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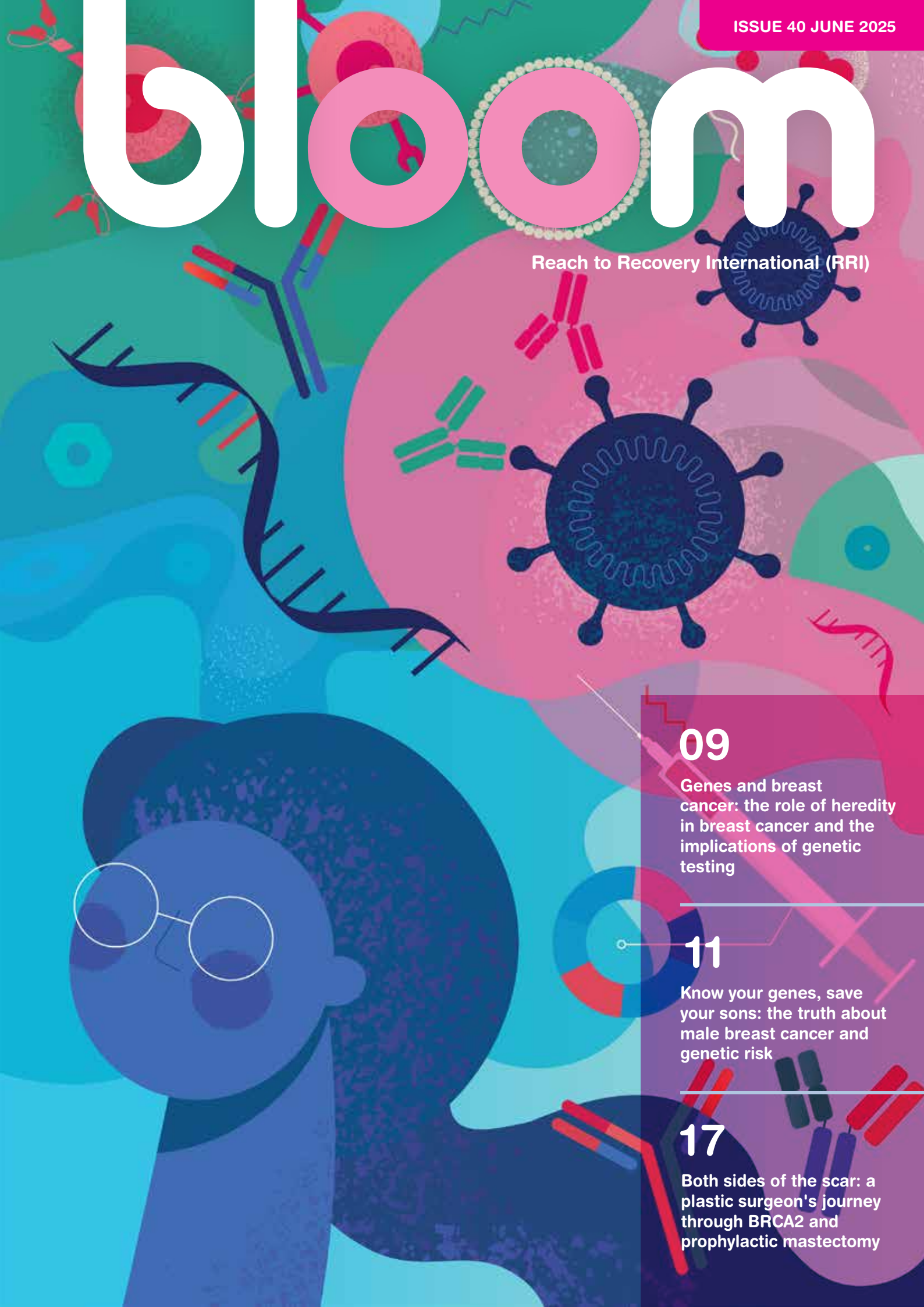
bloom

Reach to Recovery International (RRI)



REACH TO RECOVERY INTERNATIONAL

Reach to Recovery International (RRI) is a global non-profit headquartered in Baltimore, Maryland, USA. RRI is committed to improving the quality of life of individuals affected by breast cancer and their families.

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Our mission

Reach to Recovery International's mission is to:

- Unite organisations throughout the world which support individuals affected by breast cancer, including their families, in order to share ideas and best practices;
- Disseminate valuable information to support individuals affected by breast cancer throughout the world via bi-annual conferences, our website, our e-newsletter, and other forms of worldwide communications; and
- Assist our Member Organisations in achieving their goals of:
  - Improving the quality of life of individuals affected by breast cancer,
  - Providing psychosocial support to individuals affected by breast cancer, either through group meetings or activities or one-on-one peer support provided by carefully trained survivor volunteers,
  - Advocating on behalf of individuals affected by breast cancer,
  - Providing patient navigation to individuals affected by breast cancer.

Cover art: iStock.com/DrAfter123

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

Email your theme suggestions to info@reachtorecoveryinternational.org. A theme will be chosen by August 2025. 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. The views expressed in Bloom's articles are those of the authors and do not necessarily reflect the views of RRI. For more information about RRI, go to *www.reachtorecoveryinternational.org*.

Celebrate the work being done by your organisation's volunteers!

Do your organisation's volunteers do outstanding work to support those touched by breast cancer in your community? Bloom wants to hear all about it! Send us articles about the projects your volunteers are working on, and be sure to include high resolution photos. Articles should be 200 - 400 words long and should be sent in Word format to info@reachtorecoveryinternational.org. It's a great way to thank your volunteers for a job well done, and to raise awareness about your organisation!

Upcoming events:

"Juntas à Mesa" (Together at the Table) Brunch

28 June 2025 from 10:00AM – 1:00PM
Western European Summer Time

For more information and to register, visit:
www.ligacontracancro.pt/juntasamesa
(See full article on page 21)

Message from the ABC Global Alliance

In 2015, the ABC Global Alliance published the Global Decade Report, which led to the development of the ABC Global Charter. The ABC Global Charter outlined 10 actions to drive change in the care of people with advanced breast cancer over the current decade. In 2025 the ABC Global Charter will be updated for the decade 2025-2035.

To measure progress against each of the charter goals we have launched two surveys to understand the experiences of patients living with advanced breast cancer and the healthcare professionals that care for them worldwide.

If you are a patient living with advanced breast cancer or a healthcare professional who cares for people with advanced breast cancer, we want to hear from you. Your experiences matter, so please help us by completing one of our 15-minute surveys today, so we can take steps to improve care for people with advanced breast cancer in the future.

The surveys take just 15 minutes to complete, and the patient survey is available in 8 languages. Click the link or scan the QR code to take part. The surveys will be open until 31st July. event will be held in your time zone.

Message from Leonie Young

– President of RRI

“OUR MEMBERS CAN FEEL CONFIDENT THAT, THROUGH RRI, THEY ARE ACCESSING EVIDENCED-BASED RESOURCES DEVELOPED BY EXPERTS IN THEIR FIELDS AND, UNIQUELY, BACKED BY ALMOST 70-YEARS’ EXPERIENCE.”

This first edition of Bloom this year is getting the ball rolling by addressing the very relevant topic for anyone affected by cancer: Genetics and Cancer. Although not everyone diagnosed with breast cancer will necessarily have a known breast cancer mutation, for those who do this information can be both enlightening and challenging not only for themselves but also their families.

Research in this area has come a long way in recent years, focusing on treatments and even cures. It is less an unknown now, and doctors more readily recommend testing, not only to assist in treatment and/or prevention decision-making but also to help people understand what it means for themselves and their families if they have a breast cancer gene mutation. We have received a broad variety of submissions from researchers, clinicians, organisations with expertise in this area, and personal stories from those who have very generously shared their experiences.

In addition, this edition will feature a *Spotlight on Metastatic Breast Cancer* segment, with which we expand our efforts to raise awareness about, and highlight the voices of, those affected by advanced breast cancer. We hope this will become a regular feature in every edition of Bloom, and we welcome your feedback and, of course, submissions on that topic for future editions.

In the past few weeks, I had the opportunity to join and observe the peer support volunteer training workshops offered by Reach for Recovery South Africa, and also to participate in a webinar hosted by Atinuke Cancer Foundation and the Nigerian Cancer Society Lagos State Chapter to celebrate National Cancer Survivors Day 2025. I shared my views on the subject of *How Surivor-Led Organisations like Reach to Recovery International Make a Difference*. It was amazing to be joined by many RRI friends, and it is a testament to the fact that the RRI community is very blessed. The call out to join in the celebration of National Survivors Day in Nigeria said: *It’s more than a meeting, it’s a movement*. So, too, RRI is *more than an organisation, it’s a community*. When our voices join together we can make a difference and the effects ripple throughout our communities.

These connections and networks serve as a wonderful reminder of just how long RRI has been a part of the breast cancer scene – 1952 to 2025 is a very long time, with many wonderful stories and experiences to show for it. Importantly, we can see by the thoughtful and respectful collaborations of our members and colleagues over these years that the lives of those affected by breast cancer are enriched.

Knowledge is power and we work to provide this in a variety of ways for our members to enable them to make a difference in their local communities. Our members can feel confident that, through RRI, they are accessing evidenced-based resources developed by experts in their fields and, uniquely, backed by almost 70-years’ experience.

Advancing Liquid Biopsy in Australia for Breast Cancer (ALBA-BC)

Prof. Rik Thompson

ALBA-BC team members Nancy Calarco and Barbara Fougere

Prof. Rik Thompson et. al

This article is contributed by ALBA-BC co-founders Barbara Fougere (Consumer Research Partner) and Rik Thompson (Breast Cancer Researcher), as well as members of the ALBA-BC Consumer Research Partnership: Nancy Calarco, Leonie Young (Reach to Recovery International), Leslie Gilham (Breast Cancer Trials), Sharon Oakley (Metastatic Breast Cancer Action), and Linda Cummins (Breast Cancer Network Australia)

What is ALBA-BC and what are its goals?

