

Being ALIVE!!!

Welcome from the Director

My name is Lisa Purvis and I joined the ALIVE study in June 2001. I am a graduate of Johns Hopkins Bloomberg School of Public Health and have worked in the area of infectious diseases and AIDS for many years. Because of this, I have long known of the ALIVE study.

It is an honor to be working with our study team and with you, our participants. It is amazing to me that so many of you have been with the study for so many years! I admire the commitments that you have made.

In the future, we hope to provide more health information in our clinic. You may have noticed in the last few months that we have provided up-to-date information in our interview rooms and on the bulletin board in the waiting room.

But these aren't the only changes - you may have also noticed the addition of artwork and framed pictures throughout the clinic. A talented local Baltimore artist, Samm Martin, has generously loaned the paintings in the waiting room and the hallways to us. Many of the framed pictures in the hallways were donated by Johns Hopkins.

I look forward to working with and meeting with you at your next visits and welcome all suggestions and comments!

Sincerely,

Lisa Purvis

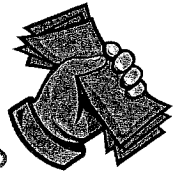


Inside this issue:

Clinicians' Corner	2
Sex and STD's Myths & Facts	3
CAB Corner/ Health Resources in Baltimore	4
More News / ACASI	5
Update on New Studies and Ongoing Studies	6
Update on New Studies (cont...)	7
New Employees / Other News	8

Here is some Information you Need to Know to Make your Visit at the Clinic Smoother

- **Check Cashing** - Balmer Pharmacy has been bought out and the new pharmacy no longer cashes checks. Ace Check Cashing in Old Town Market has also gone out of business.



So, where can I go to cash my checks?

Broadway Pharmacy at 1645 East Baltimore Street will cash ALIVE checks. But the best method is to have 2 forms of ID including a valid state issued ID that you can get from the MD Department of Motor Vehicles. This will allow you to cash checks more easily and at local banks.

- **Rescheduling Appointments** - if you have an appointment but find you have another commitment, please call and reschedule for another day. If you are in the Clinic and realize that you have another appointment, please reschedule at the front desk.
- **Length of Time in the Clinic** - we are working on ways to improve the time that you spend in our Clinic. But, the time our participants spend in the Clinic varies depending on what you are in the Clinic for.
- **Medical Records** - The ALIVE Study is a confidential re-search study. We only release your records if you ask us to. We have a consent form that you must sign before we release your records.

If your doctor or other health provider needs to see your records, please let us know when you come in for your visit and you can sign our consent form. If you want to take a copy of your records with you, there is a 2-day turnaround time for our staff to prepare them for you.

- **Visitor Policies** - For health reasons, some ALIVE participants have caretakers. Because ALIVE is a confidential study, participants are not allowed to bring escorts with them inside of the Clinic. If you need an escort, ask him/her to drop you off at the Clinic. After you complete your visit, you may use our telephone to call your escort to pick you up. Unfortunately, children are never allowed in the Clinic.
- **Food in the Clinic** - we know that it sometimes can be a long wait and that sometimes you are in the clinic around lunch time... please feel free to bring a snack in the waiting room and interview rooms. Unfortunately, snacks are not allowed in the lab, the Clinicians' offices or the ACASI rooms.

Clinicians' Corner

News from Eileen Hollander and Kathy Woodruff, Nurse Practitioners



SO WHAT'S THE BOTTOM LINE ON HIV AND "UNDETECTABLE" VIRAL LOAD?

HERE'S WHAT IS DEFINITELY NOT TRUE:

X "Undetectable" Viral Load means I no longer have HIV --- NOT TRUE

X "Undetectable" Viral Load means I cannot pass HIV to my sex partner --- NOT TRUE

X "Undetectable" Viral Load means it is okay for me to share drugs and tools (needles, water, cottons, filter, cooker, snorting straws) with someone --- NOT TRUE

IF YOU HAVE ANY QUESTIONS ABOUT HIV OR VIRAL LOADS PLEASE ASK TO SPEAK WITH ONE OF OUR INTERVIEWERS OR CLINICIANS.

