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The 1997 Annual Meeting of the Philanthropy Roundtable
October, 23-25, 1997, Newport, Rhode Island
The Doubletree Islander Hotel

The 1997
ANNUAL MEETING
of the
PHILANTHROPY ROUNDTABLE

Are we entering a GOLDEN AGE OF PHILANTHROPY?

AGENDA ENCLOSED

OCTOBER 23 - 25, 1997 ✦ NEWPORT, RHODE ISLAND

THE DOUBLETREE ISLANDER HOTEL

A Conference for Donors Only

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Addressed To

Summers, Todd

Sender's Organization

Funders Concerned About AIDS

Sender's Street1

310 Madison Ave. STE 1630

Sender's Street2

Sender's City	Sender's State	Sender's Zip
New York	NY	10017

Subject

Conf. Agenda Oct. 23-25 1997

☐ Response Needed?

Response Type	Response Date	Responder ID

Responder Name	Action Promised	Action Complet	Action Date

Notes

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Mobilizing Philanthropic Leadership and Resources in the Fight Against HIV/AIDS

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Memo

To: Joyce Bove, New York Community Trust
Ed Kacic, Irvine Health Foundation
Michael Naimy, MTS
Todd Summers, Office of National AIDS Policy

From: Paul A. Di Donato and Christopher W. Yu

Date: October 17, 1997

Re: Reading materials on return-to-work issues

Enclosed please find some background materials which might be helpful for you as you prepare for the panel next Friday. We have also enclosed for you a preliminary conference brochure. A revised copy with your names and affiliations is being printed and will distributed at the day of the conference.

Please call either of us if you have any questions. Thank you.

P.S. Information on how to get to the conference is listed in the conference brochure. If you have any questions please contact the Philanthropy Roundtable directly at 202.822.8333.

MTS

GMHC
GAY MEN'S HEALTH CRISIS

the National Association of People with AIDS

RETURNING TO WORK WITH HIV/AIDS: PUBLIC POLICY ROUNDTABLE

MEMORANDUM

DATE: August 20, 1997

TO: Public Policy Roundtable I Attendees

FROM: Barbara Small, Co-Executive Director of MTS BBS

RE: Roundtable Materials

GMHC, NAPWA and MTS want to thank you for your active participation in the first roundtable discussion on returning to work with HIV/AIDS. This first meeting demonstrated the significant level of national interest in this issue. It also highlighted the complexities of entering or re-entering employment and the need for public policy advocacy.

There is a substantial amount of work that must be done if we are to assist men and women with HIV/AIDS as they transition into the workforce. As promised, the three sponsoring agencies have reviewed the findings and recommendations from the roundtable and prepared the enclosed summary report. We are in the process of planning the next steps and should be sending you further information in September.

Three documents are enclosed:

- Executive Summary, Public Policy Roundtable I
- List of Attending Organizations and Representatives
- Alphabetical List of Attendees with Affiliation

Roundtable minutes (34 pages) have also been prepared. Please contact me if you would like a copy.

MTS 38 East 29th Street 9th Floor New York, NY 10016 Tel. 212.679.8234 Fax. 212.679.8310

Executive Summary

Public Policy Roundtable I

July 21-22, 1997

New York City

Returning to Work with HIV/AIDS: Public Policy Roundtable
July 21-22, 1997

Executive Summary

Recent treatment breakthroughs and the subsequent success of triple combination therapies for people with HIV disease have combined to change the face of HIV/AIDS across the country. For the first time in the HIV epidemic, the thought of staving off the ravages of HIV disease has moved from fantasy to fact. Access to the new therapies (in conjunction with primary medical care and a constellation of social services) has allowed countless persons with HIV/AIDS (PWAs) to dramatically improve their health and also envision a future that is not automatically equated with disease and death.

Cautiously, this change in outlook has brought with it the idea of regaining their health, and, for some, of joining the workforce. HIV/AIDS has disabled tens of thousands of hard-working individuals who are considering or may soon be able to consider returning to work. For many PWAs, their diagnosis and poor health forced them to leave the labor market. These disabled PWAs qualified for public benefits and health care programs such as Supplemental Security Income, Social Security Disability, Food Stamps, Medicaid, and even Medicare.

Returning to work (or entering employment for the first time) is a major step for any individual with a disability. Numerous challenges face PWAs as they begin to consider this option. In order to successfully transition men and women from disability into the workforce, there are key policy, programmatic, educational, and funding issues that must be considered, addressed and resolved.

In July, 1997, MTS, Gay Men's Health Crisis (GMHC), and the National Association of People with AIDS (NAPWA) held a two-day Public Policy Roundtable in New York City to begin a national focussed dialogue on these work-related issues. The sixty-five community leaders attending the roundtable included individuals living with HIV/AIDS (some of whom have successfully returned to work), key policy advocates from around the country, representatives from foundations which fund AIDS and Disability projects, and a contingent of community advocates from Canada.

From this initial meeting, it is clear that there is tremendous opportunity, energy and excitement around this issue. There is also a substantial amount of work that must be done if we are to successfully assist PWAs as they transition into the workforce. The three sponsoring organizations agreed to review the roundtable findings and recommendations, issue this summary report and plan the next steps.

It is our hope that as we move forward, we move collectively, with the intention of improving the lives, health and well being of all PWAs.

Guiding Principles and Public Policy Priorities

During the Public Policy Roundtable, the participants reached a consensus on the principles which should guide all efforts to assist PWAs enter or re-enter the workforce and on the major Public Policy Priorities.

I. Guiding Principles for Initiatives to Assist Persons with HIV/AIDS (PWAs) Enter or Re-Enter the Workforce.

1. Working must be addressed within the broader context of the Determinants of Health including: Health Care, Stable Housing, Nutrition, Income Security, Psychosocial Support, Physical Environment, Safety, and Access to Appropriate Employment.
2. The PWA must be at the center of the decision-making process.
3. Decisions about working/not working must be made without coercion.
4. Employment should be available as an option in the care continuum.
5. Programs and services must be flexible and responsive to the individual's life experiences.
6. Service providers should not make assumptions about the capacity of "hard-to-reach" populations, or any group's ability to participate in, or benefit from, employment services.
7. The PWA must control confidentiality and disclosure.
8. Decisions by private and public payers about an individual's capability of working cannot be based solely on current clinical evidence.

II. Public Policy Priorities

To facilitate individuals entering or re-entering employment, barriers created by current governmental policies and regulations must be addressed. The key issues are:

1. Welfare Reform/Workfare Programs in all states must accommodate the special needs of PWAs.
2. Current Public and Private Disability-Related Benefit policies should be modified to provide a safety net of benefits when an individual tries to transition into the workforce.
3. Education is needed in the Public and Private sectors for service providers and employers about the employment needs and capabilities of PWAs.
4. A comprehensive national strategy should be developed to coordinate the efforts and resources of federal agencies such as HRSA, HUD, DOL, etc. to respond to the employment and training needs of PWAs.

III. Cross Cutting Issues

Roundtable participants identified a list of issues that affect all Public Policy Priorities.

1. Employers and potential employers must be involved at all levels.
2. Retraining and education are key components in all employment efforts.
3. Needs of Special Populations must be addressed by availability of a broad set of employment and training options.
4. Definition of Disability should be broadened by employers and government agencies.
5. Long-term drug efficacy is unknown. Flexibility in employment and benefits is crucial.
6. There must always be a balance between advocacy for employment and access to drugs and treatments.

Roundtable Format

The roundtable began with a panel of consumers who described their experiences in returning (or trying to return) to work. Additional panels followed with presentations from organizations offering employment options and services to PWAs, from experts on governmental regulations, and descriptions of state and national initiatives. The first day of the conference ended with participants identifying the major Public Policy issues.

On the second day, attendees broke into five working groups to analyze the public policy issues and recommend action steps. Each group focussed on one priority only. The priority and charge given to each group were:

Work Group Charge	Work Groups
1. Identify Key Issues.	1. Welfare Reform/Workfare
2. Identify what needs to be done.	2. Benefits/Housing.
3. Identify Action Steps.	3. Education and Advocacy
4. Address Cross Cutting Issues.	4. Funding.
5. Identify Principles.	5. Canadian Issues

Work Group Results

1. Welfare Reform/Workfare Work Group

Key Issues: **All people with disabilities need accommodations**. Services for everyone should include: Case Management; Life Skills Training including budgeting and managing income; Psychosocial support; and English as a Second Language (ESL) programs. Special populations need special services. **Women & Youth**: Appropriate childcare and supportive services including HIV-specific childcare where medications are administered. **Ex-offenders**: Transitional support services when leaving incarceration. **People with substance abuse histories**: Substance abuse counseling to facilitate recovery.

What Needs to Be Done: Exemptions must be identified at the Federal level. We recommend in general that the Americans with Disabilities Act (ADA) be enforced and specifically that Welfare Reform:

1. Exempt beneficiaries from placements that their health care providers document would be inappropriate or dangerous.
2. Eliminate or reduce participation percentage requirements for disabled adult beneficiaries.
3. Require localities to plan disability accommodations for workfare programs as required by the ADA and implement state oversight and monitoring of compliance.
4. Exempt disabled welfare beneficiaries from rules mandating cut off of Medicaid or other basic benefits for failure to comply with work requirements.
5. Maximize and expand the federal exemption for state use of good cause exemption for TANF program to allow continuation of benefits.
6. Exempt disabled beneficiaries from arbitrary lifetime time limits.
7. Develop Work Opportunities by establishing set aside funding for disability specific welfare to work programs including cash grants and tax credits.

Next Steps

1. Outreach to other existing coalitions of advocates who focus on work related issues.

2. Invite state and local agencies involved with HIV/AIDS to the table.
3. Hold a community forum for PWAs to discuss return to work and impact of reform.
4. Build Welfare Reform state coalitions specifically to address work requirements and employment opportunities for people with disabilities, including PWAs.

2. Benefits Work Group

Key Issue #1: Private Long Term Disability (LTD) carriers should develop options to allow for trial work periods.

What to Do

1. Investigate what work incentive products are offered as part of LTD coverage.
2. Analyze the business model(s) used by LTD carriers.
3. Use local AIDS organizations to work with local insurance companies. Develop a common script.
4. Reach out to and understand other disability organizations.
5. Create an environment for voluntary change on the part of LTD carriers.

Next Steps

1. Identify existing LTD HIV/AIDS policies and network with LTD carriers.
2. Define recommended modifications to LTD policies.
3. Determine best approaches to working with the LTD insurance industry.

Key Issue #2: One uniform work incentive program for both Social Security Disability (SSD) and Supplemental Security Income (SSI) should be developed. It should be based on the current SSD program and designed in a manner that doesn't undermine health insurance coverage.

What to do

1. Make work incentives more flexible.
2. Develop Buy-in options for Medicare and Medicaid.
3. Assess and prioritize AIDS-specific issues and identify overlap with other disabilities.
4. Identify any model state programs.

Next Steps

1. Form working group to identify, assess, and coordinate current efforts.
2. Coordinate efforts with other national disability organizations such as the National Council on Disabilities and CCD.
3. Hold conference to identify universal goals within disability and HIV/AIDS communities.
4. Analyze state Medicaid programs aimed at medically needy and low-income populations.

Key Issue #3: SSI and SSD beneficiaries who return to work should be able to purchase Medicaid coverage to cover gaps in employer health coverage (i.e., prescription drugs, pre-existing condition clauses, etc.)

What to Do

1. Design a Medicaid purchase option so that ADAP programs become the payers of last resort for those without prescription drug coverage.
2. Continue Medicaid expansion efforts to change the link between disability and eligibility.

Next Steps

1. Advocate for Medicaid expansion and purchase option at state and national levels.
2. AIDS Action Council will broadcast current White paper and seek national "buy in" from state, local and national AIDS organizations to strengthen bargaining position.
3. Plan conference for state organizations and a session at national AIDS conference.

Key Issue #4: Housing regulations at state and local levels need to be flexible to accommodate part-time and full-time employment.

What to Do

Create new regulations so that employed PWAs can remain in subsidized housing rather than risk eviction.

Next Steps

1. Identify states and locales where this is an issue.
2. Identify state advocacy groups.
3. Document the inconsistencies in current regulations vis-a-vis the goals of employment initiatives such as Workfare and state's housing programs.

Key Issue #5: PWAs must have access to support services such as training and childcare in order to transition into the workforce.

What to Do

Tie re-training, education, and other employment readiness programs to support services.

Next Steps

1. Identify stakeholders and advocates in these support areas.
2. Investigate current efforts to access support services benefits.
3. Plan strategy to modify eligibility as needed.

3. Education and Advocacy Work Group

Key Issue #1: Government workers should be knowledgeable about HIV/AIDS and treatment.

What to Do

1. Mandatory training of government workers in HIV/AIDS, work transition and public benefits;
2. Educate vocational rehabilitation professionals at state agencies including educational institutions to work with PWAs .
3. Train ASOs to work with vocational rehabilitation and similar agencies.

Key Issue #2: PWAs Need Access to Education and Training Services

What to Do

1. Determine in which states the Order of Selection limits vocational rehabilitation for PWAs.
2. Examine and remove barriers to education in federal programs (SSA, HRSA, JTPA, etc.).

Next Steps

1. Develop and expand outreach to PWAs regarding educational and training opportunities and vocational rehabilitation services.
2. Create linkages to all populations, particularly institutionalized and other "hard to reach" groups.
3. Revise Departments of Rehabilitation Order of Selection to include PWAs in affected states.
4. Investigate potential Small Business Administration support for people with disabilities.

Key Issue #3: Employers should be Included in Employment and Training Programs and Receive Incentives for Hiring PWAs.

