

National Eye Health Education Program (NEHEP) History Interview

Judy Stein *and* Rosie Janiszewski

Conducted by Edward McManus

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Mr. McManus: Rosie Janiszewski and Judy Stein are here to talk about NEHEP and its history. And first I kind of wanted to get an update from them on what are the latest—even though this is going to go through 2001, I was just kind of curious for myself what are the latest things going on with NEHEP?

Ms. Janiszewski: Well the latest things going on with NEHEP...well, we're currently in a five-year planning phase for 2006 through the next five years and that is working with the NEHEP planning committee, the partnership and the subcommittees. We're preparing a plan that will then be presented to the National Eye Advisory Council in September for their approval. So that's what's currently going on overall for the program. We are also going to revisit doing a national survey that we did when the program was launched in 1991 and we are getting geared up to do that and that will be building on the questions that were asked then as well as adding some questions that were not relevant at the time such as low vision and older adults and we'll be doing that with the Lions Clubs International who were the co-funders before so it will be a nice transition, the follow up on that. Some of the newest things that we have going are the community awards programs where we give \$10,000.

Mr. McManus: Oh Right. How much is that up to now?

Ms. Janiszewski: Well, we—this year we funded 52 projects at \$10,000 a piece.

Mr. McManus: Wow that is really significant.

Ms. Janiszewski: So we started with 34 programs the first year.

Mr. McManus: What was the first year?

Ms. Janiszewski: 2003.

Mr. McManus: Because that was really—I'd kind of forgotten about that. That was really a nice edition for your partners. How many partners do you have?

Ms. Janiszewski: We currently have probably about 62 partners.

Ms. Stein: Of course the community awards go to many people that aren't partners.

Ms. Janiszewski: Probably um, I would say 99% of them go to people that are not within the partnership. Because they're intended for local organizations. Universities cannot apply, any medical

research institutions cannot apply. I mean it's really local community based. So a lot of our partners are not even eligible as organizations.

Mr. McManus: Yeah, I wrote up a lot about the annual conferences. Do you still have—I don't know if it was always an annual conference?

Ms. Janiszewski: Every two years.

Mr. McManus: Every two years and you had one last year?

Ms. Janiszewski: We had one last year in South Carolina, the next one we're going to skip 2006 and we'll go to 2007. So it will be a two years.

Mr. McManus: How would you say that NEHEP is doing these days?

Ms. Janiszewski: I think that—from my perspective I think its going very well. Um, I think with the expansion and to Healthy People 2010, and the 10 vision objectives that we're adding to that program, I think provides a lot of the partnership organizations a greater opportunity to get involved in programs that the NEI has.

Mr. McManus: I want to get some of these questions I have before I show you a draft.

Ms. Janiszewski: Um-hmmm.

Mr. McManus: But I decided to be really straight forward about Healthy People 2000 and Healthy People 2010. We'll see what Carl thinks about this. And I described Healthy People 2000 as a real missed opportunity. And I say that really, Carl and I were sort of against that kind of collaboration and dealing with it. And then I—one of the things I say, who was to ever think that a pediatric surgeon like Edward Koop was going to be the national spokesman for health which kind of came out in 2000 and then when 2010 came around it was a real opportunity. So, all that will blend in pretty good.

Ms. Janiszewski: Um-hmm.

Mr. McManus: I had some specific questions back to the beginning and your outlooks will be were very useful. But I remember a lot of discussion about diabetic eye disease and glaucoma and at the beginning Carl was leary about doing glaucoma, because you know, diabetes we had definitive trials, with glaucoma... You probably don't remember but Timolol had just been approved and that was not an NEI supported study and some of the others... So, he was a little unsure about starting off with glaucoma. Then it looks like they kind of went on a parallel track but I can't remember if they did or they didn't.

Ms. Stein: They did.

Ms. Janiszewski: Yeah.

Ms. Stein: They were pretty much parallel.

Mr. McManus: But you remember, was—do you remember those concerns in the beginning too?

Ms. Stein: Well, the messages, we didn't have the strong science in glaucoma that we did in diabetic eye disease so we really struggled with the partners and the planning committee to figure out what our message was with glaucoma. Who our target audience should be, how old they should be. I remember there was a lot of debate about Blacks over what?

Ms. Janiszewski: Over 40, over 50.

Ms. Stein: And everyone over what?

Mr. McManus: I'll just step back a little bit too. Clinical trials, international programs, and NEHEP are three of the major chapters in the book because they are considered by Carl and I to be three of the major things where the NEI made their mark. And that's why the NEHEP is addressed. As I get into it and get back, I remember enough, and you gave me enough that I already have quite a good chapter and I want to make it as good as I can. That's about kind of where I am and you know where these concerns are and they ended up kind of going on a parallel course.

Ms. Stein: You know I think we had some marching orders to do glaucoma.

Ms. Janiszewski: Exactly.

Mr. McManus: Well I put Tony Fisket and Terry Lierman and Merck and then Carl might take it all out before it's all completed. I think it was Tony. Tony Fisket from Merck.

Ms. Stein: From Merck.

