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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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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.

Cover photo: © 1370858695 istockphoto.com/SouthWorks.

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

Email your theme suggestions to info@reachtorecoveryinternational.org. A theme will be chosen by February 2023. 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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Celebrate the work being done by your organisation's volunteers!

Do your organisation's volunteers do outstanding work to support those touched by breast cancer in your community? Bloom wants to hear all about it! Send us articles about the projects your volunteers are working on, and be sure to include high resolution photos. Articles should be 200 - 400 words long and should be sent in Word format to info@reachtorecoveryinternational.org. It's a great way to thank your volunteers for a job well done, and to raise awareness about your organisation!

Upcoming events:

RRI's Second virtual session on *Problems and solutions in connections with advanced breast cancer* will be rescheduled from 19 November 2022. Look for an announcement in early 2023.

World Cancer Day 2023

4 February 2023

www.worldcancerday.org

Thriving Together: 2023 Conference on Metastatic Breast Cancer

28 – 30 April 2023, Philadelphia, PA, USA

<https://www.lbcc.org/community/events/thriving-together-2023-conference-on-metastatic-breast-cancer>

ABC Web Series is a series of 6 webinars on Tough Issues in Metastatic Breast Cancer organized from 13 October 2022 to 13 October 2023. In each webinar, we discussed/will discuss challenging clinical issues, for which available data is scarce, and hence expert guidance is key. This discussion will lead to the development of a new guideline statement that will then be further discussed and voted during the ABC 7 Consensus Conference. Four of the six sessions have not yet been held and will be held in 2023 as follows:

How to optimally treat a patient with advanced/metastatic breast cancer in visceral crisis

9 February 2023, 16:30 – 17:30 CET*

Managing a patient with advanced/metastatic breast cancer and HIV

20 April 2023, 14:30 – 15:30 CET*

Optimal management of an older, frail person with advanced/metastatic breast cancer

15 June 2023, 14:30 – 15:30 CEST*

Managing a patient with advanced/metastatic breast cancer with leptomeningeal disease

31 August 2023, 13:30 – 14:30 CEST*

* Please use the time converter to check your time: <https://www.timeanddate.com/worldclock/converter.html>

Register to attend at: https://docs.google.com/forms/d/e/1FAIpQLScPThXb8l_0s3oeuy-S7uk_M0xv8o5bPqaPfNMEbeAfTm0PjA/viewform

Your registration allows you to attend any or all of the sessions.



Cathy Hirsch,
Immediate Past President

Introducing the new President of RRI

Many of you were present at Reach to Recovery International's first virtual session in September when we welcomed RRI's new President. For those of you who did not join the virtual session, it is my great pleasure to present to you Leonie Young of Brisbane, Australia!

Leonie is well known to everyone familiar with RRI. She has been an active participant in RRI activities for many years and is our Regional Representative for Australasia. She is a frequent contributor to Bloom and a valued speaker at our Breast Cancer Support Conferences.

Leonie has been a breast cancer survivor since 1987 and, ever since her diagnosis, has been involved with many aspects of cancer consumer advocacy, support, training, and mentoring. Her volunteer work is done at the local, national, regional, and international levels. She serves on multiple committees, including:

- The Australia & New Zealand Urogenital and Prostate Cancer Trials Group (ANZUP) Consumer Advisory Panel
- The International Society for Quality of Life Research (ISOQOL)
- The National Breast Cancer Foundation Grant Review Committee
- The Cochrane Collaboration

- The Queensland Cancer Clinical Network Executive Committee (Queensland Health), and
- The Clinical Oncology Society of Australia (COSA) Council.

Much of Leonie's experience comes from her work as Peer Support Co-ordinator for the Wesley Hospital Choices Cancer Support Centre in Brisbane, Australia, where she has served since 2002, and with Breast Cancer Trials, where she served as an inaugural member of their Consumer Advisory Panel (1998 to 2018) and as Chair of the panel (2008 – 2018).

Additionally, Leonie is an Ambassador for Amoena Australia, which is a supplier of breast forms, clothing, and lingerie, and she is a peer support volunteer with the Cancer Council Queensland. She is a co-founder and co-facilitator of EveryCloud Consumer Advocacy Training Programs, has an Honorary Degree of Doctor of the University from Griffith University in Brisbane, and was the recipient of RRI's Terese Lasser Award in 2019.

