



AIDS COMMUNITY RESEARCH INITIATIVE OF AMERICA

ABOUT ACRIA

Mission and Background

Founded in December 1991, the AIDS Community Research Initiative of America (ACRIA) is a collaborative and independent 501(c)(3) not-for-profit organization that studies new treatments for HIV/AIDS and related diseases and conducts a comprehensive HIV health literacy program.

ACRIA is a small agency, with a 24-person staff and an average annual budget of about \$3.2 million. When ACRIA was founded, we operated primarily in the New York City metropolitan area but quickly grew to become a national organization. Today, ACRIA is one of the few AIDS not-for-profits recognized by the U.S. Office of Personnel Management as eligible to participate in the national Combined Federal Campaign, a designation first awarded in 1998. ACRIA meets all of the Better Business Bureau's Standards for Charity Accountability, allowing us to display the BBB Charity Seal.

Current HIV-Related Services

To leverage limited resources, every program at ACRIA is conducted as much as possible in collaboration with other agencies and healthcare providers. To ensure that our programs remain relevant, we reexamine the current state of the AIDS epidemic in the United States regularly. ACRIA works in two program areas to fulfill its mission:

Research. ACRIA conducts research into experimental HIV therapies, modalities with potential to minimize or eliminate the side effects of antiretroviral drugs, and key behavioral questions of importance to HIV-positive individuals, researchers, and care providers. Our Research Department has tested over 100 HIV medications and therapies, several of which have become important components of highly active antiretroviral therapy (HAART). Our research initiatives are often community driven, and through our clinical trials literally thousands of PLWAs have been provided access to lifesaving medications while they were still in the experimental stage. In addition, our past performance regarding our ability to recruit diverse participants in clinical trials and the high quality of our data frequently lead to our being sought out by drug companies to test promising new therapies, in preference to larger, more academic institutions.

ACRIA has also completed several behavioral research protocols. Our most prominent efforts of late have been directed at defining the emerging needs and circumstances of the rapidly growing HIV-positive population 50 years of age and older, culminating in the pioneering *Research on Older Adults with HIV* (ROAH) study. Results from ROAH have received national and international attention and have been presented at many prestigious venues in this country and elsewhere. The initial findings were presented the XVI International AIDS Conference in

Toronto in 2006. Additional information derived from ROAH, along with our experiences running the older adults HIV programs described below, were presented at the XVII International AIDS Conference in Mexico City in August 2008.

Our Research Department is continuing to work in this area, and is currently conducting studies of the rapid identification and treatment of depression in HIV-infected older adults and of the social service needs of older HIV-positive clients of a major AIDS service organization.

HIV Health Literacy Program (HHLP). This program component, started locally in 1997 as ACRIA's Treatment Education Department, aims to ensure that all individuals living with HIV have the knowledge and resources they need to gain access to the best possible care and to make informed decisions about using lifesaving therapies. Initially serving exclusively PLWAs in the New York City metropolitan area, HHLP has since its inception conducted group workshops and individual/family tutorials. All of these workshops, and similar staff training sessions, are conducted in collaboration with and at the service sites of New York City AIDS service organizations (ASOs). Discussions at the individual level are necessarily tailored to the specific needs, circumstances, and interests of each client, while the group workshops offer detailed information on topics such as Basics of HIV Pathogenesis and Treatment; Clinical Trials; HIV Drug Resistance & Resistance Testing; HIV & Hepatitis C Coinfection; Opportunistic Infections; Side Effects Management; The Healthcare Provider-Patient Relationship; Understanding Lab Results; and Women's Treatment Issues. In addition, since 2001 we have conducted our local technical assistance program—four days of intensive training, including both didactic teaching and skills-building exercises, followed by ongoing technical assistance—to staff of public and private agencies serving people with HIV/AIDS, helping them to integrate HIV health literacy and treatment education into their existing service menus.

In 1999, the HHLP expanded to serve a national audience, first by creating and publishing free HIV treatment publications for distribution to not-for-profit AIDS service organizations and healthcare providers throughout the country, then by providing treatment education training, technical assistance, and capacity building to service providers in areas of the U.S. that do not have sufficient existing resources to meet the needs of their HIV-positive populations. We currently maintain a list of seven educational booklets on HIV health literacy and a prevention, treatment, and policy quarterly. All of our publications are available in English and Spanish.

As a direct outgrowth of the pioneering ROAH study, HHLP has developed significant new programming aimed at raising awareness of issues around HIV and people over the age of 50 and bringing needed prevention, education, and services into organizations that serve older adults. Our first program for older adults was Project SEE (Senior Education and Empowerment), conducted in collaboration with the Council on Senior Centers and Services in the senior centers of New York City. In mid-2007, we were selected to serve as the lead agency of a consortium of AIDS and senior service organizations working together under the auspices of the New York City Council to bring HIV education, prevention, and services to senior centers and other senior service providers in each of New York's 51 City Council Districts. In 2008 and 2009, the City Council authorized a second and third year of the initiative, expanding the program to community centers, houses of worship, retirement organizations, and other places where older adults congregate.

