

NEWS AND VIEWS FROM

Park House

Vol. 17 No. 1

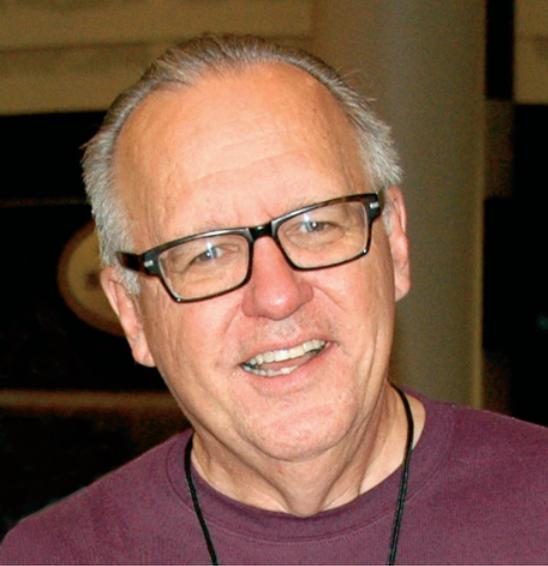
Spring/Summer 2015



Support and nurture from a loving family helps make each of its members stronger—and healthier, as well. Close-knit bonds can ease the stresses of life by providing security, comfort and companionship. For Anita, who has lived with HIV for 21 years, shown here surrounded by some of her doting grandchildren, the connection to family is very important in her life. Read Anita's story on page 4, an inspiring tribute to living successfully day to day.

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Despite improved drug therapies, persons living with HIV still face significant challenges

Manager's musings

Jim Maurer, Park House manager/development associate

Why a Park House in 2015?

The common understanding these days is that HIV is a chronic medical condition that can be controlled with medications. So what is the need for “special” services for persons living with the disease now? While it is true that HIV has become much more manageable with improving medications that counteract the effects of the virus, many of those infected still face multiple barriers to self-sufficiency.

Park House serves individuals living not only with HIV, but with mental illnesses, other chronic medical conditions and/or chemical dependency. Park House is a unique program providing supportive nursing care, psychosocial support, creative/complementary therapies, nutrition and collaborative treatment planning with physicians and case managers.

In a recent report the World Health Organization (WHO) discussed the need for coordinated, integrated care for persons living with mental illnesses and chronic medical conditions in order to prolong their lifespan. WHO noted that there is evidence that oftentimes people with a severe mental disorders do not receive the same levels of care and treatment for their physical health as the general population. “In the majority of cases, people with mental

disorders are often at a disadvantage as compared with the general population due to unemployment, living in institutions, isolation and exclusion, as well as socioeconomic status—all risk factors that can prevent recovery as well as lead to poor health and premature mortality,” the report emphasizes.

Park House clients maintain a nearly 100 percent medication adherence rate. The result? Most Park House clients have an extremely low to undetectable HIV viral load. The education and support clients receive at Park House about HIV and the necessity for taking their medications as prescribed are keeping them healthy and active in the community.

As you will read in this newsletter, HIV/AIDS is a family matter. All of our clients belong to a family system. Dealing with the reality of HIV within that system has involved learning, coping and surviving for everyone in the family. We have been there for our clients who have struggled with talking about their HIV status with their partners, their children, their parents and their siblings— and in the case of Anita’s story, with their grandchildren. Anita’s story is particularly warming as the family is so rooted in their faith and love for each other that they are able to support each other

no matter what challenges face them. It is an inspiring story of family strength.

I want to take this opportunity to once again thank those who support Park House by volunteering or with monetary gifts. Your contributions are most helpful to our programming and deeply appreciated by our staff and clients. They give Park House the strength and the means to continue to serve the HIV/AIDS community.

Ongoing, special events continue to offer other ways for you to assist Park House and other Minnesota HIV/AIDS service agencies:

Wild West Bingo will take place on Saturday, May 16, at the Hyatt Hotel in downtown Minneapolis, hosted by the fabulous Miss Richfield, 1981, and the 13th *Red Ribbon Ride* is July 16 – 19. All are welcome to participate in both events.

We have a Team Park House/Allina Health registered for the *Ride*. Join us as a rider or a crew person. A new two-day option allows you to join the event in Mankato and ride on Saturday from Mankato to Waconia and on Sunday to the State Capitol in St. Paul. For more information go to: redribbonride.org

A handwritten signature in purple ink that reads "Jim".

