

**PINE RIVER SUPERFUND CITIZEN TASK FOTCE
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October 22, 2001

Division of Extramural Research and Training
National Institute of Environmental Health Sciences
P.O. Box 12233
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To Whom It May Concern:

As Chair of the Pine River Superfund Citizen Task Force or CAG, the community advisory group (CAG) to the U.S. EPA for the superfund sites in Gratiot County, Michigan (formed under OSWERD Directive 9230.0-28), I am very pleased to write this letter of support for the application by Dr. Wilfried Karmaus for a grant to support the proposed Community Based Prevention and Intervention Research.

I want to emphasize in this letter that our task force, which is one of the largest and most active CAG's, originated the effort to get this grant. It was the CAG, which learned about the possibility of support from NIEHS for this proposed study. The CAG then sought out Dr. Karmaus to produce the proposal and conduct the research. As you probably know, the communities in the Pine River watershed have been subject to a number of previous environmental-health studies. Especially following the PBB crisis, which unfolded after 1973, a variety of local residents became subjects of health subjects. As we have said in a different context, unfortunately the earlier medical researchers only wanted our bodily fluids as the empirical evidence for their peer reviewed publications.

When they found patterns between exposures and health conditions in their samples, they did not return to report first to these communities. In fact they never reported to us. When they documented a cancer cluster in Breckenridge, Michigan, they blamed it on bean dust. In 1997, at the first 'recent' public hearing on the watershed's continuing contamination, Michigan Department of Community Health officials stated that there were absolutely no links of Breckenridge's health problems with the pollution in upwind St. Louis. However, when the CAG filed a Freedom of Information Act request for all state files related to Velsicol Chemical, the firm responsible for the PBB mistake, we found a file on the cancer cluster.

More recently, when the CAG asked if workers had been dropped from Michigan's PBB registry, we received an affirmative answer. About 1990, the workers were dropped. The reasons given make research sense:

Offspring were not enrolled, as was done with the rest of the PBB cohort. This is a relatively small group (n=251 workers plus some family members) compared to the rest of the cohort (n=5,000+). Also we discovered that these data files had been kept separate from the rest of the cohort data for some time. As a result, the worker files have not received the type of rigorous data quality evaluation and cleaning that the rest of the cohort data files have received. Finally, we know that the worker group differed systematically from the rest of the cohort: they were younger, mostly male, had higher PBB exposures, different mechanisms of exposure and different occupations and lifestyles (manufacturing vs agricultural).

The CAG members who saw his memo were outraged. They confirm the fundamental difference in the worldview of state health researchers and residents of concerned communities. If anyone is to be dropped from a study with 5,000 participants, why pick the 251 people with the higher exposures? All of the other reasons given, such as ignoring the offspring, are either admissions of oversight on the part of the researchers or correctable.

Likewise community members were upset when state health officials said in 1997 (and subsequently) that there is no higher rate of any known health problem in the county with links to the contaminants to which residents have been exposed. One member brought forth a table in Benjamin Golden, *The Truth About Where You Live*, that shows [p. 125] the county ranked number twelve out of the nation's 3,000 counties in breast cancer deaths among minority women. Since studies of PBB, the chemical that caused Velsicol to be closed, have linked it to breast cancer [Alden K. Henderson, et al, "Breast Cancer among Women Exposed to Polybrominated Biphenyls," *Epidemiology* 6 (September 1995), 544-546], and since minorities seem more likely to live near the river where the plant was located, residents find it worrisome that their concerns are dismissed out of hand by state officials.

I site the above specific incidents only to convey in unequivocal terms why this community wants health concerns studied by experts of our choosing. They also explain why we have sought a scholar to do this research who is committed to full community involvement in the review of the process and results at each stage of the study. Aware of the problems of community participation, we also have thought intensively about issues of community definition and inclusion. While we are the 'official' EPA recognized representatives of the community, we would be the first to admit that we are aware that no group speaks for the many members of this watershed who seldom vote or come to public meetings. In fact one of the most disturbing legacies of the contempt for local concerns displayed by both the global firms which have polluted our environment and some public officials responsible for regulating their behavior, has been a pervasive cynicism about politics, the policy process, and the possibility of real remediation. This cynicism is especially common among our youth. As one said last week before our monthly CAG meeting, "I know this place stinks, and I'm going to get out as soon as I complete school."

We therefore have sought and agreed to participate in the process planned under this grant proposal for innovative efforts, such as focus groups, to assess community concerns and hopes. We are dedicated as an organization to work with this planned research, not as passive subjects, but as active overseers. We want this project to answer the questions which most of us have about the potential impacts of our exposures. As the initial work answers some questions, we also expect to guide decisions about the subsequent research needs.

Finally, I want to make one more point crystal clear. The CAG voted in September 1999 to seek this grant. At that time we had not yet found Dr. Karmaus and did not know how the proposal would develop. When the initial grant request was rejected in 2000, we supported pursuit of the follow-up proposal, which in-turn was rejected in the summer of 2001. At the monthly CAG meeting on October 17, 2001, the CAG voted unanimously, as on two previous occasions to pursue again this grant with Dr. Karmaus. In no way has our support declined or changed. The CAG, while it meets in St. Louis, still includes members from Alma, Breckenridge, St. Louis, and the wider watershed, especially downstream through Midland and Saginaw. The CAG now has formed a health committee to prepare for this study, including men and women from St. Louis and Alma, as well as people from the wider watershed.

We are sorry for the long letter of support. We simply want to make clear that concerns about community involvement expressed by previous reviewers of this grant have been based on a fundamental misreading of community intent as understood by the CAG. We do not know how to express more clearly our desire for this research to be done and our concerns addressed. **We want to request that this letter be made available to any reviewer of the grant to make clear there is a community desire for this research.**

Should any reviewer have questions about community support, I would urge and offer an opportunity to ask any questions of me or the CAG, especially before attempting to assess our support as anything less than complete. I can be reached at (989) 463-7203 [work] or (989) 463-6170 [home].

Sincerely,

Edward C. Lorenz
Task Force Chair