March 2010



**HIV CLINICAL TRIALS INITIATIVE
Service Profile—2008**

In many ways, clinical trials are ACRIA's heart.

When ACRIA was founded in 1991, it was as a response to the slow pace of government and academic research in the field of HIV and AIDS. A group of physicians, activists, and people with HIV, under the leadership of prominent AIDS physicians and researchers, brought for the first time an activist, community-based approach to the study of new treatments for AIDS and HIV. Since then, we have contributed to the development of ten medications that have been approved by the FDA, helping countless thousands of HIV-positive individuals live longer and healthier lives.

A great deal has changed since 1991, and ACRIA's clinical trials program has changed with it. Today, the drugs we study include not just new antiretrovirals, but new combinations and dosages of existing HIV drugs, and medications being assessed for their efficacy in combating the side effects of both HIV and the drugs used to combat it. In addition, our past performance regarding our ability to recruit participants in clinical trials and the high quality of our data, frequently leads to our being sought out by drug companies to test promising new therapies, in preference to larger, more academic institutions.

ACRIA has been involved in twelve clinical trials during 2008:

- TaiMed Biologics' study comparing 2 doses of an anti-CD4 monoclonal antibody (ibalizumab) in patients who have failed HAART and have few treatment options.
- A collaborative study with AIDS Research Alliance Los Angeles looking at the effects of pomegranate juice or placebo on quality of life and cardiovascular health in HIV-infected people.
- A Napo Pharmaceuticals study looking at crofelemer, a medication extracted from a plant found in Central and South America, for HIV-related diarrhea.
- A lipodystrophy study for the National Institutes of Health on how growth hormone (Serostim), rosiglitazone (Avandia), or both affect glucose and insulin levels in HIV-infected patients with insulin resistance.
- A Bristol-Myers Squibb study examines treatment failure in patients on an antiretroviral regimen containing atazanavir (Reyataz).
- A study for Boehringer Ingelheim examines the safety, efficacy, and absorption of tipranavir with low-dose ritonavir among a diverse and treatment-experienced HIV-positive population. [now in follow-up]
- A Tibotec study comparing once-daily darunavir (Prezista) versus twice-daily darunavir, (Prezista) each with low-dose ritonavir in an HIV-infected population with limited drug resistance. [now closed]
- A lipodystrophy study for Theratechnologies examining the effectiveness of TH9507, an investigational drug, in reducing the excess abdominal fat of HIV-positive patients when compared with a placebo. [now closed]
- A study for Pfizer providing early access to maraviroc (Selzentry), the first in a new class of antiretrovirals called CCR5 antagonists. Maraviroc received FDA approval on August 6, 2007. [now closed]
- A study for BioAlliance testing a new and convenient delivery system for miconazole (Lauriad), an established medication for oral thrush, compared with clotrimazole. [now closed]
- A Neuroges-x study examining the safety and efficacy of a Transacin patch for the treatment of painful peripheral neuropathy. [now closed]
- An Etravirine Expanded Access study being conducted for Tibotec that provides early access to this non-nucleoside reverse transcriptase inhibitor awaiting FDA approval. [now closed]

In addition, ACRIA continues to operate TrialSearch, our online, searchable database of enrolling clinical trials across the United States. TrialSearch contains information on approximately 200 enrolling clinical trials, presented in a user-friendly format where individuals can search for trials by geographic location, condition, treatment, and/or individual-specific characteristics.



**BEHAVIORAL RESEARCH
Service Profile—2008**

Behavioral research began at ACRIA in 2003 to address the fact that little was known—or being asked—about the burgeoning population of older people with HIV. Today, ACRIA has become a recognized authority and resource on HIV in older adults, and our behavioral research has broadened into other areas as well. ACRIA's collaborative relationships with a broad range of academic researchers assure the highest quality of our scientific research efforts.

Research On Older Adults with HIV (ROAH)

By far the largest and most ambitious research undertaking to date has been ACRIA's groundbreaking Research on Older Adults with HIV (ROAH) study. With a 1,000-person cohort, ROAH is the largest study ever conducted of an older population living with HIV and AIDS. Study participants were residents of New York City, the North American epicenter of the epidemic, and their demographic breakdown mirrored that of the city's older HIV-positive population. ROAH is unique also in the kinds of questions it asked, for the first time probing in depth the sexual and drug-taking risk behaviors of older people with HIV, as well as gathering data on medical and psychosocial issues. Two preliminary studies, now published in peer-reviewed journals, were conducted in 2003 and 2004 and provided the groundwork for this large seminal study. ROAH's findings were released in June 2006.

