



The 411

All the news that fits we print

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Announcements

The 411 is a quarterly newsletter of the Partnership for Family Health (formerly Northern Manhattan Women & Children HIV Project). We welcome your contributions to the newsletter. Please submit articles, information, and announcements to lolani Grullon via the contact information listed below.

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The Family Care Center's Consumer Advisory Board Sets The Record STRAIGHT!

In November of 2003, the Consumer Advisory Board (CAB) of the Family Care Center was re-established and had its first meeting. Previously, consumers of the FCC participated in the larger Harlem Hospital Center Infectious Diseases board. The FCC board was being established to focus specifically on the pediatric program. Among the many things discussed during this meeting was the development of the board's mission statement. After much discussion the mission was decided: **"This board is a way for people who are affected by HIV to express their ideas and have their opinions heard concerning the development, policies and services delivered at the Family Care Center."**

The board has been effective addressing issues such as the selection of a new program logo, examining the effects of frequent medical appointments on school attendance, which was instrumental in encouraging the program to move more quickly to pilot an evening clinic session. Most recently the board has responded to articles published in the New York Post addressing clinical trials and the participation of children at Incarnation Children's Center (ICC) in those trials. During the board's March meeting, copies of the Post articles were distributed. Members felt that since children of the Family Care Center have used the services of Incarnation Children's Center and participate in clinical trials, it was imperative that the board respond and set the record straight. The following is their response:

The recent article "Guinea Pig Kids" written by Douglas Montero and published in the New York Post on Sunday, February 29, 2004, is an example of biased reporting, poor source documentation and, above all, racism. In his article, Mr. Montero refers to events that happened as far back as 1989. He failed to mention, though, that in 1989, all pediatric HIV/AIDS medication was experimental and available only through clinical trial studies. Unlike today, clinical trials were the only access to HIV treatment for all children whether in foster or biological family care. Few medications were available to adults, much less to infants or children. As parents and families we were scared that our children had few if any treatment options at all!

Please keep in mind that it is very important to have these studies for the sake of all the children infected, affected and devastated by this debilitating disease. As members of the African American/Latino community, we recognize that ever since the Tuskegee experiments on black males with syphilis, Blacks have been reluctant to participate in medical research and/or clinical trials. Institutional Review Boards were established to protect the rights of research subjects so that the unethical and immoral practices of Tuskegee Institute Study could never be repeated. This article serves to undo the progress that has been made as it relates to participation in clinical trials for the benefit of our people.

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EATING TIPS

A strong connection exists between what you eat and your immune system's ability to fight off disease. Eating healthy food is especially important when you are HIV positive in order to increase your physical strength so that you can enjoy life as normally as possible. Good nutrition is a co-therapy that can help to maximize your medical management of HIV disease. Aggressive nutrition can prevent or delay the loss of your muscle tissue, a process that is also called HIV wasting. Research indicates that your nutritional health is a major factor influencing HIV survival. Currently, there is no cure for HIV disease or AIDS, but you can affect the disease process and improve the quality of your life by maintaining a positive attitude and a healthy lifestyle. Some healthy lifestyle changes you can make include:

- following appropriate medical interventions to treat infections;
- choosing to eat healthy food;
- managing stress in positive ways;
- engaging in regular weight resistance exercise; and
- integrating natural or alternative therapies into your personal health management plan.

All of these therapies work together to help your immune system fight HIV. People with HIV or AIDS tend to lose their muscle tissue and protein stores with varying amounts of fat loss. There are three major reasons why you may lose weight, experience muscle wasting and develop HIV-related malnutrition. If you

have a poor appetite, you may not eat enough protein, calories, vitamins and minerals that your body needs; your body's metabolism speeds up during active infection so you need extra calories and protein from food to maintain your weight; and if you have chronic diarrhea, your body loses calories, protein, vitamins and minerals.

Your muscle tissue is very important to keep you strong, maintain body functions and help process medications. You can do this by eating food and drinking fluids high in calories so that your body does not use your muscle tissue for energy during active infection. These types of food give your body energy: complex starches or carbohydrates, simple sugars and fats. You also need food that provides your body with protein to build and maintain your muscle mass. You can choose a combination of animal or complemented vegetable protein sources depending on your preference. You also need to engage in daily and repetitive weight resistance exercise to gain muscle strength.

