



The Update

VANCOUVER ISLAND AIDS SOCIETY

MAY 1990

VOLUME 3, NUMBER 5

A.V.I.'s Annual General Meeting

Our annual general meeting is now officially set for Monday, June 25, 1990 in the Unitarian Church at 106 Superior Street at 7:00pm. All are welcome!

Renew! Renew! Renew!

To all members of A.V.I.

Make sure your membership is valid, in order to vote at the June 25, 1990 Annual General Meeting. All new volunteers who do not have a membership with A.V.I. are urged to contact James in the business office before May 25, 1990 to purchase your membership that allows you to vote at the upcoming meeting. You must be a member one month in advance of the meeting to have a voice.

General Business Meeting Change

The A.V.I. general business meeting has been changed permanently to Fridays at 3:00pm.

'Candlelight Vigil

The annual candlelight vigil will be held on Sunday May 27, 1990 at 8:30pm in Confederation Square (Menzies at Bellville). Please come and unite in honour through poems, songs and remembrance.

This year, members and volunteers are invited to sponsor a candle in the memory of someone who has died, or in support of those persons living with HIV who continue their personal fight against AIDS. The minimum donation to sponsor a candle would be \$10.00 and AIDS Vancouver Island would of course supply a receipt for tax purposes to donors.

If you cannot attend the vigil, but would still like to sponsor a candle we will arrange to have your candle represented at the service.

If you do not wish to sponsor a candle, candles will still be available and your attendance appreciated and welcome.

Volunteer Appreciation

"Thank you, Thank you, Thank you!"

Without all the many committed volunteers who put in so much time and energy, AIDS Vancouver Island would be completely unable to supply any of its' services to this community. From front line-service delivery to behind the scenes management operations and all the hundreds of jobs in between, volunteers are providing essential and successful services. Thank you for the energy and caring that makes AVI the supportive atmosphere that it is!

Volunteer Party!

There will be a volunteer appreciation party held at Rumors Cabaret on Saturday, May 26, 1990 at 7:00pm - 9:00pm. In honour of our volunteers, A.V.I. with the assistance of Rumors Cabaret, 1325 Government Street, is hosting a volunteer party. Food and refreshments will be provided. Please plan to attend.

HIV/PWA Workshop

There will be a workshop with Dr. Damjan Metten, Saturday, May 5, 1990 at 1:00pm in the A.V.I. office, Suite 106. Dr. Metten is from Grabiola Island and is involved in alternative therapies. There will be no charge to attend this workshop.

CONTENTS

OFFICE NEWS.....	1
AVI SPEAKING ENGAGEMENTS.....	2
AIDS STRATEGY PLAN FOR CANADA.....	2
VACCINE TRIALS.....	3
THE MEDICAL COLUMN.....	5
LIBRARY NEWS.....	6
CALENDAR OF EVENTS.....	7

READ THE FINE PRINT

The Volunteer Update is published monthly by the Vancouver Island

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Reference Material
NOT FOR LOAN
AVI Resource Centre

G.A.I.N. Gain

To all persons on G.A.I.N. for Handicap (Ministry for Social Services and Housing). Did you know you are eligible for a discount for gasoline and I.C.B.C. coverage, if you are on or eligible for the above assistance. If you'd like more information, please contact David Swan at 384-2366.

Conference for AIDS Workers

AIDS Calgary is sponsoring a conference for AIDS workers, Monday, October 29, 1990 and Tuesday, October 30, 1990. The symposium is titled "Disrupting Complacency - The Challenge for the 90s," and is specifically designed for those involved in all areas of AIDS education (classroom, outreach, community and health care).

The conference will be held at the Calgary Convention Centre and if you would like more information on it, contact Stew Stefansson or Karen Whyte at AIDS Calgary Awareness Association; #300 - 1021 10th Avenue S.W., Calgary, Alberta (T2R 0B7) or call (403) 228-0198.

A.V.I. Speaks to Vancouver Island

The following are the scheduled A.V.I. speaking engagements for the month of May (33 in all).

May 1 - The Victoria School Board Alternative Program Staff.

