

American Cancer Society, California Division, Inc.
Northern California Pain Initiative Advisory Council Meeting
January 26, 2007, 10 am to 3 pm
ACS Great Valley Region Office, Sacramento

Meeting Summary Notes

Attendance: Beverly Nicholson, RN, CNS, AOCN (Chair), Dr. Mark Blum (Vice Chair), Kathy Keller, PharmD (Secretary), Judy Citko, JD, Penney Cowan, Vicky Ferraresi, PharmD, Donna Kalauokalani, MD, MPH, Ben Rich, JD, PhD, Daryl Walker May Sung, MPH, Ann Gouré, Alecia Sanchez

By Phone: Annie Borgenicht

Liaisons/Guest: Ronna Popkin (Alliance of State Pain Initiatives), Kathe Kelly (Southern California Cancer Pain Initiative)

Absent: Janet Edrington, RN, MS, CNS, OCN, Thurman Hunt, MD, Bill Marcus, JD, Judi Nurse, Lori Reisner, PharmD, Glenn Yokoyama, PharmD, Marcia Grant, RN, DNSC, FAAN, Cathy Dawson, Steven Rickards

Welcome and Introductions: Beverly Nicholson welcomed everyone and called the meeting to order at 10:15 am. She asked everyone to introduce him/herself. Annie Borgenicht joined the meeting by conference phone.

Acceptance of Conference Call Summary Notes

The November 13th NCPI Advisory Council conference call summary notes were accepted as presented.

New Nationwide American Cancer Society Pain Goal

May Sung provided a handout and shared a PowerPoint presentation that that was created by the American Cancer Society's National Government Relations Department (NGRD). She indicated that NGRD held a pain policy meeting December 6, 2006 that brought together many of the state based pain initiatives with the Alliance of State Pain Initiatives (ASPI) to explore opportunities to build on the great work already taking place in pain management in the states. In November 2006 the National American Cancer Society Board of Directors approved a new Quality of Life Nationwide Objective for pain control geared to improve state pain policy grades across the nation based on the Pain Policy Report Card. The objective is that **by 2015: All 50 states and DC will have received a grade of B or higher; and 10 states will have received a grade of A.** The ultimate goal is for every state to be engaged at some level in the efforts to promote better cancer pain control for patients, survivors and their families and those at the end of life.

California's grade has been and continues to be "C." There is great opportunity in California to collaborate and impact on current pain policy. A **handout** created by Alecia Sanchez, Lobbyist, outlined the ACS legislative activity on pain management since 1997 to present. Beverly indicated that a workgroup on Law and Government

Policy will be established under the leadership of Bill Marcus to address this area of work.

Discussion ensued and the following suggestions for possible pain policy activities emerged:

- Outreach to new Attorney General and the Bureau of Narcotic Enforcement (BNE) to build a working relationship with them. Identify appropriate upper level management from BNE to be a liaison with NCPI and participate in our meetings and conference calls so that we can help build greater understanding of the need for improved pain management from the perspectives of people with pain and health care providers. Daryl Walker volunteered to work with Bill Marcus and others on this.
- Review current format of patient education materials to ensure relevance to patients. Explore different formats in addition to the written format, including, visual and auditory.
- Define what “remove restrictions” means. Remember to change practice in addition to policy.
- Hold pain hearings around the state, like Missouri did – develop questions that could be asked. Involve legislators, patients and providers.
- ASPI provide models from other pain initiatives that might be helpful to NCPI
- Question was asked about what the Medical Board would do now that AB 487, the law that required continuing medical education on pain management, is ended. It was thought that probably there would not be further legislation, but the idea of using a “check box” for providers to indicate whether they have fulfilled the requirement under penalty of perjury, when they are up for their medical license renewal.

Southern California Cancer Pain Initiative (SCCPI)

- Kathe Kelly, the new Executive Director of SCCPI, provided an overview of SCCPI and their activities. SCCPI has hosted professional education courses, such as the *Pain Resource Nurse Training Course*, which is in its 15th year; next one is scheduled for September 6-7, 2007 at City of Hope. *Promoting Excellence in Pain Management & Palliative Care for Social Workers* is in its 2nd year and has been well attended, reaching about 140 in the past; next one is scheduled for August 23-24, 2007. Other activities include: the Education for Physicians for End of Life Care, the Survivorship program, Pocket Card, Newsletter and website and links to resources. They monitor regulatory issues as they can. SCCPI’s membership is 2,500 with steady growth. The Board continues to find ways to fund SCCPI activities on an ongoing basis. It was shared that ACS California Division has provided small grant funding over the past few years for their newsletter and more recently on professional education courses. A small grant request to the California Division is currently being reviewed at this time. Kathe indicated that SCCPI looks forward to a continuous collaboration with NCPI. Check the SCCPI website at <http://sccpi.coh.org/> for more information.

