

CAB-Share The Ride

A Community Advisory Board Newsletter for Informed Families

CAB Feature - Siriraj ID Clinic - Thai CAB Active in 2005

By Uraporn Kottapat

The Siriraj Infectious Disease Clinic Thai CAB in Bangkok has about 60 participants who join the meetings and activities. In August the Siriraj ID Clinic team initiated a CAB registration form and 27 participants registered. During the monthly meetings and focus groups the members share their experiences of child rearing, schooling, and guardian in law issues. The group set several goals for the CAB in 2005 and meets regularly, assessing them throughout the year.

2005 CAB Goals: (1. Get knowledge and information that involve CAB members such as health promotion, adherence, and research that is continuing and/or coming to the Siriraj ID Clinic. (2. Monthly CAB Meetings (3. Encourage Group Support (4. CAB Newsletter (5. Join activities with other CABs (6. Participate in Kid Camp (7. Participate in CAB meetings at October 2005 PACTG Meeting.

CAB Activities: The primary Thai CAB activities are the monthly meetings where group support is priority and topics always involve sharing experiences, problems of members and how to cope with the problems and problem solving. The CAB meetings are also an important place where the clinic care team educates the group members by giving information to support them as care givers to their children. For example, the pharmacist will talk about adherence; a pediatrician will talk about HIV; and there are discussions about health insurance and how to get free medicine. CAB members and their children also joined other NGO or hospital CABs to participate in activities such as an art camp that was organized by HIV-NAT, Kid Camp of Queen Sirikit National Institute of Child Health. The clinic's second Kid Camp was in August 2005 at Pattaya. The objective of the camp was to share HIV disclosure experiences. Next year they plan to send CAB members and their families to join the camp organized by the Thai MOPH. Other activities that involve CAB members are, the chair and vice chair of the Thai CAB, who are active and devoted members, traveled to the United States to participate in the October 2005 PACTG Meetings. A caregiver from the CAB volunteers as a facilitator in the child play area of the Siriraj ID clinic. A 2006 New Year Party on December 25, 2005. A new initiative of the Thai CAB is to set up a peer support group to encourage young people at the site to join the meeting where information is shared. The very first topics will be about HIV knowledge and sex education. The first meeting is expected to be held in a few months. This will build up a strong young people group ready for preparing the Adolescent CAB at the site. (continued on page 5)

January 2006

Second Edition

Published By:

Pediatric AIDS Clinical Trials Group
Community Constituency Group
Advocacy Working Group
HIV/AIDS Research Information
Contributors: Global CAB Members

pactg.s-3.com/cab.htm

Contact: Claire Schuster
CSchuster@s-3.com

In this issue...

- 1
CAB Feature - Siriraj ID Clinic
- Thai CAB Active in 2005
- 2
World AIDS Day: December 1,
2005
Youth Insight into PACTG
Meetings
- 3
Monica's Story - Vulnerability
and Awareness to HIV/AIDS
- 4
PACTG Family Mapping
Project: HIV Vaccine Family
and Community Preparedness
Study
- 5
CAB Feature - Siriraj ID Clinic
(continued from page 1)
Monica's Story (continued from
page 3)
- 6
219C Team Update Letter
HIV/AIDS Trivia - Do you
know?
- 7
PACTG Open Protocols
- 8
Positive Hook-ups: WEB Links
YOUR TURN

Youth Insight into PACTG Meetings

This October several youth attended the PACTG meeting in Washington, DC. I was one of those in attendance my name is Ricky. The experience was fun and I learned a lot. The meetings were well presented. They were broken down into picture format which was interesting to look at and easy to understand. Some terms were more difficult to understand than the pictures. I understand this was a scientific meeting but it would be nice if more plain English was used and a little less scientific terms.

I really enjoyed the meeting with the Principal Investigators. I liked the doctor from Chicago don't know his name, sorry, ... but keep it up man. Hopefully these meetings with the investigators will continue as I learn a great deal from them and I think the youth are providing valuable insight to the investigators. Meeting other youth from around the world has inspired me to speak out more in my local community and hopefully get more youth involved in advocacy and the PACTG.