ALBA-BC stands for *Advancing Liquid Biopsy in Australia for Breast Cancer*. We formed this group because patients with breast cancer clearly asked for better access in Australia to these blood tests for cancer detection.

Our team includes people from many different areas: breast cancer patients and advocates, cancer doctors (both medical and surgical), scientists developing new tests, experts in data analysis, health economics, survivorship, and more. We're based in cities across Australia—Brisbane, Sydney, Canberra, Melbourne, and Perth—and we're all working together to make these blood tests better understood, more available, and useful for monitoring and personalising treatment for breast cancer.

Our hope for the future is that these tests become affordable and accessible for all patients, that doctors feel confident using them in treatment planning, and that patients clearly understand what their results mean for their care.

What is a liquid biopsy and what can it find?

A *liquid biopsy* is a test that usually involves taking a blood sample, but it can also be done using other body fluids like urine, saliva, or fluid from around the lungs or brain. It helps doctors look for signs of cancer in the body—like cancer cells or pieces of cancer DNA—without needing to do surgery or take a tissue sample from the tumour. Since it's much less painful than a traditional biopsy, some experts prefer calling it something like a *blood test for cancer detection* to avoid fear or discomfort.

ALBA-BC is focusing on the following blood tests that can detect cancer cells in the body. These are the tests their partner labs are working on right now.

Circulating Tumour Cells (CTCs)

Circulating tumour cells, or CTCs, are cancer cells that have broken away from the tumour (usually in the breast but possibly other sites if the cancer has spread) and entered the bloodstream. The blood is a tough environment for these cells, and many of them die there, but some manage to survive. If CTCs are found after the original breast tumour has been removed, it may be a sign that the cancer has returned or spread to another part of the body.

Finding CTCs in the blood can help doctors see if a treatment is working—sometimes even before it shows up on scans. These cells can also be studied to learn how the cancer is resisting treatment, which could help doctors choose a better or more targeted therapy. The more CTCs someone has, the more serious the cancer may be.

Right now, it's still challenging to find and study these cells because there are very few of them in the blood compared to other blood cells. And it can be hard to tell for sure if they are cancer cells. But researchers are working hard to improve this. For example, in our ALBA-BC Alliance, Professor Sudha Rao in Brisbane is using advanced technology to study both CTCs and immune cells, which could give doctors more useful information about how to treat each person's cancer.

Circulating Tumour DNA (ctDNA)

Circulating tumour DNA, or *ctDNA*, is tiny pieces of DNA that are released into the blood when cancer cells die. Just like how a baby's DNA can be found in the mother's blood during and even after pregnancy, cancer DNA can stay in the blood for some time after being released.

ctDNA is different from normal DNA, and researchers can tell it apart using special techniques. Finding ctDNA in the blood can show that cancer is present—even before it shows up on scans or causes symptoms. Changes in ctDNA, like something called *methylation* (which affects how genes behave), can also help explain how the cancer is growing or resisting treatment.

Just like with CTCs, studying ctDNA can help doctors choose the best treatment for each person. In Brisbane, as part of ALBA-BC, Prof Paul Leo is using a very sensitive test that can spot ctDNA based on the unique gene patterns of a person's original tumour. Associate Professors Clare Stirzaker and Darren Korbie in Sydney have also developed powerful tests that can detect even tiny amounts of ctDNA with these methylation changes.

How can these blood tests help in breast cancer?

These blood tests that look for cancer cells or cancer DNA in the body could be helpful at many different stages of breast cancer.

For example, they might one day help with *early detection*, especially in women at high risk of breast cancer or in the 40% of women who have *dense breast tissue*. In these women, mammograms can sometimes miss cancer, so having an extra tool could be very useful.

In cases of *advanced breast cancer*, these blood tests can show whether treatment is working—sometimes even before scans can detect a change. They might also help spot *residual disease*—leftover cancer cells—after surgery, which could be an early sign that the cancer has spread.

These tests are also being studied to help *track treatment progress*. For instance, if a woman is having chemotherapy before surgery (called neo-adjuvant therapy), a drop in the number of cancer cells or cancer DNA in her blood may mean she's responding well to treatment.

In the future, these tests might even help predict which chemotherapy drugs will work best for a person's specific type of cancer and whether patients should have chemotherapy all together, helping to *personalise treatment*.

What are the challenges?

One big challenge is how fast this field is growing. Every month, hundreds of new research studies are published about these blood tests—on how they work, how they're used in real patients, and how they can guide treatment. Even for doctors and researchers, it can be hard to keep up. So, it's no surprise that it can feel overwhelming for patients too.

Another issue is knowing which tests are trustworthy and what the results really mean. Even if a test is available, not all cancer doctors may feel confident using it or trusting the results. On top of that, many of these tests aren't yet covered by insurance or the healthcare system, so people often have to pay for them themselves, which can make access difficult.

Where are things at in Australia and around the world?

In the United States, a test called *CellSearch* is approved by the Food and Drug Administration to detect CTCs, and many studies have shown that finding more of these cells can mean a worse outlook. However, in breast cancer, we don't yet have proof that adding this test into the treatment course actually improves the survival rate or the duration of survival.

There are also several ctDNA tests approved in the U.S. (and possibly Europe). One encouraging study used a ctDNA test in colon cancer patients in Australia. It showed that some people (those with Stage IIb cancer) could safely skip chemotherapy after surgery without affecting their outcomes. This is one of the first signs that ctDNA testing can help guide real treatment decisions.

In Australia, only a few of these blood tests are available so far, and patients usually have to pay for them themselves. These tests haven't yet been proven to change treatment outcomes in a reliable way, but they're being studied. Many Australian cancer doctors are interested in this research—about 14 out of 34 members of the ALBA-BC group are clinicians—and they are supporting trials to see how useful these tests could be in improving survival, optimising treatment, and/or keeping cancer from coming back.

What liquid biopsy means to our Consumer Research Partners:

Nancy: *As a metastatic breast cancer survivor one of the things I've gone in search for is a more accurate way of monitoring this disease. Standard tests are bloods and scans. We wait until something shows up in a scan which means solid mets. To have liquid biopsy that can pick up changes much earlier could be life-saving. Ideally it could tell if treatment is working or not, thus moving onto a different treatment sooner rather than later.*

Sharon: *When you're living with metastatic breast cancer, getting clear answers about what your cancer is doing can feel like a full-time job. Traditional biopsies are often invasive and exhausting. And when the cancer's in your bones—which it so often is—sometimes it's just not possible to biopsy at all.*

That's why liquid biopsies would be life changing. Instead of having to go through a procedure, this test just needs a simple blood sample. From that, oncologists could pick up tiny bits of cancer DNA or tumour cells floating around in your bloodstream.

It means we wouldn't have to wait for a tumour to grow big enough to see on a scan—it could be tracked to see what the cancer is doing at a cellular level. They could determine if treatment is working, if the cancer's changing, and whether it's time to try something different.

It's quick, non-invasive, and gives us real-time insight into a disease that's constantly shifting.

For those of us living with incurable breast cancer, this kind of test would help us spend less time waiting, less time in hospital, and more time living the life we've got—on our own terms.

Leslie: *Given this is for lay people and from a patient's perspective I'd love to move away from the term 'liquid biopsy' and instead simply use 'blood test'.*

The word biopsy relates to pain and discomfort for patients. The term liquid biopsy is similar to the issues around de-escalation and the need to move that to treatment optimisation.

Linda, TNBC Survivor: *After being diagnosed with aggressive TNBC (Triple Negative Breast Cancer) in 2019, I was fortunate to came across information regarding ctDNA blood testing for early detection/monitoring of this cancer and was able to find a local lab doing this blood testing. I was also fortunate to be able to self-fund my own 3 monthly ctDNA blood testing. In 2020 my ctDNA testing revealed a positive result for tumour DNA. At this point I pushed my care team to re-examine my regular scans and conduct a more extensive breast ultrasound which confirmed a re-occurrence in a lymph node. I underwent surgery to remove the affected nodes. I firmly believe that by alerting me to the presence of tumour DNA in my blood the ctDNA testing empowered me to advocate for myself and most probably saved my life!*

The genetic testing boom: supporting more people living with inherited cancer risk

Robyn Smith, *Programs and Advocacy Manager, Inherited Cancers Australia*

Robyn Smith

I'm a self-proclaimed data nerd and I know that information, like statistics, drives decisions. I also work for a charity that supports people with gene mutations that predispose them to cancer. The increase in genetic testing is important to Inherited Cancers Australia (ICA), which educates and supports people with inherited cancer risk so they can make informed decisions about managing their high cancer risk.

In recent years, many studies have driven an increase in genetic testing. Some of those are related to tumor or somatic genetic testing. When people with cancer have their tumors tested, they are often found to have inherited gene mutations such as BRCA1 or BRCA2. This may impact the person's cancer treatment and also have implications for biological family members.

As of 1 January 2025, Australian eligibility criteria for genetic testing for people with breast cancer has broadened, so it is available to nearly all breast cancer patients.[1] According to data gathered for the Australian Government's Medicare Benefits Schedule, genetic testing for breast and ovarian cancer patients increased by 1,042% in January – March 2025 from January – March 2024 – a huge increase!

We know that five to ten percent of breast cancers in Australia are due to gene mutations,[2] so we expect there to be more people identifying with gene mutations because more people are undertaking genetic testing. This also means there is likely to be a complementary increase in the amount of people undertaking cascade genetic testing. Cascade testing is genetic testing (a blood test) for people who have a biological relative with a gene mutation.

Genetic services are already in huge demand and many genetic services, through no fault of their own, can no longer provide the follow-up they once could. This is where organizations like ICA come in. We help those who are making decisions about managing their cancer risk by providing them with information and support. There are often long public wait times for prophylactic surgeries such as risk reducing mastectomy and people can feel anxious during that time. We aren't providing medical advice; what we do provide is connection with others in a similar situation (peer support mentors). We also hold educational events to empower people with information.

