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SPECIAL REPORT: AIDS IN COSTA RICA

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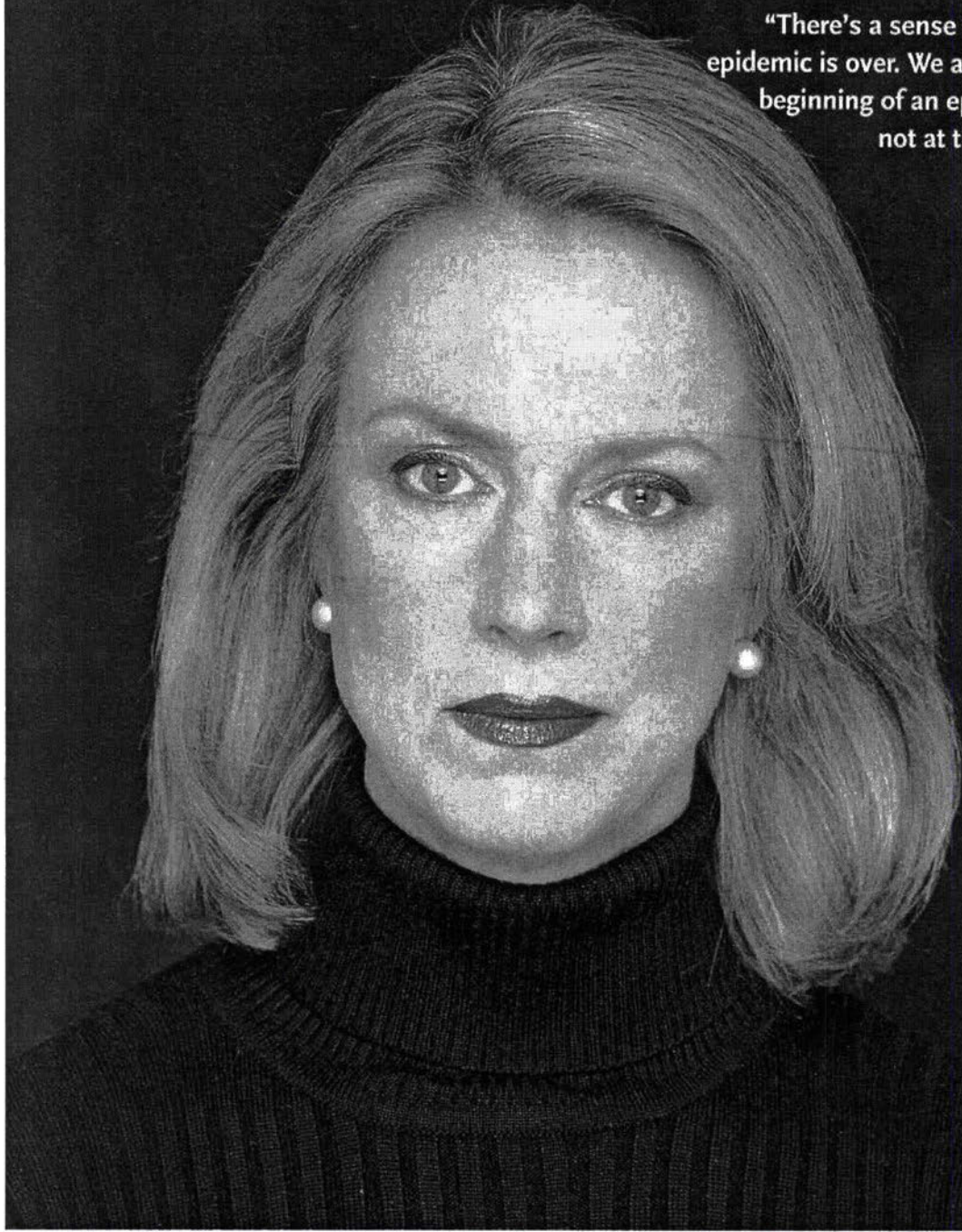
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"There's a sense that this
epidemic is over. We are at the
beginning of an epidemic,
not at the end."



