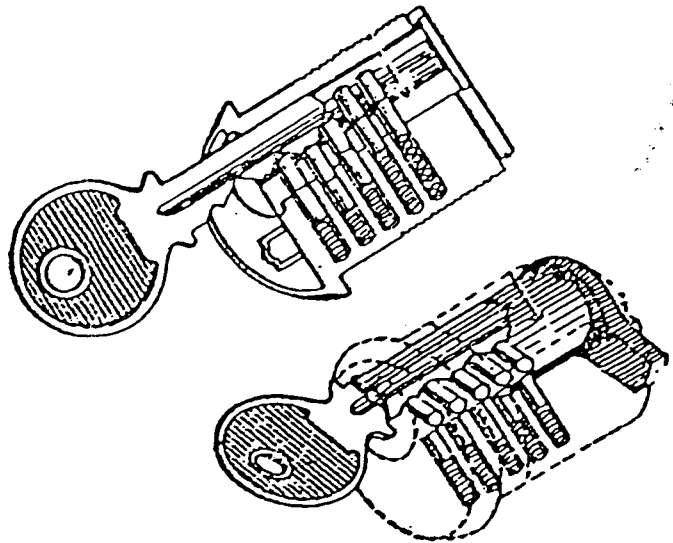




Vancouver PWA Newsletter

Issue 45 March 91



MAI DRUG ACCESSED

Clarithromycin is as yet unproven, but anecdotal reports indicate that it could be a very promising treatment for Mycobacterium Avium Intracellulare. This new treatment possibility has now been made available in Canada for those unable to use the standard therapy, under the Emergency Drug Release Program.

For an overview of how this drug works, see the AIDS Treatment News column in this issue of the Vancouver PWA Newsletter. Thanks to the efforts of Vancouver PWA's Treatments committee members, we are able to have the drug supplied by its manufacturer, Abbott Laboratories, and several members are about to start using Clarithromycin within two weeks. For those who have not responded to the standard therapy for MAI or those for whom it is not possible, this single orally-administered drug can replace the standard treatment of five drugs, of which one must be administered intravenously. Persons who have failed to respond to the standard treatment and are interested in accessing Clarithromycin should have their physicians contact :

Dr. Sabih Khan,
Emergency Drug Release Program,
Bureau of Human Prescription Drugs,
Health and Welfare Canada,
Place Vanier, Vanier Ontario K1A 1B8

NO FINANCIAL BARRIERS!

As well as the success of our efforts to get Clarithromycin for our members, we are pleased that access has been arranged through the Infectious Disease Clinic at St. Paul's Hospital for Erythropoietin, a treatment that aims at the causes of AZT-induced anemia for those unable to tolerate standard treatments. See the AIDS Treatment Highlights column for an overview.

However, we have more work to do. These promising drugs may not be accessible for everyone that needs them because they are very costly. Erythropoietin can cost up to \$1200.00 monthly if the patient is not covered under an insurance plan. Clarithromycin can cost a PWA patient up to an estimated \$375.00 monthly, since a bottle of one hundred 250 mg pills costs \$250.00, and an average daily dose would appear to be in the vicinity of 1250 mg. Alpha-interferon for Kaposi's Sarcoma can cost up to \$50,000 per year.

The effect on a person with HIV infection paying for such very expensive drugs is grave financial hardship, impoverishment and a reduction of the quality of life. Some might be tempted to do without the costly drugs and, more rapidly than need be, develop serious AIDS-related complications.

We need access to effective AIDS treatments without financial barriers, for everybody!
Douglas Starratt, Editor

SHARE KNOWLEDGE

Dear Editor:

Knowledge brings empowerment. Knowledgeable, empowered PWA stay healthier and live longer. This is a basic tenet of the PWA movement.

General Practitioners and other health care workers who do not have the time to assist in sharing knowledge and thus ending "confusion" are working with the wrong group of people. This taking time to "share knowledge" is absolutely necessary (mutually) for a helpful, healthy relationship between PWA and General Practitioner.
Dan Cotton

NURSE ON DUTY

Just a reminder . . . I'm at the PWA offices every Tuesday between 4 and 8 pm. I can offer health consultation and referral, supportive counselling for PWA's and friends/partners of PWA's. I can also provide some help with Ministry of Social Services and Housing. If I can help please drop by or call me at my office at 660 - 6776.

Thanks,
Patrick

Outreach Nurse to the Gay Community.

OUT OF TOWN?

Our Help Line at 1 -687-4792 is available for collect calls during office hours for B.C. Residents wishing to talk things over with a Peer Counsellor.



UMMMMMMMMMM!!!!!!!

Free massage for members! Contact Bart , who has been doing massage for us for over a year, at 872-4323 to make an appointment. Fridays only.

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ACT UP DEMO

Vancouver ACT UP (the AIDS Coalition to Unleash Power) is an organization of AIDS activist's independent of either AIDS Vancouver or The Vancouver Persons with AIDS Society.

On January 29th, as Premier Vander Zalm was about to appear at the UTV studio for his state of the province address, he was confronted by over 20 AIDS activists. Unable to enter the studio and direct questions to him personally as planned, we attempted to challenge his policies at the entrance way. Our list of questions included a demand to know why his government continues to refuse to fully fund AIDS drugs and therapies, and his reasons for refusing prisoners access to condoms and why security precautions were cited.

One person was arrested and charged with "breach of the peace" when he attempted to get the Premier's attention by jumping on the hood of his limousine and banging his open hand on the windshield. After he was wrestled to the pavement and handcuffed, he was taken to the city lock up. Having been injured, he was bandaged up by the jail nurse and later released without charge. Unfortunately, his request to be taken to the hospital was denied and he had to get to St. Paul's on his own, where he was x-rayed, prescribed painkillers and discharged.