In 2024, we sought to better understand the experiences and health needs of people with inherited breast, ovarian, and prostate cancer risk. We surveyed over 880 Australian people with a known inherited risk[3] and found that, not surprisingly, nearly 75% of them had one or more first-degree family member with a cancer diagnosis and over 50% had two or more second-degree family members with a cancer diagnosis. Two thirds of respondents had undertaken some risk reducing surgery.

For people with a BRCA gene mutation, for instance, current guidance recommends considering removal of ovaries, fallopian tubes, and breasts at age 35 to 40 to manage cancer risk. While we in Australia are lucky to have these services, what was alarming was that 65 percent of respondents didn't seek psychological support during their decision-making process, and 85 percent did not access a menopause specialist service. There was high emotional and financial burden on individuals and families.

We found that patients' backgrounds and experiences played an important role in seeking support, connect, and education so they could make informed decisions about cancer risk. For people with gene mutations related to cancer, there is a real opportunity to manage cancer risk, but people need information and support to be able to do that.

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[1] https://www9.health.gov.au/mbs/fullDisplay.cfm?type=item&q=73295&qt=item

[2] https:www.canceraustralia.gov.au/cancer-types/breast-cancer-young-women/what-are-risk-factors-breast-cancer

[3] https://d20suj4g28m6xs.cloudfront.net/9bc637f562472ce9faa4f4be953552c5.pdf

> "WE KNOW THAT FIVE TO TEN PERCENT OF BREAST CANCERS IN AUSTRALIA ARE DUE TO GENE MUTATIONS,[2] SO WE EXPECT THERE TO BE MORE PEOPLE IDENTIFYING WITH GENE MUTATIONS BECAUSE MORE PEOPLE ARE UNDERTAKING GENETIC TESTING."

Life with medically induced menopause

Robyn Smith, *Programs and Advocacy Manager, Inherited Cancers Australia*

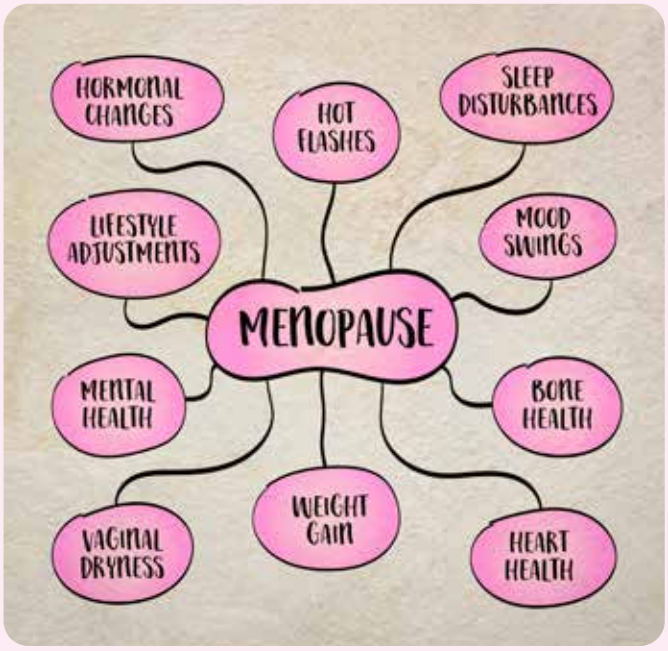
At Inherited Cancers Australia, we support people with gene mutations that predispose them to cancer as well as people with a strong family history of cancer, mostly breast, ovarian, prostate, or bowel cancers. We have online support groups with thousands of members. In these groups, there are weekly, if not daily, posts about people managing Medically Induced Menopause (MIM).

MIM happens through medical treatment or surgery to remove the ovaries, and it can be temporary or permanent. Current guidelines for people with gene mutations such as BRCA, PALB2, or lynch syndrome recommend removing the fallopian tubes and ovaries at age 35, 40, or 50, depending on family history and the gene mutation. These are often people who are going into MIM at a much younger age than the general population, and they are experiencing it essentially overnight.

There is a lack of dedicated information for people in this community, so we undertook a national survey and held focus groups to gather information about the needs and experiences of people experiencing MIM. Of the 764 survey respondents, 61 percent had negative or somewhat negative feelings about their experience, and 57 percent found it difficult to obtain specific information about MIM. Many respondents reported that there was a lack of adequate support from medical professionals, and they had to find what little information was available on their own. Many felt their symptoms were not properly explained and they did not know menopause clinics or specialists existed.

Inherited Cancers Australia recently partnered with Jean Hailes for Women's Health, a non-profit foundation dedicated to improving women's health across Australia through every stage of life, to develop evidence-based information and resources dedicated to this topic. We hope through our partnership we have filled huge gap and will help people make informed decisions about managing MIM.

As someone who is experiencing MIM personally after having my tubes and ovaries removed to reduce my risk of ovarian cancer, I can attest to the information gap for this topic that existed until now. When I had my surgery several years ago, I was told by a healthcare professional to simply "stay on the (contraceptive) pill for the rest of your life and you'll be fine". With the new information and resources we are developing, people can be assured that more can be done to manage MIM than simply staying on a pill for the rest of your life.



iStock.com/marekuliasz

> "AS SOMEONE WHO IS EXPERIENCING MIM PERSONALLY AFTER REMOVING MY TUBES AND OVARIES TO REDUCE MY RISK OF OVARIAN CANCER, I CAN ATTEST TO THE INFORMATION GAP FOR THIS TOPIC THAT EXISTED UNTIL NOW."

Genes and breast cancer:
the role of heredity in breast cancer and the implications of genetic testing

Prof Monique G. Zaahl, *CEO, GENEdiagnostics (Pty) Ltd. South Africa*

Prof Monique G. Zaahl

Following the sequencing of the human genome in 2010, genetic testing has become increasingly significant in identifying heritable diseases. The discovery of mutations in the BRCA1 and BRCA2 genes marked an early milestone in understanding the genetic basis of increased risk for breast and ovarian cancer.

Subsequently, research projects around the world, coupled with the development of advanced technologies like Next-Generation Sequencing (NGS) and Whole Exome Sequencing (WES), have highlighted the role of numerous other genes in heritable conditions.

Hereditary in breast cancer

Hereditary breast cancer represents a small portion of all breast cancer cases, estimated to be between five and ten percent. This form of cancer arises when an individual inherits a gene mutation from a parent, thereby elevating their risk of developing the disease. A notable indicator of hereditary breast cancer can be a family history of the condition, particularly among first-degree relatives such as parents, siblings, and children.

The most frequent genetic causes of hereditary breast cancer are mutations in the BRCA1 and BRCA2 genes. These genes play a crucial role as tumor suppressors, aiding in DNA repair and the regulation of cell growth. When these genes undergo mutation, they may lose their functional capacity, leading to an increased likelihood of cancer development.

In addition to BRCA1 and BRCA2, other genes such as PTEN, PALB2, CHEK2, and CDH1 have been linked to an elevated risk of breast and ovarian cancer. Individuals who inherit mutations in these genes, including BRCA1 and BRCA2, face a significantly higher lifetime risk of developing breast cancer, which can be as high as 80 percent depending on the specific gene involved and their family history.

It is important to remember that inheriting a mutated gene does not invariably mean that an individual will develop breast cancer.

Genetic testing in breast cancer

According to the World Health Organization (WHO), breast cancer is the second most common cancer affecting women worldwide. The WHO data reveals a significant disparity in diagnosis rates based on the Human Development Index (HDI) of a country. In nations with a very high HDI, the lifetime risk of a breast cancer diagnosis for women is one in 12. This contrasts sharply with countries with a low HDI, where the risk is one in 27. Breast cancer is a significant health concern in South Africa, being the most common cancer in women there, with a lifetime risk of one in 26. Furthermore, significant rises have been noted in breast cancer cases in South Africa over the past 20 years, accounting for 14-30 percent of all cancers in women.

Genetic testing plays a vital role in identifying mutations in genes associated with breast cancer. This allows for the pre-symptomatic detection of individuals and their families who have an elevated risk of developing breast and ovarian cancer. Early detection is critical as it significantly improves the effectiveness of treatment and leads to a more positive prognosis.

For women who are found to carry such mutations, several options for risk reduction may be considered. These include increased surveillance, preventive measures, and prophylactic surgeries like mastectomy, amongst others. It's important to note that certain populations, such as Ashkenazi Jews and Afrikaners, have a higher incidence of BRCA mutations. This makes genetic testing and counselling particularly important within these groups.

The early detection of breast cancer through genetic testing not only enhances survival rates and lowers morbidity but can also reduce healthcare costs by enabling prompt diagnosis and effective treatment.

Genetic testing and counselling services are available to evaluate an individual's risk and provide comprehensive information regarding potential management strategies. Furthermore, genetic testing is instrumental in decreasing mortality rates and guiding effective treatment approaches.

For more information about available genetic testing and counselling services in South Africa, contact info@genediagnostics.co.za.

> “IN ADDITION TO BRCA1 AND BRCA2, OTHER GENES SUCH AS PTEN, PALB2, CHEK2, AND CDH1 HAVE BEEN LINKED TO AN ELEVATED RISK OF BREAST AND OVARIAN CANCER.”

Challenges in patient understanding of breast cancer biology and biomarkers

Results from a global survey on advanced/metastatic breast cancer

Understanding biology and biomarkers in connection with advanced breast cancer

Dr. Fatima Cardoso

Dr. Fatima Cardoso, *ABC Global Alliance President*
Portugal
On behalf of the Patient Biomarker Survey Steering Committee

People with advanced/metastatic breast cancer (ABC/MBC) require an understanding of the cancer biology and biomarkers relevant to their diagnosis to participate in shared decision-making with their healthcare team. Improved understanding can also alleviate some of the uncertainty that comes with a diagnosis and improve patient-reported outcomes.

ABC Global Alliance has partnered with AstraZeneca to conduct a global survey of people living with ABC/MBC, exploring their understanding and recall of related biomarkers, and their experiences and challenges in learning about the type of breast cancer they have. Findings from the survey are summarised in a series of materials outlining key challenges and opportunities for change across the ABC community, with the goal of empowering patients with information and knowledge to take an active role in their care.

