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Personal Statement:

As a Healthcare Consumer and Volunteer CVD Heart Survivor Int'l Patient Advocate with lived experience with multiple conditions including Heart Disease, Diabetes, etc... my interests/objectives are to help advance and support healthcare consumer voices & values - by adding my voice, personal healthcare experience and perspective as a consumer and patient in support of other healthcare consumers, patients, family members, caregivers, and related community health stakeholder patient-centered needs and priorities identified by actual healthcare consumers, including patient-reported outcomes (PROs).

As a patient and survivor of a rare cardiovascular Congenital Heart Disease (CHD) condition reported as diagnosed in less than 1% of the population (and usually found during autopsy) - I know first-hand what it is like to live with a chronic, disabling and/or life-threatening medical condition. Some rare conditions are difficult to diagnose, and I was misdiagnosed for 48 years. I also know and especially value that many healthcare consumers/patients have to deal with challenging simultaneous health and wellness issues including day-to-day quality-of-life concerns, socio-economic environmental stress factors and other basic survival issues that can make their health outcomes even more complex.

While my heart condition is rare, there are over 2 million Americans with other forms of CHD and millions more with the most common and acquired forms of heart disease making heart disease the #1 killer in America - killing and disabling more men, women, and children than any other medical condition.

Since doctors said I was lucky to be alive, with the support of my family, I decided to use my 2nd chance in life to help increase awareness, education and support for cardiovascular health and more patient-centered care and research in whatever ways possible. I believe that life should not be lived by luck – it takes deliberate informed decisions and proactive actions. This led to my decision to use my personal health experiences to serve as a healthcare research advocate and volunteer Citizen Scientist Architect-of-Change to help advance more patient-centered healthcare and socio-economic outcomes that help address and improve daily quality-of-life throughout our communities especially for those experiencing chronic, disabling and/or life-threatening medical conditions - so they can survive, thrive and lead the most productive lives possible and celebrate as many great birthdays as possible.

PUBLICATIONS

- Alikhaani, J. (January 2020). "Clinical Practice Guideline: Nosebleed (Epistaxis)", Tunkel, David E.; Anne, Samantha; Payne, Spencer C.; Ishman, Stacey L.; Rosenfeld, Richard M.; Abramson, Peter J.; Alikhaani, Jacqueline D.; Benoit, Margo McKenna; Bercovitz, Rachel S.; Brown, Michael D.; Chernobilsky, Boris; Feldstein, David A.; Hackell, Jesse M.; Holbrook, Eric H.; Holdsworth, Sarah M.; Lin, Kenneth W.; Lind, Meredith Merz; Poetker, David M.; Riley, Charles A.; Schneider, John S.; Seidman, Michael D.; Vadlamudi, Venu; Valdez, Tulio A.; Nnacheta, Lorraine C.; Monjur, Taskin M., *Otolaryngology–Head and Neck Surgery*, vol. 162 (1): pp. 8–25.
- Alikhaani, J. (January 2020). "Plain Language Summary: Nosebleed (Epistaxis)", Tunkel, David E.; Holdsworth, Sarah M.; Alikhaani, Jacqueline D.; Monjur, Taskin M.; Satterfield, Lisa, *Otolaryngology–Head and Neck Surgery*, Vol. 162 (1): pp. 26-32. (This article is part of the following special collection(s): [Guidelines and Quality Improvement](#).)
- Alikhaani, J. (October 2018). Exploring Meaningful Patient Engagement in ADAPTABLE (Aspirin Dosing: A Patient-centric Trial Assessing Benefits and Long-term Effectiveness), Faulkner, Madelaine, MPH; Alikhaani, Jacqueline; Brown, Linda; Cruz, Henry; Davidson, Desiree; Gregoire, Ken; Berdan, Lisa, MHS; Rorick, Ty, RN; Jones, W. Schuyler, MD; Pletcher, Mark J., MD, MPH, *Medical Care*, Vol. 56, pp. S11–S15.
- Alikhaani, J. (November 2017). Incorporating Patient and Caregiver Experiences Into Cardiovascular Clinical Trial Design, Collins, Sean P.; Levy, Philip D.; [Holl](#), Jane Louise; Butler, Javed; Khan, Yosef; Israel, Tiffany L.; Fonarow, Gregg C.; Alikhaani, Jacqueline; Sarno, Eric; Cook, Alison; [Yancy](#), Clyde W., *JAMA Cardiology*, vol. 2(11), pp. 1263-1269.