What to Do

1. Expand Tax Incentives for hiring people with disabilities, particularly SSA beneficiaries.

2. Work directly with private employers and employees to provide and coordinate training programs on supplemental health benefits programs.
3. Include local chambers of commerce and business community in job creation for people with disabilities and HIV.
4. AIDS Service Organizations should act as employer models by committing to hire PWAs, and developing model programs with flexibility and creative accommodations (flex time, job sharing, part-time, etc.).
5. Require state, county and city universities and colleges (and private institutions which receive federal funding) to develop opportunities for PWAs.

Next Steps

1. Investigate expansion of Empowerment Zones to target employers hiring PWAs who reside in these zones.
2. AIDS Service Organizations develop and deliver up-to-date training on HIV/AIDS, treatment and employment information to the employer community.

Key Issue #4: Research is needed to Demonstrate the Health and Monetary Benefits of Employment for PWAs.

What to Do

1. Increase studies of monetary benefits and savings from social security-to-employment programs in both the public and private sector.
2. Research study on relationship of employment and health for PWAs and other disabilities.

Next Steps

1. Advocate for evaluation of state training and educational programs in enrollment of and responsiveness to people with HIV/AIDS.
2. Encourage ASOs to evaluate "return to work" and "affirmative action" for PWAs and report on ASO employment of PWAs.
3. Advocate for research on the feasibility and economics of job accommodations such as flex time, job sharing, and telecommuting.

4. Funding Work Group

Key Issues

1. Development of a comprehensive national strategy for a federal response for HIV employment. This needs to include two main areas: streams of funding (HOPWA, CARE, JTPA, Vocational Rehabilitation, etc.) and oversight mechanisms/agencies (Departments of Education and Labor, HRSA, Housing and Urban Development, etc.).
2. Develop a national coalition to secure a comprehensive response to the employment needs of people with HIV disease.
3. Establish national technical assistance program to aid local CBOs to establish and fund HIV employment programs.
4. Obtain clarification from HHS (ie HRSA) concerning eligibility of vocational rehabilitation services under the CARE Act.
5. Develop coalition with larger disability community to facilitate and coordinate use of vocational rehabilitation funds for people with HIV disease.
6. CARE Act funding for outreach to vocational and rehabilitative service agencies.

What to Do

1. Obtain HRSA guidance that is clear and usable.
2. Educate PWAs and local Planning Councils on program.

Next Steps

1. Meet with HRSA officials, Title I providers, CAEAR Coalition, etc.
2. Identify most effective model(s).
3. Draft language to clarify permissible uses of CARE funds for HIV employment.
4. Mobilize CARE Act planning councils to secure clarification.
5. Identify existing disability coalitions and common strategies to expand vocational rehabilitation resources and educate federal policy-makers about emerging needs of people with disabilities for employment services.

5. Canadian Work Group

Key Issue: The group developed a list of principles based on the Ottawa Charter for Health Promotion that guides most HIV services in Canada. These guiding principles give a sound context for addressing return to work issues for PWAs in a holistic and humanitarian context. The principles were adopted by the Roundtable (see first page).

What Needs to Be Done:

Advocacy and Education

1. Develop an advocacy strategy in collaboration with other community partners, including cross disability organizations and health care providers.
2. Educate community organizations and health care providers on return to work issues for people living with HIV/AIDS.
3. Meet and advocate with federal and provincial policy-makers and senior bureaucrats responsible for return to work programs.
4. Meet and advocate with private insurers to ensure policies/programs are based on community return to work principles.
5. Meet and advocate with business and labor associations to ensure appropriate return to work policies are in place for people living with HIV/AIDS.
6. Advocate with the Health Protection Branch and pharmaceutical companies to undertake extensive post-marketing surveillance to ensure longitudinal clinical data on efficacy and toxicity.
7. Ensure return to work issues are appropriately addressed in the third phase of the National AIDS Strategy.

Research: Develop national research on the needs of people living with HIV disease with respect to return to work issues.

Next Steps

Establish a national working group on return to work issues that will be responsible for:

1. Integrating existing community work into national initiatives.
2. Developing position statement on return to work issues.
3. Developing specific advocacy initiatives on return to work issues.
4. Integrate return to work information into HIV and rehabilitation module currently in development.

San Jose Mercury News

AIDS charities hurt by all the good news

BY HOLLY A. HEYSER
Mercury News Staff Writer

The news about AIDS could hardly sound better: Miracle drug "cocktails" touted in headlines, Newsweek's "End of AIDS?" cover story, the proclamation by Magic Johnson's wife in Ebony magazine that her husband has been "healed."

But a devastating side-effect of all that good news is emerging: People are prematurely concluding that the end of the epidemic is at hand, and they're cutting off their contributions to organizations that help people with AIDS.

ARIS in San Jose has seen contributions fall 7 percent, just a year after donations had gone up 32 percent.

Ellipse in San Mateo used to get checks in the mail every day, but now it gets one or two a week.

See AIDS, Page 22A

AIDS charities feeling effects of positive news

■ AIDS
from Page 1A

The San Francisco-based NAMES Project — guardian of the AIDS Memorial Quilt — has seen donations plummet 20 to 25 percent at its fundraising events.

And the AIDS Alliance of Contra Costa County closed recently, at least in part due to declining contributions.

Make no mistake — AIDS workers are thrilled that new drugs, called protease inhibitors, are working wonders against the intractable disease when combined with other drugs. But they look at their plummeting fundraising figures and tremble with fear because they know the truth: The crisis is not over, and neither is their work.

There's no cure. There's no vaccine. People are still getting infected with HIV, the virus that causes AIDS. Not everyone who has HIV has access to the expensive new drugs; as many as half those who *do* have access to the drugs don't benefit from them. When the drugs *do* beat the virus back to undetectable levels, nobody knows how long the effects will last. Even if the benefits persist, the patient has to take medications for life; even then, many still will need help to get by as they live longer than expected.

Reaction to pills

"(The press implies) you take these pills and feel better, and it's not like that," said Lynn Waltz, a Fremont man who is fighting back the AIDS virus with 30 to 40 pills a day. "As likely as not, you take these pills and spend the whole day retching."

Try going back to work feeling like that, try people with AIDS. And try getting health insurance again even if you are lucky enough to get a job.

The fact that people with AIDS aren't dying off at such a rapid pace anymore means client loads are increasing — not decreasing — for organizations that serve people with AIDS.

It's difficult to assess the depth and extent of the funding problem. Most AIDS service organizations haven't finished their fiscal year yet — the year during which all the grand pronouncements about the effectiveness of new drugs came out — so they don't have final numbers.

And some organizations say they're doing all right. "I don't think we've experienced a substantial decrease in funding," said Tiffany Moore-Goeman, director of HIV Community Housing and Services for Catholic Charities of the Archdiocese of San Francisco.

Contributions drop

But others see contributions dropping. Most donors saying, "It's over, right?" and put one and one together.

It's not just generous individual donors who have gotten the wrong message — some foundations and corporations are backing away, too.

"I'm definitely hearing from funders that now's a good time to put emphasis on other diseases," said Valerie Papaya Mann, executive director of AIDS Project East Bay.

"I'm just not convinced there's still a need," one corporate donor told Vicky Kellogg, development director for ARIS, AIDS Resources, Information and Services of Santa Clara County. "It was like someone punched me in the stomach," Kellogg said.

Her boss heard the same thing at another meeting with donors last month. "The message to him was, 'We have given to AIDS, we want to give to other things, and now there's some hope so we're going to give to other things,'" Kellogg said.

Hope? Tell that to Pam Reber of San Jose. She was diagnosed with AIDS in 1994. She tried taking protease inhibitors but she had to quit because they made her too sick.

Help from ARIS

After leaving work, Reber stayed in her own apartment until her savings ran out. Two years ago, she had to move into ARIS' housing for women with AIDS.

"Without this, I wouldn't have a home," Reber said of the ARIS program. At 40, the former Home Depot cashier lives on a monthly disability check that pays less than a full-time minimum wage job.

The state helps pay for AIDS drugs for people who make up to $50,000 per year, and Medi-Cal pays for medical care for those who can't work because of the disease. But AIDS service organizations provide other services vital to the well-being of people with AIDS: Housing, food, support groups, legal advice, rides to doctor visits and friendly faces.

Colette Drane-Hoffman, executive director of Ellipse in San Mateo, maintains these services are vital. She cited a Centers for Disease Control study showing that good nutrition and emotional support are leading factors in prolonging the lives of people with HIV. In addition to medication,

But with her funding decline, Hoffman says she's going to lay off some staff members on July 1. The impact on clients will be compounded by the fact that she's not getting as many volunteers as she used to, either.

Prevention education — another specialty of the NAMES Project in San Francisco — also is still considered vital. "The lives being saved, people going back to work are things to be celebrated, but we mustn't forget what's causing this," said NAMES Project Executive Director Anthony Turney.

"All these therapies have zero impact on preventing even one infection."

AIDS DONATIONS

Organizations that serve people with AIDS report that charitable giving dropped since news surfaced about the effectiveness of new treatments for the disease. Here are some early reports from what is happening up and down the state:

- **AIDS Project Los Angeles:** Special events bringing in less money — income from the AIDS Dance in April dropped nearly $190,000 from previous year's take of $850,000.
- **AIDS Foundation, San Francisco:** Contributions are leveling off after years of steady growth.
- **AIDS Project East Bay, Oakland:** Corporate and individual donations are dropping, but no figures are available yet.
- **ARIS, San Jose:** Donations have dropped about 7 percent this year after increasing 32 percent the previous year.
- **AIDS Alliance of Contra Costa County:** Closed recently, due in part to declining contributions.

Source: Various organizations

Price of Success

Powerful Treatments Create Growing Rift Among AIDS Groups

Social-Service Agencies Fear Losing Funds as Money Goes to Provide Medicine

'I Want You Out of Business'

By LAURIE MCGINLEY
Staff Reporter of THE WALL STREET JOURNAL

Cleve Jones, founder of the mile-long AIDS quilt, got a warm reception in October as he walked to the podium of a Washington, D.C., hotel to speak to AIDS social-service providers. But his message sent a chill through the audience.

Mr. Jones, who had almost died of AIDS, was now strong thanks to advanced AIDS medication. His message was that drugs, research and treatment—not social services – should be the priority for public and private funds.

"My point was, 'AIDS Inc., I want you out of business,' " he says. "Some people wanted to string me up."

Little wonder. For years, an army of AIDS social-service providers have been dedicating their lives to caring for people with AIDS, with little help from medical science. But now their world has changed. With new medications restoring some people to robust health, pressure is building to shift funds away from social services like transportation, housing and counseling, and into drugs and treatment. Without drugs and treatment, "What good are these services?" asks Jules Levin, executive director of the National AIDS Treatment Advocacy Project in New York.

Decade of Programs

That has left the social-service providers, having spent a decade setting up an array of programs with government and private funding, scrambling to protect their programs. "You can have the best medicines and medical services in the world, but if people can't get to the appointment, what good does it do to have a doctor sitting there someplace?" asks James Loyce Jr., executive director of AIDS Project Los Angeles, the biggest social-service provider in the area. Such providers say it is much too early to start slashing services; while the new drugs are a godsend, they don't work for everyone and they might ultimately be a big disappointment. Cuts, they warn, will hurt the neediest most.

Nasty conflicts, fueled by a combustible combination of selflessness and self-interest, have already erupted in some communities, as well as on the national level. They will worsen as more people seek the costly new combination therapies, which can easily cost $12,000 a year. While a big increase in the size of the federal AIDS funding pie would ease the strain, that is unlikely, given Washington's yearning for a balanced budget. And some agencies are finding it harder to raise private money, a development they blame on glowing news reports about a new class of drugs known as protease inhibitors, which are taken with older medications to produce a potent anti-HIV "cocktail." "The 'cure' headlines are hurting us," says Allen Carrier, the director of communications for AIDS Project Los Angeles.

'Lives vs. Jobs'

In the meantime, those pushing hard for treatment funds say the social-service agencies have become giant bureaucracies out to perpetuate themselves. "This is lives vs. jobs," says James Driscoll, the San Francisco-based director of AIDS policy for the Log Cabin Republicans, a gay political group. In an angry rebuke, Steve Johnson, director of public policy for the Northwest AIDS Foundation in Seattle, says he will be happy to find other work. "I'm tired of burying my friends," he says.

Says Mary Lucey, an analyst for the city of Los Angeles's AIDS office, who is herself HIV positive: "Everybody is in turmoil."

Ms. Lucey, a member of the planning council that sets local priorities for federal AIDS spending, sparked one such clash in September. She proposed a modest 4% across-the-board reduction in funding for dozens of social services, in order to increase by $800,000 funding for outpatient medical care, a category that includes doctors' visits, expensive tracking procedures called viral-load tests and a small drug-reimbursement program. (Most drugs for low-income people with AIDS, including the protease inhibitors, are paid for by Medicaid or a separate state drug-assistance program.) Ms. Lucey's proposal passed, but drew heated protests from some social-service providers.

Growing Divide

"People started taking sides and becoming very defensive and protective of their categories," she says, citing "sheer greed" as a motivating factor. Her action, while modest, defined a chasm in the Los Angeles AIDS community that will widen under continued financial pressure. "It's going to get vicious," she predicts.

On one side of the divide in California is Michael Weinstein, the confrontational founder and president of the Los Angeles-based AIDS Healthcare Foundation, a sprawling but financially struggling medical provider. The 44-year-old Mr. Weinstein, who wears a lapel pin saying "Treatment=Life" and recently held a fundraiser honoring the industry scientists who developed the protease inhibitors, is pressing hard for shifting more funds into medical services. "When there wasn't effective treatment, money being wasted didn't matter so much," he says. "But now, every $2,500 in primary care and $10,000 in money for drugs pulls another person into the lifeboat." With the new treatments, he says, the need for support services will diminish.

On the other side of the divide are people like Sue Scott, executive director of the AIDS Service Center, a Pasadena

agency that provides counseling, day care, family support and free food. Ms Scott, who is 60, vows to block any move to defund social-service organizations like her own. She says that services, especially those involving food, housing and transportation, will become even more important as people go on the complicated drug regimens. "People need stable environments and support systems around them for the drugs to really work," she says.

