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HIV/AIDS Advocacy in North Carolina

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**Piedmont HIV Health Care
Consortium**

North Carolina AIDS Action Network

Overview

- Timeline of Events
- Objectives of Advocacy
- Partnerships
- Highlights of Efforts
- Results of Collaboration

Advocacy Timeline

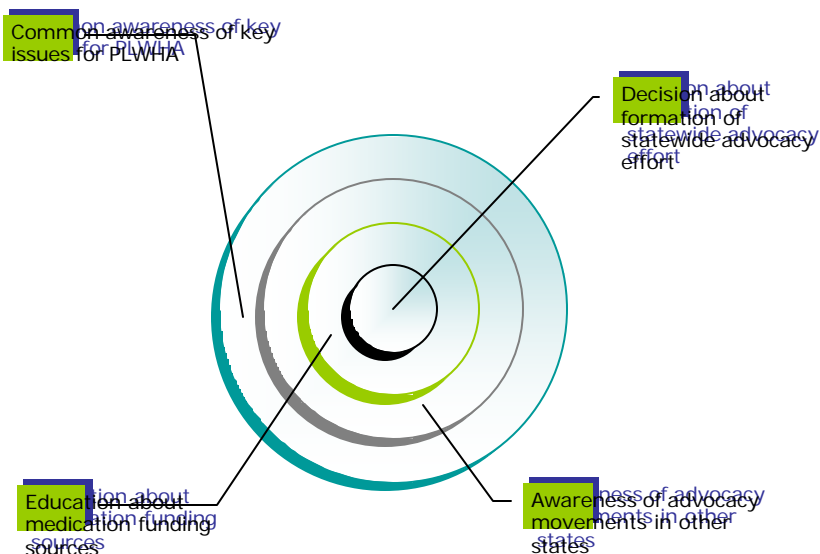
- 12/15/01 – NC ADAP closes to new enrollees
- 01/02 – Positive Living takes the lead on addressing the issue
- 3/02 – Researched other advocacy efforts going on in the country
- 4/02 – Connected with three lead organizations – Project Inform, The AIDS Institute (Florida AIDS Action), and R2-Solutions.
- Spring 2002 – Met with pharmaceutical companies to get financial support for advocacy efforts

Advocacy Timeline cont'd

- 6/02 – Met with NC AIDS Director to assess the needs of the ADAP program
- 7/02 – Started building relationships with individuals and organizations across the state
- 8/02 – Set date for a statewide advocacy planning meeting
- 9/02 – Continued discussion with advocacy experts

North Carolina HIV/AIDS Advocacy Planning Session October 2002

- Convened key stakeholders to discuss HIV/AIDS Advocacy in NC
- Used current ADAP crisis as drawing card – 800 people on waiting list



Key Stakeholder Affiliations

- PLWHA
- AIDS Service Organizations
- Community Health Centers
- Community Based Organizations
- County Health Departments
- Corporate Partners

Key Stakeholder Affiliations cont'd.

- Title II Consortiums
- Title III Clinics
- Medical Providers (nurses, physicians, nurse practitioners)
- Faith Based Organizations
- Research Based Institutions

NC Planning Session Discussion Topics

- Outcomes
 - Increasing awareness
 - Action steps
- Barriers
 - Economy
 - Exhaustion of human resources
 - Cynicism
- HIV/AIDS in NC
 - Epi-data
 - Poverty

NC Planning Session Discussion Topics cont'd

- Values
 - A whole laundry list
 - Memorialized in a relational statement
- Network Representation
- What will we call it?

North Carolina AIDS Action Network

- Formed a steering committee
- Elected Officers
- Began meeting regularly to establish a legislative agenda
- Informed media of our new advocacy network
- Launched NC Fact Sheet
- Trained PLWHA to be advocates
- **MADE FULL EDUCATION/INFO. ASSAULT ON NC LEGISLATURE**

HIV/AIDS in North Carolina

HIV
Human Immunodeficiency Virus,
transmitted from one person to another
by exchanging body fluids through sex,
sharing needles and from mother to infant.



