

# **Creative approaches to developing and disseminating culturally appropriate genetics education information to African American communities**

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# Project Goal

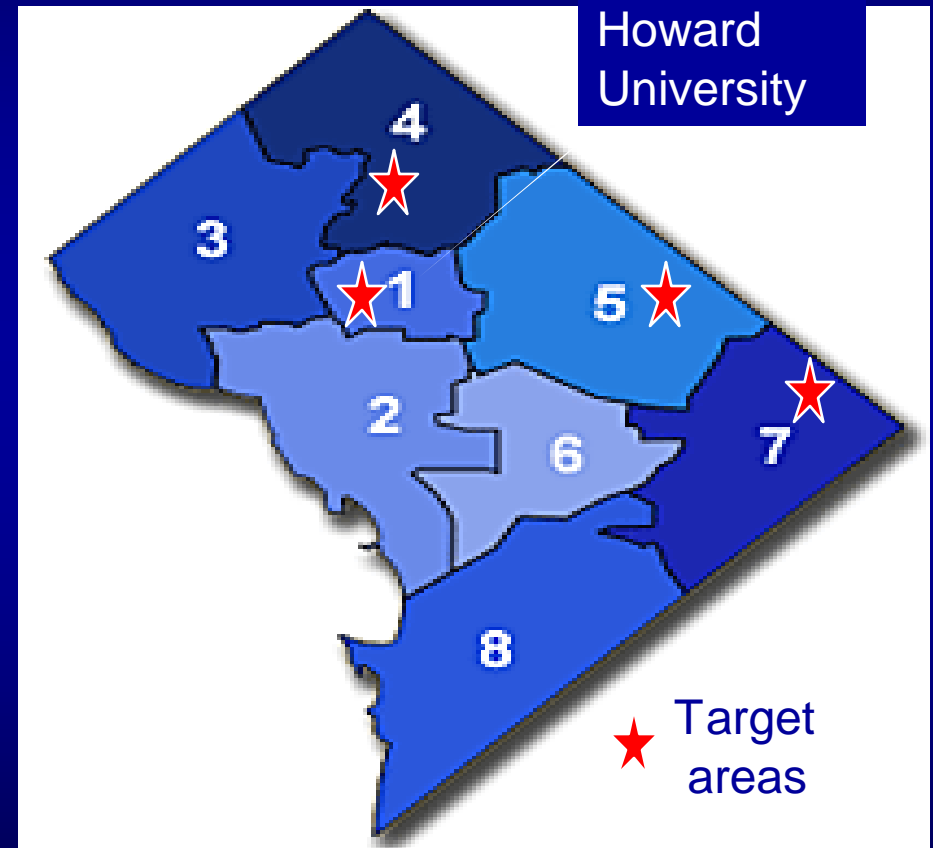
- To improve the genetic literacy of African Americans in the Metro Washington DC area and facilitate their active participation in efforts to promote health and eliminate health disparities

# Objectives

- Design and develop culturally relevant materials on genomics and ELSI (ethical, legal, and social implications)
- Disseminate genetics educational materials into the African American community
- Engage African Americans in ongoing dialogue about human genome research, its associated implications, and the role of genomics in the elimination of health disparities at community events

# Our Community

- According to the U.S. Census, Black people make up 55.4% of the total population of DC
- Heart disease, cancer, hypertension, and diabetes are the leading causes of death for African Americans in target areas



# Why the need for genetics educational materials

- Focus groups were conducted to assess the knowledge of African Americans and their perceptions regarding genetic research and genetic testing.
- Information revealed:
  - Participants wanted more information about the connection between genetics and disease
  - Greater understanding of the possible impact of genetic tests on employment opportunities and insurance coverage
  - Need for information that was easily understood
  - Wanted greater understanding of genetics research based on what they had heard in the news

# Do's and Don'ts

## •Do

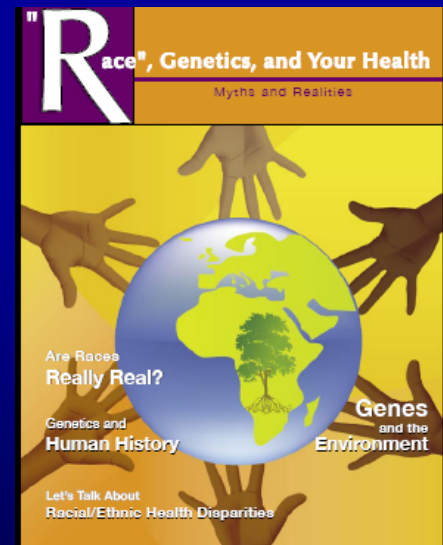
- Create interactive materials –include games, puzzles, etc.
- Make colorful brochures that represent the community
- Talk “to” the audience and not “at” them

## •Don't

- Present information as a ‘talking head’
- Provide information that is not easy to understand

# Development of Educational Materials

- The Importance of Family Health History
- Race, Genetics and Health
  - 2 handbooks
  - 1 Public Service Announcement (PSA)
  - 1 Website
  - Toll free number



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# Community Participation

- **Focus Groups**
  - 3 focus groups (N = 22)
- **Community Advisory Board**
  - 6-8 community members
- **Responsibilities**
  - Reviewed draft materials
  - Provided feedback and suggestions



# Feedback Summary

- **Very open to offer feedback and suggestions**
- **Liked the concept; felt the materials would be useful for the African American community**
- **Preferred that more of the images reflected African Americans and the African American culture**

# Local Dissemination Efforts

- **Bi-weekly community education workshops – combining an interactive visual presentation with the handbooks as educational materials**
- **Community forum discussions with African Americans in the Washington, DC Metro Area on family health history, race, genetics, and the environment**

# Next Steps- Town Hall Meeting

- Plan and host a town hall meeting in February 2008
- Topic areas
  - Genetic testing
  - Genetic discrimination
  - Genes and environmental interactions
  - Family health history
  - The impact of race and the environment on health

# Challenges

- **Changes in staff**
  - **Project Coordinator**
  - **Principal Investigator**
  - **Local Evaluator**
- **Changes to the project's objectives and timeline**
- **Working through University policies procedures**
- **Time consumption to edit and revise of materials**

# Rules of (Community) Engagement – Lessons Learned

- Important to gather as much community input as possible
- Ask questions of community leaders- they are closest to the community
- Recruit members with interests that support the group's objectives to the community advisory board
- Show appreciation of community- respect the invitation

# Conclusion

- **Our hope is to:**
  - **Provide a mechanism for African American families to discuss their family health history with family members and their health care providers**
  - **Address the concerns of the community regarding race, genetic testing, and the health of African Americans**
  - **Increase awareness and promote understanding of genetics and health**

# Thank You's

- Local community leaders and families
- Project Staff
- Community Advisory Board
- March of Dimes Foundation
- March of Dimes Foundation National Capital Area Chapter
- HRSA
- APHA

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# Family Health History PSA

