Judith Hirschfield-Bartek Transcript

Judith Hirshfield-Bartek: -- in the outside world. So, you know, and I had a very happy childhood. And we went to temple on the high holy days and sat in the third row because my grandfather was a founding member. And I went to Hebrew school. I had confirmation, we didn't have bat mitzvah in those days where I grew up, so you had confirmation with ten or 12 other girls, and that was pretty much it.

Judith Rosenbaum: Did you have any siblings?

JHB: I have two older brothers, and they were bar mitzvahed. And my mother was a pretty outspoken person, in a positive sense, not in a negative sense, and certainly wasn't afraid to stand up for her beliefs on different issues. She was very smart. I always told her she was ahead of her time, pretty worldly, and not an at-home housemother. She worked, ran a business.

JR: What kind of business?

JHB: She had a clothing business, actually. You know, I sort of remember her being around, I don't remember her feeling that she wasn't around, but I also knew that she worked really hard too.

JR: What kind of work was your father in?

JHB: My father was also in the clothing business. So my mother ran one store and my father ran the other store.

JR: And were your parents both born here?



JHB: Parents were both born here. My mother was born four miles from where we lived, so she grew up in the same area, grandparents. My grandfather came over from Germany when he was three years old by himself, or with his older sister, who was about nine or ten at the time, on a boat. And my grandmother, she was born in Argentina, and then came to Asbury Park, New Jersey, which is this little, next town over from where we lived, from Deal. And she came over I guess in the early 1900s with her parents, who were both Russian, Russian Jews. My great-grandfather was drafted and sort of bought his way out of the draft with vodka, and then they escaped from Russia. In those days, South America, the land you settled on in Argentina became your land, so they settled and then brought over other family that are still down in Argentina. But my great-grandmother had this vision of you have to be in the United States to really make it, so they came in the late 1800s.

JR: And did your grandparents live, were they alive when you were growing up?

JHB: My grandmother on my father's side was alive and my grandparents on my mother's side were alive. And then I was young, actually, when my grandfather died, so it's really my two grandmothers that I remember the most.

JR: And were they in the area?

JHB: Yup. My maternal grandmother grew up down the street, and my paternal grandmother was four miles away in the next town. Very much a part of my life, both of them. And very, very different. My grandmother on my father's side was very social action oriented. Grew up in New York City during the time of the Depression, started several what they called Aid Organizations for people who had no money, no shelter, no food. Actually, one of them still exists today, called the Harriet Aid Society out of New York City. My grandmother on my mother's side was pretty cold. Also a business woman, not a lot of warmth to her. Probably my passion for social justice probably came from my grandmother on my father's side.



JR: Was that something that she talked about (inaudible)?

JHB: You know, I don't think she talked about it as much as she just lived it, and it was just sort of seeing her. And she was a very poor woman, but she always had enough, little bit of money, and a lot of time to, whether it was working at a hospital for children or working for the Harriet Aid Society, whatever it was, Hadassah, whatever it was, she always had time to be involved, very much involved.

JR: And were your parents active in the community that you were growing up in?

JHB: I think they were active in the Jewish community and the temple, but not beyond the temple. Everything sort of, the central part of our social life was really out of the temple.

JR: And you said you belonged to a Conservative --

JHB: Conservative temple, mm hmm.

JR: And so how did you celebrate holidays, like (inaudible) Shabbat or something?

JHB: Because they were in business, they actually worked many Friday nights, and if they could not -- well, what we tried to do was we actually tried to celebrate Shabbat on Thursday evenings. And so we would all get together, our grandparents, and my parents, and our family, and be together on Thursday evenings. And then Friday evenings most of the time they worked. It was a rare occasion they would be off.

JR: And were you and your brothers involved in the temple as well, like through youth group or something?

JHB: I was involved in the youth group a little bit, my brothers were not involved at all. But I can't say we really had very active youth group either. I sort of remember USY a little bit, but not a very active group.



JR: And did you go to any, like, Jewish summer camp or any of those kinds of things?

JHB: No. I don't really remember having Jewish summer camps around where we lived. And part of that may have been because we were on the ocean, and who went to camp in the summer when you could go to the beach every single day? But I don't recall really Jewish summer camps at all. And I was trying to think.

JR: Was your family involved in Israel or any kind of Zionist kinds of organizations?