RECENT RESEARCH ENGAGEMENT / INVITED PARTICIPATION / COMMUNITY OUTREACH

American Heart Association, "Go Red for Women", American Heart Month Segment, KTLA 5 News, February 2020, Los Angeles.

American Heart Association and American Diabetes Association "Know Diabetes by Heart" 2019 – 2020 National Media Campaign (to increase awareness and education about link between diabetes and heart disease).

IPFCC (Institute for Patient and Family-Centered Care), 2020 "9th International Conference on Patient and Family-Centered Care Partnerships for Quality, Safety, and Equity, Annual Conference", Patient Partner Abstract Review Panel Member, August 18-20, 2020, Nashville, TN.

CVCT 16th Global Cardiovascular Clinical Trialists Forum, Patient Partner Panel Member "Innovative Approaches to Informed Consent in Pragmatic Trials (Joint Session: CVCT and The Society of Clinical Trials)", December 5 – December 7, 2019, Washington DC, Maison Francaise, French Embassy.

American Heart Association Campaign Patient Partner to Improve Education and Awareness about Youth e-Cigarette use and Cardiovascular Disease Outcomes.

DCRI Think Tank (Duke Clinical Research Institute), Duke University, Patient Partner Panel Member *“Innovative Approaches to Accelerating New Drug Evaluation for Chronic Cardiometabolic Diseases – Leveraging Intermediate Non-Clinical Endpoints and Pragmatic Clinical Trials”*. October 2-3, 2019, Washington, DC.

ACC (American College of Cardiology), Patient Partner Panel Participant, *“The Integration of Patient-Reported Outcomes (PROs) into Cardiovascular Care”*, November 6, 2018, Washington DC.

ACC (American College of Cardiology), Patient Partner Panel Participant, *“Right Measures for the Right Care of Heart Failure Patients”*, November 7, 2018, Washington DC.

CVCT 15th Global Cardiovascular Clinical Trialists Forum, Patient Partner Panel Member speaker on *“Inclusion of Minorities in Clinical Trials”*, November 29 – December 1, 2018, Washington DC, Maison Francaise, French Embassy..

White House Briefing Participant, *“Making Health Care Better Series: Cardiovascular Disease”*, September 2016, Washington DC.

Participates in various ongoing consumer/patient education programs including: Reagan-Udall Foundation for the FDA, BD4P (Big Data for patients) Training Symposium; also participated in several FDA training opportunities specifically designed and required for FDA Patient Representatives to help inform and educate patient consumer engagement partners...

RESEARCH PATIENT PARTNER / CLINICAL TRIALS ENGAGEMENT

As an inaugural member of the American Heart Association Citizen Scientist Task Force (CSTF), helped to conceptualize and develop cardiovascular research projects that have yielded a number of clinical trials proposals that are at varying levels of progress in the following areas: chest pain, hypertension in underserved populations, transitions of care for stroke survivors, etc... (see some examples below)

Additionally, my research & advocacy experience and involvement consists of service on numerous focus groups and patient panels with a variety of community patient advocacy organizations.

Research engagement efforts included the following:

CVD HOMERuN Study

Role: Patient Adviser Research Partner, and PFAC (Patient & Family Member Advisory Council)

Goal of Study: HOMERUN is a cardiovascular disease research project. As a Patient Advisor/Leader, I was integral in developing the study design/conception, helped build and approve the patient engagement pyramid, which served as the framework for how the aims and outcomes would be identified. I helped review the social media data and guide the AHA team to focus on lifestyle and emotional wellness. I participated in several focus groups on the study

design, helping the team to target and identify aims that matter the most to hypertension patients, including quality-of-life, medication management, connectedness with the doctors, and other care management team members and stakeholders...