People's Advocate

AIDS CZAR SANDRA THURMAN'S JOB IS TO MAKE HIV A TOP PRIORITY IN THE WHITE HOUSE. A&U'S B. ANDREW PLANT FINDS OUT HOW SHE'S GOING TO DO IT

Interviewer and photographer stand together for several minutes on the doorstep of Sandra Thurman's Atlanta home. As the two decide the Director of the National Office of AIDS Policy must not be home—perhaps detained after one of her several appearances that day—the door suddenly swings open. A well-dressed Thurman is replete with giant curlers in her hair, she holds a makeup brush in hand and quickly effuses, "Come on in...I'll be right back...I'm on the phone and trying to look good for y'all!" as she dashes back up the stairs.

Maybe Thurman's guard is down because I worked with her in a former life, but the more likely answer is that this scenario depicts Thurman's life since President Clinton appointed the statuesque blonde to her current position on April 7, 1997.

Thurman somehow manages to interject a casual sense into the urgency that surrounds both her and the weighty issues she deals with constantly. This unique approach to calm in the face of chaos seems to be Thurman's way of saying, "I'm spinning plates in the air but this is what it takes and I'm okay with it; let's do what we need to do."

Thurman's dash to the door in curlers is also an indication of her schedule. She simultaneously coordinates a dizzying round of appearances, speeches, testimony, trips, policy sessions, briefings, and just about anything else necessary to make positive changes in the lives of people affected by HIV. Too few items on that list bring her back to her native Atlanta where she maintains a home she rarely sees. She is happy this day to be packing in a breakfast speech, a midday interview, an evening appearance with Ted Kennedy,

final planning for an escape to a family wedding in a nearby state, and this interview.

This seemingly flippant trademark approach to urgency has disarmed many a surprised critic and belies what the forty-something Thurman takes as a very personal charge: Fighting AIDS and fighting to make people everywhere understand that there is unfortunately no good news in this pandemic as of yet.

In a speech that morning, Thurman rolled out the all-too-familiar bad news once again. "There's a sense that this epidemic is over," she says, recounting for her interviewer words spoken earlier in the day. "We are at the beginning of an epidemic, not at the end."

Then she cites statistics like this: "Every year 40,000 to 60,000 Americans become infected with HIV." And these are not just sound bites or one-speech weapons. Thurman keeps the statistics coming, knows them backward and forward, wants you to know them and isn't ashamed to share the intense singleness of her purpose.

As she did that morning, she also underscores the global picture of the disease: "AIDS is spreading so quickly in the developing areas of Africa that all of the medical and social gains of the past few decades stand to be wiped out," Thurman says passionately but very evenly. She goes on to say that, in many ways, Africa is a grim picture of our own future with AIDS, if we won't heed the call and "get really serious about this disease."

It's ironic that the same woman who has been accused of being too political is surprisingly and refreshingly frank. For her, there is no political correctness in speaking about AIDS. When it comes to straight talk about HIV, Thurman is unwavering. She

PHOTOGRAPHED BY ROBERT MILAZZO EXCLUSIVELY FOR A&U

*"I hope I have
made some
waves and some
changes that
really matter to
people with this
disease."*

has a bureaucrat's job and an advocate's heart.

"The easy part of HIV is over," she says plainly. "We've been through early stages of learning more about the disease and knowing the basics of what we need to do. We know how to help people live longer and healthier lives. Now, we have to put that collective experience to work."

Thurman backtracks to make sure her point is clear. "We've had our good news," she says. "Now we have to *manage the disease* and that's much more difficult. It's time to help people go back to work, get on with their lives and *just help them live*."

"The real threat is that, on so many fronts, we are afraid to talk about it," Thurman says. "And, as long as we fail to talk about HIV, the people affected by it won't feel the support they need, we won't be doing what we need to do and they'll still be right there under a dark cloud."

That morning, President Clinton's AIDS Czar, as Thurman is known colloquially, was the feature attraction at AID Atlanta's second annual corporate breakfast. AID Atlanta, the oldest and largest AIDS service organization in the South, is where Thurman cut her teeth in the war against HIV, eventually serving as the agency's executive director from 1988 to 1993. Under her leadership, the agency evolved from fourteen employees, a \$250,000 budget, and a budget deficit equal to the budget itself into a multimillion dollar model direct-service provider with ninety employees and 1,000 volunteers. It is still considered one of the

top six such organizations in the country, and former colleagues credit Thurman as being one of the people who set the agency on its imitable course.