Kristan Voss joins team as program therapist

Park House is pleased to announce the arrival of Kristan Voss to fill the position of program therapist. On the job for just over two months, Kristan has hit the ground running and is looking forward to settling into her new position. “I am interested in working with under-served populations,” says Kristan. “I was attracted to the flexibility, the collaboration and the opportunity to help develop programming options for persons living with HIV/AIDS.”

She says she’s learned a great deal about HIV/AIDS in the short time since she’s come on board—much of it from the clients themselves. “I’m becoming keenly aware of the bigger picture that living with HIV entails,” she says. “There are real struggles associated with this disease such as stigma, effects of medication, nutrition, housing, and transportation



issues—as well as a need for psychosocial support.”

“I see my primary task as working with my colleagues to develop and facilitate group therapy sessions for our clients that target their mental health and other issues.” Rounding out her tasks, Kristan is involved

in charting client medical records, helping to coordinate treatment plans and interacting with clients to address social and other needs.

As the “new kid” Kristan appreciates the welcome she’s received at Park House. “I think the clients are responding well to me, and I’ve gotten good feedback,” she observes. “What I think is great about Park House is the exposure to a lot of different ideas, the openness to new group suggestions and the helpful, respectful and engaging environment.”

Kristan has graduate degree in counseling and psychological services from St. Mary’s University in Minneapolis. She interned at Park Avenue Center, focusing on chemical dependency, and has worked in sex offender treatment at the Minnesota Correctional Facility—Lino Lakes.

A publication of

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Content development, photography, and production by
Hustad Marketing & Communications, Inc.

Published by Park House

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*Thinking of friends
we have lost*

**In
Memoriam**

Robert H.

Geminie C.

Joseph P.

Anita's story

Together ness and love give family strength to live with HIV



The apartment where Anita and her husband live immediately strikes one as the kind of place where a lot of living occurs. Everywhere there are signs of activity. A large collection of well-loved, stuffed toys occupies a prominent place next to the center island that separates the kitchen from the living room. The coat rack is filled to capacity. Beneath it, shoes and boots of all sizes and descriptions. Shelves are filled to overflowing with games, videos and books. And the sound of children's laughter and boisterous energy fills the room.

This is the epicenter of Anita's world. A mother to six and grandmother to 24, it's clear that—as she puts it, “family is a big, big part of my life,” noting that, “Husband and I spend a lot of time with our grandkids and our kids.”

In most regards their life together is typical of many close-knit families. “We do a lot of games and other activities,” Anita notes. “In the sum-

mer, we go outside to the park and hang out there. And, we barbecue.” While her children have homes and jobs and lives of their own, spending time together is still a high priority for them all.

Unfortunately, Anita's story did not have such a tranquil beginning. As a teenager, she found herself in an abusive relationship, and after a particularly severe beating at the hands of her “boyfriend,” she landed in the hospital with serious injuries. She required a blood transfusion which would ultimately have unintended consequences. Unbeknownst to Anita, the infusion meant to save her life also infected her with HIV.

Some years later, Anita met the man to whom she's been married for 28 years—and with whom she had children. But, with an increasingly compromised immune system, several years into the marriage, Anita became extremely ill. She had pneumocystis pneumonia and was

diagnosed with AIDS. “I was on my deathbed with no T-cells,” she put it. Miraculously, she rallied.

Not surprisingly, the illness and the AIDS diagnosis came as a total shock. “I went through a depression stage where I didn't want to take any medication because I was in denial,” says Anita.

But, there was more bad news to come. This time it was that Anita's husband had contracted the disease from her. “It took years for him to find out he was HIV-positive because he had no symptoms,” Anita observes. It was a discovery that could have understandably had a disastrous effect on their relationship.

Fortunately, it didn't. “Husband was a little scared, but he wasn't mad,” Anita reflects. “When husband found out he was HIV-positive, he told me that it wasn't going to change anything. He still loves me the same. We have a good relationship. We share

Anita's story—continued on page 5

a lot of time together, and he takes good care of me. When he said, 'I do,' he meant it—until one of us is gone.”

There was, of course, considerable concern over the health status of the children. To Anita and her husband's great relief, tests confirmed that they were all uninfected. Once that was laid to rest, Anita says she was able to get on with her life, take her medications and make sure her kids' HIV-status remained negative. Today, things much improved. "I'm stronger now. My T-cell count is up, and my viral load is undetectable. I'm a true believer that if you take your medication, you can live a long time."

