## Interview with: Ms. Joanne Angle, Executive Director of ARVO

Interviewed by: Dr. Carl Kupfer

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Dr. Kupfer:

Ms. Joanne Angle, the Executive Director of ARVO, and today is the 18<sup>th</sup> of May, 2006 and I will be conducting an interview. Please begin with your role at ARVO.

Ms. Angle:

To assist the National Eye Institute (NEI) in getting the word out about new research grant opportunities we started doing (email) BLASTS to the ARVO membership to let them know when there were these opportunities outside of the normal structure of the application for research grant process. That seemed to draw a lot of attention from our members and a lot of support for NEI being a party to this because they felt that that was something they would not necessarily have known about because they might not have made an effort to automatically check the pages about what new was coming out. It also was an opportunity, I think, for our members to understand that NEI was branching out and doing some things in collaboration with other institutes. So I think that gave them a sense that NEI wasn't being extremely isolated but that they were actually beginning to do some of those things. I think that also we helped NEI and the members felt very strongly about the fact that we were endeavoring to assist them in their search for ARVO funds was a founding organization of the National Alliance for Eye and Vision Research (NAEVR) and the Alliance for Eye and Vision Research (AEVR) and as such the whole purpose of that was to support NEI and to secure reasonable funding for that. Through this mechanism the ARVO members felt that they were able to support NEI in a way that before they hadn't been able to. In other words, it was a little bit more of a concerted effort than had existed before where one or two people would start to do something. At that time there was more interest in expanding funding for NEI so they felt that this was an opportunity for NEI to benefit from that. So I thought that was a good thing. I think in many cases we've had sort of a symbiotic relationship as we've moved forward. I think that the NEI has been very open to any concerns over the years that our members have raised and that we brought to the attention of the NEI, when there were opportunities for the staff or the director to make a change. Sometimes that was not possible and sometimes that was our burden to explain to our members that there were other forces at work within the Government that override many of the things that we think were perfectly logical.

Dr. Kupfer:

You mean the membership does not have a lot of changes at the NEI.

Ms. Angle:

Well, I think the move to support more educational training grants was supported. I think the move not to have the many big centers and large trials as other institutes had done was what they wanted and supported.

Dr. Kupfer:

You mean the clinical trials?

Yes, the clinical trials and the multi-center grants and there're some institutes that have grants to support large initiatives that just go on and on and on and that while clinically trial-oriented originally, it's almost as though they've become funding for those institutions apart from the clinical trials that they've done. So they thought that the research grant—individual research grant component emphasis by NEI was a strong feature and they were very resistant to any change. And so when change to this focus was brought forward I think the membership felt very comfortable in indicating that was not what they wanted to see happen.

Dr. Kupfer:

Right. Well this is discussed in the book as you might imagine. From what you were saying the fundamental researchers were very concerned when they look at a clinical trial costing \$5 Million dollars a year but this was taking money away from basic research in the laboratory. Well we addressed that very, very closely and made the point that there were two very large appropriations one that was \$15 Million dollars and one that was \$5 [million] specifically for clinical trials.

Ms. Angle:

Right.

Dr. Kupfer:

And we were able to compete very successfully for those funds and built our clinical trial program on that basis. But anyway, I'm glad to hear that. We heard, of course, a lot of concern upon the part of the investigators about large clinical trials and it was perfectly reasonable that they saw that. I must tell you though that the clinical trials represented a particular situation where if you're going to commit to asking the question, is treatment A better than treatment B? And it's going to take you five years to recruit the patients and another five to get the answer, you've got to support that institution for ten years, you're locked in. But once that is over and they come in for another grant it all starts over again to prove that this is something that's good.

Ms. Angle:

Right. And I think that was the major concern is that they didn't want to see that this was just an automatic renewal because they set up those processes.

Dr. Kupfer:

It's interesting you bring this up because I'm writing the clinical trial chapter now—well I've written it but I'm making it a little more readable. And one of the things that has come up is that the Cancer Institute did use clinics throughout the United States, a group of clinics would be interested in carcinoma of the lung, another group of clinics would be interested in GI tract problems and once they were funded their funding would go on and on and on and we stayed away from that model. The only time we even approached it was in the AIDS situation because the new drugs for AIDS were occurring so rapidly that we couldn't afford telling a potential clinic that they were going to have to put in a new application and it takes six months to review it and then another three months to decide to fund it. So that was the only time that we used what you might call the Cancer model. But otherwise we used the hard institute model where everything has to be peer reviewed. And even the clinical trials, of course we had the Data and Safety Monitoring Committee (DSMC) looking at the trial and continually making judgments as to whether to continue

or change or what have you. Well I'm glad to hear that that was a discussion because we've had that discussion quite a bit.

