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AIDS COMMUNITY RESEARCH INITIATIVE OF AMERICA

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summer 2004

Over 50 with HIV

This issue of *ACRIA Update* discusses a topic of rapidly growing importance to the HIV community and public health system nationwide – the aging of the United States HIV population. ACRIA became interested in pursuing research around the health and supportive needs of people living with HIV/AIDS (PLWAs) who are 50 or older three years ago when this group was identified as an emerging special needs population by our Research Policy Advisory Committee for New York State.

Limited research exists on the HIV-positive over 50 population. It is a fairly recent phenomenon that the aging HIV population is growing. Until the introduction of HAART, most people with the virus lived a relatively short time. Most were never able to celebrate completing their fifth decade.

So many questions from epidemiology, clinical, behavioral and policy standpoints remain unanswered. What difference does being over age 50 make when living with HIV? How many people are infected after age 50? What percentage are infected before 50 but only find out their HIV status after 50? How many are living with HIV past 50? What is the effect of aging and chronic infection with HIV? What are the differences between being HIV-positive over 50 and HIV-negative over 50? Is disease progression different for people with HIV who are over 50 compared to those under 50? Are stigma issues more pronounced for the older HIV-positive population? What about delivery of services to an aging HIV population? For many years, service providers and policy makers have prioritized culturally appropriate services. Is it time for us to stress the need for age-sensitive services? Should AIDS service organization staff be educated about issues such as menopause and hypertension?

We are very fortunate to have Andrew Shippy, Research Associate at ACRIA, present a discussion of many issues facing HIV-positive individuals as they age past 50 years. Coincidentally, this article also highlights significant gaps in knowledge about key issues of importance to older PLWAs. ACRIA's Medical Director, Jerry Ernst, MD, has contributed an article that discusses some of the common diseases and conditions that older PLWAs may face while continuing to manage the complexities of HIV. It, too, touches upon some of the unknowns of HIV in an aging population.

Finally, but perhaps most importantly, we've included a number of personal PLWA perspectives to offer our readers a snapshot of how older individuals are coping with this disease. We asked these men and women to focus on their experience of being over 50 and living with HIV. A particularly noteworthy aspect of the personal perspectives is that some hardly touch on aging issues, while others speak specifically about dealing with them. Perhaps for some people, living with HIV is living with HIV and aging doesn't stand out as a particularly heightened concern. For others, age-related issues such as heart disease, hypertension, osteoporosis, and depression make living with HIV an even greater challenge. Another aspect of the personal perspectives is that, for the first time, we have been asked not to identify some authors by name, possibly indicating that stigma for older PLWAs is a greater concern than for many of their younger counterparts.

Obviously, we've identified many more questions than answers. ACRIA is making a lasting commitment to conduct research on health and supportive needs of PLWAs as they age. It is a part of our work in which we hope to make significant progress in the months and years to come. Hopefully, this issue of *ACRIA Update* will, in some small way, contribute to this purpose.

J Daniel Stricker, Editor in Chief

ACRIA UPDATE

ACRIA STUDIES IN PROGRESS

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ACRIAis an independent, non-profit, community-based AIDS medical research and treatment education organization dedicated to rapidly improving the length and quality of life for people living with HIV/AIDS. Bulk copies of *ACRIAUpdate* are available free to agencies that provide services to people living with HIV/AIDS. For more information, call 212-924-3934 ext. 121.

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Tipranavir Open Label Safety Study

People whose virus has become resistant to approved HIV treatments or who are intolerant to them will take tipranavir with Norvir, along with other anti-HIV drugs, for an open period of time. Participants should be 13 years of age or older, have a viral load above 10,000 and a CD4 count below 100 to enroll in this program.

The Effect of Reyataz on Cholesterol Levels

People who have high cholesterol levels and a viral load below 50 while taking Kaletra will either switch to Reyataz or continue taking Kaletra. The study will last 12 months. Study participants will be reimbursed $25 for each visit.

Reyataz Compared to Kaletra

People whose viral load has risen to over 1,000 while taking an NNRTI as part of their first HAART regimen will switch to either Kaletra, or to Reyataz / Norvir. Everyone will also take Viread and either Videx EC or Zerit XR. The study will last for 22 months. Study participants will be reimbursed $25 for each visit.

Phase I Study of a New GlaxoSmithKline NNRTI

People who have become resistant to an NNRTI and who have a CD4 count over 200 and a viral load over 2000 will take one of four doses of W695634G alone, or take placebo pills, for 7 days. Those who complete the study will be reimbursed $590.

For the above trials, contact Dr. Douglas Mendez at 212-924-3934 ext. 126 or Dr. Yuriy Akulov at 212-924-3934 ext. 124.

Standard of Care Treatment vs. ZEST Once-Daily Regimen

(Closed to Enrollment) This trial is studying whether people on their first HAART regimen who take their drugs two or more times a day can switch to a once-daily regimen. People in the trial either remain on their current medications, or switch to Zerit XR, Epivir and Sustiva (ZEST) taken once daily.

Nurses in AIDS Care Study

ACRIA is collaborating with researchers at Indiana University and with the Association for Nurses in AIDS Care (ANAC) to conduct a study of issues facing nursing professionals who provide care to people living with HIV. The study is being conducted via the Internet and participation is anonymous. Nursing professionals can participate by visiting our website, www.acria.org or webdb.iu.edu/Hperweb/icts/hiv_survey/index.html.

Editor's Notes

• All material in *ACRIA Update* is presented for educational and informational purposes only, and is not intended as medical advice. All decisions regarding one's personal treatment and therapy choices should be made in consultation with a physician.
• *ACRIAUpdate* refers to most drugs by both their commercial and scientific names upon their first reference in an article. Thereafter in the article, they will be identified with the name by which we feel they are most commonly known, either commercial or scientific.

HIV and Aging

by Andrew Shippy

The HIV/AIDS epidemic in the United States is changing. Government agencies, community-based organizations, and even the media are finally aware that HIV doesn't discriminate. Most of us know that women and people of color are at risk for HIV-infection, but older adults are rarely mentioned. Since the beginning of the epidemic, there have been hundreds of books, thousands of newspaper and journal articles, and hundreds of thousands of Internet pages about HIV and AIDS. But a 1998 review in the *Journal of Gerontological Nursing* found only 54 publications, including two books (*AIDS in an Aging Society* [1989] and *HIV/AIDS and the Older Adult* [1996]), that discussed older adults living with HIV. Few of these publications were research studies. Most were review articles, letters to the editor, or case studies that discussed the population of older HIV-positive adults.

Since that 1998 review, several more books have been published and three academic journals have devoted special issues to the topic of HIV and older adults: *Research on Aging* (November 1998), *Journal of AIDS* (June 2003) and *AIDS* (January 2004). Many of the articles in these journals are scientific studies of older adults, but they still consist of case studies, secondary data analyses (using previously collected data to explore a research question that is separate from the original study's goals), or studies that focus on specific groups of older adults (veterans or white gay men, for example).

Background

Although fewer people are being diagnosed with AIDS in the United States and deaths continue to decline, the number of older adults living with HIV/AIDS is larger than ever. Between 1991 and 1996, the number of new AIDS diagnoses rose twice as fast in people over 50 than in those younger than 50. And although the rate slowed from 1996-2000, increases in the older population continued despite great improvements in treatment for HIV that became widely used beginning in 1996-1997. According to the Centers for Disease Control and Prevention (CDC), there are more than 78,000 people age 50 years or older living with AIDS in the United States. The most accurate statistics about these older adults are based on an AIDS diagnosis. Some states don't include HIV statistics in their reporting, and, among those that do, the incidence of HIV in older adults may be under reported. New York State began including HIV statistics in 2000. The most recent statistics show that 25% (about 22,000 people) of all people living with HIV and AIDS in New York City are age 50 or older.

> ***"As people age, various illnesses become more common…and many of these diseases share common symptoms with HIV/AIDS"***

You might wonder why this issue of *ACRIA Update* about "older adults" includes people in their 50s. For practical reasons early in the HIV epidemic, the CDC defined older adults as anyone 50 years or older. People over 50 often have different experiences and complications than younger people. Over the years, people have continued to use this definition of "50" because it has been useful when scientists study age-related differences between younger and older adults. The information about aging with HIV/AIDS can be confusing, especially when studies report conflicting results. There are many questions that need answers. People have begun to realize that older adults face issues about their health and well-being that we had never considered before.

One of the largest problems all older adults face is ageism – discrimination based on negative attitudes toward aging and older people. Until we correct ageist assumptions and attitudes about older adults, there will be limits to what we know about how HIV affects their lives. Many healthcare providers don't consider older adults to be at risk for HIV. Thus, relatively few prevention efforts have focused on older adults. One common, but incorrect, assumption is that older adults aren't sexually active or, if they are, they know how to avoid HIV infection. Older adults and their healthcare providers usually avoid discussions of sexual behaviors and substance use. Older adults may be unwilling to discuss risky behaviors because of the stigma that society attaches to these behaviors. Others may be in monogamous relationships with a partner who engages in risky behavior without their knowledge. This lack of communication is particularly dangerous for older adults since HIV-related illnesses can be difficult to distinguish from typical age-related health problems. As people age, various illnesses become more common. Alzheimer's disease, arthritis, diabetes, breast or prostate cancer, high blood pressure, and vision / hearing loss affect millions of older adults each year, and many of these diseases share common symptoms with HIV/AIDS. The lack of discussion about risk factors and HIV-related symptoms can lead to misdiagnosis or a delayed diagnosis of HIV and a potentially critical lag in beginning anti-HIV treatment.

