NEMA NEWS

Featured In This Issue

Ryan White Funding & the Newark EMA Page 2
Restore ADDP Income Eligibility! Page 4
AIDS Watch 2011 Page 6
AIDS Pill Helps Gay Men Page 8
Thank Goodness I'm Fabulous! Page 12
Living Will … Necessary? Page 14

Spring 2011 Issue 27

Ryan White Part A Funding & The Newark EMA

By: Ketlen Alsbrook, MPA (Project Director)

For almost twenty years, the City of Newark has served as the Grantee for the Newark Eligible Metropolitan Area (EMA) Ryan White Part A Grant Program. The Newark EMA, named after New Jersey's largest city, contains a diverse population of 2 million residing in five counties – densely populated urban Essex and Union, suburban Morris, and rural Sussex and Warren. The EMA, which occupies much of northern New Jersey, is disproportionately affected by HIV with 13,161 people infected (40% of the state epidemic but only 23% of the state's population) as of 12/31/09. Medical care is the primary focus of the Part A continuum, though other ancillary and support services are provided as well.

As the most populous city in the EMA and the state, the City of Newark has the responsibility of ensuring the administration of federal funding from Part A of the Ryan White Treatment Extension Act of 2009. Under the authority of the Newark EMA Chief Elected Official, Mayor Cory A. Booker, the Department of Child and Family Well-Being (DCFWB) administers the Ryan White Program throughout the EMA. Each year, DCFWB applies for, receives, and subsequently disburses Part A dollars through annual grant awards to more almost 50 hospitals, health centers and community-based organizations. This continuum of care provides health and social services to over 6,500 PLWHA each year.

Note: The general public is encouraged to attend the Council meetings and provide written and/or oral testimony on issues pertaining to the care & treatment needs of People Living With and Affected by HIV/AIDS who reside in the Newark EMA: namely Essex, Morris, Sussex, Union and Warren Counties. Minutes of Council and Committee meetings are available by request at the Planning Council office or on our Web page.

Nota: Se anima al pública en general en atender a las reuniones del concilio y proveer testimonio oral y/o escrito sobre situaciones pertenecientes a las necesidades de cuidado y tratamiento de las personas que viven con y son afectadas por el VIH/SIDA y que viven en Newark EMA; es decir Essex, Morris, Sussex, Union, y Warren. Resumen de los reuniones de Concilio y de los comités están disponibles a petición en la oficina de Concilio.

Visit us on the Web at:

www.NewarkEMA.org

The comments expressed in this newsletter are not necessarily those shared by the Newark EMA HIV Health Services Planning Council. Any comments regarding the newsletter should be sent in written correspondence to the Editorial Board at the above address.

Los comentarios expresados en este periódico no son necesariamente los compartidos por el Concilio de Planificación de Servicios a la Salud de Newark EMA. Cualquier comentario en relación al periódico debe ser enviado por escrito a la Junta Editorial a la dirección mencionada.

Helpful Websites for the Consumer

AIDS Information: www.aidsinfo.nih.gov

Network Therapy.com (mental health): www.networktherapy.com

NJ AIDS Resource Directory NJ Dept. of Health & Senior Services: www.state.nj.us/health/aidsresourcedirectory.shtml

NJ Access Resources: www.atdn.org/access/states/nj/nj.html

NJ Housing Resource Center: www.njhousing.gov/njhrc/consumers/specneeds/hiv-aids.html

Everything HIV and AIDS in NJ: http://hiv-aids-nj.com

Newark EMA HIV Health Services Planning Council

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2011 Planning Council Meetings

March 16th	4:00pm @ Broadway House
April 20th	1:30pm @ NEMA Office
May 18th	1:30pm @ NEMA Office
June 15th	4:00pm @ Broadway House
July 20th	1:30pm @ NEMA Office
August 17th	1:30pm @ NEMA Office
September 14th	4:00pm @ Broadway House
October 19th	1:30pm @ NEMA Office
November 16th	1:30pm @ NEMA Office
December 21st	1:30pm @ NEMA Office

2011 Committee Meetings

(Held at the Planning Council Office)

Continuum Of Care @ 9:30am on Thursday:
Apr 14 , May 12, Jun 9, Jul 14, Aug 11, Sep 8, Oct 13, Nov 10, Dec 8

