

Dr. Janet B. Hardy

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This is an interview with Dr. Janet B. Hardy, a Professor of Pediatrics Emerita at Johns Hopkins University. The interviewer is Dr. J. Rosser Matthews, a DeWitt Stetten, Jr. Memorial Fellow for 2001-2002. The interview was conducted in Dr. Hardy's office at Johns Hopkins on July 11, 2002.

Matthews: Why did you enter the field of medicine? Why did you specialize in pediatrics?

Hardy: Well, it's sort of a long story. I had originally intended to be a breeder and trainer of show ponies. My family lived in Victoria, British Columbia, and I was a Canadian by birth. And when I returned to my family after living, after attending school in England and finishing the equivalent of high school there, they asked me what I wanted to do to earn a living because it was, I guess, shortly after the Depression had hit, and it was clear that show ponies were not in the cards. And so I said to my father, who was an internist, "Oh, I've decided to be a physician," and he said, "Over my dead body." And the more he objected, the more appealing the idea seemed to me. Anyway, we struck a compromise, and that was that I would go to the University of British Columbia, and if I graduated and did well enough to get into medical school, then he would finance it. And I, in due course, graduated quite well and I was admitted to McGill University, and he thought that it was all his idea from the beginning. Why did I become a pediatrician? I think that caring for kids appealed to me in medical school more than any other specialty, and so I undertook a pediatric training. And I had to have my first year in Canada. It was during World War II and I was a Canadian citizen, but I didn't have to stay in Canada

after that. I was married in medical school to a Virginian, and I still am, as a matter of fact. So I decided, after one year in Montreal on the house staff in pediatrics, that I shouldn't have all my eggs in one basket, and so I came to Hopkins.

Matthews: That was in what year?

Hardy: That was in 1942, when I came to Hopkins. And I've been here in one way or another ever since.

Matthews: Okay. And how did you eventually become involved in the Collaborative Perinatal Project?

Hardy: Well, I went through the residency here, and I became involved in a long-term epidemiological study of tuberculosis. And from there, I took a job in public health in Baltimore, and I worked in public health for five years, I think, and became, eventually, assistant commissioner for preventive medicine. I had a wide range of public health experience. I took courses in the School of Public Health while I was doing that. And I missed the research and I liked the sort of public health approach. Anyway, in 1957, I was invited to head up Hopkins a collaborative study. That invitation was based, I think, on two things. One was that in 1945, in addition to the epidemiological study that I took over, I became the first pediatrician in charge of the newborn nurseries, and there were no neonatologists. In fact, the obstetricians had looked at the babies until that time, and the pediatricians were consultants when things went wrong. So by the time I came back, I'd had both neonatal experience, and that taught one a lot of obstetrics, and administrative experience as an assistant commissioner. When I came back, the collaborative study was in the early planning stages, and some of the other budget directors were appointed about

the same time that I was, but most of them were appointed in 1958, I believe, and so we had a good deal of influence on what data was collected and how it was collected. There had been a high-level advisory committee to the NINDB, which sort of laid out the overall plan, but we tended to fill in the details. And I guess the PRB came into being in 1958. I'm not really sure, but I think that that is when it began.

Matthews: That's the Perinatal Research Branch?

Hardy: Yeah, the Perinatal Research Branch. And I think, as I recollect, that Heinz Berendes was probably appointed the director of that Branch in 1959. He wasn't there right at the beginning, but I don't recollect exactly when he did become director. But I spent quite a lot of time in Bethesda that first year.

Matthews: In the paper that you've just written, you touch briefly on earlier studies. You say there was a '46 to '58 British cohort study, and you mention others. Can you elaborate on that a bit further? What did that shape?

Hardy: Well, the second British cohort study really had a major impact in helping to shape the CPP in terms of the data that were collected, the obstetrical data and the neonatal data.

Matthews: What did that project involve?