JHB: You know, raising money for Israel, Israeli bonds, those kinds of, you know, being aware of -- I can remember actually my parents who were the first in the area that I remember in the early '60s actually going to Israel on a, it was a pleasure trip, it wasn't a work trip. But I do remember them going and coming back very excited, and the land of milk and honey, and just pretty excited about what they saw. And this was before actually the Jerusalem War, the wars. And that's, very little memories of my childhood otherwise.

JR: How would you say that your relationship to Judaism has changed over time?

JHB: Well, it's kind of interesting because actually my husband is not Jewish, and he grew up Catholic, although he's not a practicing Catholic and goes to temple, and has taken Hebrew, and participates in all the Jewish holidays. So I think that for me, we belong to a reform temple, and I think for me I've learned so much more after I got married, of course had children, and wanted to learn so much more about Judaism and this whole idea of social action, which is the part that I love about reform Judaism, is the whole piece of being involved in the community. So I think that for me the big change has been from knowing that I was Jewish, but really only maybe feeling it two or three times a year, versus the pleasure of having children, wanting them to learn all about Judaism, and for them to sort of participate or being conscious of a world around them that's part of a bigger picture, bigger community. Sort of trying to be aware of that every

single day in what we do.

JR: So what are the kinds of ways that you try to do that?

JHB: Well, I'm involved in the Jewish Community Relations Council, which in Boston is the social justice piece of the Combined Jewish Philanthropies. I'm involved in their public policy committee, and we get involved in not just Jewish issues, but broader issues: housing, mentally ill, immigrant issues, education issues, those kinds of things, and trying to work with our legislators in ensuring that legislation is passed in those specific areas to help individuals. Even at our kids bar and bat mitzvahs, rather than have centerpieces -- and it was a like a novel idea at that time -- we, for Matt's bar mitzvah, I put together these big baskets of food for Passover and we delivered them to Family Table, instead of having flowers or the glitz and glitter nonsense that people get into. And for Mara's we did stuffed animals that went to the Ronald McDonald House. And, you know, what we did by having a little card on the table that said this is what we're doing instead of flowers, or instead of some ridiculous centerpiece, other people started to do the same thing, and said, oh this is a great idea. So that was sort of one way to start to get our kids to think about being involved. And the temple is really great at, in becoming a bar or bat mitzvah, there are certain things that you need to do, and a lot of it is community service, and I think that's a great way to help teach kids about, not only how fortunate we all are with what we have, but that you always have to remember that you've got to give back.

JR: And are your kids involved in that kind of stuff as well (inaudible)?

JHB: Yes. Actually, Matthew is very involved, and he was very involved with the youth group in temple, and one of the officers, and continued all the way through high school, and going to Hebrew High. And is involved with Red Cross, and involved with a lot of different community service programs, organizing them at his high school. And Mara is involved. She's getting there (laughter). But even this summer actually she's in a



community service program in Costa Rica, and living in a village, and building a community kitchen for the village, and working with kids, teaching them English. And, you know, just think it's great that she's, at 15, sort of courageous enough to go do that in a group where she didn't even know who the kids were.

JR: And what temple is it that you belong to?

JHB: Shalom, in Newton. It's a wonderful temple.

JR: Yeah, I've heard good things about it.

JHB: Yeah, it's really terrific. And we have actually a new rabbi and assistant rabbi over the last couple of years, and they're just absolutely terrific, I adore them both.

JR: And so how would you connect your sort of sense of Jewish social justice to your own activism?

JHB: Well, I'm not sure what came first, the chicken or the egg, because I think I was really involved with breast cancer activism before I really thought about that as sort of Jewish social activism. But back in the early 1990s, I worked for a woman who is a breast cancer activist, Susan Love, and she was part of developing a national organization called the National Breast Cancer Coalition. And at the time the intent of the group was to focus energy around breast cancer as an issue, and that we needed much more in terms of research than the unfair share of the dollar that we were getting -- not just breast cancer, but women's health in general. And sort of became involved that way, and then that activism and the skills I learned in being involved in the lobbying, and rallying individuals and women, and all those kinds of things sort of tied over to, in Boston we started a group called the Jewish Coalition of Breast Cancer. And actually that was started by a couple women before I even got involved. And it was started around the issue of genetic testing and Ashkenazi Jews, and there were several breast cancer genes identified to be more prevalent in Ashkenazi Jews. And there were several of us



that were actually fearful of how this information could be misused, and really in Boston we were the first and only group in the country to say, we don't want to stop the research, but we want women to be educated before they march in a line to participate in the research. And we also wanted public policy safeguards to protect not just Jewish women but all individuals against genetic discrimination, because we're sort of at a cutting edge where, we're sort of at a crossroads in society. I mean, stem cell research, and it goes on, and on, and on, and then probably the issues will continue, and our feeling was unless there's some concerted vision about public policy safeguards that may need to be in place, this technology could be either used to help personkind or cause havoc for personkind. So that was sort of, I don't know if I've exactly answered your question, but it was sort of how it all just evolved. It wasn't anything that I thought about in terms of, oh, this is a Jewish issue and I want to be involved, it just seemed natural to sort of take those skills that I had and carry it over to the Jewish Women's Coalition.