Ms. Angle: I can think of a couple of other things if you'd like to hear.

Dr. Kupfer: Yes.

Ms. Angle: Although the Center for Scientific Review was independent, the National Eye Institute

was willing to step in when the community recognized that there were issues that affected how their grant applications were being reviewed and in some cases the personnel issues to facilitate the review process. And I think that was extremely important to give a sense of support to the researchers that in the end what they were submitting was going to get the best review, the most timely review and move to the grant process. And I know that that was an area in which they felt that we were able to bring the issues before the NEI

and to vent them and to get support in the course of action.

Dr. Kupfer: How did these issues come up, in what sort of forum?

Ms. Angle: Well, they came up in a number of ways. Often it was people talking amongst

themselves then sharing with the ARVO office. Often it came through either committee meetings or via a particular trustee who then bought it forward to the leadership. In the late 90s our organization became more outgoing on interacting on a regular basis with the CSR staff and with the leadership. Prior to that I think the questions and issues were

directed more through you and your staff at NEI then over to the CSR and back then.

Dr. Kupfer: Well you bring up an interesting point, I don't remember the dates but I don't think I

began receiving an invitation to meet with the trustees until the '90s.

Ms. Angle: Well, I'm sure you didn't (laughter).

Dr. Kupfer: Right. I never could understand why because there is one episode that occurred in the

'80s, maybe you know about it. But we at the NEI decided we would really make a very, very significant push for clinical trials and that was a major part of our program. We had gotten these two large grants and gave us the resources and just about that time a

movement occurred in the ARVO to do away with the clinical trial and epidemiology

section.

Ms. Angle: Really, oh see I didn't know that.

Dr. Kupfer: And I was very confused because we should be working together and here they were

doing away with it. I could never get the rationale except I think there had been a wrestling match early on in the—I think even before the NEI was formed, as to who was really going to run ARVO was it going to be the laboratory people or the clinical people.

And the clinical people really owned ARVO initially. And they didn't want to give up

any control. And I think when they finally were forced to give it up there was a lot of animosity against the clinicians and this way someone tried to phase out the program.

Ms. Angle: Very interesting.

Dr. Kupfer: I told you something you didn't know.

Ms. Angle: Yes, I didn't know that.

Dr. Kupfer: I was hoping to find out why that occurred. But going back to the fact that at least until the '90s I was never asked to meet with the trustees and even when I was invited it was an outsider coming in for a brief 25-30 minutes and then asking, thank you, that's fine,

goodbye.

Ms. Angle: It was a very interesting situation and actually it's somewhat the same today. The current

Director, Paul Sieving, comes and generally talks with the Board at our meetings whether they're in Ft. Lauderdale or here in a local area. He comes for about 20 minutes, he comes in and says what he thinks is important and then there are times for questions and comments. But he has no difficulty in communicating with ARVO if there are things that he wants or anything that he needs. These are brought back to the Board or to other entities within ARVO. But, my sense of it all is that the Board never wanted to be considered as being either being beholden to the National Eye Institute or as spokespeople for the National Eye Institute. They thought that there should be an element of distance, but that there should be dialogue and that there shouldn't be any concern about ARVO to providing information or for you to ask for information on behalf of our members. The relationship as far as an on-going working relationship was felt to need a little distance. I would do it, I would probably do it differently but that's

the way that they wanted it structured. That's the way they still think thru today.

Dr. Kupfer: That's interesting.

Ms. Angle: And I don't know if they feel that they get enough information otherwise. I don't know if

the NEI has felt that they don't get sufficient support or have sufficient opportunities for interaction. I know for example, currently Dr. Sieving does go and I know that you did too, go to ARVO where we have an Ophthalmology Department Chairs' meeting and now we also have a Basic Chairs' meeting at which he speaks. We have a Clinician-Scientists Luncheon which you knew about that is in support of that program at NEI. The interaction of the people at the ARVO meeting, shows more give and take than has been in the past because of the comfort levels people have all the way around for an exchange of information. In addition NEI does its Grants Workshop. We now have a Research Grant Administrations Workshop that ARVO supports and NEI staff participates and has input into that. So I think we have more on-going working relationships that have been built over the years that make it less of a stand-off.

