I'm honoured to be able to speak in front of so distinguished a group.

It isn't often that a patient has the opportunity to get up in front of an audience of oncologists and make a diagnosis of what's ailing them. While I know most of what you will be learning at this conference is about the scientific advances your counterparts all over the world are making in the treatment of cancer, I am glad that the issue of communication with the patient is also on the agenda here.

And the issue of communicating with patients has never been more important. The Internet is revolutionising the dissemination of medical information at the same time that advances in cancer research and treatment are moving so rapidly that there really is talk about a cure for cancer in sight in the next decade.

At no time in medical history has the cancer patient had more reason for hope — and more information at their fingertips. This is both a good and a bad thing: the Internet has opened the floodgates of a medical information revolution at a time when the pure science of medicine is advancing at such an astonishing rate that many doctors have to scramble to keep up with it. For an oncologist, this must be a particularly trying time, for their patients are suddenly aware of new treatments that the doctors themselves are only just learning about.

In the past, oncology to most patients was a medical mystery, shrouded in secrecy and discussed only in arcane medical journals; today a patient need only log on to the World Wide Web to get access to medical meeting abstracts, medical journals, and new sites like oncology.com devoted to the cancer patient. Cancer is big news in the traditional media now too, as the TV networks and magazines are covering cancer breakthroughs as front page, cover-story news. The problem is that there is almost too much information, and people need to be made to understand that just because a new treatment worked on two lab rats in California does not mean it will soon be available at their local hospital.

Nine years ago, I learned about this first hand when I was diagnosed with Chronic Myelogenous Leukaemia, which you know as CML. My immediate instinct was to learn everything I could about this disease that was threatening to kill me so I could figure out how to stop it. Of course I was going to rely on my oncologists and on the experts in bone marrow transplantation — there was never any question of that. But I knew that I had to be actively involved, to be my own advocate, to make the decisions about who was the best doctor for me, what was the best hospital, and which of several treatment options was my best hope.

I had to educate myself from Ground Zero — complete ignorance. One day I wasn't even sure what leukaemia was or what the bone marrow had to do with the production of blood cells. There were difficult decisions to be made, such as whether to get transplanted with T-cell-depleted marrow.

Within weeks I was an avid student of the human immune system and transplantation biology.

Remember that nine years ago there was no widespread Internet access. So information was much harder to come by. Because I was trained as a journalist, digging up facts and statistics came easily to me, and I was able to use the resources of my newspaper, The Wall Street Journal, to find articles and information about leukaemia. My mother was a nurse trained in oncology and I was lucky to have a friend with a doctorate in biomedical research that had access to Medline, the online database of the National Institutes of Health. So I had some very good help.

The problem I encountered initially was that the doctors at my local cancer hospital simply weren't prepared to handle a patient with tough questions and a critical eye on their results. I found what I still believe to be a shocking unwillingness to acknowledge that a patient might actually have done some homework and have some tough, intelligent, pointed questions to ask about their success rate in treating patients. Fortunately, I had the means and
the time to pursue my investigation until I found a doctor who was willing to answer my questions and a hospital whose results made me confident enough to travel 3000 miles from home for a bone marrow transplant.

I was treated at the Fred Hutchinson Cancer Research Center in Seattle, Washington. As you all know the pioneering work done there earned Don Thomas and his team a Nobel Prize. My doctor was a part of Dr. Thomas’ team, Dr. Rainer Storb, who is a native of Germany. To me the most impressive thing about Dr. Storb was his willingness and even his eagerness to engage in a dialogue with a patient.

It made all the difference in the world to be able to have an intelligent conversation, to discuss the statistics and how they might apply to my case, and not to be treated with the condescension and impatience I had encountered at the other hospital.

I wrote a book about my experience in an effort to help other patients navigate through what I call “the netherworld of medicine”. I hoped that doctors would read the book as well to see things from the other side. But I also have some perspective on what it must feel like from a doctor’s point of view to have patients come in for a consultation and waste what seems like valuable time with too many irrelevant questions. Sometimes now when I see Dr. Storb he tells me he has to spend far too much time in the clinical coordinator’s office with new patients who have read my book and want to ask too many questions.

I am sure that as a busy, stressed-out oncologist, it must seem like your worst nightmare to be confronted with patients bearing stacks of printouts from the Internet. For every intelligent, analytical patient who has really studied the relevant material and is up on what the key issues for them are, there may be a dozen more who don’t meet that criteria and are misinformed by their own research efforts.

