## APPENDIX

## I. HIV COUNSELING, TESTING REFERRAL AND PARTNER/CONTACT NOTIFICATION (CTRPN)

### Testing

Reasons for early identification of HIV status include getting the individual into early care, avoiding risks and adverse effects of therapies, determining eligibility for financial support and benefits specific to HIV disease, not putting others at risk, and removing uncertainty that may encourage denial. (Cohen, 1998)

Diagnosis of HIV is based on detecting serum antibodies to HIV. There is a window period between HIV infection and development of HIV antibodies. Therefore, persons testing negative, but with recent exposure, should be tested again within three to six months. During the window period, individuals may have negative or indeterminate results. Indeterminate results are specimens that are positive on Enzyme Linked Immunosorbant Assay (ELISA) tests and have at least one positive band on Western blot testing. Causes of indeterminate results include being in the window period, infection with another retrovirus such as HIV-2, or production of autoantibodies, as occurs with some other diseases. Newer technologies allow for HIV antibody testing with oral mucosal transudate (collected from the lining between the lower cheek and gum). Other test methodologies are indicated in cases in which suspicion of infection is high but antibody testing yields a negative result, and waiting months to repeat the antibody test is undesirable. For example, patients who are suspected of having early infection may be in the "window period" and test negative or indeterminate. In such cases, tests for HIV RNA (viral load assay) and/or HIV p24 antigen may be positive before HIV antibody is produced. However, standard HIV RNA viral load assays are not licensed for this purpose and false-positive tests are possible, especially if the result is low titer. (Cohen, 1998) Retesting may be advised if symptoms are exhibited but test results are negative.

### Counseling

It is critical to provide pre- and post test-test counseling to all individuals who test for HIV. Post-test counseling for persons who newly learn that they are HIV infected may require more than one session. This is a difficult time in which individuals may experience a range of emotions from indifference to denial and anger. Individuals should be provided with resources for primary medical care, referrals for nonmedical services and psychosocial counseling. Required components of counseling include:

***Confidential vs. Anonymous testing*** A description of the difference between anonymous and confidential testing should be provided, as well as the benefits of each.

***Risk Assessment*** The counselor should engage the client in a confidential discussion, enabling the client to recognize and accept personal risk for HIV. Because the risk assessment process serves as the basis for assisting the client in formulating a plan to reduce risk, it is an essential component of all pre-test counseling.

***HIV-Prevention Counseling*** Counseling provides a critical opportunity to assist the client in identifying his or her risk of acquiring or transmitting HIV. Counseling also provides an opportunity to negotiate a plan to reduce or eliminate the risk. Prevention counseling (pre-test counseling) should prepare the client to receive and manage his or her test result. (For this reason, prenatal counseling and voluntary testing of pregnant women, rather than mandatory testing of pregnant women and newborns, is in the best interest of both mother and child). Prevention counseling should also: (1) facilitate an accurate perception of HIV risk for those who are unaware, uninformed, misinformed, or in denial; (2) translate the client's risk perception into a risk reduction plan that may be enhanced by knowledge of HIV infection status; and (3) help clients initiate and sustain behavior changes that reduce their risk of acquiring or transmitting HIV. Unless it is prohibited by state law or regulation, clients should be offered reasonable opportunities to receive HIV-antibody counseling and testing services anonymously. The availability of anonymous services may encourage some persons at risk to seek services who would otherwise be reluctant to do so.

***Notification of HIV Results and Prevention Counseling*** Providing HIV antibody test results to a client involves interpretation based on the test result, the person's specific risk for HIV infection and dealing with the client's reaction to his or her test result. The client will most often focus on the result itself. Client-centered counseling is required to reassess behavioral risk that may influence the interpretation. When the client receives HIV test results, the primary public health purposes of counseling are: (1) to reinforce perception of risk for those who are unaware or informed; (2) to help uninfected persons initiate and sustain behavior changes that reduce their risk of becoming infected; (3) to arrange access to necessary medical, prevention, and case management services for persons with a positive test result; (4) to assist those who may be infected to avoid infecting others and remain healthy; and (5) to support and/or assist infected clients to ensure the referral of as many sex or needle sharing partners as possible.