JR: So how was it that you got involved in general in breast cancer as sort of a political issue? Actually, one question I'd ask before that is whether you had been involved in sort of women's issues before you got involved in this particular --

JHB: I really, I can't say I was really involved in too much. I mean, I really quite honestly was not so uninvolved with the Right to Choose issue -- although funny, because I am definitely a child of the, you know, I was a teenager of the '60s and '70s. And I was involved in Vietnam War, into Vietnam War activities, but not as much as many of my other friends. Maybe I didn't have confidence, I don't know what it was, but I was someone that sort of took a backseat at that time. So --

JR: Were your parents political people?

JHB: Totally not. Totally apolitical. And that may have been part of the reason why that I didn't become probably too involved. But can't use that as all my excuses. (laughter) So I think actually, well, two-fold. One is my mother did die from breast cancer, and so,



but I was already involved as a nurse, an oncology nurse at the time that my mother was diagnosed. But I think again it was one of those things that evolved in life. I happened to be working for Susan Love, she happened to be working on putting together this coalition with other women activists across the country, she happened to say to me, you know, why don't you become involved in this? I think you'd really get a lot out of it and have a lot to give. And I have to say honestly, though, I never really thought about the family connection until I was in Israel. And I went over on a nursing fellowship to work at Hadassah Medical Organization, in Ein Kerem, as a breast care nurse specialist, and working with my counterpart at HMO. And this was sort of modeling for her the program I had set up here, at Beth Israel Deaconess. And I was giving a lecture on women, feminism, and breast cancer and the political arena, and I put a slide up, and it was a slide of my mother at my wedding blown up about ten feet high. And my daughter was on one side of the picture, and I was on the other side of the picture. The National Breast Cancer Coalition has an exhibit, and they had taken my mother's picture from the exhibit and blown up the picture, and we were actually having a rally at the capital that day in Washington, and there were about 20 of these pictures that we were marching up onto the steps of the capital that made the most amazing pictorial for the visitors and for other people that were at the rally. Anyway, so my daughter is on one side, she was about 12 years old at the time, I'm on the other side, and my mother's in the middle. She has since died 18 years before, I'm giving this talk, and all of a sudden I like broke into tears, I have never done that before, in front of this entire group, filled auditorium. And I said, I guess, I just never put it all together, but part of my passion I'm sure is from the fact that, you know, I feel like that my mother's legacy and all of our mothers', and daughters', and sisters' legacy really can't carry onto the next generation.

JR: So it had a real personal (inaudible)

JHB: Yeah, it did. And I'm sure that's what drives me even more, is looking at my daughter, and watching her age and mature, and her body grow, and she has a beautiful



little build. And I think to myself, will these breasts turn against her someday, and I worry about that. I think that's part of the piece of the passion that drives me.

JR: So once you were working for Susan you then got involved in a (inaudible)

JHB: Well, yeah, then I got involved. And it takes up a tremendous amount of time, because it was traveling, you know, once or twice a month, building relationship within the State House, our legislators, and within Congress. Working with legislators, educating them about breast cancer. You know, at that time it was like, well, you have mammography, what do you need more? And how do you educate them and explain to them that there is so much more that is needed. And so we set to work, in a very long, arduous process of trying to secure more funding. But not just get more dollars, because dollars can be empty if you don't sort of see how they're spent, but I keep a pulse on how the money was spent. And so not only do we say we need this much more money, but this is how we want this money to be spent, and we want a seat at the National Cancer Institute's decision-making table on how the money is spent. So we were asking for more than any other activist group had at the time, other than the AIDS community, which was clearly our model.

JR: And so were you successful in most case legislation?

JHB: We were very, very successful in the first couple of years in getting more money. And then from a fluke in appropriations during the time of President Bush senior, we ended up with \$210 million in the Department of Defense for breast cancer research, and many of this looked --

JR: The Department of Defense, like the Army?

