

bloom

Issue
16
May
2013

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.



Reach to Recovery International Welcomes a new President

Welcome to the latest edition of Bloom and the first edition with Cathy Hirsch as the new President of RRI.

Cathy's appointment marks the beginning of the next phase of growth for Reach to Recovery International (RRI) and the end of a highly productive period for RRI, with the retirement of lifelong RRI advocate and now immediate Past President, Ann Steyn.

The RRI Board of Management is delighted that Cathy has accepted the voluntary role of President and extends its deep thanks to Ann for her contribution and commitment to the work of RRI.

Cathy is an attorney and breast cancer survivor from Baltimore, Maryland, in the United States. Prior to taking up the RRI Presidency, she was a member of RRI's International Advisory Committee. Cathy is also the founder and President of *Within Reach*, a non-profit foundation and program partner of the American Cancer Society providing Reach to Recovery

services to breast cancer patients in the Baltimore area.

Cathy's personal experience with breast cancer and her vast experience in supporting other women through community-based programs and volunteering make her suitably skilled to serve RRI's foundation principle, that 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.

Ann Steyn announced the appointment at the 17th *Reach to Recovery International Breast Cancer Support Conference* in South Africa earlier this year, a successful summit that is highlighted in this edition of Bloom.

I look forward to working with Cathy and the RRI Board of Management to continuing our global work to improve supportive care for women affected by breast cancer.

We are motivated by the awareness that the scale of our challenge continues to grow, with an estimated 1.5 million women who are affected by breast cancer each year.

I would once again like to thank our former President, Ann Steyn, for her efforts to establish RRI as one of the world's leading peer support services for women affected by breast cancer.

I have every confidence that Cathy will continue the work of RRI, growing our reach through direct connection with the women and communities who are impacted by the disease.

This includes the readers of Bloom, who are vital to our connection. Thank you once again for your support.

Jeff Dunn
Chair, RRI Board
of Management

New RRI Membership

RRI's new membership guidelines have just been released! Existing and new members must reapply now using our easy online form.

[Click here to apply!](#)



Contents

- 04 Pink Ribbon Survivors Network
- 05 The Transformation of Internet Interventions
- 07 Connecting, learning, supporting
- 08 Cancer Experience Registry
- 08 Overcoming Cultural Barriers
- 09 E-health and digital support: is this the future?
- 12 RRI 2013 Conference Highlights
- 13 A tribute to Terese Lasser
- 15 Global Kitchen
- 15 Join Reach to Recovery International

Email your bloom submissions!

The theme of the next edition will be *Human Rights and cancer care*. Submissions close 19 July 2013. Please send submissions in Microsoft Word format with any photos to info@reachtorecoveryinternational.org

bloom

Issue 16, May 2013.
Bloom is published by Reach to Recovery International. Contributions to Bloom are welcome, please email info@reachtorecoveryinternational.org. For more information about RRI, go to www.reachtorecoveryinternational.org.



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.



Message from Cathy Hirsch

President of Reach to Recovery International

The theme for this issue is E-Health and Digital Support: Is this the Future?

In this edition of *Bloom*, we examine the impact of internet technology on addressing the breast cancer burden. As the newly-appointed President of Reach to Recovery International, I am delighted that my first message to you introduces a topic that promises significant results.

Just a generation ago, any woman anywhere in the world who received a diagnosis of breast cancer had to rely almost exclusively on her health care providers for information. Health care providers were the gatekeepers of information about surgeries, treatments, side effects, staging, and prognoses. Patients looked to them for guidance on what to eat, how to exercise, and where to find prosthetics. An educated woman with access to a well-stocked library or bookstore might have gleaned answers on her own, but only with great effort and inconvenience.

With the explosive growth of the internet and related technologies, all that has changed. In many parts of the world, a savvy breast cancer patient with a computer, tablet, or smart phone can now access countless articles, applications, and tools to help guide her on her breast cancer journey. Health care providers are benefitting as well, with new technology making it easier for them to gather and track information and to streamline practices.

Researchers at the University of Virginia School of Medicine are studying "internet interventions" designed to allow patients to deal with certain health issues simply by logging on to their computers and following simple instructions. In their article on this ground breaking work, Dr. Lee

Ritterbrand and Dr. Frances Thorndike reveal the promising results of an internet intervention involving cancer survivors who were suffering from insomnia. They suggest that similar interventions can be developed to help cancer patients and survivors in a multitude of ways. (Page 5 - 6).

LIVESTRONG's Naveen Rao surveys the vast array of technological developments that have emerged in the last decade and examines how these new tools can provide patients with information and can empower them to communicate more effectively with health care systems. Dr. Rao credits technological innovations with spurring the health care industry toward modernization. (Page 9 - 11).

We also hear from Dr. Rama Sivaram of the HEAL Consultancy of Pune, India, who shares her unique perspective as a breast cancer survivor who learned to embrace the digital age in order to communicate more effectively with both health care professionals and patients about breast cancer. Dr. Sivaram suggests a plethora of ways the new technology can be used efficiently and effectively in the war on breast cancer and stresses the importance of patients being not just "literate" but also "eliterate." (Page 7).

The Pink Ribbon Survivors Network of Colorado has developed a free, online educational library that provides educational tools for health care providers as well as information and resources for breast cancer patients. The Network's co-founders, Kelly Adams and Dr. Robert Fisher, report that their online library is the first centralized source of breast care literature for professionals. (Page 4).

Email: cathyhirsch@reachtorecoveryinternational.org



Cathy Hirsch

Another first-of-its-kind resource is being developed by the US-based Cancer Support Community. Joanne Buzalgo, PhD, discusses that organization's "Cancer Experience Registry," which is designed to learn more about the unique needs of people who have experienced breast cancer and metastatic breast cancer. (Page 8).

Also in this issue, Pink Ribbon Pakistan CEO Omer Aftab discusses cultural barriers that prevent women in Pakistan and other parts of the world from educating themselves about, and seeking treatment for, breast cancer. He shares some success stories from his organization's ongoing campaign to break down those barriers. In addition, we'll introduce a volunteer with Portugal's *Vencer e Viver* who is truly unique among that movement's peer support volunteers. (Page 8).

