

Minutes  
Board Meeting  
Thursday March 9, 2017  
Hyatt Regency Princeton, Wilson Suite  
Princeton, NJ

**Roll Call:** Frank Boscoe, Bruce Riddle, Heather Stuart-Panko, Lori Swain, Eric Durbin, Nan Stroup, Winny Roshala, Deirdre Rogers, Chuck Wiggins

**Board Member Excused:** Chris Johnson

**Ex Officio:** Betsy A. Kohler

**Staff:** Charlie Blackburn

**Guests:** Maria Schymura (Incoming Treasurer), Recinda Sherman (staff), Ann Marie Hill (facilitator)

Chuck welcomed everyone to the meeting. He asked for additional agenda items. Lori asked to speak about the Walk the Hill event and the Firefighters Registry Act. Nan wanted to discuss the assignment of reviewers for documents.

1. **Consent Agenda**

**Chuck**

- Minutes
- Finances
- Membership
- Executive Director's Report
- Correspondence

**THE MOTION TO APPROVE THE CONSENT AGENDA FOR MARCH 9, 2017 WAS PASSED**

2. **Financial Updates**

**Charlie**

Charlie provided the semi-annual financials review. He thanked Bruce Riddle for his role as Treasurer. He noted that the financials are in relatively good shape. There were issues earlier in the year with receiving NCI invoices timely. These have since been resolved and has resulted in a much better cash flow situation for the organization. He also went over major bank account and investment pieces, all funds, and future considerations. The next review is at the June in-person meeting in Albuquerque, New Mexico.

3. **Policies Review**

**Lori**

Lori Swain presented the updated policies review document to the Board. She provided the document to the Board prior to the meeting. She split the items into two pieces. One document was a group of policies that had minor edits and require little conversation or debate. The second piece included policies that would require more expert opinion in a certain topic area. Lori recommended voting on the first document and then vote on the second document after expert input in April 2017.

Bruce added that he wanted input on the CINA impact and membership dues. The Board discussed amending the membership non-paid dues policy to "member privileges MAY be revoked".

Members present discussed the second document and decided to address the items at the April 2017 meeting.

**ACTION: THE MOTION TO APPROVE THE PRESENTED POLICY MODIFICATIONS WAS APPROVED PENDING THE CHANGE OF “MEMBER PRIVILEGES MAY BE REVOKED”.**

**4. Walk The Hill**

**Lori**

Lori discussed the Walk the Hill event at NCRA this year. She reviewed the major goals of this event. Specifically, Lori noted a specialty registry point. The Firefighters Registry Act is an example on how we could modify the language to better accomplish the goal of the act. Lori needs a message from NAACCR on what the point would be. The Board discussed a good message is to mention the VPR linkage and the willingness of registries to work with the registries. They thought pointing out that this could be more of an occupational study. They recommend looking at this from a larger scale and not necessarily just local or regional. Lori noted that the current assumption is that this bill will not pass but is still a good opportunity to bring the role of cancer registries forward. It was decided that Chuck and Maria will work with Lori in coming weeks to finalize the message.

**5. Report on Hispanic Coding**

**Frank**

Frank said that they are performing a study at the New York Registry. He noted that they are using a list from 1990 and Hispanic surnames. He suggested moving to an updated list of 2010. The net effect is that we have many more names there would be a 2% change. He noted that we should explain why the change in a comment or footnote in the next publication. After discussion, it was determined to back fill the change also. Betsy asked if this would be used in the Pacific Islander Algorithm and Frank thought so.

**6. Report on Geocoder**

**Recinda**

NAACCR contracts with TAMU for services to the geocoder. The payment for this service is through the NCI Sole Source contract. Frank said that New York started using the service through SEER DMS last year. He immediately noticed some issues from his file. He identified these issues several months ago. The geocoding group has met several times over the last few months. However, Frank has seen little improvement in the process. Recinda provided background also. Specifically, there are some fundamental differences in geocoding. Some issues are due to funding. Others are a result of maintenance. The group came up with four recommendations.