JHB: Yeah. I mean, I can tell you the story and you can use it if you want. Basically at the time when President Bush was president, in power, there was something called a firewall agreement, and it meant that any monies that were taken out of a budget could



not be moved to another budget. They had to be put in to supposedly put into the deficit, in lowering our overall deficit. Well, what we had proposed was we wanted money taken from the Department of Defense budget, one percent, which was way over \$200 million, and brought over to the National Cancer Institute, to be used for breast cancer research. And so Tom Harkin, who was Senator Tom Harkin, his two sisters had died from breast cancer, and so the issue was very close to his heart. And he was on DOD appropriations, and he said, all right, well, I'm going to propose that this money be moved. And the Senate said, well, you can't, because we had this agreement with the President, you can't move money. But the thing is that at the time, Congress was looking for a women's issue to grab onto, because they had just had the Clarence Thomas, Anita Hill sort of fiasco that went on very, very publicly, and they were quite embarrassed by it. So they sort of wanted to help us, but not really sure how to go about doing it. Well, they needed us too, and they thought this would be the women's issue that they could support. Anyway, so Tom Harkin makes his proposal and gets shot down. He goes home that night, and he takes the entire DOD budget, and he says I'm going to find something. And he went line by line, and he found a one line item that said breast cancer programming. What it was was a program for women in the Army, or for spouses of men in the Army, for screening. But it was a line item budget. So he went back to the floor the next day, with us all watching in the gallery, and said, I propose to move one percent of the DOD budget over to breast cancer programs. And what could they say? Because the line item was there. And so he won, and they voted for it, and that created a breast cancer research program. Now 99 cents of a dollar goes directly to research. It's a very well streamlined program. It's been, I think it's in its eighth year. It's cochaired by the Executive Director of the National Breast Cancer Coalition and it has different, well study groups is what they call them, and in the study groups they've invited women with breast cancer, who can be scientists, and researchers, or passionate activists, to read the grand proposals and have a say in the decision on how the money gets spent. So, I mean, it's like, just as an example, they wanted this program to be very



innovative and very different. They wanted to fund researchers who were not able to get NCI funding, because the NCI is a very, for lack of a better word, incestuous government agency, and the same people get funded over, and over, and over, and over again. I think things have changed since then, but at that time, and so Judah Folkman (sp?) is a perfect example. He couldn't get NCI funding. So we wanted to be able to just really bring in many talented researchers who had wonderful ideas, and give them the opportunity to research those ideas. So the program has continued to be very successful. So that's one success. But there's millions, well, tens of other things that we've worked on, from access for underinsured and uninsured women, to genetic privacy issues. We worked very hard on the patient's bill of rights. You know, it really does cross the gamut on issues that we work on.

JR: So what was the day to day work in doing these kinds of campaigns?

JHB: Well, in the very beginning it was doing a lot of the research on legislative issues. Within Massachusetts putting together a phone chain of women and educating them about the issues, so that they would at any moment be able to pick up the phone, or write a letter, or fax a letter to our Congressmen. Sometimes it was at the drop of a hat running to Washington and walking the halls. Now, you got to remember -- well, I'm sure you know this, is that grassroots activism is very, very different than lobbying on an issue.

JR: Right.

JHB: So there was a lot of internal pleasure that you get out of grassroots activism.

JR: Just in talking to people?

JHB: Yeah. We're pretty lucky in Massachusetts, because, I don't know, you know, I think it was very easy to educate our Congressmen, and it was very easy to gain their support. And now we're like the model state for the rest of the country, because we have such a wonderful relationship on these issues with our Congressmen that we can call



them up and say, these are our legislative priorities of the National Breast Cancer Coalition, and can you help us get these through? Particularly Senator Kennedy, you know, I have to point him out, definitely in particular. He's definitely our hero on many different rights issues, but particularly some of the issues that we care about.

JR: And so were you also continuing doing patient care at this time?

JHB: Yeah. All of my work for the National Breast Cancer Coalition, and also the Massachusetts Breast Cancer Coalition, and then more recently Jewish Women's Coalition on Breast Cancer, is totally volunteer, on my own time. Although when I worked at the Faulkner, they supported me in taking time off to do it, and at the Beth Israel Deaconess it's a little bit different, so I take it as my own time off when I do go.

