Remembering the Past for the Future
By Linda Davis, MSW

The philosopher George Santayana said that “those who cannot remember the past are condemned to repeat it.” Every nine and a half minutes, someone is diagnosed with HIV/AIDS. The disease strikes indiscriminately – both sexes, all ages, all races. Fortunately, the medical community now has advanced knowledge and medications that allow patients to have higher quality, longer life spans. But, although we have come a long way in treating this disease, we haven’t found the cure. Complacency is one of our biggest foes.

Who is Ryan White? It both amazes and pains me how often I’m asked that question. The first generation that lived through the fear, hopelessness, and loss when the AIDS virus first surfaced in the US has been replaced by a generation that is both ignorant and apathetic when it comes to the disease.

Before Ryan White, AIDS was a disease widely thought of as a “homosexual problem,” because it was initially diagnosed among gay men in New York. That perception changed after White was first diagnosed among gay men in New York. By 1981, when it comes to the disease.

I wish that this new generation could have seen the AIDS Memorial Quilt displayed at the National Mall in Washington, D.C. The quilt was started in 1987 in San Francisco. Each panel is 3 feet by 6 feet, the size of the average grave and is a memorial to and celebration of individuals lost to the AIDS pandemic. At that time, many people who died of AIDS-related causes did not receive funerals, due to both the social stigma of AIDS felt by surviving family members and the outright refusal by many funeral homes and cemeteries to handle the deceased’s remains. Lacking a memorial service or grave site, the quilt was often the only opportunity survivors had to remember and celebrate their loved ones’ lives.

This quilt can no longer be displayed at one time because of the number of panels that have been added. It continues to grow, currently consisting of more than 46,000 individual memorial panels (more than 91,000 people) and weighing an estimated 54 tons. How many more panels will be added? We must not only remember the past, but also educate future generations, until there’s a cure.

Davis is a medical social worker and a member of the Ryan White Care Team.

The state of HIV testing laws in West Virginia

Christine Teague, PharmD, MPH, AAHIVE

New HIV testing legislation went into effect in June 2011. West Virginia’s HIV testing laws had not been updated in 15 years. Many changes have taken place in HIV treatment and prevention, and the old laws were inconsistent with federal recommendations. So what has changed and what does it mean for you?

West Virginia Senate Bill 488 eliminates administrative barriers to HIV testing with the goal of at least a one-time screening of everyone between the ages of 16 and 65. In the past, a patient had to sign a consent form before having the test, or “opt in.” The new bill eliminates this step. Now, the patient is informed that an HIV test will be done as part of routine care, at which point, the patient can refuse or “opt out” just as he or she may for any medical procedure.

Anyone can still get anonymous testing at a local or state health department. All HIV testing is conducted on a voluntary basis and recommended by healthcare providers as part of routine screening for the following: 1) treatable conditions; 2) routine prenatal and perinatal care; 3) high risk behavior; 4) a patient’s HIV status if a health care worker may have been exposed or; 5) the patient’s general care. Specific pre- and post-test counseling requirements are now at the discretion of the healthcare provider.

There are several reasons the federal government (and now the state of West Virginia) recommends universal HIV screening without a written consent and pre- and post-counseling: 1) HIV is a chronic disease more easily managed earlier due to advances in treatment; 2) one out of five individuals do NOT know their status; and 3) once identified, individuals with HIV can lower the risk of transmitting the disease.

In West Virginia, it is common for clients to be diagnosed late in their disease, already having progressed to AIDS. They have a harder time controlling their infection and are more likely to have other complications. Including testing in routine medical care and removing lengthy counseling requirements lessens the stigma of being tested and opens the door to providing treatment before symptoms appear.

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Everyone should be tested at least once and annually if they are considered high risk. High risk behavior includes the following:

1) unprotected sex with an HIV-positive person
2) unprotected sex in exchange for money or drugs
3) unprotected sex with multiple partners
4) anonymous unprotected sex
5) needle sharing
6) diagnosis of a sexually-transmitted disease

If you haven’t been tested, you should. The test is both safe and quick. It makes your waiting time shorter. It makes your waiting time shorter. It makes your waiting time shorter.

