

bloom

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Reach to Recovery International - RRI

Reach to Recovery International is committed to improving the quality of life for women with breast cancer and their families.



Message from Cathy Hirsch

President of Reach to Recovery International

In this edition of *Bloom*, we focus on human rights in cancer care and examine some of the inequalities that can impact upon incidence, mortality, survival, and patient experience. We also highlight programs and initiatives that seek to address inequalities in cancer care.

Anyone who has ever attended a Reach to Recovery International Breast Cancer Support Conference has seen firsthand that the cancer burden weighs more heavily for some than for others. By bringing together breast cancer patients, survivors, caregivers, health care providers, and advocates from around the globe, we shine a spotlight on the similarities we all share as citizens of the world who are committed to conquering cancer. We also reveal the glaring differences that can exist regarding the quality of screening, treatment, and support that patients may receive.

RRI's parent organization, the Union for International Cancer Control, is working to revise and refresh the World Cancer Declaration, which sets forth 11 goals, or targets, in order to significantly reduce the global cancer burden by 2020. The UICC has sought input from its member organizations, including RRI, and we have proposed amendments to 5 of the targets and proposed the addition of a 12th target. Our suggestions, aimed at reinforcing the importance of psychosocial support and community-based cancer control,

are discussed fully in this edition.

The International Psycho-Oncology Society (IPOS) is the world's leading multi-disciplinary international association in addressing psychological, social, and behavioral issues regarding cancer care. IPOS recognizes that proper psychosocial care is crucial to providing high-quality health care that maintains quality of life. To that end, it created the IPOS Human Rights Task Force in 2008 to raise awareness of, and support for, psychosocial cancer care. The task force recently circulated to IPOS membership a draft "*Joint Declaration for the Recognition of Psychosocial Cancer Care as a Human Right.*" William Breitbart, M.D., who chairs the task force, has submitted a report on the contents of, and rationale behind, the draft declaration.

In a special report commissioned by the Editors of *Bloom*, IPOS Director Professor Jeff, known well to all of us as Chair of the RRI Board of Management and CEO of Cancer Council Queensland, examines the pros and cons of conceptually framing psychosocial care, in the form of distress management, as

a human rights issue in order to mobilize global action. Professor Dunn explains IPOS's position that distress should be measured as the "Sixth Vital Sign." He proposes a long-term, coordinated approach for integrating psychosocial care into quality cancer care programs.

The goal of the Cancer Support Community is to eliminate disparities in the quality of social and emotional support available to patients throughout the world. This international non-profit organization has affiliates throughout the United States and in seven additional countries. Emily Martin profiles the Cancer Support Community and the comprehensive services it offers.

By relating the personal stories of five cancer patients from different parts of the world, Rebekka Schear, MIA, and Claire Neal, MPH, of LIVESTRONG Foundation illustrate a variety of disparities that may exist from country to country or even within a particular society. In many low- and middle-resource countries, information about cancer and screening procedures for early detection may simply be unavailable. Treatment facilities

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Email your bloom submissions! The theme of the next edition will be *How does age affect access to treatment and rehabilitation?*. Submissions close 17 October 2013. Please send submissions in Microsoft Word format with any photos to info@reachtorecoveryinternational.org

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

Reach to Recovery International is a program of the Union for International Cancer Control and Cancer Council Queensland.



The theme for this issue is *Human rights – access to, and quality of, treatment and supportive care for those affected by cancer.*

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may be prohibitively distant or may be unaffordable to many patients. Similar

barriers may exist even in high-resource countries for low-income patients or patients who live in rural areas. In any part of the world, any one of a number of forms of discrimination may prevent a patient from accessing the treatment she needs. The authors share a **LIVESTRONG** success story resulting from a grant the foundation awarded in 2010 to improve cancer care in Haiti. They report that the grant led to “great success in screening thousands of women, treating patients for cancer[,] and providing those in need of palliative care with pain relief.”

In Australia, breast cancer survival rates are lower for Aboriginal and Torres Strait Island women than they are for non-indigenous women. Australia’s lead national cancer control agency, Cancer Australia, has been working hard to reduce this disparity through an ongoing awareness and educational campaign. Cancer Australia reports on the steps it is taking and the progress it has made.

The availability -- or unavailability -- of the drug trastuzumab, or Herceptin illustrates inequality in breast cancer care between high-, middle-, and low-resource countries. While proven to be effective in saving the lives of women with HER2-positive tumors, trastuzumab is available in less than half the countries of the world. Bloom reports on efforts underway to add trastuzumab to the World Health Organization’s Model List of Essential Medicines -- a move that

hopefully would result in making the drug more accessible and more affordable.

Despite tremendous progress overall, in some parts of the world breast cancer is still a very private matter, not to be mentioned outside the home or physician’s office. In Pakistan, for the first time ever, a well-known public figure has recently stepped forward to acknowledge that she, personally, has battled breast cancer. Dr. Fehmida Mirza, a former Speaker of Pakistan’s National Assembly, has joined the Pink Ribbon Campaign, which raises awareness of breast cancer nationwide and promotes early detection and treatment. Omer Aftab of the Pink Ribbon Campaign describes the boost that Dr. Mirza’s participation is providing to the campaign’s efforts.

There is no dispute that medical research is key to developing new treatments and possible cures for cancer. But how should patients be approached to participate in studies so that they don’t feel coerced or violated? What information should be provided to patients or their families, and can blood or tissue samples that patients provide be used for additional purposes to which the patients did not agree? These questions are raised by the Taiwan Breast Cancer Alliance, which hopes to generate broad discussion on the topic of research versus patient rights.

Dutch artist Shirley Bianca lives and works in Cologne, Germany. After being diagnosed with breast cancer in 2000, Shirley used her artwork to express the roller coaster of emotions she was experiencing. Using goache and oil paint, she ultimately created a series of paintings

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Cathy Hirsch

that she calls her “Message of Hope.” In this edition of Bloom, Shirley shares her work with our readers via a web link.