Mr. McManus: And Terry was his lobbyist and they wanted and I put that in there—they wanted to start a glaucoma education program and we said no that we'll do diabetic retinopathy and maybe later on get into glaucoma. And that's Carl and my recollection of that part. And then when I'm looking at the history, it looks like they kind of merged. I never felt that uneasy, quite frankly, about the science basically because we had drugs approved by FDA for glaucoma but I know that Carl would have like for them to have been NEI supported clinical trials.

Ms. Stein: Well, it was also kind of a preventive thing, a blindness prevention thing, so I think we were always comfortable that it was a good thing to get people at risk in to get their eyes examined because if we found something at least it could be controlled.

Ms. Janiszewski: Correct. And I think the problems with glaucoma really came with the age groups. We knew African Americans were at greater risk but there were no trials to say what age.

Mr. McManus: No epidemiology data, okay.

Ms. Janiszewski: So like that. I think when we did the KAP survey I think we had African Americans over age 50 and then our message ended up being African Americans over age 40.

Ms. Stein: Yeah, and I don't remember why we made that change, do you?

Ms. Janiszewski: Yeah, I don't remember.

Ms. Stein: There was a reason at the time.

Ms. Janiszewski: And then there were other organizations in the glaucoma field, Prevent Blindness also had in all their publications 35 and under. So the age difference was probably the one variable that was the least.

Mr. McManus: Okay.

Ms. Janiszewski: But um... Did you have, did you also look at planning the partnership?

Mr. McManus: Yes

Ms. Janiszewski: Because that has—that really shows the parallel track they both took.

Mr. McManus: Right. I did. Uh, then early on when we were trying to get help from Heart and Lung because they had a program, there was a guy named White.

Ms. Stein: Michael White.

Mr. McManus: Mike White. And he was the head, was he the head of that program?

Ms. Stein: He was the head of the high-blood pressure program—education program back, way back when.

Ms. Janiszewski: Way back when.

Ms. Stein: Way back when.

Mr. McManus: He participated in the first conference. He was helpful to us I remember.

Ms. Stein: Yeah, I think so. Yeah, I remember him.

Mr. McManus: I remember Janet and Mel Blank.

Ms. Stein: He gave a presentation.

Mr. McManus: Then, when we started our education program there was just Cancer.

Ms. Stein: And Heart.

Mr. McManus: And Heart. And did—I remember Diabetes kind of ceding their program to CDC in the beginning.

Ms. Janiszewski: Well CDC, they—no, no. CDC always had a diabetes program from day one. NIDDK didn't come on board until probably much later with their education program. The National Diabetes Education Program.

Mr. McManus: Right, right.

Ms. Stein: Was it after ours?

Ms. Janiszewski: It was way after ours because they looked at ours as the model.

Mr. McManus: Way after ours. And she—you'll have to look at it but I mean, I remember that it's about the same thing that CDC had the program and not...and I actually remember...

Ms. Janiszewski: But it wasn't an education program.

Mr. McManus: Oh, it was a, it was the controlled...

Ms. Janiszewski: It was not an education program. It was their diabetes control and prevention program which dealt with service delivery.

Mr. McManus: That's right and they had grants...yes.

Ms. Janiszewski: It was not an education.

Mr. McManus: But did they put any education activities in it?

Ms. Janiszewski: I mean, you could use the money to do education but it wasn't necessarily a national program. If they developed something it was done in the state level it was not done at the national level.

Mr. McManus: Okay.

Ms. Stein: But the National Diabetes Education Program is jointly sponsored.

Ms. Janiszewski: Right, but that came after ours.

Mr. McManus: Yeah, I remember.

Ms. Janiszewski: But at that point that's when they were looking at more surveillance.

Mr. McManus: See, I was just trying to set up that when we started NEHEP, it really was looked at by a lot of people here. It's not something that NIH should do, I mean Heart and Cancer really were strongly for it.

Ms. Stein: We were probably the first smaller institute to start an education program.

Mr. McManus: And Arthritis?

Ms. Stein: They really don't have one.

Ms. Janiszewski: And I don't even think they have anything.

Mr. McManus: But it's down at the CDC.

Ms. Janiszewski: Arthritis?

Mr. McManus: Arthritis when we were at the Alliance, they get something like \$13 million a year that they give out to the Arthritis Foundation.

Ms. Stein: But is that just to run their information and referral service or is it an education program?
There's a big difference.

Ms. Janiszewski: Yeah, caused a lot of...

Ms. Stein: There's a big difference.

Ms. Janiszewski: Yes.

McManus: Clearing house. Sure.

Ms. Stein: Clearing houses are not education programs.

Ms. Janiszewski: Right because that's how Aging does it because they have their ADEAR program for Alzheimer's.

Ms. Stein: But it's not an education program.

Ms. Janiszewski: Um-hmm, yeah.

Mr. McManus: Okay. Who else has an education programs now?

Ms. Janiszewski: It's still only the four, as far as I know.

Ms. Stein: Uh, Neurology might be having something but I'm not sure if it's the same kind of program.

Mr. McManus: I'll try to clear this up...

