

VOLUNTEERS AND THE HIV EPIDEMIC

Living with AIDS

By Loretta Gutierrez Nestor and Karen J. Peterson, Ph.D.

HIV infection brings personal tragedy. It also challenges society. The spread of HIV, the virus that causes AIDS, threatens to unravel social and economic development in countries across the globe. Everyday, 5,000 more people become infected with HIV. By the year 2000, experts predict that about the number of people infected may reach 30 million worldwide.¹

In the United States, by the end of the 1990s, AIDS may kill 1.18 million Americans. By 2000, the cumulative impact of HIV/AIDS on the United States—on our population, our economy and our personal lives—may equal that of any war in our history.²

"HIV/AIDS, although already in epidemic proportions, seems easy to ignore since it does not yet touch many of us personally," says Benniville N. Strohecker, president of Harbor Sweets. "But it will. And it will touch us with disastrous potential."⁷

Loretta Gutierrez Nestor, a frequent contributor to VAL, is the manager of transformation training, Blood Services, American Red Cross (ARC) in Washington, D.C. and former director of the ARC's National Office of Volunteers. She is a member of the Points of Light Foundation and a board member of the International Association for Volunteer Effort.

Karen J. Peterson, Ph.D., quality assurance associate with the Office of HIV/AIDS Education, American Red Cross, Washington, D.C., is gratefully acknowledged for reviewing drafts and providing a great deal of technical information.



Volunteers historically have responded to broad social problems, including drug abuse, homelessness, illiteracy and disenfranchisement. Now, we must expand these efforts to include HIV and AIDS. As community leaders, we are uniquely equipped to confront the HIV challenge, to dispel people's fears about the dread disease, and encourage prevention efforts as well as services to those already infected.

"The HIV and AIDS epidemic is a rip in the fabric of our society," says Robert D. Hass, chairman and CEO of Levi Strauss & Company.⁷ "Left unattended, it will unravel. But we can pull together as a nation to face this emergency of national proportion." Albert Bowers, Ph.D, chairman and CEO of the Syntex Corporation, adds, "All of us should be asking ourselves the following questions: What will you do when an employee (or volunteer) becomes HIV infected? When an employee (or volun-

teer) is believed to be infected with the HIV virus? When co-workers refuse to work with a person thought to have HIV? When an infected employee (or volunteer) asks for your help? I urge you to take action. Because this is a crisis situation."⁷

If your organization thinks it's time to become involved in HIV and AIDS issues, it will be important to ask these questions:

- What is the need in your community?⁹
- How many volunteers are needed?
- What are the functions they will perform?
- Who is already active in this arena in your community?¹⁰

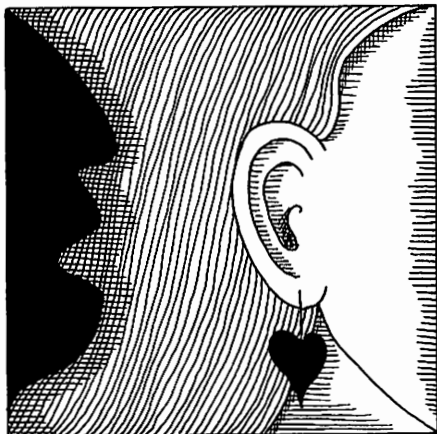
Hundreds of volunteers are already responding across America. They are involved in the following activities and many more:

- Prevention education
- Shopping for food and other needs
- Driving to doctors appointments
- Helping in support groups
- Buddies/friends/listeners
- Legal help with wills and discrimination
- Home care
- Spiritual support
- Referrals for other sources of help
- Telephone hotlines
- Training trainers on HIV/AIDS
- Media/promotion
- Fundraising
- Community activist
- Legislative advocate
- Social support
- Etc.

Of course, a volunteer administration system should be in place for HIV/AIDS volunteers as for any volunteer program. Any number of resources are available which outline proper procedures for re-

cruitment, orientation, training, retention, record-keeping and recognition.

