bloom

ISSUE 24 JUNE 2017

REACH TO RECOVERY INTERNATIONAL

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

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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.

Upcoming events

Berlin, GERMANY
IPOS World Congress of Psycho-Oncology
1-4 August 2017
www.ipos2017.com

New Delhi, INDIA
RACE to rein-in-cancer International Oncology Conference
18-19 November 2017
www.race2ric.org

Kathmandu, NEPAL
International Cancer Conference on the Challenges for Cancer Control in Developing Countries
18-19 January 2018
website pending

Kuala Lumpor, MALAYSIA
UICC World Cancer Congress
1-4 October 2018
www.worldcancercongress.org

Prague, CZECH REPUBLIC
19th RRI Breast Cancer Support Conference
12 – 15 June 2019
website pending

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 August 2017. Regardless of whether your suggested theme is chosen this time, it will remain under consideration for future editions.

SUBMIT YOUR ARTICLE

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Bloom is published by Reach to Recovery International, Inc. 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

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

Preparations now underway for World Cancer Congress Malaysia 2018

Reach to Recovery International is currently accepting applications to host the 20th RRI Breast Cancer Support Conference! Now that plans are underway for the 19th RRI conference, which will be held in Prague, the Czech Republic, on 12 -15 June 2019, we are welcoming bids from organizations interested in hosting the 20th conference in 2021. Please note that RRI Breast Cancer Support Conferences are large in scale and the official language is English. We always welcome bids from organizations interested in hosting smaller scale, regional conferences suitable to our delegates.

A copy of the Selection Criteria for bid proposals can be downloaded here.

REACH TO RECOVERY INTERNATIONAL

www.ipos2017.com

Message from Cathy Hirsch - President of RRI

Cathy Hirsch

It is with great pleasure that I announce the location and date of the 19th Reach to Recovery International Breast Cancer Support Conference! We will next meet on 12 – 15 June, 2019 in Prague, the capital city of the Czech Republic. Our host, the Alliance of Women with Breast Cancer (AWBC), serves as an umbrella organization for 45 patient groups throughout the Czech Republic and is a member of Europa Donna. AWBC, with support from the Czech Society of Medical Oncologists, the Association of Czech Breast Radiologists, and Masaryk Memorial Cancer Institute, is developing an in-depth program with the theme "Building Bridges Toward Recovery." The program will feature presentations from internationally renowned experts in the field of breast cancer support and care. As always, the conference will offer many opportunities for networking, socializing, and sharing best practices.

The conference website will be available in January of 2018, and early-bird registration will begin at that time. We are delighted that this early announcement allows ample time for our members to plan, and we are excited to welcome you to one of the most beautiful cities in the world!

What's in this issue?

We are constantly hearing about new developments in research and treatment that are saving or extending lives and often improving the quality of life of women with breast cancer. In this issue, we examine some of the more promising or in some cases controversial developments. Please keep in mind that, in keeping with Reach to Recovery principles regarding neutrality when it comes to patients making decisions about their medical care, RRI neither endorses nor condemns any of the studies or trials or the treatments resulting from them.

Many breast cancer patients and survivors struggle over making decisions on whether to undergo genetic testing. Our medical editor, Dr. Mirat Shah, presents a comprehensive overview of exactly what genetic testing can and cannot tell us. From Greece, we hear from Joanna Grecos about a program there that's designed to help women there make informed decisions about genetic testing.

Aromatase inhibitors, which lower the amount of estrogen in the body, have become the standard of care for post-menopausal patients whose breast cancer is estrogen receptor positive. Unfortunately, these drugs sometimes come with unpleasant side effects that can range from mild to severe. We have included a report from the USs National Cancer Institute about a clinical trial that is examining the effectiveness of a common anti-depressant in managing joint pain caused by aromatase inhibitors. In addition, Janine Porter-Steele, a Breast Care Nurse in Brisbane, Australia, has provided and overview of when and why aromatase inhibitors are prescribed. In a similar vein, we have a report on two drugs that, when used in conjunction with an aromatase inhibitor, have proven to extend the lives of post-menopausal women with metastatic breast cancer.

Hair loss from chemotherapy can add even more distress to patients undergoing cancer treatment. The American Cancer Society summarizes what's known so far about "cooling caps," which some patients are trying in hopes of keeping their hair. The Society also reports on a small number of studies examining whether marijuana can help with some side effects from cancer treatment such as nausea, vomiting, and neuropathic pain.

Dr. Isabel Rubio of Spain and Professor Riccardo Audisio of the United Kingdom discuss nipple-sparing mastectomy surgery as well as their joint efforts to create an international registry that should help establish exactly when the surgery can be safely offered. From Cape Town, South Africa, breast surgeon Dr. Jenny Edge reviews the controversy over whether breast surgery can be beneficial for women with metastatic breast cancer.

When we think about cancer research, those of us who aren't physicians or scientists usually don't think that we could be part of a research team. Leonie Young of Brisbane, Australia is the Chair of the Consumer Advisory panel for the Australia & New Zealand Breast Cancer Trials Group. She explains that lay persons such as ourselves can play very important roles!

We will also share, in this edition, news from members in Portugal, Greece, Nepal, India, and South Africa. As long promised, we have included a working link to survivor and artist Shirley Bianca's Message of Hope – a series of beautiful paintings, put to music, that chronicles Shirley's breast cancer experience. From now on, you will also be able to access Shirley's Message of Hope on the Media page of reachtorecoveryinternational.org.

To whet your appetite for the 19th Reach to Recovery International Breast Cancer Support Conference, our Global Kitchen features a recipe from the Czech Republic. Enjoy!

For Some Breast Cancer Survivors, Drug May Reduce Treatment-Related Joint Pain

By NCI staff, USA

Istock

A drug most commonly used to treat depression may also reduce joint pain in some women being treated for early-stage breast cancer, according to the results of a randomized clinical trial.

After undergoing treatment for early-stage breast cancer, many postmenopausal women take drugs known as aromatase inhibitors to reduce the risk of the cancer returning. These drugs, however, can cause significant pain in women's joints and muscles.

The clinical trial showed that duloxetine (Cymbalta®), which is approved to treat depression and anxiety as well as fibromyalgia and nerve pain caused by diabetes, provided some relief from pain associated with aromatase inhibitors.

"Joint and muscle pain can lead some patients to discontinue treatment with these life-saving medications," said N. Lynn Henry, M.D., Ph.D., of the Huntsman Cancer Institute at the University of Utah, who led the study. "Based on our results, duloxetine seems to be an effective drug for some patients who experience this pain."

Dr. Henry presented findings from the study, which was led by the NCI-supported clinical trials group SWOG, at the San Antonio Breast Cancer Symposium on December 9.

New Strategies Needed

The body uses an enzyme called aromatase to make estrogen. Drugs that block the activity of this enzyme, called aromatase inhibitors, have been found to reduce the risk of cancer returning in postmenopausal women whose breast tumors rely on estrogen to fuel their growth.

But many patients taking these drugs experience pain in the knees, hips, hands, and wrists, which can make everyday tasks difficult. About 20% of patients stop taking aromatase inhibitors due to side effects, according to Dr. Henry. She noted that patients are generally recommended to take aromatase inhibitors for 5 to 10 years, so new strategies for managing the side effects are needed.

For the duloxetine trial, the researchers enrolled 299 women at 43 NCI Community Oncology Research Program (NCORP) sites across the United States. The women had been treated with aromatase inhibitors for early-stage breast cancer and were experiencing joint pain caused by treatment. The women were randomly assigned to receive a 12-week course of duloxetine or a placebo.

Participants completed questionnaires about joint pain, depression, and quality of life at the beginning of the trial, and then again after 2, 6, 12, and 24 weeks. The pain questionnaire used a 0-10 scale; the researchers defined a clinically significant change in average pain as a decrease of 2 or more points from the time a patient entered the study.

Duloxetine and Placebo Reduced Pain

Over the first 12 weeks of the trial, the pain scores of women in the duloxetine group fell an average of 0.82 points more than those of the placebo group. Other measures, including worst pain, joint pain, and stiffness, underwent similar declines.

For the duloxetine group, the average pain score decreased from 5.44 at baseline to 2.91 at 12 weeks. But the average pain score also dropped in the placebo group during the same period, from 5.49 to 3.45. Both reductions were clinically significant, according to the standards of the trial.

The finding of a strong placebo effect in the control group was not entirely unexpected, noted Dr. Henry. Other studies of treatments for pain have reported similar effects, although the reasons are not clear. "This trial demonstrates the need for more research" on responsiveness to placebo, she added.