May 2 - Edward Milne Community School (Sooke) - Grades 11 & 12 in two sessions (9:50 - NOON)

May 3 - Edward Milne Community School (Sooke) - Grades 11 & 12 in two sessions (9:50 - NOON)

May 4 - The Drug and Alcohol Rehabilitation Service (DARS) (Victoria)

May 7 & 8 - Port Alberni High School - Grade 11s in 6 sessions (all day)

May 9 & 10 - Spectrum High School in 4 sessions with Grade 12s (2:15 - 3:15)

May 10 & 11 - Edward Milne Community School (Sooke) - Grades 9 & 10 in 4 sessions (9:50 - NOON)

May 11 - The Drug and Alcohol Rehabilitation Service (DARS) (Victoria)

May 15 - Spectrum High School - Grade 12s in 2 sessions (2:15 - 3:15)

May 16 - The Drug and Alcohol Rehabilitation Service (DARS) (Victoria)

May 17 - Spectrum High School - Grade 12s in 2 Sessions (2:15 - 3:15)

May 18 - The Drug and Alcohol Rehabilitation Service (DARS) (Victoria)

May 24 - Willows Elementary (Oak Bay/Victoria) - Grade 7s at 1:00pm.

May 25 - The Drug and Alcohol Rehabilitation Service (DARS) (Victoria)

May 26 - West Side Foster Parents Association at 7:30pm

May 31 - Nanaimo District Secondary in 2 sessions (all day)

A National AIDS Strategy for Canada?

Perrin Beatty, the Minister for Health and Welfare Canada, has spoken about developing a National Strategy on HIV Infection and AIDS to be in place early in 1990.

The Canadian AIDS Society, and other interested groups - including the AIDS Network of Edmonton Society - were asked to submit their ideas on that strategy to Sadinsky and Associates. The CAS document, "Working Together: Towards a National AIDS Strategy in Canada" September 1989, led to the development of "A Working Document for the Development of a National Strategy on HIV Infection and AIDS" by Sadinsky and Associates, October 1989. The working document was then submitted to Health and Welfare Canada.

The CAS document contained 77 recommendations under 10 headings:

- Education and Prevention
- Treatment
- Care and Support
- Testing
- Legal and Discrimination Issues
- Research
- Roles and Responsibilities
- Economic Considerations regarding AIDS/HIV
- International Issues
- and
- Managing the National AIDS Strategy.

Most of the recommendations were included in the Working Document under five objectives. The CAS and interested groups then had the opportunity to respond to the Working Document, which we did in December. Our response included changes and additions to activities so the National Strategy would more completely reflect the CAS

document, and/or address other concerns that we as community-based groups felt were important.

The Working Document

Objective 1

"Establish the Dimensions and Characteristics of HIV Infection and AIDS in Canada."

The activities for this objective included seroprevalence studies, seroepidemiologic studies, surveillance and reporting, reference services, an economic analysis, and human rights issues.

Along with the activities proposed, we recommended that the provinces be encouraged to implement an anonymous reporting system. We also expressed our concern that the cost of the studies being recommended should not take away from funding for Education & Prevention and Care & Support programs.

Objective 2

"Breaking the Chain of Transmission of Infection - through cooperative targeted behaviour change programs."

The activities here are to look at prevention and education strategies, conduct attitudinal and behavioural research, look at programs to target specific groups, implement a national awareness program, review testing, implement workplace programs, and show leadership.

There were two major problems with some activities being recommended. Homosexual/Bisexual men, IV drug users and street people appear to be given very low priority on targeting programs and the national awareness campaign was too vague. With these two concerns being met, this becomes a strong and important objective.

Objective 3

"Contribute to the Effort to Develop a Vaccine for HIV Infection and Therapies for AIDS-related disease."

These activities looked at a national reference service, research funding, scientific resources, coordination of granting programs, a national clearing house, and joint international research programs.

While we agreed with the activities being suggested, we recommended that Canada should consider taking a leading role in psycho/social research projects since so much is already being done internationally in the biomedical field.

Objective 4

"Ensure That Those Who are Infected, Their Supporters and Care Givers Have Access to Appropriate Treatment, Care and Support Services."

Activities proposed here are: drug treatment and clinical trials, national psycho/social research, access to services, ways to increase professional care and support, and ways to support community-based and PWA organizations.

We recommended several changes and additions to the activities to fully meet the objective. The activity around clinical trials and drug costs was too vague. Our recommendations clarified these activities to cover subsidies for drugs and added an "open arm" component to the clinical trial protocol.

Objective 5

"Strengthen National Mechanism and Partnership to Facilitate National Collaboration and Cooperation, and to Maximize the use of Available Resources and the Benefits of Collaboration and Cooperation."