Although the purpose of her talk this day was to thank corporate contributors, Thurman delivered her troubling perspective on the epidemic. She wanted major donors and anyone else who would listen to understand that they needed to feel really good about giving to the cause, because they are going to keep giving.

She laughs uneasily and notes that it's important to say "thank you," but that it is also imperative to follow with a plea for more. "I appreciate every dime from every angle, but we need the *will and the cooperation*—on every level—to keep going strong and hard."

So, what does Thurman think it will take to tackle the HIV crisis? She quickly outlines four "hot topics" for "this round of the fight."

"Expanded access to care has to be a top priority," Thurman says, "working through Medicaid. I'm excited about the wonderful new head of Medicaid; he can help us do that."

In September, Timothy Westmoreland, a lawyer and recognized expert on AIDS policy, was named to run Medicaid, the national health insurance program for poor and disabled Americans.

"I think we all know that this disease is increasingly hitting people with limited access to knowledge, people with limited access to good healthcare and

Controversy Comes with the Territory

More than once during her tour of duty as Director of the Office of National AIDS Policy Sandra Thurman has confided to friends that "this could be it," meaning she could be taking a stand that could get her fired. Perhaps the most controversial stand she has taken has been on needle exchange.

"Science is clear on needle exchange," Thurman says. "There is a reduced rate of HIV transmission and exchange programs just don't encourage drug use. In fact, needle exchange programs can be a conduit to get people into care. Care as in drug treatment and care for a disease they may not even know they have."

While there is no federal funding for

needle exchange and it pains Thurman personally that there is no such intervention, she says she understands the need for such a position. "We have to fight the battles we can," she says. "Controversy comes with the territory and this is just one of those hot-button issues."

In the meantime, she says we can support needle exchange programs initiated on other levels, like local efforts. "We need to challenge every day the link between HIV and substance abuse," Thurman says. "Because there are a lot of people—some of them in Congress—who do not understand that vital and terrifying link."

Her support of vaccine development is less controversial, but her commentary on the short-term viability of such at least

makes people nervous.

"I am excited about current vaccine research and trials," Thurman says, "but there is no cure right now. In fact, there is no viable vaccine in sight."

She says our best efforts, which she acknowledges will take more years and dollars than we want to consider, should go toward a safe, effective, and easy-to-administer vaccine.

"This is a tough nut to crack," Thurman says, shaking her head. "We're not nearly there yet, but there are some good efforts, exciting developments, and great people involved."

And the lady knows of what she speaks. Not only is the AIDS Czar intimately involved with vaccine trials and funding for

people who are poor," Thurman says. "That's going to put the impetus on Medicaid in a lot of ways."

