



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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We've Changed Our Name! "Partnership for Family Health"



We have very exciting news to share with all of you! The Northern Manhattan Women and Children HIV Project has changed its name: we are now the "Partnership for Family Health: Northern Manhattan HIV Consortium." The members of the Consortium remain the same - the Mailman School of Public Health at Columbia University, Harlem Hospital Center, Metropolitan Hospital Center, Mt. Sinai Hospital, New York Presbyterian Hospital Columbia Campus, and St. Luke's Roosevelt Hospital Center - and we will continue to provide women, infants, children youth and families living with HIV/AIDS comprehensive, multidisciplinary medical care, mental health and social services, education and access to research and clinical trials. But, under our new name, we hope to be able to achieve even more successful outreach and form even deeper and more effective partnerships

across the city. Emphasizing "Family Health" in the name of our project more adequately represents our model of comprehensive and holistic care - encompassing all our innovative programs, from the Male Caregiver Program to the Adolescent Initiative Project.

Also be on the lookout for our new website, www.pffh.org. This website will enable us to expand our reach to people and organizations associated with the project, keep up to date with current events in the AIDS community and stay in touch with consumers. We look forward to working with all of you to continue our tradition of the highest level of care - while at the same time adapting to the changing needs of the northern Manhattan community.

Who's New at the Partnership

by Iolani Grullon



I'd like to introduce myself. My name is Iolani Grullon and I came to work for Partnership for Family Health in May of this year. It's very exciting for me to be here working for the community where I was born and raised. I was born right here at The Babies Hospital at Columbia

Presbyterian and was raised just a couple of blocks away. I've seen many changes take place in our community in the past thirty years. The quality of healthcare for the people of this community, and especially the quality of HIV/AIDS care is wonderful. The Partnership for Family Health is just one of the many organizations dedicated to improving HIV/AIDS healthcare. I'm very happy to be part of something that has helped in making great changes.

My position here is very different from any of my previous ones and also very rewarding. In the short time I've been here I've already met so many great people and I'm so impressed with the work we accomplish for my community. The mission of the Partnership is something that I hold very near and dear to me, as we all have been affected in one way or another by HIV/AIDS. I look forward to providing outstanding

service to all of you and forming great relationships in the years to come.

Please don't hesitate to call me or email me any time, I'd love to speak with all of you personally.

.....
Quiero tomar la oportunidad de presentarme a la comunidad me llamo Iolani Grullon y vine a trabajar para Partnership for Family Health en Mayo de este ano. Estoy muy contenta de volver a la comunidad donde naci y me crie. Yo naci aqui en Babies Hospital at Columbia Presbyterian y me crie a dos cuadras de aqui. En los treinta anos que tengo en esta comunidad e visto muchos cambios, la calidad de cuidado medico para la gente de esta comunidad especialmente la calidad de cuidado medico para esos afectados por el VIH/SIDA es ecepcional. Estoy contenta de ser parte de algo que a ayudado a crear tantos cambios maravillosos.

Mi posicion aqui es muy diferente a todas mis posiciones pasadas porque esta me gratifica mas espiritualmente. En este corto tiempo e conocido muy buenas personas y estoy muy impresionada con el trabajo que nosotros hacemos para la comunidad. La mision del Partnership es una que yo tomo muy a pecho porque todos hemos sido afectados por el SIDA de alguna manera o otra. Estoy anticipando servirles a todos y formar grandes relaciones en los anos que vengan.

Por favor no dejen de llamar o escribirme cuando quieran, me gustaria hablar con todos en persona.

What's New at the Partnership

by Emily Nishi

The role of a father as a primary caregiver in the life of his children has been viewed somewhat skeptically in the eyes of the 'establishment.' Fathers are changing this image as they become more involved and active in raising their children. Male caregivers in families living with HIV/AIDS have begun to develop a unique voice and presence in Title IV programs. In New York City, men

have been advocating for appropriate services for a number of years. The Partnership for Family Health is responding to these needs by forming a program specifically for male caregivers.

Four men from three sites attended the AIDS Alliance for Children, Youth and Families Voices 2003 conference with Jay Winig, a social worker from Mt. Sinai Hospital. Using the conference as a catalyst, these men along with several others have begun weekly support/advocacy meetings at Mt. Sinai. These meetings provide

a confidential place to talk about issues including stress, struggles of parenting and health issues that they or their children are facing. This is an inspiring group of men who are courageously advocating for their own needs, as well as the needs of their children. If you or someone you know is a male caregiver interested in participating in a support group or a group that focuses on advocacy issues, please contact Jay Winig at 212.241.4645.

