and then it became more important after my son was born. But my husband was born in Israel. He speaks Hebrew. And he was a secular Israeli.

EB: But is he a citizen?

AS: And he's a citizen. He was there until he was seven. And then, even after he moved to the US, he would continue to go back to Israel in the summers. So I have picked up a fair amount of Hebrew through him and his mother. We did affiliate with a

synagogue.  We joined a temple in Newton and then Temple Israel when we came to Sharon.  Over time, we've gotten to know the rabbis and the cantor, and I started taking my first Torah study group this year.  Study course, I guess you would call it.  So I've become much more – Judaism has become a much more important part of my life as I've gotten older.

EB:  So your relationship to Judaism has really changed through time.

AS:  Absolutely.

EB:  Fascinating.  It's wonderful to hear the story.  We're going to be getting into your activism in a moment, but first I want to maybe bridge -- especially because you're studying Judaism more now -- do you see your activism as being related to Jewish values, however you understand --

AS:  Absolutely.  Absolutely.  I've never thought of myself as an activist, I have to say first.

EB:  Labeling is very difficult.  And there is some of that in this interview.  But the world sees you --

AS:  I think the word that I would use is advocate.

EB:  Advocate.

AS:  Over time, I've always defined myself more as an advocate than as an activist.  But yes, Jewish values play a very important part.  And I think the two key values are education and compassion.  Caring, loving, giving, which were even though my family was not religious, those things were extremely important.  So loving and care and education have always played roles.  And trying to tie those together in medicine was the perfect way to do that.

EB: Were there any role models, Jewish or otherwise, for that?

AS: Well, a lot of my friends – because of where we lived, a lot of my friends' parents were physicians, so I knew a lot of adult physicians. But I really never had a role model, and I still can't say that I have a role model. And that's been one of the more frustrating parts of my career. I'm always searching for a role model. I have mentors who have been wonderful, but none of them are really what I am, and so I've really defined myself over time, but I wish I'd had more of that. I would strongly encourage young women to look early for those role models and follow them.

EB: So, you're a trailblazer. You will be the role model. That's pretty intense.

AS: Yeah, my mother never went to college – or she went to college after I did, I should say. I was the first woman in my family to attend college. And I went to MIT, of all places. I've always -- I've never followed a previously laid trail, I guess that's fair to say.

EB: First in your family to go to college, maybe first in your family to delve into Torah study. It's absolutely fascinating.

AS: First, in medicine. Right, I did not follow particular role models, it's true.

EB: I think that separates you from the crowd in a beautiful way. I really do.

AS: I was certainly encouraged by my family to do all of those things. But there was nothing to imitate.

EB: And being a trailblazer apparently wasn't so easy then.

AS: I never thought of it as a hard thing. I always wanted to – these were all things that I really wanted to do and really interested me.

EB: They were just in there.

AS: They were. Right. They were very important to me. They were always inside. It never seemed like a horrible challenge, and I think that's to my parents' credit largely, that no matter what I wanted to do, they wanted the most and the best for me.

EB: I'm going to move right into womanhood. I'm wondering – first generation to go to college, but also first female then to go to college, right? How has being female affected your path toward advocacy or activism?

AS: That's a harder question. Always being female, never looking at it from the other way, I never felt discriminated against or treated any less than anyone else because I was a woman. The only thing I felt was the lack of role models or mentors who were women. But that wasn't to the discredit of my male mentors or would-be models. They were always perfectly nice. I think, though, that if I had had a personal mentor that was a woman, I might have proceeded faster, or with a stronger sense of direction, rather than trying to find my own way. No, but I do think certainly being compassionate and having a caring side is more of a woman – not all, but more of a woman's thing than a man's thing. And that's always been such an important part of my career and my advocacy that it's hard for me to imagine doing what I've done as a man and feeling – to feel it as a man but without that kind of motherly compassion almost.

EB: Is that because so many of the women, the sick women you deal with – I understand from reading about what you do – they were infected with HIV through having sex with older men, usually to get drug or drug money? Has that put you in a very parental role or motherly role, nurturing role toward those women?

