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Folder Title:
Meeting with Act-Up Philadelphia 11/4/93

Stack:	Row:	Section:	Shelf:	Position:
S	66	5	5	3

Jane Shull
Phila FIGHT
6th Floor
201 N. Broad St.
Phila PA 19107

Nick Left, MD ?
930 Washington Ave
Phila. PA 19147

Michael Glick, DMD
Dir, Infectious Disease Ctr
Temple University School of Dentistry
Philadelphia, PA 19140

Matthew Ruben (ACT UP, CCI)
221 Church St. #2
Philadelphia, PA 19106-4514

Robert Kahn (ACTUP/Phila, ACTO, PhilaFight)
108 Fairmount Ave
Phila PA 19123

Jonathan Lax (AU, FIGHT, etc).
1524 Pine St. 19102

David Gary Smith (Phila FIGHT)
4707 Windsor Ave
Phila PA 19143

Could I have name & address !

Mike Spence
201 N. Broad 4th Flr
Philadelphia, PA 19107

Jon Paul Hammond
H.C.#5 1900 N. 20th St.
Phila. PA 19121

See email from K.G. - Philadelphia letter.

Anna Forbes
2430 Avon Road
Ardmore, PA 19003

Timothy P. Cwiek
1725 Fernon St.
Phila., PA 19145

Joseph Ondercin
Suite 505, Pepper Pavilion
Graduate Hospital
1800 Lombard St
Philadelphia Pa, 19146

JOHN L. TURNER, M.D.
505 PEPPER PAVILION
GRADUATE HOSPITAL
1800 LOMBARD ST.
PHILA, PA 1914[illegible]

DAVID FAIR
WE THE PEOPLE LIVING WITH AIDS/HIV
OF THE DELAWARE VALLEY
425. S. BROAD ST.
PHILA PA 19147-1126

DARRELL DAVIS
We The People
425 South Broad

Judy Rappaport, RN
137 N 21st St
Phila. PA 19103

Michael Greenberg
2300 Walnut St. No 218
Phila PA 19103

KIYOSHI KUROMIYA
CRITICAL PATH AIDS PROJECT
2062 LOMBARD ST.
PHILADELPHIA, PA 19146
PHONE (215) 545-2212
FAX (215) 735-2762
EMAIL kiyoshi@cpp.pha.pa.us

David Acosta, Executive Director
The GALAEI Project
119 N. Broad St.
Phila, PA 19107

MR DAVID FAIR, EXECUTIVE DIRECTOR
WE THE PEOPLE LIVING WITH HIV/AIDS
OF THE DELAWARE VALLEY
425 S. BROAD STREET
PHILADELPHIA, PA 19147-1126

OFFICE PHONE: (215) 545-6868
(10 AM - 6 PM (FULL STAFF) M-F
6PM - 12 MIDNIGHT (PART STAFF)
OFFICE FAX: 215-545-8437

HOME PHONE: (215) 922-4836 (WITH ANS. MACHINE)

BEEPER: 940-1913

(FROM THE PWA'S POINT OF VIEW)

PHILADELPHIA'S LEADING EXPERT ON

HIV/AIDS IN THE CITY, FOUR SUBURBAN

COUNTIES, + SOUTH JERSEY, WHO WROTE

1,200 PAGES
ALL OF THE PHILA EMA AIDS PLAN ('93-'94)

GOING TO HRSA, PLUS TWO OF THREE

SUBCOMMITTEE REPORTS OF THE CONSORTIUMS
PLANNING + EVALUATION COMMITTEE.

#1

- individ prof. actions -

Ibogaine - ?$95 million needed

? of who would be excluded / included in trials -

? Third party claims used against a product.

? amino acids - by prescription ?

