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Connecting Patient / Family Library Patrons To Information, Ideas and Resources

November 2003

from

The Duke Patient/Family Resource Center

The Duke Patient/Family Resource Center is:

- A lending library offering books, audio and video tapes, magazines and free brochures dealing with cancer and certain blood disorders and with issues of coping, survivorship, caregiving, and grieving
- Open 8:30 to 5:00 every day the Morris Clinics are open
- Located in the White Zone, first floor, of the Morris Cancer Clinic, Room 15123.
- Our phone number is 919-684-6955. Our email address is FamilyLibrary@mc.duke.edu

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Information on the Web, Part II

Specialty Websites



Last month, we pointed to some of the basics of assembling accurate information about your cancer on the Web. One starts by visiting Cancer.gov to learn the standard treatment options for your cancer in its particulars (stage, cell type, level of aggressiveness). One may then continue with Cancer.gov/clinical trials to collect a list of the promising new treatments and procedures that hover on the horizon and that might be available to you should your medical condition so indicate. We also suggested learning to use Google.com to "google up" the unfamiliar terms and drug names you've encountered in your explorations. This will help you fill out the picture of your treatment horizon.

This month, we turn to what we are calling the "specialty websites," websites devoted exclusively to a particular cancer. There are hundreds of these, which is understandable because there are over a hundred different cancers, and also because the more common cancers are often covered by more than one specialty website. The usual sponsors of such sights are "coalitions," "alliances," or "associations" of groups devoted to offering hope for those with a particular cancer. e.g. the "Kidney Cancer Association,"(KCA). In addition, for many cancers, there are personal web pages put out by individuals where relevant information has been amassed, e.g, "Steven Dunn's Kidney Cancer Page." Some of these sites are excellent and they tend to speak to their audience as survivor to survivor.

Usually the specialty websites echo Cancer.gov when it comes to treatment options, but they offer a wealth of additional resources including

- breaking news on the particular cancer, its treatment, prevention and detection.
- discussion forums or chat groups where you can communicate with fellow survivors.
- medical response forums in which a medical person responds to the questions that appear in the forum.
- links to standard treatment options as well as clinical trials.
- medical explanations of cancer, of this cancer's risk factors, and of conditions associated with this cancer. For those with broadband, there may be streaming video presentations.
- announcements of "Live Chats" (on the internet) with respected doctors.
- encouraging survivor stories.
- medically vetted survivor advice on the kinds of issues folks with this particular cancer tend to have.
- connections to cancer activist opportunities.
- links to a variety of related websites, some of them hard to find by other means.

Less often, a website will offer specially designed questionnaires or software modules that help individuals assess their risk for this particular cancer, or even prognosticate their chances of survival or recurrence once they have this particular cancer. The ones I have encountered were designed by medical professionals. Of course, it is best not to use these sorts of modules as your sole source of medical advice.



The easiest way to find the relevant specialty websites for your cancer is to turn to your friend <http://www.google.com> and type in the cancer by name: e.g. liver cancer or cancer of the liver. Usually the first 4-5 web locations that Google furnishes you will be the

most popular resources for that cancer. They will lead you to others.

Here are some illustrations of the resources you can connect to through specialty websites.

- For prostate cancer, I went to The National Prostate Cancer Coalition Website (NPCC) and found that following a sequence from "Treatment Information" to "Treatment Options" and finally, "Treatment Side Effects", I was led to a second website entitled Phoenix5.org, where one can find some choice advice by a survivor on how to stop rectal bleeding from radiation treatments. I would never have heard of Phoenix5.org without this link.
- For ovarian cancer, I went to The National Ovarian Cancer Coalition (NOCC) website and checked for "Breaking News." As a person at heightened risk for ovarian cancer, I was excited to read that an early detection "proteomics" test is being licensed and will appear in clinical trials beginning in April. I also checked the "Doctor Search" feature of this website and was reassured to find that it led me to (among others) the five main gynecological oncologists at Duke.
- For kidney cancer, I went to the Kidney Cancer Association (KCA) website and followed a trail to clinical trials (kidneycancertrials.org) from which I could link to "Steve's Strategic Guide to the Clinical Trials System." It turned out to be the best discussion of clinical trials I've yet encountered and had I known about it last month, I would've reviewed it then.

