



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

October 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 I Clinical Trials



Since our audience for this newsletter reaches us through the internet ("the web"), we plan to devote our next two issues to helping you find some useful paths through the maze of cancer information that can be found there. This month we will focus on clinical trials information on the internet. Next month, we will review some of the specialty cancer websites. We will address you all throughout as if you were the patient, but we realize many of you will be the friends and relatives of patients, often the one who has undertaken to find more information on the patient's behalf.

We suspect that you all, at one point or another, have immersed yourselves in an internet information quest and that the experience has left you with many unanswered questions, or, at points, frank discouragement. All those websites of drug companies and unfamiliar medical centers boosting their products or services, the quack remedy sites half-written in Chinese, the medical abstracts that you can't make much sense of, the reams of chat from cancer survivors and their relatives, representing all stages and sub-varieties of your disease - you can get up from the computer after an evening of this with little more than a splitting headache. Notwithstanding all of this, you can't help but feel that the truth is out there. Somewhere.



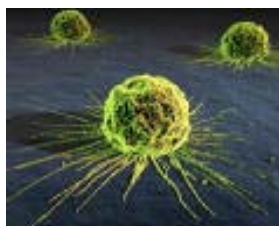
We can't promise you absolute truth, obviously. But often what web-surfers are seeking is simply a brighter horizon: the new possibilities for treatment that are faster, gentler, cheaper and, hopefully, more effective than what is currently available. In fact there is such an horizon (if we temporarily hold the "cheaper" part of

the order). It consists of all those drugs and procedures still in clinical trials. Clinical trials are the only scientific and the only *approved* way to try new medicines and medical procedures on human subjects. Every comprehensive cancer center and most reputable medical centers will have a number of such trials available to their patients.

Almost everything that now makes up the standard of care for any cancer, everything that is FDA approved, was at one point run through clinical trials to determine its safety, its efficacy, its best dose level and frequency, and to which cancers and which patients it is most relevant. Thousands of volunteer human subjects have participated in these trials and made it possible for the standard of care to evolve toward greater efficacy, safety, gentleness, speed, and - as the insurance companies jump on the bandwagon - affordability. Not every drug and treatment on trial will make the cut, to be sure; but if you want to glimpse the outlines of future cancer care, just browse the clinical trials lists.

This issue of *In the Know*, we will guide you to internet information that helps you understand clinical trials and helps you search the national listings of these trials. Next month, we will take up the additional useful web information that can be found on specialty cancer websites.

Website Reviews



<http://cancer.gov/clinicaltrials/>

The National Cancer Institute web site *cancer.gov* has a page devoted to information about clinical trials. On this page, you can:

- find general information about participating in clinical trials
- search for clinical trials for your disease
- read about results of recent clinical trials

Preparing for your search with general information

It will be very useful if, before beginning a search, you scroll down on the left and look under "Educational Resources." There read the little publication "If You Have Cancer: What You Should Know about Clinical Trials." This offers a good introduction to the subject (free copies of it are available at the Resource Center).

Your search will be most meaningful if you have accurate and complete information about your disease, including the exact cell type from the pathology report and the stage of disease. Don't hesitate to ask your medical team for this information. Many teams routinely give their patients copies of their pathology reports. To improve your understanding of the standard treatment options for your disease, you may take these specifics and visit the *PDQ Treatment Summary* section of the Cancer.gov website. On the Cancer.gov home page, click on "Types", then either choose from the list of common cancers or pick the letter of the alphabet appropriate for your less common cancer. The heading "Treatment" will come up. Choose either the patient version of the health professional version. The patient version is basic and general; whereas the health professional version is highly detailed and technical. We suggest that the family member with the greater knowledge of medicine and medical terms be the one to tackle the health professional version.

Doing your search for clinical trials

Now let us turn to the search process. Cancer.gov/clinicaltrials allows you to search for clinical trials for any specific cancer. If you use the *NCI Clinical Trials (PDQ®) Search Form (Basic)*, you will have the option to select the type of cancer, type of trial, and the geographic location you are interested in. If you use the *NCI Clinical Trials (PDQ®) Search Form (Advanced)*, you can further select for stage of disease, type of treatment, location by state, city, or hospital, phase of clinical trial, and other search criteria.

