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In the Affirmative, Vol.1, No.1 (Dec 1993)

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IN THE AFFIRMATIVE

A NEWSLETTER FOR MAINE'S HIV/AIDS COMMUNITY

DECEMBER 1993

PREMIERE ISSUE

VOLUME 1 NUMBER 1

THIS ONE'S FOR YOU

What is IN THE AFFIRMATIVE? I'm hopeful that it won't be just another newsletter for persons with HIV disease. There are already plenty of newsletters and bulletins and journals and pamphlets and what have you aimed at telling you what's going on with HIV and AIDS, but either they're too complicated and academic to plow through or they're just too superficial to take seriously. IN THE AFFIRMATIVE will try to exchange ideas, news, treatments, therapies, and life experiences concerning HIV disease with you and in return we hope to hear from you about what you'd like to see in this newsletter.

This is a newsletter for, by, and about persons with HIV disease and persons working within the HIV community here in Maine.

IN THE AFFIRMATIVE is a forum of persons living with or working with HIV disease to exchange ideas and experiences that will encourage and support persons with HIV/AIDS to believe in our sense of value, self-worth, healing ability and empowerment. IN THE AFFIRMATIVE wants to encourage a greater sense of community as we all try to maintain physical, spiritual and emotional harmony.

In short, we want to share our feelings with you and you to share your feelings with us. We want to foster a sense of wonder and excitement about being alive right now, today, at this very moment. We want to acknowledge the pain and anger of HIV disease while encouraging all that there is hope for a quality of life, perhaps even more fulfilling, in our lives that will come from within.

There is no cure for HIV/AIDS, which we're calling HIV disease, but there is lots that can be done to improve the quality of our lives. While we may not be able to improve the quantity of our lives to the degree we would hope, I do believe we can improve the quality of our lives in tremendous ways. And surprisingly, there is no one way to do this.

There are many ways and they are as diverse as the people who do them. There is a holistic approach, the medical approach, the spiritual approach, the use of imagery, relaxation, yoga, acupuncture, and on and on. There are any number of combined approaches and some work for some people and others work for other people.

We hope to provide you with information, ideas, and first person accounts concerning improving the quality of your life while living with HIV disease.

While we can't predict how long we will live or even how well physically we will be, we want to encourage you to believe that spiritually and emotionally we have great power to make our lives more than bearable, but livable. And one of the ways to start is to talk about, write about, and share your feelings, questions, and opinions with others. This can be done with family and friends, or in a group, or through IN THE AFFIRMATIVE.

We would love to hear from you. Tell us about your ways of dealing with HIV disease, share with us the triumphs and tragedies of your life. Share the roller coaster ride of life with us and tell us what you would like to read about here IN THE AFFIRMATIVE.

John Preston, a past president of the AIDS Project, wrote in the Casco Bay Weekly that his doctor's advice to him was to "do something." The doctor said he wasn't sure what worked and didn't work, but that his experience showed him that people who were doing something to improve their lives seemed to actually live better and live longer. The "something" you will find in your search. The search itself may well be therapeutic. There is some evidence that persons with an illness (not just HIV) who attend support groups live longer than those that don't. Perhaps that is so because they are "doing something." IN THE AFFIRMATIVE is doing something, help us to help you to "do something."

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AWARDS

Mary "Winnie" MacDonald, a special person among us, received a wonderful award from the University of Maine at Orono recently. It was the respected Maryann Hartman Award given to distinguished Maine women and their accomplishments in the arts, politics, business, education and community service, and who by their inspiration increase campus and community awareness of contemporary women's accomplishments.

Winnie is well respected in the AIDS community for her forthright and courageous handling of her own AIDS diagnosis. She was infected with HIV about ten years ago, but was not diagnosed until she had AIDS seven years later. Determined to help others thru education and working with various committees, she is truly an inspiration to everyone who meets her.

Winnie was one of three women honored that night. Her award was presented to her by Sandy Titus, Support Services Coordinator at TAP. Winnie was beaming as friends and family looked on. She gave a very touching speech and thanked the awards committee.

