Nothing to Disclose
Discussion Topics:

1. NINDS and OGHHD Mission
2. Health Disparities and Health Equity
3. NINDS strategic planning process
4. NINDS Portfolio Analysis and Public request for information (RFI)
5. Inclusion in clinical research
6. Diversity Training and NIH Health Equity Programs
7. Questions???
The mission of NINDS is to seek fundamental knowledge about the brain and nervous system and to use that knowledge to reduce the burden of neurological disease for all

Strategies:

• Invest in basic, translational and clinical research
• Identify gaps in research and public health needs
• Train a talented and diverse research workforce
• Support development of tools and resources to enable discoveries
• Communicate and collaborate with all stakeholders, including the public
• Evaluate and continuously improve all NINDS programs
NINDS Health Disparities Statement:

The NINDS is committed to reducing the disproportionate burden of neurological disease borne by underserved groups of society, including racial and ethnic minority, rural, and socioeconomically disadvantaged populations, by funding a spectrum of research from basic science through clinical studies and training the next generation of health disparities investigators.
MISSION STATEMENT:

• The NINDS Office of Global Health and Health Disparities leads the coordination and development of programs and initiatives that foster national and international research on disparities and inequities in neurological disease.

• Objectives for the Office include:
  – building sustainable capacity in Low and Middle-Income Countries (LMICs) to conduct and apply research to address public health challenges associated with neurological disorders;
  – supporting bilateral partnerships between the U.S. and middle-to high-income countries in research areas that are of mutual interest; and
  – advancing research on tailored prevention and treatment strategies aimed at improving health outcomes in underserved and understudied populations in the US, (including racial and ethnic minority, rural, sexual gender minority, and socioeconomically disadvantaged populations, through investments in research and training).
  – Congressional Reporting

*Strategic Planning for next 5 – 10 years
Why are we so concerned about disparities?

It’s a major problem...!!!

Stroke has the greatest disparity in neurologic mortality!!!
Major Neurological Health Disparity

Ischemic Stroke
Hemorrhagic Stroke

MRI GRE

CT
Recent Pattern of Racial/Ethnic Disparities in Stroke Mortality
(1999 – 2018)

In fact:

- Between 1949 and 1951 the white-to-nonwhite (largely black) stroke mortality was 1.63 for men and 19.2 for women.

- We have made little progress to reduce the racial disparity in stroke in the last 70 years!

- George Howard, PhD, UAB School of Public Health, Dept of Biostatistics
The slave market in Atlanta, Georgia, 1864 (Library of Congress)
Slaves work in Sea Islands, South Carolina. (Library of Congress)
Geographical stroke disparities

Stroke Death Rates, 2014 - 2016
Adults, Ages 35+, by County

- 23.1 - 62.9
- 63.0 - 70.0
- 70.1 - 76.4
- 76.5 - 84.1
- 84.2 - 194.9
- Insufficient Data

Stroke Belt
Alabama
Arkansas
Georgia
Louisiana
Mississippi
North Carolina
South Carolina
Tennessee

Rates are spatially smoothed to enhance the stability of rates in counties with small populations.

Data Source:
National Vital Statistics System
National Center for Health Statistics

NIH National Institute of Neurological Disorders and Stroke

CDC Center for Disease Control and Prevention
Nearly 20% of the U.S. population resides in non-metropolitan areas where they experience many of the same health challenges as their urban counterparts.

Rural Americans are a population group that experiences significant health disparities.

Rural risk factors for health disparities include geographic isolation, lower socioeconomic status, higher rates of health risk behaviors, limited access to healthcare specialists and subspecialists, and limited job opportunities.
Williams, Olajide and Ovbiagele, Bruce. “Stroking Out While Black- The Complex Role of Racism.” JAMA Neurology, Aug 2020

Major Points:

a.) NINDS funded REGARDS found that only 40% of Black-White incidence disparity is attributed to prevalence of traditional risk factors.

b.) 60% of the remaining disparity unclear factors.