Preparations are underway for the next Reach to Recovery International conference to be held in 2015. Please continue to read *Bloom* and check our website for the latest developments.



Message from Ann Steyn

Immediate Past President of Reach to Recovery International 2007 - 2013

Dear RRI Volunteers, Survivors, Sisters, Friends!

Thank you so much for the love and support you have given me over the past six years. It has been an honor and privilege being your RRI President. With your support RRI has taken root in new countries, the programme has grown to encompass all aspects needed to carry out our Mission Statement – advocacy, education, as well as supportive care.

My abiding memory will be of meeting incredible women doing amazing work – I salute you and wish you well in your future endeavours

I am delighted that Cathy Hirsch is the new RRI President. With her warmth and experience she will do a great job. I am sure I speak for all of you when I say that we are looking forward to the new chapter that she is opening for RRI. Welcome Cathy!

Navigation Breast Cancer Survivorship



By Kelly A. Adams, BA and Robert E. Fisher, MD Co-founders of the Pink Ribbon Survivors Network

In the past several decades, the number of cancer survivors has increased dramatically as a result of improved early detection and effective treatments. Currently, there are more than 13 million cancer survivors in the United States¹, about 2.9 million² of which are breast cancer survivors. The number of cancer survivors is expected to reach 18 million by 2022³. This data highlights the growing scale of cancer survivorship and the importance of efforts to address the health and psychosocial concerns of cancer survivors and educate the primary care providers who take care of these patients.

With new breakthroughs in treatment, the follow up of breast cancer survivors has become ever more complex. Women completing their breast cancer treatment need access to information and resources to help navigate survivorship as well as an informed primary care physician for their long term follow up care. Noting the importance of providing cancer survivorship online resources, **The Pink Ribbon Survivors Network**, a non-profit organization of Colorado

Cancer professionals, has created an online educational library to address this need for medical education. Founded in 2011 by cancer care professionals in Colorado, the organization has developed a free, online website that summarizes clinical knowledge regarding breast cancer follow up care for primary care physicians. The website also has a “Curriculum for Recovery Library” to assist breast cancer survivors in finding information and resources, and provides cancer care professionals with the first ever multi-disciplinary virtual library devoted to breast cancer survivor clinical research.

The organization provides educational tools for primary care providers in the community, clinical literature which fosters multi-disciplinary care among oncology professionals, and a comprehensive listing organizations and relevant literature to assist breast cancer survivors in navigating survivorship and begin their healing and recovery. With an online library of 15 categories, this resource has collected hundreds of publications relevant to the long term care of breast cancer survivors. Topics on the website library include nationally recognized guidelines for follow up care, hereditary/genetic issues of breast cancer occurrence, cognitive effects of treatment, gynecologic issues of survivorship, and lifestyle interventions to

advise for patient recovery. The website also offers an online multi-disciplinary cancer professional library devoted to breast cancer survivorship issues.

Previously, oncology professionals, including physicians, nurses, social workers, and navigators, had no centralized source for professional literature covering breast cancer survivorship topics. With the launch of the Pink Ribbon Survivors Network website, we have provided such a comprehensive virtual library and an environment to exchange information and foster multi-disciplinary care.

Bringing together medical information technology, innovative thinking, and a desire to reach out to improve the quality of life for breast cancer survivors; this is the mission of The Pink Ribbon Survivors Network. www.PinkRibbonSurvivorsNetwork.org.



**PINK RIBBON
SURVIVORS
NETWORK**

COMMUNITY
EDUCATION
RECOVERY
GROWTH

¹ Siegel R, DeSantis C, Virgo K, et al. 2012. Cancer treatment and survivorship statistics, 2012. CA Cancer J Clin 62:220-241.

² <http://www.cancer.org/cancer/breastcancer/overviewguide/breast-cancer-overview-key-statistics>

³ Ganz PA, Kwan L, Somerfield MR, et al. 2006. The role of prevention in oncology practice: Results from a 2004 of American Society of Clinical Oncology members. J Clin Oncol 24:2948-2957.

The Transformation of Internet Interventions

The Internet has transformed the world. This is not hyperbole given that almost 2.5 billion people have already used the Internet to learn, communicate, share, interact, watch, read or play.

The impact of the Internet, however, is arguably most profound in the area of health. More than 70 per cent of those who use the Internet have searched for health information(1). The majority of these health-based websites provide simple, text based information. However, a growing number of websites are taking full advantage of all the Web has to offer by providing interactive, tailored, engaging interventions to address a wide range of behavioral and mental health problems. These “Internet interventions”(2) are being developed and evaluated by researchers around the world with great success (see <http://www.isrii.org>). They operationalize face-to-face therapies and deliver them as adjunctive care or stand-alone programs. This work has evolved into a new field called eHealth that includes not only Internet interventions, but an extensive array of emerging technologies and their use in the provision of health care. The ground breaking work being conducted addresses a primary issue

that poor health outcomes are often the result of lack of access to care. Barriers to care are caused by many factors, including a limited number of specialty providers; location of these providers; and expense. But the Internet can readily overcome many of these barriers.

The Behavioral Health and Technology (BHT; <http://bht.virginia.edu>) Laboratory at the University of Virginia in the School of Medicine was one of the first labs to focus exclusively in this area of eHealth generally, and Internet interventions specifically. The research being conducted there started in the mid-to-late 1990s, when this type of work was rarely undertaken and seen by many as unlikely to catch on, and continues to help lead the path forward.

Although the research being accomplished at the BHT lab is not exclusive to cancer, a significant number of projects are cancer focused. The first cancer-based research trial at the BHT lab focused on the particularly problematic issue of sleep and the experience of insomnia in cancer

survivors. In 2004, the BHT team began working on the development and testing of an Internet intervention for insomnia for adults with primary insomnia, called SHUTi (Sleep Healthy Using The Internet) (3). However, learning that as many as 63 per cent of cancer survivors experience sleep difficulties and more than 30 per cent meet diagnostic criteria for insomnia – a rate that is two to three times higher than that of the general population – it was clear that cancer survivors had a particularly acute need for this intervention. To test SHUTi with cancer survivors, a study was supported by the University of Virginia Cancer Center through the Mary Semmes Scripps Fund for Integrative Medicine and based on funds from the National Institute of Mental Health (Grant R34MH70805). Twenty-nine cancer survivors were recruited to participate between July 2008 and July 2009 – and the results were impressive: Those who received the Internet intervention experienced significant reductions in the severity of insomnia, the amount of time awake when in bed, the length of time it took to fall asleep, and general fatigue, as well as



improvements in the soundness of their sleep and feelings of restoration when waking(4). These promising results have already led to additional and upcoming trials to further test this and other Internet interventions with cancer survivors.

