



Newsletter

PATRONAGE FOR EGG LECITHIN STUDY SOUGHT

by Nicholas Gray

After lengthy research, approval for funding (by the PWA Coalition), protocol development and participant selection - the Egg Lecithin Study (AL-721) has begun. It was delivered hassle free through customs, and presented to an eager press at a news conference held at the Coalition office on September 24, 1987.

Interest in this new therapy is high, both in Vancouver and across Canada. Inquiries are coming in from across Canada, and we encourage those interested in the product to contact us for an information package that will explain what it is, where it comes from, what it does, how to use it, and the protocol to obtain it.

Due to financial limitations, the current study is limited to ten participants that were chosen by lottery. It is our hope that we can expand the study as funding becomes available. Currently we are supported by donations from the Vancouver community. Concerned people have made this possible, and all of us at the Coalition extend our thanks for that continued support, and we are looking into alternate methods of expanding the study.

One concept for expanding the study is to solicit patrons from the Vancouver populace at large, to sponsor an individual PWA/PWARC to enter this study. Cost to patrons will be approximately \$102.00 per month, per person. If you are interested in sponsoring a PWA/PWARC, or want more information about Egg Lecithin, contact Kevin Brown through the Coalition office, 683-3381.

WE DESERVE A BREAK TODAY !

If you are reading this, then you are not with the 24 PWA/PWARC's taking a much needed break from the city. Thanks to the planning efforts of Warren Jensen, Nicholas Gray and Garry Andrews, the originally planned group was able to swell from 15 to 24 leaving home no one that had expressed a desire to go !

COALITION MEETS WITH BURROUGHS WELLCOME : report by Nicholas Gray

An informative, productive meeting was held Sept. 22nd at St. Paul's Hospital between a capacity crowd of Coalition members and representatives from Burroughs Wellcome. Chaired by Greig Layne and arranged by Benoit Lantier, the evening, while not answering all our questions, established a rapport with the company, who gave and received feedback, and opened lines of communication for the future.

The primary reason for questions left unanswered, or inadequately answered is - and we must continue to remember this - that this is a study. As a study it has been set up to establish certain data over a controlled length of time, number of people, and quantity of drug. It would be unfair and unprofessional for the company to report trends as they see them - however encouraging they may seem. Trends can change, and the study must be complete to provide data that we can base future decisions on. Too many times in the past trends have been reported, hopes have been raised, and then we (the proposed recipient of the drug) get frustrated when the drug is not released or pulled from release. DDC is a current example of a drug showing great promise and low toxicity, only to be recently revealed to create severe neurological disorders. Retrovir has only been clinically studied for two years. The need for hope pushed it quickly through many protocols for its release. However, studies need to continue, or we will never have complete answers to our questions.

Here are some of the questions we do have answered :

- Since Nov. 1986, 426 participants have engaged in the Canadian Retrovir studies. Of these, 30% are currently still on full dose - 1200mg per day - although 60% of this group has had to temporarily discontinue use due to hematological toxicity or opportunistic infection. Retrovir appears to retard the replication of the virus. It does not appear to prevent any opportunistic infections.
- Dosage was determined through previous studies. The first double blind placebo study used 250 mg administered every four hours. It was determined that 200 mg every four hours was just as efficient. The four hour regime was based on the concept that we should maintain minimal levels of Retrovir in our blood constantly (locally, this theory is disputed), and taking it every eight hours, the drug levels went below efficient levels. Studies are ongoing regarding six hour dosages as well as the efficacy (Linda Houle's favorite word!) of lower dosages. (daily totals of 400-600-800 mgs)
- Toxicity was the big question of the evening of the evening. How toxic is it now, what ill effects can occur if we go off, (temporarily or permanently), etc. The main toxicity concern is hematological, and that is why our blood levels are of great concern to the study. Levels must be monitored so that irreversible bone marrow damage does not occur. Most side effects reported (anemia, fatigue, nausea, rashes) have been reversible by adjustment of dosage or removal of a secondary medicine. Some drugs are totally non compatible with Retrovir, Ribavirin being the most obvious. Studies are now underway between Retrovir and Pentamidine, Septra, Dapsone, Ampligen and Acyclovir, and data will be forthcoming. There is no data regarding Retrovir and Egg Lecithin, but as a food product, the current study sponsored by the Coalition should pose no problems.
- Going off the drug posed another great concern. Little data exists regarding people

who have removed themselves from the study, as these patients have not provided follow up data. However, it does appear that people are not doing worse when they go off drug. Theoretically, the virus returns to full activity within six weeks of removal of the drug, however, if the drug is reintroduced to the system, it very quickly returns to efficient levels, and the virus is again retarded. For this reason, doctors in some cities are considering drug holidays, allowing participants to give their bodies a break, and wash out built up toxins. Wash out period for Retrovir is considered to be six weeks, but again, there is no firm data on this.

