

CHAPTER TWENTY-ONE RESOURCES

By Drs. E. David Crawford, Edward P. DeAntoni & Aubrey Pilgrim

During the year of 1992, 44,000 men died from prostate cancer. In the year 2000, about 31,000 died. Most of those men who died in 1992 had not been diagnosed until they had symptoms or pain. Of course, at that time they already had advanced cancer. Today most men are being diagnosed earlier and their cancers are being cured. **The answer to cancer is early detection.**

Each year, the last week in September is designated as Prostate Cancer Awareness Week (PCAW). The women breast cancer patients have designated the whole month of October as Breast Cancer Awareness Month. We are hoping that the whole month of September will be designated as Prostate Cancer Awareness Month. The following is a report submitted by Dr. DeAntoni, who works with Dr. Crawford for the PCAW.

Prostate Cancer Awareness Week (PCAW) has become the nation's largest cancer screening program. Since its inception in 1989, PCAW has attracted over 3 million participants. The number of screening centers has increased from fewer than 100 in 1989 to a high of 1800 in 1992. In 1995 nearly 1000 locations provided free or low-cost prostate cancer screening with digital rectal examination (DRE) and prostate-specific antigen (PSA) testing to an estimated 350,000 men.

This public awareness and education program was conceived and instituted by the Prostate Cancer Education Council (PCEC) which represents urology, oncology, patient advocacy, minorities, clinical and behavioral research. Because of the alarming percentage of men presenting with advanced, incurable prostate cancer, the PCEC was formed in 1988 to promote awareness, screening and early detection of prostate cancer. The PCEC established the goal of having a majority of the at-risk population (men 40 years of age and older) screened annually for prostate cancer.

This goal was prompted by the results of a PCEC commissioned national survey conducted in March 1989 on knowledge, attitudes, and health practices regarding prostate cancer. The survey documented that only half of men over 40 were receiving annual physical examinations, and of those examined less than half received a digital rectal examination (DRE) as part of the examination process. Prostate cancer ranked eighth in importance of health issues discussed between physician and patient. The Council reported these findings on what it labeled "the ignored male disease."

PCAW was initiated to raise public awareness of the disease and its generally late diagnosis by the recruitment of asymptomatic men for tests for prostate

cancer, specifically the DRE and the prostate-specific antigen (PSA) test. The PCEC did not want financial barriers to prevent men from being screened, and it requested that all PCAW-sanctioned centers offer screening free of charge.

In 1989 mass media promotional campaigns were initiated both nationally and in major population centers, educational materials were distributed, and nearly 15,000 men were screened with DRE at 91 participating institutions throughout the country. A portion of these men also had blood drawn for PSA analysis. With the feasibility of a national prostate screening program confirmed, in 1990 over 750 screening sites were recruited and 150,000 men were tested. Screening protocols were solidified, data collection and reporting methods improved, and local efforts streamlined.

PCAW has been able to raise the public awareness of prostate cancer. It has contributed to the increasing percentage of localized cancer being detected. Advanced cancer cannot be cured, but if detected early, there is hope for cure. Early detection is essential. If you have not been tested recently, perhaps you should participate in the PCAW week. There should be screening sites near you.

Anti-screenerers

The efforts of the PCAW and similar programs have definitely reduced the number of advanced prostate cancer being detected. Dr. Fernand Labrie says that screening could completely eliminate advanced prostate cancer. Cancer can be cured if it is still localized in the prostate. It only kills after it escapes the prostate and becomes hormone refractory. Screening tests can detect the cancer when it is still localized. But there are some people who have criticized those who do screening. They accuse the doctors of creating patients and possibly doing unnecessary surgery on those patients who do not have significant cancers.

Even if the doctors do nothing more than inform a patient that he has cancer, then the patient may be overly worried, distressed and depressed. Some people believe that a person is better off not knowing that he has cancer, even though the cancer could possibly kill him. They believe that ignorance is bliss, that it is better not to know than to worry and be depressed.

I don't understand the anti-screenerers logic.

I am not very religious, but I have studied the Bible. In Matthew, ch. 5, ver. 29, it says "...If thine right eye offend thee, pluck it out and throw it away..." I believe the same should be said about the prostate.

HOW COULD ANY SANE PERSON NOT WANT TO KNOW IF HE HAD SOMETHING GROWING INSIDE HIM THAT COULD KILL HIM, ESPECIALLY IF THAT SOMETHING COULD BE ELIMINATED.

