

CHOICES

THE NEWSLETTER OF HAWAII ISLAND HIV/AIDS

May

06



Medicine Men by Sally Chew

Six years after Peter Staley and Tim Horn brought HIV treatment into the digital domain with AIDS-meds.com, the website is now one of the most respected resources for information about HIV meds. It's also known as the place where the community gathers online to discuss the latest news, questions and controversies surrounding anti-retroviral therapies. Earlier this year, AIDSmeds.com became part of POZ.com. Sally Chew chats with the dynamic duo about their 40 years of combined experience with the chemistry and activism behind HIV treatment

Peter, is it true that you were working as a bond trader on Wall Street when you got HIV?

Peter: Yes, I came to New York in '83 because I was hired by JP Morgan. It was the Reagan years, so it was a wild ride. I probably became infected my very first summer, but I didn't find out until the fall of '85. It was a very scary time to find out I was positive. I kept quiet at work because people got fired for having HIV in those days.

How did you find the AIDS activists?

It took me a year to meet anyone else who was positive. I finally found them in a support group. Then I realized there was political stuff going on. At first, I didn't know what I could do to help. But I was making a fortune by that time, so I started cutting checks to the People With AIDS Coalition and the Lavender Hill Mob, which had started zapping Reagan officials for not doing anything about AIDS.

On my way to work in March of '87, I got a flyer from a new group that was doing its very first demonstration—right on Wall Street—and it was ACT UP. My mentor, the head trader on the bond desk, muttered something like, "I think they all deserve to die because they took it up the butt." I just had to sit there and stew. But I went home that night, turned on Dan Rather and heard that the FDA was now saying they were going to speed up drug approvals. I said to myself, "Shit! That's power!"

Did that mean you were ready to disclose at work?

Not at first. I started showing up at ACT UP meetings in my coat and tie. If I went to a demonstration, I would hold up a poster in front of my face. But when the market crashed that fall—on Black Monday—my CD4s also crashed to a little more than ten. That's when I said, "That's it—this job is killing me." So I went in to my boss and told him I was HIV positive and that I had to get on disability.

A week later, at an ACT UP demonstration, Channel 4 local news shoved a mike and a camera in my face. That night, I appeared on the news with the words aids victim under my face. After that, I became a full-time activist and a media whore for ACT UP.

We're going to jump right over a decade of AIDS activism—a time that included your founding of the Treatment Action Group (TAG), which famously covered Senator Jesse Helms' home with a giant condom—and skip to your founding of AIDSmeds.com. Why did you decide to launch the website?

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CHOICES

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Hawai'i Island HIV/AIDS Foundation

Mission Statement

The Hawaii Island HIV/AIDS Foundation is a non-profit organization dedicated to assisting those affected by HIV/AIDS to maximize their quality of life, and to ending the spread of HIV. We also utilize the lessons learned in the HIV epidemic to care and advocate for others in the fight against related diseases.

Vision

To build a healthier, stronger, and more sustainable community that supports all its members with a focus on HIV issues.

Core Values

Responsiveness: To people with HIV/AIDS and their families and to the prevention education needs of the community.

Accountability: To our consumers, funding sources, and the community at large.

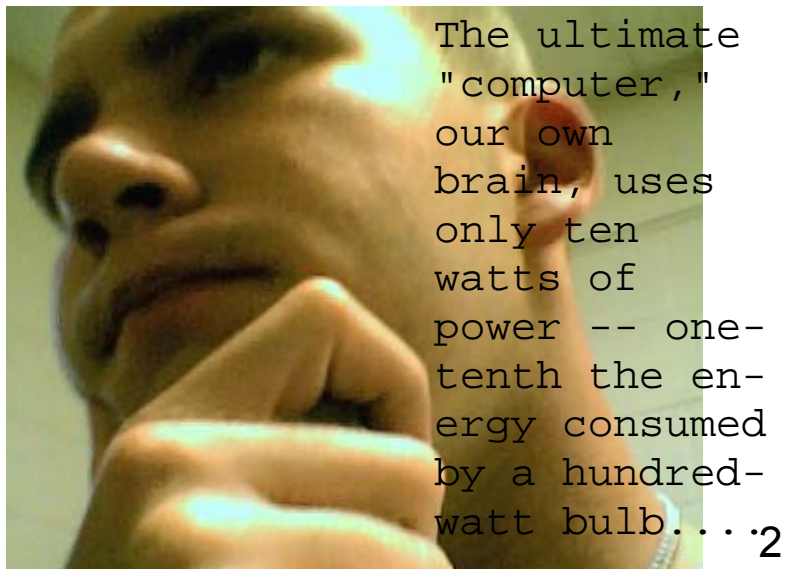
Integrity: To provide services to the entire community in a humane, loving, non-judgmental manner.