Hardy: That project involved follow-up of all the babies born in one week in March of 1958, I think. I'm temporarily blocking on the date. The CPP was very different in that the British data about the obstetrics was retrospective and was much less intense than the data the CPP collected. But we had a lot of consultation from British scientists who'd been involved in setting up that study, and their experiences and suggestions were very helpful. Actually, Dennis Varnum [sp] who was one of the two principals -- he was the

obstetrician, came over and spent a month or so at Hopkins or between Hopkins and the NIH. I think we paid for his coming, but we shared him with the NIH. And Baird along with Raymond Ellsly [sp.] came over and stayed for some weeks. He was also an M.D. John Spence from Newcastle upon Tyne, who'd done a somewhat similar kind of study. It was very different in some respects, but it was the following up of families was similar. The other person who had a marked influence was Dr. Emmy Warner, who was the director of the Hawaiian study, and she, I guess, got underway about 1955. She had a much smaller sample, but she followed all the children born in 1955 on the island of Kauai. She was a psychologist, or maybe she is a psychologist. I think she's still alive. And so she really had a major input to the psychosocial stuff. She also followed up on her sample until they reached the age of 33, and that encouraged me to follow up on the Hopkins sample, the Hopkins population. So she left her mark, a good mark.

Matthews: You mentioned also in the article that you said that Dr. Louis Hellman and Harry Gordon both advised you not to become involved with this project. Why did they say that?

Hardy: Well Louis Hellman was a close friend of mine, and I knew Harry Gordon very well. And they thought this project was doomed to failure and that it should fail. I think that they were both miffed, actually, by the fact that the Human Embryology and Development Study Section, which was a powerful study section, was not consulted and especially not given the oversight for the CPP, that was one thing. And they were genuinely concerned about the large expense involved and the fact that it might well dry up all the research money that was available in the developmental area.

Matthews: Do you have any idea on why Harry Gordon was later selected to head the Gordon

Commission?

Hardy: You know, I have no sure knowledge, but it was generally believed by the people I knew that Dr. Shannon, who was then head of NIH, deliberately selected him because this was or at least neonatal pediatrics was his area of expertise and because he was vocally opposed to the CPP.

Matthews: Someone also told me he might have been a personal friend of Shannon's. You heard that or not, that Gordon was?

Hardy: He may have been. I don't know.

Matthews: That's another theory I've heard.

Hardy: But I know it was generally believed that that was the reason for the selection. And I've seen the Gordon Committee report, at least a summary of it, and it was my sort of general impression that Harry Gordon and the committee really couldn't come up with very good reasons for disbanding the study. Their criticisms were rather nitpicking.

Matthews: Right. So you think that's why he didn't have or wasn't successful.

Hardy: Well, I think that's why he wasn't successful. And I think that the fact that he did not make the report very conclusive. I think that led to the appointment of the Lilienfeld Committee, which followed soon afterwards, and I think the belief was that Lilienfeld would be more objective and probably had a better background.

Matthews: Right, of course, Lilienfeld's hypothesis was what motivated the study.

Hardy: Right.

Matthews: I'd like to move now to the events -- I found out it was in June and July of 1971 that you testified, according to the *Congressional Record*. In those years, that year, you testified

before the House and Senate Appropriations Committee when the president's budget advocated a \$2.1 million reduction in funding for the CPP. Can you talk about those events?

Hardy: I have no recollection of testifying for the committee. I really haven't. I remember very well some later testimony in the adolescent pregnancy and child-life stuff, but absolutely no recollection. But I do remember very well going, you know, sort of organizing the campaign.

Matthews: You don't remember the actual testimony, but can you just talk about what you trying to accomplish in those years? It would seem that was another sort of effort budgetarily.

Hardy: Well, the effort that I was involved in started with a telephone call from the director of the NINDB late one night, and he said -- and I don't remember the year it was; it was while Nixon was president -- he told me that the CPP budget had been eliminated from the NIH; no, actually from the president's budget. I don't remember the total sum of money, but it seems to me that it was in the range of \$10 million. And he said that there was -- the director who called me said-- there was nothing that he could do to contest it and that it would mean that the project would be closed within six months. And he asked me if I would do something, do what I could, and I said, "Well, what do you expect me to do?" And he said, "Well, I would suggest that you go to see your congressmen, representatives and senators," and so I said all right, I would do what I could. I went to see Senator [Charles McCurdy] "Mac" Mathias, who was the senior senator from Maryland, a Republican, and I told him what the situation was and that we had begun the analysis of the data till actually it was not quite complete, and how could work this back

