

## Health Information: Thorough, Fast, Free and Honest is Not Enough

### 2007 Miles Conrad Lecture

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#### Abstract:

The Web and sophisticated search engines are radically changing information seeking behavior. And the National Library of Medicine (NLM) has been responsive to the changing environment. Since 1997, NLM has added patients, families and the general public to its user base. As a result NLM has created databases specifically for the public and heavy usage of these services has demonstrated to us that there is an essential role for unbiased, agency-provided health information. The U.S. role in hosting the worldwide Human Genome data deposit exemplifies this remarkably effective curatorial function. The waves of new and yet newer genetic sequences and molecular data are arranged to replace and refine each other rather than to contradict.

In response to Acts of Congress followed by actions of editors of medical journals, NLM implemented CLinicalTrials.Gov for the proper registration of clinical trials prior to patient recruiting. NIH and NLM are now being urged to report the results of clinical trials as well as to explain these matters to the public at large. Almost untouched by all information providers are the looming questions: do users actually understand what we say? Do users use the information they understand? If people learn in different ways, what is the alternative to lots of words on radiant screens? And how should libraries behave if the people come not to trust establishment figures -- or even their government. To date, NLM has been responsible and innovative. But new and great accomplishments are expected -- and lie ahead.

#### \*\*\*Transcript\*\*\*

Ladies and Gentleman, I'm very pleased to have been chosen as this years Miles Conrad Lecturer. I know the award means alot to you and to the field. I'm duly impressed and grateful. I'm not much of a lecturer, so I'm providing a sharp contrast with my predecessor. Enormously grateful to have been associated with the National Library of Medicine since 1984 and I should note that these are accomplishments of NLM the institution and the wonderful people of NLM, not mine. Backed by the tax base that you all provide. When I joined the NLM in 1984, it was just before they would be celebrating their Sesquecentennial celebration (150 years in 1986) so I knew they'd gotten along without me very well for 148 years. My job was to see that it didn't get worse and maybe got better and get started with some planning initiatives. I agree with the previous speaker -- planning is the cheapest thing institutions do and perhaps the most powerful.

I don't hesitate to say that NLM is the best source of biomedical information, at least for most people. Free to all -- No advertisements, no products, no politics

What do we do? A number of things --- these are the projects that NLM has launched;

--Medline designed for use by doctors and scientists

<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?DB=pubmed>

--Entrez for genomics researchers best in the world. It's a life sciences search engine.

<http://www.ncbi.nlm.nih.gov/Entrez/index.html>

--Medline Plus, for patients family and the public.

<http://medlineplus.gov/>

--Genetics Home Reference Project

<http://ghr.nlm.nih.gov/> This was designed for support of information needs of someone with family members with a genetic disease. Those can be pretty demanding and pretty well-informed patients or laypersons. I first encountered this type of patient when dealing with mothers of hemophiliacs in Missouri. They know alot about clotting, they know alot more than most doctors, and they know how to get the right tests for their kids.

--Toxtown

<http://toxtown.nlm.nih.gov/> This was launched from the division of Toxicology and Environmental Health; playful program meant to get children interested in problems of toxicology. If you don't know chemistry, it's difficult to understand toxicology. Most doctors have forgotten what they once knew

about chemistry so they're not a big help either. The playful approach, almost a cartooning approach has gone over quite well with elementary school and middle school student populations. A new element will be the Toxtown Mystery that they will like even better.

We have gotten into the area of specialized information services that we've created for special populations. These really amazed me.

\* Arctic Health - <http://www.arctichealth.org/>; 8 countries with populations in the Arctic of which we're one. They have special needs. This was very popular.

\* Native American <http://americanindianhealth.nlm.nih.gov/> - because that population said to us, "we want one of these."

\* Asian American - <http://asianamericanhealth.nlm.nih.gov/> They said, "We want one of these." I thought that was really pretty amazing because I grew up in the Melting Point generation. My grandparents came from Sweden, threw away old language, got as American as possible as fast as possible, but we have a different society now. These info sources are pretty well used and well respected, pretty appreciated too.

