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## AIDS... makes us friends



By Lapter  
Chiang Mai University HIV/AIDS  
CAB Member  
Chiang Mai, Thailand

AIDS... makes us friends. Having heard this phrase for so long, I just really understood its meaning after having a chance to attend the Thai AIDS/HIV infected people's network meeting last May 2006. A lot of AIDS/HIV-infected people from different parts of Thailand came to join, sharing their experiences, and providing updates of AIDS related activities which we have been working on for more than ten years. During this meeting I had learned that I was not the only one who had to cope with

the disease but there were many hundreds/ thousands people with me.



We have learned a lot, fighting with the dreadful HIV especially the meaning of the word "friend."

I have known about my HIV positive status for nearly eight years. I had been living alone feeling disheartened, sorrow, and

hopeless for many years because no one in my community understood AIDS. If villagers knew someone was infected with AIDS, they would turn away and object to that pitiful individual. That was why I did not want anyone even my own family to know my infected status. At first when I was informed about my bad news, I felt as if I would not be able to live in this world anymore. I was afraid that my parents would know and people in the community would not welcome an infected person like me. I thought I might be isolated and have to live with the disease on my own. The best way I could

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## Stories of Stigma



Submitted by  
Harriet Shezi Children's Clinic  
Johannesburg, South Africa

### Thuli's stigma story

Thuli Sibeko passed away in 2005 October. She was on ARV's for six months, and was staying with her maternal parents in the beginning. Thuli's

mother died without having to disclose to her parents. After her mother's death in January 2005, her granny discovered that the child was infected with HIV after the child's admission to Chris Hani Baragwanath Hospital. The Doctor disclosed the status to granny and referred the child to Harriet Shezi Children's

Clinic. Granny then decided that the child should stay with her father because of diagnosis. At this time the child had missed on a number of doses that resulted

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# Experience of a Peer-Support Group in Improving Adherence to Antiretroviral Treatment



By Santos C.S., Queiroz A., Cristóvão D., Silva O.L., Darmont M.Q.R., Aguiar N., Martins H.S.

Hospital dos Servidores do Estado, Infectious Diseases Department  
Rio de Janeiro, Brazil

**Issues:** Social and family support is critical for HIV positive patients and is a major factor for improving adherence to treatment. Brazilian government offers free antiretrovirals (ARV) to any patient who needs them but adherence has been identified as a crucial issue to prevent wasting of resources.

**Description:** "VIVA A VIDA" is a peer-support group that started in August 1996 involving patients, families and friends of HIV/AIDS patients aiming at a better social control through active participation of this population in the management and care of those affected. Activities of the group include: visits to patients admitted to the hospital or at their home, discussion of problems with a multi-professional team, information and guidance about available sources of social and material support and working with adherence.

Main tools for adherence are:

- (1) individual interviews and group discussion with patients and families explaining the goals of ARV and OI treatment and prophylaxis,
- (2) identifying non-adherent patients and underlying social or individual causes and seeking help from the health care team.
- (3) obtaining material or human support such as food supplies or help with children.



**Noemi Aguiar with CAB members from Hospital dos Servidores in Rio de Janeiro, Brazil. Project VIVA a VIDA provides social and psychological support to people living with HIV/AIDS including pregnant women, mothers, and the gay community.**

**Lessons learned:** Although not easy to quantify, the activities of the group in improving adherence and gathering social support had a positive impact on the quality of life and reduction of hospital admissions of the patients followed at HSE. Patients trust the group and the group understands their language, whereas healthcare workers frequently do not. They share common burdens of HIV disease, co-infections, unpalatable medications and social problems. They welcome the role of

care givers and other voluntary tasks which help them integrate into their family and the healthcare team.

**Recommendations:** Every HIV/AIDS clinic should foster or encourage activities of peer-support groups to help guide the healthcare team in identifying obstacles to the management of patients and finding solutions to maximize adherence.

## GRUPO VIVA A VIDA

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**Donations of basic food packages are given to HIV-positive mothers and their children once a month. They are also distributed to HIV-positive children on special occasions like Christmas, Easter, Children's Day, and birthdays.**

Ms. Santos, leader of the "VIVA A VIDA" group presented this poster at the XVI International AIDS Conference in Toronto, Canada, August 2006.