At the home page, click on the one or the other of these forms under the heading, "Finding Clinical Trials." Up will come a screen that allows you to give the specifics. Not every question needs to be answered. When ready, press Enter and you will get a list of trials that fit your search criteria. This list will include the title and basic information. For more detailed information, you just click on the title of the trial. Under each trial is a brief description, including the objectives of the study, the criteria patients must meet in order to participate, and what treatment on the trial involves. Some of the eligibility criteria are very technical and you may have to ask your medical team for the information.

If your time at the computer is limited and you want to quickly print out a list of only those trials that interest you, use the advanced search form. (It will ask you for a ton of specifics, but not every question needs to be answered). It will bring up a list in which each trial has a checkable box next to it. Check the ones of interest, then hit "display for printer" at the bottom of the page. Your chosen trials will come up in a reading sequence (no need to keep clicking back and forth). This can be sent to the printer, then taken home to read at your leisure. If you can afford to take more time, click through the trials one at a time, looking for key information such as where the

trial is being run and who is eligible.

Don't be discouraged if a trial that interests you is not open at a North Carolina location. Talking to your doctor or calling up the drug company can sometimes open up new avenues of access (especially if your doctor agrees with your judgment of the trial).

Read recent clinical trials results

Back on the home page, you will see a heading "Recent Clinical Trial Results." Almost every week, there is some breaking news about cancer. Cancer.gov/clinicaltrials provides an expert summary of recent clinical trials results. This is a good source to check when you hear something on the news about a new treatment for cancer. You may also want to check in periodically just to see what's new. This week, some of the top stories in clinical trials results concern the very promising use of letrozole after tamoxifen for breast cancer adjuvant therapy, the timing of chemotherapy treatment for low grade lymphoma, and use of sentinel lymph node biopsy in the staging of breast cancer.

Additional general information under Educational Resources (all of the following are "clickable URLs")

Besides the publication that we referred to earlier, "[If You Have Cancer: What You Should Know About Clinical Trials](#)," there are several other publications listed under Educational Resources (on the home page) that will be relevant to many patients. For example,

[If You Have Cancer and Have Medicare... You Should Know About Clinical Trials](#). Resource for Medicare recipients who have cancer. It provides general information about cancer clinical trials, Medicare coverage, and questions to ask before joining a clinical trial.

[Taking Part in Clinical Trials: Cancer Prevention Studies](#). Provides information about cancer and clinical trials, and helps people decide if participating in a chemoprevention trial is right for them.

[Clinical Trials Education Series](#). The Clinical Trial Education Series is designed for cancer patients, health professionals, and the general public. It consists of 13 different educational materials (books, booklets, slides, videos) that can be ordered separately or viewed online.



<http://www.cancer.duke.edu/CTrials/>

A list of cancer clinical trials being done at Duke is available on the Duke Comprehensive Cancer Center's webpage. You can find further details on many of these trials by looking them up at the cancer.gov/clinicaltrials site, using the sponsor and trial number that you got off the Duke list.



<http://www.google.com/>

The search weapon of choice for millions of Web surfers is the search engine "google.com". It loads instantly and it searches widely and with great intelligence. Suppose you pick up the newspaper in the morning and find a little blurb about a new drug for ovarian cancer, e.g. OvaRex. Go to your computer and "google it up." (Type ovarex into the search slot and press enter). In a matter of less than a second, for broadband, and a few minutes for dial-up, a list of some 4,000 web locations will appear, ranked in order of criteria such as how often they are accessed and how many other sites link to them. Without getting past the first 10 of these "references" - the most highly ranked ones - you will be able to learn important things about this drug, e.g. that it is a "biological" type of treatment; that it induces the patient's immune system to attack the cancer; that it can buy good time for a woman with advanced ovarian cancer; and that many different cancer centers around the country are sponsoring a late phase clinical trial on it.

Google will be your friend while you are browsing the lists of trials on Cancer.gov because the references to which it leads contain more information than can be found merely from the description of the trial. As each trial turns up new names and new terms, you can google them up and compile an informed little list. For those of you with broadband, you can leave Google.com active in one window, and the Cancer.gov/clinicaltrials list in another, switching back and forth as you accumulate information.