Although the trials conducted by the research team at the BHT lab are resulting in exciting outcomes, a significant problem ensued: How do we make these programs available to individuals once the trials end? While some governments around the world are providing strong support for this low-cost but highly effective approach (with the Australian government one of the strongest), many places do not provide the necessary financial support needed to establish and maintain Internet interventions and other eHealth programs. Even in places where there is current financial support, the long term future is uncertain. As a way to address this, investigators at the BHT lab helped create a company (<http://www.behealthsolutions.com>) to offer empirically validated interventions to end users through a variety of channels without depending on government support for maintenance and provision of services. SHUTi, for example, is now available for a fee directly to individuals (<http://www.shuti.me>), but arrangements are also being established to make it and other programs like it available through insurers, employers, clinicians, clinics, wellness programs and more.

One particularly remarkable, and unexpected, side effect of this work is the enthusiasm expressed by other researchers from around the world, most notably in Australia, who want to use the infrastructure that has been developed as part of the creation of SHUTi and other BHT developed interventions. Interestingly, much of this new work is

SHUTi, for example, is now available for a fee directly to individuals (<http://www.shuti.me>), but arrangements are also being established to make it and other programs like it available through insurers, employers, clinicians, clinics, wellness programs and more.

happening in the field of cancer. For example, development and testing is underway through collaborations with H. Lee Moffitt Cancer Center in Florida to develop an Internet intervention to help patients better cope during chemotherapy. BeHealth is also working with Fox Chase Cancer Center in Philadelphia to create a skin cancer prevention program for young adults. Many other projects, including those focused on melanoma and breast cancer, are expected to begin in the coming year with colleagues from the US and Australia.

This is an exciting time for innovative research given the rapid pace of technology improvements, but it is particularly exciting for oncologists, cancer survivors, clinicians, and care givers. Researchers are pushing the boundaries as to how to bring effective treatments to countless people who would otherwise be unable to receive them.

References

1. Fox, S. (2013). Pew Internet: Health. Washington, DC: Pew Internet & American Life Project. Available from: <http://www.pewinternet.org/Commentary/2011/November/Pew-Internet-Health.aspx>.
2. Ritterband, L. M., Gonder-Frederick, L. A., Cox, D. C., Clifton, A. D., West, R. W., & Borowitz, S. M. (2003). Internet interventions: In review, in use, and into the future. *Professional Psychology: Research and Practice*, 34(5), 527-534.
3. Ritterband, L. M., Thorndike, F. P., Gonder-Frederick, L., Magee, J. C., Bailey, E., Saylor, D. K., & Morin, C. M. (2009). Efficacy of an Internet-based behavioral intervention for adults with insomnia. *Archives of General Psychiatry*, 66(7), 692-698.
4. Ritterband, L. M., Bailey, E. T., Thorndike, F. P., Lord, H. R., Farrell-Carnahan, L., & Baum, L. D. (2012). Initial evaluation of an Internet intervention to improve the sleep of cancer survivors with insomnia. *Psycho-Oncology*, 21(7), 695-705.

Authors: Drs. Lee Ritterband and Frances Thorndike are faculty of the Behavioral Health & Technology lab at the University of Virginia School of Medicine in the Department of Psychiatry and Neurobehavioral Sciences. They also co-founded BeHealth Solutions, LLC, a company dedicated to increasing public access to evidence-based Internet delivered health interventions, including SHUTi (Sleep Healthy Using The Internet), a program for insomnia; and BeStudy Manager, an online platform to allow more rapid and efficient development of Internet delivered interventions. Dr. Ritterband is an Associate Professor and Director of the BHT lab as well as VP of Research and Development at BeHealth Solutions. Dr. Thorndike is a Clinical Psychologist and Assistant Professor in the BHT lab and the Chief Science Officer of BeHealth Solutions.

Volunteer Spotlight



Agostinho Cruz Branco was diagnosed with breast cancer in February 2011. He found a lump in his left nipple and his doctor confirmed cancer after a biopsy. It was very difficult for him to accept his diagnosis as he always thought that cancer would happen to somebody else and not to him. After surgery and treatments he was contacted by Ercilia Cardoso (coordinator of Vencer e Viver movement in the North of Portugal), who invited him to be volunteer.

At first he refused but then thought that perhaps he could be helpful in offering support to other men with same problem and accepted the invitation.

Today he is a very active and involved volunteer with Vencer e Viver, very happy to give support not only to other men, but also to the family members who often suffer alongside patients.

Submitted by: Vencer e Viver movement, North Portugal Region

Connecting, learning, supporting – ‘e-Health and digital support: is it the future?’

Rama Sivaram, Indian breast cancer survivor, shares her thoughts.



As a survivor of five years, I am lucky. I have an education, finances, a supportive family and friends, all of which have helped me adjust and cope. More importantly,

I have been able to consider what we as individuals and survivors of breast cancer can do to serve others using e-health and digital support.

My diagnosis prompted me to befriend the internet. I learnt about myself and the gaps between my knowledge and practice. I explored a range of issues to try and answer all the questions arising from my diagnosis, and found a wealth of information available on different things:

- Basic cancer information especially regarding breast cancer
- Life after cancer
- Available services and skills
- Differing schools of thought with respect to surgical procedures and preferences and chemo-radiation therapies
- My right to and a second opinion
- My patient rights to information about treatment choices
- Choice versus trust
- Treatment protocols
- Psycho-social impacts
- Survivorship and support groups
- Capacity building
- Connecting to professionals, patients and advocates through select social networking sites.

As a result of my search, I am a more optimistic survivor, with better health seeking behavior and a better quality of life. I am also a more committed advocate, community educator and counsellor, because of the depth of knowledge gained.