PSA became widely used in 1989. Before then, 60% to 70% of men diagnosed had metastatic cancer. Today less than 25% are found to have metastatic cancer. Early screening and detection could eliminate that 25%.

One of the best arguments ever for screening came from a prostate cancer screener who posted to the Internet. "I have never met a man who complained of being screened for prostate cancer".

REAL MEN COOK Foundation

Dr. Fred Parrott, an African American, is a retired gynecologist. In November of 1994, he had a radical prostatectomy. His father had died of prostate cancer, so he had been closely checking his prostate for some time. African Americans have the highest risk for prostate cancer at almost twice the rate of any other race, yet very few of them bother to get checked. Dr. Parrott is appalled that so many of them are dying needlessly.

Dr. Parrott set up the Real Men Cook Foundation to offer free screening and education for African American men. The following was written by Dr. Parrott:

The "REAL MEN COOK" Foundation was started in 1994 with the mission of bringing prostate cancer education and awareness into the minority community. Eila C. Skinner, M.D., Associate Professor of Urology, USC/Norris Cancer Center, Department of Urology is the Foundation Medical & Program Director. Clifton V. Lee, M.D., FACS, Medical Director of the Western Women's Medical Clinic, is a consultant for the Foundation.

Some of the sponsors are Unilab Corporation, Alza Pharmaceutical Corporation, Miller Brewing Company of the Irwindale-Brewery and TAP Pharmaceuticals.

The Foundation's program is comprehensive and consists of education and awareness support. The program has provided early detection for over 3,000 high-risk African American men 45 years or older with a family history of prostate cancer. We have provided screening of high-risk men on the campuses of six churches. Our outreach program has spoken to over 350 ministers, 15,000 men, and over 500,000 or more households.

The Real Men Cook Foundation is a tax deductible organization.

Thank you and God bless,

Fred Parrott, M.D. 310-822-1982 Fax 310 827-5483

PAACT

Patient Advocates for Advanced Cancer Treatments (PAACT). We talked a bit about Lloyd Ney and PAACT in Chapter 13. Lloyd's PAACT organization has given advice and helped thousands of men. His newsletter goes out to about 30,000 survivors.

Lloyd died in 1997. He survived for over 14 years after being told that he had about three months to live. But the PAACT organization is still alive.

Lloyd had a vision. He wanted to build a cancer research center devoted entirely to prostate cancer. He believed that a cure can be found. It just takes time and money. Lloyd was right. We can find a cure. PAACT is a non-profit organization and all donations are tax deductible.

If you have not done so, please call PAACT and get on the mailing list. If you have just been diagnosed, they will send you several pamphlets and information that can help you. You will not be asked for a donation but if you would like to make a tax deductible donation, it will be most appreciated.

The net proceeds from the first edition of this book was donated to PAACT. PAACT, 1143 Parmelee NW, Grand Rapids, MI 49504. Tel. (616) 453-1477 Fax (616) 453-1846

Prostate Cancer Research Institute

Dr. Stephen Strum is an oncologist, specializing in prostate cancer, in the Los Angeles area. He treated Lloyd and worked with him for several years. Dr. Strum also has a vision. He has set up the Prostate Cancer Research Institute in the Los Angeles area.

Here is a portion of his vision statement:

“Our vision is to see that prostate cancer is no longer a threat to any man’s life. We know this can be accomplished. Our vision of this involves the true expression of love on the part of those involved in this project. The love of fellowman should override any ego or greed or tendency to hoard one’s knowledge. This coupled with a burning desire to see a resolution of the problem of prostate cancer will create the fuel necessary for success...”

Dr. Strum spends a lot of time on the Internet answering questions and giving advice about prostate cancer. He has set up a Web page with several articles and helpful information on Gary Huckabay’s server. You can find a list of papers at www.prostatepointers/strum/. They also have a website at www.prostate-cancer.org.

There is an Internet list on which Dr. Strum and several other doctors participate. It is called the P2P (Physician 2 Patient) list. The doctors answer questions sent to them about prostate cancer, diagnoses, treatments and therapies. Anyone can subscribe to the free list by sending e-mail to:

majordomo@prostatepointers.org

subject: leave blank

message: subscribe p2p

Dr. Strum publishes a very informative newsletter that is sent free to anyone who requests it. Write to the address below or send e-mail to:

pcri@prostate-cancer.org

Dr. Strum's Institute is a non-profit organization. Any donation is tax deductible.

