

# HOSPICE Bulletin



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Quarterly newsletter of the National Cancer Society of Malaysia, Penang Branch.

## MONEY IS NOT EVERYTHING BUT IT HELPS

by Dato' Seri Dr T. Devaraj

An academic who came a few years ago to look at our programme and plans was impressed. His question was spot on - do you have the money? So this issue of funds needed for our community service is indeed crucial. Can we continue providing a free service almost totally dependent on public donations in the long term? A free community service of compassionate care in the home has become a brand. While I think we should continue this for the Hospice-at-Home Programme two questions arise. One is how long can we continue seeking funds in this manner? Will funder fatigue set in in the years ahead? Another is that if we should decide on having an in-patient hospice service as well then, this approach may have to change to make it sustainable.

It will be pertinent to once again thank all our donors – the public and the families we have cared for - thus enabling us to provide this unique service in our community for the last twenty - five years. In addition we owe thanks to the many individuals and organisations who have raised funds for our Hospice-at-Home Programme. We do hope you all will continue to do so for many more years.

On our part we will continue to actively lobby the Ministry of Health (MOH) for appropriate funding. Our view is that the MOH tasked with the responsibility for health and health care of the country has a duty to fund delivery of health care in the homes of its citizens. The acceptance that doing so will enhance over all care in the country is still not in the sights of the MOH. That the need has been there all these years and now rapidly growing with the advent of so many NCD's (non - communicable diseases such as cancer, cardio-vascular, diabetes, respiratory and dementia) is not of public health concern in Malaysia but all over the world.

The World Health Organisation in 2016 called all countries to adopt "Integrated Care" as a better way to manage and deliver health services. This it said "ensures people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease management, rehabilitation and palliative care services, at the different levels and sites of care within the health system and according to their needs throughout their life course". The reference to sites of care here includes care in the home.

Coming back to the MOH its annual grant only covers fifteen percent of the operational costs. Further it has to be applied for on a yearly basis with no guarantee that any funds will be given for that year, let alone the amount. This year, for instance, the grant was reduced by RM100,000 to RM50,000! However there is a tiny light at the end of the tunnel. For instance a Deputy Minister of Finance in 2009 is on record stating that as we were doing the job of the government we should be helped dollar for dollar. This thought was echoed by the Deputy Director General Health of the MOH in 2014 at the Malaysian Hospice Congress held in Kuala Lumpur. To pursue this will be my call to the Malaysian Hospice Council, the umbrella body for hospice organisations in Malaysia.

This leads me to my final thoughts that as civil society has a role to play in any democracy to be successful funds must be made available to enable various NGO's to fulfil this role. To continue to perceive an NGO as a charity (and thus voluntary and dependent on just good natured people and its funding nothing to do with governance) – both by the government, be it federal, state or local council, is an anachronism long overdue to be discarded. The way to go is for public sector as well as the private sector to acknowledge the role of and work along with civil society for the public good.



# Contents:



## Happenings:

### • CARERS' MEETINGS\_Penang Island

**Venue:** Rumah Hospis Pulau Pinang  
**Day :** Every Friday  
**Time :** 0900 – 1100

## Happenings:

### • Monthly Meeting/Professional Development

A monthly meeting with doctors and nurses of Penang Hospice Society is held on the first Friday of the month from 9am to 1pm. Palliative care nurses present a new medical topic at every meeting.

### • Clinical Attachment Of Nurses

18 students undergoing the one year course "Advanced Diploma in Palliative Care" with the Ministry of Health would be following our Palliative Care Nurses in batches of 3 from 6 November 2017 to 26 January 2018. These students on attachment would be shadowing medical staff as part of their training experience to develop their skills and knowledge in Palliative Care.

### • 47th Joint Clinical Meeting of Hospice Groups

The last quarterly joint clinical meeting of hospice groups for the year was hosted by the Palliative Care Unit of Hospital Bukit Mertajam at 3pm, on Tuesday 21 November 2017. Over 20 clinical personnel from Penang Hospice Society, Palliative Care Unit of Hospital Bukit Mertajam and Palliative Care Unit of Hospital Pulau Pinang attended. Palliative Care Nurse Subaahsini Selvarajan of Penang Hospice Society shared her experience undergoing the one year full time Advanced Diploma in Palliative Care training programme. The next clinical meeting will be held at Rumah Hospis Pulau Pinang (250A Jalan Air Itam 10460 Penang) on Tuesday at 3pm on 6 March 2018.

