



AIDS CARE AND TREATMENT IN OUR NATION
ryanwhiteaction.org



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INTRODUCTION



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The Ryan White ACTION (AIDS Care and Treatment In Our Nation) Campaign was launched by The AIDS Institute, the American Academy of HIV Medicine, the HIV Medicine Association and the National Alliance of State and Territorial AIDS Directors (NASTAD). The goal of the campaign is to promote public education and awareness of the Ryan White CARE (Comprehensive AIDS Resources Emergency) Act.

The Ryan White ACTION Campaign Media Toolkit is designed for the many constituencies who want to have a voice in the Ryan White CARE Act reauthorization process. The information contained within this toolkit will help you communicate with the media and deliver clear and consistent messages about the Ryan White CARE Act and the positive impact it has had on the lives of many Americans.

The media can be a valuable tool to use to deliver your key messages to specific audiences; however, what you say, and how you say it, can have a significant impact on whether the media covers it and how they present your message to the public. Often the most difficult part of gaining the media's attention is developing a story angle that is both newsworthy and informative to media's specific audiences.

Media responds strongly to personal stories. Therefore, while statistics will be important, your media outreach success will be enhanced by including personal profiles of people affected by the Ryan White legislation, and those potentially affected by proposed changes to the legislation. This toolkit provides the basic factual information on the CARE Act that you will need to reach out to media. However, it will be important to weave the personal stories into any pitch you make to the media.

Media Relations (Tab 2) provides tips and information for reaching out to the media; *Techniques Used to Respond to The Media* (Tab 3) provides tips and information for responding to media inquiries and conducting media interviews; *Media Tools* (Tab 4) contains background information about the Campaign that you can use when talking to members of the public or the media; *Media Templates* (Tab 5) contains boilerplate press materials; and *Campaign Contact Information* (Tab 6) gives you contacts for public relations professionals working on this project.

MEDIA RELATIONS



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DEVELOPING MESSAGES AND TARGETS

There are generally two ways of communicating with the media: on a proactive basis, where you are reaching out to the media to inform them and pitch them on story ideas about your campaign or event; or on a reactive basis, where you are responding to specific media requests. This toolkit is designed to address both approaches.

Target Audiences and Media

It will be important before beginning outreach to determine the message you are trying to communicate and the audience you wish to reach. If your goal is to influence Members of Congress and other legislators, then your key audiences will be media in the hometown and districts of target Members. If your goal is to reach out to the general public and educate them about the legislation and how it impacts your community, then your key audiences will consist of health media for the newspapers (daily and weekly), radio stations and televisions stations in your area. Understanding your audience and your message will help you more effectively direct your outreach to appropriate reporters and media outlets.

Story Angles and Pitch Ideas

Below are a few questions you should ask yourself before reaching out to a reporter.

- Is your story timely? Does your story angle have a “hook” that the reporter can tie to current news or an upcoming event? (i.e. expiration of the legislation, new legislation that impacts your community, looming crisis in funding or care, etc.)
- Does the story you are pitching include a local angle? (i.e. does said legislation or crisis affect that state or city?) Stories that provide information about a reader’s community are much more likely to be picked up than those with little or no relevance to local readers.
- Will targeted audiences consider the information important or useful?
- Is there anything unique or unusual about the information? Can the information be tied to breaking news?
- Are there any interesting personal stories, facts or data that can be included as part of the story?

The materials created for the national outreach provide useful tools for your local media outreach. In this toolkit, you will find several documents on the Campaign, including a “Facts at a Glance” and “Key Messages” (Tab 4) that can help you create localized story angles. For example:

- As the expiration date of the Ryan White CARE Act (September 30, 2005) approaches, media in all markets will be interested in stories that illustrate the impact of the funding on their communities. Pitch a story about changes (or flat funding) for the Ryan White CARE Act and how those changes will affect your community.
- Use key dates to pitch stories—such as Latino AIDS Awareness Day (October 15) and World AIDS Day (December 1).
- Use major events and conferences taking place in your area as news hooks to pitch stories.
- Determine whether your local newspaper or broadcast news provides a column or segment of the news in which it highlights a member of the community. If so, identify “heroes” in your community who help provide HIV/AIDS care and treatment with Ryan White funding.

Identifying Media Outlets in Your Region

The next step in reaching out to media on a proactive basis is compiling a good media list. The following identifies different categories for list building:

Daily and weekly newspapers: Each state has one or more major daily newspapers and each community has a number of weekly, community-based newspapers. Often, these will also include newspapers created for audiences that may be highly appropriate to your issue (i.e. urban, or minority, etc.).

Local television and cable access stations: There are four major network affiliates in each market: NBC, ABC, CBS and Fox.

Local radio: Radio stations are important audiences. In addition to network affiliates, you should include any radio stations that provide public affairs programming (i.e. talk radio). Radio stations with purely musical formats should not be included.

Internet and Satellite Radio: In the last 10 years, many (if not most) regional newspapers and television stations have developed on-line versions of their media outlets, thus enabling them to share their news stories with a national audience. Some newspapers duplicate the text from the hardcopy of the newspaper into the on-line version, while others have on-line reporters who exclusively write stories for the publication’s website. Most regional television stations mix local news with national news obtained primarily from wires such as the Associated Press and

Reuters. Increasingly, more radio stations are making their on-air news broadcasts available via the Internet using audio files and transcripts. In the case of satellite radio services, more local radio stations are being created that provide local information to far away listeners. For example, travelers in New York can tune in *real time* to traffic and weather news in Portland, Oregon via satellite transmission.

Trade publications: Trade publications target very specific audiences who have a particular interest in a subject matter (i.e. health, education, travel, etc.). Trade publication reporters are often considered “experts” in the areas they write about, and therefore, when you communicate with them, you should include more in-depth information about the Campaign that more general reporters may find unnecessary.

Identifying Reporters for Each Outlet

As discussed under Media Lists, reporters are often assigned to news beats, which means they cover a specific subject matter or demographic. In the case of the Ryan White ACTION Campaign, reporters who cover health and government are perfect examples of the types of reporters you want to target. Below are brief descriptions of key media players you will want to familiarize yourself with:

Editor/Managing Editor: The editor and/or managing editor has overall responsibility for the print publication and determines which stories will run and what will be cut. Publishers rely on editors to ensure that news content meets journalistic standards and fulfills the needs and demands of its audiences.