4

Dr. Kupfer: Yes.

Ms. Angle: I think it's more common and it's not viewed as out of the ordinary.

Dr. Kupfer: Well, that's good.

Ms. Angle: So that people don't feel that they have to hold back at any time, that they have to wait

for a specific time to ask a question or do something. I have some more (laughter).

Dr. Kupfer: Oh yes, go ahead.

Ms. Angle: I think that we also the fact that for a number of years, even in addition to the activities of

AEVR-NAEVR, ARVO did testify—had leadership testify on behalf of the funding levels for the National Eye Institute and the National Institutes of Health (NIH) because

obviously some of our members are funded through other institutes.

Dr. Kupfer: Right.

Ms. Angle: And that we have felt that that was an important contribution that we could make to

support the National Eye Institute. We also have appreciated the Travel Grant support that has been given to ARVO and that that sort of has been a good model for us to use to point to others. It's drawn young researchers in and has given younger researchers an opportunity to really understand a little bit more about the National Eye Institute before they even got their first grant in most cases. So we felt that that was a way by awarding these grants we've been actually able to promote the National Eye Institute even though it

was your money that allowed us to do that.

Dr. Kupfer: Could I just ask you a question? I noticed that there are many, many travel grants given

by the pharmaceutical companies and that sort of thing.

Ms. Angle: There are some.

Dr. Kupfer: Oh.

Ms. Angle: There aren't that many.

Dr. Kupfer: Oh, is that right?

Ms. Angle: NEI still is the largest one. Santen gives 7. Kowa gives 2 which I learned that I was

pronouncing wrong. Pfizer doesn't give any right now—there's one other one...

Dr. Kupfer: How many is NEI giving now?

NEI gives about almost 80. We've kept a limit of the maximum amount is \$700. We really haven't increased it, so we've really been able to keep it at a fairly high number.

Dr. Kupfer:

That's smart.

Ms. Angle:

This past year the number of grants increased dramatically because ARVO contributed \$50,000 for 50 travel grantees from outside the US because as you know the ones within the NEI grant are restricted to the US. In addition to the some of the pharmaceutical support, we also have support from journals. We also have support for travel grants from other organizations. But the only other large grant is from Retina Research Foundation— Alice McPherson.

Dr. Kupfer:

Alice McPherson's organization?

Ms. Angle:

Alice McPherson's organization, and that's about 20 grants a year.

Dr. Kupfer:

And do they decide who receives them?

Ms. Angle:

No, no—it all goes through the ARVO travel grant process. We have this very elaborate programming system to ensure that there's a tie to the actual review of the grants to the abstracts submitted. So it still works that way. Um, how else have we helped you? I'd like to think that one of the things that we've done over the years early in my tenure was the completion of the animals and research statement which we think brought some unity within the organization on this topic. And also people who were submitting grants by making known the parameters for what is acceptable and not acceptable.

Dr. Kupfer:

Um-hum.

Ms. Angle:

And then I just think that we've been able to offer NEI a broad spectrum of researchers as potential nominees for committees and for jobs at NEI, or for any type of need that NEI might have for identifying people working in a certain area. I mean we can use the ARVO database to identify women in support of NEI programs.

Dr. Kupfer:

Did you find that the membership was prepared to spend time on study sections because that's quite a responsibility. They find out very quickly.

Ms. Angle:

It's a continuing issue. And again that's been a continuing dialogue that we've had with the CSR about the study sections. It's very interesting because...

Dr. Kupfer:

When you say CSR you mean just of the NEI or in general?

Ms. Angle:

Well, yes but we look at the captive study sections as our main interests. Whether they'll remain captive is a whole other issue. But in particular the study sections are the ones that we look at, but some of the problems are across the Board with CSR, such as the

issues related to timeliness of pink sheets and tapping people to serve on a variety of study sections. Whether it would be the Ad Hoc Reviews or whether they're across disciplinary or they're special ones. I think all are hard to fill at any level because there are so many demands due to the mix that you need at any given time to fill the study sections. And again the process of trying to get clinicians able to participate continues to be a long-term problem and has gotten worse. We've encouraged CSR to have a booth at ARVO and they've done that for several years. Although now with the change in leadership at CSR, although we have a dialogue with them, through Tony—I'm having a terrible time with names today, uh Scarpa, the Director, participation has been discouraged. There are other changes underway and there is concern that we might loose our captive study sections.