Diversity: To embrace the philosophy of "inclusiveness".

Collaboration: To establish and maintain partnerships within the community that maximizes resources and decreases duplication of services.

Leadership: To set the highest standards for responsibility to our mission, vision and values, and be recognized as a positive, inspirational role model in our community.

Advocacy: A collective public voice to speak on behalf of those affected by HIV/AIDS.



Study: HIV testing should be expanded in hospitals

All patients who undergo treatment in a hospital should be offered HIV antibody tests regardless of whether they're in a high-risk group, according to a study in the April issue of the journal *Mayo Clinic Proceedings*, Reuters Health reports. Currently, hospital patients are screened for HIV only if they're deemed to be at a high risk for infection, but researchers at Boston Medical Center write that HIV antibody testing should become routine in U.S. hospitals. They also point out that the Centers for Disease Control and Prevention has recommended routine testing for inpatients since 1993.

The scientists are basing their recommendation on a study that showed about half of HIV infections found through routine testing in hospital settings would not have been identified because the patients were not considered to be in a high-risk group. The study also showed that routine testing can identify HIV infections at earlier stages of the disease when HIV is easier to treat. Without routine testing, those deemed not at risk for the disease might not be diagnosed with HIV infection until they are experiencing AIDS-related complications, the researchers say. (*The Advocate*)

coming from scientists, doctors and legal agencies. Eleven states have legalized the use of marijuana if prescribed by a physician for medical conditions such as relieving nausea after chemotherapy, and AIDS-related wasting. But the Supreme Court last year decided that federal law enforcement officials can arrest anyone using the potentially addictive drug, even if it's for medical reasons and in a state that has legalized this use.

WHAT IT MEANS: Critics of the FDA see this announcement as the latest in a string of decisions that they claim are more political than scientific in nature – some see the influence of the Drug Enforcement Agency, whose director has opposed laws legalizing medical marijuana use, while scientists attempting to study the drug in controlled trials find themselves in a Catch-22. They claim that the government stymies their efforts to document the medical effects of marijuana by noting that there is little evidence to support its medical use, while the reason for the dearth of studies is that few agencies, including the National Institutes of Health, the largest source of research funding in the US, are willing to fund the work. Small studies funded by states or non-government interests have begun to show some potential benefits of smoking marijuana in alleviating pain, but it seems that documenting these effects in large, controlled trials may just get more challenging.

BET launches youth HIV script writing contest

Black Entertainment Television and the Kaiser Family Foundation, through their Rap-It-Up HIV public education initiative, have teamed up with Scenarios USA to create the "2006 Scenarios USA/Rap It Up Story and Scriptwriting Contest." The contest, which carries the theme "What's the Real Deal on Growing Up in the Age of AIDS?" encourages young people ages 13 to 18 to write about what HIV means to them personally and to their friends, family, and communities. The script submission deadline is June 9.

Contest winners will have their scripts made into short films, and they will work with professional film directors in casting, shooting, and editing their projects. The winning films will be shown on BET in spring 2007.

"Informing young people about HIV is essential to stopping the spread of the disease," said Tina Hoff, vice president and director of entertainment media partnerships at the Kaiser Family Foundation. "Engaging young people to share their experiences with HIV to help inform their peers is a powerful way to build understanding and break down the stigma that surrounds HIV/AIDS."

For more information about the script writing competition, go online to www.Rap-It-Up.com, www.bet.com, or www.scenariosusa.org. (*The Advocate*)

FDA Challenges Benefits of Pot

By Alice Park | [Friday, Apr. 21, 2006](#) | [Permalink](#) | [E-Mail](#)

The fight to legalize the medical use of marijuana was dealt a blow Thursday when the Food and Drug Administration contradicted an earlier review by the respected Institute of Medicine and concluded that "no sound scientific studies supported medical use of marijuana."

This finding, based on past studies by the FDA and other government health agencies, will further muddy the already confusing messages

Lift yourself

I want more strength and faster results from my workouts. Will the popular bulk-building supplements creatine and HMB interfere with my HIV meds? —Bulk Mailer

Dear Bulk,

There's no evidence that amino acid workout enhancers creatine and HMB (beta-hydroxy beta-methylbutyrate) interact with HIV meds. But I wouldn't rush to use them—especially creatine.