Producers: Serve a similar role as the editor/managing editor of print publications, but for broadcast news through television and radio outlets.

Assignment Managers: Assigns reporters to cover specific stories. Assignment Managers often rotate within the newsroom, so it is important to call the media outlet and ask to speak to the Assignment Desk if you do not know the name of the current assignment manager.

Guest Bookers: Though rarely listed in media directories, guest bookers are responsible for booking guests on television and radio news shows. Their job is to find guests that meet the criteria outlined by broadcast producers.

Anchors/Hosts: Television anchors and radio hosts are usually not the appropriate person to contact to pitch story ideas, since they usually tell the stories assigned to them by producers.

Reporters: If you have an ongoing relationship with a reporter, or you know specifically which reporter you need to contact to pitch a story, you can often bypass the editor/managing or producer. However, it is important to understand that when pitching a story to a reporter, the reporter in turn has to “pitch” your pitch to his editor/producer. Therefore, when presenting story ideas to a reporter, it is imperative that you provide the reporter with the relevant information he will need to get approval from the editor. Below is a list of reporters you are likely to pitch the Ryan White ACTION Campaign story angle to:

Metro/Community Reporters: Report on issues of importance within the metropolitan area of a city or community. Stories include, but are not limited to local government, human-interest stories, local crimes, community activities and business.

Government Reporters: Many large print publications have reporters stationed in the Washington, D.C. area to cover the Federal Government and how policy decisions might affect their readership. It is very helpful to familiarize yourself with the issues the cadre of government reporters in Washington is covering to potentially use past coverage as a hook for a future story (i.e. you wrote about Ryan White the last time it was reauthorized, would you be interested in covering the issue again?). As is the case with trade publication reporters, newspaper and magazine beat reporters are usually experts in the areas they cover, so you should take additional steps to provide them more in-depth and statistical information about the CARE Act.

Health Reporters: An estimated 1.1 million Americans are infected with HIV/AIDS and 40,000 new infections occur each year, making this an important story for health reporters.

Creating a Media List

Once you determine which media you will target to pitch your story angle, you will create a media list containing media contact information, such as e-mail addresses and phone/fax numbers. While there are a number of software programs and media directories that provide media contact information, these can be expensive. Therefore, we recommend calling local outlets directly to inquire which reporters are covering the news beats you want to reach. Though this is much more time consuming, contacting the media outlet directly allows you to introduce yourself to key members of the staff, such as managing editors or producers and begin to develop working relationships.



MEDIA MATERIALS

Media Alert/Advisory

A media advisory is a one-page notice that informs and/or invites media to an event or to interview someone. It highlights the basic who, what, when, where, why and how of an event or individual you want the media to cover. An example would be “Ms. White is available for an interview.” (See Tab 5 for sample). In addition to sending your media advisory to everyone on your media list, be sure to also send all media advisories to the Associated Press (AP) Day Book, which is a wire service that logs national and local events open to the media. Be sure you include a time and place for your event, and information about interviews and/or photo opportunities.

Press Release

A press release is a shortened version of a news article that is used to entice the media to want to learn more about your organization, program, cause or product. Press/news releases can be one to two pages in length (400-500 words) (See Tab 5 for sample) and should contain information with news or feature story value. Since the media literally receive hundreds of press releases a week via e-mail and fax, it is important that you make your press release stand out from all the others. The first step to ensuring that your release gets read is to make sure it is newsworthy and contains information that is relevant to the media’s target audience.

Pitch Letter

Though similar to a press/news release, a pitch letter targets a specific person, such as an editor or producer asking them to consider writing a story about a specific topic or person. For example, you can send a pitch letter to a newspaper editor asking him to consider writing an article. Or as discussed under story angles (Tab 3) you can use a pitch letter to inform an editor about something unique to a given community, for example, the looming crisis in Tennessee. A pitch letter allows you to propose a story angle to a reporter, while at the same time enabling you to inform him about the Campaign, and why he/she should consider it important. A pitch letter should only be one-page in length and no more than 4 or 5 paragraphs. As in the case of press/news releases, put the most important information in the first paragraph—be concise and straight to the point. In the concluding paragraph include contact information and tell the reporter you will be following up with them by phone.

Fact Sheet

A fact sheet provides detailed background information about the Campaign. One to two pages in length, fact sheet information can include history, interesting and compelling statistics and contact information.

How to Send Out Media Materials

When developing your media list, pay attention to how a reporter wants to receive their material. Most reporters today prefer to receive media materials via email; although, some still prefer fax or mail.

When sending e-mails, make sure your subject title fits into the subject line of the e-mail. Like your press release headline, the e-mail subject title should grab a reporter's attention and entice him or her to want to read more.

Do not send press releases as word document attachments unless the reporter requests it. Instead, put the text of media material into the body of the e-mail. Different types of software and software upgrades often mean that e-mail recipients are unable to open or read attached documents. Text contained within the body of an e-mail virtually guarantees your material will be delivered intact.

Once you have sent out your materials, it is important to follow-up with calls directly to the reporter to ensure your materials are received. While surveys have shown that reporters don't like to be called directly, it is the only way to ensure your story is reviewed. Some reporters receive hundreds of emails a day, without a follow-up call, many of them go unread.

TECHNIQUES USED TO RESPOND TO THE MEDIA



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FIELDING MEDIA INQUIRIES

This section provides tips on responding to media calls and requests, and/or preparing for and conducting an interview.

Preparing for an Interview

Gather as much information as possible from the reporter. Understand who the reporter is and why he/she is calling:

- Identify the reporter and his/her affiliation. If possible, determine the reporter's audience—size, geographic location, ages, occupations and interests.
- Establish the focus of the story.
- Find out the reporter's deadline.
- Find out who else will be interviewed for the story.
- Ask how the reporter learned about the Campaign or was referred to you.
- For television or radio interviews, find out if the interview will be live, taped or 'live to tape' (meaning it's a live interview that is aired at a later date.) For radio, ask if there will be listener call-in. This information will help you not get caught unaware by a caller you weren't expecting during the interview.

