page 4 Update on the 19th Reach to Recovery International Breast Cancer Support Conference in Prague.

 Page Finding positive meaning and coping with life beyond breast cancer.

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



# Table of contents

- 04. Message from Cathy Hirsch and Update on the 19th RRI Breast Cancer Support Conference in Prague
- 05. Finding positive meaning and coping with life after breast cancer
- 06. Welcome to The Recovery Room!
- 07. Finding strength after breast cancer
- 08. Personal growth after breast cancer: paying it forward
- 09. Go live your life
- 10. Personal growth after breast cancer: my journey to survivorship
- 11. H-E-A-L-T-H
- 12. Breast cancer survivors find personal growth through peer support
- 13 17. Spotlight On
  - Kenya: Introduction to Ongata Ngong Palliative Community Care
  - South Africa: Breast Health Foundation to host second annual One Step at a Time Cancer Warrior Walk!
  - Portugal: Movimento Vencer e Viver holds 3rd National Meeting
  - Australia: Choices 20th Anniversary Fashion Extravaganza
  - Greece: ALMA ZOIS: a 30-year old FAMILY
- 18. Global Kitchen: Date, Apricot, & Chia Bliss Balls from Australia

*Cover photo:* © Cecilie\_Arcurs | istockphoto.com

# **Our mission**

Reach to Recovery International is built on one 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, Inc. Board of Directors

Cathy Hirsch President, Treasurer

Ann Steyn Vice President, Immediate Past President

Ranjif Kaur Past President

Karen DeSantis Secretary

David Hirsch Legal Counsel

Special Adviser to RRI Professor Jeff Dunn, AO

## **Bloom Editorial Board**

Cathy Hirsch President, Reach to Recovery International

Ann Steyn Immediate Past President, Reach to Recovery International

Ranjif Kaur Past President, Reach to Recovery International

Mirat Shah, MD Hematology-Oncology Fellow, Johns Hopkins University

Holly Barnard Design

## **Medical Contributors**

Cheng Har Yip, MD Breast Surgery

Jowie Mbengo, MD Radiology

Maggie Watson, BSc, PhD, Dip Clin Psych AFBPS C Psychol Clinical Psychology

# **Upcoming events**

## WORLD CANCER DAY

4 February 2019 https://www.uicc.org/what-we-do/convening/world-cancer-day

Prague, CZECH REPUBLIC 19th RRI Breast Cancer Support Conference 12–15 June 2019 http://www.reachtorecovery2019.org/

Banff, Alberta, CANADA 21st World Congress of Psycho-Oncology 23–26 September 2019 https://ipos2019.com

#### Lisbon, PORTUGAL ABC Global Alliance Meeting 16–17 November 2019 https://www.abcglobalalliance.org/events-initiatives/future-events/

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

Email your theme suggestions to information@reachtorecovery international.org. A theme will be chosen by February 2019. Regardless of whether your suggested theme is chosen this time, it will remain under consideration for future editions.



## SUBMIT YOUR ARTICLE

# bloom

Bloom is published by Reach to Recovery International, Inc. For more information about RRI, go to www.reachtorecoveryinternational.org.





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



REACH TO RECOVERY INTERNATIONAL IS COMMITTED TO WORKING TO IMPROVE THE QUALITY OF LIFE OF WOMEN WITH BREAST CANCER AND THEIR FAMILIES THROUGH A WIDE RANGE OF SERVICES OFFERED WORLDWIDE.

# Message from Cathy Hirsch -President of RRI



#### Cathy Hirsch

No one wants to get breast cancer. If I could live my life over again *without* cancer, I would. That said, I have to admit that, for me, a lot of good came out of that very bad experience. I can honestly say that I am a better person because of what I went through. I've spoken with countless women who say the same thing.

As the saying goes, "Whatever doesn't kill you makes you stronger." What is it about breast cancer patients and survivors that allows them to find silver linings in such a dreadful event? We examine that question in this edition of *Bloom*.

Our topic is *Personal growth after breast cancer,* and *Bloom* Medical Contributor Maggie Watson along with Claire Foster, both mental health and health psychology professionals specializing in cancer, outline what it takes to survive and thrive after breast cancer. Lynn Panton and Ashley Artese, experts in the area of exercise training and its effects on the body, report on their research into the importance of strength training to the well-being of breast cancer survivors. Oncology Physical Therapist Leslie Waltke offers practical tips for incorporating physical activity into your life in order to live your best life possible.

We hear success stories from and about survivors as well. Leonie Young shares the story of a survivor in Brisbane, Australia who decided after her recovery to focus on her love of art and painting and to mentor other survivors to find their own inner artist. Janet Ladd recounts that breast cancer gave her the opportunity to reflect on her life and the motivation to make major changes that have led to greater happiness. Rama Sivaram describes the personal growth she underwent as a result of her breast cancer journey, and Carol El-Jabari reports on a group of survivors in Jerusalem who volunteer to improve the lives of patients and enhance their own lives and the lives of other volunteers at the same time.

We also shine our spotlight on organizations in Kenya, South Africa, Portugal, and Australia as they continue their efforts to improve the lives of women in their communities. In our Global Kitchen, we feature a recipe from Australia for a healthy treat that may find its way onto your holiday table!

## Update on the 19th Reach to Recovery International Breast Cancer Support Conference in Prague

Before we tackle the topic of *Personal growth after breast cancer*. an update on the rapidly approaching conference in Prague!

