Actor and Activist

Blair Underwood is one of the most powerful voices in the fight against HIV/AIDS, which can cause serious neurologic complications.

BY SUSANNAH GORA

Over the decades, he has captivated audiences with roles on TV shows such as *L.A. Law*, *The Event*, and *Sex and the City*; in movies like *Deep Impact* and *Madea's Family Reunion*; and in theatrical productions such as the recent Broadway revival of *A Streetcar Named Desire*.

But behind the scenes, Blair Underwood has played a different role: the impassioned activist on a mission to improve people's lives, especially those with human immunodeficiency virus (HIV), which is the cause of acquired immune deficiency syndrome (AIDS). Through his years of tireless work, Underwood has become one of the most powerful voices in the fight against HIV/AIDS. It's essential, Underwood says, to create "conversation and awareness" around this still-stigmatized disease. And one of the least publicized and understood aspects of HIV/AIDS is its effect on the nervous system, known as neuro-AIDS.

Activism has been an important part of Underwood's life for decades. Nearly 25 years ago, Underwood cofounded an organization called Artists for a New South Africa. Originally, the organization—which still exists today—was meant to bring attention to apartheid. But as apartheid was dismantled in the 1990s, explains Underwood, "We shifted our focus to HIV and AIDS." The impact of the disease on families in South Africa—especially children—"was what really shook me to my core," he says. "It got my attention. And the more work we did in South Africa, especially when it came time to raise money, the more I thought, 'What are we doing in our own backyard, in America? How do we bring attention to this plight?'"

In 2003, he served as the spokesperson for YouthAIDS along with actress Ashley Judd. In more recent years, Underwood has been involved with the AIDS Healthcare Foundation (AHF), which opened The AHF Blair Underwood Healthcare Center in Washington, D.C., in 2009. "It's very humbling," he says of the honor. The clinic offers free testing, healthcare, and medication for people with HIV/AIDS.

Washington, D.C., has the highest rate of HIV infection in the United States, at roughly 3 percent—which is higher than the infection rates in many parts of Africa. "It's one of the most frustrating statistics," Underwood says, "because this is not only in our country, but in our nation's capital."

NEURO-AIDS

AIDS begins with HIV infection. People who are infected with the virus may have no symptoms for 10 years or longer, but they can still transmit the infection to others during this symptom-free period. If the infection is not detected and treated, the immune system gradually weakens (called immunodeficiency) and AIDS develops.

Although HIV/AIDS primarily affects the immune system, it also affects the nervous system, which includes the central nervous system or CNS (the brain and spinal cord) and the peripheral nervous system (all the nerves outside the brain and spinal cord). The neurologic effects of HIV/AIDS, collectively known as neuro-AIDS, can be the result of HIV's direct impact on the nervous system (for example, in HIV-associated neurocognitive disorders); of certain cancers and opportunistic infections, which take advantage of a weakened immune system; and of the toxic effects of the drugs used to treat the disease. In the United States, neurologic complications are seen in more than 50 percent of adults with HIV.

According to the National Institute of Neurological Disorders and Stroke (NINDS), HIV damages the brain and spinal cord, which can cause confusion and forgetfulness, behavioral changes, headaches, progressive weakness, and loss of sensation in the arms and legs.

"Within the brain, while the virus doesn't affect neurons directly, it does cause inflammation, which can result in

PHOTOGRAPHS BY ANN JOHANSSON

"I've often said, and I believe this—it's a **biblical tenet**—'To whom much is given, much is expected, and much is required.'"

—BLAIR UNDERWOOD

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the death of neurons and resulting cognitive problems. Within the peripheral nervous system, the virus can cause neuropathy, which is painful and involves loss of sensation," says Kevin Robertson, Ph.D., professor of neurology and director of neuropsychology at the University of North Carolina, Chapel Hill, and chair of the Neurology Collaborative Science Group within the AIDS Clinical Trials Group, which is under the Division of AIDS, National Institutes of Allergy and Infectious Diseases, National Institutes of Health.

