** North Dakota Cancer Coalition-(NDCC)**

**Steering Committee Meeting**

**Friday, September 14, 2018**

**9:30am – 4pm Central Time**

**In-Person Meeting**

*Conference line option 1-866-347-9524 (all are encouraged to attend in person)*

**Jamestown Regional Medical Center**

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| **Name** | **Present** | **Name** | **Present** |
| **Shannon Bacon- Secretary -** American Cancer Society (ACS) | X | **Stefanie Meyer- Past Chair-** NDSU MPH |  |
| **Jacob Davis-** Prevent Child Abuse North Dakota | X | **Susan Mormann**- NDDoH- Director Community and Health Systems | X |
| **Tara Schilke**- **Vice Chair -** Bismarck Cancer Center |  | **Beth Nelson-** Altru Cancer Center | X |
| **Jodie Fetsch**- Custer Health (Local Public Health |  | **Jesse Tran-** NDDoH Comprehensive Cancer Control – Program Director | X |
| **Janna Pastir**- NDDoH- Health Promotion | X | **Geneal Roth**- **Treasurer**- Quality Health Associates of ND | X |
| **Julie Garden-Robinson**- NDSU Extension Statewide | X | **Mary Sahl**- Sanford Health-Treatment | X |
| **Cindy Gohner**- BCBSND |  | **Joyce Sayler**- NDDoH Community & Health Systems-Community Clinical Coordinator |  |
| **Brad Hawk-** Commission on Indian Affairs | X | **Barb Sherburne**- Sanford Health |  |
| **Shane Jordan-** Trinity Health Cancer Center |  | **Kendra Roland**- Great Plains Tribal Chairman’s Health Board |  |
| **Jolene Keplin-** Turtle Mountain Tribal Health Education | X | **Zheng, Yun (Lucy)**- ND Statewide Cancer Registry | X |
| **Mallory Koshiol- Chair –** Sanford Health | X | **Cristina Oancea –** ND Statewide Cancer Registry | X |

**Meeting Agenda**

9:30am Roll Call, Welcome, and Ice Breaker (Mallory)

10:00am Business Items: (Mallory & Geneal)

Review of June minutes – Approved

Treasurer Report – Current balance is $10,039.71. Executive Committee will draft up some guidelines about how these funds can be used. Treasurer’s report approved.

10:15am NDCC History (Susan)

