

Message from Cathy Hirsch

President of Reach to Recovery International

We preface this edition of *Bloom* with sad news. It is with deep regret that we report the passing of the Honorable Jan Steyn, husband of Reach to Recovery International's immediate past president, Ann Steyn. In this issue, we pay tribute to a truly remarkable and accomplished man.

Breast cancer represents a major interruption to any patient's life. First comes the shock of diagnosis and the inevitable anxiety and fear. Once the diagnosis is absorbed, a flurry of activity follows: scheduling medical appointments; learning about surgery and treatment options; weighing those options and making decisions; notifying relatives, friends, and co-workers of plans; making logistical arrangements so our lives and those of our loved ones can go on with as little disruption as possible. Then come the endurance tests of surgery and treatment. For most of us, treatment does eventually end and, if we choose to do so, we can pick up our lives where we left off. Others, however, cannot easily resume the lives they had expected to lead. Young survivors who have yet to start a family or are still in

the process of building a family may find their dreams derailed by infertility, which often accompanies cancer treatment. In this edition of *Bloom*, we examine the issues faced by survivors who hope to have children after breast cancer.

There are a number of options available to those affected by infertility, ranging from traditional adoption to surrogacy to making use of an egg or embryo bank. Gwendolyn P. Quinn, Ph.D., of the Moffitt Cancer Center provides a comprehensive overview of the various alternatives and offers advice for patients to determine which option is best for them.

LIVESTRONG Foundation works extensively with young adults who were diagnosed with cancer during their reproductive years. Emma Marquez, LBSW, and Anne Marie Norman of LIVESTRONG report that more and more oncologists raise fertility concerns with patients prior to treatment, so that patients have the option of preserving gametes before fertility is affected. They explain that LIVESTRONG Fertility and other leaders in the field work tirelessly

to increase awareness of the issue and to develop programs to help defray costs and provide emotional support.

Ashley Koenings and Jamie Hill, also of LIVE**STRONG**, address more specifically the work being done by LIVE**STRONG** Fertility and recount one of the organization's many success stories.

Up to seven percent of Australian women who are diagnosed with early stage breast cancer are under the age of 40, and Breast Cancer Network Australia is addressing the need to educate and support young patients who may be facing fertility issues. BCNA, in collaboration with the University of New South Wales, has developed a booklet to provide young patients with clear and current information about cancer treatment and fertility.

Although uncommon, it is not unheard of for a woman to develop breast cancer while pregnant. Understandably, such an untimely diagnosis would create in the patient a great deal of confusion and conflict about treatment choices.

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Email your bloom submissions! Email your bloom submissions! The theme of the next edition will be *Returning to work after cancer*. Submissions close 18 April 2014. Please send submissions in Microsoft Word format with any photos to info@reachtorecoveryinternational.org



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 is administered by Cancer Council Queensland.







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Breast Cancer UK reports in this edition of *Bloom* that it has developed web-based text and fact sheets specifically tailored to these patients. All are free and easily accessible online.

Two *Bloom* readers share their personal stories about starting families after breast cancer treatment. Mrs. Daren Gowen of Capetown, South Africa was a young, unmarried teacher when she learned she had breast cancer and would have to undergo chemotherapy. She worried that she would never marry and that, in light of her cancer history, she could not - or even should not - have children. Years later. Mrs. Gowen reflects on her journey and reveals a "happily ever after" ending.

Similarly, Xiuman Wu of Taiwan was only 27 when she was diagnosed with stage III breast cancer. Only a year after her chemotherapy ended, Xiuman and her husband were surprised by an unplanned pregnancy. The couple's concerns for both Xiuman's health and the health of the unborn child proved unfounded: nine months later a thriving baby girl was born, and three more children eventually followed. Xiuman considers the children to be four of many blessings she has received.

Luba Osinceva shares another perspective: that of a parent whose strength to battle breast cancer was fueled by her desire to see her daughter into adulthood. Luba was diagnosed with stage IV breast cancer when her daughter was only 6 years old. That was 15 years ago and, today, Luba is still going strong!

In other matters, our parent organization, the Union for International Cancer Control

(UICC), updates us on the refreshed World Cancer Declaration that was launched in November 2013 at the World Cancer Leader's Summit in Capetown, South Africa. The Declaration sets forth 9 targets that support one overarching goal: "There will be major reductions in premature deaths from cancer, and improvements in quality of life and cancer survival rates."

The International Pyscho-Oncology Society turns 30 this year and Professor Jeff Dunn, Chair of Reach to Recovery International's Board of Management, reflects on the progress the IPOS has made in integrating quality psycho-social care into routine clinical oncology practice. Professor Dunn further maps out challenges and opportunities for the way forward.

We receive a preview of the 16th World Congress of Psycho-Oncology and Psychosocial Academy from the Chair of the Congress, Luzia Travado. The Congress will be held in Lisbon, Portugal this year from October 22nd to October 24th. The main theme will be "Integrating Psycho-Oncology into mainstream cancer care: from research to action."

Siglinde Kallnbach and Marianne Koch of Cologne, Germany report that Kallnbach's participatory performance art creation, "a performancelife e.V.," was presented earlier this month at the carnival/parade in Cologne-Ehrenfeld. The evolving performance is designed to show empathy for and solidarity with those who are fighting cancer.