Both AIDS Healthcare Foundation and AIDS Service Center have a big financial stake in the debate: They depend heavily on the federal Ryan White CARE Act to make ends meet. (The nearly $1 billion federal program – named for the Indiana teenager who emerged as a forceful opponent of discrimination against AIDS patients before he died of the disease in 1990 – is designed to provide medical and other services for uninsured and underinsured people with AIDS).

Los Angeles County gets between $26 million and $31 million a year from the act's two main titles, divvied up among various providers and community-based organizations. The category most important to Mr. Weinstein, outpatient medical care, is already the top priority, getting a little less than half the funds; he thinks the category should get at least two-thirds of the total, given medical advances.

Michael Weinstein

Ms. Scott says even the relatively small 4% cut approved by the Los Angeles planning council will hurt. Combined with a new federal rule limiting certain expenses, the cost to her agency, which now gets $1.2 million a year in federal funds, could reach "hundreds of thousands of dollars." In just one area, case management (in which case workers refer clients to services and help get them signed up for federal benefits) the cuts total $18,000. That means the employee who has been doing quality assurance – running focus groups and distributing questionnaires to measure client satisfaction – will be reduced to half-time status, unless other funding can be found.

Meanwhile, Mr. Weinstein's organization is likely to get an extra several hundred thousands dollars because of the 4% shift in priorities, a drop in the bucket for the $30 million nonprofit. Mr. Weinstein has set his sights on bigger game: Citing rising costs, he is urging the county board to earmark any new Ryan White funds for the coming year, which could be in the millions, for outpatient medical care, a proposal that Ms. Scott and other social service providers vigorously oppose. They want any extra money divvied up according to the planning commission's priorities, with medical providers getting some but not all of the funds.

While praising much of the work of the service providers, Mr. Weinstein also claims they are out to save themselves. "A whole industry has developed around this and as much as people said they wanted pink slips, now that the time is upon us, most aren't willing to downsize," he says. But Ms. Scott retorts that Mr. Weinstein is no different. "If Michael Weinstein wants all the money, he's doing the same thing," she says. "I don't know how you can say, 'My service is better than yours, so I'm not doing a fiefdom, but you are.' "

For Mr. Weinstein, the year has been one of tumult, in large part because of the protease inhibitors. The New York native founded the organization in the 1980s to provide AIDS hospice care after a close friend was left lying on a gurney in a hospital hallway. Today, the foundation treats 3,000 people a year, most of whom are uninsured and indigent, at four outpatient clinics and two residential facilities, and is the largest community-based AIDS medical-care provider in the country.

Impressed by the new protease inhibitors, Mr. Weinstein made them widely available to his patients months before the drugs were reimbursable by the state. In the process, he says, he ran up a $1 million deficit and a soaring drug bill; he recently settled a lawsuit from a pharmacy-benefits manager by agreeing to pay $3 million over time.

"We prescribed those drugs from the day they were available, because we weren't going to decide who is going to live or die," Mr. Weinstein says. His action earned him the loyalty of patients like Bruce Teague, 43, a former stock broker whose health has improved markedly since he went on one of the protease inhibitors in the spring. "Without these things, I die," he says.

But Mr. Weinstein's budget-busting upset the other providers, who contend that management mistakes, not altruism, have caused the foundation's financial problems; in particular, his decision to open a new hospice earlier this year, despite declining demand. They worry that if the county has to bail him out, they could be affected. And his actions infuriated some county officials who saw them as a tactic to squeeze more funds from them.

Meanwhile, there are signs that social-service agencies are beginning to adjust to the idea that greater resources must go to medical services. "Some social-service people are thinking that overall, it's got to go that way," says John Schunhoff, acting director of public-health programs and services for Los Angeles County. "They just wish it wouldn't affect their agencies." And all the Los Angeles providers, medical and social, face another potential financial threat; they are expecting the state of California to press them to pony up some money for the state's cash-strapped AIDS-assistance drug program.

Many of the Los Angeles providers are trying to figure out how to reposition themselves for the future. At AIDS Project Los Angeles, officials are finding that it is taking more effort to raise the same amount of private funding. "People are starting to think, maybe we should be a $15 million organization, not a $21 million one," says Mr. Carrier, the communications director. Ms. Scott says she made certain that the lease to her new building will allow her to cut the space in half in five years, if necessary. And, in her most optimistic moments, she likes to kick around ideas about what to do with the agency down the road, like turning it into a gay senior citizens' center. She says she is determined not to become institutionalized and tells her staff they should view their work as good experience, not a lifelong career.

The debate about priorities is going on in other parts of the country as well. Late last year, just as the first protease inhibitor was coming on the market, a group of AIDS advocates in Washington, D.C., successfully pressed the local HIV planning council to shift $400,000 in funds from services to the city's underfunded drug-assistance program. "There was a lot of upset over that," says Hank Carde, a local activist. But this year, he says, there was general agreement about making medical treatment and drugs a top priority.

The dispute between drugs and services broke out at the national level in October, just as Congress was getting ready to adjourn, and is still reverberating through the AIDS community. A group of AIDS activists and drug-company lobbyists were trying to get $100 million in funding earmarked for the state AIDS drug-assistance programs, which are experiencing sharp cost increases because of the new AIDS drugs. But a coalition of local communities and social-service providers argued successfully that the funds should be sprinkled throughout all the services covered under the Ryan White bill, in part because of the increased need for primary medical care and diagnostic tests. The result: $50 million went to the state drug programs and the other $50 million went to social-service and medical programs.

The move infuriated Jeff Getty, an Oakland, Calif., activist, who gained fame when he had a bone-marrow transplant from a baboon. Some portion of the money going to the service agencies will fund medical services and viral load testing, and perhaps some drugs as well. But Mr. Getty, says, it won't be enough. "The rest will go to case management and counseling," he says. "The whole thing is a smokescreen."

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FRIDAY, JUNE 6, 1997 B1

AIDS Charities Suffer as Treatments Improve

By Beth Burkstrand
Staff Reporter of The Wall Street Journal

PHILANTHROPY

Medical progress in the battle to control AIDS has some AIDS charities ailing.

Since the discovery last year that new drugs can help control the disease, a number of AIDS organizations nationwide have seen their donations slide. In April, AIDS Alliance closed its Contra Costa County, Calif., office, citing a funds shortfall of $20,000 to $30,000 a month. At the Names Project Foundation, sponsor of the AIDS Memorial Quilt, revenue is running 22% below the $2.5 million budgeted for the first half of the fiscal year, and attendance at this spring's quilt displays was about half what it was last winter. Last week, the foundation's executive director, Anthony Turney, told his 45-member staff that about a quarter of them would lose their jobs in coming weeks.

Causes come and go, and some shrinking of the massive AIDS network seems inevitable in any case. But Anthony Fauci of the National Institute of Allergy and Infectious Diseases worries that the public has a "dangerous perception" that the battle has been won, even though the disease remains the leading cause of death in the U.S. for people between 25 and 44 years old. AIDS charity workers also say the decline comes as funds are needed to help patients buy the expensive new drugs, as well as to provide traditional services.

"All these new drug cocktails are great and wonderful," says the quilt project's Mr. Turney. But, he adds, "the fact of the matter is that protease inhibitors don't do a damn thing to prevent one infection."

Getting that message across, however, is tough. At Gay Men's Health Crisis, one of the nation's largest AIDS service organizations, registration for the New York City AIDS walk in May was so low six weeks before the event that organizers spent almost $10,000 on a mass mailing explaining the need for support. Attendance rose slightly, but donations fell by more than $300,000 from last year's $5 million.

The AIDS Action Committee of Massachusetts saw fund raising from its Boston AIDS Walk fall about $190,000 to $2.8 million in 1994, and officials thought they had seen the worst. But at the walk held last weekend, contributions declined by another $330,000 – the largest drop in memory. Volunteers at the event reported that people didn't want to donate because they thought the new drugs were essentially a cure.

That isn't the case, though the drugs can sharply cut the level of infection. Marc Haslam of Clearwater, Fla., almost had to give up his AIDS medicine last year, a move that might have made him resistant to the drug, the equivalent of a death sentence. The agency that paid for his prescriptions closed its doors after a fund-raising event that was expected to generate $300,000 ended up $70,000 in the hole instead. At the last minute, Mr. Haslam was able to line up federal assistance. "It was extremely stressful," he says.

In response to the decreasing donations, some organizations are looking at cutting back services or trying to consolidate them with other agencies. AIDS Project Los Angeles, where fiscal-year donations are down more than 10% from the previous year, is thinking about reducing its home health care, dental care and food programs, says its communications director, Allen Carrier.

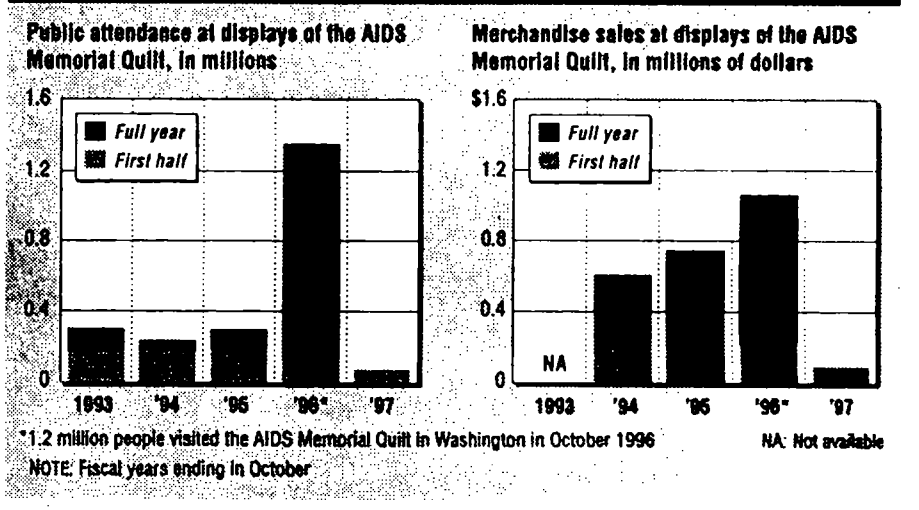
Meanwhile, AIDS Community Project of Tampa Bay has turned over care for homebound AIDS patients to a local hospice, and it is negotiating for Catholic Charities to take over its pediatric AIDS services. The Tampa Bay organization relies primarily on memorials for its funding. But its traditional clients are living longer while the disease is taking a bigger toll on lower-income groups, where such donations are harder to come by. The Tampa project has received just $2,000 in donations so far this year, says director Kathleen Farrell; last year, it brought in $29,000.

AID Atlanta has been more fortunate – because of its own forward thinking. Beginning last summer, it sent letters to previous and potential donors emphasizing that money was needed for prevention and to keep services, like food and nutrition counseling, that are crucial to helping the new drugs work. "We started a year ago by saying the challenge of the good news is that our clients will increase because they are living longer," says Ed Marshall, the agency's development director. The organization also sent speakers to civic organizations, businesses and schools. The October 1996 AIDS walk climbed to $1.1 million from $800,000 in 1995, and the group is counting on the same strategy to work again this year.

The San Francisco AIDS Foundation relies on an annual walk for about 19% of its funding. Alarmed by the experience of other groups, it is trying to make its needs known well in advance of the July 12 event. To make sure it reaches its $3 million goal, the foundation is targeting corporate teams, hoping that the companies that lent support in the past will pick up any slack. If the walk doesn't meet its goal, the effect will ripple through the community: The foundation gives more than $1 million each year to smaller organizations in the area.

Sandra Thurman, director of the Office of National AIDS Policy, which advises President Clinton on AIDS-related issues, neatly sums up the current situation: "All of the interest in AIDS initially was generated because it was a disease of crisis," she says. "AIDS is no longer the disease du jour."

Faltering Cause



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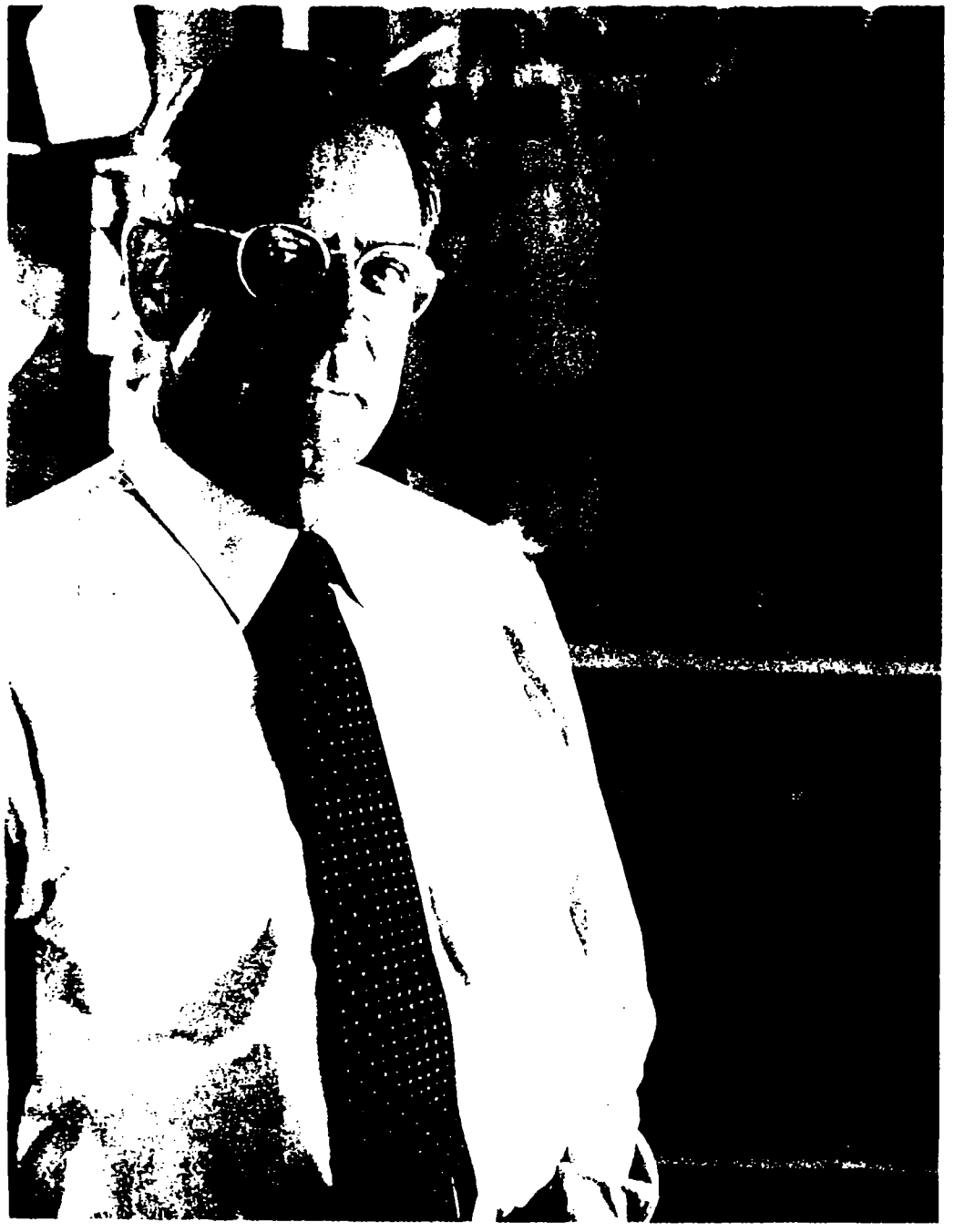

PAUL DANIELS, FOR THE CHRONICLE

Anthony Turney, executive director of the Names Project Foundation, which maintains the AIDS Memorial Quilt: "The public perception is that if AIDS isn't over, its demise is certainly on the horizon."

