

Comprehensive Cancer Care: Integrating Complementary & Alternative Therapies  
Providing Good Information to People with Cancer

Moderator: Ralph Moss, PhD

Presenters: Steve Dunn; Samuel Epstein, MD; David Hankins, PhD; Sarah O'Donnell; Susan Okie, MD; Andrew Sparber, RN, MS, CS

Commentator: Ralph Moss, PhD

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Jim Gordon: Congressman Lane Evans, who is supposed to be here, is on the floor of the House, so he's not here to be the moderator. Ralph Moss, as soon as he arrives, is going to be both the moderator and the commentator. I'm just going to fill until he gets here. This is a panel on providing good information to people with cancer. We have a number of panelists here representing different ways of providing information, and through different media, different styles, and to some degree, to slightly different groups of people. Two of our panelists have to leave a little early – Susan Okie and Sarah O'Donnell – so let's begin with the two of you. Let's begin with Sarah O'Donnell. She is not Anne Alexander. This shows you some of the difficulties of providing good information. At the last minute Anne Alexander was not able to come.

Ms. O'Donnell: If I were Anne Alexander, I'd be 5'7" and skinny. I'm the Alternative Medicine Editor for *Prevention Magazine*, the first one ever appointed, and I've been on the job in that position since February. Before that I was in the book division at Rodale Press, where I've written a number of books on herbal medicine and alternative therapies. I come here today having just finished an article on herbs and cancer for *Prevention*. When it comes to talking about how to find good information, I've just been in that boat, and I'm going to share really quickly what that experience was like for me.

One of the things that I brought to this experience was a slew of information gathered at various herbal conferences and symposiums. It seemed that everywhere I went I'd hear these discussions among the herbalists and the other alternative practitioners saying, "I get calls all the time from oncologists. It's so terrific. These oncologists are talking to me, they're asking me about what I do. I'm consulting with patients." I thought to myself, wow, what a great story this is, these alternative-conventional partnerships.

When it came time to start this piece, I called up all my herb buddies, and my naturopath buddies, and my alt med buddies, and pretty soon everybody got really quiet. And all of a sudden they said either, "You know, I just don't remember who that was I was telling you about," or "You know, I don't think they're going to be real comfortable getting a call from you." And I thought, oh, that's interesting.

I started doing my research. For a 2,500 word article, I must have spoken to 24 or 25 people, including this gentleman right here. I read everything I could get my hands on. What began to emerge was a pattern. At that point I started feeling a little more confident that this story, herbs and cancer, this very little story might have some validity, so I started going ahead.

Actually, not everybody agrees. In fact, most oncologists disagree vehemently and won't even discuss this possibility. You might ask the question, as America's leading mainstream health magazine, what are we doing covering a story like this when so many people disagree with us pretty violently? The answer is that if one of our readers is diagnosed with cancer, that person's going to want to know about the options. It's our job to give them the best information we can to help them make safe, smart choices.

If there was one thing that I took away from this experience, it was that I wish these guys could just talk to each other. I wish the alternative practitioners and the conventional

practitioners would drop this wall of distrust. They're both in the same game. We know that. They're both out there to help the patient. A conventional oncologist is not trying to hurt his patient; he's doing or she's doing what she thinks is best. One thing dialogues like this are good for is hopefully to break down that wall. Since we're a little pressed on time, I'm going to end my remarks. I'll be really happy to answer any of your questions about how we go out and gather good information and how we deliver it. Thanks.

Dr. Moss: Hi. I'm Ralph Moss and have been pressed into service as both the moderator and commentator on this panel. I'm sorry I was late; I got caught up in an interview. Susan Okie will go next, because she has to leave early, and we'll try to make time for questions as well.

Dr. Okie: I'm Susan Okie. I'm a health writer, medical writer, at *The Washington Post*, the weekly Health section of the paper. I have been a national medical writer and also I've been the science editor of the paper. I don't consider myself an expert on alternative cancer therapies, but I came here to tell you a little something about how we cover medicine in general, how we make decisions about what stories are and what stories aren't, and how alternative therapies fit into that whole scheme of things as best we can figure it out.

What we do is very broad. I cover all sorts of fields, not just cancer. There was a time when we had an AIDS reporter, but now we really don't have any disease that has its own reporter. I cover lots of biomedical research, alternative medicine in sort of a broad way, public health, infectious disease, emerging diseases – there are many subjects that I write about as part

of the Health section. Virtually all of our medical reporters we have sort of a similar breadth in the things they do.

As far as cancer treatment goes, our job as journalists, at least at the *Post*, is to report on changes in our current understanding of the biology of cancer, how to prevent it, what causes it, how to treat it. We try to educate people about their risk, especially for the more common cancers, and what they can do to reduce the risk. We report advances in treatment when they're supported by solid scientific evidence. That's where this theme of good information comes in as far as I'm concerned. We cannot report on every little new wrinkle, either on the standard chemotherapy front or on the alternative front or in any field of medicine, because so much is happening in all of those areas. A lot of our job is to winnow through the incredible amount of information that reaches us by various channels, and try to figure out what makes the most sense to put in the newspaper.

This is much harder than it was when I started reporting on medicine, which was back in about 1975, because there are so many more sources of information. There's the Internet now, there are many faxes, there's e-mail, there are many more public relations firms. Sometimes it seems that the PR firms are hiring other PR firms. There are many layers of public relations people between us and the scientist or the doctor or the alternative medicine practitioner or whomever it is that we eventually want to talk to. I sometimes get very frustrated because I feel as though one whole half of my time is spent winnowing through this vast amount of information trying to decide what's important, before I can begin to report on or write the story that I'm supposed to be working on.

Story choice is partly the reporter's decision, partly the editor's decision. I'm not going to tell you that it doesn't reflect individual people's interests and biases. There are biases that

probably determine what we decide is a story. Some of those may be my biases, some of those may be my editor's biases. There are times when what happens to somebody at the paper or what somebody hears at a dinner party ends up turning into a story. We all saw that example with Gina Kolata's story about the antiangiogenesis drugs which seems to have been based on this dinner party remark, if one believes that the remark was really made. I'm not questioning that the remark was made, but it's interesting to see how that turned into a big front-page story based on an anecdotal thing. We try to be fair, and we try to be objective, and to take a broad look at things, but we are human. There isn't, as far as I know, any way that anybody's come up with of scientifically sifting through all of this information, so it's a human process.

We do get a lot of information about cancer, both prevention and treatment. We get a lot about AIDS and about heart disease, but cancer is certainly one of the biggest areas. We get things from the federal government, from the CDC, from universities, medical schools, drug companies, advocacy groups, patients themselves, and individual practitioners, not just oncologists but people who are doing all kinds of treatments for cancer and for other diseases. Alternative medicine is getting to be more and more in the news. It's obviously a topic of interest to a lot of people. I and other reporters at the *Post* are writing more about it these days, but deciding when we write about a new treatment or something that people are taking can be difficult. For all treatments we usually have a standard that we don't want to write about something based on anecdotal evidence. We would like to write about it when it's been studied in a good scientific study, ideally a randomized controlled trial, or some kind of well-designed comparative trial that shows that it's just as good as something else or that it's better than something else.

