

OREGON HEALTH & SCIENCE UNIVERSITY

ORAL HISTORY PROGRAM

INTERVIEW

WITH

*R. Ellen Magenis, M.D.*

Interview conducted December 9, 2008

by

Susan Hayflick, M.D.

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December 9, 2008

Site: OHSU Vey Auditorium, Doernbecher Children's Hospital, Portland, Oregon

HAYFLICK: This interview of Dr. Ellen Magenis was conducted on December 9, 2008 in the Vey Auditorium at OHSU as part of the Oral History Program. The interviewer is myself, Dr. Susan Hayflick. This is tape number one.

Ellen, maybe we can start with where you grew up. And tell me some things about your childhood that you remember particularly.

MAGENIS: I grew up in Gary, Indiana. I was born there, within a few months of my parents arriving in Gary—they were both born in Georgia, in the hills, and decided that it was a good time to move because there was a steel mill and there was a job. And of course it wasn't too long after I was born that the Great Depression started. But, it was a good move because there were still some jobs in the steel mills. I went to school in Gary, Indiana. The schools were founded, just as Gary was a founded town, so that in the middle part of the town, streets were very straight and rigid. Fortunately they named the streets on one side of Broadway in order of the states as they came into the union. And on the other side, it was the presidents in order. So it was easy to remember Washington, Adams, Jefferson, and so on, as far as the presidents.

There were quite a few small stores, and one big department store. The town grew and grew. In their wisdom, the founders of Gary decided that for the education of the children, with so many immigrants, they needed a well-rounded program. They constructed a program that was called the Work Study Program. Every child each year had to be in a play. Each year they had to give a speech. There were also certain testing categories that they had to complete before advancing. Even more than today. In addition the students had to take auditorium and observe the students performing.

We all had to take gym, even if you weren't very coordinated, and certain other activities that would be considered play that weren't quite so rigid. We had to participate in games that were structured and unstructured. We also had to take swimming lessons: Gary was very close to Lake Michigan.

Even in the grade schools, the students had to take dancing; there were special teachers who could teach more modern dancing but also parochial dances.

HAYFLICK: Do you remember what some of the activities you participated in were?

MAGENIS: Well, not the dancing. [laughs]

HAYFLICK: Why not?

MAGENIS: I wasn't that coordinated. So it's rather amazing that I have a couple of very coordinated kids, and some that aren't.

HAYFLICK: [laughs] It's genetic, right?

MAGENIS: I believe so. I did take sewing and cooking. I always liked school, and my only embarrassments would be if they paid more attention to me than I felt was necessary. I was always fairly shy.

HAYFLICK: How did you do in school?

MAGENIS: Quite well.

HAYFLICK: What were your particular strengths?

MAGENIS: Well, especially in high school, it was the sciences. I did quite well in those. I was on the honor roll, even in grade school. Since we lived very near the edge of town, where there were sand dunes. To have a lawn, you had to haul in dirt, since everything was on sand. There were little swampy places, and I became very interested in the small animals, and I would take our dog and go searching. Oftentimes, I brought interesting creatures to show our nature study teacher in grade school.

HAYFLICK: So you were a budding wildlife biologist?

MAGENIS: [laughs] I don't know, but I enjoyed doing that.

HAYFLICK: What was it about science that really excited you? What grabbed you?

MAGENIS: The thinking. And the sort of actuality of it rather than abstract and remote, just talking about "things". I didn't like religion. I don't know how to indicate that, though my family was fairly religious. I grew up as a Jehovah's Witness.

HAYFLICK: Oh, I didn't know that.

MAGENIS: Went door to door as the family expected me to do.

HAYFLICK: That was quite a break, then, from your upbringing. Your sort of turning your back to religion.

MAGENIS: Well, I always questioned it. It didn't make sense. To me, anyway. I'm not sure that I spoke about it very much. I had to play the piano at the meetings because Jehovah's Witnesses don't believe in "churches." I would play and everybody would sing. That was fun.

HAYFLICK: So you were particularly good in science. Were you, people often draw attention to the relatively few women in science. And you were—

MAGENIS: Well, not early on in grade school, or even high school, because we really were part of a melting pot. Old customs and rules were frequently not followed. Girls were more free to choose what they wanted to do.

HAYFLICK: So that wasn't so unusual in your school for a girl to be "smart".

MAGENIS: Early on. But in high school and getting honors, et cetera, there weren't quite so many. It was in college and medical school where I faced a great many more problems being female.

HAYFLICK: Yeah. Yeah. Can I ask you, just still back in your high school, were there particular scientific projects, or do you have particular memories that really kind of cemented your interest in science or medicine?

MAGENIS: I just took everything that was available. There were some rather unusual courses because of the war and the steel mills, et cetera. For example, we had whole terms on meteorology and on aerodynamics.

HAYFLICK: Were you good in math as well?

MAGENIS: Not—well, I always did quite well, but I had to work a lot harder in those areas than I did in the other kinds of more physical sciences.

HAYFLICK: Yeah. Math is maybe a little bit more like religion than like biology.

MAGENIS: [laughs] I would say so. I hadn't thought of it, though. Yes.

HAYFLICK: So tell me then about finishing high school. Was it assumed that you would go to college? Or was that difficult?

MAGENIS: It was assumed. My father did extra work so there would be more money. He even built a chicken house outside the city and sold chickens so that I could go to college.

HAYFLICK: Were you the first person in your family to go?

MAGENIS: Well it's hard to say, what they really called colleges. My father went to eighth grade, and then to agricultural college. Which seemed in that era to be more frequent than going to a high school.

HAYFLICK: But you did a full high school. And then where did you go to college?

MAGENIS: Indiana University.

HAYFLICK: So you stayed—

MAGENIS: In Indiana.

HAYFLICK: Yeah. So you stayed near home, but a little bit—

MAGENIS: Near enough. Yes. And to be able to get the advantages of how much the cost would be.

HAYFLICK: Yeah. So tell me a little bit about what that experience was for you, going off to college and being in college.

MAGENIS: Well, it was a little scary at first, but I had some good roommates. And we got along quite well. So I essentially enjoyed it.

HAYFLICK: Did you dig right into the science? Or did you kind of explore some other areas?

MAGENIS: Well, you had to take certain kinds of courses that weren't just science. But mostly I took science. After getting there, of course I knew all along, what my father wished since he kept saying, "Are you going to, are you thinking about medical school?" He was a frustrated scientist in his own way, extraordinarily interested in nutrition. So I never had white bread. [laughter] And took my cod liver oil every day, ate my vegetables, dieted and exercised. Every morning he would get up in front of the window (in Indiana, it could be ten below, when it got really cold) and do his exercises. He did this in spite of working in a physical job in the steel mill.

HAYFLICK: Yeah. I was going to say, it's amazing how little things have changed, then. Because we're still focused on diet and exercise as the biggest influence. And brown bread. Fortunately we've left the cod liver oil behind. Most of us.

MAGENIS: But they get their vitamin D in other ways, then.

HAYFLICK: Yeah. Yeah. So tell me some of your memories of your schooling. Particular classes that were memorable, or particular professors who were inspirational to you.

MAGENIS: There were at least two women teachers that I enjoyed a lot in high school and tried to emulate. Their teaching was direct and to the point. But again, I was rather shy. Somewhat withdrawn, I suppose. And having to do social dancing when I got into freshman high school was a pain.

HAYFLICK: But you persevered.

MAGENIS: But I persevered. And even more, not so much later in college, where females were pretty well welcomed. Of course, with my family being steel mill workers with manual jobs, and very little money, I was not one of the sorority girls, until I was a junior, and then after I was awarded Phi Beta Kappa, one of the *good* sororities wanted me. I thought, not now.

HAYFLICK: [laughs] So you turned your back—

MAGENIS: Too superficial. And of course there was one person that I will have to mention from college: Kinsey.

HAYFLICK: Right. He was a professor at the university.

MAGENIS: He was a professor of genetics. His work was on the gall wasp. He was able to find and name two new types of oak trees because gall wasps only live on oaks.

HAYFLICK: But that's not what he was best known for, was it?

MAGENIS: Oh, no. You couldn't get out of his class and get a grade if you didn't do an interview, a sex interview with him and his graduate students.

HAYFLICK: So that qualifies as coercion.

MAGENIS: Yes. [laughter] Exactly. One wouldn't get by with it today, I don't think.

HAYFLICK: That must have been—

MAGENIS: But that was very, very interesting. A kind of an eye-opener.

