HOW TO GET EVERY HEALTH FACT YOU'LL EVER NEED

YOU'VE GOT A MEDICAL PROBLEM. BUT YOUR DOCTOR DOESN'T KNOW ALL THE TREATMENTS AVAILABLE—OR YOUR HMO WON'T TELL YOU. HERE'S THE WAY TO GET UP-TO-THE-MINUTE NEWS ON EVERYTHING FROM A CRACKED TOOTH TO MIGRAINES TO CANCER. BY PAMELA WEINTRAUB

LONG AGO, BACK IN WHAT SEEMS TO BE another epoch, the family doctor was available to treat and console us no matter what the complaint. And if he couldn't, the specialist he recommended would.

But medicine has changed. Today, a growing number of us receive our medical care from giant HMOs—health maintenance organizations—that profit by streamlining. One common HMO strategy: the gatekeeper philosophy, in which you may see a specialist only after you've been referred by your primary care physician—who may earn more the fewer referrals she makes. As a result, doctors have been pitted against patients, and patients have increasingly come to view themselves as medical consumers and guardians of their own treatment.

Fortunately, the advent of big, impersonal medicine has been accompanied by another trend: the explosion of medical information available to us through patient support groups, hot lines run by experts, and especially the Internet.

The impetus to get the information out there comes from the top. Health and Human Services Secretary Donna Shalala says the government is now "committed to using the new technology, including the World Wide Web and the Internet, to provide health information to the public."

Of course, if you're planning to do your own research into your symptom or condition, or that of someone you care about, you'll have to tread with caution, particularly if you're venturing online. Internet forums, called news groups, attract not just generous and experienced patients and doctors, but also charlatans

HOW TO FIND THE TOP EXPERT, THE BEST HOSPITAL

When it comes to specific medical problems, the most famous hospital is not necessarily the best. To make sure you are accessing prime healthcare for a serious problem:

- Search the medical literature and see which doctors and institutions publish most often on that topic. It's likely that these facilities and individuals offer the most cutting-edge treatment.
- Ask three doctors for referrals. If one name pops up on every list, it is likely that that physician is widely regarded as the most expert in your area.
- Don't rely on "best doctor" surveys published in popular magazines. Many M.D.'s contend these are nothing more than popularity contests.

PHOTOGRAPH BY NOLA LOPEZ

trying to market snake oil cures. Web sites are hosted not only by major teaching hospitals, but also by supplement manufacturers promoting their products and inexperienced practitioners hoping to get work.

Mary Jo Deering, director of Health Communication and Telehealth for the Office of Disease Prevention and Health Promotion of the U.S. Department of Health and Human Services, says that for lay people seeking medical information, the Internet can be an excellent place to start. Nonetheless, she cautions, "getting medical information from the Internet can be like getting drinking water from a fire hose. There's too much of it. You need to find smaller spigots, and you need to make sure you know the source of the water before you drink."

Of course, you can also sleuth around in the real world. What follows is a guide to culling useful medical information from the increasingly sophisticated resources available, and then evaluating that information before you use it to heal yourself or your family.

THE TOP TEN CLEARINGHOUSES ON THE WEB

When you first start researching health and medical issues on the Internet, you'll want to have a sense of the playing field: What groups are up there, and which ones can you trust? You'll also want to hone in on your area of interest quickly. For instance, type the term "pediatrics" into the search engine AltaVista, and you'll pull up 117,400 web sites. Your kids could be adults before you read them all!

But you don't have to. What follows are the ten most reliable gateways to health information on the web:

1. healthfinder

Established this spring, healthfinder points the way to those Internet venues recommended by the U.S. government. Look here for selected online publications, clearinghouses, databases, web sites, and support and self-help groups, as well as the government agencies and not-for-profit organizations chosen by the crack Telehealth team at the Department of Health and Human Services. Address: http://www.healthfinder.gov/

2. HealthGate

Especially recommended for its medical search tools and women's health area, called HealthGate Healthy Woman. Address: http://www.healthgate.com/

