

A close-up photograph of a woman with dark hair, smiling broadly, wearing a bright pink t-shirt. A white cancer awareness ribbon is superimposed over the center of the image, behind the text.

Towards a future free of the fear of cancer

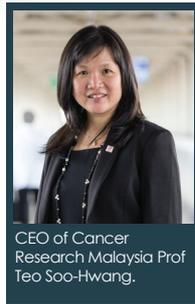
Tan Sher Lynn speaks to Cancer Research Malaysia (CRM) about their various initiatives as they work towards the day when cancer can be cured and no longer feared.



Reversing cancer

Bringing hope and cure to cancer patients through impactful research

Cancer, also called the big 'C', is often associated with death and despair. Cancer Research Malaysia (CRM), the first independent, non-profit cancer research organisation funded and staffed by Malaysians and conducting Asian-specific cancer research, aims to reverse the stigma and fear of cancer.



CEO of Cancer Research Malaysia Prof Teo Soo-Hwang.

"And when it comes to breast cancer, all women are told that they have a one in 19 chance of getting it, which is only an estimate. The fact is, depending on genetics, some women have a 60% chance while some have a 20% chance; some women should get screened in their thirties while some have risks that are so low that they may have less benefit from screening. As a result, we may miss opportunities for cancer prevention," Prof Teo explains.

To solve this problem, CRM is currently working on the Malaysia Breast Cancer genetic (MyBrCa) study to characterise rare variants and genetic loci associated with the risk of breast cancer among Asians. Such analyses will lead to unique insights into the genetic predisposition of Asian breast cancer and provide opportunities for the development of risk-stratified approaches to screening and the development of targeted therapy.

3. Providing services to patients throughout Malaysia

"A main part of CRM is to push the frontiers of technology and make sure that it is available to Malaysians throughout the country," Prof Teo says.

"Previously, genetic counselling was only offered in CRM, Hospital Kuala Lumpur and the hospitals of Universiti Malaya and Universiti Kebangsaan Malaysia. We have launched a nationwide study called MaGiC (Mainstreaming Genetic Counselling for Genetic Testing of BRCA1 and BRCA2 in Ovarian Cancer Patients in Malaysia), and expanded counselling services to 25 government and private hospitals all over Malaysia," she explains.

CRM also set up the Patient Navigation Programme in 2014 to provide follow-up support for poor patients to make sure they can access the services and treatments they need.

"We understand that cancer survivorship can be improved if better services are provided especially to poorer communities," she says.

Upholding good governance

CRM believes in good governance to ensure that the grants and donations they receive are wisely spent and they achieve this through three ways:

1. Internationally renowned Scientific Advisory Board with Professors from Oxford, Cambridge, Duke's and UICC
2. Scientific programmes which are peer-reviewed by experts in the field of cancer research
3. Collaboration with the best scientists in the world, including researchers in Cambridge and Southampton, to ensure that programmes undertaken are impactful.
4. Having a tight governance framework and a board of independent trustees to ensure all systems are in place.

"For the past 15 Years, we are proud to say that 90% of our funding has gone to cancer research. This is a very important aspect of who we are," Prof Teo says.

"Our logo, which is a reversed, lowercase 'c', captures the essence of CRM, which is to reverse the grip of cancer on our lives through impactful research," says CRM's CEO Prof Teo Soo-Hwang.

According to Prof Teo, CRM is focused on three areas:

1. Developing new cures for head and neck cancers

Asians make up about 70% of oral cancer incidences worldwide and the highest rates of nasopharyngeal cancer are found in Southern China and Southeast Asia. "These cancers are almost unheard of in the West, where the majority of research takes place. In CRM, we are trying to find new ways of treating these types of cancer more effectively, such as through immunotherapy which boosts the patient's immune system," she says.

2. Asian genetics

"Asians are different from Caucasians in terms of the diseases they get and how they respond to treatment. Even though Asians make up three billion of the eight billion people living on earth, in the majority of genetic studies done, only 5% of the subjects are Asians."

For more information about CRM, visit www.cancerresearch.my or call 03-2712 3224.