Sometimes when alternative treatments come along, the evidence can be based on a few cases or on a lot of anecdotes. It becomes difficult for us as reporters, non-scientists, to evaluate when do we write about it. When is there enough evidence to write about it as a news story, especially since what we put in the paper often drives the market, drives what readers will do? Industries can go up and down, and treatments can acquire new legitimacy if they're in the popular press, or they're in a major paper, or on TV, or whatever. I find that I am getting a lot of press releases and a lot of calls from PR companies these days about alternative treatments. It takes quite a bit of research on my part to try to figure out which ones to write about and where is the scientific evidence for them.

We don't like to write about things based on anecdotal evidence of cures, because we've seen in standard medicine as well as in alternative medicine a lot of times when people claimed that something cured cancer or cured another disease, and then it didn't seem to pan out when there was a study done. I'm thinking of laetrile, Kemron, Interferon was mentioned to me, IL 2 and the killer cells that were a big supposed breakthrough back 15 years ago and haven't really turned out. The press often gets criticized when we put these things on the front page and then they don't pan out later on. I will try to shorten this up so that we can go on to other people.

We do have a responsibility to write about alternative treatments when they become really popular or turn into a cause celebre. There have been a number of treatments over the last 20 years where so many people were going to such great lengths to take them and had so much faith in them, sometimes with good success and sometimes not, that it became a news story. It became important to try to figure out, was there evidence that this worked, what does the treatment consist of, does it have any side effects? Basically we want to find things that will help people, that will not interfere with treatments that might already be available and effective,

that don't have major risks to them, and that are not going to be a waste of money. It's sort of consumer reporting in that sense.

People differ about whether cancer or other patients who are getting standard therapies should also spend their money and effort on adjunctive therapies. They should be free to do that, so long as it can be determined that the therapy isn't dangerous to them and is not going to interfere with whatever else they're doing. I agree with what Dr. Benson said, that mental and emotional states, and faith, and hope have a huge impact on people's health and how their body fights diseases. There's a lot of evidence that the quality of your personal relationships, freedom from pain, your nutritional status, your ability to sleep and to relax, all of those things have a major impact on health and on your ability to get over a disease. I don't want to be in the position of needlessly depriving somebody who has a disease like cancer of hope, or interfering with their right to try anything, but I do feel that alternative treatments for cancer and for other diseases need to undergo careful scientific study. Thanks.

Dr. Moss: Thank you very much. Our next speaker will be Steve Dunn. Steve is the founder of the CancerGuide web site, which is one of the outstanding sites on the Internet for access to information. Steven was himself a cancer patient with a dire prognosis who has done very well using treatments that he discovered in large measure through his own information search. Right? Is that fair?

Mr. Dunn: That's right. I think everyone here will be very interested to hear that not everybody's forgotten about interleukin-2, because that happens to be the treatment that allowed me to be with you today. Sometimes the magic works. I was diagnosed in 1989 with widely

metastatic kidney cancer. As I lay in my hospital bed at one point, and I don't quite know why, I said, "If I ever get out of this alive, I'm going to do something to try and help other people."

After a while it was pretty clear that the best thing I'd found was the Internet. I've been really active on the Internet for about four or five years creating my CancerGuide web site.

CancerGuide is intended to help patients research their options. It is not primarily focused on alternative therapies, but I do have a section on alternative therapies and I think it's important. I've also spent quite a lot of time participating in Internet discussion forums including mailing lists and newsgroups. I can give you a front-line report on what's going on on the Internet right now in cancer support.

The first question is, why do patients turn to the Internet for information in the first place? The first thing that happens is somebody walks out of their doctor's office with a diagnosis of serious bad cancer. They don't understand very much of what they've just been told. They're in shock. After the shock starts to wear off, they really want to understand, and that's the first thing that patients are looking for. Once they begin to understand the basic situation, they want to double-check that the recommendations they got from their doctor are the latest, the greatest and the absolute best possible thing.

Unfortunately, an awful lot of patients receive a terrible prognosis or they are offered extremely difficult and toxic therapies. People are looking for alternatives, something that might improve the prognosis, or reduce the toxicity. One of the things they're looking for is certainly alternative therapies. And finally, if they can find it, most people would really like to talk to someone who has been before where they are now.

The big thing on the Internet that everybody's heard about is the World Wide Web, right? What I'd like to emphasize is actually something different. It's interactive support on the

Internet, interacting with people. This is an incredibly powerful thing. Most people don't realize it, but if you get on an Internet discussion forum and you post a question, you may have the attention of 300 people or 3,000 people. You may be able to pick the brains of 3,000 people at once. You're likely to get a lot of different responses and points of view.

The information you get is often self-balancing and self-correcting. If somebody puts out bad information, somebody else is likely to come back and say, wait a minute, what about this? It's kind of interesting to contrast that with a web site. If a web site has bad information what does it do? It just sits there and misinforms you. There are several different kinds of discussion forums on the Internet that I'd like to talk about – mailing lists and newsgroups. Minor technical differences between these can create a rather large difference in how these can be useful to patients.

How many people here are on a mailing list? A fair number. For those that may not know about it, a mailing list is an e-mail discussion group. You subscribe by sending a special e-mail message to an e-mail address. Once you're on an e-mail discussion group or a mailing list, any time anybody posts a message to the list, you get it. If you post something, everyone else gets it too. There is a mailing list available for almost every specific cancer out there. There's an organization called the Association for Cancer On-line Resources. I'm a member, and it has provided nearly 100 mailing lists for different types of cancer.

It's unbelievable the power of the concentration of knowledge and experience that you get when you have several hundred patients all dealing with the same problem sharing information and support. (You may be interested in knowing the number of patients with renal cell carcinoma that I met during my entire treatment and diagnosis phase. That number is zero.) We have well in excess of 200 patients with kidney cancer, though, on my kidney cancer mailing

list. I'd like to give you just one example of what that can actually mean to somebody. I'm going to quote from a message that came across the list just last week. This message is not necessarily that unusual or atypical. "The information that I've received from this list has been more than wonderful. If I hadn't stumbled on it, we would have been sitting in the dark for the last couple of weeks, thinking that my husband was going to be just waiting to die. Now he has informed choices."

The culture on these lists varies because they're all different. However, there are a number of things that are common. Most of the people on these lists are patients. There are only a few physicians or professionals. Advertising is strictly prohibited and effectively controlled. Perhaps you have heard of a flame war or an argument that degenerates into personal recriminations. Flame wars on mailing lists can usually be effectively moderated by a group of people called list owners who have some special privileges. Every person who subscribes to a list gets a welcome message. It says what the list is about and it lays down what the ground rules are. The list owners get to write the welcome message. That makes a big difference. In extreme cases, a list owner can remove a subscriber who is excessively disruptive. They can also just use moral suasion to get the discussion back on track if things are going awry.

Alternative therapies are certainly a topic on these lists. There are a few lists that don't allow any discussion of it, but there are only a few. I think they're making a big mistake. Most lists do allow noncommercial discussion of alternative therapies. When a message is posted, usually responses come back reflecting a wide range of responses on the skepticism scale, and mostly pretty informed.

The second type of discussion group is a newsgroup. How many people have read newsgroups on the Internet? A fair number again. A newsgroup is different from a mailing list.

