



DR. SUSAN LOVE FOUNDATION
— for breast cancer research —

Exploring Breast Cancer Health Disparities: Supplemental Information & Resources

Financial Aid Resources:

- [Genentech](#)
- [Needy Meds](#)
- [Patient Advocate Foundation Co-Pay Relief](#)
- [PAN Foundation](#)
- [Cancer Care Co-Payment Assistance Foundation](#)
- [Healthwell Foundation](#)
- [The Assistance Fund](#)
- [Cancer Care](#)
 - [Financial Assistance Program](#)
 - [Co-Payment Assistance Foundation](#)
 - [Search](#) organizations who give out financial aid for your specific needs
- [The Sam Fund](#)
- [Komen Financial Assistance](#)
- [Komen Treatment Assistance Program](#)
- [CDC's National Breast and Cervical Cancer Early Detection Program](#)
- [Pink Fund](#)
- [Alliance in Reconstructive Surgery \(AiRS\)](#)

Transportation Resources:

- [American Cancer Society Road to Recovery](#)
- [Uber Health](#)
- [Air Charity Network](#)
- [Angel Wheels](#)

Resources & Information for People of Color:

- [HUED app](#): connects patients with black/Latinx health care providers
- [Komen Breast Cancer Education Toolkit](#)
- University of Michigan Health Lab: [How to advocate for yourself as a minority during appointments](#)
- Oprah Magazine: [This Is How the American Healthcare System Is Failing Black Women](#)
- Texas A&M University PowerPoint presentation: [The Importance of Minority Participation in Clinical Trials](#)
- [Dr. Susan Love Foundation for Breast Cancer Research](#):
 - Webinar: [Fostering Diversity and Inclusion in Breast Cancer Research](#)
 - [Local Breast Cancer & General Cancer Organizations](#)

- Black women:
 - From Dr. Susan Love Foundation for Breast Cancer Research:
 - Blog: [Dr. Susan Love Foundation Stands with the Black Community](#)
 - Blog: [Diversity in Breast Cancer Research: Black Lives Matter](#)
 - [Tigerlily Foundation](#):
 - [Young Women's MBC Disparities ANGEL Advocate Program & Application](#)
 - [Sisters Network Inc.](#)
 - [African American Breast Cancer Alliance \(AABCA\)](#):
 - [Black Women, Breast Cancer](#), PDF
 - [Coping and Healing for the "Strong Black Woman"](#), PDF
 - [Black Women's Health Imperative](#):
 - [My Sister's Keeper \(MSK\)](#)
 - [Sisters By Choice \(SBC\)](#):
 - [SBC Mobile Clinic](#)
 - [Financial and other resources](#)
 - [Smith Center for Healing and the Arts](#)
 - [The Denise Roberts Breast Cancer Foundation \(TDRBCF\)](#)
 - [Free mammograms](#)
 - [Philadelphia Black Women's Health Alliance](#)
 - [Sisters on a Mission](#)
 - [Women of Essence](#)
 - [Breast Cancer Prevention Partners](#)
- LatinX women:
 - [Cancer Facts & Figures for Hispanics and Latinos](#)
 - [Breastcancer.org: Some Latina Women Feel Overloaded With Information After Breast Cancer Diagnosis](#)
 - [Specific Populations and Breast Cancer: Hispanic/Latina](#), PDF
 - [Latinas Contra Cancer](#)
 - [Spanish Language survivor support group](#) - Santa Clara County, CA
 - [ALAS Wings](#)
 - [Campeonas Breast Health Outreach](#)
 - [Nueva Vida](#)
 - Memorial Sloan Kettering: [Psycho-Oncology Latino Initiative](#)
- Asian American women:
 - CDC: [Higher Breast Cancer Risk Among Immigrant Asian American Women Than Among US-Born Asian American Women](#)
 - Cancer Support Community: [Increasing Breast Cancer Awareness Among Asian-American Women](#)
 - Department of Health and Human Services Office of Minority Health: [Cancer and Asian Americans](#)
 - Living Beyond Breast Cancer: [Finding New Purpose: Chien-Chi Huang](#)
 - [Asian American Health Initiative: Asian American Cancer Program](#)
 - Memorial Sloan Kettering: [Chinese American Cancer Care Access Program](#)
 - [Asian American Cancer Support Network \(AACSN\)](#)
 - CDC: [National Breast and Cervical Cancer Early Detection Program](#)
 - [Asian Health Coalition](#)
- American Indian/Alaskan Native women:
 - American Cancer Society: [The Circle of Life](#)
 - [American Indian Cancer Foundation](#)

