

1540 MARKET ST., SUITE 60
SAN FRANCISCO, CA 94102

Telephone (415) 863-4676

Office Club

9/21/89

TO: Burroughs-Wellcome Activists, Phone Tree
FROM: Paul Boneberg, Mobilization Against AIDS
Boycott Subcommittee

RE: Initiating a boycott

If we are to proceed in a boycott of Burroughs-Wellcome, it is imperative that we have a plan of action beyond a press conference and gathering organizational endorsements. If we call for a boycott but do not create the mechanism to persuade tens of thousands of people to alter their normal buying habits we will fail. Such a failure weakens our position with Burroughs-Wellcome, all other pharmaceutical companies, elected officials and the media. This is a card we should play only if we are serious.

An effective boycott could be, in my opinion, created in these phases:

1. Media Opening -- As previously discussed, a wide range of AIDS-involved groups should endorse the boycott and a press conference should be held.

2. Community Activism - People who care about AIDS must be told repeatedly not to purchase Sudafed and Actifed. To do this would involve:

- a. Inserts in all mailings done by AIDS-involved groups.
- b. Prominent mention of the boycott in all of the groups' newsletters.
- c. Generic "don't buy" ads should be repeatedly placed in publications with sympathetic readership.
- d. Generic posters & flyers should be made and distributed to supportive groups nationwide.

3. Expansion of boycott beyond AIDS-involved people.

- a. Elected officials, religious leaders, non-AIDS involved groups should be asked to endorse.
- b. Cities such as San Francisco, LA, New York, etc. should be expected to endorse the boycott. Endorsement of the boycott could be put in the form of a ballot initiative as well.

4. Pharmaceutical chains could be asked to not carry these drugs. If they refuse, informational pickets, etc., could be organized.

For a boycott to succeed, sustained, repetitive education of the public is needed. In addition to many groups endorsing the boycott, a few will need to take primary responsibility for its success. In addition, funds must be raised to cover the costs of printing, advertisements, phones, travel, etc.

Cost would be roughly --

\$20,000	Printing
20,000	Advertising
10,000	Phone & Travel
\$50,000	Total Boycott Cost

I suggest that one or two groups take primary responsibility and all groups contribute \$500 to \$1,000 in seed money. It appears to me that ACT-UP NY is one of the groups that should take a primary leadership role.

The plan outlined above is very rough. However, it would reach over one million people repeatedly and many more occasionally. It is within the capacity of existing groups to undertake.

In summary, I urge us to proceed with the boycott, but only after a plan is agreed to and responsibilities clearly assigned.

Mike Sarver

Burroughs Wellcome Co. Community Advisory Board

Brief Developmental History Key Contributions & Accomplishments (Draft)

Note: This is a first draft of a report for use by B.W. Co. and CAB members to understand and represent the purpose and activities of the Community Advisory Board. Please review this document and note your additions or revisions. These will be included in a draft to be submitted to Valerie Scott in May. Alan Hayes will be following up with you next month.

The HIV Community Advisory Board (CAB) was founded by Burroughs Wellcome Co. (B.W. Co.) in 1990 to help the company broaden its understanding of the perspectives and needs of people affected by HIV. Recommendations and feedback from the CAB during its periodic meetings—and consultation throughout the year—have helped shape the company's educational, service and research initiatives relative to HIV.

Highly accomplished and influential men and women from the HIV community have served on the CAB since its formation. The CAB is representative of the community of people affected by HIV, and comprises people of color; those with diverse professional backgrounds such as treatment education, advocacy, and public policy; and those with diverse social/cultural experiences such as substance abuse and treatment activism. CAB members generally serve two years, bringing extensive knowledge about the disease, leadership experience with AIDS service organizations, and an understanding of the issues and trends within HIV-impacted communities.

Past and Present CAB Members Include:

- Moisés Agosto (1992-94)
- Marina Alvarez; AIDS Educator & Consultant; Bronx, NY (1993-95)
- Buddy Clark (1991-92)
- Pablo Colón, D.P.M.; Latino AIDS Treatment Issues Group (LATIG); New York, NY (1994-95)
- Novella Dudley (1992-93)
- Chuck Frutche (1992-94)
- Danny Jenkins; Director, Youth Services; Los Angeles Lesbian & Gay Community Services Center; Los Angeles, CA (1994-95)
- Ronald Johnson (1992-93)
- G. M. "Missy" LeClaire (1991-92)
- Martin Levine, Ph.D. (1991-92)
- Leon McCusick, Ph.D. (1991-92)
- John Manzon; Executive Director, APICHA; New York, NY (1993-95)
- Sandra McDonald (1992-93)
- Michael Puente (1991-92)
- Robert Remien, Ph.D. (1992-94)
- Anthony Rizzolo (1991-92)
- Suzi Rodriguez (1992-94)
- Angela Shiloh-Cryer; Director of Education, NO/AIDS Task Force; New Orleans, LA (1993-95)
- Mike Shriver (1992-94)
- Marie St. Cyr; Executive Director, Iris House; New York, NY (1994-95)
- Ron Stall, Ph.D., M.P.H.; Associate Professor, UCSF Center for AIDS Prevention Studies (CAPS); San Francisco, CA (1994-95)
- Joel Thomas; Board of Directors, Project Inform; San Francisco, CA (1994-95)
- John-Peter Wilhite; Director of Education, AIDS Services of Austin; Austin, TX (1993-95)
- Reggie Williams (1992-93)
- Phill Wilson; Director of Public Policy, AIDS Project Los Angeles (APLA); Los Angeles, CA (1992-95)

The CAB has tackled a variety of issues, and worked with the company to address some difficult problems faced by the company in its attempts to reach consumers. The CAB has discussed and made recommendations to B.W. Co. on issues and concerns in the following areas:

- Product marketing
- Treatment education
- Internal company policies, practices and culture
- Public policy processes and decisions
- Reaching underserved communities
- Accessing influential community leaders in treatment and advocacy
- Shaping the perception of the company within the HIV community
- Drug pricing

The agendas from the CAB meetings consistently focus on informing CAB members of current activities and decisions about drug development, clinical trials, and product marketing programs. CAB members share their perspectives and make recommendations on various concepts and programs which company personnel consider in developing their program strategies and in finalizing related plans. CAB members with specific areas of expertise—clinical trial enrollment, communication to Spanish-speaking patients, substance abuse—are regularly consulted by company personnel.

The agendas for CAB meetings have evolved from primarily addressing the company's need for understanding the HIV community and its concerns to one which, in addition, integrates CAB member's opinions and ideas in the areas of HIV product development, marketing, and information.

Key Contributions and Accomplishments

Treatment Education

The company's utilization of the CAB has been strongly focused in the area of treatment education. The intent of this focus has been to educate patients, care providers and others who have influence in patients' decision-making about treatment options.

- The CAB has been consulted on the development and production of a variety of treatment education media. CAB members have advised in the areas of clear and appropriate use of language and terminology, and cultural sensitivity. In addition, the CAB has suggested effective ways to market and distribute materials. Among these are:
 - Pamphlets and brochures for Zovirax, Retrovir, Mepron, herpes, HIV, and PCP
 - Brochures in Spanish for Zovirax and Retrovir, and HIV disease
 - Videos for educating patients about HIV and PCP, a special video targeting women with HIV, and accompanying booklets
 - Public service announcements to encourage seeking treatment for HIV
 - Use of 800-telephone lines for treatment information
- The CAB has been consulted on, and generated initial concepts for, the development and implementation of treatment education venues. CAB members have advised on the development of these programs to ensure the use of clear messages, culturally appropriate language, understandable terminology, and accurate community representation in the materials. The CAB has offered ideas on program assessment, and its members have served as leaders in these programs. Among these are:

- Treatment education forums
- Disease pathogenesis forums
- HIV treatment advocacy community meetings
- AIDS professionals telephone conferences

The CAB has been integral in the company's shift to approaching the treatment of HIV via the "disease pathogenesis" model.

