

THE FLORIDA
PROSTATE CANCER
RESOURCE
DIRECTORY

2nd Edition

#### The Florida Prostate Cancer Resource Directory

2nd Edition September 2001

#### The Florida Prostate Cancer Network, Inc.

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A directory listing does not constitute an endorsement by The Florida Prostate Cancer Network. This information is for educational purposes only and should never be used as a substitute for a consultation or an office visit with a physician.

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## The Florida Prostate Cancer Resource Directory

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#### Introduction

"YOU HAVE PROSTATE CANCER" is a terrifying statement to hear. Yet, it is estimated that over 198,000 men nationwide will be diagnosed with prostate cancer in the year 2001, and 15,000 of those men live in the state of Florida.

You, the newly diagnosed patient, along with your loved ones, have walked through the door called cancer for the first time. You are now in a new "world" with a new language, new expectations and many questions racing through your mind.

The Florida Prostate Cancer Network's (FPCN) Prostate Cancer Resource Directory has been developed by patients from the perspective of the patient. FPCN's goal is to provide you with answers to some of your questions and resource information to help you find the answers to questions that are not addressed in this directory.

This is your first experience with the language of cancer. What are your treatment options? You have just been bombarded by a series of options from your physician; you can't remember all the details and what the pros and cons are for each option. Perhaps you don't have the money for some of the medicines prescribed by your physician. You may have insurance questions regarding treatments, medicines, therapies, or help for your spouse. What if you only have one car for transportation in your family? How do you get transportation assistance? How do you find a support group of men who have faced the life changes you are facing; and who can help you understand that you are not alone? How do you find more information about this disease? Where does your spouse or partner turn for support?

As you step through this door called cancer, start the journey with us. We will introduce you to cancer terminology, increase your awareness of the disease, educate you on your options and support you and your loved ones.

The Florida Prostate Cancer Network Prostate Cancer Resource Directory is dedicated to the thousands of men and their loved ones who have been affected by prostate cancer. FPCN is a Florida-based, nonprofit 501C(3), survivor-based organization. FPCN is funded through individual contributions, foundation, and corporate grants and memberships. FPCN does not receive any government funding. We are dedicated to educating the public about the extent and impact of cancer in our state and to reducing cancer mortality and morbidity in Florida through early detection, access to state-of-the-art treatment, and education.

Yours Truly,

Robert J. Samuels, FPCN Chairman Prostate Cancer Survivor



Robert Samuels retired in 1992 as Vice President of Manufacturers Hanover's Corporate Banking and International Sector (Chemical Bank) and is founding Chairman of the Florida Prostate Cancer Network, Inc.

As a health activist and organizer, Bob is involved in numerous activities including:

- Founding Chairman of The National Prostate Cancer Coalition
- Chairman of the Florida March "Coming Together To Conquer Cancer"
- Member of the National Cancer Institute's Prostate Cancer Progress Review Group
- Member of the National Cancer Institute's Consumer Advocates in Research and Related Activities (CARRA)

Mr. Samuels also serves on the boards of the H. Lee Moffitt Cancer Center & Research Institute, The Florida Aquarium, and The Community Foundation of Tampa Bay.

<sup>\*</sup> American Cancer Society Facts & Figures 2001

INTRODUCTION INTRODUCTION

#### **FPCN's Mission Statement**

To prevent premature deaths in Florida caused by men's cancer, specifically prostate cancer, through education, advocacy of early detection methods, access to state-of-the-art treatment, promotion of research, and information on support groups.

#### **About FPCN**

The Florida Prostate Cancer Network was founded in December 1997 in Tampa, Florida by Robert Samuels. It is the only statewide non-profit organization focusing exclusively on prostate cancer. The grassroots organization is managed by a small staff and a large number of volunteers.



Attendees at the Africain American Men's Health Forum 2001 receiving medical instruction.

#### **FPCN Board of Directors (2001)**

Carol Anderson, Ft. Meyers Sheldon Barat, CPA, Tampa Karen Crown, Belleair James Ferman, Jr. Tampa Arthur Fisher, III, Esq., Tampa Cynthia Harris, PhD., Tallahassee Jerry Karp, Tampa Michael Katin, M.D., Ft. Myers Steven Newman, Plantation Paul Pizzo, Esq., Tampa Julio Pow-Sang, M.D., Tampa Robert Samuels, Tampa Russ Sloan, St. Petersburg Mark Soloway, M.D., Miami Mark Swierzewski, M.D., Tampa Kerry Brown, Esq., General Counsel

# Current & Former Buccaneer Football Players raise awareness of Prostate Cancer



#### **FPCN** in Pictures

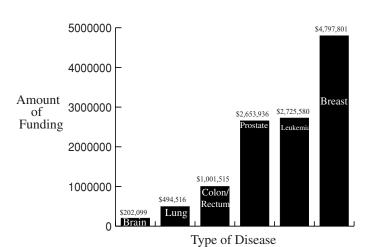
General
Schwarzkopf and
Bob Samuels
agree to change
the name of the
Annual Gala
Award



Bob Samuels with Senator and Mrs. Mack at the Annual Gala 2001

#### New Cases in Florida - Year 2001\* 15000 Prostate 15,000 12000 Lung Breast 12,900 12,500 Number 9000 of Cases Colon/ Rectum 9,400 6000 3000 Type of Cancer

## National Cancer Institute (NCI) Funding in Florida by Disease Area\*\*



<sup>\*</sup> SOURCE: American Cancer Society Facts & Figures 2001

#### **Chapter 1**

#### **Your Prostate and Prostate Health**

#### **Your Prostate**

The prostate is about the size of a walnut and is located in front of the rectum, behind the base of the penis and underneath the bladder. Only men have a prostate. The prostate is one of the male sex glands, which along with the testicles and the seminal vesicles, secrete the fluid called semen.

The prostate is made up largely of muscular and glandular tissues. Its main function is to produce fluid for semen, which transports sperm. During the male orgasm (climax), muscular contractions squeeze the prostate's fluid into the urethra.

Sperm, which are produced in the testicles, also are propelled into the urethra during orgasm. The sperm-containing semen leaves the penis during ejaculation.

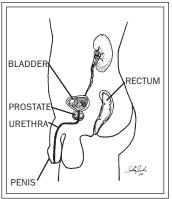


Illustration by: Curtis Jenkins

Side View of the Interior of Male Urinary System and Prostate

<sup>\* \*</sup> National Cancer Institute

#### **Why Are Prostate Checkups Important?**

Your Prostate and Prostate Health

There are two main reasons for having annual prostate checkups:

#### • The diagnosis of prostate problems.

BPH or prostatitis may cause annoying or painful symptoms. A prostate checkup is the first step in determining the cause of the symptoms.

• The early detection of prostate cancer. Prostate cancer is often curable, with early detection. But, the early stages of prostate cancer may cause no symptoms and can only be detected by regular checkups.

The American Urological Association endorses the American Cancer Society's policy that both a prostate specific antigen (PSA) blood test and a digital rectal examination (DRE) should be offered annually, beginning at age 50, to men who have at least a 10 year life expectancy and to younger men who are at high risk. For men at high risk for prostate cancer, such as those with a family history of the disease or African Americans, testing may begin at a younger age (e.g. 45 years). An immediate checkup should be performed on any man who suddenly develops persistent urinary symptoms. A yearly examination may help avoid the potentially serious consequences of advanced prostate cancer.

#### Some Symptoms That May Indicate a **Prostate Problem**

- A weak urinary stream
- Difficulty starting urination
- Interruption of the stream (stopping and starting)
- Pain or burning with urination
- Urgency (difficulty postponing urination)
- Frequent urination
- Awakening frequently at night to urinate
- · Blood in urine

#### **The Prostate Check**

The first step in any medical checkup is a thorough medical history, including a family history. Your doctor will ask you questions about any past problems, treatments, or medical procedures and about any symptoms you are having, particularly problems with urination.



Early diagnosis of prostate cancer increases the chance of a cure.

#### **Examination**

A physical examination is the second step. The prostate is an internal organ, so the physician cannot look at it directly. However, the doctor can feel the prostate by inserting a gloved, lubricated finger into the rectum.

This simple procedure is called a digital rectal examination (DRE). This necessary examination allows the physician to estimate whether the prostate is enlarged or has lumps or areas of abnormal texture. While this examination may produce momentary discomfort, it causes neither damage nor severe pain.

If the results of the digital rectal examination suggest that you may have a significant prostate problem, your doctor may refer you to a urologist. This is a doctor who specializes in diseases of the urinary tract and male reproductive system. The urologist may perform additional tests, including blood tests, urine tests, and/ or other diagnostic procedures, to determine the nature of your prostate problem.



When examining the prostate, your physician inserts his/her forefinger (wearing a lubricated glove) and presses gently on the lower wall of the rectum

#### The PSA Blood Test

The PSA test detects the level of prostate specific antigen in the blood. PSA is a protein originally found in semen, the fluid that carries sperm. Normally, PSA is made in the epithelial cells of the prostate, which produce some of the semen that comes out of the penis at the time of sexual climax (orgasm). PSA is only made by prostate cells. Small amounts of the protein get into the circulatory system and can be measured in the blood. Certain prostate conditions, including cancer, can cause high levels of PSA in the blood. Once a small blood sample is taken, the level of PSA is measured by an accurate laboratory method called an immunoassay.

Many factors can cause the PSA to rise, but PSA itself is harmless. The PSA blood test is used, along with the DRE, to find men who may need further testing. PSA cannot diagnose prostate cancer, however, only a biopsy can do that. The PSA test also is used to track the progress of men being treated for prostate cancer. If treatment is effective, the PSA should remain in the normal range. Improved methods of PSA testing are being developed. In the future, these may help your urologist decide whether the rise in PSA is due to prostate cancer or to a less serious problem.

#### **Prostate Cancer**

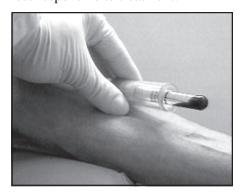
Each year, almost 200,000 new cases of prostate cancer are diagnosed in the U.S., and almost 35,000 deaths are caused annually by the disease. Approximately one in every six men will develop this form of cancer, which is second only to lung cancer as the leading cause of cancer death in men, and the likelihood of developing prostate cancer increases with age.

Every man over age 40 is at risk for prostate cancer. And African Americans have the highest risk for developing the disease. Having a father or brother with prostate cancer also greatly increases a man's likelihood of developing the disease. In addition, studies show that a high-fat diet may contribute to the development of prostate cancer.

Prostate cancer is a malignant tumor that most often begins in the outer part of the prostate. As the tumor grows, it may spread to the inner part of the prostate. It must grow fairly large before it presses on the urethra and interferes with urination. Cancer that is confined within the prostate and has not spread is called localized prostate cancer.

Prostate cancer also may spread (metastasize) to other parts of the body, such as the lymph nodes, the lungs, and the bones, especially the bones of the hip and lower back.

If prostate cancer is allowed to progress without treatment, it may spread to other organs, causing disability and sometimes death. Advanced prostate cancer is more likely to cause symptoms. However, by the time prostate cancer has reached this stage, it is less responsive to treatment.



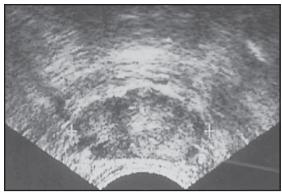
Certain prostate conditions, including cancer, can cause high levels of PSA in the blood.

#### **The Early Detection of Prostate Cancer**

Early detection is especially important in prostate cancer, because when this form of cancer is diagnosed early, the chances for a cure are greatly increased.

The *digital rectal examination* is a simple procedure where the physician inserts a lubricated gloved finger into the man's rectum. This examination can help the doctor detect a mass. To confirm the presence of cancer, the urologist will perform a *biopsy*, which involves obtaining a small sample of the prostate to determine whether it contains cancer cells. In order to tell if the cancer has spread outside the prostate, several tests are useful for detecting and staging prostate cancer. Not all of these tests are needed in all men.

The *prostate-specific antigen (PSA)* test is a blood test that can indicate the presence of prostate cancer. However, the PSA test is sometimes difficult to interpret because PSA is produced by both normal and cancerous prostate cells. In general, the higher the PSA level, the greater the chance that the cancer has spread beyond the prostate.



Transrectal ultrasonography is a safe and easy way to "see" the prostate gland.

Transrectal ultrasonography is a safe and easy way to "see" the prostate gland. Ultrasound provides an image of the prostate that the doctor can use to measure the size of the prostate, look for cancerous tissue, and calculate the PSA density (the PSA level divided by the size of the prostate). A needle biopsy of

the prostate is usually performed under ultrasound guidance.

A prostate biopsy analysis of the tissue gives important information about the cancer. The tumor grade is determined by examining the tissue under a microscope to measure the amount of disorganization of cells. A Gleason grade, which ranges from 2 to 10, is one scale that can be used to estimate the tumor's growth rate. Generally, the lower the grade, the slower the cancer grows. Most localized cancers of the prostate are of an intermediate grade, (Gleason grades 4, 5 or 6). The Gleason grades for the two most prominent groups of cells is called the Gleason Score.

#### **The Five Gleason Grades**

- Grade 1 Cancer is well differentiated
- **Grade 2** Cancer is still well differentiated, but is arranged more loosely and is more irregular in shape
- Grade 3 Most common grade of prostate cancer.

  Cancer is moderately differentiated,
  varying in size from small to large
- **Grade 4** Cancer is poorly differentiated, unable to form separate units, highly irregular, and has distorted shapes; progressive invasion of neighboring tissue
- **Grade 5** Cancer is undifferentiated and bears no resemblance to normal cells.

It is important to understand that at least two physicians work with you through the diagnosis phase, one who will analyze your prostate disease (the *pathologist*) and one who will detect and treat it (usually a urologist and/or *radiation oncologist*). At present, the only definitive method for determining the presence or absence of cancer in a prostate gland is by the analysis and interpretation of tissue samples by a pathologist. The interpretation of tissue samples is a result of the pathologist's medical judgement, and legitimate differences of opinion can exist. A second opinion might be valuable in certain circumstances.

A bone scan produces a nuclear image of the bones. this test, which may detect the spread of cancer to the bones, may not be necessary in all patients, especially

those with small cancers, low PSA levels and low Gleason grades.

Your Prostate and Prostate Health

Computed tomographic scan (CT scan) is an X-ray procedure that produces cross-sectional images of the body. The CT scan may help detect lymph nodes in the pelvis that are enlarged because of cancer. Generally, a CT scan is used only if the cancer is large, of a high grade, or associated with a very high PSA level.

The *lymph nodes* in the pelvis usually are the first place that cancer spreads from the prostate. The doctor can make a rough estimate of how likely it is that cancer has spread to the lymph nodes. This estimate is based on the cancer's size in the prostate and on results of the biopsy. A high PSA level also may indicate that the cancer has entered the lymph nodes. However, cancer in the pelvic lymph nodes often is microscopic. If there is a high risk that the cancer has spread to the lymph nodes, the doctor may recommend that they be surgically removed and examined under a microscope. Because there are many lymph nodes elsewhere in the body, the loss of some of the pelvic lymph nodes does not usually cause problems.