By 12 weeks, 69% of patients in the duloxetine group and 60% of patients in the placebo group had a 2-point improvement in pain compared to before starting treatment. At 24 weeks, which was 12 weeks after the patients had stopped taking duloxetine or the placebo, the average pain scores were similar for the groups (3.37 in the duloxetine group and 3.42 for the placebo group).

The most common side effects of duloxetine were nausea, fatigue, and dry mouth, which is consistent with other studies involving the drug.

Exploring Multiple Approaches

"These results of the duloxetine study are very promising," said Ann O'Mara, Ph.D., of NCI's Division of Cancer Prevention, who was not involved in the study. "Duloxetine is the first drug to show a benefit for this population of patients in a large, randomized clinical trial."

Dr. O'Mara suggested that patients taking aromatase inhibitors might ultimately need to try multiple approaches to manage their pain. Exercise such as walking and acupuncture are among various strategies that are being studied as ways to reduce pain, she noted.

"Clinicians need to be clear with their patients about the potential side effects of duloxetine, but this drug may help patients decrease their pain and become functional again," she added.

Aromatase inhibitors: A frank discussion

By Janine Porter-Steele

Breast Care Nurse, Clinical Nurse Manager
The Wesley Hospital Choices Cancer Support Centre
Brisbane, Queensland, Australia

Janine Porter-Steele

Sally, age 56, has been prescribed Arimidex after her treatment. She is not sure why and is quite confused. Her breast cancer is oestrogen receptor positive, which she believes can't be right because she has been through menopause and her friend, Angela, had breast cancer but she hasn't been given this medication.

To answer Sally's question, there are some types of breast cancer that need the female hormone oestrogen in order to grow and keep producing cancer cells. These cancers are described as being oestrogen receptor, or ER, positive. Many women are confused as to why their breast cancer is oestrogen receptor positive when they have been through menopause. Simply put, even though Sally's ovaries no longer produce oestrogen, body fat does. Body fat uses an enzyme called aromatase to create small amounts of oestrogen. Aromatase inhibitors such as Arimidex prevent this enzyme from working by reducing the amount of oestrogen available to stimulate cancer production. This is also a good reason for maintaining a healthy diet and exercise to reduce excess body fat, especially around the middle!

An aromatase inhibitor will only be prescribed if your type of breast cancer has receptors in the cell that bind to the hormone oestrogen. All breast cancers are tested for this and other proteins to help determine treatment. It is likely Sally's friend, Angela, had a breast cancer that was hormone receptor negative so there was no benefit to her having this medication. Some women may have progesterone receptors that are positive but negative oestrogen receptors; the benefits of aromatase inhibitors are less clear in these instances, but your specialist will discuss this with you. Also, this type of medication is not usually given to women who are premenopausal and an alternative drug called tamoxifen is used. Researchers have found aromatase inhibitors can be more effective in postmenopausal women and have fewer concerning side effects than tamoxifen. Trials have begun in premenopausal women to see whether by suppressing ovarian function through other medications and giving an aromatase inhibitor a similar promising outcome can be achieved.

Sally is worried about side effects. She got very tired during her chemotherapy and felt unwell in the days after her treatment and her doctor has advised her she will be on this tablet for at least five years. She is further confused as she has read there are different aromatase inhibitors and she's not sure which one is best. Aromatase inhibitors include the drugs anastrozole (Arimidex), exemestane (Aromasin), and letrozole (Femara). They all work in very similar ways and are often prescribed according to doctor preference. Even though they have the same action, women who have side effects while taking one brand can sometimes swap to a different brand and have no side effects.

In general, aromatase inhibitors are lower in serious side effects than tamoxifen. The risk of blood clots or uterine cancer is negligible, but there are other important side effects. One is bone loss and an increased risk of osteoporosis. There are some simple strategies to manage this, such as: having regular bone density tests to detect changes; maintaining a diet with appropriate amounts of calcium (1300 mg per day for post-menopausal women); keeping check on Vitamin D levels, as Vitamin D encourages calcium uptake which helps support healthy bones; and engaging in regular, weight bearing exercise to help bones stay strong and healthy. Sally would benefit from seeing a physiotherapist or exercise physiologist who can help design a good exercise plan for her.

A common side effect of aromatase inhibitors is joint pain. Exercise can again help relieve some of these symptoms and sometimes fish or krill oil with Glucosamine can be helpful, but it is important before taking this or any other herbal medicine to check with the doctor or specialist first.

Sally says she is getting hot flushes and has heard aromatase inhibitors can make them worse. She wants to take an herbal supplement to reduce them. As with the fish oil supplements, Sally needs to check with her specialist about the advisability of taking supplements to reduce hot flushes. Many of these products are based on plant oestrogen, which may be a risk factor for recurrence of her breast cancer. There are some simple, practical ways for Sally to manage hot flushes, including avoiding alcohol, drinking plenty of water, dressing in layers, avoiding or learning to manage stressful situations, or taking a medication (other than Hormone Replacement Therapy) to control them. Sally would gain from talking more with her treating team and having an appointment with her breast care or cancer care nurse to discuss these concerns and gather some good practical strategies for managing them.

Sally requests some appropriate websites to help her access good, evidenced-based information to assist decision making and talking to her specialists regarding side effects. The list below is not exhaustive, but a quick tip is to use websites recommended by your treating team. Websites ending in .gov or .org, or are from well-known, established international organisations or treating hospitals, are generally reputable.

American Institute for Cancer Research (AICR). (2014) http://www.aicr.org/food-that-fight-cancer

American Institute for Cancer Research (AICR). (2013) http://www.aicr.org/reduce-your-cancer-risk/diet/elements_alcohol.html

American Institute for Cancer Research (2012) What you need to know about obesity and cancer. http://www.aicr.org/learn-more-about-cancer/infographic-obesity-and-cancer.html

Breast Cancer Care UK https://www.breastcancercare.org.uk/

Breast Cancer Network of Australia (BCNA) https://www.bcna.org.au/understanding-breast-cancer/treatment/hormone-therapy/

Jean Hailes for Women's Health https://jeanhailes.org.au/

Memorial Sloane Kettering Http://www.mskcc.org/cancer-care/integrative-medicine/about-herbs-botanicals-other-products

NIH Office of Dietary Supplements http://dietary-supplements.info.nih.gov

FDA Approves Ribociclib, Expands Palbociclib Approval for Metastatic Breast Cancer

By NCI staff, USA

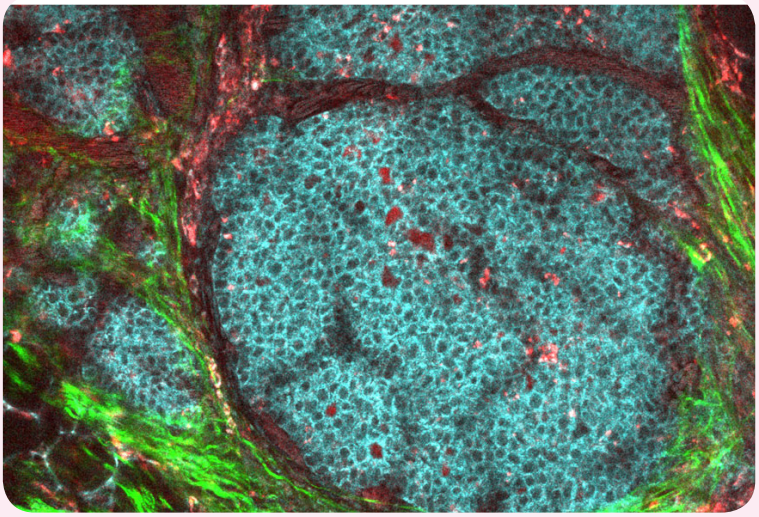

Image of a breast cancer tumor in a mouse. *National Cancer Institute.*

The Food and Drug Administration (FDA) has approved a new targeted therapy, ribociclib (Kisqali®), and expanded its earlier approval of palbociclib (Ibrance®), for the initial treatment of some women with breast cancer. Both drugs are approved in combination with an aromatase inhibitor for the treatment of postmenopausal women with advanced or metastatic breast cancer that is hormone receptor (HR) positive and HER2 negative.

In 2015, palbociclib was granted accelerated approval based on evidence from a phase II clinical trial. The FDA grants accelerated approvals based on preliminary evidence showing that a new therapy addresses an unmet clinical need. For the FDA to give the therapy regular approval, however, it requires more in-depth studies to confirm the clinical benefit. Palbociclib now has a regular approval based on positive results from a large phase III trial.

These approvals are likely to affect many patients with metastatic breast cancer, said Stanley Lipkowitz, M.D., Ph.D., chief of the Women's Malignancies Branch of NCI's Center for Cancer Research. "The vast majority of patients with metastatic breast cancer are HR positive, HER2 negative," he explained.