Sofia Abreu, the National Coordinator of Movimento Vencer e Viver, fills us in on an event that has become an



annual celebration in Portugal. Each year on Portugal's national day of breast cancer prevention, thousands of pink balloons - each representing a new case of breast cancer expected to be diagnosed that year - are released into the air over five cities. The event is called "Um Balao, Uma Vide," or "A Balloon, A Life." This past October 30th, 5,000 pink balloons were released.

From our Global Kitchen, Mary Hemrajani of the Hong Kong Breast Cancer Foundation shares a delicious and healthy recipe for Turkey Bites, which can be served as an appetizer or main course.

We anticipate making an announcement soon on the 18th Reach to Recovery International Breast Cancer Support Conference. We look forward to sharing the location and dates of the conference with you on the Reach to Recovery International website.



REACH Join Now!





Become part of the Reach to Recovery International Network

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.

Please visit www.reachtorecoveryinternational.org for more information and to download the membership application.

Attention existing RRI member organisations - please submit the new application form to keep your membership active!!

Jan Steyn Remembrance

It is with deep sadness that *Bloom* reports the passing of the Honorable Jan Hendrik Steyn, husband of our beloved immediate past president, Ann Steyn.



Nelson Mandela, Jan Steyn, Ann Steyn

Like his wife, Jan Steyn dedicated a great deal of his time to helping others. He studied law at Stellenbosch University and, upon his graduation in 1950, became a member of the Cape bar. At age 36, he was appointed to the Cape bench, becoming one of the youngest judge's in South Africa's history.

Jan believed strongly that any society's degree of civilization is measured by the way that society treats its prisoners. He opposed corporal punishment, believed that an accused's financial situation should be kept in mind when setting bail, and promoted non-custodial sentences whenever possible, especially for first-time offenders. Jan made frequent visits to prisons to assess conditions first-hand. On one particular trip to Robben Island, he invited two of his fellow judges

to accompany him. During the visit, an inmate reported to the judges that the prison commander tolerated regular assaults upon the prisoners by guards. The commander attempted to silence the inmate by threatening him, but the judges insisted that the inmate be allowed to continue. Subsequently, the judges wrote a report that resulted in the commander's removal from his post. Years later, the incident was appreciatively recalled by the inmate in question -Nelson Mandela – in his autobiography Long Walk to Freedom. The bond that Jan and "Madiba" formed as a result of that meeting remained strong between them for the rest of their lives.

Underpinning all of Jan's work was his commitment to moving South Africa toward a free society, founded on the rule of law and the protection of fundamental rights. He envisioned for his country a modern economy and urban upliftment. With the Soweto uprising in 1976, Jan was pulled to lead in another direction. He had immediately recognized the need for a coordinated response to the uprising and had helped organize a summit of industrialists and black urban leaders. The summit led to the formation of the Urban Foundation, a nonprofit organization funded by businesses, with international support, to facilitate access to housing, education, and business opportunities in South Africa's urban black communities. In 1977, Jan was granted special leave from the bench in order to run the foundation.

In 1990, when the ban on the African National Congress was lifted and Nelson Mandela was released from prison, South Africa's then-President F. W. De Klerk appointed Jan to chair an independent trust to assist in the political transition. Jan continued to steer the trust for the next six years, guiding it through the ultimate abolishment of apartheid. Once the job was completed, Jan was able to return to the bench. He was appointed to the Courts of Appeal of Botswana and Swaziland. He also served on the Lesotho Court of Appeal for 18 years, the last 11 as President of that Court.

These career highlights touch on only a fraction of the public services Jan performed. While a judge, he chaired several commissions of inquiry. For seven years, he headed up the Independent Commission for the Remuneration of Public Office Bearers, and for 10 years he was a chancellor of the Medical University of South Africa (Medunsa). Jan held honorary doctorate degrees from both Medunsa and the University of Cape Town, Stellenbosch. Upon his retirement from the Lesotho Court of Appeal, he was knighted by King Letsie III.

Despite health problems, Jan continued to write articles for the media about social issues of importance to him and many others. He took great pleasure in his many friends and family members, including the seven children, 15 greatchildren, and a great grandchild he shared with Ann. Ann's long and successful tenure as President of Reach to Recovery International was a particular source of pride for him. Reach to Recovery International extends heartfelt condolences to the Steyn family on the loss of this outstanding man. He created a lasting legacy, and he will be missed by many.

Alternative Family Building Options for Cancer Survivors

by Gwendolyn P. Quinn, Ph.D., Moffitt Cancer Center, USA

Many women diagnosed with cancer may not be aware of the potential risk of infertility, feel too overwhelmed with treatment planning to think about it, or may not have time to pursue any options. An equal number of survivors may be uncertain about their current fertility status. In the past, the presence or absence of menses was considered an indicator

of fertility, but recent evidence shows that is not a reliable measure. It is not unusual for some female survivors to retain their fertility but to experience premature ovarian insufficiency (also known as ovarian failure or premature menopause) about 5 years post-treatment. A reproductive endocrinologist can provide an assessment of fertility status.

