



PLWHA:

People of Courage



SECTION 4

PLWHA: People of Courage

“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.”

Denver Principles, 1983

People living with HIV/AIDS (PLWHA) throughout the world have demonstrated their courage and tenacity not only in the ways they have learned to live with a potentially life-threatening illness but also in the countless ways they have organized themselves to challenge ignorance, apathy, fear, stigma, and discrimination. Many have taught themselves and their peers the “science” of advocacy and community organizing. Some, as demonstrated in this section, have raised advocacy and organizing to high art. They have used their newfound knowledge and skills to create strong and visible grassroots organizations and national networks that are at the forefront of the global response to the pandemic. In the process, they have gone on to become recognized leaders in their local communities, their home countries, and internationally.

From the **AIDS Coalition to Unleash Power (ACT UP)** in the United States—a pioneer in HIV/AIDS advocacy—to the **Network of African People Living with HIV/AIDS (NAP+)** in Kenya, the **National Guidance and Empowerment Network of People Living with HIV/AIDS (NGEN+)** in Uganda, and the **Thai Network of People Living with HIV/AIDS (TNP+)**, this section highlights the contributions made by groups representing PLWHA. Individually and collectively, the stories underscore the critical importance of the Greater Involvement of People Living with HIV/AIDS (GIPA) principle in all aspects of local, national, and global responses to HIV/AIDS. Despite great strides in achieving GIPA in many parts of the world, much remains to be done. In too many places, PLWHA are left out of the decision-making processes that directly affect their lives. The stories told here should help decision makers and PLWHA better understand the importance of GIPA and ensure that PLWHA are truly and meaningfully involved in all aspects of our collective response to the HIV/AIDS pandemic.

Some of the major advocacy issues and strategies that are evident in the stories of PLWHA associations include access to life-saving treatments, respect for human rights, and an end to the silence and discrimination that too many PLWHA still face. The stories also highlight the creative use of internal and external advocacy strategies, the powerful role of self-help groups and networks in supporting advocacy efforts, and the importance of defining winnable advocacy objectives and goals.

▣ Featured in This Section

Name of Organization	Country	Advocacy Focus/Strategies
4.1 AIDS Coalition to Unleash Power	United States of America	<ul style="list-style-type: none"> ▪ Theatrical and confrontational style of advocacy ▪ Use of media to deliver the message ▪ Internal/external approach
4.2 Network of African People Living with HIV/AIDS	Kenya	<ul style="list-style-type: none"> ▪ Reducing stigma through leadership development ▪ Use of networks
4.3 National Guidance and Empowerment Network of People Living with HIV/AIDS	Uganda	<ul style="list-style-type: none"> ▪ Reducing stigma through personal disclosure ▪ Greater involvement of PLWHA
4.4 Thai Network of People Living with HIV/AIDS	Thailand	<ul style="list-style-type: none"> ▪ Defining the issue ▪ Building alliances



4.1 AIDS Coalition to Unleash Power *New York City, USA*



▣ Background

The AIDS Coalition to Unleash Power (ACT UP) was established in 1987 in New York City. Its mission is to advocate for the rights of PLWHA and for supportive government policies. ACT UP New York was one of the first HIV/AIDS advocacy organizations in the world.



▣ Advocacy Environment

As HIV began to spread primarily in the gay communities of the United States in the late 1970s and early 1980s, the basic facts about the disease were not known. Scientists could not tell us if it was transmissible and, if so, by what means. Moreover, they were unable to advise people how to protect themselves. At the same time, there were no advocates for HIV/AIDS and no HIV/AIDS organizations.

Most Americans were not prepared to stand up and work to combat an unknown illness infecting primarily the gay community. In the early days of the HIV/AIDS epidemic, the challenge was to create an advocacy environment in which people could learn about the disease, advocate for supportive services, and pressure government to not waste time in undertaking research initiatives.

The enormity of the problem and the resistance on the part of the government to respond to it demanded new and unusual measures. What was needed was an organization that was not afraid to do whatever had to be done to break through the denial and silence that characterized the first few years of the HIV/AIDS epidemic in the United States.

This is the environment that gave birth to ACT UP. Initially, ACT UP New York was composed mainly of gay men and women. Over time, it has played a significant role in shaping the direction of HIV/AIDS advocacy around the world.

▣ Advocacy Focus and Strategy

One of the founders of ACT UP New York is Eric Sawyer, who has been an HIV/AIDS activist since the early 1980s, when the first statistics were publicized about a strange illness afflicting gay men. During the mid-1980s, as people who became sick often lost their housing, Sawyer began to develop his skills in creating housing for and advocating for the housing needs of PLWHA. He partnered with a housing developer in Harlem and began talking to the New York City Department of Housing Preservation and Development about establishing a skilled-nursing facility. At this point,

he decided to focus his advocacy on addressing the housing needs of PLWHA and pressuring the U.S. government to invest in more research on HIV/AIDS. In a telephone conversation, Larry Kramer, ACT UP's founding father, shared with Sawyer his idea of starting an advocacy group that would draw attention to the lack of funding, research, and support services for PLWHA. Kramer invited Sawyer to attend a meeting to discuss formation of such a group. At the meeting, Sawyer was asked to help stage the first of many civil disobedience demonstrations against HIV/AIDS. It was 1987, and ACT UP was born.