The attention attracted by the ROAH report, with its enormous implications for HIV/AIDS treatment and services in the years to come, continued into 2008 and beyond. For the third year in a row, ACRIA led a symposium on ROAH at the Gerontological Society of America conference in November 2008. During the year, ACRIA researchers gave invited presentations at the prestigious Silver School of Social Work at New York University (keynote address), the University of Maine School of Social Work and Center on Aging Colloquium, the American Academy of HIV Medicine, and the New York City Bar Association AIDS Committee. ROAH presentations were also featured at the XVII International Conference on AIDS in Mexico City in August 2008 and the United States Conference on AIDS in Fort Lauderdale in September 2008. ROAH-related topics have also been presented at the Conference on Senior Centers and Services Conference, the American Society on Aging/National Conference on Aging, Weill Cornell Medical College, the Services and Advocacy for GLBT Elders Conference, Georgetown University Medical School, the State Society on Aging of New York Annual Conference, AARP, and the Midwest AIDS Training and Education Center in St. Louis.

In November 2008, ACRIA presented a seminar on ROAH at Cambridge University in England and consulted with a group of scientists, staff, medical providers, and people living with the virus at the Chelsea-Westminster Hospital in London. The meeting resulted in the beginning of a collaboration of a ROAH-like study in the United Kingdom. ROAH researchers worked throughout the year on a book to be published in 2009 by Nova Science Publishers. The book, which will summarize the findings of ROAH and address the issue of aging and HIV, will be aimed at consumers, healthcare providers, paraprofessionals, advocates and policy experts.

An extension of the ROAH study, with a greater focus on the social supports, caregiving resources, and formal service needs and utilization of this population is being worked on in partnership with the Gay Men's Health Crisis (GMHC). In addition, funding opportunities for a nationwide ROAH study are being explored.

Meanwhile ACRIA continues to pursue its behavioral research with this population. A study launched earlier with joint funding from The Robert Mapplethorpe Foundation and the Keith Haring Foundation, aimed at demonstrating that depression can be quickly diagnosed and effectively treated in older adults with HIV utilizing the Project RESPECT model developed by The MacArthur Foundation was conducted throughout the year. The findings were enormously encouraging, and the project gave birth to the development of a new group intervention for depressed older adults with HIV that has now been dubbed "The Mapplethorpe-Haring Model."

In addition, ACRIA has ongoing collaborations with Indiana University, Syracuse University, Hunter College, the University of Alabama, and the Association of Nurses in AIDS Care (ANAC) to study various issues related to HIV and aging.



AIDS COMMUNITY RESEARCH INITIATIVE OF AMERICA (ACRIA)

Service Profile

HIV Health Literacy Program (HHLP)

Workshops, Training, Technical Assistance and Counseling

- During 2008, ACRIA's HIV Health Educators conducted over 700 workshops and trainings on HIV healthcare and treatment issues for clients and staff of agencies providing non-medical services to people with HIV in New York City.
 - Over 8,000 people attended the workshops, 30 percent were HIV-positive clients and 70 percent were staff of agencies serving them.
 - Approximately 92 percent of the attendees were people of color.
 - Women accounted for 55 percent of workshop attendance.
- Since January 2008, ACRIA's HIV Educators have conducted over 3,300 such workshops at almost 600 service sites.
- On the national level, ACRIA provides intensive regional technical assistance and training—four days of technical assistance and training at a regional site, with ongoing support and follow-up training—to nonmedical service providers, aimed at enabling them to incorporate health and treatment education into their established service menus. Our HIV Health Educators have provided this assistance to staff of agencies in San Antonio, Texas; San Diego, California; Detroit, Michigan; Baltimore, Maryland; Madison, Wisconsin; Charlotte, North Carolina; Miami/Dade/Broward Counties in Florida, Miami (twice), New Orleans, LA, and Arkansas.
 - Although ACRIA does not collect information on the race and ethnicity of people receiving technical assistance, we do ask about the demographics of their agencies. From their reports and our observations, approximately 90 percent of participants are people of color, and 100 percent of them represent agencies that serve minority populations.

Treatment Publications

- *Achieve*, our quarterly prevention, treatment and politics publication, is distributed free and in bulk, by request only, to AIDS service organizations and other agencies.
 - Bulk orders of the last Fall 2008 issue were sent to 790 agencies in all fifty states and the District of Columbia and Puerto Rico. Because budgetary constraints prevent us from printing enough copies of this periodical to meet the demand, we have had to limit the number sent to any one agency to 30 copies, despite commonly receiving requests for as many as 200 copies.

