

Sifting Through the Complexity: Sean Hosein and Treatment Update

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Sean Hosein's interest for research in AIDS related fields was spurred in 1982 by a New York Times story on "Gay cancer". Something about the phrasing struck him as being odd and the content of the story confirmed that the focus was on the inevitability of cancer for male homosexuals...

By then, Sean had already taught himself a lot about the immune system, because of allergies that had plagued him since childhood and for which doctors had failed to provide satisfactory answers or treatment. A self-confessed book worm, Sean would spend hours at the library collecting every possible bit of information about allergies, the immune system, vitamins, especially Vitamin C, through the work of Norman Cousins (ANATOMY OF AN ILLNESS). From way back, Sean has also been an avid consumer of medical journals. Having started with what was then scant and easily understandable information, Hosein kept up with everything, rushing to the library to look up new terms and storing masses of knowledge that he would soon be able to put to good use. He is currently reading AND UNDERSTANDING up to 150 medical and scientific journals per month, most of which are impenetrable to the non-initiated. Also he sees links and cross-references to be made where most people, even in the medical profession, lack the background to do so.

Hosein describes the beginnings of his work as if he had found himself in an uncharted city block, without names or signs for the streets. By 1985, much more information was available. By then, it was enough to read Time Magazine and the popular press to know as much as most physicians about AIDS/HIV. After 1985 there were 4 journals specializing on the subject, then 10 then 12.... Hosein kept up with it all and he soon had the feeling that some of the theories were not coherent, that researchers were not communicating. There were parallel discoveries but no dialogue. In 1986, Hosein felt he knew enough to write a short article about AIDS, the links between the immune system and the virus. Soon after that, he helped a friend document his own case against a doctor who wanted to remove his spleen. Hosein researched his argument and provided the friend with documentation and photocopies. The confrontation that ensued was the start of a new trend: doctors being

challenged by well informed AIDS/HIV patients. This victory inspired Sean to pursue his quest for information from every possible source in order to establish links between - as yet - unrelated areas. His columns got progressively longer, leading to a prototype newsletter, produced, edited and distributed on a voluntary basis with the cooperation of Bernard Courte and George Smith. The newsletter became TreatmentUpdate/TraitementSida, distributed through CATIE.

The way Hosein describes AIDS/HIV research to-day, a "war on cancer" is by drawing several boxes, labeled VIROLOGY, IMMUNOLOGY, RÉTRO-VIROLOGY each heading in a forward direction of its own, without the vitally needed communication between areas of research, the cross-fertilization that would ensure progress all around. A breakthrough may lack impact because it does not apply to the whole picture. "What we desperately need" says Hosein "is an APOLLO type of project, that would allow the pooling of resources. There is so much work going on, so much funding, but the efforts are scattered, nobody has a full picture or a clear grasp of the whole. AIDS is the most complex epidemic we have ever seen, where different types of effort have to be carried out at the same time and in a hurry: helping the sick and carrying research on new drugs, early detection so that people with HIV can work on sustaining their immune system and maintaining their level of health." Sometimes these efforts may seem contradictory, or there seems to be a conflict in priorities.

In his writing, Hosein does not advocate particular forms of treatment. He presents up-to-date information, gleaned from his numerous sources of scientific and medical information and simplified so as to make sense for non-specialists. He also writes about nutrition and vitamin supplements, another area where the information is disseminated, confusing, when not contradictory. Some issues are very cloudy in alternative areas because nothing is "scientifically proven". Nowadays though, there are many references in medical journals to the use of vitamins, Chinese herbs and acupuncture as possible strategies to enhance the immune system and the quality of life for people with HIV/AIDS. Although we are often led to

believe that some drugs can bring instant relief, there is no such thing as a quick fix in terms of health. Asked what one should do with \$100 to buy vitamins and supplements, Hosein does not answer right away. "There really is no specific, simple answer. What I would say is, before you do anything, get your blood cells checked for nutritional deficiencies, THEN get nutritional counseling, THEN see where your \$100 should go. This will vary greatly from one case to the next. But, in every case, vitamins and supplements should only be considered as part of a package, a strategy to keep in as good a condition as possible so that when a cure comes around, you will be able to take advantage of it." Sean Hosein insists on the importance of a strategy and he says he likes the French word "démarche" which means approach, literally a way of walking, to self-empowerment.

After the international conference on AIDS, held in Amsterdam, Hosein says he sees a change in the focus of research and treatment. A vital shift from virology - the war strategy - to immunology - the domain of preservation of the immune system and prevention - which confirms the importance of a holistic strategy.