AS: I've worked with men and women with HIV throughout. The research that I did – some of the research that I did focused on those relationships between men and women. But I've really – all of my patients since the beginning of my work – and that includes even before HIV came around. Just my general medical work at the hospital involved people who are impoverished, many of them very – many of them homeless, many of

them addicted to drugs. Most of them, if you delve into it, have horribly abusive backgrounds. Women working for men, supporting themselves through prostitution. Gay men working on the streets. Just one after the other. The stories are horrible. They almost all responded so incredibly positively to someone who genuinely cared about them. People would say to me, "No one has ever shown that they cared about me." To imagine that. They didn't imagine that. They didn't have that ever in their lives. That they would feel that first in their lives from a doctor at a time when they have a fatal illness is just a horrible thing. So I'm not saying men can't do the job. Of course, they can, and they do. I'm just saying that I think that they responded – my patients have always responded to that mothering attitude that I come from.

EB: Where did this come from in you, this ability, this gift?

AS: I think a lot of women have it. I don't feel like it's unique. But my mother was certainly the role model for that. And as I mentioned having someone in my family who also needed extra attention and extra care, I had practice with that from when I was very young.

EB: You said your mother was also a role model, and I'm wondering -- for the caring and compassion -- how did you learn that from her? What did she display?

AS: She was tremendously open about how she felt and about hearing how we felt. She was an unbelievable listener. And no matter what was going on, she always made time to spend with each of us, to hear from each of us. Friends in high school would call her to talk to her because they just knew she was a good listener, she was a good talker, interested in what people were doing. I can't give you specific examples, but that was around me all the time, that warmth and caring.

EB: Obviously, she also didn't judge people because, obviously, you do not judge people.

AS: That's right. That's right. She taught me a lot of openness about people. My father did too. My father was a very funny, entertaining, irreverent man in a way. He would make a lot of jokes that would seem completely out of line. But his heart was incredibly warm. And he was just a wonderful warm open man. So yes, I always felt that people were equal, deserved equal care regardless of anything in their lives, and deserving of love.

EB: Obviously, you lost your dad.

AS: My dad died thirteen years ago. And my mom just died last month. Yeah.

EB: I'm so sorry.

AS: Thank you.

EB: Pretty young to lose them both.

AS: Yeah.

EB: We've been going through that in my family, so I totally understand. It's hard to keep switching gears because this is so personal, some of the stuff you're saying. But we will push forward.

AS: That's fine. That's fine.

EB: Did you ever feel that the Women's Movement had an impact on your choices?

AS: I wasn't aware of the Women's Movement directly impacting me. But it was certainly – there's no question that the evolution in opportunities for women made it possible. I think it would have been a much harder struggle if MIT wasn't starting to look at women more openly. Although they'd had women – MIT has a history of having women from a relatively early time. It was around the time that women were becoming more numerous

there.  Not yet, but they were working on it.

EB:  Coming as faculty?  Or just as students, you mean?

AS:  Just as students.  The faculty happened later.  In fact, that was just in the news, I believe that was last year or the year before, inequity at MIT.  So, it's still around.  There's still inequity where I work.  But part of it is choice also.  I spend part of the time with my son.  And it has not been as important to me to climb to a job of full professor and work seventy hours a week in order to do that as it is for me to be there and do what I want to do and still have some time of my own for my family.

EB:  Absolutely.  So you do find that in the traditional woman's role and your work, there's a time when choices must be made.

AS:  Absolutely.

EB:  And you have made a choice.

AS:  I have.

EB:  You just said you have made the choice to not sacrifice the family life for the career.

AS:  That's right.  Right.  And until I had a child, I spent as much time as I possibly could working toward my career and my advocacy.  But when my son was born, things change.  Things change.  And I did decide – I would not have been able to make those decisions consciously in advance.  But when necessity rings, you do what you need to do.

EB:  I've often heard people say maybe I just wasn't as ambitious as I thought I was until I had that child.  It does put a new spin on that.

AS:  It absolutely does.  It certainly does.

EB: Did anyone in your family have these expectations for you to sacrifice career for family, or is it pretty much your –?

AS: No, I think it was my choosing. I'm happy with the arrangement that I've worked out, and my bosses along the way have all been very understanding. I think now men know that women often make these choices, and they're much more accommodating. So it was not a struggle. It has not been a struggle for me because of the people that I've worked with.

EB: That is wonderful.

AS: I've been very fortunate. Yeah.

EB: Right. You didn't feel any hostility or resentment, yeah.