Volunteers and volunteer administrators face added challenges in helping people with HIV/AIDS. There are two major ones: First, volunteers must learn to serve people with a new and unfamiliar disease—to treat and comfort people with HIV/AIDS



Buddies/friends/listeners.

who face great suffering and possibly death, and to provide information, treatment and solace to others infected with the disease but show few or no clinical symptoms.

Second, volunteers must provide this help while coping with their own fears and pain in caring for people who do not get well or whose outcome is uncertain. Adding to the strain is the need to be especially mindful of behaving respectfully and sensitively toward individuals who some consider to be social pariahs. Caring for people who have developed AIDS can be emotionally threatening to volunteers. Specifically, problems arise from the following:⁴

1. Although much is known about the special circumstances under which HIV is transmitted, some volunteers unfamiliar with this evidence may still consider caring for people with HIV or AIDS as potentially threatening to themselves and their families. (Risk to them is very low, as has been shown by studies of health care workers and family members who have had close contact with HIV-infected patients.)
2. As noted, special emotional stamina is needed to care for people infected with HIV who, in what should be the prime of life or in any age group, may be rapidly deteriorating and dying.
3. Some people with AIDS get very sick

and place unusual burdens on paid and volunteer staff because of the intensity of their physical and emotional needs. Many with AIDS go through the "roller coaster" phenomenon. In other words, not all who have developed AIDS are always sick—their health goes up and down with opportunistic infections and their treatment. Some caregivers may become overtaxed, fatigued and overwhelmed by the intensive care required by people with AIDS.

GET THE FACTS

HIV/AIDS is spread by:

- Sexual contact involving the exchange of blood, semen or vaginal secretions
- Sharing contaminated needles or syringes
- Infected mothers to their children before or after birth
- Blood transfusions. (The risk of becoming infected through a blood transfusion is now very low. Since 1985 blood centers have tested all donated blood. Any blood testing positive for HIV antibodies is destroyed.)

HIV is NOT spread by:

- Donating blood
- Casual contact, such as hugging, hand shaking and "social" kissing
- Use of public bathrooms or swimming pools
- Sneezing, coughing or spitting
- Dishes, food or beds used by an infected person
- Mosquitoes or other insects
- Pets

(Source: American Red Cross, Washington, D.C.)

4. Perceptions founded on fears and incomplete information about people with HIV or the risk of contracting HIV may impair a volunteer's ability to care for individuals. (Though many who become volunteers, such as family members or friends, have a strong commitment—beyond fear. Many volunteers are committed to the larger societal health issue, and want only to serve and share their love with others.)

5. Some people with HIV/AIDS are infants and children whose uncertain future can be especially emotionally draining for paid and volunteer staff. Since some of these children have been abandoned by the parents, paid and volunteer staff are

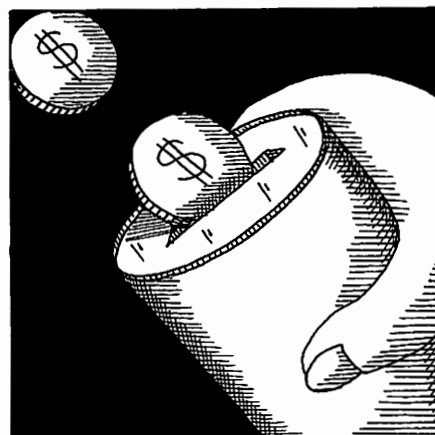
likely to feel an added sense of responsibility for nurturing them.

6. Paid and volunteer staff must deal with families and other loved ones who may be under stress that is even more severe than that usually faced by those close to dying patients. With a thorough understanding of these problems, paid and volunteer staff can play a critical role in effecting the psychological outcome for people with HIV.

People with HIV as Volunteers⁶

In HIV work, the boundaries between providers and receivers of service sometimes become blurred. A rich resource of skill and willing volunteers to consider lies in the over 1 million people living with HIV, according to Irene K. Wysocki, director of volunteer services of the San Francisco AIDS Foundation. They offer first-hand personal experience, enormous talent and an extraordinary motivation to help others. As volunteers they become role models for other people infected with HIV.