#### **Radio-labeled Antibody Scans**

An antibody that binds to the prostate specific membrane antigen (PSMA) may be able to detect cancer that has spread beyond the prostate and into soft tissue. Many prostate cancer cells produce the PSMA protein, which stays attached to the cancer cells. During the scan an antibody, with radioactive material attached, is injected into a vein. The antibody then circulates throughout the body, but only binds where it finds the PSMA protein. After four or five days, the antibody that does not bind to the PSMA is cleared from the body. Ideally, most of the remaining antibody will be bound to the prostate cells bearing the PSMA. In disease recurrence following prostatectomy, this type of test may indicate whether the cancer is limited to the prostate and may be useful in identifying patients most likely to benefit from salvage local therapy. Unfortunately, there are limitations to this type of scan, because it may be difficult to interpret. Currently, the only commercially available scan of this type is ProstaScint.

#### **Treatment Information**

Treatments of Prostate Cancer		
STAGES	CHARACTERISTICS	TYPE OF TREATMENT
T1 or T2	Cancer is localized in the prostate	Surgery, radiation therapy (radiotherapy), watchful waiting
T3 or T4	Cancer is locally advanced	Radiation therapy; combination of hor- monal therapy and radiation
N+ or M+	or M+ Cancer has spread to pelvic lymph nodes experimental (N+) or distant organs approaches (M+)	

The Partin Coefficient Tables, originally developed at the Brady Urological Institute of The Johns Hopkins Medical Institutions, are sometimes used to offer estimates of four different items that may be important in deciding how to treat a patient:

- The probability that the patient has completely organ-confined disease
- The probability that the patient has "established capsular penetration," which means that the prostate cancer has extended into and perhaps through the capsule of the prostate
- The probability that the patient has extension of his prostate cancer into the seminal vesicles
- The probability that the patient has prostate cancer that has spread into the lymph nodes

While the data is not definitive, these calculations can have an impact on how the physician and the patient arrive at a treatment decision. Detailed information about the Partin Coefficient Tables is available on two web sites:

http://rattler.cameron.edu/prostate http://comed.com/Prostate/partin/ introduction.html

#### **How Is Prostate Cancer Treated?**

Your Prostate and Prostate Health

The stage of a prostate cancer reflects the extent of the cancer: how big it is and whether it has spread. T1 and T2 cancers are confined to the prostate gland. T1 refers to a tumor that is not felt during a DRE (digital rectal examination) but cancer cells are found. T2 refers to a tumor that the doctor can feel by DRE. T3 cancers have grown beyond the gland itself and spread to the surrounding tissues. T4 cancers have spread beyond the seminal vesicles and into the pelvis or rectum. Cancer that spreads elsewhere, regardless of the extent of the local tumor or "T stage", is classified as N+, if it has spread to the lymph nodes and M+, if it has spread to other distant areas.

The doctor should explain the treatment options, if a diagnosis of prostate cancer is made. Various treatments may include surgery, radiation therapy, hormonal therapy, and occasionally chemotherapy. The doctor will advise you of the treatment that is most appropriate for your particular case. Treatment of early-stage prostate cancers may not be necessary in some patients who are very old or very ill.

Watchful waiting has been advocated as a reasonable approach for some men with prostate cancer. Although untreated prostate cancer continues to grow, it may do so quite slowly. In fact, the growth of the cancer may be so slow that it causes no problems in a particular man's lifetime, even if it is left untreated. No one can predict how long it will take a specific cancer to spread or how long a particular man is going to live. Unless a man is expected to live at least 10 years, watchful waiting with no immediate treatment may be appropriate.

Age is not the only factor to consider. Family history and other health problems also are important. Again, watchful waiting is a reasonable option for elderly men, particularly when the cancer is small and appears to be low grade. Studies show, however, that prostate cancer may be a significant threat to life or health within 10 years if the cancer is of a higher grade or advanced stage.



Surgery performed for treatment of localized prostate cancer is called "radical prostatectomy."

Surgery performed for treatment of localized prostate cancer is called radical prostatectomy.

Through a vertical incision in the lower abdomen or behind the scrotum, the entire prostate and seminal vesicles are removed. When the cancer is confined within the tissues removed at surgery, radical prostatectomy can cure localized prostate cancer. The PSA level in the blood should fall to undetectable levels (near zero) shortly after radical prostatectomy, since the entire prostate has been removed. PSA then becomes an excellent test to detect even small amounts of cancer left behind after surgery.

Either of two approaches can be used for surgical removal of lymph nodes:

- 1) In surgical lymphadenectomy, pelvic lymph nodes are removed through an incision in the lower part of the abdomen. This is usually done at the time of surgery to remove the prostate.
- 2) Alternatively, a *laparoscope* (a miniature telescope connected to a TV monitor) can be used by a doctor to look at and remove the lymph nodes through four small incisions in the lower abdomen. Removing lymph nodes using a laparoscope usually requires a much shorter stay in the hospital than does open surgical lymphadenectomy. But you also may require a second surgical procedure if the nodes are negative. This is usually done only when there is a high risk that the tumor has spread to the lymph nodes.

There are risks and side effects associated with surgery. About 1 of every 200 to 400 men die from complications such as heart attacks or blood clots related to the operation. Patients are usually in the hospital for two to four days after a radical prostatectomy and wear a Foley catheter (a tube through the urethra and into the bladder to drain urine) for two weeks afterward. Most patients have at least some degree of incontinence (leakage of urine from the penis) for up to two or three months after surgery. The great majority of men eventually regain good urinary control after surgery.

Your Prostate and Prostate Health

Impotence is sometimes a side effect of radical prostatectomy. The nerves that help cause erections lie very close to the prostate. These nerves can sometimes be spared during surgery, depending upon the location of the cancer. If the nerves can be spared, recovery of erections is best in younger patients who had no difficulty achieving erections before surgery. For men who do have problems with erections after surgery, there are a number of ways to help restore erections and the ability to have sexual intercourse.

Radiation therapy is another effective treatment for localized prostate cancer. The radiation can be administered externally or internally with radioactive seed implants (brachytherapy) or with the two in combination. External beam radiation therapy is usually delivered on an outpatient basis for seven to nine weeks. This treatment utilizes a machine that generates high energy X-rays. There appears to be no major difference between the two treatments in the percentage of men still alive ten years after treatment. Whether there are differences in results after that time is uncertain.

*Interstitial irradiation (Brachytherapy)* involves the permanent placement of radioactive "seeds" inside the prostate. Different types of radiation seeds are used, and there is not agreement on which type is best. Interstitial irradiation for prostate cancer has been used for more than 20 years. Previously, the radiation sources were implanted into the prostate through a lower abdominal incision, but the results were not as good as those obtained with other treatment techniques. Today radiation seeds are inserted using needles through the skin.

There are side effects associated with radiation therapy. Some degree of discomfort with urination, frequent and urgent urination, and diarrhea are common during radiation therapy. Side effects are especially likely during the second half of the treatment course. In most patients, these symptoms usually go away within a few months.

Men treated with radiation therapy for prostate cancer may eventually become impotent. As is the case with patients treated by radical prostatectomy, younger and more sexually active men are more likely to remain potent.

Hormonal therapy may be useful because prostate cancer cells depend, at least partially, upon male hormones for growth. Testosterone is the most important of these hormones.

Treatment that deprives the cancer cells of testosterone can slow the growth of prostate cancer. Hormonal therapy can consist of either surgical removal of the testes (orchiectomy) or monthly injections of a drug called luteinizing hormone releasing hormone (LHRH) analog, which blocks the production of testosterone by the testes. Sometimes an oral drug called an anti-androgen is used in combination with surgical castration or an LHRH analog. Anti-androgens block the effects of any remaining male hormone produced elsewhere in the body, particularly male hormones produced by the adrenal glands.

Hormonal therapy is not considered a curative form of treatment, but rather, a way to temporarily slow the growth of prostate cancer cells. Hormone therapy usually is not used unless there are signs that the cancer has spread beyond the prostate. Hormone therapy causes hot flashes in about half of men and usually produces impotence and loss of libido (sexual desire). Hormonal therapy also may be used in conjunction with radiation therapy.



"It is estimated that during 2001, approximately 15,000 cases of prostate cancer will be diagnosed in Florida and almost 3,000 men will die of this silent killer."

Bob Samuels - Founder of the Florida Prostate Cancer Network

As a result of attempts to decrease cancer reoccurance and the side effects of treatment, several new treatment methods for localized prostate cancer have emerged and are gaining acceptance. *Cryosurgery* involves freezing the prostate and has been used in one form or another for more than 50 years. Previous results with this technique were less than satisfactory. However, a new probe for prostate freezing is being tested, along with better methods for delivering freezing temperatures to the prostate while protecting the urethra. Early results are encouraging, but long-term effectiveness and safety are unknown.

Although some of the methods being tested may show early promise, they are currently unproven. Doctors need to treat many more patients and see how they respond before it is known whether these new approaches are effective in treating prostate cancer.

A man with prostate cancer must work with his doctor to decide which tests and treatments are right for him. You should discuss these, and any other questions that you have, with your doctor.

#### Glossary

#### **Adjuvant Therapy**

Treatment used in addition to or following the main treatment for cancer; i.e. hormonal therapy, chemotherapy, radiation after surgery.

#### **Adrenal Glands**

Two small endocrine glands, located above each kidney, which secrete several steroid hormones.

#### **Androgen**

Any male sex hormone. Testosterone is the major androgen.

#### **Anti-androgen**

Any substance capable of inhibiting testosterone or its biological effects.

#### **Benign**

Not malignant; noncancerous; benign growths do not generally spread to other organs or come back when they are removed.

#### **Benign Prostatic Hyperplasia (BPH)**

Noncancerous enlargement of the prostate that may cause difficulty in urination.

#### **Biopsy**

Removal of a small tissue sample for microscopic examination.

#### **Bone Scan**

A nuclear image of the skeleton.

#### **Brachytherapy**

Internal radiation treatment given by placing radioactive material directly into the tumor or close by it. Also called *interstitial radiation therapy* or *seed implantation*.

#### **Cancer**

An abnormal growth that can invade nearby organs and spread to other parts of the body; a cancer is also called a malignant tumor.

#### Catheter

A tubular, flexible surgical instrument used to withdraw fluid from the bladder by inserting it into the urethra through the penis.

Your Prostate and Prostate Health

#### **Chemotherapy**

Treatment with drugs to kill cancer cells.

#### **Computed Tomographic Scan (CT Scan)**

An X-ray that produces cross-sectional images of the body.

#### Cryosurgery

A surgical procedure that involves destroying diseased tissue of the prostate with a freezing method.

#### **Cystitis**

An inflammation of the urinary bladder.

#### **Differentiation**

The normal process through which cells mature so that they can carry out the jobs they are meant to do. Cancer cells are less "differentiated" than normal cells

#### **Digital Rectal Examination (DRE)**

Insertion of a gloved, lubricated finger into the rectum to feel the prostate. Some tumors of the rectum and prostate gland can be felt during a DRE.

#### **Early Detection**

Early detection means finding the disease at an early stage, before it has spread to other areas in the body. The PSA blood test can help find prostate cancer at an early stage.

#### **Ejaculation**

Release of semen from the penis during sexual climax.

#### **External Beam Radiation**

Radiation focused from a source outside the body on the area affected by the cancer. It is much like getting a diagnostic X-ray, but for a longer interval of time.

#### **Foley Catheter**

A catheter inserted through the urethra and into the bladder: used to drain urine.

#### **Gleason Grade**

The most often used prostate cancer grading system, which assigns a Gleason grade ranging from 1 through 5. The grade is based on how much the arrangement of the cancer cells look like normal prostate cancer cells. Because prostate cancers often have areas with different grades, a grade is assigned to the two areas that make up most of the cancer. These two grades are added together to give a Gleason score between 2 and 10.

#### **Gleason Score**

A method of classifying prostate cancer cells on a scale of 2 to 10. The higher the Gleason score (also called Gleason sum), the faster the cancer is likely to grow and the more likely it is to spread beyond the prostate.

#### **Hormonal Therapy**

The use of medications or surgical removal of the testicles to prevent male hormones from stimulating further growth of prostate cancer.

#### **Incontinence**

Lacking normal voluntary control of bladder and/or bowel function.

#### **Inflammation**

Swelling and pain resulting from irritation or infection.

#### **Impotence**

Inability to achieve or sustain an erection.

#### **Interstitial Irradiation**

The permanent placement of radioactive seeds (isotopes) inside the prostate.

#### Isotopes

Radioactive molecules that can be used for cancer treatment.

#### Laparoscope

A miniature telescope connected to a monitor. After insertion through a small incision in the abdomen, the

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laproscope allows the surgeon to view lymph nodes near the prostate and the pelvic cavity.

Your Prostate and Prostate Health

#### Libido

Sexual desire.

#### **LHRH**

Luteinizing hormone-releasing hormone; a hormone produced by the hypothalamus, a tiny gland in the brain.

#### **Luteinizing Hormone Releasing Hormone** (LHRH) Analog

Man-made hormones that block the production of the male hormone testosterone and are sometimes used to treat prostate cancer.

#### **Lymph Nodes**

Small glands located throughout the body that help defend the body against infection.

#### Malignant

Cancerous

#### **Metastasis**

The spread of cancer cells from the primary site to distant areas of the body by way of the lymph system or the bloodstream.

#### **Metastasize**

To spread by metastasis.

#### **Orchiectomy**

Surgical removal of the testes.

#### **Pathologist**

A doctor who interprets tissue samples to determine the presence or absence of disease.

#### **Perineum**

The area between the anus and the scrotum.

#### **Prognosis**

A prediction of the course of a disease; the outlook for the cure of a patient.

#### **Prostate**

A gland of the male reproductive system that surrounds the urethra, which is just below the bladder, and produces some of the sperm-carrying fluid of the semen.

#### **Prostate Cancer**

A malignant tumor of the prostate gland.

#### **Prostate-Specific Antigen (PSA)**

A protein made by the prostate gland. Levels of PSA in the blood often go up in men with prostate cancer, but they may go up for other reasons.

#### **Prostate-Specific Antigen (PSA) Test**

Blood measurement of a substance produced by prostate cells, which can increase if prostate cancer is present. The PSA test is used to help find prostate cancer as well as to monitor the result of treatment.

#### **Radiation Oncologist**

A doctor who has special training in radiation therapy for the treatment of cancer patients.

#### **Radiation Therapy**

X-ray or other radiation treatment for cancer.

#### **Radical Prostatectomy**

Complete surgical removal of the prostate and seminal vesicles.

#### Semen

Fluid containing sperm and secretions from the male reproductive organs.

#### **Seminal Vesicles**

Small, saclike glands attached to the prostate that produce some of the fluid for semen.