JR: And so how did that feel to be doing both (overlapping dialogue; inaudible)

JHB: Oh, it's a big balancing act, and I suffered at home. You know, I was away a lot in the very beginning, at least once or twice a month for a couple of days at a time, and then I'd come back and have to make up the work that I missed at work. And it was one of those, you know, how do you figure this out, because you really can't have it all, and you've got to sort of figure out where the balance is going to be. I haven't figured it out yet, but (laughter) my kids have gotten older --

JR: (overlapping dialogue; inaudible)

JHB: No, actually I did last March pull back to working part time, here, and I think that helped a lot.

JR: And how do you explain the kind of work that you do to your kids? Like, what you, is it hard to communicate to them about what it is that you do?



JHB: Well, in the beginning it was harder, you know, they were little. And my husband was great, "mom has to go to Washington, you know, she's working in Washington now." But as they've gotten older I know that they clearly understand, because for example -- well, I did two things. One is I brought both Matt and Mara with me different times to the National Breast Cancer Coalition's advocacy conference, so they could really sit and see, you know, what is all this about. Come to Congress, lobby with me.

JR: What kind of work does your husband do?

JHB: He does software marketing and sales. And a lot of traveling. And that was the other thing, it would always seem that whenever I had a board meeting away, he would always have some sort of, like, his boss would call and say, you have to go out of town, and it would make me totally crazy. Because mine was volunteer and his was paid, and it would be like, what are we going to do with the kids?! And we don't have any family nearby, and ah! It would just cause me to go into such a tailspin half of the time. But they survived. (laughter)

JR: Yeah, kids are pretty resilient actually.

JHB: Yeah, they are. They survived. We figured it out.

JR: Yeah. So what role would you say your work plays in how you define yourself?

JHB: Oh, you know, it's so interesting because so much of my identity at this point is the work that I do. You go through, when you're younger, you sort of have this vision of what can I do to maybe make a difference in people's lives? And people say to me, well, how do you do the work that you do -- and I'm talking about now my day job, my paying job. And people will say, how can you do that? How can you constantly see women, work with women that have breast cancer? And to me it's a honor to meet all of these people. I'm sorry, I can't help that they have breast cancer, right now I can't always help that they have breast cancer. But at least I can help them get through their process, and so that's



kind of how I look at it. Like, when I meet somebody I'll say, I'm sorry, I wish I was meeting you at Star Market, but I guess we have to meet here, so what can I do to help you?

JR: (inaudible) make the best of it at least.

JHB: Yeah, yeah. And it's a really wonderful feeling when someone says to you, before I spoke to you on the phone or before I met you I was in a total panic, and now you've explained things and I feel so much better. And I think that the work, it's just become part of me feeling good about myself, and like you have to feel good about yourself to feel good about all aspects of your life. And so I feel good about what I do at work, and then I go home and I'm happy, and I enjoy my family.

JR: So what are the kinds of things that you've been involved in here in terms of setting up the program?

JHB: Well, the program here is an opportunity for women who have been diagnosed with breast cancer to come in in one day and get an opinion on their slides, their imaging, and meet a team of breast specialists, a team of physicians that really specialize in all specialties of treating breast cancer. So, breast surgery, dedicated breast surgeons, medical oncologists that have a clear, huge portion of the practice that are breast cancer, and radiation oncologists who do a lot of breast radiation therapy. And breast pathologists, which most hospitals don't have pathologists that specialize in breast pathology. And then a radiologist that are imagers, breast mammographers. So it's working with a wonderful team of people, and then really giving women what I think is a real expertise on how they should pursue their treatment, and often we share an expertise that changes the whole way they go about being treated. Or our pathologist maybe views something and it changes the entire pathology, which to me, if your pathologist is not a good breast specialist, and can't review and know the different nuances of breast pathology, it can change your entire treatment from maybe



substandard treatment to coming and getting a good opinion, and really getting excellent treatment.

JR: This might sound kind of like a weird question, and it's sort of hard figuring out the right way to phrase it, but how would you say, do you see your work as fitting into or sort of challenging traditional women's work?

JHB: I think being a nurse is probably traditional women's work. But the part that makes its challenge is that I'm a pretty outspoken person, and so in my role in advocating for women and for the care they receive, I think it's a little nontraditional. I mean, I work at a place that they value questioning and challenging of maybe what a recommendation might be. And sometimes I'll say, like, to a physician, well, I don't know, why do you think they should do that? I mean, they've got this, this, and this, and don't you think maybe it should be that way. And they'll go, oh yeah, that's a good idea, maybe we will do it that way instead. So, you know, I think that that's a little nontraditional within nursing, but traditional within Beth Israel Deaconess. I mean, you know, we're known for a nursing service that really works closely with physicians and advocates for patients.