Dr. Kupfer:

Well that would be a disaster, 'course that's part of the whole scheme of reducing the NIH to six organizations.

Ms. Angel:

Yes, exactly. And of course we've been very vocal on that also, working in conjunction primarily with Alliance.

Dr. Kupfer:

Well the Alliance has done a terrific job on that.

Ms. Angle:

Yes, and ARVO as a part of that, I mean the majority of the people who are speaking out are ARVO people.

Dr. Kupfer:

Sure.

Ms. Angle:

They are involved in it. But we've been very active on the reauthorization issue and it continues. In fact, there's a hearing to be held tomorrow with Zerhouni as speaker and then they have an equivalent of the old public witness testimony. Steve Ryan was supposed to speak again, but actually he is not able because he had a death in the family.

Dr. Kupfer:

Ohhh.

Ms. Angle:

But Peter McDonald is coming down and is going to do it. And it will be mentioned that we are proposing a question for the hearing from the Senate side—the hearing that will mention reauthorization and give us an opportunity to respond to it. So that's been everything that we've been concerned about and do so these were a few of the things that I thought might be of interest.

Dr. Kupfer:

That's good, if I could pick up from there. Do you, I don't know if you have any data on the course that we used to give, because I don't know the time we began and the time we ended (chuckles). And that was about 13 years.

Ms. Angle:

I can't tell you the exact time you ended but it was around, it was after I got there. And it was before we moved to Ft. Lauderdale. So, our first year in Ft. Lauderdale was '95. So

I'm thinking maybe '93 might have been—'92 or '93 might have been the last year. Steve Podos might know—that's one person and the other person might be Rick Ferris.

Dr. Kupfer: Maybe. We talked there; I mean I was there every year too.

Ms. Angle: I don't know. The other thing, would the grants people know? Because wasn't it a

grant?

Dr. Kupfer: Uh, I don't think so. This was actually run outside the NEI, tuition was paid and that sort

of thing and we had a contractor, and maybe I can reach her. I don't know.

Ms. Angle: At one point I had her number and I talked to her, but I don't have it anymore.

Dr. Kupfer: Sure, sure. I'll dig it up. I just thought maybe you had a fantastic remembrance

(laughter).

Ms. Angle: I honestly don't know, but I know it was before we even moved the office here.

Unfortunately, our historical records are...

Dr. Kupfer: It's a problem.

Ms. Angle: It is a problem. And you want to know about feedback to the membership?

Dr. Kupfer: The feedback is important.

Ms. Angle: Yes, actually it's very interesting. We were working with our foundation, as you know

ARVO established a foundation.

Dr. Kupfer: Um-hum.

Ms. Angle: And over the last five years we've done two ARVO courses—two courses at the ARVO

Annual Meeting, that were ARVO sponsored courses on conducting eye research, eye clinical trials. And all along we keep getting this, when are you going to bring back the course that used to be taught at ARVO that was sponsored by NEI? So we've done a

proposal...

Dr. Kupfer: You mean a clinical trial?

Ms. Angle: A clinical trial.

Dr. Kupfer: Actually I have the name of it—Clinical Vision Research, Biostatistics and Epidemiology

Approaches.

There have been continuing requests that we do a more robust one. And so ARVO and the foundation have put together a proposal which we floated to a pharmaceutical company. And that person, having been intimately involved with NEI, seems to think it might be a go. So we may be able to revive this and get this going. And actually we're going to do it a little bit differently. It will be what we call the traveling show. If we can have enough people that want to take it to places. But we're also going to try to do it as web modules. So that people can come in at their own pace, do what they need to do, or else prepare in advance to come to a course and then be able to ask more relevant questions, and bring their own examples forward. So that's the proposal that's on the table.

Dr. Kupfer:

Are you trying to make use of what was done in the NEI course in terms of the material?

Ms. Angle:

We don't even have the material.

Dr. Kupfer:

That's what I'm getting at. You could get it. Rick would have it. Fred Ederer would still have it perhaps.

