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MEDICAL INFORMATION: HOW CAN YOU TELL IF IT'S ACCURATE?

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It's not uncommon to read or hear about some startling medical breakthrough or miraculous medicine several times a week. Exactly how accurate are these promises of hope for patients suffering from cancer, AIDS, Parkinson's disease, Alzheimer's, and other deadly disorders? Too many exaggerated reports emanate from eager but inexperienced reporters, overzealous editors or researchers anxious to get publicity for further funding.

Last year, the lead story on ABC's "World News Tonight" touted the results of animal studies as "the very best news there has been in many years, perhaps ever, about Alzheimer's disease." The *St. Louis Post Dispatch* and the *Milwaukee Journal Sentinel*, among others, published prominent front page stories saying that experiments with mice on low-calorie diets could, as the *Journal Sentinel* story put it, "lead to anti-aging, life-extending drugs" for humans. However, if you keep reading, this is really what researchers hope might result decades from now, which is a real let down.

Here are some other examples. *Time* magazine ran a cover story and the *Washington Post*, *Los Angeles Times* and many other newspapers gave Page 1 play to stories claiming that scientists had created a "smarter" mouse, a step that could lead to "creating baby Einsteins," "boosting human brain power," "improving human memory", as well as treating stroke and "human learning disorders."

In one two week period, *Newsweek* published a cover story on new hope for Alzheimer's patients, the *Los Angeles Times* published three Page 1 stories on new treatments for AIDS and *New York* magazine ran a cover story promising not only "a global conquering of cancer in five to 10 years" but breakthroughs in pain management, AIDS research, heart surgery, and more."

The print media are in a desperate struggle to reverse declining circulation in an increasingly competitive marketplace. As the director of research at one prominent cancer center noted, "**The media want to have something new, something that will catch the public's eye, so it can't just be 'progress has been made.' . . . It's got to be something really splashy and sexy.**"

However, some have gone overboard, especially with respect to new treatments for patients with debilitating or fatal diseases. Television, radio and the print media are the major sources of new health information, and exaggerated reports on "breakthroughs" are not only misleading and deceptive, but can have harmful and unanticipated repercussions for everyone.

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Medical Miracles or Misguided Media?

All too often, patients will demand a treatment trumpeted on TV or in the press for some new breakthrough that has yet to be proven, even when other more effective remedies are readily available. In addition, the subsequent dashing of unwarranted enthusiasm and false hopes often leads to widespread confusion, cynicism and depression. Many patients and their families start losing faith in all traditional medical treatment protocols and resort instead to much riskier experimental therapies. This is particularly true for patients with malignancies that have failed to respond to chemotherapy and radiation.

Inaccurate coverage of purported medical breakthroughs can also have serious social and political implications. Stories on cancer cures that don't pan out have contributed to a drumbeat of coverage about the disease that leave people with the fearful impression that we are in the midst of a cancer epidemic. In point of fact, cancer death rates have shown a steady decline since 1990. As one science writer noted, **"There is no disease that has been 'cured' as repeatedly as cancer has."**

While cancer doesn't kill as many people as heart disease, the excruciating pain, emaciation and general debility that can often characterize the advanced stage of many malignancies make it the illness that people fear the most. Therefore, it should not be surprising that cancer is the disease that is the most frequently claimed to be "cured" in the media.

For example, in 1998 the *New York Times* triggered a worldwide media frenzy with a Page 1 **"major breakthrough" story that featured a quote about curing cancer in two years.** This was based on studies in mice with an anti-angiogenesis compound that inhibited the growth of blood vessels. Malignancies require a markedly increased blood supply to keep growing. They accomplish this by stimulating the formation of new blood vessels to bring in nutrients and oxygen. This particular chemical, endostatin, resulted from decades of ground breaking research by Judah Folkman, a highly respected Harvard researcher. The story appeared more credible because Dr. Folkman's papers were regularly published in the most prestigious scientific journals and he had a reputation for being conservative. It was not Dr. Folkman who was responsible for the hype, but rather a reporter who based his prediction on information about when endostatin might be tried on humans.

