

**AMERICAN HEART ASSOCIATION**

**LAY STAKEHOLDER  
RESEARCH AND SCIENCE INITIATIVE**



# MISSION STATEMENT

## TO BE A RELENTLESS FORCE FOR A WORLD OF LONGER, HEALTHIER LIVES

### **To be a relentless force:**

We are unyielding in our commitment to fund research, shape stronger health policies, and implement programs that save lives.

### **For a world:**

We're going beyond borders, both literal and symbolic, to ensure equitable access to quality care.

### **Of longer, healthier lives:**

We're creating a culture of health that enables people to enjoy more years and more life in those years.

**What about cardiovascular diseases and stroke? Why aren't they mentioned anymore?**

While our work remains anchored to our core, we've broadened our focus to meet the holistic health needs of the people we serve. Take One Brave Idea for example. This research enterprise is rooted in the fact that precursors of heart disease could be found anywhere in the human body.

# LAY STAKEHOLDER REPRESENTATIVES IN RESEARCH AND SCIENCE



The **Lay Stakeholder** volunteer is an individual without formal training as a scientist who possesses a strong interest in advancing cardiovascular and or neurovascular science and healthcare.

Interest could be based on an intimate experience with a cardiovascular or neurovascular disease or disorder, a survivor with a disease or disorder, a family member with experience, a caregiver and advocate.



# WHY PATIENT ENGAGEMENT ?

- Increases the **accountability** and **transparency** of the research process.
- Provides **real-world** understanding of what most impacts those affected by heart disease and stroke.
- Helps **shape** the research agenda and strengthen its impact on the mission.
- **Bridges** the gap between scientists and patients.
- Gives **voice** to the issues stakeholders think are most important.
- Integrates a diverse range of **views** (researchers, health professionals AND service-user representatives so research becomes more effective).
- Improves **understanding** of the benefits and burdens of patients in research studies.
- **Informs** others of the human dimension of research and its outcome.
- Prompts a sense of **urgency** for finding cures and more effective prevention, diagnosis, and treatments.

## RESEARCH

Since 1949, the AHA has invested more than \$4 billion in research to enhance our knowledge of cardiovascular diseases and stroke.

# BRIDGING THE GAP SCIENTISTS/PATIENTS

## AHA-Scientific Review Submission/Proposal Review

- \*Required Lay Summary Form for All Applicants**
- \*Patients/Lay Reviewers review the Lay Summary & Score (Impact on Mission)**
- \*Meeting Day-Patients/Lay Reviewers provide insight regarding understanding of lay summary and its relevance to Impact**

# BEST PRACTICES/TRAINING PATIENT ADVOCATES

## TRAINING BEGINS BEFORE SELECTION

- AHA LAY STAKEHOLDER JOB DESCRIPTION
- LAY STAKEHOLDER RESPONSIBILITIES & EXPECTATION

## TRAINING BEGINS BEFORE PROJECT/COMMITTEE ASSIGNMENTS

- TALK THROUGH PROGRAM
- ORIENTATION FOR COMMITTEE MEETING/PROJECT

## TRAINING CONTINUES AFTER ASSIGNMENTS

- NEWSLETTER FOR EDUCATION

# WHAT ARE REQUIREMENTS FOR THE PROGRAM?

- \*Intimate experience with Cardiovascular/Neurovascular Disease or Disorder
- \*Survivor with a disease or disorder/Patient
- \*Family Member w/ Experience
- \*Caregivers
- \*Advocate(s)/Thought Leaders

*We aim to have a demographically diverse group of qualified Stakeholders from communities across the country. When possible, we assign Stakeholders to committees in which they've expressed an interest.*



# OUTCOMES & KEY SUCCESS FACTORS OF THE PROGRAM

## LAY VOLUNTEER

- Share information learned with the community and family members.
- Gain an increased awareness and respect for the importance of the research enterprise.
- Demystify the research process.
- Gain confidence in the rigor of AHA's selection of research projects.
- Satisfaction of contributing to a cure for the prevention for heart disease and stroke.
- Awareness that your real-world experience can influence the direction of science.

## SCIENCE VOLUNTEER

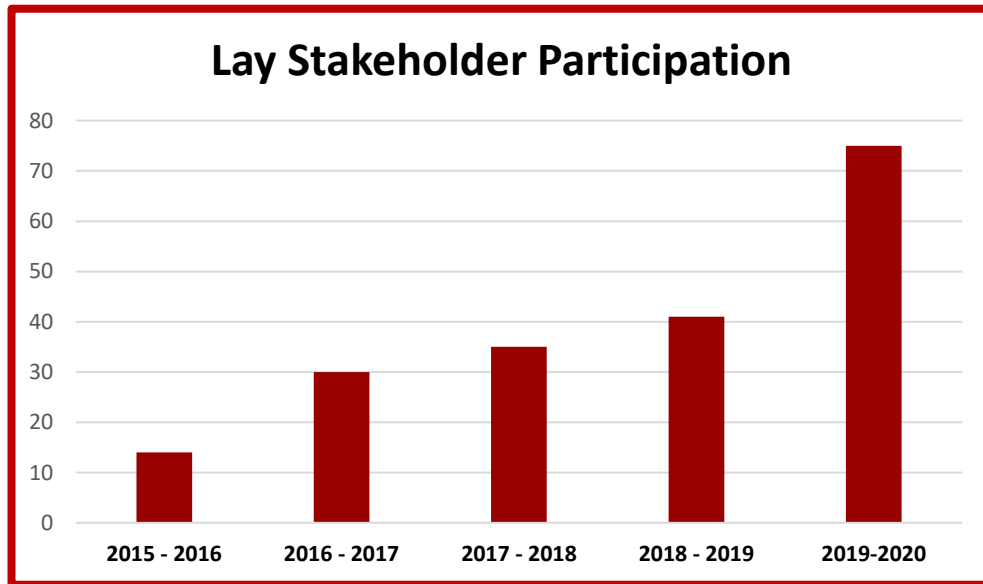
- Clearer connection with research focus and patient
- Respect for patient voice
- Broaden perspective for connecting science with patient
- Enhances more patient-centered research.
- Minimize scientist(s) intellectual biases regarding patient involvement



# CHALLENGES

1. BUY-IN
2. VOLUNTEER SELECTION AND ENGAGEMENT
3. BUDGETING
4. STRATEGIC PLANNING
5. COORDINATION

# LAY STAKEHOLDERS PARTICIPATION IN SCIENCE AND RESEARCH IS GROWING



The number of lay volunteers in science and research is projected to be **greater than 75** for 2019-2020 fiscal year.

2015 – 2016	2016 - 2017	2017 - 2018	2018 - 2019	2019-2020
14	30	35	41	>75

# QUESTIONS

