

## Bio for FDA Patient Engagement Advisory Committee Meeting: September 2019



### **Amye L. Leong, MBA**

*President & CEO, Healthy Motivation;*

*Patient Engagement Advisor, Food and Drug Administration;*

*PCORI Ambassador;*

*Former Director of Strategic Relations, United Nations Bone and Joint Decade,*

*The Alliance for Musculoskeletal Health;*

*Past Chair, Arthritis Foundation, Central California Coast Leadership Board*

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### **Personal Statement**

Amye Leong is an internationally-recognized patient advocate leader, health communications and policy strategist, speaker, author, educator, and patient partner researcher. She is President/CEO of Healthy Motivation, a health education and advocacy consulting firm in Santa Barbara, California USA. Clients include governments, industry and non-government organizations in 18 countries who seek expertise in patient-centered care and communications, patient engagement in research, advocacy and patient advisor and education programs, as well as strategic planning, group facilitation, marketing to patients, conflict resolution, and building networks and collaborators. Diagnosed with rheumatoid arthritis at age 18 and later with Sjogren's syndrome and osteoporosis, she became wheelchair-bound within 6 years. She spent 5 years in a wheelchair, hospitalized over 303 days, and was totally disabled on Social Security Disability. After 22 surgeries and 18 joint replacements, she developed America's largest network of 40-plus young adult arthritis education/advocacy programs, voluntarily halted disability payments, and started consulting firm, Healthy Motivation, to become a respected medical and motivational speaker, national and international health advocate, strategic advisor, facilitator, research partner and health policy strategist. She is a recognized key opinion leader in musculoskeletal care, patient motivation and engagement, and patient advocacy communications.

## **Experience and Leadership**

She has advised the US Food and Drug Administration, Critical Path, National Institutes of Health (NIH), Patient-Centered Outcomes Research Institute (PCORI), and the Agency for Health Research and Quality (AHRQ) on the topics and strategies to integrate the voice of patients and stakeholders into research development, outcomes and meaningful uses. She served on the NIH Director's Council of Public Representatives and the Editorial Board of the International Journal on Self-Help and Self Care. She also served as the primary patient advocate on the task force developing rheumatoid arthritis treatment guidelines for the American College of Rheumatology, the professional group leader of arthritis care guides for health professionals. She helped guide the National Institute of Arthritis, Musculoskeletal & Skin Diseases (NIAMS) Clinical Trials grant review process to incorporate patient advocates as grant reviewers. She also served as the patient advocate leader on the National Steering Committee of the Centers for seven centers of the Research and Education on Therapeutics (CERTS). Since 2002 Amye has served as a Leader of Patient Research Partners in Outcome Measures in Rheumatology (OMERACT), an international research consortium developing evidence-based outcome measures for use in clinical trials where she continues to provide strategic leadership to other research units. She also serves on the Board of Directors of the Archstone Foundation, which provides funding for innovative projects that prepare society in meeting the needs of an aging population, and as Board Member, Treasurer and Executive Committee member of the Alliance for Aging Research, dedicated to accelerating the pace of scientific discoveries and their application to vastly improve the universal human experience of aging and health. She was also named an Ambassador for the Patient-Centered Outcomes Research Institute (PCORI).

She served for 15 years as Spokesperson and Director of Strategic Relations for the United Nations-endorsed health initiative, the Bone and Joint Decade, the Global Alliance for Musculoskeletal Health where she provided motivating educational presentations to diverse patient and health professional audiences, and facilitated collaborations among decision-makers in 63 countries from governments, industry, payers, academics, foundations, professional societies and patient groups to work together to address the looming epidemic of musculoskeletal disabilities.

Locally, Amye served as Chair of the Arthritis Foundation California Central Coast and Vice Chair of the California Arthritis Foundation Council, advocating with state health policy leaders and legislators on the needs and issues affecting over 6 million of Californians with arthritis and musculoskeletal diseases.

Amye was honored at the White House by President G.W. Bush with the 2001 President's Service Award, America's *highest* national honor for community service and the only person from the rheumatology community to ever receive this honor. The Arthritis Foundation named Leong one of its *America's Fifty Heroes* and awarded her its highest honor, the Harding Award. As a Community Hero, she was selected to carry the Olympic Torch for the 1996 Centennial Olympic Games. She was appointed to the NIAMS Advisory Council and chaired the Surgeon General's National Council on Self-Help and Public Health under C. Everett Koop. She is the author of *Get a Grip: A Take Charge Approach to Arthritis* (2002), its Spanish translation, *SUPÉRATE!* (2004), and *The Complete Idiot's Guide to Arthritis* (2009) along with Patient Advocacy and Arthritis in the *World Health Organization Bulletin* (2004) and over 34 other peer-reviewed journal articles. Amye earned a BA in Communications (summa cum laude) from the University of California and MBA from Purdue University. Amye and her family were seriously affected by the January 2018 California Fires and subsequent Montecito Mud

Disaster that destroyed their home while still inside. Still recovering from the trauma, she lives in Santa Barbara with husband, Robert Price of Montecito, and an adorable aging cat.

**Patient Engagement in Research (author sampling from 34 citations in peer-reviewed journals)**

1. Considerations for evaluating and recommending worker productivity outcome measures: An update from the OMERACT Worker Productivity Group, The Journal of Rheumatology, March 2019. **Key patient research partner.**
2. Core outcome sets specifically for longterm observational studies: OMERACT special interest group update in rheumatoid arthritis, The Journal of Rheumatology, February 2019. **Primary patient research partner on leadership team.**
3. Advancing stiffness measurement in rheumatic disease: Report from OMERACT 2018, The Journal of Rheumatology, February 2019. **One of two patient research partners on lead team.**
4. Combining online and in-person methods to evaluate the content validity of PROMIS fatigue short forms in rheumatoid arthritis, Quality of Life Research, May 2018. **Leading patient advocate on leadership team.**
5. Outcome measurement instruments for safety in rheumatology: A scoping review of available instruments to inform the OMERACT safety working group, Annals of the Rheumatic Diseases, June 2017. **Only patient research partner on leadership team.**
6. Quality assessment of websites providing educational content for patients with rheumatoid arthritis, Seminars in Arthritis and Rheumatism, January 2017. **Only patient research partner on leadership team.**
7. Successful stepwise development of patient research partnership: 14 years' experience of actions and consequences in outcome measures in rheumatology (OMERACT), The Patient, September 2016. **Key international leader of patient research partners.**
8. American College of Rheumatology white paper on performance outcome measures in rheumatology, UCLA recipient of ACR grant. **Only patient advocate on leadership team.**
9. Patients as partners: Building on the experience of outcome measures in rheumatology (OMERACT), Arthritis and Rheumatism, March 2016. **One of 4 patient research partners on team.**
10. 2015 American College of Rheumatology guideline for the treatment of rheumatoid arthritis, Arthritis and Rheumatism, November 2015. **Only patient advocate on team.**

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