Your Brighter Future Starts Here

With a new president, renewed civic engagement and talk of meaningful health care reform, we’re ready to once again dream big. We can’t afford not to. Our ability to survive and thrive with HIV/AIDS—and one day bring an end to the crisis—demands renewed political organization from people living with and affected by the virus. That is why POZ and the National Association of People with AIDS have launched The Denver Principles Project. Its goal? A brighter future for all people living with HIV.

May 1, 2009

AIDS activism was launched 25 years ago with the creation of The Denver Principles—a revolutionary manifesto written in 1983 by a small group of people with AIDS at a health conference in Denver. The Denver Principles declared the rights and responsibilities of people with AIDS; it was the foundation of the self-empowerment movement for people with HIV. It informed the treatment activism, public education and awareness efforts that followed. For people with HIV, The Denver Principles became our Declaration of Independence, Bill of Rights, Constitution and Magna Carta rolled into one.

A few weeks later, the same people who wrote The Denver Principles founded the National Association of People with AIDS, or NAPWA. Their vision was that NAPWA would represent the HIV community, providing a powerful, unified voice for us in the media, on Capitol Hill and with the legislative and executive branches of our government.

There is a great need again for those of us living with and affected by HIV/AIDS to come together in a single national organization—one that is bigger and louder than any we have known before. Twenty-eight years into the AIDS epidemic, there is still much to be done to change the way we test for, prevent and treat HIV. And the only way to bring about significant change today is if a modern group of AIDS activists and advocates demands it—just as our brave predecessors did more than a quarter of a century ago. By joining forces in a massive, national membership in NAPWA, we can once again make our voices and needs heard by those who have turned a deaf ear to our cries.

Self-empowerment has always been the key to AIDS activism. That is why, 25 years after The Denver Principles were created, 25 years after NAPWA was founded and 15 years after *POZ* published its first issue, *POZ* and NAPWA have used The Denver Principles as the basis for an exciting new joint initiative called The Denver Principles Project.

The project is intended to raise awareness of The Denver Principles among service providers and their clients and to encourage today's HIV community to recommit to The Denver Principles' tenets of self-empowerment. The project will also enable NAPWA to build the largest possible network of people living with HIV/AIDS and allies ever assembled, giving it the voice and authority it needs to be a powerful advocate. With Congress embarking on national health care reform, it is a critical time to amass and flex our collective power and will. Our voices must be heard by Obama and his administration if we are to secure our health care needs.

We know that the answer to addressing the AIDS epidemic lies, in part, in a large and involved base of supporters—a NAPWA membership whose collective experience will create the knowledge to help guide the development of best practices for preventing and treating HIV. The involvement of people with HIV is essential to help determine the path for better treatments—and a better quality of life, longevity and dignity.

The powerful voices of people living with HIV have been largely absent from key discussions about AIDS; the stigma around the disease has increased; prevention campaigns are few and far between; too many people can't get treatment; and our leadership is fractured. At this unique moment in American political history, we must, as a community, recommit to The Denver Principles. We must again demand a seat at the same table with those making decisions that affect our lives. We must take the power to control our health, and our lives, back into our own hands. We must render health care information truly unbiased and ensure that all people with HIV have the right and ability to access the information tools and care they need to survive. By doing these things, we can lead each other, and the world, to a new place of better health care.

People living with HIV/AIDS have always been and will always be the most authoritative resource on the subject. In the early days of the epidemic, the direct feedback from the HIV community provided substantially more empirical data about how to best fight AIDS than any scientific findings at the time. At *POZ* magazine, we reflected what we heard from the community, writing about, for example, a particular drug's side effect. The story would get the attention, and sometimes ire, of the pharmaceutical companies. By using our editorial coverage as a way to highlight the needs of the community, we helped, in part, ensure that the issue was addressed and that new medicines were eventually developed with fewer side effects. As a result of listening to tens of thousands of people with HIV throughout our 15-year history, *POZ*'s stories of what it's like to live with HIV in America became among the most extensive, comprehensive and accurate depictions of their kind. We saw firsthand how, when people with HIV/AIDS are willing to share information about how they live with the disease, that information can be used to help develop and shape best practices and outcomes for the whole HIV community.

