

bloom

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**Introducing: the
hosts of the next RRI
Breast Cancer Support
Conference**

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**The fight against breast
cancer illustrates the
health-care challenges
of women in poverty**

Reach to Recovery International (RRI)

RRI is committed to improving the quality of life of individuals affected by breast cancer and their families.



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We respectfully acknowledge the Indigenous women of our global community, the traditional custodians of our environment.



Reach to Recovery International, Inc. is a global non-profit organisation based in Baltimore, Maryland, USA.

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Our mission

Reach to Recovery International's mission is to:

- Unite organisations throughout the world which support individuals affected by breast cancer, including their families, in order to share ideas and best practices;
- Disseminate valuable information to support individuals affected by breast cancer throughout the world via bi-annual conferences, our website, our e-newsletter, and other forms of worldwide communications; and
- Assist our Member Organisations in achieving their goals of:
 - Improving the quality of life of individuals affected by breast cancer,
 - Providing psychosocial support to individuals affected by breast cancer, either through group meetings or activities or one-on-one peer support provided by carefully trained survivor volunteers,
 - Advocating on behalf of individuals affected by breast cancer,
 - Providing patient navigation to individuals affected by breast cancer.

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What would you like to read about in the next edition of *bloom*?

Email your theme suggestions to information@reachtorecoveryinternational.org. A theme will be chosen by August 2020. Regardless of whether your suggested theme is chosen this time, it will remain under consideration for future editions.



SUBMIT YOUR ARTICLE

bloom

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Bloom is introducing a new column!

Do you know a breast cancer survivor who provides outstanding peer support for an organisation in your community? Starting with our next edition in June 2020, we will be featuring a deserving peer-support volunteer in each edition of *Bloom*. These features will also be posted permanently on www.reachtorecoveryinternational.org. Send your nomination along with a 200–400 word article about the volunteer to info@reachtorecoveryinternational.org. Please also include a high-resolution photo of your nominee. It's a great way to say thanks for a job well done, and to raise awareness about your organisation!

Upcoming events

World Cancer Day

4 February 2020

<https://www.uicc.org/what-we-do/convening/world-cancer-day>

World Cancer Congress

20–22 October 2020

Muscat, Oman

<https://www.worldcancercongress.org>

20th RRI Breast Cancer Support Conference

3–6 March 2021

Guadalajara, Mexico

Website pending

World Cancer Congress
Muscat, Oman
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“ REACH TO RECOVERY INTERNATIONAL IS COMMITTED TO IMPROVING THE QUALITY OF LIFE OF INDIVIDUALS AFFECTED BY BREAST CANCER AND THEIR FAMILIES THROUGH A WIDE RANGE OF SERVICES OFFERED WORLDWIDE. ”

Message from Cathy Hirsch - President of RRI



Cathy Hirsch

It is my pleasure to announce the location and dates of the 20th Reach to Recovery International Breast Cancer Support Conference! We will meet next from 3–6 March 2021 in Guadalajara, Mexico—a city known for its friendly citizens, temperate climate, and excellent food! Our local hosts, Fundación Voluntarias Contra El Cáncer and Corporativa de Fundaciones, are already working hard to plan an information-packed programme which will have the theme *Enriching lives*. They plan to have the Conference website online and begin accepting early-bird registrations by May of 2020. As is the case with all RRI Conferences, special care is being taken to ensure that, in addition to being informative, the Conference will also be entertaining and fun! In this edition of Bloom, we'll introduce you to the Conference hosts and to the vibrant city of Guadalajara.

What's in this issue?

No matter who we are or where we live, receiving a breast cancer diagnosis is a life-altering experience. Making decisions about surgeries and other treatments, going to countless medical appointments, dealing with side effects and disruption to our daily lives—all while facing down our own fear and emotional turmoil as well as that of our loved ones—can be overwhelming. For some individuals facing breast cancer, however, the situation is even worse. Too many people around the world do not have access to the screening, treatments, or follow-up care they need. The barriers may be financial, geographic, or cultural. To these people, the hardships that many of us face when diagnosed with breast cancer may seem like luxuries.

The theme of this edition of *Bloom* is *Breast cancer in underserved populations*, and we focus on what's being done or can be done to address breast cancer disparities. Some of our writers view the situation from a global perspective, while others report on projects underway to help the underserved in their own communities.

We also shine our spotlight on work being done by groups based in Canada, India, Kenya, and South Africa. To help you get excited about your trip to Guadalajara, our *Global Kitchen* features two healthy recipes from Mexico.

“NO MATTER WHO WE ARE OR WHERE WE LIVE, RECEIVING A BREAST CANCER DIAGNOSIS IS A LIFE-ALTERING EXPERIENCE.”

Introducing: the hosts of the next RRI Breast Cancer Support Conference

Esther Cisneros Quirarte, *President, Fundación Voluntarias Contra El Cáncer*
David Pérez Rulfo Torres, *CEO, Corporativa de Fundaciones*
Guadalajara, Mexico

Fundación Voluntarias Contra El Cáncer, A.C.

Fundación Voluntarias Contra El Cáncer, A.C. (FVCC) was founded in 1986, and its corporate purpose is to promote the early detection and treatment of cancer and other diseases as well as to encourage philanthropy in the areas of prevention, healthcare, hospital, and social assistance. These actions are intended for and focus on vulnerable sectors of the population.



Since 2013, FVCC has had a comprehensive programme of breast cancer rehabilitation—the biggest of its kind in the country—that includes:

- navigation of oncological patients and their families
- emotional support to breast cancer survivors
- individual and group psychotherapies for patients and their families
- women's empowerment by teaching them a trade and assisting them in achieving personal and economic growth
- a guided imagery program for patients during their chemotherapy

The programme has benefited 270 low-income women who would not have been able to access these resources on their own. It has helped strengthen their self-images and improve their self-confidence.

In order to support this and other programmes, FVCC has organised 7 annual Cena Gala

Pasarelas, or Gala Dinner Catwalks, at which 20 women, all breast cancer survivors, model the Liverpool fall-winter collection. The events send a message to society of courage, resilience, and above all solidarity with those who are going through this difficult experience.

For the last 6 years, FVCC has also promoted the care of both patients and caregivers in Hospitales Civiles de Guadalajara by organizing cultural and recreational events within the hospital. FVCC recognised that many patients and their families could not afford to feed themselves while in hospital, and that the hospital needed more space for dignified and hygienic dining. It undertook the task of raising funds through sponsors to build 3 dining rooms, each with a capacity to

host 110 people. Thanks to these efforts, an average of 2000 free meals are provided at the hospital daily.

Since 2015, FVCC has organised the annual half marathon *21 K with Cause* as one of its action programmes, not only to raise funds but also to educate the population about the importance of leading an active life and engaging in sports to reduce the risk factors for cancer and other diseases.

Corporativa de Fundaciones, A.C.

FVCC works closely with Corporativa de Fundaciones, A.C. (CF), which is a leading community foundation based in the State of Jalisco, Mexico. CF promotes alliances between people, social investors, and Civil Society Organizations (CSOs) to benefit





Women participating in the Cena Gala Pasarela.



Volunteering forum organized by Corporativa de Fundaciones.

the community and empower the most vulnerable members of society. Since its establishment in 1999, CF has identified many of the problems facing CSOs working in social spheres. It helps CSOs expand their technical knowledge and management and leadership skills so they can better address societal needs and interests. CF's main purpose is to strengthen and sustain innovative social projects and programs with a human rights and evidence-based perspective. It transfers skills and capacity building to members of CSOs to help them better respond to the most pressing issues

of the community, with more efficient, cost-effective and environmentally sustainable efforts that ensure greater social impact.

Through its intervention schemes, CF provides Fundación Voluntarias Contra El Cáncer with technical tools and other useful resources to fully achieve sustainable strategic plans. CF also works with other CSOs to support the social and economic empowerment of women who live in vulnerable conditions in the metropolitan area of Guadalajara.



Volunteering forum: choice of life and/or social responsibility.

An introduction to Guadalajara

Maria José Gómez, *Guadalajara, Mexico*

Guadalajara is home to an array of traditions that are not only the heritage of the State of Jalisco but also belong to the wider global culture. It's the source of intangible cultural musical expressions such as Mariachi and home to world-renowned distilleries which dot the agave-filled landscape of Tequila—the only place where Tequila can be made owing to its geographical indication status. Charrería, or the Mexican rodeo, is a popular national sport that originated there. Wherever you roam in Guadalajara, you will be surrounded by what it means to be Mexican. Far more than a city, and more still than a venue, Guadalajara has endless experiences and memories waiting to be had.

Guadalajara boasts many UNESCO world heritage sites such as Hospicio Cabañas, one of the oldest and largest hospital complexes in the Americas. The hospital started as an orphanage in 1791 and now functions as an Art Museum and venue, with daily tours in both Spanish and English. Draping the walls and ceilings of Hospicio Cabañas you will find murals and frescos by acclaimed Mexican muralist José Clemente Orozco that depict Mexico's history and give a unique insight into the story of Mexico from one of Jalisco's most remarkable minds.

Journeying a mere hour outside of Guadalajara, you will discover a true wonder of the state, Guachimontones. Guachimontones is another UNESCO world heritage site and home to the world's only circular pyramids. Dating back to 400 BC, this pre-Hispanic wonder, set deep in the Jaliscan landscape, consists of a total of 10 circular complexes, four rectangular plazas, and two ballcourts. This adventure is a once in a lifetime experience.