While people with HIV may be unable to maintain a full work schedule, they are nonetheless productive and can often provide substantial volunteer hours. Many are also young, well-educated and professionally trained. Many want to make a meaningful contribution to society—not only as a way to reciprocate the love and understanding they have encountered in their lives, but also to counter the feelings



Fundraisers.

of frustration and powerlessness that often accompany a potentially fatal disease.⁶

According to Wysocki, there are many effective ways to recruit these volunteers. For example:

- Contact the HIV/AIDS agencies in your area and, if they publish a newsletter, ask them to mention the volunteer opportuni-

ties that exist at your agency.

■ Speak with these agencies' volunteer managers and inform them of your needs; not only could these managers refer volunteers who have decided they would rather not work in HIV/AIDS, but you also might be able to "share" volunteers who have a lot of hours to donate but who will



Support Groups.

burn out if they allocate their time solely to HIV and AIDS.

■ Place a classified ad or listing in the local gay press or in HIV/AIDS-related publications, as well as Latino, African American or general community publications.

■ Post a notice on bulletin boards at the public health department, hospitals, clinics, the social services department, churches, synagogues and other places of worship, and HIV/AIDS service organizations in your area. Involvement of people with HIV or AIDS not only will enhance the acceptance and civic pride of the individuals, but also will do much to broaden the definition and value of volunteerism in this country.⁶

Cultural Diversity and HIV/AIDS

Some culturally diverse urban areas (which include experienced and recovering drug users as well as some gay and ethnic communities) have been hit particularly hard, such as New York, San Francisco and Los Angeles. Though African Americans and Latinos make up about one fifth of the population, they make up nearly half of the diagnosed AIDS cases in America. HIV has struck these groups in disproportionate numbers. Three times more African American babies and one and a half times more Latino babies than white are born with HIV/AIDS.² It is especially important to involve culturally di-

HIV/AIDS VOLUNTEERS DOs AND DON'Ts¹¹

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DOs

- Have organizational policies on HIV and AIDS.
- Educate yourself and others.
- Define expectations of volunteers and write job descriptions.
- Keep confidentiality of people with HIV and AIDS.
- Make resources available.
- Dispel myths.
- Avoid burnout—take care of yourself.
- Realize that you may not be suited for this type of volunteer work.
- Comply with Americans with Disability Act.
- Operate with complete integrity.
- Know that you will encounter some controversy.
- Give hugs to HIV-infected people who want them, be sensitive to those who don't.

DON'Ts

- Don't refer to people with HIV or AIDS as victims.
- Don't give medical advice if you are not qualified.
- Don't make promises you can't keep.
- Don't deny your own fear and pain.
- Don't let bias and prejudice get in the way.
- Don't contribute to myths and rumors about HIV or AIDS—get the facts.³
- Don't discriminate against or stigmatize people with HIV or AIDS.
- Don't deprive people with HIV or AIDS of the opportunity to volunteer.
- Don't say you're open-minded when your actions reflect something different.
- Don't avoid people with HIV or AIDS.
- Don't be afraid to talk about the disease.

(Some items adapted from *Simple Acts of Kindness: Volunteering in the Age of AIDS*, published by United Hospital Fund, New York, N.Y.)

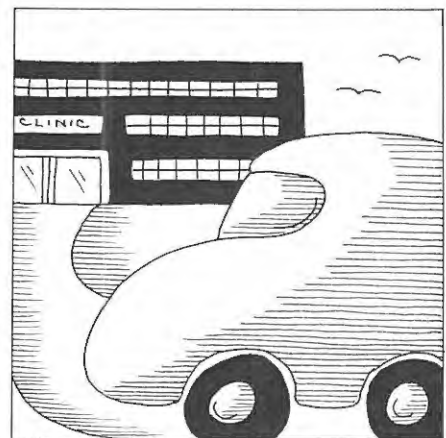
verse people as volunteers. It is also important to provide materials in appropriate languages for your specific target groups and to provide cultural sensitivity training to volunteers who have little experience dealing with people of color.



Advocates.