? assumptions of what is said & why -

? mythology - institution industry activism

role in reshaping GP160

? of future - in discuss direction/ planning

against + immigration

DOUBLETREE
Doubletree Hotel
Philadelphia
Broad Street at Locust
Philadelphia, PA 19107
(215) 893-1600
Fax # (215) 893-1628

November 1, 1993

Mr.Steven Lee
NATIONAL AIDS POLICY COORDINATOR
750 17th Street
North West Suite 1060
Washington, DC 20503

Dear Mr.Lee,

Following your request, the Doubletree Hotel Philadelphia is pleased to acknowledge the following reservation for NATIONAL AIDS POLICY COORDINATOR.

Day	Date	Time	Function	PP	Setup	Room Charge
Thu	11/ 4/93	8:30 AM-10:30 PM	Meeting	20	Conference	$150.00

To confirm on a definite basis, please sign the enclosed copy of this letter and return it to my attention by November 3,1993.

Should we not hear from you by November 3,1993, we will assume that this is a cancellation. After this date the space will be released.

Based on your expected attendance and guarantee, we reserve the right to re-negotiate the amount of function space allocated for each function.

Also enclosed you will find two copies of the menu and arrangements I have prepared for your function. Please sign one copy and return to our office.

This agreement will bind both the above named group and this facility and may be cancelled by either party only upon the giving of written notice no later than ninety (90) days prior to event date.

The performance of this agreement by either party is subject to acts of God, war, government regulations, disaster, strikes, civil orders, curtailment of transportation facilities, or other emergencies making it inadvisable, illegal, or impossible to provide the facilities or to hold the function. It is provided that if agreement may be terminated for any one or more of such reasons by written notice from one party to the other.

Termination of this agreement within ninety (90) days of scheduled function will result in penalty to the above named group of 50% of the estimated total Food and Beverage Revenue. Food and Beverage will be calculated on prior discussion of menu or actual year-to-date averages for the meal period.

Thank you for your interest in the Doubletree Hotel Philadelphia. We look forward to serving you in the near future.

Sincerely,

Domenic Romeo
CATERING SALES MANAGER

BAC/klb

Enclosure

ACKNOWLEDGED BY: _____

DATE: 11/1/93

CK-104

D O U B L E T R E E H O T E L P H I L A D E L P H I A

AR#:

Posting: NATIONAL AIDS POLICY COORDINATOR CC

In Charge & Billing:
Name: Mr.Steven Lee
Address: 750 17th Street North West Suite 1060
Washington DC 20503

Phone: 202-632-1090
Fax: 202-632-1096
GUAR:_____ SET:_____

Date	Time	Function	Room	Attendance
11/ 4/93	8:30A - 10:30P	Meeting	Concerto A	20

ARRANGEMENTS/AUDIO VISUAL

MEETING/CONCERTO A
- Set Conference Style for (20) people

MENU

BEVERAGE

EXTRA ITEMS/ARRANGEMENTS

Tax: 7% (Liq. Not Taxed)
Gratuity: 19% TO APPLY FOR FOOD AND BEVERAGE

| Coatcheck: N/A
| Parking: N/A
| Music: N/A
| Flowers: N/A
|
| Linen: CAPTAIN'S CHOICE
| Labor Charges: $35 for Coffee Breaks Under 25 People.
| $50 for Meals under 20 People
| Room Rentals: $150.00
| Electrical Reqrmts: N/A
| Miscellaneous: N/A

Arrangements By: Domenic Romeo Date: November 1, 1993

Client Signature M. Stella Lee Date: 11/1/93

ALL GUARANTEES DUE 72 WORKING HOURS IN ADVANCE OR HOTEL HAS RIGHT TO CHARGE FOR EXPECTED ATTENDANCE

[11] From: Arthur Lawrence 10/30/93 11:20AM (3057 bytes: 51 ln)
To: Kristine Gebbie, Ben Merrill
cc: Steve Lee
Subject: Re[2]: ACT UP Philadelphia
---------- Message Contents ----------

Yes.

I have had extensive follow-up with ACT-UP members in the area. They are principally concerned with vaccine research issues, but also have the same other issues as most any other chapter of AU.