JR: What would you say have been the most challenging aspects of the work that you do?

JHB: The most challenging aspect of the work that I do is, although it's changing somewhat recently, but to see for many, many years that we only have the same treatments to offer women. Sometimes I call it mixing recipes. Do you give them six months of chemotherapy, do you give them four months of chemotherapy? Do you give them these three drugs or those three drugs and a fourth drug? And I really feel like we need to sort of get out of the box and move on to something different. And I think the other part that's challenging is that we focus so much energy on treating this disease, but we really have to find out what's causing it. And that's a lot of focus of the activist groups that I work with, particularly the Mass Breast Cancer Coalition, which I'm also on the



board of. And our focus is really, I mean, we certainly have to treat the women that are being diagnosed, and we don't want to forget about that, but we really need to focus a national agenda on looking at causes and how to prevent the disease. And I don't mean preventing the disease with more drugs, I mean like, what is it and about the environment that we can change to prevent this disease?

JR: And are those pieces of the campaign things that have been receptive to those kinds of questions?

JHB: Well, I think that women who have breast cancer or are involved, yes, they're very receptive and understand. I think too the research community and to the legislative community, it's very hard to get them to understand, or want to do the research. And you got to remember that environmental research doesn't really have too much bottom line profit, and a lot of this is driven by bottom line profit. There's no doubt about it. That's not to say that there aren't wonderful researchers out there and physicians out there that want to see better treatments available, but we all know the reality of what drives this whole industry and that's bottom line profit. There's no doubt about it.

JR: Have you faced specific challenges as a woman in the kind of work you do? I mean, I imagine there are a lot of women who are (overlapping dialogue; inaudible)

JHB: You mean like the glass ceiling kind of challenges or do you mean the?

JR: I mean no, I mean in -- this question, it might be no. I mean, it might not apply in this case where there are so many women doing this kind of work.

JHB: I mean, when you say, do you mean now the breast cancer activism kind of work or?

JR: Yeah.



JHB: Well, the biggest challenge have been, quite honestly, arrogant Congressmen, not in Massachusetts, but in other parts of the country that believe in the old pat on the back, don't worry dearie, we'll take care of it. I think that certainly has been the challenge. I personally remember that experience in the beginning days, but I haven't had that -because in the beginning days, there were so few of us that we had to meet with as many Congressmen as possible, so you could be meeting with a senator from Idaho, even though you're from Massachusetts. But now we've been fortunate enough to network so that we have women in just about every single state that have become familiar with their Congressional delegates. But I think that's what the challenge was in the beginning especially, was that arrogant sort of pat on the back, dearie attitude.

JR: And what would you say have been the most rewarding things about your work?

JHB: All of it. I don't know if I could say one thing -- well, I mean, if I separated out the nursing piece in terms of caring for patients, and what I get paid to do, versus the nursing activist piece, I love going to Washington and being with women all across the country, and going with them, and walking the halls, and meeting with Congressmen, or I did some testifying on genetic privacy legislation, and I think that, I just absolutely love it. It just gets my juices going. I wish I could do it full time, I don't care that I get paid for it or don't, I wish I could do it full time. I really do. I think that is so much for me what it's about. And it also makes me very appreciative of despite all the issues we have going on in this country, very appreciative of the democratic process, and how important it is that we remember that. That there's no other country in the world where people can be as vocal as we are.

JR: Had you done this kind of political kind of campaigning stuff before you came to this issue?

JHB: No. No -- well yes and no. When I was a graduate student I took a course called the nurse and the legislative process. I thought it would be kind of cool to take. And it



was taught by this wonderful woman who had been a nurse and then went to law school, Regina Villa (sp?). And I thought, this is kind of cool, I'm going to remember this kind of stuff and maybe do it someday. And this was back in the early '80s, and I did work on an issue. And it was actually the legalization of marijuana for medicinal purposes. And it was a bill at the state house. And I can remember I wrote a very, very detailed paper, and the LA, the legislative assistant, said to me, this is so great. We're going to be able to use all of this to try to get our bill through. And I thought to myself, wow, this really is like -- you don't realize as a citizen how much of an impact you can have by meeting with a legislator and trying to impress upon them one issue or another. And so that was my only other experience though. And then it sort of sat, and it brewed with me for a good probably ten years, and then I became involved ten years later.

JR: And have you used these kinds of strategies or activist kind of things for other issues as well?

