

Families Connections

The Newsletter for Positive Families



THEHEARMEPROJECT YOUR WORLD. YOUR WORDS HIV@AIDS 2006 STORY WRITING CONTEST

Do you have a story to tell? Would you like to have your work reviewed by a celebrity panelist of judges? Do you want to be heard?

- Youth ages 14 – 22 years of age (Must be a US Resident)
- One entry allowed per person
- Story can be up to 5 pages typed or neatly handwritten
- Contest is open from September 1 – December 1, 2006
- First Prize: \$2,500
- All persons under the age of 18 must have signed parental consent to enter the contest

Grab your pens, laptops, creative juices and get writing. Your original story (not someone else's already published) is wanted!

The story can be fiction (a made-up story) or non-fiction (true to your life) – you choose!

Stories must “be about personal vulnerability to HIV/AIDS ...The characters in the story must be impacted by HIV/AIDS.”

This is your chance to help others understand how HIV/AIDS effects you, your friends, your family & loved ones!

For more information & complete contest details, log onto www.hearmeproject.org or call Stacey at (314) 454-4714 to have the complete contest rules and regulations mailed to your home! Please note, the above contest is not a Project ARK sponsored event. Please read rules carefully before entries are submitted!

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The Importance of Adherence

by Nina Marks

If you're living with HIV, your health-care provider has probably stressed the importance of taking each and every dose of your medication. Missing doses allows the virus to "get the upper hand" on your meds and there's a good chance they will stop working for you.



Adherence is an important and sometimes difficult challenge.

Once again, a study has proven the importance of treatment adherence.

In a clinical trial, half of a group of HIV+ people took their meds on their own, in the privacy of their homes (self-administered), while the other half took them in the presence of a health-care worker (directly observed). The half that was directly observed while taking their meds did not miss any doses.

Even though the people in the observed group started out with lower CD4+ cell counts and higher viral loads, their CD4+ cells went up more than the other group, and their viral loads went down more. They also had less serious side effects from the medication.

If you find yourself skipping doses of your meds, bring it up with your doctor. There may be ways that he or she can share with you to make adherence to your treatment easier. **RW**

Nina Marks is an HIV treatment educator living in Los Angeles.

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Setting Treatment Goals

Why do you go to your doctor? Most people don't think about this question very much. We just go to our doctors because we're sick and that's what we're supposed to do. But what do you really want and expect from your medical care?

If your HIV treatments worked perfectly, what goals would your treatment help you reach? Would you like to return to work, spend more time with family, travel, have a baby or change careers? At first it may seem as if your personal goals are not directly related to your medical care. But think about it. Suppose you want to return to work full-time. If the side effects of your meds cause fatigue, then you may have some trouble reaching this goal. Goals for treatment may also be specifically medical, such as lowering viral load, gaining weight or boosting your immune system.

HIV treatment should allow you to work toward many of your goals, both medical and personal. Your doctor can help you figure out which goals are realistic now, and which ones may need to be delayed until later. When you look at treatment as a way to stay healthy and meet your goals, it becomes easier to stick with your treatment plan.

Think about the aspects of HIV treatment that are important to you. Here are some things to consider:

- Are you most concerned about feeling better and becoming more active?
- Is it more important that the medications bring down your viral load?

- Are you most concerned about reducing the risk of side effects?
- Do you need a treatment regimen that doesn't restrict the types of foods you eat?
- Is it much easier for you to use meds that only need to be taken twice a day?
- Do you want to focus on boosting your immune system?

Remember, you may not be able to meet all your goals at once. So you should be prepared to make some compromises. Everyone has a different perspective on what the goals of treatment should be. Your treatment plan can be tailored to meet your personal goals and treatment needs. **RW**

Source: "Talking with Your Healthcare Provider," a Provider-Patient Relationship Workbook, published by the AIDS Action Committee of Massachusetts, Inc. Reprinted and edited with permission.