A little history of NLM; we began in 1836 under the auspices of the Department of the Army with the mission of providing medical books for officers. 1879, the NLM created Index Medicus, the index for biomedical literature of the world at a time when the US did precious little of those scientific discoveries and progress. Nowadays, we are primarily serving physicians, healthcare professionals, and scientists. In 2005 Barry Marshall, clinical researcher, and Robin Warren, microbiologist, Nobel Prizewinners attributed their success to the National Library of Medicine; Marshall said that access to the literature was essential to this discovery. Dr. Marshall worked about a thousand miles outside of Perth. These two guys out in the sticks discovered that inflammation in the stomach (gastritis) as well as ulceration of the stomach or duodenum (peptic ulcer disease) is the result of an infection of the stomach caused by the bacterium *Helicobacter pylori*. All of our conventional wisdom about gastritis was untrue and that was a shock to all us healthcare professionals who knew about sippy diets and anxiety produces ulcers. I tell this to my medical students that there are still important discoveries to be made, library based discovery; a whole lot of discoveries still waiting.

Other progress coming from that same sort of basic clinical research, I'll just touch upon a few. We now have newborn screening for several hundred conditions in 39 states. Risk factor have been determined for BRCA1 and 2 regarding cancer of the breast and ovaries. Those are important discoveries and really do help people & guide therapies. Treatment selection for cancer of the breast - whether or not it is susceptible to estrogen; has estrogen receptors and in the case of Warfarin again back to the anti-coagulation studies of years ago, we can now tell, based on the genetic condition of the patient, we can now smooth out the Warfarin therapy because it is very easy to either under-coagulate or over-coagulate these patients. So those are just examples of the payoffs, if you will, of the research.

Since 1997, NLM has transitioned to developing services aimed at patients, their families and the public. Might say that was plaguery late in the game for you guys to wake up but of course, you know, libraries are not there to serve librarians. Libraries are always in outreach mode, but the fact is that we had no money to do outreach at all. We just didn't.

In 1989, Bill Nasher, Chairman of the House Appropriations committee, gave me him six million dollars to use for outreach; to spend on under-served populations and that was how it started. Every time I was up before the committee to testify, he would ask me, he would ask "Doctor, what did you do with that six million dollars?" which I thought was great. That's exactly what he should be doing. Kent Smith had me prepared; I had every dime accounted for. So it has increased but not as much as it should.

IN '97 things started to happen; it was a real major transition for us. The transition owes much to the strong encouragement and support of the US Congress. But I should say that was preceded by formation of the NLM long range plan by NLM users and advisors (1985, 2006). That's a twenty-year plan so we updated it in 2006. Ideas incorporated into the long range plan were strong defended by the NLM Board of Regents. Some of that transition was fun.

[ video clip]

8 million documents; introducing Grateful Med; Dr. William Frist - searched for his own articles. Arlen Spector - I'm delighted to see that the Superhighway of Medical Information will now become a free one.

"Starting today, the National Library of Medicine will be making housecalls "on the house".

Gore -- I daresay that this Development by itself may do more to reform and improve the quality of health care in the US than anything else we've done in a long time.

That first episode with Sen Frist was essentially getting the endorsement of the Congress to allow this medical stuff to go up on the Internet; that wasn't allowed to begin with --that was supposed to be for the physics research and stuff. That was a big help for us because that essentially eliminated 13/14ths of our cost. This internet is not just a political slogan -- it's the best communication system the poor old planet had ever had. So we were very eager/grateful to get there and he was a big help to us.

The interviews with Arlen Spector and with Tom Harkin were tremendously helpful. What we wanted there was we wanted them to understand that we were going to be offering these services for free -- without a fee-- whereas for twenty odd years we had been under an injunction from the Appropriations Committee and the OMB to charge for that, again and we had carefully accounted for that

[video clip]

"flu shot" should I get a flu shot? That's not gonna' work. term "should" was not found. Look we've got a good query right here. Let's Search on vaccination against influenza in elderly persons. [end of clip]

What's happened since those days, which were really not so long ago? Two things have changed worth discussing

1. Shift in the way that Biomedical research was conducted, published and shared on the Internet
2. Major shift has occurred -- not so hot! We now assume that patients have access to medical information relevant to their care. That's a new thing. I'm not always sure that it's always the case or that it's always good, I do know that you can't go backwards.