# CAB Update: Tygerberg Hospital



By Marie Theunissen  
Tygerberg Hospital  
Cape Town, South Africa

## SITE UPDATES:

-Weekly meetings are held every Wednesday morning at 08:30 am to discuss general running of PACTG. These meetings are also used as a format to iron out any problems we might encounter.

1041: We reached our target more than a month ago. We required 42+ve infants to reach our target. We are still waiting for the go ahead to recruit 20 more +ve for this study.

1043: We had a protocol review of this study at our previous meeting held last month. This study is headed by Dr Heinrich Weber of Kidcru and will take place at Tygerberg, Hottentots Holland Hospital, and Macassar Community Health Centre. The aim of this study is to decrease the risk of mother to baby HIV transmission especially in mothers who did not receive treatment as a result of not knowing her status. A debrief of this protocol was discussed at one of our CAB meetings and one interesting comment was that even though the informed consent forms were in all three languages [Xhosa, English and Afrikaans], people in the community still didn't grasp the concept of the study, especially the medical jargon. It was further suggested that the use of cartoonish diagrams be used to simplify everything.

1060: This study will be expected to be functional in the next 2 months as they are still in the process of protocol registration. It is expected that children between the ages of 6 months to just before their third birthday will be re-

cruited. This study will compare the responses to initiation of NNRTI based versus PI based ART infected infants who have not yet received a single dose of nevirapine. The two arms of this study will run parallel to each other to maintain a balanced result. We are looking at ways to recruit only positive participants so as to cut down on extra costs. Participants from 1041 can be co-enrolled to 1060.

Our CAB meetings have been rescheduled from the last Wednesday of the month to the last Thursday to accommodate those whose work routine has changed. Our aim is to maintain our numbers. As a result, we have had not less than 15 or more people in attendance at each meeting.



Besides the monthly meeting, we now have workshops that we hold on a Saturday morning. There is no specific programme -we just go on members' ideas. This is more of an arts and crafts workshop. At the last one held a month ago we made a wonderbox made using basic cheap material. The box serves as an insulator to help keep food warm for a long time. It came in very handy when we experienced power-cuts a few months ago.

## ACTIVITIES:

Because our waiting rooms are now so full, Patiswa and some of our counselors hold sessions in the waiting room with the mothers. The topic for discussion is based on the type of questions they might ask. The most popular one being formula feeding and condom use in

married African couples. [Perhaps we could have a debate on this in your next issue?]

On the 28-30 July the All Saints Anglican Church in one of our richer communities held an HIV Awareness Week in which Galroy Benjamin, Joan Coetzee, a number of Dr's from our adult and children's clinic took part and myself. The topics ranged from community involvement in HIV care especially the church [Joan], stigma [Galroy], and Living positively with HIV, [Marie.] We have extended our roles to not just the outside community to but to the prisoners as well. One of them being inmates of a maximum security prison in Caledon. I was a bit skeptical and frightened at first but I received an overwhelming response so much that I cannot keep up with the letters I received from inmates.

We also have nutritionists come and do their demo in our waiting areas and because most of our African mothers do not talk openly about sex etc. They showed them a video on how to use condoms and why etc. Some were embarrassed and looked away when they showed how to put a condom on a penis.

One other point of interest I would like to share with you is that we are getting a lot more fathers bringing children because their mothers are unable to do so for one reason or the other.

I will have the different speeches that were done at the AIDS workshop for the next edition.

Looking forward to hearing from you in the next issue.

NB. We have a new CAB choir!

# Stories of Stigma (continued from page 1)



to treatment failure, and the child was not receiving any treatment. Thuli was then moved to stay with her father and two brothers and two sisters from different mothers who have also passed away.

Her elder sister of 17 years was the one who was giving the treatment to Thuli, but was not aware of the diagnoses. She would give the meds whenever she remembered. This resulted to the child failing the first regimen and was put onto the second regimen. Dad was then contacted by one of the counsellors to discuss disclosure, and he objected to disclosure and said that they must give meds and not to disclose to her because he is scared that she might reject Thuli. He disclosed to his sister who was at the Nursing College, but could not assist him because she was staying at the College residence. The 17 year old continued to miss the doses until the child got very sick until she passed away.