3. InteliHealth

The impressive medical site of Johns Hopkins University E-mails you the latest medical news and provides information on a range of health problems and drugs. Send questions to a Johns Hopkins doctor; access daily pollen and pollution counts; look, too, for upcoming areas such as women's health, men's health, and pediatrics, among others. Address: http://www.intelihealth.com/

4. Health O@sis

Produced by the Mayo Clinic, this expansive site features such areas as nutrition, pregnancy, and women's health. Address: http://www.mayo.ivi.com/

5. Medscape

Vast databank of medical information. Address: http://www.medscape.com/

6. Hardin MD

The MD here stands for "meta directory." This list of lists, perhaps the most extensive and organized on the Internet, comes from the Hardin Library for the Health Sciences at the University of Iowa. There are many directories on the Net, but this one is notable for its expertise as well as its size. Medical experts in each discipline have suggested the links—electronic references to further information sources. Address: http://www.arcade.uiowa.edu/hardin-www/md.html

7. Medical Matrix

Another respected index to the world of health and medicine online. All sites and sources have been ranked and reviewed by experts. Address: http://www.medmatrix.org/

8. Thrive

If you crave a splash of color, this health 'zine jointly produced by Time Inc. and America Online has a stylish spin. Especially useful are its bulletin boards and community of participating experts. Address: http://www.thriveonline.com/ Also available through America Online at Keyword: Thrive.

9. PharmInfoNet

A comprehensive guide to drugs. Address: http://pharminfo.com/

10. Reuters Health Information Services

An excellent source of the latest health information from the established news service's journalists. Address: http://www.reutershealth.com/

How to search the literature

For the past 26 years, if your doctor has been interested in learning what's been published on a particular topic, he likely would have tapped into MEDLINE, a gigantic database of abstracts (article summaries) from the world's 4,000 most prestigious journals. Now, facilitated by the Internet, the federal government has made this powerful tool available via the National Library of Medicine web site. (Address: http://www.nlm.nih.gov/)

The new Internet search tool is easy to use, says Donald Lindberg, M.D., director of the National Library of Medicine. "Just type in the name of the disease or medical problem you want information on," he explains, "and you'll find the relevant abstracts come up." To search effectively, Dr. Lindberg adds, "you might enter certain restrictions—for instance, only those studies published in English, or only those more recent than two years old."

For years, Alyson R. had been incapacitated by migraines once a month or so. Her doctor had told her that anything worth taking would be prophylactic—that is, she would need to take the medicine every day. Was this true, she wondered? Were there other, less sweeping treatments around?

Without any training, Alyson entered the NIH web site and typed in one word: migraine. She limited the search to the last two years. She found 912 articles, many of which seemed either overly technical or not pertinent to her search for a drug. So she focused her query a little more tightly, adding the words, "and drugs." This time the search engine returned just 96 stories, and some were clearly related to her primary concern. One of them, called "Acute Migraine Therapy: The Newer Drugs," sounded perfect. The researchers lived in Belgium, but the abstract provided an E-mail address.

Alyson then clicked on a button labeled "related articles" and found one describing a range of treatments being used by experts near her home. The article itself was unavailable on the web, so she ordered it through the NLM site—and ultimately went to the article's primary author for help.

How one medical detective mom helped her son

Danny Z., diagnosed with attention deficit hyperactivity disorder (ADHD) in nursery school, was severely hyperactive. But his symptoms had been successfully treated with the drug Ritalin, and as a result, he was able to shine in a normal class in public school. One day, though, Danny came home with a dreadful, incessant blink. Like some children with ADHD, Danny had a tic.

Believing Ritalin might be the cause, Danny's psychiatrist immediately took him off the drug and placed him on a series of medications that, in turn, exhausted him, enraged him, or did nothing at all. "I had to pull him out of school," says Danny's mother, Nicole. "Our local doctor told me that once a tic occurs, any kind of stimulant medication is strictly forbidden because it can literally *cause* Tourette's syndrome. Instead, he proposed a series of increasingly exotic medicines." Terrified, she decided to research the situation over the Internet and with some top medical experts. Here's what she was told:

- **Local child psychiatrist:** Once a child starts to tic, he must never again receive Ritalin or any stimulant medication, because the treatment itself may push him into full-blown Tourette's syndrome.
- **Internet news group:** Danny should cease all medication and change his diet. (After this advice was posted, a dozen people responded to say there was no definitive scientific evidence linking ADHD and diet.)
- **Internet mailing list:** The idea that Ritalin can actually cause Tourette's syndrome has never been documented and amounts to a medical old wives' tale. In fact, the latest medical literature suggests that stimulant medication combined with anti-tic medication is often the treatment of choice for children like Danny. A member of the mailing list even referred Nicole to several journal articles documenting the research.
- **Top expert in attention deficit disorder at a major teaching hospital:** Danny was so hyperactive that only stimulant medication could effectively treat his symptoms. For this child, a different stimulant—Dexedrine—combined with the relatively mild anti-tic medication clonidine was the treatment of choice.

Encouraged to accept the diagnosis of the expert (who later became her son's doctor) by knowledgeable members of the mailing list, Nicole moved forward. Danny's hyperactivity was once more under control, and though a mild tic persisted, he was able to return to school.

IF YOU WANT SOMEONE ELSE TO DO THE SEARCHING

The following medical research groups can dig out information for you, for a small fee:

Phone: 800-949-0090 or 501-329-5272; web site: http://www.thehealthresource.com/; E-mail: moreinfo@thehealthresource.com

Will search more than 4,000 medical journals and send you the results within three days for $99, or overnight for $149. Phone: 888-INFO400; web site: http://www.medsearchinc.com/

When doing your medical research, say the experts, you'll benefit from contact with a credible patient support group. Mary Jo Deering of the U.S. Department of Health and Human Services says support groups sponsored by reliable organizations can be found in library directories. You can also call the National Health Information Center, whose mandate is to connect consumers with the organizations that can help them most. The toll-free number is 800-336-4797. Support groups are also listed in the Center's web site at http://nhic-nt.health.org/ or through headquarters for the Self-Help Sourcebook, at http://www.cmhc.com/selfhelp/.

In addition to support groups that function in the real world, there are a variety of such groups meeting only in cyberspace. A number of established and well-attended groups thrive on America Online and CompuServe. Simply sign on and search the health and medical areas for topics of interest to you.

Such groups are even more numerous on the Internet. To participate in a bulletin board–style forum, or news group, on the World Wide Web, hook up through the Health Sciences Campus of Virginia Commonwealth University (http://views.vcu.edu/views/fap/ng.html) or the Self-Help and Support section of healthfinder (Address: http://www.healthfinder.gov/selfhelp.htm).

News groups and bulletin boards are often especially helpful for those overwhelmed by so many journal articles *(continued on page 152)*

IS THAT HOT NEW TREATMENT RIGHT FOR YOU?

Say you've read about a study or treatment that seems tailored to your health problem. How can you determine whether it really is? According to Mark Lebwohl, M.D., chairman of the dermatology department at Mount Sinai Medical Center in New York and one of the world's foremost researchers on skin disease, you can start with these steps:

- Pick up the phone, call the researcher who spearheaded the study, and ask, point-blank, whether she is still using the technique on her patients. "These people are readily accessible," Dr. Lebwohl comments. "Just call information in their city and ask for the number of their institution." If the researcher isn't treating her own patients with the technique, you shouldn't consider it for yourself.
- Call up the major foundation or patient support group representing the particular health problem and ask for their advice. Do *they* recommend this treatment? Why or why not? Like the list of problems, the number of nonprofit and patient support groups is extensive; instructions for finding the best are in "How to Find—and Join—a Patient Support Group," left.
- Determine the standing of the journal the study appeared in. "A great drug that did marvelously well will generally be written up in the best journal," Dr. Lebwohl notes. "If the results were exceptional, the study may be published in *The New England Journal of Medicine*, for instance." Remember, in general, the top journals are on MEDLINE, so if a study shows excellent results and appears there, you're in good shape.

Health Facts

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and conflicting opinions they don't know where to turn. Nancy B., for instance, went to the dentist with a dull toothache that had persisted for a couple of weeks. X-rays revealed a vertical fracture near the root. Her dentist's suggestion: Pull the tooth and replace it with an implant. Nancy was set on saving the tooth, something she learned from the medical literature was possible.