Corporate Contribution Policies

- The CAB has advised the company on its corporate contribution policies and practices. Collectively, CAB members have a perspective which serves as an overview of the priority service needs of patients and service requirements of AIDS service organizations. While the CAB does not make recommendations on specific grants and contributions, it helps guide the company's understanding of key issues and the value of various types of organizations, and helps the company determine how to collaborate with and derive benefit from its work with grantees.

Drug Pricing

- The CAB has consistently advocated for maintenance of drug prices and drug assistance programs. The company informs the CAB of its intention to increase prices, and discusses the impact of such changes to the HIV community. The CAB has advised the company on how to effectively position price announcements and changes in pricing or drug support program policies. The CAB's influence brought about the company's decision to impose an annual price cap for patients for whom high doses of Zovirax were prescribed.

Outreach to Underserved Communities

- The CAB has regularly been consulted on how to reach patients in underserved communities with treatment information. CAB members have helped develop brochures and videos which target or address the needs of Latino and African American communities, and women. CAB members have spoken on radio and television programs about treatment issues and options. The CAB has recommended that the company ~~conduct~~ educate minority communities through outreach workers to help people with HIV consider treatment options.

Community Perceptions of B.W. Co.

- The CAB has advised the company on strategic actions which have resulted in reforming the HIV community's perception of B.W. Co. In the late 1980s, after the introduction of Retrovir, the company faced the overwhelming challenge posed by an angry, resistant activist community. Over the years, the CAB has recommended activities and programs which have worked effectively to help the HIV community see the value of working with the company in the development of drugs and of conducting treatment education venues. Among the activities in which the CAB has been involved are the "Living with HIV" campaign and the Frontline Forums and Frontline Forum Teleconferences.
- Many community members and treatment professionals observe the CAB as an integral link to, and strong commitment from, the company by the HIV community. In addition, by the CAB members' interaction with company personnel (and through the increased understanding of the operations of a corporation), the CAB has been able to inform the HIV community about the drug development, introduction and marketing processes. Overall, the HIV community's view of B.W. Co. is more of one as "ally" in the fight for treatment for the disease than that of "foe." Subsequently, the company

has been able to become less defensive and more proactive in engaging the community in company activities.

Introduction of New Drugs/Change in Marketing Strategies of Current Drugs

- The CAB has provided consultation on how the HIV community might react to the introduction of new drugs such as Mepron and Valtrex. The CAB suggested ways in which to position key messages and to help counter concerns which may be voiced by treatment activists and patients. Regarding Valtrex, considerable discussion was conducted to assist the company in understanding the HIV community's perception of both the potential value and the danger in applying for Zovirax OTC approval. The company has utilized the CAB regularly on the development, introduction and marketing strategies of Mepron, Zovirax, and Retrovir.

Access to HIV Community Leadership

- The CAB has provided B.W. Co. management with access to HIV community leaders, which has led to collaboration on projects. Through introduction at individual meetings or through arranged conferences, the CAB has helped the company's network of contacts grow, and improved its influence with them. The Counterpart Conferences, conducted by and for leaders from AIDS service organizations, is an example of a program which has been influenced through CAB recommendations. B.W. Co. initiated and has sponsored these conferences since 1992. In addition, the company has asked the CAB to assist it in understanding how to gain endorsement from ASOs and CBOs for the company's education programs.

Public Policies and Regulatory Practices

- The CAB has periodically voiced its representative insight into public policy issues.

While this is an area in which the company has been very careful to develop positions

and engage in advocacy, the CAB has helped the company understand how public policy influences HIV community perceptions of drug development and availability, access to treatment, treatment education, and overall patient health. The CAB has consistently encouraged the company to resist the implementation of mandatory HIV testing policies, and has supported the increase of use and extension on Ryan White Care Act funding. Regarding federal funding, the CAB advises the company on the implications of federal budget decisions and legislation (such as the Madison Project), and on how those decisions impact the HIV community. In addition, the CAB has consulted with the company to brainstorm tactics to expedite patient access to drugs, and to gain accelerated approval from the FDA. The CAB provides its perspectives on how patients are affected by governmental and other bureaucratic systems, and by the lack of response to urgent health matters. An outgrowth of the CAB is the HIV Public Policy Coordinating Committee, comprised of current and former CAB members with an expertise in policy matters.

Understanding the HIV Community

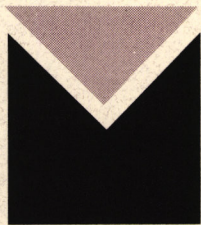
- The CAB has informed the company about how its drugs are perceived through peer communication and individual experience. CAB members will also report on various community issues, to help company personnel gain additional insight into hard to reach patient groups. The CAB has given substantial testimony to help the company shift the perception of Retrovir and Mepron. CAB members have shared information about how various common opportunistic infections—MAC, herpes zoster, pneumocystis carinii pneumonia, etc.—affect patients.

Media Relations

- The company often seeks advice from the CAB on how to present information to community press in order to gain balanced treatment of that information.

Summary

- The CAB has regularly encouraged B.W. Co. to take leadership positions in changing the way pharmaceutical corporations deal with their consumers. The company was also encouraged to challenge the accusations of activists, and to address the treatment education concerns of patients. The CAB serves as a catalyst for direct communication and promotion of understanding for B.W. Co. to make sound decisions in support of the HIV community's treatment education needs; marketing its drugs intelligently; and working to ameliorate a sensitive, polarized relationship with HIV community leadership.



Mobilization Against AIDS

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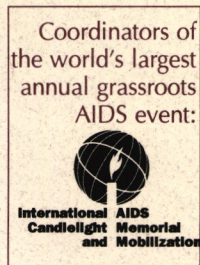
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*California's
oldest nonprofit
AIDS advocacy
organization*



MEMORANDUM

*By Facsimile
(919) 315-0421*

Date: 7 September 1994
To: Fred Gregg, Burroughs Wellcome Co.
From: Mike Shriver, Mobilization Against AIDS
RE: Public Policy Ad Hoc Group

Fred:

Thank you for the fax update regarding the son-to-be Public Policy Ad Hoc Group. I am well aware that with Phill Wilson returning to the Community Advisory Board, there is a natural linkage from the PPAHG to the CAB through Phill and I think this is a great idea.

In following up on your last points, a retainer fee of \$1,500/year is acceptable noting that the originally constructed PPAHG is now far less formal and far less structured. This is fine. Below, I have drafted a boilerplate "Action Alert" for Public Policy Issues that would originate from the PPAHG to you (and then from you to the BW Public Policy Committee) and also understand that we would also be prepared to convene a conference call when needed to brief BW Co. on emerging issues.

Please get back to me at your convenience so we can continue this process. Sorry for the delay, but things here have been maddeningly busy, between the health Commission, the AIDS Cure Act fallout and the FY 1995 Appropriations PLUS HHS/PHS HIV Prevention, I have not had a single moment to myself since May. Last weekend, I was in your hometown of New Orleans, keynoting at an FDA conference. What a city!

Look this over and give me a call. In response to your last fax, I wanted to make this form as user-friendly as possible, as easy to read as possible and not too terribly time-consuming in developing a response.

mds.

draft

MEMORANDUM

Date:
To: Fred Gregg
From: Public Policy Ad Hoc Group
Re:

HIV/AIDS PUBLIC POLICY ALERT

ISSUE

Such as HIV antibody testing, accelerated approval, off-label drug usage, appropriations (etc.).

