Publish or Perish

The skinny on AIDS treatment newsletters

March 1, 1999 By Bob Lederer

Are you the type who rushes home from work at lunchtime to see if the latest AIDS treatment newsletter is waiting in your mailbox? Of course not. But when you want the latest lowdown on managing HIV and its opportunistic infections (OIs), this raft of publications is a great place to start. Many PWAs will attest that newsletters, journals and magazines help them work as partners with their docs in medical decision-making.

A rich array of national periodicals—from elementary to advanced, each with its own style and slant—offers generally well-researched, carefully reviewed articles (see "Best of the Rest"). Unfortunately, this is less true of many small, local newsletters, which—despite the best of intentions—may not have the resources to check information as thoroughly, and especially to dig behind—and out from under—the drug-company press releases that deluge their offices (as they do ours). Whichever your preference, the following tips may help you make the most of the experience:

1. Stay skeptical.

Read all treatment information from any source with a critical eye. Be wary of absolute statements, particularly must-take prescriptions such as, "Always treat infection X with therapy Y." Remember that everyone responds differently to treatment and has a unique tolerance for side effects and other drug downsides. Also, opinions vary among researchers, practitioners and PWAs about how useful a given treatment may be. You may want to seek out a second, third or 33rd opinion from other newsletters.

2. Check for expert review.

For each study cited, check whether the original source is a medical journal, a conference, a newspaper, or just someone's unpublished findings. Most medical journals and major conferences (such as the World AIDS Conference) use a system called peer review, in which independent experts evaluate the findings before publication. Reports labeled "late breaker" are less thoroughly checked, and should be viewed with greater caution.

3. Consider vested interests.

When reading reports of data, ask yourself if the person commenting—whether researcher, doctor or activist—might have a built-in bias. Few newsletters unearth the facts about which sources take

consulting fees from which drug companies. But at a minimum, any finding directly out of the mouth of a company scientist should be taken with a grain of salt. And even when there's no obvious financial incentive for researchers to put an unduly positive spin on their results, be aware that few journals publish negative studies (those showing no benefit).

4. Make sure downsides are listed.

One way to evaluate a newsletter's reliability is by keeping track of how often information about a particular treatment includes not only benefits but also disadvantages, such as resistance, side effects, adherence difficulties and high cost. If negative information is absent or downplayed, heads up.

5. Look for non-drug options.

When trying to reverse a particular condition (whether symptoms like diarrhea or lipodystrophy, or full-fledged OIs like crypto or PML), seek out newsletters that list a range of options, including the nonpharmaceutical. *Treatment Update* and *STEP Perspectives* offer a fair amount of such coverage; *BETA* and *AIDS Treatment News* do so occasionally.

6. Ask for more info.

Several organizations that publish newsletters also produce summaries on specific subjects (available by mail or off the Web). Especially useful are Project Inform's "Quick Sheets" on various treatment issues, and the AIDS Treatment Data Network's "Simple Fact Sheets." For info on the uses of many nutrients and herbs—often not covered in detail elsewhere—contact DAAIR (Direct AIDS Alternative Information Resources; 888.951.5433; www.daair.org); the Boston Buyers Club (800.435.5586; www.bgladco.com/bbc); or the HIV Resource Center at AIDS Project Los Angeles (323.993.1612).

7. Call a treatment hotline.

If you're stuck—can't find the facts you need or can't understand what you find—call a hotline: Project Inform (800.822.7422), PWA Coalition of New York (212.647.1420) or, for women, Women Alive (213.965.1564). But note that none is up-to-par on alternative treatments and nutrition.

So check out the periodicals roundup on the next two pages—then take a deep breath, get *Treatment Issues' AIDS Medical Glossary*, and settle down with a newsletter or three. At first the technical jargon may intimidate, but once you find your inner nerd, you'll be well on the way to empowerment. Now just imagine all the questions you'll soon be able to drive your doctor crazy with.

Thanks to Carlton Hogan for contributing to this article.

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