Partnerships Needed

The volunteer community cannot do this alone. "We need partners," said Levi Strauss Chairman and CEO Robert D. Hass. "It will take corporate effort—federal, state and local governments, business, labor, our educational institutions, the religious community, health care professionals, and private citizens working together. Men and women have a responsibility to their fellow human beings not to abandon or discard them when they most need our care and concern. It's not someone else's fight. It's ours. We have the resources to do it. We have the ability to make a difference.



Drivers.

The question is, do we have the will?"⁷

"AIDS challenges every segment of society," according to Admiral James D. Watkins (Ret.), secretary of the Department of Energy and former chairman of the

Presidential Commission on the Human Immunodeficiency Virus Epidemic, (1989). "Why are we waiting to do something until we are in a crisis situation? I can't tell you the passion that's out there in this country waiting for the leadership to say 'Okay, we're beyond the rejection and the denial and the vilification of others and we're ready to wage war on the virus rather than on groups of people.' It won't be an easy war."⁷



Legal Aides.

Sources of Information and Footnotes

¹ "The Rising Cost of AIDS," by Siddharth Dube, *Choices* magazine, April 1992.

² "The AIDS Plague," Marvin Cetron and Owen Davies, *American Renaissance*, 1989.

³ "Get The Facts," *Red Cross News*, July/August 1987.

⁴ *Coping With AIDS*, U.S. Department of Health and Human Services, 1986.

⁵ *Caring For Someone With AIDS*, U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control.

⁶ "An Untapped Volunteer Resource: People With HIV Disease, ARC or AIDS," Irene K. Wysocki, *The Journal of Volunteer Administration*, Spring 1991.

⁷ *Business and Labor Speak Out on AIDS*, National Leadership Coalition on AIDS, Washington, D.C.

⁸ *Volunteer Recruitment Strategies* (ARC 3318), American Red Cross, Washington, D.C., November 1990.

⁹ *AIDS Needs Assessment Manual* (VC10672), United Way of America, Alexandria, Va., 1990.

¹⁰ *The Community Collaboration Manual*, The National Assembly, Washington, D.C., January 1991.

¹¹ *Simple Acts of Kindness: Volunteering in the Age of AIDS*, United Hospital Fund, New York, N.Y.

¹² The original "Ten Principles for the Workplace" were developed by the Citizens Commission on AIDS for the New York City and Northern New Jersey Region (February 1988). This document can be obtained from the National Leadership Coalition on AIDS in Washington, D.C.

HELP FOR THE CARE GIVER⁵

Providing care can be a stressful and emotional experience. You may feel very frustrated watching a person become sicker despite your efforts. To help cope with feelings of frustration, share your feelings with others, including other care givers, counselors, clergy or health professionals. Call your local HIV/AIDS service organization for support.

Try to arrange some backup help so you can have some free time occasionally. This is especially important during times when the person with AIDS is very ill. You may need to be relieved of your responsibilities periodically so you can also maintain your energy level.

When caring for someone who is very sick, it is important not to ignore your own needs. Unless you take care of yourself, you will not

have the inner resources to care for the person with AIDS.

Remember that you are not alone. There are others like you who have gone through this experience before. You gain knowledge and strength from what they can tell you.

If you would like more information about caring for a person with HIV or AIDS, if you would like to volunteer, or if you would just like more information about HIV and AIDS, contact a doctor, your local health department, your local American Red Cross, your local HIV/AIDS volunteer health group, or call 1-800-342-AIDS. The Spanish hotline is 1-800-344-7432. The deaf access hotline is 1-800-AIDS-TTY.

(Sources: Departments of Health and Human Services, Centers for Disease Control and Public Health Service.)

American Red Cross HIV/AIDS Instructor's Manual, Stock No. 329572, revised 1992.

Daedalus Journal, Spring and Summer 1989, Vol. 118, Nos. 2 & 3, covered different aspects of living with AIDS.

Helpers in the War on AIDS: A Community Responds to an Epidemic. Edited by C. Adams.

San Francisco: San Francisco State University Journalism Department, 1988.

Other resources include *Volunteer Readership* catalog published by The Points of Light Foundation, United Way of America, local Red Cross chapters and local Volunteer Centers.