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Staff Members

Project ARK Family Advisors

Something That's not a Condom:

Information on Microbicides

by Anna Forbes, MSS

Millions of women are getting infected with HIV because they can't make their men use condoms. About 60% of the 14,000 people infected with HIV every day are women. Most of them get HIV from having sex with their husbands or boyfriends.

Keisha is on the Pill, so she and Michael never talked about birth control. But she does think about HIV. When she asked Michael to use a condom, he said, "Don't you trust me, baby?" Keisha worries about HIV, but not as much as she worries about losing Michael.

When Jack drinks, he gets ugly. Sometimes Irene swears she'll pack up the kids and leave. But what would they live on? Irene knows Jack sleeps around. One time she brought out a condom and Jack blew up. So she just takes her chances.

Keisha and Irene feel they can't ask their men to use condoms. They want to be safe, but they have no way to protect themselves.

Some women use the female condom, a plastic pouch a woman can put in her vagina before sex. Many couples like the female condom, once they get used to it. But the outer ring of the female condom is visible when it's in place. So it may not be a good option for a woman who needs a method she doesn't have to discuss with her partner.

Women need a method that's safe, comfortable, inexpensive, easy to use and that no one has to know about. To meet this need, scientists are working on products called microbicides (my- KRÓ- bi-sydz). Microbicide means "germ-killer". Some people call them "Super Lubes" or "Chemical Condoms."

Microbicides will look like the other over-the-counter birth control products and medicines you get in the drug store now. They will come as creams, foams, gels and inserts. But their purpose will be to prevent infection with HIV and other sexually transmitted diseases (STDs).

Some may protect against both pregnancy and infection. Others will only protect against infection but won't stop a woman from getting pregnant. Some are being tested to see if they are also safe to use in the rectum


(butt) for men who have sex with men or for men and women who have anal sex.

Over sixty products that might work as microbicides have been found already. Now scientists have to find out which ones are safe to use and will work the best. One of them, Carraguard™, is going into final testing this year. It is a gel made from carrageenan, a seaweed product often used as a thickener in ice cream and pudding. In the vagina, Carraguard™ gel covers the cell walls like a coat of paint and makes a temporary barrier that HIV can't get through. Women who used Carraguard™ in safety tests found it didn't irritate their vaginas. Now 5,000 women are volunteering for a study to see how well it prevents infection in "real world" conditions.

Another product moving toward final testing is BufferGel. BufferGel works by keeping the pH balance in a woman's vagina low even after sex. This helps disable any HIV that enters her during sex and lowers her chances of getting infected. If BufferGel passes the rest of its safety testing, it will be tested next to see how well it prevents infection.

If Carraguard™, BufferGel or any of the leading products really works, we could have a microbicide in the stores within the next five years. These new microbicides aren't available now because they are still being tested to see which ones work. This process would move faster if there were more money to do testing. Right now, only two cents out of every dollar the U.S. government spends on AIDS research goes toward finding a microbicide. Without more money, finding an effective microbicide could take a lot longer than five years.

It's time to say that condoms alone just aren't enough. Keisha, Irene and millions of others need to have other ways to protect themselves. The time for microbicides is now.

For more information about microbicides, contact the Global Campaign for Microbicides at phone: 202-454-5048 or on the internet at www.global-campaign.org. 

Anna Forbes is a writer, teacher and community organizer who has been working on HIV/AIDS issues since 1985.

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JOINING A COMMUNITY ADVISORY BOARD

By David
Mariner

Background Information on CABS

Community involvement is an important way of keeping AIDS research on the right track. There are many ways to get involved. One way is to join a clinical trial. Another way is to become active in the planning and development of research trials.

Many local and national AIDS research networks receive advice from members of HIV-affected communities through Community Advisory Boards (CABs). CABs are patient advisory groups that give the patient's perspective on whether a trial offers ethical, reasonable approaches to the issues that are relevant to that community.

CABs provide input at all levels of the research process, from what will be studied, to the design and running of the trial, to assistance finding and keeping volunteers in the trials.