- **Follow-up Action: Mindy Halpern, an Orange Region ACS staff served as liaison to SCCPI and has recently left the Society. SCCPI would like for ACS to identify another representative.**

Review of NCPI Accomplishments and Strategic Plan

Beverly reviewed the accomplishments of the last year and invited the group to provide additional input to the strategic plan. The following are ideas from the group:

Priority Goal #1: Educate and empower people with pain, their families and caregivers, that pain management is an integral aspect of health care and the quality of life, as well as promote societal attitudes and behaviors that support quality pain management.

- Special thanks to Vicky Ferraresi and Chuck Hakkarinen (Vicky's husband) for building the NCPI website.
- Include McMann (sp?) publications in news releases on the report card. Outreach to oncology news.
- **Follow-up: Ann Gouré agreed to help put together a list of publications with interest in pain management.**
- Outreach to organizations and people that we're not currently reaching. Reach out to "healthy TV", such as the recent article in SF Chronicle about Joe Montana and football players with chronic pain.
- Determine target audience for messaging. Use social marketing principles.
- Work with workers compensation or other government agencies to do outreach.
- Look at potential issues about message management, such as the oxycontin issue.
- Look at the Governor's health care reform proposal to tie in a pain policy piece.

Priority Goal #2: Improve the pain management practices of health care providers.

- Find out a way to determine the number of participants on each phone line for the second audio conference on March 14, a project to educate providers on the American Pain Society pain guidelines for adults and children.
- Identify a new California Medical Association (CMA) contact to help promote the second audio conference on March 14.
- Determine if it would be feasible to distribute the recording of the audio conference that was done by iLinc, the audio conference company.
- **Follow-up action: It was suggested to explore securing a grant from Elan Pharmaceutical to fund a project to duplicate and distribute a CD recording of the audio conference, and share Dr. Chris Miaskowski's PowerPoint pending permission from her and/or UCSF.**

Priority Goal #3: Advocate for public policy to promote quality pain management and access to pain management services.

- Suggest connecting with the D.C. Pain Care Forum at the national level – Bill Marcus is on it and ACS is a part of it.

Priority Goal #4: Develop strategic collaborations to promote the mission of the Northern California Pain Initiative.

- Do a regular newsletter; discussed concerns related to time and intensive labor. Discussed an e-newsletter vs. hard copy and advantages and disadvantages for both.
- Sharing *Short Briefs* (a daily communication for nurse practitioners) could be very helpful.
- Do an editorial page/section in *Practical Pain Management*. Editor is Dr. Forrest Tenant.
- Judy Citko shared about the Chinese American Coalition for Compassionate Care, a project of the California Coalition for Compassionate Care, a newly formed coalition of about 40 organizations to educate the public, patients, survivors and caregivers about advance care planning, palliative care and end-of-life issues. The ACS through the Northern CA Chinese Unit is a key collaborator in establishing the CACCC. Their website is www.caccc-usa.org

Priority Goal #5: Formalize structure of the Northern California Pain Initiative and continue development of funding sources to ensure viability.

- Dues for membership – Donna K. indicated that the Missouri did collect a \$20 annual due from about 200 members, which provided them the website and resources.
- Infrastructure - look at internal infrastructure issues and membership; what kind of organization does NCPI want to be; as an independent 501c3; need for dedicated staff, etc.

Priority Goal #6: Promote quality pain management that is culturally appropriate to populations being served.

- ASPI has funded a project that is developing a pain assessment tool with the Hmong population.
- Janet Edrington at UCSF and member of the NCPI Advisory Council is conducting a research project to assess pain in Chinese cancer patients.

Review of NCPI Structure and Operating Guideline

Beverly referred the group to the handout, *Operating Guidelines of the Northern California Pain Initiative (July 2006)*, which was developed with much help from Bill Marcus with input from ACS General Counsel. It will be used to guide the operation of the NCPI going forward. Beverly indicated the main subcommittees of the NCPI will be in three different areas:

1. Regulatory and government policy
2. Professional education
3. Public education

Alliance of State Pain Initiatives (ASPI)

Ronna Popkin, Outreach Coordinator for ASPI, provided an overview of the network of interdisciplinary, state-based organizations dedicated to improving the care of persons with pain. Their name was changed to reflect the broader area of pain, instead of

focusing only on cancer pain. They are looking for people who may be interested in joining the ASPI Advisory Council. For questions on pain initiatives, call Ronna Popkin. For policy and communications, call Matt Bromley. Dr. June Dahl is the Cofounder and Senior Advisor. Ronna spoke about their 18th Annual Meeting, scheduled for June 21-23, 2007 in Boston, “*Celebrating 20 Years of Progress: Transforming the Culture of Pain Care.*” Refer to www.aspi.wisc.edu for more information.

