

Scientific Symposium on Exposures to
Environmental Contaminants Affecting Children

Plenary Session 2

LCRA - McKinney Roughs
Cedar Creek, Texas

Saturday, October 28, 2000

Federal Perspective Panel Questions

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DR. GOLDMAN: We have time for questions. I would like all the speakers from the Federal Perspectives panel to come up here. We have a limited amount of time for questions. If you want to have a conversation with these folks, I am sure they will be here during the break. We are going to have a break right after this. Please keep the questions brief so that we can hear some in depth answers from the members of our panel.

DR. CARPENTER: I'm Bob Carpenter. I was really interested in hearing some of the comments and the fact that you are going to be interested in studying behaviors associated with environmental exposure.

DR. GOLDMAN: Yes. Sam, I think that is really one for you.

DR. WILSON: Yes. I think this topic that you are touching on, of the research definition, so to speak, of environmental health is one of the topics that we are dealing with right now at the NIH and, I think, in other federal agencies. This topic is expanding the definition of "environment health" so that the definition is much

broader, capturing areas such as nutrition, lifestyle, quality of life, and the built environment we all live in and that our children grow up in. As a function of this expanded approach to environmental health, research in the behavioral sciences and in environmental factors that influence behavior are very much a part of the research agenda. There are many, very substantial research problems within this expanded definition, that are consistent with NIH funding support and further development, including in this area of the behavioral sciences. One other comment is that the emerging topic of health disparities and environmental justice research will also involve the area of behavioral research projects. So, I think that we are going to see an expansion in NIH support for these types of projects in the future.

DR. GOLDMAN: Okay. I think I'm going to go on to the next question.

DR. GURNEY: My question is going to be more of an editorial statement. I'm Jim Gurney from the University of Minnesota. And I'd like Martha to address this question. Martha, in your talk you alluded to the issue of a national registry for childhood cancer. In terms of being able to help or hopefully, facilitate the registry, those of us who do studies of childhood cancer right now are, of course, asking every single treating hospital to get higher standard information, but before we can even contact the parents to ask questions that are generally not related to the child's treatment even if those children are no longer treated at that hospital and haven't been for many, many years, the hospitals maintain strict control and prevent contact with them.

And what I'd like to say is that it is a very difficult issue that does not just speak to -- it takes a lot of time and money and energy, but it also threatens the scientific validity of the work that you are doing.

I think that until the issue of a national human subjects approach is accomplished, we are going to have a very, very difficult time moving forward in childhood cancer research.

DR. LINET: I agree with you 100 percent. I should point out though, the issue of ethical committees, as they are called in some other countries, is not just purely a U.S. issue.

For example, in Britain, which has essentially a National Childhood Cancer Registry, there are something like 240 ethical committees that need to approve research projects. So Scandinavia, the use of the databases, the national registries -- there are also ethical committees.

So this is not a U.S. issue. Most of you are aware of the history of the institutions of these committees that had to do with the Nuremberg trials and some of the horrendous abuses that patients and others underwent in this country in the early course of clinical trials. I am not going to review that.

But in the course of setting up this National Childhood Cancer Registry, we have been working hand in hand with the Office of Protection Research Subjects to try to identify the legal underpinnings of whether or not we can actually use one central IRB that parents of children who choose to provide their information to the registry would have a contact with and sign informed consent initially to be included in the registry.

Of course, any subsequent biologic specimens, et cetera, would need to probably require additional, hopefully, centralized IRB approval.

But we are all painfully aware of it, those of us who, as you do, do multicenter research. And the idea is to tread delicately and appropriately between

the need to inform subjects of the risks and the benefits of their research, but not to really hold up and oppose research.

MR. ANDERSON: I am Sparky Anderson with Clean Water Action. I appreciate what you said about the Supreme Court ruling coming up. However, Congress as we know, has been dealing with getting in the way of some of the science involved with better protecting public health.

In particular, a few weeks ago they passed an appropriation measure that had a rider attached to it that [inaudible] the [inaudible] setback of reestablishing and setting new standards for protection in our drinking water. As a matter of fact, for those who do not know, the last time we adjusted the standard was in 1945.

There are plenty of signs, plenty of medical information [inaudible] European countries have standards that are a hundred times more protective than we have here in the United States.

What can the health-care professional communities and the medical research communities do to get Congress or get the EPA to moving quicker to get the allowable standards and other scientists no longer need to be debated. I think we should put these standards in place and enforce them.

