Phone Interview with Jean Heller

*Heller begins to discuss the study

Heller: Believe me, every doctor in the country knows about it [the Tuskegee Syphilis Study] … It really influences everything they do. The whole nut of it is informed consent.

Interviewer: Definitely, it was so influential to medical policies today.

Heller: Now something you probably haven't thought of, you know all those medicine commercials you see on television where they spend 90% of the time telling you all the horrible things that could go wrong? That's informed consent. The chances of any of those things happening are very, very slim, but they have to tell you that it's informed consent. It's kind of interesting – it reaches into every little facet of your life, even the aspirin you take when you get a headache.

Interviewer: And has that directly stemmed from what happened in Tuskegee?

Heller: Yes – specifically Tuskegee altered the way … institutions that get federal money have to justify their human or animal experimentation. The disclaimers you see on the medicine commercials aren't mandated by the Tuskegee study, but they are definitely influenced from it. It touches the lives of everyone.

Interviewer: Definitely. Our first question is – we were wondering if you could tell us the story about how you found out about the Tuskegee study.

Heller: It's pretty much the same as it is in the story I sent you to read. There was a young man in San Francisco in what was then the Public Health Service. The US Public Health Service is the predecessor to the Center For Disease Control – and the US Public Health Service was surveying, pretty much nationally, cases, instances of sexually transmitted diseases. It was up to this young college student, whose name was Peter Buxton, to try to get a handle on the incidences of syphilis in San Francisco. During the course of doing his work, he heard about this study and he didn't want to believe it was true, so he started asking his supervisors about it and they just looked at him and answered one way or the other. One supervisor wrote him a note and said, this is really none of your business, there is nothing wrong with it, just do what you're paid to do and be quiet – I'm paraphrasing – those are not his words. He got frustrated and went to a friend of his in San Francisco who was a reporter, but she was not a investigative reporter – she knew me though – and she said, I'll pass this onto somebody who might have time to look into this – which she did. And that's how I got the letters. Just a couple of letters that she'd gotten, but one of the letters that said, there is nothing wrong with this, it's none of your business, ignore it – because that letter did not specifically deny that the study was taking place. In fact it took cognizance of the study. It acknowledges that something like that was going on. That's how I found out about it, and then it was just a matter of hammering on people until they gave me the information I wanted.

Interviewer: Once you had published your exposé, what was the reaction within the community to the study?

Heller: Well, when I went down to Tuskegee before the story broke, just to see the community and get a flavor for it, and I went back again after the story and was very proud of myself, it was a huge story. I was a kid just out of graduate school and here I was with the biggest story of the summer, except for Watergate. Everybody was talking about it, everybody was upset about it, Kennedy was going to hold hearings in the Senate about it – everything was going to change, everybody said. I had caused it and I was proud of having done it. And then, I went back to Tuskegee into the aftermath and I was sitting on a park bench in the town square with Charlie Pollard, who was one of the survivors. He said, "You know, this used to a friendly town and now people cross the street to avoid shaking my hand." I think that the story is in the one I did in 1997, but I started to cry … It was like "What have I done to these people? I truly felt like I had wrecked their lives."

Interviewer: Within the community, was there any stigma from the families of victims towards their relatives who were patients of the study?

Heller: I don't think it was uniform. I think there were some wives who looked at their husbands like, what have you done to me? Of course, the wives could have caught it. But I think everyone understood that these men did not know what was happening to them, and that was the great crime of the study. These men were lied to. They had no idea what was happening to them. No idea what they had, no idea that they were getting fake medicine, no idea that it wasn't an honor to be part of a federal government study. They were driven around in cars. They were given hot meals. They were given certificates of thanks for their participation. They felt like it was an honor. I think when they found out, it wasn't so much a stigma on them coming from their families as was a deep sorrow and not understanding why it happened to them – what had they done to deserve this; fear that they had passed the disease on, to their wives, to their girlfriends, to their children, for God's sake, and that had happened. They're still looking for all the people who were victimized – I mean they chose one hundred men with syphilis for this study and they probably found four hundred right now who have been infected by the participants. I don't know that for fact, but I know it's a lot. I think there probably was some angst among family members, but I think everyone just felt used. That's the way it came across to me – they just felt used. It was their lives at stake.