KEY PLAYERS (PRO/CON)

*Pro: AIDS Action Council, AmFAR, TAG, MAA, the big 6, NAPWA
Con: ACT UP/New York, Project Inform, the Buyers Club Network*

MITIGATING FACTORS

*Herein would be the issues that would otherwise have no venue for discussion such as "AmFAR has traditionally been silent on this issue but is now moving towards aggregating resources toward a Think Tank organization. Supporting this idea *(proposal) would keep BW Co. in line with the movement and direction of AmFAR but would also counterpoise them against community-based treatment providers such as project Inform or DAIR.*

Secondarily, this section would include the political environment and other political implications, such as how this issue impacts policy, funding, who is the key Administration mover and shaker (such as Dr. Phil Lee or Secretary Shalala or even Varmus, Paul or Fauci).

RECOMMENDED POSITION

The Ad Hoc Group would detail its recommendation and attach to this any and all supplemental information to support their recommendation. However, they would also search out and include all information from the "opposing" view plus background information (from archives, newspapers, etc.). Also, Position Papers, as relevant, from other ASOs/CBOs would be attached.

Attachments.



BURROUGHS WELLCOME CO.

to Mike Shriver

from

FRED F. GREGG

Date 6/2

Senior Manager
HIV Community Relations
Extension/Phonemail: 58986

Please submit
a proposal ^{around} ~~as to~~
the "consulting" arrangement
w/ you, Inzi, Phill +
Moises as to Public
Policy as discussed w/
Ron Gentile — CAN YOU
GET TO ME ^{BY} JUNE 13? (OVER) →

Maybe issues
submitted on
standard form:

Issue:

Suggested Position:

Pro:

Con:

→ or
whatever you
think?

MEMORANDUM

BURROUGHS WELLCOME CO.

FROM: Fred F. Gregg**TO: CAB Members****CC: Daniel Dallabrida****DATE: September 24, 1993****SUBJECT: Antiviral Representatives (AVRs) Reference List**

As a follow-up to our CAB meeting this week, attached is the current listing of our AVRs. They will be encouraged to contact their local CAB member to discuss local activities and any appropriate collaboration. As discussed, we will also send them the minutes from our meetings and encourage them to call the appropriate person if they have any questions on the content of these reports.

Please keep me posted (preferably in writing) of any "success" stories within your work with the AVRs or any additional thoughts you have concerning their effective role with the CAB.

Thanks for a great meeting!

CABAVR.DOC

AVRs and Addresses

Cesar Araujo
East 10000
Imperial Hwy E 134
Downey, CA 90242
(310) 803-3287
x 91900
DSM J. Neu
RSD J. Slater

Ravi Bhoot
25 River Road #13A
Nutley, NJ 07110
(201) 667-2851
x 91040
DSM D. Holt
RSD P. Hossenlopp

Richard Byrd
P.O. Box 208
15 Windsor Street
Jamestown, RI 02835
(401) 423-3138
x 91100
DSM W. Regan
RSD P. Hossenlopp

Beverly Constant
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Meadows, TX 77477
(713) 933-1539
x 91300
DSM Hattaway
RSD D. Bolls

Stella S. Corzo
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Miami, FL 33174
(305) 221-7809
x 91180
DSM A. Hartmann
RSD W. Mannheim

Arnold N. Davis
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Bayside, NY 11360
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x 91210
DSM D. Holt
RSD P. Hossenlopp

Gary Dumas
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Poway, CA 92064
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x 91280
DSM E. Fernandez
RSD J. Slater

Christine Felton
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x 98430
DSM D. Rasmussen
RSD W. Murray

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x 91450
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RSD J. Slater

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x 91460
DSM T. Davies
RSD P. Hossenlopp

Ron McGough
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x 91560
DSM G. Whaley
RSD D. Bolls

Deepak Mehta
343 Old Ridge Court
Rochester Hills, MI 48309
(313) 373-4174
x 94430
DSM J. Lawrence
RSD L. Oswald

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x 91390
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RSD A. Anderson

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x 97220
DSM Novis
RSD P. Hossenlopp

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DSM L. Feldman
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x 95590
FAX# (301) 977-5640
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RSD W. Murray

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DSM R. Pope
RSD W. Murray

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RSD J. Slater

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RSD P. Hossenlopp

Sylvia Velez
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DSM R. Cooper
RSD B. Zell

Kaye Whitman
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Washington, DC 20003
(202) 543-3501
x 96010
DSM J. Pishotti
RSD W. Murray



Facsimile Cover Sheet

PROFESSIONAL / COMMUNITY RELATIONS

TO: MIKE SHRIVER

Company/Organization: MOBILIZATION AGAINST AIDS

Phone: 415-863-4676

Fax: 415-863-4740

FROM: FRED F. GREGG, GROUP MANAGER

Company: BURROUGHS WELLCOME CO.

3030 Cornwallis Road

Research Triangle Park, NC 27709

Phone: 800-722-9292 (8-5PM E.S.T.) OR 919-315-8986

Fax: 919-315-0566

Date: 7/29/94

Pages including this

cover page: 1

Comments:

Mike - I hope this finds you doing well! I apologize for taking over a month to respond to your "HIV/AIDS Public Policy Think Tank". You know how the workload is.....not to mention access to the hierarchy..

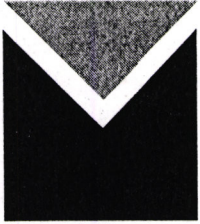
After review with Ron Gentile, these are the key issues as we move forward:

- he feels the **structure is too formal** as described - - he wants no set conference calls and/or meetings and whereas these activities will be pulled together as needed..(this is real world when trying to get a V.P.'s time...)
- within this context he would like to **pay an annual (individual) retainer** of around \$1,500 to keep everyone "on call" and of course all requested meeting expenses and related fees would be paid for as well...it is safe to assume that this retainer is negotiable if work demands dictate..
- he would like to **see a draft "form"** (i.e., one page layout with suggested headers for the content..) from you as to how you suggest we present issues to the **Public Policy Coordinating Committee (PPCC)** - - they will want to see a one page document that spells out the issue, pro/con for each position B.W.Co. could take on the issue, etc...would you construct such a draft form for review as your expertise would be helpful as this will dictate the success of any such issue in getting the company to consider adopting a position on and/or support of....**CAN YOU PROVIDE THIS BY AUGUST 15 (fax to me)?**

I am assuming that you are keeping Phill, Suzi and Moises in the loop on this issue...?

Call me if you have any questions or can not make the August 15th date -

Thanks and take care, Fred



**Mobilization
Against AIDS**

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Executive Director

*California's
oldest nonprofit
AIDS advocacy
organization*

Facsimile Transmittal

Date: 1/4/95

Please deliver to:

Phill Wilson

A.P.L.A.

Fax #: (213) 993-1595

Moises Agosto

N.M.A.C.

Fax #: (212) 544-0378

Suzi Rodriguez

Fax #: (310) 598-3016

From:

MIKE SHRIVER

Executive Director

MOBILIZATION AGAINST AIDS

Number of pages to follow: 3

Please confirm receipt of this fax to (415) 863-4676.

Phil, Moises, Suzi:

For our first report to BW Co. for the Public Policy Ad Hoc Group. Please review this document and make changes or just approve it so that I can forward this on to Fred. I hope this finds you well!