## About Hospice Bulletin

**HOSPICE BULLETIN** is the quarterly newsletter of the National Cancer Society of Malaysia, Penang Branch with input from Penang Hospice Society. We welcome your contribution to the bulletin. Please submit at least six weeks before issue date which are the first day of January, April, July and October.

All items submitted for inclusion in the Hospice Bulletin must be signed but authors's requests to remain anonymous will be respected. Contributions can be sent to: The Editorial Team, National Cancer Society of Malaysia, Penang Branch, 250A, Jalan Air Itam, 10460 Pulau Pinang.

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The views expressed in HOSPICE BULLETIN are not necessarily those of the National Cancer Society of Malaysia, Penang Branch, the Penang Hospice Society or of the Editorial team.

[www.penanghospice.org.my](http://www.penanghospice.org.my)  
[www.relayforlife.org.my](http://www.relayforlife.org.my)  
[www.ncsmpenang.org](http://www.ncsmpenang.org)

# Happenings:

- **Penang Hospice Society's Training Programme 2018**

The annual training programme for nurses and doctors for 2018 is listed below. Our objective is to create an awareness of caring in the community as part of continuing care of patients when discharged from hospitals. At the same time we want to share with nurses and doctors some knowledge and skills regarding communication, coping with loss and grief and for nurses practical skills that will be useful in their roles as nurses in acute care settings. We also look forward to learning about caring through mutual sharing in interactive sessions. Each course is limited to 30 participants.

- **Basic Communication Skills Workshop - Wednesday 28 March 2018**

An introduction to the essential components of communication that improves your skill and help build confidence in communicating with patients and their families/carers.

- **PALLIATIVE CARE IN THE COMMUNITY - Wednesday 27 June 2018**

Introduction to an innovative caring service in the homes of patients to illustrate the need for seamless care.

- **COPING WITH LOSS AND GRIEF – Wednesday 15 August 2018**

An opportunity to better understand loss, grief, mourning and bereavement in adults and children in the context of a multi-ethnic and multi-religious society. The focus will be on how to support and help family carers.

For a copy of the programme and registration form please write to [penanghospicesociety@gmail.com](mailto:penanghospicesociety@gmail.com)

# RELAY FOR LIFE PENANG 2017 – FIGHTING CANCER TOGETHER

*A Brief Report*

*By Mui Siew Koon, Chairman of Survivors*

**Relay for Life Penang 2017 – Fighting Cancer Together was launched on 26 July 2017 by Professor Dr Abdul Rahman Mohamed, Deputy Vice Chancellor, Industry and Community Network of Universiti Sains Malaysia, representing the Vice Chancellor Professor Datuk Dr Asma Ismail.**

The actual relay was held from 6.00 pm, Saturday 30 September till 10.00 am, Sunday 1 October 2017, in the sports complex of the said university.

Dato' Seri Dr T. Devaraj was the Organizing Chairman again.

This year, being the 13th time Relay for Life was being held was plagued with many problems such as some political issues, the challenging economy of the country, the implications of GST, the dwindling enthusiasm from sponsors and participants, the weeks of uncertain weather coupled with flooding in many areas in the state, the increasing growth of NGO's all vying for funds, etc.

In spite of the bad weather and uncertainties the stadium area of Universiti Sains Malaysia was full of activities a couple of days before the actual date. Workers and volunteers were all working very hard to get things organized.

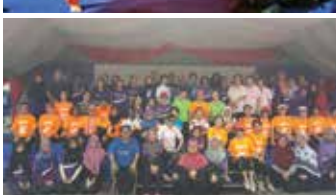
Luckily rain stopped just before the relay. As usual, at 4.00 pm the programme started with music, singing, different types of dancing, and merriment. Participants numbering 2,000, young and old, local and from outstation, in their vibrant purple T-shirts were already geared to have fun-filled activities and food from food trucks stationed outside the relay grounds. The many activities included lots of games tailored for the young and not so young, quizzes, henna painting, lucky dip / draw, viewing of a cancer-related exhibition, medical check-ups, etc.

A very important aim of the relay is to encourage and inspire cancer survivors to rid themselves of the stigma associated with the disease. Thus registration for them again was free. Also in appreciation of their effort they were each given a turquoise T-shirt and a certificate of participation, a neck cushion, a red goodie bag containing useful bulletins, coupons for a welcome snack (cupcake / muffin and a Milo drink), for head and shoulder massage, henna painting and a piece of cake. This year 209 survivors turned up though the number who registered was 252.

