

October 2, 2007

Dear Liam,

I apologize for the delay in getting back to you about your concerns resulting from your interview with Anne Lifflander on September 7. One of the staff members who is involved has been away for more than half the time since you first e-mailed me, on Saturday, September 8, and then I myself have been away.

Before addressing the points that you have raised, I would like to reassure you that research interviews like the one we conducted with you are *always* voluntary and confidential. We have received and acknowledge your withdrawal of your consent. Please be assured that we will not use any part of our interview with you.

We apologize for the difficulty with the logistics of the interview. We had hoped that meeting you in Boston, where you had recently relocated, would be more convenient for you. In retrospect, it probably would have worked better to interview you by phone or have you come to Vera's offices in New York. We interview in places that the people we are interviewing choose and that are most accessible for them, including in restaurants, offices, parks, or their homes.

In my earlier, brief e-mail reply to you, I mentioned "misunderstandings." I think the most important one involved our willingness to accept your material. Anne tried to make clear, and I want to reiterate, that she was not refusing to *ever* accept whatever you wanted to give us (disks, audiotapes with identification of the speaker, videotapes of interviews that were later broadcast with aliases and faces blurred—whatever you prepared for Anne on September 7 or have put together since then). She just wanted to be sure that you understood and accepted the way we will use the material that you give us before we accepted the material. I want to make absolutely clear two things (and I hope I can do so in this e-mail) that apply to *all* the interviews that we conduct as part of this research study and all material that is given to us by interviewees: 1) We cannot ourselves initiate contact to clinical-trial participants or their families, 2) We will have to verify any factual information that you or any other interviewee gives us before using it in our report (factual information includes the name of any person whom you or anyone else interviewed and whose interview you or anyone else wants us to use. You are correct in your understanding of what Anne told you: If you or anyone gives us a tape or a transcript of an interview and tells us that the speaker was X, we have to confirm with X that he or she, in fact, said what the transcript or tape says).

Of course, if you decide to give us permission to use our interview with you (or decide to continue the interview), we do not have to verify *your* observations or comments or opinions, since we will have gotten them directly from you with your informed consent. Furthermore, if you want to give us names of people *who are not trial participants or their families*, we will be happy to write to them, tell them that you suggested we contact them, and ask them to contact us if they want to learn more about our research protocol, or want to be interviewed (we may already have reached out to some of the people whom you are eager for us to speak to—and they may have responded, or not, and may have agreed, or not, to be interviewed. If they did *not* respond or did *not* agree to an interview, knowing that you were eager for them to be interviewed may convince them to do so—confidentially or for attribution).

I would now like to address some of the methodological issues which seem to be at the crux of the problems that occurred during the interview and that are the basis for my saying, above, that we cannot initiate contact to participants or their families. The research being conducted by Vera as part of the clinical trials project is subject to federal (CFR45Part46) and state (NYS Public Health Law Article 27F) laws and regulations. These guide the way we collect and use information. In compliance with the federal regulations, all research protocols must be approved by our Institutional Review Board and we require that our staff stay within the approved protocols. The protocol for *this* study was designed to ensure that we do not ask or encourage anyone to violate New York State's statutory restrictions (in 27F) on the disclosure or re-disclosure of HIV status without permission and also ensure that we honor our contractual commitments not to reveal the name of any individual who has AIDS or is HIV-positive.

As you point out in your September 8 e-mail, Anne halted the interview, sought legal counsel, and then, on advice of the Vera lawyer who is involved with this project, ended the interview at that point. This was done out of concern that to continue the interview in the setting where it was being conducted (the corner of a hotel lobby) and in the way that you were urging (which included playing an audiotape which might reveal real names) posed a privacy risk to the foster children who participated in clinical trials and their families.

We believe that interviewing young adults who participated in the clinical trials and the people who cared for them is crucial for this project. In developing a protocol that gives meticulous care to preserving confidentiality and privacy, our goal is to provide conditions that will make those most affected by this issue comfortable in stepping forward without fear of exposure. That does limit our ability to directly approach people for interviews or to confirm information given by another source. Although we tried to make this clear early in the interview, in retrospect, it might have worked better to have discussed this more fully with you beforehand.

As Anne told you before and during the interview, and as I want to re-emphasize now, we think that our study will be better if we can interview as wide a range of people as possible. For that reason, the study will benefit if you decide that you *do* want to give permission to use the September interview, or if you decide to be re-interviewed. It will also benefit if you ask people to contact us, so that they can tell us about their experiences with clinical trials. I believe that Anne gave you the postcards that we are using for outreach—cards which tell anyone who is willing to speak to us where to call—but she will be glad to give you additional cards if you would be willing to give them to people who participated in the trials or their families (whom we *cannot* contact directly) or to anyone else who you think would rather hear from you about the possibility of talking to our researchers than receive a letter from Vera.

With this response, I have tried to address all the points that you made in your September 8 e-mail. We share your desire to learn about, and report fully on, foster children who were enrolled in clinical trials of HIV and AIDS treatments in the late between 1987 and 2001.

Sincerely yours,



Michael Jacobson