



*“Unity is strength... when  
there is teamwork and  
collaboration, wonderful  
things can be achieved”*

*– Mattie Stepanek*

## News

Volume 2, Issue 1  
January 2019

# THE BLUEPRINT

J. Renee Savickas, Editor

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## President's Message

Welcome to 2019's 1<sup>st</sup> Newsletter of the year! Not only is this the first “Blueprint” of 2019, but also, it's the first under the leadership of our new Editor, Board Member and Communications Committee Chair, Renee Savickas!

We are looking forward to special NASPCC activities for this 2018-2019 year! With our new Board and with growing numbers of new state prostate cancer organizational involvement in NASPCC we have an even larger critical mass focused on helping prostate cancer patients and their families. Activities that will continue this year will include Quarterly Coalition Conference Calls on topics important to the state coalitions, such as one such Call on Best Practices and one on Step Therapy. These are in addition to our quarterly national Webinars which are free for attendees, have 100 portals, and are archived on our website, [www.naspcc.org](http://www.naspcc.org). We are excited that **CancerCare** has asked us to once again co-sponsor an ONLINE Prostate Cancer Support Group that is starting up soon. See the Flyer in this Newsletter! Our NASPCC Facebook Page posts articles 2-3 times a week containing updated medical and scientific news we receive even before those articles come out in print. We want everyone to be empowered with information to help in their own informed decision-making. The Newsletter (“The Blueprint”) will be produced and distributed quarterly.

**Step Therapy** is now one of NASPCC's Advocacy & Public Policy Committee's priorities (and a priority for NASPCC). Our Executive Committee Member Tom Kirk and I will be presenting in a plenary session on Step Therapy at the upcoming 2<sup>nd</sup> Annual AUA Advocacy Summit in Washington, D.C. on March 4, 2019. The Invitational Roundtable is part of our Bone Health Access Initiative that NASPCC is promoting and which is supported by Amgen.

NASPCC plans to attend important 2019 national medical meetings, such as **ASCO GU** (February 2019), **AUA** (May 2019) and **ASCO** (June, 2019) and I will continue to represent NASPCC at the **Early Detection Research Network of the NCI**, on the **UCLA Prostate Cancer SPORE**, and as the **Advocate for the Canary/PASS Active Surveillance Study at Stanford**. I will continue to write quarterly articles for **Prostatepedia** as well.

And, of course, NASPCC continues to make our **Informed Decision-Making Laminate** available as both Awareness and an Educational tool on a nationwide basis. We welcome its use and distribution by all state prostate cancer coalitions and organizations across the U.S., since it helps enable men to make informed decisions about their own healthcare and to be able to have informed discussions with their physicians about their options. See <https://naspcc.org/docs/Laminate6-16-17.pdf>.

NASPCC also works with companies and foundations that develop products and tests that benefit patients. For example, this past week Tom Kirk and I represented NASPCC at a **Patient Advisory Council** held by **Dendreon** in Huntington Beach, California. We serve on other Advisory Boards as well in order to provide the prostate cancer patient and family input on research, therapies and quality of life concerns. We are grateful to these sponsors who provide assistance to NASPCC and support and enable us to achieve so much. And of course we are grateful to our patients and their families.

We welcome any ideas, suggestions or offers of assistance to help us with any of our 8 Advisory Committees: Education & Awareness; Budget; Advocacy & Public Policy; Communications; Medical Advisory; State Coalition Development; Fundraising; and Annual Meeting Committee. *Remember that you don't have to be on the Board or even be the official state coalition representative to NASPCC to serve on a Committee.* \*\*

We are looking forward to a productive 2019 – to a productive 15<sup>th</sup> year – our Gala Year!!! We started NASPCC in October 2004 and are planning a Gala to coincide with our 15<sup>th</sup> Annual Meeting in 2019, 15 years later. **PLEASE CALENDAR THE DATES NOW FOR THE 15<sup>TH</sup> GALA ANNUAL MEETING: OCTOBER 11-13, 2019!!!!!!**

Respectfully submitted, Merel Grey Nissenberg, Esq.

