

# **HelpBook**

What to Do If Cancer Strikes

An Eight-Step Guide for Cancer Patients on How to Get the Best Care Followed by an Information Section and Resource Directory

Published by

### **CANCER RESEARCH INSTITUTE**

ONE EXCHANGE PLAZA 55 BROADWAY, SUITE 1802 NEW YORK, NY 10006 1-800-99CANCER www.cancerresearch.org Copyright © 1991 Cancer Research Institute

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Writers: Alanna J. Fearing

Jill O'Donnell-Tormey, Ph.D.

Designer/Technical Illustrator: Elizabeth J. Rosen

Illustrator: Kitty Chang Paquette

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The Cancer Research Institute is not engaged in the practice of medicine and is not offering direct medical advice. We are providing only general information to assist the cancer patient and, in our Resource Directory, sources of more detailed information. CRI does not provide referrals.

### **FOREWORD**

If you or a loved one has been diagnosed with cancer, you are fortunate to live in the age of modern medicine. Decades of research efforts, including those supported by grants and fellowships from the Cancer Research Institute, have opened the door to a range of therapies that give many cancer patients new hope not only for survival, but also for a healthy, productive future.

However, today's array of treatment possibilities poses a new dilemma for the cancer patient: With many different procedures and courses of therapy available, how can you be sure that you receive the best treatment?

The Cancer Research Institute has put together a guide that will help any cancer patient through this dilemma. This guide focuses on helping you or a loved one get the best care possible, and provides addresses, phone numbers, and website URLs you'll need to take the next step.

Beating cancer, or helping a loved one through the disease, may be the toughest fight of your life. I wish you luck and strength. And I hope this HelpBook will give you confidence that you and your doctors, working together, can get you the best care that modern medicine has to offer.

Jill O'Donnell-Tormey, Ph.D.
Chief Executive Officer & Director of Scientific Affairs
Cancer Research Institute



In today's world, a diagnosis of cancer is no longer a reason to despair. Nowadays, many forms of cancer can be cured—provided the patient receives the right treatment.

Unfortunately, some patients don't get the most appropriate treatment for their condition. Advances in cancer therapy are coming so quickly these days that not all doctors and hospitals are able to offer the latest and best treatments for every type of cancer. And sometimes patients don't have enough information at their fingertips to seek out the treatments they need.

How, then, do you make sure that **you** get the best possible care? Educate yourself. Ask questions about anything you don't understand. And, most important of all, get expert advice on how and where your particular cancer should be treated, as well as what resources are available to help you live a normal life during and after your recovery. In other words, **take an active role in all aspects of your care**.

You **can** improve your chances of surviving cancer. The eight steps laid out in this guide will show you how. As you read through the steps themselves and the Resource Directory section, you will find answers to many of the questions that may be on your mind. And don't hesitate to call on the organizations listed in the Resource Directory—they can be of great help to you and your family.

# THE EIGHT STEPS

- Talk openly with the doctor who tells you your diagnosis.
- 2 Get a second opinion.
- 3 Inform yourself about your cancer.
- 4 Decide carefully on your treatment plan.
- 5 Be a smart patient.
- 6 Make the most of available support services.
- 7 Consider your finances.
- 8 Take charge of the future.



# TALK OPENLY WITH THE DOCTOR WHO TELLS YOU YOUR DIAGNOSIS

Your first step as an actively involved cancer patient is to discuss your case thoroughly with the doctor who told you that

you have cancer. Don't hesitate to ask all the questions that are on your mind, whether that physician is your family doctor, an oncologist (cancer expert), or some other type of specialist. The doctor should answer your questions clearly, help you understand your medical condition, and advise you on what to do next.

# What — exactly—is your diagnosis?

Be sure the doctor tells you exactly what kind of cancer you have and what stage it's in (see What is Cancer?). You'll need to know the "official" definition of your cancer if you later want to talk to other medical professionals about your illness.

## How was your diagnosis determined?

Talk with the doctor about how your diagnosis was determined. Ask what tests were taken and what they showed. The most reliable test for diagnosing cancer is a biopsy, which is a form of tissue analysis. Also, find out whether the doctor is planning to order more tests to confirm the results of earlier ones. A good question to ask at this point might be, "How sure are you that my tests, and the resulting diagnosis, are accurate?"

## What does the doctor advise you to do next?

Following the discussion of your diagnosis, the doctor will likely recommend the next steps you should take. If the doctor is not an oncologist, he or she should advise you to see one for further analysis and treatment. If the physician is an oncologist, he or she will recommend a course of treatment (see How is Cancer Treated?).

If a course of treatment is prescribed, ask the doctor to fill you in on the pros and cons of the recommended treatment and on other possible treatments. Ask the doctor to explain why he or she chose the specific treatment being proposed. Also, you may want to ask how the doctor's recommendation compares with the treatment suggested by the Physician Data Query (PDQ). This computerized service of the National Cancer Institute (NCI) can give a physician or a patient up-to-date information on appropriate treatment options for every type and stage of cancer. For more information on PDQ, see How Can the National Cancer Institute Help Patients?





# GET A SECOND OPINION

It's always wise to get a formal second opinion on how your cancer should be treated. A second opinion is particularly important if your cancer was discovered by a doctor without

much experience in dealing with your type of cancer. New developments in cancer treatment are happening so fast that it's practically impossible for every doctor to be aware of all the most up-to-date ways to deal with the disease. And when you get a second opinion, the doctor giving it should automatically reevaluate your diagnosis to make sure that it's accurate.

# Will your doctor mind if you get a second opinion?

No reputable physician will question your right to a second opinion. Since cancer is a complex and serious disease, most doctors—even oncologists—will want to know that at least one other physician has reviewed your case. Doctors don't mind working together when cancer strikes because they recognize that cancer is best dealt with by a team of experts who know about all the latest advances.

In fact, it's very important to let your doctor know you're seeking a second opinion because he or she must send a complete transcript of your medical records to any other physician who sees you.

# Will you lose too much time if you get a second opinion?

Some people worry that they will jeopardize their health if they take the time to get a second opinion. But this is seldom the case. In all but rare situations, doctors agree that it is well worth a reasonable delay in treatment to spend the time necessary to be sure your case has been properly evaluated.

## Where can you get a second opinion?

Perhaps the best place to get a second opinion is a hospital designated as a Cancer Center or Comprehensive Cancer Center by the National Cancer Institute. At these hospitals, you will be able to see highly experienced doctors

who have access to state-of-the-art facilities and equipment. To locate an NCI-designated center near you, call the Cancer Information Service (CIS) at 1-800-4-CANCER (see How Can the National Cancer Institute Help Patients?) or refer to the state-by-state list in the Resource Directory.

If you find that there is no NCI-designated center within a manageable distance from your home, you could ask CIS to refer you to a hospital involved in an NCI Community Clinical Oncology Program (CCOP). CIS can give you the names of local oncologists in private practice, too, although the service does not formally recommend any doctor on its list. You can also contact a special type of second-opinion panel affiliated with the R.A. Bloch Cancer Foundation by calling 1-800-433-0464. These panels are made up of top cancer experts who meet with the patient to discuss his or her case.

You could also ask your doctor for a suggestion, call one of the organizations listed in the Resource Directory, or contact a hospital affiliated with a major medical school. Remember, as a rule, **you want a second opinion from a doctor who has had many years of experience in treating your type of cancer.** The doctor should also have ties with a large, well-equipped hospital noted for serving cancer patients.

# How can you check the credentials of physicians giving opinions?

If you want to make sure that a doctor you're getting advice from is well-qualified, you should check on several specific points. Find out whether the doctor trained at an NCI-designated cancer center or a major teaching hospital and whether he or she is currently affiliated with such a facility. Also, determine whether he or she is certified in medical oncology by the American Board of Medical Specialties and is a member of the American Society of Clinical Oncology (ASCO). Find out, too, how many years of experience the doctor has in treating your type of cancer.

You can learn what you need to know by asking the doctor directly or by referring to the *Directory of Medical Specialists*, which lists only board-certified physicians who have passed comprehensive tests. The official ABMS directory of board-certified specialists can be found online at www. abmsdirectory.com. You can also check to see whether your doctor is listed

in the *American Medical Directory* of the American Medical Association by using their DoctorFinder service online at www.ama-assn.org. These books should also be in the reference section of your local library. Your state or county medical society can give you information on doctors in your area as well. The book *Choices*, by Marion Morra and Eve Potts, which is listed in the Resource Directory, contains helpful checklists for evaluating the expertise of both doctors and hospitals.



# INFORM YOURSELF ABOUT YOUR CANCER

While you're getting a second opinion, you may want to educate yourself about your particular cancer and how to cope with it. By becoming a better-informed cancer patient, you may find it easier to discuss your condition and to participate in the choice of a treatment plan. If you're not comfortable seeking information on your own, you may want to ask a friend or family member to help you.

## What short informational booklets are available?

Easy-to-understand free booklets on cancer in general, specific types of cancer, and ways to treat cancer are available from NCI's Cancer Information Service and from such private organizations as the American Cancer Society or the Leukemia and Lymphoma Society of America (listed in the Resource Directory). The Cancer Information Service or the American Cancer Society can refer you to other organizations in your area that will provide information as well.

