

Singapore Patient Advocate Connection (SPACE)

Elevating the Voices of Patients, Families and Caregivers

Organised by the SingHealth Patient Advocacy Network (SPAN)*
Supported by the SingHealth Duke-NUS Institute for Patient Safety and Quality,
and SingHealth Group Office of Patient Experience

Date	:	29 October 2022, Saturday
Time	:	9.30am to 1.00pm
Venue	:	The Ngee Ann Kongsi Auditorium, Academia (on SGH campus) 20 College Road, Singapore 169856 <i>Please click here for directions on getting to Academia.</i>
Aim	:	i) To grow patient advocacy in Singapore ii) To raise awareness on the importance of partnering patients to improve care quality iii) To provide a platform for collaboration opportunities between HCWs and patients/caregivers
Theme	:	Amplifying the Patient's Voice for Patient Safety
Target Audience	:	SPAN, SPAN@Institutions, Patient Support Groups, patient-led organisations, patients, caregivers, healthcare workers
GOH	:	Mdm Rahayu Mahzam, Senior Parliamentary Secretary, Ministry of Health
Attire	:	Smart Casual (eg. polo tee with jeans)

Programme (subject to changes)

9.00am	Registration and Pre-event activities
9.30am	Welcome and Introduction by Ms Josie Liow and Mr Chew Kim Soon, Co-Chairs, SingHealth Patient Advocacy Network (SPAN)
9.40am	Opening Address by Ms Rahayu Mahzam, Senior Parliamentary Secretary, Ministry of Health
9.55am	Performance: Be Hype, Be Happy! by Dance Group of Survivors from the Singapore Cancer Society, led by Trainer Ms Ramlah De Rose <i>Though visually impaired, Ms Ramlah De Rose has been a trainer for Be Hype, Be Happy, a dance support group at the Singapore Cancer Society for cancer patients and survivors.</i>
10.05am	Power of the Patient, Family and Caregiver in Co-creating Healthcare Innovation and Experience by Ms Ai Ling Sim-Devadas, Breast Cancer Survivor & Mentor, SPAN Mr Mohan Pillay, Caregiver & Co-Chair, SPAN@SGH* Dept of Emergency Medicine Dr Ng Mingwei, Associate Consultant, SGH Dept of Emergency Medicine <i>*SGH – Singapore General Hospital</i> <i>Beyond giving feedback, what can patient, family and carers do to make healthcare better? Find out how to unleash the power of patients, family and carers in healthcare innovation and experience, through co-creation and partnership. Learn first-hand insights from patient advocates and clinicians who work hand-in-hand to improve the A&E patient experience.</i>
10.45am	Tea break & Networking Gallery <i>Immerse in a rich exchange over tea break with leaders of patient organisations (refer to Annex for list of participating organisations) on best practices that have helped amplify the voice of patients.</i>
11.30am	Performance: Magic Show by Mr Eugene Chia, Entertainer and Cancer Survivor & Patient, Changi General Hospital
11.35am	Amplifying the Patient's Voice in Improving Healthcare by Ms Nidhi Swarup, Founder & President, Crohn's & Colitis Society of Singapore <i>Each experience in the healthcare journey is unique, from the diagnosis of a chronic disease and its impact on the patient's life, the support network of fellow patients, to the ripple effect on the family. Hear Nidhi's story on how she set up her charity with the intention of bringing together people with the same medical condition to lend support and knowledge, build public awareness and promote research. The charity has also built links with similar groups globally to extend the support network for her patient community.</i>
11.55am	Lived Experience: Telling Your Story to Inspire Change by Dr Edmund Chow, Programme Leader, LASALLE College of the Arts Mrs Wendy Tan-Kuah, Cancer Survivor & Leader, Singapore Sarcoma Support Group Mr Ellil Mathiyar, Double-cancer Survivor & Mentor, SPAN, and Co-founder & President, Ostomy Association of Singapore (OAS) <i>How do we tell stories to inspire change in our healthcare sector? Through this interactive seminar, participants will understand the Hero's Journey, and identify the three basic principles and five types of conflicts in stories. Real patients' experiences will be told. This will demonstrate how one can apply personal narratives to enrich the human experience in healthcare and to positively improve healthcare services in general.</i>
12.35pm	Panel Discussion <i>Get answers to your burning questions in this Q & A segment that will touch on patient advocacy and healthcare improvement.</i> Panelists: <ul style="list-style-type: none">Ms Josie LiowMs Nidhi SwarupDr Edmund ChowProfessor Tan Kok Hian, Group Director & Senior Associate Dean, SingHealth Duke-NUS Institute for Patient Safety & Quality and Advisor, SPAN <i>(Moderated by: Ms Ai Ling Sim-Devadas)</i>
12.55pm	Closing by Professor Tan Kok Hian
1.00pm	End of Symposium

*The SingHealth Patient Advocacy Network (SPAN) is a self-driven network of patients and caregivers who represents the collective voice of patients. Working in partnership with the healthcare team, SPAN provides important patient perspectives and plays an active role by giving inputs on how SingHealth can improve the experience of patients and their caregivers navigating through her institutions.