Interviewer: So, in your article you mentioned about how the men were all "African American, poor, and lacking formal education." Can you talk about the significance of this in the study?

Heller: It didn't have a role. The reason that population was chosen is it had the black population was the highest per capita incidence of naturally occurring syphilis in the country. They were chosen not because they were uneducated, although that certainly helped, not because they were poor, although that certainly helped, they were chosen

simply because they were part of a population that had more syphilis than any other population around. Really they were targets of opportunity, strictly targets of opportunity. There was no humanity in this whatsoever. No consideration given to their station. No consideration given to them. They were just targets. They were just convenient Guinea pigs.

Interviewer: So what you're saying is that it was simpler for the government to use them, it was the easiest option, essentially.

Heller: Yeah, I mean it was the easiest option in that you had a huge population of syphilis in a fairly small area. It was rural so they were easy to corral, easy to control. There was a Public Health Service nurse who was stationed there. It was her job to keep this station under control. She had to report to the white doctors when one of these men, and it occasionally happened, when one of these men found out what they had, and they went over to Montgomery and checked themselves into a clinic for treatment. The doctors literally would go to the clinic and tell the clinic that they would shut them down if they admitted anyone else from Tuskegee. They'd pull the poor guys out of the clinic and send them home. They'd find out on their own what they had. They went to get treatment. These Public Health Service doctors pulled them out of the clinics and sent them home. I mean, it was unconscionable. And the nurse, this nurse, who was in charge of reporting them, was a black woman – Nurse Rivers.

Interviewer: Also in your article, you talked about how many African Americans began to believe that AIDS was a white conspiracy to commit genocide against the African American race. How do you feel that this sense of distrust is related to Tuskegee?

Heller: Well, I'm not an expert, but the experts tell me it is almost 100% that the aftermath of the Tuskegee study disclosure was so great that blacks would not trust anything that white doctors wanted to do. I'm not sure if it's that great anymore, I would hope it isn't. But as one person said in that article, this is going to take medicine a long, long, long time to overcome the impacts of what the Tuskegee Study did to their credibility.

Interviewer: Do you know of other examples of this distrust, or any further repercussions this distrust had?

Heller: Well, I think it was pretty much system wide. If they ever trusted white doctors, they ceased trusting white doctors. They wouldn't take part in AIDS research, they wouldn't take part in sickle cell anemia research, they wouldn't take part in any of it. And a lot of these latter studies, especially into AIDS and sickle cell anemia, were studies which were totally legitimate, totally justified, and completely aimed at improving the health and quality of life in black communities. But blacks didn't trust them, and if I were black, I wouldn't either. I mean every single one of these doctors who conducted the Tuskegee Syphilis Study was white. Every one. The only black medical person was Nurse Rivers.

Interviewer: You noted in your article that reports of the study were regularly posted in respected medical journals – if that was the case, then how did the study manage to stay secretive?

Heller: Well, they were noted medical journals, but they were not widely read medical journals. The reports were written in such a way that the shortcomings of the study never were mentioned. It never mentioned how the doctors convinced these people to participate. It never mentioned they were lied to, never mentioned that they were lured into the study, it never mention that they were not told what they had. The reports were simply statistics that were coming out from the study. No medical person reading those articles could have known the horror of what was behind it. In the study of syphilis in the Tuskegee, Alabama area, we are finding that X number of deaths were caused by heart problem or multiple problems or, you know, whatever problems. None of this background was ever mentioned. So, if a doctor had been reading those reports, he would have no idea what was going on. They never said they lured these people with hot meals; they never said they did spinal taps without their consent; they never said in these articles that the people were made to feel like royalty this one day a year, when the doctors came to town. They were told that they were very special, to prevent them from trying to run away. They never said any of that. No legitimate doctor could have read those articles and known what was behind them. So, I don't fault the medical community at large for not getting on this case sooner.