Theatrics Generates Media Coverage

ACT UP held its first demonstration on March 24, 1987, on New York City's Wall Street, the financial capital of the world. The demonstration highlighted the fact that, even though the government had allocated funds to HIV/AIDS research, a hiring freeze at the National Institutes of Health meant that none of the money was finding its way to research. The demonstration also demanded that pharmaceutical companies invest more in clinical trials to investigate and develop effective drugs against the disease.

ACT UP demonstrations were decidedly theatrical. For the organization's first demonstration, Joseph Papp, one of New York City's leading theater directors, directed his theater staff to develop life-size puppets of the director of the U.S. Food and Drug Administration, which hung in effigy from a lamppost. In time, as the government and public health community considered measures to institute mandatory testing and quarantining of PLWHA, ACT UP seized on another opportunity to develop further and refine its advocacy style. At the Gay Pride Parade, a group of activists created a stage on the back of a flatbed truck. They depicted a scene of a concentration camp, with Sawyer wearing a mask of Ronald Reagan (the U.S. president at the time) and laughing at the people in the "camp" who were covered with Kaposi's sarcoma lesions. A sign read, "Test drugs, not people." As the truck drove the parade route, thousands of onlookers and television viewers became aware of the fight to fund HIV/AIDS research and protect the rights of people against mandatory HIV testing.

"It is time for the legal, medical, public health, and activist communities to join together to pursue a principled fight for the human right to health. Working independently we have won many battles. By uniting, I believe, we can win a universal right to health."

Eric Sawyer
ACT UP Founding Member,
2001

The gay movement brought to HIV/AIDS advocacy the recognition that highly staged, theatrical antics could attract the attention of the media and thus the general public. Drawing from lessons on how the media covered the civil rights, antiwar, and gay rights movements of the 1960s and 1970s, ACT UP believed that the only way to get noticed and reach the public was to stage provocative, media-friendly events. It also learned

that newspapers often misrepresent events, making it especially important for demonstrators to carry a banner bearing the group's message. The banner in the photograph would tell the story even if the news coverage did not.

Timing and Press Releases Boost Coverage

ACT UP's advocacy style also involved the staging of a "scene/demonstration," again in New York City's financial district but in front of the New York City Department of Housing Preservation and Development. To ensure coverage on the 5:00 and 7:00 p.m. news broadcasts, ACT UP scheduled the demonstration for 4:00 p.m. It notified and briefed the media via a press release accompanied by a list of issues and demands. Citing the number of PLWHA probably living in the subway system or city shelters and the potential public health disaster if PLWHA were housed with people with untreated tuberculosis, the press materials demanded government funding of medically appropriate

housing for PLWHA. As for the “scene/demonstration,” ACT UP set up a stage representing a squatter’s camp of homeless PLWHA while 20 activists chained themselves to old, beaten furniture that they scattered in the middle of the street as part of the camp. The demonstration caused major traffic delays. In response, the city brought in garbage trucks as police and fire department personnel tried to cut the activists from the furniture in an attempt to end the demonstration. By this time, however, the demonstration, the issues, and the demands had been broadcast on the news for hours. Shortly after the demonstration, officials in the New York City Department of Housing and the New York State Homeless and Housing Assistance Program announced the formation of a \$50 million capital fund to build medically appropriate housing for PLWHA. The advocacy had been a success. Such theatrical demonstrations came to be a driving force and characteristic style of ACT UP’s advocacy.

A Combination of Internal/External Advocacy Relations and Actions Increases Advocacy Power

Through a network of friends from the gay community—people who worked in government, social services, health care, unions, and as advocates for low-income families—ACT UP brought together activists and professionals to create a critical alliance of those affected, those infected, and professionals working on their behalf. Many gay men and lesbians trained and working as doctors, lawyers, and social workers entered their respective professions with a sense of social responsibility to their community. Clearly, ACT UP harnessed the social responsibility of various professionals to create a wide-ranging network.

Through its alliance of committed individuals, ACT UP developed an “internal/external” strategy, in which lobbying from the inside was supported by advocacy on the outside. Often, the same representatives from the medical professions, social services, and government who met civilly with public officials and decision makers during business hours would exchange their business attire for activist street clothes later in the day and loudly engage in eye-grabbing demonstrations. This dual approach enabled ACT UP to reach people they never would otherwise have been able to reach. Over time, ACT UP developed several important alliances within government and vice versa. Each gained from the relationship, which had started as adversarial but ended up as collaborative.

Along with lobbying public officials from behind the scenes, ACT UP carried out demonstrations that targeted individual people, thereby attempting to hold specific individuals accountable for policy decisions that affected people’s lives. The organization developed ways of publicly shaming people for their indifference or counterproductive policy initiatives. By acquiring inside information, ACT UP learned who was holding up funding or drug approvals and then targeted the appropriate people for “actions.”

In addition, both “insiders” and “outsiders” wrote articles for supportive newspapers and magazines and invited editorials demanding expedited eligibility for social services. The same individuals also called for the creation of a “coordinating” agency for PLWHA that would allow PLWHA to rely on one government agency for all their needs. The insider-outsider alliance led to the creation of what is now called the Division of AIDS Services.