RRI's Board of Directors and Advisors are confident that this transition will be seamless and that Leonie will take RRI to new heights in advocating and ensuring that all breast cancer patients, survivors, caregivers, and families have access to the support they need, regardless of where they live.



Message from Leonie Young

– President of RRI

The changes in our world since 2019 have had an incomprehensible impact on everyone's lives, some more than others. Everyone who has had a chronic illness diagnosis has had to manage the uncertainty of this diagnosis, and women and their families affected by breast cancer are among the many who have to manage these challenges.

This edition of Bloom focuses on health literacy. Health literacy is measured by how well or how poorly lay people or those unfamiliar with medical terms and understanding interpret and manage their personal health. This may be in prevention, decision making, or managing a health crisis.

The way the RRI family shares and encourages each other is one reason I am excited and passionate about stepping into the role of President of RRI. In this edition you will read some inspiring stories from women and organisations who work to overcome poor resources and lack of information in their countries in order to help breast cancer patients make decisions that are best for them and their families. We thank them for sharing these stories to help and encourage others to be courageous and advocate for themselves and those around them. Their examples demonstrate how support in building health literacy can achieve great results.

In the telling of our stories we are also reassured by the support and interaction we have from health professionals and cancer organisations who are a part of our RRI family and who dedicate their professional lives to supporting people and their families affected by a breast cancer diagnosis.

While acknowledging health professionals in our organisation, we must congratulate Dr Maira Califfi, who was recently elected to the Union for International Cancer Control (UICC) Board of Directors, and Jeff Dunn, PhD, who has long been a Special Adviser to RRI and is now the President Elect of the

UICC. We extend our heartfelt thanks to Dr. Fatima Cardoso, the President of the ABC Global Alliance, who provides her time so freely in support of RRI's initiatives, particularly with our first two virtual sessions.

Both virtual sessions were planned for this year; however, due to unavoidable circumstances, the second had to be postponed. The session in September focused on the issues and challenges of an early breast cancer diagnosis; the postponed session will focus on issues and challenges for those with an advanced breast cancer diagnosis. The virtual sessions will be regular features next year and we would like to hear from you about what you are interested in knowing more about. These sessions are a wonderful opportunity to increase your own knowledge and raise awareness in your communities about the topics discussed. I know how difficult it can be to find available speakers for support groups, so these sessions may be a way for you to bring your community together for peer connection and information all at one time. These are just a few ways the RRI community can work together and join our voices to raise awareness about breast cancer and peer connection.

Our congratulations go to recipients of this year's Terese Lasser Award, Stephne Jacobs, South Africa, and the Health Professional Award, Dr Maria Califfi, Brazil, who are two remarkable role models in their commitment and dedication to women, men and their families affected by breast cancer

My thanks and appreciation goes to Cathy Hirsch and her team and to all of you, too, for continuing to be committed to making a difference in your part of the world. As I start out in this new role, I especially look forward to learning more about you, where you live, how you are working to support your communities and, importantly, how as a team we can help champion each other's efforts.



IEEPO Position Paper Chapter Two, Lay Language Summary: Humanising health literacy

Alastair Kent, *Former Executive Director, Genetic Alliance*
Susan Thornton, *Chair, Lymphoma Coalition*

Challenge: improving health literacy

Health literacy refers to a person's ability to understand and use information to make decisions about their health. Lack of self-care and poor health literacy can result in people taking less responsibility for their own health and not engaging effectively with their healthcare systems. It is crucial for patients to be involved in the design and delivery of solutions as they can provide perspectives and terminology that may be different to those of researchers and healthcare providers.

Ambition: empowering patients to better understand their health

When sharing medical information it needs to be clear, succinct and simplified, while being delivered to people in creative formats that engage them, such as audiobooks, podcasts, visuals (videos and drawings) and theatre. Traditionally, patient organisations have played a key role in promoting health literacy and have an excellent track record in providing educational resources, training programmes and comprehensive libraries for health-related education. It is therefore essential they are effectively resourced and supported by all stakeholders as well as invited to participate in scientific and high-level policy and health technology conferences.

