Cutter Forum: AIDS and hemophilia treatment.

At the close of the XVth World Federation of Hemophilia Congress, held June 27 to July 1, 1983 in Stockholm, Sweden, Cutter Biological invited a select group of American medical experts to discuss a recurrent theme at the conference: AIDS and hemophilia treatment.

For those professionals who were unable to attend the Congress, Cutter is providing a summary of the discussion. Co-chairing the July 1, 1983 Cutter Forum were Dr. Louis Aledort and Dr. Shelby Dietrich.

Cutter Forum Participants

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C.J. Cornell, Jr., MD, Dartmouth-Hitchcock Medical Center, Dartmouth, New Hampshire.

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Jeanne M. Lusher, MD, Children's Hospital of Michigan, Detroit, Michigan.

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At this year's Congress, talk of AIDS dominated the discussions. Physicians and researchers alike pointed out that the fear of AIDS is actually causing patients more problems than the disease itself.

Fear of Factor

Scared by the heavy media coverage of AIDS, many hemophilic patients are apparently cutting down on their treatments — sometimes with serious results. Said one treating physician, "We've had people come to the center in shock because they allowed bleeding to go on without treatment. We have seen neuropathies occur in patients who had previously been very sophisticated treaters, because they are convinced they're going to get AIDS via a single transfusion." Some treatment centers report that patients are presenting for their annual physical exam this year with ~~ecchimosis~~ ecchymosis and bleeds they are not treating, all due to a fear of contracting AIDS.

Treating physicians
~~Hospitals~~ have reacted to the AIDS scare as well. Many report that they have cut down on prophylaxis. When the story first broke in the press in January, some institutions actually suspended surgery on all patients, not just patients with hemophilia. Within a few months, though, all had resumed surgery.

One physician said he feels that worry about AIDS has simply made some patients end a habit of overtreating themselves, and adopt a more conservative approach to dealing with bleeds. "We had many patients on home prophylaxis or home therapy, who took that as a liberty to treat themselves whenever they had an ache or a twinge. I think now they are being more selective. . .They're waiting two or three hours to see if it gets worse or better, and only if it gets worse will they go ahead and treat."

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One physician reported "some demand from our patient population, not only the younger ones but all ages, for heat-treated ~~factor~~ concentrate." Although there is no evidence that heat treatment prevents factor from transmitting AIDS, some physicians seem to feel that it can't hurt. A few doctors add that they are using the heat-treated material because it may reduce the possibility of transmitting other viruses, including hepatitis, although there ~~is~~ are no proof data at present that supports this position.

The Call for Cryo

The threat of AIDS has also rekindled demands for donor-specific cryoprecipitate. At least one doctor told of "getting ten phone calls a day from extremely anxious parents who were demanding that their child get cryoprecipitate because the treatments come from single volunteer donors . . . . We have had a practice for a long time, as I think many pediatric centers have, of using cryo in the younger children. But with all the mass media attention to AIDS in mid-January and February, we have had calls from parents whose children who were on cryo earlier, and who were demanding that the child go back to it." Another physician reported a similar situation. "But what happened was that the AIDS hysteria died down at the same time that the Red Cross had produced a larger supply of cryoprecipitate. Suddenly those families weren't all that enthused about going back to cryoprecipitate, which require ~~with~~ deep freezers freezes and so forth. So the Red Cross was calling me weekly and saying, 'What are we going to do with all these cryos?'" The availability of the substance is, however, limited in many areas.

More and more, patients want to know who their donors are, regardless of whether they are using cryo or ~~factor~~ concentrate. As a good example, one doctor recalled

a woman with factor XI deficiency who was coming in for elective surgery. "She had lined up ten type-specific donors as a source of plasma for her procedure, and she wanted to know why she couldn't have those donors give the plasma for her, since she knew these individuals and felt reasonably sure that none of them would transmit AIDS to her. Well, whether she's right or not, someday we may have to use computer technology to provide people with good information about their donor plasma."

There was a general consensus that selection of blood donors has become a crucial matter. Some researchers advised that blood banks should ~~select~~ screen blood donors ~~on the basis of~~ for circulating immune complexes, ~~hepatitis~~ and positive hepatitis markers as a possible means of eliminating transmission of AIDS. They added that they will continue to prescribe the blood products presently marketed because of the overriding benefits. In support of current treatment methods, one MD said, "Data related to the patients with hemophilia in Sweden show that the longevity and lifetime of hemophilia there is very close to that of the normal population, which is very encouraging. Data compiled on people with hemophilia in one U.S. State show similar results, and I think that's an optimistic aspect and should be emphasized. It may be related not only to good hemophilia care, but also to better medical care throughout the United States and obviously, Sweden."