AIDS
Acquired Immunodeficiency Syndrome,
a medical condition that occurs when HIV
destroys the immune system.

22,000	North Carolinians are living with HIV/AIDS.
15,000	North Carolinians <i>know</i> they have HIV/AIDS.
1,500	Women, men and children are diagnosed with HIV/AIDS each year in North Carolina.
1,014	New cases of AIDS were reported in 2002. This is a 16% increase over 2001, when 871 new cases were reported.
99	99 of North Carolina's 100 counties have reported multiple cases of HIV/AIDS.
77	Out of every 100 new reports of HIV infection come from minority communities.
25	Percent of North Carolina's HIV/AIDS cases come from rural counties, one of the highest rates in the country.
4	The rate of HIV infection for women has risen four times faster than for men.
1	North Carolina led the nation in 2002 in the number of people waiting for life-sustaining HIV/AIDS medications.

the bottom line

0

The number of North Carolinians that have been cured of HIV/AIDS.

Data source: 2003 HIV/STD Prevention & Community Planning Epidemiologic Profile for North Carolina, HIV/STD Prevention & Care Branch, NC DHHS.



What is ADAP?

ADAP is a medication assistance program for individuals living with HIV/AIDS. The costs of these medications can range from \$10,000 to \$20,000 a year.

Who is eligible?

People living with HIV who earn less than 125% of the federal poverty level (less than \$11,075 for one person per year) and who are uninsured or are underinsured. This would disqualify even someone working full-time at minimum wage with no health insurance.

How is it funded?

In 2002, ADAP was funded through approximately \$13 million in federal dollars and \$8.355 million in state dollars. No new federal funding is expected for 2003, meaning that the state's investment is especially critical this year.

Why is this a concern?

Due to lack of funding, ADAP has been closed to new enrollees since December, 2001. Based on current trends, the ADAP waiting list could swell from 217 (current as of January 24, 2003) to more than 700 by July 1, 2003, unless new funding is provided.

the bottom line

**Raise the eligibility level for ADAP from 125% to 200% of the federal poverty level.
Provide an appropriation of \$13.76 million for ADAP for the 2003-04 fiscal year.**

North Carolina has the most restrictive eligibility criteria in the country. It is one of only 3 states with eligibility levels below 200% of the poverty level (\$17,720 for one person per year). Raising eligibility to 200% and fully funding the program would eliminate the waiting list and allow hundreds of North Carolinians to access life-sustaining medications.

What are the benefits?

1. *Saves money*

Providing HIV/AIDS medications early on is cheaper than letting the disease progress. Preventing advanced HIV/AIDS can save more than \$20,000 per year per patient in additional drug and hospitalization costs.

2. *Helps working North Carolinians*

Providing medications can increase productivity through fewer sick days due to untreated HIV. Increasing income eligibility will allow people to stay on the job and off of other public assistance programs.

3. *Aids in prevention*

Getting people into treatment can increase their access to prevention information and reduce risky behaviors. Keeping people in treatment can prevent the development of drug-resistant strains of HIV. There is also evidence that drug therapy can lessen the risk of transmission of HIV.

NCAAN Highlights

- February 2003 – Held 1st Consumer Advocacy Training
- March - April 2003 – Mass Mailings to NC Legislature
- Jan. – May 2003 – Personal visits/calls to legislators and state officials
- April 2003 – Met resistance, anticipated failure, kept fighting anyway
- May 2003 – Logged a win in our column

NCAAN Highlights

- Continued development of relationships – Community; Government; Corporate
- June 2003 – Present – smaller (local) advocacy networks popping up all over
- June 2004 – 2nd Consumer Advocacy Training, 1st Legislative Rally

Results of Collaboration

- Many Voices – One Message
- Standards are created, set and expected to be followed
- Leaders Emerge
- Dreams Become Reality
- Strength in Numbers