About the Speakers

Ms Ai Ling Sim-Devadas



Breast Cancer Survivor
Organising Co-Chair
Singapore Patient Advocate
Connection 2022
Mentor
SingHealth Patient
Advocacy Network (SPAN)
Member
Global Patient and Family Advisory Board,
The Beryl Institute

Ai Ling is a cancer survivor and currently Mentor of the SingHealth Patient Advocacy Network (SPAN). As the immediate past Co-Chair of SPAN, she is passionate about what patients and families can do to make healthcare better, safer, and more patient and family centred. Ai Ling has helped shape the role of SPAN in our healthcare system by roping in the patient's voice to improve care delivery and experience. Some of her notable contributions include the design and implementation of the Patient Advocate Communication Training (PACT) – a mandatory programme for new patient advocates, as well as the development of a patient engagement guide for healthcare professionals.

With a strong professional background in healthcare communications, patient experience and volunteer management, Ai Ling brings valuable perspectives from both ends of the care spectrum – that of a healthcare provider and a patient. Ai Ling is also a Certified Patient Experience Professional (CPXP), and serves on The Beryl Institute Global Patient and Family Advisory Board. Beyond patient advocacy, she volunteers with palliative care charities and is a Board Member of Ambulance Wish Singapore, a charity that fulfils last wishes for terminally ill patients.

Mr Chew Kim Soon



Caregiver to late mother
Organising Co-Chair
Singapore Patient Advocate
Connection 2022
Co-Chair
SingHealth Patient
Advocacy Network (SPAN)

As a dedicated caregiver to his late mother who suffered from multiple conditions including Parkinson Disease, Kim Soon actively shares his experience and knowledge with the healthcare team and fellow caregivers with a keen interest in the improvement of patient safety and care quality. Currently retired, he has over 32 years of experience in marketing communications, relationship management and analytics within the corporate banking sector.

As Co-Chair of the SingHealth Patient Advocacy Network (SPAN), Kim Soon taps on his skills and expertise to bring forth the patient's voice in initiatives aimed at improving healthcare. His key contributions include the *Plain English Glossary* which helps healthcare workers "speak the patient's language" amidst the prevalent use of jargons, co-leading a survey on the "Concerns of Patients and Caregivers through COVID-19" to evaluate how the experience of patients and/or caregivers may have changed through the pandemic, concerns, and how options such as medication delivery and telehealth may impact the experience. Results of the survey were presented to SingHealth senior management. His passion to amplify the patient's voice is also evident in his commitment to share his perspectives with new nurses at onboarding sessions.

Ms Josie Liow



*Caregiver to daughter with
heart condition*
Co-Chair
SingHealth Patient
Advocacy Network (SPAN)

Josie is a dedicated caregiver to her daughter, who was on the Left Ventricular Assist Device (LVAD mechanical heart pump) for more than eight years before her heart transplant in 2021. To care for her daughter, Josie quit her job as a regional director and worked closely with the healthcare team to achieve the best outcome. She received the Singapore Health Inspirational Caregiver Award in 2014.

As Co-Chair of the SingHealth Patient Advocacy Network (SPAN), Josie actively represents the voice of patients and caregivers through initiatives aimed at improving care quality. Some of the key projects she has been involved in include being part of the Singapore General Hospital's biennial management retreat – SGH Advance 2020 – where she shared perspectives and insights to help shape the envisioned concepts of tomorrow's hospital. She also co-led and presented the survey on the "Concerns of Patients and Caregivers through COVID-19" to SingHealth senior management together with Kim Soon, and has shared her caregiving story with healthcare professionals at various platforms as part of staff education, amongst many others.

Mr Ellil Mathiyan



Double-cancer Survivor
Mentor
SingHealth Patient
Advocacy Network (SPAN)
Co-founder and President
Ostomy Association of Singapore
(OAS)

Ellil is a double-cancer survivor with extensive experience working with patient support groups, and journeying with patients from diagnosis to rehabilitation after treatment.

As the immediate past Co-Chair of the SingHealth Patient Advocacy Network (SPAN), Ellil's notable contributions include his role as a member of the Singapore General Hospital's (SGH) Emergency Medicine Building (EMD) Commissioning Committee for its new premise, and the development of the Patient Advocate Communication Training (PACT) – a mandatory programme for new patient advocates.

