Questions Toward a Cure

A group of activists has launched a quick and easy survey aimed to help guide and speed along cure-related studies. Your input is important because these studies will ultimately require the participation and steadfast support of people living with HIV.

December 6, 2011 By Tim Horn

What expectations do you have, and risks are you willing to take, when faced with the option of participating in clinical trials of therapies that might help develop a cure? These are essential questions community advocates are looking to answer as they begin working with researchers and regulatory agencies like the U.S. Food and Drug Administration (FDA) on the development of ethical human studies.

An online survey, developed by Project Inform's David Evans and the Program for Wellness's Nelson Vergel with assistance from the Treatment Action Group's Richard Jefferys, is seeking input from all people living with HIV. "The survey shouldn't take any more than 10 minutes to complete, and we hope it will go a long way in helping us speed the pace of HIV cure research," Evans says.

At issue are the kinds of risks that the FDA will allow in early phase clinical studies of promising treatments to either eradicate HIV from the body or to help the immune system better control the virus without the need for antiretroviral drugs.

"There are complex considerations in the FDA's regulation of early studies that might carry certain health risks, especially if those studies are designed more to move the science forward than to achieve an immediate cure in the individual," explains Evans, a former senior editor of AIDSmeds. "We believe that soliciting the opinions of people with HIV regarding the potential risks involved will help inform discussions regarding the design of these trials, and shed light on the extent to which individuals are willing to assume some risk—even if the study would only help people further down the road."

Evans and his colleagues designed the survey to help measure the willingness of people with HIV to participate in research for more altruistic reasons, and to gauge the factors that are most strongly associated with a person's willingness. The activists hope that the survey results will lead to frank, well-supported discussions with the FDA divisions that will ultimately be responsible for reviewing many cure-oriented HIV treatments.

The survey is timely, given that a number of research teams are designing studies that may

require HIV-positive volunteers to take some risks and to understand that they may not necessarily benefit medically, on a personal level, from the approaches being tested.

To provide survey participants with some context and background information before they complete the online questionnaire, the activists have also drafted a detailed summary of research that is either currently under way or earmarked for development, along with descriptions of the potential risks and benefits involved. (*Editor's note: We also recommend an POZ web exclusive, entitled "What Would You Do to Cure HIV?," authored by Evans and published in May 2011*).

"The more people we can get to take the survey and the greater the diversity of our respondents, the more legitimate our results will be," Evans notes. "If we're to have frank discussions with researchers and FDA staff, we're going to need data of our own when addressing community wishes and concerns. This is our chance to ensure that people living with HIV are fairly represented as we begin advocating for research that we've been waiting three decades for. Now more than ever, we need the voices of people living with HIV in research advocacy, and this survey is a great first step in this direction."

In addition to using the survey results in their advocacy work, Evans and his colleagues intend to share their findings, likely in connection with the 2012 International AIDS Conference that will take place in July in Washington, DC.

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