If you are experiencing fertility issues due to cancer treatment but are interested

in having a family, you have options. It is important to identify your ultimate goal. Is it to experience a pregnancy? To have a child who shares your or your partner's DNA? To contribute to the support and care of an infant or teen? Some of these family building options may seem incredible and others not suited to your own morals and values. One of these options is to receive donor eggs (oocyte donation).

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Alternative Family Building Options for Cancer Survivors

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If your body is no longer producing eggs, you can select eggs from a donation bank and even select physical or racial/ ethnic traits that match your own. The donated eggs can be fertilized with partner or donor sperm and the embryo implanted into your uterus or that of a surrogate. Another option is to select a donor embryo. Similar to an egg banks, these are banks of embryos created from other couples (usually as part of an IVF process) who have completed their families and allowed the embryos to be adopted by other families. One way to think of this is that it is like selecting a child for adoption.

Surrogacy can take many forms. A surrogate or gestational carrier can be used to carry an embryo to term for women who are unable to sustain a pregnancy. It may be the biological embryo of the couple, or an adopted embryo or even a combination of donor egg or sperm.

Traditional adoption of an infant or child is also an option, but in some states and countries it can be difficult for a cancer survivor to adopt due to their medical history. However, many survivors have built their families through private or international adoptions. There are several forms of adoption: agency, independent, open vs closed.

Some women decide to be connected to the lives of children through stepparenting or through involvement with nieces and nephews or god-children. Still other women find that a childfree life suits their career goals. It is important to know the alternative family building options that exist as well as to examine your goals and wishes.

Resources:

Egg donation

Perspectives on adoption after cancer

Financial Assistance

Cancer Friendly
Adoption Agencies

Blind Faith – The Story of My Two Beautiful Daughters

by Mrs. Daran Gowen, Learning Support Teacher, Somerset West, Capetown, South Africa

I was diagnosed with breast cancer at the tender age of 32. My mother had been diagnosed with bilateral breast cancer in her 40's, and my maternal grandmother had died of ovarian cancer at 51, so I always knew that I might be a carrier of the breast cancer gene. However, nothing can ever prepare you for the devastating news that you have cancer. I was young, relatively healthy, had the best job I had ever had and my future career and life doing something I loved was spreading out before me, like a glorious golden path. That all came to a crashing halt with my biopsy results, confirming a highly aggressive, triple-negative malignant breast tumour.

Nearly a year later, after surgery for a lumpectomy, extensive radiation, and nasty chemotherapy, I returned to work and started to put the pieces of my life back together and think about my future. I always knew that I wanted to have children, and had come close to finding a wonderful partner to share

my future with. But when faced with a life-threatening cancer, I made the tough choice to undergo chemotherapy that would possibly render me sterile for the rest of my life. My diagnosis was so serious that I wasn't even advised to think about alternative means to maintain my fertility. My oncologist wanted to start my treatment as soon as possible. However, by some miracle, my cycle was never affected by my CMF-chemo. That was a huge relief and confidence builder for me - at least something in my body was still relatively normal!

Through my cancer treatment, I parked any ideas or aspirations for my future. I think many cancer patients share a similar experience. During treatment, you are too overwhelmed, tired, fragile and scared to think ahead or do anything much but survive the treatment. But when it was over, I had many serious issues to face. I worried about the effect my cancer would have on my self-image and esteem. Would any man ever want to get involved with me again, and how would I discuss my scars?

However, I experienced so many wonderful gifts during this time. I had an amazingly supportive family, friends and church to help me get back on



my feet. Our wonderful church pastor helped me renew my confidence as a young single person and face my fears of getting involved in a relationship again. With time, my ex-boyfriend and I got back together, became engaged, and got married a year later.

For me, getting pregnant was a very complex issue. I was told my fertility would be affected, and the effect of chemotherapy on the fetus was unknown. More importantly, I knew getting pregnant would have an impact on me and was risky. I wondered was it even irresponsible

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Blind Faith - The Story of My Two Beautiful Daughters

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for me to bring children into the world, with the risk of them also carrying the breast and ovarian cancer gene. I suppose it helped that I was positive, strong-willed and determined to not let cancer take over my life. I also had a very good relationship with my oncologist, and I shared my aspirations to be a mother. He encouraged me to try and have a 'normal' life, and recommended I wait a year after my scans were clear before trying to conceive.

I came home from work one Friday night, feeling unusually tired and queasy. It was then I realized I was pregnant! I was so gloriously happy! It was a dream come true, and something I never thought could happen. I had a completely normal pregnancy and gave birth to my daughter in 1998. Five years later, a second pregnancy resulted in another beautiful, healthy baby girl. We named both girls after types of flowers as they are the blossoms of my life. I have had 16 wonderful years of fun and adventures with them, and being a mother has been my greatest joy in life.

I was free of cancer for over 16 years, until 2012, when I found another small breast lump which turned out to be malignant, and I opted for a full mastectomy. Having to go through breast cancer with any age children is very traumatic, but with help and

support, we survived my recurrence as a family. It does cause me anxiety that they will have to face the possibility of having breast cancer, but I am optimistic that improved detection techniques and treatment options will mean that, in the future, even if a particular patient's breast cancer cannot be cured it will be treated as a chronic condition and not a life-ending disease. Perhaps my approach has been risky, but my life has been so much richer as a result of having children after breast cancer. Of course, it wouldn't have been possible without an understanding and supportive partner, who has been through a lot! But that is a story for another time.