A New Prescription for AIDS Groups

The success of new treatments has charities redefining their roles

By PAUL DEMKO

OMAHA

AT THE NEBRASKA AIDS PROJECT'S new $1-million wellness center here, clients can lift weights, take writing classes—or go to work packing boxes for an international-export company.

For most of the 12 years that the charity has been in operation, few of its clients were strong enough to pump iron, let alone perform a workaday job. "We're talking canes, walkers, and wheelchairs," says Joseph J. Conrad, who is both a trustee and a client of the AIDS charity.

But as new drug treatments known as "AIDS cocktails" have become widely available, the disease has been transformed for many people from an almost certain death sentence into a chronic, manageable illness.

Last year, for the first time since the start of the epidemic, the number of deaths from AIDS dropped—by 19 per cent compared with the first nine months of 1995. Many people with the disease today are more active, more mobile, and less in need of in-home support than they had been.

As a result, AIDS groups are trying to figure out exactly what services they should provide:

▸ Some AIDS hospices have shut their doors because of a dearth of patients, while others are being converted into apartments. (See story on Page 27.)

▸ Food-delivery organizations, which have sprung

JEFF BEHRMANN, FOR THE CHRONICLE

Joseph J. Conrad, a client and trustee of the Nebraska AIDS Project, in Omaha: "I would stay home all day and lay on the bed with my remote control. Now I couldn't even tell you what's on TV."

A New Prescription for AIDS Groups

Continued from Page 1

up in most major cities during the last 15 years, are debating the need to continue bringing freshly cooked meals to the homes of AIDS patients.

► Other AIDS groups have begun to offer back-to-work seminars and job training in addition to such traditional services as medical and psychological counseling. "Clients are wanting not to learn how to die, but how to live," says John B. Huckaby, director of client services at AIDS Foundation Houston.

And as the disease continues to evolve from one that primarily affected gay, white, middle-class men to one that disproportionately strikes poor blacks and Hispanics, AIDS groups have increasingly been called on to meet needs that have long been the domain of social-service charities such as the Salvation Army or Catholic Charities. Many of the new clients are asking for help with problems that go beyond AIDS, such as drug and alcohol addiction, homelessness, and mental illness.

"They're showing up at our door with H.I.V., but H.I.V. is the least of their concerns," says Mr. Huckaby of AIDS Foundation Houston.

'Are We a Poverty Organization?'

Such developments have led to concern and confusion among AIDS groups about what their mission is. "Are we an AIDS service organization, or are we a poverty organization?" asks Lee E. Klosinski, director of education at AIDS Project Los Angeles, which has seen the number of clients that it serves swell by 1,000 in the past year, to about 6,100. "That's one of the most important questions we have to deal with."

The optimism of AIDS activists about the medical advances is tempered by the fact that many people with the disease cannot take advantage of the new treatments. Some cannot afford the expensive drugs, while others have trouble following the exacting regimens, which can require taking up to 20 pills each day. Still others simply do not respond to the medicines. At AIDS Action Committee of Massachusetts in Boston, for instance, about a third of the

drugs, and many clients continue to die from the disease—250 last year alone.

"We're thrilled that some people are benefiting from the new drugs," says Larry Kessler, executive

Continued on Page 26

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director of AIDS Action Committee of Massachusetts. "But the key word is *some*."

Confusion among AIDS groups about what their mission is, coupled with a spate of news articles in the last year declaring that the epidemic is over, has led to steep drops in donations to some AIDS-related charities. In the last year, a handful of large charities that provide services to people with AIDS have had to lay off employees. And many other organizations fear that they will soon see similar drop-offs.

Dealing With Guilt

Despite those myriad concerns, most AIDS charities are forging ahead with new services—or changing the direction of existing programs.

Groups that used to devote much time to providing bereavement counseling must now help clients cope with the guilt they feel because they are still alive and healthy while many of their friends died in the days before the new medications were available.

"They're showing up at our door with H.I.V., but H.I.V. is the least of their concerns."

Legal services have also changed. In addition to helping with wills and other estate plans, charities are now helping clients placate creditors or declare bankruptcy, because many AIDS patients spent beyond their means at a time when they thought they would not be alive to face the bills.

For the numerous AIDS charities that were created solely to deliver meals to homebound people with the disease, the decision is whether to remain in business at all.

Most of those organizations continue to see escalating demand. Community Servings in Boston, for instance, recently opened a new building and is now serving three times as many clients as it did before. Even so, some charity officials question how long they will be able to justify delivering hot meals to patients who are responding favorably to new medications.

"It won't wash," says one charity executive, who declined to be named. "If people are better able to care for themselves, there's less justification for taking meals to their doorstep."

At least one meal-delivery service is taking steps to adjust to the new needs of clients. Project Angel Food in Los Angeles, which serves 800 meals a day, will soon allow clients to choose whether to have meals delivered once a week instead of every day. Clients who choose that option will receive one fresh meal on the day of delivery and six frozen meals for the rest of the week. In a survey of its clients, Project Angel Food found that more than 40 per cent wanted to receive frozen meals.

AIDS Groups Go Forth With New Services Despite Steep Drop in Support for Some

"With their improved health, clients are more mobile and they are less interested in staying home in the middle of the day," says John L. Gile, executive director of Project Angel Food. "They may have doctor's appointments, or volunteer activities, or they may be getting back to work."

Here in Omaha, many of the clients who visited the Nebraska AIDS Project for a lunch of burgers and fries one recent summer afternoon are thriving, thanks to the new treatments.

"At one time I was so sick I couldn't walk," says Frank H. McKee, a 49-year-old former hydraulic-lift operator. "The doctor gave me six months to live. That was 18 months ago."

Mr. Conrad says: "I would stay home all day and lay on the bed with my remote control. Now I couldn't even tell you what's on TV."

Many of those who are responding to the treatments say they feel well enough to trade in their disability checks for paychecks. But they have some reservations.

Mr. Conrad, a 38-year-old former salesman for Marriott International, points out that if he makes $5 or more in a month, the federal government will cut off his Medicaid benefits.

Mr. McKee fears getting sick again and letting down his employer. "I'd just be putting more work on other people," he says, "and I'd be denying my employer what I committed."

Employment Programs

The Nebraska AIDS Project has found a way to deal with that fear. The charity has contracts with local companies to pack boxes, label products, and perform other similar jobs. It then hires its clients to take on the jobs, allowing them to do as much as they want.

Many other AIDS groups across the country are also helping people with the disease return to work. Among the efforts:

- In Philadelphia, ActionAIDS plans to spend at least $10,000 to create a job bank that will list corporations interested in hiring people who have H.I.V. The charity hopes eventually to serve as a temporary employment agency for people with AIDS, where clients could call in on the days they felt well enough to work and be assigned a job.
- In the District of Columbia, the Whitman-Walker Clinic, with the help of a $183,000 federal grant, is running an 18-month pilot program to provide job training to people with H.I.V.
- In New York State, AIDS Rochester will start a job-training program this fall to teach its clients basic skills, such as how to write a résumé and how to prepare for an interview.

Some leaders of AIDS charities are reluctant to offer such programs, however. They point out that back-to-work programs are plentiful in many cities, especially as federal and state welfare programs increasingly emphasize getting people off the government dole and into jobs.

"There are probably 10 services here for job preparedness," says Ben McFadyen, executive director of the Triad Health Project, a Greensboro, N.C., organization that provides services to people with AIDS. "We don't have the resources to do that."

Drop in Donations

A shortage of money is a problem for other AIDS-related organizations as well, with several experiencing steep drops in donations.

The Names Project Foundation, keepers of the AIDS Memorial Quilt, has seen donations tumble by 25 per cent since last November. What's more, attendance at quilt displays—long considered to be an almost-mandatory rite of passage for people affected by the epidemic—has fallen by more than half, and the number of memorial panels being submitted has dropped by 43 per cent.

"If people are better able to care for themselves, there's less justification for taking meals to their doorstep."

As a result, revenue from the sale of souvenirs, such as coffee mugs, has declined by almost 60 per cent. In June, the charity laid off nine full- and part-time employees from its 51-person staff.

"The public perception is that if AIDS isn't over, its demise is certainly on the horizon," says Anthony Turney, the charity's executive director. "This is not a phenomenon that is just applicable to the Names Project."

Mr. Turney worries that the downturn in fund raising may be only the beginning of major financial problems for AIDS groups. He says that foundations and corporations are often slower than individuals in changing their giving priorities and that those donors could be next to shun AIDS groups.

One long-time fund-raising staple has also taken a few hits: AIDS walks. AIDS Action Committee of Massachusetts saw revenue from its annual walk drop by $350,000 this year, to $3.4-million. Gay Men's Health Crisis raised $4.7-million from its walk in May, a decline of $300,000. And the Minnesota AIDS Project in Minneapolis saw proceeds from its annual walk drop by about 7 per cent this year, to $765,000.

Cindy Nelms, executive director of Mobile AIDS Support Services in Alabama, says that her group is bracing for a drop at its walk next month as well. She says that the decline in AIDS deaths translates directly into fewer walkers.

"The largest single faction of people who come out are people who have lost someone to the disease," Ms. Nelms says. "Thank God there are going to be a whole lot less people who can say they lost a friend in the last year. But as a result, fewer people are mobilized to turn off the TV, throw the dog and the family into the car, and go off to the AIDS walk."

Not all charities are finding that donors are walking away from AIDS, though. Despite the drop in contributions to its walkathon, Gay Men's Health Crisis saw its first increase in donations since 1994. For the fiscal year that ended June 30, the charity brought in $21-million, a jump of almost 25 per cent.

The Whitman-Walker Clinic has had similar fund-raising success lately. The charity raised $3.5-million in the first six months of this fiscal year, an increase of almost 20 per cent over the same period in 1996.

At the Nebraska AIDS Project, donations rose by 50 per cent last year. And a capital campaign to pay for a new wellness center brought in an additional $178,000, helping the charity close in on its $1-million target.

Joseph Hall, the group's executive director, attributes part of the gain to more-aggressive solicitation of individual donors. But he also says that the charity faces a relatively easy time because of the wealth of many of the residents in this prosperous prairie city of steak houses and stock speculators. "You can't swing your purse without hitting a billionaire," he likes to say.

But even with healthier patients, a new facility, and strong fund-raising figures, Mr. Hall looks at the future with some trepidation.

"The AIDS virus has run a very unpredictable and tricky course," he says. "Hopefully we haven't lost our ability to be just as flexible and tricky."

Empty Beds Put Some AIDS Hospices Out of Business

Carol J. Cody, founder of Christopher House, an Austin, Tex., inpatient medical facility for people with AIDS that closed in February: "It's the dream of people that go into this work that they're not needed anymore."

Since 1989, 1,200 people with AIDS have died at Boston's Hospice at Mission Hill.

In January, the 18-bed facility shut down: It had only two patients left.

Hospice at Mission Hill is just one of dozens of charities that sprang up in the last 15 years to provide live-in care for people with AIDS. Some are traditional hospices, where people go for treatment of pain and to die peacefully. Others are hospitals that provide treatment only to people with AIDS, so people can seek out expert care and avoid the discrimination that they sometimes face at institutions that treat a broader range of diseases.

But now many of those nascent charities are struggling with what everyone agrees is good news: a lack of clients. In the last two years, as new drug treatments known as "AIDS cocktails" have become widely available, the need for end-of-life care for people with AIDS has dwindled. Some of those charities are now shifting their programs to meet the need for more independent housing, while others, such as Hospice at Mission Hill, are declaring their jobs to be finished and are closing down.

Among them:

▸ In Bellingham, Wash., Humphrey House, a six-bed facility that provides 24-hour medical care for AIDS patients, has never been full since it opened its doors last year. Two people have died at the facility, but five have gotten well enough to leave. The charity is now considering changing its mission to that of providing apartment-style housing.