If you haven't taken advantage of early-bird registration yet, please plan to do so soon! The deadline for early-bird registration is 7 March 2019, after which the registration fee goes up! You can find the registration guidelines here:

#### **Registration Guidelines**

You can submit your registration here:

**Registration & Abstract Submissions** 

We will be accepting abstract submissions until 24 January 2019 so please file yours online as soon as possible. You can access the abstract guidelines here:

#### **Abstract Guidelines**

You can submit your abstract via the same online portal where you registered:

**Registration & Abstract Submissions** 



Our hosts in Prague are working hard to put together a worldclass program! Among the many internationally acclaimed speakers they have lined up are names you will surely recognize, including:

- Professor Fatima Cardoso, MD, PhD, who leads the ABC (Advanced Breast Cancer) Global Alliance
- Musa Mayer, renowned breast cancer advocate and author of several books, including:
  - Examining Myself: One Woman's Story of Breast Cancer Treatment and Recovery,
  - Advanced Breast Cancer:
    A Guide to Living with Metastatic
    Disease, and
  - After Breast Cancer: Answers to the Questions You're Afraid to Ask
- Dr. Maira Caleffi, a breast surgeon, member of the Board of

Directors of the UICC, and founder of the Brazilian Federation of Philanthropic Institutions for Breast Health Support (FEMAMA)

 Professor Jeff Dunn, AO, the long-time Chief advisor to RRI who is also a member of the Board of Directors of the UICC and the Chair and Research Program Director of the Department of Social and Behavioral Science at the University of Southern Queensland, Australia

In addition to the information-packed conference program, the local hosts are preparing an exciting social program that includes a Welcome Reception, Gala Dinner, and Closing Ceremony, followed by the Avon Walk to End Cancer that will take us through the heart of their beautiful and historic city!

We look forward to welcoming you to Prague!

# Finding positive meaning and coping with life beyond breast cancer

**Claire Foster,** Professor of Psychosocial Oncology and Director of Macmillan Survivorship Research Group, Health Sciences, University of Southampton, UK

**Maggie Watson,** University College London and Institute of Cancer Research, UK

Negative consequences of breast cancer are well documented. Recently attention has turned to issues such as: managing fear of cancer recurrence; regaining a sense of body integrity; managing health and well-being; and building coping resilience through personal growth. Evidence collected by psycho-oncology professionals\* is yielding important information on potential benefits to breast cancer patients.



Claire Foster



Maggie Wataon



#### Fear of Cancer Recurrence

Research is underway testing how to support women living with troublesome fear of recurrence. Early results are promising and show a reduction in worry. For example, *Conquer Fear*, an Australian study, is helping survivors accept the uncertainty of whether their cancer might come back by teaching strategies to control worry and where they place their attention, helping them focus on what they want out of life and helping them choose a sensible level of cancer screening and stick to it. Participants work with trained therapists in five individual, face-to-face sessions over 10 weeks. *Conquer Fear* is not yet being used in clinical practice.

© Thodonal | Dreamstime.com

### **Regaining a Sense of Body Integrity**

Women may experience body image concerns with consequences for psychological and physical health, and relationships. A number of studies demonstrate promising results in reducing body image concerns through psychotherapy, psychoeducation, or physical activity interventions made available at different stages of treatment and mostly as a series of face-to-face or group-based sessions.

#### **Health and Well-being**

Increasing physical activity is beneficial for health and well-being. Evidence shows physical activity increases fitness, reduces fatigue and depressive symptoms, and improves quality of life. Some of the strongest evidence comes from studies involving women with breast cancer. A number of reviews show that increasing physical activity, by any level, is linked to improved health outcomes. Finding support to make changes to physical activity levels can be really helpful.

#### **Resilience Building**

Following a breast cancer diagnosis some women experience "post-traumatic growth" where they may enjoy their time with others more, can focus on the things they enjoy and let go of the things they do not, and try to seize new opportunities. Adaptive coping strategies are associated with this sense of post-traumatic growth as well as having good social support. Not all women experience post-traumatic growth, but research is underway to determine whether support helps women gain benefits from their breast cancer experience.

#### Summary

- The impact of fear of recurrence can be improved with support
- Body image concerns can be improved with support
- Increasing physical activity has proven benefits
- Finding positive meaning improves coping and managing future stresses

\*The authors are mental health and health psychology professionals specialising in cancer.

# Welcome to The Recovery Room!

By Leslie Waltke, PT, DPT, Wisconsin, USA



A breast cancer diagnosis and treatment can be equated to a natural disaster.

It often hits suddenly with little to no warning, causing physical harm, fear, and damage. And then, "it's over." It fades from the headlines. The ground stops shaking and the winds and rain cease. The physical and psychological scars may remain and fester.

Cancer treatment too often leaves in its wake a significant and destructive impact on physical health and well-being. And, as survivors know, just because "it's over" doesn't mean it's over.

Oncology physical therapy is the area of cancer care that assesses and treats the musculoskeletal (muscle and bone), cardiopulmonary (heart and lungs), and physical and functional problems resulting from cancer and cancer treatment, both during treatment and in survivorship. Common symptoms and problems faced by breast cancer patients and survivors are fatigue, pain and weakness, shoulder problems, balance problems, neuropathy, pain from aromatase inhibitors, difficulty walking, and lymphedema. A physical therapist's primary role in cancer care is to prevent, reduce, or eliminate these symptoms, with the goal of keeping people strong and healthy during treatment, ultimately returning them to their highest level of function and comfort in survivorship.