Make your checks payable to:

Prostate Cancer Research Institute.

5777 W. Century Blvd. Suite 885

Los Angeles, CA 90045

Tel. 310-743-2110, Fax 310-743-2113

e-mail: pcri@prostate-cancer.org

Other Resources

There are lots of resources that can help you fight your cancer. Below are just a few:

American Cancer Society

The American Cancer Society offers a wide variety of services and literature to patients and their families at no charge. You can check with your local chapter (look in the white pages), or contact the national office at 1-800-227-2345, or write to American Cancer Society, 1599 Clifton Road NE, Atlanta, GA 30329-4251

Canadian Cancer Society

This is the sister organization of the American Cancer Society, providing the same resources, information, literature and community support services. Call: 1-416-961-7223 Write: Canadian Cancer Society
10 Alcorn Ave., Ste. 200 Toronto, Ontario, Canada M4V 3B1

National Cancer institute (NCI)

The NCI provides written material and information on a variety of cancer-related topics, and it makes referrals to local and regional cancer-treatment centers. Call: The Cancer Information Service 1 800-4-CANCER (1-800-422-6237)
Write: Office of Cancer Communications, National Cancer Institute, Bldg. 31, Rm. 10A16, Bethesda, MD 20892

US-TOO International

US-TOO International is one of the largest patient-organized support groups in the country. It's growth and success is primarily due to the efforts of Hank Porterfield, a prostate cancer survivor. US TOO publishes a newsletter that will be sent to your support group for free.

The net proceeds from the sale of this book will be donated to the US TOO International. But they always need money, so if you can afford it, any donation is tax deductible. The net proceeds from the sale of this book will be donated to US TOO.

Call them for nearest local support group. Call: 1-800-808-7866. Write:US TOO
930 N. N. York Rd., Ste. 50, Hinsdale, IL 60521-2993
They have a web site at: www.ustoo.com

CaP CURE

CaP CURE was organized primarily for research sponsorship. The organization was founded by Michael Milken. At age 48 he was diagnosed with advanced prostate cancer. He immediately set up a foundation to try to find a cure for himself and all other prostate cancer victims. His foundation is second only to the U.S. government in providing funds for research. Their web site is at www.capcure.org

CaP CURE is the world's largest private source of prostate cancer research funding. CaP CURE was founded in 1993 with an urgent mission: identify and support prostate cancer research that will rapidly translate into treatments and cures. Together with survivors, scientists and advocates, CaP CURE has established a system that encourages collaboration, reduces bureaucracy and speeds the process of discovery. If you have an idea for a prostate cancer research project, go to their web site and file an application for a grant.

CaP CURE reaches out to private industry, the patient advocacy community and government research institutions. These partnerships provide a model to speed the cure for prostate cancer - and all cancers.

Michael believes that diet is a very important factor in treating prostate cancer. His organization has developed a couple of cookbooks that include many of the recipes that Michael uses. The cookbook is *The Taste for Living Cookbook: Mike Milken's Favorite Recipes for Fighting Cancer*. It combines nutritional guidelines for people living with cancer with great tasting, thoroughly tested, easy-to-prepare recipes. Sample recipes can be found at: <http://www.tasteforliving.com> . To order, call toll-free, 1-877-884-LIFE. Retail price: \$27.50 (All profits go to fund prostate cancer research)

The Association for the Cure of Cancer of the Prostate
1250 4th Street, Suite 360
Santa Monica, CA 90401

(800) 757-CURE or (310) 458-2873 Fax: (310) 458-8074
E-mail: capcure@capcure.org

American Foundation for Urologic Disease (AFUD)

The mission of the American Foundation for Urologic Disease is the prevention and cure of urologic disease.

The Foundation is a 501(c)(3) nonprofit corporation, founded in 1987.

Up to 5,000 calls are received each month on the A.F.U.D. toll free information lines.

More than \$2.4 million is earmarked for research and public education initiatives. [FAMILY UROLOGY](#), the official magazine of the Foundation reaches over 100,000 individuals quarterly.

The Foundation offers a [membership program](#) to help support the foundation's mission and to keep medical professionals, patients, family members and friends informed about urologic disorders, the latest treatment options and up-to-date research findings.

American College of Radiology

Educational programs for medical professionals. Will provide names for referral services.

1891 Preston White Drive

Reston, VA 22091

1-800-532-9934

<http://www.acr.org>

American Prostate Society

Newsletter containing prostate cancer information available.