However, over time, the voices and real-life experiences of people with HIV became subsumed by increasing—and welcome—attention to HIV/AIDS by those outside the community. As therapies for HIV improved, the fervor of AIDS activism waned. It wasn't that people with HIV stopped communicating what they needed; it was that our voices increasingly were drowned out.

The onset of new treatment regimens in the mid-1990s altered the landscape around HIV: We weren’t dying from HIV as we were before. There was, understandably, a sense of relief—maybe even a justifiable reason to pause and rest after so many years of fighting for our lives.

As a result, fewer of us came forward to speak about our needs and concerns or participated on the boards of trustees of provider organizations. Over time, the HIV community became less unified, less focused on activism—and less visible. Complacency and AIDS fatigue set in. AIDS was labeled as “manageable” in America, portrayed as “out of control” only in the developing world. AIDS all but fell off the radar of mainstream America by the late ’90s.

Meanwhile, the epidemic raged on and continued to spread across the U.S. population. New infections skyrocketed among African Americans and Latinos, especially among gay men (and other non-gay-identified men who have sex with men) and women. The virus affected more young people, more women and more people older than 50. While progress continued on the treatment front, federal funding flatlined for programs that assist people living with HIV, such as Housing Opportunities for Persons With AIDS (HOPWA), AIDS Drug Assistance Programs (ADAP) and those under the Ryan White CARE Act.

As a result, many Americans with HIV, especially those who were newly diagnosed, could not access and/or afford care, treatment and other needed services. For too many people with HIV, a life of isolation, fear and ill health was the norm. The stigma that has plagued HIV since it was discovered has yet to wane. Though we have come a long way on the treatment front, we have much work yet to do. We must encourage voluntary testing (about 21 percent of the 1.1 million people estimated to be positive in the United States don’t know it). We must get those who need treatment into care. And we must reduce the stigma around the disease so we can more effectively prevent and treat HIV.

But though it may appear that AIDS activism has been significantly diminished, it hasn’t—it has not been effectively organized, galvanized or led. The massive, interactive readerships of *POZ* and AIDSmeds prove that tens of thousands of people living with and affected by HIV are all too willing to participate in an active community of others trying to survive HIV. From the daily e-mails and phone calls we receive and the responses to our online and magazine polls and surveys, to the comments posted on our news stories, editorial coverage, blogs and forums, and to the more than 80,000 active members of POZ Personals and POZ Mentors, we know that there is a lively, engaged group of people ready to fight for their own lives—and those of the people standing beside them.

Because *POZ* and AIDSmeds are educational, informational vehicles, we recognize the need to connect our readership to a national advocacy group empowered to advocate on behalf of its members. By encouraging our readers to become members of NAPWA, and by hosting information about that membership in a secure environment that protects an individual’s privacy, we can daylight the critical, collective information that has been contained for years in the communication within our readership. As a result, the whole community can use and benefit from the real-life wisdom of people living with HIV.

The Denver Principles

The pioneering activists who created The Denver Principles—Richard Berkowitz, Bill Burke, Michael Callen, Bobbi Campbell, Bob Cecchi, Artie Felson, Phil Lanzarratta, Tom Nasrallah, Bobby Reynolds, Mathew Sarner, Gar Traynor, Dan Turner, Elbert (last name unknown) of Kansas City and an individual whose name is unknown, from Denver-—rejected the label of “victim” for people with HIV because it implied passivity and defeat. They noted that we are only occasionally “patients”—stating that our correct moniker be “people with AIDS.” Later, this was amended to “people living with HIV/AIDS” using the acronym PLWHA.

The Denver Principles asserted the right of people with HIV/AIDS to participate in all forums about HIV, on the boards of provider and other organizations and in the development of policies and programs that would directly, and indirectly, affect our lives. The Denver Principles empowered the HIV community to create an extraordinary peer-to-peer service delivery system, implement highly successful community-based HIV prevention strategies and successfully combat stigma. In the years since, UNAIDS, the World Health Organization (WHO) and other international organizations have used The Denver Principles as a model for service delivery to disenfranchised communities

The authors of The Denver Principles wrote:

We condemn attempts to label us as “victims,” a term which implies defeat, and we are only occasionally “patients,” a term which implies passivity, helplessness, and dependence upon the care of others. We are “People With AIDS.”

