EMERGENCY DRUG RELEASE PROGRAM

ISSUE #27 DECEMBER/JANUARY/FEBRUARY 1989

THE DRUGS PENTAMIDINE AND DEXTRAN SULEATE ARE NOW

AVAILABLE IN CANADA UNDER THE EMERGENCY DRUG RELEASE

PROGRAM AT HEALTH AND WELFARE CANADA.

PENTAMIDINE IS NOW AVAILABLE FOR THE ONGOING SUPRESSION of PCP. Drugs that a person and his physician believe would be useful in treating HIV infection are also now available through the E.D.R.P. Physicians should call the numbers below for more information on procedures to access drugs. It is still unclear as to exactly what drugs will be available through the E.D.R.P. This is why we need your assistance in finding out exactly what this program will do for HIV infected people.

WE ASK OUR READERS TO KEEP US POSTED ON SUCCESSES AND/OR FAILURES. PLEASE CALL US IF YOU REQUIRE MORE INFORMATION OR ASSISTANCE.

PHYSICIANS SHOULD CALL:

VANCOUVER

COALITION

Dr. Michelle Beryl-Edwards, Assistant Director, Bureau of Human Prescription Drugs, (613) 991-0109

Dr. Gordon Johnson, Director, Bureau of Human Prescription Drugs, (613) 991-0107

APOLOGIES: FOR THE LACK OF DECEMBER & JANUARY ISSUES. THIS WAS DUE TO SHORT STAFFING ON THE NEWSLETTER. ANYONE INTERESTED IN VOLUNTEERING, PLEASE CALL THE OFFICE OR DROP BY.

BONES OF CONTENTION

ON NOV. 17/88 IN LONDON ONTARIO THE LOCAL AIDS COMMITTEE of London and the PLWA (People Living With AIDS) activist group AIDS ACTION NOW! staged a demonstration and die-in. They were there to voice the concerns of PLWAs and HIV infected people across Canada. Their intended audience, besides the public at large, was the AIDS research community. Perhaps 90% of this community were gathered for a WOKSHOP ON CLINICAL TRIALS ON HIV DISEASE IN CANADA. Others in attendance were a number of primary-care physicians, drug company representatives, and representatives of community based groups from across Canada. These included; Bruce Davidson, of the Nova Scotia PWA Coalition, PLWAs Chuck Groschmal and Dr. Wayne Boone of AIDS ACTION NOW!, yours truly of the VANCOUVER PWA COALITION, and Jeff Braff of the Canadian AIDS Society. THIS MARKED A FIRST IN CANADA, to have people on the recieving end of these studies as members of such a workshop. THIS HISTORIC GATHERING DID NOT DISAPPOINT.

The demands of the demonstrators (which were fully endorsed by the PLWA workshop participants) centered around issues of drug access and personal choice. The demands were: RECOGNITION OF CATASTROPHIC RIGHTS AND FREE ACCESS TO AIDS RELATED DRUGS AND TREATMENTS; NO DRUG TRIALS INVOLVING PLACEBOS, A NATIONAL TREATMENT REGISTRY, AND PLWA presence on all boards and committees dealing with drug trials.

For all appearances the distance between the PLWAs and the research community was unbridgable, and very distressing for all. This was until, on reflection, it was clear we all wanted the same things. We all were interested in making useful drugs available to all HIV infected people, and we all wanted to gain mastery over this virus. Only one stumbling block stood in the way.

This is the problem of placebo controlled studies. PLWAs across Canada have been very vocal in this regard and THE OBJECTION HAS BEEN UNIFORM. We have viewed placebo-controlled studies AS UNETHICAL with a disease like AIDS. In my view, this is not a problem of placebo use, but rather A PROBLEM OF CHOICE. It is simply unfair to force a person with a life threatning illness into aposition of being subject to treatment with a placebo. Especially when there are alternatives.

So the problem is this: TO DEVELOP A STUDY MODEL THAT RECOGNIZES BOTH THE CONSTRAINTS OF MEANINGFUL RESEARCH, AND THE REALITY OF PATIENT AUTONOMY. The only sure way,

it would seem, to prove the usefulness of a drug beyond doubt is to subject the drug to a double blind placebo controlled study. At the same time, to obtain the necessary informed consent of study participants, even the appearance of coercion has to be removed. To give consent of one's own free will, implies that there is a choice.

2.

cont'd

Bones of Contention : cont'd

I was given the opportunity to offer one possible solution: A STANDARD DOUBLE BLIND PLACEBO CONTROLLED STUDY WITH AN ADDITIONAL ARM. On recruitment the subject is given a choice. The study participant could opt for the drug being studied, or enter into the main body of the study and be subject to the randomization process of a standard double blind placebo controlled study. This appears to to solve the the problems at hand. WITH THIS MODEL EVERYBODY WINS: meaningful research can be conducted with fully informed study participants, and no one would be forced into THE POSITION OF BEING AN UNWILLING GUINEA PIG.

The only concern that was raised was that all potential participants would opt for the treatment arm of the study. I don't believe this is necessarily so. The path of optimum survival is not clear in the case of an experimental drug. The drug indeed might do more harm than good. We must allow that people often enter into studies for purely altruistic reasons. In any case we won't know if this model will work UNTIL IT IS TRIED. I think it must be tried. All of the PLWAs attending the conference fully supported this proposal. So did a great many of the doctors. Only time will tell if this model will be used and is useful. I hope we don't have to repeat the American experience.