Although specific treatment guidelines have been created for children, pregnant women, and other patient populations, no specific recommendations exist for older adults. This presents a challenge for physicians, particularly when treating older patients with other age-related illnesses. Beginning anti-HIV treatment requires a complex and intensive regimen of at least three medications, in addition to those that people are already taking for other illnesses. This is often at odds with a common process of slowly adding medications to reduce side effects in older patients. In spite of the need to understand how HAART (Highly Active AntiRetroviral Therapy) will affect the

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HIV and Aging *(continued from previous page)*

growing number of older adults living with HIV, older adults have often been ignored in clinical research. Since older adults are rarely included in controlled medication trials, little is known about age-specific drug actions, possibly dangerous interactions with other medications, or side effects. Older adults often have medical problems (for example, high cholesterol, triglyceride, or blood sugar levels, and/or liver or kidney disease) that disqualify them from participating in many trials. Because the number of older adults with HIV is growing, clinical trials should either be modified to include older adults, or separate studies specifically designed for older adults should be designed.

Quality of Life

HIV-positive people are now living longer and healthier lives than before the widespread use of HAART. In the United States, HIV is becoming more like a chronic illness than the acute crisis it once was. The incidence of opportunistic infections has dropped dramatically, but now other physical and mental illnesses have increased as people live longer. Research efforts during the first two decades of the HIV epidemic mostly focused on keeping people alive and relatively healthy. Given the success of HAART, it is now important for researchers to focus on the quality of life of people living with HIV. There's more to life than undetectable viral load and high CD4 counts. Much of the HIV/AIDS literature is based on a medical, or disease, model of wellness. In other words, if a person doesn't have a particular set of symptoms, then they aren't sick. In some cases, this is the best we can expect from a healthcare system, especially one that is stretched thin by budget cuts, escalating insurance costs, and increasing numbers of patients with multiple and complicated illnesses. However, biological markers don't tell the whole story, particularly in research studies designed to understand the quality of life of older HIV-positive adults.

Depression

In the past several years, more attention has been paid to mental health problems among people with HIV. Many of these studies focus on depression. Depression is a common psychological illness, both in HIV-positive people and older adults, but that doesn't mean people have to live with it. Older HIV-positive adults may be more likely to have more symptoms of depression than younger people with HIV and are significantly more likely to be depressed than people their own age who are HIV-negative. Estimates of depression among people living with HIV range from 15% - 60%, depending on what definition is used.

One of the problems in describing the rate of depression among older adults with HIV is that researchers use a variety of measures to identify depression. Some prefer to use a clinical diagnosis of depression (someone who receives a clinical diagnosis has a set of symptoms that don't go away over time and interfere with their daily life), and their results reflect the lowest percentages of depressed individuals. But, just because a person isn't clinically depressed, it doesn't mean that everything's coming up roses. Many HIV-positive people might not meet the criteria for a clinical diagnosis but have several symptoms of depression that can have a negative impact on their lives. This is one case where the glass being half-full isn't so good!

Researchers who have used other measures of depression find evidence of depression among the majority of the people in their studies. A study of 113 HIV-positive adults (age 47-69), published in the journal *Psychiatric Services* in 2000, found that 25% of the study participants (the majority of whom were white men) scored in the moderate to severe range on the Beck Depression Inventory, a popular depression scale. One problem with this scale is that it was designed to assess the level of depression among people who had already received a diagnosis of "clinical" depression. In 1996, a study published in the *Journal of Psychosomatic Research* of 120 low-income, mostly minority people living with HIV found that 53% of the participants scored higher than the cutoff score on the Center for Epidemiological Studies Depression scale (CES-D), representing significant depression. This measure wasn't designed to diagnose clinical depression. Instead it has been used in hundreds of studies to describe the prevalence of depression symptoms in diverse groups. Some people criticize this measure because some of the items focus on physical symptoms of depression that may be caused by other illnesses or drug side effects instead of depression itself.

Regardless of the measure used, research has shown that older adults with HIV are more likely to experience symptoms of depression than younger HIV-positive people and older HIV-negative adults. Older HIV-positive adults who are depressed are more likely to have financial problems, have fewer people to turn to for support, lack HIV-related information, live alone, have thoughts of suicide, and experience greater levels of stigma related to HIV and aging than older adults who aren't depressed. Depression may interfere with adherence to treatment, health care visits, participation in social activities, and personal relationships.

It can be difficult for doctors to diagnose depression because many of the symptoms are similar to common HIV symptoms, coinfection with hepatitis C, or drug side effects. The most common symptoms of depression include fatigue, poor appetite, weight loss, loss of sex drive, and sleep difficulties. These symptoms sound a lot like a list of medication side effects and are similar to symptoms of HIV itself. Healthcare professionals and older adults with HIV need to pay attention to these symptoms, especially if they occur with other warning signs of depression. These can include emotional symptoms (mood swings, having 'the blues' or feeling so sad that nothing can cheer you up) and mental symptoms (sudden or increased forgetfulness, difficulty keeping track of appointments).

Social Support

Social support is the emotional and practical assistance that family members and friends provide for people living with HIV. Social support is an important resource for everyone, but it becomes particularly important for people as they age.

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Personal Perspective

Why Am I Still Here?

By Paul Muller

Living with AIDS over 50... I had to sit and think on that a while to bring it into focus. I am a "Long-Term Survivor," having been HIV-positive almost half my life. Is HIV/AIDS still a major concern for me now that I'm over 50? One thing I like about writing a "personal perspective" is that you're thinking about only your own situation. So let me begin.

I truly did not expect to be around this long. To give you an idea of how long I've been living with AIDS, I remember my first HIV prescription: 100 mg of AZT, two pills five times a day. How far we've come now that HAART has been instrumental in saving so many lives.

I used to be consumed with the thought of dying from some AIDS-related illness, and having seen so many die over the years affects how I feel now. I knew that I had hepatitis C back when they called it non-A/non-B hepatitis, but I never bothered with it or with treatment when it became available, since I figured I'd die of AIDS first. But as the years piled up, my thoughts started to change: "Hey, maybe I'm not going to die and should start looking forward to some kind of future." So when I turned 50, I went on treatment to try to clear the Hep C virus or at least get some improvement in my liver function.

"Hey, maybe I'm not going to die and should start looking forward to some kind of future"

I continue to take meds for HIV, but other problems manifest themselves as I age – things like hypertension, high cholesterol, and depression (which was the hardest thing to deal with). Conversations with my doctor are now only partly related to HIV – they're more about checking my prostate and getting the colon cancer tests that are recommended for men over 50. Thankfully, on those fronts, so far, so good. But they've become another set of issues to deal with.

I also found that as more time passed I started to lose interest in sex. I had to address whether it was due to the fog of depression or all the medications I was taking. Oh, yeah! It was solved with Viagra, but there I go again – another pill to take. Still, it was one of the best improvements in my quality of life.

Even people that I've known for years are not the same anymore. As time goes by, I've found it has become easier for me to talk about living with the virus, but I've noticed that some of my HIV-negative friends cop an attitude when I try to make sure they have correct information about the virus. On the other hand, some of my positive friends (depending on how they were doing) have been there to support me.

So I decided to reestablish my relationship with my family. We had been estranged for many years due more to my lifestyle than any actual problems with family members. Now I wish I had repaired the relationship earlier. You see, when I reconnected with them, the first thing I brought to their attention was that I was living with AIDS. That prompted three other family members to acknowledge that they were positive but living in denial. I bring this up because I had been volunteering and getting trained in AIDS education since 1988. I was reaching out to help reduce fear and offer a beacon of hope to others living with the virus – everywhere but at home.

As I continue to age, the fire to educate and advocate for others and myself is still there. The only difference is that now I pay more attention to myself, doing whatever I can to manage or lessen the impact of aging. I lost about 30 pounds, which helped lower my blood pressure and means one less medication to take. I exercise at least three days a week and talk more to nutritionists about how to prepare healthy meals. I still volunteer, cooking in drop-in centers for the homeless, and educate. However, it's more about Hep C than HIV/AIDS now.

I am looking forward to having a more productive life, being able to deal with the other concerns that come with aging. Though at times I wonder – why am I still here after 24 years with HIV while so many family members and friends have died?

Sometimes I feel like not waking up the next morning. That's when I reach out to old and new friends so they can remind me that it's only a feeling and shall soon pass. I finally feel comfortable enough to develop a regular relationship and deal with whatever comes along. So here's to 52 years and looking forward to 52 more.

