



# Newsletter

## COALITION ENTERS FIELD OF AIDS THERAPY RESEARCH

BY NICHOLAS GRAY

Proving once again that we are Persons with Ability, the Vancouver Persons with AIDS Coalition took a major step last week in enhancing it's own empowerment by approving funds to begin a pilot research study into the effects of Egg Lecithin ( AL-721 ).

In the absence of government research, or support of that research, ( it seems the Federal governments interest into AIDS therapy began and ended with AZT ), and after months of personal study and communication with the New York PWA Health Group ( which also runs it's own study ), Kevin Brown, at the August 9th business meeting, that we wait no longer for government action, take the power into our own very capable hands, and fund a limited trial of Egg Lecithin ( AL-721 ).

Egg Lecithin ( AL-721 ), developed several years ago at the Weizman Institute in Israel, is a potent form of lecithin derived from the yolk of eggs. Completely natural, it comes into Canada as a food product, and appears to provide benefits without any damaging side effects. In a nutshell, Egg Lecithin removes cholesterol from the outer membrane of the cells ( T-cells and possibly the virus ), increasing fluidity of the membranes, and apparently making it harder for the viruses to find a receptor site on the T-cells - part of the process by which they infect the cell. New York has been involved in this research for several months now, with encouraging initial results. ( More information on this study, and Egg Lecithin is available in the office. ) continued on page 2

Dr. Karen Gelmon, from the AIDS Care Team, has agreed to be our medical consultant and advisor. Because of the expense and accessibility of the substance - it must be brought in frozen from the United States at a cost of roughly \$200.00 US per Kg. - our study will be small but significant. Initially the study will include a cross section of from seven to ten PWA/PWARC's, to be monitored by Dr. Gelmon for a period of three months. Protocol for the study is being established now, working with Dr. Gelmon, who is currently creating a proposal for a larger study of Egg Lecithin to present to the Federal government for approval and funding. However, Dr. Gelmon believes that approval of the larger study will take a minimum of six months. We at the Coalition hope that our study will not only provide data to bolster Dr. Gelmon's proposal, but make a clear statement to the government, medical community, and the public that people with AIDS are actively taking a part in the research, funding and practical application of handling this disease.

With our study we also hope to create an awareness, in the minds of the public and the media, of the appalling lack of serious research into AIDS therapy in Canada. Our government has displayed no genuine leadership in the field of research, instead choosing to distract the public with much heated debates on condoms and quarantine, while daily the death toll mounts.

Personally it gave myself, and others present, a great sense of power to initiate a project of this sort. Immeasurable credit must go to Kevin Brown for steadfastly researching and following the Egg Lecithin concept, and to the community, without who's fundraising efforts we would not have had the money to embark on such a project. We are proud of ourselves and the community for this demonstration of empowerment.

Those interested in participating in the study, or in seeking information should contact Kevin Brown through the Coalition office, 683-3381.

#### ADDITIONAL DRUG UPDATES : by Kevin Brown, Greig Layne and Nicholas Gray

##### DTC ( Imuthiol ) : Promising new drug!

The Coalition has received interesting news on DTC ( Imuthiol ), which acts as an immune modulator. A double blind, placebo controlled study of 90 patients with ARC in five centers in France showed impressive improvements in all areas, after only four weeks, with no significant side effects. Not only did symptoms in the treatment group improve, but T-helper cells increased dramatically, and these T-cells appear to be viral resistant!

DTC appears to be completely safe, is taken orally, costs almost nothing to manufacture, has shown major clinical benefit in a well controlled trial, and would probably work even better if combined with antivirals.

The Coalition is working on obtaining more information. Interested parties can contact

## DRUG UPDATES : continued

Kevin Brown at the Coalition office - 683-3381

### DDC :

Widely talked about as a replacement for AZT, DDC is an antiviral that works on the same theory as AZT - providing a false building block for the virus - but is seen as likely to be more effective, and it appears less toxic in current human trials, with a temporary skin rash the biggest problem to appear thus far. DDC has the same institutional push behind it as AZT, and will probably move through testing relatively quickly.

### AEROSOL PENTAMIDINE :

Good news for those of us that have had PCP and wish to avoid it! Interest is rising for using Pentamidine in an aerosol form ( you would inhale the drug once a week ) to act as a prophylaxis to prevent a recurrence of pneumocystis pneumonia. Many of us with PCP cannot tolerate Septra or Dapsone on a continual basis, so aerosol Pentamidine is a great option, especially since it has no side effects and is easy to use! This treatment is getting rave reviews from the New York Coalition and we in Vancouver have lobbied like hell to try it here. Dr. Lindsay Lawson has shown interest in this new treatment, and has submitted a proposal to Ottawa for its use. With luck, we may have it here in a few weeks.