No trip to Guadalajara would truly be complete without an extensive sampling of its cuisine. Food is a pillar of the society here and features in every aspect of life. A few notable dishes include; Carne en su jugo, Torta Ahogado, and Birria, which is a spicy stew, traditionally made from goat meat or mutton. Birria is often served

at celebratory occasions, such as weddings and baptisms, and holidays, such as Christmas and Easter; however, it is also a daily staple and is a must-try. And why not try for dessert some Jericalla, a traditional dessert made from milk, eggs, vanilla, cinnamon, and sugar?

These are but a few of many attractions Guadalajara has to offer. This vibrant city exists in its flavors, smells, and sights, and there are uncountable memories and stories yet to be told. The adventure awaits you.



A participant in a Charrería, or Mexican rodeo.



Basilica de Zapopan



Catedral de Guadalajara



An Agave field in the town of Tequila, just outside Guadalajara.

Guadalajara's city center.



Mariachi



“

THESE ARE BUT A FEW OF MANY ATTRACTIONS GUADALAJARA HAS TO OFFER. THIS VIBRANT CITY EXISTS IN ITS FLAVORS, SMELLS, AND SIGHTS, AND THERE ARE UNCOUNTABLE MEMORIES AND STORIES YET TO BE TOLD. THE ADVENTURE AWAITS YOU.

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Grappling with breast cancer health disparities around the globe

Fred Hutch global cancer initiative uses collaborations, common sense strategies to tackle health disparities in low- and middle-income countries

**Diane Mapes, Fred Hutch News Service
USA**



Breast cancer is the second leading cause of cancer mortality among women in Tanzania. The Breast Health Global Initiative, founded by Fred Hutch and Susan G. Komen, is working to improve outcomes for women here and in many other countries around the world. Photo courtesy of Carolyn Taylor

Each October in the U.S., women are accustomed to hearing messages about early detection and breast cancer awareness. But what's the best way to raise breast cancer awareness in countries with no mammogram machines and few cancer treatment centers? That's the quandary faced by global health experts like [Dr. Ben Anderson](#) of Fred Hutchinson Cancer Research Center and Seattle Cancer Care Alliance, a surgical oncologist and health systems researcher who, [17] years ago, helped create the Hutch-led international health alliance [Breast Health Global Initiative](#), or BHGI. Anderson has spent the years since coming up with pragmatic solutions for low- and middle-income countries, where women are traditionally diagnosed at much later stages and misguided good intentions often result in squandered resources.

"A common error is to package up a bunch of mammography equipment and ship it off to some country where it sits in the corner because you don't have the infrastructure to make it relevant," he said. "In Latin America and Africa, the majority of women are presenting with palpable masses. If you don't have a set-up where you can evaluate it, sample it and prove that it's breast cancer, you're unable to move forward. Screening in that setting is irrelevant." What's more relevant, he said, is implementing a tailored triage approach based on the resources that are available.

That doesn't mean Anderson and his team are parachuting into third world countries and MacGyvering mammogram machines out of spare parts. Instead, BHGI develops a flexible framework that can be used in a number of different countries to give patients the best possible cancer prevention, diagnosis and treatment bang for their ever-limited buck. "You have to build a foundation before you build a first and second story," Anderson said of the programs he and fellow BHGI researchers have put into place in countries like Vietnam, Tanzania, [Ghana](#), Uganda, Colombia, Peru and Brazil. "You have to begin with what you've got."

The global breast cancer picture

Dr. Catherine Duggan, a Hutch public health scientist who works with Anderson and BHGI's global collaborative partner [Breast Cancer Initiative 2.5](#), said in the U.S., the five-year survival rate for breast cancer is around

90 percent, which means out of every 100 women diagnosed, nearly 90 are still alive five years out. "That's wonderful and attributable to advancements in treatment and early diagnosis," she said. But that sunny statistic doesn't hold true for low-income countries. In some sub-Saharan countries, for instance, 70 out of every 100 women will die within five years of diagnosis. Sometimes, it's because their cancer is particularly aggressive. More often, though, it's because of delays, logistical challenges and/or lack of access to cancer care. "It's a whole combination of things," Duggan explained. "First, you're living in a remote area. There's no health insurance. You have to have enough money to see your local doctor in a clinic and that could be two or three hours away."

BHGI's assessment of breast healthcare [services in Tanzania](#), for instance, showed that women there traveled six hours on average to get to the one cancer treatment center in the country. The average time between first symptom and first care appointment? Around 20 months. Women are diagnosed much later in these countries," Duggan said. "And you see all these horrific lesions. There are stories of women showing up with tumors so big, their breast just falls off. This is the heart of what we're doing, trying to help."

Obstacles to diagnosis and treatment

Stigma is another huge barrier to care in these countries. Duggan said one woman refused to

seek treatment for her breast cancer until all of her daughters were married for fear they might not find husbands if anyone knew she had the disease.

"In Tanzania, if you say you have cancer, you might be shunned or divorced by your husband," she said. "So people don't seek care." Those who do try to pursue screening or receive a biopsy or treatment face an almost insurmountable bureaucratic obstacle course. A woman who finds a lump first has to save enough money to see a primary care doctor, who often tells her it's an abscess and sends her home with antibiotics. After that, she has to save up money to see a specialist for a mammogram or ultrasound but since they are few and far between, she usually has to go to a regional hospital for a biopsy. After the biopsy, she then has to save again and finally travel with her tissue sample to the closest pathology lab for analysis. But Tanzania has a shortage of pathologists (ditto for radiologists, breast surgeons and medical oncologists) so again there are delays. If a lump (or other symptom) turns out to be cancer, the woman then has to save money so she can travel to the capital for treatment. And all the while, the cancer is spreading and getting worse.

"Treatment is free once you're diagnosed with cancer," said Duggan. "But all the stages up to that—mammography, biopsy, pathology and surgery aren't free. You have to find the money for your medical care and travel and by the time you get there, it just might be too late." Not surprisingly, half of all women



Tanzania's population is nearly 52 million, similar to England's, but the East African country has very limited imaging services, including mammography. Radiation therapy is available at only two national hospitals. Chemotherapy is available at the three national hospitals and at two of four zonal hospitals. No breast surgeon specialists work in the country, which also experiences chronic shortages of morphine. Photo courtesy of Carolyn Taylor



Peruvian women take part in a public education workshop on breast cancer and breast health during a BHGI site visit in 2012. Photo courtesy of Dr. Ben Anderson

diagnosed with breast cancer in Tanzania die of the disease.

Partnerships and policy changes

How does a team of scientists even begin to put together an action plan for a country mired in health care holdups? It starts by putting together a crack team of collaborators.

... Anderson likens the group to a nerdy version of Marvel's *The Avengers*. "They're superheroes fighting crime," he said. "We're just well-intending individuals with varied skills teaming up to help women address cancer in low and middle-income countries. But I like the analogy."

Usually, the first order of business when implementing change in a country's breast health management system is conducting an assessment, like the one BHGI recently put together for Tanzania's Ministry of Health, which pinpoints delays and backlogs; referral inefficiencies; equipment, medication and personnel shortages; and the need for standardized protocols and guidelines. "We do a country-based institutional analysis," said Anderson. "We analyze some component of the health care system to identify opportunities for next steps." After that, representatives of the country's health care system work with the BHGI and other stakeholders (local clinics, regional cancer centers, etc.) to update diagnosis and treatment guidelines. Then they begin what Anderson and Duggan refer to as "phased implementation" of their resource-stratified recommendations. "Implementation research takes you outside the test tube and into the real

world where the women are," said Anderson.

As a low-income country, Tanzania's phased recommendations start with the very basics—developing and displaying educational materials to battle misinformation and raise breast health awareness; introducing patient record-keeping to clinics; repurposing obstetric ultrasound machines for breast imaging. They then move on to more sophisticated tweaks, like ensuring all breast tissue is saved for pathological analysis; offering decentralized endocrine therapy to all women with ER+ (estrogen receptor positive) tumors; and training health workers in clinical breast exams, medical history-taking and ultrasound imaging. "The whole point is that it's resource appropriate," said Duggan. "You start at the basic level of breast cancer care and you shouldn't move up to a higher level unless you've got certain aspects of care established properly. A country or region can't go on to establish screening mammography if the health system can't diagnosis and treat women with palpable disease properly."

Duggan said tamoxifen (a drug used to treat ER+ tumors) is cheap and effective so low-income countries are advised to test for the estrogen receptor in breast tumor tissue. That's not the case for another common target in breast cancer, [HER2](#). "In Tanzania and other low income countries, there's no point in testing for HER2 because nobody can afford [Herceptin](#) and the test itself is very expensive," she said.

Busting up bottlenecks to treatment

In middle-income countries like Peru, the initial steps are the same—a health care assessment plan and phased implementation—but the starting point begins further along the care continuum. "Peru has more cancer centers and much more widespread infrastructure, but they have a lot of problems that stem from a dysfunctional referral system," said Duggan, who along with Anderson and others, authored a [study](#)* published in *The Lancet* earlier this month about BHGI's efforts there. "People get stuck with their wheels spinning and don't get referred quickly enough. Or they live in remote areas and have to travel to receive care."