Judy Rappaport was to have called me on Friday (she is unavailable for me to contact her...on vacation, or something) and did not. Ergo, I will contact her on Monday. In the absence of her call on Friday, I nosed around with several persons who have hooks into AU/Phila activities. The read that I am getting is that the original plan for a loud and vocal demo at the Franklin Institute has been canned. It will be replaced with a more silent sort in which every 3.5 minutes an AU member of the audience will stand with some sort of sign to show another person in the US has become infected during that time.

The strategic placement of your meeting at the end of the day, the phone call which you accepted, my extensive follow-up, and cooler heads in Philadelphia have all contributed to the throttle-back. The health department did caution that there is a fringe element of a very small minority that still wishes to simply be disruptive all day. The majority, however, is making every effort to keep it reasonable.

Per our discussion, I have not made arrangements for hotel in Philadelphia and trust that you can lift the doormat at Tom Vernon's house. I will give Steve all of the material which I have on Monday so that you can have a complete package. The only item which is in process is that the White House did not provide the political briefing materials until late Friday afternoon, meaning that the congressional delegation folks have to be contacted starting on Monday. I'll split the task up so that they all get contacted.

A final note about the visit, now that I'm on a roll, is that the health department public affairs folks called and asked if you wanted the sessions closed to press. My response was that with the exception of the breakfast with Huntley and private time (if you know what I mean.....your nature and comfort pauses), that this was not a closed event. I also added two principles: (1) this is a *serious* visit and it should not be allowed to become a media circus, and (2) as you would be visiting service sites, that the confidentiality and dignity of the patients and clients should be paramont in everyone's mind.

Spock, out.

DATE: October 26, 1993

TO: Arthur Lawrence, Ph.D.

FROM: Kay Graham
Phila. AIDS Activities Coordinating Office

SUBJECT: Kristine Gebbie's visit - November 4, 1993

Below is the information regarding Ms. Gebbie's stay on the evening of November 4, 1993.

The Broad Street hotel ACT-UP referred to is now called The Double Tree.

Location: Broad & Locust Streets
Phila PA
Phone: 215-893-1600

Contact: Dominic Romeo - **Phone - 893-1687**

Prices: Meeting room for 20 people - set up theater style
$150.00
Room for Ms. Gebbie - $125.00

Please note, I spoke with Mr. Romeo yesterday and the hotel is holding the rooms, but only for one day. Perhaps someone from your office can call today to make a reservation.

I will be in touch with later this week. Any questions, call me at 215-875-5688.

AGENDA FOR GEBBIE MEETING NOV 4

1. Stop the drug wars: 1) expedited human testing for addiction interrupters such as Ibogaine, 2) no restrictive regulation of vitamins and minerals, amino acids, herbal medications, and nutritional substances, 3) make medicinal marijuana a schedule 2, not a schedule one drug, with no prosecution of those who grow marijuana for their own medicinal use.

2. The community wants multi-drug therapeutic vaccine trials, which include the Salk HIV immunogen. We also think that basic pathogenesis research and treatment and prophylaxis research needs to be funded, but not at the expense of therapeutic vaccine trials.

3. We need a uniform system of unique identifiers to protect the confidientiality of persons getting HIV services.

4. We need to treat the AIDS pandemic like the public health emergency that it is. We need full funding for Ryan White--the kind of funding that is allocated when a natural disaster strikes this country at the cost of human lives. We also need more basic research funding to get new drugs in the pipeline.

Community Condom Initiative

Philadelphia, PA, Nov. 4, 1993

Contact: Matthew S. Ruben
221 Church St. #2
Philadelphia, PA 19106-4514
(215) 592-7353

or, c/o ACT UP, 201 S. Camac St.
Philadelphia, PA 19107
(215) 731-1844

The Philadelphia Community Condom Initiative (CCI) is a community-based advocacy group working to get condoms and other STD risk-reduction devices distributed in Philadelphia recreation centers. CCI seeks to pool the resources of a variety of local organizations and individuals in order to meet young people's need for sexual risk-reduction devices and educational materials across the city.