Below is a review of nine excellent and interesting specialty websites, six of them devoted to a particular cancer, three others to related topics (i.e. clinical trials, the Medline cancer guides and quack remedies).

Website Reviews

NPCC: National Prostate Cancer Coalition

Website address: <http://www.pcccoalition.org/>



Prostate cancer is a serious challenge for men, not so much because of its mortality rate (indeed it is the most survivable of the common cancers), but because of the great variety of treatment options - each involving a different balance between effectiveness and the risk of highly unwanted side effects such as impotence, incontinence, and rectal bleeding. The National Prostate Cancer Coalition has risen to this challenge by putting together the most feature-rich website of any that I have encountered, notable for the tech-savvy, engineering can-do style that men tend to bring to serious battles. There are 41 headings under treatment information alone, each leading to about half-a-dozen further links. A sample of features:

- A link to an excellent primer on prostate cancer on Phoenix5.org, which includes some good hard-headed advice, e.g. "It is not wise either to overtreat your disease based on fear of recurrence, nor to undertreat your disease based on fear of impotence or other side effects. Most people would agree that when ordering your priorities, staying alive is at the top of the list, keeping firmly in mind that dead men don't have erections either."
- Links to several streaming videos that explain the prostate situation in graphic detail.
- A whole section for the partners of men with prostate cancer.
- A link to docboard.org so you can find out if there are any legal actions out against your doctor.
- An easy- to-use "prostate cancer calculator." Input your medical information and learn how likely you are to have a recurrence after surgery or to have the surgeon find lymph node involvement.
- A not-so-easy to use "PC Tools II" for helping to select your treatment and a "tumor volume calculator." Each are software modules that must be downloaded and unzipped. I did this, but got no further and could find no instructions. These were

the only disappointing features I found.

NABCO: National Alliance of Breast Cancer Organizations

Website address: <http://www.nabco.org>



Men may try to overwhelm their disease with technology, women try to do it with supportive talk. Since even metastatic breast cancer, with current treatments, has an impressive long-term survival rate, there are a lot of people to talk to and a lot of talking going on. The National Alliance of Breast Cancer Organizations' website is an excellent way to connect to it. Way at the bottom of their heading "Specialized Resources for Breast Cancer Information," you will find a link to the famous listserv "bclist," which is one of the largest cancer discussion forums on the internet. Or right from the home page, you can begin your search for support groups in your area. (I checked the latter and it seems largely up-to-date for folks in the Triangle.) Also linked to, under the heading "recurrence and advanced breast cancer," is the bcmets.org website which can connect you to a listserv for advanced cancer survivors.

NABCO's website is not devoid of treatment information, though this tends to be a little more in the background. Way at the bottom of the headings under "Newly Diagnosed," you can find a link to the National Comprehensive Cancer Network's (NCCN) Breast Cancer Treatment Guidelines for Patients. Here you can find the standard treatment options for every stage and nuance of breast cancer. If you have just found a lump, you might want to check the heading "Breast Cancer Work-Up" to learn what to expect when you take this problem to the doctors. If you already know that you have the disease, you might want to click on the "decision trees" listed in the top banner of the NCCN and review what to expect for the different stages. The information is well organized.

I was disappointed to find not a single word about nor link to lymphedema, which is one of the more unwelcome side effects of breast biopsy. Nor could I find any reference to inflammatory breast cancer. But turn to Google and you will find that there is a National Lymphedema Network and several sites devoted to inflammatory breast cancer.

NOCC: National Ovarian Cancer Coalition

Website address: <http://www.ovarian.org>



The National Ovarian Cancer Coalition won the Oncolink Editor's choice award this September for "the highest quality cancer information on the internet." The site is pleasingly organized and easy to use, all of its main headings staying there on the left as you click from place to place so that you can avoid endless back-tracking. I found the "Breaking News", the "FAQs" and the "Medical Profiler" headings useful and fascinating. There is a lot of breaking news on ovarian cancer these days, as well as a lot of questions that are going to get frequently asked. The Medical Profiler leads you to the NexCura site where you can input your medical information and receive an assessment of your statistics (your chances of recurrence, for instance) under different conditions based upon past clinical studies.