#### **Surgical Lymphadenectomy**

The surgical removal of pelvic lymph nodes.

#### **Testicles**

The male reproductive glands found in the scrotum. The testes (or testicles) produce sperm and the male hormone testosterone.

#### **Testosterone**

The main male hormone; made primarily in the testes,

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that stimulates blood flow, growth of certain tissues, and the secondary sexual characteristics. In men with prostate cancer, it can also stimulate growth of the tumor.

Your Prostate and Prostate Health

#### **Transrectal Ultrasonography**

An examination that produces an image of the prostate by inserting a probe into the rectum to direct sound waves to the prostate.

#### **Tumor**

Any abnormal swelling in or on a part of the body. The term is usually applied to a benign or malignant abnormal growth of tissue.

#### **Tumor Grade**

A classifying system that indicates how quickly a cancer is growing.

#### **Tumor Stage**

The classification of a primary tumor, by its size and the presence or absence of metastasis, in order to plan treatment.

#### **Urethra**

The tube that carries urine from the bladder and semen from the prostate and other sex glands out through the tip of the penis.

#### **Urologist**

A doctor who specializes in diseases of the urinary tract and the male reproductive system.

#### **Watchful Waiting**

An approach to handling localized, slow-growing prostate cancer by having regular checkups instead of immediate treatment.

#### **Steps to Take When Looking for a Physician**

(The following information is taken from the book The Wellness Community Guide to Fighting for Recovery from Cancer by Harold H. Benjamin, Ph.D.)

Because a good relationship with the right physician is of overriding importance to you, you should probably commit as much time and energy as is necessary to attain such a relationship. The following are steps that may be helpful.

#### STEP ONE:

Choose a medically competent physician. In most cases, this is done by recommendation and reputation. There also are situations where your insurance carrier or HMO will select your physician.

#### STEP TWO:

Ensure that the relationship is, at the very least, cordial. It does not have to blossom into a full-blown friendship for it to be effective and efficient. It is only necessary that it be agreeable.

#### STEP THREE:

Make sure that the expectations of both you and your doctor are clearly understood by each of you.

There are as many variations of the patient-physician relationship as there are patients and doctors. Some patients want every bit of information they can get. Others want to hear nothing but instructions. Some want to know what the treatment alternatives are and want to make the final decision themselves. Others want the doctor to decide what's best. Some consider waiting in a waiting room an acceptable inconvenience, while others find it intolerable. Some want to ask questions, write down answers, and have other people in the examining room. Other's don't. Physicians, just like everyone else, also are different, and those differences must be taken into account.

Very often, it is difficult for the patient to start the conversation with the doctor. After all, physicians have always been authority figures. But start it anyway. With very few exceptions, your physician is as anxious to have the conversation as you are. The dialogue should continue as long as necessary, and you should probably initiate new conversations when any part of the relationship appears unsatisfactory.

#### STEP FOUR:

If your needs as a patient conflict seriously with the doctor's style, consider whether it's in your best interest to find another physician. Most people find it difficult and sometimes embarrassing to leave a physician. Although this rather drastic step should be taken only after serious consideration, it's not impossible or unthinkable. If the situation is irreparable, it's appropriate.

**CHAPTER 1** 

Often cancer patients are treated by a group of physicians that may include an oncologist, radiologist, surgeon, and/or some other specialist, along with the family doctor. One of the patient's most frequent complaints is that no one is in charge; each physician acts almost independently, and there is no one to whom the patient can talk to get *all* the information needed to make a decision. Therefore, it's important that you try to get one of the doctors to be the coordinator of the team and the repository of all information.

One admonition: Don't ask for a prognosis or inquire about longevity statistics unless you are actually ready to hear the answer.

#### **Guidelines For Visiting With Physicians**

The following guidelines are designed to help you more thoroughly understand the information and instructions given to you by your physician.

- Before the visit, prepare a written list of the questions to ask your doctor. Take the list with you to the visit, in order to ensure that all your questions are answered.
- Before the visit, also prepare a written list of the information you want the doctor to know about you.
- If you don't understand something your doctor says, say so. If you don't speak up, you may follow the wrong advice or take an improper amount of medication
- Take someone with you when you visit your doctor. Your support person may be able to listen to and understand the doctor with greater objectivity.
- Get a second opinion when a major course of action is contemplated.
- Along with your physician, decide who will make the final decision about your treatment.

You should do everything in your power to ensure that your relationship with your physician is as trouble-free as possible.

#### Questions to Ask Your Primary Doctor or Urologist if Diagnosed with Prostate Cancer

• What is the Gleason score of my cancer?

- Can you feel my tumor with your hands?
- How aggressive is my cancer? Is it going to spread in months? Years? How many years?
- Is my cancer confined to the prostate? What is the probability that my cancer has already spread beyond the prostate?
- Do I need further X-rays such as a bone scan, CT, or MRI to determine if my cancer has spread?
- Do I need treatment right away?
- What are all the treatment options available to me?
  - Radical Prostatectomy? (surgery) What are the risks and benefits?
  - Radiation Therapy? What is the difference between external beam and seeding? What are the risks and benefits of each?
  - Cryosurgery? What are the risks and benefits?
  - Hormone Treatment? What are the risks and benefits?
  - Observation? What are the risks and benefits?
- What are the possible side effects of each treatment?
  - How will the various treatment options affect my sex life?
  - What are the chances that I will have problems with incontinence or impotence? What are precautions that can be taken to avoid these problems?
- Am I a candidate for clinical trials? Do you participate in any clinical trials in this office?

## **Questions to Ask Your Radiation Oncologist about Radiation Therapy**

- Do the physicians in this office have experience with both external beam treatment and seed implants?
- Is three-dimensional (computer generated 3-D view of the prostate) or conformal (targets the radiation to the prostate) treatment planning offered at this facility?
- Are the radiation oncologists working with me board certified in their specialty?
- How many brachytherapy procedures (seed im plants) have the physicians in this group done, and how many times a week do they do them?
- Does this radiation therapy center participate in clinical trials?

• Is there always a physician nearby while the external beam treatments are being given?

Your Prostate and Prostate Health

- If external beam therapy is given, how many treatments are recommended and over what time period?
- What kind of side effects may result from each type of radiation therapy?
- What are the advantages or disadvantages of getting radiation therapy instead of surgery or another treatment?
- Can an operation, or some other treatment, be done after radiation therapy in case it doesn't work?

#### Don't Rush

Unless there is compelling medical reason to act quickly, take the time to learn about your particular cancer, the risks and possible side effects of various therapies, and the impact they may have on your life. Remember that there is generally time for you to become informed.

#### **Get The Facts - Education is the Key**

Start learning about prostate cancer. Learn what it is, how it acts, and what treatments are available.

#### **Become Your Own Advocate**

By educating yourself, you become an advocate for your personal health care.

#### Form a Partnership With Your Doctor.

This partnership should be mutually supportive and based on candid, honest dialogue.

#### **Consider a Second Opinion**

Doctors understand getting a second opinion to confirm their diagnosis. In seeking a second opinion, urologists, radiologists, oncologists and general practitioners may offer different perspectives. Each will provide considerations based on your individual situation.

#### **Talk About Your Cancer**

Prostate cancer is a family affair that affects those closest to you. Talk with your partner and family about your cancer.

#### **Consider a Support Group**

Support groups are made up of peers who understand your situation, because they've been there themselves. Bring your partner, a family member, or a friend along. Ask your doctor if he or she knows the location of any local prostate cancer support groups.

#### **Seek The Best Opinion**

It is your responsibility to investigate the services available through your insurance coverage and health care provider. When you are ready to make a treatment decision, ask the doctor how many cases like yours she or he has treated.

While first rate treatment is available at many hospitals throughout the United States, many may not be equipped or experienced in all treatments available. Be assured that community hospitals, as well as large regional medical institutions, offer doctors who are experts in your type of cancer.

#### **Maintain Good Records**

Throughout this process, you need to maintain good records. First, this is important for your insurers. Second, it is important to have your medical reports available for review when seeking second opinions. These reports provide a profile of your condition and will help you avoid undergoing tests you may have already taken.

#### **Don't Play Doctor**

Alternative medicine has many advocates. However, until more is known about the efficacy of various alternative treatments, it is important to consult with your doctor before using them. Although many alternative therapies may complement traditional therapies, they also may interfere with diagnostic tests and treatments.

#### **Continually Seek Information**

Because prostate cancer diagnosis methods and treatments are undergoing rapid changes, continually seek updated information. Discuss any new information, ask questions, and be honest with your doctor and health care team.

#### **Get Involved**

Studies show that patients who take an active role in their disease and treatment have better outcomes.

#### **Clinical Trials Information**

#### What is a Clinical Trial?

A clinical trial is a study conducted by research physicians to evaluate new and experimental treatment options. Your physician may recommend that you take part in a clinical trial.

There are many different types of cancer clinical trials, including *prevention trials*, *early detection trials* and *quality of life studies*. If you decide to take part in a clinical trial, you may benefit from a new drug, procedure or symptom control method.

#### **Phase 1 Trials**

The first step of a clinical trial involves a small number of people who help evaluate how a new drug should be administered.

#### **Phase 2 Trials**

After the information is gathered from the first phase, researchers generate information about the safety and benefits of the drug. This study usually focuses on a specific cancer.

#### **Phase 3 Trials**

This phase compares a new drug, a combination of drugs or a procedure with the current standard. A large number of people are involved in this phase.

To participate in a clinical trial, a patient must have specific characteristics that have been identified by the researcher. These characteristics are called eligibility criteria. This criteria also helps to insure the safety of the participants by protecting them from known risks. All participants in a clinical trial must give their informed consent. All patient information is confidential. Taking part in a clinical trial is completely voluntary and can be done at any stage of prostate cancer. Being a clinical study participant does not prevent you from getting any other medical care that you may need. You are always free to leave a

clinical trial at any time. It is important for you to check with your insurance company prior to your commitment to the study to find out what costs they will cover.

Your participation in a clinical trial may not only help you directly, but it may also help other men with prostate cancer.

You can find out what clinical trials are available by visiting these web-sites:

www.drkoop.com www.americasdoctor.com http://clinicaltrials.nci.nih.gov www.centerwatch.com www.centerwatch.com www.florida-cancer.org (click on Hope)

or you can write:

#### **Clinical Trials**

U.S. Nat. Library of Medicine 8600 Rockville Pike Bethesda, MD 20894

#### **CHAPTER 2**

#### **Support Groups and Organizations**

This chapter contains a listing of Florida-based prostate cancer support groups listed alphabetically by city. Many cities also serve surrounding areas. Specific meeting details are listed when available. However, please verify these by calling the contact name.

#### Florida Prostate Cancer Support Groups

Meeting Location	<b>Meeting Dates</b>
	& Times

#### Aventura, FL

#### Man to Man

Aventura Hospital 4th Sunday, Medical Plaza 11:30 am

Rm. 101

Aventura, FL 33180 (954) 433-7171

Contact info:

American Cancer Society 1-800-ACS-2345 Coordinator: Gilbert Baerga (305) 594-4363 x 230

Attendees: 50-60

#### Aventura, FL

Contact info:

#### **Advanced Prostate Support**

Comprehensive Cancer
Center 3rd Monday,
20950 NE 27th Court 4:30 pm

Aventura, FL 33180 (305) 682-7000

American Cancer Society 1-800-ACS-2345 or Attendees: 12 NOTES: Specialty group for

metastasized and rising PSA

Meeting Location Meeting Dates & Times

#### **Boca Raton, FL**

#### **Prostate Cancer Support**

**Boca Raton Community Hospital** 

**Education Center** 

800 Meadows Lane 1st Thursday, Boca Raton, FL 33486 7:30 pm

(561) 395-7100 Contact Info:

Facilitator: Marjorie O'Sullivan (561) 395-7100

x992

Attendees: 10-15

#### **Boynton Beach, FL**

#### **NEW LISTING**

Bethesda Memorial Hospital Oncology Department

2815 S. Seacrest Blvd. 2nd Wednesday, Bovnton Beach, FL 33435 5:30-7:30 pm

(561) 395-7100 Contact Info:

Facilitator: Eileen Delrosario (561) 737-7733 x4948 e-mail: eileen.delrosario@bethesdahealthcare.com

#### **Bradenton, FL**

#### Man to Man

Manatee Memorial Hospital 3rd Thursday,
Education Complex 2:00 pm
206 2nd Street East Does not meet
Bradenton, FL 34208 in June, July,
(305) 682-7000 August.

Contact Info:

American Cancer Society 1-800-ACS-2345 Ron Guadio, Chaplin (954) 433-7171 Facilitator: Pat Grimes (941) 755-7256

e-mail: the\_patric@hotmail.com

Attendees: 20-50

Meeting Location	Meeting Dates
	& Times

**Meeting Location Meeting Dates** & Times

#### Man to Man

Blake Medical Center

4th Thursday, Sand Dollar Room 2020 59th Street West 7:00 pm

Bradenton, FL 34209 (941) 792-6611

Contact Info:

American Cancer Society 1-800-ACS-2345 or Coordinator: Janet Vogel (941) 498-6572 Coordinator: Heather Wiley (941) 745-1214 Facilitator: Pat Grimes (941) 755-7256

e-mail: the patric@hotmail.com

Attendees: 25-30

#### Brandon, FL

Man to Man

1st Monday, Oakfield Medical Plaza 7:00 pm Class 228 Does not meet 228 S. Moon Ave. in June, July, Brandon, FL 33511 August. Contact Info:

American Cancer Society 1-800-ACS-2345 or Susan Carlton, CCS (813) 685-0670 x 115 Facilitator: Joe Geraghty (813) 681-6057

Attendees: 15-30

NOTES: Across from Brandon Hospital. Next to

Senior friends.

#### **Brooksville, FL**

#### Man to Man

Florida Community Cancer 1st Monday, Center 6:00 pm 11307 Cortez Blvd.

Brooksville, FL 34613

(352) 596-1926

Contact Info:

American Cancer Society 1-800-ACS-2345 Facilitator: Betty Lawrence (352) 596-1926

Notes: Next to Oak Hill Hospital

#### Clearwater, FL

#### **Cancer Patient Support**

Services (CaPSS)

3rd Wednesday, Powell Center Pavilion Community Room 2:00 - 3:00 pm

303 Pinellas Street Clearwater, FL 33756 (727) 462-2100

e-mail: concerpm@gte.net

Contact Info:

Kim Sibille, Prog. Mngr. (727) 462-2125 Facilitator: John Llauget (727) 462-2141

Attendees: 10-12 NOTES: Men only.