AS: No, no. It's only come from inside. I would like to be doing more, but it's just not possible to do more with a limited number of hours in each day.

EB: Explain to me exactly where you -- I feel reading your dossier that you've broken some new ground for women physicians, for public health, for the population you serve. Could you comment on that?

AS: Yeah, I don't look at it quite that way, but –

EB: That's okay. I'd like to hear how you look at it.

AS: I was at Boston City Hospital when the AIDS epidemic hit, and it hit those populations that I was interested in serving already. I was already there. It was a new disease, a horrible disease, fascinating from a scientific perspective, but really struck those people who had the least ability to deal with it. So I got involved at a very early time in the history of HIV in Boston trying to set up all sorts of things to make it more palatable, if that -- so to speak. I would say probably the most important ground that I

broke, I developed an AIDS 101 curriculum to teach the house staff what AIDS was, what it meant, how to care for people. And that included the compassion side, how to tell people about death, life expectancy following their illness, that there were things we could do, that there were things we couldn't do. These were not things that residents and interns or even attendings were very accustomed to doing unless they were in oncology. Was not a common thing for house staff to be confronted by. So I was involved in that. I helped develop the first HIV testing protocol, because at the time the HIV test came out there were no guidelines for how to tell people what a test meant, what a test didn't mean. If it was positive did that mean that they were definitely positive or not? Because the tests were much cruder then. And how to relay that information. So I wrote protocols and taught it to the house staff. But when people would come in with AIDS, they were much sicker than they are now and would frequently die very very quickly. I would personally go and meet each one of them. And at least they felt that there was someone who knew something about their illness and was involved. I got very personally involved in it for several years. That was the eye level. So those were some of the biggest things that I did. I did also some work looking at age discrepancies between men and women and found that the women – women are much younger than men, which sort of suggests – it's sort of been suggested before, but at the youngest ages, under twenty in particular, the AIDS epidemic predominantly hit women, girls. And people had been thinking of AIDS as a men's epidemic, and drug users, but even through heterosexual spread there would be a couple of women prostitutes, and then almost everyone else is men. But that wasn't true. Under twenty, it was a girls' epidemic. Most of them are quite liberated. I should say women. But under twenty, the vast majority were women or girls. And so they had to be – and were not drug users. They had to be receiving it through heterosexual contact with older men. This was, I think, my earliest contribution in terms of the literature, just trying to understand some of those interplays there and what young women needed to be watching for.

EB: How does all of that play in how you define yourself? That went a little internally. So, in terms of how you define yourself, you have your work, you have your self-definition. How does it come together, if you can? This is a tough question. These are very tough questions.

AS: Yeah, this is hard.

EB: But you're doing so beautifully.

AS: I'm a person who rises to the occasion. I think that if there is a need around me that I feel like I can do something about that, I will see it as my responsibility to accomplish that. I always wanted to be one of these people who traveled internationally and saved the third world, and I never did that. But I've done it on a different scale, on a closer scale.

EB: When they say think globally, act locally, you did that. That's exactly what you did.

AS: I've always really worked on a local level.

EB: People often talk about the third world inside the first world.

AS: Right. I think that most people don't realize just how severe things are right around us. And to live in that environment of Boston City Hospital and see how so many people are living, what they don't have, and how horrible their day-to-day lives can be, it is like traveling to a foreign country to walk into that hospital.

EB: I have contact with – and I can't remember her name – the doctor who's the rabbi's wife, the Failure to Thrive program there at Boston City, because she has a different last name, so when you're talking to me, I know. I was born in that hospital, my parents started as working class, very similar to yours.

AS: Yeah, there certainly are people there who are not in those dire situations. I love the idea that the hospital and I personally could provide and really try to provide good care and attention to people regardless of the fact that they had never known a day's true comfort and certainly inner comfort, inside love. To think that they could still get the kind of attention that they needed made me feel good. I didn't go far, but I did always choose the hospital that was the hardest, the field that was the most challenging. So I see myself in that way, and also I think the other way I define myself is as a person who cares a lot and tries to really show that compassion. I don't always do it with seriousness. Sometimes it's with -- there's a lot of humor in my day-to-day managings. But to let people know that I don't see myself as something above them or separate from them. That even though I'm more educated and live outside Boston City Hospital, I am one of them, and I can relate to them to some extent.

EB: And how open are they to that message that you bring?