Solution: investment in health literacy as an essential life skill

Overall, improving health literacy is an overarching need encompassing health and educational policy, ethics, and active policy making on the part of governments. It is understood that if health literacy was taught in schools from an early age, all citizens could grow up with a better understanding of how their bodies work and the role of science and medicine in maintaining and restoring their health. It is therefore important for governments to invest strategically in health literacy education and to mandate health literacy as a fundamental life skill to be taught in schools

Call to action (see all here): [\[https://www.ieepo.com/en/ieepo-position-paper/chapter-two.html\]](https://www.ieepo.com/en/ieepo-position-paper/chapter-two.html)

Develop strategies that address the challenges in achieving health literacy.

Case study:

Song and dance in disease prevention in Sub Saharan Africa. Available to read here. [\[https://www.ieepo.com/en/ieepo-position-paper/chapter-two.html\]](https://www.ieepo.com/en/ieepo-position-paper/chapter-two.html)

From IEEPO Position Paper Engagement Toolkit.
March 2022/M-XX-00008639

IEEPO is funded and organised by *Roche*

Health literacy and breast cancer

Rama Sivaram, Pune, India



Rama Sivaram

India's National Literacy Mission defines literacy as acquiring the skills of the 3 R's—reading, writing and arithmetic—and the ability to apply them to one's day-to-day life. In India, 81% of youths from ages 15 – 24 and 63% of all adults are literate, based on a study conducted by the United Nations Educational, Scientific and Cultural Organization (UNESCO) from 2005 – 2010. This is by and large basic foundational literacy and numeracy. How does it relate to functional literacy in the lives of the Indian people, especially with respect to health? Does it increase and optimize self-reliance, the awareness that drives cognitive thinking skills, and engagement in one's own health care? What percentage of people with basic literacy do engage in their own health care? This is debatable, as it takes much more than the 3 Rs' for people to understand the reasons for various deprivations and move towards change with respect to their health.

In 2021 the female literacy rate in India was 91.95% according to Global Data, a data analytics and consulting company. What does that mean, however, in terms of health literacy when lifted out of academic and research portals? Seen from the public space, it means very little. In a UNICEF study conducted in 2011, India was ranked at 123 out of 135 countries in female literacy with respect to health literacy. The focus on foundational literacy is to equip people with day to day survival skills and thus pave the way to do away with disparity in social norms, gender and poverty. Health literacy therefore occupies a lower step or is the next step.

The World Health Organisation (WHO) Health Literacy Toolkit defines Health Literacy as the "ability to engage with health information and services." Health Literacy is multi-layered and dynamic and is affected by many variables, from general literacy to social, cultural and financial status and norms, access to health information and facilities, and mindset and conscious critical thinking skills to make optimal health-related decisions and utilize health systems effectively. This is beyond mere awareness, and people need to develop higher-level skills that are cognitive and social so as to truly benefit from being health literate and take charge of their health.

Researchers, clinician and nurses' health literacy and awareness studies undertaken in low- and middle-income countries mostly

conclude that there is a lack of awareness and a need for health literacy programs. This is also true for developed countries to a somewhat lesser degree. Disparity is a global malaise. There are pockets of low literacy in every society where there is a big social and economic divide. Those in such pockets lack awareness, knowledge, health status, health facilities, financial stability, and general literacy and are further impeded by cultural norms, myths, misconceptions and skepticism in modern medicine and science.

In the early 1980's, a new communication theory model emerged. This was the information deficit model that describes public skepticism in science communication as rooted in lack of knowledge. If people knew more, they would accept more. Thus, the way in which information is passed from the expert to the non-expert is important, and each community and country has to go beyond mere awareness education and campaigns.

This brings us next to pinning down health literacy in breast cancer in India. By and large it is acknowledged that one of the barriers to breast health literacy is the unequal status of women, regardless of a woman's socio-economic and educational background. Studies on health literacy in breast cancer are few and far scattered. Those studies that do exist usually consider: demographics; menstrual status; number of pregnancies and gestational stage at times of delivery;

family history; and knowledge, attitude and practice/behaviour in regard to risk factors, symptoms, myths and misconceptions, family history, screening, breast self-examination, and a basic understanding of breast cancer. These academic exercises lose track of the goal of achieving effective, functional health literacy in breast care, from prevention to palliation. The Stanford Social Innovation Review, "Stop Raising Awareness Already," suggests that awareness campaigns are often based on flawed logic that assumes that changes in knowledge automatically produced changes in behavior. Raising awareness may be a part of the equation but it is clearly not the complete answer to effecting real, widespread changes in attitudes and especially behavior.