The Partnership Looks At The Issue of Transition

by Elizabeth Lee

On July 18th, 2003, a remarkable group of service providers came together to tackle one of the newest issues in the world of HIV/AIDS; transitioning our HIV+ young people to adult services. Organized by the Adolescent Initiative Project of the Partnership for Family Health, and co-sponsored by the Children's Hope Foundation, Columbia University College of Physicians and Surgeons and the New York/New Jersey AIDS Education and Training Center, "Changing Times, Changing Lives" was one of the first conferences of its kind in New York City.

Today, with medical advances dramatically lengthening the lives of HIV+ individuals, adolescents infected both perinatally and behaviorally are facing much more promising prognoses. However, HIV+ adolescents face tremendous challenges as they mature to

adulthood. Transition to adult services, a necessary component of this development, has proved to be one of the most daunting obstacles of all. In collaboration with adolescents, caregivers, and providers, this conference was developed to address the issue of transition for the target audience of service providers working with HIV+ adolescents.

After a brief review of the few long-term studies of HIV+ young people, attendees heard from Dr. Patience White, Executive Director of the Adolescent Employment Readiness Center in Washington, D.C. Dr. White works with adolescents possessing a wide range of chronic health care conditions and disabilities in order to improve their job readiness and life skills. Dr. White focused on the tremendous amount the HIV community has to learn from other

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Joseph, Consumer Advocate at the Partnership for Family Health and Shavonne at the 2003 Voices Conference

Growing Up: One Site's Perspective on Transition

by Robert Warford, NP

Over the past twenty years the advances in the treatment of pediatric HIV infection have led children with HIV and those who care for them on a life's journey. What was once a terminal illness with a life expectancy of less than two years has transformed itself into a chronic illness in a maturing population. As HIV-infected children remain healthy through advanced treatments their transition into adolescence is an uncharted course. The angst of adolescence is a memory we all share. Adding to it the burden of HIV may seem overwhelming. It often is.

Adolescents with HIV are a special group with special medical and social needs. One of the challenges practitioners face in managing adolescent patients with chronic illness is maintaining them in care. Adolescents often feel "immortal" and deny the severity of an illness. Adolescents with HIV disease are no different.

The success of treating pediatric HIV infection has highlighted the problem of how to provide treatment to young adults outgrowing pediatric services. As a rule, as children grow up they move on to adult medical providers. For adolescents with HIV this move fails to consider the significance of the long-standing relationship between the pediatric team and child. Our adolescents have experienced more loss, abandonment and illness than most other children their age. Many children with HIV have seen their parents and siblings die from HIV. Quite often, it is the pediatrician and the pediatric team who serves as the only link to the child's past. (continued on page 6)

HIV Testing in the Latino Community

by Miguel Mejia

We have begun a new millenium and yet within our Latino community we do not fully understand what is happening with HIV disease. Even though there has been a tremendous effort on the part of public health workers to increase awareness about this issue, there remains a great deal of reluctance towards HIV testing within the Latino community.

We should not place all the blame on the quality of the messages or the effectiveness of our health educators and counselors. We need to remember that the images created at the beginning of the epidemic were those of fear, pain and death. Moreover, there were feelings of shame, guilt and taboos to deal with, all of which remain in spite of the new advances.

That's why, today more than ever, we should inform our families, youth and friends about HIV/AIDS. Education should be conducted in a less negative and more responsible way.

The reality is that more and more of our Latino brothers realize they're HIV+ through the following three scenarios:

- 1) When they visit the emergency room because they have symptoms of an opportunistic infection.
- 2) When beginning a new relationship they go to a clinic for a test.
- 3) Through medical recommendation when there is evidence of a sexually transmitted infection.

We have to begin by understanding that HIV/AIDS is contagious and that there is no cure. HIV is preventable and we need to know how to protect ourselves from it. There are many benefits to knowing if you are HIV+. Getting an HIV test is the only way to know if we're infected. This gives us an opportunity to protect ourselves, care for ourselves and not infect other people.

When getting HIV results we should know the following:

- What is a positive result?
- What is a negative result?
- What is an indeterminate result?
- What does it all mean?

Many agencies are already using Orasure as a method to test for HIV. This test is done by rubbing a small sponge inside the cheek to look for the HIV antibodies.