Improving Asian breast cancer prognosis with Asian-centric research

Today, breast cancer remains one of the most common cancers in the world. However, due to breast cancer research over the years, treatment of the disease has come a long way, significantly improving the survival rate and prognosis.

Dr Matin Mellor Abdullah, Consultant Clinical Oncologist and President of the Malaysian Oncological Society and Professor Dato' Dr Yip Cheng-Har, Consultant Breast Surgeon, talk about how breast cancer treatment has evolved over the years and how research on Asian breast cancer is vital to improving survivorship in the region.



Dr Matin Mellor Abdullah, Consultant Clinical Oncologist and President of the Malaysian Oncological Society

Evolution of breast cancer treatment

According to Dr Matin, breast cancer treatment has been evolving for the last 30 years or so. "There has been refinement of treatment, meaning specific treatment is advised for patients who may benefit the most from it. Recognition of the heterogeneity of breast cancer and appropriate treatment of the different subtypes continues to evolve.

"For instance, today, for patients with relapse in hormone receptor positive breast cancer,

there are new treatments in the form of the CDK4/6 inhibitor which is an improvement from the previous standard. However, triple negative breast cancer (which is oestrogen receptor-negative, progesterone receptor-negative and HER2-negative) remains a challenge and treatment with platinum chemotherapy may be best. Meanwhile, breast cancer with BRCA mutation can benefit from a new drug called PARP inhibitor," he says.

Prof Yip notes that over the last decade, management of breast cancer has progressed from mastectomy to breast-conserving surgery, such as immediate breast reconstruction after mastectomy, and sentinel lymph node biopsy instead of axillary dissection. "Over the years, various chemotherapy regimens, different types of hormone therapies, as well as the newer radiotherapy techniques which have fewer long-term side-effects to the heart and the lungs have been developed. Trastuzumab (a type of targeted therapy) was approved for use in the adjuvant setting in 2006 and became the standard of care for HER2 over-expressing breast cancer. All these treatments have led to improved survival from breast cancer."

"Moreover, in the past 10 years, there has been more innovation in local therapy. This includes the development of intraoperative radiotherapy so that patients need not undergo six weeks of radiotherapy post-operatively. In addition, many types of targeted therapies (mainly anti-HER2 agents) have been developed."

"There have also been advances in the development of personalised medicine, where treatment is targeted at the specific type of breast cancer. There are even drugs that have been developed specifically to target hereditary breast cancer, such as the BRCA-associated breast cancers. Immunotherapy is currently on trial as a method of treatment for breast cancer. All these latest advances in breast cancer treatment are unfortunately very expensive and not affordable to the majority of patients in Malaysia," she says.

Should there be research targeting Asians?

According to Dr Matin, most of the ways in which breast cancer is treated currently is based on research done on Caucasian patients. Hence, breast cancer research done specifically on Asian women is necessary to determine how Asian breast cancer may differ from the Western population.



“We need to determine what are our risk factors, the genetic characteristics of our cancer and if current conventional treatments give us the same benefit. By conducting research on Asian women, we may identify some of the differences in Asian breast cancer that may be harnessed to improve outcomes of the treatments.” she says.

According to Prof Yip, pharmacogenetics, a new area of research, shows that different ethnic groups may have different responses to drugs used to treat cancer due to their different genetic make-up. “Clinical practice guidelines on the management of breast cancer are available in Malaysia, and these guidelines are based on evidence that a certain treatment will give the best outcome. However the evidence is generated from clinical trials done in Western countries. Local research will help in formulating guidelines which are specific for Malaysian women,” she rationalises.

Differences between the East and the West

According to Prof Yip, the median age when breast cancer is diagnosed is 50 for Malaysians compared to 60 in the West. “However, this may be due to population demographics. Malaysia has a younger population with a median age of only 27.7 (which means that 50% of the

population is below 27.7), compared to 40.2 years in the United Kingdom. Moreover, if we look at the age-specific incidence of breast cancer, such as the incidence of breast cancer in each age group, it is still higher in the West compared to the East. The common statement that ‘breast cancer occurs in younger women in Malaysia compared to the West’ is true when we look at percentages but not when we look at the incidence, which is the number per 1,000 population,” she says.