Please see the flyer for the **Online Prostate Cancer Support Group** being offered by **CancerCare** and co-sponsored by **NASPCC**. This is an excellent opportunity to have a free clinician-run support group deliver private support group services to people who feel that they could benefit from this resource, and the Support Group runs for 15 weeks. Each person who registers receives a private ID, allowing total anonymity for him to ask questions and seek ideas 24/7. **PLEASE REGISTER AND TAKE ADVANTAGE OF THIS SUPERB OPPORTUNITY!**

## Moving Forward on the Bone Health Access Initiative in 2019

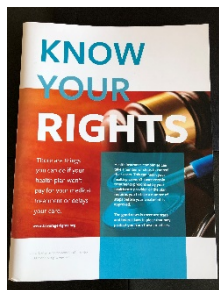
### By Thomas N. Kirk

In the last Blue Print Quarterly Newsletter of November 2018, you may recall the article about the **Bone Health Access Roundtable** we held on October 14<sup>th</sup> in Washington, DC (page 7).

<https://www.naspcc.org/attachments/article/41/NASPCCNewsNov18.pdf>. This was a major step in NASPCC's Bone Health Access Initiative accepted by the Board's Executive Committee in mid-2018.

We had a group of over 20 people at the Roundtable representing experts and researchers such as Samuel Denmeade, MD from Johns Hopkins Sidney Kimmel Comprehensive Cancer Center, Karl Sjostrand, PhD from Progenics Pharmaceuticals, all the NASPCC Officers and many Board Members, NASPCC State Coalition representatives from active states, Patients and Family Members from the Prostate Cancer Support Community and the Breast Cancer and the Lung Cancer Communities as well as Advocates from other organizations active in the Step Therapy movement, such as the Cancer Support Community's Cancer Policy Institute and the Arthritis Foundation.

Our Goal was to: 1) Discuss the landscape of access to coverage for bone therapies, and 2) Plan appropriate action steps because we have become aware of health insurance policy changes regarding bone therapy access that took place in mid-2018 that will have an effect on prostate cancer patients. We developed an Agenda that covered Step Therapy/"Fail First" Policies that affect access to treatments such as Bone Targeting Agents (BTAs) and shared a number of resources including a "Know Your Rights" brochure created by the Aimed Alliance. <https://aimedalliance.org/wp-content/uploads/2018/08/Know-Your-Rights-Brochure-for-Individuals-with-Cancer.pdf>



We also shared at the meeting other resources from the Epilepsy Foundation on Step Therapy <http://advocacy.epilepsy.com/StepTherapy> and from the Arthritis Foundation <https://www.arthritis.org/Documents/Sections/Advocate/Step-Therapy-Green.pdf> and other advocacy organizations to bring us up to speed on this issue, such as the Crohn's & Colitis Foundation <http://www.crohnscolitisfoundation.org/steptherapy/state-content/infographic1.pdf>

You may also recall that Don Lynam, Chair of NASPCC's Advocacy & Public Policy Committee agreed that Step Therapy will be a top priority for our organization as we move forward. Following the Roundtable, we have joined the Aimed Alliance Coalition <https://aimedalliance.org/step-therapy/> and the Part B Access for Seniors and Physicians Coalition (ASP) working to address Step Therapy issues at the State and Federal level, and we have signed on to letters written to Federal Officials on proposed changes in Medicare by CMS on Drug Pricing. <http://partbaccess.org/wp-content/uploads/2017/06/12.10.18-ASP-Coalition-letter.pdf>

*There is much work to do and part of the **Bone Health Access Initiative** agenda calls for learning what State Prostate Cancer Coalitions are hearing about access challenges, particularly about regarding access to BTAs such as **Xgeva** and **Zometa**. We also need information and stories from patients and family members about their understanding of "value" in bone health treatments. Please let either Tom Kirk or Merel Nissenberg know of any information you have or discussions you would like to have about these issues by emailing us at: [tomkirk\\_99@yahoo.com](mailto:tomkirk_99@yahoo.com) or [mgrey@ucd.edu](mailto:mgrey@ucd.edu).*

## Important Activities Upcoming...

NASPCC will continue to participate in several important Medical Meetings most of which are held yearly, starting with the **ASCO GU** (GenitoUrinary Malignancies) **Meeting** scheduled for **February 14-16, 2019** in San Francisco. We plan to also attend the **2019 AUA Meeting** (American Urological Association) in May 2019 in Chicago and the **2019 ASCO Meeting** (American Society of Clinical Oncology) in June 2019 in Chicago as well. Of course this does not include NASPCC's invitation to present at a **Plenary Session of the 2<sup>nd</sup> Annual AUA Advocacy Summit** taking place March 4-6 in Washington, D.C. (on the important topic of Step Therapy) nor does it include President Merel Grey-Nissenberg's continued participation in the **NCI's Early Detection Research Network (EDRN)**, in the **UCLA Prostate Cancer SPORE** (NCI's Specialized Programs of Research Excellence) or as the **Advocate for the Canary/PASS Trial** on Active Surveillance being conducted through Stanford University.

