

NOSN

NATIONAL ONCOLOGY STATE NETWORK

STATE LEGISLATURE TEAM TELECONFERENCE WEDNESDAY, NOVEMBER 14, 2018

7:30am Hawaii/ 8:30am Alaska/ 9:30am Pacific/ 10:30am Mountain/11:30pm Central/ 12:30pm Eastern

Present: Warren Fong, M.D. (Chair); Wendy Alfaro; Nichole East; Diane Gerards-Benage; Jose Gonzalez; Dawn Holcombe; Mariana Lamb; Chuck Miller, M.D.; Nicette Short; Sedrick Spencer, Celgene; Carol Teal-Christner; and Guest: Patricia Alvarez-Sahagun, State Government Affairs, AstraZeneca.

Absent: Liz Hanpeter, AbbVie; George Malouly, Celgene; Maria Sipala; Amy Supraner; and Tammy Thiel.

MINUTES

I.

State Cancer Caucus:

A. **California** – (Nicette)

Update:

1. Nicette reported that things are moving along. There is an informal meeting scheduled for December 13th in Sacramento. She is pleased with the anticipated participation, as everyone is excited to participate. Especially UC Davis, they are sending three representatives; also confirmed is the American Cancer Society, Cancer Action Network, Children’s Hospital, Susan G. Komen, Leukemia & Lymphoma Societies.
2. The main purpose of this first meeting is to introduce stakeholders, establish goals and set structure for education and collegiality.
3. For the first year, the Cancer Caucus will be informal, including both the Assembly and Senate, Democratic and Republican and will have no official Chair. This is mainly due to California’s complicated and lengthy laws for creating an “Official Caucus.”
4. After this event, the scheduling will begin for the January 2019 Breakfast Caucus, which will include both stakeholders and legislators.

B. **Florida** – (Amy/Maria)

Update: No report provided.

C. **Hawaii** – (Dr. Miller)

Update:

Dr. Miller reported that it is a work in progress. HSCO is working on hiring a lobbyist. He is a local in Hawaii and been in the industry for approximately 15 years. Dr. Miller thinks something will be put together before the end of the year. Nicette offered her assistance as well.

D. **Illinois** – (Diane)

Update:

Diane reported that the next meeting will be scheduled towards the end of January or beginning of February.

State Cancer Caucus: (cont.)

E. **Utah** – (Carol)

Update:

Carol reported that Utah has just completed an RFP to hire a lobbyist and will then proceed with creating a cancer caucus.

II.

State Legislation:

A. Continuous monitoring of the following legislation.

1. Oral Parity Legislation -
2. Opioid Legislation –
3. Step Therapy Legislation -
4. Out of Pocket/Co-Pay Caps –
5. Co-Pay Accumulators -
6. Off-label law (*not all states have this*) – California, Hawaii and Connecticut. However, Connecticut’s law is outdated and needs to be revised.
7. Drug Recycling Law (*similar to NM*) – Jose mentioned that the legislation is in draft and that he would share it with the group.

B. Renewal - CQ Roll Call legislative Monitoring tool. **(Attached)**

1. Do you find this tool valuable?
 - a. Early renewal – one year agreement \$8,025
 - b. One year agreement - \$8,100
 - c. Pricing expires on January 22, 2019.

Vote:

- Carol uses the tool and finds it valuable.
- Dawn uses the tool and finds it valuable. She was able to catch a few pharmacy bills that would have otherwise flown under the radar.
- Diane does not use it.
- Dr. Miller does not receive it anymore.

III.

New Business:

A. National Organization for Rare Disorders (NORD) - NOSN held a conference call with Tim Boyd, Director of State Policy at NORD. NORD is a small association of 5 employees based in DC. However, they have numerous volunteers across the country. They have a few Rare Disease Legislative Caucuses and Advisory Councils in five states. Tim said NORN cannot advocate for one disease over another nor take public policy positions officially. However, he is willing to work with NOSN on issues that are appropriate. We all agreed to keep one another in the loop as issues arise to see if we can potentially collaborate. One issue he was very interested in was, Co-pay Caps and Co-pay Accumulators as those effect every specialty. We mentioned that we are interested in that as well but that COA is taking the lead and introduced him to Ricky.

B. ASCO Governance Committee – Dr. Miller mentioned that he met with the committee but that ASCO is mainly focused on national issues and is not interested in joining forces with NOSN any time soon.

IV.

FYI:

There will be no teleconference held in December. If an urgent issue should arise, we will communicate via email.

V.

Next Teleconference:

The next teleconference is scheduled for **Wednesday, January 16th** at 7:30am Hawaii/ 8:30am Alaska/ 9:30am Pacific/ 10:30am Mountain/11:30pm Central/ 12:30pm Eastern. The monthly **NOSN Partner call** is immediately following.

The meeting adjourned at 9:58AM.