c.) Some part of this (60%) stroke disparity may be related to the Levels of Racism framework:
   1. Structural, 
   2. Inter-Personal 
   3. Internalized racism

d.) More research funding in these areas is required with an “equity lens”.
• **Goal:** Develop a comprehensive plan to guide research investments over the next 5 – 10 years

• **Components/inputs into the planning process:**
  o NANDS Workgroup led by Drs. Karen Johnston and Edwin Trevathan
  o Health Equity Coordinating Committee (HECC)
  o NINDS Health Equity Workgroup (HEW)
  o Health disparities portfolio analysis
  o Request for Information (RFI)
  o Trans-NIH WG (16 ICs)
  o Literature review
  o Previous recommendations 2011
  o HEADWAY Workshop on September 22-24, 2021 (Capstone of the process)

• **Outputs/products:** Reports of the planning process, findings, and key recommendations (as approved by the NANDS Council) to be widely disseminated to researchers and the public.
Definition:
Health People 2020 defines health disparities as a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage.

(May be related to race/ethnicity, socio-economic status, gender, age, geographic region, etc.)

http://www.healthypeople.gov/hp2020/advisory/PhaseI/sec4.htm#_Toc211942917
Healthy People 2020 defines *health equity* as the “attainment of the highest level of health for all people. Achieving health equity requires valuing everyone equally with focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and health care disparities.
NANDS Steering Committee Orientation and Mission:

- Advise the NINDS on our process and make recommendations
- Develop comprehensive recommendations
- Focus on areas where the NIH/NINDS can have an impact
- Participate in the HEADWAY workshop and present draft recommendations for public input
- Points to Consider:
  1. Leveraging prior neurological research investments
  2. How can we strengthen the science?
  3. Identification of strategies/interventions known to address biologic- and socio-determinants of health
  4. Ensuring sustainability through community participation and other partnerships
Sub-Committees

**Sub A** – Determine strategies, targets, interventions, type of collaborations needed to optimize interventions that can be implemented and scaled-up.

**Sub B** – Discuss impact of SDOH and ACE and how this impacts HD in neurological disease across the lifespan. How can this be addressed through research interventions that can be scaled-up.

**Sub C** – Discuss and develop an NINDS Health Equity Research framework

**Sub D** – Calculate the excess death from neurological conditions in US (in blacks and other R/E groups compared to whites).

**Sub E** – Develop strategies and best practices to communicate HD-related scientific information and NINDS programs and funding announcements to diverse communities, including investigators, medical providers, and community members.

**Sub F-1** – Develop and outline strategies and best practices for training, recruitment, and retention of a diverse health equity research workforce.

**Sub F-2** – Develop and outline strategies and best practices for increased health equity training in the neurosciences/neurology.

**Deliverables**

Each subcommittee has incorporated their findings and recommendations into separate manuscripts for publication in a special issue of the journal *Neurology*
How many US deaths from neurological disease would have been averted had NH-Black Americans experienced the same mortality rates as NH-White Americans?

- **Methodology**
  - Death Counts – NCHS/CDC – 2010-2019
  - Neurological Disease – ICD -10
  - National Institutes of Health Research, Condition, and Disease Categorization (RCDC) system
    - Neurological Disease (e.g. ICH)
    - Potential Neurological Manifestations (e.g. HTN)
  - Non-Hispanic White (NHW) - reference

- **Steven H. Woolf, M.D., M.P.H,**
  - Director Emeritus of the Center on Society and Health at Virginia Commonwealth University
  - Professor of Family Medicine and Population Health.
  - C. Kenneth and Dianne Wright Distinguished Chair in Population Health and Health Equity
Age-Adjusted Mortality
Neurologic Disease by Race and Ethnicity
(2010-19)

Difference – NHB vs NHW
Nadir – 2011 4.2/100,000
Peak – 2019 7.0/100,000

Race-ethnicity
NH White
NH Black
NH Asian/Hawaiian
NH AIAN
Hispanic
Avertible Neuro Disease Deaths by Year if NHB Americans had Same Mortality Rate as NHW Americans

Total N=29,986
HEADWAY
Health Disparities and Inequities in Neurological Disorders Workshop