"I am the landlord of my body, and AIDS is an evictable tenant I have learned to coexist with." Michael Jeter R.I.P.

Paul Muller, 52, is a member of ACRIA's Community Advisory Board and a hepatitis C peer educator with the Harm Reduction Coalition.

HIV and Aging *(continued from page 4)*

Older adults living with a chronic illness may be even more acutely aware of the beneficial role that social support can play in adapting to the stress related to their changing life circumstances. Social support boosts psychological well-being and can reduce the number and intensity of physical symptoms for people with HIV.

Unfortunately, several recent studies of older adults living with HIV have found that these individuals may be at risk because they don't get the support they need from family members and friends. Several studies of HIV-positive adults over age 50 have found that many don't receive adequate emotional support or enough help with daily chores. Two of these studies specifically asked participants if they received the emotional and practical support they needed and found that 42% - 57% of these older adults don't receive enough emotional support and 27% - 79% don't receive all the practical assistance with daily chores that they need.

> ***"If we knew what it was we were doing, it would not be called research, would it?" – Albert Einstein***

Older HIV-positive adults who don't receive adequate support may feel more isolated and stigmatized than those who get the support they need. They may also have difficulty managing their illness (adherence to medications and scheduling health care visits, for instance). Anxiety, depression and thoughts of suicide are higher among people who lack social support resources. People must rely on formal healthcare providers to get the support they need to cope with HIV. However, HIV-positive adults who don't receive support from family and friends were less likely to use formal healthcare services. This can be a real problem for the large numbers of HIV-positive seniors who live alone and are isolated from family and friends.

Several barriers may reduce the amount of support that family and friends can provide. One such barrier may be an individual's reluctance to disclose his or her HIV status. On average, older adults are less likely to disclose than younger people. Friends and family may not be aware of the older adult's need for assistance because of the stigma and fear associated with HIV/AIDS. Older adults may be at greater risk for negative attitudes from family and friends if they do disclose. Another barrier is the size of many older HIV-positive adults' informal social networks. These older adults may have smaller social networks because they don't keep in touch with family and friends, while others may be unable to maintain connections because loved ones have moved away, died, or are too ill to keep in touch regularly.

Finding Light in the Tunnel

Much of this discussion has focused on the challenges that older adults with HIV face. Are there *any* benefits to being an older HIV-positive adult? As more older adults become infected with HIV and others who were infected when they were younger live longer, healthcare professionals need to be aware that many older adults living with HIV feel that their life experiences have provided them with skills to cope with their illness better than younger adults.

Researchers from Columbia University School of Public Health found that older adults felt that there were some advantages to being older. The sample included 45 men and 18 women living with HIV, between ages 50 and 68. Many participants felt that older adults had more skills because they had been through other challenges in the past and had learned to recognize their strengths and limits. Older people may also feel less cheated because they have accomplished many of the goals in their lives, compared to people who are diagnosed at a younger age. Another potential benefit is that older adults tend to respect their health and their lives more than younger people. The participants in this study said that they were more likely to stay on top of their medications and listen to their doctors than younger adults. They were also less likely to take risks and were motivated to change behaviors to improve their health. Several people also thought that they were more patient and content with their lives than younger adults. They believed that younger people were more likely to get stressed out by daily hassles or routine problems than they were. In addition, some older individuals are less threatened by illness and disability. They may be better able to accept limitations related to HIV than younger adults.

Study participants discussed the fact that it is common for older adults to slow down because of chronic illnesses, while younger people may try to keep up with their friends and family, so adjusting to HIV may be harder for young people. Older adults may also have fewer family or job responsibilities so they can focus on their personal needs better than younger people. Many of the study participants said that taking care of one's health requires a lot of time and attention. Older adults may simply have more time than young people who have to manage family and job responsibilities. Healthcare providers shouldn't assume that older HIV-positive adults aren't able to cope with and adapt to their illness.

Where do we go next?

Most of the research efforts during the first two decades of the HIV epidemic focused on keeping people alive and relatively healthy. Few people thought there would be a need to worry about growing old with HIV when all most people hoped for was to extend their lives a few months. Given the success of HAART, it is now important for researchers to focus on the quality of life of people living with HIV. Older adults are one of the fastest growing segments of the HIV population, but relatively little research has focused on seniors living with HIV. There's a lot of work ahead as more and more people live longer with HIV and as new infections among older people continue to rise. One of the biggest challenges will be to change attitudes toward older people and their lifestyles. Obviously someone figured out that older people are sexually active – why else would Bob Dole appear in advertisements for Viagra?

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Personal Perspective

Love, Sex, Friends, Medications, Spirituality, Health

By Marilyn McBride

I'm a 50 year old mother who has been HIV-positive for ten years. I'm currently in great health and spirits due to loving friends and a spiritual family that has supported me since day one. At first, I thought that my life was over and I wouldn't be around to see my grandchildren grow up. I really wasn't expecting to live to see 50, so I thank God for my health and recovery from substance abuse.

I was an intravenous drug user and shared needles with my mate. Ten years ago, there may have been messages out there about cleaning needles and not sharing, but those messages never reached me. I used drugs for 28 years but never got sick or have had to take any sort of medications even since finding out I'm HIV-positive. My mate is very ill now, but I remain open-minded and prayerful.

HIV is a part of my daily life, but I don't take medications or have health problems other than the things that go on in a woman's life as she gets older. I'm concerned about health issues such as menopause and weight gain. A good diet and exercise can help keep the immune system healthy and stress-free. I realize no one has a stress-free life, but lowering my stress is a major part of my well-being.

Of course I want things to be better, but I'm very fortunate to have programs and resources available to help me. I have lots of the same concerns that younger women with HIV have: "Will I ever take meds?" "How's the quality of my life?" "Am I just existing or really living?" I sometimes wonder if, at my age, my body will hold up against the medication side effects, which is scary.

While remaining strong and healthy often crosses my mind, I have had great experiences over the past year with people who are positive like me. I'm very active. Using my passion for sharing about HIV with younger and older women is what I want to do with the rest of my life. I attend training seminars. I advocate and share my experience with other women who are positive, women who are going through the same things I am. The women's group called SHE (Strong, Healthy and Empowered) at Test Positive Aware Network (TPAN) in Chicago gives me a chance to vent and talk about things like love, sex, friends, medications, spirituality, and health. I went to our State Capitol and spoke with legislators about housing, drug prices, and resources for people with HIV. I felt very proud to be a part of that.

Life at 50 can be very exciting. Keeping busy and active is the key to my strength, along with my Higher Power and my will to live. I'm very comfortable talking about my illness. I find peace and fulfillment sharing about how I became infected, hoping it will enlighten other women to protect themselves.

My family has struggled with me throughout my illness. They have encouraged me and loved me through the whole ordeal. Family is very important! When friends no longer want to be your friend because you are HIV-positive, it's reassuring to have a support system that's there if you need it.

I want to live to see a cure and be a part of research. I'm in a study now that lasts for a year and looks at the effect of HIV on my kidneys, which is a much bigger problem for African-Americans. The older I get, the more I want to be involved.

I'm not afraid of the world because of what I have. I know who I am and what part I will play in making a difference and trying to help make things better.

"Yet I could have confidence in myself if anyone could. If others have reason for confidence in their own efforts, I have even more!" Philippians 3:4

Marilyn McBride, 50, lives in Chicago and is a member of T.E.A.M. (Treatment Education Advocacy Management), an advocacy and HIV learning training.

Nursing Professionals: We Want You for an Important Web Research Study

ACRIA is collaborating with researchers at Indiana University and with the Association for Nurses in AIDS Care (ANAC) to conduct a study of issues facing nursing professionals who provide care to people living with HIV. This study is being conducted entirely via the Internet and your participation will be completely anonymous.

Completion of the survey will take about 20 minutes.

If you are a nursing professional and want to participate in this study, simply copy the link below into your Internet browser or visit our website www.acria.org for the link.

http://webdb.iu.edu/Hperweb/icts/hiv_survey/index.html

It's Always Something . . .

Medical Complications of Aging with HIV

By Jerome Ernst, MD

Aging affects us all – something that was unfortunately not true for most of the HIV-positive population until recently. But thanks to the wonders of modern science, many HIV-positive Americans are joining the march to older age together with millions of their fellow citizens. In the year 2000, 34 million people in the United States were older than 65 years; by 2025, this number will almost double. And, given effective antiretroviral therapy, HIV-positive people will face the same burdens of diseases of aging as everyone else, with the added problems of HIV/AIDS and the complications of drug-drug interactions – the effects of antiretroviral drugs on drugs used to treat diseases that affect the elderly and vice versa.

In the following paragraphs, a few ailments common in older people will be discussed. They include high blood pressure (hypertension), heart disease, high cholesterol and triglycerides (hyperlipidemia), colorectal cancer, prostate cancer, and osteoporosis (reduction in bone mass). A bit about each condition and how being HIV-positive affects its treatment will be presented. Of particular concern are the interactions between the drugs used to treat these ailments and the antiretrovirals used to treat HIV.

