

**IECRN National Leadership Forum  
June 1, 2006  
Closing**

**Presenter:**  
**Barbara Alving, MD**  
Acting Director, NCRR

DR. SACHS: You all did a great job and we really enjoyed the reports. I think it was really very helpful.

I will urge everybody to go on the site and you'll see the reports probably tomorrow, as well as the Web cast.

Now, I'd like to ask Dr. Alving to come back up and close the meeting.

Thank you.

DR. ALVING: This has been an extraordinarily dynamic meeting and we greatly appreciate all the effort and organizational time that you've put into it.

I would like to thank Jody Sachs of doing an outstanding job, working with her committee, to organize this. Jody.

[Applause.]

DR. ALVING: And now you're going to say, "Okay, so show us the money. Where are we going, NIH?"

I have to make a confession. NIH gets funded annually from Congress. I used to think, before I came to NIH, "Isn't that wonderful? These investigators are funded for four years

and five years and it must be just great," but, actually, what we live on year-to-year, as we manage our budgets in the institutes and centers, is a year-to-year appropriation.

I've been here seven years. I've never seen it on time or on target.

Now, is this NIH's fault? So I think what we have to look at is an overall national agenda and I think it's up to the individuals who are going to benefit most from our efforts, and that's really the American public, to really make their thoughts known about what is important to them and what their priorities are, because Congress does respond to priority-setting and so I think that is an overall thought.

When you say we need more money to continue, let's say, bridge funding, for example, between studies, that means if you get money for that, then money doesn't go for something else.

When I once worked in NHLBI, we had a very forthright and careful director, French, you may remember, who said, "Okay. You get this, what are you going to give up," and it's a constant priority-setting.

What I would like to say is that maybe during the doubling of the budget, all of us have gotten much more dependent on NIH funding and I think it's time to really look

for all the other sources of funding that you can get.

What I would like to see is NIH funding go to as many people as possible. You can use that as leverage to get funding from other sources. Otherwise, we're going to create communities of haves and have nots.

The work that you are doing is extraordinarily important. NIH is very, very much focused on the community and on actually preventive medicine, as well as interventions in critical care.

I think all that you're doing is important. As you have seen, there isn't any specific home for this within the categorical institute so much.

They are, more or less, funding clinical trials and, certainly, when I was categorical, that is, disease focused, I really didn't think about, well, how is this getting done. I just knew we paid a lot of money to some data coordinating center that did an outstanding job. Isn't that correct, Dr. Wright? Isn't that how it usually went?

There's NERI, New England Research Institute. We have EMIS, Fred Hutchinson, all throughout Westat, all throughout the country, multiple, and they have the skills that they, too, rely on funding coming in, trial ends, funding goes away.

And let me just say, as you say, and ask for continued funding, as is only appropriate, I've never met a study yet that didn't ask for continued funding. Women's health initiative. How can you close shop on this outstanding cohort of women who have been collected forever?

Framingham. If you were an IC director, would you have the courage to shut down Framingham? It is on its third generation now.

So there is this devotion to continuity, shall I say, but then there's the other tension of churn, how do we get new money for churn.

And in an area and in an era of very tight budgets, we have to look at what we have and say, okay, what are the priorities, what is the churn rate.

And you're seeing this now with RFAs that used to be five years in duration, they're now four years in duration. You're seeing negotiations going on once you do get funding.

These are very, very tight times, but we're trying to do is manage in a very proactive fashion. This is still a \$28 billion National Institutes of Health and there is much we can be doing.

But I just want you to know that this goes on constantly as we try to think how we can best work with the

funding that is appropriated by Congress to bring the best results

I think you have really shown what can be done with NIH funding in very creative ways.

So what we want to do is continue to hear from you. We like to hear good things, but we're really interested in the critiques that are really going to make things improve and you're going to send them to Jody Sachs.

I think if you can think of better tools, better ways we can develop Web sites, develop tool boxes, we're going to develop glossaries and get them out there.