Organized by the NINDS Office of Global Health and Health Disparities

Available on NIH Video Cast

Day 1: https://videocast.nih.gov/watch=43834

Day 2: https://videocast.nih.gov/watch=43837

Save the Date • September 22–24, 2021
RFI: Background and Characteristics

A. NIH marketing
   • Responses collected through April-July 15, 2020

B. Direct solicitation
   • Non-Profits 376
   • Professional societies 92

C. Format
   • Multiple choice demographic questions
   • Short answer questions

D. Submissions
   • Responses 141

E. Analysis
   • Qualitative HD Coding
     – HD definitions and categories were developed from HD literature, expert consultation, NIMHD framework, and portfolio analysis collaboration
     – Majority consensus
   • Categories coded (combinatorial elements)
     – Neurological Disease Areas
     – Vulnerable Populations
     – Interventions
     – Gaps
   • Responder excerpts

Responder Type

- Health Care Provider
- Researcher
- Patient Advocate
- Patient
- Caregiver
- Government Official

Proportion of Responders (%)
<table>
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<tr>
<th><strong>KEY</strong></th>
<th>Other</th>
<th>Pain</th>
<th>PD</th>
<th>Dementia</th>
<th>Brain Injury</th>
<th>Stroke</th>
<th>Epilepsy</th>
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<th><strong>A. Organizations by neurological disease area</strong></th>
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<td><strong>1. TBI, Stroke, Pain well represented</strong></td>
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<td>Collaborative Working Group from Columbia University, NYU, and St John’s University</td>
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<td>National Multiple Sclerosis Society</td>
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1. **Health service** – describes measures to increase health services, care, or HCP capacity (providers/interpersonal) (i.e. bias training; HC system/community; more nurses or increase in Spanish speaking staff; hire more primary care physicians)

2. **HD Research or Research strategy** - Describes measures to increase HD research capacity, funding, prioritization, or knowledge (i.e. more research; adding CHWs, increasing trial inclusion)

3. **Subject Capacity** - describes increasing patient/individual level resources (i.e. health literacy increase or snap benefits or employment opportunity, food access, housing access, supply population with blood pressure monitors)

4. **Health Policy** - Describes structural healthcare management (i.e. ACA/expand acceptable insurance in health system)

5. **Advocacy and awareness** - describes social campaign at any level (not research strategy) (i.e. Using social Pressure to Invoke Change, develop or empower community or to promote structural change like food security, or transportation)
Selected Examples:
- Reasons for Geographic and Racial Disparities in Stroke/VCID in a Biracial Cohort (REGARDS), 2001-Present; VCID added in 2018
- Brain Attack Surveillance in Corpus Christi (BASIC) Study 1999-Present
- The Northern Manhattan Study (NOMAS), 2003-2020; Cognitive component added in 2015
- Atherosclerosis Risk in Communities (ARIC) Neurocognitive Study, 2010-present
Only 16 of 58 applications described community engagement strategies.
Why are recruitment and inclusion of diverse populations (e.g. race, ethnic, gender, age) important for clinical trials:

1. Diversity of clinical trial participants is needed to help ensure that the trial population is representative of the patients who will use the medicine, medicinal product or intervention and ensure that the results are generalizable. (Rigor)

2. Participants in research should reflect the diversity of our culture and conditions, taking into account race, ethnicity, gender, age, etc.

3. The lack of diversity among research participants has serious ethical and research consequences.
Why are recruitment and inclusion of diverse populations (e.g. race, ethnic, gender, age) important for clinical trials:

**IT’S THE LAW...!!!!**

The NIH is mandated by the Public Health Service Act sec. 492B, 42 U.S.C. sec. 289a-2 to ensure the inclusion of women and minority groups in all NIH-funded clinical research in a manner that is appropriate to the scientific question under study. The primary goal of this law is to ensure that research findings can be generalizable to the entire population. Additionally, the statute requires clinical trials to be designed to provide information about differences by sex/gender, race and/or ethnicity.
Why Diversity matters to NINDS?

