

**National Association of Insurance  
Commissioners (NAIC):**

**SPECIAL (EX) COMMITTEE ON RACE AND INSURANCE  
HEALTH WORKSTREAM**

*Disease Prevention from the Consumer Perspective—*

**Presented by:**

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# ALS Overview

- ALS, or amyotrophic lateral sclerosis, is a progressive neurodegenerative disease that affects nerve cells in the brain and spinal cord.
- ALS robs people of the ability to walk, talk and eventually breath.
- At diagnosis, people are given 2-5 years to live.
- There is no cure.
- 34,000+\* people living with ALS in the US.

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# ALS & Preventive Services / Health Equity



- "There is a 65% increase in diagnostic delay for African American patients compared to Caucasian patients," Dr. Kelly Gwathmey, VCU's ALS Clinic Director, said. "The key is finding these patients early in their disease to initiate medications that slow progression and prolong their lives."
- "Doctors did not initially diagnose Dewayne and instead decided that he must have HIV, multiple sclerosis, an immune disorder, neuropathy, or be a drug user." Chelsey R. Carter, PhD MPH, Presidential Postdoctoral Research Fellow and Assistant Professor at Yale University.



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# ALS & Preventive Services / Health Equity Policy Solutions

## Policy Interventions

- Coverage of genetic counseling & testing.
- Nondiscrimination protections for genetic testing in life, long-term care, and disability insurance.
- Policy requiring diversity in clinical trials.
- Policy and funding for diversifying health care and research workforces.

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