But advice from the news group sci.med.dentistry caused her to take her dentist's advice after all. The guidance came from an orthodontist: "It's nice to think if we can put rovers on Mars, we can fix anything else in the world," he wrote. "A vertical fracture comes under the category of heroics. There are things that might be tried and they might work or they might allow you to keep the tooth for a certain period of time. After spending maybe $4,000, you might then lose the tooth and have to spend additional money to deal with a bridge or implant. Wouldn't it be better to take the tooth and spend the money on the bridge or implant now and forget the heroics?" The input, along with her dentist's opinion, helped Nancy choose the treatment she determined was best.

If your problem is long-term and intensive, you may also want to join a mailing list—a group of net users who exchange E-mail. Such lists are private; posts are delivered to a limited number of members by E-mail and are not posted on a bulletin board for everyone to view. Since joining a mailing list is a commitment, moreover, those who participate are generally especially knowledgeable and concerned about other members of the group.

One woman, suffering from what turned out to be a particularly complex case of Lyme disease, had this to say: "Joining the mailing list was like attending a cocktail party with some of the world's most sophisticated people—all suffering from my condition—who had, collectively, read every relevant journal article, investigated every clinical trial, and visited every major medical center and every Lyme expert in the world. As far as I'm concerned, there was no single book, no single article, and no single expert who had as much depth of information, at such high quality, in one place."

For a directory of Internet mailing lists, check out CataList (Address: http://www.lsoft.com/lists/listref.html), Liszt (Address: http://www.liszt.com/intro.html) or PAML (Address: http://www.neosoft.com/internet/paml/). □

HOW TO INVESTIGATE ALTERNATIVE THERAPIES ON THE WEB (AND OFF)

According to Stephen Barrett, M.D., a nationally renowned consumer advocate and author of *The Health Robbers: A Close Look at Quackery in America*, "Alternative medicine has become the politically correct term for questionable practices formerly labeled quack and fraudulent." While some alternative therapies are effective, this unregulated field is ripe for predators of the desperate and uninformed. As you research the ocean of alternative-medicine material online and off, says Dr. Barrett, be on the lookout for red lights signaling questionable information. Avoid, at all cost, sites or publications that:

Market products.

Promote "alternative" methods in general; there are more than a thousand such methods, and the majority are worthless. For more information on medical scams, check out Quackwatch, Dr. Barrett's web site devoted to the topic, at http://www.quackwatch.com/. □

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Babysitters

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WHOSE FAULT IS IT?

There are people who would say Adams and other parents who've had neglectful sitters simply didn't hire right. Wendy Sachs, who also owns a nanny placement agency in Philadelphia, thinks videotaping is largely media hype and says only one or two families who've used her placement service have ever expressed any interest in it. "When I see those film clips of abusive nannies on TV, my thought is, Where did they get this person? The families who are having problems are the ones who are not using the really pristine agencies," claims Sachs.

Jeff Jones, owner of the Elite Alternatives nanny placement agency in Dallas, offers hidden videotaping to any of his clients who want it, but says in three years only three families have used it. And the result? "Everything was fine," Jones says. He attributes his successful placement record to his rigorous prescreening of candidates, which includes a medical exam, a psychological evaluation, a detailed reference check, and Jones's own "gut feeling" about a person. His candidates, he says, tend to be highly motivated in their work because they do it in conjunction with other professional goals, such as getting a master's degree in child development.

Joy Shelton, founder and president of the American Council of Nanny Schools, says she's had no reports of videotaping from the 600 nannies who've graduated from U.S. schools. In any case, a nanny school graduate, she notes, would have nothing to fear. "They are trained to use the soundest behavior-management techniques for children," she says, "whether it's potty training, developing good eating habits, or building a sense of responsibility." According to Shelton, a professional nanny follows a structure much like that of a good day care center, with a varied schedule, creative thinking exercises, and activities designed to build gross and fine motor skills.

"The real problem," Shelton says, "is that there are many more placement agencies than there are [trained] nannies to place. I think many times, parents are so desperate for childcare, they settle for far less than they should."

She's got that right, says Judith S. Lederman, a suburban New York mother of three and a public relations executive. In the past *(continued on page 154)*