Coordinators of
the world's largest
annual grassroots
AIDS event:



**International AIDS
Candlelight Memorial
and Mobilization**

(Updated 11/18/94)

PPCC MEETING DATES
FOR 1995

<i>January 9</i>	1:00-3:30 pm Room C3414 - Medical - Main Bldg.
<i>February 6</i>	1:00-3:30 pm Room C3414 - Medical - Main Bldg.
<i>March 6</i>	1:00-3:30 pm Room C3414 - Medical - Main Bldg.
<i>April 3</i>	1:00-3:30 pm Room C3414 - Medical - Main Bldg.
<i>May 1</i>	1:00-3:30 pm Room C3414 - Medical - Main Bldg.
<i>June 5</i>	1:00-3:30 pm Room C3414 - Medical - Main Bldg.
<i>July 10</i>	1:00-3:30 pm Room C3414 - Medical - Main Bldg.
<i>August 7</i>	1:00-3:30 pm Room C3414 - Medical - Main Bldg.
<i>September 11</i>	1:00-3:30 pm Room C3414 - Medical - Main Bldg.
<i>October 2</i>	1:00-3:30 pm Room C3414 - Medical - Main Bldg.
<i>November 6</i>	1:00-3:30 pm Room C3414 - Medical - Main Bldg.
<i>December 4</i>	1:00-3:30 pm Room C3414 - Medical - Main Bldg.

MEMORANDUM

Date: 4 January 1995
To: Fred Gregg
From: Public Policy Ad Hoc Work Group
RE: January 9, 1995 Public Policy Alert

Issue: The reauthorization of the Ryan White CARE Act in the 104th Congress. Because of the size (\$770 million dollars of discretionary domestic resources, the second largest domestic discretionary program funding a continuum of HIV/AIDS care programs across the nation) of the program and the need to increase appropriations into a fully reauthorized bill, the CARE Act needs to be reauthorized as soon as possible into the 104th Congress.

Key Players: There are incidental players who do not completely support the proposed reauthorization bill (as was submitted to Congress in the 103rd Congress) and most notably, these groups are unhappy because:

- a) their amendments are not currently part of the reauthorization package (*Center for Women Policy Studies, Legal Action Center* (substance abuse issues); or
- b) there is still disagreement over the formula for Title I of the act and how to make the formula more equitable for Title I cities other than New York City, San Francisco and cities in New Jersey, as well as Miami (*AIDS Healthcare Foundation* [LA], *Campaign for Fairness in Federal Funding* [Wisconsin]).

These concerns are surmountable.

As for groups in support, the list is all-encompassing, including the national AIDS organizations, the "big 6", the AIDS Action Council, AmFAR, TAG, the CAEAR Coalition (Title I), NASTAD (Title II), the Title IIIb Coalition (Title IIIb), the AIDS Policy Center for Children, Youth and Families (Title IV), Campaign For Fairness in Federal Funding (marginally), the Title II National AIDS Coalition, NMAC, NAPWA, etc.

Mitigating Factors: There is unbelievable pressure already present in the 104th Congress to block grant everything possible in health and human services, including Ryan White. There is already a Washington Post article dated 11/22/94 wherein a GOP staffer on the House side discussed "dismantling the Ryan White" program as part of the Republican agenda for 1995.

Lastly, as for a mitigating factor, the Congress, for the first time, has changed hands from Democrat to Republican, and, as a result, has lost several key staffers and several key caucuses from its roll. This means that a lot of the work that needs to be done in order for a smooth reauthorization will either need to be done by a relatively new or green staffer, or else it must be done by community members for the committees who will reauthorize.

Recommended Position: BW Co. must come aggressively out in front of supporting the reauthorization of the CARE Act as well as reauthorizing the Act while **RETAINING THE INTEGRITY** of the bill. Specifically, there should be no disruption between Titles I and II of the bill and both need to be protected. If the CARE Act is not reauthorized, this will literally mean disaster across the country, first in the cities receiving Title I resources. Bankruptcy is guaranteed at least in San Francisco if it loses Title I. If Title II is not reauthorized, every state will lose the major source of its AIDS Drug Assistance Program. Even if Ryan White were to be folded into a giant state-based block grant, we will still see the elimination of the funding stream and control over federal resources for HIV/AIDS care.

Secondly, BW Co. should seriously consider financially assisting advocates pushing for the reauthorization of the CARE Act. Both BW Co. and the advocacy community have a shared interest in preserving the essential programs funded through CARE.

MUST BE SUBMITTED ONE WEEK PRIOR TO MONTHLY PPCC MEETING DATE

Date: _____

To: Fred Gregg FAX # (919) 315-0421

From: Public Policy Ad Hoc Group*

Re: _____

HIV/AIDS COMMUNITY PUBLIC POLICY ALERT

ISSUE

KEY PLAYERS (PRO/CON)

MITIGATING FACTORS

(Background and political environment)

RECOMMENDED POSITION

* Members: Suzi Rodriguez, Phill Wilson, Mike Shriver and Moises Agosto

USZM/94/2076

FFG/cm*

MKT 12/09/94

Burroughs Wellcome Co.
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Daniel Dallabrida & Associates

MEMORANDUM

TO: MOISES AGOSTO SUZI RODRIGUEZ
MARINA ALVAREZ ANGELA SHILOH-CRYER
CHUCK FRUTCHEY MIKE SHRIVER
JOHN MANZON JOHN-PETER WILHITE
ROBERT REMIEN PHILL WILSON

FROM: KATHY RISSO
Daniel Dallabrida & Associates
Phone: (415) 255-6186
Fax: (415) 552-8314

DATE: October 18, 1993

RE: • CAB PHONE LIST UPDATE
• B.W. CO. PERSONNEL PHONE LIST
• AN ARTICLE FOR YOUR INFORMATION

CC: Fred Gregg, B.W. Co.
Cynthia Wyatt, B.W. Co.

Attached please find a revised CAB phone list. The address and phone numbers for Suzi have changed. Also, at this time, Marina Alvarez does not have a FAX number. We hope in the next few weeks to be updating this again with a new number for her.

At the last CAB meeting, a few of you requested a phone sheet be published for B.W. Co. personnel. Attached you will find a personnel list with phone numbers and fax numbers for people involved with CAB meetings. As we become aware of changes, we will let you know.

Finally, Daniel has asked that I send this article from the November, 1993 issue of *Out*, about ACT UP, for your information.

I hope this finds you all well. If there is anything else I can provide you with, let me know.

Kathy

93/94 HIV COMMUNITY ADVISORY BOARD

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I N S I D E S T O R Y

WHAT'S GOING DOWN ACT

Has the organization come of age or is it over the hill?



WITH

UP?

ally Chew reports on activism in a changing epidemic.

IT'S NOON IN ST. LOUIS and 95 degrees and windless on the grassy little triangle at the corner of Washington and Grand. Kim Marley brushes away sweat and rocks a poster-board sign on her Nike Crosstrainers. HEALTHCARE NOT WEALTHCARE, it shouts in block letters over a gray, gritty photograph of a young white man KILLED BY GREED.

Kim is off for an hour from her day job educating Missourians about breast cancer. She peers through chin-length hair at a circle of eight mostly white-sneakered men around her. Their T-shirts betray contact with the coasts: Mixed in with the ACT UP/STL white-on-black, there are designs from Boston, New York, and Los Angeles. Kim is irritated by the small turnout—and just as thrilled that this is happening at all. It's been a year since the last ACT UP civil disobedience. She studies a chant sheet, looking up briefly to warn a reporter, "I don't chant well; my voice goes too high-pitch."

Someone hoists a coffin spotted with blood-red hand prints, another stuffs a wad of dollar-bill-like fliers into the back pocket of his shorts, and the group is off down the sidewalk toward an orange brick building on Lindell Boulevard: office of the Division of Family Services, the city's dispenser of Medicaid. HIV clients are getting a "runaround" and DFS director John Lofton won't talk about it. Today there will be shouting, arrests, and even a little police brutality. Just like old times.