#### Daytona Beach, FL

#### Man to Man

American Cancer Society 3rd Thursday, 146 Orange Avenue 5:30 pm Daytona Beach, FL 32114

(904) 239-8500

Contact Info:

American Cancer Society 1-800-ACS-2345 Coordinator: Carrie Corbett (904) 253-1633 x113

Facilitator: Scott Fahner (904) 239-8543

Attendees: 15-30

#### Delray Beach, FL

#### Man to Man

**Delray Medical Center** 1st Wednesday, 5352 Linton Blvd. 7:30 pm

Delray Beach, FL 33484

(561) 495-3335

Contact Info:

American Cancer Society 1-800-ACS-2345 Carol Burleson, Mngr. (561) 495-3335

Facilitator: Lawrence Yore, MD (561) 496-4444 Ann Crane, Doctor's Office Manager (561) 495-4444

Notes: Mail must go to: Man to Man

c/o Ann Crane

5130 Linton Blvd, Suite F-6 Delray Beach, FL 33484

Meeting Location	Meeting Dates
	& Times

Meeting Location Meeting Dates & Times

#### Fernandina Beach, FL

#### Man to Man

First Presbyterian Church
Fellowship Hall
7:30 pm

19 North Sixth Street

Fernandina Beach, FL 32034

Contact Info:

American Cancer Society 1-800-ACS-2345 or

Teri Coutu, CCS (904) 264-6039

Facilitator: Dr. Jones

#### Ft. Lauderdale, FL

#### Man to Man

Broward General Hospital
Cancer Center Conference Rm
1600 S. Andrews Ave.
Ft. Lauderdale, FL 33316

3rd Tuesday,
5:00 pm
No Meetings
June, July,
August

Contact Info:

American Cancer Society 1-800-ACS-2345

District Health Line (954) 759-7400, CODE: 19-069 Facilitator: Linda Sapp, Soc. Worker (954) 355-5307

Facilitator: Ronald B. Fauer, MD, FACS

Attendees: 25-50

#### Man to Man

Holy Cross Hospital
Cancer Center
4725 N. Federal Highway
4:00 pm

Ft. Lauderdale, FL 33308

(954) 771-8000

Contact Info:

American Cancer Society 1-800-ACS-2345 Facilitator: Ronald Sirois, MD (954) 771-7620

Inquiries: Donna

#### Ft. Myers, FL

#### Man to Man

Southwest Regional Medical

Center 3rd Wednesday, Patty Berg Cancer Center 5:30 - 7:00 pm

2727 Winkler Ave., 3 South

Ft. Myers, FL 33901 (941) 939-1147

Contact Info:

American Cancer Society 1-800-ACS-2345 Sharon Ivy, CCS (941) 936-1113 x 120 Facilitator: Carlo Lane (941) 369-9256

#### Ft. Walton Beach, FL

#### NEW LISTING

#### Man to Man

Bert Fish Medical Center 3rd Tuesday, Main Hospital 7:00 pm

3rd Floor, Room 301 401 Palmetto Street

New Smyrna Beach, FL 32168

Contact Info:

American Cancer Society 1-800-ACS-2345

Pamela Reed (386) 253-1633 x115

Facilitator: Jim McGee Notes: Send mail to:

American Cancer Society 1510 Ridgewood Avenue Holly Hills, FL 32117

(also see listing for Shalimar, FL)

 Meeting Location
 Meeting Dates

 & Times
 Meeting Location
 Meeting Dates

 & Times
 & Times

#### Gainesville, FL

#### Man to Man

American Cancer Society Office
Winn Dixie Hope Lodge
2121 SW 16th Street
Gainesville, FL 32608
1 (888) 295-6787

2nd Monday,
7:00 pm

http://www.cancer.org

Contact Info:

American Cancer Society 1-800-ACS-2345 Coordinator: Lauran Dean (352) 376-6866, Option #2, x 119

Facilitator: Roy Cline (352) 336-8523 e-mail: rscline@bellsouth.net

#### Hollywood, FL

#### Man to Man

Memorial Regional Hospital
Cancer Center
David Ross Center
1150 N. 35th Avenue,
2nd floor
15t Wednesday,
5:30 pm

Hollywood, FL 33021 (954) 987-2000

Contact Info:

American Cancer Society 1-800-ACS-2345 Co-Facilitator: Bettye Bradswaw, LCSW (954) 987-2020 x5768

#### Hudson, FL

#### **NEW LISTING**

Man to Man
Regional Medical Center
14000 Fivay Road
Hudson, FL 34667
Contact Info:

3rd Saturday,
10:00 am
No meetings
July & August

Eileen Turner (727) 863-1019 x113

Facilitator: Blair Moger

#### Jacksonville, FL

#### Man to Man

American Cancer Society

Midtown Center

4030 Boulevard Center Dr.

Jacksonville, FL 32207

Last Tuesday,
6:30 pm

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Contact Info:

American Cancer Society 1-800-ACS-2345 Carol Peters, CCS (904) 398-0537 x310 Facilitator: Frank Donaldson (904) 355-3910

#### Jacksonville Beach, FL

#### Man to Man

Palms Presbyterian Church Last Thursday, 3410 South 3rd Street 5:30 pm Jacksonville Beach, FL 32608

Contact Info:

American Cancer Society 1-800-ACS-2345 Veronica Medina, CCS (904) 264-6039 x113 Facilitator: Richard Huffstetler (904) 249-0022

#### Jupiter, FL

#### **Prostate Support Group**

Jupiter Medical Center
Meeting Room 1

1210 S. Old Dixie Highway
Jupiter, FL 33458
(561) 744-4465

2nd Wednesday,
5:00 pm

Contact Info:

American Cancer Society 1-800-ACS-2345 Facilitator: Crystal Dillard, SW; (561) 744-4465

#### **Key West, FL**

#### Man to Man

Key West Memorial Hospital 3rd Wednesday, 5900 College Road 7:00 pm
Key West, FL 33040
Contact Info:
American Cancer Society 1-800-ACS-2345
John Conroy, CCS (305) 294-9385

& Times

**Meeting Dates** 

Support	Groups	and	Organizations
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**Meeting Location Meeting Dates** & Times

**CHAPTER 2** 

**NEW LISTING** 

**Meeting Location** 

1st Monday, **US TOO** 6:00 pm **Key Cancer Center** 

Hospice Contact Info:

Facilitator: Mark Perman, MD (305) 296-0021

#### Kissimmee, FL

#### **NEW LISTING** Man to Man

**American Cancer Society** 3rd Monday, Osceola Cancer Center 6:00 pm 1300 West Oak Street Kissimmee, FL 34741 Patient Service Center (877) 258-2619

Notes: Date, time & location are subject to change. Please call to verify

#### Lady Lake, FL

#### Man to Man

The Villages 1st Wednesday, La Hacienda Center 7:00 pm Julio Iglesias Room No Summer **Avenide Center** Meetings June. Lady Lake, FL 32159 July, August

Contact Info:

American Cancer Society 1-800-ACS-2345 Dana Anderson, CCS (352) 326-9599 Facilitator: Bill Hennings (352) 750-0249

Attendees: 40-50 Notes: All Males

#### Lake City, FL

#### **NEW LISTING** Man to Man

**American Cancer Society** Lake City Medical Center

2nd Tuesday, 7:00 - 9:00 pm 1050 N. Commerce Blvd.

Lake City, FL 32055

Contact Info:

Margaret Shaw, CCS (352) 376-6866 Notes: Meeting times are subject to change. Please contact the Gainesville office for the most current information or call Suwannee Valley Resource Room in Lake City, (904) 758-3047

#### Lake Worth, FL

#### **Prostate Cancer Support**

JFK Hospital 4685 S. Congress

2nd Wednesday, Lake Worth, FL 33461-4710 1:00 - 2:00 pm (561) 964-2662

Contact Info:

Nancy Arnold (561) 964-2662 x1068

Attendees: 20-30

#### Lakeland, FL

Man to Man 3rd Wednesday, American Cancer Society 5:00 - 6:30 pm 809 S. Florida Avenue No Summer Lakeland, FL 33801 Meetings

(863) 688-2326

Contact Info:

American Cancer Society 1-800-ACS-2345

Facilitator: Dick Whittemore

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#### Lecanto, FL

#### NEW LISTING Man to Man

Boissoneault Oncology Institute

522 Lecanto Highway 1st Wednesday, (352) 527-0106 11:30 am

Contact Info:

Eileen Turner (727) 863-1019 Facilitator: Summer Waite

#### Leesburg, FL

#### Man to Man

Lake Square Presbyterian

Church Fellowship Hall 3rd Thursday, Radio Road 2:00 pm

Leesburg, FL (352) 728-1620

Contact Info:

American Cancer Society 1-800-ACS-2345 Chris Daly, CCS (352) 326-9599 x 112 Facilitator: Bill Heroy (352) 483-1963 Co-Facilitator: Leroy Finke (352) 383-0158 Attendees: 15-35 (Families welcome)

#### Margate, FL

#### **US TOO**

Northwest Medical Center

Cafeteria 2nd Monday, 2801 State Road 7 7:30 pm

Margate, FL 33603 (954) 741-4276 Contact Info:

US TOO 1-800-808-7866

Facilitator: Aaron Neuhaus (954) 741-4276

Marvin Stein, MD (954) 739-6960

Attendees: 40-50

NOTES: Refreshments served.

#### Melbourne, FL

#### Man to Man

Home Builders and Last Monday, Contractors Building 7:00 pm

1500 A West Eau Gallie Blvd.

Melbourne, FL 32901

Contact Info.

American Cancer Society 1-800-ACS-2345 Facilitator: Gene Rocque (321) 777-0716

Attendees: 65-75

#### Miami, FL

#### Man to Man

Cancer Resource Center

Baptist Health Resource Plaza 2nd Tuesday, 8750 SW 144th Street 7:30 - 9:00 pm

Suite 200

Miami, FL 33176

Contact Info:

American Cancer Society 1-800-ACS-2345 Cesar Scheker (305) 594-4363 x 229

Facilitator: Tom Pietrogallo

Attendees: 15-17

NOTES: Men-only nights and family nights

#### Naples, FL

#### Man to Man

Moorings Presbyterian Church
791 Harbor Drive

Revite 44

Last Monday,
October - April,
7:00 - 9:00 pm

Route 41

Naples, FL 34103

Contact Info:

American Cancer Society 1-800-ACS-2345 Joanne Camero, CCS (941) 261-0337 x 111

Facilitator: Phil Fess (941) 596-2985

Attendees: 15-60

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#### **New Port Richey, FL**

Man to Man

North Bay Hospital 2nd Saturday, 6600 Madison Street 10:00 am

New Port Richey, FL 34652

Contact Info:

American Cancer Society 1-800-ACS-2345

Eileen Turner (727) 863-1019 Facilitator: Bill Summerset

#### New Smyrna Beach, FL

#### Man to Man

Bert Fish Medical Center 3rd Tuesday, Main Hospital, 3rd Fl, Rm 301 9:00 am 401 Palmetto Street

New Smyrna Beach, FL 32168

Contact Info:

American Cancer Society 1-800-ACS-2345

Pamela Reed (386) 253-1633 x 115

Facilitator: Jim Mc Gee NOTES: Send Mail to:

American Cancer Society 1510 Ridgewood Avenue Holly Hills, FL 32117

#### Ocala, FL

#### Man to Man

Urology Center of Florida 4th Wednesday 3201 SW 34th Street 7:00 pm

Contact Info:

American Cancer Society 1-800-ACS-2345 Peg Iwata, CCS (352) 629-4727 x 113 Facilitator: Frank Fleming (352) 237-2553

Frank Mattucci (352) 401-0592

Attendees: 30

#### **US TOO**

Munroe Regional Medical Center Chuck Rhodes (352) 867-9642

#### Orange Park, FL

#### Man to Man

Orange Park Methodist Church

Family Life Center 2nd Monday, Reed Street 6:30 pm

Orange Park, FL 32073

Contact Info:

American Cancer Society 1-800-ACS-2345 Teri Coutu, CCS (904) 264-6039 x 114

Facilitator: Dr. Mark Blasser

#### Orlando, FL

#### Man to Man

American Cancer Society

1601 W. Colonial Drive 3rd Tuesday, Orlando, FL 32804 6:00 - 8:00 pm

(407) 843-8680 x 511

Contact Info:

American Cancer Society 1-800-ACS-2345

Missy Hansen, Program Manager

Attendees: 30-40

NOTES: Serving Osceola, Seminole and Orange

counties.

#### Palatka, FL

Man to Man

Putnam County Library
Meeting Room
601 College
Palatka, FL 32177

3rd Thursday,
12:30 pm
(Every odd
numbered
month)

Contact Info:

American Cancer Society 1-800-ACS-2345

Teri Coutu, CCS (904) 264-6039

Facilitator: Henry Hirschman (904) 325-2179

**CHAPTER 2** 

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#### Palm Coast, FL

#### Man to Man

Memorial Healthcare Center 3rd Thursday, 309 Palm Coast Parkway 9:00 am Palm Coast, FL 32137

Contact Info:

American Cancer Society 1-800-ACS-2345 Pamela Reed (386) 253-1633 x 115

NOTES: Send Mail to:

**American Cancer Society** 1510 Ridgewood Avenue Holly Hills, FL 32117

#### Panama City, FL

#### Man to Man

American Cancer Society 2nd Thursday, 2012 A. Lisenby Ave. 7:00 pm Panama City, FL 32405 (850) 785-9205

Contact Info:

American Cancer Society 1-800-ACS-2345

Carissa Anthony (850) 785-9205 Facilitator: Bob Jones (850) 265-9480

#### **Pembrook Pines, FL**

#### Man to Man

Memorial West Hospital 2nd Friday, Out Patient Conf. Room 11:00 am 703 N. Flamingo Road

Pembrook Pines. FL 33028

Contact Info:

American Cancer Society 1-800-ACS-2345 Marilyn Shazier (954) 564-0880 x 122

Facilitator: Tracy Lautenbach (954) 430-6880 x 9712

#### Pensacola, FL

#### Man to Man

Sacred Heart Children's 1st Saturday, Hospital 9:30 am

5151 North 9th Ave. Pensacola, FL 32504

Contact Info:

American Cancer Society 1-800-ACS-2345

Samona Foy, CCS (850) 438-2224

Coordinator: Diane Carvagal (850) 438-4491 x 111

Facilitator: John Bayliss (850) 432-3779

#### **NEW LISTING**

Baptist Hospital 1st Saturday, Kugelman Cancer Center 5:30 pm Pensacola, FL

Contact Info:

Marsha DeSonier (850) 469-2224

#### Plantation, FL

#### **Prostate Cancer Forum**

West Side Regional 2nd Tuesday, Class Room C 6:30 pm 8201 W. Broward Blvd.