Both ribociclib and palbociclib work by inhibiting molecules that help control cell division called cyclin-dependent kinase (CDK) 4 and 6. These enzymes are commonly found in higher than normal amounts in breast cancer cells.

This class of drugs has had a tremendous impact on the length of time that advanced or metastatic breast cancer is controlled, Dr. Lipkowitz stressed.

"A CDK4/6 inhibitor combined with an aromatase inhibitor should be considered as first-line treatment for patients with advanced or metastatic breast cancer," he said.

Clinical Findings

The approval of ribociclib was based on interim results from a phase III trial of 668 postmenopausal women with HR-positive, HER2-negative advanced or metastatic breast cancer who had not received prior treatment for advanced cancer. The participants were randomly assigned to receive ribociclib plus the aromatase inhibitor letrozole (Femara®) or placebo plus letrozole. The trial was funded by Novartis, the manufacturer of ribociclib.

After 18 months of follow-up, the progression-free survival rate was 63% for the ribociclib group and 42% for the placebo group. The median time to disease progression was about 15 months in the placebo group and was not yet reached in the ribociclib group by the time of analysis. Approximately 53% of patients in the ribociclib group and 37% of those in the placebo group responded—that is, they had measurable tumor shrinkage after treatment.

The most common adverse events for patients in the ribociclib group were neutropenia, nausea, and infections. Significantly more patients in the ribociclib group than the placebo group had neutropenia or leukopenia—a side effect of CDK4/6 inhibition in blood cells.

The majority of serious adverse events experienced by patients in the ribociclib group were reversed by ribociclib dose reductions or interruptions, the study authors noted.

The expanded approval of palbociclib was based on a phase III trial (called PALOMA-2) of 666 women with HR-positive, HER2-negative breast cancer who were randomly assigned to receive palbociclib plus letrozole or placebo plus letrozole. Compared with placebo, palbociclib extended median progression-free survival by about 10 months, from 15 months in the placebo group to 25 months in the palbociclib group. About 55% of patients in the palbociclib group and 44% in the placebo group had measurable tumor shrinkage after treatment.

At the time of the analyses, the length of patient follow-up in both ribociclib and palbociclib trials was not long enough to determine whether the therapies improved how long patients live. Investigators from both studies are continuing follow-up and expect to report on overall survival in the future.

In combination with letrozole, both ribociclib and palbociclib had similar benefit and side effect profiles, said Dr. Lipkowitz. One difference between the two drugs is that ribociclib altered the heart rhythms of 3% of patients, while palbociclib did not have this effect, he noted. A direct comparison of the two drugs would require a separate study, he noted.

The bottom line, he continued, is that a CDK4/6 inhibitor—either ribociclib or palbociclib—may be used as first-line therapy for women with HR-positive, HER2-negative advanced or metastatic breast cancer.

Cooling Caps Show Promise in Reducing Hair Loss from Chemotherapy

By The American Cancer Society

Two studies by researchers from cancer centers across the US found that scalp cooling devices can often help reduce hair loss during chemotherapy. The studies looked at women undergoing chemotherapy for breast cancer. In both studies, scalp cooling was linked to the prevention of significant hair loss in about half the women using the devices. Both studies were published February 14 in the *Journal of the American Medical Association*.

Hair loss is a common side effect of certain types of chemotherapy – including the types often used to treat breast cancer. Although hair typically grows back after treatment ends, it can take a long time. Reducing this side effect is considered important to overall treatment by improving quality of life for many women. According to both studies, women rate hair loss as one of the most distressing side effects of chemo.

Scalp cooling devices, also called cooling caps or cold caps, are worn on the head during chemotherapy treatments to try to prevent or lessen hair loss. They are thought to work by tightening up blood vessels in the scalp, which reduces the amount of chemo that reaches cells in the hair follicles. They are also thought to decrease activity in the hair follicles, making them less likely to be affected by the chemo. Newer versions of these devices use a computer to circulate a cooled liquid through a cap that is worn during treatment. A second cap made from neoprene covers the cooling cap in order to hold it in place and keep the cold from escaping.

In one study, 182 women getting chemotherapy for breast cancer were randomly assigned to either a scalp cooling device or no scalp cooling. Those who wore the cooling cap were significantly more likely to have less than 50% hair loss after their 4th chemo cycle than those who had no scalp cooling. Some women reported minor side effects including headache, scalp pain, and skin problems.

In the other study, 106 women in a scalp cooling group were compared with 16 in a control group who did not use the device. Results were similar, in that women who wore the cooling cap had significantly less hair loss after 4 rounds of chemo. Side effects were similar, too.

Results varied depending on the specific type of drug the women received. Len Lichtenfeld, MD, deputy chief medical officer of the American Cancer Society, cautions women to fully understand the potential benefits and limitations of the devices before making the decision about whether to use them. He says any decision should be made after realistic and honest discussions with a woman's health care team.

Cold Caps

The study of 106 women used the DigniCap, the first scalp cooling device to be cleared for marketing by the US Food and Drug Administration (FDA). The other study used the Paxman scalp cooling system, which is currently being evaluated by the FDA. At this time, scalp cooling in the US with the newer systems costs about $1500 to $3000 total per person and so far is not likely to be reimbursed by health insurance, according to an editorial accompanying the studies. Other versions of cap cooling devices can be rented or purchased online, and some cancer treatment facilities in the US allow patients to use them.

Although cold caps have been around for many years, some doctors have been concerned they could interfere with chemo by keeping it from reaching any stray cancer cells lurking in the scalp. Some believe that the scalp cooling might protect any cancer cells there and allow them to survive the chemo and keep growing.

However, recent studies have shown no link between scalp cooling and cancer cells spreading to the scalp, or decreased survival among women with breast cancer. None of the women in the JAMA studies developed cancer spread to the scalp during the 2-to-3-year study periods; researchers will continue to monitor them for up to 5 years.

The American Cancer Society medical and editorial content team. Our team is made up of doctors and master's-prepared nurses with deep knowledge of cancer care as well as journalists, editors, and translators with extensive experience in medical writing.

Marijuana and Cancer

By The American Cancer Society

Marijuana is the name given to the dried buds and leaves of varieties of the Cannabis sativa plant, which can grow wild in warm and tropical climates throughout the world and be cultivated commercially. It goes by many names, including pot, grass, cannabis, weed, hemp, hash, marihuana, ganja, and dozens of others.

Marijuana has been used in herbal remedies for centuries. Scientists have identified many biologically active components in marijuana. These are called *cannabinoids*. The two best studied components are the chemicals *delta-9-tetrahydrocannabinol* (often referred to as THC), and *cannabidiol* (CBD). Other cannabinoids are being studied.

At this time, the US Drug Enforcement Administration (DEA) lists marijuana and its cannabinoids as Schedule I controlled substances. This means that they cannot legally be prescribed, possessed, or sold under federal law. Whole or crude marijuana (including marijuana oil or hemp oil) is not approved by the US Food and Drug Administration (FDA) for any medical use. But the use of marijuana to treat some medical conditions is legal under state laws in many states.

Dronabinol, a pharmaceutical form of THC, and a man-made cannabinoid drug called nabilone are approved by the FDA to treat some conditions.

Marijuana

Different compounds in marijuana have different actions in the human body. For example, delta-9-tetrahydrocannabinol (THC) seems to cause the “high” reported by marijuana users, and also can help relieve pain and nausea, reduce inflammation, and can act as an antioxidant. Cannabidiol (CBD) can help treat seizures, can reduce anxiety and paranoia, and can counteract the “high” caused by THC.

Different cultivars (strains or types) and even different crops of marijuana plants can have varying amounts of these and other active compounds. This means that marijuana can have different effects based on the strain used.

The effects of marijuana also vary depending on how marijuana compounds enter the body:

- When taken by mouth, such as in baked goods, the THC is absorbed poorly and can take hours to be absorbed. Once it’s absorbed, it’s processed by the liver, which produces a second psychoactive compound (a substance that acts on the brain and changes mood or consciousness) that affects the brain differently than THC.
- When marijuana is smoked or vaporized (inhaled), THC enters the bloodstream and goes to the brain quickly. The second psychoactive compound is produced in small amounts, and so has less effect. The effects of inhaled marijuana fade faster than marijuana taken by mouth.

How can marijuana affect symptoms of cancer?

A number of small studies of smoked marijuana found that it can be helpful in treating nausea and vomiting from cancer chemotherapy.

A few studies have found that inhaled (smoked or vaporized) marijuana can be helpful treatment of neuropathic pain (pain caused by damaged nerves).

Smoked marijuana has also helped improve food intake in HIV patients in studies.

There are no studies in people of the effects of marijuana oil or hemp oil.

Studies have long shown that people who took marijuana extracts in clinical trials tended to need less pain medicine.

