

## A Guide To Treatment Information Resources

In our HIV treatment education work at ACRIA, one of our responsibilities is to become familiar with a multitude of topics and the many resources available that address them. We spend as much time gathering information and verifying its accuracy as we do explaining what we've learned to other people. Over time, we've gathered hundreds of information resources, the most useful of which we'd like to share with you.

For example, a few months ago, someone called to discuss his concerns that his cheeks

were getting thinner and thinner. He asked if we knew of any useful websites about facial wasting. Thankfully, we knew of a few. Several weeks later, he called back to discuss some of the information he'd found on the sites. He let us know what he'd learned, and we talked through several surgical options he was considering, including the pros and cons of each.

This experience reminds us of the power that these various resources can provide. We hope that you find that this issue of *ACRIA Update* is both useful and empowering.

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### From Primary Sources to Anecdotes: Making Sense of Treatment Information

by Rebecca Young, Ph.D

Staying "informed" about treatment options – whether for your own health decisions or to help clients and friends with theirs – can be overwhelming. I don't know whether it's more frustrating to find that there's no information on a treatment you're interested in or to find that there's so much information that you don't know where to start – let alone how to sort out the good stuff from the fluff. Is the information really not there or are you not looking in the right places? What if there's a ton of information but it seems contradictory and messy?

I am trained in epidemiology and in social science research and have spent a lot of time teaching college and graduate students how to think about finding and evaluating information. I also had cancer a few years ago and was unexpectedly thrown into a situation in which I needed to make complicated decisions that involved a whole area of health

and treatment I knew nothing about – and I needed to move quickly. In this article, I suggest some strategies for locating reliable information that I have found useful both in teaching and in making my own treatment decisions. I also try to untangle some of the terminology about information sources that always seem to pop up but aren't usually defined – terms like "primary sources" and "anecdotal evidence."

#### Journals, Books, Newsletters, Websites – What Difference Does It Make?

There are obvious differences between a journal and a book, but there are some important "hidden" differences, too. Even a lot of my college students aren't sure about the difference between a journal and a magazine. Each of these sources has a different process that authors have to go through in order to get published, and that has an effect on how reliable the information is. *(continued on page 3)*

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ACRIA is an independent, non-profit, community-based AIDS medical research and treatment education organization dedicated to rapidly improving the length and quality of life for people living with HIV/AIDS. Bulk copies of *ACRIA Update* are available free to agencies that provide services to people living with HIV/AIDS. For more information, call 212-924-3934 ext. 121.

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## Tipranavir Open Label Safety Study

People whose virus has become resistant to approved HIV treatments or who are intolerant to them will take tipranavir with Norvir, along with other anti-HIV drugs, for an open period of time. You must be 13 years of age or older, have a viral load above 10,000 and a CD4 count below 100 to enroll in this program.

## The Effect of Reyataz on Cholesterol Levels

People who have high cholesterol levels and a viral load below 50 while taking Kaletra will either switch to Reyataz or continue taking Kaletra. The study will last 11 months. Study participants will be reimbursed \$25 for each visit.

## Reyataz Compared to Kaletra

People whose viral load has risen to over 1,000 on two separate tests while taking an NNRTI will switch to either Kaletra, or to Reyataz /Norvir. Everyone will also take Viread and either Videx EC or Zerit XR. The study will last for 22 months. Study participants will be reimbursed \$25 for each visit.

## Phase I Study of a New GlaxoSmithKline NNRTI

People who have never taken anti-HIV medications before will take one of four doses of W695634G alone or take placebo pills for 10 days. Participants who complete the study will be reimbursed \$900. Opening in May of 2004.

## Standard of Care Treatment vs. ZEST Once-Daily Regimen

This trial will study whether people on their first HAART regimen who take their drugs two or more times a day can switch to a once-daily regimen. People in the trial will either remain on their current medications, or switch to Zerit XR, Epivir and Sustiva (ZEST) taken once daily. They will visit ACRIA nine times over 11 months. You are eligible if you are HIV-positive, age 18 or over, and on an initial HAART regimen (one or more NRTIs, at least one agent must have a twice-daily dosing schedule, and no NNRTI in the past or in current regimen) with a viral load below 50. Study participants will be reimbursed \$25 for each visit.

**For the above trials, contact Dr. Douglas Mendez at 212-924-3934 ext. 126 or Dr. Yuriy Akulov at 212-924-3934 ext. 124.**

### Editor's Notes

- All material in *ACRIA Update* is presented for educational and informational purposes only, and is not intended as medical advice. All decisions regarding one's personal treatment and therapy choices should be made in consultation with a physician.
- *ACRIA Update* refers to most drugs by both their commercial and scientific names upon their first reference in an article. Thereafter in the article, they will be identified with the name by which we feel they are most commonly known, either commercial or scientific.

## From Primary Sources to Anecdotes *(continued from first page)*

Start with journals. Usually, a “journal” refers to a publication that goes through a process of “peer-review.” Peer-reviewed journals are the gold standard for reporting on scientific research. Publishing an article in a peer-reviewed journal is much more difficult than publishing in other sources (a magazine, newsletter, website, or even a book). That is because the article must go through a process of systematic review by other scientific experts.

The process looks like this: a scientist (or usually a team of scientists) writes up research results and sends them to a journal where they’d like to publish. The editor of the journal takes the name of the scientist(s) off the study and sends it to two or three experts in the particular field of research for detailed comments and criticism. The main job of the scientific reviewers is to make sure that the article is clear, gives enough details about how the study and analysis were done, and takes into account other relevant research in the field. It is quite unusual for a peer-reviewed article to be published exactly as it was originally written. If the results of one study contradict other research that has been done or are very surprising given current scientific ideas, then the review will be particularly important. Reviewers should make sure that the article gives a reasonable scientific rationale for how to make sense of this new study in light of other research.

The process is a very conservative one, which is troubling in some ways. On the one hand, it’s hard to get results out quickly – especially very new or surprising results – and it’s hard to use lively or enthusiastic language, which makes these journals pretty boring to read. On the other hand, when it works as it should, the peer review process pushes scientists to explain how new work fits in with existing studies and also makes sure that scientists can give clear and plausible explanations of how

they reached their results. This helps to minimize scientific fraud (faking results to get grants, credit, or Nobel Prizes). Since the review is done anonymously, by multiple independent experts, this means that information presented in a journal has been held to a higher standard than information from any other source, so it is considered the most reliable. That doesn’t necessarily mean that it is the most *useful* information, though.

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***“Before you even start reading any website you visit or print material you pick up, ask, ‘Who published this?’ ”***

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Magazines, newsletters, books, and websites have editors – some very knowledgeable and strict – who might do a lot of the same things as peer reviewers. Some of these sources also use “fact checkers” whose job it is to check that the information is accurate. While all peer-reviewed journals have a pretty similar process, there is endless variety in how these other sources decide what to publish. This is called the “editorial policy” and it is completely up to the person or organization who publishes the material. Which brings me to another major consideration – who is the publisher?

There’s a huge difference between a website or newsletter published by an individual and one published by an organization that has a formal process for review and standards for what kind of information to include. Before you even start reading any website you visit

or print material you pick up, ask, “Who published this?” (Another thing to pay attention to is when it was published; obviously you want the most current information you can find, all other things being equal.) Is the publisher an organization you recognize? Many medical associations, universities, trusted non-profit organizations, and government programs (such as institutes within the National Institutes of Health) run very reliable websites. If you aren’t familiar with the organization that published something, is there information about the organization’s mission and the editorial process anywhere in the publication or on the website? Do they list the original sources for any claims that are made about how a treatment works or for information that is presented as “fact” (whether about how a treatment has been tested, how it works, how the body works, disease process, or anything else)? If you’ve never heard of the organization that publishes the material, you should definitely find out more about them before you make any treatment decision based on their information.

The same goes for books. Academic presses (those run by universities) usually have a stricter process for making sure that there is accurate information in their books than do “commercial” or “trade” presses. Beware of presses or websites that are run by people trying to sell health or medical products, especially if ads or “testimonials” about products appear alongside treatment information. And what about knowing who funds the publisher or author, whether it’s a website, press, or organization? It’s a good idea, on the one hand, to “follow the money” so that you have an idea of how independent the publisher is from companies that have an interest in selling their products. On the other hand, pharmaceutical companies often give large grants for treatment education that have no strings attached – in some cases, the organiza-

*(continued on next page)*

## From Primary Sources to Anecdotes *(continued from page 3)*

tions who get these grants are very thoughtful and careful about keeping their information as unbiased as possible. How well they manage this kind of separation depends on the overall commitment of the organization that acts as the publisher and on the kind of editorial process they have in place.

You may have heard people use the terms “primary sources,” “secondary sources,” and “anecdotal evidence.” In the treatment world, “primary source” refers to the original publication that establishes any treatment-related “fact.” Primary sources (usually peer-reviewed journal articles) are the first and strongest link in a chain of information. The best way to explain this might be to think of the game telephone, in which a simple message gets distorted just because it has gone through multiple people who try to repeat it, but change it slightly – usually without meaning to. The same thing can happen with science. But sometimes information has to go through additional steps to be useful. For example, in a game of telephone, if the first person says something in French, and you don’t understand French, it’s not a very helpful message for you. If someone in between the first person and you translates it into English, there’s a chance something is lost in translation, but there’s also a chance you can get something out of the message. Likewise, primary sources aren’t the most useful source for every reader or every purpose.

### **Not Sure If You’re Reading It Upside Down? Maybe It’s Not The Most Useful Source.**

So what are the disadvantages of primary sources? They are sometimes too limited in terms of the particular conditions or drugs they consider, too technical, and too focused on specific “study situations” to be useful for making an individual decision. Each primary source is an original report of a single study. Secondary sources are more varied, but what they have in common is that they draw directly on one or more

primary source. Sometimes “secondary” reports are written just to simplify or shorten a primary report, and sometimes they are written to draw a broader picture of a treatment issue. Sometimes they do both. For example, the Fall 2003/Winter 2004 issue of *ACRIA Update* – “Drugs! Drugs! Drugs!” – used material from hundreds of “primary” sources to provide an easy-to-understand overview of all currently approved antiretrovirals available in the United States.

“Anecdotal evidence” is the slipperiest, because this refers to information that doesn’t come from scientific study, but from personal observation, experience, or even opinion. Sometimes anecdotal evidence can be pretty convincing, especially when it’s evidence that comes from your own body! And anecdotes often lead to specific studies or more carefully-considered “case reports.” But in general, an “anecdote” specifically means that the information has not been tested in a systematic way, and the results may not be reproducible even if they *were* studied in a systematic way.

Although primary research reports are the gold standard for distributing specific information, they aren’t meant to address an individual’s medical decisions. To be useful, these primary reports must be put in the context of other research and clinical practice. Most people won’t want (let alone have the necessary time and training) to read many primary research reports and synthesize them for themselves. So what to do? Look for clearly written reviews that pull together multiple primary sources (rather than ‘testimonials’ and anecdotes or single studies). The most useful reviews are not just a laundry list of studies or results, but those that actually synthesize multiple studies – that is, they help the reader make sense of patterns in the findings, major remaining questions, and so on.