Expertise in Information and Lived Experiences Underpins Advocacy

The ACT UP strategy combined activism with expertise. Accordingly, ACT UP evolved into an organization well versed in the day’s issues and with the personnel and know-how to develop solutions. As decision makers lobbied by ACT UP came to realize that the organization commanded solid expertise and was not just a group of “radical rabble-rousers,” they recognized the wisdom of working with rather than against ACT UP.

Given that ACT UP members were individuals with established relationships with PLWHA and, more often than not, PLWHA themselves, the organization was able to provide practical solutions to government as it was formulating its response to the epidemic. A prime example is the development of the Division of AIDS Services and publicly funded housing programs for PLWHA.

▣ Ongoing Challenges

Attempts to Build Bridges Beyond the Gay Community Falter

ACT UP's brand of HIV/AIDS advocacy caught fire within the U.S. gay communities; in the span of a couple of years, ACT UP chapters took root in many major U.S. cities and later in cities around the world. Yet, one of the challenges faced by ACT UP—despite efforts to expand advocacy to the broader HIV/AIDS-affected communities—was the public's perception of the organization as a “gay group.” Even though ACT UP posted meeting notices throughout the city and not just in gay enclaves, conducted meetings in “non-gay” community venues, and forged alliances with other groups, the organization was unable to develop a broader base. As the 1980s ended and the epidemic moved beyond gay men to other hard-hit communities—African Americans and Latinos, IDUs, the homeless—ACT UP's inability to attract and retain individuals from these communities proved to be a critical blow. It was and still is a lesson on how stigma and homophobia can undercut HIV/AIDS advocacy efforts.

Building Bridges Internationally Remains a Challenge

Another challenge faced by ACT UP has been how to develop relationships with HIV/AIDS activists across the globe. Since the 1987 International AIDS Conference in Washington, DC, ACT UP has been involved in HIV/AIDS work at the international level. While many of the factors that create vulnerability in the United States cut across cultures, what may work in New York may not necessarily work in Bangkok, Nairobi, or Quito. Yet, despite substantial differences, there are many similarities. Discrimination, stigma, denial, sexuality, fear, and hatred are global issues that create a highly complex and challenging advocacy environment.

▣ Questions for Dialogue

1. What led ACT UP to develop its signature media style of provocative demonstrations and street theater? What were its benefits? What were its limitations?
2. How did ACT UP develop and use “expertise”? How did this strategy complement the organization's more public, rabble-rousing style?
3. Consider the policy and political environment in which your organization works. Which aspects of ACT UP's strategy could work? Which ones would not? Why? How could you modify ACT UP's strategy to work in your environment?

This story was based on an interview with Eric Sawyer, a founding member of ACT UP and the Health GAP Coalition. For further information about the organization, please visit www.actupny.org.



4.2 Network of African People Living with HIV/AIDS

Nairobi, Kenya



Background

Founded in 1994, the Network of African People Living with HIV/AIDS (NAP+) is based in Kenya and operates under an active secretariat in Nairobi. Its mission/goal is to create a network that can provide support to PLWHA and PLWHA organizations in Africa. It builds the capacity of empowerment groups and develops the leadership skills of individuals in the network.



Advocacy Environment

In many ways, the HIV/AIDS policy environment in Africa in the early 1990s resembled that in the United States in the 1980s. There was an urgent need to establish networks that would lend support to PLWHA, challenge stigma, and develop channels for advocacy. Yet, the governments of most African countries were neither paying attention to the growing pandemic in their midst nor investing in HIV/AIDS education, prevention, or treatment. In addition, few people who were living with HIV/AIDS were willing to disclose their health status.

Unlike the United States, however, the political environment in many African nations was not only indifferent to HIV/AIDS and any attempts at organized advocacy, but it was also actively hostile to any such efforts. Kenya, under the government of President Moi, who had been in power for over 20 years, had a history of violent government responses to demonstrations, effectively discouraging the development of PLWHA networks that would have organized and advocated on behalf of PLWHA.

Nevertheless, some efforts by PLWHA to organize and advocate on their own behalf did flourish. The story of NAP+ and one of its founders, Michael Angaga, is a case in point.

In 1993, Michael Angaga, currently NAP+'s regional coordinator, received an invitation from the United Nations Development Program (UNDP) to travel to Senegal to review HIV/AIDS research protocols to be implemented in four African countries. As Angaga was exiting from the plane, he met a colleague from Zambia who had disclosed his HIV-positive status. Although Angaga had known of his colleague's status for three years, he had never before met someone who was openly living with HIV/AIDS. The experience left Angaga with an indescribable feeling of hope and possibility. The knowledge that people could "come out" as HIV positive and function from a position of strength and leadership opened a new path for Angaga. It was this recognition and sense of hope that Angaga sought to share and foster in other PLWHA.

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"The knowledge that other people could 'come out' as HIV positive and function from a position of strength and leadership opened a new path."

From statements made
by Michael Angaga
NAP+

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With a new vision, Angaga and a pioneer group of activists set out to create a support network for PLWHA. In inquiring about the major advocacy issues facing HIV-positive people, Angaga and his colleagues saw that, for each individual or group, simply working in isolation was a barrier to action. In isolation, groups cannot gain access to critical information or gauge the relevance of their work. Most important, isolated groups miss out on the positive reinforcement that comes from working together. Positive reinforcement is one of the most important—but often most frequently neglected—strategies in advocacy planning.