The working paper proposes establishing a Canada Council on AIDS - a large body representing all interested groups working directly with AIDS, and smaller sub committees to handle the various issues surrounding AIDS.

We recommended that in addition to this activity, the Minister of Health and Welfare convene an annual conference with his provincial counterparts to discuss the issues around AIDS.

From the AIDS Network of Edmonton Society Newsletter January/February 1990 (Volume 5, Number 1)

The Salk HIV Vaccine trials beginning soon

On March 19, the U.S. Food and Drug Administration approved nationwide trials of the Salk HIV immunogen, developed by Dr. Jonas Salk of polio-vaccine fame. Dr. Salk believes AIDS patients may be able to boost their resistance through injection of his HIV immunogen, which consists of inactivated pieces of the virus. Tests with 90 AIDS volunteers at the University of Southern California's cancer centre have shown promise, and Dr. Salk hopes for a breakthrough similar to his defeat of polio in 1955.

In addition, Salk has asked the state of California for permission to inject his HIV immunogen into ten volunteers who are free of AIDS. He theorizes that the volunteers'

immune system will develop antibodies that may provide resistance-building injections for AIDS patients, and that this could lead to an AIDS-prevention vaccine. Last week, U.S.C. announced that they had signed up more than enough volunteers - about 65, mostly nuns and priests - and that trials will commence soon.

Chuck P. - March 30, 1990

From the Vancouver PWA Society Newsletter - May 1990 (Issue 36)

About the trial...

...the VaxSyn HIV-1 clinical trial:

The trial, involving ten participants, is an early phase trial designed mainly to test toxicity (in the United States, this would be known as a Phase 1 Trial). Vaxsyn HIV-1 uses gp160, a compound which is an important component of the envelope coat of HIV. The participants in the trial will be HIV+ patients.

The researchers, from The Montreal General Hospital, hope to find out if VaxSyn-1 can produce an immune response in people already infected with HIV. A noteworthy feature of this approach is that the vaccine will be given to people in the early stages of HIV infection.

However, this is an early-phase trial designed mostly to find out if this recombinantly-produced molecule is toxic to humans. I will not answer whether or not VaxSyn-1 can successfully produce an immune response in uninfected people.

Vaccines are a form of immunotherapy. Traditionally, they have been used to build up an immunity to an infectious agent in uninfected individuals. However, this trial is designed to test if VaxSyn HIV-1 can produce a new immune response in people already infected with HIV and thereby hopefully inactivate the virus, or at least postpone the onset of opportunistic infections in these individuals. If this type of treatment ultimately proves successful, it may have application for uninfected individuals, but it is much too early to speculate on that.

Canada should be doing more research on anti-AIDS vaccines. Not only can this provide access to treatments which might not otherwise be available here, but it also contributes to the worldwide research effort. Hopefully, information from the Canadian study will be combined with results from the U.S. trials and we will be able to get some answers more quickly.

How can local groups help? You can encourage clinical researchers all across Canada to get involved in studies such as this one. And you can speak out about the need for more research when the opportunity presents itself.

Surviving and Thriving with HIV/AIDS

People with HIV/AIDS who are long-term survivors tend to show some common characteristics. They have a commitment to life, to reach their goals and leave no unfinished business, a sense of meaning and purpose in life. They have a sense of personal responsibility for the way they live their lives and have learned to confidently take care of themselves. By actively coping, they generate beneficial healing effects for themselves and others. They are involved in helping others with HIV/AIDS and communicate their experiences openly with others.

Although they accept their diagnosis, they refuse to see it as an automatic death sentence. They enlist the aid of their physician as a partner in maintaining health rather than giving in to play the role of the passive unquestioning patient. They consult with supportive persons with HIV/AIDS soon after diagnosis. They learn ways to cope by altering their lifestyle, they find positive ways to adjust to their illness and become more sensitive to their own needs.

Some personal characteristics often seen in long-term survivors include assertiveness, a sense of humour, a sense that life has meaning and purpose, even after HIV/AIDS enters their lives.

Long-term survivors organize a supportive social network, but they know when to withdraw to nurture themselves and take care of their own needs. Often they have a spiritual sense that something worth knowing exists beyond the self.

Above all, they take active responsibility to enjoy life!