HYPERTENSION (HIGH BLOOD PRESSURE)

Hypertension affects over 60% of people aged sixty or above. It is the most common reason people visit internists and a major risk factor for heart disease – people with high blood pressure are more likely to have heart disease than people with normal blood pressure. Hypertension increases the risk of heart attacks, strokes, heart failure, and early death. When people are successful in lowering their blood pressure to normal, the risk of developing any of these complications is also lowered.

Blood pressure can be lowered in two ways – by living a more healthy life and with drugs. By a healthier life, I mean by losing weight if one is overweight, stopping smoking if one smokes, reducing one's alcohol consumption if one drinks, and moderate exercise. These changes are often enough to treat mild hypertension.

There are a large number of antihypertensive drug options for patients whose blood pressure does not respond to these interventions. Frequently, both a healthier way of life and antihypertensive drugs are needed.

> *"Given effective antiretroviral therapy, HIV-positive people will face the same burdens of diseases of aging as everyone else..."*

Definitions of hypertension continue to change. For me, a person needs to be treated if their blood pressure is above 135/85 mm mercury. The first number is known as the systolic reading. It is the pressure measured in the arteries when the heart is contracting. The diastolic reading, or second number, is the pressure measured in the arteries when the heart is no longer in contraction. The contracting state is called systole and the relaxed state is called diastole. Thus, a blood pressure of 135/85 means that the systolic blood pressure is 135 and the diastolic is 85.

People with high blood pressure usually remain symptom free for years before they develop the complications of stroke, heart attack, heart failure and renal failure. The time course for developing these complications is sped up by abnormal levels of lipids, or fats, in the blood (dyslipidemia), cigarette smoking, diabetes mellitus, obesity, lack of exercise, high salt diet, and situational stress.

Weight Reduction

Clinical trials have shown that the more weight one loses, the greater the fall in blood pressure. Even a weight loss of several pounds may be enough to enable one to do without drugs or to reduce the amount of drugs needed to control blood pressure. If weight gain recurs, hypertension may return.

Exercise

Exercise also helps reduce high blood pressure. After exercise, blood pressure may fall as much as 6 to 7 mm Hg, independent of any weight changes. It has been shown that moderate-intensity exercise is as effective as higher-intensity exercise. A 20 to 30 minute daily walk may be just as effective at lowering one's blood pressure as an intensive workout.

Dietary Adjustment

A recently published clinical trial done in people with mild hypertension showed that increasing fruits and vegetables in one's diet resulted in a moderate reduction of blood pressure. The reduction in blood pressure was almost doubled if one also reduced their dietary fat intake. Some patients who were on a high fruit and vegetable and low fat diet had normal blood pressure after only eight weeks.

Sodium Restriction

Salt restriction has been shown to reduce the need for drug therapy in hypertension. This seems to occur with or without weight reduction. The problem most patients have is maintaining a low salt diet over time. I usually tell my patients to do the best they can but not get crazy over it.

Alcohol Restriction and Smoking Cessation

Reducing alcohol intake to less than two shots of liquor or 8 ounces of wine a day is effective in reducing blood pressure and may even help prevent the disease. And, while stopping smoking may not affect blood pressure levels, it does eliminate an additional risk factor for cardiovascular disease.

Stress Reduction/Relaxation Training

Stress reduction has not been shown conclusively to be effective in reducing blood pressure when used as the main treatment. Also, it has not been proven that a high-stress job by itself is enough to produce high blood pressure. Current thinking is that it is how one copes with stress that may cause hypertension rather than the stress itself.

Drug Therapy

Different physicians use different drugs, usually choosing the one that best suits the particular patient and with which the prescribing physician is most familiar. In general, most physicians start with a diuretic, then add either a beta blocker, ace inhibitor, or calcium channel blocker. Further changes depend on the patient's response.

HIGH CHOLESTEROL AND TRIGLYCERIDES (HYPERLIPIDEMIA)

Based on years of clinical trials and experience, it is becoming clearer and clearer that a large number patients who are at risk for heart disease because of high cholesterol levels in their blood will benefit from having their cholesterol lowered. Of course, this is in addition to losing weight, reducing dietary fat intake, exercising, controlling blood pressure, and stopping smoking. Since most HIV-positive patients over 50 have one or more risk factors for cardiovascular disease, they are prime candidates for changing their habits and lowering their cholesterol.

Lipids are fatty substances in the blood. The one most everyone knows is cholesterol. There is the good cholesterol, called HDL (high density lipoprotein), and the bad cholesterol, called LDL (low density lipoprotein). Total cholesterol is the sum of these two components plus a few others that are present in much smaller amounts. HDL helps remove cholesterol from the body, while LDL helps deposit it in the walls of blood vessels where it can cause heart disease and strokes. A study published in the April 8, 2004 issue of *The New England Journal of Medicine* showed that the lower one's LDL, the lower the risk of further heart disease in people who already have heart disease. Up until this study, health guidelines called for lowering LDL in the blood to 100 mg/dL in people with risk factors for heart disease. Now, most physicians are trying to get their patients to go even lower. One result is that more people will need to be placed on statin drug therapy, which, together with a low fat diet, is the most effective way today to reduce LDL levels (see chart above for cholesterol ranges).

Statins are very effective and powerful cholesterol-lowering drugs, which reduce the formation in the body of cholesterol, among other things. These are generally well tolerated. Usually a single dose, taken at bedtime, is enough to lower one's LDL significantly. The most common side effects are mild gastrointestinal complaints and headaches. Liver enzyme elevations occur in 1% to 2% of users and resolve when the drug is stopped. Sore or weak muscles with elevated blood muscle enzymes occur in less than 0.5% of users. It is estimated that currently only a third of the 40 million or so people who need to be on statins in this country are actually receiving them. Lipitor (atorvastatin), the drug used in the study mentioned above, costs around $1,400 annually for the 80 mg a day dose used in the study.

A variety of statins is currently available. Lipitor (atorvastatin) is probably the most effective LDL cholesterol-lowering statin, achieving reductions of LDL in the blood of up to 55%. Pravachol (pravastatin) and Lescol (fluvastatin) achieve reductions of about 34% at their highest doses, while Mevacor (lovastatin) and Zocor (simvastatin), at their highest doses, produce a further 6% and 12% decrease, respectively. These reductions are much greater

(continued on next page)

National Cholesterol Education Program Guidelines

Total Cholesterol (mg/dL)	(lower is better)
below 200	Optimal
200 to 239	Borderline high
240 or above	High

LDL Cholesterol (mg/dL)	(lower is better)
below 100	Optimal
100 to 129	Near or above optimal
130 to 159	Borderline high
160 to 189	High
190 or over	Very high

HDL Cholesterol (mg/dL)	(higher is better)
below 40	Low
60 or over	High

From the *Third Report of the National Cholesterol Education Program (NCEP) Expert Panel on Evaluation, Detection, Evaluation, and Treatment of High Blood Cholesterol in Adults (Adult Treatment Panel III) Final Report*, September 2002

It's Always Something

(continued from previous page)

than those achieved by a low fat diet alone, which usually produces a reduction ranging from 5-15%.

Patients with HIV

Lipid abnormalities are common in HIV-positive patients, especially in those on protease inhibitors and some other antiretrovirals. The risk of having high cholesterol increases with the length of time on medications. Most commonly, we see an increase in LDL cholesterol and triglycerides (another lipid found in the blood). Only a few controlled studies have been done looking at the relationship of heart disease to high cholesterol in HIV-positive patients. These studies suggest a correlation of having heart disease and increased cholesterol levels. However, there is no evidence to suggest that the strong correlation of increased cholesterol and heart disease in the HIV-negative population is any different in the HIV-positive population. Certainly, all patients with cardiac risk factors such as smoking, hypertension, a family history of heart disease, age, and a sedentary life style need to reduce their cholesterol levels.

Along with antiretroviral agents and statins, HIV-positive patients may be taking a range of drugs to treat or prevent opportunistic infections and conditions associated with HIV and AIDS. Many of these drugs are broken down by the body in ways affected by statins and vice versa. This means that some drugs may increase statins to toxic levels, resulting in increased adverse effects from the statins, particularly the breakdown of muscle tissue. These effects vary by drug, so the choice must be individualized according to what other drugs the patient is taking (See Table). Grapefruit juice can also increase the levels of some statins, so it's probably best to talk to your healthcare provider about this possible interaction if you're taking a statin.

Probably the statin with the fewest interactions with antiretrovirals is Pravachol as it is broken down in the body by a mechanism not affected by protease inhibitors. Given that the strongest statin is Lipitor, many HIV-positive patients will probably prefer using this statin. Therapeutic drug monitoring (checking blood levels of drugs being taken to try to avoid high levels that could be toxic or low levels that might not work) may be useful until the necessary drug interaction studies are done.