### ANOTHER AZT UPDATE :

In our August Newsletter, we reported that restrictions on the use of AZT were being relaxed, and that anyone from sero-positive to AIDS could receive the drug upon approval from their doctor. This information was given to us by Burroughs-Wellcome when their representatives were in town on a Canada wide P.R. sweep. The truth of the matter is that AZT is still classified as an experimental drug in Canada, and can only be given within the confines of a study. It is available to someone who is sero-positive and has a helper cell count of less than three hundred. So, while it is true that the drug is available to a wider range of people, it is not available to someone who has only tested positive. More information can be obtained through Sharon at the office.

### MEETING WITH BURROUGHS-WELLCOME REGARDING AZT :

On tuesday, September 22nd, representatives from the Burroughs-Wellcome Company, will be in Vancouver to answer any questions you may have about the anti-viral drug, AZT. Joining us at our tuesday evening support meeting will be representatives from the companies medical department, and one from their marketing division. They will be prepared to answer any and all questions we have about the drug, so if you have some be sure to be there. That's Tuesday, September 22nd at 7:30 pm, at St. Paul's Hospital, Comox Building, Room LM-5 ( in the basement ). If you already know what your questions are, give Sharon a call and let her know, and then the representative can be prepared with an answer. ( Sharon can be reached at 683-3381 )

## TWO BENEFITS FROM CAST OF "CATS" :

Two benefits put on by the cast of "CATS" highlight this month's social calendar.

The first, a special performance of the hit play "CATS", happens August 30th, and monies raised will go to AIDS Vancouver. An after theatre party at Graceland should cap an exciting, high energy evening. Every person involved with "CATS", from ushers to performers have donated their time and effort to the evening. The City of Vancouver has waived rent on the theatre for the evening, and one generous, unnamed individual has sponsored enough seats to allow all PWA/PWAR's the opportunity to see this very special performance.

The following Sunday will find many of the same performers shedding their catskins to resurrect Hollywood legends at "CATS Hollywood Canteen". The brainchild of cast members Liza Balkan and Blaine Parker, this cabaret style show will happen at midnight, after the regular performance of "CATS", and will feature most of that cast, joined by members of the Art's Clubs current hit, "Black and Gold Revue", with Billie Monroe on hand to oversee everything. Cast and crew, who again got all services and space donated for the event, are excited about this unique evening to benefit the Vancouver Persons with AIDS Coalition. Tickets are available for \$20.00 at Little Sister's ( 669-1753 ) Art's Club ( 687-1644 ) or the Coalition office ( 683-3381 ) - and that's Sunday, Sept. 5th, at Midnight at the Art's Club Theatre on Granville Island.

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## HOT HEAVENLY BODIES :

A solid cross section of the community showed their support on August 8th, as the PWA Coalition unveiled their Hot Heavenly Bodies evening of entertainment and dancing at the Commodore Ballroom. Over \$4,000.00 was raised, and the Coalition extends its thanks to each individual who contributed to the creation and execution of a very successful evening - the Bovines, Buddy's Fitness Club, David Charlton, the amazingly dexterous K.C., Nicholas Gray, and of course, Billie Monroe. Extra special thanks must go to Ray Kilback, Taavi Nurmela, and Sharon Holtzberg who took the night from a concept to a reality, and to John Kozachenko, who personally sold over \$1,200.00 in raffle tickets.

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## BABA TAAVI'S SPIRITUAL CORNER :

As you walk through the rich flower garden of life, imagine what kind of flower you might be ; a gracious rose, an amusing daffodil, a stately lily, a charming Venus flytrap, a distinctive skunk cabbage, some vile fungus under a log..... OOOOPS! Oh well.... radiant blessings to all.

BABA TAAVI

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## **McLAREN HOUSE OPENS : by Brian Peel**

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The Housing Committee of AIDS Vancouver has announced the opening of the first housing facility for PWA's in Vancouver. The house - to be called McLaren House after the late PWA, Ted McLaren - is an older, five bedroom home in the Shaughnessy area. It is set in a third of an acre of garden with mature apple, pear and plum trees. The balance between proximity to downtown and the feeling of privacy and seclusion is unique.

Admission to McLaren House will be based primarily on financial need : rents will be fixed at 25% of the individuals total monthly income. A persons ability to live successfully in a group home setting will also be important to the selection process. The Housing Committee has adapted material from the Shanti Project in San Francisco to provide a loose framework of guidelines, but it is hoped that the residents themselves will set most of the house rules. To this end, residents meetings will be held on a weekly basis, and the house is expected to be self governing.

