# *2nd* GENOMIC AND GENETIC COUNSELLING CONFERENCE

13th & 14th November 2021

## THEME: GENETIC COUNSELLING FOR EVERYONE

**ORGANISED BY:**

Genetic Counselling Society Malaysia

**IN PATNERSHIP WITH:**

PERSATUAN GENETIK MALAYSIA

13TH NOVEMBER 2021 (SATURDAY)
1:00 PM - 6:00 PM MYT (GMT+8)

14TH NOVEMBER 2021 (SUNDAY)
2:00 PM - 5:20 PM MYT (GMT+8)

VIRTUAL ZOOM

# ACKNOWLEDGEMENT

**The Organising Committee of the *2nd* Genomic and Genetic Counselling Conference is very grateful for the generous support and contribution given by the following companies for making this conference a success.**

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# GCSM PRESIDENT'S MESSAGE

Genetic Counselling Society Malaysia

## MS YOON SOOK YEE
### PRESIDENT OF GENETIC COUNSELLING SOCIETY MALAYSIA (GCSM)

Dear friends and colleagues,

On behalf of the Organising Committee, we are delighted to welcome you to the *2nd* Genomics and Genetic Counselling Conference of the Genetic Counselling Society Malaysia (GCSM) in partnership with Persatuan Genetik Malaysia (PGM). This conference, in conjunction with Genetic Counsellors' Awareness Month, will take place on the 13th and 14th of November, virtually.

The COVID-19 pandemic has had a tremendous impact in Malaysia and globally. We extend our deepest condolences to those who have lost a loved one and those who suffered during this pandemic. As the pandemic continue to pose uncertainties on the possibility of an in-person event, this year's conference will be conducted virtually to safeguard the safety of all attendees.

In this era of unprecedented advances in the use of genetics in healthcare, there is vast improvement in diagnostics and precision treatment across a spectrum of diseases but with new opportunities, comes new challenges. The need for genetic counselling has increased exponentially and role of genetic counsellors to manage emerging counselling issues is evolving. In Malaysia, the use of genetic testing in diagnosis and treatment is following the trends as seen in many other developed countries and we will need to prepare to meet the challenges of using genetic profiles in our population. Genetic information has to be used in an equitable and fair manner without discrimination for those who have inherited genetic conditions.

GCSM acknowledges that there is a great need to have more genetics counsellor in the country. These counsellors are expected to be in high demand in the oncoming years because of the new breadth and depth of analyses thanks to the advancement in research, resource and technology. To that end, GCSM aims to lead in developing national best practice policy statements, the setting up of an effective certification and registration process in partnership with the Ministry of Health and partner organisations. This step forward will provide a platform for the safe delivery and accurate interpretation of genetic information to patients and their family members.

This year will be an exciting year for GCSM as we launch the *2nd* Genomics and Genetic Counselling Conference of the Genetic Counselling Society Malaysia (GCSM) in partnership with Persatuan Genetik Malaysia (PGM). The conference is aimed at both healthcare providers and the public with different objectives and presentations delivered by different speakers, both internationally and locally. We encourage you to join us at both events to understand about the utility of genetic counselling and the role of genetic counsellors as we move forward in a genetic based future.

# PGM PRESIDENT'S MESSAGE

## PROF DR ABD RAHMAN MILAN
### PRESIDENT OF PERSATUAN GENETIK MALAYSIA (PGM)

*Selamat sejahtera* and a warm welcome to all the speakers, participants and organising committee members of this Second Genomic and Genetic Counselling Conference organized by the Genetic Counselling Society of Malaysia in partnership with the Genetics Society of Malaysia (PGM). As the President of the PGM, it is indeed a great honour to express my support for this collaboration which has great importance to our country.

The rapidly developing areas of genetic and genomic sciences have become mainstream subjects and point of care in all fields of medicine. The First Genomic and Genetic Counselling Conference, which was held in 2019 at the University of Malaya Medical Centre, was the first of its kind in Malaysia and the region. It established that genetic counselling as an important branch of genetics and genomics and received widespread support for its application in the healthcare system.

For this Second Conference, I noted there are many exciting new fields in genomic and genetic counselling. This conference, which is held virtually with complimentary registration, will examine various topics in basic genetic counselling, communication skills, new areas in genetic medicine and empowering genetic counsellors with the latest knowledge on genomic medicine. We hope in the near future, genetic counsellors will be given official recognition leading to creation to posts in the Malaysian government.

I urge all students and members of PGM as well as genetic students in Malaysia to take a special interest in genetic counselling, and consider furthering your studies in the field of genetic counselling. You may enrol in Masters of Science (Genetic Counselling) locally or Master of Genetic Counselling in overseas tertiary centres. This information may be obtained during the virtual conference or you may contact the conference organiser.

We have prominent speakers from overseas, as well as from Malaysia to speak on these new developments. I wish everyone a wonderful conference and help improve genetic and genomic healthcare services in Malaysia.
*Terima kasih.*

# GCSM COMMITTEE

| | | |
|---|---|---|
| **President** | : | Ms. Yoon Sook Yee |
| **Vice-President** | : | Dr. Ch'ng Gaik Siew |
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# ORGANISING COMMITTEE

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| | | Mr. Yashvin Kumar |
| | | Mr. Tan Jian Hong |

# PROGRAMME

## DAY 1 13TH NOVEMBER 2021 (SATURDAY) 1:00 PM - 6:00 PM MYT (GMT+8)

| TIME | TOPIC | SPEAKER |
|---|---|---|
| 1:00 PM - 1:10 PM | Welcoming Speech | **Ms. Yoon Sook Yee**<br>*President, Genetic Counselling Society Malaysia (GCSM)*<br>**Prof. Dr. Abd Rahman Milan**<br>*President, Persatuan Genetik Malaysia (PGM)* |