With respect to the political context, Angaga also realized that the freedom to disclose one's status without repercussions was a critical precondition to reducing stigma and discrimination. Yet, a sense of isolation is a major barrier to disclosure. To address isolation, bolster individual efforts, and create safety in numbers, NAP+ developed a regional network of PLWHA to help foster an environment conducive to advocacy. NAP+ recognized the importance of making it possible for PLWHA to be open with and learn from each other. It also understood that PLWHA must counsel and support each other in order to lay the foundation for advocacy.

▣ Advocacy Focus and Strategy

Prioritizing Stigma

Building on relationships developed during the research protocol seminar in Zambia, a small secretariat emerged to support the initiation and development of PLWHA empowerment groups in different regions of Africa. The formation of the secretariat was one of the first steps in creating the support needed to carry out advocacy. In 1994, at one of the early AIDS conferences in Mombasa, Kenya, PLWHA came together, explored pathways for action, and formally declared themselves an organization. Other participants at the conference reported experiences similar to Angaga's earlier experience—a sense of elation that HIV-positive people could openly talk to and support each other. As participants at the 1994 conference discussed the formation of an organization, they asked, "What are our priorities?"

Given that stigma was and continues to be one of the greatest obstacles in the fight against HIV/AIDS, Angaga and the core founding group of NAP+ decided that addressing stigma through PLWHA empowerment was a critical first step. Angaga recalls that even the core group of individuals who had gathered in Mombasa to explore these issues had to struggle to be honest and open with each other—despite the knowledge that they were all HIV positive. Unless stigma was addressed, they wondered, how would PLWHA be able to demand equal treatment in employment, health care, and civic leadership. Thus, NAP+'s advocacy goal called for decreased stigma.

Recognizing Empowerment Groups and Safe Environments as Essential to Addressing Internal Stigma, Rights, and Leadership Development

To challenge and overcome stigma, NAP+ decided that its principal advocacy methods would focus on establishing empowerment groups and developing PLWHA leadership through IEC efforts. NAP+ produced quarterly publications, periodic reports, and manuals, such as *Food for the People Living with HIV/AIDS*, to enable local PLWHA empowerment groups to assist their constituents.

One of NAP+'s signature programs is the Ambassadors of Hope program. PLWHA from around Africa travel as "ambassadors" to other countries to talk about and raise awareness about HIV/AIDS

and to lead and create support groups for PLWHA, particularly in countries where such groups do not yet exist. The program takes the first steps to reduce isolation and stigma, especially internalized stigma, and helps to foster an environment that will support the development of an advocacy network.

The Ambassador of Hope program is based on the concept of peer learning. It develops visible leaders who can in turn promote public awareness and education. A striking and innovative feature of the program is that PLWHA, often reluctant to reveal their health status in their home country, can take advantage of the opportunity to travel to other places and provide leadership in open and public ways. This strategy yields several benefits. First, it gives PLWHA the powerful experience of functioning as a leader in a safe environment; second, it provides a role model for PLWHA in the host country and demonstrates that a person can live with HIV/AIDS; and, third, it builds capacity and leadership in both the host country and the ambassador's country of origin. The opportunity to be "freer" in other countries gives people a way to "practice being out" as they develop their leadership skills, which they eventually use back home.

Promoting Visibility and Exchange of Information Through Networks and Conferences

NAP+ continues to expand its reach in Africa, ensuring the wide visibility of PLWHA. It is an important vehicle for the promotion of increased information, education, and networking among PLWHA and the wider HIV/AIDS community. NAP+ sponsored its first conference for PLWHA in Kenya in 2000. A second conference was held in Pretoria, South Africa, in December 2002 with over 150 delegates in attendance.

▣ Questions for Dialogue

1. What were the necessary conditions for PLWHA advocacy that NAP+ identified in the context of Africa in the early 1990s?
2. What are some of the benefits and risks to using personal disclosure as an advocacy strategy? How has NAP+ addressed them?
3. What are some of the important processes and structures that NAP+ has put in place to build and sustain its network?
4. How do stigma and discrimination affect the advocacy efforts of your group? Can you apply any of the lessons learned by NAP+?

This story was based on an interview with Michael Angaga, founder and regional coordinator of NAP+. For further information about the organization, please visit www.naprap.org.



4.3 National Guidance and Empowerment Network of People Living with HIV/AIDS *Kampala, Uganda*



▣ Background

Founded in 1995, the goal of Uganda’s National Guidance and Empowerment Network of People Living with HIV/AIDS (NGEN+) is to empower HIV-positive people to better their lives in powerful ways. It provides counseling and support groups for PLWHA.



▣ Advocacy Environment

In Central and East Africa in the late 1980s, little information was available about HIV/AIDS. At the same time, with virtually no government-sponsored prevention programs in existence on the African continent, tremendous community-wide denial, resistance, and a lack of awareness about HIV/AIDS were the norm. The one exception was Uganda. Under the leadership of President Museveni, Uganda had developed an HIV/AIDS education and awareness approach extending from the highest levels of government to all sectors of society. Uganda demonstrates what is possible when political will at the top provides the basis for action. The formation of NGEN+ with the support of President Museveni is a story of action on the ground meeting political support from “above.”