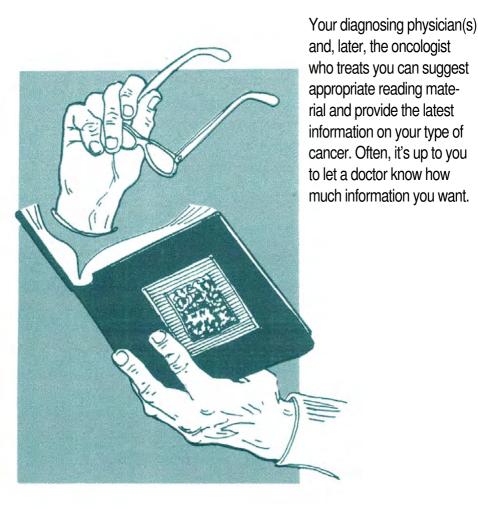
# Can you yourself investigate treatment options through PDQ?

The Cancer Information Service can provide you (as well as your physician) with information from the Physician Data Query database (see How Can the National Cancer Institute Help Patients?). Tell the CIS staff your diagnosis, the location of your primary cancer, and the stage of disease. They will send you a computer printout that discusses your type of cancer and lists NCI's recommended treatment possibilities. You will want to discuss the information you get with a doctor who can help you interpret it.

## What if you want even more information?

Your local library or bookstore should have some good sources of information on cancer. Three excellent books that cover many aspects of the disease are listed in the Resource Directory (see Reading Materials for Further Information).

A word of caution, however, is in order. Don't spend every waking hour gathering information. Stick to material written specifically for patients. Don't frustrate yourself by trying to read highly technical medical literature. Also, keep in mind that things are moving very fast in the cancer field, so information in books and newspaper or magazine articles can get outdated quickly.



# DECIDE CAREFULLY ON YOUR TREATMENT PLAN

Once you have gotten a second opinion and gathered some information on your own, you are ready to take the most important step of all: deciding on the specifics of your treatment plan—what it should be, where it should be provided, and who should administer it.

# What form should your treatment take?

If all the doctors you've consulted agree on a particular course of treatment, your decision should be fairly clear-cut. When there's a difference of opinion, the doctors involved should talk together to explore their points of view and develop a clear recommendation. If the doctors cannot resolve their conflicting viewpoints, a third opinion may be in order. If you don't want to get a third opinion, you should probably go with the treatment recommendation of the doctor who has the most experience in dealing with your type of cancer.

Sometimes, you may be presented with more than one entirely appropriate treatment plan. For example, in certain cases, a breast cancer patient may be told that she has a nearly equal chance of recovery with a mastectomy (removal of the entire breast) or with a lumpectomy plus adjuvant therapy (removal of the tumor only, followed by radiation or chemotherapy). In a case like this, the patient can look to the doctor for a thorough discussion of the pros and cons of each alternative and for the doctor's informed opinion, but only the patient herself can make the final decision on treatment.

You may also have a very personal choice to make if your doctor has told you that you are eligible to receive an investigational therapy. Investigational therapies represent the most recently developed ways to treat particular cancers. They are given to patients whose conditions meet specific criteria in carefully regulated tests called clinical trials (see What Are Investigational Treatments and Clinical Trials?). Many patients eligible for a clinical trial are also good candidates for a standard therapy such as radiation

or chemotherapy, and so must make a carefully considered choice in consultation with their doctors.

# Are there treatments you should always avoid?

Under all circumstances, you should avoid unconventional, or scientifically unproven, treatments (for example, laetrile or macrobiotic diet). Treatments like these may appear to help some people, but they are not backed by sufficient scientific data to prove their effectiveness. The great danger of relying on such a treatment is that you might be steered away from a treatment that really could help you. And if you start out with an unconventional treatment and later find out that it isn't working, it may be too late to get the full benefit of a proven therapy.

Your doctor, the Cancer Information Service, or the American Cancer Society can tell you whether a treatment is unconventional, investigational, or standard. Bear in mind that unconventional treatments are altogether different from investigational treatments, which are scientifically tested in clinical trials. Also, keep in mind that many doctors do not disapprove of psychological or nutritional approaches that improve a patient's emotional well-being or physical stamina, provided such approaches are used along with clinically proven therapies.

## Where will you be treated and who will treat you?

Once a decision on your type of treatment is made, you still have to determine where you will be treated and who will treat you. You may well end up being treated by one of your diagnosing physicians. But the "where and who" decision depends largely on the type of care you need. If you've been told that you have a rare form of cancer that requires highly sophisticated equipment to give you the best chance for a cure, you may need to stay at an NCI-designated cancer center. (People living far away from such a hospital may be able to take advantage of the travel and lodging assistance available through the special programs discussed in Step 6.)

Many cancer cases, however, can be treated successfully at a local hospital, provided it has the right facilities. If you've gotten treatment advice from

a doctor at an NCI-designated hospital, he or she can often recommend a local oncologist to handle your actual care. In some cases, a local oncologist and a doctor from an NCI-designated center will work cooperatively in treating you. Many local oncologists in private practice stay in regular contact with NCI-designated cancer centers to keep current with developments in cancer therapy.

In deciding who will treat you, you also need to consider the physician's personal style of relating to patients. Many people feel more comfortable with a doctor who welcomes questions and answers them thoroughly and clearly in language the average person can understand. Remember, though, that a good "bedside manner" is no substitute for expertise.

# Where should you go to receive an investigational therapy?

If you have opted for an investigational therapy, you might be treated at the Clinical Center of the National Institutes of Health, an NCI-designated facility, a hospital participating in NCI's Community Clinical Oncology Program, or a hospital affiliated with one of the NCI Clinical Trials Cooperative Groups (see How Can the National Cancer Institute Help Patients?). Some trials are run outside the NCI system (by drug companies, for example). Using the Physician Data Query, NCI's Cancer Information Service can tell you or your doctor whether an institution in your vicinity or elsewhere is participating in an NCI-approved clinical trial that might be appropriate for you. Many independently run trials are also listed in the PDQ. In addition, your doctor can consult NCI's Cancer Therapy Evaluation Program (CTEP) to learn about available clinical trials for individual patients.



## **BE A SMART PATIENT**

During your medical treatment, you can take many positive steps to help it along. You need to stay informed about what is taking place and how your recovery is

progressing. Just as important, you need to stay strong and fit, both physically and psychologically.

## How can you make the most of a medical appointment?

Open communication between you and your doctor is the goal here. To help communication along, many people like to bring a prepared list of questions to every appointment. Your list might include questions about new or continuing symptoms you're experiencing, ways to manage possible side effects of your treatment, upcoming tests, or information that has come to you through reading or talking with others. If you find your doctor unwilling to answer your questions, don't hesitate to press for a response. You might even consider changing doctors if the problem continues.

## How will you know what kind of progress you are making?

In the course of your treatment, you will likely be given tests to determine how well it's working. Discuss the results of these tests with your doctor so that you know where you stand. Knowing you are responding well provides a great lift to the spirits. But learning that you are responding less well than expected can have a positive side, too; it can be a sign that it's time for you and your doctor to consider another form of treatment. For example, if you've already tried all standard therapies, you may want to think about entering a clinical trial to try an investigational treatment.

## Can you benefit from different types of rehabilitation therapies?

Besides getting your cancer under control or into remission, the main goal of cancer treatment is to enable you to go forward with living your everyday life as normally as possible. To that end, many cancer patients can benefit from one or more forms of rehabilitation.

Some patients need physical, occupational, or speech therapy. Many patients can benefit from individual or group psychological counseling. It's not unusual for cancer patients to be overwhelmed by feelings of confusion, fear, denial, anger, or depression. Such reactions can even get in the way of successful treatment if they interfere with a patient's ability to follow medical advice or to eat and sleep properly.

Meeting with a psychologist or a psychiatrist can help you sort out your feelings and develop a positive attitude toward your situation. No one should hesitate to get professional help to deal with the emotional issues surrounding cancer.

Whatever the necessary rehabilitative program, it's important to carefully plan and integrate it into your treatment regimen. It shouldn't wait until your treatment is completed, nor should it necessarily stop at that point. Discuss this aspect of your treatment with your doctor or another member of the hospital staff.

# Do you need to follow any special diet while you are undergoing treatment?

Cancer itself, or the treatment you get for it, can cause you to lose your appetite or to taste food differently. Even so, it's important to eat well during your treatment. The right diet will help you keep up your strength and withstand the possible side effects of treatment. Your doctor may want to have a dietician help you plan well-balanced meals that are higher in calories, protein, or specific nutrients than your normal diet.

If you find cooking itself distasteful or too tiring, as some cancer patients do, you might want to request help from friends or family or call one of the organizations listed in the Resource Directory.

# How do you avoid "overdoing it" during treatment?

During your treatment and rehabilitation period, you may be more tired than usual. It can be a real mistake to try to carry on at the same pace that you were accustomed to when you were totally healthy. So you may have to ask others to take on some of the family or job responsibilities that you usually handle. You may even need to arrange a part-time work schedule for a while. In general, you should just make sure that you get all the rest and relaxation time you need—and set your highest priority on getting well.