### Session 1 Genetic Counselling in the Era of Precision Medicine

Chairperson: Ms. Yoon Sook Yee - Certified Genetic Counsellor FHGSA, RegGC HGSA, President of GCSM, Malaysia

| | | |
|---|---|---|
| 1:10 PM - 1:30 PM | Introduction to Genetic Counselling | **Dr. Annie Hasan**<br>*President, Board of Genetic Counselling India, India* |
| 1:30 PM - 1:50 PM | Career in Genetic Counselling - Where Will This Take Me | **Assoc. Prof. Alison McEwen**<br>*Head of Genetic Counselling, University Technology Sydney, Australia* |
| 1:50 PM - 2:05 PM | Awareness and Perception of Genetic Counselling Services Among Healthcare Providers in Malaysia | **Dr. Ch'ng Gaik Siew**<br>*Clinical Geneticist, Hospital Pulau Pinang, Malaysia* |
| 2:05 PM - 2:45 PM | Forum:<br>The Evolving Role of Genetic Counsellors | **Dr. Annie Hasan**<br>*President, Board of Genetic Counselling India, India*<br>**Assoc. Prof. Alison McEwen**<br>*Head of Genetic Counselling, University Technology Sydney, Australia*<br>**Prof. Sultana Faradz**<br>*Professor of Medical Genetics, Diponegoro University, Indonesia*<br>**Prof. Carmencita D. Padilla**<br>*Chancellor, University of the Philippines, Manila, Philippines*<br>**Ms. Sharifah Azween Syed Omar**<br>*Genetic Counsellor, Hospital Canselor Tuanku Muhriz, Universiti Kebangsaan Malaysia, Malaysia*<br><br>**Moderator:**<br>**Ms. Yoon Sook Yee**<br>*Certified Genetic Counsellor FHGSA, RegGC HGSA, President of GCSM, Malaysia* |

# PROGRAMME

## DAY 1 13TH NOVEMBER 2021 (SATURDAY) 1:00 PM - 6:00 PM MYT (GMT+8)

| TIME | TOPIC | SPEAKER |
|---|---|---|
| **Session 2 Utility of Genetic Testing** | | |
| Chairperson: Dr. Ch'ng Gaik Siew - Clinical Geneticist, Hospital Pulau Pinang, Malaysia | | |
| 2:45 PM - 3:05 PM | Navigating the Information From Direct To Consumer (DTC) Genetic Testing | **Dr. Jacqueline Savard**<br>*Senior Lecturer, Deakin University, Australia* |
| 3:05 PM - 3:25 PM | Diagnostic Genetic Testing | **Ms. Yusnita Yakob**<br>*Head of Molecular Diagnostics, Institute of Medical Research, Malaysia* |
| 3:25 PM - 3:35 PM | BREAK (Sponsor's session) | |
| **Session 3 Reproductive Genetics** | | |
| Chairperson: Ms. Juliana Lee - Certified Genetic Counsellor FHGSA, RegGC HGSA, Secretary of GCSM, Malaysia | | |
| 3:35 PM - 3:55 PM | Introduction to Pre-implantation Genetic Diagnosis | **Dr. Tristan Hardy**<br>*Medical Director of Genetics, Monash IVF Group, Austrialia* |
| 3:55 PM - 4:15 PM | Genetic Counselling Challenges in Reproductive Genetic Testing | **Ms. Juliana Lee**<br>*Certified Genetic Counsellor FHGSA, RegGC HGSA, Secretary of GCSM, Malaysia* |
| 4:15 PM - 4:45 PM | Case Studies Discussion | **Dr. Tristan Hardy**<br>*Medical Director of Genetics, Monash IVF Group, Austrialia*<br>**Dr. Sann Lin Ko**<br>*Anatomist/Embryologist, Moe Kaung Fertility Centre, Moe Kaung Treasure Maternal & Child Hospital, Myanmar*<br>**Dr. Helena Lim Yun Hsuen**<br>*Consultant Obstetrician and Gynaecologist, KL Fertility Centre, Malaysia*<br><br>**Moderator:**<br>**Ms. Juliana Lee**<br>*Certified Genetic Counsellor FHGSA, RegGC HGSA, Secretary of GCSM, Malaysia* |

# PROGRAMME

## DAY 1 13TH NOVEMBER 2021 (SATURDAY) 1:00 PM - 6:00 PM MYT (GMT+8)

| TIME | TOPIC | SPEAKER |
|---|---|---|
| **Session 4** | **Cancer Genetics** | |
| Chairperson: Ms. Tiara Hassan - Assoc. Genetic Counsellor, Cancer Research Malaysia, Malaysia | | |
| 4:45 PM - 5:05 PM | Somatic and Germline Cancer Genetic Testing for Risk Management and Treatment Choice | **Prof. Dr. Gareth Evans**<br>*Professor in Medical Genetics and Cancer Epidemiology, University of Manchester, UK* |
| 5:05 PM - 5:25 PM | Harnessing the Power of Cancer Genetic Testing in Low & Medium Income Countries | **Prof. Dr. Rajiv Sarin**<br>*Professor in Oncology & Cancer Genetics, Tata Memorial Hospital, India* |
| 5:25 PM - 5:55 PM | Case Studies Discussion | **Prof. Dr. Gareth Evans**<br>*Professor in Medical Genetics and Cancer Epidemiology, University of Manchester, UK*<br>**Prof. Dr. Rajiv Sarin**<br>*Professor in Oncology & Cancer Genetics, Tata Memorial Hospital, India*<br><br>**Moderator:**<br>**Ms. Tiara Hassan**<br>*Assoc. Genetic Counsellor, Cancer Research Malaysia, Malaysia* |
| 5:55 PM - 6:00 PM | Closing Remarks | |