Plantation, FL 33324

Contact Info:

American Cancer Society 1-800-ACS-2345 Liaison: Liz Gassew, RN (954) 476-3994

Facilitator: Steve Newman

Attendees: 10-15

#### Pompano Beach, FL

#### Man Talk

Cancer Center

3rd Wednesday, North Broward Hospital 201 E. Sample Road 6:00 pm

Pompano Beach, FL 33064

(954) 941-8300

Contact Info:

Facilitator: Mona Ross (954) 786-6460

**CHAPTER 2** 

**Meeting Location Meeting Dates** & Times

**Meeting Location Meeting Dates** & Times

#### Port Charlotte, FL

#### Man to Man

Port Charlotte Cultural Center, Centennial Hall 4th Friday, 9980 NW Aaron Street 2:00 pm Port Charlotte, FL 33949

(941) 625-4175

Contact Info:

American Cancer Society 1-800-ACS-2345 Administrator: John Lancaster (941) 639-8125

e-mail: jdlancpg@isni.net

Attendees: 80

#### Sarasota, FL

#### Man to Man

Sarasota Memorial Hospital 4th Monday, 1700 South Tamiami Trail 2:00 pm Sarasota, FL 34239 (941) 917-9000

Contact Info:

American Cancer Society 1-800-ACS-2345

ACS (941) 368-3858

Coordinator: Marion Stuart (941) 365-2858 x 28 Co-Chairman: Scott Styles (941) 925-9132 Martin Sara (941) 359-9976 Alan Stone (941) 383-2698

Paul Zatz (941) 358-0252

#### Sebring, FL

#### **NEW LISTING**

**Highland County Prostate Cancer Support Group** 

2nd Tuesday, 12:00 noon

American Cancer Society 11 Marantha Blvd. c/o Marantha Village Sebring, FL 33870 (863) 382-2828

Notes: Call local office to register

#### Shalimar, FL

#### Man to Man

Good Shepard Lutheran Church 3rd Tuesday, 1 Meiggs Drive 7:00 pm Shalimar, FL 32579 Contact Info:

American Cancer Society 1-800-ACS-2345 Carol Ann Fowler, CCS 850-244-3813 x 117 Facilitator: Donald Kempwerth (850) 651-2905 (also see listing for Ft. Walton Beach, FL)

#### St. Augustine, FL

#### Man to Man

Flagler Hospital 3rd Tuesday, Osceola Classroom 400 Health Park Blvd 6:30 pm

St. Augustine, FL 32086

Contact Info:

American Cancer Society 1-800-ACS-2345

Teri Coutu, CCS (904) 264-6039

Facilitator: Joe Peacock (904) 471-2593

#### St. Lucie, FL

#### **NEW LISTING**

#### Man to Man

3rd Tuesday, St Lucie West 6:00 pm Sunlight Community Church 477 Cashmere Blvd.

St. Lucie, FL Contact Info:

American Cancer Society 1-800-ACS-2345 Kim Glass-Benedetto (561) 287-7467

#### St. Petersburg, FL

#### Man to Man

**Edward White Memorial** 2nd Thursday, Hospital 6:30 pm 2323 Ninth Avenue N. No meetings in St. Petersburg, FL 33713 June, July & Contact Info: August Facilitator: Jim West

**CHAPTER 2** 

Meeting Location Meeting Dates & Times

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#### **NEW LISTING**

Bay Pines VA Hospital 10000 Bay Pines Blvd. PERC Library, Room 1E236 St. Petersburg, FL 33708 Contact Info:

Last Monday, every other month 7:00 pm

Coordinator: Dee Austin, CCS (727) 546-9822

Facilitator: Joe Ziegler

Note: No meetings in June, July & August

NEW LISTING

Northside Hospital
6000 49th Street North
St. Petersburg, FL 33709
Contact Info:
Coordinator: Dee Austin, CCS (727) 546-9822

Facilitator: Bill Hughes

#### Stuart, FL

#### **NEW LISTING**

Man to Man

American Cancer Society

Martin Memorial Cancer Center
501 East Osceola Street

Stuart, FL 34994

Contact Info:

Kim Glass-Benedetto, CCS (561) 287-7467

Note: Meets in the 2nd Floor conference room

#### Sun City, FL

#### Man to Man

American Cancer Society
St. Andrews Presbyterian Church
1239 Del Webb Blvd. W.
2:00 pm

Sun City, FL 33573

Contact Info:

Patient Services Center (800) 227-9954. Call to

register

Facilitator: Dr. Dallis Tuthill

Notes: For program questions call Brandon Unit

(813) 685-0670

#### Tallahassee, FL

#### Man to Man

TMH Adult Care Center
2039 N. Monroe Street
Tallahassee. FL 32303

2nd Tuesday,
7:00 pm

Contact Info:

Jennifer Johnson, CCD Mgr. (850) 297-0588 x 117 ACS Cancer Control Director (850) 297-0588 x 118 Facilitator: Jim Henderson (229) 377-7298

Fax (229) 377-5036 e-mail: jchend@web.tv

#### Tampa, FL

#### **NEW LISTING**

Florida Prostate Cancer Network 6105 Memorial Highway

Building F, Suite M
Tampa, FL 33615
Contact Info:

1st Wednesday,
4:30 - 6:30 pm
3rd Wednesday,
7:30 - 9:00 am

Susan Bruno (813) 806-2800 or (866) FLA-FPCN toll free Facilitator: Richard Brown, PhD

#### Florida Prostate Cancer Network

Supporters of Survivors Group Hillsborough Community College

Dale Mabry Campus

Student Services Bldg 3rd Wednesday, Room 108, 110 or 112 4:30 - 6:00 pm

4001 Tampa Bay Blvd.

Tampa, FL Contact Info:

Bob Samuels (813) 806-2800 or (866) FLA-FPCN toll free

Meeting Location	Meeting Dates
	& Times

### Meeting Location Meeting Dates & Times

#### Man to Man

Moffit Cancer Center 2902 Magnolia Drive

Room 3039

Tampa, FL 33612 3rd Wednesday, (813) 929-3932 4:30 - 6:00 pm

or

**University Community Hospital** 

3100 E. Fletcher Tampa, FL 3613 (813) 971-6000

or

St. Joseph's Hospital

3001 Dr. Martin Luther King Blvd.

Tampa, FL 33603 (813) 870-4000

Contact Info:

American Cancer Society 1-800-ACS-2345 Karen White, CCS (813) 254-3630x 321

Meetings: Moffit and UCH meet: 4th Thursday, 2:00 pm St. Joseph meet: 4th Thursday, 5:00 pm

Notes: Meetings rotate between hospitals, please

call for meeting location

#### Tarpon Springs, FL

#### **US TOO**

Helen Ellis Memorial Hospital
1395 S. Pinellas Ave.
Blue Room, 2nd floor
Tarpon Springs, FL 34689
Contact Info:

4th Monday,
4:00 pm
No meetings
July, August,
November,
December

US TOO 1-800-808-7866 or

Evelyn Waldroupe (727) 945-1929

Facilitator: Dr. Jacobs Attendees: 14-30

#### Venice, FL

#### Man to Man

Venice Healthpark
Lions Eye Center
1201 Jacaranda Blvd.
Venice, FL 34292

1st Monday,
2:00 pm
No meetings
July & August

Contact Info:

American Cancer Society 1-800-ACS-2345 or Mary Weaks, CCS (941) 497-4309 x 21 Facilitator: Roy Goree (941) 485-8010

Edward Law (941) 484-7993 e-mail: pat\_ed\_law@msn.com

Fax (941) 480-9177

#### Vero Beach, FL

#### **US TOO**

Indian River Memorial
Hospital
Cancer Center

2nd Tuesdays,
6:30 pm

1000 36th Street Vero Beach, FL 32968

Contact Info:

Facilitator: Curtis Folds (561) 567-0071 after 6pm

#### **NEW LISTING**

#### Man to Man

Indian River Memorial
Hospital

Last Tuesdays,
7:00 pm

Cancer Center 1000 36th Street Vero Beach, FL 32960

Contact Info:

Kim Glass-Benedetto, CCS (800) 224-6844 x 115

**CHAPTER 2** 

Meeting Location Meeting Dates & Times

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#### **Wellington Beach, FL**

#### **Prostate Cancer Support**

Wellington Regional Medical

Center

MRI Classroom 1st Friday, 10101 Forest Hill Blvd. 7:00 pm

State Road 7

Wellington, FL 33414

Contact Info:

Marsha Isreal (561) 790-7175

Facilitator: Jesse Seligman (561) 963-3412

Attendees: 60-90

NOTES: Spouses are invited. Located in back of

hospital. Refreshments are served.

#### **US TOO**

Wellington Regional Medical

Center 1st Friday, MRI Building 7:00 pm

Ash Adams (561) 686-4503

#### West Palm Beach, FL

#### Man to Man

The Helen & Harry Gray

Cancer Institute 1st Tuesday, Teleconference Room 3:00 pm

1309 N. Flagler Drive

West Palm Beach, FL 33401

http://www.ihswpb.com

Contact Info:

American Cancer Society 1-800-ACS-2345 Facilitator: David Most (561) 366-4189

e-mail: dsmost@ihswpb.com

Attendees: 15-20

NOTES: All cancer groups. Valet parking.

Refreshments served.

#### Winter Haven, FL

#### Man to Man

Winter Haven Memorial

Hospital 4th Tuesday, 200 Avenue F N.E. 1:00 pm

Winter Haven, FL 33881

(941) 283-1121 Contact Info:

American Cancer Society 1-800-ACS-2345 Facilitator: Rev. Bill Allen (941) 283-1121 x 3363

Attendees: 15

#### Zephyrhills, FL

#### Man to Man

East Pasco Medical Center

Wellness Center 3rd Wednesday, Conference Room 2:00 pm

7050 Gall Blvd.

Zephyrhills, FL 33541

(813) 788-0411

Contact Info:

American Cancer Society 1-800-ACS-2345

Beth Riddle, CCS 1 (800) 940-1969

Facilitator: Donald Charest (813) 788-0411

Hospital Contact: Carol Brown (813) 788-8326

For more information on additional support groups in Florida, contact:

US TOO at

1-800-808-7866 or

check their web site at

www.ustoo.org

#### **Cancer Organizations**

#### **American Cancer Society**

Florida Division, Inc. 3709 W. Jetton Ave. Tampa, FL 33629-5146 813-253-0541 800-ACS-2345 (800-227-2345)

Fax: 813-251-8723 www.cancer.org

#### **American Foundation for Urologic Disease**

1128 N. Charles Street Baltimore, MD 21201 800-828-7866 / 410-468-1800 admin@afud.org www.afud.org

#### **American Institute for Cancer Research (AICR)**

1759 R St., NW, Washington, DC 20009 202-328-7744 (General Information) 800-843-8114 (Nutrition Hotline, Publications Dept.) aicrweb@aicr.org www.aicr.org

#### **American Prostate Society**

1340-F Charwood Road Hanover, MD 21076 410-859-3735 Fax: 410-850-0818 cgerard@www.ameripros.org www.ameripros.org

#### Cancer Care, Inc.

National Office 275 7th Ave New York, NY 10001 800-813-HOPE (800-813-4673) Fax: 212-719-0263

info@cancercare.org www.cancercare.org

#### **Cancer Information Service**

800-4-CANCER (800-422-6237) TTY 1-800-332-8615 cis.nci.nih.gov

#### **CaPCure**

1250 4th Street, Suite 360 Santa Monica, CA 90401 800-757-2873 / 310-458-2873 Fax: 310-458-8074 capcure@capcure.org www.capcure.org

#### Florida Prostate Cancer Network

6105 Memorial Hwy.
Bldg. F Suite M,
Tampa, FL 33615
813-806-2800 or Toll Free (866) FLA-FPCN
Fax: 813-806-4662
www.florida-cancer.org

#### **National Cancer Institute**

NCI Public Inquiries Office Building, 31, Room 10A03 31 Center Drive, MSC 2580 BETHESDA, MD 20892-2580 800-4-CANCER (800-422-6237) TTY 800-332-8615 www.nci.nih.gov

## **National Center for Chronic Disease Prevention** and **Health Promotion**

Division of Cancer Prevention and Control Centers for Disease Control and Prevention 4770 Buford Highway, NE, MS K-64 Atlanta, GA 30341-3717 888-842-6355 cancerinfo@cdc.gov www.cdc.gov/cancer/prostate

#### **National Coalition for Cancer Survivorship**

Suite 707 Silver Spring, MD 20910-5600 Phone: 877-NCCS-YES (877-622-7937) Fax: 301-565-9670 info@cansearch.org www.cansearch.org

1010 Wayne Avenue

www.4npcc.org

#### **CHAPTER 2**

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#### **National Prostate Cancer Coalition**

1156 15th Street, NW, Suite 905 Washington, DC 20005 202-463-9455 Fax: 202-463-9456 info@4npcc.org

#### **Patient Advocates for Advanced Cancer**

**Treatments** 1143 Parmelee N.W. Grand Rapids, MI 49504 616-453-1477 / 616-453-1846 paact@osz.com www.osz.com/paact

#### **US TOO**

930 North York Road Suite 50 Hinsdale, IL 60521-2993 1 (800) 323-1003 http://www.usto.com

#### The Wellness Community - SW Florida

3900 Clark Road **Building P-3** Sarasota, FL 34233 941-921-5539 hope@wellness-swfl.org www.wellness-swfl.org

#### The Wellness Community - Greater Miami Area

(Opening 2002) 305-665-4311 www.wellness-community.org

#### **The Wellness Community**

5770 N. Federal Highway Boca Raton, FL 33487 561-912-9300 twcboca@aol.com www.twcboca.org

#### **Internet Resources**

#### Cancerfacts.com

www.cancerfacts.com support@cancerfacts.com

#### **CancerNet**

cancernet.nci.nih.gov

#### **CancerResources**

www.cancerresources.com lifecare@aol.com

#### Florida Prostate Cancer Network

www.florida-cancer.org

#### **Male Health Center**

www.malehealthcenter.com

#### **OncoLink**

oncolink.upenn.edu/disease/prostate

#### **Prostate Cancer InfoLink**

comed.com/prostate

#### **Prostate Cancer Research Institute**

www.prostate-cancer.org

#### **Prostate-Help**

prostate-help.com

#### **Prostate Pointers**

www.prostatepointers.org/prostate gary@prostatepointers.org

## Assistance for Prostate Cancer Patients and Their Families

#### **Pharmaceutical Assistance**

#### **American Cancer Society**

800-ACS-2345 (800-227-2345) www.cancer.org

#### Cancer Care, Inc.

800-813-HOPE (800-813-4673) www.cancercareinc.org/database/ database\_search.html www.cancercareinc.org/services/drug\_companies.htm

#### Health and Human Services (U.S.)

877-696-6775 www.hhs.gov

#### **Hill-Burton**

A brochure about the program is available in Spanish. 800-638-0742 www.hrsa.dhhs.gov/osp/dfcr/obtain/consfaq.htm

#### **Internal Revenue Service**

800-829-1040 www.irs.ustreas.gov

#### Medicaid

888-419-3456 www.hcfa.gov/medicaid/mcaicnsm.htm

#### Medicare

800-Medicare (800-633-4227) www.medicare.gov

#### **Needy Meds**

www.needymeds.com

## **Pharmaceutical Research and Manufacturers of America**

Directory of Pharmaceutical Manufacturers' Indigent Programs 800-PMA-INFO (800-762-4636) www.phrma.org

#### **Social Security Administration**

Spanish-speaking staff are available. 800-772-1213 TTY: 800-325-0778 www.ssa.gov/SSA\_Home.html

#### **United Way**

800-411-UWAY (800-411-8929). www.unitedway.org United Way of Florida, Inc. 307 East 7th Avenue, Suite 204 Tallahassee, FL 32303-5566

#### **Veterans Affairs**

Spanish-speaking staff are available in some offices. 800-827-1000 www.va.gov/benefits.htm

## Pharmaceutical Companies (Indigent Drug Programs)

Many pharmaceutical companies have programs which provide prescription medicines free of charge to patients in need. Your physician needs to make a written request (on physicians' letterhead) on behalf of the patient. The criteria is different for each company. Ask your physician.