One of the most powerful tools a physical therapist will use in getting people back to full energy and health is exercise. Clinical trials have shown that exercise for people with cancer improves quality of life, lengthens life, decreases the risk of breast cancer recurrence, and can even decrease the risk of dying from cancer. Exercise is powerful medicine!

Here are some things you can do *today* to get yourself on track to feeling stronger, more flexible, and energetic:

- If you are not yet walking for exercise, start today! Research shows that even 10 – 30 minutes of walking 4 to 6 times a week can impact health, cancer recurrence, and life expectancy! If you need to, start with 5 minutes 1-2 times a day, and build from there. Anything, is always better than nothing!
- Make sure the skin and muscles around your chest and shoulder are fully strong, flexible, and mobile by strengthening and stretching. Yes, after being cleared by your breast surgeon, pushing, pulling, carrying and lifting weights are safe and good for you!
- Refocus your mindset! Too many people accept that long term limitation and discomfort are to be accepted and tolerated after a cancer diagnosis. Not so! It is never okay to not be okay. And it is never too late to reduce pain and improve your mobility and health.

In some areas of the world cancer physical therapy is standard of care, while in other areas, physical therapists unfortunately don't even exist.



Leslie Waltke, PT, DPT

# 66 EXERCISE IS POWERFUL MEDICINE! 99

Harnessing the power of social media, I am happy to introduce you to The Recovery Room, a question and answer platform specifically for cancer patients and survivors. The Recovery Room provides free access to a physical therapist and information on health and recovery after cancer.

Often in cancer care we get so focused on treating the cancer, we forget to take care of the person. It is time to change that! The Recovery Room brings cancer recovery right into your home and life. Care for yourself like you are the most important person on the planet, because you are. And exercise like your life depends on it, because it does.



Visit The Recovery Room today on Facebook or Youtube (click below).



Still having stiffness or discomfort at your chest or shoulder? Look for The Recovery Room video entitled "The four best stretches after breast cancer surgery and radiation" posted October 25, 2018.

# Finding strength after breast cancer

Lynn Panton, PhD, FACSM, Florida State University, USA Ashley Artese, PhD, Roanoke College, USA

Breast cancer is one of the most common forms of cancer in women. Advances in cancer treatments have led to improved survival rates; however, cancer treatments can lead to numerous side effects including accelerated losses in muscle mass and bone mineral density (BMD) along with gains in body fat.<sup>1-4</sup> These changes can result in losses in strength and physical function as well as increases in bone fractures. Along with other side effects such as pain, fatigue, and lymphedema, they can ultimately decrease quality of life.

# Liste Acode in and the second se



Lynn Panton, PhD, FACSM (right) and Ashley Artese, PhD

# What does the research say about strength training for breast cancer survivors?

Strength training can be an excellent way to reverse treatment-related effects on body composition, bone, strength, physical function, and quality of life. Research has shown that breast cancer survivors can improve upper and lower body strength as well as physical function in as little as eight weeks with a strength training program.5 While improving muscle and fat mass can be a little more challenging to achieve, a previous study in our laboratory found that three months of high intensity strength training (60-80% of one-repetition maximum), performed twice per week, increased muscle mass by 2.2% and decreased fat mass by 1.7%.6 While programs of longer durations are generally needed to positively impact BMD, a previous study in our laboratory showed that moderateintensity strength training was sufficient in improving strength and maintaining BMD over the course of six months in breast cancer survivors.7 While improvements in BMD were not observed, maintenance of BMD is also a positive outcome since breast cancer survivors have an increased susceptibility for bone loss. BMD has been shown to decrease by 1 to 2% each year after menopause, and the losses may be higher in the first few years of menopause in healthy women. Therefore, being able to maintain BMD in breast cancer survivors is a positive outcome, especially in the upper body, which is more susceptible to losses because of cancer treatment and disuse.

In comparison to strength training alone, a combination of strength training with high impact movements such as hops and jumps may produce additional benefits for bone.<sup>8,9</sup> Winters-stone et al.<sup>9</sup> found that a one-year program that consisted of strength training combined with a series of high impact jumps resulted in improved BMD at the hip compared to losses experienced by a control group. Another recent study in our laboratory compared the effects of two exercise

interventions: (1) functional impact training (FIT), which combined strength training and a variety of different high impact exercises, and (2) yin yoga, which focused on nonweight-bearing stretching and relaxation postures. The research participants exercised together twice per week for six months, and performed each workout for 45 minutes. While the FIT program was not able to elicit improvements in body composition or bone compared to the yin yoga, body composition was maintained along with BMD in the spine and right hip in both groups. While data are still being analyzed, results look promising as both interventions improved lower body strength, physical function, and quality of life. In addition, the FIT program increased upper body strength, which is especially important as surgery and treatment can result in reductions in arm strength. A longer FIT program may be needed for improvements in body composition and bone.

**Starting a strength training program?** Research has shown that strength training is safe to perform both during and after breast cancer treatment. If you are looking to begin a strength training program, here are a few tips and guidelines to get you started:

- Talk with your primary care physician and oncologist: Let your doctors know that you are interested in beginning a strength training program. It is important to discuss your current medications and/or treatments and how they may impact your ability to exercise or perform certain movements – some exercises may need to be modified.
- Wear compression garments: If you have lymphedema or are at risk for the development of lymphedema, it is recommended to wear compression garments during exercise to help prevent swelling in the affected arm. Research has shown that strength training can even be beneficial in reducing lymphedema symptoms.<sup>10</sup>
- Always warm up: Perform a warm-up of walking or cycling for a few minutes before beginning your strength training program to raise the body temperature and promote

blood flow to the working muscles. In addition, do some light dynamic stretches to gradually increase upper and lower body joint range of motion.