STEP

While you are undergoing treatment, and possibly after, you may find that you need a helping hand to keep your life functioning smoothly day to day. Some people can call on a network of family and friends for help. But if you can't, or if you need more help than family and friends can provide, other sources of assistance are available to you, many of them locally based. Check with your physician or nurse for referrals to such services and see the Resource Directory for a listing of helping organizations along with their contact information.

# What kinds of home services are available locally, and where can you find out about them?

Some of the services you might need are home nursing care, provision of special medical equipment (such as a hospital-type bed), child care, meal preparation, assistance with housework, and transportation to and from local medical appointments or hospital stays. Help like this can actually preserve a patient's independence and make life more manageable.

You can find out about such resources by calling the Cancer Information Service, the American Cancer Society, and other organizations listed in the Resource Directory. You could also try your local visiting nurses association, the social services department in your local hospital or community, or local church and civic groups. Your state, county, or city health department can also assist.

# What help is available for people who need to be treated far from home?

Through special programs, free or low-cost travel and lodging can sometimes be arranged for people who need treatment far away from home. The Corporate Angel Network, a nonprofit agency, finds free seats for cancer patients on corporate aircraft. If possible, another person (or both parents of a child) is allowed to accompany the patient. People using this service must make back-up commercial reservations. The Air Care Alliance can also refer you to volunteer pilot organizations that provide free air medical transportation to those in need.

To meet lodging needs, the Guest Room Program of the American Cancer Society can arrange free hotel or motel accommodations for up to six weeks for cancer patients and their families. The families of seriously ill children can call on Ronald McDonald House for free or low-cost lodging.

## Where can you get moral support?

Many cancer patients find it both comforting and helpful to talk with other people who have experienced cancer. Moral support and practical tips from people who have "been there" can lift your spirits and help you cope with your illness.

The American Cancer Society and many other private organizations sponsor volunteer networks, ongoing support groups you can join, and camps and retreats you can attend. Besides providing a listening ear, some of these groups can also help you locate important services like those discussed above. A partial listing of support organizations appears in the Resource Directory. The Cancer Information Service or the American Cancer Society can put you in touch with others in your area.



# CONSIDER YOUR FINANCES

As part of dealing with your cancer in a realistic way, you must think through how you will pay for your care. Diagnosis and treatment are expensive. So are rehabilitation and some support services. What's more, you may not be able to work full-time during this period in your life.

People without the money or insurance to cover the bills may have to work hard to find a way to obtain first-rate medical treatment. Even people who have health insurance need to do some financial planning at this time. But no one should ever automatically assume that high quality care is not available just because money is a problem. Ironing out financial concerns early on can lift a great burden of worry from your shoulders, freeing you to focus your energy on the most important issue—getting well.

# What questions should you ask about insurance coverage?

If you are covered by an individual or group health insurance plan, you need to find out exactly what your plan will pay for. Some plans will cover only standard types of treatment and will not pay costs associated with investigational therapies. Plans vary widely on the amount that you must pay before your coverage starts (your deductible). Some plans pay for only 30 days in the hospital; others cover many more. Most plans have upper limits on what they will pay toward treatment for a given health problem on an annual or lifetime basis. Some plans will cover certain home care services; others will not. Plans pay different percentages of the cost of various services.

You should investigate your plan carefully and talk with a claims representative to clear up gray areas. You will also want to look into your disability benefits for income maintenance. Before you call your insurance company, however, it's best to talk with your doctor or a hospital financial representative. Medical personnel are often better equipped than you are to deal with insur-

ance staff and to ask the right questions about coverage. Also, they can help guide you if you find you need to dispute a denied claim.

## What if you have limited funds and no health insurance?

If you lack both insurance and the money to pay for your care, you may be able to call on the government for financial aid. The individual states (operating under federal guidelines) run the Medicaid program for people with limited means. You can find out about your eligibility for Medicaid by contacting your state or local department of social services (or welfare office).

In some states, you're automatically eligible for Medicaid if you're eligible for Supplemental Security Income (SSI). But even if you're not eligible for SSI, you may still qualify to receive Medicaid under the "medically needy" category. And some people whose income and assets exceed the "medically needy" guidelines are able to get a portion of their medical expenses paid through Medicaid once they have paid a certain amount themselves. If you are initially denied Medicaid benefits but feel that the denial is unfair, you can request an individual hearing to have your case reevaluated.

Another avenue for governmental assistance is the Veterans' Administration for those who have served in the Armed Services and their dependents.

Also, some hospitals that have been given federal aid for construction purposes are required by law to treat needy patients under the Hill-Burton program. You can find out where such hospitals are listed by calling the Hill-Burton Uncompensated Services Hotline noted in the Resource Directory. Your Department of Health and Human Services Regional Office or the Cancer Information Service can also give you this information.

# Are there any special financial aid programs for elderly or disabled people?

The federal government administers the Medicare program to provide health care benefits for people over 65 years of age and disabled persons. This program covers many significant health care costs, but certainly not everything. Many people on Medicare have additional insurance to pick up where Medicare leaves off. Some Medicare recipients are also eligible for Medicaid.

You can inquire about your eligibility for Medicare by calling your local Social Security Administration office.

## What other financial assistance is available?

Some voluntary health organizations provide small amounts of money directly to cancer patients. Among these are the Leukemia and Lymphoma Society of America and Cancer Care, Inc., in the New York/New Jersey/Connecticut area (see Resource Directory). Look for the names of other charitable organizations (such as the Salvation Army, the United Way, and organizations affiliated with a particular religion) under "Social Service Organizations" or "Social and Human Services" in the yellow pages. You might also try your church, union, or fraternal organization.

# Who can help you sort through financial issues?

Every cancer patient should discuss finances and payment options with his or her physician or with the social services or financial department of the hospital providing treatment (or with the hospital where you want to be treated).

Your doctor, nurse, or hospital financial representative can help you understand your insurance coverage and submit claims, deal with Medicare or Medicaid paperwork, and figure out how to meet the cost of any bills remaining.

Because doctors and hospitals know how expensive good care can be, they are some times willing to reduce costs or work out flexible

payment plans for patients who owe them money. Other sources of help with financial planning are your community's department of social services, the Cancer Information Service, Cancer Care (in the NY/NJ/CT area), and the American Childhood Cancer Organization (see the Resource Directory).



Many advances over the past several decades have made cancer a much more treatable, and, in some cases, curable disease. As a cancer patient, you no longer have to feel that the future is gloomy or out of your control. Take command of your future by paying attention to your own health and well-being, making sure you see your doctor for follow-up care, and looking ahead with hope and zest for living!

# How do you monitor your own health?

Once you've had an experience with cancer, you need to pay closer attention to your health than someone who has not. Some cancers do recur, most often within five years of the original diagnosis. So listen to what your body is telling you and stay on the alert for signs that something isn't right. Your doctor can tell you specifically what to watch for.

# How does the doctor provide follow-up care?

Your doctor follows up your case by scheduling regular checkups. He or she may also recommend periodic testing that will uncover a problem before it has a chance to get out of hand.

# What else can you do to stay fit?

One of healthiest things you can do following cancer treatment is get on with your life. Nowadays, cancer patients can look forward to resuming the same level of activity they enjoyed before their illness. And why not? As a cancer survivor, you will have triumphed over a very tough enemy!





Cancer is a group of as many as 200 different diseases characterized by the uncontrolled growth of abnormal cells in the body. Normal cells can become abnormal when they are exposed to **carcinogens** such as radiation (for example, ultraviolet rays of the sun), or particular drugs or chemicals. They can also turn malignant (cancerous) when they are attacked by certain viruses or when some not-yet-fully-understood internal signal occurs.

Once cells become malignant, they multiply more rapidly than usual. Then they often form masses called **tumors** that invade nearby tissue and interfere with normal bodily functions. Cancer cells also have a tendency to spread, or metastasize, to other parts of the body, where they may form a **secondary tumor**.

Cancers are classified according to the type of cell and the organ in which they start:

- Carcinoma, the most common kind of cancer, arises in the epithelium, the layers of cells covering the body's surface or lining internal organs and various glands.
- Melanoma, an increasingly prevalent form of cancer, starts in the pigment cells located among the epithelial cells of the skin.
- Sarcomas originate in the supporting (or connective) tissues of the body, such as bones, muscles, and blood vessels.
- Leukemias begin in the blood-forming tissues—the bone marrow, the lymph nodes, and the spleen—all important components of the immune system.
- **Lymphomas** are born in the cells of the lymph system, the body's circulatory network for filtering out impurities.

Within these broad classifications, cancers are often divided into more specific categories based on the cell subtype and the affected organ.

Cancers are also classified in terms of how far and to what organs they have spread:

- An *in situ* cancer is one that is confined to the place where it originated.
  - An invasive cancer has spread to surrounding tissues.
  - A metastasized cancer has invaded distant sites in the body.

In diagnosing cancer, a doctor takes all these aspects of classification into account to arrive at a decision on what type of cancer a patient has and what stage it is in. Proper diagnosis and treatment depend on accurate classification.



Cancer treatment can take many different forms, and it is always tailored to the individual patient. Many factors must be considered in making a decision on treatment: the type and location of the cancer; the extent to which it has already spread and can be expected to spread; and the patient's age, sex, general health, and personal treatment preferences. The goal of treatment can be either bringing cancer under control or into remission, or relief from disease symptoms.