SUMMER CAME SLOWLY and late to ACT UP this year. The April March on Washington wasn't the hoped-for blitz, with the military ban and gay leaders' visit to the White House seeming to eclipse AIDS. Then on May 18, a certain alarming press release curled off ACT UP fax machines around the country, announcing the demise of the Washington, D.C., chapter and predicting that "other ACT UP chapters will soon follow suit."

"Trying to keep ACT UP afloat has become like rearranging the deck chairs on the Titanic to keep it from sinking," D.C. founder Stephen Smith was quoted as saying in

Sally Chew, formerly of New York Woman, has traveled extensively as a wire-service reporter.

the release. "What happened today with ACT UP/DC is just the tip of the iceberg."

With membership in decline all over the country, the news on vaccines and antivirals so grim from the Ninth International Conference on AIDS in Berlin, and the face of AIDS work looking so different, so long-term, in this second decade, not a few paused to wonder if Smith was right. The Clinton-era apathy was palpable. And what about the flight of so many ACT UP street warriors into AIDS service organizations and community advisory panels? Was this the end of ACT UP as we knew it?

Certainly the internal bickering had been loud enough over the years to be worrisome. Most chapters have been touched by the tug-of-war between treatment issues—learning the science and pushing for new and better drugs—and so-called social issues: the needle exchange, housing, social service, sexism, and racism crises that are now part of AIDS. The debate, a question not just of human resources but also of political priorities, has torn chapters apart. In late 1990, for example, a pro-treatment faction had split off from ACT UP/San Francisco to form ACT UP/Golden Gate; a year later, members of New York's Treatment and Data Committee started an independent, by-invitation-only group called the Treatment Action Guerrillas (later the Treatment Action Group).

Then came 1992, burnout year for ACT UP activists all around the country: too many leaders lost to AIDS, too many letdowns from science and the policymakers, and too much confusion over what to do about the AIDS era's first Democratic White House. The malaise lasted well into 1993.

But a sinking Titanic? ACT UPers and outsiders alike are unwilling to accept Smith's national doomsday scenario. Sure there is an identity crisis to overcome, they say, but ACT UP is rising to the occasion. "I do see a lot of people taking breathers, but that doesn't mean we're giving up," says Helene Schpak of ACT UP/Los Angeles. "We're seeing the anger rise. More and more people are aware that our efforts are just not enough. And I think that the anger leads either to greater apathy or greater action. We're seeing both right now."

The argument is that this has been a year of hard-won accomplishments, and it's a convincing argument. More

CLEVELAND

Established: 1993.
Membership: 25.
Favorite action: Defaced a homophobic billboard that depicted a chef cooking "homo stew" with the caption "Jeffrey Dahmer The Gay Gourmet."
Most effective: A die-in at the Gay Pride march.

DALLAS

Established: 1988.
Membership: Core of 20; 30–40 at actions.
Favorite action: Demo against the religious National Roundtable at the Dallas County Convention Center in

August 1992 drew 200, including gay and lesbian ministers preaching across the street. Banged on the Center's huge glass doors, leading to an arrest.
Most effective: At a suburban school board meeting, 25 protesters—many high schoolers from a local gay and lesbian youth group—protested the lack of an AIDS curriculum. The board had to put the issue up for a vote.

GOLDEN GATE

Established: 1990.
Membership: 30–50 at meetings, 300 on mailing list.
Favorite action: Shut down the Pacific Stock Exchange in

June 1992 over Abbott Laboratories' unwillingness to develop HIV immunoglobulin.

Most effective action: At local FDA headquarters in October 1990, demanded that the drugs ddI and ddC be approved. Many arrested. Approval of ddI followed in 1991, ddC in 1992.

MILWAUKEE

Established: 1989.
Membership: 200–250 on mailing list.
Favorite and most effective action: Zapped governor's meeting discussing whether state would build more prisons. Urged

compassionate release for PWAs, so there would be no need for more prisons.

NEW YORK

Established: 1987.
Membership: 250 at meetings.
Most effective actions: FDA in 1988; Hoffmann-La Roche in 1992.

PHILADELPHIA

Established: 1988.
Membership: 40 at meetings.
Favorite action: Demonstrate in front of the Hotel Atop the Bellevue in September 1991 when President George Bush addressed a fund-raiser for senate candidate Dick



The tug-of-war between treatment issues and so-called social issues—a question not just of human resources but also of political priorities—has torn chapters apart.

integrated into community-level health care and politics than ever before, ACT UP's clout has also become a matter of fact with corporate and government decision-makers all over this issue.

After all, it was in 1993 that the Centers for Disease Control began using a broader AIDS definition, as ACT UP had long demanded. The CDC now recognizes invasive cervical cancer, pulmonary tuberculosis, and recurrent bacterial pneumonia—diseases common to women or intravenous drug users with HIV—as indicators of AIDS, three and a half years and 12,000 letters from the public later. ACT UP also helped put the HIV-positive Haitians interned at the Guantánamo Naval Base in Cuba into the

public eye and kept them there until their release in June, and engineered an unprecedented meeting in April between Health and Human Services Secretary Donna Shalala and 18 lesbians, 15 of them HIV positive. Not to mention the social service and education breakthroughs all the time now on the local level.

If none of this has been as evident to the world outside as, say, the 1988 FDA campaign to speed medicines to market or the AZT price wars at Burroughs Wellcome, it's partly a media problem: ACT UP isn't as photogenic as it used to be. The group is rightfully taken to task for failing to sustain a colorful public image, and the media for being too easily bored. But the change was *(continued on page 130)*

hornsburg. A brief riot followed.

PORTLAND, ME.

Established: 1991.

Membership: Core of 10; 200 on mailing list.

Favorite action: Memorial Day 1992 in Kennebunkport, 50-75 activists marched in parade and staged civil disobedience. American Legionnaires acknowledged AIDS deaths as comparable to war casualties.

Most effective: Battled "The Dracula Bill," state legislation proposed in early 1993 to eliminate required counseling and consent for HIV-antibody testing. Convinced chief

sponsor to temper his enthusiasm for bill. It failed.

SAN FRANCISCO

Established: 1988.

Membership: 25 at meetings. Favorite action: Demos at the international AIDS conference in June 1990, with 10,000 marching against the HIV immigration ban and 300 arrested at a demo urging the CDC to broaden the definition of AIDS.

Most effective: Secured an AIDS hospice at Vacaville, California, prison medical facility and pushed for compassionate release.

ST. LOUIS

Established: 1990.

Membership: 30 active; 100 on phone tree.

Favorite action: Took an AIDS tree to the mayor, Christmas 1991. Ornaments included tombstones naming the deceased, plus condoms, dental dams, lube, red tape, and needles; a pink triangle on top. Sang Christmas carols with new, activist lyrics in City Hall.

Most effective action: Urged anonymous testing through the state AIDS education and testing clinic in 1991, which then emphasized contact tracing. Clinic now

explains to each patient the option for confidential and anonymous testing.

WASHINGTON

Established: 1993.

Membership: Core of 20; 300 on mailing list.