Let's start with the first topic, the shift in biomedical research

PubMed ( <http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?DB=pubmed>) provides Access to the Medline File; 16.9 million articles, approximately 5500 journals (52% of which are non-U.S -- about the way it has been for decades)

[Reads from slide]

Direct links to full text of approximately 5200 journals; linking and special services.

PubMed Central has 908 K articles -- that is almost a million -- from approximately 308 journals given by the publishers and authors.

About 4% are actually submitted a la NIH scheme so individuals are still somewhat recalcitrant. The advanced people are kind of seeing a new way.

So again there was this shift. The GenBank and Human Genome projects led the way. Jim Watson made everyone agree in that Bermuda meeting that all the data would be deposited and available within 48 hours - totally and completely, openly and free. That made all the difference in progress of the Human Genome. So we keep most of that now. People were scared of that initially. They told us "Don't you know that there are 53 Billion nucleotides. What'll ever happen to that? You can't handle it." and of course we can. Project has grown enormously to include more than human species.

Reads slide:

Genbank and Entrez databases  
-- 157 B nucleotides; 87M sequences; 155,833 species  
Densely cross-linked and links to external files  
Heavily curated Heavily used  
Almost perfectly international and cross-cultural

If I had time, I would take it out and show you. It is quite realistic to take out those molecules and spin 'em around. Look at them from different points of view and extract them from larger proteins. It's done all the time. Online. Free. So again, this shift -- I mean that was the big deal.

Most recently NIH/NLM developed a road map and the top priority project on roadmap coming out of that retreat, out of 45 projects, voted by every single institute there including ours, was this Molecular Library / Small Molecule Database. NLM is part of it. I'll talk more about that but I also want to note this congressional and publisher requirement for clinical trials is another kind of aspect of this shift to the new way of doing biomedical business, this sharing of this data in a public fashion

#### Molecular Library/ Small Molecule Database

Started out with 500,000 molecules that had been tested against cancer (NCI) and about 350,000 that were part of the toxicology and environmental health collection at NLM -- so that was about 850,000 molecules and the plan was to take ones that were produced in the physiological and medical aspects tested in laboratories that had been awarded contracts by NIH and that is being done. But of course it takes time for that stuff to come in so in the meantime we found that we had something like 13 million small molecules donated to us by more than 50 commercial and scientific organizations in the private sector, selling information services. They can see the benefit of donating these molecules to a public source so everyone can get at them and they can get at them. They can take advantage of these programs like the ones that spin molecules and also their customers can buy them. So that turned out to be a pretty good success.

Now about the Clinical Trials.Gov - basically the FDA made that a requirement (video of Collins?) we undertook this Registry because we required to do so by the FDA  
Human genome project completed -- sharing of data promptly. Human Genome Sequencing Consortium 16 laboratories in six countries delivered on the promises. Bold and audacious. That set the pace. It is impossible to imagine that accomplishment without sharing the data promptly.

So I was speaking about the molecular library and got a little bit ahead of my slides. And I underestimated the number of molecules -- really 15.6 million molecules submitted by commercial sector. Vast majority of the molecules contributed without us spending a dime. That's including Elsevier. We have arm wrestles with them periodically but they came to us and said "We think this is a good idea. We have a molecular database; we'd like to pitch it in." And I'm glad.

So now the second part of that change is the healthcare problem. They kind of assume that patients are gonna be able to look after themselves to an extent that I don't think is entirely realistic but that's happened anyway. I think there is an area where libraries and information centers are definitely part of an answer. So PubMed gives free access to high quality bio-medical scientific information to doctors, scientists and also the public. The special information services fill a very particular need; and I am thinking here about that Genetic Home reference Project. But in the end, these files get very very heavy use. More than 750,000,000 searches in a year! Nearly a billion in fact -- A number that we would not have thought we could support technically even five years ago.

Endorsement (self-endorsement I should say)- [clip] unprecedented medical discovery. taking charge of our health care. problem is volume of information can be overwhelming. Search on term, "diabetes". It returns so many hits, millions and millions, only a small percentage of which are reliable. [end clip]

That is the Google phenomenon, but it's not enough. It still doesn't answer the question of what's the best thing to do about Uncle John's diabetes. It is useful; I use it myself but we have to do better.