	Lipitor (atorvastatin)	**Abitrate, Atromid-S** (clofibrate)	**Lofibra, TriCor** (fenofibrate)	**Lescol** (fluvastatin)	**Lopid** (gemfibrozil)	**Mevacor** (lovastatin)	**Pravachol** (pravastatin)	**Zocor** (simvastatin)
Agenerase (amprenavir)	t	m	m	m	m	6	m	6
Reyataz (atazanavir)	t	?	?	?	?	6	?	6
Lexiva (fosamprenavir)	t	?	?	m	?	6	m	6
Crixivan (indinavir)	t	m	m	m	m	6	m	6
Kaletra (lopinavir)	t	m	m	m	m	6	m	6
Viracept (nelfinavir)	t	m	m	t	m	6	m	6
Norvir (ritonavir)	t	m	m	m	m	6	m	6
Fortovase (saquinavir)	t	m	m	m	m	6	m	6
Rescriptor (delavirdine)	t	m	m	t	m	6	m	6
Sustiva (efavirenz)	t	m	m	m	m	t	m	t
Viramune (nevirapine)	m	m	m	m	m	m	m	m

6 = do not take these drugs together m = no interaction, the drugs may be taken together
t = use together with caution; a dose adjustment may be necessary ? = no data available
Table compiled from data extracted from drug labels, medical publications and HIV-related databases.

COLORECTAL CANCER

Cancer of the colon and rectum rises in prevalence in people over 50, from a rate of 15 cases per 100,000 people who are between 40 and 50 years of age to 400 cases per 100,000 people who are over 80. These rates can be greatly reduced by screening. There is no evidence that the rate of this cancer is higher in HIV-positive patients than in the HIV-negative population, but as the HIV-positive population ages, this may change. I routinely suggest to all of my patients who are over 50 that they have a colonoscopy – a test done under sedation, usually as an outpatient in the hospital. In this test, a flexible tube (colonoscope) with a light at the end is passed under direct vision through the anus and rectum into the colon and the entire length of the colon is visualized. Preparation for this test involves cleaning out one's colon the night before the test by drinking large amounts of a liquid preparation that causes a lot of diarrhea.

In this procedure, the doctor is looking for polyps (small benign growths that have the potential to turn cancerous), which can be removed through the colonoscope with special instruments. Since cancers of the colon can come from these polyps, removing them before this happens prevents the disease. The rate of major complications from this procedure, such as bleeding or

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Personal Perspective

Smell the Coffee!

By Joan Warner

Family, friends, jobs, and drugs were a huge part of my life – and then came my HIV diagnosis in 1990 at the age of 51. I had developed a serious case of diarrhea that had gone on for two and a half months. I visited four different hospitals, but no one could tell me what was wrong. They gave me Kaopectate and Imodium A-D, but nothing worked. In order to endure the train ride to work, I had to pin hand towels around my butt like Pampers. At one point, I decided that, if I didn't eat, the diarrhea would stop. That didn't work – it just kept coming and I lost 40 pounds. I looked and felt like I was going to die. My family was even making preparations for my final day. It took the leadership of my oldest daughter to say, "Mom, why don't you and I both get tested for HIV?"

I had heard whispers that diarrhea could be a symptom of *The Monster* (that's what HIV was called then), and I knew that I had put myself at risk by sharing needles. So I wasn't surprised at my HIV diagnosis – but I still cried like a baby. Why was it that not one of those doctors had asked me if I would be willing to take an HIV test? How easily symptoms that are common to both HIV and aging – fatigue, weight loss, digestive problems, and memory loss – are overlooked. How many people over 50 have fallen through the cracks because of an inaccurate diagnosis and have then had to face advanced disease, opportunistic infections, and death? The medical profession needs to take a fresh look at this population. *Yes!* Some older people are using recreational drugs, by injection and in other ways. *Yes!* Many older people are having unprotected sex. Wake up and smell the coffee!

"How many people over 50 have fallen through the cracks and had to face advanced disease, opportunistic infections and death?

I know that HIV is something that I will have to live with from now on, but as I grow older, I'm also experiencing other health issues. Four months ago, my doctor told me I had high blood pressure. Even though it runs in my family (my mom had it for as long as I can remember), it was a bit overwhelming to try to deal with this new diagnosis. The constant dizziness and throbbing in my head is a lot for me to get used to, and sometimes these symptoms occur even though I have taken my high blood pressure medication.

Another health issue is severe arthritis. Arthur, my pet name for my condition – sometimes I need to put a little humor into all of this for my own survival – was already attacking the larger joints in my body (knees, hip, and elbows) and has now decided to branch out to many of the smaller joints (fingers and toes).

The good thing is that I've always been blessed to have the support of my family and dearest friends. And meeting people in this field of HIV/AIDS has broadened my support network tremendously. In 1996, the parole board mandated me to participate in a program at the Osborne Association, an agency that operates a broad range of services for people involved in the criminal justice system. Little did I know that this part of my journey through life would allow me to meet and interact with so many incredibly wonderful people.

One of my biggest concerns early on in my diagnosis was what was going to happen to my love life. Was the condom going to break or slip? Would I infect someone else? I have been able to work through that, and now I'm just waiting for the right partner. I hope the wait won't be too long.

Although I have spoken at different HIV groups, I would absolutely welcome participating in any non-HIV-related group that targets older folks.

Meanwhile life goes on. My HIV viral load is undetectable, and my body was able to clear the hepatitis C virus on its own, without treatment. I wake up every morning and put my feet on the floor even if I feel a little dizzy and even if my feet are swollen and in pain. I can still see, walk, talk, and think. So with all this being said, I enthusiastically look forward to another milestone in my life (turning 65 this September) and many more wonderful years in my life's journey.

Joan Warner, 64, a member of ACRIA's Community Advisory Board, is a training instructor with the Osborne Association's Peer Education Empowerment Training Program.

It's Always Something *(continued from page 10)*

perforating the colon, is less than 1%, and fewer than one out of a thousand people who have a colonoscopy die from complications.

PROSTATE CANCER

The most common cancer occurring in men is prostate cancer. Indeed, over 80% of men who died for reasons other than prostate cancer and then had autopsies were found to have cancer in their prostate glands that had not spread. This means that most men who have localized prostate cancer will not die *of* it but *with* it. The problem for physicians and patients is identifying which patients will have the aggressive, life threatening cancers that spread out of the prostate. Prostate cancer is more common in older men, with over 80% of the disease being diagnosed in men over 65. Men with a history of prostate cancer in their families and African-American men are at higher risk. Again, whether or not HIV-positive men have a higher rate of this disease will only become apparent as the over 50 HIV-positive population grows.

The most common test for screening for prostate cancer is the rectal exam. Although it is an inexpensive test, it is not all that sensitive. This test picks up only about two thirds of cancers in men who don't have any symptoms.

The PSA (prostate-specific antigen) test is a blood test that was first used to monitor the spread of prostate cancer and is now being used as a screening test. PSA is a protein made by the prostate and is found normally in the blood. The amount of this protein in the blood increases in men who have prostate cancer. The PSA test is more sensitive than the rectal exam but often detects cancers that will not spread. Recent reports show that some men have cancer with low levels of PSA in their blood and other men with high levels do not have cancer. Illnesses such as prostatic inflammation or enlargement can cause elevated levels. Once someone is found to have an elevated PSA level, a needle biopsy of the prostate gland is usually done and, if cancer is found, an operation may be suggested. Whether or not surgery is recommended depends on many factors including the patient's age and the appearance of the cancer cells under the microscope.

Patients should not undergo PSA testing lightly. Because a high PSA level often leads to biopsies and surgery which may not always be necessary and can cause serious complications, it is important that all of this be explained to the patient before they have the test, in fuller detail than space allows here. Sort of like the informed consent one gets before having an HIV test. The complications of surgery include impotence and urinary incontinence – and, although not everyone gets these complications, not everyone with prostate cancer needs surgery. The subject is a complicated one, much more knowledge needs to be gathered, and patients should be well informed before they embark on screening tests for prostate cancer. Some physicians recommend that only high-risk patients undergo such screening.

OSTEOPOROSIS (REDUCTION IN BONE MASS)

The most common bone disease is osteoporosis. In this disease, the structural integrity of the bone is affected, the density of bone is lower, and bones become more fragile – they break more easily. This disease results in over 1.3 million bone fractures a year in the United States; about half are vertebral fractures, 25% occur in the hips and 25% in the wrists. Women over 50 are three times as likely as men to have vertebral or hip fractures and six times as likely to have wrist fractures.

Bone density has been reported to be lower in both HIV-positive men and women when compared to the HIV-negative population. However, the differences shown have not been significant and may not be related to age. It has been shown to occur regardless of whether or not patients are on antiretroviral therapy. A recent study from Spain suggests that the longer one is HIV-positive, the greater the loss of bone density. The significance and validity of this study will become apparent as the HIV population over 50 increases and more studies are done.

What's next?

This article is not meant to be and is by no means exhaustive in its discussion of diseases and conditions that affect the HIV-positive population over 50. What should be clear, however, is that the diseases of aging will become more prevalent in the HIV-positive population as it itself ages. It does not seem that being HIV-positive protects anyone from these illnesses. Whether these diseases will be less or more prevalent and how, if at all, their characteristics will differ from their manifestations in the HIV-negative population remains to be seen. The interactions between drugs used by someone with HIV and those used to treat the diseases of aging need further exploring. And, of course, the added costs of these medications will continue to be a problem for most Americans.