All in all it was an excellent meeting. PWA/PWARC's were joined by Karen Gelmon and Anne Beardsell (heads of the two studies), and the well posed questions were clearly and succinctly answered (to the best of her ability) by Burroughs Wellcome's Linda Houle. The meeting provided a human touch between company and participants, and proved that there is more to this than data. Linda reaffirmed from a company standpoint the importance of the study, and our participation in it. Retrovir, although not perfect, is still our strongest hope of extending our lives, and lessening the life of the virus. I thank Burroughs Wellcome for sharing Linda Houle and Jim Rowan with us, and pray that the studies reveal the information that will allow them to move as quickly as possible with this and future drugs.

One final note about the meeting. Burroughs Wellcome stresses its intention to continue supplying the drug to those that wish to take it, whether within the confines of a study or not. More also will be included as the current studies grow. If you have met Retrovir protocol, you should receive the drug within two weeks. If not, or you have any other questions, a toll free number (1-800-361-9686) is available, and Burroughs Wellcome will do their best to answer questions and speed up the process.

MORE MEETINGS : COALITION REPS AND HEALTH MINISTER : by Kevin Brown

On August 27th, 1987, Sharon Holtzberg and myself were pleased to be able to meet with the Hon. Peter Dueck at his office in Victoria. There were many items on our agenda to discuss, most importantly the proposed amendments to the Health Act, Bill 34.

While the discussions remained frank and cordial, we came away feeling nothing had been resolved surrounding our items of concern. Information was shared, but our frustration levels remained high. However, communication is important, and we are pleased to have lines remain open between the minister and the Coalition. We are currently in the process of setting regular meetings with Dr. Rekart at the provincial lab. We continue to lobby to make our views known to the province.

MEDITATION CLASS OFFERED : reported by Nicholas Gray

Kristen Penn, a student of Stephen Levine and editor of " Karuna : a journal of Buddhist Meditation ", is offering an Insight Meditation class for HIV infected persons and their supporters. The classes run for seven tuesdays beginning Nov. 10th at noon, at 1019 Broughton. Payment is by donation, but registration beforehand is required. To do so, call 733 - 4888

EXPRESSING THANKS : by Nicholas Gray

Talent. Sometimes it makes me want to cry. How can people be so good? And why can't I? That was the over riding feeling for me during the " Hollywood 'CATS' Canteen ". They were having so much fun up there (and hard work) that I wanted to join them. To carry a tune and tell a joke.....they did it so well without me. Many jokes, many tunes and a little message later, a very weary ensemble of extraordinary talent found it's way to bed. Their three hour marathon followed a matinee and evening performance of " CATS ". The benefit for the Coalition was a class act. Thank you is never enough when people reach out with style. (A huge hand also for the " Black and Gold Revue ") The arts have always been responsive. The best way to convey a message has always been to weave it in a staory or disguise it in a song.

The Arts Club was packed with an exurberant, responsive crowd, bouying the show to success. Much of the same crowd could be seen the previous sunday at the benefit performance of " CATS " for AIDS Vancouver. A high style affair, it afforded the opportunity for tuxedo and fancy dress. Limosines and double decker buses were the popular forms of transport from play to party. After a superb show, cast and audience assembled at a party at Graceland, graciously hosted by Angela Hyde Courtney.

Two classier affairs will not be had for a while.....at least not ones that I'll get invited to.

KEVIN'S SIX WEEK BRAN MUFFIN MIX :

Mix all dry ingredients in a large bowl :

- 1 package Raisin Bran (15 oz. size) OR
- 1 litre (4 cups) of All Bran and 1 cup raisins.
(feel free to add more raisins)
- 3 cups brown sugar.
(sometimes I add ½ cup of molasses)
- 5 cups whole wheat flour.
- 5 teaspoons baking soda.
- 1 teaspoon salt.
- spice to taste : approx. 1 - 2 teaspoons of cinnamon or allspice.
- the rind of 1 lemon or orange, grated.