Community Service Advisory @ 2:00pm on Thursday:
Apr 14, May 12, Jun 9, Jul 14, Aug 11, Sep 8, Oct 13, Nov 10, Dec 8

Comprehensive Planning @ 9:30am on Friday:
Apr 8, may 13, Jun 10, Jul 8, Aug 12, Sep 9, Oct 14, Nov 4, Dec 9

Research & Evaluation @ 10:00am on Monday:
Mar 21, Apr 18, May 16, Jun 20, Jul 18, Aug 15, Sep 19, Oct 17, Nov 21, Dec 19

Services include but are not limited to primary medical care, medical case management, oral health care, mental health and substance abuse treatment and counseling, medical nutritional therapy, housing, food, legal assistance and transportation.

The Grantee staff includes Ketlen Alsbrook, MPA (Project Director), Dorian Cooper (Grant Accountant) and a team of Program Monitors: Veronica Osorio, Myriam Garcia, Krystal Lin and Angelica Alton. Shanon Mettlen serves as the Grants Manager/Monitor for Union County. Doreen Elmore provides administrative support for all grantee functions.

The Grantee Office is located at 110 William Street, Newark, NJ, 07102, Room 209.

Restore ADDP Income Eligibility!

By Deloris Dockrey, Community Organizer

Advocates are asking New Jersey State legislatures to restore the AIDS Drug Distribution Program (ADDP) income eligibility to 500% of federal poverty levels (FPL). In the State's 2010 budget, income eligibility for ADDP was reduced to 300% FPL in an effort to reduce the State's deficit by $7 million. This action dropped 957 people living with HIV/AIDS from the ADDP program and these people lost their prescription benefits. Through the actions of advocates and pharmaceutical companies, and new streams of federal funding, a new program, *Temporary AIDS Supplemental Rebate and Federal Assistance Program,* provides pharmaceutical assistance to those individuals with incomes between 301% and 500% FPL. It might appear that the problem has been solved, but the new program is temporary and there is no guarantee that the program will continue in the 2011 State budget.

The AIDS Drug Distribution Program is essential for people living with HIV/AIDS in New Jersey. Antiretroviral medications improve health outcomes and reduce the need for more intensive medical intervention such as hospitalization. Research supports the benefits of providing antiretrovirals to infected individuals. These benefits include reducing community viral load, improving health outcomes, and reducing mother to child transmission. Treatment is prevention. In addition, providing medications reduces the need for other more expensive medical costs, as it is far less expensive to pay prescription costs than medical care costs.

Since the changes in the income eligibility requirement, several actions have been taken to support the restoration of the ADDP program.

As time passes or situations change, living wills may need to be changed. The law allows for the revocation or termination of the advance directive by entering a new document. It is always best to draft a new directive that reflects your most current wishes for end-of-life health care. The new directive would be subject to the same process to be considered valid. Everyone who had a copy of the directive should receive the new directive. The former directive and all copies should be destroyed.

While the law does not require everyone to have a living will, it protects the fundamental right to execute one. Having an advance directive for health care or living will in place is an effective way to avoid unnecessary confusion or disagreement among family members and health care providers in times of crisis. Most importantly, it allows one to maintain control over his or her treatment decisions despite incapacity. The process has been simplified, and it is accessible to all. There is no reason for anyone to be without an advance directive.

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1. Bryn N. Whittle, Esq., serves as the Treasurer of the NEMA HIV Health Services Planning Council. Ms. Whittle, a public interest attorney, is a strong advocate for PLWHAs and the disabled.
2. Patient Self Determination Act of 1990, §42 USC 1395cc and N. J. S. A. §26:2H-53 et. seq.
3.Patient Self Determination Act of 1990, §42 USC 1395cc http://www.state.nj.us/health/healthfacilities/documents/ltc/advance_directives.pdf
4. In most states, PLWHAs can receive free or low cost assistance with the preparation of directives.

This form is useful to individuals who may not have a family member or friend who could act on their behalf. Third, the *combined directive* allows individuals to appoint a health care representative and give instructions. The health care representative would be expected to carry out the written wishes in consultation with the health care provider. State laws govern the formation and validity of a living will.