The Maryann Hartman Awards were first given out in 1986 in memory of Maryann Hartman who was on the faculty of the University of Maine. She was a teacher, scholar, advocate, friend, mother, and a woman of courage and vitality with an interest in women's issues. She died in 1980 of cancer.

Past recipients of this award include May Sarton, author; Joan Benoit-Samuelson, world-class marathon runner; and Margaret Chase Smith, former Senator; among others. *-Linda Jipson*

TICKETS

THE AIDS PROJECT IN PORTLAND OFTEN HAS TICKETS TO AREA PLAYS AND ENTERTAINMENT PROGRAMS. THESE TICKETS ARE AVAILABLE BY CALLING TAP. OFTEN THEY ARRIVE ONLY DAYS BEFORE A PROGRAM, SO TAKE A CHANCE AND CALL THE TAP OFFICE TO SEE IF WE HAVE SOME TICKETS TO SOMETHING YOU'D LIKE TO SEE. THESE TICKETS ARE FREE AND AVAILABLE ON A FIRST COME-FIRST GET BASIS.

TAKE NOTE

*SPECIAL NOTES
ABOUT JUST SOME OF THE SERVICES
AT THE AIDS PROJECT
22 MONUMENT SQUARE 5TH FLOOR
PORTLAND, MAINE*

*THERE IS A SUPPORT GROUP
FOR HIV-NEGATIVE PARTNERS OF PERSONS
WITH HIV DISEASE ON MONDAYS FROM
6:30 TO 7:30 PM*

*THERE IS A GREAT LUNCH FOR ALL
ON THURSDAYS FROM NOON TO 1 PM
GOOD FOOD AND GOOD COMPANY.*

*THERE ARE ALSO MEALS IN THE FREEZER
TO TAKE HOME FOR CLIENTS PREPARED BY
VOLUNTEERS. LET US KNOW WHAT KIND
OF FOODS YOU'D LIKE. PLEASE HELP
YOURSELF TO THESE FINE FOODS.*

DRUG STUDIES

News of Drug Studies Available Through
The AIDS Consultation Service
at Maine Medical Center

The AIDS Consultation Service (ACS) at Maine Medical Center announces through *Maine AIDS Care*, its quarterly newsletter, that it is, or will be participating in the following drug studies:

A Study of the Effect of Cimetidine on CD4 Lymphocyte Count. This is a randomized, blinded study of cimetidine (a drug normally used to reduce gastric acid output) versus a placebo for 8 weeks, followed by open label treatment with cimetidine for 8 weeks. Although the mechanism of action of cimetidine is unknown, the drug blocks the chemical histamine, and there is some evidence that histamine suppresses immune cells. One small pilot study of cimetidine in HIV-positive persons suggests a 50% increase in CD4 lymphocyte count.

D4T/Stavudine. This parallel track program is designed to provide the investigational antiretroviral agent stavudine to those patients who have failed or are intolerant of alternative antiretroviral therapy. The program consists of randomized, blinded evaluation of 2 doses of stavudine. Information is collected during therapy to evaluate efficacy, safety, and tolerance of D4T.

Combination Studies with Delavirdine. Delavirdine, a new antiretroviral developed by UpJohn Co. has shown a high level of inhibition of HIV in initial laboratory studies. This effect is enhanced when used in combination. The first phase of the study, which compares AZT and placebo vs. AZT and delavirdine will be available to patients with CD4 counts between 200 and 500, who have not been on AZT for more than four months. A second study will compare DDI plus delavirdine for patients with CD4 counts less than 200, who have not been on DDI for more than four months. These trials are expected to begin in 1994.

For more information call
The AIDS Consultation Service
at (207) 871-2099 or 1-800-871-2701

NEWS ITEM

BRITISH FIRM SAYS DRUG KILLED HIV-INFECTED CELLS

(Reuters 11/24/93) London- A drug under British development as a cancer treatment has been shown to kill HIV-infected human white blood cells, according to a research team in London. Scotia Pharmaceuticals, the manufacturer of EF 13, reported that in-vitro tests indicate that the drug kills white blood cells infected with the AIDS virus at concentrations that were not harmful to normal, uninfected cells.