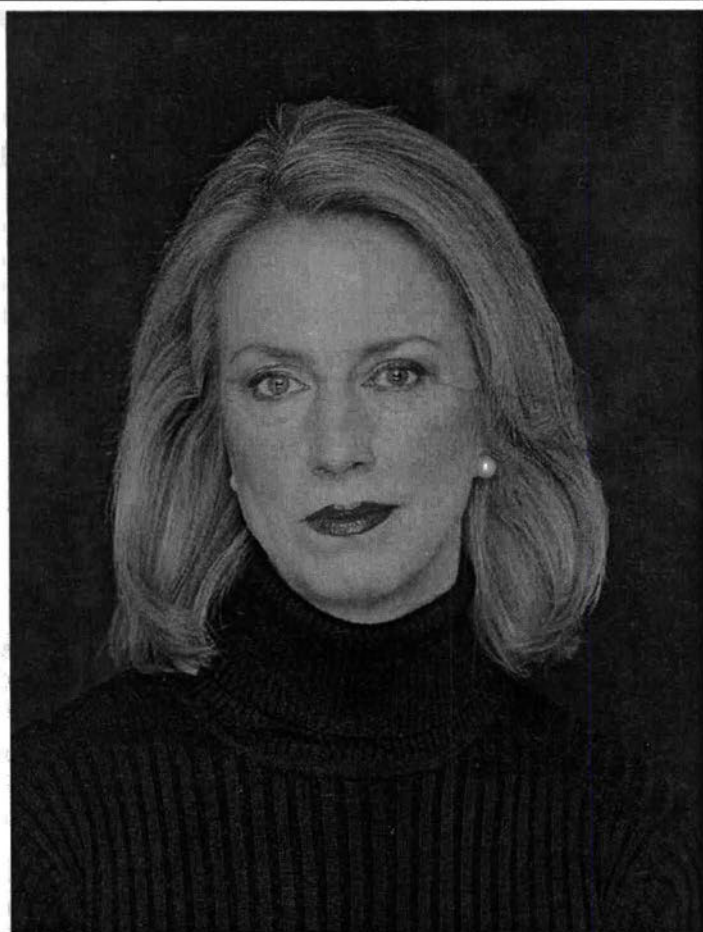
Her second hot topic is reauthorization of the Ryan White CARE Act, which she characterizes as the largest single AIDS package for care and treatment. "That's been a good, amazing thing and we have to keep that and ask for more. See, I'm saying 'thanks,' but asking for more again!"

"We're also going to have to work with the CDC [Centers for Disease Control and Prevention] to take a hard look at revamping prevention efforts," she says. "There is still an extraordinary stigma around AIDS, especially in places it is hitting hardest, and that works against prevention in a big way."

"We invest more than other developed nations combined in this disease and we still can't seem to hit it hard enough from the prevention side. We are going to have to say what we have to say, do what we need to do and change what we need to change. From the academic level to the grass-roots level."

This is the first time I have seen Thurman look so gravely serious and furrow her brow. "We just have to get better at prevention," she says with a slow, studied emphasis. "We don't even have a choice about that one."

Her fourth and final hot topic is the U.S. response to the international AIDS crisis. "In seven years, we didn't see an increase in our country's international AIDS spending, while there was a three hundred percent increase in the epidemic," Thurman says.



"I've gone from being a tough, young, energetic activist to being one tough old broad, but I think that's what it takes."



cy Programs at The Task Force for Child Survival and Development at The Carter Center (as in former President Jimmy Carter), celebrated the bicentennial of the first successful vaccination and included worldwide events.

such, but in one of her past lives she headed up something called The Year of the Vaccine.

That effort, which came during her stint as Director of Advocacy

in so many ways Thurman seems to have "been there, done that," and each piece of her high-profile puzzle seems to make her a better advocate for people affected by AIDS. And apparently that is her goal—to work as hard as she can for as long as she can helping the people who she thinks need to be championed in a serious way.

"I want people with AIDS to feel like I do everything I do for them individually every day," Thurman says, pausing and showing the strain of someone who not only helps set policy regarding the disease, but someone who has lost friends, cleaned bedpans, and held one too many bedside vigils.

She is a tired, but somehow tireless, advocate who needs her cheerleaders now

more than ever. Having served nearly three years, and longer than any of her predecessors, Thurman says she is exhausted yet ready and willing to batten down the hatches. "This battle will get tougher before it gets any easier," she says.

"Even when it is time for me to go, when I leave the White House," Thurman says, obviously not quite ready for that day to come, "I am not quitting work in HIV and AIDS. I will honor my commitment to people with AIDS and those who love them. I've gone from being a tough, young, energetic activist to being one tough old broad, but I think that's what it takes."

"This," she says, referring to the disease, "has just got to be stopped."

—B. Andrew Plant

"My main job is to do battle wherever I need to keep HIV and AIDS on top of the agenda in the West Wing. My job is to advocate AIDS issues. Other people are charged with making sure other things rise to the top. *This* is my one and only agenda item."



obviously frustrated. Exasperated. "We spend \$125 million in U.S. aid on thirty-four million AIDS cases and \$6 billion or \$7 billion in this country on less than one million cases. We have to do more globally; it's just the right thing to do."