So these special information services we've developed fulfill a very particular need. [For this segment, Lindberg was walking attendees through available menu options at MedlinePlus.gov]

Developed Special information services (goes to live demo of web site options at NLM)

--Clinical trials.gov - I'll go into this more in a bit.<http://www.clinicaltrials.gov/>

--NIH Senior Health ( <http://nihseniorhealth.gov/>); We did this in conjunction with the Aging Institute. Older people experience trouble with their neurological systems, trouble with cancer. We need to do something like this with all of our Institutes.

Again, that Genetics Home Reference tool <http://ghr.nlm.nih.gov/>; excellent reference tool.

Interactive tutorials -- that's an important thing I should draw your attention to. Tiny portion of one; came from this point of view. Medline Plus is done by librarians, it is very good but it is still the old mental model of retrieval & delivery. It requires medical expertise (scientists and doctors) but that simply isn't the way patients and families think at all. So this provides tutorials done in a deliberate explanatory manner.

Patients and families have different requirements; uses proper pedagogical approach, a Q&A process; you have to get the right answer in order to move forward in the tutorial. About 175 of these things. We've received positive feedback from practitioners; they're not trained in patient education, they have no time to do this properly. In fact, the point at which you deliver a negative diagnosis is not a good teachable moment. Patients benefit from going through this kind of learning activity at their own pace at a later point. I'm very keen on that. Introduced Spanish language translations.

Trying to decide where to go next with this. Appreciate your advice on this. Many have suggested perhaps Chinese? I guess the city of New York might want that; there's more than one slant on Chinese too

Online Surgical Operations -- I thought this one was nuts; why would a patient want to see an operation? but patients want to be able to watch the surgical procedure in the operating room. They love it -- we have people who want to provide it. (note [not part of transcribed comments]: may want to include a reference to an example video such as that for rhinoplasty (Nasal valve reconstruction); MedlinePlus offers an hour long video documenting such a surgery done at the Univ. of Maryland.)

Toxtown --- again, its hard to get over the barrier of not being chemists.

Household Products (database) - <http://hpd.nlm.nih.gov/> interesting and very useful; you'd be amazed at what's under people's sinks and in their garage.

In an effort to respond to what we know is half the population -- those w/o Internet Access, half the population,-- we made a good partnership with the public libraries of the country with whatever medical library back up they wish. Big Success. Between the two of them, we now have the GoLocal Project <http://www.nlm.nih.gov/medlineplus/golocal.html> where let's say in the case of the flu shot example, you've decided okay, I'm going to get a flu shot, the next obvious question is -- okay, so where do I go to get it? That's where GoLocal comes in because there's no way in Bethesda Maryland where we are that we can tell you "okay, up there in Philadelphia, around the corner is a Gristede's or a Safeway where you can get the shot." You have to get that knowledge locally. And we also invested some grant money in Consumer's Union to get drug pricing information that's useful to patients. (see Daily Med at:<http://dailymed.nlm.nih.gov/dailymed/about.cfm>; NOTE: I can't be sure that this is the same one he was discussing, but it was the only drug resource I found at NLM's site.)

Clinical Trials.Gov

In 1997, Congress got tired of simply asking NIH to do something about making information about trials available to their constituents about clinical trials; it was hard for the patients, no good way to find it, they simply couldn't find it. So they said to the commissioner of the FDA, the director of NIH, the director of NLM, shall make a database (they didn't know what else to call it) that registers these clinical trials. It was headed by Alexa McCray, Director of Lister Hill. She accepted this challenge and inside of eighteen months she had something up and running. But previous to that, nobody at NIH even knew how many clinical trials there were. We obviously started collecting information on NIH trials first on the principle of "clean up your own backyard first before you complain about the neighbor's grass" but we had some trouble doing it. She did a nice job; she and her collaborators; point and click and get more detailed information -- you could tell when a trial is completed or if they

were recruiting for it. [screen shot of interface] Even better, when a paper was published about that trial, you could look here down at the lower right hand corner and see the number of the clinical trial registry and you could look it up, navigate in both directions. So it was all going along well until a string of calamitous news stories came out. You may remember this Paxil story -- the assertion was that drug co reported the good results for the drug as an anti-depressant for adult patients and denied or suppressed the bad results of being suicidal in children. Don't know if it was true or not but the CEO lost his job. This was followed by Vioxx, from the Merck company, a perfectly marvelous drug for arthritis but it had side effects also so that resulted in another resignation. And there were a lot of articles and news stories essentially saying "y'know what's going on here? who do we trust?"