Here, in New Jersey, the directive must be written by a competent person age eighteen or older. To be valid, the individual must sign and date the directive either *in the presence of* two adult witnesses, who are not named as the health care representative in the directive, or *in the presence of* a notary public, attorney at law or other person authorized to administer oaths. Most states, including New Jersey, have forms to aid someone in creating a valid directive. Alternatively, individuals may seek the assistance of an attorney to customize their document to meet their needs .

A copy of the valid living will should be placed in one's medical files. Some hospitals upload the document to your electronic medical record in the event that a medical crisis arises and the document is needed immediately. Unlike some other states, New Jersey does not maintain a statewide registry at this time.

The State legislature dropped similar bills in the Assembly and in the Senate (Bill A3286/S2214) to restore the income eligibility level for the AIDS Drug Distribution Program (ADDP) to 500% of the federal poverty level, and that process in ongoing. Advocates support these bills and are meeting with their State representatives in support of the bills. Also, advocates participated in a public hearing hosted by the Governor's Advisory Council on HIV/AIDS and Other Related Blood-borne Pathogens in Newark to speak about the impact of the changes to the income eligibility requirement. But, much more needs to be done by advocates and people impacted by these changes.

With no cure and no vaccine available, antiretrovirals are the only proven tools available that slow the spread of new HIV infections. It is imperative that life-saving medications are available to people living with HIV who are uninsured and underinsured. Advocates must remain vigilant and must continue to educate and inform policy makers of the necessity of ADDP for the health and well-being of people wishing to live long productive lives with HIV.

A Statement by Frank J. Oldham, Jr., President & CEO, NAPWA (National Association of People With AIDS)

February 15, 2011

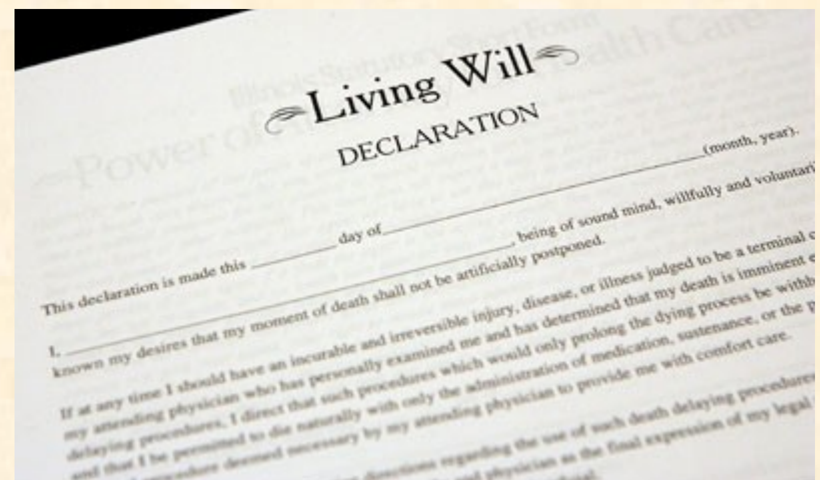
Today, on the eve of **AIDSWatch 2011**, hundreds of HIV citizen advocates are preparing to descend on Capitol Hill to ask their elected representatives for three things: 1. Implementation of the new National HIV/AIDS Strategy. 2. Defend and Implement the Affordable Care Act and 3. Fund HIV prevention, treatment and research programs at levels that meet the true need.

All these things will cost money, and that makes them a tough sell in today's political climate. The president's budget request keeps HIV program spending at about 2010 levels – disappointingly less than what is really needed, but perhaps the best we can hope for this year. House Republicans would like to roll funding back to 2008 levels – roughly a 20% reduction from 2010 – and the results would be disastrous. Disastrous in human terms. The reality of the proposed cuts is that lower-income Americans living with HIV will not have access to the antiviral drugs that keep healthy – and also make them less likely to pass the virus along to others. More Americans will become infected as awareness and prevention programs dry up.

Funds for researching better treatments and one day a real cure will shrink, just when the biological mechanisms by which HIV invades the immune system and hides where drugs can't reach it are becoming understood. More people will get sick and die, and a disproportionate number of them will be poor and of color.

