Health Information On-Line

Consumers are using the Internet to get information about health. How reliable is this information? That's not an easy question to answer.

A survey by CDB Research & Consulting indicates that consumers are showing a growing interest in obtaining information about health and beauty aids on-line as a means of supplementing traditional medical counsel.

However, easy access to virtually limitless health and medical information has pitfalls, experts caution. "My advice to consumers about information on the Internet is the same as it is for other media: You can't believe everything you see, whether it's in a newspaper, on TV, or on a computer screen," says Bill Rados, director of FDA's Communications Staff. Since anyone--reputable scientist or quack--who has a computer, a modem (the device that permits a computer to dial and connect to the Internet or an on-line service), and the necessary software can publish a Web page, post information to a newsgroup, or proffer advice in an on-line chat room, "you must protect yourself by carefully checking out the source of any information you obtain."

World Wide Web

By far, the most consumer-friendly part of the Internet is the World Wide Web. While the rest of the Internet displays text only, the Web, as it has come to be called, has the ability to display colorful graphics and multimedia (sounds, video, virtual reality).

Many legitimate providers of reliable health and medical information, including FDA and other government agencies, are taking advantage of the Web's popularity by offering brochures and in-depth information on specific topics on their Web sites. Material may be geared to consumers as well as industry and medical professionals (see "Sources of Internet Health Information").

But con artists have also infiltrated the Web. "A physician was browsing the Web when he came across a site that contained a fraudulent drug offering. He called us to report it," says Roma Jeanne Egli, a compliance officer in FDA's division of labeling and nonprescription drug compliance. "The person who maintains the site claimed he had a cure for a very serious disease, and advised those with the disease to stop taking their prescription medication. Instead, they were told to buy the product he was selling, at a cost of several hundred dollars."

Egli advises consumers to be skeptical when someone advocates a purported "cure" to be purchased and taken in lieu of prescribed medicine.

Although the Internet can be a reliable source of information, it is important to be aware that what is found there is only as good as the quality and integrity of the original information. What you find cannot be taken as gospel. It should be checked out and supported by other sources. (See "Is This Site Reliable?")

If you come across a suspected fraudulent nonprescription drug on the Internet, alert FDA by E-mail: otcfraud@cder.fda.gov.

FDA On-Line

The FDA home page provides an excellent jumping off point for those who want to learn more about the agency and the drugs, food supplements, and medical devices it regulates. It includes a detailed index and special menus for such groups as consumers, health professionals, and industry representatives.

Warning letters from FDA to regulated companies, inspection manuals, monthly import detention lists, medical device problem reports, and other often-requested materials are available without having to go through the time and paperwork of filing a traditional Freedom of Information request. Users can reach the Electronic FOI Reading Room directly from the FDA home page. Because it is expensive to print and mail materials, FDA offers many of its publications on the Internet. "Our goal is to have virtually all consumer education material available on the Internet," says Rados. "We now have more than a hundred different publicatons to choose from."

In addition to providing consumer education materials, the FDA site also offers technical information to help industry professionals file regulatory materials. Material can be downloaded to a computer and then printed out. Those who don't have a personal computer can try accessing the Internet from their local library or from a community organization.

FDA also has a "comments" button on many of its Web pages so that visitors can offer suggestions and feedback. However, questions about specific drugs, devices, or food supplements should be addressed to the agency in writing at "FDA" , Rockville, MD 20857, or by calling your local public affairs specialist. A list of FDA Public Affairs Specialists is available on the FDA Web site. Before beginning any particular therapy, however, consult with your doctor or pharmacist.

Exchanging Information

In Internet "newsgroups," such as Usenet groups, people post questions and read messages much as they would on regular bulletin boards. Through "mailing lists," messages are exchanged by E-mail, and all messages are sent to all group subscribers. In "chat" areas on some services and on the Internet's IRC (Internet Relay Chat) users can communicate with each other live.

Assessing the value and validity of health and medical information in news and chat groups demands at least the same--and maybe more--discrimination as for Web sites, because the information is more ephemeral and you often can't identify the source. Although these groups can provide reliable information about specific diseases and disorders, they can also perpetuate misinformation.

Other information services are commercial on-line services, fee-charging companies that provide vast amounts of proprietary information. They often include health and medical databases, electronic versions of popular newspapers and magazines, and their own chats and newsgroups, as well as Internet access.

The fact that information may be screened by a commercial service does not necessarily make it more reliable than other sources. And most services do not verify what is posted in their newsgroups, nor control what is "said" in chat rooms. Health and medical material obtained through services also should be corroborated by your physician or other medical sources.

Regulatory Concerns

The fact that it is easy to publish health and medical information and reach vast audiences without having the information verified by other sources presents potential issues for FDA and other government agencies. Product information on the Internet is unlike traditional forms of advertising and labeling. Current regulations on prescription drug advertising differ between print and broadcast media. The Internet presents additional challenges.

While regulatory agencies try to devise ways of ensuring that accurate and well-balanced health and medical information is presented on the Internet, consumers will have to use a lot more discretion in evaluating what they see. A Web page can be changed very quickly. It is easy to put up, and easy to take down. There is no guarantee that what you see one day will be there the next." So on the Internet, as elsewhere, "caveat emptor"--let the buyer beware--are watchwords for the foreseeable future.