***Partner Notification/Names Reporting*** In an attempt to track the HIV/AIDS epidemic better, the Centers for Disease Control and Prevention (CDC) wants all states to adopt HIV reporting systems, in which state health authorities would collect the name or coded identifier of everyone who tests HIV positive. Some reasons given by the CDC for this requirement are:

- Recent advances in treatment, particularly protease inhibitors, have the potential to increase the quality and quantity of life.

- Mandatory Names Reporting will help facilitate partner notification programs to expand access to testing. An estimated 40% of people at risk for HIV have never been tested. Partner notification is particularly important for many women, whose risk of HIV transmission is through the partner's risk behavior.

- There is a need to increase and improve HIV surveillance efforts and data. Public health officers have been hampered by the inability to gather accurate, disaggregated data to respond accordingly to the epidemic. The numbers currently available of HIV cases are based on estimates while trends in the epidemic are informed by AIDS reporting. AIDS

reporting does not provide an accurate reflection of HIV cases, as infection usually takes place years prior to the reporting. New treatments which delay the onset of AIDS will also decrease data available when reporting is further delayed. Even a policy which exempts anonymous test sites from such reporting would provide a minimum number of HIV cases, which would be more accurate than the status quo.

•There are increased opportunities for disease intervention. HIV seropositivity reporting would allow local health officers to conduct risk-reduction counseling and prevention education. Such efforts will increase the number of high risk people accessing testing, who are informed about their HIV status, and interrupt transmission to more people. (Kwong, 1997)

Many people, however, feel that HIV names reporting systems discourage already hard-to-reach at-risk individuals from getting tested so they can get treatment and counseling to protect their own health and the health of others. Of the 700,000 estimated HIV-positive Americans, as many as 300,000 may be unaware of their status. Name reporting, it is felt, contradicts the strong movement toward better medical privacy in America. (AIDS Action, 1998)

The Multi-State Evaluation of Surveillance of HIV (MESH) study surveyed HIV positive and negative people in eight states about the attitudes and factors that influenced their HIV testing decisions. Nearly 20% of those surveyed listed fear of name reporting as one reason for avoiding HIV testing. Since 50% of HIV positive Americans don't know they are infected, anything that discourages testing to this extent should be a serious public health concern. (Forbes, 1997)

An effective domestic violence screening protocol is critical to the implementation of partner notification. Domestic violence includes physical, sexual, economic, emotional, and psychological abuse. Domestic violence, from the PWA/PWHIV viewpoint, includes spouses, partners and other people in the community. It is important that, in a situation of past or potential domestic violence, contact tracing be stopped. Providers should be trained as to how to screen for domestic violence. Public health research suggests that domestic violence is an issue for 25% of HIV-infected women. Any domestic violence screening protocol should be implemented in a consistent, sensitive, and culturally, linguistically-appropriate manner.

***Referral Process*** A thorough client assessment often indicates a need for services that cannot be provided by the counselor. The counselor has two opportunities to make referrals: (1) the HIV prevention (pre-test) counseling session, and (2) the test notification/prevention counseling session.

## II. PSYCHOSOCIAL, SUPPORT AND MENTAL HEALTH SERVICES

Some of the psychosocial and health behavior co-factors which have been identified as impacting the immune systems of HIV-Infected individuals and their mental health needs are:

grief, depression, cognitive belief that HIV equals death, trusted support, self-assertiveness, coping style and body care performance (i.e., nutrition, sleep and physical exercise). (BETA, 1995)

It is crucial for physicians and other medical practitioners to take into account the psychological effects of a Highly Active AntiRetroViral Therapy (HAART) regimen and should not overlook or ignore signs of psychological distress. In addition, a medical practitioner should also evaluate the amount of stress a person is under since stress adversely affects the immune system.

Physicians should take a thorough sexual, drug, and psychiatric history of the client with HIV, and should have a working knowledge of AIDS. Risk reduction should be discussed with patients and the medical provider should ensure that the patient has a working understanding of safer sex. A trusting relationship must be established with a patient who may see themselves as outcasts and find trust difficult. Patients may have to clarify their relationships with lovers and family members, especially if they are being blamed and rejected. Therapists should learn about friends and family who have died of AMS as well as friends and family who can provide support. A constant concern in psychotherapy is whether, how, and what to tell others. Patients may feel contradictory needs to conceal and confide. Physicians frequently lose sight of the mental health needs of patients.

