


living

NEWS AND TREATMENT INFORMATION FROM THE BC PERSONS
WITH AIDS SOCIETY JAN / FEB 2000 / ISSUE 4



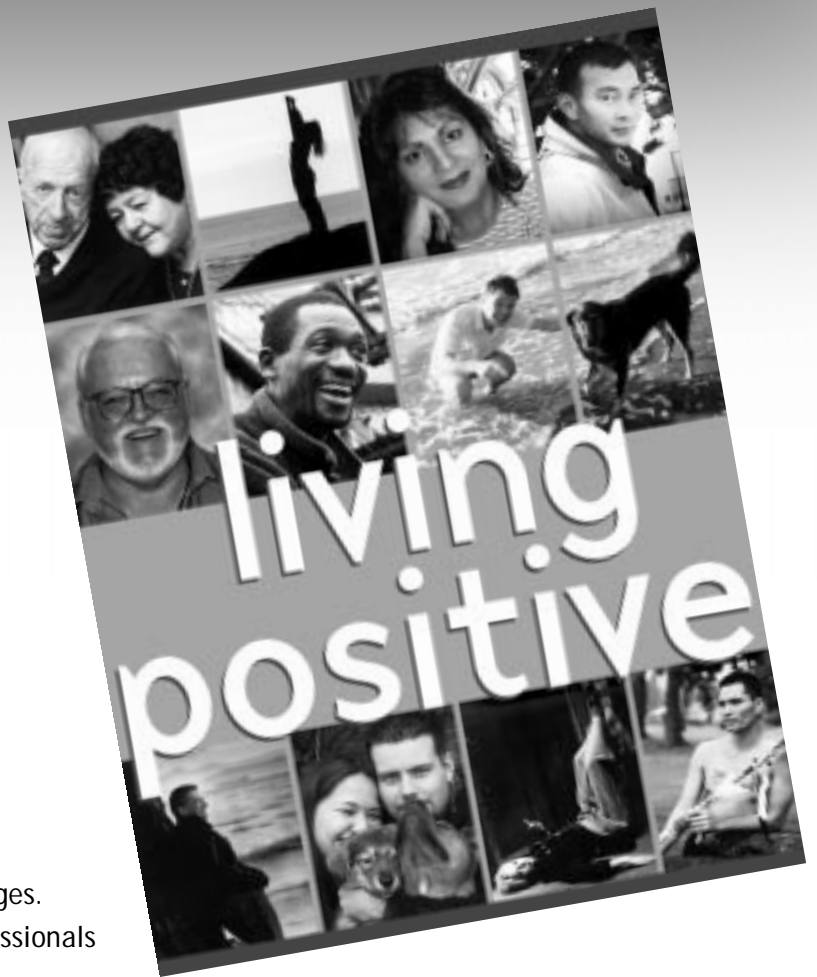
**"I've got some
bad news...
the test came back
positive."**

From disbelief and fear to acceptance and confidence – Ron Fremont describes what HIV has meant to him. PAGE 9



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The British Columbia Persons with AIDS Society empowers persons living with HIV disease and AIDS through mutual support and collective action. The Society has over 4,000 members.

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think +

opinion and editorial

In memory of friends

Dear Editor,

Many BCPWA members were saddened hearing the news that Judy Krueckl had passed away on Sunday September 26, 1999. Other members did not know Judy and therefore the loss to our community would not be understood. We wish to honour Judy with these few words and remember one woman who was comforting people dying with AIDS from the first moments of the epidemic.

Judy worked as a social worker at St. Paul's Hospital in downtown Vancouver. She championed attitudinal changes within the medical system at a time when most of the rest of society turned their backs on us. In the early days of the epidemic gay men were not only faced with societal discrimination, but, also many were disowned by their families, either prior to or upon discovery of illness. Judy became the mother, grandmother and sister to many of these men struggling through their final days as she sat by their sides in hospital rooms and fought for their rights everywhere she could.

As the epidemic grew and other disenfranchised people became ill Judy was at the front of the bandwagon striving for care with dignity for everybody infected with HIV.

Every now and then those of us who have been jaded by dealing with death after death resulting from AIDS are shocked back to reality and affected by the passing of someone special, and not from AIDS. I for one will not forget the unconditional love and support Judy provided. She was a pioneer and is an icon to our community. Judy - rest in peace.

Tom McAulay

Dear Editor,

We have lost a real friend to our community. Chester Meyers, 1945 – 1999

Chester inspired many of us to take care of ourselves through vitamin and mineral supplementation. To state that he had an enormous impact on my health and life would be an understatement. The community has no replacement for him and it is a loss not only to the BC community but nationally.

Rest in Peace Chester.

Walter Taylor

Dear Editor,

Sheldon Polski, has left the stage.

He came from Winnipeg and eagerly joined us here at BCPWA. He worked in Support Services and left an indelible mark on all that met him. Most of all, we remember him as our friend.

He was quick of wit, fast with a joke, and always ready with a song, changing the lyrics to fit any given situation. I remember him rehearsing and performing the role of Caiaphas in Theatre-Under-The-Stars version of Jesus Christ Superstar.

He went on to become a Board Member for BCPWA although his term was cut short due to failing health. Over the ensuing years he had many rallies and many health battles and finally, back home with his family, he passed away on November 3, 1999.

I'm not sure he ever realized the strong, positive impact he had on most of the people that had the opportunity to know him. We were all enriched by his presence.

Sheldon, your light still shines in all who remember you, Your Friends,

Kasandra and Michael

Living + is published by the British Columbia Persons with AIDS Society. This publication may report on experimental and alternative therapies, but the Society does not recommend any particular therapy. Opinions expressed are those of the individual authors and not necessarily those of the Society.

British Columbia Persons With AIDS Society's 1999-2000 Board of Directors. From left to right: Vice-Chair Tom McAulay, Keith Jewers, Ken Whitehead, Secretary Monty O'Toole, Paul Latham, Joel Leung, Chair Glen Hillson, Bo LeDrew and Treasurer Jeff Anderson. Camera Shy: Malsah and John Goedhart.



National adherence survey results in

On December 1, GlaxoWellcome and BioChem Pharma announced the results of a Canadian survey of PWAs on the issue of drug adherence. More than 83% of the 320 respondents from across Canada reported that they were not "fully adherent" to their therapy. This, despite the fact that 71% acknowledged that non-adherence is a very serious issue. "We hope the HIV Adherence survey can be a benchmark for future efforts by the pharmaceutical industry, AIDS service organizations, allied health professional and people living with HIV/AIDS, to address this complex issue.

A new book called *faithful, free or both* written by Montreal physician, Dr. Eric-Albert Lefebvre was released the same day. It is intended to be a resource for patients and caregivers providing information and direction for successful HIV therapy. Copies can be obtained for free from CATIE by calling 1-800-263-1683.

New board shows stability and promise

At the end of October, the membership of BCPWA cast their votes and elected a new Board of Directors. Many of the seats went to returning directors, giving the organization stability at the helm.

At the first meeting of the new board the executive committee was chosen.

Returning to the board for another term in office are: Chair, Glen Hillson; Vice-chair, Tom McAulay; Secretary, Monty O'Toole; Treasurer, Jeff Anderson; Members John Goedhart, Bo LeDrew, Joel Leung, Malsah.

And joining them on the board, new directors Keith Jewers, Paul Latham and Ken Whitehead

On behalf of the board, Living + would like to remind all members that your voice is important and needs to be heard. Board meetings are open to all members and you are welcome to attend. The Board meets every second Wednesday at 3:00 pm. For date and location information, or to have an item placed on the agenda, please contact Katharine at 681-2122 ext. 292 or 1-800-994-2437 ext. 292.

Bristol Myers Squibb receives warning

Bristol's "Droxia ICAAC Symposium On HIV Use" is off-label promotion, FDA says. The FDA issued a warning letter to Bristol-Myers Squibb Oct. 27 regarding a company-sponsored symposium on

hydroxyurea use in HIV patients.

The letter, from the agency's division of drug advertising, cites a Bristol promotional presentation at the September Inter-science Conference on Antimicrobial and Chemotherapy for both promotion of an unapproved use and not disclosing fatalities that occurred during clinical trials of that use.

Hydroxyurea is approved as Hydrexa for several oncologic indications and as Droxia for use in sickle-cell anemia patients. Neither form is approved for HIV.

On Sept. 28, Bristol sponsored a presentation entitled, "Hydroxyurea and its Role in Treating HIV Disease." The slide presentation, given by a Bristol representative, included "a slide that stated that the 'activity' of hydroxyurea has been 'proven as first line therapy...in asymptomatic HIV patients in combination with ddI +/- d4T [Bristol's Videx and Zerit]," FDA stated.

Another slide, "labeled 'Immune Control of HIV,' stated: 'A new triple therapy combination?' followed by the answers: '1. Hy-

continued on next page

news reel

NEWS FROM HOME AND AROUND THE WORLD

droxyurea 2. ddi 3. Anti-HIV immune response.' This presentation suggests that hydroxyurea, in combination with ddi, effectively controls the immune response that occurs with HIV," FDA states.

The timing of the presentation also drew the agency's attention: days before ICAAC began, a trial investigating hydroxyurea in HIV treatment was discontinued due to toxicity and two deaths in the 68-patient hydroxyurea arm.

"The primary endpoint of the study was loss of viral suppression and drug toxicity necessitating discontinuation," FDA notes. "On or about Sept. 24, 1999, NIH terminated study ACTG 5025 because the rate of discontinuation for drug toxicity was significantly

higher in patients randomized to the hydroxyurea treatment arm. Moreover, the hydroxyurea treatment arm had two fatal cases of pancreatitis."

Precautions regarding the two fatalities have since been incorporated into Bristol's Videx labeling. The revision also mentions two other deaths from pancreatitis that occurred in Videx patients who were not taking hydroxyurea. The label was changed late in October.

FDA asserts: "It is our understanding that BMS was made aware of these events on or before Sept. 24, 1999, but in the presentation on Sept. 28, the BMS representative discussed the use of hydroxyurea in HIV disease and promoted hydroxyurea as 'very well tolerated.'" Information regarding a 1,200 mg daily dose of hydroxyurea was also presented, despite greater toxicity of the drug at elevated doses.

The warning letter summarizes: "Although BMS was aware of reports of serious adverse events and fatalities associated with the use of Hydrea or Droxia in the treatment of HIV disease, and knew that this information was not yet widely publicized in the medical literature, it did not disclose this information."

Issuance of a warning letter suggests that FDA is remaining vigilant regarding promotions of off-label uses after the Washington Legal Foundation won a lawsuit against the agency that permitted fewer restrictions on off-label promotions.

However, the WLF decision requires that a promotional campaign for off-label use be grounded in articles that appeared in peer-reviewed journals or conferences.

The Bristol presentation took place in the company's promotional booth in the commercial exhibit hall at ICAAC; it was not listed in the abstract book for the conference-sponsored presentations. The company invited participants to the presentation by mail before the conference.

Bristol is directed to submit a corrective action plan by Nov. 12. The plan should include a proposed corrective "Dear Healthcare Provider" letter to be distributed to all attendees of ICAAC and other physicians who may have received Bristol information regarding hydroxyurea for HIV therapy.

Former Eatons' employees lose benefits

Among the many casualties in the demise of Eatons are 114 former employees who were receiving long-term disability benefits - many with AIDS. The *Globe and Mail* newspaper reported on October 23, 1999 that Eatons notified recipients they had received their last cheque earlier in the month. The article featured the story of a 40-year-old gay man who worked as a display manager in a large Toronto store. He tells of continuing to work through Christmas of 1994 because of his commitment to his work, despite pneumonia and severe diarrhea.

FDA rejects new AIDS drug

Gilead Sciences of California announced on December 3, 1999 that they are terminating further development of their first anti-HIV drug, adefovir dipivoxil (Preveon). The action was not entirely unexpected as it came on the heels of last month's decision

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OPEN HOURS CHANGE AT PARC

The Pacific AIDS Resource Centre Building will move to restricted access after 4:00 pm starting on or soon after Monday, January 17, 2000.

This change is because almost all services available at PARC (including BCPWA's Lounge and AV's Project Sustain) now close at 4:00 pm,

Members and others will still be allowed to sign-in to the building after 4:00 pm for previously arranged appointments and visits to the PARC Library and BCPWA Treatment Information Program.

Advisory group recommends monthly health allowance

by GLEN HILLSON

An estimated 3600 PWAs in British Columbia are receiving Disability Level II (DBII) payments from provincial B. C. Benefits. The monthly payment for DBII is \$771. In 1996 BCPWA started to apply for additional monthly allowances for members for health goods under Schedule C of the Disability Regulations. As of this summer, 225 PWAs were receiving health care allowances amounting to an average of over \$400 per month. These awards have come at the expense of thousands of hours of Society staff labour poured into the application and appeal processes. One-third of all cases brought before the BC Benefits Appeal Board in 1998 were from BCPWA.