Mix in a separate bowl :

- 1 litre buttermilk.
- 4 eggs, beaten.
- 1 cup oil.
- 2 teaspoons of vanilla.

Add wet ingredients to the dry. Mix thouroughly. This mixture can now be stored in a large glass jar, in the refridgerator for up to six weeks, allowing you to bake the quantity you need as you need it. When baking, preheat oven to 400°, and bake in a muffin tin for 15 to 20 minutes.

Kevin Brown

FACTOR ONE & K 150 : AN INDEPENDANT STUDY : reported by Glen Gilmore

On, tuesday, Sept. 8th at the Holistic Therapy meeting, we had the opportunity to meet Melita LaRose, and hear her speak about two herbal products that she firmly believes are effective body cleansers / solvents. Factor One acts as a solvent, turning lymphatic jell back into a fluid, enabling it to flow through the lymph system. K 150 acts as a stress reducer and relaxant.

Interest at the meeting was high, and furthur discussions with Melita has led to her offer of sponsoring a study of these products with five PWA's and five PWARC's. Her company will absorb the cost of the product for the three month study, provided participants of the study follow the intake requirments and complete a questionnaire. All study data will be strictly confidential, however, the signing of a consent form may be required. Other requirements of the study will be minimal. All Melita wants is feedback - weekly reports on our health and well being, and how we feel the product is working.

If you are interested in trying these herbal products, (they are 100% pure and contain no toxins) first, contact your personal physician, then contact the Coalition office at 683-3381. Leave your name, address, and phone number. Glen Gilmore will act as contact person with Melita. Additional information can be obtained from him, and questionairres should be returned to him c/o the Coalition office (box 136 1215 Davie St., Vancouver) Products will be delivered directly to participants by CARSHA New Breed.

There is no protocol for this study other than the desire to participate. They are herbal products only - no claims of medicinal value or cure is being made by any party involved.

Although we can only accept ten participants in this study (names to be drawn by lottery in late October), these products can also be obtained through the Coalition's Alternative Therapy financing.

HYPNOTHERAPY STUDY : reported by Nicholas Gray

Kamal Baig, M ed, Ph D, a highly respected hypnotherapist is looking for interested HIV infected people who would involve themselves in a study testing the use of psycho-transformational therapy in affecting the progression of AIDS.

After reviewing his creditials, reading his proposal (available in the office) and discussing it with Phil Sestak, here's what it looks like to me :

Dr. Baig has worked extensively with psychiatric cases which normally required medications, and working to ease them off existing medications. He has written a book about this work, and his concepts of the bio-chemical link between the nervous system and the immune system. It is his hope that the proposed study would provide the much needed substrate which can give tangible form and coherence to the nebulous concept of holistic medicine, and particularly between this treatment and AIDS.

Anyone interested in information or participation in the study, leave a message for Nicholas Gray at the Coalition office, 683-3381.

BENEFITS AVAILABLE TO PWA/PWARC's : compiled by Rick Froese

A variety of benefits are available to PWA/PWARC's from Social Services and various public funded organizations. The following is a partial list of these benefits one can avail oneself of. If you have knowledge of additional benefits that we could all share, please contact the Coalition office (683-3381) with the information.

SOCIAL SERVICES :

Much of what is made available to you though Social Services is dependant upon your worker, and their interpretation of your needs. The following are personal and household items that have been supplied by them for various health related needs: Humidifier, fans, woolvest for your bed, as well as other beddings, toiletries (above the counter variety recommended by your doctor), wheelchair rental, kitchen supplies, theraputic shoes, and walking canes or crutches.

Parks Board passes are also available. These allow you use of the Aquatic center, West End Community Center, Kits pool, etc. Bus Passes can be obtained for a cost of \$28.00 per year.

Food Supplements such as Ensure or Sustacal can be obtained when recommended by your physician. Your B.C. Medical provided by the Social Services department also provides twelve visits per year for chiropractic, massage or physiotherapy. They will also honor visits to Naturopaths and some psychologists, again when recommended by your doctor.

THE VANCOUVER PERSONS WITH AIDS COALITION :

The Coalition raises monies from within the community to fund Alternate Therapies. What this means to the PWA/PWARC is that they can approach us for financial assistance for a variety of Therapies not covered by Social Services or B.C. Medical. Vitamins, food supplements, massages, counselling, workshops, books, tapes, are just some of the uses put to these funds.