Favorite action: Zapped Donna Shalala over Kristine Gebbie's support of Oregon's health-care rationing and the internment of HIV-positive Haitians at Guantánamo Bay. Most effective: Protested outside Rose Garden ceremony when Gebbie's appointment was announced. ACT UP criticisms got into *The Washington Post* and wire reports.—ELISE HARRIS

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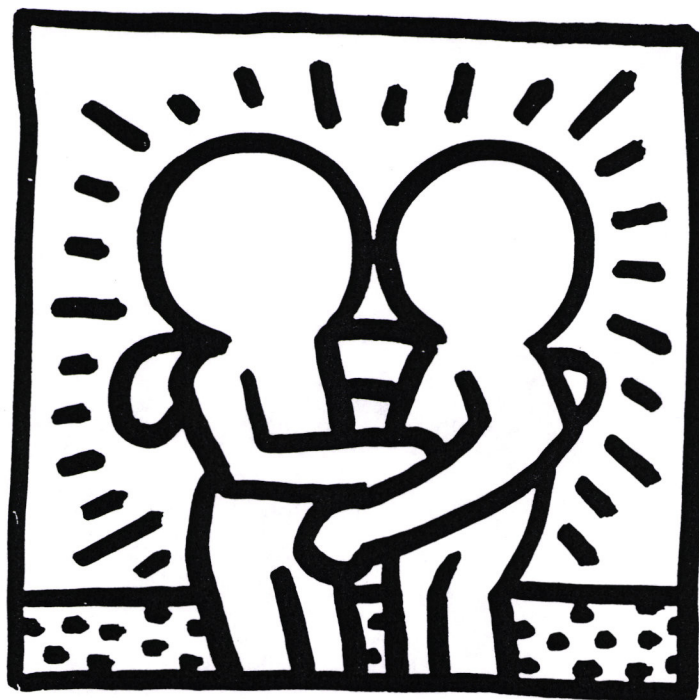
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ACT UP (continued from page 75)

probably inevitable. The peculiarities of the epidemic—its effects on most areas of life by now—have forced activists into taking the longer, lower-profile, tactical view, anathema as that would have been to the spirit of the early ACT UP, when bureaucratic slowdowns seemed so singularly to blame for all the dying.

"More than ever now, we're dedicated to not looking for a magic bullet but looking at the long term," says Gdali Braverman of ACT UP/Golden Gate. "The media is always focusing on the moment, and because ACT UP is such a media-genic organization, the public sees what we're working on *now*. But people still don't understand how much of a brain-tank of a group this is, how much work is being done behind the scenes that isn't shown."

A June 8 Health and Human Services fax to White House press secretary Dee Dee Myers during the Berlin conference made it clear that, whether or not the Clinton administration is listening to what ACT UP has to say, there is no longer any question of being overlooked at that level. "Heads Up," one office of the government's executive branch told another. "A big ACT UP press conference here this morning."

THE REAL STORY about ACT UP/DC is hard to find among the suspicious bookkeeping, brutal personality assassinations, and lessons about how and how not to carry on in the capital. One version has Michael Davidson, a D.C. native visiting from ACT UP/Seattle who would eventually file suit against the D.C. chapter, wearing a MICHAEL PETRELIS GET A LIFE sticker around the city. (It was high-profile ACT UPer Petrelis who had made the motion to shut D.C. down.)

There may be something to glean from the Washington experience. Other chapters (including the new one, ACT UP/Washington, started in D.C. over the summer by members of ACT UP/Seattle) will be on guard against "incorporation": It didn't look good when the D.C. founders filed papers of incorporation putting chapter assets under their own names the same day the membership voted to close up shop.

Also, according to several people watching this unfold, including Jason Heffner, who served on the federal AIDS commission for four years, there were political mistakes worth not repeating. "The D.C. shutdown was the result of a superficial understanding of activism," says Heffner. "The chapters that continue are ones that have focused on specific issues and [channeled] the street actions into that, and not the other way around. In D.C., it was the public events that drove the rest."

So far, few of ACT UP's 79 other chapters have fallen into that trap (see box, pages 74 and 75). The group as a whole has succeeded, again and again, at tailoring its methods to its targets. It's one explanation for ACT UP's ability to outlive groups like Queer Nation (and possibly the more recently formed Women's Action Coalition) to which it bequeathed its 1968-style direct-action tactics. ACT UP has discovered that there is more to effecting change than yelling in the street. "People in power have learned to give a certain kind of lip service," according to Esther Kaplan of ACT UP/New York. "How do you get that verbal response and then call people on it? That has to be over a period of time, not a fire-works display."

Many of the latest battles have been waged without ACT UP's traditional modus operandi: the large-scale pickets and civil disobedience of earlier years. It's partly a question of numbers. The AIDS industry has absorbed some of the people and dulled some of the rage, and Clinton's victory has done the same. It's harder than it used to be to rile the masses. But at some point, right about the time the scientists and policymakers started listening, ACT UP started turning away from consciousness-raising and the media and toward the decision-makers. There has arguably been some loss to the public—less information going out and fewer recruits coming in—but the gains on the inside have been considerable, thanks in part to the threat of direct action.

"A lot of people around the time of Clinton's election were saying activism is going to fade," says Kaplan. "But ACT UP has maintained its degree of threat. We're more forward-looking and making bigger demands. I think we're at an historic moment. ACT UP can mobilize. It's effective. It can dog people when it chooses to."

The Barbara McClintock Project to Cure AIDS—named after a late research geneticist whose ground-breaking work on DNA replication wasn't recognized until more well-connected colleagues reproduced her findings—may be the ideal testing ground for the new ACT UP. The group's ability to manage its insider/outsider status will make or break the proposal to establish a Manhattan Project-style program that is free of the conflicts of interest that have stalled AIDS research in the past.

The plan is to either take Clinton up on his promise to implement such a project or find a congressional sponsor. ("That Clinton could say in his campaign that AIDS is his obsession... He must be taking Prozac now," offers ACT UP/New York member Mark Milano.) The strategy: focus on educating people like Donna Shalala, for example, or Senator Al D'Amato, while

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dogging them relentlessly in public. At the end of July, 125 people signed up at a general meeting in New York to join a series of McClintock "SWAT teams"; in early August, 15 went undercover in corporate drag to a Washington reception for senior government and other health officials and managed to hand out 200 copies of the proposal (and disrupt a speech by Kristine Gebbie, Clinton's controversial new AIDS advisor). The response—a mixture of interest and annoyance, as intended.

Milano shakes his head at the speed with which the government dispatched \$6 billion to the victims of the Midwestern floods this summer. "Easily, less than a billion could start up a McClintock Project. They wanted to go to the moon, and they did. They wanted to build a bomb, and they did. In no time flat. Well, they could take our breath away with AIDS."

ACT UP has often found itself at cross-purposes with national policy groups. And chapters in cities as far ranging as Philadelphia, New Orleans, and St. Louis tangle with their local AIDS service organizations all the time.

JEFF LEVI WON'T FORGET the October day in 1988 when he, in his role as then executive director of the National Gay and Lesbian Task Force, sat down for an appointment at the Washington headquarters of the Food and Drug Administration. Hours earlier, hundreds of activists had held the place hostage in the name of the AIDS Coalition to Unleash Power—and Levi's hosts were still a little uneasy.

"It was particularly warm inside," he

recalls. "I guess the air-conditioning was broken or something. So at one point I said, 'I know some people who could come and open some windows for us.'" Everyone fell silent. "They were horrified," says Levi, "until they realized I was joking."

From the start, ACT UP hoped that lobbyists and service providers would sprinkle their conversations with remarks like Levi's, and that the whole process would strengthen

ACT UP's hand. In truth, it hasn't been that easy. ACT UP has often found itself at cross-purposes with national policy groups. And chapters in cities as far ranging as Philadelphia, New Orleans, and St. Louis tangle with their local AIDS service organizations all the time on budget priorities, under-representation of PWAs in decision-making positions, and the service organizations' failure to use their greater access to make radical demands.

