Building an Activist Agenda to Cure AIDS

March 6, 2012 By David Evans

A couple of months ago a rag tag group of activist--including Project Inform (represented by myself), the Treatment Action Group (TAG) and the AIDS Treatment Activists Coalition (ATAC)--reached out to some of the world's leading HIV researchers and companies working on HIV cure research and asked them to spend an entire day with us talking about potential barriers to moving such research forward at the fastest possible pace.

We also asked them to tell us the things that people like us--ordinary people with HIV and their allies--could do to boost research momentum and progress. At first, we were worried they might not be willing to add yet another day to an already long conference, the Conference on Retroviruses and Opportunistic Infections (CROI), taking place the following week. Would they see activists as worthy allies? Would they consider our goal--to map out an advocacy agenda to increase and hasten HIV cure research--something worth spending their time on?

The answer, gratefully, was a resounding and enthusiastic, "Yes!" The next hurdle, the meeting itself was equally uncertain. Cure research is in its infancy, and there is still much that remains unknown. There exists a shaky (at best) consensus on the right studies to do and the order in which to do them, and no one is quite sure where the money is going to come from to carry out those critical experiments. Equally unclear is whether people with HIV will be willing to put their lives on the line (literally) for the kinds of risky early research that will be necessary to prove key concepts.

What's more, our group of 63 participants--which included representatives from the U.S. Food and Drug Administration (FDA), members of the International AIDS Society (IAS), along with the academic and industry researchers and activists from the U.S. and Europe--have competing interests and concerns. I was prepared to come out of the meeting with no more than a hodgepodge of unrelated ideas, uncertain priorities and even disagreement. I'm exceedingly pleased to report that we got so much more. There's more work to do in order to take the ideas that came out of the workshop and wrestle them into a solid activist agenda, but we've moved forward by a giant step and the interest among the workshop participants--researchers, regulators and activists alike--is now focused on a set of priorities that I believe will make a significant difference.

We'll be putting out a full-length report covering all of the discussions and the outcomes, but

here’s a sneak peak at some of the things we felt would be important to work on in the coming year:

Funding: We don’t actually know how much money globally is going toward cure research, but one thing is abundantly clear--there isn’t enough for long-term projects that will help build the infrastructure of people, labs and concepts necessary to take us all the way to the goal post. Most academic and industry investment is focused on getting quick results. Cure research is probably going to take us a while, and every time we have to pause to raise more money it delays us further and keeps scientists from focusing on the toughest--but most important--problems to solve.

Big Risks: Some cure research could be quite risky, with little chance of benefit, for the people asked to put their bodies and lives on the line as guinea pigs. How much risk is too much? Where should we draw the line? How can we ensure that when people volunteer for studies they really understand what they’re getting themselves in for? We can’t move forward with vital early stage human studies without a satisfactory answer to these questions.

Coordination: Lastly, we have the issue of coordination and research silos. Currently some feel that cure-oriented research, particularly research happening in other fields outside HIV, is occuring is uncoordinated and fragmented.That hinders our ability to move forward as quickly as we could. Alternatively, there have been previous efforts in various scientific fields to impose more central control and coordination and that has the danger of increasing bureaucracy and stifling innovation. Finding the right balance and making sure that the structures are in place to coordinate cure research is a vital concern.

I’ll do my best to keep you all up-to-date as we take concrete actions to address these concerns. I may also occasionally ask for your direct help, to write letters, make phone calls, take surveys or lend your voice or time in some other way. The experts at our workshop affirmed that they can’t do it without the community, and the community is you!

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