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Privacy Key Word in Dioxin Study
Dr. David Garabrant

Privacy is sacred in our country. Everyone is entitled to guarantees that personal information will be kept out of the public eye. That belief in the importance of privacy is one of the guiding principles for our team of University of Michigan scientists as we begin to study dioxins in the Midland and Saginaw areas.

We are now contacting Michigan residents to participate in our study. If they agree, we will measure the level of toxic dioxin compounds in the soil and dust of their homes, and we will use blood tests to see whether those dioxins are also in their bodies. The goal is to see whether dioxins in the environment are ending up in people's blood.

Our University of Michigan study won't look at health effects but it will determine whether residents near the Tittabawassee River have more dioxins in their blood than people elsewhere -- a key fact we all need to know first before taking further steps.

We will gather personal information about the participants for use in the study. This will include name, age, where people have lived, what they eat, their jobs and their hobbies, as well as the levels of dioxin in their soil, household dust, and blood.

All of the information about participants in this study will be kept strictly secret. Why? For a number of reasons.

One is for the protection of each participant. If it should turn out that there are dangerously high levels of dioxins in their blood, that information, if made public, could hurt their chances of getting health and life insurance coverage. We will make sure that that information is not made public.

Also, if it turns out that there are high enough levels of dioxins in the soil to make that property be deemed by the state a hazardous waste facility, that could hurt the property owner's chances of selling it. If the participant wants this kept secret, we will keep it that way.

To be sure, we also will give each participant the option of finding out what the result is in his or her case, with the understanding that once they know this they might be required by law to divulge it, for example before a property sale. But they have the option of not being told their individual results, and if that's their desire we will not tell them and they will not face the need to divulge the information.

In order to assure the highest degree of confidentiality, we have three safeguards:

* Study design -- Only overall summaries of data, not specific details about individuals, will be included in our final report that will be made public. Nothing in the report will have any details that could be traced back to any individual or property.

* Security -- We assign each participant a different ID number. All ID numbers are kept in a secured location at the University of Michigan's Institute for Social Research. Only a very few researchers with a need to know have access to this information. Anything that could trace back to a participant -- such as telephone records or payments for participation -- will be kept out of U-M financial statements.

* Legal protection --- As is standard for this type of field study, we have received a Certificate of Confidentiality from the National Institutes of Health. This provides participants and researchers

with legal protection. None of them can be compelled to testify in court or in front of any other public body about information that could hurt a person's financial standing, employability, reputation or insurability, or have any other adverse effects.

With those three safeguards in place, this highly sensitive information will be kept confidential. My fellow researchers and I have spent our professional lives conducting scientific studies. We have always respected the privacy of participants. And U-M's Institute for Social Research, part of our research team, has a 50-year reputation for integrity and confidentiality.

Another reason for confidentiality is that we know that part of the success of this study will depend on the degree of cooperation we receive from residents. The higher the level of participation, the higher the quality of our study and the more representative our sample will be. To encourage a high degree of cooperation by residents we are doing everything possible to reassure them that their personal information is secure and will not be made public.

We are also making sure that this study is being conducted with the highest integrity and independence. This University of Michigan study is funded by the Dow Chemical Co. but, to ensure independence, Dow has no say over it. All decisions about how to do the study and report the results to the public are being made by the University of Michigan team. In addition, there is oversight by an independent scientific advisory board, and public input from a community advisory panel. For details, please see our Website, www.umdioxin.org.

The University of Michigan dioxin exposure study will benefit everyone in the region. It will answer important questions so that all of us can get the facts we need before taking the next steps. In order to be successful, our study must inspire confidence and respect for its integrity, and that is why we are placing so much importance on protecting confidentiality.

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