Collect and organize your thoughts:

You do not have to talk to the reporter immediately. The reporter has had time to prepare, so you should grant yourself the same opportunity. It is important, however, to respect a reporter's deadline. If you do not get back to the reporter in time, especially if responding to a potential negative story, you risk seeing or hearing a report that says "X could not be reached for comment."

Use your preparation time to do the following:

- Read through the tips and suggestions that follow in this toolkit.
- Prepare for likely questions.
- Outline two or three key points you want to make.
- Think about your visual appearance (in the event of a television interview). (Clothes that are blue or red appear well on television—avoid white—it can be too bright for television cameras.)

- If you are in a situation that does not allow you to fully prepare, then in a friendly manner ask the reporter for the following:

The nature of the story he/she is working on.

Specific questions she would like addressed.

The deadline, in case you would like to provide supporting information after the interview.

- In a situation in which a hostile reporter is asking loaded questions, it is important to KEEP YOUR COOL and REMAIN CALM. Do not try to debate a reporter. Provide him/her with accurate, concise information. Offer to send the reporter information or call him/her back when you have some supporting documentation in hand.

During the Interview

- **Emphasize positive stories and profiles.** The success of the legislation is best illustrated in the many personal stories of people who have benefited by it. Media like to tell a story through real-life case histories and examples. Have 2-3 individuals involved in the Campaign who have an interesting story to tell and are comfortable sharing it with the media. Statistical information and percentages are also solid evidence of the overwhelming success of the legislation. (See Tab 4 for key statistics).
- **Be Consistent.** All responses to media inquiries should be consistent. To ensure consistency, share background information with other individuals who might be speaking with the media on the Campaign's behalf.
- **Technique.** The key here is to be HONEST, SINCERE and CONFIDENT. If you do not know the answer to a reporter's questions, then say so. If you can find out, then do so.
- **Avoid Speculation.** Do not be speculative or answer hypothetical questions. If a reporter leads with, "Assume that..." or "What if...", respond with something such as, "I am unable to speculate on that, however..." and state your positive message.
- **Remain Positive.** Convey positive messages and responses. Positive remarks are the best. For example, if a negative question is posed, don't say, "No, the Ryan White CARE Act is not about X." Instead say, what the Ryan White CARE Act is about.
- **"No Comment".** Do not say "No Comment." It sounds as if you have something to hide. If you do not have an answer, say so and let the reporter know that you, or the appropriate Campaign spokesperson, will get back to them with information. If you do not want to discuss something, rephrase the general message or refer to your key messages on the topic—you don't have to answer specifics. Be firm, but not abrasive.

- **Keep It Simple.** Technical terms may be foreign to a reporter. If a reporter fully understands you, he is more likely to incorporate your response in the story.
- **Be Concise.** State your answer and stop. Do not fill in silent pauses. Often a reporter will ask a question, wait for your response, and then be silent, waiting for you to elaborate. If a reporter seems to utilize this technique, provide your answer, stop, and ask the reporter if there are any other questions. A pause also provides you with the opportunity to add your two or three key points or collect your thoughts.
- **Press Contacts.** Keep a record of press contacts. This will help you remember which reporters are fair and balanced and should be called upon when you have something to say.
- **Television Interviews.** Often television coverage will only air your response, so it is best to restate the question at the beginning of your answer. (i.e. Q: "What is the goal of the Campaign?" A: "The goal of the Campaign is ...")

Media Terminology

Media terms have different meanings to organizations and members of the media. It is therefore important from the outset to lay down the ground rules surrounding a media interview. Below are some key terms you must know.

- **Off-the-Record.** means no part of the interviewee's statement can be printed or broadcasted. Understand that NOTHING is off-the-record when speaking to a reporter. If you do not wish to have a statement of fact appear in print or broadcast do not provide the information or quote to the reporter. Also, please note that any information provided via e-mail can be considered "on the record."

Often people provide reporters information off-the-record because they know and trust them. However, you must be prepared to deal with the circumstances of your off-the-record remarks being made public. There is no law that states a reporter cannot use off-the-record remarks. It is an ethical decision every reporter must make, and in some cases they will break this unwritten rule to meet their perceived obligation of being a journalist.

- **On-Background.** means that the interviewee's name is not identified and she is instead referred to as a "spokesperson for the Ryan White ACTION Campaign." *However*, some organizations and reporters interpret on-background to mean not using your name or the company name. Therefore, it is important to clarify ahead of time with the reporter his definition of on-background.

HOW TO RESPOND TO MEDIA REPORTS

Responding to Print Media Reports

There are three basic options to respond to information printed in a newspaper or magazine—a letter to the editor, an opinion/editorial piece (Op/Ed), and an editorial board meeting.

- **Letter to the Editor.** Letters to the editors are only used as a direct response to a published story in that newspaper. Letters are written to complement the paper on a previously published article, to correct inaccurate facts or highlight and counter bias. Letters should be short and to the point (on average 2-3 paragraphs at the most). The letter should state your position clearly and concisely. If the letter is too long, it will be edited down, perhaps by someone who does not understand the issue. The letter should be one double-spaced page, including the author's address and phone number.
- **Opinion/Editorial Piece.** Most newspapers reserve space for readers to voice opinions. Op/Eds express a strong opinion and take a firm position on an issue or event. For local papers, the Op/Ed should be localized and aim to provoke conversations among members of the community. To determine level of interest, or likelihood of placement, you should contact the editor of the editorial/opinion page in advance and discuss your idea.

The author or signer of the Op/Ed is critical. His/her signature provides credence and accountability to the piece, and therefore, the author/signer should have in-depth knowledge of the Campaign. The subject of the Op/Ed should be timely and preferably tied to current news. The average length is 700-800 words, although it varies by publication, for example, for local papers, 500-700 may be more appropriate. Note: Editors will often solicit contrary viewpoints to Op/Ed pieces.

- **Editorial Board Meetings.** You may request a meeting with editors and writers covering a specific issue. The intent of the meeting is not necessarily to generate media coverage, but to provide news organizations with background information and introduce yourself as a resource. For some topics, editorial board meetings could result in the paper talking an editorial position.