The country has made important inroads through its national cancer control plan and early diagnosis programs, which promote breast self-examination for women over 20 and mammography for women over 40. Peru also pays full coverage for cancer treatment. But 75 percent of its breast cancers are diagnosed at stage 3 or 4, and a recent study found fewer than half of women 40 and older receive annual mammograms. There, the BHGI's collaborators (in this case, [PATH](#)) focused on a series of impactful steps to improve women's outcomes: bumping up breast health awareness; training professional midwives and others in clinical breast exams; increasing the use of ultrasound guided fine-needle aspiration for biopsies; developing a patient navigation program to

avoid bottlenecks; and strengthening health care systems to support diagnosis at the community level. "They trained community health workers who could perform clinical breast exams at the local clinics and if they found a lump, they could send them to a local hospital where they had trained people to do ultrasound guided biopsies," said Duggan. "If they were diagnosed, they were referred to a regional cancer center for surgery and treatment. It was all done locally—taking away the burden of travel and distance."

Bringing it all home

Another important outcome of the work in Peru, Anderson said, was that it reinforced the usefulness of breast self-exams and clinical breast exams—both hotly contested in policy circles—in low-resource environments. "In Peru, we found that if a woman had a prior clinical breast exam, they were twice as likely to come in earlier [when they found a symptom]," he said. "More than 90 percent of the women detected their own cancers and came in for evaluation."

The BHGI's methods have been so successful, Anderson said, that similar approaches have been adopted by the National Comprehensive Cancer Network, the American Society of Clinical Oncology and the World Health Organization.

The lessons learned in other countries can be shared here at home, too.

"We're trying to develop strategies that would also be useful in underserved communities in the U.S.," said Anderson. "We're bridging gaps. Overall, we're doing much better in breast cancer but there's room for improvement. The biggest gap is getting what we already know works to the communities that are not receiving it." As Duggan put it, "We have to be very aware as we move into a brave new world of precision oncology and immunotherapy" that there are still people here in the U.S. being left behind. "Not everyone has access to all of these amazing novel therapies, especially as not everyone has a home or enough food to feed their children," she said. "And some women don't—or can't—even access mammography. That's changed a bit with the Affordable Care Act, but not for example among illegal immigrants who are afraid to get health care because they might get deported. If they have a doctor they trust, they could at least get a clinical breast exam."

Health disparities in cancer care—both here and globally—can seem insurmountable at times, she said, but the Breast Health Global Initiative team is determined to "keep chipping away at things." "There's increasing awareness across many organizations including the National Institutes of Health that something has to be done at home as well as in these low-income countries because there are more and more divisions between people who have and have not," she said. "Personalized medicine is fabulous, but the small steps are important, too."

Examples of Cancer Health Disparities

National Cancer Institute



Photo by Sandra San Miguel

Cancer affects people of all races and ethnicities in the U.S.; however, the burden is greater for certain populations. Below are selected statistics that illustrate the impact of cancer health disparities by socioeconomic status, racial/ethnic group, and cancer type.

Cancer Disparities by Socioeconomic Status and Medically Underserved Populations

- People with lower socioeconomic status (SES) have disproportionately higher cancer death rates than those with higher SES, regardless of demographic factors such as race/ethnicity. ([American Cancer Society-ACS](#))
- Studies have found that SES factors are associated with an individual's or group's risk of developing and surviving cancer—more than race or ethnicity. SES factors include access to education, certain occupations, health insurance, and living conditions—including exposure to environmental toxins.
- SES appears to play a major role in influencing the prevalence of behavioral risk factors for cancer (for example, tobacco smoking, physical inactivity, obesity, excessive alcohol intake, and health status), as well as in following cancer screening recommendations.
- Individuals from medically underserved populations are more likely to be diagnosed with late-stage diseases that might have been treated more effectively or cured if diagnosed earlier.

Cancer Disparities by Racial/Ethnic Groups

AFRICAN AMERICANS

- For all cancers combined, cancer incidence rates between 2007 through 2011 were the highest overall in black men (587.7 per 100,000 men) compared to any other racial or ethnic group. ([NCI](#))
- African Americans have the highest mortality rate of any racial or ethnic group for all cancers combined and for most major cancers. ([DHHS Office of Minority Health- OMH](#))
- For all cancers combined, the death rate is 25 percent higher for African Americans/blacks than for whites.
- African American women with cancer have higher death rates despite them having a lower risk of cancer overall (compared to white women). ([ACS](#))
- African American men have lower 5-year cancer survival rates for lung, colon, and pancreatic cancers compared to non-Hispanic white men. ([DHHS OMH](#))

AMERICAN INDIAN AND ALASKA NATIVE

- Cancer is the second leading cause of death among Native Americans over age 45. ([NCI](#))
- While overall cancer mortality rates from 2001 through 2010 decreased by 1.4 percent per year among whites and by 2.1 percent per year among African Americans/blacks, they decreased by only 0.7 percent per year among American Indians and Alaska Natives. ([NCI](#))
- American Indians and Alaska Natives continue to have the poorest 5-year survival rates among all racial and ethnic groups, for all cancers combined. ([NCI](#))

ASIAN AMERICANS, NATIVE HAWAIIANS, AND OTHER PACIFIC ISLANDERS

- Asian Americans and Pacific Islanders have the highest incidence

rates for both liver and stomach cancers and are twice as likely to die from these cancers as whites. This may be caused by a higher prevalence of infections with hepatitis B virus (liver cancer) and the bacterium *H. pylori* (stomach cancer). ([ACS](#))

- Native Hawaiians/Pacific Islanders are 30 percent more likely to be diagnosed with cancer compared to non-Hispanic whites. ([DHHS OMH](#))

HISPANICS/LATINOS

- Hispanics and Latinos have the highest rates for cancers associated with infection, such as liver, stomach, and cervical cancers. Higher prevalence of infection with human papillomavirus (cervical cancer), hepatitis B virus (liver cancer), and the bacterium *H. pylori* (stomach cancer) in immigrant countries of origin contributes to these disparities. ([ACS](#))
- Although Hispanics and Latinos have lower incidence and death rates for the most common cancers than non-Hispanic whites, they are more likely to be diagnosed with advanced stages of disease. ([NCI](#))

[Breast Cancer Disparities]

- Where breast cancer rates stabilized between 2002 and 2011 in non-Hispanic white women, rates continue to increase among African American/black women. ([JNCI](#))
- African American/black women are more likely to die from breast cancer despite white women having higher incidence rates for the disease.
- African American women are almost 40 percent more likely to die from breast cancer compared to non-Hispanic white women. ([DHHS OMH](#))
- African American women with breast cancer are less likely than white women to survive five years after diagnosis. The survival rate among African American women is 71 percent, compared to 86 percent among whites. ([JNCI](#))
- Recent NCI-supported research indicates that aggressive breast tumors are more common in younger African American/black and Hispanic/Latino women living in low SES areas. This more aggressive form of breast cancer is less responsive to standard cancer treatments and is associated with poorer survival.
- Rates for triple-negative breast cancers (HR-/HER2-) were highest among non-Hispanic black women compared with all other racial/ethnic groups with an age-adjusted rate of 27.2 per 100,000 women; a rate 1.9 times higher than the non-Hispanic white rate, 2.3 times higher than the Hispanic rate, and 2.6 times higher than the non-Hispanic API (NHAPI) rate. ([JNCI](#))
- Overall, compared with non-Hispanic white women, African American/black women are screened less frequently for breast cancer, are more likely to have advanced disease when a diagnosis is made, have a poorer prognosis for a given stage of disease, and have less access to medical care. ([NCI](#))

The Fight Against Breast Cancer Illustrates the Health-Care Challenges of Women in Poverty

By Quyen D. Chu, MD, MBA, FACS



Quyen D. Chu, MD, MBA, FACS

Progress has been made in expanding access to health care for low-income populations, but the quality of care still lags behind and can result in less successful outcomes for underserved patients. You don't need a complex study to learn that health disparities and inequalities exist in the United States. Those research studies exist, but you can clearly see those differences in hospitals, clinics, and doctors' offices every day.

“OF ALL THE FORMS OF INEQUALITY, INJUSTICE IN HEALTH IS THE MOST SHOCKING AND THE MOST INHUMANE...”

—Dr. Martin Luther King, Jr

Like many medical providers, I encounter these disparities in my work as a physician in Louisiana, particularly when caring for women with breast cancer. Fortunately, the death rates for this disease declined 40% from 1989 to 2016, largely because of improvements in early detection and targeted therapies. But not all women have benefited equally. Despite similar incidence rates, African American women are 40% more likely to die of breast cancer than white women.¹

The Breast Cancer Mortality Gap

This mortality gap exists in almost every state, but the differential rises to 60% or higher in my home state of Louisiana. The fate of a woman with breast cancer, sadly, can rest upon where she resides.

Let me share a recent case that illustrates this reality. A mother of three was diagnosed with advanced breast cancer. It could have been detected earlier—and likely cured—if she had been able to access the health-care system and have a supportive social network.

Instead, she selflessly neglected to care for herself so she could tend to her children, her sick parent, and a debilitated spouse. She finally sought help at her nearby emergency room after the perfume she used no longer masked the stench of her fungating and eroding breast cancer.

Her limited means meant she could barely pay the rent, much less purchase health insurance. Instead of being treated at a nearby private facility, she was referred to a safety-net hospital 100 miles from her home.

Once at the hospital, she was told that she would need up to 6 weeks of radiation and months of chemotherapy followed by a mastectomy. Besides the mortifying news of being diagnosed with cancer, she worried about the welfare of her loved ones. As if these challenges were not enough, she had to contend with navigating the health-care system.

These barriers are not unique to this patient in Louisiana. They also are real for people in metropolitan California, remote Appalachia, or South Texas. If there is any silver lining for this patient, it is that she lives in a state that recently embraced the Patient Protection and Affordable Care Act (ACA). As a result, her medical expenses are covered.