HAYFLICK: It sounds like you probably wouldn't have volunteered for that otherwise.

MAGENIS: Probably not. But he was an interesting lecturer. And he would give some of the sex study results in class. In many ways, it made one feel more free.

HAYFLICK: Do you have any particular stories or memories from his classes?

MAGENIS: He did talk about homosexuality, in humans and in other animals and possible causes. It was somewhat of a shock that some of the students had after they started taking the course, that actually he was going to do a lot of real genetics teaching and talk about his course work including the experimental parts. And I guess they thought it was going to be fun and games.

HAYFLICK: Yeah. He was an accomplished scientist.

MAGENIS: Yes.

HAYFLICK: Yeah. Why did you take the course?

MAGENIS: It was part of genetics. He interspersed his studies on sex, and compared it of course, with both human and animal sexual activity. This made it very interesting.

HAYFLICK: Yeah. You had mentioned that there were two female professors that you found to be influential. Can you tell me a little bit what the courses were, and what it was about them that impacted you?

MAGENIS: There were very few females who were professors, in college. There were more in high school, where there were several women, women teachers, who taught more about the individuals doing the sciences, rather than the science itself. They were more interested in how the world works. For example they did lecture about Marie Curie, her research and her life.

HAYFLICK: So they showed you, maybe, that it was possible for a woman to not only be a scientist, but get a doctoral degree and return as a university professor?

MAGENIS: Well much of what I did was due to the push from my father, who, when he was talking about medical school, and how interesting that would be, I was shying away from it. I was a little afraid of even talking about it. But he just kept saying, "Ruthie—" that's my first name— "You can do it. I know you can do it. You've shown."  
So I said, "Dad, I will apply to one school. If I get in, I'll go."

HAYFLICK: [laughs] And the rest is history.

MAGENIS: History.

HAYFLICK: So do you think without his encouragement to look hard at medicine that you would have stayed focused on science and maybe gone a more—

MAGENIS: Probably. Probably.

HAYFLICK: Do you think you would have landed where you did in science?

MAGENIS: I don't know. With that kind of background, there wasn't, and with the system, there weren't many models of what one could do, or couldn't do. But you did learn, as a woman, that you had to be pushy. And sometimes a little antagonistic. Hopefully not so much that it spoils things.

HAYFLICK: In order to be taken seriously?

MAGENIS: Yes.

HAYFLICK: It sounds like that didn't come naturally to you.

MAGENIS: To push? When it was necessary, I think, it would have.

HAYFLICK: Did you face that in college? Or was that really once you got in medical school?

MAGENIS: It was more in medical school.

HAYFLICK: Why do you think that is?

MAGENIS: Well, there were three girls out of 128 in my starting class. So you were noticed. But I did enjoy my lab partners as a freshman student, beginning student, in medicine. One of them was named John Roll. So they called him "Toilet Paper."  
[laughter] I don't know if he still carries that.

HAYFLICK: Were these your anatomy partners?

MAGENIS: Yes.

HAYFLICK: Did you choose each other as partners? Or was this an assignment?

MAGENIS: No. We were told. But it worked out quite well. There was one other woman who was at my same table. And she ended up quitting.

HAYFLICK: So then you were down to two.

MAGENIS: They started teasing her, and apparently she'd never been subject to some of the things boys will say. And I had only brothers.

HAYFLICK: How many brothers?

MAGENIS: No sisters. Three of us, (two brothers).

HAYFLICK: So you were toughened up a bit.

MAGENIS: Toughened up a bit.

HAYFLICK: So then there were only two women in your class.

MAGENIS: When she left, yes. And then another one was able to transfer in the junior year. There were three black medical students as well.

HAYFLICK: Did you band together or gravitate to the other women?

MAGENIS: I think we talked more than otherwise. But my partner did have problems with trying to deal with some of the language. And having worked in the steel mill, it was not quite the same for me. She was very sheltered. Her father was a physician.

HAYFLICK: I see. It sounds like some of your early upbringing helped to prepare you for the challenges that you faced as a woman early in medicine.

MAGENIS: I think so. Yes.

HAYFLICK: Did you enjoy medical school?

MAGENIS: Most of it. But in the junior year and late sophomore year, I became very much involved with one of the other students. And we eventually married. And then I got pregnant in my early junior year. And I was told that I couldn't go to school while I was pregnant. So that I would have to stay out. So I had already had maybe three months into the year. And so I couldn't go to medical school. But instead, I worked in one of the laboratories.

HAYFLICK: Which lab? What were you doing?

MAGENIS: It was mostly chemistry, which I didn't like quite as well as some of the other kinds of labs. But it was a good lab to be in. And of course then when I came back, I had to repeat the first part again, and that put me behind all my classmates that I knew, including my husband.

HAYFLICK: Did they give you a reason why a pregnant woman couldn't go to class?

MAGENIS: Oh, it was just accepted, according to them, that you shouldn't have to try to prevail under that strain or the actual activities, limitations. Particularly toward the end of pregnancy.

HAYFLICK: So you were out for, was it one year?

MAGENIS: One year.

HAYFLICK: And then you picked up again.

MAGENIS: Right. But a year behind where I would have been. Yes.

HAYFLICK: And then you went into—

MAGENIS: And that was in spite of World War II, where it began to be quite clear how much women could do.

HAYFLICK: A lot of opportunities in filling in for the men who had gone off to fight?

MAGENIS: Well, that appeared to be what happened, in factories and everywhere.

HAYFLICK: What did you do after medical school?

MAGENIS: Well, I had another baby and started part of an internship. Later I went back and completed the internship, which was in Iowa City. Then I decided that maybe I should stay out of the program, because we thought that we wanted maybe four children. I ended up with seven pregnancies.

HAYFLICK: And you chose to go into pediatrics?

MAGENIS: Well, it seemed to be the logical thing to do, and it was more accepted. So after the several years out, I thought I can't just go back in. So I redid an internship here in town at Portland Adventist Hospital. And then tried to get some work, and eventually got a job up here.

HAYFLICK: Did you do—

MAGENIS: I went into the residency program in pediatrics.

HAYFLICK: So you did your pediatrics residency here at OHSU.

MAGENIS: Yes. And my genetics. It was one of the first schools that had a formal genetics program.

HAYFLICK: Yeah. How many residents were there when you were starting? Do you remember how many were in each year?

MAGENIS: Like the pediatrics?

HAYFLICK: Yeah.

MAGENIS: Probably six. Something like that.

HAYFLICK: Do you remember much from your peds residency?

MAGENIS: I hope I do, even if I can't place exactly where I got it.

HAYFLICK: Did you enjoy that time?

MAGENIS: Well part of it. The first year of medical school was in Bloomington, with a different set of professors. Most of them were quite interesting. I don't remember any women professors down there. But being one of the few females, you always got more attention than you really wanted. I think I'm much better now, but I used to always try to be on time to class, but, I'd usually get there right on the dot, or later. [laughs]

I remember one time when Dr. Kime, who was an anatomy professor, but also a surgeon. When I walked in to class a few minutes late, he made sure that that was very much noticed by everybody. I tried to sit down in the back. It didn't work. And when I did sit down, he berated me for being late. And then, I don't know if he was really angry, but he jerked the arm off the skeleton that was in the front of the room and brought it up, put it across my lap and asked me questions about origins and insertions of muscles. Fortunately, I had gone over the material. [laughter]

HAYFLICK: So you did well, despite the—

MAGENIS: I did okay. But as a woman, I don't know about you, I certainly got more attention. And as we went along, we gained a couple women. So there were maybe four of us total.

HAYFLICK: Were some of the attending pediatricians women, then?

MAGENIS: Well, in the residency, oh, yes. I mean, that was many years later.

HAYFLICK: So there had been enough passage of time that women had begun to really be a presence in pediatrics.

MAGENIS: So I was out for what, ten, ten years, at least.

HAYFLICK: Did you think about not going back?

MAGENIS: Sometimes. But I had a husband that kept pushing it. Thought that I should finish up.

HAYFLICK: What kind of medicine did he practice?

MAGENIS: He was family practitioner.

HAYFLICK: How did you come to genetics? That was a pretty unusual medical focus then.

MAGENIS: Well I think even in high school there were certain areas I found more interesting than some of the materials about the weather. But it was also because of the war that they had quite a few different courses you could take that would be very

helpful if you got into the army. But mostly college, there were several professors teaching genetics. Did I mention that Watson was getting his PhD at that time, when I was in Bloomington?

