

**Pine River Superfund Citizen Task Force
P. O. Box 172
St. Louis, MI 48880**

September 3, 2001

Dr. Anne P. Sassaman
Director
Division of Extramural Research and Training
National Institutes of Health
P.O. Box 12233
Research Triangle Park, N.C. 27709

Dear Dr. Sassaman:

I wish to express my profound concern with the grant review process used by your agency in processing a Community Participation in Environmental Health Research grant application (Number 1 R01 ES10680-01A1) submitted jointly **FOR** the Pine River Superfund Citizen Task Force (an official U.S. EPA community advisory group [CAG]) by Wilfried Karmaus of the Department of Epidemiology of Michigan State University, Alma College, and the Mid-Michigan District Health Department. While I do not know the internal dynamics of that process in our case, the appearance reinforces the conventional wisdom about the biases in the current federal health research process.

That process, even when evaluating grants ostensibly targeted on communities with lower socio-economic status, results in awards to the well connected and the well funded major medical research centers. Furthermore, that process avoids support for significant lay involvement in the prerogatives of scientific specialists. While I hope I am wrong that the process has been so little reformed, please let me explain the history of this regions's experience with the environmental-health policy process, particularly that ostensibly controlled by neutral scientists. Understanding that background will show you why we know that at best the recent process has been one more example of the contempt of scientists for the wishes of average citizens, and at worse may be one more case of the utter corruption of the federallly funded scientific research process.

Those living in the Pine River watershed in Michigan have had long-term experience with the failure of scientists, especially public scientists, to support our concerns about the environment and our health. As early as 1935, the year in which both Michigan Chemical (later Velsicol Cemical) and Midwest Refinery (later UDS/Total) began operation along the river complaints from local residents led to the state commissioning the University of Michigan to study fish deaths. That report, which blamed refinery emissions, led to no public policy response. More scientists were working for the polluters than ever worked with us on inestigating it. Again in August 1941, 121 local citizens filed a petition with the City of St.

Louis calling for a clean-up of the river. Forwarded by the City Engineer to the state, no further action was taken. Throughout the next two decades, periodic complaints from residents were filed with the state and even forwarded to the federal level, with no action. Occasionally, federal researchers or elected officials, including even Senator Edmund Muskie of Maine, gave attention to the contamination coming from the chemical company and refinery. However, no concrete action followed until the PBB crisis of 1974, when Velsicol finally committed an act which directly impacted someone outside of the area. Only then did state and federal investigators and the national medical research establishment descend upon us. Even then, the wishes of the local community were ignored. Health researchers may have wanted our bodily fluids, they did not want to wait around to tell us the results of their tests. In fact, after they published their findings in peer reviewed journals, they moved on to other topics and seemed to forget us.

Why has this taken place. Residents of the community know it is because of both national indifference and contempt for such local communities, as well as because of corporate corruption of the policy process. We know we are dealing with powerful interests capable of corrupting the highest levels of policy making. Lest you believe I make wild accusations, typical of the backward parts of the country, I will be specific.

First I must alert you to special features of our community that by chance have given us a slight opportunity to resist what has been done to us. First, we have a remarkable group of citizens willing to give much time to resolve our concerns. Especially in that group are some senior citizens with both exceptional education and experience in industry which allows us to check the skilled scientists produced by industry and federal regulators. Second, we have in the community one of the country's good, small liberal arts colleges, with a commitment to community service. While we may lack the research capability of NIH, we can gather a lot of information and we have done so to understand how we have gotten where we are. I wish to share this with you so that you know why we understand the contempt behind your recent communication with us. I also hope you understand that as citizens, equal in value to any of your scientists, we cannot tolerate that contempt. We are not a society dominated by elite "witch-doctors." We are a democracy where our public health professionals work for the community.

While I know the historical review that follows is fairly long, your response to our grant shows you need to review it. As fellow citizens, I would even say you owe it to us to read it and think about it. We can begin with a national event that shows the forces we are against.

In 1962, when Rachel Carson was about to alert us to the threat of DDT, a threat more conventional scientific experts ignored, Velsicol came forward with a legal threat of its own. Our students have gone to the Rachel Carson Papers at Yale University to document this incident. On August 2, 1962, Velsicol's General Counsel, Louis McLean wrote to the President of Houghton Mifflin (Silent Spring's publisher) and to The New Yorker (which was serializing the book), threatening a libel suit if the publication took place. It was the courage of Paul Brooks, Editor at Houghton Mifflin and E.B. White at The New Yorker that called Velsicol's bluff.