To aid in the preparation process, organizations and states have tried to make the process as simple as possible. The federal government stipulated that health care institutions that receive Medicaid or Medicare must inform patients about advance directives. They must also record whether a patient has an advance directive for health care in the medical file. This provides a great opportunity for a patient, who does not already have a directive, to discuss the technical medical terms that can be intimidating to the average person.

In New Jersey, there are three forms of Advance Directives for Health Care. First, the *proxy directive*, also known as a Durable Power of Attorney for Health Care, allows an individual to appoint a health care representative or a proxy to make decisions on his or her behalf. This is useful to individuals who have someone they trust to carry out their wishes. Second, the i*nstruction directive* allows individuals to provide written instructions that would be followed by the health care providers.



A Living Will: Is it really necessary?

By Bryn N. Whittle, Esq.

A Living Will, also known as an Advance Directive for Health Care, is a legal document that allows competent individuals to give instructions about the health care they would like to receive in the time of a health care crisis when they would be incapable of expressing their wishes. It arises from federal and state law which grants competent adults with a fundamental right in collaboration with their health care providers to control decisions about their health care. If an individual is in a coma, vegetative state or otherwise incapacitated, his or her fundamental right to decide on life-sustaining measures is compromised. Since an unexpected life-threatening event can happen at any moment, the presence of a living will can make a difference.

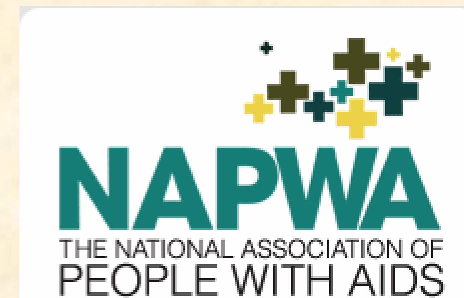
For many, especially those living with chronic illnesses like HIV and AIDS, it is still taboo to discuss end-of-life issues. Before strides were made in treatment options, being diagnosed HIV+ or with AIDS was seen as a death sentence. Therefore, preparing a Last Will and Testament or Living Will was construed as giving up on the prospect of living. Individuals would wait until the last possible moment to prepare such documents at their bedside. For some, it would be too late as they slipped into a state of incapacity.

Today, even though being HIV+ is no longer characterized as a death sentence, the stigma and uneasiness of preparing a Living Will is still prominent.

And disastrous in budgetary terms. HIV programs are so small a part of the Federal budget – less than one tenth of one percent – that even eliminating them entirely will not materially reduce this year's deficit. But the proposed cuts will contribute to deficits in years to come, as Americans whose new infections this year could have been prevented for a few dollars come back next year, needing drugs and support services that will cost far more, for years to come. If our objective is to balance the budget for years to come, not just this year, we should be expanding these programs, not cutting them back.

On the eve of AIDSWatch 2011, NAPWA calls on all concerned "Americans to say **No** to irrational across-the-board cuts for the sake of cuts, and demand that Congress evaluate programs on their merits and protect those – like HIV prevention, treatment and research programs – that save money in the long run. *And Most Importantly, Most Importantly: SAVE AMERICAN LIVES!*

** Mr. Oldham's statement was extracted from the NAPWA website, www.napwa.org*



AIDS Pill Helps Gay Men Avoid HIV, Study Finds

**Excerpted from article by Marilynn Marchione - Nov. 23, 2010 06:17 AM Associated Press*

Scientists have an exciting breakthrough in the fight against AIDS. A pill already used to treat HIV infection turns out to be a powerful weapon in protecting healthy gay men from catching the virus, a global study found. Daily doses of Truvada cut the risk of infection by 44 percent when given with condoms, counseling and other prevention services. Men who took their pills most faithfully had even more protection, up to 73 percent. Researchers had feared the pills might give a false sense of security and make men less likely to use condoms or to limit their partners, but the opposite happened - risky sex declined.

The results are "a major advance" that can help curb the epidemic in gay men, said Dr. Kevin Fenton, AIDS prevention chief at the U.S. Centers for Disease Control and Prevention. But he warned they may not apply to people exposed to HIV through male-female sex, drug use or other ways. Studies in those groups are under way now.