In order to bring about change, breast cancer awareness programmes must include health literacy programmes at the inception. Simply providing an overload of information to people who are not equipped to understand it is not the solution. My own experience of conducting awareness and screening programmes for more than 20 years has brought me to the realization that service providers need to: foster a cooperative, equal learning climate; create mechanisms for planning and execution; and remain in constant contact with the communities they serve in order to better understand the community members and their experiences. To progress from just awareness to functional health literacy we

need to revamp and delve deeper into the following:

- Setting awareness goals that include improved understanding of health matters. Providing information about health is not enough. There is abundant research that shows simply giving information is unlikely to change behaviour. Steps must be taken to ensure that the recipients of the information are able to understand it and take the steps necessary to act on it. Service providers are key to improving understanding in the communities they serve.
- Focusing more on educational psychology and principles of adult learning. New tools must be identified for informal adolescent and adult learning to close the gap between what one already knows and what one needs to learn, to put into practice and be prepared for timely action.
- Enabling the 4 universal adult learning assumptions of Malcolm Knowles. These are:
 - Self-concept leading to self-direction
 - Experience as a resource for learning and praxis (transformative action)

- Readiness to learn so as to orient oneself with developmental tasks and cognitive skills
- Orientation to learning as a progression to application and motivation to learn.
- Planning holistic content using learner experience as examples and paving the way for dialectic inquiry. This requires asking questions and learning to think. Learning through instinct and learning through deliberation are different. The first is for basic survival and the latter for quality of life.
- Facilitating dialogue as a deliberate tool for both understanding and praxis for making informed decisions and bringing about desirable change. Such dialogues can enhance the capacity to obtain, process, and understand basic health information and services sufficiently to make appropriate health decisions.

A concluding small, but significant, take home for all of us is summed up in this ancient Vedic folklore:

A condescending scholar with lots of information and knowledge seated in a boat and crossing a river decided to converse

with a fellow traveller. He asked, "Have you read the Veda? The traveller replied, "I have heard about them but never had time to read them." The scholar exclaimed, "Oh! 25% of your life is wasted! Ok, have you read the Upanishad then? "The fellow traveller said, "No." The scholar declared, "Then another 25% of your life is wasted!" By the time the third question was coming the boatman cried out there was a hole in the hull and the boat was sinking. The fellow traveller asked the scholar, "Do you know how to swim?" All the pomp went out of the scholar's voice and he cried, "I have been so immersed in my knowledge that I never had time to learn to swim." The fellow traveller curtly said, "Then your entire life is going to be wasted now."

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Changing breast cancer perspective through health literacy

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

India, the world's second-most populated country, is an accumulation of history, cultures, and traditions. Although the country boasts of a rich heritage, some stigmas such as ingrained patriarchy, and widespread superstitious beliefs are dense shortcomings for its development. It is imperative that India rises above its current conservative mindset of gender bias and acquires a more feminist perspective. Globally, women are striving for equality, and the story is no different in India. The average Indian woman faces far more gruelling struggles than many others, however, in light of the deep-rooted understanding in her society that her priority needs to be to fulfill multiple household roles. Self-care is her last concern. When such a woman, whose whole family is emotionally and physically dependent on her, gets diagnosed with breast cancer, unfortunately, her first feeling is of guilt and shame. She is reluctant to seek medical help as she prioritizes the needs of the family over her own. She is also in denial, aggravated by other factors like lack of education and low socio-economic status causing further delays in treatment¹⁻⁴. This is why most breast cancers in India present at an advanced stage.

In such a context, health literacy (HL) is a pressing priority. Although there is a large

gap in HL in India and systemic changes need to be made, Prashanti Cancer Care Mission (PCCM), in its own capacity, is trying to bridge it. PCCM actively runs various initiatives and programs like large community screening camps along with awareness programs to educate people about the key risk factors of breast cancer and the importance of early detection. These camps and talks are conducted in corporate companies, schools and universities, municipal corporations, and various communities including slum and outlying pockets covering under-privileged sections of the city. PCCM annually reaches out to over 5,000 community members in order to promote breast cancer awareness. It also runs a successful social media campaign for women to be mindful and vigilant about the risks associated with breast cancer.