It was not always like this. Up until the late 1980s, meetings of AIDS research groups did not include patient representatives. This was changed through the hard work of activists.

Today, government-funded clinical trial networks are required to set up CABs. Each local CAB elects members to serve on a nationwide Community Constituency Group (CCG). This system allows the leaders of the national networks to hear the concerns of community members.

One Man's Experience

"I had always wanted to have more involvement and a voice in AIDS research," said Willis Courtney of Washington State. So Willis decided to become a member of the Washington Regional AIDS Program CAB.

"My first meeting was straight forward. Everyone made me feel comfortable by introducing themselves and letting me know about their involvement on the board. When the meeting was over I was overwhelmingly impressed by the involvement of the CAB in clinical trials and studies. It was like a dream come true – I would get my chance to become involved in AIDS research!"

Willis acknowledges that being a CAB member can sometimes be intimidating. There are lots of new terms to learn and understanding the research process can take time. He believes that having a mentor was a key part of his success; "My mentor, Brian Mahoney, got me started by going over information that he had in his archives. I still tell everyone how he sent me home with an armload of research!"

What makes Brian a good mentor? According to Willis: "Brian is very knowledgeable because of his years of experience and involvement in the field of AIDS and he has a lot of patience to teach. He was very willing to work with me until I understood the new concepts."

Willis has come to enjoy his time working at CAB meetings: "When we meet, we greet one another with hugs and smiles. To me it's like a reunion. We come together ready to take on our responsibility as CAB members."


His advice for new CAB members? "Just sit back and be yourself, give your full attention to what's going on and take notes. I found that taking notes in my own words allowed me to understand what was being said. Brian was very good at teaching me how to interpret studies and to break them down to understand what I had read."

Getting Involved

While all HIV+ people are encouraged to become active members of CABs, it is important to be well informed about treatment issues in order to make a valuable contribution.

As well as working with a mentor, you can prepare by attending treatment education workshops and programs at local AIDS organizations, African-American HIV University (www.blackaids.org/university/) and NATAF meetings (www.namc.org, click on conferences and then NATAF). Also consider joining the AIDS Treatment Activists Coalition (ATAC) at www.atac-usa.org.

The following AIDS research networks have opportunities for community representatives:

- Adult AIDS Clinical Trials Group (AACTG): aactg.s-3.com/ccginfo.htm
- Community Programs for Clinical Research on AIDS (CPCRA): www.cpcra.org/index.htm
- Pediatric AIDS Clinical Trials Group (PACTG): pactg.s-3.com/inccg.htm
- HIV Prevention Trials Network (HPTN): www.hptn.org/community_program.htm
- HIV Vaccine Trials Network (HVTN): www.hvtn.org/community/ 

David Mariner is a community educator with CPCRA.

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By Sandra K. Trisdale, Ph.D.

Resources for HIV+ Heterosexuals

Straight and HIV+? Sometimes feel like you're the only one around? Getting connected can often be more difficult for HIV+ heteros. Try some of the following resources to help you get started:

Internet Resources

The Body: www.thebody.com

Links to dozens of excellent HIV websites.

The Center for Positive Connection: www.positiveconnections.org

Newsletter, links, social events, educational lectures, personal ads, HIV+ hetero cruises.

Heterochat: www.geocities.com/SouthBeach/cove/1812/home2.html

Chat room (English and Spanish), links, info on HIV+ hetero summits and conferences.

HIV Straight: www.geocities.com/gene316

Chat room, links, personal ads, support, upcoming events in the hetero community, lists of hetero support groups around the U.S.

Magazines

Currently, there is no magazine aimed solely at HIV+ heterosexuals. However, there may be articles of interest in the following:

POZ magazine and POZ En Espanol: (800) 9READPOZ or www.poz.com.

Body Positive Magazine and SidaAhorá: (212) 566-7333 or

www.thebody.com/bp/bpix.html. Body Positive also runs social events in the NYC area.

Newsletters

Some of the best newsletters involving hetero issues are aimed primarily at HIV+ women. (But guys love them, too.)

