



# Community Genetics Forum:

## A model for engaging the “Public”

Public Participation in Nanotechnology Workshop  
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Vence L. Bonham, J.D.

Chief, Education and Community Involvement Branch  
National Human Genome Research Institute,  
National Institutes of Health



# THE GENOME IS MAPPED. NOW WHAT?

It will be decades before scientists identify and understand all of our genes. But that hasn't stopped them from making dramatic discoveries

By **MICHAEL D. LEMONICK**

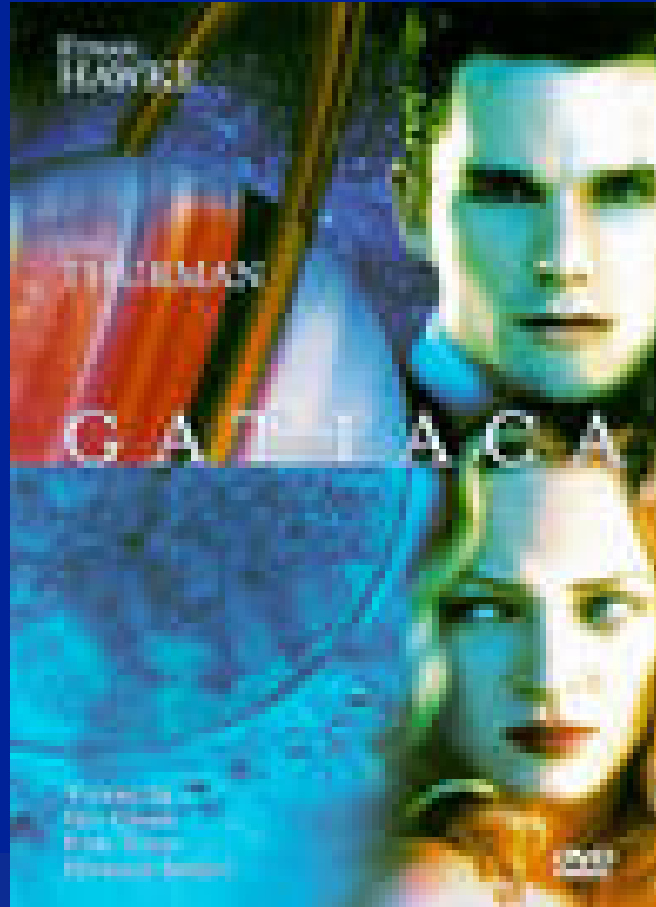
IT WAS SUPPOSED TO BE LIKE PUTTING

ard Hughes Medical Institute, "it's written in a foreign language. It's a very complicated problem. It's going to be a long time



# Fact or Fiction

## Genetic Discrimination



# Public Participation

How can a Federal Agency (NHGRI) effectively engage communities in conversations about genetics?

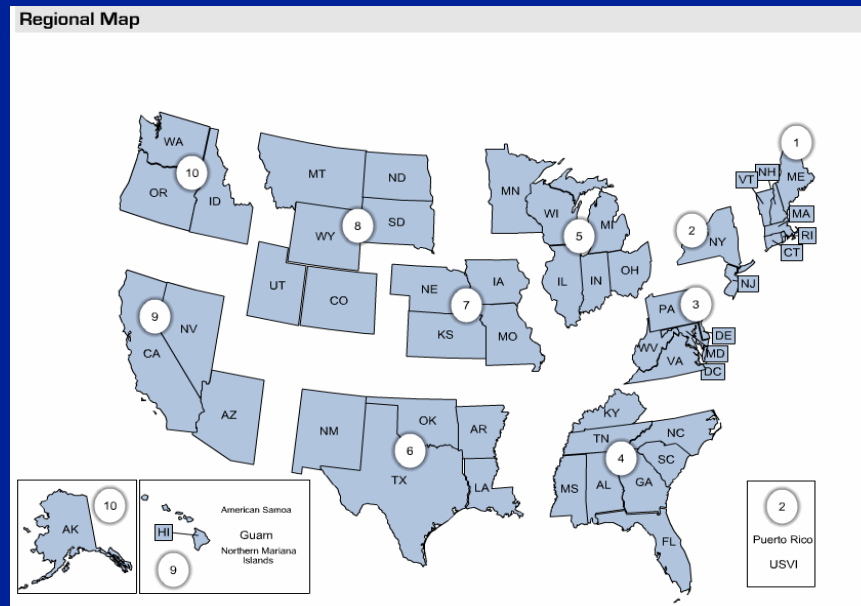
- To learn from the public
- To educate the public
- To involve individuals and communities (not always all 3 together)







# Community Genetics Forum: Beyond the Beltway



# Community Genetics Forum Goals

- To increase awareness and understanding of the field of genetics, genomics, and the ethical, legal and social implications of genetics research
- To engage the community in a dialogue to identify questions, concerns and education needs related to genomics
- To engage a target audience including underrepresented minorities and special populations
- To facilitate the establishment of sustainable community relationships that continue beyond the forum



# Community Genetics Forum

- NHGRI works with local organizations to carry out community engagement programs
- 8-12 months planning
  - Small, community group consultation
  - Identification of topics of interest
  - NHGRI experts involved in Forum event
- Host organization within the geographic community
- Evaluations to determine whether goals were met





# 2005 Forum

- University of Washington and Community Advisory Board planned, hosted, evaluated the program
- Included diverse and underrepresented communities from the Seattle and Washington area
- Included business leaders, policymakers, teachers and students
- Included underrepresented American Indian and Alaskan Native communities in genetics participating both in the Forum itself as well as the planning of the event.
- 15 Representatives of NHGRI actively participated in the Forum including Francis Collins, PhD, MD, NHGRI Director



# 2006 Forum

- University of North Carolina/Duke University hosting the 2006 Community Genetics Forum
- Community Conversations over a six month period (libraries, churches, community groups, schools)
- Movie Series and Community Conversations
- Forum to be held September 14-16, 2006
- Targeting communities across the state of North Carolina



# Community Genetics Forum: Strengths

- Model systematically addresses need for engagement on national level
  - New location each year, different region
  - Sustainable relationships following Forum keep interactions alive in past regions
- Subsequent Fora informed by earlier processes and programs
- Consistent funding/managing from NHGRI allows for Fora to improve each year and take advantage of lessons learned



# Community Genetics Forum: Weaknesses

- One year interaction with Institutions
- Forum held in multiple day conversations, may not be enough time to sufficiently “engage”
- Funding from NHGRI is limited to one year
  - Therefore connections and relationships must be sustainable outside of this funding



# Public participation: Challenges

- Public perception of Federal Agency organizing event in genetics is not always positive
- Goals/approaches of NHGRI may not be consistent with those of academic or community organization
- Goals are NHGRI's; but must be carried out by local organization





# Community Genetics Forum: Principles

- Involve community members and stakeholders in planning at the beginning
- Utilize Forum as a conversation, not as an event
- Allow local host organization the room to make decisions while ensuring that overall goals are met



# Principles

- Active Involvement of Senior Leadership
- Listen to the public
- Educate (Fact vs. Fiction)
- Aggressively engage those underrepresented in genetics and science