Fertility Preservation: Finding Hope for

Finding Hope for Building a Family

by Emma Marquez, LBSW and Anne Marie Norman, LIVE**STRONG** Foundation

Survivors who reach out to the Foundation regarding LIVESTRONG Fertility run the gamut: young men and women still in school; childless married couples; single professionals; small families with the potential to grow. None of these survivors anticipated a series of strategic phone conversations and appointments with sperm banks or fertility centers when they envisioned bringing children into the world.

An increasing number of oncologists are including fertility on checklists addressing concerns of newly diagnosed cancer survivors. The concern is real; cancer treatments can affect post-treatment fertility and family building in many ways. An individual cancer survivor's infertility risk is unique and dependent on factors that include treatment type, age, and cancer diagnosis. Each survivor should ask their oncologist or a reproductive endocrinologist about his or her individualized risk.

LIVESTRONG

FOUNDATION

There is hope for a family after treatment – reproductive technology allows for the preservation of gametes (sperm, eggs or embryos) before undergoing treatment. Then, after treatment, assistive reproductive technology (ART) can be used to achieve a pregnancy. Other options, such as donor sperm or eggs, surrogacy, and adoption are also available for exploration.

Fertility concerns are on the radar, but many cancer survivors are suffering extreme disbelief as they research options for fertility preservation and post-treatment family building. A young couple interested in preserving embryos in anticipation of the female partner's cancer treatment could incur a cost of approximately US\$12,400 per cycle. The couple may also pay nearly US\$400 per year for long term storage of the frozen tissues.

The price tag of fertility preservation is a barrier for many survivors who hope for a family. In response to this need, the LIVE**STRONG** Foundation and other leaders in the field of fertility have created financial assistance programs to support those who want to bear children

post cancer treatment. LIVE**STRONG**Fertility provides discounted rates for preservation and free fertility medications for women. Other organizations offer family building grants that cover expenses such as in-vitro fertilization, adoption, surrogacy, and more.
Similarly, many individual fertility centers make efforts to discount and finance procedures for cancer survivors.

The hidden costs of fertility preservation and family building are a significant challenge. But, resources exist to empower every cancer survivor, regardless of diagnosis, to hope for his or her ideal family after cancer treatment. Resources like LIVE**STRONG** Fertility's Emotional Support Navigators provide survivors and their loved ones a way to move forward, informed and empowered.

For more information on LIVE**STRONG** Fertility, visit: www.LIVE**STRONG**.org/Fertility.

Personal story: Luba Osinceva

Hello,

My name is Luba Osinceva and I am 61 years old. I am a director of the Post-Mastectomy Rehabilitation School, a public foundation. I am also a nurse, masseur, cosmetologist, instructor in exercise therapy and physiotherapist.

In 1999, I was diagnosed with breast cancer. At the time I felt physically healthy, but suddenly the word "cancer" was very frightening to me. I was shocked and scared. Luckily, I had my husband, my daughter, my sister and numerous friends to awake my desire and willingness to fight for life.



After the surgery I had an accurate diagnosis – stage IV breast cancer. I underwent a standard treatment: radiation therapy, surgery and chemotherapy. In addition, I used complementary treatments: herbal medicine, dietary supplements and exercises.

My husband and friends helped me to restore my health after treatment. I really needed that help, especially the moral support, because my health was seriously compromised and I was about to give up. They did not let me. They helped me to survive. In addition, my faith in God supported me and even strengthened during my illness. Having survived cancer helped me to understand that there is nothing more precious than life, and there cannot be anything more precious than this gift of God that we get only once. But the main reason why I could not give up to the illness was my little daughter who, at the time, was only 6 years old.

Unfortunately, cancer is very common nowadays. But I concluded for myself that there are no incurable diseases and that if one *can* fight he or she *must* fight for life.

Many people saw my struggle during my illness and, after I had conquered it, many of them started asking me for an advice. I was very happy to help them with all possible suggestions that I could give.

In 2010, several other survivors and I organized the Post-Mastectomy Rehabilitation School, the purpose of which is to:

- help women who are healthy prevent advanced illness by undergoing medical examinations on a regular basis,
- help women who are ill keep a positive attitude and believe that cancer is curable, and
- help those who have already undergone treatment to rehabilitate and lead a healthy lifestyle.

Unfortunately, many people leaving hospitals after treatment are not provided with any kind of rehabilitation plan, which makes it very hard for them to adapt and live after surgeries and treatments. The Post-Mastectomy Rehabilitation School provides hope to many women by welcoming them and providing the help they need.

Breast cancer information and support – pregnancy, fertility, young women and more

Breast Cancer Care UK

Breast cancer during pregnancy is rare and women who are diagnosed with it at this time often feel very isolated. That's why UK breast cancer support charity Breast Cancer Care has tailored information freely available for women in this situation.

As well as web-based text, anyone can download free factsheets from the website. These include the titles:

- Breast cancer during pregnancy
- Treating breast cancer
- Fertility issues and breast cancer treatment
- Younger women with breast cancer.