▸ In Los Angeles, the AIDS Healthcare Foundation used to reserve its three 25-bed hospices for people who were expected to die within six months. But now many of its clients receive aggressive care that is expected to return them to health. "There isn't a demand for hospice care," says Michael Weinstein, executive director of the non-profit organization.

▸ In San Francisco, Maitri AIDS Hospice has changed its name to Maitri: Residential Care for People Living With AIDS. This month the charity moved from an eight-bed facility into a new 15-bed complex. But for the first time, nine of those beds will be reserved for people who are still undergoing treatments to combat the human immunodeficiency virus, which causes AIDS.

▸ In Austin, Tex., Christopher House opened three years ago to provide in-patient medical care for people with AIDS. For two years, the 15-bed facility was full. Last year, only about half the beds were needed. And in February, when Christopher House decided to close its doors, only two patients remained.

"It's the dream of people that go into this work that they're not needed anymore," says Carol J. Cody, the charity's founder and executive director.

Waiting Lists Evaporate

In Austin, Christopher House is not the only organization providing end-of-life care that has witnessed a drop in AIDS patients. Hospice Austin—which takes care of not just AIDS patients but anyone who is terminally ill—is taking over the building that Christopher House occupied. But few of its residents will be suffering from AIDS: only 7 per cent of its clients are infected with H.I.V., down from 15 per cent two years ago.

Tim Wolfred, executive director of Maitri, says that his charity often had a waiting list of 30 people in the past. But about a year ago, the waiting list evaporated and only about five of the eight beds have remained full since.

"The drug cocktails have given people new hope," Mr. Wolfred says. "People are psychologically reluctant to say, 'I can't turn this around.' "

Because of that reluctance, Mr. Wolfred and other hospice officials say, people with AIDS often come to them when they are close to death, sometimes with only a day or two left to live. That makes it difficult for the charities to do what they are supposed to do—ease clients' pain and help them come to grips with death.

"It's hard to be a true hospice at this stage of the AIDS epidemic," Mr. Wolfred says, "because there's so much hope."

—PAUL DEMKO

With AIDS Advance, More Disappointment

By LAWRENCE K. ALTMAN

In the last year, the widespread use of combinations of new and older drugs has changed the face of AIDS, promising to transform a fatal infection to a manageable chronic disease.

There are several combinations, many that include the new protease inhibitors, or antiviral drugs. All can drive the amount of H.I.V., the AIDS virus, below the levels of detection in the blood for up to 18 months, which is as long as testing has been done. With such therapy, some individuals have left their death beds and many who were less seriously ill are leading more normal lives.

"The good news is that there are a bunch more smiling faces in my clinic today than were there a year or two ago," said Dr. Julio Montaner, an AIDS expert in Vancouver, British Columbia.

But for an unknown number of other people, the drugs are failing. For them, combination therapy is another in a long list of bitter disappointments.

After the initial flush of success, many important problems and questions have emerged. Among those cited in interviews with 20 experts were these:

¶Has publicity about the initial wave of success created unrealistic expectations about a therapy for which long-term effectiveness and safety are unknown?

¶Is the therapy failing some people because they took the wrong combinations, before doctors fully understood how the drugs should be prescribed?

¶Can an AIDS-damaged immune system ever be restored to normal?

¶Are health officials doing enough to monitor strains of H.I.V. that have become resistant to new therapies?

These are among the problems and questions that 21,000 experts will discuss at a five-day scientific meeting on AIDS that starts in Washington on Wednesday, along with perhaps the biggest question in the minds of everyone with AIDS: Can the disease be cured?

HOPE VS. HYPE

A special report.

Although no one has accurate numbers on how many people use combination therapies, it is estimated that among the roughly 750,000 people infected with the human immunodeficiency virus, tens of thousands of people in the United States are using them. And there is no question that many doctors' practices have changed dramatically.

Dr. Jeffrey B. Greene said that he

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had been making house calls on dying patients too sick to come to his office about twice a month in the 13 years he has been treating AIDS in Manhattan. "I have not made a house call in six months," Dr. Greene said. "It's pretty incredible."

At Case Western Reserve University Hospitals of Cleveland, Dr. Michael M. Lederman said that on average, about 8 of the 650 patients in the hospitals' AIDS clinics died each month over the last three years. But the number of the hospitals' AIDS deaths has fallen in recent months and in December, for the first time, there were none.

Dr. Chris M. Tsoukas, an AIDS expert at McGill University in Montreal, said the new therapies had contributed to about a 50 percent decline in the daily number of AIDS patients at several hospitals in Canada.

Dr. Tsoukas said that his team cared for about 1,000 people infected with H.I.V., and that each day in recent years 8 to 16 of them were in the hospital. But, Dr. Tsoukas added, "For the first time in the 14 years that I have been practicing, we have had not had more than three patients in the hospital in a single month."

Clearly, the era of treating H.I.V. with a single drug is over, and the new combinations appear to be the most potent therapy developed in the 16-year battle against acquired immune deficiency syndrome, experts said. But too little time has passed for anyone to know whether the drugs will lose their effectiveness, and after what period, and some experts are concerned that the gains have been oversold as victory against the disease.

"A triumphant attitude has emerged that makes it sound like we are on the verge of solving this whole thing," said Dr. Ronald Bayer, a professor at the Columbia University School of Public Health in Manhattan. Dr. Bayer, who has been interviewing doctors who have treated AIDS since the disease was identified in 1981 for an oral history project, said: "The thing that is amazing is how so many have forgotten that we have seen moments of what appeared to be great promise quickly turn to disappointment." One example is AZT, which, though effective, is not the cure that some people had hoped it would be. Another is a genetically engineered product known as recombinant CD-4, which failed to have any benefit in clinical trials.

Some patients have not been helped by combination therapies, although again, no clear numbers are available. But one reason for some of the failures has become clear. Some doctors had been tacking a protease inhibitor on to whatever else a patient was taking, a practice that appears not to work in many cases. Many experts now say at least two drugs that a patient has never taken should be used for initial anti-H.I.V. treatment or when a switch is made from a failing drug regimen. And the drugs must be started simultaneously to avoid drug resistance.

"Doctors really did not appreciate that point" when protease drugs first became available a year ago, said Dr. Roy M. Gulick, an expert at New York University. Thus, he and other doctors said, many patients were started out on a drug regimen that would fail a large number of them.

Guidelines published in The Journal of the American Medical Association last July suggested using at least two new drugs, a lesson practitioners have been learning through experience and in discussions with one another. But the Food and Drug Administration has approved the use of a single protease inhibitor.

The reality, experts said, is that no one knows what proportion of those who are taking the drug combinations are benefiting from them. Practitioners generally do not track such information the way researchers did in the clinical studies that first showed the benefits of the combination therapies.

"The hype around this is unfair," said Dr Ian Weller, an expert at University College and Middlesex School of Medicine in London. "We should be cautiously optimistic, but we have taken three paces forward when we should have taken one in terms of what messages we are giving to the community. The downside is that many patients are setting their sights too high."

The Potential

Trying to Keep Up With Innovations

The Food and Drug Administration has approved the marketing of three new protease drugs since December 1995 under its plan to accelerate development of AIDS drugs, bringing to nine the total number of drugs approved for combating the disease. The agency's approval of protease inhibitors was based partly on a few short studies that had involved small numbers of patients, and often were sponsored by drug companies.

If the drugs are stopped, the virus bounces back. Based on current knowledge, the drugs must be taken for a lifetime.

Doctors say that they are just beginning to learn how to use the drugs most effectively. The F.D.A. is investigating a suspected new complication from protease inhibitors — spontaneous bleeding among hemophiliacs.

Dr. Gulick, the New York University expert who helped lead one of the major combination studies, said, "Things are changing almost faster than we can get the word out to people."

So much so that Dr. Victoria L. Sharp said that her team of AIDS doctors at Beth Israel Medical Center in Manhattan had added an extra set of weekly conferences devoted to keeping abreast of new developments in protease drug combination therapy and discussing how to use them in managing difficult cases.

To help clarify therapy options, the National Institutes of Health have appointed two panels to develop new guidelines and update old ones for treating H.I.V. infection. Their reports are scheduled to be issued later this year.

One important aspect of combination therapy is the measurement of its effectiveness, which is made possible by new tests to gauge the amount of H.I.V., the so-called viral load, in the blood. Such monitoring is now considered crucial to guiding therapy. A patient can continue the same regimen as long as viral load is low. A significant rise in viral load can signal the need to change therapy.

But some private and state health insurance plans do not pay for viral-load tests that may need to be done several times a year, each at a cost of $100 or more. Doctors said that when they could not use the new tests to direct treatment, patients were not receiving optimal care. The total cost of combination therapy can be as much as $15,000 a year, and the amount paid by insurance plans varies with policies.

And with more drugs available to combat H.I.V. and the many opportunistic infections that can occur as complications of AIDS, the number of potential combinations increases substantially and the number of studies that can be done far exceeds the ability to pay for them.

"If you talk to investigators around the country you will hear that many have studies that are just languishing," particularly the long-term ones, said Dr. Donald Abrams of San Francisco General Hospital, "and I am not sure we are currently learning how to best use them."

Dr. Fred T. Valentine, an AIDS expert at New York University who headed the F.D.A.'s advisory panel on H.I.V. drugs, [illegible] ent success of combination therapy confronted scientists, drug companies and health officials with a major problem: How can enough patients be recruited for the studies that are needed or planned to develop the simpler regimens and better therapies that are still needed?

The Challenge

Restoration To Normality?

A major question that has not been answered is whether a ravaged immune system can be restored to normal functioning. Some evidence of change in the immune system has been observed, but not a reversal of the damage done by the AIDS virus.

Soon after combination therapy begins, two things usually happen. One is that the amount of the virus in the blood drops. The other is that the number of special immune cells in the blood, known as CD-4 cells, rises and then reaches a plateau lower than a normal level. Until the viral load measurements were introduced, the CD-4 count was the main laboratory test used to follow an individual's course and to guide therapy.

"The CD-4 tells you where you are in a disease and the viral load tells you where you are going in the disease," said Dr. Anthony S. Fauci, who heads the National Institute of Allergy and Infectious Diseases.

"If your CD-4 count is a normal 1,000, even if your virus level is high, right now you are in good shape," Dr. Fauci said. "But if your virus level is high, you are going in the wrong direction. If your CD-4 count is low, say 50, even if your viral level has been brought down to undetectable, you are at an advanced stage of disease."

If the immune system of an AIDS patient is functioning fully again, it might be possible to reduce drugs used to prevent pneumocystis carinii pneumonia and other infections that thrive in people whose immune systems are damaged. No one knows how high an individual's CD-4 count would need to rise to make it practical to stop preventive drugs. In fact, it may never be possible.

Research by Dr. H. Clifford Lane at Dr. Fauci's institute suggests that when an AIDS patient's CD-4 count drops, certain types, or clones, of CD-4 cells are lost. These are the ones that may allow the immune system of such a patient to respond to the specific infectious agents that cause opportunistic infections in AIDS. But even when the overall CD-4 count rises after an individual starts combination therapy, certain clones may be lost permanently.

"You have more of the same clones," Dr. Fauci said, "but if you have lost certain clones, that loss may be permanent and the individual may not respond to opportunistic infections as a healthy person would."

The observation that the CD-4 count does not fully return to normal suggests that the new therapies do not completely reverse the damage the immune system incurs from longstanding H.I.V. infection. And that leaves researchers with a new challenge: to find new ways to try to restore the immune system to normal. Tests are under way to determine whether IL-2, a substance that the body normally uses to allow CD-4 cells to multiply, will work.

The Regimen

Cutting It Down To a Few Pills

Combination therapy regimens are arguably the most demanding of any in medicine. An individual must swallow dozens of pills a day, and the number can exceed 60 for those who need additional drugs to combat opportunistic infections. Some combinations include two drugs, others three.

Depending on the drugs in the combination, the regimen can require a person to take some drugs on an empty stomach and others with food. Additionally, some drugs must be refrigerated. Also, some protease inhibitors can drastically alter the potency of other drugs to cause serious unwanted effects.

So a major goal is to develop new drugs or reformulate existing ones so that a pill could last a day or contain more than one drug.

Until simpler regimens are developed, combination therapy can fail for many reasons. Among them: failure to adhere to the schedule, inability to fully absorb the drugs because of AIDS-related intestinal upsets, and resistance by some strains of the virus to drugs.

H.I.V. resistance to AZT was a common problem in the past. About 15 percent of new AIDS cases on the East and West Coasts of the United States are caused by H.I.V. strains resistant to AZT.

Experts say that the possibility that strains of H.I.V. will emerge that are resistant to combination therapies is a frightening one. In theory, a combination of two or more drugs deals the virus such a blow that H.I.V. cannot multiply and resistance does not have a chance to evolve. But the theory depends on all the drugs being taken as prescribed.

But people generally dislike taking pills regularly — many fail to finish something as simple as a recommended course of antibiotics for common infections. In AIDS, skipping just a few doses can be a fatal step because it can allow drug-resistant strains of H.I.V. to take over.

"Even when patients feel well and have responded to therapy beautifully," said Dr. Valentine, the N.Y.U. expert, "the schedule of taking drugs several times a day reminds them that they have a lethal illness, and that is tough to take."

No one knows what proportion of new H.I.V. infections are the results of strains already resistant to protease inhibitors and how often resistance occurs among those taking the combinations. The reason is that such monitoring is not done on a systematic basis even by research-oriented AIDS groups.

"Not a lot of work is going on in looking at people who recently became infected and trying to identify what proportion are resistant to drug X or Y," said Dr. Sten H. Vermund, who heads the department of epidemiology at the University of Alabama in Birmingham. "We are waiting for some leadership on this arena."

Dr. Lawrence Corey of the University of Washington in Seattle said health officials were lagging in creating programs to monitor drug resistance for H.I.V. and other viruses. But such viral surveillance systems are about 50 times more costly than those for bacteria, Dr. Corey said.