This method does not use needles, so it's not painful. This test has been well accepted by the community because people feel more at ease without the use of needles.

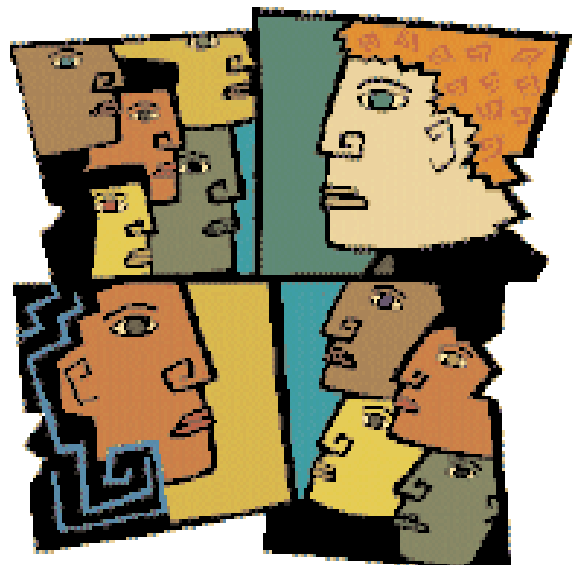
Even when there are doubts, myths and fears within the Latino community, we should continue to educate and promote HIV testing as much as possible. We cannot forget that the Latino community is sensitive to its beliefs and culture when implementing educational messages about HIV/AIDS so that our messages will be more effective. The power of information is indispensable and the credibility of our services are as well. We should be direct and sincere, and educate truthfully without offending one's culture and beliefs.

Getting infected is not divine punishment, but could well be the result of bad sexual education.

For more information on the services and treatment available in your area, please call the National HIV/AIDS hotline at 1-800-342-AIDS (1-800-344-2437) from 8:00A.M. – 2:00P.M. or the HIV/AIDS Treatment Information Service (HIVATIS) 1-800-HIV-0440 from 12:00P.M. – 5:00P.M.

Miguel Mejia is a Health and HIV Prevention Educator and Latino Patient Coordinator for Whitman Walker Clinic in Washington, D.C.

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Newborns Get HIV Tests Sooner

The Comprehensive Newborn Screening Program began mandatory HIV testing for all babies born in New York State on February 1, 1997. Early identification is crucial in preventing mother to baby transmission of HIV. The earlier we identify a baby who has been exposed to the HIV virus, the earlier the anti-retroviral drugs can be administered, thus possibly preventing transmission. This year the New York State Department of Health is cutting the time limit for testing newborns for the HIV virus in order to give drug therapies a better chance of preventing transmission from mother to baby.

According to the New York State Department of Health beginning on February 1, 1997, and continuing through July 31, 1999, the Newborn Screening Program (NSP) returned all HIV test results obtained through newborn screening to the pediatrician of record. It was then the pediatrician's responsibility to report the newborn's HIV test result to the mother. Universal newborn HIV testing conducted through the NSP resulted in the identification of all HIV-exposed births; however, HIV test results were often not

available until two weeks after birth, which is too late to initiate therapy to prevent perinatal transmission. The current guidelines, set in 1999, require informing the pediatrician of the HIV screening result within 48 hours of birth, but that time frame has also proven to be too late to make a significant difference in preventing transmission. Starting November 1, 2003 every baby born to a mother who has not been tested for the HIV virus will be tested within 12 hours of birth, with the results available within one hour of testing. There is no parental consent needed for infants to be tested.

Medical studies have shown that if anti-retroviral drugs are given to newborns within 12 hours of birth, the rate of transmission of HIV from mother to baby is about 6 percent, as opposed to the 25 percent rate of transmission when anti-retroviral drugs are given after 12 hours but within 48 hours of birth. This 25 percent rate of transmission is the same as if no drugs were administered.

For more information on this subject visit www.health.state.ny.us/nysdoh/aids/index.htm



In Memoriam Delia Rodriguez Educator, Artist, AIDS activist

A bilingual teacher in the Puerto Rican public school system and mother of four, Ms. Rodriguez' life took an unexpected turn in 1986 when she was told she had contracted HIV. She was given only two to six months.