As with all Breast Cancer Care's patient information, the treatments and care pathways discussed refer to UK guidelines,

so not all of it is relevant worldwide. However, they contain plenty of useful and important information. And it is reviewed regularly by healthcare professionals and people with relevant experience related to breast cancer to ensure it is accurate and user-friendly.

Nine languages

There is also more general information on **Diagnosing and treating breast cancer** available free in nine languages, both as text and audio files. People can either access files online or download them in the following languages:

- Arabic
- Hindi
- Bengali
- Polish
- Cantonese
- Punjabi
- French
- Urdu.
- Gujarati

Breast Cancer Care is the only UK-wide charity providing specialist support and tailored information for anyone affected by breast cancer. Our clinical expertise and emotional support network help thousands of people find a way to live with, through and beyond breast cancer.





Making fertility decisions after breast cancer

Breast Cancer Network Australia (BCNA)

Fertility is a priority for many young women with breast cancer, but too often they receive varying guidance about how to make important decisions about future family planning.

In Australia, approximately 3-7% of women with early-stage breast cancer are under 40 years of age at diagnosis. Most young women diagnosed with breast cancer undergo chemotherapy, which often leads to reduced fertility.

After being diagnosed with early breast cancer, many young women will need to make quick decisions as to whether to preserve fertility before they start chemotherapy. It is crucial these women are given clear and current information about their fertility choices soon after diagnosis. Breast Cancer Network Australia's (BCNA) Fertility-related Choices: A Decision Aid for Younger Women with Early Breast Cancer is a free booklet for young women who have recently been diagnosed with early breast cancer.

There are a number of methods for preserving fertility. Younger women who are planning to become pregnant in the future, or even those who haven't given children much thought, should be encouraged to consider some of these options before they start cancer treatment.

The booklet contains information about cancer treatment, how it can affect fertility, and fertility options to consider.

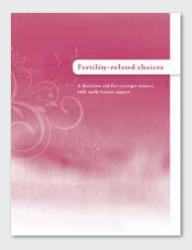
It may be helpful to young women who:

- have recently been diagnosed with early breast cancer
- are still of reproductive age (having regular periods and no menopausal symptoms)
- are thinking of starting a family or having more children in the future.

The booklet is a unique collaboration between University of New South Wales and BCNA. Health care professionals are encouraged to seek out the free resource and use it to help start a discussion about fertility with their patients.

Maxine Morand, BCNA CEO, reports that fertility concerns are sometimes overlooked by health professionals when younger women are diagnosed with breast cancer or undergoing treatment, despite this being an issue of huge importance to individual women. According to Maxine, "Younger women diagnosed with early breast cancer need to make decisions quickly about their fertility, and whether they would like to pursue fertility preservation measures. This decision needs to be made before beginning chemotherapy." She adds that young women need to be better supported and informed when reaching decisions about fertility: "We know that fertility is an extremely important issue for younger women newly diagnosed with breast cancer but in the past information available was often inadequate."

Maxine says BCNA's booklet helps health professionals better navigate this often complicated issue with their younger breast cancer patients: "This fantastic



resource helps professionals to broach this issue with their patients and help ensure younger women are provided clear and current information about their fertility choices soon after diagnosis."

The booklet is available online at www.bcna.org.au/store/products/fertility-related-choices-decision-aid. For Australian residents, a hard copy can also be ordered by calling BCNA on freecall 1800 500 258. *Please note: Due to limited supply there is a maximum of 3 booklets per order.*

About Breast Cancer Network Australia (BCNA)

Breast Cancer Network Australia (BCNA) is the peak national organisation for Australians personally affected by breast cancer. BCNA works to ensure that Australians affected by breast cancer receive the very best support, information, treatment and care appropriate to their individual needs.

Visit us at www.bcna.org.au to find out more about our programs and services, including the free *My Journey Kit* for Australian women newly diagnosed with breast cancer.

"Um Balão, Uma Vida" (A Balloon, a Life)

by Sofia Abreu, National Coordinator of Movimento Vencer e Viver

Within the context of the national day of breast cancer prevention, on October 30th 2013, the Portuguese League Against Cancer's Reach to Recovery peer support group, Movimento Vencer e Viver, promoted a national action called "Um Balão, Uma Vida" (A Balloon, a Life) by releasing, at the same time, 5,000 pink balloons, distributed in five cities around the country: Lisbon, Oporto, Coimbra, Funchal and Angra do Heroísmo.

On this day, joined by a common purpose, the volunteers of Movimento Vencer e Viver wished to alert Portuguese women to the importance of screening and early detection in fighting breast cancer.

Each of these balloons corresponded to a new case of breast cancer that arises every year in Portugal.

The 5,000 balloons soared into the sky, simultaneously in 5 cities, and raised awareness of the importance of screening and early detection of breast cancer.

http://www.ligacontracancro.pt



2014: Galvanising efforts to achieve the World Cancer Declaration Targets

Union for International Cancer Control (UICC)

In 2014, the Union for International Cancer Control (UICC) will be working with its 800+ members in 155 countries to help translate global commitments to noncommunicable disease (NCD) prevention and control into concrete actions to reduce the cancer burden, based on comprehensive national cancer control plans.