This should have been a warning to us how far our polluters were willing to go. It was confirmed for us after 1974, when the PBB crisis seemed about to destroy Velsicol. Of course, Velsicol survived. It did so by some of the most effective and ruthless corruption of the federal

environmental policy process. As the PBB crisis worsened by 1980, the company hired key federal officials, including Michael Moskos as its CEO and John Rademacher as VP for Environmental, Health, and Regulatory Affairs, and Richard Denney as General Counsel. Who were these three. Our students have found out. Moskos (now head of the Federal Reserve Bank of Chicago) was a former Nixon and Ford Administration adviser on economic policy, who probably would have been a second Ford Administration cabinet. Recall that the final PBB negotiations were going to take place under another Republican administration to which Velsicol wanted access. Rademacher had been a top EPA official, including Regional Administrator. Denney until 1980 had been Associate General Counsel in EPA's Toxic Substances Division. In my field of public policy, we call what Moskos, Rademacher, and Denney did, "rent seeking," that is earning extra money by cashing-in on government service. Lest my comments about Moskos sound too partisan, Velsicol also retained the firm of the Carter Administration's HHS head, Joseph Califano to smooth the way around hostile democratic environmental-health investigators.

We in this community know the results of such rent seeking. In November 1982, the U.S. EPA reached a consent agreement with Velsicol that was billed by the negotiators as the "largest cash settlement in U.S. history." In fact, the cash value of the settlement was greatly over-inflated. The settlement was rushed to completion in an attempt to save the careers of several members of Congress from Michigan (James Dunn and Cedarburg). [UPI story, 19 November 1982] They lost. So did this community. Velsicol, knowing the time pressures upon their friends in EPA, had driven a hard bargain in the negotiations. The final consent decree was fundamentally flawed. Most helpful to Velsicol was its exemption from river clean-up. After we filed a FOIA with the state in 1999, we learned of the last minute changes in the consent decree, specifically the river exemption. Since as I write EPA is in the midst of paying the full cost of removing Velsicol's contaminants from the Pine River, that was a \$40 million mistake. Not bad work for Moskos, Rademacher, and their lawyers. But, you may say, that is "Monday morning quarterbacking." It is not.

On the day the consent decree was announced, Hugh Kaufman, now in EPA's Ombudsmen's office, complained to The New York Times (19 November 1982, A:18; and 21 November 1982, 4:7), "This [agreement] is a clear signal that companies that improperly dispose of hazardous wastes can negotiate at the last minute and wind up paying nothing but administrative costs." Kristine Hall of the Environmental Defense Fund, warned "It makes me nervous to think they are putting that stuff in clay so close to the river. It is very chancy." [Now we're spending not only \$40 million to remove the worst contamination in the river, according to Velsicol's own consultants, 900,000 gallons of water a year is passing through the clay into the river. Most important to this community, it was not only national critics who objected to the settlement before it was complete. People here sought to participate in the settlement process with Velsicol during the four years of negotiations. They were consciously kept out of that process, exclusion we have documented. A letter sent by the Governor's environmental aid to a county councilman, whom he mistakenly suspected shared his views, rejected inclusion of local citizens in an advisory committee. He noted, "We have learned from past experience that it's awfully easy to frighten the public to a degree which may be unwarranted about toxic chemical problems." [letter William R. Rustim to Arnold Bransdorfer, 27 March 1978]

We could continue, but I hope you now understand how we have experienced federal errors and contempt in the past. With the return of EPA to our community in 1998 to clean-up sediment in the Pine River and later to impose fines on the refinery, we hoped a new era was dawning. In some ways it has, especially with the authorization of CAG's and granting to them Technical Assistance Grants (TAGs). However, even our recent experience has been marred by contempt and manipulation of the community. The former EPA coordinator for the Velsicol site became hostile to our dealings with everyone from the state Department of Community Health to the Saginaw-Chippewa tribe. She held private meetings with both of them to try to undermine cooperation with the CAG. Tragically, EPA meddling at the tribe has caused the leadership to try to remove from membership their environmental coordinator, who is a member of our CAG (Detroit News, August 2001). The EPA community involvement coordinator, likewise, has tried to manipulate the city government, other local institutions, and split them from the CAG. (see TAG Quarterly Report, March 2001).

Now we have experienced similar treatment from your office. On August 21, 2001, a letter so confusing we could not possibly interpret its directions arrived at Dr. Karmaus's office, sent by Frederick Tyson of your staff. It referred to dates in May 2001 as in the future, even though it was dated in August. It seemed to tell of an imminent meeting in September, yet the year was 2002. Then the report forwarded with it responding to our grant proposal, contained comments that could not have been based on a careful reading of the grant proposal. Worst, when these problems were brought to Dr. Tyson's attention, he separated the date errors, which were so factual he could not continue to claim they were accurate from the comments on the grant, holding the errors there were really differences in interpretation. Yet, even a cursory review of the grant proposal and the comments listed as "critique 1" show at least that reviewer, if not others who voted on this grant, either could not have read the proposal or deliberately misrepresented it in order to deny funding and move on to grants they wished to award.. For the sake of brevity, I will emphasize only three egregious errors made in the second paragraph of "Critique 1", after the paragraph on significance.