In addition, the company noted, normal human lymphocytes, a form of white blood cells, developed resistance to HIV infection after exposure to EF 13. The research team from the medical college of St. Bartholomew's Hospital conducted the tests when it realized that some traits of HIV-infected cells are similar to those of cancer cells

IN THE AFFIRMATIVE

Is a newsletter for Maine's HIV/AIDS community published through The AIDS Project in Portland, Maine.

Letters, articles, and remembrances should be sent to In The Affirmative, c/o The AIDS Project, 22 Monument Square 5th Floor, Portland, ME 04101 or call 774-6877. Do not send originals, only copies, please, as we may not be able to return submitted materials.

News, information, and features are as up-to-date as possible prior to publication of this newsletter. As there is no cure for AIDS, medical information included in this newsletter is submitted for your information only to be used as you, the reader, so chooses.

Contributors to IN THE AFFIRMATIVE include:

Andy Goodband
Linda Jipson
Michael Martin
Bill Osborne
Lee Richards
Sandy Titus

It's About Choices

Life is about choices. The narrower our choices seem, the more difficult life is. If we believe that life is just a series of bad to worse choices or that life only gets harder, then we are doomed to sadness, anxiety, and finally debilitating depression. If we believe that life is challenging and filled with moments of wonder and hope, then life is open to happiness and fulfillment. These are perhaps two extremes, life is really a mixture of both, but if we can make a choice between hope and despair (and I believe we can), we can empower ourselves with a better life.

It's about choices. And choices are often about making decisions that will change our lives in ways we are not used to, that change the day to day habits we have grown accustomed to. They may be habits we aren't happy about, but we have grown to accept them as the best of a bad situation. They are habits because we haven't chosen to break them. The expression "better the devil you know than the devil you don't know" is applicable to many aspects of our lives and to change means to risk. We can choose to stay in our so-so lives or we can be brave and move on with a hope for something better. The key is hope. Hope is the lifeblood of all human existence and without it despair dominates.

While none of us chose to be HIV positive or to have AIDS, we can, in time, choose how we are going to live now that we know we face an often fatal disease. We can choose to ride through this process thinking only that our lives are totally ruined because of HIV or we can choose to live our lives with the idea that each day is an opportunity unto itself, that everyone, I mean everyone, will die someday. But that while we are alive, we will live as best we can and find options and choices that improve our minds and bodies and well-being.

I do not mean to undervalue the trauma of this disease, it struck me with a deep depression and suicidal thoughts. Even today, five years after testing positive, I still have periods of darkness concerning my future. Silly as it may sound, I put a note on my bulletin board with a simple affirmation that said, "I can LIVE everyday" to remind me, that when I awake every morning, I have a choice. I can either succumb to hopeless despair that I am HIV positive, or I can live each day for its own sake. I can be living my life, or I can be dying my life. In the end, I find living better.

It is about choices. And I encourage us all to open up our lives to choices that will make us happier, healthier and more secure. We can be dying with HIV/AIDS or we can be living with HIV/AIDS. When we decide which it is to be, then we can begin to make the little choices that have a big impact upon our lives.

- Michael Martin

**THE LEWISTON/AUBURN AREA OFFICE OF
THE AIDS PROJECT
IS MOVING.**

**THE NEW ADDRESS IS ONE AUBURN CENTER
(CORNER OF MAIN AND COURT STREET, AUBURN)
ENTRANCE BESIDE NO TOMATOES
AND ACROSS THE STREET FROM AUSTIN'S**

**ALSO MOVING ARE THE TRI-COUNTY HEALTH SERVICES
AND THE STD CLINIC, ALL TO ONE AUBURN CENTER**

TAKE NOTE



LEWISTON/AUBURN

BOOK REVIEW

IMMUNE POWER : THE COMPREHENSIVE HEALING PROGRAM FOR HIV

by Dr. Jon Kaiser (St. Martin's, 18.95)

The Advocate, June 29, 1993 - Jon Kaiser's *Immune Power* presents what may well be the most life-changing and lifesaving treatment program for HIV. With five-plus years' experience as a primary care physician with more than 1,000 people with AIDS, Kaiser believes "AIDS is finally the disease that is going to bring together standard (medical) and holistic therapies. This is absolutely necessary," he says, because "neither alone is enough to maximize the body's immune system to resist the progression of HIV."