Through its clinical program, moreover, PCCM strives to provide HL not only to the community but also to its breast cancer survivors. PCCM believes that attention to health literacy at the individual level is necessary in order to provide exemplary survivorship care. Taking into consideration that patients should have a care-free and disease-free life post breast cancer, PCCM has a robust follow-up protocol. We take additional measures to follow up

with our patients and report each patient's concerns about health through a systematic questionnaire targeted to improve HL by addressing social, psychological, and sexual well-being and any other health issues that may be faced by a breast cancer survivor. Such systematic questionnaires, referred to as PROMs (patient-reported outcome measures) are effective tools to capture data on the overall health of breast cancer survivors⁷.

To enhance its efforts regarding HL in the community and in its patient population, PCCM has also newly initiated eHealth Literacy surveys. These will help in not only assessing the impact of PCCM awareness initiatives but also in changing the perspective about breast cancer.

Overall, there is low health and cancer literacy among Indian women as compared to the western population⁸. Evident through its body of work, PCCM is truly committed to improving breast cancer literacy in the community. We believe that key to overcoming breast cancer is through self-awareness, early detection and removing the taboo from the word "breast". The Indian woman has come a long way but needs to go even further to put her own health before all her other responsibilities.



Laleh Busheri teaching health literacy to a group of women.

“

WE BELIEVE THAT KEY TO OVERCOMING BREAST CANCER IS THROUGH, SELF-AWARENESS, EARLY DETECTION AND REMOVING THE TABOO FROM THE WORD “BREAST”.

”



Dr. C. B. Koppiker, Oncolastic Breast Surgeon and Head of PCCM, regularly promotes breast cancer awareness.



PCCM staff and mobile breast care unit

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Alma Zois contributes to health literacy of women with breast cancer in Greece

Christiana Mitsi, *Psychologist, Scientific Director of Hellenic Association of Women with Breast Cancer (Alma Zois)*

Korina Tsompanisaki, *Social Worker, Alma Zois Athens, Greece*

It is well known that, after a diagnosis of breast cancer, life changes completely. A woman undergoing the diagnosis and the treatment worries about all the changes that will occur to her body, daily routine, goals and future.

Having all the information she needs, having access to the latest data about personalized medicine, and being aware of what her choices are provides a better understanding of what is going on, a better attribution of the reasons for the diagnosis of breast cancer and, finally, leads to a sense of control by the breast cancer patient. This sense of control is essential in the process of going from treatment to survivorship because it helps minimize worry and anxiety.

Women who are fortunate enough to be treated at a certified breast center unit, staffed by a team of health care professionals who have expertise in the various aspects of breast cancer treatment, are provided with all the necessary information about the available choices and a personalized plan. In these circumstances, women are made to feel they are part of the team working together and leading them back to health and wellbeing.

Unfortunately, being treated in a certified breast center unit is not an everyday practice in Greece because the National Health System is fragmented. Usually, the patient tries to find a doctor by word of mouth. There is lack of communication between the specialties so the patient has to relay any information about her condition and the reports she has received from various specialists to every doctor with whom she consults. More often than not, the patient has to deal with a sense of helplessness or with having to be her own patient navigator in a place that is unknown and unfamiliar to her. The breast cancer patient sometimes

feels unoriented, alone and unaware of what is going on, what her choices about the treatment are and what methods are available in order to deal with breast cancer. In this condition patients often turn to “Dr. Google,” sometimes with catastrophic results since all the information available on the internet is not necessarily reliable or personalized.

For this reason, the education and empowerment of breast cancer patients is one of the basic goals of the Hellenic Association of Women with Breast Cancer (Alma Zois). Alma Zois uses a variety of strategies and programs to provide useful information about every issue that may arise during the breast cancer journey. For example, one of the strongest programs that leads to well informed breast cancer patients is a set of 10 seminars, presented annually, that follow the format of “meet the expert” and cover subjects of interest to women who are diagnosed with breast cancer. The purpose is to provide all the necessary information about methods of treatment, issues about fertility, genetic testing, importance of biopsy and decodifying the information, latest data about living with a metastasis, and multiple other seminars. This important educational information helps the patient obtain control and become empowered. The program has been in place for 14 years, and during the COVID-19 pandemic it was transformed into a webinar. This allowed more than 5,000 patients around the country to participate, making it one of Alma Zois’ most successful patient education programs ever.



Christiana Mitsi



Korina Tsompanisaki

“ALMA ZOIS USES A VARIETY OF STRATEGIES AND PROGRAMS TO PROVIDE USEFUL INFORMATION ABOUT EVERY ISSUE THAT MAY ARISE DURING THE BREAST CANCER JOURNEY.