- Start out slowly: Begin using low weights and gradually progress in small increments over time. You can start out performing 8-12 repetitions for 1-2 sets, twice per week. Work up to doing 4 to 6 exercises for the lower body and 6 to 8 exercises for the upper body. Visit the National Institute of Health website Go4Life for free resources and examples of exercises that can be completed for a strength training program <u>https://</u> go4life.nia.nih.gov/exercise-type/strength/
- Listen to your body: Rest if you feel sick or fatigued and feel free to decrease the frequency, weight, repetitions, or sets as needed.

#### References

 Freedman RJ, Aziz N, Albanes D, et al. Weight and body composition changes during and after adjuvant chemotherapy in women with breast cancer. J Clin Endocrinol Metab. 2004;89(5):2248-2253.

 Irwin ML, McTierran A, Baumgartner RN, et al. Changes in body fat and weight after a breast cancer diagnosis: Influence of demographic, prognostic, and lifestyle factors. J Clin Oncol. 2005;23(4):774-782.

 Shapiro C, Manola J, Leboff M. Ovarian failure after adjuvant chemotherapy is associated with rapid bone loss in women with early-stage breast cancer. J Clin Oncol. 2001;19(14):3306-3311.

 Vehmanen L, Saarto T, Elomaa I, Makela P, Valimaki M, Blomqvist C. Long-term impact of chemotherapy-induced ovarian failure on bone mineral density (BMD) in premenopausal breast cancer patients. The effect of adjuvant clodronate treatment. *Eur J Cancer.* 2001;37(18):2373-2378.
 Benton MJ, Schlairet MC, Gibson DR. Change in quality of

 Benton MJ, Schlairet MC, Gloson DH. Change in quality of life among breast cancer survivors after resistance training: is there an effect of age? *J Aging Phys Act*. 2014;22(2):178-185.
 Madzima TA, Ormsbee MJ, Schleicher EA, Moffatt RJ, Panton LB. Effects of resistance training and protein supplementation in breast cancer survivors. *Med Sci Sports Exerc*. 2017;49(7):1283-1292.

7. Simonavice E, Liu P-Y, Ilich JZ, Kim J-S, Arjmandi B, Panton LB. The effects of a 6-month resistance training and dried plum consumption intervention on strength, body composition, blood markers of bone turnover, and inflammation in breast cancer survivors. *Appl Physiol Nutr Metab.* 2014;39(6):730-739.

 Zhao R, Zhao M, Xu Z. The effects of differing resistance training modes on the preservation of bone mineral density in postmenopausal women: A meta-analysis. Osteoporos Int. 2015;26(5):1605-1618.

 Winters-Stone KM, Dobek J, Nail LM, et al. Impact + resistance training improves bone health and body composition in prematurely menopausal breast cancer survivors: a randomized controlled trial. Osteoporos Int. 2013;24(5):1637-1646.
 Schmitz KH, Ahmed RL, Troxel A, et al. Weight lifting in women with breast-cancer-related lymphedema. N Engl J Med. 2009;361(7):664-673.

# Personal growth after breast cancer: paying it forward

**By Leonie Young,** Choices Peer Support Coordinator Brisbane, Australia

In 2005, Christine was diagnosed with breast cancer and underwent surgery, radiation, chemotherapy, and hormone therapy. Christine is a very private person who worked in the media and, in her spare time, followed her passion of painting and created a haven to express herself.

"We hear stories all the time about women diagnosed with breast cancer, but when it becomes personal, you're never prepared," Christine says. "We all think we're different somehow and these things happen to other people."

Christine decided to concentrate on something she loved—her art—and eventually put her time and energy into painting full time, exhibiting her works, teaching others to find their inner artist, and sharing her love of painting.

Importantly, she acknowledged the value of finding good support and information, the type she found through Choices (The Wesley Hospital Choices Cancer Support Centre, Brisbane, Australia), and set out to give back to the program and help other women find meaning in their lives after a cancer diagnosis.

Christine gives her time freely and conducts wonderful art therapy classes at Choices. The Choices rooms are decorated with her colourful paintings, as she donates not only her time but also her paintings to the breast cancer cause. We know there are many women who are enjoying life and art more fully because of Christine's generosity. One young woman who attended art therapy with Christine discovered she herself had a genuine talent! We can't forget her dropping by to tell us that she was on her way to her first art exhibition - that, is an exhibition of her own paintings! After art therapy she had continued on and is now an accomplished artist in her own right.

Most recently Christine facilitated an art session for a newly formed group at Choices for younger women with advanced cancer. Just seeing everyone concentrating on their work, forgetting for a moment the ongoing treatments and uncertainty, reminded us there is hope.

Every woman diagnosed with breast cancer struggles through difficult times, and no more so than those with advanced disease. Everyone agrees that their lives changed forever when they heard those words "you have cancer," but most say, when asked to think about it seriously, that their lives were





Christine creating a mural at Choices

ultimately enhanced through this sadness and loss.

Finding others who have had a similar experience is one of the best ways to find hope and personal growth. Christine found this for herself and she shared it with others. When we find our own way to pay it forward, we not only experience personal growth but we can help others find their way too.