JHB: Well I think what I've learned is how to mince your words. How to make your point without being caustic. And I think if you're smart in your process, and you make sure that you have the data that you need, the information that you need, and you're calm when you go about doing it, you know, you can make your point across. I mean, I certainly know I get wordy sometimes, but you can command a respect if you're smart in the way that you go about doing it.

JR: So what kinds of campaigns are working on now? What kinds of aspects of breast cancer issues?

JHB: Couple of things that we're working on now. Well, of course the Jewish Community Relations Council has a pretty full agenda and we're working on, now that the legislature is still working on the budget and there's the Senate budget and the House budget, this is now at the State House. And so we're working on trying to get some of the language from the Senate budget put into the final budget. In terms of the breast cancer piece,



well, summer's a little bit of a quiet time. We had this big push for the patient's bill of rights. That was a couple of weeks ago. And the piece that we're working on within the Mass Breast Cancer Coalition is about eight years ago the Center for Disease Control worked on a program that was giving money to offer free mammography screening and cervical cancer screening to uninsured women and underinsured women. Well, the program was great in that it offered screening, but it had a major gap in it: once you're diagnosed, who's going to pay for your treatment? So women weren't availing themselves of screening, because they were concerned that if they were diagnosed, how were they going to pay for it anyway? And so the National Breast Cancer Coalition, that was a huge priority of ours. And President Clinton before he left office signed into order the CDC Treatment Act, which would mean that if you were screened through this program, you would automatically be Medicaid eligible, because if you met the financial criteria for the program, then you would automatically meet the financial criteria for Medicaid. But that's federal, and you have to have state match dollars because it's Medicaid. And so we're working now within our budget process to make sure it's included in the budget. And the House has their version, which Speaker Finneran put together, and the Senate has their version, which is much better. And so we're trying to get the two to find a common ground and use the Senate version language.

JR: Do you think of yourself as a political person now?

JHB: No, I don't. My friends all tease me, when are you going to run for office? There's an alderman position open in Newton, maybe you should think about running. I'm like, no, I don't want to do that! It's actually more fun doing it the way that I do it. I can sort of, if I have to, misbehave, and I don't have to worry about a vote, and I can have a different passion about it, because I don't have to worry about who's going to vote for me, or who I'm going to tick off. What was the question again?

JR: Whether you think of yourself as political.



JHB: So I guess I don't. I just sort of see myself as this is just a natural extension of what I do, and I don't think of it too much as political, I just think of it, it's what needs to be done.

JR: But do you think of yourself as an activist?

JHB: I do think of myself as an activist. I do think of myself as someone that definitely has a passion on an issue. But it's good to have a passion on one issue, it helps you keep focused and stay on top of it.

JR: Well especially this is a huge issue, and there's so many different areas to work on that are really pressing.

JHB: Right. Yeah, that's definitely --

JR: That could keep you busy for several lifetimes.

JHB: Well, and the thing is, you know, I always say to my friends, I (inaudible) the day that they call me and they say, I'm really sorry but we have to fire you from your job because we've solved this problem, we don't need your work anymore. I mean, I'd be really happy when that day comes, and then maybe I'll find a different issue. But I think working on activism, breast cancer issues and being a political activist, and seeing the success of what a very small group of women could achieve makes me realize that, you know, there are so many issues out there that people could be involved in. And I mean, I think you're seeing this yourself with talking to the different women from the Jewish Women's Archives, and someone comes up with an idea, I'm drawing a blank on the woman last year who, she just boggled my mind. You know, she sort of got up and turned to her husband in bed one morning and said, I really can't stand what's going on in Bosnia. I really have to become involved in this. And she did it. And I always say to my daughter, you can do anything you want in your life if you put your mind to it, because your mind can be your biggest stumbling block or it can be your biggest supporter.



JR: Do you feel like there were things that you had to overcome in order to take on this kind of work for yourself?

JHB: Only things that I had internally, like, you know, can you be articulate enough to make your point? Can you not be so scared that you forget what you wanted to say? You know, those kinds of things. Otherwise, I mean, I've always been someone that spoke my mind, and I think that that's a big piece of this. But I've learned so much from the women that I've come in contact with over the years that, you know, have walked those halls with me and gone to those advocacy conferences. I've just learned so much from them. And so much about living and life from women with breast cancer, versus many of my friends who have just about every single thing they want, but they still figure out ways to complain. It's very sobering.

JR: Right. How would you say your contributions have affected others?