A Global Whitepaper and two Summaries of the survey findings are available on the ABC Global Alliance website: an executive summary for the wider ABC/MBC community and a lay summary for patients, caregivers, and advocates.

Please visit https://www.abcglobalalliance.org/resources#biomarker-survey

Please note that thanks to the accessibility tool installed on the website all contents are made available in more than 100 languages. Watch the video explaining how to see all contents translated at https://youtu.be/sf0tvvgsNml

Reprinted from Uncovered: the Male Breast Cancer Journal, May 22, 2025, Published by the NY Cancer Resources Alliance & AngioMedia, https://malebreastcancerjournal.blogspot.com/2025/05/know-your-genes-save-your-sons-truth.html

Know Your Genes, Save Your Sons: The Truth About Male Breast Cancer and Genetic Risk

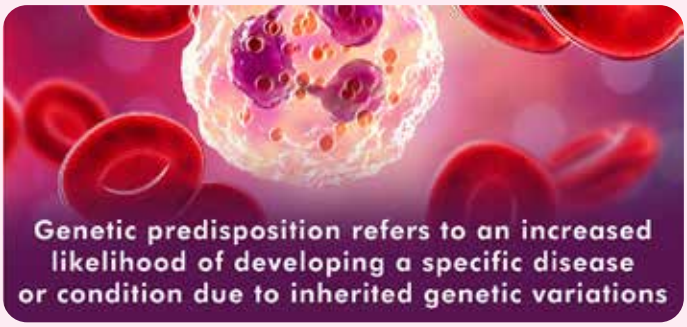
Yeah, you read that right. Breast cancer doesn't care if you have pecs instead of breasts. It's time to kill the myth: male breast cancer is real, dangerous, and often overlooked. But here's what most men don't know: this isn't just about you—it's about your kids. Your genes carry the story, and if you don't know your predisposition, you might be passing down a deadly risk to your sons and daughters.

GENETIC RISK IS A FAMILY MATTER

Let's cut to it. BRCA1 and BRCA2 mutations can hide in your DNA and silently stack the odds against you. These mutations don't just increase your chances of breast cancer; they spike your risk for prostate and pancreatic cancers too. And if you carry them, there's a 50/50 chance your children do too.

This isn't fear-mongering. It's fact. Early detection through genetic predisposition testing can save lives—yours and theirs.

That's where Bard Diagnostics comes in. In partnership with the Male Breast Cancer Global Alliance, we're making noise about the quiet threat most men don't even know they carry. We provide cutting-edge genetic testing that helps uncover hidden risks. It's painless, fast, and it might be the most powerful health decision you ever make.



HERE'S THE HARD TRUTH

Every year, over 2,700 men in the U.S. are diagnosed with breast cancer. Around 530 of them die. That's more than one man a day. Think it won't happen to you? Think again. Male breast cancer might be rare compared to women, but when it hits, it often hits harder. Why? Because we don't talk about it. We ignore the signs. We delay the checkups. And sometimes, we don't even know it's a thing until it's too late.

KNOW THE RISKS

Here are some factors that can crank up your risk:

- Age (most cases hit between 60 and 70)
- A family history of breast cancer
- Radiation exposure
- Hormone therapy or conditions causing high estrogen levels
- Liver disease
- Obesity
- Genetic mutations like BRCA1 and BRCA2

If you have a family history of breast, ovarian, or prostate cancer, this is your cue. Don't just get checked for you—get checked for them. Your kids deserve to grow up with a dad who made smart choices.

GET AHEAD OF THE GAME WITH GENETIC TESTING

Genetic predisposition testing with Bard Diagnostics reveals if you're carrying BRCA or other high-risk mutations. It's simple. It's confidential. It's life-saving.

Don't just wait for symptoms. That weird lump under your nipple, skin dimpling, or fluid leaking from your chest isn't "nothing" just because you're a dude. If something feels off, it probably is.

WHAT YOU NEED TO WATCH FOR

Here are the signs that should have you picking up the phone:

- A lump or swelling, usually painless
- Skin irritation or dimpling
- Nipple pain, redness, or inversion
- Discharge from the nipple
- Swollen lymph nodes under the arm

If you notice any of these, don't brush them off. Don't "wait and see." Don't tough it out. That's not brave. That's reckless.

REAL STORIES, REAL MEN

This isn't just numbers. These are fathers, brothers, sons, and friends. The Male Breast Cancer Global Alliance has created a community of male survivors and advocates who prove that early detection saves lives. Their stories are proof that catching this early makes a huge difference.

THE BOTTOM LINE

Breast cancer doesn't make you less of a man. Ignoring it might. Real strength is in prevention, in action, and in knowledge. Whether you've got a family history or you just want to be sure, getting tested is one of the smartest moves you can make.

So, here it is, plain and simple: check your chest, know your genes, and talk to your doctor. Then get in touch with Bard Diagnostics for testing that could change your life—and maybe your kids' lives too.

This isn't just awareness. This is a wake-up call.

Be the guy who got checked. Not the one who wished he had.

For more information about the MALE BREAST CANCER GLOBAL ALLIANCE PREDISPOSITION TESTING PROGRAM, contact us at: www.mbcglobalalliance.org or contact our hotline at: 516.522-0777

Addressing healthcare disparities through free genetic testing and counselling in Greece


Korina Tsompanisaki

Korina Tsompanisaki, *Social Worker, Hellenic Association of Women With Breast Cancer ("Alma Zois")*
Greece

Genetic testing plays a crucial role in identifying individuals who may be at higher risk for certain types of cancer, including breast cancer. Early diagnosis through genetic testing can lead to earlier interventions such as more frequent screenings, preventive measures, and lifestyle changes that can significantly improve health outcomes. However, in Greece, significant social inequalities persist that prevent many individuals from benefiting from these services.

Uninsured women are one of the most vulnerable groups, as they do not have access to prescription-based genetic testing. Additionally, men diagnosed with breast cancer are not referred for genetic testing, although they may also carry hereditary mutations that put them at risk. Another significant issue is that many women cannot prove their family history, as histological examination of their diagnosed relatives is required to confirm genetic risk.

To address these inequalities and reduce social discrimination in healthcare, our association has implemented a free genetic testing program that includes free genetic testing and genetic counselling as well aspsychological screening, both pre- and post- testing, in order to help women make informed decisions. This program is available to uninsured women, men, and individuals who, according to international guidelines, require genetic testing. This initiative ensures that those who might otherwise be excluded from these essential services due to financial or insurance barriers will have the opportunity to undergo necessary genetic testing.

By offering free genetic testing, our association helps bridge the gap in access to healthcare services, allowing individuals from vulnerable social groups to take appropriate preventive measures. This initiative not only empowers individuals with crucial health information but also contributes to reducing inequalities in healthcare within the community.

Our efforts highlight the importance of equality in healthcare access and supporting individuals in receiving the care and information they need, regardless of their socio-economic background.

> "THIS INITIATIVE NOT ONLY EMPOWERS INDIVIDUALS WITH CRUCIAL HEALTH INFORMATION BUT ALSO CONTRIBUTES TO REDUCING INEQUALITIES IN HEALTHCARE WITHIN THE COMMUNITY."

One continent, one vision: reaching out to rural communities for familial breast cancer genetic testing


Nerina C van der Merwe

Nerina C van der Merwe B.Sc.Agric, Ph.D. Genetics,
Registered Principal Medical Scientist specializing in familial breast and ovarian cancer syndrome, Division of Human Genetics, School of Pathology, National Health Laboratory Service and University of the Free State South Africa

A team of South African researchers believes the implementation of a new diagnostic test called the BRCA 2.0 POC Research Assay, which uses new technology involving rapid point-of-care (POC) testing, will reach more communities and hopefully contribute to saving more lives. This new technology, once it is validated as a diagnostic genetic test, is the future of rural familial breast and ovarian cancer testing in South Africa when performed in parallel with genetic counselling. Because the assay (test) is reliable and user-friendly, it is extremely suitable for use in rural clinics and it eliminates the need for the clinics to invest in expensive laboratory equipment. By performing the test at the community clinic, patients no longer need to travel to a major hospital for genetic testing. It will be available to more patients and related family members who are currently unaware that they might have inherited a disease-causing change in high-risk cancer genes such as BRCA1 or BRCA2.

The team is very excited that the potential implementation of this first-tier screening test at the point-of-care will benefit not only the patient but also those unaffected but at-risk family members. Its implementation has various benefits; not only is it inexpensive and accurate, but the results are available within 90 minutes. It can furthermore be done using saliva or a buccal (inside cheek) swab, which is less invasive than taking a blood sample. The biggest benefit is the availability of genetic counselling while the test is running. Talking with a counsellor can provide patients and family members with the opportunity to ask questions about genetic testing and cancer, which will simultaneously improve the lack of cancer awareness in South African communities. By talking during a face-to-face consultation, the counsellor can ensure that the patient and related family members understand the value of the test. This will eventually result in an increase in the currently low uptake of genetic testing in related at-risk family members, as this cancer type is inherited.

Implementation of the POC assay in conjunction with genetic counselling in rural settings will meet the goals set for Africa by the World Health Organisation (WHO). One of those goals is to extend health services to currently unreached populations, such as rural settlements, to ensure that all patients have access to testing. Other goals are to improve the process of delivering care and to proactively identify and increase breast cancer services to all age cohorts. By performing the POC assay in rural settings all these goals will be addressed, as the test itself will be more cost-effective and the waiting period for test results will be considerably shorter.

> “BY TALKING DURING A FACE-TO-FACE CONSULTATION, THE COUNSELLOR CAN ENSURE THAT THE PATIENT AND RELATED FAMILY MEMBERS UNDERSTAND THE VALUE OF THE TEST.”