Here is another example of how poverty limits a person's options for treatment. A woman with early-stage breast cancer may be able to save her breast by having just the cancer removed provided she receives radiation therapy. But if she cannot access a radiation facility in her hometown because she is underinsured or a facility is not available, she will lose her breast through a mastectomy. Writer Eli Khamarov once wrote, “Poverty is like punishment for a crime you didn't commit.”

I understand why companies do not like mandates. However, would it be an onerous task to require insurance companies to grant sick patrons a grace period while women like this one undergo this treatment?

Formidable Challenges: Focus on Louisiana

These formidable challenges are amplified in a state like Louisiana. The 2017 American's

Health Rankings reported that Louisiana is the second least-healthy state, and according to the U.S. Census Bureau's 2017 American Community Survey, Louisiana is the second most-impooverished state, with one of the lowest median incomes. Fortunately, with the expansion of the ACA, the number of adults without health insurance in Louisiana was cut in half, from 22.7% in 2015 to 11.4% in 2017.²

At the same time, about 26% of Louisianans reside in rural areas. Access to insurance coverage, health-care providers, and major cancer centers is an acute problem for those residents. Social isolation, lack of phones, and limited access to transportation further exacerbate their difficulty in obtaining health care. A recent report, “The State of Oncology Practice in America, 2018: Results of the ASCO Practice Census Survey,” found that although 19% of the U.S. population lives in rural areas, only 7% of oncologists practice in these regions.³

A “perfect storm” of poverty, low levels of education, severe socioeconomic challenges, and catastrophic natural disasters make for less-than-ideal outcomes for Louisiana's most vulnerable patients with cancer. The incidence of breast cancer in Louisiana is 28th in the nation, but the breast cancer mortality rate is the second highest. African-American women in Louisiana present with significantly higher rates of late-stage disease than the national average.⁴

Public-Private Solutions

We confront these realities every day at the Ochsner-Louisiana State University Health Sciences Center in Shreveport. We are a

public-private partnership hospital that serves as the safety net for the vast number of uninsured Louisianans. Due to the ravages of the 2005 hurricanes, our Feist-Weiller Cancer Center is, for all practical purposes, the major station—and often the only station—to care for the neediest Louisianans. More than one-third of women with breast cancer must travel over 200 miles to see us for their care. Many of them arrive with the disease in its latest stage. We search for the solution every day. The short answer is we need both the public and private sectors addressing these deadly inequalities.

We had no data to determine whether the work my colleagues and I do has made an impact on breast cancer care, especially on an underserved population. But in 2009, we published a report in *Cancer Epidemiology, Biomarkers & Prevention* that looked at 786 patients with stage 0 to 3 breast cancer.⁵ Despite the fact that African American women have higher-grade tumors and more triple-receptor negative tumors than white women, we found that our multidisciplinary practice has mitigated such differences. We were able to achieve this because we had a patient-centric approach. The 5-year overall survival rate for African American women with operable breast cancer was 81%, which was comparable to the 84% in white women.

These results were achieved in a population where 72% of our patients were classified as having either free care or Medicaid. What's more, 86% of patients resided in a geographic area with a reported median annual income of less than \$30,000, and 60% of the patients were African American.

So, this can be done, but not alone. National organizations such as ASCO, the American Cancer Society, the Commission on Cancer of the American College of Surgeons, and the Susan G. Komen Foundation have advocated vigorously for disadvantaged women. They show how the private sector can help share the burden of caring for them.

Physicians, of course, have a unique role to play in championing novel therapies and expanding treatment options. Years ago, when socioeconomic factors forced many women with breast cancer to undergo a mastectomy, our institution initiated a novel program that allows radiation to be given over a 5-day course rather than the traditional 6-week course. As a result, more women who live a distance from our center are now able to save their breasts.

There is no one simple answer for the lack of access to quality health care that some low-income women with breast cancer face. However, there are ways that hospitals, insurance companies, medical

providers, and nonprofit organizations can make a difference. It starts with seeing these women as human beings in need of the same health care so many of us enjoy. President John F. Kennedy reminded us that “if a free society cannot help the many who are poor, it cannot save the few who are rich.”

Disclaimer: This commentary represents the views of the author and may not necessarily reflect the views of ASCO or The ASCO Post.

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A ‘PERFECT STORM’ OF POVERTY, LOW LEVELS OF EDUCATION, SEVERE SOCIOECONOMIC CHALLENGES, AND CATASTROPHIC NATURAL DISASTERS MAKE FOR LESS-THAN-IDEAL OUTCOMES FOR LOUISIANA’S MOST VULNERABLE PATIENTS WITH CANCER.

—Quyen D. Chu, MD, MBA, FACS

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After a Breast Cancer Diagnosis, Men May Be More Likely to Die than Women

National Cancer Institute, USA

Men may be more likely than women to die after being diagnosed with breast cancer, particularly during the first 5 years after diagnosis, a new study suggests.

In the study, the 5-year overall survival rate after a diagnosis of breast cancer [was 77.6% for men, compared with 86.4% for women](#), researchers reported in *JAMA Oncology* on September 19.

The findings add to previous research showing differences in death rates between men and women with breast cancer while also providing information about some of the factors that may contribute to the disparity between the sexes.

One factor identified by the authors was the lack of adequate treatment for many men with breast cancer, a phenomenon known as undertreatment. Another was the later diagnosis of the disease in men than in women.

Differences in clinical characteristics, such as the types and stage of breast tumors, age at diagnosis, and cancer treatment between men and women with breast cancer played a major role, accounting for 63% of mortality disparity, the researchers reported. However, after all those factors were accounted for, male patients still had 19% higher chance of dying than female patients within 5 years of diagnosis.

“We were not able to investigate other known or suspected contributors for the disparity in death rates in this study, such as compliance to cancer treatment, tumor genetics, and lifestyle factors, such as obesity, smoking, and alcohol use,” said Xiao-Ou Shu, M.D., Ph.D., of Vanderbilt-Ingram Cancer Center, who led the research.

“If we want to learn more about why outcomes of male breast cancer differ from those of female breast cancer, then we need more studies that focus on men with the disease,” Dr. Shu continued. These studies should include multiple outcomes, such as cancer remission, recurrence, and death rates from breast cancer and all causes, she added.

Focusing on Men with Breast Cancer

Fewer than 1% of breast cancers diagnosed each year occur in men, noted Alexandra Zimmer, M.D., of the Women’s Malignancies Branch in NCI’s [Center for Cancer Research](#), who was not involved in the study.

“So far, we have been mostly lumping men with breast cancer and women with breast cancer in clinical trials and evaluations,” Dr. Zimmer said.

As a result, the treatment of male breast cancer has largely been based on studies involving women with the disease, she continued.

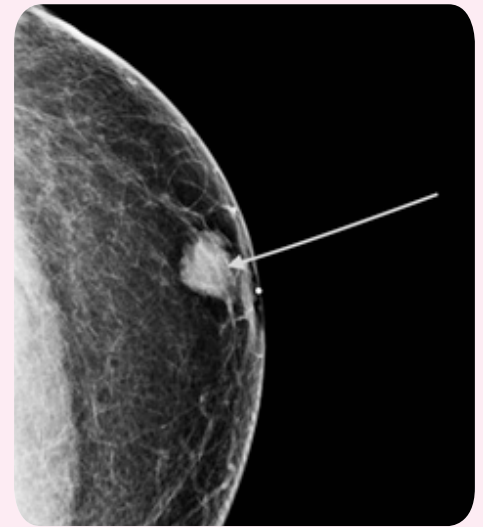
“The results of this retrospective study suggest that men with breast cancer deserve dedicated studies that will help us to better understand the biology of the disease in males,” Dr. Zimmer said.

Higher Death Rates, Later-Stage Cancers

To conduct the analysis, Dr. Shu and her colleagues used information from the National Cancer Database to compare death rates for 16,025 men and 1,800,708 women who were diagnosed with breast cancer between 2004 and 2014.

The National Cancer Database, which is sponsored by the American College of Surgeons and the American Cancer Society, includes more than 70% of newly diagnosed cancer cases in the United States.

In the study, men had higher death rates than women across all stages of breast cancer, even after the researchers adjusted for differences in patients’ clinical characteristics, such as the type and stage of disease, treatments received, age, race/ethnicity, and access to care.



Diagnostic mammogram showing a left breast mass in a male patient.

Credit: Cureus July 2017. doi 10.7759/cureus.1481. CC BY 3.0.

In addition, the study found that a larger percentage of men than women were diagnosed with advanced-stage disease, which the researchers said could be attributed to a lack of awareness of and screening for breast cancer in men.

A higher percentage of men than women in the study had stage IV breast cancer at diagnosis (5.8% versus 3.8%), for example.

Despite having more aggressive disease overall, male patients were more likely than women to be undertreated, the researchers found. For instance, men were less likely than women to receive radiation therapy, including those who had breast-conserving surgery.

Clinical characteristics and undertreatment explained only about two-thirds of the difference in mortality. “Hopefully, future studies will be able to identify additional factors,” said Dr. Shu.

Unanswered Questions

As with all retrospective studies, Dr. Zimmer noted, the analysis had limitations. For example, the researchers lacked detailed information about treatment, such as which types of chemotherapy had been used.

What’s more, the National Cancer Database does not include information about the cause of death or the recurrence or progression of cancer.

“This study should be used mainly as a way to generate hypotheses for further studies, rather than to establish any firm conclusions at this point,” said Dr. Zimmer.

One of the messages of the study for men who are experiencing symptoms of breast cancer, she continued, “is to look for help and to consider treatment as soon as possible.”