It's like a public bulletin board. Anybody can see all of the messages on a news group. Anybody, without doing anything first, can post a message to a newsgroup. Newsgroups do have some rules as far as what you're supposed to post and what you're not supposed to post, but there's no way to enforce the rules. A newsgroup does not typically have an owner, or a list owner the way a mailing list does. Newsgroups are full of an awful lot of a certain product from the Hormel corporation known as Spam. There's an enormous amount of advertising, some of it not even related to cancer. In addition, there isn't anybody to help moderate flame wars, and they can get way out of control. Alternative therapies are a very major topic on the newsgroups. A lot of people post advertisements, often rather outrageous, for various nutritional supplements. These tend to draw extremely angry results and a debate that has a lot more heat than light come out of it.

I'm sounding pretty down on newsgroups, but there are some really positive aspects. There are a number of doctors and informed patients who do monitor the newsgroups closely. When a lot of patients ask questions they really do get answered by somebody who knows something, and they're read all over the world. If you post a question asking for something obscure, you just might get an answer. There aren't nearly as many newsgroups as there are mailing lists. There are probably only four or five cancer-related newsgroups, so you don't get that strong focus on an individual disease.

I'd like finally to make a few remarks about web sites. There is excellent information on normal treatment of cancers available from a number of sites, such as the National Cancer Institutes, CancerNet, University of Pennsylvania's OncoLink, and the American Cancer Society. But if you're going to go out on the web looking for authoritative information on alternative therapies, that's an entirely different story. You just heard Bob Wittes say that the

NCI took down what little information it had because they thought it was outdated and inappropriate. There's relatively little information at the major sites.

It's hard to understand what would be meant by authoritative information in a field that's characterized by highly controversial evidence and such a wide divergence of opinion. The range of different alternative therapies is so mind-boggling that it's extremely difficult to imagine a truly comprehensive survey. The person who might come closest would be Ralph Moss, but the entire concept of authoritative information is in big trouble. There are some good sites on alternative therapies, they just aren't quite that ambitious – Commonweal (Michael Lerner's site) where he has put the entire text of his wonderful *Choices in Healing* book. The University of Texas Center for Alternative Medicine has put out some rigorous summaries of the scientific evidence for several therapies. Ralph's site has a number of very interesting articles from his newsletter. Another site worth considering is also Steve Barrett's QuackWatch, which takes a strongly skeptical view but I think everybody ought to see it.

The web is the ultimate venue for freedom of speech. Nothing like it has ever been seen before, and absolutely anybody can put up a web site. There are an awful lot of sites on alternative therapies that are advertisements and that are questionable. It's very difficult for patients to assess the information. There's no option conceivable for eliminating sites that are questionable or bad. It's not going to happen, and if anybody's thinking of it, just give it up. You can hope to educate patients. One of the most important things is to consider the information in an appropriate context of all of their other available options. What would they give up to use this therapy? What is their prognosis without it? How solid is the information? Patients need to get an appreciation for the quality of the evidence and people need to have an appropriate level of skepticism.

If you're too skeptical about alternative therapies you might pass up something that could improve the odds. On the other hand, if you're not skeptical enough, you're probably going to fall for the first sales pitch you accidentally come upon. It's also important that patients review the information with other informed people – their doctors, the mailing lists I've already mentioned, and anybody else they can find. I emphasize these points on my web site, but it's really difficult. It used to be the exceptional patient who went and researched their disease, or went out and aggressively sought options. It will soon be the exceptional patient that doesn't go out and seek the best information on their disease.

Dr. Moss: Steve, what's your web site?

Mr. Dunn: My web site is called CancerGuide and the URL is [Cancerguide.org](http://Cancerguide.org).

Dr. Moss: Thank you so much, Steve. We'll hold our questions until the end. Our next speaker is Dr. Samuel Epstein, Professor of Environmental and Occupational Medicine at the University of Illinois Medical Center in Chicago.

Dr. Epstein: When I was told I'd been put on this panel, I expressed considerable bewilderment and surprise, because the field of alternative medicine and cancer care therapy isn't an area in which I consider myself authoritative. But Ralph assured me that I would find something to say, so I will try.

Dr. Moss: I've never known you not to.

Dr. Epstein: First of all, I think we've got to recognize that treatment is damage control. That's the important point. Treatment is damage control. When you look at the major escalation of cancer rates since 1950 to now, one can take the a priori position that the majority of these increases are a reflection of avoidable exposures to carcinogens in consumer products, air, water, food and the workplace. This raises a particularly important point, and that is, as survivors, as people who have been impacted by cancer, which in many instances is avoidable, you have a very special responsibility.

First of all, you have a responsibility to yourselves, to making sure, as far as possible, that you get better, and that you take advantage of all possible therapies. Secondly, for your voice to be heard in the broad political community and in the media. In November of last year, the cancer drug industry announced a March on Washington for September of 1998, to be headed presumably by Gen. Schwarzkopf, a Million Man March. They say a Million Man March. I thought one talks about a million person march, but be that as it may.

There have been full-page advertisements in *The New York Times* and elsewhere. It's being exclusively financed by the cancer drug industry, with support from cancer survivor groups. In all the paperwork that's gone out, there's not a single mention of the word prevention. So, to those of you who work with Ellen Stovall, who runs the cancer survivor groups and is really an outstanding leader of this group, I say lend your voice to the message that prevention is important. When the NCI is asking for 5 billion dollars by the year 2003, and when you go through its budget, it's very difficult to find any evidence that the budgetary allocations are anywhere over a hundred million – in fact my estimates are lower still for prevention – then indeed this responsibility becomes even more acute for you.

The second point was raised by Senator Harkin this morning. He promised to give the potential FDA commissioner candidates a good going over on a variety of issues, and he singled out in particular the whole question of their attitude toward alternative medicine. I'm delighted to hear that he's going to be doing that. Alternative medicine needs at least as fair a shake as does conventional therapy. However, the question of what are the criteria for efficacy is critical here. At the present moment, efficacy as defined by FDA and accepted by NCI is a tumor response, a shrinkage in tumor size by about six months or so. If a drug does that, it's considered to be efficacious, irrespective as to whether or not there's any evidence that it increases survival, and irrespective as to whether there may be any evidence that this actually decreases survival.

This strikes me, with due respect, as a somewhat limited definition of efficacy. Such a limited definition of efficacy is to a certain extent borne out when you look at cancer survival rates over the last 10, 20, 30 years. You find that in general the increase in survival rates has been pretty mediocre, minimal to mediocre. In instances where it appears to be substantive, that can be more than explained by what's called lead time bias, or diagnostic bias. Very simply, if you do sputum cytology tests, and you pick up the cancer cells the year before, they'll have an extra year of survival. It's the same with ductile carcinoma in situ for breast, or pre-invasive prostate cancer. The survival rates for some of these cancers is, to say the least, questionable.

The next point is that when the Office of Alternative Medicine gets going, for which I'm delighted to hear that the budget is going to be about 20 million, I very much hope that they're not going to accept the responsibility in any way for conducting clinical trials. I hope that the Office of Alternative Medicine will screen the evidence for these trials being promising or

otherwise, and then pass them on to the NCI for controlled clinical trials with an independent board of supervisors.