Ricky

Informational Note: The PACTG CCG has presented CAB Retreat sessions since the December 2003 PACTG Meetings. In August 2004 the CCG initiated interactive sessions specifically for adolescents and investigators. Subsequent CAB Retreats have enjoyed an increase of adolescent participation with six young people attending in August 2004, nine in July 2005 and 15 in October 2005. At the October 2005 PACTG Meetings, the CCG Adolescent Working Group and adolescent members planned and led an afternoon session on disclosure and identified scientific questions for investigators to respond to in an interactive session.

World AIDS Day: December 1, 2005

Did you know that...

- 39 million people around the world are living with HIV/AIDS?¹
- Most people with HIV/AIDS (95%) live in developing countries?²
- In 2004, there were about 14,000 new HIV infections every day?²
- During 2004, about 4.9 million people were infected with HIV, including 640,000 children under 15 years old? ¹
- Young people between the ages of 15 and 24 make up half of new adult HIV infections?²
- Across the world, most people living with HIV do not know that they are infected?³

On December 1, 2005, people from across the globe took a moment to observe World AIDS Day. Since the first World AIDS Day was organized in 1988, communities have come together on December 1st to educate, raise awareness, raise money and take action in the fight against HIV/AIDS. The 2005 World AIDS Campaign organized the global event around the theme "Stop AIDS: Keep the Promise." This theme is a reminder to governments and policy makers to keep their promises about HIV prevention, treatment and care. The World AIDS campaign is inviting people to make their own promises to take action against HIV/AIDS. If you would like to post your promise on the internet, visit the World AIDS Campaign website and click on "World AIDS Day" at: <http://www.worldaidscampaign.info/>

Events were planned from Barbados to Brazil, South Africa to Switzerland, and Nigeria to New York, among many other places around the world. Here are some ideas of what you could do to observe World AIDS Day:

- Talk to your friends about HIV/AIDS, healthy living with HIV/AIDS, HIV/AIDS research, and how to prevent becoming infected.
- Share what you know about HIV/AIDS with people in your community, at schools, or a local World AIDS Day event.
- Learn about HIV/AIDS clinical trials or teach someone what you know.
- Wear a red ribbon and bring ribbons to share with your family, friends or co-workers.
- Learn more about HIV/AIDS through the internet or at the local library.
- If you know someone who might want to get tested for HIV, but is nervous to go alone, offer to go with them.
- Send a letter to your congressperson or another political leader.
- Write an article or draw a picture for the CAB newsletter.
- Organize an event to raise money for HIV/AIDS.

Written by Claire Schuster, PACTG Operations Center

- 1 UNAIDS, AIDS Epidemic Update, December 2004
- 2 UNAIDS, Epidemiological Slides, December 2004
- 3 WHO, The World Health Report 2004-Changing History, May 2004

Staff Members

PACTG CCG Advocacy Working Group

Monica's Story - Vulnerability and Awareness to HIV/AIDS

By Sibu Sishuba, South Africa ('The Hear Me Project' Submission)

It was Friday morning, 26 November 1998. Monica, who was 15 years old, had just finished writing exams. She went out of the school gate looking around for a companion to the bus stop, but saw no-one. It was very quiet – her friends had probably left school earlier.

As Monica walked alone she passed the gangsters on the corner of a shop. They followed her very slowly and she got suspicious. The gangsters changed directions quickly, but still got to her. One of them came up to her with a knife in his hand and told her to keep quiet. He dragged her into the bush behind the bus stop. She was very shocked and scared. The gangster took Monica's belongings, searched through everything and took her money and bus ticket. He pushed her to the ground and blindfolded her with her sweater. He put his knife to her throat and told her not to move or scream ...or else she'll die. He then forced himself on her and raped her while his friends waited for their turns to rape her. Suddenly they heard a sound like that of a police car and ran away. The leader followed after his friends and told Monica not to move away.

She was left there in a state of shock and disbelief. Very traumatized, she tried to walk back to the bus stop. She saw other students and they noticed she needed help. They took her to school to get help and called the police. She was then taken to the police station where she received counseling and she laid a charge. The police took her around the corners to check if they would find the gangsters but there were no sign of them anywhere.

Monica was taken home where she had to tell her parent about the rape. She was told by the police to go to the local clinic for a physical examination. They would also give her the relevant medication and run some tests. Her mother took her to the clinic, but they refused to help her because she didn't have a letter from the Police Department. They went back to get the letter and she was seen at the clinic. After the necessary examinations were done she was sent to the district surgeon for an HIV test and a pregnancy test was done two weeks later. The results of the HIV test came back negative and Monica was told to come back after three months for a re-test.

