



The 411

All the news that fits we print

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“GIRL TALK” WITH THE AIP YOUTH BOARD

AIP's Youth Taking Charge Board has a history of making an impact on the community; but its latest project is among the most personal and most effective venture yet. Members of the Youth Board were approached by People Using Media to do Prevention (PUMP), an organization that provides HIV education through video production and trainings, to collaborate on a special project. As Katia Perea, PUMP outreach worker, explains, "Youth Board members have such an extensive knowledge of health information, but at the same time are going through all the same adolescent experiences as their peers. They provide a unique and very important perspective."

In a video entitled "Girl Talk," Perea facilitates a dialogue with six young women from the Youth Board. Set in an informal style, the

video mimics a conversation that might occur among any group of girlfriends. The topics range from sexual identity to basic health facts, demonstrating the ease with which Youth Board members discuss a range of challenging issues. Sujeidy Marte, one of the youth featured in the video, explained, "It was a really great experience working with other girls who felt the same as I towards prevention. I think we were successful at getting out the message that sex can wait." Another of the recurrent themes is the widely held misconception among youth that if a person is HIV positive, he or she "looks sick." As several of the girls point out, *(continued on page 5)*



New York-Presbyterian Reflects on 15 Years of Perinatal Transmission Study

by Seydi Vazquez

The Women and Infant Transmission Study (WITS) has been in existence since 1987. Conducted at New York-Presbyterian Columbia Campus as well as six other United States sites, WITS is a clinically based observational cohort study that utilizes clinical, behavioral, developmental, laboratory and pathogenesis in order to gain understanding of HIV+ pregnant women and their children.

The study has played a significant role in defining the determinants of perinatal HIV transmission and the implications of HIV-1 infection on the mother and infant. The study has a database and specimen repository that

spans the various eras of therapy - pre-anti-retroviral therapy, monotherapy and present potent combination therapy. It provides an opportunity to examine the evolving natural history of infection, the effect of therapy on HIV pathogenesis and the consequences of therapy on the overall health of HIV-1 exposed and infected children and their mothers.

It will also help gauge the long-term impact of ART on HVI-1 infection in clinical practice and explore whether in utero and postpartum ART exposure is associated with untoward effects in uninfected as well as infected children. *(continued on page 6)*

Hot Topics

Message from Emily

During the year following 9/11, I was able to participate in a very special project folding origami cranes. This was a way for the Project to recover and move forward after September 11th. Folding 1,000 origami paper cranes is a powerful worldwide symbol of peace and long life. Over several months I taught the staff of all Project sites how to fold a crane. Next I visited each site and taught children, youth, parents, grandparents and caregivers how to fold a crane. During this time, the Project also received a donation of several hundred cranes from a town in Japan that wanted us to know that they supported us during such a difficult time. Together, we far exceeded the goal of making 1,000 cranes. The cranes have been distributed among the five sites for display. If you remember making some and haven't seen them around the clinic, bug your program coordinator!

This was a wonderful project for me to be a part of. I do not get to visit the sites as often as I'd like and it's rare that I get to spend time with our consumers. Thank you so much everyone!

Emily Nishi, Project Director



HIV+ artist Judy Ann Seidman created this mural for an activist organization in South Africa working for HIV/AIDS awareness. Her work is featured by Visual AIDS, a program that strives to increase public awareness of AIDS through the visual arts, raising money to provide direct services to artists living with HIV/AIDS. For more information on Judy Ann and other HIV+ artists, please visit: <http://www.thebody.com/visualaids>.

HIV+ Adolescents Featured on Radio Documentary

WNYC, a New York City public radio station and NPR affiliate, aired a five-part documentary, titled "Growing Up Positive," during broadcasts of NPR's "Morning Edition" March 17 - 21. The documentary profiled a number of children who were infected with HIV at birth, never expected to live past infancy, and are surviving today with the help of highly active antiretroviral therapy. According to WNYC, an estimated 10,000 young people infected with HIV at birth are still alive across the country. As the adolescents attest, growing up with HIV and AIDS forces a person to face life and death health issues. But often their heaviest burdens are emotional. For example, Siomara Cruz is 19 years old. Like others her age, she started beating the odds early - HIV positive children living past age five in the late 1980s was rare. Today, she is discussing the possibility of having children. Other youth featured discuss family issues, career options, and other topics common to the adolescent experience; however, at the same time, they have to deal with adherence to medication schedules, drug side effects, drug resistance, and the other issues that the Project works with everyday. More information about this documentary, including summaries, transcripts and audio links to the segments, is available at www.wnyc.org.