Responding to Television and Radio Reports

- Radio and television broadcasts are more difficult to respond to than print stories due to the limited time electronic media devotes to news packages.
- The techniques used to respond to radio or television stories are similar to those of print, although appearance, speaking style and inflection come to bear in an electronic presentation.
- To respond to a previously aired story, contact the reporter or the news director at the station and ask for the opportunity to present your side of the story. If a broadcaster interviews you, remember that he probably will use only a 15-30 second “sound bite” from your entire interview. Therefore, state your main points concisely, clearly and frequently.

Media “Don’ts”

- Don’t call during hours when you know a reporter is on deadline. Traditionally, deadline hours are between 4:00–5:00 p.m., however today’s 24/7 news cycle means that deadline hours vary. Educate yourself about these times, and avoid contacting reporters during these hours.
- Don’t tell a reporter you will give him an exclusive story, and then offer it to a competitor. It is fair to provide a reporter a timeline for which you are willing to hold a story, but let them know if they are not willing to commit to a story within a specified timeframe you will offer it to another media outlet. However, when informing them of your intent to seek out other media outlets that this information comes across as a “threat.”
- **Don’t treat the media as “advertising agents.” The responsibility of the media is to “inform” the public about issues, events, products that are of importance to them. If you approach the media in a way that suggests you want them to help you “sell” your product or purely “influence” the public to see an issue your way, you lose their respect and they will likely be unwilling to deal with you in the future.**

MEDIA TOOLS



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KEY MESSAGES

Why the Ryan White CARE Act should be renewed, strengthened and expanded:

The Ryan White CARE Act is a success story

Since 1990, it has provided states, cities, counties, clinics and hospitals with funding to provide HIV/AIDS treatment and care to poor, underinsured and uninsured Americans and families who otherwise would not have access.

It forges partnerships between federal, state, local and private agencies.

By helping to fund the distribution of lifesaving medications, the Ryan White CARE Act has been an integral part of an effort that has decreased AIDS deaths in the United States from a peak of about 50,000 in 1995 to only about 18,000 in 2003, and increased life spans and quality of life for thousands of others.

Congress has renewed the program twice—in 1996 and 2000—both times with strong bipartisan support.

The CARE Act provides services to over 500,000 HIV-positive individuals in all 50 states, the District of Columbia, Puerto Rico and the U.S. territories.

CARE Act programs are currently funded at \$2 billion in FY2005.

HIV/AIDS is still a serious problem in the United States

HIV/AIDS is an infectious disease.

As of late 2003, there were 1.1 million people in the United States living with HIV/AIDS.

The CDC recently estimated that, from the end of 1999 through the end of 2003, the number of persons in the United States who were living with AIDS increased from 311,205 to 405,926—an increase of 30 percent.

An additional 40,000 people in America become infected with HIV/AIDS each year.

While deaths have decreased in recent years, the CDC reports that HIV/AIDS is still one of the leading causes of death of Americans between the ages of 16 and 54.

More people with HIV/AIDS need help

Due to funding restraints, nine states currently have waiting lists for people in need of drugs (Alabama, Alaska, Arkansas, Idaho, Kentucky, Montana, Nebraska, North Carolina and West Virginia).

In states like Mississippi and Tennessee, and others around the country, people with AIDS are losing their health care coverage including drug coverage due to state Medicaid cutbacks and other funding constraints.

A May 2004 report by the Institute of Medicine, “Public Financing and Delivery of HIV/AIDS Care: Securing the Legacy of Ryan White,” found that over 233,000 HIV-positive Americans do not have consistent access to highly active antiretroviral therapy (HAART).

The CDC estimates there are 211,000 people with HIV/AIDS in the U.S. who are not receiving drug treatment, but should be.

Minority populations represent nearly 70 percent of people served by Ryan White programs, but recent studies show that minorities’ access to these programs is hampered by “key barriers” such as “restrictive eligibility criteria” for publicly funded health insurance, “distrust of government” and stigma associated with HIV.

The HIV/AIDS epidemic has changed, and the CARE Act must address those changes

Better treatments have led to an increasing number of persons in the United States who are living with AIDS. From the end of 1999 through the end of 2003, the number of persons in the United States who were living with AIDS increased from 311,205 to 405,926—an increase of 30 percent.

Newly infected people are increasingly likely to be poor, to be members of a minority community, and to have inadequate access to healthcare.

In 2003, African Americans, who make up approximately 12 percent of the U.S. population, accounted for half of the AIDS cases diagnosed.

Although Hispanics make up about 14 percent of the population of the United States and Puerto Rico, they account for approximately 20 percent of all new diagnoses.

Women account for a growing proportion of new AIDS diagnoses, rising from 8 percent in 1985 to 27 percent in 2003.

Eighty percent of people who benefit from Ryan White ADAP funding have annual incomes of less than \$19,500 or 200 percent of the federal poverty level for an individual.

While the majority of AIDS cases are still in urban areas, more and more people in rural areas, like the South, are being infected.

A person's ability to receive treatment for HIV/AIDS should not depend on where they live

Due to funding restraints, nine states currently have waiting lists for people in need of drugs.

In some communities, people have to wait months for a doctor's appointment.

A small increase in ADAP and "flat funding" for all other Titles of the CARE Act will do little to help eliminate current waiting lists, and nothing to extend care and treatment to people who aren't even on those lists.

Flat funding will exacerbate the current crisis in the availability of primary care and adherence support services for persons living with HIV/AIDS and funded by the CARE Act.

ABOUT THE RYAN WHITE ACTION CAMPAIGN

Campaign Partners

The Ryan White ACTION Campaign is made up of the following organizations working together to get the Ryan White CARE Act renewed, strengthened and expanded:



The AIDS Institute promotes action for social change through public policy research, advocacy and community education. It began as a grassroots community advocacy effort in the late 1980s. Over the past several years, TAI expanded its vision to become a leading national public policy research, advocacy and education agency with offices in Tallahassee, Tampa and Washington, DC. Affiliated with the Division of Infectious Diseases and Tropical Medicine at the University of South Florida College of Medicine, The AIDS Institute remains focused on HIV/AIDS while incorporating work on related health care issues such as hepatitis, as well as other infectious and chronic diseases.