To support these efforts, in November 2013, at the World Cancer Leaders' Summit in Cape Town, South Africa, UICC launched a refreshed World Cancer **Declaration** including 9 targets and one overarching goal: There will be major reductions in premature deaths from cancer, and improvements in quality of life and cancer survival rates. By more closely aligning the Declaration with the emerging global NCD framework (including the Global Monitoring Framework for NCDs, Global NCD Action Plan 2013-2020 and Global Coordinating Mechanism for NCDs) and the post-2015 development discourse, UICC believes that the Declaration targets will resonate more widely, allowing the

cancer community to reach out to nontraditional partners in the development, disability, education, employment and many other sectors for innovative partnership.

The Declaration targets span the entire continuum of care for cancer, and have been enhanced to acknowledge the importance of quality cancer care, and equitable access to effective, safe patient-centered services that are critical to the management of breast cancer. Declaration targets 6 and 7 refer specifically to the need for affordable early detection programmes including breast cancer screening, as well as accurate diagnosis and referral, and access to multimodal treatment including surgery, systemic therapy and radiotherapy.

UICC encourages breast cancer advocates to use the Declaration:

To urge governments to implement policies and programmes that the cancer community knows will be successful if they are adequately resourced and embedded within national cancer and NCD plans.

To reach out beyond health ministries to gain the political backing of all sectors of government for a health systems approach to breast cancer control www.portal.bhgi.org

To continue pressing for cancer and other NCDs to be embedded within the next generation of internationally agreed development goals.

This year old **World Cancer Day (4 February)** a 2nd edition of the UICC's
Advocacy toolkit was launched, including
a series of evidence sheets that support
each of the World Cancer Declaration
targets, practical advocacy tools,
and a guide to mainstreaming cancer
in the post-2014 agenda. For more
information on the 2014 World Cancer
Day campaign, "Debunk the myths"
please visit: www.worldcancerday.org





JOINING FORCES — ACCELERATING PROGRESS



SAVE THE DATE

MELBOURNE WELCOMES DELEGATES TO THE 23RD UICC WORLD CANCER CONGRESS

3-6 DECEMBER 2014

PRELIMINARY PROGRAMME
AVAILABLE MID-SEPTEMBER 2013
AND REGISTRATION SHORTLY AFTER

PLEASE VISIT
WORLDCANCERCONGRESS.ORG



eld in conjunction with the Clinical Oncology Society of Australia (COSA) Annual Scientific Meeting

Scars with Blessings – Extending My Dreams with Powerful Love

Xiuman Wu, Taiwan Breast Cancer Alliance (TBCA)



In 1997, at the age of 27, Xiuman Wu was diagnosed with stage III breast cancer. Now, 17 years later, she has four children. During recent years she has fulfilled dreams with her peer support group, including taking family wedding pictures and climbing the highest mountain in Taiwan - Jade Mountain (3,952meters). Even though she faced challenges in the training process, she conquered the mountain and created a wonderful memory. Through her story, she encourages people affected by cancer and brings hope to young survivors.

Xiuman Wu's Personal Story

Close your eyes. Imagine a doctor informing you: "You have cancer." What thoughts go through your head? It was April of 1997, during the spring of my life, when I learned that I had breast cancer and it had already spread to 15 lymph nodes. This unexpected turn in life resulted in many "impossible" things coming true. Reflecting back, breast cancer was actually God's blessing in disguise - a blessing that has grown over the years. The first blessing came in October of the same year when I married my Canadian boyfriend of six years. During this most difficult time he continued to love me, just as Jesus's love encouraged me to push forward. A year after chemotherapy, while still using Tamoxifen and despite taking precautions, I found myself pregnant, and in May of 1999, God gave us a second blessing – a beautiful baby girl. Forgetting my health issues, I was determined to have another baby.

Three miscarriages and three years later, a 0.6cm object was discovered in my lung. After an unsuccessful operation, the lump was monitored for over a year until I became pregnant again. Blessings three and four came 9 months later: a baby boy and the lump disappearing. God's grace did not stop - two more children followed. It was as if God had replaced the three miscarriages with three healthy children

In 2012, a cook book for cancer patients resulted in my connecting





with Taiwan Breast Cancer Alliance (TBCA). Because of TBCA, I started to courageously dream. In 2013, I participated in mountain climbing activities and concurrently started to write poetry and songs, dreaming of praising God with one of my songs at the peak of Mt. Jade. Three days before the climb, a routine check-up revealed 2 lumps where my right breast had been. I dared not tell others for fear my dream would die. As the remembrance of the pain of chemotherapy flooded over my mind, and the realisation of the potential need to start it again, the tone

and contents of my songs deepened. Only after descending Mt. Jade, did I tell others and then underwent surgery. The biopsies showed the lumps were benign. The scars left by the knife are to me a reminder of God's mercy and grace.

In retrospect, as a mother of four children, the past 17 years have been occupied with raising children. To others this may seem not to be any significant contribution, but I believe that my life has been filled with grace and mercy and that I will increasingly experience God's grace and mercy as I grow old.