Last year BCPWA convinced what is now called the Ministry of Social Development and Economic Security to develop a process for streamlining provision of Schedule C allowances and make them more equitable. An advisory group consisting of representatives of BCPWA (3), the B. C. Centre for Excellence in HIV/AIDS (3), a community physician, a palliative care specialist, a nutrition specialist, Vancouver Burrard MLA Tim Stevenson and his Constituency Assistant, representatives from the Ministry of Health and four from the Ministry of Social Development and Economic Security met regularly for eight months in 1999. A final 92-page report from the group is now with the Minister's office. Following are some excerpts from the report:

Guiding principles for the development of a basket of goods and services that provide for the health needs of person living with HIV/AIDS

1. Health is multi-dimensional
There are key broad determinants of general health as follows:

- health services
- income and social status
- social support networks
- education
- employment/working conditions
- physical environments
- personal health practices and coping skills
- healthy child development

2. Poverty is a barrier to health promotion

Research shows that lower socio-economic status is associated with shorter life-expectancy, not only in persons living with HIV/AIDS but other diseases as well. People who live in poverty are multiply disadvantaged because many forms of health promotion and treatment are not funded by our Western medically-based health system.

3. Meeting health needs as an investment

Health promotion and harm reduction ultimately save the government money. Healthy people rely less on medical interventions and are more likely to attach to the labour market.

4. Treatment options are critical

Currently funded treatments for HIV/AIDS alone do not maximize the quality of health care. Non-western therapies have proven effective for the management of symptoms and drug

side effects. They can also address many of the underlying complication of HIV disease. Different cultural approaches to health are also recognized.

5. Immediate action is vital

The Ministry of Social Development and Economic Security is the ministry of last resort that is relied upon to meet essential health needs that are not met elsewhere.

The "basket of goods" allowance recognizes the following health needs of PWAs:

- nutrition/dietary needs (including vitamin and mineral supplementation and pure water)
- complementary therapies (herbal/medicinal, tactile and spiritual treatments)
- clean and safe housing
- alcohol and drug treatment
- psycho-social needs
- urban/rural differences
- needs of pregnant women and families
- needs of infants and children
- needs of aboriginal people

The report acknowledges that the needs for health supports varies from one individual to the next and evolves over time. A flat monthly allowance which would allow recipients financial freedom to access the health goods and services they need, when they need them was determined to be the most sensible. This would negate the need to get approval for funding of specific items.

Recommendations

All persons who have DBII designation primarily because of their HIV/AIDS status and anyone else who is DBII for another disability but also has symptomatic HIV disease would automatically be eligible for the monthly health allowance of \$411 for singles, \$690 for cou-

continued on next page

ples and \$456 for children.

Persons already receiving Schedule C allowances greater than the recommended amounts would be grandparented at their existing rates.

What happens now?

The Advisory Committee's report is now in the hands of the government. We are determined to do everything we can over the next few months in order to convince the government to implement the recommendations in the year 2000. While the cost of the recommendations is substantial it is clear they constitute a sensible investment in the future health of citizens of British Columbia.

By the time this article is published we hope to have more news on the status of Schedule C and we hope also that we will be able to offer copies of the Advisory Committee report to anyone interested.

(BCPWA representatives on the Advisory Committee were Tarel Quandt, Tom Mountford and Glen Hillson.) ⇨

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THE MAT PROGRAM – MAXIMALLY ASSISTED THERAPY

Helping HIV positive people with antiretroviral medications

by HEATHER HAY, VANCOUVER
RICHMOND HEALTH BOARD

The HIV/AIDS community has had mixed feelings about "directly observed therapy" based on the historic experience of how tuberculosis was managed by public health authorities. Mandatory directly observed therapy was imposed on patients with tuberculosis and compromised their freedom and privacy.

HIV/AIDS medications are very complicated and demanding. Many people who are infected are not in a position to benefit without social supports such as clean and safe housing, proper nutrition and addiction treatment.

Supporting people who want to take medications is a positive step forward for the health of our community as long as participation in "maximally assisted" and "directly observed" therapy programs is voluntary and accompanied by informed consent.

Hats off to the parties undertaking this important piece of work that will assist people living with HIV/AIDS to live healthier, better lives.

Glen Hillson, BCPWA Chair

The Vancouver/Richmond Health Board in partnership with the BC Centre for Excellence has opened a new site in the Downtown Eastside (DTES) to support HIV positive clients who require assistance with their HIV medications.

Often antiretrovirals must be refrigerated, taken with food or taken at specific times of the day. For many individu-

als, the lifestyle and environment in the DTES can create barriers to taking antiretroviral medications.

At "The MAT Program", residents of the DTES have access to two antiretroviral programs – MAT and DOT. MAT (Maximally Assisted Therapy) is for any client on antiretrovirals who needs added support in taking their medication. This is the second MAT program for the community, with one already available at Vancouver Native Health. DOT (Daily Observed Therapy) is a clinical trial of a once a day regi-

Residents have access to two programs, MAT (Maximally Assisted Therapy) and DOT (Daily Observed Therapy)

men for clients who have never taken HIV medications before.

"The MAT Program" is open seven days a week and is located at 501 East Hastings. Lunch is also provided for clients in the MAT/DOT program at the Native Health Positive Outlook Program.

Program staff include registered nurses, support workers, an on-site pharmacist and consulting physicians.

An additional site will be opened in the coming months to continue to improve access to HIV treatment in our community.

For more information please call Sharon Ritmiller at 659-1136 or Shelley Dean at 659-1166. ⇨

MAT/DOT is a service provided in partnership by the Vancouver/Richmond Health Board, the B. C. Centre for Excellence and the Vancouver Native Health Society.



RON FREMONT is a Support and Outreach Worker for YouthCO. He currently volunteers with BCPWA on the Living + Editorial Board, has volunteered with the support department for special events, completed BCPWA's peer counsellor training program, and is part of the "Theatre Positive" group.

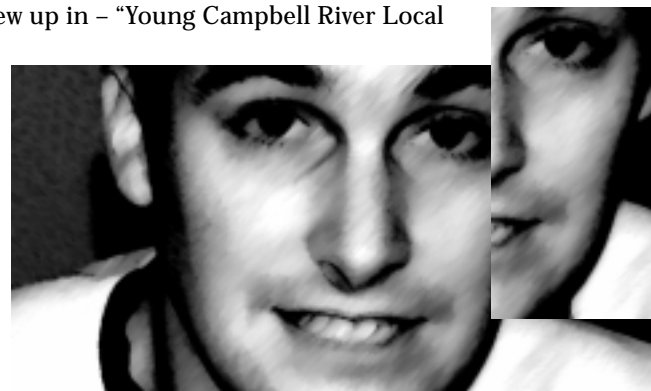
He was also a figure skater featured in Disney on Ice. What follows is Ron's personal story of living with HIV disease, based on a word associated format. It was presented as the opening address at "AIDS Impact" a conference for caregivers, support workers, counsellors and Health Care Professionals.

DISBELIEF "I've got some bad news – the test came back positive."

I could hardly believe that the nurse uttered those nightmarish words to me! I sat in her office in total disbelief, shocked! A tear ran down my face. There was absolutely no way this could be happening to me! The test must be wrong! There must have been a mistake! These results must belong to someone else. How could this disease now be part of *my* life? I started to sob uncontrollably and repeated, "Why me! Why me! Why me!" My body trembled. My mind raced. I was emotionally out-of-control! The nurse said, "It's gonna be all right. I know of a good counsellor who can help." I didn't want a counsellor. I wanted a rock to crawl under. What, if anything, could the nurse do? How could this be happening to someone like me? I'm educated, friendly, and middle class. There was absolutely no way HIV was circulating throughout my system. No way!

FEAR After a few days, I started to put myself back together again. I was still in denial, but as the reality sunk in, my level of fear rose. I became amazingly scared. Was I going to die? When? Where? Would anyone even care? I could just imagine the headline in the local paper in the small town I grew up in – "Young Campbell River Local Dies of AIDS." My mind swirled around with thoughts of discrimination, fear, and regret. I felt that I had been put back in the closet. All the work I had done to make myself feel proud of being a gay person was in vain. All I knew was that I was going to die...or was I?

What HIV has meant to me



LOSS As time went by, I began to feel a tremendous amount of loss. Loss, not just of my identity, but also of my friends. Would my friends and family support me in my time of need? I felt myself becoming more reclusive, more introverted, more alone. My former self was someone I could only dream about. Where was that smiling, energetic person I once knew? Where was the guy whose face would look back at me from the mirror. Had I lost him? I feared losing more than just my former self. What about friends and family? What about my boyfriend? Would I lose everything? What was going to be my reality?

DISCLOSURE My fear of disclosing my new status was overwhelming. I had to think about who I wanted to tell. Like I do with so many things, I made a list of the people I would tell first. It was hard. I felt in many ways like I was making up the guest list for my funeral. The conversation would start with, "I have something to talk to you about. I have HIV, and I know I'm not dead yet, but I just want you

to be prepared for what might happen...." I was not prepared for people to care as much as they did. I was not prepared for the affection and warmth I felt from the friends and family members I told of my new status. They cried, they held me, they reminded me of how much they loved me. Wow! But then there are still all those people in my life who don't know of my HIV status. My dad, my grandparents, some of my closest allies. I don't know why I don't have the guts to tell them. It seems so odd because I am so open with so many people I know. At work, my partner, most friends – they all know. I seem to have delegated a select few as the ones I don't feel comfort-

able telling. I always do the easy stuff first and save the hard work for the rainy day that never comes.

BETRAYAL How could he have infected me? He knew he was HIV-positive. He just decided to assume that I was too. Wrong! I accept that it takes two to tango, but I feel very betrayed and ripped-off that he felt it was his right to decide for me whether I wanted to be infected. Ironically, I don't blame anyone, but I have strong negative feelings toward him. How can someone play God like that? I think accountability should fall to people who are infected (and know they are) to stop the spread of this disease. How hard is it to use a condom?

ANGER I was angry. Why did HIV have to happen to me? Angry at the stereotypes that still exist in our society. Why is HIV still infecting people? Why do I need to feel different from anyone else? Why do I have to hide my condition? Why is HIV put in a special, "don't talk about it" category? I try not to allow myself to get caught up in this type of thinking, but sometimes it's hard. I get very angry because I feel that I have to be cautious about who knows.

SHAME I feel stupid and ashamed that I was careless enough to get the virus. I live with it daily! I'm supposed to be well-educated, and HIV is not supposed to happen to people like me, right? Wrong! I feel like I should have known better. AIDS had been killing people for more than a decade before I came along. Why did I not get the message? Practise SAFE SEX!

LONELINESS Am I the only one? Even though I am a support worker and I counsel HIV-positive youth, I often feel like there is no one out there who is the same as me. When I am at a bar or at a social function, I look around the room and feel like there is no one else my age, no one else with my story. I

MY FEAR OF DISCLOSING MY NEW STATUS WAS OVERWHELMING. I HAD TO THINK ABOUT WHO I WANTED TO TELL.



know they are there, but no one openly talks about it. Why? Where are all the young people? I have to remind myself of all the prejudice and all the fear people have about disclosing. My story is my own and no one else's. I need to honour that.

ACCEPTANCE I have begun to accept my situation. HIV is part of me! I feel confident in who I am, what I stand for, and where I am going. It has taken me a long time to forgive myself for past actions that have led me to where I am today. My partner has helped me to accept that HIV is a disease, just like cancer or diabetes. We people who are HIV-positive need to let go of the secrecy and stereotypes associated with HIV. Only then will others accept this disease as it really is – a disease! Really it is! Its so hard to let go of all the misinformation and stereotypes that have been circulating for years. I don't always know where the future is going, but one thing I do know is that I will be part of the future.

FOREGIVENESS I need to forgive the sexual abuse. I need to forgive myself for allowing the sexual abuse to continue. I need to forgive the person who infected me. I have come such a long way since I was diagnosed with HIV in April 1997. I have forgiven myself. There is so much power in forgiving yourself. The guilt and anguish related to blaming myself for contracting HIV has been tremendous. It's time to move on.

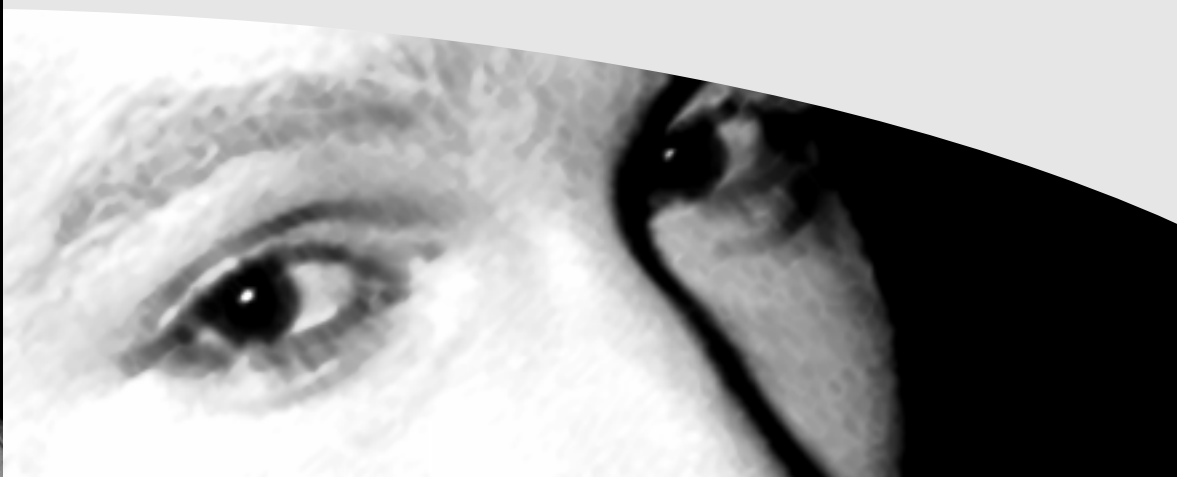
PURPOSE Since testing positive I have definitely ridden the roller coaster of emotions. And, if you had asked me in April 1997 where I thought my life was going, I wouldn't have been able to give a straight answer. I was between jobs, scared, and totally unsure. But, I thought to myself, "There is a reason you got this disease, Ron. Now do something with it!" I started to volunteer as a speaker in high schools,

telling my personal story. Each time I finished a speaking engagement, I would feel more confident, more assured, and something in me said that I was going to be okay. I was able to rationalize that this was why I got HIV, to help spread the message that anyone can get this disease and to teach people how to protect themselves against it. This continues to be my purpose.