AS: People open right up with almost – very little encouragement. It can be ten or fifteen minutes in an office, and they're unbelievably grateful because they're not the –

EB: So the fact that you're Jewish, white, etc., the barrier is just broken. You do it.

AS: Right. I wish more people did it. But they don't. Some do. But yeah, I've always seen that as an important part of my job. At home in my own personal and social life and family life as well as at work.

EB: How do you bring that to your home life? These breaking down barriers is what you're referring to?

AS: No, just the openness and letting people know that I care about them and I'm available to them.

EB: How do you explain your work to Ethan? How do you explain what you do at work?

AS: He knows that I work with people who have AIDS. And he doesn't know what AIDS is except he knows it's a very bad disease that needs a lot of treatment. He doesn't really understand enough yet, I think, to go into more details. He does understand a lot about poverty and people who don't have and people who are different and people who are emotionally challenged and people who are physically challenged. I think these concepts my husband and I have introduced to him from a very early age, and that we need to treat all people well and understand their shortcomings and not penalize them for it.

EB: You're trying to teach him to be open and not judge, just like you and your mom.

AS: Right.

EB: This is a good question. I love this question. What have been or continue to be the greatest challenges for you in this work?

AS: The challenges of HIV have changed tremendously so that the same people are still affected, the disease is not as challenging as it used to be, or it's not as life-threatening, and so the challenges have changed from illness, death and dying to ones of taking medications, overcoming personal barriers to taking medications, overcoming addiction and habits enough to be able to take those medications, to have safe sex even though you feel like you're doing fine and other people can't tell that you're ill. So they are less dire, they're more subtle. The challenges are more subtle. But they're different also. Now, there are nutritional – I've become very involved in the nutritional aspect in the last five years. And the nutritional aspects have changed. There used to be a problem with terrible weight loss and wasting away to death, and now the challenges involve disfiguring changes in body shape that upset people a lot, but they're not life-threatening.

EB: The disease or the medication?

AS: Well, we don't know, and it's probably an interplay between the two. So I'm trying to help figure that out from a research standpoint. But it's not the same degree of emotional trauma for the person and their family and their children as it used to be.

EB: I feel there's less stigma to the disease – this might not be true. Is it easier for you –? You don't have to deal so much with that issue with your patients? Or was that ever an issue for you and your patients?

AS: It's interesting. Well, it wasn't ever an issue between us, but certainly, all of my patients had terrible problems with stigma from the outside world. And those who were very involved in the gay community knew enough other people who were HIV-infected that they didn't necessarily suffer from the stigma as much. But people who were in the drug-using world or were heterosexual were always worried about the stigma. They still are, although because they don't look as bad and get sick and die as rapidly as they used to, it usually doesn't become a major issue. I think many people who have HIV now are working, look fine, many have families, and the outside world doesn't necessarily know. So the stigma is more internal and doesn't affect them as much on a day-to-day level. You were asking how it's changed, how challenges have changed. I have shifted more from patient-oriented work, which was so dire at the beginning, to research, even though I was doing research, away more from the basic epidemiologic social research more to the medical, the scientific research to try to understand what's going on with body shape changes and metabolism, again, because the death and dying and social issues are just not as pressing anymore.

EB: So not you could afford the luxury of dealing with the self-image of women with the body fat redistribution issue, but in a sense, you can afford the luxury of getting into these – they're hugely important, but death was at the back door, now isn't it?

AS: That's right, that's correct. That's correct.

EB: How has the medical, the Jewish, the neighborhood, the synagogue, and all the communities that you're in responded to your advocacy activism work?

AS: I'm not sure that my various worlds know that much about one another. I think that the people at the temple, including the rabbis and the cantor, know me quite well as a person, but I don't think they – we don't really discuss what I do at work that specifically. They know I'm a physician. They know I do HIV research in nutrition. But I don't make it a point to tell people, maybe because I don't see myself as an activist. I don't make it a point to tell my friends, my neighbors, my synagogue, [or] my son's school community what it is that I do professionally. Vice versa, at work a lot of the people, most of the people I work with are not Jewish, both patients and coworkers, and I don't think that they have a clear view of my involvement at home. They know a lot about Ethan and Ronenn. They know a lot about my family, all my various lives know a lot about my family. But I don't think that – there hasn't been a lot of interplay between them.