- Individual copies are mailed to over 7,500 people per issue—most affiliated with AIDS service organizations or other agencies serving people with HIV—in the fifty states, District of Columbia, and Puerto Rico.
 - Additional copies, individual and bulk, went to destinations to every country in Latin America and Algeria, Barbados, Belarus, Bermuda, Canada, Denmark, France, Germany, Ghana, Greece, Iceland, India, Indonesia, Italy, Kenya, Nigeria, South Africa, Sweden, Switzerland, Uganda, Ukraine, United Kingdom, Zambia, and Zimbabwe.
- ACRIA publishes topic-specific informational booklets—seven by the end of 2008—on issues of particular importance to people living with HIV and AIDS. Written in language that is easy understood by laypeople and published in English- and Spanish-language editions, these booklets are distributed free and in bulk, by request only, to AIDS service organizations and other agencies serving HIV-positive individuals across the United States and around the world. In 2008 we published two new publications on HIV and Older Adults and Preventing HIV in Older Adults in English and Spanish that included Senior serving organizations
- *Treatment Issues for Women/Asuntos de tratamiento para las mujeres.* Since its publication in October 2002, 43,500 English-language copies of this booklet have been distributed, as have 20,800 Spanish-language copies.
 - *Understanding Your Lab Results/Como comprender sus resultados de laboratorio.* Since its publication in March 1999, 118,000 English-language copies of this booklet have been distributed, as have 39,300 Spanish-language copies. We are currently out of stock of this publication in both languages and seeking funding for both reprints.
 - *Managing Drug Side Effects/Control de los efectos secundarios.* Since its publication in September 1999, 98,555 English-language and 28,000 Spanish-language copies of this booklet have been distributed. We are out of stock of the English and Spanish language version and and seeking funding for both reprints.
 - *Clinical Trials Explained/Explicación de los estudios clinicos.* Since its publication in October 2000, 71,000 English-language and 21,000 Spanish-language copies of this booklet have been distributed.
 - *Viral Hepatitis and HIV/Hepatitis viral y VIH.* Since its publication in March 2004, 37,000 English-language and 21,000 Spanish-language copies of this booklet have been distributed.
 - *HIV and Older Adults.* Since its publication in January 2008, 45,000 English-language and 21,000 Spanish-language copies of this booklet have been distributed.
 - *Preventing HIV in Older Adults.* Since its publication in March 2008, 29,000 English-language and 15,000 Spanish-language copies of this booklet have been distributed.

January 2009

COMMUNITY RESEARCH INITIATIVE ON AIDS, INC.
(d/b/a AIDS Community Research Initiative of America (ACRIA))

STATEMENTS OF ACTIVITIES

YEARS ENDED DECEMBER 31, 2008 AND 2007

	2008	2007*
Changes in Unrestricted Net Assets		
Revenue and Other Support		
Contributions		
Foundations	\$ 105,000	\$ 255,000
Corporations	28,500	39,000
Individuals	113,379	99,017
Government	1,279,840	553,934
Gross benefit income	765,125	1,012,693
Less: Direct benefit expense	(41,418)	(68,000)
Hosted events	109,670	4,475
Merchandise sales	130,359	72,762
Direct mail	11,599	14,853
Protocol contract income	175,679	188,372
Interest income	19,444	34,724
Other income	3,216	2,600
Realized gain on investments	2,506	2,278
Unrealized gain (loss) on investments	(880)	1,093
	2,702,019	2,212,801
Net assets released from restrictions		
Satisfaction of program restrictions	50,000	50,000
	2,752,019	2,262,801
Expenses		
Program Services		
Research	949,883	908,188
Education	1,711,964	838,230
Total Program Services	2,661,847	1,746,418
Supporting Services		
Management and general	134,439	147,688
Fundraising	502,279	352,982
Total Supporting Services	636,718	500,670
Total Expenses	3,298,565	2,247,088
Increase (Decrease) in Unrestricted Net Assets (carried forward)	(546,546)	15,713

* Certain amounts have been reclassified for comparative purposes.

See notes to financial statements.

COMMUNITY RESEARCH INITIATIVE ON AIDS, INC.
(d/b/a AIDS Community Research Initiative of America (ACRIA))

STATEMENTS OF ACTIVITIES

YEARS ENDED DECEMBER 31, 2008 AND 2007

	<u>2008</u>	<u>2007</u>
Increase (Decrease) in Unrestricted Net Assets (brought forward)	\$ (546,546)	\$ 15,713
Changes in Temporarily Restricted Net Assets		
Contributions	-	27,324
Net assets released from restrictions	<u>(50,000)</u>	<u>(50,000)</u>
Decrease in Temporarily Restricted Net Assets	<u>(50,000)</u>	<u>(22,676)</u>
Decrease in net assets	(596,546)	(6,963)
Net assets, beginning of year	<u>1,393,012</u>	<u>1,399,975</u>
 Net Assets, End of Year	 <u><u>\$ 796,466</u></u>	 <u><u>\$1,393,012</u></u>

See notes to financial statements.