Reach to Recovery International is built on the simple yet universal principle: a woman who has lived through breast cancer and gives freely of her time to help another woman facing the same experience is a valuable source of support. That support may be provided in the form of information or practical help, but often the most valuable support a Reach to Recovery volunteer can offer is simply to listen, without judgment, as a new patient shares her fears and concerns. In this edition of Bloom, members of the Sarawak Breast Cancer Support Group of Malaysia, all of whom were trained by former RRI President Ranjit Kaur, reveal what they’ve learned about effective listening. Our Malaysian friends also share a recipe for a healthy and delicious green salad.

Please enjoy this edition, and continue to check reachtorecoveryinternational.org for the latest information on the next RRI Breast Cancer Support Conference, to be held in 2015.

News

from around the world

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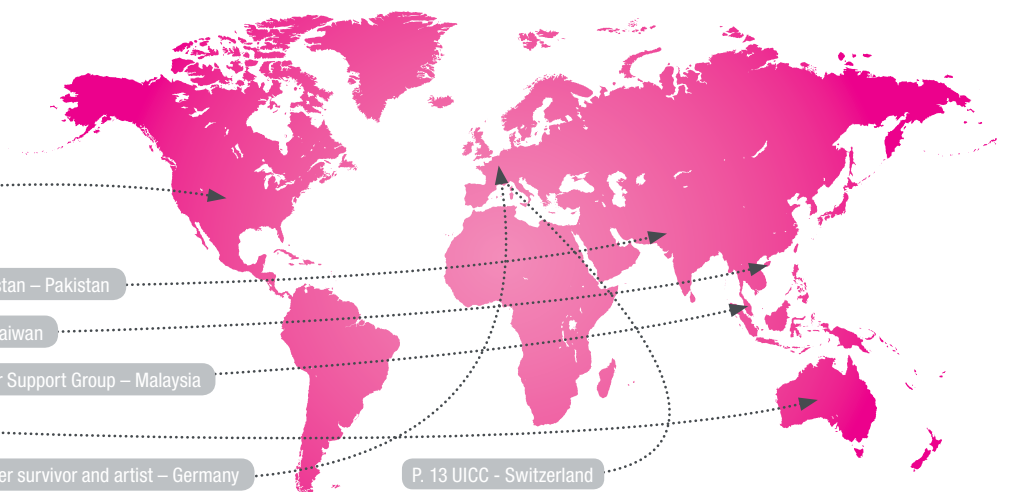
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Psychosocial cancer care as a human right: International Psycho-Oncology Society Task Force report

William Breitbart,
M.D., Chair, IPOS Task Force on Human Rights

The International Psycho-Oncology Society (IPOS) established the IPOS Human Rights Task Force in 2008 to raise awareness and support in the international cancer community of the importance of Psychosocial Cancer Care as a Human Rights issue. The Task Force has drafted a “Joint Declaration and Statement of Commitment Calling for the Recognition of Psychosocial Cancer Care as a Human Right” that is now being considered by the IPOS membership and the IPOS Federation for approval.

The *right to health* is a fundamental part of our human rights and of our understanding of a life in dignity as stated in numerous international human rights declarations and covenants. The right to psychosocial cancer care is protected under existing human rights law and the right to health, and includes: access to cancer prevention services, screening for distress, diagnosis and treatment of psychosocial sequelae of cancer throughout the course of cancer treatment, including survivorship, end of life care and bereavement services.

Approximately forty percent of cancer patients, and family members, experience levels of psychological distress that requires specific intervention. Of the 28 million people worldwide with cancer (as well as their family members), only a minority of those in need receive proper psychosocial cancer care by trained professionals, resulting in widespread unnecessary suffering.

The IPOS Joint Declaration calls on members of the international cancer community to:

1. Identify, develop and implement strategies for the recognition of psychosocial cancer care and treatment as fundamental human rights
2. Work with governments and policy makers to adopt the necessary changes in legislation to ensure appropriate psychosocial care of patients with cancer, cancer survivors



3. Advocate for improvements in access to and availability of psychosocial cancer care required for the effective treatment of the emotional, interpersonal, familial, and social impact of cancer or those at risk of developing cancer
4. Advocate for adequate resources to be made available to support the implementation of psychosocial cancer care and psychosocial oncology services where needed, including support of such services in cancer centers, and ongoing professional training in psychosocial cancer care
5. Advocate for academic institutions, teaching hospitals, universities, and health care systems to adopt the necessary practices and changes needed to ensure that psychosocial

care, resources, personnel, infrastructures, review boards and systems are created and sustained

6. Encourage and enlist other international and national organizations, associations, federations and interested parties to join this global campaign for the recognition of psychosocial cancer care as a human right
7. Encourage the recognition that psychosocial cancer care must be provided in a manner consistent with the diversity of cultural, social, and religious contexts of individual regions and countries worldwide

This IPOS Joint Declaration marks the beginning of our campaign. We hope to obtain national and international cancer organizations signatures. This declaration is a critical first step in utilizing existing human rights laws as a means to advocate for optimal psychosocial cancer care resources in every country worldwide.

The IPOS Human Rights Task Force has readings related to human rights and psychosocial cancer care that can be accessed on the IPOS website: http://www.ipos-society.org/members/members_human_rights.aspx.



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www.ipos-society.org/ipos2013

A rights-based approach to cancer care

Rebekkah Schear, MIA
Claire Neal, MPH
LIVESTRONG

To those who were present to hear it, Patient D's cancer story was jarring. It was May 2011, and LIVESTRONG Foundation staff members were in Cape Town, South Africa attending the Voice of Cancer patient forum, which the Foundation supported through implementation of the Patient Empowerment Project. This project, a joint initiative with the American Cancer Society, trained cancer patients to share their stories with policymakers, media and healthcare workers to bring visibility and improvements to the challenges they face in the healthcare system.

