Who Do You Trust?: Self-Appointed Experts Further Confuse the Issues Surrounding HIV.

GUEST COMMENTARY

by GENEVIEVE M. CLAVREUL Ph.D.

Recently I attended an informational session on the management of HIV infection which was billed as an "Amsterdam Update." This special session was to give people living with HIV, their families, friends and care partners a clinical overview and update from the VIII International Conference on AIDS. The panelists were: Drs. Marcus Conant of San Francisco, and Jeffrey Rollstin, Steven Oppenheim, Douglas Richman and moderator Brett Cassens, all of San Diego. Publicity indicated the program was "supported by an educational grant from Burroughs-Wellcome Company."

Sadly, the information given was spotty at best, and misleading at worst. It's not that many of the answers were not helpful but that too many of the responses betrayed a disturbing lack of objectivity about promising developments and an equally disturbing support for others unrelated to growing bodies of evidence. Many responses implied an insider's knowledge but betrayed an appalling lack of up-to-date information. And, as in everything related to the complex politics of AIDS — so saturated with hidden issues of profit and professional rivalry for funds — beneath the surface were issues shaped as much by unspoken agendas as by science.

This was most apparent in the attitude of the presenters to the drug AZT, a product (surprise) of the event's sponsor, Burroughs-Wellcome. Despite disclaimers to challenges to the objectivity of the panel regarding the sponsor's best-selling product, minimal reference was made to the drug's well known negative side effects. AZT was clearly the star of the show. One could easily come away with no sense of the risks involved in its use or of the serious reservations many have regarding its potentially deleterious effect on bone marrow. ddI and ddC were mentioned mainly as enhancers of AZT. There was no mention of feared connections between AZT use and the high incidence of non-Hodgkin's lymphoma as reported by Richard D. Moore, et al., 1991 in the Journal of the American Medical Association.

Most troubling was the clear message that people who are HIV-positive begin AZT early, long before progression of the disease. Earlier this year, the U.S. Veterans Administration released a study comparing early vs. late treatment of AZT. It found that while the group receiving early treatment did experience a reduction in progression to AIDS, by no means had AZT improved the rate of overall survival. In fact, the study's secondary findings indicated that once AIDS developed in patients who had received early AZT treatment, more of them seemed to have multiple infections; a slightly higher proportion died; and the median survival time was slightly shorter than in patients who received late AZT therapy. These findings confirm early work of Doumon et al., released in 1988 in France. Early AZT use *is not* necessarily wise and it is certainly not universally recommended, Burroughs-Wellcome's balance sheet notwithstanding.

This all-too-cozy relationship between doctors and drug companies is not limited to AIDS, but experiencing it in this context — many years into this struggle — underlined for me the danger of relying on corporate giants as the major source of information on the drugs they market. The pressure on the panelists to present the hosts' bread-and-butter products in the most favorable — even the least unfavorable — light is too strong, even if not conscious. Few physicians show themselves willing to offend such a magnanimous host as Burroughs-Wellcome. The firm has sought to muffle criticism even within the activist community by offering its "educational grants," including a one million dollar gift to ACT-UP/ New York.

Let me address some of the audience questions to correct the information given and, where they exist, to point out some of the underlying issues:

1. DRUG EFFECTIVENESS TRIALS:

In response to questions about reports at the conference on two drugs which had shown early promise — Tagamet (also known as cimetidine) and Ampligen (double-helix interferon), panelists indicated that no new studies had been done, implying the drugs had been disappointing.

This is not accurate. Tagamet, a prescription medicine licensed in 1977 for peptic ulcers and stomach bleeding, has shown widespread indications that it acts as an immune modulator, tending to strengthen immune response by blocking histamine receptors on immune system cells. It is currently available, gives every appearance of being non-toxic and has demonstrably increased CD4 cells in many individuals. No current studies are planned — not because of the inherent nature or effectiveness of the drug — but because the manufacturer's patent will run out next year, making it financially unprofitable for further research investment. Ampligen has shown promising results when used in conjunction with AZT — contrary to Dr.Oppenheim's claim no new work had been done on this drug. It enhances the effects of the AZT without additional toxic reaction when employed to suppress outbreaks of AZT-resistant strains of the virus, as documented by Dr. David H. Gillespie of Hahnemann Hospital in Philadelphia. The study results were available at the Conference. Again, lack of funding has slowed progress in our understanding of Ampligen's possible benefits.

2. MYCOPLASMA AS A CO-FACTOR:

Professor Luc Montagnier, the French researcher from the Pasteur Institute in Paris, has developed a theory that tiny bacterial agents known as mycoplasma are an infectious co-factor in the evolution of HIV-infection into full-blown AIDS. This research may be critical in finding a way to save the lives of millions currently infected but who remain healthy, as the presence of mycoplasma in HIV infected individuals is thought to accelerate the progression to AIDS. If mycoplasma fermentans is treated it could slow or stop the progression of the disease. Virologist Doug Richman of UCSD Medical Center indicated that Montagnier had retreated from his earlier statements because he had found no compelling evidence to support his hypothesis. As evidence, he noted that Montagnier had not presented any new papers in Amsterdam. He went on to indicate that an agent he referred to as mycoplasma pneumoniae is relevant only to non-AIDS-related pneumonia and is meaningless when it comes to HIV.