HERE'S WHAT IS TRUE:

- √ Having an "Undetectable" Viral Load is excellent for your health, but it does not mean you don't have HIV anymore.
- √ Once you are HIV positive you are always HIV positive. So far, there is no cure.
- √ If you have an "Undetectable" Viral Load you still have HIV and you can still pass HIV to your sex partner through oral, vaginal and anal sex.
- √ If you have an "Undetectable" Viral Load you can still pass HIV to someone with whom you share drugs or tools (needles, water, cottons, filter, cooker, snorting straws).
- √ No matter how "good" your Viral Load is you can still pass HIV to your sex partner and to someone with whom you share your drugs and tools.
- √ If you are HIV positive, it is important to have your Viral Load checked every 3 to 4 months so you will know if you need treatment. Although medications can't cure (get rid of) the virus, they can be very effective in controlling the virus and in keeping you healthy.

SEX AND STD'S (SEXUALLY TRANSMITTED DISEASES) MYTHS & FACTS!

MYTHS! THESE ARE NOT TRUE!

X It's okay to have unprotected sex if my partner and I are both HIV positive. NOT TRUE!

X Oral sex is safe. I don't need to worry about using protection if my partner and I only do oral sex. NOT TRUE!

X If a woman has unprotected sex with someone and then douches afterward she won't get HIV. NOT TRUE!

X If I haven't caught anything after all these years, I'm not going to. NOT TRUE!

X I'm doing the same thing I was doing before the last time I got tested. I was HIV negative then, so I know I'll be negative again. NOT TRUE!

X If a woman doesn't "cum" (have an orgasm) during sexual intercourse, then her partner can't catch HIV from her. NOT TRUE!

X If a man doesn't "cum" (have an orgasm) during sexual intercourse, then his partner can't get HIV from him. NOT TRUE!

X I won't get HIV because I use condoms "most" of the time. NOT TRUE!

X A woman can't get pregnant if she's on street drugs or methadone. NOT TRUE!

X If I haven't gotten pregnant after all these years, I won't. NOT TRUE!

X If I have a sexually transmitted disease and I get treated, my partner does not have to be treated. NOT TRUE!

X My partner is so nice looking and so clean. I am sure we don't need to use condoms. NOT TRUE!

FACTS! THESE ARE DEFINITELY TRUE!

√ It is still important to use protection even if you and your partner are both HIV positive. TRUE!

√ Oral sex is not safe. You still need to use protection. A man should wear a condom if someone is performing oral sex on him. A dental dam should be placed on a woman's vagina if someone is performing oral sex on her. TRUE!

√ Douching after sex will not prevent a woman from getting HIV or any other STD. TRUE!

√ Just because you haven't "caught" anything before, doesn't mean you won't "catch" anything this time. If you were not practicing "safer sex," you've probably just been lucky! TRUE!

√ Unless you've been practicing safer sex 100% of the time there is always the possibility that your HIV status could have changed. TRUE!

√ Even if you and/or your partner do not "cum" (have an orgasm) during sex, HIV can still be passed. TRUE!

√ Any fluid which comes out of a man's penis or a woman's vagina (before, during or after the "cum") can pass HIV. TRUE!

√ Using a condom sometimes, or even "most" of the time, won't protect you from getting HIV or any other STD. Condoms must be used every time for vaginal, oral or anal sex. TRUE!

√ A woman can get pregnant while she's on street drugs or methadone. TRUE!

√ Just because you haven't gotten pregnant for a long time, without using birth control, doesn't mean it won't happen this time. TRUE!

√ Both you and your partner must be treated if one of you has an STD. TRUE!

√ You can never be certain what diseases someone has or does not have just by looking at them. It is your responsibility to protect yourself and others!!! TRUE!

CAB Corner

Overview of CAB

The Community Advisory Board (CAB) is made up of study participants, study staff, and community representatives who have an interest in the ALIVE activities and want to make a contribution to the study.

The CAB serves as a place:

1. To exchange information
2. Provide feedback from the community about programs
3. Discuss new and continuing projects.

Specific activities include:

1. Commenting on the design of the study
2. Reviewing surveys used in the study
3. Contributing to the ALIVE newsletter



The CAB met on February 15, 2002 and 19 participants attended the meeting and shared many suggestions for the Being ALIVE! newsletter. The CAB also had a great suggestion for the ALIVE study to provide a "Message of the Month" which would be a monthly calendar that would showcase public health information. Look for this in our waiting room area. Thanks to everyone for your time and your ideas!

The CAB meets four times a year, over lunch. The next CAB meeting will be on Friday, August 9, 2002. If you are interested in becoming a CAB member, please call Lisa Purvis, at 410-955-7510.