Among substance users (including those injecting drugs as well as those using alcohol, crack and cocaine, among others), psychiatric disorders and drug use may interact with physical and emotional consequences of the illness in such complicated ways that causes and effects become difficult to distinguish. (Harvard, 1994)

Other issues which impact on mental health include past and present sexual abuse and women's issues of lack of empowerment, especially for female partners of substance users, increased complacency and the erroneous perception of lowered risk for HIV.

Individuals with HIV infection face issues unique to the disease, as well as issues confronting patients with other chronic, progressive, life-threatening conditions. These include the following:

***Disclosure***

Patients should be counseled about the possible negative ramifications of disclosure, such as discrimination. Some patients will find they benefit from group support meetings with others who have I-UV infection. Disclosure of HIV status may be intertwined with disclosure of sexual orientation, sexuality, or drug use.

***Income Maintenance***

Obtaining, keeping, losing and changing jobs are particularly stressful concerns to HIV positive people, largely because of health insurance and the necessity of obtaining adequate health insurance covering HIV. There are agencies designed to assist individuals' return to work, but

new employment may cause fear of HIV screening, so it is important that those going back to work be placed with an HIV-friendly agency. Peer education work can supplement income and lift self esteem.

***Discrimination in the Workplace or School/Legal Issues***
Discrimination may be encountered in such venues as, but not limited to, employment, fair housing, school, and health care settings. Anti discrimination legislation differs across the states.

***Special Issues***
Management of HIV infection may coincide with other concerns that must also be addressed including, but not limited to, treatment on demand for the substance user, mental illness in conjunction with chemical abuse (Mentally Ill Chemical Abusers-MICAs), homelessness, family planning for a couple considering pregnancy, reproductive health services for the pregnant woman, and permanency planning.

## III. PEER INTERVENTIONS, INCLUDING SUPPORT, ADVOCACY AND TRAININGS FOR ACCESS TO SECONDARY PREVENTION SERVICES

Utilizing peer case managers, wherever possible, is an effective and meaningful mechanism to facilitate the provision of comprehensive health, mental healthcare and social support services as a viable means of providing ongoing secondary prevention services. The goal of such peer programs is to empower people living with HIV, as well as family members and significant others as identified by the individual, and then to develop an ongoing relationship and partnership which are essential for successful case management. Such case management includes identifying those who need services, assessing their specific needs, developing a specific care plan, implementing and monitoring the plan, reassessing the plan and, if necessary, terminating the plan when appropriate with the client. Community-based organizations which offer HIV case management are in a particularly strong position to provide peer interventions, although funding limitations may prevent programs from the provision of stipends to peer counselors. In addition, some organizations and consumers have trepidation about peer-delivered educational services, particularly surrounding the provision of treatment education. These constraints and concerns notwithstanding, peer interventions have been shown to be beneficial not only to the client being served, but also to the individual providing the services.

Peer work has been documented to increase a PWA/PWHIV's feeling of self-esteem. It is, however, important to acknowledge and address the fact that going to work in an AIDS organization and becoming an advocate for other PWA/PWHIVs can be stressful for a peer, since it may pose an internal conflict of interest. In addition, back to work issues may emerge. To address these concerns, peer counselors/educators must be provided with ongoing support and case management services surrounding issues which may surface due to professional interaction with other PWA/PWHIVs.

Throughout the course of HIV infection, case management centers around the provision of social services, benefits and entitlements, including, but not limited to housing and financial assistance.

In addition, peer delivered services should include, but not be limited to, trainings around useful day-to-day skills such as advocacy (for both medical issues and entitlement issues), the provision of appropriate referrals and discussions surrounding how to barter for needed services.

## IV. HARM REDUCTION

Harm Reduction is a strategy that acknowledges that licit and illicit drug use, risky sexual acts and other behaviors that could result in negative consequences are part of our world and chooses to work to minimize their harmful consequences rather than simply ignore them. (Harm Reduction Coalition, Oakland, CA)

The debate on condom use between HIV infected partners remains unresolved, where the issue of HIV transmission, exchange of new viral strains, and risk of concomitant HIV disease progression is concerned. Based on the possibility of transmission of STDs between HIV infected partners, safer sex/condom use must be regarded as sound public health policy, as a means of further disease prevention. The serious or potentially fatal outcome of infections with certain STDs, particularly syphilis, gonorrhea, hepatitis, HSV 2, and human papilloma virus, in people with advanced HIV disease, must be underscored. In addition, a recent study showed that HIV infected men receiving HAART and have no detectable viral levels in plasma may still have virus in seminal cells. (Zhang, et.al., 1998)

Misconceptions about HAART therapy as a cure rather than a treatment, survivor guilt and fatalism have caused many to be concerned that some HIV infected and non infected individuals are rejecting sexual risk reduction techniques. There has been much publicity about the return of risk activities such as “barebacking” (intercourse without barrier protection). It is important for individuals to realize that safer sex is still imperative for HIV infected individuals, and for service providers to understand that non-judgmental harm reduction, that is, meeting people “where they are at”, is an intervention that can be utilized within the context of sexual risk reduction.