It is very important to eat small amounts of food throughout the day, even if you are not hungry. A high protein, high calorie eating plan that is rich in complex starches and includes moderate amounts of fat is best for you to help prevent muscle wasting with HIV disease. This may change if you have specific symptoms or other existing medical problems. Your nutritionist or physician can help you decide how to modify your eating plan if you have specific symptoms.

From God's Love We Deliver www.glwd.org

RECIPE CORNER

Strawberry Yogurt Popsicles
Makes 12 popsicles

2 cups fresh (chopped) or frozen strawberries
2 cups low fat vanilla yogurt
12 small paper cups
12 wooden sticks

Combine strawberries and yogurt, mix well, fill cups with mixture, and cover cups with plastic wrap or tin foil. Insert a stick through the plastic wrap or tin foil and freeze the Popsicles until firm. Gently tear away paper cup from frozen yogurt Popsicle before eating.

Remember to supervise children while eating popsicles and throw away sticks after eating.



Adherence Initiative Update by Saba Jearld

The Northern Manhattan Pediatric and Perinatal Adherence Initiative (NMPPAI) is now in its 7th year of continued funding. Throughout the years this adherence intervention has been a collaborative effort bridging the state government, Mailman School of Public Health (MSPH), and local hospitals in order to provide services to specific members of the Northern Manhattan community. During the first five years the project was funded by the AIDS Institute of the New York State Department of Health as a demonstration project. The most recent two fiscal years have been funded with RYAN White Title II monies. Under the overall coordination of the Center for Applied Public Health, the intervention is under the auspices of the Partnership for Family Health and the adherence services are delivered at two clinical sites: New York Presbyterian and Metropolitan Hospital.

The overall goals of the intervention are to improve HAART adherence among HIV positive pregnant women, adolescents, children and their caregivers; to ensure quality and consistency of services; and to continually evaluate processes and outcomes. At maximum the intervention has provided services to over 110 clients and caregivers. Furthermore, services are coordinated at the two sites by specially trained providers, referred to as Intervention Specialists (IS) and adherence services are integrated into the routine delivery of HIV care as much of the clinic staff are involved and work in conjunction with the IS to provide adherence services. Driven by the Trans-Theoretical Model, which conceptualizes the adoption of health behaviors along a continuum of behavioral stages, the project attempts to stage clients, provide counseling and services applicable to their stage, and assist them in maintenance of adherence. After clients are staged and treatment plans are created, client-tailored adherence services are provided. These services include, but are not limited to: pill swallowing training for children transitioning from liquids to pills, provision of reminder tools (i.e. pillboxes, beepers), assistance with integrating HAART into the clients schedule, preparing

clients for and management of side effects, attending clients' appointments with prescribing clinician to assist in HAART explanation, and administration of medicines provision of culturally and linguistically appropriate HIV/HAART literature to clients and caregivers.

In addition to the adherence services the project provides directorship for a group entitled the Caregiver Luncheon. Commencing in the summer of 2001 the project has held over 17 luncheons. Funded by a donation from Town Total Health, a homecare company and pharmacy, the luncheons convene caregivers of clients participating in the project from the three original project sites New York Presbyterian Hospital, Metropolitan Hospital, and Harlem Hospital. Topics covered have included disclosure of status to children, rights regarding research, benefits of attending HIV/AIDS conferences. More importantly, the luncheons have been a place for a core group of caregivers to meet and share with people in similar situations.

Finally, the NMPPAI provides services but it has also opened up the opportunity to collect useful data. On the qualitative data front two field workers conducted semi-structured interviews with 30 parents accessing pediatric HIV care and providing care to at least one HIV positive child at the three original project sites. Subsequently, readers from the MSPH research team have identified and coded themes in the transcripts that explore personal, environmental, contextual, and organizational factors affecting medical adherence and/or treatment adherence. Thus far the 30 interviews have gleaned an invaluable amount of information. Some of the issues presented include challenges and resources for caregivers of HIV-positive children, the relationship between disclosure and medication administration to HIV-positive children, and parent-provider interactions in pediatric HIV care.

Choosing Your First Regimen

By Anne Monroe

Choice is good, right? Definitely! But it can be confusing. Especially if you've decided to get started with anti-HIV treatment and you're trying to pick a first regimen. The goals of anti-HIV treatment are to get the amount of HIV in your blood (viral load) as low as possible and keep it down for as long as possible, to improve your immune system by increasing your disease-fighting CD4 cells, to reduce illness and to improve your quality of life. There are guidelines to help you and your doctor choose your first treatment regimen. But if you take a peek at the guidelines you'll see that there are lots of drugs that are effective and are "Strongly Recommended." So how do you make a choice?