Ellil is also a multiple award winner, including the Inspirational Hero Patient Award 2015 (Changi General Hospital – CGH), Inspirational Patient Award 2017 (SGH), Singapore Patient Advocate Award 2018 (Tan Tock Seng Hospital) and the Singapore Cancer Society (SCS) Outstanding Volunteer Award 2018. Besides being President of OAS, Ellil holds leadership roles in the Colorectal Support Groups at SGH, CGH and SCS. He is currently helping to set up SPAN at CGH.

Dr Edmund Chow



Programme Leader
LASALLE College of the Arts

Edmund is an applied theatre director and educator who has worked across schools, universities, hospitals and prisons in Singapore and New York. His research interests are in cultural practices in Afghanistan, arts education, emotions and corporate storytelling. He has an M.A from New York University and a Ph.D from the University of Manchester.

In 2020, Edmund co-presented a workshop at the Asia-Pacific Medical Education Conference on the power of storytelling and emotions for effective healthcare practice. Currently, he is the Programme Leader for MA Arts Pedagogy and Practice at LASALLE College of the Arts.

Dr Ng Mingwei



Co-Chair
SPAN@SGH* Dept of
Emergency Medicine

Associate Consultant
Dept of Emergency Medicine,
Singapore General Hospital

Mingwei is an Associate Consultant at the Singapore General Hospital's Department of Emergency Medicine (SGH DEM) and is currently pursuing his subspecialty interests in Toxicology, Disaster Medicine and Medical Education. Together with Mohan, he is actively involved as Co-Chair of SPAN@SGH-DEM as he firmly believes in the importance of the Patient's voice in moving us towards true patient-centred care.

Quoting Mingwei – "The days of paternalistic medicine are over and patients increasingly want to be given a say in the management of their care." Outside of work, he spends most of his free time with his 2-year-old daughter who is obsessed with koalas and bubbles.

Mr Mohan Pillay



Caregiver to family

Co-Chair
SPAN@SGH* Dept of
Emergency Medicine

Be it for his immediate family or extended family and friends, Mohan has been the go-to person for advice and guidance in navigating the Singapore health system. Mohan often finds himself wearing the hat of a caregiver in helping his family and friends in their healthcare journey. Mohan has been an active patient advocate with SPAN since 2019 and has been involved in numerous key initiatives, such as Design Thinking workshops for the upcoming Eastern General Hospital and review of the National Dental Centre Singapore's chatbot, amongst others.

Mohan is currently a faculty member of the Patient Advocate Communication Training (PACT), a mandatory training programme for new patient advocates, to equip them with knowledge and skills to become effective patient and family advocates.

Concurrently, Mohan also serves as Co-Chair of SPAN@SGH* Department of Emergency Medicine, where patient advocates work hand-in-hand with healthcare staff to co-create solutions that improve care quality and patient experience.

**SGH – Singapore General Hospital*

Ms Nidhi Swarup



Crohn's & Colitis Patient

Founder & President
Crohn's & Colitis
Society of Singapore

Global Partnership Lead
SingHealth Patient
Advocacy Network (SPAN)

Nidhi was diagnosed with Crohn's disease in 2011 after two years of being unwell and multiple consultations with numerous specialists across hospitals in Singapore. Realising a service gap for patients suffering from Crohn's disease, Ulcerative colitis and related inflammatory bowel diseases (IBD), she set up the Crohn's & Colitis Society of Singapore (CCSS) in 2012 as a charity that focuses on patient education, public awareness, patient support and promotes research in related conditions.

Nidhi is a key opinion leader representing CCSS and has also facilitated the formation of IBD Patient Support Groups in Thailand, Malaysia, Philippines and India. From 1 Jan 2021 to 31 Dec 2022, she was appointed to the Fee Benchmarks Advisory Committee by the Ministry of Health Singapore, which makes recommendations on reasonable fee benchmarks for healthcare services in Singapore.

As Global Partnership Lead of the SingHealth Patient Advocacy Network (SPAN), Nidhi plays a key role in SPAN's partnership with SingHealth to support the World Health Organisation (WHO) and strategic international partners in patient advocacy efforts, including Patients for Patient Safety (PPFS) initiatives, such as empowering and engaging patients, caregivers and healthcare professionals through workshops and events.

Mrs Wendy Tan-Kuah



Cancer Survivor

Leader
Singapore Sarcoma Support Group

Wendy was diagnosed in 2014 with advanced stage uterine leiomyosarcoma, a rare type of cancer that affects the smooth muscle tissue. She underwent a full hysterectomy to remove all the female organs, as well as a 5.5cm tumour near the ovary.

Previously a self-confessed workaholic, Wendy spent most of her time managing her education consultancy before her diagnosis, which she saw as a wake-up call. Not wanting to waste any time, she left her business to her “Three Musketeers” – her husband and two sons, and went on 14 holidays in a year.