This brings me to another interesting point. Talking about breast cancer as Devra Davis was this morning, just to give you one example of how this whole field of chemotherapy has become a massive industry, which has its own agendas, and in many instances these agendas don't necessarily coincide with public health needs. I was reminded of this by the following. By 1996, we had about six studies showing that regularly taking aspirin reduces risks of breast cancer by about 30%. I haven't seen a word about this, other than the original studies, in any of the NCI or ACS paperwork. However, it has been recently found that one of the mechanisms of aspirin is it inhibits an enzyme called cyclooxygenase 2, or cox-2. Cox-2 is pretty interesting, because when you inhibit that, you block angiostatic effects. You block growth of the blood vessels into tumors. Now that this effect of aspirin is out, two or three drug companies are manufacturing cox-2 inhibitors, which are going to be damned expensive – will probably be as expensive as taxol will be compared to the manufacturing cost – and this becomes a major industry. How many of you in this room have heard of evidence that aspirin inhibits, reduces risk of breast cancer? Hands up, anyone? Well that's a 100% response. Splendid. None of you have heard about that. Within one year, you're going to be hearing about the major advances of cox-2 inhibitors. We're talking about a major industry which has its own agendas, and the agendas don't necessarily correspond with the patients' interests.

Basically that's about all I have to say, with one exception – and that is the question of clinical trials and informed consent. I recently have reviewed some of the evidence of informed consents in randomized controlled trials, and find them to be singularly deficient. In 1992, I believe it was, I was invited by *The Los Angeles Times* to do an editorial on some aspects of

women's breast cancer. This was about the time when the tamoxifen chemoprevention trials were getting going. NCI and ACS were enrolling about 16,000 women, healthy women, who were supposed to be at high risk for various reasons, like being over 60. They divided them into two groups. One group was going to be given tamoxifen and the other a placebo. There was a slim rationale for this. However, the published scientific evidence on tamoxifen showed that it was one of the most potent known liver carcinogens.

Having worked in experimental pathology for God knows how long, and carcinogenesis, I was particularly interested by this for one additional reason. First of all, the carcinogenic effects in rodents who induced at blood levels equivalent to the human therapeutic, and secondly, tamoxifen induces irreversible DNA adducts. Many carcinogens will form what are called adducts, tie themselves on to DNA, but you can generally easily break them down by very simple methods. When you have a carcinogen that creates irreversible DNA adducts this means you've got one hell of a carcinogen. One of the people who did the studies, Gary Williams, called this a rip-roaring little carcinogen. Look at the patient consent form. Is there a word on this? Not on your sweet fanny. Not on your life. In addition to that, what we've seen for the tamoxifen chemoprevention trials, they were run for a short period of time, many women had only been on them for three years. On the basis of a statistically significant reduction in the incidence of breast cancer, these trials have been heralded as a great success and they're going to be extended with Raloxifene trials. Let me just point out the following.

First of all, the British scientists who are in charge of an international breast prevention trial were highly critical of these claims of NCI. They said you have no way of knowing whether this is simply delaying the onset of breast cancer as opposed to preventing it. There's substantial basis for that belief. But over and above that, when you look at the incidence of complications,

thromboembolic, pulmonary embolism, uterine cancer, you find that the mathematics show as following. On the short-term basis the benefits of tamoxifen are about 1.7%, the life threatening risks are 2.2%. Look at the patient consent form. The risks are trivialized. There is no mention of liver cancer at all.

Let's turn on to Raloxifene, or Evista. You've all seen these full-page advertisements in *The New York Times* and elsewhere on Evista, this new Eli Lilly drug. Evista is in the same general mode as tamoxifen. It's what's called a serum selective estrogen receptor modulator, except it's an antiestrogenic to the breast. Unlike tamoxifen it is also antiestrogenic to the uterus. Eli Lilly was pushing this for treatment of postmenopausal osteoporosis. However, I was asked by Jim Lehrer to do a 20-minute segment on Raloxifene. I said I don't have all the data, so I got the package of raw data from Eli Lilly in a short period of time and looked at the warning section. Not a word about anything except a little flushing, a little this or that. You think it's fine. You go on. Buried away is a couple of pages on experimental data. In the experimental data it shows that both in mice and in rats it induces a high incidence of ovarian cancer. In the mice it induced them at levels about a third of the therapeutic. At the bottom of that section it says the clinical relevance of these tumor findings is unknown. However, in the warnings to women, there is not one word about it.

Now NCI's getting ready to do head-to-head clinical trials with Evista or Raloxifene and tamoxifen. For Evista the trials are based on the fact that 50 women in one study had been shown to have, within two and a half years, a slightly lower risk of breast cancer, but in the other trial none. Here we have two trials that are going to be run head-to-head on healthy women who are told this can reduce your risks of breast cancer, suppression of data on risks of ovarian cancer, and suppression of data on risks of liver cancer. This is the quality of information you

can sometimes get from randomized controlled clinical trials. And recently, the draft report of the Inspector General, pointing out other problems. I don't know whether they've been in *The Washington Post*. They've been in *The New York Times*.

Participant: It's in *The Washington Post* today.

Dr. Epstein: It was. I didn't see the paper today. This raises very fundamental questions about the honesty and the quality of the data.

What we're talking about now is that, although this is the greatest democracy in the world, when it comes to the question of health care, we sacrifice democracy. We say our need to know can be restricted without raising major objections. On the question of cancer prevention, how many of you here know, of the common household products you buy, of cosmetics and toiletries, of the common foods, that many of them pose major, grave, avoidable risks of cancer. FDA knows about it, NCI knows about it, ACS knows about it, but they have never been to Congress to say, advise the public about this. Develop appropriate legislative responses, go to regulatory agencies, develop appropriate regulatory responses, etc. There has been a total absence of outreach.

When two speakers before me this morning, one from the NCI and ACS, told you everything's great, cancer rates are going down, major advances, this is totally untrue. The decline in cancer rates is minimal or nonexistent. In many instances, particularly for the nonsmoking cancers, there's a continued increase in the incidence of cancer rates. The evidence for therapeutic efficacy is minimal to extreme. I'm making a plea – although many of you in this audience have got your own burden, you are cancer survivors, you've dealt with terrible body

blows – I'm asking you to accept another terrible body blow. Say no to the march. We don't want 5 billion dollars for the NCI in 1993 to carry on fooling the public (as they have been doing for 30 years about great advances and miracle cures) into believing that they have anything other than not always benign neglect of prevention.

Dr. Moss: As I said, you are never at a loss for words. Our next speaker is David Hankins who is Chairman and Program Director of the International Cancer Alliance.

Dr. Hankins: First of all, this is my volunteer hat. My real job is as a researcher at Johns Hopkins and NIH and anywhere I can find a place to do my craft. I'm a molecular biologist. I don't have cancer. I learned a tremendous amount about 10 years ago that got me involved in a program called the ICARE Program, from the International Cancer Alliance for Research and Education. A number of people here in the Washington area – Cynthia and Dick Helms being the most notable, with Sam and Colleen Nunn and several others – have pushed us as scientists to jump off of a cliff that we couldn't afford, because none of us were good fund-raisers. What evolved is one hell of a good program for information, as well as, we think, for science. The products that we have are free. We have cancer therapy reviews for 43 different kinds of cancers. You get those is by calling 1 800 ICARE61. We tried to get ICARE4U, but we didn't. 61 has no significance, but it works.

If you call ICARE 61, the first thing we'll do is sign you up on a patient registry. We don't want any vital statistics and any confidential information. It's just a way for us to start a dialogue. We work with people and talk to them about their cancers. We help them put together

a kind of a dream team that will help them solve their problem. This has allowed us to go down into the cave with a cancer patient.