HAYFLICK: At the university.

MAGENIS: Yes.

HAYFLICK: Did you know him?

MAGENIS: Just by sight.

HAYFLICK: He's got a distinctive appearance.

MAGENIS: Yes. [laughs] He does. Then you hear a few stories. I'm sure he was very busy, but he always had a rather unusual personality. It was in most zoology classes that there was a lot of genetics. One of the Nobel Prize winners from Germany was in our department who then got his prize on radiation effects. His stories were also interesting; Muller. Hermann Muller. There was also Sonneborn who was working on paramecium, particularly methods of propagation.

HAYFLICK: Mm-hmm. So maybe it wasn't so unusual for you to end up in genetics. It sounds like that had been a thread of interest throughout your education.

MAGENIS: All along. And it was available at Indiana.

HAYFLICK: Right. They have—

MAGENIS: And we had an embryologist , geneticist too.

HAYFLICK: Indiana, of course, is still known for their genetics department. Their medical genetics group.

MAGENIS: Genetics group.

HAYFLICK: Yeah. What was the state of genetics when you started your training here at OHSU? What was the state of the genetics department or the genetics training program?

MAGENIS: There was none. Dr. Koler, chair of Experimental Medicine was trying to hire Frederick Hecht from the University of Washington.

HAYFLICK: You were it.

MAGENIS: Well, No. Fred Hecht came down from Seattle, having just finished his residency there and had genetics training as well. So it was Fred and myself that

started the genetics clinic program. I helped, with assistance of course, to get the laboratory started.

HAYFLICK: Yeah, I'm particularly interested in hearing about that time. But I'm curious, was there something equivalent to a residency or fellowship training in genetics, then?

MAGENIS: Here? No.

HAYFLICK: So you went from pediatrics to sort of starting a genetics clinic based on your—

MAGENIS: With Fred.

HAYFLICK: With Fred, based on your—

MAGENIS: With Fred's University of Washington experience and my past course work at Indiana; then two more researchers with genetics training came on board within a couple of years.

HAYFLICK: Were there many other genetics clinics around the country at that time?

MAGENIS: Not very many. There were some, and of course, University of Washington has always been excellent. As for the genetics clinical program, after we got the clinic started, we found that in Idaho, they had a clinic. There was a practitioner who was interested in genetics who was a neurologist, and started getting some clinics going there. I used to go to Idaho quite a lot, and help them get moving, and their laboratories, also. And people think that it's the "boonies." But I can tell you that those were some smart people. They actually started a clinical laboratory service before we were allowed to, including charging.

HAYFLICK: Interesting. Tell me about starting the laboratory, how that came about.

MAGENIS: Well, we were doing some research studies. Particularly when we felt we needed to look at chromosomes or some of the other types of laboratory studies.

HAYFLICK: What year would this have been, Ellen? What was the year then, roughly? Plus or minus a few?

MAGENIS: Well, it was 1966, we did what we called "GL studies". All our other studies were research supported. These GL studies were actually fee-for-service. Recently, we were able to obtain the results of an old study, GL3. I was hoping to show it today as a contrast to the Druker material. Of course there were no bands. We did have a system, though, arranging the chromosomes into groups by size. Even though there

wasn't a band to be seen. If we saw something like banding, we thought something was wrong.

HAYFLICK: So you could count chromosomes, and you could see if there was a-

MAGENIS: Could arrange by size, and the centromere position.

HAYFLICK: Right. Or if there was a-

MAGENIS: And then you began to see little variations, which were primarily repetitive areas.

HAYFLICK: What, so that was '66 when you started a fee-for-service.

MAGENIS: That was '66. It was probably a year or two-

HAYFLICK: Earlier?

MAGENIS: Earlier, when we were beginning. And our numbers are still "GL"; that we put in the front. People seem to think that stands for Genetics Lab. It stands for Gaines Lab. That's where we were located.

HAYFLICK: I see.

MAGENIS: You know, in the beginning, all genetics labs were down in the basement.

HAYFLICK: Sure. So you were in Gaines Hall, initially.

MAGENIS: We were in Gaines, then moved to a couple of other places. Well, actually, the very first, but it wasn't very long, was after the TB hospital closed, when our laboratory was in the surgical amphitheater of the TB hospital. I used to worry a little bit, but I thought oh, no, the bugs are not going to survive. And we were in one of the other research buildings for a little while, where we had to turn all the lights down to work on the microscope. And when you turned them back on, the cockroaches would skitter.

HAYFLICK: [laughs] So you, '66 was, correct me if I'm wrong here, but that was within about ten years of the right number of human chromosomes being known. That was '59, wasn't it? Or was Lejeune's-

MAGENIS: Well that was when Downs was-

HAYFLICK: '59 was Lejeune's-

MAGENIS: Yeah.

HAYFLICK: –discovery that Down Syndrome was an extra chromosome, twenty-one.

MAGENIS: Yes.

HAYFLICK: When was the number of, the normal number of human chromosomes? That must have been in the early '50s, then? Or maybe–

MAGENIS: It was the late '40s, I believe.

HAYFLICK: Was it?

MAGENIS: Yeah. Or early '50s.

HAYFLICK: So where did you learn to, chromosome preparation is I think still, in 2008, as much art as science. Where did you learn? Or where did the technologists, where did you learn to do it if you were starting a laboratory?

MAGENIS: Well, when Fred came down from Seattle, he brought along a tech from the laboratory up there. So that was a pretty good way to get started.

HAYFLICK: So it was like getting bread starter from somebody who–

MAGENIS: Yes.

HAYFLICK: Somebody experienced who could help you set it up. Yeah.

MAGENIS: And make changes as we needed to.

HAYFLICK: So it was probably a small laboratory to start.

MAGENIS: Oh, yes! A couple of people is all.

HAYFLICK: And most of your samples would have come from your clinic, your genetics clinic–

MAGENIS: From the clinics.

HAYFLICK: –with Dr. Hecht.

MAGENIS: And some from the outside.

HAYFLICK: Yeah.

MAGENIS: Well, I was in the clinic, too.

HAYFLICK: Right.

MAGENIS: And I ran the clinic for a number of years, as well as the laboratory.

HAYFLICK: So I'm going to guess that that was one of the few cytogenetic, clinical cytogenetics operating in the U.S. at that time. My guess is there would only have been a handful.

MAGENIS: Well, I mentioned Idaho. There were a few little places where people got interested and started things going. But it was particularly interesting. I really miss it, because we would go, in Idaho and other surrounding places, we would go to different towns, sometimes small towns, and meet a lot of the other physicians.

HAYFLICK: So tell me about some of the particular, either individual patients or families or chromosome cases that you remember. Sort of some of the discovery moments of your early career.

MAGENIS: Well, it was mostly based on something that looked a little different cytogenetically or clinically. It was really nice to be able to compare patient information and laboratory information. So I think it was very natural to start trying to do something with that data that we were obtaining. In the early days, one family that I remember very well was because there was a specific chromosome segregating that seemed to break. There was a little material in between to show that it wasn't just a clean break. And we decided to look at the parents. One of the parents had it. We then decided to look at other family members. We ended up with a huge pedigree that was put in kind of a circle such that we had—photography and our art department helped get that out.

So, and it took us up to the graveyards to look at names. Into the houses. Drive up to wherever the family member lived and usually got a sample. I remember one family very well. Actually, two, in which the father did agree to do it. And sat there, and we did it. And then he keeled over in a faint. And his two little boys came out and said, "Dad, we did better than you." [laughter] It was quite fun.

HAYFLICK: Yeah.

MAGENIS: And then, oftentimes I'd take one of my kids along. There was only one time that I was really worried, because he locked the car door and we couldn't get into the car. And one of these mothers didn't want me to do her baby on the kitchen table, which is what I usually did. And so she held the child. Well I tried probably a third time. And in the wrong position. The baby was only about six months old and wiggly. I have to excuse the fact that I didn't get it. But when I got back to Portland, my daughter went next door, there were twins just her age, and announced to them that babies don't have blood. [laughter] Mother couldn't miss. So I had to talk with her a little bit about that. It was difficult.

HAYFLICK: Was blood the only tissue that you were doing chromosomes on then?

MAGENIS: Oh, sometimes we would look at hair roots. But if you wanted good preparation, it was blood. And saliva sometimes. It wasn't quite the same as being able to see and follow as more and more banding came in.