in? I told him I'd never done this before or I didn't have the remotest idea what to do, and he told me that letters must be very brief, it was a good idea to have all the project directors contact the representatives from their states, and that we were fortunate in that there were a lot of states represented. And he turned me over to one of his young aides, who took me in hand and gave me a short course on how to approach Congress people. So I got, called all the other project directors, told them what the situation was, how to approach the Congress people, and actually, this young man had helped me draft a letter. I sent that out with the suggestion that people adapt it to their own situations so that the Congress didn't get umpteen letters that were all the same. Then Mr. Mathias suggested that I make an appointment and go see Mr. Flood, and I thought the chances of getting an appointment were much better if Tom Scott, who was the project director in Pennsylvania, made the appointment because Flood was from Pennsylvania. He got an appointment and we went to see Mr. Flood, and Mr. Flood was sympathetic. And he treated us like children, as an aside. And he said to us that, yes, he would see to it that the budget was replaced in the appropriation. He said, "However, we can't put in the total sum. We have to make some token cut." And so I think out of the \$10 million or so, we cut 4 or 5 percent. So it sailed through.

Matthews: So that kept the project going. You could do the data analysis.

Hardy: Yes.

Matthews: In our conversation last fall, you also spoke about how later you and Eunice Shriver lobbied Congress, and this led to the passage of the Teenage Pregnancy and Parenting Act. Would you comment on those?

Hardy: Well, that was educational and interesting and has resulted in a lifelong relationship with Eunice Shriver. She's a remarkably hard-working, intelligent, and committed person to the things she believes in.

Matthews: But what did you do that led to the passage of that act?

Hardy: Well, what I did was -- and that takes us back a bit to 1974 -- I observed in the Hawkins data that the teenage mothers and their babies had the worst outcomes, pregnancy outcomes and childbirth outcomes, of any group. They were much worse than any other group of mothers, age group of mothers or class or mothers. The mothers had more pregnancy complications, the babies had higher mortality, perinatal, neonatal, and they tended to have a higher mortality in the first six weeks or so of life. And so as the CPP was closing down, I turned my attention to more trying to build an intervention program, and Dr. Theodore King was chairman of obstetrics, and he had started a tiny teenage clinic in which, because he thought these mothers were at very high risk obstetrically. And so we teamed up. At that point, Eunice Kennedy Shriver was very interested in developing a demonstration intervention program for teenaged mothers, and so we had lots of discussions, and she decided that the Kennedy Foundation would fund an intervention program at Hopkins that would be in the Department of Obstetrics but that I would run it, and that happened. And we had three successive programs. One thing led to another. We were very fortunate in that we had a good control group in that the Children and Youth Program at Hopkins, which was quite independent, had a small program for pregnant girls enrolled in that program, and it was a program that provided primary care to about 18,000 young, well, kids through age 18 in the East Baltimore area.

I had nothing to do with it, but it made a very nice control group because the kids, all the teenagers got the same kind of obstetrical care, but the Children and Youth teenagers did not have the added things that the teenage obstetrical program provided, and so they added separate prenatal care. Anyway, to cut it short, the obstetrical program was called the HAP program, Hopkins Adolescent Program.

Matthews: What's the acronym?

Hardy: Hopkins Adolescent Program, and it was for teenage mothers. And it took care of all the teenage mothers who were not already in the Children and Youth Program. So we had three or four hundred a year, I guess. It was a quite big program. It was very comprehensive in terms of its ancillary services like social service education and so forth. And also, we had special obstetrical nurses who sort of watched over the teenagers in the HAP program and who very often sat with them in labor. And we cut down on obstetrical complications, and it was really quite dramatically successful. However, it ended when the babies were six weeks old and were transferred into public health clinics and so forth, and so we started the second program in which we followed the teenage mothers and their babies from the HAP program in a continuation which provided primary care to the mothers and to the babies at one site and usually at one visit. And we got the mothers back in school and stuff like that. In fact, we found that many fewer of the mothers became pregnant again than in the CNY program. And that led to the third program, and the third program was a pregnancy prevention program, which we conducted in several local schools, matching up schools, a school with a program in a school in which we didn't provide a program but collected data. And we found that the

repeat . Fewer kids in the program schools became pregnant, and they had fewer repeat pregnancies and they stayed in school better and did better. And it was in relation to those programs that Mrs. Shriver and I went to Congress, and what we did was to visit an endless number of congressmen. Mrs. Shriver often made appointments for us and we traipsed up and down the halls of Congress. It was really very interesting. I learned a lot.

