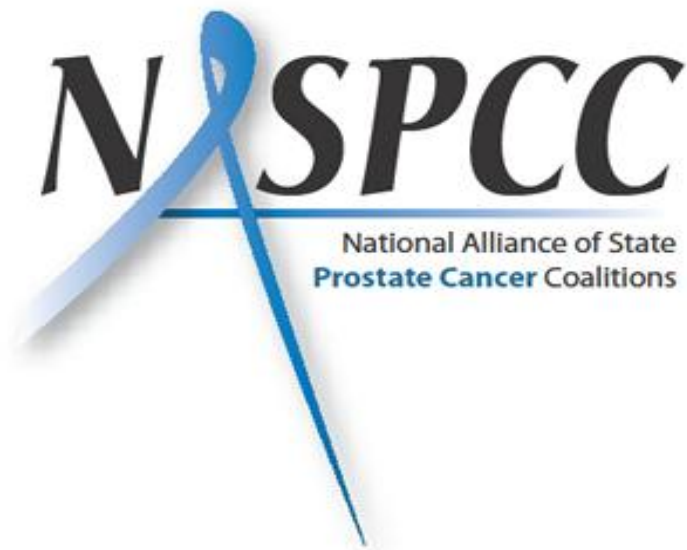


A GUIDE FOR SUCCESS  
EDUCATION AND BEST PRACTICES COMMITTEE  
OF  
NASPCC  
2010



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## **Introduction**

The Education and Best Practices Committee (EBP) of the NASPCC is charged with a two-fold task of providing summaries of best practices from various state prostate cancer coalitions and non-state affiliated groups and with providing new information to our members. The summaries of the Best Practices and new information learned can then be used by state prostate cancer group leaders to assist them in the promotion of their awareness activities in the battle against prostate cancer.

In our contacts with state leaders, members of the media, legislators, social workers and many others we ourselves have been educated about new groups, new avenues of exposure for our state groups, and many other pieces of information that we now share with our NASPCC member groups.

Best Practices that the committee has compiled come from a series of polls of our state affiliations. They run the gamut from organizational strategies, funding strategies, outreach strategies, awareness strategies, and inclusion strategies. We have found that there is no single “Best Practice.” What might be successful in one region or state may not be successful in others. However one thing that we have learned through the course of our compilation of data is that persistence pays off. With repetition our goal of elevating the fight against prostate cancer to a national priority will succeed. Repetition is the key. As we do battle against prostate cancer and the medical and political bureaucracies we must not silence our voices and we must stay on message.

We encourage all state affiliated groups to use as many varied methods as possible to reach our goal of making prostate cancer a national health care priority. In an effort to achieve this goal the EBP Committee has compiled this resource guide for use by all states.

## Section A – Organization of a Board of Directors

*“Never reach out your hand unless you’re ready to extend an arm.”*  
*Elizabeth Fuller*

*“The only justification for the director’s existence is that he should direct.”*  
*Louis D. Brandeis*

*“The diligent director is the one who exhibits in the performance of his trust the same degree of care and prudence that men prompted by self-interest generally exercise in their own affairs.”*  
*Benjamin N. Cardozo*

## Organization of a Board of Directors

As a result of our polling, the EBP Committee learned that state groups involved in the NASPCC were concerned about how to develop a vibrant, dedicated, effective working Board of Directors. In many cases, chapters reported that due to limited interest, they will accept anyone who wishes to join. This often leads to the problem of board members being members in name only. An alternative approach is to actively recruit members to the board based on pre-determined needs with the implication that this is a prestigious invitation. Some sources of names of potential directors are your present directors, your urologist, your oncologist, support group leaders, leaders of medical and health organizations, members of other leading prostate cancer groups such as MaleCare or US TOO, friends, and relatives. Several state groups have reported that once a person is recommended he/she is invited to attend two meetings after which the Board will vote on the nomination. Some states use an interview process to determine membership on their Board. This assures knowledge of prostate cancer.

Some of the desired needs expressed by our chapters are (but not limited to):

- Leadership skills
- Enthusiasm
- Media connections – print and electronic
- Legislative connections
- Medical connections and expertise
- Fund raising ability
- Geographic location
- Survivorship/Caregivers
- Support group leaders
- Representatives of minority groups
- Computer skills
- Attorney

Frequently individuals express a desire to join or help but cannot devote the time needed. To meet such a challenge, some chapters have created a category of “board advisor” or “dedicated volunteers.” Such an individual(s) assist the chapter with one or two activities/events. The work is thus accomplished and the “advisor” does not feel overwhelmed.

Chapters should also refer to <http://www.managementhelp.org/boards.htm> for help in organizing successful boards.

## **Recruiting is Selling. It's a SELLING job.**

You must convince the prospect that your state has serious problems relating to PC. If he does not agree that there are serious problems, he is not a prospect. Move on to another prospect.

You must be able to define the major problems of prostate cancer verbally and enthusiastically within 30 seconds.

You need to show him/her in writing those same problems.

You need to convince the prospect that you and your organization have specific goals to help solve those problems. No more than three goals.

Convince him that he/she can make a difference.

Convince him/her that he/she will have a successful experience being a director.

Convince him/her that you will be an effective leader. You know what you are doing. And will do in the future.

Convince him/her that other states have successful coalitions. That you know how and why they are successful. That you have access to the leaders of those coalitions and that they want to help you.

Tell him/her that important organizations within your state want your coalition to succeed and will help you.

Tell him/her who you will be recruiting in the future.

Convince him/her that he/she is needed, that your organization will be more effective with him/her on board.

Give him/her materials that include a list of your directors, brochure, newsletter, annual report, newspaper publicity, a plan, letterhead, etc.

*Our thanks to Mr. John Sias of the New Hampshire Prostate Cancer Coalition for helping to compile the above material.*

### **“Characteristics of the “Ideal” State Prostate Cancer Coalition\***

1. Has a clear vision of what it wants to accomplish
2. Has a mission statement that is simple, easy to remember and explain
3. Has only a few *MEASURABLE* goals
4. Has a written detailed strategic action plan to achieve the goals
5. Monitors the plan on a frequent regular basis
6. Has written by-laws
7. Has a board of directors which meets regularly
8. Has directors and officers liability insurance
9. Acquires 501(c)(3) status with the IRA
10. Develops a budget
11. Acquires enough money to achieve its goals
12. Recruits a sufficient number of volunteers to help accomplish the goals
13. Recruits mostly PCa survivors who have a vested interest in the groups success
14. Collaborates with all groups in the state that are fighting prostate cancer
15. Has a president who can and will concentrate on the job
16. Has a public speaking program
17. Has its own brochure or can procure some from other groups
18. Has a web site
19. Publishes an annual report
20. Communicates via TV, radio, newspapers, magazines, banners, etc.
21. Shares information and successes with other state coalitions
22. Has contacts with state and local leaders in government
23. Has contacts with the medical community
24. Has contacts with the media
25. Has the ability to direct individuals to the proper channels for assistance
26. Grows each year
27. Has a paid executive director.

\*While these represent an “ideal” coalition, it is certainly possible to have a strong, viable coalition without meeting all of these goals.

*The above ideas are the compilation of learning experiences of many state prostate cancer coalitions.*



## **Suggestions for Board of Directors Management**

1. Determine the organization's mission and purpose – the mission should be clear and concise, and easily defensible and supported by all members of the board.
2. There should be periodic reviews of the mission.
3. The leader of the board should have clearly defined duties; should provide timely feedback to the group; and should undergo a yearly review.
4. The board should ensure that board run activities are consistent with the mission and cost effective.
5. The board has the responsibility of developing a fund raising strategy and carrying out the plan.
6. There should be a yearly review of the board's finances.
7. The board should have a strategic plan in place for the long term – three to five years.
8. Selection of board members and the board membership should change regularly in order to ensure the opportunity for new ideas.
9. All board members must buy into the mission, strategic plan, and by-laws, any dissent will lead to loss of respect within the community.
10. The board should be open and public about its finances and activities.

*The material above comes from the Delaware Association of Non-Profits and Mr. John Sias of the New Hampshire Prostate Cancer Coalition.*

*This document is a sample recruitment letter used by the Maine Coalition to Fight Prostate Cancer. It was sent to all PCa Support Groups throughout the state*



## **Maine Coalition to Fight Prostate Cancer**

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*"The Maine Coalition to Fight Prostate Cancer is dedicated to ending the devastating impact of prostate cancer on men, their loved ones and the State of Maine."*

### **CALL FOR BOARD MEMBER NOMINATIONS**

November 14, 2008

TO: Maine Prostate Cancer Support Group Leaders  
FROM: Nelson Leavitt, President, Maine Coalition to Fight Prostate Cancer  
RE: Nominations for Board of Directors of the Coalition

Started in 2004, the Maine Coalition to Fight Prostate Cancer (MCFPC) has been steadily increasing its efforts and visibility to support a state-wide fight against prostate cancer. Our advocacy group continues to forge partnerships with key organizations in the State of Maine, and we are seeking additional persons to serve on the Board of Directors.

We invite you to nominate persons – men and women -- for our Board of Directors; this may of course include yourself. Our Board generally meets monthly in central Maine, with distant board members often joining meetings via teleconferencing. Our work includes exhibiting at cancer and health awareness conferences, outreach efforts to enhance the network of support groups, and special projects such as professional education of primary care physicians on the latest advances in prostate cancer detection and treatment. You can learn more about the MCFPC at our recently launched website, [www.mcfpc.org](http://www.mcfpc.org).

We are developing some significant momentum in Maine and have received several grants recently to support our efforts. We aim to see as many "blue ribbons" in the public realm of cancer awareness as we do ribbons of other colors! We respectfully ask that you announce this call for nominations at your support group meeting, and respond to our email address with the names and contact information of any people who may be interested in joining our cause.

Thank you in advance for your assistance with our board recruitment effort. You can email me at [info@mcfpc.org](mailto:info@mcfpc.org) if you have any questions about this letter.

Encl: "Pass it On" brochure

**Board Nomination Form**

Name of person submitting nomination \_\_\_\_\_ Date \_\_\_\_\_  
Name of nominee \_\_\_\_\_ Spouse \_\_\_\_\_  
Home Address \_\_\_\_\_  
Home Phone \_\_\_\_\_ Work Phone \_\_\_\_\_ Cell \_\_\_\_\_  
Age \_\_\_\_\_ Date of Birth \_\_\_\_\_  
Place of Work \_\_\_\_\_  
Address \_\_\_\_\_ Fax # \_\_\_\_\_

**Qualifications:**

- Willing to participate actively in board committee meetings (4 per year, plus board Retreat)
- Committed to the mission of PCF
- Has prior experience with PCF or is tied to our mission

If yes, in what capacity: \_\_\_\_\_

**Fundraising**

- Will give an annual gift to the annual fund
- Will solicit others for gifts to the annual fund
- Will contribute toward the annual fundraiser
- Will solicit others for gifts for the annual fundraiser

**Professional skills (check all that apply):**

- Attorney
- CPA
- Physician
- Educator
- Banker
- Insurance
- Real Estate
- Financial Planner
- Marketing/PR
- Public Relations
- Contractor
- Human Resources
- Community Volunteer
- Politician/lobbyist
- Philanthropist

Potential conflict of interest and other boards on which the nominee serves: \_\_\_\_\_

\_\_\_\_\_

Personal description of why the person is being nominated to this board. \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

*The following three forms have been required in some instances when state groups apply for grant money. For this reason we have included them in this guide. As with all of the information that we have provided, state leaders may adapt these in ways that best suit their individual needs.*

## State Prostate Cancer Association

### Statement of Understanding for Members of the Board of Directors

*As a member of the Board of Directors, I am fully committed to the vision and work of the (state name) Prostate Cancer Association and am dedicated to carrying out its mission. I understand that in accepting this position:*

With other board members, I am responsible for using good faith efforts to assist in friend raising and fundraising for the organization. I will work with other board members to develop our dreams and expectations for the future. I will take part in reviewing, approving, monitoring, and achieving these objectives

In addition to being committed to our mission, I understand that it is my duty to use good faith efforts to achieve the necessary funds to meet our mission's goals.

I take responsibility to learn as much as I can about the organization, its work and outreach, and its vision for the future.

I accept the by-laws of the (name) Prostate Cancer Association and understand that I am morally responsible for the health and vitality of our service work.

I understand that as a board member, I am expected to personally participate in the group's annual giving program each year. I will participate at some capacity so that the group will experience 100% board involvement.

I understand that as a board member, I lead the way. I am a model for others to follow. If I, as a board member, do not care enough to work and give, why should others?

I will actively engage in fundraising in whatever ways are best suited for me and most effectively serve the purposes of the (state) Prostate Cancer Association. These may include individual solicitation, undertaking special events, writing mail appeals, and the like.

I will be an enthusiastic booster and a positive advocate for the (state) Prostate Cancer Association.

I will attend board meetings, be available for phone consultation, and serve on committees when needed. If I am not able to meet my obligations as a board member, I understand that the board may request my resignation.

By signing this document, I understand that no quotas are being set, and no rigid standards of measurement and achievement are being established. Every board member makes a statement of faith to be a partner with every other board member to strive for success. We trust each other to carry out the above agreements to the best of our ability.

---

Chair, Board of Directors

---

Date

---

Board Member

---

Date

# State Prostate Cancer Association Confidentiality Agreement

It is the policy of the \_\_\_\_\_ Prostate Cancer Association that trustees, volunteers, and employees of the \_\_\_\_\_ Prostate Cancer Association may not disclose, divulge, or make accessible confidential information belonging to or obtained through their affiliation with the \_\_\_\_\_ Prostate Cancer Association to any person, including relatives, friends, and business and professional associates, other than to persons who have a legitimate need for such information and to whom the \_\_\_\_\_ Prostate Cancer Foundation has authorized disclosure. Trustees, volunteers, and employees shall use confidential information solely for the purpose of performing services as a trustee or employee for the \_\_\_\_\_ Prostate Cancer Association. This policy is not intended to prevent disclosure where disclosure is required by law.

Trustees, volunteers, employees, and contractors must exercise good judgment and care at all times to avoid unauthorized or improper disclosures of confidential information. Conversations in public places, such as restaurants, elevators, and public transportation, should be limited to matters that do not pertain to information of a sensitive or confidential nature. In addition, trustees, volunteers, and employees should be sensitive to the risk of inadvertent disclosure and should for example, refrain from leaving confidential information on desks or otherwise in plain view and refrain from the use of speakerphones to discuss confidential information if the conversation should be heard by unauthorized persons

At the end of a trustee's term in office or upon the termination of an employee's, volunteer's, or contractor's relationship with the \_\_\_\_\_ Prostate Cancer Association, employment, he or she shall return, at the request of the \_\_\_\_\_ Prostate Cancer Association, all documents, papers, and other materials, regardless of medium, which may contain or be derived from confidential information, in his or her possession. .

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

- \_\_\_ Director
- \_\_\_ Advisor
- \_\_\_ Employee
- \_\_\_ Volunteer

# State Prostate Cancer Association

## Conflict of Interest

Because of the public service nature of the organization, it is particularly important that the community have confidence in the management and administration of the \_\_\_\_\_ Prostate Cancer Association. If a member of the Board of Directors, Advisor, volunteer, or an employee could derive any gain or financial profit either directly or indirectly by membership on the Board or through employment with the organization, the objectivity or the loyalty of the member or employee could be questioned. The best interest of the \_\_\_\_\_ Prostate Cancer Association should always be the objective of the decision-making process.

In order to establish a procedure for dealing with the conflict of interest issue and to encourage disclosure, all Board Members, Advisors, volunteers, and employees shall be required to submit a disclosure at the beginning or term or employment.

If a matter subsequently arises in which a member of the Board an Advisor or a volunteer has a conflict or what may be perceived as a conflict of interest, the member shall promptly disclose it to the Board. If such a matter arises with an employee, the employee shall promptly disclose it to the executive officer of the Association, who will then discuss it with the full Board.

If a situation involves or has the potential to involve a conflict or interest, the Board Member, Advisor, volunteer, or employee may disclose any known significant reasons why the transaction might not be in the best interest of the \_\_\_\_\_ Prostate Cancer Association. The Board Member, Advisor, volunteer or employee shall not participate n the discussion or vote on the transaction. The reason for the individual(s) absence will be recorded in the minutes.

I have read and am fully familiar with the \_\_\_\_\_ Prostate Cancer Association statement regarding conflict of interest. I am not presently involved with any transaction, investment, organization, or any other matter in which I would derive either directly or indirectly any gain or financial profit because of my membership on the Board or employment by the Board. I will always consider the best interest of the Association. I also agree to disclose any such interest that may occur in accordance with the requirements of this statement.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_ Director  
\_\_\_ Advisor  
\_\_\_ Employee  
\_\_\_ Volunteer

## **Section B – Funding**

*“The importance of money flows from it being a link between the present and the future.”*

*John Maynard Keynes*

*“Waste neither time nor money, but work the best use of both.”*

*Benjamin Franklin*

*“Donors don’t give to institutions. They invest in ideas and people in whom they believe.”*

*G. T. Smith*

## Funding Sources

Another issue of concern to our state chapters is funding. Many of our chapters have developed some creative ways to raise money to fund their activities. The EBP Committee polled our members to determine the optimum ways to raise money. Our conclusion is that there is no single best practice for generating revenue, but there are many ways to do so. As a result of our polling we determined that chapter sources of funds generally can be placed in five broad categories. The categories are:

*Grants:* many chapters receive grants. The sources of these are corporations, foundations, and state and local governments.