I use that analogy because I'm from Tennessee, and the scariest moment I've ever had was when I was lost in a cave. What you want to do is get out of there. You really don't want to hear discussions about this politics or that politics or this or that. At that moment you want to find out how do I get out of this damn cave. Once you get out, you want to know how do I stay out. That's basically what we've been trying to do.

What has evolved is a tripartite program – three groups of people have come together to help save your life. Those are the top doctors in the world, the top researchers in the world and the top patients in the world. We define the top 1% of doctors and researchers by standard means. We don't care whether they're really in the top 1%, they can be in the top 2 or 3, but basically what we're trying to do is get the brightest minds, get you on their agenda and vice versa. It turns out that we select the top patients in the world by saying are they difficult to ignore. We want to bring bright people to challenge everything, not just alternative, but to challenge establishment, to challenge everything. What I have learned as a scientist has been tremendous and I have a lot of patients to thank for that. I'm a leukemia person, I deal in leukemia. I learned that we're really not curing 90% of the patients with acute lymphocytic leukemia in kids. It's somewhere around 50%. We get 90% remissions, and then they come back down with either leukemia or maybe even some other disease. It's not a pleasant journey.

Our organization has what we call a 12-part survival program. The first thing you do if you sign up is get the *Cancer Therapy Review*. In some of those 43 different kinds of cancer, this is not much more than a glorified PDQ. Some of them are behind, they're not up-to-date. We try to keep them up-to-date – we have a number of patients, doctors and researchers working

on them all the time. We have a document called Patient Experiences. We want you to hold those close to the chest, and we want this document here, the one for breast cancer, to say to you, you're not going to die. We want you to have the confidence that you're not going to die, because this is all written by people who are not dead. We don't let any dead people write in this book. We also have a web page called [icare.org/icare](http://icare.org/icare), and it's a reasonable web page. It's going to get a lot better. Some people from MIT Media Lab have just helped put something together and it's going to get better. We want that web page to introduce you to all the people that we know which includes Steve Dunn and lots of other people. We want to work with every organization that we can.

We have a version of the *Cancer Therapy Review* that we're trying to do, which is called the Clinical Trial Matching Program. Basically what we want to do is learn everybody's name and address and so forth – the pharmaceutical industry, the academic scientists and centers who want to participate in clinical trials, who have participated or are currently participating in clinical trials, all the government officials that help make those decisions about how a clinical trial gets started, and of course our target group is the patients and primary care physicians. We want to get all of these groups talking to each other electronically.

We're working with Oracle and GTE to try to help create, select electronic matches, so that they can go in there and search and find those things. It doesn't do you any good to know about a clinical trial if you can't get in it. It doesn't do you any good to know about the HER 2 clinical trial for breast cancer and know that there's a lottery, if you don't know that the one in Pittsburgh might be easier to get into than the one in Florida. If it's a lottery, you might die before you get chosen in the lottery. We're just getting this off the ground. It's not ready to go

yet. I don't know when it will be ready to go. It's a combination of how we can pull everybody into it as well as raise the money.

I want to say one thing about the *Cancer Therapy Reviews*. Everything in the organization, what has evolved out of our triangle, is groups of three. The editorial panels are the 30 top doctors in the world in breast cancer, the 30 top researchers in the world in breast cancer and the 30 top patients in the world in breast cancer (and we don't really know who those are). In any case, those people are the ones that review it. They all review it from their different perspectives. They challenge alternative, they challenge everything that the patients bring in. I met Gar Hildenbrand and Chuck Simone and others because the intellectual underpinning of everything we're doing is done with think tanks. We bring these people together, have the think tanks, and then try to convey that information in the *Cancer Therapy Reviews*.

This organization's spiritual leader was a person named Dr. Charles Huggins, University of Chicago. In 1944 he found that prostate cancer was hormone-dependent in a rat. He did a castration for a different reason, and the prostate cancer went away. He said aha, there must be something going on there. He tracked that down. It turned out to be testosterone. The anti-testosterone kinds of therapy came out of that. He won a Nobel Prize in 1966.

1944 to 1966 is 22 years. Why did it take so long? How many people died over that? He told me most of that 22 years had almost nothing to do with science. It had to do with politics, the establishment and all of the things. So we set up some symposium think tanks amongst scientists to do two mission statements, which were our only two mission statements until we met Cynthia Helms and her gang. The first was to try to be an active advocate for creativity and open thinking, so-called freedom to think creatively. The second mission

statement was to work on behalf of the patient in the medium term by promoting translational research and movement from laboratory to clinic, the so-called freedom to test.

Then we evolved this other thing, because we had to raise money. We have some grants called Freedom of Pursuit Awards – you give a scientist the money and leave him the hell alone. In order to raise some money for that, we basically went to whoever we knew that was rich. I happened to be doing some DNA fingerprinting in thoroughbred horses as a hobby. I knew a lot of rich horses, so I went out to the Virginia Hunt Country, and those rich horses live right next door to some rich people. It turned out that those rich people weren't immune to cancer. Nor did the fact that they were rich make them able to get good, solid information about cancer.

That's where we got dragged into that thing. I'm grateful to all of those patients who have given me that opportunity, because the most important thing that has come out of that for me as a scientist is that we learn. It's like bringing Bill Blass and Calvin Klein, if I can be so presumptuous, bringing those people – we are supposed to be the designers of the new medicine. It's bringing us into the department store which we've allowed ourselves to be shut out of. If Bill Blass gets to come in and watch somebody try on those clothes he's designing, he's going to find out they don't fit. That's what's happening to us as scientists. Thank you.

Dr. Moss: Our last speaker is Andrew Sparber, who is a liaison nurse with the clinical center of the National Institutes of Health.

Mr. Sparber: I've been a psychiatric consultation liaison nurse for the last 9 years at the clinical center, and it's given me a chance to find out a lot of what goes on at the Institutes. The clinical center is where the Institutes intramurally do all the protocols on the patients. I have a

chance to listen to a lot of cancer patients. Listening is one of the key things that we hear throughout this whole conference, how important it is to listen to individuals diagnosed with cancer or other diseases, and what can be going on with them. The other thing that it's enabled me to do is to see the NCI from the inside. It has been really good to work with a lot of physicians there and some of the support they have for some of the work I'll be talking about.

By the way, I'm from the Public Health Service, not the Navy. If I just say Surgeon General Koop most people understand, so that's why I'm in uniform today.

Again to listening and how important it is. We have patients seeing their physicians or other providers and they certainly have questions about what they're using in alternative or complementary therapies. Question marks come in the physician's mind. The physician wonders, what kind of resources do I have? If you look at the typical medical problems that physicians have to face, or other providers, there are great resources – the libraries, the databases, other physicians. But when it comes to questions about complementary or alternative medicine, where do the physicians turn? Maybe they go into their neighborhood and ask their neighbor, what's this all about, or if they go on the Internet or they get on one of the other systems. Are there books available?

A lot of physicians really don't know where to turn. Even though we have the OAM on campus there, and slowly they're becoming more visible for the physicians and the researchers there, there's still a question of where do we turn? Should we even ask the question? The other issue at NIH is that it's so research-oriented. Research is one of the first things on physicians' minds, so that adds another dimension of focusing and talking with a patient.