EB: Does this affect you one way or another?

AS: It just is. It just is. I feel very strongly Jewish and guided by being a person of the book, so to speak, an intellectual, that's not a very good word –

EB: Works for me.

AS: An academic. As well as having a strong feeling for tzedakah, for giving, so there's no question that my Judaism influences my work. But I don't go to work and just – no, I don't feel on a day-to-day basis or even a minute-to-minute basis that the temple community has much impact on my –

EB: I get it, I get it, I totally understand that myself. Now, on these challenges that you just talked about, are there any specific challenges that relate to your being a woman?

AS: Well, certainly, the body shape changes affect women tremendously, and the stigma affects women tremendously and in quite different ways. Women who want to raise children often can no longer have children, and who want to marry often can't marry, or can't form relationships in which marriage is a possibility. The issues are quite different. In fact, men and women who have HIV are so different, it's almost like two different worlds. Men who have HIV need to worry about their health, and they worry – they need to get to the doctor, and they need to take their medications, and they need to eat right, and that often means they either cook for themselves or the woman in the house cooks for them. A woman who has HIV often prioritizes everything before herself, her child, her family, her parents, her whoever, but she has to worry about whether or not she can have children, whether or not her kids can get to school on time, whether or not the child needs to go to the doctor or the dentist and often puts taking her own medications and treating her own illness far behind. Many more men become involved in research for that reason. They see their HIV as a priority so that they will become enrolled in studies. Whereas for women, that's way down on the priority list. And so yes, the relationships, their relationships with men, affect them much more. There is not a community like the gay men have a wonderful community of support that has a lot to do with why HIV [and] why the state of HIV therapy is where it is today. But women who are, for example, an African American woman who used to work the streets, is now trying to treat her illness and manage a relationship and raise a child or two children, she doesn't have a community that supports her, and she's really on her own. It's quite a different – it's a very different social illness.

EB: I never thought about that.

AS: It's entirely –

EB: Makes total sense. Going past the challenges, what has been most rewarding about the work you do?

AS: By far, the most rewarding is just seeing a smile on people's faces and their thankfulness for my attention, for what I'm doing, for being there. Just knowing that I've been able to make some difference to them inside, whether or not I've made a difference to them medically, just knowing that I've touched them.

EB: So obviously, your work has huge impacts on these people, the direct patients, and the recipients of the benefits of your research. Is there any way your contributions have affected others? Colleagues, for example.

AS: I've done a fair amount of work now in nutrition so I'm now a somewhat known voice in the field of nutrition. I don't do much speaking or attended a lot of conferences in the last year or so, just because of my illness. But I'm certainly known in the community, and I'm involved in quite a number of multi-center studies going on around the country so people often ask me for my opinion and appreciate my opinion.

EB: In other words, you're doing cutting-edge research, and you're sought after.

AS: I suppose yes.

EB: I'll write your resume for you if you need a new job.

AS: I suppose.

EB: Wow.

AS: I do a lot of – I run a reading center which reads two types of scans, DXA scans and CAT scans, that we use to analyze body composition, how much lean a person has and how much fat in different regions of the body. And now, with body shape changes, this has become a key issue. So I often will be running the reading program for a multi-center study around the country or even around the world where I will be the one person overseeing all of the DXA scans being read for that study and CAT –

EB: So women get their bodies read.

AS: That's right.

EB: So you are having some success getting women as research subjects.

AS: These are women and men. Some of the studies focus more on women and some more on men. But all of them, yes. Yes, there are some women involved – young women, older women. I think the field is trying to cover all grounds and learn about all people. We're trying to figure out what, for example, medications do in changing body shape. But we really have to look at that quite separately in women than in men because we start with such different shapes and different --

EB: And this is something that if I looked at a woman, I'd say her body looks odd? I would really notice it from the outside?

AS: Well, she would look different than you, but there are other people in our society who are not HIV-positive who will look like her also. So you wouldn't necessarily stop and say what is wrong with that person. You would just -- you might notice though, that she has a large belly or that she has a large hump on the back of her neck. Even though her face is quite thin or her legs or her buttocks are very, very thin.

EB: That is very painful, I'm sure.

AS: Especially for someone who had a nice figure before [and] was very proud of their body. And there are some of the things that we incur with aging, but to a more extreme extent at a much younger age.