The American Academy of HIV Medicine is an independent organization of AAHIVM HIV Specialists™ and others dedicated to promoting excellence in HIV/AIDS care. Through advocacy and education, the Academy is committed to supporting health care providers in HIV medicine and to ensuring better care for those living with AIDS and HIV disease. As the largest independent organization of HIV frontline providers, the AAHIVM's 2,000 members provide direct care to more than 340,000 HIV patients. This is more than two-thirds of the patients in active treatment for HIV disease. Nearly 50 percent of the Academy's members receive Ryan White CARE Act funding, with 18 percent of the Academy's members practicing in community clinics.



The HIV Medicine Association is an organization of medical professionals who practice HIV medicine. HIVMA represents the interests of its patients by promoting quality in HIV care and by advocating for policies that ensure a comprehensive and humane response to the AIDS pandemic informed by science and social justice. HIVMA represents the diversity of medical sub-specialties practicing HIV medicine—including internal medicine, family practice, infectious diseases, oncology and obstetrics-gynecology. HIVMA has more than 2,700 members representing 49 states, the District of Columbia, Puerto Rico, the Virgin Islands and 36 countries outside of the United States.



The National Alliance of State and Territorial AIDS Directors represents the nation's chief state health agency staff who have programmatic responsibility for administering HIV/AIDS health care, prevention, education and supportive service programs funded by state and federal governments. State AIDS Directors in all 50 U.S. states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands and the U.S. Pacific Islands are represented by NASTAD with an office in Washington, DC. NASTAD strengthens state and territorial-based expertise and brings them to bear in reducing the incidence of HIV infection, and on providing care and support to people living with HIV/AIDS.

The Ryan White Story

Ryan White was diagnosed with AIDS at age 13 and gained international notoriety fighting for his right to attend school. In the process, he opened the hearts and minds of millions of people. He was, as Ted Koppel described him on *Nightline*, "an extraordinary young man; brave, tolerant and wise beyond his years."

During the time between his diagnosis in 1984 and his death in 1990, Ryan was featured on numerous television shows and magazine covers and was the subject of a television movie about his life. He became friends with world-renowned athletes and entertainers, including Elton John, Greg Louganis and Michael Jackson, all of whom offered Ryan and his family their support. He spoke out often and eloquently about the challenges he faced and the need for greater compassion towards people with HIV and AIDS. Despite the ravages of the illness to his body and the discrimination he faced, Ryan remained a positive, healing force throughout his life.

Ryan contracted HIV through blood-based products used to treat his hemophilia. He learned that he had the virus when he contracted a life-threatening lung infection. At the time, he was told he had no more than six months to live. While recuperating and thinking about the limited time he had left, Ryan told his mother Jeanne that he wanted to live a normal life, go to school, be with friends and enjoy day-to-day activities.

Unfortunately, Ryan's school and his community responded with fear and ignorance. The local superintendent refused to allow Ryan to attend school, a move supported by teachers and parents. Ryan and his family fought the decision, but Ryan was forced to "attend" school by telephone for months while his case made its way through an administrative appeals process. Once the state board of education ruled that he should be allowed to return to school a group of parents sued to keep him out. The courts ultimately ruled in Ryan's favor, and he did return to school.

Sadly, he was met with taunts and unfounded rumors and some students chose to be home-schooled rather than attend with Ryan. Ryan weathered the storm with tremendous patience and grace, never demonizing those who sought to demonize him.

Ultimately, though, the family decided to move to another community. According to Ryan, they made this choice because of their "desire to move into a bigger house, to avoid living AIDS daily and a dream to be accepted by a community and school." They moved to Cicero, Indiana, where Ryan enrolled in Hamilton Heights High School and was welcomed with open arms. The students had taken it upon themselves to learn about AIDS and educate their parents and teachers, as well. Ryan thrived in his new environment, attending school events, learning to drive and making the honor roll.

Ryan's story captured the attention of the media and the public and his courage, determination and positive attitude made him a hero for many. Though constantly surprised by the notoriety he received because of his seemingly simple wish just to go to school, Ryan nevertheless recognized the value of the spotlight and seized the opportunities he was given. Throughout all of his appearances, he gave voice to the desires of thousands of people with HIV/AIDS who wanted only to be treated with respect and compassion and given the opportunity to live as normal a life as possible. Ryan's visibility and outspokenness were especially crucial in the early days of the AIDS epidemic.

Because Ryan was infected through blood products and not through sexual contact or intravenous drug use, many found him more sympathetic than others with HIV and AIDS. Ryan, however, rejected all attempts to portray him as "innocent." He never drew a line between himself and other people living with HIV and AIDS and always urged compassion and support for all people living with the disease.

Ryan died on Palm Sunday, April 8, 1990, with his mother, his sister Andrea, his grandparents, his uncle and his friend Elton John at his bedside. Ryan's funeral was among the largest in Indiana history. Elton John performed at the ceremony, which included Michael Jackson and First Lady Barbara Bush among the mourners.

Ryan's legacy lives on in many ways. The Ryan White CARE Act is a federal program established shortly after his death that funds services for over 500,000 people with HIV/AIDS each year. The annual Ryan White Youth Conference brings together young people working on HIV/AIDS in communities across the country and the Ryan White Forest commemorates the lives of people with AIDS in Israel. Ryan's mom, Jeanne White-Ginder continues to speak with audiences across the country, carrying Ryan's message of love, compassion and hope.

Legislative Status of the Ryan White CARE Act

Since 1990, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act has made federal funds available to metropolitan areas and states for health care costs and support services for low-income, uninsured and underinsured individuals and families affected by HIV/AIDS. The program authorization must be renewed by Congress every five years. In October 2000, it was extended through the 2005 fiscal year, which ends Sept. 30, 2005.

Funding for CARE programs in Fiscal Year 2005 totaled \$2.073 billion. The President has requested level program funding (or "flat funding") for all Titles in FY2006, except a \$10 million increase in the AIDS Drug Assistance Program. That amounts to a total request of \$2.058 billion for Ryan White programs. If Congress does not extend the program by Sept. 30, it will still continue to operate under the current program rules. However, important changes to the program that could improve access to health care and medications for people with HIV/AIDS will be delayed.

