



# LAY STAKEHOLDERS IN SCIENCE AND RESEARCH

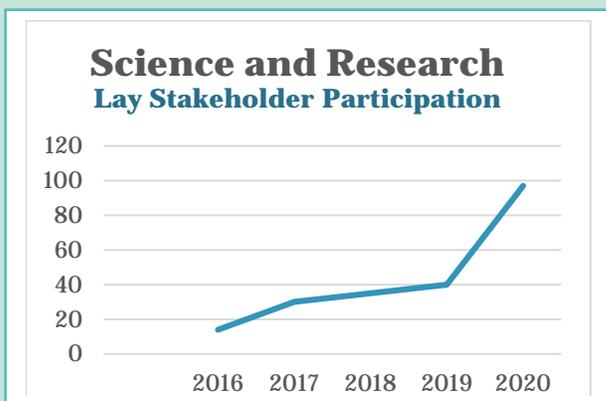
ISSUE 9

## LAY STAKEHOLDER IN SCIENCE & RESEARCH TASK FORCE

The AHA Lay Stakeholder Task Force in Science and Research reporting to the AHA Research Committee has broad responsibility for engagement of lay stakeholders in all aspects of the AHA research enterprise. The first meeting of fiscal year 2020-2021 took place via Zoom on August 17th.

### WELCOME NEW TASK FORCE MEMBERS

Bill Roach, BA, MS, JD (Chair)  
Jim Bischoff, BS, Med  
Norrina Allen, MPH, PhD  
Lauren Evanovich, PhD  
Bernie Dennis, BA, MA  
Larry Sadwin, BS  
Sally Powers, BA  
Jackie Ng-Osorio, DrPH, MPH, BA  
Shirley Yoshida, MBA  
Tara Robinson M.ED



### CONGRATUATIONS TO OUR MANUSCRIPT WRITING GROUP

SOON TO BE PUBLISHED - Lay Stakeholder in Science and Research Manuscript will report on the progress of the lay stakeholder initiative.

Bill Roach, BA, MS, JD  
Jim Bischoff, BS, Med  
Marvis Donalson, BBA  
Sandra B. Dunbar, RN, PhD  
Bernie Dennis, BA, MA  
Debbie Hill, BS  
Sally Powers, BA  
Jackie Ng-Osorio, DrPH, MPH, BA  
Loren E. Wold, PhD

- |                                |   |
|--------------------------------|---|
| Evolution of the initiative    | Expectations for peer review & guidelines |
| Program expectations           | Evaluation                                |
| Building support               | Follow-up                                 |
| Selecting the right volunteers | Challenges                                |
| Training                       | Lessons learned                           |
| Volunteer engagement           | Future of the program                     |



Christine Rehash, AHA Lay Stakeholder for the 2020 AHA/ACC Guideline for the Management of Patients with Valvular Heart Disease first learned she had a congenital heart condition in 2000, when her doctor detected a heart murmur during a routine physical. Christine underwent uneventful testing for nine years until she was diagnosed in 2009 with a leaky mitral valve. By late 2012, the conditioned had worsened, causing her heart to become enlarged as it worked harder to move blood between its chambers. Christine’s doctor recommended open-heart surgery to repair the valve before things became worse.

*“As we start another week of fighting through the pandemic, a heartfelt thank you for the opportunity to contribute. This was very much a learning opportunity like no other. In certain aspects, it was a crash course in cardiology which has underscored even more my admiration and sincere appreciation for my cardiac team.”*



Jang Jaswal was born in India, 61 years old, young at heart (literally)! Jang completed his Masters in Genetics and Biochemistry and worked as a Biology lecturer in Fiji Islands. At the age of 32 he migrated to United States where he suffered numerous heart attacks, strokes and total renal failure. Jang underwent angioplasty, numerous stent implants, bypass surgery, peritoneal and hemodialysis, defibrillator implant, and a heart and kidney transplant. He is a modern medical miracle and direct beneficiary of all the research supported by American Heart Association. Jang is AHA's national ambassador for heart failure. His goal is to raise awareness about a healthy heart lifestyle, help and encourage those suffering from heart-related issues to enjoy life and be happy.

Jang Jaswal's is serving on the Revascularization Guidelines Writing Committee for the AHA. We asked Jang what he thought about the guidelines writing process. Here's what he had to say,

*"Without any certified medical knowledge, I was very apprehensive of serving on a committee involved in evaluating applications for awarding research fellowships or writing any guidelines. Moreover, the idea of working with well accomplished cardiologists, surgeons and researchers appeared quite intimidating. Despite all that, a strong urge to contribute and repeated assurances by the team of AHA, I undertook the assignments and am I glad I took that challenge."*

*"Participating in these committees gave me a firsthand insight into the procedures used to help attain the AHA goals of improving the lives of people worldwide. The dedication, hard work and commitment that goes into it is humongous. As a witness to distribution of the funds to the research projects impacting patients suffering from heart or stroke related issues, the significance of fundraising became much clearer. The committee members were very cordial and encouraging which helped me to feel confident. Though some of their discussions were barely within my comprehension, the members were patient enough to explain in the information in simpler layman terms. They always made me feel welcomed and heard me as an active participant in the discussions and decision making. My opinions mattered equally as of all others in the committee. "*

*Moreover, I had a chance to see both the professional and human sides of these world-renowned doctors and scientists. I was really impressed by their humility when one of them carried my bag to the terminal of the airport as I was having some difficulty doing so due to my bad back.*

*Overall these experiences gave me a sense of accomplishment by voicing patients' viewpoints and preferences among the doctors and scientists. I look forward to more of these opportunities and highly recommend it to anybody up for a real challenge.*

A big thank you to Joni Byun for her contribution on the lay stakeholder orientation training materials!



## **UPCOMING VOLUNTEER OPPORTUNITIES PEER REVIEW, COMMITTEES & WRITING GROUPS**

- ❖ [AHA/CHF Congenital Heart Defect Research Awards](#)
- ❖ Peripheral Artery Disease (PAD) Guidelines Writing Group
- ❖ Intracerebral Hemorrhage (ICH) Guidelines Writing Group
- ❖ Strategically Focused Network on [Cardio-Oncology](#)

If interested in serving please contact [Elizabeth.Cooper@heart.org](mailto:Elizabeth.Cooper@heart.org) or [Angela.McCarty@heart.org](mailto:Angela.McCarty@heart.org)