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Education: B.A., University of Southern California, Los Angeles, CA

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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. (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.

- 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.

RECENT RESEARCH ENGAGEMENT / INVITED PARTICIPATION / COMMUNITY OUTREACH

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

Charles R. Drew University, iHeart Accelerated Radio "Good News Radio Magazine" Program invited guest to speak about Heart Disease, April 2019, Los Angeles, California

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 (**A**spirin **D**osing: **A P**atient-centric **T**rial **A**ssessing **B**enefits and **L**ong-term **E**ffectiveness)
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 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

Used my personal healthcare story/experiences to deliver patient/citizen advocacy messaging to city, state, federal legislators and others via phone, in-person, fax, email, and media:

- Congresspersons
- Senators
- State Assembly members
- City Council members
- Others…

As a heart survivor and patient volunteer, supported consumer affairs campaigns and other public support for patient / healthcare issues.

Also participated in public forums and committee meetings on health care reform and access to care for needed therapies, better service and outreach to traditionally underserved communities in Los Angeles County including women and communities of color.

- CHC/LA Community Health Council *(Member of Planning Committee for South Central Los Angeles and related areas)*
    - As a member of the CHC Workgroup for the California Health Benefit Exchange, I was invited to participate by the CA HBEx Board and provided input and feedback regarding consumer perspectives and effective strategies, messages, and outreach activities to facilitate enrollment into coverage.
        - *Goal/Mission: Accountability and input on state programs to define essential health benefits and patient access focusing on underserved communities of color*

- AHA - American Heart Association and American Stroke Association – Greater Los Angeles
    - Annual Advocacy Days Planning Committee Member and Event Panel Speaker/Presenter
    - Advocacy Alliances - comprised of American Heart Association/American Stroke Association, American Cancer Society, American Lung Association, Campaign for Tobacco Free Kids, Stand Up to Cancer, LiveStrong, Cancer Action Network and Housing Rights Advocates. This was a joint and landmark prototype effort highlighting the need for similar efforts as many patients often have a combination of illnesses like heart disease and cancer and struggle with the same and/or similar problematic issues – causations and outcomes…
        - As a patient survivor spokesperson for the Los Angeles AHA Prop 29*(California Cancer Research Act)*, I testified at LA County Huntington Park City Council hearing for smoke-free housing ordinance *(ordinance was successfully passed).* Invited to testify at other similar hearings.

    - UCLA
        - Stroke/Brain Attack Center/Cardiology
            - Research Funding Overview and Outcomes Briefing, Advocate Team Member Participant
        - Research Outreach to Patients
            - Dept. of Radiology NIH Heart Study
            - Jules Stein

    - Go Red Heart Match, Buddy/Peer Support for heart disease patients, survivors, and caregivers
    - Volunteer health advocacy quarterly webinars

- Multi-racial Americans of Southern California *(Health Committee for "Race in Medicine" Forum at UCLA)*
- NORD - National Organization for Rare Disorders Member
- NAMI - National Alliance on Mental Illness Member
    - Targeted and initiated discussions on need for more focus on developmentally disabled patients suffering from other chronic and/or life-threatening medical problems and treatments often in conflict with ongoing psychiatric medications and related issues affecting those unable to communicate concerns on their own behalf such as those lacking guardians or properly administered conservatorships, and other issues such as hospital mental health patient dumping due to overcrowding/lack of sufficient beds, housing, etc…

Panel Participation/Presentations/Educational Expos/Events

- Patient Pavilions and Poster Sessions:
  - ACC: ADAPTABLE Aspirin Clinical Trial
  - HomeRun Clinical Trial
  - ACC: WomenHeart
- American Heart Association
  - City Council Ordinance hearings for AHA healthcare initiatives/alliances
  - Pasadena magazine
  - Northridge hospital
  - Rite Aid
  - Huntington Hospital
  - Brotherhood Crusade
  - Macy's
  - Suzi Ragsdale Concert Tribute
  - Morgan Stanley Smith Barney

Media Appearances *(CV and Diabetes Campaigns and examples of TV, Newspaper, Magazine coverage…)*

- Healthcare
  - "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