PRIDE I am proud to be alive. Proud to be a gay man! And proud of being HIV-positive! I feel very blessed to be alive in a time when there is medication to help slow the HIV in my body. I have an amazing sense of pride for the way the gay community has rallied to help care for HIV-positive people. HIV is not a death sentence anymore! It has given me direction and renewed my sense of who I am. It has not been an easy path for me. But, by overcoming HIV, I have become the person I had envisioned many years ago.

I AM PROUD TO BE ALIVE. PROUD TO BE A GAY MAN! AND PROUD OF BEING HIV POSITIVE!

CONFIDENCE Since testing HIV-positive, my confidence has grown tremendously. Although I still have days when I feel overwhelmed, I have to say that HIV has changed my life for the better. I handle myself in such a different manner from how I did three years ago. I believe confidence comes from life experience. Things such as HIV happen to everyone, but the key is how you react. I feel like I have taken the right path for myself in dealing with my HIV diagnosis. Every time I share my story with people like you, I get a little bit stronger. Thank you for allowing me to share with you today. ❖



Canada will give \$50 million to fight HIV/AIDS in Africa

Canadian government unveils financial support on World AIDS Day, Dec. 1

Canada's International Cooperation Minister, Maria Minna, today announced \$50 million in new funding to support projects that are successfully fighting HIV/AIDS in Africa.

Today's announcement coincides with World AIDS Day and also includes a commitment to host an international conference in the Spring of 2000 to focus on prevention and care issues, including mother-to-child transmission and AIDS orphans.

"HIV/AIDS is killing millions of people. In just ten years, there will be more than 40 million orphaned children who will lose parents to AIDS and millions more will lose teachers or health care providers," said Minister Minna. "All countries have a responsibility to aggressively and unrelentingly attack this disease."

The Canadian International Development Agency (CIDA) is currently supporting the Canadian Public Health Association (CPHA), the Centre for International Cooperation in Health and Development (CCISD), and the University of Manitoba, with \$55 million for their projects attacking HIV/AIDS in Africa.

Today's new \$50 million announcement will allow for expanded programming in HIV/AIDS in Africa. It will also allow for these organizations to negotiate new projects to continue their work that has proven to be so successful in prevention, education, and training.

• CPHA promotes and assists commu-

nity-based prevention and support responses to the HIV/AIDS pandemic in Angola, Botswana, Lesotho, Malawi, Mozambique, Namibia, South Africa, Swaziland, Tanzania, Zambia, and Zimbabwe. It supports community organizations working in various areas, including gender and human/child rights advocacy groups. In addition, it will support peer education groups who educate communities about issues such as the use of condoms and how to prevent sexually transmitted diseases (STDs).

More than 70 per cent of all people in the world infected with HIV/AIDS live in Africa. The pandemic is so devastating that it seriously threatens the entire continent's economic and social

- CCISD targets high-risk groups, particularly women, in Benin, Burkina Faso, Côte d'Ivoire, Ghana, Guinea, Mali, Niger, and Senegal to educate them about STDs and how to protect themselves against these diseases. In addition to health personnel, CCISD trains owners and staff members of pharmacies in Ghana on how to recognize the more common STDs. Medication kits for individual STDs have been developed, and pharmacists are now able to dispense effective treatments and offer advice on condom use and other preventive action against HIV/AIDS.
- The University of Manitoba, in col-

laboration with the University of Nairobi, the municipalities of Nakuru and Nairobi, and Kenya's Ministry of Health, work with clinics in Kenya to control the spread of STDs and promote a reduction in high-risk behaviour among commercial sex workers. Specialists from the University of Manitoba provide training to health workers so they can learn how to diagnose and treat STDs. In addition, they establish peer education groups with commercial sex workers who promote condom use and behaviour to prevent STDs.

More than 70 % of all people in the world infected with HIV/AIDS live in Africa. The pandemic is so devastating that it seriously threatens the entire continent's economic and social development. In some areas, it threatens to wipe out more than half the entire labour force. It has already killed 11 million Africans, and more than 22 million adults and children are currently infected.

Since 1987, CIDA has been active in fighting HIV/AIDS. CIDA has supported the World Health Organization's (WHO) Global Program on AIDS (GPA) and is supporting UNAIDS, the successor to GPA. CIDA recently expanded its HIV/AIDS activities into Eastern Europe, and new initiatives in Asia are currently under development.

CIDA's total disbursements for HIV/AIDS programming during the 1998-99 fiscal year was \$21.7 million.

Funding for the initiative announced today was provided for in the February 1999 federal budget and is therefore built into the existing fiscal framework.



LIFE Employment Program

FOR MORE INFORMATION PLEASE CONTACT

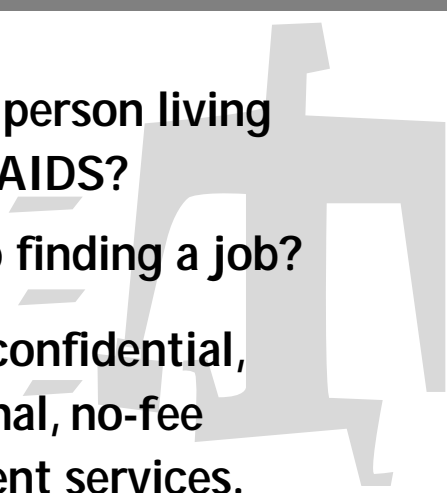
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Alliance Health Care Group in conjunction with BCPWA is pleased to offer
Going Forward to Work Career Exploration Group

For individuals with HIV/AIDS who are considering a return or entry to work. The group will meet twice weekly from February 22 – March 30, 2000, and will explore the option of working or retraining, and discuss resources available. Individual career counselling services are also available on a continuous basis.

For more information on the services available, please contact Lisa Kallio at 730-6010, or attend the next information session, Tuesday, January 18, 10 -11:30 AM, PARC Board Room.

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For further information and an application form contact:
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or Human Resources at 1107 Seymour Street.

Visit our web-site at www.bcpwa.org
for further information on volunteer positions

Tofu Chocolate Cheesecake (Vegan)

I promise that you will wow your friends with this one. It's the best!

A

1/2 c. melted margarine
1/4 c. light or dark brown sugar
2 c. graham wafer crumbs

B

1 c. cocoa powder
1/2 t. salt
2 blocks tofu, crumbled
1 T. vanilla

C

1 c. strong coffee
1 1/2 c. light or dark brown sugar

D

5 sq. unsweetened chocolate, melted

Press ingredients from (A) into the bottom of a 10" spring-form pan. Bake at 300° F. for ten minutes or until light browned. Cool.

Blend all (B) ingredients in food processor. Mix (C) ingredients to dissolve sugar, then add to (B) in food processor. Pour (D) into food processor while it's still warm. Mix until very smooth. To make it very, very smooth, put tofu mixture in blender in four batches after mixing it in the food processor.

Spread tofu mixture over graham base. Sprinkle with shaved chocolate and refrigerate at least four hours before serving.

AIDS drug rejected

continued from page 6

by the U.S. Food and Drug Administration (FDA) not to license adefovir for sale in the U.S.

Several articles have appeared over the past two years in TIPNEWS about adefovir. It is a modestly potent nucleotide reverse transcriptase inhibitor. Its major appeal was that nucleotides are a new class of drugs. Cross-resistance within existing classes makes the search for new classes of compounds crucial. A major safety problem involving kidney toxicity with adefovir became apparent during the clinical trials.

The drug is under review by European regulators and the company is holding off on a decision about its future there until it gets some feedback from regulators. There was no mention in the press release about development plans for Canada, but it seems a safe bet that it will never be licensed here for the treatment of HIV.

Adefovir is active against hepatitis B and will still be tested in clinical trials for that use – but at much lower doses than for HIV.

Patients currently receiving adefovir on clinical trials will have the option to enroll in the expanded access program. Adefovir will be made available to patients who are receiving it through expanded access as long as their treating physicians believe they are benefiting from the treatment.

Hopes are still reasonably high that Gilead's other drug in development, PMPA (tenofovir), will turn out better. It has just entered multi-national phase III clinical trials. It appears to be a more potent drug than its now-deceased cousin, but more data is needed to ascertain whether it is safe and how it will work in combination with other antiretroviral drugs. ❖

Glen Hillson

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AND LIVING WITH
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TREATMENT INFORMATION PROGRAM MANDATE & DISCLAIMER

In accordance with our mandate to provide support activities and facilities for members for the purpose of self-help and self-care, the BCPWA Society operates a Treatment Information Program to make available to members up-to-date research and information on treatments, therapies, tests, clinical trials, and medical models associated with AIDS and HIV-related conditions. The intent of this project is to make available to members information they can access as they choose to become knowledgeable partners with their physicians and medical care team in making decisions to promote their health.

The Treatment Information Program endeavors to provide all research and information to members without judgement or prejudice. The project does not recommend, advocate, or endorse the use of any particular treatment or therapy provided as information. The Board, staff, and volunteers of the BCPWA Society do not accept the risk of, nor the responsibility for, damages, costs, or consequences of any kind which may arise or result from the use of information disseminated through this project. Persons using the information provided through this project do so by their own decisions and hold the Society's Board, staff, and volunteers harmless. Accepting information from this project is deemed to be accepting the terms of this disclaimer.

Take off your socks for your docs!

*Feet are sometimes neglected by physicians,
but maintaining their health is essential*

Ask any person with advanced HIV or AIDS about their feet and you will probably hear a litany of complaints ranging from ingrown nails to rampant warts, fungus, and neuropathy. Not only are HIV-positive people's feet immune-suppressed, they are also under increased strain because they are an extremity with less circulation, are trapped in stuffy shoes, and contain thousands of nerve endings.

Although feet have always been susceptible to toxicity and nerve damage, many primary care physicians fail to look at patients' feet on a regular basis. Many patients also find it easy to ignore early foot problems, but some foot afflictions can become dangerous and can lead to serious and harmful conditions even among healthy populations – and can be magnified and overwhelming for HIV-positive patients and their doctors.

Dr. Jon Tinkle is a HIV specialist podiatrist who recently edited *Clinics and Podiatric Surgery – HIV and the Lower Extremities*, a text by W.B. Saunders about HIV-positive foot complications and their remedies. He currently has a practice at Davies Hospital in San Francisco.

Practicing in the heart of the AIDS epidemic, Tinkle has been in a unique position to see thousands of HIV-positive foot problems walk into his office over the years. A pleasant and unassuming individual, Tinkle says that he doesn't like to step on other people's toes, but many times primary care HIV doctors ignore their patient's foot problems until the situation becomes far too serious. Often, HIV and AIDS patients

HIV-related foot problems are widespread and are best treated when caught early. As HIV disease progresses, foot ailments worsen.

never even remove their socks for physicals and routine follow-ups.

HIV-related foot problems are widespread and are best treated when caught early. Although Tinkle has never heard of any study done to measure this, he suspects that between 70 percent and 80 percent of both HIV and AIDS patients have foot problems that need attention. And as HIV disease progresses, foot ailments worsen as well.

continued on next page

treatment information

Neuropathy: the nerve!

Few podiatrists specialize in HIV, let alone know how to treat the complications aggressively. Tinkle feels that education is the key to better foot health. To that end, he travels around the country lecturing other doctors in the field. One of the more important topics he addresses, and one of the more common foot problems he encounters, is neuropathy.

The nerve pain of neuropathy can be caused by drugs, by secondary infections such as cytomegalovirus (CMV), or by the HIV virus itself. Tinkle says that people with the condition should first try to determine the cause of the pain, to see if a change in medications is in order. The next step is to begin physical therapy, including massage and acupuncture. He is particularly fond of micro-current and its newer version called the "H-wave." Studies in New York have shown favourable results with H-wave treatment, which is something like electrical acupuncture, requiring an about an hour a day.

When treating the symptoms of neuropathy, Tinkle prefers not to add more drugs to treat nerve pain—after all, it's drug toxicity that most likely caused the problems in the first place. He does recommend vitamin B, but said he has not seen many results from nerve growth factor as of yet.