As a way of working past her grief, Delia drew upon her experience as an educator and traveled through the United States to counsel other women with HIV/AIDS. For seven years she worked as a health consultant on HIV for such companies as Borinken Health Center, Cicatelli Associates, and various pharmaceutical companies. Delia was also a distinguished sculptor who used art as both a personal catharsis and as a way to communicate the complex emotional terrain of being HIV Positive.

Those who knew Delia and the enormous contribution she made to people living with HIV greatly (sic) her art and her life. She was one of those rare people whose actions took on the beauty, simplicity, and healing that is inherent in the best works of art.

(taken from Ms. Rodriguez' Memorial Service program)

The Partnership looks At The Issue of Transitioning

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disease communities, who have been managing the issue of transition for years.

Attendees then heard from a panel of adolescents who brought to light just how difficult transition is – on both the logistical and emotional levels. They also suggested that much of the work needs to be accomplished on the provider level – the process of letting go for the pediatric providers and the welcoming process for the adult providers. Breakout sessions focused on strategies for successful transition within the fields of medical care, social work/case management, adolescent development, and entitlements. In the afternoon, attendees heard presentations from all of the other breakout sessions to continue the dialogue amongst the larger group.

Conference participants praised the conference for its ‘good speakers,’ ‘good networking opportunities’ and the concrete, applicable strategies developed in the smaller sessions. The Partnership for Family Health is looking forward to developing more tools to assist in the transition process and incorporating the suggestions of participants, including engaging more adult providers, focusing on other psychosocial issues, incorporating the topics of adherence and disclosure, and many more. To receive conference materials or to be notified of upcoming events and opportunities, please contact Elizabeth Lee at el2127@columbia.edu.

Growing Up: One Site’s Perspective on Transition

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To sever the connection between these adolescents and their pediatric team that has long served them would serve to reinforce the sense of abandonment and isolation they commonly experience.

The Center for Comprehensive Care (CCC) believes that the transition from pediatric to adult services must consider the special needs of adolescents with HIV. The CCC is in a unique position to achieve this goal. Our center serves pediatric and adult patients in the same setting providing “one stop shopping” for families with HIV. Medical, mental health, social work, nutrition and child life services are all coordinated in the same clinic setting. This allows ongoing communication between the pediatric and adult teams assuring a continuum of care. The CCC is committed to maintaining the longstanding and strong relationships established with the pediatric team and to provide our adolescents with familiar staff and surroundings.

Many children and families at the CCC have a strong and long-standing relationship with the pediatric mental health and social work teams. The teams are expert in the evolving needs of children and families with HIV. They provide direction and continuing support as adolescents transition into adult services. For the adolescent with HIV, the net result is a seamless transition from pediatric to adult services. The perception to the adolescent becomes one of advancement rather than abandonment. The transition to adult services is enhanced by the ongoing support and input of the pediatric team.

As children pass from adolescence to adulthood to the CCC can begin to transition the child into age appropriate services. For young women these include reproductive counseling, routine gynecological screenings, treatment of HIV associated genital infections, colposcopy, and pre, peri and post-partum care.

This life’s journey we share with our parents has highlighted the progress made in treating and living with HIV. Planning for college, careers, relationships and families has become part of the treatment plan. It is our goal to maintain adolescents in care, enhance their health, well being and development and to prepare them for the challenges for living a life with HIV.

A Day of Fun at Riverbank State Park at the 2003 Youth Pridefest by Hector R. Garcia



The 2003 Youth Pridefest was held this year at Riverbank State Park. The festival was coordinated by the Adolescent Initiative Project (AIP) as well as various other non-profit organizations. The festival included organizations from around the city dispensing information on HIV prevention methods, safer sex kits. There was also a talent show, free food, and other games such as volleyball. Also, Riverbank State Park was a great location, with its hand ball courts, roller skating rink, track and field, an outdoor pool, and so much more.