John Kozachenko

FUN FUNDRAISER

The Women and HIV/AIDS Support Network held a very successful fundraiser at **The Talk of the Town** on February 8, 1991. Over \$600.00 was raised and will assist them in their ongoing work of providing services which include a drop-in and phone line for women with HIV/AIDS. For more information on the support network, please call Jackie at the PWA Society at 683 3381, or Bridget at AIDS Vancouver at 687 5220.

The highlight of the evening was a wonderfully outrageous and camp rendition of "The Rocky Horror Picture Show." Many thanks to Jackie, Flo, the cast and the staff of Talk of the Town.

John Kozachenko

AIDS AND RELATED ISSUES IN THE ABORIGINAL COMMUNITY

From January 20th through 22nd, Vancouver hosted the Second Canadian Conference on AIDS and related issues in the Aboriginal Community, which attracted more than 600 participants from a variety of health care and community services professionals.

Over the course of the three days, workshops and panel discussions were held on issues ranging from "condom education for disease prevention" to "AIDS and its Threat to Aboriginal peoples."

The close of the first day's program saw a performance of Evan Adam's play entitled "Snapshots", the story of a young native man living through the loss of his lover and learning he himself has AIDS, while half way across the continent his two sisters deal with their brother's homosexuality and diagnosis of AIDS.

Several important resolutions were passed including "the incorporation of traditional medicine with that of existing medical care, "that AIDS is a political issue and that the government must deal with land claims as it directly affects the spirit of the nation", "that AIDS education and progressive policies be implemented in prisons" and "that there would be availability of safe sex materials to all in the native communities."

The final address of the conference was given by Elijah Harper, MLA for Rupertsland Manitoba, who made several pertinent statements. Most notably "that we are aware of how AIDS affects the poor and that the aboriginal people's are the poorest of the poor" and "that people in the position of power should make every effort to understand the issues of AIDS because part of what it means to be a leader is to listen to the people over these issues."

John Kozachenko

MEDICAL FORUM REPORT

On January 23, 1991, Dr. Karen Gelmon spoke on Kaposi's Sarcoma and the Alpha-interon Trial.

This was an excellent presentation, unfortunately the turnout was less than we had hoped for. The whole purpose of these forums are to give the members information on treatment, therapies, new trials and provide an excellent opportunity for the members to voice their concerns or complaints. The Forums are relaxed and give the opportunity to directly question the presenter. Despite the poor attendance, Dr. Gelmon did give a good overview of the difficulties in treating KS and the unpredictable course this disease takes.

She noted that some patients with this illness may only ever develop one lesion, then there are those who develop crops of lesions over a period of time, and finally, those who develop lesions quickly and often internally. The treatment prescribed depends upon the degree of involvement, and where the lesions are. Facial lesions are often treated for cosmetic concerns, either with radiation therapy or cryosurgery, which is actually freezing of the lesions with liquid nitrogen. With some of the recent studies that have been published in the U.S. where low dose interferon has been tried, the results have been encouraging, so the Canadian trial will hopefully support the efficacy of Interferon as a treatment.

This needs to be established so that the drug will be made available to people with KS through the various Cancer Control Agencies. As it stands now, the cost of this drug is not covered in B.C. for KS. The drug is to be administered daily by subcutaneous injection, much as a diabetic takes his insulin daily. The dose will depend to a certain extent on the individual's tolerance to Interferon. Side effects include depression of the hemoglobin, nausea, headaches, and fevers which may continue during the first few weeks of treatment. The cost? If an individual is using 3 million units daily, it works out to about \$50,000 per year!

Dr. Gelmon explained that there has been a lot of difficulty in getting this trial going because

the supplier of Interferon (Schering) has been very difficult to deal with. The investigators were initially told they could enroll as many people in the trial as they wanted, and then were told they could enroll no more than eight! Locally they have enrolled eleven participants and are hoping to have sixteen before too long. To qualify for this trial, the individual must also be on AZT and appropriate PCP prophylaxis. Despite the restrictions they are working under, they do hope to gather useful information with the present trial design. Dr. Gelmon noted that a response is usually seen within two and one-half months to four months. Those who are responding favourably will be kept on the drug. A favourable response would be clearing of the lesions and a reduction in the number. Patients will be followed through IDC.

For more information on this trial, eligibility and possible enrollment, please speak with Pat or Nancy at Infectious Disease Clinic at St. Paul's Hospital 631-5060.

Al Hawkins

BLOOD TESTS DEFENDED

The logic of the author of 'Blood Testing: the Benefits' fits well with that of those conservative M.D.'s and researchers who would stop all forms of blood testing including T-Cells after the T4 helper cell count had decreased to 300.

From then on they would, barring opportunistic infections, see the patient every 3 months to re prescribe AZT and look at only blood work related to the anemia and liver problems which can be caused by AZT.

Clearly, this 'medical model' type relationship between doctor and patient is dehumanizing (I would suggest, to both parties) and makes the PWA a powerless victim.

Yes, the Blood Testing Program is expensive and yes, it has been misused. The misuse has come from misinformation, and inadequate information. Education of our members is, as always, the key.

P24 Antigen/antibody testing is specific to a certain part of the HIV viral body. This test has not lived up to the earlier expectations. It should be

noted that P24 is FDA approved. There are other tests that are being used experimentally now, that look at other parts of the HIV viral body. One thing we do know about P24 testing: when you get a numerically large positive (BC testing only gives you + or -) your viral load has greatly increased which means your anti-retroviral agent (AZT, DDI, ddC) is not very effective and other options need to be considered i.e., changing the drug you are taking, combining with one or more of the other drugs etc.