Incidentally, the site "NexCura" does medical profiles on many of the common cancers and can be linked to through several cancer specialty websites. Bear in mind that since their statistical profiles are based on only the largest scale studies, there may be a void when it comes to your particular cancer and/or its particular variant. Ovarian stage IIc clear cell cancer, for instance, is sufficiently rare that in large studies it is either lumped with the "early" cancers and profiles out as having very cheerful statistics or with the "advanced" cancers where it profiles out as having much gloomier statistics.



MPIP: Melanoma Patients' Information Page

Website address: <http://www.mpip.org/>

Another excellent cancer website, MPIP's extensive features include prognosticating tools, a research library with honest-to-god medical articles in it, a chat room and bulletin board where archives of chat

can be accessed, and many encouraging survivor stories. It also provides a way, called "Patnet", to link to other survivors at a comparable stage of the disease for private internet communication. This can be done by giving only a moniker and not your real name. The clinical trials heading directs you, as it should, to the usual - i.e. the National Cancer Institute list - but then throws in 35 additional trials locations where there may be studies enrolling patients outside of the nationally advertised lists.

Under their prognostic calculator, I found a link to two key pieces of reading for persons grappling with their statistics. One is the famous essay by evolutionary biologist Stephen J. Gould, entitled "The Median is not the Message." The other, "A Word About Cancer Statistics," (no author given) also explains medians and means very lucidly.

ALCASE: Alliance for Lung Cancer Support, Advocacy and Education

Website address: <http://www.alcase.org>



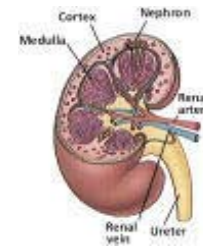
The best of a somewhat disappointing list of lung cancer specialty websites, Alcase offers a telephone buddy system under "Support", a very useful Lung Cancer Manual under "Education" and good links to clinical trials search sites (also under "Education"). I especially like the "Emergingmed.com" site that finding clinical trials will lead to. Don't neglect to scroll down to find the right links.

It is not the easiest site to navigate. There are dead end trails from which you can't get back. I also found I could not access news headlines earlier than two months ago. Readers should note that the online version of the Lung Cancer Manual must be read using Adobe Acrobat Reader (download that if you don't already have it), and must be downloaded one chapter at a time. (It then becomes printable and well as readable).

Readers with a lung cancer concern who have some medical background may wish to access a new set of guidelines for prevention, screening, diagnosis and treatment of lung cancer that has emerged from a research team here at Duke. Go to

http://www.chestjournal.org/content/vol123/1_suppl/

Don't neglect to scroll down.



KCA: Kidney Cancer Association

Website address: <http://kidneycancerassociation.org>

(Warning: once you click on this URL, you can't get back to the newsletter from the back button.)

The KCA is known by kidney cancer survivors for its solicitous phone service for the newly diagnosed, a service that they are trying to slowly transfer to the Web. This is one reason for what I found to be an annoying aspect of the website which is that in order to get any treatment information, one must register by giving personal contact information and wait for e-mail confirmation of one's registration. This may take 24 hours. But once done, you will not only be able to browse the treatment section of the site but will, I am told, receive information updates tailored to your particular concerns.

A definite reason for liking the KCA's website treatment section is that - after you've registered - it will link you to Steve Dunn, a kidney cancer survivor, whose excellent work on guiding others through the treatment labyrinth has been supported by funding from the KCA. Way down the list of things to find in the treatment section (why is the good stuff always at the bottom of website lists??), you will see "Off-site renal cell cancer evaluated trials database, maintained by Steve Dunn." Click on this and you will arrive at the point of entry both to an education about clinical trials and a list of the trials that Dunn has found most significant for one reason or another, each one explained to you by him. What a service for the confused! His advice has been medically vetted. More about Dunn below.