The opening ceremony started at 6.00 pm. Dato' Seri Devaraj gave his address, followed by Professor Dr Abdul Rahman Mohamed, who also presented certificates of appreciation to our sponsors. Cake cutting was performed on the stage by the chairmen of survivors, representatives of outstation groups together with Dato' Seri Devaraj and Professor Abdul Rahman. Ribbon cutting was done and survivors walked the first lap accompanied by our VIPs, cheered by family members and supporters standing along the track.

At 8.00 pm the solemn luminaria ceremony took place. Lights were turned off and a minute's silence was observed as a mark of solidarity to those who were struggling with cancer and as a mark of respect to those who lost the battle. Poems were recited. Both the chairmen of survivors shared their cancer journeys. After this quiet event, the field was once again full of life and music from different groups showing their talents and skills. Various games were played to keep the crowd interested. Activities stopped at midnight and resumed at 7.00 am the next day. Competitions were held. There were more games and more merriment and stage presentations.

At 10.00 am on 1 October 2017, Dato' Seri Devaraj closed the relay, thanking all who have helped to make the relay a success, in particular our sponsors, donors, participants from far and near, volunteers and staff members. Certificates were presented to individuals and teams for their wonderful collections and attendance. Then the long-awaited lucky draw with some 50 prizes was held before the final group photograph was taken.



# NOVEMBER JAZZ

## Charity Dinner Show

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The annual charity dinner show fundraiser "Novemberjazz" was organised by the society for the 4th year on 9 November 2017 at the E&O Hotel. Though it has become increasingly difficult to raise funds lately, with the help of the society's supporters, this year's event helped raise RM119,000. To all our donors and sponsors who came forward to support the event, our heartfelt gratitude to all of you.



# THANK YOU

## Penang Irish Association

The Penang Irish Association has been a staunch supporter of Penang Hospice Society. The members have been raising funds for the society since 2011. Through the Luscious Ladies in Pink which is an annual fundraising event of the Association, RM25,000 was raised for us. The Association represented by Mr John Fin presented a cheque for RM25,000 to Dato' Dr Sharom Ahmat at the Novemberjazz 2017 dinner show on 9 November. To-date the Association has donated RM185,000.



## OXA's donation

National Cancer Society of Malaysia, Penang Branch acknowledges with thanks the kind donation of RM 1,200.00 by OXA (Old Xavierians' Association) on 11 November 2017 at their annual dinner.

We are privileged to be among the 20 NGOs to be remembered once again. We are indeed very grateful to the association for its constant support.





## "SING" Charity Concert organised by Jammin Sensation in Aid Of Penang Hospice Society

The society thanks Jammin Sensation, a music school that has come forward for a second time to raise funds for the Society on 29 November 2017. We thank the school for helping raise RM8,000 in aid of our "Hospice-at-Home Programme".



## Penang Wanita Gerakan – Glowing Christmas Charity Night

The Wanita Gerakan Penang organised and co-ordinated a food and fun raising event called "Glowing Christmas Charity Night" for Penang Hospice Society and Pure Lotus Hospice of Compassion on 9 December 2017 at their premise in Macalister Road. This event raised RM15,000 for each society.



## Penang Melodic Group

The Penang Melodic Group is no stranger to us. Their members have been supporting the society since 2014. This year they held an Art & Music concert on 17 December 2017 at the Dewan Budaya of Universiti Sains Malaysia to help raise funds our programme. A donation of RM50,000 was presented to Penang Hospice Society.



# Relay For Life as “Engawa”: A Personal Thought

By Dr Daisuke OKABE

## Editorial board:

Dr Daisuke Okabe, PhD (International Communication) is a lecturer in Japan. We thank him for being with us at both our Relay for Life 2016 and 2017 and for sharing his thoughts with us. We look forward to meeting up with him again in the near future. We would be very grateful if he could continue to contribute short articles for our Hospice Bulletin.



## Why Relay? Celebrate, Remember, and...

I have been involved in Relay For Life, even intermittently, for more than ten years since 2006. But... why do I relay? Well, it may be because my father got cancer when I was 17? Or is it because I got cancer after seven years of my father's cancer diagnosis? Or is it because many of my friends died (some relayers in Japan euphemistically use "graduate") from cancer? All of those reasons could be true: I wanted to celebrate cancer survivorship; I wanted to remember my friends. Still, they seem not enough for me now. Why relay NOW? It should be because I see Relay as an "engawa" for cancer survivors' support. Let me briefly explain what "engawa" is first.