### Syringe Exchange

Access to treatment on demand is the best way to reduce drug users’ risk of HIV infection in injection drug users. Not all drug injectors are motivated to quit, however, and even those who are highly motivated may find few services available.

For those who cannot or will not stop injecting drugs, the best way to avoid transmitting HIV is to use a sterile needle for each injection, or at least not to share needles. Users who share should disinfect their infection equipment thoroughly with bleach, although this is not as safe as always using a sterile needle and syringe.

Syringe exchange programs have sprung up around the United States to address drug injection risks. These programs not only distribute clean needles and safely dispose of used ones for injection drug users, they generally also offer a variety of related services, including referrals to drug treatment and HIV counseling and testing. Syringe exchange programs also have the potential to act as a bridge

to primary medical care, tuberculosis, hepatitis and sexually transmitted disease screening and treatment.

**Recreational Drug Use**

It is important for PWA/PWHIVs to remember that social and party drugs, including but not limited to alcohol, marijuana, poppers, cocaine, ecstasy, crystal methadrine, Special K and Mushrooms may cause judgment to be impaired leading to risky behavior. In addition, some studies have shown that use in conjunction with protease inhibitors increases the potency of Viagra, which can also lead to risky behavior. (James, 1999)

**Tobacco Use**

A team from the Centers of Disease Control and Prevention found that smoking among HIV positive people was associated with the development of oral candidiasis, oral hairy leukoplakia, and bacterial pneumonia, among 106 long-term smokers, compared with 126 HIV positive people who had never smoked. (Conley, L.J., et al., 1995) (Nutrition, 1999) .

## V. TIMELY HEALTH CARE MAINTENANCE

It is imperative for a PWA/PWHIV to be informed as to what is needed and when it is needed to remain healthy. A detailed medical history is a crucial fist step in HIV treatment, and should include a review of the HIV test result, a discussion surrounding antiretroviral drugs used in the past, previous infections, and sexual and substance use history, but it is also important for a PWA/PWHIV to be knowledgeable of his or her own medical history so self advocacy is possible. Such medical issues as, but not limited to, diabetes, high blood pressure, history of hepatitis or STDs, hypersensitivity to drugs and gynecological history for women, should be known by the individual as well as the physician.

A comprehensive physical examination, including assessments of eye and oral health, neurologic status, skin and lymph nodes, and HIV-associated signs and symptoms, accompanied by open discussion of the patient's concerns and fears, allows the provider to define the state of HIV infection, determine the optimal treatment, and lay the foundation for an effective partnership with the patient. It is imperative that genotyping is performed to discern a patient's resistance to various HAART drugs so that, at the outset of treatment, information can be collected to offer an individual appropriate therapy and future therapy options may remain intact.

Women need to know about how they can be infected, and should get tested for HIV if they think there is any chance they have been exposed. This is especially true for women of child bearing age, post-menopausal women and lesbians. If a woman of childbearing age tests positive for HIV, she can take steps to reduce the risk of infecting her baby. Women get vaginal infections, genital ulcers, pelvic inflammatory disease (PID), and genital warts more often - and more severely - than uninfected women. Cervical cancer was added to the list of HIV-related infections in 1993. HIV-infected women should get pap and pelvic exams at least twice a year. HIV infected women get thrush (a fungal infection) in their throats, and herpes (a virus that causes cold sores and genital herpes) about 30% more often than men. Genital cancers show up more often in women than in men. More research is needed on how HIV medications affect

women. Most medications used for HIV have not been studied to see if they affect women differently, if they affect menstrual cycles, or if they interact with birth control medications. And hormone therapies, which are being studied to prevent wasting syndrome, can make someone seem more male (grow facial hair, for example).