You have to realize you are interdisciplinary. So many of the MDs don't know all of the IT language. Many of your IT experts don't know what SOAP means. They think that's actually soap and they're kind of clueless, but they may not want to ask.

So you've got to assume that you're talking to people who have many different innate languages.

So, please, bring all of your ideas and suggestions to Jody Sachs. You're going to say, "Okay. So, well, what's next?"

We are debating that. We are looking at that. We looked at this meeting and we are looking at the overall funding

and the roadmap funding.

In the meantime, keep doing what you're doing very vigorously. Any way that you can combine your efforts, raise them to another level. I think it is wonderful to see how you are working together.

This provides for you greater visibility and it is going to serve you in the long run wherever we go and whatever source of funding you use.

So let's just take maybe two minutes so you can do a rebuttal or say something.

Anybody want to say something? I was very honest. That's one of my -- I'm from Indiana. I know Kevin is from Minnesota. I'm from Indiana.

Okay. Let's hear it.

DR. HICKNER: John Hickner, from Illinois, from Chicago. I'm not sure if that makes me honest, though.

DR. ALVING: Chicago, I don't know.

DR. HICKNER: Maybe you can't trust me.

DR. ALVING: Let's hear what you have to say.

DR. HICKNER: Just a question. One of the other roadmap projects was the National Clinical Research Associates Group, which had to do with health manpower training.

DR. ALVING: Yes.

DR. HICKNER: Research training. I know that hasn't gone through all the process yet.

Can you let us know where that is in the process and if there are any decisions about outcomes for that program?

DR. ALVING: I would say there are no decisions yet about that.

There certainly have been decisions about the CTSA's and we're all taking a great big gulp, we at NIH, you in the community, as we move forward on that.

MS. MELESE-D'HOSPITAL: Isabel Melese-D'Hospital, from the EMSC National Resource Center.

I just have a really quick question about dissemination. Is this going to be disseminated on, say, the NIH guide to grants and contracts or something that has a very wide dissemination in terms of finding out what the results of the reports are and giving feedback and so forth?

DR. ALVING: We would like to do that and are planning to do that. And what I would also like to hear from you are ways that you think that needs to be done.

For example, I think the Westat survey needs to be widely disseminated and I want to see many more hits on Web sites.

So I believe in redundancy. So I would really

appreciate any thoughts that you have that aren't attached to dollars. I mean, there is a lot you can do without exorbitant sums of money.

That's another thing when you talk about evaluation. We are very much for evaluation, but as you know, there is evaluation and then there is evaluation and sometimes contractors can come in and say, "Yes, we do this evaluation, we're experts, and that's a million dollars and that's a million dollars you don't get."

So we have to say how can we do things in a very cost-efficient and useful manner.

DR. SACHS: Let me add my two cents. There are two ways you can help.

One, fill out any comments and put them in the box, because they are all going to be posted on the Web site.

Two, fill out the evaluation form you received, because we want to know what your thoughts are for this particular meeting.

And, three, when you go on the Web site, there is a forum box where you can put in your comments, where you want to see the results posted, what you suggest are next steps, what you suggest to us.

We will take all those comments and we will also post

them all, so they'll be publicly viewed. We need to hear back from you on a lot of those issues, what your needs are from this point on.

DR. ALVING: And be sure, for those of you who have funding from the other institutes and centers, NIDDK, NHLBI, NCI, please, be sure to let your project officers and program officers know what you are doing so that they are very aware of it.

It's easy not to be aware of all the other activities that are going on and I'd like to say we do, as I've said before, have an NCRR informatics committee and a trans-NIH informatics committee. We are very actively working with the caBIG effort and Ken Buetow.

So it was very interesting to see your posters. They were excellent posters. And I'm glad they're on a disk, because we all don't see everything at once. So we can go back and read.

Again, thank you so much. You're a great group. You're doing very creative things.

So come on, soldier on with us as we get through some of our budget storms and you know that sunny days can come again. Right?

In the meantime, there's still \$28 billion. So you can

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still do something with that somewhere.

[Applause.]