The Centers for Disease Control and Prevention in Atlanta are planning a pilot national survey this year of H.I.V. resistance similar to programs it conducts for drug-resistant bacteria, said Dr. Harold W. Jaffe, an official of the Federal agency.

Development of resistance to drugs does not make the virus more virulent but increases the difficulty of treating H.I.V. So a deep concern is that individuals who develop protease-resistant strains will transmit them to others. If this happens often enough, the resistant strains could create a significant public health problem.

Because of the costs of combination therapy and the likelihood that resistant strains will develop among people who do not adhere to the demanding schedules, many experts have discussed whether doctors should withhold such therapy from those individuals they believe will not comply with the regimen.

Dr. Bayer, who has been holding meetings to discuss the problem at Columbia, said, "The issue is of major concern and one with which we are hardly grappling."

The Outlook

Conflicting Views On Declaring a Cure

The ultimate success of combination therapy would be to cure AIDS, a concept that has been so far from conventional thinking that few experts have bothered to formulate a definition. Thus there is widespread confusion about what to call a cure.

Proof would require a process of several steps starting with treating an infected individual. After blood tests showed no evidence of H.I.V. multiplication and no evidence of the virus's genetic material hiding in cells for a period of time, then the individual would have to agree to stop therapy and undergo frequent testing to determine if the virus returned. Reappearance could occur after therapy is stopped if H.I.V. found a sanctuary, for example, in the brain or semen.

One reason for skepticism about curing AIDS is that the virus integrates itself into the machinery of normal cells. Dr. David D. Ho, the head of the Aaron Diamond AIDS Research Center in Manhattan, has developed a mathematical model that assumes that the life span of the cells that H.I.V. infects is up to three years. If those cells die out and no H.I.V. is left in the body, then Dr. Ho theorizes that the cells that replace the old ones should be uninfected. Thus, a cure.

But some assumptions in Dr. Ho's model have been challenged at recent meetings and their accuracy can be determined only by testing the theory in people. Dr. Ho's team has said it eventually intends to do so by asking infected people participating in a small study to stop the drug after H.I.V. has remained undetected for a period.

The possibility of a cure is also being tested in a federally financed national trial that will take several years to complete. Participants must agree to drop one drug from a three-drug combination in step-ladder fashion after H.I.V. has remained undetectable for a lengthy period and then go through testing to determine whether the virus-free state persists.

Even if the combinations do not cure AIDS but their knockout punch lasts many years, present and future combination therapy would qualify as a major medical advance and point the way to new theraples for other diseases.

New Drug Combinations: 3 Case Studies

Combination therapy has shown very different results in three actual cases of infection with H.I.V., the virus that causes AIDS. While an individual's CD-4 count may not change substantially, the viral load (a recently developed measure of the level of infection) can drop sharply in some cases and drop and rebound in others.

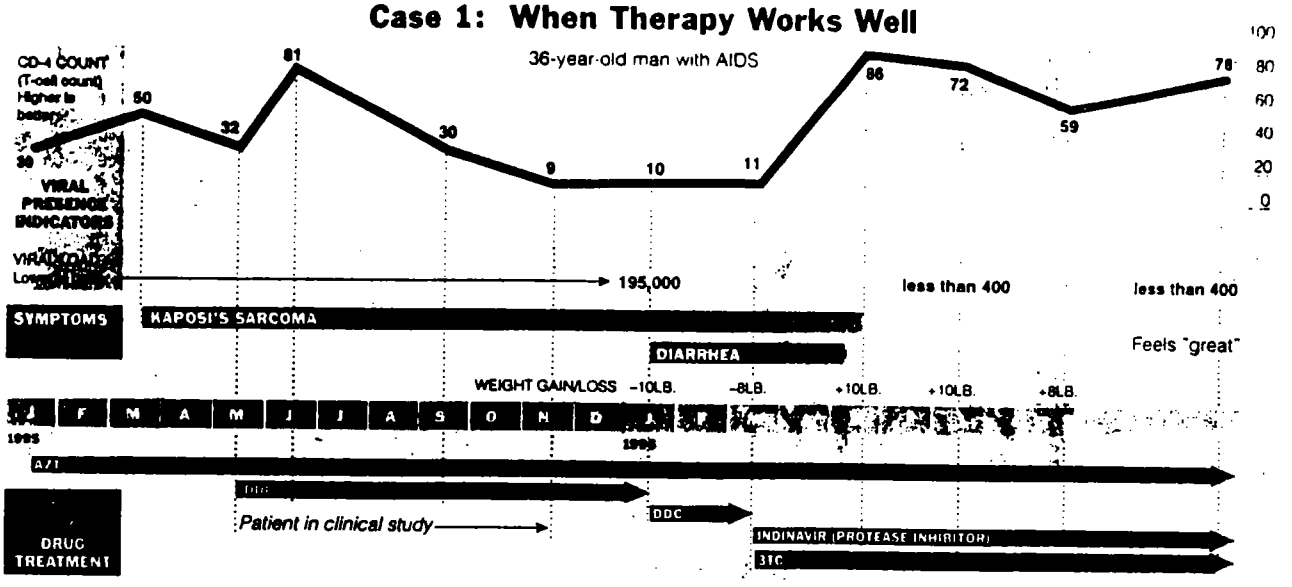
THE TWO INDICATORS OF ILLNESS

CD-4 COUNT Number of immune cells per microliter of blood. More than 500 is considered a normal value; less than 200 meets one of the Centers for Disease Control and Prevention's definitions of AIDS.

VIRAL LOAD Number of copies of H.I.V. RNA per milliliter of serum or plasma, a measure of level of infection. The lowest detectable level with certain methods is 400; readings as high as several million have been recorded.

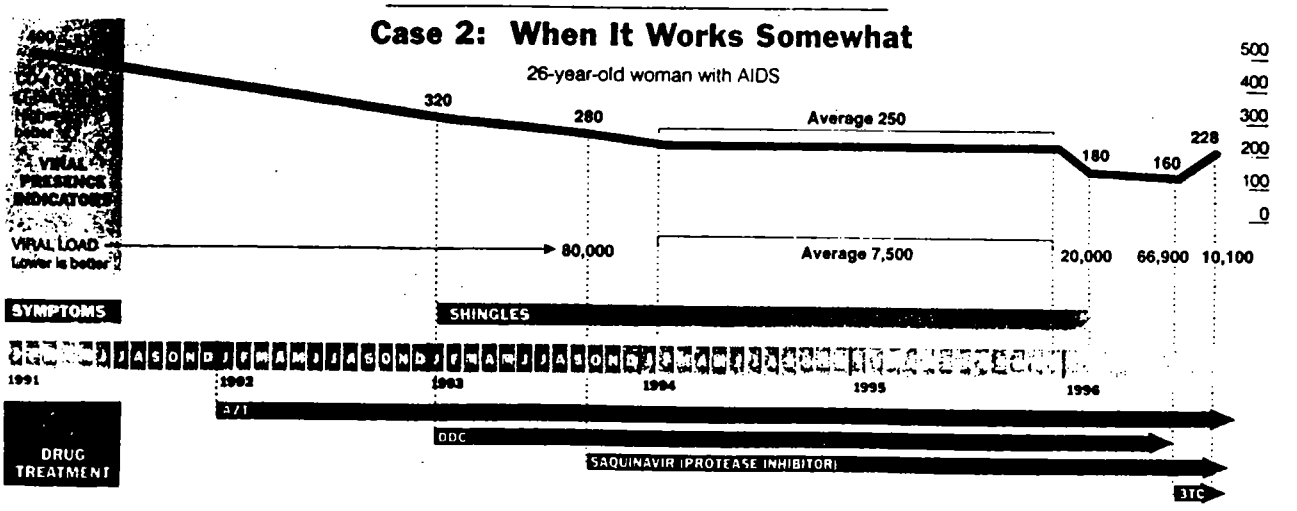
Case 1: When Therapy Works Well

36-year-old man with AIDS



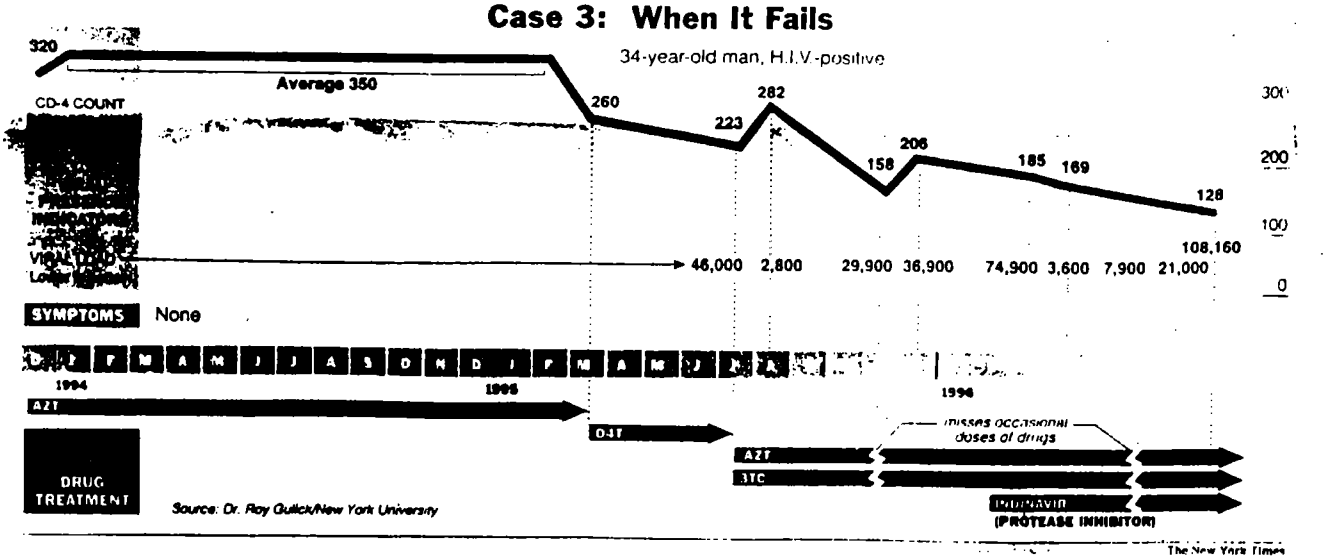
Case 2: When It Works Somewhat

26-year-old woman with AIDS



Case 3: When It Fails

34-year-old man, H.I.V.-positive



Source: Dr. Roy Gulick/New York University

The New York Times

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Expense Means Many Can't Get Drugs for AIDS

By ROBERT PEAR

WASHINGTON, Feb. 15 — Even though new drugs show great promise in combating AIDS, many patients are finding that they cannot easily get the costly medicines because of restrictions imposed by health maintenance organizations and by state programs set up to assist people with low incomes.

Some H.M.O.'s say they limit pharmacy benefits to a specified amount — $3,000 a year a patient is typical.

That is far less than the cost of the drug combinations often recommended by doctors. These regimens, some of which combine new protease inhibitor drugs with older antiviral medications, can easily cost $10,000 to $15,000 a year, and doctors say AIDS patients may need to take the drugs indefinitely.

In research reported in the last year, the drug combinations appear to be highly effective in suppressing H.I.V., the virus that causes AIDS, and in improving patients' health. These reports have raised hopes and generated a huge increase in demand for the drugs, surpassing the expectations of drug manufacturers, private health plans and AIDS drug assistance programs financed by Federal and state authorities.

Experience with the new AIDS drugs may foreshadow the difficult trade-offs that await taxpayers and policy makers as scientists develop costly treatments for other diseases like cancer or Alzheimer's.

"You try to ration things as ethically as possible," said Paul G. Loberti, administrator of the AIDS office in the Rhode Island Health Department.

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Each state has a drug assistance program to provide prescription drugs to low-income people who are not covered by private health insurance or Medicaid. At President Clinton's insistence, the Federal Government has sharply increased its contribution to these programs and will provide 85 percent of the $300 million they spend in the coming year. But in interviews, officials in several states said the money was still not enough to meet the demand for the new drugs.

In Missouri, John K. Hubbs, chief of the AIDS bureau of the state Health Department, said: "We have established a limit on the number of patients to whom we can provide protease inhibitors: 132. And we have imposed a cap of $10,000 on what we will pay for a patient's combination drug therapy."

The AIDS drug assistance programs in Arkansas, Nevada, South Dakota and Oregon do not cover any of the protease inhibitors, which block reproduction of the AIDS virus. Covering such drugs "would blow our budget out of the water," said Lisa McAuliffe, coordinator of the Oregon program.

In Colorado, the AIDS drug program ran out of money on Dec. 10, three and a half months before the end of the fiscal year. "Because the medicines were so new, we had no idea what the demand would be," said Pamela R. Snyder, the program director. "The drugs are effective. People want them. The demand just grew and grew."

Illinois officials tightened the eligibility criteria and reduced the list of approved drugs to 28, from 112, so they would not run out of money. The state covers one of the three protease inhibitors. Thomas J. Schafer, a spokesman for the Illinois Department of Public Health, said the state would soon impose an annual limit, perhaps $12,000 for each person receiving AIDS drugs through the program.

The Florida Health Department, which just added the protease medications to its list of approved drugs, is getting $24 million of Federal money this year, up from $17 million last year. But David W. Poole, chief of AIDS patient care at the department, said, "We anticipate needing many more dollars."

In Washington State, the AIDS drug assistance program ran short of money last summer, and state officials temporarily froze enrollment, taking no new patients for a month. The program reopened in August after Mike Lowry, the Governor at the time, provided $200,000 from an emergency fund.

New York, with more AIDS cases than any other state, has the nation's most comprehensive drug assistance program. It serves 10,000 people and covers more than 200 drugs, but it has avoided most of the financial problems seen elsewhere. New York receives a large amount of Federal money, $70 million in the coming year.

In addition, unlike about 20 states that rely entirely on Federal grants, New York contributes $12 million of state money, derived from a tax on health insurers.