HAYFLICK: Yeah. So tell me, remind me a little bit about the history of banding. When that started and how you brought that into the laboratory?

MAGENIS: Well, in the late '60s, people were beginning to use banding, and had some different stains that allowed us to know that different chromosomes could stain differently from each other. So that in a metaphase spread, you could sometimes pick out the ones that you wanted. It was mostly fluorescence, so that one could distinguish the materials under a fluorescent microscope. That's how we learned a lot about the areas that don't really have a product. I'm not sure that we still know exactly what they're for, but there's a lot of "heterochromatin", and usually around the centromeres. But one thing it did was allow us to do parental origin. So quite early, we were looking at Down Syndrome to see if the extra chromosome came from the mother or the father.

And I remember one family very well that was a Portland family that sold vegetables. This family was quite well known. And in that family, the mother had children, one of which had Down Syndrome. They were very interested and willing to give samples so that we could look and see who contributed the extra chromosome. By looking at the marker regions, we could tell that it was from the mother.

And then, her older daughter married, became pregnant, and her child was shown to have Down Syndrome; Oh, that was quite an ordeal for the family. So we decided to look at origin in this family. It was a second meiotic error from the father. So it wasn't even related in origin. These findings increased our interest to go on and try to look further, in other families.

HAYFLICK: Did you communicate that to the family?

MAGENIS: Oh, sure!

HAYFLICK: Was that reassuring to them?

MAGENIS: Yes.

HAYFLICK: So you were using heteromorphisms in identifying parent of origin. Is that right?

MAGENIS: Yes. Yes.

HAYFLICK: Very interesting. So you've seen a lot of changes in the world of cytogenetics.

MAGENIS: Oh, yes.

HAYFLICK: Tell me about—

MAGENIS: Even in starting other labs and so on, for a time. Did I mention that we had a satellite lab down at the State Hospital for the mentally retarded?

HAYFLICK: No. Tell me about that.

MAGENIS: Yeah. It was in where position that I was essentially running a one-tech laboratory that we were able to find several previously unpublished chromosome errors. It was a fertile place to find chromosome abnormalities.

HAYFLICK: Were there particular—

MAGENIS: And so we also made trips to Fairview for specific abnormalities. Some of the family studies actually started because of a relative who was placed in Fairview.

HAYFLICK: Were there particular discoveries you remember from the Fairview patients?

MAGENIS: Smith-Magenis.

HAYFLICK: Tell us about that.

MAGENIS: Well, there was an “older” woman at Fairview. She'd been there since she was fourteen, and at the time we saw her she was sixty-five years old. Jean Macfarlane, MD, I don't know if you know her, but she lives in Salem, and was sometimes asked to come over and do some evaluations at Fairview. She saw Jesse; Jesse had been labeled since being placed at Fairview as a Downs. Jean said, “She's not Downs.” Eventually she was able to get a sample, and sent it to Portland to be analyzed. Here was this little deletion. It was the timing that allowed the diagnosis, because we couldn't have seen such a small deletion earlier, of chromosome 17.

And that next fall, looking at the abstracts of the American Society of Human Genetics, I saw this abstract that was going to be presented about two patients with 17p deletion which appeared like our deletion<sup>17</sup>. The author was Ann Smith.

HAYFLICK: Did you—

MAGENIS: So I made sure I went to her talk, and she had two patients. By that time, we already had six. So we decided to collaborate, and have collaborated ever since.

HAYFLICK: What year was that? Do you remember roughly when the publication—

MAGENIS: In about 1982.

HAYFLICK: How did you feel about having a syndrome named after you?

MAGENIS: Well it wasn't, at first. It's only later that people started calling it Smith-Magenis. It was just another 17p deletion.

HAYFLICK: [laughs] But it's known now pretty consistently as Smith-Magenis Syndrome.

MAGENIS: Smith-Magenis.

HAYFLICK: How do you feel about that?

MAGENIS: Well, it's easier to find other cases this way. And Ann being an organizer type, has had at least every other year, and sometimes every year, conferences that are specifically on Smith-Magenis, and their many types of problems.

Well, good old Jesse died recently. She was eighty-eight. Our first SMS patient.

HAYFLICK: Did you stay in communication with her or her family?

MAGENIS: Oh, yes! Except there wasn't much family. We really tried. She had, supposedly, five brothers and sisters. And there was only one that we were able to contact at all, and he wasn't interested. He was younger, and he really didn't know Jesse. She'd been in Fairview.

And so now we're trying to get data around her death. Because they don't usually die young, but seem to have a near normal life span. A few have severe heart defects, and will die in the newborn period. But mostly, they're pretty good survivors.

HAYFLICK: Hmm. Eighty-eight.

MAGENIS: When she died, she was her own guardian, and the caretakers couldn't find any family members. I brought up this brother as an option, and they said they'd heard about him, but they couldn't find him. Because they can't find him they are not allowed to give us any information about autopsy. I don't think she had a complete autopsy. She'd had evidence of a stroke, I guess, two or three weeks before, but it seemed to have resolved. So, I'm still pushy, to try to get the information. I think, the family physician in Salem will probably try to pull his materials up, that he had sent off to the Salem Hospital files. Because of the fact that there was no kin to give permission, the hospital could not provide us with the information. And that was apparently a rule.

My oldest daughter who is an attorney told me that these rules are very strict. But I think the physician may tell me more, if I go and visit him, personally.

HAYFLICK: Yeah.

MAGENIS: Because it's one of the conditions for which there is little data as to cause of death. I know the Smith-Magenis group is very interested in such data. She did have a pacemaker placed toward the end, for her known left bundle branch block. She occasionally would have fainting episodes.

HAYFLICK: Your experience of staying in contact with a patient or a family for decades is something that you're kind of known for around here, at least in the genetics group.

MAGENIS: Oh, really?

HAYFLICK: You have a, you develop particular relationships with many of the families in their care. I think that they see you as a sort of a lifelong resource for them, because many of them have rare genetic disorders.

MAGENIS: That's right. And it's been very difficult to get them to be seen back in the clinic.

HAYFLICK: Yeah. So that brings me to the Prader-Willi story. So you're also known particularly for your work in that area. Can you talk a little bit about how you got interested in Prader-Willi Syndrome? And a little bit about your work?

MAGENIS: Well, again, from the laboratory, and seeing some of the patients. I kept seeing this deletion on chromosome 15 in a different set of patients that didn't appear to have the same clinical features. So we did all kinds of stains. We did everything we could think of to show that it was not the same deletion. (Well, it turns out, they are the same deletion). So I approached the University of Washington to request funds to pursue this puzzle. We still had a relationship with the University of Washington and, for a time, there was a funding source that allowed us to have monies for meetings with other cytogeneticists. So we met with the University of Washington and other Washington cytogeneticists both locally, and at national meetings as part of the PACNORG (Pacific Northwest Regional Genetics Group). It was during this period that we found how much data we could generate together.

But even in that group, when I stated that these deletions are the same, I was laughed at. I said, "Well, show me what's different?"

"Well, we don't have the tools yet." But it brought up the whole area that's now called imprinting.

HAYFLICK: So this is the—

MAGENIS: And found the origin was different. Looking at origin. And chromosome fifteen was a good choice. It showed heterochromatin differences which enabled us to determine origin even early on. And including the very few Prader-Willi patients who have had offspring. And of course, when they have a child, it is now a maternal loss, the child will have Angelman syndrome.

HAYFLICK: So this is the Prader-Willi/Angelman chromosome 15 deletion story?

MAGENIS: Yes.

HAYFLICK: So you're, tell us—

MAGENIS: I was considered a radical. "It was not, couldn't be." But we did every kind of comparison that we could think of, that we had the tools for.

HAYFLICK: Your discovery was that they were the same—

MAGENIS: Deletion, but a totally different phenotype.

HAYFLICK: Was that the first time the basis for Angelman Syndrome was recognized?

MAGENIS: Yes. Some pediatricians at CDRC became interested, also. And said that there was a probable Angelman case that they had been working with. I'm not sure that they called it Angelman. They brought the child in, and there it was—a probable Angelman syndrome case. And chromosome 15 was deleted. That's what I wanted to do. See if the child had clinical Angelman "syndrome" as the diagnosis before the chromosomes were examined.

HAYFLICK: That was the late '80s. Is that right?

MAGENIS: Yeah. In the '80s, yes. There was a lot going on in the '80s. A lot of new tools and new thinking.