▣ Advocacy Focus and Strategy

Major Rubaramira Ruranga returned from the war in rural Uganda in 1986. In 1989, after hearing from a friend about HIV and how it is transmitted, the major decided to undergo testing. At the time, the only facility offering HIV testing was a research institute, which performed the testing without providing information or counseling about the disease. When Ruranga’s test results came back positive a month later, the major was more afraid than “when I fought my enemies hand to hand in the bush.” He knew that this enemy had no cure, and he was sure that it meant a death sentence. On hearing that he was HIV positive, the major had only one question: How long would he live?

Years of fear and loneliness in facing his HIV-positive status eventually motivated Ruranga to serve as a spokesperson and advocate for the rights, needs, and concerns of PLWHA in Uganda and worldwide. The experience also led him to become involved in the creation of NGEN+.

Using Disclosure as an Advocacy Strategy to Address Stigma and Discrimination

Throughout his years of working in HIV/AIDS, Ruranga has observed several barriers to the battle against HIV/AIDS. For example, the general public assumed that PLWHA were all sick and/or about to die. That impression stemmed from the fact that many of the public images and stories of PLWHA focused on individuals near death.

Ruranga believed that such a misconception deserved to be challenged. After all, it not only lulled people into believing that they were neither HIV positive nor at risk of the disease if they “looked” healthy, but it also suggested that HIV-positive people were unable to work or otherwise contribute to society. He knew that both impressions were wrong. He also observed that many public reactions to PLWHA were stigmatizing and dehumanizing.

Accordingly, Ruranga decided that he needed to disclose his HIV-positive status; on World AIDS Day in 1993, he revealed his condition at a national event. Coming from an able-bodied military man in uniform, the mere disclosure of the major’s HIV status challenged many misconceptions about HIV/AIDS. Ruranga therefore helped undermine the popular assumption that an HIV-positive individual looked sick or was about to die.

Organizing PLWHA to Become Centrally Involved in Mainstream Institutions

Another issue that concerned Ruranga was the creation of separate HIV/AIDS institutions such as HIV/AIDS-specific health centers, especially as they were isolated from the rest of the health care sector. He felt that disease-specific institutions marginalized and further stigmatized PLWHA. Indeed, the fact that HIV/AIDS care was not integrated into Uganda’s basic medical and public health approach to diseases was leading to the creation of a separate health care infrastructure that the country could not well afford. In opposing a separate system of care, Ruranga stressed that the response to HIV/AIDS should address the cofactors of poverty, gender relations, and violence. He also recognized that HIV-positive people needed to speak for themselves if HIV/AIDS care was to come into the mainstream health care system and address more than just the health aspects of the disease. This recognition led Ruranga to become a strong and ardent supporter for the involvement of PLWHA in all aspects of the response to HIV/AIDS.



“There are still problems of a bureaucracy that does not seem to see where HIV/AIDS is going. We still find problems getting funds to improve the empowerment of PLWHA, and to use their newly gained experience to the maximum.”

Major Rubaramira Ruranga,
Founder of NGEN+



For these reasons and because he wanted to help other men in the military, Ruranga went to Uganda’s president—whom he had met through his military service—to ask for his support to start an organization. With financial support from the president, Ruranga created NGEN+. The group’s vision was to provide education, foster PLWHA self-empowerment, and promote capacity development among PLWHA—with the goal of full involvement in Ugandan society.

To achieve its goals, NGEN+ has helped organize PLWHA into local networks throughout Uganda, thus creating a common voice to advocate and lobby for an improved quality of life. NGEN+ has served as an important vehicle that brings together PLWHA to share experiences and skills, promote “positive living” among themselves, and encourage HIV prevention within their networks and in the community at large. Through empowerment, the PLWHA community is able to work effectively with and mobilize government departments, other NGOs, and the private sector to become more involved in HIV prevention and care and support for PLWHA and their families.

Operating in 18 districts of Uganda, PLWHA networks have provided training on issues of positive living; communication skills, networking, lobbying, and advocacy; and information on HIV transmission, prevention, and management of the disease. NGEN+ has trained members of the Ugandan Armed Forces, the Uganda Police, and the Prison Service. It also lobbied the Ministry of Health for improved access to highly active antiretroviral therapy (HAART).

Mentoring to Build Leadership

Ruranga has made it a point to mentor and develop the capabilities of the PLWHA he has counseled. When people have come to him for help, he has not only sought to help them, but he has also gone on to support them further in developing their own leadership skills. Some of these people have taken their place among the nation's leading advocates for HIV/AIDS. They include the Reverend Canon Gideon Byamugisha, who is one of the few Anglican leaders to disclose his HIV-positive status and to challenge the church on how it deals with HIV/AIDS; Milly Katana, now a representative on the Global Fund to Fight AIDS, Tuberculosis and Malaria; and Beatrice Were, the director of the International Community of Women Living with HIV/AIDS. Ruranga saw that supporting the development of PLWHA leadership was inseparable from the advancement of issues and, therefore, an integral component of HIV/AIDS advocacy.