Lowering viral load does not seem to take neuropathy away in the feet. Higher stress levels, however, do seem to increase it.

No fun in fungus

Another common foot problem is fungus. This tends to get worse as immunity is diminished. It is first seen in discoloration of the nail plate as well as nail thickening. Doctors treat this by first cutting down the nail and then adding a topical antifungal. Tinkle prefers

Nixoral shampoo on fungus nails because it seems to penetrate deeper. If fungus problems have grown serious, he also treats with Lamasil and Sporanox oral medications.

Warts on the feet, caused by strains of human papilloma virus (HPV), are called plantar warts. These little devils can become very resistant and hard to treat. They also indicate that the patient is HPV-positive. Although different from the other HPV strains, which cause genital and other skin area warts, all other infectable parts of the body should be inspected for warts as well. The current treatments include cutting them off, burning them with acids, and freezing them.

According to Tinkle, there are two types of plantar warts: single, small size

No kidding; infected nails, if let go too long, can lead to a bone infection. The treatment for this complication is IV drug therapy – and possibly amputation.

warts and the dreaded mosaic, which can get very large and are hard to get rid of. Recently Tinkle and others have begun using bleomycin – a chemotherapy drug – injected directly into the wart. But even with the best treatments, they can come back.

Tinkle warns that a very common place to catch these warts are public showers at gyms. HPV can live in wet areas and are very contagious. "I owe a lot of my business to that gym's shower over on Market Street," he remarked. He recommends wearing sandals or flip-flops to avoid catching the wart virus on the feet.

Measuring trouble by the foot
Kaposi's sarcoma (KS) is often first detected around the feet and can look like a bruise or bug bite. Anything that looks new and unusual should be shown to your doctor. When skin lesions appear,

there could also be internal lesions. Regular foot inspections could lead to early KS detection.

Bone tumours and fractures can cause pain and changes in foot appearance and structure, even leading to tumours. Mostly these tumours are benign; sometimes they need surgery. These are fairly rare problems, but more are seen in HIV-positive populations.

As T-cells drop, the soles of the feet get increasingly dry, a problem that can also result from drugs. Because that dryness can lead to cracking and infections in the feet, Tinkle says it is important to use moisturizer on the bottom of the feet.

Heel pain can be more chronic in people with HIV, especially during seroconversion. Muscle bands around the heel will tighten up, caused by body aches. "We use a special support if it is not just a transient problem," Tinkle remarked.

Last, but not least, ingrown nails are the number one problem for HIV-positive patients. No one is quite sure whether they are caused by drugs or HIV. The best treatment is to first cut the nail away from the infected skin. Tinkle notes that topical creams don't work well at all. Ingrown nails may not become serious and clear up on their own, but if they persist beyond three days to a week, see a doctor.

No kidding: infected nails, if let go too long, can lead to a bone infection. The treatment for this complication is IV drug therapy – and possibly amputation. ❖

Jeff Getty, ACT UP/Golden Gate Writers Pool

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Start Making Sense



Scientific papers can be hard to read and may even conceal faulty research. TIP researcher **DAN O'NEILL** gives you some tips on making sense of the statistics.

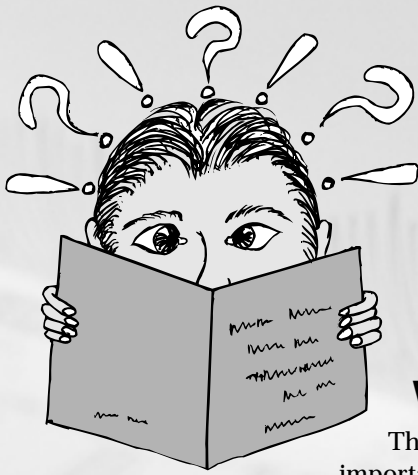
SEX, DRUGS, AND STATISTICS – SUCH STUFF MAY SOUND like interesting reading, but by the time it has been distilled into a clinical paper about HIV/AIDS, it has become the driest homework assignment you've ever had.

Not only can scientific papers be hard to read, but they may also conceal faulty science, hidden agendas, or corporate greed. They may also contain information that enables you to make a choice about a treatment, such as a drug or complementary therapy, or to make an evaluation of the advice of a doctor, pharmacist, nurse, treatment advocate, or friend.

This article can give you some guidelines about how to discriminate between good articles and poor ones.

A high index of suspicion is a good place to start – if the paper proves its point rather than merely sounds plausible, it may be better science. The questions who, where, when, how, what, and so what can help unravel the real content of an article.

They may also contain information that enables you to make a choice about a treatment, such as a drug or complementary therapy, or to make an evaluation of the advice of a doctor, pharmacist, nurse, treatment advocate, or friend.



...if a drug company does two studies, one that shows a good result and one that shows a bad result, only the good one gets published.

Who

The credentials of the author are important in assessing the article. Are the authors known in their field? Are they from a respectable institution? Are they known to have a particular point of view? A person who writes for *Continuum*, a journal which denies the "HIV causes AIDS" relationship, may be less credible to you if you want to find an anti-HIV therapy to prevent AIDS. Are the authors on the payroll of a drug company, or have they received funding from an institution that may have a particular agenda? Are there ghost writers listed who are from drug companies? Just because a study has drug company sponsorship does not mean the study has no value. But if a drug

Was the study done at a respectable university or hospital, or was it done at an unaccredited cancer institute in a third world country?

company does two studies, one that shows a good result and one that shows a bad result, only the good one gets published ("publishing bias"), so you may not be able to get the full story from one study. Language may be attenuated to meet corporate needs – "mild" diarrhea may not be "mild" when it persists for weeks or strikes at an inopportune moment!

Where

Was the study done at a respectable university or hospital, or was it done at an unaccredited cancer institute in a third world country? Can the geographical conditions be extrapolated to Canada? Where is the study published? Is the journal respected and is it peer reviewed? The answers to these questions don't tell you if a paper is useful or biased, but a favourable study of a drug in a drug-company sponsored review journal has a different weight from one in the *New England Journal of Medicine*. Similarly, positive comments about a natural therapy on a website that has a "buy now" banner flashing at you are different from those in a scholarly journal of alternative medicine.

When

With HIV/AIDS, most papers before 1996 can be viewed as historical documents. Even studies more than a year or two old may be supplanted with newer studies, or they may have been continued to provide longer-term data. Sometimes studies that may show a difference in therapies at a few months show convergence to similar efficacy (or lack of efficacy) at one year. In the management of a slow, potentially chronic condition like HIV, the duration of a study is of key importance.

How

Is the methodology sound? Have non-leading questions or open questions been used to solicit subjective data from individuals? Sometimes specific questions are needed to find out answers to questions; for example, the true prevalence of a previously unknown side effect such as truncal obesity can often only be determined by looking for it. How many people were in the study? A small study can be used to show that there is no statistical difference between therapies even though a larger study could be powered to show that there was a difference. Does the study compare one therapy to an established standard? What were the controls? Is a barely adequate therapy being compared to placebo? Is the time-frame realistic? A four-week study of a drug for HIV might give some information about early tolerability of the drug, but it cannot give useful information about efficacy because the short-term is not necessarily predictive of long-term results. Is the study double-blind or open-label? In a double-blind study neither the person receiving the medication nor the person giving it knows which test group the person is in. In an open-label study, the medications are identified. Is it a cross-over study? Cross-over studies, which have little use in slow diseases like HIV, will have one group on therapy A and another on B, and after a period of time (and sometimes a wash-out) the groups will switch therapies. This process can show if positioning of therapy plays a role in the results. Are the study groups controlled for

Comparisons made between different studies or by comparing product monographs are suspect at best and bogus at worst.

demographics (age, sex, race) and for medical condition (baseline viral load, previous therapies, CD4+ count). Is the study prospective (devised to test a hypothesis) or retrospective (data already collected are analyzed to see if it supports a hypothesis)? In a retrospective study, are data not related to the original study purpose being extracted? Is the study a meta-analysis (a summation of studies that looked at similar questions)? Meta-analyses are necessarily subject to “publishing bias” – that is, favourable results are more likely to be printed than unfavourable ones. The large numbers of statistics that are pooled in such reviews do not have the statistical power of prospective studies. Have data been censored or stratified in any way to hide or skew results? Separating efficacy of low and high baseline viral loads may be a way of making unequal therapies look equal. Finding numerical subsets in large groups do not necessarily represent natural groups, so “non-progressors” in a ten-year cohort may be “ten-year non-progressors” rather than true non-progressors.

What

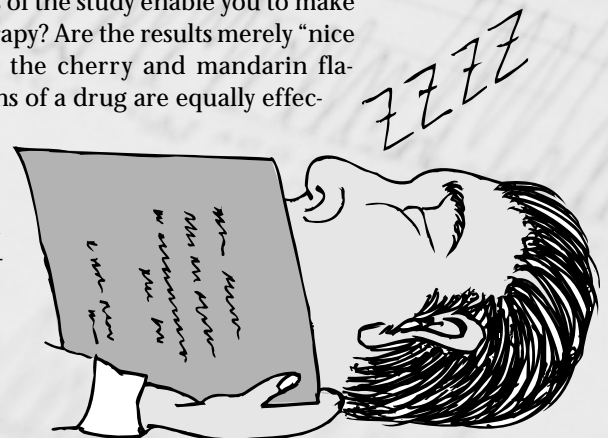
What was the premise of the study? What do the results show? Do the conclusions fit the data? Do they show equivalence or superiority of a new therapy? Are the results based on as-treated or intent-to-treat data? “As-treated” refers to those people who actually took the therapy as prescribed, whereas “intent-to-treat” refers to all people who were offered the therapy, whether they took it or not or whether they dropped out early or not. As-treated results can be used to disguise serious side effects that a potent therapy may have since the remaining results show the efficacy not the drop-outs. In other cases, as-treated results can remove the bias that discriminates against a therapy easily available outside the study compared to a novel agent that someone might see as his/her only hope of treatment. Has statistical manipulation been used to tease out a few promising statistics from a sea of insignificance? What relevance does the population studied have to the information you want? A study that looked only at gay men might not be applicable to women, children, or in-

jection drug users, or a study of young adults might not have meaning for the elderly. Are the differences shown by the study important? A drug that triples mean survival time from one to three days is of less importance than one that doubles mean survival time from two to four years.

Are error bars or confidence intervals clearly described in the data? Does the confidence interval or the P value render the finding meaningless? A P value of $P < 0.05$ means that the stated range of a result is taken to be statistically significant – that is, not likely to be due to chance alone. If drug combination XYZ showed that 50% of people achieved viral load < 50 copies/mL $\pm 10\%$ with $p < 0.05$, it means that the study shows that 40%–60% of people will have under 50 copies/mL at least 19 times out of 20 [$> 95\%$] when that XYZ drug combination is used. If in the same study, combination ABC shows 45% $\pm 5\%$ with $P < 0.05$, then the range would be 40%–50%, 19 times out of 20, which could not be considered different from XYZ. Comparisons made between different studies or by comparing product monographs are suspect at best and bogus at worst. Does a statistically significant difference relate to a clinically significant difference? For example, a therapy may be shown to caused a statistically significant drop of 50% in viral load, yet such a change is less than $0.5 \log_{10}$, which is the limit of clinical significance.

So what

Do the conclusions of the study enable you to make a choice about therapy? Are the results merely “nice to know” (such as the cherry and mandarin flavoured formulations of a drug are equally effective), or do they enable you to do something differently, or to ask some new questions? ✧



The fine line between education and marketing

Under the well-intentioned banner of education and treatment advocacy, the pharmaceutical industry seems to be marketing new drugs to anyone who has an influence on PWA's treatments

Though much of the American media continues to believe that AIDS has become a non-issue nationally, it has at least recognized the growing severity of the problem in the developing world. But whether speaking from the perspective of women, gay men, children, injection drug users, people with hemophilia, or any community in the “changing face of AIDS,” unresolved problems continue to threaten the lives and well-being of HIV-positive people nationwide.

There has been considerable discussion recently of problems of treatment access and the inadequacy of currently available treatments, but precious little public discussion of the growing role that the pharmaceutical industry is playing in treatment education for HIV-positive people. Under the well-intentioned banner of education and treatment advocacy, the pharmaceutical industry has begun to spread its tentacles in unprecedented ways. Treatment education is indeed an important need at this stage of the epidemic, but there are profound questions about where that information comes from and whose interests it promotes.

A little history

The pharmaceutical industry has a legitimate, long-term stake in issues regarding HIV therapy. There would be no protease inhibitors and other advanced therapies without industry. Government's work generally focuses on basic science, primarily learning how HIV causes disease, but it lacks the capacity for actual drug development.

Putting aside the critical topic of drug pricing, it is reasonable for industry to expect to see a fair return on their investment. Like it or not, it is the way our economic system works. Therefore, it would be naïve not to expect industry to competitively and aggressively market its products.