So, not only am I just lucky, I am lucky to be literate, and to have access to information technology. In my own country of India, I have tried to put my

literacy to good use in order to help other women. Some of the following suggestions for e-support might be relevant to women in other countries who also read Bloom:

- Establish interim mobile counselling for diagnosis and side effects of treatment, if face-to-face counselling isn't an option.
- Send SMS reminders for a breast self-exam or check-ups and medical appointments.
- Send a regular educational reminder via SMS about breast cancer awareness and action.
- Share online resources with other women and groups.
- Create of mobile groups to provide help and support.

- Create of a micro-website to unite women in your group who are active online.
- Write a blog about your own experience and what worked and didn't work for you.
- Create of issue-specific discussion groups on social networking sites, such as TNBC or ER/PR, HER2 neutral groups.
- Search for the latest peer-reviewed research and stay updated of developments in knowledge and understanding of breast cancer.

There are so many things we can do online, building our connection through Bloom!



Cancer Experience Registry

Cancer is more than just treating the tumor – there are often emotional and social challenges to overcome as well. The Cancer Support Community (CSC), an organization providing high-quality emotional and social support through its international network of local affiliates, satellite locations and online, has launched a global registry that will help the cancer community better understand the social and emotional needs of people living with a diagnosis of cancer. The Cancer Experience RegistrySM (CER), is a first-of-its-kind initiative collecting the experiences of people sharing their cancer journey by answering a series of questions online and will connect them to a network of support and resources. The registry is designed to learn more about the unique needs of people who have experienced breast cancer and metastatic breast cancer – the Cancer Experience Registry: Breast Cancer and the Cancer Experience Registry: Metastatic Breast Cancer.

“One thing that we have learned so far is that the experience is very different for people living with metastatic disease from those who have been diagnosed with less advanced disease. Frequently, the needs of people living with metastatic disease have been overlooked and the Cancer Experience Registry is an opportunity to raise awareness about the specific social and emotional needs of those living with metastatic disease. The findings from the Cancer Experience Registry will be used to inform innovative educational and support programs, policy and next steps in research” says Joanne Buzaglo, PhD, VP of Research & Training at the Cancer Support Community.

Participants have voiced the importance of sharing their experiences with one another, noting that *“You have just become a member of a very special group of people that no one ever wants to join. It can be a long, hard journey, but we are here to help you through in any way we can.”*

The Cancer Experience Registry provides an important vehicle for anyone who has ever faced a cancer diagnosis – whether just diagnosed, in treatment or years beyond treatment – to let their voices be heard. You are invited and encouraged to join the registry by visiting www.CancerExperienceRegistry.org.

The CER consists of questions that measure the social, emotional, spiritual and financial impact of cancer. After completing the questionnaire, individuals will be able to compare their responses with others in the breast cancer community. Information shared through the Cancer Experience Registry will remain anonymous and will be used to identify gaps in care, help develop innovative programming, and inform next steps in research and policy. The findings will be published in an Annual Index and will be available to the cancer community at large and to all people who take part in the Cancer Experience Registry.

Overcoming cultural barriers to secure social change

Pakistan is ranked 135th on Gender Development Index of 174 countries and ranks lowest in the South Asian region in terms of GDP per capita for women. It ranked 100 out of the 102 countries measured on the Gender Empowerment Measurement (GEM) 1999. The level of women’s health in Pakistan is among the lowest in the world, according to a World Bank report. In the conservative society of Pakistan, women cannot dare to say anything about the female breast in the public domain or even in private. On top of that, the increasing radicalization of the conventional Pakistani society makes it difficult to talk about breast cancer awareness, the single largest cause of death for women in Pakistan.

In 2001, the situation towards breast cancer was so critical that the word “breast” was considered vulgar on state TV and there was no concept of a discussion on awareness. This is why in 2003, Pink Ribbon Campaign was launched. Pakistan has the highest rate

of breast cancer in whole of Asia where one in nine women is at the risk of a breast cancer diagnosis, accounting for 40,000 deaths every year. Dismally low public spending on health and a strictly traditional society collude to worsen the impact of breast cancer in Pakistan.

The campaign has used a top-to-bottom approach with focus on public-social-private partnerships. The successful advocacy interventions of the campaign resulted in signing agreements with federal and provincial ministries to include breast cancer in reproductive health packages and ban taxes on the import of all drugs and tests related to breast cancer. Launch of nationwide Youth Awareness Program in partnership with Higher Education Commission and issuance of 500,000 commemorative stamps by Pakistan Post Office have also been successful results.

Through the Ministry of Health we have been instrumental in initiating a trial Cancer Registry and inclusion of a chapter on Breast Self-Examination in the

training manual of Lady Health Workers. We also succeeded in running a Free National Breast Screening Program in 14 cities with the support of government.

Pink Ribbon Free Public Service Messages on breast cancer awareness are now being run by all Cable TVs supported by Pakistan Electronic Media Regulatory Authority (PEMRA). Pakistani Prime Minister’s wife became the campaigns’ Chairperson for 2 years. We also hosted a six days visit of the wife of the British Prime Minister Mrs. Cherie Blair to Pakistan in 2006 in support of the campaign.

The impact of the campaign despite the numerous challenges has been significant as according to the statistics of Ministry of Health there has been a 30 per cent increase in patient turn-up at the Breast Clinics nationwide since 2004 when Pink Ribbon started its campaign in Pakistan.

By Omer Aftab, Pink Ribbon Pakistan
www.pinkribbon.org.pk

E-health and digital support: is this the future?

While healthcare has notoriously been a slow industry to innovate, the last decade has seen a number of trends emerge that are pushing the field toward modernization. Modifications include: far-reaching policy reforms to payment and delivery of care, rapid advances in enterprise and consumer technology, and changes to the health and demographics of the population, which are all playing a role in making a strong case for the use of new tools in health care.

These tools have been given a number of names, such as mHealth, digital health, ehealth, and telehealth. Although these sub-genres each have their own nuances, the central premise behind them is the same: Patients spend most of their time outside of the doctors' offices, so it makes more sense to arm them with the appropriate tools to help monitor, track, communicate, and learn about their own health conditions. The potential for this new wave of technology to transform the way health care functions is very evident in cancer care, which typically involves a high-touch, highly complex treatment journey for patients, caregivers, and health care professionals.