*Donations:* many chapters receive donations. They have a wide variety of sources including their own board members, other individuals, service clubs, corporations, businesses, pharmaceuticals, and PCa support groups, web site solicitations.

*Merchandise Sales:* several chapters sell items such as wrist bands, bumper stickers, T-shirts, and calendars to raise money.

*Fund Raising Events:* many chapters use special events to raise money. These include golf tournaments, pledge drives, a telethon, 50-50 raffle, silent auction, walk-row-run-a-thon, dinner and speaker, wine tasting, and an annual appeal.

*Special Events:* chapters have been creative in developing special events as fund raisers. Some special events include “Pints for Prostate”, “Show Your Blues”, “Boys and Their Toys”. For information You can Google these events for more details.

The following chart is the compilation of the data we acquired. The various funding sources are listed at the top of the page and the states to the left of the page. We encourage member states to network and share ideas. For example, if the board of directors in the State of North Carolina wishes to sponsor a golf tournament, they can contact the leaders of the five states that indicated they had golf tournaments. State leaders can assist one another. The use of this data can be a valuable tool for networking, developing contacts, and avoiding mistakes made by others.

We have also included two sample annual appeal letters from our members.



## Funding Sources

Funding Sources ↓	Dues	Pharmaceuticals	Donations-Grants/corporate	Donations - charitable foundation	Donations - service Club	Donations - in memoriam	Donations - board members	Donations - individual	Support Groups	Tobacco - CDC	Annual appeal	State grant money	ACS grant	Merchandise sales	Pledge drive	Golf tournament	Endowment	Special events (raffles, a-thons)	Comprehensive Cancer program	In-kind donations	Tobacco excise money	
2009 Members ↓																						
1. Alaska																						
2. Arkansas			•	•		•	•	•		•	•					•		•		•	•	
3. California		•					•	•														
4. Colorado		•	•									•				•		•				
5. Connecticut		•																				
6. Delaware										•		•										
7. Florida																						
8. Georgia				•	•		•	•						•		•		•				
9. Hawaii							•		•	•		•										
10. Illinois								•				•						•				
11. Indiana										•		•							•			
12. Kansas																						
13. Kentucky																						
14. Maine			•	•	•	•	•	•		•	•	•	•			•		•	•			
15. Maryland		•	•	•		•		•									•		•			
16. Massachusetts	•	•	•	•		•		•									•		•			
17. Michigan		•				•								•								
18. Nevada																						
19. New Hampshire							•	•				•										
20. New Jersey														•					•			
21. New Mexico							•	•														
22. New York																				•		
23. North Carolina																						
24. Ohio																						
25. Pennsylvania																						
26. Rhode Island																						
27. South Carolina																						
28. Tennessee																						
29. Texas							•								•	•		•				
30. Virginia																						
31. West Virginia																						
32. Washington											•							•	•			
33. Washington, D.C.										•												

*The following is a sample fund raising letter that can be adapted for your state.*

Date  
Mr. and Mrs.  
Address  
City State Zip

Dear Mr. and Mrs. XYZ:

**You are important to us.** Because you have supported our mission in the past, your gift has made an impact on the lives of men right here in \_\_\_\_\_. Mr. and Mrs. Altenburger, you also helped to provide the education, screening and improved treatment that so many men in \_\_\_\_\_ need. You have been a *champion* to the \_\_\_\_\_ Prostate Cancer Foundation (PCF).

**But we still have a problem, and I hope you will continue to help us.** In \_\_\_\_\_, more men die from prostate cancer than women die from breast cancer. We usually see startled surprise from people when we tell them that statistic. Yet due to a lack of awareness of the high risk and the need for early detection, premature death from prostate cancer is rising (before age 65).

I know firsthand the dire need for both of these. In 2006, I visited my doctor and had my annual screening. My PSA was normal. Just six months later, the \_\_\_\_\_ PCF sponsored a screening at my church, and I agreed to re-screen to show other men the importance of annual screening. I thought I was *fine*. A couple of weeks later, the \_\_\_\_\_ PCF sent me a certified letter saying my PSA was elevated. After a biopsy, I was diagnosed with prostate cancer!

**Today I am cancer free**, thanks to early detection and state-of-the-art treatment. But I'll tell you - without the help of the \_\_\_\_\_ PCF, I was in the dark. Men don't talk about health issues - especially prostate cancer - and the materials \_\_\_\_\_ PCF gave me helped me make the informed decision about my health. The support group that I attend gave me the emotional support I needed. That's why it is *imperative* that we help continue to strengthen the \_\_\_\_\_ PCF. Without its resources, I'd *still* be in the dark. The \_\_\_\_\_ PCF is the only organization in the state whose sole purpose is to fight prostate cancer.

I know there are *at least* six men in your life who are important to you. One of them will be diagnosed with prostate cancer in his lifetime. I was the one in six, and I plan to continue helping other men ... one at a time.

I hope you will encourage the men in your life to be screened and refer others to the \_\_\_\_\_ PCF for valuable resources. I also hope you will continue to be a champion of the \_\_\_\_\_ PCF and support our mission. Your gift will save lives.

Sincerely,  
Board of Directors

***P.S. Prostate cancer doesn't slow down just because the economy does - and neither will we. Please join our fight. Any gift amount is welcome.***

*The following is a second example of a fund raising letter. This one was developed for use in Maine by the Maine Coalition to Fight Prostate Cancer.*

Dear

There are 220,000 men diagnosed with prostate cancer in the USA each year, more than any other cancer, men's or women's (except skin cancer). Far too many men in Maine have had PC become a part of their lives. It's the second leading cause of death by cancer in Maine and it is estimated that one in six men will get prostate cancer in their lifetime.

The Maine Coalition to Fight Prostate Cancer (MCFPC) reaches out to the men of Maine, develops and works with support groups throughout the state and one of its main messages is to get the word out that prostate cancer screenings should become part of men's annual physicals with a baseline beginning at age 40, age 35 if the man is in the high risk category.

Each year Gov. Baldacci issues a proclamation declaring September as Prostate Cancer Awareness Month. This year we have sent letters to the editor, issued press releases, worked on public service announcements, arranged for some free prostate cancer screenings and have asked libraries statewide to display posters and books. We have launched a new website, <http://www.mcfpc.org> which provides general information, lists support group information throughout the state, contains links to other sites, and lists events happening throughout Maine. I hope that you will check out our web site and tell others about it.

Everyone in the MCFPC is a volunteer and naturally we are always seeking contributions to help us carry out our work forward. We have an ambitious agenda for the upcoming year:

- \*Produce informational materials for men, their partners and advocates to be distributed state wide and displayed on our website
- \*Participate in numerous health fairs, symposiums, forums, conferences statewide
- \*Provide primary care physicians education on prostate cancer and early detection and advances in treatment options.

Each member of the Coalition is reaching out to family, friends, colleagues, and the general public to help raise the contributions needed so that our work can continue. We are grateful for any contribution. Checks can be made out to MCFPC, a 501© (3) non profit and mailed to Nelson Leavitt, 84 Fairview Avenue, Augusta, Maine 04330 or to me.

Sincerely,

## Section C – Awareness

*“The world is not a problem, it is your unawareness.”*  
*Bhagwan Shree Rajneesh*

*“Power comes not from the barrel of a gun, but from one’s awareness of his or her own cultural strength and unlimited capacity to empathize with, feel for, care and love one’s brothers and sisters.”*  
*Addison Gayle, Jr.*

*“Knowing is not enough;, we must apply. Willing is not enough; we must do.”*  
*Johann Wolfgang von Goethe*

## Awareness Activities

All chapter members were polled in 2009 about what they do to raise awareness of PCa in their states. We were impressed by the varied approaches used by our member groups. Most employed a multi-media approach to inform the general public as well as the medical community of the value of early detection and the need to elevate prostate cancer research to a national priority. Our member groups have used the print media, electronic media, television and radio, visuals, and oral presentations. Several groups, such as the New Mexico group operate a lending library providing reading material for those in need.

Chapter awareness events generally fell into broad categories which are condensed below:

*Health Fairs:* chapters have participated in these events at businesses, churches, senior citizen locations, and civic locations.

*Presentations:* chapters have reported activities such as conducting symposia, panel discussions, displays at libraries, city halls, and other locations. Many Coalitions have a Speakers Bureau.

*Publicity:* all chapters reported using the following to increase awareness of PCa : newspaper ads, banners, signs, brochures, web sites, newsletters, e-mails, public service announcements, letters to the editors and word of mouth. We encourage each chapter to have press kits available for the media.

*Lobbying:* several states engage in legislative lobbying.

*Outreach to the Medical Community:* some states groups reach out to primary care physicians, urologists, and radiologists by encouraging them to prominently display prostate cancer brochures in their offices and to encourage their patients to avail themselves of support groups

*Cooperation/Collaboration With Other Groups:* many chapters report working with other PCa groups to get the message out about prostate cancer, specifically the importance of early detection. Some of the groups are the American Cancer Society, ZERO, Us TOO, Malecare, and the Institute of Prostate Cancer Research.

The following page is a chart of the awareness activities as reported to us by our member chapters. We encourage all state leaders to use the information within this section to begin to network with colleagues. If for example, a state group wishes to sponsor a symposium or launch a Speakers Bureau a review of the chart will indicate which states have conducted the activity and the leaders can network via phone, e-mail, or personal visit.

## Awareness Activities

–

## Increasing Awareness Tools

A valuable tool to use in increasing awareness of prostate cancer is to maintain contact with elected officials, both on the state level and at the national level. All too often important legislation comes up for action, unless our elected officials are lobbied to support a measure, the bill may fail to pass. At the same time we can use our contacts with elected officials to encourage them to submit legislation that is of importance to the prostate cancer community. The following template explains how to quickly make contact with your officials.

### HOW TO FIND YOUR ELECTED OFFICIALS

Follow the directions as given and you will find who your elected officials are and how to make contact with them.

1. Go to [www.votesmart.org](http://www.votesmart.org)
2. On the left side of the opening page, under “Find Your Representative” you are directed to type in your 9 digit zip code in the box headed “Search by Last Name or Zip Code”
3. If you do not know your 9 digits, refer to any piece of junk mail or a catalog
4. Type in the 9 digits in this order xxxxx-xxxx –you **MUST** type in the hyphen .Click on GO.
5. Scroll down the screen that comes up and you will find the elected officials in your district, both state and national.
6. Place the cursor on the name of the elected official you want to contact and click. Information about that official will appear on the screen.

Good luck and don't hesitate to use this website!!!

## **Speakers Bureau Information**

Many state coalitions have developed Speakers Bureaus to raise awareness of prostate cancer. In some cases the coalition directors all serve as speakers; in other states the coalition directors actively recruit medical professionals to make presentations on their behalf; in other cases the coalition directors recruit prostate cancer survivors to tell their individual stories. However when Speakers Bureaus are established, the work that speakers do is invaluable in raising awareness of prostate cancer.

### **Sample Letter To Perspective Speakers**

The \_\_\_\_\_ Coalition to Fight Prostate Cancer is in the process of developing a Speakers Bureau for the purpose of making presentations about the importance of early detection in the battle against prostate cancer. As a prostate cancer survivor you are well aware of the value of early detection. Your name was suggested as a possible speaker.

The presentations would be brief, usually about 10 – 15 minutes and include a bit of personal history and then information about who is at risk, emphasis on early detection in saving lives, symptoms, types of screenings (PSA and DRE) and anything else you would feel comfortable discussing. We also encourage you to discuss the value of support teams and finally to answer, if possible questions from the audience. We will provide our \_\_\_\_\_ brochure and a list of state wide support teams to distribute. We also have a brochure dealing with what women need to know about prostate cancer.

Our goal is to have a number of men and women throughout the state who are willing to make presentations in their local area(s). We will arrange the presentation locations. You will not have to do anything except the presentation and then a note, e-mail, or phone call to let us know how the presentation went and how many were present. Naturally, if you have additional suggestions as to where a speaker might be welcome we would be happy to have that information.

It has been said that as individuals there is nothing more important we can do than save a life. This undertaking is very important and I hope that you will agree help save lives of men here in \_\_\_\_\_.

Sincerely,



## **Speakers Bureau Announcement**

A ***SPECIAL OPPORTUNITY*** for your church group, fraternal club, community association, or veterans organization to become informed about Prostate Cancer!!!!

The ***Virginia Prostate Cancer Coalition Speakers Bureau*** has available spokespersons to increase Prostate Cancer awareness among members of community assemblies across the Commonwealth of Virginia.

These speakers possess levels of patient expertise which permits them to enlighten and familiarize your group with a powerful message covering the risks, symptoms, diagnosis, treatment alternatives, side effects, follow-up care, and life style impact of the most common cancer in men.

For those occasions when the purpose of your meeting program is to inform and inspire, the VPCC can provide knowledgeable talkers on Prostate Cancer. The experiences and knowledge of these patients, survivors, spouses, significant others, and family members provide informed insight into all aspects of their journey in the world of Prostate Cancer.

These Coalition members participate on a volunteer basis and there is **NO CHARGE** to an organization for engaging VPCC orators.

Contact: Ray Walsh at 703-425-1474, or [rwalsh@vapcacoalition](mailto:rwalsh@vapcacoalition)

### ***Our Mission***

The Virginia Prostate Cancer Coalition is dedicated to spreading the word about prostate cancer. The best way we know to do this is to talk to the members of our community, especially our community leaders.

### ***Our Speakers***

Know prostate cancer first hand, either as survivors or family members of survivors. They may not know all the answers but they do know what they are talking about.

Are dedicated to their cause. They bring with them an enthusiasm that will excite and incite but never bore.

Are accustomed to speaking to groups both small and large.

Are free of charge for qualified community groups and organizations

*Out thanks to the Virginia Prostate Cancer Coalition for allowing us to use this information, a compilation of some of their materials.*

## **Suggested Locations for Presentations**

The following is a list of groups /places that generally like to have presentations made to their members. Presenters can leave brochures, pins, wrist bands, contact information, support team location and times, and other materials.

Public Libraries - many libraries sponsor public service presentations

Service Clubs – Elks, Kiwanis, Rotary, Moose, DAR, Lions, Optimists, etc.

Military Groups – VFW, American Legion, Disabled American Veterans, Fleet Reserve  
Navy, etc.

Community Adult Athletic Groups – Softball, Baseball, Volleyball, Bowling Leagues,  
Religious Groups- Knights of Columbus, DeMolay, etc.

Vehicle Groups – Bikers, 4-Wheelers, Snowmobilers, Antique Auto Groups, etc.

State Legislatures

Contact Wellness Coordinators at businesses & industries & grocery stores etc. These  
Individuals welcome the opportunity to have speakers make brief presentations

School Settings – Contact association leaders at schools of all levels, include adult  
education offices & vocational schools.

Generally recognized employers of men – police dept, fire dept, lumbering companies,  
truck drivers, longshoremen, public works dept., construction workers, etc.

Churches

Chamber of Commerce Offices (great place for contacts)

Employment Groups – Realtors Assoc, Insurance Assoc., Bar Assoc. etc.

## How To Reach Out to Groups

### *A suggested plan on how a Coalition speaker might secure a speaking engagement*

Locate the name of the Rotary club (or any other group) on the list of Rotary clubs in your state – this information is found via a web search, ie: Rotary Clubs in \_\_\_\_\_

Identify the club secretary, his name, email and phone number, e-mail the secretary.

- a. use the “suggested letter to a club secretary” if you wish
- b. attach an information sheet about prostate cancer
- c. make sure you include your name, email and phone, include your business card

If you do not hear from either the secretary or the Program Chair, then use the phone

### *A suggested letter to a Rotary/Kiwanis/VFW/AMVets/ etc club secretary*

Dear Rotary Club Secretary, (or any other group)

Helping to reduce the number of New Hampshire men dying of prostate cancer is the mission of our Coalition. We would like to speak to your Rotary club about the dangers of prostate cancer.

One of six of your club’s male members will get prostate cancer sometime during his life.

One of every 33 male Rotarians in New Hampshire will die of prostate cancer.

If there are 3,000 male Rotarians in our state, this means that almost 500 Rotarians will get prostate cancer and another 91 will die of this disease.

We have set a goal of speaking to all Rotary clubs in the state.

Please give this to your Program Chair so he or she might contact me.

### *What to bring to a meeting when you are the speaker*

Books about prostate cancer

Blue prostate cancer bracelets

Brochure of the Coalition

Brochures of American Cancer Society – examples listed:

“After Diagnosis”

“Cancer Facts for Men”

“Facts on Prostate Cancer”

“Should I Be Tested For Prostate Cancer?”

Cell phone number of person introducing you. (If you have a problem on the way there)

Driving directions

Lapel pins

Name of person introducing you.

Scotch tape

Sign - 9 x12 of the state Prostate Cancer Coalition, tape it to the podium facing the audience

Sign up sheets to receive monthly newsletter.

Walnuts – to show the actual size of a prostate

Your Coalition business cards.

*Our thanks to John Sias and the New Hampshire Prostate Cancer Coalition for the material in the above list. For additional information about the N. H. Coalition and to view a powerpoint presentation used by the group’s speakers go to : [www.nhprostatecancer.org](http://www.nhprostatecancer.org)*

## Suggested Locations for Free Standing Displays

These places are great locations for free standing displays. Groups can leave materials about prostate cancer on display and regularly replenish the supply of materials.

