

The WIHS Woman

The Connie Wofsy Women's HIV Study



The Children

by Cheryl Conover*

The children are born
So precious and new
Helpless, loving
Totally dependent upon you

They give you a smile
So trusting and sweet
Now they have your heart
For Keeps

Full of love
Full of energy
Full of hope
Full of trust

You relish in every move they make
Their first breath, first word
The first step they take

The children grow
Day by day
Getting stronger, smarter
More unique in every way



They challenge you
Test you
Trying to find their way

Firmness, consistency,
Clear rules are the key
Combined with lots of love
And hugs, hugs, hugs
The happiest your children will be

I have five
And I love them more
Each and every day!

*Cheryl Concover is a Medical Record Abstractionist for the Bay Area WIHS group.

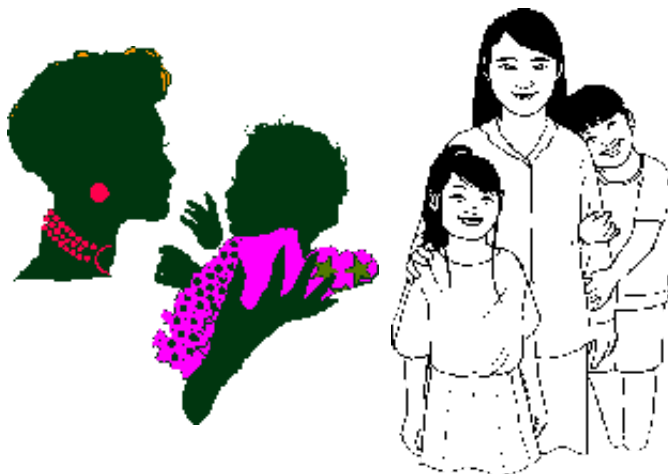


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GIFT INCENTIVES

By Nancy Hessol, Project Director



When you come in for your 6-month WIHS study visit, in addition to paying you \$40 for your continued participation, we also give you a thank you gift. Over the years, these have included skin lotion, manicure kits, water bottles, fanny packs, key chains, make-up, shampoo, etc. We are also trying to make sure that these gifts get distributed fairly, so that no one gets less than someone else does. From now on, we will be giving out these gifts the same way to all our study participants when they come for their 6-month follow-up visit. Participants will still have a choice between the various gifts but now everyone will get gifts that are of similar value.

We will also continue to offer all study participants a reward if they show up on time to their study appointment. The reward is a choice between a Safeway supermarket gift certificate and a Wendy's Hamburger's gift certificate.

I hope you all enjoy the gifts we give you. We certainly enjoy your continued participation in our research project.

CAB CORNER

by Moher Downing, Community Liaison



WIHS WOMEN LEARN TO SURF THE WEB

On Thursday, May 13, eight of your WIHS sisters attended a computer class here at the University of California, San Francisco, to learn how to "Surf the WEB." As an extra bonus they were given free e-mail addresses at "Chickmail.com." Yes, these lucky women are now on the Internet and can receive e-mail from anyone and from any part of the world! They also had a fabulous lunch and were paid \$10 for their time and expenses. Now they know what all those secret, funny words mean, such as "mouse", ".com," and "Web site." As this issue goes to press, the computer training will have already been repeated on June 17 for the women who signed up, but couldn't attend because of the death of our dear friend and WIHS sister, Bunny Knuckles. The May attendees will also be invited to come back for a refresher class. If you are interested in a future class, please call me, **Moher Downing at (415) 597-4654** and let me know.

NCAB WATCH OUT!

WIHS woman, Donna Haggerty, our alternate National Community Advisory Board (NCAB) Representative, attended the NCAB meeting in June in Chicago. WIHS paid for her to fly to Chicago and stay in the conference hotel. Donna also attended the last NCAB meeting in December when it was in San Francisco. At that meeting, NCAB reps from around the country came here for a special training at WORLD. In the fall issue

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WIHS BIOS

of the WIHS Woman, look for Donna's story about her trip to Chicago.

LOCAL CAB

Our local CAB has been quiet for several months. Why? Well, we were having problems with getting enough of you to come to our meetings and participate in the decision-making process of running a CAB and advising the WIHS study researchers. We would plan these meetings, get lots of yummy food, ask you all to come, and it would just be us, the WIHS staff there. For that reason, we decided to reduce the number of meetings and plan special events for you and other HIV+ women in the Bay Area. We would like to have another CAB meeting in the fall. Would you come? What would it take to interest you in our CAB? It is your study, and you are empowered to make decisions about your study visits, your test results, and future studies. Give me a call if you are interested in attending a future CAB meeting--**Moher Downing at (415) 597-4654.**



A little bit about myself....

My name is Nichole Daigle, I am 20 years old and I have a 18 month old son who is the ultimate joy of my life.

