Building a Partnership to Promote Minority Research Engagement in MS

2017 NMQF National Leadership Summit and Spring Health Braintrust
About Multiple Sclerosis

- MS is a disease of the central nervous system
- It is the most common disabling neurological disease among young adults
- Effects include visual impairment, motor weakness/paralysis, bowel and bladder dysfunction, cognitive impairment, depression and anxiety, and many others
- There are 14 FDA-approved disease-modifying therapies with more in the pipeline
  - But no evidence to support personalized choice of therapy
- MS is found worldwide, and is more common away from the equator
Two Misconceptions about MS
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Misconception #1: MS is a white matter disease
Two Misconceptions about MS

Misconception #1: MS is a white matter disease

Misconception #2: MS is a white person’s disease
Minorities Are Missing in MS Research

Recent examples (2011):

**RRMS Trials for Ocrevus®**
- White (1500 patients)
- Black or African American (72 patients)
- All Other (84 patients)
- 91%

**PPMS Trial for Ocrevus®**
- White (689 patients)
- Black or African American (14 patients)
- American Indian or Alaska Native (5 patients)
- All Other (24 patients)
- 94%

*From FDA’s Drug Trials Snapshots*
Why Does It Matter?

• We can’t apply results of studies to populations that weren’t represented
  • No hope of personalized medicine for minorities with MS without greater inclusion and participation

• We have an incomplete picture of MS if everyone isn’t included
  • For instance, what causes MS may be different from group to group

• Research priorities won’t reflect topics that matter to everyone
  • Lack of inclusion and participation means lack of engagement; lack of engagement leads to lack of a voice in decision-making
With funding from PCORI:

1. Form a multi-stakeholder network to combine knowledge and assets
2. Gather information and resources to understand what is driving this imbalance
3. Develop and implement targeted outreach efforts
4. Analyze our effectiveness and adjust accordingly
5. Disseminate our findings and materials
The MS Minority Research Engagement Partnership Network

- **People with MS/Project Advisors**
  - Shawn Feliciano
  - Anita Williams

- **MS Researchers/Clinicians**
  - Lilyana Amezcua
  - Mitzi Williams
  - Daniela Pimentel Maldonado

- **MS Advocacy Organizations**
  - Accelerated Cure Project – Hollie Schmidt
  - MS Association of America – Gina Murdoch
  - National MS Society – Deb Frankel

- **Strategy/Public Health and Science Communications**
  - Feinstein Kean Healthcare – Monique LaRocque and Melissa Glim

- **Minority Health Associations**
  - MANA – Amy Hinojosa
  - National Black Nurses Association – Erica Davis
  - National Hispanic Medical Association – Minerva Campos
  - National Minority Quality Forum – Laura Lee Hall

- **Pharma/Biotech**
  - Biogen – Terrie Livingston and Jeff Smith
  - Genentech – Daniel Machemer and Damian Fiore
Understanding Barriers

People with MS
- Mistrust
- Cost and logistics
- Lack of family support
- Lack of information

Clinicians
- Fear of having patient go elsewhere
- Concern about safety
- Lack of awareness about research studies

Researchers
- Lack of translation resources
- Anticipation of rejection
- No incentive (e.g., for CROs to reach to minority sites)
Understanding Facilitators

Offering an opportunity to their patient
Contributing to the development of new treatments

People with MS
- Health benefits
- Language-appropriate materials
- Altruism
- Convenience

Clinicians

Researchers
- Better research
- Ability to answer more questions
Data Collection Plans

• Survey people with MS (iConquerMS members, National MS Society, MS Association of America, others)
  • Demographic and MS characteristics
  • Clinical care
  • Perceptions about and past experience with research
  • Importance of various barriers and facilitators

• Understand barriers and facilitators among MS clinicians and researchers
  • Institutional and transactional factors
  • Personal experiences and perceptions
Outreach Ideas

- People with MS
  - Social and traditional media
  - Community meetings and partner events
  - MS Sunday

- MS researchers
  - Publications, presentations
  - Outreach through funders

- MS clinicians with minority patients
  - Materials about the importance of diversity in research
  - Information about clinical studies
How You Can Help

• Publicize our survey for people with MS
• Tell us about complementary efforts and resources
• Let us know about research opportunities of interest to minority individuals with MS
• Learn more at http://tinyurl.com/MSMinorityResearch
• Contact us at msminorityresearch@acceleratedcure.org
Thank you for your attention!