### **Nontobeko's stigma story**

Nontobeko twenty nine years, born in eastern Cape, came to Johannesburg in 1995 for work. She fell in love with Mduduzi who was working in the mines. In 1997 got pregnant and found out that she was HIV positive. Nontobeko disclosed her status to Mduduzi who blamed her for this disease and they were separated the same year. In 1998 had a baby girl named her Nompilo.

She is an 8 year old, staying with her mother. They are renting a back room at Molapo in Soweto. When the child's cd4 was 8%, pre treatment counseling was done at Harriet Shezi clinic to start her with ARV's, mom disclosed the child's status to the Landlord for support, instead the landlord said she cannot stay with the dying child in her yard who will infect her

and other tenants and chased them away. She is now living in town in a shack made of woods. Nontobeko is not attending school anymore, as a part time domestic worker she cannot afford, for Nompilo to travel to school and mom is very stressed because of being stigmatized. She feels sorry for disclosing her child status to the landlord.

### **CAB Member's story**

I was not aware of my status, and I breast fed my child from birth until nine months. My child started to be very ill. She was then admitted to the Hospital and tests were done inclusive of HIV test. I received counselling and I agreed to have my child tested. I was called by the counselor and was told my results. I was shocked and felt as if my world was falling apart. At the time the counsellor reassured me, and all I was thinking of was that my child is not going to survive. She received treatment for the infection she had at the time, and I was told that on discharge the child will be referred to Harriet Shezi where she will be followed up till she is ready to start ARV. I disclosed to my husband, although I was very scared, to my surprise he said that we are in this together and he was supportive. At Harriet Shezi we received a lot of support and education and later when the ARV became available my child was put on to them and up till now she is doing okay. I also became very strong and decided to do counselling as well to help other people infected with HIV. I am presently a counsellor at Harriet Shezi and I enjoy doing my job. I am a living proof that HIV doesn't mean death, but that you can live positively with it.

### **Dipitso Mokoena's story**

Mom did not test during pregnancy. The child started getting sick at 9 months and was told that the child has bronchitis and

pneumonia and was put onto prophylaxis treatment until last October. The child became very ill and the Doctors suggested that an HIV test to be done on the baby, and the results were positive. The child was then referred to Harriet Shezi Children's Clinic by that time she was very sick, always sleeping and also tired. Then she was introduced to the study trial and got ARV's, the improvement was tremendous even at school, she was not coping well until she started ARV's. She easily forgot but even now the teachers at school recommended her that she is trying very hard and now the mom says she even knows how to write her name. The child is 7 years old now.

She didn't disclose to her partner because of his denial, but she disclosed to the paternal granny and they are no longer together. The paternal parents are also not supportive and on the other family side she didn't disclose to her father afraid of stigma because he drinks and talks a lot. She's staying with her father and she's the only child.

Her father is receiving his pension grant and the child also. The problem is she is not working as she has not disclosed to her family except a friend who is a neighbour. She's afraid to tell her sister because she is also stigmatizing people who are infected so her support is her friend and neighbour.

She's very hopeful about the ARV's because she sees it working. Before the child was in and out of hospital but now she's better. Also, the myths about ARV's disappeared when she started ARV's though she's scared, but now she sees the light at end of the tunnel.

Thank you Harriet Shezi Clinic for bringing back hope to our children.

# AIDS... makes us friends (continued from page 1)



do at that time was to keep my secret and disclose to no one. Finally I could not do that. As the time passed by, my body could not cope with the virus anymore. I became ill with oral thrush and pruritic papular eruptions. I could perceive that many suspected my condition. They wondered why I was sick for months. At last I had to tell my family that I was infected. Though nobody in the family expressed negative response to this issue, I felt like a monster in the family as they looked at me. The expression in their eyes was composed of sorrow, regret, and pity.

That was not as hurtful as when I went to the hospital for treatment and met someone I knew. He asked me not to cough nearby him since the virus was spreadable, although I always covered my mouth coughing. Again when I had a wart on the skin, I needed to go to the hospital for many visits as the doctor did nothing for me until it became rotten and had a foul smell. I was transferred to a provincial hospital for surgery. During the time when no food and drink were permitted orally, I told the nurse that I had to take antiretroviral agents. A moment after, another nurse came in to inspect what my body surface looked like. The only thing I could say from her manner was that I was extremely disgusting for her. That was what I had faced. That led to my feeling that no one understood me.