Spurring Greater Involvement of PLWHA

Ruranga has been active in pushing for PLWHA representation on the Uganda AIDS Council (UAC). Until recently, no PLWHA had a voice on the UAC. In addition, three PLWHA now sit on a partnership forum with civil society. This seemingly small step took years of education and much persuasion until the UAC understood the vital importance of PLWHA participation.

▣ Questions for Dialogue

1. How did Ruranga's personal story and social position (i.e., his class, profession, or family's or friends' status) advance his advocacy? What were the risks or limitations, and how did he minimize them?
2. How did NGEN+ promote the greater involvement of PLWHA in decision-making bodies?
3. Is there a leader or someone of stature in your community who has connections and resources similar to those of Ruranga? How could your organization work or partner with that person?
4. Why is it important to develop the leadership capabilities of PLWHA? What avenues exist for your group to gain and practice leadership skills? Does your group have an opportunity to assist in developing the skills of other groups?

This story was based on an interview with Major Rubaramira Ruranga, founder and coordinator of NGEN+. For further information about the organization, please visit www.enda.sn/africaso.org/ngen.html.



4.4 Thai Network of People Living with HIV/AIDS

Bangkok, Thailand



▣ Background

The Thai Network of People Living with HIV/AIDS (TNP+) was formed in 1997. It provides broad national representation to the issues and concerns of PLWHA and functions as a national support network to Thailand's many small PLWHA groups.



▣ Advocacy Environment

Paisan Tan-Ud, the former chair and one of the founders of TNP+, helped create the organization at a time when most people in Thailand had little information about HIV/AIDS. In addition, as was the case in many developing countries, most doctors were both uneducated about HIV/AIDS and unable to care adequately for persons with the disease. Seeing too many friends living under duress and others dying from AIDS without care and support, Paisan and other PLWHA friends and colleagues decided that the delivery of care and speaking out on HIV/AIDS was not enough. They wanted—and needed—to do more. With this sense of passion, they set out to establish a PLWHA network.

When the organizers of the Asia Pacific Islands AIDS Conference in Chiang Mai, Thailand, in the mid-1990s provided Paisan and his friends with the opportunity to meet at their conference, Paisan realized that they had a unique opportunity to bring people together. They seized the moment to gather PLWHA from all over Thailand in one room—the first time that PLWHA from Thailand had ever assembled—and used the opportunity to push for greater organization and networking among themselves. From this one chance to network and strategize, a national group emerged. A year later, a national network was formed, with Paisan elected as chairperson.

▣ Advocacy Focus and Strategy

TNP+'s mission is to improve the quality of life for PLWHA and all those affected by HIV/AIDS. The organization adopted the following objectives:

- Support and strengthen PLWHA groups;
- Campaign for human rights and social welfare for all PLWHA and those affected with HIV/AIDS; and
- Cooperate with NGOs and government entities to respond to the epidemic.

At the outset, TNP+ identified two critical tasks for itself: (1) challenge and push the government to support PLWHA and their concerns as a way to confront the epidemic; and (2) support the government in its efforts to eliminate barriers created by other international bodies as it tries to support PLWHA.

In the five years since its formation, TNP+ has grown from 100 groups based mostly in northern Thailand to 495 groups located in every region of the country. Financial support from the government has been central to TNP+'s growth. TNP+'s advocacy and pressure from community groups has led to the creation of an HIV/AIDS budget within the national government budget. TNP+ also successfully convinced government officials to allocate a percentage of the HIV/AIDS national budget to PLWHA groups. Financial support from AIDSNet, a large NGO in Chiang Mai, has also been pivotal to TNP+'s growth.

Identifying Allies

From the outset, TNP+ recognized the importance of identifying and forming partnerships with allies. Thus, TNP+ members built and strengthened their relationships with other NGOs that were similarly dedicated to both guaranteeing the right to health care for all and making treatment available to PLWHA. These relationships proved critical. It was through Médecins sans frontières (MSF)/Doctors Without Borders and the AIDS Access Foundation that TNP+ discovered that treatment was available to prevent certain opportunistic infections (OIs). This piece of crucial information led TNP+ to identify and select the 100% Bactrim Campaign as its first advocacy effort.

Choosing a Winnable Issue

During its first year, TNP+ devoted itself to identifying its strengths and advocacy focus along with the strategies the organization would adopt to pursue its goals. It used the opportunity of a subsequent national AIDS conference and the gathering of PLWHA to determine its first advocacy focus and long-term plan. It identified access to preventive treatment for pneumocystis carinii pneumonia (PCP) as its priority banner issue. Commitment to the issue led, in 2000, to the creation of the 100% Bactrim Campaign, which informed the group's later campaigns and activities.

Two factors led TNP+ to decide on the Bactrim campaign as opposed to another campaign. First, given that PCP is a major killer of PLWHA and that Bactrim can prevent and/or treat the disease at a relatively low cost, TNP+ recognized that the government could make the drug available. Second, with only two tablets a day needed, the Bactrim regimen is simple to follow. The careful choice of an advocacy objective—a *winnable issue*—permitted TNP+ to realize a success around which it could structure other campaigns and achieve future successes, particularly the strengthening of the basic infrastructure of the health care system. In addition, the campaign managed to save hundreds, perhaps thousands, of lives. Since its beginnings, the campaign has made it possible for 80 percent of TNP+ members to receive Bactrim prophylaxis.