Genetic testing for breast cancer in India: understanding women's sentiment

Rama Sivaram, *Consultant, KEN Hospital Research Centre, Pune; Mentor and Faculty, Sanjeevani Life Beyond Cancer India*

Rama Sivaram

Breast cancer is the most common type of cancer globally, and India ranks amongst the highest in number of cases with 98,337 estimated breast cancer deaths in the year 2022. As the most common cancer in India, it accounts for 28.2 percent of all female cancers, with an estimated 216,108 cases diagnosed in 2022. Added to that burden, on average Indian women are diagnosed at a much younger age than women in western countries.

It is evident from the current scenario that this is a growing women's health concern. It is also evident that diagnostic measures are available and the down-sides of breast cancer screening are minimal. Genetic testing is an important and effective tool for the future. In India, five to 10 percent of all breast cancer cases can be attributed to hereditary and genetic predispositions that increase a woman's risk and susceptibility. Key findings of a study in a diagnostic lab in India show BRCA1 mutations were more common, accounting for 68.7 percent of all detected mutations, while BRCA2 mutations are less frequent than BRCA1 but still pose significant risk and also need targeted therapeutics. The more critical observation is that younger women between ages 20 and 45 have a higher BRCA positive rate, making them more vulnerable to more aggressive disease in the absence of a family history of breast cancer. Identifying BRCA mutations early can offer better survival outcomes through tailored treatments.

Genetic testing specifically targeting genes such as BRCA1 and BRCA2 has emerged as a powerful tool in identifying individuals who carry these high-risk mutations. This identification allows for the implementation of early detection measures, the adoption of preventive strategies, and the personalization of treatment approaches, ultimately aiming to improve outcomes for those at increased risk. It is very useful in identifying a genetic risk, making decisions that will prevent or minimize any inherited disease or disorder, and/or choosing the right treatment.

Trajectory of genetic testing for breast cancer within India

Before the beginning of the 21st century, India had scarce dedicated research and application of genetic testing specifically for breast cancer. Data on Hereditary Breast and Ovarian Cancer syndrome (HBOC) and their mutations were largely unavailable. Family history and genetics were recognized as risk factors, however, which eventually led to studies of genetics and genetic markers post 2000. India was not ignorant of the role of genetics in health and diseases prior to these studies. As early as the 1970s, technology and expertise were directed towards the diagnosis of other genetic disorders. Breast cancer risk assessment was not a priority.

February 2002 marked the historic moment in genetic testing for breast cancer in India with the creation of the first comprehensive Hereditary Cancer Detection and Prevention Programme (HCDPP) at the Cancer Institute (WIA) in Chennai. Specialized services for the assessment of hereditary cancer risk with a specific focus on breast cancer was put in place. In 2008 the genetic testing landscape expanded to commercial entities. Protocols and eligibility guidelines for testing were set. Early research efforts provided crucial evidence of genetic factors implicated in breast cancer in the Indian context, thereby providing a scientific foundation for the increasing adoption and clinical utility of BRCA1/2 testing. A sample time-line shows that between the years 2010 and 2018 over 32 international guidelines were published on HBOC management.

In 2014, the universal adoption of multi-gene panels incorporating non-BRCA genes was recommended. India's first major meeting to discuss genetic counselling and testing for HBOC took place in 2019 in Mumbai. In 2020, the first expert consensus document on genetic counselling, testing, and management of HBOC in India was published. This year an updated version of the consensus document was published.

The sentiment of women

The discipline has grown and with it awareness of and improved access to genetic testing has grown and expanded in India's larger cities. Some institutional barriers remain, such as high costs, limited access, insufficient infrastructure, reliance on western data to develop tests that may not translate well to Indian women, and a dearth of facilities and staff in rural areas. However, another significant barrier can be the women themselves. A woman's feelings, beliefs, and personal values significantly influence whether she chooses to undergo testing, how she interprets the results, and how she manages her risk. Especially in rural settings, lack of awareness, misconceptions, and social and cultural norms can still be obstacles. Sentiments may also vary and be influenced by the demographics of age and life stage, where the priorities of the younger and the older women differ.

The role of the genetic counsellor is to educate the women with balanced and simple information. One must not forget to address a woman's deepest fear, the script that keeps playing in her mind

and is not easy to erase and which we hear over and over again from different women: “Will my daughter get it? Will she inherit this mutation?” Addressing this angst and guilt needs to be done sensitively. The counsellor must have the ability to adapt their communication style to the woman’s needs, give her ample freedom to express herself, listen actively with empathy and respect, and avoid any coercive tactics. The woman must understand that the benefit of knowing one’s risk is motivation and time to prepare, make an informed decision, and take positive action. Knowing one’s genetic risk can provide relief and reduce anxiety associated with uncertainty.

Dealing with uncertainty and ambiguity where a genetic test reports "variants of uncertain significance" can also cause confusion and anxiety, as their impact on cancer risk is not yet clear. This again requires clarification from both the counsellor and medical or clinical geneticist.

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Integrating genetics, research, and holistic support in breast cancer care: 25 years of Prashanti Cancer Care Mission

Laleh Busheri, *CEO, Prashanti Cancer Care Mission*
India

Laleh Busheri

Prashanti Cancer Care Mission (PCCM), a non-governmental organization founded in 1996, marks 25 years of transformative work in breast cancer care this year. What began as a modest initiative has evolved into a comprehensive model for holistic, affordable, and research-driven treatment.

To strengthen its research efforts, PCCM established the Centre for Translational Cancer Research (CTCR), which focuses on clinical and translational studies in breast cancer. With over 50 national and international publications across clinical, translational and genetics domains, PCCM's research is contributing significantly to the global breast cancer research landscape. One of its landmark initiatives was the creation of Pune's first breast disease biobank housing over 1800 samples with annotated clinical data.

Recognizing that five to ten percent of breast cancers are hereditary, often linked to BRCA1 or BRCA2 gene mutations, PCCM integrated genetic counselling and testing into its clinical workflow. Through its Genetics Clinic, established in 2017, PCCM provides subsidized counselling and testing for patients who meet recommended criteria, such as early age of diagnosis or family history of cancer. To date, over 500 patients have received genetic counselling, with more than 400 undergoing testing. CTCR also conducts studies to better understand hereditary breast cancer in the Indian population. These studies may inform the development of context-specific guidelines and policies for genetic testing in India. Although genetic testing remains an emerging aspect of Indian Health care, PCCM has made it an integral part of its care model. Insights and real-life stories from this initiative are shared in my book, *Genetic Testing – A Game-Changer in Breast Cancer Management*.

PCCM has also recently launched a Preventive Clinic offering community-based breast cancer risk assessment for the wider community. True to our holistic approach, this clinic also provides complementary nutrition and mental health counselling to all individuals creating a well-rounded support system for those seeking to understand and manage their risk.

Among the many individuals who walk through the doors of this newly launched Preventive Clinic, one story stands out for its quiet strength and far-reaching impact. Neena (name changed), a 32-year-old woman, came to us seeking clarity, haunted by a strong family history of cancer. Neena did not have breast cancer but she came to the clinic to understand her risk because her mother had succumbed to ovarian cancer and her maternal aunt had been diagnosed with breast cancer. Though she had no symptoms herself, Neena's intuition told her there was more beneath the surface. Our genetic counsellors recommended a multigene panel test, a simple yet powerful blood test that screens for mutations in genes known to increase cancer risk.

Four weeks later, the results arrived: Neena carried a pathogenic BRCA1 mutation. It was a moment of truth, but not fear. Equipped with expert guidance and emotional support, Neena made a courageous, proactive choice: a prophylactic (preventive) bilateral mastectomy with immediate reconstruction. She is also planning to have an oophorectomy (removal of the ovaries) in the future, as she feels her family is complete with two children. This step helps lower her risk of ovarian cancer, which is higher with the BRCA1 gene.

Her decision not only reshaped her future; it empowered her to become a guide for others. She has fully recovered from the surgery and now mentors women facing similar crossroads, offering both practical advice and the kind of solidarity that only someone who's walked the path can give. Her story embodies the very purpose of our Preventive Clinic: to replace uncertainty with understanding, to transform risk into resilience, and to remind each individual that knowledge is not just about prevention. It is also about reclaiming agency, health, and peace of mind.

I have personally witnessed the importance of combining medical excellence with clear information and empathetic support. Patients like Neena remind us why it's essential to equip individuals with the knowledge they need to make empowered decisions. At PCCM, we remain dedicated to transforming lives through personalized care, genetic counseling, and research. Neena's journey is one of many that exemplify our ongoing commitment to delivering holistic, patient-centred breast cancer care.

Personal stories of hope and resilience from survivors:

Liana's story

Both sides of the scar: a plastic surgeon's journey through BRCA2 and prophylactic mastectomy

Dr Liana Volkwyn, *Plastic Reconstructive and Aesthetic Surgeon*
Brooklyn, South Africa

My dual role

The very reason I became a plastic surgeon was my mother. She was diagnosed with breast cancer during my first year of medical school and I remember feeling overwhelmed, not just as a daughter but as a future physician wanting to do something. Watching her go through treatment lit a fire in me. It became not only my mission, but also her dream for me: to help women like her heal, rebuild, and reclaim their sense of self after breast cancer. That's why I pursued plastic surgery with a focus on breast reconstruction.

For years, I've stood beside patients during some of the most vulnerable moments of their lives. I've used my hands to help restore what cancer tried to take. But nothing could have prepared me for the moment when I learned I carry the BRCA2 gene mutation and, suddenly, I wasn't just the surgeon. I was the patient. The professional became personal. And the journey I had guided so many women through became my own.

The BRCA2 discovery: a personal reckoning

After my mother passed away from breast cancer, we pursued genetic testing as a family. It was 2012, and the BRCA screen available at the time was limited. The results came back negative and, while that offered a temporary sense of relief, something in me remained unsettled.

Over the next several years, I continued working closely with breast cancer patients, many of them young women, and I couldn't ignore the growing voice in the back of my mind. Since that initial test, three more of my maternal aunts had been diagnosed with breast cancer. The pattern was impossible to dismiss.