Book, Video & Audio Reviews

- *Cancer Answers: Encouraging Answers to 25 Questions You Were Always Afraid to Ask*, by Errol C. Friedberg. [Book]

A good sound, quickie cancer education for the less well informed (and most people are less well informed about cancer than they think). Tells you what a cancer is and how it works, runs down the commonest types, briefly explains staging and treatment, gives some interesting statistics, diplomatically touches upon alternative and psychological curing. The publication date will tell you that the treatment part and some of the recommended medical centers are probably out of date. But the book does a nice job of providing the basics for people just coming to grips with a diagnosis.

- *Patient to Patient: Cancer Clinical Trials and You* [Video]

A ten minute overview of the subject from cancer survivors.

- *Cancer Survival Toolbox: An Audio Resource Program* from the National Cancer Institute [6 Audiotapes]

Sometimes, people can benefit from some coaching and suggestions on how to communicate with the health team and be an advocate for themselves. The Patient and Family Resource Center has an excellent resource, the *Cancer Survival Toolbox*, to fill this bill. A series of audiotapes, the *Toolbox* brings the expertise of both health care providers and patients to a variety of topics to help patients and families through the cancer journey. Listen to them on that long drive up to Duke.

Discussion: Common Questions about Clinical Trials

How might clinical trials fit into the picture of my treatment?

There are many types of clinical trials, including prevention trials and supportive care trials. Right now, we're going to consider only treatment trials. There are three common situations in which a patient is invited to participate in a clinical trial. The first is when they have had standard therapy and either it did not work or it stopped working. They, then, may be invited to participate in a study of a new treatment. The second is when someone is diagnosed with a type and stage of cancer for which we have no good treatments. In some cases, what is the standard therapy may only benefit a small percentage of those who receive it, and that benefit is often a

prolongation of life by a few weeks. In that case, a patient might be invited to move directly to a clinical trial looking for better treatments. In these first two situations, it is usually a Phase I or Phase II study that is offered. Phase I and II studies are not offered to patients who have not been treated with the standard treatment for their disease, if one is available. Finally, and most common, are clinical trials that compare standard therapy with treatments that have been studied in humans and may be better, in terms of response, survival, or toxicity, or some combination of these. These studies that compare standard with newer treatments are Phase III studies.

Weighing the Pros and Cons

While a clinical trial is a good choice for some people, this treatment option has possible benefits and drawbacks. Here are some factors to consider. You may want to discuss them with your doctor and the people close to you.

Possible Benefits

- Clinical trials offer high-quality cancer care. If you are in a study and do not receive the new treatment being tested, you will receive the best standard treatment. This may be as good as, or better than, the new approach.
- If a new treatment approach is proven to work and you are taking it, you may be among the first to benefit.
- By looking at the pros and cons of clinical trials and your other treatment choices, you are taking an active role in a decision that affects your life.
- You have the chance to help others and improve cancer treatment.

Possible Drawbacks

- New treatments under study are not always better than, or even as good as, standard care. They may have side effects that doctors do not expect or that are worse than those of standard treatment.
- Even if a new treatment has benefits, it may not work for you. Even standard treatments, proven effective for many people, do not help everyone.
- If you receive standard treatment instead of the new treatment being tested, it may not be as effective as the new approach.
- Health insurance and managed care providers do not always cover all patient care costs in a study. What they cover varies by plan and by study. To find out in advance what costs are likely to be paid in your case, talk to a doctor, nurse or social worker from the study.

What if I start a clinical trial and then decide I don't want to continue?

You should never feel coerced, or pressured, to join a clinical trial, or to continue on one you've started. It is always your right to decline, at any point in the treatment. That said, there are a couple things to think about, as you are contemplating participating in a clinical trial.

With some treatments, whether or not it is being given as a clinical trial, there are 'points of no return'. For example, if you agree to participate in a clinical trial of high dose chemotherapy followed by bone marrow transplant, you would not want to take the chemotherapy which destroys your bone marrow, then decide that you don't want the bone marrow transplant, which supplies new bone marrow. Before agreeing to any treatment, it is always wise to ask, where are the points of no return? If I have this treatment, are there doors that close as far as my future options?