The Fear Spreads

Beyond the physiological considerations, the threat of AIDS has caused serious psychological difficulties for many patients with hemophilia. In some cases, wives have discontinued sexual relations with their hemophilic husbands, because

they fear it will give them AIDS. Some patients have even become afraid to hold their own children because it might give them the disease.

The physician who wants to test a patient for AIDS runs the risk of putting the patient into a state of terror. Doing serial examination of T-4 and T-8 ratios, one physician said, "immediately brings the question to the patient's mind, 'Why are you doing this?'. . . We say we're worried about AIDS and warn them about unexplained fevers, weight loss, and tell them to bring any lymphadenopathy to our attention. Unfortunately, that can turn the patient into a hypochondriac. He constantly feels for the lymphadenopathy and takes his temperature three times a day."

Many at the conference warned colleagues to avoid fueling patient's fears by giving them inconclusive data. One MD said, "The major concern I have is that physicians or others who deliver health care will magnify the panic by telling patients they have 'pre-AIDS' or AIDS, based on the methodology we have used for the last four or five years in defining T-cell populations." Another MD added, "With the anxiety our fellow physicians are causing patients, we're going to see more fear of AIDS than actual cases of AIDS."

Do ~~Flipped~~ Reversed T-cell Ratios Mean AIDS?

Diagnosis of AIDS remains a tough problem for doctors. At the conference, the usefulness of current methods of diagnosing the disease were seriously questioned. Physicians seemed to ~~feel~~ believe that T-cell abnormalities alone are not ~~a sure~~ certain indicator. One explained, "There are about fifteen cases of AIDS out of twenty thousand treated male hemophiliacs in the country . . . But something like one in three of all hemophiliacs will have T-cell abnormalities." Another

physician added, "I tell most of my patients that I think if we had had the knowledge or the foresight to do some of these T-cell studies four or five years ago, we would have seen the same abnormalities we're seeing today. I think they're a consequence of therapy and we just didn't look for them a long time ago . . . So I try to put into perspective for my patient the fact that if I test their mother or sisters, and they just had a viral illness, they're going to have these abnormalities, and it may be related to the chronic exposure to hepatitis B or to the proteins in the concentrate." A physician who has dealt with AIDS directly also doubted the validity of T-cell tests. "I had one patient who died of AIDS . . . The difference between him and all our other patients who did have T-3, T-4 and T-8 ~~flip~~ reversal was his total T-3 numbers. His absolute number of T-3 was markedly down, whereas the rest of the patients — although they had ~~flipped~~ reversed — had normal total T-3 numbers. I think, too, if one looks at people who have common colds, he will see a lot of ~~flip~~ reversal in the T-3 and T-8."

Lymphadenopathy, on its own, is an equally unreliable indicator of AIDS. One MD said that as many as one third of all children with hemophilia may have lymphadenopathy, while another noted "We had one adult patient that we were quite concerned about because he had posterior cervical lymphadenopathy to such an extent that we even biopsied. But now it's disappeared and he's fine. So I really don't think that the hysteria that is often based on this symptom is valid."

Reassuring Patients

The key message of the Forum was that while there is a threat of transmitting AIDS through blood transfusions, physicians should make a point of telling their patients it is not nearly as great as the media has made it seem. One physician

noted, "The fact is, we haven't seen an exponential increase in AIDS patients among the hemophilia population as has been seen among homosexuals. Right now, the figures are not doubling every six months, as some originally predicted they would." Another MD added, "I have to sit down individually with all the patients and discuss the AIDS problem with them. But I stress that I am not very concerned because the majority of our hemophiliacs are not affected by it."

Another physician pointed out that due to incomplete data in the U.S., no one is sure what patients with hemophilia are dying from, or how long they are living. "We don't have good mortality data. We are not keeping good data on the ages of our patients, and I think that CDC or not, AIDS or not, that our country critically needs some conglomerate data base that shows how long our patients live, what they die of, and we should update that information annually."

Despite all the apprehension about this new disease, physicians should emphasize to patients that personal care and proper treatment remain much more important, than AIDS. One researcher put the situation into perspective this way: "The very essence of our treatment programs could potentially be threatened by the fear of a disease that has not even killed ten hemophilic people since 1982 . . . I had eight patients die of trauma and cerebral hemmorhage last year, and I didn't have any die of AIDS. I think we have to remember that our patients are getting hit on the head or mugged, that they're falling down stairs, they're bleeding to death, and that those problems are much more immediate than anything having to do with AIDS."