Beta 2 is not HIV specific but can be indicative of HIV viral load. Neopterin is the less widely used. It also measures viral load.

T-cell counts/ratios are good as markers to institute antiretroviral therapy and PCP prophylaxis and in conjunction with P24 or Beta 2 or clinical condition to change antiretroviral therapy.

Unfortunately, after the T4 cell count falls below a certain point (approx. 200) it becomes unreliable by itself.

How often should PWA's be tested? This depends on many factors, including P24's, T-cell counts, clinical condition, changes in therapy. In these situations more frequent testing is needed. In 'normal' times 4-6 month intervals are probably adequate; in 'not normal' times, 4-6 weeks would be more appropriate. When possible of course, all this should be done in consultation with your general practitioner.

Dan Cotton

COMPOUND Q UPDATE

Trichosanthin, Compound Q, is one of the most promising drugs under investigation and in use. It has been in use in China for quite a while mostly as a drug to induce abortion. It has been in use in the U.S. for approximately 3 years. Martin Delany of Project Inform did the first study with 10 men who, as Delany put it "didn't have a 100 T-4 cells between them". They also had many concurrent opportunistic infections including neurological involvement. He was very lucky only 3 of them died. There has been one other death possibly related to Compound Q in L.A., the man had a herniation of his brain stem. At this point it is

estimated that somewhere between 800 and 1000 people have taken Compound Q. The drug is now in phase two trials with the U.S. Federal Food and Drug Administration.

Compound Q is very selective; it only kills infected Macrophages and leucocytes. Anti-retrovirals, (also called chain terminators as they terminate the reproductive chain of the cells, mostly T-4 Cells like AZT) DDI, ddC, have little or no effect on infected macrophage or leucocyte blood cells. Compound Q, very importantly, crosses the blood/brain barrier. Obviously, this means that Compound Q will very significantly reduce viral load. It is thought that this great reduction is at least one of the reasons that we see an increase in T-4 cells, between 30% to 400%. The lower the number of T-4 cells before the infusions of 'Q' the lower the increase after, as a general rule.

Yes, it is true that some people with T-4 cells at higher ranges 350+ have become what Delany calls "his graduates" which means their T-cell counts and ratios have returned to "normal" levels.

It must also be said that Compound Q is a potentially dangerous drug. There can be very dangerous side effects including anaphylactic shock. Careful monitoring by a knowledgeable medical person during and for 3 days after infusion is necessary. There should also be emergency drugs immediately available in case of a severe reactions. The usual side effects seem to be like the flu in reverse. You're really sick a few hours after the infusion and you get better over 2-3 days.

These side effects last for 2-3 days and can be very uncomfortable. Almost all the groups infusing Compound Q in the U.S. require the PWA having the infusions have 200 or more T-4 Cells, no current opportunistic infections, no neurological involvement and liver functions in 'normal' range.

PWA with T-4 cells less than 50 who have infused Q usually have very little increase in their T cells and because of the killoff of infected macrophages and leucocytes these people are wide open in the weeks following their Q infusion to very serious O.I.'s which can be deadly.

Sources: Project Inform Perspectives

Lecture by Dr. Larry Waites, head of FDA phase II trials S.F. California, conversations with Dr. Payne, researcher, Phoenix, Ar.

Dan Cotton

AIDS TREATMENT HIGHLIGHTS

AZT: 300 MG May Be Equally Effective

A study published October 11, 1990, in *The New England Journal of Medicine* compared three different doses of AZT (also called zidovudine, or Retrovir) and found all three equally effective, according to several different measures. The doses were 300, 600 or 1500 mg per day; as expected, the low doses had less toxicity.

This phase II, unblinded, 'pilot' study enrolled a total of 67 volunteers, all of whom had symptomatic HIV infection, but not AIDS. All had T-helper counts of 200 to 500, and were either p24 positive or had plasma viremia, when they began the trial. (For the viremia measure, this study used a quantitative test for the amount of virus present, not the older viral cultures which were only positive or negative but did not indicate an amount.)

Those randomly assigned to the 300-mg dose had the greatest T-helper improvement, from an average of 321 to 412 during the first 12 weeks of treatment. Several other measurements - the proportion who became p24 negative, the decrease in p24 levels in the others, and the reduction in plasma viremia - were the same in all dosage groups. Clinical improvement, measured by weight gain, Karnofsky performance scores, and reduced fatigue, was better in the low and medium doses (300 and 600 mg) than in the 1500-mg dose.

None of the 22 who were p24 positive at the 12th week became p24 negative later - suggesting the limited effectiveness of AZT. In fact, the p24 levels increased 14 percent during this second phase (the median of 28 weeks after the 12th week of treatment). This increase was comparable in all three dosage groups.

The researchers concluded, "The consistency of the clinical and laboratory data...suggests that 300 mg of zidovudine a day has antiviral and CD4-lymphocyte-enhancing effects similar to those of a 600-mg dose, with less toxicity than higher doses." However, "Our findings must be corroborated before this dosage is routinely adopted."

They also conclude that "The minimal effective dose of zidovudine for the treatment of HIV infection has yet to be determined, and further studies of very low daily doses are warranted."

John S. James

AIDS Treatment News, Issue Number 113, October 19, 1990

Comments: Three weeks ago my AZT dose was reduced to 200 mg daily due to recurring anaemia. I'll keep you posted as to the effectiveness of this low dosage.

Incidentally I spoke with several PWA's who did not know there is medication available to relieve the particular AZT side effect of pressure and discomfort in the throat and thorax region often causing the urge to gag. Ask your doctor about Motilium or Prepulsid: they can make quite a difference.