ADHERENCE INITIATIVE DEVELOPS INNOVATIVE CAREGIVER PROGRAM

by Saba Jearld

The Northern Manhattan Adherence Initiative (NMAI) began as a five-year demonstration project funded by the New York State Department of Health AIDS Institute to deliver HIV treatment adherence support services in a clinical care setting. As a Special Project of National Significance (SPNS) grantee, the project has also received evaluation funding and guidance from the HIV/AIDS Bureau of the Health Resources and Services Administration. Currently, the NMAI has received funding to continue adherence support for an additional year, making this the 6th year of the initiative with continued funding.

On March 28th, NMAI held its 9th caregiver support luncheon. The event was a great success, with a showing of 15 caregivers (parents and guardians of children with HIV) hailing from the three different adherence support project sites: Harlem Hospital, Metropolitan Hospital, and New York-Presbyterian Hospital Columbia Campus. Like the other caregiver support events before it, this lunch provided an opportunity for the adult family members of clinic patients to relax, enjoy the company of friends and new acquaintances, and discuss issues relevant to their experiences parenting HIV-positive children.

An HIV positive adolescent, who receives his health care from the Family Care Center at Harlem Hospital, candidly shared his experience of being positive, including his experience with disclosure,

fluctuating health, and battle with anti-HIV medication adherence. This segment, facilitated by a staff psychologist from the Family Care Center, provided an informal opportunity for caregivers to have dialogue with a HIV positive adolescent and to pose questions. Many of the participants were grateful to be able to have the opportunity to talk about their concerns for their own HIV positive children moving into adolescence and their issues with promoting medication adherence for their growing children.

This and previous NMAI caregiver support group events have been made possible by a generous donation from Town Total Health, a licensed and JCAHO-accredited homecare company and pharmacy. The group has evolved since its inception in July 2001, from a collection of NMAI caregivers at a grand celebratory dinner in the Columbia University Health Sciences Faculty Club, to an ongoing, stable source of social support. Whereas the earlier events were led by a featured speaker, the recent lunches have been less formal and more discussion-oriented, with topics and activities suggested by the participants and facilitated by a health educator, Desiree Minott, from the Family Care Center.

In the past, by rotating its location from clinic to clinic with each new event, the group drew caregivers from all three of the Northern Manhattan Adherence Initiative program sites. While

some of the participants had already established close relationships with other parents accessing services at their particular clinic, the convening of a cross-site support group seems to have broadened the sense of community and connection among caregivers in the NMAI program. With the involvement of caregivers from each site in the role of hosting and welcoming others, and with the development of a core set of regular attendees, ownership of the support group has increasingly been taken into the hands of its members.

The Family Care Center's offer of a permanent venue has enabled the group to meet on a more regular (monthly) basis and to settle into a comfortable, familiar environment for open discussion, which has nurtured the purpose of the group in building social support, community, and commitment to the health of children and those who care for them.

For more info, contact Saba Jearld at saj2002@columbia.edu



La nutrición

Consejos para reducir su colesterol

por Margaret A. Davis, RD, CNSD

Los aumentos de colesterol en la sangre se están volviendo comunes en personas que toman medicamentos anti VIH. Si quiere evitar tomar medicamentos para disminuir los niveles de colesterol, hacer una dieta baja en colesterol y bajar de peso puede disminuir el colesterol puede ayudarlo. Usted debe reducir la cantidad total de grasa en su dieta. Hay dos tipos de grasa: saturadas (la mayoría provienen de animales pero tambien coco, palma y chocolate) y no saturadas (que provienen de vegetales como el maíz, aceitunas, maníes, etc.) Si usted quiere reducir sus niveles de colesterol, debe reducir la ingesta de la grasa animal o saturadas.

Leer las etiquetas de los alimentos para verificar su contenido en colesterol y hacer cambios en la forma de preparar sus alimentos puede ayudarlo a alcanzar los objetivos mencionados anteriormente. Algunas de las cosas que puede hacer para disminuir los niveles de colesterol son: quitarle la grasa a las carnes, comprar carnes magras (con poca grasa), remover la piel del pollo y otras aves, comer más pescado, evitar embutidos como salchichas o tocino, comer solo la clara de los huevos, hornear o cocinar a la parrilla en lugar de freír. Debido a que las personas VIH+ necesitan altos niveles de proteína, debe incorporar a su dieta frijoles y nueces. Ya que son una buena fuente de proteína y tienen bajos contenidos de colesterol. Reducir las porciones de comida también ayuda a bajar de peso y a disminuir el colesterol. Una rutina de ejercicios que incluya aeróbicos puede ayudarlo a cumplir esos objetivos. Como siempre, consulte con su médico acerca de qué es lo mejor para usted. Buena suerte!