The question is just what constitutes legitimate marketing and what is, instead, an inappropriate intrusion into public efforts to educate HIV-positive people, caregivers and the many case managers and treatment advocates hired by AIDS service agencies. Left unchecked, industry's growing influence in this area threatens to upset the balance of control over the practice of medicine. In short, we need to ask where the line is drawn between marketing and education. The pervasiveness of industry support makes it a difficult issue to raise – few if any major agencies can afford to utterly reject industry funding – and Project Inform is not interested in criticizing the choices made by others. But the issue must be addressed.

Pharmaceutical companies have always wined and dined doctors and cluttered their offices with sales materials, but these efforts go far beyond their brochures. At best, they help inform physicians of advances in medicine and how best to use new drugs. At worst, they are biased marketing efforts designed to sway doctors' opinions with vacation trips, gifts, expensive dinners, free samples, and (hopefully) everything short of outright bribes. To be fair, it is reasonable to assume that doctors have adequate training to objectively evaluate what they hear and sufficient integrity to act in their patients' interests. Whether they listen to their inner wisdom or the drug company pitch is a matter of conscience. Historically, though, efforts to influence the consumer's choice of therapy ended at the doctor's door.

A major change in the law took place a few years ago which permitted drug companies to engage in “direct-to-consumer” marketing, resulting in aggressive ad campaigns in televised and print media. The companies argued that this would help educate consumers on medical matters. The physician, they argued, was still the gatekeeper.

The pharmaceutical industry also has a history of meeting with AIDS activists to review medical data and get input on drug development and patient assistance strategies. At such meetings, activists often had a chance to ask more questions than was possible at scientific conferences. Surely, industry often saw these meetings as an opportunity to influence activists' points of view, but to the extent that the meetings included people from many different groups, there was little opportunity for industry to corrupt individuals.

Some may have taken industry's bait, but most did not. And where people were seen as becoming too closely tied to industry, they were watched more carefully by their peers and their roles as representatives were called into ques-

tion. Over the years most treatment activists became highly knowledgeable about AIDS research and were typically the first to challenge the views and behaviour of drug companies.

Training a new population

Industry is now trying to extend its span of influence directly to almost anyone working in the field of AIDS who might be in a position to impact the treatment choices of HIV-positive individuals. Prime new targets include casual contributors to newsletters, newspapers, and magazines (as opposed to writers specializing in treatment information); hotline operators; case managers; treatment advocates/educators; and general AIDS agency personnel with access to particular communities.

Industry is especially interested in case managers and treatment advocates who help coordinate patients' relationships with medical and social care systems. To industry, people in these jobs represent new gateways to a largely untapped "market" made up of the harder to reach populations. While everyone agrees on the need for wider treatment education services, several companies have taken advantage of this opportunity and are now directly running or hosting educational programs aimed at people in these gateway jobs. The programs claim to be balanced and fair, but there is little question that many, if not most, are designed to deliver either subtle or obvious messages about the companies' products.

These programs for "intermediaries" take multiple forms. Some are simply "community meetings" hosted by pharmaceutical companies in major cities. People in the targeted jobs are carefully identified and individually invited by industry to attend these meetings. Another approach arranges broad-based

meetings with specific agencies, hoping to catch in the net everyone who might have direct access to the patient population or the messages delivered to it. Such meetings often come with the hint of being some kind of agency inspection tour for potential grants and funding. Administrative and development personnel, as well as program managers, are asked to attend. But whether the meeting is held for individuals, agencies, or local groups, the outcome is largely the same: a company's pitch about the importance and competitive value of its products, along with the implication that the company might do something for the agency or groups involved. Very often the companies view their roles as being responsive because, indeed, community groups look for help and support in providing treatment education.

The program claims to be balanced and fair, but there is little question that many, if not most, are designed to deliver either subtle or obvious messages about the companies' products

Whether this requires letting the fox in the hen house, however, is another matter.

Historically, scientific data have always been presented primarily to medical and scientific peers for review. That way, challenges to the analyses of data were guaranteed and overt product promotion was quickly called to task. Not so in these new programs, as the only medical or scientific personnel present are usually those working for the company. No one should expect a company presentation to be objective or unbiased. It is their job to present their products in the best light possible. To say that such efforts sometimes stretch the truth is an understatement.

Through just these two vehicles, activists, case managers, administrators, program managers, and treatment ad-

vocates are being exposed to slick, carefully targeted sales pitches, thinly disguised as "treatment education," while a carrot of implied funding potential whispers in the background. Such presentations to agency workers are but the first step.

Taking the message to the consumer From the very beginning of the treatment era of the AIDS epidemic, companies jumped in (with varying degrees of integrity) to support development of educational materials on a number of topics, such as prevention, HIV 101, etc. Some have done a fine job while keeping their own interests at bay. Others have not.

Industry has today moved lock, stock, and barrel into the AIDS field industry, supporting the total existence of a number of newsletters through advertising or targeted support. While advertising doesn't necessarily corrupt the writers or the content, it does use the relationship between the patient community and non-profit agencies as a conduit for sending industry information directly into patients' homes. And if the newsletter source allows itself to become primarily dependent upon such ads for support, it exerts a subtle but powerful pressure to avoid displeasing the funders, since the alternative may be to go out of business.

Most companies offer a variety of support and grant programs to help AIDS agencies. There is nothing inherently wrong with this, and like most groups, Project Inform seeks industry grants. When well managed, such relationships stop far short of letting the companies influence what agencies do or how they do it. A new expansion of this is that industry now often pays for the creation of treatment education programs. Well enough, if the writers are allowed to maintain their independence and editorial distance. But not every agency is in the position of strength needed to negotiate such murky waters.

continued on next page

Of greater concern is that industry goes beyond providing financial support and sometimes simply writes the programs for some agencies. The appeal is obvious, especially for groups that lack staff support and time to develop their own materials. Industry comes along and delivers a slick, packaged product, ready for immediate use. Sometimes, at least a semblance of community input is allowed into the program, but the end product is still primarily the work of the company, not the community group.

Many feel this is an improper intrusion into community affairs, but more importantly, a dangerous precedent. The offer to provide training packages is often accompanied by significant levels of financial support to the agencies involved, intended to help defray the cost of presenting the programs. For groups trying to serve their communities on a limited budget, it is an offer that is hard to refuse.

Examples of industry programs present a varied picture. Some seem reasonably well balanced. But others include misinformation and distortions, either by intent or accident. Others contain what seem to be images calculated to provoke culturally rooted emotional responses in targeted communities. Though these programs don't necessarily pitch a specific product by name, none seem to acknowledge that one of the reasonable choices available to people is to choose *not* to use treatment for some period of time. Nor do they address the strategy and drug resistance questions so key to wise treatment choices. And many contain product-specific messages or implications by describing strategies that can only be engaged by using the sponsor's drugs. The message, even when it is not directly competitive against other company's products, is simple and clear.

- Everyone should be on treatment, regardless of the stage of HIV disease.
- Everyone needs to take the drugs for the rest of their lives.

- Effective treatment strategies require the use of one or more of the sponsors' drugs.
- People who don't use treatment and adhere to the regimens are irresponsible.

Just whose interests are served by such messages and how do they help people make wise treatment choices?

Looking for balance

There is an important need for educational outreach to hard-hit populations, and treatment is one of the things that must be talked about. Many agencies are struggling to find the money to provide such services. Many do not have the staff or the time to develop professional programs of their own. So when industry comes knocking, it looks like the answer to many problems, especially if the company says all the right things about community input and objectivity. And at least some of the companies are reasonably fair and balanced in their approach.

No one faults agencies for their participation. They are trying to meet a real need, and many, if not most, know how to inject a sufficient degree of skepticism into the process to counter the drug company pitch. But not always. Even with the best intentions, it is hard to avoid the influence of the pharmaceutical industry.

If industry is sincere about wanting to provide support for community education, it must learn to do it in ways that separate proprietary interests from generic treatment messages. If the marketing departments can't live with that, they should take their money elsewhere and community agencies must be prepared to reject the offer. Ideally, industry should not produce or write the educational programs, but instead only provide resources – no strings attached – to agencies or groups developing the material. Though still fraught with difficulties, having a strong and diverse community input process into anything produced by industry makes a second-best approach.

Perhaps a few good, culturally relevant programs may be all that are needed. By keeping the number small, the potential for catching any abuses would be greatly enhanced. There is perhaps no need for multiple companies to write or support different programs at all. If the message is truly generic and non-competitive, maybe all of industry should contribute to a single fund for the development of a limited number of independently reviewed programs.

AIDS communities must begin to debate and challenge the role of industry influence. This doesn't mean agencies need to reject industry funding. On the contrary, as the one most profiting from the epidemic, the pharmaceutical industry indeed should be offering support back to the community. Support must come with the fewest possible strings and should completely detach itself from the direct creation of educational materials by industry. If we fail to draw a line in the sand over these rapidly evolving practices, real damage will be done to the independence of our non-profit sector as well as to the welfare of our constituents.

Industry control of treatment education materials is but the tip of the iceberg. Just below the waterline is a large cadre of new industry employees hired right out of the AIDS and activism communities. Whether such people represent an infiltration of industry by the community – or the other way around – remains to be seen. In a number of other diseases, the pharmaceutical industry is the primary source of support for services like education, hotlines, even support groups. Unless this sounds like an acceptable future for the AIDS community, a large and critical debate must begin, right now. ❖

PI Perspective 28, September 1999

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New guidelines for treatment of HIV

Report from the Advisory Committee on Drug Evaluation and Therapy

by GLEN HILLSON

The standard approaches to treating HIV infection consist of combining two nucleoside analogs (AZT, ddI, ddc, d4T, 3TC, abacavir) with either a protease inhibitor (indinavir, ritonavir, nelfinavir, saquinavir soft gel, amprenavir) or a non-nucleoside (nevirapine, delavirdine, efavirenz). Less commonly, particularly in treatment-experienced patients, drugs are combined in other ways. Using combinations of two protease inhibitors may have some advantages and for this reason the B.C. Centre for Excellence in HIV/AIDS recently decided to approve the following combinations as standard therapy:

• ritonavir 400 mg + hard or soft-gel saquinavir 400 mg – twice a day

• ritonavir 100 mg + soft-gel saquinavir 1600 mg – once a day

• ritonavir 400 mg + indinavir 400 mg – twice a day

• ritonavir 100 mg + indinavir 800 mg – twice a day

In each case, the addition of two nucleosides to the combination is recommended.

The primary rationale for these approaches is that ritonavir acts as a pharmacokinetic enhancer for indinavir and saquinavir. That means it slows the metabolic absorption of those drugs, which increases the trough levels between doses and the overall exposure of the patient to the drugs. (Insufficient

drug exposure is thought to be one of the main reasons for treatment failure.) This interaction between drugs allows for less frequent dosing, smaller daily doses, lower costs, and fewer eating restrictions (generally drugs are easier to stomach with food).

Since these changes come mostly as a result of pharmacokinetic studies (measurements of drug levels in the

A considerable amount of data on ritonavir and saquinavir shows they work well in combatting HIV but produce more side effects than only one protease inhibitor

blood at various points in the dosing interval), more work needs to be done to evaluate both the safety and efficacy of these combinations. A considerable amount of data on ritonavir and saquinavir in combination shows that this combination works well in combatting HIV but produces more side effects than combinations containing only one protease inhibitor. It remains to be seen if other dual protease inhibitor combinations will produce similar results. ☞

Abacavir approved by Health Protection Branch

Another nucleoside analogue reverse transcriptase inhibitor gets added to the arsenal

by GLEN HILLSON

In early June of this year, the Health Protection Branch approved abacavir (Ziagen) for the treatment of HIV infection. Abacavir is a nucleoside analog reverse transcriptase inhibitor (same class as AZT, ddI, ddc, d4T and 3TC). The B.C. Centre for Excellence in HIV/AIDS is now providing abacavir to patients whose physicians prescribe it.

In clinical trials, abacavir showed high potency (comparable to 3TC) as an antiretroviral agent in treatment-naïve patients. High level resistance to abacavir seems to develop more slowly than 3TC. HIV must mutate several times before it becomes fully resistant. Abacavir is cross-resistant with other nucleosides, so the more nucleosides a patient is resistant to, the less effective abacavir is likely to be for them.

Abacavir can produce a range of side effects, most of which are gastrointestinal. Up to 5% of patients may experience a “hypersensitivity reaction” characterized by fever, rash, and other flu-like symptoms such as nausea and diarrhea. If these symptoms occur, patients must consult a physician immediately to be evaluated for hypersensitivity. Treatment with abacavir must be discontinued if hypersensitivity occurs, and that patient must never take abacavir again. In clinical trials, some patients who took abacavir after having a hypersensitivity reaction died.

Price Dispute

Treatment activists are upset by the exorbitant price charged by Glaxo Well-
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come for abacavir. The price has been set (pending regulatory approval) at \$12.50/day which is \$3 more than any other nucleosides. Canadian activists will be trying to persuade the Patented Medicine Prices Review Board (PMPRB) to roll back the price. In August abacavir received its Canadian patent, which gives the PMPRB jurisdiction to regulate the price.