HEALTH RESOURCES in BALTIMORE

Baltimore Crisis Response Inc. (BCRI)

BCRI is a helping organization serving Baltimore City. It is for those persons who are experiencing mental health problems including feelings of depression, suicidal thoughts, and feelings of being out of control. BCRI operates an Information and Referral Hotline, 24 hours a day, 7 days a week. They also provide in-person and residential care. Please call 410-752-2272 for more information.

The Broadway Center Comprehensive Women's Center (911 Broadway/CWC)

911 Broadway and CWC are programs providing treatment to individuals suffering from substance abuse and/or dependence. The programs also offer additional services like job training and family therapy as well as referrals to

other programs. Please call the following for more information:

- 911 Broadway 410-955-5578
- CWC 410-502-7778

Hepatitis C Support Group

Anyone interested in Hepatitis C or in the support group is welcome to attend. Meetings are on Tuesdays from 1:00 p.m. to 2:00 p.m. in Carnegie Room 240 in the Johns Hopkins Hospital. Call Chuck at 410-614-8353 or just come to the meeting. Food and coffee will be provided.

Narcotics Anonymous (NA)

NA is a society of men and women for whom drugs are or had become a major problem. The group meets regularly to help each other stay clean. Anyone may join, the only requirement is the desire to stop using. Please call 1-800-317-3222 (24 hours/day) to learn more about meeting

times and locations.

Needle Exchange

The Needle Exchange provides new needles for free as well as HIV/AIDS education. To become a participant, you must register on the mobile van or at a participating pharmacy. Participants must be injecting drug users. This program is confidential and no identification is required. Please ask our interviewers or clinicians about specific locations and times of operation for the vans and pharmacies.

These are just a few examples of the resources in Baltimore - there are many more resources available. Please ask to speak with one of our interviewers or clinicians for more information.

More News...

News Flash: Hepatitis C

Doctors are reporting an epidemic of Hepatitis C (HCV) in gay men. However, HCV is not limited to gay men. So if you include anal, vaginal, or oral intercourse among your sexual practices, please use a condom!

People who have both HIV and HCV can feel sicker faster. So, it is very important to see your doctor.

Treatment for HCV has improved so that even if you are not completely cured, the treatment can help a sick liver repair itself.

News Flash: Get to the Root of the Problem

Weight loss, chronic diarrhea, no energy, and noticeable changes in your muscles, might be related to HIV or may be related to some other illness. Therefore, it is very important to get to the root of the problem. Never assume anything! Treating symptoms under assumption or leaving symptoms untreated could be doing your body more harm than good. Find the cause.

So speak to your nurse, counselor, and/or doctor and explain your symptoms. Infections, left untreated, can harm your immune system. As a result, nutrition can become a problem and can lead to weight loss.

Do your body some good! Get to the root of the problem.

Reference: The Body: An AIDS and HIV Information Resource

ALIVE Study in the News

In February 2002, the Food and Drug Administration approved a highly sensitive test that can detect small amounts of HIV and hepatitis C in blood. This allows blood banks to determine the presence of these viruses at a much earlier stage than before, using the previous screening tests. What this means is that the new test, called Procleix and manufactured by Chiron Corp., will protect more people from receiving contaminated blood.

ALIVE participants enrolled in the Gen-Probe Study helped with the testing of this new blood screening test. This is just another way that our ALIVE participants have helped medicine and other people!

ACASI - What is it? Why do we use it?

If you have not been to the ALIVE Study in a while you may not know that you might use a computer to answer some questions on a system called ACASI. That stands for Audio Computer Assisted Self-Interview. The questions on ACASI are some of the same ones you used to answer on paper with an interviewer. The difference is, after an interviewer gives you a short training, you will answer the questions on a computer by yourself to increase your privacy and comfort level.



The ACASI system is very easy and fun to use! You can go as fast or as slow as you want, and it can make the interview process a little faster. We really hope you will enjoy the ACASI system.