The four major types of treatment are **surgery**, **radiation**, **chemotherapy**, and **immunotherapy**. These treatments are sometimes used alone and sometimes in combination. When one treatment is used to supplement another, the supplementary treatment is called **adjuvant therapy**.

- Surgery—the removal of a malignant tumor in an operation—is the oldest and most frequently used cancer treatment. It is most effective when a cancer is small and localized (confined to one area of the body). If a tumor has spread, the nearby tissues and lymph glands are removed along with the malignant growth in an operation called radical surgery.
- Radiation works by destroying cancer cells. It can take two different forms—external and internal. In external beam radiation, a machine sends x-rays or gamma rays into the tumor. In internal radiation, a radioactive substance, like radium, is put into the body by means of a pill, injection, or insertion in a sealed container. Radioactive particles may also be attached to proteins, called monoclonal antibodies, that home to tumor cells or supportive tissues and deliver their radioactive payload in a more targeted way. Radiation is often used alone in cases where a tumor is unsuitable for surgery or particularly receptive to destruction through radiation. It may also be used in conjunction with surgery (before and after) and sometimes with chemotherapy.

- Chemotherapy kills cancer cells through the use of drugs or hormones. Taken either orally or through injection, chemotherapeutic agents are used to treat a wide variety of cancers. They may be given alone or in combination with surgery or radiation or both. Chemotherapy is an established way to destroy hard-to-detect cancer cells that have spread and are circulating in the body.
- Immunotherapy uses the body's own immune system to destroy cancer
  cells. This form of treatment is still being intensively studied in clinical trials; it
  is currently available only to some cancer patients. The various immunological
  agents used include substances produced by the body (such as the interferons, the interleukins, and tumor necrosis factor) and laboratory-produced substances (such as monoclonal antibodies and vaccines). Immunological agents
  work in different ways and can be used independently or in combination with
  other forms of treatment.

Some people hesitate to take advantage of the best type of treatment for their cancer because they fear the possible **side effects**. It is true that people undergoing radiation or chemotherapy often experience such symptoms as fatigue, loss of appetite, skin problems, hair loss, nausea, or oral/dental problems. The severity of these conditions, however, varies from one patient to the next and many times can be controlled. In any case, the side effects of cancer therapy usually are not permanent conditions, and enduring them for a time is well worth the potential benefit of effective treatment.

The National Cancer Institute (NCI) is the federal government's agency for cancer research and control. Part of the National Institutes of Health in Bethesda, Maryland, NCI conducts research on cancer prevention, diagnosis, treatment, and rehabilitation in its own laboratories. It is also a major source of funding for such research by scientists at many other institutions throughout the United States.

On the cancer control front, NCI provides information about all aspects of cancer to both health professionals and the general public. In addition, the agency offers investigational treatment programs for patients meeting specific criteria at the NIH Clinical Center and evaluates and supports other cancer treatment facilities nationwide.

Cancer patients and their families can take advantage of NCI's vast resources for information and assistance by calling on the following NCI-supported services and facilities:

### Cancer Information Service (1-800-4-CANCER)

The Cancer Information Service (CIS) can answer a wide variety of questions about the causes of cancer, cancer prevention, specific types of cancer, as well as ways to detect, treat, and otherwise cope with the disease. Free booklets are available on these topics.

Besides giving out general information, CIS staff can refer patients to local and regional hospitals and physicians that can provide first or second opinions or medical care. CIS can also refer patients to local organizations that provide support services. These services include rehabilitation (physical, occupational, and speech therapy), psychological counseling and support groups, home care (nursing, medical equipment, housekeeping, child care, and meal preparation), transportation and lodging away from home, and advice on financial aid. CIS can be reached between 8:00 a.m. and 8:00 p.m. (Eastern Standard Time) on Monday through Friday. Spanish-speaking staff are available.

## Physician Data Query (PDQ)

PDQ is NCI's computerized service for providing both doctors and patients with upto-date information on cancer treatment. This database lists current treatment options for specific types of cancer at particular stages. It also notes what clinical trials are being conducted to test investigational therapies and where they are taking place. Patients may find information from PDQ useful as a way to confirm their physician's choice of treatment or to learn about clinical trials located in their area. The CIS staff can search the database if they know a patient's diagnosis, the location of the primary cancer and the stage of disease. Since the information provided can be fairly technical, patients should plan to discuss it with their doctors.

PDQ information can be obtained by calling the Cancer Information Service at 1(800)422-6237. Most doctors can access PDQ as an on-line service through the National Library of Medicine or through several commercial vendors.

### **NCI-Affiliated Cancer Treatment Facilities**

As part of its commitment to improving treatment for cancer patients, NCI financially supports and oversees several types of facilities that have the latest diagnostic and treatment capabilities. These facilities also conduct extensive research, enabling them to offer patients the opportunity to receive investigational treatments being tested in clinical trials.

The Clinical Center of the National Institutes of Health in Bethesda is NCI's "home base" for conducting selected clinical trials. Patients who qualify for trials at the NIH Clinical Center receive their treatment free of charge.

NCI-Designated Cancer Centers and Comprehensive Cancer Centers offer a broader range of diagnostic and treatment services, as well as patient referrals. These national leaders in the fight against cancer are located throughout the United States. All have demonstrated that they do high-quality work in providing patient care, in finding new ways to prevent, detect, and control cancer, and in furnishing professional training and public information. The Comprehensive Cancer Centers are further distinguished by their fulfillment of even more rigorous criteria set by the National Cancer Advisory Board.

In an effort to make sure the newest cancer treatments are getting to other hospitals and clinics, NCl also supports **Community Clinical Oncology Programs** (CCOPs) and **Clinical Trials Cooperative Groups** (which focus on particular types of cancer or cancer therapies). Through these two programs, community hospitals, clinics, and physician groups are able to participate in clinical trials and bring excellent cancer care to local patients.

Telephone numbers and website URLs for NCI's many services and related facilities are listed in the Resource Directory.

**Investigational treatments** are promising means of treating cancer that are still in the testing stages. Investigational treatments include new chemotherapeutic agents or new combinations of such agents, different ways of administering radiation therapy, new techniques for using two or more standard treatments in conjunction, a large number of immunological therapies (alone and in combination with other therapies), targeted therapies (such as small molecules), and other forms of treatment.

The testing of investigational treatments is done in highly regulated and carefully controlled patient studies called **clinical trials**, many of which are sponsored by the National Cancer Institute. These trials are responsible for numerous advances in cancer treatment because they provide scientific proof that new therapies are safe and effective for patients.

Many built-in safeguards protect patients in clinical trials. To be used in a clinical trial, an investigational drug must be approved for investigational use by the Food and Drug Administration (FDA). The trial itself is subject to the same ethical and legal codes that apply to medical practice in general. It must be approved by an Institutional Review Board composed of doctors, other medical staff, scientists, clergy, and citizens from the community or institution where the trial is to take place.

All clinical trials must follow a specific **protocol**, or plan, that is designed to answer specific questions and to guard a patient's health and well-being. Patients are admitted to a clinical trial only if their medical conditions meet the specifics of the protocol. Those who take part must sign an informed-consent form to indicate that they understand the potential benefits and risks involved. Each participant's medical progress is monitored on an ongoing basis.

Trials take many different forms. Some trials test a single treatment on a single group of people. Others compare a new treatment with the best known standard therapy, using two groups of patients with similar disease characteristics. In such trials, the group receiving the standard therapy is called the **control group**. Sometimes the control group receives no therapy at all—but only in cases where no effective therapy exists for the type and stage of cancer being studied.

Clinical trials are conducted in four separate phases aimed at discovering certain types of information about the treatment in question:

- Phase I trials are meant to determine safe dosage and side effects. They are conducted with a small number of patients. Only people with advanced cancer who cannot be helped with standard treatments take part.
- Phase II trials seek to gauge the effectiveness of a treatment for different types of cancer.
- Phase III trials compare the new treatment with the best known standard treatment(s) to decide which is better.
- Phase IV trials establish the new treatment as a standard therapy for patient use.

No treatment moves from one phase to the next unless it proves its potential in the previous phase.

Patients in clinical trials have the first opportunity to benefit from new treatments—and can be assured that great care will be taken to protect their welfare. If an investigational treatment appears to be having unexpected harmful results, the trial is stopped immediately. And once test results indicate that an investigational treatment is clearly more helpful than standard treatments, all patients in a comparative testing situation begin receiving the new treatment. Furthermore, participation is voluntary from the start of a trial to its finish. A patient can drop out at any point and receive the best known standard therapy.

People involved in clinical trials can have the added satisfaction of knowing that they have personally helped advance cancer treatment.

Additional information on clinical trials can be found online at www.clinicaltrials.gov, a service of the National Institutes of Health.



## RESOURCE DIRECTORY

National Cancer Institute
Cancer Information Service

Other Organizations Providing Referrals for Second Opinions and Medical Help

Medical Facilities for Diagnosis and Treatment or Second Opinions

Groups Providing Financial Information or Support

Groups Offering
Cancer Information, Moral Support and
Coping Techniques, or
Patient Advocacy

Sources of Information on
Home Nursing and Medical Equipment,
Homemaker Services, Child Care, Meal Preparation,
or Local Transportation

Groups Furnishing
Free or Low-Cost Transportation or Lodging for
Cancer Patients Being Treated Away From Home

Reading Material for Further Information

If you have difficulty reaching any of the organizations listed in this directory, please call us at:

Cancer Research Institute 1-800-99-CANCER

We also welcome your comments on this booklet and your suggestions for improvement.



