

**SERVICES OFFERED**

**GUIDE TO
COMPREHENSIVE
CANCER CARE**

**PATIENT / FAMILY
RESOURCE CENTER**

SELF CARE GUIDES

TESTS & PROCEDURES

**COMPLEMENTARY /
ALTERNATIVE CARE**

HOME

In the Know

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

April 2005

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

Resource Center Coordinator: [Harriet Whitehead, PhD](#)

Cancer Patient Education Program Director: [Kerry Harwood, RN, MSN](#)

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Cancer Specialty Websites Update

In November 2003, we published a newsletter reviewing cancer websites devoted to particular cancers. We tried to encompass the most common cancers (e.g. lung, breast, prostate) and some of the related side issues that cancer patients face, such as understanding clinical trials or avoiding quack remedies.

Many things change on the Web in a year and a half. Some of our reviewed websites disappeared; others diminished, others beefed up substantially. New websites covering the same topics came online. Not surprisingly then, it's time for an update on the cancer specialty websites. We will be repeating some of the words from that earlier newsletter, but adding much that is fresh.

This year, we will recommend that readers start out with one of the generic cancer websites, such as cancer.gov or medlineplus.gov (reviewed below). These all-cancers websites have become more powerful and more prominent on Google even as the one-cancer websites have diminished. For one of our most common cancers, colorectal, there is no full-featured single cancer specialty site of any quality. Specialty sites for this cancer as well as for the majority of the less common cancers will show up on Google, but they will be of use largely for finding supportive information and sometimes links to clinical trials. The main body of treatment and medical information must be located elsewhere.

All-Cancers Websites: A Place to Get Started



Website address: www.cancer.gov

Here you can click directly on the commonest cancers, or find the less common ones alphabetically. Then click on "Treatment" and chose either the "patient" or the "professional" version of the "PDQ." PDQ means physician's data query and it is a cancer-and-its-treatment statement. There is no barrier to reading the professional version (you don't have to prove you're a doctor), but the terms will be more technical, the scary statistics will be cited, and the tone will be bluntly scientific. On the other hand, the "patient" version often strips things down too much. You decide. Spanish language versions available.



A Service of the U.S. National Library of Medicine and the National Institutes of Health.

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

Go straight to the search window and type in your cancer. One of the links on the page that comes up will be to the National Cancer Institute above, but there will be lots of other links to pursue as well. For instance, often there will be a video or an interactive tutorial walking you through some of the commonest procedures you may encounter when receiving tests and treatments for this cancer. (Streaming video and interactives usually require a broadband connection and a fast computer.) Spanish language versions available for most documents and interactives.

Website address: www.nccn.org


For the most direct link to the current standard of care for your cancer, you can always go to the National Comprehensive Cancer Network. On the home page, click on "Treatment Guidelines for Patients," then find your cancer on their list. Spanish language versions available; also links to clinical trials.



Website address: www.mdanderson.org

Right under the main picture will be a button called "Diseases and related conditions." Scroll down to find your cancer (or related condition), then hit "Go." M.D. Anderson is one of the country's foremost cancer centers, and it has, I'm told, at least 70 employees manning its well-appointed and up-to-date website. It is a pleasure to check out the latest from here. I have encountered research news items on this site that weren't available anywhere else. The site also links one to an excellent department of integrative and complementary

medicine. Since the link is obscure, here it is
<http://www.mdanderson.org/departments/CIMER/>

 Last but by no means least, the easiest way to find the relevant specialty websites for your cancer, as well as many of the generic sites, is to turn to your friend <http://www.google.com> and type in the cancer by name. The first page of results will usually give you all you need.

By the way, what is your cancer's name? Some of us stumble right out of the gate when it comes to the name of our cancer. Usually the organ where the cancer originated will do, .e.g. prostate cancer or cancer of the prostate; lung cancer or cancer of the lung. If there are subtypes of that organ's cancer, e.g. *renal cell* kidney cancer vs. *transitional cell* kidney cancer, these will come up listed under the main organ, i.e. kidney cancer. You will still need to know what subtype to read up on, of course, but you can get to first base by the organ name. However, less common cancers, and especially cancers that can originate in various organs, often have more difficult monikers. Did your doctor say, "Hemangioendothelioma?" Oops. Get her to spell that out for you before you go online. (Yes, hemangioendothelioma does come up on Google!)

Specialty Websites For Single Cancers

You will find that most of the single cancer specialty websites echo the National Cancer Institute when it comes to the treatment options. Indeed, why would they do otherwise? The difference is they often mediate the treatment information to you in a more user-friendly way and, when they're good, they offer a wealth of additional resources. These include:

- 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.
- inspiring 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.

A word of caution: Many specialty websites purport to link you to a list of the best doctors/hospitals in your area. Few actually deliver the goods. If you click on that link on many websites called, "Finding the Best Care," chances are you won't find it. I have clicked away and been led to lists of community hospitals so obscure that I wince to think of the patients who followed this advice. To help out, I have put a couple of suggestions at the end of this newsletter under the heading, "Really Finding the Best Care."

NPCC: The National Prostate Cancer Coalition

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



Let's start with the fabulous. The National Prostate Cancer Coalition's website is an old friend from 2003, still going strong. 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 43 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.