For the last four years, I have been working on a survey of NCI adult patients. I represent the collaborative efforts of these different departments, from nursing, social work,

pharmacy, recreation, ministry, NCI, OAM, and admissions. It has been a chance to pull together people who have the same kind of interest. The survey has served that purpose. Bioethics has been an important part of that also. It has created a dialogue.

We talk about the focus on providing good information for patients. We also have to provide some good dialogue between health professions. There's a lot going on at the clinical center. There's the same kind of a groundswell of interest in the clinical center that we see in the community. It doesn't always come from the top down. When I had a chance to do this survey, the question in my mind was, what's going on at home here in the clinical center? We did a protocol, and we looked at 100 cancer patients and also patients diagnosed with HIV. At least with the cancer patients they were representative of the larger NCI adult population in-house. We wanted to look at a whole variety of questions. I was able to borrow David Eisenberg's survey and we adapted it to this setting.

The clinical director of NCI has been wonderful in giving support and saying okay, go ahead and find out what's going on. There's a lot of education of the researchers – we can say this is what your patients are using and doing. Hopefully that can open up some discussions. About 63% of the patients we interviewed were using some kind of alternative or complementary medicine. We also have a higher level of educated individuals that come here, and there may be some correlation there.

One of the outcomes in doing the survey was opening up things more at the clinical center for discussion. This is the first protocol of that kind to go through. It was organizational caring. Patients were very thankful for being asked all these questions. Usually for an hour someone's asking them all these dimensions of what kind of health practices they're using, their

beliefs, relationships with their physicians – a lot of the same questions that David Eisenberg did, but we adapted it to this setting.

Feedback to NIH clinical center. In a couple of weeks I'll be presenting to the NCI's Caller Information Service on the results of the survey. Giving back this information to different levels in the organization is going to be important.

Professional education. We need a lecture series. You look across the street to USUHS and there's a lecture series of what's going on in this field. There is some of that that does go on, however. Again this is a magnet to bring individuals who are interested in alternative medicine together.

Other initiatives. One of the other spin-offs was that an herb survey was done on one of the chronic conditions, in the outpatient clinic, with 500 patients, looking at what kind of herbal products patients are using. It too was a nursing initiative there. It's so important to begin to have that pink elephant really appear in the living room, that's going on in your own back yard.

Also the Management Information System screens, or MIS screens. That's our computer screen that we had developed. It's an assessment screen that nurses use to assess patients and ask patients about what are they using. So we're working more on some of the information systems and gathering that information.

Patient education. We've had a poster for patients – talk to your physicians about what's going on, what you're using. We've got some web sites on there.

Choice-making. Individuals who come to NIH see NIH as an alternative to what's available, but they come many times because nothing else is available. When we get to the point where perhaps none of the protocols have worked, and there's nothing else available, the desperation level goes up pretty high. We asked, if nothing was available both here as well as

outside, what would you try? It goes way up in terms of what people were willing to try. This is important. We have some responsibility for opening up dialogues with patients and working with them about the best choices for them. It's a critical time in those individuals' lives.

Bioethical forum. We're looking at some of the bioethical issues in the research environment. With patients using alternative medicines, it's another whole issue. We're in phase one and phase two studies of what herbal products are affecting – those are some of the other spin-offs we're working on.

This is my battlefield scene. My boss always says when we're out there doing the clinical work we're really out there on a battlefield. We need to be aware of the communicational, the territorial issues that are typical in organizations. It can be difficult to break in. It's important to look at what happens in the environment. Here an individual says, these herbs really helped my wife's medical problems, and the physician is speaking to the nurse. Many individuals or health professionals are using herbs or acupuncture or whatever. They don't always tell their colleagues. There's some underground kind of discussion going on – well, try this, try that. There's a lot of interest with health professionals, but the environment in the hospital setting doesn't provide that okay-ness to talk about that. Another reason for the survey is to give that okay-ness to talk about such issues.

Courage. Courage is important. Here the physician is telling the nurse, I think I will recommend acupuncture for Mrs. Stacy's pain. To bring that up in a clinical conference, is that okay to do? There are unofficial rules in health organizations. There's so much medical ritual in rounds and clinical, other kind of modalities, that those things don't usually get brought up. It's important for those of us who are in the system, who know about some of the therapies, to speak

up. Acupuncture's real easy to talk about now at NIH with their consensus conference, and we have acupuncturists there.

It's important to be able to speak up and begin to bridge those gaps and say well, try this, maybe that's okay. Here's a clinical case conference going. They're speaking about acupuncture, and this patient, saying I believe this energy center is affecting the thyroid. We had a clinical case conference where we did some of that.

That's a long way to go, and again the primary purpose of NIH is research. Maybe we'll see other kinds of research in the future – the importance again of integrating the health systems. We're seeing that more in the clinical center, particularly for support services for patients. Thank you.

Dr. Moss: We have an unusual situation in that Susan and Sarah are going to have to leave shortly. I'd like to have the questions sent up for Susan and Sarah, and let them answer. Then I'd like to make some commentator remarks. Then we'll do the rest of the questions. I'm supposed to get the questions and screen them. We do this Soviet style here. To Sarah, how did you decide which herbs to feature in your story?

Ms. O'Donnell: That became clear after I started. After I interviewed a number of people, the pattern that emerged centered on the same herbs that got mentioned over and over again by people who were using them. Astragalus came up over and over again as something that seemed to enhance the immune system and help rebuild it during chemotherapy and radiation. Aloe came up specifically for its ability to seemingly help ease mouth sores and other

problems induced by radiation. Green tea came up time and time and time again. It's in trials all over the place as a preventive and now it's in tests as a possible cancer treatment.

Ginseng was mentioned. The biggest group of herbs that were mentioned really were the medicinal mushrooms being used by herbalists and naturopaths and even in some oncologist/herbalist partnerships. Maitake mushroom comes up very often. So those were the herbs that I felt, and there are some tests, or studies – there are Oriental studies. They certainly are not proof. There is no proof as we would accept it that any of these herbs helps, but those were the ones I focused on because those were the ones that came up most often.

Dr. Moss: I guess this is for Susan. Do you examine who paid for or financed the story or research?

Ms. Okie: We do ask who paid for the study. We try to have that in the stories, particularly if it's a drug company or if it's a manufacturer or somebody who has a lot monetarily to gain. Sometimes there can be conflicts of interest on the part of the researchers themselves that are not always revealed, and sometimes those are hard to find out. Some journals have rules about that but they can be difficult to find out.

Dr. Moss: Also for Susan, have you reported on the AMAS test, that's the Antimalignan test for cancer that Dr. Bogoch invented in Boston?

Ms. Okie: No, I'm not sure which test that is. I have seen a recent, either a wire story or a press release, on a generic test for cancer. There was a similar one that I remember reporting

on about 10 years ago that was being investigated either at the NCI or at the Uniformed Services University of the Health Sciences, but I don't know about the one that you're referring to.

Dr. Moss: AMAS was reported in an NCI monograph in 1977, and it's sort of been percolating on the back burner ever since then. Sam Bogoch is the guy.

Ms. Okie: I don't know if that's the same one that I did a story on once. It might be. It was a blood test. It may be the same.

Dr. Moss: For Susan, for the patients who don't have Internet access, how do you decipher for the patient which alternative is appropriate to offer as patient education?