> In Love and Light, Greig

3.

NOMINATIONS FOR THE BOARD SOUGHT

ANNUAL GENERAL MEETING : SUNDAY, MARCH 26, 1989

AT PRESENT WE HAVE NINE POSITIONS ON OUR BOARD OF DIRECTORS. These positions will be coming up for election at our Annual General Meeting. The positions are AVIALABLE TO ALL MEMBERS. If you are interested in being on the Board or know of someone who would, please contact the Personnel Committee. Being a member of the Board requires a committment to attend meetings and to be involved in the policy making and running of the Society. As we enter another exciting year, there are many things to become involved in. As part of the Board you can participate directly in shaping the furure of our group. Committee Chairs must be members of the Board, so if you've been wanting to get involved, this is the perfect opportunity. WITH MANY IMPORTANT PROJECTS COMING UP THIS YEAR WE NEED THE TALENT OF OUR MEMBERS TO KEEP THIS ONE OF THE MOST VIBRANT AND BUSY COALITIONS AROUND. Please consider devoting some of your time to our cause. Nominations are being accepted NOW and until Friday, March 10th, 1989. So please think about this and let us know, Thank You,

HIV P24 ANTIGEN TEST

4.

BETA, MICROGLOBULIN TEST

WHAT ARE THEY? HOW DO I GET THEM?

AS A CLINICAL TOOL FOR MONITORING THE COURSE OF HIV infection, T-helper counts have gained nearly universal acceptance. But T-counts fluctuate wildly from day to day, even in healthy, seronegative individuals. T-cell counts cannot tell you whether HIV is actively replicating in your blood, or whether a particular treatment regimen is helping or not. At best, T-cell counts are a vague and general marker of progression towards AIDS. Which is great for many people, because it makes it easier for them to engage in denial.

But for those of us who want to learn as much as we can about what is going on re: HIV in our own bodies, who want to be able to assess the efficacy of particular treatment(s)—well, for us T-cell counts don't provide many answers. But two relatively new blood tests, presently av ailable in Seattle but not in Vancouver, can help you better assess either the effectiveness of treatment(s), or your chances of progressing towards AIDS (if you are positive but healthy).

P24 ANTIGEN TESTING :

AN ANTIGEN IS ANY SUBSTANCE THAT YOUR BODY REGARDS AS foreign, and which your body produces antibodies to attack. The P24 Antigen Test detects the presence in your blood of a particular core protein (P24) of the AIDS virus. P24 antigen is measured in picograms per millitre (pg/ml) of blood. The more rapid the rate of replication of HIV in your blood, the higher your P24 count will be.

Researchers have noted that, in many patients, P24 antigen counts decrease substantially after AZT therapy is commenced. In one recent study of patients who have a low tolerance for AZT, P24 counts varied from undetectable (less than 30 pg/ml) to above 400 pg/ml, dependant upon the dose of AZT the patient was on when the testing was done. If you are on a half dose or less of AZt, or using a combination of antiviral therapies, and you want to find out whether your treatment(s) is reducing HIV activity in your blood, P24 antigen testing can provide crucial answers.

If you are positive but healthy, and are undecided as to whether you should commence early anti-viral therapy, the research says that, if there are detectable levels of P24 antigens in your blood, this is highly predictive of disease progression. If this should turn out to be your situation, DO NOT WAIT UNTIL YOU GET SICK TO COMMENCE TREATMENT. If your risk of progression towards AIDS is very high,

cont'd.

P24 Antigen Test Cont'd.....

the sooner you commence effective anti-HIV therapy the better. P24 Antigen testing costs \$88.25 US and is available weekdays, 9am-9pm, at

UNIVERSITY OF WASHINGTON ADMIT LAB 1959 N.E. PACIFIC STREET SEATTLE, WASHINGTON PHONE: (206)548-6066

If enough of our members are interested, we will arrange monthly, sameday return trips to Seattle to have these tests done. A list will be posted in the PWA offices, if you want to sign up.

If you want this testing done, but are unable to make the trip, it is possible to send your blood to Seattle by overnight delivery. Care must be taken regarding packaging and speedy delivery.

One final note. If you are on AZT, and you want to maximize the amount of information gained from P24 antigen testing, TIMING IS IMPORTANT. You would be wise to talk to myself (Chuck) or read the medical research before going and having the test done.

THE MOST IMPORTANT MEDICAL RESEARCH ON P24 TESTING IS AVAILABLE IN THE LIBRARY AT THE PWA OFFICES, OR PHONE US AT 683-3381 AND WE'LL MAIL IT TO YOU.

BETA, MICROGLOBULIN TESTING:

LIKE THE P24 ANTIGEN TEST, THE BETA₂ MICROGLOBULIN (B₂M) test is obtainable at The University of Washington (see above). The cost is \$21.50 US.

To put it simply, the B₂M test is an indicator of the rapidity of lymphocyte cell turnover or death of the cells. In a healthy, sero-negative person, B₂M will measure less than 2.5mg/l. Studies have shown that B₂M rises above 2.5mg/l. in Hiv infection. The further above 2.5mg/l. your count rises, the more rapidly the disease is progressing in your blood. One leading researcher estimated that a positive but healthy person with a B₂M count above 5mg/l. will likely develop AIDS within two years. Another researcher estimates that at least a quarter of men who have T-helper cell counts above 400 and B₂M above 3mg/l. will develop AIDS in less than 3 years.