As for the tools themselves, they range from devices that track movement and location, to plug-and-play technology that turns a smartphone into a medical accessory, to a diverse range of apps and Web tools that can provide information enable better interaction with the health care system, make tracking medication adherence easier and much more.

One of the challenges, particularly in cancer care, is gauging the effectiveness of these tools' impact on improving patients' lives. To that end, the LIVESTRONG Foundation conducted a preliminary investigation into the current tools in the digital cancer care space have available to patients. The Foundation was also able to interview a colorectal cancer patient and survivor who has used several digital tools during his own treatment journey to understand how these tools can improve patients' lives.

Mobile and Web Tools Abound

In an analysis of publicly available cancer care tools, the LIVESTRONG Foundation catalogued 103 web and mobile applications designed specifically for cancer patients. The research revealed a diverse set of offerings with

Table 1

Categories	Description	Examples
Get Help	A direct way for users to seek help and engage with treatment centers.	Clinical Research Trials Ask Dory
Reference	Educational resources about cancer-related issues, from diagnosis through treatment and beyond.	Cancer.net Breast Cancer Diagnosis Guide
Self-Management	Monitoring and tracking tools for treatments, appointments, medications, symptoms, self-exams, etc.	LIVESTRONG Cancer Guide + Tracker Cancer Coach
Safety/Prevention	Promote a healthy lifestyle and recommended behaviors in hopes of preventing cancer occurrence.	Cancer Risk Reduction SURVEYOR Health
Social Support	Communication and support groups for patients on the web. Many provide reference and educational information while also addressing psychosocial needs.	CancerCare.org The National Children's Cancer Society – Online Community



multiple features, formats and target audiences. The tools were found through a combination of Web searches and literature review; general trends were analyzed to investigate the characteristics of currently available resources.

- Of the 103 tools in the analysis, 41 were Web-based and 54 were mobile applications available through the iOS and Android platforms
- Five major types of organizations were behind these resources: corporations, government agencies, nonprofits, delivery systems such as hospitals, and independent developers
- Resources fell into five major categories: get help, reference, self-management, safety and prevention, and social support (Table 1)

The availability of web and mobile-based support tools for the cancer community has steadily increased over the last five years, with more than 30 tools released in 2012 alone (Figure 1). As more tools are developed in the coming years, the overall quality of these resources should improve due to better technology, more engagement from patients, providers, and insurers, and similar innovation in other areas such as diabetes management or pre- and post-surgery tools.

Cancer care is expansive and includes a wide variety of patient needs, such as the tracking of numerous physician visits, managing doses, and the treatment of pain and other associated symptoms. As a result, cancer support comes in many forms—such as reference materials, referrals to healthcare providers, and psychosocial support. The areas addressed by currently available resources skewed heavily towards management tools and reference materials (Figure 2). The “get help” and “social support” categories had far fewer resources for patients.

Another such disparity exists in the audience of these resources, as the vast majority of tools address the needs of patients currently undergoing treatment (Figure 3). Patients in this

stage require tools to help manage their interactions with clinicians, track treatments, medication, appointments and monitor symptoms. The needs of post-treatment survivors, which can be equally burdensome in addressing late effects from chemotherapy, long-term side effects of radiation, post-operative complications from surgery, ongoing fear of recurrence and other psychosocial needs are hardly addressed by current offerings. Even though there is some overlap between different stages of the treatment journey, such as access to support communities and general informational resources, post-treatment survivorship is one area where additional tools and resources would be a welcome addition. The LIVESTRONG

The LIVESTRONG Survivorship Care Plan is one of the only tools currently available for patients and clinicians to address survivorship needs.

Survivorship Care Plan is one of the only tools currently available for patients and clinicians to address survivorship needs. Two key developments that could spur development in this area are the Office of the National Coordinator for Health IT’s (ONC-HIT) Meaningful Use program’s Stage 2 requirements that raise the bar for how many patients must receive digital information from their doctor, and the American College of Surgeons’ Commission on Cancer’s 2015 standards for patient centered care that require access to materials such as navigation, emotional distress screening, and a post-treatment summary and survivorship care plan.

The Patient’s Perspective

Analyzing the tools currently available on the market can provide some insight into the growing prevalence and reach of technology. However, limited data was available on the actual use and effectiveness of these resources by patients, caregivers, or survivors. In order to investigate how patients can adopt these technologies into their day-to-day experiences with cancer treatment, the LIVESTRONG Foundation conducted an informational interview with “R.” (name omitted to protect privacy), a colorectal cancer “e-patient” who has used a multitude of digital tools during his ongoing journey.