Viral load testing, CD 4 count, initiating appropriate prophylaxis, screening and preventive therapy for tuberculosis, improving adherence to regimens of preventive therapy for tuberculosis via directly observed therapy (DOT), testing and treatment for syphilis, oral examinations, eye examinations, neurologic testing, pap smears and pregnancy counseling are all requisite elements of early and regular medical assessment. It is also important that complete analysis and understanding of lab values be included in a regular medical assessment.

**Prophylaxis for Opportunistic Infections?**

The CDC has published extensive guidelines for the prevention of opportunistic infections in HIV-infected persons. Offering appropriate information and prescribing appropriate preventive medication are a major effective intervention in secondary prevention. General considerations in prescribing preventive medications include recognizing appropriate risks and considering risks and adverse effects from interactions with other medications. (USPHS/IDSA, 1997).

Many individuals with initially very low CD4+ T-cell counts respond to HAART with dramatic increases in CD4+ T-cell counts to levels above that indicating a need for prophylaxis. The question is: can the consumer safely stop prophylaxis? An observed decreased incidence of opportunistic infections in individuals receiving HAART suggests some improvement in immune function. Nonetheless, a person with a near normal or middle-stage appearing CD4+ T-cell count who has very low counts prior to HAART almost certainly has residual immune deficiency masked by the current CD4+ T-cell count. How to assess the actual risk of discontinuation of prophylaxis is unknown. Health care providers and consumers should consider the individual's risk for opportunistic infections based on their nadir CD4+ T-cell count until there is data to suggest otherwise. They should reevaluate individuals on prophylaxis closely (Cohen, et.al, 1998, Furrer, 1999)

**Regular Oral Care**

Preventive oral care is imperative for HIV-infected people. About 95% of HIV-infected patients will exhibit oral manifestations at some point in their disease. Those of bacterial origin are the most common, and also the most serious, due to amplified risk of serious gingival and periodontal problems. Patients should be encouraged to use proper oral hygiene, including brushing and flossing, to prevent the growth of bacteria in the mouth. Care from an oral health specialist (preferably one trained in the care of HIV-infected people) is an important component of early intervention and secondary prevention.

Primary care physicians and PWA/PWHIVs must also be educated about the importance of oral care. The immune system can be poisoned through oral diseases. Ulcers or thrush may appear in the mouth, candidiasis due to use of certain prescribed medications may occur and oral hairy leukoplakia may develop. It is recommended that gums be cleaned three times a year to prevent the onslaught of gingivitis and periodontal problems. Diluted peroxide or Pridex can be used

between cleanings to promote oral health. PWA/PWHIVs should take oral health seriously and question their infectious disease physicians and/or seek a specialist in oral health. Coordination should occur among infectious disease specialists, oral health specialists and primary care physicians surrounding oral health issues. PWA/PWHIVs should be questioned about when their last oral checkup occurred, whether flossing is done regularly, and whether medications taken are causing a dry mouth condition and oral bleeding. Ensuring this coordination is difficult, as many consumers report that finding a dentist who is qualified and willing to treat PWA/PWHIVs is particularly difficult.

### Routine Immunization

Vaccination recommendations are based on weighing the benefits of vaccination against the risks. Although vaccination recommendations for HIV-infected patients are similar to those for non-HIV-infected patients in many respects, HIV can alter the efficacy and safety of vaccinations, and the susceptibility of the patient to the diseases for which immunization can confer protection. Thus, HIV infection changes both the risks and benefits of specific vaccinations.

In HIV-infected adults, the CDC strongly recommends pneumococcal and hepatitis B vaccines. Hepatitis A vaccination is indicated if the patient is at increased risk of exposure, in particular if the patient is a man who has sex with men in an area with an increased prevalence of hepatitis A, has a clotting factor disorder, or is traveling to endemic areas. Influenza and HiB vaccines should be considered. The potential benefit of these vaccines is not as great, and must be weighed against the potential negative effects of vaccination. In particular, the low prevalence of invasive hemophilus influenzae type B disease may not justify vaccination. Clinicians should administer diphtheria and tetanus vaccines to HIV-infected individuals in the same manner as in non-HIV-infected persons. The risks of live vaccines such as measles, mumps, and rubella must be weighed against the potential benefits of vaccination. The risks of the latter two vaccines may outweigh the benefits in adults. Measles vaccination may be worthwhile in adults born after 1956, if they face significant risk of exposure to measles.