IN CONCLUSION: BY JUDICUOUSLY EMPLOYING T-CELL TESTS, P24 antigen tests, and Beta₂ Microglobulin tests, you can get a much clearer and more comprehensive picture of what is going on re: HIV in your own blood. HAPPY TESTING!

SUPPORT/STUDY GROUP FORMING

THE PREVALENT BELIEF AMONG THE GENERAL PUBLIC, THE professional community, and even PWAs is that AIDS is inevitably fatal. There is a small but growing number of individuals who are alive and well 3, 4, and even 5 years after AIDS diagnosis.

WE ARE INTERESTED IN FORMING A SUPPORT/STUDY GROUP of about 6-8 PWAs who are sincerely committed to their survival. We are planning to meet once a week and basically follow Dr.'s Simonton's Strategy as outlined in their book "<u>Getting Well Again</u>", as well as other resources; (Louise Hay, Bernie Segal etc.).

THE OBJECTIVES OF THE GROUP WILL BE:

-to learn and practice relaxation & visualization and affirmation techniques

-to develop a sense of resposibility for one's health

-to commit oneself to life and develop strategies to foster positive beliefs, feelings and attitudes.

-to set short term/long term goals

-to learn various proven support techniques (such as re-evaluation counselling)

INTERESTED PARTIES CAN CONTACT ERIC D. OR STEVE S. THROUGH

THE PWA OFFICE AT 683-3381

FEDERAL FUNDING SECURED FOR 1989

HEALTH PROMOTION DIRECTORATE OF HEALTH & WELFARE CANADA has come through, once again, with \$50,000 in funding for 1989. This contribution is an increase from 1988. These much appreciated funds will pay the salary for our staffperson, plus office operations, travel, and library expenses. These Federal funds will cover 25% of our 1989 Budget. We are applying to the City of Vancouver for an additional 25%. The balance of our financial needs will be met (we hope!) by your donations and by our own fundraising efforts.

Our sincere thanks go out to Mr. Darryl Sturtevant, Project Officer at HPD and to Ms. Rita Stern, Director, for their steady backing and firm belief in the value of our programs and activities. THANK YOU FROM ALL OF US.

VITAMIN EXCHANGE

BRING IN THE PRODUCTS YOU NO LONGER USE. WE'LL TURN THEM OVER TO SOMEONE ELSE. VITAMINS, SUPPLEMENTS, ENSURE, SUSTACAL, AL721. YOU GET THE IDEA. THANK YOU!

THE Vth INTERNATIONAL CONFERENCE ON AIDS

MONTREAL, JUNE 4-9th, 1989

VANCOUVER PWAs TAKE LEADING ROLE

A TEAM OF VOLUNTEERS (PWAs) ARE NOW PREPARING A MAILING LIST of PWA Coalitions and Non-Governmental groups worldwide!

This is being done to foster interest and to solicit proposals that will be part of this very important conference from groups like ourselves that in the past have not always had a strong voice in events like this one.

THINGS ARE HECTIC AS WE'VE BASICALLY DIVIDED THE WORLD INTO regions and each member of the team is responsible for contacting their assigned area. Our own Kevin Brown is being considered as an important speaker at the opening of the proceedings.

THE CONFERENCE'S THEME IS 'AIDS: THE SCIENTIFIC AND SOCIAL Challenge'. That means that non-governmental, PWA and other grass root groups will have a lot more visibility than in the past. If anyone has ideas for Forums, Discussion Groups, or Abstracts, or if you have any questions about the conference, please call the office and ask to talk to someone on our committee. The next planning committee meeting, which our representative will attend, will be in Montreal on January 12th.

> Don D. Programme Committee Vth Int'l AIDS Conference

7.

THOUGHTS ALONG THE WAY: Contemplation in a World of Action

IT'S BEEN A YEAR SINCE I JOINED THE COALITION. AT PRIVATE INNER moments not unlike the rest of you I've been all a tangle of irritations sometimes deepening to hidden and repressed anger: bitterness, disillusion with society and our so-called medical establishment, and with my own rocky core; beating out at the mythological propoganda of the AIDS crisis, and rejecting out of my hand many of its pathetically fabricated and outright lies. Sometimes I cry myself to sleep and say to the stillness of myself inside "what, if anything has been positive about this asymptomatic seropositive, ARC, AIDS epidemic? Hark, perhaps the attempt to remake my life through developing an HIV strategy to save it from mere viral replication and the passage of time. . . Ya! That work is before me as well as the rest of you and it is difficult and serious as well as not completely clear as to how to even plan an HIV strategy. Discipline of mind and spirit, uniqueness of expression, ordering of daily vitamin-mineral-herbal regime, seeking alternative, non-toxic antivirals, and developing the most effective thoughts about my struggle to surviveall of these are the chief things I wish to achieve in my HIV strategy. The best strategy in the beginning is to be able to develop a way to waste less time and to stop procrastinating. Waiting until the last minute is what some of our future problems can be all about while we could be ever mindful in the present.