HAYFLICK: Yeah. Contiguous gene syndromes.

MAGENIS: Yes.

HAYFLICK: Imprinting. It wasn't—

MAGENIS: But now there's array testing. We have a patient whom we have studied in collaboration with Sarah Elsea, who appeared to possibly have Smith-Magenis syndrome. And after chromosome testing we didn't find any abnormalities. And Sarah sequenced the SMS region on chromosome 17 and did not find any abnormalities.

Eventually Sarah did array testing and found a deletion of chromosome 2 long arm. Clinically the child was similar to the Smith-Magenis patients. There are other reports in the literature of patients with this deletion who have features somewhat similar to SMS. However, they have very distinctive bony abnormalities of the hands and feet.

HAYFLICK: It's unusual for a clinician/geneticist to also operate a clinical laboratory. That's a little bit less common, particularly these days. And I'm wondering how you think your role as both physician and laboratory director, and really involved very intimately with the lab, how you think that either helped or hindered you in both of those arenas.

MAGENIS: Well, I think it helped, because it gave me an "in" to be able to look at the patients and then do the chromosomes, and come up with something different. The thinking was good.

[tape change]

HAYFLICK: This interview of Dr. Ellen Magenis was conducted on December 9, 2008 in the Vey Auditorium at OHSU as part of the Oral History Program. The interviewer is myself, Dr. Susan Hayflick. This is tape number two.

We were talking a little bit about your being both clinical geneticist, that is, hands-on practicing physician to patients with genetic disorders, and also the head of a very well known clinical cytogenetics laboratory. And I was asking you how you thought your role in both of them either benefited or maybe in some ways perhaps limited, but how that influenced your work.

MAGENIS: Some of this, I'm not quite sure how to say. But I think that it allowed a lot of background information, including the emotional parts, and parts that might be devastating to be dealt with in both respects. You're not going to take away the devastation, but you can stay involved. And I think that's one of the reasons why I wanted to stay involved, as did many of the patients. They want to come back, and they want to find out more. Go home and read about it and see what they find, and then come back again.

And that endeavor is not always acceptable to some of one's colleagues. And I think that's the area I've had the most trouble with, particularly recently.

HAYFLICK: So you maybe found yourself being able to follow patients from their first visit through their cytogenetic maze, back to the discussion of an abnormality to further—

MAGENIS: Exactly.

HAYFLICK: Further studies, or further exams of other family members and maybe even reaching into other generations or extended family members.

MAGENIS: Yes.

HAYFLICK: But that was often, and perhaps now maybe more than ever, with all the limitations on how we practice medicine, that that was not how most people did it and maybe connected you, I think, to families in a way that wasn't so typical for physicians.

MAGENIS: Certainly male physicians. But other female physicians that I have known, because there are more now, more in pediatrics, more in some of the laboratories. And the attitude is different. And I think they see some of the limitations as I do, as well, when all the talk seems to turn to money rather than what we can do to help the families and the patients.

HAYFLICK: Yeah. So the forces that influence the way we practice, you've seen a lot of changes in your years as a professional. You've seen changes in the technology, and certainly the ability to diagnose. You've seen changes in the economic structure of medicine.

MAGENIS: And the ability to support the families.

HAYFLICK: Yeah. You've also been in a—

MAGENIS: And there's also jealousies, particularly if others think you have a possibility of making more money, and they would want to do that.

HAYFLICK: Jealousies, you mean, among other physicians.

MAGENIS: Yes.

HAYFLICK: Geneticists aren't known for being particularly highly paid physicians, though, are we?

MAGENIS: Physicians anyway. But there still are some that are entrepreneurs out there.

HAYFLICK: Right.

MAGENIS: And if you believe that males and females, that if you trained them appropriately from birth, you could change their attitudes, it becomes quite clear that males are males and females are females, for the most part.

HAYFLICK: Yeah.

MAGENIS: Some ambiguities, but—

HAYFLICK: That that Y chromosome really actually has some purpose?

MAGENIS: [laughs] Yes, I guess. Yes. And I'm totally blessed with the fact that I have two daughters (out of seven), so, quite different.

HAYFLICK: So one of the other changes over time that I imagine you've observed, or maybe even had some unique perspective on, is that you're working in the field of genetics, which has both a very prominent scientific history, with the discovery of the structure of DNA and many, many that followed, but also has a somewhat colorful and maybe dark history with eugenics. And I'm interested in some of your perspective on differences you've seen on maybe how patients have been cared for, particularly those with genetic disorders, how they've been viewed by society, some of your perspectives on those things that have changed, what you've seen.

MAGENIS: Spending time at Fairview, and how the sexes were managed, gave a rather dark picture of what people thought in the past. That you don't bring children into the world that will be mismanaged, or can't be taken care of appropriately in the "normal" way. And it's true that sterilization was extremely common. Jesse had been sterilized fairly early on after her Fairview arrival. And my thinking on it is it's mixed. It's hard to be cut and dry, depending on the situations that occur.

I remember one family that lives not too far from Portland who had a daughter with Angelman Syndrome. She was in school and there were some dangers that she might, because she was attractive, and might have some "unwanted" attentions. The family wanted to have her sterilized because of that. They had to sell their house in order to be able to get the funds for legal coverage to be able to do it. So that's quite a different story than had been going on even fifteen years before, as far as the attitude.

HAYFLICK: They would have borne the burden probably of at least some of the caretaking of any child that their daughter would have had.

MAGENIS: Yes. And the marked limitations that the patients with Angleman syndrome have, even though they're not usually some of the more difficult ones as far as their personalities.

HAYFLICK: Yeah. Have there been other societal attitude shifts that you've, maybe particularly welcomed or particularly been at odds with?

MAGENIS: Well I think women are allowed to do a lot more than they were in the past. And there's, on the whole, some increased respect for abilities. Not always. So I think there is at least beginning to be some more respect for being able to do things other than sit at home, cook and make babies. Even though we're often very good at that. [laughs] And for being different.

HAYFLICK: Well, it's still a—

MAGENIS: It's still a man's world. As you go up higher.

HAYFLICK: There's certainly a-

MAGENIS: And more money.

HAYFLICK: Continued inequities and certainly much of the burden of raising a family still remains with the-

MAGENIS: With the mom.

HAYFLICK: Most of the time, yeah. What about for your patients? Changes in attitudes, or changes in their worlds that you've seen over the past decades?

MAGENIS: I think that there is much less possibility of having large institutions like Fairview, and change of attitude is part of the reason why it was closed. On the other hand, what they seemed to do with a lot of the patients was to "group them" together into smaller places. And in my own view, I think that a number of the activities that they did, that often is decried, is the fact that they had working farms. Fairview was among the many places where patients could be outside working and also learn. While many people seemed to feel that they shouldn't have to do anything, which many of them could. And even have some understanding and help with others.

Fairview attendants were better trained than oftentimes other caretakers elsewhere. And there were quite a few problems, including deaths because of that. Because caretakers didn't realize that treatment often needed to be scheduled, which was really important. And they weren't placed on the appropriate diets. So I thought there were some good things about Fairview. It wasn't all just horrible. We went there enough to see many caretakers that were very caring. Both men and women caretakers.

HAYFLICK: Do you remember your first impressions when you- I was never to Fairview. I have a kind of a mental image of it that's probably mostly informed by the newspapers in its very much later years. But do you have, can you tell us your impressions of Fairview when you first went?

MAGENIS: Fairview had one large building, but for the most part, patients were in cottages which housed only a few patients. And the caretakers would get to know the patients; some of the ones that they were interested in taking care of were difficult patients. And some of the physicians went to extraordinary lengths to try to help the patients and the families.

On the other hand, there were some mandatory events, such as the sterilizations until twenty years ago, maybe. I think they seldom do that now. And unfortunately, they had some inappropriate caretakers who used patients for sexual satisfaction. Thus there were pregnancies as a result. They learned that caretakers needed to be carefully screened.

HAYFLICK: Were there children there?

MAGENIS: Yes. Some very small, very difficult patients were children who needed round-the-clock care. And since they had caretakers there around the clock, for some of these patients care was very good. Of course, there were quite a few for a long time at Fairview who were left over from the days when if a child didn't learn in school, the child could be put in an institution rather than trying to help educate them and hopefully make them a little more self-reliant.