Professor Dato' Dr Yip Cheng-Har, Consultant Breast Surgeon

According to Dr Matin, the reported survival rate of Malaysian patients is lower than that of Western populations. “The reasons for the lower survival rate in our patients are multifactorial, and include late presentation due to various reasons, like attempting alternative therapies first before going to the hospital as the disease progresses, delays in making a diagnosis, delays in receiving treatment and not receiving the optimal treatment,” he says.

Final thoughts and advice

Both Dr Matin and Prof Yip advise women to maintain a healthy lifestyle and weight, as well as exercise adequately to reduce their risk of cancer.

“Treatment is expensive, and the ACTION (Asean Costs in Oncology) Study has shown that

in Malaysia, 45% of families have been known to experience financial catastrophe (defined as spending 30% of the household income) after a family member is diagnosed with cancer. It has also been shown that it is cheaper to treat early breast cancer than to treat advanced breast cancer, and hence early detection is important. The methods of early detection are breast self-examination, clinical breast examination and mammography for women above the age of 45. With detection of smaller tumours, it may not be necessary to remove the whole breast, and chemotherapy may not be required,” Prof Yip explains.

“Research is certainly very important in any field, including breast cancer. Research seeks to identify the norm and variations from the norm that may be exploited for our benefit. Cancer Research Malaysia is doing a good job by carrying out research that may be relevant to the Malaysian population,” Dr Matin says.

Prof Yip echoes his view. “Cancer Research Malaysia, with its large breast cancer research programme covering breast cancer genetics, treatment, and psychosocial aspects, together with its outreach projects, can contribute to an in-depth knowledge about breast cancer in Malaysian women.” she says.

Treating Cancer by genetics

Cancer genetics research paves the way for more effective and personalised treatment



analysing cancer cell DNA samples to see where the mutations lie through advanced computer software. Dr Pan, who completed his PhD at Duke University, USA, is analysing the RNA molecules of cancer cells.

Both are dealing with over 20 terabyte of data, which is a million times bigger than a regular photograph. "There are three billion DNA in a single cell. A single cancer cell may have 1,000 to 100,000 'alphabets' that are different compared to a normal cell. We need to find the 1,000 'alphabets' that are different out of the three billion that are the same between a normal cell and a cancer cell," Prof Teo explains.

"This project is intellectually challenging. Since we know very little about breast cancer in Asia, there is a huge gap that needs to be filled," Dr Mamduh says.

"After my PhD, I wanted to do something impactful to mankind. CRM is a great organisation in that context. In a country like Malaysia, we need more people to do the work locally in order to address locally important issues," says Dr Pan.

"It has always been known that there's a lack of research into Asians. We can only address this gap if more Malaysians like them come back and contribute," Prof Teo emphasises.

As a direct outcome of the study, CRM is exploring clinical studies to test whether the newest drugs developed may be more or less effective on Asian women.

The future of cancer treatment will be based on specific gene changes found in cancer cells in addition to the cancer's location. "Personalised or precision medicine is about understanding a person's condition at the molecular level in order to know what treatment suits him or her best," says Prof Teo Soo-Hwang, CEO of Cancer Research Malaysia (CRM).

Nevertheless, according to Prof Teo, the majority of cancer genetics studies done in the West are on Caucasians. "There were no large studies published about genetics of cancer in the Asian population. This basically means that we assume treatment options for Asian women are the same as Caucasian women. We cannot be sure whether this assumption is right or wrong until more research is done on the Asian population," she states.

"CRM's previous research found that a genetic element (A3B) that is essentially found in 10% of Europeans, are found in 50% of Asians. If a woman has this genetic element, it changes her risk of getting cancer and also the type of cancer she gets. Patients with this genetic element tend to have a lot of immune cells accumulated, so

immunotherapy may work well for them. To ascertain whether this assumption is conclusive or not, we have won the Newton Ungku Omar Grant to work with Cambridge researchers to analyse 400 tumours from the Malaysian population," she explains.

This study, builds on the Malaysian breast cancer genetic study (MyBrCa), which is one of the largest breast cancer genetic studies in Asia and contributed to more than 100 genetic loci to help scientists understand why some women are more likely to develop breast cancer.