City-sponsored efforts have thus far been severely limited in scope because of financial and political constraints. By helping to bring about the implementation of a program administered with the help of recreation center staff and neighborhood, regional and city-wide groups, CCI hopes to significantly improve the growing AIDS crisis among Philadelphia youth.

1. Limited Access, More Cases

Young people in Philadelphia have very little access to free condoms and other devices that will help them avoid transmitting and receiving sexually transmitted diseases (STDs). In Most neighborhoods, no programs exist to give young people the information and devices they need to protect themselves from potentially fatal STDs.

Meanwhile, the number of diagnosed cases of "full-blown AIDS" in Philadelphia is rising:

- During the first half of 1992, the number of cases reported to the city averaged about 55-60 per month. The first half of 1993 saw that average triple to about 180 per month.

In addition, the percentage of those infected during adolescence continues to increase, and will only increase further in the future without risk-reduction and education initiatives targeted at youth.

2. Recreation Centers: Possible Solutions

Public facilities have not effectively taken on the responsibility of making condoms and other devices and materials available on a widespread basis. The city's recreation centers constitute favorable environments to start addressing this problem, and CCI has begun to

organize communities to push for programs in the centers, for the following reasons:

- Recreation centers exist in virtually every neighborhood — there are more than 180 separate facilities in the city.
- Recreation centers are open year-round and frequently stay open later than schools.
- Many communities experience high-school dropout rates of up to 50 percent, and many dropouts use recreation center facilities.
- Many young people who are sexually active before high school go to the centers.
- Different age groups come into contact at recreation centers, providing opportunities for both peer counseling and the establishment of positive role models.
- The vast majority of summer recreation center staff are young people.
- Recreation centers are low-pressure environments — young people do not have to enroll or register in order to gain access to STD/HIV risk reduction and education.
- There are indications that some youth (and their parents) will come to the recreation centers on their own initiative if they know that risk reduction and education are available there.

3. Federal Assistance: Unclear Funding Situation

Having already participated in the formation of the Prevention Point needle exchange program, the city seems willing to include STD/HIV risk reduction in a broader recreation center-based educational program focusing on sexuality, drugs and violence. In order for such a program to work, and in order for risk reduction to be a part of it, communities must be organized and funding must be made available. CCI is in the process of accomplishing the former; with the help of the AIDS Policy Coordinator, the federal government can take the lead on the latter.

Present funding streams, new funding streams, pilot-program initiatives, funding to municipalities, funding to private organizations — any and all methods of federal funding would help combat the growing health crisis among Philadelphia's young people, a crisis whose dimensions threaten to expand beyond all control if we do not act now.

DRUG STUCK IN (?) THE SYSTEM

DRUG: Ampligen

ACTION: IV drug which is both an anti-viral and immune booster
synergistic with AZT- data presented at ICAAC
possibly synergistic with IL-2 (?)

MAKER: HEM Pharmaceuticals
Philadelphia, PA

USES: HIV disease
Hepatitis B and C
certain Cancers

Company is underfunded and has been supplying 18 patients in Phila. Miami, Pittsburgh, California, and Houston with drug after their trials have ended. Infusion is either two or three times weekly.

Patients have been on the drug from 3 years to 8 years. Data has been published and is in publication currently.

Company cannot afford to provide drug until it is "reinfused" with investment funds or sold.

FDA APPLICATION:

For Cost Recovery with these 18 patients. Was filed by company September 23, 1993.

Now stuck in the bureaucracy: patients have asked for a meeting with the FDA which has been stonewalling. Company has answered all FDA questions.