”

Breast cancer education challenges in Indonesia

Shanty Gultom, MD, *Indonesian Breast Cancer Foundation*



Shanty Gultom, MD

A common theme at Breast Cancer Surgical Oncology seminars in Indonesia is the high rate of patients first presenting with advanced breast cancer. For decades now, records have shown the rate has remained well above 50%*. Education has a direct effect on early detection, which in turn affects the patient's prognosis. Clearly, more must be done to educate the Indonesian public about breast cancer so the rate of advanced disease can be reduced.

After delivering a training program on breast cancer patient support in Medan a few weeks ago, I approached a woman who was accompanying her daughter, a breast cancer patient. They came from a district in the southern part of North Sumatra Province, which is about 600 km away from Medan. There is no hospital with cancer services in the district where they live. I asked the mother, "Has your daughter gone through a surgical treatment?" "Not yet," she replied, adding "My daughter is currently undergoing chemotherapy to shrink her lump." Hmm, I thought. That means, her breast lump is already big and it is very likely that she came late for treatment to the hospital in Medan. I asked her, "Why [didn't] you take your daughter to a medical doctor for treatment when her breast lump [was] still small?" She replied, "I didn't know if the medical doctor [would be] able to treat my daughter's breast lump. All I know is that, in the public health centers in the place where I live, the medical doctors only treat minor illnesses, such as cough, cold, high blood pressure, diarrhea, [and] typhus. In my village, if the disease is severe, we go to a quack, a shaman or a witch doctor." What the woman told me is indeed a view held by many Indonesians. They do not understand that the competence of medical general practitioners in public health centers is certainly different from that of specialist doctors.

That is one of many stories that are typical in Indonesia. For generations, people in rural areas have generally believed that it is better to consult a shaman than a medical doctor. Even worse, the traditional elders who usually are esteemed as "smart people", get angry with their neighbors who go to a medical doctor for treatment of a serious illness.

Making the problem even worse, many new breast cancer patients look for information on the internet and are fooled by misleading information. Often, the first articles that pop up in response to an internet search contain non-medical treatment information, or non-surgical treatment without chemotherapy. These can mislead breast cancer patients about what to do next.

Another obstacle is English proficiency. Breast Cancer patients or supporters who know to look for accurate information are often frustrated when the information is provided in English and they are not sufficiently proficient in that language. In order to address this problem, I suggest to the breast cancer patients and supporters that they look for information on the American Cancer Society website, www.cancer.org. I personally find it helpful to consult that website for information on how to support and accompany breast cancer patients. If the patient or supporter has difficulty with the English language, I instruct them to pay close attention to any accompanying images, because basically the images simply illustrate the text or, if the information is presented on the website in video format rather than text, what the speaker is saying. I tell them to take a screenshot of anything that seems important. Then they can use Google translate to convert the English text from the screen shot into their own language. Above all, I encourage them to stay optimistic about learning.

In order to improve health literacy regarding breast cancer, the Indonesian Breast Cancer Foundation has organised a series of educational sessions called the ECHO (Extension of Community Health Care Outcomes) Project. At a recent session, a midwife complained to me that it is not easy to educate women in the

community in which she works about the importance of breast self-examination, mostly due to lack of breast cancer literacy. She told me that the women say they feel fine and that there are no lumps in their breasts, and they argue that there is no need for breast self-examination, even as a form of early detection. They have little interest in learning more. To deal with this we, as the hub team of ECHO Project, try to build the enthusiasm of session participants by choosing the didactic materials they need most and choosing experts who deliver the presentations and discussions in a fun and lively way. So far, the ECHO Project sessions have been well received.

The level of public literacy about breast cancer is the main benchmark for achieving the vision of reducing the incidence of advanced breast cancer in Indonesia. This indeed is not an easy job for a nation as big as Indonesia, but if all of us who are concerned about breast cancer are willing to share our knowledge, I am confident we will be able to reduce the number of advanced stage diagnoses soon.

* <https://www.indonesianjournalofcancer.or.id/e-journal/index.php/ijoc/article/view/920>

Spotlight on: Portugal!

Win and Live Movement holds 7th PINK LUNCH

*Carolina Negreiros, Leonor Sousa, Fátima Amaral
Oporto, Portugal*

On 15th of October the Win and Live Movement of the Portuguese League Against Cancer (Northern Branch) hosted the 7th PINK LUNCH to honor those who have survived and fought breast cancer. The lunch promoted breast cancer awareness and raised funds for support.

