

NASPCC Quarterly State Coalition Conference Call Summary
April 30, 2018

Roll Call:

Participants	State
Merel Grey Nissenberg	California
Beverlyn Eckert	Arkansas
Tom Kirk	California
Johnny Payne	South Carolina
Ira Baxter	Tennessee
Broderick Crawford	Missouri
Don Lynam	Kentucky
Mary Anderson	North Carolina
LaTanya Patton	Missouri

Welcome – Merel welcomed everyone and thanked them for participating on the call. Merel provided an update on NASPCC activities. The third webinar series will be held on May 9th on “Genetic Testing & Genetic Counseling in Prostate Cancer” and will be presented by Leonard Gomella, MD. She asked that members be sure to register and participate on the webinar. Merel shared that she was a panelist (Informed Decision-Making) at the March 12-14, 2018 AUA Advocacy meeting in DC. Also, she has also submitted the next Prostatepedia article on Genomic Testing for review. She shared that a follow-up webpage project is being discussed on patient resources. CancerCare selected NASPCC to work jointly on offering their upcoming Prostate Cancer on-line support group. The announcement for the CancerCare On-line Prostate cancer Support was made on the 17th of March. Information will be sent to the state coalitions and stakeholders.

Housekeeping - LaTanya reminded the participants to speak one at a time and to practice phone etiquette and mute the phone when not speaking to eliminate back ground noises.

Discussion – LaTanya introduced the subject and the format for the discussion and the agenda. Speakers – Johnny Payne, Ira Baxter and Tom Kirk. Jan Marfyak representing New Mexico was unable to participate. The Speakers were asked to share best practices, challenges, etc, for their respective coalitions.

Johnny Payne

Johnny shared that the South Carolina coalition has had success with attendance at events and activities.

- They focus on educating the community and raising awareness of the journey of a man with prostate cancer and the impact that it has on the family.
- Johnny spoke about the benefit and importance of leveraging the partnership between the coalition and the US Too Chapter in his state.
- Facebook is utilize to publicize events; members and supporters receive an electronic newsletter.

Tom Kirk

Tom shared three ideas or points:

- First, that as an introduction he has been around the prostate cancer world for a long period as President & CEO of Us TOO for almost 12 years, and other time as well in the voluntary world, such as at the National Alzheimer's Association (that has a network of support groups at the national level) for about the same length of time, and in Wisconsin working in a community agency also for about the same

length of time. Within his time with the NASPCC he has been volunteering as the VP of the CPCC for about a year and helped the NASPCC with the new Strategic Plan and continue to volunteer as a Member of the Executive committee and a number of NASPCC committees. The Strategic Plan and new NASPCC Mission Statement is on my Power Point from the Annual Meeting at <https://www.naspcc.org/attachments/article/38/NASPCC-WorkplanPresentation.pptx>

- His second point was that he moderated the "Meet the States" panel session we did at the 2017 Annual meeting and that the Power Point is on the Alliance website at <https://www.naspcc.org/attachments/article/38/MEET-THE-STATES-Summary.ppt>. The panel had Merel from CPCC, Bev from AR PC Foundation, Johnny from SC, Jan from NMPC Association, and Frank from GAPCC (who has since left and been replaced). He then mentioned some of the Best Practices he has seen at the CPCC, like monthly Board conference calls in a large state, recent new Newsletters focused on CA, involvement of the State cancer plan with CDOC, involvement of volunteers in their areas of interest like Bill Doss and Prostate Cancer Proclamations for September over the years, Stan conducting both a Northern and Southern Support Group Annual Leader's Training Workshops, new CPCC brochures that contained the phrase "A Proud Participant in the National Alliance of State Prostate Cancer Coalitions" and an Annual Report featuring Board Members' involvement in CPCC accomplishments. Many of this information appears on the CPCC website www.prostatecalif.org. He mentioned the increased posting of news and information through the CPCC Facebook page.
- His third point was to point out that the resource titled "A Guide for Success", created by NASPCC volunteers in 2010 is on the NASPCC website at https://www.naspcc.org/docs/NASPCC_GUIDE_EBPC_rev_4-11.pdf. He pointed out page 8 which describes "Characteristics of Ideal State Prostate Cancer Coalitions" such as: a clear vision and mission statement, developing a budget, collaborations, contacts with local leaders and the media (and as mentioned by Ira, the importance of radio to spread the word and deliver messages). Finally, he mentioned on pages 76 through the end of the Guide, in Section F, is a great series of helpful information of "Leadership Training for Support Group Leaders" which is very useful.

Ira Baxter

Ira shared his thought on the practices of the Prostate Cancer Coalition of Tennessee. He shared the following:

- Recommend reading the "Guide for Success" on the NASPCC website. It is 88 pages of good information.
- Determine your core competencies. We built ours on assisting men and their families that are dealing with prostate cancer through education and support.
- Align your group with an academic institution if possible. We are aligned with the Vanderbilt Medical Center.
- Have a physician on board that is passionate about prostate cancer. We have one of the area's leading urologist as our medical director.
- Use social media. Have a professional looking web page. Create a logo and have business cards.
- Build partnerships. We work with area cancer centers, churches, pharmaceutical companies and area colleges. We do a lot of education through these partners, learn of individuals that need support, increase awareness, and recruit other members.
 - They came involved with Biden Cancer Initiative through our partnership with the Vanderbilt Ingram Cancer Center. Ira was able to meet with the former Vice President at his "Sundae Social" the Vice President started to learn from cancer survivors.
- A regular monthly support group meetings is held at a neutral site with free parking and offer a light snack. We recently starting advertising on the radio and are in the process reprinting flyers for the meetings. Last month we added the ability for men outside of the area to call in and communicate to the group via the phone.

- Regular events on Men's Health Month are held in June and Prostate Cancer Awareness Month in September.
- Stay active and recruit other members.
- They are starting a fund raising initiative.
- Looking to partner on some state health policy initiatives that impact prostate cancer.
- Look for grants.

Suggestions:

- A calendar invitation should be sent to the representatives of the state coalitions as a reminder of future calls (Broderick)
- Utilize the Alliance Guide for Success on the web-site (Tom)
- Like NASPCC on Facebook (Johnny)
- Visit the NASPCC website for information ie. Annual meeting
- Share topics of interest with the Communications Team (LaTanya)
- Electronic Newsletter Blue Print – it was suggested that newsletter list dates, times and subjects for the coalition calls, events, etc., (LaTanya)
- Partnership with Farm Bureau in respective areas (Bev)

Reminders:

- Deadline for the news items for the Blue Print is June 20, 2018 and should be submitted to LaTanya Patton via kcscooda@aol.com.
- Blue Print next edition is due out July 1st.
- The annual meeting will be October 12-14, 2018 in Washington, DC.

Meeting Schedule

The state coalition next call will be July 31, 2018 at 6:00p. The subject for the call is Social Media.

Adjournment

The call was concluded at 7:00p.

Summary prepared by LaTanya Patton

*This call was inadvertently not recorded. Future calls will be recorded.