The Cancer Information Service of the National Cancer Institute offers comprehensive information on cancer and its treatment and refers patients to medical, rehabilitation, and support services. In a category by itself, the Cancer Information Service is the one resource that can put cancer patients in touch with all other local, regional, and national organizations that can provide assistance.

### National Cancer Institute Cancer Information Service

1-800-4-CANCER (1-800-422-6237) www.cancer.gov

### OTHER ORGANIZATIONS PROVIDING REFERRALS FOR SECOND OPINIONS AND MEDICAL HELP

#### **AMC Cancer Fund**

Cancer Information and Counseling Line 303-233-6501 in Colorado 1-800-321-1557 www.amc.org

### **American Cancer Society**

404-320-3333 1-800-ACS-2345 (1-800-227-2345) See a local telephone directory for the number of a local unit. www.cancer.org

# American Childhood Cancer Organization

301-962-3520 1-800-366-2223 www.candlelighters.org

# American Society of Clinical Oncology (ASCO)

517-483-1300 www.asco.org

#### CancerCare

212-712-8400 1-800-813-HOPE (1-800-813-4673) www.cancercare.org

#### **CancerNet**

888-651-3038 www.cancer.net

#### R.A. Bloch Cancer Foundation

816-854-5050 1-800-433-0464 www.blochcancer.org

### MEDICAL FACILITIES FOR DIAGNOSIS AND TREATMENT OR SECOND OPINIONS

# NCI-Designated Cancer Centers (including Comprehensive Cancer Centers\*)

#### ALABAMA

# University of Alabama Comprehensive Cancer Center\*

1802 Sixth Avenue South, Room NP 2500 Birmingham, AL 35294-3300 205-934-5077 1-800-UAB-0933 or 205-975-8222 www.ccc.uab.edu

#### ARIZONA

#### The Arizona Cancer Center\*

3838 North Campbell Avenue Tucson, AZ 85719 520-694-CURE (520-694-2873) 1-800-327-CURE (1-800-327-2873) www.azcc.arizona.edu

#### **CALIFORNIA**

# Chao Family Comprehensive Cancer Center\*

University of California at Irvine 101 The City Drive Building 23, Route 81 Orange, CA 92868 714-456-7890 www.cancer.uci.edu

### City of Hope National Medical Center\*

Beckman Research Institute 1500 East Duarte Road Duarte, CA 91010 1-800-826-HOPE (1-800-826-4673) www.cityofhope.org

# Jonsson Comprehensive Cancer Center\*

University of California at Los Angeles 8-684 Factor Building Box 951781 10833 Le Conte Avenue Los Angeles, CA 90095-1781 310-825-5268 www.cancer.mednet.ucla.edu

### Salk Institute Cancer Center

10010 North Torrey Pines Road La Jolla, CA 92037 858-453-4100 http://salk.edu/faculty/cancer\_center.html

# Sanford-Burnham Medical Research Institute

10901 North Torrey Pines Road La Jolla, CA 92037 858-646-3100 www.sanfordburnham.org

#### **Stanford Cancer Center**

Stanford University 800 Welch Road, Room 284 Stanford, CA 94305-5796 650-736-1808 http://cancer.stanford.edu/

# USC/Norris Comprehensive Cancer Center\*

University of Southern California 1441 Eastlake Avenue Los Angeles, CA 90033-0800 323-865-3000 1-800-USC-CARE (1-800-872-2273) http://uscnorriscancer.usc.edu/

# University of California at San Diego Moores Cancer Center\*

3855 Health Sciences Drive La Jolla, CA 92093 1-800-926-8273 http://cancer.ucsd.edu

### **UC Davis Cancer Center**

University of California, Davis 4501 X Street, Suite 3003 Sacramento, CA 95817 916-734-5800 www.ucdmc.ucdavis.edu/cancer

# UCSF Helen Diller Family Comprehensive Cancer Center\*

University of California, San Francisco 1450 HD-371, UCSF Box 0128 San Francisco, CA 94158-9001 1-888-689-8273 http://cancer.ucsf.edu/

#### **COLORADO**

#### University of Colorado Cancer Center\*

University of Colorado at Denver and Health Sciences Center P.O. Box 6508, Mail Stop F434 13001 East 17th Place Aurora, CO 80045 720-848-0000 www.uccc.info

#### CONNECTICUT

#### Yale Cancer Center\*

Yale University School of Medicine 333 Cedar Street, Box 208028 New Haven, CT 06520 1-866-YALECANCER (1-866-925-3262) www.info.med.yale.edu/ycc

#### DISTRICT OF COLUMBIA

# Lombardi Comprehensive Cancer Center\*

Georgetown University Medical Center 3800 Reservoir Road Washington, DC 20057 202-444-4000 http://lombardi.georgetown.edu

### **FLORIDA**

# H. Lee Moffitt Cancer Center & Research Institute\*

University of South Florida 12902 Magnolia Drive Tampa, FL 33612 1-888-MOFFITT (1-888-663-3488) http://www.moffitt.org

#### **GEORGIA**

#### Winship Cancer Institute

Emory University 1365-C Clifton Road, NE Atlanta, GA 30322 404-778-1900 1-888-WINSHIP (1-888-946-7447) http://winshipcancer.emory.edu

#### **HAWAII**

#### **University of Hawaii Cancer Center**

University of Hawaii at Manoa 677 Ala Manoa Boulevard Honolulu, HI 96813 808-586-3010 www.crch.org

#### <u>ILLINOIS</u>

# Robert H. Lurie Comprehensive Cancer Center\*

Northwestern University Galter Pavilion 675 North St. Clair, 21st Floor Chicago, Illinois 60611 312-695-0990 1-866-LURIECC (1-866-587-4322) www.cancer.northwestern.edu

# University of Chicago Comprehensive Cancer Center\*

5841 South Maryland Avenue Chicago, Illinois 60637-1470 773-702-6180 1-800-289-6333 http://cancer.uchicago.edu

### **INDIANA**

#### Indiana University Melvin and Bren Simon Cancer Center

1030 West Michigan Street Indianapolis, Indiana 46202 317-944-0920 1-888-600-4822 www.cancer.iu.edu/

# Purdue University Center for Cancer Research

Hansen Life Sciences Research Building, Room 141 201 South University Street West Lafayette, IN 47907-2064 765-494-9129 www.cancerresearch.purdue.edu/

## **IOWA**

## Holden Comprehensive Cancer Center\*

University of lowa 5970 "Z" JPP lowa City, IA 52242 319-353-8620 www.uihealthcare.com

### MAINE

# The Jackson Laboratory Cancer Center

600 Main Street Bar Harbor, ME 04609-0800 207-288-6000 http://research.jax.org

## **MARYLAND**

## **Greenebaum Cancer Center**

University of Maryland 22 South Greene Street Baltimore, MD 21201 410-328-7904 1-800-888-8823 http://www.umgcc.org

# Sidney Kimmel Comprehensive Cancer Center at John Hopkins\*

The Harry and Jeanette Weinberg Building 401 North Broadway Suite 1100 Baltimore, MD 21231 410-955-5222 http://www.hopkinsmedicine.org MASSACHUSETTS

### Dana-Farber Cancer Institute\*

450 Brookline Avenue Boston, MA 02115-5450 617-632-3000 1-866-408-DFCI (1-866-408-3324) www.dana-farber.org

# David H. Koch Institute for Integrative Cancer Research

Massachusetts Institute of Technology 500 Main Street Cambridge, MA 02139 617-253-6403 http://ki.mit.edu

### **MICHIGAN**

# Barbara Ann Karmanos Cancer Institute\*

Wayne State University School of Medicine 4100 John R. Street Detroit, MI 48201 1-800-KARMANOS (1-800-527-6266) www.karmanos.org

# University of Michigan Comprehensive Cancer Center\*

1500 East Medical Center Drive Ann Arbor, MI 48109-0752 1-800-865-1125 www.cancer.med.umich.edu

# **MINNESOTA**

## **Masonic Cancer Center\***

University of Minnesota 424 Harvard Street SE Minneapolis, MN 55455 612-624-2620 1-888-CANCERMN (1-888-226-2376) www.cancer.umn.edu

## **Mayo Clinic Cancer Center\***

200 First Street Southwest Rochester, MN 55905 507-284-2511 http://cancercenter.mayo.edu

### **MISSOURI**

### Siteman Cancer Center\*

Washington University School of Medicine 660 South Euclid Avenue Box 8100 St. Louis, MO 63110 314-747-7222 1-800-600-3606 www.siteman.wustl.edu

### **NEBRASKA**

## **Eppley Cancer Center**

University of Nebraska Medical Center 985950 Nebraska Medical Center Omaha, NE 68198-5950 402-559-4090 www.unmc.edu/cancercenter

## **NEW HAMPSHIRE**

## **Norris Cotton Cancer Center\***

Dartmouth-Hitchcock Medical Center One Medical Center Drive Lebanon, NH 03756 603-653-9000 http://cancer.dartmouth.edu