In July of 2005, Health and Human Services Secretary Mike Leavitt outlined the changes the Bush Administration would like to see in the program. They were embodied in five principles—serving the neediest first, focusing on life-extending services, increasing prevention efforts, increasing accountability and increasing flexibility.

Under these principles, a list of core medical services for HIV-positive people would be developed in order to prioritize federal funding. The Administration is proposing that 75 percent of Ryan White funds in Titles I-IV be spent on core medical services, and HHS would develop and maintain a list of core ADAP drugs.

States and local service providers also would be required to increase coordination of care delivery. Additionally, they would be encouraged to adopt routine HIV testing at public facilities, and allow the HHS Secretary to reallocate any unspent funds to the state AIDS Drug Assistance Programs with the most need.

The Senate is expected to act first on the bill this fall (2005), and its Committee on Health, Education, Labor and Pensions will draft legislation. The House Energy and Commerce Committee is then expected to draft a version of the bill for consideration by the full House of Representatives.

Here is a list of the members who serve on these committees:

Senate Committee on Health, Education, Labor and Pensions

Committee Chairman, Mike Enzi (R-WY)

Republicans

Senator Judd Gregg (NH)	Senator Johnny Isakson (GA)	Senator Jeff Sessions (AL)
Senator Bill Frist (TN)	Senator Mike DeWine (OH)	Senator Pat Roberts (KS)
Senator Lamar Alexander (TN)	Senator John Ensign (NV)	
Senator Richard Burr (NC)	Senator Orrin Hatch (UT)	

Democrats

Senator Edward Kennedy (MA) <i>Ranking Member</i>	Senator Barbara Mikulski (MD)	Senator Jack Reed (RI)
Senator Christopher Dodd (CT)	Senator James Jeffords (I) (VT)	Senator Hillary Rodham Clinton (NY)
Senator Tom Harkin (IA)	Senator Jeff Bingaman (NM)	
	Senator Patty Murray (WA)	

House Committee on Energy and Commerce

Committee Chairman, Joe Barton, (R-TX)

Republicans

Ralph M. Hall (TX)	Heather Wilson (NM)	Greg Walden (OR)
Michael Bilirakis (FL), Vice Chairman	John B. Shadegg (AZ)	Lee Terry (NE)
Fred Upton, (MI)	Charles “Chip” Pickering (MS), Vice Chairman	Mike Ferguson (NJ)
Cliff Stearns (FL)	Vito Fossella (NY)	Mike Rogers (MI)
Paul E. Gillmor (OH)	Roy Blunt (MO)	C.L. “Butch” Otter (ID)
Nathan Deal (GA)	Steve Buyer (IN)	Sue Myrick (NC)
Ed Whitfield (KY)	George Radanovich (CA)	John Sullivan (OK)
Charlie Norwood (GA)	Charles F. Bass (NH)	Tim Murphy (PA)
Barbara Cubin (WY)	Joseph R. Pitts (PA)	Michael Burgess (TX)
John Shimkus (IL)	Mary Bono (CA)	Marsha Blackburn (TN)

Democrats

John D. Dingell, (MI), Ranking Member	Bobby L. Rush (IL)	Mike Doyle (PA)
Henry A. Waxman (CA)	Anna G. Eshoo (CA)	Tom Allen (ME)
Edward J. Markey (MA)	Bart Stupak (MI)	Jim Davis (FL)
Rick Boucher (VA)	Eliot L. Engel (NY)	Jan Schakowsky (IL)
Edolphus Towns (NY)	Albert R. Wynn (MD)	Hilda L. Solis (CA)
Frank Pallone Jr. (NJ)	Gene Green (TX)	Charles A. Gonzalez (TX)
Sherrod Brown (OH)	Ted Strickland (OH)	Jay Inslee (WA)
Bart Gordon (TN)	Diana DeGette (CO)	Tammy Baldwin (WI)
	Lois Capps (CA)	Mike Ross (AR)

FACTS AT A GLANCE

The Need

- HIV/AIDS remains a leading cause of death among Americans between the ages of 16 and 54.
- About 1.1 million people in the U.S. are living with HIV or AIDS.
- Another 40,000 people become infected with HIV each year.
- The CDC estimates there are 211,000 people with HIV/AIDS in the U.S. who are not receiving drug treatment, but should be.
- While the number of AIDS deaths has declined (3 percent decrease from 1999 through 2003), the number of AIDS diagnoses has increased (an estimated 4 percent during the same period).
- Because of funding variations, the care and treatment provided for HIV/AIDS patients varies widely from state to state.
- Nine states currently have waiting lists for people in need of drugs.
- Some communities report up to a six-month waiting period for a primary care visit. In other states, including Mississippi and Tennessee, people with AIDS are losing their health care coverage including drug coverage due to state Medicaid cutbacks.
- Newly infected people are increasingly likely to be poor, to be members of a minority community and to have inadequate access to healthcare.
- While the vast majority of AIDS cases are still in urban areas, more and more people in rural areas, like in the South, are being infected.

The Program

- The Ryan White CARE Act programs work with states, cities, clinics, hospitals and local community-based organizations to provide care and treatment to low-income, uninsured or underinsured people with HIV/AIDS and their families.
- CARE Act programs are the “payer of last resort.” They fill gaps in care not covered by other resources.
- By helping to fund the distribution of expensive, lifesaving medications, the Ryan White CARE Act has been an integral part of an effort that has decreased AIDS deaths in the United States from a peak of about 50,000 in 1995 to only about 18,000 in 2003.

- CARE Act services increase access to care for underserved populations, improve the quality of life for those affected by the epidemic and by providing earlier access to care and treatment, reduces the use of more costly health care services such as in-patient care.
- The Act was named in memory of Ryan White, an Indiana teenager who contracted AIDS at age 13 from a blood transfusion and died in 1990, and who became a leading public spokesperson on the needs of people with AIDS.
- The Ryan White CARE Act was originally approved in 1990 and has been renewed twice since then, in 1996 and 2000—each time with wide bipartisan support.