More recently, scientists reported that THC and other cannabinoids such as CBD slow growth and/or cause death in certain types of cancer cells growing in lab dishes. Some animal studies also suggest certain cannabinoids may slow growth and reduce spread of some forms of cancer.

There have been some early clinical trials of cannabinoids in treating cancer in humans and more studies are planned. While the studies so far have shown that cannabinoids can be safe in treating cancer, they do not show that they help control or cure the disease.

Relying on marijuana alone as treatment while avoiding or delaying conventional medical care for cancer may have serious health consequences.

Possible harms of marijuana

Different compounds in marijuana have different actions in the human Marijuana can also pose some harms to users. While the most common effect of marijuana is a feeling of euphoria (“high”), it also can lower the user’s control over movement, cause disorientation, and sometimes cause unpleasant thoughts or feelings of anxiety and paranoia.

Smoked marijuana delivers THC and other cannabinoids to the body, but it also delivers harmful substances to users and those close by, including many of the same substances found in tobacco smoke.

Because marijuana plants come in different strains with different levels of active compounds, it can make each user’s experience very hard to predict. The effects can also differ based on how deeply and for how long the user inhales. Likewise, the effects of ingesting marijuana orally can vary between people. Also, some chronic users can develop an unhealthy dependence on marijuana.

Cannabinoid drugs

There are 2 chemically pure drugs based on marijuana compounds that have been approved in the US for medical use.

- Dronabinol (Marinol®) is a gelatin capsule containing delta-9-tetrahydrocannabinol (THC) that’s approved by the US Food and Drug Administration (FDA) to treat nausea and vomiting caused by cancer

(continued next page)

Marijuana and Cancer *(continued)*

chemotherapy as well as weight loss and poor appetite in patients with AIDS.

- Nabilone (Cesamet®) is a synthetic cannabinoid that acts much like THC. It can be taken by mouth to treat nausea and vomiting caused by cancer chemotherapy when other drugs have not worked.

Nabiximols is a cannabinoid drug still under study in the US. It's a mouth spray made up of a whole-plant extract with THC and cannabidiol (CBD) in an almost one to one mix. It's available in Canada and parts of Europe to treat pain linked to cancer, as well as muscle spasms and pain from multiple sclerosis (MS). It's not approved in the US at this time, but it's being tested in clinical trials to see if it can help a number of conditions.

How can cannabinoid drugs affect symptoms of cancer?

Based on a number of studies, dronabinol can be helpful for reducing nausea and vomiting linked to chemotherapy.

Dronabinol has also been found to help improve food intake and prevent weight loss in patients with HIV. In studies of cancer patients, though, it wasn't better than placebo or another drug (megestrol acetate).

Nabiximols has shown promise for helping people with cancer pain that's unrelieved by strong pain medicines, but it hasn't been found to be helpful in every study done. Research is still being done on this drug.

Side effects of cannabinoid drugs

Like many other drugs, the prescription cannabinoids, dronabinol and nabilone, can cause side effects and complications. Some people have trouble with increased heart rate, decreased blood pressure (especially when standing up), dizziness or lightheadedness, and fainting. These drugs can cause drowsiness as well as mood changes or a feeling of being "high" that some people find uncomfortable. They can also worsen depression, mania, or other mental illness. Some patients taking nabilone in studies reported hallucinations. The drugs may increase some effects of sedatives, sleeping pills, or alcohol, such as sleepiness and poor coordination. Patients have also reported problems with dry mouth and trouble with recent memory.

Older patients may have more problems with side effects and are usually started on lower doses.

People who have had emotional illnesses, paranoia, or hallucinations may find their symptoms are worse when taking cannabinoid drugs.

Talk to your doctor about what you should expect when taking one of these drugs. It's a good idea to have someone with you when you first start taking one of these drugs and after any dose changes.

What does the American Cancer Society say about the use of marijuana in people with cancer?

The American Cancer Society supports the need for more scientific research on cannabinoids for cancer patients, and recognizes the need for better and more effective therapies that can overcome the often debilitating side effects of cancer and its treatment. The Society also believes that the classification of marijuana as a Schedule I controlled substance by the US Drug Enforcement Administration imposes numerous conditions on researchers and deters scientific study of cannabinoids. Federal officials should examine options consistent with federal law for enabling more scientific study on marijuana.

Medical decisions about pain and symptom management should be made between the patient and his or her doctor, balancing evidence of benefit and harm to the patient, the patient's preferences and values, and any laws and regulations that may apply.

The American Cancer Society Cancer Action Network (ACS CAN), the Society's advocacy affiliate, has not taken a position on legalization of marijuana for medical purposes because of the need for more scientific research on marijuana's potential benefits and harms. However, ACS CAN opposes the smoking or vaping of marijuana and other cannabinoids in public places because the carcinogens in marijuana smoke pose numerous health hazards to the patient and others in the patient's presence.

The American Cancer Society medical and editorial content team. Our team is made up of doctors and master's-prepared nurses with deep knowledge of cancer care as well as journalists, editors, and translators with extensive experience in medical writing.

Introducing INSPIRE: International Nipple Sparing Mastectomy Registry

Isabel T. Rubio
Hospital Universitario Vall d´Hebron, Barcelona, Spain

Riccardo A. Audisio
St Helens & Knowsley Teaching Hospital NHS Trust, UK Principal Investigators

Left to right: Isabel T. Rubio and Riccardo A. Audisio.

Nipple Sparing Mastectomy (NSM) is a surgical technique where the mammary gland is removed but the skin envelope is preserved; noticeably, the pigmented epithelium of the areola and the nipple is also preserved to optimize cosmetic outcomes. The skin envelope is then filled with an autologous flap, an implant, or a combination of the two. A new registry may help experts determine whether this procedure is safe for patients with invasive breast cancer.

At the time called subcutaneous mastectomy, NSM was introduced in the 1960's by Bromley S. Freeman for the treatment of benign conditions such as "severe cystic disease, unremitting mastodynia, chronic mastitis, trauma, fibrous disease, [and] familial history".

Half a century later, the technique has been widely disseminated and technically improved. The cosmetic results can be outstanding (excellent/good 70-80%), although complications are not infrequent (nipple partial necrosis 2-10% and total necrosis 0-5%). Much attention has recently been given to this procedure since Angelina Jolie, the well known actress, filmmaker, and activist, underwent NSM in 2013 for risk-reducing purposes.

NSM is part of the armamentarium of up-to-date breast surgeons and is routinely offered to patients with a high risk of developing breast cancer (BRAC 1-2, ATM, CHEK2, etc.) or with pre-invasive breast cancer, There is some question as to whether the procedure is safe for patients with invasive malignancy of the mammary gland.

As of today over 1,600 publications are available on PubMed and the topic has been reviewed extensively. Surprisingly, despite the growing interest in the procedure, NSM has never been validated and its oncological outcomes are still unclear. For this reason, some breast surgeons are reluctant to offer NSM to their breast cancer patients.

There is published data presenting a local recurrence rate of <3%, which is compatible to any other breast cancer procedure, However this data is limited and we are unable to identify the perfect candidate or pinpoint the most adequate work-up required to optimize our clinical decisions.

On one side, some surgeons are unable to offer their patients the breast procedure that achieves the best cosmetic results; on the other, there is evidence that NSM has sometimes been performed incorrectly and on the wrong patient (e.g. when the skin or the nipple-areola complex are affected by cancer cells).

These considerations force us to seek out evidence-based answers. What is the maximum tumour size associated with minimal local recurrence rates? How far should the lesion be from the skin? Should this be measured with an MRI, or is ultrasound/ physical exam sufficiently informative? Does any biological characterization oppose the value of NSM? Are there age limitations? Is there a Body Mass Index threshold? Are associated comorbidities a contra-indication? What is the complication rate? How gratifying are the patient-reported outcomes (PROs)? Is the association with adjuvant radiotherapy detrimental?

Obviously, a randomized clinical trial is not feasible: it would not be ethical or viable. Hence the value of a phase IV trial: a prospective collection of high quality data. Patients are treated liberally, as per the Unit decision. A structured follow-up will follow (including photographic evidence) and the outcomes will provide the long-awaited answers.

INSPIRE is the non-randomized prospective observational multi-center cohort study (Phase IV "real life" trial) designed to provide these answers; it will recruit patients affected by invasive breast cancers (either single or multifocal), DCIS, and candidates for risk reducing surgery.

All retrieved data, entered by contributing centres with an input from patients' representatives, will be safely stored at the University of Leiden, the Netherlands. Each Unit will have access to its own data, and the comprehensive figures will be analyzed at the end of follow-up.

All consecutive patients who undergo NSM are eligible for inclusion in this prospective database. An International Quality Registry will secure standardized collection of data from all patients undergoing NSM from participating centers. We are pleased to say that over 100 cases have already been recruited from 15 Asian, South American, North African and European countries. The recruitment is progressing smoothly and all Breast Units are invited to enter their cases into the INSPIRE study.