Emerging international directions in psycho-oncological care Supporting women affected by breast cancer with pregnancy and fertility issues



Prof Jeff Dunn Chair, RRI Board of Management Secretary, International Psycho-Oncology Society CEO, Cancer Council Queensland

2014 marks 30 years since the founding of the International Psycho-Oncology Society, an affiliate of RRI. The organisation was formed in response to the need for international cooperation across medical and scientific disciplines to investigate and improve psychosocial care and quality of life for cancer patients. The founding members of IPOS identified a gap in clinical understanding of the psychological, social, and behavioural issues in cancer care, and set about addressing these through research, advocacy, and education related to the subspecialty of psycho-oncology.

The formation of IPOS was one of the early significant steps towards universal acknowledgement of the importance of psycho-social care in cancer control, signposting the establishment of psychooncology as a specialist discipline. Since then, an abundance of emerging evidence has demonstrated a relationship between psycho-social care and patient quality

of life, underpinning the advancement of psycho-oncology research and practice. In many jurisdictions, including the United States of America (USA), Canada, the United Kingdom, and Australia, this advancement has been guided by patients themselves, who have demanded a more holistic quality of care pivoting on patient-centred service.

Outcomes include action by the USA's Institute of Medicine (IOM) in 2008 to integrate psycho-social care into routine clinical practice, establishment of the IPOS International Standard of Quality Cancer Care in 2010, and refresh of the Union for International Cancer Control's (UICC's) World Cancer Declaration in 2013 to call on all nations to provide cancer patients with universal access to distress management.

Today, much work remains to integrate best-practice psycho-social care into routine clinical oncology practice on a worldwide scale, leveraging from partnerships and collaborations between groups such as IPOS and RRI. Closer cooperation between nongovernment organisations, international associations, health policy makers, medical professionals, government bodies and civil society is key to future progress. Emphasis must be placed on communication and collaboration, across disciplines and sectors, in order to achieve collective aspirations for higher standards of quality cancer care.

Future challenges and opportunities

Over the course of 30 years the pioneers of psycho-oncological care have forged significant progress. They have informed our medical and scientific understanding of mental health as it relates to quality of life, disease progression, and survival. They have helped to investigate and explain the psychological, behavioural, and social factors that influence cancer control, enhancing efforts to improve public health through scientific discipline. They have advocated for patient quality of life and

universal access to supportive care. And they have persisted in their striving to overcome a complex challenge. That is, how to enable the integration of bestpractice psycho-social care into routine cancer clinical practice, on a global scale.

While the dimensions of the challenge are considerable, the opportunities for addressing it are multiplying, through the concerted efforts of cancer control stakeholders to work in collaboration and partnership. Recent progress suggests that the international influence of psycho-oncology will continue to be defined by collaborative efforts to enable the translation of research into practice. The development of costeffective and culturally appropriate strategies to underpin psycho-oncological care will be particularly important in driving a global agenda for change. As will global demand from patients for comprehensive cancer care.

There can be no doubt that psychooncological care has a pivotal role to play in informing peer support and outreach for women affected by breast cancer, helping to improve coping and adjustment in relation to issues such as pregnancy and fertility, along with all aspects of each woman's cancer experience.

International Psycho-Oncology Society website, 2014. IPOS History, Vision and Mission. Retrieved January 2, 2014, from http://www.ipos-society.org/about/history_vision_mission.aspx.

Watson, M, Dunn, J, Holland, JC: Review of the history and development in the field of psychosocial oncology. International Review of Psychiatry, Early Online: 1–8, 2013.

Bultz, BD, Holland, JC: Emotional distress in patients with cancer: the sixth vital sign. Community Oncology 3:311-314, 2006.

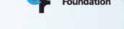
Watson, M, Dunn, J, Holland, JC, op. cit.



Psychosocial Academy of the International Psycho-Oncology Society.

This year we are celebrating our 30th anniversary and have prepared a very exciting congress under the main theme:

Integrating Psycho-Oncology into mainstream cancer care: from research to action.







ABSTRACTS SUBMISSION IS NOW OPEN







LIVESTRONG **Fertility Program**

by Ashley Koenings and Jamie Hill

Sarah Lisle was 25-years old when she was diagnosed with breast cancer. At the time of her diagnosis, no one discussed how treatment might affect her fertility or presented her with options for fertility preservation. Sarah was unmarried, and the thought of having children was far from her mind. She just wanted to get past treatment and move on with her life, which she did.

Five years later, Sarah was married and had a newly purchased home in Austin, Texas. She was two months shy of finishing a five-year course of tamoxifen, a drug used to combat estrogen-driven breast cancer. She and her husband were getting excited at the prospect of finally starting a family of their own. Then Sarah found a new lump. It was cancerous and estrogen-driven, which meant her oncologist would likely recommend the removal of her ovaries. The hope of having children suddenly started to diminish for Sarah and her husband.

Sarah's oncologist sprang into action and advised her to freeze embryos

LIVESTRONG

FOUNDATION

for the opportunity to have children in the future. That's when she was connected to the LIVESTRONG Foundation and the LIVESTRONG Fertility program (formerly Fertile Hope).