Thurman's colleagues say she constantly educates herself about her challenges, worries about the competing demands and carefully outlines priorities. Policy-making and priority setting never seem to be intimidating to this third-generation activist. She insists there is no other way to tackle her job.

"My main job is to do battle wherever I need to keep HIV and AIDS on top of the agenda in the West Wing [of the White House, where the president has his offices]," she says. "It's not that the people in the administration don't care. There are just so many pressing issues. My job is to advocate AIDS issues. Other people are charged with making sure other things rise to the top. This is my one and only agenda item."

Thurman notes that it is tough to keep the perti-

interns. "I run the office much like a nonprofit agency," Thurman says, "with a lot happening after hours. We order take out and work late into the night or go visit people we need to see. People who we need to hear from or people who need to hear from us." Anyone listening would get the idea that Thurman relishes operating in what she calls "campaign mode."

"There's no. 'We're elected, we can slow down now,'" she says, laughing at the thought. "There's no one victory that lets us really relax [other than the obvious eradication of AIDS]. The trick is to maintain the appropriate intensity without tipping over. Long term that can be vitally challenging."

Thurman says she survives—without tipping over—because she has indeed worked in HIV and AIDS, running community based organizations, hotlines, a clinic, and the like. "I've worked in and around HIV/AIDS for seventeen years," she says. "I understand the delivery of health and social services and I understand the health policy process."

She says she appreciates criticism of her and her

THERE'S NOTHING I LIKE BETTER THAN A GOOD FIGHT

nent issues "in front of all who need to hear about them" because there has been incredible progress in health and social issues surrounding AIDS. "It's sometimes hard to infuse folks with urgency when the main challenges are the ones they may never see."

The "folks" the AIDS Czar refers to may at different times include members of Congress, the president's staff, CEOs of major corporations, grass-roots AIDS service agencies, special interest groups, drug companies, journalists, and religious leaders.

"It's incredibly labor intensive, but a lot of what we do is to facilitate communication," she says, "whether it's among members of the Presidential Advisory Council on AIDS and other branches of the government, or between advocacy groups with differing viewpoints."

Thurman looks serious again and obviously wants to make sure she made her point. "AIDS doesn't discriminate. The people it affects continue to be a more diverse group, so a major part of my office's job is to hold the entire, very different AIDS community together on a daily basis."

She is proud to point out that she does this "with help from a lot of talented people." Colleagues say a major strength of President Clinton's number one AIDS policy advisor is that she knows what she can and cannot do and, accordingly, surrounds herself with a diverse array of talented and knowledgeable experts.

The Office of National AIDS Policy staff actually consists of only four full-time staffers and a handful of

actions, "but I hope I have made some waves and some changes that really matter to people with this disease."

"If I had not been a political animal I could not have done this," she says, referring to critics who have called her a politico. "If I didn't understand the politics of the disease as well as the services delivery side of AIDS, the concerns of the people who I represent would not be represented well, or maybe at all."

"I couldn't do this job—I couldn't survive—if I hadn't grown up in politics," she says. "But we have been lucky. We've been able to move some things that really mattered in front of the right people."

That movement and success may be due in part to Thurman's tenacity. "There's nothing I like better than a good fight," she says, laughing and obviously reflecting on political fights. A spark in her eye indicates the necessary battles may even be invigorating. "You can't please everybody every damn minute and nothing we do is ever enough!" she says.

One ally who brought balance to Thurman's passionate campaign for people with AIDS is Richard Socarides, who served as the White House liaison to the gay community from 1996 until October 1999.

"I'll miss him desperately," the AIDS Czar says, "because he was very knowledgeable and patient; he knew what to do when the people we needed action from were not responding. I would be ready to rip their heads off, frustrated with my colleagues, and he

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Sandra Thurman

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was good at tempering my anger. Richard has had the ear and the respect of the people who matter in this process and those are the kinds of allies we need."

Since her Spring 1997 appointment, the woman who is prone to referring to herself in the third person as "Miss Thing" has headed the office the Clinton/Gore Administration created to provide HIV policy leadership at the federal government level. She has fostered allies and sometimes drawn ire, but she also has arguably accomplished far more than any of her predecessors (though she seems too gracious to say so).