And into the fray comes Cathy DiAngelis, JAMA Editor-In-Chief, and Jeff Drazen, the editor-in-chief of the New England Journal of Medicine, and twelve other smaller but equally fine journals united in an informal association (the ICMJE -- International Council of Medical Journal Editors) and they issued simultaneously an editorial statement saying we're tired of being used in this fashion. Not going to go on with it and unless you guys register those trials ahead of time before you initiate a study or approve a patient, we will not publish the results when you come to report it. And of course, this shocker here is that in all of my professional career, publication is greatly to be desired and you do the work, the research, and you write it up carefully. Somebody would say don't forget copies to the mother and the wife and stick on your CV - it'll brighten it up. But that's not the kind of papers we're talking about; a paper which says a drug has a good effect on depression is a billion dollar paper if you can get into JAMA or the New England Journal. That's the problem we're looking at, so this had a very salubrious effect. When that carrot broke, the writers of these papers and the sponsors of such research said, "Holy moley, we'd better get into this clinicaltrials.gov thing or we're just not going to have any outlet for the work, the papers." so it was a pretty courageous thing for these editors to do because they compete heavily for these papers and the work could have gone to a non-participating journal. [graph illustrating the dramatic rise in the registrations filed with CT.gov; filings just under 15,000 in 2005 shoots up to more than 30,000 filings by second quarter of 2006]

What's the new, new thing in biomedicine?

Genetics and Genomics -

Slide belongs to Francis Collins, Director of the National Human Genome Research Institute; he discovered the gene for cystic fibrosis almost 20 years ago, long before he came to NIH, at the University of Michigan. Still is no cure for the disease. Essentially he was saying the following:

Cystic Fibrosis; mostly genetic but some environmental components

Cardio-vascular; both strongly genetic \*and\* environmental

Same with HIV/AIDS - It's not necessarily just an infectious disease. There are people who don't get AIDS regardless of behavior so there is a genetic element. Even with the virus present in their system, some people just don't get the disease

Collins is doing a fine job working towards a law to protect people against the misuse of this genetic data. And he's recommending that all of us register the history of our families.

What is really new then is the whole genome analysis. So what do we do then? The current idea, the current thinking is to do a series of large observational studies of normal populations. Not interventional, Strictly long-term observational data gathering. 20 years in length with hundreds of thousands of participants.

Then add to the regular medical record that genetic data - combine those two sets and so they use the term Phenome for this. For the first time ever, the clinical record (the identifiable patient data) will be coming to the National Library of Medicine. Up until now, sort of deliberately and proudly and wisely, we've never had this. Never had this before and now we have to do this. Best example of why and easiest to understand is the Framingham Mass Study.

Framingham Mass Study (1947)

Studied primary artery disease in normal adult populations  
identified risk factors

"This project is designed to study the expression of coronary artery disease in a normal or unselected population and to determine the factors predisposing to the development of the disease through clinical and laboratory examination and long term follow up of such a group"  
-- Gilcin Meadors 1947

This is a remarkable study; the most famous one of its kind in the world. Most everything we know about coronary artery disease we know on the basis of this Framingham study. This started just after World War II in the early '50's. Increasing epidemic rate of deaths attributed to coronary heart disease and it didn't turn and start going down until this study had identified the risk factors. Importance of this study. Graph shows peak in coronary heart disease in late '60's and decline in the number of deaths since those factors have been identified.

Now, three generations of women and men involved in on-going examination; multiple phenotypic markers obtained at the same age within a family and measurements over decades; DNA samples from 9000 participants

This wonderful population is volunteering to such an extent that the sponsors, the National Heart Institute (now the National Heart, Lung, and Blood Institute, or NHLBI) are scrambling to find funding to do the genetic testing. I think we'll learn a lot.