Some of you reading this story who have attended one of the Reach to Recovery International Breast Cancer Support Conferences may have been fortunate to have received one of Christine's bookmarks with an inspirational verse—she always makes sure we have a supply to share at these amazing meetings—and we hope to give them to delegates who attend the RRI Conference in Prague this coming June!

> WE HEAR STORIES ALL THE TIME ABOUT WOMEN DIAGNOSED WITH BREAST CANCER, BUT WHEN IT BECOMES PERSONAL, YOU'RE NEVER PREPARED.

> > **99**

# Go live your life

By Janet Ladd, PCC, SPHR, Maryland, USA



Janet Ladd, PCC, SPHR

Go live your life. These were the four simple words I heard from my doctor after a year-long journey through cancer – starting with the cancer diagnosis, a mastectomy, and a number of reconstructive surgeries and treatments. "You are done," he said, "go live your life." As I exited the medical offices, I realized I was shaking. I don't even remember walking to my car in the parking garage. I thought it must be relief. After all, I did it. I beat breast cancer. I weathered the weeks of initial tests: from possible cancer to probable cancer to, yes, most definitely, YOU HAVE CANCER.

With no apparent risk factors, and having prided myself on leading a healthy lifestyle, I was devastated by the diagnosis. I survived the call to my husband at work, sobbing and questioning, "What did I do wrong?" I endured the heart-wrenching moments of looking into my children's eyes, my son with two missing front teeth and my daughter with a scratch on her nose from a recreational soccer mishap, wondering whether they would have a mother to watch over them as they grew older. How could I ever explain this thing called cancer when I didn't understand it myself?

I weathered the surgeries and treatments associated with my diagnosis over the course of a very long year.

To this day, fourteen years later, I am still struck by the depth of my experiences and, in light of them, how awkward those four simple words, "go live your life," really were. They were spoken as if I could go home and flip a switch. Up position: cancer roller coaster. Down position: life as normal. After all, what is normal after cancer?

Reflecting on these experiences and supporting a number of cancer patients and survivors as a Reach to Recovery volunteer, l've come to appreciate that:

 It is critical to trust our instincts and listen to our bodies. Don't delay going to the doctors, even for "routine" or "minor" ailments. As I discovered, knowing something isn't quite right and acting on that instinct can make a big difference.

- Life is delicate and uncertain. From one day to the next, one never knows what life may bring. Cancer, a ravenous beast on one hand, served as a powerful wake-up call on the other. In the quiet of my own recovery, I questioned what was trying to manifest through the cancer experience? What lessons were being served? I realized that, in the busyness of life, I had forgotten to cherish the simple things, to honor what I most valued, and to live with intention. I realized I had been operating at the effect of life – letting it drive me – instead of being at the helm of my own ship.
- Our individual attitudes and behaviors matter. A lot. Never doubt that our ability to hold compassion for others, connect in meaningful ways, and appreciate the good (which is always available, despite what the news and politicians may depict), affects the quality of our individual lives as well as those around us. Our families. Our colleagues. Our communities. The world.

After surviving cancer, I decided to make a career change and build on my education by going through an accredited coach training program. As a leadership/life coach today, I have the opportunity to work with amazing individuals and organizations alike. I am constantly reminded that dreams are worth the effort and that adversity can be a wonderful, although not always gentle, teacher. I believe we have the ability to thrive – not in spite of adversity but in light of it. Thankfully, a traumatic event like illness, layoff, or divorce is not a prerequisite for increased consciousness. We can live with a greater sense of awareness, purpose, and choice if only we pause long enough to reflect. Are we leading the life we choose? Do we take time to "be" and not merely do? Are we living our purpose most days? For what are we most grateful? How do we "show up" each day and, through our own attitudes and behaviors, influence those around us?

I il innvite you to your future. What is it that you choose as you go live your life?

TO THIS DAY, FOURTEEN YEARS LATER, I AM STILL STRUCK BY THE DEPTH OF MY EXPERIENCES AND, IN LIGHT OF THEM, HOW AWKWARD THOSE FOUR SIMPLE WORDS, "GO LIVE YOUR LIFE," REALLY WERE.



bounce-forward.com

# Personal growth after breast cancer: my journey to survivorship

By Rama Sivaram, Pune, India

Everything seemed to be going right, until that dark night when I discovered the lump. Overnight my life changed; from a person, I became a breast cancer patient. This was the beginning of chaos: my identity as a confident oncology health educator and counselor was replaced by a bold-print, four-digit number in my medical file, under the words "Breast Cancer and Oncology," my name small and insignificant in a little box. *I was suddenly a number*! The speed at which things began happening, from tests to treatment, robbed me of my rightful feelings. Suddenly, time shrunk into a whirlwind of protocols and a hundred hands feeling me. Never had my breast received such attention, *BUT WHAT ABOUT ME*? Like a good woman, I allowed family, doctors, well-wishers, and all and sundry to take over my life. Nobody was listening. *LISTEN TO ME PLEASE* ended in a whimper.

What did it mean to me to be on other side – a breast cancer patient. I finally had the time to break. Chemotherapy is long, lonely, leisurely, and catharsis by protocol. The side effects helped purge my fragmented thoughts and runaway emotions. This feeling of losing control can be overwhelming. I felt cleaved and separated, not only from the loss of my breast but also in the way in which I began looking at things – the clutter in my life. Being an ardent reader of Emily Dickinson, I could relate to this verse:

> I felt a cleaving in my mind As if my brain had split; I tried to match it, seam by seam, But could not make them fit.