Margaret es una dietista del área de San Francisco, con mucha experiencia en el tratamiento del VIH. Reimpreso por cortesía de www.PositiveWords.com © 2001 por Dallabrida & Associates

Tips for Lowering your Cholesterol

by Margaret A. Davis, RD, CNSD





Increases in blood cholesterol are becoming more common in people taking anti-HIV medication. If you want to avoid taking medications to lower cholesterol, following a low cholesterol diet and losing weight may help. Fats in general should be decreased in your diet. There are two types of fat: saturated fat (which mostly comes from animals, but also coconuts, palm oil, and chocolate/cocoa seeds) and unsaturated fat (which comes from plant sources such as corn, olives, peanuts, etc.).

Reading food labels for cholesterol content and altering your food preparation can help you meet the goals discussed above. Trimming meats of visible fat, buying leaner cuts of meat, removing the skin from poultry, eating more fish, avoiding cured meats such as bacon or sausage, taking the yolks out of eggs, and baking or broiling rather than frying are some of the things you can do to reduce the fat and cholesterol in your diet. Since your protein needs are higher with HIV disease, you may want to incorporate soy, beans, and nuts in your diet as these are good sources of high quality protein and are low in cholesterol. Reducing the overall amount you eat can also help promote weight loss and lower your cholesterol. A regular exercise routine that includes aerobic or "cardio" exercise also helps meet these goals. As always, discuss these issues with your doctor.

Margaret is a dietitian with extensive experience in treating HIV clients in the San Francisco Bay Area. Reprinted courtesy of www.PositiveWords.com (c) 2001 by Dallabrida & Associates

GET INVOLVED! SMART's FIRST ANNUAL "POWER WALK"

 The 1st annual POWER (Positive Women Energized & Revitalized) Walk is scheduled for Saturday, September 13, 2003. This is a fundraising event for SMART (Sisterhood Mobilized for AIDS/HIV Research & Treatment), a NYC based organization led by and for HIV-positive women that provides treatment education skills to enable women to advocate for themselves and other people living with HIV/AIDS. The theme of the walk is "having women in power support women to reclaim their power." For more info, contact Susan Rodriguez at (917) 593-8797. 

The Ryan White National Youth Conference: A Lesson in Community

by Janilda Valentin, AIP Youth Board member

The Ryan White National Youth Conference on HIV and AIDS (RWNYC) is the only national conference dedicated to building the HIV prevention health services and advocacy skills of young AIDS activists, youth peer educators, HIV positive youth and those who work in support of young people.

On the weekend of February 14, I was able to experience one of the best Valentine's Days ever, not because it was Valentine's Day, but because I had the privilege of attending the annual Ryan White Conference. This conference is known all over the world. People come from everywhere to share with us their stories, experiences and a little bit of their life with HIV/AIDS. This year the conference took place in Dallas, Texas. Not only was I able to meet new people, but also I had the opportunity to get to know Texas.

The conference gave me an opportunity to get to know more about HIV and AIDS. We all think that we know what HIV/AIDS is all about, but we actually don't. It's not the same thing when you sit in a room full of people that are sharing with you their life stories, not because they have to, but because they want to. It takes so much courage, not only to stand in front of people and speak, but also to accept this virus. The conference allowed me to understand what a large group of people can do when they come together. I never seen so many people come together and have such a great time regardless of whether they knew you or not. Once you were in that conference, everyone there was your friend.

"You sit in a room full of people that are sharing with you their life stories, not because they have to, but because they want to."

The conference ranged from all kinds of ages. Every one there showed the same energy, age was not a problem for anyone. The good part was that unless you shared your HIV status, we would never know who was positive or negative cause we all look the same.

I met people from all over the United States. At the end of the day of each day we all knew that we were there for



The author, conference organizer Robert Warren, and the author's sister, Brily Valentin.

one purpose: to make a difference in the world and the AIDS Community.

I am very thankful for the opportunity that I had and I hope that many people are able to experience what I have experienced for those three days.

Girl Talk Video (continued from page 1)

someone can have absolutely no symptoms; he or she could also not know their own status. Youth Board members will incorporate the video into outreach and presentations.

