



ADAP Advocacy Association

aaa+

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ADAP Advocacy Association (aaa+)

Annual Report – 2007

Performance Against Priorities

The ADAP Advocacy Association (aaa+) was formed in 2007 to provide a unified voice to promote and enhance the AIDS Drug Assistance Programs (ADAPs) and improve access to care for persons living with HIV/AIDS. aaa+ identified a clear objective to work with advocates, community, health care, government, patients, pharmaceutical companies and other stakeholders to assure that access to services recognize and afford persons living with HIV/AIDS to enjoy a healthy life.

In 2007, several nonprofit management priorities were established – which included launching the organization as a legal entity, completing its governance infrastructure, and obtaining its tax-exempt status. The policy objectives of the organization were enumerated in our values statement, which reads:

- That the voice of persons living with HIV/AIDS shall always be at the table and the center of the discussion.
- That HIV/AIDS advocates should welcome the opportunity to join the skills, experience and voices with others on issues of disability and access to adequate healthcare for all Americans.
- That advocacy efforts targeted to our federal government shall always carry the needed messages applicable at the state and local level.
- That messages and information shall be in accessible formats understandable to – and also deliverable by – grassroots advocates in any setting.

Among its numerous accomplishments in 2007, aaa+ launched its website, provided up-to-date information and resources to its supporters, secured adequate start-up funding for the organization, was involved in supporting various HIV/AIDS-related coalitions, and corresponded with both the legislative and executive branches on relevant issues.

2007 ACCOMPLISHMENTS:

July 23, 2007 – The fight to improve access to quality care for persons living with HIV/AIDS was strengthened with the formation of a new national, nonprofit association. aaa+ was incorporated as a District of Columbia nonprofit charity and applied for tax exemption under section 501(c)(3) of the Internal Revenue Code.

July 25, 2007 – aaa+ announced its dedicated, diverse volunteer Board of Directors. The organization benefited from the combined experience of three HIV-positive members, one ADAP recipient, two physicians, one attorney, four influential AIDS community leaders and a lifelong disability rights champion. The board of directors included: Gary Rose (Jersey City, NJ), John D. Kemp, Esq. (Washington, DC), Bishop Joyce Turner Keller (Baton Rouge, LA), Keita Simmons (Stuart, FL), Philip A. Haddad, MD (Shreveport, LA), Rani G. Whitfield, MD (Baton Rouge, LA), and William E. Arnold (Washington, DC).

July 27, 2007 – **aaa+** announced it had retained Brandon M. Macsata, Managing Partner of The Macsata-Kornegay Group, Inc. as its CEO. The **aaa+** Board of Directors engaged Macsata as the CEO of the organization charged with all facets of its administration, funding, management and marketing. Macsata previously served as Executive Director & CEO of the American Congress of Community Support & Employment Services, prior to going into private consulting. Macsata has also been living with HIV/AIDS since March 2002 and is a former ADAP recipient.

August 2, 2007 – **aaa+** commended Representatives Elliott Engel (D-N.Y.) and Ileana Ros-Lehtinen (R-Fla.) for re-introducing the “Early Treatment of HIV Act” (ETHA). **aaa+** supported efforts to have Congress pass the bipartisan ETHA during the 1st Session of the 109th Congress.

August 12, 2007 – **aaa+** recognized its board member Bishop Joyce Turner-Keller for being named as POZ magazine's "Woman of the Month." Bishop Turner-Keller was also one of POZ magazine's 35 Ones to Watch in 2006. She serves as Executive Director of the Aspirations Holistic Tutorial Services in Baton Rouge, Louisiana.



September 6, 2007 – **aaa+** called attention to the cash-strapped AIDS Drug Assistance Programs (ADAPs) needing additional federal funding to improve access to medications for persons living with HIV/AIDS. While Congress has approved funding increases over recent years, they have not been large enough to address the growing need for supports and services.

October 17, 2007 – **aaa+** applauded the pricing schedule announced by Merck & Co., Inc. for its novel HIV integrase inhibitor, Isentress. **aaa+** supported the efforts of the Fair Price Coalition, which had been negotiating an introductory price with Merck.

October 24, 2007 – **aaa+** recognized its board member John D. Kemp for being presented with a national New Freedom Initiative Award by U.S. Secretary of Labor Elaine L. Chao for his contributions toward enhancing the employment of Americans with disabilities. Kemp is a principal at the Washington law firm of Powers, Pyles, Sutter & Verville P.C. He serves on countless boards of directors, including being a founding board member of **aaa+**.



2007 PERFORMANCE:

With respect to its nonprofit management objectives, **aaa+** far exceeded its expectations in 2007. The organization successfully completed multiple priorities, including:

1. On May 23rd, **aaa+**'s Steering Committee approved its Concept Paper.
2. On May 30th, **aaa+** seated its first board of directors: Gary Rose, John D. Kemp, Esq., Bishop Joyce Turner Keller, Keita Simmons, Philip A. Haddad, MD, Rani G. Whitfield, MD and William E. Arnold.
3. On June 1st, Brandon M. Macsata was retained as CEO.
4. On July 6th, **aaa+** obtained its Articles of Incorporation from the District of Columbia as a NonProfit Corporation.
5. On July 13th, **aaa+** obtained its Employer Identification Number from the Internal Revenue Service.
6. On July 20th, **aaa+**'s board of directors approved its Bylaws, approved its Mission-Vision-Values Statement, appointed its officers and finalized its 2007 sponsorship opportunities.
7. On September 17th, **aaa+** applied for its registered trademark on the organization's name and logo.
8. On November 6th, **aaa+** obtained its 501(c)(3) tax-exempt status from the Internal Revenue Service.