Although Patient D was too ill to attend the forum and speak in person, her close friend Ursula was able to share her story on her behalf. The audience at the forum learned that Patient D had a small facial growth that went undiagnosed and untreated as a result of multiple lapses in the South African healthcare system. After months of cancelled appointments, being turned away at the clinic, hours in line to see a clinician and weeks waiting for results, she was eventually diagnosed with cancer. By this point, her tumor had grown to the size of a baseball, distorting the structure of her face and causing immense pain. Patient D was deemed terminal and sent home to die without any relief, after being turned away from another clinic.

Sadly, Patient D's story is all too common. Today, more than half of new cancer cases and almost two-thirds of cancer deaths occur in low and middle-income countries (LMICs), yet only five per cent of the world's cancer resources are spent fighting the disease in these countries.¹ As a result, there is a vast disparity in cancer outcomes between those who live in countries with resources, and those who do not. The Global Task Force on

Expanded Access to Cancer Care and Control calls this disparity the *cancer divide*, noting that it 'directly relates to inequities in access to healthcare and to differences in underlying socio-economic, environmental, and health conditions.'²

Yet *where* you live should not determine *whether* you live. In other words, improving access to cancer care around the world and especially for those in LMICs is not just a moral imperative. Access to cancer care is a *human right*.

Consider this:

Within the field of international development, it has been widely established that health is considered a human right. The framework for a human rights-based approach to health was carved from several key United Nations (UN) treaties – most notably, the Universal Declaration of Human Rights (1948) and the International Covenant on Economic, Social and Cultural Rights (ICESCR) (1966). Article 12 of the ICESCR recognizes 'the right of everyone to the enjoyment of the highest attainable

standard of physical and mental health.'³ In more recent years, the UN committee responsible for implementation of this treaty has expanded and clarified this definition to include underlying determinants of health and the notion that all people have the right to healthcare that is available, accessible, acceptable and of a certain quality.

The World Health Organization acknowledges that 'every country in the world is now party to at least one human rights treaty that addresses health related rights. This includes the right to health as well as other rights that relate to conditions necessary for health.'⁴

Despite the fact that the right to health is clearly articulated and accepted at the international level by every country in the world in some form, the world still suffers from vast inequalities in health – particularly in terms of access. But what does *access* to health really mean?

When we look at the definition according to the UN Committee on Economic, Social and Cultural Rights, they lay out four dimensions of *accessibility*:

- 1) Non-discrimination
- 2) Physical accessibility
- 3) Economic accessibility
- 4) Information accessibility

Overlaying this expanded definition of *accessibility* onto the cancer context globally, we start to see the specific challenges countries face in terms of access to cancer care. But how do these dimensions of accessibility impact individuals and families in their everyday lives?

It took 21 year old Kristi Schurman over a

L I V E S T R O N G ®

year to find a doctor in the United States who would address her health concerns and take her symptoms seriously. Because of her age, several doctors told her that despite her debilitating symptoms, she 'was too young to have any major problems' and that 'it was in her head and she would be fine.' After facing repeated challenges in accessing timely and quality diagnosis, she was told she had endometrial stromal sarcoma, a rare and serious form of cancer. When we talk about the dimension of non-discrimination, we are talking about equal rights to access healthcare without bias or judgment, especially for vulnerable and marginalized populations.

With a facial tumor that had been growing for more than six months, 11 year old Francine Tuyishime and her father walked all over Rwanda trekking miles on foot visiting hospitals and traditional healers to find treatment. Eventually, a traditional healer in the Rwinkwavu area recommended she visit the Partners in Health-supported Rwinkwavu Hospital, where she was diagnosed and treated successfully. Francine's story articulates the dimension of physical accessibility: that every person has a right to health facilities, goods and services that are within a safe physical reach.

After being diagnosed with leukemia in Jordan, Abdel Nasser had to sell all of his belongings, and he and his wife were forced to leave their home and live with his parents in order to attempt to afford his treatment. But the cost of care was so immense that it was only with the assistance of the King Hussein Cancer Foundation that Abdel was able to receive treatment. Nasser's story illustrates our right to economic accessibility: the concept that payment for healthcare services and services related to the underlying determinants of health must be based on the principles of equity and affordability for all, including socially disadvantaged groups.

When we talk about information accessibility, we mean that all people have the right to seek, obtain, and communicate information and ideas concerning health issues. As a result of her diagnosis and treatment for non-Hodgkin's lymphoma, Norma Rodriguez suffered from severe stigma in her community in Mexico. Many community members, some friends and even a few family members refused to visit her home for fear that she was contagious and her children were even isolated at school. Norma and her family suffered from extreme social isolation

as a result of the misconceptions and myths prevalent in her community, which may not have been so ubiquitous if the community had access to quality information about cancer.

All people have a human right to access healthcare, inclusive of cancer care. The stories of Kristi, Francine, Abdel, and Norma illustrate that access to cancer care is a significant challenge in low and middle income countries as a result of the lack of resources dedicated to cancer control, but it remains an issue in upper

"The chance to live should not be an accident of geography."

– Her Royal Highness, Princess Dina Mired of Jordan

income countries as well. Though cancer is widely known to be treatable in the developed world, a predominant myth exists that cancer is too expensive and complicated to treat in the developing world. Yet strategies and tools exist to address cancer in low and middle income countries that can and must be applied now. In fact, some of the most respected minds in global cancer control agree that "these barriers can be overcome and people in even the most remote and challenging settings can receive the care they deserve."

The **LIVESTRONG** Foundation has been working with Partners in Health (PIH) to prove that high quality cancer care is possible in resource poor settings. Five years ago in Haiti, very few people with cancer were diagnosed and those that were had very few options

for treatment. Patients either had to pay for expensive treatments out of pocket or even travel to other countries to receive the care they needed. In October 2010, the Foundation awarded PIH and their sister organization in Haiti, Zanmi Lasante, a grant of \$1 million over three years for a cancer care program. The goal of this three year grant was to build upon existing health programs and their partnership with the Haitian Ministry of Health to launch the first comprehensive and integrated cancer program in the country. The program would work to detect cancers at earlier stages when they are potentially curable, to train clinician and community health workers, to strengthen diagnostic and treatment capacity, to establish protocols for drug procurement, and to optimize palliative care for patients with advanced cancers.