Matthews: And what was in the act that?

Hardy: Well, I do remember very well going to Congress, to hearings, because we took some of the girls from the Hopkins program over to testify. And what was in the Act. The Act established the Select Committee on Children, Youth and Families, the U.S. House of Representatives, and this was in 1986. National Perspectives on, well you can read the fine print at this point better than I can. But what we did, in essence, was to present the problem, and we had a lot of data about the problem, and to present the solutions that we'd found in the Hopkins program. And it led to the setting up of -- and this must be 1986; no, that's '85. This must be later testimony. There must have been earlier testimony because President Kennedy established the Teenage Pregnancy Care and Prevention, I think it was called, Program in DHEW, it was then, and that program still goes on after a fashion. And Mrs. Shriver has a huge program called the Community of Caring, which is an education program in the schools, and that grew out of our program, went far beyond our program, you know, education in our program, but it didn't grow out of it.

Matthews: So I guess you've said how this all relates to the Collaborative Project, that it was the initial data from that that sort of sparked your interest.

Hardy: It really was the initial data that sparked the interest.

Matthews: That led to these later studies, then.

Hardy: Yes.

Matthews: Okay. I know you've just written an ending to this article, but what would you see as some of the legacies of the Collaborative Project?

Hardy: Well, I think there are several. There is the legacy of the data, first of all, and, unfortunately, when the Collaborative Study was orphaned in 1976, the data was sort of bundled off and handed to an outside contractor who had no knowledge of it, no experience with it, to archive. And it was archived in the National Archives, as you well know, having seen the 50 feet of documents. And it was archived in a very inaccessible form. A lot of it's illegible. It was archived for mainframe computers, and we don't use those much nowadays, and it was archived in a sort of 80-column punch-card form. We and a few other people did the data that I had I got from NIH, and I did not, until relatively recently, get the archived data. But the data is really terrific. It's astonishingly complete. I don't know of any other data that was collected with the attention to bias and the attention to careful documentation that was provided for this data, and I elaborated on that a bit, so I won't go into it. The next thing is the publication. I knew about major publications in the areas of my interest. But I was astonished when in, I guess it was 2000, in December of 2000, Mark Kleminoff [sp.] sent me a list of publications that used data for populations from the CPP, and there were 400 of them. I never conceived of that.

Matthews: He has it all on a Web site now.

Hardy: Well, it's on a Web site now, and Matt Lawnecker's [sp.] done quite a lot with that. We had quite a bit of data computerized in the Pathways study that we had gotten from the tapes, abstracted from the tapes that I got from people at NIH, and the data. I had a population of about 2,000 people in the Pathways study that I'd followed, and I did not see any immediate use for a lot of the fine items in the data, and so I just settled for getting the major summaries and things like that. And relatively recently, I realized that I wanted to use items from the individual exams that the summaries would not meet my needs, and I explored collaborating with Dr. Duka [sp.], Steve Duka [sp.] at Harvard, on some studies that had to do with schizophrenia. And so I decided that we would use user-friendly computer data that can be used on a PC, and so I got some support from the Stanley Foundation, and for the last year and a half or so, we've been doing that. And we finally have a prototype ready to be distributed to a few people, 25 people, for comments and criticisms, and they'll take those comments and criticisms and produce a CD that will have all of the data from all institutions, and hopefully in a usable form. It's been much harder than I anticipated technologically to do.

Matthews: You want to comment on this?

Hardy: I'd like to make one further comment. We've been able to access and transpose these data because I have a very skilled computer man working with me -- he's a real genius, John Waller [sp.] and because I'm very familiar with the data, and the documentation in the archives is not very good.

Matthews: You want to talk about sort of the legacy of the project in terms of discipline building, and you mentioned neonatology.

