

Minutes

NAACCR Board of Directors In-Person Meeting

Sunday, June 10, 2018
8:00 am – 5:00 pm Eastern

8:00 am Roll Call and Welcome

Nan

1. Introduction of new Board members

- Angela Meisner
- Wendy Aldinger
- Kyle Ziegler

Nan welcomed all new Board members. Each provided a little background and information. New Board members are not voters in official BOD voting sections. In addition, all current Board members introduced themselves as well as provided a little background.

2. Recognition of Outgoing Members

Nan

- Heather Stuart-Panko
- Chris Johnson
- Chuck Wiggins

Nan thanked all outgoing Board members for their service. All Board members also thanked the outgoing members for their time and service. Nan went into detail on each outgoing Board member's strengths and contributions to NAACCR and the Board.

3. Overview of Day/Week

Betsy

- BOD Schedule

Nan and Betsy reminded the Board about today's schedule as well as the week's schedule. All Board members are encouraged to meet vendors, members, chairs, and attendees as much as possible. In particular, there will be significant time spent on coordinating thoughts and actions on the Strategic Management Plan, Registry of the Future, and March Board Meeting priorities.

4. Update on 2018 Meeting

Charlie

- a. Meeting Report

Charlie provided an update on the 2018 Annual Conference. Attendance is expected to be approximately 385. Workshop registration is strong and the Hackathon first day was a huge success. Charlie thanked all those involved in planning the session. He said that there was an immense amount of planning involved and mostly by volunteers. He said that everyone should be commended for their hard work. Isaac also provided detailed background on the planning and progress thus far in the project. He said that if it were planned again that the efforts could be cut by half. Nan would like the Board to incorporate a plan on how to use the information and project solutions. If NAACCR likes the ideas then one idea is to engage the participants in the future to bring the ideas along more. Lori Swain recommended setting a debrief meeting.

In addition, the Board motioned to approve all Hackathon participants to receive free registration to the 2018 NAACCR Annual Conference. This was highly supported among the Board.

THE MOTION TO APPROVE THE COMPLIMENTARY REGISTRATION FOR HACKATHON PARTICIPANTS WAS APPROVED.

b. NAACCR Location 2021

Betsy

Betsy and Charlie are traveling later in the month to source cities for the 2021 NAACCR conference. Current cities on the list for consideration are Palm Springs, Los Angeles, and Denver. Maria said that Palm Springs may be prohibited by certain states. Betsy will take this into consideration when we make the visit.

c. Chair for 2019 Vancouver Meeting

NAACCR is needing a Program Committee Chair for the 2019 Vancouver meeting. Heather suggested to ask Ryan Woods as a Chair. Heather said that she would connect with Mr. Woods first. Nan asked that Kim Vriends be asked to be involved in the planning group. Chuck suggested a gentlemen who could speak at the Vancouver meeting, Evan Adams. He will make the contact and relay the information to this individual. The group also suggested Steve Schwartz from Seattle, Sarah Nash, and Jennifer Hafterson.

8:30 am Consent Agenda (ACTION)

Nan / All

5. Minutes

6. Finances

7. Executive Director's Report

8. Correspondence

- LOS Andrew Larson
- Desert Sierra Registry Membership
- IACR Network Representative Request

9. Registry Certification Report

THE MOTION TO APPROVE THE CONSENT AGENDA AS PRESENTED WAS APPROVED.

8:35 am Governance

10. Standing Rules Committee Establishment (Separate Attachments-Review)

Lori

a. Bylaws Changes/Parliamentarian

Lori and Maria have been working on the questions presented by some Board members. They have a goal to vote on these in July 2018. The committee will include Betsy, Nan, Maria, and Lori. Charlie will act as a staff assistant to this group. A parliamentarian will be engaged during the year. This is included in the 2018-2019 budget and will be approved during the budget process. In addition, there will need to be Bylaws Committee developed and the idea was to have this same group act as the Bylaws Committee when needed. There may need to be an additional person or two added to the Bylaws committee depending on the needs of the group. In addition, Heather described the Canadian Cancer Council, "Council" and what their role is in Canada in respect to other Canadian organizations. She also provided the cycle of membership on the Council and key members on the committee. Nan suggested inviting

Kim Vriends to NAACCR leadership calls to retain communications with no Canadian representative on the NAACCR Board for 2018-2019. Heather also announced current and pending key retirements.