"Personally, I am extremely tired," she says, "but I think we have elevated this office to where it needs to be. We are treated as a respected 'policy shop.' That means we're altogether more effective. Quite frankly, we need that role—I don't want to sit around and do PR for the White House, with all due respect."

Thurman obviously does have reverence for the post she holds and the role the current presidential administration lets her office play. "The new and evolving role of this office means it will be harder for the next administration to kick this function off the agenda," she says. "It would be harder to let it backslide. Whoever ends up in [The White House] will be able to proudly support this post as a policy function."

And policy making and policy change have indeed been on Thurman's agenda and, by definition, on the president's. "My God, to be in this office at the advent of new [drug] therapies was such a privilege," she says. "Now we just have to be sure everyone gets those medications, we have to know what the long-term effects are and we have to push for the next round of medical miracles."

Another area in which Thurman wants to see miraculous change is in the global cooperation on AIDS. "I am proud that we are moving the international issues into the forefront," she says, "but we have to keep pushing. There are a lot of similarities between what's happening here and in developing parts of the world. Did you know that less than five percent of thirty-four million people infected with the AIDS

virus have access to treatment?"

She shakes her head, as if she personally has to deliver care to each of those people and doesn't know how she is going to do it.

"It's like the early days of the epidemic was in the United States," Thurman says. "There is no government response in many areas, I've seen families abandon their children and other things that it is just hard to fathom. As human beings we cannot just sit by and watch. We can at least help people die with dignity."

Thurman obviously isn't one to be happy

"If we can break the code of silence around the epidemic, we can set an example that it's okay to talk openly and plainly about AIDS."

with an "at least" response.

"In the early days, practical support was all we could do," she says, "but we can respond [internationally] based on what we know and with compassion—and passion—when we remember what happened to us. That just makes us better as human beings. We have to take what we know and what we've done to the tenth power."

A recurring theme for Thurman is applying lessons learned. She is adamant that even the tiniest parts of good outcomes should be shared everywhere possible. And there are some very positive international examples from which we can learn, she says.

"Uganda has the single best prevention program," Thurman says. "They've been able to reduce the rate of infection by half. The same kind of turnaround can be seen in Thailand. In both instances, active, effective government leadership spearheaded a multi-system approach. Their leaders realized that AIDS is not just a health issue—it's an economic issue, a security issue and an issue important to civil society in general."

"If we cannot slow the infection rate, by

2005 we will see more than 100 million HIV infections worldwide. That pandemic—surpassing an epidemic—is upon us. If we see that day, it will be the worst health crisis since the bubonic plague; it will surpass [the bubonic plague] in terms of global impact," she says.

Thurman shakes her head and looks at her interviewer intently, not sure how to make her point more plainly to *everyone*.

"AIDS needs to be on everybody's radar screen," she says. "Everyone is at risk themselves, their families. Sadly but safely, I can now say that there is not someone who doesn't know someone who is infected with HIV, whether you know you do or not. If we can break the code of silence around the epidemic, we can set an example that it's okay to talk openly and plainly about AIDS. That will get us where we need to be with prevention, with action—with real support from every corner and every sector."

Thurman also thinks there is a lot of information and a lot of those lessons she talks about to be shared once we get people talking. "We know the components of successful programs," she says. "We just have to get everyone to emulate them. Let's shamelessly copy others who have gone before us and done some of the right things."

The woman who will tell you she lives for the day her role will no longer be necessary takes another tired, studied pause. "AIDS isn't a chic disease anymore," Thurman says, again saying what other AIDS champions might be hesitant to say. "It's not as popular to come out in support of this disease like it used to be. I appreciate and admire the people who are part of the battle all the more because of it."

"In general, we lack the will to do what we need to, but that's changeable," she says, sounding hopeful and enthusiastic that we can muster what it takes. And besides, if others can't muster the will to do what needs to be done, Sandra Thurman seems to have enough energy and charisma to lead us all through the war on AIDS. ♦

B. Andrew Plant is an Atlanta-based freelance writer. This is his first feature-length contribution to A&U. He also wrote an HIV exercise video review that appears in the LifeGuide section of this issue.