- [Breast Cancer Stories](#)
- o Department of Health and Human Services Office of Minority Health: [Cancer and American Indians/Alaska Natives](#)
- o CDC: [Cancer in American Indians and Alaska Natives in the United States](#)
- o [National Native Network](#)
- o The Rural Monitor: [Reducing Cancer Among Native Populations: Models for Research, Prevention, and Treatment](#)

Resources & Information for Men:

- From Dr. Susan Love Foundation for Breast Cancer Research:
 - o [Male Breast Cancer by Dr. Susan Love](#)
 - o [Bret Miller](#)
- HealthTalk.org: [Breast Cancer in men: Peer support and support groups](#)
- Living Beyond Breast Cancer: [I Am a Man Diagnosed with Breast Cancer](#)
- [Komen](#): free, 6-week telephone support groups for men with breast cancer
 - o [Men Can Get Breast Cancer Too brochure](#), PDF
- National Cancer Institute at the National Institutes of Health: [Male Breast Cancer](#)
- African American Breast Cancer Alliance (AABCA): [Breast Cancer in Men](#), PDF
- Penn Medicine: [Questions to Ask Your Doctor About Male Breast Cancer](#)
- Breast Cancer Hub: [Male Breast Cancer Advocates](#)
- [Male Breast Cancer Coalition](#)
- [HIS Breast Cancer Organization](#)
- [John Wick Foundation](#)
- [The Bret Miller 1T Foundation](#)

Resources & Information for LGBTQ+:

- From Dr. Susan Love Foundation for Breast Cancer Research:
 - o [Research Worth Watching: Going Beyond Sex & Gender](#)
 - o [Resources for Lesbian & Bisexual Women](#)
- Cancer Research UK: [I'm trans or non-binary, does this affect my cancer screening?](#)
- [National LGBT Cancer Project](#)
 - o [Survivor, Family and Friends Advisory Board](#)
- [Living Beyond Breast Cancer: LGBT With Breast Cancer](#)
 - o [Disparities in Breast Cancer Risk and Care for Lesbian, Gay and Bisexual People](#)
 - o [Disparities in Breast Cancer Risk and Research for Transgender People](#)
 - o [Information on how to find support groups and links to support groups](#)
 - o Blog: [Getting the Care You Need: LGBTQ People and Breast Cancer](#)
 - o Blog: [Breast Cancer inFocus: Getting the Care You Need as a Lesbian, Gay or Bisexual Person](#)
- National LGBT Cancer Network:
 - o [Lesbians and Breast Cancer Risk](#), PDF
 - o [Information for LGBT caregivers](#)
 - o [Transgender/Gender-Nonconforming People and Cancer](#)
 - o [Cancer Resources for the LGBT Community](#)
- Cancer Network:
 - o [Trans People and Cancer](#), PDF

- [Access to Care and Cancer Disparity Fact Sheet for Transgendered and Transsexual Individuals](#), PDF
- [National Transgender Discrimination Survey Report on Health and Health Care \(2017\)](#)
- [Komen: Breast Health for the LGBTQ Community](#), PDF
- [Keep A Breast: LGBTQIA+ Community & Breast Cancer](#)
- [Memorial Sloan Kettering Cancer Center: LGBT Support Resources](#)
- African American Breast Cancer Alliance (AABCA): [LGBT Women](#), PDF

Resources & Information for People with Disabilities:

- [Equal Rights Center Accessible Healthcare Toolkit](#), PDF
- [CDC: Women with Disabilities and Breast Cancer Screening](#)
- [Every Woman Matters: Portraits of Montana Women Living with Disabilities](#)
- New York State Department of Health (NYSDOH)'s [Breast and Cervical Cancer Early Detection Program \(BCCEDP\)](#)
- [Oregon Office on Disability and Health Mammography Accessibility Project](#)
 - [Taking Charge of My Health Toolkit](#)
- [The Association of Maternal & Child Health Programs \(AMCMP\)'s TOOLBOX](#)
- CDC's The Right to Know Campaign Breast Cancer Screening:
 - [Free Flyers, Fact Sheets, and Dissemination Guide](#)
 - Tip sheets: [English](#), [Spanish](#)
 - [Disability and Health Promotion](#)
- American Association on Health and Disability (AAHD): [Women with Disabilities and Risk Factors for Breast Cancer](#), PDF
- Alaska Department of Health and Social Services: [Tips for Women with Disabilities on Understanding Breast Cancer](#), PDF
- [Women with Disabilities and Breast Cancer: Know Your Rights](#)
 - Tip sheets: [English](#), [Spanish](#)
- African American Breast Cancer Alliance (AABCA): [Impaired Women](#), PDF

Why be your own advocate?