Laying the Groundwork: Advocacy for Access to ARV

About the same time that TNP+ initiated the Bactrim campaign, members began to hear about antiretroviral (ARV) therapy from friends and researchers who had attended the 1996 International AIDS Conference in Vancouver, Canada. Realizing that the high costs of ARVs would make treatment inaccessible to most PLWHA, TNP+ decided to run a campaign in parallel with the Bactrim campaign aimed at reducing the price of ARVs. In many ways, the Bactrim campaign served as a pilot project for the ARV campaign by strengthening the group's capability and the infrastructure for developing and implementing an ARV treatment program.



"We needed to show the government and the people of Thailand that access to antiretroviral treatment for PLWHA was really a human rights issue and about equity and equal access for all. It was not a money issue."

Paisan Tan-Ud,
TNP+



To reduce the price of ARVs, TNP+ saw that it would have to develop relationships with a new set of partners. In addition to the relationships already formed, TNP+ forged alliances with, among others, university professors, the Consumer Protection Foundation, and the Center for AIDS Rights. Nonetheless, TNP+ had to overcome several obstacles to ensure that ARVs would become more accessible. One of the most daunting obstacles revolved around compulsory licensing and safety monitoring procedures (SMPs) for the production of drugs. Even though Thailand commanded the expertise and ability to produce several of the needed new drugs, international trade law prohibited the country from producing generic drugs. The production issue became one of the major advocacy issues that TNP+ had to address in fulfilling its commitment to make ARV

treatment available to PLWHA. The organization recognized that it had to learn about the issue and teach others about it.

Advancing Advocacy by Raising Visibility of Issues Inside Thailand and Internationally

In 2000, TNP+ held its first PLWHA public demonstration in front of the Ministry of Public Health, with about 200 people in attendance. The demonstration was intended to pressure the government to invoke its legal right to use compulsory licensing to ensure access to affordable medicines, in this case, to produce the pill form of ddi (didanosine), an ARV drug used in combination therapy. Vowing not to leave until the government issued a response, the demonstrators continued their action for three days and two nights. The government finally responded by requesting more time. TNP+ agreed to end the demonstration but put the government on notice and vowed to return if its issues were not addressed. In addition to pushing the government to use its right to produce generic drugs, the demonstration increased awareness of HIV/AIDS, particularly the need for treatment, and raised the profile of TNP+.

To gain national and international support for its issues, TNP+ wrote letters to world leaders, met with representatives from the government Office of Intellectual Property, and lobbied the government's Generic Production Office. In addition, TNP+ met with treatment activists from the Treatment Action Campaign in South Africa and partnered with international organizations, such as MSF, Health GAP, and ACT UP.

Although TNP+'s activities, as of this writing, have not led the Thai government to produce the pill form of ddi, its campaign can boast of several other successes. The pressure that TNP+ brought to bear on the government has brought TNP+ into the public's consciousness, thus raising its stature in the eyes of both the citizenry and the government. TNP+'s work, along with other treatment advocacy organizations' efforts, contributed to the decision on the part of the World Health Organization (WHO) and UNAIDS to review issues related to drug pricing. TNP+ also initiated a review of the SMPs, which led to the government's undertaking a similar review. As a result, the Thai government changed the law governing drug pricing so that certain drug prices would be more equitable and affordable.

Knowing the Issues

Like ACT UP before it, TNP+ recognized the importance of becoming well informed on the issues. As part of its advocacy work, TNP+ leaned about and became an expert on a range of issues previously foreign to the group—government structure and how it operates, national and

international law, drug production, and international relations. Its enhanced knowledge increased TNP+'s credibility with decision makers and won allies both nationally and internationally.

Recognizing Access to Health Care as a Human Rights Issue

Another accomplishment of TNP+ is its ability to integrate HIV/AIDS into the broader issues of health care in Thailand, forming coalitions with groups that address issues related to the elderly, children, and other consumer groups. TNP+'s response to a government health plan provides an example. In 2001, the Thai government initiated a type of universal health care program called the "30 baht plan,"² launching the program with the following slogan: "30 baht cures all diseases." The program covered all diseases except chronic liver failure and HIV/AIDS.

In 2002, a year after the 30 baht plan took effect and just before World AIDS Day, TNP+ decided the time was right to push for access to ARV treatment for PLWHA and that the "30 baht plan" was the ideal vehicle for its advocacy campaign. Accordingly, TNP+ set a goal of securing ARV treatment coverage under the "30 baht plan." TNP+ again organized a demonstration in front of the government house and, within a week, drew 1,000 participants who demanded that the "30 baht plan" cover ARV treatment.

At a press conference, TNP+ deftly made the case that the main barrier to access to treatment for PLWHA was the lack of political will, not the lack of financial resources as the government claimed. It identified government corruption and military spending as problems that, if addressed, would free up resources for HIV/AIDS care. TNP+ pointed out that, while HIV/AIDS was the number one killer in Thailand, the government still maintained that treatment was too expensive and not cost-effective. To refute that argument, TNP+ noted that, even though a study on the cost-effectiveness of treatment for HIV-positive individuals had never been performed, such studies had been performed with other diseases.