A final goodie to be found right on the home page of KCA is a very fine discussion called "Dealing with the Disease."

Steve's *Strategic* Guide to the Clinical Trials System

Website address: http://cancerguide.org/clinical_trials.html



This one is for everybody, not just kidney cancer survivors.

Steve Dunn will ask you to put on your thinking cap when you read his guide - some paragraphs need more than one pass to get his meaning - but many cancer patients are having to think hard already about their clinical trial choice and are doing so with little or no context within which to operate. Dunn does an excellent job of providing context. He sets out the purpose of trials, the scientific requirements that restrict who can enroll and who can stay enrolled, the significance of the different phases of trial, and (very usefully) the meaning of adjuvant therapy.

A sample of Dunn's advice: Among the many issues people have to wrap their minds around when considering clinical trials is the problem of "randomization." In Phase III trials, which are the most sophisticated and therefore the most desirable usually, you will not be able to choose which "arm" (direction of treatment) to be assigned to - the arm that gets just the standard treatment or the arm that gets the new experimental (and potentially more hopeful) treatment. The choice will be made by a computer. It's not just your imagination here - there is an ethical problem with this. Steve Dunn gives us these thoughts on the subject:

"In order to ethically conduct a randomized trial, there has to be a belief that both treatments are equal, or, more accurately, given that the trial is being conducted because it is not known which treatment is better, it has to be uncertain which treatment is better. If there is sufficient uncertainty about which is better, *equipoise* is said to exist and the trial is considered to be ethical. As far as I can tell, *equipoise* is a rather fuzzy concept, and there is no clarity about just how much uncertainty there has to be in order for there to be *equipoise*. Just exactly who has to have *equipoise* to make randomization ethically acceptable turns out to be a very interesting question! Often individual doctors have strong opinions as to which treatment is better, but don't agree. It has been argued that it is ethical for a doctor to offer a randomized trial to his patient even if he personally thinks one of the treatments is better, as long as it can be said that there is uncertainty in the medical community as a whole. This is called *community equipoise*.

I don't think there is any clear answer to the question of how much the evidence can favor one arm in a trial before it becomes unethical to randomize, nor can I discern any clear practice in the conduct of trials. One thing I am absolutely certain of is that *you* can decide how much uncertainty there has to be before *you* are willing to be randomly assigned! In the end, when it comes to your decision about a randomized trial, the only equipoise which matters is your own. If you believe the evidence substantially favors one arm of the trial, then you are not in equipoise. This does not necessarily mean the trial could not be a choice for you (see more in the section on strategies below) but it does mean you are very likely to be uncomfortable with being randomized and risking assignment to a treatment which in your view is probably inferior."

I like this guy!



Medline Plus

Website address: <http://medlineplus.gov>

Spanish language website address:

<http://www.nlm.nih.gov/medlineplus/spanish/medlineplus.html>

Some of you may find either no website for your cancer or a disappointing one. Spanish speakers may prefer to research their cancer through medical literature written in their own language. If either of these conditions apply to you, try the Medline Plus site. Often it will google up along with the other sites when you type in your cancer type but, if not, use the address above. Once on, go to "Health Topics (or "Temas de Salud)," then find your cancer alphabetically. While much of what you learn on treatment and clinical trials is identical to the Cancer.gov, Medline does a nice job of collecting and presenting every little tidbit of news out there on your particular cancer and on cancer in general. Highly readable.

Quackwatch



Website address: <http://www.quackwatch.org/>

Rather than our lecturing you about all the useless and even harmful medical misinformation you can encounter on the Web, we'd rather direct you to Quackwatch where you can receive the same lesson in a more entertaining way. Quackwatch has won so many awards that it posted them in a special section. If you're curious about a questionable therapy of some sort, don't start with the search function, which will disappoint, rather scroll down the home page - WAY DOWN - (why is the good stuff always at the bottom??) and you will come to an alphabetical index of questionable theories, therapies and products.

Enjoy!

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