Secondly, it is helpful to understand how the results of clinical trials are determined. Many people participate in clinical trials for more than one reason. First, they are hoping the treatment will work for them. In addition, they hope others will benefit from the knowledge gained through their participation. The results from most clinical trials are calculated based on data from 'all enrolled' or 'all randomized'. That means that even if someone drops out of the trial, their data will still be included for that treatment. While it is always your right to stop participating in a clinical trial, your contribution to medical knowledge and the treatment of patients in the future, will be strengthened if you carefully consider your participation before you start, and only drop out if things happen or your situation changes in ways you could not predict before you started.

How can I be my own advocate?

Thousands of cancer clinical trials are being conducted across the United States. Many of these, especially Phase III studies and studies of treatments for rare cancers, are done through cooperative research groups. These are groups of institutions who agree to enroll patients on the same studies, so the answers can be found more quickly. Duke participates in several cooperative research groups so has access to many research studies beyond those that are started here at Duke. Sometimes, there are small studies being conducted by only a few institutions. Some patients and families like to keep track of the studies being done for their type of cancer, even if they are not currently available at Duke.

There are good reasons to do your own exploring, independently of your doctors and not in the teeth of an emergency. Having an awareness of what is in the pipeline makes you a better advocate for your own care. If your own treatment should reach a fork in the road,

where decisions must be made, simply knowing the names and some of the characteristics of new treatments in the pipeline can help you raise the right questions with your doctor and respond intelligently to his/her suggestions. "I want to try that drug that they've altered so it doesn't have so many side effects." Or, "I hear that this treatment carries a risk of blood clots and people in my family tend to get clots." Or, "I'm willing to risk that trial where the dosage is stepped up, so I can hopefully keep this cancer from recurring." We're citing here real example of the kinds of things patients we have known have communicated to their doctors. We even know patients who, when learning that a certain promising trail was not offered at Duke, pushed for getting it here - and succeeded!

New materials in the Patient and Family Resource Center

Cancer and cancer treatment

- *Playing for Time: The Fight Against Ovarian Cancer* (video)
- *Gilda's Disease: Sharing Personal Experiences and a Medical Perspective on Ovarian Cancer* by M. Steven Piver, with Gene Wilder
- *Person to Person: Patient's Talk about Rituxan, Exploring and Understanding Non-Hodgkin's Lymphoma* (video from Genentech)
- *100 Questions and Answers about Lung Cancer* by Karen Parles & Joan H. Schiller
- *100 Questions and Answers about Prostate Cancer* by Pamela Ensworth & John Heaney

Complementary therapies and self care

- *Physicians' Desk Reference for Nutritional Supplements*
- *Seated Yoga: Simple Relaxation Techniques* by Carol Dickman (video)
- *The Force Program* by Jeff Berman (*fitness program for cancer survivors, reviewed in the September 2003 newsletter*)
- *What to Eat When You Don't Feel Like Eating* by James Haller
- *Alicethenics* (exercise video) by Alice Saland

Personal narratives (good reading for the waiting room)

- *Icebound: A Doctor's Incredible Battle for Survival at the South Pole*, by Dr. Jerri Nielsen
- *The Victoria's Secret Catalog Never Stops Coming and Other Lessons I Learned from Breast Cancer* by Jennie Nash

Coping in difficult circumstances

- *Measure Our Days: New Beginnings at Life's End*, by Jerome Groopman
- *Living With It: The Ties that Bind*, a video set of mothers and daughters and of wives and husbands discussing the woman's metastatic breast cancer

Caregiving

- *Always on Call: When Illness Turns Families into Caregivers* by Carol Levine (Edited collection)
- *Chemosabe: A Guide to Being a Personal Advocate for a Chemotherapy Patient* by Brenda L. Joyner

Humor

- *Thanks for the Mammogram: Fighting Cancer with Faith, Hope and a Healthy Dose of Laughter* by Laura Jensen Walker
- *Lisa's Story* by Tom Batuk (Funky Winkerbean comic strip series on the breast cancer experience)

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