The highlights included praise for the volunteer work of Emília Couto, who has been a dedicated volunteer for more than 20 years, and the launch of a booklet about the history of the Win and Live Movement since its creation in Oporto in 1982. This booklet shows the improvements in the services and support provided to breast cancer patients over the last 40 years.

Initially, the support provided by the Win and Live Movement at the Portuguese Institute of Oncology in Oporto was restricted to volunteers visits to hospitalized patients.

Later, volunteers began giving support in crowded waiting rooms, in corridors, in corners, always seeking a place with a little privacy when talking to patients waiting for medical appointments. Today, the Win and Live Movement has its own support office in the area of the hospital dedicated to breast cancer, which reflects the hospital administration's recognition of the important work done by volunteers. The Win and Live Movement also now has an office dedicated to counseling and body image, where support and essential products for the well-being and self-esteem of women are available to all breast cancer patients.

Another important achievement of the Win and Live Movement of the Portuguese League Against Cancer described in the booklet is the institutionalization of October 30th as National Day for Breast Cancer

Prevention. This was the outcome of a petition that the Win and Live Movement presented to the Portuguese Parliament.

All these achievements have led to a greater interaction of volunteers with civil society, such as participation in sporting events, collaboration with schools, presentations in workplaces, among other activities.

The booklet also highlights the Win and Live Movement's international collaboration through the Bloom e-Newsletter and participations in meetings and other international events. This compilation of history and important events in the fight against cancer was offered to everyone present. The booklet was written by the Win and Live Movement's Coordinator, Carolina Negreiros, and the design was conceived by a student of the Art and Training School Árvore.



Treating DCIS – An Oncoplastic Approach

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

At 40, Surekha (name changed), mother of two young girls, received a life-altering diagnosis. She was diagnosed with DCIS (Ductal Carcinoma In Situ), a non-invasive breast cancer that if left unattended may turn malignant. Her disease was extensive and occupied one-fourth of her left breast, making it a highly risky condition. Thus, even though she had the earliest form of breast cancer, she was advised to undergo a mastectomy by her surgeon in Calicut. Other doctors gave her the same advice.

Sureka explains, "I was not prepared to lose my breasts. I did not want the cancer to snatch a part of me. I wanted to show my girls that their mother is a fighter. This is when I met Dr. Koppiker*, a well-known oncoplastic breast surgeon. He was the only doctor who fiercely advocated conserving my breast and avoiding a procedure like mastectomy." Surekha underwent an oncoplastic procedure called therapeutic mammoplasty with contralateral reduction mammoplasty. DCIS, characterized by abnormal cells in the milk ducts, can be either low grade or high grade. Despite Surekha's case being a high-grade, multifocal DCIS, a more complex case to treat, she was still able to undergo a breast conserving surgery. Her case was labelled as extreme oncoplasty due to the extensive nature of her disease which would require that a large volume of her breast be taken out. That said, most DCIS cases are managed at Dr. Koppiker's facility with breast conserving surgery.

The incidence of DCIS, a non-invasive form of breast cancer, has increased markedly in recent decades. Even with the non-invasive nature of the disease, 16% of low-grade cases of DCIS and 60% of high-grade cases are expected to advance into invasive carcinomas. As a result, most diagnosed cases of DCIS are treated with the same regimen as invasive breast carcinoma. Even today, in most of the centres in India mastectomy is the primary treatment for patients with DCIS. Dr. Koppiker is a staunch believer that losing breasts to breast cancer is not always the best or only option because mastectomy has been associated with several severe sequelae such as body

asymmetry, postural instability, depression, loss of self-esteem and poor quality of life. His oncoplastic approach tries to conserve the breast *whenever possible*, providing good aesthetic outcomes without compromising on oncological safety.

Like most high-grade DCIS patients Surekha endured the whole spectrum of cancer treatment, including chemotherapy and radiation therapy. But despite a high-grade DCIS diagnosis at an early age, and having been advised mastectomy at other centres, she was able to conserve her breasts at Dr. Koppiker's practise. Today, after 7 years, she has almost forgotten her arduous journey and is leading a physically and emotionally scarless life.