PATIENT CONTACTS:

Jonathan Lax 0: 215-545-6620
fax: 215-545-0888
H: 215-732-2152

needs to see Randy Wykoff

Michael Kachur: 0: 215-299-1106
H: 215-561-8168

COMPANY CONTACT:

Dr. William A Carter O:215-988-0080
Fax: 215-988-1554

MEETING WITH KRISTINE GEBBIE
Philadelphia
November 4, 1993

GROUND RULES FOR THE MEETING

1. Tonight's discussion will be based on and will follow those items set forth on the distributed agenda.

2. Designated individuals will introduce and discuss Items 1, 2 and 3 on the Agenda.

3. Discussion on those agenda items will be limited to fifteen minutes per item including responses from Kristine.

4. Item 4 on the Agenda presents an opportunity for individuals to raise issues of individual and/or community concern and to create and to facilitate diaglogue with Kristine on those issues.

Participants in this segment of the meeting will be limited to two minute presentations of their issues, questions and concerns.

This will be followed by a question and answer period as time allows.

PEPTIDE T

A CASE OF ACCESS DENIED

Some time this summer, individuals who had been purchasing Peptide T through buyers clubs, lost the ability to do so when a company called PepTech removed the drug from the underground market. A chain of amino acids, Peptide T appears to block the entry of HIV into cells bearing the CD4 receptor, a passageway into the cell to which HIV is strongly attracted. Most importantly, Peptide T has been found to help with AIDS related neuro-cognitive problems[1] (e.g., confusion and what was formerly referred to as AIDS-related dementia) and has also been found to greatly ameliorate peripheral neuropathy. Thus, the deprivation of Peptide T has left many individuals unable to focus and concentrate and unable to walk.

A number of reasons have been offered to explain the action by the drug company including fear of FDA retribution (for having supplied the buyers clubs in the first place) when Peptech applies for drug approval, and corporate maneuvering, the type which affects all small companies developing worthwhile drugs as they try to outsmart and one-up their competitors.[2] This points out the problems of people with HIV disease who grow dependent upon drugs manufactured by small companies who lack moral and ethical commitment to the community.

This abrupt denial of access to drugs which are not yet FDA approved must stop. A thorough investigation should be made of these companies and their practices leading to the establishment of appropriate new procedures and practices for drug companies to follow on the long road that leads to FDA approval with appropriate penalties for the abrupt withdrawal of beneficial drugs. This may have to include governmental regulation and policing so that the community is not left at the mercy of their marketplace-based whimsical and capricious decisions.

prepared by Michael Greenberg for distribution at meeting with Kristine Gebbie, Director, Office of AIDS Policy

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[1]See Critical Path AIDS Project, No. 27, October-November 1993

[2]See Notes from the Underground, The PWA Health Group Newsletter, September 1993.

Anna Forbes, consultant to the Philadelphia Department of Public Health, (215) 875-5621 or (215) 649-8113

FAST FACTS ABOUT HIV/CD4 REPORTING BY UNIQUE IDENTIFIER RATHER THAN BY NAMES

As of October, 1993, 29 states had adopted some form of mandatory HIV name reporting. Adoption of name reporting was fairly rapid (except in high incidence states) because of federally facilitated linkages between name-based incidence reporting and enhanced access to federal funds.

Name reporting has not yet been adopted in most high incidence states because of adamant, vocal opposition by the advocacy, civil rights and consumer communities. Name-based reporting demonstrably discourages people from obtaining testing, whereas anonymous testing encourages use of HIV and CD4 testing by high risk individuals. Case studies substantiate this observation:

1) In 1988, Louisiana and Illinois both mandated HIV testing for individuals obtaining marriage licenses. The number of marriage licenses requested dropped significantly and the number issued in neighboring states rose. Both states have since rescinded this policy.

2) In a 1990 study published in AIDS, 60% of people surveyed at anonymous test sites said they would have avoided testing altogether if mandatory name reporting were required. Bisexual male participants indicated the highest refusal rates of all survey respondents.

3) When South Carolina instituted mandatory name reporting, attendance at one Charleston HIV test site decreased by 43% overall. Attendance by gay men decreased by 51%. Simultaneously, attendance at the nearest anonymous HIV test site in Augusta, Georgia rose by 61%.