# PROGRAMME

## DAY 2 14TH NOVEMBER 2021 (SUNDAY)
## 2:00 PM - 5:20 PM MYT (GMT+8)

Chairperson: Ms. Yoon Sook Yee - Certified Genetic Counsellor FHGSA, RegGC HGSA, President of GCSM

| TIME | TOPIC | SPEAKER |
|---|---|---|
| 2:00 PM - 2:10 PM | Welcoming Speech | **Ms. Yoon Sook Yee**<br>*President, Genetic Counselling Society Malaysia (GCSM)*<br>**Prof. Dr. Abd Rahman Milan**<br>*President, Persatuan Genetik Malaysia (PGM)* |
| 2:10 PM - 2:30 PM | Introduction to Genetic Counselling | **Ms. Rifhan Mazlan**<br>*Assoc. Genetic Counsellor, University Malaya Medical Centre* |
| 2:30 PM - 2:50 PM | What Can A Genetic Test Tell Me? | **Ms. Yoon Sook Yee**<br>*Certified Genetic Counsellor FHGSA, RegGC HGSA, President of GCSM* |
| 2:50 PM - 3:15 PM | Introduction to Newborn Screening | **Dr. Leong Huey Yin**<br>*Clinical Geneticist, Hospital Kuala Lumpur* |
| 3:15 PM - 3:40 PM | Dilemma in Prenatal Genetic Testing | **Assoc. Prof. Dr. Sofiah binti Sulaiman**<br>*Feto-Maternal Medicine Specialist, University Malaya* |
| 3:40 PM - 3:50 PM | BREAK (Sponsor's session) | |
| 3:50 PM - 4:15 PM | Cancer Genetic Testing : Understand Your Family History and Plan Ahead | **Ms. Tiong Shing Yiing**<br>*Genetic Counsellor, Loh Guan Lye Specialists Centre* |

# PROGRAMME

## DAY 2 14TH NOVEMBER 2021 (SUNDAY)
## 2:00 PM - 5:20 PM MYT (GMT+8)

| TIME | TOPIC | SPEAKER |
|---|---|---|
| 4:15 PM - 5:15 PM | Forum : Family Communication - Genetic Counselling and Bringing the Family Together | **Healthcare Professional:**<br>**Prof Thong Meow-Keong**<br>*Clinical Geneticist, University Malaya Medical Centre*<br><br>**Genetic Counsellors:**<br>**Ms. Rifhan Mazlan**<br>*Assoc. Genetic Counsellor, University Malaya Medical Centre*<br>**Ms. Suzanah Abd Hamid**<br>*Psychology Officer, Hospital Wanita dan Kanak-Kanak Sabah*<br><br>**Patient and family support groups:**<br>• Malaysian Rare Disorders Society (MRDS)<br>• Prader-Willi Syndrome Malaysia (PWSM)<br>• The Hemophilia Society of Malaysia (HSM)<br>• Persatuan Pesakit Imunodefisiensi Primer Malaysia (MyPOPI)<br>• Kuala Lumpur and Selangor Albinism Association (KLSAA)<br>• Dystrophic Epidermolysis Bullosa Research Association Malaysia (DEBRA Malaysia)<br>• Malaysia's Neurofibromatosis Community<br>• Pertubuhan Kebajikan Pesakit Ichthyosis Malaysia (PEKIM)<br><br>**Moderators:**<br>**Ms. Yoon Sook Yee**<br>*Certified Genetic Counsellor FHGSA, RegGC HGSA, President of GCSM*<br>**Ms. Juliana Lee**<br>*Certified Genetic Counsellor FHGSA, RegGC HGSA, Secretary of GCSM* |
| 5:15 PM - 5:20 PM | Closing Remark | |

# SPEAKERS & FACILITATORS

**Dr. Annie Hasan**
*President,*
*Board of Genetic Counselling India, India*

Dr Hasan is the President of Board of Genetic Counseling India since 2014. She is also a Sr. Consultant & HOD of Department of Genetics and Molecular Medicine in Kamineni Hospital, Hyderabad. She holds a PhD in Genetics from Osmania University and a DBT Fellowship from CCMB. Dr Hasan has over 37 years of research experience and her areas of interest include molecular pathology in cancer, neuro-degeneration, diabetes related complications and pharmaco-genomic based medicine. Prior to Kamineni Hospitals, she spent 8 years abroad working in different areas of Human Genetics and Molecular pathology with attachments at Welington School of Medicine, New Zealand, Stanford, Sloan Kettering and Cancer Genetics, Incorp, USA.

Dr Hasan is actively involved in research, training, diagnostics and counseling. She has 130 publications in national and international journals, more than 150 presentations in national and international conferences or meetings. She also an active speaker in the area of Genetics and Molecular Medicine in colleges, hospitals, research institutions and universities. Her areas of expertise include karyotyping, cytogenetics, FISH, RT-PCR, Differential Display Analysis, Sanger and NGS interpretation of sequencing data, as well as bioinformatics for genotype-phenotype correlation. Dr Hasan was nominated as a Fellow of the National Academy of Sciences in 2010. She is the founder co-ordinator of the first full time programme in “Genetic Counseling“ in India.

**Assoc. Prof. Alison McEwen**
*Head of Genetic Counselling,*
*University Technology Sydney, Australia*

Associate Professor Alison McEwen leads the Genetic Counselling Discipline within the Graduate School of Health at University of Technology Sydney (UTS). She has 16 years’ experience as a Genetic Counsellor in Wellington, New Zealand and is a Human Genetic Society of Australasia (HGSA) certified genetic counsellor. She completed her PhD in 2011 and undertook training in professional supervision in 2016.

Research interests include genetic counsellor education and training and the evolving roles of genetic counsellors. Alison uses qualitative and co-design research methodologies.

Alison is the President of the Human Genetics Society of Australasia (HGSA) and is only the second genetic counsellor to take on this role, highlighting the importance of this appointment for the profession.

Alison has held leadership roles in the Australasian Society of Genetic Counsellors (ASGC) and the Human Genetics Society of Australasia (HGSA) and has a particular focus on the education, training and certification of genetic counsellors.

