

LAY STAKEHOLDER REPRESENTATIVES IN SCIENCE AND RESEARCH

The **Lay Stakeholder** volunteer is an individual without formal training as a scientist who possess 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.

PATIENT ENGAGEMENT

Patient engagement is vital to the landscape of Science and Research.

- 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.

BRIDGES THE GAP BETWEEN SCIENTISTS AND PATIENTS

Involving the patient in AHA Science and Research reviews bridges the communication gap between scientists and patients with the objective to alleviate barriers in understanding the focus of why research is necessary.

Lay Stakeholder(s)

- 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 of cardiovascular and neurovascular disease and or disorders.
- Awareness that real-world lay stakeholder experience can influence the direction of science.

Scientist(s)

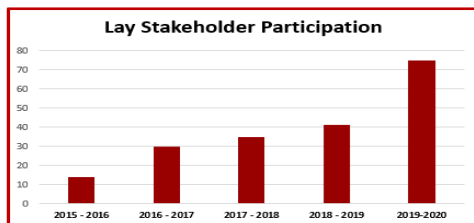
- Clearer connection with research focus and patient
- Respect for patient voice
- Broaden perspective for connecting science with patient
- Enhances more patient-centered research.
- Minimize scientist(s) intellectual biases regarding patient involvement

LAY STAKEHOLDER VOLUNTEER REQUIREMENTS

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.

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

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

"I really appreciate your note and the letter of appreciation...But it is I, who should be thanking you for this tremendous experience. As, I said before - I did participate in this process on two previous occasions - via WebEx. Being there in person has a significant advantage. You really feel as if you are a part of this entire process. To sit in the room with such brilliant and knowledgeable professionals was so inspiring. You could not treat your lay reviewers with any more respect. During both phases - I could not have felt any more welcome and comfortable. I felt as if my input was truly valued. I thank you for this opportunity. I am excited about sharing this experience with our San Diego Board. I know that you know - we all work so hard to raise money for heart research-and to be one of the few who gets to see exactly where that funding goes is such a gift." -Susan Mahler PhD