After only two years, the program is seeing great success in screening thousands of women, treating patients for cancer and providing those in need of palliative care with pain relief. The work being done by Partners in Health is making a significant difference in addressing the growing cancer burden in Haiti, and at a global level, this work is demonstrating that high quality cancer care is both necessary and possible.

All of the data we have now projects that the global cancer burden will increase over the coming decades. But if our human right to cancer care is fully realized, and world leaders commit to expanding access to cancer care and implementing what we know works, 20 years from now a person facing a cancer diagnosis may have a very different story than Patient D. A story of opportunity. A story of surviving. Hopefully even a story of thriving.

www.livestrong.org



Cancer survivor Abdel Nasser and his family at home in Zarqa - Jordan

¹ Global Task Force on Expanded Access to Cancer Care and Control in Developing Countries. (2011). *Closing the Cancer Divide: A Blueprint to Expand Access in Low and Middle Income Countries*. Harvard Global Equity Initiative, Boston, MA: Knaul, F.M., Frenk, J., & Shulman, L.

² Ibid.

³ (n.d.) *Human Rights-Based Approach to Health*. Retrieved from www.who.int/trade/glossary/story054/en/

⁴ Ibid.

⁵ Farmer P, Frenk J, Knaul FM, Shulman LN, Alleyne G, Armstrong L, et al. *Expansion of cancer care and control in countries of low and middle income: a call to action*. *The Lancet* 2010;376:1183-1186.



Former National Assembly Speaker joins Pink Ribbon movement

After recently being diagnosed with breast cancer the Former Speaker of the National Assembly, Dr Fehmida Mirza, announced joining the Pink Ribbon movement to become the beacon of hope for breast cancer survivors in Pakistan.

Breaking the smoke screen of social taboo associated with breast cancer for the first time in Pakistan, a well-known public figure has shown the courage to stand up and share her story. Dr Mirza said that breast cancer is one of many types of cancer so it should be seen as a disease rather than associating it with the sexuality of women. It is important to raise awareness among Pakistani women about early detection, since diagnosis at an early stage increases the chances of survival.

Dr Mizra shared her opinion as she said “Our women should know that life after cancer is worth living.” During her speech she shared her experience and encouraged other women to support the cause for the good of everyone. “It means so much to me to be part of a breast cancer awareness campaign. I wholeheartedly support the vital work of spreading awareness and engaging survivorship undertaken by Pink Ribbon Campaign,” she said.

Addressing the ceremony, CEO of Pink Ribbon Mr Omer Aftab, said that Pakistan has the highest rate of breast cancer in Asia. “We are glad that for the first time a renowned and influential female politician has offered support for Pink Ribbon in addressing this issue of breast cancer in Pakistan.”

He further added, “We need support from all corners to address these alarming statistics of breast cancer, as these numbers depict thousands of women who have experienced this fatal disease in their lifetime. Also, we look forward to engaging breast cancer survivors as we believe that their message can save

Prevalence of breast cancer is the highest amongst all the cancers in Pakistan at 38.5 per cent. Every year 40,000 women die from breast cancer in Pakistan. The incidence is also increasing in young girls in Pakistan.

With early diagnosis, a patient’s chance of surviving breast cancer is higher than 90 per cent.

We need more support to extend our message across the nation, ensuring that no one has to bear the horror of losing a mother, a sister, a wife, or a daughter.
Omer Aftab, Pink Ribbon Campaign

many women who are at risk of diagnosis.”

Pink Ribbon Campaign is a nationwide breast cancer awareness campaign. Currently, it is spreading awareness through information and resources nationwide. It also sensitizes girls and women by arranging various events and activities that create a direct interaction. Pink Ribbon also organizes medical camps to provide advice and clinical checkups in collaboration with partner hospitals. Moving forward, Pink Ribbon intends to establish a ‘Centre of Excellence for Breast Cancer’ to further provide adequate support to the people at large.

Submitted by: Omer Aftab, Pink Ribbon Campaign
More information about Pink Ribbon Campaign visit:
www.pinkribbon.org.pk or www.facebook.com/pinkribbonpk



Research vs. patients' rights

When Linda was having breakfast one morning, the phone rang. It was a research institute. It took Linda a while to figure out what the phone call was about.

Five years earlier, when Linda was undergoing breast cancer treatment, her doctor asked her to participate in a research project. All it required was her blood sample. Linda agreed. What Linda did not expect was to be told that her blood sample was being used in a completely different experiment five years later. "I am upset," said Linda. "I have no idea what they have done with my blood. The phone call reminds me of the time I was sick, just when I am beginning to feel alright."

Doctors are well respected and still seen as authoritative figures in Taiwan. When doctors ask patients to participate in research, most of the patients are too polite to say no. Patients are given big piles of papers that are full of difficult medical terms. Somewhere in the maze of the paperwork, there may be a sentence stating that the sample can be used in other experiments or research without informing the patients. Patients often sign the consent form, not understanding the nature of the research or how their samples are put to use.

Another controversial practice is how doctors obtain patient tissue for research use. Some doctors ask the family members for permission when the patients are still in the recovery room. Understandably, the patients feel disrespected when they wake up.