"Currently, we have 3,500 breast cancer patients and 3,500 healthy women taking part in the research. With this material, we are able to understand in depth about Asian breast cancer. We shall be able to obtain some important data by the middle of next year," says Prof Teo.

Among the key scientists involved in the study are Dr Muhammad Mamduh Zabidi and Dr Pan Jia Wern. Mamduh, returned to Malaysia upon completing his PhD in Austria. His thesis was published in one of world's top academic journals, 'Nature'. Dr Mamduh is

Patient Navigation Programme

Reducing barriers and assisting patients through their breast cancer journey

According to the CEO of Cancer Research Malaysia (CRM) Prof Teo Soo-Hwang, Malaysia has the lowest breast cancer survival rate in the region. “Singapore has 83% of five-year survivorship; Korea has 92% while Malaysia has only 49%. About 50% of Malaysian women are diagnosed in a late stage (3 and 4). Stage for stage, we also have a lower survival rate than many other countries.

“This is because many women do not return to the hospital for treatment after being diagnosed with breast cancer. They prefer to seek traditional or alternative treatments that do not work. We face two challenges in Malaysia, which are late stage presentation and the lack of adherence to treatment,” she notes.

Even though efforts in raising awareness about breast cancer have been carried out for many years, Teo observes that it made little difference to the survival rate because people will always choose what they want to believe. She thinks that the way to change is to set up centres that provide better services for cancer patients, especially poor patients who cannot access the services and information they need.

Having returned from being on the Eisenhower Fellowship where she met Dr Harold Freeman who set up the Patient Navigation Programme (PNP) in the US and was able to improve cancer survivorship in his community, Teo believes that such a programme would benefit Malaysians as well.

“Coincidentally, the Sime Darby LPGA golf tournament was being held for the first time

in Malaysia and they wanted to raise money for breast cancer. So, we collaborated with them and used the funds raised from the tournament to support our PNP to improve breast cancer outcomes for poor women in Malaysia. In November 2014, we started the Pink Ribbon Centre in Hospital Tengku Ampuan Rahimah in Klang, a typical hospital where the majority of patients are poor and present with late-stage cancers,” she shares.

The centre is run by a dedicated team of doctors, nurses and community navigators. Community navigators sort out things like logistic and financial barriers as well as emotional support systems to make sure that patients have access to the services they need. Since community navigators are also breast cancer survivors themselves, patients have more confidence that they will be taken care of.

PNP coordinator Maheswari Jaganathan is a nurse trained in oncology, palliative care and counselling. She trains the nurses and community navigators in the programme. “PNP is something very new in Malaysia. Usually, hospital nurses only care for the patients during a certain phase of their treatment. In our navigation programme, the team of doctors, nurses and navigators walk with them the entire journey until their treatment is completed, which can be six months to a year. We understand their condition, background, and the community they come from, and visit them in the ward before



and after their operation. We also visit their family members,” she shares.

Besides following up with patients on a one-to-one basis, community coordinators work closely with the nurses in the hospital to improve the hospital system to ensure faster and better services in terms of diagnosis and treatment.

Thanks to the PNP, for the past three years, the default rate of patients not coming back after being told that they had cancer has dropped dramatically from 12% to 3%. In total, the PNP team has navigated more than 700 women and about two thirds of those are cancer patients. They are currently talking to other hospitals to set up similar centres all over the country so that more women can have a better life quality and survival rate after diagnosis.

“Being diagnosed with cancer is, in itself, devastating. The treatment that followed was not a walk in the park either. For that, I am entirely grateful to the nurses and navigators in the programme who were with me throughout my entire journey. It is because of their constant encouragement and undivided attention that I managed to complete my otherwise difficult treatment.”

Mdm N, Stage 2 Breast Cancer Patient

Genetic counselling

Empowering people to make the right decisions about genetic testing and risk management

The breast cancer 1 (BRCA1) and breast cancer 2 (BRCA2) genes are the genes most commonly affected in hereditary breast and ovarian cancer. Although BRCA genetic testing was developed more than 20 years ago, and is used widely to identify high risk individuals, very few Malaysian have access to the testing, mainly due to the lack of genetic counsellors and genetic services in Malaysia, according to Yoon Sook-Yee, Genetic Counsellor and Head of the Familial Research Project of Cancer Research Malaysia (CRM).