Creatine can turbocharge your workout and shorten recovery time. But according to a 2005 study in the journal *Antiviral Therapy*, it does this by moving water from your bones and other tissues to your muscles. This can potentially worsen dehydration and the pain of peripheral neuropathy (PN), a condition common among positive people.

Our kidneys and liver (which process HIV meds) already make and store a natural form of creatine. Taking extra creatine, in pills or powder, can stress both organs. The *Antiviral Therapy* study said that because of how creatine works, it may cause kidney damage, plus stomach and muscle cramps. As with any other supplement, talk to your doctor before taking creatine, especially if you have kidney problems.

I speak from sad experience. I once took the bodybuilding dose of creatine: 20 grams the first week, ten the next two, none for five to eight weeks, then start over. But after week three, I had intense stomach cramps and an excruciating distended abdomen. It was not a performance I'd ever repeat.

HMB seems less dangerous. It doesn't use your own body fluid to achieve its effect (which is preventing muscle breakdown, allowing you to work out longer without fatigue). There's some evidence that HMB can add weight if you're too skinny, correct HIV-related muscle wasting and lower blood pressure and cholesterol, but much of this information comes from HMB's manufacturer, so be sure to ask your doctor for a second opinion. It's of particular concern that little is known of HMB's long-term side effects.

My prescription: Instead of using workout enhancers, you need to do the bodybuilding work yourself. With a combo of commitment, consistency, dedication and good nutrition, you will achieve results without side effects.

+Jeffrey Gross Is A Certified Fitness Trainer
Based in Chicago
Got A Question For Our Trainer? E-mail It To

Women on Top

An HIV gel slides toward FDA approval

Microbicides would allow ladies to control their own sexual safety, without depending on men to wear a condom and avoid unsafe sex on the side. Though activists have pushed the products as a funding and research priority since 1990, not one has been approved—prompting charges that the medical establishment ignores women's safety. (It's an equal-opportunity offender: No gels for men exist either.) In January, however, the Food and Drug Administration put the HIV-blocking vaginal microbicide VivaGel on what it dubs its "fast track" to approval. Fast-track status means that the FDA will speed the review of all findings. It doesn't mean more funds will be pumped into VivaGel's development. The manufacturer, Starpharma, hopes for approval as early as 2008. Anna Forbes from the Global Campaign for Microbicides, says, "2008 is very optimistic. VivaGel hasn't entered Phase III [human] trials yet."

VivaGel is the second microbicide to be fast tracked (the first was in 2003 and is still in Phase III trials), and dozens more are creeping up the pipeline. "It's good news, but we need to move the whole pipeline forward," Forbes adds. "Nobody knows which one is going to work."

Global funds for microbicides more than doubled from \$66 million in 2000 to \$163 million in 2005. "We had several microbicides in advanced trials, and people noticed that women now make up the majority of new infections. It caused a shift in public discourse," says Forbes. "But we still have only half the funding we need." The International Partnership for Microbicides recently received a \$30 million grant, but the organization's Joseph Romano, MD, says it needs \$100 million more by 2007 to get even one microbicide through Phase III trials. And then, hopefully, fast track a sexual revolution.

Green Light on PAP Meds

April 19, 2006—The government gave the green light today for people with HIV who are enrolled in the new Medicare Part D prescription program to continue receiving low- or no-cost drugs through drug companies' pharmaceutical assistance programs (PAPs). Some companies feared that getting meds through both programs would break the law and vowed to start cutting people off by May 15.

Peter: I burned out on AIDS activism in '97 and left TAG. It was a really weird time for many people with HIV because we had spent a long time living in the moment and never thinking about the future. Suddenly, after years of thinking we were going to die, we had these powerful meds. Maybe we were going to stick around. I had a hard time figuring out what I wanted to do. It took me two years with a career counselor to decide about my future.

Why the Internet?

Peter: Very early surveys of Internet users showed that its second most popular use (after searching for pornography) was looking for health care information. I was doing my own HIV research online. At that time, there were only a couple of major sites—the Body and AEGIS. They were both thorough but shared the same Achilles' heel: They were hard to navigate, and they were intimidating for newly diagnosed people.

Sort of like libraries without librarians?