With the exception of influenza, which is given yearly, vaccines should be given early in the course of HIV infection if possible to increase the likelihood of adequate responses and to minimize the risk of disseminated infection from live vaccines in immunocompromised patients. In all cases, vaccination may be safest when patients are following effective antiretroviral regimens, as this therapy may limit the risk of increasing HIV replication as a consequence of vaccination. (Hecht, 1998)

## VII. TREATMENT EDUCATION

Treatment education is one ongoing method by which the HIV/AIDS community is better educated to understand treatment options available to them and the implications of that treatment. This education must be culturally, linguistically and gender sensitive as well as user friendly so consumers can clearly understand *all* their treatment options, including adjunct therapy options. Treatment education should be accessible to all who need it, which may require

bringing it to the people rather than waiting for the people to come to it. It can be delivered by service providers and/or peers. Peer-delivered treatment education has been shown to positively impact the acceptance of information disseminated. The possibility of development of resistant strains of the virus, like "wild type virus"(the type of HIV that replicates best in a person not taking anti-HIV drugs- Richman, 1998) makes bringing the information to "people on the block" an imperative.

Because the consumer's understanding of HIV treatment is often best accomplished when treatment education is provided by both health providers and other sources such as web sites, magazines, community-based organizations, basic information about HIV and HIV treatments should be incorporated into the delivery of all HIV/AIDS services. Organizations that provide basic services to people with HIV, as well as those programs that are specifically for treatment education, should be guided by certain principles:

***Treatment education should be individualized***
All persons require information about their treatment options, including information so that they can make a decision as to whether or not they want to engage in a treatment protocol. The extent and components of treatment information that will be beneficial will differ for each person, and should be assessed on an individualized basis. The characteristics of treatment education should not be based on presumptive judgments about people of any racial, ethnic, gender, age, behavior, language or any other category.

***Treatment education is an essential part of the medical care of people with HIV infection***
An essential component of medical care for people with HIV infection is education about HIV and health promoting measures, including antiretroviral and prophylactic medications. If a patient will benefit from more intensive treatment than can be provided in a medical visit, other resources are available and should be arranged, either on-site or at another facility. Referral to a community-based treatment education program should be considered.

***Providers of HIV services should be able to articulate basic information about HIV***
At a minimum, all service providers should be able to assist their clients with information about:

- HIV transmission
- the effect of the immune system
- the ability of antiretroviral and prophylactic medications to affect the course of HIV disease
- Medication to treat opportunistic infections
- the importance of adherence for the efficacy of a medication regimen
- the importance of open communication with a regular provider of HIV medical care
- programs that ensure access to medical care and related services
- medications to treat side effects
- reactions to recreational and illicit drugs while taking HIV-related medications
- complimentary, alternative and adjunct therapies

***Treatment education should reflect current clinical and scientific practice and research***

All providers of treatment education must ensure that information supplied to consumers is accurate, up-to-date and provided in a practical, user-friendly form because individuals must make their own decisions based on this information. It is important to acknowledge that an important part of treatment education is recognizing that once people have the information needed to make decisions about their treatment options, that decision should be respected and supported by the provider.

The provision of culturally sensitive, linguistically appropriate, gender specific compassionate treatment education can enhance an individual's informed decision about whether to follow physician recommendations.

**Adherence**

Adherence is defined as the extent to which a patient's health-related behaviors correspond with medical advice. A frequently used rationale for advocating adherence is that it prevents or delays the evolution of drug-resistant HIV strains.

It has been found that social support is important in its potential to encourage long-term adherence. Data on social support from the Columbia Community Health Advisory and Information Network (CHAIN) point out that, for many participants, there is little social support to assist in adherence. (Messeri, 4/98)

Providers must dispel the conclusion of non-adherence as a result of profile of a patient (risk behavior, educational level, income, gender, or personality). Good communication skills between health care provider and consumer are essential, and the ability to be honest about non-adherence is critical. To build strategies to ensure that dosages are not missed, it is important for those taking any kind of drug regimen to avoid repercussions from illicit drug use and/or sheer forgetfulness. Homelessness and mental illness are also issues that may complicate the ability to adhere. For instance, if you need your medication refrigerated and you are homeless, that creates a problem.

The continuum of care plays an important part in adherence, once the individual enters the system, whether that individual is homeless, mentally ill, or has sufficient support mechanisms. How the individual is treated, informed and educated on medications, side effects and the realistic consequences of non-adherence lays the ground work as to how well the individual will tolerate the regimen.

