

Susan Strong



*Director of Patient Engagement,
Heart Valve Voice US*



Susan Strong is Director of Patient Engagement for Heart Valve Voice US. As the founding President of the Board of Directors, Susan is a passionate advocate for heart valve patients. In addition to her role at Heart Valve Voice US, Strong serves as an American Heart Association Heart Valve Ambassador, a PCORI Ambassador, and is actively involved as a patient stakeholder in clinical research. She also consults and provide patient support through her own organization, Strong Heart Now.

More than one way to be 65+

Engaging older adults
in the era of COVID-19
and beyond





Hodgkin Lymphoma
Dx 1983



Her2+ BC
2017



TAVR
2014



Today:
Grateful

A Tale of Two Low Risk TAVR Patients

Clinical research as a care option:

Jim-65

Simon-84

Patients at the Heart of a Study: Patient Centricity

Study Design:
Measure what
Matters

Reduce Patient
Burden

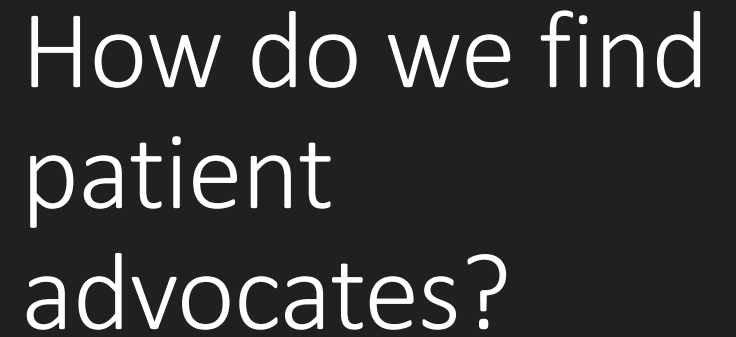
Mock Trial
Visit

Virtual and
Hybrid

Enhance
Patient
Communicatio

Inclusiv
e

Cultural
Humility



Patient Advocates/Leaders/Ambassadors

PCORI
Ambassador
Program

Patient
Groups

Savvy Coop

WEGO Health

Community/
Social Media

Who are PCORI's Ambassadors?



Ambassador Center

Looking for an Ambassador in your area with similar interests? Or simply looking to connect with a fellow Ambassador? If so, take a look at our new Ambassador Center.

Find Ambassadors by:

Stakeholder type

Health conditions of interest

State

Search List of Ambassadors:

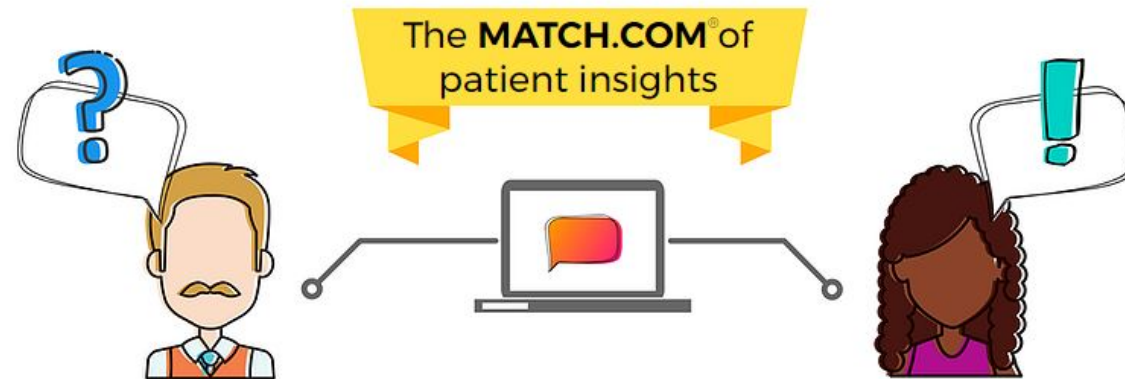
Enter keyword(s)

Search Ambassadors

Or, just [browse the list of Ambassadors](#).