"Girl Talk" could not come at a more critical time. HIV/AIDS disproportionately affects young women of color throughout the United States - according to the Centers for Disease Control, despite comprising 26% of US female population between 13 and 24, black women and Latinas account for roughly 77% of all reported HIV infections in that age group.

The video has already made an impression. Justine Cuesta, social worker with Metropolitan Hospital notes its true reflection of its target audience. She explains, "not only is the subject matter clear and straight forward, but it's engaging; youth watching see themselves in the video."

To order a video, please contact the Project.

Featured Initiative: Clinician's Disclosure Group by Nancy Cincotta, MSW

The Clinician's Disclosure Group is a cohort of mental health professionals who work at Metropolitan Hospital, Mount Sinai Medical Center, New York - Presbyterian Hospital, Columbia Campus, and Harlem Hospital. We meet monthly to discuss the range of issues facing children, their families, and the medical and the mental health providers when information regarding HIV status is disclosed.

The diagnosis of a life threatening illness in childhood impacts on the whole family. AIDS is among the most complex of such illnesses. The needs and desires of all the pertinent family members involved are part of the assessment and decision making process of and how and when to discuss HIV status with a child.

The range of issues discussed in this group has paralleled the nature of the work in this arena. From the time of diagnosis, throughout the individual's life, disclosure remains a pertinent issue. Family systems and caregiver responsibilities are so complex that what may initially seem simple, may have implications on many different levels for the child and caregivers.

Children, especially as they grow into adolescence, bring with them unique issues of development, unrelated to illness. How is it that children come to know what they know? Knowledge about family systems, illness, and a family's own culture seem at times intrinsic to the child, but in the same way, it may seem children come to know about their own HIV status in a number of informal ways. Challenges facing caregivers who understand that formally imparting knowledge about HIV status can lead to questions which in some cases will represent a dramatic shift in what children believe their family constellation to be. In other cases it may simply confirm information they have already absorbed in a number of ways.

As children age, relationships take on new forms and decisions about disclosing and not disclosing have many new implications. For children, adolescents, parents and caregivers facing and dealing with these complex issues can seem burdensome and frightening. It is often the mental health professionals who help both children and adults to be able to discuss and deal with their unique situations. As a result there has never been a time when this group has come together when

there has not been a complicated situation worthy of discussion with peers, a frustration to work out, an approach to refine, an ethical concern to debate, or support to be offered or sought. The rich, complex and ongoing nature of this work informs and inspires this group.

For more info, email nancy.cincotta@mountsinai.org.

Perinatal Study (continued from page 1)

Currently, we are in the fourth phase of the study. In addition to the previous aims, which include defining the natural history of HIV-1 infection in infants, children and adolescents, the study also aims to determine the immediate and late effects of exposure to ART in uninfected fetuses, infants, children and adolescents.

At NY Presbyterian Hospital we have 99 children and 37 mothers that are in the study. 10% of those patients have been in the study since the beginning. A patient study visit consists of history and physical, neurodevelopmental, laboratory studies such as blood and urine and patient interview on medications, illness, drug use etc. The study visit can add an additional fifteen minutes to the health care. When possible, visits are combined in order to limit the times the patient needs to travel to the clinic.

The success of the study depends on the recruitment of new clients along with the continuing participation of enrolled clients. Over a sixteen-year period the study has been fortunate to have such a large wealth of information on HIV-1 infected pregnant women and their children. Researchers have published over 140 publications such as "Perinatal human immunodeficiency virus infection HIV infection," and "Combination antiretroviral strategies for the treatment of pregnant HIV-1 infected women and prevention of perinatal HIV-1 transmission." The study has played a significant role in defining the way health care providers care for the pregnant HIV-1 infected women and the newborn. With the support of clients, the study aims to continue to gain understanding and provide a rational basis for improving interventions and for understanding the disease and its treatment.

For more information on the WITS study, contact Seydi Vazquez at 212-305-5000.



Partner Spotlight: Harlem United Shares Stories of Success

by Tata Traore



Mariam came to Harlem from Ivory Coast, West Africa. Like many other immigrants, she came in search of greener pastures, and found herself in a dilapidated, overcrowded, one-bedroom apartment, with her five children. For some time she had suffered from persistent illnesses, and so at her physician's advice, she was tested for HIV. When she and two of her children tested positive, she came to Harlem United's Bondala Program, where she was immediately impressed that our staff spoke her dialect fluently, and offered culturally competent services.

Clients are immediately impressed that staff speak their dialect fluently, and offer culturally competent services.