In 2016, she volunteered to lead the Singapore Sarcoma Support Group after finding out that the KK Women’s and Children’s Hospital, National Cancer Centre Singapore and National University Cancer Institute Singapore were setting it up. Today, she dedicates her time to supporting others in their healthcare journey, despite having undergone a major palliative surgery earlier this year. Motivated and inspired by the courage and determination of fellow patients to get well, Wendy finds joy in sharing her experiences to help them through the journey.

Professor Tan Kok Hian



Advisor
SingHealth Patient
Advocacy Network (SPAN)

Group Director & Senior Associate Dean
SingHealth Duke-NUS Institute for
Patient Safety & Quality (IPSQ)

In 2017, Prof Tan initiated the SingHealth Patient Advocacy Network (SPAN), which is strategically guided by the Patient and Caregiver Engagement Framework for the SingHealth cluster. Working in close partnership with SingHealth Group Nursing and the Group Office of Patient Experience, SPAN is a reflection of SingHealth’s commitment to designing a healthcare system that is truly for patients, by patients.

Prof Tan is an expert member of Patient Safety in World Health Organisation (WHO) and serves as a WHO consultant in patient safety. He was awarded the Benjamin Henry Sheares Professorship in Obstetrics and Gynaecology, the highest honour accorded to distinguished faculty members for outstanding contributions in the field. From June 2017 to May 2021, he was appointed the inaugural Chair of the National Quality Council, which serves as the national advisory panel to the Ministry of Health on health quality priorities and strategies.

Annex

NETWORKING GALLERY

List of Participating Organisations/Groups

Organisation /Group	What the Group offers	What the Group seeks
Caregivers Alliance Limited (CAL)	<ul style="list-style-type: none"> Caregiver training and support Tailored Caregiver workshops Bilateral collaboration opportunities 	<ul style="list-style-type: none"> Outreach opportunities to share on CAL's services and programmes Referral of caregivers to persons with mental health issues and dementia Invitations for CAL to conduct caregiver training, with the provision of training rooms
CARe Programme Support Group (Cognitive Assessment & Rehabilitation)		
Caring Hearts Support Group (CHSG) @ National University Heart Centre, Singapore (NUHCS)	An avenue for patients (especially cardiac patients) to get connected with cardiac patients from National University Heart Centre Singapore (NUHCS) to foster engagement, and share stories/experiences to make a positive difference in their own lives, as well as that of other patients.	<ul style="list-style-type: none"> Understanding of other patient support groups/organisations/individuals and the experiences they offer, so as to gain insight of other diseases; <i>and</i> To explore areas of collaboration to improve the lives of patients, through various activities such as (but not limited to) joint activities, learning journey and best practices
CGH Breast Care Support Group	Public education on breast conditions, Breast Self-Examination and breast cancer awareness	<ul style="list-style-type: none"> Sponsors for monthly support group meetings Sponsors for Breast Cancer Awareness Month (BCAM) Donors for Breast Centre fund (for research and education)
Crohn's & Colitis Society of Singapore		
Haematopoietic Cell Therapy and Transplant Programme (HCTTP) Peer Support Group	<p><u>For patient peer supporters (volunteers)</u></p> <ul style="list-style-type: none"> Guidance and Skills training Empowerment to be self-reliant as a group <p><u>For newly diagnosed patients</u></p> <ul style="list-style-type: none"> Environment to foster engaging and valuable conversations Peer supporters who share own experiences to help newly diagnosed patients A safe place for patients with the need to talk to a peer supporter on intensely personal issues, experiences, struggles and thoughts. 	<ul style="list-style-type: none"> To connect with other support groups/societies of equal standing for collective benefit Awareness of its existence
Parkinson Society Singapore	Collaboration opportunities for opening of new extension in the society's premises	Collaborators and volunteers for extended premises
Rare Disorders Society (Singapore)	Existing parent/patient support network to engage, empower and help caregivers caring for loved ones with a rare condition	<ul style="list-style-type: none"> Corporate donations for Carry Hope 2023, annual fundraising campaign for rare patients, as well as participation from companies to form teams and participate in the Carry Hope Challenge as ambassadors Access to affordable care and treatment, especially when Rare Disorder patients see multiple specialists, and approvals from regulators for new treatment/s often take time Skill-based volunteers to help as Social Media Curators and Programme Executive
SGH Liver & Pancreas Support Group (LPSG)	<ul style="list-style-type: none"> Support for patients/caregivers with liver and pancreas diseases, being the only such Support Group in Singapore Visitors to the station will receive info brochure and coasters (while stocks last) 	<ul style="list-style-type: none"> Patients and caregivers to join the support group Public awareness of its existence
Singapore Cancer Society		
Singapore National Stroke Association (SNSA)	Monthly programmes for Stroke Survivors	<ul style="list-style-type: none"> To rent an activity space for SNSA to conduct programmes Long term partnership/s with donors
Singapore Sarcoma Support Group		