From the onset, Anita and her husband were open and honest with the children about the situation they all faced. As they grew up, there followed many age-appropriate discussions concerning HIV. Even at an early age, they knew important basics, including that you can be close and still be safe because you don't get HIV from kissing and hugging.

As grown adults, Anita's children are still very involved and interested in the subject HIV/AIDS. By the time grandchildren entered the picture, common sense and honesty about HIV were deeply ingrained in the whole family. They attended Camp Benedict where families go to learn about living with the disease—and often speak there to share their insights and knowledge with others who are learning to live with HIV for the first time.



Board games are a particularly favorite pastime for Anita and her grandchildren.

Like most people, Anita also needs to take time out for herself. So, three times a week she attends Park House as an outlet that provides her with the opportunity to focus on taking care of herself. "It's really made a big change in my life," she says.

She feels the benefits from the warm, supportive and affirming environment Park House provides. It allows her to pursue hobbies, to socialize with others, go on group outings and engage in recreational activities. "I like to do painting, and I like to make jewelry," she says. "I often put jewelry up as bingo prizes which we play often at Park House. It's one of my favorite games to play."

Anita particularly appreciates the wonderfully supportive, helpful staff. "You can go to any of them and talk about anything."

Anita also finds the programming at Park House helpful in her ongoing

journey with HIV/AIDS. She finds sharing personal experiences with other clients very helpful. Everybody has a unique story. "You share with people one-on-one or in a group, and you learn a lot from each other," she observes, noting that these interactions can be reassuring, inspiring, and helpful in feeling less vulnerable or isolated.

For someone who already has a large extended biological family, it's

noteworthy that Anita also considers her friends, mentors and support groups at Park House as her other family. Because, after having experienced the debilitating effects of despair, violence and a relentless virus, she is a thriving endorsement to the power of love and constructive human engagement. "I'm going to continue to keep staying strong," she concludes—then adds, "I'm going to stay at Park House, and I'm going to continue to take my medication."



Saturday afternoons can include enjoying a wide range of activities. Here, granddaughter Amorie gives Anita's nails a "makeover."



Keeping family and friends HIV safe

Medical director's viewpoint

Hanan Rosenstein, MD, *Park House medical director*

Since the beginning of the HIV epidemic, we have worked diligently to prevent transmission to others – those close to us, those that we do not know very well (or at all), and to us (if non-infected). This job belongs to everyone: the HIV-positive person, the HIV- person that is putting themselves at possible risk, the medical community, and the general community, as well.

We must consider the ways HIV can be transmitted to others. HIV sexual transmission is known to everyone, but there are dangers in the home and in the work place as well. The residence of an HIV-positive person should have a “spill kit”, in case, that person cuts themselves accidentally. This kit should contain:

- Plastic gloves (disposable) Spray bottle of 10% bleach (Purex, etc.)
- Paper towels
- Butchers gloves (Kevlar or similar) to pick up broken glass.

The clean up must be performed with the plastic gloves. Any blood should be sprayed with the bleach solution and allowed to remain for about 10 minutes and then cleaned with the paper toweling. All the clean up papers should be disposed of in plastic bags. The broken glass (if any) should be double bagged and disposed safely. No one should walk without shoes if there is any

broken glass present. All workplaces should have “spill kits,” as well. Since workplaces will not necessarily know if anyone there is HIV-positive, they should clean up any blood in the above safe manner.

The usual method of HIV transmission is sexual. Until last year, protection against transmission was only “safer sex” methods. We now have two effective drug preventions of HIV transmission. IT SHOULD BE NOTED THAT, WHILE VERY GOOD, THESE ARE NOT 100%. If the HIV-positive person is on antiviral medication and their viral load (amount of virus) is undetectable, their chance of transmitting the virus to others is very low (not zero). Last year, the FDA approved the use of Truvada (a combination of two anti-HIV medications) to be used prophylactically. That is to prevent acquiring the virus sexually from others. The studies that proved this works were performed with CONDOMS. Use of Truvada without condoms was not tested and therefore not recommended. The following are the instructions regarding PrEP, Pre-Exposure Prophylaxis.

WHAT IS PRE-EXPOSURE PROPHYLAXIS (PrEP)?

