We’d been sitting in a waiting room in the Bronx for an hour, in a room filled with people who were struggling, who barely spoke English, who needed help, only to have a smug doctor tell me to Google my mother’s serious condition and devise a plan for her.

Yvonne, Latino American, caregiver for her mother with Alzheimer’s Disease

Alzheimer’s Disease (AD) in Underserved Populations
A Landscape Analysis: Situation, Barriers & Solutions

The Problem
• African Americans and Latinos are more likely to develop Alzheimer’s Disease than non-Hispanic whites.
• Death from Alzheimer increases in all groups in the United States, but even more in African Americans and Latinos.
• African American’s represent ~20% of the 5.4 million Americans with AD, yet they account for less than 5% of trial participants.

Project Goals
• Identify disparities in Alzheimer’s Disease, specifically in the African American and Hispanic populations
• Examine what can be done to address these health disparities
• Identify the role Biogen can play in addressing disparities in Alzheimer’s Disease

Barriers to Diagnosis and Clinical Trial Participation in African American and Latino Communities

Disease Awareness
• Lack of disease awareness and understanding
• Dementia seen as normal aging
• Focus on other diseases: Diabetes, Heart disease, Colon Cancer

Stigma
• Negative connotation around mental health issues
• Mental health issues seen as curse in some cultures
• Fear and denial barriers to timely diagnosis

Healthcare Providers
• Screening and memory conversations not suggested or initiated
• Little questioning or demand for second opinion
• Little time with patients

Clinical Trials
• Low awareness
• Lack of trust: Previous unethical procedures barrier; belief that enrollment could happen without consent
• CTs not recommended – sometimes lack of options

What Can Be Done?
• Targeted disease education in culturally appropriate language
• Differentiate AD vs normal aging
• Educate about brain health, cognition and cognitive impairment
• Increase understanding of the AD continuum: disease starts 15-20 years before the first symptoms
• Identify Ambassadors and Key Influencers in the communities
• Engage churches and faith organizations
• Create Ambassador Programs
• Engage Clinical Trial sites – support recruitment of trial coordinators
• Work locally – city to city
• Be present and invest in relationships

What Can Biogen Do?
• Targeted disease education
• Co-development of service models: ensure input and feedback from diverse communities in the development of services and tools in AD
• Primary care physicians education with partners in the community – identify and support initiatives to educate and raise awareness about AD
• Support church organizations and other integrated and credible organizations to promote clinical trials in general
• Engage and support our clinical trial sites

Potential Challenges
• Credibility of industry and lack of relationships
• Commitment from clinical trial sites, e.g. due to lack of time
• Short timelines and lack of long term commitment

“The first person to be cured of Alzheimer’s is a person in a Clinical Trial”
African Americans Against Alzheimer’s

Sources: Alzheimer’s Association, LatinosAgainstAlzheimer’s, AfricanAmericanAgainstAlzheimer’s, Alzheimer’s Disparities Leadership Summit
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