



**NCPI Advisory Council Conference Call
September 16, 2008
4 –5 PM
Dial-in number: 1-888-447-7153
Participant Code: 6419469#**

Summary Notes (DRAFT)

I. Introductions

Beverly Nicholson, Chair, called the conference call to order, and roll call was taken. **Attendance:** Beverly Nicholson, Kathy Keller, Mark Maginn, Judy Citko, Penney Cowan, Kathe Kelly

II. Review of Meeting Notes

Summary notes of August 26th conference call of the Pain Stakeholders planning workgroup with Dr. Aaron Gilson, and the summary notes of the August 19th Advisory Council conference call were accepted. Please forward any corrections to May or Beverly.

III. Old Business

- ❑ **ASPI meeting October 30 – Nov. 1 Attendance** – Beverly indicated that Penney Cowan, Ben Rich and she will be attending the ASPI Annual Meeting in Austin. Mark McGinn cannot attend this year.
- ❑ **Status of National Pain Care Policy Act (Attachment A)** – Beverly asked the Advisory Council to reference the attached material to the agenda document. ACSCAN supports the changes that have been made to the legislation. Beverly submitted a letter of support from NCPI for the National Pain Care Policy Act.
- ❑ **New Co-chairperson Position** – Since Dr. Mark Blum resigned this position because of his retirement from Kaiser, the position is still open for nominations. Since the last call, Dr. Donna Kalauokalani withdrew her nomination due to timing of her new responsibilities, and Kathy Keller wishes to remain as Secretary. Advisory Council members should submit nominations to Beverly.
- ❑ **Pain Stakeholders meeting update** – Beverly confirmed the following information pertinent to the pain stakeholders meeting:
 - ❑ Date is scheduled for Friday, December 5, 2008, Sacramento, CA at the Sheraton Grand Hotel.
 - ❑ Progress report on Agenda - A planning workgroup has put together a draft “working agenda.” Dr. Aaron Gilson with the University of Wisconsin Pain and Policy Studies Group will be our keynote presenter. The group has solicited input from other potential faculty. An updated working agenda will be shared.

- Progress report participant list/Save the Date – Kathy Keller has compiled an invitation list based on suggestions from Advisory Council members and others. A Save-the-Date notice is being finalized which will be shared with those who have agreed to invite pain stakeholders to attend. A response email box has been set up at the ACS California Division office to receive requests for registration information. A confirmation along with additional information will be sent out as registrations are received.

IV. New Business

- **September is National Pain Awareness Month** – Congratulations to Penny Cowan, American Chronic Pain Association and colleagues at “For Grace” who worked with Senator Carole Migden (D-3rd District) to introduce Senate Resolution 33, declaring September as National Pain Awareness Month in the Golden State (Attachment B). Beverly thanked Penney and “For Grace” for championing this every year. She indicated that NCPI can plan ahead to do something for National Pain Awareness Month and invited Penney to bring it up to her and the Advisory Council next year.
- **Summary of ACS CAN Activities** – Beverly shared the e-mail from Rebecca Kirch, ACS CAN Associate Policy Director (Attachment C) and attached files re: prescription monitoring programs.

V. ASPI 2009 Conference to be held in San Francisco

Beverly indicated Ronna Popkin, Outreach Coordinator with the Alliance of State Pain Initiatives (ASPI) shared the proposed date and location for the ASPI 20th Annual Meeting is Friday October 23 - Sunday October 25, 2009, at the Hyatt Regency in San Francisco. ASPI will look to us for suggestions and to help host a Saturday evening event that is traditionally held with the ASPI annual meeting.

VI. Standing Agenda Items

- SCCPI Liaison Report - Kathe Kelly
- Web Updates –
New Lets Talk Pain Web site – (**Attachment D**)
http://www.letstalkpain.org/pain_coalition/mission.html
- Upcoming Conferences/Educational Opportunities

VII. Announcements – Open Agenda

Next Conference Call: October 21, 2008, 4-5 pm (same call access information).