"HIV can be identified from the spinal fluid within days of infection," says Christina Marra, M.D., professor of neurology and adjunct professor of medicine at the University of Washington, "and it probably affects the brain within days of infection as well." (Much of Dr. Marra's work has focused on syphilis in people with HIV/AIDS; she is currently studying the connection between HIV infection of the brain and syphilis infection of the brain.) "Anybody can get CNS tuberculosis or CNS syphilis," says Dr. Marra, "but someone with a healthy immune system is less likely than a person whose immune system has been weakened."

Fortunately, says Dr. Robertson, "The antiretroviral treatments that we developed primarily as a result of the AIDS Clinical Trials Group, which is funded by the National Institutes of Health, have led to a dramatic reduction in opportunistic infections. The larger issue now is what happens as a direct result of HIV on the central and peripheral nervous systems." These remain problems, Dr. Marra stresses, not just for people who are being treated "but also for the many people who are not—either because they don't know they are infected, or choose to forego treatment, or don't have access to treatment."

THE SON ALSO RISES
Top to bottom: A young Blair Underwood; with his mother and father, who was a colonel in the U.S. Army; and with his father in Cameroon to trace their family roots.

COURTESY BLAIR UNDERWOOD

SPEAKING OUT

More than 1.1 million people in the United States are HIV-positive; according to the Centers for Disease Control and Prevention, nearly one in five of those people is unaware that they are infected. Knowing one's HIV status is essential. "It's important to know where you stand," explains Underwood, who was featured in AHF's "Man Up" campaign promoting the importance of testing: "You owe it to yourself, to your loved ones, to your lover or lovers, and to your family. It's a matter of being responsible."

Although awareness of the disease has increased dramatically since the epidemic began in the early 1980s, plenty of misinformation still exists. "One of the sad realities is that there are many people who still think that HIV/AIDS is just a gay disease," Underwood says. "That's just not the case…. Anybody can contract it."

A stigma still clings to the disease as well, according to Dr. Robertson. "The stigma has lessened somewhat, but bias still exists against people living with HIV/AIDS."

Remarkable advances have been made in the treatment of the disease over the years. "When I started doing this work, in 1987," says Dr. Robertson, "we were using a single drug—azidothymidine (AZT)—which only made a small dent in disease progression. Since then, we've done a lot to improve individuals' quality of life and longevity."

"We still can't cure anybody—people remain infected after treatment," says Dr. Marra, "but the immunodeficiency can be reversed, which means people can have a normal lifespan." Of course, "the goal is a cure, some way to eliminate the virus," Dr. Robertson says. "To me, a cure means a treatment that kills all the virus in the body," he says.

The advances in treatment have brought about another challenge: Some people don't take the disease seriously enough. Says Underwood: "When you look at Magic Johnson, who has been HIV-positive for more than 20 years and is healthy, it's easy to think, 'Well, he's fine.' I've heard young people say, 'Getting HIV is no big deal. I'll take care of it, take a pill or whatever.' But that's easier said than done: Magic has had access to the best doctors, the best medication, and the best research in the world. He has done tremendous work in bringing that information to the masses, but [living with HIV] is still not a life you want to live, from what I understand, in terms of the medication that you have to take over and over. You want to protect yourself from ever contracting the disease." Indeed, the most effective way of combating HIV infection is not with drugs—which have side effects and are costly—but with prevention.

Some of the robust public support for the cause may have waned over the years as well. In Hollywood, the ubiquitous red ribbon of the early 1990s is all but gone from celebrity lapels and dresses. "It's not surprising, this 'fast-food' mentality" about social issues, says Underwood. "Especially in Hollywood, the question at an awards show becomes, 'What's garnering peo-

MANY ROLES
Left to right: Blair Underwood on *LA Law*; in *Madea's Family Reunion*; and in *A Streetcar Named Desire*.

ple's attention at this moment?'" That's part of why it's so important, he says, "to get the statistics out."

Underwood's family has been personally affected by AIDS: His wife Desiree lost a cousin to the disease. "She contracted HIV through a blood transfusion," Underwood says of his wife's cousin. "It was tragic all around.... Situations like that help me make the decision to be outspoken about this disease."