Pre-Exposure Prophylaxis, or PrEP, is a new HIV prevention method in

which people who do not have HIV infection take a pill daily to reduce their risk of becoming infected. The pill, called Truvada®, contains two of the many medications that can be used to treat people who already have HIV. These medications prevent HIV from making copies of itself and turning into an infection that's spread throughout your body. In this way PrEP medicines can help keep the virus from establishing a permanent infection. So, PrEP is a way for people who are at very high



risk of getting HIV to lower their risk by taking a daily pill. PrEP is only meant for people at very high risk for getting HIV because they may often be exposed to the virus—for example, someone who is HIV-negative but has an HIV-positive partner and doesn't consistently use condoms.

Viewpoint—continued on next page

In 2012, the U.S. Food and Drug Administration (FDA) approved the use of the drug Truvada® as PrEP to be taken once daily and used in combination with safer sex practices to reduce the risk of sexually acquired HIV infection in adults who do not have HIV but are at high risk of becoming infected.

Taking medicine before exposure to a germ or a virus is nothing new. For example, public health officials often advise travelers to take a medication before they visit areas where malaria is common. However, the use of medication to prevent HIV infection has only recently been studied.

DOES PrEP WORK?

Studies have shown that PrEP provides a high level of protection against getting HIV for gay and bisexual men, heterosexual men and women, and injection drug users, if the medication is taken consistently.

Results from two studies of PrEP, released in July 2011 (the TDF2 study and the Partners PrEP study) showed that daily oral doses of two specific antiretroviral drugs can be used to prevent transmission of HIV from men to women and from women to men. This follows findings of the iPrEx study among men who have sex with men (MSM), reported in November 2010, which found that daily oral doses of the same two antiretroviral drugs taken by HIV-negative study participants reduced, but did not eliminate, the risk of getting HIV.

In addition, in June 2013, published results from the Bangkok Tenofovir Study showed that daily oral doses of one of the two antiretroviral drugs used in other PrEP studies reduced the risk of getting HIV among injection drug users.

In all of these studies, people who took the drugs consistently—enough that regular blood tests showed detectable levels of the drug in their systems—had much higher levels of protection than those who did not.

Specifically:

iPrEx: PrEP reduced the risk of getting HIV by 44% among all the study participants, and by more than 90% among men with detectable levels of the drug in their blood.

Partners PrEP: PrEP reduced the risk of getting HIV by 75% overall, and by 90% in people with detectable levels of the drug in their blood.

Bangkok Tenofovir Study: PrEP reduced risk of getting HIV by 49% overall, and by 75% in participants with detectable levels of the drug in their blood.

WHAT MEDICATIONS ARE USED IN PrEP?

A combination of two medications (tenofovir and emtricitabine) sold under the name Truvada® is approved by the FDA for daily use as PrEP for people at very high risk of getting HIV infection through sexual exposures. The same combination of medications is also recommended for people at very high risk of getting HIV through needle-sharing injection drug use. PrEP can only be prescribed by a health care provider and must be taken as directed to work.

CAN ANYONE USE PrEP?

For some individuals at very high risk for HIV, PrEP may represent a much-needed additional prevention method—but it will not be right for everyone. PrEP is an intensive approach that requires strict adherence to daily medication and regular HIV testing. You and your health care

provider should consider the following factors in deciding whether PrEP is right for you:

- Only people who are HIV-negative should use PrEP. An HIV test is required before starting PrEP and then every three months while taking PrEP.
- PrEP should never be seen as the first line of defense against HIV. PrEP is most effective when combined with other prevention efforts like condom use and safer injection practices.
- PrEP involves taking daily medication consistently and frequent visits to a health care provider.
- PrEP medications can cause side effects like nausea in some people. These side effects can be treated and are not life threatening.
- PrEP may also be an option for HIV-negative women whose partners have HIV infection during conception, pregnancy, or breast feeding.

GUIDANCE ON PrEP USE

CDC has issued the following guidance on the use of PrEP among different populations:

MSM: In January 2011, CDC published interim guidance for physicians on HIV Pre-Exposure Prophylaxis for Men Who Have Sex with Men to help guide clinical practice as formal U.S. Public Health Service guidelines are being developed.

Heterosexuals: In August 2012, CDC published interim guidance for clinicians considering the use of PrEP for the prevention of HIV infection in heterosexually active adults. This guidance included recommendations similar to those for MSM, as well as new recommendations for women who may become pregnant while taking PrEP and to couples in which one partner is HIV-positive and the other is HIV-negative.