UNIQUE IDENTIFIERS AS AN ALTERNATIVE TO NAME BASED REPORTING

Most activists and consumers of HIV/AIDS services, including ACT UP/Philadelphia and ACT UP/New York, understand the need for accurate epidemiological data. ACT UP supports the creation of systems to track such data for the purposes of learning about the medical progress of HIV/AIDS, planning effectively for service delivery and competing successfully for state and federal funds provided that confidentiality is maximally protected.

Such tracking can be done by unique identifier as effectively,

and arguably more effectively, than by name-based reporting

The following are a few of the unique identifier systems that are now being used or field tested in connection with HIV and/or CD4 data reporting:

Maryland: Recently received funding under a CDC Cooperative Agreement (Program Announcement #343) to field test a unique identifier system for lab-based HIV and CD4 reporting. It is based on a transposition code (non-computer generated) of public record data elements.

Texas: Received CDC funding under the same CDC Cooperative Agreement (see above). Their unique identifier is used for HIV reporting only and is derived from public record data elements submitted by providers in plain text (unencrypted) form. These elements are then encrypted through a computer algorithm by the state Health Department.

Washington: Some Washington state labs use unique identifiers for CD4 reporting. Like Texas, their system is based on submission of plain text, public record data elements to the state Health Department.

Oregon: Some providers use unique identifiers for lab-based reporting of CD4 test results. The Oregon Department of Human Resources has left the decision as to whether to use name-based or unique identifier reporting up to the physician. The result has been undetectable duplication of records at the state level.

In Philadelphia, We the People of the Delaware Valley Living with HIV/AIDS has just submitted a proposal to AmFAR for a public policy grant with which to field test a new unique identifier system called DoubleLock. Like some of the systems above, DoubleLock proposes to encrypt public record data elements. However, unlike the above, it has the following advantages:

1) it processes a verifiable, non-public record data element together with the public record data elements. As a result of this addition, identities cannot be later traced through "cross-matching; the process of using a secondary public data base to generate a second list of codes and then comparing those codes to the codes of people known to have HIV, in an effort to find matches.

2) it proposes to generate codes through a voice messaging system that providers access by telephone. This means that providers will not need to release plain text data about their clients. It makes the enhanced security of computer encryption available without requiring providers either to have or to use a computer.

ACT UP/Philadelphia endorses DoubleLock and urges that funding to field test it be made available as rapidly as possible.

COMMUNITY BASED CLINICAL TRIALS NETWORK

October 19, 1993

Kristine Gebbie, RN, MN
National AIDS Policy Coordinator
The White House
Washington, DC 20515

Dear Ms. Gebbie:

The Community Based Clinical Trials Network (CBCTN), through the support of AmFAR, has enrolled over 10,000 HIV-infected patients receiving primary care through over 500 physicians throughout the United States in the Observational Data Base Project (ODBP), a long-term cohort study. In addition, the CBCTN also has access to several thousand more HIV-infected individuals who are followed through the practices of participating physicians. We are writing on behalf of the CBCTN to offer our opinions on issues surrounding further development of therapeutic vaccines to treat HIV disease.

The debate over whether any of the therapeutic vaccine candidates currently in development will offer clinical benefit remains unresolved. That is why clinical trials are necessary. Patients with HIV have been and continue to be denied scientific answers and access to treatments that they believe may offer benefit. Our patients want and deserve an answer. Over 900 HIV patients in Philadelphia, 500 in Houston and 400 in Boston have requested that their names be placed on a waiting list for therapeutic vaccine studies should the CBCTN site in any of those cities be able to provide access. Through the network as a whole, thousands of patients and their clinicians have expressed their convictions: that research on these products must continue; that an answer to the question of clinical efficacy must be determined expediently; and that they desire to participate in clinical trials of therapeutic vaccines.