Figure 1

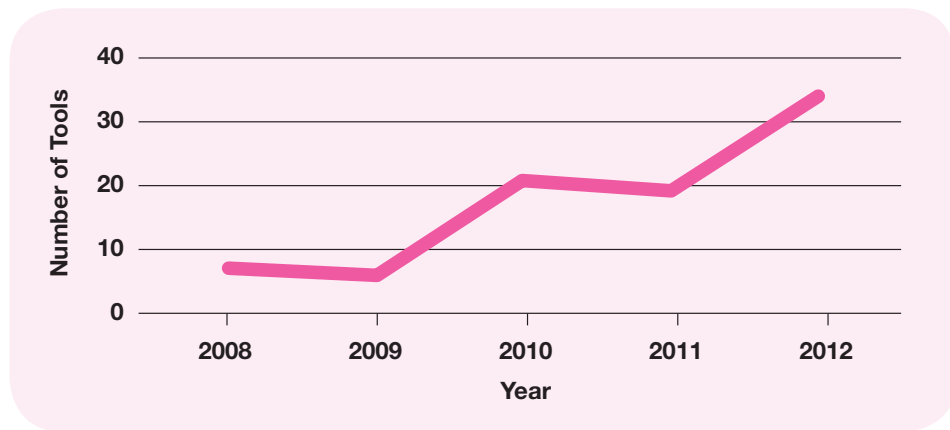


Figure 2

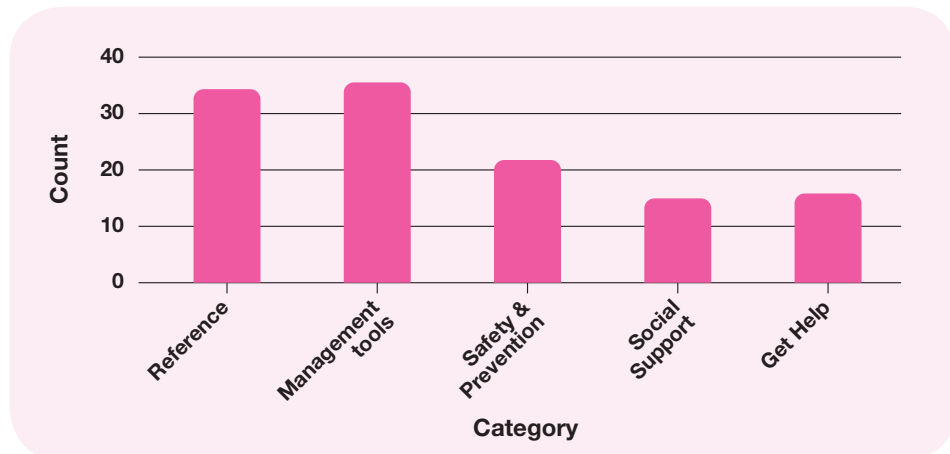
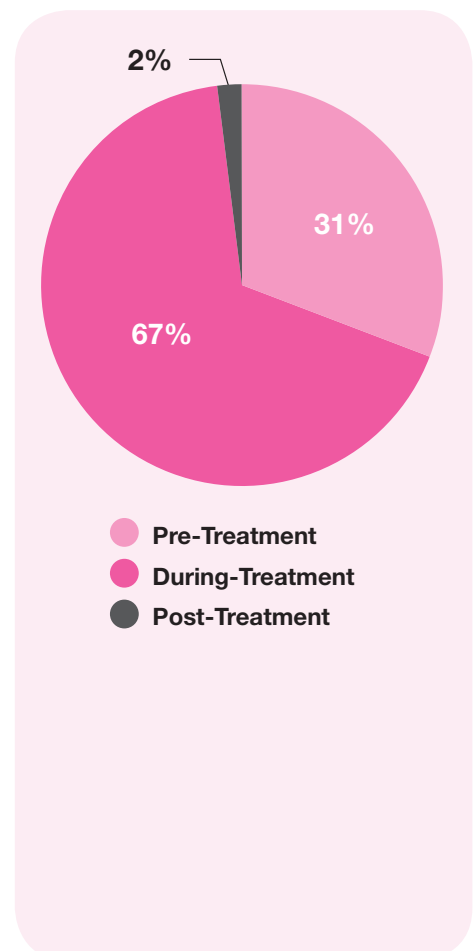


Figure 3



Initially given a prognosis of six to eight months to live, “R.” has been through four bouts of colorectal cancer over the last two and a half years, during which he has educated himself on the ins and outs of treatment, recovery, remission, recurrence. He has also mastered the self-navigation skillset required to juggle interactions between him, his doctor, his oncologist, his cardiologist, and other appointments including chemotherapy and radiation. He uses a variety of digital tools to manage his own care (Table 2).

In speaking with R., it becomes clear that the benefits of digital tools for patients have the potential to improve convenience, communication, and confidence for patients:

[Technology] has enabled me and my medical team to keep a consistent and constant view of my vitals. This helps to be ahead of issues that come up quickly, like getting a neutropenic fever, which I learned is likely to happen in the days after chemo. My point of view is that it's important to keep track [everything]... sometimes it involves medicine, and sometimes those medicines are leading edge or experimental. [In 2012] I went through a round of a particular chemo and had a very negative reaction to it, including dangerous hypertension. Keeping track of those vitals is important, since we don't have nurse access 24/7. I also like to keep track of emerging news that may affect me and my issues.

Probably the largest factor comes from the confidence of being informed. Especially early on in the cancer journey, one is dealing with a lot of unknown, and there is fear from that. On top of that you are sick, and don't necessarily know what you should be worried about. Keeping track of vitals; BP, temperature, and weight are all leading indicators to being in reasonable balance or the harbinger of issues that are coming. Being able to keep an eye on this provides a sense of stability to everyone, including yourself: "Am I OK? Is this normal?"

Is e-Health the Future?

"The future is already here, it's just not evenly distributed." – William Gibson

While “R.’s” experience illustrates the benefits and specific applications of digital health tools, he is the first to admit that his level of engagement is the exception and not the norm in today’s health care system. Most patients are still a few years away from active use of technology in their own care. He suggests that one thing that will help promote broader adoption of technology by cancer patients is the role of the doctor. Doctors are still unaware of the benefits that smartphone apps, medical devices, informational websites, and even basic



Table 2

Name	Description
iTriage	Smartphone app for diagnostic and medical information
ICE	“In case of Emergency” app to store personal medical information in an accessible format
Withings	Smartphone-compatible blood pressure, pulse, and weight monitoring tools; used mainly to manage and monitor hypertension
E-mail	Transmit Withings readings and other information to doctor via weekly e-mail
Calendar	Smartphone calendar to keep track of chemotherapy and other appointments
Social Media	Twitter, Facebook, and blogging to communicate with the broader cancer community; web and blog reading to gain knowledge for self-empowerment

communication through e-mail can confer on patients. Another challenge is that the sheer number of resources available can overwhelm patients and doctors alike when it comes to choosing and trying an app, a website, or other tool.

Despite these challenges, all signs are pointing forward for the continued growth of e-health in cancer care. The promise of the cancer tools profiled by LIVESTRONG Foundation centers on patient engagement and empowerment, a growing area of focus for health care organizations in light of a shift away from episodic care towards a more holistic approach. As options for patients to choose from increase, there are early signs that both the public and private sectors will be increasing their oversight and regulation to ensure quality and effectiveness. For example, mHealth company Happtique recently announced a certification program for health apps, and the Food and Drug Administration (USA) has announced it will issue guidance on mHealth this October.