Triple Nucleoside Therapy

Abacavir has been studied in combination therapies containing only nucleosides (AZT + 3TC). These studies were designed at a time when "protease-sparing regimens" was a popular catchphrase in research. The results in patients with viral loads below 100,000 copies appeared to be comparable to other combinations. Patients with higher viral loads did not fare as well. The logic of saving the other classes of drugs for later is questionable since treatment with protease inhibitors and non-nucleoside reverse transcriptase inhibitors (NNRTIs) also requires having nucleosides on board. If all the nucleosides have been burned up in "nuke-only" therapies, then what are people supposed to combine with the other classes of drugs later?

One motivation for exploring triple nucleoside therapy may have been the hope that it would provide a safer approach to drug treatment. Emerging news of serious nucleoside-associated side effects resulting from mitochondrial toxicity (e.g. lactic acidosis) will likely quell that hope. (See article in this issue for more information on lactic acidosis).

GlaxoWellcome announced on November 30, 1999 that they intend to seek regulatory approval in the U.K. to package AZT, 3TC and Abacavir in one tablet. ☚

Side effects of nucleosides

Mitochondrial toxicity and lactic acidosis

by GLEN HILLSON

The development of newer and better HIV therapies in the last half of this decade has improved the health and extended the lives of many PWAs. But we have all learned that treatments are not without their risks. The average length of clinical trials is relatively short, and often the results provide few clues about the complications that may arise from long-term use. Very few mechanisms are in place to ensure that side effects are being monitored after drugs are approved. The current methods for reporting side effects are passive, voluntary, and physician-centred. Following on last year's bad news about lipodystrophy (a metabolic disorder causing redistribution of body fat, elevated lipids, and glucose intolerance), the latest news, and a term PWAs are likely to become more familiar with, is lactic acidosis.

For some time now, it has been observed that nucleoside analogs (AZT, ddI, ddC, d4T, 3TC, abacavir) can cause toxicities that result in myopathy (weakened muscle), neuropathy (nerve damage), and the suppression of bone marrow production, as well as liver and pancreatic abnormalities. Although the relationships between nucleosides and these effects are not well understood at this time, lines of evidence indicate that the commonality of these side effects is mitochondrial dysfunction. (Mitochondria are cellular structures responsible for breaking down sugars and fatty acids and converting them to energy. Liver and muscle cells both have high concentrations of mitochondria).

Lactic acidosis as a side effect of HIV drugs is the latest of the mitochondrial problems to emerge, and it can be seri-

ous for people who are affected. In technical terms, the drugs inhibit mitochondria oxidative phosphorylation causing a build-up of lactic acid and fat in body tissue. The most frequently reported complication of lactic acidosis is liver dysfunction. After a few weeks on nucleoside therapies, some patients have exhibited symptoms of abdominal pain, nausea, vomiting, jaundice, and weight loss. These symptoms are accompanied by gradual elevation in liver transaminases (AST and ALT). In extreme cases, this condition has resulted liver failure and death.

The most frequently reported complication of lactic acidosis is liver dysfunction.

Recognizing lactic acidosis is complicated by a number of factors. HIV patients often have elevated liver enzymes caused by hepatitis co-infection, by other drugs (both legal and illegal) that cause liver dysfunction, or by HIV itself. The B.C. Centre for Excellence in HIV/AIDS has advised physicians who treat HIV-positive patients of this potential complication and has recommended regular monitoring including laboratory tests.

In most cases, lactic acidosis will resolve itself if detected early enough and if nucleoside treatment is discontinued.

Additional information on mitochondrial toxicity and lactic acidosis is available from the Treatment Information Program at BCPWA. ☚

Treatment ABCs on the Road

The ABCs team has visited 12 communities so far, with plans for 22 more in the spring when the weather is more conducive to travel

by DAN O'NEILL, with assistance from BRYAN MCKINNON, TIP

Meeting the treatment information needs of people living with HIV in British Columbia is the goal of the "Treatment ABCs on the Road" project. This multidisciplinary joint initiative between the B.C. Persons with AIDS Society and the B.C. Centre for Excellence in HIV/AIDS has just completed Phase 1 – travelling throughout northern and central B.C. and to Whitehorse, Yukon. This pilot project of outreach treatment information was presented in November at the Canadian AIDS Society Skills Building Symposium in Winnipeg.

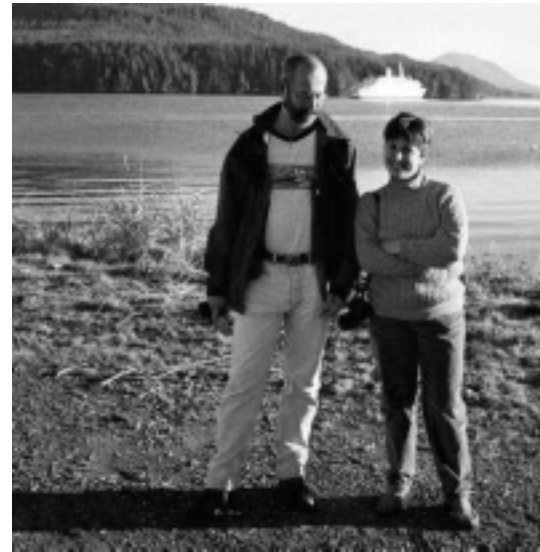
Most people living with HIV/AIDS in B.C. live in the Lower Mainland or southern Vancouver Island, where almost all the medical and social resources are concentrated. People with HIV who live in smaller communities or rural areas often have difficulty accessing services such as treatment information. Some communities have excellent HIV/AIDS support groups or societies, but, for many people, a trip to the coast is the only way to get information. The ABCs workshops attempt to provide treatment information wherever people live without the opportunity for face-to-face interaction with others living with HIV.

To assess need, we conducted a mail survey (with telephone follow-up) of community groups and Native Friendship Centres throughout the province. Where there was an AIDS organization in the community, we drew on their expertise and experience to ensure that our program was appropriate and that we were able to reach the right audience.

Two experienced counsellors or staff from the Treatment Information Pro-

gram joined forces with a doctor and a nurse from the Centre for Excellence to lead community workshops for people living with HIV, friends and family affected by HIV, physicians, nurses, home care workers, other health care providers, drug and alcohol counsellors, needle exchange workers, social workers, students, and other interested peo-

ple. These workshops included discussions concerning HIV pathogenesis, antiretroviral therapy, women and HIV, pregnancy and HIV, opportunistic diseases and co-infections (especially hepatitis C), nutrition and supplementation, and complementary and alternative therapies. The nurse educator, Lois Brummet, also discussed nursing and



TOP Dan O'Neill and Dr. Silvia Guillemi in Bella Bella.

BOTTOM Dr. Brian Willoughby and Loise Brummet, RN, in Yukon



Paula Braitstein and Dan O'Neill in Whitehorse, Yukon.

HIV, especially regarding treatment, care, and support. The professionals representing the Centre for Excellence (Drs. Guillemi, Harris, Madsen, O'Shaughnessy, and Willoughby) have spoken about medical management of HIV, especially antiretrovirals. Occupational exposure has been a popular topic with nurses and doctors, as well as with all people working with injection drug users.

So far, the ABCs team has visited twelve communities with plans for 22 more in the spring when the weather is more conducive to travel. According to Dr Michael O'Shaughnessy, Director of the Centre for Excellence, under-reporting of HIV in rural communities and especially on reserves is a significant barrier to providing good health care. We are pleased that 47 First Nations people have attended the workshops so far out of the total of 129 people. Four of the 12 workshops have taken place on reserves. Key issues that have arisen from the workshops are the desire for partnerships between local groups and BCPWA for information sharing and

peer training, the need to address concerns about confidentiality in the medical and social care communities for people with HIV, the barriers to care faced by injection drug users because of isolation and denial, and the lack of reliable information about nutrition and alternative and complementary therapies.

The feedback we received from the evaluations has shown that the half-day format has not provided enough time for all the questions and that most people feel a need for continuing contact between BCPWA, the Centre for Excellence, and communities outside Vancouver and Victoria. We are looking forward to improving our planning and presentations for the resumption of the "Treatment ABCs on the Road" in the spring of 2000.

(Funding for the BCPWA involvement in the "Treatment ABCs on the Road" program has been provided by unrestricted educational grants from the pharmaceutical companies who make HIV medicines.) ❖

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Therapeutic nutrition guidelines approved

Landmark guidelines are the first in Canada

by BRYAN MCKINNON

The B.C. Centre for Excellence in HIV/AIDS approved the first therapeutic guidelines for nutritional intervention in Canada this past November. Detailing nutritional strategies for wasting, lipodystrophy, pregnancy, and childhood, these guidelines also include indications for when doctors should be referring their patients to a dietitian. The guidelines were developed by Diana Peabody, a registered dietitian with the Oaktree Clinic and probably the city's foremost HIV nutritional expert. Peabody is also working with the U.S. Department of Health, assisting in the development of American national guidelines, although the U.S. government will not go so far as to include micronutrient supplementation.

Summary of therapeutic nutrition guidelines

Malnutrition is a common but complex condition associated with HIV disease. Inadequate nutritional intake can be caused by anorexia, oral and gastrointestinal complications, side effects of medications, and psychosocial factors. Malnutrition manifests as weight loss/weight redistribution, lean muscle-mass depletion, micronutrient deficiencies, and altered metabolism. Malnutrition may hamper the immune system and increase the risk of opportunistic infections, disease progression, and mortality.

Nutritional therapy is one way PWAs can take control of their health right

from day one. Early nutritional intervention should be an integral part of continuous health care for people with HIV disease so that they can maintain weight, preserve or restore muscle mass, minimize side effects, and support the immune system. Doctors should be referring their newly diagnosed HIV-positive patients to a registered dietitian for nutritional assessment and counselling.

Nutritional assessment

The goals of a nutritional assessment are to establish current nutritional status and adequacy of diet and to identify any risk factors for future nutritional com-

Malnutrition manifests as weight loss or redistribution, lean muscle-mass depletion, micronutrient deficiencies and altered metabolism.

plications. The dietitian should assess for physical signs (wasting), weight and weight history, height, body composition (using BIA (Bio-electric Impedance Analysis) and skinfold caliper), nutrition history, medical history, nutritional requirements, and micronutrient deficiencies.

Nutrition Therapy

Nutritional requirements: Energy requirements are highly variable and depend on clinical condition, metabolism, activity level, and viral load. In asymptomatic HIV, energy requirements are elevated by 10%. With a fever, acute infection, or the need for weight gain, caloric need may be increased by 30–50%. Energy requirements are de-

creased to promote weight loss in obese patients who may have increased cardiovascular risks with highly active antiretroviral therapy (HAART).

- Asymptomatic, stable weight: 30–35 kcalories/kg/24hr
- Need to gain weight: 35–40 kcalories/kg/24hr
- Acute infection: 40–50 kcalories/kg/24hr
- Severely malnourished: 20 kcalories/kg/24hr to start, with gradual increase
- Need to lose weight: 25–30 kcalories/kg/24hr

Protein requirements are highly variable as well, depending mainly on clinical status. Extra protein is needed for improved immune function and lean muscle mass. It is essential to meet energy requirements (calories) in order to avoid wasting.

- Asymptomatic: 1.1–1.5 g/kg/24hr
- Symptomatic or malnourished: 1.5–2.0 g/kg/24hr
- Acute infection with fever: 2.0–2.5 g/kg/24hr

Micronutrient supplements: Any supplementation regimens should be carefully considered in consultation with a doctor because of possible drug interactions and the potential for inciting existing liver and kidney complications. Also, many vitamins and minerals are toxic if taken in too large a dose.

Although micronutrient supplementation remains somewhat controversial in the scientific community, there is general consensus that all HIV-positive individuals should be taking a multivitamin with minerals once a day. Two micronutrients that PWAs should investigate are vitamin C (500 mg/day) and natural source vitamin E (400 IU), which are widely recommended, relatively inexpensive, and non-toxic. Others include vitamin B complex, vitamin B12, selenium, zinc, vitamin A, calcium (with magnesium), and glutamine.

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Symptom management

Diarrhea (and the associated nutrient losses) can be relieved by eating small, frequent meals and avoiding foods and beverages that are high in fat, fibre (e.g. bran), sugar, caffeine, and alcohol. Soluble fibres such as oatmeal, rice, and Metamucil are well tolerated.

Nausea is a frequent side effect of medications and can be alleviated by eating small, frequent meals and snacks consisting of bland, low fat, low sugar foods and beverages. Coffee, alcohol, and other gastric irritants should be avoided.

Loss of taste acuity or abnormal tastes (dysguesia) can be managed by chewing food well to stimulate taste buds and by using flavour enhancers such as salt, spices, marinades, and sauces. Chocolate and vanilla are particularly effective taste and smell stimulators.

Anorexia (the loss of appetite) is difficult to treat. General strategies include eating small, frequent meals at regularly scheduled intervals, eating well when appetite is best, and "making every bite count." More aggressive tactics such as assistance with shopping and cooking and the use of appropriate community supports may be needed.

Lipodystrophy syndrome

Once thought to be solely associated with HAART, there is still no clear understanding of lipodystrophy, which includes body composition changes and metabolic abnormalities. Fat redistribution results in loss of fat under the skin on the face, buttocks, arms, and legs; loss of deep fat in the face, which seems largely irreversible; and an increase in abdominal girth. Metabolic abnormalities include dyslipidemia (especially hypertriglyceridemia), hyperglycemia, hyperinsulinemia, and insulin resistance. Although diet and exercise have little effect on fat redistribution, they can cause favourable, albeit limited, reductions in the effects of metabolic abnormalities.