Attachment A

Excerpt of Email from Mary Bennett re: Status of National Pain Care Policy Act

[<mbennett@painfoundation.org>](mailto:mbennett@painfoundation.org)

09/14/2008 07:00 AM

Please respond to Mary Bennett
[<mbennett@painfoundation.org>](mailto:mbennett@painfoundation.org)

may.sung@cancer.org

To

cc

Subject
The National Pain Care Policy Act - IMMEDIATE RESPONSE NEEDED

ACTION ALERT

Forward to a Friend

Dear Supporter of the National Pain Care Policy Act, H.R. 2994,

GREAT NEWS! The National Pain Care Policy Act is approaching the finish line. WE ASK FOR

YOUR IMMEDIATE RESPONSE! On Friday, September 12th, an Amendment to H.R. 2994 was drafted. This revised bill will be introduced for vote in the House Energy and Commerce Committee on Tuesday, September 16th.

Below is the summary of the proposed changes AND a CONSENSUS LETTER addressed to the Members of the House Energy and Commerce Committee. We need as many organizations as possible to sign-on to this letter. As a supporter of the National Pain Care Policy Act, we ask that you RESPOND BY MONDAY, SEPTEMBER 15th, CLOSE OF BUSINESS, 5 PM (eastern time) with your endorsement of this letter. Please review the Summary of Changes and the Letter to the Members of the House Energy and Commerce Committee.

Summary of Changes:

Section 1

Title. The title has been updated to read "National Pain Care Policy Act of 2008."

Table of Contents. The title for Sec. 4 has been changed from "pain consortium" to "pain research."

Section 3

IOM Conference on Pain. The date for convening the conference has been

changed

from 2008 to 2009. The date for the IOM report to Congress has been changed from 2009 to 2010. Specific authorization amounts for the conference have replaced

“such sums as necessary.” The AINS authorizes \$500,000 for FY2009 and FY2010.

Section 4

Pain research at NIH. In the spirit of the 2006 NIH Reform Act, and to ensure the

Director of NIH retains flexibility in determining research priorities, the AINS

does not codify the existing Pain Consortium at NIH. Instead, the AINS encourages

the Director to aggressively expand research on the causes of and potential

treatments for pain. It also requires the Pain Consortium, or another entity the

Director deems appropriate, to provide recommendations on pain research initiatives that could be funded through the Common Fund.

Coordinating Committee. The AINS creates an interagency coordinating committee

charged with identifying critical gaps in pain research, eliminating duplication

of efforts at HHS and other federal agencies, and expanding collaborative pain

research across federal agencies and the private sector. Membership on the

committee is diverse and includes leading experts on pain from both the public and

private sector. The committee is subject to review by the Secretary every two

years. This interagency coordinating committee replaces the FACA advisory

committee contained in the original bill.

Section 5

Best Practices in Pain Care. The AINS strikes Sec. 904, the Program for Pain Care

Research and Quality, which would have required the Director of AHRQ to create a

program to collect evidence-based best practices regarding pain care. Instead,

the primary responsibility of collecting and disseminating this information will

remain with the numerous physician specialty groups and academic institutions involved in pain care. AHRQ will retain the discretion to continue its

current efforts with respect to pain without a statutory mandate. Education and Training. The AINS includes specific authorization amounts

for a

grant program to provide education and training to health care professionals in

pain care. It replaces “such sums as necessary” with an authorization of

\$5,000,000 per year for the program.

Section 6

Outreach and Awareness Campaign. The AINS moves the campaign period from

2008-2010 to 2009-2011. It also requires an evaluation and report on the campaign's effectiveness. Finally, the AINS includes specific authorization amounts for the campaign. It replaces "such sums as necessary" with an authorization of \$2,000,000 for FY2009 and \$4,000,000 for FY2010 and FY2011.

Note: The estimated cost of this legislation over five years is \$25.5 million

Attachment B



From ACPA Web Site

September as Pain Awareness Month in the Golden State

August 21, 2008

For the 5th consecutive year, For Grace has sponsored a resolution proclaiming September as Pain Awareness Month in the Golden State. This year we worked with Senator Carole Migden (D-3rd District) who authored and introduced the resolution, SR 33, for us yesterday.

The resolution calls upon all Californians to observe this month by participating in appropriate ceremonies and activities and by learning how to improve the quality of life for people in California suffering with pain.

September, due to the efforts of Partners for Understanding Pain, is recognized nationwide as the month to acknowledge pain as a major health issue in the country.

We at For Grace extend a heartfelt thank you to the many California legislators and staffers who despite unforeseen difficulties made this proclamation happen two days before all adjourn for the year!