By the end of 2017, as a member of our hospital's breast clinic and someone immersed in this world daily, I decided it was time to revisit my own genetic risk. I underwent comprehensive genetic testing, and in early January of 2018, I received the news: I carry the BRCA2 gene mutation.

Even with everything I knew professionally, the result landed heavily. I wasn't just a surgeon anymore. I was a high-risk individual with a choice to make about my own future, and that changed everything.

My decision: choosing prophylactic mastectomies

Receiving my BRCA2 diagnosis in 2018 didn't mean I had cancer, but it meant I had a much higher chance of getting it. This was something I couldn't ignore, especially given my family's history. Despite my medical background, the decision to undergo a bilateral prophylactic mastectomy wasn't clinical, it was deeply emotional. It brought up memories of my mother's journey, especially the final stages of her illness, which were devastating to witness.

People often call me brave for making this decision. But to me, it wasn't about bravery, it was about prevention. I had watched someone I love suffer unimaginably. I had seen what cancer could take away. My choice came from a place of love, determination, and the desire to do everything in my power to avoid walking that same path.

Yes, I weighed the options. Yes, I considered surveillance. But ultimately, I wanted to take control of my risk rather than live in its shadow. I wanted to act while I was healthy, not wait for a diagnosis to make the decision for me. That clarity became my guide, and it led me to surgery.

My experience: surgery and recovery through dual lenses

When I elected to undergo a bilateral prophylactic mastectomy, I knew I was making a deeply personal and preventative choice, but I also knew it wouldn't be simple. I chose to remove not just my breast tissue, but my nipples as well. And waking up from surgery to find that part of my body gone was more emotionally challenging than I had anticipated. No amount of medical knowledge could fully prepare me for that moment.

Ironically, or perhaps fittingly, given how medicine often humbles us, I went on to experience nearly every complication in the textbook. On the first night after surgery, I bled out and had to be resuscitated. What followed were weeks of complications, including a persistent seroma on my back that required repeated drainage.

That experience, in particular, shifted my perspective profoundly. As a plastic surgeon, I had drained countless seromas in the clinic, often with clinical detachment. I knew it could be uncomfortable, but I hadn't fully appreciated just how excruciating the pain could be until I was the one on the table. Yes, draining a seroma brings relief but, in that moment, the pain is sharp, intimate, and deeply personal.

> "RECEIVING MY BRCA2 DIAGNOSIS IN 2018 DIDN'T MEAN I HAD CANCER, BUT IT MEANT I HAD A MUCH HIGHER CHANCE OF GETTING IT. THIS WAS SOMETHING I COULDN'T IGNORE, ESPECIALLY GIVEN MY FAMILY'S HISTORY."

It made me realize that while sometimes we do have to hurt in order to heal, we should always strive to do it as gently, kindly, and compassionately as possible. That lesson now sits with me in every consultation, every procedure.

I also chose to undergo bilateral latissimus dorsi flap reconstruction. It was the right decision for me, but it came at a cost. The latissimus is a major shoulder stabilizer, and since surgery, I've lost significant strength in my upper body. Some aspects of my surgical work are harder now, some

procedures physically challenge me in ways they never did before. It's been an uphill battle, one that still tests me.

And yet, despite everything, the complications, the pain, the permanent changes, I would choose this path again because every day I wake up cancer-free is a gift. And every patient I now guide through their own journey knows that I truly understand, not just with my hands, but with my whole heart.

Rebuilding: physically, emotionally, and professionally

Recovery wasn't just about healing incisions, it was about rebuilding myself piece by piece, both physically and emotionally. My body had changed. My strength had changed. And my identity had shifted in ways I didn't fully expect. But so too had my empathy, my voice, and my understanding of what it means to walk through this fire and come out the other side.

Reconstruction gave me back a sense of wholeness, but not the kind that's skin-deep. It was a wholeness rooted in acceptance of scars, of vulnerability, of strength I didn't know I had. Choosing the latissimus dorsi flap was right for me, even though it came with loss of muscle, of physical capability, of ease. But I've learned that rebuilding isn't about going back to who you were, it's about honouring who you are now.

This journey changed the way I show up in my work. I've always prided myself on being honest and transparent with my patients, but now, I make it a point to share my story with full honesty and full disclosure. I tell them about the challenges, not just the outcomes. I let them know that the road can be hard but that it's navigable, and that they're not alone.

I've found that sharing my lived experience brings a deep sense of comfort to my patients. They know they're not just hearing clinical advice, they're hearing from someone who's been through it, felt it, and come out stronger. And in that space of mutual understanding, healing happens a little differently. A little deeper.

Message to others: empowerment through knowledge and choice

If there's one thing I've learned on this journey, both as a plastic surgeon and as a woman who chose prevention, it's that knowledge is power, but it must come at the right time. Genetic testing is a deeply personal decision, and I believe it's one you should make when you're emotionally ready to live with the result. Because once you know your genetic status, whether it's BRCA2 or any other mutation, that knowledge becomes part of your story. It informs your choices, shapes your future, and stays with you. And for that reason, you need to be in a place where you feel emotionally prepared to receive and carry that information.

Just as important is making sure you don't walk this road alone. Cancer, whether it's a diagnosis or a looming possibility, is not something we face in isolation. It affects every aspect of our lives and the people who love us. Your support system matters. Whether it's family, friends, healthcare providers, or a community of others who've walked this path, having people who will stand with you, lift you, and carry you when you feel weak is essential.

I didn't choose this path because I was fearless. I chose it because I wanted to live fully, intentionally, and on my own terms. To anyone reading this who is facing a decision about testing, treatment, or reconstruction: take your time, gather your strength, and surround yourself with love.

You are not alone. And your story, whatever it looks like, is yours to shape, with honesty, courage, and support.

Jacqui's story

Stories of strength

Jacqui Pike
Australia

My name is Jacqui Pike. I'm a breast cancer survivor living in Australia, but originally from South Africa. I was first diagnosed with breast cancer in May 2020. Having gone through surgeries, 24 rounds of chemotherapy, and 6 weeks of radiation therapy, I felt worn out. Everything happened so fast I didn't have time to dwell on anything. I had stayed annoyingly cheerful throughout everything; my naivety, family support and positivity got me though it all.

I'm a writer. I write content for business proposals, so I wrote an article on LinkedIn relating how I tackled my cancer to the way I work as a proposal manager. Writing my story helped me process what I had gone through, and it inspired many people that read it, which made me happy. I had breast cancer, did everything I needed to do, stayed positive, and I had won – end of story.

The next year I focussed on losing the weight I'd picked up from chemo and getting strong and healthy again. Then fast-forward to June 2022 and my yearly scans picked up a different cancer in the other breast. Luckily, only at Stage 0. This news was so unexpected and was totally gut-wrenching! I felt totally defeated; I had done everything and truly believed that I had beaten it. Nothing anyone said made any difference to me. Stupid words like "you've done this before; you can do it again" made me want to curl up and die or punch them in the face. I did not want to do this again. Knowing what I had to go through again made it 1000 times worse.

It took an incredible amount of effort to ride this storm again; the biggest wave was learning to trust myself and my beliefs again. And yes, I had the pity party, the "why me", and the tears and frustration that came with it. But I'm not ashamed – sometimes you need to hit the bottom to pull yourself up.

This time I took control and asked to be tested for the BRCA gene as I have two girls. Luckily, it was negative – which was a huge relief. I then made the decision to have a bilateral mastectomy and reconstruction. Unfortunately, I had complications with the implants and my weak radiated skin resulting in a total of nine surgeries during my whole cancer ordeal. It was exhausting recovering – over and over. I really needed time to catch my breath – so I wrote another article.

The power and impact of words should not be underestimated. It is a way of expressing your feelings, emotions, and triumphs on paper. Writing helped me heal and lead to the creation of *Stories of Strength*, a boutique writing service in Brisbane, Australia, documenting the journeys of inspirational people who have overcome adversity. Everyone has a story to tell, especially cancer patients. Visit **www.storiesofstrength.au** for more information and to connect.

And let the healing begin!

Stories of Strength

"THE POWER AND IMPACT OF WORDS SHOULD NOT BE UNDERESTIMATED. IT IS A WAY OF EXPRESSING YOUR FEELINGS, EMOTIONS, AND TRIUMPHS ON PAPER."

Spotlight on metastatic breast cancer

Dr. Andrea Smith

Launch of Metastatic Breast Cancer Action Australia

Dr. Andrea Smith
Board Director, MBCA Australia

We are delighted to share with you the news that a brand-new national breast cancer advocacy organisation has recently been launched in Australia. Metastatic Breast Cancer Action Australia (MBC Action Australia) is a grassroots, consumer-led organisation dedicated to the needs of people living with metastatic (also known as advanced, secondary or stage IV) breast cancer. The origins of the organisation can be traced back to a two-day research workshop for people with MBC that explored their advocacy, information, and support needs. The key recommendation from the workshop was the importance of forming a dedicated MBC organisation. Consequently, several of the workshop attendees committed to setting up such an organisation. Just six months later in October 2024, MBC Action Australia was launched.

MBC Action Australia's mission is to improve the lives and health outcomes of the women and men living with MBC in Australia. Led by people living with MBC, we use our collective voices and experiences to advocate for improvements in policy, support, and services specific to the needs of our community. We work with supporters and collaborate with other organisations on shared priorities. By working together, we aim to enable people with metastatic breast cancer to live their lives to their full potential for as long as possible.

Spotlight on our members: Portugal

Sofia Abreu

“Juntas à Mesa” Brunch

Sofia Abreu, *Coordinator, Movimento Vencer e Viver (Win and Live Movement)*

Portugal

On June 28, from 10 a.m. to 1 p.m., the first edition of the “Juntas à Mesa” (Together at the Table) Brunch will be held in Lisbon. The event is especially dedicated to women with breast cancer and survivors.

With the aim of promoting the sharing of information and inspiration, this initiative invites all participants to sit down at the table to reflect and learn about topics relevant to their well-being. In this inaugural edition, the topic will be “Nutrition and Breast Cancer” and will focus on the importance of nutrition in prevention, during treatment, and post-treatment.