The two years was correct. Last month, researchers from Massachusetts, Wisconsin and Texas reported some success in terminally ill cancer patients. The best results were seen in a 50 year-old patient whose malignant jaw tumor shrank by 62 percent following two months of treatment. A pancreatic malignancy in another was reduced by 19 percent after a year. In five other patients the cancers didn't shrink, but they did fail to grow. However, there were no dramatic recoveries in the 61 patients treated. Since endostatin seems safe and has no adverse side effects, researchers remain excited about its potential. The consensus of opinion appears to be that in the future, it may eradicate some cancers and hold others in check, so that the patient has more of a chronic disease rather than a fatal illness.

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It is also possible that endostatin may be used to potentiate the effects of chemotherapy, radiation or other novel approaches. One of the presentations at our Eleventh Congress in Hawaii last month reported that a specific form of electromagnetic field therapy could also have antiangiogenesis effects in two different animal tumor models. Both a rapidly growing rodent adenocarcinoma and slower human lung carcinoma clearly showed evidence of significantly reduced blood vessel growth following treatment. Administering a pulsating electromagnetic field in combination with a low sodium diet and administration of polarizing solution has resulted in a dramatic reversal of advanced metastatic malignant disease, but this appears to mediated by other mechanisms.

This new report of some success in humans with endostatin has again resulted in desperate patients demanding treatment with this or one of the other two dozen antiangiogenesis drugs currently being tested. The problem is that there are very few clinical trials and these are limited to very specific patients. It is not unlikely that entrepreneurs will take advantage of this situation to promote "natural" antiangiogenesis or other anticancer products that are worthless, but many patients will flock to because they feel they have'little to lose.

The magnetotherapy results have not yet been widely publicized. However, should the media pick up on this, as they are starting to do because of promising results using this approach in other disorders, cancer patients will also clamor for this treatment. This is certain to create even more confusion. As emphasized at last month's Congress, electromagnetic devices vary widely in terms of the fields they deliver as well as clinical trial results and basic science studies that can support their claims. It is not clear what field characteristics provide maximal reduction of blood vessel growth or other anticancer properties. **Many EMF devices will be worthless, but as also illustrated at our Congress, patients with a strong belief that they will benefit often do so for a while, because of powerful placebo effects. Their glowing testimonials will then be used to advertise success and attract many others.**

There are numerous other examples of media misinformation and hype that can victimize the hopeless. In the mid-1980s and again around eight years ago, new treatments for AIDS, a disease regarded as inevitably fatal, were also widely promoted with, according to one science reporter, "too much euphoria and too few caveats" .

The executive director of one AIDS organization agreed, explaining that this exaggerated and overoptimistic coverage had contributed significantly to widespread complacency among those most at risk. "They became more lax in their personal sexual behavior and slackened their vigilance because these headlines made them think that AIDS was now curable."

In other instances the relevance of animal studies has been seriously distorted. For example, one of the telltale signs of Alzheimer's disease, another hot topic, is the formation of amyloid plaques that clog up brain tissues. The ABC news story reported that scientists had developed a vaccine that not only prevented the formation of plaques but could also dissolve existing plaques in mice. This was a piece of good, solid, scientific research that certainly deserved to be reported. However, the study should never have been extrapolated to humans for several reasons.

Mice don't get Alzheimer's. These mice had been genetically engineered to produce the plaques and none developed any other signs or symptoms remotely suggestive of the disorder. Scientists are not even certain whether plaque actually causes Alzheimer's, or represents a result of the disorder.