Finally when I attended the group of HIV-infected people who came to hospital for treatment, we did activities

together. I found many people whose lives are similar to mine. They encountered bad experiences in their lives and were still living for hope. They were waiting for antiretroviral agents which were very expensive at that time. They were waiting for a cure and for the day when they could lead normal lives in the community. They hoped that one day others would realize that AIDS was a treatable chronic disease with antiretroviral drugs available.

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***“We stood side by side  
working for people living  
with AIDS in our  
community...”***

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What we did in the group was to encourage one another. We showed sympathy to one another knowing that anyone could become sick with opportunistic infections. We also exchanged our knowledge and information about opportunistic infections and antiretroviral agents to make sure that our friends would be able to take care of themselves. The last thing was our power when we were together as a group to roll out the antiretroviral treatment for HIV-infected people, the only hope for our lives.

I found that everyone cares for one another especially at the time when we had to take our medication. We laughed and cried together thinking of bitter experiences in the past and hopeful life in the future. We stood side by side working for people living with AIDS in our community so that they could reach medical service for antiretroviral drugs. We provided knowledge about HIV in the community for more acceptance and positive relationships.

Nowadays we are still working in many places throughout the country in the pattern of multidisciplinary health care centers. I have a chance to learn and gain experience by going out to teach about opportunistic infections, antiretroviral agents, counseling, and communication regarding AIDS. As a CAB member, I have a chance to share information and give suggestions to the research team. I inform HIV-infected persons and people in the community about research projects which I might write about some other time. The last thing is that I have found “HIV-infected friends” who are more than ordinary friends. They make me feel cheerful and inspire me to live in this globe as everyone does. I feel myself valuable for family, friends, and people around me.

# Chiang Mai CAB



## Dr. Linda Aurpibul presents PI032 to the CAB.

By Udom Likhitwonnawut  
Co-Chair of Chiang Mai University HIV/AIDS CAB (CMC)  
Chiang Mai, Thailand

During the '90s, Chiang Mai, a booming city in northern Thailand, was the epicenter of the HIV pandemic in Thailand. The pandemic started from the highly vulnerable group, namely sex workers and the clients, and spread rapidly to other vulnerable groups (women, young people and children). As a result, Chiang Mai was flooded with international and national aid organizations, government agencies, and academic institutes working independently or jointly to combat HIV. Naturally this led to confusion, misunderstanding, exploitation, and outright abuse. In the field of research, many research studies were conducted in the city and nearby areas by various organizations; some were legitimate with sound scientific agendas, but some weren't. Regardless of the legitimacy, these research studies shared one common thing. They were developed by researchers using a top-down approach with no input from the beneficiaries and affected communities. Research ethics was only a novelty and only a handful of people seemed to understand what it was really about. At the same time, the number of people living with HIV/AIDS increased exponentially and many of them

became vocal and actively involved in HIV interventions and activism to advocate for the rights of PHAs particularly access to information and treatment.

Responding to the situation, a group of like-minded administrators and researchers initiated, with tactful coaching from the international research community, the formulation of the Chiang Mai CAB to support HIV research conducted by the Research Institute for Health Sciences (RIHES), Chiang Mai University. The initiative was, in the beginning stage, a collaboration of RIHES and the Center of Disease Control Region 10 (CDC 10), Chiang Mai. Later on RIHES assumed the leading role after the change of director in CDC 10. Since the inception in 2000, the Chiang Mai CAB has evolved somewhat. The evolution helps to define its roles and responsibilities. A few members resigned for various reasons, and new ones were recruited to replace them. The original CAB was intended for the HPTN (HIV Prevention Trials Network), but currently the Chiang Mai CAB has been involved with HVTN (HIV Vaccine Trials Network), HPTN, ACTG (The AIDS Clinical Trials Group), and PACTG (The Pediatric AIDS Clinical Trials Group). From the original single CAB, a second CAB was established for an IDU trial by RIHES. This article is focused on the original CAB only.