The event will feature three guests of honor:

- Dr. Paula Ravasco, PhD in Clinical Nutrition, Oncology and Metabolism
- Sofia Ribeiro, actress and breast cancer survivor
- Joana Cruz, radio presenter and survivor who will take on the role of moderator

It will be a morning of socializing, learning, and sharing in a welcoming environment designed to strengthen bonds and promote physical and emotional health care.

This is the first of several meetings: “Juntas à Mesa” will be a biennial event, always with new themes, experts and moments designed especially for these courageous women.

Participation is free, but subject to prior registration, which is limited to capacity.

Find out more and register at: www.ligacontracancro.pt/juntasamesa

Spotlight on our members: India

Embracing wellness: reset and self-regulate your circadian rhythm after breast cancer

Rama Sivaram, *Consultant, KEM Hospital Research Centre, Pune; Faculty and Mentor Sanjeevani Life beyond Cancer India*

Rama Sivaram

Many breast cancer patients and survivors experience not only long-term side effects from treatment but also a mental toll that lingers. Getting medications for these debilitating symptoms can be an option, but more and more oncologists and other health care professionals are recognizing that every woman needs to be seen and taken care of holistically. This goal of integrative cancer care is to understand both the science and art of healing, using both the western sciences and medicine combined with complementary therapies. While many complementary therapies are being practiced selectively across the world, we at Sanjeevani Life beyond Cancer, India have embraced every aspect of integrative cancer care wholeheartedly.

I became interested in circadian rhythm three years ago because it governs the activities of our vital organs and plays a fundamental role in maintaining overall health and well-being. It is integral to coordinating our 24-hour cycles of day and night. I wanted to understand my own circadian rhythm in order to know why some symptoms haunt me, especially at particular times of the night. If each one of us become mindfully aware of what, when, and why some unwanted symptoms occur, we can do something to fix the situation. This kind of self-care enhances and supports the body's capacity to maintain homeostasis, the self-regulating process that keeps the internal environment of the body stable even when external conditions change.

What is circadian rhythm?

Circadian rhythm is the body's internal clock. It is a pattern of physical, mental, and behavioral changes that organisms experience over a 24-hour cycle (day and night). It matches with day and night, light and dark, and the organs in our body, running in the background and carrying out essential functions and processes. The brain has a small, powerful master clock called the suprachiasmatic nucleus (SCN), and the entire body has its own peripheral clocks in each organ. Almost all tissues and organs have their own biological and circadian rhythm. Our circadium rhythm is programmed from the inside but we take cues from the outside environment, which includes light, temperature, physical activity, social cues, stress, and more. As the sun moves, the body tells us to wake, eat, digest, play, rest, sleep, etc.

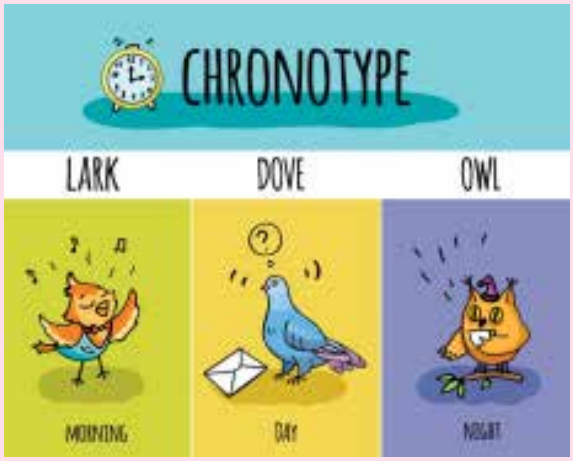
The inter-play between circadian rhythms is increasingly recognized, especially in the context of cancer care. It is well-established that cancer and its treatments can significantly disrupt circadian rhythms. This disruption leads to circadian rhythm disorder, where our body's internal clock, which regulates sleep-wake cycles and other biological processes, become out of sync with our environment, leading to sleep problems and other health issues.

Light and dark: our timekeepers

Our lives are shaped by the earth's rhythmic shifts of night and day. In order to stay alive, all living things, from bacteria to human beings, adapt and adjust to the daily patterns of light, darkness, and shifts in temperature. How does this happen? When the sun rises and light passes through our eyes through the optic nerves, the brain release hormones which signal different organs and tissues to start or stop work. Our bodies adapt to daylight by waking up and becoming active. They adapt to night by sleeping, allowing them to conserve energy, repair damage, improve immunity, promote growth, and remove waste.

The chronotype

Each one of us has, within our DNA, a natural, genetic inclination for a particular type of circadian rhythm that tells us when to sleep and when to wake and be alert and energetic. This is called our chronotype. However, humans have developed technology that can affect our circadian rhythms by changing the amount of light exposure we receive



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To determine your chronotype, observe your natural sleep-wake patterns, rest-activity cycles, and energy levels throughout the day for an extended period of time. Are you a morning lark, day dove, or night owl? Is something getting in the way of your body's natural inclinations? Our sleep/wake cycles can be affected by many factors such as illness, stress and anxiety, jobs, living arrangements, social lives, or daily habits.

and the temperatures of our environments. These changes, along with other changes to our routines, can send signals to our master clock that affect how it functions. If you know your chronotype, however, you can make changes to put your circadian rhythm back on track.

Self-care and the daily activity clock

Sleep clinics use actigraphy, a non-invasive device that can be worn to monitor your rest-activity cycles over 24 hours. This can give us insight into our chronotypes as well as an understanding of our circadian rhythm and how our master and peripheral clocks perform. A simpler way for each one of us to help ourselves is the daily activity clock. This is a simple paper and pen tool for developing mindful self-awareness of how our individual habits, external environments, and disease disrupt the body's natural circadian rhythm and homeostasis.

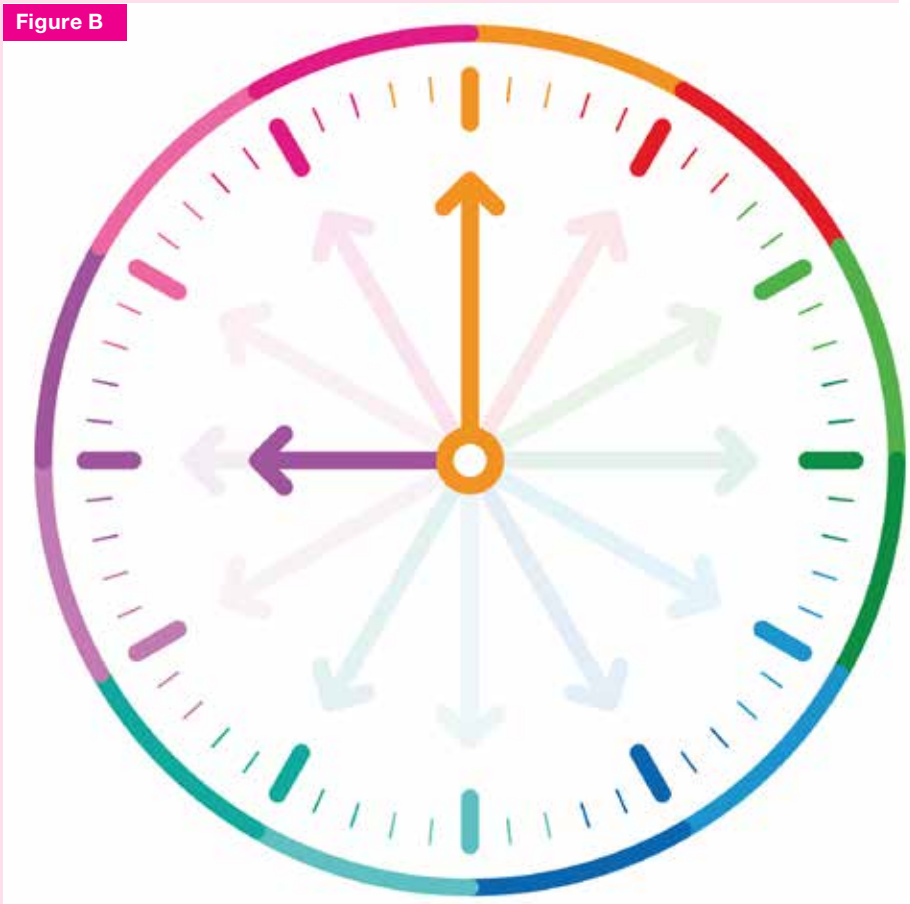
Figure A is an example of a completed Activity Clock. Each one of us can make a copy of the blank clock in Figure B and document every hour of our day, from the moment we wake up until we fall asleep. This will include all activities, rest time, sleep hours, eating, drinking, playing, exercising, watching TV, travel, hunger pangs, number and times of meals, moods, etc. Do this for at least two weeks until you recognize a pattern.

Being mindful and making small lifestyle changes, one at a time, can help gradually restore the body's natural clock and maintain a stable internal environment despite changes in the external environment. This will enhance quality of life and help prevent conditions that affect our health, like high blood pressure, insomnia, digestive issues, insulin or sugar spikes, pain, mental health issues depression and anxiety, and more. We can track what makes us feel worse or what makes us feel better.

The activity clock tool helps us track our daily activities and daily needs in order to make an achievable wellness plan. Embracing wellness is closely connected to the circadian rhythm. It requires understanding and embracing the right circadian rhythm for you.

Figure A

Figure B



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Spotlight on our members: Nigeria

National Cancer Survivors Day 2025: A call to action, a celebration of life

Tinu Lawal, *Founder, Atinuke Cancer Foundation, Chair of Nigerian Cancer Society (Lagos Chapter) Nigeria*

Tinu Lawal

On Sunday, June 1, 2025, the Atinuke Cancer Foundation once again raised the global banner of hope, strength, and survivorship as it marked National Cancer Survivors Day® (NCSD) with a powerful and moving virtual gathering.