11. Non Paid Dues June 2017 – May 2018

- a. AJCC
- b. CAP

The Board discussed outstanding dues and will take measures to engage AJCC and CAP to see if they want to remain NAACCR members. There have been conversations in the past, however, a new strategy will be developed by Betsy, Nan, and the Board.

9:00 am Program Updates

12. Canada

Heather

Canada is trying to get the national death clearance back into place. They are getting close to signing agreements but remain quite restricted. Heather noted that the new proposed certification criteria will impact this in the future. 2018 changes are new and they are trying to make the necessary change to adapt as best they can at this stage. The council met with chronic disease to discuss about linkages they use for data across Canada. They are missing cancer in the data to know what the approximate cost is with individuals with chronic disease. CPAC has a new report coming out. They will highlight the maximization of cancer linkage data to know the bigger picture. The Canadian Cancer Statistics report is currently embargoed but will come out next week.

13. NPCR

Chris

There is a rollout of CDC software which supports version 16 but not 18. 18 should be available near August 2018. Chris said they are expecting delays as a result of these changes and it may impact the NAACCR Call for Data. Chris advised that SEER, CDC, and NAACCR connect to address any future impact. New colorectal screening guidelines were announced. CDC is staying with 50 and older for screening. Chris noted excellent collaboration between CDC and NCI. He also noted that continued CDC funding announcements have not yet been released. Deirdre mentioned that there is some disconnect with SSDI and collection criteria. Chris noted that there will be a new NPCR field that will need to be evaluated by NAACCR for future years.

14. SEER

Chuck

Chuck received his new contract on May 1, 2019. This was the first day of the contract period. In addition, registries are working through the new reports required. However, SEER has placed many of these new reporting requirements on hold. The *Annual Report to the Nation* was recently released. The focus of this year's report is prostate cancer. SEER is hosting a Quality Improvements Expert meeting at the NAACCR Annual Conference. SEER will convene a SEER DMS meeting in September 2018.

9:30 am Overarching Discussions

15. 2017 - 2018 Accomplishments Overview

Betsy / All

Betsy provided NAACCR accomplishments and overview for the Board to review. This was a written report provided prior to the meeting and no questions were asked.

16. Setting of 2018-2019 Priorities for Association

The Board spent time on consolidating the initiatives into an actionable plan for the next year. Members broke up into groups to tackle the initiatives below. The recommended plans for moving forward were captured under each steering committee future plans for moving forward.

- a. March Meeting Action Items
 - i. Advocacy Plan Lori/Chuck
 - ii. Membership Coordinator Chuck
 - iii. Marketing Consultant None Assigned
 - iv. Education PD (Implement Action Plans) None Assigned
 - v. Tool to Update SMP Nan
 - vi. XML SAS Investment Tools Frank/Isaac
 - vii. Membership Levels and Categories Nan/Deirdre/Randi
 - viii. Sustainability Isaac
 - ix. Overarching Relationships None Assigned
 - x. Change Management and Organizational Involvement Betsy
- b. Registry of the Future Action Items
 - i. New and Emerging Data Sources
 - ii. Expanding the Scope of Cancer
 - iii. Confidentiality and Data Security
 - iv. Research and Reporting
 - v. Timeliness of Reporting
 - vi. Business of Cancer Surveillance
- c. Strategic Management Plan Action Items
 - I. Secure a Chair/Co-Chair for Communications SC
 - II. Secure Member Engagement Coordinator
 - III. Implement Team Charters in all SCs
 - IV. Formalize SC reports that will provide continue updates to the SMP
 - V. Develop marketing strategy with some emphasis on improving social media presence
 - VI. Identify best practices and model programs from successful non-profit associations that will enhance member engagement and recruitment and promote leadership development
- d. NAACCR Office Focus 2018-2019
 - i. Camp Lejeune
 - ii. Virtual Pooled Registry
 - iii. Global Initiatives
 - iv. Best Practices-CDC
 - v. Expanding Education-CDC
 - vi. Annual Report to the Nation
 - vii. Technology and System Upgrade (IMS Activities)
 - viii. Education Plans
 - ix. XML