Ms. Stein: Brain...

Ms. Janiszewski: Well people have...

Ms. Stein: Brain awareness stuff.

Ms. Janiszewski: But that's usually done with industry. A lot of people have public service campaigns and different educational campaigns but not, to my knowledge the national program the scope of what we have.

Mr. McManus: Partnerships... What I'm trying to do is show how it was difficult in this culture to kind of pull it out, being a small institute, you know. And uh, okay. Let's see what else I have. You know when we agreed there was a lot of debate in the first conferences about what the terminology was going to be about who you referred people to. And was the answer, was it an eye doctor?

Ms. Stein: Eye care professional.

Mr. McManus: Eye care professional. Not an eye doctor.

Ms. Stein: No, eye doctor had a negative connotation for one of eye care professionals.

Mr. McManus: Okay. I do quite frankly say that there was a competition between the professions that was long-standing before our thing, and whatever we did might lead to a patient being referred—at least the suspicion, or the jealousy that a person might be preferred one place and maybe they should go another. And I just thought it. And I also say that the National Society to Prevent Blindness had an education program and you know, and the bottom line for that, so they were jealous of our starting, and in fact, I was approached and said why don't you just give the money to us in a grant and we'll do it all. And one of the things I say is had that been that been a viable alternative and had they been doing the job we would not have had to have the National Eye Health and Education Program or at least that's the way I handled. But at least we're saying that when you all review it

you can decide whether it's in and we'll see if Carl wants to be that confrontational. Okay. You know the dilated eye exam was another thing that I can, I kind of remember a lot of the discussion and I do talk about the committees that were set up the planning committees. I think the planning committee in this instance, you know, over the years was very useful...

Ms. Stein: Still is.

Ms. Janiszewski: Um-hmm.

Mr. McManus: Yeah. And was it—I remember some discussion about the dilated eye exam maybe being too difficult for optometrists to do. Do you remember any of that?

Ms. Stein: No.

Ms. Janiszewski: Uh-uh.

Ms. Stein: The only thing that I remember about dilated eye exam was that it was a concept that people weren't familiar with and we had a hard time trying to figure out what words to use and how to explain what it was. But I don't think there ever was—to my mind, that there was never a problem where one could do it and one—anybody could or couldn't do it.

Ms. Janiszewski: Right.

Mr. McManus: As you get to writing this stuff sometimes you know, you want to make things more controversial than they were because this makes more interesting reading. So, I'll chuck that...

Ms. Janiszewski: Another thing was at the time were optometrists were allowed to dilate the eye because it was based on state by state...

Mr. McManus: Oh that's a good point.

Ms. Janiszewski: I remember looking at—I think that was a part of the discussion.

Mr. McManus: So I could say something like that.

Ms. Stein: The availability to use eye drugs?

Mr. McManus: I could say something like...yeah.

Ms. Stein: I think it had to...

Mr. McManus: I could say something like that that there was, you know cause that had to be authorized in the state, and there was some discussion and I'll just leave it. I won't go back to try to find out exactly what it was unless I end up talking to Tony Adams or something...

Ms. Janiszewski: I was going to say yeah, talk to them. But I remember looking...

Mr. McManus: You're right, you're absolutely right.

Ms. Janiszewski: In the AOA News, they'd always have a map in there of what states could now use...

Ms. Stein: Dilate the eyes.

Ms. Janiszewski: Dilate the eyes and use drugs.

Mr. McManus: I could say that there was some controversy about that because this was being decided on a state by state basis and probably you know it gave them ammunition to get it done.

Ms. Stein: And we we're recommending it for everybody at risk.

Mr. McManus: It probably gave them ammunition. You never know. And please, if you have any thoughts as you go along. One of the other things is the AAO meeting at the Academy that we had—I forget where it was, when I think Bruce at the American Academy of Ophthalmology (AAO), when Bruce Spivey wanted to meet with us, and I think you were there Rosie, I know Judy was there. And he was really concerned about—it's like the American Academy of Ophthalmology first realized we were having a NEHEP program. We were about two years into planning. We'd been very careful, and uh—but he was concerned about the training of retinal specialists.

Ms. Stein: I don't remember any of that.

Mr. McManus: Yeah.

Ms. Stein: What about it?

Mr. McManus: They were very concerned that we were moving ahead with the program and they didn't have enough uh...

Ms. Stein: Oh, they didn't have enough people to examine...

Mr. McManus: Yeah.

Ms. Stein: ...to examine people. I do remember something about that.

Mr. McManus: To me that was one of the most—its funny how that was one of the most confrontational meetings I'd ever had with those guys about anything.

Ms. Stein: Well was I at it? You might have had it yourself...

Mr. McManus: Carl and I may have had it with Julian Morris.

Ms. Stein: Yeah, it's probably not down at my level.

Mr. McManus: Well, we might have been leery of uh...

Ms. Stein: I do remember the issue, now that you mentioned that...

Ms. Janiszewski: Now when you mention that versus...

Ms. Stein: And I guess what, I guess there might have been talk about waiting... until

Mr. McManus: Yes, exactly.