Monica was very frustrated with the entire trauma that she suddenly had to deal with and she never went back for a HIV re-test. She started to worry about her life. Monica became a victim of discrimination in the community because of the rape. She didn't have friends and she had no boyfriend. She began to notice that her body had become weak - she often had fevers and also had STDs. She treated these infections but they kept coming back. This was a wake-up call for her to have an HIV test done. She went back to the clinic where she was tested again for HIV. The results came back positive. She just saw her dreams being shattered. Monica had a dream just like all teenagers. She had a dream of furthering her studies. She wanted to be professional, get a good job, have a beautiful home, a very nice car, get married, have children and start a business. Monica thought all these dreams will never be accomplished if she is HIV positive. She also saw her life being flushed down the drain, all she could see was herself getting sick and dying. She became negative about life, she didn't see any reason for achieving her dreams, and she became ignorant, reckless and got involved in risky behavior. Life meant nothing to her. She was also at risk of re-infection and also thought of committing suicide.

Monica found it extremely difficult to deal with her positive status but knew she had to make peace with this. She then started counseling and she was referred to MSF Clinic where she started taking medication to boost her immune system and where she is monitored by "Doctors without Borders", the MSF doctors. She also became a member of Ilitha Lomso support group in Khayelitsha where she met many people living with HIV. She then decided to learn more about HIV and did a counseling course offered by Lifeline.

She also learned more about disclosure and started disclosing her HIV status to people who she trusted for support. She also disclosed to raise awareness that HIV was not too far away, anyone can be infected with HIV. Monica decided to impact her community with this knowledge and became a Community Health Worker. (continued on page 5)

PACTG Family Mapping Project: HIV Vaccine Family and Community Preparedness Study

What is the Family Mapping Project (FMP)? - In 2004, the PACTG launched the Family Mapping Project. The overall goal of the FMP is to understand how to teach adolescents about HIV vaccines and how to enroll them into future HIV vaccine studies. This study is being conducted at the Los Angeles County + University of Southern California (LAC+USC) Medical Center. Through this study, we will learn how to involve adolescents, families and communities in HIV vaccine studies in the United States and across the world. This type of project is known as an HIV vaccine preparedness study (VPS) because it prepares sites and communities to take part in future HIV vaccine studies.

Why is it important to teach and involve adolescents in HIV vaccine studies? - After more than 20 years of research, scientists are still trying to find an HIV vaccine to prevent people from getting infected. Right now, some studies are looking at whether new HIV vaccines will work in adults. However, none of these vaccines are being tested in adolescents under 18 years old. Because of the high rates of HIV infection among adolescents, it is essential that youth be included in HIV vaccine research. By involving adolescents in HIV vaccine studies, we are able to understand if and how vaccines will work in adolescents. The Family Mapping Project looks at whether adolescents, their families and communities would be willing to take part in these studies. By teaching adolescents about HIV vaccines, the Family Mapping Project helps them better understand what an HIV vaccine is, how vaccine studies will work, and equips them to share information with their communities.

How does this Family Mapping Project work? - The Family Mapping team interviews adolescent and adult clinic patients (who are called "indexes"). During the interview, they ask the indexes to name people in their social network, like family members and friends (who are called "alters"). Alters who do not have HIV are invited to join the study. Both indexes and alters are asked: What they know about HIV; Beliefs about HIV; Their HIV risk behaviors; What they know about HIV vaccine studies; If they would take part in future HIV vaccine studies; Reasons that they would or would not take part in these studies.

In addition to the interviews, the indexes and alters learn about what an HIV vaccine is and how a vaccine study will work. They also learn how to prevent HIV, including HIV risks of different activities, how to use a condom, and how to effectively communicate with their partners about this sensitive health topic.

What are the Family Mapping Project's goals? - The study has four main goals:

- Find out how well family and social network approaches can be used to involve youth at high-risk for HIV infection in HIV vaccine preparedness studies
- Look at what influences people's willingness to take part in future HIV vaccine studies
- Look at how brief HIV prevention education sessions affect HIV knowledge, beliefs, and HIV risk behaviors
- Use social network methods to involve community leaders in HIV vaccine preparedness efforts

How many people will take part in the Family Mapping Project? The study will enroll 50 index patients and 100 of their social network members (alters). So far, 40 index patients and 41 alters have been enrolled.