What Services are Provided?

- Ambulatory health care
- Home-based health care
- Insurance coverage
- Medications
- Support services
- Outreach, testing and referral to identify HIV-positive individuals who know their HIV status
- Dental care
- Technical assistance and education for providers
- Demonstration projects

Who Benefits?

- CARE Act programs reach more than 500,000 individuals each year.
- In 2004, the CARE Act assisted about 136,000 people through its AIDS Drug Assistance Programs (ADAPs).
- About half of the people who receive CARE Act benefits are African-American, while about 20 percent are Hispanic.
- Women account for nearly one-third of the people receiving services funded by the Ryan White CARE Act.

- Eighty percent of the people receiving assistance from ADAPs have annual incomes less than around \$19,500 (around 200 percent of the federal poverty level), and 51 percent have incomes less than approximately \$9,700.
- A majority of people served by the CARE Act are uninsured, with only small percentages reporting some other source of coverage (15% private; 9% Medicare; 7% Medicaid and less than 1% with both Medicare and Medicaid).

FREQUENTLY ASKED QUESTIONS

Q: What is the Ryan White CARE Act?

A: Since 1990, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act has made federal funds available to metropolitan areas, states, clinics, hospitals and community-based organizations for health care costs and support services for low-income, uninsured and underinsured individuals and families affected by HIV/AIDS.

Q: What is the Ryan White ACTION (AIDS Care and Treatment In Our Nation) Campaign?

A: The Ryan White ACTION Campaign is a national media campaign designed to raise awareness about the importance of the Ryan White CARE Act and why it needs to be reauthorized—or renewed—this year and adequately funded.

Q: Who is involved in the Ryan White ACTION Campaign?

A: The coalition behind the Ryan White ACTION Campaign includes The AIDS Institute, American Academy of HIV Medicine, HIV Medicine Association and the National Alliance of State and Territorial AIDS Directors. The National AIDS Minority Council will also be assisting the campaign through access to its national network of service providers. If you are interested in supporting the campaign, please contact Arlyn Riskind at 202/457-8100 or ariskind@lipmanhearne.com.

Q: When does the Ryan White CARE Act expire?

A: It was first signed into law in 1990. The Act's authorization expires every five years. The current law expires on September 30, 2005. This does not mean that programs won't continue. Congress will continue to fund the CARE Act programs regardless of authorization status.

Q: How many people are helped by the Ryan White CARE Act?

A: Approximately 577,000 people currently receive HIV/AIDS health care and antiretroviral treatment through the Ryan White CARE Act.

- Q:** How much money does the Ryan White CARE Act receive from Congress each year?
- A:** Currently, over \$2 billion per year is spent to support care, treatment and support services among those with HIV/AIDS.
- Q:** Is the same or more or less amount of money to be allocated in the reauthorization of the Ryan White CARE Act?
- A:** There are targets of maximum funding amounts that may be included in the reauthorization bill. However, the process of funding the Ryan White CARE Act each year is a separate process, called appropriations. Each year advocates call for adequate funding increases to allow the program to meet the growing needs of low-income people with HIV/AIDS without other sources of health care coverage. For the past few years the Ryan White CARE Act has not received increased funding with the exception of minimal and inadequate increases to the AIDS Drug Assistance Program (ADAP).
- Q:** Does the coalition have a basic position on how the CARE Act should function?
- A:** There are differences among some of the groups about how the Ryan White CARE Act should be altered in the future. But there is common agreement that the CARE Act is a very important part of the care and treatment system in the United States and that it needs to be strengthened and adequately funded.
- Q:** If I work at an AIDS organization in an urban or rural area what should I know about this year's Ryan White CARE Act Reauthorization?
- A:** We suggest that people living with HIV, family members, medical providers, social service workers and agency administrators let their Members of Congress know about the importance of the CARE Act programs. We also suggest that people become familiar with the Administration's proposal for reauthorization that will guide Congressional action. This proposal and a variety of additional stakeholder positions can be found on the Resource Section of our website at www.ryanwhiteaction.org.
- Q:** What do you consider to be the five (5) most important provisions for reauthorization of the Ryan White CARE Act?
- A:**
1. Medical care and access to medications is critical. Today, unlike in the past, we have drugs that can save lives and improve the quality of life. People living with HIV, no matter where they live, should have access to well-trained medical providers and access to the drugs that will keep them alive.
 2. While medical care and drugs are crucial, we must also ensure the social support that people need to deal with HIV in their lives and to adhere to the drug regimens. For example, in some locations this may mean the need to ensure transportation to medical appointments.

3. Many persons living with HIV/AIDS have co-occurring mental health and substance abuse issues. For those who are in need of such services, mental health therapy and substance abuse treatment must be made available.
4. All the various programs within the Ryan White CARE Act as well as those that relate to it (Medicare, Medicaid, etc.) must be better coordinated in order to provide a true continuum of care and to reduce costs due to unnecessary duplication, paperwork and red tape.
5. Regardless of how the system may change, additional funding is needed to meet the medical, social support and housing needs of people living with HIV.

Q: What are the best ways someone affected by HIV can get involved and help?

A: Let your Congressional representatives know how important the Ryan White CARE Act is to you.

In addition, there are a number of national organizations engaged in advocacy around the reauthorization of the Ryan White CARE Act. Here are a few with their websites:

The AIDS Institute (theaidsinstitute.org)

National Alliance of State and Territorial AIDS Directors (nastad.org)

American Academy of HIV Medicine (aahivm.org)

HIV Medicine Association (hivma.org)

Communities Advocating for Emergency AIDS Relief Coalition(caear.org)

AIDS Alliance (aids-alliance.org)

AIDS Action (aidsaction.org)

National Minority AIDS Council (nmac.org)

National Association of People with AIDS (napwa.org)

Title II Community AIDS National Network (tiicann.org)

Q: President Bush recently released principles from the White House guiding reauthorization. In those, he calls for a shift in Ryan White funds to areas most in need. What does this mean for both rural areas and urban areas?