Pregnancy

The nutritional health of a pregnant woman influences pregnancy outcome. Nutritional health is even more crucial for HIV-positive pregnant women, who have a higher than normal risk of premature delivery and of having low birth weight infants. These infants are also at greater than normal risk of developmental complications and mortality. Complementary therapies, such as megadoses of vitamins and some herbal preparations, should be assessed for appropriate use in HIV-positive pregnant women.

The following nutrition requirements are superimposed on the nutritional requirements for combatting HIV:

- Additional 300 calories/24hr to support fetal growth and development
- Additional 15 g/24hr of protein
- Prenatal multivitamin-mineral daily (to include at least 0.4 mg folic acid)
- Other micronutrient supplements as needed (e.g. iron, calcium)

Rate of weight gain is based on pre-pregnancy weight (BMI=body mass index):

- Underweight (BMI <19.8): 12.5–18.0 kg
- Healthy weight (BMI 19.8–26): 11.5–16.0 kg
- Overweight (BMI >26): 7.0–11.5 kg

Infants and children

HIV-positive children are at a high risk of malnutrition and growth failure because of poor appetite, abdominal pain and nausea, aversion to foods with antiretroviral medications mixed in, and socioeconomic issues affecting the family and the parent dealing with their own illness. Nutrition therapy, which becomes even more important in children, has as its goals to maintain normal growth and development, prevent nutrient deficits, improve adherence to medications, support the immune system, and enhance quality of life.

Conclusion

Nutritional complications are prevalent in HIV-positive individuals, aggravating disease progression and the risk of mortality. Nutrition intervention can improve health and well-being, ameliorate symptoms, and enhance adherence to drug therapies. Therefore, nutritional assessment and counselling provide important adjunctive therapy in the treatment of HIV infection. All HIV-positive patients should be given the benefit of referral to a registered dietitian, preferably with expertise in HIV disease. Optimizing nutritional status in a population coping with chronic, life-threatening disease may not only prolong life, but also significantly improve the quality of life. ❖

BIA DAY

Monday, January 31, 2000 4:30 PM - 7:15 PM

You can drop in, have your BIA test (Bio-electric Impedance Analysis) performed (less than 5 minutes) and analyzed (about 10 minutes) by Diana Peabody, HIV-specialized nutritionist with the Oak Tree Clinic. This hands-on practical workshop will take place in the Training Room of the Pacific AIDS Resource Centre, 1107 Seymour Street.

FOR MORE INFORMATION contact BCPWA Treatment Information Program, 604-893-2243

Building blocks for living well with HIV/AIDS

Highlights of Dr. Lark Lands' presentation on maintaining long-term health

by JEFF GRAHAM

On September 23, 1999, at the Parkhill Hotel in Vancouver, Dr Lark Lands, science editor of POZ magazine and an internationally recognized expert and educator on health enhancement for persons with HIV, presented "Building Blocks for Living Well with HIV/AIDS." Her talk centered on eight steps, or building blocks, deemed essential for maintaining long-term health and vitality in persons infected with HIV. The basic principles of these building blocks are explained below.

Apples and other good nutrition

One of the most important things a person can do to power the body's immune response and to build cells is to maintain a healthy diet. Eating high-quality, nutritious foods rich in complex chemical mixtures is much more important than merely taking supplements and is usually much more enjoyable too! Dr Lands recommends the "rainbow approach" to grocery shopping – include lots of colour like yellow and orange and red items from the produce section and deep browns from whole grain fibre when putting food into your basket. Substitute healthier ingredients whenever possible in recipes to make them more flavourful and nutritious.

Botanicals

Medicinal herbs, or botanicals, can help offset side effects from HIV. One herb in particular, silymarin (a milk thistle extract) has been shown anecdotally to help prevent damage to the liver and to allow the body to better cope with liver-toxic drugs.

C-vitamins and other nutrients

The intake of additional key nutrients, in addition to a healthy diet, slows the progression of disease and increases tolerance of drugs. Regardless of which drugs are used to fight HIV, maintaining a sufficient and steady supply of nutrients will ensure that the body has the ability to absorb the drugs completely, to transport them to where they are needed to attack the virus, and to eliminate them as waste. While more rigorous scientific research still needs to be undertaken to verify the efficacy of specific nutrient regimens, considerable anecdotal evidence gathered by Dr Lands and others shows that the consumption of nutrient supplements, especially antioxidants such as vitamins C and E, can help boost the body's defenses against HIV. However, there are several other nutrients that should not be overlooked, including magnesium, selenium, zinc, essential fatty acids, B-vitamins, and glutamine.

Damage control

To effectively combat the progression of HIV, good mental and physical health are imperative. Prevent infection by any means possible. Some evidence suggests that the amino acid glutamine may help reduce the risk of infection, as well as maintain optimal immune system function, muscle tone, and intestinal tissue strength. Nutrients like folic acid may help prevent the start of cancers previously considered rare but increasingly common among long-term HIV survivors. Eliminate oxidative stress, which may prevent certain drugs from working effectively. Antioxidants like vita-

mins C and E can largely eliminate this problem.

Exercise

Exercise helps to maintain muscle tissue, prevent wasting, and improve overall health. More specifically, a regular exercise regimen has been found to improve insulin sensitivity, reduce the threat of cardiovascular disease, and strengthen muscles.

Full body approach

All of these building blocks taken individually are important, but together they allow the body to effectively utilize medicine to combat HIV. A healthy, strong body and high self-esteem are crucial. Remember, preventing problems is always preferable to fixing them.

Good feeling

The mind has a powerful affect on the body. Evidence abounds of the power of positive thinking on overall health, happiness, and long-term survival. Conversely, negative attitudes and feelings often hasten illness and, ultimately, death.

Hope

Get it, keep it, hold it, and live with it every day! New developments in treating HIV are happening regularly, and new drugs and treatment regimens are holding much promise. Ignore the naysayers and know that there is always something you can do to fight this virus.

Interspersed throughout her discussion of the various building blocks, Dr Lands raised the problem of lipodystrophy as a side effect of antiretroviral therapy. Lipodystrophy is the puzzling syndrome seen in increasing numbers of people in which fat is lost from the arms, legs, and face but is gained around the abdomen. She explained why this problem may be happening, suggesting that it is a deficiency of testosterone,

continued on next page

Nutritional therapy can be effective against diarrhea

by DIANA PEABODY, RDN

Diarrhea, which has always been a problem associated with HIV disease, seems to be occurring more frequently with highly active antiretroviral therapy (HAART). While some people will still need anti-diarrheal medications, some nutritional strategies can help reduce the severity of diarrhea and, perhaps, reduce reliance on Imodium and the like. Remember, a registered dietician can help you modify your foods to suit your individual situation.

Food strategies

Eat small amounts of food often throughout the day, and eat slowly. Large amounts of food delivered to the gut send a signal to the bowel to empty. Very cold or hot foods also stimulate the bowel.

Eat plenty of soluble fibre such as white rice, white bread, and mashed potatoes. Oatmeal is terrific food for the gut, so eat some every day, or even twice a day.

Some foods make diarrhea worse

because they increase the speed of transit through the gut. These include high fibre foods like whole grains and raw fruits and vegetables; fatty, greasy, or creamy foods; fruit juice; and dried fruits (especially prunes).

Diarrhea lasting longer than two weeks can cause lactose intolerance. Try lactose-free milk or soymilk. Sometimes a small amount of cheese or yoghurt can be tolerated because these are low in lactose.

Caffeine, alcohol, and cigarettes aggravate diarrhea because they stimulate the bowel. They are not healthy choices anyway.

Supplement strategies

Make sure you are taking a multivitamin because vitamins may not be well absorbed. Make sure you are not taking more than 500 mg of vitamin C or really high doses of other vitamins. Check your herbal remedies to make sure none of them cause or aggravate diarrhea.

Glutamine is effective in reducing diarrhea and helps the intestines to heal. Studies have used 30–40 grams a

day, but it is really expensive. Ten grams a day works well for most people. Buy it in the powder form from vitamin or health food stores.

Taking probiotics like acidophilus, as well as eating yoghurt that contains live bacterial culture, can help replace beneficial bacteria that normally live in the gut.

Recipes

Congee: Boil 1 cup of white rice in 7–9 cups of water or broth for several hours. Small pieces of vegetable, meat, or chicken can be added. Eat several times a day, including the broth.

Rice water: Rice water is an old-fashioned remedy that works quite well. Boil half a cup white rice in 4 cups of water for 1 hour. Drink the water throughout the day.

Clove tonic: Make 1 cup of green tea. Add 10 cloves. Simmer until tea is reduced to half a cup. Take by spoon as a tonic throughout the day. This recipe is from Guyana, where they don't have Imodium. ❖

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glutathione and other thiol compounds, and side effects from medications. Regular exercise, preferably a combination of progressive resistance and aerobic activity, along with testosterone replacement therapy and nutrient uptake, should help ameliorate this condition. On a related note, Dr Lands asserted that appearance is more than a cosmetic issue – it is also a health issue. She urged AIDS activists to pressure insurers to pay for cosmetic improvements, including surgery, to boost mental health and long-term survival. ❖

The presentation, as well as the following question and answer period was video taped. The tape is available for viewing from the PARC Library.

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Light could be the medicine of the future

Research underway may open new doors for treating HIV disease and AIDS

by STEPHEN MCMANUS

Ruby lasers arrived in the 1960s, and people were amazed that it was possible to cut the hardest substances with light. Today, refinements in the technology have resulted in many types of lasers using gases and semi-conductors. Medicine uses laser light as a high-precision surgical tool. Microsurgery, even to repair DNA, is becoming a very interesting potential use of lasers.

In the 1970s, it was discovered that "soft" (non-surgical) lasers could stimulate biological activity. The healing process could be accelerated with low-energy laser light. Wounds and muscle injuries responded to laser light, as did pain and inflammation. Infection could also be cleared from wounds. The results of this research are today's practical uses of low-level lasers to promote healing in physiotherapy and sports medicine, dentistry, and veterinary medicine.

The current research in laser science has great relevance for PWAs. Reports to the Vancouver AIDS Conference (1996) and to the Geneva AIDS Conference (1998) included results from a study called "Laser Treatment of HIV Patients." Low-level laser therapy has been used to increase production of immune and defensive cells and to raise the immune-status of persons with AIDS. As one would expect, reactions to laser therapy were varied, but most patients experienced substantial improvement. In fact, improvements were substantial enough for most to return to an active life and to work. Particularly interesting for the PWA experience is

the absence of undesirable side effects.

How does it work? In a narrow band of frequency, controlled pulses of laser light have highly stimulating effects upon cells. Cell production increases in response to laser light, resulting in a normalization of blood formula. Cells are induced to mature to their greatest potential, which does not necessarily occur under normal conditions. These cells become excited and active in their specific roles. Some cells are actually stimulated to merge, becoming giant cells that exceed the abilities they had as individual cells.

Reactions to laser light vary and depend upon the state of development of the cells as the light is encountered. Multiple effects occur through several "pathways," inducing a "cascade" of reactions, as one event sets off another. Reactions thus occur for hours, even days after exposure. As well, cells stimulated outside the body and then transfused back into a patient communicate effects to other similar cells, setting off reactions.

This increased production of cells and their highly active state induced by low-level lasers concerned oncologists. Would cancer cells also reproduce rapidly? Cancer cells placed in a glass dish outside the body did reproduce rapidly under laser light. However, in the presence of immune cells under normal conditions in the body, cancer cells were inhibited.

HIV-positive patients treated with laser therapy, as reported at the last two

conferences, had increased numbers of lymphocytes (CD4s, in particular) and a decreased viral load. Their immune statuses improved, symptoms decreased or resolved, and no one worsened. Patients from the 1996 study continue to do well. None of the patients received antiretrovirals before or during the study.

Viral hepatitis has also been treated with laser therapy. Biochemical examination showed bilirubin levels becoming normal 4–5 days earlier than in patients receiving traditional therapy. A decrease in liver size and disappearance of intoxication appeared after 3–5 laser treatments.

Laser therapy has also been investigated as a treatment for other illnesses,

Low-level laser therapy has been used to increase production of immune and defensive cells and to raise the immune status of persons with AIDS.

such as diabetes and some cancers. Male infertility and even baldness have been responsive to laser light. Although laser therapy is still partially in the realm of research, we can expect to see its use continue to expand into mainstream medicine. Biostimulation and immune-enhancement are sure to emerge as important new specialties.

There are plans for a Vancouver clinical trial with laser therapy to be used on HIV-positive patients. Stay tuned!

Interested in more information on lasers therapy? Ask the Treatment Information Project at PARC. ✦

NEWS FROM THE TREATMENT INFORMATION PROGRAM

Co-director hired, new research project launched

Bryan McKinnon was hired as the new Co-Director of the Treatment Information Program in September. Bryan will be sharing the position with longtime Director Paula Braitstein who is returning to school, but who will continue to work a reduced schedule.