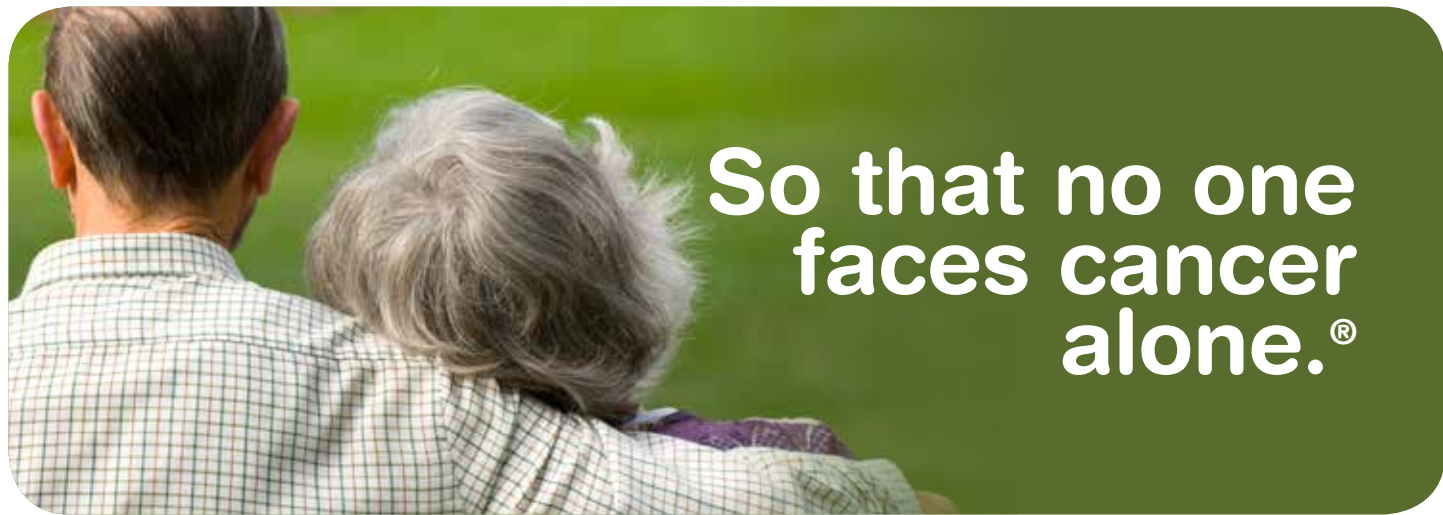
There is currently a debate in Taiwan about what doctors need to explain to patients when asking for blood or tissue samples.

"A specimen taken today can be the key to the medical breakthrough for the future generation," said Gloria, CEO/Founder of Taiwan Breast Cancer Alliance. "We understand the importance of research and study, but we also need to protect a patient's basic rights."

While medical research is vital to developing new treatments and improving outcomes for patients, consideration must be given to the needs and concerns of those patients who do participate in research studies. Health professionals, researchers and patients must work together to ensure patients have a good understanding of what will be required of them and how their information and blood or tissue samples might be used.

If you live in Taiwan and have had a similar experience or have questions, please contact the Taiwan Breast Cancer Alliance at tbca.npo@msa.hinet.net.

Submitted by: Taiwan Breast Cancer Alliance



So that no one faces cancer alone.®

There are 13.7 million cancer survivors living in the US, and more than 1.5 million people will be diagnosed with cancer this year.¹

The good news is, people today are living longer, better lives after cancer due to advances in screening and treatment technologies. Additionally, the cancer community has learned that psychosocial support is an important component of comprehensive, quality cancer care, and screening patients for social and emotional distress is now standard for all institutions, accredited by the American College of Surgeons Commission on Cancer.

As people adjust to the 'new normal' of life with cancer, there are many programs from the international nonprofit Cancer Support Community (CSC) that can empower them to take on an active role in their care, and to live a better life with cancer.

CSC's professionally facilitated online support groups, 'The Living Room', are designed for people with cancer, as well as their family members and caregivers. When face-to-face support groups are not an option, these support groups and discussion boards are accessible 24/7 all over the world at www.cancersupportcommunity.org.

For support on the go, My Cancer Manager is an iPhone app that can be used to track cancer related concerns over time, record thoughts and questions in a personal journal, access educational and support resources and report progress to a healthcare team. It can be downloaded free of charge from the App Store.

For people hoping to improve the lives of others with cancer, The Cancer Experience Registry is an initiative that

collects the experiences of people who have ever had any type of cancer through an online survey. In addition to being a valuable data source for the psycho-oncology community, the registry aims to create a community where cancer survivors can share their insights, learn about others' experiences and about important resources that can help them. Upon survey completion, participants can compare their responses with others in the registry and get connected to resources that can help. A patient who has been feeling distressed might be surprised to see that they're not alone – nearly half of people with cancer feel the same way.²

The mission of the Cancer Support Community (CSC) is to ensure that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community. In 2009, The Wellness Community and Gilda's Club joined forces to become the Cancer Support Community. The combined organization, with more than 50 years of collective experience, provides the highest quality social and emotional support for people impacted by cancer through a network of over 50 licensed affiliates, more than 100 satellite locations and a vibrant online community, touching more than one million people each year.

Backed by evidence that the best cancer care includes social and emotional support, the Cancer Support Community offers these services free of charge to men, women and children with any type or stage of cancer and to their loved ones. As the largest professionally led non-profit network of cancer support

worldwide, the Cancer Support Community delivers a comprehensive menu of personalized and essential services including support groups, educational workshops, exercise, art and nutrition classes and social activities for the entire family. In 2012, CSC delivered more than \$40 million in free services to patients and families. The Cancer Support Community is advancing the innovations that are becoming the standard in complete cancer care. So that no one faces cancer alone.® For more information, please visit www.cancersupportcommunity.org.

Emily Martin
Cancer Support Community

Cancer Registry Experience

If sharing your cancer journey could enhance the lives of others, would you help?

Click to join the movement today!

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COMMUNITY.**
A Global Network of Education and Hope

¹ Siegel, R., DeSantis, C., Virgo, K., et al. (2012), Cancer Treatment and Survivorship Statistics, 2012. CA: A Cancer Journal for Clinicians. doi: 10.3322/caac.21149.

² Zaboraj et al: The prevalence of psychological distress by cancer site. Psycho-Oncology: 10:19-28, 2001

Reach to Recovery post-training reflections – Effective listening

Sarawak Breast Cancer Support Group



30 breast cancer survivors from the Sarawak Breast Cancer Support Group, Kuching, Malaysia attended a three day workshop in July on how to be effective listeners. They were very privileged to have renowned and revered Reach to Recovery International trainer Ms Ranjit Kaur to present.

The following are post-training reflections from some of the participants.