What has the Family Mapping Project found so far? - Using the social networks in a clinic-based youth population seems to be a good way to recruit and prepare other youth in the community for future HIV vaccine studies and teach them about HIV prevention.

- HIV(+) indexes are willing to involve their social network members in the study but are more likely to invite alters to whom they have disclosed their HIV status.
- Early findings suggest that less than half of indexes would be willing to invite their family/friends to take part in future HIV vaccine studies. Even fewer alters would be willing to participate in such studies. This may be explained when the Family Mapping team looks at HIV vaccine knowledge and why people would or would not take part in an HIV vaccine study.

How has the community been involved in the Family Mapping Project? - The Family Mapping team has met with community members from the start of the project. Members of the site's Youth Advisory Board (YAB) have advised the team on how to design the study and improve study enrollment. They also suggested how to make HIV prevention and vaccine education materials easier for youth to understand. The team is also planning to start meeting with the site's Women's Advisory Board to get feedback.

What's next for the Family Mapping Project? - The Family Mapping Project will complete enrolling indexes and alters. The team will use the findings to:

- Learn more about why people decide whether to take part in HIV vaccine studies
- Find out if people's understanding of HIV vaccines affects whether they would take part in HIV vaccine studies
- Study what types of people are willing and not willing to take part in future HIV vaccine studies
- Find out if people change their HIV risk behaviors after learning how to prevent HIV.

Written by Claire Schuster, PACTG Operations Center

Monica's Story (continued from page 3)

She became a role model to many young people. Even though she had to deal with discrimination from many people and was stigmatized because of the rape and her HIV status, she told herself to remain strong and live with a positive attitude. She also had to fight peer pressure from friends who tried to convince her that clubbing; smoking and drinking would take her mind off things. This affected her life badly. She got depressed, frustrated and she wanted to quit the job as she thought she got too much exposure from being a Community worker. Fortunately, Monica could use her own experiences to impact other youth positively.

She joined the "loveLife Program" as a volunteer. LoveLife is a "brand" for young people in South Africa. It is designed to give youth friendly services. The services are HIV education and training, raise awareness to young people about issues that affect them which are Peer pressure, Drug and alcohol abuse, Unwanted teenage pregnancy and unprotected sex. She worked for loveLife until her contract terminated. She had committed herself to the organization and had built a good reputation and she got the opportunity to travel around the country in youth camps where she got selected to represent loveLife in Kenya.

Monica got a job as a counselor for a research project. The project (PACTG P1031A) gives her the opportunity to give pre and post test counseling to HIV positive and negative women who are in labor or who had just given birth. Through this project, Monica joined the Adolescents Community Advisory Board at Tygerberg Hospital (Cape Town, South Africa) and she is now a member of the International Community Advisory Board (CAB).

She also got the opportunity to visit the USA for few days in October 2005, to attend an international meeting of CAB members as part of a bigger meeting. The Community Advisory Board is a link between the community and the research teams. The members of the CAB are taught about protocols and they get the opportunity to review the protocols to see if they are really ethical. The CAB is kept updated of any new matters arising about the studies and about any new studies and medicines registered. They are kept informed about any changes in treatment of HIV and they sit in some of the meetings with scientist, doctors and professors to ask questions about the studies.

Monica also decided to further her studies. In 2005 she enrolled for a degree in Psychology at the University of South Africa (UNISA). She did very well with all her assignments during the year and earned enough credits in order to write the final examinations in November.

Monica became very positive about life, she became happy again, and her self-esteem and confidence were boosted. In the community and at Church she made a great impact. She received support from her family, friends and at Church and that is where she met her fiancé. They had known each other for five years and they had fallen in love as friends. Her boyfriend is HIV negative and he is happy with her status. He has been there to support and encourage her through the most difficult times in her life and they are very happy together. The friendship became stronger and as the years went on they realized that they really love each other. They are planning to get married, in March next year.

She is still living healthy and positive. She is making sure she takes good care of herself by eating healthy, exercising and by being stress-free. Monica would still love to encourage young people to make informed decisions. She says HIV can turn a person's life drastically. She also wants to make young people aware that prevention is better than cure, especially when cure is not available. To the youth that is already infected Monica would love to encourage them to seek assistance, get counseling, get treatment go for your dreams and live a positive healthy lifestyle because a person only gets one chance to live please make the best of it.