The Denver Principles made specific recommendations for people living with HIV. Specifically, it suggested that we:

1. Form caucuses to choose our own representatives, to deal with the media, to choose our own agenda and to plan our own strategies.
2. Be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations.
3. Be included in all AIDS forums with equal credibility as other participants, to share our own experiences and knowledge.
4. Substitute low-risk sexual behaviors for those which could endanger themselves or their partners; we feel that people with AIDS have an ethical responsibility to inform their potential partners of their health status.

In addition, it made recommendations for health care professionals, including that they:

1. Come out, especially to their patients who have AIDS.
2. Always clearly identify and discuss the theory they favor as to the cause of AIDS, since this bias affects the treatments and advice they give.
3. Get in touch with their feelings (e.g., fears, anxieties, hopes, etc.) about AIDS and not simply deal with AIDS intellectually.
4. Take a thorough personal inventory and identify and examine their own agendas around AIDS.
5. Treat people with AIDS as a whole people, and address psychological issues as well as biophysical ones.

6. Address the question of sexuality in people with AIDS specifically, sensitively and with information about gay male sexuality in general, and the sexuality of people with AIDS in particular.

The Denver Principles also made some suggestions for the general public. They were to:

1. [Offer] support and membership in our struggle against those who would fire us from our jobs, evict us from our homes, refuse to touch us, or separate us from our loved ones, our community or our peers, since available evidence does not support the view that AIDS can be spread by casual, social contact.
2. Not scapegoat people with AIDS, blame us for the epidemic or generalize about our lifestyles.

And, finally, The Denver Principles laid out the right of people with HIV/AIDS:

1. To live as full and satisfying sexual and emotional lives as anyone else.
2. To receive quality medical treatment and quality social service provision without discrimination of any form, including sexual orientation, gender, diagnosis, economic status or race.
3. To obtain full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment and to make informed decisions about their lives.
4. To ensure privacy and confidentiality of medical records, to receive human respect and the right to choose who their significant others are.
5. To die—and to LIVE—in dignity.

While some of the specific language in The Denver Principles may feel outdated or incomplete today, the essence of self-empowerment, our right to participate in the decision-making processes that affect our lives and our right to enjoy the same full, long life as anyone with any other health condition are as relevant today as when the words were first written.

Why You Should Join The Denver Principles Project

By generating a large and empowered NAPWA membership, The Denver Principles Project will move NAPWA closer to realizing the dream of a representational national voice for people with HIV/AIDS envisioned at NAPWA's founding in 1983. With a strong membership—and all the participation, involvement, scrutiny and accountability that implies, NAPWA will become more closely aligned with the vibrant community it represents, and its voice will be that much more compelling and effective.

A single national organization of people living with HIV/AIDS will result in enormous efficiency in the way aggregate data on our perspectives and experiences are collected and leveraged to improve our lives. It could potentially help many AIDS organizations, large and small, save money by eliminating expensive redundancy. The wisdom contained in our collective knowledge, once all identifying information has been removed, will be made available for Denver Principles Project participants to access and use.

For many years, fearing discrimination, criminalization and stigmatization, the HIV community was understandably afraid to come forward on any level. But thanks to modern technology that can easily protect people’s privacy while giving them a channel through which to safely share their stories, information and feedback, more and more people have been willing to contribute to the collective knowledge of what it’s like to live with HIV.

For 15 years, POZ has listened to your stories, fears, complaints, successes and advice. With each passing month, more and more of you take our polls and surveys, e-mail us, write us letters, comment on our website or blogs, participate in our forums or communicate with each other privately through Mentors or POZ Personals. Your trust in our technological expertise and our respect for your privacy have allowed us to get a great deal more feedback that helps us write about what’s important to you and answer the questions you pose. Imagine if that same wealth of knowledge could be shared, securely and privately, among yourselves and with lots of other groups trying to best answer your needs?