* Susan gave an overview of the NDCC, 1989 – Present
* Viewed current logo and original logo.
* Year 1 of NDCC was 1989. Formed to assist the department to form a state plan as part of a 5-year grant from National Cancer Institute.
* Seven priorities from very first state cancer plan were reviewed.
* Original member organizations were reviewed.
* First task that the coalition took on was to review cancer data and recommendations and to create a report. We still have 1 hard copy available. Susan will see if we can make it digital form to preserve as historical document. Also convened sub-groups.
* In 1995, DoH started receiving CDC funding for breast and cervical early detection (women’s way). One of the requirements was to have a program coalition for women’s way, so NDCC morphed into that. 3 subcommittees. Had a leadership council made up of physicians and providers (became medical advisory board that helped shape women’s way program). Women’s Way is no longer required to have a coalition.
* NDCC was then dormant from 1998 – 2002.
* 2001: a group went and attended the Comprehensive Cancer Control Leadership Institute (the founding members of the original coalition). Decided to get the NDCC active again.
* 2002-2003: NDCC created infrastructure. Elected officers for the first time and outlined guiding principles. In 2003, they created bylaws. For the first time, set up regular scheduled meetings. Filed for non-profit status, but never completed the paperwork, never became a 501c3.
* Because ND had a state plan and an engaged coalition, our state was able to successfully receive CDC Comprehensive Cancer Control dollars and has been able to continue to receive that grant.
* Then CDC had priority steps they wanted coalitions to meet. Had workgroups for the state plan, recruitment, and data.
* DoH had administrative assistant to provide support to the cancer coalition at that time.
* Examined data sources statewide, looked at strengthening some of the data.
* 2004: The coalition started establishing workgroups. Knew they immediately needed Recruitment workgroup and Data Surveillance/Evaluation. Then they looked at disease continuum workgroups: Prevention, Early Detection/Screening, Diagnosis/Treatment, Quality of Life. Cross-cutting workgroups were Advocacy, Public Awareness, Professional Education/workforce development, research, disparities. They didn’t create all of these at once, and some of them never fully formed.
* June 2005 – NDCC Kick-off summit. Worked on writing the state plan. They formed workgroups to write the chapters of the state plan. Workgroups met almost every month. Every chapter was reviewed by the larger group.
* 2006 annual meeting – finalized.
* 2007 cancer summit – rolled out NDCC plan 2006-2010. This is when coalition moved from planning to implementation. Priorities at that time for coalition centered around 2 sections of state plan: Prevention and focused on Screening (specifically colorectal cancer).
* How the NDCC changed over time.
  + We reviewed list of past Chairs.
  + New logo launched in 2008. Lavender colors represent all cancers.
  + Minimal changes to the purpose of the coalition, and bylaws have stayed close to the same.
  + Workgroup structure has changed and adapted over the years.
* In 2008, revised mission statement to be shorter. It became: Working together to reduce the impact of cancer for North Dakotans.
* “A Cancer Free Future for North Dakotans” is the tagline used on most communications from coalition.
* 2007 NDCC Organizational Chart was displayed. Policy and advocacy workgroup functioned for about 4 years and then disbanded (struggled). Communications workgroup task was to create a website and a newsletter (disbanded after they did that). Education/training morphed into Screening & Early Detection workgroup. Prevention workgroup disbanded in 2014 because a lot of the work was being done by other partners – Jesse still stays connected to the coordinated chronic disease management. Data/evaluation didn’t have strong participation. Some Ad-hoc committees (community grant, annual meeting).
* In 2012, the UV protection workgroup was created and also the HPV prevention workgroup (now managed by immunization).
* 2017 NDCC organizational chart reviewed. UV protection program put together their backpack program for the schools but are no longer meeting. HPV taskforce is active. Screening & Early Detection is active. Survivorship has not been meeting.
* First state plan (2006-10; 2011-16; 2018-2022). The new plan (coming soon!) has more information on evidence-based strategies.
* NDCC membership grew from less than 100. We have over 200 members today. This has been pretty consistent over the past 8 years.
* Treatment & Survivorship workgroup was key in developing cancer patient survey. This is performed every other year.
* HPV taskforce has been a driving force in raising state vaccination rates.
* Sun safety workgroup has developed educational materials used across the state by NDSU extension, schools, daycares, etc.
* Screening & early detection awareness campaigns for breast and colorectal.
* 2008 meeting focused on grant writing. 2009 small-group breakouts on variety of topics. 2010 Affordable Care Act. 2011 Genetic counseling. 2012 PSE change. 2013 Chronic disease conference. 2014 small group breakout sessions variety of topics including legislative process, EBIs. 2015 Colorectal Cancer Screening and Dr. Wender (ACS) as keynote. 2016 focused on Palliative Care.
* NDCC member participation in CCC sub-contract program. Coalition member organizations are encouraged to apply for the sub-contract program. Many member organizations have been recipients. Have had 108 subcontracts issued since 2008. Most have gone to coalition member organizations. Ranged from $5,000 - $10,000. Awarded 14 different organizations this year, most at $10,000.
* Funding sources for NDCC:
  + NDCC account: comes from conferences and summits that were held at one time, or donations that are given.
  + Financial support from NDDoH:
    - Participant travel/lodging/meal/registration costs for NDCC sponsored meetings, other related NDDoH or state and national trainings.
    - Meeting and event site costs.
    - Speaker costs for trainings/meetings.
    - Conference call line used for NDCC calls.
    - NDCC website development and hosting fees.
    - Supplies for NDCC related meetings
  + Member organizations might also directly cover costs as identified.
* NDDoH and NDCC
  + Initially, DoH served as administrative support. Served on its committees, had leadership roles, served as workgroup leads, provided logistical and clerical support for coalition activities.
  + Now: Participant travel/lodging/meal and registration costs for NDCC sponsored meetings or other trainings, meeting and event site costs, speaker costs for trainings/meetings, conference call line used for NDCC member calls, NDCC website development and hosting fees, supplies for NDCC meetings.
* The group discussed that it would be good to share this historical overview with others at the next in-person all-member meeting.

10:30am BREAK

10:45am Cancer Coalition Video

* Viewed [**Cancer Coalition video**](https://www.publichealthpractice.org/cancer-coalitions)
* Group shared key take-aways including:
  + Recommendation to review mission at each meeting
  + Engage businesses and strategic membership. Value proposition.
  + Coalitions across country can learn from eachother
  + Evolving structures
  + Coalitions need to be ready to lead change
  + Teamwork is essential
  + Idea: Develop video introducing new members to our coalition
  + Comp cancer role to share data, and coalition can act independently to impact laws.
  + We all have these goals and can’t accomplish them individual but can accomplish them as a group.
  + Having a common purpose that drives our interactions, binds us together.

11:15am Introducing 9 Habits of Successful Comprehensive Cancer Control Coalitions (Mallory)

* We want to use this as a tool to guide our coalition.
* We’ll start by doing self-assessment tools under each habit. Today we’ll start with 2 of the habits.

11:45am LUNCH

12:30pm Welcome back / physical activity

12:45pm Habit #8: Flexible Structure (Tara)

* We each rated the coalition based on the three areas in the flexible structure area. Identified a need to more strategically recruit. Also recognized need for greater inclusion of Native American North Dakotans. Noted that we sometimes aren’t clear to members on what we want them to do, but that if we could be clearer on our objectives that would be helpful. Helping members find an active role can be more challenging when the member’s work doesn’t align as easily with coalition activity. It was noted that we have been flexible in adapting to new needs and change.