- ✓ Someone else might not be around. Hospitals may have advocates who you can request (sometimes known as medical advocates, sometimes as social workers) but that's not always the case.
- ✓ You can overcome the provider's bias. Chronic pain patients can face tremendous bias, which only increases with intersectional marginalized identities.
- ✓ It's your body!

Research practitioners and offices: You can start by looking up which providers are in-network for your insurance. Then you can start checking out practice websites, and review sites. [ZocDoc](#) is a review site where the phone-averse can make their appointment, but there are plenty of others to choose from. For plus-size folks, [Can We All Go?](#) (app) and [FatFriendlyDocs](#) can be useful.

Call your provider's office: Without giving them any information about yourself, get information that is vital to you. For example: are there any practitioners of color? Is this practice affirming of transgender people? Will this practitioner work from a Health at Every Size perspective? Is this office sex worker-positive? Again, you can do this anonymously or using a pseudonym, then call back to make an appointment if you want.

Make your appointment: You can ask that certain information be given to the practitioner. For example, you may have a history of trauma from healthcare practitioners that leads to white coat hypertension (high blood pressure that is the result of being extremely nervous at the doctor's office). You could also notify them of any disabilities you have and any support you will need during the appointment.

Write it all down: Writing things down ahead of time can help you organize your thoughts before and during the appointment so that you make the most of your time with the practitioner. Here is a sample format that you can use:

- Goal(s) for this appointment
- Symptom(s) I have
- Concern(s) I want addressed
- Question(s) I want answered
- Numbers for the doctor – this may involve things like bringing your glucose monitor, or a log of when/how often you use your inhaler, or anything else that the doctor has requested or that you think might be helpful.
- Research – You can print out (or save on your phone or tablet) any research that you think you might want to bring up.

Advocating for others during medical appointments:

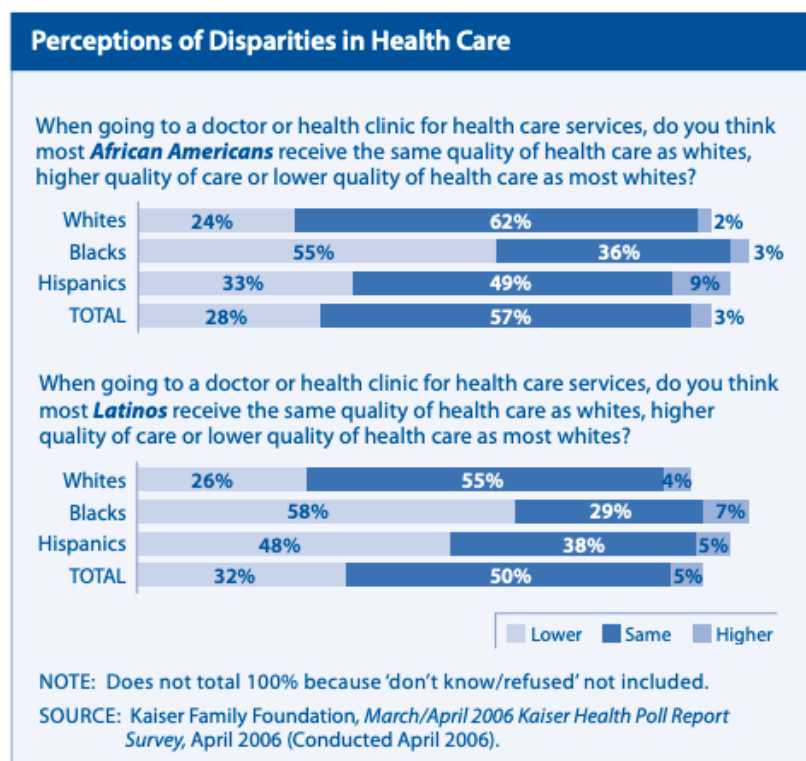
The patient advocate can act as a trusted advisor, playing an integral role when the patient has difficulty understanding medical bills, medication side effects or plans for surgery, among a host of other things. Patients can bring their own advocates: a friend, family member or even trusted colleague. If they're not available to attend the visit, the patient will sometimes call their advocate, so they can hear the information, ask questions, and help the patient decide on next steps. This type of support can be critical to helping a patient achieve optimal well-being.