CAB Feature - Siriraj ID Clinic (continued from page 1)

Exceeded Expectations: The CAB assisted in monitoring the content of the educational curriculum of the QS01 project. The focus of the project is the preparation process for HIV diagnosis disclosure in HIV-infected children. The CAB has also initiated ideas for promoting and expanding the network to enroll younger parents to be members of the group and expanded group support to include feelings, housing, job and education for other members. The CAB members have shared their ideas about CAB activities including monthly meeting topics, special speakers, and the extra activities in their group. Some CAB members agreed to abandon their travel per diem in order to save the money to spend in group activities such as the New Year party and a one day trip. A youth from the site will join the International Adolescent Working group call that started in Dec 2005.

CAB Challenges: (1. Siriraj CAB Newsletter – This was placed in the CAB plan even though in the past the main job of the CAB was its group support. When the group talked about this topic during a recent monthly meeting someone hesitated to receive the newsletter because they were afraid of social disclosure and the effect of it. (2. Discrimination from school and other healthcare providers. (3. Impact of HIV disease among HIV infected caregivers including general health problems, opportunistic diseases, loss of work, and financial problems. (4. Expand network to enroll younger parents to be members of the group. Now that the CAB is a stronger group the old members started to invite other parents who were new cases in the Infectious Disease clinic to join the monthly meetings.

Calendar of Events

CAB Call - 3rd Thursday at 10am ET
Adolescent CAB Calls -
1st Saturday at 9am ET
2nd Thursday at 7pm ET

HIV/AIDS Trivia - Do you know?

WHAT DOES THE RED RIBBON SYMBOLIZES?

Love (passion & tolerance to those affected)
Blood (pain of those who have died from AIDS)
Anger (helplessness in facing a disease w/o cure)
Sign of warning (not to carelessly ignore!)

WHAT ORGANIZATION FOUNDED THE RED RIBBON?

Visual AIDS, 1991.

WHAT IS THE "3 BY 5" INITIATIVE?

On World AIDS Day 2003, WHO and UNAIDS released a plan to provide ARVs to 3 million people by the end of December 2005.

AS OF JUNE 2005, "3 BY 5" HAD MET ITS INTERIM MILESTONE TO TREAT 1.6 MILLION PEOPLE? True or False?

False. Approximately 1 million people were receiving treatment by June 2005. However, coverage more than doubled, from 400,000 in December 2003. 14 countries are providing ARVs to at least 50% of those who need it.

WHAT COUNTRY HAS THE HIGHEST HIV PREVALENCE RATE?

Swaziland; >40% of pregnant women are infected with HIV.

HOW MANY CHILDREN WORLDWIDE HAVE BEEN ORPHANED BY HIV/AIDS?

13 million children

WHAT AGE GROUP MAKES UP HALF OF NEW ADULT HIV INFECTIONS?

Young people between the ages of 15 and 24.

Contributed by Claire Schuster, PACTG Operations Center.

See World AIDS Day article on page 2 for select references.

PACTG Website for HIV Positive Youth: www.positivelife.net

Website Features: Current HIV/AIDS news for youth; Links to HIV research; Helpful information on real-life topics; Monitored bulletin board for youth around the world; "Ask the Experts" section

219C Team Update Letter

December 12, 2005

Dear Participant in PACTG 219/219C, the "Pediatric Late Outcomes Protocol",

Your doctors, nurses, and the PACTG 219C team would like to thank you and your child for participating in the study. Since it opened in 1993, over 4,600 children and adolescents have participated in the study, including 2,850 who are HIV-infected and 1,670 who are not infected. Currently one-third of the children in 219C are greater than 10 years of age.

We have learned many important things from the 219C study. Some of these include:

- Treatment with protease inhibitors allows children to live longer and improves their growth.
- We have found no unexpected side effects from HIV medications in either infected or uninfected children and youth.
- About one-in-five children with HIV infection experiences pain and discomfort. This information helps us identify and treat pain in your children.
- It is important but challenging to tell children about their HIV diagnosis. We have learned that this knowledge affects their behavior and their willingness to take medications.
- Psychological testing, while time-consuming, helps us identify learning and behavioral problems.

Without your participation, we could not have made these important advances in our understanding of HIV infection in children.