Jerome Ernst, MD is ACRIA's Medical Director and sees both HIV-positive and negative patients in his medical practice.

ACRIA is looking for new COMMUNITY ADVISORY BOARD members.

ACRIA's Community Advisory Board (CAB) fosters partnership between the education staff and the local community impacted by HIV/AIDS. Involving community members in the development of our education programs ensures that community values and cultural differences are respected in ACRIA's educational work.

Community Advisory Board members meet every other month, review program materials and help us identify education needs.

For more information about the CAB or if you are interested in volunteering at ACRIA, please call Mark Milano at (212) 924-3934, ext. 123.

Personal Perspective

Awakening a Giant

By J. Edward Shaw

HIV remains an important part of my life for many reasons, but I'm always wondering how the disease impacts my natural aging process. True, HIV is still one of the top priorities in my life, along with essentials like financial independence. But as I grow older, other issues have equal importance – did I do the best that I could have; did I leave something unfinished; will my legacy allow others to enjoy my labor?

When I was first diagnosed with HIV in 1988, never in my wildest dreams did I expect to be around sixteen years later. Early on, my sources of support were very fragile, due in part to five long years of ignorance and denial. My friends, associates, and even a few relatives were getting sick and dying. Getting services was the last thing on my mind. I was in a deep state of depression. Death seemed only weeks away.

Once I realized that I'd escaped death, I slowly began to access services, starting with medical care after overcoming my mistrust of the establishment. My next serious need was better housing, since I was living in an SRO (single room occupancy) at the time.

"Did I do the best that I could have; did I leave something unfinished; will my legacy allow others to enjoy my labor?"

Since then, my support structure has changed dramatically. I've removed myself from certain people, places, and things and, through a multi-layered approach to AIDS advocacy, a new support structure now has a life of its own. When I awake in the morning, I celebrate life anew.

One challenge that remains constant is medical insurance. Fortunately, I qualify for the AIDS Drug Assistance Program (ADAP), which serves as a backup. To date, I've never had a problem accessing services because of my age.

When time permits, I find myself at a local senior center. I just can't adapt to that social setting, however, due in part to my high energy level. I am otherwise very comfortable with most types of services. After nearly sixteen years of living with this disease, I'm not fighting myself any longer, and my ability to adapt to various kinds of services has increased tremendously.

Over the past several years, I've overcome a multitude of challenges that have propelled me into advocacy and activism, including local and national speaking engagements. Knowledge is truly a powerful tool. Education is a key factor that has led to my participation in various forums. Participation in advocacy, prevention, and treatment/care planning bodies has laid the groundwork for me to present numerous workshops on such topics as "HIV and Older Adults." Some talks have included historical information, such as addressing many people's belief that HIV/AIDS is a form of biological warfare relating to the Tuskegee Syphilis Study. Other talks highlight socioeconomic factors like poverty, unemployment, underemployment, and other forms of institutionalized racism. As Rev. Dr. Martin Luther King, Jr. said, "We are not makers of history, we are made by history."

When I'm asked about my family, fond memories of my childhood come into my mind. But now both my parents have passed on and an older brother and younger sister have become estranged, maintaining only limited contact. Over the years, however, I have enjoyed many, many extended family members who serve as a sort of support structure.

When I'm asked about love, my response is "great." TERRIFIC in capital letters. Let me qualify that statement. I'm not currently involved in a romantic relationship. Not that opportunities haven't presented themselves – quite the contrary.

Living with HIV/AIDS for sixteen years has changed my life dramatically. I'm indebted to my faith, the healthcare professionals, and all of the many wonderful people who have made my life full of growth. Asking questions and attending conferences and educational forums over the years have been the key to all that I've accomplished. "If you don't know, learn. If you do, teach." These words generated hope, opportunity, and a second chance for me. They rekindled a sleeping giant who now focuses on advocacy, activism, and social change.

J. Edward Shaw, 63, is a member of the National Association on HIV Over 50 and is Vice Chair of the New York Association on HIV over Fifty. He is on the Board of Directors of the New York City Legal Action Center and serves as the Community Co-Chair of the New York State HIV Prevention Planning Group. He was appointed to the first New York City Commission on AIDS.

Personal Perspective

I'm Too Old For This

I first encountered the word "homosexual" at age 14 in a 1954 *Time* magazine article and shuddered with the dread suspicion that it described me. The surprise of knowing that I was not "the only one" was completely annihilated by the disgust and derision I realized was implicit in the word. I resolved to do whatever necessary not to be "one of them." This was possible for me because I also found females entrancing and proceeded to date, marry, and father two sons. I did retain an active interest in (and craving for) male anatomy, which was partially satisfied by my work as a general surgeon, which required the regular examination of men's bodies.

I successfully "passed" as straight until I suffered two episodes of bleeding in my brain around age 50. These afflictions resolved quickly, but left me with an exaggerated propensity to honesty. I lost my surgical practice because of a mild case of "frontal lobe syndrome," which led to careless comments made to patients, usually dealing with some sexual topic. I came out to my wife regarding my desire for sex with men. She was surprised and hurt. We continued to live together but had no further sexual contact. I did not feel free to pursue gay contacts because of my guilt over leaving her "high and dry." After several years, she found a lover and I then began visiting the only gay club in our area. We agreed that divorce best suited our situation.

After six months of "What's that troll here for?" looks at the club, a guy approached me for a "yours gets mine" exploratory phallic comparison. The next week, a different young man wanted oral sex. The third week, a beautiful stranger went to a motel with me. I enjoyed the taste of his pre-cum, believing that HIV was not present in this fluid. At my request, he introduced me to anal sex. I put the condom on him. After he ejaculated, I found the condom in the sheets. I do not know when he removed it. He told me that his older brother had died of AIDS, but even with that information, I neglected to ask him his status. The next morning, while I was in the shower, he left without saying goodbye.

Three weeks later, I had a three-day bout of flu-like symptoms. Soon I had a sore, patchy white tongue ... thrush. I took an HIV antibody test at the county health department. It came back negative. The thrush responded to oral Diflucan. Then it recurred. Six months later, I repeated the HIV test. This time it came back positive.

The health worker who informed me of the results was very respectful and supportive, but I couldn't help but wonder what he was thinking about a stupid old fart who contracted a potentially lethal illness by allowing lust and denial to prevail over knowledge and good sense. I left the office shaken and confused. I felt a need to tell someone but was afraid. Eventually, I called my ex-wife and told her, then my sons. They all were alarmed and confused, but comforting.

"I couldn't help but wonder what he was thinking about a stupid old fart who had contracted HIV by allowing lust and denial to prevail over knowledge and good sense."

Fortunately, I had joined a support group for HIV-positive men. I had thought that a gay physician would be a useful resource for such a group. As it turned out, many of them had been living with the virus for years and were better informed about the disease and its treatment than I was. Now I had new friends who didn't bat an eye when I revealed my terrible new secret. I polled them about whom to tell, and the unanimous opinion was to keep it private, to inform only those with a need to know. They also reassured me that sex was possible, but to be safe. My subsequent visits to the gay club felt furtive; I was certain that guys could tell I was a leper. Each day when I awoke, my first thought was a renewed realization of my infection.

I was 62 years old at the time of my HIV diagnosis. I had already lived a lot longer than many and had few regrets, so I was not terribly threatened by the prospect of dying. My professional career was over anyway. My main regret was that I had not experienced my dream – the love of a man. What worse barrier to the realization of that dream could I imagine than HIV infection? My greatest chagrin about my status was that it severely limited my dating prospects!

I took Trizivir, and within five months my viral load was undetectable. As I became inured to my status, I occasionally for-

By Name Withheld, MD, FACS

got to take my twice-daily dose, especially if I was at the gay club until 3 am. Getting a pill box to carry in my pocket helped. The expense of the drugs led me to the Veterans Affairs hospital, where the co-pay is $7 a month for each prescription, roughly 1/100 of the retail cost of Trizivir. I have received my infectious disease outpatient care at the VA from the same specialists I saw as a private patient. (This is the same VA hospital that Dr. Abraham Verghese references in his book about treating early AIDS cases, *My Own Country: A Doctor's Story*.) The providers there are up on the latest information and very encouraging. One even told me, "You will die of something other than AIDS." – music to my ears! I was accustomed to the VA style and culture, since I volunteered there before my HIV diagnosis. It involves a lot of "hurry up and wait"-ing. Many folks not accustomed to the VA find it demeaning, but I am grateful for the good care. I pay roughly $40 - $100 a month for all of my care there above what my private insurance covers. This involves more than my HIV care, since I have other health problems. I was hospitalized there for blood clots in the artery connecting my heart to my lungs and received very good care.

Since my retirement at age 50, I have depended on disability insurance for my income. This will cease at age 65, this year. My retirement savings are not enough to support me, so my main concern at present is how to supplement the social security income I will receive. Although HIV infection causes severe financial difficulties, my VA eligibility covers most of the cost, so being old enough to have been in the military is a big advantage.