Women Alive: (800) 554-4876 or (323) 965-1564 or www.women-alive.org.

WORLD (Women Organized to Respond to Life-Threatening Diseases): (510) 986-0340 or www.womenhiv.org.

Subscriptions to the magazines and newsletters are available, with a donation requested from those who can afford it. Don't forget your local AIDS service organization. Many support and social groups start on the local level. 

Sandra K. Trisdale, Ph.D., an expert in HIV and mental health, writes frequently for PositiveWords, WORLD, and other HIV-related publications. She lives in San Diego, CA.

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Calendar of Events

Cardinals Game-Sept. 13

CAB Meeting-Sept. 19

Annual Pumpkin Prowl-Oct. 26

Preventing the Flu

By Nancy Wongvipat, M.P.H.


The flu is caused by the influenza virus. A case of the flu can sometimes develop into pneumonia. Vaccination, although not always effective, is one of the best ways of preventing the flu. It is recommended that all people with weakened immune systems (such as HIV+ people) get flu shots.

Although vaccination may cause a small, temporary increase in viral load, getting sick with the flu could be worse. Wait four weeks after you get the flu shot to measure your viral load so that you do not see this false result.

Other possible side effects include pain, redness and swelling where you got the shot. You might also feel some weakness, fatigue or nausea for a day or so. Some flu vaccines can cause an allergic reaction in people who are allergic to eggs.

Although vaccination has been shown to work better for people with at least 200 CD4 cells, it is also recommended for those with fewer CD4 cells. Vaccination is recommended for HIV+ children and for HIV+ pregnant women who have not received a flu shot in the past five years.

There have been rumors that the flu shot is bad for HIV+ people, but flu shots have been studied more than any other vaccination for people with HIV. They are considered to be safe and effective.

Flu season is from November until April. A different vaccine is offered each year, based on the most active type of flu. Healthcare providers recommend that you get your shot sooner rather than later, especially as it takes up to 1-2 weeks for the vaccine to become fully effective. For best protection, you should get the shot by mid-November, before flu season. Get the go ahead from your doctor before getting the flu shot. 

Nancy Wongvipat, M.P.H. is Manager of Prevention Programs at AIDS Project Los Angeles.

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Why Some HIV+ Teens Won't Take their Meds

By Bryan Robinson

Taking anti-HIV medications is hard for everyone, but it can be particularly hard for HIV+ teenagers. Experts say refusal to take medication can represent the rebellion and growing pains teens undergo as they seek independence. It can also reflect their desire to feel normal – they do not want to take medicines when none of their friends do. They may also feel depression over their illness, especially if they have watched their parents die.

Donna Futterman, a doctor who works with HIV+ teenagers, points out that some teens who were born with HIV and have grown up with the disease also have trouble taking medicine. This negative attitude towards anti-HIV drugs may have come from the early days of treatment when some patients used AZT just before they died. Dr. Futterman said: "If one of your parents died while on medication, you lose a lot of hope. 'My mother died, why am I going to live?'"

Some HIV+ young people wind up in foster care after losing a parent. "We've found that those who have been bounced around in foster care have really had a hard time keeping up with the medicine simply because they have not had the role models, someone who could show them that the illness is not necessarily bad," said Chris Waisman, a social worker who works with Dr. Futterman. "They will frequently feel that since the illness is bad, then I am bad. A typical way to deal with these bad feelings is to deny them."

Treating feelings of depression, isolation, fear and denial can lead teens to a better attitude towards themselves and taking anti-HIV drugs. For help and support go to: www.adolescentaids.org. 

Bryan Robinson is a reporter for ABCNEWS.com in New York City. A longer version of this article first appeared on ABCNEWS.com in April 2002.

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Good habits, established early, will reap long-term rewards.

HIV+ Teens By Desiree Minott

Building a Relationship... with your Medicines

Taking anti-HIV medications is a lifelong responsibility. The question is: How can you take on this challenge? The answer is to build a relationship with your medications, almost like a marriage.