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Problems between ACT UP/NY and the Gay Men's Health Crisis, for example, are legendary. Early tirades about GMHC complacency from playwright Larry Kramer, a founder of both bodies, established ACT UP as a sort of watchdog; GMHC, in turn, finds ACT UP sometimes rocks the wrong boats. One of the most touchy moments in a long, tense relationship came in 1989 when then deputy GMHC director Tim Sweeney condemned the chapter's campaign to harangue city health commissioner Steven Joseph for reducing estimates of the number of New Yorkers exposed to HIV, thereby cutting into the city's eligibility for AIDS funds. ACT UP protested outside Joseph's home and dogged him in person and over the phone. Sweeney found the approach "inappropriate." (Even now this issue remains thorny; Sweeney declined to return six weeks of phone calls.)

The Democrats' return to the White House is putting further strain on these fragile relationships; with Bush, common enemy No. 1, out of the way, nothing is as clear as it was. If the March on Washington was the first Clinton-era unity test for the gay rights and AIDS communities, the president's choice of Gebbie to lead his government's fight against AIDS was the toughest so far.

ACT UP began protesting her appointment the moment it was announced in June, circulating information on her past support for laboratory-based name-reporting of people with low T-cell counts, health care rationing, and internment of "casually irresponsible" HIV-positive citizens. Gebbie tried to distance herself from some of this. And heavyweights like the AIDS Action Council and the American Foundation for AIDS Research stayed quiet, arguing, as AmFAR co-founder Mathilde Krim puts it, "It's not the ideal [choice], but it's the decision of the president. She's a good woman, she's well informed, she's dedicated."

Krim adds, "This is the very beginning of the Clinton administration. Apart from increasing funding, he hasn't done so much. But he's still such a quantum leap above Bush that we think we should give him more time."

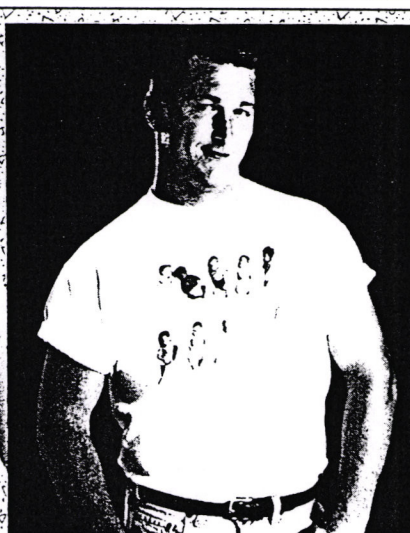
ACT UP balks at requests for "more time." The group counts 15 AIDS promises Clinton has broken, ranging from lifting the HIV immigration ban and adopting the recommendations submitted by the AIDS commission during the Bush administration to instituting a prevention campaign and a Manhattan-style project.

Behind the faith in Bill Clinton, Esther Kaplan in New York senses "a lot of

disrespect for grass-roots activism and an interest in presenting sanitized versions of gay political demands and moving away from something as depressing and seemingly unwinnable as AIDS. What we're left with is a denial of the fact that AIDS has been the defining experience for the gay community. Emotionally as well as politically."

It's the same complaint ACT UP has of many gay rights groups now, especially in the wake of the campaign to lift the military ban. AIDS activists also resent the way the ban and gay civil rights issues seem to have swallowed up the already small space the media devotes to gay issues, leaving AIDS sorely under-covered. Torie Osborne, executive director of the National Gay and Lesbian Task Force, rejects these arguments, which she says are based on AIDS activists' failure so far to articulate a new agenda for the Clinton years. "AIDS has been replaced by some other issues, but that doesn't mean that the gay movement is to blame. It doesn't mean that you have to choose between AIDS and gay issues."

"There is a grieving process that is being misdirected at gay organizations, and it is about two things: the horrible reality that there is no good news about AIDS, that it's part of the landscape, and



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the fact that single-issue movements represent the intrusion of other issues."

The solution offered by Gdali Braverman in San Francisco: "We need to sit down as a collective and decide who's going to be good cop and bad cop—and worse cop."

THE MEMBERSHIP of ACT UP/New York is half what it was a year ago but still too big at 250 for the main room at New York's Gay and Lesbian Community Services Center. People lean in from the surrounding hallways, prop themselves against pillars, mill about at the back.

One meeting in the summer of 1993 is more tearful than usual. A meeting facilitator breaks down and storms out, overwhelmed by the impossibility of her job. Later, people are crying about the news that ACT UP stalwart Tim Bailey has died. For a moment there are just sobs and the wop, wop, wop of the ceiling fans. And then fury.

"I feel like I live in Somalia, or fucking Bosnia, with a bunch of people who don't know they live there with me!" yells one woman at the end of a story about sitting on Bailey's hospital bed painting his toenails with polish "that had to have gold in it." The rage catches on around the room, finally crescendoing into a group

indictment of the "let's get loaded and forget the issues" feeling at New York's Gay Pride parade the week before. Someone shouts "ACT UP!" and the roomful takes the cue: "FIGHT BACK, FIGHT AIDS!"

After three of those, there is a frustrating silence, full of "Where do we take this?"

Three days later, a van takes a casket containing Bailey's body down to a parking lot crowded with his friends and fellow activists outside the Capitol in Washington. The body never gets to the White House, as planned—or even out of the parking lot, thanks to the D.C. police, who are alternately horrified and laughing. But there is something about the event (which gets a lot of press) that is just the public pie-in-the-face that was called for.

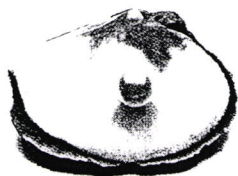
Sometimes the righteous attitude ACT UP is so famous for inspires a dramatic, spontaneous spectacle that does more justice to the horror of AIDS than anything planned out carefully or officially approved by the ACT UP body. Other times, symbolism won't do, and the attitude can backfire. That's the substance of most of the criticism from outside ACT UP these days: that somehow the group is not moving quickly *enough* into different strategies for different times.

Peter Staley, an ex-ACT UPer who helped found the Treatment Action Group

in 1992 out of his feeling that ACT UP was too tied to old, predictable ways of doing grass-roots activism, still sees it that way. He was embarrassed, for example, by ACT UP activists' insistence in Berlin on sticking show booths, just like in years past. "They now have these indestructible booths so they can peel off the stickers after you leave. It's become a kind of a joke. They know the game, we know the game."

In much the same way, ACT UP is sometimes accused of letting its brash style interfere with the poverty and racism work—around homelessness, needle exchange, and under-representation of minorities in treatment trials, for example—that is defining the new face of AIDS. Yannick Durand, director of education for the Brooklyn AIDS Task Force, hasn't heard from ACT UP in a while. But she will say frankly that "working with them was a mixed blessing." While she has high praise for their ability to make noise around an issue, she says, "Sometimes it was difficult because even though you had people working in the community, it was as though they knew better than you what your field was. It didn't feel like a joint effort."

"This is something I've experienced with people who work in more mainstream organizations," she says. "I don't know if it's a class issue, a race issue, or



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ker Toys now. The brain drain that paralyzed it for a while in 1992 when the Treatment Action Guerrillas left isn't likely to repeat itself. "People used to do things that were very unaccountable to the group," says Esther Kaplan. "Now there is a sense of mutual responsibility. It's the organization maturing."

In the same vein, there seems to be a better understanding of how to handle the fruits of the group's own success: ACT UP members serving on advisory panels and taking jobs with AIDS service organizations and lobbying groups.

It was a big problem at first, especially in New York. According to Wolfe, "People started to believe people were listening to them because they were on some board, that that was where the action was, not in the streets. If you're going to meet with people, you have to be accountable to people in the streets."

"People used to do things that were very unaccountable to the group," says Esther Kaplan of the New York chapter of ACT UP. "Now there is a sense of mutual responsibility. It's the organization maturing."