Riders, crew, volunteers and beneficiaries gather to officially kick off the 2015 Red Ribbon Ride

Recruitment, fund raising, training click into high gear



RED RIBBON RIDE

In the middle of a Minnesota winter (albeit, a relatively mild one this year), it's hard to believe biking season is just 'round the corner. Still, an enthusiastic gathering of supporters and interested riders gave the 2015 *Red Ribbon Ride* a rousing kickoff, marking the official start to this year's event. The time is now for signing up as a rider or volunteer, for raising money, and soon—hitting the open road on training rides.

This year's kickoff included the unveiling of the *Ride's* new logo (seen

above), testimonials, an entertaining presentation by Doug Melroe—detailing the nitty-gritty of what to expect on the ride, and the opportunity to talk with *Ride* beneficiaries. Also, introduced—a new two day option, *Ride Light*, if you will.

This year's four-day, 300-mile event takes place July 16 – 19, leaving from the Mall of America and ending at the State Capitol. For more details or to sign up, go to the *Ride's* website:

redribbonride.org



Beneficiaries on hand to share with attendees how the *Ride* helps their organizations. L to R—Front row: Antoine Jefferson, African American AIDS Task Force; Mary McCarthy, Rural AIDS Action Network; Senay Kindler, One Heartland; Annie Elmer, Minnesota AIDS Project; Joe Larson, The Aliveness Project; Scott Zahren, Hope House of the St. Croix Valley. Back row: Chris Briggs, Clare Housing; Jim Maurer, Park House; Aaron Zimmerman, Red Ribbon Ride.



Rider profile—Doug Melroe

Fitness guru, Red Ribbon Ride supporter talks the “Zen of biking” and why he rides

If you ask Doug Melroe what the *Red Ribbon Ride* is all about, he first makes a point: “It will change your life.” He then explains how the *Ride* is an amalgam of sorts, combining physical activity with a spiritual journey. “It clears your head and focuses your heart,” he said.

For the last 30 years, Doug has worked for *The Firm*, a preeminent fitness facility in the Twin Cities, as a trainer, facilitator, mentor and good listener. When bike rides to raise money for AIDS service organizations began in the late 90s, many of Doug’s clients were participating. It took several years of coaxing, but—according to Doug, “I finally had to put my butt on a bike for four days and just do it.” This year will be his sixth ride.

“The first year is the one you never forget,” says Doug. “I did the *Ride* in honor of friends I had lost—people who had helped me become who I am—and are now my angels.” Specifically, Doug mentions David Gray, an original owner of *The Firm*, as someone who profoundly influenced him and whose memory still continues to

motivate. He goes on to acknowledge others, as well—clients, friends and staff. “My history, *The Firm’s* history, and the history of AIDS all kind of mesh together.”

The *Ride* is often filled with profound, cathartic moments. “One of the gifts of the *Ride* is the time you spend alone, reflecting,” says Doug. He describes the waves of emotion he experienced on his first day riding. “I cried a lot because I was thinking of my friends and how much I missed them.” He also discovered that he was carrying significant survivor’s guilt. “I felt guilty because I made it, and my friends who were HIV-positive didn’t.”

Eventually, those thoughts began to subside, replaced by feelings of empowerment. “I realized that I have a right to be here,” Doug explained, “and because I’m here, I can make a difference. My friend David can’t do it—but he would, if he was here, and he wouldn’t give up. Why should anything stop me?”

Doug says that each year he experiences the *Ride*, the more he appreciates the unique gifts it offers—the inspiration that comes from getting to know some of the Positive Pedalers, meeting interesting, engaged people

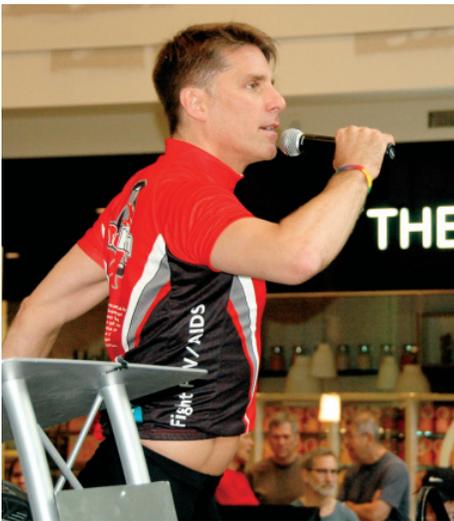
with whom he would not ordinarily rub shoulders, and the sharing of a common, worthwhile purpose.

In many ways, the *Ride* is a great equalizer where labels and position and status are set aside, and a group of like-minded people pull together and try to make a difference. “Pretty soon, you feel like family,” says Doug. Some years ago, someone coined an expression describing this phenomenon as *The Traveling Bubble of Love*.