7188 Ridge Road

Hanover, MD 21076

(410) 859-3735

Fax: (410) 850-0818

<http://www.ameripros.org>

California Prostate Cancer Coalition (CPCC)

Advocate for prostate cancer legislation and funding.

1710 Webster Street

Oakland, CA 94612

(510) 893-7900

Canadian Prostate Cancer Network & Saskatoon Chapter

Support group for men who have prostate cancer. Provides educational presentations.

W.A. Edwards Family Centre

333-4th Avenue North

Saskatoon, Saskatchewan, S7K 2L8 (306) 382-4236

Cancer Liaison Program

Works directly with cancer patients and advocacy programs, by providing information and education on the FDA approval process.

FDA

5600 Fishers Lane

Room 9-49CFH-12

Rockville, MD 20857
(301) 827-4462
<http://www.fda.gov>

Center for Disease Control and Prevention

Provides free information on different forms of cancer, on cancer research and on community resources.

1600 Clifton Road
Atlanta, GA 30333
1-800-311-3435
<http://www.cdc.gov>

Choices In Dying

Provides legal assistance, and pain management.

1035 30th Street, NW
Washington D.C. 20007
1-800-989-9455
<http://www.choices.org>

Education Center for Prostate Cancer Patients

Provides newsletters and educational material.

380 N. Broadway
Suite 304
Jericho, NY 11753
1-888-545-8396

Health Care Financing Administration Medicare Issues

Provides information relative to Medicare Policy.

Health Care Financing Administration - Medicare Issues

U.S. Department of Health and Human Services

7500 Security Blvd.
Baltimore, MD 21244-1850
1-800-638-6833

Man-To-Man, American Cancer Society

Education and support groups throughout the nation.

<http://www.cancer.org/m2m/m2mprog.html>

Medicare

Contact: HCFA Press Office (202) 690-6145

Improved Web Site Design Makes Medicare Information More Accessible

Go to www.medicare.gov

Medicare has added new and expanded information about Medicare benefits, nursing home staffing levels, health plan options and other topics to its website.

The new site makes it easier to find, read and print online information about Medicare, including information on health plan options.

Health Care Financing Administration (HCFA) originally launched www.medicare.gov in 1998. It is one part of the comprehensive National Medicare Education Program that also includes the Medicare & You handbook; 1-800-MEDICARE (1-800-633-4227), HCFA's toll-free telephone line; and partnerships with local and national organizations across the United States.

National Hospice Organization

Provides information and referrals to local hospice programs via a toll-free phone number.

1901 N. Moore Street
Suite 901
Arlington, VA 22209
1-800-658-8898
<http://www.nho.org>

National Prostate Cancer Coalition

A network of groups and individuals dedicated to promoting awareness, education and increased research funding for prostate cancer.

1158 15th Street, NW
Washington, D.C. 20005
(202)463-9455
<http://www.4npcc.org>

R.A. Bloch Cancer Foundation, Inc.

Support center for peer counseling.

4410 Main Street
Kansas City, MO 64111
1-800-433-0464
<http://www.blochcancer.org>

Social Security Administration

Provides information concerning government benefits.

6401 Security Blvd.
Room 4-C-5 Annex
Baltimore, MD 21235
1-800-772-1213
<http://www.ssa.gov>

The Office of Alternative Medicine Clearinghouse

Exchanges information with the public about complementary and alternative medical practices.

P.O. Box 8218

Silver Spring, MD 20907-8218

1-888-NIH-OCAM (644-6226)

The Wellness Community

Devoted to psychological and emotional support for cancer survivors and their families.

2716 Ocean Park Blvd.

Suite 1040

Santa Monica, CA 90405-5211

(310) 314-2555

<http://www.la.wellnesscommunity.org>

Cooley's Personal Web-site

Offers advice on surviving prostate cancer through a program entitled, "patients helping patients."

<http://www.cooleyville.com>

<http://www.prostate-help.com>

Cytogen Corporation

A pharmaceutical corporation, provides information on their company and contains a support group list.

<http://www.cytogen.com>

Doctor's Guide

Guide to prostate cancer information and resources.

<http://www.pslgroup.com>

Health Central

Dr. Dean offers information about prostate cancer.

<http://www.healthcentral.com>

Prostate Dictionary

Provides definitions for medical terms about prostate cancer.