Held on the first Sunday of June of every year, NCSD is more than a celebration; it is worldwide movement honoring the strength of cancer survivors while shining a spotlight on the ongoing challenges they face.

We approached the planning of this year's NCSD celebration with the knowledge that, whether you're black or white, cancer treats everyone without respect. Cancer doesn't discriminate. It doesn't ask your name or check your bank balance. It doesn't care about your passport, your title, your fame, or your zip code. However, although cancer itself is biologically impartial, the systems that surround it – access to care, treatment outcomes, survivorship support, among others – often are not. Cancer chooses no favorites. But survivorship does! And that's where our collective power lies. We can work together to ensure that every cancer patient has access to the care and support they need.

This year's theme, "Hope, Strength & Survivorship," was more than a slogan; it was a lived experience. Hosted on Google Meet, the two-hour program brought together voices from across the globe. The virtual event united trailblazers in cancer care from eight different countries. They shared personal testimonies, practical strategies for post-treatment life, and reflections on advocacy, resilience, and global solidarity among cancer foundations and in cancer care.

The program opened with my own heartfelt address, which was followed by a one-minute prayer to honor heroes who have lost their lives to cancer, the signing of the Nigerian national anthem, and a brief impactful overview of National Cancer Survivors Day and its global significance. Distinguished guests then delivered goodwill messages, underscoring the critical importance of cancer survivorship support and advocacy. These included:

- Her Excellency Dr. Zainab Shinkafi-Bagudu of Nigeria, President-Elect of the Union for International Cancer Control (UICC)
- Dr. Kemi Ogunyemi of Lagos, Special Adviser to the Lagos State Governor
- Prof. Abidemi Omonisi of Nigeria, President of the Nigerian Cancer Society

The highlight of the day was the global panel, when the speakers, several of whom are members of Reach to Recovery International (RRI), presented powerful stories and perspectives on thriving beyond cancer. These speakers were:

- Faresis Takawira, a Regional Representative of RRI and leader of Conquerers Breast Cancer Trust, Zimbabwe, whose topic was *Spiritual Resilience: Faith as a Pillar During Cancer*
- Chief Tomi Akingbogun of Nigeria, whose topic was *Diagnosis to Determination: My Journey as a Cancer Survivor*
- Leonie Young, DUniv, of Australia, President of RRI, whose topic was *The Power of Peer Support and Survivor Networks: Survivor-Led Groups Like Reach to Recovery International Make a Difference*
- Rama Sivaram of India, a consultant and teacher in the field of cancer supportive care and advocacy, whose topic was *Life After Treatment: Redefining Normal*
- Philippa Kibugu Decuir of Rwanda, Founder and CEO of Breast Cancer Initiative East Africa, also covered the topic *Life After Treatment: Redefining Normal*
- Donjeta Zeqa, President of Europa Donna Albania, whose topic was *Living with Cancer: Quality of Life Matters*
- Dr. Maira Caleffi of Brazil, breast surgeon and founder and Volunteer President of FEMAMA and IMAMA, whose topic was *Late Effects of Cancer Treatment and How to Manage Them*

The session transitioned into an engaging interactive segment with reflections and reactions from the global audience, creating a sense of connection and shared healing across borders.

Professor Abidemi Omonisi offered the closing thank you, emphasizing the importance of continued collaboration, research, and compassionate care for all patients and survivors. The event concluded with a joyful group screenshot and a virtual toast to survivorship, reminding everyone that, though cancer may have touched us, it does not define us. Survivorship is a journey and one worth celebrating together!

At the Atinuke Cancer Foundation, we remain committed to advocacy, education, and empowering survivors to live full, purposeful lives beyond cancer. NCSD 2025 was not just a virtual meeting: it was a movement of resilience, unity, and global solidarity.

Together, we thrive; together, we triumph!

Spotlight on our members: South Africa

Feathers of support: how Reach for Recovery South Africa helps survivors rise

Stephné Jacobs, *Board Chairperson, Reach for Recovery, South Africa*

Stephné Jacobs

Lara Nel, Lara Art & Design

For Reach for Recovery South Africa, hope is more than a sentiment — it's a practice. It's expressed in a calm voice during a hospital visit, in a care bag packed with essentials, in the softness of a cushion held after surgery. And it lives in the presence of every volunteer who has chosen to turn their own breast cancer journey into support for someone else.

Mission moments that matter

Every visit, call, and conversation tells a patient, "*You are not alone*." Over the past two years, 225 Reach for Recovery volunteers reached more than 11,000 women across South Africa. They made 4,802 hospital visits, 1,085 follow-up calls, and distributed 4,641 care bags. In doing so, they offered both practical help and the kind of calm, compassionate companionship that's hard to quantify.

Our dedicated volunteers have made a significant impact by providing 3,570 fibre-filled breast forms and 4,701 post-surgery cushions, offering comfort and support to women during their recovery journey. Additionally, they have extended their care to 5,292 women at breast clinics, ensuring that no one faces breast cancer alone.

Thanks to the generous support of our donors, 1,496 women received Ditto silicone prostheses, which are often their only option for a comfortable, confident return to daily life.

In October of 2023 and 2024, our breast cancer awareness outreach hit a high point, with 444 breast health education events led by trained survivors. These volunteers brought early detection messages directly to communities, schools, and clinics, many of which lack consistent access to screening or care.

Quiet strength, shared experience

Our work is grounded in a peer support model: survivors supporting those who are newly diagnosed. This creates a special kind of trust. Patients see someone who's "been there," and who now stands on the other side, offering reassurance and practical wisdom.

Importantly, volunteering benefits not only patients but also the volunteers themselves. Research indicates that peer supporters often experience increased emotional resilience and personal growth. For instance, a 2019 systematic review by Lu and Wittenberg found that breast cancer survivors who became peer supporters reported enhanced emotional well-being. Another study by Andersson, Nilson and Sæther in 2018 revealed that survivors often find new meaning and self-confidence by helping others navigate a path they know intimately.

These findings reinforce what many of our volunteers already know: when you give your time to support someone else, you also restore something within yourself.

Honouring experience, building skills

Last year, we proudly honoured Helen Hugo, who had volunteered for 41 years, alongside 21 women who had each served for over two decades. These women embodied the spirit of sustained service and continued to mentor the next generation of support volunteers.

In celebration of our 58th anniversary, we launched Club 58 — a summit designed to enhance training, foster peer connections, and strengthen volunteer support. From 24th July to 27th July, volunteers will engage in workshops, knowledge-sharing, and mentorship, developing as caregivers, leaders, educators, and advocates. We believe that when volunteers are well-supported, their impact grows exponentially.

Looking ahead

With 80 percent of South African women lacking access to medical aid, Reach for Recovery's mission is more vital than ever. We're expanding our reach, training more volunteers, and adapting to meet women wherever they are.

Each act of support—every hospital visit, prosthesis provided, and heartfelt conversation—reinforces our unwavering commitment: no one should face breast cancer alone. Together, we're not just offering support; we're building a resilient community where recovery is not only possible but powerful.

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The recipes in this edition of Bloom were created by Amanda Kuit, a Clinical Dietician and Nutritionist from Capetown, South Africa.

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Global Kitchen

Healthy dishes from South Africa

Mediterranean Chicken Casserole

PREP TIME: 15 MINUTES
COOK TIME: ABOUT 40 MINUTES
SERVINGS: 10

Ingredients:

1.5 kg (2¼ lbs) chicken breast (without bones and skin)

2 large onions, halved, thinly sliced

3 celery sticks, cut into slices

2 garlic cloves, crushed

800 gm (12 oz) button mushrooms, thickly sliced 400 gm

400 gm (4 oz) diced fresh tomatoes

250-300 ml (1 – ½ cups) chicken stock

800 gm (12 oz) fresh green beans

20 ml (4 tsp) fresh thyme leaves

freshly ground black pepper

brown or wild rice

Instructions:

1. Add the chicken to large pot/casserole and cook for 20 minutes, take chicken out and keep the stock.
2. Cut chicken into cubes and cool down.
3. Meanwhile, cook brown or wild rice in a large saucepan of boiling water following packet directions or until al dente. Drain well and keep aside.
4. Add the onion and celery to a frying pan, add small amount of stock and cook, stirring, for at least 5 minutes. Transfer the onion mixture and chicken stock to a cooking pot.
5. Add garlic and green beans and cook over low heat, until green beans are al dente. Add tomato and Chicken cubes and bring to boil.
6. Add mushrooms and cook for 10 minutes. Taste and season with pepper.
7. Spoon into a casserole dish, sprinkle with thyme and serve with brown rice

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Global Kitchen

Healthy dishes from South Africa

Stuffed Gem Squash

PREP TIME: 30 MINUTES
COOK TIME: 60 MINUTES
SERVINGS: 10

Ingredients:

15 gm (3-4 medium cloves) garlic, crushed

50 gm (¼ cup) roasted red pepper (roast in the oven)

100 gm (½ cup) cauliflower rice

100 gm (½ cup) mushroom, chopped

50 gm (¼ cup) baby marrow (zucchini), cut into slices

50 gm celery (¼ cup), cut into slices'50 gm

(¼ cup) brussel sprouts, chopped

50 gm (¼) radish, chopped

5 gem squash (in northern hemisphere, acorn squash may be closest substitution), halved and steamed

5 gm (1 tsp) fresh basil, chopped

Instructions:

1. Preheat the oven to 180° C (350° F).
2. Steam the gem squash and roast the red peppers in the oven for 20-30min.
3. Take out the pips of the gem squash and scoop out most of the flesh into a bowl (leave about 5mm of gem squash in the bottom and sides of the gem squash.
4. Remove red peppers from oven into a liquidizer (blender).
5. Add all the veggies except the gem squash and liquidize until smooth.
6. Season to taste and add 10 ml (2 tsp) oil (use tru'e or olive oil).
7. Scoop veggies mix into cavities and bake in preheated oven for 30 minutes or until veggies are soft with a little crunch.
8. You can use this recipe to stu' tomatoes, large baby marrow, brinjal, peppers, or cabbage rolls.

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