- “If one of us is the person being the advocate during challenging times—the one who speaks with the doctor about treatment options—we have a text chat group that we report everything back on. Sometimes, being a patient advocate will require the responsibility to be shared rather than placed on one family member. I find that this creates an atmosphere where our loved one feels more supported and like less of a burden on one person.”
- An advocate can facilitate a discussion and ensure that all the predetermined questions are answered. The patient can then just focus on listening to the responses. The advocate should also be a note-taker and discuss everything with the patient again after the visit. This is especially important with topics, such as when the shock of the cancer diagnosis can prevent patients from retaining much information.

Who do I educate? On what?

In contrast to the general public’s continued lack of awareness, the level of awareness among physicians has risen sharply. In 2002, the vast majority (69%) of physicians said that the health care system “rarely or never” treated people unfairly based on an individual’s racial/ethnic background. In 2005, less than a quarter (24%) of physicians disagreed with the statement “minority patients generally receive lower quality care than White patients.”

FIGURE 1



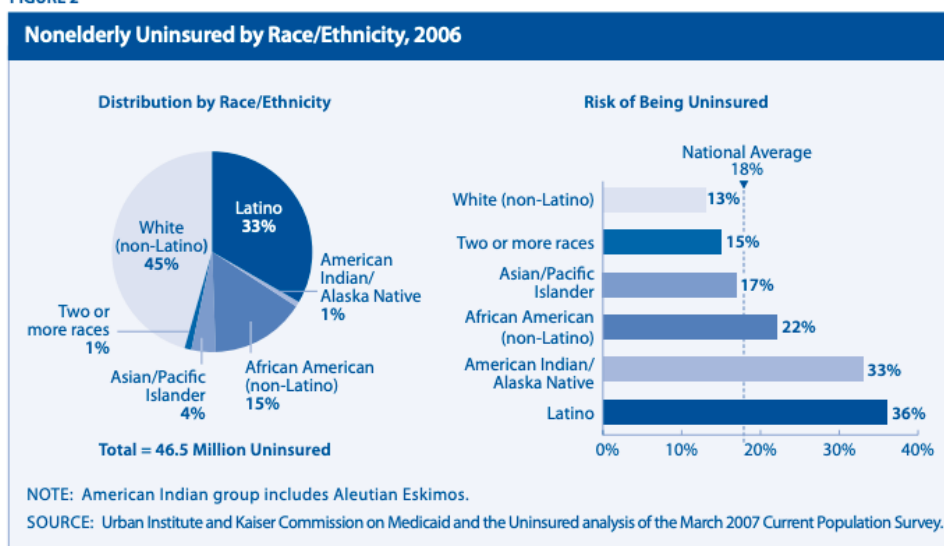
Expanding health insurance coverage:

Racial/ethnic minority populations—who constitute only about one-third of the U.S. population—are disproportionately represented among those without any health coverage. Compared with the insured, the uninsured are less likely to have a regular doctor or to get timely

and routine care and are more likely to be hospitalized for preventable conditions. Thus, expansions to health insurance coverage are of particular importance to racial/ethnic minority groups.

Minority Americans are much less likely to have health insurance offered through their jobs, and even after accounting for work status, minority Americans are still more likely than Whites to be uninsured. As such, Medicaid, a source of coverage for many of the nation's poor and disabled, is an important safety net for about 1 in 4 nonelderly African Americans, American Indians/Alaska Natives, and Latinos, and about 1 in 10 Asian/Pacific Americans and Whites.

FIGURE 2



Improving the capacity and number of providers in underserved communities:

Despite efforts since the 1970s to increase the number of health professionals in medically underserved areas, members of racial/ethnic minority groups are still underrepresented in the health care workforce and are more likely than Whites to live in neighborhoods that lack adequate health resources. For example, 28% of Latinos and 22% of African Americans report having little or no choice in where to seek care, while only 15% of Whites report this difficulty. African Americans and Latinos are also twice as likely as Whites to rely upon a hospital outpatient department as their regular source of care, rather than a doctor's office where opportunities for continuity of care and patient-centered care are greater.