From The Nova Scotia PWA Coalition

Garlic aids AIDS

Results from a pilot study treating AIDS patients with a special liquid garlic preparation (Lyolic), have been reported in the German Journal of Oncology 21 (1989). Previous studies have shown that garlic enhances natural killer cell function (NK) in normal subjects, and that decreased activity means a poor prognosis in AIDS patients. Seven patients with the HIV virus completed the twelve week study. At the outset, all patients had abnormal NK cell activity. Five grams of Lyolic extract were taken daily during the first six weeks and ten grams were taken daily for the second six weeks. After six weeks, six out of seven patients had normal NK activity and all had normal activity after twelve weeks. Helper-Suppressor ratios reverted to normal in three patients and improved in two. During this study period, the patients

noted improvement of diarrhea, interruption of the recurrent cycles of genital herpes, candidiasis and pansinusitis with recurrent fever.

The antimicrobial spectrum of garlic by in vivo and in vitro studies include many of the opportunistic microbes associated with AIDS.

Recently, a study in China demonstrated the potent antiviral activity of an intravenous preparation of garlic in reducing the morbidity and mortality of the cytomegalovirus (CMV) in bone marrow transplant patients. CMV infections are frequently encountered in AIDS.

The antiviral spectrum of garlic may include the HIV. Therapeutic factors in garlic include germanium, magnesium, selenium, seventeen amino acids, thirty three sulphur compounds, vitamins B, A and C. Garlic is one of the richest compounds of organic selenium and germanium, the latter of which has been shown to induce production of interferon, enhanced N activity and activate macrophages in experimental animals.

The authors of this small preliminary trial on AIDS patients suggest further human studies are warranted to explain the role of garlic preparations as a combined immune enhancer and antimicrobial/antiviral agent.

"Alive" - Feb/Mar 1990.

From The Nova Scotia PAW Coalition - April 1990
(Issue 5)

The Medical Column

Interferon and Interleukin

Current anti-HIV strategies using drugs such as AZT and DDC are aimed primarily at preventing new infection. These drugs do virtually nothing for chronically infected cells which act as reservoirs for HIV. This must be taken into account when designing treatment strategies for HIV+ people. A group of substances which may help the body suppress such reservoirs are cytokines. These are chemicals such as the interferons and interleukins all of which are produced by the body. Reduced levels of cytokines are thought to be one of the reasons why the immune systems of HIV+ people cannot defend the body properly against invading organisms. Cytokines have been used as potential anti-cancer and anti-viral agents with some success. For instance interferon-alpha has been of use in some cases of Kaposi's Sarcoma and one trial of interferon-beta showed it to be effective in treating CMV (Cytomegalovirus) infections.

Journal of Biological Response Modifiers 1989;8:501-510
Taken from the March 1990 ACCESS Newsletter -
Sudbury, Ontario.

AZT Resistance - Real or Unreal?

Real AZT resistance studies are being done in San Diego. Under certain laboratory conditions, they have identified circumstances in which strains of the virus evolved in a dish while being treated with AZT: they no longer respond to it. This has never been identified or confirmed yet in a human being. Whether this is related to what we have seen in people is really unclear.

There is no real definition for AZT resistance, and the researchers are urging people to be cautious about determining their resistance to AZT. I know a lot of guys in San Francisco jumped to DDI because they felt they were resistant to AZT, and within six weeks jumped right back to AZT.
PWA Action Coalition Newsline - March 1990
Taken from the Vancouver PWA Society Newsletter - May 1990

(Issue 36)

DDI: Promising...but experimental

Whether or not DDI is as effective as AZT in slowing HIV infection is not yet known, but it may be more tolerable in certain people with HIV infection. Additionally, research studies are planned to see whether combination or alternating therapy using both AZT and DDI may provide the benefits of each drug while minimizing their side effects and development of drug resistance.

Thus far, the phase 1 trials of DDI have shown some transient increases in T-helper cell numbers and decreases in p24 antigen levels. In one of those studies, patients with AIDS dementia also showed some signs of improvement. These benefits, however, have generally been of a short term nature. The use of DDI in patients with HIV infection remains promising but experimental, and long term benefits, especially prolongation of survival or progression from ARC to AIDS, have not been established.

Side Effects:

Along with these hopeful findings, it is also important to note that DDI does appear to have some side effects, the majority and most common of which are minor, such as headache, rash, and insomnia. At high doses however, DDI has been associated with peripheral neuropathy (a painful sensation in the feet, legs and hands), gastro-intestinal disturbances including diarrhea, pancreatitis (abdominal pain due to inflammation of the pancreas), increases in liver enzymes (denoting possible liver toxicity) and mental changes including disorientation and seizures.