The Denver Principles Project provides a platform for, and invites, every member of the HIV community to share his or her concerns, provide feedback, participate in polls and share his or her thoughts on the community’s priorities. The more of NAPWA’s members who participate, the more representative, and therefore authoritative, our collective knowledge about the needs and preferences of people living with HIV/AIDS in the United States will be. POZ and NAPWA will ensure the confidentiality of all members and will represent your views with full integrity.

Our collective knowledge can allow each individual member to tap into the experiences of tens of thousands—and one day, hundreds of thousands—of other members in order to learn about treatment, lifestyle and social issues. In other words, anyone who joins NAPWA will no longer be alone—members will have the advice of thousands of friends to help them better understand how to live with, treat someone for, develop treatments for and provide support services to those who are HIV positive.

For people working at AIDS service organizations (ASOs) and other community-based groups, our collective knowledge can provide insight into how they can improve the services they provide us. Our collective knowledge will result in the development and distribution of comprehensive online and print resources and educational materials to local organizations participating in The Denver Principles Project.

For national organizations that represent specific communities, access to our collective knowledge will help their leaders better understand our needs; in particular, it will enable them to assess the needs of particular segments of the HIV community in order to better position their organization to attract funding for their specific needs.

For health care professionals and researchers, our collective knowledge will allow them to develop best practices and lobby the government for more funding for tactics that work, based on collective evidence provided by people living with and affected by HIV. Participation in The Denver Principles Project may also allow medical professionals to inform the membership of specific services and clinical trials.

The power of The Denver Principles Project is illustrated in our recent experience with the American Psychological Association (APA). A partnership among POZ, NAPWA, APA and AIDSmeds allowed the APA to survey the POZ audience. In addition, these four groups and other organizations that join The Denver Principles Project may use the data and findings to develop standards of care and best practices for the mental well-being of people living with HIV; those best practices will then be distributed widely. As a result, the mental health concerns of the HIV community will be supported and addressed in a manner that reflects their everyday experiences and personal needs.

A second example of the impact of The Denver Principles Project is how the Association of Nurses in AIDS Care (ANAC) plans to work with POZ, AIDSmeds and NAPWA. The member nurses of ANAC will encourage HIV-positive individuals to support The Denver Principles Project and join NAPWA. When the people they treat become members, the nurses will help them answer surveys about their needs and experiences. The resulting collective data will help ANAC, AIDSmeds and other organizations analyze what type of information is needed for nurses who treat people living with HIV. That insight will be used to create continuing education (CE) programs for ANAC’s nurses. In turn, these CE programs will be offered to all ANAC members and, perhaps more important, to nurses who do not specialize in HIV/AIDS care. The result will greatly improve and expand an understanding of best practices for all nurses as they assist and care for people living with HIV.

Simply put, The Denver Principles Project will gather previously unavailable information and daylight it in a national, secure, accessible, functioning, collective knowledge base that will benefit everyone living with and affected by HIV as well as every organization currently working for the betterment of the whole HIV community.

The Benefits of The Denver Principles Project

All supporters of The Denver Principles Project who are members of the National Association of People with AIDS (NAPWA)—including people living with HIV/AIDS, health care providers and organizations—will be invited to answer surveys and give feedback. This feedback will be assembled in a user-friendly search engine—once all identifying information has been removed. The more people who participate, the more information there will be about what it means to live with HIV/AIDS today. All this valuable information will help greatly improve the vital services provided to people living with HIV/AIDS on both local and national levels.

Our collective knowledge will:

- Provide AIDS service organizations (ASOs) and other providers—including our doctors and nurses—insight into our real-world experiences.
- Inform our regional and national leaders, especially those fighting for our rights and necessary services, about our needs, concerns and fears as well as ways we can contribute to help improve our care.

- Provide the leaders of our community with a better understanding of our specific needs so they can better represent us when lobbying for policies, laws and budgets on Capitol Hill.
- Provide health care professionals and researchers with our real-life experiences so they can develop best practices.
- Help us learn more about important advocacy campaigns and specific services being offered by ASOs and health care providers (including cutting-edge clinical trials), in a single online location—all while maintaining our need for privacyand anonymity.
- Allow us to learn more about other positive people’s treatments, lifestyles and social experiences so we can all enjoy the healthiest, best lives possible!