### Existing activities

Several activities are provided to support the CAB, these are:

- Bi-monthly meeting – every two months a CAB meeting is held for half a day. The main focus is to follow up on the existing trials conducted by RIHES and to provide advice about the up-coming trials;
- Annual CAB retreat – the two-day retreat focuses on capacity building and networking;

- CAB newsletter – the bi-monthly newsletter keeps the members and audiences up to date on the various issues such as existing trials, informative articles on health-related issues, profiles of CAB members, and HIV events;
- International meetings and workshops – CAB representatives occasionally attend international meetings and workshops of various networks (HVTN, HPTN, ACTG);
- Special events – Occasionally the CAB, with the support from RIHES, participates in HIV special events such as World AIDS Day and cross visits to other HIV trial sites not under RIHES.

### What the CAB does and does not do

The Chiang Mai CAB is unique in the way that it is not involved with any particular trial, but, through time, has become involved with various trials conducted by RIHES. It is also unique that it was formed **before** the existence of the trials in which it would eventually become involved. Several meetings were held before the actual trial was introduced to the CAB for advice. Confusion and frustration were normal at the beginning as well as doubt about the sincerity or the integrity of those involved. However with guidance and support from the staff of RIHES and CDC 10 as well as other HIV activists, the Chiang Mai CAB perseveres and gradually defines its roles and responsibilities. The CAB meets every two months for half a day. Currently the main role of the CAB is to advise researchers on protocol design, recruitment strategy, exclusion and inclusion criteria, potential social harms and the ways to prevent or mitigate them, and educational and recruitment materials, all of which makes the trials attractive, easy to understand to lay persons, and ethically sound.

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# Chiang Mai CAB (continued from page 6)



While the utmost role of the CAB is to protect the human rights of volunteers; the CAB sometimes becomes confused about what is right and what is privilege and responsibility. In a few occasions, the CAB strives to find balance between the scientific objectives and the needs and concerns of the volunteers and community. The CAB also monitors the on-going trials to ensure that trials progress according to the protocols and the volunteers are protected and provided for as needed. Other contributions of the CAB include advising the researchers on community activity to educate the public about HIV research in general. In certain circumstances, the CAB also advises the researchers on recruitment, retention, and follow-up of volunteers to prevent unintentional harms. However, it is not involved in actual recruitment of volunteers. The Chiang Mai CAB is not involved in community mobilization or community education to raise awareness about HIV research or a particular trial. Because the CAB is involved with many trials with different objectives, methodologies, starting up times, and beneficiaries, most of the members cannot keep up with the details and idiosyncrasies of the trials. Therefore, they cannot perform at full potential to provide sound and practical advice on sustained basis. Most members also find it difficult to provide advice on the scientific agenda and other technical issues.

## What the CAB is and is not

As mentioned above, the Chiang Mai CAB is an all-purpose CAB (Multi-trials CAB) that oversees various trials conducted by RIHES for the past six years. CAB members are not recruited from a particular community or geographic area. Instead CAB members are so diverse and come from all walks of life. Some are NGO workers, some are religious persons (Buddhist monks and a Christian priest), a few are officials of local governments, one is a respected commu-

nity elder and one is a representative of a youth network, a few are members of PHA support groups, and some are government health officials. The proportion of males to females is about the same. In another word, CAB members are representatives of the community of HIV workers and civil society rather than representatives of a particular community or population. Some CAB members feel that they are not adequately representing the real community. The lack of real community representatives raises some concerns.



The CAB may not be able to put forward genuine concerns of the community to researchers in timely manner; the current CAB may not be relevant to the targeted communities or populations. But by not representing a particular community, the CAB can claim that there is no hidden agenda or conflict of interest between the CAB, the community, and the trial. The CAB can, thus, perform its roles without prejudice and bias.

## Challenges

The differences in experiences, backgrounds, ages, and other qualifications complicate the way the Chiang Mai CAB functions as an advisory body. The diversity can compromise the capacity and effectiveness of the CAB if left untouched. The challenges are many. One of the challenges is how to strengthen the capacity of the CAB as a whole. In the past, annual retreats were conducted to train the CAB on specific topics such as protocol design, re-