Your first treatment regimen will probably contain a protease inhibitor (PI) or a non-nucleoside reverse transcriptase inhibitor (NNRTI) along with two nucleoside reverse transcriptase inhibitors (NRTIs). This combination will attack HIV at different parts of its life cycle to pack a strong punch against the virus.

The PIs listed in the guidelines as "Strongly Recommended" are probably all about the same in terms of how effective they are against HIV. (The PI Kaletra probably reaches the highest anti-HIV levels in the blood.) Possible long-term side effects of all PIs are changes in the location of fat on your body (fat redistribution), high blood fat levels, changes in the way your body processes sugar (insulin resistance) and kidney stones (with Crixivan). You may also experience changes in liver function tests or inflammation of the liver (hepatitis).

All PIs may cause stomach upset (nausea, vomiting, diarrhea, stomach pain, gas) or a rash. Patients on Norvir may have tingling or numbness in the mouth.

Sustiva is an NNRTI that is "Strongly Recommended." Another NNRTI, Viramune, is often used to treat HIV and is listed in the "Recommended as Alternatives" category. Studies have shown that Sustiva is as effective against HIV as the PIs. Regimens with NNRTIs are considered more "patient-friendly" than regimens with PIs. NNRTIs have easier dosing schedules and, usually, fewer side



effects than PIs. One possible long-term side effect of NNRTIs is liver damage. Additionally, a potential side effect seen with Viramune is hepatitis. In the short term, Sustiva can cause rash, drowsiness, insomnia, central nervous system side effects (confusion, inability to concentrate, dizziness, vivid dreams), stomach upset (nausea, stomach pain) and fever. Viramune may be associated with rash, stomach upset and headaches.

A final consideration when comparing NNRTIs with PIs is that only one mutation in the genetic material of

HIV causes drug resistance to NNRTIs. And not just the NNRTI you're taking; resistance wipes out the entire class of drugs. With PIs, the development of resistance is a multi-step process. Also, if you are resistant to one PI you may not be resistant to the entire class.

There are lots of drugs that work well against HIV. So when you and your doctor talk about a treatment regimen, think about what will work well for you and your lifestyle. Think about the dose schedule and the number of pills, think about side effects and think about resistance. There is no first regimen that is best for everyone, but there are ways of finding out what might be the best one for you!

Anne Monroe is an HIV clinical trials advocate in New York City.

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Cómo elegir el 1er régimen de tratamiento por Anne Monroe

Tener opciones es bueno pero a veces tener que elegir puede ser una tarea confusa. Especialmente si ha decidido iniciar tratamiento anti VIH y tiene que escoger su primer régimen. El objetivo del tratamiento anti VIH es disminuir el nivel de VIH en la sangre (carga viral) y tratar de mantenerlo así por el mayor tiempo posible, mejorar el sistema inmunológico al aumentar el número de las células CD4 que combaten enfermedades, reducir las posibilidades de enfermarse y mejorar la calidad de vida. Existen guías para ayudar a su médico y a usted a elegir su primer régimen de tratamiento. Si usted lee las guías de tratamiento notará que hay muchos medicamentos en la sección de "Muy recomendados". Entonces, ¿Cómo decidirse?

Es probable que su primer régimen de tratamiento contenga un inhibidor de la proteasa (IP) o un inhibidor no nucleósido de la transcriptasa reversa (INNTR) en combinación con dos inhibidores nucleósidos de la transcriptasa reversa (INTR). Esta combinación ataca al virus en diferentes etapas de su ciclo de vida.

Regímenes que contienen IP
Los IP listados en la sección "Muy recomendados" de las guías son prácticamente iguales en cuanto a su efectividad contra el VIH. El IP Kaletra es el que probablemente alcanza los mayores niveles anti VIH en la sangre. Los posibles efectos secundarios a largo plazo de los IP incluyen cambios en la ubicación de grasa en su cuerpo (redistribución de grasa), niveles altos de grasa en la sangre,

cambios en la manera en que su cuerpo procesa al azúcar (resistencia a la insulina) y cálculos renales (con Crixivan). Es posible que también existan cambios en los análisis de la función hepática o inflamación de hígado (hepatitis). Todos los IP pueden causar malestar estomacal (náuseas, vómitos, diarrea, dolor estomacal y gases) o erupciones en la piel. Los pacientes que toman Norvir pueden tener una sensación de hormigueo o adormecimiento alrededor de la boca.

