

CAB-Share the Ride

A Community Advisory Board Newsletter for Informed Families!

September 12, 2005



1st Edition

Pediatric AIDS Clinical Trials Group
Community Constituency Group
Advocacy Working Group
Domestic and International
Research Information

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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.

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Welcome to the first edition of CAB-Share the Ride!

It is very exciting to finally get this publication up and running. We want all CAB's to feel that this is your newsletter. There are informative articles about adherence, personal stories, up and coming protocols and much more.

We will focus a CAB site in each edition. We want to know what works for your site, we also would like to know about some of your struggles. This will be a tool for sites to network with each other.

We would like to invite everyone to join us on the Pediatric CAB conference calls on the third Thursday of every month. These calls also enable us to come together and network. You may access the call at 10:00am on the third Thursday of every month. In the United States dial 1-888-408-5343, South Africa 0800-991-271, Thailand 001800-441-8583. When prompted by the operator punch in the access code 892833. These calls enable us to keep informed about research, our sites and issues that our families may be facing.

We would like to welcome all to the up-coming PACTG meeting on October 21-25 at The Grand Hyatt in Washington D.C.

There will be a community retreat, 9:00am to 3:30pm on Friday, October 21. The adolescents will also have a private session with the investigators from 4:00pm-6:00pm on this same day. The community session will include a mock CAB meeting. During this meeting, Dr. Pat Flynn will present on How ARV medicines work. We will have further discussion on how to effectively communicate with our Primary Investigators.

There will be an interactive with the site Primary Investigators and community representatives on Saturday, October 22 from 4:00pm-5:00pm. We would like for the site staff and community to come and learn from each other on how we can serve one another.

Our hope is that this publication will be a tool used by all sites. We hope to get information out about new trials getting ready to open, trials closing and on-going information about open trials. We also have access to data about drug resistance, medication adherence, drug interactions, co-infections, behavioral issues and much more.

With changes to the PACTG on the horizon, we would like to keep all informed as much as possible. If there are concerns about the new changes or if you have ideas for articles, please contact Lisa Summers at hugakid@charter.net. We will do our best to get answers and publish them in the newsletter.

Positive Life Website Announced

The PACTG announces the launch of the Positive Life Website for HIV positive youth at www.positivelife.net. The purpose of the site is to provide information to improve the quality of life for youth with HIV/AIDS and to provide information on AIDS research and clinical trials. The site is intended for youth ages 13-24, and is not suitable for young children. The web site can be accessed by english speaking youth all over the world.

The home page features an extensive Current News section which includes HIV related news articles as well as a news archive. The articles are updated weekly; each article focuses on issues that may be of interest to youth internationally.

A "Bulletin Board" was added in February to allow visitors to ask questions and share concerns about HIV/AIDS. All bulletin messages are reviewed by staff before they are posted. The site also contains an anonymous "Ask the Expert" section where a visitor can post a question that will be answered by a site clinician. Here, youth may discreetly ask questions they do not wish to ask to ask at clinic or at home.

To help visitors locate PACTG clinics in their area, a clinic directory has been added that includes links to the main PACTG clinics in the U.S. and internationally. Any PACTG clinic listed that has it's own web site can have it linked to from their directory listing free of charge.

The preceding article is an excerpt from an article appearing in the May issue of the PACTG International Newsletter.

Beliefs About HIV

A belief is a personal creed that can be accurate, wrong, or in between. In respect to health maintenance, it can be the difference maker in a good quality of life, death, or somewhere in between. No matter what our health condition, the beliefs we hold will have significant ramifications on our quality of life. For those with a life threatening illness, these beliefs have much more weight. Some may assert that HIV does not exist and never go for Care after their diagnosis. Some may believe that HAART or western medicine as a whole is not helpful. There are multiple of other beliefs such as HAART therapy is their life sustaining treatment. Whatever our belief may be about HIV, there is no arguing that these beliefs will greatly influence our life if we are HIV positive or the caregiver of a child/youth who is HIV positive.