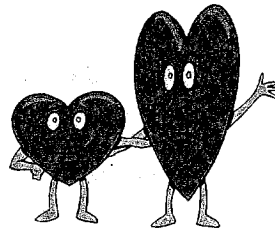
Update on New Studies and On-Going Studies

ACTG 5108

- This is a 23-25 day drug interaction study enrolling healthy, HIV- volunteers that looks at the effects of Efavirenz and Nelfinavir (drugs that are used to treat HIV) when given with Pravastatin, Simvastatin, Atorvastatin (drugs that are used to lower serum cholesterol).
- To be eligible, participants must be HIV-, between the ages of 18-60 and healthy. Women must not be pregnant.
- Please call Ilene at 410-614-2766 or Denice at 410-614-2667 for more information.

CIDUS/STRIVE

- This is an educational and harm reduction project. The study is enrolling Hepatitis C positive and negative individuals.
- To be eligible, you must be between the ages of 18 and 25 years old.
- Please call Karen at 410-614-5799.



The Heart Study

- This is a study about a heart condition known as sub clinical atherosclerosis. This condition happens when cholesterol and calcium form fatty plaque that can lead to blocked heart arteries.
- To be eligible for the Heart Study, you must be between the ages of 25-45 and women must not be pregnant.
- Eligible participants will be required to complete three painless visits.
- Please call Barbara at 410-955-7514 between 11 a.m. - 1 p.m. to see if you are eligible.

Liver Study

- Chuck is still seeing participants already enrolled in the Liver study. If you have not seen Chuck for a while, please call Chuck at 410-955-7510.

NEURO-REACH Study

- This study is looking for people between the ages of 15 to 40 for a study of injection and non-injection drug users. The purpose of the study is to reduce high-risk drug use and sexual behavior among drug users.
- Participants will receive free and confidential testing and counseling for HIV, hepatitis, and STDs. Drug treatment and other resources will be offered. Participants will be reimbursed for their time.
- Please call to call Jonathan at 410-550-6336 for more information and to see if you qualify. Free snacks and beverages provided.

Project ACCESS

- This project focuses on assisting HIV+ individuals with accessing health care and services.
- We are currently recruiting new participants for this study. If you refer someone who is eligible for

Project ACCESS continued....
the study, you will be reimbursed when that person is enrolled into the study.

- If you are HIV positive and would like more information about this study please call **Matt at 410-614-4593** for more information.

Project GIVE

- This is a program that is designed to help children in Baltimore City who are affected by homelessness, and/or intravenous drug use by family members. The program is for families with children between 2 and 18 years of age.

- This program will provide the opportunity to get free hepatitis C testing and free hepatitis B shots for children.

- Please call **Buffy at 410-274-7472** to learn more about the program.

REACH

- This study focuses on HIV and Hepatitis C risk reduction.
- The study is enrolling IV drug users that are between the ages of 15 and 30 years of age.
- Please call **Hank at 410-614-4581** for

more information.

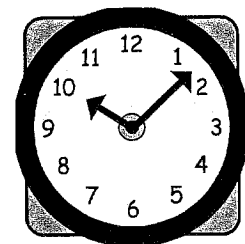


TANG II

- You may have been wondering whatever happened to the TANG study? - We have recently hired a new coordinator, **Marsha**, and she is now seeing those participants enrolled in the TANG study.
- If you have not been seen for the TANG study in a while, please call **Marsha at 410-955-7510**.



Participants enrolled in studies are reimbursed for their time. Please call the individuals listed above to learn the specifics and more about the studies.



New Employees

Nadine
Briggs



You may remember Nadine from our lab where she was our lab tech for many years. Nadine is now an interviewer.

Barbara
Nasir



Barbara joins us from another project at Hopkins. Barbara coordinates the Heart Study.

Marsha
Young



Marsha has worked with a children's study at Johns Hopkins. Marsha now coordinates TANG II study.

It is Never too Late to Return to the ALIVE Study!

Once you are in the study, you are in! If you have not been to the Clinic in a while, please call us or drop by to schedule an appointment.

Come and see us soon!

1235 East Monument Street
Suite 250

Telephone: 410-955-7510

Toll Free Telephone: 1-877-955-7510

Thoughts for the Season from the ALIVE CAB meeting:

"Don't take anything for granted."

"You don't appreciate what you have until it's gone!"

Address Lottery

Call us or stop by with your new and correct address and enter a \$25 Lottery. The winner will be drawn at the next CAB meeting. The winner does not have to be present at the meeting to receive the prize.



Suggestion Box



We welcome your thoughts and suggestions! Please feel free to provide us with your input about the study or if you would like to contribute to the newsletter, by leaving a message in our Suggestion Box that is in the waiting room.