Breast cancer in underserved populations in India

Laleh Busheri, CEO, Prashanti Cancer Care Mission
Pune, India



Cancer is the second leading cause of death following coronary diseases. Cancer is a group of diseases characterized by uncontrolled growth of cells. In India, breast cancer accounts for a total of 14% of all cancers. About 175,000 cases are diagnosed in India annually, with a mortality rate of 50%. The study of these cases shows the unique profile of the disease in India as compared to the Western world. The leading causes of the disparity have been prominent in India in recent years. While emerging screening techniques like digital breast tomosynthesis and breast MRI have led to a decline in the mortality rate, the disproportion of breast cancer morbidity and mortality has continued to affect the underserved class.

In the underserved class, breast cancer is detected very late, primarily due to lack of awareness, and many succumb to the disease due to lack of funds to either start their treatment or complete it. Women from low socio-economic classes and ethnic and racial minorities are deprived of facilities for screening and are victims of delayed diagnosis. Women from rural areas lack access to health care systems, dedicated doctors, and screening technologies and therefore present later with advanced staged cancer. Low income, illiteracy, lack of awareness, unavailability of funds and government initiatives and schemes, lifestyle changes, and psycho-social hardships all contribute to the increased mortality-to-incidence ratio. Women in vulnerable populations have difficulties continuing treatment and maintaining a follow-up as a result of inadequate health care systems and social stigma in addition to the above-mentioned factors. Depression, anxiety, body image and sexual well-being create reluctance among women, which acts as a barrier in diagnosing early stage cancers. The financial burden to pay for the healthcare costs further pushes the impoverished patients into destitution. Lack of medical expertise contributes to missed cases and aggravation of the disease. Performing total mastectomies due to a dearth of surgeons trained in reconstruction and oncoplastic surgeries depresses and demotivates patients from approaching clinicians.

All of these factors reinforce the need to develop new cultural approaches for early screening and detection. Awareness drives play a vital role in addressing these issues and should be designed in a way to reach out to the unattended and vulnerable crowd. Educating men to remove the social taboo attributed to the disease will foster openness and mindful thinking within families.

Willingness to discuss this issue is a step towards a successful outcome. Similarly, the development of infrastructure and educating and training clinicians will help overcome the shortcomings in the medical field.

Using community service platforms with trained clinical staff, large scale screening campaigns and educational drives have been successful in India in the last few years. Further specialization in patient-level and system-level determinants will lead to effective utilization of the upcoming technologies to implement personalized and multimodality approaches into clinical practice.

At Prashanti Cancer Care Mission, Pune (PCCM) we have developed a model of patient care that takes cognisance of our special social needs and treats both the patient and the disease. PCCM is a CSR-funded (Corporate Social Responsibility-funded) and philanthropy corpus-funded organisation that runs the Orchids Breast Clinic, which provides patients treatment with world class breast techniques such as Oncoplastic and Reconstruction Breast Surgery. It also operates the Pink Ribbon Support Group that runs patient counselling and support efforts. Together they form a complete circle of activities where both the patient and her disease are treated.

We start with awareness talks and symposiums for the general public where we spread awareness of breast cancer, dispel breast cancer myths and educate women about the treatment options available to them. We run breast cancer screening camps to screen for breast and cervical cancers. Patients are diagnosed at Orchids with high-end radiological diagnostic machines. Upon diagnoses, patients are counselled by our expert medical team headed by Dr. C. B. Koppiker for a course of treatment that will give them the best possible outcome, keeping their needs and wishes at the forefront. Dr. Koppiker is an expert

breast surgeon who has pioneered breast conservation with advanced onco-plastic techniques in India (Koppiker et al., 2019). Onco-plasty combines the safety and care of cancer surgery with the aesthetically pleasing outcomes of plastic surgery. In Dr. Koppiker's practice, breast conservation accounts for 70% of all breast cancer surgeries. Of the mastectomies performed, 81% of patients had breast reconstructions with either silicone implants or patient tissue (Flaps) (Koppiker et al., unpublished observations).

We offer in-house day care facilities for pre-surgery and post-surgery chemotherapy. Chemotherapy is provided at a reduced cost depending on patient requirements. With the help of a specialised and generous patient-funded corpus, we are able to provide Herceptin to patients with HER2+ disease, at a reduced cost. A food bank helps needy patients meet their specialised dietary requirements during treatment. In addition, the Pink Ribbon Support group organises patient meet-ups, picnics, support groups and Yoga therapy classes.

We offer genetic counselling to patients diagnosed at a young age and those with a strong family history of cancer. For patients diagnosed with disease-causing mutations, the cancer treatment is tailored to prevent future cancers also. Young patients who need to make reproductive decisions are counselled, keeping in mind their and their children's futures.

We have built a program that provides holistic support to the patient in her journey with breast cancer – from pre-diagnostic awareness to post-treatment support. For women who may lack emotional and/or financial support, we try to fill that gap. We are also training a future generation of specialised breast cancer surgeons with an MCH program in Breast Oncoplasty in association with the University of East Anglia.

Breast cancer in India from the perspective of a health care educator and survivor



Rama Sivaram

Rama Sivaram
Pune, India

They sat before me, a health care educator as well as a survivor, for over 15 years. Some are still there limping through life and some are gone, leaving behind nothing because they had nothing left to leave behind. The luckier ones like me live with our losses, gains and gratitude because we are better off in so many ways that have positively impacted our health and our lives than our less fortunate sisters.

My less fortunate sisters are many; I have lost count. I may have forgotten many faces, the events have gone but the memories remain; memories of naked eyes, trembling hands and the slight tremble in their voices which remind me of this 3-line excerpt, which I had romanticised as a young teen and never forgot.

... But I, being poor, have only my dreams; I have spread my dreams under your feet; Tread softly because you tread on my dreams.

Aedh Wishes for the Cloths of Heaven, 1899 W.B Yeats

Today, the beauty of the lines come to me with an altogether new meaning; the romantic replaced by the stark reality and pain that comes with growing up through breast cancer. I have held close and counseled with soothe-saying many women whose stories were brimming, unshed tears in their eyes. I learnt that all of us are born equal but live through or die unequally in life and in breast cancer. I was being served and they were not. Their hopes and dreams were to be cured and live. But their dreams were fragile and broken by the harsh realities. Each time a memory flashes it is as if they are laying bare their lives of impoverishment and inequity – a gaping disparity rendering them the vulnerable population

“What can 3 ₹ (Indian Rupees) buy today? At best, if I save 3 ₹ per day for 30 days I can buy 2 kgs of wheat for a family of 4 for 3 days.”

This vulnerable population is the underserved population - groups of people who for various reasons do not have equal and optimal

access to health and health care services. As a member of BRICS (an acronym for the association formed by the nations with the five major emerging national economies: Brazil, Russia, India, China and South Africa), the United Nations ranks India as a middle-income country, standing 130 out of 189 countries in the latest Human Development Index (HDI) ranking by the United Nations Development Programme. HDI is driven by health, education and income. While there is a change from the earlier years, what is glaring is that the country's Gross Domestic Product on health care is 1.02% as against the global average of 6%. The National Health Profile of 2018 shows a dismal public health spending of 1.02% which translates as 3 ₹ (about .04 USD, or 4 cents) per person per day for health. Imagine for 1 year (365 days) a person has 1095 ₹ (about 15 USD). It is no wonder we are an underserved population when our out of pocket expenditure on health care is over 63%. The World Health Organisation's health financing profile for 2017 in India shows that 67.78% is out of pocket expenditure on health and the average global out of pocket expenditure is 18.2%. (from https://www.downtoearth.org.in/dte-infographics/india_s_health_crisis/index.html). The intention to increase this to 2.5% is simply a drop in the ocean of 1.21 billion people in India (0.62 billion males and 0.588 females, Census, 2011), replete with inequalities and inequities across the states and across gender. Where does that leave these vulnerable women who are mostly at a financial disadvantage to meet their health needs, let alone fight breast cancer? If a woman has 3 ₹ per day for her health, she is likely to save it for her family; she can't even get 5 candies for her child for that, and food is such a precious commodity every rupee

matters. She is a compulsive nurturer.

Managing the health care of a population of our size is difficult, as we are a nation of diversity in languages, religions, states, society, culture and climate. Adding to the difficulty are the facts that India has a mixed socialist and capitalist economy with a big rich – middle – poor chasm, a growing market economy and pluralistic systems of medicine. The health system in India is continuously grappling with local needs and global demands. Government reforms in healthcare are a never-ending task influenced by winds of change ranging from global transformations, political economy, and international organisations. The onus of responsibility on the State to respect, protect and fulfill the health needs of its community is a big one. The Ministry of Health and Family Welfare has launched many schemes and initiatives for women; however, they do not meet the needs of women who require long term treatment and survivorship or palliative care. Often, women seek alternative treatment from the local vaidhu (medicine man) and religious observances, and some seek healing through AYUSH, an accepted system of medicine in India that stands for Ayurveda (an ancient Indian system of holistic healing), yoga and naturopathy, unanni and siddha (both also ancient systems of traditional medicine), and homeopathy.

Women's cancers lie deep in these disparities

With respect to reproductive health and women's cancers, women are more underserved due to inequalities and inequities. Inequality is uneven distribution of health or health resources due to immediate needs and priorities like epidemics,

communicable diseases, vertical health programs and budget allocation. Inequity is unfair, avoidable differences arising from poor governance, gender, geography, social and cultural norms and economic and cultural exclusions. Access to health care and health outcome are determined by these factors. What hurts most is the inequity, which is a societal evil. Cancer cells may be the real culprits, but we are all partners in the crime of inequity. What we see is only the tip of the iceberg.