Ms. Okie: The kind of research that Steve was talking about is beyond the scope of what I'm able to do at the newspaper. That's a really good question, because it seems like the Internet resources that he's talking about are of great value to people. We try to put web sites or other types of information increasingly in our stories. We have these resource lists, and we list web sites. But it's hard to say in the absence of the Internet. More and more people who want to find out these things, if they don't have a computer will have to go to the library, will have to go somewhere where they can use the Internet. The kind of detailed information that he's talking about is really beyond the scope of what a newspaper can do.

Dr. Moss: Some of these are very long statements, and I think I should give them to you – they're more statements than they are questions. Somebody asks both Sarah and Susan, what are the best ways to submit information or releases?

Ms. Okie: Don't call. When people call me I usually say, can you send it in the mail, or send me a fax? It's hard to get this kind of stuff straight over the phone, so either a letter or e-mail. The *Post* has an on-line version of the paper, and a lot of the reporters have e-mail addresses. People have taken to sending me e-mail, and that works quite well. But I read the mail, the faxes and the e-mail all myself.

Ms. O'Donnell: I go through my mail every day. That's really the best way for me to get information and decide whether it's something I can use and get back to you.

Dr. Moss: Also for Susan, why have there not been more major articles on alternative medicine versus tamoxifen, angiostatin, etc. Is there an institutional bias at *The Washington Post* or *New York Times*, etc.? Is there an institutional bias in favor of pharmaceuticals as opposed to non-patented ...

Ms. Okie: It's easier, because of the kinds of criteria and training that we use in reporting on treatments, for a drug that's been tested to make it into the paper than it is for an alternative medicine therapy. I'm not trying to defend the stories on the anti-angiogenesis drugs. Those were really premature, and there were no human data. It shouldn't have been on the front page as it was. I am trying to do more on alternative medicine, but I try to find what scientific

studies exist. It's harder to find them in at least U.S. journals than it is to find things on standard drugs or experimental drugs.

Oftentimes the studies are in German, and they're in German journals that we can't get a hold of, and they're articles we can't read when we do get a hold of them. I find that by looking at the studies, I'm having to rely on somebody else's translation or somebody else's survey of the literature. It's more difficult to write what I would consider a reliable news story evaluating the evidence on alternative treatment. It takes a lot more digging. That may be why you don't see as many, but that situation seems to be changing, slowly.

Dr. Moss: I want to thank you for coming, and I know you have some work to do.

Ms. Okie: I'm sorry to have to leave now, but thank you very much.

Dr. Moss: I'm supposed to, as commentator, comment on all of the presentations. It's a little hard, with so many differences between the presentations. Although everything was interesting, we got a little bit off the topic of the session. I know from prior dealings in meetings like this that there are a lot of people who are struggling right now with the question of making decisions.

I'm director of an information service for cancer patients called, with no false modesty, *The Moss Reports*. I would like to review for you some of the ways that I write my reports and how I access information, especially when it comes to alternative therapies. I've never really analyzed this before, so bear with me.

The first thing is, if a person has a diagnosis of cancer, you have to thoroughly understand the strengths and limitations of conventional medicine. It's premature to talk about alternative or complementary treatments until you've understood what the likelihoods of long-term remission are with a conventional approach.

I collect cancer textbooks going back to the 19th century and as recent as this year. They're at my elbow and I use them constantly. Some of them can be over \$200, but you can get these at the library. There's hardly a good library that wouldn't have at least one of them. You can't afford easily the one that's published, probably subsidized by the American Cancer Society, and that's Philip Rubin. It's published by ACS and he's at the University of Rochester. He's a radiologist and has something of a bias towards radiation therapy, but not in a bad way. It's just that you get more of the perspective of a radiologist.

The most famous of the books and the one you're most likely to find in the library is Devita, *Cancer Principles and Practice of Oncology*, fifth edition, 1997, published by Lippincott Raven, and it's very vast. I have found something over 40 errors in the Devita book. Use this with great caution. I've sent these errors to Dr. Devita and to his editor at Lippincott. I also complained directly to a representative of the company a month ago, and was told that they would get back to me with this, and I've gotten no answer. The book is famous, it's used all over the world, people think this is just the greatest thing in cancer. There are many worrisome things. Most of them are typos, but when you get that many typos in a cancer textbook, as Mark Twain said, be careful about reading health books, you can die of a misprint.

There are areas where Devita is wonderful, and the thing that interests me the most, and should interest you the most, is that whether we're talking about remissions, regressions, which are shrinkages of tumors, or increases in overall survival, Devita's actually the best source. It's

not great, it doesn't always have it. Sometimes the curtain slips a little bit and you can get to see the lack of correlation between responses, which, by the way, are legally defined by FDA as shrinkages of 50% or more for one month or more. One month will do for an official remission of cancer.

The best cancer textbook in my opinion is James Holland, *Cancer Medicine*. It's beautifully done, beautifully edited, has color pictures if you need that sort of thing. It's easier to use, easier on the eye. It's well-indexed as opposed to Devita, where you often can't find what you're looking for. Like all the textbooks, you may be disappointed if you have a rare kind of cancer. Oftentimes those are the really difficult situations. The chapter on alternative medicine in Holland is much better in Devita. It's written by Joe Jacobs who's the former director of the Office of Alternative Medicine, whereas the Holland chapter is written by Victor Herbert and Steven Barrett, QuackBusters.

Participant: Remission is not defined as a month. That's response. Remission is the absence of disease.

Dr. Moss: Partial remission or complete?

Participant: PR is not partial remission, that's partial response.

Dr. Moss: I stand corrected. Thank you.

Another good textbook is Haskow. Haskow is more for use of residents. It's not as detailed. The Holland book is an enormous book – two volumes. My recommendation if you

can get it would be to look in the Holland book for a number of reasons. One is to reinforce your own understanding. You can use any medical dictionary. There's also a cancer dictionary by Roberta Altman and Dr. Sarg, which is quite good, quite comprehensive.

I would also look at the PDQ on-line or you can call 1 800 4 Cancer. In general, the best thing to do is read the physician statements in PDQ. Mary Ann Napoli at the Center for Medical Consumers some time ago compared the statement for the lay person with the statement for the physicians. There were big differences, even in the factual data that was given and the interpretations. Things tend to be more sugar-coated in the PDQ statements for the patients. I never even bother to look at them. Go straight for the professional ones. You can interpret these things.

If you need help you can always find people on-line who can help you. You can look at the Cancer Information Service statements, the PDQ, the clinical trial database which is also available on-line through the University of Bonn. The PDQ professional statements are available through the University of Bonn site. Am I right on that? That's how I get them.

Participant: I'm not sure about the University of Bonn. CancerNet has all the PDQ statements. CancerNet also has the NCI's clinical trial database which is very useful, and there is a service for European clinical trials called TelScan, which is also a major resource if you're looking for trials there.

Participant: New Medicine has CD-roms out with everything on everything.

Dr. Moss. This is all free, what we're talking about here. We could talk about the clinical trial database for hours. I have my reservations about clinical trials, and not just to be contrary. The percentage of responses, not remissions, in phase one trials is 5%, and it may not be such a good deal for cancer patients if there are other options. What I find these trials valuable for are the names of the participants. These are some of the most active people involved in research. You may not fit into any of the categories, but you may be able to be treated by those people out of trial.