There are always some science buffs who prefer to dip into the primary liter-

ature, at least now and then. Once you’ve found a peer-reviewed journal article on a topic that is important to you, how do you make sense of it? If you don’t have much experience reading science, it’s not going to be easy. But it’s usually possible to get *something* out of it. Your best bet at first might be to get someone who is experienced to talk you through it. Take an interesting or important-looking article to your favorite community-based treatment organization, to a nurse practitioner, or to a friend who is more experienced and comfortable reading science. The most important sections to read are the “Discussion” and “Conclusion,” because this is where the results of the study will be discussed in relation to other research and the implications for clinical care or future research will be addressed. The hardest part to read is going to be “Methods,” and unless you’re trying to become a treatment expert, you can happily skip over that.

Another issue with primary sources is that they aren’t as accessible as other material. Medical journals are expensive, they often aren’t available on the web, and most public libraries can’t afford them. But there are ways that regular people can get their hands on them. Lots of college and university libraries, as well as public libraries in some large (or affluent) cities, buy subscriptions that offer online access to a huge number of journals. With college and university libraries, there’s a chance that you can get a visitor pass. Call the library at the college to find out if they have a visitor program. Some research institutes and non-profit organizations also have libraries, and these are sometimes open for visitors by appointment. One of the best library collections is the National Library of Medicine, which has great databases available free and without a subscription on the web, including some free links to journals.

### **Safe and Satisfying Surfing**

The web is like the ocean – it’s vast, it’s

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always moving, and there’s lots of nourishment in there, as well as quite a few sharks. And don’t forget how much garbage is dumped in the ocean! Seriously, though, the web is a fabulous source of information if you have some basic knowledge about how to use it effectively. As a teacher, one of the most interesting and frustrating things I’ve learned about how students use the web is that most seem to approach it as a “free-for-all” – type a keyword or two into Google.com and let it rip! And while Google is one of my favorite search engines, there are usually better places to start if your goal is to find useful treatment information. In this issue of *ACRIA Update*, for example, there is an annotated resource list that includes dozens of websites run by reputable organizations – start your search by picking some of those websites. Go directly to them and then search within the site for information that’s relevant to you.

This kind of search limits the information you get, which is a mixed blessing. If you just type “Crixivan” into a search engine (Lycos, Google, MSN, Yahoo, etc.) you’ll get thousands upon thousands of entries, and it will definitely contain some great links to useful information. But there is no quality control – you may wind up with a list of sites that ranges from AEGIS (see the resource list!) to the long-winded and inexpert ranting of Joe Anybody on his personal webpage. Plus, even if they were all great, thousands of entries are overwhelming. Where do you look first? Lots of folks just go down the line, first-come, first-served fashion. It’s helpful to know that most search engines list results in two different ways: “sponsored links” versus the regular search results. “Sponsored links” are paid advertisements. Companies or organizations pay other websites to list their sites whenever

certain keywords are entered. The regular search results usually list webpages in order of how many “hits” they have – that is, how many times other people have looked at that particular page.

It’s worth a brief aside here to note that doing a “web search” is not the same as searching an electronic database. A web search will bring up relevant material from any publicly accessible website. Electronic databases, on the other hand, are “closed systems” that only include information from specific sources. For example, the National Library of Medicine gives you access to databases such as PubMed, a gigantic collection of citations and abstracts from biomedical journals. The full texts of some of the articles listed on PubMed are even available for free. Databases like PubMed are great for finding primary source material (those peer-reviewed journal articles), but aren’t always best for finding very user-friendly overviews of treatment issues. For that kind of search, you’ll need to surf the web or visit the websites of specific organizations.

Regardless of how you start your search, there are a few more specific tips for evaluating the websites you end up on. Remember to check out who runs the site (the “publisher” or “sponsor”), who pays for it, and a description of the editorial policy. There will often be a tab somewhere near the top called “About Us” that should contain this information. The best sites will also give you information about the qualifications or experience of the people writing for or editing the site and give you some way to contact the site for more information. Ideally, there will be citations listed for any claims made on the site. If they accept advertising, it should always be clearly distinguished from the “information” they are providing.

Finally, a pet peeve of mine and lots of other educators is that stuff on the web circulates forever, but can deceptively look as fresh as the day it was published. Beware of outdated material! Know that people and organizations can pay websites to make sure that their material stays accessible long past its useful shelf life. All the best websites date their pages – this is usually a little line somewhere near the bottom of the page that reads “last updated on (date).” If you’re looking for information that was listed in a “back issue” of a journal or a newsletter, you might look for a tab or link to “archives.” Some journals allow free access to archives even if you have to pay for current issues, while others give up the new stuff for free and make you pay to get things from the archive. Go figure.

**My Way or the Highway? Naaaah.**

It’s no surprise that there is no single right way to get treatment information. But there are definitely more and less useful ways. My biggest concern in this article has been to help you understand the tradeoffs you make by going to one source versus another. Nobody wants to spend all their waking hours pouring over treatment information (unless there’s some treatment-fetish crowd I’m not aware of, which I guess I shouldn’t rule out...). I hope these tips help you make the most of the time and energy you spend zooming around the information superhighway. Happy Cruising!

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# HIV TREATMENT INFORMATION RESOURCES

## Organizations, Newsletters, Websites, and Hotlines

\* Some materials available in Spanish

The following list includes treatment organizations, websites, and hotlines that we trust and have found useful in our work at ACRIA. Our brief descriptions try to give you an idea of the information available on each site but aren't intended to be complete. Each entry includes the name of the organization or website (often both); the treatment newsletter published (in italics), if any; the website address where applicable; and addresses and phone numbers for organizations that are willing to mail materials if you call or write them. Some agencies have hotlines that provide counseling and referrals to other services. Email addresses are provided for international sites and for many of

the sites without other contact information. We've focused on sources that provide treatment information about HIV, viral hepatitis, topics of specific relevance to women, and access issues. We apologize in advance to those organizations that we've invariably missed – space is a consideration, of course, but we may have simply overlooked a useful national treatment organization or website. We welcome your feedback – if you find that a listed resource contains inaccurate or outdated information, please let us know. Similarly, we welcome suggestions of additional HIV treatment resources to add to the list. Please email your suggestions to [treated@acria.org](mailto:treated@acria.org).

### AEGIS (AIDS Education General Information System)

[www.aegis.com](http://www.aegis.com)

A huge website with dozens of valuable features including: headlines that are updated weekly, sometimes hourly, from international media that link to abbreviated or full articles about HIV-related topics (not only treatment); links to law libraries, news services, community treatment newsletters, peer-reviewed journal abstracts, conference abstracts, many other references; and much more. Great archival material that helps put the history of the epidemic in context.

### AIDS Action Baltimore *AIDS Action Bulletin*

2105 N. Charles St., Baltimore, MD 21218  
410-837-2437

[aidsactionbaltimore.org](http://aidsactionbaltimore.org)

Archived articles from *AIDS Action Bulletin* going back to 2002; information about Out Front, a peer-led HIV prevention program for young gay and bisexual men in Baltimore. The annual report and newsletter are available by calling or writing.

### AIDS Community Research Initiative of America (ACRIA) \*

#### *ACRIA Update*

230 W. 38th St., 17th fl., New York, NY 10018  
212-924-3934

[www.acria.org](http://www.acria.org)

Community research and education organization. Site includes issues of *ACRIA Update*, quarterly treatment newsletter, going back to 1997; *Understanding Your Lab Results*, *Managing Drug Side Effects*, *Clinical Trials Explained*, *Treatment Issues for Women*, and *Viral Hepatitis and HIV* (English & Spanish); all available in both PDF and HTML; publications and newsletter are available for free to people with HIV and community-based organizations by calling, writing, or completing online order form. The site includes [TrialSearch@acria.org](mailto:TrialSearch@acria.org), a growing, searchable database of enrolling HIV-related trials throughout the United States.

### AIDS Survival Project *Survival News*

139 Ralph McGill Blvd., Ste. 201, Atlanta, GA 30308  
404-874-7926

[aidsurvivalproject.org](http://aidsurvivalproject.org)

Site includes a listserv for announcements and their newsletter, *Survival News*. Call, email, or snail mail them for information and they'll send you as much as they can track down. They have an extensive treatment resource library in their Atlanta center, hold seminars for newly diagnosed people or those who want treatment information from the bottom up.

### AIDS Treatment Activists Coalition

[atac-usa.org](http://atac-usa.org)

National coalition of AIDS treatment activists working together to end the AIDS epidemic by advancing research on HIV/AIDS. Site includes materials relating to current advocacy issues and a new newsletter describing the coalition's activities. Allows people to register for inclusion in email discussions and gives people the opportunity to get involved in activist discussion and action.

### AIDS Treatment Data Network (The Network) \*

611 Broadway, Ste. 613, New York, NY 10012

212-260-8868 / 800-734-7104 (New York State only)

[atdn.org](http://atdn.org)

Fact sheets about available antiretroviral medications, opportunistic infections, HIV treatment issues in plain English and in Spanish. Write or call for copies of fact sheets. Parts of the website are devoted to information about HIV/HCV coinfection. The Network also provides case management as well as referrals over the phone, although it is not a counseling hotline. **The Access Project** collects and distributes information about medications and other resources available through Medicaid, AIDS Drug Assistance Programs (ADAPs), and industry-sponsored patient assistance programs. Contact **The Access Project** by calling The Network or sending an email to [TheAccessProject@aol.com](mailto:TheAccessProject@aol.com).

### *AIDS Treatment News*

c/o Philadelphia FIGHT, 1233 Locust St., 5th fl., Philadelphia, PA 19107  
800-TREAT-1-2 (800-873-2812)

[aids.org/atn](http://aids.org/atn)

Searchable archive of invaluable bimonthly treatment newsletter, published since 1986. Call or write to subscribe via email or hard copy. The archives provide a fascinating history of the treatment concerns and advocacy of the HIV community over the years.

### AIDSHotline.org \*

[www.aidshotline.org](http://www.aidshotline.org)

California Hotline: 800-367-AIDS (800-367-2437) / San Francisco and outside of CA: 415-863-AIDS (415-863-2437) English and Spanish  
9 am-5 pm Mon, Wed, Thurs & Fri, 9 am-9 pm Tuesdays (PST).  
Searchable database of 1,200 organizations that provide HIV/AIDS & STD services in California; cooperative effort of the San Francisco AIDS Foundation, San Francisco Department of Public Health, and California Department of Health Services; excellent Frequently Asked Questions about HIV, STDs, Hepatitis, Crystal Meth, and more.

### AIDSinfo \* HIV/AIDS Treatment Information Service

PO Box 6303, Rockville, MD 20849-6303

[aidsinfo.nih.gov](http://aidsinfo.nih.gov)

800-448-0440 (English, Spanish, and Portuguese, 12-5 pm EST)

TTY: 888-480-3739 / International: 301-519-0459

A website of the U.S. Department of Health and Human Services; contains current and archived guidelines, including those for the use of antiretroviral agents in adults, pediatrics, and to prevent mother-to-child transmission; a glossary of terms; fact sheets and information relating to the guidelines, medications, vaccines, and clinical trials. Call or write for more information.

### AIDSmap

Lincoln House, 1 Brixton Rd., London SW9 6DE England

Phone: 44 (0) 20 7840 0050 Email: [info@nam.org.uk](mailto:info@nam.org.uk)

[aidsmap.com](http://aidsmap.com)

Comprehensive website providing detailed information about all aspects of

HIV, the immune system, current and investigational antiretrovirals, opportunistic infections, prevention, and much more. Includes the latest news, links to organizations around the world, and various publications. One of the best!