Global demographic and epidemiologic transitions

Breast cancer emerges “as one of the leading causes of cancer among women (14.3%) in India, with 144,937 new cases and 70,218 reported deaths.” The Population Based Cancer Registry (PBCR) cites breast cancer as accounting for 25% to 32% of all female cancers in urban areas. 144,000 Indian women are estimated to be diagnosed with breast cancer every year. A fraction of these diagnosed women receive comprehensive multimodal treatment with a multidisciplinary team. An already strained health care system is today facing the growing pandemic of chronic or lifestyle diseases including cancer. The burden is compounded by a shortage of trained oncologists, comprehensive centers restricted to tier 1 cities, and lack of uniform protocols and regulations in practice. Unlike the western population, breast cancer strikes younger women in India who present at a later stage with poor survival outcomes. Prevalence of triple negative disease is also higher than in the western populations and has poorer outcomes. Screening, diagnosis and diagnostic workup, treatment, palliation and survivorship care and services are still inadequate for want of trained oncology teams and also for want of more funds at the level of the institutions, insurance and the patients.

The Partial Eclipse

Breast cancer is partially eclipsed due to systemic deficiencies and different priorities in the health care system like low funding for non-communicable diseases, more funding for treatment models and less for screening and prevention. No one wants to talk about the “Big C” in general and breast cancer in particular because of rampant myths and misconceptions, the socio-cultural cloud, gender politics, and lack of awareness. The dark shadows confronting the breast cancer scenario in India are:

- The general population and even paramedical professionals have a low level of awareness about basic screening practices. The practice of self-breast examination is about 35%.
- The benefits of population-based and opportunistic screening improves early detection of cancers, but only 10% of

the women in the reproductive age have undergone breast examination.

- High incidence and late detection together impact treatment costs and mortality; The survival rate of women diagnosed at Stage 3 or 4 decreases 2.7 times as compared to those diagnosed at Stage1, and cost of care nearly doubles.
- The proportion of cases detected in late stages (III+IV) is around 55%.
- 40%-50% of oncologists are concentrated in the top 10 metro cities.
- India has 585 patients per oncologist
- The underdiagnosis rate is high, with 30% - 50% of women not being diagnosed, due to lack of diagnostic infrastructure, low patient awareness and low physician awareness.
- Lack of health insurance.
- The Indian cancer registries cover 8.2% of the population as compared to 90% in the US and the UK (from National Cancer Registry Programme Reports).

What makes ME worried about the trend of breast cancer in India?

- **Rising numbers** of cases of breast cancer
- **Increasing incidence** of breast cancer in younger age
- **Late stage at presentation:** This directly decreases long term survival of the patient
- **Lack of awareness and screening**
- **Aggressive cancers in younger women:** “48% of patients are under 50. An increasing numbers of patients are in the 25 to 40 year range. Of course, one reason for higher numbers of younger patients is our population pyramid, which is broad at the base and middle and narrow at top. This means that we have a huge population in the younger age group and much lesser in older age group.” (from PBCR report for Mumbai (2006 - 2008).

On the horizon

Progress in the fight against breast cancer is being made, even if frustratingly slowly. Non-Governmental Organisations, the media, and the government are paying greater attention to awareness, screening, and surveillance and are working toward widespread, affordable multimodal treatment and improved palliative and supportive care. The Pink Ribbon campaign, which began in the US in 1991, finally made its way to India in the 21st century. More and more survivors are telling their stories and advocating for others, an essential step toward erasing

inequities and inequality. We are finally getting armed, removing each barrier one by one.

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With respect to reproductive health and women’s cancers, women are more underserved due to inequalities and inequities. Inequality is uneven distribution of health or health resources due to immediate needs and priorities like epidemics, communicable diseases, vertical health programs, and budget allocation. Inequity is unfair, avoidable differences arising from poor governance, gender, geography, social and cultural norms, and economic and cultural exclusions.

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Israel Cancer Association activity in underserved populations for breast cancer/metastatic breast cancer patients and their families



Orit Spira, M.S.W.

Orit Spira, M.S.W.

Head of the Rehabilitation and Welfare Department, Israel Cancer Association

The Rehabilitation and Welfare Department at the Israel Cancer Association (ICA) offers various activities geared towards breast cancer (BC) and metastatic breast cancer (MBC) patients of underserved populations in Hebrew, English, Arabic, Russian and Amharic across the country.

Support groups for breast cancer/metastatic breast cancer patients and their partners constitute a source of emotional support while creating the conditions for reciprocal empathy, reinforced solidarity and a sense of belonging. They alleviate loneliness during the disease trajectory, bolster self-confidence, impart tools to cope with crisis and provide up-to-date information. Our support groups also include a group for parents whose daughters are coping with BC/MBC. The groups are led by psycho-oncology professionals at the ICA Strong Together® Support Centers throughout Israel.

A project entitled Survivors towards a Healthy Life® offers workshops for BC/MBC patients, their partners and families. The aim of these workshops is to help cancer survivors cope with the aftermath or trajectory of the disease, enhance their quality of life, provide them with tips on how to lead a healthy life, and encourage them to return to their normal personal routine and active community life.

The participants take part in a series of professionally moderated meetings which address various topics: returning to one's normal life and family routine, parent training, sexuality, health challenges after or during treatment, coping with long-term side effects, engaging in physical activity tailored specifically to the needs of MBC patients and BC survivors, developing a customized nutrition plan during and after the disease, utilizing integrative medicine and returning to their work environment.

Workshops are held throughout the year across the country at the ICA Support and Activity centers and branches and by ICA regional social workers.

Yearly seminars on BC/MBC for patients and their families inform them of various topics such as, treatment methods, managing side effects, and aspects of coping with the disease both by the patient herself and her family. These seminars take place all over Israel and across all sectors of the population.

Reach to Recovery® female volunteers who have coped or are coping with MBC/BC and have undergone special training, enable them to support women currently coping with both BC and MBC across the country. The volunteers are uniquely matched to their patients in age, type of treatment and language, offering support based on their personal experience.

Patients share their stories of coping with the disease on our ICA website, proving that patients can live a full life while coping with BC/MBC.



“

YEARLY SEMINARS ON BC/MBC FOR PATIENTS AND THEIR FAMILIES INFORM THEM OF VARIOUS TOPICS SUCH AS, TREATMENT METHODS, MANAGING SIDE EFFECTS, AND ASPECTS OF COPING WITH THE DISEASE BOTH BY THE PATIENT HERSELF AND HER FAMILY. THESE SEMINARS TAKE PLACE ALL OVER ISRAEL AND ACROSS ALL SECTORS OF THE POPULATION.

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Underserved and marginalized: the importance of models of care and support

Carol El Jabari

Palestine

Breast cancer is the most common cancer among women in Palestine (approximately 34/100,000 [Palestinian Ministry of Health 2018]) and most women there present with late stage disease. Cancer rates are increasing and some of the challenges to raising awareness and providing education and services are influenced by a community deeply affected by conservatism, a lack of access to a range of cancer care, and a stigma associated with cancer.

Patient's Friends Society - Jerusalem, a Palestinian non-profit organization, is a leader in psychosocial support, patient navigation and health education, serving people from all over the country. Since 2000, our support group has made great inroads in providing support for women living with cancer, training peer-to-peer supporters, producing educational materials, conducting conferences and more. Our most recent innovation was to introduce a *palliative* day centre via a community centre in Hebron, the largest city in the country. This attracts cancer patients, their families, and even well people in the community. We focus on creating programmes where well persons and cancer patients interact. When this happens, they break down barriers such as fear and ignorance, while well people learn that cancer is not the monster in the room.

The centre provides a safe, comfortable environment for patients and families and a centre for students and teaching staff from universities to interact, learn and eventually to become informed advocates.

Breaking down barriers such as fear, ignorance and access to services are positive outcomes of this initiative. As the first such day centre in Palestine, this is a model for services and care in a conservative society and financially strapped country. This model can be replicated with a modest investment of goods, rent, human resources and the will to succeed. Being accountable to patients, the community and donors is essential, too.

“ BREAST CANCER IS THE MOST COMMON CANCER AMONG WOMEN IN PALESTINE (APPROXIMATELY 34/100,000 [PALESTINIAN MINISTRY OF HEALTH 2018]) AND MOST WOMEN THERE PRESENT WITH LATE STAGE DISEASE. ”



Sunrise cancer support group members October 2019



Sunrise cancer support group participating in the Palestine marathon – a first for these great ladies! March 2019

The Fijian Women's Breast Cancer Project

Teresa Mazzaferro Cuda

Australia



From left to right. Lily (De Santis) Young, Teresa M Cuda, Kristen McDonald

The Fijian Women's Breast Cancer Project, started in 2014, was an ongoing collection of bras and preloved breast prosthesis donated by generous Australians to help women in Fiji. I became involved in this project nearly from its inception. I visited the country in June 2017. My short time in Fiji was an educational and life-changing experience. I armed myself with my reliable phone, a small camera, and a SRL digital camera as well as a journal to collect evidence and data that would help me in the future to reflect upon each of the experiences: my thoughts, my feelings, my own evaluation of the situation as a woman that had breast cancer, as a former interpreter for the Australian health system and also as a free lance journalist/photographer. This experience evolved into a campaign which hoped to raise awareness educate women in the Pacific area of the risks of breast cancer because there is a limited level there of chemotherapy, radiotherapy, and surgery. Good palliative care is inconsistently available and most advanced treatment is carried on in India.