1:15pm Habit #9: Priority Workplans (Mallory)

* Nikki Campbell of Montana Cancer Coalition joined and share about their approach for developing priority workplans.
* Essential workplan components: comprehensive, cost-sensitive, culturally sensitive, evidence-based and data driven, ensure best practice, outcome oriented, respectful of individual’s rights, dignity, privacy, and safety.
* Annually: MTCC Steering Committee meet (2-day leadership retreat) to review strategic plan, discuss priorities that have been chosen for each implementation team objective, assess whether to continue or modify the approach. Steps were reviewed (see slides).
* Priority workplans have helped MTCC determine who needs to be at the table.
* Review membership list annually to see who has been consistently involved and who needs to be engaged.
* Outcomes are compiled into an annual report that is on website and shared at annual meeting. Can be shared with stakeholders, media, is also used in chronic disease newsletter or webinars. Coalition work is communicated to comp cancer, to department of health, and to health officer. This helps create buy-in.
* Coalition video is available on their website.

2:00pm Identifying Priority Objectives for NDCC 2018-2019 (Shannon)

The group divided into small groups and assessed objectives from cancer plan to identify potential priority objectives.

**Screening objectives:**

* Objective 10 (breast) and 11 (cervical): Determined that there are many groups working on these including women’s way. It might not be necessary for coalition to focus on this for the next year.
* Objective 12 (colorectal): Because the statewide CRC roundtable is doing significant work on this and the ND CRC screening initiative is working with FQHCs, it was determined this is probably not top priority for NDCC, although still a significant need in the state.
* Objective 13 (melanoma screening): Felt it is something we need to work on collaboratively and a significant area of need. There might be some barriers to be successful and to track effectively. There aren’t a lot of sources of information to track screening numbers. Felt they could recruit organizations on this.
* Objective 14: oropharyngeal – felt they could work on this as a coalition, not being addressed other places. Significant area of need because rate of late-stage diagnosis is high in ND. Could measure by late-stage diagnosis and incidence rates. Not sure about recruiting individuals.
* Melanoma comes out as a possible priority area under screening. Head & Neck cancers have a high rate of late-stage diagnosis, so could explore interventions around head and neck. Melanoma in screening might not be where we reach the most impact, so perhaps focus is on prevention.

**Prevention objectives:**

* It was suggested to develop a master plan outlining what various organizations are doing within each objective statewide.
* HPV vaccination: There is state taskforce and significant work being done in this area. While the need is high, it might not be necessary to focus NDCC effort in this area beyond continuing to support the HPV taskforce and other current work.
* Tobacco: Susan shared an overview of a significant amount of work already being done in this area. Every local public health unit receives funding across the state (6.5 million per biennium), charged with implementing best practices from CDC. Using CDC tobacco prevention, they also fund tribal communities for tobacco prevention work. Project going on in every casino working to get casinos to become smoke free (seeing success, multiple have gone smoke-free). ND Quits cessation lines, and the Baby & Me program are active. Cessation quit **grants that look at bi-directional communication with EHR and quitline are underway.** Also have local youth coalition, support efforts of youth across the state. They have their state plan they put together for tobacco control, which aligns with CDC best practices. We should promote the grants to coalition members. There is some media still going, but media outreach probably took the largest hit when the tobacco center for policy was closed last year. Public education taskforce in tobacco convenes on regular basis. Group called Project 19 is still looking at ways they can look at increasing tobacco tax in ND.
* Obesity: This was discussed as something that we need partners to come together around. The group wondered why children weren’t included in the objective.
* Environmental: Group felt it was important but measuring success may be difficult. Radon legislation was discussed. Other strategies would be educational, and we’d need to track numbers reached. Safe home project in other states as possible example. Jesse is working with environmental health. They are going to do the testing, and the hope is that different organizations might help do mitigation. If test is positive, could possibly use as opportunity for education about mitigation.
* Reducing sunburns: Discussed policies related to tanning beds, etc.

**Quality of Life:**

* Identified that we need to better understand the data and the gaps to address an objective.
* Prioritized three objectives in this area:
  + Improving awareness, knowledge of cancer survivorship
  + Continuum of Care
  + Access to hospice: DoH has maps on hospice networks. We could overlay that with registry data to look at how many people were diagnosed with cancer and what are the needs. Part of the strategy could be to also tell the story and bring in the human side of this issue.
  + A lot of work being done in CAH’s in hospice and palliative care. Somebody from the CAH quality network (Jody Ward possibly) would be good to include.
  + Biden’s moonshot initiative includes palliative care work.
  + There is a palliative care taskforce in ND.

3:45pm Next Steps / Closing (Mallory)

* Executive committee could review these as small group
* Use our next steering committee to narrow down
* Engage wider membership – bring down to top 5 and have members vote or get input
  + Next coalition call – share the 5 and have them weigh in. and remind them that we plan to do this on annual basis. Share strategies with the objectives.
* Exec committee will meet and refine roles, responsibilities, bylaws.