Kaiser is convinced that combining standard medical therapies with vitamins, herbs, exercise, stress reduction, emotional and spiritual growth and - if necessary - changes in relationships, living situations, or jobs maximizes the immune's system's ability to do its job. He insists that people with AIDS begin his "comprehensive program" as early after diagnosis as possible.

Immune Power outlines what circumstances necessitate which types of therapy and lists recommended dosages and any side effects. He uses case histories as living proof that faithful adherence to his program has at best resulted in a prolonged period of viral dormancy in a relatively large percentage of his patients and has at least maximized the quality of life for those living with HIV.

IN-PERSON INTERVIEW

In order to reflect the views and opinions of local persons with HIV disease, we asked one such person to share his feelings after he read Dr. Kaiser's bestselling book. David Harvey shared his thoughts with Sandy Titus of the AIDS Project. And here is what he had to say about the book and how it related to his own HIV infection.

"It made me feel good about myself. It affirmed my own gut instinct about long term survival-wellness through basically cleaning out my body and using common sense rather than drugs. When I first read the book chapters on changing lifestyle - giving up alcohol, giving up recreational drugs, and things like sugar and coffee - taking responsibility for your own wellness, I was really happy because it affirmed what I've been doing all along since I've gotten sober. I felt lucky I had done some of the big part/hardest areas - changing habits of drinking and drugging to healthier living. When you are in those bad habits, you are depressed all the time and can't make good choices.

"I'm not so alone now in what I believe. Someone else has the same belief system. I did Chinese herbs, supplements, etc.. Now I'm not shouting in the dark. Someone else believes in it, is researching it, and it totally affirms me. I'm eating healthier now. I'm more conscious of nutrition. Diet itself, nutrition is really helpful. Never did grains. Didn't realize I could get proteins from other sources, such as pasta. It's important knowing healthy foods. The nutrition part of the book is just great!

"It helped me not to be so critical or negative about western medicine. I can go to extremes - not go to the doctor when I really should - say I can do it myself. Or thinking that if I got antibiotics they would weaken the immune system. The book helps me get through my fear about that. Also my fear of knowing what my numbers are. I think I could deal with an annual exam.

"The only way I knew I was well was knowing my chest x-ray was O.K.. I wasn't really keeping an eye on things.

"I almost feel like I'm a graduate of his research. Many of these things I've always believed in myself, so it's easy for me to do the things in the book. Makes me want to go to San Francisco, that's for sure, and see him. His whole idea of being in support groups is stuff I've been doing for the past seven years. Groups like AA and Al-Anon. Support groups for people who are HIV-positive.

"It's total affirmation of what I've always believed in, but when you are doing something alone, in Maine, isolated, away from the gay community, you think you are missing out on something. I feel better now about what I do and where. It encourages me to get involved with the community and become more vocal. I'm definitely taking this book to my doctor and asking her to read it before I see her."

NEWS ITEMS

MAINE FIRM DEVELOPING TREATMENT FOR DIARRHEAL INFECTIONS IN AIDS AND OTHER PATIENTS

(Business Wire 11/19/93) Portland, Maine-

Instead of making the milestone payment owed to ImmuCell Corp., Univax Biologics Inc. will make three monthly installments of \$10,000 each from December 1993 to February 1994. Univax has been conducting clinical trials of CryptoGAM, an ImmuCell product.