At the present time, our research group, the PACTG, is being reorganized and the future of 219C is unknown. However, it is likely that your participation will continue for at least the next 6-12 months. The clinical information and specimens that you have contributed to the study are extremely valuable and will continue to be used for research on HIV infection in children. Your information and specimens will be kept safely, with your privacy protected, and used only for the kind of studies described in the consent form. In the next several months, you may be asked to sign a new consent in order to ensure that these specimens are used according to your wishes.

We will keep you informed as we learn more about the future of 219C. Thank you again for your participation. 219C could never have happened without your help.

Gratefully,

The 219C Study Team

PACTG Open Protocols

- PACTG 219 / 219C Pediatric Late Outcomes Protocol, Version 4.05
- PACTG 369 A Phase I/II Open Label Study of Nitazoxanide (NTZ) for the Treatment of *Cryptosporidium parvum* in HIV-infected Infants, Children, and Adolescents, Vers 2.0, 2/18/05, Complications RAC
- PACTG 394 A Phase I Study of the Safety, Tolerance, and Pharmacokinetics of Tenofovir Disoproxil Fumarate in HIV-1 Infected Pregnant Women and Their Infants, Vers 1.0, 1/08/04, Perinatal RAC
- PACTG P1006 The Effects of Highly Active Antiretroviral Therapy (HAART) on the Recovery of Immune Function in HIV-Infected Children and Young Adults, Vers 4.0, 5/2/05, Immunology Vaccine RAC
- PACTG 1020A Phase I/II, Open-Label, Pharmacokinetic and Safety Study of a Novel Protease Inhibitor (BMS-232632, Atazanavir, ATV, Reyataz™) in Combination Regimens in Antiretroviral Therapy (ART)-Naïve and Experienced HIV-Infected Infants, Children, and Adolescents, Vers 5.0, 9/23/04, Prim Therapy RAC
- PACTG P1021 An Open Label Study to Evaluate the Safety, Tolerance, Anti-viral Activity and Pharmacokinetics of Emtricitabine in Combination with Efavirenz and Didanosine in a Once Daily Regimen in HIV-infected Antiretroviral Therapy Naïve or Very Limited Antiretroviral Exposed Pediatric Subjects Vers 2.0, 12/22/04, Prim Therapy RAC
- PACTG P1025 Perinatal Core Protocol, Vers 3.0, 6-28-04 Peri RAC
- PACTG P1026S Pharmacokinetic Properties of Antiretroviral Therapy During Pregnancy, Vers 4.0, 5/17/05, Peri RAC
- PACTG 1030 A Phase I/II Study of Lopinavir/Ritonavir in HIV-1 Infected Infants 6 Months of Age, Vers 2.0, 05/26/04, Prim Ther RAC
- PACTG 1031A Mother Infant Rapid Intervention At Delivery (MIRIAD) International Version – Cape Town, South Africa, Vers 2.0, 9/07/04, Peri RAC
- PACTG P1034 A Comparative Trial of Protease-Containing and Protease-Sparing HAART Regimens in HIV-Infected Adolescents with an Evaluation of Therapeutic Drug Monitoring, Vers 1.0, 11/14/03, Adolescent RAC
- PACTG P1038 A Phase I/II Safety, Tolerability, and Pharmacokinetic Study of High Dose Lopinavir/Ritonavir (Kaletra®) with or without Saquinavir in HIV-infected Pediatric Subjects Previously Treated with Protease Inhibitors, Vers 2.0, 6/08/05, Prim Therapy RAC
- PACTG P1039 A Phase III Randomized Trial of the Safety and Antiretroviral Effects of Zidovudine/Lamivudine/Abacavir versus Zidovudine/Lamivudine/Lopinavir/Ritonavir in the Prevention of Perinatal Transmission of HIV, Vers 2.0, 8/4/05, Peri RAC
- PACTG P1041 A Randomized Double Blind Placebo Controlled Trial to Determine the Efficacy of Isoniazid in Preventing Tuberculosis Disease and Latent Tuberculosis Infection among South African Infants with Perinatal Exposure to HIV, Vers 1.0, 2/18/04, Comp RAC
- PACTG P1043 Phase III Randomized trial of the Safety and Efficacy of Three Neonatal Antiretroviral Regimens for Prevention of Intrapartum HIV-1 Transmission, Vers 2, 4/6/03, Peri RAC
- PACTG P1055 Psychiatric Co-Morbidity in Perinatally HIV-Infected Children and Adolescents, Vers 1.0, 12/10/04, Comp RAC
- PACTG P1059 A Phase I, Open-Label Study to Evaluate the Safety and Tolerability of Recombinant HIV-1 Vaccines in HIV-1 Infected Young Adults with Control of HIV-1 Replication and on Stable Highly Active Antiretroviral Therapy, Vers 1.0, 1/31/05, Imm Vac RAC
- PACTG ATN 015 Short Cycle Therapy in Adolescents Following Continuous Therapy with Established Viral Suppression: The Impact on Viral Load Suppression, Vers 3.0, 7/29/04, Coendorsed ATN
- PACTG ATN 024 A Randomized, Open-Label Trial of Three Hepatitis B Vaccination Schemas In HIV-Positive Youth, Vers 2.0, 6/25/04, co ATN
- PACTG ATN 048 Correlates of HBV-Specific B Cell Memory Following Vaccination in HIV-infected Adolescents and HIV-uninfected Adolescents, A Substudy of ATN 024 and ATN 025, Vers 1.0, 5/11/05, co ATN