But the fact is that this medical information revolution is a tide that cannot be turned back. The Internet is not going away, but the good news is it is getting better all the time. There are some wonderful Web sites put together by the government, by great hospitals and universities and by patients themselves.

You probably already use the Web yourself; many of your hospitals will be moving to some Web-based practice management programs in the future if they haven’t already. If you read the Journal of the American Medical Association or the New England Journal of Medicine you have already seen articles talking about the pros and cons of Internet medical information. One thing many agree on: the Internet makes it possible for the democratic dissemination of medical information so it isn’t just for the privileged few. I was lucky to have smart educated friends and access to the best care. But I can honestly tell patients from all income and education levels who read my book and call me for advice that the information they need to help them make informed decisions is available to them for free on the Internet at most public libraries.

One benefit to the expanding use of the Internet is the mission that many former cancer patients have undertaken to help steer new patients to reliable information and show them how to use it. Cancer survivors who have already weeded out the good Web sites from the bad provide through their own Web pages direct links to crucial information, and many of them carefully monitor the latest developments. At the very least, these sites allow patients to meet their doctors better informed and better able to ask the crucial questions that could save their lives.

Today, not only is information from Medline available on the Internet, but Fred Hutchinson and most of the nation’s other major cancer-treatment centres also have Web sites offering information about their doctors and how to contact the right experts, as well as updates on the latest advances in their treatment. Some of these centres are in turn linked with patient-sponsored Web sites and e-mail groups, and they provide guidance while vetting Web sites for accuracy and timeliness.

The University of Pennsylvania’s OncoLink service (http://www.oncolink.com/), for example, guides patients to e-mail discussion groups and to sites like Blood and Marrow Transplant Newsletter (http://www.bmtnews.org/), the creation of Chicago-area leukaemia survivor Susan Stewart. Conversely, Art and GrannyBarb’s Leukemia Links (http://www.acor.org/leukemia/) — a Web page put together by leukaemia survivors Art Flatau of Austin, TX, and Barbara Lackritz of St. Louis — allows Web surfers to connect directly to OncoLink and other cancer-treatment-centre Web sites, as well as to medical journals, news articles and survival stories from other patients.

At the heart of the patient-developed resources is the same reason I wrote my book — a deeply felt desire by those who have fought cancer to light the path for others. Boulder, CO, computer programmer Steve Dunn, who successfully battled metastatic kidney cancer at the age of 32, did research which led him to something his doctor had not told him about: what was then an experimental therapy with high-dose Interleukin-2, combined with interferon. He now operates a Web site called CancerGuide (http://www.cancerguide.org/), which helps patients figure out how to do their own research and evaluate things like clinical trials and medical jargon.
Mr. Dunn also offers visitors the pros and cons to researching one's own disease and treatment. Yes, it is "empowering", providing an antidote to despair while enabling patients to make more-informed decisions. But it can be intimidating and dangerous: patients might confront some dismal statistics, or, worse, misconstrue data and make a life-threatening decision. As oncologists this is something you will no doubt have to contend with as more patients come to you with information from their own research.

So to conclude, this really is the era of the self-educated patient and a sea change in the doctor-patient communication. My recommendation to you is that since you cannot beat this revolution, you might as well join it. The time is here for the medical community to embrace the idea of a true partnership between doctor and patient and to help steer the patient to reliable sources of information and away from some of the bad information that is also out there. I advise you to get out there on the Web and surf around a little: you need to know what it is your patients are reading so you can be prepared to deal with it. I would also advise visiting some of the cancer-specific e-mail discussion groups. You don’t even have to identify yourself, you can simply 'lurk' and read the traffic. I think you will be very amazed at the level of conversation that goes on between patients about their treatments, the drugs they are taking — and their encounters with their oncologists.

While I always counsel patients to inform themselves, there is one message I always try to leave them with: that even the best information can’t substitute for one-on-one contact with an experienced physician. But for you oncologists, I would like to say that the relationship is not just about sharing information, but about respecting and having some empathy for your patients. At the risk of sounding preachy, I want to take this opportunity to say bedside manner makes more difference than you can ever know. I was treated at two cancer treatment centres — at one I felt treated like a number, with little respect or understanding for what I was going through and the sheer terror that I felt. At Fred Hutchinson I was treated with respect, with concern and with just plain kindness. I can’t begin to tell you how much that makes a difference to a cancer patient.

Thank you

Reference
