



Amye L. Leong, MBA

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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 and health policy strategist. She is a recognized key opinion leader in musculoskeletal care and patient advocacy communications.

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.

She earned a BA in Communications (summa cum laude) from the University of California and MBA from Purdue University. She lives in Santa Barbara with husband, Robert Price of Montecito, and an adorable aging cat.