**AIDSmeds.com**

**AIDSmeds.com**

Treatment information, news, and question & answer forums. The site enables you to check drug-drug and drug-food interactions. There's also a tool to graph your lab results. The site also includes basic information for people who are newly diagnosed.

**Alternative Medicine Homepage** [www.pitt.edu/~cbw/altm.html](http://www.pitt.edu/~cbw/altm.html)

Definitions of various alternative therapies; links to lists of complementary and alternative medicine (CAM) providers and related databases and websites.

**American Foundation for AIDS Research (amfAR) \***

**HIV/AIDS Global Link / Treatment Insider**

120 Wall St., 13th fl., New York, NY 10005  
212-806-1639

**amfar.org**

Articles about various HIV-related issues, including treatment, often with a global focus. Click on the amfAR Global Link on the left of the screen to access *Treatment Insider* in English, French, Spanish, or Chinese as well as a lot of other useful information. The *HIV/AIDS Global Link* can be ordered online and is free to the HIV/AIDS community. This site has lots of valuable content but is somewhat difficult to navigate. Write or call for hard copies of amfAR publications.

**The American Liver Foundation (ALF) \***

75 Maiden Ln., Ste. 603, New York, NY 10038

800-GO-LIVER (800-465-4837)

**liverfoundation.org**

Brochures and information about liver disease available online (hard copies can be ordered for a fee); contact information for local chapters nationally; and a list of national and local clinical trials relating to liver disease. Call to get information about liver problems and for referrals.

**American Medical Association**

**Journal of the American Medical Association (JAMA)**

515 N. State St., Chicago, IL 60610

312-464-4147 Email: [srt@ama-assn.org](mailto:srt@ama-assn.org)

**ama-assn.org**

Free registration allows full text access to *JAMA's* research articles, review articles, special communications, and editorials six months to five years after publication. More recent issues require a subscription.

**American Social Health Association (ASHA) \***

PO Box 13827, Research Triangle Park, NC 27709-9940

919-361-8400 / National Herpes Hotline: 919-361-8488

**ashastd.org**

Information about sexually transmitted diseases, fact sheets, a sexual health glossary, and illustrated instructions about how to properly use female and male condoms. Call or write, and ASHA will try to send you information, although it's primarily web-based. Clear and helpful site map.

**The Antiretroviral Pregnancy Registry**

**apregistry.com**

1011 Ashes Dr., Wilmington, NC 25405

US & Canada: 800-258-4263 / International: 910-256-0238

A voluntary, observational study designed to collect and evaluate information on the outcomes of pregnancy exposures to antiretroviral medications. Women are enrolled through their healthcare providers only. Healthcare providers may call or write for further information.

**Asian & Pacific Islander Coalition on HIV/AIDS (APICHA)**

**APICHA News / Navigator**

**www.apicha.org**

150 Lafayette St., 6th fl., New York, NY 10013

212-334-7940 / Infoline: 866-APICHA-9 (866-274-2429)

Available in Urdu, Bengali, Hindi, Thai, Japanese, Korean, Tagalog, Mandarin, and Cantonese.

New York-based AIDS service organization dealing with health issues in the Asian & Pacific Islander population. *Navigator* is an excellent guide

covering treatment issues, benefits, and other topics pertinent to people living with HIV – available in Bengali, Chinese, English, Hindi, Japanese, Korean, Thai, and Vietnamese. Copy the order form on the website and fill it out – the first copy is free. Call the Infoline for information and copies of APICHA publications. Requests for materials may also be made by mail.

**Association of Nurses in AIDS Care (ANAC) *HIV + Nurse***

3538 Ridgewood Rd., Akron, OH 44333-3122

330-670-0101 / 800-260-6780

**anacnet.org**

Primarily meant for nurses and other healthcare professionals, the site includes PDF versions of ANAC's quarterly newsletter, which is also for lay people, *HIV + Nurse*, as well as other treatment and symptom management information. Call or write for copies of *HIV + Nurse*.

**Association of Nutrition Services Agencies (ANSA)**

1030 15th St. NW, Ste. 860, Washington, DC 20005-1511

202-289-5651

**aidsnutrition.org**

Helpful fact sheets on nutrition as it relates to various HIV medications, drug side effects, and HIV disease. PDF version of *Nutrition Guidelines for Agencies Providing Food to People Living with HIV Disease* is available to view and download.

**AVERT**

+44-01403 210202 Email: [confidential@avert.org](mailto:confidential@avert.org)

**www.avert.org**

International AIDS charity based in England; includes PDF versions of booklets for young people and adults about HIV treatment, sexually transmitted diseases, and other topics; information and statistics about the global epidemic; quizzes that can be useful as educational tools; a detailed history of the epidemic; and much more.

**Babes Network \* *BABES Talking (English & Spanish)***

1120 E. Terrace, Seattle, WA 98122

206-720-5566 x 12 / Toll-free: 888-292-1912 **www.babesnetwork.org**

Site for women with HIV/AIDS; treatment information, personal stories, support groups, peer counseling; and issues of *BABES Talking* newsletter going back to 1998. Email, call, or write to receive copies of the newsletter.

**Being Alive: People with HIV/AIDS Action Coalition \***

**Being Alive Newsletter**

621 N. San Vicente Blvd., West Hollywood, CA 90069

310-289-2551

**beingalivela.org**

Advocacy and information organization. Site includes information about current political actions, prevention oriented chat rooms, and links. The *Being Alive Newsletter* is available online going back to 1996. You can also call or write to receive the newsletter.

**The Body \***

**thebody.com**

Comprehensive site offering treatment information from a variety of sources, including community periodicals, conference coverage, and recent news. Site also has forums to submit questions to the site's medical consultants on issues ranging from hepatitis C/HIV coinfection to lipodystrophy to nutrition and exercise. Check out the women's section (profiles, articles, and question & answer forum):

**www.thebody.com/features/women**

**Body Positive \* *Body Positive magazine / SIDAahora***

19 Fulton St, Ste. 308B, New York, NY 10038

212-566-7333

HelpLine: 800-566-6599 Mon-Fri 10-6 pm EST

**bodypos.org**

Organization primarily dedicated to support for PLWHAs, including groups and referrals; includes a link to The Body website for back issues of *Body Positive* magazine and *SIDAahora*; publishes an English/Spanish HIV/AIDS resource directory for the greater New York area. Call the HelpLine for referrals (mental health, drug treatment, testing sites), questions about transmission, safer sex, and emotional support. The staff at Body Positive will also respond to letters.

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## Personal Perspective

### The Good Stuff

by Lisa Frederick

In 1775, Samuel Johnson, the British writer, said, “Knowledge is of two kinds. We know a subject ourselves, or we know where we can find information upon it.”

I’m the consummate information junkie, always on the prowl for the most recent, cutting edge information. As an HIV treatment educator, I often say in my workshops that we’re drowning in information yet still starving for knowledge. We need to sift out the good from the bad. Good treatment information sources are vital, and our work couldn’t be done without them. It really bothers me when I hear information repeated that doesn’t have a bit of truth to it.

I first became interested in being an educator when I took an “AIDS in America” class in college. I was so blown away by what I heard, so touched and moved, that I tried to teach anyone who would listen everything that I had learned. A few months later, my brother, who had been estranged from my family for about 15 years, showed up at my dad’s doorstep and announced that he had AIDS. My dad freaked out and treated my brother like a leper. At first, I was extremely hurt by my dad’s reaction. Then I realized that it was based on fear, and the little information that he had about HIV/AIDS was wrong. I pulled together all the information from my “AIDS in America” class as well as some information I got online and sat down with my dad to educate him to the best of my ability at that time. My brother lived for only two more months, but during that time, my dad was his biggest support. Many of his fears were put to rest due to our talk, and I’ve wanted to be an educator from the moment my father thanked me.

I’ve been a treatment educator for a year and a half now, so by most standards I’m still considered a “new jack.” Part of being a good educator is the commitment to deliver practical, relevant information and a willingness to learn from others. So I make it a point to tap into the treatment resources of my co-workers, especially the more seasoned ones, because they have a good handle on which resources are reliable and up-to-date. My clients are also a source of treatment information; I learn from them and

benefit from their knowledge, even as they learn from me. Being an information junkie, I love sifting through various resources. I’ll spend hours on a search engine, reading and comparing information. I take information to co-workers to compare what I’ve found with the information they have on a particular topic.

I love to get the complete research article, but sometimes I can only find the abstract, a short summary of the article, including the background and reasons for the study, the methods used, the results, and the conclusion. Since the abstract isn’t complete – and sometimes inaccurate because it may have been written before the study was completed – further research often reveals more than what is stated in the abstract. Because of this, I try to get a good amount of information that supports the abstract before I pass that information on. Literally, I sometimes spend all day researching an issue, comparing information. My day is really made when I find contradictory information. I compile articles and abstracts from different conferences, then go to the online sites that I’ve grown loyal to and sites I come across using a search engine and examine all of the data critically.

I look for specific things in the treatment resources I use. I lean toward resources that give me a personal perspective. When presenting a topic, I often learn additional information from the workshop participants that is critical to a more complete picture. For example, while getting ready for a workshop on women and HIV, I prepared lots of clinical information about Human Papillomavirus, cervical cancer, and Pap smears. There I was, about to deliver all of this heavy-duty information to the group of women, thank them for attending, and leave. But as I was getting ready, I felt that something more personal was needed, so I conducted some further research and compiled a list of issues that would put a personal spin on the clinical information. I love statistics – numbers paint a picture for me, and I thought that including them in the workshop would bring the information home to the women. It wasn’t easy to find this information online, so I kept searching until I came across a source that helped me make my presentation more complete. African American and Hispanic

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*“I often say in my workshops that we’re drowning in information yet still starving for knowledge.”*

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women are disproportionately infected by HIV/AIDS and these are the women I work with. I must allow discussion of issues of economic independence, sexual empowerment, stigma, discrimination, and more in order to bring it full circle. The women in the workshop had so much to say about these personal issues. It opened the door so wide that we were able to look at the clinical information with more insight; we were able to talk with great candor.

I also look for resources that are intelligent and adult. I don't like information that underestimates the intelligence of the readers or uses cartoons. Even the most basic information for people with limited HIV knowledge can be presented in an intelligent, adult manner. I think this preference comes from my work in case management. It always bothered me to see adults being treated as though they were children by caseworkers, doctors, or other service providers.

I once was at an AIDS service organization to conduct a staff training when a staff member came into the room and said, "Here's Lisa with the good stuff." That really made me feel good. Another time, while I was conducting a workshop about sexually transmitted diseases, a question came up about curing syphilis – a participant disagreed with what I was presenting. I welcome stuff like that. First, I re-read the information I had presented, then I conducted a further search, read through information from reputable sources, and then I consulted a co-worker who has been providing treatment education for many years and has personal experience with syphilis. After I was satisfied with my various sources, I revisited the topic in my next workshop with the group. It turned out that my original understanding was right, but it was worthwhile doing further research into the subject so that I could have a better discussion with the participant who had disagreed with my information.

On the flip side, a participant once questioned some information that I was presenting about the effect of heroin on HIV disease progression. I spent days searching for data to support what I had stated. Although much of the information I found was suggestive of my original understanding, I couldn't find anything definitive. I consulted my co-workers and supervisor. After picking their brains, I decided to revisit the topic and retract my statement until I found more concrete information.

The bottom line is that I try to be as diligent as possible in choosing good treatment resources so that I can keep bringing "The Good Stuff."