Ms. Stein: There were enough doctors to examine everybody, but we were determined to go ahead because we figured that the demand would drive the...

Mr. McManus: Exactly. And we—Carl and I figured it was...

Ms. Janiszewski: Because they were afraid that all these people would be going in to—they would be diagnosed with having diabetic eye disease and they'd have to be treated and there wasn't enough people to treat them.

Mr. McManus: Right.

Ms. Stein: And we just didn't think it would be this problem.

Mr. McManus: And my feeling about all of that was that this is a catch up issue for them.

Ms. Stein: Right. And that this would help push them into doing what they should be doing anyway.

Mr. McManus: Exactly. So I...

Ms. Janiszewski: Then they wouldn't keep up with the—and also the demand was just like they would be overwhelmed...

Ms. Stein: Stampede.

Mr. McManus: Actually, the way that I put this and I'll look forward to your comments, is that one of the things that we didn't do is have legislation to start NEHEP.

Ms. Stein: Yes we did.

Mr. McManus: Authorizing legislation. We had appropriation language put in one appropriation Bill by Terry Lierman.

Ms. Stein: Yeah.

Mr. McManus: And there never was our authorization language has never changed.

Ms. Stein: Oh, oh, oh, hmmm.

Mr. McManus: And when Heart and Lung did it and Cancer did it there were major, major reauthorization hearings, you know that...and so everybody in those communities had a chance to be part of that and a lot of these kinds of frictions that came up were settled then. So the American Academy of Ophthalmology couldn't say that they didn't know what was going on. But the way we did this, I think caused some of those problems later on and I say that and in retrospect it probably would have been better even though I didn't like going through all that authorization stuff and all that, you know because maybe you never get something done. It would have helped—I probably wouldn't do it again today, but it would have helped that particular problem. It would have let them, you know, get all their arguments out and everybody, but I think that the way I finally came down on it, is the program probably never would have come out as clean as it did, you know with all those people having a chance to change things.

Ms. Stein: I don't ever remember discussing that particular issue because all I remember is that we had our marching orders and we were marching (laughter).

Mr. McManus: We did but it would have—some of that you know, consensus building and stuff. And you guys did a great job with all the conferences and like that, I mean it really, it was needed because we hadn't done any of it before. And most of those—those other two programs, I can remember when the legislation went through on Cancer and Heart and they were—that was weeks of hearings when they did that kind of stuff. And it would have really probably..., so I have a little bit in it—I like to say it's kind of interesting for somebody looking at how you get things done in the government.

Ms. Stein: Yeah.

Ms. Janiszewski: It's real good to know.

Mr. McManus: Well, it was a cost for you guys because you had to work uphill because we didn't do that.

Ms. Stein: Well, ignorance is bliss sometimes (laughter).

Mr. McManus: Uh, okay. The applied research projects—and I know this is one of those things where I was dilly-dallying over in here and you guys were trying to do your stuff and uh—but do you remember, the way I remember the history of it is that Carl—we didn't have any research, we didn't have the research base on how you would go about intervening. And so one of the things, the ways to do it was to start to try to do that research base as you were going, at the same time you were launching a program. What were your recollections about that?

Ms. Janiszewski: Well, I think the research programs didn't come out until probably is it '93, '94, something like that? I think they were..

Mr. McManus: Funded then.

Ms. Janiszewski: Funded, yeah. I think that was the qualitative—or the quantitative research that we kind of looked at. We did research all the way along the way.

Mr. McManus: Right, right, right. The focus groups and how the message would—yes, but I'm talking about the Chuck Bash that apply, with Chuck Bash and the SUNY people and the Oklahoma group and there might have been another project in there.

Ms. Stein: There were just the three, there was just the three of them.

Ms. Janiszewski: Um, I'm not quite sure that—I think there probably just in hindsight, there probably should have been a stronger applied research program that we could have learned from. Um, I don't think it hurt our program, but to date there still is no...

Mr. McManus: Its had no impact.

Ms. Janiszewski: Yeah, I mean 15 years later we still have research on what works and what doesn't work. So, what we've done is we've taken all our examples from other diseases and tried to apply those to eye health. I mean we recently funded—that was just recently what three or four, maybe four or five projects um, in health education again, but ...

Ms. Stein: It's never been a strong program.

Ms. Janiszewski: It's never been a strong program, no one has ever taken it on...

Ms. Stein: It's never really been—it's never really been a big priority.

Mr. McManus: Yeah, I mean I wanted you to—if I'd have stated low vision would be one where I would have had two or three low vision centers.

Ms. Janiszewski: But then there's probably more of that, I mean if you're looking at centers, but if you're at the research of what works and what doesn't work, there's probably more of that in the low vision research than there is in the others.

Mr. McManus: Then there is in the others—yeah.

Ms. Stein: Um-hmm.

Ms. Janiszewski: Cause no one is really looking at education and what works and what doesn't work.

Mr. McManus: Yeah.

Ms. Janiszewski: So you take those principles from other disease areas and just apply them.

Ms. Stein: I think the Bash project had some good results with the telephone intervention from that first round. I don't think the other two had anything we could use.