Doug readily admits that participating in the *Red Ribbon Ride* takes effort and commitment. “You’re giving of yourself,” says Doug, “but the dividends come back ten-fold—from the donations, from the people that believe in you, from the people you meet on the *Ride*, from the experience, from knowing the money you raised is going to a good cause—and from the exercise. It’s four days of exercising and it feels so good.”

Rider profile—continued on page 10





Doug Melroe leads bikers in the *Red Ribbon Ride* through warm-up/stretching exercises prior to ride-out from the Mall of America.

The *Red Ribbon Ride's* mission is primarily about raising money to fight HIV, but the benefits to those who participate in the *Ride* are far-reaching and transformative. Doug asserts the spin-off helps make our community a better place and can be helpful to individuals on their career path, working through personal issues or committing themselves to other important causes.

When asked about training for an event like the *Red Ribbon Ride*, Doug's response is reassuring. "Everybody's different. The thing is—there is so much support that no matter what your physical fitness level, what your age, what your bike is like—there'll be somebody to help you, and you'll get through it." Remember, there's no shame in trying. He encourages people to get out on their bikes when they can. "Training rides (especially those conducted by the *Ride*) can help you become a better, safer rider—plus they're a lot of fun."

Finally, Doug reiterates an essential mantra of the event—*It's a ride, not a race*. "Get ready for an amazing journey—and enjoy it."

Injecting Drug Users: In June 2013, CDC published an update to interim guidance for physicians on the use of PrEP for injecting drug users. This guidance recommends that PrEP be considered as one of several prevention options for people at very high risk of getting HIV from injecting illegal drugs.

For more information, visit CDC's PrEP Resources page.

FREQUENTLY ASKED QUESTIONS

Since PrEP is effective, why bother with risk-reduction strategies? Can't I just take a pill and be safe?

Like all prevention methods, PrEP is not 100% effective. Therefore, it provides the most protection when used with—not instead of—condoms, safer sex practices, use of clean injection equipment, and other HIV prevention methods. PrEP adds another layer of protection. It's also important to remember that PrEP will not prevent you from getting syphilis, gonorrhea, chlamydia, or other sexually transmitted diseases. Similarly, for those taking PrEP because of injection drug use risks, PrEP will not protect you from getting hepatitis C, skin, or heart infections.

Are there other ways for HIV-negative people to prevent HIV by taking medication?

Postexposure prophylaxis (PEP) also uses a combination of specific HIV drugs to prevent HIV, but PEP is used after single events rather than to reduce risk over the long term. For example, PEP may be used after a sexual assault, after a health care worker is exposed on the job, or after an episode of unprotected sex or needle-sharing injection drug use. PEP is taken for only 28 days im-

mediately after a potential exposure and must begin within 72 hours to be effective.

Who pays for PrEP?

Private and public health insurance plans often cover Truvada for PrEP. If you are eligible, your health care provider can get Truvada for you at no cost from the drug's manufacturer through its PrEP-specific medication assistance program. Eligible patients are US residents (they need not be citizens or current visa holders) who meet the low-income cutoff and have no health insurance or no PrEP coverage under their health insurance. Your local health department may also be able to direct you to other kinds of assistance programs.

We recommend PrEP, for those HIV-positive persons regularly exposed to HIV-positive persons. This may be within their closed relationship, or with frequent unknown "hook ups." If in a monogamous relationship and the HIV-positive partner is undetectable, you might consider this to be safe. Adding PrEP could add additional protection. It is important that there are other STDs out there that are not protected by PrEP.

There have been several recent HIV transmission while on PrEP. It was determined that the transmitted virus has mutated and was resistant to one of the medications in Truvada. Again, use of condoms is very important. Use of PrEP, in heterosexual couples wishing to have children has not been studied, but may be a possibility for safety in pregnancy. Because of the continued number of HIV infections in adolescents, parents should discuss PrEP with their sexually active gay teens. Part of the discussion must include the necessity of complete adherence and use of condoms.

WILD WEST BINGO

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PARK HOUSE exists to enhance the quality of life, maximize human dignity, promote independence, and minimize hospitalization of persons living with HIV/AIDS. PARK HOUSE is a structured day health program which provides supportive nursing care, psychosocial support, creative/complementary therapies, nutrition and collaborative treatment planning with physicians and case managers.

Superhero Bingo A-GoGo flashback—November 15, 2014, Hyatt Regency Hotel

The night great big muscles came out to play