Training about adherence for specific cultural differences (transgender individuals, drug users, racial and ethnic minorities) should be provided to case managers and health care providers to assist individuals, eliminate stigmas surrounding non-adherence and stimulate options to increase the possibility of adherence. An example of a fact which could be helpful to individuals might be: "The length in which individuals are now taking anti-HIV drugs, drug holidays have created a new problem with adherence. Twenty-three percent of all patients reported having taken a drug holiday. (Stopping medications for three months and then beginning again)"(Journal of the International Association of Physicians in AIDS Care, 1998).

Complications to adherence that must also be considered are the possible interactions between different prescribed medications to decrease absorption levels. In addition to interactions with other antivirals, an individual needs to be aware of interactions with health conditions that need prophylaxis medications, anti-depressants, anti-anxiety medications, tuberculosis medications, hepatitis C medications, methadone and birth control pills.

It is important to note that just because an individual is on medications, there is no guarantee that viral loads will go down or that an individual will feel better. Some experts predict a high likelihood of failure as treatment continues. "I've seen people with months of unquantifiable virus who suddenly have measurable virus," says Dr. Mike Saag. "The initial response of most investigators would be to blame it on adherence, but I know some of these people haven't missed a dose" (POZ, 10/98) Even though an individual is adherent, he or she may still experience "drug failure" It should be noted that it is not the person who fails, it is the drugs that fail. Treatment failure may also result from pre-existing drug resistant strains of HIV or from resistance that develops during antiretroviral therapy. (Journal of the International Association of Physicians in AIDS Care, 1998)

**Clinical Trials**

There are numerous organizations and Internet sites which will provide PWA/PWHIVs with updated information about clinical trials. It is important that the information be as up to date as possible, so access to the Internet may be helpful in identifying appropriate clinical trials. Examples of organizations with Internet sites which can provide timely information include (but are not limited to): AIDS Clinical Trials Information Service (ACTIS); AIDS Clinical Trials Group (ACTG); AIDS Clinical Trials Group; AIDS Community Research Consortium (ACRC); AIDS Treatment Data Network Clinical Trials; AMFAR AIDS/HIV Treatment Directory; UCSF HIV InSite; and National AIDS Treatment Advocacy Project (NATAP) and Project Inform. Newsletters such as but not limited to, BETA (Bulletin of Experimental Treatments for AIDS), AIDS Treatment News and, PI (Project Inform) Perspective.

**Oral Health as a Component of Treatment Education**

The importance of oral health cannot be overstated. As discussed in section VI, treatment education should include HIV-related oral manifestations and the need to ensure that oral health is not over looked.

**Dermatology as a Component of Treatment Education**

Disease progression as well as the side effects of medication may have dermatological consequences. Both consumers and their health care providers should recognize skin problems occur in the general population but seem to be more common and troublesome in persons with HIV disease. These include seborrheic dermatitis, psoriasis, herpes zoster (shingles), herpes simplex, warts, molluscum contagiosum, fungal infections, and drug rashes.(National AIDS Treatment Information Project, 1998)

## VIII. NUTRITION AND HEALTH PROMOTION FOR PEOPLE LIVING WITH HIV

Good nutrition is critical for people living with HIV and AIDS. Basically, nutrition should be viewed as an essential co-therapy that can help maximize their medical management of HIV. HIV-positive individuals need to increase the amount of food eaten to maintain lean body weight. A balanced diet is imperative, including plenty of protein and whole grain foods, with some sugar and fat. Plenty of liquids should be drunk to help the body deal with medications being taken. Eating well can help:

- Prevent or delay the loss of muscle tissue or "wasting"
- Strengthen the immune system
- Reduce viral mutations
- Decrease the incidence and severity of opportunistic infections and hospitalizations
- Lessen the debilitating symptoms of HIV/AIDS

Malnutrition or wasting is a leading cause of death among people with AIDS -- contributing to between 60% and 80% of fatalities. And, with many people now living for long periods after becoming infected with HIV, good nutrition is increasingly important.

Food safety is imperative for immunocompromised individuals. Kitchens should be kept clean, foods washed, and food preparation and storage should be done carefully. People should drink water that is safe and free of microorganisms. If tap water isn't pure or is questionable, it should be thoroughly boiled.