HAYFLICK: So there were, I'm trying to think of the times, and I would imagine there were patients at Fairview who now, particularly through newborn screening with congenital hypothyroidism, with phenylketonuria, PKU, who would actually not only not be at Fairview, but wouldn't be developmentally disabled. They would have been identified—

MAGENIS: No. But they were beginning to get more information in that regard. And there were several that became quite interested in genetics, or were geneticists, that would come to Fairview

HAYFLICK: So you would have seen a population of patients that really don't, at least in developed countries, don't exist anymore. That is for untreated—

MAGENIS: Unless it's missed.

HAYFLICK: Yeah. Yeah.

MAGENIS: And then there were the newborns that stayed as newborns their entire lives, who seemed to have fairly good cardiovascular systems. And that becomes very difficult, I think, when there is no sign of anything that they can see or tell you about other than just being there, being alive. And I don't know if we, I don't remember seeing anything recently like that, and I don't know why. So maybe something is being done well now. But there would be bed after bed after bed of some of these that were just—

HAYFLICK: In a big open ward?

MAGENIS: In a more open ward for most of them, where caretakers could walk around and see them and try to keep them alive.

HAYFLICK: Was it an emotionally difficult experience, going to Fairview? For you?

MAGENIS: First time. Even second time. Or particular ones you got interested in that were often more able. Like Jesse and some of the others. Depending on the syndrome, they might have a sense of humor that was quite different from the norm. It was very interesting what they found funny.

HAYFLICK: You developed, over time, you developed relationships with some of those patients.

MAGENIS: Mm-hmm.

HAYFLICK: As you have with many in the Prader-Willi/Angelman community in Oregon. Actually, in the Pacific Northwest.

MAGENIS: Well, particularly the Smith-Magenises. They didn't have quite a lot of problems. On the other hand, they have personalities that may be very, very interesting. The first time when we went to get a blood sample from Jesse, the oldest patient, and there were all kinds of notes in her charts about some of the difficulties she had presented. On the other hand, she was often very agreeable. And she knew when I came, she'd hold out her arm and sit down. And when she was transferred, then, into Shangri-la—did you know we had a Shangri-la outside Portland? [laughter]—Jesse didn't like to wear clothes. And of course they have their sleep problems at night. Authorities thought she was “bright enough” that she could live on her own.

So they placed her in a couple of rooms. She had a bedroom and a kitchen, and thought that she could take care of herself. And of course here she was, at night, awake. And several times she decided to take a walk. Well one time she took a walk without any clothes on, and she got picked up by the police! The tasks that they thought she could do, she couldn't. So that eventually they realized that she needed to have some structure— but she treated it sort of as a lark.

But I don't know what happened about that episode, but then one of the next times, we came out to try to get another blood sample and in follow up, she put out her arm as usual. And as soon as I got close enough to do the actual puncture, she pulled her arm away. And I said, “Jesse, we need to do this,” and so on and so on. So next time, she put her arm out, and as soon as I got close, she pulled her arm away.

So I thought, she loves all kinds of bright things, and I don't wear jewelry. So I decided to try another approach. She smoked. They used to let Fairview kids smoke. And so I said, “Here's a dollar.” And I put it down. Well, as soon as I got close to her arm, she grabbed the dollar and put it in her purse. Same thing. I thought okay; well let's try one more time.

HAYFLICK: That didn't work. [laughter]

MAGENIS: And so I had one of the nurses sit on the dollar. And then she let me do it. And as soon as she got her dollar, she ran down the hall to the cigarette machine and got her cigarettes. So she was happy, one way or the other. But she thought it was the funniest thing. Every time she did that, she'd laugh and carry on when she'd pull her arm away. Totally deliberate.

HAYFLICK: Yeah. So she had a bit of a sense of humor as well.

MAGENIS: Yes. Yes. They tend to.

HAYFLICK: Yeah. Yeah. And we could probably figure out what era that was, when cigarettes cost less than a dollar.

MAGENIS: [laughter] Yes.

HAYFLICK: Yeah.

MAGENIS: Toward the end, in her upper eighties, she didn't smoke anymore. But she still didn't like her clothes on. And every night she would go to bed with her dolls. And she had about twenty. They were all over the place. She had to go to bed with her babies. So you see a lot of very interesting behaviors in these patients.

HAYFLICK: Yeah. Yeah. It sounds like one of the, besides the chromosomal difference that you identified, one of the things that sort of has kept you connected to the community is the personalities of those people involved. Maybe some of the particular personality traits of Smith-Magenis Syndrome.

MAGENIS: Right.

HAYFLICK: But also the continued discovery that you know, the personality traits, the sleeping problems. There's been sort of a continued process of discovering what the extent of the syndrome is about. And similarly for Angelman and for the Prader-Willi communities. Yeah. Are there particular things that drew you to those communities? Or was it really the chromosomal, the cytogenetic abnormalities?

MAGENIS: Well, that was usually the initiating factor. And then you'd go to see what it was like, or maybe you'd seen the person in clinic and thought they had a chromosome abnormality. And that keeps one interested. And the families themselves who want to know if you find something else out. It's amazing how educated some of them will be after a while. You have to listen.

HAYFLICK: The ones who've had prenatal diagnoses, and are well informed coming in.

MAGENIS: Made decisions, yeah.

HAYFLICK: Yeah.

MAGENIS: As to what they want to do. One person who lives close to where I live had prenatal diagnosis, which was abnormal. The fetus had trisomy 9 mosaicism. It was really agonizing for the parents to decide what to do. The parents decided to keep the

baby. The child now at age 3 recognizes her parents, is mostly loving, walks and stays close to her parents. She has very limited speech. There is clearly a parent-child bond.

HAYFLICK: Sure.

MAGENIS: With the mother and the child. And the child seems to recognize the caretaker.

HAYFLICK: The whole area of prenatal diagnosis must have come along after your laboratory came along.

MAGENIS: Oh, yes!

HAYFLICK: Can you talk a little bit about the—

MAGENIS: In the beginning obstetricians would discuss the issues. Wouldn't it be a good thing to have prenatal diagnosis? But as far as true screening, the way it's done now is relatively new.

HAYFLICK: Were you involved in bringing that program to life here at OHSU?

MAGENIS: We weren't that involved with the OB community at that time. Much more now, and with the genetics.

HAYFLICK: So when the OBs were ready to start offering amniocentesis for prenatal diagnosis, did they come to you?

MAGENIS: The ones that were interested in doing that wanted to know more, and we did have more discussions, yes. And I think they anticipated the difficulties that it could cause. Including legal issues if there was an abnormality and felt that they couldn't handle the situation.

HAYFLICK: Are there other aspects of your career that you'd like to tell me about? Other aspects that I haven't specifically focused attention on? Things that I might not even know about?

MAGENIS: I think some of the problems that I've had have been with male individuals who disagreed with some of the thinking, and often were, to my view, somewhat prejudiced as to listening to the families and seeing what could they tolerate, what's best here, instead of forcing decisions upon them.

HAYFLICK: You maybe brought a unique perspective as a female physician to those discussions.

MAGENIS: Probably. And especially knowing exactly what a pregnancy and delivery is; one could discuss that with the patients, because among some women there is

a great deal of fear of what's going to happen, what's going to happen with their body afterwards. So many of these "glamour magazines" show individuals that are "stars" who have the "baby bulge." And pregnancy and delivery, some of it's not real. Or understanding, sometimes, the monetary situation may be very difficult with a child that's handicapped. It can be very expensive.

HAYFLICK: Requires a lot of time and emotional attention to have those conversations.

MAGENIS: And maybe they need surgeries. Even those that seem to have only cardiac problems.

HAYFLICK: Can I ask you some questions about maybe some of the changes that you've seen at OHSU in your time here? There have certainly been a lot of structural changes in the way the place looks, with buildings going up and canyons being filled up with hospitals, et cetera. You've seen a lot of buildings going up, I imagine. But when you came, you were in pediatrics. But there was a department—

MAGENIS: There was a department of pediatrics, oh, yes.

HAYFLICK: And a department of genetics at that time?

MAGENIS: No. When I came?

HAYFLICK: Yeah.

MAGENIS: No.

HAYFLICK: What was the department before—

MAGENIS: They certainly did genetics, and we had a laboratory, but there was no specific department.

HAYFLICK: So it was when Dr. Koler, Dr. Robert Koler took over the department. There was a department of experimental—

MAGENIS: Experimental medicine.

HAYFLICK: Medicine.

MAGENIS: That's what he ran for years. It wasn't called genetics.