Regímenes que contienen INNTR
El INNTR Sustiva es "Muy recomendado". Viramune, otro INNTR, que es frecuentemente usado como tratamiento anti VIH se encuentra en la categoría "Recomendado como alternativa". Las investigaciones han demostrado que Sustiva es tan efectivo en contra del VIH como un régimen que contiene un IP. Los regímenes que contienen INNTR son más fáciles de tomar que los que contienen un IP. Los INNTR tienen un horario de toma más cómodo y generalmente producen menos efectos secundarios. El daño hepático es un posible efecto secundario a largo plazo de los INNTR. La hepatitis es un efecto secundario posible con el uso de Viramune. Sustiva puede provocar erupciones en la piel, mareos, insomnio, efectos secundarios del sistema nervioso central (confusión, inhabilidad para concentrarse, mareos, sueños vivenciales), malestar estomacal (náuseas, dolor estomacal) y fiebre. Viramune puede provocar erupciones en la piel, malestar

estomacal y dolores de cabeza.

En el momento de tomar decisiones... En el momento de comparar un INNTR con un IP hay que tener en cuenta que una sola mutación en el material genético del VIH causa resistencia a los INNTR. Y no solo al INNTR que está tomando, ya que la resistencia elimina la posibilidad de utilizar a todos los medicamentos de esa clase. El desarrollo de resistencia a los IP es un proceso en varios pasos. Además, si usted es resistente a un IP no necesariamente lo será a la clase completa.

Hay muchos medicamentos que funcionan bien en contra del VIH. En la consulta con su médico acerca de un régimen de tratamiento, piense en lo que será mejor para usted y su estilo de vida. Tenga en cuenta el horario de dosis, el número de pastillas a tomar, los efectos secundarios y las posibilidades de desarrollar resistencia. No existe un primer régimen que sea bueno para todos, pero existen maneras de encontrar el que sea mejor para usted.

Anne Monroe es activista de estudios clínicos sobre el VIH en Nueva York.

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The Latino Experimental Fantastic Theatre, Inc.

The Latino Experimental Fantastic Theater, a nonprofit organization, was founded in 1994 to develop and strengthen social and cultural awareness of Latinos in New York City. Through its interactive theatre and community-based programs, LEFT develops and conducts stimulating productions to reveal, challenge and address cultural, social, economic and political issues affecting the health and general well-being of the Latino population in New York City. Through performances and educational programs, LEFT reaches a multi-ethnic and multi-generational audience from the five boroughs, where the majority of the people are economically disadvantaged or lacking access to the arts and theatre opportunities. LEFT has also played a major role in developing and providing opportunities to emerging playwrights and artists.

LEFT's first productions, "Scenes from the Heart" and "Journey Inward" addressed identity and assimilation issues, and the economic struggles faced by Latinos in NYC. "Some People Have All The Luck" dealt with the spiritual concerns of the Latino community, and "Julia" covered literacy and immigration issues.

LEFT has produced over 25 full-length productions, including but not limited to: "Betty's Garage", focusing on domestic violence, "At Risk", three one act plays concerning teenage pregnancy, AIDS, drug abuse and

special education, "Evelina's Heart", a multimedia play inspired by the life and accomplishments of Dr. Evelina Lopez Antonetty, a Puerto Rican activist and community leader who during the 60's and 70's was at the forefront of the Latino community's challenges in the areas of parent activism, civil rights and community empowerment. Most recently, LEFT produced "For the Love of Liz", a play about the empowerment of women during war times and the role they play in society, and "Positive Women", a play about Latina women living with HIV/AIDS (this production was originally developed in 1997, and is back by popular demand, as part of LEFT's HIV/AIDS prevention program.) "Positive Women" conveys the seriousness of the AIDS situation in the Latino community. It highlights how these women confront their own situations with courage and faith, and serve to inspire their families, friends and communities to become more involved in the fight against HIV/AIDS.

"Positive Women", was presented as part of the first National Latino AIDS Awareness Day Conference on October 14, 2003, during an unprecedented event, and in collaboration with the Hispanic Federation, LUCES (Latinos Unidos Contra El AIDS), the Latino Commission on AIDS and the Clemente Soto Velez Cultural & Educational Center. Over 70 community-based organizations and over 50 community members from all over the City attended this event.