The chief challenge in finding "My Man" is my exclusive attraction to men who are 40 years younger than I am. I cherish many friends of my own generation, but have no desire to share orgasms with them. Upon reflection, HIV infection, although I know it remains an ominous threat, has not yet been the calamity for me that it has been for others. My most urgent concerns are financial and romantic. In those areas, my advancing age and previous health problems cause more grief than the HIV.

Name Withheld, 65, is a retired general surgeon living in Tennessee.

HIV and Aging *(continued from page 6)*

Until healthcare providers and AIDS service organizations recognize that older adults are at risk and need appropriate prevention interventions and treatment education programs, older adults will have to squeeze into existing programs to receive the services they need. Research is needed to better understand both the unique challenges that older adults face and the resources that they need. For many older adults, HIV isn't viewed as one of the most stressful parts of their lives, particularly when they have to cope with multiple illnesses and other personal and emotional challenges in their lives. The research that has been conducted to date rarely makes a distinction between long-term survivors who have 'aged into' the over 50 group versus those older adults who are newly infected. It is now important to understand the ways in which HIV affects the aging process for these distinct groups of people, especially when age-related diseases begin to affect these adults.

It's good to know that many HIV-positive older adults are able to find happiness and strength while coping with such a challenging illness. It is important to recognize the accomplishments of the past two decades of HIV care. In a way, we're lucky to be in a position to concern ourselves with how older adults will live with HIV. One of the most important goals for researchers and healthcare providers now should be to maximize the quality of life for older adults living with HIV by changing attitudes, asking questions, and offering supportive services for older adults and the family members and friends who help them.

Andrew Shippy is a Research Associate at ACRIA and a doctoral candidate in Applied Developmental Psychology at Fordham University. His research focuses on well-being and adaptation among vulnerable populations of older adults.

Selected Resources for Older People with HIV

Organizations

National Association on HIV Over Fifty (NAHOF)
www.hivoverfifty.org (617) 233-7107

New York Association on HIV Over Fifty
www.nyahof.org (212) 481-7594

HIV Wisdom for Older Women www.hivwisdom.org (913) 722-3100

Video

AIDS Is Ageless: HIV Over Fifty Produced by AIDS Project Hartford
www.aidsprojecthartford.org (860) 951-4833

Books

AIDS in an Aging Society: What We Need to Know Riley, Ory & Zablotsky 1989
HIV & AIDS and Older People Kaufmann 1995
HIV/AIDS and the Older Adult Nokes 1996
Aging with HIV: Psychological, Social, and Health Issues Nichols, et al. 2002
HIV/AIDS and Older Adults: Challenges for Individuals, Families, and Communities Emlet 2004
Midlife and Older Adults and HIV: Implications for Social Services Research, Practice, and Policy Poindexter & Keigher 2004

Research Journals (issues devoted to HIV and older adults)

Research on Aging, November 1998, Special issue, 20 (6)
Journal of AIDS, June 2003, Volume 33 Supplement 2
AIDS, January 2004, Volume 18 Supplement 1

Some community centers and medical facilities offer groups for older people living with HIV. Call the organizations in your area to see what's available.

Responses to Treatment in Older Adults

by Andrew Shippy

Many of the illnesses common among older people are related to the aging process. As people age, their bodies aren't able to repair and rebuild damaged cells (organs, tissues) as rapidly as those of younger people. So, what does this mean for older adults with a disease like HIV that attacks and destroys the body's defenses (CD4 and CD8 cells)? HIV-positive older adults are more likely to have additional medical problems like diabetes and high blood pressure, and more physical limitations than younger adults with HIV. In the early years of the HIV epidemic (before HAART), older adults' health deteriorated more rapidly than that of younger individuals – regardless of CD4 count. Several studies found that older adults had lower CD4 counts at diagnosis, faster progression to an AIDS diagnosis, more opportunistic infections, and a shorter survival rate than younger adults, regardless of when they were first diagnosed with HIV.

Recent studies have found that a person's age doesn't interfere with the ability of HAART to reduce viral load, but there may be differences between younger and older people in how well the immune system responds to treatment. A study published in *AIDS* (2000) by Roberto Manfredi and Francesco Chiodo in Bologna Italy examined the effect of HAART on older people (defined as 55 or older) compared to younger people (35 or younger). The study included 21 older people (8 women, 13 men) and 84 younger people (29 women, 55 men). The researchers found that both groups responded to HAART, especially in reducing viral load. However, CD4 counts did not increase as much in the older people relative to the younger ones. On average, CD4 counts increased from 212 to 289 for older adults after one year of HAART. During the same period, CD4 counts rose from 231 to 345 for younger people.

Some people may have a very low CD4 count even though they have an undetectable viral load. This may be related to decreased activity in the thymus (the gland where CD4 cells are made). A 2001 study in *AIDS* conducted by researchers in Los Angeles included 80 HIV-positive veterans (13 were over 55 and 67 were younger). Although both groups of veterans showed dramatic reductions in viral load once they were on treatment, the researchers found significant differences in CD4 levels at 3, 9, 15, and 18 months. After one year on HAART, average CD4 counts increased by 50 for the older men, compared to increases of 100 for the younger ones. This difference was not related to baseline HIV viral load, coinfection with hepatitis C, or the race/ethnicity of participants.

Patients who have significantly lower viral loads but who don't have increases in CD4 counts shouldn't necessarily be considered (or consider themselves) treatment failures. These results should affect decisions about when to begin treatment and what preventive medications to use to reduce opportunistic infections as well as when evaluating treatment success for older people. These studies represent an important first step in understanding how their age may affect older adults' response to HIV treatment, but more studies are needed to understand the long-term effects of age on HAART in older adults. This research is becoming more important as the HIV population ages and the number of new infections in older adults remains high.

Personal Perspective

Moving Forward

I must say first and foremost that I'm blessed through all life's experiences.

Living and appreciating life – I wonder if I would have really enjoyed life the way I do now, being an HIV-positive woman at the age of 54. I did not ever think that would be me – well, it is. It's been 10 years now, and life goes on.

I live a good healthy, positive life and plan to see 55. And more smiles.

I have my up and downs, like not wanting to take my medications because my stomach gets bigger or I'm going out and don't want to have to keep running to the bathroom because of side effects. I just need a break from the everyday reminders that I'm HIV-positive. I take a day at a time and appreciate life a day at a time, not thinking about my medical condition 24/7. It works for me.

I said a long time ago that my higher power didn't bring me this far to let me go now.

I have the strong support of family and friends who continue to be there for me. I really couldn't do it alone. On the days that I don't want to take medication or even go out, my phone will ring. It's one of my peers reaching out to me for support.

Loving life and wanting to live.

That wasn't the case when I first found out. I thought I would die, like yesterday. Then I met people who were positive for a longer time and were living with it. I remember a friend telling me where to go for education on HIV, support, guidance, empowerment, so that I would be able to live longer and would want to live as long as God allowed. I've connected myself to a whole lot of agencies for HIV-positive people. I keep up on new information concerning HIV and the new medications. I like to read about long-term survivors. Living with this virus would be harder for me if I didn't have the resources that I do.

A lot of us who are HIV-positive say that the virus is living with me, I'm not living with it. I'm

By Yolanda Birthwright

glad to say I've been undetectable for a very long time. Can't stop now. Enjoying life too much.

I find it is very important to connect with people who are living their lives and not feeling sorry for themselves. We laugh, we go out, we play, we cry, we have our fears, we wonder. We still go on because we want to live. Some have moved away, some got married, some went back to school. Some are gone now. They will always be in my heart. A lot of times something they said will come to mind, like: "Take your medication. They don't work for me, so you're blessed."

Music and singing. Games. Conversations, connecting. Moving on and on.

Yes, I have HIV, but I will not let it dictate or run my life. I have never been in the hospital because of HIV. I was sick only one time, when my T-cells went below 200. I am happy to say that I haven't felt that sick since. I chose to get on meds with the help of my doctor. Had side effects until I found the meds that work for me. Glad that I still have a lot of choices in regards to medication. There are now a lot out there to choose from if I need to.

Showing up everyday or as close to every day as your body allows. It will tell you when to rest. I listen.

Annette, a dear friend, introduced me to yoga. I'm so grateful to her because since I started doing it four years ago, my body has gotten so much better. I used to ache every day. I was overweight – not good. So exercising was one of the best things that happened to me. I do tai chi, get massages, acupuncture…

Living with HIV isn't as bad as seeing the World Trade Center come down in front of your eyes. Had to go to therapy again. I'm still here, though.

I get aches, I get pains in my feet sometimes, I keep on pushing, learning yoga to take the pain away. Better than staying home and doing nothing and feeling sorry for myself. That doesn't work for me. I got my driver's license at the age of 50. I got a car. Now I travel long distances.

Can't forget the day a friend of mine gave me a kitten. He was four weeks old, that's my Spunky and now he's six years old and having a pet has enhanced my life.

I even had locks – long ones – for 13 years. They were salt and pepper. Just this year, I made a change by cutting and changing the color. I'm a changed person and I wanted a 360 degree change. What a difference.