Public libraries

City halls

Community bulletin boards at grocery stores, churches, etc

Hospitals

Malls

Break rooms at various companies

Barbershops

Café's

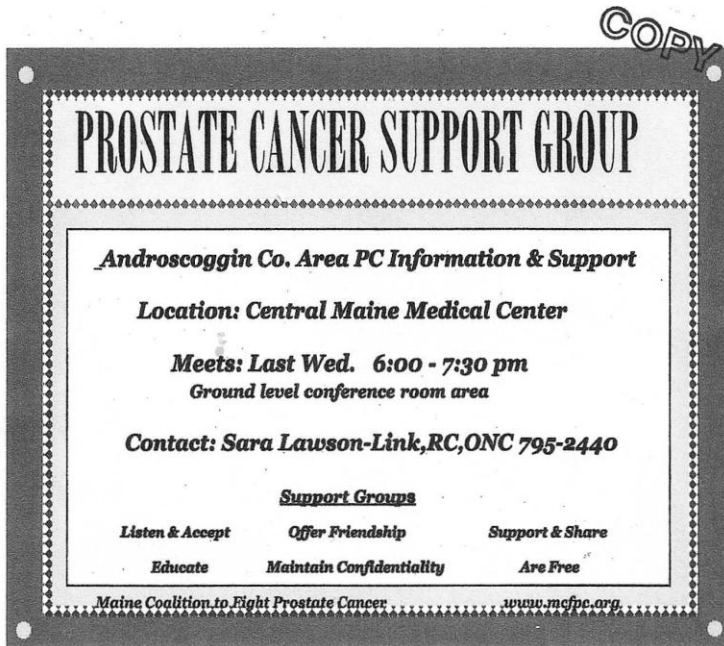
Primary care physician's offices

Urology offices

Oncologists offices

Banks, Credit Unions

In addition to actual displays of materials, we suggest that notices of support group meetings such as the one shown below be placed in public locations. We suggest:



Community bulletin boards

Library bulletin boards

Grocery store bulletin boards

City halls

Physician's offices

Men's restrooms in:

Sport venues/Restaurants

Bars/Convenience Stores

Retail Stores/Tire Sale Stores

Garages

## Letter to a Library Director

*The following sample letter was used by the Maine Coalition to introduce itself to library directors throughout the State of Maine. It was sent to over 300 libraries throughout the state. The group received kudos about the displays and some newspaper coverage as well. It is offered here as a sample of raising awareness and for other state groups to adapt for their needs.*

Dear Library Director,

The Maine Coalition to Fight Prostate Cancer was founded in the fall of 2005. We are an incorporated non-profit organization. Since our inception we have been involved in helping men and their loved ones who are dealing with the disease of prostate cancer.

September has been proclaimed "Prostate Cancer Awareness Month" by the President of the United States. Here in Maine, our own Governor Baldacci has followed suit by issuing a similar proclamation. The official issuance of the proclamation for 2008 will be on Sept. 3, 2008.

To raise awareness of the disease, and help people to cope with the many problems associated with the disease, we have undertaken a letter writing campaign to the newspapers throughout the state. We also are asking libraries throughout the state to place in a prominent location, a poster, several of our brochures, a list of support team locations, and a list of recommended books on the subject. We will be mailing these materials shortly. The support team list and the reading recommendations can be photocopied for public distribution and we encourage you to do so. We also encourage you to arrange a display of books dealing with prostate cancer in specific and cancer in general. All the libraries in the state that have internet access have received this information via an e-mail from \_\_\_\_\_, the Director of the \_\_\_\_\_ Library. Those libraries without internet/e-mail access are receiving this letter prior to the mailing of our materials.

I believe that there is nothing more important a person can do than save a life. By displaying our materials you may be contributing to saving a life. Thank you for your help in this project. If you have any questions please feel free to contact me at 784-2086.

Sincerely,

Mona A. Ervin, Chair  
Maine Coalition to Fight Prostate Cancer

## Sample Proclamation of Prostate Cancer Awareness Month

*Another useful tool to raise awareness of prostate cancer is to secure a gubernatorial declaration proclaiming September as Prostate Cancer Awareness Month. The following is a sample of such a declaration.*

**WHEREAS**, prostate cancer is the most commonly diagnosed form of cancer (non-skin) and the second leading cause of cancer-related death among American men; and

**WHEREAS**, we do not fully understand the factors that contribute to the development and progression of prostate cancer into an aggressive disease, and additional research is important to refine the screening and treatment of prostate cancer; and

**WHEREAS**, the American Cancer Society estimates in *(state)* there will be ( ) new cases of Prostate Cancer along with the death of *(# and state)* men caused by the disease in *(year)*; and **WHEREAS**, about ( % ) of prostate cancer affects men under the age of 65, during their prime years at work; and

**WHEREAS**, at any age, deaths due to prostate cancer devastate families, through loss of income, partnership, and support; and

**WHEREAS**, through *(state health plan)* we are committed to make *(state)* the healthiest state and assure statewide adoption of strategies to improve prevention and treatment of chronic disease; and

**WHEREAS**, all men in *(state)* should become aware of their own risks of prostate cancer, talk with their health care providers about these risks, and have the opportunity to be screened for prostate cancer at an appropriate age ; and

**WHEREAS**, data from the National Center for Health Statistics shows a decline in the prostate cancer mortality rate of 25 percent between 1990 and 2003, with the reason for improvement most likely due to wider-spread screening and improved treatment of the disease , thus intensifying the need for expanded public knowledge,

NOW, THEREFORE, I, *(name)*, Governor of the State of *(name)*, do hereby proclaim the month of September, *(year)* as

### **PROSTATE CANCER AWARENESS MONTH**

throughout the State of *(state)*, and urge all citizens to recognize this observance.

## **Prostate Cancer Awareness Month – September Ideas for the month**

These are not in any sort of priority order

1. Have the Gov. declare Sept. as Prostate Cancer Awareness Month- set up a photo op with the Gov. (refer to sample provided - p. )
2. Letters to the editors of all the major newspapers in state – members of the various support teams throughout the state are helpful in this endeavor.  
Letter templates should be directed to early detection  
Letters to be modified to meet individual situations of the senders
3. Get local mayors to issue a local prostate cancer awareness proclamation .
4. Appearances on local cable programs and other local television shows such as the public broadcasting stations in the local area, and local newscasts Health Beat Reports
5. Compose and mail public service announcements to local radio and television stations -should be directed to early detection
6. Notices sent to all urologists and primary care physicians about the September Proclamation - should be directed to early detection
7. Televised panel discussion about PCa - panel to include a survivor, a physician and a care giver -
8. Posters with factual data about Prostate Cancer in all public libraries in the state along with support group information and book displays - - should be directed to early detection
9. Some type of display/ announcement/ hand-out about prostate cancer at a local athletic game in early September - should be directed to early detection
10. Interviews/press releases from local, state, and national elected officials about prostate cancer- should be directed to early detection
11. Publicity on the web site
12. Publicity in the newsletter
13. Posters about prostate cancer in men’s rooms in restaurants, bars, grocery stores, convenience stores, auto repair shops, anywhere men frequent

## Working with Newspapers

One effective way for non-profit organizations to express their views is to contact their area newspapers. It remains difficult in this day and age of declining readership and raising production costs to use the press effectively. Where it used to be only one or two papers that had exclusionary rules, now many do. The EBP Committee has compiled a list of guidelines that will enhance your chances of getting published. While some of these guidelines may not work for you, others may.

Guidelines – in no particular order:

1. Op –Ed’s or letters to the editor should be exclusive to each paper. Editors do
2. not want to print the same letter as a competitor. Be sure to note that the letter is exclusive to the paper.
3. Articles must fit the local guidelines. Prior to submitting an article/letter/ op-ed piece research the paper’s guidelines. Many papers list their requirements on the editorial page. In particular, do not go over the word limit. You do not want the paper to edit your words.
4. Letters should have a local or personal angle. For example, do not write “Men who are prostate cancer survivors” write “ I am a prostate cancer survivor” and continue with the story – use the local human interest angle to your advantage. If possible, include a properly captioned photo.
5. Articles should be clear and concise – get to the point, keep the statements brief, readable, and do not put in irrelevant details.
6. Take part in a controversy – respond to the controversial data at once with a letter. This will generate interest in the topic and will help to further raise awareness of your issue(s).
7. In the case of a controversy or to mark a significant event have several people write letters to the paper – then the paper’s editors may select one or two to print.
8. Use the media to announce an important event – a web site launch; an appointment/election to office in the organization; the presentation of an award;
9. Hold a contest. Approach your local school about having local students in Health Classes compete in an essay/poster contest. They can write/diagram a prostate cancer issue of your choosing. Publicize the event with an article and photo. Newspapers generally like events having to do with children.
10. Honor an institution and publicize it. For example, if a group donates money or an organization hosts a screening, draw the publics’ attention to the event with photos and accompanying article. Follow up with an “unsolicited” thank you letter to the editor.
11. Tie in an article/letter with a news event of the day. For example, if a new drug is announced or new clinical trials begin or new treatment methods are announced, issue a press release about the event.
12. If your group has a Speakers Bureau, encourage the group that will hear the presentation to notify the press so that both the speaker and the group receive new coverage.



13. Send letters to the editor/ op-ed pieces on special days – do not let any day go by without some sort of recognition. For example, raise awareness of prostate cancer for Fathers Day, Mothers Day, Veterans Day, the Fourth of July, Memorial Day, and Christmas. We want our loved ones around for a very long time. The tie in to Veterans Day, Memorial Day and the Fourth of July is that military personnel are often exposed to toxins that are linked to prostate cancer we must not let their sacrifices on our behalf to go unnoticed.

Speaking with a Reporter – there are several tips in speaking to a representative of the media.

1. Be composed – stay calm
2. Be clear – get right to the point
3. Be concise – make it easy on yourself and the reader by keeping your statement brief – do not overwhelm the reporter with too many facts, avoid the details

Use a Fax Blast – this is the distribution of information by fax to media outlets via fax. This is an excellent option if you are able to secure it. Local government offices and groups may be able to be of assistance.

Resources:

<http://newslink.org/>

<http://www.congress.org/congressorg/dbqmedia/>

<http://refdesk.com/.html>

*Our thanks to Wendy Poage (Colorado) and Sandra Jaeger (Maine) for much of this information.*

## Letters to the Editor

Letters to the editor are a popular section of local newspapers. Readers often look at the title given to the letters and the name of the writer and then read the letters. The nature of prostate cancer is unfortunately one that affects both sexes, as such letters are an effective way of keeping the disease in the forefront of people's minds.

Letters can be written for Father's Day encouraging men to have a complete prostate exam (DRE and PSA). Veterans Day and Memorial Day are also opportunities to use to encourage loved male family members and friends to have an exam. Due to the higher rate of prostate cancer among veterans returning from the Vietnam War, Veterans Day is an opportunity to write a letter to the editor highlighting this fact and encouraging those men to have the prostate exam.

September is Prostate Cancer Awareness month and this is a time when the newspapers should receive and print letters from the public encouraging men to have prostate exams. Each day should be viewed as an opportunity to send a letter to the editor.

In this age of declining newspaper revenues, many newspapers have changed their guidelines for accepting letters to the editor. Prior to writing a letter we encourage everyone to contact their local newspaper to request a review of the guidelines.

## Other Letters/Cards

What better gift can one person give to another than the gift of life? Christmas is a wonderful time for a man to give his loved ones this gift – a complete prostate exam. A letter can be included in the Christmas card by the man offering this as his gift or by the woman asking for this gift. Women can also request that her loved one(s) gift her for her birthday with a complete prostate exam. A couple's anniversary is another opportunity for loved ones to be reminded of the need for a prostate exam

### *Sample Mother's Day letter provided by Mona Ervin – Maine Coalition*

My dear husband, since the day we met you have made me happy. Over the years we have shared our dreams, hopes, and life experiences. As Mother's Day approaches, I have one desire – YOU - . That is correct, I want you around for a very long time, together we have been the bedrock of our family and I want that to continue.

My gift for (Mother's Day; our anniversary; my birthday; Christmas) is for you to have a physical with our family physician. The physical is to include a PSA test and a DRE. These two tests, in combination are very good indicators of prostate cancer. Everyone fears cancer and prostate cancer is no longer a life-ending disease if diagnosed in its early stages. For those who are diagnosed with prostate cancer, there are many treatment options available as well as numerous clinical trials. The American Cancer Society estimates that in 2008 roughly 186,320 men will be diagnosed with prostate cancer and about 28,660 will die of the disease. I do not want you to be a statistic our family does not want you to be a statistic. Please do this for yourself, if not for yourself, for me and our family. WE WANT YOU ALIVE AND WELL FOR A VERY LONG TIME. Happy Mother's Day is best expressed with the gift of life from a loved one – YOU.

*Sample Father's Day Letter provided by Lew Musgrove – Nevada Coalition*

It has been said that men take better care of their cars than they do their own body. It is time to take control of your health. The prostate cancer patient community believes that the PSA (a simple blood test taken from your arm) and DRE (Digital Rectal Exam) tests should begin regularly at age 40 and repeated each year to establish a baseline number. Usually the number is less than one, however, the change in the number is more important than the number itself.

If you are African - American, have or had a bloodline relative with prostate cancer, or you just don't know your family history, then you are considered "high risk" and should start your baseline testing at age 35.

If the PSA number starts to rise, the prostate is sending a signal that something is happening and you need to find out what it is. It isn't always cancer, but this is no time for you to gamble. It is a time to find out what is going on in your prostate.

Set an annual date such as Father's Day, your birthday or during September, which is prostate cancer awareness month, to have your blood test. Write the number and put it where you can find it.

Dr, William Catalona, from Northwestern University, recently stated: "Prostate Cancer is an insidious disease that arises silently, passes through a curable phase silently and becomes incurable silently. If you wait for symptoms to signal its presence, it is too late to cure it."

Prostate Cancer is not a matter of IF but a matter of WHEN. Autopsies on 90-year-old men have found that they had prostate cancer, but actually died of something else. If you have established a baseline PSA and it starts to move, you are taking control of the WHEN because "Early Detection Saves Lives."

## **Sample Newsletters**

Several of the states in the NASPCC distribute a newsletter. Some are monthly while others are quarterly. We have included two samples. The first is from the California Prostate Cancer Coalition. The second is from the New Hampshire Prostate Cancer Coalition.

The two samples that we have included represent two different but successful styles. The California Newsletter contains a message from the state coalition president, articles detailing legislative activity, medical discussions on a wide variety of topics such as diet, new treatments, and clinical trials and provides an opportunity for donations. The New Hampshire Newsletter does not contain articles. It is a series of two or three statements of facts about events transpiring in New Hampshire. This newsletter also provides the opportunity for donations.

States leaders have noted that a newsletter is a way of informing their contacts about the groups' activities and as a way to recruit individuals to help in their cause and as a way to raise money. For the states with newsletters please refer to the Awareness Chart. For specific questions please contact the state representative to the NASPCC about that states' newsletter, method of acquiring e-mail addresses for distribution, and any other questions.

# NEWS

*"Making Prostate Cancer History in California!"*

**Volume 8, Issue 2**  
**April 2006**

## **PRESIDENT'S MESSAGE**

The global world of prostate cancer awareness is in need of proactive enthusiasm and a lot of work. Other cancers have taken the limelight and are the new objects of affection for various groups. Further, there is still debate about whether early detection has any beneficial effect on survival at all. At the 2006 Prostate Cancer Symposium in San Francisco held Feb. 24-26, one of the presenters advocated that it makes no difference when to diagnose prostate cancer; that we are over-diagnosing and over-treating; and that there is no real discernible benefit in making the diagnosis sooner rather than later. On the other hand, the second and third day of the Symposium were largely devoted to how to treat (and problems associated with) locally advanced prostate cancer, hormone-refractory prostate cancer, and metastatic prostate cancer! If it made no difference when one makes the diagnosis, men would all be early-stage with clinically insignificant prostate cancer that was never going to progress. We know this is not true. *Over-detection would not have to mean over-treatment in any event.* That's another reason why CPCC is proud of its new Early Detection Guidelines that advocate for a first, baseline DRE and PSA at age 40 (or 35 if at high-risk, such as African-American men or those with a certain or an indeterminate family history of prostate cancer). CPCC's Guidelines further advocate for yearly testing thereafter and stress that **IT IS THE CHANGE IN THE PSA RATHER THAN THE ABSOLUTE NUMBER ITSELF THAT MAY BE SIGNIFICANT (PSA Velocity) AND SUCH A CHANGE SHOULD BE DISCUSSED WITH ONE'S PHYSICIAN.** Paralleling this admonition is a paper that was presented at the Symposium by Dr. Judd Moul of Duke University Medical Center which found that the importance of PSA Velocity is age-related, and a lower number is more significant for younger men. I have prepared a Report of the 2006 Prostate Cancer Symposium and it will be on CPCC's Website for your use.

The National Alliance of State Prostate Cancer Coalitions (NASPCC) held its first Regional Meeting in late February in Durham, North Carolina for the Southeastern Region, and it was a resounding success. One of the programs presented there by the North Carolina Prostate Cancer Minority Action Awareness Team will be compiled into a Resource Guide and transported to other states for use by their coalitions to increase outreach to minority communities. The Georgia Prostate Cancer Coalition will be the recipient of the first Pilot Project but I am hopeful that California will be able to also greatly benefit from the program. I was delighted to preside over the Regional meeting. On another front, the IMPACT Newsletter, Vol. 5, Issue 1 was just distributed and it describes the importance of the IMPACT program in California; describes its current status; and has a calendar of screening and other events. We must stay vigilant and look for every opportunity to spread the word that, as with many solid tumors, the earlier prostate cancer is detected and diagnosed, the greater the chance of successful treatment. If anyone has any ideas on increasing awareness or would like to volunteer for any of our activities, please contact us!