First: Critic 1 states, "While the letter of support from the Pine River Superfund Citizen Task Force . . . is dated March 9, 2001, it only refers to Task Force support for the project when reviewed in September 1999." That statement is, quite simply, a misreading or distortion of the letter and the grant application. We must ask, has this person really read either the Pine River Task Force letter of March 9, 2001, or the text of the grant proposal? Of course, the letter of March 9, 2001, mentions the vote of September 15, 1999, because, quite simply, that is the date on which a vote was taken to seek a grant. In fact, as Dr. Tyson should have been able to tell that critic, later in the week of September 12, 1999, I, as Chair of the Pine River Task Force contacted him to see how to apply for the grant. He and this critic should have been reminded of this history if you had only read the grant application. Page 29, points out, "It was the Pine River Superfund Citizens Task Force that approached the investigators for the research project proposed here." Critique 1 also omitted from its summary of the letter of March 9, 2001, the sentence that follows the reference to the vote of September 15, 1999. That sentence could be no clearer in saying the Task Force support continues. It reads, "For the past year the Task Force has remained committed to this study."

I find it impossible to see how any reviewer could see this grant as needing any stronger

community support. First, it was originated by a community (not by a medical school or university). Additionally, in the second paragraph of the letter of March 9, 2001, the community, as represented by the Task Force, provided an eloquent summary of how previous health studies have treated citizens as “guinea pigs,” abandoning them after results were published in obscure (to the general public) epidemiology journals. Dr. Karmaus and the community have made absolutely clear throughout the grant proposal that they are committed to a new model of community collaboration with health researchers. The model of health risk perception on page 33 was so innovative, a team from the CAG was asked to come to a conference on “Federal Facility Cleanup” sponsored by the Institute for Science and Interdisciplinary Studies at Amherst, Massachusetts, to share it with communities from throughout the U.S. The Pine River has no federal facility, yet conference organizers were sure they could learn from the Pine River model.

I believe, that innovation, alone, should justify funding of this grant as a test of a new model of community participation. Surely, there are no grounds to say the support of the community has not clearly been renewed in 2001! In fact, our model of community involvement, we suspect, is so innovative that it may be the reason our grant is being misread. Are there not on your advisory committee those committed to an expert driven, top-down model of community participation.

Second: Later in the same paragraph, critique 1 states: “It is unclear if the revised proposal, which leaves out addressing the refinery and bean processing facility in Alma and Breckenridge and related respiratory and dermatological concerns, has been discussed and is supported by all 3 communities.”

That statement would not be so inappropriate had not your review of the communities’ first grant criticized “This diversity of exposures and health outcomes is also a weakness . . .” In most of life you cannot have it both ways, and I would presume not in health grant revision. Either we should study all exposures of concern to these communities (what we really wish to do), or we need to focus to get your grant support. Yet, when we focus, as your reviewer last year suggested, we cannot get the grant.

There is another weakness in the argument of Critique 1 related to the focus on thyroid admissions. Women in Alma downwind from the refinery report thyroid problems and want this study. How can your “critic” know that this study is only wanted by one community as a result of our focus? Given that St. Louis has two superfund sites and a number of state regulated contamination sites, while lying down-river and down-wind from Alma, we propose giving special attention to its residents and former workers at its chemical plant. However, we use words such as “in particular” (p. 32), which do not mean solely! At many points we make clear we are studying three communities, not only St. Louis.

Third: Critique 1 then states “there has not been any new information or pilot data generated or additional work done with the communities.” Since this quotation is patently untrue, on its face, it is difficult to understand the meaning of this statement. Look no further than Figure 4, p. 32. In 2000-2001, we conducted a study of hospital admissions to find the excessive thyroid admissions to the area hospital. This is NEW information. What more can we say?

We are a community that qualifies as a site of environmental injustice, because of our socio-economic status. That is why we have a CAG. We need this grant to gather more data. If you are not satisfied with “new information,” such as the thyroid data, you must be saying you want us to produce not merely information but also conclusions that justify the grant we are seeking. If we had those conclusions, we would not need this grant. To be charitable, it seems your critique 1 has the process rather backwards. The reviewer seems to be committed to offering us this grant if we do the impossible - conduct a multi-million study to justify the grant.

Most disturbing perhaps are the many references to what has AND has not been done in this community, without any contact with us to verify the validity of the references. Actually, your critic displays rather extensive knowledge of the PBB incident and related matters, that involved this region, but either lacks sufficient knowledge or ignores other information that would allow valid conclusions about the region’s health. For example, the critic suggests we await more studies done by others - either ATSDR or the indifferent scholars mining the PBB registry. In fact, in 1988 ATSDR did an assessment of health issues in St. Louis in 1988. However, do not all researchers in the field of public health knows ATSDR’s resource limits prevent it from doing the type study we need.