HAYFLICK: Did you know that department before Bob took over the experimental medicine department?

MAGENIS: Oh, we'd worked together, sure.

HAYFLICK: Yeah. Do you remember—

MAGENIS: And I was in that department. And at CDRC. Before they called it CDRC, it was CCD.

HAYFLICK: CCD. The Crippled Children's Division.

MAGENIS: Crippled Children's Division.

HAYFLICK: Yeah. Was the CCD here when you came to OHSU?

MAGENIS: CCD was here. There was a small building. And it was only in the '70s that the CDRC building was constructed. They got a lot of federal money to build that building.

HAYFLICK: Right.

MAGENIS: And our laboratory moved there. So we were no longer in the basement with the cockroaches.

HAYFLICK: [laughs] So you got into the new building. That was probably quite a nice space.

MAGENIS: Yeah. We had most of the second floor. And the clinic was right down the hall. And so many of the other special disciplines were right there. For example, some of the dietitians became interested in Prader-Willi syndrome and would conduct individual diet plans.

HAYFLICK: When did you move over to the department of genetics? When was that formed?

MAGENIS: Hmm. I can't remember the year. But it was while Bob Koler was still—

HAYFLICK: Yeah.

MAGENIS: —the chair.

HAYFLICK: Do you remember the name of the chairman before Bob? I'm just trying to remember his name. He was quite a famous— I've lost his name as well.

MAGENIS: That's funny, I can't remember his name, either. It's gone.

HAYFLICK: When did you join the department? Was that in the '60s or '70s? You moved from—

MAGENIS: Well, when it was changed from Experimental Medicine, we all just kind of were in the department.

HAYFLICK: Yeah. But you still–

MAGENIS: But I was also at CDRC.

HAYFLICK: Yeah. Yeah. Can you talk a little bit about your, because I know you have a strong connection to CDRC. Can you talk a little bit about the culture of CDRC, and what drew you to that program?

MAGENIS: Well first of all, because of interest in genetics, I got involved with some of the families that would be seen at CCD, who did not like their approach. But eventually our clinic was moved there, which then with the new building became CDRC. There were special funds that allowed chromosome studies and some of the other genetic examinations. But by that time, we already had a fee-for-service laboratory function. And all of these changes seemed to work very well until there was a change in higher administration.

And so much of success in interactive functioning depends on the beliefs and personality of the President and the President's staff.

HAYFLICK: Shapes the whole place. Yeah.

MAGENIS: A different Kohler and a very different personality.

HAYFLICK: Yeah. Sounds like some of the changes that came with those new administrators were not welcomed.

MAGENIS: By many of us.

HAYFLICK: Yeah. Yeah. Maybe like for many places, there were some upsides and downsides to the administration. Certainly the university grew and increased its scientific depth and strength.

MAGENIS: Yes, in many ways. However, there were many arbitrary changes without maximum input.

HAYFLICK: Did you ever think about taking a more administrative role, either in this department or at another university? Did you ever think about becoming a department chair or a university president?

MAGENIS: No.

HAYFLICK: Why not?

MAGENIS: Not as interesting. The administrative people that one is interacting with often have different mindsets than the medical practitioners and patients. The needs of the people that you are dealing with are quite different.

HAYFLICK: It didn't have the same appeal—

MAGENIS: And I don't like being told “what to do”. I need to think it out.

HAYFLICK: Yeah. I think in some ways, I, in contrast to you, I am not a parent, but I wonder, perhaps, if the best training for university administration is being a good parent. Having good parenting skills. Figuring out how to get along with people and get what you need, and sort of shepherd a group, a diverse group, in one direction.

MAGENIS: Yeah.

HAYFLICK: Do you have regrets through your career? Any professional regrets?

MAGENIS: Most often when I feel regret, it's because I haven't done something when I had the opportunity. And maybe it was the right decision, but sometimes when there's a lot of money involved, the personalities of the group, even though the substance of what you would actually be doing might be very acceptable. It just makes life more difficult. And I felt with my brood of kids and relatives, that it would make it unpleasant.

HAYFLICK: Do you feel that there were any professional decisions you made, scientific decisions you made, discoveries you think you could have— No? Any sort of regrets about not pursuing a project?

MAGENIS: Yes. But on the other hand, again, dealing with people and some of their thinking, especially if their thinking was rigid; it would seem at first to make sense to try to sway them. However, when a person gets into an authority position that seems almost supreme, you tend to give up. And I'm sorry for those instances when I gave up.

HAYFLICK: Do you have any specific ones you are comfortable talking about? Or not so?

MAGENIS: Well probably not in this setting.

HAYFLICK: We could do it over a beer?

MAGENIS: Yeah. [laughter] I don't like beer. But on the other hand, it would be nice otherwise to be able to talk some things out, even if they can't be rectified.

HAYFLICK: Sometimes it helps just to air things.

MAGENIS: Mm-hmm.

HAYFLICK: It sounds like one of the personality traits that you have that contributed to your success and staying power is the ability to push in ways that were sort of discouraged for women of your day.

MAGENIS: Yes.

HAYFLICK: That you were not willing to sit back. Why? Do you attribute that to just who you are as a person? Or is that your parents coming through?

MAGENIS: I had a wonderful mom who tried to look out for everybody, but there were limits. And you do right. You don't do wrong. You do right. I could hear her so many times saying to my brothers.

HAYFLICK: You talked about your dad a bit, but not so much—was your mother, was she a working woman as well, outside the home?

MAGENIS: Only occasionally. Both parents came from the South. My father had a little more education. My mother went to sixth grade, but always was able to manage things in the family. So she was a good person to be able to emulate. And a lot of love.

HAYFLICK: How did she feel about your going on in medicine?

MAGENIS: She was okay with it. She was fine. But she would never have pushed it in the way my father did. One of my brothers was slow, and there was always that comparison. And sometimes I wondered if he just hated the whole thing. But he was always supportive. We never had any problems about that. In fact, he would seem to be proud of me that I could do it, even if he couldn't.

HAYFLICK: Did your father follow your career as you became well known?

MAGENIS: In his way, yes. He was much more of a loner. He was an only child on a farm in South Georgia. Hillbilly country. So my parents had to really push it to get where they were.

HAYFLICK: Yeah.

MAGENIS: And take care of things.

HAYFLICK: Yeah. Did he have that same ability to push people that you have? Was that a trait that you gained from him, do you think?

MAGENIS: He was just more of a loner. But by example, sometimes things happened. But he never was quite the same as my mom, who wanted you to behave

appropriately and not cause trouble. Don't hurt anybody else with what you're doing. Her mother was like that, too.

HAYFLICK: Were they proud of you?

MAGENIS: I think so. I think my father was probably a little concerned that I didn't take to religion.

HAYFLICK: You had your own form of religion called science.

MAGENIS: [laughs] Yes. Yes.

HAYFLICK: Yeah.

MAGENIS: And they always, they were very concerned about education, and making sure that we children had the opportunities to get educated. My younger brother was, he had quite a sense of humor, too. But he died when he was nine of what surely would not have been that much of a problem today. He had strangulated bowel post having had surgery for appendicitis.

HAYFLICK: Oh, yeah.

MAGENIS: But my father was always interested. And he wanted to make sure, because they weren't quite sure why he died. And he insisted that if he was going to sign for it, he wanted to be there at the autopsy. So he did.

HAYFLICK: It helps to have answers.

MAGENIS: Yes.

HAYFLICK: I think that's why science, I wouldn't call it a form of religion, but it's a different approach to getting answers.

MAGENIS: Answers. Mm-hmm. Exactly.

HAYFLICK: Are there other highlights in your career, or comments on where the field of genetics is now? I imagine you've seen some pretty big changes in your area of cytogenetics. But in the field as a whole, that you'd be open to reflecting on?

MAGENIS: Well if we include the clinical aspects, there have been changes that I personally think were good particularly with increasing abilities to make diagnoses, and others that I think were not. A lot of what I consider the drawbacks are the money aspects. There may be, even particularly in the university setting, because there is less money that is supposed to go around to help people. And you're not supposed to be a Gates, or even the Knight family, or even a Drucker, who seems to be able to manage all that has happened without getting too superiorly oriented.

HAYFLICK: Yeah. There's a certain challenge in that accomplishment. But I think you're right. He has—

MAGENIS: And because this university didn't treat him very well when he needed this equipment, and when he needed a different space. I felt that it was the kinds of things that I'd been getting at times.

