In the Hot Seat

Advocates have access, but industry sets the agenda

August 1, 1998 By Dave Gilden

April saw a flare-up among AIDS activists as only a small, select group met with Glaxo Wellcome, while others (including ACT UPers on both coasts) were excluded from the confab. A national ad-hoc coalition had asked for a sit-down with the company to discuss an expanded-access program for its experimental protease inhibitor amprenavir. Glaxo agreed with surprising alacrity—and then proceeded to hand-pick participants, flying seven treatment wonks to its North Carolina offices on the company tab (I was patched in by phone at GMHC).

ACT UP/Golden Gate was especially miffed. In a letter circulated on the eve of the meeting, the Golden Gaters complained that the drug giant barred ACT UP because of its campaign (including a boycott and demos) last year for expanded access to its other new anti-HIV drug, abacavir. “We do not think that other community members should attend a meeting where people with HIV who have long worked on expanded access are explicitly excluded,” the letter concluded.

Those who made Glaxo’s list complained, too—all the way to North Carolina. But once there, they showed their mettle: By meeting’s end, they had argued Glaxo out of its plan to limit access to small trials using amprenavir to rescue treatment failures. Instead, Glaxo promised to distribute the drug to anyone not benefiting from current regimens.

This exchange had more positive effects than many such meetings that, taken together, mark the regression of treatment activism into uncoordinated lobbying. As community unity withers, a new breed of professional “advocate” has appeared, with the drug industry’s complicity and largely outside public view. Every big AIDS nonprofit has at least one such employee, not to mention a staff partially funded by pharmaceutical grants. And there are several unaffiliated players who also depend on drug money. So far, most of these advocates are modestly paid, hard-working ex-activists.

These industry-advocate meetings serve three main functions. They offer an advance peek at data from lab experiments and clinical trials, with the figures presented to portray a compound uniquely structured to avoid drug resistance and serious side effects. This spin usually turns out to be false later, when better information is available, but by then the hype is on.

Discussion also turns on the design of upcoming trials. Some activists are now so expert that they

can advise the companies on how best to construct studies so as to recruit volunteers and collect useful data. Even when acrimonious, these pro-bono consultations are highly valued by the industry.

If convinced of a drug's worth, advocates intercede with the FDA in favor of its approval. But in return, they demand certain quid pro quos. No. 1 on the list is expanded access—as with amprenavir. Campaigns for access to experimental drugs have a long and honorable history, but of late they have lost much of their urgency.

For now, protease regimens have stabilized many, and community-inspired changes at the FDA plus technological advances have greatly sped drug development. In place of tens of thousands receiving an experimental drug for years, current expanded access enrolls a few thousand for a few months before the FDA allows normal sales. These programs have become one more part of a drug's premarketing buildup, and advocates' best intentions pave the road to corporate profits. It would be easy to condemn treatment advocates for allowing themselves to be co-opted. Yet present relations mark a natural evolution wrought by the "give us more drugs now" activism of yore.

I can't help but wish that the agenda at these get-togethers was set less by the companies and more by the community. If the times are no longer so desperate, there is surely opportunity to address the larger picture: Pharmaceutical research has given people with HIV a future chock-full of lab tests, pill taking and side effects. It's a life, but one with enormous burdens that concern the drug industry not at all. The community spurred on the pace of drug development—it will have to work just as hard to win practical treatments accessible to all.

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