- e. Other
 - i. ACCR TRS Task Force (Separate Attachment)
 - ii. Modifications to Certification (See ITEM #33 Attachment)
 - iii. SMO Engagement Plan/Steps for 2018-2019 Nan

1:00 pm Finances and Budgets

17. New Funding Announcement

Betsy

Betsy informed the Board that NAACCR was been selected as a subcontractor with Battelle to work on a Camp Lejeune contract. The Board congratulated Betsy for her hard work on securing the funding.

18. 2018 Financial Reporting Update

Maria/Charlie

Charlie provided the Board with the update of the current financials for the year ending May 31, 2018. In summary, the financial position of NAACCR is stable.

19. Going Concerns Vote of Confidence (ACTION)

Charlie

The Board is required to give the association a vote of confidence for operations and budget for the next twelve months. This is an item where the vote of confidence is then forwarded to NAACCR's auditors.

THE MOTION THAT THE NAACCR BOARD OF DIRECTORS IS CONFIDENT THE ASSOCIATION WILL REMAIN IN BUSINESS OPERATIONS FOR TH NEXT 12 MONTHS WAS PASSED.

20. 2018-2019 Budget Review and Approval

Maria / Charlie

Charlie presented the Fund 10 and Fund 15 Budgets for review and approval. He detailed the specifics of the budgets, changes, and highlights to the Board. All Board members discussed the budgets in detail. Charlie answered their questions. Overall, this is at a minimum, a break-even budget with flexibility allowing for reinvestment back to NAACCR later in the year.

1:30 pm Strategic Alliances Update

Written update provided.

21. Future Directions to SC

- Tightly develop a framework to develop an advocacy position. Join One Voice Against Cancer OVAC.
- Investigate feasibility of a Volunteer Coordinator position. This position would be framed around people who are outside the organization.
- Work with all Canadian colleagues, Sponsoring Member Organizations, and other key stakeholders.
- Investigate a SMO engagement plan.
- Taylor a message to SMOs and decide who needs to take the lead in a particular situation.

22. Governance Directions to Board or Other Groups

- Administrative coordination of positions. Job descriptions, budget, hiring process.
- Tool to update SMP. This is done but there was discussion on possibly doing more integration in web site.
- Membership levels and categories.
- Sustainability and succession planning.
- Stability and possible policy or review of policy for staff salary stability for increases.
- Overarching relationships with SMP and other stakeholders.
- Bylaws and Standing Rules and parliamentarian.
- Board self-assessment. Chris suggested checking with past BOD members on possible ideas.
- Change management board.
- Host a Board/Chair meeting in Chicago where some SMOs are located. This will be discussed later in the meeting.
- Succession planning.

23. IACR Issues

a. Regional Networks Representative

Betsy

Betsy received a request to have NAACCR appoint a Regional Network Representative. Betsy outlined the obligations for this position. Since this work and role relates closely to her duties and experience with IACR, it was determined that Betsy would be the best fit as this representative.

THE MOTION TO APPROVE BETSY AS THE NETWORK REPRESENTATIVE WAS PASSED.

b. IACR Location in 2019

Betsy

IACR contacted Betsy to see if NAACCR was interested in hosting IACR in 2019. Betsy checked with Vancouver to see if it was feasible. Unfortunately, the room rate estimate would be too high for international attendees, \$299. It is not practical for Vancouver. However, the Board discussed options for 2020 or a separate meeting. Betsy and Charlie will investigate the option of moving the dates to the fall with Venue West.

2:00 pm Professional Development

24. Steering Committee Update and Plans for Year

Deirdre, Maria

Written update provided.