#### **3M Pharmaceuticals**

6W13, 3M Center P.O. Box 33275 St. Paul, MN 55133-3275 800-328-0255

Fax: 651-733-6068

Product(s) Covered By Program: Aldara cream, Maxair Autohaler, Maxair Inhaler, Minitran (patches), Norflex, Norgesic Forte, Q Var Inhaler, Tasmbocore, Theolair

www.3m.com/pharma

#### Abbott Laboratories, Inc.

Pharamaceutical Products Division
Patient Assistance Program
P.O. Box 1420
Abbott Park, IL 60064
800-222-6885, Option #1
Product(s) Covered By Program: Live

Product(s) Covered By Program: Lupron

#### **Alza Pharmaceuticals**

Indigent Patient Assistance Program c/o Documedics 1250 Bayhill Drive, Suite 300 San Bruno, CA 94066 800-577-3788

Fax: 800-482-1896

Product(s) Covered By Program: Bicitra, Ditropan, Ditropan XL, Elmiron, Mycelex Trouche, Neutra-Phos, Neutra-Phos-K, PolyCitra, PolyCitra-K, Testoderm, Testoderm TTS Coupons, Urispas, Concerta Coupons, Flexeril

www.alza.com

#### **Oncology Connection Program**

1250 Bayhill Drive Suite 300 San Bruno, CA 94066 800-609-1083

Fax: 650-564-7070

Products Covered: Doxil, Ethyol

www.alza.com

#### Amgen

One Amgen Center Drive Thousand Oaks, CA 91320-1799

Fax: 805-447-1010

Amgen SAFETY NET® Program: 888-272-9376 Product(s) Covered By Program: EPOGEN® (Epoetin alfa), NEUPOGEN® (Filgrastim) www.amgen.com

#### **AstraZeneca Foundation**

Patient Assistance Program
P.O. Box 15197
Willmington, DE 19850-5197
800-424-3727
Product(s) Covered By Program: Zoladex (goserelin acetate) injectable, Casodex (bicalutamide)
www.astrazeneca-us.com

#### **Aventis Pasteur**

Discovery Drive Swiftwater, PA 18370 Cindy Cook, Associate Product Manager 800-VACCINE (822-2463) Fax: 570-839-4617

Products include: TheraCys BCG live intravesical

#### **Aventis Pharmaceuticals**

Patient Assitance Program P.O. Box 759 Somerville, NJ 08876 800-221-4025

Product(s) Covered By Program: ALLEGRA,
ALLEGRA D, AMARYL, ARAVA, ARAVALOADING DOSE, AZMACORT INHALATION
AEROSOL, BENTYL, CANTIL, CARAFATE SUSPENSION, CARAFATE TABLETS, CLAFORAN,
DDAVP, DDAVP INJECTION, DDAVP RHINAL,
HIPREX, LANTUS, NASACORT, AQ NASAL
SPRAY, NASACORT NASAL INHALER,
NILANDRON, TILADE INHALER

#### **Bayer Corporation**

Bayer Indigent Program P.O. Box 29209 Phoenix, AZ 85038-9209 800-998-9180

Product(s) Covered By Program: Adarat, Baycol, Cipro, Precose. Must have name of drug to check if covered.

www.bayer.com

#### Boehringer Ingelheim Pharmaceuticals, Inc.

c/o Express Scripts/Specialty Distribution Services P.O. Box 66555 St. Louis, MO 63166-6555 800-274-8651

Product(s) Covered By Program: Aggrenox (capsules), Atrovent (inhaler and nasal spray), Cafcit (injection), Catapres-TTS (patches), Combivent (inhaler), Flomax (capsules), Micardis (tablets), Micardis HTCD, Mobic (tablets), Varimune (oral solutions and tablets)

Control Substances: Oramorph (tablets), Roxanol (oral solution), Roxicondone (oral solution and tablets)

www.boehringer-ingelheim.com

#### **Bristol-Myers Squibb**

Patient Assistance Program P.O. Box 4500 Princeton, NJ 08543-4500 Mailcode P25-31 800-332-2056

Fax: 609-897-6859

Call for product information

www.bms.com

#### Cephalon, Inc.

1800 Robert Fulton Drive 3rd Floor Reston, VA 20191 877-229-1241

Fax: 800-777-7562

Product(s) Covered By Program: Actiq

www.cephalon.com

#### ConvaTec Professional Services (A Bristol-Myers Squibb Company)

Acess Program P.O. Box 5254 Princeton, NJ 08543-5254 800-422-8811

(CHEMO): BICNU, CEENU, ETOPOPHOS, LYSODREN, MUTAMYCIN, PARAPLATIN, PLARINOL-AQ, VEPESID (etoposide), VEPESID (teniposide), VUMON MJO PRODUCTS (CHEMO): BLENOXANE, CYTOXAN, CYTOXAN LYOPHILIZED, DROXIA, HYDREA, IFEX, and MESNEX/mesna combo packs, MEGACE, MEGACE ORAL SUSP, MYCOSTATIN PASTILLES, RUBEX, TAXOL, TESLAC MJO (IMM): FUNGIZONE ORAL SUSP, VIDE, VIDEX ORAL SOL, ZERIT, ZERIT ORAL SOL

Product(s) Covered By Program: BLO PRODUCTS

#### **DuPont Pharmaceuticals Company**

Darlene Samis
Chestnut Run Plaza
Hickory Run Bldg.
974 Centre Road
Wilmington, Delaware 19805
800-474-2762
www.dupontmerck.com
dminquiry@dupontpharma.com

#### **Elan Pharmaceuticals**

www.convatec.com

1 Research Way Princeton, NJ 08076 800-345-2252 Fax: 888-625-6587

Product(s) Covered By Program: Abelcet®

#### Glaxo Wellcome Inc.

Patient Assistance Program
P.O. Box 52185
Phoenix, AZ 85072-9711
Patient Assistance: 800-722-9294
Product(s) Covered By Program: All marketed
Glaxo Wellcome prescription products

www.glaxowellcome.com/pap

#### Janssen Pharmaceutica

Janssen Patient Assistance Program 1800 Robert Fulton Drive Reston, VA 20191-4346 800-652-6227 www.janssen.com

#### Nabi (formerly known as Univax)

5800 Park of Commerce Blvd. NW Boca Raton, FL 33487

Fax: 561-989-5899

Customer Service: 800-327-7106 Products include: WinRho SDF

www.nabi.com

#### **Novartis Pharmaceuticals**

Patient Assistance Program P.O. Box 8609

Somerville, NJ 08876

Patient Assistance Program: 800-277-2254 Product(s) Covered By Program: Certain single source and/or life-sustaining products. Controlled

substances are not included.

www.novartis.com

#### **Nycomed Amersham**

3350 N. Ridge Avenue Arlington Heights, IL 60004 800-228-0126

Product(s) Covered By Program: Iodine Seeds

#### **Ortho-McNeil Pharmaceutical**

Ortho-McNeil Patient Assistance Program P.O. Box 938 Somerville, NJ 08876 800-797-7737

Product(s) Covered By Program: Prescription products prescribed according to approved labeled

indications and dosage regimens

www.ortho-mcneil.com

#### Parke-Davis

The Parke-Davis Patient Assistance Program
P.O. Box 1058
Somerville, NJ 08876
908-725-1247
Product(s) Covered By Program: Accupril,
Dilantin, Lipitor, Loestrin, Neurontin and Zarontin

#### Pfizer, Inc.

Prescription Assistance P.O. Box 230970 Centerville, VA 20120 800-646-4455

Product(s) Covered By Program: Antivert, Atarax, Cardura, Diabinese, Feldene, Glucotrol, Glucotrol XL, Minipress, Minizide, Norvasc, Navane, Procardia, Procardia XL, Renese, Sinequan, Viagra, Vibramycin, Vibra-Tabs, Vistaril, Zoloft, Zyrtec www.pfizer.com

#### **Proctor & Gamble Pharmaceuticals, Inc.**

P.O. Box 231 Norwich, NY 13815

Attn: Customer Service Department

800-830-9049

Product(s) Covered By Program: Actonel, Asacol, Dantrium Capsules, Didronel, Macrodantin, Macrobid www.pg.com

#### Roche Laboratories, Inc.

Roche Medical Needs Program 340 Kingsland Street Nutley, NJ 07110

Roche Medical Needs Program: 800-285-4484 Product(s) Covered By Program: Roche product

line with some exceptions

Oncoline/Helpline Reimbursement Hotline:

1(800) 443-6676

www.roche.com/pharma/Index.htm

#### Roxane Labortories, Inc.

P.O. Box 16532 Columbus, OH 43216 800-520-1631

Product(s) Covered By Program: Aggrenox (capsules), Atovent (inhaler and nasal spray), Cafcit (injection), Catapres-TTS (patches), Combivent (inhaler), Flomax (capsules), Micardis (tablets), Micardis HTCD, Mobic (tablets), Varimune (oral solutions and tablets)

Assistance for Patients and Their Families

Controlled Substances: Oramorph (tablets), Roxanol (oral solution), Roxicondone (oral solution and tablets)

info@Roxane.com www.roxane.com

# **Sanofi-Synthelabo, Inc.** Needy Patient Program

c/o Product Information Department 90 Park Avenue New York, NY 10016 800-446-6267 Product(s) Covered By Program: Aralen, Danocrine, Drisdol, Hytakerol, Mytelase, NegGram, pHisoHex, Plaquenil, Primaquine, Skelid, www.sanofi-synthelaboUS.com

#### **Schering Laboratories/Key Pharmaceuticals**

For Intron A/Eulexin: 800-521-7157
For Other Products:
Schering Laboratories/Key Pharmaceuticals
Patient Assistance Program
P.O. Box 52122
Phoenix, AZ 85072
800-656-9485
www.schering-plough.com

#### **Smithkline Beecham Pharmaceuticals**

One Franklin Plaza-FP1320
Philadelphia, PA 19101
800-546-0420
Product(s) Covered By Program: Most SmithKline
Beecham outpatient prescription products are
covered. Controlled substances and vaccines are
not covered.
www.sb.com

## **Tap Pharmaceuticals**

Access to Care Program

Patient Assistance Program 800-453-8438 Products include: Lupron and Prevacid www.tapurology.com

## **Wyeth-Ayerst Laboratories**

Professional Services 150A-3
Indigent Patient Program
P.O. Box 13806
Philadelphia, PA 19101-9649
800-568-9938
Product(s) Covered By Program: Various products (not including schedule II, III, or IV products).

## **Transportation Assistance**

Free transportation assistance to and from cancer treatment facilities is offered through the following organizations.

#### **Air Care Alliance**

6202 South Lewis Avenue Suite F2 Tulsa, Oklahoma 74136-1064 918-745-0384 888-260-9707 www.aircareall.org

#### **American Cancer Society**

Florida Division, Inc. 3709 W. Jetton Ave. Tampa, FL 33629-5146 813-253-0541 800-ACS-2345 (800-227-2345) www.cancer.org

#### **Angel Flight Southeast**

8742 Airport Blvd. Leesburg, FL 34788 800-352-4256 www.angelflightse.org

#### Cancer Care, Inc.

National Office 275 7th Ave. New York, NY 10001 800-813-HOPE (800-813-4673) www.cancercareinc.org/database/ database\_search.html

#### PatientTravel.org

Mercy Medical Airlift 4620 Haygood Road, Ste. 1 Virginia Beach, VA 23455 800-296-1217 www.patienttravel.org

#### **Insurance Information**

The costs of initial treatment, prescriptions and continuing care are certainly a concern for the patient.

Get all the benefits your policy provides:

- 1.) Determine exactly what your insurance covers. Get a copy of your policy and review it.
- 2.) Keep careful records of all your expenses and claims.
- 3.) File claims for all costs. If your first claim is denied, file again. Involve your physician.
- 4.) Get help with filing your claim if you need it. Friends, family, or a social worker can help.

A number of organizations can help uninsured cancer patients or those with inadequate coverage.

#### Cancer Care, Inc.

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

Fax: 212-719-0263 info@cancercare.org

www.cancercare.org/campaigns/advocacy4.htm

## Florida Department of Elder Affairs

800-96ELDER (800-963-5337)

www.myflorida.com

Local Elder Help Line can connect you with local SHINE Program (Serving Health Insurance Needs of the Elderly)

Elder Help Line can also link you to local Area Agency on Aging

# **Health Insurance Association of America**

555 13th Street N.W. Washington, D.C. 20004 202-824-1600 www.hiaa.org

#### **Hill-Burton**

A brochure about the program is available in Spanish.
800-638-0742
www.hrsa.dhhs.gov/osp/dfcr/obtain/consfaq.htm
DFCRCOMM@HRSA.GOV

#### Medicaid

7500 Security Boulevard Baltimore, Maryland 21244 888-419-3456 www.hcfa.gov/medicaid/mcaicnsm.htm

#### Medicare

800-638-6833

Florida Contact: Blue Cross & Blue Shield

800-333-7586 TTY: 800-754-7820

Español teléfono: 904-355-3680

www.medicare.gov

#### **National Cancer Institute**

800-4-CANCER (800-422-6237)

TTY: 800-332-8615

cancernet.nci.nih.gov/facing\_forward/facmanag.html

## **Patients' Advocate Foundation**

780 Pilot House Drive, Suite 100-C

Newport News, VA 23606

800-532-5274

Fax: 757-873-8999

www.patientadvocate.org

patient@pinn.net

#### **Social Security Administration**

Spanish-speaking staff are available.

800-772-1213

TTY: 800-325-0778

www.ssa.gov/SSA\_Home.html

## **Veterans Affairs**

Spanish-speaking staff are available in some

offices.

800-827-1000

g.vhacss@forum.va.gov www.va.gov/benefits.htm

# **Hospice Information**

This chapter contains a listing of Florida-based hospice centers listed alphabetically by city and the county(s) served. Hospice programs provide high quality medical care and psychological support for and your family.