McKinnon has worked and volunteered in AIDS community based organizations for the past five years, most recently as administrative coordinator at A Loving Spoonful.

Shortly after arriving in Vancouver in 1996, McKinnon began volunteering at PARC with WINGS Housing, and first met Braitstein at this time when he interviewed her about the Treatment In-



Bryan McKinnon

formation Program for a local radio show.

Of the many new initiatives within the department, McKinnon will personally head the project Taking Charge Of Your Health, a series of workshops to be conducted in the spring which will encompass such topics as Treatment ABC's, Nutrition, Complementary Therapies and Advocacy.

Complementary Therapies Project
Another new BCPWA staff member brought in to Treatment Information is Tamil Kendall, who was hired to coordinate the Complementary Therapies Project. Kendall, who has conducted research on sexual and reproductive

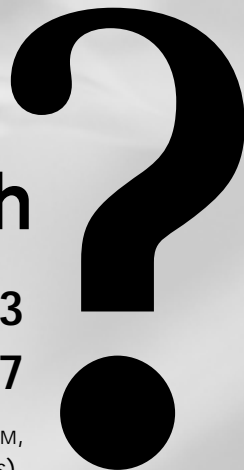
health in the context of community development, is nearing completion of her Masters in Communication from Simon Fraser University. Kendall says she is happy to have found a group of people who see health as a total system, and is excited to put her skills in the service of BCPWA members.

The project hopes to increase the awareness and capacity of people living with HIV to make decisions about complementary therapies through a series of community based workshops. The research component of the project will describe patterns of use of complementary and alternative therapies by people living with HIV/AIDS in the province of BC, and seek to better understand the experiences and attitudes of doctors towards complementary therapies. Thus improving the quality of information and support available to PWAs who are choosing complementary or alternative approaches to treatment.

If you are interested in learning more about the Treatment Information Program or you would like to become a volunteer, call 604-893-2243, or drop by PARC and pick up a volunteer application.

BCPWA TREATMENT INFORMATION PROGRAM

Questions or concerns about your treatments or health



LOCAL (604) 893-2243

LONG DISTANCE 1-800-994-2437

You are welcome to drop by anytime Monday to Friday, 10 AM to 5 PM, at 1107 Seymour Street, Vancouver (down the street from St. Paul's), and you can even email us at pwatreat@parc.org

positively **Happening**

Our deadline for the next issue is January 19, 2000.

Although we strive to have correct, up-to-date listings, it is not always possible.

who to call

Pacific AIDS Resource Centre:
(604)-681-2122 or 1-800-994-2437

PARC Partners:
AIDS Vancouver *
BC Persons With AIDS Society
Positive Women's Network
Fax: 893-2251
* A/V Fax 893-2211

VANCOUVER & BC AIDS GROUPS

A LOVING SPOONFUL 682-6325
AIDS VANCOUVER* 681-2122
ASIAN SOCIETY FOR THE INTERVENTION
OF AIDS 669-5567
BC CENTRE FOR EXCELLENCE IN HIV/
AIDS* 604-806-8515
BC NATIVE AIDS AWARENESS PROGRAM*
660-2088
BCCPD AIDS AND DISABILITY ACTION PRO-
GRAM* 875-0188
BC PERSONS WITH AIDS SOCIETY
(BCPWA)* 681-2122
CANADIAN HEMOPHILIA SOCIETY - BC
CHAPTER* 688-8186
DEYAS, NEEDLE EXCHANGE 685-6561
DOWNTOWN EASTSIDE CONSUMERS
BOARD 688-6241
DR. PETER CENTRE 631-5801
FOOD FOR THOUGHT 899-3663.
FRIENDS FOR LIFE SOCIETY 682-5992
HEALING OUR SPIRIT BC FIRST NATIONS
AIDS SOCIETY 604-879-8884
HIV-T SUPPORT GROUP 929-3862
HUMMINGBIRD KIDS SOCIETY 515-6086
LATIN AMERICAN HEALTH/AIDS/EDUCA-
TION PROGRAM 255-7249
LOWER MAINLAND PURPOSE SOCIETY 526-
2522

MCLAREN HOUSING SOCIETY 669-4090
PELVIC INFLAMMATORY DISEASE SOCI-
ETY (PID): 684-5704
POSITIVE WOMEN'S NETWORK* 681-2122
ext. 200
VANCOUVER NATIVE HEALTH SOCIETY
254-9937
WINGS HOUSING SOCIETY: (VANCOUVER)
899-5405
YOUTHCO 688-1441

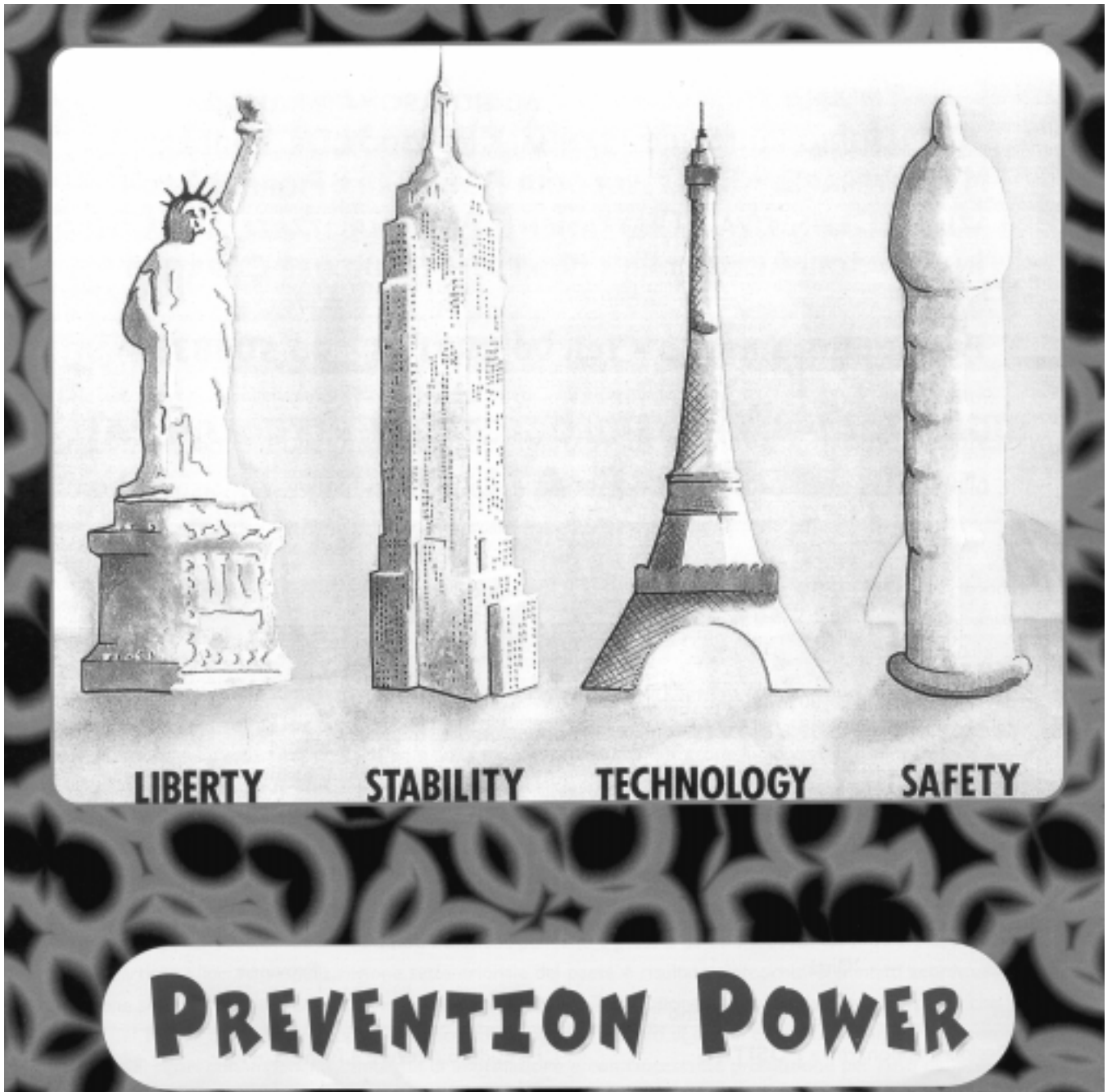
VANCOUVER CLINICS & COMPLEMENTARY THERAPIES

BUTE STREET CLINIC 660-7949.
DOWNTOWN SOUTH COMMUNITY HEALTH
CENTRE 606-2640
GASTOWN MEDICAL CLINIC 669-9181
OAKTREE CLINIC FOR WOMEN 875-2212
PINE FREE CLINIC 736-2391
REIKI SUPPORT GROUP 990-9685
NATURAL CHINESE HERBS SOCIETY
(S.T.A.U.N.C.H.) 872-3789
TRADITIONAL CHINESE ACUPUNCTURE:
681-2122 ext. 243

RURAL AIDS GROUPS

ABBOSFORD VALLEY AIDS NETWORK 853-
2201 ext. 221
AIDS PRINCE RUPERT SOCIETY: (250) 627-
8823
AIDS RESOURCE CENTRE - OKANAGAN &
REGION (250) 542-2451 Penticton: 800-616-
2437 Princeton: 800-616-2437.
AIDS SOCIETY OF KAMLOOPS 1-800-661-
7541
AIDS VANCOUVER ISLAND 250-384-2366
CAMPBELL RIVER SUPPORT GROUPS
(250)-335-1171. Collect calls accepted.
CARIBOO AIDS INFORMATION AND SUP-
PORT SOCIETY (CAIS) 250-392-5730
CHILLIWACK CONNECTION - NEEDLE EX-
CHANGE PROGRAM 795-3757

CHILLIWACK YOUTH AIDS MENTOR PRO-
GRAM 795-3757
COMOX VALLEY SUPPORT GROUP (250)
338-7400
CRANBROOK AIDS SOCIETY 250-489-4995
DAWSON CREEK REGIONAL AIDS SOCIETY
(250) 782-5709
KELOWNA - OUTREACH HEALTH SERV-
ICES (205) 868-2230
LANGLEY HOSPICE SOCIETY 530-1115
NANAIMO AND AREA RESOURCE SERV-
ICES FOR FAMILIES (250) 754-2773
NORTH ISLAND AIDS COALITION HARM
REDUCTION PROGRAMS (250) 974-8494
NORTH ISLAND AIDS COALITION,
CAMPBELL RIVER (NIAC) (250) 286-9757
NORTH ISLAND AIDS COALITION, COMOX
VALLEY (NIAC) (250) 830-6345
PORT ALBERNI SUPPORT TEAM ASSOCIA-
TION (PASTA) ON HIV/AIDS (250) 723-2437
PRINCE GEORGE NATIVE FRIENDSHIP
CENTRE, NEEDLE EXCHANGE (250) 564-
3568
PRINCE GEORGE: AIDS PRINCE GEORGE
(250) 562-1172
PRINCE GEORGE: NORTHERN INTERIOR
HEALTH UNIT (250) 565-7311
QUESNEL SUPPORT GROUP (250) 992-4366
SURREY HIV/AIDS SUPPORT NETWORK
589-8678
THE HEART OF RICHMOND AIDS SOCIETY
277-5137
VERNON - YOUTH AND FAMILY SERVICES
OUTREACH (250) 545-3572
VICTORIA AIDS RESPITE CARE SOCIETY
(250) 388-6220
VICTORIA PERSONS WITH AIDS SOCIETY
(250) 382-7927
WEST KOOTENAY/BOUNDARY AIDS NET-
WORK OUTREACH SOCIETY 1-800-421-
WHITE ROCK/SOUTH SURREY HIV/AIDS
PROJECT 531-6226
WINGS HOUSING SOCIETY: (VANCOUVER
ISLAND) (250) 382-7927 (Victoria) or 1-800-
665-2437.



Here's a little something we found in Italy's *Positifs*, Octobre 1999.

I POSITIVELY NEED IT!



NAME

ADDRESS

CITY

PROVINCE/STATE

POSTAL CODE

COUNTRY

PHONE

FAX

EMAIL

Yes! I want to receive Living+

I have enclosed the following for 6 issues of Living +

- \$25 Canada (non-BCPWA members) \$40 USA \$45 International
- I want to donate the above subscription to a PWA who can't afford it.
- I am a PWA and can not afford the full subscription price.
- Enclosed is my donation of \$_____ for Living +

living+

Cheques should be made out to BCPWA and mailed to:
1107 Seymour Street
Vancouver, BC
Canada V6B 5S8

**work hard,
have fun,
learn lots,
join the team...**

the TIP TEAM!

Treatment Information Counsellors wanted

QUALIFICATIONS

- willing to learn
- willing to work in a dynamic team environment
- no previous treatment knowledge necessary
- be HIV+

For more information or to apply, please call BCPWA Human Resources Department, at 893-2247.

VISIT

WESTERN CANADA'S MOST POPULAR AIDS WEBSITE



GET ANSWERS!

HIV AND AIDS TREATMENT, NEWS + LINKS

www.living+
www.bcpwa.org