Yoon is a genetic counsellor accredited by the Human Genetics Society of Australasia (HGSA) and one of only two accredited genetic counsellors in Malaysia, serving a population of up to 5,000 new breast cancer patients and 1,000 new ovarian cancer patients each year.

“Genetic counselling provides the individual with the information needed to make decisions about genetic testing based on their risk assessment, family and social structure, psychological impact of the different possible test results and concerns about insurance and possible discrimination.”

“It is therefore important for individuals who have a family history of clusters of cancers such as breast and ovarian, patients who have had cancer at a young age, or patients who have had several types of different cancers, to go for genetic counselling,” she says.

And so, in 2016, CRM launched the MaGiC Study (Mainstreaming Genetic Counselling for Genetic Testing of BRCA1 and BRCA2 in Ovarian Cancer Patients in Malaysia) in collaboration with Professor Nazneen Rahman at the Institute of Cancer Research, Royal Marsden Hospital, London to institute mainstream cancer genetics training modules for oncologists and gynaecologists in 25 sites across Malaysia.

“So far, more than 200 ovarian cancer patients have volunteered to participate in the programme, and CRM has trained 31 oncologists and 28 gynae-oncologists nationwide,” she says.

Malaysians at risk of heredity cancers may be offered genetic testing without charge if they meet the research testing criteria. Members of the public who would like to participate in the MaGiC study can speak to their doctors or go to the nearest study site in each state.

“I was diagnosed with cancer at the age of 28. I have a family history of breast and ovarian cancer. I am so glad I found out about my genetic status and now I understand why there are so many cancers in my family. Most importantly, I now know how to manage my two daughters and their risk in future. I would not be able to do that if it were not for CRM” – Ms LPL

Why volunteer at CRM?

By Wong Lup Hang, patient representative of the Scientific Advisory Committee

I have been volunteering for four years in CRM. What drives me to volunteer for them is the fact that I think CRM is making a real impact in peoples’ lives, particularly in Asia.

More and more people are going to have cancer in the future because of lifestyle factors. The only real difference we can make is by doing research about cancer. With a potpourri of different races, Malaysia is really ‘truly Asian’. What better place to do Asian-centric research than here?

Some people may wonder whether CRM is credible enough to undertake such significant research projects. The answer is a definite ‘yes’. If not, why were we selected by prestigious grants to receive

their funding? Why would the world’s top universities like Cambridge partner with us?

I am not a scientist. My background is in business and the automotive industry. So I contribute by looking at CRM’s sustainability and fund-raising efforts, so it can grow as how a company grows. Cancer Research UK received 635 million pounds from the UK public as donations. We Malaysians should really put our hearts and finances together to fund research in Malaysia. CRM has the potential to be great. Let us together purposefully build this place to be what it is meant to be.”





Reversing cancer, one day at a time



Through **impactful research**, we work towards the day when cancer is a disease that can be **cured** and we are able to **reverse the fear, ignorance** and **silence** around cancer.



As a non-profit organisation, we rely on public funding to ensure the sustainability of our work. At least **90% of proceeds** from charitable contributions goes into research.



Some of our key successes from 2000 – 2017

- We successfully published more than 160 scientific articles in 10 years in highly accredited international medical journals.
- We won multiple international research grants including the highly coveted Wellcome Trust Collaborative Award and the Newton-Ungku Omar Fund.
- We developed a peptide vaccine which is a type of immunotherapy that activates the immune system to fight cancer and is now being tested in preclinical models in head and neck cancers.
- We developed a rapid and cheaper method to accurately identify individuals genetically predisposed to breast and oral cancer.
- We developed one of the first genetic counselling and genetic testing programmes in Malaysia to assist families with higher risk of breast and ovarian cancer.
- We established the first Patient Navigation Centre in Malaysia to assist breast cancer patients throughout their journey from diagnosis to completion of treatment.

Join us in reversing cancer. Donate to cancer research today. For more information on Cancer Research Malaysia and how you can contribute, please visit our website at www.cancerresearch.my.



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