<http://www.comed.com/Prostate/Glossary.html>

Prostate Pointers Website

An award winning prostate cancer site that is maintained by prostate survivors, and offers many features.

Prostate Pointers

www.prostatepointers.org/prostate/Prostate.html

Web MD

Provides several types of information available to prostate cancer patients and their loved ones.

<http://my.webmd.com>

Government

Cancer Information Service (CIS)

Provides the latest information for patients and researchers.

<http://cis.nci.nih.gov>

Cancer Prevention and Control

Focuses on five priority areas, including the Prostate Cancer Control Initiative.

<http://cdc.gov/cancer>

Center for Disease Control and Prevention

Provides free information on different forms of cancer, on cancer research and on community resources.

<http://www.cdc.gov>

Food and Drug Administration

A listing of prostate cancer approved drugs and an explanation of how they are approved.

<http://www.fda.gov>

Health and Human Services

Provides a home page to access information about prostate cancer.

<http://www.hhs.gov>

Medicare

Provides direct access to Medicare benefits information. This site offers the 20 most commonly asked questions and explanations of Medicare policy and the option to contact Medicare directly.

<http://www.medicare.gov>

National Library of Medicine

Current and archival, published information can be accessed through this site.

<http://www.nlm.nih.gov>

On-Line Mailing Lists

To subscribe to the following on-line mailing lists, send an e-mail to the address listed in the description of the mailing list. Nothing should be listed in the subject

line. Subscribe by typing in the body of the message the name of the mailing list you would like to be included on, and type your first and last name.

After sending the e-mail, within a few minutes, you should receive a confirmation message from majordomo. Please follow the instructions *exactly* in order to activate your subscription.

Prostate Problems Help List (PHML) - A very active list- several people who can answer your questions

To subscribe send an email to:

LISTSERV@HOME.EASE.LSOFT.COM

Subject: Leave blank

Message: subscribe PHML

Physician To Patient

To: majordomo@prostatepointers.org

Subject: (blank or a dash)

subscribe p2p

end

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The Circle

Support for wives, families, friends, and significant others of men with prostate cancer -- and, of course, the men themselves. To subscribe, send an email

To: majordomo@prostatepointers.org

Subject: (blank or a dash)

subscribe circle

end

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SeedPods

A mailing list for those interested in brachytherapy (radioactive seed implants) as a treatment for prostate cancer. To subscribe, send an email

To: majordomo@prostatepointers.org

Subject: (blank or a dash)

subscribe seedpods
end

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RP

A mailing list dedicated to the needs and concerns of radical prostatectomy patients. The sole purpose of this list is to narrowly focus on the concerns of those who have already had an RP or have selected RP as their treatment. To subscribe, go to:

<http://www.prostatepointers.org/mailman/listinfo>

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IceBalls

A mailing list offering information and support to those interested in cryosurgery for prostate cancer. To subscribe, send an email

To: majordomo@prostatepointers.org
Subject: (blank or a dash)

subscribe iceballs
end

Within a few minutes, you should receive a confirmation message from majordomo. Please follow the instructions **exactly** in order to activate your subscription.

Prostate Cancer and Intimacy

PCAI is an unmoderated mailing list for frank and open discussion of the sexual issues surrounding PCa. To subscribe, send an email

To: majordomo@prostatepointers.org
Subject: (blank or a dash)

subscribe pcai
end

Within a few minutes, you should receive a confirmation message from majordomo. Please follow the instructions **exactly** in order to activate your subscription.

Search Engines

For almost any item, use one of the search engines such as www.yahoo.com, www.excite.com, www.lycos.com or any of the others to search for any item. There are millions of web sites. For instance to find sites that offer the Osbon ErecAid Vacuum Erection Device (VED) for erectile dysfunction, just type in Osbon ErecAid and you will get several hits.

Copernic is an excellent software program that launches several search engines simultaneously to find what you are looking for. If one search engine doesn't find what you are looking for, the others probably will. Using this software may return as many as 100 hits or more. One version of Copernic is free, but they also have a sophisticated software version that costs about \$75. You can choose the option to access most all foreign web sites and give the results in those languages. If you do a lot of searches, it may be worth it. To find out more go to www.copernic.com .

Join the National Prostate Cancer Coalition (NPCC) and help us help ourselves. If we all speak with one voice we will be heard. Contact the NPCC at 1300 19th St. N.W., Suite 400, Washington, D.C. 20036. <http://www.4npcc.org>