*Sincerely, Merel Grey Nissenberg, Esq.*

CPCC wishes to thank the following sponsors for contributing significant funds to our budget so that we can carry out our fiscal objectives.

*We wish to thank the California Prostate Cancer Coalition for the use of this newsletter. Due to page constraints, we have only used the President's Message. The Actual newsletter has many articles. To read the entire issue go to: [www.prostatecalif.com](http://www.prostatecalif.com)*

# *News Update*

New Hampshire Prostate Cancer Coalition • [NHProstateCancer.org](http://NHProstateCancer.org)

May 29, 2009

- **Prostate cancer is a *silent* disease.** Dr. William Catalona of Northwestern U. says, “Prostate cancer is an insidious disease that arises *silently*, passes through a curable phase *silently* and becomes incurable *silently*. If you wait for symptoms to signal its presence, it is too late to cure it.”
- **Third annual all-day Strategic Plan meeting** held on May 9. Two guests and 13 of 15 directors made the plans for the next 12 months. Led by a professional facilitator, the plan puts on paper WHAT will be done, WHO will do it, and WHEN that person will do it. We monitor our plan every month to check our progress in achieving our goals.
- BRFSS (Behavior Risk Factor Surveillance System) survey answers **two key questions about prostate cancer in N.H**  
Question #1 “Did you ever discuss prostate cancer with your Health Care Provider?  
Yes, 68.9%. No, 31.1%.  
Question #2. “When was the last time you discussed prostate screening with your Health Care Provider?  
Answer:

In the last year	67.0 %
In the last 2 years	15.1 %
In the last 3 years	8.7 %
3 or more years ago	9.2 %

  
BRFSS is the world’s largest telephone survey.
- **Making our web page more interactive.** Harry Purkhiser and Fundraising Comm. are developing a plan to do just that.
- **Director Jim McCormick** spoke to the Rotary clubs in Pittsfield and Concord this month. Jim is one of five Coalition speakers whose goal is to speak to all 59 Rotary clubs in the state about the dangers of prostate cancer. And to urge men to talk to their doctor about getting screened.
- John Heaney, MD, read the minutes of the NH Urological Society meeting pertaining to **development of an interactive DVD and development of a folder** to be distributed to newly diagnosed men and their family.
- **Hollis Brookline Rotary Club contributes \$500** to the Coalition’s speaking program at the request of off going Coalition director Chuck Wood. And Anthem Blue Cross Blue Shield in a request from Paul Mertzic will send us a check for \$500.
- **Coalition “progress” stories in the Manchester Union Leader** on May 24 and the Hollis Brookline Journal on May 22.
- You can now **contribute to the Coalition online**. Go to [NHProstateCancer.org](http://NHProstateCancer.org). Just push the button on the bottom of the Home page. Steve Ladew and Sal Magnano are working out the final details.
- **Attorney Ned Whittington**, who authored our by laws, has resigned from the board after three years. At the suggestion of Bob Dedrick, the board will recognize off-going directors **with a framed certificate**.

- **FAQ. We are developing 80+ questions and answers to** “Should I get screened for prostate cancer?” Will be on our web site in the near future.
- **Use our website.** NHProstateCancer.org. It lists the meeting times and places of the state’s five support groups in Manchester, Nashua, Concord, Keene and Dover. Plus links to 13 national prostate cancer organizations. Plus links to PC stories in New York Times and Wall Street Journal.
- **Prostate Cancer Walk** in Boston on Fathers Day. At the Boston Common bandstand at 11.
- **Our Coalition’s logo** appeared on the American Cancer Society full page ad in the Concord Monitor.
- John Heaney, MD, invites all to the Norris Cotton Cancer Center’s **Survivors Day** on May 31 from 1-3:30 in Lebanon at the AVA Gallery.
- Bob Dedrick represented the Coalition at the **Mass. PC Coalition’s Symposium** in Boston. He reported on new drugs: MDV 3100 and Abiraterone (Abi) and the vaccine, Provenge. All are awaiting FDA approval.
- June 7 is **Concord Hospital Cancer Survivor Day**. Bill Mullen and Bob Dedrick will bring the Coalition’s Display Board to the event.
- **Director Harvey Keye spoke to 200** senior citizens this month about the dangers of prostate cancer. He placed a blue bracelet on the wrist of many women and urged each to remind the men in their lives to see their doctor about prostate cancer screening.
- Watch for our **Father’s Day “Letter to the Editor”** in your local newspaper.

## 211

Another way to increase your group's visibility is to register with 211. 211 is a special telephone number reserved in the United States and Canada as an easy to remember three digit telephone number meant to provide quick information and referrals to health and human service organizations. 911 is an emergency number that was overused and abused by the public. To reduce the over usage on the 911 system, 211 was developed.

The United Way of Metropolitan Atlanta was the first to introduce a 211 service in 1997. The United Way and the Alliance of Information and Referral Systems partnered to create the system. On July 20, 2000, the FCC approved the 211 system for nation-wide use in the United States.

211 provides free information and referral to callers on where to obtain assistance from local and national service programs, local and national governmental agencies and local and national non-profit organizations as well as where to volunteer or make donations. Referrals are given from databases accessed by specialists. For example **physical and mental health resources** include medical information lines, crisis intervention services, support groups, counseling, drug and alcohol intervention, rehabilitation, health insurance programs, Medicaid and Medicare, maternal health, children's health insurance programs.

211 center hours vary. Many are open 24/7 to refer callers. We encourage all state non-profit groups to register with the 211 system in their states. In 2008, 211 services in the United States answered more than 14 million calls. This [list](#) shows the extent of 211 coverage in the United States.

If you have new information to share, please send us an [email](mailto:www.211us.org) at [www.211us.org](http://www.211us.org)

- [Alabama](#)
- [Alaska](#)
- [Arizona](#)
- [Arkansas](#)
- [California](#)
- [Colorado](#)
- [Connecticut](#)
- *Delaware*
- [District of Columbia](#)
- [Florida](#)
- [Georgia](#)
- [Hawaii](#)
- [Idaho](#)
- [Illinois](#)
- [Indiana](#)
- [Iowa](#)
- [Kansas](#)
- [Kentucky](#)
- [Louisiana](#)
- [Maine](#)
- [Maryland](#)
- [Massachusetts](#)
- [Michigan](#)
- [Minnesota](#)
- [Mississippi](#)
- [Missouri](#)
- [Montana](#)
- [Nebraska](#)
- [Nevada](#)
- [New Hampshire](#)
- [New Jersey](#)
- [New Mexico](#)
- [New York](#)
- [North Carolina](#)
- [North Dakota](#)
- [Ohio](#)
- [Oklahoma](#)
- [Oregon](#)
- [Pennsylvania](#)
- [Puerto Rico](#)
- [Rhode Island](#)
- [South Carolina](#)
- [South Dakota](#)
- [Tennessee](#)
- [Texas](#)
- [Utah](#)
- [Virginia](#)
- [Vermont](#)
- [Washington](#)
- [West Virginia](#)
- [Wisconsin](#)
- *Wyoming*

The four states in italics do not currently have a 211 system.



## The Contact List

One tool that each coalition should have is a contact list of individuals and organizations that can offer valuable assistance. Below is a sample of which individuals/groups should be on a contact list. Know that one contact can lead to another and the list will grow. The more “friends” your coalition has, the better your chances are of elevating local, state, and national awareness of prostate cancer.

However, it is worthless to maintain a contact list if it is not utilized. Every effort should be made to contact individuals on the list on a regular basis. One way to maintain this contact is to send each contact your coalition’s newsletter. Whenever possible, highlight in the newsletter the activities/accomplishments of a particular contact. This may serve to “spur” on another contact and lets the entire group know that your coalition is viable, active and that they are part of a vibrant, worthwhile organization.

- American Cancer Representatives in your state
- Cancer Consortium members in your state
- Comprehensive Cancer Control members in your state
- Health Educators – some large cities have such a person, large corporations do as well
- Individuals who are willing to donate funds
- Individuals who can write grants
- Leaders of all NASPCC state coalitions
- List of cancer treatment centers
- List of hospitals state wide
- List of “friends” who will help with various projects
- List of libraries state wide
- Media contacts – radio, television- including cable outlets, newspapers
- Misc. contacts for web site, newsletter, printing of brochures, mugs, t-shirts, etc
- Native population’s health contacts
- Oncology Workers – nurses, PA’s, lab techs.
- Political contacts – local, county, state, national
- Social Workers
- Speakers Bureau contacts
- State hospital association leaders
- Support Group leaders within your state
- Trained Man-to-Man/ Buddy-to-Buddy representatives
- Urologists – state wide or regional
- Wellness Directors/Human Resources Directors of schools, businesses, and government groups

In addition to the individuals listed above, each coalition should have a list of organizations, both for profit and non - profit that are viewed as colleagues in the screening, treatment and care of prostate cancer patients, their partner, and families. A partial listing should include:

Alliance for Prostate Cancer Prevention – [www.apcap.org](http://www.apcap.org)

American Urological Association – [www.aua.net](http://www.aua.net)  
ASCO – [www.asco.org](http://www.asco.org)  
Malecare – [www.malecare.com](http://www.malecare.com)  
Mens Health Network – [www.menshealthnetwork.org](http://www.menshealthnetwork.org)  
National Cancer Institute – [www.cancer.gov](http://www.cancer.gov)  
National Comprehensive Cancer Network – [www.nccn.org](http://www.nccn.org)  
Pharmaceutical companies  
Prostate Cancer Foundation – [www.prostatecancerfoundation.org](http://www.prostatecancerfoundation.org)  
Prostate Cancer Research Institute – [www.prostate-cancer.org](http://www.prostate-cancer.org)  
The National Institute of Health – [www.nih.gov](http://www.nih.gov)  
The Prostate Net – [www.prostate-online.org](http://www.prostate-online.org)  
Urology Health – [www.urologyhealth.org](http://www.urologyhealth.org)  
UsToo International – [www.ustoo.org](http://www.ustoo.org)  
Women Against Prostate Cancer – [www.womenagainstoprostatecancer.org](http://www.womenagainstoprostatecancer.org)  
Zero – [www.zerocancer.org](http://www.zerocancer.org)

A simple way to maintain the contact list is to create a spread sheet. The information on the spread sheet should include the group or individual name, street address, web address, phone numbers (home, office, cell, and fax) and an e-mail address.

## Alternative Media

There are many new and exciting alternative ways of communicating our messages, all worth exploring. Among the new technology are Facebook, YouTube, Twitter, and Second Life.

**Facebook** is a free networking site. As of 2009 it has grown to over 250 million users who can post information, join networks and interact with other people. It is a form of rapid, large scale communication. Messages can be posted on a Facebook page and users can join in on live discussions.

Facebook provides us with an opportunity to reach a wide ranging group of men and women. Organizations also use Facebook to raise money for their causes. Currently the #1 most popular cause on Facebook in terms of users is “Support Breast Cancer Research” with 1,444,427 members and \$31,277 raised. Organizations can also broadcast calls to action and promote local events.

Many groups are currently using Facebook raising money, increasing their visibility, and developing their communities. Among the users are the American Cancer Society, Michigan Department of Community Health, the Prostate Cancer Coalition of North Carolina, Us TOO International, and the Prostate Cancer Foundation.

**YouTube** is a free video sharing website on which individual and organization users can upload and share videos. YouTube is used by media corporations such as CBS, and the BBC as well as individuals. People find videos by searching or by following a user defined channel, such as “non-profit.” You might want to search “psa” or “prostate cancer.” Many people view surgeries and other medical procedures on You Tube. Posting video position papers, such as “Why I Think PSA Screening is Important,” is a method our state coalitions might explore.

**Twitter** is a service for individuals to communicate and stay connected through the exchange of quick frequent answers to a single question. For example, “Are support groups really helpful for prostate cancer survivors, after all, I am alive.” Answers can be quick and simple. There may be reasons why individuals cannot or will not discuss issues unless in the privacy of their homes. By utilizing Twitter, dialogues can begin. Twitter has about 35 million users, world wide. Several prostate cancer organizations, the Prostate Cancer Foundation, Zero, and MaleCare use Twitter. Twitter’s prostate cancer support is facilitated by MaleCare.

**Second Life** is a virtual reality space that is worth exploring. It is used by many non-profits, such as the National Cancer Institute, American Cancer Society and MaleCare as an educational tool. ACS is well known for being the first non-profit to fundraise on Second Life.

## Grand Rounds

Grand rounds are a ritual of medical education. They generally consist of presenting a medical problem(s) and treatment options. They originally were a part of residency training where new information was taught and clinical researching skills were enhanced. Traditionally a patient was present and would answer questions. Grand rounds have evolved over the years. Today a patient is no longer present and the sessions are generally lectures involving clinical problems in medicine or focus is given to one disease. Often medical facilities offer continuing education credits to attendees who are generally doctors, residents, nurses, nurse practioners, physician assistants, or other medical personnel.

Grand rounds are well suited to advocating for prostate cancer screening. Physicians attend the grand rounds for the information imparted and for the education credits. Generally the sessions are brief, lasting no more that 2 hours. Encouraging a hospital to sponsor a grand round on prostate cancer, led by a respected member of the medical community, who supports prostate cancer screening , can have beneficial effects. The Maine Coalition to Fight Prostate Cancer has been successful in doing this. Thus far the Coalition has cooperated with three of the largest hospitals in the state in sponsoring prostate cancer grand rounds.

The initial step is to identify a respected physician, who is qualified by his/her specialty to make a presentation on prostate cancer screening. Next is to meet with hospital grand rounds staff to schedule a presentation. At the same time the physician is preparing his/her presentation – a power point program works well. The next step is to promote the grand round to a targeted group – primary care physicians and urologists are generally the two most important groups to convince of the need for screening.

If allowed by the hospital, on the day of the presentation, your state coalition should have a display set up near the location of the presentation. Provide the attendees with your brochures, the NASPCC brochure, and support group meeting information, statistics sheets, your card, and any other pertinent information. As the physicians enter and depart the session, be there to advocate for prostate cancer screening - make contacts and connections.

A word of caution is needed. The process of getting a physician to present and getting on the hospital schedule can and usually takes a long time. Once one grand round has successfully occurred, it becomes somewhat easier to have others. Do not give up. Be persistent.

## **Section D – Under Utilized, Under Served**

*“There is a hugely underserved population out there.”*

*James Cameron*

*“Class differences in health represent a double injustice: life is short where its quality is poor.”*

*Richard G. Wilkinson*

*“When a person is down in the world, an ounce of help is better than a pound of preaching.”*

*Edward Bulwer Lytton*

## **Engaging Women in the Fight Against Prostate Cancer**

It has been said that behind every successful man is a successful woman. In the role of daughter, wife, mother, sister, mother-in-law, or friend, women can and do have a huge impact on the lives of the men they love. Many suggestions have been put forth as to how women can become more pro-active in the battle against prostate cancer. In addition to serving on the boards of the many prostate cancer state coalitions and accompanying their male loved ones to support team meetings there are other things that women can do. A question posed to our member chapters was, what is the role of women in your states' fight against prostate cancer? While most groups acknowledged that women's voices are wanted, very few have actively recruited women significant numbers. It is the view of this committee that the "uncapped potential" of women must be used in the fight against prostate cancer.

Some states have begun innovative programs to actively involve women.

In **New Jersey** the wives of some of the survivors have created a "Stand By Your Man" calendar for 2010. These same women also speak to women's groups about PCa and help market the calendar. New Jersey is also the headquarters of Women Against Prostate Cancer established by Betty Gallo and other women.

In **New Mexico** there is a sub-group of women known as "Angels." They act as mentors to women who are entering or going through or have gone through the prostate cancer treatment with their significant others.

In **North Carolina** there is a "dual awareness program" that works with breast cancer awareness activists and prostate cancer awareness. Women are very involved in promoting awareness of both diseases.

**Arkansas** has women Survivor-Mentors on call as well as men Survivor-Mentors; and the Arkansas chapter is in the process of starting an Arkansas Chapter of Women Against Prostate Cancer.

In **Texas** the NAPSCC state chapter makes frequent presentations to women's groups and youth groups. All women have some male relatives. By presenting to the women, information about prostate cancer reaches the men.

In addition to the above programs we encourage state groups to provide women with the following suggestions compiled from the Dean and Betty Gallo Prostate Cancer Center, the Men's Health Network, and Phyllis Blanchard, wife of John Blanchard, a prostate cancer survivor and the past President and CEO of the Prostate Cancer Research foundation of Canada.

Women should be important partners to the men in their lives and are encouraged to:

- get the facts and understand why regular prostate cancer exams are important
- urge him to begin the conversation with the physician about annual PSA and DRE exams
- remind him that with early diagnosis and treatment, 95% of men survive
- say that you want him around forever, sex or no sex
- find health providers that have weekend or evening appointments close to his work
- find out if he would prefer a male or female physician
- schedule his appointment
- go with him to the physician
- schedule a "date" with him afterward and have some fun
- book his tests and appointments
- recruit male friends or relatives to help reinforce good health habits
- point out the connection between good health and good physical and mental performance in sports, work, etc
- remind him that his children will be influenced by the good example that he sets
- remind him that he has a lot to live for
- encourage him to celebrate Men's Health Week by seeing a physician for a thorough examination. Set up his appointment as a Men's Health Week gift
- attend support team meetings with him.

## **Gay, Bisexual, and Transgendered Man with Prostate Cancer**

Approximately 9-10 % of American prostate cancer survivors are Gay, Bisexual, or Transgender. These men and transgender women find it particularly difficult to seek medical help. For example, Gay and Bisexual men - particularly African-American men - have the lowest use of PSA tests compared with every other group of men in a study conducted at Charles Drew University in Los Angeles. The data is from an examination of 19,410 men who participated in the California Health Interview Survey.