The thought behind I strove to join Unto the thought before, But sequence ravelled out of reach Like balls upon a floor.

- Emily Dickinson 937

Perception of cancer and the self is collective. Our perception of disease, our valuation of self, doctors, beliefs, myths, statistics, cause, and effect are metaphors. Sometimes they send wrong signals "shaming and silencing" the patients as Susan Sontag once wrote in describing her own illness as a metaphor. Sometimes, however, they help patients gain new understanding of their person and experiences. *I was beginning to see myself from outside of myself.* I unleashed all kinds of thoughts. I was Pandora's Box, releasing all the evils while still keeping hope hidden inside. My moment of personal growth began anew through this turmoil with hope in my soul. "Hope" is the thing with feathers -That perches in the soul -And sings the tune without the words -And never stops - at all

- Emily Dickinson 314

The first thing I did was let go. I accepted the reality that some things are meant to be and some not. Some things are good and some not. If I could resolve issues, I strove to do so with the least amount of pain to myself and any significant others as possible. What I could not change I just let go. I was amused to find a little bit of me in another verse. I imagine most of us ask for things that make us happy first. If that proves futile then we seek, at least, reprieve from pain. Short of that, we resort to drugs to numb us, then we ask for sleep, and when things don't go the way we want we die little deaths.

The Heart asks Pleasure – first – And then – Excuse from Pain – And then – those little Anodynes That deaden suffering –

And then – to go to sleep – And then – if it should be The will of its Inquisitor The liberty to die

- Emily Dickinson 588

Life is not a bed of roses. There are thorns along the way, and we have the choice of facing and living the journey of our lives through positive action or otherwise in adversity. Survival is a basic instinct and cancer teaches us the brevity of life. Life and death are two book ends, and the journey between them is important. It is not about how long but how well we live and how fulfilled we are. I choose to make this journey fruitful, not just growing in years but also maturing in my personal growth. Cancer has helped me realize my goal.

I had no time to hate, because The grave would hinder me, And life was not so ample I Could finish enmity.

Nor had I time to love, but since Some industry must be, The little toil of love, I thought, Was large enough for me.

- Emily Dickinson 763

Today, there is me, Rama, no longer a number in a chart. Apart from nurturing a healthy self-esteem and sense of self-worth, I also practice mindful graciousness, forgiveness, and empathy in order to understand myself and the world better and in context. Sometimes I succeed, sometimes I don't. But that is what a life well lived is all about.

> If I can stop one heart from breaking, I shall not live in vain; If I can ease one life the aching, Or cool one pain, Or help one fainting robin Unto his nest again, I shall not live in vain-

- Emily Dickinson 982

(Quotations are from Dickinson, Emily. *The Complete Poems of Emily Dickinson*. Little, Brown. 1924).



Rama Sivaram

# H-E-A-L-T-H

By Rama Sivaram, Pune, India

Nothing comes easy—survival of the fittest happens after facing and overcoming challenges, be it with food, relationships, environment, professions, or politics. We need:

## Healing on a day to day basis

We are exposed to innumerable things in our daily life – some good and some not so good. In food, what we eat is not all organic. Even if it were, there could be soil bacteria in it in the absence of chemicals and pesticides. There is environmental exposure to many undesirable things like pollutants and contaminants. Then there is vulnerability – where we are exposed to good and harmful relationships. So, we are exposed to many things that are good and can hurt as well. This eventually leads to disease. Sometimes more can cause harm. The body and mind are ready to fight – have to deal with both the good and bad. To heal we need, along with medicines, change in our mindsets and change in our habits. So, healing is an ongoing process. Today if you are healed of one thing, tomorrow it may be something else. We need to focus deep within and listen to our bodies and mind and enable healing daily.

## Education

E

4

Τ

We learn the hard way only after something happens to us. To become aware is a way to overcome challenges. It is not enough to have knowledge, we need to use it to make a choice.

## Attitude

To truly survive we would have to work with our attitudes towards food, relationships and beliefs (many types). We have the potential to change to improve every way and our symbolic relationships with the world.

## Loving

Loving means unconditional acceptance and believing in the goodness of all. Sometimes there is co-dependency which is toxic – an excessive reliance on others for approval and identity.

## Time

Respecting Time is a challenge for us – a time for everything upon this earth. Do things when they need to be done.

## Harmony

When all this comes together proactively there is an internal and external harmony and there is a sense of well-being. It is not about how long we live, but how well and with quality we live. This is **HEALTH** – all about well-being.

# Breast cancer survivors find personal growth through peer support

**Carol El-Jabari**, *Executive Director* **Suhiela Karean**, *Programs Coordinator Patient's Friends Society, Jerusalem* 





Social support and coming together (a sisterhood of sorts) really make a difference for cancer patients and their families. Here members of the Patient's Friends Society's Sunrise Group are getting ready to cook lunch for a big gathering at our Palliative Day Centre in Hebron.

Sunrise group members in Palestine are preparing for exercise and swim classes.



A joyful gathering of Hebron University students in support of members of the Sunrise Group in Hebron. The women are from all walks of life, some under treatment while others are longer-term survivors.



Hebron University Nursing and Midwifery students spend the day with our cancer support group members, creating a fun day of physical activity. Raising awareness about lifestyle changes and empowerment is so important!