One of the goals of LIVESTRONG Fertility is to increase access to fertility preservation services and treatments for men and women diagnosed with cancer. This is primarily accomplished through a collaborative program that works to reduce the financial barriers for fertility preservation. LIVESTRONG works with

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LIVESTRONG Fertility Program

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nearly 400 fertility centers across the U.S. that have agreed to discount their fertility preservation services at least 25 percent to men and women diagnosed with cancer. In addition, women receive a free round of pre-cycle hormone medications, which amounts to more than \$4,000 in savings per woman.

For men and women diagnosed with cancer, this financial assistance can be the difference between being able to preserve fertility and being unable to do so. These individuals face mounting medical bills and, unfortunately, the cost of fertility preservation is not cheap. For example, a woman hoping

to preserve her embryos prior to treatment could be looking at a price tag of \$12,400. Typically none of these expenses are covered by insurance plans. Since 2004, cancer survivors have saved nearly \$13 million in fertility center discounts and medication costs through LIVE**STRONG** Fertility.

LIVESTRONG aims to increase awareness about fertility and cancer among healthcare professionals through professional education slides that answer a lot of important questions about fertility preservation for oncology patients. The foundation also aims to empower cancer survivors to explore

options and get educated through online tools like the Fertility Risk Tool and the Family Building Options Tool.

In April 2011, Sarah and her husband were able to welcome a baby girl, Lillian DeAnne, into the world. Through increased awareness and reduced financial barriers, LIVE**STRONG** tries to increase hope among cancer survivors to build families of their own in the future.

See more of Sarah's story at: www.LIVE**STRONG**.org/Sarah and learn more about LIVE**STRONG** Fertility at www.LIVE**STRONG**.org/Fertility

A performancelife e.V. – empathy for and solidarity with people suffering from cancer

by Siglinde Kallnbach and Marianne Koch, Cologne, Germany

On March 4th, 2014, they marched for the 4th consecutive year: a performance life e.V. once again particiapted in the annual carnival-parade in Cologne-Ehrenfeld.

A performancelife e.V is the creation of the performance artist Siglinde Kallnbach and is meant to convey empathy for and solidarity with all people suffering from cancer. Kallnbach developed the evolving, participatory performance in 2001, after her own cancer diagnosis in 2000. She also organizes exhibitions and other types of performances by recruiting other participants and serving as conductor.

In Kallnbach's words, "Colourfulness and happiness of Carnival are good medicine for cancer patients." "We always have a lot of fun," adds Jürgen Raap, the artist who paints the beautiful canvases that are carried during each of the carnival-performances.

You can view previous performances by visiting http://www.verein-a. performancelife.com and clicking on "video."

Top: Siglinde Kallnbach (orange hair and skirt) and Jurgen Raap, just behind her (red hair). **Bottom:** Participants in the 2013 performance of a performancelife e.V at the carnival-parade in Cologne-Ehrenfeld.







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

Turkey Bites

Submitted by Mrs Mary Hemrajani, Vice Chairman, Hong Kong Breast Cancer Foundation

Preparation time: 10-15 minutes Cooking time: 20 minutes Serve 4-5 persons

Ingredients

- Minced turkey 450g or 1lb (approximately)
- ½ Onion (finely chopped)
- 2-3 gloves garlic and small piece of ginger (finely chopped)
- Green parsley (finely chopped)
- 85 g porridge oats (approximately)
- 1 egg white, beaten
- Lettuce piece for serving
- 2 tsp virgin olive oil
- Salt and pepper to taste

Method

- Mix all dry ingredients: minced turkey, chopped onion, ginger, garlic, parsley, oats in a bowl. Add salt and pepper and season to taste.
- Add 2 teaspoons of olive oil and beaten egg white.

- Mix well with your hand, the mixture should stick together, if the mixture is too wet, add more oats to absorb the moisture.
- Shape the mixture into small patties.
- Heat up a non-stick frying pan and sear the turkey patties on each side until well coloured (3-4 minutes).
 Shallow fry till fully cooked.
- Serve in lettuce leaves as it is or with tangy tomato mint salsa.

Cooking tips

- Make smaller size patties to avoid overcooking the turkey patties.
- Best serve with Tomato Mint Salsa:
- Mix tomato, mint leaves, lime juice, ginger, chili (optional) and olive oil in a mixer. Season to taste.

Healthy tips

- Turkey meat is low fat, low calorie and low in cholesterol, at the same time it is rich in vitamins and protein. It is known to be one of the healthiest white meat.
- Oat is high in dietary fibre, vitamin A, vitamin B complex, magnesium etc...It also helps to lower our cholesterol.
- Virgin olive oil is monounsaturated fat, it is known to be good for health.

Reach to Recovery International Governance Structure

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Events

Glasgow, Scotland

9th European Breast Cancer Conference (EBCC 9) 19 –21 March 2014

www.ecco-org.eu

Melbourne, Australia

2014 World Cancer Congress 3 – 6 December 2014

www.worldcancercongress.org

Lisbon, Portugal

16th World Congress of Psycho Oncology

20 - 24 October 2014

www.ipos-society.org/ipos2014

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.

Reach to Recovery International

is a program of the Union for International Cancer Control and is administered by Cancer Council Queensland.

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.