Many HIV+ teens feel there are three things you need to build a strong marriage with your anti-HIV drugs:

TRUST

You must trust that the medications are going to work to help you live a longer, healthier life, if you take them correctly. If you don't know how your anti-HIV medications work to keep you healthy, ask your doctor or nurse. (It is also important to have a doctor you trust!)

You need to believe that the benefit of a healthy life is worth taking the drugs, even though there are going to be good and bad times. There are going to be times when taking your medications will make you feel sick with side effects like stomach aches or nausea. There may be ways your doctor can help you manage these side effects so that you feel better. Trusting that the good that will come from taking your anti-HIV medications outweighs the bad is the first step towards building a strong relationship.

COMMITMENT

You must be committed to taking every dose of your anti-HIV drugs, every day. (This is called adherence.) You have to realize that there are no holidays or days off from taking your medication. That is why it so important to choose which drugs to take wisely.


When you are planning your drug regimen with your doctor, try to come up with drugs that have dosing schedules, side effect profiles and food requirements that fit in with your lifestyle and daily routine. Then make a commitment to take your pills.

Just like in any relationship, there may be difficulties. You may not want others to know or notice that you are taking pills, especially when you are in school or hanging out with friends. If you are having trouble and find yourself skipping doses, speak to your doctor about the problem. There may be things that can help make your regimen easier to take. Here are some tips:

- Many HIV+ teens have medication dosing times that are before and after school.
- Tell your doctor what you can or cannot do when it comes to taking your medications. For example, how many times a day you can take medicines and how many pills you can swallow at one dose.
- If you have to carry your medications, use a small and discrete jar or pillbox.
- Try using a beeper or pager.

SUPPORT

Many HIV+ teens feel they could not have made it without the support of friends, family and medical staff. Build a support system that includes regular trips to the doctor for check ups. Things like substance use and depression can get in the way of good adherence. Don't be afraid to ask for help if you are dealing with tough issues.

Once you have trust, commitment and support in place, you are on your way to building a strong marriage with your medications. 

Desiree Minott is a health educator working with teens with HIV in Harlem, NYC.

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Kid Stuff

By Amy Buch

Keeping HIV+ Kids Healthy and Happy

Every parent wants his or her child to be healthy and safe. When your child is HIV+, there are some extra steps to take to make sure that he or she gets the right care. However, just as HIV+ adults are living longer, healthier lives with improved treatments, so too are HIV+ children. In fact, a November 2001 study showed that the use of anti-HIV medications reduced the risk of death by over 50% in HIV+ kids.

HIV is somewhat different in children than in adults. HIV+ children normally have much higher CD4 cell counts than adults, but may also have higher viral loads (the amount of HIV in the blood). HIV+ children are challenged by the fact that HIV is attacking their developing immune systems. As a result, HIV+ children are more likely to get bacterial infections such as pneumonia or sinusitis (inflammation of the skull that opens into the nasal cavity). HIV+ children also may be more likely to have diarrhea or thrush. Sometimes, the signs of HIV in children appear on the skin. Conditions such as warts or molluscum contagiosum (small bumps on the skin) appear among HIV+ children.


Recommendations have been made to prevent both HIV+ children and adults from getting opportunistic infections (OIs), diseases that attack the body when the immune system is weak. All HIV+ children up to the age of one are given medicine to prevent pneumocystis carinii pneumonia (PCP), a type of pneumonia that is more likely to affect HIV+ individuals. After the first year, some children will still be given medicine depending on their immune systems. If an HIV+ child tests positive for exposure to tuberculosis (TB), other medicines

will be given to keep TB from developing. Depending on the child's age and immune system, medication might also be given to prevent mycobacterium avium complex (MAC), which is caused by a germ that can affect the lungs or the gut. In some cases, these kinds of preventative medications can be stopped as the immune system becomes stronger. Getting your child vaccinated and following these guidelines will help to keep him or her from getting sick. In addition, it is important to get regular check ups from a doctor experienced in treating HIV+ children to monitor your child's needs for anti-HIV medications.