Robert

ANTIVIRAL THERAPIES:

Where We Have Been And Where We Are Going

Over the past nine years, we have come a long way in our fight against HIV. We have moved from not even knowing what HIV was to a more complete understanding of how HIV works to produce a continued regression of the immune system.

The early research response to HIV was to try to inactivate any co-factor disease. Now we are looking at inactivating HIV itself. We now have a monkey model where HIV lives and multiplies and yet the monkey remains healthy. We see here a passive acceptance where no viral activation occurs. The virus lives out its life and causes no damage to the cells.

We are beginning to take a new look at AZT. The drug may not in fact kill the virus, but rather stop its activation. AZT may not allow the virus to be stimulated. Part of the answer to HIV infection may not be a cure, but rather finding a way to live with it. We are now looking for ways to keep HIV in long term remission.

ddI has proved to be a good drug for some people and is especially useful where AZT resistance occurs. Overall, however, DDI may be too toxic a drug for most. ddC works by inhibiting the

building blocks of the virus. This drug is probably better than AZT because there is less bone marrow toxicity associated with its use.

ddI, ddC and AZT are a family of drugs which may work best in some sort of combination regimen. If these drugs fail, we also have D4T and AzdU. We need trials of these drugs to determine their effectiveness and discover their toxicities. Overall, the AZT model for fighting HIV is there and we can use the model for developing other related drugs.

Besides the AZT model for inactivating HIV, we also have approaches that attempt to improve immunity. We believe that both TP5 and DTC improve the activation of CD4 cells. These drugs, however, do not kill the virus if T-helper cells are below 200. The effects of TP5 and DTC are such that one gets a greater benefit at an earlier stage of HIV disease. A study of DTC conducted some three years ago showed an 85% reduction of opportunistic infections among the group taking the drug. In a study of TP5, a derivative of the thymus, a group with asymptomatic HIV disease did not progress to AIDS at the rate of a control group. Combinations of TP5 and AZT are also being studied to determine the effectiveness of such combination therapies.

Another approach to fighting HIV is passive immunotherapy. The reasoning behind this therapy is simple and straightforward. We take the plasma of those that are coping well with HIV disease and transfuse it into those that are not doing as well. The plasma carries antibodies that the host created and these antibodies can be used by the recipient to fight the advance of the disease. Serious studies of passive immunotherapy are now under way. This is obviously not a cure, but it may buy quality time for those least well. Passive immunotherapy may also offer a model for other therapies. We need to find out what is therapeutically useful in the plasma and learn to synthesize it.

Other therapeutic approaches are also emerging. Soluble CD4 is still being looked at. Butil DMJ stops the bridging from cell to cell which allows HIV to spread to new cells. Protease inhibitors stop the virus from multiplying and have been very promising in the test tube. Once you have stopped HIV from spreading and multiplying, you have a disease in remission.

Is long term remission possible? Only continued research and study will tell us the answer. But after a latency period, the development of new approaches to fighting HIV appear to be starting up again.

Being Alive Newsletter, December 1990

Comment: I like the overview of hopeful new treatment modules discussed in this article. - Robert

EPO APPROVED!

The FDA approved a license for Procrit, a synthetic form of erythropoietin (EPO), which significantly reduces anaemia in people treated with AZT. A protein formed in the kidneys, EPO stimulates the production of red blood cells. EPO had already been licensed for patients with kidney failure and is marketed by Amgen, a pharmaceutical company, as a product called Epogen. Another company, Ortho Biotech, conducted trials of their version of EPO in people with AIDS. While these trials progressed, Ortho provided free EPO through a treatment-IND program. Now Ortho's drug, with the market name Procrit, has been licensed for anaemia in HIV-infected patients.

Procrit is an extremely expensive drug: one dose (7000 units) will cost about \$70.00. Patients typically need three doses a week and Ortho speculates that the annual cost will be from \$6,000.00 to \$8,500.00.

reprinted from GMHC Treatment Issues, January 10, 1991.

Comment: This treatment is now available through the Infectious Disease Clinic at St. Paul's hospital. Contact Ann Beardsell at 631 5074.

MAJOR STRIDE IN MAI THERAPY

The price of keeping people alive longer with prophylaxis for PCP is that they develop other infections that interfere with the quality of life. Mycobacterium avium or MAI is one such infection. Before the 1980s, only fifty cases of this infection were reported in all the world's medical literature. Now, it is estimated that as many as 50% of PWAs may have MAI in the course of their HIV disease.

MAI manifests with multiple symptoms which may be non-specific. Very often, this infection can be confused with other things and is difficult to diagnose.

Calendar

Mar 6 Healing Circle contact Don at 682-2989 or Lela at 689-8476 to register.

Mar 7 What to do Before You Can no Longer Manage. Free class, register 689-0571.

Mar 11 Finance Committee Meeting
Buddy Support Group

March 12 Board of Directors 7pm.

March 13 Healing Circle contact Don at 682-2989 or Lela at 689-8476 to register.

Program Committee 11am

Chinese Medicine 4 - 8 pm by Appointment.

March 25 Finance Committee Meeting.
Buddy Support Group

March 26 Board of Directors Meeting

March 27 Program Committee 11am

March

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M O N D A Y S

Advocacy Committee Meeting: Meetings 10am 1st & 3rd Mondays every month Mar 18, April 15, 29. We deal with access to treatments, human rights, political and legal issues. services include media relations, speaker's bureau , Monthly Medical Forum, Drug Treatments & Trials. Members are encouraged to attend and get involved. Contact Rick Waines, 683 3381.