Although McLaren House won't be staffed as such, homemaking and nursing care will be available through the public health department. Cleaning and gardening crews from AIDS Vancouver will maintain the house and grounds, and volunteers will be on call to provide any of the basic support tasks.

Referrals for admission to McLaren House have been made as broad based as possible, and self referrals are strongly encouraged. If you are interested in the possibility of living at this group home, contact Brian Peel at 687-2437 or 687-5220. The doors open September 1st.

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## **AD HOC COALITION FORMS :**

Reaction and opposition to Bill 34 ( Quarentine legislation ) continues to grow, and steps were taken August 13th to present a structured attack on the proposed bill. The unnamed Coalition, while formed to battle the current proposals, intends to remain intact to confront additional issues as they arise. While statements were made to the press after the meeting, this and additional meetings will be closed to the media. All parties interested in involving themselves with this lobbying effort are invited to attend. The August 27th meeting will name the Coalition, and hear reports from various sub-committees formed to investigate strategies to present a unified, effective opposition. That meeting is from 7:30 to 10:30, at St. Paul's Anglican Church, 1130 Jervis. For more information contact Joie Davis at 682-1044.

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## **ST. PAUL'S INFECTIOUS DISEASE CONTROL CLINIC :**

It's morning, you feel like shit, and you can't get in to see your own doctor. Sound familiar? Despair no more. The infectious Disease Control Clinic at St. Paul's will see to your medical needs. Remember that the next time you don't feel so hot.

## AMENDMENTS TO THE HEALTH ACT :

Most of us should be aware of the implications of the amendments to the Health Act - possible isolation, quarantine, and disregard for civil liberties. Faced with these worst case scenarios, the Coalition has been busy fighting for our rights! We have lobbied, by direct letter, every MLA in British Columbia, expressing the views of PWA's on these amendments. We feel that when Bill 34 comes before the legislature this fall, it should generate interesting debate. Kevin Brown and Sharon Holtzberg have also secured a meeting with the provincial Minister of Health, the Hon. Peter Dueck, to take place in Victoria on August 27th. These amendments will be discussed, as well as a possible solution searched for. Details of this meeting will be in the next newsletter.

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## ALCOHOLIC'S ANONYMOUS AND HIV : by Greig Layne

For some people, news that their health can no longer be taken for granted, may bring on the realization that they have a problem with alcohol. Others, who have managed to stay sober in A.A., may feel the need to discuss issues around their health, sobriety, and the virus. To meet this need, an Alcoholic's Anonymous group has formed for people who are HIV anti-body positive, PWA, and PWARC. The group meets Thursdays at 7:00 pm, in the Living Room of the PWA Coalition office, 1150 Bute Street. For additional information contact Greig at 682-8066.

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## LEGAL SERVICES NEEDED :

The Coalition has been providing free legal services for PWA/PWARC's wishing power of attorney and/or wills. Our lawyer is now becoming over extended with the numerous requests. If you are a lawyer, or know of someone who is, and would like to do volunteer work on a very flexible schedule, please contact Sharon at 683-3381.

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## CHARITABLE TAX STATUS AND MORE!:

At last, the Vancouver Person's with AIDS Coalition has been granted charitable tax status. What that means is all your generous donations are now tax deductible..... And we have more space! Cramped for too long in one room, we have now moved our library and drop in facilities next door, giving Sharon some privacy to do her work, and creating a comfortable space for discussion that require a little privacy.....and speaking of comfortable, now that we have this extra space, we need a couch. Something clean, attractive and functional would be most welcome. If you have one, call Sharon at 683-3381.....And while we're asking, our library could use an infusion of books. If you have any books relating to AIDS, health, diet, spirituality or any subject that will enhance the quality of the PWA/PWARC's life, and your no longer using them, we would appreciate having them in our library. Again, if you have some, call Sharon, 683-3381. ....and Mary at Nature's Energy Food on Denman at Robson now carries Louise Hay tapes.

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## AIDS : THE NEW EPIDEMIC : a video review by Bill Iver

What's more boring than sitting in a classroom listening to a gray coloured man with a piece of chalk drone on in front of a black board? Watching it on video, that's what. This is the basic format of " AIDS: THE NEW EPIDEMIC ", the B.C.'s government's long awaited AIDS education program, available free for some time now at video stores. A combined effort of the Provincial Ministries of Health and Education, the video assiduously avoids everything humanity has ever learned about either effective education, or engaging television production.