Peripheral neuropathy seems to be the most common side effect, usually occurring in patients who are taking high

doses of DDI (above 800 mg/day). Unfortunately, this side effect often does not go away immediately when the patient stops taking the drug. Recovery is generally long term (weeks or months), and in a few cases complete recovery has been slow to occur. Another common side effect is increased levels of uric acid. Uric acid is a breakdown product of cells, and too much uric acid can result in inflammation and pain in the joints (gout) and may cause stones to form in the kidneys. However, all possible side effects of DDI, like its benefits, are still not known.

People with AIDS Action Coalition - March 1990
Taken from the Vancouver PWA Society Newsletter - May 1990
(Issue 36)

Library News

We have added a couple of new Videos to our shelves recently.

The first Videotape (in three sections) is # 73 "Facing AIDS," which has a half hour documentary on Wilf Gaidosch (a made for CBC Canadian Reflections production). The third section is the interview with Kobe - known to a number of us here in Victoria and done for CHEK - TV's Daily Edition. Both of these programs offer a perspective on the quality of life after being diagnosed HIV+ and the willingness to share very personal feelings with others (as these two individuals do). Section two of tape # 73 is a one hour Horizon program titled "Can AIDS be Stopped?" in which the world's medical community pursues research in the quest for answers. This British production gives a good concise history of AIDS, it's discovery and progress, the current world situation and prospects and ideas for cures and prevention of transmission. This section is very good viewing if you think you need a quick updating of your knowledge. "This Librarian certainly learned something new!"

The second videotape (also in three sections) is # 74 "Life Matters - AIDS." The first section looks at PWAs and their buddies interspersed with some establishment representatives showing some judgemental viewpoints and attitudes with some factual information (a PBS production). The second section is a short (15 minute) segment on AIDS in jail and how it was, and is, being handled by the guards. Finally, in section three is the latest in the series "The AIDS Quarterly" at PBS films. The show focuses on new drugs, money and morals. Good up to date information for us all.

The A.V.I. library is in Suite 106, at 1175 Cook Street and open during our office hours of 9:00am - 5:00pm,

Monday to Friday. Come in, relax and browse through the written material, as well as the video and audio tape over a cup of coffee or take material out (over a reasonable period of time). Enjoy!

-Helen

Poetry Corner

In memory of Ryan White

I have a disease,
I am sick,
It was not a choice
I had to pick.

Don't close your eyes,
But look at me,
I am a person,
Let me be.

Don't cover your ears
And refuse to hear,
I have a life
That I hold dear.

I need your help,
Give me a hand,
Together we can
Help understand.

Don't turn away,
Please don't leave,
I need to know
You do believe.

I haven't changed,
I'm still me,
I need you all
To learn to see.

I am afraid
To face this life,
I need your strength
To face the strife.

Don't push me away,
Don't give the show,
But hold me close,
I need your love.

C. Flello
April 19, 1990

S M T W T F S

		1	2 Family, Friends & Lovers Support Group 7:30pm 923 Burdett	3 Women's Support Group 7:30pm	4 Business Meeting 3:00pm	5 HIV/PWA Workshop 1:00pm
6	7 HIV & PWA Support Group 7:30pm (unfacilitated)	8	9 Family, Friends & Lovers Support Group 7:30 pm 923 Burdett	10 Women's Support Group 7:30 pm	11 Business Meeting 3:00pm	12
13	14 HIV & PWA Support Group 7:30pm (facilitated) Support Volunteer meeting 6:30pm	15	16 Family, Friends & Lovers Support Group 7:30 pm 923 Burdett	17 Women's Support Group 7:30 pm	18 Business Meeting 3:00pm	19
20	21 HIV & PWA Support Group (unfacilitated)	22 Board Meeting 7:30pm Begbie Hall	23 Family, Friends & Lovers Support Group 7:30 pm 923 Burdett	24 Women's Support Group 7:30 pm	25 Business Meeting 3:00pm	26 Volunteer Party at Rumors 7:00pm
27 Candlelight Vigil 8:30pm Confederation Square	28 HIV & PWA Support Group 7:30pm (facilitated)	29	30 Family, Friends & Lovers Support Group 7:30 pm 923 Burdett	31 Women's Support Group 7:30 pm		