CVD Heart Failure Study

ROLE: Patient Advisory Research Development Team Member

Goal of Study: Improve outcomes for heart failure patients discharged from hospital emergency departments, by increasing patient knowledge about heart failure and reducing disparity gaps in patient care. Explore how a quality improvement initiative such as the American Heart Association's [Get With The Guidelines®-Heart Failure](#) can improve processes of care within the emergency department to address poor outcomes/disparities in care. "Each year, doctors discharge nearly 200,000 heart failure patients after treating them in the emergency department, according to the American College of Cardiology Foundation. But many of those patients aren't sure about next steps — what medications they should be taking, or when and with which doctor to follow-up... contributing to poor outcomes..."

OTHER PCOR-CER(Patient-Centered Outcomes Research) ENGAGEMENT

CVD ADAPTABLE Aspirin Study [ADAPTABLE \(Aspirin Dosing: A Patient-centric Trial Assessing Benefits and Long-term Effectiveness\)](#)

ROLE: Patient ADAPTOR, Research Steering Committee and Executive Committee Patient Partner Member representing the pSCANNER – CDRN (Clinical Data Research Network) <http://pscanner.ucsd.edu>-UCLA Campus

Goal of Study: Determine the best dose of aspirin to use to prevent heart attacks and strokes in people with heart disease. "Aspirin has been used for more than 40 years to prevent heart attacks and strokes in people diagnosed with heart disease, but the best dose has yet to be determined..."

This is a landmark PCORnet Study <https://pcornet.org/>. As a patient representative for the pSCANNER CDRN, participates as a patient-partner in the design, development and implementation of the first demonstration project to be conducted through PCORnet. pSCANNER is a major innovative new research network comprised of and representing over 30 million patients including University of California Health-systems, Veterans Administration, and Community Health Centers and more... Successful outcomes from this research project and implementation will enhance national capacity to conduct improved, more efficient research that can yield greater impact than ever before to help save lives and improve the quality-of-life and related essential resources for patients as well as their family members, caregivers, healthcare providers, other community healthcare stakeholders, and related socio-economic community networks and resource banks.

Health_eHeart / Heart Research Alliance

ROLE: Patient Partner Steering Committee Member
<https://www.health-eheartstudy.org/>

WomenHeart Champion Research Patient Engagement and Development: Mayo Clinic Science and Leadership Training Program Alum and Patient-Centered Research Development Focus Groups, Patient Panels, and related.

MetaLARC US/Canadian Healthcare Research Project

ROLE: United States Patient Rep Partner

CVD Ischemia - WISE

ROLE: Patient Advisory Research Team Member

CVD Heart Failure - Emergency Medicine/Hospital Readmissions

ROLE: Patient Partner Executive Committee Member

AWARDS / RECOGNITION

- American Heart Association *Learn and Live* Appreciation Award for Outstanding Achievement in Support of the American Heart Association's efforts in Cardiovascular Science, Education and Community Programs
- National CMS Medicare - Quality Innovation Network National Coordinating Center (Beneficiary and Family Member Advisory Council – BFAC)
- NPAF - National Patient Advocate Foundation Volunteer State Policy Liaison, and President's Advisory Council Awards
- AARP Volunteer District Liaison
- City of Los Angeles Mayor's Office
- LAPD (Los Angeles Police Department) CPAB Advisory Board Service Award Certificate
- Los Angeles City Council
- California State Senate
- California State Assembly
- California San Fernando Valley DPSFV Harry S. Truman Award for Volunteer of the Year *via Democratic Advocates for Disability & Labor Rights Issues*

COMMUNITY / ORGANIZATIONAL / NON-PROFIT BOARD INVOLVEMENT / LEADERSHIP, RESEARCH ENGAGEMENT AND RELATED PAST AND/OR CURRENT EXPERIENCE