*Lisa Frederick is an HIV Treatment Educator at ACRIA in New York.*

**British Columbia Persons with AIDS Society *Living +***  
1107 Seymour St., Vancouver, BC, V6B 5S8, Canada  
604-681-2122 Email: info@bcpwa.org **BCPWA.org**  
Site includes low-literacy pamphlets on HIV/AIDS treatment-related issues that you can order or download as PDF files, policy and advocacy position papers, *Living Positive* manual, available by calling, writing or sending an email, and bimonthly magazine, *Living +*, online and by subscription.

**The British HIV Association** **bhiva.org**  
Extensive site of medical association that publishes HIV, hepatitis B/HIV coinfection, hepatitis C/HIV coinfection, and pregnancy treatment guidelines, sometimes at odds with the U.S. guidelines.

**Canadian AIDS Treatment Information Exchange (CATIE)**  
555-505 Richmond St. W, Box 1104, Toronto, ON, M5V 3B1, Canada  
416-203-7122 / 800-263-1638 (Canada only) **www.catie.ca**  
Loads of treatment information in French & English, including news bulletins, *TreatmentUpdate*, CATIE's treatment newsletter, lots of other useful publications, and HIV-related clinical trials enrolling in Canada. Send information requests to librarians using an online form or call with questions.

**The Canadian Women's Health Network**  
419 Graham Ave., Ste. 203, Winnipeg, MB, R3C 0M3, Canada  
204-942-5500 / Toll Free: 888-818-9172  
TTY: 866-694-6367 / In Winnipeg: 204-942-2806  
Email: cwhn@cwhn.ca **cwhn.ca** (English) / **rcsf.ca** (French)  
A comprehensive website about women's health issues, not HIV-specific; includes opportunity to subscribe to monthly electronic newsletter; PDF versions of *Network* newsletter; database of resources in Canada; lots of links to publications and information.

**The Center for AIDS Hope and Remembrance Project \*  
Research Initiative / Treatment Action! (RITA!)**  
PO Box 66306, Houston, TX 77266-6306  
713-527-8219 / Toll Free: 888-341-1788 **www.centerforaids.org**  
Treatment information and advocacy site that includes their treatment newsletter, *RITA!*, online (archived issues date back to 1999); it can be ordered by filling out an online order form or calling; clear, downloadable facts sheets including one about each available anti-retroviral; and the opportunity to subscribe to a weekly treatment and research email newsletter.

**Centers for Disease Control and Prevention (CDC) \*  
National Prevention Information Network (NPIN)**  
National STD and AIDS Hotline (24 hours a day):  
800-342-AIDS (800-342-2437) / 800-243-7889 TTY  
800-344-7432 Spanish **cdcnpin.org**  
NPIN, the prevention arm of the CDC, includes: statistics; frequently asked questions; slide sets; many publications that are available to download and to order; access to *Morbidity and Mortality Weekly Reports (MMWR)* dating back to 1991; and the opportunity to receive information through email from a variety of CDC HIV/AIDS mailing lists. People at the hotline answer prevention questions about STDs, make referrals to local health departments, and send out information that may be found on CDCNPIN website.

**Centers for Disease Control and Prevention \*  
National Center for Infectious Diseases – Viral Hepatitis**  
Voice mail line: 888-4HEPCDC (888-443-7232) 24 Hours a Day  
**www.cdc.gov/ncidod/diseases/hepatitis/spotlights/c\_strategy.htm**  
Basic information about hepatitis A, B, C, D & E; statistics; fact sheets; slide sets; little coinfection information; the *National Hepatitis C Prevention Strategy (2001)* in PDF and HTML; vaccination information available in many languages; most material is prevention-based, since the CDC is not a treatment agency.

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### Clinical Care Options

Detailed information about HIV, hepatitis B, hepatitis C, and more; medical and research news, review articles, conference coverage; intended for healthcare providers; might be heavy going for some people with little background; registration required to access most of the site.

**clinicaloptions.com**

### ClinicalTrials.gov

Searchable database of clinical trials for various diseases, including HIV, that are sponsored by the National Institutes of Health, other Federal agencies, and the pharmaceutical industry; information about the clinical trial process.

**clinicaltrials.gov**

### Community Programs for Clinical Research on AIDS (CPCRA)

8757 Georgia Ave., Ste. 1200, Silver Spring, MD 20910  
301-628-3000

**www.cpcra.org**

The CPCRA is a clinical trials program that conducts research through a national network of community-based sites; website includes results of completed CPCRA studies; CPCRA is currently enrolling patients for the SMART study, a large international study comparing two HIV treatment strategies - one group starts antiretroviral therapy only when their CD4 counts reach 250 or less, and the other will start or stay on therapy no matter what their CD4 counts ([www.smart-trial.org](http://www.smart-trial.org)).

### Community Research Initiative of New England (CRI)

23 Miner St., Boston, MA 02215-3318  
617-778-5454 / 888-253-2712

**crine.org**

Site includes a terrific, full-color chart of antiretrovirals, including a printable PDF version - great if you have access to a color printer; information about Massachusetts' HDAP (HIV Drug Assistance Program) and other drug access programs; descriptions of CRI's clinical trials enrolling. Call for information about clinical trials or Massachusetts' state ADAP (HDAP) or to talk to the education and outreach staff. Written requests for information will be fulfilled with a packet of information and/or a referral to another organization or research agency; CRI's work is exclusively in Massachusetts.

### Critical Path AIDS Project

2062 Lombard St., Philadelphia, PA 19146  
215-545-2212

**critpath.org**

Site devoted to advocacy and education; includes many resources in the Philadelphia area. Call or write for information and referrals.

### Department of Veterans Affairs - National Hepatitis C Program

**hepatitis.va.gov**

Useful, practical information about hepatitis A, B and C as well as links to more technical materials.

### Direct Access Alternative Information Resources (DAAIR)

118 Park Ave., Newark NJ 07104  
973-497-2333 Email: [info@daair.org](mailto:info@daair.org)

**www.daair.org**

Non-profit buyer's club (operations currently suspended); the site is no longer being updated, but includes much historical information on alternative therapies; the HIV Treatment Info Pages still contain good backgrounders: detailed Treatment Information Sheets on alternative therapies such as DHEA, glutathione, glycyrrhizin, NAC, and silymarin (milk thistle); articles on *Evaluating Therapies*, *Lipodystrophy*, *Food Safety*, *Neuropathy*, and other topics; and an extensive section on countering toxicities of antiretrovirals. As with most information on alternative therapies, much of what is presented is unproven speculation, but the site remains a good starting place for people making decisions about such treatments.

### e-medicine

**emedicine.com**

Comprehensive medical site with relatively detailed information about many diseases including HIV and viral hepatitis.

### European AIDS Treatment Group (EATG) \*

EATG e.V. Mindenerstrasse, 33 D-40277, Düsseldorf, Germany  
Tel: +49 211 788 3481 Email: [Office@eatg.org](mailto:Office@eatg.org)

**eatg.org**

Site maintained by European treatment activists; features treatment news, links to articles, policy statements, opportunity to subscribe to monthly electronic newsletter or join EATG discussion list; information available in many languages.

### Food and Drug Administration (FDA) HIV and AIDS Page

Richard Klein, HIV/AIDS Program Director

Office of Special Health Issues

Office of International and Constituent Relations

5600 Fishers Ln., HF-12, Rockville, MD 20857

301-827-4460 / Fax: 301-443-4555 **www.fda.gov/oashi/aids/hiv.html**

Site includes transcripts of Advisory Committee Meetings; FDA news releases; brand, generic, and approval dates for each antiretroviral; a helpful FDA A-Z index; links to related sites; and the opportunity to sign up for email announcements about product approvals, significant label changes, safety warnings, notices of upcoming public meetings, and more.

### Gay Men's Health Crisis (GMHC) \* *Treatment Issues*

Dept. of Medical Information, 119 W. 24th St., New York, NY 10011  
212-367-1456 / Hotline: 212-807-6655

**gmhc.org**

AIDS service and advocacy organization. Site includes information about GMHC's many services, current and archived issues of *Treatment Issues* going back to 2000, fact sheets, and educational brochures available for sale. Call hotline for information about HIV/AIDS, testing, support, and referrals for services.

### Henry J. Kaiser Family Foundation

650-854-9400

**kff.org/hiv aids**

Site contains reports, information, and fact sheets about national and international HIV/AIDS issues; substantial and very useful. Single copies of the policy-related fact sheets and surveys are available by calling.

### The Hepatitis C Support Project \* *The HCV Advocate*

PO Box 427037, San Francisco, CA 94142

**hcvadvocate.org**

Thorough, consistently updated information about viral hepatitis and coinfection; includes fact sheets (many in Spanish), articles, news updates, conference coverage, links to other viral hepatitis websites, and PDF versions of *The HCV Advocate* newsletter dating back to 1999. Write to request materials by mail.

### Hepatitis Foundation International (HFI)

504 Blick Dr., Silver Spring, MD 20904-2901

301-622-4200 / Toll-free: 800-891-0707

**www.heplink.org**

**hepatitisfoundation.org hepatitisresources-calif.org**

Fact sheets, news updates, an online learning center, brochures and pamphlets (for sale); fact sheets are available in other languages by calling or emailing HFI. Call for information about support groups, resource materials, and medical referrals. People seeking information about hepatitis can also write with questions.

### Hepatitis Resource Network

**h-r-n.org**

Information about medications in development for the treatment of hepatitis C, clinical trials for hepatitis C, and slide presentations about HBV/HIV and HCV/HIV coinfection.

### HighWire

**highwire.stanford.edu/lists/freeart.dtl**

Extensive list of medical journals, some of which include HIV-related study results, with information on when issues become available for free; includes links to each journal.

### HIV & Hepatitis Education Prison Project *HEPP Report*

401-277-3651

**hivcorrections.org**

Contains text articles and PDF versions of *HEPP Report*, a monthly newsletter detailing treatment issues for inmates; the January 2004 issue includes a table of interactions between methadone and anti-HIV medications; archived issues available back to 1999. Hard copies of the newsletter aren't currently available, but you can call for information about HIV, viral hepatitis, and statistics.

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# 10 Things To Know About Evaluating Medical Resources on the Web

The number of Web sites offering health-related resources grows every day. Many sites provide valuable information, while others may have information that is unreliable or misleading. This short guide contains important questions you should consider as you look for health information online. Answering these questions when you visit a new site will help you evaluate the information you find.

## 1. Who runs this site?

Any good health-related Web site should make it easy for you to learn who is responsible for the site and its information. On this site, for example, the National Center for Complementary and Alternative Medicine (NCCAM) is clearly marked on every major page of the site, along with a link to the NCCAM homepage.

## 2. Who pays for the site?

It costs money to run a Web site. The source of a Web site's funding should be clearly stated or readily apparent. For example, Web addresses ending in ".gov" denote a Federal Government-sponsored site. You should know how the site pays for its existence. Does it sell advertising? Is it sponsored by a drug company? The source of funding can affect what content is presented, how the content is presented, and what the site owners want to accomplish on the site.

## 3. What is the purpose of the site?

This question is related to who runs and pays for the site. An "About This Site" link appears on many sites; if it's there, use it. The purpose of the site should be clearly stated and should help you evaluate the trustworthiness of the information.

## 4. Where does the information come from?

Many health/medical sites post information collected from other Web sites or sources. If the person or organization in charge of the site did not create the information, the original source should be clearly labeled.