Art Therapy Group Use the visual arts to explore personal issues and concerns. No experience necessary -this is not an ordinary 'Art Class'. Facilitated by an experienced Art Therapist, Noel Silver. Call or leave message for Noel at 685 5240 for more information.

Finance Committee: 2nd & 4th Mondays Works to ensure proper financial procedures and puts forward funding proposals. Mar 11, 25, April 8, 22 Anyone interested is requested to contact the General Manager, Chris Sabean or Harry 683 3381

Buddy Support Group: For buddies of PWA's, sponsored by AIDS Vancouver. Meets every second Monday at 7:00 pm at AIDS Vancouver, 1272 Richards Street. Mar 11, 25 Apr 8, 22 Call 687 5220 for information

Personnel Committee Meeting: Meetings every second Monday at 4pm, at the Society's Offices - works to provide policy and assistance in organizing human resources (volunteers and paid staff). You may have a talent or experience that would help. Contact John Liesch 683 3381.

T U E S D A Y S

Executive Committee: Meets 2pm 2nd & 4th Tuesdays to coordinate business of the Society and to prepare for Board Meetings by setting agenda.

Board of Directors Meeting: The Board of the Vancouver Persons with AIDS Society meets 2nd & 4th Tuesdays at 7 PM at the Society Offices. Open to all interested members. This your opportunity to stay abreast of Society activities; and have a voice in our future. Mar 12, 26 Apr 9, 23

Meditation Class "Living in Each Moment"

From 2 pm - 4 pm This class is open to people living with HIV, friends and supporters. For more information and location, please contact Kirsten at 872 0431

Safe Company: Patrick Loftus, outreach nurse available for consultation, counselling, HIV, STD tests 4 - 8 pm in our offices.

Women and AIDS Drop-in 7:00 to 8:30 pm

For women to seek out information and support concerning AIDS/HIV First and third Tuesdays of each month at Vancouver Women's Health Collective, No. 302, 1720 Grant Street. Call Jackie at 683 3381 for details or call us at 255 9848 during drop-in hours. ¡Se habla Español! Children welcome!

Living with AIDS Therapy Support group open to PWA's. at GLC 1170 Bute Street. Due to intense nature of this group, a commitment to full 8 weeks is required. Led by experienced facilitator for 10 participants only. Call Jackie to register.

W E D N E S D A Y S

Program Committee Meeting: All members welcome. Meets at 11 am every second Wednesday to develop and facilitate individual programs such as Retreats, Support Groups etc. Members are welcome and encouraged to participate. Contact Bryan Wade

Partners of Persons with HIV/AIDS and Family and Friends of persons with HIV/AIDS. Both groups will meet every Wednesday 7:30-9:30 pm at St. Andrews-Wesley Church. Rooms to be posted. Call Bridget MacKenzie at 687 5220 or Joy Moon at 299 4828 for more information.

Healing Circle meets evenings Call Lela at 689 8476 or Don at 682 2989 to register for this program. Not a drop-in!

Chinese Medicine for Society members. Consultations at PWA offices 4-8pm Call office or sign up on waitlist at reception desk to register. Facilitated by a Professional practitioner, by appointment only.

T H U R S D A Y S

Therapeutic Touch: free to full PWA Society members at our offices. Sign up at reception.

Get Over It: AA Meeting of special interest to HIV concerned persons. 7 pm in PWA Society's Living Room Lounge.

Narcotics Anonymous: New Hope. Open to HIV positive or negative. Meets every Thursday, 8:30 to 10 pm, in the PWA Society's Living Room Lounge. Narcotics Anonymous 24 hour Helpline 873 1018.

Body Positive Support Group: For those testing HIV positive. Confidential Discussion Group meets Thursday evenings at 7:30 pm in PWA offices. For more information contact Kenn Mann at 683-3381

F R I D A Y S

Movie Night Cancelled till further notice for lack of support. If you want it resumed, call Program Committee...

S A T U R D A Y S

Drop-in: Open to all HIV infected persons. An ideal time for people living in outlying areas or working during the week to meet others for support and to seek out information and resources. The Library is open and peer counselling is available. Held in the PWA Society's Living Room Lounge Saturdays from 11 am until 3 pm. For info call the Vancouver PWA Society.

E V E R Y D A Y

Living Room Lounge our relaxed drop-in centre is open weekdays 10 until 5 and Saturdays 11 to 3. Juice and fresh-brewed coffee.

Referral Information available in our Library weekdays 10 to 5 and Saturdays 11 to 3. For people looking for medical information, alternative therapy, and other services

The current standard therapy for MAI includes the following: INH, Rifampin, Ethambutol, Ciprofloxacin, Clofazimine, and Amikacin.

We see a fairly good response rate to this regimen. There is some improvement of symptoms, The infection, however, does not get cured, and persistent, low grade symptoms may interfere with the quality of life. The four or five drug regimen, however, may be difficult to keep up, since some need to be taken intravenously.

Now there is a new antibiotic, clarithromycin, which may offer a one drug anti-MAI therapy. This compound is related to erythromycin, but has a wider spectrum of activity and is more fat soluble. Clarithromycin is available in Ireland, Italy and a few other countries (*including Canada, under EDRP. See below*).

We have two studies of clarithromycin as treatment for MAI. A 1989 study looked at how much clarithromycin was needed to treat MAI in the test tube. An effective dose was fairly easy to attain. The researchers found that clarithromycin was the single best drug that they tried as treatment for MAI-infected rats.

At the recent ICAAC, Paris researchers reported on a double blind study of clarithromycin for MAI in AIDS patients. The study was divided into two groups of twenty-three patients. The clarithromycin group showed a steady decrease in MAI levels over the six weeks, whereas the placebo group showed a steady rise.