# SPEAKERS & FACILITATORS

## Dr. Ch'ng Gaik Siew

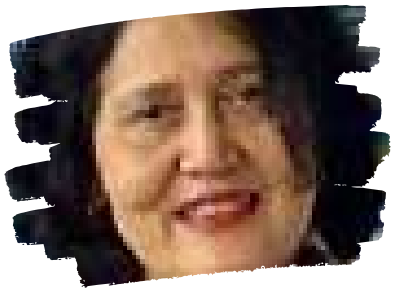
*Clinical Geneticist,*
*Hospital Pulau Pinang, Malaysia*

Dr Ch'ng Gaik Siew is a consultant clinical geneticist and paediatrician and currently heads the Department of Genetics, Penang Hospital under the Ministry of Health. Dr Ch'ng formerly worked for 11 years in the Department of Genetics, Kuala Lumpur Hospital, which serves as the national referral centre for inherited metabolic disorders and genetic disorders in Malaysia.

Dr Ch'ng obtained her medical degree from UKM (National University of Malaysia) and the United Kingdom postgraduate qualification in Paediatrics (MRCPCH, UK). She went on to complete the Clinical Genetics Fellowship programme and spent the last year of training at the Institute of Human Genetics, International Centre for Life, Newcastle-upon-Tyne, UK.

Dr Ch'ng has an active involvement in continuing medical education, professional development and research in genetics and rare disorders. She has been appointed as the Honorary lecturer for MSc in genetic counselling course from UKM and a committee member of the National Task Force for Paediatric Palliative Care. She is the vice-President of Genetic Counselling Society Malaysia (GCSM) and a life- member of Asia Pacific Society of Human Genetics.

She also serves as a resource of information to other health care professionals on genetic and rare disorders through the role as care coordinator in management of complicated multisystemic genetic disorders, in addition to rendering professional advice for patient advocacy groups and the general public. She is an appointed Medical Board of Advisor to We Care Journey, a SMA support group. Dr Ch'ng has keen interest in mindfulness-based therapies (eg. Mindful Self-Compassion) and their clinical application in supporting caregivers and patients with life-limiting genetic disorders.



## Prof. Sultana Faradz

*Professor of Medical Genetics,*
*Diponegoro University, Indonesia*

In 1978, she graduated from the Faculty of Medicine Diponegoro University (FMDU) and was recruited as a lecturer on Histology at FMDU. In 1988 and 1990 she joined cytogenetics course in Tottori University Japan, followed with cancer cytogenetics at the Prince of Wales Hospital Sydney in 1992 and followed with her PhD on Medical Genetics (1994-1998) at the UNSW, Sydney during which she did her course on Clinical Genetics at Sydney Children Hospital (1994-1995), Clinical epidemiology at School of Community Medicine, UNSW Sydney (1995), a research fellow at Queen's University Kingston Canada (1996 and 1997). She was a research fellow at AMC Hospital, Amsterdam (2000), RUNMC Nijmegen (2000) and the MIND Institute at the University of California, Davis (2002). Since 2001, she started working as a genetic counselor in 2 hospitals. In 2003, she has been appointed as a professor of medical science. She is a member of National Research Council in 2005-2011. In 2005, she awarded the best lecturer at MFDU. In 2006 she led the establishment of the First Master Program on Genetic counseling in Indonesia in collaboration with several centers in overseas. Since 2007 she has been appointed as a director of Center for Biomedical Research at FMDU. In 2008 she awarded a best scientist from the Mayor of Semarang Municipality and in 2009 awarded Australian Alumni Finalist in Research and Innovation from the Australian Embassy in Jakarta. In 2010 she awarded a Program Scheme Academic Mobility Exchange fellowship for research project on DSD at Murdoch Children Research Institute/ University of Melbourne for 3 months. She was appointed as a vice Rector for development and collaboration in 2011-2015. In 2012 she awarded as National best researcher in Medicine from Bakrie foundation. Since 2013 she is a member of Indonesian Academy of Science (AIPI). In 2013, 2015 and 2016 she received an award from Diponegoro University for the achievement of International scientific article publication with major research in intellectual disability and disorders of sex development. She published her research for >70 articles in peer reviewed journal with H index 16. She is a member of APSHG, HGSA, ASHG and president of InaSHG (Indonesian Society of Human Genetics). She is now teaching Medical Genetics for undergraduate, post graduate program MSc Genetic counseling and Doctoral program, and Obstetrics and Gynecology on Fertility, Endocrine and Reproduction Sub specialist program.

# SPEAKERS & FACILITATORS

**Prof. Carmencita D. Padilla**
*Chancellor,*
*University of the Philippines Manila, Philippines*

Dr Padilla is Academician of the National Academy of Science and Technology (NAST)-Philippines and Professor of Pediatrics of the University of the Philippines Manila. She is the Founding Director of the Institute of Human Genetics and the Newborn Screening Reference Center at the National Institutes of Health-Philippines. She is responsible for setting up the clinical genetic services in 1990 and the national newborn screening services in the Philippines. In the Asia Pacific region, she is part of the pioneering group that established the Asia Pacific Society for Human Genetics and served as president in 2008-2010. Dr. Padilla is Council Member of the Human Genome Organization and Country representative of NAST to the InterAcademy Partnership for Health.

Dr Padilla has more than 150 publications. In the area of policy making, she is responsible for the Newborn Screening Act of 2004 (Republic Act No. 9288) and the Rare Disease Act of 2016 (Republic Act No. 10747).

cdpadilla@up.edu.ph

**Ms. Sharifah Azween Syed Omar**
*Genetic Counsellor, Hospital Canselor Tuanku Muhriz,*
*Universiti Kebangsaan Malaysia, Malaysia*

Ms Sharifah Azween is presently a Genetic Counsellor in Clinical Genetics Unit, Hospital Canselor Tuanku Muhriz, UKM. She obtained her first degree in Genetics from Universiti Kebangsaan Malaysia and subsequently was awarded the MSc in Genetic Counselling from Cardiff University, United Kingdom.