## 5. What is the basis of the information?

In addition to identifying who wrote the material you are reading, the site should describe the evidence that the material is based on. Medical facts and figures should have references (such as to articles in medical journals). Also, opinions or advice should be clearly set apart from information that is "evidence-based" (that is, based on research results).

## 6. How is the information selected?

Is there an editorial board? Do people with excellent professional and scientific qualifications review the material before it is posted?

## 7. How current is the information?

Web sites should be reviewed and updated on a regular basis. It is particularly important that medical information be current. The most recent update or review date should be clearly posted. Even if the information has not changed, you want to know whether the site owners have reviewed it recently to ensure that it is still valid.

## 8. How does the site choose links to other sites?

Web sites usually have a policy about how they establish links to other sites. Some medical sites take a conservative approach and don't link to any other sites. Some link to any site that asks, or pays, for a link. Others only link to sites that have met certain criteria.

## 9. What information about you does the site collect, and why?

Web sites routinely track the paths visitors take through their sites to determine what pages are being used. However, many health Web sites ask for you to "subscribe" or "become a member." In some cases, this may be so that they can collect a user fee or select information for you that is relevant to your concerns. In all cases, this will give the site personal information about you. Any credible health site asking for this kind of information should tell you exactly what they will and will not do with it. Many commercial sites sell "aggregate" (collected) data about their users to other companies – information such as what percentage of their users are women with breast cancer, for example. In some cases they may collect and reuse information that is "personally identifiable," such as your ZIP code, gender, and birth date. Be certain that you read and understand any privacy policy or similar language on the site, and don't sign up for anything that you are not sure you fully understand.

## 10. How does the site manage interactions with visitors?

There should always be a way for you to contact the site owner if you run across problems or have questions or feedback. If the site hosts chat rooms or other online discussion areas, it should tell NCCAM – 2 visitors what the terms of using this service are. Is it moderated? If so, by whom, and why? It is always a good idea to spend time reading the discussion without joining in, so that you feel comfortable with the environment before becoming a participant.

*From the National Center for Complementary and Alternative Medicine website: [nccam.nih.gov](http://nccam.nih.gov)*

## Personal Perspective

### Ode to the World Wide Web

by Tim Horn

I confess. I am an unabashed World Wide Web junkie. I shudder at the thought of how much time I have spent over the years gawking at websites dedicated to sex, automotive design and repair, sex, online auctions and shopping (I will never set foot into a store to go Christmas shopping again), sex, and what always claims to be the best bouillabaisse recipe known to man. And those are just for fun.

Where the WWW really matters to me is in all things work-related and, by extension, my life as an HIV-positive person. In short, it has become my information highway to virtually all things happening in the HIV/AIDS research world. With high-speed Internet access and the click of the mouse, I can track down results from a multitude of clinical trials and basic science studies, reams of background information about virtually all diseases that plague the world, and detailed contact information for researchers engaged in HIV/AIDS work just about anywhere. The real challenge is making heads or tails of the information out there, which means weeding through the junk (there's a lot of it) – passing my favorite muscle bear site along the way, of course – to find materials that are balanced, contain citations and references, and are clear in their focus and intent. This, however, is easier said than done.

The official birth of the WWW was in 1989, when Tim Berners-Lee at the European Center for High Energy Physics in Geneva set out to develop a way for researchers to “link” to pertinent research documentation using the Internet, born seven years earlier. By 1990, Berners-Lee had developed a rather crude browser program that he named the World Wide Web.

In 1993, Mark Andreessen of the National Center for Supercomputing Applications in Illinois launched Mosaic X, an easy to install and easy to use browser that quickly became a runaway hit. By 1994, tens of thousands of versions had been installed on computers throughout the world. This program contained many of the features that are familiar to Web users today using Netscape – which is the successor company established by Andreessen to exploit Mosaic X – and Microsoft's Internet Explorer.

According to Richard Griffiths, an Internet historian at Leiden University in the Netherlands, there were approximately 3,000 viewable Web sites in 1994. Twelve months later, the number of Web sites had climbed to 25,000. By January 2001, the number of Web sites surpassed 30 million, with the vast majority of them containing multiple indexed pages. In early March 2004, Google – arguably the most effective Web search engine – claimed to have indexed 4.2 billion Web pages. If we assume that the average Web site contains 50 pages and that Google has succeeded in indexing two-thirds of the Web's total number of pages, it's not unreasonable to conclude that we're now dealing with approximately one billion Web sites.

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*“While I still travel to conferences... it is a relief to rely on the suitcase lifestyles of others who post their proceedings on the web.”*

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I don't recall the first time I accessed the WWW. When I started my work in HIV/AIDS treatment education and advocacy in 1992, first as a writer of the *AIDS/HIV Treatment Directory* for the American Foundation for AIDS Research (amfAR), research tools as convenient as the World Wide Web were definitely not at my disposal. Research required sifting through voluminous paper files, some six to 12 inches thick, to ferret out documents I needed, mostly copies of articles from the eight or so medical journals we

subscribed to. Then there was the travel. Preliminary data from clinical trials were being presented at HIV/AIDS conference sprouting up all over the world. If we wanted the information immediately – which was always the case when treatment options were few – expensive and exhausting travel was the only way to make this happen.

Today, I still rely on the same sources of information I've always relied on. However, millions of abstracts for articles in hundreds of medical journals are now at my fingertips. PubMed, maintained by the National Library of Medicine, contains more than 15 million citations for biomedical articles dating back to the 1950s. PubMed is also great about providing links to the full articles – which are now archived on the websites of various medical journal publishers – many of which are free. Within seconds, I have access to data reported in tried-and-true journals like *AIDS* and the *New England Journal of Medicine*, to some of the more quirky (and never uninteresting) information reported in journals like *Ginecologia y Obstetricia de Mexico*.

While I still travel to conferences and meetings to catch glimpses of early data from studies that won't likely be published in medical journals for another six months or so, it is a relief to now be able to rely on the suitcase lifestyles of others who remain dedicated to posting the proceedings of these conferences on the Word Wide Web. There is Medscape, which has long been a personal favorite source for conference coverage and more general topic reviews. I've also come to greatly value the extensive conference coverage provided by Jules Levin, through the National AIDS Treatment Advocacy Project (NATAP), and the folks at HIVandhepatitis.com.

If I'm looking to see how the results of a particular clinical trial falls within the "trajectory of knowledge" involving a specific anti-HIV drug or an opportunistic infection, I call upon comprehensive websites maintained by amfAR and the U.K.-based AIDSmap. And there is no shortage of expert data-driven commentary on the WWW, ranging from comprehensive reports published by the Treatment Action Group and articles published in GMHC's *Treatment Issues*, to more basic take-home messages printed in the likes of this publication and one of the websites I work for, AIDSmeds.com. And, of course, there is a never-ending supply of review articles, published by medical journals, to help keep things in perspective.

For general overviews of virtually all human diseases that don't require a medical residency to understand, I am partial to information published by e-medicine and the beatified Merck Manual. There's also no beating the cut-and-dry information found in prescription drug package inserts – for virtually all diseases – that can be accessed through websites maintained by pharmaceutical companies.

This is hardly a detailed review of all the websites I visit on a regular basis (apologies, in advance, to friends and colleagues not mentioned here). The point is that there are many websites, designed with different goals and aimed at different audiences, containing valuable information regarding the ongoing research – and evolving management – of HIV infection. Much like Rebecca Young explains in her review of sources of information, it is important to be aware of where the information comes from and the type of information that is reported. For the work I do, primary sources – for example, clinical trial results reported in peer-reviewed medical journals, commentary-free data presented at conferences, and prescription drug package inserts – remain the most important sources of information available to help me understand, for myself, how things have changed (or how they have not). In this way, the sources of information that are most important to me haven't changed in the 12-plus years I have been doing this work. What has changed, fortunately, are the ways I can go about accessing these sources.

*Tim Horn is Executive Editor of The PRN Notebook, published by Physicians' Research Network in New York. He is also the head medical writer for AIDSmeds.com.*

**HIV i-Base \* HIV Treatment Bulletin** [www.i-base.org.uk](http://www.i-base.org.uk)  
British site that includes thorough HIV treatment and conference reports; you can receive PDF versions of publications via email or by ordering them online; information is available in Spanish, French, Italian, Portuguese, Greek, and Chinese.

**HIV Drug Interactions** [www.hiv-druginteractions.org](http://www.hiv-druginteractions.org)  
+44 (0)151 794 5553  
Detailed charts and articles about interactions between drugs/herbs and protease inhibitors and non-nucleosides (NNRTIs) as well as in interactive database that allows you to choose drugs to check about possible interactions; includes links to full relevant journal articles; site sponsored by the University of Liverpool.

**HIV Pharmacology.com** [www.hivpharmacology.com](http://www.hivpharmacology.com)  
Email: [info@virology-education.com](mailto:info@virology-education.com)  
Articles, conference reports, and information focused on pharmacokinetics and drug interactions. Free registration required. This site does not work in Netscape.

**HIVandHepatitis.com** [hivandhepatitis.com](http://hivandhepatitis.com)  
PO Box 14288, San Francisco, CA 94114  
Regularly updated website featuring HIV, hepatitis B, hepatitis C & coinfection treatment information, news reports & conference coverage, including the opportunity to submit questions to the site's medical consultants.

**HIV InSite** [hivinsite.ucsf.edu](http://hivinsite.ucsf.edu)  
Comprehensive site includes vast amounts of treatment information and news, including sections devoted to policy issues; women and children; global issues; statistics; links; and the HIV InSite Knowledge Base, a detailed, online textbook about various aspects of HIV disease and its treatments from the University of California at San Francisco and San Francisco General Hospital.

**HIV Medication Guide \*** [www.hivmedicationguide.com](http://www.hivmedicationguide.com)  
Notis Inc., 2408 S. Shore Rd., Sudbury, ON, P3G 1M3, Canada  
Searchable guide to drug interactions; dosing schedules; pamphlets/fact sheets about individual anti-HIV medications; all information is available in English and French; some materials available in Spanish, too.

**HIVresistanceWeb** [hivresistanceweb.com](http://hivresistanceweb.com)  
Lots of information about resistance, genotypic and phenotypic tests; links to related abstracts; much of the information is relatively old (2002 or earlier).

**Infectious Diseases Society of America (IDSA)**  
**HIV Medicine Association (HIVMA)** Email: [hivma@idsociety.org](mailto:hivma@idsociety.org)  
**HIV E-News / HIV Quality Care News**  
66 Canal Center Plz., Ste. 600, Alexandria, VA 22314  
703-299-020 / 703-299-1215 [www.idsociety.org](http://www.idsociety.org) / [www.hivma.org](http://www.hivma.org)  
Website of healthcare professionals who specialize in infectious diseases; includes clinical practice guidelines for HIV and other illnesses; click on "Journals & Publications" to get *IDSA News*, abstracts from recent issues of *Journal of Infectious Diseases* and *Clinical Infectious Diseases*, and free access to complete issues over a year old. Sign up, call, or send an email to receive HIVMA's periodic E-newsletter, *HIV E-News*, to keep informed of time-sensitive issues, and *HIV Quality Care News*, a bimonthly newsletter for in depth coverage of HIV news by mail.