These clinicians and patients are aware that there is no consensus on the potential treatment advantages that might be discovered through clinical trials of these vaccines. They are aware of the status of previous and ongoing trials of these products and of the various opinions that have been expressed concerning them. However, they believe that these issues must be addressed through the standard scientific mechanism - well designed, randomized, controlled clinical trials of high scientific merit.

We understand that there is reasonable concern about whether there is sufficient data about any of the vaccines to warrant moving forward with a very large efficacy trial. We propose that a Blue Ribbon panel achieve consensus about which surrogates are hoped to most useful in predicting clinical efficacy, and that all products undergo accelerated Pase II testing in the next 6-12 months to optimize dose and schedule (including multi-product testing) using these surrogates. Those that are found to be most active can then be launched into a large trial. Given that an efficacy trial of over 10,000 people will take many months to organize, this time would be best spent by identifying which products have the most promise, and then investigating them for clinical efficacy. While there remains tremendous uncertainty about our

current surrogate marker data, it will remain uncertain until an efficacy trial is completed to allow clinical correlation.

The undersigned members of the CBCTN believe that a large, multi-product clinical trial, utilizing clinical endpoints to determine the efficacy of these therapeutic vaccines, is a viable approach that could be undertaken. We believe that such a clinical trial, designed to the recommendations of the Blue Ribbon Panel of scientists that was assembled specifically to make such recommendations, could efficiently and expeditiously resolve this debate. We are prepared to support a trial of this design, such as the protocol being developed by Deborah Birx, M.D. of the Department of Defense, and are prepared to assist in carrying out a multiple product trial designed to the highest standard of scientific validity. Other clinicians at many of our sites are prepared to dedicate their efforts to this end.

For too long, our patients and their clinicians have been excluded from this debate while scientific research involving these vaccines has been hampered, delayed and denied to them. For too long, political infighting within the nation's research institutions, and agendas having little to do with the welfare of persons living with HIV have superseded scientific rational. We hope that the best interest of patients and sound scientific research can be placed at the forefront of this debate and are open to discussions of how the scientific study of these products might best proceed. New approaches may be required; however, we are convinced that scientific research on therapeutic vaccines must continue.

In summary, while we respect that healthy debate over the most scientifically valid manner in which research for these vaccines should continue may result in higher quality continuing research, we are concerned that the current climate surrounding these vaccines could delay or even halt further investigation of them. We are concerned that scientists, clinicians and patients from communities throughout the nation, who may have insights into these issues, have not had the opportunity to participate in decisions concerning therapeutic vaccines. We request that you meet, perhaps by telephone conference, with representatives of the CBCTN to provide that opportunity. Jane Shull, of the CBCTN in Philadelphia, has agreed to coordinate the logistics of such a meeting. Ms. Shull may be contacted at (215) 557-8265; however, please also feel free to contact any of the signatories below with whom you may have previous acquaintance.

Sincerely,

Houston Clinical Research Network

Chris Jimmerson
Director of Operations

Wayne Bockmon, M.D.
Medical Director

Wisconsin Community Based Research Consortium

Lisa Al-Hashimi, MSM, RN
Director

Ian Gilson, MD
Principle Investigator
Observational Data Base

Donald A. Romig, MD
AIDS Wellness Program
Medical Director

Philadelphia FIGHT

Founding Principal Investigator

Alice Stenerson, RN
AIDS Wellness Program
Program Manager
Santa Fe, NM

Executive Program Director

Hawaii AIDS Research Consortiu

Margo Heath-Chiozzi, MD
Principal Investigator
AIDS Clinical Research Progran

Sue Congdon, RN BSN
Research Study Coordinator

Bay Area AIDS Consortium

Daniel W. Wedge
Executive Director

Dorece Norris, M.D.
Medical Director

Nelson-Tebedo Community Clinic for AIDS Research

Nicholaos Bellos, M.D.
Principal Investigator

Deborah Trott
Director of Clinical and Client Services

Brown University AIDS Program

Gail Skowron, MD

Gail Skowron, M.D.
Assistant Professor of Medicine
Clinical Trials Coordinator, Brown University AIDS Program

Kenneth H. Mayer, MD

Kenneth H. Mayer, M.D.
Professor of Medicine and Community Health
Director, Brown University AIDS Program
Chief, Infectious Disease Division, Memorial Hospital

Community Research Initiative
of South Florida, Inc.