During the second six weeks of the study, the first group received a placebo and four drugs from the standard regimen. MAI levels began to move up. The second group was given clarithromycin and the four drugs. Their MAI levels steadily decreased. The researchers concluded that clarithromycin either alone or in combination was a reasonably effective treatment for MAI.

Excerpted from "Being Alive" February 1991.

See also: AIDS Treatment News Number 113

Comment: Thanks to lobbying efforts by our members, Clarithromycin is now available in Canada, for those unable to use the standard treatment.

Contact Dr. Sabih Khan

Emergency Drug Release Program

Bureau of Human Prescription Drugs

Vanier Place, Vanier Ontario K1A 1B8

ANTIVIRAL COMBINATIONS

"... A member of the audience asked whether to add DDI to AZT, if DDI were available. I don't have an answer. But if I had been on AZT for a year and a half, and had evidence of disease progression, and I could take both drugs, I would consider doing so. There's a place for combination therapy."

"I liked having the AIDS activists in the Conference; sometimes they raised the most cutting questions. On combinations, the traditional way is to test drug A, get to know everything about it, then test drug B, and only later try combining the two. But since everybody seems to agree that combinations is the way to go - they've been talking about it for years now - activists asked why not go ahead and do it? The answer was, 'That's not the way we do it.' The question was useful, because if you watched the speaker who was answering it, you could see written all over his face the thought, 'Isn't this stupid?' That may be the first time the thought occurred to him - having to say it publicly - that maybe we ought to move on."

Question: is there any data based on previous experience with other diseases as to how the drugs should be combined? "The answer unfortunately is no. These are synthetic nucleoside analogs, and except for acyclovir to treat herpes, there is not yet another model; it is not the same as chemotherapy.

"It's not as bleak as it sounds. We think that much of this data now will come from animal models, and that we won't have to wait to do the whole thing.

"There are some experiments on combining drugs, for example the ddC study at Stanford which is testing alternations of this drug with AZT."

AIDS Treatment News, Issue Number 106, July 6, 1990

An excerpt from Sixth International Conference Overview by Marcus Conant, M.D.:

Comment: I think we will hear more in the near future about combination drug therapy. - Robert

ORAL INTERFERON UPDATE

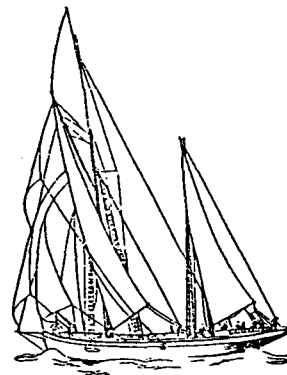
Oral alpha interferon continues to be a hotly debated topic. So far, no one has been able to duplicate or confirm the dramatic results reported in Kenya last year. More troubling is the verified tale of two patients who were told they had experienced enormous CD4 rises while in Kenya, yet upon returning home found that the new found CD4 cells mysteriously disappeared somewhere over the Atlantic, leaving them with the same low counts as when they began their journey. Unfortunately, people doubting or contesting the Kenyan results are sometimes accused of racism, which is sad and utterly unfair to people with AIDS everywhere. People with AIDS of all colours will gladly welcome a real solution no matter where it comes from, and would probably take special delight in one which caught the stuffy elements of the medical establishment with their pants down. But people with AIDS are also increasingly shrewd in their demands for evidence of effectiveness. No one can or should promote a drug for long without backing it up with research. To its credit, the World Health Organization is making a sincere effort to test the validity of the claims, planning new studies in several countries.

Community response in the US remains divided. The New York Native, at first a loud supporter, has now printed articles reporting questions about the integrity of the original study. Some of the AIDS buyer's clubs are selling various versions of the product despite personal scepticism, some are blatantly promoting it, while the most aggressive are making arrangements for its manufacture and distribution. The strongest claims are coming from people who are selling the product. While their motives needn't be questioned, the substance of their claims might. PI is awaiting long-promised reports from two such groups, but so far we have seen nothing. To our knowledge, no controlled studies are as yet underway, and what are sometimes billed as studies are in fact large scale distribution programs with random data reporting.

Anecdotal claims are also mixed, as always. Roughly the usual percentage of people are report-

ing to feel better. While positive anecdotes aren't always meaningless, they have been made about every product ever used in this epidemic. In all, the case for oral interferon remains thin but this does not prove it wrong either. Perhaps the riskiest aspect of the current avalanche of claims, counter-claims, and accusations of fraud is the possibility that whatever value the drug might have could be lost in the flurry.

P. I. Perspective, October 1990



FUNERALS ARRANGED

The reduction of stress in the life of a PWA promotes a healthier and happier outlook. One of the ways to reduce stress is to have funeral arrangements pre-arranged and set aside. Formal pre-arrangements may be made, but written instructions attached to a copy of your will are enough to give you a sense of calm, and help enormously those who are left to make final decisions.

Vancouver PWA Society has a funeral director volunteer who may be called without obligation to answer any of your questions regarding cremation, memorial services, funeral services, etc. He is available on a 24 hour basis, and will make hospital or home visits. It is less stressful to deal with the unavoidable than to go on in fear of the unknown.

Jackie Hegadorn

EVALUATION PROJECT IS NOW COMPLETE

The evaluation of the PWA Society is officially complete. The Society's Evaluation Project Review Team met with the evaluators, Steve Goldberg and John Collins on February 4 to receive the Report and to discuss its 49 recommendations.