Occasional tickets are donated to the Coalition to provide entertainment to the PWA/PWARC. In the past theatre and movie tickets, tickets to sporting events and concerts, dances and parties have been provided. These are generally distributed on a first come first serve basis, so stay in touch with the office.

Meeting new friends and re-involving oneself in life is another benefit offered by the Coalition. To that end we have sponsored Retreats, workshops, pot lucks as well as the regular tuesday night meetings. If you want to keep informed, hang around, because we stay on top of all the news regarding AIDS treatment (and even instigate some of it !)

When first diagnosed, the Coalition can provide peer counselling, information on doctors, specialists and procedures, as well as walkmans and relaxation tapes to make your stay in hospital more tolerable.

There is alot that the Coalition has to offer, so call us. We are here to help each other.

BENEFITS AVAILABLE : continued

AIDS VANCOUVER :

AIDS vancouver provides a variety of services to those diagnosed and their supporters. Support groups exist for sero-positives, as well as friends and family of PWA/PWARC's. They have Emergency assistance funds available to help out with rent, bedding, health and medical supplies. Wheelchairs, crutches, canes, shower seats and furniture can be provided depending upon need. They also provide Buddies for those that wish them. Buddies are knowledgeable volunteers who are matched with appropriate PWA/PWARC's for as long as the PWA/PWARC desires. Volunteers are also made available to drive you to and from treatments, help with domestic chores, and just talk.

For more information regarding their various services, contact AIDS Vancouver (687-2437)

AND ONE HEALPFUL HINT :

We must remember that Dental Hygiene is of extreme importance. The mouth uses a lot of our immunities dealing with the various germs, infections, addictives and pesticides that we put into our bodies everyday. Brushing, flossing and mouthwash are daily necessities, and we must stay on the look out for candida, and stop it before it spreads. Regular check ups and cleanings are a must.

My sincere apologies for any information that has been left out, or has been provided incorrectly. For additional information, or to supply us with information, contact Rick Froese through the Coalition office at 683-3381.

WITH LOVE : a Tribute to Taavi Nurmela by Sharon Holtzberg

It is with great honour that I write this tribute to Taavi Nurmela, who passed from us on September 23, 1987.

Taavi was one of three founding members of the Vancouver Persons with AIDS Coalition. His strength, wisdom and determination were an inspiration to so many over the past four years.

To me, Taavi was a friend and a teacher. Although his physical presence is no longer here, his spirit is a strong one. Taavi allowed me the privilege of being with him during his dying process. Through long hours we talked and shared, or sat quietly holding hands. Taavi talked excitedly about going into transition. He was a model we can all learn from. This was a tremendous period of growth for the both of us, and a very, very special gift for me.

Baba Taavi, you are an inspiration!

With love and light from us all, Sharon.

ONGOING EVENTS

MONDAY : BUSINESS MEETING : 11:30 am.

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

TUESDAY : SELF - SUPPORT GROUP : 7:30 to 8:30 pm. on alternate Tuesdays.

Open to PWA/PWARC's only. Discussion surrounds concerns held by the group at the time of the meeting. There is no specific topic, just a chance to talk.

TUESDAY : HOLISTIC THERAPY : 7:30 to 8:30 pm on alternate Tuesdays.

Oct. 6th : Margaret Gabriel on Aromatherapy. This is a treatment using essential oils obtained from plants, flowers and leaves.

Oct. 20th : Ken Renneberg on Shiatsu (acupressure). This is a technique in which the therapist applies pressure on meridian points to help revitalize body functions.

Nov. 3rd : Julie Becker on Natural Hygiene, cleansing the body through diet. Ms. Becker has worked with Harvey and Marilyn Diamond, authors of " Fit for Life ".

Tuesday night meetings are held at St. Paul's Hospital, Comox Building, 1056 Comox, Room LM-6 in the basement.

PERSONAL NOTES :

REIKI : In the spirit of empowerment the Coalition now offers Reiki to its members. Reiki is a gentle yet powerful healing art , useful in the management of any state of dis-ease. For more information, or to arrange treatment, contact Greig Layne at the Coalition office, 683-3381.

PWA (Painter with AIDS) available for apartments and other painting needs. Experienced and willing. Contact by calling 688-9682

BABA TAAVI'S SPIRITUAL CORNER :

Bless everyone !

Baba Taavi