Boon Lui: I have learned that active listening is the key to effective counseling of newly diagnosed women. Listening attentively with compassion and empathy enables clients to find their own solutions to their problems (be it emotional, financial, social or medical). Through our active listening, they get to know that someone is there for them, acknowledging their emotions and feelings, and exploring together with them the strategies to cope with the problems they face. This is the precious and unique support we could give as breast cancer survivors and counseling volunteers.

Mary C: It is so important to listen yet so difficult to master. After the course, I realized that in the past, I talked too much during counseling and offered medical advice which I'm not in the position to do. The greatest benefit I got from the workshop was to listen more and talk less.

Angeline: I used to worry about how best to respond to difficult questions that arose during counseling. But I have learnt that being quiet and simply offering a listening ear is sufficient. It truly seems to make a great difference in the sessions. I don't make any decisions for the client. In fact, I am reminded to be

mindful of the client's feelings, to respect her and keep her stories confidential as they are just so personal and private.

Maria: I am reminded not to give any medical assurances, but to direct the woman to her doctors for medical information. We need to understand their concerns and we can only do so through listening attentively.

Juliet: The workshop helped me tremendously, especially during a role-play when I shared my experience as a cancer patient. I had never cried since I was diagnosed, but that day, during the role-play, as I recalled the old events and emotions, my tears just fell so naturally. After that, I felt extremely relieved to have poured out my feelings! I finally felt that it was all behind me and I could move on.

Sing Dee: I thought I had been a good listener and supporter to other women with breast cancer, but through the workshop, especially through the role-play, I discovered that I hadn't been one. I had merely tried to sell them my personal coping strategies. I need to consciously listen to their feelings - which aren't normally overtly expressed so I might have to piece them together like a jigsaw puzzle. From there, I give them relevant information, empathise with their emotions and needs and just be a supportive friend.



I am not here to solve their problems or make decisions on their behalf.

Catherine: I realize that when I listen, women will tell me everything, they will pour out all feelings, they may cry. But when I start talking, they zip up and retreat into their shell. I used to talk a lot when I visited them, thinking that by talking, they would feel my friendliness and be put at ease. Now I learn to shut up and just listen. As RTR volunteers, we might even have unresolved issues that we have harboured for decades. We should deal with those issues and put them behind us. Nonetheless, we are all weak in some ways, and by recognizing our own weaknesses, we identify well with the newly-diagnosed who need our support to deal with their crisis.

Submitted by: Boon Lui,
Committee Member, SBCSG
(Sarawak Breast Cancer Support
Group), Kuching, Sarawak.



2014 | DEC
3-6
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RRI demonstrates leadership on refresh of the UICC World Cancer Declaration



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Secretary, International Psycho-Oncology Society
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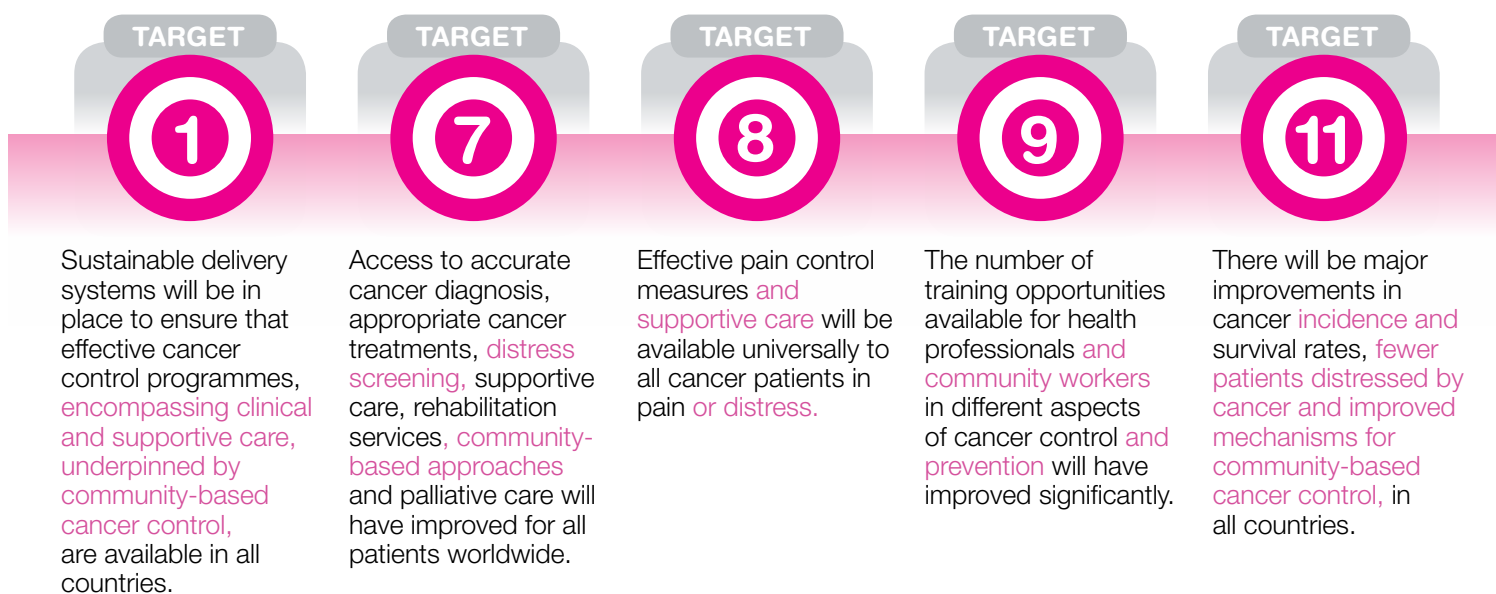
As some Bloom readers will know, the Union for International Cancer Control (UICC) recently announced a refresh of the World Cancer Declaration, seeking input from UICC Member Organisations such as Reach to Recovery International.

RRI works in partnership and collaboration with cancer control organisations such as the UICC to deliver on the RRI mission and accelerate work towards attainment of the World Cancer Declaration (WCD).

RRI was pleased to provide input to the current

review, upholding our commitment to improve quality of life for those affected by breast cancer.