"This is a great day in the fight against AIDS... a major milestone," said a statement from Mitchell Warren, head of the AIDS Vaccine Advocacy Coalition, a non-profit group that works on HIV prevention. Because Truvada is already on the market, the CDC is rushing to develop guidelines for doctors using it for HIV prevention, and urged people to wait until those are ready.

As a result, it forces them to make some decisions that put them at risk. That's where the T.G.I.F program comes in. Through HIV prevention and harm reduction counseling, and a little bit of encouragement, they are able to greatly lower their risk for HIV and STDs.

As a woman of transgender experience, I feel that there is so much more that needs to be done inside and outside of HIV.

The T.G.I.F. (Thank Goodness I'm Fabulous) Peer Advocate Project is here to provide young African-American and Latino Transgender girls a safe space, especially the "ballroom" and "sex work" girls. The T.G.I.F. Peer Advocate Project introduces and supports behavior change through community support, HIV/STI prevention education and safer sex information to reduce the transmission of HIV within these communities. Visit www.aaogc.org for more information about T.G.I.F. and other programs offered.

Introducing…Anastasia! “Thank Goodness I’m Fabulous!”

By Anastasia Willis,
T.G.I.F. Project Coordinator
(AAOGC)

My name is Anastasia Willis. I started off at The African American Office of Gay Concerns (AAOGC) as a program participant. I attended the T.G.I.F. (Thank Goodness I’m Fabulous) group meetings. These group meetings are for transgender women between the ages of 16 and 45. During our meetings, we would talk about HIV and STDs, along with other issues that transgender women of color have to go through. This group has really helped me to be truly comfortable with who I am, and proud of who I am.

I work for Gary Paul Wright, Executive Director of AAOGC, where I am the T.G.I.F. Project Coordinator. My duties consist of community outreach in the Greater Newark Area, and coordinating the T.G.I.F. Peer Advocate Project.

I’ve been working at AAOGC for about a year now, and I can truly say that I enjoy what I do here. I have a chance to help and uplift my community. Transgender people are putting themselves at risk for HIV and other STDs. There is so much discrimination toward the transgender community.

"It's not time for gay and bisexual men to throw out their condoms," Fenton said. The pill "should never be seen as a first line of defense against HIV." As a practical matter, price could limit use. The pills cost from $5,000 to $14,000 a year in the United States, but only 39 cents a day in some poor countries where they are sold in generic form. Whether insurers or government health programs should pay for them is one of the tough issues to be sorted out, and cost-effectiveness analyses should help, said Dr. Anthony Fauci, director of the National Institute of Allergy and Infectious Diseases.
"This is an exciting finding," but it "is only one study in one specific study population," so its impact on others is unknown, Fauci said.

It is the third AIDS prevention victory in about a year. In September 2009, scientists announced that a vaccine they are now trying to improve had protected one in 3 people from getting HIV in a study in Thailand. In July, research in South Africa showed that a vaginal gel spiked with an AIDS drug could cut nearly in half a woman's chances of getting HIV from an infected partner.

Gay and bisexual men account for nearly half of the more than 1 million Americans living with HIV. Worldwide, more than 40 million people have the virus, and 7,500 new infections occur each day. Unlike in the U.S., only 5 to 10 percent of global cases involve sex between men.

"The condom is still the first line of defense, because it also prevents other sexually spread diseases and unwanted pregnancies", said the study leader, Dr. Robert M. Grant of the Gladstone Institutes, a private foundation affiliated with the University of California, San Francisco.

The strategy showed great promise in monkey studies using tenofovir (brand name Viread) and emtricitabine, or FTC (Emtriva), sold in combination as Truvada by California-based Gilead Sciences Inc.

The company donated Truvada for the study, which involved about 2,500 men at high risk of HIV infection in Peru, Ecuador, Brazil, South Africa, Thailand and the United States (San Francisco and Boston). The foreign sites were chosen because of high rates of HIV infection and diverse populations.

Until the CDC's detailed advice is available, the agency said gay and bisexual men should:
-Use condoms consistently and correctly.
-Get tested to know their HIV status and that of their partners, and get tested and treated for syphilis, gon-orrhea and other infections that raise the risk of HIV.
-Get counseling to reduce drug use and risky sex.
-Reduce their number of sexual partners.