As someone who recently spent six years as a social worker in an HIV pediatric clinic and as a father of twelve-year old girl with AIDS, my beliefs may not be held by others but these beliefs are supported by very convincing first-hand experience. In my six years, the relationship developed with most of my patients became that of an extended family member. Unfortunately in this time, approximately 30 of my younger cousins were laid to rest. Of these 30, there is no doubt in my mind that at least 25 of my patients died because of years of not taking their medications. For many, their body became so weak that even when they finally committed to their regimine, it was too late for their bodies to recover and it became a slow death. Many of our surviving patients went through periods of non-adherence leading to major infections and weakening of their bodies, but were luckier in that when they decided to committ to their HAART, their bodies were able to recover, though never back to 100 percent of their former selves. I see this first hand in my daughter who had poor adherence during her first few years of life and now must cope with most notably pulmonary problems and stunted growth.

With just these few words I am permitted to share with you, maybe I can convince some of those who are wavering on their beliefs about the medications for HIV. They are the main life sustaining choice we have. I accept that for many they are not easy to adhere to because of taste, side effects, size, stigma, cost, access, number of pills, and many more reasons. But there is no choice, we must find a way to make taking the medications as routine as brushing out teeth once, twice, or three times a day. One last thing for caregivers of an HIV person, in particular, those caring for a youth. "Yes" they are old enough to take on the responsibility of their own medications. But if you believe as I do that taking the medications are vital, no questions asked, I suggest that we still supervise our young ones a portion of the time, not because we do not trust them, but because taking the HIV medications is so vital to their quality of life. If you believe as I do, can I get an "AMEN"!! Will Noel.

Staff Members

PACTG CCG Advocacy Working Group

JOINING A COMMUNITY ADVISORY BOARD

By David Mariner

Background Information on CABS

Community involvement is an important way of keeping AIDS research on the right track. There are many ways to get involved. One way is to join a clinical trial. Another way is to become active in the planning and development of research trials.

Many local and national AIDS research networks receive advice from members of HIV-affected communities through Community Advisory Boards (CABs). CABs are patient advisory groups that give the patient's perspective on whether a trial offers ethical, reasonable approaches to the issues that are relevant to that community.

CABs provide input at all levels of the research process, from what will be studied, to the design and running of the trial, to assistance finding and keeping volunteers in the trials.

It was not always like this. Up until the late 1980s, meetings of AIDS research groups did not include patient representatives. This was changed through the hard work of activists.

Today, government-funded clinical trial networks are required to set up CABs. Each local CAB elects members to serve on a nationwide Community Constituency Group (CCG). This system allows the leaders of the national networks to hear the concerns of community members.

One Man's Experience

"I had always wanted to have more involvement and a voice in AIDS research," said Willis Courtney of Washington State. So Willis decided to become a member of the Washington Regional AIDS Program CAB.

"My first meeting was straight forward. Everyone made me feel comfortable by introducing themselves and letting me know about their involvement on the board. When the meeting was over I was overwhelmingly impressed by the involvement of the CAB in clinical trials and studies. It was like a dream come true – I would get my chance to become involved in AIDS research!"

Willis acknowledges that being a CAB member can sometimes be intimidating. There are lots of new terms to learn and understanding the research process can take time. He believes that having a mentor was a key part of his success; "My mentor, Brian Mahoney, got me started by going over information that he had in his archives. I still tell everyone how he sent me home with an armload of research!"

What makes Brian a good mentor? According to Willis: "Brian is very knowledgeable because of his years of experience and involvement in the field of AIDS and he has a lot of patience to teach. He was very willing to work with me until I understood the new concepts."

Willis has come to enjoy his time working at CAB meetings: "When we meet, we greet one another with hugs and smiles. To me it's like a reunion. We come together ready to take on our responsibility as CAB members."


His advice for new CAB members? "Just sit back and be yourself, give your full attention to what's going on and take notes. I found that taking notes in my own words allowed me to understand what was being said. Brian was very good at teaching me how to interpret studies and to break them down to understand what I had read."

Getting Involved

While all HIV+ people are encouraged to become active members of CABs, it is important to be well informed about treatment issues in order to make a valuable contribution.