The limits imposed by H.M.O.'s on pharmacy benefits are not explicitly directed at people with AIDS but affect them more than others.

Ronald D. Wackett, the pharmacy director at Mid Atlantic Medical Services, a managed care company in the Washington area, said its health plans often set annual limits on drug coverage at $2,000 or $3,000 a person.

Michael H. Savage, a spokesman for Mid Atlantic, said that if people with AIDS needed drugs beyond that limit, "they are pretty much on their own."

Moreover, he said: "It is not the H.M.O. imposing the limit. The employer purchasing the health plan chooses the benefit levels that he or she wishes to offer employees."

H.M.O.'s with no limits on prescription drug benefits fear that they will get disproportionate numbers of patients with AIDS. Wayne E. Rosenkrans, a spokesman for Kaiser Permanente in the Washington area, said, "Some of our infectious-disease physicians have been told by a few of their new AIDS patients that the pharmacy limits instituted by other health plans caused the patients to switch to Kaiser when they had the opportunity."

Susan M. Dooha, a policy analyst at Gay Men's Health Crisis, an AIDS service organization in Manhattan, said that "preauthorization requirements and caps on prescription drugs are becoming a significant problem" for people with AIDS.

"People with H.I.V. spend huge amounts of time trying to keep their drugs covered by insurance or by one government program or another," Ms. Dooha said. "It's a major preoccupation, a full-time job."

A psychiatric social worker with AIDS who is employed by the New York State government and who did not want to be identified, said he had spent a full week negotiating with a pharmacy, an insurance company and a drug manufacturer over who would pay for a protease inhibitor that he began taking last April.

"It was an incredible hassle," he said. "My body was wasting away. I was desperate. But the drug has been a savior. It's bought a year of life for me."

Doctors say it is extremely important for people with the AIDS virus to take their drugs exactly as prescribed. Interruption of the therapy can promote the emergence of a resistant strain of H.I.V.

The Food and Drug Administration has approved three protease inhibitors: Invirase, made by Roche Laboratories; Crixivan, by Merck and Company, and Norvir, by Abbott Laboratories.

The manufacturers all have pro-

grams to provide the drugs free, as a last resort, to patients who have no health insurance or experience gaps in coverage. But the logistics of these arrangements can be daunting.

Jan D. Weiner, a spokeswoman for Merck, gave this example. An AIDS patient with private insurance typically gets Crixivan through Stadtlanders Pharmacy, a specialized drug distribution company in Pittsburgh. After several months, the patient may reach the $3,000 limit on his pharmacy benefit.

If the patient has too much income to qualify for Medicaid but too little to afford the drug, he may get Crixivan free through Merck's patient-assistance program. In the next year, the patient may become eligible for $3,000 worth of drug coverage through his private health plan.

So the patient may bounce between private health insurance and Merck's free-drug program.

Dr. Richard O'Connor, a medical director at Physicians Health Services, an H.M.O. based in Trumbull, Conn., said: "We are seeing a proliferation of very expensive drugs not only for AIDS, but also for cancer, multiple sclerosis, depression, hypertension and other conditions."

Several studies suggest that the protease inhibitors, though expensive, may cut the cost of treating AIDS by reducing the need for hospital care, home health care and other services. "The studies suggest that overall costs will come down, but we don't have enough information to document that in our plan," said Mohan Vodoor, a vice president of the Health Insurance Plan of Greater New York, an H.M.O.

Medicaid helps finance health care for more than half of all people with AIDS. Sally K. Richardson, deputy administrator of the Federal Health Care Financing Administration, recently told state Medicaid officials that they must cover the three protease inhibitors.

In his new budget, President Clinton proposed per-capita limits on Federal Medicaid spending. People with AIDS and state officials strenuously oppose such limits, saying they would threaten access to promising AIDS drug therapies.

About the Roundtable

The Philanthropy Roundtable is a national association of individual donors, corporate giving representatives, foundation staff and trustees, and trust and estate officers. Its Associates include grantmakers who are involved in philanthropy on a professional basis, as well as individual donors for whom giving is a serious avocation.

The Roundtable is founded on the principle that voluntary private action offers the best means of addressing many of society's needs, and that a vibrant private sector is critical to the wealth-generation that makes philanthropy possible. Its work is motivated by the belief that philanthropy is most likely to succeed when it focuses not on grand social designs, but on individual achievement, and where it rewards not dependence, but personal initiative, self-reliance, and private enterprise—in other words, where it seeks to expand, rather than restrict, human liberty and opportunity.

The Roundtable attracts independent-minded grantmakers who understand that philanthropy is difficult to do well, and who realize they can benefit from being part of an organization that is dedicated to helping them achieve their charitable objectives. Besides offering advice and counsel, the Roundtable puts donors in touch with peers who share similar concerns and interests. Roundtable Associates thereby gain access to the most valuable resources available: other donors, their ideas, and their experiences in what works and what doesn't.

One of the hallmarks of the Roundtable's work is its strong commitment to donor intent, and to helping philanthropists ensure that their intentions will be adhered to in the long-term administration of their trusts. As an organization dedicated to serving donors' needs, the Roundtable represents a unique resource for those who want to make the most of their giving potential.

History

The Philanthropy Roundtable began in the late 1970s as an informal network of grantmakers who were troubled by what they perceived to be an increasing politicization of philanthropy, and who wanted to promote greater respect for private, voluntary approaches to individual and community betterment. The goal of the Roundtable's founders was to provide a forum where philanthropists, and those who worked for them, could discuss the principles and practices that inform the best of America's charitable tradition.

For many years, the Roundtable operated under the aegis of the Institute for Educational Affairs, gradually building into a nationwide organization of donors supporting a formal program of conferences and publications. In 1991, it became a self-standing organization with an independent board of directors, a small staff, and an expanded agenda of services and activities. For the first time, regular annual contributions were requested of those wishing to join the Roundtable. Currently, over 430 donors are Roundtable Associates.

Despite its rapid growth, the organizational structure of the Roundtable has remained lean. In 1996, it carried out a full program of meetings, publications, and consulting services with a staff of only five and a budget of just over a half-million dollars. Its activities are described on the pages that follow.

Programs and Services

The Roundtable's programs and services for grantmakers include:

- An Annual national meeting, held each fall, which focuses on a theme of central importance to philanthropy. Donors gather from around the country for this three-day conference.

- Regional meetings, held in different cities throughout the year, which bring grantmakers together to discuss issues of common concern and to develop effective strategies to address them.

- *Philanthropy*, a quarterly publication which explores the issues of greatest concern to grantmakers and welcomes articles by donors and others about new ideas and developments in philanthropy.

- Monographs addressing both practical and philosophical matters pertaining to charitable giving.

- A website (http://philanthropyroundtable.org) with current information of interest to donors.

- Consulting and referral services on starting, restructuring, and administering giving programs, designed especially for individual donors and small foundations that have limited staff and resources.

- Referral services for donors seeking advice on tax, legal, and other matters.

The Roundtable's programs and services are available to donors only. The solicitation-free environment we seek to maintain precludes paid fundraisers from participating.

Who Joins the Roundtable?

To be eligible to join the Roundtable, donors do not need to meet specific giving requirements. Rather, the organization's aim is to be as inclusive as possible, so that donors of all giving levels may participate.

While the Roundtable is open to grantmakers only, certain public charities that engage in grantmaking activities may be eligible to join if they devote more than half their operating budget to grants to external organizations. Community foundations are also welcome to become Associates.

Roundtable Associates represent some of the largest foundations in the country and some of the smallest, as well as many donors who give personally, rather than through foundations. Believing that donors with modest amounts to give are as likely to develop innovative ideas and programs as their counterparts with greater resources, the Roundtable views donors of all varieties as an asset to the organization and to one another.

Individual Donors

The Roundtable welcomes individual donors who might not otherwise have the opportunity to participate in professional grantmakers' associations. Those for whom philanthropy is a serious avocation, but not a full-time endeavor, find the Roundtable offers a comfortable forum through which to meet other donors who share common concerns and interests. The Roundtable also represents a valuable resource for individual donors who are thinking of establishing foundations, and in particular those who seek to develop strong provisions regarding donor intent.

Foundation Staff and Trustees

Whether a foundation is family-oriented or governed by an independent board of trustees, the experiences and practices of other foundations can provide useful direction and knowledge. On matters ranging from foundation administration to trusteeship and program development, board and staff members of foundations find that the Roundtable supplies helpful information and an opportunity for valuable interaction with colleagues from other grantmaking organizations.

Corporate Giving Representatives

The work of corporate giving representatives is complicated by the fact that they are entrusted not with carrying out the wishes of a single donor, but with fulfilling the interests of an organization that has many constituencies, including shareholders, employees, consumers, and local communities. The Roundtable provides a forum for corporate donors to explore effective ways of merging their charitable and business interests.

Trust and Estate Officers

Trust and estate officers hold responsibility for directing much private giving. However, those who are affiliated with banks, investment firms, and law firms often have little access to information about effective philanthropy. Through its meetings and publications, the Roundtable provides a means for busy professionals to become better acquainted with some of the principles and practices that inform successful giving.

Publications

Death, Taxes and the Independent Sector
by Alan Reynolds

Discovering Charity
by Gaylord K. Swim

Donor Intent
by Robert H. Bork and Waldemar Nielsen

The Market Foundations of Philanthropy
by Richard B. McKenzie

The Promise of Community: Local Voluntary Organizations as Problem-Solvers
by James L. Payne

The Promise of Community: Strengthening Civil Society
by Paul Heyne

Should Foundations Exist in Perpetuity?
by Heather H. Higgins and Michael S. Joyce
Introduction by Craig Kennedy

Starting a Private Foundation
by Paul K. Rhoads and Stephanie Denby

Becoming an Associate

Individual donors, corporate giving representatives, staff and trustees of foundations, and trust and estate officers are welcome to join the Roundtable. Suggested annual contributions begin at a modest level in order to encourage broad participation. However, the Roundtable depends on larger donations for its continuing operations. Therefore, while the amount of the annual contribution is left to the discretion of each donor, Associates are asked to be as generous as possible in making their donations.

Suggested Annual Contribution Levels

	Individual Donors	Institutional Donors*
Basic	$250	$500
Sustaining	$500	$1,000
Leadership	$1,000 and up	$2,500 and up

** Institutional donors include foundations, corporations, and trust and estate officers.*

Roundtable Associates automatically receive a subscription to *Philanthropy*, invitations to attend all regional and annual meetings, complimentary copies of monographs, discounts on publications and conference registration fees, and consultation services free of charge. To join the Roundtable, please complete the enclosed registration form and return it along with your contribution.

The Philanthropy Roundtable is a nonprofit, tax-exempt organization under section 501(c)(3) of the Internal Revenue Code. All contributions are fully tax-deductible.

THE PHILANTHROPY ROUNDTABLE
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"It is well to remember that it requires the exercise of not less ability than that which acquires it, to use wealth so as to be really beneficial to the community."

— ANDREW CARNEGIE

Associate Registration Form

The Roundtable welcomes individual donors, corporations, foundations, and trust and estate officers as Associates. All Roundtable Associates are eligible to receive:

- A subscription to *Philanthropy*
- Invitations to annual and regional meetings
- Discounted conference fees
- Complimentary copies of monographs
- Program and management consultation

Suggested Annual Contribution Levels:

	Individual Donors	Institutional Donors*
Basic	$250	$500
Sustaining	$500	$1,000
Leadership	$1,000 and up	$2,500 and up

** Institutional donors include foundations, corporations, and trust and estate officers.*

The Roundtable also accepts grants for projects and operating support

Enclosed is my tax-deductible contribution of $_____ to become a Roundtable Associate at the basic / sustaining / leadership (circle one) level.

Mr.
Mrs.
Ms.
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Name

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Title

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Affiliation

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Address

_____
City *State* *Zip*

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Mobilizing Philanthropic Leadership and Resources in the Fight Against HIV/AIDS

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510 Madison Avenue
Suite 1630
New York, NY 10017
Tel 212.573.5533
Fax 212.949.1672

August 12, 1997

Whitney L. Ball
Executive Director
The Philanthropy Roundtable
1150 17th Street NW, Suite 503
Washington, D.C. 20036

COPY

Dear Whitney:

Joyce Bove and I were very happy that we were able to meet with you to discuss possible FCAA participation at your October annual meeting. I hope these ideas fully capture our conversation and refine some of the ideas further.

As I envision this panel discussion and dialogue, the underlying issue, in many respects, is as follows: what are some of the work place and economic implications of HIV/AIDS as a potentially manageable disease. As we discussed, with the advent of promising new treatments, we may be on the verge of HIV/AIDS being a manageable health condition. If that is the case, government, philanthropy, the private sector and HIV/AIDS organizations will have to begin to change the current HIV/AIDS paradigm. Presently, the construct used and assumed for everything from funding and social services to health care is one of illness to death. It may be that the new paradigm must be one of varying health and disability status.

A fascinating implication within this larger issue is the impact involving work. If large numbers of individuals with HIV/AIDS can and should stay in the work force or can return to it, what are the implications for work place policies and practices, employers, existing government benefit and other programs for people living with HIV/AIDS, the individuals with HIV/AIDS in question, AIDS organization programming, and directions in philanthropic funding for HIV/AIDS?

The proposed FCAA panel would address this particular issue. The goal would be for participants to:

1) increase their knowledge and awareness of the now rapidly changing nature of the HIV/AIDS epidemic in the United States in the areas of public health, medical care and research, and workplace issues, including learning how to distinguish between the facts and the fictions of reports on recent medical and other advances in the battle against the epidemic;

2) learn and strategize about ways in which the changing nature of the epidemic, especially work place and economic changes, already is or could affect their grantmaking strategies and programs (whether or not participants engage in HIV/AIDS funding presently); and,

3) learn about and brainstorm around ways that the "new paradigm" in HIV/AIDS, especially in the work arena, could radically alter prevailing philosophies, structures and norms in the areas of HIV/AIDS services, government funding, public policies and philanthropic involvement in all of these areas;

I would envision a format as follows:

Three or four presenters limited to ten minute presentations. FCAA staff will work with presenters to ensure non-duplicate and comprehensive coverage of the range of issues listed here. Attempts will be made to highlight areas of disagreement in the approaches and policies suggested by the presenters to spur debate. This will be followed by a debate and dialogue format facilitated by the moderator among the panelist. This will be followed by questions and conversation between the audience and the panel.