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### THE SECOND ANNUAL UROLOGY ADVOCACY SUMMIT TO BE HELD MARCH 4-6, 2019 WASHINGTON, D.C.

NASPCC is excited to announce that the **AUA (American Urological Association)** will be holding a Second Annual Urology Advocacy Summit in **Washington, D.C.** from **March 4-6, 2019** and that NASPCC has been asked to participate in a Plenary Session. (NASPCC President Merel Nissenberg presented on Informed Decision-Making last year at their first ever such Summit.) This year NASPCC will be part of a session on Regulatory Burdens and we will be speaking on Step Therapy, a new Priority for NASPCC since we adopted it as such after the Invitational Roundtable on Step Therapy that we held on October 14, 2018 in Washington, D.C. following our 14<sup>th</sup> Annual Meeting.

The Advocacy Summit gathers together stakeholders from the medical, patient and research communities, and, according to the AUA website, "The conference will host speakers ranging from urologists to patients, to government employees and members of Congress..." Further, participants will be able to meet with lawmakers and their staffs. The keynote speaker is Bob Woodard, who needs no introduction. Lawmakers and other government officials are also expected to attend the Summit. Please visit the AUA website, [www.aua.org](http://www.aua.org) in order to learn more about the Summit and to register. **Patients and patient advocates are not only welcome but needed; let's use our critical mass to let Summit attendees and those in Congress know what really matters to patients**

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## Save the Date

The California Prostate Cancer Coalition (**CPCC**), “a Proud Participant in the National Alliance of State Prostate Cancer Coalitions”, is planning a *Statewide and Beyond* Conference in San Francisco in conjunction with **UCSF** (University of California, San Francisco – home of Eric Small, Matt Cooperberg, Peter Carroll, and Felix Feng, among others) currently titled “**1<sup>st</sup> Annual Conference on Informed Decision-Making in Prostate Cancer**”. The date we want you to save is **Saturday, June 8, 2019!** Many more details, including schedule, hotel, registration and the like will be forthcoming next month!



**SAVE THE DATE**  
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**SAVE THE DATE**

**UCSF** Helen Diller Family  
Comprehensive  
Cancer Center

The California Prostate Cancer Coalition (CPCC) and  
The UCSF Helen Diller Family Comprehensive Cancer Center Present

**THE 2019 PATIENT CONFERENCE ON PROSTATE CANCER:**  
**“USING CURRENT AND CUTTING-EDGE INFORMATION  
TO HELP MAKE INFORMED DECISIONS”**

**June 8, 2019    8:00 a.m. to 5:00 p.m.**  
Lunch Included • Limited Seating • At UCSF

For Patients, Families, Caregivers, Health Care Providers and  
all those interested in information and tools  
to make informed decisions in prostate cancer.

**FEATURING AN OUTSTANDING PANEL OF EXPERTS**

For Information, e-mail: [vegstan2@ix.netcom.com](mailto:vegstan2@ix.netcom.com) or [mgrey@ucsd.edu](mailto:mgrey@ucsd.edu).

The following information was provided by, LaTanya Patton, MO

# Save the Date!

## PCORI Metastatic Key Stakeholder Webinar Series

The **goals** of this FREE webinar series are to:

- 1) engage key stakeholders in cancer metastasis; and
- 2) advance patient-centered metastasis research

**December 5, 2018**

**11a.m. – Noon CDT**

Palliative care,  
goals of care and  
symptom  
management

**January 16, 2019**

**11a.m. – Noon CDT**

Access disparities in  
cancer and cancer  
research

**February 12, 2019**

**Noon – 1p.m. CDT**

Metastatic prostate  
cancer research  
priorities

**March 13, 2019**

**Noon – 1p.m. CDT**

Challenges in clinical  
trials and tissue  
collection in  
metastatic cancer

Information about **registration** and webinar objectives to come.