EB: Of course. It's a wearing illness.

AS: Right, exactly.

EB: I get it. I had Graves' disease. My eyes were -- I looked bizarre.

AS: Oh. Yeah, you don't want anyone to be able to see. Don't want to be wearing --

EB: Absolutely. It would shock you to know that I had a stranger, a doctor, come up to me and say you must have Graves' disease, in the middle of a bank.

AS: It wouldn't shock me.

EB: Would you ever do such a thing?

AS: It wouldn't shock me. I frequently see – because I'm looking, I'll frequently see things –

EB: You will see it, but you –

AS: – and I rarely say anything.

EB: How odd is that?

AS: No, that's a little out of line.

EB: How has your life changed as a result of your advocacy activism work?

AS: That's a good question. Because I think that this interview process is actually making me think about that and synthesize that in a way that I never have before.

EB: It's very tough, though, I know.

AS: I had always hoped to do more. I always expected more of myself. I wanted to do more research, really break the field open, discover the cure, figure out the whole problem. I've always been a little disappointed in my scientific success. And I've blamed that in part on my lack of – we talked about before – mentorship. Women as mentors.

Not really knowing where my career was going at any one point, taking longer to get there, making some choices that maybe weren't the best to do. But feeling good about what I'm doing for people as individuals makes me feel good about what I've done. I think that's the biggest thing that it does for me. It makes me feel that I've been successful, very successful, on some level, to people, even though maybe I didn't accomplish this huge ideal that I had set for myself a long long time ago.

EB: But the personal connections with the patients have compensated for this little bit of a sense of disappointment in the actual medical research breakthrough dream?

AS: The personal connections, yes. I think that's true.

EB: Now you said you wished more people were advocates and activists. What advice do you have for people who are interested in becoming advocates or activists? And they need a push? What advice might you have to push these people?

AS: I don't know. I've thought about this a lot. There are programs to educate doctors to be more compassionate human beings. Certainly, the Schwartz Center is very involved in providing compassion and caring, teaching physicians and care providers in the field of oncology. But to a certain extent, it comes from inside. And I always wonder how much you can teach this. You can tell people not to parade a naked patient down the hall and to make sure that they have a gown on and the curtains are closed. But to really take the time to sit and talk and listen is what I feel has made it meaningful for me, and I don't know how you get people to do that, especially given the environment of medicine now where there is this real need to see huge numbers of people in a short period of time. Have good mothers, that would be my advice. Have a good mother. To mothers, I would say teach that to your children so that they grow up with from a very early age caring and taking the time to care.

EB: What if we approach it from the other side? What if you have a very open and caring person who's similar to you? What advice do you have for them to become a medical public health patient advocate? So they have the emotional part, they have the great mothers, how about the other part? How do they find that path?

AS: The first thing would be as early as you can to get a good mentor. A good woman mentor. And to discuss the things that she knows she wants to do and that the mentor can provide. I think even when someone is in medical school and they don't even know which field they're going into to, have someone that can say, "Well, I'd rather be doing – I'd eventually like to do more research, what should I be thinking of in terms of my next step, to really be planning ahead?" To study public health, I found my master's in public health invaluable. Going back to school at a later time was wonderful for me. I knew exactly what I was going for. I was going because I wanted to do research. You see the whole family here. I was going because I really wanted to do research. And I could see that some of the research around me was just not good and was a little off-target in a variety of ways, and I felt that if I was going to be good that I really needed to do it from the bottom up. So I went to get my degree so that I could learn to do a lot of this study design and analysis for myself. Or if someone else was doing it for me to be able to critically look at it and say this is good, this is the way we should do it. I would say never compromise on quality, the level of quality that you expect. If you want something to be done well, do it well and expect others to do it well, too, and teach them what they need. And I also would absolutely encourage women to get involved in mathematics, science, if they like it [and] not to feel held back because they're women. There's plenty of opportunity now in understanding in terms of accommodating schedules for family later in life. So I think to be involved in public health advocacy to some extent you do need that kind of education. You need a sense of –

EB: And the medical school and the public health are really that vastly different places?

AS: They overlap, but they each lack what the other provides in terms of my own career. Medical school did not provide me with enough statistics or enough ethical – public health ethics to really have a good sense of the whole field. Getting my master's in public health really provided me with a different perspective on how to do research and how to approach public health problems that I didn't have after being a resident. It's really a different way of asking questions and solving and resolving the answers.