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Cynthia Toussaint has had Reflex Sympathetic Dystrophy (aka, Complex Regional Pain Syndrome, CRPS) for 26 years and founded For Grace in 2002, originally to raise awareness about the disease. She later developed fibromyalgia as an over-lapping condition. Before becoming ill, she was an accomplished ballerina and worked professionally as a dancer, actor and singer.

Attachment C E-mail from Rebecca Kirch

Rebecca
Kirch/NA/ACS/US
09/02/2008 07:45

Subject

Pain Awareness Month & New ACS CAN
Materials

Good morning all:

Here is an e-mail update to kick off September's National Pain Awareness Month:

1. National Pain Care Policy Act (S 3387/HR 2994): Since celebrating Senate introduction of the federal legislation last month, ACS CAN has made available on its website a "take action" button as well as a template letter to the editor in response to your requests. It appears this feature has been very useful, as many ACS CAN advocates in several states across the country have steadily been using the feature to send letters to their House and Senate members urging cosponsorship. Thank you very much for encouraging these efforts. Here again is the link for those who wish to use it: http://action.acscan.org/site/PageServer?pagename=pain_campaign

2. New Prescription Monitoring Program Materials: ACS CAN is pleased to provide the attached new materials on prescription monitoring program legislation for your use. You will see they are cobranded, and I want to recognize here the wonderful assistance of Aaron Gilson, PhD at the University of Wisconsin's Pain & Policy Studies Group in developing the Model Legislation in particular. And for those of you who were at NGRD's pain advocacy strategic meeting back in December 2006, I do hope you will take note that my map-making skills have improved dramatically! Please do provide feedback on these materials so we can be sure they are as helpful as possible.

New tools include: 1. Fact sheet explaining PMPs and issues of concern
2. US Map of PMPs 3. Cover Memo and Model PMP Legislation

(See attached file: PMP fact sheet.doc)(See attached file: Model PMP legislation.rtf)(See attached file: pmp map 2008.ppt)

3. NCIC Pain Pilot: We just wrapped up the initial phase of the National Cancer Information Center Pain Pilot Project, and owe many thanks to the wonderful CIS/ONIS team who assisted in this six week pilot. The results are being analyzed now from a total of 221 calls across 34 states over the four week survey period. More than half of these callers indicated they were experiencing pain, and nearly all were amenable to discussing their pain with NCIC. We are now in the process of writing up the pilot findings, and you will hear more about the results in a future update.

4. State Summits: Many states are hosting pain summits, stakeholder meetings, and/or trainings in the coming weeks and months. First on the roster is in Montana on September 5, with plans for meetings as well in Maryland (10/24), Indiana (12/4) and California (12/5). Please let us know of other such meetings you are planning so we can share the information and lessons learned.

5. Next Steps: We will be scheduling a pain advocacy update call to take place in October. For those of you planning to attend the ASPI meeting in Austin, this call will be a good chance to share information among colleagues before converging there.

Rebecca A. Kirch
Associate Director, Policy
(202) 661-5725
rkirch@cancer.org

Attachment D

Lets Talk Pain Web Site – excerpt

9/08

http://www.letstalkpain.org/pain_coalition/mission.html

Our Mission and Values

Let's Talk Pain is a Coalition dedicated to improving awareness and understanding of pain management and is made up of organizations committed to improving pain care throughout the nation. Our goal is to encourage people affected by pain and their healthcare professionals to talk more about pain, to listen actively, and to act in ways that improve care for people who live with pain.

The Coalition believes that with improved communication and understanding between healthcare professionals and their patients, meaningful change can occur in the therapeutic outcomes and the patient's quality of life. By working with pain management specialists, primary care physicians, nurses, caregivers, and media, the Coalition will provide information to the public about pain treatment and overall management. To enhance this dialogue, the Coalition will offer tools and resources found on this Web site that will help people affected by pain and their healthcare professionals talk more openly and willingly about pain.

About the Coalition

The American Pain Foundation, American Academy of Pain Management, the American Society for Pain Management Nursing, and PriCara®, Division of Ortho-McNeil-Janssen Pharmaceuticals, Inc., have created the Let's Talk Pain Coalition to help address the concerns that many people have about their pain care. Through a nationwide campaign, the Coalition will provide information to encourage individuals with pain and their healthcare professionals to improve how they communicate with each other about pain and its treatment. By providing those affected by pain with helpful tools and up-to-date information, the Coalition will help foster improved communication between those affected by pain and their healthcare professionals, which will result in improved treatment outcomes.