# **NEW JERSEY**

# Cancer Institute of New Jersey\*

Robert Wood Johnson Medical School 195 Little Albany Street New Brunswick, NJ 08903-2681 732-235-2465 www.cinj.org

### **NEW MEXICO**

# University of New Mexico Cancer Research and Treatment Center

1201 Camino de Salud NE 1 University of New Mexico Albuquerque, New Mexico 87106 505-272-4946 http://cancer.unm.edu

## **NEW YORK**

### Albert Einstein Cancer Center

1300 Morris Park Avenue Bronx, New York 10461 718-430-2000 www.einstein.yu.edu/cancercenter

# Herbert Irving Comprehensive Cancer Center\*

Columbia University College of Physicians and Surgeons 1130 St. Nicholas Avenue New York, New York 10032 212-851-5273 http://hiccc.columbia.edu

# Memorial Sloan-Kettering Cancer Center\*

1275 York Avenue New York, New York 10065 1-800-525-2225 www.mskcc.org

# New York University Cancer Institute

New York University Langone Medical Center 522 First Avenue New York, New York 10016 212-263-3551 www.nyuci.org

#### Roswell Park Cancer Institute\*

Elm and Carlton Streets Buffalo, NY 14263-0001 1-800-ROSWELL (1-800-767-9355) www.roswellpark.org

### NORTH CAROLINA

# Wake Forest University Comprehensive Cancer Center\*

Wake Forest University Baptist Medical Center Medical Center Boulevard Winston-Salem, NC 27157-1082 1-888-716-WAKE www.wfubmc.edu/comprehensive-cancercenter

### **Duke Cancer Institute\***

Duke University Medical Center 2424 Erwin Road Hock Plaza Suite 601 Durham, NC 27705 1-888-ASK-DUKE www.cancer.duke.edu

# UNC Lineberger Comprehensive Cancer Center\*

University of North Carolina at Chapel Hill 101 Manning Drive Chapel Hill, NC 27514 1-866-869-1856 www.cancer.unc.edu

## <u>OHIO</u>

# Case Comprehensive Cancer Center\*

Case Western Reserve University
11100 Euclid Avenue, Wearn 152
Cleveland, OH 44106-5065
216-844-8797
http://cancer.case.edu/
Ohio State University Comprehensive

#### Cancer Center\*

521 James Cancer Hospital 300 West 10th Avenue Columbus, OH 43210 614-293-7521 http://osuccc.osu.edu

## **OREGON**

## **OHSU Knight Cancer Institute**

Oregon Health and Science University 3181 S.W. Sam Jackson Park Road Portland, OR 97239-3098 503-494-8311 www.ohsu.edu/xd/health/services/cancer/

## **PENNSYLVANIA**

# Abramson Cancer Center of the University of Pennsylvania\*

3400 Spruce Štreet, 16th Floor Philadelphia, PA 19104-4383 1-800-789-PENN (1-800-789-7366) www.penncancer.org

### Fox Chase Cancer Center\*

333 Cottman Avenue Philadelphia, PA 19111 215-728-2570 1-888-FOX-CHASE (1-888-369-2427) www.fccc.edu

# University of Pittsburgh Cancer Institute\*

5150 Centre Avenue Pittsburgh, PA 15232 412-647-2811 www.upci.upmc.edu

### **Kimmel Cancer Center**

Thomas Jefferson University BLSB, Room 1050 233 South 10th Street Philadelphia, PA 19107 1-888-955-1212 1-800-JEFFNOW (1-800-533-3669) www.kimmelcancercenter.org

### The Wistar Institute

3601 Spruce Street Philadelphia, PA 19104 215-898-3700 www.wistar.org

### **SOUTH CAROLINA**

### **Hollings Cancer Center**

Medical University of South Carolina 86 Jonathan Lucas Street Charleston, SC 29425 843-792-0700 http://hcc.musc.edu

## **TENNESSEE**

## St. Jude Children's Research Hospital\*

262 Danny Thomas Place Memphis, TN 38105 901-595-3300 www.stjude.org

# Vanderbilt-Ingram Cancer Center\*

Vanderbilt University Medical Center 2220 Pierce Avenue Nashville, TN 37232 615-936-8422 1-877-936-8422 www.vicc.org

### **TEXAS**

## **Cancer Therapy and Research Center**

University of Texas Health Science Center at San Antonio 7979 Wurzbach Road San Antonio, TX 78229 210-450-1000 www.ctrc.net

### Dan L. Duncan Cancer Center

Baylor College of Medicine One Baylor Plaza Houston, TX 77030 713-798-1354 www.bcm.edu/cancercenter

## **Harold C. Simmons Cancer Center**

University of Texas Southwestern Medical Center 2201 Inwood Road Dallas, TX 75390 214-645-HOPE (214-645-4673) 1-866-460-HOPE (1-866-460-4673) www.simmonscancercenter.org

# The University of Texas M.D. Anderson Cancer Center\*

1515 Holcombe Boulevard Houston, TX 77030 1-877-MDA-6789 (1-877-632-6789) www.mdanderson.org

## **UTAH**

### **Huntsman Cancer Institute**

University of Utah 2000 Circle of Hope Salt Lake City, UT 84112 801-585-0303 1-877-585-0303 www.hci.utah.edu

### VIRGINIA

## **University of Virginia Cancer Center**

1300 Jefferson Park Avenue Charlottesville, VA 22908 434-924-9333 1-800-223-9173 www.medicine.virginia.edu/research/ research-centers/cancercenter

### Massey Cancer Center

Virginia Commonwealth University 401 College Street Box 980037 Richmond, VA 23298 804-828-0450 www.massey.vcu.edu

### WASHINGTON

# Fred Hutchinson Cancer Research Center\*

1100 Fairview Avenue North P.O. Box 19024 Seattle, WA 98109 206-667-5000 1-800-804-8824 www.fhcrc.org

### **WISCONSIN**

# University of Wisconsin Paul P. Carbone Comprehensive Cancer Center\*

600 Highland Avenue, Room 7057 Madison, WI 53792-0001 608-263-6400 1-800-323-8942 www.cancer.wisc.edu

# CLINICAL TRIALS COOPERATIVE GROUPS

# American College of Radiology Imaging Network

Mitchell Schnall, M.D., Ph. D., Chair 1818 Market Street, Suite 1600 Philadelphia, Pennsylvania 19103 www.acrin.org

# American College of Surgeons Oncology Group

Heidi Nelson, M.D.., Co-Chair David M. Ota, M.D., Co-Chair 2400 Pratt Street Durham, North Carolina 27705 www.acosog.org

## Cancer and Leukemia Group B

Richard Schilsky, M.D., Chair 230 West Monroe Street, Suite 2050 Chicago, Illinois 60606 773-702-9171 www.calgb.org

#### **Cancer Vaccine Collaborative**

Cancer Research Institute
One Exchange Plaza
55 Broadway, Suite 1802
New York, NY 10006
212-688-7515
www.cancerresearch.org/collaborative

# CureSearch Children's Oncology Group

Gregory Reaman, M.D., Chair 440 East Huntington Drive, Suite 400 Arcadia, California 91006-3776 800-458-6223 www.curesearch.org

# **Eastern Cooperative Oncology Group**

Robert Comis, M.D., Chair 1818 Market Street, Suite 1100 Philadelphia, PA 19103 215-789-3645 www.ecog.org

# European Organization for Research on Treatment for Cancer

Francois Meunier, M.D., Director General Avenue E Mounier 83, BTE 11 BT-1200 Brussels Belgium 011-32-2-770-71-47 (NCI Liaison Office) www.eortc.be

## **Gynecologic Oncology Group**

Philip J. DiSala, M.D., Chair Four Penn Center 1600 JFK Boulevard, Suite 1020 Philadelphia, PA 19103 215-854-0770 www.gog.org

## National Cancer Institute of Canada, Clinical Trials Group

Ralph Meyer, M.D., Director Queens University 10 Stuart Street Kingston, Ontario K7L 3N6 Canada www.ctg.queensu.ca

# National Surgical Adjuvant Breast and Bowel Project

Norman Wolmark, M.D., Chair East Commons Professional Building 4 Allegheny Center 5th Floor Pittsburgh, PA 15212 412-330-4600 http://nsabp.pitt.edu

## **North Central Cancer Treatment Group**

Jan C. Buckner, M.D., Chair Mayo Clinic 200 First Street, SW Rochester, MN 55905 507-284-5999 http://ncctg.mayo.edu

## **Radiation Therapy Oncology Group**

Walter Curran Jr., M.D., Chair 1818 Market Street, Suite 1600 Philadelphia, PA 19107 215-574-3191 www.rtog.org

# SWOG (formerly Southwest Oncology Group)

Lawrence H. Baker, DO, Chair 24 Frank Lloyd Wright Drive P.O. Box 483 Ann Arbor, MI 48106 734-998-7130 www.swog.org

# GROUPS PROVIDING FINANCIAL INFORMATION OR SUPPORT

### Cancer Care, Inc.

212-712-8400 1-800-813-HOPE (1-800-813-4673) www.cancercare.org

# Cancer Financial Assistance Coalition

www.cancerfac.org

# Candlelighters Childhood Cancer Family Alliance

713-270-4700 www.candle.org

# Hill-Burton Uncompensated Services Hotline

U.S. Department of Health and Human Services 1-800-492-0359 (in Maryland) 1-800-638-0742 www.hrsa.gov/gethealthcare/affordable/ hillburton