Ronna spoke about contract awards/grants. NCPI received 1 of 5 grants awarded to pain initiatives during the last cycle. Most are \$5,000 awards. ASPI hopes to continue the ability to provide funds. They are looking to build on the momentum of the Report Cards, to get Nursing and Medical boards to influence policy for practice change. They also provide “*Institutional Change*” grants to work with institutions and organizations to improve overall pain practice;

Ronna discussed Membership Guidelines, and indicated that NCPI meets all the guidelines to be a Pain Initiative, and would ask that we add the ASPI logo with the verbiage that NCPI is a member of ASPI. A survey is conducted every other year. One activity per survey period (2 years) is required to maintain membership.

Follow-up action: Add ASPI logo to the verbiage of “NCPI is a member of ASPI.”

Power Over Pain - Action Network

Annie Borgenicht spoke about The American Pain Foundation’s Power Over Pain – Action Network. The goal is to create a massive consumer voice to improve pain management. The POP Action Network is a newly developing grassroots network comprised of people affected by pain, working in collaboration with healthcare providers and other organizations. Annie has agreed to serve as the POP leader in California, and she looks forward to working with NCPI to build the network. Contact Annie Borgenicht for more information or Mary Bennett, American Pain Foundation Director of Mobilization, via phone 410-897-2135 or email, mbennett@painfoundation.org

Monthly Conference Call Schedule

After discussion, the following days of the week and times were best possibilities:

- Mondays @ 12 Noon – (6 votes)
- Tuesdays @ 12 Noon – (5 votes)
- Wednesdays @ 12 noon – (4 votes)

Follow-up action: Staff will send an email to the rest of group and get as much input as soon as possible.

Discussion of Priorities for 2007 and Appointment of Committees

Beverly indicated that the priority areas of work would fall under the following subcommittees:

- Regulatory and Government Policy – Bill Marcus to chair
- Professional Education – Kathy Keller and Mark Blum to co-chair;
- Public Education - TBD

Additional Ideas:

(Items with multiple votes are noted in parentheses)

- Seek a disparities grant to convene the different research projects that are working with ethnic communities to assess pain. Each can share with others what they are doing to address this issue; project needs to be low maintenance.
 1. Reach out to Intercultural Cancer Council
 2. Robert Wood Johnson
 3. Alliance of State Pain Initiatives
- A small Institutional Change project that could be undertaken with a facility; start with a single institution
- Collaborate with SCCPI to avoid duplication; special focus around regulatory work
- Utilize people's strengths and passions; look at ways to engage membership of NCPI
- Reach out to communities and organizations outside of the already "converted", such as the Bureau of Narcotic Enforcement; Narcotics Officer Association
- Legislative bill to require certain training for narcotics officers that are doing these investigations
- Power Over Pain Action Network (consumer relations)
- Communication/outreach to Bureau of Narcotic Enforcement or other appropriate law enforcement groups (6 votes)
- Paid membership
- Different way to teach pain by involving person with pain to be the teacher; institutional change (4 votes)
- Focus on specific projects that further mission statement (3 votes)
- Leverage projects (1 vote)
- Diversity (1 vote)
- Collaborate with SCCPI (1 vote)

The group felt that we should focus on a few things from the Strategic Plan. After reviewing the different project ideas, the group voted for their top two projects of choice, resulting in the following:

Priority 1: Communication/outreach to Bureau of Narcotic Enforcement (BNE) to build a working relationship. Need to educate outside the community of pain experts, i.e., bring a narcotic enforcement officer representative from BNE (mid management or higher) or from California Narcotics Officers Association (CNOA) into the NCPI Advisory Council; Daryl Walker could work with Bill Marcus to help to identify the appropriate persons to build the relationship with BNE and the NCPI. An idea is for the Medical Board to require all officers to participate in a training program on pain management and Patient Bill of Rights

Priority 2: Teaching pain management differently – rather than didactic method, using a person with pain to teach medical residents; educating through the media and health care providers; opening the providers' eyes; include a strategy to incorporate institutional

change. Maintaining education standards for JCAHO – JCAHO changes processes but not outcomes; only measures number of people attending education programs but not how providers practice. Outcomes could be greatly influenced with one-on-one bedside teaching through medical and nursing schools.

Expenses Summary Report

The NCPI is a project of the American Cancer Society, California Division, Inc. and therefore uses the 501c3 status of the Society and is under the governance of the California Division Board. In this case, the NCPI does not require a Treasurer. NCPI expenses are tracked under a specific activity code within the ACS accounting system. The NCPI received a small grant (about \$10,000 from the dissolution of the Northern California Cancer Pain Initiative (NCCPI) in 2004. By December 31, 2006, the NCPI spent approximately \$4,637 on operational expenses. This does not include staff time provided by May Sung and Jen Renell, staff assistant (Tony Daquipa before her).

Adjournment

Information about future conference calls/meetings will be sent out.

Beverly adjourned the meeting at 3 pm.

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