Hardy: Yes. Well, I think that really has been its greatest contribution, or one of the greatest contributions. You know, it's sort of fun to have lived a long time because I have very clear memories of what was. And pediatrics during and right after the war, World War II, was, by today's standard, a very, very, very limited specialty. I guess other specialties were also, you know, equally limited, but pediatrics has come a long, long way in all areas, but particularly in terms of neonatology, pediatric neurology, and developmental pediatrics, and then in pediatric biochemistry and in understanding of things like maternal viral infections and fetal development as a whole.

Matthews: And you said that was one of the . . . I read some of your congressional testimony. You said rubella, that was important.

Hardy: Well, rubella was important. We really lucked into the rubella epidemic _____. It was a great opportunity because here was the Collaborative Study already collecting blood from mothers and babies and studying placentas, and we very quickly developed a relationship with John Sever [sp.] in the Perinatal Research Lab, which provided us with facilities for doing a lot of viral and other immunological studies. And I remember the first cases of congenital rubella that we recognized. They were in early September of 1964. We had these extraordinary, we called blueberry-muffin babies. They were babies born who were jaundiced but had petechial rashes, sort of purple, blotchy rashes that led to the name blueberry muffins. They were very sick, and very quickly we got common histories of maternal infection with rubella in the first trimester. But we made here a couple of rather important sort of observations that had not been made before, and with Dr. Sever's [sp.] help, and one of them was that the rubella syndrome extended beyond the first trimester

of pregnancy. And we had babies whose mothers had rubella around 15, 16 weeks or so who had heart disease, and it was rather specific and not as severe as the early heart disease that went with the recognized rubella syndrome, but it was nonetheless there. They also had encephalomyelitis early after birth, and they had hearing losses. But it had been believed up to that time that if the mother did not have rubella during the first trimester, she would not have a damaged baby. The other thing was, we realized that the babies were infectious. We thought they would be when we found they had a virus, and we devised a little scheme for proving it. That was, I went to the nursing school that we had at that time and I said, "Look, student nurses who've not had rubella as children who work in the newborn nurseries, particularly the NICU, the intensive care nursery, are likely to come down with rubella. Will you be on the lookout and let me know?" And we were able to trace infections in student nurses back to individually infected babies. And we were fortunate, really, in that we had a good team. The ophthalmologists were interested, so we cultured all the cataracts of virus, and we had a very active and a very good hearing and speech team, and so all the kids with rubella were, and all the Collaborative Study kids were watched very closely for hearing problems, and so we had a kind of concentrated opportunity to really get a picture.

Matthews: Right.. Was there a vaccine developed?

Hardy: Yeah. As people began to realize what a huge problem this was, they became excited in developing a vaccine. The thing that really fascinated me was, I went back to the early obstetrical, early Australian literature. I had known all my pediatric life that a man named Norman Gregg in Australia had first described the typical rubella syndrome. But I

found that a lot of things that we were seeing and considering to be brand-new observations had already been made in Australia in the early '40s, 1941. So I think that there was something peculiar about the '64-'65 epidemic the 1940-'41 epidemic in Australia. I think they were much more virulent, but nobody's been able to prove that.

Matthews: Is there anything else you'd like to add that we haven't touched on?

Hardy: Yes. You brought up the question of rubella, but there are other infections. And in 1958, there was an epidemic of flu, and we had a small viral laboratory here. The Pediatric Virology Lab was just getting started. And so we did a study on influenza in pregnancy using the pretest Collaborative Study patients. We didn't find very much in the babies, but we did find an increase in the rate of prematurity and a slight increase in the rate of cardiac congenital anomalies. That was one of the sort of opportunities that the CPP gave us. It gave us -- and I would imagine some of the other institutions -- opportunities to put things together across disciplines that had not been there before, and it gave us an opportunity to develop neonatology that we'd not had before. And the whole business of developmental pediatrics, which deals with things like hyperactivity and learning problems and so forth, came into being as the Collaborative Study genre grew older.

Matthews: Well, thank you, Dr. Hardy, for doing the interview.

Hardy: Well, it's fun to be reminded. And I've never regretted my participation.

Matthews: Right. Okay. Thank you.

End of Interview