Paula Specti, M.D.
Medical Director

Rick Siclari, M.B.A.
Executive Director

S.W. Community Based AIDS Treatment Group
1800 N. Highland, Suite 610
Los Angeles, CA 90028

Bisher Akil, M.D.
Principal Investigator

Jill Glassbrenner
Executive Director

Kansas City AIDS Research Consortium

Gary R. Johnson
Administrative Director

James F. Stanford, M.D.
President and Clinical Director

Baltimore Community Research Initiative

David A. Wheeler, MD
Principal Investigator

Brenda Woods-Francis, RD, MPH
Executive Director

AIDS Community Research Consortium

Michael Edell
Executive Director

Stanley C. Deresinski, M.D., F.A.C.P.
Medical Director

Central Texas Medical Foundation
HIV Study Group

Earl B. Matthew, M.D.
Medical Director

Caryll Pithey, R.N.
Project Director

Community Research Initiative/ New England

Calvin J. Cohen, MD
Research Director
Principal Investigator

Julie K. Marston, MPH
Executive Director

cc Honorable Senator Barabara Boxer
Honorable Representative Barney Frank
Honorable Senator Daniel Inouye
Honorable Senator Edward Kennedy
Honorable Senator Edward Rockefeller
Honorable Representative Craig Washington
Honorable Representative Henry Waxman

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The monthly newsletter and calendar of We the People Living with AIDS/HIV of the Delaware Valley, Inc.

ALIVE & KICKING!

Number 25 November 1993

State cuts funding for winter heating assistance

The Pennsylvania Department of Public Welfare is planning significant changes in its Low Income Heating Assistance Program (LIHEAP) which may result in as many as 33,000 formerly eligible people from keeping the heat on this winter.

Many low-income people with AIDS, especially those on fixed incomes from Social Security disability, have relied on LIHEAP funding every year to keep the heat on. State officials say they have no choice but to decrease the amount of funding available for the program this year because of a $5 million reduction in federal funding for the program.

"The media was full of reports on the deaths of elderly people because of the heat last summer," said Sabrina Cason, a housing counselor with We The People Living with AIDS/HIV. "This winter's big news will be people with AIDS freezing to death in their homes so that Harrisburg can save a few bucks. It should be unacceptable, but in the state capital the lives of people with AIDS don't seem to matter much."

LIHEAP funding is available to low-income people to help them pay high winter heating bills, fix heaters and furnaces and avert utility shutoffs. More than 80,000 Philadelphians received benefits under the 1992 program, but less than 50,000 will qualify under the new rules.

Changes planned for this year include a delay in the starting date for the program until December 6th, and an early closing date of January 13th, except for "crisis" situations. In previous years the program began in November, when temperatures in Philadelphia usually begin to fall and heating systems are needed 24 hours a day. The late start date means that the program, including the crisis period, will only be available for three-and-a-half months rather than six months as in previous years.

DPW is also changing eligibility requirements. In order to receive a grant, an individual or family income must be no greater than 135% of the federal poverty level. In previous years, the eligibility ceiling was 150% of the federal poverty level.

Eligibility for "crisis" support is also being tightened. Under the new DPW plan, an individual or family must be facing immediate termination of service or owe at least $350 to the heating company before becoming eligible for an emergency grant. Past regulations required only the imminent threat of termination of service or an arrearage of $200. The state is also reducing the amount of funding available for an emergency grant, from $300 to $250, and other reductions in grant levels are expected as well.

Acting Governor Mark Singel has said that it would take an additional $15 million to $20 million to fund the program at last year's level and that the Casey Administration does not have the money. An aide to state Sen. Vincent Fumo, who chairs the

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