## Leukemia and Lymphoma Society of America

(National Headquarters) 914-949-5213

1-800-955-4572

See a local telephone directory for the number of a local unit.

www.leukemia-lymphoma.org

**GROUPS OFFERING** CANCER INFORMATION, **MORAL SUPPRT AND** COPING TECHNIOUES. OR PATIENT ADVÔCACÝ

## **Air Charity Network**

1-800-549-9980

www.aircharitvnetwork.org

### AMC Cancer Fund

Cancer Information and Counseling Line 303-233-6501 in Colorado

1-800-321-1557

www.amc.org

# American Association for Cancer Research (AACR)

215-440-9300

1-866-423-3965

www.aacr.org

# American Brain Tumor Association (ABTA)

847-827-9910

1-800-886-2282

www.abta.org

# American Cancer Society

(National Headquarters)

404-320-3333

1-800-ACS-2345 (1-800-227-2345)

www.cancer.org

# American Cancer Society Cancer Action Network (ACS CAN)

1-800-ACS-2345 (1-800-227-2345)

www.acscan.org

# American Childhood Cancer Organization

301-962-3520

1-800-366-2223

www.candlelighters.org

## **American College of Surgeons:** Commission on Cancer

312-202-5085

1-800-621-4111

www.facs.org/cancer/index.html

## **American Hospice Foundation**

202-223-0204

1-800-347-1413

www.americanhospice.org

### American Pain Foundation

1-888-615-PAIN (1-800-615-7246) www.painfoundation.org

## **American Psychosocial Oncology** Society

434-293-5350

www.apos-society.org

# American Society for Radiation Oncology

703-502-1550

1-800-962-7876

www.astro.org/Patients/

## **American Society of Breast Surgeons**

410-992-5470

1-877-992-5470

www.breastsurgeons.org

# American Society of Clinical Oncology (ASCO)

517-483-1300 www.asco.org

# American Urological Association Foundation

410-689-3700 1-866-RINGAUA (1-866-746-4282 www.urologyhealth.org

# Anderson Network, A Program of Volunteer Services

1-800-345-6324 www.mdanderson.org/andersonnetwork

# Arab Community Center for Economic and Social Services (ACCESS)

313-842-7010 www.accesscommunity.org

# Association of Cancer Online Resources

www.acor.org

# Association of Community Cancer Centers (ACCC)

301-984-9496 www.accc-cancer.org

# Association of Oncology Social Workers (AOSW)

215-599-6093 www.aosw.org

# Association of Pediatric Hematology/ Oncology Nurses (APHON)

847-375-4724 www.apon.org

# Blood and Marrow Transplant Information Network

847-433-3313 1-888-597-7674 (during regular business hours) www.bmtinfonet.org

## **Cancer and Careers**

212-685-5955, ext. 32 www.cancerandcareers.org

### **Cancer Hope Network**

908-879-4039 1-800-552-4366 www.cancerhopenetwork.org

# Cancer Information and Counseling Line (CICL)

1-800-525-3777 www.amc.org/programs.html

## **Cancer Legal Resource Center**

1-866-843-2572 www.cancerlegalresourcecenter.org

## Cancer News on the Net

www.cancernews.com

# Cancer Pain Management in Children

www.childcancerpain.org

# **Cancer Research Foundation**

312-630-0055

www.cancerresearchfdn.org

# **Cancer Support Community**

202-659-9709

1-888-793-WELL (1-888-793-9355)

http://cancersupportcommunity.org

# **Cancer Survivors Gathering Place**

www.cancersurvivorsplace.org

## **Cancer Trials Support Unit**

1-888-691-8039 www.ctsu.org

### CancerCare. Inc.

212-712-8400 1-800-813-HOPE (1-800-813-4673) www.cancercare.org

### CANCER101: Basics for the

Diagnosed 646-638-2202 www.cancer101.org

### CancerGuide

www.cancerguide.org

### CancerHelp

www.cancerhelp.8m.com

## CancerQuest

404-727-0308 www.cancerquest.org

# CaringBridge

651-789-2300 www.caringbridge.org

## Center for Mind-Body Medicine

202-966-7338 www.cmbm.org

# Center to Advance Palliative Care

(CAPC) 212-201-2670 www.capc.org

# Centers for Disease Control and Prevention (CDC)

404-639-3311 1-800-311-3435 www.cdc.gov

## **Children's Brain Tumor Foundation**

1-866-228-4673 www.cbtf.org

# Children's Cause for Cancer Advocacy

202-336-8375 www.childrenscause.org

## Children's Hospice International

703-684-0330 1-800-24-CHILD (1-800-242-4453) www.chionline.org

# Children's Organ Transplant Association

1-800-366-COTA (1-800-366-2682) www.cota.org

# City of Hope Pain and Palliative Resource Center

626-256-HOPE, ext. 63829 (646-256-4673, ext. 63829) www.prc.coh.org

## Closure

www.closure.org

# **Coalition of Cancer Cooperative Groups**

1-877-227-8451

www.cancertrialshelp.org

# **College of American Pathologists**

1-800-323-4040, ext. 7439 www.MyBiopsy.org

#### Conversations!

The International Newsletter For Those Fighting Ovarian Cancer! 210-401-1604 www.ovarian-news.org

### **Corporate Angel Network**

914-328-1313 1-866-328-1313 www.corpangelnetwork.org

### CureSearch for Children's Cancer

1-800-458-6223 www.nccf.org

## Dia de La Mujer Latina

281-489-1111 www.diadelamujerlatina.org

# **Education Network to Advance Cancer** Clinical Trials (ENACCT)

240-482-4730 www.enacct.org

# **Exceptional Cancer Patients (ECaP)**

814-337-8192 www.ecap-online.org

## **FDA Cancer Liaison Program**

1-888-INFOFDA (1-888-463-6332) www.fda.gov

# Federation of American Societies for Experimental Biology (FASEB)

301-634-7000 www.faseb.org

# Hope for Two: The Pregnant with Cancer Network

1-800-743-4471 www.pregnantwithcancer.org

### **Hospice Education Institute**

207-255-8800 1-800-331-1620 www.hospiceworld.org

## **Hospice Foundation of America**

202-457-8511 www.hospicefoundation.org

# ICare: International Cancer Alliance for Cancer Research Education

301-656-3461 www.icare.org

# I'm Too Young for This! Cancer Foundation

1-877-735-4673 http://stupidcancer.com

# **Imerman Angels**

1-877-274-5529 www.imermanangels.org

## Inspire

703-243-0303 1-800-945-0381 www.inspire.com

## **Intercultural Cancer Council (ICC)**

713-798-4617 http://iccnetwork.org

# International Association for Hospice and Palliative Care (IAHPC)

936-321-9846 1-866-374-2472 www.hospicecare.com

## **International Myeloma Foundation**

818-487-7455 1-800-452-CURE (1-800-452-2873) www.myeloma.org

## **International Psycho-Oncology Society**

434-293-5350

www.ipos-society.org

# Jack and Jill Late Stage Cancer Foundation

404-537-5253

http://jajf.org/home/

### **Kidney Cancer Association**

847-332-1051

1-800-850-9132

www.kidneycancer.org

# Leukemia and Lymphoma Society of America

914-949-5213

1-800-955-4572

www.leukemia-lymphoma.org

# Lymphoma Research Foundation of America

212-349-2910

1-800-500-9976

www.lymphoma.org

# **Lesbian Community Cancer Project**

773-561-4662

www.lccp.org

### LIVESTRONG

512-236-8820

1-866-236-8820

www.livestrong.org

## Look Good...Feel Better (LGFB)

202-331-1770

1-800-395-5665

www.lookgoodfeelbetter.org

# Lotsa Helping Hands

www.lotsahelpinghands.com

## **Lung Cancer Alliance**

1-800-298-2436

http://lungcanceralliance.org/

## **Mautner Project**

202-332-5536

1-866-MAUTNER

(1-866-628-8637)

www.mautnerproject.org

## Men's Health Network

202-543-6461

www.menshealthnetwork.org

## **Minnie Pearl Cancer Foundation**

615-467-1936

1-877-467-1936

www.minniepearl.org

## MyOncofertility.org

1-866-708-3378

www.myoncofertility.org

# National Asian Women's Health Organization

925-468-4120

www.nawho.org

#### **National Association for Home Care**

202-547-7424

www.nahc.org

## **National Bone Marrow Transport Link**

1-800-LINK-BMT (1-800-546-5268)

www.nbmtlink.org

#### **National Brain Tumor Foundation**

1-800-770-8287

www.braintumor.org

### **National Breast Cancer Foundation**

972-248-9200

www.nationalbreastcancer.org

### **National Cancer Coalition**

919-821-2182

www.nationalcancercoalition.org

### **National Cancer Institute (NCI)**

1-800-4-CANCER

(1-800-422-6237)

www.cancer.gov

# National Cancer Survivors Day Foundation

615-794-3006

www.ncsdf.org

# National Center for Complementary and Alternative Medicine

301-519-3153

1-888-644-6226

www.nccam.nih.gov

# National Coalition for Cancer Survivorship

301-650-9127

1-877-NCCS-YES

(1-877-622-7937)