Although the ABC story did include a few brief caveats, the overriding message was one of excitement over a major breakthrough. This again gave false hope to the desperate families of patients with this dreaded disorder willing to try anything that might benefit their loved ones. As one medical editor warned, "The minute you package something as a 'breakthrough' or even suggest that it might have something to do with humans, you've overhyped it." Unfortunately, the bottom line is that "splashy and sexy" is what boosts ratings and sells advertising.

The Publish Or Perish Syndrome

Reporters and editors are not always the only ones to blame. Lots of scientists are eager for public acclaim if they can be in the spotlight by appearing on popular talk shows to promote their research, and especially if they have written a book. More often it is because they are anxious to have their research grants renewed or need to satisfy the publication requirements of their university .

Some seem simply carried away with enthusiasm over their discoveries, which also results in exaggerated reports of their findings. Ego plays a major role. Natalie Angier, who writes for the *New York Times* said a prominent scientist once told her that the only recognition more important to most researchers than winning a Nobel Prize was getting his name on the front page of her paper.

For government scientists who work at the National Institutes of Health or the National Cancer Institute, the temptation to exaggerate may prove particularly irresistible if their budgets are coming up for congressional approval. They think that if politicians believe their tax dollars are producing results, they will be more willing to provide continued or increased funding for more of their research.

Pharmaceutical companies and other private industries are increasingly funding medical research. **Scientists they sponsor may also overstate their findings since they want something that can be patented in order to reap financial rewards. Academic and other research institutions may be similarly guilty because they know increased publicity and prestige can be parlayed into increased funding.** Some scientists have become masters of the sound bite and to attract attention, have used such pop culture terms as "Doogie Howser" (to name a mouse), "Sonic hedgehog" (for a gene) and the "Werewolf syndrome" (for a medical condition). As one reporter explained "You do something cute, you do something clever, you sell it a little bit hard, you give us what you think we want—and to some extent we do want, and you can launch yourself on to the front page."

How Do Doctors Get Their Information?

Most physicians first find out about new drugs and cutting edge advances from the same media sources as their patients. In many instances, this is well in advance of receiving the journal it has been reported in – if they subscribe to it. A variety of web sites such as Medscape (www.medscape.com), On Health (www.onhealth.com), Discovery Health (www.discoveryhealth.com), Intelihealth (www.intelihealth.com, InternalMDlinx (www.internalmedlinx.com) track fast breaking news and provide links to obtain more detailed information.

Some will also send a daily newsletter e-mail with a 24 hour update on advances in a particular specialty (cardiology, gastroenterology, dermatology, rheumatology, sports medicine) or general news the public will be reading about. While designed for physicians they are also free to anyone who signs up, as opposed to Physicians On Line (www.pol.net) which requires medical certification. Medical conferences provide another source of information, although these are also covered in detail by most of the above services.

Information about new medications is more often apt to come from pharmaceutical company representatives who visit physicians' offices on a regular basis and whenever a new product is launched that is pertinent to a specific specialty. They supply samples and literature even when they don't have an opportunity to talk directly with the doctor. Some physicians schedule time for this, will see only certain representatives, delegate one of their staff to get the information, or refuse to see any. Physicians are also flooded with free or non-subscription journals and publications dealing with their specialty or general subjects financed by pharmaceutical companies. As with literature distributed by detail personnel, some of these articles may be biased and promotional.

Medical texts are often out of date by the time they appear, so **most doctors rely on reputable peer reviewed journals like the *New England Journal of Medicine* to insure timely, accurate and objective information. That is not always what they get.**

Medical Journal Clout & Big Bucks

Every week, the most prestigious medical and scientific journals in the world send advance information on their latest research findings to news organizations all over the world. Most also send along press releases touting their most important items and hoping to see their journal's name on the evening TV news, Page 1 of major newspapers, and in cover stories in national news magazines. **There are over 25,000 science and medical journals but only a few have major impact.** Medical writers get the vast majority of their stories about medical breakthroughs not from interviewing scientists, attending conferences and meetings or visiting research laboratories, but secondhand from publications like the *New England Journal of Medicine*, the *Journal of the American Medical Association*, *Nature*, *Science*, *Lancet* and the *British Medical Journal*. According to some, medical coverage is sometimes little more than "a kind of translation service" for **these journals who essentially have "a stranglehold over information about biomedical research."**