Ms. Angle:

Who's that? Fred?

Dr. Kupfer:

Ederer, E-d-e-r-e-r. He was in charge of clinical trials at the NEI. He taught in the course. Dan Siegel who ran the OBE after Fred. And I could think of one or two other people—Ted Colton is a professor of statistics at Boston University. He was one of the outside people and he taught the biostatistics, he would have that.

Ms. Angle:

Okay. Yes, anything that you could give me, that would be lovely.

Dr. Kupfer:

Okay.

Ms. Angle:

One of the things that we are concerned about. We're fine on. I think we can do the epidemiology side without too much trouble, but the bio stat side is one are a in which we know we have to spend some extra time working. So anything that outlined what was covered would be really very helpful.

Dr. Kupfer:

Well, the people I mentioned usually kept their book for me every year. Now whether they finally threw them out, I don't know, we'll find out.

Ms. Angle:

I don't know at all.

Dr. Kupfer:

Okay.

Ms. Angle:

I don't know of any criticisms of the course, which is one of the questions that you had. Everyone just says, when are we doing it again? Dr. Kupfer:

Good, good. That's good to know. Ed had some questions that he wanted to add. I don't have them because I just spoke with him this morning. He wanted to know what your view was on the impact on program planning by the NEI? That generated a tremendous amount of concern as you might imagine.

Ms. Angle:

I think that as far as I can determine, it was actually on the whole favorably accepted. I think that there were always those people that were concerned that either their pet area wasn't covered enough, for example, lens. You know—everyone always wanted to have the largest portion. So I think that there was always concern that one area might be slighted over another. Then in the grants process it might lead to an inequity of the division of the—parceling out of the grants.

Dr. Kupfer:

Right.

Ms. Angle:

In actuality I don't think we saw that occur. I think that it was an early concern that didn't materialize. On the other hand it did help people because it gave them something to point to and say, well this is the areas in which there are national concerns. And there are opportunities and we need to be looking at these as ways to remove our whole field forward. So I think it depended on what they were. I think that they point with pride to the fact that there is a leadership role played by NEI in doing this.

Dr. Kupfer: activities?

Right. Another question was, was ARVO aware of the NEI's role in international

Ms. Angle:

That's very interesting, because actually I had meant to make a note because I was thinking about that a while ago. I was going to say, it was good that you were involved in IAPB and other groups because ARVO early on—well since I've been here, has had a number of international numbers. But when I came it was at 20% and now it's at 43%.

Dr. Kupfer:

Um-hum.

Ms. Angle:

And I remember you saying to me was, what are you going to do Joanne when you get to be over 50% international members? Well, I think the organization was aware that they had a large number of international members, but that in the context of the National Eye Institute they didn't see that the National Eye Institute by way of funding this group of members, which is always the major concern of our organization. With NEI unable to do much for the international contingent, when we established AVER that was a major concern because our contribution to that organization is based upon per capita membership. And when we assess 43% who are outside of the US for something that can be deemed essentially a US cost, it began to generate some issues. As such ARVO itself now has begun to take on a more proactive international outreach and is doing a lot more. In fact, now we had two international people that are on our Board, Shigeru Kinoshita was just named to the Board and Martine Jager the other one. Someone from Australia will be elected next year because there are two Australian's running against each other

for one of the sections. Donald Tan, chairman of the International Committee was added to the Board as an Ad Hoc member.

Dr. Kupfer: Who was that?

Ms. Angle: Donald Tan from Singapore.

Dr. Kupfer: Right, right.

Ms. Angle:

And we've branched out in all of our committees to add more people—and we've now added chapters. So, from our perspective, we're trying to be proactive. In the past, because we couldn't see a way to bring money to this community, which is of course one of the things that they wanted, I don't think that they felt that NEI had a great relevance to them. So we made a great point of saying, if you didn't have the NEI you wouldn't have the grants funded in institutions throughout the United States that allowed you to collaborate with those institutions or to bring your researchers over to work. So, if you pointed some of these relationships out then it made it a little bit more palatable on how they viewed the whole process. And we also said you have the NEI because it has a number of research opportunities and pointedly brings in people from outside the US to come for fellowships and to be a part of the intramural program. The one thing that I think has been missing and that we're now looking at, and that's the role of prevention in the grand scheme of things—because if you look at the most of the things that the NEI's focused on, it's been sort of basic science. There's been some elements of the epidemiology studies and some other trials and things that have been conducted outside the US. And I know there's been a long-term activity in China for example by NEI, but with these there's not been a big focus on prevention because it's always been felt that the CDC should be the one that handles that aspect. But now as we're working on the translational prevention has become more relevant. And as you did with some of the studies from the vitamin A and other nutritional things that do have an impact upon on either preserving or reducing severity of problems, then the prevention side tends to become a little bit more within the realm. And we just joined IAPB for example and we hadn't done that before. And we've been approached by IFOS to join them, although we're having some difficulties, and they have an international outreach also. So, we're beginning to look out a little bit more. And I know in some instances NEI has been very tied about what they can do outside the country because of the level of funding.

Dr. Kupfer: Well, you'd be interested in reading the chapter on international (chuckles) activities.

Ms. Angle: And I know that you've done other things too.

Dr. Kupfer: You know, it was sort of amusing to me in a way when I was—found out in a very roundabout way that the NEI was going to host a signing by the Indian delegation to have a memo of understanding between India and the United States in vision research. And that

was done last year, I guess, 2005.

Ms. Angle: Right.

Dr. Kupfer: Well the first one was done and went something like 1978.

Ms. Angle: Oh really?

Dr. Kupfer: Oh yeah. And I was the one who organized it with India.

Ms. Angle: Oh really?

Dr. Kupfer: We also had an agreement between the United States and the Chinese government.

Ms. Angle: That one I knew about.

Dr. Kupfer: We had an agreement between the United States and Italy.

Ms. Angle: No, I didn't know that.

Dr. Kupfer: And as a matter of fact that was signed by Mrs. Heckler who was the Secretary of HHS at

that time. And this has been completely lost by the community. Now these are very important relationships because they do allow the utilization of resources to have

collaborative work.

Ms. Angle: Right.

Dr. Kupfer: We have had several agreements with the Japanese government. In fact, the present

group of Chairman of Departments of Ophthalmology in Japan represents people who

came to the NEI Intramural program and we trained them in research.

Ms. Angle: Um-hum. Yeah. I didn't know about that, but that would have been a very important

fact for us to show as we were saying why we need to support the NEI and why we need

to use our dollars to do this.

Dr. Kupfer: And the Japanese are fully aware of this. And we had two programs. We had a program

with a senior Japanese scientists were allowed to come and work in the United States, short term or long term, but they were allowed to (?), and Americans would go to Japan.

John Dowling took advantage of that.

Ms. Angle: And yes, he's been going back since.

Dr. Kupfer: That's right, that's right. And then we have the young Japanese ophthalmologists who

have had some environmental research coming and spending two or more years in the

Intramural Program. And they were often paid—the Japanese government paid...

Ms. Angle: They paid for it.

Dr. Kupfer: So there are all sorts of ways to utilize it. And then there's another thing I can't seem to

get people interested in, the rumor between the United States and India right now is to

foster fundamental research which I think is good.

Ms. Angle: Yeah.

Dr. Kupfer: But the real opportunity is to do controlled clinical trials.

Ms. Angle: I was just going to say, the clinical trials.

Dr. Kupfer: It's so inexpensive there.

Ms. Angle: Really?

Dr. Kupfer: It's one-tenth the cost and recruitment—well the country has a billion people—very, very

fast.

Ms. Angle: Well then you have the mechanism set up with Aravind and those...

Dr. Kupfer: That's right. Have you been to Aravind?

Ms. Angle: Um-hum.

Dr. Kupfer: Good—good for you. Good for you.

Ms. Angle: In conjunction with NEI did that workshop in India, and then the workshop at ARVO.

Following that the memorandum was signed. In fact, we did a workshop at ARVO this year where the people who had been at the two workshops shared their information with others so that they could get more people involved in looking at opportunities either subcontracting for portions of the grant to get some work done outside of the US, for clinical

trials, or for some of the pedigrees.

Dr. Kupfer: That's right.

Ms. Angle: Because that's a huge issue.

Dr. Kupfer: That's right. The thing that concerns me is that what is happening.

Ms. Angle: Reinvention of the wheel?

Dr. Kupfer: No, no—not so much that but the people who have realized that India is a good place to

do clinical trials. It's a pharmaceutical company...