EB: You had to then bring a lot together to accomplish all this, that personal part you talked about, that public health perspective, and then the nuts and bolts medical.

AS: I never really thought of having to pull them together. They were just all different aspects of what I wanted to do.

EB: It unfolded for you naturally.

AS: Right.

EB: It's interesting to hear that. Yeah. Have you been involved in any other causes? It's a funny word, but I think it might work. You're not as soft as the other one.

AS: Over the years, I've certainly done small things. Even when I was in B'nai B'rith, I had fundraisers for Israel, and there have certainly been times when I have. In the last year, I've become very involved with an organization called the Treehouse Foundation, and if you don't know what the Treehouse Foundation is, I wish the whole world knew what the Treehouse Foundation is. It's a program – it's a new community, it's a group of people trying to organize a community from the ground up for getting kids out of the foster care system into permanent residence

EB: With families? Or what do you mean by residence?

AS: With families. So that it involves adoptive parents, grandparents, a large network of the elderly, and kids being adopted out of foster care. And there's a successful model in Illinois already. It's now nine years running. And they're doing wonderful wonderful things, and now in Massachusetts, we're trying to be the second place that brings kids out of the foster care system.

EB: And older parents are okay for this.

AS: Well, they're adoptive parents, who are age-appropriate parents, and then there also is a whole community of seniors that will live in the same community that will provide tutoring and stability, and so it provides meaning for the elderly, gives them a new cause in life, and it provides –

EB: Yeah, pulls it together. Does this involve children that have been in and out, in and out, they're like fourteen, fifteen now? Or they could be six, seven, eight?

AS: They're all different ages, all different ages in the foster care system.

EB: Just get them out of the system.

AS: Right. There are ten thousand kids in Massachusetts who are now in foster care. A good third of them will never be adopted. And many adoptions fail after foster care system, and these kids bounce in and out of the foster care system all the time. So the point is –

EB: How did you get involved in that?

AS: We were planning to adopt a child when I got sick. And we had to give up on the adoption. And one of my friends who knew that I was interested in the field sent me a brochure about this, and I contacted the director, and I've been working with her.

EB: You could have dropped the whole thing, right? You have a child, Treehouse, whatever, but you didn't. How come?

AS: Well, again, the child that we – we were going to be adopting from Russia, so it was a whole different system. But again, it's the same community. These are kids who are often from abusive families, they have no money, their families have often been in drug-using situations. I have some familiarity with the background that these kids come from. And I know that they don't have homes and they won't have homes probably ever, and if they do, they won't be very supportive homes. I heard about this, the idea that there was maybe a way to totally change their lives for permanent and allow them to not become addicts and abusees but to become productive happy members of society just struck me as such a wonderful thing to be able to do.

EB: You are almost thinking about preventative measures.

AS: It is. They've already had a lot of trauma. They've already experienced a lot of trauma but the idea that –

EB: Better now than later in terms of preventative – and also, you had talked earlier about feeling a sense of responsibility, feeling – so when this Treehouse thing comes up and you tie it into your other work, it was what else would I do.

AS: Right, exactly.

EB: I can picture you saying that, what else would I do, that's who I am.

AS: These are kids who need something. They're there, so they're in great need. They're there. There's something that I can do. It just seems very natural. When I saw adults who had already been so traumatized and messed up to the point that they got AIDS, I would think, "How could I change these people's lives?" I can't. There's no way to change someone's life. You can attempt to get them out of addiction, but you can't –

they're not people who can now pick up and feel good about going to college and getting educated, or even getting a high school – or learning to read in some situations, or they're new immigrants, and they don't speak English. I speak Spanish, so I do a lot of my work in Spanish too. To teach them to – it's just not possible. The way to do that is to start with healthy childhoods. A lot of foster care kids end up in prison before they're adults, and to think that maybe there is a way to turn their lives around now just struck me as perhaps the only way to prevent what I've seen later in adulthood.

EB: That's a real vision, absolutely. If you have a brochure --

AS: I do.

EB: I would love to see that.

AS: I have lots of material.

EB: Do you think of yourself as political?

