

NCC Genomic Special Interest Group (SPIG)
April 12, 2011
Spring Planning Meeting Notes
Atlanta, GA

Present: E. Hill De Loney (Midwest), Chuck Conner (Southeast), Chykezie Maduka (Southeast), David Collins (South), Arlene Sparks (Midwest), Ronnie Williams (South), Eugenia Smith (Northeast), Candice Combs (West), Frieda Brown (South), Sharon Shad (Northeast), Sandra Daniel (????), Tim Tramble (Midwest), Frieda Gonzales (Southwest), Debra Jackson (Northeast), Jean Frank (Midwest), Joann Malumaleumu (West), Ella Greene-Moton (CPHCG/NCC)

Absent: Darlene Leysath, (Southeast), Katrina Brooks (Southeast), LaShawn Hoffman (South), Freda Motton* (Midwest), Margarita Holguin (West), Catherine Haywood (South), Sandy Good* (Southeast), Imogene Wiggs (Midwest), Katie Barnes (Southeast), Antonio Tovar* (South), Winona Hollins-Hauge (West), Yvonne Lewis (Midwest), Sharrice White-Cooper (CDC), Shantrice L. Jones (CDC)

*** Interested/limited participation**

Welcome/Overview:

E. Greene-Moton officially welcomed participants to the NCC Genomic SPIG breakout during the spring planning meeting in Atlanta and invited the meeting participants to take a moment to introduce themselves by sharing their name and the PRC and organization they represent (see attendees above). Participants were encouraged to sign the sign-in sheet to ensure that they could be kept in the loop with all communications.

She provided a brief overview of the Genomics SPIG. She shared that the group grew out of the discussions and recommendations during the GenoCommunity Think Tank held in St. Louis MO in 2010 and that the group has been meeting via conference calls over the past several months to firm up the group's goals and objectives.

Several documents were shared with the meeting participants to help clarify past discussions (**i.e., definitions, the SPIG's proposed focus, the draft proposed goals and objectives, ongoing discussions, and a proposal request to the Templeton Foundation**). Background information was provided on each of the documents as well as the overall purpose of the SPIG prior to moving to the proposed discussions. The overview also included information on a possible funding opportunity from the Templeton Foundation as well as the West Virginia funding opportunity from the National Human Genome Research Institute (NHGRI).

Group Discussions: During the discussion period, E. Greene-Moton asked participants to take a few minutes to review the draft goals and objectives document and provide comments with the hopes of approving the document and moving it beyond the draft phase.

- **The Overarching Goal** (review and comments)

T. Tramble shared that while he could support the second portion, he had some concerns about the lead statement of the goal. One concern was that the goal and objectives should be measurable. Others agreed and as the group continued to discuss the statement, E. Greene-Moton suggested the following change in the language of the overarching goal:

The development of an **informed and effective community voice in Genomics, integrating Genomics into the current research agendas of local PRC programs**

Other modifications were made to the short term and long term goals

- **Short Term Goals**

- (a) **facilitate** a better understanding of the research
- (b) reflect community values and concerns in the research
- (c) **advocate for** the translation of research into useful applications benefiting the community
- (d) encourage community participation in the research
- (e) develop research projects that reflect community interests and address community health issues

- **Long Term Goals**

- (a) develop expertise **through capacity building** 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)
- (d) promote the development of local community-linked infrastructure in all NCC Regions

The above modifications were made to the short term and long term goals and approved by the group. Given the limited time, meeting participants agreed to continue discussions and or updates over email and monthly calls.

Notes captured by E. Greene-Moton