The DCIS cohort at Dr. Koppiker's unit is managed mostly by breast conserving therapy and, whenever needed, oncoplastic procedures for better cosmetic outcomes. Breast cancer patients from our single institutional cohort who were diagnosed with DCIS report no major post-operative complications and good to excellent cosmetic scores. Patient reported outcome measures (PROMs) indicate better acceptance and improved quality of life (QoL) for these patients.

In India, mastectomy remains the main procedure used for clinical management of breast cancer, with close to 80% of patients undergoing mastectomy regardless of the stage and type of disease at diagnosis. The need of the hour is to change the mindset of the medical fraternity and population at large about the advantages of oncoplastic techniques. A breast cancer diagnosis does not always have to equate to losing a part of your body. Breast conservation surgery can be a safe alternative and with techniques used by plastic surgeons can leave patients with natural looking breasts. Prashanti Cancer Care Mission is striving through various efforts to increase awareness in the medical community, train surgeons in these techniques, and inform the general public of the choices available to them.

**Dr. C.B Koppiker is a Oncoplastic Breast Surgeon and is the head of the practise at Prashanti Cancer Care Mission.*

Spotlight on: India!



Laleh Busheri

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Please enjoy these recipes, which are favourites in Australia!

Vegan Paté

Global
Kitchen



PREP TIME: 15 MINUTES
COOK TIME: 30 MINUTES
SERVINGS: 6 (as appetizer)

Ingredients:

1 carrot
1 aubergine (eggplant)
1 red bell pepper
1 head garlic
1 tablespoon olive oil
salt and pepper for seasoning
1 can chickpeas drained and rinsed
¼ cup (35g) Walnuts
12 sundried tomatoes soaked for
10 minutes in just boiled water
2 tablespoons olive oil
½ tsp salt
1 tablespoon capers

Directions:

1. Preheat the oven to 190°C/375°.
2. Chop the carrot, aubergine and red bell pepper into 1-inch chunks and lay out on a flat baking tray lined with parchment paper. Season to taste with salt and pepper.
3. Put the head of garlic on its side and slice a small amount off the top so just the tips of the cloves are exposed, keep the end where all the cloves attach intact. Drizzle with a small amount of olive oil, season with salt and pepper and wrap in a tin foil package.
4. Bake the vegetables and the garlic for 30 minutes, until soft. Allow to cool.
5. Add the vegetables and garlic to a food processor with the rest of the ingredients and blend until smooth. You might need to do this in 2 batches depending on the size of your food processor.

Recipe Notes

Store in an airtight container in the refrigerator for up to 5 days.
Serve with fresh, crusty bread or crackers.

Pavlova

Global
Kitchen

Pavlova is a classic Australian dessert (although this is disputed by New Zealanders who claim it as their own!) and is a favourite for special occasions. The pavlova is baked on an oven-safe plate which can be used as a serving dish so there's no risk of breaking the pavlova while transferring it. Feel free to substitute an equivalent amount of any combination of your favorite fruits in place of the suggested ones.

SERVINGS: 8



Ingredients:

- 2 teaspoons butter, melted
- 2 teaspoons sifted cornflour, plus 1 extra tablespoon
- 5 egg whites
- 1 ¼ cups (275g) caster sugar
- 1 tablespoon cornflour, extra
- 1 ½ cups (375ml) thickened cream, whipped
- 1 cup (250g) strawberries, halved
- 1 mango, sliced thinly
- ⅓ cup (80ml) fresh passion fruit pulp

Directions:

1. Preheat oven to 150°C (130°C fan-forced)/300°F. Grease a 29cm/11in round oven-proof plate or cake stand with butter, leaving a 3cm/1in border. Sift the 2 teaspoons cornflour over the greased area.
2. Beat the egg whites in a large bowl with an electric mixer until soft peaks form. Gradually add the sugar, beating until dissolved, scraping the side of the bowl. Use a large metal spoon or spatula to fold in extra 1 tablespoon sifted cornflour.
3. Pile the meringue into the centre of the prepared plate. Use a metal spatula or the back of a spoon to spread the meringue into a 23cm/9in circle, making a shallow well in the centre.
4. Reduce the oven temperature to 100°C (80°C fan-forced)/225°F. Bake pavlova on the bottom shelf of the oven for 1 ½ hours or until dry and crisp. Turn off the oven. Let cool in oven with door ajar. Top with whipped cream, strawberries, mango and passion fruit and serve.