Ms. Janiszewski: No, but the other thing that—which is interesting is with the Stoneybrook one is that it didn't look good for ophthalmology so that paper has yet to be published anyway, they refused to publish it because it doesn't look good for their profession.

Mr. McManus: Yeah.

Ms. Janiszewski: I mean her research her wasn't the best but she had some really interesting results and she can't get anybody to publish it.

Mr. McManus: I wonder if the Paul Lee papers on diabetic retinopathy were ever...

Ms. Janiszewski: Those were never...

Ms. Stein: Was that part of ours?

Ms. Janiszewski: No, that wasn't part of ours.

Mr. McManus: No, no. That was a grant that he put in.

Ms. Janiszewski: Those were never published either.

Mr. McManus: Because you know, they, the—some people took from that research that part of the problem with motivating diabetics to come in for an eye exam was the record of the ophthalmologist in doing those eye exams.

Ms. Janiszewski: That was part of the problem with the Stoneybrook one too. So.

Mr. McManus: Yeah, yeah, very interesting. I don't know how will we get...

Ms. Janiszewski: Even today she can't get it published. Nobody will publish it.

Mr. McManus: Well, I'll say something about that later, what I'm going to say, I don't know.

Ms. Stein: Maybe you can publish it in your book (laughter).

Mr. McManus: Yeah.

Ms. Janiszewski: Maybe you can put it in Outlook.

Ms. Stein: An appendix.

Mr. McManus: Well, it's nice to have it some—I mean it will be in this oral history. So it's nice to have it someplace where if anybody ever needs to go to it, you know they can be directed there without any fault or any body's part if it's done right. Okay, uh. You know one of the things in NEHEP—in the chapter on NEHEP, I put the 25th anniversary exhibit as part of the NEHEP chapter.

Ms. Stein: Sure.

Mr. McManus: And I kind of explain it that—what I said as one of the first cases of multi-tasking. We didn't use those terms in the government but the NEHEP folks, because we only had so many people, you know, and so the exhibits were included as a part of NEHEP. And the low vision exhibit was really more part of the NEHEP than the 25 year anniversary exhibit.

Ms. Stein: Yeah, that's true, yeah.

Mr. McManus: But still, there was overlap between, you know, everybody in NEHEP helped out with the exhibits—it's kind of multi-tasking.

Ms. Stein: Of course.

Mr. McManus: But the celebrations themselves were first held in ophthalmology departments and then optometry.

Ms. Stein: Oh, you're talking about the public information network?

Mr. McManus: Yeah, yeah, yeah, the network. I needed the name for that.

Ms. Stein: The Vision Public Information Network.

Mr. McManus: And that came out of the people who did the exhibits.

Ms. Stein: Yes. The way that sort of bubbled up is that when we traveled around the vision exhibit that went to science museums?

Mr. McManus: Right.

Ms. Stein: As we went to each place we worked with local host committees that were composed of representatives from our grantee institutions in that area plus other people. And the representatives from the grantee institutions were generally people from the public affairs office or developmental office or community relations office, that kind of thing. And we had such a good experience working with those people that it occurred to us that they would be a good group for us to, to get together...

Mr. McManus: Whose idea was that?

Ms. Stein: Whose idea?

Mr. McManus: I'll take credit for first setting it all up.

Ms. Stein: Oh, okay (chuckle).

Mr. McManus: I just wanted you to know that.

Ms. Stein: I don't remember.

Mr. McManus: I don't say that I was there... But anyhow.

Ms. Stein: The first meeting was just a couple of people in a restaurant in San Francisco, adjacent to an American Academy of Ophthalmology meeting.

Mr. McManus: Right.

Ms. Stein: And we kept the two—we started a group for people representing eye research centers and departments of ophthalmology and then we started a separate group for schools and colleges of optometry and they were meeting separately for seven or eight years. And when they met it was always adjacent to their professional annual meeting. And then I personally had always wanted to merge the groups together.

Mr. McManus: What year did you do this?

Ms. Stein: Maybe you wanted to do it too, I don't know.

Mr. McManus: No, no—I say that they were merged and I think that that's one of the greatest things that happened and one of the first real collaborations of you can say that ophthalmology, optometry collaborated with NEHEP and they were on the eye council together but they didn't—it wasn't really a true collaboration, as was this. I think it was one of the greatest things that happened to bring those two groups together.

Ms. Stein: Yeah, and they're still together. They've been, uh, it's been one group for four or five years now.

Mr. McManus: I'm hope it was in our time frame when I was looking back at Healthy People 2000, you participated in the first news conference that they had, the big kick off. You remember that? It's in Outlook I read through that.

Ms. Janiszewski: We weren't involved in 2000.

Mr. McManus: No, Judy presented at 2000?

Ms. Janiszewski: Because Julian—that fell under Judy's uh, Julian's office at that time. Healthy People was not out of this office.

Mr. McManus: Oh, okay then it could have been information...I thought it was you though. I'll have to check that.

Ms. Janiszewski: No Healthy People was something that was with Julian's office in 2000.

Mr. McManus: I'll check.