As for the PBB registry, one of our needs is to utilize PBB information to help this region. We know that studies of the PBB registry has shown high exposures to PBB are associated with breast cancer, digestive system cancers, endocrine disruption, and child development. Our undergraduates already have found those studies and made them available to the community!

The problem with the PBB research is that since the 1980’s, for reasons known only to national health experts, local workers were dropped from that sample in the 1980s. The PBB registry focuses on farm families, presumably including some local residents. However, the PBB research is nearly useless to local citizens and even to the local medical community. Despite publication of a number of studies growing from the PBB registry, no research team in the last two decades has come back to this community or sent a spokesperson to explain to the lay public or local physicians what they have found. One of the major innovations to be tested under our grant proposal would be the close community collaboration lacking from the PBB research. The references to PBB, therefore, remind us again of our concern that national researchers have only contempt for us.

We could review the remainder of the criticism of our grant proposal. However, I believe we have made our point. Many of Critique 1's comments are groundless and can be made only out of ignorance, carelessness, or worse. I must be candid. We are a community with few resources. We are not Johns Hopkins Medical School. However, we know we have submitted an innovative proposal - even a researcher from Mt. Sinai School of Medicine told us that during an EPA conference last Fall (2000). How many of your community participation proposals originate in affected communities that qualify under EPA environmental justice guidelines? I do not mean how many include communities. I must emphasize, I mean how many ORIGINATE in local communities? How many proposals include continuous community input into the study as it is being conducted as would ours?

The members of the Pine River Task Force as well as other residents of these communities are determined to have our health concerns addressed. We do not want the health grant process corrupted by special influence. We are sure our grant proposal could be improved. Of course, we welcome your advice on improving it. However, it shows utter contempt for us, if not corruption of the health policy process to treat us as we have been treated. Our grant proposal clearly was not carefully reviewed and your follow-up letter demonstrated you could have cared less about communicating with us.

As so often in the past, the process we have been exposed to proves the national health and environmental science process is not guided by dispassionate, neutral analysis of evidence, as NIH would claim, but by carelessness and, most probably, favoritism toward the well connected and the powerful. We did not seek to be placed into the middle of a debate about health research reform, just as we did not ask for all the contamination to which we have been exposed. However, we are determined to demand and receive fair, responsible treatment for ourselves and other communities like us.

Thank you for a prompt, thorough, and FAIR review of our concerns. If necessary, we would be glad to meet with you or your "Special Emphasis Panel" to resolve any concerns with our proposal and with the review process. As a courtesy to this community, which has been forced to wait far too long for a comprehensive response from our officials, we expect that any such meeting will be arranged in a timely manner. We would be glad to host such a meeting so that the panel could visit and understand better the communities seeking this grant. The next regular CAG meeting is Wednesday, September 19, 2001, at 7:00 p.m., in St. Louis, Michigan. We can guarantee, if you come, you can gain a sense of diverse community perspectives on this grant proposal.

You can reach me at (989) 463-7203 or lorenz@alma.edu.

Sincerely,

Edward C. Lorenz, Ph.D.
Chair

DRAFT LETTER FROM MEMBERS OF CONGRESS ON PINE RIVER HEALTH GRANT

August 29, 2001

Frederick L. Tyson, Ph.D.
Program Administrator
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Dear Dr. Tyson:

As you no doubt know, members of Congress often are asked to support the concerns of well funded interests and institutions. It is less seldom that we are approached by average citizens and community organizations. It therefore gives me great pleasure to write urging you to review a matter of great concern to the Pine River Superfund Citizen Task Force, representing residents in one of the less affluent yet environmentally stressed regions of my state/district.

Northern Gratiot County, Michigan, where the Pine River Task Force is based, qualified for such a community advisory group (CAG) under U.S. EPA's environmental justice regulations. The region is much below average in most economic indicators and is the location of a variety of contaminated sites, including the river with the highest levels of sediment DDT ever found in the U.S.. Also, the region has experienced well documented indications of health impacts from multiple environmental exposures. There was a cancer cluster in the downwind community of Breckenridge. St. Louis experienced intense exposure to PBB and DDT. Alma faced a cocktail of contaminants, including especially volatile organic compounds, chromium six, and lead. The only health assistance these communities have received from the wider research community has been specialized, dare I say esoteric studies (such as those originating from the PBB registry), the results of which have never been shared with the residents.

Consequently, I would urge you to give special attention to the letter from the Pine River Superfund Citizen Task Force regarding grant 1 R01 ES1-680-01A1. I would appreciate being informed of the progress of your review. You can contact Mr. _____ of my staff, at _____ with any questions or information.

Sincerely,