## Relay as "Engawa"

"Engawa (縁側)" is part of Japanese traditional architecture, which is a transitional space between inside and outside. It is not completely outside, but not completely inside, either. "Engawa" looks like a veranda of western architecture, but it is not. "- gawa (側)" means side or edge, and "en (縁)" means relationship. "Engawa" is often used as a space where the host and guest(s) can have a casual conversation, and/or just admire the garden or the nice weather. It is a place where neighbours just drop by and have a chat. So, why is Relay "engawa"? It is related to the current situation of cancer in Japan.



## Cancer, Social Exclusion, and Need for “Engawa”

As Susan Sontag, an American literary critic, rightfully argued, in her book, “Illness as Metaphor”, cancer was a stigmatised illness. Nowadays, due to the advancement of medical technology, a great number of cancer survivors can be alive, and, thus, some people say, “cancer is now de-stigmatised”.

However, there is a growing problem of employment status among cancer survivors in Japan. It is revealed that cancer survivors who had to take leave for their treatment for a while or those who were forced to quit their jobs cannot make a comeback or restart working. Studies have shown that is partly because of poor understanding of their (present/potential) employers or colleagues, and society towards cancer. Some people might still believe cancer survivors cannot work just like other employees because of their cancer history.

# Relay For Life as “Engawa”: A Personal Thought

*Continued*

But that is not necessarily true. Given an enough understanding towards cancer and a proper support (if necessary), survivors can be great assets since many of cancer survivors have already had their professional work experience in their own fields. In fact, the Japanese government is taking measures to encourage companies and organisations to hire cancer survivors. Although such trend should be welcomed, I believe it is also important for the general public to learn firsthand about cancer and lives of cancer survivors to make our society more inclusive. This is where Relay For Life as “Engawa” comes into play.

In Relay For Life, participants can learn a lot about cancer, and have a chance to talk to cancer survivors directly and casually. Every participant is allowed to join and leave whenever and whatever ways s/he likes. Relay For Life is different from other gatherings such as support groups, which tend to be closed to the public (Of course, those are also important as such, though). Through such casual conversations among participants at an “engawa”, we all will have an opportunity to connect with one another regardless of cancer history, type and stage of the disease, or any other social identities, and to deepen our understanding towards cancer, which will help us all work together to fight against the disease.



## “Engawa” outside Japan

Last year, I attended Relay in Malaysia, both in Penang and KL. It was my first time participating in this event overseas. I was quite moved by the warm welcome from the volunteers and other participants, and found a sense of unity to fight against cancer. This year, I was privileged to talk to many participants and share my cancer journey with them. I also had a chance to learn how eager caregivers such as family members, medical professionals, volunteers are to help and encourage cancer survivors, which was an amazing experience for me. That is exactly what I have read in a material of Relay For Life by the American Cancer Society: “No matter who you are, there’s a place for you at Relay”.



Due to my limited linguistic and cultural knowledge, what I have seen and experienced should be only a piece of Relay in Malaysia. I am not sure whether Relay in Malaysia is also an “engawa” because sociocultural and historical background of each country is different. So, we’ll see.

## Acknowledgement

I am grateful to Madam Mui Siew Koon for giving me this opportunity to write my personal note.

## WISH LIST

### WAYS YOU CAN HELP US...



#### **Donate Cash**

We welcome all levels of donation, whether it is a one-time gift or a monthly donation.

Tax-exempt receipts will be issued for all donations. Please make cheques payable to:

Penang Hospice Society

#### **Donations In Kind**

\*\*Wheel chairs with head and neck support

\*\*Oxygen concentrators

\*\*Syringe drivers

\*\*Sheepskin rugs

\*\*Rippie mattresses

#### **FULFILLING SMALL WISHES**

Hosting and treating hospice patients to tea, dinner, hotel stay, picnic, sight-seeing and short holidays. We look forward to seeing every wish come true. Wishes are small and simple, but they are all important to our patients. Those wishing to be a part of this fulfilling programme are welcome to join us!

#### **ADMINISTRATIVE ITEMS**

\*\*Computers & Printers

#### **VOLUNTEER**

\*\*Volunteer your time and talent. Volunteering is a great way to help. We invite you to share your time, talents and resources to help us in our cancer awareness campaigns and fundraising events.

To recruit us, call 04-226 4140 or write to us at: [penanghospicesociety@gmail.com](mailto:penanghospicesociety@gmail.com)

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Tel: 604-228 4140 Fax: 604-226 4676 Email: [penanghospicesociety@gmail.com](mailto:penanghospicesociety@gmail.com)