AIDS 101

OR

THE SECOND INTERNATIONAL AIDS SYMPOSIUM FOR HEALTH PROFESSIONALS

THE SECOND INTERNATIONAL AIDS SYMPOSIUM FOR HEALTH PROFESsionals was held in Vancouver, November 13, 14, & 15, 1988. Sponsored by the B.C. Ministry of Health, the National Department of Health and Welfare, Continuing Education in the Health Sciences U.B.C., in co-operation with St. Paul's Hospital, it was a basic course in the reality of AIDS. The Symposium was divided between Plenary Sessions and the three workshop categories: Physicians, Nurses, and Public Health/Epidemiology. Emphasis fell on the facts as we know them today, basic treatment being used and investigated by the St. Paul's Care Team, and the next target groups; Youth & IV Drug Users. (As to being an International Symposium, representation was from Canada and the United States.) The information presented explained the definitions of AIDS and Opportunistic Infections, their treatments and prognosis, and all that this entails including Home Care, Testing, Law, Ethics, Transmission, Precaution, and Palliative Care.

FOR THOSE OF US ALREADY KNOWLEDGABLE ABOUT THIS DISEASE there wasn't much to learn except how hard our doctors and nurses work against seemingly insurmountable odds. There was almost no hope offered and this was felt clearly throughout the Symposium. Unfortunately the hope, and the very positive cases of long term survival were not explored. Hopefully next time a bit more can be said about the successes people are having, rather than an emphasis on the opposite.

With approximately 500 registrations divided between 25% Drs., 50% Nurses and 25% Others, many from outside the Lower Mainland, it was a sobering experience for most.

DEXTRAN SULFATE REMINDER:

IF YOU ARE INTERESTED IN DEXTRAN SULFATE, WE HAVE INFO-PACS available. Up to this point in time twenty-three (23) people have ordered it for personal consumption and individual use through our amalgamated group. If you think you might be interested in being on our list call the office and request that your name and telephone number be put on our Dextran Sulfate buyer's list. The bulk of these orders have come from Vancouver, but orders are also now being handled from Lethbridge, Calgary, and Edmonton, Alberta as well as Winripeg Man., and Toronto, London, St. Catherines, and Windsor, Ont. If you want additional information call the Coalition and leave a meesage for me. The next deadline order date for Dextran Sulfate is Friday January 06, 1989. Following this the ordering date will be approximately one month later on Wed., Febuary 01, 1989.

> Mark Alternate Therapies

PEOPLE WHO CARE

DR. JOEL EPSTEIN, D.M.D., M.S.D.

THIS GOOD SOUL IS THE MAN TO SEE FOR TREATMENT OF COMPLEX problems associated with HIV. He presently treats at CCA (Cancer Control Agency) and will head the 'High Risk Dental Clinic ' at VGH when it opens.

He's treated my oral KS for over three years. His staff are always friendly and welcoming. Dr. Epstein, in my opinion, is the best in Canada at what he does. He's committed, inquisitive, and brings home to Vancouver the latest treatment methods. This benefits all of us. In the dark old days, when UBC's high risk dental clinic was telling us all to get lost, Dr. Epstein welcomed us without hesitation to his Mouth & Mucosa Clinic at Shaughnessy Hospital. It was the only place in town that would take us. His receptionist, Shamin, took away my fears with her comforting words and loving smile. Dr. Epstein gave me help and hope. In his care I got the best that dentistry had to offer. He's a hero, and he's still there on the front lines today.

Warren Jensen

9.01

IN APPRECIATION OF NURSES

Nurses on the battlefield

Their hearts also get wounded, but they keep working

dreams

that each HIV person they touch

may respond to their human touch

How long

can nurses go on like this

giving strength to provide for our survival

Nurses walk the corridors in white dress with earth and strength - solidly

\$ \$ \$ \$ \$ CASINO NIGHTS \$ \$ \$ \$ \$

DECEMBER 12th, 13th, & 14th WERE OUR NIGHTS AT THE ROYAL DIAMOND CASINO, 535 DAVIE STREET AT RICHARDS. THE EVENINGS WERE PROFIT-ABLE FOR US. THANK YOU TO THE VOLUNTEERS WHO WORKED LATE INTO THE NIGHT AND ESPECIALLY PAUL WHO WAS OUR BANKER EVERY DAY. ALSO A SPECIAL THANKS TO THE MANAGEMENT AND STAFF AT THE CASINO, A VERY PROFESSIONAL AND NICE GROUP OF PEOPLE.

Ongoing Events: NEW MEETING TIMES

10.

DROP IN CENTER / LIBRARY; The Coalition Library and Drop In Center is open weekdays from 1 pm to 5 pm, as well as Wednesday evenings from 7 pm to 9 pm.

MONDAY : MEMBERS MEETING - EVERY SECOND MONDAY OF THE MONTH

We are currently revamping this event. Coming up soon will be 'MONTHLY MEDICAL MEETINGS' between the medical community (ie. St. Paul's AIDS Care Team members) and the consumers of their services (our members and other concerned individuals). Watch the Newsletter for further details.

BODY POSITIVE SUPPORT GROUP: sponsored by AIDS VANCOUVER

(testing HIV Positive) Confidential Discussion Group meets Monday evenings at 8 pm, at Gordon House, 1019 Broughton street . for more information contact Ken Mann at AIDS Vancouver, 687-2437

BUDDY SUPPORT GROUP: for Buddys; sponsored by AIDS VAN.

Meets every SECOND MONDAY AT 7:30 pm, at GORDON HOUSE, at 1019 BROUGHTON.

TUESDAY : PROGRAM COMMITTEE MEETING 11 am - 12:30 pm , Members welcome and encouraged to participate.

PERSONNEL COMMITTEE MEETING : 2:30 pm

You may have a talent or experience that would help. Come and find out.