search ethics, and reading informed consent. A cross visit to a different trial site was conducted to provide an opportunity to learn from others. But these activities are few and far between. The wide range of relevant issues and topics also pose another challenge: how to prioritize them. Another challenge is how to coach new members and facilitate the learning process of the new members. It is a big challenge for new members to keep up with various trials and difficult terminology used during the meetings which can make new members feel alienated. So far no efforts have been made to facilitate the learning process of new members except the annual retreats. Then there is a challenge about how to keep CAB members updated on new development and advances in HIV science, prevention, vaccine, and treatment development. Currently it is up to individual members to educate themselves. The bi-monthly CAB newsletter provides an outlet to disseminate the information and keep CAB members connected. However the newsletter is compromised by the available space for articles and news, contributions from various stakeholders, and frequency. One suggestion is through CAB networks within the country and between countries or international CABs. By connecting to other CABs and international CABs, the local CAB can avoid becoming overly occupied with the local issues and become more connected with wider issues and better informed about the new technologies. However connecting to international CABs will raise the issue of language barrier, too. Another key challenge is how the CAB remains relevant to the concerns of the community without true representation. One possibility is to invite the volunteers to attend CAB meetings occasionally so that CAB members can interact directly with the volunteers. Another possibility is to

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# Chiang Mai CAB (continued from page 7)



invite the CAB to observe community education activity.

## End note

The Chiang Mai CAB has evolved slowly during the six-year period. The process is slow, tedious and ambiguous at times. Some members feel committed, some feel uncertain, and a few feel frustrated. Despite the uncertainty, the overall experience is rewarding nonetheless. The CAB has rendered added value to the trials in the form of community participation. Moreover, the CAB was able to advise the researchers on practical issues such as the

language used in informed consent, communication and education materials, and on ethical issues. However there is room for improvement to strengthen the partnership between the community, CAB, and the research community which is so important from the community standpoint. So far, the CAB role is quite limited and closely guided. It acts more or less as a conduit between the researchers and lay people in HIV research trials. The CAB should have bigger roles in planning and budgeting, protocol development, priority setting, and capacity building for example. Its roles and responsibilities need to be re-defined and

reviewed occasionally to utilize its full potential. In order to reach its full potential, the CAB needs an enabling and supporting environment to grow and mature. This includes systematic supports from the research community in terms of logistic support, capacity building, and technical support. With an effective and functioning CAB, the common goals of finding effective ways to prevent HIV infection and mitigate its impact can be reached eventually without compromising the integrity of the research.

## Calendar of Events

- **CAB Support Call:** The calls are held quarterly on the third Thursday of the month. The next call is scheduled for *Thursday, October 19th at 10 AM (Eastern)*.
- **Global Adolescent Working Group Call:** The calls are held every other month on the first Saturday of the month. The next call is scheduled for *Saturday, November 4th at 9 AM (Eastern)*.

Please contact Claire Schuster at [CSchuster@s-3.com](mailto:CSchuster@s-3.com) for details.

## CAB— Share the Ride Staff Members

### Community Education Working Group:

Teopista Nakyanzi, Chair

Charlene Bowman

Vinnie Di Poalo

Dawn English

Patiswa Ketelo

Mama Wandoa Mwambu

Claire Schuster

Dorothy Shaw

**CAB website:** <http://impaact.s-3.com/cab.htm>

# Lay Summaries for Select PACTG/IMPAACT Studies

The IMPAACT Community gratefully acknowledges IMPAACT for its approval and implementation of a system to ensure that lay summaries of publications/manuscripts and presentations describing clinical trials findings are distributed to trial participants and the IMPAACT Community Advisory Board in a timely manner. Please note that no public statements can be made about the information contained in these summaries until the manuscripts are published. For further information about these summaries, please contact Claire Schuster at [CSchuster@s-3.com](mailto:CSchuster@s-3.com)

## 219C Program, “Pediatric Late Outcomes Protocol”

- A Population Pharmacokinetic Analysis of Pediatric-Doses Nevirapine (from PACTG 245, 356, 366, 377, 403): *Re-assessing the Dosing Regimen: a Role for Nonlinear Mixed Effects Models*. (DACS 606)
- PACTG 219C, Pediatric Late Outcomes Protocol: *Predictors of Adherence to Antiretroviral Medications in Children and Adolescents with HIV Infection*. (DACS 607)
- *Neurodevelopmental Functioning in HIV-Infected Children Before and After the Introduction of Protease-Inhibitor-Based Highly Active Antiretroviral Therapy (HAART)*.
- Protocol 219 and 219C - Pediatric Late Outcomes: *Use of Antiretroviral Drugs during Pregnancy and Possible Problems with Mitochondria in HIV-Uninfected Children* (DACS 614)
- 219 and 219C-Pediatric Late Outcomes: *iDACS 621 - DNR/Hospice Care and Quality of Life among Children/Adolescents with AIDS*