I began working in the Department of Medicine on April 14th. I enjoy reading suspense / mystery books, going to the movies, eating out, and being around my son. My favorite color is red, my favorite time of year is Christmas, and my favorite thing to do is make my son smile.

Nichole works at the San Francisco WIHS Administration Office. Welcome to the WIHS!



What's Happening with Prophylaxis for OI's ? (Opportunistic Infections)?

The New Guidelines for People Living with HIV

By Meg Newman, MD



The United States Public Health Service ([USPHS](#)) and the Infectious Disease Society of America (IDSA) have a working group that gathers together to talk about guidelines for prevention (prophylaxis) and treatment of opportunistic infections. These guidelines have been helping patients and health care providers since 1994 determine which medications to use for prophylaxis and when to start them.

In March of 1999 a draft proposal of the guidelines came out for review. Some of the most exciting things in the report, especially for patients and providers, relates to the safety of **stopping** certain medications. Yup, I said **stopping** medications. These guidelines are to be evaluated again later in the year but most people believe they will be approved.

Discontinuation of PCP Prophylaxis in Adults??

Prophylaxis for PCP is divided into either primary or secondary. People who have never had PCP take "Primary Prophylaxis" to prevent the disease from ever coming. People who take PCP prophylaxis after having had an episode of PCP take "Secondary Prophylaxis" to prevent it from ever occurring again. The new recommendations for those on Primary Prophylaxis (no history of prior PCP) state that for those responding to HAART with an in-

crease in T-cells (CD4+ T-lymphocytes) to >200 cells/uL, for a sustained period of **at least** 3-6 months, prophylaxis discontinuation can be considered. Some experts think it would be wise to have a sustained reduction in viral load as additional criteria for before stopping PCP Primary Prophylaxis.

The data that says stopping is safe comes from 4 different studies that showed that people with a sustained increase in T-lymphocytes did not get PCP if they stopped their PCP prophylaxis (Septra, Dapsone, Ataviquone). As with any study there are other details to consider. Half of the patients in the studies had > 300 T-cells (CD4+ lymphocytes) when they discontinued their PCP prophylaxis and many of the patients had a sustained reduction of their HIV viral load (plasma RNA) below the level of detection. The studies followed patients for only about 6-12 months.

What if my T-cells (CD4+ T- Lymphocytes) go below 200 after I have stopped Primary PCP Prophylaxis?

Nobody knows for sure how much risk you would be at but most experts think it would be important to restart your PCP prophylaxis to keep you from getting PCP.

What about "Secondary Prophylaxis"?

It is possible and likely that if your T-cells have gone above 200 T-cells for a sustained period of time that you **might not** get PCP again. Right now there is "insufficient data" (this means that right now there are not enough studies to prove or disprove something) to recommend stopping secondary prophylaxis.

Good News: stay tuned for new information and recommendations in the next year as studies are taking place to answer this question.

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*****The safety of discontinuing prophylaxis in HIV-infected children receiving HAART has not been studied and the recommendations above pertain to adults with HIV only.*****

What's Up with Discontinuing Primary MAC (Mycobacterium avium Complex) Prophylaxis?

One observational study has suggested that for people who have responded to HAART with an sustained increase in the T-cells from < 50 cells/uL to > 100 cells/uL that new MAC infection is very uncommon. It is reasonable to consider stopping of MAC primary prophylaxis when the T-cells are > 100 cells/uL and there is a sustained lowering of viral load.

What about Discontinuation of Secondary Prophylaxis for those who have a Diagnosis of Disseminated MAC?

It is likely that people who have a sustained response to HAART with T-cells > 100 and a suppressed viral load are at low risk for recurrent MAC. At this time there is "insufficient data" to recommend stopping MAC treatment.

Good News: A number of studies are in a progress with patients who have a diagnosis of disseminated MAC and now have low viral loads and T-cells greater than 100. This is a question that will be answered soon. We hope and think it is likely the studies will show that it is safe to stop MAC therapy once a patient has increased their T-cells above 100 or 150.



Bunny Knuckles & Carol Siporen

Bunny Knuckles and Carol Siporen were both active members of our local WIHS CAB and national WIHS CAB. Carol died on 6/24/99 at Alta Bates Medical center and Bunny died on 5/8/99 at Alameda Medical center (Highland Hospital).

Remembering Yvonne (Bunny) Knuckles By Donna Williams

I remember the first time I met Bunny, of course she wasn't known as Bunny then. She was known as Yvonne Knuckles. I was working at the Planned Parenthood Care clinic and Yvonne had been recently released from prison. Yvonne had not received much HIV care except for what care she received in prison. I remember her being very anxious about what was going to happen to her during her medical visit at the clinic. She was very quiet and she did not ask many questions. That was first meeting with Yvonne Knuckles.