Medical journals were originally designed to publish research advances, new treatments, up to date reviews and stimulate dialogue. Now they are major market-movers. Stock prices soar for companies whose drugs receive a favorable story, especially if it attracts massive media coverage. Some journals have become cash cows for their owners. The *New England Journal of Medicine* is published by the Massachusetts Medical Society for its members but the total number of subscriptions is now around 185,000. When it last disclosed internal financial data around 20 years ago, yearly profits were less than $400,000. Annual income now is about $20 million and growing.

The desire to increase revenue has changed how journals conduct business and how the public gets medical news. It's not that articles are distorted or unreliable, but **in the race for profits and publicity, journals often hype the material sent to the media.** Inflating the importance of some new finding can increase advertising from sponsoring drug companies, and attract others. This is what really brings in the big bucks.

Recent medical journal investigations seem to support the warning that **"The love of money is the root of all evil"**. Most editors insist that authors disclose any financial relationships or possible conflicts of interest with regard to the products or companies they mention. Members of the editorial board of a journal responsible for accepting articles to publish are held to the same or higher standard. *The New England Journal of Medicine* (NEJM) founded in 1812 is considered to be the paragon of morality because of its strictly enforced "Ingelfinger Rule". Franz Ingelfinger, editor-in-chief in 1969, stated that he would not publish a study if it had previously been discussed in "any other book, journal or newspaper". This was extended in 1977 by his successor, Arnold Relman, to apply to radio, TV or any other form of communication. Most reputable journals now also abide by this.

Redux (dexfenfluramine) became the first new drug approved for the treatment of obesity in twenty two years and the first approved for long term use in June, 1996. The clinical studies were published in NEJM along with a glowing editorial signed by several of the editorial staff. (For several weeks before and after, NEJM carried lavish and costly advertising spreads). **Largely because of this endorsement, over 2 million prescriptions were written in the last half of 1996!** It was withdrawn in 1997 because of deaths due to pulmonary hypertension, cardiac valve disorders and other problems. Redux had initially been rejected because of safety concerns and some panel members strongly objected to its approval. None of this was mentioned in the editorial.

It was subsequently found that several of the editors had strong financial ties to Redux. A reporter later claimed the NEJM had violated its ethics policy numerous times because they had published over 19 articles since January 1997 by researchers with drug company ties that had not been disclosed! While initially disputed, the editor admitted these transgressions and apologized in this year's Feb. 24 issue. **If the sacrosanct NEJM can't be relied upon to be completely honest, who can doctors, journalists and the public trust?**

Getting Tangled Up In The Web

More and more doctors are using the Internet to find out more about fast breaking news. So are many others. It is estimated that 100 million people will surf the web this year searching for medical information. According to the former JAMA editor-in-chief who is now at Medscape, depending on what they are looking for, there could be anywhere from 20,000 to 2 million sites to visit! In addition to those drowned by the deluge of data others sink because what they retrieve is erroneous.

Anybody can post whatever they want to on the Internet and there is no control over what is being provided to the public. It is impossible to keep track of all the sites that provide medical information and advice, particularly with respect to recommendations for treatment. In addition, there are numerous chat groups devoted to specific diseases where patients swap stories of their experiences and also offer therapy suggestions. In some instances these may be misleading but in others they can be very useful, especially when dealing with rare disorders. As illustrated in a prior Newsletter, the ability to interact with others with similar problems that are uncommon has been lifesaving.

Unfortunately, chat groups can be easily infiltrated by bogus patients whose sole purpose is to promote some drug, device, herbal preparation, or other alternative medicine approach and can choose to remain anonymous. It's difficult to give authoritative advice about something you know nothing about and don't know where to get reliable information. This can be particularly perplexing when you are confronted by a patient with a progressive illness or who has failed to respond to treatment, and you have little else to offer.