Peter: Yeah, no one was holding your hand. Talk about intimidation. So my idea was to create one really well-written “book” for the person who was just diagnosed. Our through was to help people remain calm and know it's not too much to learn if you take your time, breathe and read on. Especially if you allow other positive people to take you through it.

From the earliest days of HIV, there has been a very healthy skepticism among positive people about getting information from official resources. The HIV treatment newsletters that sprang up in the first days of the crisis and were created entirely by positive people were the boilerplate for what I wanted to do.

Enter Tim Horn, whom you met during the TAG years and hired just before AIDSmeds launched in 2000. Tim, when did you become positive?

Tim: I found out that I was HIV positive during my junior year of college in 1991. It wasn't so much the fact that I was HIV positive that freaked me out, but the fact that I did not understand what HIV was or what it was doing to my body. Compounding matters was the fact that I was way up in western Massachusetts on a college campus and I didn't feel very comfortable talking to anybody about it there. To overcome my fears and to quench my thirst for information—What is a virus? What is HIV? What is a T cell?—I threw myself into learning as much as I possibly could.

That must have come in handy by the time you got to New York. Did you join ACT UP?

Tim: I had already missed the ACT UP boat by the time I graduated and got to New York. But I ended up connecting with the American Foundation for AIDS Research (amfAR), writing and then editing their AIDS/HIV Treatment Directory, surveying everything that was going on in clinical trials with these experimental therapies.

I also hooked up with TAG, partly because I was interested in how we, as people living with HIV, could drive the research engine and influence the agenda for our own medical care. I worked with several other organizations, including the PWA Health Group, and later moved to Mexico City to help educate medical providers. They were gearing up for the availability of protease inhibitors down there.

I returned home after about 13 months. I was diagnosed with non-Hodgkins lymphoma—and officially received an AIDS diagnosis. There were a lot of questions as to whether I would be able to fight it off, because of the severity of the situation, but I did. As soon as that was over, I wanted to get back into the work I was really interested in. I'd known Peter for some time, and he asked me to work with him on developing the contents of AIDSmeds.com.

Where does AIDSmeds.com get its information, and how do you make sure it's accurate and up to date?

Tim: I've come to value primary sources of information. When I first started doing work for amfAR, there was no World Wide Web. You had to have subscriptions to all of the medical journals, and you had to travel to the various conferences. To this day, those two sources still have the best primary information.

Peter: Plus, we have contacts with most of the treatment activists, government and private researchers and medical people at the pharmaceutical companies.

How much do you rely on doctors, activists and readers themselves to inform the work that you do?

Tim: Our fellow advocates have always been a major source, not only for information but also for encouragement in terms of the issues that are the greatest focus right now. We also work with researchers, both those who do their own work and those associated with the pharmaceutical industry. Doctors treating people who are living with the virus, along with HIV patients themselves, are perhaps the most vital sources of information.

How has the info on AIDSmeds.com changed since the website was founded in 2000?

Peter: Our Lessons section has become much more comprehensive. Now it includes information about nutrition, depression and topics specific to women and children with HIV, for instance. We introduced real-time translation into Spanish in 2004. That was a gamble, but it worked and is partly what's made the site so international. Our traffic used to be 90% U.S. users and 10% international, and now it's almost evenly split.

Our target audience back then was the person who was newly infected and looking for basic information. But we asked ourselves what more we could offer. We've added interactive tools like Graph My Labs and Check My Meds, both of which are hugely popular. Any time people add a medicine or a vitamin to their regimen, they can see how it interacts with their HIV meds. Graph My Labs helps decipher the lab work most positive people get every three months.

Tim: There is no arguing that HIV positive people have it better today than they did in the past. But in terms of sorting through the information, it's harder than ever. Simply because HIV has become such a complex medical disease to understand, doctors have so little time to spend talking with their patients and there are so many sources of information out there now to choose between. The point of AIDSmeds.com is to be not only a source but also to keep things as reliable and as accurate as we can.

You get a lot of traffic in your Forums. What goes on in there?

Tim: When we first started the Forums in 2001, we were getting mostly medical questions about HIV from positive people. Over time, we also started to get lots of questions from people worried about their transmission risk and wondering about testing. So we created a separate Forum for HIV negative visitors to receive support and accurate information. AIDSmeds has become less of a 7-Eleven of treatment information and more like a family home. We have people who stop in with a particular issue but end up staying around because of the sense of camaraderie. Our family continues to grow as members provide information and support.

Is it the family feeling that makes the Forums so successful?