# Florida Hospices

## **Altamonte Springs, FL**

Hospice of the Comforter 595 Montgomery Road Altamonte Springs, FL 32714 (407) 682-0808 (407) 682-5787 Fax

Administrator: Robert G. Wilson Referrals: Marianne Larosa

County(s): Orange, Osceola, Seminole

#### Auborndale, FL

Good Sheperd Hospice of Mid-Florida 105 Arneson Avenue Auborndale, FL 33823 (863) 297-1880 or (863) 965-5601 Fax

Administrator: Mary Ellen Poe County(s): Hardee, Highland, Polk

#### **Boca Raton, FL**

Hospice by the Sea 1531 W. Palmetto Road Boca Raton, FL 33468-3395 (561) 395-5031 (561) 394-4515 Fax

Administrator: Trudi Webb County(s): Broward, Palm Beach

## **Bradenton, FL**

Hospice of Southwest Florida 3355 26th Street W. Bradenton, FL 34205 (941) 739-8940 (941) 739-8937 Fax County(s): Charlotte, De Sota, Manatee, Sarasota

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Assistance for Patients and Their Families

# **Brooksville, FL**

Hernando Pasco Hospice - Satellite Office 12260 Cortez Blvd. Brooksville, FL 34613 (352) 597-1882 (352) 597-4667

Administrator: Rodney S. Taylor

County(s): Hernando

#### Cape Coral, FL

Hope Hospice 130 Del Prado Blvd. Cape Coral, FL 33990 1-800-788-8091 Toll Free or (941) 574-4888 http://www.hopehospice.org e-mail@hopehospice.org

Administrator: Samira K Beckwith County(s): Glades, Hendry, Lee

#### Clearwater, FL

Hospice of the Florida Suncoast Hospice House - Resident only 1308 Viewtop Drive Clearwater, FL 34624-3737 (813) 586-4432

Administrator: Mary J. Labyak

County(s): Pinellas

# Clewiston, FL

Hope Hospice 532 West Sagamore Street. Clewiston, FL 33440 1-800-935-1673 Toll Free or (941) 983-7771 http://www.hopehospice.org e-mail@hopehospice.org

Administrator: Samira K Beckwith County(s): Glades, Hendry, Lee

# Daytona Beach, FL

Hospice of Volusia / Flagler (See Port Orange)

# Florida Hospices

## Fort Lauderdale, FL

Hospice Care of Broward County 309 SE 18th Street Fort Lauderdale, FL 33316-2886 (954) 467-7423 x23 or (954) 524-6067 Fax e-mail: hospice@safari.net

Administrator: Susan G. Telli County(s): Broward, Dade, Monroe

## Fort Myers, FL

Hope Hospice - Home Office 9470 Healthpark Circle Fort Myers, FL 33908-3617 1-800-835-1673 Toll free (941) 482-4673 Home Office (941) 482-2488 Home Office Fax (941) 590-0276 Hospice House 1-800-889-1344 Toll Free Hospice House http://www.hopehospice.org e-mail@hopehospice.org

Administrator: Samira K Beckwith County(s): Glades, Hendry, Lee

#### Fort Pierce, FL

Hospice of the Treasure Coast PO Box 1748 Fort Pierce, FL 34954-1748 (407) 465-0504 or (407) 465-6309 Fax

Administrator: Sharon A. Rivers

County(s): Indian River, Martin, Okeechobee, St.

Lucie

## Gainesville, FL

Hospice of North Central Florida 4200 NW 90th Blvd. Gainesville, FL 32606 (352) 378-2121 or (352) 379-6290 Fax

Administrator: Tim Bower Referrals: Clair Milliman

# Hudson, FL

Hernando Pasco Hospice 12107 Majestic Blvd. Hudson, FL 34667-2460 (727) 863-7971 or (727) 868-9261 Fax

Administrator: Rodney S. Taylor Referrals: Evelyn Passarella

#### Jacksonville, FL

Hospice of Northeast Florida 4266 Sunbeam Road Jacksonville, FL 32257 (904) 268-5200 or (904) 268-9795 Fax

Administrator: Susan Ponder-Stansel

#### **Methodist Hospital Hospice**

580 W. 8th Street Jacksonville, FL 32209-6553 (904) 798-8340 or (904) 798-8339

Administrator: Dorothy D. Bray

#### **Key West, FL**

Hospice of the Florida Keys VNA of the Florida Keys 1319 William Street Key West, FL 33040 (305) 294-8812 or (305) 292-9466 Fax

Administrator: Liz Kern Referrals: Pat Haggerty County(s): Monroe

#### Lakeland

Good Sheperd Hospice of Mid-Florida 105 Arneson Avenue Auborndale, FL 33823 (863) 297-1880 or (863) 965-5601 Fax

Administrator: Mary Ellen Poe County(s): Hardee, Highland, Polk

# Florida Hospices

# Lehigh Acres, FL

Hope Hospice 205 East Joel Blvd. Suite 304 Lehigh Acres, FL 33972 1-800-788-8092 Toll Free or (941) 9368-2040 http://www.hopehospice.org e-mail@hopehospice.org

Administrator: Samira K Beckwith

# Largo, FL

Hospice of the Florida Suncoast 300 E. Bay Drive. Largo, FL 33770 (727) 586-4432 or (727) 581-5846 Fax

Administrator: Mary J. Labyak Referrals: Sharon Brown County(s): Pinellas

#### **Central Community Service Center**

Pinebrook Business Complex 7411 114th Ave. N. Largo, FL 33773 (727) 586-4432 or (727) 581-5846 Fax

Administrator: Marcy Pruitt County(s): Pinellas

#### **Main Community Service Center**

300 E. Bay Drive. Largo, FL 33770 (727) 586-4432 or (727) 581-5846 Fax

Administrator: Sandra Sunter

County(s): Pinellas

# Lecanto, FL

Hospice of Citrus County 3350 W. Audubon Park Path Lecanto, FL 34461-8450 (352) 527-2020 or (352) 527-9240 Fax

Administrator: Marjorie B. Budd

County(s): Citrus

#### Maitland, FL

VITAS Healthcare Corp of Central Florida Maitland Center Parkway Suite 300 Maitland, FL 32751-7267 (407) 875-0028 or (407) 475-2674 Fax

Administrator: Mark Taylor

County(s): Orange, Osceola, Seminole

## Marianna, FL

Hospice of Northwest Florida 2917 B Optimist Drive Marianna, FL 32448 (850) 482-8520 or (850) 482-8985 Fax

Administrator: Diane DaCosta

County(s): Holmes, Jackson, Washington

#### Miami, FL

Catholic Hospice 14100 Palmetto Frontage Road Suite 370 Miami, FL 33016-1557 (305) 822-2380 or (305) 824-0665 e-mail: hospice@safari.net

Administrator: Barbara J Janosko

County(s): Dade, Monroe

# Florida Hospices

# **Hospice Care of Broward County**

1200 NW 78th Avenue Suite 101 Miami, FL 33126 (305) 599-7755 or (305) 599-3588 e-mail: hospice@safari.net

Administrator: Susan G. Telli County(s): Broward, Dade, Monroe

## **Hospice Care of South Florida**

7270 NW 12th Street Penthouse 6 Miami, FL 33126 (305) 591-1606 or (305) 591-1618 Fax

Administrator: Rose Marie R. Marty

County(s): Dade

#### **VITAS Healthcare Corp of Florida**

12515 N. Kendall Drive Suite 210 Miami, FL 33186 (305) 275-9944 or (305) 275-4995 Fax

Administrator: Rose Marie R. Marty

County(s): Dade

#### Miramar, FL

VITAS Healthcare Corp of Florida 3700 Executive Way Miramar, FL 33025 (954) 576-9333 or (954) 704-2094 Fax

Administrator: Katherine Hirstius

Referrals: Kathy Donlan County(s): Broward, Dade

## Naples, FL

Hospice of Naples 1095 Whippoorwill Lane Naples, FL 34105 (941) 261-4404 or (941) 262-2429

Administrator: Diane S. Cox

County(s): Collier

# **New Port Richey, FL**

**CHAPTER 3** 

Hernando Pasco Hospice - Satellite Office 4422 Grand Ave. New Port Richey, FL 34652 (813) 849-2629 or (813) 848-0110 Fax

Administrator: Rodney S. Taylor

Referrals: Rose Milks County(s): Hudson, Pasco

## **Hospice of Pasco**

3589 Universal Plaza New Port Richey, FL 34652 (727) 845-5904 or (727) 845-7254 Fax

Administrator: Katherine Hirstius

Referrals: Kathy Donlan

County(s): Pasco

## Niceville, FL

Hospice of Northwest Florida 101 Hart Street Niceville, FL 32578 (850) 729-1800 or (850) 729-7883

Administrator: Sheila H. Glover

Referrals: Dona White

County(s): Okaloosa, Walton

#### Ocala, FL

Hospice of Marion County 3231 SW 34th Ave. PO Box 4860 Ocala, FL 34478-4860 (352) 873-7434 or (352) 873-7432 Fax

Administrator: Alice J. Privett Referrals: Debbie Saussy

County(s): Marion

Referrals: Rebecca Thomas County(s): Okeechobee

# Florida Hospices

## Okeechobee, FL

Hospice of Okeechobee 411 SE 4th Street Okeechobee, FL 34974 (863) 467-2321 or (863) 467-8330 Fax

Assistance for Patients and Their Families

Administrator: Pat Ballenger

#### **Ormond Beach, FL**

Hospice Care of Memorial Hospital 500 Memorial Circle, Suite C Ormond Beach, FL 32174 (904) 676-6166 or (904) 672-0314 Fax

Administrator: Stephanie Williams

Referrals: Joanne Stanford

County(s): Flagler

## Palm Harbor, FL

Hospice of the Florida Suncoast 2765 Tampa Road Palm Harbor, FL 34684 (727) 586-4432 or (727) 789-7834 Fax

Administrator: Timothy R. Arsenault

#### Panama City, FL

Hospice of Northwest Florida - Panama City 502 N. MacArthur Ave. Suite B Panama City, FL 32401 (850) 785-3040 or (850) 785-2552 Fax

Administrator: Judy Smolk County(s) Bay, Calhoun, Gulf

## **Hospice of the Emerald Coast**

2929 Highway 77 Panama City, FL 32405 (850) 769-0050 or (850) 769-0321 Fax

Administrator: Sue Nelson Referrals: Donna Mezzanotte County(s) Bay, Calhoun, Gulf

# Pensacola, FL

**CHAPTER 3** 

Hospice of Northwest Florida 2001 N. Palafox Street Pensacola, FL 32501 (850) 433-2155 or (850) 433-7212 Fax

Administrator: Judy Smolk County(s) Bay, Calhoun, Escambia, Gulf, Holmes, Jackson, Okaloosa, Santa Rosa, Walton, Washington

#### Pinellas Park, FL

Hospice of the Florida Suncoast Hospice House-Woodside 6770 102nd Ave. N. Pinellas Park, FL 33782 (727) 541-4199 or (727) 547-1947Fax

Administrator: Sandy Rex Referrals: Admissions Counselor

County(s): Pinellas

#### Pompano Beach, FL

Hospice of the Gold Coast Health Services 911 E. Atlantic Blvd., Suite 200 Pompano Beach, FL 33060-7372 (954) 785-2990 x63 or (954) 785-2993 Fax

Administrator: Darlene McCullogh County(s): Broward, Palm Beach

## Port Charlotte, FL

Hospice of Southwest Florida 3028 Caring Way Port Charlotte, FL 33952 (941) 627-0848 or (941) 627-1875 Fax

Administrator: Bonnie, Harvey Referrals: Barbara Benson

County(s): Charlotte, De Sota, Manatee,

Sarasota

# Florida Hospices

# Port Orange, FL

Hospice of Volusia/Flagler 3800 Woodbriar Trail Port Orange, FL 32119 (904) 322-4701 or (904) 322-4702 Fax

Administrator: Deborah Harley Referrals: Holly Van Hoose County(s): Flagler, Volusia

## Rockledge, FL

Brevard Hospice PO Box 565002 Rockledge, FL 32956-5002 (407) 253-2222 or (407) 253-2238 Fax http://www.iu.net/wmh

Administrator: Cynthia Harriss-Panning

Referrals: Terry La Duke County(s): Pinellas

## Saint Augustine, FL

Community Hospice Northeast 1955 US 1 South, Suite D3 Saint Augustine, FL 32086 (904) 824-3735 or (904) 829-0912 Fax

Administrator: Sharon Arsenault

County(s): Pinellas

#### Saint Petersburg, FL

Hospice of the Florida Suncoast South Community Service Center 5639 49th Street N. Saint Petersburg, FL 33709 (727) 586-4432 or (727) 521-5622 Fax

Administrator: Grace S. Case

County(s): Pinellas

# Sarasota, FL

Hospice of Southwest Florida 5955 Rand Blvd. Sarasota, FL 34238-5189 (941) 923-5822 or (941) 925-0969 Fax

Administrator: Gary Lamm Referrals: Merissa Werly

County(s): Charlotte, De Sota, Manatee,

Sarasota

# Sebring, FL

Good Sheperd Hospice of Mid-Florida PO Box 1884 Sebring, FL 33871 (863) 471-3700 or (863) 471-9542 Fax

Administrator: Marry Ellen Poe County(s): Hardee, Highlands, Polk

#### Stuart, FL

Hospice of Martin & Saint Lucie 2030 SE Ocean Blvd. Stuart, FL 34996 (561) 287-7860 or (561) 287-7982 Fax

Administrator: Mary C. Knox Referrals: Tamara Oleson

County(s): Martin, Okeechobee, Saint Lucie

#### Sun City Center, FL

LifePath Hospice 1647 Sun City Center Plaza, Suite 104 Sun City Center, FL 33573 (813) 634-7621 or (813) 633-3861 Fax

Administrator: Kathy Fernandez

County(s): Hillsborough

# Florida Hospices

#### Tallahassee, FL

Big Bend Hospice 1723 Mahan Center Blvd. Tallahassee, FL 32308 (850) 878-5310 or (850) 309-1638 Fax

Administrator: Virginia Fielder

County(s): Franklin, Gadsden, Jefferson, Leon,

Liberty, Madison, Taylor, Wakulla

## Tampa, FL

LifePath Hospice 3010 W. Azeele Street Tampa, FL 33609 (813) 877-2200 or (813) 872-7037 Fax

Administrator: Kathy Fernandez

County(s): Hillsborough

#### Tavares, FL

Hospice of Lake & Sumter 12300 Lane Park Road Tavares, FL 32778-9660 (352) 343-1341 or (352) 343-6115 Fax

Administrator: Pat Lebotsky County(s): Lake, Sumter

## Titusville, FL

Hospice of Saint Francis 2395 South Washington Ave. Suite 3 & 4 Titusville, FL 32780 (321) 269-4240 or (321) 269-5428 Fax

Administrator: Bruce Walters Referrals: Barbara Borman

County(s): Brevard

County(s): Charlotte, De Sota, Manatee,

Sarasota,

#### Venice, FL

Hospice of Southwest Florida 220 Wexford Blvd. Venice, FL 34293 (941) 496-4611 or (941) 497-1648 Fax

Administrator: Bonnie E. Harvey Referrals: Diane Welnitz

## Vero Beach, FL

VNA Hospice of IRC 1111 36th Street Vero Beach, FL 32960-4802 (561) 567-5551 x12 or (561) 569-1444 Fax