There is a mountain of information readily available with just a few clicks of a mouse or keystrokes, but it can take hours to examine the first few hundred of thousands of postings. Even if you are fortunate enough to find what you are looking for, it's not always possible to determine if the content is accurate and/or current. Not all sites list dates for their postings.

Physicians are increasingly being confronted by patients armed with pages of printouts touting some product they have never heard of from a source that is also unknown and can't be evaluated. Having a well informed patient can make a doctor's job much easier, but as one AMA official commented, "**Do it yourself medical research does not necessarily make a more informed patient.**" Nor does lugging journal articles to a checkup create an ideal beginning for a productive doctor-patient dialogue. You can't bring a telephone book to your doctor and expect him to read it, examine you at the same time, and render an opinion.

The dot.com epidemic has spawned numerous commercial ventures with catchy mottoes and eye-catching graphics that offer fast breaking medical news, medical encyclopedias, information on clinical trials, chat groups and "Ask an Expert" services. Some of these may seem authentic but financing for many often comes from drug company or other advertisements, on-line stores and sponsorship from other health care groups and the information provided may be specifically selected or skillfully manipulated to benefit these sources.

A large percentage of patients and their families seeking medical advice and information have illnesses that limit mobility and socialization, such as cancer, depression, chronic fatigue syndrome, multiple sclerosis, diabetes, Parkinson's and Alzheimer's disease. Patients with disfiguring or other embarrassing problems also turn to the Internet as a last resort.

It is estimated that there are some 50,000 sites that offer information, advice and support for such problems. Most of these offer compelling testimonials that can be quite convincing to desperate patients searching for any ray of hope. In some instances they refer to definitive studies in impressive sounding journals and/or are endorsed by M.D.'s with a string of strange degrees and titles designed to provide further proof of authenticity. In general, the more intense the marketing pitch, the less the credibility of the product being promoted, regardless of its scientific patina.

Caveat Emptor

It is best to stick to sites that emanate from the government, academic institutions, and recognized national medical and scientific organizations. Others may request personal details presumably designed to tailor responses to your specific situation but which can be turned over to others who would view you as a highly potential consumer. This is often accomplished by asking you to register, thus providing useful demographic information that can be passed on to others such as age, sex, education, geographic location, e-mail address and more.

It's usually wise to avoid sites that ask for a lot of personal information and if registration is a prerequisite, be sure to study the site's privacy policy. Establishing and maintaining a Web site can be expensive and reliable ones will clearly state the source of funds and separate various promotional activities from content. **Steer clear of those with a coating of scientific jargon that offer lavish personal testimonials rather than published peer reviewed studies.**

Be especially wary of sites promoting "alternative medicine" or "natural" products. If you are nervous and have muscle aches, you may be a victim of parasites according to one of these. Not to worry. You can easily get rid of the problem with a $75 battery operated device which, together with certain herbal preparations you can also purchase without a prescription will eradicate all the harmful bacteria and viruses that could possibly be responsible for your complaints. For just $14.95, another will let you learn self-healing methods developed at the world's largest "medicineless" hospital in China that offers a universe of cures, including the secret to spontaneous remission for cancer of the bladder. The Chinese Association of Urine Therapy offers another panacea. According to this Taiwanese organization, **drinking one's urine cures everything from baldness to cancer.**

While most of these are harmless, some patients may avoid or delay seeking medical advice for a condition that could be readily cured in its early stages but is more difficult to treat by the time a physician is finally consulted. A few sites could actually be dangerous.