The decision to be tested for HIV is the first step in taking responsibility for yourself and the health of others with whom you may be intimately involved.

HIV testing locations

Many testing sites offer free testing, but some charge a fee. Some locations require an appointment; others accept walk-ins. Call ahead to be sure! On the Internet you can find a list of testing sites in your area by entering your zip code.

Go to www.hivtest.org.

By phone, you may call:

WV AIDS/STD Hotline 1-800-642-8244
CAMC Ryan White Program care coordinator in Charleston (304) 388-9337 or toll-free: 1-877-565-4423
National HIV/AIDS Hotline 1-800-342-2437
Your local county health department

Free, Confidential HIV Rapid* Testing Locations

The Covenant House
600 Shrewsbury St. Charleston, WV
The Covenant House offers free rapid testing the first Wednesday of each month from 1 to 3:30 p.m. by appointment only. Contact Paul Milam at (304) 344-8053, ext.19 or pmilam@covenancehouse.org.

The West Virginia Bureau for Public Health
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*This test requires only a mouth swab. Your results are ready in 20 minutes.

CAMC Ryan White Clinic FAQs

Why do I have to wait so long to see my doctor?

Be patient and plan ahead. The doctor may be spending additional time tending to the very ill, scheduling other specialist referrals, or making medication changes. All patients appreciate this extra effort when needed. If you have an appointment, schedule your day so that you do not have to hurry to be somewhere else. If you have other appointments close to your clinic visit, please call and reschedule at (304) 388-9677 or 1-800-348-9677.

Why does it take so long to get a needed form for another agency?

The forms often need to be signed by your doctor who is only in the clinic a few days a month. Plan ahead. If you think you will need a form in the near future, ask for a copy while you are at the clinic.

Why doesn’t the Ryan White Clinic hire full-time doctors?

The Ryan White Program is funded by the federal government (the Ryan White Care Act). Our grant money is limited and cannot fund full-time staff members.

Why does it take so long to return my calls?

We serve more than 400 clients and our care coordinator is the only full-time staff member at the Ryan White Clinic. She is the go-to person for all questions and requests, plus she coordinates all of the Ryan White clinics. She makes every effort to return phone calls in order of importance.

Why do I have to sit in the waiting room like I am on display?

There are always several types of clinics operating on any given day, so no one knows why you are here, or who you are seeing. The Ryan White Clinic has a room right beside the waiting room called the “Neighborhood” that offers more privacy while you wait. This room is filled with educational materials and information about how to join a supportive HIV community.

How can I help?

1) Plan ahead and keep your personal life organized
2) Make a list for your next visit, including questions for your doctor, prescriptions you need updated, and forms you may need in the future.

These steps will help put you in charge of your medical care.
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Teague is the CAMC Ryan White program director.

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CAMC Ryan White Clinic FAQs

Why does it sometimes take months to get an appointment scheduled?
The infectious disease clinics are only offered a few times a month. Your doctor has a full-time job elsewhere and is only scheduled at the clinic four or five days per month.

Why should I preregister?
It makes your waiting time shorter.

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Before Ryan White, AIDS was a disease widely thought of as a "homosexual problem," because it was first diagnosed among gay men in New York and San Francisco. That perception changed after White, a 13-year-old hemophiliac, contracted HIV from a contaminated blood treatment. Shortly after his death, one month before his high school graduation, the United States Congress passed the Ryan White Care Act, a major piece of AIDS legislation, which is the newest largest provider of services for people living with HIV/AIDS in the United States.

I wish that this new generation could have seen the AIDS Memorial Quilt displayed at the National Mall in Washington, D.C. The quilt was started in 1987 in San Francisco. Each panel is 3 feet by 6 feet, the size of the average grave and is a memorial to and celebration of individuals lost to the AIDS pandemic. At that time, many people who died of AIDS-related causes did not receive funerals, due to both the social stigma of AIDS felt by surviving family members and the outright refusal by many funeral homes and cemeteries to handle the deceased’s remains. Lacking a memorial service or grave site, the quilt was often the only opportunity survivors had to remember and celebrate their loved ones’ lives.

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Fall 2011

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Christine Togue, PharmD, MPH, AAHIVE

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