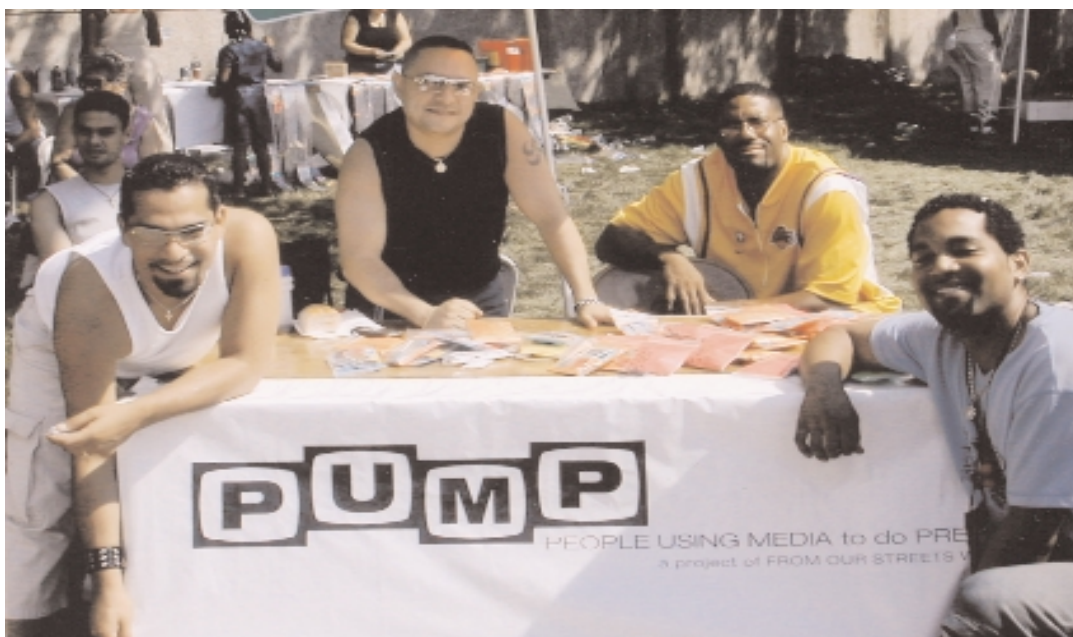
My definition of youth pride fest is a festival where LGBT youth can come and not worry about scrutiny or harm. It's a place where at least once a year, they can come to a place and just be themselves and have fun. I feel that the festival is a place where old friends can meet up and talk about life or where the youth can be informed about health and other related services. HIV

counseling and testing was offered on site as well. Most importantly youth are connected to gay youth friendly providers. At last year's Pridefest, at least one youth discovered his HIV positive status and since then he and his partner are in care at Project STAY (Services To Assist Youth).

The location was great. There was a river front view, which was beautiful. There was plenty of room for people to come and relax and hang out. Plus the location had numerous other options, so if you didn't enjoy what was going on at Pridefest, you can go to the pool or go play basketball, or go roller skate. Though attendance, in terms of gay youth, was down this year, there was quite a mixture this year. From what I understand, there have been complaints about the fact that there were not as many youth this year as there was last year. I agree with that complaint, but would like argue that the mix of "straight" and "gay" could have been just as great. Some say that the Pridefest should be a LGBT only festival and I can agree to that, but in order to bring both gay and straight communities together, couldn't a festival such as this one be used to bring together both communities and try to come to an understanding of one another.

Overall, I thought this year's Pridefest was a success and a small step away from being a totally gay youth event. There could have been more LGBT youth, but overall, The Youth Pridefest was a pretty festive event.

Hector R. Garcia is Health Educator/Peer Coordinator for the Minority Task Force on AIDS.



UPCOMING CONFERENCES

October 13 - October 15: Washington, DC
6th International Conference on Healthcare
Resource Allocation for HIV/AIDS (ICHRA):
Healthcare Systems in Transition
(514) 398-3231, www.iapac.org

October 15: Nationwide, United States
1st National Latino AIDS Awareness Day
(212) 584-9300, www.latinoaids.org/index.shtml

October 20: New Brunswick, NJ
20th Anniversary Conference on Sexuality
Education: Network for Family Life Education
(732) 445-7929, www.sexetc.org

October 30 - October 31: Catonsville, MD
HIV Counseling for Youth
(410) 328-1215, www.thebody.com

November 1: New York, NY
Hands of Hope: Family Matters
(212) 305-1923

November 15 - November 19: San Francisco, CA
APHA
131st Annual Meeting and Exposition
Behavior, Lifestyle and Social Determinants of
Health
(202) 777-2476, www.apha.org

SAVE THE DATE!

Thursday, October 30

***“Get Connected”
Youth Conference***

2 pm - 7 pm

Lerner Hall, Columbia University
2920 Broadway (at 114th St.)

A conference sponsored by the Partnership for Family Health, New York City
Mission Society, Impact, The Valley, Northern Manhattan Perinatal Partnership Inc.,
and Harlem LIVE

For more information please contact Elizabeth Lee, 212-342-0154 or el2127@columbia.edu



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