For more information: http://www.essoweb.org/eurecca-inspire/

Contact for participation: maespino@vhebron.net

In the United Kingdom the INSPIRE study, sponsored by St Helens & Knowsley Teaching Hospitals Trust, does have ethical/ HRA approval. Any interested centre is welcome to contact Mrs Jeanette Anders, Research Development and Innovation Manager at the following email: Jeanette.Anders@sthk.nhs.uk

Should women who are diagnosed with metastatic breast cancer have breast surgery?

Dr. Jenny Edge

Breast Surgeon, Christiaan Barnard Memorial Hospital
Cape Town, South Africa

Dr. Jenny Edge

In the USA alone, there are over 150,000 people living with stage 4, or metastatic, breast cancer (MBC).[1] Some women are diagnosed with MBC at the time of presentation. According to the Surveillance, Epidemiology and End Results (SEER) database in the US, roughly 6-10% of women fall into this category at the time of diagnosis.[1] (In lower income countries, more women have locally advanced or metastatic breast at the time of diagnosis.) Others develop stage 4 disease after having had initial treatment.

The number of people with MBC is increasing for two reasons. First, women with metastatic disease are living longer due to more numerous and effective treatments. Second, some women are being upstaged because of increased sensitivity of imaging. Small lesions in the lungs, liver, or bones which may have been unnoticed in the past are now being detected. If everyone with locally advanced or stage 3 breast cancer was given a Positron Emission Tomography (PET) scan, about 30-50% would be diagnosed with metastatic disease.[2]

Traditionally, MBC is treated systemically (with chemotherapy or endocrine therapy) and surgery is not offered. However, people have wondered for a long time if surgically removing the primary breast tumor could improve survival. One theory is that decreasing overall tumor burden (either tumor tissue bulk or circulating tumor cells released from the primary tumor) may improve outcomes. Another theory is that the primary tumor communicates with metastatic tumors through complicated metabolic and/or immunologic pathways. Interrupting this may improve survival. A third theory is that the primary tumor releases cells to seed metastases which in turn release cells to seed the primary tumor site. This "self-seeding" leads to more aggressive disease.[3]

Retrospective studies have suggested that surgery may lead to improved overall survival for people living with MBC.[4] However, these studies have many problems. The main one is that surgery may have only been offered to women with a better prognosis (younger, smaller primary tumor, good functional status, etc.) introducing selection bias. Prospective study is needed. We continue to wonder: can outcomes for women with MBC be improved by removing the primary tumor?

Several recent prospective studies attempted to answer this question. One was conducted by investigators in India and enrolled 350 women. The women were randomly assigned to receive surgery or no surgery (along with other standard treatments). There was no difference in survival between the two groups at two years.[5] Another study was conducted in Turkey and enrolled 274 women. They too were randomized to surgery or no surgery (and received other standard treatments). There was no difference between the two groups at three years. However, at five years, more patients who had received surgery were still alive. This study may have some flaws, including more patients with less aggressive breast cancer in the surgery group and more patients with more aggressive breast cancer in the no surgery group.[6] A study conducted by researchers in the US enrolled 112 patients. They were not randomized but could elect to receive surgery after standard therapy. This study also showed no improvement in survival at three years.[6]

Given the conflicting data, how do we advise patients? For the most part, these studies illustrate that women living with MBC are unlikely to benefit from surgery to remove the primary tumor. The majority of people with MBC should not receive surgery. There is a small subset of women with what is called "oligometastatic" disease, which is metastatic cancer that is small volume and only spread to one or a few sites. This selected group may benefit from a different treatment approach which could include surgery.[7] Patients in this category should discuss this with their breast cancer doctors. This recommendation is reflected in the current European Society for Medical Oncology (ESMO) guidelines.[8]

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Genetic testing: When and why it may be indicated for breast cancer patients

By Mirat Shah, MD

Hematology-Oncology Fellow, Johns Hopkins University, USA
Medical Content Editor, Bloom

Mirat Shah, MD

Case 1

Sarah is a 39-year old woman who noticed a lump in her right breast. It did not go away so she mentioned it to her family doctor. Her family doctor requested a mammogram of both breasts and a biopsy of the suspicious area. The mammogram showed a 1.5 cm suspicious area in Sarah's right breast but no other areas of concern. The biopsy of this area confirmed a diagnosis of breast cancer.

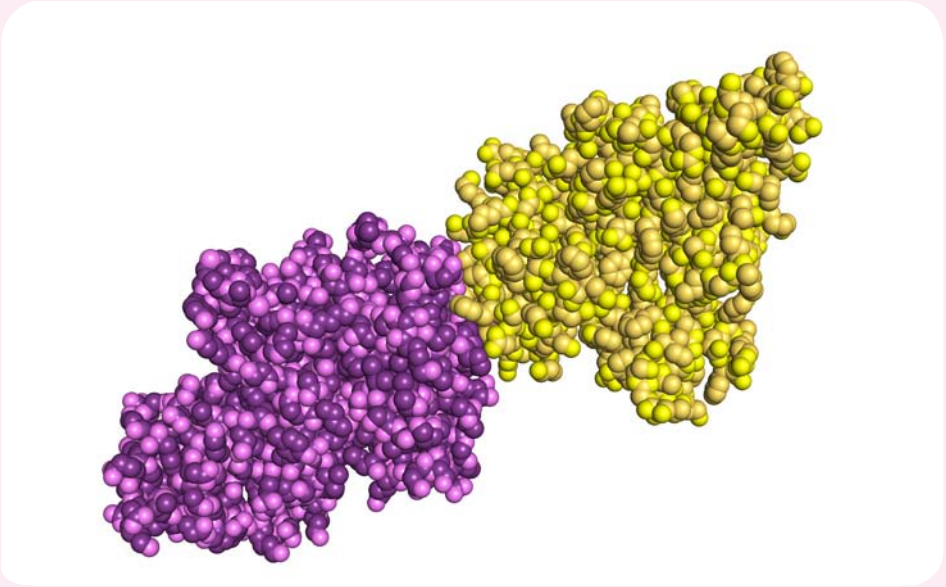
Additional staining identified her cancer as estrogen receptor (ER)- negative, progesterone receptor (PR)-negative, and HER2-negative. She was referred to a surgeon to discuss surgery for her breast cancer. The surgeon asked her if any other family members had cancer. Sarah mentioned that her mother was diagnosed with breast cancer at age 45. The surgeon referred her to a genetic counselor who recommended testing for inherited genetic mutations that make her more susceptible to breast cancer.

Hereditary Cancer Testing

There are many reasons your breast cancer doctor(s) may refer you to a genetic counselor. These include your age at diagnosis, family members with cancer, or specific features of your cancer (e.g. triple negative breast cancer). This type of testing examines your germline DNA (DNA inherited from your parents and passed on to your children) for certain genetic mutations associated with breast cancer. The most well-known of these mutations are in the BRCA1 and BRCA2 genes but there are others. Testing for germline DNA is important because it may impact your decisions about the type of breast cancer surgery you want (breast conserving surgery versus mastectomy versus double mastectomy). You may also be at risk for other types of cancer (e.g. ovarian cancer).

Your family members (parents, siblings, children) may also be at risk for breast cancer and other cancers. It is important to remember that your test results can impact your family. If you and your doctor do decide to pursue testing, you may wish to discuss this with your family before you get your results; some may wish to get tested themselves, while others may request not to know your results. You can discuss with your breast cancer doctor if this type of testing is right for you.

> **"IF YOU AND YOUR DOCTOR DO DECIDE TO PURSUE TESTING, YOU MAY WISH TO DISCUSS THIS WITH YOUR FAMILY BEFORE YOU GET YOUR RESULTS; SOME MAY WISH TO GET TESTED THEMSELVES, WHILE OTHERS MAY REQUEST NOT TO KNOW YOUR RESULTS."**



BRCA2 molecule

(continued next page)

Genetic Testing *(continued)*

Case 2

Maya is a 46-year old woman who had a screening mammogram which showed a suspicious area in her left breast. She underwent a biopsy which confirmed a diagnosis of breast cancer. Her breast cancer was ER-positive, PR-positive, and HER2-negative. She had breast conserving surgery with a "sentinel lymph node biopsy" (a biopsy of the lymph node(s) closest to your breast cancer). Maya's tumor was 2.2 cm in size and zero lymph nodes were positive for breast cancer out of three tested. She is planning to take tamoxifen but is not sure if she should take chemotherapy first. Maya wants to do everything necessary to prevent her breast cancer from coming back but also wants to avoid the side effects of chemotherapy unless she really needs it. Her oncologist suggests ordering the OncotypeDX test to help her make up her mind.