NASPCC suggest that men who are Gay or Bisexual and Transgendered women be referred to Malecare. Malecare is the worlds first, and still, only, nonprofit organization to create and facilitate cancer support groups for gay men. Malecare provides support services both in person and on line. Malecare also partners with the National Lesbian, Gay, Bisexual, Transgender (LGBT) Cancer Project, Out With Cancer. Out With Cancer works to improve the lives of Lesbian, Gay, Bisexual and Transsexual people diagnosed with cancer with advocacy and support.

Online resources for Gay and Bisexual men and Transgender women diagnosed with prostate cancer include:

**Information resources:**

<http://www.malecare.com>

<http://www.lgbtcancer.com>

**Online support group:**

<http://www.outwithcancer.com>

**Listserv**

<http://health.groups.yahoo.com/group/prostatecancerandgaymen/>

State coalition leaders can learn more about Gay and Bisexual men and Transgender women diagnosed with prostate cancer, by reading, A Gay Man's Guide to Prostate Cancer, available through any online store or from a bookstore.

Based on work begun by in 1997 Darryl Mitteldorf, LCSW, THE JOURNAL OF THE ASSOCIATION OF GAY AND LESBIAN PSYCHIATRISTS issued a Special Double Issue called, "A Gay Man's Guide to Prostate Cancer". It is helpful to the partners, family members, support systems and physicians of men with prostate cancer. The special double issue was developed into the book.

Also worth reading on line:

**Article 1:** "The Gay Man's Camp Guide to Cancer"

**Article 2:** "A Gay Man's Guide to Prostate Cancer"



If you are an Gay or Bisexual man or a Transgendered woman and are experiencing difficulty reaching other men in your area to talk to; or if you live in a distant location making it impossible to attend support group meetings; or are experiencing feelings of isolation we encourage you to contact Malecare in order to get information about establishing a chapter in your area. The contact person is:

Darryl Mitteldorf, LCSW  
Executive Director  
Malecare, Inc.  
Fighting Cancer, Together  
<http://www.malecare.com>  
[darryl@malecare.com](mailto:darryl@malecare.com)  
212-844-8369

Please visit and consider signing the Petition to Make Prostate Cancer a National Priority at <http://www.prostatecancerpetition.org>

## **Minority/Underserved Outreach**

A polling question asked of the member chapters pertained to specific outreach to minorities and the underserved. This includes men with no insurance, insufficient insurance, men living in remote areas, incarcerated men, men from minority ethnic groups, and gay and bisexual men. Very few chapters reported that they have activities specifically aimed at reaching the underserved populations. It is likely that all are making efforts to reach these groups but do not see it as distinct from their other programs.

However, some chapters did report activities/events geared specifically to this population. The following are the specifically mentioned activities/events:

Culture-specific groups such as African-Americans, Hispanics, Native – Americans, Chinese-Americans, etc can be reached via churches, culture specific groups, the Internet and face to face meetings.

Many chapters work hand in hand with other groups that have ties to minorities and the underserved. Some chapters reported financial donations to these types of organizations. The logic is that frequently members of minority groups and the underserved will trust the messenger when the messenger is one of their own.

Chapters also reported attending minority health fairs

The California Chapter has created the IMPACT Program which has counseling specifically geared toward underserved men.

Several states provide language specific materials to organizations that work with English language challenged groups of men. Many language specific materials can be found on line by accessing the Canadian, Spanish, etc division of the American Cancer Society. Additionally, a web search will help locate prostate cancer educational materials in many languages such as Somali. Also, many high schools and community college student or teachers willingly translate materials that are not copyright protected.

Finally many chapters reported inviting respected members of minority communities to serve on their boards.

Many states have Minority Health Directors and there is a national organization of minority health directors. We have provided the complete list of the National Association of State Offices of Minority Health Directors with the most current data for our members to use. In some cases the individual leaders may have changed but the position of Minority Health Director remains in place.

**NATIONAL ASSOCIATION OF STATE  
OFFICES OF MINORITY HEALTH  
DIRECTORS**

**ALABAMA**

Gwendolyn Lipscomb, Director  
**Office of Minority Health**  
Alabama Department of Public Health  
201 Monroe Street, Suite 710  
Montgomery, Alabama 36104  
Phone: (334) 206-5396  
Fax: (334) 206-5434  
Email: [glipscomb@adph.state.al.us](mailto:glipscomb@adph.state.al.us)

**ARIZONA**

Patricia Tarango, MS, Bureau Chief  
**Arizona Health Disparities Center**  
Office of Health Systems Development  
Arizona Department of Health Services  
1740 West Adams, Suite 410  
Phoenix, AZ 85007-1219  
Phone: (602) 542-1436  
Fax: (602) 542-2011  
Email: [tarangp@azdhs.gov](mailto:tarangp@azdhs.gov)

**ARKANSAS**

Christine B. Patterson, MSW, LCSW, Director  
**Office of Minority Health and Health  
Disparities**  
Arkansas Department of Health  
4815 West Markham Street - Slot 22  
Little Rock, Arkansas 72205  
Phone: (501) 661-2193  
Fax: (501) 661-2414  
Email: [Christine.Patterson@arkansas.gov](mailto:Christine.Patterson@arkansas.gov)  
Wynona Bryant-Williams, Ph.D.  
Director  
**Arkansas Minority Health Commission**  
1123 South University, Suite 312  
Little Rock, Arkansas 72204  
Phone: (501) 686-2720  
Fax: (501) 686-2722  
Email: [wynona.bryant-williams@arkanas.gov](mailto:wynona.bryant-williams@arkanas.gov)

**CALIFORNIA**

Terri Thorfinnson, Acting Chief  
**Office of Multicultural Health**  
California State Department of Health Services  
1501 Capitol Avenue, Suite 6054  
P.O. Box 997413 MS 0022  
Sacramento, California 95899-7413  
Phone: (916) 440 7628  
Fax: (916) 440-7565  
Email: [terri.thorfinnson@dhcs.ca.gov](mailto:terri.thorfinnson@dhcs.ca.gov)

**COLORADO**

R. Mauricio Palacio, Director  
**Office of Health Disparities**  
Colorado Department of Public Health and  
Environment  
4300 Cherry Creek Drive, South, C-1  
Denver, Colorado 80246-1530  
Phone: (303) 692-2329  
Fax: (303) 691-7746  
Email: [mauricio.palacio@state.co.us](mailto:mauricio.palacio@state.co.us)

**CONNECTICUT**

Nancy E. Berger, MPH, Director  
**Office of Multicultural  
Health/Comprehensive Cancer**  
Department of Public Health  
410 Capitol Avenue  
P. O. Box 340308, MS# 13MHCC  
Hartford, CT 06134-0308  
Phone: (860) 509-8098  
Fax: (859) 508-7227  
Email: [nancy.berger@ct.gov](mailto:nancy.berger@ct.gov)

**DELAWARE**

Herman Ellis, Interim Director  
**Office of Minority Health**  
Division of Public Health  
Delaware Department of Health and Social  
Services  
417 Federal Street - P.O. Box 637  
Dover, DE 19903  
Phone: (302) 744-4701  
Fax: (302) 739-6659  
Email: [herman.ellis@state.de.us](mailto:herman.ellis@state.de.us)

**FLORIDA**

Tamara Yang Demko, JD  
Assistant Secretary for Health and Acting  
Director  
**Office of Minority Health**  
Florida State Department of Health  
4052 Bald Cypress Way, Bin A07  
Tallahassee, FL 32399-1708  
Phone: (850) 245-4016  
Fax: (850) 487-3729 Fax  
Email: [Tamara\\_Demko@doh.state.fl.us](mailto:Tamara_Demko@doh.state.fl.us)

**GEORGIA**

James T. Peoples, Executive Director

**Office of Health Improvement, Office of Minority Health**

Georgia Department of Community Health  
2 Peachtree St., 38<sup>th</sup> floor  
Atlanta, GA 30303-3159  
Phone: (404) 463-4013  
Fax: (404) 657-2769  
Email: [jpeoples@dch.ga.gov](mailto:jpeoples@dch.ga.gov)

**HAWAII**

Elaine Andrade, Coordinator  
**Office of Health Equity**  
Hawaii State Department of Health  
1250 Punchbowl Street  
Honolulu, Hawaii 96813  
Phone: (808) 586-4191  
Fax: (808) 586-4193  
Email: [elaine.andrade@doh.hawaii.gov](mailto:elaine.andrade@doh.hawaii.gov)

**ILLINOIS**

Doris Turner, Chief  
**Center for Minority Health Services**  
Illinois Department of Public Health  
535 West Jefferson Street, 5<sup>TH</sup> Floor  
Springfield, IL 62761  
Phone: (217) 785-4311  
Fax: (217) 558-7181  
Email: [Doris.Turner@illinois.gov](mailto:Doris.Turner@illinois.gov)

**INDIANA**

Carolin Requiz, Director  
**Office of Minority Health**  
Indiana State Department of Health  
2 North Meridian Street, 8G  
Indianapolis, Indiana 46204  
Phone: (317) 233-7596  
Fax: (317) 233-7943  
Email: [crequiz@isdh.in.gov](mailto:crequiz@isdh.in.gov)  
Nancy Jewell, MPA  
President/CEO  
**Indiana Minority Health Coalition, Inc.**  
3737 N. Meridian Street 3<sup>rd</sup> floor  
Indianapolis, IN 46208  
Phone: (317) 926-4011  
Fax: (317) 926-4037  
Email: [njewell@imhc.org](mailto:njewell@imhc.org)

**IOWA**

Janice Edmonds, Wells, MSW, Consultant  
**Office of Multicultural Health**  
Iowa Department of Public Health  
Lucas State Office Building  
321 East 12<sup>th</sup> Street, 4<sup>th</sup> Floor  
Des Moines, Iowa 50319-0015  
Phone: (515) 281-4904  
Fax: (515) 242-6384  
Email: [jwells@idph.state.ia.us](mailto:jwells@idph.state.ia.us)

**KANSAS**

Sharon Goolsby, Program Manager  
**Kansas Office of Minority Health**  
Kansas Department of Health and Environment  
1000 SW Jackson, Suite 540  
Topeka, Kansas 66612-1368  
Phone: (785) 296-5577  
Fax: (785) 296-6231  
Email: [sgoolsby@kdhe.state.ks.us](mailto:sgoolsby@kdhe.state.ks.us)

**LOUISIANA**

Durand Rudy Macklin, Director  
**Bureau of Minority Health Access**  
628 North 4<sup>th</sup> Street, 9<sup>th</sup> Floor  
Baton Rouge, Louisiana 70821  
Phone: (225) 342-4886  
Fax: (225) 342-3738  
Email: [rmacklin@dhh.la.gov](mailto:rmacklin@dhh.la.gov)

**MAINE**

Lisa Sockabasin, Director  
**Office of Minority Health**  
Maine Department of Health and Human Services  
State House Station 11B  
286 Water Street, 8<sup>th</sup> Floor  
Augusta, ME 04333-0011  
Phone: (207) 287-8016  
Fax: (207) 287-9058  
Email: [lisa.sockabasin@maine.gov](mailto:lisa.sockabasin@maine.gov)

**MARYLAND**

Carlessia A. Hussein, RN, DrPH, Director  
**Office of Minority Health and Health Disparities**  
Maryland Department of Health and Mental Hygiene  
201 West Preston Street, Room 500  
Baltimore, MD 21201  
Phone: (410) 767-0094  
Fax: (410) 333-5100  
Email: [hussieinc@dhhm.state.md.us](mailto:hussieinc@dhhm.state.md.us)

**MICHIGAN**

Andrea Woodruff, M.A., Acting Manager  
**Health Disparities Reduction/Minority Health Section**  
 Michigan Department of Community Health  
 3056 W. Grand Blvd. Ste. 3-150  
 Detroit, Michigan 48202  
 Phone: (313) 456-4421  
 Fax: (313) 456-4428  
 Email: [woodruffa@michigan.gov](mailto:woodruffa@michigan.gov)

**MINNESOTA**

Mitchell Davis, Director  
**Office of Minority and Multicultural Health**  
 Minnesota Department of Health  
 Freeman Building, 5C  
 625 N. Robert Street - P.O. Box 64975  
 St. Paul, Minnesota 55164-0975  
 Phone: (651) 201-5818  
 Fax: (651) 201-5801  
 Email: [Mitchell.Davis@health.state.mn.us](mailto:Mitchell.Davis@health.state.mn.us)

**MISSISSIPPI**

Lovetta Brown, MD, MPH, Director  
**Office of Health Disparity Elimination**  
 Mississippi Department of Health  
 570 E. Woodrow Wilson Blvd. - Osborne 120  
 Jackson, Mississippi 39215-1700  
 Phone: (601) 576-7266  
 Fax: (601) 576-8215  
 Email: [lbrown@msdh.state.ms.us](mailto:lbrown@msdh.state.ms.us)

**MISSOURI**

Cheryl Avant, Chief  
**Office of Minority Health**  
 Missouri Department of Health and Senior Services  
 930 Wildwood Drive, P.O. Box 570  
 Jefferson City, Missouri 65102  
 Phone: (573) 751-6064  
 Fax: (573) 522-1599  
 Email: [Cheryl.Avant@dhss.mo.gov](mailto:Cheryl.Avant@dhss.mo.gov)

**NEBRASKA**

Raponzil L. Drake, Administrator  
**Office of Minority Health**  
 Nebraska Department of Health and Human Services  
 301 Centennial Mall South - PO Box 95007  
 Lincoln, NE 68509-5007

**NEVADA**

Mae Norris, Acting Manager

**Office of Minority Health**

Nevada Department of Health and Human Services  
 3811 W. Charleston Blvd., Suite 205  
 Las Vegas, Nevada 89102  
 Phone: (702) 486-7026  
 Fax: (702) 486-7281  
 Email: [mnorris@health.nv.gov](mailto:mnorris@health.nv.gov)

**NEW HAMPSHIRE**

William D. Walker, Director  
**Office of Minority Health**  
 New Hampshire Department of Health & Human Services  
 97 Pleasant Street Thayer Building  
 Concord, NH 03301-3857  
 Phone: (603) 271-8459  
 Fax: (603) 271-4727  
 Email: [bwalker@dhhs.state.nh.us](mailto:bwalker@dhhs.state.nh.us)

**NEW JERSEY**

Linda Holmes, Executive Director  
**Office of Minority and Multicultural Health**  
 New Jersey Department of Health and Senior Services  
 John Fitch Plaza B P.O. Box 360  
 Trenton, New Jersey 08625-0360  
 Phone: (609) 292-6962  
 Fax: (609) 292-8713  
 Email: [linda.holmes@doh.state.nj.us](mailto:linda.holmes@doh.state.nj.us)

**NEW MEXICO**

Sam Howarth, Ph.D., Director  
**Office of Policy and Multicultural Health**  
 New Mexico Department of Health  
 1190 St Francis Drive  
 Santa Fe, NM 87502  
 Phone: (505) 827-1052  
 Fax: (505) 827-2942  
 Email: [Sam.Howarth@state.nm.us](mailto:Sam.Howarth@state.nm.us)

**NEW YORK**

Wilma E. Waithe, Director  
**Office of Minority Health**  
 New York State Department of Health  
 ESP Coming Tower Building, Room 780  
 Albany, New York 12237  
 Phone: (518) 474-2180  
 Fax: (518) 473-4695  
 Email: [wew01@health.state.ny.us](mailto:wew01@health.state.ny.us)

**NORTH CAROLINA**

Barbara Pullen-Smith, Executive Director

**Office of Minority Health and Health Disparities**  
North Carolina Department of Health and Human Services  
1110 Navaho Drive, Suite 510  
1906 Mail Service Center  
Raleigh, North Carolina 27699-1906  
Phone: (919) 431-1613  
Fax: (919) 850-2758  
Email: [Barbara.Pullen-Smith@ncmail.net](mailto:Barbara.Pullen-Smith@ncmail.net)

**NORTH DAKOTA (Effective July 1st)**

John R. Baird, M.D.  
Field State Medical Officer  
**Office for the Elimination of Health Disparities**  
North Dakota Department of Health  
600 East Boulevard Ave – Dept 301  
Bismarck, ND 58505-0200  
Phone: (701) 241-8118  
Fax: (701) 241-2336  
Email: [jbaird@nd.gov](mailto:jbaird@nd.gov)  
OR

Sherri Paxson, BS, MT (ASCP) BB  
Director, Division of Chronic Disease  
**Office for the Elimination of Health Disparities**  
North Dakota Department of Health  
600 East Boulevard Ave – Dept 301  
Bismarck, ND 58505-0200  
Phone: (701) 328-2372  
Fax: (701) 328-2336  
Email: [spaxson@nd.gov](mailto:spaxson@nd.gov)

**OHIO**

Cheryl Boyce, Executive Director  
**Ohio Commission on Minority Health**  
77 South High Street, 7th Floor - Suite 745  
Columbus, Ohio 43215  
Phone: (614) 466-4000  
Fax: (614) 752-9049  
Email: [cheryl.boyce@ocmh.state.oh.us](mailto:cheryl.boyce@ocmh.state.oh.us)

**OKLAHOMA**

Demetrio (J.R.) Gutierrez, Chief  
**Office of Minority Health**  
Oklahoma State Department of Health  
1000 NE 10th Street, Suite 211  
Oklahoma City, Oklahoma 73117-1299  
Phone: (405) 271-1337  
Fax: (405) 271-9228  
Email: [Demetrio@health.ok.gov](mailto:Demetrio@health.ok.gov)