MR. COOKE: Sparky, I'll try to be judicious in my response by saying that Congress has found a new way to regulate EPA through the appropriations process.

When it was determined that doing these things on a frontal assault was not successful they discovered that they could put riders on bills which basically went unnoticed because the overall funding level for the agency remained the same or even yet, even increased, while at the same time they put restrictions on what -- or dedicated money from EPA to specific projects in their district to do things.

So it is a different game, and it is a game. I have to say that the majority of folks do not understand this. I must say I am not sure they will understand it for some time.

I guess I do not have a lot of advice to you. I will tell you that there is another rider involving the eight-hour standard specifically involved. —I have got copies of them, in fact.

So we are dealing with this stuff, Sparky. We have to do what Congress tells us to do. There is sometimes an executive branch that says one thing and then the Congress comes back and says, “yes,” but, you know, we're going to limit the way you do that.

So Lynn, from her experience, may actually be able to have another response.

DR. GOLDMAN: Really, just to add to that, I became aware very soon, after going to Washington and my job at EPA was my first experience in the federal government that it was an eye-opener in a lot of respects.

But who they heard from -- the members of Congress -- who they were listening to were a very small band of interests, really the water purveyors in this case, the actual entities, whether public or private who are delivering the drinking water to people's homes.

They are the ones who are going in and saying, "we do not like the standards." The people who have the Superfund sites that need to be cleaned up for example.— If you lower the drinking water standard, that has huge impacts for how much they have to clean up their dumps.

That is what is driving this. Who do they need to hear from? They need to hear from the people who are drinking the water, that they do not want the arsenic in their water, which gets back to Rob's point, education of the medical community, education of the people out there, because many of these communities with arsenic in the drinking water are really quite rural and quite isolated and are not places where there are a lot of stars and dots on Dr. Wilson's map.

So there is a lot of work that needs to be done so that they are not simply hearing from those monied interests. It becomes a health issue.

MR. COOKE: For example, earlier this year I went to public hearings on water issues, TMBL's in Arkansas and Louisiana, where 2,000 people showed up to protest what EPA was doing.

After three and a half hours of testimony protesting potential standards they allowed me to speak. There was not one single person that stood up in that audience that said this is about health and by the way, it is important. Not one single person in four hours.

So the legislators that were there listening to that testimony -- what do you think the impression was when they left or what do you think the impression was left by the newspaper article written about that?

DR. GOLDMAN: Okay. Rob wants to add.

DR. AMLER: Just wanted to add again -- and remember, you did not hear any of us lobbying for these ideas. But you can. Although I do not do lobbying, I do an awful lot of breathing.

I am told time and again by people who work for congressmen and senators that they hear from lots of different people, but when they hear from

physicians and nurses, that they have a real respect for the credibility of these people as not having a hidden agenda or not having some separate agenda, but really being concerned for the health of the citizenry.

And so if you do become involved in this do not underestimate how much your professionalism, your background, your profession itself counts when you are sitting in front of that person.

What you say may have a greater impact than ten people who are representing a particular lobby or group or industry.

DR. GOLDMAN: That is right. There are more of them but you are more credible.

DR. GOLDBLUM: I am Randy Goldblum from Galveston Medical.

Gregg, I have a question for you. Following up on your scenario where the ozone cloud creeps across Houston and got to a football field -- and apparently I didn't see the article in the Chronicle -- but it elicited an asthma exacerbation in a number of children.

I think the reason that seems so obvious when you put those people together is we do not have a surveillance system in place. Active surveillance systems are very uncommon with severe diseases like cancer. How does one go about getting systems into the public health mode to be real time?

MR. COOKE: It is a good question. One of the things we have got to do first is we have to have the monitoring system to look at the environmental impacts available.

Now, previously, we did not have the data to be able to draw the connection between environmental conditions and impacts.

And so the first thing -- which is actually nonresponsive to your question, but I am good at that -- is to get the actual environmental monitoring network in place so when things happen we know it.

There have been huge fights by folks, by congressmen who threatened bodily harm if we would put an air monitor in their district because they knew that if we had one there it could potentially detect a problem, but if we did not have one there it was easy to deny the fact that the problem existed.

You would be stunned. How can we make those environmental links if the monitoring network's not there? So, I mean, I think we have to have a basic environmental data necessary that has got integrity, that can be QAQC, that is beyond scientific reproach before we can draw the next level of analysis.