Even when health care resources are geographically accessible, language and cultural barriers are sometimes a problem. Approaches to strengthening communication and relationships between patients and providers include greater use of medical interpretation services, expanding the racial/ethnic diversity of the health professions workforce, and developing provider training programs and tools in cross-cultural education. Since minority health professionals are more likely than Whites to practice in minority and medically underserved areas, a more diverse health workforce could help to improve access and adherence to treatment.

Although evidence of racial and ethnic health care disparities is substantial, the evidence-base for developing interventions to eliminate these disparities remains limited. Increasing the knowledge base on causes and interventions to reduce disparities is crucial.

Resources to educate yourself and others:

- [Tools to Create and Map Accessible Facilities and Transportation in Communities](#)
- [Removing Barriers to Health Care: A Guide for Health Professionals](#), PDF
- [What Are Health Disparities? Why It's Important to Fight for Health Equity—Especially Right Now](#): lists organizations and groups doing both scientific research on health disparities and pushing for policy changes for underserved communities
- [Right to Health](#)
- [John Wesley Community Health](#)
- [APA Health Equity Ambassadors Program](#)
- Social media accounts to follow for current information:
 - @tigerlily_foundation
 - @outwithcancerstudy
 - @drsusanlovefoundation
 - @sistersbychoice1989atl
 - @sistersnetwork
 - @blkwomenshealth
 - @smithcenterdc
 - @womenofessencebcsg
 - @bcppartners
 - @latinascontracancer
 - @alas_wings_
 - @nnnkeepitsacred
 - @malebreastcancercoalition
 - @menhavebreaststoo
 - @hisbreastcancer
 - @forthebreastofus
 - @lgbtcancernetwork

Ways to take action!

- 1 Support the organizations listed above by following them on social media and/or make a charitable donation!
- 2 Volunteer as a professional patient advocate (especially social workers):
 - An advocate may be a member of your family, such as a spouse, a child, another family member, or a close friend. Another type of advocate is a professional advocate. Hospitals usually have professionals who play this role called Patient Representatives or Patient Advocates. Social workers, nurses and chaplains may also fill this role. These advocates can often be very helpful in cutting through red tape.
 - [Professional Patient Advocates: What They Do and How it Works](#)
 - A professional navigator can help identify challenges you are facing in your care and brainstorm solutions. They can also help you find financial assistance and help identify important questions to ask your doctors.
 - Some patient navigators work for community-based organizations or work independently and are hired on a freelance basis directly by patients. Independent

- patient advocates may focus on one particular disease area, such as cancer. Others focus on billing and health insurance claims. They may help to coordinate care among several providers, accompany patients to medical appointments or sit with them in the hospital.
- Two resources for finding patient advocates are the [National Association of Healthcare Advocacy](#), which requires members to sign a code of ethics, and the [Alliance of Professional Health Advocates](#), which requires participants to have professional liability insurance.
 - [Get certified](#)
- [Be an ally to BIPOC patients:](#)
 - Listen to those who bear the brunt of racism.
 - Talk to your children about how to interrupt bullying safely and how to report it
 - Speak with someone who looks much like you about how racism affects you and those who do not look like you.
 - Write a letter to the CDC, NIH and other systemic institutions that are responsible for public policy. See this [letter to the CDC](#) as an example.
 - Write a letter to your state and local representatives in support of declaring racism a public health crisis.
 - If you are white, [recognize and utilize your privilege](#) even if it's just speaking truth when you see mistreatment.

3

Join/volunteer at community health organizations:

- [Volunteering in Public Health](#)
 - Many people who want to help others do not need health care experience to support efforts like educating the public about health and safety issues, answering phones at clinics and health hotlines, or delivering meals to seniors.
 - Volunteering plays a key role in strengthening our society by acting as a bridge between socioeconomic divides. On a community level, the organization you become a part of is likely to collaborate in social networks with other volunteer organizations and local governments, providing services that help build a cohesive society.
- Volunteer to be an interpreter/translator during medical appointments at clinics, interpreting at health fairs or screening events, translating healthcare-related documents, or providing health educational workshops.
 - [UC Berkeley Volunteer Health Interpreters Organization](#)
 - Medical Interpreting Training School: [How to Become a Certified Medical Interpreter](#)
 - [International Medical Relief interpreters](#)

Healthcare Disparities Research

People of Color:

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