**International Association of Physicians in AIDS Care (IAPAC)**  
**Journal of IAPAC / IAPAC Monthly / Navigating HIV Resistance**  
33 N. LaSalle St., Ste. 1700, Chicago, Illinois 60602-2601  
312-795-4930 [www.iapac.org](http://www.iapac.org)  
Organization formed by physicians to educate healthcare providers about HIV/AIDS and to develop global educational and advocacy

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strategies to improve the quality of care provided to all people living with HIV/AIDS. Articles from *Journal of IAPAC*, quarterly, peer-reviewed journal, are available for free online, as are articles from past issues of *IAPAC Monthly*, the organization's monthly newsletter; monthly publication, *Navigating HIV Resistance*, is also available online for free; and other treatment publications are available for sale.

**International AIDS Society – USA** *Topics in HIV Medicine*  
415-544-9400 [iasusa.org](http://iasusa.org)

Professional organization providing continuing medical education programs for physicians; site contains back issues of *Topics in HIV Medicine*, their bimonthly publication that features summaries of talks from IAS courses, highlights of scientific meetings, and review articles; call for copies of the publication. Site also contains IAS guidelines, including *Recommendations for the Use of HIV Resistance Testing* and *Recommendations for the Management of Metabolic Complications*.

**Johns Hopkins AIDS Service** *The Hopkins HIV Report*  
[hopkins-aids.edu](http://hopkins-aids.edu)

Offers an up-to-date literature review; animation of the HIV life cycle; a Question of the Week; PDF versions of useful publications including *Medical Management of HIV Infection*; and current and archived issues of *The Hopkins HIV Report*, a monthly newsletter. Materials are geared toward healthcare providers but are a good resource for anyone familiar with the basics.

**Latino Organization for Liver Awareness (LOLA) \***  
PO Box 842, Throggs Neck Station, Bronx, NY 10461  
718-892-8697 / 888-367-5652 (outside NY only) [lola-national.org](http://lola-national.org)

Bilingual, bicultural organization dedicated to raising awareness about liver disease through informational materials, community outreach, referral services, support groups, and more; fact sheets in English and Spanish are available by calling LOLA; site also includes a useful section about liver donation and transplantation.

**Major Drug Database** [geocities.com/pchang\\_99/drugdatabase.html](http://geocities.com/pchang_99/drugdatabase.html)  
Database of sales information for major pharmaceutical companies, including those that make HIV-related drugs. Site includes information about market shares, patent expirations, sales projections, and medical information; features information about more than 360 drugs from 33 companies (not all HIV-related).

**Management of Hepatitis C: 2002; Consensus Development Conference Statement**  
[consensus.nih.gov/cons/116/116cdc\\_intro.htm](http://consensus.nih.gov/cons/116/116cdc_intro.htm)  
Consensus statement from the National Institutes of Health (NIH) for the treatment of hepatitis C (available in HTML and PDF); created by a non-governmental group of researchers, doctors, patients, and advocates; addresses HIV/HCV coinfection; easy-to-read, comprehensive document; site includes videocasts of the three-day conference that led to the development of the consensus statement.

**Medscape** [www.medscape.com/hiv-aidshome](http://www.medscape.com/hiv-aidshome)  
Allows free access if you register with a password. Site includes: articles on research and clinical treatment of HIV/AIDS; MEDLINE (database of abstracts of HIV research articles) and DrugInfo (database of drug information); conference coverage; continuing medical education; patient information on HIV health topics; select articles from medical journals; and an "Ask the Experts" section. Content is relatively technical, but not overly so. Probably the best site to find out about an individual drug (search the DrugInfo database).

**Merck Manual** [merck.com/mrks/mmanual/home.jsp](http://merck.com/mrks/mmanual/home.jsp)  
Comprehensive, up-to-date clinical manual used by many physicians for diagnosis and treatment of various disorders, including HIV/AIDS; go to Table of Contents or use the search engine to find whatever it is you're looking for; the manual can be ordered online or accessed free of charge through the website. Dense but valuable resource.

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## Personal Perspective

### The Journey

by Octavio Vallejo, MD, MPH

As a person living with AIDS for more than a decade and a health care professional, I learned early on that knowledge is power. Indeed, treatment information is the cornerstone to surviving AIDS with a high quality of life and minimal complications from both the disease and the medications we have to take.

I access HIV treatment information for the work that I do and for my own personal use. The journey involved in recognizing the best sources of treatment information hasn't been easy. However, it has paid me back with a new perception about HIV disease – I went from the original perception that I faced a death sentence to my current hope for a long, productive life.

Nowadays it is very easy to find HIV treatment information, but I had to learn how to choose the best sources of information and exert caution on how to apply this knowledge in my personal treatment decisions as well as when I provide recommendations to others in my work. I remember the time before HAART, when we only had AZT. Treatment information seemed totally beyond my reach and understanding. HIV treatment was very intimidating, and only a few "divine" minds had the right to that information. But something happened. The people who led the treatment advocacy movement became the leaders of treatment education. In this way, I received my first training from treatment educators who were the faculty for the National Skills Building Conference in 1994. They transformed complex treatment information into information that was easy to understand and practical. It was identified as the best way to empower people living with HIV.

These treatment educators taught me some of the basics – to pay attention to the numbers of participants in a clinical trial (the "n" of the study), time of follow-up, balance within the groups in the study, and the type of analysis used. For example, "Intent-to-Treat" is the strictest kind of analysis – data from all patients is used, whether they completed the trial or not. "As-Treated" is more forgiving – patients who drop out are not counted, which can make the treatment look better. They also helped me learn how to choose the best sources of information. Is the newsletter or website free of com-

mercial bias, for example? Does the source of information have an editorial advisory board? Does the material present counterpoints? Was the information previously published in a peer-reviewed journal? Is the information relevant to the concerns of the HIV community?

My first source of treatment information is the Internet. For me, websites such as Medscape, Clinical Care Options, AIDSmeds, New Mexico AIDS InfoNet, and The Body are the best places to initiate a search. Other electronic resources offer updated research information regarding HIV treatment, complications, and opportunistic infections; some of them have interactive services where you can post specific questions and concerns.

Another way that I obtain updated treatment information is by attending national and local conferences, meetings, and symposia. The major AIDS treatment conferences are the Conference on Retroviruses and Opportunistic Infections (CROI), the Interscience Conference on Antimicrobial Agents and Chemotherapy (ICAAC), the International AIDS Society (IAS) Conference on HIV Pathogenesis and Treatment, and the International AIDS Conference. There are other, more specialized conferences including one on metabolic complications and another on resistance. I also try to attend local medical updates presented by HIV clinicians who attend the HIV conferences and present the highlights. The websites of some of these major medical conferences include excellent webcast programs where you can see and hear many of the presentations. The level of most of the presentations is quite complicated, and I often need to ask fellow physicians their opinions and what they got from the presentations.

After getting the “raw” version about a specific topic, I like to hear other people’s perspectives about the research that’s presented. The results of a research study can be interpreted in more than one way, so I need more than a single perspective to better understand the pros and cons of the results. I ask a lot of questions of other treatment educators and physicians, including my own doctor. I also check the information from AIDS newsletters that usually summarize and put together the topic from different perspectives. Personally, I prefer the newsletters that have panels of experts and those that include the input of community representatives and treatment advocates so that I can get the information from different perspectives. This way, I can form my own opinion. Among the newsletters that I constantly review are *ACRIA Update*, *Positively Aware*, *NATAP Reports*, *Numedx*, and *Topics in HIV Medicine*. I particularly like

*ACRIA Update* and *Positively Aware* because they present complex information in easy, friendly, and concise ways so that I don’t have to spend a lot of time reading. Obtaining HIV treatment information isn’t really the major challenge, though – it’s how to interpret and apply that new information in our lives. There is so much to be learned in the field of HIV treatment. I learned long ago that what works for others will not necessarily work for me. Two individuals can respond to the same treatment in very different ways, depending on factors such as genetics, age, gender, ethnicity, and others that we don’t yet understand. That’s why I really enjoy meetings that include panels of experts during which clinical cases are presented. Most of the time, the disagreement among the experts on how to approach the same case is the best education that you can get. In other words, what I learn from such panels is that “one size does not fit all.”

Finally, whenever something new comes out about HIV treatment, I always check my resources and ask my doctor about it. The most successful treatment plan is one that I have faith in, one that fulfills my expectations, and one that doesn’t interfere with my lifestyle needs. However, I recognize that this treatment plan is a result of getting the best information, from the best sources, with the best analyses and interpretations. The journey involved in gathering good treatment information is full of choices. I was taught by other people living with HIV how to make the best choices, so I truly trust resources that use the peer-to-peer model of sharing education and include the voices of the HIV community in their content.

I enjoy sharing new treatment information with other people who, like me, live with uncertainty, fear, and doubt about antiretroviral therapy. It is quite fulfilling to see the faces of friends and clients – some of whom are native Spanish speakers with fewer information resources – when they learn more about their treatment options and go to their doctors empowered with new knowledge. Treatment information can be extremely intimidating – even more so when you don’t speak English well. Working with monolingual Spanish-speaking communities infected and affected by HIV has made me appreciate how treatment information can change and improve people’s lives.

*Octavio Vallejo, MD, MPH, is Community Health Program Manager at the Pacific AIDS Education and Training Center in Los Angeles. He has been living with AIDS since 1990. For the last 14 years he has worked exclusively in the field of HIV, working shoulder to shoulder with people infected and affected by HIV/AIDS.*

**National AIDS Treatment Advocacy Project (NATAP) \***  
580 Broadway, Ste. 1010, New York, NY 10012  
212-219-0106 / 888-26-NATAP (888-266-8287) **natap.org**  
Treatment information, news reports, and extensive conference coverage related to HIV/AIDS, and HIV/HSV and HIV/HCV coinfection; PDF publications can be downloaded, some in Spanish. Treatment information about coinfection is also available by phone and mail.

**National Association of People with AIDS (NAPWA)**  
**Positive Voice Update**  
1413 K St., NW, Ste. 700, Washington, DC 20005  
202-898-0414 / 703-998-3144 **napwa.org**  
National advocacy and education organization that hosts trainings and conferences, sponsors and promotes an annual National HIV Testing Day (June 27th, this year), and AIDSWatch, to help U.S. Congress members understand the needs of people with HIV/AIDS. NAPWA's free, advocacy-oriented, periodic email based newsletter, *Positive Voice Update*, last published in December 2003, will go back to being print-based later in 2004. NAPWA's recent publication, *Your Passport to Managed Care: A Tool for Making Managed Care Work for You*, can be ordered for free in English or Spanish using a link on the site.

**National Center for Complementary and Alternative Medicine \***  
NCCAM Clearinghouse, PO Box 7923, Gaithersburg, MD 20898  
Toll Free Hotline: 888-644-6226 (Mon-Fri 8:30 am - 5:00 pm)  
TTY/TDY: 886-464-3615 **nccam.nih.gov**  
Part of the National Institutes of Health; not HIV-specific, although much of the information is relevant to HIV; site offers information about complementary and alternative medicines (CAM), trial sites conducting clinical studies of these therapies; a description of the clinical trial process; an online newsletter; and alerts about possibly dangerous interactions between CAMs and other medications. Call for information or to have documents faxed or mailed to you. Hotline is available in English and Spanish.

**National Foundation for the Treatment of Pain** **paincare.org**  
Not HIV-specific. Organization dedicated to providing support for people who are suffering from stubborn pain, their families, friends, and the physicians who treat them; offers a patient forum, advocacy programs, information, referrals, support resources, and direct medical intervention.