"LIVING IN THE MOMENT" MEDITATION CLASS: From 2 pm - 4 pm.

This class is open to PWAs/PWARCs, sero-positives, freinds and supporters. For more information and location, please contact Kristin at 872-0431

SUPPORT MEETINGS: Every Tuesday evening from 7:30 - 8:30 pm,

at the Coalition Drop in Center, at 1170 Bute Street. These meetings are open to PWA/PWARCs only. Discussions about concerns held by the group at the time of the meeting. A good place to talk about your fears, conerns, and triumphs.

WEDNESDAY :ADVOCACY COMMITTEE MEETING, 11am-12:30pm

Deals with political and legal issues, members are encouraged to attend and get involved.

:FINANCE COMMITTEE, 2 pm - 3:30 pm

Come and lend a hand, help is always needed.

DROP IN CENTER, The Drop In Center/Library is open

Wednesday evening from 7:00 pm to 9:00 pm, at the Coalition office, 1170 Bute Street. There is no meeting as such, Just an opportunity to meet other PWA/PWARCs, have a cup of coffee, and check out our library. If you can't stop by during the day, make sure you come by Wednesday night.

:HEALING CIRCLE, 7:30 SHARP - 9:00pm in the first floor

lounge of the Comox Building of St. Paul's Hospital. Facilitated by various volunteers, the Healing Circle is open to all members, their friends, supporters, etc. Please support this worthwhile event. PLEASE BE PUNCTUAL.

THURSDAY :BOARD OF DIRECTORS MEETING: 2:30 pm at the Coalition

office. Open to all interested members. This is your opportunity to stay abreast of Coalition activities, and have a voice in our future. The four standing commitees(Advocacy, Finance, Personnel, and Program) are always open to new volunteers, and welcome your participation.

:PERSONNEL COMMITTEE MEETING, 4pm- 5pm

You may have a talent that would help

ut.

:TAI CHI CLASS, At this time Tai Chi class has been sus-

pended. If there is interest shown the classes can continue. If you want to participate, please call the office and express this and we will start a list and endeavor to have this program again.

GET OVER IT: Alchoholics Anonymous Meeting, 7:00 pm

at the Coalition Drop In Center; open to HIV positive, PWA/ PWARCs. friends, lovers, and supporters.

"COPING WITH LOSS AND GRIEF" Sponsored by AIDS VAN.

Meets the FIRST and THIRD Thursdays of each month, from 7:30 to 9:30 pm at ST. ANDREWS WESLEY CHURCH LIBRARY at NELSON and BURRARD. For more information call 299-4828 or contact AIDS VANCOUVER at 687-2437.

(continued on next page)

THURSDAY(cont.) LOVERS, FAMILY AND FRIENDS, Support group sponsored

by AIDS VANCOUVER. Meetings are held every Thursday evening at 7:30 pm in the LIBRARY at ST. ANDREWS WESLEY UNITED CHURCH, NELSON AND BURRARD.

BY APPOINTMENT ONLY:

REIKI: A gentle yet powerful healing art, excellent in the

management of fear, pain, and stress in general. This is FREE to Coalition Members. Please contact Jackie at 683-3381.

HEALING: Healing sessions done privately, in a relaxing,

peaceful environment. Just sit in a chair and be charged with relaxing, soothing energy. For more information, please contact Jackie at 683-3381.

HAIRCUTS: Hairdresser with 18 years experience will cut

your hair at home any evening for \$6.00. Coffee and visit included. Inquire about Perms etc. For more information call Terry at 687-6551.

PASTORAL CARE TEAM: MCC Support Services for those

who are sick, and counselling for those looking for spiritual comfort. Services include: Home and Hospital visits for the sick, spiritual and/or Christian counselling, relationship counselling, and grief counselling. For more information call the office of Metropolitan Community Church of Vancouver, at 681-8525.

PERSONAL: ATTENTION PWA/PWARC's :

juicing it. Wheatgrass is the best natural remedy you can possibly use. It kills intestinal parasites, restores blood, is liquid oxygen - a very good vitamin?mineral and is in fact a complete food. Call Ken Hooker at 685-7920.

PERSONAL: DONATIONS NEEDED: PWA moving into bare apartment. Needs: Desk, Tables, pots & pans, and other kitchenware, Vacuum Cleaner, Floor Lamps & T.V. Thank You. PLEASE CALL THE OFFICE 683-3381

WOMAN WHO IS HIV+

are PWA's. CONFIDENTIALITY RESPECTED. Contact Jackie at the office 683-3381.

HOME TO SHARE ON SATURNA ISLAND

WANTED: PWA WHO CAN TAKE CARE OF THEMSELVES, IS MELLOW, AND COULD HELP CHOP WOOD. TO SHARE WITH A PWA:

FURNISHED 2 BEDROOM COTTAGE

EXCELLENT RETREAT/LIVING SPACE

SHARE RENT/HEAT/LIGHT/WOOD

\$200 PER MONTH

CALL JACKIE AT THE OFFICE TO LEAVE MESSAGE 683-3381

COPING WITH HIVCOPING WITH HIVCOPING WITH HIV

I AM DOING A STUDY TO EXAMINE THE WAYS GAY MEN COPE WITH being HIV+. Information gained from this study will help provide a clearer picture of the needs of HIV+ people and programs that can best meet those needs. If you are an HIV+ gay man who has NOT been diagnosed with AIDS, and if you are interested in taking part in the study, PICK UP A QUESTION-AIRE FROM THE PWA OFFICE at 1170 Bute Street. CONFIDENTIALITY IS GUARANTEED. If you have any questions about the study contact Dean Nicholson at 736-0445 or leave a message at 228-4756. Thanks.