A similar project is "The Sister Study" for women who have sisters who have had breast cancer. Started by the NCI. One gets cancer and one didn't; closest relative you have is a blood sibling. The obvious question, then, must be why one and not the other? We want to look at that data. Kind of a new world.

Now I want to step away from NLM and its primary mission; its primary mission is to "collect, organize, and make available biomedical science information to the world for the benefit of public health". We do this well, but there's something else to be explored.

Getting good medical and/or health care has become more difficult recently, as well as more expensive. Certainly it is the case, often for individuals, the best decision for personal health care may be different from - or even at odds with - the best public policy for the whole population. The questions keep changing so answers can't remain the same

A 1999 report from the Institute of Medicine To Err is Human drew attention to the relatively high number of medical errors in patient care over the course of a year. Bottom line of the study was to say that this is not due to terrible people; it's a system failure. Systems are what we're all involved in. So that's part of what patients are concerned about now.

What proposed solutions are there? What ideas do we have? Well

- Certainly developing and disseminating scientific information for patients, families and the public.
- Development of Electronic Health Record for all and a full copy for the patient; that's my idea.

For what reason? What are the areas in question?

Obesity & Diabetes  
Heart attack alerts & stents  
PSA & prostate cancer care  
Human genome knowledge & impact on health and living style  
Drug ads vs. clinical trial results  
Medicare Part D prescription drug "benefit"

Specifically, we're information people. What is the information that needs to be conveyed? I would say much more specific information than is being made available in publications. That's the problem.

Example: Diabetics should have their HbA1C tested every 6 months and retinas examined every 12 months. Flat out. That's it. Every patient with diabetes should know this. There is no point in putting

this out in JAMA or in the NEJM; the patient should know that. They should be able to go to the hospital and say "This says here that I should have this tested every six months and now it's been eight months. Why don't I have it?" We have to look out for ourselves nowadays, at least to that extent.

Persons being anti-coagulated to prevent blood clots, etc. should have abnormally prolonged prothrombin time tests -- normal isn't a good score. I've seen educated intelligent people die because they couldn't understand that normal was the opposite of what was necessary. The drug should be prolonging the effect.

Another thing, what do we do when we get a test result that seems to show a negative result (some fatal disease?) One action to consider if any lab test shows up like that is to repeat the test, possibly at another lab. Get a second opinion.

Prescription medications can seriously interact with over the counter drugs; over the counter drugs or some of these supplements can counteract effects of a prescription drug. You must tell your physician of all the medications that you are taking.

So Telegraphic summary of these efforts:

? Electronic patient records - May exist at the individual institutional level but they don't hook up to a national system. 95% of the problem is social; only 5% is technical. Really not a major computational issue.

? For us, we're getting rave reviews for NLM's information services, but I have to wonder can we be certain the patients are actually benefiting?

Let me just go through a few questions along that line. So why might good health information not result in healthy behavior?

Imperfectibility of Mankind

Weight reduction club meeting for lunch (photo not part of PDF file, but it got a laugh from the audience)

Can't find relevant information

-- Gastro-esophageal disease (when what they really are looking for is heartburn). Daily treatments may vary in cost from .79 cents to \$8.00. Does it matter? Well, some people may figure on someone else's dime, not a problem. Others think "I'm not going to spend \$8.00 for .79 cents worth of relief. " Can't comprehend it when found.

Assessing health literacy, while a popular term, is pretty darn tough to do. The issue is not just one of vocabulary. Not just an instance of getting the terminology down to 5th grade, 6th grade or 8th grade at all. I know lots of educated, intelligent people who really don't know what's under their skin and need an explanation. Improves their understanding

Quotes study by Williams MV et al. Inadequate functional health literacy among patients at two public hospitals. (JAMA 1995)

-- 42% could not understand taking medications on an empty stomach

-- 26% could not understand the information on an appointment slip

-- 60% could not understand a standard informed consent form

Here's an informed consent form. It's essentially lengthy, legal gobbledegook, tough to understand. Here's something that's been rewritten; it's a little better. (both quoted forms taken from Doak LG et al., Strategies to improve cancer education materials. Patient Education 1996)

I'm afraid most patients really - has anyone here ever had to sign one of these things? You're cold, you're scared, they've taken your glasses away - well most people just sign it.