- I. We recommend NAACCR move to a commercial or business entity to support a national-level geocoder to serve the needs of the cancer surveillance system. NAACCR requirements for this system include adequate customer support and precise and accurate geocoding, favoring accuracy over completeness. Additionally, the geocoder must be secure, encrypted, transparent (at a minimum we understand the underlying files used), and able to incorporate our NAACCR defined quality codes.
  - Options for national geocoder (will require additional funding):
  - Academic partners, including our current partner TAMU
  - Large commercial partners, e.g. Google, ESRI
  - Smaller vendors, e.g. GeoStan, Geocodio
  - Technology partners, e.g. IMS, Westat
- II. We recommend NAACCR develop a standard method of defining data quality (in process).
- III. We recommend continuing to work with TAMU to resolve current data quality issues. We need solution to current issue no later than August to enable registries to re-geocode in time for CFD. Individual registries, like NY, may want to use home-grown or other propriety systems until a suitable national system is again available.

- IV. We recommend a limited-duration NAACCR employee to help facilitate geocoding—working with states to identify potential problems and coordinating with entity for resolution.

Recinda and Frank elaborated more on recommendation #4 above. They said that proper geocoding at a national level would require a person to assist registries and users on how to use the tool and interpret data. Recinda said that county is not impacted as much. Tract level is impacted quite a bit. Chuck reiterated that this product does need to be upgraded and possibly replaced.

Lori Swain recommended that the Board consider using reserves to solve this problem. She added that the Board should weigh other opportunities with this topic if reserves are used. Frank and Chuck also think that looking at self-funding is a good opportunity. The Board would like the geocoding group to begin to develop a scope of work, needs, wants, and eventual start to a budget.

## 7. Preparing for What Lies Ahead

AM Hill

Ann Marie reviewed current funding research and comparison of this administration's plans and the Obama administration. Overarching topics included:

- NAACCR in the Trump Era
- Big Data/Precision Medicine
- Branding NAACCR
- Cancer Registration Advocacy Committee

In particular, the Cancer Moonshot is in question. Bruce, reviewed the current government fiscal year budget cycle and impact the continuing resolution may have on NIH / NAACCR. Ann Marie asked the Board to consider what our action will be as a result of very swift and quick decisions by the administration. It was recommended that NAACCR take measures to project changes, identify challenges, contingencies, and then more contingencies. Charlie provided a background graphic on major funding over the last five years. Bruce noted that 80% of NAACCR's budget is from federal sources but a large portion of the remaining 20% comes from states that use federal dollars for the conference and educational products.

Chuck noted that he is not sure if it will be as bad as it looks with many people overreacting.

Ann Mare Hill asked "Will NAACCR speak up for NAACCR?"

### Ideas

Have conference every two years.

Focus on CRAC (Cancer Registration Action Committee) Committee starting up.

Lori recommended having conversations with NCI and CDC to see what will go away if funding is removed.

Consider more active role in advocacy.

Chuck advised approaching this from a more national entity and how we speak to this in the current environment.

Can NAACCR develop products that can be valuable to other audiences? What things are important to us and how can be utilized by other disease registries.

NAACCR as a model for other registries. Can we absorb and operate registries.

Tap into volunteer coordinator.

Bruce Suggestion: Join one voice action. Message on cancer data and where it comes from. Describe to state cancer registries how they advocate for population-based cancer surveillance data from states. Develop a message.

Train registry staff on advocacy.

Tell them our story.

We need to own the term Big Data and change to "Data you can trust"

Join OVAC

Can NAACCR work with a different set of audiences?

Develop an inward thinking group of people to internally look at our data.

### **Big Data/Precision Medicine**

Eric noted that national population-based data enhanced with sequencing will empower the big data piece. He see it as the state registries and not necessarily NAACCR. Precision medicine. State law may require it to be changed.

Other ways to use data. Can we merge our big data with pharma companies? Merge our expertise with big data.

Look for grants and contracts to see if we can repackage products and services to sell.

Carry the example to legislators.

## **8. Summarization and Development of Action Plan**

**All**

**The group summarized a few action items listed below:**

- A. Volunteer enhancement.
- B. Repackage registry data in a way never done before and then sell it.
- C. Sell NAACCR geocoder.
- D. Sell VPR
- E. Implement CRAC
- F. Package and advocacy strategy.

## **9. Adjournment and Next Meeting**

The meeting adjourned at 12:00 Eastern. Betsy and Chuck thanked all in attendance and special appreciation for Ann Marie Hill's guidance and attendance. The next meeting of the Board is scheduled for April 19, 2017 at 2:00 PM eastern.

**2016-2017 Board Meeting Times and Dates: Time: 2:00 PM – 4:00 PM Eastern; Dates: April 19 (Board/Chair Teleconference), May 17**