"The additional three months are needed to adequately explore the outstanding dosage and drug delivery questions that must be answered before initiating Phase II/III studies," said Michael F. Brigham, chief financial officer of ImmuCell.

CryptoGAM is a polyclonal antibody product which is administered orally for the treatment of cryptosporidium in AIDS patients. This infection, for which there is no effective treatment, occurs in 10 to 15 percent of American AIDS patients, frequently resulting in death.

Cryptosporidium parasites invade the small intestine, causing severe and often debilitating diarrhea. CryptoGAM has been under study by Univax Biologics under an investigational New Drug Application approved by the Food and Drug Administration.

FDA TO IMPOSE NEW SAFETY RULES ON TRIALS

(Washington Blade 11/19/93) In an effort to prevent harmful side effects of experimental drugs from endangering patients participating in trials, the U.S. Food and Drug Administration recently proposed new rules for clinical testing. The recommendations would require scientists conducting clinical trials to report any deaths, serious symptoms, and situations that force patients to stop taking the experimental drug, regardless of whether or not it appears to be linked to the drug.

Scientists would also have to describe each case and explain why they believe they are, or are not, linked to the drug's side effects. The proposal was drafted following the deaths of five patients enrolled in a trial of fialuridine, an experimental hepatitis B drug. Fialuridine may also have been responsible for the deaths of five other patients in a previous trial.

NEWS ITEMS

DISABILITIES ACT WINS A ROUND IN AIDS CASE

(New York Times 11/23/93) New York- A federal judge in New York handed down the first decision upholding the authority of the Americans with Disabilities Act over health plans that discriminate against AIDS-infected employees.

The Mason Tenders District Council Welfare Fund, which represents a group of New York construction companies and laborer's unions, slashed medical benefits for construction worker Terrance P. Donaghey, Jr. and three other employees with AIDS, one of whom died recently. The Mason Tenders contended that it acted properly in denying AIDS coverage so that it could maintain its ability to reimburse members for other illnesses.

Judge John E. Sprizzo rejected a motion by the fund, which claimed exemption from the act under a federal pension law called the Employee Retirement Income Security Act. The ruling means that the burden of proof is on the fund to prove that it was not illegally discriminating against Donaghey.

The ruling cannot be appealed without the judge's approval, and Sprizzo announced that he had no intention of certifying an appeal. He did, however, schedule a January conference to establish a timetable for further arguments and hearings.

MEDICAL BRIEFS ON HETEROSEXUAL TRANSMISSION

(Advocate 11/02/93) With an increase of more than 100 percent since 1989, heterosexual transmission is now the fastest growing category of HIV infection, according to a September 9 article in the Medical Tribune.

The number of cases accounted for by gay and bisexual men rose 21 percent, while cases involving heterosexual intravenous drug users increased 43 percent. The only decline occurred among blood-transfusion recipients.

ABOUT THERAPEUTIC TOUCH...

✓ Therapeutic Touch is a contemporary interpretation of several ancient healing practices. It is a consciously directed process of energy exchange during which the practitioner uses the hands as a focus to facilitate the healing process.

✓ Therapeutic touch is a scientifically based practice.

✓ Therapeutic Touch is practiced by nurses and other health professionals. It is used alone or in conjunction with other modalities, including conventional medical treatment.

✓ Therapeutic Touch is based on the idea that human beings are energy in the form of a field. When you are healthy, that energy is freely flowing and balanced. In contrast, dis-ease is a condition of energy imbalance or disorder. The human energy field extends beyond the level of the skin and the Therapeutic Touch practitioner attunes him or herself to that energy using the hands as sensors.

✓ Therapeutic Touch promotes relaxation, and a sense of comfort and well-being. Research has shown that Therapeutic Touch is effective in decreasing anxiety, altering the perception of pain, and mobilizing the individuals own healing energies to restore health, balance, and order.

THERAPIES

Therapeutic Touch, first described by Dr. Dolores Krieger, is an active healing similar to the laying on of hands. It involves human energy balancing. Therapeutic Touch treatments have resulted in relief of pain and anxiety, increased hemoglobin levels, stimulation of the immune response and accelerated wound healing.