## Perinatal Transmission Scientific Committee

- PACTG 316: A Phase III Randomized, Blinded Study of Nevirapine for the Prevention of Maternal-Fetal Transmission in Pregnant, HIV-Infected Women: *Characteristics and Management of HIV-1-Infected Pregnant Women Enrolled in a Randomized Trial: Differences Between Europe and the USA*.
- PACTG 358, A Phase I Trial of the Safety, Tolerance and Pharmacokinetics of Oral Indinavir Co-administered with Lamivudine (3TC) and Zidovudine (ZDV) in HIV-1-Infected Pregnant Women During Gestation and Postpartum, and in Their Infants Post Maternal Dosing: *Pharmacokinetics and safety of indinavir in HIV-infected pregnant women*.
- PACTG 386, A Phase I Trial of the Safety and Pharmacokinetics of Fortovase (Saquinavir) Co-Administered With Low Dose Ritonavir, ZDV and 3TC in HIV-Seropositive Pregnant Women During Gestation and Postpartum, and in Their Infants Post-Maternal Dosing: *Clinical Response, Safety and Tolerability to Saquinavir With Low-Dose Ritonavir in HIV-1 Infected Mothers And Their Infants*.
- PACTG 1026s, Pharmacokinetic Properties of Antiretroviral Drugs During Pregnancy: *Reduced Lopinavir Exposure During Pregnancy*.

## Primary Therapy Scientific Committee

- PACTG 382, A Phase I/II, Open-Label, AUC-Controlled Study to Determine the Pharmacokinetics, Safety, Tolerability, and Antiviral Activity of DMP 266 (Efavirenz) in Combination with Nelfinavir In Children: *Efavirenz Pharmacokinetics in HIV-1 Infected Children are Associated with CYP2B6-G516T Polymorphism*.
- PACTG 1020A, A Phase I/II Open Label Pharmacokinetic and Safety Study of a Novel Protease Inhibitor (BMS 232632, atazanavir) in Combinations Regimens.
- PACTG 1021: An Open-Label Study to Evaluate the Safety, Efficacy and Pharmacokinetics of Emtricitabine in Combination with Efavirenz and Didanosine in a Once Daily Regimen in HIV Infected Antiretroviral Therapy Naïve Pediatric Patients.

## Complications of HIV Scientific Committee

- PACTG 247: A Randomized Controlled Trial of Increased Caloric Density Formula Feeds in Infants Born to Women Infected by Human Immunodeficiency Virus.
- PACTG 1010: Effect of Antiretroviral Therapy on Body Composition in HIV-Infected Children
- *Predictors of Medication Responsibility and Adherence in Youth with Perinatally Acquired HIV: Results from PACTG 1042s*.

## Vaccine/IBT Scientific Committee

- PACTG 351, Phase I/II Trial of CD4-IGG2 in HIV-Infected Children: *Susceptibility of Pediatric HIV-1 Isolates to Recombinant CD4-IgG2 (PRO 542) and Humanized Monoclonal Antibody to the Chemokine Receptor CCR5 (PRO 140)*
- PACTG 1015: Treatment Interruptions vs. Continuation of Anti-HIV Therapy: *Intensification of HIV-Specific CD4 and CD8 Activity by Cycling HAART Therapy in Pediatric Patients with Less than 50 Copies/mL*.

## Adolescent Committee

- PACTG 381: Establishment and Maintenance of Long-Term Undetectable Plasma HIV-1 RNA: Correlation with Immunologic Reconstitution and Viral Dynamics: *Long-Term Observation of Adolescents Initiating HAART Therapy: Three-Year Follow-Up*.
- PACTG 381: Establishment and Maintenance of Long-Term Undetectable Plasma HIV-1 RNA: Correlation with Immunologic Reconstitution and Viral Dynamics: *HIV-1 Drug Resistance, Replication Capacity, and Immune Outcomes in HIV-1 Infected Youth Failing Primary Highly Active Antiretroviral Treatment*