If the year over year growth of available resources and the example of one patient serve as early indicators of the impact

these tools hold, then the next few years hold great promise for what lies ahead in digital health. The emerging challenges will be to measure the quality of these new resources, assess the impact they have on patients’ quality of life and health care outcomes, and make sure access remains relatively even across age, race, gender, and different disease stages and types. To this end, the LIVESTRONG Foundation has recently made substantial investments in a research collaboration that will develop and evaluate digitally integrated survivorship care plans, tools that empower patients with knowledge and actionable next steps in their post-treatment journey. It will take a concerted effort from all health care stakeholders – clinicians, oncologists, technology companies, regulators, insurers, and of course, the patient community – in order to fully realize the potential that these new technologies have to transform the way we care for cancer patients.

Written by Naveen Rao, MHS, Health Information Technology Manager at the LIVESTRONG Foundation.

www.livestrong.org.au

2013 RRI Conference Highlights



17th REACH TO RECOVERY INTERNATIONAL
BREAST CANCER SUPPORT CONFERENCE
20 – 22 MARCH 2013
CAPE TOWN
SOUTH AFRICA

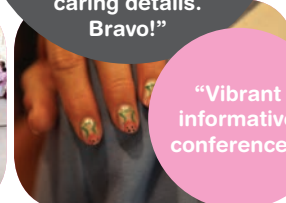


"One of the best conferences that I have attended in 15 years. Thank you for the most thoroughly organized event with special attention to caring details. Bravo!"

"Wide spectrum covering every aspect of the fight against breast cancer. Most informative on services rendered globally."



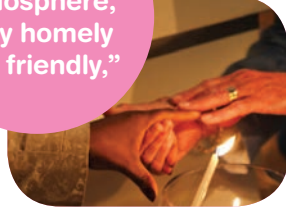
"Congratulations to the organising committee in making us feel so very welcome. Very well organized and a very lovely warm welcome to Africa"



"Vibrant informative conference."



"Topics were diverse and provided something for everybody."



"Wonderful atmosphere, very homely and friendly,"



"So much information of value, and so much food. Thank you for looking after us."



"A wonderful experience and lots of knowledge and new friends."



"This conference has been very good and there has been a lot to learn. I would like to attend such a conference every year!"



"So many topics to choose from, I would have liked to have listened to more but sessions clashed."



"Accommodating delegates near the conference centre was very, very thoughtful."

"This is the best conference of all I have attended - thank you!"



"I liked it - BIG like."

"Brilliant programme, excellent speakers, well organised conference."



"The presentations were very good - please provide us with these at every conference -if it is possible."

Tribute to Terese Lasser (1904-1979)

The Founder of Reach to Recovery

2013 marks the 60th Anniversary of Reach to Recovery, a movement founded by the pioneering advocate and breast cancer survivor, Terese Lasser. In this edition of Bloom, we pay tribute to her memory and reflect on her legacy – the Reach to Recovery movement.

In 1952, at the age of 48, Mrs. Lasser found a lump in her breast. She went into the hospital for a quick-section biopsy, performed under general anesthesia, with assurance from her doctor that such lumps were usually benign. She awoke to find herself, in her words, “bound like a mummy in surgical gauze.” Much to her surprise, a Halstead radical mastectomy had been performed.

Following her mastectomy, Mrs. Lasser was dismayed to learn that her doctor and hospital staff did not know where she could get a breast prosthesis and could not recommend rehabilitation exercises to help her recuperation. At that time, the incidence of breast cancer was on the rise, but there were few programs available to support women diagnosed with the disease.

As part of her own emotional recovery, Mrs. Lasser was determined to bring together women affected by breast cancer in order to better address their unmet needs. She ardently believed that peer support could help other women with coping, adjustment, quality of life, and survivorship issues. She also believed that women could work together to overcome the stigma of breast cancer.

Mrs. Lasser courageously set to work convincing the cancer community that women with breast cancer could benefit from the opportunity to talk with other women who had experienced the disease. She formed the Reach to Recovery movement on this simple, yet universal, principle: women who have lived through breast cancer and give freely of their time to help other women facing the same experience are a valuable source of support.



Women affected by breast cancer enthusiastically embraced the program, and in 1969 the American Cancer Society took on custodianship of Reach to Recovery, expanding breast cancer peer support throughout the United States. In 1972, the American Cancer Society's then Vice President for Service and Rehabilitation, William M. Markel MD, wrote in the epilogue of Terese Lasser's autobiography, *Reach to Recovery*:

"The merger of the Reach to Recovery Program with the American Cancer Society in 1969 brought the vast resources of the Society into play. Now that a national voluntary health agency with strong professional and lay leadership was committed, Reach to Recovery had access at the grass-roots level to the more than 3,000 American Cancer Society units throughout the country.

The program could be brought into the small community hospital as well as the large urban medical center. Ted (Terese) Lasser's inspired leadership and the technical expertise and the organizational skills of the ACS together created a force that showed great promise...

Our expectations were more than realized...we give hearty thanks to Ted Lasser and her devoted Reach to Recovery Volunteers, to the many physicians who have supported and used the Reach to Recovery Program, and to the lay and professional Volunteers and staff at all levels of the ACS, locally and nationally, who are helping make Reach to Recovery available to the woman who has had breast surgery, wherever she may be."

Just two years later, in 1974, the Reach to Recovery principles were introduced to hospitals and cancer treatment facilities throughout Europe and Reach to Recovery International had begun. Through the efforts of the ACS, RRI was quickly embraced by many countries throughout the world. Reach to Recovery has become one of the world's most active community-based breast cancer support movements, with active affiliates in more than 100 countries.

International uptake of RRI saw the ACS entrust custodianship for the

global program to the Union for International Cancer Control (UICC) in 1994.

Insightfully, the ACS recognized the strong potential for program enhancement and mutual benefit by harnessing UICC networks to facilitate a shift in strategic focus from direct intervention and service provision to member development activities and networking, knowledge synthesis and transfer, capacity building through collaborations and partnerships, and global advocacy.

In recent years, RRI has successfully broadened its scope of activity to accelerate progress towards attainment of the World Cancer Declaration, encompassing capacity building, education and awareness, prevention and early detection, and activism.

RRI has been particularly effective in uniting women across economic divides and world continents, empowering a grassroots movement to improve universal cancer control.