During her studies in United Kingdom, Ms. Azween had opportunities to do an internship in Clinical Genetics Department at Guy's & St Thomas' Hospital in London and Western General Hospital in Edinburgh, Scotland.

At UKM, Ms Azween involved in development of Master of Medical Science (Genetic Counselling) programme and as a teaching personnel for the programme.

# SPEAKERS & FACILITATORS

**Ms. Yoon Sook Yee**
*Certified Genetic Counsellor FHGSA, RegGC HGSA,*
*President of GCSM, Malaysia*

Ms Yoon Sook Yee, is one of the two certified Genetic Counsellors in Malaysia and is accredited by the Human Genetics Society Australasia (FHGSA). She was the Head of the Familial Cancer Programme in Cancer Research Malaysia and the Principal Investigator for a nationwide study on the *Mainstreaming of Genetic Counselling and Genetic Testing for Ovarian Cancer Patients in Malaysia (MaGiC) study*. She practices as a Cancer Genetic Counsellor in Cancer Research Malaysia and University Malaya Medical Centre and various other private hospitals in Malaysia. Her current research focus is on hereditary cancers in Malaysia, with a research interest in the psychosocial aspects of genetic testing and counselling in Malaysia. She is also currently the President of the Genetic Counselling Society Malaysia and through the society, aims to increase the awareness of genetic tests and genetic counselling in Malaysia.

**Dr. Jacqueline Savard**
*Senior Lecturer,*
*Deakin University, Australia*

Dr Jacqueline Savard is a senior lecturer in health ethics and professionalism at Deakin University. She is a lecturer of ethics and professionalism within the School of Medicine and teaches ethics and bioethics into both undergraduate and postgraduate units across the university. She has spent the past 10 years studying direct-to-consumer (online DNA) testing in Australia. Her research interests mainly focus on the ethics of new genomic technologies, how genetic information is used in daily life and how these new evolving ideas can be communicated and used to engage with the publics who access and use these technologies.

# SPEAKERS & FACILITATORS

**Ms. Yusnita Yakob**
*Head of Molecular Diagnostics,*
*Institute of Medical Research, Malaysia*

Ms Yusnita Yakob is currently the Head of Molecular Diagnostics Unit, Specialised Diagnostics Centre at the Institute for Medical Research (IMR) Kuala Lumpur. She has over 20 years of experience in the field of molecular diagnostics for inborn error of metabolisms, including mitochondrial and also rare genetic disorders. Her contributions included development of the molecular genetics testing for mitochondrial disorders, neuromuscular diseases and many more and all these testing are currently available to all hospitals in Malaysia and abroad. She also serves as a senior scientist and actively involved in a number of collaborative research projects, as well as being a Technical Assessor in the field of Molecular Genetics for Department of Standards Malaysia (DSM).

**Dr. Tristan Hardy**
*Medical Director of Genetics,*
*Monash IVF Group, Austrialia*

Dr Tristan Hardy is the Medical Director of Genetics for Monash IVF Group, one of the largest providers of reproductive services in Australia and Asia, including KL Fertility. He is a dual-qualified obstetrician/gynaecologist and genetic pathologist, with particular expertise in preimplantation genetic testing. He has a Masters in Reproductive Medicine and a PhD in novel approaches to preimplantation genetic testing.

# SPEAKERS & FACILITATORS

**Ms. Juliana Lee**

*Certified Genetic Counsellor FHGSA, RegGC HGSA,*
*Secretary of GCSM, Malaysia*

Ms Juliana Lee is the first Malaysian genetic counsellor to be certified by the Human Genetic Society of Australasia (HGSA). She is also a registered genetic counsellor with HGSA and registered counsellor with the Board of Counsellors Malaysia. She obtained her BSc. (Hons.) in Genetics from the National University of Malaysia (Universiti Kebangsaan Malaysia) in 2002 and completed the Graduate Diploma in Genetic Counselling at the University of Melbourne in 2003. She began practice at the University Malaya Medical Centre in 2004 till 2014 before moving to private practice. Throughout her career, she has made significant contributions to the development of the genetic counselling profession especially in Malaysia and aims to improve access to genetic counselling services among the Asian community. She is the founding member of the Malaysian Rare Disorders Society (MRDS), President of the Professional Society of Genetic Counselors in Asia (PSGCA), Secretary of the Genetic Counselling Society Malaysia (GCSM) and a visiting lecturer in the Masters of Medical Science (Genetic Counselling) course in the National University of Malaysia. She specialises in paediatric, reproductive and cancer genetics.

**Dr. Sann Lin Ko**

*Anatomist/Embryologist, Moe Kaung Fertility Centre,*
*Moe Kaung Treasure Maternal & Child Hospital,*
*Myanmar*

Dr Sann Lin Ko is a clinical embryologist at Moe Kaung Treasure Maternal & Child Hospital in Yangon Myanmar. Prior to that, his work experience as anatomist and medical educationist at Defence Services Medical Academy from 2011-2020 comprise of giving anatomy lecture, facilitating medical education course and medical genetic courses and supervising Master & PhD research and thesis in anatomy. He also obtained his PhD (Anatomy) from Defence Services Medical Academy and recently obtain his Certificate in Embryology & Andrology from I-Ceat-Clinical & Embryology Academy of ART, India.

His area of expertise includes anatomy teaching, medical education, and research, on top of clinical embryology & andrology. He holds several memberships including Myanmar Medical Association, Myanmar Anatomy Association, Undergraduate & Postgraduate Board of Studies (Anatomy) of Defence Services Medical Academy, Yangon. He is also one of the focal person for International Federation of Associations of Anatomists (IFAA) as well as regular member & country representative of Myanmar of the Professional Society of Genetic Counselors in Asia (PSGCA).