Thanks, DN 13.

AIDS UPDATE

THE NOVEMPER <u>BETA</u> (ISSUE#2) (BULLETIN OF EXPERIMENTAL TREAT-MENTS FOR AIDS), published by the San Francisco AIDS Foundation, provides a very easy to read comprhensive survey of 14 anti-virals that are currently available, being tested, or on the horizon for HIV infection.

THEY RANGE FROM LOW DOSE AZT, DEXTRAN SULFATE, AL721, CD-4. Asummary chart describes how the treatment appears to work, its availability, cost, how administered, side effects, and comments.

COPIES OF THIS ISSUE ARE AVAILABLE IN OUR LIBRARY.

PEOPLE SAY THAT WHAT WE'RE ALL SEEKING IS A MEANING FOR LIFE. I don't think that's what we're really seeking. I think that what we're seeking is an experience of being alive, so that our life experiences on the purely physical plane will have resonances within our own innermost being and reality, so that we actually feel the rapture of being alive.

> Joseph Campbell Mythologist

"LOVE IN MOTION": WHAT A FANTASTIC SHOW!!

ON FRIDAY DECEMBER 23rd, A BENNEFIT CONCERT WAS HELD at the Commodore Ballroom to raise money for the purchase and installation of a chairlift to make the GLC and the PWA Society offices accessible to everyone.

THE SHOW WAS WONDERFUL! SOME OF VANCOUVER'S BEST TALENT performed that night on the Commodore stage. The artists contributing their best were: LONG JOHN BALDRY, DAVE TAYLOR, JIM FOSTER, JOANIE BYE, JOHN ELLIS, LORI PAUL, LEE VAN DIVER, AMANDA HUGHES, KIRSTEN NASH, DARYL BURGESS & THE RYTHYM SNAKES, AND MARK HASSELBACH.

A SPECIAL THANKS GOES OUT TO LORI PAUL FROM ALL THE MEMBERS of our Society for the great show and the professional job she did in producing it, and also thank you to all the other people involved behind the scenes. We'd like to encourage Lori and friends to consider us again when planning the next show; we are very lucky to have your support.

MANY, MANY THANKS TO A VERY SPECIAL PERSON

OUR HEARTFELT THANKS GO OUT TO WARREN ROBERTSON AND the many people who help him to raise money for, and deliver Christmas hampers to PWAs. This expression of caring was much appreciated by those who recieved the hampers, which were very well put together. You know how to shop! Thanks again from us.

WISH LIST

THE VANCOUVER PERSONS WITH AIDS SOCIETY IS ALWAYS IN NEED of various items to help our volunteers to do their work and to make our offices a good environment for counselling and information gathering. SOME OF THE ITEMS WE NEED ARE:

TYPEWRITER PAMPHLET RACK DESKS FILING CABINET COMPUTER COMPUTER PROGRAMS 35mm CAMERA (AUTOMATIC) SHELVING

IF YOU ARE THINKING OF DONATING SOMETHING TO THE SOCIETY please consider some of these items. THANK YOU.

THANK YOU!! Thank you so much to the anonymous person who donated the colour TV for our Library/Lounge. It is a valuable addition and has been used a lot both for viewing video tapes from our Library and our Friday night video movie nights. Thanks again!

NEW ADDITIONS TO OUR LIBRARY

HERE ARE SOME OF THE NEW ITEMS THAT HAVE BEEN ADDED TO THE LIBRARY RECENTLY:

AIDS: A Guide for the Primary Physician. Edited by King K. Holmes MD, Ph.D & Arno G. Motulsky MD,Sc.D. University of Washington Press, 1987. AIDS/HIV Experimental Treatment Directory. Compiled & Published by American Foundation for AIDS Research (Am FAR) August 1988

Living With Dementia. by C.J. Gilleard. Charles Press 1984

Beyond AIDS: A Journey Into Healing. George Melton & Wil Garcia

Brotherhood Press. 1988

How to Cope With Your Doctor. by Bernard Virshup, MD

Praxis Press. 1985

The AIDS Fighters: The Role of Vitamin C and Other Immunity-Building Nutrients

Ian Brighthope, MD & Peter Fitzgerald. Keats Publishing. 1987

The Anti- Psychiatry Bibliography and Resource Guide. by K. Portland Frank

Press Gang. 1979

Fighting Depression. by Harvey M. Ross, MD . Larchmont Books 1987

If Only I Could Quit: Becoming A Nonsmoker. by Karen Casey

Harper/Hazelden. 1987

Minding The Body: Mending The Mind. by Joan Borysenko, Ph.D

Bantam New Age Books. 1987

AIDS: A Handbook for Professionals. Edited by Donna Snowden & David F. Cassidy. Carswell. 1989

Reflexology: The First Steps. by Yvette Eastman Ptarmigan Press. 1985

AS WELL AS THE ABOVE THERE ARE OTHER ADDITIONS IN THE way of audio and video tapes and books being added all the time. COME IN AND CHECK THEM OUT

"LIVING WITH AIDS" AVAILABLE FROM US FOR A REDUCED PRICE.