Administrator: Janine Cacciatore Referrals: Ginny Fitzgerald County(s): Indian River

#### West Melbourne, FL

Holmes Regional Hospice 1900 Dairy Road West Melbourne, FL 32904 (407) 952-0494 or (407) 952-0382

Administrator: Roberta Van Dusen

Referrals: Paula Ludwig County(s): Brevard

## West Palm Beach, FL

Hospice of the Palm Beaches 5300 East Ave. West Palm Beach, FL 33407 (561) 848-5200 x211 or (561) 863-2955 Fax http://www.hpbc.com

Administrator: Dane Fielding County(s): Palm Beach

# Florida Hospices

#### Winter Haven, FL

Good Sheperd Hospice of Mid-Florida 105 Arneson Avenue Winter Haven, FL 33823 (863) 297-1880 or (863) 965-5601 Fax

Administrator: Marry Ellen Poe County(s): Hardee, Highlands, Polk

#### Zephyrhills, FL

Hernando Pasco Hospice 7066 Fort King Road Zephyrhills, FL 33541 (813) 780-6797 or (813) 788-5119 Fax

Administrator: Rodney S. Taylor Referrals: Dawn Woodward County(s): Hernando, Pasco

# **National Hospice and Estate Planning Information**

# **American Association of Retired Persons** (AARP)

400 Carillon Parkway Suite 100 St. Petersburg, FL 33716 800-424-3410 727-571-2277 TTY: 727-561-9544 www.aarp.org

## **Foundation for Hospice and Homecare**

228 Seventh Street SE Washington, DC 20003 202-547-6586

# Growth House, Inc.

415-255-9045 growthhouse.org info@growthhouse.org

#### **Hospice Association of America**

228 Seventh Street, SE Washington, DC 20003 202-546-4759 www.nahc.org/HAA

#### **Hospice Education Institute, Inc.**

190 Westbrook Road Essex, CT 06426-1510 800-331-1620 hospiceall@aol.com

#### **Hospice Foundation of America**

777 17 Street #401 Miami Beach, FL 33139 800-854-3402 www.hospicefoundation.org

# **Hospice Helpline**

800-658-8898

#### **Hospice Link**

Hospice Education Institute 190 West Brook Road, Suite 3B Essex, CT 06426-0713 800-331-1620

#### **Hospice Net**

www.hospicenet.org

## **Hospice Web**

www.hospiceweb.com/index.htm hospice@hospiceweb.com

Assistance for Patients and Their Families

# Joint Commission on Accreditation of **Healthcare Organizations (JCAHO)**

One Renaissance Boulevard Oakbrook Terrace, Illinois 60181 630-792-5000 Fax: 630-792-5005

www.jcaho.org

#### **Medicare Hotline**

800-638-6833 www.medicare.gov

## **National Association for Home Care (NAHC)**

228 7th Street, SE Washington, DC 20003 202-547-7424 Fax: 202-547-3540 www.nahc.org

# **National Hospice and Palliative Care Organization**

1700 Diagonal Road Suite 300 Alexandria, VA 22314 800-658-8898 www.nho.org

## **Patients' Advocate Foundation**

780 Pilot House Drive, Suite 100-C Newport News, VA 23606 800-532-5274 Fax: 757-873-8999 patient@pinn.net

www.patientadvocate.org

Chapter 4 Advocacy CHAPTER 4

# **Advocacy**

Visit the Florida Prostate Cancer Network's (FPCN) Web site at www.florida-cancer.org for the most up-to-date information on legistlative advocacy initiatives in Florida.

Be sure to click onto CapWiz - a service provided by FPCN - to contact your U.S. or Florida State Government officials.

(Executive Summary of the Recommendations of the Florida Prostate Cancer Task Force (Chapter 98-305, Florida Statutes) January 2000)

# **Executive Summary**

How much does the public know about prostate cancer?

- Do they know that older men, African American men, and men with a family history of prostate cancer are at high risk?
- Do they know where to get current and accurate information about prostate cancer?
- Do their doctors talk to them about screening and treatment options?
- Do they know that, as of January 2000, Medicare will cover annual prostate cancer tests and that many managed care plans cover the tests if they are ordered by a physician?

Chances are the answer to some of these questions is "no." To address this need, the Florida Legislature created the Prostate Cancer Task Forces in 1998 "to identify where public awareness, public education, research, and coordination about prostate cancer is lacking and to prepare recommendations to increase research on prostate cancer and the public's awareness of the importance of the early detection and treatment of prostate cancer" (Florida Laws, Chapter 98-305).

In Florida, as in the United States, prostate cancer is the most common type of cancer in men. It is estimated that 15,000 men in Florida will be diagnosed with prostate cancer this year and that 2,400 will die from it (American Cancer Society). These numbers are comparable to the number of women who are diagnosed and die from breast cancer each year. Florida has the second largest number of prostate cancer cases in the United States, which is attributed to the state's large population and high percentage of elderly. Yet, very little attention - and no state funding - is given to prostate cancer.

Trends in Incidence and Mortality: From the early 1980s until 1992, the rate of newly diagnosed prostate cancer cases (incidence) more than doubled. The increase was mainly due to the introduction of the prostate-specific antigen (PSA) blood test, which can detect cancer before symptoms appear. Since 1992, the incidence rate has decreased as more men are routinely screened. The rate of deaths (mortality) from prostate cancer was fairly constant until 1993, but after this time it began to decrease slowly but steadily. This decrease may be due to the detection of prostate cancer at an early stage when treatment can be successful, and/or improvements in treatment methods.

Racial Disparities: African American men are 50% more likely to develop prostate cancer and more than twice as likely to die from it than men of other racial and ethnic groups. In addition, the recent decrease in prostate cancer mortality among white men has not occurred among African American men.

Early Detection: There has been much debate in recent years about prostate cancer screening. The American Cancer Society (ACS), the American Urological Association, and the National Comprehensive Cancer Network (NCCN) agree that "the majority of evidence, while not conclusive, supports the view that prostate cancer early detection can save lives." The groups recommend that "providers offer men the option of prostate cancer early detection and discuss the potential benefits, side effects, and uncertainties... prior to testing" (Prostate Cancer Treatment Guidelines for Patients, NCCN and ACS, June 1999). However, the National Cancer Institute says "there is insufficient evidence to establish whether a decrease in mortality from prostate cancer occurs with screening," the American College of Physicians suggests, "rather than screening all men for prostate

cancer as a matterof routine, physicians should describe the potentialbenefits and known harms of screening, diagnosis, and treatment; listen to the patient's concerns; and then individualize the decision to screen." The U.S. Preventive Services Task Force recommends against routine PSA testing.

**Risk Factors and Causes:** The cause of prostate cancer is not known. Older men, African American men, and men with a family history of prostate cancer (e.g., father or brother) are at higher risk for getting the disease.

What can be done? The following recommendations address public, patient, and professional education, research, insurance coverage and evaluation. The Florida Prostate Cancer Task Force also recommends the creation of an ongoing Prostate Cancer Advisory Committee to address the issues more thoroughly and to monitor progress toward achieving the goals listed below.

# FLORIDA PROSTATE CANCER TASK FORCE RECOMMENDATIONS

#### **Education**

1. Public Education

GOAL: Increase awareness about the risk factors and tests for prostate cancer, so men can make informed decisions about screening.

Specific Recommendations:

- \$1 million per year should be appropriated for a community-based statewide educational campaign to be coordinated by the Department of Health and based on the Massachusetts Prostate Health Awareness Program.
- The campaign should include:
  - 1) multi-media educational material, e.g., brochures and posters, videos, computerbased resources, and radio and television announcements
  - 2) an annual statewide symposium and local forums on prostate cancer
  - 3) newspaper articles/feature stories
  - 4) radio and television talk/call-in programs (particularly for the Hispanic and African

American men and men with a family history of prostate cancer)

- Representatives from the general public, prostate cancer survivors, and health care professionals should be involved in planning.
- Communication strategies and educational messages should be based on research that demonstrates effective ways for reaching audiences of various racial and ethnic groups, age groups, and literacy levels.
- The Department of Health should consider the creation of a division of men's health, in which the prostate cancer program could be located.
- The campaign should encourage men to talk to their doctors and to make informed choices about early detection. For men who do not have a doctor or health insurance, particularly men in high-risk categories, strategies need to be developed to identify and refer them to a source of care.

#### 2. Patient Education

GOAL: Increase patient awareness about their disease, diagnostic tests, treatment options, side effects, and quality of life issues.

Specific Recommendations:

- It is not necessary at this time for Florida to produce its own patient education material, because there are several excellent brochures currently available. However, efforts should be made to ensure that these materials are easily available.
- As part of the statewide educational campaign, a toll-free telephone number and an Internet site should be established and widely publicized to provide easy access to accurate and reliable information on prostate cancer, diagnostic tests, treatment options, side effects, quality of life issues, and other patient concerns.
- Develop an inventory of resources, including support groups, and ensure the information is available to prostate cancer patients and their families.
- Consideration should be given to amending Sections 458.324 and 459.0125 of the Florida Statutes requiring physicians to inform prostate cancer patients about treatment options, as is currently required for breast cancer patients.

#### 3. Professional Education

GOAL 1: Increase health care providers' awareness of the latest guidelines on prostate cancer screening, early detection, and treatment.

GOAL 2: Increase communications between physicians and patients about the early detection of prostate cancer.

Specific Recommendations:

- The statewide educational campaign should promote continuing medical education (CME) programs on prostate cancer.
- Medical societies and associations should help distribute information about CME programs, paticularly to community physicians and primary care providers.
- Medical and nursing school curricula should include a minimum of one classroom hour of instruction on prostate cancer.
- Health care providers should be encouraged to counsel their patients, particularly those at high risk for prostate cancer, about when to be screened, intervals for repeat testing, diagnostic tests, and any potential complications from these tests.
- Health care providers should be made aware of, and encouraged to use, patient education material.

#### **Insurance Coverage**

GOAL: Reduce the financial barriers for the early detection, diagnosis, and treatment of prostate cancer. Specific recommendations:

- Amending state insurance laws to mandate coverage for prostate cancer testing is not recommended because of the relatively small number of men who would benefit, the relatively low cost of screening, the potential increase to premiums, and the number of men for whom screening is covered through managed care plans and Medicare.
- Managed care and health insurance companies should be encouraged to expand coverage for cancer patients to include the cost of treatments that are part of clinical trials. Legislative changes to ensure such coverage should be explored.

- More information is needed about financial barriers to care, such as:
  - 1) the number of insurers that do not provide coverage for testing for prostate cancer
  - 2) the number of men affected by these policies
  - 3) gaps in coverage for prostate cancer diagnosis and treatment
  - 4) the number of men who do not get prostate cancer tests because it is not covered by their insurance policy, and the percentage who cannot afford to pay for the test themselves
  - 5) the impact of mandated coverage in others
- Develope strategies to address the needs of the uninsured and underinsured men who cannot afford prostate cancer testing and diagnostic and treatment services.

#### Research

GOAL: Advance and apply knowledge about the prevention, early detection, and treatment of prostate cancer.

Specific recommendations:

- The Task Force concurs with the priorities for prostate cancer research developed by the National Cancer Institute.
- Research that addresses issues unique to Florida, (e.g., cancer among Hispanics and immigrants from the Caribbean and Central America).
- Research on quality of care and treatment outcomes in Florida should be conducted, (e.g., complication rates for prostate cancer surgery in community hospitals vs. university hospitals, discrepancies in medical care, and survival rates among subgroups of the population).
- Since there are few investigators in Florida working on prostate cancer research, the state should make funds available to recruit qualified researchers to the state, as well as seed money for new investigators to stimulate prostate cancer research at Florida's research institutions. The Florida Biomedical Research Fund should be considered as a possible source of funding.

CHAPTER 4 Advocacy Advocacy CHAPTER 4

- An inventory of researchers involved in prostate cancer research in Florida should be developed and maintained for both health care professionals and the public.
- Men should be encouraged to enroll in randomized, controlled clinical trials to evaluate screening and treatment methods.

## **Evaluation and Ongoing Activities**

GOAL 1: Analyze state data to evaluate progress toward increasing early detection and decreasing mortality.

GOAL 2: Establish a Prostate Cancer Advisory Committee to provide direction and to help monitor the implementation of the Prostate Cancer Task Force recommendations.

Specific Recommendations:

- Analyze trends in the following:
  - 1) incidence and mortality rates for all ages as well as age-specific rates
  - 2) the percentage and rate of early stage prostate cancers
  - 3) differences in rates for white and non-whites
  - 4) differences in rates for Hispanics and non-Hispanics
  - 5) the incidence-to-mortality ratios
  - 6) differences in rates by geographic area
- Add questions about prostate cancer testing to the Behavioral Risk Factor Surveillance System.
- Examine data on the complication rate of prostate cancer surgery at community hospitals vs. university hospitals, and assess the need to establish centers of excellence for the treatment of prostate cancer.
- A Prostate Cancer Advisory Committee should be created to:
  - 1) advise the Department of Health on prostate cancer education programs
  - 2) provide direction, evaluate progress, and serve as a link between state government and the community
  - 3) work with the Cancer Control and Research Advisory Council to ensure that prostate cancer programs are coordinated with the Florida Cancer Plan and other cancer control programs in the state

Prostate Cancer affects many Floridians - either directly or indirectly. However, there are no state programs to increase awareness of prostate cancer or to ensure that men at risk for prostate cancer are aware of the options for testing. The State has taken a first step by creating the Prostate Cancer Task Force. The recommendations described in this report offer a framework for the next steps.

For more information contact:



Florida Prostate Cancer Network 6105 Memorial Highway Building F, Suite M Tampa, Florida 33615 813-806-2800 813-806-4662 fax www.florida-cancer.org

# **Guide To Elected Officials**

While prostate cancer is the #1 diagnosed cancer in men and the second leading cause of cancer related deaths in American men, prostate cancer receives just 3.6 percent of the federal dollars for cancer research. Florida currently does not recognize prostate cancer as a health priority and has no state-funded programs for prostate cancer research and education. This web site allows you to search for contact information on elected officials for the state of Florida. Let your voice be heard!

http://www.leg.state.fl.us/citizen/findleg/county.html

CHAPTER 4 Advocacy

You also can visit the Florida Prostate Cancer Network Web site for more links to this site and more information.

http://www.florida-cancer.org

Or contact us at:

#### Florida Prostate Cancer Network

6105 Memorial Highway Building F, Suite M Tampa, FL. 33615 (813) 806-2800 (866) 352-3236 (toll free) (813) 806-4662 FAX

The Government section at the front of your local telephone directory also lists the names, addresses, and phone numbers of your locally elected officials.

# Chapter 5

# **More Prostate Cancer Information**

The staff and volunteers of the **Florida Prostate**Cancer Network realize that this directory
may not answer all of your questions about prostate
cancer. For a list of free **publications** or **videos**,
please contact us at the address or phone number
listed above. Or visit our Web site at
www.florida-cancer.org