Alternative Health

Long-term survivors can help us now

June 1, 1994 By Bob Lederer

The recent deaths of long-term survivors and AIDS activists Michael Callen and Aldyn McKean remind us of the urgency of their passionate quest: large-scale, diverse population studies of long-term survivors. Meanwhile some preliminary research -- publicized largely due to Michael's and Aldyn's efforts -- has yielded valuable clues useable today by people with HIV and AIDS mapping survival strategies.

Michael lived 12 years after his first opportunistic infection; he co-founded numerous AIDS self-empowerment groups, pursued a fabulous singing career and wrote the ground-breaking book, *Surviving AIDS* (HarperPerennial), which reviewed existing research and presented in-depth interviews with 13 long-term survivors, all spiced with Mike's salty, sassy commentary.

Aldyn lived 14 years after his first AIDS-related symptoms, but despite a T-cell count of under 200 since 1983, did not develop an opportunistic infection until last fall; he was a co-founder and brilliant voice of ACT UP/New York and became its leading advocate at the international AIDS conferences.

Last year's international AIDS conference in Berlin provided the greatest tribute to these and other activists' hard work. Four sessions were devoted to the factors influencing survival, and at the opening plenary, Aldyn gave a powerful speech including a plea for devoting more resources to long-term survival research.

Aldyn and Michael tirelessly posed the simple but often ignored question: What can people with HIV learn about staying alive from whose who've done it longest? That such an obvious scientific question took so long to be taken seriously is another indictment of a research establishment more intent on finding profitable drugs than on saving lives.

According to the U.S. Center for Disease Control, a long-term survivor is anyone who has lived twice the median 18-month survival period after AIDS diagnosis. By that three-year definition, San Francisco Health Department statistics show that long-term survivors increased from 11 percent of people with AIDS in 1981-1985 to 18 percent in 1988-1990. These figures exclude people who initially have Kaposi's sarcoma because many live much longer. The fact that a handful still live 8, 10, even 14 years since diagnosis challenges the media incantation that AIDS is inevitably fatal.

Figures are not yet available for HIV positives remaining healthy for many years, but hundreds are known within the HIV community.

A wide range of factors influencing long-term survival have been studied separately. One factor unlikely to be important is the use of toxic anti-HIV drugs such as AZT, ddI and ddC. Considerable data presented at the same Berlin conference and since showed little or no life-extension from these drugs, especially when used for early intervention. Interestingly, Michael Callen reported that “the overwhelming majority of the [25] long-term survivors I interviewed have refused to take AZT.”

But primary health care, including access to prophylactic (preventive) drugs and treatments for each complication along the way, is important for life extension. The lack of such access is reflected in much lower survival rates for women and people of color with AIDS, two predominantly poor, underserved groups.

Research on biological factors -- viral potency, quality of immune response, co-infections and genetics -- has begun and must continue. While these studies may prove fruitful, they should not, as often happens, crowd out other vital research areas.

Most encouraging thus far -- even though they’re still relegated to small, underfunded studies due to their minimal profit potential -- have been studies of nutrition, stress management and psychological factors:

- Of the 296 HIV positives from the San Francisco’s (Gay) Men’s Health Study followed for six years, those taking daily multivitamin tablets had 30 percent less progression to AIDS than those who did not. A Johns Hopkins University study of 2,000 HIV positive injection drug users found that those with normal Vitamin A levels (best obtained from beta carotene) survived 11 months longer, on average, than those with deficiencies.
- A two-year study at the University of Miami Medical School found that among gay men with HIV trained in stress management -- moderate exercise, guided relaxation and positive thinking -- those who maintained the practices most, and those least in denial, had the lowest rates of disease and death.
- A study of three- to nine-year survivors by the New York State Psychiatric Institute found, as Aldyn summarized it, that "what distinguished the survivors was that they exhibited considerable psychological resilience and continued to maintain hope and goals and to derive satisfaction from their lives.

- Several researchers found that important factors in long-term survival were social networks, psychosocial support, psychotherapy and altruistic involvement with other people with AIDS. Aldyn and Michael stated publicly on numerous occasions that their activism helped keep them alive.
- Repeated studies have confirmed that, as Michael explained, “Survivors tend to have extraordinary relationships with their health-care providers... a healing partnership... [Survivors] were neither passively compliant nor defiant.”

“These people were all fighters -- skeptical, opinionated, incredibly knowledgeable about AIDS and passionately committed to living,” Michael summarized.

Two leading researchers in *psychoneuroimmunology* (mind-immunity connections) found laboratory evidence which “essentially confirmed” that traits like these can improve immune function in PWAs.

Aldyn called all these findings “critically important because they can be immediately put to use by people with HIV and AIDS. That such studies continue to go unreported by the media is monstrous.”

But he noted that these small studies merely reveal separate pieces of a “giant jigsaw puzzle.” Aldyn added, “It is extremely unlikely that a single therapeutic agent will ever work for all people with AIDS at all times. No single factor shows a perfect correlation to rates of disease progression.” He also called for “large, coordinated long-term survivor studies that can look at a wide range of variables.” And he emphasized that most existing studies focus on “gay, white men in industrialized countries;” thus “advocates need to push for more long-term survivor studies that include women, people of color, injection drug users, blood product recipients and people in the developing world.”

In the wake of Aldyn’s death, his friends and colleagues have organized the *Michael Callen/Aldyn McKean Fund for Long-Term AIDS Survivor Studies* to press for more attention to this vital area of investigation. The best way to honor their lives, besides donating to this fund, is to heed Aldyn’s admonition: “Advocacy for large, more-inclusive long-term survivor studies must become a regular and consistent part of AIDS activism.”

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