The facts tell a different tale. Indeed, Montagnier presented no new papers — because an entire conference about the relationship of AIDS and mycoplasma had been held in Scottsdale, Arizona in October of 1991. And the agent he has been researching is not *mycoplasma pneumoniae but mycoplasma fermentans*, a different entity altogether. In a telephone conversation Dr. Montagnier indicated to me that he still considers mycoplasma to be of crucial importance in understanding how HIV activates and may even be a relevant factor in the cases of the so-called AIDS-like disease — recently the subject of so much media attention — a fact he noted in a paper published as long ago as 1990.

Indeed, Dr. Montagnier believes that it may be the spread of a hardy new strain of mycoplasma in the '70s colliding with HIV, which until then had lain dormant in Africa, that triggered the epidemic. He believes mycoplasma is still a mystery and may yet yield major keys to understanding that could translate into real progress in the fight to end the epidemic. Dr. Richman's dismissal of this line of research — like that of his fellow virologist Anthony Fauci, head of the National Cancer Institute in Bethesda — may reflect a concern that if the focus shifts away from virus-hunters to mycoplasmologists, so will the research grants which mean money and influence.

3. WOMEN AND AIDS:

It was disturbing that the issue of women and AIDS was presented by a male physician and the individuals on the podium were all white males, since there are many competent women clinicians who attended the Amsterdam Conference. Nor am I merely engaging in feminist nit picking since, twice, information given about women and HIV was suspect.

Dr. Oppenheim stated that studies indicate that there is no change in the menstrual flow of women with HIV-infection. Having personally interviewed hundreds of women with HIV/AIDS, I find it impossible to accept such a statement and I question the validity of studies that reach such a conclusion. Over 90 percent of the women I interviewed report that a change in menstrual flow was the first indication of a problem. Perhaps this is a case in which the results of data collection are directly effected by the techniques and the expertise of the interviewers!

Dr. Jeffrey Rollstin, an OB-GYN, answering a question about transmission of HIV through breast milk minimized a risk that many feel to be as potentially deadly for infants as is unprotected sex for adults. For years we have known that breast milk was a potential source of transmission, but the information was intentionally not released at the request of the Pan American Health Organization (PAHO) which receives its funds from the World Health Organization. PAHO spokesperson Dr. Lydia Bond reasoned that in underdeveloped countries, specifically in Africa, infants would die of starvation in any case if denied breast milk. Hiding this mode of transmission from mothers where other alternatives for nourishing the child are abundantly available, strikes me as criminal. Every mother deserves to know the risks to her child so that she can be tested and proceed accordingly.

4. NEOPTERIN:

Asked whether more had been discovered about the usefulness of monitoring Neopterin within the system of an HIV-positive individual as an early predictor of disease progression before the outbreak of actual symptoms, the panel dismissed the possibility rather casually, as if the notion had been discredited.

Again, the weight of scientific evidence flies in the face of their dismissal. Neopterin is now considered "a marker of immune activation" (Dr. Echeverria LaBarga, Spain). This means that Neopterin production is stimulated as soon as the body perceives itself under attack from a foreign substance. This response is triggered by all sorts of viruses, not just HIV; what is important is that elevated Neopterin levels can indicate trouble before other means of detection will give any evidence. Mark Gompels of London found "Neopterin was the most significant overall predictor of disease progression." There is a "consistently increased level of Neopterin in the more advanced stages of HIV," according to Antigoni Katsoulidou of Athens. "In neurological disease, elevated Neopterin levels in cerebrospinal fluid usually indicated a patient with HIV encephalitis or cerebral toxoplasmosis," says Dr. Armand Pierre-Liaudet of the Laboratoire de Biochimie in France. Alfred Saah of Baltimore considers Neopterin to "provide ... more sensitive prognostic information than Beta 2-microglobulin."

My experience at the "Amsterdam Update" — something of a misnomer, since so much of what was up-dated was old news for those involved in AIDS research — convinced me that current information from a clear, informed and objective source of current knowledge uncontaminated by the agendas either of the drug companies or the various factions within medicine is lacking. Another problem we must address: the lack of clear channels of communication between busy clinicians, often overwhelmed with the needs of their sick patients and the researchers in their laboratories doing cutting-edge work to discover new medical initiatives that could save these patients lives. I do not mean to single out for special criticism those clinicians who spoke; I wish only to appeal for the creation of better, more objective channels to disseminate the facts — to doctors as well as concerned persons outside the medical profession.

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