Ms. Angle: Oh yes, Alcon, and—yeah.

Dr. Kupfer: So Waver and they write the protocol. They decide who's going to look at the data,

how's its analyzed and everything like that. And that's the wrong way to train

ophthalmologists to learn how to do these things themselves. And there are some very

good statisticians in India.

Ms. Angle: Um-hum.

Dr. Kupfer: So, I think this is something that really should be done the right way.

Ms. Angle: Yeah.

Dr. Kupfer: We are probably the only institute. I think this is correct, that has consistently had a

contract with the WHO to do a lot of this development.

Ms. Angle: Yes, and I did know about the WHO one, yeah and I forgot about mentioning that one.

Dr. Kupfer: Yeah.

Ms. Angle: But anyway, I think that in general, the whole international aspect of things is actually

beginning to blossom.

Dr. Kupfer: Well, that's good.

Ms. Angle: And it's important. We have to do it. I mean we can't continue the way that we have

been, and operate efficiently. And you know our theme for our meeting was

networking—I mean global networking and this year it was 'Building International

Collaborations,' because that's how it's all going to go forward.

Dr. Kupfer: But the collaboration has to be where the some of the grants are actually having as their

PI the foreign national.

Ms. Angle: Yes.

Dr. Kupfer: I'm very proud of one fact. Do you know who Balasubramanian is?

Ms. Angle: Oh, Balu?

Dr. Kupfer: Balu. He is the third Indian scientist to receive a grant from the NIH as the PI with no

collaboration. Do you know what institute he got the grant from? Give you one guess.

Ms. Angle: Laughter.

Dr. Kupfer: I'm very proud of that because that's what we have to do. We can't treat them as

technicians and think that they are going to see more of the material that's valuable to,

what do they call that uh, "Fed Ex research."

Ms. Angle: That's a good term. I'll be anxious to see that chapter—very anxious to see it because I

think it will help us do a better job promoting the role of NEI.

Dr. Kupfer: In promoting, you said you wanted to focus on...

Ms. Angle: It's very interesting because one of the things that Ed McManus did when they had the

big changes at Prevent Blindness America, is that he put them in the situation of getting ARVO a seat at the table, so I represent ARVO at this meeting for two reasons. One was because we've always felt that they were sort of our community outreach arm, and the second thing is because of their governmental activities and what they're doing on the Hill. So we felt that there was a good relationship that needed to be developed. And of course they're very interested in the screening part and insuring that children would get proper care if they can. But it's not in every state and its not in very community, so there's a lot of work that can be done and yet there's a lot of concern about the screening about who should be doing and when it should be done and it's somewhat—unfortunately in some cases because it clouds the overall issue of at least making an attempt to do some

screening and you may miss a few but you may catch those that you really need to.

Dr. Kupfer: Well, this is a role for the citizens in the community to play.

Ms. Angle: Exactly.

Dr. Kupfer: You take a fellow who's an engineer or a lawyer or any level of intelligence and you can

teach him how to do refraction in a couple of hours. There's nothing mystical about it.

Ms. Angle: Right and the instrumentation is very easily used by someone with minimal training.

And so you even have a better reading and a better outcome than you had before.

Dr. Kupfer: Right, Right.

Ms. Angle: But it is a bit of an issue trying to do, but let me just out line everything. So, ARVO as a

whole has really not embraced prevention as an area in which they've had a lot of growth or a lot of interest and it is only now are we beginning to do that. This is something we don't even do on the international sites so it doesn't matter if the prevention side is involving the international populations or the regular populations with specific disorders

or diseases. So it's a learning process on the ARVO side also.

Dr. Kupfer:

Sure. Well, there are a number of organizations that do a lot of work overseas. Hopkins of course, the Doheny has a large component, UCLA in San Francisco has a large component, and you really go down the line and see, but they haven't been brought together and that would be something that ARVO could do because all of these people are members of ARVO.

Ms. Angle:

I don't think it's jelled yet, but—and the Board actually, I made them put it on the Board—agenda for this past meeting. I said we need to start having a discussion about what our role is going be. And so we started, but because there's not really anybody on the Board that is prevention focused, the discussion wasn't as fruitful as I would have hoped it would be. But I'm hoping that for example if Hugh Taylor gets elected next year or even Paul Mitchell who's also running, that one of the two of them will help to spur that side of things.