HAYFLICK: Yeah.

MAGENIS: And usually is not quite so obvious in the male. And I think part of that was his personality.

HAYFLICK: Sara has prompted me with a few questions to ask. Who were some of the most influential people in your career, either positively or negatively?

MAGENIS: There have been quite a few that, and I wish I could say there were more women. But I remember Mary Ban in high school, who took an interest.

HAYFLICK: She was one of your teachers?

MAGENIS: Yes. And the science teachers, as a group. I began to realize that if you're interested in the sciences, there is an almost universal help that is given from people that have become teachers in those fields. And so there would be several, several of them, whose names at this point I have to get out my yearbooks. [laughs]

HAYFLICK: That's from a ways ago. How about at OHSU? Were there people who we would now refer to as mentors of yours?

MAGENIS: Well, with the good and the less good, Fred Hecht. He was brilliant in many ways. But emotionally, he had a lot of difficulties with relationships. And one has to remember that, and then, of course, there are the others I've worked with several times: Neil Buist, Everett Lovrien.

HAYFLICK: Everett Lovrien.

MAGENIS: And trying to work with that personality was not always easy. But he was a good man.

HAYFLICK: I didn't know Fred Hecht, but I certainly knew Everett Lovrien. He was here when I first came. And he was a very independent thinker, and quite an independent actor.

MAGENIS: Exactly.

HAYFLICK: He liked to do things his way. He was very charming and fun, but he liked to function a little bit outside of the mainstream.

MAGENIS: That's true. And we don't know where he is right now. We are trying to find him for some further history.

But when a couple of my sons were older, they became more interested in what I was doing. They're not in the humanities; they're engineers. And they came in with me one night. (When some of them were little, sometimes I'd have the little ones, even, on a floor on a pallet so they could sleep.) And they noticed Everett Lovrien, as he was going up and down the hall. Well, if there was some equipment he needed and it was left in the hall, he'd take it. [laughter] So there he came, and of course I was there late. So the boys included that in their memos as far as the nighttime escapades. With my name on it. And they framed that, my kids, and put it up on the wall. They thought it was so funny.

HAYFLICK: He was a real character. Yeah.

MAGENIS: Not mean.

HAYFLICK: No, not at all.

MAGENIS: Were there people who you would say negatively influenced, or were troubling in your career? If you're comfortable talking.

HAYFLICK: Mostly at a higher level.

MAGENIS: Yeah. There were, there was one, at least two, that I think had some kind of defect in abilities in relationships. And those are more recent.

HAYFLICK: Can you talk a little bit about sort of how you coped with that? Or how you managed?

MAGENIS: Well, sometimes you can't really manage. People that switch you from one position to another to put their friend in your spot. Things that you feel that you have built up. And I don't know that I should say much, other than that. A couple of them are still around.

HAYFLICK: Can I ask you, we were trying to remember the name of the chairman of experimental medicine before Bob Koler became chair. It was Edwin Osgood.

MAGENIS: That's right!

HAYFLICK: Sara has reminded me. Did you know Dr. Osgood?

MAGENIS: Not well. But yes.

HAYFLICK: What was the overlap of your time at OHSU?

MAGENIS: He was, several years. But he was doing less and less. But what I remember is his thinking ability.

HAYFLICK: Can you describe a little bit about him? I, of course, didn't know him.

MAGENIS: Well I was very late in his career. And he was not talkative as some are. I would have to go in and talk with him. But he had a lot of special values and interests. He was able to think through problems logically and often to correct them. Fred, who didn't seem sometimes to value so much of other people's personalities, I think valued him quite highly. And Bob Koler.

HAYFLICK: Sounds like Osgood had a reputation for being a very smart person.

MAGENIS: A good person, too. Yeah. And then there were some other people around at different levels that were quite notable.

HAYFLICK: Yeah. Yeah.

MAGENIS: But there were some very good people that stayed on for quite a while. Even with some of the changes that most of us didn't appreciate. And mostly administrative.

HAYFLICK: Can you comment, Ellen, just looking back over what you would say has pleased you the most?

MAGENIS: Being able to work with the families, and with my peers, without fear. With some of the administrators you oftentimes have anxieties about, because you feel that you're not being effective in carrying out what needs to be done. People that don't interact.

HAYFLICK: You've found certainly a strong group of colleagues at various stages of your career, as I've commented on before. A strong connection to many of the families, and many of the family support networks that you've maintained a very close connection with. Those have been highlights for you.

MAGENIS: Yes.

HAYFLICK: Yeah.

MAGENIS: We had a very successful, I would say, Christmas party for the Prader-Willis in spite of the fact that of course the main reason why we felt it was necessary is because they couldn't be taken to regular holiday functions with food

available, because they'd even gobble enough that they would have to eject some of the food.

HAYFLICK: Yeah.

MAGENIS: But parents go along with it. And I think one of the difficulties through those years were do-gooders who believed that everybody, including the mentally retarded or unbalanced, had the right to do their "own thing." And not thinking about what it does to the families, et cetera, or to their health. And had some legal run-ins with some of them in trying to teach about appropriate diets for Prader-Willis for example. For several years, we were able to use some of the dietitians at CDRC, until they started having fewer and fewer actually hands-on kind of people. So such people can be difficult in their drive and, what shall I say, enthusiasm for rights. Well, we have rights. But we don't have unlimited rights, supposedly intelligent people. So we have to be curbed sometimes.

HAYFLICK: So you're referring to the inclination for most people with Prader-Willi Syndrome to eat incessantly and really in a pathological way—

MAGENIS: Exactly.

HAYFLICK: —that leads to progressive morbid obesity and really very—

MAGENIS: And even death.

HAYFLICK: —very serious medical complications.

MAGENIS: Right.

HAYFLICK: And that it's not within the, within the rights of a person with Prader-Willi Syndrome to drive themselves to death through food, that there's a need to intervene.

MAGENIS: That's what I'm trying to say, and others. Yes. But no, there are some helps. And maybe along the way they'll figure out exactly what the food drive is due to.

There's a new researcher here, Dr. Marks, who's been working on morbid or pathologic cachexia, and particularly in patients with cancers. And is coming up with very rational kinds of partial solutions. I've been wondering if he might have insights with other syndromes such as, Prader-Willis.

HAYFLICK: As the other side of the coin.

MAGENIS: As the other side of the coin.

HAYFLICK: Is that Dan Marks here at OHSU?

MAGENIS: Mm-hmm. Do you know him?

HAYFLICK: Yeah. He works in the weight regulation center.

MAGENIS: Right.

HAYFLICK: Yeah. Regarding Fairview, you had quite a lot of professional activities down there. Did you participate in the legislative activities around Fairview?

MAGENIS: No. No.

HAYFLICK: Were you asked to? Or your opinions were not necessarily sought?

MAGENIS: Not in that regard. I thought it was not wise to close it as quickly and as completely, and the problems that happened once they were sent out into communities or smaller homes.

HAYFLICK: It certainly shifted the problems, didn't it?

MAGENIS: That did.

HAYFLICK: Yeah.

MAGENIS: And with so many of these conditions, it's not just a single problem that needs attention. As you've been pointing out, the legislation to downsize to the smaller homes. Right now there is, one of the Prader-Willi homes, the small homes, I think it only has three individuals in it. But they're ones that are on the more intelligent side. And they're being allowed to drink alcohol (so we have been told), which Prader-Willis don't need in addition to the usual calories, in that regard. They've been allowing the clients to go to nude programs. (I don't know what you call those), where they have nude dancing and other things like that, including the alcohol. And one wonders how much one should push this home.

HAYFLICK: Weren't you instrumental in bringing about the idea of putting people with Prader-Willi Syndrome together in adult foster kind of situations? Because their problems are consistent between them in needing to manage access to food?

MAGENIS: Oh, they are felt to need to be with others like them.

HAYFLICK: But wasn't that a— I remember—

MAGENIS: I don't know if that was my idea or a bunch of us. It's best described as, when there are several siblings sitting at the dinner table being served. And one of them says, "He got more than I did!" And if the child with Prader-Willi syndrome is

around others who can eat normally, it can be very difficult to maintain the Prader-Willi diet.

HAYFLICK: Yeah.

MAGENIS: To try to manage one so differently than others.

HAYFLICK: Yeah.

MAGENIS: And doesn't seem quite so onerous to have the kinds of diets that allow them to have to stay within a reasonable weight.

[End of interview]

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