"Living with AIDS: Reaching Out" by Tom O'Connor through a generous donation from the author is now available from PWA for \$14, this very informative handbook which covers topics like; Nutrition, Stress, Diet, Opportunistic Infections, Physicians and other health-care providers, and Vitamins among other topics is an excellent book to have around for reference. Regularly approx. \$24 this book is available for only \$14 while supplies last.

AZT BILLING UPDATE

ON THE 13th OF NOVEMBER, 1988, KEVIN BROWN, AN UNNAMED person, and the Vancouver Persons With AIDS Society launched an action in the SUPREME COURT OC B.C. to seek relief from the provincial government's unique AZT billing policy. B.C. is the only place in Canada where people are being billed for this expensive drug. The provincial government has refused to accept the advice of many people and has let this situation continue far too long. In the meantime we continue to encourage all those affected to ignore all bills for AZT. IF YOU HAVE ANY CONCERNS OR QUESTIONS, PLEASE CALL US.

WHAT YOU MAY NEED FROM A LAWYER :

IN ORDER TO HELP PEACE OF MIND AND TO REMOVE YET another source of stress in our lives, it is a good idea to have our 'affairs' in order. There are several documents necessary to retain control in a future of uncertainty.

POWER OF ATTORNEY

ENDURING POWER OF ATTORNEY FOR HEALTH CARE

LIVING WILL

NOMINATION OF COMMITTEE

LAST WILL AND TESTAMENT

Information on these documents is available from the Coalition office. We are also currently looking for Legal Services for our members.

ROBERT SALKELD DECEMBER 12, 1955 - DECEMBER 1, 1988

Bob died at 6:30 AM on December 1st, 1988, at St. Paul's Hospital, with his good friend David caring for him. Throughout his peaceful transition, Bob was alert and comfortable. When I saw him two days prior, he said he was content and prepared, but hoped to live to see his 33rd birthday.

Bob did a lot of work for our society on our computer. In fact, Bob knew more about computers than any of the rest of us. A self confessed workaholic, we would often question him on when he'd eaten last and when he'd last rested. Being needed gave him his reason to press on. Cheerful, friendly, and knowledgeable about many things, we didn't know him long, but we sure miss him.

ART PSYCHOTHERAPY GROUP STARTING:

WE ARE PUTTING TOGETHER AN ART PSYCHOTHERAPY GROUP TO meet on Thursday evenings (7:30pm) in one of our offices. The group will be facilitated by Noel, an Art Therapist in training.

ART PSYCHOTHERAPY IS AN IMPORTANT PREVENTATIVE, INTEGRATIVE and healing tool. In a safe nurturing environment, people spontaneously create art, using pastels, paint or clay. ARTISTIC SKILLS ARE NOT NEEDED to express moods, relive dreams or recreate life events. Subjective experience of the art is more important than the finished product. With this focus, one gradually discovers personal symbolic language. People who experience language as an inhibitor find satisfying expression in art. Extemely verbal people who use language as a barrier from emotions, find release in art, and gain a deeper understanding for themselves.

THE USE OF ART AS THERAPY IMPLIES THAT THE CREATIVE PROCESS can be a means of both reconciling emotional conflicts and of fostering self-awareness and personal growth. Using art as a vehicle for psychotherapy, both art and the verbal associations are used in an effort to help the individual find a more compatible relationship between inner and outer worlds.

THE PWA GROUP WILL BE STARTING SOON AND IF THERE IS ENOUGH interest a second group can be started. Please call the office to sign up or for more information.

DAN'S DEAD

Well, here I am, dead at 33. Yeah, I'm pissed off about it. I thought, being the Rebel that I was, that I could beat this bitchin' disease. I know one of you out there will do it soon, though. Never lose faith.

And even though I didn't become famous, it occurred to me that I did get rich.

My life was filled with vibrant and colourful emotions, buckets of tears and barrels of laughter and yes, real good sex too!

To all of you who played a role in my life, large or small, rocky or smooth, I thank you.

The experience was good for me. Hope I was good for you.

Love to all you Earthlings - love each other - and never forget "WE ARE THE CHAMPIONS OF THE WORLD".

DANIEL G. JOHNSON - THE WARRIOR

JANUARY 5, 1954 - NOVEMBER 15, 1988

LETTER TO THE EDITOR

18. EDITOR:

IT WAS WITH SOME ALARM THAT I READ THE ARTICLE "CONVINCING Your Friends To Take The Test" in issue #26, (November 1988) by the acronym M.A.P.. I feel there needs to be some balance and thought given to the complex issues involved with antibody testing and disclosure of the results, whether the results are negative or positive.

AIDS is a difficult and threatening issue to a lot of people in the world. They react with blame, anger and denial. Each one of us, regardless of our status, race or gender, is vulnerable to acts of isolation, homophobic violence and discrimination. One of the gravest concerns about testing is the lack of confidentiality of those results, and the ensuing damages to people without specific legal and constitutional protection.

Certainly the HIV antibody test has a great value in screening blood and body tissues, to help ensure the greatest safety to members of society at large. As well, there are people who need to know the possible risk of transmission when considering such things as pregnancy. Many doctors find a positive test result helpful in diagnosing HIV infection and AIDS, although the Centre for Disease Control has not yet required a confirmatory antibody test for several years.