Ms. Stein: Healthy People 2000 which was way before that.

Ms. Janiszewski: Um-hmm.

Ms. Stein: I don't recall. I don't ever remember being involved in it.

Mr. McManus: Okay. What were your thoughts, I told you how I explained it. What do you guys think about the opportunity for Healthy People 2000?

Ms. Stein: We weren't involved in it.

Mr. McManus: No, I mean was it a missed opportunity as I said?

Ms. Janiszewski: I would say probably since we're in it 2010.

Mr. McManus: Then it's really worked out well.

Ms. Janiszewski: Mike Davis, if you want Healthy People history you might talk to Mike Davis on that because to my knowledge is that the Eye Institute was not willing to take the lead.

Mr. McManus: No Carl and I didn't want to do it.

Ms. Stein: Even with Healthy People 2010 I think there was limited enthusiasm. You really pushed it.

Ms. Janiszewski: I pushed it yeah.

Mr. McManus: And I pushed it because then I was advising the PBA. John Shoemaker was really—you know I was on their board and he was really lobbying me for that and when he finally told me that all of the state departments of public health look at that for their marching orders if you want to get anything done at the state level. I never understood that. And they had to have a government representative lead it to the federal level. I think I've written about this pretty well when you see it. It makes us look at it as kind of like a real missed opportunity. 2000 was too. And it doesn't hurt me much to say this cause in the chapters that I've written, I haven't said many things that we've missed the boat on, so it makes it all more credible too. I think that was one we really uh—but then I think it was part of some of the culture around here that you just explained. I mean no other small institute has an eye health education program, you know, it's a part of the culture you

deal with in this place, which is too bad. Who are the major collaborators in the low-vision program for organizations?

Ms. Janiszewski: AFB and the Lighthouse.

Mr. McManus: The Lighthouse, not the Lions?

Ms. Janiszewski: Uh-uh.

Mr. McManus: AFB and the Lighthouse.

Ms. Stein: Um-hmm.

Ms. Janiszewski: And then of course optometry and ophthalmology.

Mr. McManus: Yeah, but really the AFB and the Lighthouse. Okay.

Ms. Stein: Do the Lions do something in low vision?

Ms. Janiszewski: They do now because we have materials for them but they didn't address low vision at all.

Mr. McManus: Okay, you did talk about those others—but I just thought that the Lions had done more but they didn't.

Ms. Janiszewski: No.

Mr. McManus: What was the name of the shopping mall group?

Ms. Stein: International Council of Shopping Centers?

Mr. McManus: National Council of ...

Ms. Stein: International, I-C, International Council of Shopping Centers?

Mr. McManus: Yeah, what was the story about that a little bit? And this was the low vision exhibit.

Ms. Stein: The low vision exhibit. Well, as I recall and I will credit you with this, Ed (chuckle), that Jean and I went and talked to you about doing something, some kind of exhibit for low vision. And I don't remember how the idea came up that it should be at shopping centers, but it was during a conversation.

Mr. McManus: I think it was you guys idea.

Ms. Stein: Okay well—whatever (laughter), nobody wants to take credit for that one.

Mr. McManus: It's a good one.

Ms. Stein: But we knew that we wanted something that people wouldn't have to pay for. So we wanted to get it into a place where people would be able to go there for free. And the target audience would be likely—I think the target audience for the low vision program had already been established by then.

Ms. Janiszewski: Um-hmm.

Ms. Stein: And so we were just looking for a way to get out to that community that would make it easy for them to get the information, so we thought shopping centers would be the right

approach and Jean and I went to a meeting of the International Council of Shopping Centers, and they had a place there called, “Street of Dreams” and we were the first government agency that ever went there. And what it was, it was organizations sort of pitching...

Mr. McManus: We're the first government agency?

Ms. Stein: Maybe only, ever. I mean who ever knows if ever anybody else has? But the idea was that an organization could go and pitch an idea to shopping mall marketing directors and see if they liked the idea. So there were a bunch of voluntary organizations there and we went—we sort of mocked up an exhibit. We drew what we thought it might look like and we just talked to marketing directors for a few days. And there was a lot of enthusiasm.

Mr. McManus: And you won.

Ms. Stein: We what?

Mr. McManus: You won, you were selected or...?

Ms. Stein: Oh, there was nothing to win. It was just an opportunity.

Mr. McManus: Didn't you had to be selected though to...?

Ms. Stein: Well, yeah. Ten organizations went, but I don't know how much of a competition it was.

Mr. McManus: Okay.

Ms. Stein: But we did come out of that meeting with not only the feeling that it was worth doing, but we also had talked to some people from—and Jean could remember this better than me—but this company, this small company that had a chain of malls headquartered in Birmingham, Alabama. And they volunteered to host the pilot test of the exhibit right there at that meeting. So we came out and we knew if we built an exhibit that we'd have someplace to take it to test it. So it was very worthwhile.

Mr. McManus: I think that was one of, you know, very innovative kind of a thing. How does it work—you haven't really done the evaluation on it?

Ms. Stein: Well actually—oh, no, we haven't evaluated it but we're evaluating the public information network right now with 1% set aside for this.