# SPEAKERS & FACILITATORS

## Dr. Helena Lim Yun Hsuen

*Consultant Obstetrician and Gynaecologist,*
*KL Fertility Centre, Malaysia*

Dr Helena Lim qualifed as a doctor from Universiti Kebangsaan Malaysia in 1999. She obtained her specialist degree in the UK in 2006 and completed her master degree in Obstetrics & Gynaecology in the same year. She has been a Consultant in Obstetrics & Gynaecology with special interest in Fertility since then. In 2018, Dr Helena Lim received her Fellowship award from the Royal College of Obstetricians & Gynaecologists, UK (FRCOG).

Dr Helena studied medicine at Universiti Kebangsaan Malaysia between 1994-1999. She obtained her specialist qualifcation (MRCOG) in 2006 and completed her master degree in Obstetrics & Gynaecology the same year. In 2018, Dr Helena was elevated to the status of Fellow by the Royal College of Obstetricians & Gynaecologists, UK (FRCOG).

## Prof. Dr. Gareth Evans

*Professor in Medical Genetics & Cancer Epidemiology,*
*University of Manchester, UK*

Professor Evans has established a national and international reputation in clinical and research aspects of cancer genetics, particularly in neurofibromatosis and breast cancer. He has developed a clinical service for cancer genetics in the North West Region of England, which is nationally regarded. He is an important opinion leader nationally through membership of committees and was chairman of the NICE Familial Breast Cancer Guideline Development Group (2002-2010) and is now clinical lead (2011-). He lectures throughout the UK and internationally on hereditary breast cancer and cancer syndromes. He has given plenary lectures at many international meetings including the International Congress of Human Genetics and two invited lecture tours across Australia (1995, 2001). He has developed a national training program for clinicians, nurses and genetic counsellors in breast cancer genetics and established a system for risk assessment and counselling for breast cancer in Calman breast units implemented through a training course (1998-2011).

He has published 648 peer reviewed research publications; 244 as first or senior author. He has published over 100 reviews and chapters and has had a book published by Oxford University Press on familial cancer. He has an ISI web of knowledge H-index of 88 and a google scholar H-index of 118 having only published his first article in 1990. In the last 5 years he has raised over £35 million in grants for multicentre and local studies – approximately £31 million to Manchester. He is Chief Investigator on two (£1.59 & £1 million) NIHR program grant (2009-2014 and 2016-2020) on breast cancer risk prediction and also has an NIHR RfPB grant as CI (2011). He has led a successful bid for a Nationally funded NF2 service (£7.5 million pa) that started in 2010 and is involved in the national complex NF1 service. He is theme lead and cancer lead on the All Manchester NIHR Biomedical Research Centre worth £28.5 Million (2016-2020).

# SPEAKERS & FACILITATORS

**Prof. Dr. Rajiv Sarin**
*Professor in Oncology & Cancer Genetics,*
*Tata Memorial Hospital, India*

Prof Rajiv Sarin trained in Clinical Oncology & Radiation Oncology at the Tata Memorial Hospital (TMH) & the Royal Marsden Hospital London and Cancer Genetics at University of Utah, Salt Lake City. Prior to the current assignment as the Director of the institute since 2005, he was the lead investigator in Breast Cancer & Brain Tumour Radiotherapy & Cancer Genetics at TMH. Starting from the 1st registry of Hereditary Cancer in the country in 1996, he developed a model Cancer Genetics Unit comprising of a Cancer Genetics Clinic in 2003 & Genetics Lab (SARIN Lab) in 2007. Prof. Sarin is the lead investigator in the International Cancer Genome Consortium (ICGC) India project for Oral Cancers and also the ICMR Centre for Advanced Research in Cancer Genetics & Genomics. He serves as the member of two International working groups of the ICGC.

Prof Sarin is a member of various expert committees & task forces for cancer research and cancer management & he drafted the base paper for research in the Indian National Cancer Control Programme. He is the Executive Editor of the Journal of Cancer Research & Therapeutics which is the leading Indexed Cancer Journal from developing World. He is also serves on the Editorial board of leading cancer journals like Lancet Oncology, Molecular Oncology, Radiotherapy Oncology, Cancer Biomarkers, Mammology etc. Has over 75 peer reviewed publications and editorials in leading journals on various issues of cancer, health care, Cancer genetics, radiobiology etc.

**Ms. Tiara Hassan**
*Assoc. Genetic Counsellor,*
*Cancer Research Malaysia, Malaysia*

Ms Tiara is an Associate Genetic Counsellor recognised by the Human Genetics Society of Australasia board since 2017 at Cancer Research Malaysia and is one of the 7 genetic counsellor in Malaysia. She is also the current deputy secretary of GCSM. She has been actively involved in the development of decision aids to assist patients and family members in making decisions about cancer genetic testing. She is also involved in various mainstreaming initiatives to improve access of genetic counselling to Malaysians, in addition to providing genetic counselling services for cancer patients and their families.

# SPEAKERS & FACILITATORS

**Ms. Rifhan Mazlan**
*Assoc. Genetic Counsellor,*
*University Malaya Medical Centre, Malaysia*

Ms Rifhan has worked as a genetic counsellor at Medical Genetics Unit, University Malaya Medical Centre (UMMC) since 2015. She obtained her master degree from University of Sydney and was recognised by the Human Genetics Society of Australasia. Prior to this, she worked at various medical and research institutions focusing on human genetics. She is now actively involved in the clinical setting mainly providing genetic counselling to prenatal cases, adult cancer and also pediatric cases. She is now the current treasurer of GCSM.

**Dr. Leong Huey Yin**
*Clinical Geneticist,*
*Hospital Kuala Lumpur, Malaysia*

Dr Leong Huey Yin is a Pediatrician and Clinical Geneticist at the Genetics Department in Hospital Kuala Lumpur.