Peter: I think the primary reason our Forums are so well attended and so widely respected is that we have closely moderated them from the very beginning. When you don't closely moderate Web discussions, they quickly become chaotic. And then people don't stick around.

Tim: Also, because our Forums have a sense of familial bond and because so many people are visiting the Forums on a daily basis, it has become almost a self-policing site.

Are newcomers and newly diagnosed users welcome?

Tim: Absolutely. We have several members who go out of their way to make sure that each and every new visitor to the Forums is properly welcomed.

What has been the response in the Forums since you announced the merger with POZ?

Peter: Generally, the response has been very positive.

What are their biggest worries?

Tim: Some people are concerned that because we will be running banner ads from pharmaceutical companies for the first time, they will no longer be able to talk openly and freely with each other about their treatments or express any criticism of that industry. Peter and I cannot stress enough that none of that will change.

What are the benefits of merging AIDSmeds with POZ?

Peter: The idea of merging with a company that was 20 times our size got my creative juices going about where I could take AIDSmeds.com—like building more interactive tools or hiring more experts to answer questions in the Forums.

Tim: Handing over fundraising and management of the website frees us up to work on the actual content of the site. And, as you know, I'll be the treatment editor at POZ as well.

Are there political advantages to this particular merger?

Peter: The thing besides the pooling of resources that made this merger so smart was that we really weren't that competitive with each other. POZ.com has the magazine and POZ Personals, for instance. We were doing different things well. So the merger just basically brought all those resources to both audiences. That's something that in this political climate is, yes, a big plus: We're bringing more and more people with HIV together.

AIDSmeds.com has always had "HIV+ owned and operated" as its tagline. How important has that been?

Peter: It's hugely important. Community-based educational resources remain to this day the primary resources for people with HIV to flock to—and trust. Of course, these university sites and these government sites are run with budgets that are 50 times larger than what we're run with. But we've got much more experience than they do—as far as our treatment activism and knowing the history.

There are some people at the parent company who are HIV positive but others who aren't. So we've changed the tagline to "Founded and operated by people with HIV." We'll be involved in creating treatment information for AIDSmeds.com and now, also for POZ magazine and POZ.com. And we'll continue to bring users the experience and perspective of what it's like to be HIV positive. In the end, that's what's most important.

Cardinal: Condoms are "lesser evil" compared with HIV

A senior cardinal who was considered for the papacy last year said in comments published Friday that the Roman Catholic Church should soften its ban on condoms because of the scourge of AIDS.

"We must do everything to fight AIDS," said Cardinal Carlo Maria Martini, the retired archbishop of Milan, in Italy's newsweekly *L'Espresso*. "Certainly, the use of condoms can constitute in certain situations a lesser evil."

While there is no specific, authoritative Vatican policy on using condoms to protect against HIV, the Vatican opposes condoms because they are a form of what the church calls artificial contraception. Pope Benedict XVI repeated the Vatican's position last June, when he told African bishops abstinence is the only "fail-safe" way to prevent the spread of HIV.

The 79-year-old Martini was considered a liberal alternative to Cardinal Joseph Ratzinger in the 2005 conclave that elected Ratzinger, now Benedict XVI, as pope.

Martini is one of the most prominent church leaders to call for an easing of the position on condoms. Others include Belgian cardinal Godfried Danneels and Cardinal Javier Lozano Barragán of Mexico, who has said condoms could sometimes be condoned, such as when a woman cannot refuse the sexual advances of her HIV-positive husband.

Martini was responding to questions from the Italian scientist and bioethicist Ignazio Marino, who heads the transplant center at Jefferson Medical College in Philadelphia. Martini agreed with the questioner that the church could consider condoms a "lesser evil" than the risk of the disease.

"There's also the unique situation of a married couple, one of whom is afflicted with AIDS. That one is obliged to protect the other, and the other must be able to protect him or herself," the cardinal said. However, Martini noted that it's one thing to condone the lesser evil in such cases and quite another for the church to promote condom use. (AP)

STARTING JULY 1ST ALL MEDICAID RECIPIENTS WILL HAVE TO DOCUMENT CITIZENSHIP

As of July 1, 2006, people who apply for Medicaid or people who are getting re-certified as eligible will have to provide specific proof of citizenship. The proof must be a birth certificate, passport or certificate of naturalization. (Resident aliens are exempt.)

Medicaid eligibility will be cut off immediately for those who are unable to produce a birth certificate, passport or certificate of naturalization.

In Hawaii Medicaid eligibility is re-certified once a year based on when Medicaid benefits started.