**OREGON**

James L. Mason, Ph.D., Director

**Office of Multicultural Health**  
Public Health Division  
Department of Human Services  
800 N.E. Oregon Street, Suite 290A  
Portland, Oregon 97232  
Phone: 971) 673-1283  
Fax: (971) 673-1128  
Email: [james.mason@state.or.us](mailto:james.mason@state.or.us)

**PENNSYLVANIA**

Lori Ann Jenkins, Esq., Director  
**Office of Health Equity**  
Pennsylvania Department of Health  
1033 Health & Welfare Building  
7th and Forster Streets  
Harrisburg, PA 17120-17108  
Phone: (717) 772-5298  
Fax: (717) 705-6525  
Email: [ljenkins@state.pa.us](mailto:ljenkins@state.pa.us)

**PUERTO RICO**

Dalidia Colon Pieretti, Assistant Secretary  
Office of Planning, Evaluation and Statistics  
**Office of Minority Health**  
Puerto Rico Department of Health  
P. O. Box 70184  
San Juan, PR 00936-8184  
Phone: (787) 274-7874  
Fax: (787) 724-5736  
Email: [dcolon@salud.gov.pr](mailto:dcolon@salud.gov.pr)

**RHODE ISLAND**

Carrie Bridges, MPH, Chief  
**Office of Minority Health**  
Rhode Island Department of Health  
Three Capitol Hill, Room 409  
Providence, RI 02908-5097  
Phone: (401) 222-2901  
Fax: (401) 222-4415  
E-mail: [Carrie.Bridges@health.ri.gov](mailto:Carrie.Bridges@health.ri.gov)  
Website: <http://www.health.ri.gov>

**SOUTH CAROLINA**

Gardenia Ruff, Director  
**Office of Minority Health**  
South Carolina Department of Health and Environmental Control  
2600 Bull Street  
Columbia, South Carolina 29201  
Phone: (803) 898-3808  
Fax: (803) 898-3810  
Email: [ruffgb@dhec.sc.us](mailto:ruffgb@dhec.sc.us)

**TENNESSEE**

Cherry Houston, Ph.D. , Director  
**Division of Minority Health/Health Disparity Elimination**  
Tennessee Department of Health  
Cordell Hull Building, 3<sup>rd</sup> Floor  
425 Fifth Avenue, North  
Nashville, Tennessee 37247  
Phone: (615) 741-9443  
Fax: (615) 253-1434  
Email: cherry.houston @state.tn.us

#### **TEXAS**

Kimberly McCoy-Daniels, Director  
**Office for the Elimination of Health Disparities**  
Texas Department of State Health Services  
1100 West 49<sup>th</sup> Street  
Austin, Texas 78756  
Phone: (512) 458-7629  
Fax: (512) 458-7507  
Email: [kimberly.mccoy-daniels@dshs.state.tx.us](mailto:kimberly.mccoy-daniels@dshs.state.tx.us)

#### **UTAH**

Owen Quiñonez  
Coordinator  
**Center for Multicultural Health/Office of Minority Health**  
Utah Department of Health  
Community and Family Health Services  
P.O. Box 142001  
Salt Lake City Utah 84114-2001  
Phone: (801) 538-9457  
Fax: (801) 538-6591  
Email: [oquinone@utah.gov](mailto:oquinone@utah.gov)  
Website: [www.health.utah.gov/cmh/](http://www.health.utah.gov/cmh/)

#### **VERMONT**

Judy Ashley-McLaughlin, MS  
Special Assistant to the Commissioner for Minority Health  
**Vermont Office of Minority Health and Health Disparities**  
20 Houghton Street  
St Albans, VT 05478  
Phone: (802) 527-5582  
Fax: (802) 527-5405  
Email: [jashley@vdh.state.vt.us](mailto:jashley@vdh.state.vt.us)  
Website: [www.healthvermont.gov](http://www.healthvermont.gov)

#### **VIRGIN ISLANDS**

Phyllis L. Wallace, Ed.D., MS

Deputy Commissioner Administrative Services and Management and Director  
**Office of Minority Health**  
Virgin Islands Department of Health  
1303 Hospital Ground, Suite 10  
St. Thomas, Virgin Islands 00802  
Phone: (340) 777-8871 or (340) 774-0117  
Fax: (340) 774-4344 or (340) 777- 4001  
Email: [phyllis.wallace@usvi-doh.org](mailto:phyllis.wallace@usvi-doh.org)

#### **VIRGINIA**

Michael Royster, MD, MPH  
Director of Minority Health and Health Policy  
**Office of Minority Health**  
Office of Health Policy and Planning  
Virginia Department of Health  
109 Governor Street, Suite 1016 East  
Richmond, Virginia 23219  
Phone: (804) 864-7435  
Fax: (804) 864-7440  
Email: [Michael.Royster@vdh.virginia.gov](mailto:Michael.Royster@vdh.virginia.gov)

#### **WASHINGTON**

Christy Curwick, MPH  
Health Policy Analyst  
**Governor's Interagency Council on Health Disparities**  
Washington State Board of Health  
101 Israel Road, SE – PO Box 47990  
Olympia, WA 98504-7990  
Phone: (360) 236-4108  
Fax: (360) 236-4088  
Email: [christy.curwick@doh.wa.gov](mailto:christy.curwick@doh.wa.gov)  
Website: [www.sboh.wa.gov/hdcouncil](http://www.sboh.wa.gov/hdcouncil)

#### **WEST VIRGINIA**

Charlene Hickman, Director  
**Office of Minority Health**  
Office of Epidemiology and Health Promotion  
West Virginia Department of Health  
350 Capitol Street, Room 206  
Charleston, WV 25301  
Phone: (304) 558-0644  
Email: [charlenehickman@wvdhhr.org](mailto:charlenehickman@wvdhhr.org)

#### **WISCONSIN**

Patricia Guhlem, Acting Director

Office of Minority Health  
Division of Public Health  
Department of Health and Family Services  
One West Wilson Street, Room 372  
P.O. Box 2659  
Madison, WI 53701-2659  
Phone: (608) 266-1347  
Fax: (608) 267-2832  
Email: [guhlepa@dhfs.state.wi.us](mailto:guhlepa@dhfs.state.wi.us)

Betty Sones, Chief  
**Office of Multicultural Health**  
Division of Community and Family Health  
Wyoming State Department of Health  
6101 Yellowstone Rd., Suite 420  
Cheyenne, Wyoming 82002  
Phone: (307) 777-5601  
Fax: (307) 777-8687  
Email: [bsones@state.wy.us](mailto:bsones@state.wy.us)  
**(Revised 9/10/07:GMaccannon)**

## WYOMING

### Other Minority Resources

In addition to the 40 states that have minority health leaders at the state level there are a variety of other avenues to gain information and assistance in the battle against prostate cancer within the many minority communities. The following are just some of the resources available to our state coalitions:

National Center on Minority Health and Health Disparities  
National Institutes of Health  
6707 Democracy Boulevard, Suite 800  
Bethesda, MD 20892-5465  
Telephone 301-402-1366  
Fax 301-480-4090  
<http://www.ncmhd.nih.gov>

Office of Minority Health and Health Disparities  
Office of the Chief of Public Health Practices  
Office of the Director  
CDC  
1600 Clifton Road  
Atlanta, Georgia 30333  
USA  
404-639-3311

Director, Minority Health Initiatives, Families USA  
1201 New York Avenue NW, Suite 1100  
Washington, DC 20005  
Phone 202-628-3030  
Fax 202-347-2417  
[rpanares@familiesusa.org](mailto:rpanares@familiesusa.org)

### Reaching Out to Minorities – Professional Affiliations



As the United States becomes more ethnically diverse, the scientific/health community is learning that some ethnic groups are more likely to develop prostate cancer than others. The Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute (NCI) is an authoritative source of cancer information – incidence and survival – in the United States. SEER currently collects and publishes cancer incidence and survival data from population based cancer registries covering approximately 26% of the U.S. population. A breakdown of the SEER coverage includes 23% of African-Americans, 40% of Hispanics, 42% of American Indians and Alaska Natives, 53% of Asians, and 70% of Pacific Islanders. The data is from SEER statistics, 2002 to 2006. Among the ways to advocate for prostate cancer screening within minority communities is to identify and then reach out to professional affiliations of minority groups. African-American men have the highest rate of prostate cancer in the United States, at twice the rate of prostate cancer in white men. It is imperative that coalitions reach out to the African-American community. The Education and Best Practices Committee encourages coalitions to use a varied approach to reach this vulnerable population. One avenue to pursue is the internet. An internet search yields information about African - American lawyers, physicians, journalists, data processors, architects, design professionals, broadcasters, accountants, and a host of other professional affiliations of Black Americans. Additionally there are many African – American fraternities and sororities. In states with large African-American populations, members of the prostate cancer coalition should approach local chapters of national professional groups such as the ones listed below. Coalition members can offer to make prostate cancer informational presentations to the groups, submit material for the group’s newsletter, seek out new members for the coalition, and request donations. The opportunities for awareness and activism are vast.

### **African American Professional Organizations**

Association of Black Psychologists

<http://www.abpsi.org/>

Black Data Processing Associates

<http://www.bdpa.org>

National Association of Black Accountants

<http://www.nabainc.org>

National Association of Black Journalists

<http://www.nabj.org>

National Association of Black Telecommunication Professionals

<http://www.nabtp.org>

National Forum for Black Administrators

<http://www.nfbpa.org>

National Organization for the Professional Advancement of Black Chemists &

Chemical Engineers

<http://www.nobcche.org>

National Society of Black Engineers

<http://www.nsbe.org>

National Society of Black MBAs

<http://www.nmbaa.org>

Many states have separate African – American attorney’s organizations such as the examples listed below.

African-American Lawyers Association of Hawaii

Arizona Black Bar Association

Arkansas Black Lawyers

Black Lawyers of Cincinnati

California Association of Black Lawyers

New Mexico Black Lawyers Association

Fraternal organizations are another means of reaching out to the African-American community. The National Pan-Hellenic Council (NPHC) is a collaborative organization of nine historically African-American, international Greek lettered fraternities and sororities. This group is sometimes referred to as the "Divine Nine". Fraternal organizations often maintain contact with one another long after their college years through local chapters and newsletters. Outreach to both fraternities and sororities are another way of advocacy.

- [Alpha Phi Alpha Fraternity](#), Founded 1906, Cornell University
- [Alpha Kappa Alpha Sorority](#), Founded 1908, Howard University
- [Kappa Alpha Psi Fraternity](#), Founded 1911, Indiana University
- [Omega Psi Phi Fraternity](#), Founded 1911, Howard University
- [Delta Sigma Theta Sorority](#), Founded 1913, Howard University
- [Phi Beta Sigma Fraternity](#), Founded 1914, Howard University
- [Zeta Phi Beta Sorority](#), Founded 1920, Howard University
- [Sigma Gamma Rho Sorority](#), Founded 1922, Butler University
- [Iota Phi Theta Fraternity](#), Founded 1963, Morgan State University

As with the African-American community, the Hispanic community is well represented with professional organizations of their own. An internet search identifies associations of Hispanic advertising agencies, certified public accountants, attorneys, journalists, federal executives, engineers, health providers and librarians to name a few. And, as with the African-American fraternities and sororities, an internet search will yield information about Hispanic fraternal organizations.

ASPIRA Association

<http://www.aspira.org>

Association of Latino Professionals in Finance & Accounting

<http://www.alpfa.org/>

Hispanic Public Relations Association

<http://www.hprala.org/>

Latin American Management Association

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

Latin Business Association

<http://www.lbausa.com>

League of United Latin American Citizens

<http://www.lulac.org>

National Association of Hispanic Federal Executives

<http://www.nahfe.org>

National Association of Hispanic Journalists

<http://www.nahj.org>

National Association of Hispanic Public Administrators

<http://www.nahpa.org>

National Association of Puerto Rican/Hispanic Social Workers Inc

<http://www.naprsw.org/index.php>

National Coalition of Hispanic Health and Human Services Organization

<http://www.cossmho.org/>

National Hispanic Medical Association

<http://www.nhmamd.org/>

National Society for Hispanic Professionals

<http://www.nshp.org>

National Society of the Hispanic MBAs

<http://www.nshmba.org>

Society for Advancement of Chicanos & Native Americans in Science

<http://www.sacnas.org>

Society of Hispanic Professional Engineers

<http://www.shpe.org>

## Latino Fraternal Organizations

- ΓΖΑ - [Gamma Zeta Alpha](#) Fraternity
- ΛΑΥ - [Lambda Alpha Upsilon](#) Fraternity
- ΛΘΦ - [Lambda Theta Phi](#) Fraternity
- ΛΣΥ - [Lambda Sigma Upsilon](#) Fraternity
- ΛΥΛ - [Lambda Upsilon Lambda](#) Fraternity
- ΝΑΚ - [Nu Alpha Kappa](#) Fraternity
- ΦΙΑ - [Phi Iota Alpha](#) Fraternity
- ΣΔΑ - [Sigma Delta Alpha](#) Fraternity
- ΣΛΒ - [Sigma Lambda Beta](#) Fraternity
- ΩΔΦ - [Omega Delta Phi](#) Fraternity

American Indian and Alaska Natives (AI/AN), due to the great diversity of their culture present a unique challenge when determining prostate cancer rates of incidence. According to the US Bureau of the Census (2000) there are over 560 federally recognized tribes and over 100 state recognized tribes. They are among the poorest populations in the US. The National Centers for Biotechnology Information, a division of the National Library of Medicine of the National Institute of Health believes that men of these ethnic groups experience lower rates of prostate cancer due to racial misclassification as there is no single data base that gathers comprehensive cancer data for them. The Intercultural Cancer Council, fiscally organized and managed from the campus of Baylor College of Medicine has determined that types of cancer experienced in Native Communities vary significantly by region. For example, prostate cancer is more common among Northern Plains tribes and Alaska Natives than some other types of cancer. The US Department of Health and Human Services reports that cancer rates which were previously reported to be lower in the American Indian and Alaska Natives have shown to be increasing in the past twenty years.

As with other ethnic groups, efforts to reach out to and educate the American Indians and Alaska Natives to the dangers of prostate cancer must be undertaken. Outreach to tribal health leaders and to professionals from these communities is an approach. Two such groups are:

Native American Cancer Research

[www.natamcancer.org](http://www.natamcancer.org)

National Indian Health Board

[www.nihb.org/index.php](http://www.nihb.org/index.php)

**Some examples of native American professional groups are listed below:**

American Indian/Alaska Native Employees Association for NRCS

<http://www.aianea.com>

American Indian Science & Engineering Society

<http://www.aises.org>

Association of American Indian Physicians

[http:// www.aaip.com](http://www.aaip.com)

California Indian Basketweavers Association

[www.ciba.org](http://www.ciba.org)

Colorado Indian Bar Association

[www.coloradoindianbar.org](http://www.coloradoindianbar.org)

Minnesota American Indian Bar Association

[www. Maibe.org](http://www.Maibe.org)

Native American Journalists Association

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

Native American Telecommunications

<http://www.nativetelecom.org>

Native Tribal Environmental Council

<http://www.ntec.org/index.htm>

Northwest Indian Bar Association

[www.nwibar.org](http://www.nwibar.org)

Oklahoma Indian Bar Association

[www.oiba.net](http://www.oiba.net)

## Native American Fraternal Organizations

- ΑΠΩ - [Alpha Pi Omega](#) Sorority - Founded at the University of North Carolina-Chapel Hill in 1994.
- ΦΣΝ - [Phi Sigma Nu](#) Fraternity - Founded at University of North Carolina-Pembroke in 1996.

Another ethnic group to be aware of is the Asian-American ethnic group. The Cancer Journal for Clinicians notes that as with Native Americans, data on cancer incidence, mortality, risk factors and screening for Asian-Americans is not routinely available. There are cultural differences in the largely heterogeneous Asian ethnic groups. What we do know, from the National Institute of Health is that Asian-Americans have lower rates of screening compared to non - Hispanic whites. While reasons for the lack of screening by Asian-American men are conjecture, the implications for health professionals and prostate cancer advocates are clear. We need to effectively educate and communicate to the Asian-American community the message that cancer screening tests are needed despite the absence of symptoms. In states with large Asian-American populations we again urge outreach to professional groups. An internet search yields results about Asian-American lawyers, doctors, nurses, broadcast journalists, and many others:

Asian American Journalist Association

<http://www.aaja.org>

Asian/Pacific American Librarians Association

<http://www.apalaweb.org/>

Asian Women in Business

<http://www.awib.org>

Chinese American Librarians Association

<http://www.cala-web.org/>

Filipino Association for Health Careers

<http://welcome.to/fahc>

Japanese American Citizens League

<http://www.jacl.org>

Korea-America Finance Association

<http://www.nfbpa.org/>

Korean-American Scientists & Engineers

<http://www.ksea.org>

Korean Women's Association

<http://kwaoutreach.org/>

National Asian Pacific American Bar Association

National Association of Asian Professionals

<http://www.naaap.org>

US Pan Asian American Chamber of Commerce

[www.uspaacc.com](http://www.uspaacc.com)

### Asian-American Fraternal Organizations

- **ΘΔΒ** - [Theta Delta Beta](#) - "Thetas" or "The Dark Boyz" - First Filipino fraternity in California, established in 1990 at [University of California, Irvine](#).
- **ΙΝΔ** - [Iota Nu Delta](#) - The first South-Asian based fraternity in the nation, founded in 1994 at [Binghamton University](#).
- **ΚΦΛ** -
- **ΣΦΩ** - [Sigma Phi Omega](#)- "Sigmas"- Asian American sorority founded at USC Established in 1949 in response to anti-Japanese sentiment from World War II.
- **ΧΑΔ** - [Chi Alpha Delta](#) - "Chis" - first Asian-American sorority in the United States, established in 1928 at the [University of California, Los Angeles](#).
- **ΧΡΟ** - [Chi Rho Omicron](#)- "eXPOs" - Filipino cultural based Fraternity, founded at California State University, Fresno in 1995
  
- **ΒΧΘ** - [Beta Chi Theta](#) -"Beta Chi" National South Asian Fraternity and member of the [North-American Interfraternity Conference](#)
- **ΔΕΨ** - [Delta Epsilon Psi](#) - "D.Psi/D.E.Psi" South Asian Service Fraternity, founded at UT Austin (1998).
- **ΔΚΑ** - [Delta Kappa Delta](#)- "DKD" South Asian Sorority, established at Texas A&M University.
- **ΔΦΒ** - [Delta Phi Beta](#) - Co-Ed South Asian fraternity
- **ΚΦΓ** - [Kappa Phi Gamma](#)- "KPhiG" First South Asian Sorority in the Nation, founded at the University of Texas at Austin in 1998.
- **ΔΦΩ** - [Delta Phi Omega](#) - "DPO" South Asian Sorority. The Largest, Strongest, Fastest Growing South Asian Sorority in the Nation.
- **ΙΝΔ** - [Iota Nu Delta](#) - First South Asian Fraternity in the Nation, Nationally Recognized by the [North-American Interfraternity Conference](#)
- **ΣΣΡ** - [Sigma Sigma Rho](#) - first South Asian based sorority on the East Coast, "SigSigRho".