Mr. McManus: I talk about the five-year and the ten-year evaluation and talk about most government programs like that really evaluate like that. I mean that's really pretty good. And I give you guys' credit for doing that.

Ms. Stein: I don't know if others do or not.

Mr. McManus: No, I don't—nobody. I was trying to think up any program that I'd ever been associated with, you know, that had evaluated itself and that surely, especially the 10-year evaluation was kind of done in a more neutral way.

Ms. Janiszewski: Umm, they've done it differently because they've had outcome measures. Heart, Lung, and Blood has it—they evaluated at more outcomes than the process. We can only evaluate process.

Mr. McManus: I know.

Ms. Stein: Cause they can really measure...

Ms. Janiszewski: Yeah. And it has made a difference and they have—their papers have all been published in peer-reviewed journals.

Mr. McManus: Hopefully with this, Lions...

Ms. Janiszewski: Well, we couldn't get the first one published.

Mr. McManus: Yeah, but if you have comparative data, you get a baseline. I mean...

Ms. Janiszewski: Also with Healthy People gives us some baseline too now. But no one was willing to give us any data sources for us to measure the program.

Mr. McManus: Right.

Ms. Stein: We are going to evaluate the low vision exhibit. We're going to apply for 1% and set aside funds probably later this year to do an evaluation of it because it's been on the road for a couple of years now.

Mr. McManus: Uh, on the ten year evaluation there was something in there that the founding members wouldn't recommend people join NEHEP?

Ms. Janiszewski: I don't know, I'd have to go back and look at it.

Mr. McManus: And you know, I would guess—it's in there and I saw it or you know, not that they wouldn't know and they wouldn't strongly or something like that and the contractors said this is something to really look at. I really you know, think about it and if you would get back to me on that, but it's when you—because I'm going to put something in about that and I really thought it goes back to the founding members of optometry, ophthalmology, and PBA, those are probably the ones and it goes back to their original turf concerns. See I think that whole meeting we had with the Academy was a turf meeting and that's all that was. I think it goes back to their old turf concerns. But if you get a—you'll see it when you see the draft of it. And that's what I say and basically the evaluation was very positive and I just wondered if you'd looked into that any more, or had the same conclusion as I had.

Ms. Stein: I don't recall.

Mr. McManus: Yeah. And I would be very surprised if the optometrists said that, I think it said some founding members and I would guess it was ophthalmology and PBA. Well, it was a

chance you know, if I were PBA I'd probably want to get a multi-million dollar grant too, and do it all myself.

Ms. Janiszewski: They got their money now.

Mr. McManus: They what?

Ms. Stein: They got their money now.

Mr. McManus: Where did they get their money?

Ms. Stein: CDC.

Mr. McManus: Oh, with the CDC, is that still going?

Ms. Janiszewski: Yes.

Mr. McManus: Is it?

Ms. Janiszewski: Hm-hmm.

Mr. McManus: How much did they get from CDC?

Ms. Janiszewski: I have no idea.

Mr. McManus: Like a million or so.

Ms. Janiszewski: They have the National Vision Education Program.

Mr. McManus: I think that they're probably zeroed out in this budget. So, what were uh, what are your next steps, are you going to do a plan for the next five years?

Ms. Janiszewski: Um-huh.

Mr. McManus: Those are the specifics. Are there any other things that you'd like to add about your experience with NEHEP and contributions.

Ms. Janiszewski: No, I think probably the strongest thing with NEHEP is just the partnership. I mean, that's what makes the whole program is all these organizations working together you know, and whatever battles they have on the outside they don't bring it to the table when they work with us.

Mr. McManus: Um-hmm.

Ms. Janiszewski: And a lot of their programs have expanded and they've responded due to the issues that we're dealing with and have developed programs.

Mr. McManus: Yeah, we are really interested in trying to tease out when we get the NEHEP—the new survey done. When you get the new survey done. What's really happening about people's awareness and hopefully it's improved.

Ms. Stein: Um-hmm.

Ms. Janiszewski: Um-hmm.

Mr. McManus: No, I'm sure it has, that would be really exciting.

Ms. Stein: I think the other good thing about the program is that the reason it—I think the reason it exists and is so successful is that the National Eye Institute is coordinating it, managing it, whatever the format, providing materials because I think we're pretty universally viewed as a new key source of information.

Mr. McManus: And accurate.

Ms. Stein: And accurate source of information.

Mr. McManus: I think the second even more than the first.

Ms. Janiszewski: Very credible. At least that's what I heard over and over this weekend, very credible.

Ms. Stein: Right, so you know, we can sort of bring organizations together that may not have worked together before and may have competing priorities and they've come together for a mutual benefit and for a cause that's important to all of them.

Mr. McManus: Do you, uh...what is the budget for the NEHEP now?

Ms. Stein: It depends on how you break it down.

Ms. Janiszewski: It's probably about \$12.5 million or something like that.

Mr. McManus: It started out like \$1 million or something.

Ms. Stein: I'd have to—I don't remember.

Mr. McManus: It was down \$1 million, \$1.5.