As part of an overall plan of action, TNP+ joined with other networks, including a law society, to bring an alternative health care plan before Parliament. The plan was structured around two considerations: (1) the constitutional principle of nondiscrimination in access to health care; and (2) the premise that people pay taxes equally such that everyone deserves equal coverage for health care. In order for the bill to be introduced into Parliament, the partnership needed to collect 50,000 signatures. In a short time, TNP+ succeeded in collecting over 30,000 of the required signatures.

In response, the Minister of Public Health said that the government would eventually cover ARV treatment in the plan but that the "right process" had to be followed. Not content with waiting for the "right process," TNP+ formed a committee to assist the government in developing the capacity to include ARV treatment in the universal health care plan. The committee is composed of 10 people from government and 10 people from NGOs, six of whom are PLWHA, including Paisan.

▣ Challenges as TNP+ Moves Forward

Reaching Rural Constituents

An important issue facing TNP+ is the need to address the gap between what is available to people in urban versus rural areas. In rural areas, many people, including doctors, are not fully educated on basic treatment options for OIs while, in Bangkok, PLWHA are able to access ARVs as well as treatment for OIs, even if only in clinical trials. Not surprisingly, many PLWHA in rural areas are

² Baht is the basic unit of currency in Thailand.

dying more quickly. While the move to challenge the government to produce its own drugs will go a long way toward addressing urban-rural differences, much more needs to be done.

Developing Leadership

TNP+ recognizes that it must address capacity building and leadership development as priority issues. Many TNP+ members are poor and sense that their government has never valued them. Now, as HIV/AIDS advocates, they are challenging and fighting their government. Their success depends on the expenditure of time, energy, and resources to develop their leadership abilities. In addition, many network members do not have access to computers and the Internet. Given that communication is essential in coalition work and that TNP+ members must resolve complex issues, access to information is critical.

Overcoming Stigma and Discrimination

TNP+ is working on the development of a training curriculum and other educational materials on sexuality, drugs, and HIV/AIDS. The effort grows out of the recognition that much of the public—PLWHA included—lacks information or misunderstands these issues and that few programs exist to prevent or treat HIV and other diseases among IDUs. Stigma and discrimination against drug users in Thailand is particularly high. TNP+ hopes to contribute toward a national climate and policy environment centered more on human rights and away from stereotypes and moralistic judgments.

▣ Questions for Dialogue

1. What were some of the criteria that led to TNP+'s focus on the 100% Bactrim Campaign as its first advocacy objective? What were the benefits of choosing the campaign as a first advocacy objective?
2. In the "30 Baht Campaign," what were some of the strategies used by TNP+ to move coverage of ARVs onto the policy agenda?
3. In selecting its issues, designing its campaigns, and reaching its target audiences, TNP+ was keenly aware of the importance of information. What are the risks of moving forward without understanding your information needs? What types of information would help your group and your advocacy efforts? How can you obtain the needed information?

This story was based on an interview with Paisan Tan-Ud, founder and first chairperson of TNP+. Paisan has since founded and now works with the Thai AIDS Treatment Action Group.

Lessons Learned

- **Transforming language and images to represent PLWHA as partners in any response to HIV/AIDS is crucial to advocacy efforts.** The language used to describe PLWHA remains a vital part of the effort to challenge stigma and discrimination. Representations that affirm the role of PLWHA as active partners in all levels of decision making are key to helping policymakers fully enact GIPA.
- **Creating PLWHA networks provides a foundation for advocacy efforts by reducing isolation and promoting sharing of information, peer learning, attainment of rights, and visibility.** In networks, individuals are a part of something that can speak louder than each individual on his or her own. Membership in a network provides people with a social identity and sense of belonging from which they can advocate and live within their community and country. Especially for PLWHA groups engaged in advocacy, a positive group identity as an advocate rather than as a “victim” is essential.
- **Building on their direct relationship with their constituents provides PLWHA organizations with a powerful structure for representation.** PLWHA groups serve as a vital link between PLWHA and their communities and governments. They are often the major vehicle for nurturing and developing individuals committed to serving in local and national planning and policymaking bodies, thus helping ensure achievement of GIPA.
- **Developing capacity and leadership of PLWHA requires commitment and long-term investment.** Viable, effective organizations need capable members and leaders who know how to run advocacy programs, get things done, and represent the issues and their constituency. As government and donors increase the volume of resources dedicated to HIV/AIDS, adequate funding must be made available to PLWHA groups for training and capacity development. PLWHA groups also need to invest in capacity building and leadership development, including developing strategies to address the still present reality that members will be lost to the disease.
- **Recognizing that governments are not monolithic is key to advancing advocacy initiatives.** As part of this, it is essential to recognize that members of government can be allies or opponents depending on the issue. Developing effective strategies for both of these scenarios is necessary for advancing the HIV/AIDS agenda.
- **Ensuring that PLWHA networks fully represent the changing face of the pandemic is an ongoing challenge.** PLWHA organizations must work toward the inclusion and representation of all relevant constituencies. Stigma and discrimination, homophobia, and gender inequities may prevent the participation of the most vulnerable groups. A continuing challenge for PLWHA groups is to continue to build a unified constituency across race, gender, class, and sexual orientation.