Target audience: Patients, families, clinicians and researchers

THE UNIVERSITY OF KANSAS  
CANCER CENTER



MRS METASTASIS  
RESEARCH SOCIETY



This webinar series is funded in part through a Eugene Washington PCORI Engagement Award (6102-MRS).

# PCORI Metastatic Cancer Webinar Series

## Webinar 3: Metastatic Prostate Cancer Research Priorities

**Target Audience:**  
Patients, Families,  
Clinicians, &  
Researchers

**February 12, 2019: 12N – 1pm CDT**

### Webinar Topics

- ❖ Perspectives from a family member
- ❖ Androgen deprivation therapy symptom management & quality of life
- ❖ Hormone resistance cancer therapies and translational research
- ❖ Bone metastasis research priorities

**Register** in advance for this FREE webinar:

<http://bit.ly/MetProstateCancerMRS>

After registering, you will receive a confirmation email containing information about joining the webinar.



**Leah Cook, PhD**  
Assistant Professor  
University of Nebraska Medical Center  
College of Medicine  
Fred & Pamela Buffett Cancer Center



**Broderick Crawford, BS**  
Executive Director  
NBC Community  
Development Corporation

**Sally Maliski, PhD, RN, FAAN**  
Dean & Professor  
University of Kansas  
School of Nursing  
University of Kansas Cancer Center



**Benjamin Teply, MD**  
Assistant Professor  
University of Nebraska Medical Center  
College of Medicine  
Fred & Pamela Buffett Cancer Center



# PCORI Metastatic Cancer Webinar Series

## Webinar 4: Challenges in Clinical Trials and Tissue Collection in Metastatic Cancer

**Target Audience:**  
Patients, Families,  
Clinicians, &  
Researchers

**March 13, 2019: 12N – 1pm CDT**

### Webinar Topics

- ❖ Clinical trials for patients with metastasis
- ❖ Barriers to accessing clinical trials
- ❖ Tissue collection in metastatic cancer research



**Cheryl Jernigan, CPA, FACHE**  
Member, Central Institutional Review  
Board for Late Phase Adult Clinical Trials  
National Cancer Institute



**Kim Kimminau, PhD**  
Associate Director, Frontiers:  
University of Kansas Clinical and  
Translational Science Institute

**Connie Rufenbarger**  
Co-Founder, Susan G.  
Komen for the Cure  
Tissue Bank, Indiana  
University Simon Cancer Center



**Scott Weir, PharmD, PhD**  
Director, Institute for  
Advancing Medical  
Innovation, University of  
Kansas School of Medicine



**Register** in advance for this FREE webinar:

<http://bit.ly/MetClinicalTrialsMRS>

After registering, you will receive a confirmation email containing information about joining the webinar.

## In the SPOTLIGHT

*In each quarterly issue of the "Blueprint", NASPCC is proud to feature a section dedicated to a very special state coalition to acknowledge the wonderful services they provide in their state. This quarter we are honored to shine the SPOTLIGHT on:*

### **The Minnesota Prostate Cancer Coalition**

**Minnesota Prostate Cancer Coalition was formed in 2011 by prostate cancer survivors, whose mission is to enlighten, educate, support and advocate for MN men, and their caregivers as they face the prospects of diagnosis and treatment of Prostate Cancer.**

MnPCC is, grass roots, boots-on-the-ground Organization serving Minnesota.

It is very important to note that all of our Volunteers are living with prostate cancer themselves either as patients or caregivers. This gives us the authenticity and credibility to "walk the walk and talk the talk." We know of what we speak because every day of our lives, we face the fact that we have Cancer. Even when the Cancer may be in some form of "non-expression", all of us men know that we are just one PSA test away from a reoccurrence or the worsening of our condition. Hence we know the emotional pain, fear and uncertainty that accompany a diagnosis of Cancer. Our empathy for our fellow Minnesotans with prostate cancer is real and palpable.

We educate, support and advocate for our constituency by leading two prostate cancer support groups: one at the University of Minnesota and the other at North Memorial Hospital in Robbinsdale, Mn. These two groups put us into direct contact with over 50-75 prostate cancer men and their loved ones every month.