Ms. Janiszewski: It was low.

Ms. Stein: Yeah it was low. I mean it's definitely increased over the years.

Mr. McManus: But that still isn't a lot if you look at—does that include those applied research grants?

Ms. Janiszewski: Um-hum.

Ms. Stein: Yes, it includes that. And does that includes the Eye Sight and everything right?

Ms. Janiszewski: Um-hum.

Ms. Stein: So that's really all. It's really by far, the biggest budget item in our office and uh—what did Paul say?

Ms. Janiszewski: I wasn't there.

Ms. Stein: Oh. He said it was 1% or 3% of all of the whole NEI budget or something like that.

Mr. McManus: Half a percent.

Ms. Stein: Not much.

Mr. McManus: Well, very good. One of the things that I said in the chapter is that one of the reasons, the other reasons that Carl and I were kind of convinced that we had to do NEHEP was that we were trying to get the awareness of the National Eye Institute up you know. Appropriations had floundered, you know, increases in our appropriations and unless you—the whole game had change politically from a few people who know a few people

on Capitol Hill to the kind a public support the diabetes groups could generate. And we needed to get people aware of what the Eye Institute was and had come to be, and the NEHEP was a perfect vehicle. And I think it really helped the overall battle for the Eye Institute. So it worked both ways. You know the Institute was credible for NEHEP and NEHEP added back to the institute.

Ms. Stein: Well that's good.

Mr. McManus: Yeah.

Ms. Stein: I always felt—I think when I first joined the NEI and we were going to do this program, I think it was a very hard sell even though there was—not legislation, but there was a mandate to do it.

Mr. McManus: Right. Right.

Ms. Stein: I think that there was a lot of resistance in the front office about it just because it was something totally new and the way we were going about it I think surprised you because I think you had no idea what was going to be involved in developing this program. I think that the assumption was, well we're going to do a health education program and there it is.

Mr. McManus: And I do talk about all the careful planning, uh, the management initiatives and including evaluation that were really kind of part of the culture of the institute's way about program planning anyhow, it fit right in. And that was, I mean I thought public information, public education, a whole bunch of marketers, and didn't realize it was so solidly management based—and everything that you did was so well thought out.

Ms. Stein: Well, and I think to your credit. Your credit and Dr. Kupfer's when you realized that there was a way to go about it and we intended to go about it in right way that you let us do it because you wanted it to be right. So, it was right.

Mr. McManus: And you impressed the advisors too. One of them, Dr. Straatsma, was very important in the planning process and was impressed with the planning committee process. I'll see him in April and I'll ask him about that Academy meeting.

Ms. Stein: Oh, I'd love to hear. I'd love to know what he thinks about all of this because he was really critical.

Mr. McManus: And he was the guy that I thought was telling the ophthalmologists what was going on, but I don't think he did.

Ms. Stein: You don't think—you think he was just keeping it to himself?

Mr. McManus: I think because otherwise it wouldn't have been uh—but maybe he'll tell me, you know, that's just a thought, maybe he'll tell me something else.

Ms. Stein: Well he seemed to be...

Mr. McManus: He was President of the Academy at one point.

Ms. Stein: If he was as he appeared, and I have no reason to believe otherwise, he seemed to be extremely supportive of the program.

Mr. McManus: I think he was.

Ms. Stein: And I can't remember who else we had in that group. Well, Al Sommer I think was always very important to the program.

Mr. McManus: Yeah, well Al I can understand—but Straatsma had connections to the Academy, I mean he definitely had strong connections and that was a big surprise.

Ms. Stein: And he was very respected, so I think his endorsement of the program would count a lot in the ophthalmology world.

Mr. McManus: Right.

Ms. Stein: I think Julian was very important to the program.

Mr. McManus: I put that in. Actually as, you know, I didn't know how interested I'd get in doing this anyhow and as I did different ones such as Program Planning—like I didn't interview, Mike on the Program Planning, but I will now. And as I'm getting into the different things I'm getting more and more and more involved and I really give credit to Julian in the Program Planning. And then also over here with you guys because, I mean, he was the one person Carl and I would really listen to because we knew that he had a feel for what was going on in this arena.

Ms. Stein: Well we needed him a lot to help convince you (laughter) of what we were doing.

Mr. McManus: And we respected him, well we didn't know what the hell this stuff was all about.

Ms. Stein: No, and he didn't—you know, it was probably outside of his realm of experience too but he got it.

Mr. McManus: It was it was, but he was close enough to it till he could...

Ms. Stein: And he had your ear and he had your confidence. And you know when I came it took me a really long time to earn your confidence because what did you know and I'd never done it before so I had never planned a health education program.

Mr. McManus: When Rosie came you had somebody who had done it.

Ms. Stein: Yeah.

Mr. McManus: No I think the whole thing is exciting hopefully I can do a good job on it.

Ms. Stein: Now, when you talk about clinical trials are you going to talk about results dissemination? Cause that certainly has been a big deal.

Mr. McManus: I'm going to close this off for this part and we can uh—if I can close it off. Thank you.

End of Transcript