Donated breast prosthesis and bras were fitted for free to women that had undergone a mastectomy. We worked closely with the Fiji Cancer Society and the Fijian Ministry of Health which covered the costs of the shipping and managed the donated stock to make it available to nurses for breast cancer patients and volunteers. Educational visits to various locations by cancer survivors who spoke the local languages encouraged women to seek medical attention as soon as they noticed changes in their breasts and taught them not to rely only on traditional medicines. Many women do not seek medical help until their cancer has reached more advanced stages. Surplus bras were used as a free gift to encourage women to attend cancer awareness education clinics and events. This was called the "Awareness with a Gift" program. Public education is needed to raise awareness about the importance of early detection to reduce the high mortality rate from breast cancer in underserved populations.

A few points worthy to be considered as you embark on an experience such as this one are:

1. Be patient, have a passion for what you're doing. Take your time.
2. Start by developing your vision and mission. Our Mission Statement was: *Empowering women's advocates and speakers to share their knowledge and encouragement regarding women's general health and cancer prevention awareness, who will personally fit bras and prosthesis with conversations about breast health awareness.*
3. Consider what, where and how? Local, national or global?
4. What or who is your inspiration?
5. Where is your destination on the horizon: Make it larger or more comprehensive? When will it end?
6. Raise support: friends, relatives, grassroots organizations, individuals, and foundations. Make a significant number of calls, have meetings, and give presentations. Who will be your planners, marketers and collectors?



7. Be ready to use all types of media. You can announce your inspiration, intentions, plan outlines, etc.
8. Set up a collection point (well-organized, central) and properly label everything to avoid confusion and allow the process to run smoothly.
9. Plan each step of the event, allowing time to complete the task.
10. Organise delivery, which is sometimes a very costly step.
11. Perhaps the most rewarding one: the wrap up of your campaign. Thank everyone that helped and rest assured you made an impact on someone's life. You will certainly face obstacles along the way. But if you are doing something you really believe in – and that makes a genuine difference – the rewards are worth it.

We hope the Fijian Women's Breast Cancer Project, known now as Sisterhood Breast Cancer Aid Project, opens the dialogue on collaborative team-working and effective communication as well as social support, organisation and accountability. I hope our initiative will inspire other countries, communities and groups to replicate and modify ideas and strategies that could potentially be implemented and have a positive impact in their community. In a world where our footprint is increasing exponentially and the rift between the "haves" and "have nots" is rising, it makes sense to collaborate among human groups, repurpose utilities, and redirect resources and products in such a way that makes a difference in the lives of others. These efforts will never be forgotten and will save lives, making the world a better place.

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“Awareness with a Gift” recipients



“Awareness with a Gift” event



Sisterhood



Packing



Spotlight on:
Canada!

Abreast In A Boat - Our race against breast cancer

*Abreast In A Boat Society
Vancouver, Canada*

We are approaching 25 years of breast cancer survivor dragon boating and will be celebrating this anniversary during 2020! This wonderful therapeutic support and awareness group has become a worldwide phenomenon. The humble beginning of Abreast In A Boat (AIAB) in Vancouver, Canada, has grown into a global force and has changed the lives of thousands of breast cancer survivors. Today there are over 230 teams from 28 countries across the globe, with new teams forming annually.

The International Breast Cancer Paddlers' Commission (IBCPC) was created in June 2010. The IBCPC is an international organization whose mandate is to encourage the establishment of breast cancer survivor dragon boat teams, within the framework of participation and inclusiveness. Members of Abreast In A Boat along with IBCPC are currently bringing survivor dragon boating to several South American countries and the Fiji Islands. When the dragon boats start appearing, so does breast cancer awareness and support for those who have experienced breast cancer. This is especially heartening to see in areas where survivors may experience silence and isolation along with a diagnosis of breast cancer.

Abreast In A Boat is a registered charitable society whose mission is to demonstrate that those who have been diagnosed with breast cancer can live full, active and healthy lives. Abreast In A Boat also has a strong commitment to enhancing breast cancer awareness and to support breast cancer research. We paddle together, support, learn and laugh with each other. We break the silence of cancer, make new friends in the process, and we encourage others to get in the boat with us. We seek and promote a healthy lifestyle through exercise. We continue to challenge and support breast cancer researchers to better understand and treat breast cancer.

Breast cancer survivor dragon boating began as a result of a medical study, headed by Dr. Don McKenzie at the University of British Columbia's Sport Medicine Clinic, to test the then-prevailing advice that repetitive upper body activity should be avoided by those who had undergone breast cancer treatment. At that time, it was thought that exercise caused lymphedema (a painful swelling of the arm). This severely restricted and affected the quality and enjoyment of life for many post-treatment breast cancer patients.

Dragon boat paddling was chosen as it is a strenuous, repetitive upper body exercise; it provides an opportunity to work with a large group at one time; and it is fun.

Twenty-four breast cancer survivors participated in the medical trial. The women's fitness level, athletic ability and ages varied. When the medical trial finished, the participants would not put their paddles down and Abreast In A Boat was formed. Today, Abreast In A Boat has 190 members who paddle as one team on six different crews throughout the lower mainland area of Vancouver.

Anyone who has had a breast cancer diagnosis is welcome to join Abreast In A Boat to learn how to paddle and to be supported by others who are in the same boat. Together we transform ourselves and each other from being emotionally and physically debilitated by this disease to being empowered and supported.

Not in the Vancouver area? Visit the IBCPC website (ibcpc.com) and browse the global map of breast cancer survivor teams — there just might be one close to you.

Paddles Up!



Colombian *novatas* [novices] enjoying their friendship with outreach team members from AIAB and other IBCPC teams.

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WHEN YOU PUSH OFF FROM THE DOCK ... WE'RE ALL IN THE SAME BOAT. THIS ISN'T ABOUT CANCER ANYMORE. IT'S ABOUT EXERCISE AND HEALTH AND THE REST OF YOUR LIFE. WHEN WE PUSH OFF WE'RE PADDLING AWAY FROM BREAST CANCER.

—Dr. Don McKenzie

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Spotlight on:
Kenya!

Peer Support Training in Nairobi

Reach for Recovery, Kenya

November 1st and 2nd saw 20 enthusiastic volunteers gathering at the Sarova PanAfric Hotel for Reach for Recovery volunteer training facilitated by Ann Steyn. The idea came from Catherine Ngaracu, a long-standing Reach for Recovery volunteer in Kenya who was the driving force behind planning the sessions. She saw the need not only for volunteer training but also for a Trainer the Trainers programme. She also recognised a need to reach out to and involve other breast cancer support and awareness groups from different areas in Kenya as well as in neighbouring countries. There were participants from Nairobi, Kiambu, Nyeri and Rwanda but, sadly, the ladies from Tanzania and Uganda had to withdraw at the last moment. Represented amongst the Reach for Recovery volunteers were volunteers from Hope Beyond Cancer, Slopes Cancer Awareness Network,

Twakutukuza Trust, and the Breast Cancer Initiative of East Africa. All work to improve the quality of life for women with breast cancer, and all believe strongly in the importance of breast awareness education in communities.

During the two training days, all the topics found in the RRI programme were covered. There was much discussion about problems particularly associated with the regions and how to tackle them. It was encouraging to see the formation of partnerships beginning to develop between the groups. The possibility of belonging to an international group such as RRI interested them. At the end of the two days, it was an exhausted group of ladies who made their way home, proudly holding their Training Certificates and promising to keep in touch with each other through a newly formed social

media group. As a result of this training programme, the care and support of breast cancer patients in the region will be greatly enhanced.

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ALL WORK TO IMPROVE THE QUALITY OF LIFE FOR WOMEN WITH BREAST CANCER, AND ALL BELIEVE STRONGLY IN THE IMPORTANCE OF BREAST AWARENESS EDUCATION IN COMMUNITIES.

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Participants at the Reach for Recovery training programme in Nairobi

Spotlight on:
South Africa!

WE CAN 6th Annual Africa Breast and Cervical Cancer Advocacy Summit

*Carla Lind and Michele Coe
South Africa*

WE CAN stands for Women's Empowerment Cancer Advocacy Network, and the 6th Africa Summit was held in Johannesburg in March 2019. Reach for Recovery South Africa had eight delegates in attendance and it proved to be an eye opening and informative two days for us.

Day one contained impressive talks on the success of the vaccine programme to eliminate cervical cancer. There was, however, a concern that there was a low uptake of the second round of vaccinations which is essential for the success of the programme. This was put down in part to girls moving away from home. Reach for Recovery Cape Peninsula, the group where we both volunteer, is currently involved with a pilot project at Groote Schuur Hospital. This pilot project is looking at the information and support that cervical cancer patients require, and the WE CAN discussions will be of great help to us. Using the RRI Training programme, we are offering to training peer support volunteers for cervical cancer patients. There were also informative panel discussions on breast cancer and the needs of patients

and advancing the quality of life for women with advanced breast cancer. There is a big gap with no or very little support for metastatic patients in our country.

Breaking into facilitated small group discussions, where delegates selected three topics and rotated every 25 minutes, was most informative. A worksheet was completed with delegates having ten minutes to answer the questions followed by one-on-one exchange. The topics covered: Breast Cancer Early Detection v Screening, Advanced Breast Cancer, Cervical Cancer, Advocacy, and Patient Support.

Day two was mainly devoted to Patient Navigation. Louise Turner from the Breast Health Foundation explained the app specifically developed by her organisation for Patient Navigation and for the tracking of statistics. There were also talks on onco-fertility and the role that the GP can play in Oncology by monitoring the patient's well-being during follow-ups.