25. Future Directions to SC

All

- Form more task forces and groups to get work done.
- Work on items for framework of new higher education. Gather best practices from registries for getting staff acclimated not only on the registry but items outside the organization that are important in their job.
- Complete the Survey Course.
- Best practices for recruitment and retention.
- Work with RDU on education in LMS for NDI linkage and MatchPro.

- Get all continuous use items in the LMS.
- Best practices for telecommuting.
- Implement team charter for the next year.
- Global Initiatives – Develop a simplified education plan for low-resource countries to use. Define the basics and developing the materials. Look into analysis on capacity of these countries and what their needs are / capacity and education / operational level may be at.
- CDC Cooperative Agreement – Emphasis on education work on tasks in Cooperative. Agreement. Webinars, in-person workshops, and assessments.
- Hackathon update, evaluation, future steps, and debrief.

2:30 pm Research and Data Use

26. Steering Committee Update and Plans for Year

Isaac / Chris

Written update provided.

27. Future Directions to SC

All

- Annual Report to the Nation: NAACCR’s lead in 2019 ARN. Selecting the special topic.
- Select topics for webinars. E.g., Match Pro.
- Camp Lejeune activities and funding. NAACCR assist registries with linkages.
- RRIDB conversion from CDC to NAACCR. Technology and system upgrade.
- Other Virtual Poled Registry activities.
- Cancer control indicators. Advocacy document and Cancer Control Indicators Fact Sheet. Direction back to RDU to name them something else to know what is being “talked about”.
- Obtain regular statistics of use of Fast Stats and CINA etc. This could be done in conjunction with Communications Steering Committee.
- Work with Communications Steering Committee on marketing strategy and social media marketing strategy.
- Addition of a certification criterion for survival statistics.
- Tract-level statistics to develop a framework on how to pull data together. Provide tools and best practices for this activity.
- After July D.C. meeting, discuss the re-release of data in context of VPR. Use the findings of the July meeting to follow up on.
- Confidentiality of data and security- data release. Possibly parsing out the issues of data release etc.
- Develop a team charter.

3:30 pm Standardization & Registry Development

28. Steering Committee Update and Plans for Year

Heather / Randi

Written update provided.

29. Future Directions to SC

All

- XML Implementation. Develop a plan on how to proceed with next steps of implementation.
- Standards and have UDS vet new data items.
- Continue work on timeliness. Visit the recommendations from the ACCR report. When do we really need our data (wants versus reality). Is it 2 months or 12 months? Note: Critical to have Canadian representation.
- Define who the customers are that say data is needed in 2 months and then find out why they need it and really when they need it.
- Have Communications SC communicate the process and timeline of data delivery.
- NAACCR CDC Renewal- Develop best practices for registries. Work with SRD jointly with CDC on what best practices are needed to be developed.

3:45 pm Communications

30. Steering Committee Update

Lori / Frank

Written update provided.

31. Future Directions to SC

All

- Identify the chair for committee.
- Develop a mechanism where other steering committees send information to the committee. Add messages to other committee agendas to send information. The Communications Steering Committee would not write.
- Messaging to Communications SC from other committees and communication between.
- Member Coordinator with a communications slant to what they will be doing.
- Take oversight of advocacy plan.
- Marketing strategy for social media.
- Define who we are and what we can offer.
- Work with membership coordinator staff person if this happens.
- Continue to incorporate marketing in communications plan.
- Capture the need and message of the Registry of the Future activities.
- Develop a tool to update the SMP in conjunction with the Board / Governance activities.
- Develop / revise team charter.

4:00 pm Additional Business Items

32. Additional Agenda Items From Board

All

Chuck and Lori added the concept of discussing new positions of "Advocacy", "Marketing", and "Policy" positions. They presented a timeline where NAACCR embarks in planning stages of one of these positions or a hybrid. They recommend becoming a member of OVAC (One Voice Against Cancer) to help with the mission and priorities. NAACCR could use a consultant to assist with this but NAACCR can develop the mission primarily on our own. Betsy recommended that NAACCR form a group to develop the mission with members beyond the Board. Tom Tucker, Dennis Deapen, Melanie Williams, Nan Stroup, Frank Boscoe, CPAC representative are some individuals that were suggested as possible

members. This would be U.S.-Centric at first but Canadian influence and activities should be included over time to assist those registries also. A member from CPAC would be a good first step to engage Canada representation.