Although this is quite preliminary, I would see possible presenters as:

1). Sandy Thurman, Director of The Office of National AIDS Policy

Ms. Thurman is the point person for the federal government on HIV/AIDS policy. She has a decade long career in HIV/AIDS work and was former Executive Director of AID Atlanta, the South's leading community-based AIDS service organization. Ms. Thurman has also served as a member of the President's HIV/AIDS Advisory Council and as Director of Advocacy at the Task Force for Child Survival and Development at the Carter Center in Atlanta.

2). An HIV/AIDS physician and/or medical researcher

This person can update the audience on the present state of the epidemic as well as specific medical issues surrounding the return to work issue.

3). A specialist in the "return to work arena"

This person could educate the audience and lead a discussion in the many issues within the larger return to work issue.

4). Moderator:

An FCAA Board member or leading FCAA philanthropic supporter/member.

Please feel free to call with questions or additional ideas. I look forward to developing this further with you.

Sincerely,

Paul A. Di Donato
Executive Director

cc: Joyce Bove
Nick Bollman

Funders Concerned About AIDS
Panel Presentation At The
Philanthropy Roundtable Conference
Newport, Rhode Island, October 24, 1997

(Panel Plan as of September 19, 1997)

INTRODUCTION

As FCAA envisions this panel discussion and dialogue, the underlying issue is: what are some of the major implications of HIV/AIDS as a potentially manageable disease?

With the advent of promising new treatments and other advances in the battle against this epidemic, the United States may be on the verge of HIV/AIDS being a chronic, manageable health condition. Science, medicine and reality have yet to prove this is the case; however, if this is the direction in which we are headed, philanthropy, government, the private sector, and the HIV/AIDS industry (from service organizations to advocacy entities) must begin changing the current HIV/AIDS paradigm. Presently, the construct used and assumed for everything from funding and planning, to social services and health care is one of presumed illness to debilitation to death in a ten to fifteen year time frame. This new paradigm may be one of varying health and disability status (both medically and work defined disability) over a much longer stretch of time.

One especially fascinating implication within this larger issue is the impact involving return to work or first time work for people living with HIV/AIDS. If large numbers of individuals with HIV/AIDS can and should be in the work force, then what are the implications for employers in general? work place policies and practices? existing government benefit programs, especially disability and health care, and other programs for people living with HIV/AIDS? the individuals living with HIV/AIDS in question? AIDS organization programming? and directions in philanthropic funding for HIV/AIDS?

PANEL GOALS

The proposed FCAA panel would address this larger issue in an overview fashion and focus on this particular aspect of it. The goal would be for participants to:

1). enhance their knowledge and awareness of the now rapidly changing nature of the HIV/AIDS epidemic in the United States in the areas of public health, medical care, bio-medical research, and service delivery.

recommendations have a beneficial impact include the quality of the proposals and recommendations, their support by the diverse constituencies that developed and agreed to them, and the presentation of the recommendations to those who are important to their timely and effective implementation.

Funding: Financial support for this project will be secured from public and private entities, including private foundations, companies and government agencies. Given the federal government's key role in these issues, it is anticipated that a significant portion of the budget, totaling approximately $420,000, will be contributed by the primary agencies. The diversity of funding sources, however, will emphasize the interest in and support for resolving these issues by a diverse group of stakeholders.

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FUNDERS CONCERNED ABOUT AIDS

Mobilizing Philanthropic Leadership and Resources in the Fight Against HIV/AIDS

310 Madison Avenue
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Tel 212.573.5533

Fax

To: Joyce Bove, New York Community Trust, 532-8528
Ed Kacic, Irvine Health Foundation, 714-253-2962
Michael Naimy, MTS, 679-8310
Todd Summers, ONAP, 202-632-1096

From: Paul A. Di Donato
Tel: 212.573.5533; Fax: 212.949.1672

Date: October 17, 1997

Re: Philanthropy Roundtable Panel
Conference Call, Monday, October 20, 11:00 am (ET)

Pages: ~~One~~ 6 total

Thank you for arranging your schedules for this conference call. The call is scheduled for **Monday, October 20, at 11 am (ET).** The dial-in number is **1-800-311-9406, ID#24636**. The call will be the only chance for the full panel to plan the event, so I hope everyone is on the call and can stay with it to conclusion.

IF FOR SOME REASON YOU CANNOT MAKE THIS CALL AT THE LAST MINUTE, PLEASE MAKE SURE THAT YOU CONTACT BOTH ED (ph: 714-253-2959) AND ME BEFORE THE PANEL TAKES PLACE, SO THAT WE CAN ENSURE A WELL ORGANIZED, COMPREHENSIVE, AND ENGAGING PANEL. THANK YOU.

Ed and I are meeting via phone today to plan for next Monday's conference call and the panel itself. All seems set for a great panel. Unfortunately, several medical researchers and providers we contacted to be on the panel could not do it. That is the only glitch so far.

I am sending preparatory materials to all panelists which you will have by close of business (COB) Monday. If you have any questions on the materials or the substance of the panel, please call me up to Thursday, October 23rd. I (and Chris) am in transit to Chicago on Friday, 10/24 and not reachable that morning before the panel begins.

If you have any logistical questions (travel, lodging, directions, materials, etc.), please contact Chris Yu up until Thursday COB.

The 1997 Annual Meeting of The Philanthropy Roundtable

Are we entering a Golden Age of Philanthropy?

Agenda

Thursday, October 23

12:00 p.m. Registration

2:00 p.m. Opening Presentation

Can Local Churches Help Rebuild Inner City Neighborhoods?

John J. DiIulio, Jr. & Rev. Dr. Harold Dean Trulear
The Partnership for Research on Religion and At-Risk Youth
Rev. Eugene F. Rivers, 3d
National Ten Point Leadership Foundation

3:15 p.m. Break

3:45 p.m. ***Giving Better/Giving Smarter***

Peter Frumkin, Kennedy School of Government, Harvard University
Sister Jennie Lechtenberg, PUENTE Learning Center
Steve Shuck, Shuck Communities, Inc.
Moderated by: **Bruno Manno**, The National Commission on Philanthropy and Civic Renewal

5:00 p.m. Break

5:30 p.m. Newcomers Reception

6:00 p.m. Opening Reception

7:00 p.m. Dinner Presentation

Applying Business Principles and Moral Principles to Philanthropy

Foster Friess, Brandywine Funds

Friday, October 24

7:30 a.m. Continental Breakfast

9:00 a.m. ***New Kinds of Schools, New Kinds of Choices***

David Brennan, HOPE Academies
Virginia Gilder, The Hickory Foundation
John Walton, The Walton Family Foundation
Moderated by: **Chester E. Finn, Jr.**, Thomas B. Fordham Foundation

10:15 a.m. Break

10:45 a.m. Concurrent Sessions

A. ***Securing Foundation Success: Linking Donor Intent with Foundation Investment Strategies***

Sylvia Myers Maurin, PNC Private Bank

This session will be beneficial for donors who are thinking or rethinking their investment strategies. The focus will be on the establishment of investment priorities, how donor intent is integral to this, and how changing markets affect investment strategy.

B. ***The Art of Grantmaking: An Open Discussion for Funders***

Joe Dolan, Achelis and Bodman Foundations
Charles H. Hamilton, JM Kaplan Fund
Louise Oliver, George E. Coleman Jr. Foundation

An informal, "free-for-all" session examining a wide range of issues that all donors face. We encourage you to bring any questions you may have regarding grantmaking to this session, or to send them to the Roundtable by October 15, 1997.

C. ***Living Longer with AIDS: Issues for Philanthropy***

A panel presentation and dialogue concerning the major implications of HIV/AIDS as a potentially manageable disease, and how the changing nature of the epidemic could, and should, affect grantmaking strategies and programs. One topic for discussion will be the possibility of economic and/or workplace changes as people living with HIV/AIDS return to or begin working.

12:30 p.m. Lunch Presentation

Is Devolution Dead?

Will Marshall, The Progressive Policy Institute
Stephen Moore, Cato Institute
Moderated by: **William Kristol**, *The Weekly Standard*

2:00 p.m. Concurrent Sessions

A. Managing a Private Foundation

Linda Franciscovich, U.S. Trust Company of New York
Paul Rhoads, Schiff Hardin & Waite
Linda Tafoya, Castle Rock Foundation

This symposium will give grantmakers an opportunity to ask questions about any and all issues pertaining to foundation management. There will be no formal presentations, rather the three experts will make themselves available to entertain questions related to foundation start-up, administration, tax and legal matters and governance issues.

B. Donor Intent in Perpetuity

Derwood Chase, Jr., The Chase Foundation
James Edwards, McCune Foundation

As the issue of donor intent is a fundamental concern for philanthropists, this session presents the experiences of two donors and their efforts to maintain donor intent into perpetuity.

C. International Giving

G. Philip Hughes, Manchester Trade, LTD.
Curtin Winsor, Jr., William H. Donner Foundation

Just as there has been a rethinking of what works in domestic social spending, international giving has undergone a scrutiny to determine what is working effectively. Ambassador Hughes, former Ambassador to Barbados and the Eastern Caribbean, and Ambassador Winsor, former Ambassador to Costa Rica, will review what has been learned and discuss the most promising current trends.

3:15 p.m. Break

Optional Sessions

3:30 p.m. ***Visit to Shake-A-Leg***

During the break in the program, transportation will be provided for all donors who wish to tour the Shake-A-Leg center, a local rehabilitation center for individuals with spinal cord injuries and related neurological disorders. The visit will include a presentation by the center's chairman and a tour of the sailing and aquatic therapy facilities. Buses will depart from the hotel lobby at 3:30 p.m. and return by 5:00 p.m.

3:45 p.m. ***Inheritors Unlimited***

Inheritors Unlimited will hold its third annual meeting during the program break on Friday. The gathering is open only to donors of substantial inherited wealth (defined as enough inherited wealth to live on without working). This year's program will be a roundtable discussion of the challenges and opportunities faced by those who inherit substantial wealth. To start the discussion, we have invited several inheritors to prepare remarks that draw on their experience with the following issues: the search for vocation; internal and external pressures for social significance in a society mesmerized by power and money; peer issues and the secrecy surrounding wealth; raising your children with wealth; to inherit or disinherit your children; family matters; and the culture's inability to view wealth outside of an entrepreneurial/business model. This session will conclude at 5:00 p.m.

6:30 p.m. Reception

7:00 p.m. Dinner Presentation

Traditions in American Philanthropy: Past, Present and Future

David Horowitz
Co-author of *The Rockefellers*, *The Fords*, and *The Kennedys*
and author of *Radical Son: A Generational Odyssey*

Introduction by **Joanne Beyer**
Scaife Family Foundation

Saturday, October 25

8:00 a.m. Continental Breakfast

9:00 a.m. ***Questions to Ask Before You Write the Check***

Edward Kacic, Irvine Health Foundation
David Kuo, The American Compass
Jerry Martin, National Alumni Forum
Lynne Munson, American Enterprise Institute
Moderated by: **Leslie Lenkowsky**, Indiana University Center on Philanthropy

10:30 a.m. Concurrent Sessions

A. A Case Study in Strategic Planning: Mid-life Reexamination of a Foundation's Mission

Philip M. McGoohan, W.H. Brady Foundation

Faced with the imminent prospect of a substantial increase in its assets, and without a statement of donor intent, this session discusses how one foundation undertook a reexamination of its mission. The topic stretches from the earliest thoughts, through the board's decision to study the issue, to the present status of the project.

B. Preserving Family Philanthropy: Passing Purpose from Generation to Generation

Joe Ignat, Nord Family Foundation
Hugh Maclellan, Jr., Maclellan Foundation
Winsome McIntosh, The McIntosh Foundation

An exploration of intergenerational transfer and the preservation of donor intent from the perspective of second, or later, generation trustees. The panelists will talk about what works, and what doesn't, in the application of their principles and practices.

C. How to Get the Best Results from Your Charitable Investments

Jim Capua, William H. Donner Foundation
Bill Niederloh, National Results Council
William J. Phillips, The Rensselaerville Institute
Moderated by: **Chris Olander**, JM Foundation/Milbank Foundation for Rehabilitation

The panelists will discuss how to get the most for your charitable dollars. This session will include ample time for participants to join panelists in a discussion of donors' expectations of accountability, results and the need for evaluation of their philanthropic endeavors.

D. Executive Liability for Foundations: Questions to Ask and Solutions

Richard G. Clarke, CPCU, CIC, Palmer and Cay of Atlanta, Inc.
Linda G. Hammond, Palmer and Cay of Virginia, Inc.

Clarke and Hammond will present a colloquium on directors' and officers' liability and various methods of protection.

11:30 a.m. Adjourn

Sponsors' Luncheon

The Sponsors' Luncheon will take place from noon to 2:00 p.m. in the Newport Room. The Roundtable will host a luncheon for its donors who contribute $5,000 or more. There is no formal program; thus, the luncheon offers an opportunity for our principal funders to meet informally with the board of directors and the senior staff of the Roundtable.

Joyce Bono
Michael
Ed Kaiko
Paul
Chris Yu (212)949-1672

Roundtable
- 5th annual conference
  family donors
  individual donor type

Ed does intro -
  Todd
  Michael
  Joyce

8-10 minutes each

  Rights
  Services
  Comment on larger issues

Todd
- overview on research agenda & medical advances
- epi info
- where epidemic is going