It is important to recognize that cultures necessitate different types of food. It is still possible to customize menus to ensure nutritional health. For example, *Gods Love We Deliver* in New York City has developed customized menus providing good nutrition which are culturally competent for various target populations.

**Exercise**

PWA/PWHIVs should establish a regular exercise program to build and maintain muscle tissue. Overly strenuous exercise is neither necessary nor recommended. Exercise involving muscle resistance is important for stimulating muscle tissue. Increasing or at least maintaining muscle tissue, or lean body mass, appear both to help HIV positive people stay healthy longer, and to recover faster if they become ill.

## IX. PREVENTING SEXUALLY TRANSMITTED DISEASES

Individuals who are infected with STDs are at least two to five times more likely than uninfected individuals to acquire HIV if exposed to the virus through sexual contact. In addition, if an HIV-infected individual also is infected with another STD, that person is substantially more likely than other HIV-infected persons to transmit HIV through sexual contact (Wasserheit, 1992).

New evidence from intervention studies indicates that detecting and treating STDs can substantially reduce HIV transmission at the individual and community levels. Studies have

shown that treating STDs in HIV-infected individuals decreases both the amount of HIV they shed and how often they shed the virus. (CDC Fact Sheet, The Role of STD Detection and Treatment in HIV Prevention, July 1998)

People who are already infected with HIV should avoid co-infection with STDs for their own health as well. The possibility of becoming co-infected with a resistant strain is real, and that makes the virus more difficult to treat.

It is important to note that passing STDs does not require penetration of the mouth, vagina, or anus by the penis or tongue. Simple genital to genital skin rubbing is sometimes enough to allow viruses or bacteria to be passed. To protect oneself, latex condoms are recommended for oral, anal, or vaginal sex. They can be purchased in most drug stores or supermarkets. Condoms can be purchased already lubricated and you can buy water-based lubricants separately in the drug store. Use latex condoms only with water-based products. Lubricants that are oil-based like petroleum jelly or hand lotions weaken latex, making it more likely to break and decreasing its protective value.

For vaginal sex, the female condom is another prevention option. It is a soft pouch made of polyurethane that a woman inserts in the vagina before sex. Like male latex condoms, the female condom should be used only once and then thrown away. For oral sex, latex dental dams (available in most adult book stores or medical supply stores) regular household plastic wrap, or unlubricated latex condoms can all be used as moisture barriers between the mouth and a partner's vagina, anus, or penis. STDs such as hepatitis B that are transmitted through body fluid exchange can be passed by sharing syringes with an infected person.

## IX. ALTERNATIVE, COMPLEMENTARY AND ADJUNCT THERAPIES

A health treatment that traditionally does not fit into standard western medical practice is called "alternative" or "complementary".This includes many different therapies such as:

- Traditional healing practices (Chinese acupuncture and Native American healing)
- Physical therapies (chiropractic, massage, and yoga)
- Homeopathy or herbs
- Energy work (polarity therapy or reiki)
- Relaxation techniques (meditation and visualization)

Some Western practitioners do not like alternative therapies and think that patients would do better if they use western medicine. Other health care providers advocate the use of alternative therapies along in combination with western medicine (“adjunct therapy”). They think alternative therapies can reduce stress, relieve pain or stomach upsets caused by many antiviral drugs, and have other benefits for patients.

Alternative therapies can have dangerous side effects. The words "natural" or "non-drug" do not guarantee safety. The Food and Drug Administration (FDA) does not approve dietary supplements or monitor their safety or contents the way it does for prescribed drugs. Consumers

need to be careful when using alternative therapies.

It is difficult to find substantiating data on alternative therapies. Before using them, PWA/PWHIVs should try to find out: when and how this was developed; how does the therapy work? ; are there any articles or studies about this therapy? ; are the therapists trained, certified, or licensed? , and are there are any known side effects or other risks? . PWA/PWHIVs should be informed consumers and not be afraid to ask questions. It is important to get as much information as possible to make healthy decisions and to be an informed consumer.

PWA/PWHIVs should tell their doctors as much as possible about what therapies are being used by them. This is particularly important in case there is a bad reaction to a medicine being taken. There could be some alternative/complimentary therapies that should not be used together with certain HIV medications.

It is important for consumers to assess their doctor's attitudes and knowledge on alternative therapies. Ideally, doctors should keep an open mind and help their patients evaluate potential alternative therapies. (New Mexico AIDS InfoNet Fact Sheet Number 700)

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