This past year LEFT established the Theatrical Women's Support

Circle. This support circle was developed to educate and empower Latina women (at risk or affected and afflicted by HIV/AIDS) with the tools necessary to join the fight against HIV/AIDS. Utilizing a holistic health approach, and through the direct medium of theater techniques, participants are trained to raise awareness, and develop support groups in their own communities, to further prevent the spread of HIV/AIDS, and other sexually transmitted or drug related diseases. During the past year, LEFT has worked with the Amethyst Women's Project in Brooklyn (Coney Island) and the Ann's Corner of Harm Reduction (SACHR) in the Bronx. During May 2004, LEFT continues with the second phase of the Theatrical Women's Support Circle, and will work with a new site in Manhattan.

For more information on L.E.F.T. contact
Executive Director/Producer
Leticia Rodriguez at
lrprec2@aol.com or 347-526-3787



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The article claims that experimental medications were used on HIV infected children in foster care without proper parental consent and that children were secretly forced to take treatments which were ultimately detrimental to their health and well being.

In our opinion, Mr. Montero failed to report that our children had no other treatment options and that without these few medications many were dying or gravely and acutely ill. Prior to the use of these medications the mortality rate of our children was exceedingly high.

The children at ICC, during the time that your writer referred to, were there because the family dynamics made it impossible for them to go home. There were signed informed consents for all children that were enrolled in the trials. In cases of foster care children, informed consent were only signed by the agencies and the Administration for Children's Services (ACS) after exhaustive attempts to locate any biological relatives of the child. One of our CAB members indicated that his adopted son was a foster child at ICC during the time that is mentioned in the article and participated in the studies. He is now a thriving, energetic, normal 14-year-old adolescent achieving

academically. This adolescent is one representative example of the children that benefited from the access to the clinical trials.

It is extremely unfair and biased for this article to portray only one side of any situation. The Post article displayed little respect for the privacy of the children at the Center. Not only have the children at the Center benefited from the research and studies, so have other children outside of the foster care system. We hope that you do more investigating to find out just how the clinical trials program really works and not judge everyone by one person's alleged account. The Consumer Advisory Board is made up of biological, foster, adoptive, kinship, and concerned community members and we have participated in clinical trials since 1985 through the present.

Consumer Advisory Board (CAB) for the Family Care Center at Harlem Hospital Center, members represent the 250 families that are infected and affected by HIV and AIDS.

The letter was sent to the editors of the New York Post, Amsterdam News and the Daily News. The response, to date, has not been published. However, the board feels that it has been true to its mission of addressing issues affecting persons with HIV.



"Positive Today", 2002
courtesy of Thom Markee
Visual AIDS promotes AIDS awareness
and assists artists living with HIV/AIDS.
For more information, please visit
www.visualAIDS.org

UPCOMING CONFERENCES

July 7 - July 16: Bangkok, Thailand
The XV International AIDS Conference
www.aids2004.org

July 23 - July 25: Tampa, FL.
1st Ujima Annual Men's Conference
(727) 822-2437 www.ujimamen.com/aboutconf.pl

July 24: Washington, D.C.
Capitol Hill Briefing on Latinos and HIV/AIDS
(202) 347-5270 or tford@kff.org

August 12 - August 15: Washington, D.C.
2004 Minority Women's Health Summit
(888) 220-5446 www.4woman.gov/mwhs

August 13 - August 14: Newark, N.J.
Supporting Networks of HIV Care Project Regional
Intensive Training
(800) 861-5640 www.hivta.org

August 30 - September 1: Lausanne, Switzerland
3rd AIDS Vaccine 2004 Conference
aids@akm.ch

Upcoming AIP/PFFH Event:

July 10, 2004
Youth Pridefest

Youth Pridefest provides a fun, safe, and accepting celebration for youth of lesbian, gay, bisexual, or transgender experience or those questioning their sexual orientation (LGBTQ) in Northern Manhattan.

In this positive celebration we encourage the youth to be responsible and make healthy decisions about their health. HIV counseling and testing is offered to those interested. We will have anywhere from 15 to 40 gay youth friendly service agencies ready and willing to connect youth to their services.

It is also FUN! FUN! FUN! There is music, entertainment, games, good food, and most importantly, good company. It is one of the summer's best health related events in NYC!

For location and more information please contact Dawn Dickerson, 212-305-1189.



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