HIV-ASSOCIATED NEUROCOGNITIVE DISORDER

Neurologists recognize three forms of HIV-associated neurocognitive disorder, which occurs in about 40 percent of people with HIV. The least severe is asymptomatic neurocognitive impairment, in which, according to Dr. Robertson, a patient "may notice he or she is not thinking as well as before, but it doesn't have an impact on daily life—on grocery shopping, functioning at work, or taking care of the household."

In mild neurocognitive disorder, says Dr. Robertson, "there is both neurocognitive impairment as well as a mild functional impairment, where the person does have problems with daily living."

The most severe HIV-associated neurocognitive disorder is HIV-associated dementia, which involves substantial neurocognitive impairment and a severe functional impairment—"the person can no longer really work," says Dr. Robertson.

"People who have HIV-associated dementia and are not on antiretroviral drugs may improve substantially when they start antiretroviral therapy," says Dr. Marra. "But people who are cognitively impaired and are already on antiretrovirals, that's a whole other story. Right now, we really have no other treatment that works," she says.

The question of how to help people with HIV/AIDS who are cognitively impaired in spite of already being on antiretroviral drugs is one of the main issues neuro-AIDS researchers are working on today. (See box, "Neuro-AIDS Research.")

DIAGNOSIS AND TREATMENT

Neuro-AIDS is diagnosed by "neuropsychological testing, which can include memory, language, and problem-solving questions; exclusion of other diseases that could mimic neuro-AIDS, such as other infections of the central nervous system; and ruling out other factors, such as substance abuse or depression," explains Dr. Robertson. Some other diagnostic tools include magnetic resonance imaging (MRI); computed tomography (CT); spinal fluid analysis; and electrodiagnostic studies, which test, for example, the health of muscles and the nerves that control the muscles.

"The primary way we treat neuro-AIDS is by maximizing antiretroviral therapy," says Dr. Robertson. "We have looked at a number of different types of other therapies, such as those used to treat other brain disease," he says. "Unfortunately, we have not found one to be helpful in treating the neurologic complications of HIV/AIDS," he says. In addition to the use of the antiretroviral drugs, says Dr. Robertson, "We can treat other conditions that impact a person's cognitive function, such as depression, anxiety, substance abuse, and hypertension." The pain of neuropathy may be eased by analgesics, antiepileptic drugs, or certain kinds of antidepressants. More serious issues such as opportunistic infections and cancers require specialized treatments that may include antibiotics, antifungal drugs, or chemotherapy.

"However, we try to stay away from certain drugs when treating somebody who has HIV-associated neurocognitive disorder or other central nervous system problems due to HIV/AIDS," explains Dr. Robertson. "For example, efavirenz (Sustiva) is a drug with CNS side effects that have been documented in research studies. All of these drugs may be toxic to the nervous system in varying degrees. But HIV is much more toxic to the nervous system than the drugs used to treat HIV, so it's much more important to use the drugs and have the virus suppressed. I don't want to give anybody the idea that they shouldn't be taking these drugs."

BLAIR AND BARACK

Underwood's most iconic role is that of Jonathan Rollins, the talented young lawyer he portrayed on *L.A. Law* from 1987 to 1994. The show—a huge hit with audiences and critics alike—captured the zeitgeist of its time in a way few other programs did. "It was the *me me me* '80s, the decade of decadence, and to have a show with these witty, brilliant lawyers who were also very flashy with the cars and the suits and everything—it just worked," Underwood says.

He has also had memorable turns on shows including *The New Adventures of Old Christine*, *In Treatment*, and the cult favorite *The Event*—in which he portrayed U.S. President Elias Martinez.

His work on *The Event* wasn't Underwood's first brush with presidential greatness: "Around my second or third year on *L.A. Law*," Underwood recalls, "Harvard Law School invited the producers and me to come visit the law school and speak to the law school students." Underwood's character had been the president of the *Harvard Law Review*. "That's what got Harvard's attention. When I got there, they said, 'You've got to meet the [real] president of the *Harvard Law Review*.' Somebody took me over to meet him. He was very nice, and very warm." That young *Harvard Law Review* editor's name was Barack Obama. It all came full circle when, many years later, Underwood campaigned for then-Senator Obama's presidential run.