"Living with HIV isn't as bad as seeing the World Trade Center come down in front of your eyes. Had to go to therapy again. I'm still here, though."

Going through menopause now – hot flashes, mood swings – do breathing exercises, and they pass. Found out I was diabetic the same time I found out I had HIV – learned how to live with it, learned how to eat in moderation. Mind and body.

Gone through as much as I have and rising above it to become the person I am today. I have HIV, facing it, understanding it, and moving on with my life. If you should ask me how I feel, my reply would be: Blessed!

Having faith helps me a whole lot. My faith has become so much stronger, so on Sunday I go to Rivington House and give back to people who are sicker than me, who can't walk or talk or be as independent as I am. I get so much joy being there.

Much love and peace for all who feel like they can't go on. You can. I'm living proof. Clean, sober, and positive. God bless us all.

Yolanda Birthwright, 54, is a native New Yorker, born and raised in Harlem. She has worked with or is currently working with AIDS Service Center, Lower East Side Family Union, the Lower East Side Harm Reduction Center, and the Callen-Lorde Community Health Center.

Personal Perspective

There's Always Room for Hope

By Sharon

It's been ten years now, and it's hard to think of my life without AIDS. I was diagnosed in 1994, two weeks after my husband was diagnosed. He had two T-cells at the time and I had seventy. I was a married woman, raising dogs, cats, birds, children, and a husband. I could not believe that this had happened to me. I'm now 59 years old, widowed, and a grandmother to four.

I remember sitting in the doctor's office when they gave me the diagnosis – total unbelief! How could this be? What I didn't realize then was that my husband was one of a group of men who are now referred to as "living on the down-low." As I later learned from an HIV prevention group, "down-low" means a man who has sex with other men as well as his female partner.

My husband and I began to prepare to die – wrote out wills, straightened up our financial arrangements, and prepared the funerals. What I didn't expect is that new medications were on the horizon and that I would respond well to them, although my husband would not.

I knew nothing about AIDS at the time. I thought it only infected gay men on the coasts. I didn't realize that anyone could be at risk, including the over 50 population.

To increase my knowledge about this disease, I began participating in a local research sites' community advisory board. For the next several years, I learned about nukes, non-nukes, and the soon to come protease inhibitors. I found other people living with HIV/AIDS, although none were my age. Everyone was in their twenties, thirties or forties.

During this time, I was experiencing hot flashes and night sweats and didn't know if it was due to the AIDS diagnosis or the aging process. After taking hormone replacement therapy, these problems lessened a bit. However, new statistics arose from a study that showed an increased cancer risk in women using hormone replacement therapy over long periods of time. Since I already had a compromised immune system, I ceased the hormone replacement therapy immediately and began searching for natural therapies for the problem.

I realized that there were not a lot of studies for women living with HIV/AIDS, especially post-menopausal women. No one was looking at the aging process – bone loss, slower metabolism, diabetes, fatigue, and muscle loss.

For five years, I was involved as a representative to the Community Constituency Group. This group advocates for the rights of patients in clinical research. Due to our advocacy with the AIDS Clinical Trials Group (ACTG), researchers are now beginning to look at these things. The Women's Health Committee of the ACTG has numerous studies looking at HIV in pregnancy as well as post-menopausal women and aging. There is also a study comparing the effects of HIV in the under 45 population versus the over 45 population and one on the effects of exercise on muscle loss. This is a good thing, since many of us are now living longer due to the success of HAART.

I've found that services for older adults living with HIV/AIDS to be adequate if you live near a large metropolitan area. However, for many older seniors in rural areas, the stigma is still there and your status has to be concealed. I drive an hour to my doctor, and my meds come via mail order. I do this because I can't reveal my status to anyone in my area. Everyone's aunt, uncle, brother, sister, or mom could work at the hospital, the lab, or the local pharmacies. And small towns talk, especially about something as large as one of their own with an AIDS diagnosis.

As a widow and a woman approaching 60, my life has taken on new meaning. I've had to work hard to find others of my age for a support group. Many of us meet at various conferences or talk via the Internet. We have even formed a local brunch group that meets monthly, but, because of the stigma, we go out of our area for the brunch. In spite of the support group, there are times of loneliness. My general feeling is that I am not interested in dating again, just finding a companion with whom I can talk and travel, someone who understands what it is like to live with HIV and be a senior. I think this is different for a younger person diagnosed today. I can look back on a life that was full and lived well. For this reason, I have no regrets about a future that may not look as well as I would like. However, a younger person has their entire future ahead of them. With an HIV/AIDS diagnosis, that future may look bleak.

As I look back on where I've been and where I'm going, there's hope. I am doing well on the meds, enjoying my family and friends, my retirement, and my time to myself. I've said that "it can't get any better than this" – that is, if the meds continue to work and my health holds out. There is always that underlying fear that, as we age, one more thing will crop up that we have to deal with along with the HIV/AIDS diagnosis.

But I can't think of that now – I need to plant some flowers.

Sharon, 59, is an advocate for women living with HIV/AIDS, a volunteer at a pet shelter, a grandmother of four, and lives in a small town in Midwestern America.

ACRIA Welcomes Mark J. Montgomery to Our Board

Mark J. Montgomery was elected to ACRIA's Board of Directors at the May 19, 2004 meeting. Mr. Montgomery comes to this position with a longstanding involvement in New York City and Washington D.C.'s nonprofit community and in medical research in particular. Mr. Montgomery also brings a valuable financial background to the agency, with over 20 years' experience as a securities analyst and portfolio manager. He currently serves as Managing Director of Montgomery Brothers, Cappiello, LLC, a private investment firm based in Washington. We look forward to having someone of Mr. Montgomery's experience and interests on our board to help ensure that our programs continue to meet the changing needs of the HIV community nationwide and that the agency remains financially stable during extremely challenging economic times for AIDS charities.

ACRIA's CAB Presents Its First Community Hero Award

ACRIA's Community Advisory Board (CAB) presented its first Community Hero Award on April 12, 2004 to Congressman Charles B. Rangel at a ceremony in East Harlem. The CAB chose Congressman Rangel for this honor because of his longstanding commitment to the health and quality of life of people living with HIV/AIDS across the country and, particularly, racial/ethnic minorities who bear the greatest burden of new infections.

Congressman Rangel is a founding member of the Congressional Black Caucus which, in 1998, caused the creation of the Minority AIDS Initiative (MAI) in response to a crisis of infections within minority communities. Since then, this initiative has directed significant federal grants in the fight against AIDS to populations that had previously been sorely underserved by AIDS funding. ACRIA is just one of many nonprofits nationwide to receive MAI support for implementing critical programs that help minorities to more effectively access and benefit from a host of vital services, including programs that provide information about life saving treatment options. Most of these programs would not exist had it not been for Congressman Rangel's recognition of the emerging health crisis within African American and Latino communities. In accepting the CAB's Community Hero Award, the Congressman spoke eloquently about the continuing need of the federal government and private donors to do everything they can in the fight against HIV, with particular emphasis on helping those who are the poorest in our society.

ACRIA's CAB would like to thank New York City Councilmember Phil Reed's office for helping us present the Community Hero Award to Congressman Rangel.

Research Activities

The ACRIA research department has had its first article on HIV over 50 accepted to a peer-reviewed journal, *Aging and Mental Health*. "The Aging HIV/AIDS Population: Fragile Social Networks" was authored by Andrew Shippy and Stephen Karpiak. A second article – "The Aging HIV/AIDS Population: Why Are Informal Networks Unable to Provide Adequate Support?" – has been submitted to the journal *Research on Aging*.

Brady Berman and Allison Applebaum from New York University's Department of Psychology, who worked as interns on ACRIA research projects, have both been accepted to highly competitive clinical Ph.D. programs beginning next year. Brady and Allison will be completing manuscripts detailing the work they did at ACRIA, which included the assessment of cognitive function and depression in people with HIV over the age of fifty.

On April 25, 2004, Associate Director for Research Stephen Karpiak, Ph.D. addressed the Dominican Medical Association of New York on issues confronting the growing aging HIV/AIDS population. To date, the research staff has given 14 presentations on their HIV/50 research findings to New York City-based AIDS service organizations.

Free HIV Treatment Education Technical Assistance Program: Capacity Building for New York City Community-Based Organizations

ACRIA is offering a new capacity building program for community-based organizations that provide services to people with HIV in New York City. The goal of the program is to help non-medical service providers incorporate accurate, comprehensive, and up-to-date HIV treatment education and counseling into their agencies' work.

This two-part program includes:

- A four-day HIV treatment information and skills-building training to be held October 4-7, 2004; and
- Ongoing follow-up support and technical assistance for each participating agency

Participation in October's training is limited to 25 people. For information about the program and how to apply, go to: www.acria.org/treatment/nycta.html

generous contributions

The following persons, corporations and organizations made major donations between March 16 and June 15, 2004 to support ACRIA's research and education efforts:

Boehringer Ingelheim Pharmaceuticals
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Keith Cylar
Barbara Frey
Carl Parisi
Leslie Wasson

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Daisy Graciano

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