*Although we have singled out the above ethnic groups, our intent is not to exclude others. The means by which we suggest reaching out to these groups – internet searches of professional and fraternal organizations – is mutually inclusive. Advocacy for prostate cancer screening is essential for all individuals.*

## Section E – Assistance for Prostate Cancer Patients and Families

*“He stands erect by bending over the fallen. He rises by lifting others.”*

*Robert Green Ingersoll*

*“The race of mankind would perish did they cease to aid each other. We cannot exist without mutual help. All therefore that need aid have a right to ask it from their fellow men; and no one who has the power of granting can refrain it without guilt.”*

*Sir Walter Scott*

*“The purpose of life is not to be happy – but to matter, to be productive, to be useful, to have it make a difference that your lived at all.”*

*Leo Rosten*



## Laws Protecting Your Rights

The federal government has passed a number of laws designed to safeguard the rights of a patient regarding health insurance and related medical matters. The five of the most commonly know laws are explained below. In addition to the federal laws a number of states have enacted laws of their own aimed at protecting a patient's rights. In the absence of a federal **Patient's Bill of Rights**, many states have enacted their own such measures. Patients should be aware of these rights. An internet search of "patient's rights" will lead to those states that have enacted such legislation.

**Affordable Care Act (2010, known as the Obama Health Care Act)** makes insurance more affordable by providing the largest middle class tax cut for health care in history, reducing premium costs for tens of millions of families and small business owners who are priced out of coverage today. It brings greater accountability to health care by laying out commonsense rules of the road to keep premiums down and prevent insurance industry abuses and denial of care. It will end discrimination against Americans with pre-existing conditions. For additional information, go to the web sites of the Department of Health & Human Services, the Department of Defense or the Department of Justice, as each of these federal departments has jurisdiction over implementation of parts of this law.

**The Americans with Disabilities Act (ADA)** –This law prohibits discrimination against people with disabilities in employment, transportation, public accommodations, communications, and government activities. Employers are required to make reasonable accommodations to the known disabilities of a qualified applicant/employee if it does not impose an "undue hardship" on the operation of the business. An accommodation example would be allowing an employee with cancer time to have radiation or chemotherapy treatments. For more information, go to the United States Equal Employment Commission web site: [http:// www.eeoc.gov](http://www.eeoc.gov). or go to [http:// www.ada.gov](http://www.ada.gov) for links to many ADA links.

**The Consolidated Omnibus Budget Reconciliation Act (COBRA)** – This law gives workers and their families the right to continue group health benefits for a limited time, usually 18 months, after the loss of employment, reduced work hours, or other life events. For more information, go to the Department of Labor's web site: <http://www.dol.gov/ebsa/cobra.html>

**The Family Medical Leave Act (FMLA)** – This law provides eligible employees with up to 12 weeks of unpaid, job-protected leave per year beyond whatever sick leave the employer provides. The law also mandates the employer to maintain the individual's group health benefits during the leave. Under the act, a person can take a medical leave if unable to work due to cancer. For more information, go to the Department of Labor's web site: <http://www.dol.gov/whd/fmla/index.html>

**The Health Insurance Portability and Accountability Act (HIPAA)** – This law prohibits discrimination against employees and their dependents enrolled in group health plans based on their health status, provides for coverage under group health plans that limit exclusions for preexisting conditions and allows individuals to enroll in a new plan under certain circumstances. For more information, go to the Department of Labor’s web site: <http://www.hhs.gov/ocr/privacy/hipaa/understanding/index.html>

**The Patient Safety and Quality Improvement Act of 2005** – This act establishes a voluntary reporting system designed to enhance the data available to assess and resolve patient safety and health care quality issues. To encourage the reporting and analysis of medical errors, the PSQIA provides Federal privilege and confidentiality protections for patient safety information, called patient safety work product. PSQIA authorizes HHS to impose civil penalties for violations of patient safety confidentiality. PSQIA also authorizes the Agency for Healthcare Research and Quality to list patient safety organizations known as PSO’S. For more information go to: <http://www.hhs.gov/ocr/privacy/psa/regulation/index.html>

**The Recovery Act** while primarily dealing with economic stimulus programs also provides \$1 billion for prevention and wellness to improve America’s health and help to reduce health care costs; \$1.1 billion for research to give doctors tools to make the best treatment decisions for their patients by providing objective information on the relative benefits of treatments; and \$500 million for health workforce to help train the next generation of doctors and nurses. For additional information go to : [www.recovery.gov/](http://www.recovery.gov/)

**In all cases, if you have difficulty finding information using the web sites, type in the name of the law in the search box.**

**We also encourage all patients/survivors/caregivers to contact their United States Senators and Representatives. These public figures wield great power and often times a phone call from a national elected official will help in getting through the bureaucratic red tape that accompanies federal legislation.**

## Assistance with Medical Costs

Cancer is an insidious disease that can come and go and play hide and seek in the body. Its detection and treatment can impose severe financial burdens on the patients and their families. Many Americans have insurance, but too many do not have adequate insurance or lack any insurance. Very often the cost of treatment comes up in Support Group discussions. Resources are available for the individuals/families needing assistance. We have provided some information for Support Group Leaders or state leaders to share whenever possible. We also encourage cancer patients and their families discuss their financial concerns with their physician(s), medical social workers, or the business offices of their hospital or clinic.

### **Government Programs**

Most people are familiar with **Medicaid** and **Medicare**. These are government programs developed for people who need financial assistance for medical expenses. For specific information about **Medicaid** and what it covers go to:

<http://www.cms.hhs.gov/home/medicaid.asp>

1-877-267-2323

For additional information about **Medicare** go to:

<http://www.medicare.gov>

1-800-633-4227 (1-800-MEDICARE)

**GovBenefits.gov** is the official web site of the United States Government. It has information on over 1,000 benefit and assistance programs. The web site features diverse benefits such as disability and financial assistance, insurance, health care and living assistance. For additional information go to:

<http://www.govbenefits.gov>

1-800-333-4636

**HealthResources and Services Administration (HRSA)** manages **the Bureau of Primary Health Care** which offers Health Centers that provide health care to low-income and other vulnerable populations without regard to their ability to pay. The Bureau also provides primary and preventive health care as well as transportation and translation services. To learn more go to:

<http://www.hrsa.gov/>

The **Social Security Administration (SSA)** oversees programs that provide monthly income for eligible retired persons, surviving spouses, family members and the disabled. In addition to basic Social Security the SSA administers **Supplemental Social Security** which provides payments for aged, blind, and disabled persons with little or no income. Another SSA program is the **SSA Compassionate Allowance Program** that allows the SSA to target the most disabled individuals based on medical information. For further information about any of these government programs go to:

<http://www.ssa.gov/>

1-800-772-1213

<http://www.ssa.gov/ssi>

<http://www.socialsecurity.gov/compassionateallowances>

The **Veterans Administration (VHA) Cancer Program** provides for easy access to cancer prevention, detection, and treatment services to eligible veterans and their dependants. Treatment for a service-connected condition is provided and treatment for non-service conditions may be available based on the veteran's financial need. The VHA Cancer Program web site offers links to cancer facts; information about care, a list of VHA designated comprehensive cancer centers and the VA's national cancer strategy. For more information go to:  
<http://www1.va.gov/cancer>  
1-877-222-8387 (health care benefits)

### **Non-Government Programs**

**The American Cancer Society (ACS)** offers programs to help cancer patients, family members and friends cope with treatment decision and emotional challenges. For further information go to "My Local ACS Office" link at:  
<http://www.cancer.org>  
1-800227-2345

**CancerCare** is a national non-profit that offers free support, information, financial assistance and practical help to people with cancer and their loved ones. Financial assistance in the form of limited grants for certain treatment expenses are available. Additionally limited grants are provided for home care, childcare, and transportation for individuals in active cancer treatment. For further information go to:  
<http://www.cancercare.org>  
1-800-813-4673

The **CancerCare Co-Payment Assistance Foundation** is affiliated with CancerCare. This Foundation provides assistance for patients who have prescribed chemotherapy but are unable to afford the out of pocket costs or expenses required by their insurer or Medicaid.  
Web site; <http://cancercarecopay.org>  
1-866-552-6729

**Cancer Information Network** is an organization that provides legal counseling and referrals to cancer patients and survivors concerning managed care, insurance, financial issues, job discrimination, and debt crisis matters. For further information go to:  
<http://www.thecancer.info>

**The Health Insurance Assistance Service** aids cancer patients who have lost or are in danger of losing their health care coverage. This program can be accessed via the American Cancer Society.

**Families USA Program Locator** assists families who are having difficulty getting needed health insurance benefits. For more information go to:  
<http://familiesusa.org>  
1-202-628-3030

The **LIVESTRONG SurvivorCare** is a partnership of several groups that provide financial assistance to cancer survivors who are 6 months post-treatment with no evidence of disease. Survivors receive limited assistance for transportation to follow-up appointments, for medical co-pays, cancer-related medications, and neurological evaluations. For additional information go to:

<http://www.livestrong.org/survivorcare>

I-866-236-7205

**NeedyMeds** is a web-based information resource for individuals who need help paying for health care. NeedyMeds does not provide medications or financial assistance but helps people find programs that do provide these services. NeedyMeds also provides resource information about other assistance programs that offer discount drug cards, disease based assistance and free or low cost clinics. For information go to:

<http://www.needymeds.org/>

**Patient Assistance Programs** are provided by some pharmaceutical manufacturers to help pay for medications. For more information go directly to the drug manufacturer's web site and search the "patient assistance programs." You can also visit [www.curetoday.com/assistance\\_programs](http://www.curetoday.com/assistance_programs) to find a large number of pharmaceutical assistance programs.

**Partnership for Prescription Assistance** has information about more than 475 public and private patient assistance programs including more than 150 offered by pharmaceutical companies. For further information go to:

<http://www.PPARx.org>

1-888-477-2669

The **Patient Advocate Foundation (PAF)** provides education, legal counseling and referrals to cancer patients and survivors concerning managed care, insurance, financial issues, job discrimination, and debt crisis matters. For additional information go to:

<http://www.patientadvocate.org>

1-800-532-5274

The **Co-Pay Relief Program** of the PAF provides limited payment assistance for medicine to insured patients who financially and medically qualify. For further information go to:

<http://www.copays.org>

1-866-512-3861

**RX Outreach – Volunteers in Health Care** provides access to generic drugs for low-income individuals. They can be reached at 1-877-844-8442.

**Together RX Access** provides a free prescription drug card based on financial need to over 250 medications. For information call 1-800444-4106.

### **Other sources of Financial Relief**

Some non-profit community hospitals are able to provide care for patients in financial need. Some hospitals have indigent or charity care programs. For information about these programs contact a hospital social worker. State and local social service agencies are sometime able to provide help with food, housing, prescription drugs, transportation, and other medical expenses for those who do not qualify for other programs. Further information can be obtained by contacting the local or state social service agency. Another avenue to pursue for aid is the various community volunteer agencies and service organizations. This group includes the United Way of America, Salvation Army, Lutheran Social Services, Jewish Social Services, and Catholic Charities. These organizations can be found listed in the telephone directory.

## **Assistance with Transportation to Distant Treatment**

In addition to the cost associated with the treatment of prostate cancer or any cancer is the cost of transportation to receive treatment. For most patients the treatments are provided locally. Many others who must travel great distances to receive treatment necessary for their survival find the cost of travel prohibitive. Many organizations have developed programs to provide assistance for the needed cancer treatments. The Education and Best Practices Committee has compiled the following list of such aid. While not inclusive we feel that patients who need travel assistance can benefit from this list.

**AA&MDSIF Patient Travel Fund** is a fund that provides up to \$500 per family for travel expenses to clinical trials. For more information call 1-800-747-2820.

**Air Care Alliance** links patients with various free flight programs. Call 1-888-260-9707 for further information.

**AirLifeLine** has provides individuals with access to healthcare through a network of over 1,500 volunteer pilots. For additional information go to:  
<http://airlifeline.org>  
1-800-446-1231

**Angel Flight America** provides patients and their families with free transportation to medical treatment in small private airplanes. This outreach is in all 50 states. Call 1-800-446-1231 for more information.

**Angel Flights for Veterans** provides free or greatly reduced rate long distance transportation to medical treatment for patients who need to travel to distant locations for specialized evaluation, diagnosis, or treatment. Angel Flight Veterans services veterans and active duty military personnel and their families. For more information go to:  
<http://angelflightvets.org>

**Corporate Angel Network** arranges for travel for cancer patients to treatment centers using empty seats on corporate jets. Eligibility is open to all cancer patients who are ambulatory and not in need of medical support while traveling. For more information go to:  
<http://corpangelnetwork.org>  
1-866-328-1313

**Hospice Angel Network** is a charity that provides no-cost or reduced-rate patient travel services for financially-needy senior citizens and hospice patients and their families. For more information go to:  
<http://hospiceangelflight.org>

**Mercy Medical Airlift (MMA)** is dedicated to serving people in situations of compelling human need through the provision of charitable air transportation. For more information call 1-888-675-1405.

**National Patient Travel Center** provides information about long-distance medical air transportation through charities. For further information call 1-800-296-1217.

**National Patient Travel Hotline** provides information about charitable, long-distant medical air transportation and provides referrals to all appropriate sources of help available in the national charitable medical air network. To find out more go to:  
<http://www.patienttravel.org/>  
1-800-296-1217

**Volunteer Pilots Association (VPA)** provides air transportation to needy people who must travel to obtain medical treatment. Patients must be able to enter and exit the aircraft with minimal assistance and do not require medical attention during the flight. For more information go to:  
<http://volunteerpilots.org>  
1-412-221-1374



## **Lodging Information for Cancer Patients**

There are many times when a cancer patient must travel great distances to reach the needed treatments. The patient and family members have to cover the cost of transportation to the distant location but they must pay for lodging for the duration of the treatments. Many organizations now provide free or reduced cost lodging. We have provided information about a few such organizations.

The **National Association of Hospital Hospitality Houses, Inc.** is a non-profit organization that provides lodging and support for families and their loved ones far from home. The NAHHH members offer inexpensive accommodations (free, \$5 - \$15) during hospitalizations and repeated visits. A directory of NAHHH member/houses is updated regularly and published annually. For more information go to:

<http://www.nahhh.org>

800-542-9730

**Joe's House** is an on-line nation wide lodging resource for cancer patients and their families who must travel away from home to receive medical treatment. The website lists cancer treatment centers and nearby lodging facilities. Hotel partners include: Best Western International, Holiday Inn, Holiday Inn Select & Express, Crowne Plaza, Candlewood Suites, Hotel Indigo, Staybridge Suites, Extended Stay Hotel, Extended Stay Deluxe, Homestead Studio Suites, Crossland Suites, StudioPlus Deluxe Studio, Drury Inn, Drury Suites, Drury Plaza Hotel, Pear Tree Inn, Hyatt Place Hotels, and Red Roof Inns. For locations nearest your treatment go to:

[http:// www.joeshouse.org](http://www.joeshouse.org)

**Fisher House** provides free accommodations for military families. There is at least one Fisher House at every major military and VA medical center. For further information go to:

<http://www.fisherhouse.org>

888-294-8560.

**Hope Lodge** is a temporary housing program supported by the American Cancer Society. It provides free accommodations for cancer patients during treatments. For more information about this program go to:

[http:// www.cancerorg/docroot/subsite/hopelodge/index.asp](http://www.cancerorg/docroot/subsite/hopelodge/index.asp)

800-227-2345 (ACS toll free line and ask about Hope House)

Many cancer treatment centers have arrangements with local hotels/inns to provide free or reduced lodging. We encourage the patient and family to inquire about these accommodations.