# Introduction to Ongata Ngong Palliative Community Care

Spotlight on: Kenya! **By Stella Mwari Rithara,** Founder, Program Coordinator, and Palliative Care Nurse, Kenya

Ongata Ngong Palliative Community Care, known as ONPACC, is a volunteering organization that strives to care for the community in rural areas of Kenya.

Periodically, ONPACC organizes Nyoto Fitti breast cancer supportive and advocacy days, which involve gathering women in these areas to educate and raise awareness about breast cancer, and also to follow-up on any women who might be undergoing treatment for the disease. ONPACC has three trained nurses, counselors, and breast cancer survivors who volunteer their time to educate women.

Community outreach about breast cancer is an important key to identifying breast cancer early, which in turn leads to earlier treatment and improved survival rates. ONPACC focuses on reaching as many rural communities in different parts of Kenya as possible. It works closely with churches and women's groups, mostly in response to invitations. ONPACC faces many challenges, but team members go above and beyond their means in attempts to reach each community.



Nancy, a breast cancer survivor, shares her journey with students from a cooperative university.



A Nyoto Fitti breast cancer supportive and advocacy day session led my Nurse Stella for women from Elkemuke in West Kajiado County.



Photo to remember a successful women's group discussion in Ruiri, Meru County.



A session on early detection and treatment in Inyonyori, Kajiado County.

# Breast Health Foundation to host second annual One Step at a Time Cancer Warrior Walk!

**By Colleen Arend,** *Project Manager for Breast Health Foundation South Africa* 

## Spotlight on: South Africa!





The Breast Health Foundation (BHF) will be hosting the second annual <u>One Step at a</u> <u>Time Cancer Warrior</u> <u>Walk</u> in the Johannesburg Zoo on 3 February 2019 to commemorate World Cancer Day.

One Step at a Time is an initiative of the <u>Breast Health Foundation</u>, symbolic of personal triumph and victory from diagnosis and treatment to survivorship.

The journey began in 2016 when 5 breast cancer survivors trekked to Everest Base Camp. Everest represents the epitome of human conquest and achievement. A trek to Everest Base Camp in 2016, with breast cancer survivors, was a public demonstration of the strength of the human spirit.

World Cancer Day is the ideal opportunity to spread the word and raise the profile of cancer in people's minds, in the media, and on the global health and development agenda. Cancer affects everyone in different ways, and everyone has the power to take action to reduce the impact of the disease on individuals, families, and communities. World Cancer Day, which will fall on 4 February 2019, one day after the walk, gives us a chance to reflect on what we can do, make a pledge, and take action

This event is a symbolic message of defiance to go out to all people fighting cancer and stands as an example of what is possible. Exercise plays a very important role in longterm health and walking is an ideal form of exercise that can be enjoyed by survivors, their families, and supporters. The event is for anyone/ everyone affected by all types of cancer.

#### **EVENT DETAILS\*:**

Date: 3 February 2019

**Place:** The Johannesburg Zoo, Jan Smuts Ave, Parkview, Johannesburg, 2193, South Africa

Time: Gates open 6:00am. Race commences 8:30am. Event ends at 13:00pm

**Distance:** 4km walk and enjoyment of the Wellness Village thereafter. Pram and wheelchair friendly.

**Cost:** Tickets start at R100 per entry for 3yrs and up. Kids under 3yrs may attend for free, but still need to obtain a barcoded ticket for their entry.

Ticket sales: At your nearest Jet and Edgars Fashion Stores or via TicketPro online via <u>www.ticketpro.co.za</u>

To get your organisation involved in this event contact: <a href="mailto:colleen@mybreast.org.za">colleen@mybreast.org.za</a>

\*Event rules, terms and conditions apply.

LIMITED TICKETS AVAILABLE SO ACT FAST!

# Movimento Vencer e Viver holds 3rd National Meeting

#### **By Carolina Negreiros,** *MVV National Coordinator Portugal*

#### The Movimento Vencer e Viver (Win and Live Movement) is a Member Organization of Reach to Recovery International based in Portugal. It is part of the Liga Portuguesa Contra o Cancro (Portuguese Cancer League) and is comprised of Volunteers who support women who have been afflicted by breast cancer.

On the 19th of October, Movemento Vencer e Viver carried out its 3rd National Meeting in the city of Porto. 310 participants from the 5 "Núcleos" (Nuclei) of Portugal, including the islands of Madeira and Azores, were in attendance.

At the Meeting, a message from RRI President Cathy Hirsch, which congratulated Movimento Vencer e Viver on its continued success in in carrying out its life altering mission, was read to attendees.

> THE MOVIMENTO VENCER E VIVER (WIN AND LIVE MOVEMENT) IS A MEMBER ORGANIZATION OF REACH TO RECOVERY INTERNATIONAL BASED IN PORTUGAL.



**Spotlight on:** 

**Portugal!** 

3rd National Meeting open session



Meeting of the 5 Nuclei Coordinators



Thank you gifts given to the 5 Nuclei Coordinators

# Choices' 20th Anniversary Fashion Extravaganza

**By Leonie Young,** Choices Peer Support Coordinator Brisbane, Australia

October is always a busy month on the breast cancer calendar. This year, Choices (The Wesley Hospital Choices Cancer Support Centre, Brisbane Australia) celebrated its 20th anniversary with a fun fashion extravaganza.

Many local businesses, fashion houses, and celebrities joined in with cancer survivors, their families, and friends to celebrate Choices, acknowledge the support it has provided for more than 20 years, and show there is life to be lived after a cancer diagnosis.