A: There seems to be an attempt to ensure that some form of basic or core services are available to every person living with HIV, regardless of where they live. But, again, there are differences of opinion about the definition of basic or core services. More important, current funding levels need to be increased if a truly meaningful standard of care and treatment is to be accessible and available to anyone eligible for Ryan White CARE Act services.

MEDIA TEMPLATES



**AIDS CARE AND TREATMENT
IN OUR NATION**
ryanwhiteaction.org

FOR IMMEDIATE RELEASE
[DATE]

CONTACT: [NAME OF CONTACT]
[PHONE NUMBER]
[EMAIL]

MEDIA ADVISORY

What: [WHAT THE GATHERING IS and WHAT IT IS FOR]

Who: Presenting at the press conference will be:
[ORGANIZATION NAME and/or SPECIAL GUESTS or SPEAKERS w/ TITLES]

When: [DATE & TIME]

Where: [LOCATION NAME and ADDRESS]

- Why:**
- HIV/AIDS remains a leading cause of death among Americans between the ages of 16 and 54.
 - About 1.1 million people in the U.S. are living with HIV or AIDS.
 - Another 40,000 people become infected with HIV each year.
 - The CDC estimates there are 211,000 people with HIV/AIDS in the U.S. who are not receiving drug treatment, but should be.
 - While the number of AIDS deaths has declined (3% decrease from 1999 through 2003), the number of AIDS diagnoses has increased (an estimated 4% during the same period).
 - Because of funding variations, the care and treatment provided for HIV/AIDS patients varies widely from state to state.
 - Nine states have instituted waiting lists for people in need of drugs.
 - In other states, including Mississippi and Tennessee, people with AIDS are losing their drug coverage due to state Medicaid cutbacks.
 - Newly infected people are increasingly likely to be poor, to be members of a minority community, and to have inadequate access to healthcare.
 - While the vast majority of AIDS cases are still in urban areas, more and more people in rural areas, like in the South, are being infected.

About the Ryan White ACTION Campaign

The Ryan White ACTION Campaign is made up of the following organizations working together to get the Ryan White CARE Act renewed, strengthened and expanded: The AIDS Institute, AAHIVM, HIVMA and NASTAD. For more information, please log on to www.ryanwhiteaction.org





**AIDS CARE AND TREATMENT
IN OUR NATION**
ryanwhiteaction.org

FOR IMMEDIATE RELEASE
[DATE]

CONTACT: [NAME OF CONTACT]
[PHONE NUMBER]
[EMAIL]

**[YOUR ORGANIZATION NAME] Urges Congress
To Renew, Strengthen Ryan White CARE Act**

*Provides care, treatment to [NUMBER OF PEOPLE SERVED IN YOUR STATE/CITY, OR USE
"500,000 people with HIV/AIDS nationwide"] people with HIV/AIDS in [YOUR STATE/CITY, OR "U.S."]*

[YOUR CITY, STATE] – [YOUR COMMUNITY/ORGANIZATION] today urged Congress to renew the Ryan White CARE (Comprehensive AIDS Resource Emergency) Act, which provides care and treatment to people with HIV/AIDS and their families who cannot otherwise afford it.

"HIV/AIDS is still a domestic emergency, and we need the Ryan White CARE Act more than ever," said **[SPOKESPERSON AND TITLE]**. "The Ryan White CARE Act provides lifesaving care and treatment to a half million Americans each year, including **[NUMBER OF PEOPLE SERVED IN YOUR STATE/CITY]** in **[YOUR STATE/CITY]**."

"There have been significant changes in the way HIV/AIDS has spread and is treated since the Ryan White programs began in 1990," said **[SPOKESPERSON]**. "Congress must strengthen and expand the Ryan White CARE Act to keep up with these changes, to halt the epidemic and to keep HIV/AIDS from once again becoming a virtual death sentence in this country."

The Ryan White CARE Act provides care and treatment to low-income, uninsured and underinsured people with HIV/AIDS and their families. It was named in honor of Ryan White, a teenager who contracted AIDS at age 13 from a blood transfusion, and who became a leading spokesman for the needs of people with AIDS before he died in 1990.

By funding services that include distribution of lifesaving medications, the Ryan White CARE Act has been an integral part of an effort that has decreased AIDS deaths in the United States from a peak of about 50,000 in 1995 to only about 18,000 in 2003. The program, which was renewed by overwhelmingly bipartisan majorities in Congress in 1996 and 2000, is due to expire on Sept. 30, 2005. President Bush has proposed "flat funding" the program in 2006



at about \$2.1 billion, with the exception of an additional \$10 million to help with the purchase of medication.

Despite the success of the CARE Act, states and cities are already straining under a growing caseload. The Centers for Disease Control and Prevention estimates there are 211,000 people with HIV/AIDS in the U.S. who are not receiving drug treatment, but should be. And while the vast majority of AIDS cases are still in urban areas, more and more people in rural areas, like in the South, are being infected.

As a result, states and cities are facing additional hardships. Due to funding restraints, nine states have instituted waiting lists for people in need of drugs. In states like Mississippi and Tennessee, and others around the country, people with AIDS are losing their drug coverage due to state Medicaid cutbacks.

[SPOKESPERSON] urged residents to contact members of Congress and urge them to vote to renew, strengthen and expand the legislation.

“A minimal increase for ADAP, a portion of the CARE Act, won’t eliminate current waiting lists, and it won’t help people who aren’t even on those lists,” **[SPOKESPERSON]** said. “It will only pit state against state and city against city for the limited dollars available.”

“A person’s ability to receive treatment for HIV/AIDS should not depend upon what state they live in,” said **[SPOKESPERSON]**. “At a time when the nation has responded generously to the HIV/AIDS epidemic overseas, we cannot allow ourselves to become complacent about the threat that remains in our own country.”

Media notes: To interview **[SPOKESPERSON]** or other members of [YOUR COMMUNITY/ ORGANIZATION] about the Ryan White CARE Act, please contact [ORGANIZATION CONTACT] at [PHONE NUMBER].

For information about the Ryan White ACTION Campaign visit: www.ryanwhiteaction.org

CAMPAIGN CONTACT INFORMATION



**AIDS CARE AND TREATMENT
IN OUR NATION**
ryanwhiteaction.org

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