LEFT TO RIGHT: NBC/PHOTOFEST; LIONS GATE/PHOTOFEST; KEN HOWARD

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>
> —CHRISTINA MARRA, M.D.

Neuro-AIDS Research

A key study in the field of neuro-AIDS is the Central Nervous System HIV Anti-Retroviral Therapy Effects Research (CHARTER), which aims "to determine how central and peripheral nervous system complications of HIV are affected by different histories and regimens of antiretroviral therapy," according to its website (**charterresource.ucsd.edu**). The study is being conducted at six sites nationwide; Christina Marra, M.D., is one of the principal investigators at the CHARTER site at the University of Washington, Seattle.

The CHARTER study has made several important discoveries so far, explains Kevin Robertson, Ph.D., of the University of North Carolina, Chapel Hill: "One is that, even with treatment, many people have HIV-associated neurocognitive disorder. We need to pay attention to that and try to come up with ways to address it." The study has also underscored, according to Dr. Robertson, "the importance of confounding factors," such as learning disabilities, depression, poor educational background, or substance abuse, on the cognitive function of people with HIV/AIDS. "Third, we have learned how suppressing the virus can improve cognitive function," he says.

A number of other studies are in the works. Dr. Robertson is the chair of the Neurology Collaborative Science Group within the AIDS Clinical Trials Group (ACTG), which is funded by The National Institute of Allergy and Infectious Diseases under the National Institutes of Health. "We are working on several studies right now to develop better ways to treat HIV-associated neurocognitive disorder." They recently finished a large international study with sites in sub-Saharan Africa, India, Thailand, Brazil, and Peru. The study has found that both of the treatment regimens recommended by the World Health Organization for countries with limited resources improved cognitive functioning over time in those HIV-positive individuals who had never been on antiretrovirals.

In addition, Dr. Robertson is heading up a study that examines when the best time to start antiretroviral treatment is in terms of impact on the nervous system.

Finally, Drs. Marra and Robertson and colleagues are developing a study to examine whether adding certain antiviral drugs will help people whose virus is already suppressed but who are still cognitively impaired.

BRAIN DISEASE AFFECTS US ALL

As tireless as Blair Underwood's efforts to raise awareness of AIDS have been, it's not the only neurologic disease that concerns him. The American Brain Foundation, the foundation for the American Academy of Neurology (**CureBrainDisease.org**), estimates that one in six Americans are impacted by brain disease. Underwood lost his maternal grandmother, Betsy Gales, to ALS (amyotrophic lateral sclerosis, or Lou Gehrig's disease).

"She lived with us when I was 15," he remembers, "and she passed away while she lived with us. I watched how her body deteriorated from the disease. And then, years later, my mother was diagnosed with multiple sclerosis (MS)." It was a difficult time for the family.

"One of the most frustrating things about coping with a disease is lack of information," says Underwood. "When my mother started showing signs of MS, we didn't know what was happening to her. The first sign we dealt with was her depression." Later, Underwood recalls, "we learned that whether it was depression, or anxiety, or obsessive-compulsive behavior—all of those were linked to the MS."

Fortunately, Underwood's mother is doing well these days: "She's back to her old self, in terms of her personality." She attended the opening night of *A Streetcar Named Desire*, in New York, to see Underwood starring in his Broadway debut: "She was there, wheelchair and all—and she was just celebrating."

GIVING BACK

Family is of the utmost importance to Underwood: He and his wife Desiree have been married since 1994, and they have three children. Underwood and his wife believe in the idea of giving back, "and we are raising our kids to do just that….I've often said, and I believe this—it's a biblical tenet—'To whom much is given, much is expected, and much is required.'" He feels that "it all stems from understanding that you've been given certain privileges, and one of those privileges is this mercurial thing called celebrity. I often think of celebrity as currency. The question becomes, what do you do with that currency, how do you invest it in the service of others?"

Blair Underwood has done so much in the service of others—particularly in his mission to improve the lives of people with HIV/AIDS. "I've been blessed with a great deal," he says. "And to the extent that you can, it is important not just to give to people, but also to create opportunities for people to help themselves—that's a worthy and noble thing to do." NN

For more information on HIV/AIDS and neuro-AIDS, see RESOURCE CENTRAL on page 37.