• Recruitment of the most talented researchers from all groups;
• Creates Improvement in the quality of the educational training environment;
• Balanced perspective in setting research priorities;
• Improves capacity to recruit subjects from diverse backgrounds into clinical research protocols;
• Improved capacity to address health disparities.
NIH Definition of “Diversity”

- Individuals from **underrepresented racial and ethnic groups**
- Individuals with **disabilities**, who are defined as those with a physical or mental impairment
- Individuals from **disadvantaged** backgrounds (socially, culturally, economically, or educationally)

  Only applicable to high school and undergraduate candidates
The Office of Programs to Enhance Neuroscience Workforce Diversity (OPEN – WD) coordinates NINDS’s diversity activities.

Goals include:

- Increase applications from underrepresented groups
  - Enhance outreach and attract investigators to neuroscience/NINDS
  - Support training and capacity building
- Identify and root out bias in peer review and all other aspects of funding decisions
  - Include contributions to a research environment of inclusive excellence in the mix of factors in the choosing high program priority grants for “select pay” decisions
- Develop and track metrics openly
NINDS Extramural Training and Career Development Programs

- C-Clinician-scientist
- G-General
- D-Diversity
- I-Institutional

*Eligibility measured from date joined lab

- F30C
- K08/K23C
- K02C
- F31G
- F32G
- Postdoc
- K01G
- NINDS K12sC
- NINDS F32G
- K99/R00G
- Loan Repayment ProgramG
- Re-Entry SupplementsG
- JSPTPN T32sG
- NINDS T32G
- Summer Research R25G
- General R25G
- BRAIN K99/R00D
- MOSAIC K99/R00D
- F31D
- BP F99/K00D
- Faculty K01D
- Diversity Research Supplements (AD/ADRD, BRAIN, SBIR/STTR, HEAL)D
- BP-ENDURE R25 DJ
- Advancing Diversity R25 ProgramsG

- High School Student
- Undergraduate Student
- Graduate/Medical Student
- Postdoc
- New Faculty
NIH is committed to instituting new ways to support diversity, equity, and inclusion, and identifying and dismantling any policies and practices that may harm our workforce and our science.

NIH established the UNITE initiative to address structural racism in biomedical research with the goal of ending racial inequity.

Primary goals of the initiative are:

- Understanding stakeholder experiences through listening and learning
- New research on reducing health disparities and promoting health equity
- Improving the NIH culture and structure for equity, inclusion, and excellence
- Transparency, communication, and accountability with our internal and external stakeholders
- Extramural research ecosystem: changing policy, culture and structure to promote workforce diversity
DeAnna Adkins  Christina Fang  Jenny Kim  Olufunmilola Olufemi  Shardell Spriggs
Baindu Bayon  Carlos Faraco  Jim Koenig  Oreisa O'Neil-Mathurin  Kalynda Stokes
Sarah Bell  Jane Fountain  Stephen Korn  Michael Oshinsky  Chris Swanson-Fischer
Patrick Bellgowan  Lina Garcia  Sahana Kukke  Marlene Peters-Lawrence  Carol Taylor-Burds
Richard Benson  Brooks Gross  Timothy Lavaute  Khara Ramos  Michael Tennekoon
Rebecca Berman  Adam Hartman  Miriam Leenders  Ranga Rangarajan  Lauren Ullrich
Naomi Booker  Janet He  Catherine Levy  Paul Rezaizadeh  Ursula Utz
Ryan Calabrese  Rebecca Hommer  Erica Littlejohn  Cheryse Sankar  Jackie Ward
Stacey Chambers  Lyn Jakeman  Margarette Matthews  Alisa Schaefer  Vicky Whittemore
Robin Conwit  Dave Jett  DP Mohapatra  Jill Morris  May Wong
Jessica Corley  Michelle Jones-London  Claudia Moy  Paul Scott  Clint Wright
Rod Corriveau  Rashida Kamara  Glen Nuckolls  Beth-Anne Sieber
Sara Dodson
Thank you
NINDS Office of Global Health & Health Disparities (OGHHD)

Scan the following QR codes to browse our website for funding opportunities, contact information, and more!

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