Recognize that no parent can protect a child from every germ. While you may want to keep your HIV+ child from people who have colds and the flu, know that your child will eventually be around someone who is sick. Teach your child to practice frequent and thorough hand washing. Because children often rub their eyes or put their fingers in their mouths or noses, keeping hands reasonably free from germs can help keep your child well. As soon as possible, teach your child how to blow his or her nose. Follow the same precautions that you would for an HIV+ adult

to make sure that food is safe.

Any childhood illness can be hard for parents as well as for their kids. As a parent, you might find yourself wishing that you could be sick instead of your child. You may feel frustrated because the treatment or prevention that you need to give your child makes him or her uncomfortable and is hard to watch. You may feel helpless when there is not a good way to explain the situation to your child. You might also feel discouraged if your child gets sick and has diarrhea, which may set back your toilet training goals. Remember that these are normal experiences and feelings for any parent. While you want your child to be healthy and safe, try to avoid keeping him or her from enjoying normal childhood experiences. After all, this time should be the beginning of a long and *healthy* life together!

Guidelines for the treatment of HIV+ children are available at: www.hivatis.org/trtgdlns.html#Pediatric. 

Amy Buch, M.A. is the Director of Prevention Programs at the University of California in Irvine and has been teaching people about HIV for 14 years.

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Resource Corner

Preventing Drug Resistance

After starting anti-HIV drugs, most people see their viral load (the amount of HIV in the blood) decrease. Over time, however, some people see their viral load increase, even though they are still taking anti-HIV drugs. This is usually because resistance has developed. There are several possible reasons for this.

Poor Adherence

This means not taking drugs according to the instructions. For example, if you are supposed to take an anti-HIV drug twice a day, it is very important to do so: not just once, and not to skip days. If you don't follow these directions carefully, there might not be enough medication in your body to fight HIV effectively. This can cause resistance.

Drug Interactions

Some drugs speed up the way your liver breaks down protease inhibitors and flushes them out of the body. This can reduce the amount of drug in your body and allow HIV to multiply. Make sure that your doctor knows about all drugs you are taking (including over the counter, herbal, alternative and street drugs) in case you need dose adjustments.

Ineffective Drugs

Many HIV+ people already have forms of the virus that are resistant to one or more drugs. Try and find three or four drugs that are effective against your virus. A combination of these drugs will help control HIV, even if there is already some level of resistance present.

Detectable Viral Load

If your viral load is not undetectable, the virus will continue to multiply. When it multiplies, it might become resistant to the drugs you are currently taking and, possibly, to drugs you have not yet taken (cross-resistance).

Everyone agrees that the best thing is to prevent resistance in the first place. Speak with your doctor about your concerns and, above all, make sure you are taking your medications correctly. **RW**

Written by PositiveWords Staff Writer.

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Utility Assistance Phone Number DFS LIHEAP 314-340-7600
New Life Evangelistic Center 314-421-3020
Human Development Corp (HDC) 314-535-7607 south city
314-613-0019
Urban League of Metropolitan (314) 652-6954
Project Hope (314) 421-7012
Salvation Army (314) 771-3460
Dial Help (314) 371-4357
St. Vincent Depaul Society (314) 531-7837 food, utility, and
rent
United Way (314) 421-4636
Isaiah 58 Ministries (314) 776-1410
Franciscan Connection (314) 773-8485
Southside Catholic Community Services (314) 773-6100

If you are looking for more resources please contact your
Case Manager.

This newsletter was produced using PositiveWords.com, a web site created by Dallabrida & Associates and made possible by an unrestricted educational grant from Agouron Pharmaceuticals, Inc. This site provides information to help people living with HIV/AIDS who wish to take an active role in managing their own health. The information in this newsletter is meant to complement, not replace, the advice or care of a medical professional. Please consult with your health care provider(s) before you decide that you have a particular medical condition or start or change any particular treatment.

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