A lot of what people are looking for often is who are the world experts in a particular field, and you can use the Internet very often to find that. Certainly the people who write the chapters. When I mentioned the names of these textbooks, they're all edited books with multiple authors. The authors are oftentimes, by definition, world experts. If you want to know who's doing the hot work in multiple myeloma, it's a pretty good bet that the people who participate in clinical trials are going to be the ones involved.

MedLine, of course. A few years ago when I wrote *Cancer Therapy*, I spent literally thousands of dollars accessing MedLine through CompuServe. Now it's paradise to be able to go to PubMed and get this stuff for free. I am on and off MedLine all day. It's just like a completely reflexive thing with me. Sometimes I just put it up there and whatever I'm doing, I can always find a reason to go on PubMed. PubMed is a work of genius. It is really one of the greatest things in the universe. PubMed is basically the National Library of Medicine's new search engine for the 9 million articles of MEDLARS, which is MedLine plus a few other databases. There's also CancerLit, which you can get through another site, which is much harder to use, which supplements. But MedLine – do you remember the URL right off the bat of MedLine?

Participant: It's [www.ncbi.nlm.gov](http://www.ncbi.nlm.gov), and it's brilliant.

\* (The URL for PubMed is : <http://www.ncbi.nlm.nih.gov/PubMed/> )

Dr. Moss: It's an amazing program. When I put up my web site, which is, again with no false modesty, [www.ralphmoss.com](http://www.ralphmoss.com), I had 10 search engines and I did comparative reviews of all of them. PubMed hadn't really gotten going quite, but I did realize at that time that PubMed was the best. Now, nobody need bother with any of the others. What you find there is, as I say, nine million articles. Originally this dated from the summer of 1966. They've now predated it and they're now putting in articles.

Participant: Not nine million articles, but nine million citations.

Dr. Moss: Yes, nine million citations. You can find what you're looking for. Generally speaking, if I'm writing about a rare kind of cancer, and I do write a lot of reports on rare cancers, I can search the entire world literature on a very rare cancer and see what has been done. It's just a fabulous, fabulous thing. What I do goes a little bit beyond that. I have the time, not dealing with cancer in the urgency that most patients are dealing with, to contact the scientists. If you find an article that you think is appropriate to your condition you can contact the scientist. Very often the new articles have the e-mail address of the scientist involved. You can track people down.

When it comes to alternative treatments, which are the hardest, of course, to evaluate, in general, the greater the claim, the more critical should be the inquiry. It almost invariably works

out, unfortunately for all of us, that the things that have the fabulous claims are probably the most fraudulent things. I will call the researcher, if there is a researcher, or the company, or I'll certainly e-mail. I mentioned the fact that, for instance, noni juice – two newspapers were claiming cures, one of a stage four person with liver cancer, claimed by a physician. I got the e-mail address of the physician and I e-mailed her and got no reply. Then I wrote a letter and got no reply. Finally the company informed me that this doctor was just too busy to answer her mail.

Participant: It's good for some arthritis.

Dr. Moss: Maybe it is, I don't know. I can only go by the data that's available. If patients claim or are claimed to have benefited from a treatment, I will generally try to track them down. I definitely would suggest that if any of you are considering a treatment based upon an anecdote, that you do your best to track down that anecdote and think logically whether or not, aside from the wishful thinking, there's really any objective basis to believe that that person was "cured" by that treatment. Sad to say, most of these things evaporate, fall apart in your hands as you look at them.

The first problem is that people sometimes don't have cancer, although that's much rarer than it used to be. Most people do present with biopsy-confirmed cancers. In the past, they often didn't. But you usually can find mitigating explanations for why the person is in remission. It's very common for people to mistake a secondary prevention effect for a curative effect. In other words, they had an operation for their tumor. They may have been told by somebody that they had a great chance of it recurring. They did X, Y or Z, and now the cancer

hasn't returned. This gets very mixed in with things that Herb Benson was talking about, the so-called placebo. We don't want to put a nocebo on somebody who thinks they're doing well.

And on the other hand, we don't want to mislead people either, or mislead ourselves.

You have to take a hard cold look. The fact that this kind of critical evaluation has been abused doesn't justify not having it. I love the remark you made about the appropriate level of skepticism. I think that's brilliant, because we've got the professional skeptics on the one hand, who are down on everything, and we've got the professional promoters, who, as I say, there's not a cloud in the blue skies of noni-dom. You can be sure, in the Polynesian sky, it's like a Claritin ad.

The truth doesn't necessarily fall somewhere in the middle, either, because there are things out there that probably have zero value to people, and then there are a few that probably do have value. I did track down, for instance, the bovine cartilage, and did come across a couple of cases that Dr. Prudden gave me the names of. Based on the records that he sent me and my conversations with him and my general assessment of not only Dr. Prudden but of this man, I think this man was put into long-term remission of pancreatic cancer.

He had an 8.8 centimeter recurrence of pancreatic cancer and only did bovine cartilage. I know he's well. I called him and he called me back. He's been on trips to Russia and to China, and he only did bovine. Now that impressed me. It's one case, and I can't say that I did the kind of intensive investigation that Gar and Christine Hildenbrand did on the Gerson cases. I didn't send the man's slides to the Armed Forces Institute of Pathology. I don't have the capacity to do that. But I can get within a 95% likelihood of truth or falsehood on most of these things. Not everything is negative, and not everything turns out. Whether I can accept John Prudden's figures for the percentage of people who were so impacted in his study I don't know. But it's in

that file that's not the garbage file, and it's not the proven file. It's the "why don't we look into this some more" file. If I had pancreatic cancer, I might do bovine cartilage.

I go to doctors' offices look at their records. Nick Gonzalez and I have sort of a standing six-monthly date to go over records. I go in and he provides me with file after file. I'm not in the business of compiling statistical data on patient records. But if I see numerous cases of people who are living dramatically longer than the SEER data would indicate they're likely to live, it becomes a cumulative thing. I can see long-term survivors with dire illnesses, who should have been dead. It cumulatively creates an impression.

The fact that I can get to see data, even though it's not published, is impressive. I went to Germany and Switzerland last year, and I went to visit the Lucas Clinic in Switzerland. They took me into a room and there was a file on every patient treated at the Lucas Clinic since 1949. There were little cards, with indications of what the diagnosis was, with typical sort of cuckoo clock precision, and follow-ups – when they made the phone calls, and what the status was. I'm impressed. That shows that there is some thought being given to the general picture of accountability.

On the other hand, when I read a magazine article that a magnet will cure 50% of people with cancer, but I call up and they tell me, if you come down here, maybe we'll talk to you, maybe we won't. Or they say we're not going to give you the names of patients. We have to see whether we like what you're doing.

The noni people said we don't care to have an article written about noni and cancer right now. When I said I don't need your permission to write it, and I don't want anything from you, the man was absolutely shocked and said, that's a breath of fresh air. You're the first reporter who has not asked for money for writing an article about us.

I become a little bit suspicious, and I think suspicion is a good thing. The appropriate level of skepticism is what we all have to develop. It's hard, because if you're a patient, or you're the loved one of a patient, you're turning to alternative medicine because it's hope. It's a hope either that it's going to cure you when your doctor has told you it's incurable, or that it's going to lead to avoiding the harsh treatments.

Okay folks, I'm sorry to take up so much of your time, but I think maybe this is useful.