JHB: Well, sometimes I see myself as I have an obligation to be a role model to other people who, or other friends that maybe wouldn't become involved in an issue if I hadn't said something to them. Pick up the phone, make a phone call, help me out. Make a donation to a specific organization that would not continue to be able to do the work if we don't have some financial backing. You know, those kinds of things.

JR: Yeah, I thought it was great that you brought those sheets to the women during dinner, because I thought that was a really nice way for people who were hearing about all these things to see a way that they can do something.

JHB: Well, you know, that's the thing. One thing I've learned in all the lectures I've given, and all the traveling, and everything else, is that if you just stand up there and you talk, people find it interesting but you leave them nothing to sink their teeth into. But if you give people something that they can say, "oh well I signed that petition," or "I was part of that," it's a great way to bring people in.



JR: How do you think the kind of work you've done has had an impact on you?

JHB: Well, selfishly speaking, I think that it's had an impact on helping me see that if I put my mind to something that I can really work at doing it. And just making me feel good about my life and being involved in bigger issues, and maybe not worrying so much about other materialistic things that mean nothing and you can't take to your grave with you anyway. And it's important I think how people remember you when you're gone. And, I don't know, it's helped me feel that -- I hope -- that I've touched many lives along the path. Been able to, in my work especially, help someone have a better night sleep than maybe they would've if they hadn't met me.

JR: Have you had role models?

JHB: Well, I've definitely had some more recent role models over the last ten years. I think my mother was probably a role model in a different way, because she just always supported me on every little thing that I did. She was always there, someone I could talk to. So I think she was probably my first role model in giving me confidence. But I've had a lot of role models along the way, Susan Love, and Fran Visco (sp?), and Ann Maguire, and Jane Matlaw (sp?), Nancy Kaufman, many different role models for different things, Emily Parker. You know, I look at somebody and say, well, wow, they can do that, I can do that. My daughter. She's a role model for me.

JR: (inaudible)

JHB: That it's really, really important to communicate and have patience, show your emotions, don't be afraid to be affectionate. I mean, I've always known this, but I definitely think that my daughter helps me live it, and that's just to always be honest and truthful.

JR: So, I think that's basically the end of the questions that I have. Let me just make sure I didn't leave out anything major. But I always like to ask if there's anything that we



haven't covered that you'd like to tell me about.

JHB: Of course I'll think of it after you leave. (laughter)

JR: You can always email me. I'm always happy to get little updates from people. As soon as I turn off the tape recorder people always start coming up with other things.

JHB: I mean, I never really thought about what I did as being anything great, it just seemed like a very little small contribution that I could make along the way. And I think the part that married so well was that I do have a tremendous knowledge about breast cancer, and treatments, and cutting edge stuff, which is my work, which helps me do a better job with the activism piece. For example, there was a study that one of the international research groups were working on, and the physicians and researchers put together this study. Well I questioned one little piece of that study, about cardiac toxicity and how it would be followed, and it ended up being a really big issue that the National Breast Cancer Coalition sort of grabbed onto. And I kept sort of going at it and going at it, and I think if I didn't have that sort of medical piece understanding, you know, I'm not sure it would have gone as far as it did, and we changed some of the follow up and monitoring for cardiac side effects.

JR: It's interesting because it seems like you said both that your nursing work and your activist work on the one hand sometimes are in tension because they compete with each other for your time, but then also they seem to fit together (overlapping dialogue; inaudible)

JHB: They do really fit together well. And I think the one thing that baffles me is why every single nurse, oncology nurse, isn't involved in some sort of activism, and in a broader way. I mean, as oncology nurses we should all be walking the halls of Congress, and being involved in issues. And as women, we should all be involved with women's issues, I mean, that's a no brainer.



JR: Do you feel like it's hard to have work that's paid work and work that's unpaid work? What's the relationship between those?

JHB: Yeah, I do sometimes, because what happens is there's so much stuff to be done in terms of the breast cancer activism that it can sort of suck you dry at times. And then you don't have the emotion or the energy for your own family when they need you. So sometimes that can be hard. And then there are times that I'll take a step back and say, all right, I have to set a priority here. I know I'm sorry I can't go to that board meeting, because I really do have my kids' open house at school tonight and I just have to miss the board meeting.

JR: There's never enough time.

JHB: Yeah, there's never enough time. That's the beauty of summer. The kids go away, and then you get to do all these other things (laughter). Of course, I got one going off to college, so I'll have that much more time in the Fall.

JR: Right. Well, thank you so much.

JHB: All right, thanks for --

[END OF INTERVIEW]