# 5,985 and Counting

Larry Kramer calls for an entirely new system of how drugs are tested

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“Why don’t you start another organization?” I hear these words more than any others. People stop me in the street. Old ACT UPers guilt-trip me. Unhappy GMHC (Gay Men’s Health Crisis) staff call me up and beg. Letter writers and phone callers constantly suggest I get off my ass. There’s a lot of frustrated, constipated energy out there with no relief valve.

But no one’s doing anything about it except bugging me.

I can’t believe we no longer fear death and dying. Yes, we now have hope. It’s not easy to maintain anger, let alone start an organization, based on hope. Hope makes people lazy.

The people who started GMHC were the concerned type. We weren’t really frightened yet. We weren’t as scared as we were shortly to become.

The people who started ACT UP were motivated by terror. How could we not have been? Our friends falling dead all around us. (And GMHC wasn’t doing anything to stop it.) We were frightened, and our fear fueled a great anger that made history and achieved revolutionary results. The fruits of that anger are the drugs now giving us more time to live.

So now we have hope, and we have new drugs. What we don’t have is that new, focused fury of activism. If GMHC and all its clones appeal to the pastoral instincts in our community, and ACT UP appeals to its anger and frustration, what would remake our community activist today?

I’ll tell you, but the answer’s not glamorous. What we need is an organization to push for an entirely new system of how drugs are tested. There are so many new things to test and take, and so many possible combinations to take them in, that no present system can analyze even a fraction of the possible combinations.

People are dying because we don’t know which combinations work best on whom, or when to start taking them. If there are two dozen new drugs, say, to add to the nine already out there, that creates 5,985 possible two-to-four drug combinations. The NIH hasn’t even been able to adequately test combinations we’ve already had! From here on in, forget the NIH. It has ceased to be a power player.

The next wave of power belongs to pharmaceutical and insurance companies. It’s amazing how quickly drug companies are hitting pay dirt on so many illnesses. Even as we combat their murderous price-gouging and exorbitant profits, we must not stop the flow of new drugs.

The insurers are suffering growing pains. They don’t know where they’re going or how to get there, and they are more and more under the sway of the big corporations they provide insurance plans to. (These corporations-your bosses-are the ones who don’t pay for much.)

Insurance companies are not the most imaginative. I’m amazed, for instance, how little information about their clients they collect. Visa has a better idea of my profile than my insurer. But this is going to change. Slowly, slowly, slowly, they will build databases of what’s worked, what hasn’t.

Something else will change. Insurers will pay for more experimental medicines and care. This may seem counterintuitive, but it will hurt their bottom line not to. Too much of the good stuff coming along works but has not yet been properly tested. This is true for a lot of illnesses, not just HIV. If a treatment works, the insurers want it in use because it saves them money in the end.

So how do we mobilize for a targeted, methodical next step, one that isn’t exciting or romantic? What does this new organization have to do? We have to see to it that results from all possible combinations are quickly entered into a databank available to every HIV clinician anywhere.

We have to start a system of what I call “anecdotal protocols,” with a huge pool of people. The doctors must be plugged into the same network, using the same software, into which they must enter observations, blood results and side effects. Drug companies, insurers, patients and doctors have to cooperate to make this happen.

The pieces are all in place. The drugs are coming. The software is available (the program I’m most familiar with is an excellent one developed by Dr. Jeffrey Greene at New York University). And the insurers have said that, in principle, they’re open to paying the costs of protocols.

We must have our team in place to see this go forward and to see that the protocols we want are the ones insurance companies pay for.

If anyone called a meeting to accomplish any of this work, would you come? It’s boring, tedious, detailed-beyond-endurance work. It’s like starting an insurance company of our own.

But if we don’t collect this data *fast*, we’re going to take the wrong drugs or take drugs that don’t work well enough. Or we’ll come to the end of the antiviral road and find-because of cross-resistance or virus mutation-that we’ve ruined our chances for taking what’s coming along next.

Tens of thousands of people are already taking combinations. Obviously some are working better than others. But until we collect and analyze the data in a massive way, we’re all playing drug-combo roulette. That’s a future that will backfire against us unless-as in the glorious days of ACT

UP-we once again take charge.

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