We continue on with our goal of developing a Prostate Cancer Coaching Service for our community. One of our Board members is certified as a life-coach, having trained at the Mayo Clinic in Rochester. In the future we are hoping to have a permanent, formal space to meet with our men and their caregivers. Our Coach is also a person living with an aggressive form of PCa and his story and experience are very helpful to guide his assistance to others. We participate in Corporate Wellness Programs and offer information, guidance, support and contacts.

***Please see the following images for a glance at what they are up to in Minnesota!***



**11/24/2018 Minneapolis, MN Moustache Run START with 2,000**



**Check Out Those Moustaches!!**





WE WANT YOU –“10 MINUTES FOR YOUR HEALTH” and 171 were tested!





**PCEC-Renee/Dennis and MN Oncology's Phlebotomy Team**



**IT'S PARTY TIME!!**







**MN Prostate Cancer Coalition (mnpcc.org) 2018 Accomplishments:**

- Steve Roecklein lead 2 support groups (University of MN and North Memorial Health)
- MNPCC outings included: **Konawerks 7<sup>th</sup> annual Motorcycle show**, **MN Wild Hockey Fights Cancer**, **7<sup>th</sup> annual Moustache Run** and **MN Twins Cancer Awareness night**
- Dave helped organize 09/05 **Mayo Clinic “Living Well with Prostate Cancer” Patient Education Symposium** with 7 doctor presenters and 95 attendees
- Dave worked one on one with 15 different patients utilizing his **Mayo Clinic Certified Wellness Coach** credentials and extensive advanced prostate cancer experience
- Dave spent an afternoon with Bev Eckert, Executive Director and Cara Clements, their Patient Navigator at **AR Prostate Cancer Foundation** offices in Little Rock, AR
- Dave, Renee Savickas (PCEC) and MN Oncology held men’s health screening events on 03/24-**Rare Beer Festival** (54 men) and 11/24 **Minneapolis Moustache Run** (171 men)
- Dave attended **Prostate Cancer Research Institute** Los Angeles meeting with 800+ prostate cancer patients to create customized coaching programs for low, intermediate and high-risk/recurrence patients using their 2018 *“The Key to Prostate Cancer”* book.




### FREE PROFESSIONAL SUPPORT SERVICES

CancerCare helps individuals, families, caregivers and the bereaved cope with the emotional and practical challenges of cancer. Our services include counseling, support groups, educational workshops, publications and financial assistance. All of our services are provided by professional oncology social workers and are offered completely free of charge. To learn more, visit [www.cancercare.org](http://www.cancercare.org).

### CONNECT WITH US

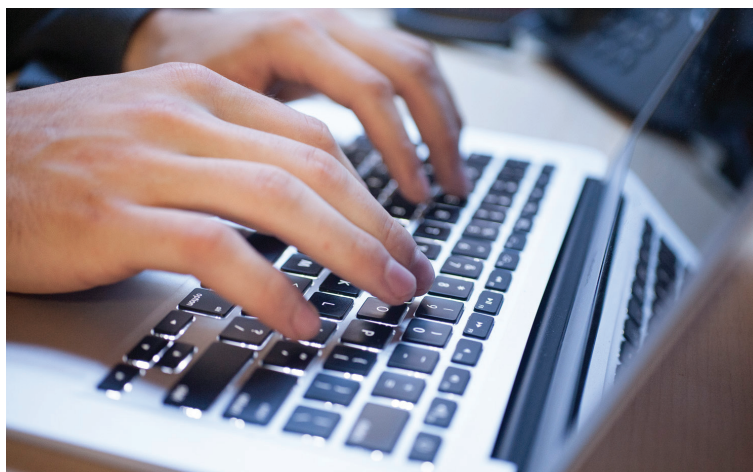
 **FACEBOOK**  
[www.facebook.com/cancercare](http://www.facebook.com/cancercare)

 **BLOG**  
[www.cancercare.org/blog](http://www.cancercare.org/blog)

 **YOUTUBE**  
[www.youtube.com/cancercareinc](http://www.youtube.com/cancercareinc)

 **TWITTER**  
[@cancercare](https://twitter.com/cancercare)

**CancerCare® National Office**  
275 Seventh Avenue  
New York, NY 10001  
800-813-HOPE (4673)



## Prostate Cancer Online Support Group

**CancerCare and the National Alliance of State Prostate Cancer Coalitions (NASPCC) are offering a free 15-week online support group for men diagnosed with prostate cancer.**

