

Cynthia Chauhan
Wichita, KS
Patient Representative
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It is important to have the patient perspective as part of FDA processes.
As a thoughtful and articulate patient and caregiver, I bring that perspective.

Experience with diseases

I have multiple disabling comorbidities and almost 20 years experience as a research advocate bringing the patient voice to the research table.

Current advocacy experience in specific disease area

Chair, Mayo Clinic Breast Cancer Specialized Program of Research Excellence (SPORE) Advocacy Advisory Committee
Chair, Midwest Melanoma Partnership (MMP) Patient Advocate Committee
Patient Representative, The Heart Failure Society of America
Patient Representative, Food and Drug Administration Oncologic Drugs Advisor Committee (FDA ODAC)
Member, Food and Drug Administration Patient Engagement Advisory Committee (FDA PEAC)
Member, Patient-Centered Involvement in Evaluating the Effectiveness of Treatments (PATIENTS) External Advisory Committee
Patient Advocate, Academic and Community Research United (ACCRU)
Member, Research Advocacy Network Advisory Board
Member, Kansas Cancer Coalition
Stakeholder, PCORI PRO Delphi Project
Stakeholder, PCORI RADCOMP Trial
Member, The Heart Failure Collaboratory

Ability to represent patients and communicate their perspective.

In addition to the above listed activities, I give talks, write articles and help to plan educational activities both for professionals and lay communities. Here are some of my published articles/books:

- Chauhan, C. *What Lies Within--A Breast Cancer Journal*. Tallgrass Books. 2002 (not peer-reviewed)
- Chauhan C, Eppard W et al The patient advocate perspective on assessing the clinical significance for quality-of-life measures. *Journal of Cancer Integrative Medicine*. 2004; Vol 2, No. 4, 155-157.
- Chauhan C, Eppard W. Systematic education and utilization of volunteer patient advocates for cancer clinical trial information dissemination at NCCTG community sites. ASCO Poster, 2004. Available for viewing at www.asco.org.
- Chauhan C, Eppard W. The Impact of Quality of Life Measurements on the Patient. *Current Problems in Cancer*, Nov-Dec, 2005.
- Chauhan, C. *Incidental Finding--Essays on Renal Cell Carcinoma*. Tallgrass Books. 2005.
- Chauhan, C. *Incidental Finding--Essays on Renal Cell Carcinoma; Second Edition*. 2006.
- Chauhan C. The Perception of Perception. *Journal of Clinical Oncology*, June 1, 2007; Vol 25, No 16.
- Chauhan C. A Patient-Reported Observation. *Value in Health, The Journal of the International Society for Pharmacoeconomics and Outcomes Research*, November/December, 2007; Vol 10, Supplement 2.
- Chauhan, C. Optimists Doing Something Different: A Patient's View of GeneQoL

- Research . *Quality of Life Research*, epubaheadofprint, Feb 4, 2010.
- Chauhan, C; Eppard W.; Smith, M. L. Education and Utilization of Volunteer Patient Advocates for Cancer Clinical Trial Information Dissemination at NCCTG and HOG Community Sites. Poster, NCI/ASCO Cancer Trial Accrual Symposium, April 29-30, 2010.
 - Chauhan, C. The Mayo Clinic Breast Cancer Advocacy Advisory Committee, Poster, 2010 Breast SPORE Roundtable Meeting, May 20-22, 2010.
 - Chauhan, C. A Day Like Any Other. Newsletter of the Foundation for Peripheral Neuropathy, Summer, 2010.
 - Chauhan, C. A Gift of Unique Beauty. *This I Believe: On Love* {edited by} Dan Gediman with Joh Gregory and Mary Jo Gediman; Pages 121-123. John Wiley and Sons, 2011.
 - Chauhan, C. et al Assessment of patient satisfaction with participation in phase II/III NCCTG clinical trials: was it worth it? (N0392). ASCO Poster, 2012. Available for viewing at www.asco.org
 - Smith, M. and Chauhan, C. Connectors, Translators, Facilitators: Research Advocacy Today *J Natl Compr Canc Netw* 2012;10:1183-1187.
 - Basch, E et al Recommendations for incorporating patient-reported outcomes (pros) into clinical comparative effectiveness research in adult oncology. *Journal of Clinical Oncology*, December 1 2012: Vol 30, No. 34. Epub 2012 Oct 15.
 - Chauhan, C. and Smith, M. Closing an on-going clinical trial: when is it betrayal of participants? *Breast Cancer Research and Treatment*: Volume 142, Issue 2 (2013), Page 461-462
 - Reeve BB, et al: Recommended patient-reported core set of symptoms to measure in adult cancer treatment trials. *Journal of the National Cancer Institute* 2014.
 - Basch, E et al: Methods for developing patient-reported outcome-based performance measures (PRO-PM). *Value in Health*; 18 (2015) 493-504.
 - Chauhan, C. Patients' views can improve clinical trial participation. *BMJ* 2016;353:i1922
 - Henry, E, et al: Delivering Coordinated Cancer Care by Building Transactive Memory in a Team of Teams, *Journal of Oncology Practice*.2016.013730
 - Chauhan, C. Living with heart failure with preserved ejection fraction, *JACC Heart Failure*: 2017 Mar;5(3):236-237. doi: 10.1016/j.jchf.2016.12.013
 - Chauhan, C. Partnering with patients to develop better heart failure trials, *JACC Heart Failure*: 2017 Apr;5(4):310. doi: 10.1016/j.jchf.2016.12.010

Knowledge and skills specific to the disease area.

1. Research and read related materials - I do this on a regular basis including oncology and heart failure journals.
2. Attend related meetings – I attend ASCO, Mayo Clinic SPORE meetings, NCI training programs, SABCS, HFSA, Heart Failure Collaboratory, ISOQOL and other meetings as able.
3. Attend workshop/seminar on clinical trials – I attended NCCTG meetings for over ten years until was dissolved. Many of the meetings mentioned in item 2 have special workshops and seminars on clinical trials
4. Relevant Organization Memberships:
 American Society of Clinical Oncology
 The International Society for Quality of Life
 The Heart Failure Society of America

Work Experience:

Retired clinical social worker

Education:

M.S.W., Louisiana State University
 B.A., Valparaiso University