



LAY STAKEHOLDERS IN SCIENCE AND RESEARCH

ISSUE 7

NOW A TASK FORCE

Lay Stakeholder Working Group

New



Lauren L. Evanovich, PhD
Patient and Advocate



Consensus Conference
Dallas, Texas

The Working Group on Lay Stakeholders in Science and Research originated as a section of the Peer Review Subcommittee. To date, the activities of the Working Group have expanded beyond peer review; lay Stakeholders not only serve on peer review panels but on Guideline Writing Committees and various Research Committees and Subcommittees as well. Recognizing this broader scope, a recommendation was made to the AHA Research Committee to convert the Working Group to a Task Force reporting directly to the Research Committee. In September the Research Committee voted on and accepted this recommendation and we are pleased to announce and recognize this new Task Force status which is a direct result of each of your efforts!

SCIENTIFIC GUIDELINE WRITING

Are you interested in providing input on content regarding patient choices, values, preferences, and issues surrounding quality of life in selecting diagnostic modalities, therapies, medications, and follow-up? If you are, then serving on an AHA Guideline Writing Committee may be an opportunity for you.

WHAT IS A GUIDELINE - Guidelines give doctors and other healthcare professionals knowledge about the best practices to diagnose, treat, and in some cases, prevent disease.

Guidelines are recommendations based on the strongest available scientific evidence.

The creation of a [Guideline](#) is a rigorous process because careful scientific study is at the heart of each guideline recommendation. When the American Heart Association develops guidelines, alone or in conjunction with other organizations, the process begins with an oversight committee made up of volunteer experts. This group identifies the major questions to be addressed regarding a topic and appoints the writing committee.

A Guidelines Writing Committee (GWC) may include one or more Lay Stakeholders along with scientific and medical experts. All are unpaid volunteers from multiple backgrounds to ensure a broad range of viewpoints.

PATIENT INVOLVEMENT - Lauren L. Evanovich, a patient and advocate who knows firsthand the experience of living with a [Congenital Heart Defect](#) is serving on the American College of Cardiology (ACC) and American Heart Association (AHA) 2020 ACC/AHA Guideline for Diagnosis and Treatment of Patients with [Hypertrophic cardiomyopathy](#) (HCM) committee.

HCM is a disease in which the heart muscle becomes abnormally thick. The thickened heart muscle can make it harder for the heart to pump blood. HCM can affect people of any age and gender. It is a common cause of cardiac arrest in young people including young athletes.

Lauren regularly attends teleconferences as part of her role to guide the committee and most recently attended the in-person HCM Consensus Conference in Dallas, Texas on September 27 and 28. This intensive, face-to-face GWC meeting provided a forum for agreement/consensus on how best to guide doctors on how to evaluate and treat patients with Hypertrophic Cardiomyopathy. The committee discussed, debated, and agreed on recommendations for specific topic areas. Next steps will include working toward final publication by incorporating the edits from the meeting. As well as, completing step # 04 and # 05 of the timeline shown below.

"I felt my contributions to the conversations were welcomed by the majority and asked for directly by some...Saturday was even more of a livelier conversation as it was about lifestyle pregnancy shared decision-making and sports, all of which I had a role in developing with Committee Chair Dr. Steve Ommen.

Lauren L. Evanovich

"We hit the jackpot with Lauren. Not only is she a very poised and articulate voice on behalf of patients (and other "lay" stakeholders), but she is a scientist herself. This last point really means that she completely grasps data, data quality, and how those can be interpreted. This insight, that Lauren has, is particularly important in HCM."

Committee Chair Dr. Steve Ommen



Expectations for GWC patient representative members include the following:

- Willingness to serve 1 – 2 years
- Attendance at scheduled calls
- In-person meetings: Kick Off Meeting & Consensus Conference
- Ability to analyze, review and write.
- An understanding of Evidence-based Healthcare

LAY STAKEHOLDERS AT SCIENTIFIC SESSIONS

For the first time this October, Lay Stakeholder Representatives will attend panels, posters sessions, and presentations at Scientific Sessions in Philadelphia, Pennsylvania. Dr. Norrina Allen, who serves on the Lay Stakeholder Task Force, is this year's Sessions Population Science Moderator. Dr Allen along with staff and other volunteers will oversee the inclusion of Lay Stakeholders in the Sessions experience.

Lay Stakeholder Representatives James Young, Bernie Dennis, and Lauren Evanovich will also be in attendance. James Young will be included on the Wrap-Up Session Panel - Trending Topics in Population Science to present what the patient advocates identified as the most interesting finding(s) in population science. The Population Sciences Panel reflects all the science they will see throughout Sessions.



UPCOMING PEER REVIEW COMMITTEE MEETINGS & WRITING GROUPS

- ❖ Collaborative Sciences Award 2020
- ❖ Established Investigator 2020
- ❖ Strategic Focused Network – Technology and Innovation
- ❖ Heart Failure Guidelines Writing Group
- ❖ Peripheral Artery Disease (PAD) Guidelines Writing Group
- ❖ Institute of Precision Medicine: AHA and Amazon Web Services: Data Grants 5.0

If interested in serving contact Elizabeth.Cooper@heart.org or Angela.McCarty@heart.org