AS: Not really. I am always aware of what's going on in politics. I read the papers. I do talk about it. I'm a diehard Democrat, you can tell by the way I'm talking that I would be. I always vote. I impress upon my son the importance of voting. But I don't get very involved in the political process.

EB: And somehow, I'm not surprised.

AS: Yeah, it's not really my –

EB: You go for the personal touch and the local level.

AS: Right. That involves a kind of salesmanship that I don't see as part of myself.

EB: We're just about winding down. I'm wondering is there anything we haven't covered that you would like to tell me about.

AS: I don't know. I didn't mention – you asked if I had been to Israel as a child or – I didn't mention that as an adult, I went to Israel a couple of times, and I went once, I wanted to – I went to Israel and I worked there at Machon Weizmann, the Weizmann Institute. But I mostly just needed a change of environment. I didn't expect Israel to mean much to me. When I got there, it was tremendously meaningful, and I don't – now, I have my whole husband's family there, so we have a connection. But I guess most Jewish people these days do eventually make it to Israel. But I certainly recommend it when it's safe enough to travel.

EB: When did you go?

AS: I went just out of college. Actually, between my junior and senior years of college. I lived there and toured around. And it was an unbelievable experience to really feel that – to really see how far back our history goes and that it's living history there, that people still – that every child knows the things that are at the roots of our cultural and religious history, things that we don't have a close feeling for here. So I didn't mention that. I'm not sure how that ties in exactly.

EB: I'm really glad you mentioned that. You wanted to say it.

AS: It meant something to me then and has always stuck with me. What else? I'll also say something about women's role in the synagogue and Jewish religion maybe. I think largely because we grew up unaffiliated, I never felt very comfortable in a synagogue. It was not my own history; it was not my own tradition. And my mother and even my grandmother, maybe my father to some extent, a lot of people blamed a lot of the hardship in my family on the Jewish religion and didn't approve of the organized religion. They went through a lot of hard times. And I think now, for me, it's certainly been worth – it took a long time to get over that discomfort of being there. And the idea that it's okay to be connected, just be okay to walk in and feel that you want to be part of that, but that's become such a big part now for me, such a big part of me, that I don't think that

Judaism was to blame for my grandmother's hard life or for some of the things that happened to my mother when she was a child, that the whole social and economic circumstances were a mess. And that Judaism was a scapegoat to some extent. But to try to separate those things out was too hard for them.

EB: And it took your generation or you yourself, maybe not just anyone of your generation obviously but –

AS: Yeah, I guess I give advice to – but you can't really – people have to do it as they feel comfortable.

EB: But your advice would be to take a baby step toward that organized synagogue setup.

AS: Yeah, or even if it's not organized, to find – for people who feel like they're estranged from it, to find some baby step that they want to do or that they want to find out about it, that they want to explore, and do first, and then see how it feels. There's been a lot of ups and downs over the past century between Judaism and the outside world, and to feel comfortable doing whatever it is that you –

EB: But it's interesting that your parents blamed Judaism and not – maybe other people would say it's the antisemites, it's the Christians. They blamed the religion.

AS: Well, they also felt that there was a lot of antisemitism around, and they blamed antisemitism too. I'm not sure that it was easy to – that they even separated in their minds how much was just the organized religion of Judaism or the outside perspective of it. My mother blamed my grandmother's horrible marriage on Judaism because she felt that Judaism prevented my grandmother from getting a divorce and that that made their lives much, much harder. But no one got divorced then; it wasn't just Judaism. Yes, Judaism played a role in my grandmother's life, and so she said well – but no one got divorced anyway; it was just not a common thing to do. Even in my mother's generation,

not that many people got divorced.  And my mother would be upset because we didn't have money and the temples would keep – or the synagogues would keep calling for money – "Please join.  Please pay this much money."  And my mother just thought that they were money mongers, that all they wanted to do was make money, make money, make money, and we again lived in a social, financially secure place where everyone who was – most people who were Jewish had a lot of money, and we did not feel part of that, and so she connected Judaism with this love of money, attachment to money.  And just there is a connection there, but again from my epidemiology background, I would see those things are both present, but it doesn't mean that Judaism caused people to make a lot of money or to –

EB:  Well, that was actually some really good things to add at the end.  I know your son is due, so I feel like I should take your picture.  I'm going to turn this off.  We are all set.  I'm just so pleased at how this went.

[END OF INTERVIEW]