Dr. Kupfer: And you can also call on consultants you know.

Ms. Angle: Right.

Dr. Kupfer: The international scene is broader than one person. I mean what Hopkins does is very

good in one area

Ms. Angle: Right, exactly.

Dr. Kupfer: What UCLA does is very good in another area. And you want to really combine the very

best of each one of these organizations. And I think the Australians between Mitchell

and Hugh Taylor have really bit off a huge amount of work to do.

Ms. Angle: Oh absolutely.

Dr. Kupfer: And uh, I think it's great that they are going to be on the Board in one way or another, but

you want to—it would be like having everyone on the Board interested in corneas and

that's all (chuckles).

Ms. Angle: No, I don't think that would occur, but at least we need to work a little bit more. To

me prevention permeates all of the whole discipline at every step.

Dr. Kupfer: Do you know Leon Ellwein?

Ms. Angle: He's retiring.

Dr. Kupfer: Yes, he's retiring but he would be a very valuable person.

Ms. Angle: Yes, he's already told me he would work with us. So I've talked with him already.

Dr. Kupfer: Right, right.

Ms. Angle: Because what I would like to be able to do is maybe do something through our

foundation and to get some funds to do some interesting things. But we have to figure out exactly what those interesting things are and then we could go forward. So if you

have any ideas, I'm open.

Dr. Kupfer: Well, I'm on a group called the Friends of Aravind. Are you familiar with that

organization?

Ms. Angle: Oh yeah, I know them.

Dr. Kupfer: They're slowly picking up steam. And in India they're very strong and then the Prasad

Center is very strong under Nag Rao. But there are other places that are very good in

India also that should be cultivated.

Ms. Angle: Sure.

Dr. Kupfer: So I think this is an area that really has tremendous growth potential. I wouldn't worry at

the beginning, the question of money. That will come as you develop the programs. Last question that Ed wants, he wanted to know—apparently he was very influential in the move from New York to Washington and he said how did that finally turn out?

Apparently Dowling was involved.

Ms. Angle: I have no idea, that was totally outside of my tenure. If they decided they should make

the move I think you should contact those people and just ask them.

Dr. Kupfer: Oh, I see. Well, no I think Ed was just interested from his own perception, I don't think

that will go appropriately into a book on the NEI.

Ms. Angle: Probably not, but he should feel free to contact them.

Dr. Kupfer: Sure.

Ms. Angle: Because I know that it was of interest because when I first started, even though we'd

been in this area since '86, there were some people who hadn't really realized how

ARVO had evolved into a much more management driven association as opposed to one person really controlling it. It became more of a Board-driven, committee-driven thing. This is not to say that it wasn't to a certain extent, but evidently one person was pretty

powerful in controlling things.

Dr. Kupfer: That was before you were—who was that?

Kathleen McCasland was there. She's the one that they hired when they moved down here. They set up an office and hired an executive and that was Kathleen McCasland. And so she probably has some inkling about some of the politics, but the people that were actually involved I think probably were the ones more knowledgeable than any of us would ever be. And of course some of those things would never be committed to paper I'm sure (laughter).

Dr. Kupfer:

Well, do you have any questions that you want to ask of me?

Ms. Angle:

No, but it sounds like you are well into your task.

Dr. Kupfer:

Yes, we're pretty much done all of the writing, it's the polishing now.

Ms. Angle:

That's great.

Dr. Kupfer:

Being sure that we're making the right quotes and things like that.

Ms. Angle:

No, I think—I've always felt very wonderful support in working with NEI. I've always felt very accepted and I hope that people have thought that they could approach me and call me or send me a note or email me as everything now is all email. So I've never felt I've been out of the loop on things and that's not always the case with other organizations and their institutes. So I feel very privileged to have had a good relationship all along on all levels.

Dr. Kupfer:

Good. Good.

Ms. Angle:

So it's made my job easier.

Dr. Kupfer:

Well, that's great. I think the idea that ARVO is growing and taking on new responsibilities and trying to meet the fact that you have a growth that you didn't really need to work very hard at.

Ms. Angle:

We don't advertise for members. I mean we let people know we are here and stuff like that and we go to more meetings now, so more people know about us, but it's basically growing.

Dr. Kupfer:

I'm going to turn this off.

Ms. Angle:

Oh sure.

End of Interview