- FDA Patient Representative
- IEEE Mobile Healthcare Apps International Platform Standards Development Team
- American Heart Association Citizen Scientist Task Force Inaugural Member, Cardiovascular Disease Research Patient Representative Partner, and Editorial/Publications Patient Editor Team Member
- American Heart Association National QIAC Task Force (Quality Improvement Advocacy Consumer Task Force)
- Medicare CMS – Beneficiary and Family Advisory Council (BFAC)
- PCORI (Patient-Centered Outcomes Research Institute) Patient/Stakeholder Merit and Peer Reviewer
- U.S. Department of Defense, Congressionally Directed Medical Research Programs (CDMRP), Heart Disease Patient Partner Research Merit Review Panelist
- PCORI Rare Disease Advisory Panel Inaugural Member
- PCORI-American Heart Association Inaugural Organizational Ambassador
- PCORI Merit Review Standing Committee on Healthcare Disparities
- UCLA Barbra Streisand Women's Heart Health Center Advisory Council Member
- AARP (American Association of Retired Persons/Real Possibilities) Volunteer Patient Advocate/District Liaison
- CUE Consumers United for Evidence-Based Healthcare Patient Rep.
- American Academy of Otolaryngology – Head and Neck Surgery Foundation (AAO-HNSF) Guidelines Development Committee
- International Cochrane Collaboration Consumer Reviewer
- Federally Qualified Health Center (FQHC) Community Advisory Board Member (*Los Angeles County California and nearby areas, 15+ locations*)

- NPAF - National Patient Advocate Foundation
 - President's Advisory Council Member
 - Patient Action League Member
- American Heart Association (AHA) and American Stroke Association – Greater Los Angeles
 - Chair, American Heart Association Volunteer Engagement and Community Outreach
 - Chair, AHA 2020 Task Force,
 - AHA Impact Goals Board Steering Committee for Greater Los Angeles (*targeting LA County underserved communities*)
 - American Stroke Association Faces of Power Committee (*targeting LA County underserved communities*)
 - Go Red For Women – Better U Program Member/Patient Rep
- Board Member LAPD Mission Station CPAB (*Community Policing Advisory Board*)
 - Quality of Life Committee (*Health and Safety Programming*)
 - Officer Appreciation Committee
 - African-American Community Outreach Roundtables and Forums
- Board Committee, ACHA - Adult Congenital Heart Association
- Board Member, DADI - Democratic Advocates for Disability Issues, Vice President
- Kennedy Advocates for Disability and Labor Rights, Vice President for Community Affairs
- NACHC - National Association of Community Health Centers Board Committee membership:
 - Farm-worker Health Committee
 - Subcommittee on Elderly Issues
 - Task Force for Healthcare in Public Housing
- Big Brothers Los Angeles Community Advisory Board
- University of Southern California Black Alumni Association Board (USCBAA)
- USC Community Development “Good Neighbors Campaign” Grant Committee Member and Grant Funding Application Reviewer
- Restore Board member (*Rehabilitation housing and services organization for abused women*)

RESEARCH SUPPORT & ADVOCACY ACTIVITIES / HEALTHCARE EDUCATIONAL FORUMS / COMMUNITY OUTREACH / LEGISLATIVE ADVOCACY & TRAINING

(Panel Participation/Presentations/Educational Expos/Events)

Media Appearances (*CVD and Diabetes Campaigns and examples of related TV, Newspaper, Magazine coverage...*)

- Healthcare
 - “Know Diabetes By Heart” Campaign (*to increase awareness and education about link between diabetes and heart disease*)
 - “For Your Sweetheart” Campaign (*to increase awareness and education about link between diabetes and heart disease*)
 - Dr. Oz TV Show: “Don’t Miss A Beat” Campaign (*to increase awareness and education about link between diabetes and heart disease*)
 - American Heart Association, American Heart Month/National Go Red Day, Go Red For Women, etc...
 - CBS News and KCAL 9
 - WTAJ 5 News
 - Pasadena Magazine
 - The Doctors TV show
 - KABC TV 7 Community Health Forum
 - Pasadena Star News
 - Los Angeles Daily News
 - Letter-to-the-Editor regarding heart health related ordinances