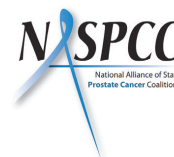
**This online group provides a safe, confidential space where men can discuss the unique challenges of living with prostate cancer, while giving and receiving support, information and guidance. This online support group will not offer medical advice and there will be no medical professional leading the group.**

### MODERATOR

Andrew Chelser, MSW, LCSW  
Men's Cancers Program Coordinator, CancerCare

### TO JOIN THIS SUPPORT GROUP, PLEASE VISIT

[www.cancercare.org/support\\_groups/126](http://www.cancercare.org/support_groups/126) to complete our online registration process. Internet access is required.



# About NASPCC and Mission Statement

National Alliance of State Prostate Cancer Coalitions (NASPCC) is a nation-wide organization comprised of state coalitions dedicated to saving men's lives and enhancing the quality of life of prostate cancer patients and their families, through awareness and education and the development of a public policy network.

## State Coalitions

The following states have participated in NASPCC:

- Alaska
- Arizona
- Arkansas
- California
- Colorado
- Connecticut
- Delaware
- District of Columbia
- Florida
- Georgia
- Hawaii
- Indiana
- Kansas
- Kentucky
- Maine
- Maryland
- Massachusetts
- Michigan
- Minnesota
- Missouri
- Nebraska
- Nevada
- New Hampshire
- New Jersey
- New Mexico
- New York
- North Carolina
- Ohio
- Oregon
- Pennsylvania
- Rhode Island
- South Carolina
- Tennessee
- Utah
- Tennessee
- Utah
- Virginia
- Washington
- West Virginia
- Wyoming

## Educational Tools

Having a prostate cancer related event in your community? Just ask! We will be happy to ship some Informed Decision-Making Laminates and or Brochures.

## The Laminate

Prostate Cancer: Informed Decision-Making for Men over 40 and Primary Care Physicians.

This is NASPCC's excellent awareness and educational tool for INFORMED DISCUSSIONS between men and their physicians. NASPCC also has brochures as well.

We will send these to you for distribution at **NO COST** and they are a reminder that your state is a proud participant in NASPCC!

## Next State Coalition Quarterly Call will be:

February 21, 2019 @ 4pm MST

Topic: Best Practices

Dial-In: 1-218-339-7800

Access 9381332#





## 2018-2019 Board of Directors

The 2018-2019 Board of Directors of the National Alliance of State Prostate Cancer Coalitions

President: Merel Grey-Nissenberg (CA)

Vice President: Johnny Payne (SC)

Treasurer: Donald Lynam (KY)

Secretary: Jan Marfyak (NM)

**Board Members:** Mary Anderson (NC), Ira Baxter (TN), Alvin Chin (VA), Judy Green (MA), Dave Hulbert (MN), Sanford Jeames (TX), Paul Kradel (WV), LaTanya Patton (MO), Harold Pharoah (NE), Renee Savickas (CO), Otto Sankey (AZ), James West (FL) and Michael Zaragoza, M.D. (DE). Tom Kirk (CA) is an invited Member of the Executive Committee and is also the Chair of the Steering Committee. LaTanya Patton is the Director-at-Large and serves on the Executive Committee.

## Advisory Board

*Christopher J. Logothetis, M.D.*  
University of Texas MD Anderson Cancer Center

*William G. Nelson, M.D., Ph.D.*  
Sidney Kimmel Comprehensive Cancer Center at The Johns Hopkins Hospital

*Alan W. Partin, M.D., Ph.D.* Brady Urological Institute  
at The Johns Hopkins Hospital

*Kenneth J. Pienta, M.D.*  
The Johns Hopkins Hospital

*Mack Roach III, M.D., F.A.C.R.*  
University of California San Francisco Helen Diller  
Comprehensive Cancer Center

*Peter T. Scardino, M.D.*  
Memorial Sloan-Kettering Cancer Center

*Paul F. Schellhammer, M.D.*  
The Virginia Prostate Center, Eastern Virginia  
Medical School

*Ian M. Thompson, M.D.*  
University of Texas at San Antonio

*Leonard G. Gomella, M.D., F.A.C.S.*  
Thomas Jefferson University Hospital  
Kimmel Cancer Center