The RRI submission urged the UICC to recognise the importance of supportive care and community-based cancer control by rewording selected WCD Targets, as follows:



RRI also recommended the creation of an additional stand-alone Target 12: Improve psychosocial and supportive care and distress screening and management.

In relation to the WCD Priority Actions, RRI recommended the clear expression of relevant priorities for supportive care and community-based cancer control.

Our suggestions strive to underpin multi-disciplinary care, including supportive and community-based cancer control, in order to address the unmet clinical and supportive care needs of cancer patients.

Equally importantly, RRI's submission suggested a focus on peer support initiatives that contribute to prevention and cancer management strategies, with emphasis on patient-centred care and appropriate health education.

These recommendations recognise that community-based cancer control and peer support can significantly ease the psychosocial and cost burdens of cancer.

In the area of cancer prevention and early detection, RRI advocated for specific emphasis on community-based cancer control, including distress screening and peer support.

Our submission further suggested that priority should be given to research and training for workers involved in community-based cancer control, to enhance prevention and early detection strategies that engage the whole community in cancer control.

At the same time, RRI reiterated that population-wide health education could be strengthened through community-based cancer control so

that health and lifestyle risk factors are efficiently and cost-effectively addressed at a population-wide level.

In the area of cancer treatment, RRI recommended the integration and translation of psycho-social research as well as clinical research, and the strengthening of collaborations between health agencies and organisations engaged in community-based cancer control.

In parallel, RRI's submission endorsed the recommendations put forward by the International Psycho-Oncology Society (IPOS) to improve WCD recognition of the IPOS International Standard in Quality Cancer Care, which treats distress as the 6th vital sign in cancer care.

For more information, visit www.ipos-society.org and www.uicc.org.

Global Kitchen



The Paku Fern has the following Botanic and common English names:

Botanic name:
Athyrium esculentum
English name:
Fern, Fiddlehead

Welcome to Global Kitchen, where we feature exotic recipes and home cooking from cultures around the world.

If you have a recipe to share, please email info@reachtorecoveryinternational.org

Paku Fern Salad Recipe

Ingredients

- 1 bunch of Paku Fern (about 300gm - pick only the tender leaves & shoots)
- 1 red chilli – shredded
- 1 carrot – shredded
- 1 big onion – sliced thinly
- 3 shallots – sliced thinly
- 1 stick of lemon grass – sliced finely
- 1 stalk of torch ginger bud (chopped finely)
- 2 tablespoon of crispy fried anchovies

Dressing

Mixed well

- 3 tablespoon Kerisik (toasted shredded coconut)
- 1 tablespoon palm sugar
- 2 tablespoon light soya sauce
- Juice of 3 Calamansi (lime)
- 3 chili padi (pounded)
- 2 tablespoon dried prawn (pounded)

Method

Step 1

Blanch the paku fern and shock them in iced water. Once cooled, toss dry.

Step 2

Toss and mix the dressing with all the ingredients in a large mixing bowl. Ready to serve.

This recipe was submitted by Sarawak Breast Cancer Support Group, Kuching, Sarawak.



Join Reach to Recovery International!



The Reach to Recovery International (RRI) Network seeks to improve the quality of life for women with breast cancer and their families by nurturing volunteer peer support and promoting other services to meet their needs, such as advocacy and consumer involvement in research. RRI is a program of the Union for International Cancer Control (UICC) and is administrated by Cancer Council Queensland.

Reach to Recovery International membership is open to organisations and groups that offer support to breast cancer survivors through peer support, advocacy and consumer involvement in research, and to individuals interested in the activities of RRI. Membership is free of charge.

To join, simply visit the RRI website and complete the membership application!

www.reachtorecoveryinternational.org

Benefits for Member Organisations include:

- Inclusion in the RRI global network
- Use of RRI Member logo on request
- Inclusion of Member organisation name, logo and link on RRI's website
- A certificate recognising the organisation's commitment to RRI's Guiding Principles and Membership Code of Conduct
- Letter of support for special occasions from the RRI President
- Quarterly Bloom e-newsletter and other RRI news

Note: RRI Membership guidelines have recently been updated. All previous RRI member organisations need to reapply to ensure their membership is valid. EXE002_0313



Aboriginal and Torres Strait Islander women's cancer awareness



Over the last six years Cancer Australia has undertaken a large body of work focused on one of the most deadly diseases for Aboriginal and Torres Strait Islander women: breast cancer.

Breast cancer is the most common cancer experienced by Aboriginal and Torres Strait Islander women and is the second leading cause of cancer death after lung cancer. Survival rates are lower for Aboriginal and Torres Strait Islander women diagnosed with breast cancer than for non-Indigenous women.¹

Compared with non-Indigenous women, Aboriginal and Torres Strait Islander women are also less likely to complete treatment for breast cancer and face a number of barriers to optimal care and treatment.²

To address this disparity, Cancer Australia has been consistently working to raise Aboriginal and Torres Strait Islander women's awareness and knowledge of breast cancer. 'Well Women Workshops', which have been running since 1997, are one component of work dedicated to improving breast cancer outcomes for Aboriginal and Torres Strait Islander women. They are run as part of a sustainable community engagement

approach designed to get Aboriginal and Torres Strait Islander women talking about breast cancer. The workshops operate at a community level with local Aboriginal and Torres Strait Islander health workers playing a key role.

"The Well Women Workshops help women understand the importance of early detection in surviving breast cancer, how to identify breast symptoms, and the importance of having any breast changes investigated," said Cancer Australia CEO, Prof Helen Zorbas. "They also help local communities understand the role of mammographic screening in reducing death from breast cancer."

Since July 2010, Cancer Australia has provided grants enabling 55 Well Women Workshops to be held by trained facilitators, using materials developed by Cancer Australia. As a result, 1,154 Aboriginal and Torres Strait Islander women have been provided with breast awareness and early detection messages. The initiative has had a successful impact on women's knowledge and behaviour with 92 per cent of respondents who had participated in the workshops saying they will make a change in their lives to reduce their risk of breast cancer.