Is This Site Reliable?

FDA staff and others familiar with Internet medical offerings suggest asking the following questions to help determine the reliability of a Web site:

Who maintains the site?
Government or university-run sites are among the best sources for scientifically sound health and medical information. Private practitioners or lay organizations may have marketing, social or political agendas that can influence the type of material they offer on-site and which sites they link to.

Is there an editorial board or another listing of the names and credentials of those responsible for preparing and reviewing the site's contents?
Can these people be contacted if visitors to the site have questions or want additional information?

Does the site link to other sources of medical information?
A reputable organization will not position itself as the sole source of information on a particular health topic. On the other hand, links alone are not a guarantee of reliability. Since anyone with a Web page can create links to any other site on the Internet--and the owner of the site that is "linked to" has no say over who links to it--then a person offering suspect medical advice could conceivably try to make his or her advice appear legitimate by, say, creating a link to FDA's Web site. What's more, health information produced by FDA or other government agencies is not copyrighted; therefore, someone can quote FDA information at a site and be perfectly within his or her rights. By citing a source such as FDA, experienced marketers using careful wording can make it appear as though FDA endorses their products.

When was the site last updated?
Generally, the more current the site, the more likely it is to provide timely material. Ideally, health and medical sites should be updated weekly or monthly.

Are informative graphics and multimedia files such as video or audio clips available?
Such features can assist in clarifying medical conditions and procedures. Bear in mind, however, that multimedia should be used to help explain medical information, not substitute for it. Some sites provide dazzling "bells and whistles" but little scientifically sound information.

Does the site charge an access fee?
Many reputable sites with health and medical information, including FDA and other government sites, offer access and materials for free. If a site does charge a fee, be sure that it offers value for the money. Use a searcher (see "Sources of Internet Health Information") to see whether you can get the same information without paying additional fees.

If you find something of interest at a site--say, a new drug touted to relieve disease symptoms with fewer side effects--write down the name and address of the site, print out the information, and bring it to your doctor. Your doctor can help determine whether the information is supported by legitimate research sources, such as journal articles or proceedings from a scientific meeting.

In addition, your doctor can determine if the drug is appropriate for your situation. Even if the information comes from a source that is reputed to be reliable, you should check with your doctor to make sure that it is wise for you to begin a certain treatment. Specific situations (such as taking other drugs) may make the therapy an inadvisable choice. Your doctor can decide whether the drug is suitable for you and may be able to offer more appropriate alternatives.

Sources of Internet Health Information

There are literally thousands of health-related Internet resources maintained by government agencies, universities, and nonprofit and commercial organizations. Following are the addresses of Usenet groups (newsgroups), mailing lists, and reputable sites that link to other sites with medical information. This list is by no means complete; it is offered as a jumping-off point.

Usenet Groups

(Access is through the Internet provider)

bionet.immunology (immunology research and practice)

misc.health.diabetes (discussion of diabetes management in daily life)

sci.med.diseases.cancer (cancer treatment and research)

sci.med.vision (treatments for vision problems)

Mailing Lists

(to subscribe, send an E-mail message to the address given; in the message area type "subscribe," followed by the name of the list and then your name)

Breast Cancer
Subscribe: listserv@MORGAN.UCS.MUN.CA

Stroke
Subscribe: listserv@lsv.uky.edu

Geriatrics
Subscribe: listserv@UBVM.CC.BUFFALO.EDU

World Wide Web Sites

American Cancer Society: http://www.cancer.org/

American Heart Association: http://www.americanheart.org/

American Medical Association: http://www.ama-assn.org/

Centers for Disease Control and Prevention: http://www.cdc.gov/

Consumer Gateway: http://www.consumer.gov/

Department of Health and Human Services: http://www.hhs.gov/

Food and Drug Administration: http://www.fda.gov/

Healthfinder: http://www.healthfinder.gov/

National Cancer Institute: http://www.nci.nih.gov/

National Institutes of Health: http://www.nih.gov/

National Institute for Allergies and Infectious Diseases: http://www.niaid.nih.gov/

National Library of Medicine: http://www.nlm.nih.gov/

Search Programs

Because the Internet contains no central indexing system, getting the information you want quickly can be a major challenge. That's where search engines come in. These powerful tools can help narrow the field if you have a specific topic to pursue, or the name of a specific organization but no address for its site. Input a few words that describe what you're looking for, and the searcher returns a list of sites related to your query.

Be aware, however, that although a searcher can point the way, it does not evaluate the information it points to. For example, a search on the words "breast cancer" is just as likely to point to a page advertising a reconstructive surgeon or a health food store's article on the purported benefits of phytochemicals as it is to the National Cancer Institute. It is up to the visitor to evaluate the information the site contains. Here are a few of the many search engines:

Alta Vista: http://www.altavista.com/

Excite: http://www.excite.com/

Lycos: http://www.lycos.com/

Webcrawler: http://www.webcrawler.com/

Yahoo: http://www.yahoo.com/Health/Medicine/

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www.fda.gov/fdac/features/596_info.html