NOCC: The National Ovarian Cancer Coalition

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



Another site reviewed in 2003 and still meriting our favor. The National Ovarian Cancer Coalition won the Oncolink Editor's choice award in 2003 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. Treatment information is found right on the home page under the larger heading, "Where do I begin?" Most crucially for women who have not yet found a surgeon, this website leads to a list of approved gynecological oncologists, who are essentially the only surgeons

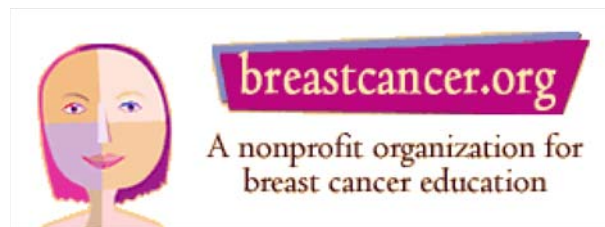
qualified to operate on ovarian cancer.

We 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" aka "NexProfiler," site 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.

The only problem we detected on this website is that once you've clicked on one of the tabs under "Resources & Other Links," you can't return to a functioning version of the NOCC website. It may look like you're back on the previous page, but none of the buttons work!

BREASTCANCER.ORG



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

Here's another website that we can list as fabulous. Breastcancer.org sprang up in the wake of NABCO's (National Alliance of Breast Cancer Organizations) disappearance, and, in my opinion, it surpasses Nabco's old website. Clearly laid out, clearly written, with extensive information on diagnosis and treatment; side effects and pitfalls (including lymphedema); recovery (including breast reconstruction), and much much more.

We enjoyed a trip through the "Celebrity Talking Dictionary," which you link to on the home page. Ostensibly created to teach you to pronounce and understand some of the medical terms you may encounter, the talking dictionary allows each celebrity to give

a little personal pitch for learning in addition to doing her or his dictionary work. The warmth of these familiar voices has a soothing effect, and one just keeps clicking on. Try Susan Lucci saying "granulocytopenia" (she knocks it off without batting an eye), or Iman's pleasantly accented personal pitch, encouraging you to gather all the information that you can.

This website also gives you PICTURES. All the things you're furtively curious about - how will I look after the surgery, does a reconstructed breast look like a real one, where are all those lymph nodes anyway? - get covered visually as well as verbally here. The women modeling for the reconstruction pictures are real breast cancer survivors (whose stories you can click on), and they seem to represent the usual expectable outcome of the various procedures. No airbrushes here, but also no fright pictures of things gone wrong.

ALCASE: Alliance for Lung Cancer Advocacy, Support and Education

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



The Alcase website was in the process of being reconstructed as we were preparing this newsletter, and its refurbished self is looking quite promising. While un-frilly, the Alcase website still offers the essential features for good, solid single cancer specialty website. The treatment feature is still a bit obscure. Go to Education, then Publications, to find their excellent discussion of treatment, doctor-patient relations, and a host of related topics under the heading "Frankly Speaking About Lung Cancer."

Alcase also offers a telephone buddy system under "Support", and good links to clinical trials search sites (under "Education"). To its credit, Alcase's "Finding the Best Care," link does, in fact, lead one to a list of excellent cancer centers.

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/

More Sites of Special Relevance

Steve Dunn's Cancer Guide

Website address: <http://cancerguide.org/index.html>

Rather than being an all-cancer, or a single-cancer specialty website, Steve Dunn's "Cancer Guide" is more like a *how to research any cancer* website. It will tell you things we haven't - such as how to get into medical journals online or offline; where to find drug information; which book publishers have a good cancer list, and the skinny on paid search services. Steve will also link you to some worthwhile sites we haven't had a chance to evaluate as well as some we decided weren't that interesting.

Most valuable, in our opinion, are Steve's "Cancer Basics", for the newcomer, and his series of "Guides to the Clinical Trials System." No one that we've encountered has a more penetrating take on why you would choose or not choose to enter a Phase III randomized clinical trial (see our November 2003 newsletter for a longer review of this).

Steve Dunn is himself a renal cell kidney cancer survivor, and his system of guides will link you to his 40 page discussion of kidney cancer. The website of the Kidney Cancer Association (KCA) which helped to fund Steve's work, has become itself simply a web-page instead of a full-featured site. Thus we recommend that people with kidney cancer concerns start with Steve.

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.

Shop Well With You

Website address: www.shopwellwithyou.org

Shop Well is a non-profit organization helping women surviving all types of cancer improve their body image and quality of life. It offers, among other features, a guide to the clothing needs of persons with different situations, e.g. clothing over an ostomy, protecting radiation tender skin, etc.; and an excellent book list.

Consumer Lab

Website address: www.consumerlab.com

Consumer Lab is an independent tester of nutritional and herbal supplements. While most of their services require a subscription, they do post free summaries of their latest findings on particular items. In these summaries you will find a list of all the brands that passed their tests. To find out which ones failed, you must subscribe.

Really finding the best care

Our recommendation is to skip cancer websites and head straight to the *U.S. News and World Report* "Best Hospitals" issue for the current year. This can be accessed at

<http://www.usnews.com/usnews/health/hosptl/tophosp.htm>

Find the button marked, "Cancer," and proceed from there.

Hopefully, one of the country's top 20 comprehensive cancer centers will be not too far away. (In this area, it's Duke.)

If you want to find just *any* cancer center in your area, go to the hospital locator on the American Cancer Society's website, http://www.cancer.org/asp/search/ftc/ftc_global.asp, go to "simple search" and type in your zip code and how large a search radius you want.

Doctors go along with hospitals. Find the best hospital in your area and it will have a roster of the best doctors in your area. Even oncologists and other specialists who have their practice "off campus," will be affiliated with one of the local hospitals.

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