**National Hepatitis C Prison Coalition \*** **hevinprison.org**  
Coalition of organizations and individuals focused on the care and treatment of people in U.S. prisons with hepatitis C; site includes contact information for coalition members, treatment information, and Department of Corrections HCV Treatment Guidelines by state (where available) in PDF format (some in both English and Spanish).

**National Institute of Allergy and Infectious Diseases (NIAID) \***  
National Institutes of Health, Bldg. 31,  
31 Center Dr., 7A50, Bethesda, MD 20892  
**www.niaid.nih.gov/publications/aids.htm**  
Governmental fact sheets about aspects of AIDS – a basic overview, prevention, vaccines, and therapies – and links to related publications (primarily CDC).

**National Institutes of Health Office of Dietary Supplements**  
6100 Executive Blvd., Rm 3B01, Bethesda, 20892-7517  
301-435-2920 **ods.od.nih.gov**  
Site contains fact sheets on vitamins and minerals; information about supplements; recall and safety notices; and the International Bibliographic Information on Dietary Supplements database (IBIDS), which provides access to published abstracts on supplements. IBIDS also contains a consumer section geared toward a more general audience. The office will try to find someone to answer your questions if you call or write. Direct requests for multiple fact sheets to the National Center for Complementary and Alternative Medicine (nccam.nih.gov).

**National Library of Medicine Gateway** **gateway.nlm.nih.gov**  
Site allows users to search many databases at the National Library of Medicine all at once, including MEDLINE/PubMed, ClinicalTrials.gov, Meeting Abstracts, and more. Some abstracts contain links to complete articles, but most journals require payment to view the full-length article, unless you can get to a medical library. Presentations from conferences are sometimes available only as the pre-conference abstract, but often contain contact information to obtain the complete poster or presentation.

**National Guideline Clearinghouse** **guideline.gov**  
Database of clinical practice guidelines for many illnesses maintained by the Agency for Healthcare Research and Quality (AHRQ). HIV-related guidelines include those from the American Academy of Pediatrics, the American Psychiatric Association, Infectious Diseases Society of America, the National Pediatric and Family HIV Resource Center, as well as the more familiar guidelines updated regularly on AIDSinfo (aidsinfo.nih.gov); this site is designed for healthcare providers, but contains useful info for all.

**National Minority AIDS Council (NMAC) \***  
1931 13th St., NW, Washington, DC 20009  
202-483-6622 **nmac.org**  
Organization dedicated to developing HIV/AIDS leadership in communities of color. Site includes links to regional and national trainings and conferences, HIV/AIDS hotlines, policy and treatment publications; and a prison initiative, which offers a regularly updated resource list for HIV and corrections. Call or write to get referrals to other agencies, publications, and general questions about HIV/AIDS answered.

**National Native American AIDS Prevention Center** **Seasons**  
436 14th St., Ste. 1020, Oakland, CA 94612  
510-444-2051 **nnaapc.org**  
Site includes information on NNAAPC's technical assistance services, Native American HIV/AIDS statistics, prevention curricula and materials developed by NNAAPC, and a resource guide to Native American AIDS service organizations and healthcare providers. Publications from a resource guide to training materials on HIV prevention for Native Americans, one catering to you, spirited people, gay people of color. Quarterly newsletter.

**National Sexually Transmitted Diseases Hotline**  
800-227-8922 / 800-344-7432 (Spanish)  
Answers questions about STDs and HIV, provides referrals for testing sites, case management and treatment information nationally.

**The National Women's Health Information Center \***  
Department of Health and Human Services **4woman.gov**  
200 Independence Ave. SW, Rm 730B, Washington DC 20201  
English & Spanish information and referral helpline (not HIV-specific):  
202-690-7650 / 800-994-WOMAN (800-994-9662)  
Mon-Fri 9 am-6 pm EST / TYY: 888-220-5446  
Information about women's health and HIV in English and Spanish put together by the U.S. Department of Health and Human Services (DHHS). Site includes a Frequently Asked Questions section about HIV, information on DHHS activities/events, women's health statistics, and related news. There's also an audio section where DHHS scientists talk about early days of HIV research. Call or write for information.

**The Neuropathy Association**  
212-692-0662 **neuropathy.org**  
Includes basic information about peripheral neuropathy, a list of physicians who deal with neuropathy, and support groups. Free registration required. The staff will answer questions about neuropathy over the phone or send materials to people.

**New England Journal of Medicine** **nejm.org**  
Allows access to articles older than six months for free if you register with a password. This journal is a primary resource that features review articles and recent medical studies/findings, including the results of HIV/AIDS clinical trials.

### **New Jersey Women and AIDS Network (NJWAN)**

7 Spring St., New Brunswick, NJ 08901  
732-846-4462 / Sister Connect Warmline: 800-747-1108 [njwan.org](http://njwan.org)  
Organization offers education programs for HIV-positive and negative women, covering topics such as pregnancy and HIV, safer sex, treatment adherence, and sexuality. Maintains a nationwide database of obstetrical services, HIV testing sites, organizations for young women, and family planning agencies to provide referrals to Warmline callers; some publications available for a fee by ordering online or calling; will fulfill information requests by mail to the best of their abilities.

**New Mexico AIDS InfoNet \*** [aidsinfonet.org](http://aidsinfonet.org)  
User-friendly, regularly updated, one page fact sheets in English and Spanish. Topics include: basic HIV and AIDS information, individual HIV medications, opportunistic infections, lab tests, side effects, complementary therapies, and many more.

### **North American Syringe Exchange Network (NASEN)**

Point Defiance AIDS Project  
535 Dock St., Ste. 112, Tacoma, WA 98402  
253-272-4857 [www.nasen.org](http://www.nasen.org)  
Links to needle exchange programs around the country as well as harm reduction sites and information. Call or write to get information about needle exchange programs in your area.

**Office of AIDS Research (OAR) \*** National Institutes of Health (NIH)  
9000 Rockville Pike, Bethesda, MD 20892 [www.nih.gov/od/oar](http://www.nih.gov/od/oar)  
Site includes the OAR's annual plan and budget for all NIH AIDS-related research; detailed descriptions of all HIV/AIDS research being conducted throughout the NIH; a glossary of acronyms; archived reports of OAR-sponsored meetings; and transcripts in English and Spanish of the OAR's "Meet the Experts" sessions.

**Office of Minority Health Resource Center**  
800-444-6472 [www.omhrc.gov](http://www.omhrc.gov)  
Site maintained by the U.S. Department of Health and Human Services; contains many publications on various illnesses, including HIV/AIDS (available online and in print); a list of upcoming conferences; many statistical reports; and a searchable database of health materials (click on "Search" on the main page); call to speak to information specialist who will do grant searches for organizations, send fact sheets, make referrals, and give information about cultural competency training and outreach services.

**On-line Dictionary** [hyperdictionary.com](http://hyperdictionary.com)  
Includes a medical dictionary, an English dictionary, a thesaurus, a computer dictionary, even a dream dictionary. And no ads!

**On-line Medical Dictionary** [cancerweb.ncl.ac.uk/omd](http://cancerweb.ncl.ac.uk/omd)  
A dictionary of medical terms; words can be searched by subject area or as single terms; the Frequently Asked Questions section is helpful.

**People with AIDS Coalition Colorado (PWACC) \***  
**Resolute: Dedicated to Surviving HIV/AIDS**  
PO Box 300339, Denver, CO 80203  
303-329-9379 [www.pwacoalitioncolorado.org](http://www.pwacoalitioncolorado.org)  
Call or write to receive copies of the newsletter, which covers HIV news and lists clinical trials open for enrollment in Colorado; site allows people to ask treatment questions; PWACC will also answer requests for information by regular mail.

**Pharmaceutical Research and Manufacturers of America (PhRMA)**  
**New HIV Medicines in Development** [www.phrma.org/newmedicines](http://www.phrma.org/newmedicines)  
Lists drugs in development for HIV/AIDS and other diseases, including manufacturer information and where the drugs are in the research process; industry news and press releases; link to information on patient assistance programs ([www.helpingpatients.org](http://www.helpingpatients.org)).

### **Philadelphia FIGHT**

1233 Locust St., #500, Philadelphia, PA 19107  
AIDS Library: 215-985-4851 [www.fight.org](http://www.fight.org)  
Community research and education organization. Houses AIDS Library; Critical Path AIDS Project (online resource directory); Project TEACH (Treatment Education Activists Combating HIV) peer training program; and Y-HEP (Youth Health Empowerment Project) peer-to-peer prevention program. Call or write for information. Although focused on the Philadelphia area, they will collect resources and send them to people around the country, as well as direct them to services in their local area.

### **Physicians' Research Network *The PRN Notebook***

20 W. 22nd St., 11th fl., New York, NY 10010-5804  
Fax: 212-924-0759 [prn.org](http://prn.org)  
News and review articles focusing on the latest issues in HIV care; includes articles on laboratory tests, HIV/HCV coinfection, HIV treatment options, drug resistance, and lipodystrophy. Intended for healthcare providers but a good resource for anyone already familiar with the basics. People requesting copies of *The PRN Notebook* without Internet access can fax or write to PRN with a mailing address and a description of their involvement with HIV (healthcare provider or PWA, for example).

**POZ \* *POZ en Español / ComboCards*** [www.poz.com](http://www.poz.com)  
1 Little W. 12th St., 6th fl., New York, NY 10014  
800-9-read-poz (800-732-3769) for single subscriptions  
866-465-2349 x219 or x246 for bulk subscriptions and ComboCards  
Bimonthly glossy magazine published ten times a year dedicated to HIV issues; available in both English and Spanish versions. Site offers online version of the magazine and an archive of past issues back to 1994. Free copies available to people living with HIV by subscribing online. Site has a section on labwork (Labwork Made Easy). The parent company of POZ, Smart + Strong, also makes ComboCards, palm cards with information on scheduling, dosing, side effects and drug interactions of specific HIV drug combinations. They are available for free ([www.combocards.com](http://www.combocards.com)).

### **Program for Wellness Restoration (PoWeR) \***

**Power Health Review** [powerusa.org](http://powerusa.org)  
Information for patients and physicians about an approach to AIDS wasting management, prevention, and reversal through nutrition, supplementation, resistance weight training, anabolic hormones, and motivational techniques; online discussion group about lipodystrophy; e-based newsletter, a speakers bureau; a review of HIV health and quality of life information, a lipodystrophy list serve; useful links including many related to lipodystrophy, AIDS wasting, and facial reconstruction; and a section on wasting/lipodystrophy in Spanish.

**Project Inform \* *PI Perspective / Wise Words***  
National treatment hotline (English & Spanish):  
800-822-7422 Mon-Fri 9-5 pm, Sat 10-4 EST [projectinform.org](http://projectinform.org)  
Advocacy, policy, and education organization. Site includes lots of HIV treatment information: newsletters (*PI Perspective* and *Wise Words*); fact sheets and articles by topic; slide presentations from several conferences; a multimedia library that can be accessed online; and literature specific to women, available in both English and Spanish. Call the hotline for treatment questions on opportunistic infections, talking with your doctor, lab work, side-effects, support from other PWAs, and to request fact sheets. Referrals to other services available.