Oncotype DX

Many women find themselves in Maya's position. Your doctor may suggest the OncotypeDX test to help you decide if adjuvant chemotherapy is right for you. Adjuvant chemotherapy is chemotherapy given after breast cancer surgery to reduce the risk of your breast cancer returning. For some women, chemotherapy does not substantially change this risk and exposes them to side effects unnecessarily, but there are no tests to know for sure which women will benefit. Oncotype DX is a genetic test done on your breast tumor after it is removed at surgery. The test looks at 21 genes in your breast tumor's DNA and assigns you a "recurrence score." This score can be low, intermediate, or high. Low recurrence score patients are at lowest risk of breast cancer returning. Some patients with low recurrence scores may choose to avoid chemotherapy whereas patients with higher recurrence scores may choose to pursue chemotherapy. This test is only currently used in women with ER-positive and/or PR-positive, HER2-negative breast cancer without positive lymph nodes. Other factors may also be important when deciding to order this test. These should be discussed with your breast cancer doctor.

MammaPrint is a test that is similar to Oncotype DX and may also help you and your doctor make decisions about chemotherapy.

Case 3

Tea is a 60-year old woman who developed terrible back pain. Evaluation of this led to a diagnosis of metastatic breast cancer. Tea had cancer in her left breast and bones, including her spine. Her cancer was ER-positive, PR-negative, HER2-negative. She has had three different types of endocrine-based treatments but, unfortunately, her cancer has grown and spread through each of these treatments. Her most recent CT scan also showed a tumor in her liver and she just started treatment with capecitabine, an oral chemotherapy (pills). She is worried that if her tumors continue to grow, there will be fewer and fewer treatments available. She is also worried about side effects from chemotherapy and is wondering if there are other treatment options for her breast cancer. Maya's oncologist suggests sending a sample of her tumor to a lab for next generation sequencing (NGS).

Next Generation Sequencing

Your doctor may suggest NGS of your tumor if you have advanced breast cancer, have received and/or are receiving standard treatments, and have limited treatment options for your cancer in the future. Specific genes within your tumor sample are sequenced to determine if certain mutations are present. The purpose of this testing is to find previously undiscovered mutations within your tumor that may respond to existing cancer therapies. There are currently many caveats to NGS. Doctors do not know the right time to order this test and which patients can benefit from it. You may need to undergo a new biopsy to have enough tumor sample for the test. In most cases, this test does not find a mutation that has an available therapy. However, for some patients without many good treatment options, this test may make sense. There are currently many different companies offering this type of test. If you have metastatic breast cancer, you can discuss with your doctor if this test is right for you.

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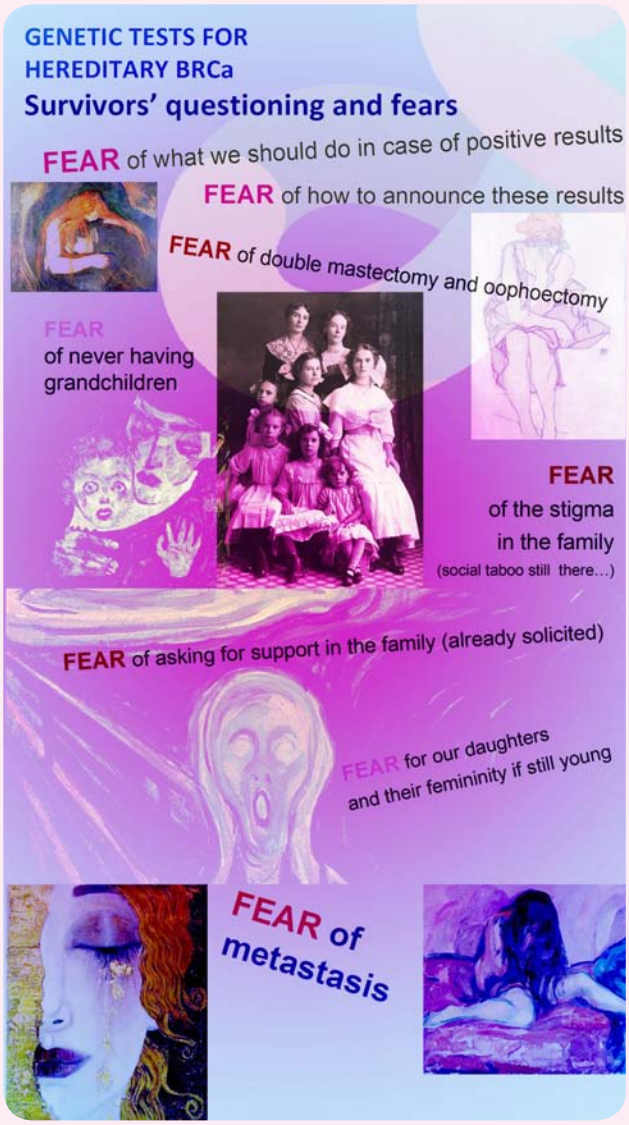
Helping women make informed decisions about genetic testing

By Joanna Grecos

Breast cancer survivor and Volunteer, Alma Zois
Athens, Greece



Since 1988, the Hellenic Association of Women with Breast Cancer "ALMA ZOIS" has been providing support to breast cancer patients and their families following the Reach to Recovery principles. The program initiates prevention and awareness projects, including a program for genetic testing for hereditary breast cancer. This program is a collaboration between Alma Zois and the National Center for Scientific Research "Demokritos," which implemented the genetic tests, and covers both prevention and awareness goals.

Because of ongoing progress in genetic science and orientation towards personalized treatments, an increasing number of oncologists in Greece are encouraging their patients to undergo the test. The cost of the examination is not covered by insurance companies but, through the program, women who have already experienced a breast cancer diagnosis now have the opportunity to get tested free of charge. The program helps both the survivors who undergo testing and the medical community in general to better understand the role that genetics may play in breast cancer.

A key goal of the program is to help those women who meet the criteria for genetic testing make the best decisions possible, for that individual, as to whether or not to undergo the testing. As part of this process, a psychologist speaks with each woman in order to understand her motivation and psychological condition, as well as to determine how to manage possible outcomes, even negative ones, that could the women and their descendants.

With constant support from the psychologists involved, the managers of the program strive to help women manage and face various fears, including:

- Fear of death
- Fear of metastasis
- Fear of asking for support in the family
- Fear of the possible results
- Fear of how to announce these results
- Fear that their daughters will refuse to be tested
- Fear of how to proceed in the event of positive results
- Fear of double mastectomy and oophoectomy
- Fear for their daughters and of losing their femininity, especially if still young
- Fear of never having grandchildren
- Fear of stigma in the family (social taboo still existing)

187 women with breast cancer have benefited from the program since 2010 when it was first implemented. Having the opportunity to make an informed choice about undergoing genetic testing allows breast cancer survivors to feel more in control of their situations. It encourages the spread of important information and raises awareness about genetic risk among the general population, thus promoting early detection and prevention for the future.

> "THE PROGRAM HELPS BOTH THE SURVIVORS WHO UNDERGO TESTING AND THE MEDICAL COMMUNITY IN GENERAL TO BETTER UNDERSTAND THE ROLE THAT GENETICS MAY PLAY IN BREAST CANCER."

Australia & New Zealand Breast Cancer Trials Group

The role of consumer advisory panels in cancer research

By Leonie Young

Chair, Consumer Advisory Panel Australia & New Zealand Breast Cancer Trials Group Brisbane, Australia

Leone Young *(third from left)*.

The Australia and New Zealand Breast Cancer Trials Group (ANZBCTG) is the largest independent oncology clinical trials research group in Australia and New Zealand, and their research program involves national and international clinical trials.

In 1994, the ANZBCTG invited a breast cancer consumer advocate to become a member of its Scientific Advisory Committee. Five years later, the Consumer Advisory Panel (CAP) was established to contribute to the research of the ANZBCTG, setting a precedent for best practice in clinical trials research.

CAP members are actively involved in all research undertaken by the ANZBCTG from clinical trial concept and development through to implementation, recruitment, analysis, and follow up. They play a particularly important role reviewing patient information and consent documentation, ensuring they are clear and understandable for potential clinical trial participants.

A further initiative of the ANZBCTG is the IMPACT (Improving Participation and Advocacy for Clinical Trials) Advocate Program. It aims to provide patient advocates with reliable information to enable them to become effective advocates for breast cancer clinical trials in the wider community. They are sponsored to attend the ANZBCTG's Annual Scientific Meeting, and attend daily tutorials and information sessions.