Difficult to identify reliable information sources; that's another problem.

Didn't subscribe to the treatment path; weren't permitted to participate in the decision-making regarding treatment. [Slide displays JAMA article (January 2007) on study done in Senegal. Quote

from screen: Poor adherence to treatment remains a major obstacle to efficient tuberculosis control in developing countries. Innovative strategies to improve access and adherence to treatment are needed. Note: Lindberg did not read this aloud; just paraphrased it.]

You may think this is irrelevant since it has to do with TB treatment in Senegal on the West Coast of Africa. But it has relevance and importance for all of us. There's a thing called DOT (directly observed therapy) we know from Boston studies that if the visiting nurse watches you take the drugs, then we know you really got them. If you just hand the patient the bottle, you may not know. So in Africa the same story. But they did a modification in this African setting, they said "We'd like you to name a friend, name a family member, and they will be ones who watch you take this stuff. We'll give the drugs to them. And that made all the difference. They got a much higher rate of compliance when the patient was allowed to exert just that little amount of control over the treatment process and participate in the decision-making to that extent.

The patient understood the words but did not get the picture.

--Nobody can teach you how to properly do an exercise from a book; you have to physically show it to them.

Need to address the different ways people learn & understand.

--We don't cater to that very well, even with our computers and we probably could and should. Need to cater to people with different learning styles I'll give you an example from a guy named Tom West, author of *In the Mind's Eye: Visual Thinkers, Gifted People with Dyslexia and Other Learning Difficulties, Computer Images and the Ironies of Creativity*. These are some of the people he writes about - Faraday, Maxwell, Einstein, Poincare, Edison, Tesla, da Vinci. Da Vinci with his mirror writing? These were people who had a lot of trouble learning and remembering and reading. Einstein, I am charmed to discover, had to have his sister do his arithmetic for him. That was my trouble, I didn't have a sister. Albert could do the tough stuff but he couldn't do the arithmetic. Anyway, there are different ways to learn, we probably should be having our computers catering more to those methods. Build a connection between visual learners and biomedical publications. One way might be interactive publications. You have an article in *American Journal of Cardiology*. It's static, all printed text on paper. But what you really want to see is the echocardiography; you want to point and click. Here's a bunch of charts and plots. Here are lines, here are square markers. I want to be able to click on the outliers and see the data! That's what I should be able to do. Here's an article about EKGs and arrhythmia; I want to see a rhythm strip, listen to it. That's the kind of publication we really want.

[video clip of unidentified dean of garbled named medical school explaining appropriate use of asthmatic medication and delivery devices ] If it's sufficiently important to patient education that we have the Dean of the medical school showing how to do this properly - it can be canned, it can be interactive, it can be from the journal -but there's sufficient room for improvement. We've got to get these kinds of patient education tools in place.

Thank you for your attention.

Question-And-Answer Period

Linda Beebe (LB): I'm staggered how far we've come and by how far we have yet to go.

I think I heard you say that we have this issue with basic literacy, we have an issue with medical literacy and we have a problem with computer literacy because that's the way many people will get their information. On the other hand, we have all this legalese stuff that gets in the way, like informed consent - and little recognition of people as human beings. So what do we do?

Lindberg: Yes, yes. Well, I am amazed at how dead and lifeless a journal page is. I love books but you look at a journal - it just sits there and doesn't \*do\* anything. There have to be ways of getting more information out of them via point and click. Particularly since the information already exists and there needs to be sharing of this information. Hard to do that; the University of California is experimenting with something that may show the way. But if it helps people learn and remember longer... So we have to find a way to deliver journals in ways that are useful and that will pay for themselves.

LB: so are the young doctors that you're seeing, rebelling against staid journals.

Lindberg: They're rebelling against insurance companies that won't pay for medical care for their patients.

LB: Well that's a good thing to rebel against.

Lindberg: They enter med school a good deal more idealistic than when they depart. I hate to see it but...

Question: Do you have any information on how receptive physicians are to a more informed patient?

Lindberg: Yeah, the question is how do physicians react to patients waving a lot of Medline reprints. I would say, there's a little bit of an age thing but the majority recognize that the better informed the patient is, the better the treatment will go. Most appreciate that those are the good patients, not the bad ones.