A group of local nurses who are Therapeutic Touch practitioners are offering Therapeutic Touch treatments to people with AIDS and people who are HIV-positive at The AIDS Project. Sessions take place on the third Thursday of each month from 3 to 5 p.m..

For further information, contact Dottie Woods Smith at 780-4797 or Barbara Tsonis at 865-3615. Or call Sandy Titus at The AIDS Project at 774-6877.



About Therapeutic Touch at The AIDS Project...

Here's what J. Robert Jackson has to say about his experience with Therapeutic Touch at The AIDS Project...

"I had a very skeptical viewpoint when I went into it. They were very good about explaining what they were doing and how they do it.

"I was the last one they did. It was fascinating to see how each person before me responded differently. When it came my turn, they did an assessment first. Then they went over it with me. Yes, I had had surgery which they recognized and they picked up on. The stress in my neck, also

"When they did the actual therapy, I decided to keep an open mind. It was not a big punch, but I was very calm and serene when I got home. It was fascinating - like a delayed reaction.

"I will be the first to tell anybody - definitely DO TRY it as a therapy. It is different than anything I've experienced before."

AIDS • FROM THE BEGINNING: 339,250 CASES OF AIDS IN THE U.S., 205,390 DEATHS IN MAINE • 443 CASES OF AIDS, (SO ME. 228, CT ME 150, NO ME 65), 228 DEATHS

IN RESPECT AND ADMIRATION

There are so many who have been overtaken by AIDS. Often their obituaries are written in a style or way that doesn't really convey the essence of the person, as remembered by friends and family. This feature of "IN THE AFFIRMATIVE" is designed to be a place where remembrances can be published without interference. Except for space limitations, we will publish notices submitted by friends and family of persons who have died of AIDS. The lives of the deceased are usually so much more full and inspiring than the death notices in a daily paper can convey or will convey.

We invite you to share your remembrances with us all in the HIV/AIDS community. We will do our best to include all notices sent to us. Materials submitted to IN THE AFFIRMATIVE should not be originals, copies only, as we may not be able to return materials submitted to us.

We all have felt the grief and pain of losing a precious loved one, often feeling that the death notice in the paper didn't really say the kinds of things we would like our loved ones to be remembered for. Here is a space for that purpose.

OBITUARIES AND MEMORIALS PRINTED HERE ARE WRITTEN IN REGARDS TO THE WISHES OF THE DECEASED AND/OR THEIR SURVIVORS. THIS SPACE IS INTENDED FOR THE PRINTING OF NOTICES UNEDITED EXCEPT FOR REQUIREMENTS OF SPACE. IF YOU WISH TO HAVE AN OBITUARY OR MEMORIAL PRINTED HERE, WRITE OR CALL, THE AIDS PROJECT 22 MONUMENT SQUARE PORTLAND, ME 04101 (207)774-6877. INCLUDE YOUR NAME, ADDRESS AND PHONE NUMBER.

WHAT CAN WE DO FOR YOU ?

What would you like to read about IN THE AFFIRMATIVE ?

YOUR LETTERS AND COMMENTS TO US ARE MOST HIGHLY WELCOMED. WE WANT TO INCLUDE NEWS, INFORMATION, AND FEATURES THAT WILL BE OF INTEREST TO PERSONS LIVING WITH HIV/AIDS AND THOSE AFFECTED BY THIS DISEASE.

You can be a big help in shaping the tone and essence of this publication. Write or call us at The AIDS Project with your ideas and thoughts.

We would be open to you who wanted to share your own views on how HIV/AIDS has changed your lives, your experiences with this disease, your own treatments, therapies, and the emotional and spiritual feelings you have gone through. Perhaps you would consent to be interviewed and share your story. Please let us know how we can make IN THE AFFIRMATIVE responsive to your needs.

Call or write : The AIDS Project, 22 Monument Square 5th Floor, Portland, Maine 04101 (207) 774-6877

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