Worldwide collaboration between researchers and consumers enhances breast cancer clinical trials research and can expedite availability of vital treatments. The following are some examples -

1. The APHINITY clinical trial has shown positive results, with pertuzumab (Perjeta) plus trastuzumab (Herceptin) and chemotherapy showing a statistically significant improvement for people with HER2-positive early breast cancer. HER2-positive breast cancer cells have an excess of growth receptor molecules on their surface. Similar to antennae, these receptors protrude from the cell, allowing specific modules to attach and influence cell growth. About 20% of breast cancers have too many HER2 receptors on their surface; these are called HER2-positive breast cancer.

   Following initial treatment with surgery, the current standard of care in the treatment of HER2-positive early breast cancer is chemotherapy and the drug Herceptin. This treatment was proven effective in earlier clinical trials such as HERA, which showed treatment with Herceptin improved outcomes for approximately one third of women with HER2- positive early breast cancer. The APHINITY clinical trial examined whether the addition of the drug Perjeta would further reduce recurrence rates and improve the survival of people with HER2-positive breast cancer.

   This study involved 42 countries worldwide with 4,805 women participating. The full results of this trial will be presented at a medical meeting later this year.

2. A new clinical trial developed by Australian researchers called EXPERT will open soon, and it will be the first ANZBCTG-led international clinical trial. EXPERT will investigate the use of gene expression profiling to identify patients with low risk breast cancer who may be able to avoid radiotherapy after surgery and as a result, the side-effects of this treatment. The study will be open in up to 30 Australian and New Zealand institutions, and once expanded to international participation, it's anticipated to be opened in 90-100 institutions worldwide.

3. The trial, PATINA is a global study and the ANZBCTG will be entering into a new collaboration with ALLIANCE, one of five cooperative research groups comprising the USA National Clinical Trials Network. PATINA will investigate the effectiveness of palbociclib in combination with targeted HER2 therapy and endocrine therapy vs targeted HER2 therapy and endocrine therapy, and is open to women diagnosed with Hormone Receptor positive, HER2 positive, recently diagnosed metastatic breast cancer.

Clinical trials are necessary to find out if new treatments are more effective than those currently accepted as the best available standard treatment. All of the major milestones in controlling breast cancer worldwide have come through clinical trials. There are many types of clinical trials for the prevention and treatment of breast cancer and studies which aim to improve a patient's quality of life. All new breast cancer treatments are rigorously tested through the clinical trials process before they are made widely available to the community.

Some countries are often not in the position to undertake large clinical trials but the hope for all women is the new treatments will be available to them as soon as possible. Speak with your doctor or local hospital to find out more about clinical trials in your area.

Spotlight on Portugal!

Human libraries shed light on coping with cancer

Movimento Vencer e Viver
Portugal

The Portuguese League Against Cancer's Health Education Department carries out an action called Human Library, which aims to demystify cancer and promote awareness, as well as to stress early detection as a fundamental tool for fighting cancer.

The "Human Library" originated in Denmark in the year 2000 as part of a youth organization called "Stop Violence". A human library consists of "books" that are real people with an experience to share who are borrowed by "readers" who are people with questions about the stories of the "books." These "human libraries" provide an opportunity for participants to share and understand each other's experiences in their community.

Following this concept of "human libraries," volunteers of the Win and Live Movement (Movimento Vencer e Viver) give their testimony, sharing their experiences and reflecting on the physical, emotional, and spiritual challenges faced by cancer survivors. Together with other "books" (for example, a caregiver, a psychologist, and an oncologist) invited by the Health Education Department of the Northern Branch of the Portuguese League Against Cancer, our volunteers share with the students their personal stories, how they faced their diagnoses, their treatments, and their fears, as well as how they overcame it all. Students sit in small groups with the "book" and can "read" it, in a one-on-one conversation where it's possible to ask questions, seek advice, and learn about the experience of these cancer survivors. The conversations allow a personal experience of sharing, questioning, and reflection that can shift perceptions and contributes to a better understanding of cancer related queries and concerns.

Spotlight on Greece!

The Alma Zois experience

Elefhteria Kourenta
Volunteer, breast cancer survivor, member of the Board of Hellenic Association of Women with Breast Cancer "Alma Zois"

Eleni Leka
Social Worker, Almas Zois

Christiana Mitsi
Pyschologist, Alma Zois

Efrosyni Tzintziropoulou
Psychologist, Alma Zois,

Athens, Greece

The Hellenic Association of Women with Breast Cancer "Alma Zois" is a non-profit organization in Greece that aims to inform and support, by all possible and reasonable means, women and their families about breast cancer treatment and prevention issues, as well as any other issues related to breast cancer.

Alma Zois' vision is to offer all women in Greece information on breast cancer prevention and early detection, and to offer comprehensive psychosocial and legal support to every woman who deals with breast cancer.

In view of the deep economic crisis that has gripped Greece since 2010, "Alma Zois" has adjusted its support programs and awareness campaigns to provide quality psychological support services without cost and to finance expensive medical tests and empower patients and families. We provide:

Support programs

- Breast Cancer Care Helpline
- Four different types of group therapy for women with breast cancer
  - Stress management groups
  - Support groups for women in chemotherapy
  - Assertiveness training group
  - Self-awareness groups
- Psychosocial support for women with breast cancer and their family members, including a Reach to Recovery-based peer support program.
- Genetic testing and counseling for women with breast cancer and their first-degree family members. In cooperation with Demokritos, the National Center for Scientific Research, Alma Zois conducts a genetic testing and counselling program for women who have already experienced breast cancer and meet the necessary medical requirements, as well as for two more first-degree members of their family.
- Legal counselling program: through a hotline service.
- The educational "I know, therefore I decide," which aims to provide valid and reliable information to women with breast cancer about any health issues that they encounter.

Awareness and prevention programs

- Workplace awareness for breast cancer prevention and early detection. This program is implemented through presentations conducted by a skilled team.
- Clinical Breast Examination and Breast Cancer Awareness Program for Young Women (20-39 years old). Through this program, young women have the opportunity to experience the process of a clinical examination by a breast health specialist and, at the same time, get informed about the importance of breast cancer early detection through regular health checks.
- The Empower campaign, which is known internationally as "Pantene Beautiful Lengths." Women and men can donate their hair to Alma Zois to make wigs of natural hair for women that who have lost their own hair due to chemotherapy.
- Greece's Race for The Cure®, which is authorized by the The Susan G. Komen Foundation®. Since 2009, Alma Zois has been organizing Greece's Race for The Cure®, a special walk or run aiming to raise awareness about breast cancer, as well as to celebrate breast cancer survivorship and honour those who have lost their battles with the disease. In September 2016 we reached the incredible number of 31.000 participants, and it has become "the largest race with a social objective throughout Greece" and "the second largest race after the Athens Classic Marathon".

Spotlight on Nepal!

First international cancer conference focusing on cancer control in developing countries to be held in Kathmandu

Swayambhunath in Kathmandu, Nepal. Photo by: Thomas Dutour, *Dreamstime*.

The Nepal Cancer Relief Society will host the first *International Cancer Conference on the Challenges for Cancer Control in Developing Countries*, bringing together World Cancer Leaders for a landmark global dialogue in January 2018.

This world-first meeting of the minds will take place in Kathmandu, Nepal from January 18 to 20, 2018, with support and endorsement from the Union for International Cancer Control (UICC) and Cancer Council Australia (CCA). Conference delegates will bring expertise from across the continuum of cancer control, including researchers, policy makers, allied health professionals, fundraisers, civil society leaders, clinicians, consumers, advocates, and government representatives. The conference will support the UICC's mission to unite the cancer community, reduce the global cancer burden, promote greater equity, and integrate cancer into the world's health and development agenda – with about 57 per cent of cancer cases and 65 per cent of all cancer deaths now occurring in low and middle-income countries.

The ground-breaking international meeting will draw on a robust program that will include invited speakers, symposia, oral abstract presentations, poster presentations, and workshops on a range of issues. Experts will examine the powerful trends contributing to the rise of cancer in the developing world, such as population ageing, rapid unplanned urbanization, and the globalization of unhealthy lifestyles. It will provide World Cancer Leaders with an opportunity to strengthen networks, share knowledge, and engage in conversation to help accelerate an international action agenda. Key program topics will explore avenues for prevention, regulation, research collaboration, translation, and capacity building.

Clinicians and allied health professionals from low and middle-income countries who have a special interest in cancer care are especially encouraged to attend. Calls for abstracts and travel grant applications will open soon, with more detailed information to be published over coming days. For more information, go to http://www.ncrs.org.np or email ncrs.cs@outlook.com.

