

C G T A C G T A  
A C G T A C G T

# NHGRI Community Engagement in Genomics Working Group

**Gwen Darien, Chair**

Executive Vice President for Patient Advocacy and Engagement, National Patient Advocate Foundation

February 11, 2019

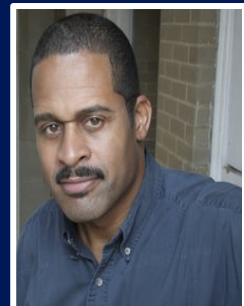
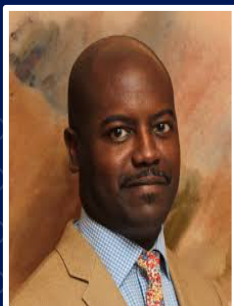


National Human Genome  
Research Institute

—  
The **Forefront**  
of **Genomics**<sup>®</sup>  
—

# Who We Are

A C G  
C G T  
A C G



# Project Partnerships

A C G  
C G T  
A C G



# Honest Feedback from Diverse Perspectives

A C G  
C G T  
A C G

**All of Us**  
RESEARCH PROGRAM





# Creating Dialog and Intersections

- National Patient Advocate Foundation
- Crow Nation – Little Big Horn College Community Meeting
- Genetic Alliance Epigenomic Infographic & Draft Guide to Community Partnerships and Needs Assessment
- Morehouse University's School of Medicine – NHGRI Strategic Planning Community Gathering
- NHGRI History Program Speaker Series: Historical Trauma

# Understanding What Communities Need

- “There is little awareness about genomics and lots of misconceptions.”
- “There are very limited resources for genetic testing or counseling in our community”
- “I think every cancer patient should know about their potential risk, and whether they should or should not be tested.”
- “These communities are very solution-oriented, so any engagement that focuses on understanding their disease, drug discovery, or diagnosis can be effective. General genomics education is of less interest.”
- “Community health educators are one of the key tools to deploy into communities with information about the impact of genetics and testing.”
- “Dissemination of culturally relevant information on the influence of genetics and environment on chronic diseases affecting our population (ex. diabetes, cancer and obesity)”

# Identifying Barriers or Concerns

- “Many LGBTQ people are very concerned about genomics. The recent news regarding the federal government's proposed definition of sex as immutable and based solely on chromosomes, many transgender people think of genomics/genetics as a tool of an enemy.
- Latinos as a group are not homogeneous in their beliefs, thinking, culture or history. There is some resistance among some - particularly those with indigenous beliefs - about sharing their spirit.

# Collaborating to Find What Works

- “Follow the lead of the communities themselves, who have already been working to improve patient experience.”
- “Fund research on patient engagement and satisfaction in the clinical encounter.”
- “Needs assessments, tools to collect patient feedback.”
- “Help bring communities and health care providers together in a discussion about genomics and health that provides a safe space for everyone to raise questions.”
- “I know we say this about every topic....bringing genomics in early and often into schools at every level will then help it to diffuse into communities.”
- “I truly believe the more we have local community based individuals working to provide the day to day outreach, education, resources and with all the available materials we would impact more on the genomics health research. We could meet with our local, Tribal and state representatives in expanding the goals of NHGRI.”





The **Forefront**  
of **Genomics**<sup>®</sup>