A similar plan would have to be implemented with the “Membership Coordinator” position.

Advocacy/Policy: Chuck and Lori

Membership Coordinator: Communications Steering Committee

Marketing: Will be handled at a later date.

33. Membership

Maria

a. Kathleen Thoburn

Ms. Kathleen Thoburn has applied for an Individual Membership. The Board discussed Kathleen’s experience and background. The Board will make additional notes to the membership application as discussed. Maria will add some language to her membership acceptance letter.

Yes: 8

No: 1

Abstain: 2

THE MOTION TO APPROVE THE INDIVIDUAL MEMBERSHIP APPLICATION OF KATHLEEN THOBURN WAS APPROVED WHILE ADDING A SPECIAL PARAGRAPH TO THE STANDARD LETTER REGARDING BOARD DISCUSSION ON HER APPLICATION IN RELATION TO PAST EXPERIENCES.

34. Recommendations Follow Up on Geocoder

Frank

The Board was waiting to hear from Mr. Goldberg on special projects and improvements. This will be done later in June. Charlie will add this to the July 2018 agenda.

35. Certification Recommendations

Chris

Chris provided the revised certification criteria document with updated footnotes and language changes. Heather would like to have further discussions with the Council. She would like to proceed with this communication and document prior to making any commitment. Chris noted assumptions on data item submission, issues with adoption, and general criteria for meeting the new level. It was decided that this will be tabled until NAACCR can reach out to Kim Vriends and Statistics Canada.

After discussion, it was determined that this will be placed on the July 2018 meeting agenda. NAACCR needs to know if moving forward with this change will assist Canada. Can the language be changed regarding the Gold and Survival criteria? Chris said that it could be. There will be a town hall meeting after the NAACCR conference once these items have been vetted. In addition, the town hall meeting will confirm that states will not lose their funding if NAACCR certification changes.

36. Policy: Publication and Commentary Submissions Update

Lori / Betsy

This item was brought before the Board in a prior month. The topic still needs to be vetted by the Communications Steering Committee.

37. Board Self-Assessment – Next Steps

All

Nan would like to implement the Board Self-Assessment but will table this at the July meeting once Frank, Nan, and Betsy have had the chance to discuss the options.

38. 2018-2019 Board Meeting Schedule

Nan/Frank/Betsy

Time: 2:00 PM – 4:00 PM Eastern;

*Dates: **Please review in advance for potential conflicts***

July 18, August 15, September 19 (Board/Chair), October 17, November 21 (possibly move to the 14th), December 19, January 16, February 20, March 20, April 17 (Board/Chair), May 15

39. Mid-Year Board-Chair meeting- Date? Location?

All

The Board discussed options for a mid-year meeting. There is consensus to move it to the date to early December with a location in the northeast.

40. 2018-2019 Document Review Schedule

All

This will be tabled until July 2018. The Implementation Guidelines document will need to be finalized.

4:15 pm Executive Director Review and Discussion

41. Review of Executive Director

NAACCR Board

Private Board Session Betsy and Charlie left the meeting.

42. Liaisons for 2018-2019

The Board Liaisons for 2018-2019 are listed below:

Strategic Alliances: Chair: Chuck Wiggins Member: Frank Boscoe

S&RD: Chairs: Winny Roshala and Lori Koch; Liaisons: Wendy Aldinger and Isaac Hands

Pro Dev: Chairs: Frances Ross and Mignon Dryden Liaisons: Randi Rycroft and Deirdre Rodgers

RDU: Chairs: Hannah Weir and Susan Gershman Liaisons: Maria Schymura and Angela Meisner

Communications: Liaisons: Lori Swain and Kyle Ziegler