As well as working with a mentor, you can prepare by attending treatment education workshops and programs at local AIDS organizations, African-American HIV University (www.blackaids.org/university/) and NATAF meetings (www.namc.org, click on conferences and then NATAF). Also consider joining the AIDS Treatment Activists Coalition (ATAC) at www.atac-usa.org.

The following AIDS research networks have opportunities for community representatives:

- Adult AIDS Clinical Trials Group (AACTG): aactg.s-3.com/ccginfo.htm
- Community Programs for Clinical Research on AIDS (CPCRA): www.cpcra.org/index.htm
- Pediatric AIDS Clinical Trials Group (PACTG): pactg.s-3.com/inccg.htm
- HIV Prevention Trials Network (HPTN): www.hptn.org/community_program.htm
- HIV Vaccine Trials Network (HVTN): www.hvtn.org/community/ 

David Mariner is a community educator with CPCRA.

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Tras las rejas


por Roy Hester

Mi nombre es Roy. Trabajo con presos VIH positivos. Parte de mi trabajo es ayudar a los presos a hacerse la prueba del VIH. Al igual que en el mundo fuera de la prisión, allí dentro existe mucho estigma con respecto al VIH.

Muchos de los hombres con los que trabajo no quieren hacerse el análisis porque temen que sus amigos los rechacen si el resultado es positivo. Lamentablemente, no se dan cuenta de que saber su estado de VIH puede ayudarlos a mantenerse saludables.

Hay otras razones por las que muchos presos no se hacen el análisis del VIH. Un hombre con quien yo trabajé, había estado preso por 15 años y nunca se había hecho el análisis. Me contó que había estado envuelto en una relación por dos años con otro preso que era VIH + pero igual se negaba a hacerse el análisis. Cuando le pregunté por qué, me dijo que temía que los demás se preguntaran de qué manera se infectó y que pensarían que era homosexual.

También trabajé con otro preso que tenía SIDA. A medida que su enfermedad fue avanzando decidió comunicarle su estado a las personas con las que había tenido sexo sin protección para que ellas pudieran hacerse el análisis del VIH.

A pesar de que puede ser difícil enfrentarse al VIH, aconsejo hacerlo para comenzar a tomar el control de su salud. 

Roy Hester es el coordinador de FamilyWorks en la prisión Sing Sing en Ossining, New York.

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How To Talk To Your School-Age Children About Safer Sex

by Mother's Voices

If you've been putting off talking to your school-age children about safer sex because you don't know how to begin, consider this: More than 60 percent of high school seniors have had sexual intercourse, and the HIV infection rate is rising faster among 15-to-24-year-olds than in any other group.

Take heart. Teaching children the ABCs of the birds and bees can be a positive experience if you follow these simple pointers:

Ease into it.

Start by discussing with your children the fulfilling aspects of healthy sexual relationships, then move into how they can keep themselves safe with abstinence, condoms and other methods. Research shows that frightening youngsters into postponing intercourse doesn't work.

Use teachable moments.

Does a sexual situation occur on TV, in popular music or the film? (When doesn't it?) Launch a discussion. You might say, "What do you think about the fact that those two had sex the first night they met?"

Better late than never.

Even if the lines of communication have been poor lately, try saying, "I know we haven't talked much, and that bothers me." Gradually

work your way up to, "I love you, and that's why I'm asking you to use a condom if you have sex."


Reinforce your values.

Discussing premarital sex doesn't condone or encourage it. Children need to hear from you that abstinence is okay, because they often get the opposite message from peers and the media.

Listen.

Despite what they might let on, your children really do want to discuss these issues. Let their questions and concerns be your guide. And be sure to show respect for their opinions, even if you disagree.

Get the facts.

If you can't accurately answer a question, explain that you will find out and get back as soon as possible. Then be sure you do. 

This article is an excerpt from, "Finding Our Voices: Talking with Your Children About AIDS," a publication of Mother's Voices.

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Calendar of Events

PACTG Meeting
October 21-25

The Grand Hyatt Washington Hotel