Interviewer: Were the reports big discoveries during that time in the medical communities or were they insignificant as far as the scientific findings?

Heller: I never found that they were any scientific findings of any meaning. The people looked over it later to say that the statistics that came out of the study were useless. They were what you would expect. Syphilis doesn't treat black bodies any differently than white. Whoa! Big deal. In the end the study had no medical significance in the end. None. Zero. Zip, zilch, nada.

Interviewer: After people found out about the study, President Clinton gave an apology to those affected by the Tuskegee Syphilis experiment. How important was this apology in moving past this event?

Heller: Well, you're talking about twenty-five years later, and I think it was the right thing to do on the twenty-fifth anniversary, whether it moved anybody anywhere is hard to say. You know I was down in Tuskegee at that time, and the people were grateful for it, but I don't think it changed anything. I think it was the right thing for the President to do – it created some feel-good moments, but in the end it didn't change anything.

Interviewer: When you went back down to Macon County and to Tuskegee, do you know if it provided any closure to the victims?

Heller: Well, there weren't many victims left alive at that time – Herman Shaw, the one with the old tractor. At the end of my article, he feels as if they were owed a great deal more, but he felt they had gotten closure. And he's the only one I can speak for because really all the others that I knew and knew me over the years had died, including Charlie Pollard. So, I mean, the community is most assuredly at peace right now with what happened, at least most of it. I can't speak for everybody, but it seems to be at peace with what happened. I think more than anything else, the money, the settlement that the federal government came up with, was the thing that helped the most – not because it was a huge amount of money, because the people down there didn't need a huge amount of money – it was enough to make a lot of them comfortable for the rest of their lives, and they were owed at least that much. In fact, the lawyer who was put in charge, Fred Gray, of finding people who were owed money, is still at it – what is it, 2013? So, forty-one years since the study was disclosed? Forty years since the federal judgment, and they still have money for people they haven't found? That's huge! It's huge!

Interviewer: What impact of the study do you see today?

Heller: We sort of hit on that at the beginning. If you are a doctor and you want to do a human experiment, something involving human experimentation, and you work for a hospital or university that gets one penny of federal money, you have got to go through all of these hoops that were set up by the National Institute of Health to justify your protocol, to justify your message, to guarantee informed consent. I think you'll see if you look somewhere in the story, there are three things, three criteria, you have to meet. And if you don't meet anyone of those criteria, you will not do the study, and if you do the study anyway and are found out, your institution, not you, will lose every penny of federal money it gets. Can you imagine what that would do to a federal center or university? Those institutions have their own committees that oversee human experimentation to protect themselves as well as their participants. There is really very little that you can do medically or that can be done to you medically in this country today that does not have some kind of safeguard written into it because of the Tuskegee study. It makes me ill watching TV commercials for medication, to listen to all the things that can go wrong, but I don't think there is a facet of medical life that hasn't somehow been touched by this, by the ramifications of this. It took almost two years, I believe, but the entire fabric of rules of human experimentation was rewritten by the National Institute of Health and these people were meeting almost weekly. They just threw everything out and started all over again. And what they came up with is almost as airtight as you can make it. Is it completely failsafe? No, it probably isn't, but every time it fails the rules get tighter.

Interviewer: How do you think that the both the protection and violation of rights play into the Tuskegee study?

Heller: It was one of the grossest violations of human rights I can imagine. You were using, abusing, and killing people. How much worse does it get? And the horrible part of it is that it started at the same time as the Nazi atrocities in Germany, and we are the ones who sat in judgment of the Germans. Does that seem right? Granted, the Tuskegee study

was not nearly as widespread an atrocity, but it was no less awful than what the Nazis did. How's that for a comparison?