The program is introduced and prodded along by that bumptious trendoid with the chipmunk smile, Stu Jeffries of " Good Rockin' Tonight ". Alas, even he can do little to spring this turkey from it's cry-o-vac coffin. So there we are, in a Victoria High School Classroom, listening to Dr. Micheal Rekart, Director of the B.C. governments AIDS program, expounding on AIDS in front of his chalkboard. As an effective T.V. personality, Rekart is reminiscent of Dick York, as the first Darren on " Bewitched ", with about half the charisma. The mostly gray nerd costume doesn't help much either. Perhaps if he were from Thunder Bay.....

So..what is the good doctor saying? Well, some standard info, accurate and dry as dust, about what AIDS is and how you might get it..all worthwhile and useful information. But, there are a number of problems. Rekart toadies to the party line in his emphasis on abstinence as the only truly effective method of AIDS prevention. It certainly is sure fire, but nearly 5 billion people on earth today can testify to it's effectiveness as birth control. It's hardly realistic to expect abstinence to make much of a dent in the spread of AIDS.

So, condoms. What about them? Rekart is very iffy, even if you use them with spermicide. Better than nothing, but not much, is the message here. That is about it for the " alternatives " department, with one exception, and it is emphasised over and over again, and that is: NO ANAL SEX, NO WAY, NO MATTER WHAT! While passing mention is made of transmission through parts of the vagina and male urethra, the message that comes thundering home is that anal intercourse is always deadly. Because of the overstated case, hammered home again at the end of this production, I believe that one could easily infer that sex is ok as long as it's not anal. The real facts show that cervical and uterine linings are possibly every bit as receptive to HIV infection as the linings of the rectum. But the blue meanies, in their frenzy of homophobic possession, would leave us the impression that the only dangerous sexual act is anal sex.

To leave teenagers with this warped impression is not just neglectful, it is downright dangerous. We cannot afford to pussyfoot with this disease, and we must make sure of exactly what we mean to say or imply in any education program. There is no room for wrong impressions or distorted inferences here. So, on a note of doom, with no mention of safe sex, good nutrition, or examples of PWA's who haven't up and died, and without a glimmer of hope or optimism, this turgid video grinds to it's dismal end. As a teacher I am appalled by the dreariness of this production as an educational tool. As a gay PWA, I am frightened by it's implications towards my community. And, as a taxpayer, I feel ripped off by this shoddy little effort. Shame on you, Victoria. This is not good enough. We all deserve better!

## ONGOING EVENTS

### MONDAY : Business Meeting : 11:30 am :

Open to PWA's and PWARC's. This is the best way to share the responsibility and decisions in the Coalition. Meetings are held at the Coalition office, 1170 Bute St.

### TUESDAY : Self - Support Group : 7:30 to 8:30 pm :

Open to PWA's and PWARC's only. Focus is on emotional reactions to specific topics.

- Sept. 1 : Political Aspects of having AIDS  
Sept. 15 : Creative Visualization and the Healing Process  
Sept. 29 : Sexuality

### TUESDAY : Holistic Therapy : 7:30 to 8:30 pm :

Open to everyone. These meetings explore a holistic approach to health.

- Sept. 8 : Melita LaRose discussing " Factor One Herbal Blend ", and it's role as a lymphatic cleanser,  
Sept. 22 : Special Meeting with Burroughs Wellcome regarding AZT.

Tuesday night meetings are held at St.Paul's Hospital, Comox Building - 1056 Comox, Room LM-5, in the basement.

## MAN MIRROR

Let me be your man mirror  
throwing back to you  
all the wonderful things  
that you really are  
as though they were mine.

And you be a mirror for me,  
from which our collective goodness  
reflect its images  
onto and into itself  
until the sources of goodness  
are lost  
and the number of reflections  
becomes infinite.

## PERSONAL NOTES :

GWM, ARC, living in Okanagan, needs contacts with other ARC's by mail or phone. It can be lonely here! contact Larry Stevens 102 Westview Village, 1999 Highway 97 South, Kelowna, B.C. V1Z 1B2 ( 769-7453 )

PWA ( Punk with AIDS ) needs temporary living space - Sept. 1st to Oct. 1st - Witty, working and smoking preferred. Contact Daniel 683-0414.

WANTED : Photographs of PWA Coalition in this years Gay Pride Parade. Contact John at 683-7777

General Practitioner in methods of healing involving psychology, philosophy, Imagery, and hypnosis willing to teach such techniques to a small group in workshops every two weeks in Vancouver. If interested please call Dr. Damian Metten at 247- 8522.

Airline steward/nurse who frequently travels between Vancouver and Switzerland seeks a PWA with no family here to move to Switzerland to be cared for by him in his home. Until Oct. 3rd contact Eric Muller ( 325-9666 ) 705 West 68th Ave., Vancouver B.C. V6P-2T3 after Oct. 3rd, write Eric Muller - Weierlimattstr. 15B CH-4514 Lommiswil SO, Switzerland.