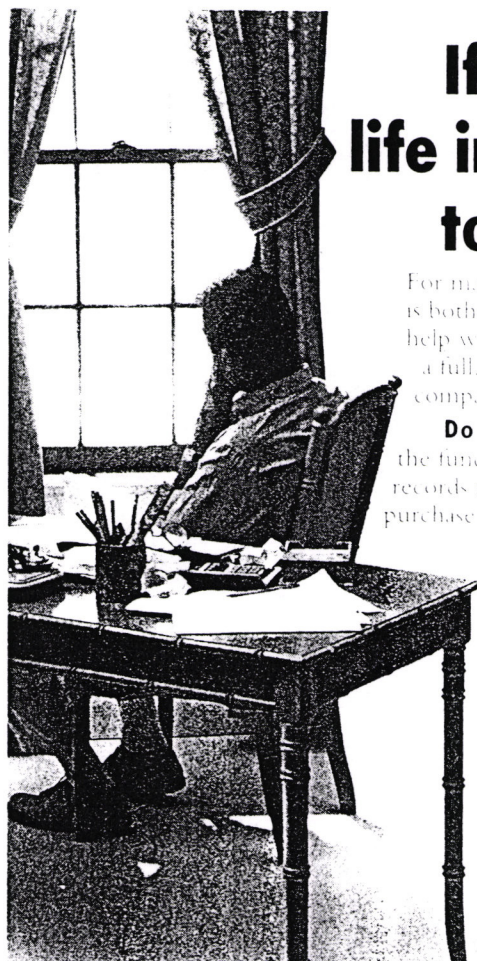
Wolfe is not the only one making connections all the time now between the group's renewed political savvy and the fact that the proportion of women is the highest ever. The argument, of course, is that women bring more and broader political experience. While many of the men drawn to ACT UP weren't activists until AIDS, the women tend to come from reproductive rights movements, the left, and various urban issue campaigns—and to be

communication. And the channels opened in the course of the caucus's April meeting with Shalala have proved invaluable. In July they were instrumental when ACT UP convinced the CDC to delay a set of severely flawed guidelines involving a cervical cancer test for HIV-positive women, another success with the long-term, inside-outside approach.

"What we're seeing in L.A., and I think around the country," says ACT UP/AN's He-

more familiar with ACT UP-style direct action. When AIDS stopped looking like a short-term medical problem and the virus began ravaging the female population too (AIDS is now the leading killer of New York women between the ages of 25 and 44), women became even more involved.

It's certainly true that little in ACT UP now rivals the group's National ACT UP Lesbian Caucus in terms of city-to-city



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what. But it felt very paternalistic."

There are plentiful examples of successful ACT UP coalitions with communities of color, especially around needle exchange, housing, and Guantánamo Bay. But the perception persists that ACT UP, being a primarily white, middle-class group, does best on white, middle-class issues.

Some predict that could be the group's downfall. Phill Wilson of AIDS Project Los Angeles says ACT UP will eventually lose its effectiveness if the membership doesn't diversify. He can't see how it will handle the epidemic's steady move into the straight, minority population otherwise. According to the Centers for Disease Control, the rate at which AIDS cases are increasing is going down among homosexuals, while it is going up among heterosexuals and intravenous drug users. Wilson says, "I'm not sure if white men as a group of people will have the same kind of rage when the debate is about black straight women."

That's the substance of most of the criticism found outside ACT UP these days: that somehow the group is not moving quickly enough into different strategies for different times.

WHEN MAXINE WOLFE THINKS of the New York chapter, which she's been a part of for all six of its years, she pictures a Tinker Toy. "beginning with the round thing in the center with all the spikes coming out of it." Early on, she says, "everyone who took from ACT UP gave to ACT UP. Then all these committees started claiming turf and became wheels at the end of those spokes. They just took from the center without giving anything back."

"They were creating an organization without a center," says Wolfe about the ACT UP of 1989 to '91. "I call it structured anarchy."

The chapter was hitting on an issue that would continue to test its internal structure: the importance of expertise in the fight against AIDS. Now more than ever, it's the details that matter. Greater access to the decision-makers, a major goal in the early years, has to some degree been achieved. With a seat at the

table, ACT UP has to match the scientists and the bureaucrats term for term. But that kind of knowledge takes exhaustive individual learning—learning that, without some kind of formal exchange, is lost to the group every time someone leaves.

Momentum is hard enough to sustain with activists dying all the time. How to go on after losing someone like Bob Rafsky, for example—a media whiz in the New York chapter whose death last spring deprived the group of what a fellow member called a "prophet"? Or Jon Greenberg, a pioneer in the use of alternative treatments? And so on.

New York is doing better with its Tin-



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lene Schpak, "is that the women are taking the forefront: on research, direct action, and coalitioning with other women with AIDS to really try and have an impact."

She is even willing to wager that "the future of AIDS activism is with women."

BY THE TIME police have cut through the red tape binding Scott Dachsteiner to Ken Schweiss and dragged both into a paddy wagon, the show of official force at St. Louis's Division of Family Services is a little ridiculous. For a dozen protesters, the city has summoned seven squad cars and 11 blue-plastic-gloved cops—not to mention the two state security police punching at Scott and Ken for the past hour. Just before the wagon takes off, somebody swings Greg Gerhart in there too. There is a roar of disapproval from the picketers on the sidewalk, a little wilted by now but still waving signs; in five minutes, their part of this action will be over too.

Bob Goss, a gray-bearded former Jesuit priest who is ACT UP/St. Louis's legal observer, and designated bail queen today, makes his way calmly to a little blue Tercel and drops his clipboard into the backseat. Air-conditioning on high, cash card in hand—"Uh oh, what's Ken's last name?"—he's off to Central West End Savings.

Goss's involvement in ACT UP was partly inspired by personal loss: Last year, AIDS killed his lover and his brother on the very same day. "If it weren't for my faith, I would have gone crazy," he explains. But activism for him is also part of a larger, spiritual scheme: a long-term battle for justice that he feels he will always be part of. "The '90s and the next century are going to be real struggles for freedom," he philosophizes, nodding at a copy of the book he wrote, *Jesus Acted Up: A Gay and Lesbian Manifesto*. "And the only way to do that is with rudeness."

That's probably what chapters in the South and the Midwest have going for them, in fact: shock value that the coasts can't muster anymore away from the fundamentalists and the unsaturated media.

Plus, there are other advantages. While the glare from service organizations and political groups can be icier—"I don't know how many people have come up to me since Pride and whined about us stopping their parade [with a die-in]," Greg Gerhart complains—these chapters, being so much smaller, aren't distracted by the same internal problems. There's very little chance, for example, that information will be hoarded in some committee's pursuit of scientific expertise.

There is no away-from-the-coasts ACT

UP formula, though. Philadelphia is probably more racially diverse than any other chapter, and St. Louis is as white as can be. Chicago's numbers are way down; Milwaukee's are holding steady. One chapter reports very few HIV-positive members; another says they are practically the only people at meetings. And how to reconcile an image of a milder Midwest with the T-shirt Cleveland member Marcos Rivero wears most of the time: DESPERATE DYING HOPELESS PEOPLE WITH NOTHING TO LOSE ARE DANGEROUS AND UNPREDICTABLE?

Maybe the most important thing to know about the ACT UPs of the Midwest and the South is that they are everywhere: a solid half of the country's chapters are headquartered between the coasts.

In St. Louis, it's 4:30, and Bob Goss is still waiting patiently on a bench in the cavernous front hall of police headquarters when the prisoners from the DFS action ("those white guys") are liberated—\$550 later. Now this could be Anytown, USA. The three emerge grinning, shoelaces swinging from around their necks, a little weakened by hunger and, for two of them, HIV status. Greg fingers the white plastic bracelet on Scott's wrist; he's more angry at his captors for depriving him of a trophy than for his surprise arrest. Then it's back out into the summer heat. ♥

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