Mariam broke the shackles of isolation and depression; with the help of Bondala staff members, she enrolled in the New York State ADAP program, so that she and her family now receive the medical treatment to which they are entitled. Moreover, with the help of Harlem United's Housing Urban Development program, she now has a two-bedroom apartment. She is a natural leader, and the Bondala staff has enlisted her as a peer leader. Her relationship with her children is stronger now, she and her family are healthier, and for Mariam, "Harlem United is my home, my mother, and my father."

Janette immigrated to the United States in search of a better job, in order to support her large, impoverished extended family in Burkina Faso, West Africa. In particular, Janette wanted to support her mother, who is ill and cannot afford treatment. While working to get established, Janette met another immigrant, also from Burkina Faso, and became pregnant. The father disappeared, and she found herself alone, threatened with eviction from a substandard, unheated, one-bedroom apartment. Janette gave birth to a baby boy, who tested positive, and she then found her way to Harlem United's Bondala program.

Language skills and cultural competence enable the Bondala staff to provide exceptionally effective HIV pre and post test counseling; and with their support, Janette

was tested. After she was found to be HIV positive, she was enrolled in the New York State ADAP program, and now receives medical assistance for her baby and herself. With the assistance of Harlem United's HUD Housing Program, working in partnership with the Bondala staff, Janette obtained a new one-bedroom apartment. For Janette, Harlem United's Bondala Program has transformed her life. She now, for the first time, enjoys peace of mind, and she is healthy enough to have a part-time job to support herself and her baby.

Fatumatta came to the United States from Guinea, West Africa, with her teenage daughter, seeking a better life. She and her daughter lived with her aunt and uncle, and she worked as a hair braider in her aunt's shop. Once she discovered her HIV status, she lived in stark terror that she would be discovered and thrown out. So fearful was she of discovery, that she would always carry all her medications and medical records with her. Fatigue often overcame her, and there were many days that she was not able to work at all; and on other days she chose to work rather than go to her medical appointments. She felt that if she did not work, she would not be able to provide for her daughter.

In time she found her way to Harlem United's Bondala Program, through which she began to gradually overcome her fears. Walking through the doors gave her a sense of relief, for it was here that she was finally able to discuss her health. Through the Bondala Program, Fatumatta got connected with Harlem United's primary care services. Here, she has individual attention and is not overwhelmed, as she was in large hospital systems. The Bondala Program connected her with the HUD Housing Program, through which she was placed in a two-bedroom apartment in Central Harlem, close to her uncle and aunt. Fatumatta now has a home and a safe place, while at the same time she is close to her support system, her aunt and uncle.

For more information about Harlem United's services, please contact Tata Traore at 212-803-2895 or tatatraore@harlemunited.org

UPCOMING CONFERENCES

JULY 9 - JULY 11: WASHINGTON, DC
National Black Religious Summit on Sexuality
(202) 628-7700, www.rcrc.org

JULY 16 - 19: WASHINGTON, DC
New Partnerships for Ending Homelessness
www.aidshousing.org

JULY 27 - 30: ATLANTA, GA
2003 National HIV Prevention Conference
(866) 277-6313
www.2003hivprevconf.org

JULY 30 - AUGUST 1: BROOKLYN, NY
2003 Black Gay Research Summit
(718) 703-4266

AUGUST 15 - 17: DENVER, CO
6th Annual Staying Alive Conference
www.napwa.org

SEPT. 5 - 6: SCOTTSDALE, AZ
4th National Conference on HIV/AIDS and Aging
www.hivoverfifty.org

SEPT. 18 - 21: NEW ORLEANS, LA
The United States Conference on AIDS
www.nmac.org

SEPT. 23 - 25: NEW YORK, NY
Statewide HIV/AIDS Policy Conference
(518) 473-2903
www.hivguidelines.org

SAVE THE DATE!

Friday, July 18

***Changing Times, Changing Lives: Transitioning
HIV + Adolescents to Adult Services***

9 am - 3 pm

A Conference sponsored by the Northern Manhattan Women and Children HIV Project, Children's Hope Foundation, and Abbott Laboratories

The 411 is a quarterly newsletter of the Northern Manhattan Women and Children HIV Project. We welcome your contributions to the newsletter. Please submit articles, information, and announcements to Elizabeth Lee at the phone, fax, address, and email listed below. Thanks to those who contributed to this issue: Janilda Valentin, Seydi Vazquez, Nancy Cincotta, Saba Jearld, Tata Traore.



Northern Manhattan
Women and Children HIV Project
722 W. 168th St.
New York, NY 10032
(212) 342-0154
(212) 342-9097 (fax)
el2127@columbia.edu