The overall impression of the evaluators is that the Vancouver Persons With AIDS Society is generally solid, well administered and organizationally sound. Their interviews inside and outside the Society confirmed that it meets real and critical needs in the lives of its members, and that it meets them in ways that other community or provincially sponsored agencies cannot do.

Members acknowledge that the Society has played an important role in their lives - sometimes a life-saving role -- and that it has been instrumental in supporting and empowering them. The Society's efforts are commendable and important in the community and definitely warrant being continued and expanded.

Results of the Membership Survey showed that many members use the Society regularly and still others use it occasionally. Members endorse the Society's services, programs, activities, and information delivery systems. They report that the staff is generally friendly, courteous and helpful, and feel that the Society presents an effective public image. Members see the Society as sensitive and responsive to the needs of its members. (Special thanks to all those members who filled out the Membership Survey and returned it!)

In addition, the survey showed that members agree that six specific measures of the Society's effectiveness are satisfactorily conducted: Program quality (69%), Information availability (78%), Newsletter usefulness (86%), Staff courtesy (87%), Society public image (56%), and Sensitivity to the needs of its members (71%). Overall, they agreed that they were well satisfied with these aspects of the Society's performance.

Furthermore, members agreed the society is fulfilling all seven points of its Constitutional Mandate: Creating positive attitudes and feelings of hope (73%); Providing support activities and facilities for self-help, self-care (81%); Acting in an advocacy role for members (73%); Providing

support services for members and non-members (79%); Creating a positive image of persons with HIV and (73%); and Developing low-cost rental housing for persons with AIDS or HIV (44%); although they acknowledged the Society has not placed a major focus on developing low-cost housing until this past year.

The Society profits from a core group of talented and hardworking volunteers. It delivers a wide array of services and programs available to members and non-members. In particular, it delivers health services not otherwise available such as certain blood testing procedures and enhanced vitamin therapies.

The Society has been instrumental in advocating drug access, human rights and non-discrimination for its members. It is one of two North American AIDS organizations whose boards are comprised solely of persons with AIDS and HIV infection and it has developed a functioning organizational structure responsive to changing needs and conditions. It has been most indispensable in "Giving a Face to AIDS" to the public.

Total Society revenues have more than tripled in the four years of the Society's formal organization. Federal government contributions have increased six-fold, while donations and fundraising revenues have increased 160 per cent. Operating expenditures have increased more than ten-fold, while member benefits have increased 450 per cent. Member benefits and operating expenses have roughly kept pace dollar-for-dollar in the same period. The United Way and the B.C. Social Planning and Research Council report that this 50% - 50% split between operating expenses and member benefits is not uncommon in the early years of charitable societies. The Evaluation Report points out that in 1990, virtually all of the Society's unencumbered revenues from fundraising and donations were spent directly on member benefits, while operating expenses were paid mainly from government grants solicited for that purpose.

The evaluators note that the Society has survived and grown in the face of changes in leadership, redefinition of membership criteria, sharp increases in membership growth, and turnovers in staff and personnel. The report cites ten different challenges which the Society should address in the near-term future: (1) Clarifying the society's vi-

Traditional Chinese Medicine Project:

Goal:

To establish the feasibility and efficacy of Chinese medicine as supplementary therapy to Western medicine in treating AIDS and HIV.

Objectives:

1. To make Chinese medicine available as supplementary therapy for the purpose of health promotion.
2. To demonstrate the value of Chinese medicine as supplementary therapy to Western medicine in treating AIDS and HIV.
3. To produce a report on the feasibility and efficacy of Chinese medicine as supplementary therapy to Western medicine in treating AIDS and HIV.
4. To provide an information package on Chinese medicine as supplementary therapy to Western medicine.

This project is designed to provide TCM as an alternative therapy and demonstrate the value of using Chinese medicine for health promotion and as supplementary therapy to Western medicine in the treatment of AIDS and HIV.

According to known pathology, 'metamorphosis' of HIV disease treatment has three major stages:

1. Halting reproduction of the virus
2. Destroying infected cells which act as 'viral factories'
3. Rebuilding the immune system.

Herbal formulas are central to Traditional Chinese Medicine, but they are not the only TCM therapeutic measures available to AIDS and HIV patients. In the holistic-approach characteristic of TCM, acupuncture, moxibustion, manipulation (Chinese massage and chiropractic adjustment) and Qi Gong (meditation) have all been used in treating AIDS and HIV with especially beneficial effects in relieving symptoms and improving the quality of life.

The project will be undertaken through international cooperation from three participants who have been involved for some time in researching Chinese medical treatment of AIDS and HIV.

The Chinese herbal therapy is one being formulated by Dr. Jaiqi Shen of Shanghai Medical University. Several similar herbal therapies are being studied by Dr. Qingcai Zhang of the Oriental Healing Arts Institute in Long Beach, California who is conducting laboratory tests and systematic clinical observations in conjunction with the therapy. In Vancouver, the project will be overseen by Dr. Jian Zhang Shen working with Dr. Allan Li, M.D. of the Asian AIDS Project, AIDS Committee of Toronto.

Funding:

This pioneer project is funded solely by the Vancouver PWA Society from the generous donations of the community. We hope to receive assistance from the Health Promotion Directorate of the Federal Government next year.

Summary:

Chinese medicine can play an important role in health promotion and as supplementary therapy to Western medicine in treating AIDS and HIV. By coordinating access and availability of this approach, we will be able to provide health promoting treatment options for our members, and at the same time contribute to the knowledge on workable treatments of all kinds for persons with AIDS and HIV.

If you are interested in this project, please sign up at the Society's office. There is a waiting list and I will fit you in as soon as possible.

Lim,

Member of the Board of Directors



Dragon, as represented in Heraldry.