Interviewer: Were there any basic human rights that were violated with the Tuskegee study?

Heller: Well, you judge that for yourself, since the time of Hippocrates, you know the first rule of medicine. First, do no harm. Well, that went out the window, didn't it? That went out the window right off the bat. They wanted to do harm. They wanted these people to die.

Interviewer: Do you think that they government had any right to do what they did?

Heller: None. None. There is none, there is no justification for it whatsoever. In the first study, the same study had been done years before in Sweden, and it came up with the same results – none, nothing useful. Why did they even have to do it again? What happened was they just bumped on this population of a lot of black syphilis victims and they said, "Oh lets do this study again." But, there was no need for it; there was no justification for it. It was literally as I said earlier, a target of opportunity. Here was nothing to be learned from it. There was only horror and grief to be had. And they knew there was nothing to be learned from it, because they knew abut this Swedish study which learned absolutely nothing. There is no way you can justify what happened in Tuskegee. I've had people try. I've had tough people come at me for 40 years and say "Well, what about this? Well, what about that? What about the other thing?" Every single one of them is a facetious argument, which can almost childishly be tore down. There is no justification for it whatsoever. None. It didn't help anybody. It was meant only to gather statistics. Statistics don't save lives, unless they lead to a new medication or a new protocol or whatever. This didn't. There are some things in life that are absolute, where you can say a 100% this or 100% that – this was one of those where you can say, "There is absolutely no justification for it. None." I think everyone admitted that.

Interviewer: What you did really influenced and changed everything.

Heller: Well, I didn't do it alone, if everyone who followed up, from Senator Kennedy, to the NIH, to a man named Barry Ellis, who was the very first man in the new office – he oversees these laws. So no, I don't get all the credit.

Interviewer: When thinking of the responsibilities that were withheld or not withheld, how does that relate to Tuskegee?

Jean: Back then, the doctors were required to write a protocol for the USPHS, which the USPHS would have to approve – no one today has been able to find that they did that. That's why I say this is a target of opportunity – they just found a huge population of syphilis victims and said they were going to do that. They never had permission; they never wrote a protocol. Nothing. So the doctors violated their oath to office, their medical oath. The USPHS violated its responsibility to oversee the rights of the citizens. And its

simple: no one involved in setting this study up and permitting it to run for forty years is exempt from violating the laws of human decency. Nobody.

Interviewer : How has this study impacted our nation's psyche? Have you seen a difference in how our nation perceives these types of things after you broke the Tuskegee study?

Heller: After the story and now are two different times. I'm not sure it is affecting the American psyche now to any extent. The new laws are in place – they are, at least for the most part, working. The medical community is now comfortable with them and I think realized pretty soon afterward that something new had to be done. I think if you asked most of the general public, they probably don't even remember it. In the immediate aftermath of the stories publication, people were going wild. There were riots. There was actually a riot at the Department of Health, Education, and Welfare; employees actually rioted – they stormed the secretary's office, and the secretary shut the study down immediately. People were flabbergasted that this would happen. My parent's best friends were a doctor and his wife, and I remember I was at home for some reason when the story broke out. I was telling my parents and their friends about what I was going to be writing, and this doctor, who is my mom and doctor's best friend, refused to believe me; he said, "No; no doctor would do that." After the story broke, he never spoke to me about it again – he was that stunned – and I think a lot of doctors were affected that way. A lot of doctors could not believe that they could have colleagues that would do such a thing. Doctors, by and large, are really decent human beings, and decent human beings don't do these things. I think the general public response to the story today is much more muted than it was then. There is an entire generation of people, born and grown to adulthood, since the story broke, who have probably heard of it, yet it affects their lives as we have discussed, every single day.

Interviewer: Thank you so much. We really appreciate you taking time out of your day to help us with our project! It was amazing to hear your perspective!