Delegates were divided into smaller groups to talk about developing an action plan for their group. This enabled Reach for

Recovery to exchange ideas and map out a way forward.

As Reach for Recovery volunteers, we had always considered ourselves to be only breast cancer peer support volunteers. Attending this summit, we realised that in fact we were also carrying out the roles of Advocates and Patient Navigators. We noted that many fellow African countries were already including cervical cancer in their advocacy and support structures and were more advanced and successful in their campaigns than South Africa.

We realised that we needed to get more involved in active advocacy to ensure our Breast Health Policy is implemented, and that there is more awareness and support for cervical cancer. As Allison Dvaladze said in closing, Take Small Steps. This was a worthwhile summit and at the end a WhatsApp group was established to enable the delegates to share information from their different countries. We worked hard, but learned wonderful life lessons from our African sisters.



Co-author Carla Lind (right) with Brenda Kithaka of Women4Cancer, Kenya



Reach for Recovery South Africa volunteers attending the WeCan Summit in Johannesburg

Impactful Moments

By Rute Vieira, Portugal



Rute Vieira (left) with MVV Volunteer Carolina Negreiros. Carolina is holding a piece designed and made by Rute. The stones in the middle of the flower represent the precious relationship Rute felt she had with the MVV Volunteers who supported her.

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SOME OF THESE MOMENTS ARE ABSOLUTELY IMPACTFUL FOR THEIR ABILITY TO BRING ABOUT CHANGES IN US THAT ARE PROFOUND AND FUNDAMENTAL TO OUR INDIVIDUAL BUILDING PROCESSES.

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Our life is the sum of different moments. Some of these moments are absolutely impactful for their ability to bring about changes in us that are profound and fundamental to our individual building processes. Since my breast cancer diagnosis, when I was 36 years old, I have lived through several impactful moments that have redefined me as a person.

One of the most striking of those moments took place on August 28, 2010. After a breast biopsy, I received a positive result for a malignant cancer and was forced to confront my own fragility as a human being.

Another of those moments occurred on October 13, 2010, the morning after my total mastectomy, at the Porto IPO (Portuguese Oncology Institute). That morning, I received an unexpected visit in my hospital room which turned out to be profoundly transformative for me. When Carolina Negreiros, a volunteer with the Portuguese Cancer League's Movimento

Vencer e Viver (Live and Win Movement), knocked on the door, her eyes and voice commanded my attention. Carolina laughs with her eyes, with a trace of empathy that disarms and conquers us. It's impossible to resist.

Carolina talked to me for about an hour. She offered me words of hope, confidence and serenity. I felt absolutely understood and supported. She gave me her testimony as a breast cancer survivor, soothing my soul and my heart. She explained to me the precautions to take and spoke for the first time about breast prostheses and bras with pockets.

The crucial impacting moment came in the last minutes of our meeting, when she told me that she had undergone mastectomy over 20 years ago, had not undergone reconstruction, and was wearing a prosthesis. In that instant, a thick black cloud was lifted off me! I thought, "How is it possible I did not notice that this woman was wearing a prosthesis?" I, Rute, the

perfectionist designer, didn't notice! That was fantastic, as it meant that others would not notice my own prosthesis or my breast asymmetry, either.

It may seem foolish to some people, but for me that finding was a crucial moment. In seconds, Carolina rebuilt a part of me that was broken. That made me believe that I was going to overcome everything, and would enjoy life with the same intensity and joy with which I had lived so far.

Carolina and I remain friends to this day, and I am forever grateful for her generosity.

Gurmeet Kaur Bhattal

By Meenakshi Deol, Research Coordinator, Homi Bhabha Cancer Hospital Registry Sangrur, Punjab, India



The author (center) with Gurmeet Kaur Bhattal (right) and Narendra Singh Bhattal (left)

Mrs. Gurmeet Kaur Bhattal is a Professor of Zoology and a retired principal of Government Ranbir College Sangrur. Mrs. Bhattal suffered a massive heart attack in June 2014 that required the insertion of two stents. Only a year later, she found a mass growing in her right breast and scheduled a check-up. Her doctor suggested mammography, which revealed the onset of breast cancer.

The pathology report established that the cancer was early stage but was triple negative, which is known to be an aggressive form of cancer. At the age of 68, Mrs. Bhattal had seen both her son and daughter get married and settle in different areas of Punjab. She was just beginning the retirement phase of life with her husband, Mr. Narendra Singh Bhattal, who had been Coordinator to Nehru Yuva Kendra under

the Central Government office. This new diagnosis was devastating. Mrs. Bhattal had always been a woman of substance, spreading energy and happiness throughout her life, but the diagnosis left her at a loss for words for the first time. Her better half supported her completely through this. Even though he himself felt broken by the situation, he kept her from falling apart.

Mrs. Bhattal was diagnosed in December 2015 and her treatment included complete removal of her right breast, followed by chemotherapy and radiation therapy. Her whole family stood by her, and she never hid her identity as a cancer patient. Once her treatment ended in July 2016, she proudly called herself a cancer *survivor*. Mrs. Bhattal's faith in God grew stronger than ever. Her courage and candor caught my attention, too, when I first met her in

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I WAS IN AWE OF HER PRESENCE AND THE POSITIVE ENERGY EXUBERATING THROUGH HER INSPIRED TO ME TO WRITE MY FIRST STORY ON CANCER SURVIVORSHIP.

—Meenakshi Deol

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Homi Bhabha Cancer hospital. I was in awe of her presence and the positive energy exuberating through her inspired to me to write my first story on cancer survivorship.

Veggie Mexican Tortilla Soup

Picture and Recipe by: brownsugarandvanilla.com

Ingredients:

- 4 tomatoes
- ½ onion medium size
- 3 cloves of garlic unpeeled
- 3 cups of water
- 1 or ½ teaspoon of chipotle chili powder or ancho chili powder
- ¼ teaspoon of dried Mexican oregano
- 1 teaspoon of sea salt

To serve:

- 1 avocado diced
- Mexican vegan cream
- Cilantro
- Sliced and fried Chili pasilla or guajillo* *optional*

Directions:

1. Put the tomato, onion, and garlic in the pot that you are going to use over high heat to roast. If you prefer you can put ½ teaspoon of vegetable oil. When everything is well roasted, peel the garlic and put into a blender jar with the onion and tomato.
2. Add the chipotle chile or ancho chili powder, salt and blend until smooth with three cups of water.
3. Return to the pot where you roasted the vegetables and add the oregano. Leave on medium heat for ten minutes or until simmering. Test and adjust seasoning necessary.
4. Serve with corn strips, diced avocado, vegan Mexican crema, sprigs of cilantro and sliced guajillo chile or pasilla chile.

**COMBINED PREP AND
COOKING TIME: 25 MINUTES**

SERVINGS: 4

Veggie Mexican Enchiladas

Picture and Recipe by: delishknowledge.com



COMBINED PREP AND COOKING TIME:
1 HOUR 20 MINUTES

SERVINGS: 6

Ingredients:

Enchilada Sauce

- 3 tablespoons oil
- 3 tablespoons all-purpose flour
- 1 tablespoon chili powder
- 1½ teaspoons ground cumin
- ½ teaspoon garlic powder
- ½ teaspoon oregano
- ¼ teaspoon salt
- ⅛ teaspoon cinnamon
- ¼ teaspoon ground cayenne
- 1 (15 ounce) can crushed tomatoes
- 1½ cups water

Enchiladas

- 2 bell peppers, sliced thin
- 2 red bell peppers, sliced thin
- 1 orange bell pepper, sliced thin
- 1 yellow bell pepper, sliced thin
- 1 onion (white, yellow or red), sliced into thin strips
- 1 tablespoon olive oil
- 1 teaspoon chili powder
- ½ teaspoon cumin
- ¼ teaspoon salt
- ¼ teaspoon ground cayenne (*optional*)
- 1 (15 ounce) black beans, drained and rinsed
- ½ cup chopped cilantro, plus more for garnish
- 8 tortillas
- 1 large, ripe avocado (for serving)
- Dairy-free sour cream (thinned with water for drizzling, *optional*)

Directions:

1. Preheat the oven to 425° F.
2. Toss the sliced peppers and onions with 1 tablespoon olive oil, chili powder, cumin, salt and cayenne pepper. Toss well to combine, then place in a single layer on a baking sheet. Roast for 25-30 minutes, until tender.
3. While the peppers are cooking, make the sauce. Heat the oil in a medium sauce pan over medium heat. Add in the flour, then quickly whisk together until combined. Add in the remaining spices and toast until fragrant, another minute or two.
4. Add in the tomatoes and water, then bring to a simmer. Cook over medium heat until thickened, about 5-7 minutes. Puree with an immersion blender or place the mixture in a blender and puree until smooth.
5. Place ½ cup of the enchilada sauce in the bottom of a rectangle or square baker (I used a 4 qt. baker), set the rest aside.
6. Remove the peppers from the oven once done, then mix with black beans, cilantro and a little of the enchilada sauce. Place some of the mixture onto a flour tortilla, roll up and place seam-side down in the pan. Continue with the rest of the tortillas, squeezing in as much as possible. (Depending on how much your peppers cooked down and how well you filled them, you may get more than 8 enchiladas. If they will fit in your pan- add 'em!)
7. Reduce the oven to 350° F, then cover the enchiladas with the rest of the sauce. Place in the oven and cook for 25 minutes.
8. Remove and let cool slightly. Top with thinned sour cream (if using), sliced avocados and chopped cilantro.