## Other Best Practices

Many semi-professional and professional sport leagues and teams have partnered in the past with a variety of anti-prostate cancer groups. We have listed some of the previous examples of such collaborations. With the proliferation of sports in America there probably is a team near you. Also, college sport venues offer another opportunity for exposure. Connections with these groups can help to spread the word about early screening to a mass audience. “Sports venues provide outstanding opportunities for visibility because of the multitudes who attend games.....” These are the words of Stephen J. Forman, MD a board member of ThinkCure, a non-profit that raises money for cancer research. Additionally the arts should not be excluded – local and regional theaters abound throughout the nation. Again, collaboration with these groups can help increase awareness for the need of early detection. With creativity and effort any of these types of collaboration can succeed at any level.

### Examples of earlier collaboration

- The Las Vegas Wranglers hosted a Prostate Cancer Awareness Weekend in 2008
- Bat For the Cure is an organization founded by Ed Randall and Tony Lacitignola and works with major league baseball teams – the contact is 877-714-2873
- USC Athletics has teamed with the Los Angeles Dodgers to support “ThinkCure”-a non-profit that raises money for cancer research
- Major League Baseball and the Major League Baseball Players Association have teamed with the Prostate Cancer Foundation for a “Home Run Challenge” on Father’s Day
- Golf Magazine has a partnership with the American urological foundation in a program called “Get On Par With Prostate Cancer”. More information can be found at <http://www.GOLF.com> – go to the link to Urology Health.
- NASCAR, Kyle Petty, and the Prostate Cancer Education Council have a partnership “Stay on Track” for Better Prostate Health. They raise awareness and produce literature.
- LTD Entertainment of Durham, North Carolina this year sponsored the 1<sup>st</sup> Annual Fight Against Prostate Cancer Benefit – the involved dining out and shopping. Participating restaurants and shops donated a portion of the evening proceeds to cancer research. This can be done on the local level, community after community.
- Poet and novelist Benjamin Zephaniah has written a play, “De Botty Business” to inform the African-Caribbean men of their increased risk of developing prostate cancer. The play focuses on one man’s journey as he faces a test for prostate cancer. The play was infused with humor, allowing the subtext to be delivered without alarming the audience or preaching. For more information Google “De Botty Business”

These are but a few of the examples of collaboration/partnerships that can be Formed with groups that are outside the “traditional” prostate cancer community.

In addition to these pairings we suggest that local NASPCC groups join with other similar groups – we all have the same goal of eradicating prostate cancer – we differ on how to get there, but the focus should be on the common goal, not differences. Other groups in the fight against prostate cancer include, but are not limited to:

- Prostate Cancer Foundation
- ZERO: The Project to End Prostate Cancer
- Men’s Health Network
- Malecare
- Prostate Health Education Network
- The Prostate Net
- US TOO

Another “Best Practice” is to follow closely the information that comes from Kathy Meade of Virginia. She has access to a wealth of valuable information.

## **Section F - Leadership Training for Support Group Leaders**

*“The basic building block of good communications is the feeling that every human being is unique and of value.  
unknown*

*“One friend, one person who is truly understanding, who takes the trouble to listen to us as we consider a problem, can change our whole outlook on the world.”  
Dr. E.H. Mayo*

*“Volunteers do not necessarily have the time; they just have the heart.”  
Elizabeth Andrew*

## **Leadership Training**

Leadership training is of vital importance to the success of any support group. Because of the many side effects of prostate cancer treatment and the life and death issues associated with cancer the training of a support group leader/facilitator is of critical importance. Many state coalitions have training programs in place; others use programs developed by the American Cancer Society or other groups. Yet some coalitions do not have training programs in place. To help all coalitions, the Education and Best Practices committee has compiled data from the California Prostate Cancer Coalition and the Maine Coalition to Fight Prostate Cancer. The material presented should not be construed to be the “best”. There is always room for modifications of any training. We present the information from the two coalitions as guides that other coalitions can adopt or adapt to meet the needs of their own consumers.

The Maine Training Program, called the Blue Ribbon Leadership Training was funded by a generous grant from the Maine Cancer Foundation. Because of the funding the training was held over two days. This gave the attendees the opportunity to begin to bond with one another and network for future support of one another. Attendees received a binder of information, a MCFPC coffee mug, a MCFPC blue T-shirt, and numerous other small items donated by the Patrick Dempsey Center for Cancer Hope and Healing.

The California Prostate Cancer Coalition training is an intensive one day program. Participants are grouped in pairs or teams and presented with a series of real, what if situations. The pairs/teams discuss the situations and come to conclusions as to how best to deal with the situations if they arise in the context of a support team meeting.

We have provided the outline of the Maine training and the What If? questions posed to attendees at the California training sessions.

## “Blue Ribbon Leadership” - Training for Prostate Cancer Leadership & Advocacy

Two-Day Trainings Session		
Day/Time	Activity	Tentative Presenter/Facilitator
<b>Saturday – Day 1</b>		
1:00 - 1:30 pm	<b>Arrival and Registration</b>	Distribute binder of materials, agenda for training
<b>Session 1</b> 1:30 - 2:30 pm	<b>Group formation exercise</b> <ul style="list-style-type: none"> <li>• Share backgrounds, “Why I came/why I care?”</li> </ul>	All participants
2:30 - 3:00 pm	<b>Refreshment Break</b>	Get acquainted time
<b>Session 2</b> 3:00 - 4:30 pm	<b>Forming, promoting and marketing a support group</b> <ul style="list-style-type: none"> <li>• Tips, best practices, affiliating with a cancer organization (ACS, Man-2-Man, Us TOO, etc.)</li> </ul>	Included in the handouts
<b>Organized Break</b> 4:30 - 5:30 pm	<b>Time to connect with other participants/partners</b> <ul style="list-style-type: none"> <li>• Relaxation break before dinner</li> </ul>	Sharing thoughts and networking
<b>Dinner</b> 5:30 - 7:00 pm	<b>Dinner with Guest Speaker during dessert</b>	
<b>Session 3</b> 7:00 - 8:00 pm	<b>Program, Program, Program: Keeping Support Groups Fresh with Good Planning and Management</b> <ul style="list-style-type: none"> <li>• Brainstorming session on program ideas for support group meetings; logistics;</li> </ul>	Included in handouts
<b>Session 4</b> 8:00 - 8:30 pm	<b>Getting Personal: Setting Goals for Your Group Leadership or Professional Role</b>	In pairs, completes goal statements for their PCa leadership for the coming year
<b>Overnight Stay</b>	<b>Socialize, Share and Slumber:</b> <ul style="list-style-type: none"> <li>• Individual/group time as desired</li> </ul>	Evening time to get more acquainted with each other, exchange names, addresses, e-mails, phone numbers, relax, and reflect on the day’s events.
<b>Sunday – Day 2</b>		
<b>6:30 a.m. (optional)</b>	<b>Qi Gong /Tai Chi/Yoga</b> <ul style="list-style-type: none"> <li>• Breathing, movement</li> </ul>	

	and meditation to cleanse, strengthen and circulate life energy – useful relaxation techniques	
<b>7:00 – 7:30</b>	<b>Breakfast in the hotel restaurant</b>	
<b>Session 5 7:30 – 8:30</b>	<b>Fellowship</b> <ul style="list-style-type: none"> <li>• Discussion of the role of spirituality in cancer care</li> </ul>	Guest speaker
<b>Session 6 8:30 – 9:15 am</b>	<b>Caring with Your Heart, Listening with Your Soul:</b> <ul style="list-style-type: none"> <li>• Dealing with difficult discussions, palliative care, and grief &amp; loss</li> </ul>	Guest speaker
<b>Session 7 9:15 – 9:45 am</b>	<b>The state group’s Speakers’ Bureau explained and the website as a resource; also NASPCC web site</b>	Board Member
<b>9:45 - 10:00 am</b>	<b>Coffee Break</b>	
<b>Session 8 10:00 – 10:45 am</b>	<b>The Role of Partners and Caregivers</b> <ul style="list-style-type: none"> <li>• Woman’s Panel</li> </ul>	Questions provided in handouts
<b>Session 9 10:45 – 11:30</b>	<b>Staying Connected: A Community of Trained Leaders</b> <ul style="list-style-type: none"> <li>• Protocols for keeping in touch with each other as leaders (web listserv, teleconference, etc.)</li> </ul>	Board Member
<b>Reflection 11:30 - 12:00 pm</b>	<b>Closing thoughts</b> <ul style="list-style-type: none"> <li>• Shared insights, and evaluation of program</li> </ul>	All participants
<b>Departure 12:00 noon</b>	<b>Good Eats and Goodbyes</b> <ul style="list-style-type: none"> <li>• Bag lunch for the road and parting gift</li> </ul>	

## Women's Questions for Leadership

Many groups invite partners to attend their prostate cancer meetings. We feel that women add unique perspective to the meetings. The questions below are ones that we feel should be shared with the groups.

1. Describe your reaction to your partner's diagnosis.
2. What in any, was your role in the decision making process about the treatment your partner received?
3. Do you feel that it was important for you to have input in the decision making process? Why or why not?
4. Did your partner consider your role to be important?
5. Do you think that it is important for you and your partner to attend physician's appointments together?
6. What has been the impact on you personally of your partner's prostate cancer?
7. What has been the impact on your relationship?
8. Do you attend any support team meeting together? What are the positives /negatives of the experience?
9. Do you feel that men and women should meet together? Why or why not?
10. What do you do for your own mental well being?
11. Do you and your partner encourage one another to discuss your intimate feelings?
12. How do you handle the side effects of prostate cancer?

Incontinence

Loss of bowel control

Hot flashes

Mood swings

13. How do you deal with sexual intimacy & impotency?
14. How do you record information about the diagnosis of prostate cancer?
15. What advice would you give to other couples facing prostate cancer?



## WORKSHOP FOR PROSTATE CANCER SUPPORT GROUP FACILITATORS

### HOW DO YOU HANDLE?

The following questions are examples of those posed to perspective and current support group facilitators in California. Prospective Group Facilitators may be asked these questions individually or in small groups and then the combined answers shared with the group for further evaluation and discussion. We thank the California Prostate Cancer Coalition for sharing these insightful questions/concerns with us. The questions can be adapted for use by other groups.

#### Questions which might be asked by new attendees at your support group

1. Which MD should I go to - to have surgery, radiation... etc.?
  - a. If I already have one.
  - b. If I do not have one yet.
  
2. Should I get a second opinion??
  - a. If I have already decided on my treatment.
  - b. If I have not yet decided on my treatment.**
  - c. Should I have my slides reread?
  
3. To whom should I go for second opinion? Same facility OK?
  
4. Is my urologist a good doctor (when there are much better ones)?
  
5. Am I in a good facility (when he is *not*)?
  
6. I'm scheduled for surgery in a few days, what should I do?
  - a. When it is a good choice, albeit not the best.
  - b. When it is nowhere near the best choice
  
7. Here's my data; what do you think I should do?

#### Some procedural situations

8. You have new, uneducated attendee and there are advanced group discussions that include Gleason scores, significance of PSA velocity, stages, etc – what do you the leader do?

9. How to set agendas, deal with time gaps, keep things moving and ensure that each person has a chance to get their questions asked and answered?
10. Medical insurance problems, especially concerning HMOs can you help? If so how?
11. A man who is being pressured by family, friends or MDs to have treatment – what can be done to support this person?
12. Is there really such a thing as a cure – how do you deal with this discussion? Questionable recommendations. e.g., surgery for high Gleason and high PSA, or other controversial local treatments, or alternative/complementary vs. mainstream, etc.?
13. Watchful waiting...active surveillance...when appropriate - when not- something for the group to discuss or should this involve a professional?
14. How should you handle an attendee who dispenses questionable information or opinions without any facts or data?
15. Guest speaker problems - interruptions, incorrect advice, quacks or unsupported opinions, what do you do?
16. How should you deal with wives, significant others, friends, etc. who attend support group meetings and are disruptive.
17. How do you deal with someone who asks the same questions over and over?
18. How do you handle a person/persons who monopolizes meetings?
19. How do you prevent frequent interruptions and digression from the subject or topic?
20. How do you deal with a nervous and upset new man coping with his new diagnosis of prostate cancer?
21. How do you deal with questions relating to the probabilities of morbidity of incontinence, impotence, or other?
22. How do you lead the discussion about laparoscopic and robotic laparoscopic RP?

23. How do you lead the discussion about watchful waiting as a treatment?
24. How do you lead the discussion of sex after treatment?
  - a. When men don't understand the aids that are available?
  - b. When he won't even listen to suggestions for injection therapy?
  - c. When he wants to know if nerve sparing works?

### **Advanced cases of PC**

25. How to lead the discussion about intermittent hormone therapy?
26. How to lead the discussion about hormone resistant PC?
27. How do you relate to and support a man not likely to live more than a few years?
28. How do you get men to volunteer?
29. With quality of life at issue, is it really important to be eating right, exercising and taking certain supplements or is that a lot of hogwash – how do you respond?
30. Tell us of other difficult situations which we haven't addressed yet?

## **Forming, Marketing and Promoting a Support Team/Group**

Many individuals have asked how to begin support groups. The Education and Best Practices Committee has compiled a simple “how to” guide with assistance from the California Prostate Cancer Coalition and the Maine Coalition to Fight Prostate Cancer. The suggestions we have prepared are guidelines and can be adapted/refined for the particular nuances of each individual location.

### **The following are suggestions for starting a support group**

The first step is to get the support of some members of the medical community; the best person to start with is your own primary care physician, urologist or other health care provider.

Let the health care provider know that the group will not dispense medical advice or discuss physicians

Ask the health care provider to tell patients about the group

Ask for help in contacting other health care providers

Locate a suitable meeting spot – suggestions include the local library; school, college, or university conference room; hospital conference room

Locations should be able to provide for privacy, handicap accessibility, sufficient parking space, ample adjustable seating space, and restrooms (remember who we are helping)

Request that the space provider donate light refreshments for the meeting

### **Announcing the formation of the group – begin marketing the group about two months in advance**

Place ads/announcements on community calendars, free local weekly papers, bulletin boards in grocery stores, pharmacies, town buildings, libraries, doctor’s offices, etc

Contact churches and ask for mention in their bulletin

Contact local community organizations such as Kiwanis, Lions, Elks, Rotarians, Masons, and Chambers of Commerce and notify them of the support group

Write a letter to the editor of the local paper

Pay for an ad in the local paper

Use cable, radio and television free public service announcements

Find a sponsor (hospital) that will agree to host, publicize, and provide a light meal as the kick off for the group. This is especially successful if the group leader is employed by the hospital.

*After all of this work, do not be disappointed if there is a low turnout – be persistent and continue to advertise and meet each month. Have the attendees spread information by word mouth. In time the group will grow.*

## **Planning the meetings**

- Always pre-plan the meeting
- Have a firm confirmation of a scheduled speaker and someone who will make introductions
- Plan to have light refreshments – preferably at the beginning of the meeting – people always gather around the refreshment and this is a great way to become acquainted and break the ice
- Be prepared to conduct the meeting even if just a few people show up – they came because they need it
- Have name tags and a marker available
- Have a signup sheet with pertinent information such as name, age, address, phone number, e-mail, etc. Let the group know that the information is *confidential* and will not be shared with anyone or any group
- Use the signup sheet as the start of a data base
- At the end of the meeting assure the group that you hope that they will continue to attend and that information about prostate cancer will be shared at each *confidential* meeting
- During the meeting ask the group for topics of discussion for future meetings
- Use the sign-up sheet information to call or e-mail attendees of the next meeting and suggest that they let others with prostate cancer know about the meeting.

## **Information About Support Group Meetings –these are suggestions only for starting a support group or reinvigorating one.**

### **The Logistics:**

- The location should be handicapped accessible
- There should be male and female bathrooms nearby
- Have refreshments available at the start of the meeting – people tend to gather around the food this serves to break the ice
- Each person should wear a name tag and referred to by name
- A sign-in sheet with name, address, phone number, and e-mail address should be circulated
- Each individual should receive a personal greeting (smile, wave, hug, handshake) from the group facilitator
- New comers should receive a special welcome and introduction to the group
- Seating should be in a circle, U shape, square, or rectangular – members of the group must be able to make eye contact with one another
- Remind all attendees that what is said in meeting is confidential

### **Suggestions for Programs without a Speaker**

Begin with any special announcements such as the speaker for the next meeting; information from groups such as your state coalition to fight prostate cancer, Us TOO; newspaper or TV reports concerning prostate cancer or individuals in the group, etc.

Each individual should be invited to share their story - never start with the new person(s)

Spend time brainstorming program themes such as “The Blessings of Prostate Cancer”

Conduct a “Brag Time” – let members of the group brag about an event that has nothing to do with prostate cancer. Examples would be “my grandchild lost her first tooth” or “look, my cast came off.” Always let the attendees leave feeling pleased.

### **Suggestions for Programs with a Speaker from the Medical Community**

- Radiologist
- Oncologist
- Primary care physician
- Pathologist
- Geneticist
- Nurse navigator
- Urologist
- Surgeons
- Psychologists
- Physical therapist
- Sex therapist
- Nutritionist
- Science person

### **Suggestion for Programs Dealing with Complimentary Therapies**

- Yoga
- Reiki
- Tai Chi
- Qi Gong
- Massage Therapy
- Reflexology
- Acupuncture/Tapping
- Meditation
- Relaxation Responses
- Dealing with stress
- Family/Relationship Counseling
- Hospice Care
- Palliative Care
- Caring for Caregivers

**Other Program Topics**

Librarians – to discuss ordering prostate cancer books

Lawyers

Presentation about advanced directives

Financial Planners – not there to sell plans!

Clergy – perhaps a panel of several denominations

Patients Rights Advocate

How to do journaling

How to create oral histories of the prostate cancer journey

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