M.A.P. claims a positive result, without intervention, is "the empirical indicator" of AIDS. This is not so; it simply reveals the presence of antibodies to HIV. If someone is positive, we presume that individual is HIV infected, and infectious. Being antibody positive does not mean an individual has AIDS. Not everyone is HIV infected develops AIDS, just as not everyone with AIDS dies.

As inconclusive as a positive result may be. it is questionable what a negative result would mean. Obviously that individual had no antibodies at the time of test was taken, but that does not mean that the person is necessarily without infection. It is commonly understood that the average human body takes between 3 and 6 months from initial exposure and infection until they create antibodies to HIV, some individuals take longer, and a few people may never develop antibodies. A person with a negative test result may feel a sense of relief and security: they missed it so far, they will continue to be safe. Studies have shown that many people with a negative test result eventually relax their guard and do put themselves at risk again, somewhere, after the test result.

The real issue is when and how people put themselves at risk for HIV infection, or any other of many serious STDs, and how to be convinced that no matter what their test result, everyone needs to practice Safer Sex guidelines each and every time.

Probably the sooner anyone starts to make changes in their life, with the goal of personal health enhancement, the better that will be for them. Obvious items on many people's checklist include: improving diet, sleep and relaxation, exercise, reducing drug and alcohol use, and effective stress management. It is not always true that the earlier someone takes a drug, the better their medical results will be. This was not true of Suramin and several other experimental drugs that have been used for people with AIDS, or other infections in the past.

Letter to the editor cont'd

Nor is it accurate to suggest that seropositive people have a lot of drug therapy options open to them. AZT is the only authorized drug being used in Canada, and is only an option if the individual meets the clinical requirements of a low T4 count (below 300) and specific infections. The protocol requires a confirming antibody status test result. Many people consider getting involved with other antivirals such as Dextran Sulfate, AL721, Iscador, Ribavirin or other substances. It is a complicated decision to use antivirals and is best made with a physician's on-going supervision and after careful consideration of various test results.

Tom O'Connor's book "Living With AIDS", and publications like "Treatment Issues" and "Body Positive" from New York and "BETA", "D.A.I.R. Update" and "Healing AIDS" from San Francisco, and the AmFAR Directory to name only a few, offer extensive listings of many other therapy possibilities such as vitamins, holistic support, research, attitude and spiritual healing.

Taking responsibility for our individual and collective health should not rely on the realization that we may be infected with a potentially fatal infection. AIDS is a sexually transmitted disease, and it can be prevented. Everyone can both celebrate our sexuality and insure that no one, especially young gay men, are at risk for any infection by following Safer Sex guidelines every time.

Thank you for allowing a wider consideration of some of the initial issues involved with testing. I hope we will continue to give due consideration to any issue before we make grand presumptions or universal recommendations.

Sincerely, Ken Mann, facilitator Body Positive Support Group

NOTE FROM M.A.P: The above letter mis-interprets, and takes out of context, a quotation from my article in the PWA Newsletter (Issue #26, Nov./88) entitled <u>Convincing Your Friends to Take the Test</u>. Ken Mann says in his fourth paragraph, that "M.A.P. claims a positive result, without intervention, is, "the empirical indicator" of AIDS". Mann fails to quote the entire sentence and takes three words out of context and merely puts quotation marks around the three words. This is utter carelessness, and sad misrepresentation on his part. What M.A.P. does say is that, "It is the empirical indicator of <u>whether</u> you may go on to develop AIDS if you do not intervene in your infection."

M.A.P.

PLEASE NOTE: BODY POSITIVE DROP-IN STARTS FEBRUARY 18th

THE BODY POSITIVE GROUP, A SERVICE OF AIDS VANCOUVER IS going to be using the PWA Coalition Lounge and Library for a Drop-in on Saturdays from 11:00 am to 3:00 pm. This is open to everyone, PWAs included, but especially HIV+ persons who would like information and be able to talk to someone about HIV infection, treatments, healthy lifestyles, safer sex techniques and other concerns.

New GM

THE VANCOUVER PERSONS WITH AIDS SOCIETY IS HAPPY TO ANNOUNCE THE HIRING OF OUR NEW GENERAL MANAGER.

CHRISTOPHER SABEAN COMES TO US FROM A BACKGROUND in law and is well qualified to fill this position. We look forward to working with him to improve and expand our programs, program delivery and services.

Hiring Committee

The butterfly finally emerges from the cocoon -

only to realize he will live but 7 days.

This doesn't seem to hinder him though,

in his quest to taste all that is beautiful.

He flaunts his own beauty -

knowing it is short lived --- but hard won.

In that cloistered place of his own design.

Daniel Johnson — The Warrior

ONE THING THAT COMES OUT IN MYTHS IS THAT THE BOTTOM OF THE abyss comes the voice of salvation. The black moment is the moment when the real message of transformation is going to come, at the darkest moment comes the light.

> Joseph Cambell Mythologist

THE VANCOUVER PERSONS WITH AIDS COALITION NEWSLETTER IS PUB-LISHED MONTHLY BY THE VANCOUVER PERSONS WITH AIDS SOCIETY: P.O. BOX 136, 1215 DAVIE STREET, VANCOUVER B.C. V6E 1N4, CANADA. OUR OFFICE ADDRESS IS SUITE #1, 1170 BUTE STREET, VANCOUVER B.C. PHONE 683-3381. THE VANCOUVER PERSONS WITH AIDS SOCIETY IS A REGISTERED NON-PROFIT SOCIETY (REG.#0760124-11-27)

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