For example, some promote *Ma-huang*, a Chinese herbal with ephedrine-like properties that may alleviate allergy and asthma complaints. More commonly, it is included as an ingredient in "natural weight loss" and "energy boosting" concoctions that have been responsible for more than thirty deaths and hundreds of serious side effects. The number is probably much greater since many adverse reactions are probably not reported or recognized. Although *Ma-huang* and similar ephedra containing herbal products are banned in many states, it is still available on web sites that do not post warnings of any sort about its dangerous side effects.

Even when adverse side effects are mentioned, they may be minimized. The very popular MotherNature.com alerts buyers about "the very public debate" raging over St. John's Wort, an herbal antidepressant that could have serious interactions with other medications. Nevertheless, it is described simply as "an effective antidepressant that causes relatively few side effects." After all, this is one of their most profitable products, with sales estimated at about $150 million annually.

Competition is so fierce that in addition to promoting their own products, some alternative medicine sites often denigrate others, presumably as a public service. Many take pains to point out every conceivably possible complication and side effect of popular pharmaceuticals their herbal preparations are designed to replace. Others have no hesitation about criticizing mainstream medicine. **At www.alternativemedicine.com you will learn that the National Cancer Institute really doesn't want to cure cancer so that it can continue to receive funding!**

As will be seen, a variety of efforts have been made to provide consumers with online help to evaluate web sites and avoid quackery. One of these is Dr. Stephen Barret's Quackwatch (www.quackwactch.com), where the retired psychiatrist and a group of volunteers identify and expose sites that they believe provide misinformation.

Data, Data Everywhere - But Not Enough Time To Digest, Discriminate And Deliberate

Medical information changes rapidly, particularly in areas of cardiovascular disease and cancer. Most people use general search engines like Yahoo and AltaVista that provide thousands of web sites but in no particular order or format. It can take forever to search through those which seem to provide the answers to what you are looking for without any guarantee that the content is authentic or up to date. Free Federal Health Directories are a much better source for finding filtered information that is reliable, especially those sponsored by the Department of Health and Human Services. **A good place to start is Health Finder** (www.healthfinder.gov). It provides a comprehensive list of reliable government and non-governmental publications, data bases, clearinghouses and support groups on hundreds of topics. They will tell you where to go to find information on hot topics such as AIDS, alternative medicine, cancer, diabetes, and food safety. Medicare and provide immediate links to health media on-line including ABC News Health, Healthcare Headline News, CBS Health, CNN Health, Fox News Health, MSNBC Health News, NPR Health and Science News, Mayo Health Oasis Headline, Reuters Health Information, *Science Daily*, *USA Today*, *New York Times* Syndicate, etc. You can also access Medline's data base of over nine million articles and abstracts from major medical journals all over the world at www.nih.gov. You are apt be overwhelmed with information if you do not **restrict your search to the last three or four years.** It is important to **be as specific as possible about your request.** "Stage 2B Breast Cancer" will avoid having to wade through a pile of papers that may not be pertinent. A very new government site (http://clinicaltrials.gov) now makes it possible to access any approved clinical trial to obtain information on the drug being tested, eligibility requirements, side effects, costs, qualifications of the doctors, with phone numbers if you need additional details about anything.

Reputable academic centers and health organizations are other valuable sources you can trust. The University of Pennsylvania Cancer Center's OncoLink (www.oncolink.com) and The American Cancer Society (www.cancer.org) provide a wealth of information and all the latest developments in diagnosis and treatment. Some commercial ventures like Medscape (www.medscape.com) and CBS Health Watch (www.cbshealthwatch.com) are also very popular and reliable. There are strong efforts to establish credentialing groups to insure the accuracy of information. One of these, the Health on Net Foundation, a Geneva nonprofit organization guarantees that sites displaying their logo have agreed to standards of conduct related to credentials, references, confidentiality, financing and advertising policies. Another is HI-Ethics, a coalition of twenty very large commercial sites that are teaming up to set standards for a "seal of approval." We will report on on these and similar attempts by others such as the American Accreditation Health Care Commission and WHQ in a future Newsletter, so stay tuned!

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