Under the auspices of the UICC and guided by the American Cancer Society's continuing leadership of the Reach to Recovery program in the United States, in 2009 Reach to Recovery International formed a Board of Management, Chaired by Professor Jeff Dunn, the CEO of Cancer Council Queensland, to steer the development and implementation of a governance framework underpinned by a five-year strategic plan that has successfully positioned RRI as one of the world's most well-recognized and active breast cancer support movements.

The work of RRI has achieved international eminence and recognition through the development of an active online community and the biennial convergence of volunteers at the *Reach to Recovery International Breast Cancer Support Conference*.

More than 60 years after Terese Lasser's diagnosis, her tireless campaigning has transformed world-wide the experience of breast cancer survivorship, inspiring the conviction that women can empower one another to help eliminate breast cancer as a life-threatening disease for future generations.

A motivating force

RRI's mission and objectives have been effectively consolidated by mobilizing the support of a global consumer movement in three major areas of activity: peer support, advocacy, and consumer engagement in research.

Bloom magazine showcases some aspects of accomplishments across these areas, demonstrating the positive impact of RRI in promoting cancer control through direct action.

Without a doubt, the outcomes of the RRI program are a credit to Bloom readers, who help to inspire a movement that today advocates globally for breast cancer monitoring and evaluation programs, public health policies, prevention and screening initiatives, service access, treatment quality, and training and education outcomes customized to culturally and linguistically diverse groups.

One of RRI's most important accomplishments and core priorities, consistent with the mission first envisioned by Terese Lasser and embraced by Reach to Recovery volunteers around the world, has been to connect tens of thousands of women affected by breast cancer to provide life-affirming support and comfort.

The RRI Board of Management and Bloom Editorial Committee offer their collective thanks and appreciation to readers for their commitment to Reach to Recovery International.



**The story of
Terese Lasser,
and her vision,
empowers all of us
– we remember
her today.**

Global Kitchen

This edition, Global Kitchen brings you a recipe from Spain!



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

Mixed Paella

as posted on iamafoodblog.com.
adapted from saveur.com
serves 6-8 or 3 very hungry people

Ingredients

- 30 threads saffron, crushed (a scant 1/2 tsp.)
- 4 chicken thighs
- 10-12 large shrimp, peeled and deveined
- salt and freshly ground black pepper, to taste
- 1/2 cup extra-virgin olive oil
- fresh chorizo, removed from casing and crumbled
- 1 tablespoon smoked paprika
- 3 cloves garlic, minced
- 3 medium tomatoes, minced or grated on the largest holes of a box grater (discard the skin)

- 1 small onion, minced
- 7 cups chicken broth
- 2 1/2 cups short-grain rice, preferably Valencia or bomba
- 1 red pepper sliced into 1 inch strips
- 12 clams

Method

Put saffron and 1/4 cup hot water in a small bowl; let sit for 15 minutes. Season chicken and shrimp with salt and pepper. Heat oil in a 16" - 18" paella pan over medium-high heat. Add chicken, shrimp, and chorizo and cook, turning occasionally, until browned, about 5 minutes. Transfer shrimp to a plate, leaving meats in pan. Add paprika, garlic, tomatoes, and onions to pan and cook, stirring often, until onions soften, about 6 minutes. Add reserved saffron mixture and broth, season with salt, and bring to a boil over high heat.

Sprinkle in rice, distribute evenly with a spoon, and add peppers. Cook, without stirring, until rice has absorbed most of the liquid, 12 - 15 minutes. (If your pan is larger than the burner, rotate it every two minutes so different parts are over the heat and the rice cooks evenly.) Reduce heat to low, add reserved shrimp, and nestle in clams hinge side down; cook, without stirring, until clams have opened and rice has absorbed the liquid and is al dente, 5 - 10 minutes more. Turn heat to high for 1 - 2 minutes to create the socarrat. Remove pan from heat, cover with aluminum foil, and let sit for 5 minutes before enjoying.

**Paella is totally customizable so feel free to make this dish vegetarian, all seafood, or all meats.

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



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. EXEC02_0313

Reach to Recovery International Governance Structure

Board of Management

Chair: Jeff Dunn, [Cancer Council Queensland](#)
Elizabeth Brien, [Reach to Recovery International](#)
Meredith Campbell, [CauseForce](#), [Amazon Heart](#)
Suzanne Chambers, [Griffith University](#)
Cathy Hirsch [Reach to Recovery International](#)
Ranjit Kaur, [Reach to Recovery International](#)
Ann Steyn, [Reach to Recovery International](#)
Jane Turner, [University of Queensland](#)
Ex officio: Mary Gospodarowicz, [UICC](#)

International Advisory Committee

Chair: Cathy Hirsch [Reach to Recovery International](#) / [American Cancer Society](#)
Edith Cooper, [CCQ Breast Cancer Support Service](#)
Megan Dwyer, [Cancer Council Queensland](#)
Ranjit Kaur, [Reach to Recovery International](#)
Stella Kyrikides, [Europa Donna Cyprus](#)
Gloria Lin, [Taiwan Breast Cancer Alliance](#)
Ex Officio: Jeff Dunn, [Cancer Council Queensland](#)

Bloom Editorial Board

Cathy Hirsch
President, Reach to Recovery International

Paul B. Jacobsen PhD
Co-Chair
International Psycho-Oncology Society (IPOS)

Anne Savage
Chief Communications Officer
Cancer Council Queensland

Lee Boerner
Foundation Director, Professional Education
LIVESTRONG

Maggie Watson
President,
International Psycho-Oncology Society (IPOS)

Joanne S. Buzaglo PhD
Vice President, Research & Training
Cancer Support Community

Jane Salisbury
Corporate Communications Manager
National Breast and Ovarian Cancer Centre

Stephanie Newell
Advocate, Breast Cancer Network Australia

EVENTS

GLASGOW, SCOTLAND

9th European Breast Cancer Conference (EBCC-9)

March 19 - 21, 2014

Go to www.ecco-org.eu/Conferences/Conferences/EBCC9.aspx

ORLANDO, FLORIDA, USA

C4YW - Annual Conference for Young Women Affected by Breast Cancer

February 21 - 23, 2014

Go to www.c4yw.org

LISBON, PORTUGAL

ABC2 - Advanced Breast Cancer

November 7 - 9, 2013

Go to www.abc-lisbon.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.