[The Boston Globe](#)[TechCrunch](#)[MedCityNews](#)

Co-designing the Future of Healthcare



Companies have questions. Patients have answers.

Too often, companies and innovators waste time and money creating products and services that don't meaningfully impact patients' lives.

Why? Because they never bothered to ask patients.

Over 100,000 patient advocates and influencers working to transform healthcare

Join the world's largest network of patient leaders and get paid for your insights and expertise

Sign up

🔍 Search for a health condition or patient leader

Trending: [Cancer](#) [Multiple Sclerosis](#) [Migraine](#) [Rheumatoid Arthritis](#)

WHO IS WEGO HEALTH

The Network of Patient Leaders

We believe these e-patients, advocates, influencers, and collaborators, are leading the charge in health. Which is why we refer to these individuals as patient leaders.



Susan Strong

Susan Strong is a patient advocate, consultant, writer, speaker, and 37-year survivor of Hodgkin lymphoma and the collateral damage of cancer treatment: including valvular heart disease and invasive breast cancer. She is director of patient engagement at [Heart Valve Voice US](#). Susan lives in the Denver area with her partner, Darryl. [Visit her website](#)

Latest Stories



What the Heck is an Interventional Cardiologist? And Other Mysteries of Heart Valve Disease

After her diagnosis of severe aortic stenosis, Susan Strong learned a lot about valve replacement via TAVR. She shares her insight into the mysteries of heart valve disease.



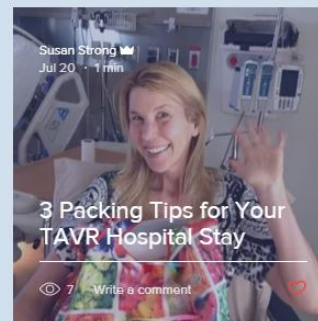
Not Your Average TAVR Patient: My Personal Experience

Susan Strong shares her TAVR experience and how she coped with being diagnosed with severe aortic stenosis.



6 Tips to Manage Anxiety Before Your TAVR Procedure

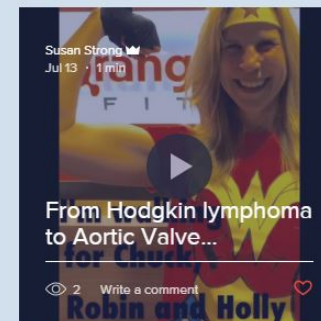
After a diagnosis of severe aortic stenosis, you may be anxious and afraid. Susan Strong shares how she learned to cope with anxiety before her valve



Susan Strong
Jul 20 · 1 min

3 Packing Tips for Your TAVR Hospital Stay

7 · Write a comment



Susan Strong
Jul 13 · 1 min

From Hodgkin lymphoma to Aortic Valve...

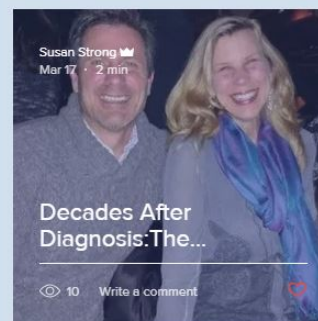
2 · Write a comment



Susan Strong
Apr 28 · 0 min

Susan's story: TAVR for aortic valve replacement

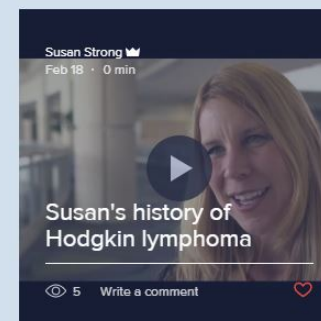
2 · Write a comment



Susan Strong
Mar 17 · 2 min

Decades After Diagnosis: The...

10 · Write a comment



Susan Strong
Feb 18 · 0 min

Susan's history of Hodgkin lymphoma

5 · Write a comment



Susan Strong
Jan 21 · 0 min

Involving Patients in Healthcare Research

3 · Write a comment

Susan
Patient Engage
Duk



Thank you!

Email: Susan@SusanStrong.com

www.strongheartnow.com