www.canceradvocacy.org

# National Comprehensive Cancer Network

215-690-0300

www.nccn.com

## National Family Caregivers Association

301-942-6430

001 JTL 0700

1-800-896-3650

www.nfcacares.org

### **National Health Information Center**

301-565-4167

1-800-336-4797

www.health.gov/nhic

# National Hospice and Palliative Care Organization

703-837-1500

1-877-658-8896

1-877-658-8898

www.nhpco.org

## **National Lymphedema Network**

415-908-3681

1-800-541-3259

www.lymphnet.org

## **National Marrow Donor Program**

1-800-MARROW2

(1-800-627-7692)

www.marrow.org

### National Ovarian Cancer Coalition 214-

273-4200

1-888-OVARIAN (1-888-682-7426)

www.ovarian.org

### **National LGBT Cancer Network**

212-675-2633

www.cancer-network.org

### **National Library of Medicine**

301-594-5983

1-888-FIND-NLM

(1-888-346-3656)

www.nlm.nih.gov

# National Organization for Rare Disorders (NORD)

203-744-0100

1-800-999-6673

www.rarediseases.org

### Native American Cancer Research

303-975-2449 1-800-537-8295

http://natamcancer.org

# New York Online Access to Health (NOAH)

www.noah-health.org

### Nueva Vida, Inc.

202-223-9100

1-866-986-8432

www.nueva-vida.org

## Office of Cancer Survivorship

301-402-2964

dccps.nci.nih.gov/ocs

### Office of Minority Health

1-800-444-6472

http://minorityhealth.hhs.gov

## **Oley Foundation**

518-262-5079

1-800-776-OLEY (1-800-776-6539)

www.oley.org

### **OncoLink**

www.oncolink.org

## **Oncology Nursing Society (ONS)**

412-859-6100

1-866-257-4ONS (1-866-257-4667)

www.ons.org

# Partnership for Prescription

#### **Assistance**

1-888-4PPA-NOW

(1-888-477-2669)

www.pparx.org

### Patient Advocate Foundation

757-873-6668

1-800-532-5274

www.patientadvocate.org

### **Patient Resource Publishing**

1-816-584-8227

www.patientresource.net

### **Prepare to Live**

www.preparetolive.org

### **Prevent Cancer Foundation**

703-836-4412

1-800-227-2732

www.preventcancer.org

### R.A. Bloch Cancer Foundation

816-854-5050

1-800-433-0464

www.blochcancer.org

### **Research Advocacy Network**

1-877-276-2187

www.researchadvocacy.org

#### Sam Fund

1-866-439-9365

www.thesamfund.org

## **Scott Hamilton CARES Initiative**

www.Chemocare.com

#### Self chec

www.selfchec.org/main.html

#### **Skin Cancer Foundation**

212-725-5176

1-800-SKIN-490 (1-800-754-6490)

www.skincancer.org

### Stand Up 2 Cancer

www.standup2cancer.org

## **SuperSibs**

847-705-SIBS (847-705-7427) 1-866-444-SIBS (1-866-444-7427) www.supersibs.org

# Support for People With Oral and Head and Neck Cancer

1-800-377-0928 www.spohnc.org

# **Teens Living With Cancer**

www.teenslivingwithcancer.org

# **Ulman Cancer Fund for Young Adults**

410-964-0202 1-888-393-FUND (1-888-393-3863) www.ulmanfund.org

# United Ostomy Associations of America (UOAA)

1-800-826-0826 www.ostomy.org

# US TOO International Prostate Cancer Education and Support Network

1-800-808-7866 http://ustoo.org

# V Foundation for Cancer Research

919-380-9505 1-800-454-6698 www.jimmyv.org

# Vital Options and The Group Room Cancer Radio Show

818-508-5657 1-800-GRP-ROOM (1-800-477-7666) www.vitaloptions.org

# Y-ME National Breast Cancer Organization

312-986-8338 1-800-221-2141 (English) 1-800-986-9505 (Español)

# YWCA ENCORE Program YWCA of the USA

202-467-0801
Contact your local YWCA to see if they have an encore program in place.
www.ywca.org

#### Your Disease Risk

314-362-5196 1-800-551-3492 www.yourdiseaserisk.wustl.edu

SOURCES OF
INFORMATION ON
HOME NURSING AND MEDICAL
EQUIPMENT, HOMEMAKER
SERVICES, CHILD CARE, MEAL
PREPARATION, OR LOCAL
TRANSPORTATION

# **American Cancer Society**

404-320-3333 1-800-ACS-2345 (1-800-227-2345) www.cancer.org

The American Cancer Society provides this specific program:

# Road to Recovery

Provides volunteer transportation assistance to and from local medical appointments, hospital stays, and rehabilitation sessions.

### Cancer Care, Inc.

212-712-8400

1-800-813-HOPE (1-800-813-4673)

www.cancercare.org

# Candlelighters Childhood Cancer Family Alliance

713-270-4700

www.candle.org

## Children's Hospice International

703-684-0330

1-800-242-4453

www.chionline.org

# The Community Health Accreditation Program (CHAP)

202-862-3413

www.chapinc.org

# Foundation for Hospice and Homecare

202-457-5811

1-800-854-3402

www.hospicefoundation.org

# **Hospice Foundation of America**

207-255-8800

1-800-331-1620

www.hospiceworld.org

# Leukemia and Lymphoma Society of America

914-949-5213

1-800-955-4572

www.leukemia-lymphoma.org

# Meals on Wheels Association of America

703-548-5558

www.mowaa.org

# National Hospice & Palliative Care Organization

703-837-1500

www.nhpco.org

## Gentiva Health Services, Inc.

1-888-GENTIVA (1-888-436-8482)

www.gentiva.com

## Visiting Nurse Associations of America

(National Office)

202-384-1420

www.vnaa.org

GROUPS FURNISHING FREE OR LOW-COST TRANSPORTATION OR LODGING FOR CANCER PATIENTS BEING TREATED AWAY FROM HOME

### **Air Care Alliance**

1-888-260-9707

www.aircareall.org

### Aircraft Owners and Pilots Association

1-800-872-2672

Provides referrals to volunteer pilot organi-

zations.

www.aopa.org

# **American Cancer Society**

404-320-3333

1-800-ACS-2345 (1-800-227-2345)

www.cancer.org

The American Cancer Society provides this specific program:

### **Guest Room Program**

Provides arrangement of free hotel or motel accommodations for cancer patients being treated away from home and for their families.

## Corporate Angel Network

1-866-328-1313

Call for free air transportation (subject to availability) to approved medical facilities for cancer patients and their families. www.corpangelnetwork.org

# National Association of Hospital Hospitality Houses

1-800-328-9730 www.nahhh.org

# Ronald McDonald House Charities

630-623-7048

Call for free or low-cost temporary housing for families of seriously ill children. www.rmhc.com

## READING MATERIALS FOR FURTHER INFORMATION

Choices: The Most Complete Sourcebook for Cancer Information (Fourth Edition), by Marion Morra and Eve Potts (New York: HarperCollins, 2003)

Cancer: 50 Essential Things to Do (Third Edition), by Greg Anderson (New York: Plume, 2009)

Everyone's Guide to Cancer Therapy: How Cancer is Diagnosed, Treated, and Managed Day to Day (Revised Fifth Edition), by Ernest H. Rosenbaum and Malin Dollinger (Toronto: Somerville House Books Limited, 2008)



The Cancer Research Institute is working every day to find new ways to treat, control, and prevent cancer. Donations to CRI allow us to continue funding the most promising scientific research all around the world. With your help, CRI can help bring safer, more effective new treatments to cancer patients sooner.

There are several ways to **make a donation** to CRI. The easiest way is to **call us** at 1-800-99CANCER (992-2623) and make your gift over the phone with a credit card. Or you can choose to **donate online** by visiting our safe and secure website at http://cancerresearch.org/donate. You may also **mail donations** to us at:

Cancer Research Institute One Exchange Plaza 55 Broadway, Suite 1802 New York, NY 10006

## Workplace Giving Programs

Contributions made to the Cancer Research Institute through employee payroll deduction programs provide extremely important support for the Institute's research programs. By contributing \$5, \$10, or \$25 per pay period through payroll deduction, individual contributors can make significant annual gifts to advance our research efforts.

Federal employees, U.S. Postal Service workers, and members of the United States Armed Forces can support the Cancer Research Institute through the Combined Federal Campaign (CFC). The Cancer Research Institute participates in the CFC as a member of the Community Health Charities federation. Our national agency code number for the Combined Federal Campaign is 11999.

State government employees and employees of municipal and county governments in many areas can also contribute to the Cancer Research Institute through payroll programs similar to the Combined Federal Campaign. In most instances, CRI participates in these campaigns as a member of the Community Health Charities.

Private sector employees can often designate Cancer Research Institute to receive their charitable contributions through the **United Way** "**donor choice**" program or through the **Community Health Charities**. If your employer does not conduct a payroll program in which CRI is a participating charity, we request that you contact us at **1-800-99CANCER** to learn how you can encourage your employer can open your payroll program to worthy charitable causes like Cancer Research Institute.

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