She obtained her medical degree from the National University of Malaysia in 2003 and her membership in the Royal College of Paediatric and Child Health, UK in 2009. Following this, she completed a 1-year fellowship in the field of inherited metabolic diseases at Sheffield Children's Hospital, UK in 2015 and obtained her fellowship in Clinical Genetics from the Ministry of Health Malaysia in 2016. She has a special interest in the dietetic management of inherited metabolic disorders and a number of these disorders can be diagnosed by newborn screening.

# SPEAKERS & FACILITATORS

**Assoc. Prof. Dr. Sofiah binti Sulaiman**
*Feto-Maternal Medicine Specialist,*
*University Malaya, Malaysia*

Dr. Sofiah binti Sulaiman is an Associate Professor of the Department of Obstetric and Gynaecology, Faculty of Medicine in University Malaya. She holds several administrative duties in University Malaya, including Committee Member of drugs and medication UMMC Faculty, Coordinator and Quality Manager of the faculty in University Malaya, and Deputy Manager of the Lactation Initiative Committee UMMC Faculty, to name a few.
Dr. Sofiah Binti Sulaiman holds a MMED, OBSTETRIK & GINEKOLOGI, UNIVERSITI MALAYA (UM) and a MBBCH, OBSTETRIK & GINEKOLOGI, ROYAL COLLEGE OF SURGEONS OF IRELAND besides obtained accreditation for first trimester scanning in Obstetric and Gynaecology. Her Area of Expertise includes General gynaecology, First trimester Scanning and Feto-maternal medicine. She is also active in research and publications mainly in Gynecology and Obstetrics.

**Ms. Tiong Shing Yiing**
*Genetic Counsellor,*
*Loh Guan Lye Specialists Centre, Malaysia*

Ms Tiong Shing Yiing is a genetic counsellor at Loh Guan Lye Specialists Centre, a private hospital in Penang, Malaysia. She obtained her Master of Medical Sciences in Genetic Counselling from Universiti Kebangsaan Malaysia (UKM). On top of this, she also holds both Bachelor and Master Degree in Biotechnology from University Malaysia Sarawak (UNIMAS).

In her current clinical practice, her area of focus is more on providing genetic counselling to breast cancer patients and their families. In addition, she also co-works with clinical geneticist in the clinical paediatrics clinic for genetic counselling.

She is also an executive committee of the Genetic Counselling Society of Malaysia (GCSM) besides holding memberships in the Genetic Society of Malaysia (Persatuan Genetic Malaysia, PGM), the Malaysian Society of Human Genetics (MSHG), the Asia Pacific Society of Human Genetics (APSHG) and the Professional Society of Genetic Counselors in Asia (PSGCA).

# SPEAKERS & FACILITATORS

## Prof Thong Meow-Keong

*Clinical Geneticist,*
*University Malaya Medical Centre, Malaysia*

Dr Thong Meow-Keong is a Professor of Paediatrics and Consultant Clinical Geneticist at the University of Malaya Medical Centre. He was a Fulbright Scholar and an Australian board-certified clinical geneticist and established the first Genetics Clinic in Malaysia in 1995. He is the current President of the College of Paediatrics, Academy of Medicine of Malaysia; Vice-President of the Medical Genetics Society of Malaysia, Trustee of the Rare Disease Alliance Foundation Malaysia, appointed member of the Malaysia Medical Council (Education) and Advisor to the Malaysian Rare Disorders Society. He was the Head, Department of Paediatrics, University of Malaya and past President, Asia Pacific Society of Human Genetics.

His clinical practice and research are focused on rare diseases, genomic medicine, inborn errors of metabolism and genetic counselling. He has published extensively in the field of paediatrics and genetic medicine in low-resource settings. He has authored/co-authored over 100 WOS/ISI journal publications, 3 books, 18 book chapters including the Oxford Monograph in Medical Genetics and an IDEAS White Paper entitled “Rare Diseases in Malaysia”. He was consulted by the World Health Organization and the Ministry of Health Malaysia on various technical issues and clinical practice guidelines. He was active in developing undergraduate and postgraduate paediatric training curriculum programs and promoted advocacy issues affecting children and individuals with rare diseases. He has won major research awards and research grants and has collaboration with major universities globally. He was elected a Fellow of Academy of Sciences Malaysia, Academy of Medicine of Malaysia and Academy of Medicine, Singapore.

## Ms. Suzanah Abd Hamid

*Psychology Officer,*
*Hospital Wanita dan Kanak-Kanak Sabah, Malaysia*

Ms Suzanah Abd Hamid is a Psychology Officer and currently attached at Sabah Women and Children Hospital, formerly known as Hospital Likas, Kota Kinabalu. She completed her training and obtained her Master of Medical Sciences in Genetic Counselling from National University of Malaysia (UKM). She graduated from International Islamic University of Malaysia (IIUM) with Bachelor of Human Sciences in Psychology and Master of Human Sciences in Communication.

Suzanah previously had her clinical attachment for genetic counselling in Genetic Clinic, Kuala Lumpur Hospital where she had the opportunity working together with the team to serve patients with rare conditions. In her current workplace, genetic clinic visitation from HKL was held twice a year in Pediatrics Clinic and she assisted geneticist during the clinic. Currently, she is providing mental health and psychosocial support to patients affected with covid19. She is also getting referrals for emotional and psychosocial support for healthcare professionals and patients either in wards or outpatients.

Suzanah is one of the executive members of Genetic Counselling Society of Malaysia (GCSM), a member of Genetic Society of Malaysia (Persatuan Genetic Malaysia, PGM) and holds a membership in Society of Psychology Profession, Ministry of Health (Persatuan Profesion Psikologi, KKM (PsiKEM)).