About the Nepal Cancer Relief Society

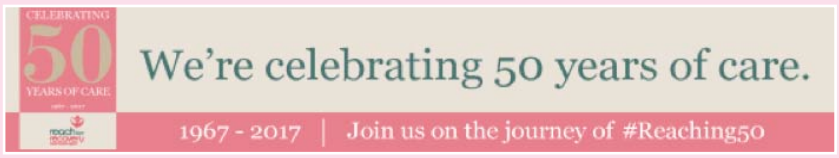
The Nepal Cancer Relief Society (NCRS) is a non-profit social organization that has been working in the field of cancer in Nepal for the last 34 years. NCRS has been working in both cancer preventive and curative aspects. Under preventive programs it conducts several awareness activities as well as cancer screening camps targeting the rural people to save their life from cancer through early detection. Under curative approach, NCRS is running Bhaktapur Cancer Hospital (a 110-bed cancer hospital with chemotherapy, radiotherapy, surgery and palliative care services). NCRS has 42 district branches with approximately 10,000 volunteers nationwide.

NEPAL CANCER RELIEF SOCIETY
नेपाल अर्बुद रोग निवारण संस्था

Spotlight on South Africa!

Reach for Recovery South Africa celebrates milestone anniversary

Stephanie Van Deventer
RFR National Manager
Cape Town, South Africa



Reach for Recovery owes its existence to a number of remarkably dedicated women.

Terese Lasser, after her own breast cancer surgery in 1952, realised there was very little support for patients who had been through a traumatic experience. She campaigned to convince the medical community that someone who has lived through a diagnosis and treatment for breast cancer is a valuable source of support and care for patients. The support network which Terese established in the United States grew and today gives hope and healing all over the world.

South Africa was one of the first countries to embrace Terese's vision. During her 1967 visit she inspired breast cancer patients to start their own group in Johannesburg. Pretoria was next, then Cape Town.

Fast forward 50 years and RFR now has 23 groups around the country, offering peer support to diagnosed breast cancer patients, breast health education, as well as a prosthesis support service to women without medical aid.

In 2013 the 17th Reach to Recovery International Breast Cancer Support Conference was held in Cape Town. With the theme "Together We Reach" and a strong focus on Africa, it was a resounding success.

With change taking place in South Africa on many levels, it became clear that RFR needed a new look and feel. Enter Stephné Jacobs, yet another gifted woman, passionate about her work as RFR Chairperson. She took up the challenge of transforming the organisation. October 2014 saw the launch of a new brand, with on-trend logo and website, while behind the scenes the structure was streamlined to reflect a professional business image.

In 2015 and 2016 RFR volunteers supported 5,683 breast cancer patients and their families. Since 2011, the Ditto Prosthesis Support Project provided 4,162 women with silicone breast prostheses to the value of R2.5 million. Without the commitment of trained RFR volunteers, who generously give their time and talents, this success would not have been possible. These very special women, many of whom have been volunteers for over 30 years, keep RFR alive.

"As we celebrate 50 years of care, I would like to express my admiration for the 'Wonder Women', our volunteers who truly believe in the value of our service, and have a deep desire to improve the lives of others through the power of shared personal experience. We are also very grateful to our partners, funders and friends who have played a vital role in our journey," says Stephné.

For more information on RFR services and projects, visit their national Facebook page at www.facebook.com/Reach4RecoverySA and their website at www.reachforrecovery.org.za.

Spotlight on India!

Join the RACE to rein-in-cancer

Dr. Rita Banik

Founder and President
RACE to rein-in-cancer

DR. RITA BANIK, www.race2ric.org

I am a breast cancer survivor, still fighting the beast in my sternum bone. I started a Charitable Trust called *RACE to rein-in-cancer* in 2012 with my friend Rashmi Kapoor, who sadly passed away due to her cancer in 2013. I managed the Trust alone until I could form a small team. Presently we have about 40 members in Mumbai, Gujarat, and Delhi, India. From the very beginning I decided that I shall not sit back due to lack of resources. I will run if I can, walk if not, but not let the race against cancer stop.

RACE to rein-in-cancer is holding an International Oncology Conference in New Delhi, India along with the Indian Science Congress Association (ISCA) and the Media India Centre for Research and Development (MICRD) on Saturday and Sunday the 18th and 19th of November 2017. The theme is CANCER TODAY: ROADMAP FOR TOMORROW. We aim to cover problems related to treatment in India at present and look at holistic approaches to the disease as well as the future scope of science and technology related to cancer. This conference will address issues common to all developing countries as the scenario is shared. We intend to also hold future conferences in Mumbai and Gandhinagar in following years.

I hope that you will be able to attend our Conference! Perhaps this will be an opportunity for you to finally visit India and combine your professional interests with enjoyment of India's beauty and culture. For more information or to register for the conference, please visit http://www.race2ric.org/index.html. For those unable to attend this year, *please consider supporting our mission in whatever way you can.* Thank you all for your interest and your generosity.

We look forward to welcoming you.

> "SATURDAY AND SUNDAY THE 18TH AND 19TH OF NOVEMBER 2017. THE THEME IS CANCER TODAY: ROADMAP FOR TOMORROW."

www.race2ric.org

A message of hope

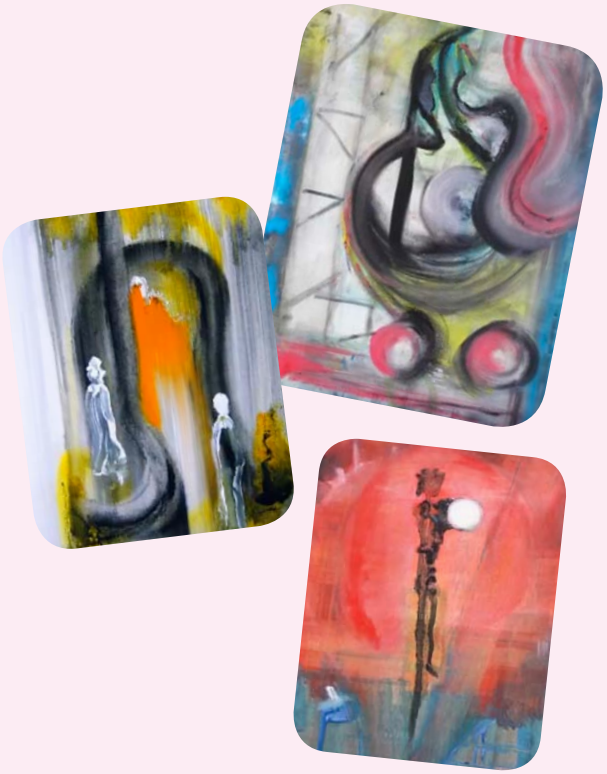
Photo by: Hans-Jürgen Bauer.

Shirley Bianca

By Shirley Bianca, *Germany*
Introduction by Cathy Hirsch, USA

When Shirley Bianca was diagnosed with breast cancer in 2000, she underwent a myriad of emotions. In dealing with these emotions, she discovered her inner artist – for the first time ever, she started painting, unconsciously unleashing her complicated feelings onto each canvas. The result was a series of paintings that chronicle Shirley's cancer journey. She calls it her "Message of Hope." Click on the link to the right to view Shirley's paintings and to learn more of her story.

Click here to view "Message of Hope."



Shirley now works tirelessly to assist other women facing breast cancer, wishing not only to give them hope but also to inspire and motivate them to unlock their own creative potentials during and after treatment. She believes creative endeavors have the potential to help heal the soul and body.

In addition to delivering her "Message of Hope" to audiences throughout the world, Shirley has volunteered since 2005 for the non-profit organization ZEBRA, a breast cancer counseling center in Düsseldorf, Germany.

> "WITH MY PAINTINGS, CENTERED ON EXPRESSION OF FEELINGS AND EMOTIONS, I LIKE TO SHARE MY EXPERIENCE IN THE HEALING OF THIS ILLNESS."

Global Kitchen

Potato Soup – Bramboračka

Nada Indruchova

TIME PREPARATION: 30 MINUTES
COOKING TIME: 60 MINUTES
SERVINGS: 4

Ingredients:

200 g (8 oz.) potatoes
100 g (4 oz.) carrots
100 g (4 oz.) celery
50 g (2 oz.) parsley
2-3 cloves of garlic
25 g (1 oz.) dried porcini mushrooms
handful of dried marjoram (to taste)
1 tsp of caraway seed
approx. 2 tsp of salt
½ tsp of ground pepper
flour
oil
1 litre (4¼ cup water)

Directions:

1. Soak the porcini mushrooms for 30 minutes.
2. Peel the vegetables and cut them into small squares. Cut the mushrooms into smaller parts.
3. Put the vegetables, porcini (with the water they were soaked in), mashed garlic, salt, pepper, marjoram and caraway into water and bring to the boil.
4. Prepare the roux with the oil and flour.
5. When the vegetables are half cooked, mix them into the soup.
6. Season to taste.

Dobrou chut'! Bon appétit!