Years later, I met Bunny as a participant in our WIHS study. **Wow!** Bunny was one of the **first** women that enrolled in the WIHS study at Highland Hospital and she **never missed a visit!** What an unbelievable difference from the Yvonne a met a few years ago to the Bunny enrolling in our study. She actually remembered me and of course who could ever forget Bunny (She always had such a presence and was such a great dresser). Bunny was now a ball of fire, ready to make things happen for people with HIV/ AIDS. She had the makings of a great activist. Bunny joined the WIHS community CAB, W.O.R.L.D., and other community organizations that helped to contribute to the fight for people with HIV/ AIDS. Thanks to Bunny's

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efforts, a lot of things are better for people with HIV/ AIDS. Bunny will be greatly missed for her contributions, her continuous fight for people living with HIV/ AIDS, and let's not forget her heart-warming smile. **WE LOVE YOU BUNNY.**

A note from the WIHS newsletter editor:

The June 1999 issue of the WORLD newsletter was entirely dedicated to Bunny Knuckles. Here is an excerpt from the newsletter:

"After being released from prison and being an IV drug user for 32 years she started a brand new life. Bunny became an advocate for men and women living with HIV and AIDS. She educated her own community but she also educated every community. She was part of many boards and did national and local work. She worked on needle exchange programs and did outreach work. There wasn't really too much that Bunny didn't do, and she never forgot where she came from....."

Bunny will live on in each of us that knew her. I will miss her so much. Her death is a great loss to this community and a great loss to me."

An excerpt from: Bunny's Heart of Gold, by Margaret Giordano-Ricks.

Remembering Carol **By Moher Downing**

At the 1997 National Women and HIV Conference in Pasadena, Carol and I went to lunch at a fancy restaurant and sat outside in the sun. It was a beautiful southern California day and we were feeling very deprived that we were expected to go back inside to

the conference and leave that wonderful sun. So we ordered more food. That didn't make us feel any better about going inside so we ordered more food and began to tell each other all about our families. We ran out of food long before we ran out of stories to tell each other about our families, so we ordered more food and continued to talk about our dreams and hopes for our sons. You see when we found out that we were both the mothers of sons, strong, handsome, wonderful sons, we really had a lot to talk about. We really didn't want to go back inside to the conference so we ordered dessert. By then, however, our wallets were empty and our stomachs were full so we took our desserts with us. We were so full we had to walk for a while. We couldn't possibly go back to the conference with our stomachs so full or we'd fall asleep. So we started shopping. We wandered in and out of several boutiques where we couldn't possibly fit into any of the clothes even if we could afford them. Finally after one of the longest lunches in history, we reluctantly walked back to the conference to attend a session on new treatments. We couldn't have been there five minutes, when Carol raised her hand to ask a very perceptive and scientific question about a particular treatment that was being described. I sat there amazed. How could she do that? I was still dumb with food and sun, but Carol's mind had turned immediately to the task at hand, and she turned herself to it completely. I fell in love with Carol that day. Her ability to eat, drink, and be happy and intimate is probably one of the reasons she held on so long to this life. Well, that and her love of her family.

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Remembering Carol

By Nancy Hessol

Carol Siporen was an amazing advocate for women with HIV and I was in awe of her exceptional abilities. She could do it all - testify before Congress to increase funding for women with HIV and AIDS, talk to the media about what it's like to be a woman with HIV, work with the AIDS Clinical Trial Group on development and implementation of clinical trials, and help out whenever we needed her. Shalom Carol.

Carol

By Donna Haggerty

I met Carol during one of the CAB meetings at 18th and Folsom. She was so easy to relate to and her knowledge of medical terms blew me away.

One of the other connections Carol and I had was in the arts. She would write her thoughts into journals and read from them while showing her paintings that went with the words. I would show my photographs. When a nervous moment would come from seeing people looking at my work I would look for Carol and sit down and talk with her. She was always the first person I would look for when we were in shows together.

One of the things that drew me to Carol was she reminded me of the girlfriends I grew up with at home. A friend that would always be there and no matter how long it had been since seeing each other would just pick up where leaving off. Friends like that are hard to find in today's world.

She left a lasting impression on me when she

called one night before we made the trip to Pasadena for the women's conference. She knew that I was on a limited income and said that when she started traveling and speaking at conferences many people were there to help her. She offered and gave me a part of a speaking fee she had received so that I would be able to enjoy the trip more. When she said that I was speechless. No one in my family ever gave me money when I went away...not even my father when I moved to New York!

We were to meet in San Francisco for lunch before she became ill. This never happened. I wish it had. Usually, I would go over to Oakland, we go out for dim sum and went back to her apartment (it had a swimming pool) and looked at her album of certificates given for excellent work at the Naval Air Station in Alameda. She said she knew I would understand what they meant to her. I did, having been a secretary.

I know that Carol is no longer in pain and is at peace. She was so loved by her partner, family and many friends. God bless you Carol.