Primary Health Care Nurse with Murrumbidgee Medicare Local Limited, Judy Reid, has delivered three workshops, two last year in the communities of Brungle and Hay and

one earlier this year at Lake Cargelligo. "The workshops are a great way to deliver health promotion in the Aboriginal and Torres Strait Islander communities. The resources are culturally appropriate and allow women to informally discuss breast cancer issues among themselves, and discuss breast cancer with health workers," said Mrs Reid.

"By starting a conversation and providing a flexible environment for discussion, they really help raise awareness about breast cancer. A central part of the success of the Well Women Workshops is spreading the awareness message. We hear a lot of participants say they would share the information they had learned in the workshops with family and friends," said Mrs Reid.

The workshops also benefit organisations involved in delivering health services. "It gives them the opportunity to learn about local barriers to the uptake of key breast awareness messages, enhances local health workers' breast cancer knowledge, and builds capacity for non-Indigenous specific organisations to work with Aboriginal and Torres Strait Islander communities," said Mrs Reid.

¹ Australian Institute of Health and Welfare Cancer Australia. Breast cancer in Australia: An overview, 2012. Cancer series no. 71. Cat. No. CAN 67. Canberra: AIHW.

² Valery P, Coory M, Stirling J, Green A. Cancer diagnosis, treatment, and survival in Indigenous and non-Indigenous Australians: a matched cohort study 2006. *The Lancet*, Volume 367, Issue 9525:1842-1848.

Unavailability of Herceptin reflects inequality in breast cancer care

Cathy Hirsch

A prime example of inequality in breast cancer care is reflected by the availability -- and unavailability -- of the drug trastuzumab, sold under the brand name Herceptin.

According to the World Health Organization, 1.38 million women worldwide were diagnosed with breast cancer in 2008, and that number is expected to climb to 2.7 million by 2030. At this time, the majority of breast cancers occur in low- and middle-resource countries. It's believed that 17 to 30 percent of all breast cancers are HER2-positive. HER2-positive tumors are generally more aggressive than HER2-negative tumors and are less responsive to standard chemotherapies. Studies have conclusively established, however, that trastuzumab in combination with standard chemotherapy significantly improves overall survival and disease-free survival in HER2-positive women with early and locally advanced breast cancer. Moreover, it increases the overall survival rate in patients with metastatic disease by at least 20 percent at a median follow-up period of 30 months.

Despite its proven efficacy, trastuzumab is unavailable in more countries than it is available. It is currently registered for

sale in only 88 countries. For that reason, Reach to Recovery International's parent organization, the Union for International Cancer Control (UICC), called upon the World Health Organization (WHO) in January of this year to add trastuzumab to its Model List of Essential Medicines. WHO's internationally recognized Model List is designed to guide countries in choosing how to address their health priorities. In a 27-page proposal to WHO, the UICC acknowledges that trastuzumab, currently produced and sold as Herceptin by Genentech/Roche, may "appear unaffordable" to some low-and middle-resource countries, but expresses its conviction that adding the drug to the Model List will "serve as a vital lever in expanding access to [the] medicine and in making [it] affordable." According to the UICC, it would open the door "to actions by governments to overcome patent barriers -- actions that were used to expand access to drugs for HIV/AIDS -- and to measures that address the need for efficient regulatory pathways for approvals of less expensive

biosimilar/biogenic products." The UICC further points to "the proliferation of chronic care centers in resource-poor settings that include testing, follow-up[,] and provisions for chemotherapy, as well as innovations in treatment delivery that could support and enable the delivery of trastuzumab to patients worldwide."

In April, the 19th Expert Committee on Selection and Use of Essential Medicines met at WHO headquarters in Geneva. The committee did not reach a final decision on the matter but instead ordered an "urgent review" of the entire section of the Model List pertaining to cytotoxic and adjuvant medicines. Under the committee's direction, the review will "require the identification of the treatable public health relevant tumors in adults, and the identification of the medicines required to treat those tumors, considering a stepwise development of cancer care systems in the overall context of health system development." A final decision from WHO is expected within the next few months.

(The information contained in this article is summarized from the UICC's Proposal for the Inclusion of Trastuzumab in the WHO Model List of Essential Medicines for the Treatment of HER2-Positive Breast Cancer, Jan. 14, 2013, and supporting documents, as well as the Executive Summary of the 19th Expert Committee on Selection and Use of Essential Medicines, http://www.who.int/selection_medicines/committees/expert/19/EC19_Executive_summary_Final_web_8Jul2013.pdf.)

Survivor Spotlight



Shirley Bianca is a breast cancer survivor and artist. After her breast cancer treatment, she began experimenting with colours and shapes on canvas. As a result of these experiments, she created a series of paintings called "Message of Hope" using gouache and oil paint. The series expresses the myriad of emotions she experienced after being diagnosed with breast cancer in 2000. Shirley invites you to share her paintings and message through a unique presentation.

[Click to see the artworks!](#)

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Events

Rotterdam, The Netherlands

[15th World Congress of Psycho-Oncology and Psychosocial Academy](#)
4 – 8 November 2013
Go to: www.ipos-society.org/ipos2013

Lisbon, Portugal

[ABC2 – Advanced Breast Cancer](#)
7 – 9 November 2013
Go to: www.abc-lisbon.org

Orlando, Florida, USA

[C4YW – Annual Conference for Young Women Affected by Breast Cancer](#)
21 – 23 February 2014
Go to: www.c4yw.org

Melbourne, Australia

[2014 World Cancer Congress](#)
3 – 6 December 2014
Go to: www.worldcancercongress.org

Our mission

[Reach to Recovery International](#) is built on a simple yet universal principle: a woman who has lived through breast cancer and gives of her time and experience to help another woman confronting the same experience is a valuable source of support. [Reach to Recovery International](#) is committed to working to improve the quality of life for women with breast cancer and their families through a wide range of services offered worldwide.

To contact RRI please email info@reachtorecoveryinternational.org or visit the website. The material published in Bloom does not necessarily express the views of RRI but is provided for the information of readers.