With respect to its policy objectives, **aaa+** stated:

- That the voice of persons living with HIV/AIDS shall always be at the table and the center of the discussion.

To that end, **aaa+** executed the following action items:

1. On June 1st, Brandon M. Macsata was retained as CEO. Macsata has been living with HIV/AIDS since March 2002.
2. On July 1st, an interactive web-based platform at <http://www.adapadvocacyassociation.org> was launched to provide valuable information and resources to a national grassroots network. In addition, **aaa+** started its VIP Club for persons living with HIV/AIDS, and others, to support the organization.
3. On July 25th, **aaa+** announced that three HIV-positive advocates were seated on the board of directors – including one ADAP recipient.
4. On September 6th, **aaa+** issued an Action Alert on National AIDS Strategy: A Call to Action. The coalition called on the next President of the United States to develop a results-oriented National AIDS Strategy designed to improve the outcomes of our national response to AIDS.
5. On September 14th, **aaa+** endorsed a Fair Pricing Coalition letter urging the lowest possible pricing of Merck's new Integrase Inhibitor.
6. On December 10th, **aaa+** endorsed a Biotechnology Industry Association letter supporting provisions related to comparative effectiveness research.

Evaluation: (GREEN) – **aaa+** performed extremely well against its priority of being a voice of persons living with HIV/AIDS. In 2008, **aaa+** should continue to promote activities that maintain persons living with HIV/AIDS being at the center of the policy discussion impacting access to care.

- That HIV/AIDS advocates should welcome the opportunity to join the skills, experience and voices with others on issues of disability and access to adequate healthcare for all Americans.

To that end, **aaa+** executed the following action items:

1. On June 8th, the Public Health Services Bureau provided “start-up” funding for the organization.
2. On July 3rd, **aaa+** joined the National ADAP Working Group.
3. On July 11th, **aaa+** joined the ADAP Funding Listserve.
4. On September 4th, **aaa+** approached Maggie Roffee of the U.S. Department of Labor to request that HIV/AIDS issues be added to her national e-zine. The e-zine is widely recognized as one of the most comprehensive electronic news source on disability-related issues.
5. On September 14th, **aaa+** joined the Fair Pricing Coalition.
6. On October 12th, **aaa+** endorsed a Flowers Heritage Foundation White Paper on “National Solution Could Help Address ADAP Funding Crunch: The Design and Implementation of an Enrollment Database.”

Evaluation: (GREEN) – **aaa+** performed extremely well against its priority of collaborating with other organizations on issues of disability and access to adequate health care. In 2008, **aaa+** should reach out to other disability organizations (non-HIV/AIDS) to further its mission.

- That advocacy efforts targeted to our federal government shall always carry the needed messages applicable at the state and local level.

To that end, **aaa+** executed the following action items:

1. On July 31st, **aaa+** wrote to Representatives Elliott Engel (D-NY) and Ileana Ros-Lehtinen (R-FL) supporting the Early Treatment for HIV Act (ETHA). ETHA would amend title XIX of the Social Security Act to permit States the option to provide Medicaid coverage for low-income individuals infected with HIV. Once approved, individuals who are HIV-positive would no longer have to become disabled by AIDS in order to access Medicaid services.
2. On July 11th, **aaa+** endorsed a national sign-on letter in Support of ETHA and Medicare Part D Improvements.
3. On July 24th, **aaa+** endorsed a national sign-on letter urging Congressional leaders to support full funding for ADAPs when they finalize the Fiscal Year 2008 appropriations bill.
4. On October 2nd, **aaa+** endorsed an AIDS Budget & Appropriations Coalition letter addressing the FY08 L-HHS-E Conference Report.
5. On December 4th, **aaa+** endorsed an ADAP Coalition letter urging the Office of Management & Budget (OMB) to support increased funding for ADAPs in the Administration's FY2009 budget.

Evaluation: (GREEN) – **aaa+** performed extremely well against its priority of targeting its message to the federal government. In 2008, **aaa+** should continue to monitor federal HIV/AIDS issues – including ADAP funding, access to care improvements and other initiatives.

- That messages and information shall be in accessible formats understandable to – and also deliverable by – grassroots advocates in any setting.

To that end, **aaa+** executed the following action items:

1. On July 1st, an interactive web-based platform at <http://www.adapadvocacyassociation.org> was launched to provide valuable information and resources to a national grassroots network. In addition, **aaa+** started its VIP Club for persons living with HIV/AIDS, and others, to support the organization.
2. On August 9th, **aaa+** VIP Club members started receiving on a timely basis CEO Updates (5) from Brandon M. Macsata, **aaa+** CEO.

Evaluation: (YELLOW) – **aaa+** was limited on its activities related to deliverables to its grassroots advocacy network. In 2008, **aaa+** should do more to monitor HIV/AIDS-related activities and sharing information and resources with its VIP Club members.

CONCLUSION:

The ADAP Advocacy Association dedicated much of 2007 to establishing itself as a legitimate national organization representing persons living with HIV/AIDS on access to care-related issues. Specifically, **aaa+** policy activities focused on improving the AIDS Drug Assistance Programs and other access to care issues. The organization overall achieved its stated priorities laying the foundation for another productive year in 2008.

Note: For purposes of this Annual Report, **aaa+** utilized a “Green-Yellow-Red” evaluation tool to rank its performance against priorities. The tool, which is used by government agencies to evaluate the cost-effectiveness of its programs, is scored as follows: Green = Achieved or Exceeded Performance Objective; Yellow = Achieved Performance Objective, but Needs Improvement; Red = Failed to Achieve Performance Objective.