### **San Francisco AIDS Foundation \***

**BETA (*Bulletin of Experimental Treatments for AIDS*)**  
995 Market St., #200, San Francisco, CA 94103  
415-487-3000 / For subscriptions call: 415-487-8060 [sfaf.org](http://sfaf.org)  
AIDS service and advocacy organization. *BETA*, treatment magazine published three or four times a year, is available online in HTML and PDF versions; for a free subscription, email or call; lots of treatment

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articles organized by topic, from *AIDS 101* to *Osteonecrosis*; extensive glossary of HIV-related terms. Call for literature, to ask questions, to find out about local services, Latino & African American support groups, needle exchange, volunteer opportunities, and more.

#### **Seattle Treatment Education Project (STEP)**

##### **Lifelong AIDS Alliance \* *STEP Perspective* / *STEP Ezine***

1002 E. Seneca St., Seattle, WA 98122-4214

206-957-1659 / Hotline: 888-399-7837 Email: [step@llaa.org](mailto:step@llaa.org)

**[thebody.com/step](http://thebody.com/step)**

**[lifelongaidsalliance.org/prevention/step.html](http://lifelongaidsalliance.org/prevention/step.html)**

*STEP Perspective* and *STEP Ezine* are both available at [thebody.com/step](http://thebody.com/step). *STEP Ezine* offers short, up-to-the-minute articles, and *STEP Perspective* provides more in-depth coverage of treatment topics. Call the hotline for HIV/AIDS treatment information, referrals, and questions about medication and treatment adherence.

#### **The Sensible Guide to Using Complementary Therapies for Optimum Health**

**[www3.sympatico.ca/devan.nambiar/content.htm](http://www3.sympatico.ca/devan.nambiar/content.htm)**

Site organized by one individual (Devan); not all HIV-specific; information on Ayurvedic medicine, acupressure, aromatherapy, traditional Chinese medicine, herbal remedies, Yoga, meditation, and lots, lots more. Not the most organized of sites, but there's plenty of information about complementary therapies here.

#### **Test Positive Aware Network (TPAN) \* *Positively Aware***

5537 N. Broadway St., Chicago, IL 60640-1405

773-989-9400

**[tpan.com](http://tpan.com)**

Site includes TPAN publications (*Positively Aware* is particularly useful, especially the annual Drug Guide), available online or through subscription; email addresses for a pharmacist and a doctor who answer questions about medications, treatment, and HIV disease; information about events in the Chicago area; and more. Call or write to request publications (*Positively Aware* available in English and Spanish).

#### **Treatment Action Group (TAG) \* *TAGline***

611 Broadway, Ste. 612, New York, NY 10012

212-253-7922

**[aidsinfonyc.org/tag](http://aidsinfonyc.org/tag)**

Treatment updates and policy analyses concerning various aspects of the epidemic, including research advocacy, treatment strategies, and HCV/HIV coinfection. Subscribe by email to the monthly newsletter, *TAGline*, which includes articles in Spanish. Back issues of *TAGline* going back to 1996 are available in PDF format. Call or write with research and advocacy questions.

#### **Viral Load Equivalents**

**[hepatitis-central.com/hcv/hepatitis/loadchart.html](http://hepatitis-central.com/hcv/hepatitis/loadchart.html)**

Useful chart for converting logs to actual numbers – useful for both HIV and HCV viral loads (For example, a viral load of log 5 = 100,000 copies); site includes lots of other clear, practical information about viral hepatitis, too.

#### **Visionary Health Concepts \***

800-491-2181

**[freehivinfo.com](http://freehivinfo.com)**

Free booklets for individuals and organizations written for people with HIV and/or HCV, available by PDF download or through regular mail; topics include *Easy-to-Understand Info About HIV Resistance*, *The Long and the Short of It: Side Effects and the Search for HIV Treatment that Fits the Individual*, and *Dosing Matters: Getting the Most out of Your HIV Regimen*. Most materials are also available in Spanish. Order online or call.

#### **Voices of Positive Women For Your Information (FYI) [vopw.org](http://vopw.org)**

66 Isabella St., Ste. 105, Toronto, ON, M4Y 1N3, Canada

416-324-8703 / Toll-free: 800-263-0961 Email: [voices@vopw.org](mailto:voices@vopw.org)

VOICES' bi-monthly newsletter, *For Your Information*, is available online or mailed to you free by subscription; although not focused on treatment, issues that affect treatment decisions are well-covered, such as stigma, isolation, youth, harm reduction, and pregnancy; site includes an extensive database of service organizations and resources for HIV-positive women and their service providers in Ontario.

#### **The Well Project**

700 Glenwood Ave., Ste. 100, Raleigh, NC 27605

434-293-2955

**[thewellproject.org](http://thewellproject.org)**

Email address and password required to access full site; site is aimed for HIV-positive women; chock full of news and information about various HIV issues – individual medications, treatment strategies, opportunistic infections, exercise, legal topics, pregnancy, and much more. Some articles are accompanied by summary slides; members can join discussion boards and receive a bi-monthly email newsletter. Hard copies of fact sheets will be sent upon request. They are producing a CD-ROM of the website, to be updated periodically.

#### **Women Alive *Women Alive* newsletter**

1566 S. Burnside Ave., Los Angeles, CA 90019

323-965-1564 / Hotline: 800-554-4876

**[women-alive.org](http://women-alive.org)**

Treatment information, fact sheets, supportive services, and lots of links. Email the staff medical advisor directly with treatment questions; the staff will also forward medical questions to the medical advisor. Hotline provides treatment information, emotional support, newsletter requests, and nationwide referrals; support group for Spanish speaking HIV-positive women at the agency.

#### **Women and HIV [www.niaid.nih.gov/factsheets/womenhiv.htm](http://www.niaid.nih.gov/factsheets/womenhiv.htm)**

NIAID Office of Community and Public Liaison, Bldg. 31,

Rm. 7A-50, 31 Center Dr., MSC 2520, Bethesda, MD 20892-2520

Information from the U.S. Department of Health and Human Services that provides a concise overview of HIV/AIDS in women.

#### **Women's Interagency HIV Study (WIHS)**

**[lawihs.com](http://lawihs.com)**

Description and updates about this large prospective cohort study designed to determine the natural history of HIV in women; opportunity to ask questions of the study's primary investigator online; limited treatment information.

#### **WORLD (Women Organized to Respond to Life Threatening Disease) *WORLD***

414 13th St., 2nd fl., Oakland, CA 94612

510-986-0340

**[womenhiv.org](http://womenhiv.org)**

Treatment information particularly about pregnancy, advocacy, news, and HIV University; newsletter. Newsletter, *World*, is by and for HIV-positive+ women and their loved ones; site is currently over a year out of date, but should be up to date again soon. Call or write with questions and requests for information.

#### **Wyoming: Positives for Positives *Positives for Positives***

1711 Carey Ave., Cheyenne, WY 82001

**[pos4pos.org](http://pos4pos.org)**

307-635-0566 / 800-492-2203 Email: [info@pos4pos.org](mailto:info@pos4pos.org)

Archived copies of newsletter available online; call, write or complete online order form to receive free individual or bulk copies; email general questions about HIV/AIDS; site includes information about advocacy actions.

*Resource list compiled by ACRIA's education department. Particular thanks to Constance T. Chang for contacting each site to verify information.*

## TrialSearch@acria.org Begins Service

After a long development process, ACRIA has recently inaugurated **TrialSearch@acria.org**. TrialSearch offers information on enrolling HIV clinical research across the country. The database presently covers the largest states nationwide and will soon add trials in smaller states as well. Ultimately, TrialSearch will be the most comprehensive listing of currently enrolling HIV clinical studies available through any source. TrialSearch includes information about government and pharmaceutical industry sponsored research as well as innovative independent protocols being conducted by HIV researchers. ACRIA's commitment is to regularly update TrialSearch so that users always have accurate information on experimental HIV therapies that offer their greatest chance of health stability. Visit [www.acria.org](http://www.acria.org) to use this new resource.

## ACRIA Begins Multi-Year NYS AIDS Institute Contract

In mid-2003, the New York State Department of Health AIDS Institute asked ACRIA to join a coalition of four partners on an application to create the national curriculum on viral hepatitis prevention and treatment for the Centers for Disease Control and Prevention (CDC). This contract was subsequently awarded to the AIDS Institute, and ACRIA has in turn begun work to help establish a national model for training care providers on these complex health issues. ACRIA's role is to collaborate with the other program partners on assessing how existing hepatitis education curriculums can be adapted for national use, and we will also be a lead partner in conducting pilot trainings of the new curriculum for organizations outside of New York State in years two and three of the program.

## Cognitive Function Study

Data analysis was recently completed on a study of cognitive function in people with HIV who are between 40 - 60 years old. Before the advent of combination therapy for HIV, dementia affected 20% of people with HIV. But ACRIA's study found that

socioeconomic status is now the largest factor affecting cognitive functioning. The study underlines the need to address the fact that people with HIV today are often from disadvantaged socioeconomic environments. The income, housing, education, nutrition and social conditions of this group may well have a greater impact on cognitive function than HIV or HAART.

The study is one of the few to assess older adults with HIV/AIDS and, importantly, had a control group that was not HIV positive. This study of over 100 people has been submitted for presentation to the 15th International Conference on AIDS in Bangkok and at the first symposium on HIV/AIDS at the Gerontological Society of America meeting in Washington this fall.

## ACRIA Studies Stigma

In April 2004, ACRIA will initiate a study with the Association of Nurses in AIDS Care, in collaboration with Indiana University. This web-based study will assess the experiences and attitudes of nurses who provide care to people with HIV. It will also measure the level of stigma this group of professionals encounters. Anyone interested in the survey can visit ACRIA's website to participate.

Data from ACRIA's first web-based study is being analyzed and will be presented at the American Public Health Association Conference in November 2004. Information was collected from HIV/AIDS service providers in 48 states, and almost

30% reported frequent unease resulting from others' perceptions of their HIV serostatus and sexual orientation. Stigma was higher among providers identifying as heterosexual, and there were significant differences in the degree of stigma based on the types of clients served. Further data analyses are being performed.

## ACRIA Brochure Distribution Achieves Milestone

ACRIA's distribution of our topic-specific health education brochures for community-based organizations nationwide surpassed 300,000 copies in February 2004. This is a remarkable achievement for our agency, particularly since every single one of these publications has been provided without cost upon request to over 1,000 non-profits across the United States. ACRIA is a relatively small non-profit, and we are making an extraordinary financial commitment to help a great many other agencies acquire written resources that explain relevant health information to people with HIV.

ACRIA began providing topic specific brochures in 1999. *Clinical Trials Explained*, *Managing Drug Side Effects*, *Treatment Issues for Women* and *Understanding Your Lab Results* have proven to be valued resources for a great many individuals and organizations. Hopefully, these publications and our newest brochure, *Viral Hepatitis and HIV*, will continue to play a useful role in the lives of a great many individuals.

## New ACRIA Brochure Available: *Viral Hepatitis and HIV*

ACRIA's newest topic-specific treatment education brochure, *Viral Hepatitis and HIV*, is now available in English and Spanish, free of charge to individuals and non-profit community-based organizations throughout the United States. In keeping with ACRIA's other brochures, the new publication has been written with the healthcare consumer in mind. Hepatitis health issues are explained in ways that are easily understood by the broadest audience possible. To receive the new brochure, complete and submit an online order form within the education section of [www.acria.org](http://www.acria.org) or call Constance Chang at (212) 924-3934 x 121. PDF copies of this and other ACRIA brochures can also be downloaded online.

# generous contributions

*Thoughtful donations were made in memory of the following individuals:*

Barry Binkowitz, MD	Ezra David Litvak
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Daisy Graciano	Frank Russo
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