HELPLINE LEGAL ASSISTANT

Volunteer needed for legal document preparation program. Legal or paralegal expertise required. Call Chris Sabean, managing director, at 683 3381

BRADLEY HAWBOLDT

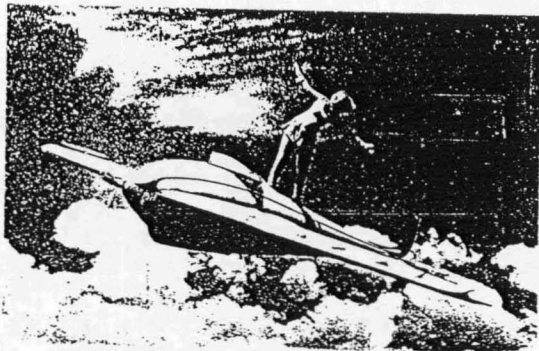
JUNE 6, 1953 - FEB. 3 1991

Dear Brad,

Thanks for sharing your last 2 days with me. We hit a spiritual peak of our 22 years as friends. I saw a strength & beauty much stronger than ever before. You were so beautiful and looked so at peace.

Bon voyage! And keep me a good seat. Miss you a lot, think of you often; We had a great 22 years.

Love Joe Ford



KEN PARKER

Feb 1945 - December 1990

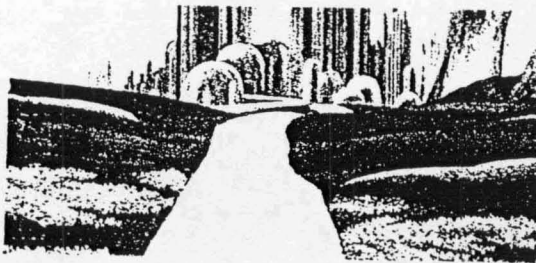
Ken Parker died peacefully in Nelson, B.C. on December 25, 1990. Ken was born in Toronto, Ont. on February 13, 1945 and lived in the east for the first part of his life, where he is survived by his mother and father, and two sisters.

Ken moved to British Columbia in 1979 and spent a lot of time in Vancouver, where he is fondly remembered by many good friends. His lover and longtime companion, Michael Collins, remains in Nelson, where Ken made his home during the last several years. Ken was a very special upbeat sort of guy and will be sorely missed by all who loved him.

M.C.

FORUM ON CHINESE MEDICINE

On April 3rd the topic of our Monthly medical forum will be Traditional Chinese Medicine with Dr. Jiang Zhang Shen, consultant for the Traditional Chinese Medicine project, at 7 pm at the Gordon Neighbourhood House, 1091 Broughton Street at Nelson. Come on out and learn more about this interesting approach as it balances and complements western medicine!



NORTHWEST HIGHWAY

*living in my car
Smell the fresh rain on freeway asphalt
See the clouds try to clear
SUNLIGHT!
Frantically search for the rainbow.
sun is smothered by the clouds.
regain lonely darkness,
pull over*

cry

*living life with AIDS
Smell the hospital corridor
See the desperate smile of a bedridden friend.
HOPE!*

*Frantically search for an unseen cure.
hope is smothered by complacency.
regain composure;*

*God he can't see me upset,
pull over*

cry

R.B. McDiarmid
from "Piano Plays in the Darkness"

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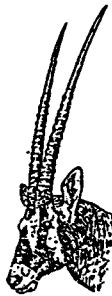
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Many thanks to our production and assembly team for recent issues: Yvonne, Alan, Floyd, Hans, Erwin, Lloyd, Michael. If you want a volunteer assignment that's fun and rewarding, come join us on the lively Newsletter team!

A member of



United Way
Affiliate Agency.

NOTICEBOARD

Victoria HIV+ Heterosexual male, age 28, wishes to meet HIV+ woman for friendship or possible long term relationship. I am initially interested in a roommate/companion but I would welcome the relationship blossoming from there—call Wally 1-727-9804

Household items needed: TVs, vacuums, sewing machines, dishes, pots and pans, tables and chairs, silverware, coffee makers and kettles. Contact Yvonne if you can help out.

PWAs Needing something specific such as a sewing machine, vacuum cleaner, appliance, etc.? Consider an ad here.

Haircuts, Styles, Etc. Hairdresser Finn Mollerup will be available every second Monday from 10 am to 2 pm at the PWA Offices. Free for full members. Sign up in the Living Room Lounge. Please come with freshly washed hair. A Hydraulic Chair is desperately needed by our friendly hairdresser Finn to use for his complementary Monday hairstyling sessions.

Need a haircut and not feeling well enough to come into the office on Mondays? We now have a member who is volunteering to come to your home or to the hospital to cut your hair.

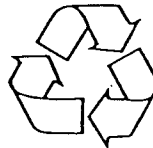
Bridge Club starting up at PWA. Want to join? Leave name and phone # with Jackie.

The Lounge is bare. Most of the stuffed Teddy Bears which graced our lounge have wandered off to new buddies in the hospital. If you have a clean, stuffed Teddy in good condition we would be pleased to accept him or her, perhaps to spend time with a special new friend in the hospital.

Mountain Bike Needed! Our Errand Volunteer Needs a Mountain Bike to challenge the hills! If you have one please call Yvonne at PWA Office 683-3381.

HIV+ man sought by HIV+ woman, early 30's for walks, talks, and social time together. I like the outdoors, dinners out, and country and western music. Please write to 'Sue' in an envelope marked PERSONAL c/o Jackie Hegadorn, Vancouver PWA Society, 1447 Hornby Street, Vancouver V6Z 1W8

Please recycle this newsletter. Share it!



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