Pending:

- PACTG P1053 A Phase II, Randomized, Open-label Study to Evaluate the Safety and Effectiveness of Two Antiretroviral Therapeutic Strategies: A Dual PI-based HAART Regimen versus a Multi-NRTI ART Regimen in ART-experienced Children and Youth Who Have Experienced Virologic Failure", Version 2.0, 6/8/05, Prim Therapy / Phase II
- PACTG P1061s Evaluation of Immunologic Memory Following Pneumococcal, Hepatitis B, and Measles Vaccination in HIV-Infected Children Treated with Highly Active Antiretroviral Therapy (HAART), Version 1.0, 8/2/05, Comp RAC

YOUR TURN

HAVE YOU EVER HAD A QUESTION YOU WERE TOO AFRAID TO ASK? A question about HIV and AIDS? About research? About medicines? How different medications interact when taken together? Or about community involvement? How do I start a CAB? What does a CAB do? What is conflict of interest? What does the community need to know about ethics and research?

Here is your opportunity to get answers! We will find someone who can give us the answer and we will put the question and answer in the next newsletter to share with the community.

DO YOU HAVE SOMETHING YOU WOULD LIKE TO SUBMIT FOR PUBLICATION IN A NEWSLETTER? We are happy to publish reports from your CAB, poems or stories you have written, or other information to share with the research community.

Send your questions or other submissions to us by e-mailing them to Claire Schuster at CSchuster@s-3.com. Claire is the PACTG Operations Center Community Support Person. Please let Claire know if you would like to be named with your question or submission. Your privacy will be respected.

Positive Hook-ups: WEB Links

Pediatric AIDS Clinical Trials Group (PACTG) pactg.s-3.com/inccg.htm

PACTG CAB - pactg.s-3.com/cab.htm

Positive Life Website (PACTG Adolescent) www.positivelife.net

Adult AIDS Clinical Trials Group (AACTG) aactg.s-3.com/ccginfo.htm

Community Programs for Clinical Research on AIDS (CPCRA) ww.cpcra.org/index.htm

HIV Vaccine Trials Network (HVTN) www.hvtn.org/community

HIV Prevention Trials Network (HPTN) www.hptn.org/community_program.htm

African-American HIV University www.blackaids.org/university

www.hiv.drugabuse.gov

National Institutes of Health (NIH) <http://www.nih.gov/healthdisparities/hdsymposium/proceedings2/sessions3/htm>

National Institutes of Allergy and Infectious Diseases (NIAID) NEWS (NIH/NIAID) NIAIDNEWS@niaid.nih.gov

National Institute of Child Health & Human Development (NICHD) <http://www.nichd.nih.gov/>

Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB) TA Library <http://www.hab.hrsa.gov/CATIE/> (Search for consumer involvement) CARE Act TA Title I Manual (Ch VI, Section 4) Recruiting Members, Maintaining Members, Nonmember Involvement

HRSA Information Center <http://www.ask.hrsa.gov/index.cfm> (Search for "Organizations That CARE: A toolkit for Employing Consumers in Ryan White CARE Act Programs")

Continuous Quality Improvement - HRSA Grantee Manual <http://hab.hrsa.gov/tools/QM/> Systematic Process, Benchmarks, Adaptive, Improved Outcomes

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

Neither Dallabrida & Associates nor Agouron Pharmaceuticals, Inc. has responsibility for any of the content of this newsletter.