If you need help getting the proof of citizenship necessary to continue your Medicaid benefits or you are thinking about applying for Medicaid, please call Teri in Kona or Kate in Hilo. It takes some time to get a birth certificate, so let us help you right now!

**Sites begin February 1st & end April 15th, 2006; CLOSED on State Holidays (see exceptions).
*** Subject to Changes without prior notification*****

City By County Zip Code Site Name & Address Day(s) Hours & Special Notes Program Type

Hawaii County

Captain Cook	96704	Yano Hall Wednesday 9 AM - 1 PM AARP Tax-Aide 82-6156 Mamalahoa Hwy For Information, call (808) 334-1212
Hilo	96720	Kamana Senior Center Thursday 8 AM - 12 NOON AARP Tax-Aide 127 Kamana Street Appointment required, call (808) 961-8777
Hilo	96720	St. Joseph Church - Conference Room Tuesday 8 AM - 12 NOON AARP Tax-Aide 43 Kapiolani Street Appointment required, call (808) 961-8777
Kailua Kona	96740	AARP Information Center Monday & 1 PM - 5 PM; CLOSED Feb.20 AARP Tax-Aide Royal Kona Resort Hotel Wednesday Appointment required, call (808) 334-1212 Japanese Spoken
Kailua Kona	96740	County Office/ Meeting Room Saturday 8 AM - 2 PM AARP Tax-Aide Kuakini Hwy & Hamana Place
Kailua Kona	96740	Hale Halewai Community Center Thursday 8 AM - 2 PM AARP Tax-Aide 75-5760 Ali'i Drive For Information, call (808) 334-1212
Kamuela	96743	Waimea Senior Housing - Meeting Room Monday & 8 AM - 12 NOON; CLOSED Feb.20 AARP Tax-Aide 67-5165 Kamamalu Street Thursday Appointment required, call (808) 885-4560 thru Apr.17 Anne Gomes



RUMMAGE SALE
WILL BE ON
SATURDAY
MAY 6
AT
KONA UNITED
METHODIST CHURCH
DONATE
VOLUNTEER
BUY

The Hawai'i Island HIV/AIDS
Foundation offices
will be closed
Monday
May, 29
Memorial Day
&
Monday
June, 12
King Kamehameha Day

CLIENT ADVISORY COMMITTEE

In years past we have had a CAC helping the Board to look at different issues from a client's point of view. We have clients on the Board of directors and other committees.

Here's another opportunity for input.

If you think this would be valuable, have the time, and interest, please send you name and email or regular mail address to: hihaf@hihaf.org.

If there is sufficient interest we'll

Free and Anonymous HIV Testing Locations and Dates

Free and anonymous HIV testing and counseling is available to the public on a regular, on-going basis. The testing is confidential and totally needle free.

Hilo/Kea'au

Hawaii Island HIV/AIDS Foundation – Kea'au Office
Shipman Business Park – 16-204 Mele Kahiwa Place,
Suite 1

Monday-Friday, 8:30am-4:00pm

Pahoa

Pahoa Family Health Center, Pahoa Village
Every 2nd and 4th Tuesday of month, 9:00am-
12:00pm

Kona/West Side

Hawaii Island HIV/AIDS Foundation – Kona Office
75-240 Nani Kailua Drive, Suite 5

In the Pines Plaza , Kailua-Kona

Monday-Friday, 8:30am-4:30pm

West Hawaii Community Health Clinic

Every Friday from 1:00pm-4:00pm

Special Dates and Locations

Saturday, February 11 – 9:00am-1:00pm


Kalani Honua Café (Hwy 137 – "red road")

For more information on testing and additional testing dates and times, please call us at 982-8800 (Hilo) or 331-8177 (Kona)

June 2006

Sun	Mon	Tue	Wed	Thu	Fri	Sat
				1	2	3 Anuenue Potluck
4	5	6	7	8	9	10
11	12 Closed King Kamehameha Day	13	14	15	16	17
18	19	20 Support group Hilo 5:00 pm	21	22	23	24
25	26	27	28	29	30	

May 2006

Sun	Mon	Tue	Wed	Thu	Fri	Sat
	1 LEI DAY	2	3	4	5 RUMMAGE SALE	6 Anuenue 
7	8	9	10	11	12 SEE PAGE 9	13
14	15	16	17	18	19	20
21	22	23 Support group Hilo 5:00 pm	24	25	26	27
28	29 Closed Memorial Day	30	31			