

## **Attachment A**

### **NCC Genomic Special Interest Group (SPIG)**

#### **1<sup>st</sup> Planning Call Notes**

**November 15, 2010**

**Present:** E. Hill DeLoney (Midwest), Catherine Haywood (South), Freda Motton\* (Midwest), Chykezie Maduka (Southeast), Margarita Holguin (San Diego), Sharrice White-Cooper (CDC), Shantrice L. Jones (CDC), Ella Greene-Moton (CPHCG/NCC)

**Absent:** Winona Hollins-Hauge (Washington), Winona Hollins-Hauge (Washington), Yvonne Lewis (Midwest), Imogene Wiggs (Midwest), Chuck Conner (Southeast), Katie Barnes (Southeast), Arlene Sparks (Midwest), Darlene Leysath, (Southeast), Katrina Brooks (Southeast), David Collins (South), LaShawn Hoffman (South), Sandy Good\* (Southeast), Antonio Tovar\* (South)

**(\*NCC members expressing an interest but limited participation)**

#### **Welcome/Introductions:**

E. Greene-Moton welcomed the call participants and asked each to introduce him or herself. She then provided a very brief summary of the SIPG (the why, what, and when) most of which was presented during the annual meeting in Seattle.

#### **Preliminary Discussion Updates:**

As a result of two opportunities identified prior to the official organization of the SPIG, discussions were underway to respond to the request for abstracts from the Genetics Alliance (which also included a partnership award nomination) and to develop language to be considered during the 2010 CDC SIP process. Unfortunately, we were unable to take advantage of those opportunities because of short and/or clashing deadlines. It was decided that we should still pull foundational information together in preparation for future funding or presenting opportunities. The group further clarified the partnership to be nominated for the Genetic Alliance Award as: NCC, the Center for Public Health and Community Genomics, the Public Health Genomics Office at CDC, and the PRC Program Office at CDC. It was noted that those partners would also be asked to provide letters of support during this process and that the SPIG should work to draft a letter of support for future use.

It was also decided that we should review the language in CDC SIP application, review the draft language we have created as well as try to identify other funders that we might want to approach for funding.

### **NCC Genomics Special Interest Group (SPIG) Overview: (as presented in Attachment A)**

The NCC Genomics SPIG will work to develop and maintain sustainable special interest projects/activities carried out by members representing NCC communities.

In addition, and while proposing to further community genomics and health activities as well as incorporating genomics into future research carried out by the PRCs, the proposed Genomic SPIG could also assist in making clear the current value and potential future value of genomics in achieving community health promotion and disease prevention (e.g. by utilizing family health histories and resources related to genetic testing, and by furthering the responsible use of biobanks).

### **NCC Genomics SPIG Proposed Goals and Objectives**

- **Short term**
  - (a) bring about a better understanding of the research,
  - (b) reflect community values and concerns in the research,
  - (c) facilitate the translation of research into useful applications benefiting the community,
  - (d) encourage community participation in the research, and
  - (e) develop research projects that reflect community interests and address community health issues.
- **Long term**
  - (a) develop expertise in the nature, purposes and anticipated outcomes of genetics/genomics research carried out throughout the U.S.,
  - (b) identify ways in which community goals and concerns can best be incorporated in the research,
  - (c) provide advice to national research organizations conducting and funding genetics/genomics research (e.g. the National Human Genome Research Institute; National Cancer Institute; Centers for Disease Control and Prevention; Agency for Healthcare Research and Quality and Health Resources and Services Administration), and
  - (d) promote the development of local community-linked infrastructure in all NCC Regions.

### **NCC Genomics SPIG Monthly Meetings:**

The group confirmed that the regular meeting date and time will be the 3<sup>rd</sup> Monday of each month at 11:00 am (ET).

### **NCC Genomics SPIG Membership: (as presented in the Attachment B-Membership Roster)**

- A special focus on engaging members from all six of the established NCC Regions (four of the six are currently participating – i.e., Midwest, South, Southeast, West).

- The SPIG membership will consist of NCC reps and/or community members from the local community boards.

The group also discussed the need to decide who should be a member of the SPIG. It was shared that feedback from some academics and practice partners indicated that they are interested in being a member of SPIG. SPIG members discussed having those folk as another layer that we consult with for expert opinion. We could have routine or scheduled as needed calls with them (i.e., quarterly). SPIG members also discussed having local community partners other than NCC Reps. who might be interested, join the SPIG. The SPIG members agreed that this could help broaden the reach in communities throughout the PRC network, take some of the load off the NCC reps, and open participation up to other communities in the PRCs that do not have Genomics as the core project.

#### **NCC Genomics SPIG Structure:**

The SPIG structure right now includes a facilitator (EGM) and the membership. We will discuss the structure in more detail on upcoming calls. A more defined structure could involve specific workgroups within the SPIG to explore multiple topics of interest.

#### **NCC Genomics SPIG Collaborations:**

The mission of the **Center for Public Health and Community Genomics (CPHCG)** is the integration of genomic discoveries into public health practice with consideration of the ethical, legal, and social issues associated with the application of these discoveries, as well as the involvement of the community at large.

A continued collaboration with the CPHCG but also building relationships with other Researchers and Funders (i.e., The Public Health Genomics Office at CDC, NHGRI, other offices at NIH, Genetics Alliance, GAPPNET), and especially joining a combined Family Health History Working Group comprised of several of the organizations mentioned above.

#### **Possible Next Steps:**

Firm-up Goals and Objectives  
Identify collaboration benefits

#### **Next Meeting:**

Next Month's call will be on December 20<sup>th</sup> at 11:00 am (ET)

#### **Call Notes/Updates Captured by:**

Ella Greene-Moton