## A Career in Genetic Counselling: Where will this take me?

**Assoc. Prof. Alison McEwen**
*Head of Genetic Counselling,*
*University Technology Sydney, Australia*

Advances in technology, including genomic sequencing and precision medicine, are dramatically changing the field of genetics, bringing enormous opportunities for improved healthcare outcomes. Globally, the knowledge and skills required by the healthcare workforce to deliver on the promises of genomic technology varies.

Genetic counsellors, trained in genetic and genomic science and equipped with robust communication and counselling skills are well positioned to take up opportunities to lead delivery of genomic medicine across all parts of the healthcare system. The current volumes of work generated by new technologies coupled with the potential for widespread access and the increasing demand for implementation into many areas of healthcare are rapidly outstripping the ability of the current genetic counselling workforce to deliver on the hope this technology offers. While the rapid expansion may seem daunting, as a profession we are well-equipped to think in ways that are agile and that see beyond the immediate challenges as we imagine new ways in which our profession can upscale.

Providing opportunities for genetic counselling students to explore their own identity and beliefs, and embedding the life-long requirement for reflective practice supervision, gives graduates a foundation from which to take up a diverse range of career opportunities. Genetic counselling PhD programs, opportunities to train in variant curation, management roles, combining a law degree with genetic counselling training, and education positions all offer exciting opportunities to take core genetic counselling skills and knowledge in new directions.

Working together, we can foster an environment in which each genetic counsellor has the opportunity to work in areas that best suit our interests and skill sets, and to have robust pathways for each and every one of us to have access to regulation and membership of this growing profession.

# ABSTRACTS

## Crossing boundaries: the ethics and challenges for health professionals when genetic information from direct-to-consumer genetic testing moves from the consumer marketplace to the clinical setting

**Dr. Jacqueline Savard**
*Senior Lecturer,*
*Deakin University, Australia*

Over the past decade, direct-to-consumer genetic tests have increased in availability and scope for which information about the self could be sought. These tests are available to consumers for purchase on the internet directly from the company or they can be accessed through a health provider working with such companies. Consumers may seek these tests for a range of reasons: to explore their genetic ancestry, to explore health concerns they may be experiencing or to explore their risk of future health issues. After receiving their results, consumers may seek clarification with a range of resources to help them understand their results – including health professionals. Direct-to-consumer genetic testing raises a range of ethical challenges, including informed decision-making about seeking a test, providing consent for the test, privacy concerns about results and concerns around how one might interpret, understand, and communicate their results within their families. While most information generated from these tests can help consumers answer questions about their life, additional challenges arise when consumers cross the boundary between the medical marketplace and the clinic, by bringing these results into the clinical setting to help inform or guide their medical care. This presentation will draw upon key research conducted in Australia that engaged with consumers of direct-to-consumer genetic testing to understand their experiences and preferences when seeking and making sense of the results from such tests. Bringing together key findings from this work, this presentation will explore the ethical challenges direct-to-consumer genetic testing gives rise to and discuss how health professionals could potentially assist and support consumers when they seek this form of testing and assist with understanding such results in the context of the clinical setting.

## Introduction to Newborn Screening

**Dr. Leong Huey Yin**
*Clinical Geneticist,*
*Hospital Kuala Lumpur, Malaysia*

Newborn screening is a health program to detect babies with life-threatening or debilitating disorders soon after their birth, prior to onset of their clinical symptoms which will allow early treatment to improve outcome. As an example, universal newborn screening is available in Malaysia for congenital hypothyroidism via umbilical cord blood testing at birth and if detected, treatment with daily oral thyroxine soon after birth prevents developmental impairments such as mental retardation. The birth prevalence for congenital hypothyroidism in Malaysia is estimated to be 1 in 2500 to 1 in 3000 live births.

Now, there are already many other rarer conditions screened at birth in different countries. In fact, newborn screening was first introduced in the world to detect Phenylketonuria (PKU), an inherited metabolic disease way back in the 1960s and mental retardation continues to be successfully avoided in PKU until today because of early detection and treatment soon after birth.

This talk will explore the utility and availability of newborn screening in Malaysia and what usually happens before, during and after newborn screening.

# Forum: Family Communication - Genetic Counselling & Bringing the Family Together

## PATIENT & FAMILY SUPPORT GROUPS

**Malaysian Rare Disorders Society (MRSD)**
*Website: www.mrds.org.my*
*Tel: +6019-771 4543*
*E-mail: info@mrds.org.my*

**Prader-Willi Syndrome Malaysia (PWSM)**
*Website: www.pwsamalaysia.org.my*
*Tel: +6012-339 5232*
*E-mail: malaysiapws@gmail.com*

**The Hemophilia Society of Malaysia (HSM)**
*Website: www.hsm.org.my*
*Email: hemophiliamalaysia@yahoo.com*

**Persatuan Pesakit Imunodefisiensi Primer Malaysia (MyPOPI)**
*Website: www.mypopi.org*
*Tel: +603-5525 5652*
*Email: mypopi@yahoo.com.my*

# Forum: Family Communication - Genetic Counselling & Bringing the Family Together

## PATIENT & FAMILY SUPPORT GROUPS

**Kuala Lumpur and Selangor Albinism Association (KLSAA)**
*Facebook: KLSAA (Kuala Lumpur and Selangor Albinism Association)*

**Dystrophic Epidermolysis Bullosa Research Association Malaysia (DEBRA Malaysia)**
*Facebook: DEBRA Malaysia*
*Tel: +603-9283 2868 or +6012-391 3328*
*E-mail: debramalaysia@gmail.com*

**Malaysia's Neurofibromatosis Community**
*Facebook: Malaysia's Neurofibromatosis Community*
*Tel: +6017-468 4788*

**Pertubuhan Kebajikan Pesakit Ichthyosis Malaysia (PEKIM)**
*Facebook: Pertubuhan Kebajikan Pesakit Ichthyosis Malaysia*
*Tel: +6012-446 7112*

# Genetic Counsellor Awareness Day 2021

Genetic Counselling Society Malaysia


Genetic Counselling Society Malaysia

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