The night was packed with opportunities to win wonderful prizes in raffles and auctions, all of which were generously donated, but the highlight was the inspiring "models" who were women who have accessed the Choices programs. Their ages ranged from 34 years to 80 years. Some were diagnosed long ago, others are living with advanced breast cancer, and one underwent chemotherapy that same morning but was determined not to miss out on the fun.

The whole evening was about the importance of support when someone is diagnosed with cancer. A fun way to experience a support group, don't you think? It may not look like a support group, but it was. The models formed friendships during practice sessions and get-togethers. Their self esteem and self confidence received a wonderful boost, their families and friends were encouraged to see their loved ones smiling again, and everyone enjoyed forgetting about cancer for a few hours and lived life.

## Spotlight on: Australia!







# ALMA ZOIS: a 30-year old FAMILY

#### By Joanna Grecos, Athens, Greece



ΠΑΝΕΛΛΗΝΙΟΣ ΣΥΛΛΟΓΟΣ ΓΥΝΑΙΚΟΝ ΜΕ ΚΑΡΚΙΝΟ ΜΑΣΤΟΥ

**Spotlight on:** 

#### Thirty years ago in Greece, breast cancer was not something to talk about.

Even today, many people, including members of the press and media, speak of breast cancer as a cursed disease.

Imagine the courage and the need of a group of survivors in Piraeus who dared, back in 1988, to create a breast cancer support association: ALMA ZOIS ("ALMA"), meaning Leap of Life. As ALMA grew and more women joined, the association was moved to Athens. In 2001, another ALMA association was created in Patras to cover all of the western part of Greece. Then in 2008, another association was created in Thessaloniki. The ALMA associations are independent, but all work on the same principle: We are a family!

As a Greek family, we stick together. We have developed a sense of belonging. After the shock of a diagnosis of breast cancer, after treatment, surgery, chemotherapies, radiotherapies, or in between them, we need the helping hand of a sister, the understanding and compassion of an older woman, the hug of a survivor, mother, grandmother, aunts, cousins—family. We need to have a shoulder to cry on, or a happy bunch of relatives to celebrate our happy times, wishing every good wish possible.

We need also to obtain valuable and trustworthy information. The family of ALMA has trained volunteers in the Reach to Recovery program for years and organized the Reach to Recovery International Breast Cancer Support Conference in Athens in 2005. We have travelled to meet others and exchange experience and points of view. We have organized conferences to promote breast cancer prevention, always with one of us speaking freely of her battle with cancer. We have mourned ALMA members who lost the battle. But we have also welcomed the babies of young survivors, and there are increasingly more of them. We provide information about breast cancer on our website, over the telephone, and in person. We communicate with each other every day via a Facebook group, sharing news, anniversaries, troubles, worries, even what we have cooked that day.

We go on excursions, to restaurants, to museums, and to the theatre. We are an open and understanding family. Some decide not to join in every activity; they are busy with personal projects or work or marriage and children. Some are more shy, some open, some cry more easily, some are more...anything!

We organize yoga lessons, jewelry lessons, dance classes, theatre groups, and writing groups. We have psychological support from specialists, individually or in groups, and via our helpline for those who live far away or cannot leave their homes. We have a nutritionist and a makeup specialist offering advice about how to be fit and beautiful during chemotherapy.

Since the Greek financial crisis, we also have a lawyer working with our social workers. We are now known to the outside world as an NGO with clear finances, checked every year by the best specialists. And we keep growing.

We are part and co-founders of the Greek Cancer Federation, and we organize meetings between doctors and patients to improve communication. We are invited every year, by every possible company or administration or municipality, to speak about prevention and early detection.

Last but not least, we celebrated this fall 10 years of the Susan B. Komen Race for the Cure, transforming this event into a huge fiesta to celebrate LIFE. This year we had 40,000 people running, walking, and dancing with us!

ALMA Patras organizes Pink the City each October to raise awareness and celebrate, while ALMA Thessaloniki organizes Sail for Pink at Thermaikos bay in spring for the same purpose.

But at the end of all this, of which we are very proud: what remains are the smiling faces and the hugs welcoming each of us in the monthly reunion we have.



Young Survivors



Breast Cancer Walk



Sale for Pink

# Date, Apricot, & Chia Bliss Balls

#### Makes 20

Prep time: 15 minutes (+ 15 minutes soaking, 30 minutes chilling and 1 hour setting time)

# **Ingredients:**

1/2 cup (75g) coarsely chopped dried apricots

- 1 tbs white chia seeds
- 1 tbs pepitas (pumpkin seeds)1 tbs crunchy almond spread
- 1/2 cup (70g) coarsely chopped dates

1/4 cup (20g) desiccated (unsweetened, shredded, and dried) coconut, plus extra to coat

# **Directions:**

- 1. Place the apricot in a bowl. Cover with boiling water. Set aside for 15 mins to soak. Drain well.
- 2. Place the apricot, dates, coconut, chia, pepitas, and almond spread in a food processor and process until a smooth paste forms. Place in the refrigerator for 30 mins or until mixture becomes firm.
- 3. Line a baking tray with parchment paper. Roll 2 teaspoonfuls of mixture into a ball. Lightly coat in extra coconut and place on the lined tray. Repeat with remaining mixture. Place in the fridge for 1 hour to set.

Global Kitchen

Looking for a healthy treat to balance out the sweets that are so abundant this time of year? Try this one, shared by our Australian friends! Date, apricot and chia bliss balls are becoming increasingly popular in the land down under. Try them and you'll taste why!

